What do people think about brain banks? A survey of public awareness and attitudes toward brain research resource donation

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BACKGROUND
• The Korea Brain Bank was established in 2014. However, as of January 2023, only 232 individuals have been registered as post-mortem brain donors.
• Brain research resources are critical for comprehending the unique characteristics of brain diseases in Koreans. However, current resources are insufficient to meet researchers’ needs. Donations of brain research resources are lower than brain-dead organ donations.
• As such, it is necessary to identify factors that may affect brain donation.

OBJECTIVES
• To understand public awareness and attitudes toward brain banks and brain research donation.
• To identify levels of potential willingness to donate, and factors that may influence decisions regarding donation.
• To examine how cultural characteristics that are strongly influenced by family in medical decision-making, including organ donation, are reflected in brain donation, and what is valued as a donor recognition program for donors and their families.
• To identify the demand for information related to the post-donation process, such as autopsy reports and research outcomes.

METHODS
• Online survey comprising structured questionnaires were administered over 7-days (2021. 10. 21. - 2021. 10. 27.)
• Sampling: A simple proportional allocation method considering age, gender, and region, based on the statistics of the resident registration of the Ministry of the Interior and Safety at Aug 2021 was conducted.
• Respondents: Men and women aged 20-59 (N=1000)

RESULTS

(1) Awareness and Willingness

Fig.1. (A) Awareness of post-mortem brain donation and a brain-dead organ donation. (B) Willingness to register as a donor

(2) Factors influencing decision-making

Fig.2. Positive factors (A) and Negative factors (B) influencing the decision to be a brain donor

(3) Donation consultation

Fig.3. Persons with whom respondents want to consult regarding their post-mortem brain donation.

(4) Donor Recognition

Fig.4. Importance of donor recognition program.

(5) Family members’ influence

Fig.5. (A) Whether to respect and follow a family member’s wish to donate their brain. (B) Whether to proceed with a brain donation after registered donor’s death if the bereaved family objects.

(6) Demand for Information

Fig.6. (A) Willingness to receive a brain autopsy report. (B) Willingness to receive updates on the outcomes of brain research that have utilized resources donated by a donor or their family. (C) Willingness to receive updates on the status of brain bank resources.

(7) Resource distribution

Fig.7. (A) Willingness to share brain research resources with overseas researchers. (B) Willingness to share research resources with industry-affiliated researchers.

DISCUSSION
• Only about 30% of people are willing to register as brain resource donors, which is lower than the percentage of individuals who are willing to donate their organs after brain death (44.8%).
• There was a significant difference in the intention to register as a brain donor between those who were aware of brain donation and those who were not (46.5% vs. 20.8%).
• Of the factors that might influence donation, public good intentions, such as contributing to research, was the main positive factor, while vague fears were the most common negative factor.
• A majority of respondents (65.7%) valued consulting with their family members when deciding to donate. Further, over 60% of the respondents showed their willingness to respect the decision of other family members. However, only 36.4% stated they would proceed with the donation if they encountered opposition from family members.
• In addition to assistance with funeral arrangements, a high proportion of respondents emphasized the importance of autopsy reports, psychological counseling, and brain function testing as crucial components of a bereavement program.
• There is a high level of interest in informational aspects such as the results of the donor’s brain autopsy and the outcomes of research utilizing the donated resources.

CONCLUSIONS
• To encourage brain donation, it is important to raise public awareness about the significance of brain banks.
• Emotional support for bereaved families should be strengthened to ensure that family objections do not undermine the advance wishes of the donor.
• It is further crucial to develop strategies that respect the donor’s desire to contribute to research and to have a meaningful death by actively sharing information on the use of donated resources. In addition, transparency in brain bank operations should be promoted to help establish trust with the public.

ACKNOWLEDGEMENTS This study was part of a research program of the Korean Brain Central Bank Promotion Project (2021M3H9A1038D4712) by the Korea Brain Research Institute with support from the Ministry of Science and ICT.
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DISCLOSURE

▪ All authors have no conflict of interest to report in relation to this study.

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RESULTS (1) Awareness and Willingness

Fig 1. (A) Awareness of post-mortem brain donation and a brain-dead organ donation. (B) Willingness to register as a donor
RESULTS (2) Factors influencing decision-making

**A. Positive Factors**
1. Contributing to brain disease research and the development of prevention and treatment methods (66.0%)
2. Having a meaningful death (64.3%)
3. Receiving medical care, including cognitive function tests, while alive (63.1%)
4. Assistance with funeral arrangements for the donor's family, such as a funeral honorarium (60.6%)
5. Emotional support for the donor's family (e.g., psychological counseling, memorial events, etc.) (60.6%)
6. Allowing family members to learn the cause of the brain disease through autopsy results (58.2%)
7. Recommendations from family members (43.0%)
8. Recommendations from healthcare provider (34.8%)

**B. Negative Factors**
1. Vague fears and sense of rejection (59.8%)
2. Lack of information or counseling about donation (56.9%)
3. Lack of predictability of how donated resources will be utilized for research (55.8%)
4. Objections from family members (52.7%)
5. Privacy concerns (52.3%)
6. The possibility of facial or physical disfigurement after donation (48.0%)
7. The possibility of learning about a brain disease (37.7%)
8. Lack of time (33.5%)
9. Incompatibility with personal beliefs (28.4%)

Fig 2. Positive factors (A) and Negative Factors (B) influencing the decision to be a brain donor.
RESULTS (3) Donation consultation

Fig 3. Persons with whom respondents want to consult regarding their post-mortem brain donation.
RESULTS (4) Family members’ influence

Fig 4.
(A) Whether to respect and follow a family member’s wish to donate their brain.
(B) Whether to proceed with a brain donation after the registered donor’s death if the bereaved family objects.
RESULTS (5) Donor Recognition

1. Providing brain autopsy report
2. Psychological counseling
3. Brain function diagnostic services
4. Assistance with charnel house (10 years)
5. Assistance with cremation or funeral expenses
6. Memorial events
7. Bereavement meetings

Fig 5. Importance of donor recognition programs.
RESULTS (6) Demand for Information

Fig 6.
(A) Willingness to receive a brain autopsy report. (B) Willingness to receive updates on the outcomes of brain research that have utilized resources donated by a donor or their family. (C) Willingness to receive updates on the status of brain bank resources.
RESULTS (7) Resource distribution

Fig 7.
(A) Willingness to share brain research resources with foreign research organizations or international consortiums,
(B) with industry-affiliated researchers.
DISCUSSION

▪ Only about 30% of people are willing to register as brain resource donors, which is lower than the percentage of individuals who are willing to donate their organs after brain death (44.8%).

▪ There was a significant difference in the intention to register as a brain donor between those who were aware of brain donation and those who were not (46.5% vs. 20.8%).

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▪ In addition to assistance with funeral arrangements, a high proportion of respondents emphasized the importance of autopsy reports, psychological counseling, and brain function testing as crucial components of a bereavement program.

▪ There is a high level of interest in informational aspects such as the results of the donor's brain autopsy and the outcomes of research utilizing the donated resources.
CONCLUSIONS

▪ To encourage brain donation, it is important to raise public awareness about the significance of brain banks.

▪ Emotional support for bereaved families should be strengthened to ensure that family objections do not undermine the advance wishes of the donor.

▪ It is further crucial to develop strategies that respect the donor's desire to contribute to research and to have a meaningful death by actively sharing information on the use of donated resources. In addition, transparency in brain bank operations should be promoted to help establish trust with the public.