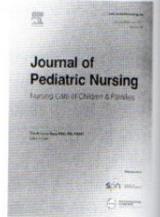




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## Care bundle for family interview for pediatric organ donation

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### ABSTRACT

**Purpose:** to develop a care bundle for best practices in conducting the family interview for organ and tissue donation with the families of children and adolescents.

**Design and methods:** methodological study, with a qualitative approach, developed in Brazil, in three stages: literature review, qualitative study with professionals and family members, and development of the care bundle. **Results:** Nine studies were selected and 17 health professionals and nine family members were interviewed. With this data, the care bundle was developed in three categories: communication of death, emotional support and information about organ and tissue donation. The recommendations were evaluated by five external professionals and all of them assessed the bundle as having the highest possible quality.

**Conclusions:** the care bundle was built following the stages of integrative literature review and interviews with professionals working in this scenario and family members who have already gone through a family interview for organ and tissue donation of children and adolescents.

**Practice implications:** the use of this material is seen as an important resource to support the professional during the conduction of the family interview in a scenario as sensitive and challenging as the care to family members facing death and the decision of organ and tissue donation of children and adolescents. Furthermore, the care bundle can increase the quality of family interviews and impact the reduction of family refusals.

**Descriptors:** Practice Guideline as Topic. Tissue and Organ Procurement. Patient Care Team. Nursing. Pediatrics. Communication.

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### Introduction

The unexpected death of a child or adolescent causes unexpected responses in the bereavement process due to the social perception that parents or caregivers will die before their children. When it is an acute and unexpected situation, there is also the possibility that many parents or guardians feel guilty for the fatality that led to their child's death, feeling as if they could have avoided it. Such feelings can trigger severe or pathological denial in the face of the sudden death event and, thus, the assimilation of death tends to be slower (Bregman, 2019; Polita et al., 2020).

When death occurs as a result of neurological damage, i.e., a Brain Death (BD), it is even more challenging. For parents or guardians, the child or adolescent, when faced with the diagnosis of BD, appears to

be asleep and the perception of death is not a reality (Moghaddam et al., 2018; Sque et al., 2018). In Brazil, from the moment the BD protocol is initiated, the family should be informed about each stage of this protocol, as well as have access to information about the results at the end of each test. After the conclusion of the protocol, the communication of the death of the child or adolescent must be made to the family members. Only after this last phase is the possibility of donation offered. The legislation in force in Brazil, mentions that the health team must be prepared to welcome the family in all these stages, including when offering the possibility of organ and tissue donation until the decision to donate or not the organs of the family member (Brazil, Ministry of Health, 2017).

One of the stages of the organ and tissue donation process is the family interview, which occurs only after the diagnosis of BD and the communication of death to the family. This is one of the most complex and difficult activities of this process because it encompasses individual, emotional, cultural, legal, and different opinions regarding the decision-making for donation (Cajado, 2017). To understand the magnitude of the complexity of the family interview, in Brazil, in 2020, 5447

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interviews were developed and, of these, 2262 resulted in family refusal (Brazilian Organ Transplant Association, 2020). It is noteworthy that, in this country, authorization for organ and tissue donation, in the case of children and adolescents, must be done by the father and mother. In case one of them is no longer alive, grandparents or siblings over the age of 18 can participate in this authorization (Brazil, Ministry of Health, 2017).

When considering the particularities and challenges of this activity, it is understood that good practices can provide the team with subsidies to conduct the interview as a unique moment between family members of the potential organ and tissue donor and health team professionals, in which, besides being respected, the family's vulnerability to the loss can be recognized. Good practices for conducting the interview involve recognizing the different stages during this process: communication of death, emotional support, and information about organ and tissue donation (Cajado, 2017; Gironés et al., 2018). Studies have shown that when the interview is coordinated by qualified professionals, trained and supported by scientific and empirical knowledge, there is more empathy and compassion towards the people who experience this moment (Gasco & Espert, 2019; Meneses et al., 2018; Oliveira-Cardoso & Santos, 2017; Polita et al., 2020).

An excellent technology that can assist in the adherence to good practices and improve the conduct of the family interview is a care bundle. A care bundle is a set or package of interventions/care, recommendations for health professionals usually supported by the best scientific evidence and that, when implemented uniformly and jointly, generate better results (Borgert et al., 2015; Resar et al., 2012; Zhang et al., 2021).

Therefore, the study had as its guiding question, "What information is capable of composing a care bundle for best practices in conducting the family interview for organ and tissue donation with the family members of children and adolescents?"

It is understood that these care guideline for best practices through the bundle will guide, support and empower health professionals who conduct the stages of the family interview with parents or guardians of children and adolescents. Certainly, these guideline will impact, directly and indirectly, the quality of assistance developed with these family members, as well as the national transplant scenario. Therefore, the purpose of the study was to develop a care bundle for best practices in conducting the family interview for organ and tissue donation with the families of children and adolescents.

## Methods

### Ethical aspects

The study was approved by the Research Ethics Committee (REC) of the two institutions where the research was developed and by the REC of the Federal University of Santa Catarina under Opinion No. 3.052.946. All participants signed the Free and Informed Consent Term.

There was no funding for the development of the research and all authors declare that there are no conflicts of interest.

### Study design, location and time period

This is a methodological study, with a qualitative approach, which seeks to present the development of a care bundle for best practices in conducting the family interview for organ and tissue donation with parents or guardians of children and adolescents. The research was guided by the stages of methodological research (Polit & Beck, 2019) and the researchers used the Appraisal of Guideline for Research & Evaluation II (AGREE II) (Brouwers et al., 2013). AGREE II is a tool that assesses the methodological rigor and transparency in which a guideline is developed.

For the content development of care bundle, the theoretical model of family interviewing from Alicante (Santiago, 2016) in Spain was used. This theoretical model is consolidated 22 years ago by professionals

with expertise in communication, mourning and organ and tissue donation, supported by the references of the communication theory from Mauro Wolf's perspective (Wolf & Figueiredo, 2006), Carl Roger's helping relationship (Roger, 1961) and William Worden's constructivist theory (Worden, 2018). This theoretical model defines three important stages of the family interview for organ donation: notice of death, emotional support and information on organ and tissue donation.

For the development of the care bundle, three distinct moments were necessary, which are presented in Fig. 1 and described in the following.

### Population and sample: inclusion criteria

The qualitative study was developed in two large health care institutions serving children and adolescents in southern Brazil. These institutions were chosen because they are references in the process of organ and tissue donation in the region. One of the stages of qualitative research was developed with health professionals and another, with family members.

For the first stage, health professionals (physicians, nurses and nursing technicians) who work directly in at least one of the phases of the development of the family interview for organ and tissue donation, according to the Alicante model, participated in the research in the pediatric context – children and adolescents between seven days of life until 14 years of age. This age range is related to the profile of patients seen in the Intensive Care Unit (ICU) of these institutions.

For the second stage, family members who have already participated in the family interview for organ and tissue donation were part of the survey when a potential child or adolescent donor was confirmed.

The inclusion and exclusion criterion for professionals was to work in units with critically ill patients (ICU, emergency service unit or even in units capable of maintaining patients on mechanical ventilation) and participate in some stage of the family interview for organ and tissue donation. We excluded professionals who were working in the sector only covering vacations or leave of absence of other employees.

Family members included in the research were required to have participated in some stage of the family interview at the study institutions between 2016 and 2019 and to be 18 years of age or older. Family members who were not present at a family interview for organ and tissue donation in the pediatric setting were excluded. The cut-off was defined by the researchers, since before 2016, there was a possibility that family members did not remember the moment of the interview. The finalization of the collection in 2019 was considered in order not to interview family members who have recently gone through the grieving process so as not to bring suffering to them.

For the qualitative research, a non-probabilistic sampling was considered, since the participants were physicians, nurses and nursing technicians in the three work shifts and family members of children and adolescents of different ages (from seven days old to 14 years old).

### Study protocol

First moment - search for evidence - an integrative literature review was developed through the following stages: (1) Elaboration of the research question; (2) Development of the criteria for the literature search; (3) Data collection; (4) Critical analysis of the material obtained; (5) Judicious evaluation and interpretation of the information obtained and (6) Presentation of the results obtained (Sousa et al., 2017).

For the development of the integrative review, keywords and combinations between the Health Science Descriptors (DeCS) and Medical Subject Headings (MeSH) were considered. The search strategy was assembled together with a librarian, and the predominant one was: ("Tissue and Organ Harvesting" OR "Organ Retrieval" OR "Organ Retrievals" OR "Tissue Harvesting" OR "Organ Harvesting" OR "Organ Harvestings" OR "Tissue and Organ Procurement" OR "Tissue Procurement" OR "Tissue Procurements" OR "Required Organ Donation Request" OR "Required Request"

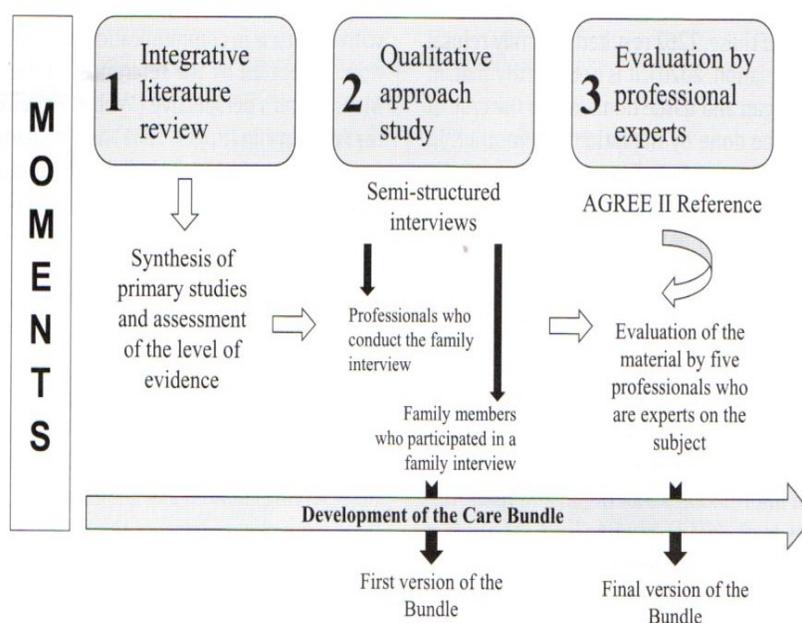


Fig. 1. Stages of development of the care bundle. (Source: authors, 2021.)

OR "Required Requests" OR "Organ Donation" OR "Organ Donations" OR "Organ Procurement" OR "Organ Procurements" OR "Organ Procurement Systems" OR "Organ Procurement System" OR "Tissue Donation" OR "Tissue Donations" OR "Donor Cards" OR "Donor Card" OR "Tissue Donors" OR "Tissue Donor" OR "Transplant Donors" OR "Transplant Donor" OR "Organ Donors" OR "Organ Donor" OR "Organ Transplantation" OR "Organ Transplantations" OR "Organ Grafting" OR "Organ Graftings" OR "Tissue Transplantation" OR "Tissues Transplantation") AND (Interview) AND ("Pediatrics").

Inclusion criteria: original articles; experience reports; editorials; guideline; directives and protocols. Exclusion: studies related to adult participants; Neonatology articles and review articles.

The database search was conducted between December 2015 and December 2020 by two researchers independently. Then, the title and abstract were read, excluding articles according to the exclusion criteria. When the articles were selected, they were read in full seeking to identify information that could support a care bundle for best practices in family interviews for organ and tissue donation in the context of children and adolescents.

Each of the stages was conducted by two researchers with experience in producing literature reviews. The search for articles occurred individually and blindly. In case of disagreement, a third researcher helped in defining the final articles for data collection. The evaluation of the studies occurred according to the strength of evidence/level of evidence, according to Melnyk and Fineout-Overholt's theoretical framework, being classified from Level 1 to Level 7 (Melnyk & Fineout-Overholt, 2019).

Second moment - qualitative research - data collection was initiated with the health professionals and, later, with the family members. The professionals were identified with the help of the administrative management of the institutions, 17 professionals. The family members were identified by the transplant coordinator of each institution through the donation process documents, taking into account the aforementioned inclusion and exclusion criteria. Twenty-eight family members were identified between the two institutions. Then, the professional contacted the families explaining about the research and, only after the family member's acceptance; the professional passed the contact details of these people to the researchers.

Each participant was explained the research objectives and scheduled a date and time according to their availability to conduct the interviews. In both institutions, there was no refusal to participate by health professionals. However, from the total of 28 family members, six refused to participate in the study. Many claimed not to want to

remember this moment. The data collection was closed when the information was saturated.

Data collection occurred through a semi-structured questionnaire containing three open questions, considering the stages of the Alicante model, for both professionals and family members: 1) Tell me what points you consider important for the health care team to talk about and explain about the BD protocol and the communication of death; 2) Tell me how you think health care professionals should conduct the welcoming of the family of children and adolescents who have just received the news of death through a BD; and 3) Describe what points you consider important for the health care team to address when talking about organ and tissue donation.

Two researchers, with extensive experience in organ and tissue donation and in conducting interviews for donation, were present for the interviews. They were conducted individually, between October and December 2019, recorded and transcribed in full, being identified with the letters E (nurses); T (Nursing technicians); M (doctors) and F (family), followed by the order number of the interviews, for example: E1, E2, T1, T2... and so on, successively. After transcribing the interviews, they were validated with the participants and, only after validation, this information was used for the analysis. The interviews had an average of 35 min for those carried out with the health professionals and 40 min with the family members. It is noteworthy that the latter were conducted at home.

In the third moment, in order to bring quality to the study and the development of the care bundle, the choice was made to develop it based on the AGREE II (Brouwers et al., 2013). This instrument is divided into 23 key items, categorized into six domains, in which each domain refers to a dimension of quality of the guideline, which are Domain 1 - scope and purpose; Domain 2 - stakeholder involvement; Domain 3 - development rigor; Domain 4 - clarity of presentation; Domain 5 - applicability; and Domain 6 - editorial independence.

Still with the concern of producing quality content, it was decided to perform the external evaluation of the care guideline according to the recommendations of the reference AGREE II. For the selection of evaluators, the following stages were followed: search of the *Lattes curriculum* (Brazilian public online system where anyone can search for resumes of researchers and studies in any area of interest) for professionals with expertise in the area of organ and tissue donation in the pediatric context, family interview, and the process of death and dying, evidenced by scientific publications on the subject and length of service. For the invitation, an e-mail was sent to the professionals explaining the method and, upon acceptance, the manuscript with the care

recommendations and the AGREE II reviewer's manual were sent (Brouwers et al., 2013).

At the end of the evaluation of the six domains, the reviewers rated the overall quality of the guideline between 1 (lowest possible quality) and 7 (highest possible quality), wrote overall notes about the recommendations, and then entered their signatures.

*Analysis of the results*

Both in the analysis of the data obtained in the literature review and in the qualitative data, there was the participation of all researchers, emphasizing the participation of professionals with expertise in family interviewing in organ and tissue donation and in the process of death and dying.

With regard to the literature review, data analysis was conducted considering the care recommendations obtained, and these data were grouped according to the similarity of the information and according to the stages of the family interview proposed by the Alicante model (notice of death, emotional support and information on organ and tissue donation).

For the qualitative data analysis, these were organized by means of tables in which the answers were approximated according to the similarity and frequency of the enunciations made by the participants according to the answers to the set of questions contained in the semi-structured instrument.

For the analytical stage of the data, the research team performed content analysis, proposed by Bardin (Bardin, 2011), divided into three stages: pre-analysis, in which the reading of the material was performed, with the organization and systematization of information and initial ideas, allowing the development of first impressions about the content addressed. Then, data exploration was organized, in which the emerging contents of the interviews were coded. Finally, in the last stage, the treatment and interpretation of results were established, as well as the analysis based on the thematic presence of the respondents' statements (Bardin, 2011). Thus, two categories were developed: Communication: alignment of information between team and family and Synchrony between the times of the team and family in the interview stages.

In the construction of the care bundle, the researchers evaluated and compared the data obtained in the first and second moments of the research, and then the care recommendations were elaborated, directing them in three axes: communication of death, emotional support, and information about organ and tissue donation, being consolidated, at this moment, the first version of the bundle. The authors sought to extract the main information obtained, presenting strategies and care actions in a simple and clear way.

For the development of the care bundle, the data obtained according to the categories already mentioned were confronted, and each care presented in the categories was classified considering the level of evidence (material from the literature review) and the strength of recommendation (material from the literature review and information obtained in the interviews). To obtain the strength of recommendation, researchers used the Grading of Recommendation Assessment, Development and Evaluation (GRADE) system. GRADE is a system developed by a collaborative group of researchers that aims to creation of a universal, transparent and sensitive system for grading quality of evidence and strength of recommendations (Guyatt et al., 2008).

The external evaluation of care recommendations using the AGREE II (Brouwers et al., 2013) occurred in the following manner: the reference determines that the evaluator responds to each domain with a scale from 1 to 7, where 1 represents that the domain had the lowest possible quality and 7, the highest possible quality. To determine the overall score, the following formula is run:  $\frac{\text{score obtained} - \text{minimum score}}{\text{maximum score} - \text{minimum score}} \times 100$ . At the end, the result should be expressed as a percentage value, considering that the closer to 100%, the higher the quality of the care recommendation.

**Results**

A total of 781 studies were identified in the literature review, with nine included for the collection of information. The database with the largest number of articles was the Web of Science and 2018 was the year with the largest number of publications. Regarding the level of evidence, there were more articles with level VI. For greater understanding, the following table (Chart 1) presents the country of origin, year of publication, level of evidence, and care recommendations Table 1.

As for the findings of the second moment, the qualitative data, 17 professionals were interviewed, including nine nurses, five physicians and three nursing technicians. The average age of the professionals was 38.2 years and the average time working in the institution was 6.8 years. As for the families, nine relatives participated: five were parents (55.6%), one, mother (11.1%) and three were siblings over 18 years old (33.3%). The average age of the parents was 38.6 years, and the average age of the siblings was 19.6 years. The following chart (Chart 2) presents the understanding and opinions of professionals and family members about the development of the family interview Table 2.

**Table 1**  
Characterization of the studies and presentation of the main care recommendations.

Country of origin, year of publication and Level of Evidence	Care Recommendations
1- Finland; 2015 Level VI (Ashkenazi & Cohen, 2015).	There is a need for professionals to have skills to deal with the process of loss and talk about organ donation. It is important to distinguish the moment of communicating death from the moment of talking about organ and tissue donation. Still, it is necessary to respect the culture and religious beliefs.
2- Japan; 2017 Level VI (Araki et al., 2017).	Reliability of the diagnosis of brain death is necessary as one of the most important factors in establishing mutual trust. Use simple, clear and unambiguous words to facilitate the family's understanding.
3- England; 2018 Level VI (Sque et al., 2018).	Clear, direct, and honest information seemed to prepare families for the catastrophic nature of the illness/injury and the reality of impending death. Lack of privacy appeared to be a problem for some bereaved families.
4- Canada; 2018 Level VII (Weiss et al., 2017).	Provide opportunities to discuss beliefs and values surrounding all aspects of brain death. Provide psychosocial, spiritual, and grief support at all times during the donation process. Give the parents the option to choose who should be with them at the time of talking about the possible donation. Professionals conducting the interview should have extensive knowledge about the organ and tissue donation process.
5- England; 2018 Level VI (Darlington et al., 2019).	Communicating death and waiting to talk about organ donation. There is a bad impression of the family when there is no sensitivity and welcoming. It is confusing for the family when professionals talk about donation right after confirming the death.
6- England; 2019 Level VI (Dopson & Long-Sutehall, 2019).	Support and assistance to nurses in coping with death in pediatrics so that they can support family members in communicating death.
7- Israel; 2019 Level VI (Mahat-Shamir et al., 2019).	Parents need time to assimilate and get through the situation of the loss and respect the child's wish for donation, if it has been expressed during life. This reality is frightening and demands support from the health care team for parents to make the decision.
8- United States; 2019 Level VI (Jones et al., 2019).	The team needs to be able to talk about brain death. They can use examples to explain and even investigate the occurrence of another brain death in the family.
9- Turkey; 2020 Level VI (Yeşilbaş, 2020).	Parents are reluctant to allow the body to be manipulated, they consider that the child may feel pain at this time. Professionals need to be very supportive and resourceful in talking about brain death. A cautious explanation is needed.

In Chart 3, the care bundle for the health team in the development of the family interview for organ and tissue donation with the families of children and adolescents is presented. The bundle is formed by considering the stages of the Alicante model (Santiago, 2016) for the family interview: 1) communication of death - is composed of three strategies and thirteen care actions; 2) emotional support - is formed by three strategies and nine care actions and 3) information about organ and tissue donation - is composed of two strategies and ten care actions. The final version of the bundle was consolidated after the evaluation of professionals with expertise in the area Table 3.

It is noteworthy that this care bundle for the health team in the development of family interview for organ and tissue donation with parents or guardians of children and adolescents is a scientific production based on literature review and qualitative study. Therefore, it must be revised again in five years, including new publications and legislation, prioritizing the use of new knowledge produced and new perceptions on the subject. If necessary, it must be updated by the authors or any other scientific team that perceives this need, being restricted only that the same content and methodological rigor described here are met.

With regard to the data from the external evaluation according to the AGREE II reference, there were five nurses who performed: three nurses from the South region of Brazil; one nurse from the North region

and one nurse from the Southeast region. All with more than ten years experience in nursing care practice in organ and tissue donation and transplantation.

The domain with the best evaluation regarding quality was domain 2 (involvement of the parties), with 98.9%. Next were domains 1 (scope and purpose), with 97.8%, domain 5 (applicability), with 95%, and domains 4 (clarity of presentation) and 6 (editorial independence), with 93.4% each. The domain with the lowest score was domain 3 (rigor of development), with 88.5%. It is noteworthy that even the lowest score was high, demonstrating the high quality of the material produced.

Finally, all evaluators (100%) recorded the overall rating of the material as 7 (highest possible quality), indicating that the care bundle for the development of the family interview for child and adolescent organ donation presents the highest possible quality, as well as all evaluators recommend the use of the material in care practice settings. The requested adjustments were incorporated into the care recommendations.

Furthermore, the evaluators noted that the bundle, the way it was built, will be useful for care practice scenarios and will help professionals for the family interview. In addition, all the evaluators mentioned the excellence in the methodological development and in the final product.

### Discussions

The manuscript presents a survey of information from the literature, professionals and families that support and back up a care bundle capable of proposing best practices to health professionals who conduct the family interview for organ and tissue donation. The literature review included in the first stage of the method show important recommendations to support best practices in the family interview stage, especially the need for the team to be skilled and confident to conduct the interview. These studies reinforce that this ability supports the family in the grieving process, besides giving the professional more security.

Another important care recommendation pointed out is directed to the team's care to disassociate the communication of death from the talk about donation. Such recommendation is empowered by the need for time for the family to assimilate the news of the death. When considering this information obtained and relating it to the Alicante model, the information certifies the need for emotional support reinforced by this model (Egry, 2018; Santiago, 2016). Authors have pointed out that the death of the child and adolescent is a unique event in the life of the parents or guardians. It requires, from the team, active listening, welcoming and a lot of resilience, especially when information about organ and tissue donation is inserted in this process (Bregman, 2019; Moghaddam et al., 2018; Polita et al., 2020; Sque et al., 2018).

As for the qualitative data obtained from the professionals and family members, it was possible to understand that there are several recommendations for care and most of them were classified as strong recommendations.

Especially for the need for synchrony between the times for effective communication with the family. This synchrony involves the importance of simple, clear information, based on honesty and authenticity from the team, allied to respect and time for these people to codify what was said. Still, it is understood that the family needs to be respected in its uniqueness about the family arrangement, beliefs, culture and space to unlink the communication of death with the decision to donate organs and tissues. Given these findings, it is important to respect the family's mourning process, since each person experiences this process in a particular way. That is, it is fundamental to understand that family members have different behaviors at this time and that mothers tend to deny the reality for a longer period of time (Adanir et al., 2014; Febrero et al., 2019; Santiago, 2016; Sque et al., 2018).

Regarding the recommendations linked to the axis communication of death, it is essential that professionals have knowledge about the dynamics and structure of each family, planning their communication directed to this, with simple, clear language, without technical terms

**Table 2**

Table of the Analysis Grids extracted from the interviews with professionals and family members.

Analysis grids	
Record Units	
Healthcare Professionals	Relatives
Only talk to family members in a private place.	Always listen and know the truth.
Speak simple words and no technical terms.	Explain with great tact and care.
We should treat them as we would like to be treated.	We feel as if life stops at that moment.
Remember that family time is different from professional time.	It is too much pressure, we need more time.
Always speak the truth, do not omit anything.	Respect for the time of acceptance of death.
Only talk about donation when they can hear.	The authorization came after the possibility of helping other children.
<p>Category 1 – Communication: alignment of information between team and family. It is understood that at all stages of the interview, it is necessary that there is a logical sequence in the team's communication, while it is important that these professionals use simple, clear words, avoiding technical terms. In addition, a calm, cozy, and private environment favors the family's understanding of what is happening. The data collected with the professionals and family members support this category.</p> <p>For us, it is always important to hear the truth, even if it brings pain and suffering. The team must not hide anything from the family. (F1)</p> <p>It is important to always talk to them in a private room, quieter, with no noise, away from the tumult, with everyone sitting down, it makes conversation easier and puts everyone at ease. (E9)</p> <p>It is not easy for us to accept that the body is there warm and it is dead. This is very difficult, the professionals have to explain very well for us to understand, especially with such a small child. (F2)</p> <p>Category 2 – Synchrony between the times of the team and the family in the interview stages. The need for synchrony of time between the team and the family at all stages of the interview must be emphasized. The team needs to be aware that its time is different from the family's and must respect this condition. The team's time goes fast, because there is pressure to speed up the release of the bed and to talk about organ and tissue donation with the family, considering the urgency of this process. However, the family experiences its own time in a process of grief and pain with the news of the death.</p> <p>The data presented below reinforce this category.</p> <p>Give your time and make yourself available, give the family a chance to see the child's body; take the child on your lap; say goodbye if they wish. (E9)</p> <p>At that time, the world comes crashing down, all we need is time, respect, and a lot of attention. That's what we need at this time. It's as if life loses its meaning. (F5)</p> <p>It is important that we always make sure that there was a minimum time interval of 30 to 40 min between the announcement of death and the talk about organ donation. (E6)</p>	

**Table 3**  
Care bundle for the health team in conducting the family interview for organ and tissue donation of children and adolescents.

Stages of the interview considering the Alicante Model	Care strategies extracted from the reports of the health team, family, and literature	Level of evidence of care	Strength of recommendation of care
Notice of death	Strategy: Planning for Conducting Notice of Death Care actions	Moderate	Strong
	<ul style="list-style-type: none"> <li>• Arrange for the family to come and inform them about the opening of the BD protocol (detailing each stage and the tests to be performed). This activity must be performed by a physician trained in critical situation communication.</li> <li>• Know the family structure in advance (identify conflicts, divorced parents, among others).</li> <li>• Arrange when, where, which medical professional will communicate the death and the best time.</li> </ul>	Low	Strong
	Strategy: Engaged and empowered team to communicate death Care actions	Low	Strong
Emotional support	<ul style="list-style-type: none"> <li>• Never communicate death to a relative alone.</li> <li>• Invite the family to go to the environment that has been prepared.</li> <li>• Introduce yourself and get to know each member of the family, always calling them by name.</li> <li>• Know the data concerning the patient and his hospitalization.</li> </ul>	Low	Strong
	Strategy: Talking about death Care actions	Low	Strong
	<ul style="list-style-type: none"> <li>• Maintain facial expression congruent with what is being said.</li> <li>• Inform about the death, highlighting the time when it was verified.</li> <li>• After reporting the death, remain silent, so the family can codify what was said.</li> <li>• If the family questions whether there is hope, one should not give hope, only reinforce that the patient is dead.</li> <li>• Resolve all the doubts that may arise.</li> </ul>	Low	Strong
Information on organ and tissue donation	Strategy: Understanding the grieving process in the face of family beliefs and culture Care actions	Low	Strong
	<ul style="list-style-type: none"> <li>• Try to understand the impact of the news and the mourning phase each family member is going through.</li> <li>• Identify how the professional can be helpful at this moment.</li> <li>• Identify the feelings expressed by the parents through active listening.</li> <li>• Provide the presence of a support network and psychological support.</li> </ul>	Low	Strong
	Strategy: Respect for family time Care actions	Very weak	Weak
Information on organ and tissue donation	<ul style="list-style-type: none"> <li>• Providing time for the family to assimilate the death.</li> <li>• Promote psychological support at all times, avoiding leaving family members alone.</li> <li>• Organize the farewell of the body of the child or adolescent, if they wish.</li> </ul>	Moderate	Strong
	Strategy: Support in conducting bureaucratic stages Care actions	Moderate	Strong
	<ul style="list-style-type: none"> <li>• Assisting the family in forwarding papers and documents for the release of the body.</li> <li>• To orient about the stages of the funeral, how to proceed, which stages to follow.</li> </ul>	Moderate	Strong
Information on organ and tissue donation	Strategy: Planning the conduct of the conversation about organ and tissue donation Care actions	Moderate	Strong
	<ul style="list-style-type: none"> <li>• Define the place and who will conduct the information about the donation. It should be a qualified professional.</li> <li>• Leave, in the environment, water, tea and tissue.</li> <li>• Provide the presence of family members with decision-making power.</li> <li>• Make sure that the family has assimilated the death and there has been enough time to disassociate the communication of death with the donation conversation (at least 30 to 40 min).</li> <li>• Welcoming all family members into the room and making them comfortable in the environment (private environment, with space for everyone to sit, no barrier and no interference).</li> </ul>	Low	Strong
	Strategy: Leading the conversation about organ and tissue donation Care actions	Low	Strong
Information on organ and tissue donation	<ul style="list-style-type: none"> <li>• Start the conversation by saying that the information to be given below is their right according to the legislation in force in the country.</li> <li>• Point out that, at this moment, the patient becomes a potential organ and tissue donor.</li> <li>• Explain, step by step, how the donation works (stages of the process, how the single list works, who will benefit from the donation, logistics, among others).</li> <li>• Investigate, together with the family members, what donation means to them.</li> <li>• Ensure they have understood what has been said and if they want some more guidance.</li> <li>• Give the family room to ask questions and make inquiries as they wish.</li> </ul>	Low	Strong

and using the word “death” to unlink life with the beating heart. The family, many times, is laymen in the subject and do not know what BD is, so they need to receive precise information about the stages of this diagnosis. It is necessary to tell the truth, without omitting any facts, because the reliability of the diagnosis establishes trust between the team and the family (Febrero et al., 2019; Gelbart, 2017; Polita et al., 2020).

The care recommendations of the emotional support axis are related to accompanying the family at all times, trying to understand the impact of this news for each family member, identifying the feelings expressed by them, so that it is possible for the team to help in the elaboration of

mourning. At this moment, it is important that the team tries to understand how it can be useful, besides developing active listening. It is emphasized that there is a recommendation to leave the family alone only if they wish to do so. The recommendations of the bundle present the need for psychological support that should be given to the family members (Gelbart, 2017; Lindsay & Heliker, 2018).

In the axis of information about organ and tissue donation, the caregivers point out, as strong points for best practices, the need for the professional to have at least two years of experience conducting the conversation about donation. This previous learning experience certifies the professional's knowledge, skills and attitudes when conducting the

interview, while also ensuring that the professional will plan the conversation with the family to make sure that all members with decision power will be present, especially in the situation of the child and adolescent, and that the environment is adequate to accommodate everyone. This professional should also consider that the current legislation makes it clear that the authorization for organ donation, for this specific population, must be signed by the father and mother, even if they are legally separated. Still, in case of death, disappearance of one of the parents or for other reasons, it is necessary to activate the legal power to help (Brazil, Ministry of Health, 2017).

In view of such peculiarities that involve death and the process of organ and tissue donation in children and adolescents, it is imperative to train professionals who provide information about donation. Only then will they be able to inform, according to the best practices, which are the stages of the donation process and be able to answer all the questions that may arise. The key points of the health team, able to help parents in making a decision about organ and tissue donation, involve the communication skills of the professional who conducts the interview, the conversation in a respectful and empathetic way, the development of emotional support in all phases of the interview, an appropriate environment to receive the family, and respect for the time between the communication of death and the talk about organ donation (Moraes et al., 2018; Wojda et al., 2017).

### Study limitations

A limitation of this study is the scarcity of current original articles related to family interviews with parents or guardians of children and adolescents, as well as the difficulty in conducting interviews with family members.

### Conclusion

The study developed a care bundle for the family interview in the scenario of organ and tissue donation of children and adolescents. That is, this material supports and subsidizes the health team when facing such a difficult and complex moment for the team and, mainly, for the family members. The developed bundle explains and helps in the development of the interview focused on three major moments supported by the Alicante model: communication of death, emotional support and information about organ and tissue donation, clarifying how each stage should ideally follow according to the literature, the assessment of professionals involved in this process and the family members who have already gone through the interview.

This strategy is easy to implement in units with critically ill patients, since there is only the cost of printing the material to be used in training sessions or even as support material for professionals. It is suggested that, for implementation, the teams organize meetings and use the references that were used to build the bundle.

In order to evaluate the implementation of the bundle, it is suggested to compare family refusal rates before and after the beginning of the use of the material in each institution, as well as to use immediate feedback from family members and professionals themselves, understanding the learning curve of the team and access to the material. This evaluation is recommended in a semi-annual comparison.

Finally, it is emphasized that the use of this care bundle is an important way to support the professional during the family interview for organ and tissue donation in a scenario as sensitive and challenging as the care of family members of children and adolescents.

### Practice implications

The care bundle for the development of the family interview for organ and tissue donation goes beyond strategies and care for the professional to talk about organ donation, because it brings implicit the training of the team that acts in each stage of conducting the family

interview as an initiative point for best practices. Supported by other studies, the bundle strengthens the ideal that health professionals should only participate in any of the stages of the interview when they have the knowledge, skills and attitude to recognize legal, ethical, moral, cultural, family and organizational parameters, especially when referring to the interview for organ donation with parents or guardians of children and adolescents.

### Implications for pediatric nursing practice

The material produced can help professionals in conducting the interview, providing them with tools for the critical steps, which will impact the quality of care and welcoming to the bereaved families and, possibly, the reduction of family refusal to donate organs and tissues in the pediatric scenario. Likewise, the bundle can also serve as scientific support to professionals during the conduction of this important stage, with the possibility of reducing the stress and suffering of these professionals in such a delicate and complex moment.

### Declaration of Competing Interest

None.

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### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pedn.2022.01.010>.

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