Response to comments: Making the decision to donate eye organs: Perspectives from the families of the deceased in Madurai, India

Dear Editor,

We thank the authors[1] for your interest in our article.[2] We appreciate the suggestions for strengthening donation outcomes from counseling sessions with family members of the deceased. Our research focused primarily on understanding factors that influenced the donation decision, and factors that could have influenced nondonors to donate. Your proposal of a structured approach to eliciting ideas, concerns, and an expectations model^[3] could be applicable in this context of eye donations; these were explored to some extent in our study as well. From data that we did not report in the published article due to reasons of space, we obtain additional insights about concerns and motivations of non-donors. Table 1 below shows that 74% of non-donor families expressed willingness to donate their own eyes in the coming days, 13% were likely to decide based on the situation, and only 13% were not willing to donate in the future. The reasons for not being willing to donate even in the future were money, caste, did not want to cause injury etc., [Table 2]. Additionally, Table 3 below shows the most important reason reported by non-donors for negligence in donating on the most recent occasion. We also asked about

Table 1: Response of non-donor family members to the question "Will you or your family members donate their eyes in the coming days"

Willingness	n	%
Yes	190	74.2
No	33	12.9
Depends upon the situation	33	12.9

Table 2: Reasons for not being willing to donate even in the future

Reasons	n	%
Family members and relatives will not agree	13	5.1
Didn't want to donate/Didn't want to cause injury	7	2.7
Caste	5	2.0
Eye problem	4	1.6
Will see in future/Decision not yet taken/	3	1.2
According to situation		
Money	1	0.4

specific concerns that had been identified in focus groups conducted before the structured interviews. For instance, Table 4 shows the results regarding apprehensions about disfigurement of the donor's face.

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Table 3: Most important reason for negligence among nondonors

Reasons for negligence	n	%
We never thought about it	125	48.8
Lack of awareness	49	19.1
No one approached us	17	6.6
We thought that the deceased is unfit due to age, illness	11	4.3
Eye problem	10	3.9
We don't want to remove eyes from the body	9	3.5
We don't know where and whom to contact	7	2.7
Opposition from the family/lack of family support	6	2.3
No one is here to take a decision	3	1.2
Caste/religion-based reasons	3	1.2
We took a delayed decision	3	1.2
Cancer	3	1.2
Unexpected death	3	1.2
Don't want to cause injury	2	8.0
No one has donated eyes in my family	2	8.0
Donated full body	1	0.4
Family member objection	1	0.4
Lack of time	1	0.4

Table 4: Response of deceased family members to the question "Do you think eye donation disfigures the face of the donor after removal of eye?"

	Donor <i>n</i> (%) (<i>n</i> =76)	Non-Donor n (%) (n=256)	Total n (%) (n=332)	P
Yes	10 (13.2)	89 (34.8)	99 (29.8)	
No	66 (86.8)	54 (21.1)	120 (36.1)	0.0003
I don't know		113 (44.1)	113 (34.1)	

Conflicts of interest

There are no conflicts of interest.

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References

- Milner I, Hussain N, Imoru P, Shah H. Comments: Pendleton's *Ideas*, Concerns and Expectations model for improving outcomes through eye donation counseling. Indian J Ophthalmol 2021;69:1019-20.
- Subburaman GB, Kempen JH, Dura Raj S, Balakrishnan V, Valaguru V, Namperumalsamy VP, et al. Making the decision to donate eyes: Perspectives from the families of the deceased in Madurai, India. Indian J Ophthalmol 2020;68:2094-8.
- 3. Matthys J, Elwyn G, Van Nuland M, Van Maele G, De Sutter A, De Meyere M, *et al*. Patients' ideas, concerns, and expectations (ICE) in general practice: Impact on prescribing. Br J Gen Pract 2009;59:29-36.

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