

# Clearing the path to vision restoration: an analysis of attitudes and associated factors towards cornea donation in Syria

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## ABSTRACT

**Objective** This study aims to assess attitudes and associated factors towards cornea donation among visitors of a main public hospital in Damascus. Findings of this study can contribute to the development of effective donation campaigns and applying cornea donation in Syria.

**Methods** This cross-sectional study included individuals who were above 18 years old and were visitors of Al-Mouwasat University Hospital in Damascus, Syria. Data were gathered using a questionnaire administered through face-to-face interviews with the participants. A validated questionnaire was used and consisted of three sections: demographic information, awareness assessment and evaluation of participants' attitudes towards corneal donation. Associations between participants' demographics and variables were tested using  $\chi^2$  test, and a p value of <0.05 was considered significant.

**Results** 637 participants were randomly interviewed. 70.8% of the sample were female and 45.7% have heard about cornea donation. 68.3% of the participants accepted donation of their cornea after death, but this decreased to 56.2% when it comes to donation from relatives after their death. The main reasons for refusing and accepting cornea donation were religious beliefs (10.8%) and intention to help others (65.8%), respectively. Women were more likely to accept donation after death than men (71.4% vs 60.8%,  $p=0.009$ ). Finally, acceptance of cornea donation would increase if participants lived in a more developed country (71.7% vs 68.3%).

**Conclusion** Despite the high willingness, corneal donation in Syria is still not enough. Corneal donation requires an ensured donation system that supports and organises the processes, a simplified education about the importance of donation, and clarifying the right instructions of religion.

## INTRODUCTION

Cornea transplantation is one of the most successful transplantation procedures that can restore vision in people with various corneal diseases.<sup>1–3</sup> However, the success of this procedure heavily relies on the availability of cornea donations.<sup>4 5</sup> Despite the high demand for cornea transplantation worldwide, there is still a significant shortage

## WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ It is known that attitudes towards organ donation, including cornea donation, can vary depending on cultural, religious and societal factors.
- ⇒ Previous studies have found that factors such as educational level, age, gender and knowledge about organ donation can also influence individuals' willingness to donate.
- ⇒ Specific attitudes and associated factors towards cornea donation among visitors of a main public hospital in Damascus, as examined in this study, may be unique to this context and population.

## WHAT THIS STUDY ADDS

- ⇒ This study adds to the existing literature on cornea donation by providing insights into the attitudes and associated factors towards cornea donation among the Syrian public, as an example of a low-income country.
- ⇒ The study found that despite high willingness to donate corneas after death, there are still barriers to cornea donation, such as religious beliefs and lack of clear education and instructions.
- ⇒ The findings can contribute to the development of more effective donation campaigns and an organised donation system in Syria, which could increase the rates of cornea donation and help address the need for cornea transplants in the region.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ The findings can inform the development of more effective donation campaigns and education programmes.
- ⇒ The findings can help increase the availability of corneas for transplant and improve the quality of life of patients in need of cornea transplantation.
- ⇒ Policymakers can use these findings to inform policies and regulations that support the development of an organised and reliable cornea donation system in Syria.

of corneas for transplantation.<sup>5 6</sup> The success of any donation campaign depends on the awareness and attitudes of the population towards donation.<sup>7</sup>

As per the 2018 census by the WHO, corneal opacities rank fourth on the list of leading causes of blindness worldwide, responsible for 5.1% of the global blind population.<sup>4</sup> In the Middle East, corneal blindness ranks fourth on the list of causes that lead to blindness in children, preceded by retinal degeneration, congenital cataract and congenital glaucoma.<sup>8</sup>

Several studies have shown a high acceptance rate for cornea donation, 80.4% in Poland<sup>9</sup> and 59%–79% in Canada,<sup>10</sup> while there are fewer but acceptable rates in the Middle East, 67.2% in Jordan<sup>4</sup> and 40.2% in Saudi Arabia.<sup>11</sup>

This study aims to assess the awareness, attitudes and associated factors towards cornea donation among visitors of a main public hospital in Damascus, the capital of Syria. The findings of this study can contribute to the development of effective donation campaigns that can improve the availability of cornea donations for transplantation. It is also important to understand the attitudes and beliefs of the population towards cornea donation as this can help address misconceptions and improve public knowledge and acceptance of this procedure and perform cornea donation surgeries in Syria, which are poorly available in the country due to lack of a well-established donation system.

## METHODS

### Study design

We conducted a descriptive cross-sectional study to investigate the awareness and attitude regarding cornea donation among individuals attending a government hospital located in Damascus, Syria. The data were gathered by our research team by interviewing individuals who were chosen at random from waiting rooms and hallways in different departments and clinics of the hospital, while intentionally avoiding intensive care units or rooms occupied by patients with critical conditions. The survey was conducted for a duration of 1 month, between 15 February 2023 and 15 March 2023, to ensure robust and comprehensive data collection process.

### Participants and data collection

To conduct this study, the authors randomly selected 637 participants who were receiving medical care at Al-Mouwasat Hospital in Damascus and were 18 years of age or older, along with their companions. Any incomplete data were excluded, and assistance was provided to illiterate participants. To avoid biases during face-to-face interviews, all data were reviewed and proof-read after entry. The study's objectives were explained to the participants and confidentiality was guaranteed. Participation was voluntary for both patients and their companions, who were asked separately.

### Questionnaire

A validated survey was adapted from previous studies.<sup>4,9</sup> To ensure precision in meaning and concepts, the survey was initially translated into Arabic, the local language, by

language experts and then retranslated back into English. A pilot study was conducted with 57 participants, and the questionnaire was subsequently revised based on primary statistical analyses. Furthermore, to assess the reliability of the survey, the Cronbach's alpha test was employed, yielding an internal consistency of 0.812. The majority of the survey questions were presented in a closed format.

The questionnaire used in the research project was divided into three sections (online supplemental file 1). The first section comprised enquiries pertaining to participants' sociodemographic or background information, such as gender, age, educational level, and the specific clinic and department of the hospital they attended. The second section consisted of one question regarding participants' awareness of cornea donation, phrased as 'Have you ever have heard of cornea donation?' Any respondents who answered negatively were subsequently given an explanation concerning corneal donation. The third and final section aimed to evaluate participants' attitudes towards corneal donation, encompassing their present status as organ donors, willingness to donate their corneas, willingness to encourage close relatives or friends to donate corneas, as well as the rationales for disinclination to donate corneas among those who reported unwillingness at the beginning of the study.

### Statistical analysis

The data collected through an electronic questionnaire on Google Forms were exported to Excel for analysis. Statistical analysis was carried out using SPSS V.23 software package.  $\chi^2$  was used to identify any correlation between the demographic variables and the awareness or attitude towards cornea donation. A p value of less than 0.05 was considered statistically significant.

### Sample size

To determine the appropriate sample size (n), the research team used Cochran's sample size formula. The calculations were based on several factors, including a 95% confidence level (represented by  $Z=1.96$ ), a margin of error of 5% (represented by  $e$ ) and an estimated proportion ( $p$ ) of the population that possesses the attribute of interest of 50% (or 0.5). The value of  $q$  was calculated as  $1-p$ :

$$n = \frac{Z^2 pq}{e^2}$$

The required sample size (n) for this study, applying the previous formula, is 385.

## RESULTS

### Demographic characteristics

Six hundred and thirty-seven participants were randomly interviewed; 45.2% (n=288) of the participants were between 30 and 49 years old and 31.2% (n=199) were between 50 and 70 years old. Additionally, 70.8% of the sample were female (n=451) and 29.2% were male (n=186). Of the participants, 46.6% (n=297) had primary school education only. Finally, 22.6% (n=144) of the

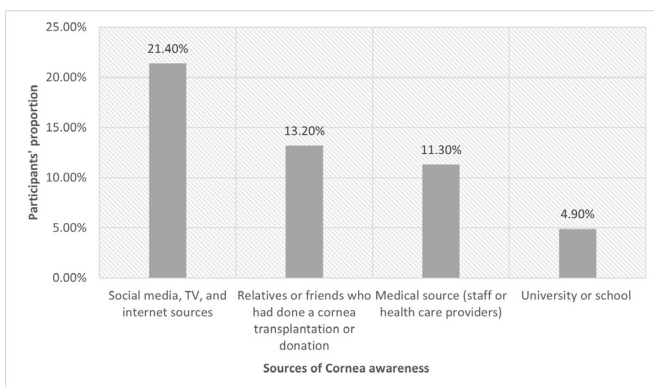
**Table 1** Sample characteristics

Variables		Frequency (n)	%
Gender	Male	186	29.2
	Female	451	70.8
Age group (years)	18–29	127	19.9
	30–49	288	45.2
	50–70	199	31.2
	Above 70	23	3.6
Educational level	Unschooling	93	14.6
	Primary school education	297	46.6
	Secondary school education	108	17
	University or Institution	139	21.8
Clinic and department of the hospital the patient came for	Ophthalmology	144	22.6
	Other departments	493	77.4

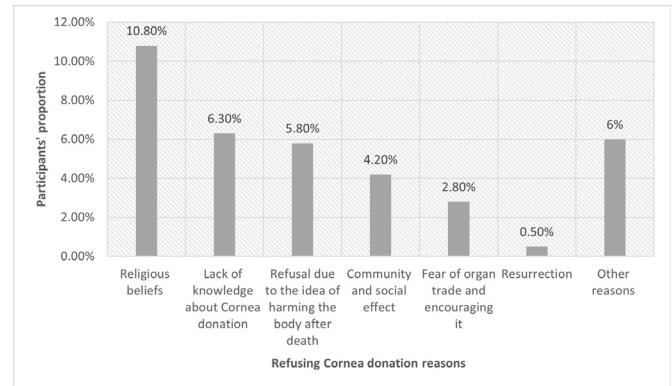
participants came for the ophthalmology department. Other details and characteristics are shown in [table 1](#).

**Awareness of cornea donation and source of knowledge and awareness**

One question was asked (‘Have you ever have heard of cornea donation?’) to assess participants’ awareness. Of the participants, 291 (45.7%) have heard about cornea donation, which means 54.3% (n=346) had not heard about it and cornea donation had to be explained to them. Of the participants, 21.4% (n=136) heard about cornea donation from social media, television (TV) and internet sources, while 13.2% (n=84) heard about it from their relatives or friends who had done cornea transplantation or donation. Other sources are shown in [figure 1](#). Participants who came to visit the ophthalmology department were more likely to accept donation of their cornea after



**Figure 1** Sources of cornea awareness among the participants.



**Figure 2** Reasons for refusing cornea donation among the participants.

death than others (54.9% vs 43.1%;  $X^2$  (1, N=637)=6.219,  $p=0.013$ ). When it comes to source of awareness of participants who came to visit the ophthalmology department, social media, TV and internet were the most common sources (n=33), followed by ‘relatives or friends who had done a cornea transplantation or donation’ (n=24).

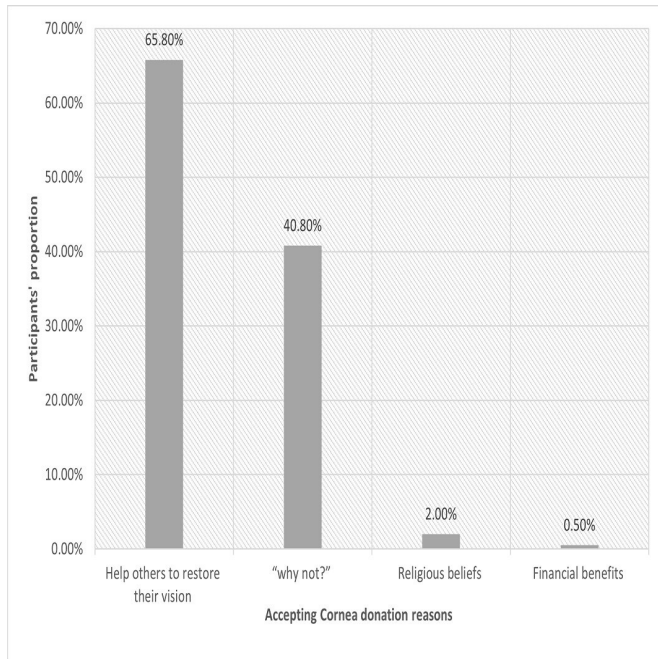
Also, the higher the educational level of the participant, the higher the chance of being aware of cornea donation ( $p>0.001$ ). However, gender and age groups did not show any significant difference when it comes to participants’ awareness ( $p=0.643$ ,  $p=0.064$ , respectively).

**Attitudes towards cornea donation and its associated factors**

Of the participants, 68.3% (n=435) accepted donation of their cornea after death, while 31.7% (n=202) refused. Surprisingly, 79.9% (n=509) of the participants encouraged others to donate their cornea after death. However, the acceptance rate for cornea donation from deceased relatives to others decreased to 56.2% (n=358). Refusing cornea donation after death was mainly due to religious beliefs (10.8%), lack of knowledge about cornea donation (6.3%) and refusal due to the idea of harming the body after death (5.8%); other reasons are shown in [figure 2](#). On the other hand, some participants accepted cornea donation after death to help others restore their vision (65.8%), some answered ‘why not?’ (40.8%), and some accepted due to religious beliefs (2%) and financial benefits (monetary compensation or reimbursement for the costs associated with the donation process, such as transportation or medical expenses; 0.5%) ([figure 3](#)).

For men who refused cornea donation, religious beliefs were the most common reason for refusal (n=36), while in women religious beliefs and lack of knowledge about cornea donation were the most common (n=33 for each).

Women were more likely to accept donation of their cornea after death than men (71.4% vs 60.8%;  $X^2$  (1, N=637)=6.890,  $p=0.009$ ), while educational level, the department visited (ophthalmology department or others) and age group did not have any significant difference when it comes to acceptance of cornea donation ( $p=0.513$ ,  $p=0.277$  and  $p=0.092$ , respectively).



**Figure 3** Reasons for accepting cornea donation among the participants.

Acceptance of cornea donation increases if the participant suffers from a condition requiring cornea donation as the only treatment (81.6%). It would also increase if they live in a more developed country (71.7%). However, more respondents would have signed up to a donor registry, if it existed, than were willing to donate their corneas (73.8% vs 68.3%).

## DISCUSSION

Corneal diseases are a significant cause of visual impairment and blindness in the developing world,<sup>4</sup> with keratoconus being a common inherited disease affecting the Syrian population.<sup>12</sup> Despite this, many countries in the developing world suffer from a shortage of donated corneas.<sup>4</sup> Therefore, assessing people's willingness to donate corneas is crucial, especially in societies like Syria. In this study, we investigated the rate of awareness and willingness to donate cornea among visitors of a central hospital in the Syrian capital.

Our findings indicate that the rate of awareness of corneal donation is low, with only 45.7% of participants expressing willingness to donate. This result is lower than what was reported in previous studies in northern Jordan and Poland, with awareness rates of 88.0% and 80.61%, respectively.<sup>4,9</sup> The Syrian war might have contributed to this low rate of awareness, as awareness of eye diseases, such as glaucoma, in Syria is generally low.<sup>13</sup> The use of social media and TV as source of awareness is prevalent, which aligns with findings from various global studies,<sup>9 14–17</sup> while universities and schools were the least reported sources of awareness. This outcome was expected given that over half of the sample consisted of individuals with minimal educational levels, including those who did not complete primary school (61.2%).

Notably, a substantial proportion of participants (68.3%) expressed willingness to donate their corneas, which closely mirrors rates reported in northern Jordan, Ghana and Singapore (67.2%, 67.3% and 67%, respectively).<sup>4 15 18</sup> However, this figure surpassed rates reported in Izmir in Turkey, Saudi Arabia and Ethiopia (54.7%, 42.4% and 37.6%, respectively),<sup>17 19 20</sup> but was lower than that reported in Poland (80.6%).<sup>9</sup> The variation in the rate of corneal donation between studies can be attributed to a number of factors, including cultural beliefs, literacy levels and access to healthcare resources for obtaining and maintaining grafts.

The department visited by the patients was found to be a significant predictor of awareness regarding cornea donation, more so than the patients' willingness to donate. Specifically, patients visiting the ophthalmology department demonstrated greater awareness of corneal donation compared with those visiting other departments. This may be attributed to patients' inclination to have knowledge about their eyes, including how to preserve them and replace damaged parts, as well as the need for individuals with chronic eye conditions to make frequent visits to ophthalmologists. These factors likely contribute to a greater level of awareness regarding cornea donation among patients visiting the ophthalmology department.

Consistent with previous research,<sup>4 14 16 19</sup> our study found a positive association between awareness of cornea donation and level of education among participants. However, we did not observe a significant correlation between level of education and willingness to donate among Syrians, in contrast to findings from Jordanian and Malaysian studies.<sup>4 16</sup> This may be attributed to the influence of cultural and religious factors in the decision-making regarding cornea donation, which may outweigh the impact of education. In Turkey and Ethiopia, the number of cornea donors increased with higher levels of education,<sup>19 20</sup> suggesting that the relationship between education and cornea donation may be influenced by cultural and geographical factors.

Our study revealed that while gender was not significantly associated with awareness of cornea donation in Syria, similar to findings from rural Pondicherry, India,<sup>14</sup> women were slightly more likely to donate corneas than men. This differs from the results obtained in Jordanian and Malaysian studies, where no significant gender differences were observed in willingness to donate.<sup>4 16</sup> This trend may be attributed to women's higher levels of empathy, where questionnaires that measure empathic ability through subjective assessment indicate that women tend to be more empathetic,<sup>21</sup> as well as the influence of our sample size, which skewed towards female participants. Men are generally fewer in number, partly because many men travel outside the country to work and/or evade mandatory military service, or are members of the army and thus receive treatment in military hospitals.

Our study, consistent with numerous prior investigations,<sup>4 14 20</sup> did not observe any significant association

between age and awareness or willingness to donate corneas. However, a study conducted in Ghana reported higher rates of consent for cornea donation among both the young and the elderly, compared with the middle-aged population.<sup>15</sup> Similarly, a study conducted in rural China found that younger individuals were more likely to be accepting of cornea donation.<sup>22</sup> Differences in age categorisation across studies may account for such discrepancies.

Similar to the majority of studies on this topic, our findings indicate that the primary motivation for cornea donation was the desire to help others restore their vision (65.8%), while financial gain was a relatively uncommon reason for donation.<sup>4 15 17 18</sup> Despite limited resources and challenging economic conditions in Syria, individuals expressed that donating corneas made them feel more noble. Our study also revealed that religious beliefs were the primary deterrent to cornea donation for both men and women, which is consistent with findings from other conservative countries such as Saudi Arabia and India.<sup>17 23</sup> Although our study did not enquire about specific religious affiliations, we noted that individuals perceived religious beliefs as a barrier to cornea donation, despite the fact that Islam and Christianity do not prohibit organ donation. Studies conducted in Saudi Arabia and the UK indicate that a low percentage of individuals were aware of the religious rulings permitting organ donation, with only 28.8% of Saudis and 2 out of 32 Muslims surveyed in Luton, UK reporting knowledge of the legislative council's 'Fatwa', permitting organ donation.<sup>17 24</sup> These findings suggest that individuals' understanding of religious beliefs at a given time and place can serve as a significant obstacle to organ donation.<sup>25</sup>

The lack of information regarding corneal donation and transplantation was identified as the second most significant deterrent to donation, a finding consistent with numerous other studies.<sup>9 15 20 26</sup> Our study revealed that this reason was more pronounced among women, which may be attributed to traditional customs that historically limited educational opportunities for women.

The majority of participants in our study (79.9%) expressed support for the cornea donation process, which is consistent with findings from a Jordanian study reporting an 82.8% support rate.<sup>4</sup> Interestingly, the number of individuals expressing support for donation exceeded the number who actually consented to donate, suggesting that some participants may have declined to donate for personal reasons while still encouraging others to donate. In other words, these individuals were not opposed to the principle of donation, but rather may have had individual reasons for abstaining from donation.

The majority of survey participants indicated a willingness to receive a cornea transplant from a donor if needed, with a rate of 81.6%. This finding is similar to the results obtained in Turkey, but higher than the proportion of individuals willing to donate corneas.<sup>19</sup> This discrepancy may be attributed to individual reasons, as previously

mentioned. However, the focus on attitudes towards receiving rather than giving, combined with inadequate information regarding the need for corneal transplants and their availability, suggests a significant gap between cornea donation and the demand for transplants in Syria. Limited awareness of the complementary aspects of donation and transplantation may contribute to this gap, underscoring the need for public discourse about the plight of individuals requiring cornea transplants and the likelihood that anyone may find themselves in this position. Our study represents the first attempt to assess Syrian attitudes towards cornea donation, whether individuals are located in Syria or another developed country. Notably, we observed an increase in willingness to donate corneas among participants (from 68.3% to 71.7%) when asked to consider donation in a developed country, indicating the potential for increased consent rates with targeted interventions.

While a questionnaire can provide valuable insights into the attitudes towards cornea donation, it cannot address the underlying issue of cornea shortages. This problem can only be alleviated through concrete action. In Syria, the primary reason for this shortage is the lack of a donation system, despite generally positive attitudes towards donation. To address this issue, we can draw on the experiences of other countries and implement effective donation systems. One such system is an opt-out approach, which presumes that individuals are willing to donate their organs after death unless they explicitly state otherwise. However, the success of this approach requires significant government support and investment in infrastructure and may not be feasible for many developing countries.<sup>27</sup> Alternatively, an opt-in system, where individuals express their willingness to donate postmortem, has been successful in increasing donation rates in countries such as Thailand.<sup>27</sup> Regardless of the approach chosen, it is important to prioritise flexibility and legislative adaptation, while also making data on the number of donors and transplants available to the public. In other words, the entire donation process should be transparent and publicly traceable.<sup>28</sup>

Given the significant impact of religious beliefs on attitudes towards cornea donation, it is crucial to incorporate religious awareness and health education into donation campaigns. Studies have shown that this approach can effectively increase the number of donors. Spreading awareness through social media platforms can also be a useful tool, as observed in a study where a 5 min questionnaire significantly increased the agreement percentage.<sup>29</sup> Incorporating a culture of donation into school and university curricula would also be beneficial, with a particular emphasis on targeting youth groups to influence their families and promote donation within the broader community.<sup>28</sup> Additionally, providing mental incentives such as certificates to honour the family members of donors may also increase organ donation rates.<sup>28</sup> It is also important to prioritise educating medical students about cornea donation to ensure that

they are equipped to discuss donation with patients and their families.

### Limitations

One limitation of this study is its sample size. The study only included visitors of a major hospital in the Syrian capital, which may not be representative of the broader population. This indicates a need for a study that encompasses the entire nation. Most participants were alone while expressing their opinions, so these opinions may change when they return to their families, as several studies have shown the influence of parents on the decision, especially of the young. Besides, cornea donation occurs exclusively after death, that is, under the supervision of the family who may not cooperate with the doctors. All of this ultimately affects the rate of willingness to donate, increasing the need to spread the culture of organ donation in general and corneal donation in particular.

### CONCLUSION

Despite the high willingness for corneal donation in Syria, it is not enough to uplift this field of health. It requires an ensured donation system that supports and organises the processes, a simplified education about the importance of donation, and clarifying the right instructions of religion.

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**Contributors** JS, JA, RA and OA-M participated in writing the manuscript. RH, RA, OA-M, FH, NA and SS interviewed the participants and collected the data. JS analysed the data statistically and made the study design. FH and JS were major contributors to creating the questionnaire. RA, JS and OA-M reviewed the literature. JS created the table and figures. AH and RH critically and linguistically revised the manuscript. AH, JS and RH contributed to the revision of the manuscript. JA prepared and revised the final manuscript. AH and JS conceived and supervised the conduct of the study. All authors read and approved the final manuscript. JS is the guarantor.

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**Patient and public involvement statement** It was not appropriate or possible to involve patients or the public in the design, or conduct, or reporting or dissemination plans of our research.

**Patient consent for publication** Not required.

**Ethics approval** This study involves human participants. The participants were explicitly informed of the study's objectives and were guaranteed confidentiality of their responses. Participation was completely voluntary for both patients and their companions. The study was conducted in strict accordance with the Helsinki Declaration and received approval from the Ethical Committee of the Faculty of Medicine at the University of Damascus (serial number 635). Participants gave informed consent to participate in the study before taking part.

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**Data availability statement** Data are available upon reasonable request. The data sets generated and/or analysed during the current study are not publicly available

in order to protect participants' privacy. Some restrictions apply to the availability of these data but are available from the corresponding author on reasonable request.

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