

## Deceased donor's family experience during the organ donation process: a qualitative study

Experiência de famílias de doadores falecidos durante o processo de doação de órgãos: um estudo qualitativo  
Experiencia de familias de donantes fallecidos durante el proceso de donación de órganos: un estudio cualitativo

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## Resumo

**Objetivo:** A família é o principal componente da doação de órgãos. Este estudo descreve a experiência da família do doador com os cuidados de enfermagem durante o processo de doação.

**Métodos:** Foi realizado um estudo fenomenológico. Os participantes eram familiares que aceitaram a doação de órgãos de um parente em hospitais, e foram recrutados por meio de amostragem intencional. Foram realizadas entrevistas em profundidade e anotações em campo, além de uma análise temática.

**Resultados:** Três temas foram identificados: Aspectos positivos do cuidado de enfermagem na unidade de terapia intensiva (UTI); Aspectos positivos do cuidado do enfermeiro coordenador de transplantes (ECT); e Aspectos improváveis do cuidado de enfermagem durante o processo de doação de órgãos. A flexibilidade dos horários na unidade de terapia intensiva para favorecer o acompanhamento dos familiares e fornecer informações adequadas e adaptadas sobre a doação são cuidados diferenciados para as famílias. Elas destacaram áreas para melhorias relacionadas à intimidade e privacidade durante o processo de doação.

**Conclusão:** As famílias dos doadores prezam e valorizam os cuidados de enfermagem no processo de doação de órgãos.

## Abstract

**Objective:** The family is the main component for organ donation. This study describes the experience of the donor's family with the nursing care during the donation process.

**Methods:** A phenomenological study was applied. Participants were family members who accepted the donation of organs from a relative in hospitals, using purposeful sampling. In-depth interviews and field notes were conducted. A thematic analysis was performed.

**Results:** Three themes were identified: Positive aspect of intensive care unit nurses' care; Positive aspects of nurses transplant coordinators' care; and Improvable aspects of nursing care during the organ donation process. The flexibility of hours in the intensive care unit to favor the accompaniment of family members, and to provide adequate and adapted information about the donation are outstanding care for families. They highlight areas for improvement related to intimacy and privacy during the donation process.

**Conclusion:** Donor's families appreciate and value nursing care within the organ donation process.

## Resumen

**Objetivo:** La familia es el principal componente de la donación de órganos. Este estudio describe la experiencia de la familia del donante con los cuidados de enfermería durante el proceso de donación.

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**Conflicts to interest:** none to declare.

**Métodos:** Se realizó un estudio fenomenológico. Los participantes fueron familiares que aceptaron la donación de órganos de un pariente en hospitales, reclutados por medio de muestreo intencional. Se realizaron entrevistas en profundidad y anotaciones en campo, además de un análisis temático.

**Resultados:** Se identificaron tres temas: Aspectos positivos del cuidado de enfermería en la unidad de cuidados intensivos (UCI); Aspectos positivos del cuidado del enfermero coordinador de trasplantes (ECT); y Aspectos improbables del cuidado de enfermería durante el proceso de donación de órganos. La flexibilidad en los horarios en la unidad de cuidados intensivos para favorecer el acompañamiento de los familiares y suministrar informaciones adecuadas y adaptadas respecto a la donación constituyen cuidados diferenciados con las familias. Destacaron áreas para mejoras relacionadas con la intimidad y la privacidad durante el proceso de donación.

**Conclusión:** Las familias de los donantes precian y valoran los cuidados de enfermería en el proceso de donación de órganos.

## Introduction

The organ donation process is a complicated process that begins after the consent of the relatives of the donor patient. For the donor's family, it is a time of great stress since they have to face the loss of a family member and quick decision-making regarding organ donation.<sup>(1)</sup> The family is the main component for organ donation to occur, and in order to promote positive outcomes of donation, healthcare professionals need to facilitate the process.<sup>(2)</sup> The needs of families are not only limited to information. A recent study has concluded that despite being very appreciative of the care delivered, families were often left with lingering unanswered questions that continued to cause them ongoing grief.<sup>(3)</sup> Healthcare staff should facilitate anticipatory mourning, family-led activities, and a meaningful parting from their relative, assisting families with their grief and increasing staff members' efficacy, confidence, and interdisciplinary.<sup>(4)</sup> Efforts are needed to improve communication with families during the hospitalization, interventions to elicit and address unanswered questions.<sup>(3)</sup> A Spanish study analyzed that satisfaction with healthcare personnel, treatment received, and emotional response are factors that influence the decision to accept the donation from the donor's family.<sup>(5)</sup> This study aims to know the complete lived experience of the donor's family with the nurse during the donation process.

## Methods

The present study followed the guidelines for conducting qualitative studies established by the consolidated criteria for reporting qualitative re-

search (COREQ)<sup>(6)</sup> and the APA Publications and Communications Board Task Force Report.<sup>(7)</sup> Qualitative methods are useful for understanding the beliefs, values, and motivations that underlie individual health behaviors.<sup>(8,9)</sup>

A qualitative phenomenological descriptive study was conducted<sup>(9-11)</sup> addressing the experiences of donor's relatives in the process of donation. Within qualitative studies,<sup>(8)</sup> phenomenology tries to understand the way of perceiving the life of individuals. Phenomenology attempts to identify the inherent nature of the participants' lived experiences, which is the subjective consideration of people when they experience events in a specific space and time.<sup>(9,10)</sup> The researcher assumes an interested and receptive attitude for an adequate understanding of the unique meaning of the participants' experience.<sup>(8)</sup> In qualitative research, data is extracted from first-person narratives of participants that have meanings for those who have experienced the same event.<sup>(9)</sup> Therefore, according to the aim and the research question of the study, phenomenology is the appropriate design.<sup>(8)</sup>

Four investigators participated in this study, 3 of whom had experience in qualitative study designs (CSM, DPC, AGP). Two held PhDs in health sciences, were not involved in clinical activity, and had no prior relation with the participants, except one researcher (VFA) who was working in the liver transplant unit during the study. Before starting the study, the investigators established in two informative meetings their position on the theoretical framework for the study, their beliefs, and motivations to carry it out.<sup>(8)</sup>

Members of the Spanish population are supposed to be willing to donate organs unless they had previously expressed (in an oral or written way) their desire against it, based on the Royal Decree 1723/2012. Spain is leading organ donation and

transplantation worldwide. Nationally, in 2019, the family refusals to the donation are at 14%, in Madrid region is above the average of 15%.<sup>(12)</sup>

For access to the sample, we contacted with hospital NTCs from the six transplant hospitals of Madrid State. They contacted families who have accepted the process of donating a family member. Once the volunteers were contacted, an agreed date and time for the interview was agreed upon.

In relation to the research question, a purposive sampling was used (not clinical representativeness).<sup>(8,13)</sup> Purposive sampling is defined as the selection of individuals based on specific intentions related with facing the research study's question or aim.<sup>(8)</sup> Sampling and data collection were maintained until the researchers obtained redundancy in the information, at the time when they did not report any new information from the data analysis.<sup>(8,13)</sup> In this study this situation happened after including 8 participants.

The inclusion criteria were relatives who have suffered a loss of a loved one, who was a potential donor and finally donated (including: father, mother, son, daughter, brother, sister, husband, and wife), family members who speak Spanish and/or English as first or second language and family members who wish to participate in the study. Also, the exclusion criteria were relatives of patients who have not participated in the organ donation process, second-degree relatives and family members of donors who do not wish to participate in the study. A total of nine donor's relatives were recruited from four Madrid transplant hospitals.

The data was collected between the months of May 2019 and July 2020. In the data collection phase, in-depth interviews were carried out based on a question guide (Charts 1 and 2) to obtain information on the specified topics.<sup>(6)</sup> The question guide was developed based on previous experiences of researchers and bibliography review. The interviews were conducted by VFA.

A total of nine interviews were undertaken, tape-recorded and transcribed verbatim. All interviews were conducted at the nurses' work base or in a space agreed by both parties, guaranteeing the privacy and intimacy of the person interviewed, according to participant preference. The researcher

**Chart 1.** The positioning of the researchers

<b>Theoretical framework</b>	Researchers based their approach on an interpretivist paradigm. This paradigm was based on the assumption that human beings construct their own social reality, and that knowledge is built through increasingly nuanced reconstructions of individual experiences.
<b>Beliefs</b>	Spanish society has a high acceptance of the donation despite being a stressful process. The care perceived by the donor's family is the key to the success of the donation process.
<b>Motivation for the research</b>	Describe nursing care during the organ donation process to be able to define improvements and advances that positively influence the increase in the donor pool.

**Chart 2.** Semi-structured relatives interview guide questions

Questions
How do you remember the experience of the organ donation process? How do you think related nursing staff during the process of organ donation? Did the nursing staff influence the decision to accept organ donation? From the donation process, from the first interview to the delivery of the body, would it improve or approach it in a different way?

collected a reflective journal. The researcher's field notes add more information as participants narrate their personal experiences, their behavior at the time of the interview allowed them to observe their reflections on the methodological aspects of data collection.<sup>(8)</sup> Only the researcher and the participant were present during the interview.

All the interviews were transcribed literally complete, as well as the researcher's field notes. The texts were compiled to allow qualitative analysis.<sup>(14)</sup> The initial analysis was conducted by CSM, AGP, and VFA. The first results were unified in joint meetings, in which the methods of data collection and analysis were discussed. The identification of the topic was decided by consensus in cases of differences of opinion. A thematic analysis was performed.<sup>(8,14)</sup> The analysis began obtaining significant units with the descriptive content. Later, a more in-depth analysis was made using the reduction of the data to classify them into groups of thematic codes. In this way, the level of abstraction and complexity of the analysis escalated from units of meaning to groups of thematic codes and finally themes.<sup>(8,14)</sup> Topics were established to embody the experiences of the donors' families. For the analysis of data, qualitative software was not used.

This study has followed the guidelines established by the COREQ,<sup>(6)</sup> and the APA Publications and Communications Board Task Force Report.<sup>(7)</sup> Also, Cuba & Lincoln criteria for guaranteeing trustworthiness were followed.<sup>(8,13)</sup> The techniques performed and the application procedures<sup>(8,13)</sup> used to control trustworthiness are described in chart 3.

**Chart 3. Trustworthiness criteria applied**

Criteria	Techniques performed and application procedures
Credibility	Investigator triangulation: each data source was analyzed. Thereafter, team meetings were performed during which the analyses were compared and themes were identified. Triangulation of data collection methods: including semi-structured interviews, and researcher field notes. Participant validation: this consisted of asking the participants to confirm the data obtained at the stages of data collection.
Transferability	In-depth descriptions of the study performed, providing details of the characteristics of researchers, participants, contexts, sampling strategies, and the data collection and analysis procedures.
Dependability	Audit by an external researcher: an external researcher assessed the study research protocol, focusing on aspects concerning the methods applied and the study design.
Confirmability	Investigator triangulation, data collection triangulation. Researcher reflexivity was encouraged via the previous positioning, performance of reflexive reports and by describing the rationale behind the study.

Clinical Research Ethics Committee at Hospital Universitario Gregorio Marañón has approved this study (code: VFA\_ENF; act: 02/2019). All participants signed an informed consent and permission to record the interviews. The study was adapted to the principles articulated in the Declaration of Helsinki.<sup>(15)</sup> To guarantee anonymity, alphanumeric codes were assigned to each participant. No documentation or personal information of the participants was communicated to people outside the research team.

## Results

Six females and three males participated in this study, and participants' mean age was 50.06 years. The mean number of days from donation to interview 69.38 days. A total of 441.15 minutes of recording. Three main themes emerged from participants' narratives: a) Positive aspects of ICU nursing care; b) Positive aspects of NTC care; and c) Improvable aspects of nursing care during the organ donation process. Also, we have included some of the patients' narratives taken directly from the interviews, in relation to the findings.

### Theme 1. Positive aspects of ICU nursing care

The families emphasized how a close relationship with the nurses is essential to face the death of the family member. The relatives interviewed highlight the kindness, affection, and consideration they felt from the ICU nurses:

*They were kind until they could not more. The nurses are all super loving. They enter trying to disturb the least. (E4)*

This closeness of the nurses was translated into accompanying families and covering their needs. Family members explained that they were treated with hot drinks, chairs were provided, and screens were placed to promote privacy:

*No one hardly ever entered inside. They brought me a linden tea. They put the folding screens on us so as not to disturb and give privacy. (E2)*

The families perceived how the nurses tried to modify and to make the unit rules more flexible, to help them at all times. They emphasize the flexibility of visiting hours and the possibility of several people being there during it, knowing the usual restrictions that ICUs have:

*The times we wanted to be, if we all wanted to be as one, if we wanted to enter 20 or no times, no one told us anything there. (E2)*

Finally, the relatives who were clear about the decision to donate did not consider the care received to be influential, although they did not deny its importance. On the other hand, family members who had more doubts about donation did value it as influential for the acceptance and continuity of the process:

*If the nurse had not raised the alarm to the coordinator to resolve the confusion, the entire donation process would have been frustrated. (E2)*

*In our case, no, because we were very certain of it, but I imagine that in other cases it can have an influence, for sure. (E8)*

### Theme 2: Positive aspects of NTC care

The families narrated how in addition to the pain of the loss, they suffered great uncertainty, they had great difficulty concentrating and making a decision, everything was confusion. At this point they

have perceived communication with nurses as a fundamental element. The relatives have narrated that during the family interview the information given was adequate and adapted:

*It was clear, bluntly. I felt that he was letting us decide” (E5).*

*They took their time talking to my mother, explaining everything to her, answering her questions (E6).*

The families narrated how there were some aspects that have not been handled correctly. They lacked knowledge of relatives to the donation without age limit:

*I think you would never imagine that, with your age, 85, you could. We were all surprised. (E8)*

*No one can imagine that with 74 years you can donate. (E4)*

Although these were very painful times, the family respected the very effective organization that organ donation presented. They also described that diagnostic and assessment tests were done as quickly as possible. Additionally, NTC offered to contact them when the organ removal surgery was over:

*The transplant coordination, spectacular. They did all the tests quickly to my mother. (E4)*

On the other hand, contact with families did not end when they allowed the donation. Families were monitored to assess their needs and if they needed help. Lastly, the relatives were grateful that they were contacted sometime later by letter or phone call to thank them for the donation and to report the success of the transplanted organs:

*He called me to tell me they were not finished, that they were going to be two hours late and he called me back. (E6)*

*They have given us the news that at least one kidney has been used. (E8)*

*I told the coordinator that I would like to know about the organs, and he gave me his contact number. I was able to find out that the lungs and kidneys had been donated (E19).*

### Theme 3: Improvable aspects of nursing care during the organ donation process

Families said they were satisfied with the nursing care and care they received but they wanted to participate in improving care. The relatives interviewed have highlighted aspects to improve during the process:

*They were informing us at a transit site and people were passing by. (E6)*

They highlighted the importance of privacy during the family interview to guarantee intimacy and time in decision making. In addition, they narrated that they heard comments during the admission to the ICU from relatives of other patients, of nurses or from the health personnel themselves, which was not pleasant:

*In the bed beside us there was another man and I heard them commenting: he is going to die. (E5)*

*I heard a doctor saying: life takes its course, here we bring them to make them handsome. (E8)*

The families narrated how during decision making and accompanying their relative in the ICU, they could perceive and see other patients and families. This was a very intense experience. Lastly, they described that the use of screens, although it was adequate, reveals the situation they were experiencing for the other people in the unit:

*They already know that when the screens are put on, it is that they are going to die. (E5)*

## Discussion

Donor family's value and appreciate the nursing care received during the process. They are able to

identify specific care and help them cope with the loss and the donation process, interventions according with previous studies.<sup>(16)</sup> This agrees with studies that conclude that nursing care is an influential factor in the process.<sup>(17)</sup> In particular, the care of ICU nurses highlights the flexibility of schedules to favor accompaniment and farewell time with the donor relative. Health professionals need to achieve confidence and transcendence by families helping them to better understand and intensify their care of donors and their families.<sup>(2)</sup> Family suffering has been related to dissatisfaction with the care received, which was manifested by the indifference and lack of interest of the staff and the delay for the release of the body, the latter being more exhausting.<sup>(18)</sup> Our results show that the lack of intimacy in the ICU can create uncomfortable situations for family members, listening to inconsiderate comments from other families and even healthcare personnel. Also, ICU nurse intervention are important for the continuity of the process for those families that are hesitant.<sup>(18)</sup>

The care of the NTC has been highlighted in the management of the times in the process and the correct and adapted information during it. Families demand socio-emotional support after consent and after the end of the donation process.<sup>(19)</sup> Some family members thanking the NTCs for their sensitivity, while other families describe it as an uncomfortable moment and do not perceive neutrality in the coordinators during the process, concluding that the different perspectives of the families are a barrier to the donation process.<sup>(20)</sup> Our results show that privacy flaws during the family interview cause discomfort in the process. Our results highlight the lack of knowledge of the possibility of donating in elderly patients. In Spain, a paradigm shift is taking place in relation to the average age of the deceased donor, being in Spain of a mean 60.7 years old.<sup>(12)</sup> This situation must be handled by the NTC since the general population may be unaware of the opportunity and know the opinion of their family member about the donation.

Families also express the need to recognize the importance of the process and to participate positively in improving the health of other people, even

without knowing who they are, from a moment of grief over the loss of a relative. Giving a utility to the death of your relative and favoring the acceptance of the loss.<sup>(21)</sup> Families experienced the decision as a proof of their connection with the death relative, not as a burden as a form of comfort during bereavement.<sup>(22)</sup> This is consistent with the care offered by the NTC, subsequently contacting the families, thanking, and informing about the usefulness of their actions. Recent study address that unanswered questions should also be introduced as part of the follow-up at a time when families are no longer overwhelmed by emotions and more capable of processing information. Such interventions should also be offered to families who have refused consent and might have even greater needs.<sup>(3)</sup>

The care received by the ICU nurses is important and helps to bear and accept the donation in the family members. The nurses must be trained in the donation process as well as accompanying the family in the grief.<sup>(23)</sup> It is necessary to explore the differences in family care according to the type of donor, especially DCD donors. Our experience with this study is positive because, despite the delicate topics to be discussed, the willingness to participate was good and the families understood the need for the research to learn about their experiences and improve the unfavorable aspects of it, as a previous study concluded.<sup>(24)</sup> These results can help to develop support and monitoring programs for donor families. In addition, transplant organizations can organize educational programs where donor family members participate by sharing their testimonies with other families.

This study has some limitations in relation to generalization that limit the extrapolation of our results to the entire population. It is important to consider a possible Spanish cultural influence on the themes generated by this research.

Even though the authors had data redundancy in the ninth participant, the situation with respect to the COVID-19 pandemic has been a great limitation when it comes to collecting the appropriate sample. The limitations in the ICU beds and the restrictions for the accompaniments and visits of relatives have affected the habitual process. Because

of that experiences since the beginning of the pandemic are different from the usual ones.

## Conclusion

Nursing care is described as an influential factor in the donation decision in those families who have doubts about it. Donor's families value nursing care within the organ donation process. ICU nurses must promote intimacy and keep trained and informed of the progress in organ donation. NTC must consider privacy during the family interview and approach donation in elderly patients with adequate information.

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## Collaborations

Fernández-Alonso V, Palacio-Ceña D, Silva-Martín C and García-Pozo A contributed to the project design, data analysis and interpretation, article writing, relevant critical review of the intellectual content and approval of the final version to be published.

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