

Research Article

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Informed Consent vs. Nondissent Approaches to DNAR Orders in Pediatrics: A Qualitative Comparison

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Introduction

Do-Not-Attempt-Resuscitation (DNAR) orders were developed as a tool to promote patient autonomy with respect to end-of-life decisions [1]. While the practice of seeking consent for a pediatric DNAR order from parents is theoretically in line with a culture of respect for parental authority [2], a growing body of literature has highlighted areas of ethical concern relating to requesting parental consent for DNAR orders when Cardiopulmonary Resuscitation (CPR) offers little chance of success. In these cases, seeking parental consent might inappropriately signal that attempting CPR has potential clinical benefit [3]. Soliciting consent may also impose an undue burden on those parents who prefer that clinicians take responsibility for end-of-life decisions [4]. Lastly, when a parent refuses a DNAR order for a terminally ill child, clinicians are forced to provide options that may not be in the best interest of the child [5].

To resolve these problems, some authors have proposed significant modifications to the process of seeking parental informed consent for DNAR orders. In patients for whom CPR would almost certainly be non-beneficial, an informed nondissent approach has been described as more appropriate [6]. In this “informed nondissent” approach, the clinician assesses the clinical status and prognosis of the patient, determines that a DNAR order is appropriate in the circumstances, and informs the family that unless they object, a DNAR order will be implemented [5]. This approach, encouraging clinicians to make explicit recommendations

accompanied by a parental opt-out, seeks simultaneously to promote the child's best interest as well as the family's emotional well-being surrounding the decision [4]. While several ethical analyses have been published on the topic of parental permission for DNAR orders in pediatrics, to our knowledge no empirical research on the feasibility and effectiveness of a nondissent approach in clinical practice has ever been conducted. We designed the current study to assess clinicians' attitudes, experiences, and beliefs regarding an informed nondissent approach to pediatric DNAR orders.

Methods

In this cross-sectional study, a combination of focus groups and qualitative interviews were conducted in two North American children's hospitals, in order to solicit attitudes, personal experiences, and beliefs of pediatric intensive care physicians, nurses, social workers, and chaplains with respect to DNAR conversations with parents. The participants were a convenience sample of pediatric intensive care professionals in the two hospitals. We chose convenience sampling to be able to expeditiously conduct a cost-effective exploratory study with potential for generating hypotheses to be further tested in future research. The interviews were conducted by two of the investigators (AO, IW). The combination of focus groups and individual interviews allowed us to leverage the focus group setting as a tool to diversify and enrich the subjects' responses, while also allowing us to capture highly personal experiences or views potentially more readily shared in an individual interview setting. This approach has

successfully been used in previous qualitative research literature [7]. Interviews and focus groups began with open-ended questions about personal experiences and opinions regarding DNAR conversations. Participants were then asked to read a clinical scenario exemplifying both an informed consent and an informed nondissent approach to a DNAR discussion (Appendix 1). Specific questions were asked focusing on the participants' impressions of the clinical scenario and on whether the participants favored an informed consent vs. informed nondissent approach in that particular scenario. This study was approved and exempted from the requirement for informed consent by the Institutional Review Board of Children's Hospitals of Minnesota. Interviews and focus groups continued until preliminary content analyses suggested that no new themes were emerging from the interviews (i.e., thematic saturation) [8]. The recordings were transcribed, anonymized and analyzed using NVivo 9 qualitative analysis software (QSR International, Victoria, Australia) [9]. Based on the grounded theory approach to qualitative analysis, themes were generated and analyzed, and a preliminary set of codes developed Grounded theory [10]. Consistent with standards of qualitative research [11], the reliability of the data was addressed by having a second investigator (NT) code a subset ($n = 2$, 28%) of the transcripts, using the coding structure developed by the first author. After resolution of discrepancies, emerging categories were shaped into a list of relevant themes regarding attitudes, personal experiences, and beliefs with respect to a nondissent approach to DNAR discussions.

Results

Three individual interviews and four focus groups were conducted, with a total of 21 participants. Two participants were physicians (10%), 17 were registered nurses (80%), one was a social worker (5%) and one was a chaplain (5%). The majority of groups or individuals did not express a clear preference between the two approaches or stated that the chosen approach should be different for different families. Two individuals (one participant in an individual interview and one of the focus group participants) reported that they clearly favored a nondissent approach in the provided scenario, while only one participant in one of the focus groups was clearly against a nondissent approach (unlike the other subjects in the same focus group), citing the potential infringement of parental authority (due to a power differential between providers and parents) as the main reason for being opposed to this approach. When a nondissent approach is chosen, the focus groups and individual interviews participants all emphasized the importance of ensuring parental understanding of the content of the discussion and the fact that they are allowed to veto the proposed DNAR order: "My concern would be if a family couldn't feel like they had that ability to veto it. I would just be worried about that population that couldn't say no".

On qualitative analysis, the following two main thematic categories were identified:

- 1) Healthcare provider role in facilitating decision making
- 2) Parental authority

These two thematic categories emerged organically from participant discussions and reflect the emphasis placed by the participants on two important elements of a DNAR decision. Each of these two thematic categories had several themes that will be discussed below (Table 1).

Thematic Categories	Themes
Healthcare provider role in facilitating decision making	Trust
	Forthrightness
	Closeness and empathy
	Consistency
	Provider comfort with end-of-life conversations
	Guidance
	Moral judgments
Parental Authority	Parental discomfort with DNAR discussions
	Parental fear of the child's suffering
	Parental religious beliefs
	Extended family members' role in decision making

Table 1: Themes identified on qualitative analysis. The themes are organized in two categories: healthcare provider role in facilitating decision making and parental authority.

First thematic category: Healthcare provider role in facilitating decision making

Several participants commented on the potentially important role played by providers and nursing in facilitating decisions surrounding DNAR orders. Conversely, other participants remarked on how detrimental certain behaviors displayed by providers can be when it comes to DNAR decisions. This thematic category was comprised of the following themes: trust, forthrightness, closeness and empathy, consistency, provider comfort with end-of-life conversations, guidance, and moral judgments. These themes will be explained in greater detail below and a few representative quotes from the transcripts will be presented.

a) Trust

Trust, as a result of long-standing relationships between families and medical providers, was described as an important factor in helping parents make a DNAR decision: "Doctor X will have these

conversations in her clinic with her long-term patients, so it's not a big surprise when somebody the parents don't know brings up the DNAR discussion".

b) Forthrightness

Many participants stated that, in many situations, providers should be forthright to the point of being "blunt": "You can say: it's fine. You are not going to get that same child back. Being that blunt and say: you are not going to get that same child back. It's ok to stop, be done. It's ok."

c) Closeness and empathy

A few participants emphasized the positive effect of an intimate involvement in the experience of patients and families and the ensuing emotional connection, as it often happens with nursing staff: "This kid had a really good day, but this is still an extremely sick kid on the maximum amount of medications. That's where as a nurse you can explain in a kind, matter of fact way to parents where their children's stability is". Participants generally agreed that it is important that any discussion about DNAR status be preceded by some expression of empathy and acknowledgment of the sadness of the situation.

d) Consistency

Examples of the negative consequences of lack of consistency in communicating with parents were provided by multiple participants: "The other part is when nurses and doctors are talking to families, the doctor goes in and says 'they look good' and then nurse says: 'they don't really look good'". Many participants specifically expressed disapproval of providers stating that critically ill patients "looks good", as this type of description is likely to provide false hope.

e) Provider comfort with end-of-life conversations

Many participants noted that variability exists in how comfortable and skilled physicians are with DNAR conversations. "A lot of times providers have been giving parents all the recommendations, but then they leave the DNR in the parents' hands. They fail to own up to the recommendations of the DNR order and then that's fully left in the parents' hands to make a call on, where that hasn't been for all other decisions and I feel like that's a disservice to the patient and the family". One of the group discussions pointed to the fact that palliative care services are very helpful, yet underutilized.

f) Guidance

Many participants expressed discomfort with the practice of overburdening parents by presenting many options without adequate guidance: "Sometimes I feel like we bombard them with a lot of options, and not a ton of guidance as to what options apply to their child". Situations in which excessive focus on specific

surgical procedures sometimes detracts from a broader scope of decision making were described: "I think it's a disservice, because sometimes an intensivist might be working with a family all day on coming to a DNAR decision, and then maybe neurosurgery or any other consulting service come in and 'oh, but we can place a VP shunt, and we can trach your child, and they'll be fine from a neurosurgical standpoint or' ... so I feel sometimes our teams don't communicate".

g) Moral judgments

One interviewee discussed how end-of-life decisions can at times become stigmatized. She described the way in which the decisions made by families are occasionally communicated to coworkers in a hushed, even unprofessional manner, rather than as a normal aspect of the care delivered.

Second thematic category: Parental authority

Multiple participants commented on the importance of respecting parental authority with regard to DNAR orders. Parental authority was often described as a foundational element of any DNAR decision: "As a mother of a child with significant needs, I would have a hard time with that [physicians being the main drivers of a DNAR decision]". "Sometimes parents aren't given permission to let their child go. There was this mother that said 'I'm done, stop it now!' and the cardiac surgeon fought with her for a while about it". When a nondissent approach is chosen, many participants emphasized the importance of ensuring parental understanding of the content of the discussion and the fact that they are allowed to veto the proposed DNAR order: "My concern would be if a family couldn't feel like they had that ability to veto it. I would just be worried about that population that couldn't say no". Many participants spent time discussing different perceived barriers to DNAR discussions or decisions. These barriers were coded as themes under the thematic category of parental authority, as they were described as interfering with, preventing, or influencing parental decision making. The following themes will be presented and discussed: parental discomfort with DNAR discussions, parental fear of child's suffering, parental religious beliefs, extended family members' role in decision making.

a) Parental discomfort with DNAR discussions

A few participants think that some parents are unable to bring themselves to initiate a DNAR discussion on behalf of their children. "I think they don't often want to be the first one, because they don't want it to feel that they are the ones who abandoned hope".

b) Parental fear of the child's suffering

One participant brought up parental fear that the child will suffer if not resuscitated as a very important limiting step in the process of making decisions about DNAR status.

c) Parental religious beliefs

One participant expressed concern that assumptions are often made about what parents will choose based on their religious beliefs: “Some families are very religious and would not even consider [stopping] but you wonder: how much are we explaining to them. Do we just say “they are devoutly Christian, or whatever they are not going to want to stop”? But we can’t make [assumptions] everybody is different, even inside of a group”. One participant conjectured that an informed nondissent approach might be preferred by parents who are not allowed to choose a DNAR order themselves because of their religious beliefs.

d) Extended family members’ role in decision making

One participant mentioned that the role of extended family members in decision making should not be underestimated.

Discussion

In this exploratory study of two North American children’s hospitals a cross section of pediatric critical care providers’ experiences, attitudes, and beliefs with respect to pediatric DNAR orders were captured and characterized. The goals of this study were to describe perceived differences between informed consent and informed nondissent approaches, and to identify other important topics related to end-of-life decision making in pediatrics, thus providing a broader framework and contextualization of how an informed nondissent approach would fit participants’ perspectives. In the three individual interviews and 4 focus groups conducted, a majority of the conversations analyzed indicated that most participants had no clear preference between the two approaches or stated that the chosen approach should be different for different families. A small minority of participants, however, held strong views in favor or against of a nondissent approach in the provided scenario. This finding suggests that use of an informed nondissent strategy should be individualized not only to the clinical situation but also to the needs of a specific family. On qualitative analysis, the following two main thematic categories were identified: healthcare provider role in facilitating decision making and parental authority. These main thematic categories emerged as foundational elements of DNAR discussions and decisions. Several themes were identified which enriched and better characterized the two main thematic categories.

The thematic category “Healthcare provider role in facilitating decision making” is comprised of seven themes: trust, forthrightness, closeness and empathy, consistency, provider comfort with end-of-life conversations, guidance, and moral judgments. Trust, with emphasis on the helpfulness of long-standing relationships between parents and clinicians, was highlighted as important. While the helpfulness of primary care providers in end-of-life decision making has previously been reported [12], the

specific role of different specialists in the process leading up to decisions on DNAR orders deserves further investigation.

The themes of provider forthrightness, provider empathy, and consistency among providers have received ample attention in previous studies [13-16]. Related to the theme of (lack of) consistency among providers, many participants described excessive focus on discussion of surgical options without attention to the broader picture. This finding may help explain previously published reports of less frequent use of DNAR orders by surgical than medical providers in adult medicine [17-20]. These differences between medical and surgical providers have yet to be studied in pediatrics. The staff’s emotional closeness with families is mostly viewed positively. One participant, however, described how nursing staff occasionally behaves inappropriately when they disagree with a family’s end-of-life decision, as a result of a moral judgment. This finding deserves further investigation, as there is a paucity of empirical findings on the role of providers’ moral judgments in clinical practice [21]. Physician comfort or discomfort with end-of-life discussions has been reported by some participants as a factor impacting DNAR conversations. Such discomfort may be related to insufficient knowledge of pediatric palliative care, as previously reported [22]. Many participants have discussed the importance of providing guidance while not overburdening parents with medical authority. This theme has received ample attention in previous studies [23] and is an important foundational concept in the theory of shared decision making in pediatrics [24].

The thematic category of parental authority is comprised of four themes: parental discomfort with DNAR discussions, parental fear of child’s suffering, parental religious beliefs, and extended family members’ role in decision making. The theme of parental discomfort with DNAR discussions in which such discomfort is described as a hindering factor confirms findings from prior studies [25,26]. The theme of parental fear of the child’s suffering previously reported in a study of dying children and their parents [12]. Deserves further investigation, as one could envision fear of pain and discomfort as either a facilitating factor (i.e., implementing a DNAR order as a way to decrease pain and suffering), or a hindering one (deciding against a DNAR order for fear of a painful death). The themes of parental religious beliefs and extended family members’ role in decision making reinforce previously published findings which characterized the importance of religious beliefs and the observed lack of agreement (with respect to the decision to discontinue life support) with extended family members [12]. More research is needed to illuminate the differences across the spectrum of religious and cultural traditions, as well as on how best to address extended family members.

This investigation is an exploratory study with several limitations. The participants were a convenience sample who

volunteered to participate, and thus potentially not representative of the units where they work, nor of the diverse cultural makeups of different units and hospitals in the United States. As participants were asked to draw on their professional experience, recall bias is possible. While interviewers completed training on moderation, it is possible that their comments inadvertently encouraged participants to expand more on some topics and less on others. Other important topics may have been missed altogether. The process of coding is subjective and influenced by the beliefs of the coder, although we attempted to minimize this subjectivity by having a second investigator code a subset of the interviews, in order to identify discrepancies. It would be interesting to assess in future studies whether there is a difference among different medical professions and specialties in the acceptability of an informed nondissent approach, a question which we did not have large enough numbers to evaluate. Despite these limitations, the current study provides important information on healthcare professionals' attitudes towards informed nondissent. A framework emerged in which healthcare providers, while vested with a crucial advisory role in the process leading to decision making, must operate within the boundaries of parental authority. We consider our findings novel and informative, as no previous empirical study has investigated clinician beliefs about the ethical validity and utility of informed nondissent.

Conclusion

In this qualitative study of pediatric critical care professionals, the informed nondissent approach was considered acceptable but not superior by a majority of pediatric critical care professionals. Many other important and diverse elements of a successful DNAR discussion emerged. When analyzed in detail, these elements can be linked to the central themes of healthcare provider role in facilitating decision making and of parental authority. Based on this framework, informed nondissent was seen by participants as a potentially useful tool, as it may facilitate decision making. Yet it was with a narrow margin, as there is a concrete risk of unduly infringing on parental authority. While this study was not a normative analysis designed to evaluate the ethical validity of informed nondissent, valuable insights about the potential advantages and weaknesses of this approach were gained. These insights will hopefully assist individual providers as well as ethicist and professional organizations in identifying when and how best to use this approach. The central role of closeness between parents and healthcare providers, the need for increased consistency among medical and surgical providers, and the importance of a communication process that prioritizes the broader prognostic picture over undue focus on surgical options, all stood out as novel findings that should be targeted when addressing the qualities of end-of-life communication in pediatrics.

Authors Contributions

Alberto Orioles conceptualized and designed the study, designed the data collection instruments, drafted the initial manuscript, collected data, carried out the initial analyses, reviewed and revised the manuscript. Jeremy Garrett conceptualized and designed the study, designed the data collection instruments, reviewed and revised the manuscript. Don Brunquell, Wynne Morrison, Kristina Catrine, and Nneka Sederstrom conceptualized the study, reviewed and revised the manuscript. Neil Tassoni conceptualized the study, carried out the initial analyses, reviewed and revised the manuscript. Ian Wolfe conceptualized and designed the study, collected data, carried out the initial analyses, reviewed and revised the manuscript.

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