The vulnerability experienced by the family of children hospitalized in a pediatric intensive care unit*

A EXPERIÊNCIA DE VULNERABILIDADE DA FAMÍLIA DA CRIANÇA HOSPITALIZADA EM UNIDADE DE CUIDADOS INTENSIVOS PEDIÁTRICOS

LA EXPERIENCIA DE VULNERABILIDAD DE LA FAMILIA DEL NIÑO HOSPITALIZADO EN UNIDAD DE CUIDADOS INTENSIVOS PEDIÁTRICOS

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ABSTRACT

The objective of this study was to understand the vulnerability experienced by the family of children hospitalized in a Pediatric Intensive Care Unit (PICU). The Symbolic Interactionism and the Concept of Family Vulnerability were the frameworks used to understand this experience. Qualitative Content Analysis was used. Data was collected through interviews and observation with 11 families of children hospitalized in a PICU of a university hospital in São Paulo. Six analytical categories regarding the family experience emerged. The categories were compared to the conceptual categories of Family and Vulnerability, and revealed the elements that defined the concept within this context. The child's hospitalization in a PICU triggers intense suffering within the family, as it refers to the possibility of losing their child. Thus, the power and the autonomy of the family in relation to their child are reduced, intensifying the feeling of vulnerability.

DESCRIPTORS

Family
Child, hospitalized
Family nursing
Intensive Care Units, Pediatric

RESUMO

Este estudo buscou compreender a experiência de vulnerabilidade da família da criança internada em Unidade de Cuidados Intensivos Pediátricos (UCIP). O Interacionismo Simbólico e o Conceito de Vulnerabilidade da Família foram utilizados como fundamentação para a compreensão dessa experiência. A Análise Qualitativa de Conteúdo foi o referencial metodológico aplicado. Os dados foram coletados por meio de entrevista e observação com 11 famílias de crianças hospitalizadas em uma UCIP de um hospital universitário, do Município de São Paulo. Emergiram seis categorias analíticas da experiência da família que, ao serem comparadas às categorias conceituais da Vulnerabilidade da Família, revelam os elementos definidores do conceito nesse contexto. Para a família, a internação de um filho em UCIP desencadeia sofrimento intenso, pois remete a possibilidade de uma perda definitiva. Assim, o poder e a autonomia da família em relação ao filho são diminuídos, intensificando o sentimento de vulnerabilidade.

DESCRITORES

Família
Criança hospitalizada
Enfermagem familiar
Unidades de Terapia Intensiva Pediátrica

RESUMEN

El estudio busca comprender la experiencia de vulnerabilidad de la familia del niño internado en Unidad de Cuidados Intensivos Pediátricos (UCIP). Se utilizaron el Interaccionismo Simbólico y el Concepto de Vulnerabilidad de la Familia como fundamentos para la comprensión de la experiencia. El Análisis Cualitativo de Contenido se utilizó como referencial metodológico. Los datos se recogieron mediante entrevistas y observación con 11 familias de niños hospitalizados en UCIP de hospital universitario de municipio de San Pablo. Emergieron seis categorías analíticas de experiencia familiar que, al ser comparadas las categorías conceptuales de Vulnerabilidad de la Familia, revelan los elementos que definen el concepto en tal contexto. Para la familia, la internación de un hijo en UCIP desencadena sufrimiento intenso, pues remite a la posibilidad de una pérdida definitiva. De tal modo, el poder y loa autonomía familiar en relación al hijo se ven disminuidas, intensificando el sentimiento de vulnerabilidad.

DESCRIPTORES

Familia
Niño hospitalizado
Enfermería de la familia
Unidades de Cuidado Intensivo Pediátrico

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INTRODUCTION

The hospitalization of a critically ill child in a Pediatric Intensive Care Unit (PICU) causes anguish, suffering and despair for the family[1-2]. In this context, the family experiences a rupture in its structure and functioning in which parents have the perception they lose power over their child, who comes to temporarily *belong* to the unit's staff[1]. In addition, the child is separated from other family members, which impedes his/her participation in family life since s/he is usually unable to participate and interact[1-3]. Families define a PICU as a place to die and the possibility that the child may die has a tremendous impact on family relations. Being away from the child and dealing with a possibly definitive separation leads the family to explore strategies to preserve its integrity and maintain life as an attempt to keep itself as a unit[1].

In the context of a PICU, the family experiences intense suffering caused by the child's health condition(s) and also by interactions experienced with the PICU environment and professionals. Nurses, as members of the health team, need to have tools to care for the child and the family as a unit.

LITERATURE REVIEW

The knowledge developed in studies[1-5] addressing the experience of families with a child hospitalized in a PICU is relevant to guide the practice of nurses in this context. Studies show there is a lack of tools and intervention protocols to support health professionals to assist the family experiencing the situation of having a critically ill child hospitalized in a PICU.

These studies reveal that the family is weakened by the child's disease and becomes vulnerable while coping with the situation. The team does not heed many of the families' demands, mainly due to miscommunication. Even though nurses strive to include the family in their care plan, they do not feel prepared to welcome families into the PICUs due to a lack of theoretical and practical instruction during their education.

There is a lack of instruments and intervention protocols to support health professionals while assisting families during daily practice in intensive care environments.

The concept of Vulnerability of the Family[6] allows for a deeper understanding of the experiences of families facing a child's disease and hospitalization. The authors make a theoretical proposition on family vulnerability, defined as a feeling of threatened autonomy and being under pressure due to the disease, the family itself and the team. The elements that trigger a family's vulnerability are previous experiences, an excess of demands that compromise the family's ability to deal with the situation and unpreparedness. The defining characteristics of vulnerability are related to the context of the disease, generating uncertainty, powerlessness, real or imaginary threats, exposure to harm, fear of the outcome, submission to the unknown and an expectation of returning to their previous life. Vulnerability in the family context is characterized by imbalance in its functioning capacity, which disrupts, causes estrangement in and conflicts with and alters family life. In the team context, vulnerability is evidenced by conflicts experienced by the family with the team, marked by a lack of dialogue and sometimes disrespect while families are detached from their role. As a consequence, the family alternates between moments when the family members are not able to do anything with another when they try to rescue their autonomy as a family, hence, there is a dynamic and continuous movement that attributes a certain transience to the feeling of vulnerability over the course of the child's disease and hospitalization. The study points to the need for further research to deepen, enlarge and validate the concept of family vulnerability in different care environments. The authors themselves published a study[7] in which they identified the concept of Vulnerability of the Family in clinical practice, enabling pediatric nurses to transfer and apply theoretical knowledge into practice and interventions with families.

Families define a Pediatric Intensive Care Unit as a place to die and the possibility that the child may die has a tremendous impact on family relations.

Considering that nurses have the responsibility to recognize the vulnerability of families in order to propose interventions to help them to alleviate suffering, we ask what it is like for families to experience vulnerability when their children are hospitalized in a PICU; how this feeling is triggered during this experience; what elements of the concept of Vulnerability of the Family are present in family interactions and how these can be identified.

OBJECTIVE

Therefore, this study's objective was to understand the experience of vulnerability in families with children hospitalized in a PICU from the perspective of the families.

METHOD

Symbolic Interactionism (SI)[8] and the concept of Vulnerability of the Family[6] were the theoretical axes that guided the processes of inquiring into and understanding the experience of families with severely ill children hospitalized in a PICU.

The common element between SI and the concept of Vulnerability of the Family is interaction. SI holds that all basic concepts arise from interaction, which is developed in social action and is symbolic when the action of each individual has meaning for the one who created the action and for the one who received it. Individuals have the autonomy

to do what they want defining their choices and directions, acting in accordance with how they define the situation. The concept of Vulnerability of the Family reveals that the family feels its autonomy is threatened when experiencing a situation of a child's disease and hospitalization. The experienced vulnerability is understood as an element of interaction of the family with hospitalization.

Qualitative Content Analysis[9] was the methodological framework used in the study. This is a research method used for analyzing textual data to acquire knowledge and understanding of the phenomenon under study. A subjective interpretation of data content is performed through the systematic classification of the coding process and identification of themes and patterns.

Data Collection and Analysis

The study was carried out with 11 families who experienced the hospitalization of a child in a PICU. A total of 11 mothers, five fathers, one grandmother and two uncles were interviewed, totaling 19 family members. Inclusion criteria were families who experienced illness and hospitalization of a child in a PICU.

The study was carried out in an university hospital in São Paulo, SP, Brazil after the Research Ethics Committee approved the project (CEP 1654/07).

Data was collected between October 2007 and June 2008 after the families signed free and informed consent forms.

Data were collected through participant observation and semi-structured interviews following the standard used to elaborate the concept of Vulnerability of the Family [6]: *What are the difficulties you have faced related to the disease both with the family and with the team?* As the interview developed, new questions were formulated according to data provided by the family members, guided by the concept of Vulnerability of the Family, such as: have you ever experienced a hospitalization of a family member in a PICU? How did you feel and cope with the situation? Did the family participate in decision-making concerning the child's care?

Data analysis was divided into two stages: the first stage included Qualitative Content Analysis[9] to understand the experience of family vulnerability in this context. Then, the analyzed experiences were summarized and the elements that intensified the Vulnerability of the Family were listed.

RESULTS

Stage 1 - The experience of family vulnerability in the context of a PICU

Analytical categories revealed that the illness of a child and his/her subsequent hospitalization in a PICU expose the family to a situation in which it feels under constant threat because hospitalization generates a condition of unexpected stress. When a family receives the news concerning its child's hospitalization in a PICU, it is afflicted with intense despair, fear and remains in a state of continuous vigilance caused by an intermittent concern, especially in the case of families experiencing it for the first time. The analytical categories are underlined and subcategories are in italics to facilitate the readers' understanding.

The vulnerability of families with children hospitalized in a PICU is triggered when the family is *under the influence of previous experiences with the disease and PICU,* which determines how the family defines the situation. *Previous experiences in a PICU* lead to the family becoming fragile and fearful since the family brings a negative meaning to the current situation. *Inexperience* also contributes to this feeling because families who have never experienced the child's disease or another family member's disease lack knowledge concerning medical procedures and conduct.

> [...] sometimes, I don't even know what the medication is or what the purpose of exams is. There's an alarm for the heart, for breathing, for everything, when one alarm goes off, it beeps, and since I don't know which one is beeping, I go after someone. I get afraid because I'm not familiar with it (F1).

When the child is admitted into a PICU, it is evident that *an increase in the families' activities* overwhelms their daily routine(s): sleepless nights due to the child's temperature, malaise or concerns that accumulate from daily care activities.

> I haven't slept for almost three days, since she got sick actually, because we get concerned. Entire nights without even closing my eyes, not to mention the daytime, and she wouldn't get better, the fever wouldn't go away even with medication, it's impossible to sleep, you know? (F4).

In the context of the disease, vulnerability is manifested by elements related to *emotional suffering from hospitalization in a PICU*. Suffering is triggered by hospitalization and is intensified when the family seeks explanations for the child's disease and starts living the stress common to this environment. The *impact of the child's hospitalization in a PICU* begins when the family gets the news. It causes despair in family members who describe the circumstance as a very difficult, horrible and terrifying moment that generates a state of continual concern. Some family members experience symptomatological repercussions such as crying, screaming, sudden hypertensive crises, insomnia, anorexia, as well as the loss of motivation to live.

> When I heard she'd be admitted (into the PICU), I was floored. This is the first time I'd seen her like this. You feel powerless, you think: My God! I cried a lot in the first days, I couldn't pull myself out of it (F2).

In this context, the elements that intensify the suffering of families are *questioning the reasons for the disease*

and the hospitalization of the child in a PICU. The family seeks some reason or even the person responsible for the situation.

> ...before, she was normal, she was super healthy. She only had a small thing when she was three months old, but normal. She's been always very well cared for, since them she had nothing, not even the flu. She is even big for her age, she's a bit chubby. Now she's in a PICU? Why her? (F3).

For the family, the *stress common to a PICU* is evident right at the beginning when it comes to see that a PICU is a totally different environment with many lights and sounds and people in continuous movement. The family suffers a considerable impact and has to learn how to deal with all these stressors; there is no other alternative and the family has to remain in this place until the child recovers.

> We know this is a university hospital. There are the residents, the professors, and I can see they are here to learn. Everything is different here, there is all the apparatus beeping all the time (F1).

The family feels *powerlessness* and *insecurity* when it perceives it is not prepared to participate in decision-making concerning health interventions that will be implemented for and on the child in the PICU, especially when these involve a risk of death. Hence, a state of *submission to the situation* is perceived; the family considers the PICU to be the only place that will help them to get their child back.

> Ah, when we came here, the health plan did not authorize the hospitalization because the waiting period was not over yet, so we came here (F1).

In this context, the family maintains *constant vigilance* in order to be available for whatever is necessary. The vigilance is also a source of support to the sick child as the family remains attentive to everything that happens to her/him.

> It's worse if I go home because I don't rest, I'm not able to sleep and end up with a headache. I'd rather stay here beside her in case she needs me (F7).

Vulnerability in the family context is manifested through the repercussions on parents, or other family members responsible for the child, leaving other activities to take care of the hospitalized child, which leads to *difficulties in family functioning*. The family changes its manner of functioning and gives *priority to the hospitalized child* to the detriment of its other members.

> My husband and I stay here practically the entire day, we take turns day and night, and the other kids, even the youngest one, stay with my mom (the child's grandmother) all the time; for everything that happened, I almost don't even get to see my children (F3).

Additionally, hospitalization forces the family to reorganize itself and the *healthy siblings become estranged*. They are left behind and other family members take care of them.

> The girls (the child's sisters) are scared from the situation and don't even come here, but since we live far away, it's better for them to stay home. We (parents) try to be with them so they don't suffer so much (F6).

Another adverse situation that hinders contact with the hospitalized child is a *lack of structure for the family in PICUs*. The place does not provide physical space or arrangements so the family can stay in comfort while accompanying the child. Since they want to stay beside the child and accompany his/her changing condition, they submit themselves to hardship, staying in the corridor or in front of the PICU because there is no place available to rest, even during night.

> You stay inside the PICU, you can go in if you want, but there're benches out there which is where we stay. My husband has been here with me since yesterday. We take turns during the night, I go in then he goes in, but we usually stay in the corridor outside with the other parents (F4).

A situation that exacerbates a family's helplessness hindering its normal functioning is when the sick child has to be submitted to medical or nursing procedures. The parents have to leave the PICU to wait for the care procedure to be performed.

> When there's a procedure, they (the health team) ask us to wait outside but sometimes it takes some time because they perform a procedure with another child and ask us to leave again. It's bad because today I was only able to stay a little while with my son, though it is better than nothing (F4).

In the context of the team, the family´s vulnerability is manifested by *divergences between the family and the team*, which are caused by *estrangement between the team and the family*, a perception that the team is being hostile, feelings of being excluded and slighted by the team. For the family, the health team keeps itself distant, and treats it in a strictly professional manner, only relating to the family during the visits and provides little information to parents. The parents feel their need for information is not totally heeded. The *team also treats the family with hostility* when they inappropriately answer the family's questions, shows a lack of patience and only instructs the family to seek information from the medical team. It leaves the family adrift and completely alone.

> They (the team) don't explain things. The physician wanted to collect blood from my child and poked him many times, he's in pain, is uncomfortable. Chickenpox broke out all inside. I asked: what is this test for? She said: wait outside and we'll tell you (F8).

The family being excluded by the team occurs when it is not allowed to participate in care provided to the child. The family wants to ensure its role but feels estranged from the team when attempts to perform any procedure for the child are impeded, when the family is set aside with no possibility to participate in the child's care. It upsets the family that makes the request of the professionals.

> My son is in isolation and I'm with him all day. When the device on his finger falls off, because he moves all the time, I call them (the nursing staff) out there. They take their time to come and I call them again, but nothing! Even the bath, they don't let me do it, not even bath him, hey, I'm a mother! He (child) took a bath only in the evening (F8).

The delay in assistance by the staff members, who often do not even introduce themselves to the family, sets off feelings of anger and being *disregarded by the team*.

> The physician said: wait outside and we will talk to you soon! We (mother) leave and then they forget and go away. When I look for them in the room, they say there are in a meeting, it's never possible (F8).

Even while being dissatisfied with the team and enduring the unit's lack of structure, the family believes it cannot change the situation because it fears retaliation on the part of the team in relation to the child or itself. As a consequence, there are moments in which the family prefers to *accept the imposed situation*, by *accepting the established rules*. With no other option, the family resigns itself to the *conditions imposed by the team*. It fears to hinder the team's work in any way or harm the child's recovery.

> The medical team is very reserved, though if you talk to them calmly, without anxiety, they answer you back, but you cannot get there nervous or demanding, otherwise they will also act like that with you. If you are gentle, you get better feedback from them (the team) (F2).

In an attempt to face vulnerability, the family implements measures to *cope with difficulties* according to its beliefs and values, counting on its support network, whether this is formed by people, entities or faith. The family starts paying attention to its rights and tries to be acknowledged by the team in its desire to participate in the child's treatment. For that, the family members seek to establish ties of trust with the team members, keeping their hope alive. From this perspective, *search for its rights*, with *trust* and a *desire to participate in the treatment* is why the family *wants to be acknowledged by the team* and knows it can *count on a support network*.

Family members identify themselves with some members of the health team and establish ties of *trust* with them. Then they feel safe exposing their doubts, complaining and even giving their opinions. They become more confident when they understand the team's work. The family *wants to be acknowledged by the team*. It believes the team has the duty to know the history of each family, since each case is unique.

> I know all the nurses taking care of my daughter, know their names, because there was a mistake with her in another hospital, I know everything that happens to her, the physician, the nurse, the medication. Everything that she's receiving, I know, that is why I don't leave her side (F3).

The family's objective is for the child to recover completely. It maintains hope the child will recover and clings to this hope to keep on fighting.

> I know that my baby has a severe situation! I said to the doctor that I'm not in a hurry to leave here, the important thing is that she gets well (F2).

The family feels very good when it manages somehow to *participate in the child's care*. Hence, it searches for information concerning the pathology on the Internet, in libraries, and from friends working in the health field.

> I read everything on the Internet about her disease, I know her disease very well, she's always been different from what I've read about her disease. She doesn't get purple, it's not perceptible, it's very subtle (F5).

Support networks are resources used by the family at this point. When the family counts on the support of relatives, friends, neighbors or religious leaders, it feels safer, supported by faith and finding certainty and hope the child will improve and be cured.

> We have to keep hope because we aren't safe. I have been so desperate these days, but my hope comes from God. I wouldn't be here if wasn't for God (F3).

Stage 2 - Elements that intensify Family Vulnerability

The vulnerability of families of children hospitalized in a PICU is triggered by the influence of situations previously experienced with diseases and PICUs, inexperience and an overload of activities.

The influence of situations previously experienced with diseases and PICUs confirms the assumptions of Symbolic Interactionism that a family is a social group in continuous symbolic interaction among itself and with the ecosystem. A family brings to their present situations diverse meanings for these situations and processes into which they are inserted. Each individual has a past to recover, which will help to define the current situation. The inexperience of individuals and an overload of activities that result from the situation leave the family without a frame of reference. This is something new and the meanings of situations are still being developed.

Consequently, in the context of the disease, vulnerability is manifested by elements related to emotional suffering with hospitalization in a PICU, such as: impact of the hospitalization of the child in a PICU, questioning concerning the reasons of the disease and hospitalization in a PICU, the stress caused by the environment, feelings of powerlessness and insecurity, submission to the situation and a state of constant surveillance.

In the context of family, vulnerability is manifested in giving priority to the sick child to the detriment of other demands. Hence, the sick child is away from healthy children; suffering caused by the lack of structure in the PICU environment is real.

In the context of the team, vulnerability is manifested as the family and team diverge, which is caused by an estrangement between the team and the family, by the family's per-

ception of being treated with hostility by the team, and their feeling of being excluded and slighted by the team.

Consequently, there are moments in which the family accepts the imposed situation, agreeing with the established rules or resigning themselves to current conditions. Other families face their difficulties, seek their rights, and have confidence and hope, desiring to participate in the treatment, to be acknowledged by the team and counting on a support network.

The elements that intensify vulnerability are:

- The PICU, as a place where severely ill individuals are hospitalized, emphasizing the possibility of the child's death;
- Stress stemming from the PICU environment, which causes anxiety and fear;
- The PICU's lack of structure to meet the family's needs during the child's hospitalization;
- The team's imposition of rules and routines that distance the family from the sick child in PICU's closed environment and impedes the family's participation in care provided for their child.

DISCUSSION

Understanding the families' experiences and identifying the elements that intensify their vulnerability within a PICU contributed to the theoretical development of the concept of the Vulnerability of the Family [6], making it possible to deepen the theory in order to contribute evidence that can be used by nurses in their clinical practice with families.

Hospitalization in a PICU is a situation of crisis for the family because it includes the possibility of the child's death. Having a critically ill child hospitalized in a PICU causes intense suffering for the family. Many studies are being conducted in this context[10-12], in which the authors seek to understand this time of crisis, identify the meanings the family attributes to this experience, grasp the experiences of the nursing team with the families of children hospitalized in a PICU and understand how nurses care for the family experiencing the process of its child's death.

In this context, the vulnerability of the family is intensified since its interactions are for the most part negative, given the hostile environment and the real and imaginary threats from a team that has power over the child, as well as the disruption the family suffers in its structure. Similar to what is found in the literature[13-14], this study also describes PICUs as a stressful environment for parents, while the family has constant feelings of anxiety and sorrow. A lack of structure and an outlook of welcoming in PICU, which denies the family the ability to participate in the care provided to their child, are elements that intensify vulnerability given the stress, suffering and anxiety they cause.

In this study, PICUs are closed environments, which have not advanced toward incorporating the family, rather practicing a care whose focus is still centered on the child and her/his pathology. Hence, PICUs do not allow opportunity for the family to be included. In turn, the family feels left aside without comfort. The family does not perceive itself participating in the child's care because it is forced to withdraw to avoid hindering the procedures, which tends to generate conflicts.

Divergences between the family and staff have been the focus of intensive care pediatric nurses[15], who seek to identify the nature of conflicts involving the PICU environment and the families of children in prolonged hospitalization. The lack of communication between the team and the family, the exclusion of parents in discussions concerning treatments or the process of making decisions, and even divergences concerning the care plan developed by the team, were issues addressed by authors that corroborate findings from this study.

To minimize conflicts generated in the PICU's context, authors[5,15-17] emphasize the benefits of communication between the team and family, in addition to the participation of the family in decision-making concerning care. The process of professional partnership involving an open and supportive, non-directive dialog between nurses and patients helps to reduce negative interactions. Thus, the family feels included in the health care of its hospitalized member based on the model of Family-Centered Care[18].

PICU's rules and routines need to be reviewed in order to strengthen the family since it has the right to remain full time with the child during hospitalization. Hence, families should not be considered visitors; they are a constant in the life of children and an inseparable part of their world[19]. Scientific evidence suggests that the well being of families directly contributes to the child's well being. Moreover, infection rates do not increase due to the visits of younger siblings or even pets. Hence, instead of imposing barriers to prevent parents from being near to their children, health professionals should propose strategies to facilitate the family adaptation to a PICU context, performing care with a focus on the family as a whole.

Allowing the family to become strong and autonomous in situations of crisis is one of the fundamental principles of care that involves dimensions of respect for human beings. Respect for human beings is the maximum principle from which should emanate ethical precepts of everything else and for all those who deal with human beings[20]. Moral responsibility favoring respect for people's autonomy is defined as a categorical imperative of moral consciousness; it is to act in such a way that the maxim of your will always prevails[21]. In the case of nurses, it means permitting the family be strengthened and autonomous in situations of crisis, developing a care practice that involves ethical dimensions.

From this perspective, nurses as moral beings responsible for their actions, are independent and active partici-

pants of the health team[21]. They have the duty to ensure the rights of patient and family autonomy. According to this principle, nurses should provide the necessary conditions for the family to make decisions by providing information and knowledge concerning the child's condition. In this way families will be able to make free and fully considered choices, thus strengthening the principle of autonomy. Nurses' actions should be based on the moral principle of duty and enhance their role of defending the rights of patients in their clinical practice.

CONCLUSION

This study made important contributions to nursing and provided a significant advancement in current knowledge concerning the functioning of families in situations of crisis caused by the hospitalization of a child in a PICU. The understanding of the elements that intensify Family Vulnerability in a PICU facilitated identifying the elements that intensify vulnerability in this context, advancing theoretical development. It is important to highlight that the experience of vulnerability does not only bring negative results to the family, but m'ay also strengthen the family so it reacts and seeks ways to recover its autonomy in the face of a situation of threat.

Based on this study and on readings and reflections concerning the experience of Family Vulnerability in a PICU allows devising strategies that can help families to have their needs heeded and minimize their suffering and vulnerability.

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