

Relational Autonomy: Moving Beyond the Limits of Isolated Individualism

abstract

Although clinicians may value respecting a patient's or surrogate's autonomy in decision-making, it is not always clear how to proceed in clinical practice. The confusion results, in part, from which conception of autonomy is used to guide ethical practice. Reliance on an individualistic conception such as the "in-control agent" model prioritizes self-sufficiency in decision-making and highlights a decision-maker's capacity to have reason transcend one's emotional experience. An alternative model of autonomy, relational autonomy, highlights the social context within which all individuals exist and acknowledges the emotional and embodied aspects of decision-makers. These 2 conceptions of autonomy lead to different interpretations of several aspects of ethical decision-making. The in-control agent model believes patients or surrogates should avoid both the influence of others and emotional persuasion in decision-making. As a result, providers have a limited role to play and are expected to provide medical expertise but not interfere with the individual's decision-making process. In contrast, a relational autonomy approach acknowledges the central role of others in decision-making, including clinicians, who have a responsibility to engage patients' and surrogates' emotional experiences and offer clear guidance when patients are confronting serious illness. In the pediatric setting, in which decision-making is complicated by having a surrogate decision-maker in addition to a patient, these conceptions of autonomy also may influence expectations about the role that adolescents can play in decision-making. *Pediatrics* 2014;133:S16–S23

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Prologue

Jake, a 10-year-old boy with recurrent leukemia, had not responded to the last possible curative treatment for his disease. Jake (not his real name) was experiencing uncontrolled bone pain. The second-year oncology fellow, Dr Adams (another pseudonym), was well trusted by the family and had been very involved in Jake's care throughout his illness. Now, Dr Adams has consulted the palliative care service about both pain management and for help with decision-making at this turning point for the patient.

Dr Adams was distressed about meeting with the family. At the last family meeting, when they were considering whether to try 1 last, highly toxic regimen of chemotherapy or instead shift to a palliative treatment plan, Dr Adams had felt conflicted about how to handle the parents' direct question regarding what they should do. She wanted to be compassionate and supportive of the family but did not want to violate the parents' autonomy by making a strong recommendation of whether they should enroll Jake in a Phase I trial that had a low likelihood of extending Jake's life or transition at this point exclusively to comfort care.

The parents were giving signals to the team that they did not want to make the final decision about how to proceed. They were clearly emotionally distraught. Given Dr Adams' concerns about guidance in decision-making, the palliative care team recommended an ethics consultation to determine the ethically appropriate range of actions by the medical team.

The concept of autonomy has dominated medical ethics in the United States since the 1970s. Autonomy was not just dominant in medical ethics. Many concurrent social movements emphasized the rights and abilities of all individuals to have control over their bodies and decision-making. The concept of patient autonomy gradually replaced physician paternalism as the guiding principle of the doctor–patient relationship and decision-making. Physicians no longer were expected or allowed to withhold information from patients and families or make decisions based on what the physician perceived to be best for the patient.

Clinicians were now viewed more as clinical experts whose job was to provide information for educated consumers so that those consumers could control their own health care decisions.

Forty years later, however, it is unclear what it means to “respect the autonomy” of patients or their caregivers. In this article, we argue that this lack of clarity about how to respect patients' autonomy is a result of the variety of different ways that the concept of autonomy is understood.

These issues are especially complex in pediatrics because most ethical theories assume a competent adult patient. Patients may lack decision-making capacity either because the patient is a minor or the patient is an adult who is cognitively disabled. In both cases, a surrogate is assigned to make decisions on behalf of the patient. In pediatrics, parents are the presumed appropriate decision-makers, guided by the “best interests of the child” standard, and their authority is only questioned if they are abusive or neglectful. Moreover, the work of pediatricians is more complicated than that of adult clinicians with regard to respecting autonomy because not only are we tasked with respecting the autonomy of parents making decisions, but we also have a responsibility, along with parents, to support the burgeoning autonomy of the children who are our patients.

In this article, we outline 2 conceptions of autonomy and illustrate how they affect our understanding of what it means for providers to respect the autonomy of patients, parents, and families. Indeed, what we consider morally valuable and acceptable depends, to no small degree, on which model of autonomy we embrace. Our conception of autonomy shapes how we understand who is the ethically appropriate decision-maker in challenging decisions, what the ethically acceptable

range of reasons may be in decision-making, and what role the clinician should have in supporting patients and families in decision-making.

THE “IN-CONTROL AGENT” INDIVIDUALISTIC MODEL OF AUTONOMY

The first model of autonomy that we describe has been labeled the “in-control agent” conception. This model characterizes autonomous agents as both highly individualistic and having an ability for deliberation and rational transcendence of emotion, prioritizing the rational over the emotional. Detailing the “autonomous man,” Code wrote that:

The autonomous man is—and should be—self-sufficient, independent, and self-reliant, a self-realizing individual who directs his efforts toward maximizing his personal gains. His independence is under constant threat from other (equally self-serving) individuals: hence he devises rules to protect himself from intrusion. Talk of rights, rational self-interest, expediency, and efficiency permeates his moral, social, and political discourse. In short, there has been a gradual alignment of *autonomy* with *individualism*.¹(pp 77–78)

Interestingly, and importantly, the in-control agent conception of autonomy highlights certain moral challenges and concerns (eg, our susceptibility as decision-makers to seduction, manipulation, or emotional persuasion in discussions about medical decisions) while remaining silent about other challenges (eg, how we can unwittingly undermine the autonomy of others if we do not recognize our impact on their developing capacities). In response to an era in which patients would not know the full extent of their diagnoses because physicians or family members would hide that information to protect them, the in-control agent model of autonomy demands that patients be given full information about their diagnosis, prognosis, and treatment options. It also guards against the kind

of persuasion by others that ill individuals or their loved ones are vulnerable to in emotionally charged conversations about bad news, treatment options, or goals of care.

Ethicists' accounts of autonomy may have intended a more nuanced interpretation than the in-control agent model suggests. This nuance is often lost in the clinical setting. Physicians in the United States are taught that autonomy is all about individualism and the rights of patients to make decisions without paternalistic interference by physicians. Classic textbooks describe autonomy as the right to make decisions for oneself and act accordingly,^{2,3} an account that allows for an emphasis on individualism that is common in US society.⁴

Degner et al⁵ developed a conceptual framework for the role that patients would want their physicians to take in decision-making and recognized 5 different orientations for the physician's role. The in-control agent would correspond either to the physician not playing a role in a patient's decision-making at all or, at the most, an agent would affirm that "I prefer to make the final decision about my treatment after seriously considering my doctor's opinion."

The emphasis on self-reliance in this account of autonomy prioritizes agents as not being overly influenced by others in making decisions. In fact, reliance on the opinions of other family members or medical professionals would be considered highly suspect.

In-Control Agent Model Prizes Rational Over Emotional

The orientation taken by the in-control agent conception of autonomy is to be rational, self-sufficient, and sensible, resistant to emotional persuasion and therefore protected from yielding one's beliefs or being easily swayed from putting into action one's commitments and personal preferences. If one is

overcome by emotions, such as fear, anger, grief, or passion, one's self-control is compromised, as is one's rational agency. Discussions that exhibit substantial emotional components may be seen as undermining the rationality that is a necessary component of autonomy for the in-control agent. The autonomous agent, by this account, must strive for rationality and transcendence of our emotions to focus on the objective content of what is at stake.

This emphasis on rational reasons for decisions has a significant influence on what parent decision-makers believe should be motivating their decisions for their child. Clinicians should provide cognitive information; that is, "the facts." Parents should then interpret these facts in the context of their goals for their child and should defend their decisions in terms that are understandable to others as not being overly influenced by emotional reactions.

The virtues highlighted by the in-control agent account of autonomy are important in preventing us from being too susceptible to seduction or manipulation when discussing information regarding an important decision. The account guards against succumbing to a paternalistic clinician who presumes to know what is best for patients. The clinician's responsibility is to support parents and patients in engaging in informed, critical reflection. The in-control agent model would, however, also consider as a violation of the patient's or family's autonomy any suggestion by the clinician about what to decide or to engage (and potentially guide) the parents in emotional discussions about how to best love their child. This normative account of autonomy proposes that we should, and also can, by sheer act of will overcome the effects of grief and other emotions in the context of making decisions. Good parent surrogates will adequately manage their emotions before making decisions for their child.

In-Control Agent Model Views Adolescence as a Quest for Independence

Although the in-control agent account is able to acknowledge the fact that children are dependent in significant ways, and that their environments play a role in developing their interests, beliefs, ends, and judgments, the prescriptive force of the in-control agent model emphasizes the realization of self-sufficiency, independence, and self-reliance as a key goal of human life. Although others may attempt to manipulate or persuade us, the goal is to attain a level of self-sufficiency and the independence necessary to critically reflect on one's motivations and interests such that one can ignore this manipulative input.

Because children and adolescents in most circumstances would not yet have achieved this independence, they would not be considered capable of participating in decision-making in a substantial way. The in-control agent does not emphasize how children move from a position of dependence to independence in their decision-making. It assumes that parents will preferentially praise and support choices that exhibit the highly valued self-reliance and lack of influence by others and that, by doing so, they will help their teenagers attain the ability to act autonomously.

If the interests of adolescent patients are considered in decisions, the in-control agent model would expect that the kinds of reasons which would be respected are ones that privilege rational reasons, rather than ones that prioritize emotional reasons or the patient's relationship with others.

THE RELATIONAL AUTONOMY MODEL

In the 1980s, feminist philosophers began to question these individualistic conceptions of agents and how they

make morally acceptable decisions.⁶ A growing recognition of how gender differences privileged certain aspects of moral knowledge led to the development of an ethics of care, which shifted the focus of how we reason about morally difficult choices. This feminist turn was also applied to conceptions of autonomy. These philosophers described a different way of thinking about autonomy that was relational rather than individualistic.

As Mackenzie and Stoljar explain:

Relational autonomy perspectives are premised on a shared conviction, the conviction that persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity. Thus the focus of relational approaches is to analyze the implications of the intersubjective and social dimensions of selfhood and identity for conceptions of individual autonomy and moral and political agency.⁷

This relational understanding of agents is diametrically opposed to the understanding implicit in the in-control agent model. This relational view of subjectivity relies on the idea that none of us is the sort of autonomous individual imagined by the in-control agent model. Instead, we are all what Baier calls "second persons."⁸ She writes, "(P)ersons are essentially successors, heirs to other persons who formed and cared for them, and their personality is revealed both in their relations to others and in their response to their own recognized genesis." In Baier's view, we all fundamentally and ineradicably exist in relation to others. She acknowledges that both good and evil result from the fact of our interdependence but holds that self-realization is only achieved relationally. The relational model sees individuals' identities, interests, ends, and beliefs as fundamentally dynamic, continually constructed and reconstructed in dialogic processes with other people (as

well as with our traditions and with history). This view of autonomy leads to a very different understanding of the sorts of discussions in which we try to persuade or influence one another. Being autonomous is not perceived to be in conflict with valuing the input of others or engaging them in important decisions. Patients and parents do not abdicate their autonomy by asking trusted family members to make decisions for them or for their providers to offer their opinions. An individual's interests are developed in conjunction with others. They are re-described and re-examined during challenging times. Dialogue with others about these interests and choices is not an affront to an individual's autonomy in this relational account. It is, instead, the only way to allow autonomy to fully flourish.

Relational Autonomy Unites Emotion With Reason

Centrally, a relational account of autonomy envisages the self-in-dialogue as one who is emotional and embodied as well as rational. This method allows for the account to emphasize features of selves that are overlooked by the in-control agent conception, such as the role of imagination and emotional dispositions and attitudes in decision-making. By highlighting the emotional aspects of decision-making, a relational account acknowledges the highly emotional experience of parents of significantly ill children. It does not undervalue those emotions in their decision-making. Parents who acknowledge their emotional experience are not betraying their autonomy or the rational elements that are also in play. Instead, it recognizes emotional responses as equally important. Thus, according to this view, providers focus not only on objective facts as a way of helping patients or parents make decisions. They should also see it as appropriate and helpful to engage families in discussions of the emotional

aspects of their child's care and of their own experience as caregivers. Providers should accept justifications for decisions that incorporate a broader conception of the child's needs in the context of the family unit.

The Relational Autonomy Model Emphasizes Adolescent Relationships

A relational account of autonomy places more emphasis on the development of the capacities for autonomy of children and adolescents than the in-control agent model. In doing so, the relational model recognizes that the embeddedness of relationships may also have negative influences, particularly on the burgeoning autonomy of individuals. Relational autonomy, such as in-control agent autonomy, has risks. Mackenzie and Stoljar⁷ articulate 3 specific ways in which oppressive socialization can impede the development of the capacities of agency.

First, oppressive social relationships can unduly influence, and sometimes even hijack, the formation of an agent's desires, beliefs, and emotional attitudes.⁷ If children never have anyone validate their desires or emotional experiences, they may have difficulty developing or articulating their wishes and experiences. Second, these relationships affect the development of "competencies and capacities necessary for autonomy, including the capacities for self-reflection, self-direction, and self-knowledge." When adolescents are given opportunities to make choices about their lives, they gain important insights about who they are and who they are becoming. Finally, these relationships affect an individual's ability to bring his or her autonomous desires or choices to fruition.

Recognition of the role that others can play in undermining the development of capacities for autonomy has implications for how to approach

the role of respecting the autonomy of adolescents. Relational autonomy recognizes a responsibility by providers to engage adolescents in decision-making within the health care setting and offer them opportunities to develop these capacities. Importantly, there may be limits to an adolescent patient's autonomy. For example, parents may override the adolescent's choice to forego moderately effective treatment if they believe it is in their adolescent's best interest to have a long-term future.⁹

THE IN-CONTROL AGENT AUTONOMY MODEL AND PALLIATIVE CARE

What are the particular consequences of autonomy as characterized by the in-control agent for pediatric palliative care? As the case at the beginning of this article illustrates, providers raised in the era of autonomy struggle with whether it is ethically appropriate to guide parents in making significant decisions, such as whether to stop pursuing aggressive treatment. For adult patients, providers are unlikely to provide a recommendation when making life support decisions and only one-half will provide a recommendation even when explicitly asked by a patient or their surrogate.¹⁰ This reticence flows from a conception of autonomy in which only the patient or parent can be the ethically appropriate decision-maker and in which any attempt to influence their decision is seen as ethically problematic. The overreliance on an individualistic approach leaves no room for clinicians or other family members to substantially weigh in on treatment choices. The implicit message given to parents who turn to trusted care providers for help is that "you're on your own, and you should be able to think clearly about this." Providers who ascribe to this model implicitly assume that being autonomous means being self-reliant and rational.

They worry about usurping a parent's autonomous decision. The consequence of this worry is that the burden of making a decision about forgoing further treatment falls squarely and exclusively on the parents' shoulders.¹¹

The in-control agent model also has implications for parents in the palliative care context. This individualistic approach to autonomy is consistent with the expectation that parents make choices for their children by maximizing their child's best interests, understood primarily as their child's self-regarding interests,¹² ie, interests in the child's own well-being or other's well-being if it promotes the child's well-being.¹³ Parents are believed to be the appropriate decision-makers for their child because they know them and their needs better than others do and are therefore best positioned to ensure that decisions maximally promote their child's best interests.

This approach to autonomy has become the primary standard by which clinicians are expected to judge parental reasons for decision-making. If parents weigh other family interests in deciding about their child's medical decisions, they are not living up to their obligations to their child.

However, other ethicists argue for the legitimacy of considering other interests, including the parents' interest in raising their children according to their own values. Buchanan and Brock,¹⁴ for example, reject those theories that "accords to parents *no* independent interest or right to decide for their children and to enforce their choice when the choice may *not* best serve their children's welfare." Likewise, Ross⁹ argues, "to assume that an individual's interests are purely self-regarding denies the intimate web in which an individual leads her life, and in which the interests of other family members become part of her own interests (as well as the fact that she

shares with these other family members some family goals which are not reducible to their individual goals)."

Lastly, the in-control agent model affects how parents and clinicians consider and incorporate child or adolescent patients' input in decisions affecting their care. Although this model has the big-picture goal of supporting children's independence to make decisions for themselves and would perhaps offer small-scale decisions to practice these skills, when dealing with a child with terminal illness, this longer-term goal seems irrelevant or the stakes too high to offer "real" decisions to a patient who has yet to demonstrate this independence and capacity to resist persuasion. In these circumstances, parents and providers validate decisions by the patient that conform to their assessments but may disregard others that oppose their decisions, often dismissing them as overly influenced by the child's emotional experience or their inability to reason about the potential consequences. Although this action is a pitfall that providers and parents can succumb to with any conception of autonomy, when the goal is the in-control agent, few adolescents will be able to act satisfactorily according to such a standard (nor would many women or individuals from many minority cultures).¹⁵

RELATIONAL AUTONOMY'S ALTERNATIVE APPROACH

If instead of privileging the individual, we acknowledge the interconnectedness of patients and families, the constraints of respecting autonomy take a different shape. It becomes legitimate for family members and medical professionals who are interrelated and connected to the patient to weigh in on decisions in ways that make Dr Adams uncomfortable. With a relational approach, it is not unreasonable for an adult patient to defer decisions to his wife if he believes that his

well-being and identity are intrinsically linked to hers, nor is it unreasonable for parents of children to ask for help from their own parents (the child's grandparents), other family members, friends, or health professionals.

Clinicians who are trusted by patients and families can now be "brought into the fold" and share in the responsibility of decision-making in ways that are not acceptable for the in-control agent. From a relational autonomy perspective, the oncology fellow's refusal to offer guidance or a specific answer to a direct question is a failure to live up to one's obligations as a clinician. The professional role for providers includes not just providing facts but also caring for the emotional needs of patients and families in these challenging situations. The trust and intimacy that arise from such an emotionally charged encounter engender responsibilities in the providers to not abandon families in these difficult times. Instead, providers have a moral obligation to help guide families through the emotionally confusing terrain of decision-making at the end of life. Backing away from these conversations or refusing to make recommendations is an abdication of a provider's responsibility to patients and families. The emotional realm is not off limits but offers essential insights into responsibilities of what it means for parents to love their child.¹⁶ Privileging these emotions is ethically appropriate and should infuse the discourse in palliative care, demonstrating not only empathy but also acknowledging the role of emotions in our decision-making.

Providers may be reluctant to engage families in conversations about palliative care because they experience the shift to palliative care as a failure of their ability to cure the patient.¹⁷ They may also seek to avoid recommending that the patient forgo aggressive

treatment to avoid the emotional burden of the recommendation because they too have held out hope for the patient's survival. As such, respecting the autonomy of families may be used as an explanation for avoiding situations in which we ourselves have other reasons to avoid them.

For parents making decisions on behalf of their children, a relational account of autonomy expands the kinds of justifications for decisions that would be considered ethically appropriate. Just as this account of autonomy challenges the pure individualism of the patient, it also challenges the best interests standard as the only ethically relevant benchmark for assessing the adequacy of a decision. In a relational account, the best interests of the child may need to be balanced against the interests of the family. We still need to see that the child's basic needs are met, but it is permissible to balance those needs with the needs of other family members and the needs of the family as a whole.⁹ A family's decision to bring home their terminally ill child may mean forgoing certain kinds of treatments because it is important for the whole family's grieving process to have the child at home.

Children's and adolescents' preferences and choices regarding medical care also are valued differently from a relational autonomy perspective; from the vantage of this model, health care providers bear the responsibility to advocate for a child's autonomy in the medical context. A relational account recognizes that the capacities for autonomy are not developed *de novo* and that persistent forms of oppression or undermining of one's sense of self-respect and self-direction can have lasting effects on the ability to develop those capacities. Undermining these capacities for chronically ill children often occurs unwittingly, as parents or clinicians "take charge" and

advocate for the child, often overlooking the child's expressed interests or requests for control over aspects of his or her care. Conflicts may arise between what may be necessary to maximize the child's best interests and the pediatric patient's desires to be fulfilled. Clinicians should model for parents how to give a child patient some level of control over his or her medical care, while acknowledging the parents' sense of responsibility to ensure the child's basic needs are met. In palliative care, clinicians can help parents put their child's comfort central in their decision-making and help parents stay attuned for signs from the child that he or she wants more input in decision-making.

In the end-of-life setting, however, a relational account of autonomy may support certain decisions that overrule a child's expressed wishes if they will have little impact on the child but significant impact on the family. One example may be an adolescent who is refusing an "anointing of the sick," a sacrament in the Catholic tradition offered for seriously ill patients. If the patient will be unaware of the sacrament, and the parents had indicated significant moral distress over the child not receiving such a religious sacrament, performing the anointing could be justified by the negative impact that not having the sacrament would have on the surviving family members. Decisions that in other circumstance would be disrespectful of the child's future autonomy are not relevant in the end-of-life setting and, as such, health care teams must help families cope with long-term implications of short-term decisions.

RELATIONAL AUTONOMY IN PRACTICE

The ethicists met separately with Dr Adams and with Jake's family. In meeting with Dr Adams, it was clear that she

thought that palliative care was the proper decision in this case. The ethics team explored with her the various understandings of what it means to respect autonomy, reassuring her that offering an opinion was not disrespectful of the parents' autonomy. To the contrary, the ethics team encouraged the oncologist to be a more active participant in a shared decision-making process to empower Jake's parents and to help them act in Jake's best interests.

In the meeting with the parents, their distress was palpable, and the ethicists asked the parents if there were other support persons whom they would like present. The parents asked to have their own parents (Jake's grandparents) as well as their minister attend. All were in the waiting room, and the meeting was resumed after a large enough room was found and introductions were made. It was an emotional meeting in which the parents acknowledged that they thought Jake was suffering but did not know how to stop. They also acknowledged fear that they would disappoint the oncology team if they stopped. The ethicists assured the parents that their decision was a loving and morally valid choice. The grandparents and minister concurred.

The ethicists encouraged Dr Adams to have another meeting with the family, this time with both parents and their support group. The ethicists encouraged her to make clear that all options were appropriate and reassured her that, if asked, offering a recommendation would not be disrespectful. The parents elected not to have their son at the meeting. The options were reviewed and when asked what she would recommend, the oncologist responded, "I wish it were otherwise, but I do believe that your son is suffering. I think following the palliative care team's recommendations for maximizing his comfort might best meet your goals for Jake. I do not recommend the Phase I trial." The parents expressed a sigh of relief and agreed to work with the palliative care team to develop a plan that would let their son come home. The palliative care team discussed issues of pain control and goals with Jake. As is often the case, he was more aware of the situation than his parents realized.¹⁸

CONCLUSIONS

How we conceptualize autonomy leads us to pose different answers about how best to respect a family's autonomy in decision-making, which includes both

respect for parental autonomy and also the developing autonomy of the child. These different conceptions of autonomy in turn have different implications for the role of providers.

In the context of pediatric palliative care, the role of parents remains the same: how best to make decisions on behalf of their child that respects the needs of the child in the context of the family. What role the child should play is complicated by the fact that the child will never become a fully autonomous adult. Whereas there has been a movement to promote the adolescent's emerging autonomy, particularly for decisions that will have impact in adulthood, this issue is sadly less relevant in the context of pediatric palliative care. As such, it may be appropriate to give less weight to the child's interest in making decisions when those decisions conflict with the interests of the family as a whole. The implications for the providers in guiding families through incredibly challenging situations can be drastically different under the 2 models. Reliance on a rational and individualistic conception of autonomy deters providers from guiding families through difficult decisions, and it may pit child against family at a time when they most need to support

TABLE 1 Implications of Different Theories of Autonomy for Pediatric Palliative Care

Variable	In-Control Agent Autonomy	Relational Autonomy
Acceptable reasons for decisions	Rational reasons	Rational and/or emotional reasons
Who is decision-maker	Patient's surrogate	Surrogate can rely on trusted intimates and providers for guidance or defer decision-making to them
Adolescent participation in decision-making	Limited, with goal of developing self-sufficiency	Respects the voice of the adolescent with goal of promoting long-term autonomy. Balance short-term autonomy with other family interests
Adolescent participation in end-of-life decision-making	Participation not relevant because not yet fully self-sufficient	Respects the voice of the adolescent, although more liberally balance other family interests because adolescent's long-term autonomy is unrealizable
Role of the provider	Provides medical expertise	Provides medical expertise; engages emotional experience of decision-maker; offers guidance in making decisions
Amount of information given to surrogate	Full information	Full information
Information given to adolescent patient in end-of-life care	Depends on patient's decisional capacity	Depends on patient's decisional capacity and parents' wishes
Role of emotion in decision-making	To be overcome	Acknowledges its importance and role
Influence of others on patient or surrogate decision making	Limited; to be avoided	Expected; individuals exist in social context

each other. By contrast, taking a more relational approach to how individuals and families are always already entwined in relationships that imbue their lives with meaning leads providers to respect autonomy by helping families

make decisions. The ethics inherent in the relational autonomy model provides clinicians with ethical justification for directly engaging families in difficult conversations that acknowledge emotions and for offering parents

guidance on the breadth of decisions that can express their love for their child. In Table 1, we summarize the implications of different theories of autonomy for decision-making in pediatric palliative care.

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