Relatives’ experiences of loved ones’ donation after circulatory and brain death. A qualitative inquiry

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Abstract

Background: Little is known about the donation-related experiences of relatives of donors after circulatory death.

Objective: The goal of this research was to explore such experiences, and to capture donation after circulatory death’s (DCD) distinctive features by contrasting them with experiences of relatives of donors after brain death.

Design: An inductive, theory-building approach based on qualitative interviews was used.

Participants: Participants were deceased donors’ next-of-kin who were involved in the decision to donate.

Results: We found that the assumption of responsibility for the deceased person’s organ donation was accompanied by questions about meaning and guilt for the deciding family member(s).

Conclusions: In conclusion, the similarities between the donation-related experiences of DCD and donation after brain death (DBD) families outweigh the differences. Our recommendations are that health care providers should provide relatives with support and a follow-up to make them feel more confident with the donation decision. Family conferences are an evidence-based tool to improve the care of moribund patients and should be implemented during the donation process and possibly during the follow-up.

Key words: donation after brain death, donation after circulatory death, ethics, qualitative research, transplantation.


Introduction

Organ donation is a widely accepted method of combating chronic organ failure. In Switzerland [1], the US [2], as well as in other parts of the world (UK [3], Germany [4]), there is a shortage of transplantable organs. Increasingly implementing DCD may impact donation rates positively. Physicians wait a defined time while observing a no-touch policy, generally 2–5 minutes [5], after circulatory arrest and then remove the organs. Regarding the effect of DCD on donation rates, the number of DCD donors has increased since the re-introduction of DCD in Switzerland in 2011 (3 in 2011, 7 in 2012, and 12 in 2013), however, there has been no clear upward trend in the total number of donations during this time [1]. In the UK, however, the number of DCD donors has been increasing year-by-year and had a positive influence on the total number of deceased donations [6].

At the University Hospital Zurich, a pioneering institution in Switzerland in this regard, DCD was re-introduced in October 2011 following a six-year stop that was due to ambiguities in the wording of the 2007 Federal Act on the Transplantation of Organs, Tissues and Cells [7] (Act). There were also contradictions between the 2005 medical ethical guidelines of the Swiss Academy of Medical Sciences pertaining to the diagnosis of death in organ transplantation [8] and the Act. A legal opinion [9] was published in 2010 which stated that controlled DCD was compatible with the Act. Also, in 2011, the Swiss Academy of Medical Sciences published revised medical-ethical guidelines concerning organ donation and including DCD [10].

In Switzerland, physicians wait 10 minutes without resuscitative measures after circulatory arrest and then diagnose brain death secondary to circulatory arrest, which is verified with cardiac ultrasound. Brain death is diagnosed clinically (coma, areflexia, and apnea [11, 7]). Death for the purpose of deceased organ donation is defined as brain death in the Act. DCD in Switzerland must include a secondary brain death determination. According to the Act, organs, tissues, or cells may be removed from deceased persons if those persons agreed to this before their death, if their relatives are aware that the donor wanted to donate or if they believe that the donor would have wanted to (substituted judgment).

DCD is not free of ethical controversies [12–17]. Although in Switzerland all DCD donors are also diagnosed as being brain dead before organ recovery, the ethical issues described in the literature may still arise; clearly the procedures before death differ in many regards from the procedure in donors after primary brain death.
DONATION AFTER CIRCULATORY DETERMINATION OF DEATH

DCD is frequently presented as an alternative to DBD. No published follow-up of DCD donor relatives exists to date, except for one study in the pediatric setting [18]. Our goal was to better comprehend the perspective of DCD donor families to improve the donation process. To aid in this understanding, we also studied the experiences of relatives of DBD donors. There is a body of literature on their experiences [19–22], but hardly any data on the Swiss context is available [19]. The information on donor experiences is important to build the re-introduction of DCD on an ethically sound basis. High quality standards, as well as high ethical standards, are important in the area of organ transplantation, because this enterprise is highly dependent on the public’s trust.

Materials and methods

We chose a qualitative approach because our study focuses on donors’ next-of-kin’s subjective experiences of donation. This way, we attempted to “document the world from the point of view of the people studied” ([23], 165). Instead of focusing on the questions “what? and how much?” we focused on answering the questions “why?” and “how?” [24]. Due to the exploratory nature of the study, we used an inductive, theory-building approach to the data.

Next-of-kin of DCD and DBD donors who donated between 1995–2005 and 2011–2012 were contacted and asked to participate by the transplant coordinators of the University Hospital Zurich via a letter. The donor did not have to have donated at the University Hospital Zurich, but what was common to all donors was that the transplant coordinators of the University Hospital Zurich oversaw their donation (some donations did not take place at the University Hospital, but at affiliated peripheral hospitals). If the relatives agreed, they contacted the first author to plan the interview. Of the total of 57 DCD donor families, 36 addresses were found. Seven interviews were performed, one with a couple. Of the total of 118 DBD donor families, 48 addresses were found and 11 interviews took place, one with a

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Table 1: Demographics
couple. We were thus able to interview nearly one in five contactable donor families for both types of donation. Data were collected between April 2013 and September 2013. The authors used focused interviews to gather the data. This interview type is used to interview persons who “are known to have been involved in a particular situation: they have seen a film, […] taken part in […] an uncontrolled, but observed, social situation” ([25], 3). The interview guide was developed on the basis of the analysis of the social situation and we wished to learn more about the subjective experiences of participants. The interviews aimed to fathom how the participants perceived the situation. The first part of the interview guide was narrative to open the field to participants. Our aim was to foster retrospection, so that the participants recalled how they reacted to the situation at the time. This article presents the results and the analysis of the first part of the guide.

All interviews were digitally recorded and transcribed verbatim. Interviews lasted an average of 60 minutes (40–82 minutes) and either took place at the participant’s home (8 interviews) or at the Institute (9 interviews). We used MaxQDA2 to code the data. The transcribed data was first subjected to open coding, where the codes were based on the data. Open coding was followed by axial coding, which aims to “sort, synthesize, and organize large amounts of data and reassemble them in new ways” ([26], 60). The coding paradigm ([27], 96) consisting of conditions, context, strategies and consequences was used to relate subcategories to categories. The last step was selective coding, when a central core category was found that brought together all the subordinate categories under its patronage.

**Quality of qualitative data**

Due to the low yield of participants, we could not sample purposively or theoretically, but had to use a convenience sample consisting of all donor relatives willing to participate. Saturation was reached in the DBD branch as opposed to the DCD branch. To ensure reliability of the analysis, the interview outline was pretested, the interviewer (first author) trained, and inter-rater reliability checks on the coding of answers conducted as suggested in Silverman ([28], 365). The first author coded all the data, whereas the other authors coded parts of it to compare how the data were analyzed by the different researchers. For validation, we used analytic induction to generate hypotheses that were grounded in the data. We also used comprehensive data treatment. In terms of attending to the context and trustworthiness, we guarded against anecdotalism by reflecting as a group on whether the examples were typical for the situation encountered. The data was collected directly from donors’ relatives. Reflexivity was taken into account as well.

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2 www.maxqda.com: Qualitative Data Analysis Software.

**Ethics**

We adhered to the ethical principles set forth in the Belmont Report and the Declaration of Helsinki. Ethics approval was obtained from the Cantonal Ethics Commission Zurich. The study number is KEK-ZH-No. 2011-0201. Informed consent was given (verbally and in writing) by all research subjects prior to their inclusion in the study. Participants were made aware that consent could be withdrawn at any time. Low-threshold safeguards were in place to aid research subjects who could potentially have been distressed by participation in our study, and participants received information on how to access them. However, none of the participants required any aid.

**Results**

We looked at our results through the lens of the coding paradigm. “Having to take responsibility” was found as the condition that caused the phenomenon to occur. “Inhibiting and promoting factors as the basis of taking responsibility” were the contextual factors that portrayed the specific set of characteristics belonging to the phenomenon. Strategies for dealing with the phenomenon were “taking joint responsibility for the decision and looking for meaning” and the consequences of actions and interactions done in response to the phenomenon were “having to live with the decision in the future with retrospection alternating between meaning and blame”. The last step was selective coding, when a central core category was found that brought together all the subordinate categories under its patronage. The central phenomenon of our research is “assuming responsibility for the deceased one’s organ donation is accompanied by questions about meaning and guilt”.

**Conditions**

Most of the donors did not have an explicit wish to donate. It was seen that the next-of-kin had to take responsibility for their loved one’s organ donation.

“Then I had to always say to myself: How would M. act? And then I knew what to do // you knew it, yes // Then I knew it!” Int. F, DCD

“It was more about the question who has the right to make a decision for this person or for the content of this person. And this now is the wrong word, but who has the competence to decide over the ownership of this body of this human being.” Int. I, DBD

Though processes are different and in case of DDB brain death diagnosis may be undertaken before palliation is discussed – thus eliminating the need to decide whether to discontinue mechanical support – DCD and DBD donor families often felt they had to make the fundamental decision to discontinue such measures. Relatives did not clearly differentiate between the decision to switch to palliation and the decision to donate, although from an ethical point of view, these two decisions are different and have to be kept separate by the team.
Another major factor in the decision to re-direct care was the donors’ future quality of life and whether the next-of-kin and the physicians thought the situation was hopeless. Interestingly, both types of donor families referred to the donor’s future quality of life, although DCD donors were actually brain dead, whereas DCD donors were severely brain-damaged and may have had the potential to live on, albeit severely disabled. Relatives of DCD donors hypothesized how they and how the donor would have been able to live with severe disability. DBD and DCD donor relatives also differentiated between the doctors as professionals and themselves as laypersons and emphasized how they had to trust in what the doctors said. Thinking that the donor would have wanted to donate was another factor in the decision that the next-of-kin had to consider. No meaningful differences in the conditions for DCD and DBD donations were found.

Contextual factors
The next-of-kin’s ability to shoulder the responsibility was affected by modulating factors, which are described below.

“But fundamentally, I had confidence [in the doctors]. One couldn’t believe it visually at all, M. was lying in bed, warm, nothing wrong with him, and they say he is almost brain dead // or was brain dead // or is already, yes, one couldn’t believe it.” Int. C, DCD

“That is not – those weren’t routine people back then. They did their job, they probably knew how to fix this and that, but they reached their limits, for sure. But due to that, I don’t know if it, I believe, through feeling that they were human and cared, one also had confidence in them.” Int. L, DBD

Generally, in the donation situation the next-of-kin were in exceedingly exceptional circumstances, often feeling overwhelmed and paralysed. In that situation, they deemed authentic sympathy of medical personnel helpful. The next-of-kin’s and, if known, the donor’s attitude towards a life “on machines” shaped the family’s willingness to end mechanical support. The discrepancy between the appearance of the donor and their actual condition and the fear of seeing the effects of donation on the donor made donation harder for family members.

Strategies
Next-of-kin had specific strategies for dealing with the responsibilities they had to shoulder and coping with donation: Taking responsibility jointly and looking for meaning in their actions.

“Yes it – it is clear, if one can say: it made sense, it at least made sense // yes // One could give this person back his eyesight, or one could prolong that one’s life with uh, he didn’t have to go to dialysis anymore.” Int. H, DCD

“A relief. A relief. I thought, now my darling can do something good. That sounds macabre and whatever, but for me it was right. It was an aid, like a walking stick. For my heart, my heart, or I should say my soul, it gave the certainty that what he did is good.” Int. K, DBD

Next-of-kin of DCD and DBD donors shared strong feelings of hope before death was diagnosed or palliation decided upon. Donor characteristics relevant to donation were praised, e.g., that being able to help others was important to the donor. Donation was employed as a means to give the otherwise senseless death meaning. Trusting physicians to do the right thing was a strategy that was used by both types of relatives when dealing with the responsibility for the decision to end mechanical support and donate vital organs. Flexibility of the ICU personnel and responsiveness to the needs of next-of-kin was viewed positively.

DCD and DBD donor families differed in that DBD families mentioned specific strategies to say goodbye to their loved one, e.g., creating keepsakes, saying goodbye to the deceased person after donation and perhaps even bidding farewell to the laid-out deceased person instead of saying goodbye in the operating room. DCD families did not bring up any strategies to bid farewell to their loved one.

Consequences
A consequence of donating was that relatives had to live with the decision in the future. Retrospection alternated between seeing donation as giving meaning and meting out blame for the donation decision.

“I live with the fact that my son helped. And that is okay for me like that. Because otherwise I would be completely unable to bear it.” Int. L, DBD

“And as I said I bear a bit of a grudge to the other son, Because he agreed to everything [donation] so quickly.” Int. D, DCD

DCD and DBD next-of-kin found that certainty pertaining to the donation decision and having aided someone through donation was helpful when looking back. Retrospetion was difficult when next-of-kin were unsure if they decided correctly (ambivalence as to whether the donor would have wanted to donate) and when donation could not be discussed with others due to fear of their reaction. After donating their loved one’s organs, donors’ relatives appreciated the importance of advance care planning, as it would have been helpful to them in the pre-donation situation. Also, next-of-kin required a lot of information about the donation process after donating and often wished to know if the transplantation was successful.

For relatives of DCD donors, donation could cause a shift in the relationship with other relatives in that blame was sometimes assigned within the family for donation. DCD donor families had difficulties with troubling media reports on brain death. Difficulty understanding their loved one was dead was an important theme for DBD donor families. Some DBD donor relatives blamed themselves for having allowed donation and thus possibly being at fault for their relatives’ death.
Synthesis

Through a careful coding process, we arrived at the central, unifying phenomenon of our research: “Assuming responsibility for the deceased one’s organ donation is accompanied by questions about meaning and guilt.” This phenomenon is common to both donor relatives’ experiences. It was found that the similarities between the experiences of the two types of donor relatives outweighed the differences and that the exact form of donation – whether DCD or DBD – was not so important in their memory.

Discussion

Strengths and limitations

A strength is that this study is the first to look in-depth at the experiences of adult DCD donors’ relatives. A study focusing on experiences of DBD donor and non-donor families was published in 2007 [19]. The findings of our study were complemented by the results of other studies. Another strength of this study is the direct comparison of the experiences of DCD and DBD donor relatives. A limitation was that saturation was not reached on the DCD branch of the study. This was due to the low number of addresses that could be found and the low participation rate. Due to the lack of saturation, we might not have a “full picture” of the experiences of DCD donor relatives. It is possible that further interviews would have revealed relatives’ concerns or comforting factors that have now remained undiscovered. We were unable to sample purposively or theoretically, which would have increased transferability and trustworthiness ([28], 388). However, we were able to interview a considerable proportion of contactable relatives. We did not pursue relatives who did not volunteer to participate out of respect for their privacy. Thus, a potential bias is that we may have overlooked concerns of such relatives. There may be a selection bias, as well as a recall bias amongst participants. Finally, our study only includes donor families, as we could not reach non-donor families. Their addresses are not routinely stored, and a newspaper appeal with consequent snowballing was unable to generate enough participants. Therefore, the experiences of non-donor families could not be illustrated in this study.

Conditions

We found that relatives frequently spoke about having had to take responsibility for the donation decision. They were influenced by their belief that the donor would have wanted to donate. This corresponds with the 2007 Act, where the relatives do not have decisional autonomy, but must reflect on what their loved one would have wanted (substituted judgment). However, most interviewees were confronted with this decision before the Act was introduced. In the absence of a federal law regarding transplantation, the 1995 guidelines of the Swiss Academy of Medical Sciences already stated that relatives should aim to make a substituted judgment regarding donation [29].

Relatives viewed donation as a means to give a “senseless” death some meaning. Having been able to help someone was viewed as helpful. In their 2007 study, Siminoff et al. [30] show that the most frequently stated “reason for donating was altruism” (p. 971), and that most “family decision makers said they donated [...] because the family had explicit knowledge of the patient’s desire to donate, or because they were confident that this would have been the patient’s preference” (p. 971). Hoover et al. [18] illustrated that “wanting to make something good out of the tragedy of their child’s death” (p. 107) was a factor that contributed to parents’ decisions in the donation process. Siminoff et al. ([30], 977) found three reasons for donation: “altruism, knowing that patients wanted to donate, and donation as a coping strategy”. As described above, the expected quality of life of the donor was another important factor in the decision to switch to palliative care and consider donation. This was also reflected in other studies, e.g., a study found that “the risk of surviving with brain damage appeared to be of greater concern to some family members than the fear of death itself” ([31], 257).

Contextual factors

Contextual factors include factors modulating the willingness to donate. The extraordinary circumstances in which the donor families found themselves made dona-
tion difficult. This was also illustrated by Hoover et al., where family members characterized the experience as a “blur” (p. 108) and described “their shock and difficulty coping with [...] sudden unexpected death” ([32], 108). We found that relatives deemed authentic sympathy of medical personnel helpful. Rodrigue’s study ([32], 497) shows that “healthcare providers’ [demonstrating] respect, sensitivity and empathy regarding the family’s tragic circumstances” leads to increased discussions about donation with healthcare providers and donation consent. Relatives in our study were concerned about seeing the effects of donation on their loved one. This fear was also visible in the 2007 study by Siminoff et al. ([30], 973), where relatives were worried “that donation would disfigure the body and/or preclude an open casket funeral”. In the study by Sque et al. [33], concerns about the integrity of the dead body were the main reason for declining donation.

Besides concerns about the disfigurement of the donor’s body, relatives had difficulties understanding that, despite the donor’s intact appearance, she was so terribly injured (DCD) or even dead (DBD). This is aptly described in Sque and Payne’s 1996 article on Dissonant Loss ([34], 1362), where they describe how “[i]t was therefore difficult for participants to equate death with the appearance of the relative [...]”. In the study by Long et al. on conflict rationalization [31], Long states that “in case of family members, the conflict results from the way the body looks, which is counter to their perceived expectation of a deceased body” ([31], 258ff.). In the 2008 study by Sque et al. [35], the use of visual information aids was deemed helpful and had a lasting impact on the participants who experienced their use. In general, Sque et al. found that information that was given in a complementary fashion and was responsive to individual needs “appeared to have an impact on the quality of information remembered at each interview time point” ([35], 544).

**Strategies**

An important coping strategy of donor relatives was to emphasize the positive aspects of donation. They also composed strategies to deal with the responsibility for the decision they had to make, such as letting specialists help with or even make the decision to donate. Flexibility of ICU personnel and their responsiveness to the needs of the donor’s next-of-kin were viewed as helpful for relatives in the donation situation. Knowledge of the donor’s advance directives was useful, too. Similarly, in the study by Sque et al. ([35], 544), it was shown that “concrete or discursive knowledge of the deceased’s donation wish [and] the chance to give meaning to the death, [...]” were key factors for relatives. Siminoff et al. [30] show that mistrust of the health care system was a reason to refuse donation. “Healthcare providers demonstrating respect, sensitivity, and empathy regarding the family’s tragic circumstances” caused families to be more likely to discuss donation and was more likely to lead to donation consent ([32], 497). As Kesselring et al. say ([19], 214f.): “Behavior centred both on the patient and on the surviving family members’ own needs” made relatives feel more acknowledged.

Sque et al. found that transplant coordinators were very aware of bereavement support in the sense that they understood the family members’ need for contact with, and mementoes of the deceased [35]. DBD families in our study mentioned much the same need, while DCD families did not bring up any strategies to say farewell to their loved ones.

**Consequences**

We found that retrospection on donation was difficult in the case of ambivalence towards the donation decision and when next-of-kin could not discuss having donated their loved one’s organs with others for fear of their reaction. In the study by Burroughs et al., support from staff, family and friends is noted for being “critical to the development of a confident and comfortable feeling about the final decision. It is important to note that this support does not end at the time of the decision, but needs to continue into the future. People need reassurance that they did the right thing” ([36], 161). De Groot et al. hypothesize that “support in exploring the relatives’ values and the deceased’s wishes can lead to stable decisions” ([37], 1196). Another study [38] showed how devastating negative feedback by others to donation could be for relatives – causing “distress, demoralization and regret for all family members” (p. 661) – as well as illustrating the uncertainty and dissonance families sometimes suffered regarding the donation process.

Regarding relatives’ difficulties understanding that the donor was dead, we found parallels in the study by Moraes et al., where participants believed that death was due to organ removal. This “reveals the non-acceptance of brain death as real death” ([39], 462). We found that family members were unable to process the information given during the donation proceedings due to stress and shock and afterwards still required information on them. In the literature, being given sufficient information was noted for being “critical to stress and shock and afterwards still required information on them. In the literature, being given sufficient time in an unpressurized manner to absorb the information they were given (at the time when the decision to donate had to be made) was associated with family members giving consent for donation [40, 41]. Also, the “role of unanswered questions became increasingly important over time, whether the questions were about the nature of the brain injury, heart attack or road traffic accident” ([35], 544). Another point in our study was that the family members wanted to hear about the suc-
cess of donation or at least hear from the recipients. The study by Exley et al. similarly illustrated that donor families "indicated that they would have liked more information and/or contact with recipients" in response to the question what they would change about their organ donation experience, if they could ([42], 49). Here one can see the importance of good and continued communication between health professionals and the donor families. Nowadays, in Zurich, transplant coordinators stay in touch with donor families and conduct a follow-up interview with them several months after donation. Although in Switzerland, donors and recipients must remain anonymous to each other, the family of the donor as a rule may be informed about the recipient’s well-being at any time.

Conclusions and policy implications

In our study, the similarities between the experiences of DCD and DBD donors’ relatives outweighed the differences. This may be in part due to similarities in procedures between the two types of donation. For example, DCD donor relatives as a rule said their goodbyes in the ICU in an unhurried fashion, before life-support was discontinued and saw their relatives again after explanation, outside of the operating room. DBD donors also said their goodbyes in the ICU. This may explain the similarities in the experiences of the two groups. In terms of the ethical challenges they present, DCD and DBD do differ. However, as seen in this body of research, the exact donation type did not remain prominently in the memory of DCD donor relatives, especially in the cohort from 1995–2005. Whether this is due to a lack of information at the time of donation, the extreme stress situation in which relatives find themselves and the complexity of DCD donation, or whether the distinction is not important to them remains the subject of future research.

We found that the relatives’ assumption of responsibility for the deceased one’s organ donation was accompanied by questions about meaning and guilt in the case of DBD and DCD. Donation may be an important factor in the grieving process, to help donor families make sense of a death that may otherwise seem pointless. Guilt may be assuaged if relatives receive the support they need from medical staff, as well as other family members and friends.

For the improvement of donation procedures, several points may be influential – families’ fundamental trust in health professionals, their decreased ability to retain information during the stress of losing their loved one, and their fear of disfigurement of their loved one due to donation. This last point is addressed by the Swiss Academy of Medical Sciences’ 2011 guidelines pertaining to deceased organ donation – the guidelines state that the dead body must be treated with respect and that the body must be returned to the family in a dignified manner (10). Transplant coordinators and other health professionals may provide relatives with the support they need in order for them to feel more confident and comfortable with their donation decision. As we show in this study, DBD donor families may find the concept of brain death difficult and sometimes suffer from guilt because of what they perceive as their role in their loved one’s death. DCD donor relatives did not mention any such feelings. We suggest that health professionals pro-actively approach relatives, address the risk of this occurring and give relatives the opportunity to contact them. Further points are that families place value on authentic sympathy and flexibility of medical personnel during the donation process and the importance of a follow-up in which next-of-kin can ask for more information on the donation process and choose to find out how the donation went. This may be done in the form of a family conference, an intervention that has been shown to have a positive effect on the care of ICU patients with a hopeless prognosis ([43], 270). Also, we recommend systematically and routinely collecting donor relatives’ experiences as part of quality management. Future research could focus on measuring the effects of interventions like family conferences and the follow-up of donor families on the well-being of donor families. By placing yet more emphasis on the points mentioned above, donation may be promoted in a way that takes relatives’ needs into central account.

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Zusammenfassung

Hintergrund: Es ist wenig über die Erfahrungen der Angehörigen von Spendern nach Herztod bekannt.

Ziel: Das Ziel dieser Untersuchung war, solche Erfahrungen zu erkunden und die Besonderheiten der Spende nach Herztod im Vergleich mit Erfahrungen von Angehörigen von Spendern nach Hirntod zu beschreiben.

Ansatz: Es wurde ein induktiver, theoriebildender Ansatz auf der Basis von qualitativen Interviews verwendet.
Les entretiens sont un outil basé sur des données qualitatives. Ils offrent un soutien et un suivi aux proches pour les aider à se sentir plus en confiance avec leur décision. Les participants étaient des proches de donneurs après la mort cérébrale. Nous avons utilisé une approche inductive des parents de donneurs après la mort cérébrale. Le but de cette étude était d’explorer ces expériences, et de décrire les aspects distinctifs du don après mort circulatoire en les contrastant avec les expériences des familles lors de don après mort circulatoire et après mort cérébrale. Nous avons utilisé une approche inductive des données qualitatives.


Résumé
Contexte: On sait peu sur les expériences liées au don chez les parents des donneurs après constatation circulatoire de la mort.

Objectif: Le but de cette étude était d’explorer ces expériences, et de décrire les aspects distinctifs du don après mort circulatoire en les contrastant avec les expériences des parents de donneurs après la mort cérébrale.

Méthode: Nous avons utilisé une approche inductive basée sur la construction de théorie à partir d’entretiens qualitatifs.

Participants: Les participants étaient des proches de donneurs décédés, qui avaient été impliqués dans la décision de faire un don.

Résultats: Nous avons constaté que prendre la responsabilité du don d’organe pour la personne décédée s’accompagnait de questions concernant le sens et de culpabilité pour le(s) membre(s) de la famille qui avaient pris cette décision.

Conclusions: Il y a davantage de similitudes que de différences entre les expériences des familles lors de don après mort circulatoire et après mort cérébrale. Nous recommandons que les professionnels de la santé offrent un soutien et un suivi aux proches pour les aider à se sentir plus en confiance avec leur décision. Les entretiens sont un outil basé sur des données probantes pour améliorer la prise en charge des patients mourant. Ils devraient être mis en œuvre au cours du processus de don et peut-être durant le suivi.

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References
41. Simpkin AL, Raubertson LC, Barber VS, Young JD. Modifiable factors influencing relatives’ decision to offer organ donation: systematic review. BMJ. 2009;339:b3991.