
DECISION MAKING IN PATIENTS WITH ANOREXIA NERVOSA: A BIOETHICAL AND METHODOLOGICAL CHALLENGE

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Abstract: The refusal of patients with anorexia to undergo medical treatment may create strong ethical dilemmas for health professionals, obliging them either to accept decisions that leave patients at risk or to apply treatment against their patients' will. In this paper we discuss the issue of mental capacity in patients with anorexia who consent to or refuse a specific treatment. We also review personal identity as an important factor in decision-making and discuss three decision-making styles: the *subjective criterion*, *substituted judgment*, and *the best interest principle*, and highlight the serious challenges associated with each one.

Keywords: *Anorexia, psychiatry, bioethics, decision-making*

INTRODUCTION

In contemporary bioethics, in particular in medical ethics, the respect for the principle of autonomy is a cornerstone in the relationship between doctors and patients. There is an assumption that all patients with mental health disorders lack autonomy because they lack capacity, which is the psychological ability to make valid decisions. However, this is clearly wrong. Not everyone with a mental disorder is unable to make reasonable and appropriate decisions about their health. In literature, several studies have demonstrated such error because people with mental disorders such as schizophrenia, depression or bipolar disorder have the capacity to judge risk-reward situations and therefore adequately decide correctly about treatments (Grisso T., and Appelbaum P., 1995; Calcedo A., et al., 2020; Okai D, et al., 2007; Owen G., et al., 2013; and Pons E., et al., 2020). This is not to asseverate that all individuals with mental disorders are the same or that they share the same degree of capacity.

Patients with anorexia regularly avoid treatments and this could be an indication to evaluate their capacity. Characteristic symptoms of anorexia include “restriction of energy intake relative to requirements leading to a significantly low body weight; intense fear of gaining weight or becoming fat, or persistent behavior that interferes with weight gain; and disturbance in the way in which one’s body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight” (American Psychiatric Association, 2013).

It could be said that anorectic patients could be a “difficult case” because even when they give the impression of rationality, they are able to understand their situation, and they are able to describe a refusal of treatment (Draper H., 2000; Gans M. and Gumm W., 2003); however, they show several “pathological values” which could manifest incapacity to decide properly (Tan J., et al., 2006).

Therefore, it could be thought that they are not autonomous in order to decide for themselves, although there is no universal agreement among professionals about such asseveration (Isis F, et al., 2018). Perhaps because the main difficulty lies in defining what autonomy means and when people’s wishes are authentic (White L., 2018; Ahlin J., 2018; 2019 and 2020). In any case, decisions made by patients with anorexia nervosa which could put their life at risk are ethically controversial. For example,

their refusal to undergo treatment may leave them vulnerable to potentially life-threatening events.

On the one hand, the values and desires of patients justify the idea that it is more important to prioritize quality of life over biological life. Patients may prioritize autonomy, liberty and dignity over beneficence. In this case, personal identity plays an important role in patients' decisions whether to accept or decline treatment. On the other hand, in controversial circumstances, health professionals may disregard patients' decisions and choose the principles of beneficence and non-maleficence over other ethical principles, because they consider that saving the patient's life should be a priority.

Unfortunately, people with mental disorders are often discriminated and stigmatized for several reasons, and when this happens professionals and relatives adopt paternalistic decisions (O'Reilly CL, et al., 2019). For instance, in health care patients with mental disorders could get the impression that they are not taken seriously and could feel discrimination in the sense that they are denied access to an appropriate doctor-patient relationship or even that they are not getting significant information regarding their psychopathology and treatment possibilities (Mestdagh A., and Hansen B., 2014). This fact occurs even at the legal level, when *a priori* mental illness or refusal of treatment are associated with incapacity (Boyle S, 2019).

At the heart of the issue is the fact that patients may be unable to determine the best therapeutic option for them. This may mean that their opinions are ignored, and as a result they may refuse treatment. A paternalistic approach should only be applied when there is enough evidence to indicate that the patient does not have capacity, as will be discussed below. Moreover, professionals should not accept each decision as it comes or systematically ignore patients' opinions. Decision-making in the context of health always depends on the specific situation, while also evaluating the degree of autonomy of each individual patient. Taking everything into account, practitioners may adopt either a paternalistic approach or a position that prioritizes the patient's autonomy (Trusty W, et al., 2019).

The aim of this paper is to identify the potential issues when making decisions for patients with eating disorders who refuse treatment, analyzing the concept of capacity to determine when patients can decide for themselves. We will also review some notions such as personal identity, authenticity and autonomy, because these terms are intrinsically related to the capacity.

The aforementioned concepts may help to better understand decisions made by patients with anorexia. In some cases, health decisions can be based on substituted decision-making, due to the patient's incapacity. Thus, it is important to review both the limitations and implications of substituted decision-making.

THE CAPACITY TO ACCEPT OR REFUSE TREATMENT IN ANOREXIA NERVOSA

An adult is considered to have the capacity to consent to or refuse a specific treatment unless there are indications to the contrary. But, when the capacity of a patient is not enough, a difficult ethical conundrum in medical practice is invoked: What degree of paternalism may be assumed in order to protect a patients' well-being?

To determine the degree of capacity in patients, healthcare professionals should evaluate their autonomous and voluntary decision-making, and assess whether they have the information they need to make an informed decision.

There are many tools for evaluating the capacity of patients to make decisions. Perhaps the most widely used instrument is Mac-CAT (Mac-CAT-T), created by Appelbaum (Appelbaum P., 2007), which examines four aspects: (1) the ability to *understand* the information related to treatment decision (different treatments, disease, and the pros and cons of the treatment); (2) the ability to *appreciate* the significance of the information on the treatment for one's own situation; (3) the ability to *reason* with relevant information so as to engage in a logical process of assessing several options; and (4) the ability to express their treatment choice. In addition to formally assessing capacity, we strongly believe that the assessment of a patient's capacity to consent to treatment should be guided by the following basic rules: (1) capacity to consent is not established by clinical diagnosis; (2) formal evaluation should focus on a specific task in a particular moment and at a precise time; (3) mental capacity can fluctuate with time (lucid moments); (4) the severity of the situation will determine the level of capacity required; and (5) the option chosen should not be considered as lacking capacity or not because it is the person who has (or lacks) capacity.

Recent meta-analysis studies have suggested that patients with anorexia nervosa may have some mental capacity affected (Vollmann J, 2006;

Grisso T., and Appelbaum P, 2006; Tan J., et al., 2003 and 2006; Guillaume S., et al., 2015). For instance, it has been reported that cognitive problems in decisions made under uncertainty (e.g., long-term decisions) could complicate the recognition of arguments for and against making decisions. Moreover, poor decision-making was observed to be more marked during the acute phase of the condition than in the recovered state. It could also be argued that the nutritional status of the patient during the acute phase could affect decision-making skills (Guillaume S., et al., 2015).

These observations make it harder to determine whether patients with anorexia nervosa can make decisions autonomously. Furthermore, results from a Mac-CAT assessment of patients with anorexia (Vollmann J., 2006; Grisso T., and Appelbaum P, 2006; Tan J., et al., 2003 and 2006; Guillaume S., et al., 2015) revealed that although patients may have some difficulties in concentrating and usually present with a distorted self-perception of reality (specifically their bodies) and values, they often have a very good understanding of the facts of their pathology and the risks involved, as well as good reasoning skills. Thus, taking all these characteristics into consideration, health professionals face a significant challenge in deciding whether to respect the patient's decision or, on the contrary, adopt substituted decision-making.

A potential problem in this evaluation is the methodology used. Mac-CAT is traditionally used to assess capacity; however, serious difficulties have been reported for its use in patients with anorexia. Tan et al. (2006) criticized the sole and strict use of Mac-CAT in assessing capacity in individuals with anorexia. They strongly believed that the patient's values and beliefs were distorted because of their condition despite scoring well on *understanding* and *reasoning*. This point is of particular importance because Mac-CAT should add the same weight to values and beliefs as it does to the other domains, as these are used in decision-making. Tan et al. considered that such distorted values and beliefs are "pathological values", such as: (1) values attached to fatness, which was generally observed by the patients to be a mark of laziness, lack of self-care, or lack of self-control; (2) depressive values linked to the lack of danger of dying that was felt by the patients, even when life was generally very difficult and painful because of the disorder; (3) the paramount importance of being thin, with patients considering a low weight to be more important than other aspects such as family, friendships, health and academic achievement; and (4) the issue of personal identity.

The necessity of introducing values in Mac-CAT was defended by Breden and Vollmann (2004) and supported by Grisso and Appelbaum (2006). Grisso and Appelbaum reported that the underlying problem was the way in which the term “appreciation” was conceived because it already introduced values and beliefs. Hence, one could now think, as Vollmann (2006) did, that “authenticity” in decision-making could be a key aspect when evaluating patients with Mac-CAT. When patients with anorexia state that they would rather die than gain weight, it could be translated that patients’ wishes are inauthentic. But, in fact there is no consensus regarding how authenticity should be evaluated, and it could involve several implications for informed consent. In this sense, Ahlin’s (2018; 2019, and 2020) work could contribute a better understanding of the concept of authenticity. The author explains the concept using some arguments. The starting point is:

“the dissenting self-reflection thesis: Judgments of inauthenticity are justified if there is sufficient reason to believe that the desire-holder would disapprove of having the desire upon informed and critical self-reflection” (2018).

Here, we may observe that such thesis, “affirmative self-reflection is re-stated as a negative”. The aforementioned idea shows in which conditions it is justified to judge that a desire is inauthentic. Hence, we could consider that desires must be authentic unless there is enough evidence of the opposite. Additionally, Ahlin provides two indicators of inauthenticity. The first one is

“It is a reason to believe that a desire holder would disapprove of having a desire upon informed and critical self-reflection if it is known that the desire is due to causal factors that are not normal to how the desire-holder is otherwise construed, taking both physical and mental dispositions into consideration” (2018).

Regarding patients with anorexia, casual factors could be associated with the pathology (typical symptoms such as body image disturbing, altered cognitive and emotional functioning (Chan, T, et al., 2014; and Danner U., et al., 2012).

The second indicator of inauthenticity is related to the concept of identity. It is expressed in the following terms:

“It is a reason to believe that a desire-holder would disapprove of having a desire upon informed and critical self-reflection if it is known that the desire does not cohere with how the desire-holder’s identity has developed over time and is presently being sustained” (2018).

In both indicators, Ahlin considers that this does not offer enough reasons to justify inauthenticity. For this reason, Ahlin provides a combination of the two indicators:

“There is reason to believe that a desire-holder would disapprove of having a desire to the extent that the desire is known to be due to causal factors that are not normal to how the desire-holder is otherwise construed, taking both physical and mental dispositions into consideration, and to the extent that the desire is known to be incoherent with how the desire-holder’s identity has developed over time and is presently being sustained” (2018).

However, it must be underlined that decisions are not autonomous only because desires are inauthentic. In fact, it is only one aspect, although very important, when the capacity is analyzed. In any case, although the concept of identity will be presented later, it is vital to asseverate that there is an intrinsic relation between values, identity and inauthenticity or authenticity.

Values identified in several steps (pre, during and post) could indicate whether a decision is “authentic” or not. At the same time, we should evaluate values and beliefs “before”, “in the course of”, and “after” the pathology because they may change significantly, as has been previously indicated.

It is important to reach consensus on the types of values and beliefs that should be considered when evaluating capacity because they may come under the category of “preference” or “will”. The concepts should be analyzed in detail, as Szmukler (2017) highlights, but in any case, preferences and will are not the same. A “preference” is made at a specific moment and with a precise aim, while a “will” is a combination of consistent decisions made during a significant time period because they are reasonably meaningful and established within personal values. An example of a “preference” is when a person refuses treatment in their last hospital admission because they do not want to suffer a specific side effect, while an example of a “will” is when a person refuses the same treatment over four years because they do not want to suffer a side effect that can

interfere with their life project. Both of these concepts are closely linked to personal identity.

With regard to anorexia patients' "appreciation" of the significance of the information given and its influence on the evaluation of capacity, it may not be adequately assessed by the Mac-CAT because "appreciation" plays a key role for patients as they have an altered perception of their body image. Thus, it could be argued that patients with anorexia nervosa lack capacity for making specific decisions – for example, refusing nasogastric feeding because they fail to "appreciate" the importance of the treatment. However, it could also be argued that the patient does have this appreciation, but has a different motivation that is not shared by most people with the disorder. This kind of incongruity could be compared with Jehovah's Witnesses who refuse blood transfusions because of their religious beliefs. Of course, not many people share these beliefs, but most people accept and respect these decisions.

The clinical assessment of capacity should not only focus on *appreciation*, *understanding* and *reasoning*. Another central aspect to consider is *whether the patients might regret their own decision in the future*. Therefore, professionals should also consider whether their patients are being represented correctly. In this case, values and beliefs "before", "in the middle of", and "after" the pathology play a key role, as well as "preferences" and "will".

Among the challenges identified there is the fundamental role played by appreciation, values and beliefs in patients with anorexia. The assessment of capacity from a qualitative point of view is of paramount importance so that beliefs and values can be taken into consideration, as well as the question of how patients and their families perceive the treatment and other specific issues.

Some authors consider the assessment of capacity must incorporate a hermeneutical perspective to observe and interpret the context, its circumstances, the experiences, values and beliefs of those patients (Kong C., 2017). This would allow us a better understanding of the situation and a deep respect for the person.

In any case, it is important to note that when a patient lacks capacity, professionals and families should take into account what the patient would have wanted. Therefore, it helps to consider values and beliefs in the evaluation of capacity. This involves a considerable amount of information that should be evaluated in light of the norms of practical rationalities, as described by Craigie (2011). Thus, it is important to discuss personal identity, since it is the essence of values and beliefs.

PERSONAL IDENTITY IN DECISION-MAKING

Patients with anorexia show a good understanding of the disease; they are aware of the possible consequences of refusing treatment, and present consistent reasoning. However, people who suffer from an eating disorder often have an altered perception of their body image that might also affect their own identity. By comparing this identity “after” and “during” the disease, we may be able to identify meaningful changes that are critical in assessing the different motivations for accepting or refusing treatment. From the point of view of psychology and sociology, personal identity can be defined as the way in which people observe themselves. Thus, such a view is identified with a specific style of life such as wishes, beliefs, and so on. However, Buchanan and Brock (1989, p. 154-155) consider that personal identity

“denotes those conditions which constitute an individual as the particular person he or she is and that make a person existing at one time, and a person existing at a later or earlier time, the same person. The criteria for personal identity, then, will be a set of *necessary* and *sufficient conditions* for this “unity relation” or, as we shall say, necessary and sufficient conditions for personal identity”.

Personal identity should be evaluated in a gradual way; it is not an “all or nothing” idea. In other words, the evolution of personal identity should be observed over a significant and substantial period of time rather than at a particular moment. This could help to understand accurately the beliefs and values of patients with eating disorders when they confront certain situations. Such motivations could indicate how the person values their decisions, and may also help to recognize whether the person can choose autonomously.

In this connection, in a qualitative study of patients with anorexia and their families to identify how the pathology affected the patients’ identity, Tan J., Hope T., and Stewart A, (2003) reported alterations in personal identity because anorexia was identified as a part of the patients’ self. These authors concluded that anorexia is not a “simple disorder” as it substantially reshapes the personality and style of the patients. It is an important feature of these patients who have great difficulty in visualizing themselves in the future without anorexia; they conceptualize anorexia nervosa as an entity inside themselves.

Several studies have reported obsession, perfectionism, and compulsion in patients with eating disorders, using psychological constructs such as “locus of control” and “clinical perfectionism”. In other words, the literature has focused on clinicians’ interpretations (2003). Tan et al. (2003) explored the views of patients and their families on compulsory treatment, and also examined capacity in the patients. This approach provided a deeper understanding of the reasons (values, beliefs and wishes) why patients accept or refuse treatment. These authors reported that compulsory treatment was only conceivable for patients and families in life-threatening situations, regardless of whether the patients had capacity or not. The results of this study also showed that patients associated compulsory treatment with suffering, imprisonment, and punishment.

As already been discussed, administering treatment without consent faces significant challenges, although it is very difficult to clearly identify capacity in patients with anorexia. Additionally, there are great difficulties in evaluating and determining whether the patients’ wishes are consistent with their personal identity.

Recognizing and introducing personal identity into the assessment of capacity could cause serious issues. For example, it could be argued that a person with advanced dementia is not the same person they were before the disease (due to their depressed mood, memory loss, cognitive deficits, etc.). Furthermore, there will be issues in determining which arguments and values (present or future) their relatives should apply when substituted judgment is adopted.

Depending on the capacity to accept or refuse treatment, authenticity or inauthenticity, and the personal identity of patients with anorexia nervosa, families and health professionals may eventually be obliged to make decisions on behalf of the patients. Some types of surrogate decision-making could be of vital importance here.

SURROGATE DECISION-MAKING

It is widely accepted that an adult is considered to have the capacity to consent to or refuse a specific treatment unless proven otherwise. Health professionals should accept individual decisions; this is a *subjective criterion*, based foremost on the principle of autonomy. However, in patients with anorexia, this *subjective criterion* may represent a serious challenge due to the fact that the patients have an altered body image, as well as

other “pathological values” (Tan J., et al., 2003, 2006 and 2008; Vollmann J., 2006; Grisso T., and Appelbaum P., 2006), which affect the legitimacy of the approach. However, a generalized refusal of such decisions could cast serious doubts on the claim that personal identity has no validity in decision-making. Moreover, when “pathological values” are assumed to be a “general rule”, this clearly contradicts the idea that patients have the right to consent to or refuse a specific treatment unless there are indications to the contrary, since “pathological values” are not a clear sign of incapacity. Therefore, the subjective criterion presents serious challenges in decision-making as there are great difficulties in defining and evaluating capacity.

When it has been established that a person cannot decide by themselves, another person must decide on their behalf. When a specific person with capacity decides on behalf of another person who lacks such capacity, decision-making is guided by *substituted judgment*. This person has a power of attorney and may be a solicitor or next of kin. However, as a general rule, even in cases in which the patient has no capacity, some degree of authorship can be retained, and participation is encouraged. The surrogate decision maker should know the patient’s views and consider their wishes and preferences during decision making. The health care proxy should identify all relevant circumstances, reconstruct such preferences, and identify the things that the patient would consider if they were making the decision themselves. The main aim of substituted judgment is to guarantee the patient’s life project and to find the least restrictive option.

In substituted judgment, the surrogate decision maker should ponder what decisions a “reasonable person” would make in that specific situation after receiving objective information. The surrogate must also consider the decisions the patient lacking capacity would have made if they still had capacity, prioritizing the patient’s wishes, values, and beliefs. Although substituted judgment is an extraordinary criterion for decision-making, five main problems with its use have been reported (Bailey S., 2002; Welie J, 2001; Broström L., et al., 2007; Torke A., et al., 2008; and Shalowitz D., et al., 2006):

1. Substituted judgment is strongly based on the views of the surrogate person making the decisions, rather than on the values of the patient.
2. It does not preserve the autonomy of the patient on whose behalf decisions are being made.

3. In some cases, substituted judgment has been used inappropriately: for example, in cases where the patient has never been autonomous and, therefore, has never had values and preferences for the surrogate to use for decision-making.
4. It is extraordinarily difficult to determine the preferences, values, and wishes of a patient. It is also important to realize that wishes and preferences are constantly changing, with a considerable number of individuals changing their own wishes regarding treatment options over time.
5. Several studies have reported that surrogates incorrectly predict the preferences and values of patients.

The serious limitations of substituted judgment mentioned above could be more pronounced in patients with eating disorders. For instance, it is difficult to determine whether refusing treatment is the result of an “authentic decision” or due to the symptomatology of the disorder. Personal identity issues may also affect the way surrogates consider the “previous” wishes and preferences of the patient or values detected “in the course of the pathology”. Hence, when health professionals reject a decision made by a patient with anorexia, they are discrediting the personality and identity of the patient because they do not share and accept such beliefs and preferences.

Furthermore, in substituted judgment, a “reasonable person” is unlikely to have the same or similar beliefs and values as a person with an eating disorder, given that a person with anorexia most probably has distorted appreciation and “pathological values”. Other challenges have been discussed in the literature. For example, Shalowitz et al. (2016) showed that when making decisions for incapacitated patients regarding end of life treatment, surrogates predicted the patients’ treatment preferences with 68% accuracy, indicating that they incorrectly predicted and made poor decisions in a third of the cases – a substantial proportion.

Overall, then, substituted judgment may be an important criterion, but it faces serious obstacles when applied to patients with eating disorders, as it is difficult to protect vulnerable patients without capacity. Consequently, other approaches such as “the best interest principle” should be explored. The best interest principle consists of excluding patients from decision making in order to maximize benefits and reduce harm to patients lacking capacity. Buchanan and Brock (1989, p. 128) stated that

“the best interest principle, however, is a principle that expresses a *positive obligation*, a duty to do what best promotes someone’s interest or is most conducive to his or her good”

However, this approach is justified only when the patient has never had capacity or when it is practically impossible to define his or her wishes and values. Examples include people in a long-term coma who have never provided serious and consistent arguments, or situations in which health professionals do not know the patient’s degree of autonomy and no relatives are available to provide this information.

Although this approach may be a good strategy for making decisions on behalf of patients who cannot decide, several studies have raised doubts about its validity. For example, Kopelman (2007, pp. 282-287) considered it to be *self-defeating* (it requires surrogates to do their absolute best for each patient), *too individualistic* (it stipulates that surrogates should consider only one person’s interest), *unknowable* (it supposes that surrogates can always agree about what is best, deliberate all the options, calculate all their benefits and harms, and pick the alternative that maximizes benefits and minimizes harm, all of which is impossible), *vague* (due to the fact that sometimes it is unclear which values should be used to judge what is best), *dangerous* and *open to abuse* (it is too easily misused).

When applying the best interest principle to patients with eating disorders, healthcare professionals can decide to administer involuntary treatments to protect the patient, especially at severe stages of the disorder (Tan J., et al., 2008; and Clough B., 2016). Tan et al. (2003b) reported that some patients and their families thought that compulsory treatment was justified if, and only if, the patient’s life was in danger. The application of treatment should be identified in terms of protecting the patient’s best interests. However, such a justification may in fact be a paternalistic decision. In some cases, in their duty to protect patients with anorexia, healthcare professionals might conclude that patients are not capable of making decisions due to their distorted values and beliefs. This is linked to the problems of assessing capacity; since there are no clear and concise criteria for this evaluation, it is inevitably subjective rather than objective and may therefore lead to paternalistic decisions.

Moreover, it is assumed that patients with eating disorders do not provide a serious argument because they have different motivations (pathological values) that are not shared by most people. However, by this logic, it could be argued that people with religious beliefs do not have

capacity because these beliefs “are not shared by most people”. Therefore, this assumption is wrong. To summarize, there is no clear justification for applying the best interest principle to patients with anorexia nervosa. It is not evident that patients with eating disorders lack capacity, and the use of pathological values to determine whether a person lacks capacity or not is controversial. Hence, strong justifications are required to apply this principle.

CONCLUSION

In this article we have discussed the considerable challenges linked to decision-making in patients with anorexia. When health professionals doubt whether or not a patient should decide for themselves, they frequently assess their capacity. However, there are serious difficulties in determining when a patient with an eating disorder lacks capacity. There is not enough information in the literature to determine when patients with eating disorders have sufficient skills to decide responsibly, although some studies indicate that, in general, such patients have considerable difficulties in deciding about their treatment. Even formal evaluations with Mac-CAT indicate that patients with anorexia score correctly in some areas, but not in appreciation. Moreover, the assessment of capacity excludes values and beliefs, as well as the authenticity-inauthenticity of the decisions, and may lead to ethical and methodological challenges.

Personal identity might influence decision-making. While it might be reasonable to assume that values and preferences play a key role in decision-making, there is currently no evidence on what types of values and motivations healthcare professionals should consider relevant when dealing with patients refusing treatment. There is also the dilemma of introducing and prioritizing the patient’s “previous” or “current” values and desires.

Decision-making styles include *the subjective criterion*, *substituted judgment*, and *the best interest principle*. However, each approach has serious drawbacks and, therefore, the final decision should be the result of a collective deliberation about the pros and cons of each one in a particular situation.

In general, the question of whether patients with anorexia nervosa should decide for themselves should not be resolved *a priori*, perhaps due to the ethical reasons involved. The specific decision, the particular context, a rigorous evaluation of cognitive factors, and the patient’s values,

desires and identity should all be taken into consideration. Systematic acceptability of patients' autonomy has been described as an ethical and clinical mistake, but it would also be wrong to systematically disregard patients' decisions merely because they have a mental disorder. Patients should be listened to carefully, and health professionals should always attempt to respect and protect them.

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