

DONATE OR NOT TO DONATE: THE VIEW OF THE FAMILY BEFORE THE ORGAN DONATION DOAR OU NÃO DOAR: A VISÃO DE FAMILIARES FRENTE À DOAÇÃO DE ÓRGÃOS DONAR O NO DONAR: LA VISIÓN DE LOS FAMILIARES ANTE LA DONACIÓN DE ÓRGANOS

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ABSTRACT

The present study aims to understand the motivations that influence families in the decision to donate or not the organs of adult relatives. This is a qualitative, descriptive-exploratory study in the case report modality, carried out with three families of patients diagnosed with brain death (BD) hospitalized in a public hospital in the countryside of the state of Rio Grande do Sul. The production of data was done through semi-structured interviews from September to December 2013 and these were submitted to content analysis. It was found that families have reasons to accept and decline the request for organ donation. The main reason for families choosing not to donate was the respect of the will of the potential donor and the lack of knowledge of what the potential donor would like to be done in this situation. The reasons for accepting the donation are related to the intention to help people who need organs and to do what the family member asked them to do. It is worth noting that more studies related to the process experienced by families, about brain death and the decision process, are needed to make it possible to understand in greater depth the situations experienced by family members during this process.

Keywords: Tissue and Organ Procurement; Brain Death; Family; Nursing.

RESUMO

O presente estudo objetiva compreender as motivações que influenciam as famílias na decisão para a doação ou não de órgãos de um familiar adulto. Trata-se de estudo qualitativo, descritivo-exploratório, na modalidade estudo de caso, realizado com três famílias de pacientes diagnosticados com morte encefálica (ME) internados em um hospital público do interior do RS. A produção de dados se deu por meio de entrevista semiestruturada, de setembro a dezembro de 2013, os quais foram submetidos à análise de conteúdo. Pode-se evidenciar que famílias têm motivos para aceitar ou negar a doação de órgãos. O principal motivo para a não doação se deve ao respeito à vontade do potencial doador ou ao desconhecimento sobre o que o potencial doador gostaria que fosse feito nessa situação. Os motivos para aceitar a doação estão relacionados à intenção de ajudar pessoas que precisam e fazer o que o familiar havia lhes pedido. Destaca-se a necessidade de mais estudos relacionados ao processo vivenciado pelas famílias, em torno da morte encefálica e do processo de decisão, para que seja possível compreender com mais profundidade as situações vividas por seus membros durante esse processo.

Palavras-chave: Obtenção de Tecidos e Órgãos; Morte Encefálica; Família; Enfermagem.

RESUMEN

Este estudio tiene como objetivo comprender los motivos que influyen en la toma de decisión para la donación de órganos de un familiar adulto. Se trata de un estudio de caso cualitativo, exploratorio y descriptivo, realizado con tres familias de pacientes con diagnóstico de muerte encefálica (ME) ingresados en un hospital público del estado de Rio Grande do Sul. La recogida de datos se realizó a través de entrevistas semiestructuradas, de septiembre a diciembre de 2013. Los datos fueron sometidos al análisis de contenido. Es evidente que las familias tienen motivos para aceptar o negar la donación de órganos. El motivo principal para rechazar la donación tiene que con ver el respeto a la voluntad del donante o por no saber cuál era su voluntad. Las razones para aceptar la donación se relacionan con la intención de ayudar a las personas y con cumplir con el deseo del familiar donante. Se destaca la necesidad de más estudios relacionados con el proceso que viven las familias de las personas con muerte cerebral y el proceso de toma de decisión para comprender mejor las situaciones que atraviesan los miembros durante este proceso.

Palabras clave: Obtención de Tejidos y Órganos; La Muerte Cerebral; La Familia; Enfermería.

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INTRODUCTION

Currently, the number of cadaveric organ donations in Brazil is increasing each year. In 2011, 4,158 transplants used brain-death (BD) donor organs. In the same year, the different types of transplanted organs in Brazil reached the landmark of 23,397 transplants. The Ministry of Health credits the increase in the number of organ donations to encourage harvesting teams and awareness of the population by means of national campaigns, making it become more supportive of organ donation. The proportion in 2011 was 10 donors per million inhabitants, and in 2015 reached the target of 15 donors per million inhabitants.¹

When BD happens, the donation of organs becomes a decision that is exclusive of the family members of the possible donor. In this sense, the experience of a situation of shock, the desperation for the unexpected hospitalization of the relative, the distrust towards the request of organ donation, the denial of BD, the suffering, the weariness resulting from the loss of the loved one, and family conflicts for decision making are among the multiple causes for refusal.²

A study that sought to know the reasons of families for refusing donation evidenced that 15.7% of all families refused to donate. Of these, 48.6% reported not knowing the desire of the potential donor, 23% reported that the wishes of the deceased person were different while in life, 17.6% emphasized the desire of the family to keep the body intact, 1.4% based on religious convictions, and 9.4% did not register the reason for refusal. The non-authorization of organ donation can also be seen by family members as an attitude of selfishness and a lack of knowledge about the subject.^{3,4}

On the other hand, the family's agreement to donate the organs comes from the desire to help people, the idea that after death we should not be attached to matter, the belief that all people should be in favor of such a decision and that the patient would feel happy and would agree with that decision for having been a kind person in life. Another relevant aspect relates to the specific possibility of helping people waiting in transplant queues. This act makes the family feel comforted and rewarded, although the pain of loss endures. There is also the perception of families that this act can contribute to encourage donation and help people who need a transplant to continue alive.⁴

Investigations conducted on the family decision process regarding donation can help to enhance the understanding of this moment in the life of the family. There is evidence in the literature of a tendency to conduct studies in periods after the event discussed here, revealing a lack of information about the family experience at the exact moment of the decision. In this sense, the results of the present study may contribute to the understanding of the motivations that influence families in the decision to donate or not to donate the organs of a deceased adult relative. For that, the research question is: what are the

motivations that influence the families' decision whether or not to donate the organs of a deceased adult relative?

Thus, the aim of this study was to understand the motivations that influence families in the decision to donate or not donate the organs of an adult relative.

METHOD

The study had a qualitative, descriptive-exploratory approach in the case report modality, which is the strategy chosen to examine contemporary events. A case report is a method used when the researcher has little control over the events and when the focus is on contemporary phenomena inserted in a given real-life context. The research scenario was the Adult Intensive Care Unit (ICU-A) of a public hospital in the countryside of Rio Grande do Sul.⁵

Three families (eight people) were contacted by the Intra-Hospital Organ and Tissue Harvesting Committee (CIHCOT) at the time of diagnosis of brain death of their relative hospitalized in the A-ICU. The criteria for inclusion in the study consisted in prioritizing families who had hospitalized relatives with a diagnosis of BD and who, before the invitation to participate in the study, had been approached by the CIHCOT with respect to organ donation. As exclusion criterion, families were excluded in the case of lack of knowledge of the relatives about BD or about the possibility of organ donation.

Data collection occurred from September to December 2013. The instrument used to collect data was a semi-structured interview. The family was invited to participate in the interview individually, according to the availability of each family member. The interviews were audio-recorded. After acceptance, explanations regarding the purpose of the study, the willingness to participate, the right to interrupt the interview at any time or even to give up its continuity, and the risks and benefits of participation were provided. It was also emphasized that the participation in the study would have no influence on the decision adopted by the family regarding the donation of organs.

Thus, all the families that had a family member diagnosed with BD at the time of data collection and who had a chance of becoming organ donor were invited to participate, and those who were available were interviewed. There was one refusal. Participants were identified by the letter "F" indicating the family member and by a number corresponding to the sequence with which the interviews were carried out.

The principles of content analysis were used to analyze the data. The development of the study complied with the guidelines of Resolution 466/12, and the research protocol was approved by the Research Ethics Committee according to CAAE: 21336813.7.0000.5346.6.

RESULTS

As a way of characterizing families, a brief description of the participants will be presented. Family 1 was composed of the potential donor, who was 58 years old, his 59-year-old wife, who had completed elementary school and worked as a farmer, and the couple's two children. The eldest son resided in another city at the time of data collection and the youngest daughter (15 years) lived with the parents and was a student. The parents of the potential donor and two older siblings were deceased, but two sisters were still alive. The wife and one of the sisters participated in the interview. This family decided not to donate organs.

Family 2 consisted of the potential donor, 53 years old, his ex-wife and two minor children, who because of the separation lived with their mother. The parents of the potential donor were deceased. The three sisters of the potential donor, with ages of 66, 63 and 57, participated in the study. This family chose to donate organs.

Family 3 consisted of the potential donor, age 22, her husband, aged 37, her minor son, her father and mother, aged 41 years, three sisters and a brother. The mother, the husband and an aunt participated in the study. This family refused to perform organ donation.

One of the potential donors resided in the rural area and two in the urban area. All patients had suffered severe head trauma (fall from the own height that evolved to subarachnoid hemorrhage, cranial concussion due to aggression, and suicide attempt that progressed to subarachnoid hemorrhage). The length of hospital stay was eight, 10 and 14 days in the intensive care unit, respectively.

Receiving the news of the family member's BD and the invitation to donate organs has repercussions within the family. Besides the impact of the unexpected event that caused the hospitalization, the family needs to decide whether or not to donate organs. It is evident that the family describes the moment of receiving the news of BD as difficult and painful, showing an attitude of denial of the diagnosis. On the other hand, there is an attempt to express somehow what is being lived based on the interpretation of the condition of the hospitalized relative.

"I did not want to believe, I did not want to believe[...] it's very painful for me. Very much! It was very painful!" F3

"We were already prepared for that. Because since the moment of the accident he never came back to himself." F5

The perceptions regarding the family member's condition associated with previous knowledge, the meanings attributed to the evidenced signs, and the information provided by the professionals contribute to the family's construction and understanding of what is happening. Thus, when asked about the

understanding of BD, the family members explained in their own words how they understand this phenomenon.

"It's the brain that stops working and does not[...] It does not respond to the rest of the body." F3

"We think it's the heart that ends everything, and no, it's the brain that ends everything. So, when the brain does not send any stimulus, it does not send any signal, it's all over." F4

The fact that the heart is the organ that controls human life can be conceived as a romanticized view that people develop of this organ that is responsible for keeping the body alive. When the family perceives that the heart is inert to the situation and another explanation is presented to them, another understanding is established and this, in turn, offers a logical perspective to understand the process of encephalic death. However, one of the aspects that make it difficult to understand the diagnosis of BD is the fact that the patient has heart beats, respiratory movements and body temperature. Thus, the family does not perceive the patient as dead and believes in the possibility of reversing the situation.

Among the reasons mentioned by the relatives for the refusal to donate stands out the lack of knowledge about the will of the hospitalized relative towards the donation. For these families, refusing to donate means respecting the wishes of their relative.

"He never thought about it and we never talked about it." F1

"I want to respect the will of my daughter. She did not want me to donate her organs." F8

"It's the feeling of knowing they were going to take a piece of him[...] It looks like my brother's going "hollow" the coffin." F2

It seems that one of the motivations that trigger the decision for non-donation is related to the feeling that removing a "part" of the relative's body will make her or him become incomplete, with an impaired identity. However, relatives reported the patient's will as one of the motivations for organ donation.

"I made that donation with peace of mind. I knew that's what he wanted me to do." F4

Such a decision can be reinforced by the conviction that a donation is an act of love, of the relative, which requires courage in order to be consolidated.

"So, it's out of love that I did that, you know?" F5

It can also be observed that when the family has time to talk and organize the situation, differences of opinion among members of the family unit can be reviewed and consensus can be reached. Dialogue helped in the understanding of what is brain death and this, in turn, can help family members understand and change their minds about a primary decision adopted.

"Little by little my husband and my daughters made me see the reality, so I changed my thought and my decision, this was very sad for me, because at the time I was stucked, paralyzed, to say that I agreed to make the donation." F3

The moment the decision is going to be expressed to the organ harvesting team is permeated by intense emotions; in this moment, doubts are exacerbated and the person may feel "paralyzed", unable to verbalize. It's as if she still needed a last minute to ponder whether donating was really the best decision. Doubts about the choice to donate may be related to the fact that by assuming this stance, the family will definitely and irreversibly accept the situation and give up all hopes of recovery. However, the choice to donate results from the view of organ donation as an act of generosity by the family, a possibility to help others, for the condition of the relative is irreversible and death becomes an undeniable reality.

"There are a lot of people waiting in the cue. Knowing that we will be able to donate a cornea or, I don't know, another organ, that this will save another life, so this is very important. His death will not be in vain. He's going to help other people." F4

In addition to the aforementioned motivations, it can be seen that the authorization to donate organs can also be a way of caring for the relative, for the possibility of relieving them from possible suffering by prolonging the clinical state. The relatives also demonstrated to see positive aspects in BD, mainly related to a possible survival with severe sequelae and total physical dependence.

"I wanted him to live, but with quality life, not with a vegetative life." F3

It is noticeable in the speech of the relatives that organ donation means the chance of survival and recovery of health for the possible receptors of the organs, making the family give meaning to the death of their relative. By donating organs, the relative does not die in vain.

"There are so many people who need to fight to survive. Since he did not have this opportunity, then he can give it to other people. I'll be happy to know that another human survived because of the donation." F5

One of the feelings reported by the relatives, both those who accepted the donation and those who declined it, was hope. Hope was related to the expectation that the family member could improve and that the possible BD was not confirmed.

"We had that hope. Now it's all over, it's all over, it's over that hope we had of him to recover, to react." F4

At the same time that families show hopeful feelings about the possible improvement of their relative, it is notable that this feeling is replaced by the hopelessness to the extent such improvement does not occur. Thus, the confirmation of BD seems to trigger the feeling of emptiness.

Another perspective that is present during the decision-making process is related to the family feeling negligent toward the relative when accepting the donation of organs. In the face of this decision, they presume to authorize not only the disconnection of all devices, but also be conniving with the death of the relative.

"One feeling I have is that, by turning off those devices, we will take his life away." F3

"It's a mixture of feelings, decision, fear, loss. It's a set of things that are all together and mixed together. One can not define it as a single thing. This is very, very painful for me." F4

Mixed feelings may be related to the internal conflict caused by the loss of the relative and the way the family members feel after the decision to authorize the donation. However, the sense of comfort and fulfillment of one's duty in helping others evidences the unselfish spirit of people who, without any interest or reward, act on behalf of another human being.

"I think all people should make that decision, although it is difficult. To help, that's what we need, to be more humanized." F3

"For me, despite all the pain I'm feeling, I'm glad to know he's going to be helping someone. That alone already comforts me." F4

It is perceived that the common good is one of the factors that justify the decision to donate the organs of the fam-

ily member who had BD. The belief that life can be present in other lives generates a sense of inner peace, and this helps to comfort the family before the death and loss of the loved one.

DISCUSSION

Considering the characteristics of the patients who had BD detected during the study, although a reduced number of patients, we identify a similarity with the profile of BD patients described in other studies where there was a predominance of male patients, BD related to traumatic brain injury, and average age characterizing young adults.^{3,7,8}

A study carried out in Santa Catarina shows a different profile of BD patients: 54.2% women, aged between 41 and 60 years, and having stroke as the cause of death in 50.8% of the cases. Based on these characteristics, BD in adults seems to be an unexpected event that affects active people and imposes on the family a painful process in the face of decision making regarding the donation of organs.⁹

For families, this acute and therefore unexpected illness makes the acceptance of the BD of the family member more difficult than in the case of chronic and terminal patients. The difference is that the latter families have more time to prepare to say goodbye to their family member, whereas in the case of BD everything happens very quickly and suddenly, making decision making more complex, a moment in which the family may be in united or not in the decision.

The confirmation of BD diagnosis is a moment of pain, sadness and disbelief. The family is usually surprised by the information, especially when there is no previous clarification about the possibility of the occurrence of BD. When the family is informed about the beginning of the tests to confirm the diagnosis of BD, it has the possibility to prepare for the death of the hospitalized relative.⁴

As BD most often occurs abruptly as a result of traumatic, congenital or acquired causes that lead to the unexpected hospitalization of the relative, families are exposed to the possibility of sudden death, without time to understand what is being experienced. This makes the process of figuring out the loss and acceptance of death long, interfering with the decision about the possible donation.^{4,10}

The realization of this study with these families at the moment of their decision, either they would choose to donate or not, was necessary to help us understand what these families went through and to show us that throughout this process the family needs to be informed and be given time to talk and decide about which is better in their point of view.

Another study showed that the presence of the family during the BD evaluation favors the understanding of what is happening to the family member, without presenting any apparent

adverse impact on the psychological well-being of the family. Thus, the presence of the family during the evaluation to confirm brain death of the patient is a viable and safe alternative.¹¹

In the reality where the study was carried out, the relatives did not follow the tests. The implementation of this practice in Brazil can represent an alternative to increase the positive attitude of families towards donation, although the most often cited reason for the family not to authorize the donation was the ignorance of the potential donor's wish on the matter. Similar findings have been observed in studies that identified the lack of knowledge about the patient's wishes regarding the act of donating their organs as a factor that causes doubts among the family members, and that becomes crucial in the donation process, interfering in the final decision.^{3,10}

A study conducted at a French organ harvesting center identified 227 eligible organ donors, of whom 30.8% did not donate organs due to family refusal. The most frequent reason for refusal was the desire to maintain the integrity of the body, followed by religion, distrust of the medical community, and revolt against society. The most common causes of death associated with refusal were brutality and rapid death, early age, denial of death, and feeling of guilt of the family. In 30% of cases, the family followed the wishes of the deceased expressed while in life.¹²

Family refusal continues to be a significant factor associated with the decrease of approximately one third of eligible organ donations and the most important cause of refusal is the desire to maintain the integrity of the donor's body.¹²

The family's lack of knowledge about the patient's desire about donation stems from the inexistence of dialogue on this subject. The justification is that the family believes that the probability of death of a family member is something remote, or because they fear death. Knowing the opinion of the deceased while he was alive regarding organ donation is important at the moment of making the decision.^{4,8}

The reinforcement of the veneration of the body present in society is emphasized by some authors as an implicit justification for the negative motivation when donation was associated with the importance of maintaining the integrity of the body. And that was the main reason at the moment of decision-making.¹³

The fear of deformation of the body caused by the removal of organs and the limited knowledge of the families regarding BD appear as difficult elements for a possible donation. This lack of information or misinformation coupled with the low level of education of family members may generate unrealistic interpretations of how the body will be returned and the equitable distribution of organs. That study showed that the high rate of illiteracy and a considerable number of semi-literate people in Brazil compromises the autonomy of people because the absence of necessary and indispensable information limits the people's free decision about their fate.¹⁴

In order to contribute to the understanding of the motivations that influence this process, research on the decision to donate the organs of family members must be closely linked to the way the approach to the family is made by professionals. Thus, families that do not allow donation justify their decision with the too recent approach, because they did not have enough time to build the reality of death. The decision is based on the fact that death was not part of the reality of these families at the time they were approached; they still experienced uncertainty regarding the diagnosis and prognosis. This observation underscores the importance of a professional and humanized approach to the request for organ donation.¹⁵

A study in São Paulo that aimed to survey the main reasons that led students to choose to become organ donors found that one of them cited religion as a motivation that led him not to be an organ donor. On the other hand, the other participants mentioned among the main reasons that lead them to opt for donation, the understanding that body is just matter, the possibility of helping other people, of providing the continuity and quality of life of the recipient, to reuse the organs, the social need for donation and religious reasons.¹⁶

Regarding non-donation, it should be pointed out that, when the family makes this decision, it does not mean that it was an easy one. The family is so saturated with emotions brought about by this experience that it prefers to remain in a context in the which they feel more secure, without further news or unknown events. So as a strategy to avoid further uncertainties, the family opts for non-donation.¹⁵

In this sense, the limited knowledge of people on BD is associated with the influence of seeing their relative apparently alive externally, with the heart beating, the body maintaining its heat, maintaining the breathing movements and healthy color. These aspects make the family have difficulty understanding the whole situation, generating doubts and ambiguity at the time of the decision. Thus, the family is torn between the desire for the patient to survive and recover and the preference for death in the face of a vegetative life.⁴

When recalling the loss process and the decision to donate organs, the family members confirmed that the fact that the decision takes place at a difficult moment for the family, organ donation and transplant can bring comfort and satisfaction, reliving the deceased family member in another person. Above all, this means doing good to other persons. Making the donation assumes several meanings: comfort to the family, satisfaction, an honor. It is very important because it means to do good to other people.^{10,16}

The possibility of changing the lives of people who await in cues for a transplant is a source of consolation, reward and satisfaction to the family, although the pain of the loss remains.

It is also emphasized that among the main reasons people cited to be favorable to organ donation is the feeling of saving lives, helping others and giving life.^{17,18}

Regarding the organ donation process, initially, the family is suspicious of the request for organ donation, believing that the patient's condition may be reversible. Before the moment of confirmation of BD, of the disclosure of the information of irreversibility of the condition and the certainty that the patient is dead, the family maintains hopes on the survival of the patient. This is due to the fact the patient still performs vital functions.⁴

The uncertainty of which decision should be made is endorsed by the family's impression that authorizing the shutdown of the devices without the awareness of the BD patient, without him having explicitly expressed willingness to do so.⁴

The pain felt has not to do with BD, but with what this event means: the definitive absence of the relative. Time is important to the idea of the death of the patient to settle down. Time, however, is not always possible because the news of the death is followed by the request for donation, not allowing relatives to elaborate this reality.

Suffering in the face of the loss of the relative encourages the family to seek a solution to the situation. Thus, authorizing the organ donation or switching off the appliances is the best way to end the suffering, because keeping the patient alive with advanced life support is the same as prolonging pain in the face of hopelessness.¹⁵

As the feelings permeating the decision of the families that experience the BD of a relative can be often ambiguous, the attitude of donating provides comfort and satisfaction. The valorization and the social importance that the donation of organs and tissues has influences the feelings of families that authorize donation.^{3,4}

A study carried out with transplant coordinators, it was found that during the family interview, the team faces issues with the understanding of the relatives, their greatness as people who understand and adhere to the cause of donation, and a change of opinion may occur, from an "unclarified decline" to an "informed acceptance".¹⁹

A discussion on organ donation by BD considered that death has different meanings for different people and has reflections on the moral difficulties of decision making on donation, and what would be its impact on the daily lives of the families that decide favorably towards donation of the organs of their relatives. In this context, death presents another possibility that until then was not common in our society, representing a new paradigm on the value of the body after death. This is because, through donation, it is possible to save or increase the survival of patients with organ failure.¹⁴

CONCLUSION

Considering the purpose of the study, we can conclude that families that experience the process of deciding whether or not to donate organs find themselves in a very difficult and unexpected moment of their lives. The relative's abrupt hospitalization and the reasons for hospitalization aggravate this situation. The concept of BD is difficult for families to understand, in the situation they are experiencing, but somehow they demonstrated a good understanding of the meaning BD.

In this study, we identified that the motivations for non-donation were related to not knowing what the potential donor, the deceased relative, would like to be done in relation to their situation, and to the intention to respect their will not to have their organs donated. The motivations for authorizing the donation were linked to the family member's willingness to be a donor and the desire to help others, and the wish to preserve the deceased relative by knowing that his organs could remain alive.

Thus, it can be emphasized that the main reason for the families to choose not to donate is the respect to the will of the potential donor. And, in the same way, the main motivation by which families choose in favor of donation is the desire to help others and save lives, sparking a reflection on the generosity and fraternity of this act, as well as the possibility of preserving the meaning of the life of the deceased relative. Among the feelings that the families mention in relation to the decision to donate or not to donate, we can observe hope, neglect, sadness, pain, mourning for loss, feeling of comfort and satisfaction.

It is hoped that the results of the present study contribute to and improve the nursing care provided to the families of BD who are potential organ donors, by raising reflections among the professionals who work in this area and who are interested in this subject, sensitizing them to understand the situation by lived by the families, favoring them to feel welcomed and respected by the health care service. It is understood that considering the perspective that influences the decision of families to donate or not to donate may contribute to increase the number of donations, to overcome the number of non-donations.

It is noteworthy that this study brings the experience of families in the moment in which these people are face to face with the diagnosis of BD and when they have to decide whether or not to donate their family member's organs. The relevance of having conducted the study in that moment is that families can express what they are experiencing, something immediate, bearing in mind that the majority of the studies bring the perspective of the families months or years after the event. It was with this justification that the study was chosen. It is noteworthy that this study has limitations, for it was carried out with three families, and the results are representative of that specific group. There is a need for more studies addressing the feelings of families so as to better understand the mo-

tivations that influence their decision, and also the importance of health and government institutions to encourage and raise awareness among the population with advertisements and campaigns demonstrating how important organ donation is.

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