

# Anxiety and Depression among Families of Deceased Donors in China

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**Key words:** Anxiety; Depression; Family; Organ Transplantation; Social Support

## INTRODUCTION

There is consensus that organ transplantation is an optimal way to address organ failure, and organ donation is becoming increasingly accepted. Unfortunately, little attention has been paid to the families of deceased donors, especially with respect to anxiety and depression. In China, where traditional values count, particularly Confucianism, which emphasizes that the body should be kept intact after death out of respect,<sup>[1]</sup> anxiety or depression may be more prevalent in the families of deceased donors. A meta-analytic review showed that irritable bowel syndrome, nonulcer dyspepsia, fibromyalgia, and chronic fatigue syndrome were related to anxiety and depression.<sup>[2]</sup> Whether donor families suffer anxiety or depression and what effects may result remain unknown. Social support is known to be a moderator of life stress,<sup>[3]</sup> but whether donor families possess comparative social support remains unclear. Therefore, we designed a study, and potential risk factors and correlations among social support, anxiety, and depression were then analyzed.

## STUDY DESIGN AND DATA COLLECTION

The study was cross-sectional and in the form of a structured questionnaire. The questionnaire was delivered by short messages containing a website link to those whose loved ones donated their solid organs and whose operation was performed between January 2014 and March 2017 in our center. The time from donation was no <1 month. Members under the age of 18 were excluded. Permission was obtained from the relevant Ethics Committees and the Organ Donation Administrative Center. We acquired

participants' informed consent before the investigation began, and we promised confidentiality of individual information.

Anxiety and depression were assessed with the self-rating anxiety scale (SAS) and the self-rating depression scale (SDS), respectively,<sup>[4,5]</sup> both of which have been validated and extensively used in medical and general populations. Surveys on separate samples of 1158 and 1340 Chinese individuals concluded that a total score of  $29.78 \pm 0.46$  or  $33.46 \pm 8.55$  can be regarded as the Chinese anxiety or depression norm, respectively.<sup>[6,7]</sup> Social supports were assessed using the social support rating scale.<sup>[8]</sup> The author investigated 128 undergraduates in the year 1987, consequently, the total score was  $34.56 \pm 3.73$ , with a Cronbach's  $\alpha$  coefficient of 0.92, thus demonstrating acceptable internal consistency.

A phone call was made by a coordinator who initially contacted the donor family and addressed the subsequent donation procedure, after which a short message was sent. In total, 139 participants met our inclusion criteria. Of all participants, 19 (13.7%) had changed their telephone number, 14 (10.1%) did not answer the phone calls, 3 (2.2%) expressed an inability to complete the questionnaire, and 2 (1.4%) refused to fill in the questionnaire directly.

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Consequently, 101 questionnaires were issued. Finally, 44 questionnaires were reclaimed successfully, with a collection rate of 43.6%, and 42 of them were valid, with an effectiveness rate of 95.5%. Data extraction was conducted independently by two investigators, and we confirmed several times that there was no personal error.

SPSS 23.0 statistic software (IBM Inc., Armonk, New York, USA) was used to analyze the data. Descriptive analysis was conducted for families' general characteristics and cognition and attitude toward organ donation, *t*-tests were applied to identify the differentiation between families' scores and Chinese norms.<sup>[6-8]</sup> Single variable logistic regression and Fisher's exact test were applied to identify risk factors for anxiety and depression, and Pearson correlations were then used to analyze correlations between anxiety or depression and social support. A  $P < 0.05$  was considered statistically significant.

## PREVALENCE OF ANXIETY AND DEPRESSION AND SOCIAL SUPPORT

A total of 42 questionnaires were included in this study. The mean age of participants was  $34.3 \pm 7.6$  years, ranging from 20 to 53 years. Twenty-two (52%) participants were males and 20 (48%) participants were females. In terms of relationship with donors, parents accounted for 12%, children 31%, spouses 31%, siblings 24%, and uncles 24%. All participants had received public education, but the majority (76%) of participants were limited to a middle school education, 3 (7%) were limited to an elementary school education, and 7 (17%) received university education or above. Their monthly income was divided into three grades: 22 (52%) were less than RMB 2000 Yuan, 4 (10%) were more than RMB 5000 Yuan, and 16 (38%) were between RMB 2000 and 5000 Yuan. The time participants took to complete the questionnaire varied between approximately 4.6 min and 44.8 min, with a median time of 12.1 min.

The prevalence of anxiety and depression was 31% and 43%, respectively. Further, 11 (26%) participants were diagnosed with slight anxiety and 2 (5%) with moderate anxiety, respectively 9 (21%) participants were deemed to be in a slight or moderate depressive state. Compared with Chinese norms, the participants showed a significant increase in scores on the SAS ( $t = 5.643$ ,  $P < 0.05$ ) and SDS ( $t = 4.620$ ,  $P < 0.05$ ; Table 1). As previously mentioned,

China is a traditional country. Individuals whose deceased loved ones participated in organ donation have a great chance of suffering from psychological disorders. On the other hand, their psychological state has always been ignored in China. Considering the low collection rate, the factual incidence rate may be much higher, as it is an anguish-filled and ominous experience. Bereavement-related anxiety or depression definitely played an important role, and whether donation *per se* promoted psychological disorders remains unclear. Merchant *et al.*<sup>[9]</sup> reported that donation had a beneficial effect on the bereavement process, given the completely different attitude towards death between the West and the East. Whether the effect would reverse in China needs further exploration, and surveys are recommended to be conducted in families who refused to donate their loved ones' organs. With respect to social support, only subject support showed an increase ( $t = 4.680$ ,  $P < 0.05$ ) compared with Chinese norms [Table 1]. The perceived social support scale,<sup>[10]</sup> which emphasizes self-understanding and self-perception, is recommended to confirm the main origin of subject support: families, friends, or acquaintances. Pearson correlations were used. Anxiety was negative correlated with social support, including subject support and object support, except support utilization. Depression was negatively correlated with all aspects of social support. Both conclusions were in accordance with findings from previous studies.<sup>[11,12]</sup>

## COGNITION AND ATTITUDE TOWARDS DONATION

A majority (86%) of participants indicated that they knew a little about organ donation, and 21 (50%) realized the shortage situation of the donor. Meanwhile, a few (17%) participants had ever discussed the donation with their loved one. The frustrating results suggest that the public's knowledge of organ donation is far from sufficient, even among Chinese health professionals.<sup>[13]</sup> Siminoff *et al.*<sup>[14]</sup> reported that families who knew more about organ donation and had more conversations about it had a greater possibility of donating. Organ donation is the extension of life. Scientific concepts of death are essential to establish in the general public, and propaganda should be enhanced. Nearly, all (98%) believed the doctor's judgment of clinical death, and 40 (95%) had faith in the equitable allocation of organs. However, the unsatisfactory follow-up rate (76%), willingness to donate (76%) or encouragement of others to donate (74%) remind us that we have failed to realize the current situation of those needing organ donations,

**Table 1: Differences of scores between participants and Chinese norms**

Items	Participants	Chinese norms	<i>t</i>	<i>P</i>	95% <i>CI</i>
SAS	35.95 ± 7.09	29.78 ± 0.46	5.643	0.000	33.74–38.16
SDS	40.10 ± 9.31	33.46 ± 8.55	4.620	0.000	37.19–43.00
SSRS	36.86 ± 8.25	34.56 ± 3.73	1.804	0.079	34.29–39.43
Subject support	21.67 ± 5.31	17.83 ± 5.32	4.680	0.000	20.01–23.32
Object support	8.26 ± 3.60	9.31 ± 2.53	-1.889	0.066	7.14–9.38
Support utilization	6.93 ± 1.90	6.92 ± 0.66	0.029	0.977	6.34–7.52

SAS: Self-rating Anxiety Scale; SDS: Self-rating Depression Scale; SSRS: Social Support Rating Scale; *CI*: Confidence interval.

and much work is needed to improve the low reported donation rate of 0.03 per million population.<sup>[15]</sup>

## CORRELATES OF ANXIETY AND DEPRESSION

Fisher's exact test was applied to analyze gender, religion, marital status, educational status, and other similar qualitative data. Cognition and attitude toward donation were also taken into consideration. As a result, monthly income showed a significant difference in three groups on anxiety, with a  $P = 0.015$  ( $<0.05$ ). The Bonferroni method was further used to determine the origin of this difference, and the revised  $P = 0.017$ . As a result, the less than RMB 2000 Yuan group was proven to have a greater possibility of developing anxiety than the RMB 2000-5000 Yuan group, with a  $P = 0.012$  ( $<0.017$ ). Differences were not found in the other two comparisons. Similarly, in terms of depression, further Bonferroni tests showed that the less than RMB 2000 Yuan group was more likely to be depressed than the RMB 2000-5000 Yuan group, with a  $P = 0.007$  ( $<0.017$ ). In addition, the group with a middle school education had a higher rate of depression than the group with a university education or above, with a  $P = 0.016$  ( $<0.017$ ). In a word, lower monthly income and educational status suggested as probable contributing factors, in spite of the limited sample. In former studies, poverty-related stress was believed to be directly related to anxious and depressive symptoms, and higher educational levels seemed to have a protective effect against anxiety and depression.<sup>[16,17]</sup>

Age, gender, marital status, occupation, or relationship with the donor may theoretically play an important role in influencing one's psychological state; however, because we were limited by the insufficient sample size, we failed to further classify this possibility. Multiple-center or nationwide studies are recommended to avoid selection bias and to obtain more favorable conclusions, and a more rigorous control group setting from the same institution and same time period would be ideal. To shorten the amount of time spent on filling in the questionnaire and to acquire a higher response rate, we simplified the questionnaire several times, yet we simultaneously failed to obtain more information, such as families' satisfaction with the donation process, their approaches to donation or their motivation to donate. Therefore, offering incentives to encourage participation in the investigation deserves further exploration.

## MEASURES AND SUGGESTIONS

A coordinator, who may largely facilitate families' decisions on donation,<sup>[18]</sup> should undergo strict training, fully understand families' suffering and be able to offer information on the donation process. Public memorial ceremonies are held annually in April in several provinces, and these ceremonies are an extraordinary opportunity for families to express their grief and relieve their distress. Reimbursements for funeral expenses or charitable contributions are an ethically permissible approach,<sup>[19]</sup> and in China, financial

compensation could be divided into the "thank you" category and the "help" category.<sup>[20]</sup> Tax deductions could be an alternative to alleviate family economic stress, although no statistically significant effects on donation rates were found in a recent study.<sup>[21]</sup> As transplant doctors, we should handle organs humanely and promise not to disfigure bodies, and health professionals' concern indirectly demonstrates this inhumane phenomenon.<sup>[13]</sup> Relevant legislation should be implemented to guarantee the transparency and fairness of organ allocation and to protect the donors' right as well. In addition, comprehensive preoperative assessments on subjects' psychological state and social support could be brought into routine.

For those with anxiety or depression state, psychological services are urgently needed. Phone calls or face-to-face interviews are first taken into our consideration, as being cared for always makes one feel good and provides families with the opportunity to release their inner feelings. Regular physical exercise is recommended, which may contribute to substantial mental health gains,<sup>[22]</sup> and mindfulness-based therapy is likewise an alternative.<sup>[23]</sup> If necessary, psychotropic medications and professional psychiatrists should be involved. What matters more are preventive measures and motivational interviewing could be an option worthy of consideration, as it has proven value.<sup>[24]</sup> Since a pilot program of organ donation after cardiac death was developed in China in 2010, as well as the subsequent national program for the donation of organs of the deceased in 2013,<sup>[25,26]</sup> remarkable progress has been made, but more progress is expected.<sup>[12,13]</sup>

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## Conflicts of interest

There are no conflicts of interest.

## REFERENCES

1. Adler JA. Confucianism in China Today; 2011. Available from: <http://www.2.kenyon.edu/Depts/Religion/Fac/Adler/Writings/Confucianism>. [Last accessed on 2017 Sep 18].
2. Henningsen P, Zimmermann T, Sattel H. Medically unexplained physical symptoms, anxiety, and depression: A meta-analytic review. *Psychosom Med* 2003;65:528-33. doi: 10.1097/01.PSY.0000075977.90337.E7.
3. Cobb S. Presidential address-1976. Social support as a moderator of life stress. *Psychosom Med* 1976;38:300-14. doi: 10.1097/00006842-197609000-00003.
4. Zung WW. A rating instrument for anxiety disorders. *Psychosomatics* 1971;12:371-9. doi: 10.1016/s0033-3182(71)71479-0.
5. Zung WW. A self-rating depression scale. *Arch Gen Psychiatry* 1965;12:63-70. doi: 10.1001/archpsyc.1965.01720310065008.
6. Wang XD. Handbook of mental health assessment scale (in Chinese). *Chin Ment Health J* 1999;13:31-5.
7. Zhang ZJ. Handbook of behavioral medicine scales (in Chinese).

- Chin J Behav Med Sci 2001;10:19-24.
8. Xiao SY. Social support rating scale: Theories and applications (in Chinese). *J Clin Psychiatry* 1994;4:98-100.
  9. Merchant SJ, Yoshida EM, Lee TK, Richardson P, Karlsbjerg KM, Cheung E, *et al.* Exploring the psychological effects of deceased organ donation on the families of the organ donors. *Clin Transplant* 2008;22:341-7. doi: 10.1111/j.1399-0012.2008.00790.x.
  10. Blumenthal JA, Burg MM, Barefoot J, Williams RB, Haney T, Zimet G, *et al.* Social support, type A behavior, and coronary artery disease. *Psychosom Med* 1987;49:331-40. doi:10.1097/00006842-198707000-00001.
  11. Zyrianova Y, Kelly BD, Gallagher C, McCarthy C, Molloy MG, Sheehan J, *et al.* Depression and anxiety in rheumatoid arthritis: The role of perceived social support. *Ir J Med Sci* 2006;175:32-6. doi: 10.1007/BF03167946.
  12. Grav S, Hellzèn O, Romild U, Stordal E. Association between social support and depression in the general population: The HUNT study, a cross-sectional survey. *J Clin Nurs* 2012;21:111-20. doi: 10.1111/j.1365-2702.2011.03868.x.
  13. Hu D, Huang H. Knowledge, attitudes, and willingness toward organ donation among health professionals in China. *Transplantation* 2015;99:1379-85. doi: 10.1097/TP.0000000000000798.
  14. Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. *JAMA* 2001;286:71-7. doi: 10.1001/jama.286.1.71.
  15. Hu XP, Liu Y, Zhang XD. The organ donation in China. *Chin Med J* 2012;125:3912-3. doi: 10.3760/cma.j.isn.0366-6999.2012.21.031.
  16. Santiago CD, Wadsworth ME, Stump J. Socioeconomic status, neighborhood disadvantage, and poverty-related stress: Prospective effects on psychological syndromes among diverse low-income families. *J Econ Psychol* 2011;32:218-30. doi: 10.1016/j.joep.2009.10.008.
  17. Bjelland I, Krokstad S, Mykletun A, Dahl AA, Tell GS, Tambs K, *et al.* Does a higher educational level protect against anxiety and depression? The HUNT study. *Soc Sci Med* 2008;66:1334-45. doi: 10.1016/j.socscimed.2007.12.019.
  18. Rodrigue JR, Cornell DL, Howard RJ. Organ donation decision: Comparison of donor and nondonor families. *Am J Transplant* 2006;6:190-8. doi: 10.1111/j.1600-6143.2005.01130.x.
  19. Arnold R, Bartlett S, Bernat J, Colonna J, Dafoe D, Dubler N, *et al.* Financial incentives for cadaver organ donation: An ethical reappraisal. *Transplantation* 2002;73:1361-7. doi:10.1097/00007890-200204270-00034.
  20. Wu X, Fang Q. Financial compensation for deceased organ donation in China. *J Med Ethics* 2013;39:378-9. doi: 10.1136/medethics-2012-101037.
  21. Venkataramani AS, Martin EG, Vijayan A, Wellen JR. The impact of tax policies on living organ donations in the United States. *Am J Transplant* 2012;12:2133-40. doi: 10.1111/j.1600-6143.2012.04044.x.
  22. Martinsen EW. Physical activity in the prevention and treatment of anxiety and depression. *Nord J Psychiatry* 2008;62 Suppl 47:25-9. doi: 10.1080/08039480802315640.
  23. Hofmann SG, Sawyer AT, Witt AA, Oh D. The effect of mindfulness-based therapy on anxiety and depression: A meta-analytic review. *J Consult Clin Psychol* 2010;78:169-83. doi: 10.1037/a0018555.
  24. Dew MA, DiMartini AF, DeVito Dabbs AJ, Zuckoff A, Tan HP, McNulty ML, *et al.* Preventive intervention for living donor psychosocial outcomes: Feasibility and efficacy in a randomized controlled trial. *Am J Transplant* 2013;13:2672-84. doi: 10.1111/aji.12393.
  25. Huang J, Millis JM, Mao Y, Millis MA, Sang X, Zhong S, *et al.* A pilot programme of organ donation after cardiac death in China. *Lancet* 2012;379:862-5. doi: 10.1016/S0140-6736(11)61086-6.
  26. Huang J, Wang H, Fan ST, Zhao B, Zhang Z, Hao L, *et al.* The national program for deceased organ donation in China. *Transplantation* 2013;96:5-9. doi: 10.1097/TP.0b013e3182985491.