A Narrative Approach to Assent in Pediatrics

Tyler Clay

ABSTRACT

Narrative approaches used in the clinical care of adults are lauded in medical literature and training, but scant attention has been paid to the use of narrative in pediatric clinical care. The structure of narrative medicine is well-suited to the clinical care of children and fosters children's decision-making capacity. This article adapts three narrative approaches that are familiar in adult clinical care: narrative emplotment, stimulation of imagination, and invitation to assent and preparation for dissent. Narrative emplotment is the contextualization of clinical care through the construction of a narrative in partnership with the patient. Stimulation of imagination is the exploration of possible future options through the use of narrative-directed questions. Invitation to assent and preparation for dissent describes preemptive steps that can be taken to re-contextualize care after a child's dissent.

INTRODUCTION

The potential utility of narrative approaches in pediatric ethics and the use of narrative cases has been explored less in pediatric medical literature than in adult medical literature, despite the powerful role of story in the rearing and education of children. The application of narrative approaches to ethical issues in adult medicine, commonly termed *narrative ethics,* is well described.[1-4] Pediatrics can greatly benefit from the potential benefits of narrative bioethical approaches, especially with some of its most difficult ethical tensions. This article describes the use of narrative ethics principles with one of these difficult tensions, one that is central to pediatric clinical care: pediatric autonomy and pediatric patient assent. A recent review of pediatric assent literature found that processes to obtain assent were not well described in the literature. This article provides a model based on narrative ethics practices.[5]

The bioethical principle of respect for autonomy in pediatric clinical care is inherently complicated. *Autonomy* is broadly defined as the ability of a person to make choices with understanding and freedom from outside influence.[6] During childhood and adolescence, patients actively develop their decision-making capacity and are restricted, to some degree, in their ability to guide their own medical choices until the age of maturity. Legally, they typically cannot consent to their own care, outside of reproductive care, mental health care, or treat-

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ment for a substance use disorders. In most instances, a parent or legal guardian must direct their medical decisions, supported through state laws and ethical guidelines that frame parents and guardians as *de facto* surrogate decision makers.[7]

Therefore, in most pediatric care, a patient's autonomy is not actualized. A child can participate in choices about their care when they provide information and ask questions. In some circumstances, a child may assent to care: they can communicate, as a non-autonomous person, their willingness to undergo an intervention. Or they can dissent: they can communicate that they do not wish to undergo an intervention. This article does not describe the circumstances in which assent should be facilitated, but instead offers a narrative approach to obtain pediatric assent. The narrative approach is a unique way to navigate dynamic relationships in pediatric care. It is a potent tool in *meaning-making*—a process by which a person can interpret and understand the world around them and themselves. This article does not attempt to replace existing models for ethical decision making, but offers an approach that can be an alternative and supplement to other approaches.

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The concept of pediatric assent originated in clinical research in the 1970s, and arguments for its utility in clinical care began to emerge in the 1990s.[8-10] Experts have discussed when it is appropriate to provide opportunities for a child to express assent. Guidelines from the American Academy of Pediatrics (AAP) state, "one should not solicit a child's assent if the treatment intervention is required to satisfy the goals of care agreed upon by the provider and parent or surrogate, but the patient should be told that fact and not be deceived."[7] The AAP's intent is to encourage pediatric practitioners to maintain a child's trust: to not seek a child's permission to treat when it is inevitable that a treatment will proceed even if they dissent.

Since the publication of the original AAP guidelines in 1995, several prominent writers have offered that assent can serve a larger, more meaningful role in pediatric care.[11-13] A recent concept analysis of the pediatric assent literature reports that pediatric assent respects a child's emerging autonomy, fosters a child's developing sense of self, and strengthens a child's role as a stakeholder in their care, as they are actively included with parents and the care team in shared decision making.[10] The analysis describes two prevailing concepts of assent: "(1) assent as an agreement for a specific decision and (2) assent as part of a continuous, interactive, process of care."[10] The latter concept of assent is continuous, as it occurs over time in the course of a child's care, and interactive, as it encourages the involvement of a child in healthcare decisions. A subsequent review of the pediatric assent literature by another group found similar overarching themes, and noted that the processes to obtain assent are not well described.[5] This article describes an approach to pediatric assent that is rooted in narrative ethics, because narrative ethics is uniquely positioned to contextualize and support the longitudinal care needs of children as they develop.

THE POTENTIAL OF NARRATIVE IN PEDIATRIC CARE AND ASSENT

Consider this case that demonstrates how a narrative approach may offer an opportunity for assent and ongoing engagement with a pediatric

patient. Jake, a 14-year-old boy, presented with chronic sacral pressure wounds and recurrent soft tissue infection secondary to paraplegia that was the result of a traumatic motor vehicle accident two years prior. Jake was cognitively intact and verbally communicative, but his interaction with the team was limited because his mother dominated care conversations. During Jake's three-week admission and antibiotic therapy, the team considered surgical intervention to close the wound. Jake's mother consented to surgery, but did not involve Jake in the decision. The care team discussed whether the mother's dominating personality contributed to Jake's decreased interest in and confidence to participate in his own care. Without his active involvement, they worried about his ability to meet his care needs as an older teen and young adult.

A narrative approach is promising for pediatric assent because it allows a care team to contextualize complex and longitudinal care and encourage meaning-making. The utility of narrative is well described in adult medicine. Rita Charon proposed the concept of *narrative reciprocity,* a process in which a clinician receives, embodies, and reflects back a patient's story of their illness as a way to share power in a clinical relationship.[14] The literature on the use of narrative in pediatrics is more scarce, despite the powerful role of story in the rearing and education of children worldwide. The existing literature focuses on its benefits to pediatric providers and not on its potential to facilitate shared decision making and empathetic care.[15,16]

Children are naturally friends of narrative. They are introduced to the ideas of plot, character, and setting early in life. In many religions and cultures, narratives are used to soothe as much as to impart moral lessons. While other approaches that facilitate assent exist, narrative is particularly well suited to assent because of its power in meaning-making.[17] In Charon's words, narrative allows providers to "enter the worlds of their patients . . . and to see and interpret these worlds from the patients' point of view."[18] The narrative model of assent presented here, developed through a review of literature and personal experience in medical training, not only facilitates assent with pediatric patients, but also strengthens their sense of agency in healthcare and bolsters their confidence in decision making. Additionally, capitalizing on the significant role of narrative for young patients is a powerful way to strengthen clinical relationships, center a child's story, and create meaning from weighty and confusing events in their clinical care.

The model shown in figure 1 adapts many skills and processes common in narrative medicine to the pediatric context. It outlines three main steps to view assent that follow the work of Charon, Frank, Wasserman, and Navin:

1. Narrative emplotment
2. Narrative stimulation of imagination
3. Invitation to assent and preparation for dissent[13,14,19]

Narrative emplotment is the contextualization of clinical care through the construction of a narrative in partnership with a pediatric patient. *Stimulation of imagination* is the exploration of potential future options with a child through the use of narrative-directed questions. *Invitation to assent and preparation for dissent* describes the preemptive steps providers can take to re-contextualize care after a child's dissent.

The opportunity for meaning-making that occurs in steps 1 and 2 is central to a narrative approach. Arthur Frank, a proponent of the study of illness narratives and narrative ethics, writes that stories require both an initial telling and retelling for their meaning to fully emerge.[20] The retelling of a story naturally lends to a continuous approach to assent. These three steps need not all be performed during one encounter, but can continue over weeks or even years. Likewise, a story need not be formed during one interaction, and can be constructed over time. Frank notes a provider's responsibility with a story is to give attention to which details change or become more important in the retellings.

This approach is most appropriate in longitudinal care settings, such as specialty clinics, primary care, or prolonged hospitalization. Providers may find they already implement these approaches in some way. While further

training in narrative medicine is not necessary to successfully implement this approach, it may increase its efficacy.

In contrast with other shared decision-making models of pediatric clinical care, which often include decision aids and focus on the parent, this approach centers the child in the story, with the goal of meaning-making.[21] This approach is not intended to replace or supersede existing models, but to act as an alternative or even supplement them. One difference is that a narrative structure, by definition, centers a child and their perspective. Although a child's choice or opinion may not hold legal weight, their preference holds some ethical weight, solely because it exists, and this approach underscores and advocates for the ethical weight of a child's story. It fosters the decision-making confidence endorsed by proponents of assent because it helps the child derive meaning from their own disease experience as they continue to define their own role as a patient cared for by a healthcare team.[10]

Any child capable of preference can benefit from this approach; it may be particularly useful with adolescents, when increased agency in healthcare decision making promotes a smoother transition to independence in adult medical care.[22,23] Additionally, given the status of narrative in some minoritized cultures and religions, the integration of narrative into practice may help bridge cultural and racial distrust in medicine, as discussed by other authors, although not specifically in the pediatric context.[24] Narratives as cultural objects and as a way to bridge cultural divides can be an important boon, especially when a clinician interacts with a child who lives in the liminal space between the parent's culture and the culture the child lives in.

To Whom Does this Story Belong?

A narrative approach to pediatric assent has the unique ability to separate a child's emerging self from their parent. Many pediatric ethical tensions center around the child-parent dynamic, and try to parse out the degree to which a child's self is separable from their parent (and the degree to which clinicians should respect that self separately).[11,22] The tension between the will of the parent and that of the child can limit a principlist approach to pediatrics, as it questions the role of the pillar of respect for self. Navin and Wasserman argue that preferences

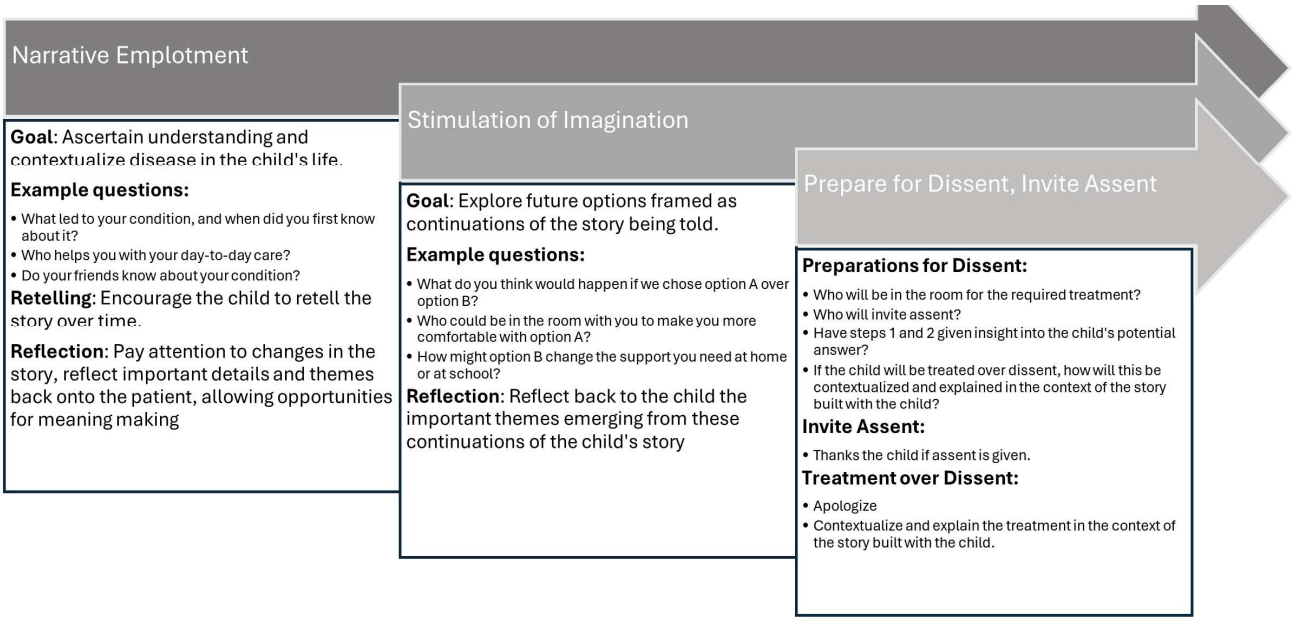

FIGURE 1. A narrative model of assent in pediatrics.

communicated by children justify their having a larger stake in their own care decisions than they are currently granted, based on the inherent moral weight of their preferences.[22,23] Thus, approaches that discount the inclusion of a child's preferences in favor of parental autonomy are less well founded. Frank writes, on the role of narrative ethics in centering the story of the patient, that a shift towards patient-centered ethics "does not devalue professional or institutional problems, but it does mark the need for a complementary form of ethics, proceeding from a different point of view."[19] A narrative approach is thus a powerful tool to re-center care decisions onto a child as the patient, as compared to a decision-aid tool focused on the parent.

A child understands clinical care through a web of relationships—with parents, with their pediatrician, and perhaps others. A child's developing autonomy is interwoven with these relationships, and so is their story. It is necessary for a provider to seek a parent's consent for an intervention, but it is as important to partner with a child to develop and explore their disease story to see how it is affected by these relationships, in pursuit of their assent. The narrative elements reviewed below show the power of the narrative approach when a child's assent is a key consideration.

Pediatric histories fall within Charon's definition of nested stories.[18] A child's disease story is typically recounted by a parent with some detail added by the child. Such a secondhand recounting of a disease process should not engender a provider's distrust of the narrator (the parent), but it can prompt a provider to seek out a first-person perspective. When a provider distinguishes a child's story from that told by their caretaker, this strengthens the role of the child in their own care and promotes their sense of agency.

Jake, in the case presented above, is a good candidate for this model. His lengthy hospitalization allows the implementation of a continuous approach. Figure 2 shows how a narrative approach could be implemented in Jake's care, to help him strengthen his confidence in speaking up in care conversations and to help him find meaning in his prior and future care. The following sections more fully describe the attributes of each of the three steps of this approach.

Narrative Emplotment

Narrative emplotment can help a provider assess a child's understanding of their situation and contextualize it in their life, even with the variable levels of development in children.[18] With narrative emplotment, a provider can contextualize clinical care through construction of a narrative in partnership with a pediatric patient. They can do this primarily by the use of questions that help a child frame their understanding of their illness in the context of their life story. They can frame a child's questions to elicit and understand the child's story, and their questions help a child further understand their own condition. Questions help a child create a narrative that can be summarized and reflected upon to gain insight. A provider can create a timeline, highlight actions and consequences, and elicit the roles of others (characters) in the illness story. The use of language common to children's stories, such as "once upon a time," may particularly engage some children. A provider can help a child recognize their experiences of disease and their sources of support. In the case of Jake, the use of narrative emplotment allows him the time and space to describe to the team how his condition affects his life and influences his reliance on others (see figure 2). This can help him consider how proposed future interventions might impact his level of independence, friendships, and family dynamics.

This use of narrative emplotment in pediatrics is distinct from Charon's in that an *illness story* that a provider elicits from a child is formed in partnership with the child, while Charon urges that an adult patient's story stands on its own.[25] In adult narrative medicine, reflection of the story back to the patient is important; in pediatric narrative consent, partnered construction and reflection is essential to invite pediatric assent. In the case of Jake, if his story indicates that recurrent soft tissue infections disrupt his life or friendships, his provider can reflect this back to him, to better contextualize

the impact of his condition on what is important to him. Through the formation, retelling, and reflection of a child's story, a child can derive meaning from their illness, and may be better able to assent or seek more information.

Narrative Stimulation of Imagination

The use of narrative can help a child assent to treatment because it can develop and direct their powerful imagination. When a provider asks a child what they think may happen in the future, they can direct the child's imagination. When someone reads a story book to a child, it's common to ask, "What do you think will happen next?" Providers can ask similar questions to help a child explore the consequences of a choice they are asked to make. This helps a child imagine their options while it lays the groundwork to correct any misconceptions a child may have. A provider can build out a child's story further to give the child the opportunity to extract meaning from their possible options. A provider can ask, "How might your life be different if you make this choice, instead of the other choice?" Such a narrative strategy helps a child extract meaning from the options they are offered.

In Jake's case, his provider can help him imagine how surgery might change his level of dependence, his schoolwork, and his ability to socialize during recovery (see figure 2). Or his provider can explore the potential impact of further hospitalization if surgical closure is not pursued, and the wound persists. To imagine the continuation of Jake's story with him and reflect his responses back to him allows space for meaning-making. For Jake, that may involve a closer consideration of his role in changing his dressings and future plans for independence at the age of maturity.

Invitation to Assent and Preparation for Dissent

To facilitate assent, a provider can give a child the opportunity to dissent, even when a decision has been made to proceed, should the child dissent.[7,13] When a child assents, the AAP recommends we show appreciation for their cooperation. When they dissent, we can prepare for how treatment over their dissent will be provided. Even when a treatment is rendered safely without a child's assent, we may lose their hard-earned trust and create moral injury. The use of the narrative model to invite a child's assent, rather than merely obtain it, can build a

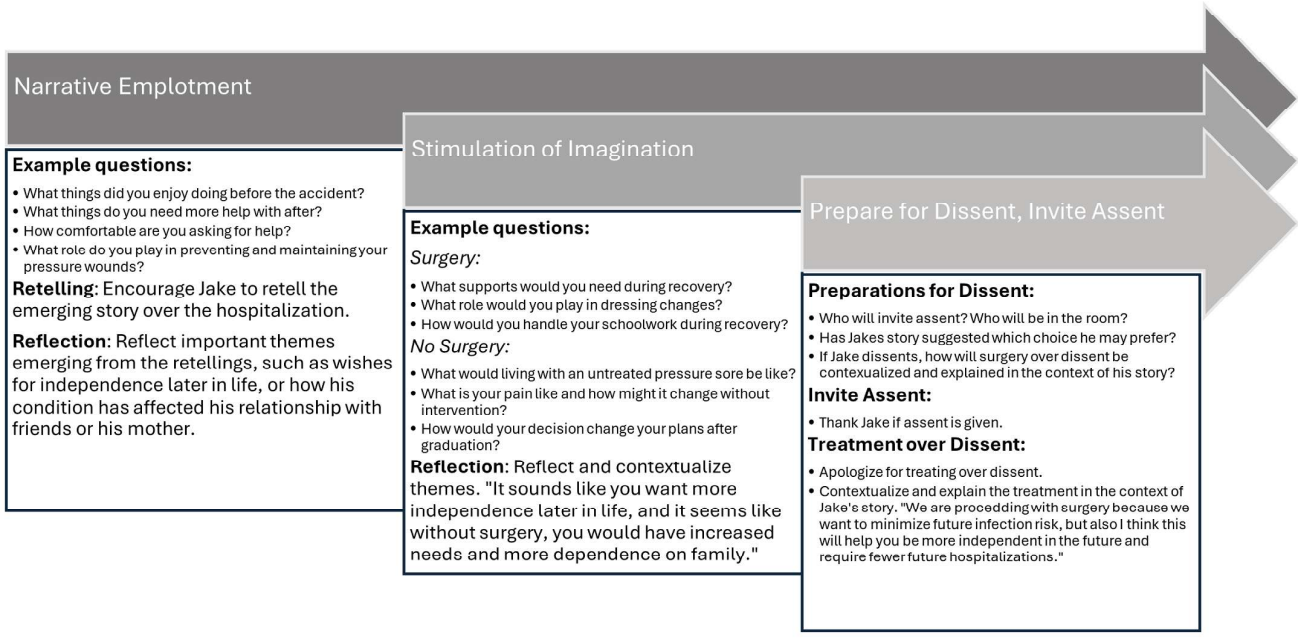

FIGURE 2. The narrative model applied to Jake's case.

strong clinical relationship that can withstand treatment that is provided over their dissent.

First, before we invite assent, we can determine how we will proceed if the child dissents. It's important to determine who will invite assent, who will be in the room when it is sought, and to what degree a strong clinical relationship already exists between the child and the provider. In this narrative model, these questions are answered by the care team, not the child.

Should the child dissent, a provider can apologize that the child will receive a treatment over their dissent and explain the rationale for the treatment. The AAP guidelines, and Wasserman and colleagues, provide advice on how to proceed when a child is treated over their dissent. Their recommendations can help avoid feelings of deceit and lay the groundwork for a continued clinical relationship. Practically, an apology can preserve a productive child-parent-provider relationship. From a moral perspective, even when a provider knows that the best course of action is to treat a child without their assent, unavoidable moral injury is created when they do not consent. As Navin and colleagues advise, "The respectful way to respond to a moral loss one has caused is to acknowledge the loss and to express regret for it, even when one has acted in what is the all-things-considered morally best way."[23]

LIMITATIONS AND OPPORTUNITIES

The time-consuming nature of a narrative approach to pediatric assent in partnership with a child and their family can limit the degree to which, and the settings in which, it can be implemented. In busy inpatient settings and in clinics with appointments scheduled back to back, the time needed to build such a narrative competes with other clinical priorities. But this process is continuous, so steps can be stretched across multiple clinic visits or multiple days of an inpatient stay. Such a clinical tool will greatly benefit children with chronic disease, whose inpatient stays can stretch for weeks, and who have frequent clinic visits. Frequent visits and prolonged admissions provide opportunities to implement this approach, especially since these children often have a narrative created *for* them, rather than in partnership with them. Also, this approach is not limited to major decisions for chronic disease patients. When smaller decisions may benefit from a child's assent, this narrative approach can be customized and implemented during one clinic visit or conversation.

Stories are powerful, but their power and weight may not always be productive. This narrative approach recommends that providers partner with a child to create their story, but this creates the possibility that a provider may unknowingly, or even purposefully, influence a child's story. Further, when a provider shares and parses through events that may have been traumatic for the child, it might cause harm, rather than help create a productive provider-patient relationship. Central to this model is respect for a child's story. Ideally providers who want to use this tool set will honor a child's story and let it blossom to its fullest potential, as it honors the aspects a child does not want to explore too deeply.

Finally, a story may not always be productive. As Mitchell notes, while stories can be rich with truth and opportunity for collaborative care with a patient, stories can be purposefully or non-purposefully misleading.[26] In these instances, a narratively competent practitioner may find it useful to identify what a story lacks, with the hope that they can help guide the teller in their creation of further narrative. Because a story requires a teller, some conditions such as encephalopathy, neurodegenerative disorders, and language disorders may limit the applicability of this approach. While this may limit the ability to perform certain steps, to elicit any form of story may still benefit and strengthen the provider-patient relationship. Even broken, incomplete stories hold narrative and ethical weight that should be considered.[31]

CONCLUSION

This proposed narrative approach to invite assent from pediatric patients provides a way to help children develop confidence and agency in their own care. A child's story can be distin-

guished from that of their caretaker, and can further develop in partnership with a parent and provider. Narrative is a powerful tool in meaning-making that can be used to facilitate a child's assent. A provider can help to contextualize a child's care through narrative emplotment and stimulation of a child's imagination about future treatment options. A continuous, interactive approach to assent, narratively driven, may be a powerful way to develop a child's confidence and decision-making ability in their future healthcare interactions. This approach is one example of the potential of narrative in pediatric clinical care. Continued thought, research, and documentation of the power of story in pediatrics is deserved, especially towards its role in various cultural and ethnic traditions.

BLINDING OF THE CASE

This case is a composite of several cases. Names, characteristics, and any other identifying details have been changed to protect the identities of those involved.

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CONFLICTS OF INTEREST

The author has no conflicts of interest or competing interests to declare.

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