Original Article

A Critical Ethnographic Study of Families of Brain-Dead Patients: Their Experiences and Attitudes to Organ Donation

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Abstract

Background: Despite the difficulty of making decisions providing facilitating mediators and removing barriers to making decisions about choosing the right path to donate the organs of brain-dead patients by families can assist in improving the services and help the lives of fellow human beings. This study aimed to explain the decision-making mediator for organ donation in families with brain-dead patients in a cultural context. **Materials and Methods:** This qualitative study with a critical ethnographic approach was conducted based on Carspecken's stages from August 2021 to March 2022. In this regard, 22 participants were selected through the purposive sampling method and considering the inclusion and exclusion criteria. Sampling was continued until data saturation. After obtaining the required ethical approval, data collection was performed through observation, semi-structured interviews, and document review. All data were recorded and managed using MAXQDA 18 software. **Results:** Based on the results, the main themes and subthemes of this study included "inefficient decision-making mediator" (the shadow of the socioeconomic situation on the medical status of organ recipients, as well as pessimistic influential individuals, social accountability, dialect difference, and ethnic beliefs) and "efficient decision-making mediator" (social learning, material, and spiritual motivation, mother role, and divine reward). **Conclusions:** The results of this study, derived from a cultural context, can be applied to carrying out future applied and empirical research. Moreover, they can be used in the field of various nursing roles, especially management, care, and education.

Keywords: *Anthropology, brain death, cultural, decision-making, organ transplantation*

Introduction

Brain death occurs as a result of accidents such as car accidents, severe head injuries, falling from a height, and strokes.[1] Due to the special conditions of brain-dead patients, they can donate some important organs of their body such as kidneys, heart, pancreas, and liver to recipients.[2] Organ donation is known as one of the vital approaches to saving the lives of other individuals and maintaining their health.[3] This process is a fundamental challenge, which is highly affected by cultural context.[4] Despite the urgent need for organ donation in Iran, this process has not yet been significantly developed as expected so many patients are waiting to receive organs.[5] Among 8000 brain deaths in Iran, the organs of around 31% have been donated.[6] The latest statistics indicate that Iran ranks 33rd worldwide in terms of organ donation.[7] The Iranian Society of Organ Donations reported about 1078 organ donation cases. More than 2500 individuals require organ transplantation, and the number of deceased patients in need of organs is about 10 people daily in Iran. Additionally, the annual organ donation rate decreased by 21% in the country during 2021 compared with the previous year.[8] Although organ donation is essential, it requires the acquisition of written informed consent based on the laws of Iran. The satisfaction and decision of the family members of brain-dead patients to donate organs are a cultural and social challenge.[9] The family members with brain-dead cases are mentally influenced by the issue of death and greatly suffer from the grief process.[10] In Iran, individuals sometimes allow organ donation voluntarily after death although decision-making is always difficult for their family members.[11] Another study highlights important considerations about

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organ donation authorization processes in Ontario.[12] In this situation, the concepts related to the brain death phenomenon are beyond the burial ceremony.[13,14] Given the fact that the family should quickly decide about organ donation, the selection process and logical thinking in this stage are certainly challenging and families need to be supported by health team members.[15] Cultural attitudes and beliefs can be addressed as one of the most important items influencing the donation process.[16] Different cultures have different attitudes toward unexpected death, and decision-making is difficult when organ donation is offered.[17,18] Like other societies, Iran includes individuals with different cultural backgrounds and values.[19]

To study organ donation decision-making in the cultural context, a qualitative research method should be applied to explain and understand conditions and assess the experiences and interactions of individuals.[20] Various approaches can be used to evaluate cultural issues. Ethnography is one of the most precise methods, which is utilized to examine concepts in a cultural context.[21] Among the different ethnographic approaches, its critical one seeks to interpret culture and change it in favor of power equality in social relations. Therefore, altruism and valuism are among the characteristics of this method.[22,23] Nurses with an accurate understanding of the concept of organ donation in the context of different cultures and microcultures can play an effective role in resolving existing inconsistencies to increase the social desire for organ donation.[23]

Cultural factors are not transparent, and social contradictions exist in the field of organ donation in Iran. Furthermore, decision-making for the families of brain-dead cases is closely related to culture. Thus, the cultural themes affecting the organ donation decision can be observed to increase the family's consent to organ donation.[15] They can also design and implement effectual, meaningful, and practical strategies to this end. Critical ethnography attempts to uncover concealed and normalized ideologies within the setting in which the research is conducted.[24] This matter is necessary for the health field. It should also be considered that cultural contradictions influence organ donation decision-making. One of the researchers for this study was a member of the organ procurement team at Shahrekord University of Medical Sciences for several years and had the experiences needed to identify the challenges and opportunities of the concept. Thus, this study sought to explain the issues in organ donation decision-making by families in a cultural context to take a fundamental step toward making the right decision and resolving cultural contradictions.

Materials and Methods

This study is a part of the doctoral dissertation in nursing. This study was performed to explain the mediators affecting the decision of the families with brain-dead patients donating an organ by employing a qualitative method with a critical ethnographic approach based on Carspecken's stages[25] from August 2021 to March 2022 [Table 1]. Critical ethnography examines the response to moral responsibility and attempts to achieve appropriate culture through the lens of power, prestige, privilege, and authority.[20] Considering that organ donation from a brain-dead patient is influenced by the cultural and social factors of their family, therefore the critical ethnographic approach was used to achieve effective social changes for the benefit of people in need of organs.

All collaborative and non-collaborative observations of the researcher were performed in the research field. This study was conducted in two educational and medical centers in Iran due to the existence of organ transplantation in these centers. The collaborative observation and fieldwork lasted six months. The participants were selected with maximum diversity using a purposive sampling technique until reaching data saturation.[26] Participants included the families of brain-dead patients, physicians, nurses, supervisors, and staff members of the training center who were selected with maximum diversity through purposive sampling.[27] Inclusion criteria were willingness to participate in the study, retell experiences, have experience in facing brain death and organ donation, and be among the close relative (e.g., parents, spouse, children, sister, and brother) or friends of a brain-dead person. Then, observation, theoretical sampling, and in-depth interviews were carried out by returning to the field and hidden participation.[28] The main methods of data collection in this critical ethnography included the participants as an observer, interviews, and oral interactions focusing on the meaning and interpretation of the participants' collection.[21] Additionally, entry to the field was possible using the reference letter, as well as the assistance of mediators and guarantors. The field of organ donation culture was first described from the perspective of an Iranian individual. The observations and interviews were performed among 22 patients' family members who were involved in the decision-making process, physicians and nurses who played a critical role in the patient's treatment and care procedure, and the organ procurement team. The same criteria defined a potential donor after brain death as a person whose clinical conditions were suspected to meet the criteria for brain death and an actual donor as a person from whom at least one the organ had been retrieved for transplantation[29] The data were collected through observation, semi-structured interviews, and document review.[30] The main researcher, as a participant observer, attended the research environment as a nurse of the organ procurement team. After confirming the brain death of the individuals who were candidates for organ donation, the researcher went to the intended center, explained the objectives of the study to the medical team, and coordinated with the organ transplant center. Then, written consent was obtained from the family for participation in the study.

The observations were initially general and then descriptive and participatory. The researcher began to

Table 1: Carspecken's stages in the study

Stage	Data collection	Analysis
Building a primary ethic record: What is going on	Fieldwork: nonparticipant observer, monological, unobtrusive, reflection	Cultural reconstruction
Researcher interpretation, etic perspective	Preliminary reconstructive analysis	Cultural reconstruction
Dialogical (emic) data generation, collaborative stage	Fieldwork: participant observer, interactive, interviews, reflection	Cultural reconstruction
Describes system relations to broader context (etic)	Conducting system analysis between locales/sites/cultures (discovery)	System analysis
Explains relational systems (etic)	Links findings to existing macro-level theories (explanation)	System analysis

document his observations of the study environment. The documents produced in the first stage turned into a complete story about the events that occurred during the hospitalization of the brain-dead patient while the family was present at the treatment center. Subjective, objective, and normative statements about the decision to donate the patient's organ were considered. A total of about 150 hours of observations were made by the researcher on the family and relatives, nurses and physicians, and those who were involved in the organ donation process. The medical team was interviewed in a separate and quiet room located in the center where the patient was hospitalized. However, most of the interviews with families were implemented in their homes by coordinating with the organ transplant centers and families, while a small part was carried out in the hospital under suitable conditions and environments. The interviews lasted 30–90 min and were unstructured in-depth, in which open-ended questions were utilized. Some of the questions asked from the families are as follows: "What is brain death and what is its difference from a coma?", "Describe when you learned of your loved one's brain death?", and "What made you decide to donate the organ of your loved one?" Furthermore, "How do you deal with the families with brain-dead cases with different cultures?", "What is the role of the family in the decision-making process?", and "What is the role of family beliefs in your decision-making?" Follow-up questions were used to access more data and deepen participants' experiences during the interviews. The method and location of the interviews were selected based on individual preference. Sampling was continued until achieving data saturation so that no new codes or data were obtained after each interview and observation, and all semantic levels were completed. After getting the participant's permission, all interviews were recorded and typed verbatim by the interviewer. To manage the interview text and data, MAXQDA 18 software was applied in compliance with the principle of confidentiality and privacy. The available documents such as the patient record, nursing reports, posters, and guides, as well as the organ donation policies related to the intended centers and the Ministry of Health and Medical Education, were assessed through observation to evaluate the policies.

Informal interviews were designed to clarify information obtained through observation, shortly after an observation period. Tone and body language were taken into account during observations and interviews. All interviews were recorded after obtaining the consent of the participants. Observations were immediately documented, while brief field notes were also written during the observations. The data were analyzed hermeneutically and reconstructively to discover tacit cultural knowledge and help healthcare providers rebuild their workplace culture. In the reconstruction process, the observations, all field notes (observations were immediately documented, while brief field notes were also written during observations), and the transcripts obtained from the interviews were reviewed several times. A list of primary codes was extracted. Next, relationships between codes were identified, resulting in categories and final claims. Reflection was used to avoid possible biases. Then, the categories were brought together to create the main themes and a final claim.[25] Guba and Lincoln criteria (credibility, transferability, dependability, confirmability) were applied for the accuracy and rigor of the data.[31] In the field of credibility, the researcher frequently contacted the participants and constantly read the interviews. The researchers completely explained all details of the study such as sampling, data collection, analysis, assessment, and comparison. Regarding dependability, peer description and coding reviews were implemented by researchers. Moreover, question simulation methods were used to confirm the results. The researchers constantly emphasized the significance of their research and examined the effects of research.[32]

Ethical considerations

This study was derived from a nursing Ph.D. thesis approved by the ethics committee at Isfahan University of Medical Sciences, Iran (ethics code: IR.MUI.NUREMA.REC.1400.060).

All participants were assured that their information would be kept confidential and that the research results would be published without specifying them. The informed consent was signed before the data collection. All methods were performed in accordance with the relevant guidelines and regulations of the Declaration of Helsinki.

Results

In this phase, 22 participants attended, including the family of organ donors, as well as nurses the head nurses, the supervisor, and the organ procurement team members [Table 2]. A total of 400 concepts were obtained from the individuals' statements, from which two main themes and nine subthemes were extracted. As summarized in Table 3, "insufficient decision-making mediator" and "efficient decision mediator" are the main themes. The subthemes of the first theme include the shadow of the socioeconomic situation on the medical status of organ recipients, as well as negative influential individuals, social accountability, ethnic beliefs, and dialect difference. However, social learning, material, and spiritual motivation, mother role, and divine reward can be addressed as the subthemes of the second theme.

Insufficient decision-making mediator

Insufficient decision-making mediator was the first main theme obtained by classifying the important concepts in this study. According to the participants, the shadow of the socioeconomic situation on the medical status of organ recipients, as well as negative influential individuals, social accountability, dialect difference, and ethnic beliefs, was among the most critical barriers to the right decision-making organ donation by families.

Shadow of the socioeconomic situation on the medical status of organ recipients

The statements and behaviors of participants represented a serious concern about the shadow of the socioeconomic situation on the medical status of organ recipients. They expressed the fear of selling organs, as well as concern about delivering the organs to ineligible ones such as officials, colluding in organ buying, selling, and donation, and receiving a large sum of money for organs by institutes as the factors affecting the possibility of unfair organs' allocation, and consequently unwillingness to donate. In this regard, interviewees 1 and 8 said, "*What if they sell our patient's organs? I always think they want to take the organs for themselves.*"

Another commented, "*They do not observe justice in organ donation, and sell organs at high prices.* " (P 13).

Negative influential individuals

In some families, a number of individuals tried to dissuade patients' family members from organ donation through pessimism and negative views. The participants referred to the role of such individuals with resistance and deterrent perspectives. Given the special position of negatively influential individuals among the family members, they sought to make the family members reluctant to organ donation. In this respect, the following opinions were presented.

"*The families were satisfied although someone of them, not the close family members, tried to hinder this important decision*" (P 2 and 6).

Table 2: Characteristics of the participants

ID	Age	Gender	Role
P 1	39	M	Family
P 2	40	M	Head nurse
P 3	51	F	Family
P 4	50	F	Family
P 5	44	M	Nurse
P 6	38	F	Nurse
P 7	49	M	Family
P 8	52	F	Family
P 9	36	M	Supervisor
P 10	53	M	Family
P 11	50	M	Donation team
P 12	48	M	Donation team
P 13	51	M	Family
P 14	40	M	Nurse
P 15	36	F	Nurse
P 16	29	F	Family
P 17	30	M	Nurse
P 18	49	M	Donation team
P 19	60	M	Family
P 20	61	M	Family
P 21	58	F	Family
P 22	55	M	Family
Mean (SD)	46.32(9.17)	-	-
Total		n=22	

"*In one case, the organ procurement team was talking to close family members, especially parents, in the room of the department head. Suddenly, one of their family members, not a close member, knocked on the door of the room, crowded the atmosphere, and addressed the negative and disappointing sentences to the father implying the ignominiousness and traitorousness of the action*" (Observation 2).

Social accountability

According to the participants, organ donation decision-making was difficult since the logical reasoning and justification of relatives and friends may be hard or impossible. Due to the family conditions, as well as the importance of organ donation causing blame and negative view on the family forever, the doubt and fear of the inability for accountability, which is associated with much negative burden and family consequences, did not allow to make the right decision about organ donation.

The 16th interviewee mentioned, "*You should not have accepted soon. I know some cases who woke up after a few months.*"

The fourth one said, "*Everyone was telling us that it is your loved one's body. How can you say this? Oh, how can you tear your loved one's body to pieces?*".

Table 3: Concepts, themes, and subthemes obtained in the study

Main theme	Subtheme	Initial code
Inefficient decision-making mediator	Shadow of socioeconomic situation on the medical status of organ recipients	Selling and exchanging organs, receiving a large sum of money, giving organs to officials, keeping organs for hospital personnel, delivering organs according to officials, not providing organs to individuals in need, as well as injustice in proper organ allocation
	Negative influential individuals	Undue interference and barrier, negative attitude, deterrence by negative individuals, and attention attraction with negative view, as well as the influence of negative influential individuals
	Social accountability	Inability to justify and reason with friends and relatives about the adopted decision, as well as the fear of blame
	Dialect difference	Communication problem, inappropriate verbal communication, difference in speech and dialect, and various dialects, as well as the lack of verbal communication due to dialect diversity
	Ethnic beliefs	Diversity in ethnic and tribal beliefs, false ethnic beliefs, ethnicity, ethnic fanaticism and barriers, tribal fanaticism, and incorrect beliefs
Efficient decision-making mediator	Social learning	Previous training, previous and similar experiences, and cyberspace, as well as the role of media
	Material and spiritual motivation	Receiving gifts from the government, supporting financially and socially, supporting charities, and getting appreciation letter in commemorations
	Mother role	Encouraging presence of mother, positive effect of mother, role of mother, positive and great position of mother in family, and influence and effect of her opinions on others
	Divine reward	Forgiveness of deceased's soul, patient peace of mind after death, and peace of child's soul, as well as considering a good place for the patient, living with comfort and peace of mind for survivors, and satisfying with God's pleasure

Dialect difference

Communication with many patient family members to transmit the message properly, clarify organ donation purposes, and decide on this issue is difficult in Iran because of the presence of local dialects, special clothes, and even various accents. The procurement team sometimes prejudged after observing the local clothes of the families and did not try to consent to them sufficiently. The individuals stated that the inappropriate understanding of what procurement team members told made the communication process harder due to difficulty in realizing their dialect. The organ procurement team expressed that the improper communication caused by the dialect differences between the procurement team and family members, especially those from rural and remote areas, led to the difficulty of organ donation decision-making in many cases. Regarding this issue, the following perspectives were offered.*"I did not understand what they said at all since they spoke Persian, while we speak our own dialect" (*P19*)*.

"*Our dialect is Turkish and understanding Persian is hard for us. We did not realize many sentences*" (P 21).

Ethnic beliefs

The participants introduced the existence of diverse beliefs and values as an important challenge in making fundamental decisions in Iran for donating the organs of brain-dead cases. Specific ethnic laws, ethnic culture, customs, and unique beliefs in different ethnicities in a purely cultural and fanatical context are among the important obstacles for family members to accept organ donation. According to interviewee 5, "*Some ethnicities insist on specific beliefs and do not decide otherwise. They believe that actions like organ donation blemish their ethnic prestige.*"

Efficient decision-making mediator

Another main theme was efficient decision-making mediator, which included the subthemes of social learning, material and spiritual motivation, mother role, and divine reward.

Social learning

Social learning is considered one of the factors of decision-making efficiency. It plays a critical role in facilitating organ donation issues. The participants pointed to the role of education and understanding similar experiences in other people, as well as the role of media and virtual space as influential factors in deciding to donate organs.

In this regard, the participants expressed, "*Such* an *event occurred for one of our relatives and they had a good experience. We knew how comfortable we would be later*" (P 21).

"*There was a lot of talk about this issue on TV and radio, and I am usually aware of all the details and peace afterward of how much help could be given to those in need*" *(P 13)*.

Material and spiritual motivation

Material and spiritual motivation can effectually facilitate organ donation decision-making by considering the conditions of the family members of injured patients, as well as special attention and support. The support of institutions and organizations, as well as giving gifts and appreciation letter by the government and Nongovernmental Organizations (NGOs), can be a motivating factor to encourage the family members for donating their patient organs. Regarding this issue, some of the participants said,

"*After donating organs, we and our patients were honored at the Nafas celebration and received appreciation letter*" (P 1).

"*In a case in which the family members decided to donate their patient organs, the personnel of a charity, who knew about their financial situation, attended the hospital management office, comforted them, and promised to assist and cooperate financially and spiritually*" (P 6).

Mother role

Mothers with a special and effective position in the Iranian culture can affect the opinions and decisions of others. The results of the study indicated a change in the decision following the presence and effect of the mother in some cases and others commented not to donate an organ. Despite the negative opinion of the father to donate his child's organ in some cases, the family decided to donate after the consent of the mother. One of the participants said, "*After advising and offering to donate organs, the family members of a brain-dead patient gathered in front of the ICU around the mother who was sitting on a chair with strength, as well as peace of mind, and asked for her view. She respectfully advised the family members to donate her child's organs while smiling, along with crying*" (P7).

Divine reward

Due to the cultural and religious context of Iran, Iranians, especially those living in the religious regions, believe afterlife, as well as receive the reward of good deeds. The participants introduced peace after death as a facilitator for making organ donation decision by emphasizing that patients' souls would be at peace after organ donation and God would consider a high position for them after death. Most participants emphasized that organ donation helped the patient peace of mind after death. Regarding this issue, interviewees 6 and 18 stated, "*Many of the individuals whom we wanted to satisfy emphasized the donation of their patient organs since God has mercy upon the patient's soul after death.*"

Discussion

The results of observations and interviews represented the contribution of a combination of efficient and inefficient decision-making mediators to the decision-making about the denotation of the organs of injured and brain-dead patients. The shadow of the socioeconomic situation on the medical status of organ recipients, as well as negative influential individuals, social accountability, ethnic beliefs, and dialect difference, was the subtheme of "insufficient decision-making mediator." However, "efficient decision-making mediator" included social learning, material and spiritual motivation, mother role, and divine reward. Additionally, some important and insignificant conditions and factors could prevent the patient's family members from making a proper decision regarding organ donation. The results of the previous research suggested the fear of organ donation, contradictory opinions of physicians, inadequate knowledge of brain death, the negative role of media (organ trade or clips showing miracle occurrence and return to the universe), the specific role of mother (mostly disagreement with donation), and the unwillingness of the deceased individual to donate during life as the deterrents influencing the donation.[33] However, some participants in this study referred to the role of media as a facilitator. Based on the literature review, family dissatisfaction is the most common reason for not donating and losing organs.[34] According to De Groot *et al*.,[30] inappropriate time for organ donation requests, family incompatibility with their patient's brain death, pressure and time limit for making decision, insufficient knowledge, inadequacy in decision-making, and family inconsistency are among the deterrents of the donation. Furthermore, the other deterrents include the lack of privacy, the share of each family member on the decision, the surprise of the family at the patient's brain death, and the lack of support and conflicting views of relatives. Donor families experience a variety of challenges, from conflict and doubt to confidence, satisfaction, and excellence, and support from them should be continued after donation due to their possible inability to cope effectively.[35] The results of the present study revealed the facilitation of donating the organs of injured ones when the important conditions and causes of making the right decision are available. Some researchers reported good patient care, proper family care and support, supportive communication with family, knowledge acquired from media about donation and previous successful experiences, and decreased desire to donate organs during life, as well as the right beliefs and culture of a family as the factors affecting consent to the donation.[30] Despite the medical team's effort to increase organ donation cases, the families with brain-dead cases undergo a vague experience, which may lead to dissatisfaction with the donation of their patient organs. However, the donor feels better and considers their decision as the right action.[36] An appropriate understanding of family decision-making can enhance

satisfaction with organ donation.[33] Given that psychosocial characteristics can lead to the tendency to organ donation, poverty, single-parent family, and low education level are significantly related to the level of consent to organ donation.[37] Furthermore, the age of brain-dead cases, the level of trust in the information presented by the healthcare system, religion, the socioeconomic situation of families, and the amount of knowledge about brain death influence the donation process.[35] Based on the previous studies, the facilitators of this process involve considering organ donation as a humanitarian action, realizing the brain death, ensuring the care provided by the medical team, and the location for offering the donation suggestion, and understanding the time of organ donation request.[33] The positive experiences of relatives, the positive role of organ procurement coordinators, the unique contribution of an individual proposing organ donation to a family, the religious beliefs of the family, and the degree of forgiveness can be mentioned as the other facilitators.[33] Regarding how to communicate with the family of brain-dead patients, Shemie *et al*. pointed out that multifaceted family support, how the family communicates with the medical center, and criteria for effective conversations, and acquiring individual skills and gaining the ability to talk to family are important in facilitating organ donation decision-making by families.[36] The families must be supported psychosocially after consent to organ donation. Moreover, highlighting family relations and financial support to improve donation cases can affect the decision.[38] Due to the continuous presence of nurses as effective members of the procurement team, they play a critical role in the organ donation process by presenting accurate information to the families of brain-dead cases, responding the questions, and passing through the grief stages.[38] The cooperation of the family members for interview and participation was one of the limitations of the present study, which was removed by explaining the objectives and significance of this research. The results of the present study, derived from culture, can be applied for carrying out future applied and empirical research, and planning on the different roles of nursing, especially management, care, and education practically.

The limitations of this study included that the findings of this study are limited to the comments of 22 participants who agreed to take part in this research; thus, they are not generalizable. Also, since the sampling in this study coincided with the spread of the Corona epidemic, the sampling was delayed and we could not meet some of the participants who were eligible to participate in this study due to the Coronavirus and social distancing and meeting health protocols.

Conclusion

The results of the present study, as well as assessing the concept of organ donation decision-making by the families of brain-dead patients in the form of a subculture, represented a relationship between the importance of this issue with decision-making mediators. These are based on the values, beliefs, and cultures of families. Additionally, cultural values, as well as the value effects of some critical concepts from the perspective of cultural communities, are considered an important challenge. The results of the study, extracted from a main culture and belief context in Iran, can be used in future applied and empirical research. They can be practically useful in various nursing roles, especially management, care, and education. According to the participants, donation societies should emphasize a rise in awareness about brain death and organ donation, as well as develop strategies to increase the satisfaction of families with injured patients to maximize organ donation cases. Furthermore, health-oriented agencies and associations should play a role in shaping individuals' attitudes toward donation by confronting and informing them about the issue of organ donation to adopt decisions in this regard. The media can affect the sociocultural intellectual foundations of organ donation by presenting documentary programs.

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Conflicts of interest

Nothing to declare.

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