



Parental involvement in neonatal critical care decision-making

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| Abstract: | <p>The paper analyses the decision-making process between doctors and parents of babies in neonatal intensive care. In particular, it focuses on cases in which the decision concerns the redirection of care from full intensive care to palliative care at the end of life. Thirty one families were recruited from a neonatal intensive care unit in England and their formal interactions with the doctor recorded. The conversations were transcribed and analysed using conversation analysis. Analysis focused on sequences in which decisions about the redirection of care were initiated and progressed. Two distinct communicative approaches to decision-making were used by doctors: 'making recommendations' and 'providing options.' Different trajectories for parental involvement in decision-making were afforded by each design, as well as differences in terms of the alignments, or conflicts, between doctors and parents. 'Making recommendations' led to misalignment and reduced opportunities for questions and collaboration; 'providing options' led to an aligned approach with opportunities for questions and fuller participation in the decision-making process. The findings are discussed in the context of clinical uncertainty, moral responsibility and the implications for medical communication training and guidance.</p> |
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ABSTRACT

The paper analyses the decision-making process between doctors and parents of babies in neonatal intensive care. In particular, it focuses on cases in which the decision concerns the redirection of care from full intensive care to palliative care at the end of life. Thirty one families were recruited from a neonatal intensive care unit in England and their formal interactions with the doctor recorded. The conversations were transcribed and analysed using conversation analysis. Analysis focused on sequences in which decisions about the redirection of care were initiated and progressed. Two distinct communicative approaches to decision-making were used by doctors: 'making recommendations' and 'providing options.' Different trajectories for parental involvement in decision-making were afforded by each design, as well as differences in terms of the alignments, or conflicts, between doctors and parents. 'Making recommendations' led to misalignment and reduced opportunities for questions and collaboration; 'providing options' led to an aligned approach with opportunities for questions and fuller participation in the decision-making process. The findings are discussed in the context of clinical uncertainty, moral responsibility and the implications for medical communication training and guidance.

Keywords: Neonatal, End-of-life, Critical Care, Decision-Making, Ethics, Parents, Involvement, Conversation Analysis

INTRODUCTION

Having a newborn baby cared for on a neonatal intensive care unit is a difficult time for parents. For some, this becomes particularly painful when they are faced with decisions around whether or not to continue life-sustaining treatment. Despite improvements in neonatal survival and outcome, death is still relatively common in perinatal medicine (ONS 2011). Stillbirths aside, a large proportion of perinatal deaths arise because of a decision to limit treatment for a baby who is suffering with serious complications after birth or following a period of intensive care in the neonatal unit. The majority of deaths (60-80%) in neonatal intensive care are 'planned' (CEMACH 2009); that is, a decision is made to redirect care from intensive to 'supportive' or 'palliative' care, usually because of statistical probabilities around survival and severe long term morbidity (Costeloe, Hennessy et al. 2012).

Professional organisations such as the General Medical Council (GMC) and the Royal College of Paediatric and Child Health (RCPCH) state that decisions to redirect care should be centred on the 'best interests' of the baby, requiring consideration beyond the clinical context, to that of the family situation as a whole. These organisations recommend that parents should be involved in and share these critical care conversations and decisions. In the UK, the National Health Service Toolkit for high quality neonatal services recommends that "Clinical care decisions, including end-of-life decisions, are made by experienced staff in partnership with the parents and discussions held in an appropriate setting" (DoH, 2009:46). In this paper, we investigate what happens when consultants and parents talk about these decisions, and show how different ways of initiating decision-making communication have an immediate impact on the alignment, or otherwise, between parties as they decide what actions to take. The implications of our findings, for training doctors to have more effective and collaborative conversations with parents, will be discussed at the end of the paper.

Neonatal decision-making

Despite national recommendations about shared decision-making, parents in a recent survey of neonatal units throughout the UK reported less than optimal involvement in the decision making process (Poppy 2009). Many parents report being distressed by insensitive communication and overwhelmed by conflicting information, suggesting that parent-doctor communication could be improved. This research highlights a need to explore the decision-making process in its empirical reality, both to understand what actually happens and, ultimately, to inform training of the health care professionals involved in this process.

The extent to which parents report, retrospectively, that they want to be involved in decision-making varies (Gillam and Sullivan 2011), although most parents report a wish to have some 'involvement' in the decision-making process. What this means is unclear, however, as it can range from awareness of a decision being made to actually making the final decision, collaboratively with the doctors or independently (Einarsdottir 2009; Caeymaex, Speranza et al. 2011; Rosenthal and Nolan 2013). Entering the decision-making conversation at different stages of its trajectory (e.g., following a medical decision that is then presented to the parents), may result in parents' differing perceptions of who ultimately made the decision about their infants treatment (McHaffie, Laing et al. 2001). These issues may be further complicated by feelings of responsibility and blame that might be being managed through these retrospective accounts. Despite national recommendations to guide the health care professionals involved in the decision-making process, many doctors are unaware of how to implement this guidance in practice (Duffy and Reynolds, 2011) and their personal opinions towards parental involvement and the continuation of treatment of the infant may differ. The impact of this can be seen through regional variations in infant outcomes of mortality and morbidity across resource-rich settings within the UK and throughout Europe.

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3 Whilst the research can highlight the differing perspectives of each party involved in neonatal
4 decision-making, what remains unknown is what this process looks like in practice. What
5 does 'involvement' actually mean and how is it achieved? If doctors are to be trained to have
6 effective encounters with parents, what should go into that training? These questions remain
7 largely unanswered, and so the current paper will address them via the analysis of actual
8 encounters between doctors and parents.
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10
11 By analysing real-time encounters, our approach contrasts with research to date on
12 parent-doctor communication in the neonatal ICU. A number of previous studies adopt an
13 ethnographic approach to evaluate the process of decision-making, observing and describing
14 conversations but not analysing them directly. For example, Coeckelbergh and Mesman
15 (2007) examined how parents and doctors describe imagined scenarios of what life would be
16 like for the baby, to facilitate moral reasoning for decision-making. These imagined scenarios
17 are considered theoretically by the authors as a tool for creating consensus and shaping action
18 in a broad sense. What is not considered, however, is how they function within actual
19 decision-making, in terms of the implications for the moment-by-moment involvement of
20 parents. In another study, Vermeulen (2004) provides a detailed account of the decisions
21 being made in a Dutch NICU. Parents were considered to be involved in decision-making
22 through the presentation of facts by the doctors that enabled exploration of parental
23 perspectives. While this provides insight into parental involvement in a broad sense, it does
24 not provide a systematic analysis of the conversational implications of, say, information-
25 giving. Similarly, Orfali (2004) compared French and American NICUs, which, she argued,
26 have contrasting ideological models of decision-making: parental autonomy in the United
27 States, and paternalism in France. In French NICUs, doctors used the results of MRI scans
28 and objective indices such as 'lesions greater than 2cm', to objectify a severe outcome and
29 medical certainty, in situations where alternative outcomes might actually be possible. In
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3 contrast to the declared ideology, paternalism was still prevalent in USA NICUs, manifested
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5 as doctors not offering treatment limitations when this could be considered an appropriate
6
7 option. The study identified important factors used in decision-making in the two countries:
8
9 the criteria for considering redirection of care and whether parental 'permission' is sought.
10
11 But the actual conversations between parents and doctors was not presented or analysed.
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14 Three further studies get us closer to these actual conversations. Anspach's (1993)
15
16 ethnographic study explored parental involvement in end-of-life decisions as an interactive
17
18 process. She identified how parental *assent* (rather than informed *consent*) was achieved
19
20 through reference to a united expert authority in which uncertainty and options were actively
21
22 limited by doctors. Furthermore, by describing the baby's enduring suffering, should
23
24 intensive care be continued, the doctors invoked "a moral precept with which most parents
25
26 would find it hard to disagree" (Anspach, 1993: 98). Two recent studies (Boss et al, 2016; de
27
28 Vos et al, 2015) examine recordings of doctor-parent conversation, but code and/or quantify a
29
30 limited range of communicative behaviours, such as the distribution of talk or the number of
31
32 parents' questions. What we do not get to see is how talk is distributed, or what types of
33
34 questions get asked, leaving their impact on doctor-parent (mis)alignment unfolding inside an
35
36 analytic 'black box' (Stokoe, 2010). The current study builds on this small body of work,
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38 opening up this 'black box', to the best of our knowledge, for the first time.
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45 *Medical shared decision-making*

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47 Outside the specifics of neonatal care, shared decision-making has received substantial
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49 attention across primary care (Elwyn, Edwards et al. 2001), paediatrics (Lipstein, Dodds et al.
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51 2014), psychiatry (Goossensen, Zijlstra et al. 2007), cancer (Butow, Juraskova et al. 2010),
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53 multiple sclerosis (Pietrolongo, Giordano et al. 2013), and end-of-life care (Roter, Larson et
54
55 al. 2000). Researchers have attempted to assess the extent and outcomes of patient
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3 involvement in decision-making through patient satisfaction measures, to determine the
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5 patients' perspective on this process.
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8 Recordings of live medical encounters are frequently used to assess the uniformity of
9
10 an intervention and enhance recall when eliciting patient views, as well as being analysed in
11
12 their own right for features of shared decision-making. In the latter case, however, coding
13
14 systems, used to measure the decision making process, are typically developed from
15
16 theoretical perspectives around decision-making, as well as patient and health care
17
18 professional perceptions. Although coding enables retrospective identification of aspects of
19
20 talk that might be regarded as important, less attention is paid to the social organization of
21
22 decision-making conversations.
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24
25 Conversation analysts, in contrast, have demonstrated the importance of analysing
26
27 actions such as 'decision-making' (alongside questioning, advising, offering, etc.) within the
28
29 interactional context in which they are produced, rather than attaching pre-determined
30
31 significance to them (Heritage and Maynard 2006). While some medical studies have taken a
32
33 more inductive, descriptive approach to analysing decision-making (Gwyn and Elwyn 1999),
34
35 conversation analysis goes further still, analysing conversational practices in terms of their
36
37 situated use and interactional import, often changing what we think we know about how such
38
39 interaction works. Conversation analysts have examined decision-making across many
40
41 contexts including antenatal screening (Pilnick and Zayts 2012), paediatrics (Stivers 2005),
42
43 primary care (Koenig 2011), diabetes (Koenig, Wingard et al. 2014), orthopaedic surgery
44
45 (Clark and Hudak 2011), oncology (Collins, Drew et al. 2005), psychiatry (Quirk, Chaplin et
46
47 al. 2012), and neurology (Toerien, Shaw et al. 2013).
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52 This work has highlighted some of the practices through which patients' co-construct
53
54 decisions through their responses to treatment recommendations. For example, Costello and
55
56 Roberts (2001) showed that patients' weak agreements and silences help shape the final
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3 recommendation as something more aligned to the patients' perspective (see also Koenig,
4
5 2011). Ekberg and LeCouteur (2014) showed that, in cognitive behavioural therapy sessions,
6
7 information-soliciting questions may co-implicate the client in decision-making by inviting a
8
9 suggestion in the next turn rather than a more minimal acceptance or rejection. Toerien et al.
10
11 (2013) showed how, in neurology treatment, 'option-listing' works better than making
12
13 'proposals' to open up a slot for patients to specify a preference. Within paediatric primary
14
15 care encounters, Stivers (2005) found that affirmative recommendations for a treatment other
16
17 than antibiotics are less likely to be followed by resistance than for a recommendation against
18
19 antibiotic treatment. Finally, in antenatal consultations with community midwives, Pilnick
20
21 (2008) showed how despite a clear orientation by the midwives to invoke shared decision-
22
23 making around a newly introduced nuchal translucency screening programme, the way that
24
25 the programme was presented did not actually provide this optionality in the interaction. For
26
27 example, the programme was presented following the presentation of routine tests and so it
28
29 had the potential of becoming normalized, with the decision itself being given less weight.
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34 These studies explicate the practices through which particular sub-types of decision-
35
36 making initiations have implications for what happens next. The aim of our paper is to
37
38 explore, using conversation analysis, the process of shared decision-making in the neonatal
39
40 unit. Our work adds to the above body of knowledge by extending it to a novel context, and
41
42 also by considering the implications for communication guidance and training by identifying
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44 effective and less effective practices.
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DATA AND METHOD

Participants and characteristics

Thirty one families were recruited from a single neonatal intensive care unit in England from July 2013 to April 2014. Families were recruited whose babies were critically ill and where a discussion around the redirection of care was a possibility in the future. The baby's consultant introduced the study to potential parents, all of whom had capacity to provide and give informed consent. Participation involved digitally recording all formal conversations between the neonatal team and the parents regarding the treatment of the infant. From the 31 families recruited, we identified 16 conversations (nine families; six consultants) in which specific conversations about the redirection of care occurred (from full intensive care to palliative care). Within these, there were five discussions about *withdrawal* of ongoing life-support, including mechanical ventilation; eight discussions about *withholding* treatment, where the child is not receiving life support but is at risk of deteriorating (and if agreed treatment would not be escalated), and eight discussions around '*do not resuscitate orders*', that is, withholding formal resuscitation (such as adrenaline and chest compressions) should the baby acutely deteriorate (RCPCH 2004). Some conversations may have included more than one decision; for example, a decision around withholding or withdrawal of treatment as well as a '*do not resuscitate order*', culminating in 21 sequences across the 16 conversations. The key clinical conditions for the sample included: one threatened preterm delivery of twins at 23 weeks gestation (one baby with the no amniotic sac); three infants with severe perinatal asphyxia; four infants born extremely preterm (<27 weeks gestation) with neurological complications; and one infant born with a lethal congenital anomaly. Parents were from mixed ethnic and religious backgrounds: three families were White Caucasian, one

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2
3 Bangladeshi, three were black African, Caribbean or other, and for one, ethnicity was not
4
5 recorded in the clinical notes; four were Christian, one Muslim and for three, religion was not
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7 recorded.
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10 11 12 *Ethics*

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14
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16 The study received approval from the XXXX Research Ethics Committee and Research and
17
18 Development approval from the participating NHS Trust. Parents and consultants gave
19
20 written informed consent for their conversations to be recorded for research purposes; names
21
22 and identifying details have been replaced with pseudonyms. The study was funded by
23
24 XXXX. The funding body played no part in the conception, design, analysis or preparation of
25
26 research outputs.
27
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30 31 32 *Procedure*

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36 For participating families, the attending doctor was asked to record all conversations that took
37
38 place in the side room/parents' room, to ensure the privacy of the recording, while targeting
39
40 those formal conversations where critical care decision-making was likely to arise. The
41
42 recordings were captured using an audio digital recorder and securely stored using encrypted
43
44 storage devices. While we acknowledge that aspects of the embodied interaction are
45
46 unavailable for analysis, consent was constrained to audio rather than video recordings. This
47
48 limitation will be addressed in future data collection where possible. Of the 16 conversations
49
50 identified, the consultation lasted for 34 minutes on average (range 9 to 67 minutes), and
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52 comprised 8 hours 35 minutes in total. Such a dataset presents issues for analysis. While
53
54 many CA studies focus on short one-to-one telephone calls, others, like ours, analyse long
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1
2
3 multiparty interactions. We present key extracts from lengthy and complex spates of
4
5 conversation alongside an explanation of the context of the conversation to aid the reader
6
7 with the analysis.
8
9

10 11 *Analytic method* 12 13

14
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16 The recordings were analysed using the analytic method of conversation analysis (CA). The
17
18 underlying principle of CA is that talk is organised in terms of social action (Drew 2005).
19
20 Whether this be requesting, advising, complaining or complimenting (etc.), turns at talk build
21
22 actions and make relevant next actions. CA explicates the patterned ways in which these
23
24 actions work, and which constitute the ordered and finessed way in which members of a
25
26 culture communicate with and understand one another (Drew 2005). Turns at talk are
27
28 analysed within the sequential context in which they are produced and their implications for
29
30 how the sequence unfolds. By recording and analysing naturally occurring conversations, CA
31
32 provides a method for understanding the ‘black box’ of what actually happens in encounters,
33
34 rather than in simulations, role-play or post-hoc accounts.
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40 41 *Analytic procedure* 42 43 44

45 Recordings were transcribed using the Jefferson (2004) transcription system which captures
46
47 how talk is delivered, including emphasis and pitch movement, volume and temporal
48
49 placement (Hepburn and Bolden 2012). Capturing these details enables analysts to pin down
50
51 precisely when encounters are progressing smoothly and when there are difficulties, which is
52
53 particularly important in workplace and institutional encounters when one is attempting to
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55 identify, say, the relative effectiveness of one question design over another, one way of
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3 explaining a service over another (see Stokoe, 2013). Decision-making sequences were
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5 analysed in terms of the implications for what participants are able to do next.
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8 9 ANALYSIS

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14 Doctors initiated decision-making sequences in two main ways: 1) ‘making
15
16 recommendations’, in which they refer to discussions within their medical team and invoke
17
18 ‘the best interests’ of the baby, and 2) ‘providing options’, in which they not only list
19
20 different possible courses of action, but also employ other features such as deferring
21
22 decisions to provide opportunity for contemplation. We will show the different trajectories
23
24 afforded by each sub-type, particularly in terms of subsequent opportunities for parents to ask
25
26 questions and the affiliative nature of those questions. Table 1 below shows the incidence of
27
28 these two approaches in the data, as well the form of parent response, which will be discussed
29
30 later.
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36 Table 1: Summary of decision format and subsequent expression of preference

| | Expression of preference | | | | Total |
|---------------------------|-------------------------------------|--------------------|--|-------------------|-------|
| | Freely done with minimal resistance | Deferred by doctor | Passive acceptance <small>(1 including deferral by parents)</small> | Strong resistance | |
| Recommendations | 1 | 0 | 4 | 4 | 9 |
| Presenting options | 4 | 2 | 0 | 0 | 6 |

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2
3 *1. Making recommendations*
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7 We present a collection of extracts where the decision point is initiated by a strong
8 recommendation for a single course of action regarding the continuation or discontinuation of
9 life-sustaining treatment. The extracts exemplify the common features for building
10 recommendations and for the response options that recommendations afford. As discussed
11 earlier, all names presented within the results are pseudonyms. In Extract 1, the consultant
12 (Dr) has just informed Mum (M) of her baby Nathaniel's genetic test results and the outcome
13 of the cardiac multidisciplinary team meeting. Nathaniel has a condition similar to Trisomy
14 18 and an associated cardiac condition. The decision was not to undergo heart surgery
15 because of a likely poor outcome for Nathaniel. We join the conversation following the
16 delivery of this news and the decision to be made is regarding the withholding of ventilator
17 support if Nathaniel stops breathing.
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34 Extract 1: F1R3, Part A (1-38)
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37

38 1 M: So what next.
39
40 2 (0.5)
41
42 3 Dr: That's what we need to discuss [now.£]=
43
44 4 M: [Huh]
45
46 5 Dr: =Wha-<we need to make sure:, what [is the] right=
47
48 6 M: [Yeah]
49
50 7 Dr: =thing, for this baby, (.) [.hhh] (0.2) to be done,=
51
52 8 M: [Yeah]
53
54 9 Dr: =at this point.
55
56 10 (1.5)
57
58 11 Dr: Yeah, Wha- what- (.) what are your thoughts.°What
59
60

1
2
3 12 have you:° ((croaky voice for 0.9))
4
5 13 (0.6)
6
7 14 M: Well I d↑on't know what, (0.8) um (1.6) I mean d- d
8
9 15 hospital's principles and stuff are I don't know.
10
11 16 [.hh]
12
13 17 Dr: [Yeah]
14
15 18 M: So, (0.3) what are my options.
16
17 19 Dr: <So what I think what we should do: [n_o:w, is] ur .HH
18
19 20 M: [Yeah]
20
21 21 Dr: (0.2) as of now we are supporting him with the milk,
22
23 22 M: Y:ep.
24
25 23 Dr: ur- an:dur we're giving him: >that< cardiac medicine:,
26
27 24 [.HH](.) to open up.
28
29 25 M: [Yeah.]
30
31 26 (.)
32
33 27 M: °Yeah.°
34
35 28 (0.6)
36
37 29 Dr: As of n↑ow we can make a f-first early decision: n_o:w,=
38
39 30 M: =Ye[ah.
40
41 31 Dr: [to: (0.2) what I would suggest, and as a team agree:,
42
43 32 Dr: [that-]ur: (0.2) .hh (0.4) just in: (.) <case if he=
44
45 33 M: [Yeah.]
46
47 34 Dr: =does:, collapse [an if he] does, (0.2) >or< 'is=
48
49 35 M: [Yeah]
50
51 36 Dr: =oxygen l↑evel drops dow:n,=
52
53 37 M: =Yeah
54
55 38 Dr: We shouldn't make any further intervention.
56
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60

The sequence is initiated with Mum's question "So what next." This makes relevant a future-oriented conversation about Nathaniel's treatment. The initial part of the doctor's response

1
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3 looks superficially collaborative, using the pronoun “we” at lines 3 and 5. However, the
4
5 decision-making itself does not turn out to be collaborative; rather the doctor will
6
7 recommend, unilaterally, the course of action.
8

9
10 We have identified two key features of recommendations, exemplified in the above
11
12 extract. First, the doctor prefaces his recommendation about Nathaniel’s treatment decision
13
14 with the phrase “the right thing for this baby” (lines 5-7). This phrase was used recurrently
15
16 throughout decision-making sequences, and often as a preface to strong recommendations
17
18 from doctors. It is almost idiomatic, and places constraints on the parents: if they disagree
19
20 with the course of action, they are not acting in the best interests of their baby. Second, the
21
22 recommendation is further couched as being the shared perspective of the team of doctors
23
24 (line 31). Challenging the recommendation of a team of experts is a difficult thing to
25
26 accomplish interactionally; doctors are more entitled to the medical knowledge upon which
27
28 decisions are made than parents are (Heritage, 2012). The recommendation itself: “what I
29
30 would suggest....we shouldn’t make any further intervention” (lines 31-38) uses a verb of
31
32 moral obligation (“shouldn’t”) which strongly favours the recommended course of action. No
33
34 other course of action is considered. Furthermore, “I would” is a modal construction which
35
36 frames the “suggestion” as patterned or predictable and therefore a course of action that is
37
38 normative (Edwards 2006), and more difficult to resist. These design features set up
39
40 acceptance as the ‘preferred’ response, and means that challenging or resisting such a
41
42 recommendation is interactionally more difficult to achieve for the parent.
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48 Note also, however, that before the actual recommendation happens, the doctor invites
49
50 Mum to share her thoughts (lines 11-12), resembling what Maynard (1992) calls a
51
52 ‘perspective display sequence’. By seeking the mother’s perspective, the doctor forecasts the
53
54 upcoming bad news, enabling his subsequent bad news to be fitted to her perspective. Mum
55
56 does not provide her perspective on ‘what next’, however, but goes on to ask what her
57
58
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options are – providing instead, her preference to get information prior to providing her perspective (line 18). But instead of listing options next, the doctor begins to deliver a recommendation “what we should do now”. The “we” is ambiguous; it might refer to him and Mum, as a collaborating unit, but it might refer to the medical team. So, although Mum specifies a preference for options, a recommendation is prioritised nevertheless; the bad news turn is not fitted to Mum’s perspective. The extract ends with the doctor’s clear recommendation (line 38). We return to the conversation a few moments later.

Extract 2: F1R3, Part B (60-91)

60 Dr: so- (0.3) we’ll see how: (.) we can take it °f-° next
 61 step (0.4) after a couple of days.
 62 M: Right but then what you’ve- from what- from what you’ve
 63 said if I- .hh got you r:ight (0.7) if the- (0.5)
 64 breathing deteriorates,
 65 Dr: >Yeah.<
 66 (0.2)
 67 M: Then you’re just going to leave it to nature to takes its
 68 course.=
 69 Dr: =Yeah
 70 (1.1)
 71 M: Do I have an option there.
 72 (0.4)
 73 Dr: The- (0.4) wha-: there- a- I- (.) there is:: (.) wh-
 74 >when you mean< †option: (.) of prolonging him,=
 75 M: =Yeahh
 76 (1.3)
 77 Dr: i- >is that-< (0.2) not causing mor:e suffering °to him,°
 78 M: .hhhh °(rihhght)° >PHH< >PHH< [(put it [this way)

- 1
2
3 79 Dr: [With [this: cardiac con-
4 -dition, (0.2) if you, (0.2) put (0.2) intervention
5
6 81 sma:ll, [just] by prolonging °his life°, (.) .hh now=
7
8 82 M: [Yeah]
9
10 83 Dr: =we know that (.) despite, (0.2) whatever the condition
11
12 84 i:s, [the long] term outcome is:
13
14 85 M: [Yeahh]
15
16 86 Dr: (0.4)
17
18 87 M: Ye:ah=
19
20 88 Dr: =N:ot (0.3) °that we would expect.°
21
22 89 M: Yeah.=

23
24
25 In the interim between Extracts 1 and 2, Mum did not accept the course of action or display
26 alignment with the recommendation, responding with only unmarked acknowledgments (e.g.,
27 “aright” and “mm”) which, according to Heritage and Sefi (1992) show implicit resistance.
28
29 She shows further resistance (lines 62-68) by formulating the *negative* upshot of what is
30 being proposed (“Right but...”). At line 71, Mum orients explicitly to the limited optionality
31 presented by the doctor, by challenging its absence (“Do I have an option there.”).

32
33
34 So, having asked for options earlier, Mum now recognizes that she has not been
35 presented with any. The doctor continues to limit optionality through questions that package
36 the alternative option negatively (lines 77-81). His turns are littered with markers of trouble
37 and perturbations (cut-offs and restarts), making the beginning of a dispreferred response;
38 one that foreshadows bad news (see Maynard, 2003) and one that does not affiliate or align
39 with Mum’s turn. That is, the doctor fails to align by not responding to Mum’s yes-no
40 question (line 73) with a ‘yes’ or a ‘no’, and by not actually providing any requested options.
41
42 Instead, he asks a negatively framed question, “>is that-< (0.2) not causing mor:e suffering
43
44 °to him,°” which is highly challenging in return, seeking agreement with an assertion as
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opposed to eliciting an answer to a question (see Bolinger, 1957, Heritage, 2002). The doctor effectively proposes that Mum's preferred course of action would result in the suffering of her own baby, at her behest.

A similar pattern can be observed in Extract 3, from a different consultation, which starts at the end of the doctor's unilateral recommendation.

Extract 3: F1R4

1 Dr: =That's what we wanted to, (1.5) °to tell you.=
 2 How do you feel b- what are you thinking.°
 3 (0.7)
 4 Dr: I >know it's not< °the easy thing [to do.°]
 5 M: [Ye:ah] and
 6 it doesn't look like I have an option.
 7 (.)
 8 Dr: .hh [it's] [No i:-] it's not about you having an=
 9 M: [there] [so:]
 10 Dr: =option [it's about what is the right] thing for=
 11 M: [.H H H H]
 12 Dr: =the baby [isn't it] Helen.
 13 M: [It's- yeah.]

Like Extract 1 ("what are your thoughts"), the doctor invites Mum to comment on the decision-making process as it is unfolding ("what are you thinking"). This time, although the question seeks the recipients' perspective, it does not work to forecast bad news delivery and does not align this with Mum's perspective because it comes *after* a one-sided recommendation: "... what we wanted to tell you" (line 1). After no ratification from Mum (line 3), the doctor orients to the difficulty of the decision, but does not present alternative

options. Like Extract 2 (“Do I have an option here”), Mum’s response makes explicit the constraint that is being imposed by orienting to the apparent lack of options that she has: “it doesn’t look like I have an option” (lines 5-6). This explicit orientation goes further than the previous extract, by actually stating that this appears to be the case, rather than enquiring about it. Indeed, in this case Mum is being informed about a decision that has essentially been made. The doctor’s account for presenting only one option is to invoke a contrast between ‘options’ and “the right thing for the baby.” The tag question (“isn’t it Helen”) pursues acceptance of the latter and from a position of certainty with regards to the answer (see Hepburn and Potter, 2011; Heritage and Raymond, 2012).

In the next conversation, from a different case, the doctor has been telling Mum about her baby’s poor condition before reporting on how he had presented the case at the ‘grand round’ (a weekly meeting for doctors and nurses to discuss the management of serious cases). We join the conversation as the doctor presents the decision of the team.

Extract 4: F24R2, Part A (1-49)

1 Dr: [We were] abou:t, ur (0.3) thirty: or thirty five doctors
 2 °and nurses were there.°
 3 (0.3)
 4 M: [(tcha)]
 5 Dr: [>And so the<] .hh good practice we discuss (0.5) with
 6 everybody. (1.6) An I did* (0.7) discuss abou:t, (0.2)
 7 >the< ca:se? (0.6) plus the family >as well it’s< al:ways
 8 babies in the centr:e, .hh (.) an the familie:s around the
 9 °baby.°=
 10 M: =Mhm
 11 (0.4)

1
2
3 12 Dr: °>But<° no baby is without the mummy daddy
4
5 13 [an' the fam]ily.=
6
7 14 M: [Yeah °def-°] =Yeh.
8
9 15 Dr: .hhh hhh (0.4) And- (2.1) we:, (.) >this is< (0.8) <our
10
11 16 professionals'>
12
13 17 M: Mhm,
14
15 18 (.)
16
17 19 Dr: °Vie:w,° (3.3) considering <how sick> (0.6) Adeline wa:s?
18
19 20 M: Mhm=
20
21 21 Dr: =>it's not just the breathing alone< how sick she was
22
23 22 (0.2) [to start] with.
24
25 23 M: [>Yeah.<]
26
27 24 M: Yeh.
28
29 25 (.)
30
31 26 Dr: .hhh How lo:ng it took (0.2) for the lactate >(to) away<
32
33 27 acid level to normali[:se,] (1.1) .hhh (0.3)=
34
35 28 M: [Mhm]
36
37 29 Dr: =an' considering Adeline's: ur (0.3) condition inside your
38
39 30 tummy:?
40
41 31 (0.8)
42
43 32 M: .hh HH[H]
44
45 33 Dr: [An'] considering amount of s- (1.5) °i-° intensive
46
47 34 care support Adeline is nee:di:ng,
48
49 35 (.)
50
51 36 M: Mhm
52
53 37 (0.6)
54
55 38 Dr: Plus: (0.5) the amount of bleeding (0.6) already happen:,
56
57 39 { (2.9) }
58
59 40 { ((paper movement for 1.4)) }
60
61 41 Dr: °if you like in the best interests of the baby and the
62
63 42 family: , =

1
2
3 43 M: =Mhm
4
5 44 (.)
6
7 45 Dr: To: consider (0.9) changing (0.4) the intensive care:
8
9 46 (0.5) into palliative care: or comfort care.°
10
11 47 M: >What does that mean.<
12
13 48 (.)
14
15 49 Dr: °Yes° (0.2) thank you.=I will explain to you.
16
17

18 Like previous extracts, we can see how a one-option decision, to move from intensive care to
19 palliative care (lines 45-46) is presented as that of an expert team (lines 1-6; 15-16) and in the
20 baby's 'best interest' (line 41, but also implicitly at line 8). Note the extent of this joint
21 decision is emphasised through the enumeration of 35 doctors and nurses. This builds the
22 recommendation that follows as corroborated (by professionals), and therefore robust, making
23 disagreement or resistance a challenging thing to do (see Potter, 1996). The doctor builds a
24 case for this future course of action by presenting a number of pieces of evidence (lines 19-
25 38) prior to the delivery of the recommendation itself. These design features - particularly the
26 enumeration of professionals in agreement and adverse aspects of the baby's condition - build
27 a strong preference for acceptance of a particular future course of action. They also work to
28 forecast the bad news recommendation that follows (Maynard, 2003).
29
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42 Rather than accept or reject the decision, Mum asks a question of the doctor, to explain
43 his recommendation (line 47). This question is somewhat challenging; Mum may not
44 understand the doctor's recommendation but her response is couched in a direct way that
45 holds the doctor accountable for not having presented something comprehensible to a non-
46 expert. A similar response to one-option recommendations was also observed in the following
47 extract from another consultation.
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Extract 5 F8R1, Part A (1-5)

1 Dr: =.hhh (0.3) we::, as a group of doctors, (0.4) an
 2 nurses, (2.9) fee::l, (0.6) in his best interest, (1.3)
 3 we should*, (1.0) change his (0.2) active intensive care
 4 into (0.4) °palliative care.°
 5 M: What does that mean.

In Extracts 4 and 5, note the use of ‘palliative care’ which shrouds the bad news, as what is essentially being proposed is that the baby will be allowed to die (see Maynard, 2003).

We return to the conversation in Extract 4 following the doctor’s explanation of palliative care, throughout which Mum produces only unmarked acknowledgments.

Extract 6 F24R2, Part B (110-137)

110 M: =Mhm
 111 Dr: But when we ↑do tha:t (0.5) .nhh ninety nine point nine
 112 nine p↑ercent (0.5) withi:n, (0.3) few minutes to (0.2)
 113 few hours (0.3) she will stop breathing.
 114 (0.6)
 115 M: You’re telling me to kill my baby °basically.°
 116 Dr: Sorry mother,=
 117 M: =You’re telling me to: like take the tube out so I can
 118 kill my baby.
 119 (.)
 120 Dr: I- (0.3) I- >I- I-< d*i*:n’t din >I- I-< I din’t say that

- 1
2
3 121 you're not (be'd) I- we are s- we are proposing:? .hh
4
5 122 [°that is why we're here.°]
6
7 123 M: [You're proposing me that] I should do that so:=
8
9 124 Dr: =No not [you]=
10
11 125 M: [>I get it.<]
12
13 126 Dr: =We are (re:al) >you know uh it's- uh< we should make it
14
15 127 very clear because we shouldn't make you to feel like you
16
17 128 done it.=
18
19 129 M: =Mkay. Well [obv- it will] be me that's doing it =
20
21 130 Dr: [>Yeah< >yeah<]
22
23 131 M: =because it's a dec- (0.2) <so: are you saying >now,< (.)
24
25 132 >that< this is what you would like to do:, or is it
26
27 133 something that (0.2) I have a decision, to make,
28
29 134 [or]
30
31 135 Dr: [Y:eah<] we are jus-, (0.3) we are recommending, what is:
32
33 136 best* i[:n the] baby's interest.
34
35 137 M: [Okay.]

36 This sequence is particularly problematic for parent-doctor alignment. The doctor first
37 explains the outcome of moving to palliative care (lines 111-113). In response, Mum
38 formulates what she takes as the negative upshot of this decision: “You’re telling me to kill
39 my baby basically.” (line 115). Leaving the patient - in this case the parent - to formulate a
40 bad news diagnosis has been identified by Maynard (2006) as a dispreferred or interactionally
41 problematic thing to do, and we see evidence of this here. By enquiring into the nature of the
42 action, Mum resists the constraint imposed by it. Like the parents in previous extracts, Mum
43 raises the issue of her lack of choice (“you’re telling me to”). Her formulation is particularly
44 challenging in that she is using an upgraded, extreme case formulation of what the doctor has
45 said: ‘kill’ as opposed to the baby ‘stopping breathing.’ This has similarities with examples of
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1
2
3 formulations identified by Drew (2003): one in a radio call-in and another in a news
4
5 interview, where in both settings, formulations were designed to be particularly tendentious
6
7 in order to create controversy. In response to Mum's formulation (with "kill" being in sharp
8
9 contrast to the more euphemistic ways that doctors typically refer to end-of-life and/or death),
10
11 the doctor issues an open class repair initiator ("Sorry mother"), which can be a marker of
12
13 interactional trouble and through which the doctor provides a slot for Mum to reframe her
14
15 action (Drew, 1997).
16
17

18
19 However, Mum continues to resist the doctor by repeating her challenging formulation
20
21 (line 117-118). She inserts new information "take the tube out" but does not reformulate
22
23 either the agency of the activities under discussion ("you're telling me") nor the marked use
24
25 of "kill my baby" (lines 116-118). By continuing with her challenge, the doctor is wrong-
26
27 footed, or put in an interactionally difficult position: note the perturbations throughout line
28
29 120: "I- (0.3) I- >I- I-< d↑i:n't din >I- I-<". He also works to reframe the decision in a more
30
31 positive light; as something the doctors are responsible for rather than Mum having to carry
32
33 that burden. Furthermore he minimizes the action by saying that "we are *jus-* recommending"
34
35 (lines 135-136), adding that the recommendation is "in the baby's best interest". Towards the
36
37 end of the extract, Mum inquires further into the degree of choice that she has ("this is what
38
39 you would like to do:, or is it something that (0.2) I have a decision, to make").
40
41
42

43
44 In Extract 6, then, we see further evidence for an emerging pattern, in which doctors'
45
46 recommendations are shored up via recourse to the 'best interest' idiom, but met with
47
48 resistance from parents and shot through with interactional trouble about the constraints such
49
50 a course of action foster. Extract 7 is a final example of parent responses to doctor-initiated
51
52 presentations of a one-option recommendation.
53
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Extract 7: F8R1, Part B (28-37)

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Dr: .hhh So- (0.2) in our vie:w, (1.7) <that's what we feel.
But ↑you have a th↑ink about [i:t?]

M: [So what's] the
difference if you ta- if: (0.4) you take him off the
ventilator, [then](0.4) he can (.) deteriorate an di:e.

Dr: [Yeah.]
(1.3)

M: S[:o]

Dr: [Ur ye-] uyoy, - °um ne-° (.) yes I should be honest
yeh.=If you don't provide this intensive care:, (.)

28
29
30
31
32
33
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37

Again, the doctor presents the medical view and invites comment from Mum (see Extracts 1 and 3). Like the mother in Extract 6, Mum's response is to negatively formulate the upshot of the doctor's recommendation using the marked term "die", which is followed by interactional trouble (a delay, line 34, and perturbations in the doctor's response, line 36).

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In this section, we have seen that misalignment and disaffiliation between doctors and parents follows a particular practice for initiating decision-making: making recommendations. In each case, the parent resists a unilateral course of action by asking explicitly about their options, asks challenging questions, or formulates challenging turns about the upshot of explanations. In other words, it seems that trouble and communicative conflict of some kind follows unilateral decision-making. We now move on to contrast this finding with what happens when an alternative approach to decision-making is taken.

1
2
3 2. *Providing options*
4
5
6

7 The second analytic section shows how decision-making can be organized differently, via
8 presenting options, and how this organization provides for quite different consequences. The
9 examples resemble a type of ‘option-listing’ identified by Toerien et al. (2013) in neurology
10 encounters, and we show not just how options are formulated but how optionality opens up
11 interactional space for parents to assert their preference and in a way that recommendations
12 do not.
13
14
15
16
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18
19

20 In Extract 8, the doctor has just informed the parents of the MRI report for their baby
21 who has had severe lack of oxygen at birth (‘severe HIE’). A prediction of moderate to severe
22 disability has been made. The baby’s breathing is currently being supported by a ventilator
23 but is reaching a stage where he will naturally be taken off to allow him to breath non-
24 assisted. The difficult decision here concerns whether the baby should be put back on the
25 ventilator if he starts to struggle, given his poor prognosis. This is the first time the decision
26 has been raised, but there have been some discussions around the possible redirection of care
27 from intensive to palliative previously.
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41 Extract 8: F4R1, Part A (1-128)
42
43
44

45 1 Dr: hh >Um< (0.8) the difficult question? (0.2) an the
46 difficult thing:, (0.3) that you will now need to go
47 away and think about? (0.3) i:s (0.4) what do we do,
48 (0.4) if after we take the tube away, (0.4) °he doesn’t
49 cope.°
50
51
52 (0.5)
53
54
55 7 M: [(°°Okay.°°)]
56
57 8 Dr: [°°Right,°°]
58
59
60

9 (0.5)

Note that, unlike the sequences presented in the first section, issues of ‘best interest/doing the right thing’ are *not* mentioned in the doctor’s preface about a “difficult question” that the parents need to “go away and think about” (lines 1-3). The design of his turn presupposes the parents’ involvement in the decision without specifying what the doctor’s perspective or preference is. The decision is, in this case, also deferred and there is no interactional requirement for an immediate answer (lines 2-3).

The conversation continues, following the doctor’s emphasis on the difficult nature of the decision and the value in having a clear plan in place.

Extract 9: F4R1, Part B (157-185)

158 Dr: [>An’] it’s< much better (.) doing all of that, an
 159 >having it<
 160 (0.4) planned properly, (0.6) rather than, (1.4) making,
 161 (0.2)
 162 s:significant change [that]=
 163 M: [Okay.]
 164 Dr: =>you know< (0.4) if he wasn’t breathing properly his
 165 oxygen levels had been sitting at forty percent for a
 166 couple of hours, (0.2)
 167 M: Ye[h].
 168 Dr: [it’s n_ot inappropriate to just give oxygen.
 169 M: [Okay.]
 170 F: [Yeh.]=
 171 Dr: =cause that will have c_aused more d_amage an, (0.4)
 172 >YOU KNOW< SO IT’S KIND OF BEING QUITE CLEAR ABOUT,

1
2
3 173 (0.2)
4
5 174 M: Yeh.
6
7 175 Dr: what we do.
8
9 176 M: °Okay.°
10
11 177 (0.5) / (?)
12 178 Dr: OBVIOUSLY BECAU:SE (0.4) >this is something that-< (.)
13
14 179 that (0.3) can: >you know< this: (0.3) he could, (0.4)
15
16 180 survive for, (0.3) a very long period of time, we
17
18 181 wouldn't ordinarily elect to take his tube out an just
19
20 182 give him morphine?
21
22 183 (0.2)
23
24 184 M: °Kay.°=
25
26 185 Dr: =°Okay,°
27
28 186 (0.7)
29
30 187 Dr: But if over the course of tomorrow he became, (0.4)
31
32 188 very [distressed] and we decided that 'actually=
33
34 189 M?: [°mhm°]
35
36 190 Dr: =we're just not gonna put his< (0.2) just his tu:be back
37
38 191 down again,' (0.5) then: we might well, (0.3) give him
39
40 192 morphine if you felt that that would help 'im.
41
42 193 (0.3)
43
44 194 Dr: °Okay,°=
45
46 195 M: =°Okay.°
47
48 196 Dr: So: (.) there's tho:se little things that we can
49
50 197 certainly do:, (0.4) when the need arises[:,]
51
52 198 F: [Yeah.]=
53
54
55
56
57
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The doctor presents the parents with information regarding support for the baby and the options that might be considered, using conditional 'if-then' formats. Should the baby struggle to breath, he could be provided with oxygen (line 168), or oxygen and morphine

(lines 178-192). Packaged within these options is also the possibility of putting the ventilator support back in place: “it’s not inappropriate to just give oxygen” (line 168), indicating that it could be appropriate to do more. Interestingly, the doctor actually lists the options that are other than reinserting the tube, thus favouring the provision of oxygen and morphine through the delivery of information, rather than in the form of a recommendation. Still, this is the less invasive of approaches in which life sustaining treatment could potentially be withheld and therefore the baby allowed to die.

The implications for the trajectory of the decision-making process are two-fold. First, by deferring the relevance of the decision to the next day, the doctor makes relevant acknowledgment tokens in response to the information being provided as opposed to an accept/reject response to a recommendation (see Silverman, 1997). Second, by presenting options, an acceptance or rejection of a unilateral recommendation is not made relevant and the parents are invited to present their preference in the future.

The segment below, from the same conversation, follows the doctor’s summary of the uncertainty regarding when the need will arise for breathing support following extubation.

Extract 10: F4R1, Part C (250-270)

250 Dr: [Be-cause, (0.2) we may need to be guided by you, we
 251 this is not a decision that we (0.6) take on our [own.]
 252 N: [mm]
 253 M: Okay.
 254 Dr: All right we’re guided by you.
 255 °What you want us to do.°
 256 (0.4)
 257 M: °Okay°
 258 (2.4)
 259 ? chm

1
2
3 260 (2.2)
4
5 261 Dr: °°Any questions.°°
6
7 262 (0.2)
8
9 263 F: hmm, (0.3) >do you,<
10
11 264 M: Not yet,
12
13 265 M: [°I° probably] will [have] £tomorrow,£ or when I go
14
15 266 F:? [hhuh] [.hh]
16
17 267 M: away and [think about it yeah.]
18
19 268 F: [U- >obviously,<](0.5) >in terms of going
20
21 269 (↑out with this,)< (0.4) the aim is to take the tube out
22
23 270 tomorrow...

24
25 The doctor closes the sequences by framing the decision as not final and one that is guided by
26 the parents. In doing so, the doctor avoids favouring a particular decision and therefore
27 removes immediate interactional constraints to make one. A third implication for this format
28 for decision-making is that the parents are able to deliver inquiries in an interactional space
29 where they are not framed as challenges. In Extract 10, the doctor invites the parents to ask
30 questions (line 261) and the father then begins to ask about what it is they need to decide
31 following extubation (line 268).
32
33
34
35
36
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39

40 Compare the father's question in Extract 10 above with the extract below, taken from
41 the same conversation as Extracts 5 and 7 in the first analytic section, where Mum is asking
42 questions following a unilateral 'recommendation'.
43
44
45
46
47
48

49 Extract 11: F8R1, Part D (59-67)
50

51
52
53
54 59 M: [(°I think we should°)] (0.5) doesn't [he,]
55
56 60 Dr: [(Other Dr name?)]
57
58
59
60

1
2
3 61 M: (.) the doctor said that the swelling on his brain would
4
5 62 get bigger before it got better,
6
7 63 M: So doesn't he nee- (.) like (0.3) it will
8
9 64 [have to get](0.5) doesn't he need like (0.2)=
10
11 65 Dr: [It's]
12
13 66 M: =time for it to see if it's gonna down at all, or (.)
14
15 67 like (...)

16
17
18 At line 63, Mum uses a negative interrogative question design (line 63) which challenges the
19
20 doctor's recommendation explicitly (Heritage, 2002); that is, "doesn't he" resists the position
21
22 being proposed in the discussion thus far. Mum is in an oppositional position to the doctor, in
23
24 which her inquiries push back against the constraint that has been imposed by his
25
26 recommendation.
27

28
29 Extract 12 comes from a conversation with the same family as in Extracts 8-
30
31 10, and occurred 20 days after the conversation in those extracts. It comes after
32
33 options have been provided by the doctor regarding withholding care and provides
34
35 a further example of how an interactional space for questions is opened up
36
37 following the articulation of options rather than recommendations.
38
39
40
41

42 Extract 12: F4R3 (171-182)
43
44
45

46 171 Dr: U:m so (0.3) yeah, (0.3) [shall] we leave it=
47
48 172 M: [>Yeah.<]
49
50 173 Dr: =there, so you- (.) °it° [GIVES YOU] SOME TIME=
51
52 174 F: [Um-]
53
54 175 Dr: =to think about this [on:e] yeah,]
55
56 176 F: [Yeah.]
57
58 177 M: [°That's (right/fine).°]
59
60

1
2
3 178 F: [>I've got a couple of<] questions [if-]
4
5 179 Dr: [↑Yes] please go
6
7 180 [ahead.]
8
9 181 F: [Just-] (1.6) when he comes ↓off:
10
11 182 Dr: Yah,

12
13
14 As in Extract 10, Dad initiates a question-answer sequence with a pre-sequence about “a
15
16 couple of questions” (line 178), which is then given the go-ahead by the doctor. The
17
18 questions have been invited rather than taking the form of a challenge to what has been
19
20 proposed (as in Extract 11, following a recommendation).
21

22
23 In the next example, the consultant has come to talk to the parents who have a
24
25 threatened delivery of twins at 23 weeks gestation. One of the twins has no amniotic sac and
26
27 the subsequent discussion focuses on the other baby, who has better chance of survival. The
28
29 consultant is talking to Dad as Mum is receiving oxygen and is unable to speak. The
30
31 consultant has informed Dad that, at this stage, the babies have a very slim chance of survival
32
33 and a significant risk or severe and significant disability. The option of palliative care has
34
35 already been raised at this point as something that some parents (with the doctors agreeing)
36
37 would think is best for the baby, and a description of palliative care provided.
38
39
40
41

42 **Extract 13: F16R1**

43
44
45 1 So- so the options are:, .hh (0.4) that (0.2) we would,
46
47 2 (1.0) °offer palliative >care,< (.) which is [just]
48
49 3 F: [(°Right°)]
50
51 4 D: (0.2) comfort and support,° .hhh or we would offer intensive
52
53 5 care.
54
55 6 (0.4)
56
57 7 D: By this, we would put a (0.2) ↑tube into the baby's ↑lungs,
58
59 8 (0.2) and, (0.2) attach him to br↑eathing (0.4) machine an
60

1
2
3 9 breathe for him, an transfer him, .hh if he (0.3) survives
4
5 10 the whole delivery, .hhh and labour, and then we would admit
6
7 11 him to the neonatal unit. .hhh

8
9 12 (2.3)

10 D: And see how he goe:s from there: but he may not (0.2) make
11
12 it.=Even if we, do all of that, he may not make it through
13
14 the labour? (0.2) .hh (.) he may not (0.3) make it (0.9)
15
16 once [he has] (0.2)

17 F: [.HHtH] Because urm=

18 D: =born.

19 (.)

20 F: the issue of:: that palliative care, (0.3) .hhh (0.2)

21 °don't° mm:: (0.7) ou- o- >of the- ↑of the, of the,< I un- I
22 understand the reasons for it, (0.4) but (2.0) tch (0.6) I
23 ↑don't she will be able to >cope.<

((Dad continues to expand on how Mum will find it hard to
resign herself to the fact that the babies will not make
it))

65 F: So:. (1.2) °it's-° (0.2) really gonna be, bit of a: (1.5)

66 >it's gonna be really hard for her emo- emo[tionally.<]

67 D: [<So] what

68 you're saying> is that you feel that mum would like to give

69 the babies every (0.2) chance.=Is that? (0.5) right?

70 (0.3)

71 F: I guess so yeah.=

72 D: =°Yeah.°

73 (0.4)

74 D: [But mum is]too sleepy [to[(0.3) [talk] at the moment.=An

75 F: [I per- #go:#] [mm[: [:]

76 D: anyway I think we have some time [to have these] (0.2)

77 F: [mm:]

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2
3 78 D: discussions.
4

5 ((Dad continues to expand on how Mum will find it hard to
6 resign herself to the fact that the babies will not make
7 it))
8
9

10 102 F: Obviously on- on the other ha- on the other hand, .HHH
11

12 103 ((chair moves/(0.6))) (5.5) i- (1.5) it might sound a bit
13

14 104 crude but (1.7) eh I wouldn't want to start:, (0.2) have the
15

16 105 urm: (0.8) tch °but° (0.4) a- added burden of: (0.6) having
17

18 106 to look after a- (0.2) ch- child, .hhh (0.4) who's gonna
19

20 107 who's gonna- (0.8) .hhh (0.3) not having, (0.2) who's gonna
21

22 108 hav:e, (0.2) °is disad- (m) whose who is kind of: (0.5)
23

24 109 disadvantaged.=
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26
27

28 The consultant presents two options: an 'either/or' decision between palliative care and
29 intensive care (lines 1-5). The options are both offered and parental choice is emphasised.
30

31 Palliative care was described earlier, perhaps explaining why more attention is given to
32 intensive care in this extract. However, intensive care is framed negatively as something
33 contingent: "if he survives the whole delivery" (lines 9-10) and with limited prospects "he
34 may not make it" (lines 13-16). Furthermore, 'he may not make it' is emphasised by
35 repetition to mark two different time points: in labour and once he has been born.
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43 Dad takes several extended turns, weighing up the two options. He acknowledges
44 palliative care as something appropriate: "I understand the reasons for it" (lines 21-22), and
45 goes on to assert what he takes to be Mum's perspective "I don't (think) she will be able to
46 cope" (lines 23-24). There is some trouble in delivering his response, which might be
47 explained in part by English not being his first language. He elaborates his perspective in the
48 omitted section (lines 24 to 64), stating how Mum will find it hard to resign herself to the fact
49 that the baby will not survive; the upshot is formulated in lines 65-66. The doctor also
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3 formulates the upshot of Dad's turn in terms of its relevance to decision-making: "you feel
4 that mum would like to give the babies every chance", and seeks confirmation of this from
5 Dad with the tag question. Dad provides a hedged confirmation with 'I guess' (line 71) and
6 after a delay, the actual decision is then deferred by the consultant, to a time when mum is
7 able to talk.¹
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14 Dad therefore able to articulate his own preference and his concerns about having a
15 disadvantaged child (lines 102-109). While he orients to the potentially problematic hearing
16 of this preference ("it might sound a bit crude"), and his turn is littered with delays and
17 perturbations, he nevertheless communicates his perspective. In particular, he assesses the two
18 options in a non-adversarial context; the perspectives are not positioned as challenges to a
19 recommendation. This supports Toerien et al.'s (2013) findings that option listing, as seen
20 here, provides interactional space for parents' preferences to be stated; going beyond a less
21 agentive and more minimal accept/reject response and thus implicitly carving out an
22 environment for shared decision-making
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34 In the final extract, the baby has severe neonatal encephalopathy and is one month old.
35 The consultant has met with the parents and community nurses for the baby's discharge
36 planning meeting. It is relevant that the baby has poor secretion management and is not
37 currently able to bottle feed. The doctor recaps the conversation thus far before moving on to
38 raise the issue of whether and how far the baby will be actively resuscitated should the need
39 arise, once the baby has been discharged home.
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54 ¹ This opportunity actually arises in the current conversation and after exploring the two
55 options extensively, the parents state their preference that they would like the twin with the
56 better chance to have intensive care and the other twin to receive palliative care. However,
57 the decision is still ultimately contingent on how long the babies can stay in the womb and an
58 assessment on the baby's condition at birth.
59
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Extract 14: F15R1

1 Dr: So:, (0.5) to recap, we talked abou:t (1.1) rooming in,
2 we talked about the vaccination. >.hh< Now one (0.7) one
3 more impo:rtant and (0.3) s:ensitive issue I wanted to
4 talk i:s, (0.4) tcha (2.9) if: (0.9) °for° our bad luck
5 if (0.2) things >you know< abruptly: stopping breathing:
6 or stops heart- .hhh/(0.8) we need to make a plan and we
7 need to write in the notes [like,]=
8 F: [>Sure.<]
9 Dr: =how far: we [should] (0.3) the reason I'm going straight
10 F: [(Sure)]
11 Dr: because you had this discussion: in: in- with the other
12 colleagues.
13 M: Yeah.
14 F: (that's [[two syllables]])]
15 Dr: [If you want me to go] slowly I can[: discu- no
16 F: [No no
17 F [>we've had this conversation<] a few times already (so)]
18 Dr: [.hhhh]so: we need to]
19 (1.1) make a pla:n, (1.8) if that (0.5) acute, (0.2)
20 arrest or stop breathing kind of things happen, .hh/(0.4)
21 how far: we should (1.3) go: like whether, (0.4) >just<
22 mask ventilation:, <suction mask ventilation oxygen:, .hh
23 or putting the tube in to the breathing pipe, (0.2) an
24 breathing, and ((pat pat pat))[pumping] the heart, and
25 {((pat))}
26 Dr: giving the medicine as well:.
27 (2.3) ((an in-breath during))
28 Dr: Because, (0.8) you had this talk (1.4) many ti:mes,
29 (0.8) I'm happy to give you and option. (.) <a wh- (1.1)
30 cha:nce for you to tell me or, >.hh< if you want me to

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2
3 31 tell, (.) what is in Aran's best interest from the
4
5 32 professional point of (0.5) °vie:w,° (0.2) I can tell.
6
7 33 Whatever you want me to do.
8
9 34 (0.2)
10
11 35 Dr: [Would-
12
13 36 F: [Yeah.
14
15 37 (0.6)
16
17 38 F: Wll- #ur:# (2.3) I'm (0.8)
18
19 39 M: Unchanged.
20
21 40 F: Unchanged as to our last decision,
22
23 41 M: Yeah.
24
25 42 F: Which was a::<an escalation from the previous decision.
26
27 43 (.)
28
29 44 Dr: >mm<
30
31 45 (0.4)
32
33 46 F: U:m: (0.8) #ur# the- the current (0.5) the current
34
35 47 thinking is that* <if: Aran <requires> (0.4) intubation
36
37 48 again,
38
39 49 Dr: [>mm<
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41 50 F: [(that) (0.2) we are fine to do that,
42
43 51 Dr: °Okay.°=
44
45 52 F: =And (0.6) then make a decision as to >whether< that's
46
47 53 continued,<once he's (.) intubated.
48
49 54 Dr: °Okay.° ((mouthed))
50
51 55 (0.6)
52
53 56 F: Ur:m: (0.4) but we would not want (0.2) ur if- if his
54
55 57 heart, (0.3) ur: gave up, we would not want that (0.3)
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57 58 [resusc]itated.
58
59 59 Dr: [Q°kay.°]
59
60 60 Dr: Q°kay.° .hh

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4 Again, the decision is presented as a collaborative activity (“we need to make a plan”, line 6);
5
6 rather than a team recommendation, and the parents are included. The doctor lists
7
8 possibilities for treatment (lines 22-26), should the need arise, which starts with the least
9
10 amount of intensive care and ends with the most. The parents are also asked whether they
11
12 would like to be *given* a recommendation or to express their preference directly, as they have
13
14 had these discussions before (lines 28-33). This option is delivered following a 2.3 second
15
16 silence from Dad. This nicely demonstrates the doctor’s responsiveness to the possibility that
17
18 the Dad may not wish to make this decision. ‘Best interest’ is only mentioned here in terms of
19
20 offering the parents the possibility of a recommendation from the doctors’ perspective (lines
21
22 31-32), rather than in the initiation of the decision point itself. This suggests that the baby’s
23
24 best interest is already known and yet ‘from the professional point of view’ raises the
25
26 possibility of alternative, parental point of views. The parents respond by presenting their
27
28 preference in an extended way, rather than taking up the option of a recommendation. There
29
30 is some hesitation from Dad at first, but this may be about making sure he is aligned with
31
32 Mum. Dad does not seem to present his preference as something dispreferred or problematic
33
34 and the absence of an account provides evidence for this.
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40 We have shown that, when doctors use an option-listing format in decision-making
41
42 sequences, the trajectory of the interaction is much smoother, with aligned participation, than
43
44 when recommendations about a particular course of action are made. Our analysis supports
45
46 Toerien et al.’s (2013) findings that option-listing provides space for the recipients’
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48 preference to be stated, going beyond a less agentic and more minimal accept-reject
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50 response.
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DISCUSSION

This paper presents an analysis of decision-making conversations between medical consultants and parents of critically ill newborn babies. Decisions about life-sustaining treatment, or withdrawing that support, represent some of the most delicate and difficult conversations a parent may have to participate in for their child. We have therefore sought to understand what conversational practices may be identified that provide for aligned decision-making between doctor and parents. We identified two main conversational organizations for decision-making, with clearly different trajectories – which we have termed ‘recommendations’ and ‘options’.

In recommendation sequences, doctors made reference to a robust, corroborated team decision, and one which should be made in the best interest of the baby. These recommendations were designed to strongly favour a particular course of action. Anspach (1993) reported similar findings when observing end-of-life decision-making, whereby doctors recurrently used recommendations and couched as a ‘united front’. Anspach argued that doing so “obscures controversy in favour of consensus and narrows the options presented to the parents” (p. 93). Our analysis revealed such recommendations constrained parents, who sometimes articulated explicitly this constraint by reference to their “limited options”. This strategy also frequently led to parents asking challenging questions and resulted in misalignment between parties. In contrast, Anspach (1993) observed that parents did not tend to resist such strong recommendations and would often withdraw from the neonatal unit instead. This difference is perhaps a reflection of a more recent assertion of patient autonomy, as opposed to the more traditional paternalism in doctor patient relationships.

Such resistance in response to recommendations has been found elsewhere in decision-making sequences. For instance, Quirk et al. (2012) found that psychiatric patients displayed

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3 resistance when decisions were pressured, but asked questions following more open decision-
4 making designs. Ekberg and LaCouter (2014) similarly found that when decision-making was
5 achieved through suggestions rather than questions, patient resistance followed next. In the
6 case of advice-giving, where the recommendation concerned the recipient's future actions in
7 particular, Heritage and Sefi (1992) showed that health visitors' advice to first time mothers
8 was more readily accepted when a stepwise approach was taken, fitting the advice to the
9 perspective of the parent. Indeed, explicit forms of advice, compared with advice given
10 through questions or assessments, have been shown to put more constraint on recipients'
11 subsequent actions. That is, recipients are not given space to specify possible contingencies
12 because an accept/reject response is expected next (Shaw, Potter, Hepburn, 2015). The strong
13 forms of resistance shown in our analysis, and following strong recommendations in these
14 other settings, demonstrate this particularly constrained position in which alternative
15 perspectives or contingencies are not provided for.

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32 We found elsewhere in our data that, when parents aligned with recommendations, it
33 was in terms of passive acceptance rather than via a more agentive statement of preference.
34 This is in contrast to active resistance, similar to that identified by Stivers (2005), in which
35 parents ask questions which challenge the recommendation. In short, there is little evidence
36 that recommendations involve collaboration, 'patient-centeredness', or shared decisions.
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Parallels can be drawn with the unilateral recommendations identified by Toerien et al.,
(2013), and Collins et al., (2005) in their research settings of decision-making in neurology
and oncology interactions, respectively.

When doctors used recommendations, we found that there was little discussion
throughout about the mechanics of the proposed course of action. This left parents to request
this information or simply accept the management of death as a given. Making
recommendations, therefore, seems to embody the expert or paternalistic model of the doctor-

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3 patient relationship (cf. Orfali 2004). In using recommendations, doctors essentially closed
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5 down the discussion, to the extent that parents' alternative perspectives were framed as
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7 challenges
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10 In contrast, we found that when doctors presented options, a different interactional
11
12 trajectory opened up, characterized by strong alignment between parties. Key features of
13
14 these sequences included an orientation to joint decision-making, the construction of the
15
16 action as a 'plan' rather than a decision, the provision of information that did not explicitly
17
18 favour a particular outcome, the listing of options rather than recommending a single course
19
20 of action and deferring the relevance of a decision from the immediate interaction. We also
21
22 found that, either through invitation from the doctor, or via a pre-sequence from parents, the
23
24 option format provided opportunity for parents to ask questions. These questions were
25
26 formatted in a collaborative, rather than challenging way. This is possible because the
27
28 questions come *before* a decision has been made; any question following a strong
29
30 recommendation is necessarily resistant. In option-giving sequences, parents were able to
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32 assert their preference without misaligning with the doctor, as well as not simply acquiescing
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34 to professional judgement.
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39 In essence, in option-listing sequences, questions and preferences arise in a non-
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41 adversarial context whereby decision-making is not contaminated by controversy between the
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43 speakers; what Whalen, Zimmerman and Whalen, (1988) refer to as 'activity contamination'.
44
45 Whalen et al showed how, in an American emergency call, an impasse was reached because
46
47 the caller and call-taker were not interactionally aligned. Rather than a question-answer
48
49 sequence, each speaker's turn became framed as a challenge and dispute became prioritised
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51 as the main activity. In our data, recommendation sequences became marked by challenges
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53 and interactional trouble; the activity of decision-making became contaminated by the
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55 adversarial context through which it arose.
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3 There are certain clinical scenarios where invoking the baby's 'best interests' as a
4 strategy may be appropriate, such as in cases where death appears to be inevitable for the
5 baby and a managed end of life strategy is preferable to prolonging life. However, even here,
6 there are always choices as to how death can be managed, that can be described and
7 discussed. In the recommendation cases, there seemed to be a commonality that the chance of
8 survival was (at least presented as) poor, suggesting that this design might be fitted to a
9 situation where limiting life support is more clearly in the best interest of the baby. However,
10 when options were put forward, this also included cases when the chance of survival was
11 equally poor. Whether the chance of survival is highly unlikely or not, however, by
12 presenting options rather than recommendations, parents are afforded the possibility of
13 exploring treatment possibilities so that they ultimately arrive at an informed and
14 collaborative decision. By exploring options, the parents are afforded the interactional space
15 to have their perspectives aligned with the doctor's. However, when doctors use
16 recommendations, parents' perspectives are not solicited and their options are closed down.
17 Exploration of alternative options is positioned as a challenge to what the doctor has
18 proposed. Beyond the mechanics of the interaction, the lack of options also leaves the parent
19 with anxieties about the commitment of the clinical team to their child if they were to take an
20 alternate path 'against advice'. Some doctors consider this expert model and the primacy of
21 their opinion to be preferable (XXXX). Doctors are instructed to use recommendations
22 (GMC advice) and a test of 'best' interests (Nuffield Council of Bioethics, 2006), without a
23 clear framework as to how these are to be arrived at (Wilkinson, 2013). Transparency in how
24 such conclusions are derived needs to be part of the conversation with parents if their
25 autonomy is to be respected. 'Best interest' is a difficult notion for parents and must be
26 carefully explored by them within the context of their unique family circumstances, alongside
27 the clinical notion of best interest and associated uncertainties. By exploring alternative
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3 options, parents have the opportunity to satisfy their short and long term needs of coming to
4 terms with the decision and this could be important in the long term outcome for parents.
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6 Parents have to live with the decision they make, so giving them the interactional space to
7 explore options is crucial.
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11 Our analysis has shown that presenting options does not necessarily equate to parents
12 taking the burden of decision-making. Doctors are still able to manage this moral
13 responsibility by making options available in two ways: 1) parents are positioned as
14 collaborative decision makers and not sole decision makers, and 2) parents can subsequently
15 be presented with the option of a stronger recommendation should they indicate a reluctance
16 to state their preference (as shown in the final extract, although this is the only example in our
17 data). As such, this approach has the potential to be individualised and responsive to the
18 recipient. Key here is offering the parent choice to begin with as once a recommendation has
19 been put on the table, a constrained 'accept/reject' response is made a conditionally relevant
20 next action and therefore becomes a challenge to be retracted. As Anspach (1993: 125) has
21 argued "...a well-intended but paternalistic attempt to protect parents from guilt may,
22 ironically, produce the very effect it is designed to minimize and may deter, rather than
23 facilitate, vigilant information processing."
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40 It is also important to note that, while presenting options can invite parents to be more
41 fully involved in decision-making, this does not preclude the possibility of certain options
42 being more persuasively presented, as we saw in Extracts 9 and 13. Indeed, Quirk et al.
43 (2012) show how decisions can be directed through the discounting of certain options that are
44 listed. As Anspach (1993) has argued, the two paradigms of minimal and more active parent
45 involvement in neonatal decision-making should be regarded as poles on a continuum.
46 Exploring how options might be presented subtly (or otherwise), in ways which steer the
47 decision, may be an interesting area for future research.
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3 Our findings support Duffy and Reynolds's (2011) observation that doctors are clearly
4 aware of national recommendations for shared decision-making but are not necessarily sure
5 about how to put this into practice. While references to 'best interest' by doctors when giving
6 recommendations are understandable, given its emphasis in national guidelines (e.g.,
7 RCPCH, 2004), to conflate its philosophical use into the language used to initiate such
8 decisions has the potential to elicit less opportunity for parental involvement – through which
9 babies' best interests could otherwise be more fully explored. This occurs because of the
10 challenging position that the parents are put in, should they wish to present an alternative
11 perspective to a morally-weighted recommendation. The use of this recommendation strategy
12 establishes that any alternative would 'only cause suffering', and defines 'a moral precept',
13 which parents are likely to have difficulty disagreeing with (Anspach 1993).
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27 Our paper has, therefore, highlighted the value of studying how decision-making
28 actually works, as a way of developing a research basis for national communication guidance.
29 It has provided empirical evidence of the *endogenous impact* of initiating a decision point
30 through these two different designs; that is, the impact that is tractable within the interaction
31 itself. These findings have important implications for training doctors to have more effective
32 and collaborative conversations with parents. By becoming astute to the way turns of talk can
33 close down decision-making sequence and, consequently, the doctor-parent alliance, doctors
34 can begin to build a tool-kit for effective practice. With the paucity of communication skills
35 training that doctors in this speciality receive (XXXX), as well as in the evidence base that
36 informs it, we hope to, through training, enable doctors to understand how to have effective
37 and mutually aligned conversations with the families in their care.
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