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# Ambiguous loss in organ donor families: A constructivist grounded theory

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## Abstract

**Aims and Objectives:** Explore families' experiences when being approached for organ donation authorisation after brainstem death.

**Background:** The complexities of potential organ donor families' experiences include challenges related to emotional distress, coping with the loss and the organ donation decision-making process, and support needed. A lack of conceptual clarity was found concerning families' experiences when being approached for organ donation authorisation, which guided the study.

**Design:** Constructivist grounded theory.

**Methods:** Seventy-one participants, including healthcare professionals and families, were recruited from two large hospitals in Chile between 2017 and 2019. Field notes, documents ( $n = 80$ ), interviews ( $n = 27$ ) and focus groups ( $n = 14$ ) were collected and analysed following Charmaz's constructivist grounded theory principles and practices until theoretical saturation was reached. The study is reported using the COREQ checklist.

**Results:** A third type of ambiguous loss of bereaved families' experience was developed as a fourfold process: (1) impending loss, (2) confirming loss, (3) ambiguous loss and organ donation decision-making and (4) organ donation as a third type of ambiguous loss. This grounded theory expands the concepts of ambiguous loss by Boss, dying by Glaser and Strauss and grief by Brinkmann, enabling explanation of families' experiences.

**Conclusion:** Families of potential organ donors develop a highly complex grieving process, which may play a significant role in the organ donation decision-making process. Ambiguity is embedded in how donor families reframe the existence of the donor through the act of giving life.

**Relevance to clinical practice:** The findings shed light on families' experiences on the organ donation process after brainstem death. The study can be used in nursing practice, education and to inform policy nationally and globally, mainly due to the current focus on quantitative measures and legislative changes fostering individual decision-making.

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**Patient or Public Contribution:** Families contributed through their first-hand experiences of the organ donation process.

**KEYWORDS**

end-of-life care, family care, grounded theory, nursing theory, theory–practice gap, transplantation

## 1 | INTRODUCTION

Extensive literature has explored families' experiences in the context of organ donation (Darnell et al., 2020; López et al., 2008; Sque et al., 2018). Organ donation after brainstem death (DBD) entails approaching families of deceased individuals to discuss organ donation authorisation as an essential process (Curtis et al., 2021; de Groot et al., 2015).

Despite the global trend of developing legislation towards opt-out systems to increase organ donation rates, limited evidence demonstrates this association over the long term (Etheredge, 2021). The opt-out system presumes that all citizens are organ donors if they do not explicitly object, for example, Spain, the United Kingdom (except Northern Ireland), Singapore and Chile. More recently, studies have highlighted how these changes can put pressure on health-care professionals and families alike (Ma et al., 2021; Silva e Silva et al., 2020).

Chile shifted into an opt-out consent system in 2010, which seems to have impacted the family approach. Before the change, the family refusal rate was at 35% on average between 2000 and 2010, while the rate increased to 51% on average in the following decade, 2010–2020 (Ministerio de Salud Chile, 2021). By law, organ donation includes living and DBD only, which DBD represents the largest group of organ donations in Chile at 82.6% (Ministerio de Salud Chile, 2021). The Chilean organ donation process is a public policy led and implemented by specialist organ donation nurses. In Chile, specialist organ donation nurses speak with families of potential organ donors after brainstem death to negotiate organ donation authorisation and to approach the family as a group rather than as individual members. Although few studies have examined how these encounters occur internationally (Jensen, 2016; Kentish-Barnes et al., 2019), we failed to identify studies in the Latin American context. Shedding light on this complexity would inform nursing practice, education and policymaking in Chile and regionally.

## 2 | BACKGROUND

### 2.1 | Families' experiences and organ donation

In the context of organ donation, one of the main struggles described in the literature relates to families' perception and understanding of brainstem death. Long et al. (2008) highlighted the paradox experienced by families when death entails a continued heartbeat and

### What does this paper contribute to the wider global clinical community?

- The third type of ambiguous loss explains the complexities of families' experiences in the context of donation after brainstem death, which may play a role in the organ donation decision-making process.
- The third type of ambiguous loss unveils families' experiences as a fourfold process: (1) impending loss, (2) confirming loss, (3) ambiguous loss and organ donation decision-making and (4) organ donation as the third type of ambiguous loss. The grounded theory was developed using Boss (1999), Glaser and Strauss (1965) and Brinkmann (2020) conceptualisations of ambiguous loss, dying and grief.
- The third type of ambiguous loss grounded theory contributes to the wider global clinical community and theoretically underpins nursing practice, education and policymaking in the context of organ donation and transplantation.

respiration provoking emotional and cognitive divergence. Similarly, the conflictive image of brainstem death is described as a death in a “warm body” by professionals working in intensive care (Forsberg et al., 2014). Altogether, it points out how challenging it is to conceive the brainstem death as opposed to the usual conception of death through a beatless heart and cold body. Further difficulties in investigating families' behaviours around donation after cardiac death are also highlighted, where families hold onto the hope of recovery until the final beat (Prescott et al., 2019).

An unexpected and sudden death characterises the organ donation process within DBD. Sque et al. (2018) explored the experiences of 31 donor families, describing how families found loss challenging due to heightened feelings from the sudden news of the impending death. This situation can psychologically impact the decision-making process (Walker et al., 2013), where families often feel unable to cope as they focus on the grieving process instead (de Groot et al., 2015; Sque et al., 2018). Association between families dealing with distressing feelings and organ donation refusal has been reported even when the family knew the deceased's positive willingness to donate (López et al., 2018).

Manzari et al. (2012) conducted a qualitative study using content analysis and interviewed 14 donor families and 12 who declined donation after brainstem death in Iran. Both groups described the emotional turmoil of the organ donation decision-making process. While donor families might alternate between suffering and solace due to donation, nondonor families described stronger and more prevalent conflictive feelings of resentment, doubt and uncertainty of their refusal than donor families. Although emotions of fear, conflict, rejection and discomfort as well as relief, and solace have been linked with the process in similar studies (Jensen, 2016; Sque & Galasinski, 2013), their role in the decision-making process has not been fully explored. Families who received emotional support and described a satisfactory perception of medical and personal attention reported not only better experiences but also higher consent rates (López et al., 2018). As a result, López et al. (2018) suggested measuring the impact of emotional reactions in family decisions and experiences, highlighting the relevance of sensitive support for families throughout the process, during the loss of their family member and the organ donation conversation. Despite the evidence of the importance of loss and grief in these families in the literature (Ma et al., 2021; Sque & Galasinski, 2013), few studies have explored families' experiences in Chile (Avilés et al., 2014).

## 2.2 | Death, loss and organ donation

Death evokes loss, a clear division between nature and culture; hence, death is a social process (Seale, 1998). When experiencing the death of a person, three terms are commonly referred to (1) bereavement, (2) grief and (3) mourning. Bereavement refers to the loss of a significant person, while grief captures the emotional, cognitive, functional and behavioural response generated by the loss. On the contrary, mourning involves cultural expressions and demonstrations towards the loss (Pérez & Lucena, 2000). Although theoretically these concepts are different, they often appear together as aspects of the experience of death and are sometimes used interchangeably. In Spanish, the three concepts can be captured in one word, *duelo*, which clusters these three subtle processes (Yoffe, 2013). Pérez and Lucena (2000) draw attention to the cultural modelling of emotions from the bereaved towards the deceased, and hence loss as an emotional experience.

The impact of death and loss may vary for families because the experience depends on diverse factors such as dynamics and relationships between their members, previous experiences around death, social network, the circumstances of the loss, expectations and how each family member deals with the end of life (Boss, 1999; Holland & Neimeyer, 2010). The seminal work of Sque and Payne (1996), the "dissonant loss" theory, expanded the understanding of loss in the organ donation context. Based on the experience of 16 donor families in the UK, the authors defined dissonant loss as "[a] bereavement or loss which is characterised by a sense of uncertainty and psychological inconsistency. The loss is assured but the effects of the

loss on those involved are unknown" (Sque & Payne, 1996, p.1367). The organ donation decision-making process leads to processes of conflict and resolution. Conflict behaviour is related to the intense emotional experience of the impending loss, while the resolution may refer to the decision to donate to move forward. Both have an impact on the emotional well-being and bereavement processes in families.

In the Norwegian context, Berntzen and Bjork (2014) interviewed 22 donor family members who experienced the organ donation process after brainstem death. Brainstem death creates a shadowy border between life and death. Families expressed that healthcare professionals did not perceive their feelings of ambivalence, which affected the communication process. The role of organ donation teams in accompanying families during the transition between life and death, in the organ donation decision-making process, and early grief has been highlighted, with recent studies conceptualising emotion management as a sophisticated skill for these teams (Avilés et al., 2021; Danet et al., 2020). Nevertheless, although the manner that families deal within death as a social process with the organ donation context is relevant, it remains unexplored. Few empirical studies have examined the interactions between healthcare professionals and families, and how the process of approaching families shapes their experiences of loss (Jensen, 2016; Kentish-Barnes et al., 2019), identifying a knowledge gap. As a result, this study set out to address this gap by developing a theory that can explain the process of approaching families in Chile. The findings aim to guide clinical practice in the context of organ donation and transplantation.

## 3 | METHODS

### 3.1 | Design

The study developed a middle-range theory of the process of approaching families (Avilés, 2020), using constructivist grounded theory as the methodology (Charmaz, 2014). By adopting a constructivist stance, the findings acknowledge the first author's role and positionality in the co-construction of data with participants. This grounded theory was developed by theorising as an ongoing activity, engaging with grounded theory strategies, using induction and abduction, acknowledging the researcher on the theorising process and developing of theory (Charmaz, 2014). To report the findings, the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was followed (Tong et al., 2007; Appendix S1).

### 3.2 | Settings and recruitment of participants

Participants were recruited from two large public hospitals in Chile (anonymised as C1 and C2). Data were collected between 2017 and 2019, commencing in C1 using purposive sampling strategies and

then moving to C2 to compare experiences and practices supporting theoretical sampling. This ensured transferability beyond one setting and engagement with grounded theory practices and strategies.

Recruitment of families commenced two months after starting data collection, enabling comparison between participants and the data set. The organ donation team made initial contact with families using the organ donation unit's records. Adult family members were recruited as family subsystems (Friedemann, 1989) per best practice in Chile, including bereaved families as individuals, dyads and larger groups who were recruited between six months and two years after the experience, regardless of their decision. This process identified donor and nondonor families who lived in the capital city for interviews. Forty-five families were phoned, resulting in 14 giving permission to be contacted by the first author, who provided further details and an invitation to an in-person meeting. Families mostly opted for their own houses as the preferred location, with three selecting a hospital setting. The locations were quiet and private, allowing nil to minimal interruption. Families who preferred their homes offered tea or coffee and even food, which facilitated building up rapport between the researcher and each family. Only after a thorough informed consent process was conducted, did data collection begin.

### 3.3 | Data collection

Data collection was carried out by the first author while conducting her PhD study, a Chilean nurse scholar and qualitative researcher who had studied the organ donation process for more than a decade. Her background as a critical care and dialysis nurse was known in both settings, facilitating access and trust. Four data collection methods were used (1) participant observation, (2) documents, (3) interviews and (4) focus groups. Using a combination of methods allowed the comparison of actions and processes, helping the theorising process (Flick, 2018).

Using purposive sampling, the data collection started with participant observation which began after the organ donation team in C1 agreed to participate and be observed in their daily work. The development of a trusting relationship allowed the first author to observe the entire organ donation process. Six full family approaches were observed in C1 from follow-up of potential organ donors to family approach, including organ retrieval and closure with donor

families (see Table 1). Training sessions for new team members and workshops conducted by organ donation teams were also attended. Observations were recorded as field notes and later transcribed to Word files. Collected documents included guidelines, statistics and forms used by the teams, which were collated and transformed into PDF files for analysis.

Observations were guided by the question, how is approaching the families for organ donation experienced? Interviews with health-care professionals explored their experiences encountering families and their roles. Interviews with families began with the open question: how did you experience the approach to discussing organ donation? Face-to-face interviews and focus groups were audio-recorded with an encrypted device and transcribed verbatim, with an average duration of 71 min. Repeated interviews were not necessary on any occasion. All data were securely stored in the DataStore Service at University of Edinburgh for data protection.

### 3.4 | Data analysis

Data were systematically collected and analysed using comparative methods and grounded theory practices and strategies (Charmaz, 2014). The use of four data collection methods and comparative methods helped to uncover and acknowledge how approaching families for organ donation was a familial and social process, where interactions between organ donation nurses and families were an essential part of meaning and interpretation.

The analysis helped to refine questions and led to the inclusion of other documents: pictures. Photographs of objects and spaces were included to further explore organ donation teams' approaches and conversations. Line-by-line coding and gerunds were initially used to focus on processes (Charmaz, 2014; Flick, 2018). The analysis was also carried out at two levels, comparing what individuals and groups said about and reflected on their experiences. In analysing families' experiences, families' subsystems (Friedemann, 1989) were compared with each other as well as contrasting those with health-care professionals' experiences. These processes allowed focussing on actions and meanings, which progressed in the development of focussed codes and then clustered into the emerging category (Table 2). The first author carried out the analysis and discussed it regularly with the co-authors. An iterative analysis process was

TABLE 1 Family approaches observed ( $n = 6$ )

N	Potential organ donor (POD)	Next-of-kin of POD	Family encounters	Process' length (h)	Donation authorisation
1	Male, 20 years, brain injury	Mother, stepfather and grandfather	3	9	No
2	Female, 64 years, haemorrhagic stroke	Son and daughter	6	26	Yes
3	Male, 60 years, haemorrhagic stroke	Wife and daughter	2	6	No
4	Female, 45 years, haemorrhagic stroke	Husband, son, daughter, sister and niece	5	26.5	Yes
5	Male, 55 years, brain injury	Son and partner	2	9	No
6	Male, 72 years, haemorrhagic stroke	Two sons	3	4	Yes

TABLE 2 Coding process for families' experiences

Data	Initial codes (n = 32)	My theoretical links	Focussed code (n = 6)	Category
I think she was always dead...it was so violent (the accident) ... don't know. Her, her body was intact, not a scratch, none. It was all in her head (Interview, Family 6, C2). Uh...it was long...and painful! In that sense, it was so complicated. Being there, being there knowing that, from my perspective, he was not there anymore. I mean, he was there, but he was not! ...My father was like that because of the machines he was connected (Interview, Family 8, C1). Rose: To see all those people transplanted...we thought that he was somewhere Victoria: Yes, we thought we was there Rose: I felt he was there...my brother. It was like magical! Although it was recalling all that we went through, experiencing all again. (Focus Group, Family 9, C1).	Being but not being there	Awareness of dying? Glaser & Strauss (1965) Ambiguous Loss Boss (1999) What do they mean? What are the implications? Grief as an emotion? Brinkmann (2020)	Emergence of Ambiguous loss	<b>Third type of ambiguous loss Boss (1999);</b> Brinkmann (2020); Glaser & Strauss (1965) (1) impending loss (2) confirming loss (3) ambiguous loss and organ donation decision-making (4) organ donation as a third type of ambiguous loss

carried out, where interviews, focus groups and memos informed new observations and conversations, and theoretical questions were refined and explored. The audit of the analytical process was developed in this manner, tracking the theorising process. Data were managed, stored and analysed using QSR-NVivo 12.

### 3.5 | Theorising process

Theorising involved constantly questioning the data against theories or concepts, and concepts to data (Reichertz, 2019). The processes of induction and abduction were essential to reach the level of abstraction of developing a grounded theory. In this study, from the inductive analytical step of line-by-line coding, towards the end of focussed coding and development of categories, data and participants' experiences were theorised employing abduction to theoretically explain and make sense of the data (Charmaz, 2014; Flick, 2018).

During the analysis process, it became evident that emotional connection was essential during the approach for each participant's experiences. Bereaved families often spoke of being in shock, overwhelming feelings of loss for impending death, drawing on aspects of the dying transition (Glaser & Strauss, 1965). The conflictive organ donation decision-making process saw families' data reflecting on how the process impacted the experience and how the narrative of "saving lives" embraced a deeper meaning for their grief and signified their loss in this context. The ambiguity of donating organs to save lives also implied that the "person was around," which involved challenging ontologically death and hence opening new venues of enquire. To explore these data in-depth, families were asked to clarify and reflect, what do you mean? What do you think about it? To make sense of what families experienced, conceptualisations of death and grief were explored, including Seale's (1998), Glaser and Strauss's (1965), Boss's (1999) and Brinkmann's (2020). Data collection ceased when the theoretical sufficiency of the core category was reached (Dey, 1999) See Table 3.

*Reading the family* was developed as a middle-range theory to guide nursing practice in approaching families to negotiate organ donation in Chile. It describes the skilled process of accessing and assessing family's emotions to negotiate organ donation authorisation. The complexities of *Reading the family* can be fully understood due to the *third type of ambiguous loss* (Avilés, 2020), explaining families' experiences.

### 3.6 | Rigour

Grounded theory methodology's rigour criteria were employed in this study (Charmaz, 2014; Glaser & Strauss, 1967). Credibility and resonance were ensured by participants' experiences leading the enquiry process. Gerunds and in vivo codes were part of the analysis to focus on processes and express explicit and implicit meanings. Workability and usefulness for nursing practice

TABLE 3 Study sample

Data	
Observations	297h
Documents	80
Interviews	27 (18) Health professionals (9) Family members
Focus groups	14 (11) Health professionals (3) Family members
Total participants	71 (51) Health professionals (20) Family members

were addressed through the inclusion of two research sites. A systematic reflexivity process was carried out by the first author, recorded in the research journal and regularly discussed in supervisory meetings with co-authors. Interactions, relationships between researcher and participants and emotions were theoretically examined and accounted, engaging in grounded theory practices and strategies for the theorising process, in which links with data were logically explained. Data collection stopped when theoretical sufficiency was reached, and data provided enough adequacy and in-depth theoretical understanding of the core category (Dey, 1999).

### 3.7 | Ethical considerations

The study was reviewed by four ethics committees in the United Kingdom (NURS028), and in Chile (AE N043/2017–N994/2017–N5459). Before starting data collection, all verbal and written informed consent (IC) processes were developed to include confirmation of reading the document, an opportunity to clarify questions, and agree to participation. The IC forms were signed in treble first by a representative of the ethics committee, and before data collection by the participant and the first author, in line with Chilean standard ethical procedures.

Although the risk of emotional distress was expected, bereaved families reported empowerment and saw the interview as an opportunity to ask questions, talk, be heard, discuss the process and a chance to contribute to society. The researcher's experience and rapport developed with families contributed to minimising the risks of emotional distress, which was reported by participants (Sandvik & McCormack, 2018). Additionally, the first author did a follow-up with all participants, including postcommunication to check on any issues, ask questions and provide information about local support if needed. Although the study included psychological referrals, this service was not used nor solicited by any participants. Formally, the ethics process concluded when a final report was sent to each ethics committee in Chile.

## 4 | FINDINGS AND DISCUSSION: THIRD TYPE OF AMBIGUOUS LOSS

Seventy-one participants, including 51 healthcare professionals and 14 families (20 family members), were included in the study. Tables 4, 5 and 6 illustrate participants' demographic characteristics and family subsystems, respectively.

The findings and discussion sections are presented together to demonstrate the process of abduction while theorising and developing the grounded theory of the *third type of ambiguous loss*. By integrating the findings with the discussion, the connection between the data and the theoretical literature is explicitly demonstrated (Flick, 2018; Locke, 2003), addressing issues directly relating to rigour in grounded theory (Charmaz, 2014; McCrae & Purcell, 2016).

The *third type of ambiguous loss* theoretically explains the experiences of families of potential organ donors when being approached for organ donation authorisation in Chile as a fourfold process, (1) impending loss (2) confirming loss, (3) ambiguous loss and organ donation decision-making and (4) organ donation as a third type of ambiguous loss (Figure 1). The conceptualisations of ambiguous loss by Boss (1999), dying by Glaser and Strauss (1965) and grief by Brinkmann (2020) enabled an explanation of families' experiences in the context of organ donation and why *Reading the family* is essential to negotiate organ donation authorisation (Avilés, 2020). Figure 1 illustrates the grounded theory *third type of ambiguous loss*, in which a family is represented as a group of individuals, and one of them is a potential organ donor, using a discontinuous line. The theories and authors employed to conceptualise the theory are shown in the diagram.

### 4.1 | Impending loss

All families interviewed experienced the unexpected and sudden death of their family members. Patients' critical illness onset was a result of a life-threatening neurological event such as haemorrhagic strokes, trauma or violent episodes that resulted in severe brain injuries.

Laura, whose mum suffered a haemorrhagic stroke, commented:

From the very first moment I saw my mum, I thought immediately that isn't looking good. But I never thought that my mum would pass away. Never. I don't think that thought ever crossed our minds.

(Interview, Family 4, C1)

Similarly, Valeria recalled when her adult daughter died from a brain injury:

It was so fast! So fast. The accident happened on Monday, and she passed way cerebrally on Tuesday [...] Again, it was all rather quickly. And that has a massive impact on you.

(Interview, Family 6, C2)

TABLE 4 Demographics of healthcare professionals (n = 51)

Healthcare professionals	
Gender	
Female	30
Male	21
Age	
18–30 years	10
31–40 years	24
41–50 years	7
51–60 years	9
No answer	1
Profession	
Nurse	32
Physician	7
Psychologist	7
Kinesiologist	2
Nursing assistant	3
Professional experience	
0–2 years	5
2–8 years	14
8–15 years	16
>15 years	16
Organ donation experience	
0–2 years	19
2–8 years	18
8–15 years	7
>15 years	7

Families were faced with trying to understand the sudden and catastrophic events while trying to come to terms with the imminent death of their family member. Cesar's wife died due to a haemorrhagic stroke and reflecting on the information process he said:

From the very beginning, the doctor told my (adult) children: 'There is no way back'. If she would've shown any signs of recovery, she would've ended up in a vegetative state. She never wanted that [...] Therefore, my children knew about it. They got this, this info clearly.

(Interview, Family 5, C1)

The use of open communication allowed families to shift from their expectations of recovery to one of an impending death. Glaser and Strauss (1965) described the open awareness context as when all actors—staff and family members—are aware of the impending death of the individual and how it critically influences dynamics and care, beginning the dying transition. Dying in this context can be understood as “a passing between the statuses of living and death according to no man-made or imposed schedule” (Glaser & Strauss, 1965, p.48), in which timing is essential. Maria, whose mother died due to a haemorrhagic stroke, mentioned:

TABLE 5 Demographics of family members (n = 20)

Family members n = 20 (family units = 14)	
Gender	
Female	13
Male	7
Age	
18–30 years	3
31–45 years	4
46–60 years	8
61–70 years	1
>70 years	4
Civil status	
Married	10
Widow/widower	5
Single	4
Divorced	1
Educational background	
Primary school	6
High school	8
Higher education	6

It was so painful and sad the process. To feel that they still are, but they aren't there in the end. They have gone. Perhaps, only the body is there because she's already gone [...] I believe that when she had the stroke, she left, just at the moment, it happened. Not in the hospital. She wasn't there. It was only her body.

(Interview, Family 3, C1)

Maria draws attention to the ambiguity between the present body and the person known as her mother, who has gone. Families spoke of their loss in terms of splitting body and mind, and it was distressing. Boss (1999) conceptualised ambiguous loss as when the loss of someone is confusing due to an unclear resolution or closure, describing two kinds of ambiguous loss, (1) the person is physically absent while psychologically present or (2) the person is physically present while psychologically absent (Boss, 1999). Theoretically, Maria described the second type of ambiguous loss. She withdrew organ donation authorisation, respecting her mother's last wishes. The families of potential organ donors experience the emotional paradox of their family members being physically present but psychologically absent, with emotions constrained until the confirmation of death.

## 4.2 | Confirming loss

Confirmation of severe brain injuries quickly leads to the diagnosis of death. The organ donation team is either already aware of the case or is contacted by the bedside staff to inform them of the oncoming



TABLE 6 Family subsystems (n = 14)

Families	Hospital setting	Pseudonym	Kindship of potential organ donor	Cause of death	Donation
1	C1	Luisa	Daughter	Haemorrhagic stroke	Yes
2	C1	Juan	Brother	Traumatic brain injury	Yes
3	C1	Maria	Daughter	Haemorrhagic stroke	No
4	C1	Laura	Daughter	Haemorrhagic stroke	Yes
		Hector	Son		
		Irma	Sister		
		Pedro	Husband		
5	C1	Cesar	Husband	Haemorrhagic stroke	Yes
6	C2	Valeria	Mother	Traumatic brain injury	Yes
7	C2	Nestor	Son	Haemorrhagic stroke	Yes
8	C1	Mario	Son	Haemorrhagic stroke	Yes
		Rose	Sister		
9	C1	Victoria	Sister	Traumatic brain injury	Yes
		Nora	Mother		
10	C2	Nora	Mother	Haemorrhagic stroke	No
11	C2	Sofia	Daughter	Traumatic brain injury	Yes
		Samuel	Father		
		Marta	Mother		
12	C1	George	Husband	Haemorrhagic stroke	Yes
13	C1	Sonia	Sister	Traumatic brain injury	Yes
14	C2	Elena	Daughter	Traumatic brain injury	Yes

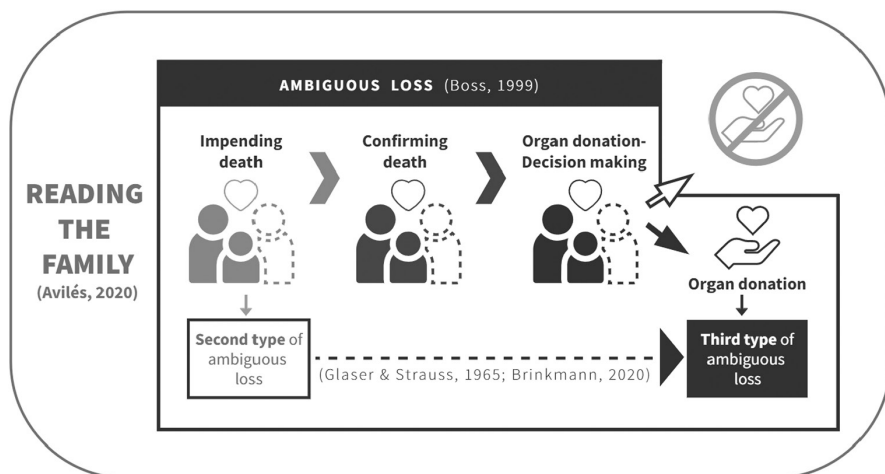


FIGURE 1 Third type of ambiguous loss. Theoretical foundations

fatal diagnosis. Constant communication between staff and families about prognosis continues when either a neurologist or the bedside consultant talks to the family to confirm the death. In this study, all the families reported receiving information throughout the hospitalisation event.

Nora's adult daughter died due to a haemorrhagic stroke, and when recalling the confirmation of death, she said:

The physician told me, 'We need to talk with you. Your daughter is dead. I wrote the death certificate, and now we need to withdraw the life support'. [...]

They said that she was dead; I asked, 'Is she breathing?' 'No. It's only the machine', he replied.

(Interview, Family 2, C2)

Despite constant communication, not all clinicians were perceived as empathetic and understanding of the complexities of families' experiences and even less of the ambiguity. In other words, not all of the staff had the skills to *Read the family* emotionally. Assimilating brain-stem death as the death of the individual is reported as challenging and confusing by families. Berntzen and Bjork (2014), p.271 described in their study of families in Norway that "some healthcare personnel

did not perceive their [families] ambivalence." The lack of awareness of what families feel and experience can hinder the communication process, which is paramount for end-of-life care and organ donation negotiation.

One expert ICU resident reflecting on delivering bad news in these circumstances said:

We deliver the bad news. I mean, the worst news that a family may get is brainstem death. We tried to avoid technical terms to make them understand [...] Once, a family said, 'No, no, it can't be possible!' Obviously, we couldn't continue. We waited for a while looking for another opportunity to talk to them again and they could get it. Sometimes they can't, obviously. It's too sudden.

(Physician 7, C2)

It was clear in the data that some professionals were able to *Read the families* struggling to understand and assimilate the bad news. Some staff reflected on the challenges of explaining the concept of brainstem death and how they define time and support needed for each family, including more time and, on occasion, several conversations. Families struggle with the dying passage because the ambiguous loss is perceived as distressing.

When interviewing another family, Sofia and her grandparents, Samuel and Marta, recalled:

**Sofia:** At the hospital, they let us in, but she was dead already.

**Marta:** She was already dead.

**Samuel:** Indeed, I said some words to her, and tears dropped off.

**Marta:** She got tears. I remember that...I always remember that.

**LA:** When did you say goodbye?

**Marta:** Yes, horrible! I said, 'She is gone, she is already gone'. As a mom, I knew it.

(Focus Group, Family 11, C2)

The ambiguity experienced by families when their family member is physically present while absent is confirmed with the death declaration. The confirmation of death places families in the certainty of the death status, which involves the duality and fragmentation of body and soul (Boss, 1999). References to this ambiguity are also found in similar studies exploring families' experiences. Sanner (2007, p.302) reported a participant saying, "the body was only a shell, and she wasn't there."

Critically, in this study, clinicians help to co-construct this ambiguity when explaining the process and confirmation of death. The following field notes described one family approach, in which the neurologist and organ donation nurses approached a family.

The neurologist explained to the family that by law, their role was to evaluate the person when the damage hasn't a surgical resolution, repeating this a couple of times. The neurologist waited a couple of seconds and said, 'I know that this is terrible,

but after all the examinations, your son is dead'. There was silence. The family said no words. The doctor added, 'Probably he died at the moment of the shooting'. The neurologist repeated the info over and over again [...]. Finally, the neurologist said, 'Please wait a moment here, the nurses should speak with you about the next steps'. He left the room saying, 'I am so sorry'.

(Field notes, Approaching 1, C1)

The neurologist confirmed the death and the ambiguity when explaining that the person probably died at the time of the injury. The person was physically present but absent. Repetition of information aims to stress the message, particularly when the clinician perceives lack of understanding by a lack of reaction from the family. However, he continues introducing the organ donation team. Clinicians perceived these conversations as problematic, fearing family's emotional reactions, and hence, the need for skilled teams to lead these conversations was introduced (Avilés et al., 2021).

### 4.3 | Ambiguous loss and organ donation decision-making

Once families are informed about the death of their family members, organ donation nurses begin organ donation conversations and negotiation of authorisation. Nora was approached after the death of her daughter and refused organ donation. She recalled.

The other day, I saw a child who needed a heart. I watched on TV. But, you know, it was so unexpected the idea of organ donation that, to be honest, I didn't want to accept that my daughter was dead. [...] It was so sudden! I was shocked.

(Interview, Family 10, C2)

The shock of losing someone close and the absence of conversations prior to death surrounding organ donation wishes can prevent the thought process of anything beyond the death of the family member. Organ donation nurses are aware of these challenges and employ edgework emotion management (Avilés et al., 2021) to change the family focus on death to a positive memorial of the family member's life. Observing family approaches, one of the field notes describes.

The organ donation nurse asked them (to the family), 'How was she?' The family began to talk about their work (the patient). A loved, kind and pleasant person. The family were smiling by recalling.

(Field note, Approaching 2, November 2017, C1)

Using open questions with the past tense, such how was she/he? Organ donation nurses highlight that their family member is dead and foster families to shift their emotions from sorrow to cherished

memories of the deceased person. By doing so, organ donation nurses can read and manage families' emotions after the loss of a family member as a critical process to beginning organ donation conversations. The complexities of these encounters emphasise the challenges of protocolising the approach, and some scholars have drawn attention to the family's specific practices (Danet et al., 2020; Jensen, 2016).

To continue, the skilful organ donation nurses explore existing donor's will and attitudes towards organ donation. If it was not clear, organ donation nurses support families' decision-making process by providing information. The importance of family knowledge, emotions and stance on organ donation conversations is paramount because nurses embrace these negotiations as a family matter.

The process within the family regarding organ donation has always been very, very much embedded in the family. Therefore, it wasn't anything new for us [...] Every time during family meetings, she pointed out, 'The day that something happened to me, I want to donate my organs'. Hence, all the family was very clear about it.

(Interview, Family 7, C1)

Families who knew about the potential donor's wishes tended to respect their will (Sque et al., 2018), and this knowledge influenced negotiations. Studies have reported that when these prior family conversations were absent, dilemmas and uncertainty could be experienced (de Groot et al., 2015). In this study, the prevalence of these prior conversations was noted; however, organ donation nurses always explained the process fully and tailored it to the family's questions and reactions. In other words, based on how nurses read the family's emotions.

The coordinator explained the procedure, the legal process to carry on, and the signatures necessary to proceed with the organ donation [...] The coordinator spoke slowly and looked at family reactions.

(Field note, Approaching 4, December 2017, C1)

The difficulty might increase depending on how families of potential organ donors deal with the ambiguity. Family members from two different families, Laura and Cesar, asserted that:

After we said, what if my mother didn't want this? It doesn't matter anymore. She wasn't in that body, and we said, 'It doesn't matter'. I am sure that my mum is happy to have helped two people!

(Interview, Family 4, C1)

We know that a part of her is somewhere... It was an act of nobility of my children, first! Because she wasn't there anymore

(Interview, Family 5, C1)

Laura and Cesar refer to the ambiguity of their loss by referring that "she was not in that body." Families alluded to the philosophical underpinnings of the sense of personhood and its social life implications (Seale, 1998; Thompson et al., 2016). When families describe the ambiguous loss in the decision-making process, it can be, (1) the ambiguity allows the family to embrace the decision-making process, and (2) the decision to donate makes the family member to be present in the social life by helping others.

Elena donated the organs of her father after an accidental traumatic brain injury and recalling her decision, she said:

Well, it's surprising to know that my father, despite his age he had his organs in good form. It's impressive! [...] The accident was so violent that it was quite impressive that he survived until the hospital. He would've died just there. Perhaps it helped to say goodbye and being prepared. Plus, to donate his organs!

(Interview, Family 14, C2)

Elena highlights her father's survival to hospital admission, which allowed the family to say goodbye, be prepared for the impending death and eventually donate her father's organs. Discussing organ donation as a possibility emerged in her narrative as a positive outcome of the situation. Negotiating organ donation is a dynamic process, and staff become essential in supporting families within these encounters.

The family also evolves quickly. They can be very convinced of their decision, and suddenly a click and everything can change. A shift that one should be attentive to perceive it.

(Organ donation nurse 7, C1)

The role of emotions in the organ donation decision-making process is not new (Sanner, 2007; Sque et al., 2018; Walker et al., 2013). López et al. (2018) explicitly relate family emotions and decision-making.

Relative's emotional reactions would indicate their capacity to cope with their loved one's death and the degree to which the death is accepted. Intense emotional reactions and the denial of death will hinder the consideration of donation and will thus be negatively related to family consent. On the contrary, controlled reactions and death acceptance may be related to higher consent rates.

(López et al., 2018, p.41)

López et al. (2018) suggested a critical but taken-for-granted idea that loss, emotions and decision-making are intrinsically related. Brinkmann (2020) proposes grief as a fundamental emotion as the responsive understanding of losing a loved one. He states, "[g]rief as an embodied emotion is not separate from the situation, rather deeply

embedded in the context of the lifeworld and the entirety of the material culture surrounding death and bereavement" (Brinkmann, 2020, p.114). Data across families could be explained by understanding grief as an emotion. An emotion that can be so intense that families are unable to articulate anything else and potentially refuse as a way of terminating communications and focussing only on their loss.

In this study, the analysis of the data revealed a delicate change in the emotional state of families when authorised organ donation, which is sensed and perceived by those who share, who stay, who *Read the family* in this context. This change in the emotional state led to donor families' experiences to another transition, a transition defined by decision-making.

For instance, I remember a case [...] The family was able to despite the sorrow, they felt that despite the tragedy of their loss, they could symbolise into 'We can give something, something that makes others live!' This case was like a perfect example. Not all of them were exactly like this, but all of them elaborated it, signifying the death amongst 24 or 48 hours and then they get...peace.

(Psychologist 1, C2)

Emotions are the language when words cannot be said due to the loss of someone who was loved. Families in this study spoke about their experiences of loss, how these emotions were managed by staff and how they made sense of their experiences. Theoretically, understanding how families of potential organ donors experience their grief as a fundamental emotion is also linked conceptually to the importance of *Reading the family* and the complexities of approaching families in this context. More importantly, it highlights the importance of specialised training for staff who support these families due to their potential consequences for families' experiences and care.

#### 4.4 | Organ donation as a third type of ambiguous loss

Donor families might transit between the second type of ambiguous loss described by Boss (1999) and another kind of loss when authorising organ donation. The narratives associated with organ donation, "saving lives," might influence how families experience the decision-making process and, finally, how they refer to their loss. Laura's family reflected on their decision.

**Pedro::** If we think objectively! She is here with us because of it.

Therefore, we helped, but also, we are helping ourselves as well because we did something that. I think that she is here, she agreed, and she is happy about what we did.

**Irma::** She is proud of it.

**Pedro::** I think so.

**Irma::** She is proud of her family and what they did, the decision [...] Life was given to another person! It is beautiful, so virtuous, and

so noble. Noble because my sister was, was. She is a woman. She was and will be! For me, for me, my sister has not died (smiling and looking Pedro, Hector and Laura). Always a good woman.

(Focus Group, Family 4, C1)

Organ donation nurses approach families at a time when the loss is often perceived as meaningless. Moraes et al. (2019, p.1543) point out that "[o]rgan donation offers comfort, because it redefines the unexpected loss of a loved one." However, families in this study went beyond. Irma, from Family 4, stressed that the presence of her sister was not only metaphorical, stating, "for me, my sister has not died." Families repeatedly spoke of a dissociation between body and mind, resonating with Boss' ambiguous loss (Boss, 1999), but transiting to a third type when consenting to donation. Some field notes are described.

The organ donation nurses thanked family's donation. They said several times, 'She will give life to many people, helping them as nobody can. We thank you, truly, we thank you on behalf of all benefited people'.

(Field note, December 2017, C1)

The narrative and metaphors employed by organ donation nurses are also in media campaigns and public policies emphasising organ donation as a social good (Ministerio de Salud Chile, 2021). Informative flyers include the phrase "I give life" on the front page (Document, Flyer1, C2), which aims to stimulate family discussions on organ donation before the need for a decision arises. Organ donation nurses' communication with donor families continues well beyond the original event and includes acknowledgement letters. It can contain information on the number of benefited people, an invitation to commemorating ceremonies and Christmas cards. One of the acknowledgments letters included the following poem.

Remember me – I will live forever  
When my life had finished, take my body and give  
everything that helps others to live fully.  
Give my eyes to someone who has never seen the  
dawn, a kid's face, a beloved woman's face.  
Give my heart to someone whose heart has made him  
suffer [...] If something is left to be buried, my sins, weaknesses  
and prejudices would be. Give my soul to God'  
(Anonym).

(Document, Christmas card 2014, C1)

The language is evocative and shifts the meaning of death by emphasising the continuation of the life of another person. Donor families reframed their loss based on these meanings and social discourse. Although donor families spoke of their deceased family member as dead and buried, the person is psychologically and physically present through the organs donated, living in another person's body—the *third type of ambiguous loss*. Sofia's family described.

**Sofia:** She is still here in the end.

**LA:** What do you mean?

**Sofia:** I mean, she keeps giving, giving her organs. She is still here. Well, for us, she always has been here no matter her organs. But a part of her is on this earth, in some people, but here.

**Sonia:** Her body, in other words.

**Samuel:** A part of her body.

(Focus Group, Family 11, C2)

In this study, families signified the organ donation decision-making in two ways: (1) to help others through transplantation and (2) to keep their family members alive through the donated organs. The meaning is deeply embedded in the resistance to accept that their life together with their loved ones has been lost. Brinkmann's (2020) conceptualisation of grief as a fundamental emotion implies the ontological loss of someone who is no longer in this world but was loved. Understanding grief as "an embodied state, an intersubjective form of communication and something deeply embedded in the social processes of culture" (Brinkmann, 2020, p.8) could explain the loss of families in organ donation and in the context of end-of-life care.

**LA:** How's the grief been for you?

**Elena:** Um...How do I experience it?

**LA:** Yes.

**Elena:** It's like. He isn't dead! No. He isn't dead. He's with me. I feel it. [...] I felt pleased when I did it, to donate his things to help someone else living. Sometimes I imagine that a piece of him is going around. His organs helped four people, just my father. So, it's something incredible. If it'd happen again, I'd do it at once.

(Interview, Family 14, C2)

The *third type of ambiguous loss* explains donor families' experiences. Families spoke of the donor as physically and psychologically present in the recipient's body. As mentioned, these descriptions are neither new nor isolated in the literature. The reports of "part of my son lives on" (Exley et al., 2002, p.49) are frequent in studies of donor families (Manzari et al., 2012; Sanner, 2007; Sque et al., 2018; Sque & Payne, 1996). Families refer to their family members living on not only metaphorically, but real for them, which generates solace and meaning. Boss (1999) has described that families who experience their loss as ambiguous suffer significant distress, and often struggle to deal with the ambiguity generated. However, in this study, donor families have learnt how to live with the paradox of the *third type of ambiguous loss*.

**Sonia:** I know that I'll never meet that person. I know. But it's enough to know that he saved someone's life, and he did well to others.

**LA:** What do you think about that?

**Sonia:** Well, I always hope to know more about the person (recipient). I think so. I'd like to know who got a piece of him. I'd love to know.

(Interview, Family 13, C1)

Often families expressed their willingness to know the recipients, despite the legal restriction of this information in Chile. The anonymity of the deceased donor is a norm in many countries despite numerous suggestions to facilitate contact between donors and recipients in the context of professional support (Galasiński & Sque, 2016). In this study, donor families questioned these limitations. The ambiguity of keeping a part of their family member alive may evoke the willingness to maintain contact with the living part.

A family, recalling one commemorating ceremony at the hospital, mentioned.

**Victoria:** Some recipients were there.

**LA:** How did you feel about it?

**Rose:** My heart jumped. I cried a lot: I'm a weeping type of person.

**Victoria:** Indeed.

**Rose:** I cried. I didn't know if we did it right. I think that I did it right, but I believe that the process should have an end, at least. No thanks to us. But to close the process. Meeting the person and knowing that the person is happy or enjoying their life now.

(Focus Group, Family 9, C1)

Although most families seem to cope with the ambiguity, not all families do; hence, careful consideration is needed. Complexities due to the philosophical implications of dealing with an ambiguous loss could explain why some families refuse organ donation as a way of terminating the process and unifying body and soul.

When families were asked about the meaning of their loss, Elena said.

When talking with my daughter, she says, 'Where would my grandpa be? [...] It's the curiosity. I don't want to know the name specifically of the person, but whether the organ was rejected. If it was rejected (the organ), he doesn't exist anymore. But we gave four (organs). For sure at least one of them remains here.'

(Interview, Family 14, C2)

When Elena says, "[i]f it was rejected (the organ), he doesn't exist anymore," the implications of the ambiguity are clearly expressed. The *third type of ambiguous loss* explicitly involves the donor's existence through their organs. The person is dead, yet psychologically and physically present through the organs donated to the recipient. The ambiguous loss of donors' families can be grounded and embodied in the belief that body, soul and spirit constitute what a person is. Therefore, how conflictive the *third type of ambiguous loss* would depend on how families manage to emotionally unify body, soul and spirit.

## 4.5 | Limitations

The study limitations are referred to its specific cultural context, and thus, transferability of this grounded theory needs to consider any

other cultural context before applying. This study explored the experiences of families who were approached for organ donation after brainstem death (DBD) authorisation only, and the transferability of this grounded theory into different cultural and clinical contexts, therefore, requires further research.

## 5 | CONCLUSION

Using grounded theory, a theory was developed to theoretically explain families' experiences as a social process. The third type of ambiguous loss for donor families implies that despite the death of the individual, the donor is physically and psychologically present through the organs donated in the recipient's body. Identifying the loss as ambiguous could explain the complexities of families' decision-making process for organ donation authorisation and how they maintain the bond as a cultural representation of relationality and connection. Families reframed the existence of the donor and signified the loss through the act of giving lives as an intersubjective connection with the person lost, who is embodied in the organs donated and embedded in the family's social life even when the person's life had gone (Brinkmann, 2020). This study critically advocates for further research in other contexts to better inform strategies for practice, education and policymaking. Particularly, when legal changes across the world are shifting into individual decision-making processes, overlooking family's experiences.

## 6 | RELEVANCE TO CLINICAL PRACTICE

The findings contribute to nursing knowledge, practice, education and policymaking in the field of organ donation and transplantation. The third type of ambiguous loss, extending Boss' (1999) work, can shed light on better and more sensitive ways to care for families in the context of organ donation. However, it also emphasises a decision-making process further complicated than expected and described in the literature (Long et al., 2008; Sque & Payne, 1996; Walker et al., 2013). The need to incorporate the deceased into social life through the idea of retaining the self has been associated with one of the factors that influence organ donation (Moraes et al., 2019), and it could also explain why some families withdraw authorisation.

This study demonstrates that the death of a person, within the Chilean context, is experienced as a family affair and must be understood as part of nursing practice and ethics. A close relationship, continuous communication and support to families are essential processes because how each family embraces and conceives the ambiguity can play a role in the decision-making process. The implications for practice include strengthening a family-centred care approach, specialised training and careful considerations regarding rituals to illustrate the dying transition for families in this context (Berntzen & Bjork, 2014).

Training in communication, organ donation process, grief and management of emotions for staff are strongly suggested (Avilés et al., 2021; Brinkmann, 2020), emphasising the challenges of encountering families and negotiating organ donation authorisation (Danet et al., 2020; Darnell et al., 2020). The level at which both staff and families relate and manage those emotions in the interactions may critically determine the process and the outcomes (Darnell et al., 2020; López et al., 2018).

In terms of policymaking, these findings advocate considering family refusal as part of these complexities and not to be seen as a failure of the process. This is essential when there is a current emphasis on organ donation rate indicators to assess and evaluate the process, in which the complexities of the family approach are absent and should be considered carefully (Avilés et al., 2021).

The implications of the study might also affect the potential contact between families and recipients. In Chile, information regarding recipients is banned by law (Ministerio de Salud Chile, 2021), an aspect that was challenged by some families in this study. Although some scholars suggest facilitating the contact between donors and recipients in the context of professional support (Galasiński & Sque, 2016), the potential attachment that families could have to recipients and the psychological disturbance for both groups are also reported (Berntzen & Bjork, 2014; Kentish-Barnes et al., 2019; Sque & Payne, 1996). A consideration is even more relevant when the third type of ambiguous loss implies philosophical and fundamental notions of the existence of their loved ones for donor families; thus, further study of these complexities is needed in other clinical and cultural contexts.

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## CONFLICT OF INTEREST

The authors declared that they have no conflict of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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