Moral justifications for surrogate decision making in the intensive care unit: Implications and limitations

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Because patients are often unable to participate in the end-of-life decision making, caregivers turn to close family members to participate in discussions regarding care in the intensive care unit. This article describes the moral justifications for families being given considerable decision-making authority. However, embedded within these justifications are also some limitations to surrogate decision making. Rather than attempt to dogmatically resolve these thorny cases regarding a surrogate's request for what healthcare providers believe are unreasonable requests, we believe more attention should be paid to how healthcare providers and intensive care units can promote a surrogate's ability to make ethical decisions. We end by offering a number of specific suggestions for improving communication with surrogates. (Crit Care Med 2003; 31[Suppl.]:S347–S353)

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Each year, more than a half million people in the United States die either in an intensive care unit (ICU) or shortly after discharge from an ICU. In either case, the patient's death is usually preceded by a conscious decision to forgo life-sustaining technology. Because patients are often unable to participate in the end-of-life decision making, caregivers turn to close family members to participate in such discussions. These conversations often cause both healthcare providers and families anguish (1–4). Healthcare providers argue that families are too emotional and can never understand the medical decisions that they are being asked to make. This may lead to an impression among healthcare providers that families are forcing them to provide ineffective, often painful care. The extensive literature on futility and the need for unilateral physician decision making reflects these beliefs. On the other hand, families criticize physicians for being unavailable and for being poor communicators. They accuse physicians of being paternalistic and argue that they, rather than physicians, should make the final decisions regarding the care of their relatives.

The purpose of this article is not to adjudicate between these conflicting claims. Rather, we hope to describe moral justifications for families being given considerable decision-making authority. However, by laying out these justifications, we will also suggest some limitations to surrogate decision making. Unfortunately, we will argue that setting these limitations will not resolve the difficult cases in which families and healthcare providers disagree regarding either the goals of therapy or the proper ways to meet these goals. The reason for this, we believe, is that reasonable people can disagree about the proper course of action in these situations. Rather than attempt to dogmatically resolve these thorny cases, we believe more attention should be paid to how healthcare providers and ICUs can promote a surrogate's ability to make ethical decisions. We will end by offering a number of specific suggestions.

First, however, some caveats. We are concerned with the moral rather than the legal authority of families to act as surrogates for their loved ones. Many states have laws defining the specific order of surrogacy and the decisions that surrogates may make and the level of evidence needed for these decisions (5). This article will neither review nor critique specific state laws, although our discussion of the moral justification for surrogacy has clear applicability to what we believe the laws regarding surrogacy should be. Second, this article focuses on the moral authority of family members (either based on biological or legal relations) to make decisions for their loved ones. However, many of the same arguments could be made for nonrelated friends. This is a complicated subject, and to simplify matters, we will be focusing solely on familial relationships. Third, again to simplify matters, we assume that the family speaks with one voice. In our experience, many families make decisions by consensus. Although the most difficult cases involve families with dysfunctional relationships, our purpose here is to provide a general model that fits most cases, rather than a road map that is applicable to every situation (1). Finally, although the purpose of this article is to focus on family decision making in the ICU, there is nothing about our moral arguments that limits their applicability to that particular environment. A similar article could be written about family decision making for one's loved one in a nursing home, for example.
Moral Justifications for Family Decision Making

One may question why families should have decision-making authority for critically ill patients. After all, patients have complicated and rapidly changing medical problems. Healthcare providers go to school for years to determine the best way to care for these patients. They have experience caring for similar patients and can be objective in their assessment of the risks and consequences of various alternatives. On the other hand, families are stressed and emotionally distraught. They make decisions based on what they “hope” will happen, rather than what is likely to actually occur. Not understanding the medical situations, they may make decisions with which physicians disagree. Based on these factors, many intensivists believe that decision making would be better off if they, rather than the family, made medical decisions.

These arguments are not unique to family decision making. Similar arguments were made by healthcare providers regarding why doctors, rather than patients, should have decision-making authority (6). Over the last 20 yrs, however, autonomy has become the preeminent value in medical decision making. Individuals vary in their conception of a good life and the importance of medical therapy in achieving that life. Given this, when confronted with medical options, which have significantly different impact on patients’ lives, patients are the best judges of how to maximize their self-interest. Moreover, optimal decision making is not the only reason to value autonomy. Most of us want to be involved in making life-altering decisions for ourselves, even if we make a decision that we later regret. Given that it is one’s own life, one wants to be “in control” of the major decisions that affect it.

These philosophical values outweigh the practical difficulties of adequately informing patients about proposed medical treatments. The fact that healthcare providers are more educated regarding medical scenarios requires them to educate patients so that they may make the decision most consistent with their values. Healthcare providers cannot teach patients to practice medicine, nor should they try. However, they can and should educate patients on the risks and benefits of proposed therapies so that when a personal choice arises, patients can be in the best position to make it.

Despite physicians’ fears, we have found that patients can be adequately informed about medical decisions. There are interventions that can likely improve lay decision making, and these will be discussed below. There may even be advantages to educating patients and giving them decision-making responsibilities. A major reason for lawsuits is dissatisfaction, and there are some data that educated patients are more satisfied with their care (7). Involved patients also seem to be more adherent and take better care of their decision-making responsibilities.

Substituted Judgment

Similar arguments can be made for why family members should be given the authority to make decisions for their loved ones. The first two justifications are comprised in what Dan Brock calls “patient-regarding grounds for family authority” (8). The most powerful argument for empowering families to make decisions for their loved ones is that surrogate decision making is an extension of the incapacitated person’s autonomy. This argument, called substituted judgment, has two forms. First, one may argue that the families are best able to represent what the patient would have wanted, if he or she were competently able to consider the decisions at hand. The family’s decision-making authority is based on their ability to speak as if they were the patient, thus promoting the patient’s values and autonomy. Of course, the degree to which a family member can do this varies. The strongest case would be in a situation in which the surrogate and patient have had a clear conversation about the patient’s wishes. This may occur after the death of another family friend, for example, or a television show dealing with death and dying. Subsequently, the patient may say, “If I were ever in that situation, my goals would be X.” Repeated conversations over time strengthen one’s conviction that the surrogate is accurately representing the patient’s wishes. Unfortunately, the evidence on which family members serve as surrogates for what the patient would have wanted is typically much weaker. Without specific conversations, surrogates must impute what they believe the patient would have wanted based on their knowledge of the patient’s personality and values. It is believed that no one knows the patient and the family, and thus the family is most likely to accurately reflect the patient’s values, hence their moral authority to serve as substituted decision makers when the patient is incapacitated.

Empirical data, however, raises serious concerns regarding this philosophical justification (9). Few patients have discussed their resuscitation preferences with a family member. A number of studies show that family members are not very accurate in their predictions of what patients would want regarding life-sustaining treatment. This is true regardless of whether there has been a specific discussion about these matters. Allowing family members to make decisions for their loved ones does little to ensure that the treatment the patient receives is consistent with the patient’s values, and thus, it does not promote patient self-determination. On the other hand, although family members’ predictive ability is not wonderful, it is better than healthcare providers’ ability to predict patient’s preference. In so far as someone must be empowered to speak for the patient, it is thus justifiable that families have this authority.

A stronger, although related justification for family’s decision-making authority, is that it promotes patient self-determination by respecting the patient’s choice of decision maker. What is being respected is not a substantive choice regarding end-of-life care but the procedural choice of who should make decisions. Studies suggest that in >90% of cases, patients want a family member to make decisions with the doctor about their care. This choice is more important than substantive choices about what should be done for many patients. Empirical data support this argument. Patients say they trust their proxy decision maker even more than they trust living wills (10, 11). Faced with an uncertain and complicated future, patients value having someone they trust negotiate with doctors regarding the best treatment. (Unfortunately, we do not know who the patient would rather make decisions when the doctor and family disagree.)

Limits of Family Decision-Making Authority Based on Substituted Judgment

Family member’s moral authority to make decisions for their loved one based on this argument is not unlimited. For example, the family must consider the incapacitated patient’s values. A surro-
gate who makes decisions based solely on what is in his or her best interest acts against this patient-regarding justification. For example, a surrogate should not be allowed to refuse a blood transfusion for a patient based solely on his or her own beliefs as a Jehovah’s Witness if there was no evidence that the patient would have refused.

**Best Interest Justification**

A second patient-regarding justification for surrogate decision making is that family members are best suited to make decisions that maximize the patient’s best interest. This argument presumes that even without an explicit discussion about the patient’s preferences, family members are most likely to know what is in the patient’s best interest. Families are where cultural traditions are taught, practiced, and internalized (12). Given these factors, family members are most likely to know the patient’s values and interests. Second, families are capable of a degree of love and intimacy that is rarely found in other relationships. These emotions lead family members to be particularly concerned about the patient’s well-being and to think carefully about which decisions are most consistent with the patient’s best interest. The combination of patient-specific knowledge and concern suggests that family members will usually make the best decisions for incapacitated patients and support the presumption of allowing them decision-making authority.

**Limits of Family Decision-Making Authority Based on Best Interest**

This justification for family decision making is contingent and revocable. A particular family member may know little about a patient’s values. For example, if the only living relative is the patient’s third cousin who has not seen the patient in >20 yrs, there is little reason to believe she knows the patient’s values. In other scenarios, there may be family dysfunction, and family members may not have the patient’s best interest at heart. To the extent that the surrogate’s authority is based on these grounds, others involved in the patient’s care have a responsibility to protect the patient’s welfare by seeking to have that family member removed as a surrogate.

Moreover, family members are typically precluded from making decisions that seem seriously contrary to the incapacitated patient’s best interest. Imagine a 30-yr-old patient who has been intubated for 2 wks after a severe community-acquired pneumonia. Despite the patient’s slow progress, the family demands that the ventilator be withdrawn because it has become “too much” and it is just not “worth it.” Proxy does not have as much discretion in defining what is meant by best interest as autonomous decision makers. This means that although a family’s choice does not have to be the ideal choice, it has to fall within a range of societally acceptable decisions. Thus, even if the family sincerely believed that this was the best decision for their loved one, healthcare providers would be justified in refusing to extubate the patient and seek to have the surrogate’s decision overridden.

Controversies can arise when best interest is invoked. First, there may be disagreement about whether the family’s decision is within the range of acceptable choices. What if the patient referred to above had been mechanically ventilated for 3 months and was only minimally better? Would forgiving the ventilator be an acceptable choice? Second, certain medical states make reference to best interest seem irrelevant. Patients in a persistent vegetative state, for example, have neither positive nor negative physical or emotional experiences, making best interest hard to define. Third, how does one balance the healthcare professional’s assessment of the patient’s best interest with the family’s appeal to patient values? Imagine the family saw that the patient was very active and thus said he would never want to be on life support. What counts as evidence regarding what the patient would want? How much evidence must be provided that this is what the patient would have wanted? Reasonable individuals can disagree regarding on how to balance these variables.

**Non-Patient-Regarding Justifications for Surrogate Decision Making**

The other justifications for family decision-making authority are what Dan Brock calls “nonpatient regarding justifications” (13). These justifications appeal to concepts of societal values such as justice rather than promoting patient-based values. Although these justifications are generally less weighty than patient-regarding justification, they are important in the amount of discretion they give families.

One non–patient-regarding reason for family decision making is that, other than the incapacitated patient, the family is the most affected by the decision. Families bear much of the cost of caring for a critically ill loved one. In SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) (14), >20% of families spent a great deal of their savings caring for these patients. Families give up their time to visit the patient in the hospital. They are the ones who must take the patient to the doctor, who get the patient’s medications, and who provide ever-increasing amounts of informal care giving. The family is responsible for arranging and paying for funerals, and they visit the grave. Emotionally, families are bereaved and experience traumatic grief and depression. Given the impact that medical decisions have on the entire family, it seems fair to give families some discretion.

One can imagine societies in which this claim has less weight. In such a society, the burden of caring for the sick patients would fall less disproportionately on family members. Society would pay to allow families time off work, arrange more support for care giving chores, and offer psychological support for family members. Even in such a society, in which financial and societal burdens are lessened, however, family members are still likely to be more affected by such decisions than unrelated persons. The emotional ties that bind family members typically are stronger than the ties between caregivers and patients, and thus, the impact of the decision is larger.

This non–patient-regarding justification for family decision making explains why family members do not have to neglect their own interests when making decisions for their incapacitated loved ones. Often, it is not clear which of a variety of choices the patient would have chosen. For example, the best interest justification does not always provide sufficient specificity regarding the right thing to do. There is often no single best answer when attempting to decide the goals that should guide the care of critically ill patients. One can be uncertain about whether it is better for a loved one to live longer but with great disability or to live a shorter period of time with a
higher quality of life. A patient may have said that he was willing to try ICU care to see if it worked but not been very specific about what “try” or “worked” meant. In these cases of uncertainty, it is reasonable for family members to select among reasonable options, based on their values and needs.

This non–person-regarding justification operates commonly in family life. We typically believe, for example, that parents know what is best for their children and care more about their children than anyone else. This does not mean that a parent cannot consider other interests when making decisions for his or her children. It might be optimal for parents to send a child to a very expensive private school. The parents can decide not to do this because of its effect on either the other children or their own interests. Two conditions must be met, however. First, the parents’ final decision should be within an acceptable range of options. Parents could not refuse to send the child to any school and then do a poor job of home schooling because it interfered too much with their schedule. Second, the parents’ decision making should primarily be guided by the child’s interest rather than their own needs.

Of course, the picture is actually more complicated because the patient’s well-being is often closely tied to the families well-being (in this way a non–patient-regarding justification may become patient-regarding). This is particularly true as patients are more quickly discharged from the hospital and sent home to be cared for by the family. Empirical data, for example, have shown a relationship between family care giving and patient well-being (15, 16). In so far as our society expects families to support their loved ones, it is appropriate for families to take into consideration how their decisions will influence their resources.

A second non–patient-regarding justification for why families should be allowed decision-making authority is because our society wishes to empower families as independent moral units with responsibility for their members. We want families to take on a number of important roles in our society. The family is where most childbearing responsibilities are assigned. The inculcation of values and the teaching of religious rituals and mores are expected to occur in the family unit. The family is also thought to have primary responsibility for its sick members and its elderly. Finally, the family is the primary social institution in which long-term, intimate, personal relations are developed.

For the family to fulfill these social and human needs requires significant freedom from external observation, oversight, and control. The family needs freedom to choose among different value structures, the power to educate its children regarding the importance of these values, and the privacy needed to allow for the flourishing of intimate relationships. Without these powers, the family is unlikely to be able to accomplish the socially desirable goals. This means allowing family members a fair amount of discretion in making decisions about other family members when those family members cannot make the decisions for themselves.

Limits of Family Decision-Making Authority Based on Non–Patient-Regarding Justifications

Again, this justification contains a rebuttal assumption—that the families in question are attempting to serve the socially desirable functions noted above. To the degree to which the family is not a locus of emotional, social, or financial support, the justification for having the family serve as a surrogate is limited. Moreover, there is a general consensus that this non–patient-regarding justification for surrogates has less moral weight than patient-regarding justifications. These justifications are largely operative when, based on the other justifications, it is unclear what should be done.

Role of These Justifications in Surrogate Decision Making

The above four justifications for family surrogacy help guide the choice of the appropriate decision maker, help guide surrogate decision making, and help establish the limits of surrogate decision making. For example, in cases in which the patient did not choose a surrogate, the moral criteria for who should be the appropriate surrogate involves asking four questions:

1. Who is most likely to know what the patient’s wishes are?
2. Who seems to care the most about the patient?
3. Who is most affected by the decisions that need to be made about the patient?
4. Does naming any of the parties as the patient’s surrogate promote the societal interest in family?

It is often relatively easy to answer these questions. Moreover, because families often make decisions by consensus, the naming of any one individual as the surrogate is somewhat artificial. On the other hand, these justifications (and their hierarchical status) suggest that biological or legal family members who are not emotionally close to the patient or who do not know the patient’s wishes and values are ill suited to serve as surrogates. In these situations, close friends are morally more appropriate based on the above justifications. The most difficult cases are situations in which family members or friends may disagree about who knows the patient best or who cares and is affected most by the decisions. In these cases, reasonable people can disagree, and mediations by ethics consultants or societal adjudication (e.g., the courts) are required to determine who is the most appropriate surrogate.

Second, the above justifications are also useful in framing the surrogates’ decision-making process. Thus, for example, the most important criterion that should guide family decision making is what they believe their loved one would want to do in the situation. Thus, families should be asked, “what do you believe [your loved one] would choose if she could speak for herself?” or, “If [your loved one] were sitting here now, what do you think he would say?” This is particularly important as, anecdotaly, family members report feeling guilt over being asked to make life-and-death decisions for their loved ones. Asking, “what do you want us to do for your mom?” may intensify these feelings. Moreover, empirical data suggest that family members more accurately predict their loved one’s wishes when they are asked what their loved ones would want (17).

Finally, as discussed above, the justifications for surrogate decision making also provide limits to family decision making. Difficult situations arise when two or more of the justifications for surrogacy decision-making conflict. The most common situations are those in which the healthcare assessment of the patient’s best interest conflicts with the family’s determination of what they believe the patient would want. These cases
are rife with ambiguity, leading to situations in which reasonable people can (and do) disagree. First, in a specific scenario, it is difficult to know what the patient would have wanted. Only 20% of individuals have living wills, and thus, families must try to interpret the patient’s wishes from previous, often vague, statements. Second, it is often difficult to know the degree to which the family’s decision is influenced by their preferences vs. their knowledge of the patient’s wishes. Although patients can autonomously make decisions that seriously conflict with societal notions of what is in the patient’s best interests, surrogates’ decisions are always more limited. For example, the principle of autonomy allows a patient to refuse a life-saving blood transfusion because of a fear, however misguided, of HIV. However, it would be justifiable to override a family who refused a transfusion for their loved one in the same situation, based solely on the family’s fear of HIV. The problem is that it is often difficult to distinguish between the patient’s values and the family’s values (often the family is unclear which is operative). Third, it is difficult to strictly delineate which choices are no longer in a patient’s best interest. Is it in the best interest of a patient with severe dementia to be intubated for 3 wks to live an extra year and a half? Things become even more complicated in situations in which the family benefits from the decision (such as a pension provided to the family as long as the patient lives). Reasonable people can differ on how to resolve these difficult cases.

Additional Limitations to Surrogate Decision Making

Other limits to surrogate decision making are based on more general ethical principles. First, surrogates, like patients, must have decision-making capacity to serve as a decision maker. A family member who lacks the intellectual capacity to understand the medical decision cannot attempt to respect the patient’s values or best interest. An uninformed decision may also be inconsistent with the surrogate’s interests. Thus, persons who lack decision-making capacity are morally precluded from serving as patients’ surrogates. Second, a surrogate cannot make decisions that the patient could not make. For example, a patient can be forced against her will to be treated for an infectious illness that places others at risk. Similar limits restrict the actions of a family member acting as a surrogate.

However, perhaps the most contentious debate focuses on limiting a surrogate’s decision-making authority based on a “futility” argument (18–25). Some physicians and ethicists have argued that futile interventions can be unilaterally withdrawn or withheld by the physician because:

- Requiring futile interventions to be provided, despite physician objections, is an abrogation of the physician’s integrity or autonomy and discounts the specialized knowledge, experience, and training that he or she possesses.
- Ineffective treatments squander resources better spent on more effective and appropriate therapies.

Drawing an analogy to physicians’ ability to refuse to provide “inappropriate treatments” such as antibiotics for viral illnesses, proponents argue that a surrogate’s decision making is limited to medically reasonable options (26). Government and professional groups agree that healthcare professionals or institutions may decline to provide a particular treatment because such choice would violate their conscience or professional judgment (27, 28). This is especially true if the physician suspects that the intervention would result in harm or greater suffering with minimal chances of deriving significant benefit. According to this argument, medical indications for interventions should be used to determine what should and should not be offered, including life-sustaining therapy. If patients or their surrogates request inappropriate care, society places the burden of refusing to provide inappropriate care squarely on the shoulders of physicians, who should not hesitate to do so.

However, these arguments have been subject to vigorous debate (26). Except in cases of so-called physiologic futility, in which a physiologic basis exists whereby the intervention cannot possibly be effective (e.g., reconnecting a severed spinal cord), all judgments about futility are in fact debates over whether it is reasonable to engage in therapies with a very low probability of success and how to define a successful outcome. Some scholars argue that life-sustaining therapy is fundamentally different from other forms of therapy and that it cannot be withheld unless the patient or surrogate refuses (29). The debate thus depends on who, in times of conflict, should define appropriateness, and on whether decision making in life-and-death situations is different from other clinical scenarios. Unfortunately in the clinical setting, this theoretical discussion often degenerates into an emotional power conflict. (Many of the same arguments could be made, interestingly, in those cases in which the family wishes to forgo therapy and the doctors wish to continue therapy.)

We are unlikely to resolve this debate. Luckily, an analysis of the data from SUPPORT suggest that the cases of futility are relatively infrequent (21). Moreover, even proponents of futility agree that unilateral physician decision making should only be made after careful discussions with the family. This is because only then can the goals of therapy be clearly understood and the risks and potential benefits assessed in the light of the patient’s values and wishes. It is the responsibility of the health professionals caring for the patient to determine the patient’s physiologic condition, the goals of therapy, and the probability of success. Without a thorough discussion of goals, the concept of futility may be misused and invoked by physicians because it allows them to make unilateral determinations about the appropriateness of care.

Unfortunately, recent studies suggest that informed families are the exception rather than the rule. Multiple studies suggest that clinicians’ communication in the ICU is inadequate. Nurses and physicians underestimate the information needs of ICU patients and their families (30) and frequently lack the skills to communicate complex medical information or to address a family’s emotional needs. Attempts to communicate are often ineffective: half of family members fail to understand even basic information about the patient’s diagnosis, prognosis, or treatment (31). As a result, anxiety and confusion among family members are widespread (32). Communication with families has been “consistently identified as the most important and least accomplished factor in quality of care” by family members of ICU patients (33). In two studies of families of deceased patients, one in the ICU, communication concerns was the family’s number one complaint (34, 35).

Many of the ethical difficulties noted above may be resolved by improved communication. Therefore, the first step in decreasing ethical conflicts and improving the family’s ability to serve as a sur-
More attention should be paid to how healthcare providers and intensive care units can promote a surrogate’s ability to make ethical decisions.

ICU lengths of stay. Mortality was not different. The authors suggest that family conflicts and instances of futility can be decreased with the use of regular meetings (39). Lilly et al. (40) performed a before-and-after study of 530 adult ICU patients. The intervention consisted of multidisciplinary meetings within 72 hrs of admission, with follow-up meetings to discuss palliative care options when continued advanced supportive technology was not achieving the patient’s goals. The intervention group had a shorter length of stay, decreasing the number of days on which the healthcare providers and family could disagree on length of stay. Again there was no change in mortality. Unfortunately, neither study measured family satisfaction, further studies of outcomes and descriptive data to determine the most effective way to communicate with families are desperately needed.

Second, informational and decisional aids may also help educate families. In oncology, there is a great deal of data regarding the usefulness of aids to improve patient’s understanding of their condition, their decision-making process, and their satisfaction with care (41–46). For example, giving patients an audio tape of their first consultation increases patient satisfaction. A one-page list of questions both increases satisfaction and patient understanding of his or her illness. Structured decisional aids improve a patient’s satisfaction with the decision-making process. In the ICU, giving families an informational brochure increased their knowledge of the patient’s prognosis (47). The Society of Critical Care Medicine and the American Thoracic Society have developed Web sites containing educational materials for families about the technologies available in the ICU and common diseases.

Although no substitute for regular family meetings, informational and decisional aids also help reduce the burden of physician-to-family communication because standard information can be conveyed using the aids. Healthcare professionals can then begin family meetings by asking if the information in the aids was understood and answer any questions. Methods to reduce the communication burden on physicians are especially important because intensivists report that they lack sufficient time to communicate with families. Time physicians spend at family meetings is usually either not reimbursable or under-reimbursed relative to other activities under current reimbursement rules. Thus, methods to improve the efficiency of physician communication are urgently needed.

Summary

When, as is often the case in the ICU, the patient cannot participate in decision making because of incapacity, decision making must be extended to the patient’s surrogate. For the reasons outlined above, we believe that the family is usually the most appropriate surrogate and should be given some discretion in making the choices that they believe represent the patient’s wishes, are in the patient’s best interest, and that take their personal circumstances into account. To optimize decision making and decrease conflict, family needs for information and support must be attended to. In an environment of cost containment, intensivists will need to develop educational aids and organizational tactics to meet these needs.

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