

BRIEF COMMUNICATION

Frequency of brain tissue donation for research after suicide

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Objectives: To describe the frequency of brain tissue donation for research purposes by families of individuals that committed suicide.

Methods: All requests for brain tissue donation to a brain biorepository made to the families of individuals aged 18-60 years who had committed suicide between March 2014 and February 2016 were included. Cases presenting with brain damage due to acute trauma were excluded.

Results: Fifty-six cases of suicide were reported. Of these, 24 fulfilled the exclusion criteria, and 11 others were excluded because no next of kin was found to provide informed consent. Of the 21 remaining cases, brain tissue donation was authorized in nine (tissue fragments in seven and the entire organ in two).

Conclusions: Donation of brain tissue from suicide cases for research purposes is feasible. The acceptance rate of 42.8% in our sample is in accordance with international data on such donations, and similar to rates reported for neurodegenerative diseases.

Keywords: Suicide; ethics; community mental health; molecular biology; neuroanatomy

Introduction

Obtaining central nervous system tissue is essential for neurobiological research in mental health. There is a growing demand for the availability of human brain tissue, with greater interest in using these tissues for investigation of basic biological processes associated with mental illness. In the current scenario, however, brain tissue biobanks dedicated to psychiatric disorders are extremely scarce.¹

Little is known about organ donation for research.² The main reasons and facilitators found for donation to biobanks are: 1) the desire to help others; 2) open dialogue within the family about the organ donation process^{3,4}; and 3) a desire to contribute to medical progress.^{2,5} Preliminary reports indicate that the donation process does not induce anxiety among families, and suggest that this practice should be offered to all bereaved families.⁶

In transplant studies, a majority of the people are willing to donate, but less than 50% of their families consent at the time of organ removal.⁷ Data on research-related donations report consent rates varying from 18 to 92.8%, depending on the methodology used.² Higher rates are found among patients with neurodegenerative diseases who provide explicit consent in life.²

Unlike in neurodegenerative diseases, in psychiatric disorders death is often unpredictable – and violent. Suicide

is the most tragic consequence of mental illness, and there is now a strong consensus on the link between them.^{8,9} This reinforces the importance of developing biobanks and biorepositories of brains of individuals who committed suicide. Such violent deaths represent an opportunity not only to study the biology of suicide, but also the most serious expressions of the various associated mental disorders.

There is evidence to suggest that the organ donation rate in cases of suicide – specifically for transplantation – is higher than in other causes of death.¹⁰ Data on organ donation for research in cases of suicide, however, are absent.

Based on the extreme lack of data on organ donation for research in our population¹¹ and the need to better understand population stances in relation to brain tissue donation for research, the aim of this study was to describe the frequency of brain tissue donation for research purposes by family members of individuals who committed suicide during the first 2 years of operation of a brain tissue biorepository established specifically for this purpose in Brazil, as well as to elucidate and report reasons for not obtaining consent for such donations.

Methods

This is a descriptive study. All research took place in the morgue of the Medicolegal Department of the General Institute of Forensics (Instituto Geral de Perícias, IGP), an autonomous agency of the Rio Grande do Sul State Department of Public Safety.

The study included requests for brain donation made to relatives of individuals who had committed suicide and undergone autopsy between March 2014 and February 2016. According to the biorepository protocol, individuals aged 18-60 years who had committed suicide were eligible for inclusion. The exclusion criteria were brain lesions due to trauma at the time of death or suicide by drug overdose.

Consent could be signed by the next of kin or legal representative (in order: spouse, parents, children, grandparents, brothers, and uncles). At the time of the request, family members were informed of the objectives of the study and all questions were answered. The project was approved by the local Ethics Committee, and all individuals provided informed consent for participation in the study.

Due to logistical reasons, all approaches were made during the week during office hours. Per protocol, the next of kin or legal representative of each subject could authorize donation of the whole brain or of a fragment of the prefrontal cortex. This option was offered because previous international studies have shown that a substantial proportion of families are reluctant to consent to whole-brain donation.⁶ Regardless of consenting to the donation, family members were also invited to a subsequent interview that included psychological autopsy and a study of organ donation and bereavement. When the next of kin or legal representative did not consent to the donation, the reason for refusal was explored. Individuals were approached by qualified professionals trained to deal with bereavement (two psychiatrists, two psychologists, and a nurse). Support was offered to participants who either requested it or were deemed by the interviewer to need it during the request for organ donation.

Results

During the period of analysis, 56 suicide cases referred to the Medicolegal Department in Porto Alegre were reported and eligible for the study. However, 24 of these fulfilled the exclusion criteria. A further 11 cases whose families were not present to sign the consent form were also excluded. Finally, in the 21 remaining cases, nine (42.8%) legal representatives authorized tissue donation: seven consented to fragment donation and two to whole-brain donation. The other 12 (57.2%) refused to donate.

The sample was composed mainly of men, with a mean age of 39 years. Those responsible for providing informed consent were most often siblings, followed by the children of the tissue donor (Table 1). The stated reasons

for donation were mainly to help others in the same situation. Reasons for refusing donation included disagreement among family members (three cases), subjects who had allegedly expressed an unwillingness to donate – presumably for transplant reasons – while alive (two cases), insecurity about the donation (one case), and insecurity about the cause of death (one case). For the remaining five refusals, no reason was volunteered.

Discussion

We report new data regarding the frequency of brain tissue donation by legal representatives of individuals who committed suicide. Consent was obtained in 42.8% of cases in which donation was discussed. Donation of a tissue fragment was more frequent than whole-brain donation.

This acceptance rate is in accordance with international data on donations in cases of neurodegenerative diseases. Garrick⁴ reported an acceptance rate of 54% in research-related donations of brain tissue. An Australian study³ reported 58% acceptance rates; the main reasons were the desire to help others and open dialogue within the family about the organ donation process. Some studies are outliers, such as Millar's,⁶ in which 96% of families authorized retention of tissue samples for research and 17% agreed to whole brain donation. The extent to which local and idiosyncratic factors influence these rates is unclear.

Previous international studies on the difference between partial or whole-brain donation suggest that fear of mutilation caused by the retrieval process and discomfort regarding an incomplete body are the main reasons why families prefer to donate fragments only.^{3,4,12} Although the apparently low number of whole-brain donations could indeed reflect this reluctance by Brazilian families, such interpretations should be made with caution. This is still an early case series, with substantial room for change.

This study addressed families bereaved by suicide, and there are no comprehensive investigations on how this process differs in comparison to donations made to biobanks when consent was given in life. While consent for donations in the context of neurodegenerative diseases is usually given by the patient, when the cause of death is suicide this rarely occurs.¹³ Families affected by suicide may find it difficult to consent to donation, as the grieving process can impair understanding of information.¹⁴ Furthermore, the bereavement generated by

Table 1 Sample characteristics

	Donation n = 9	Refusal n = 12
Gender, male	7 (77.8)	10 (83.3)
Age, mean (standard deviation)	39.4 (12.6)	39.6 (9.7)
Kinship of person authorizing donation		
Parents	2 (22.2)	3 (25.0)
Siblings	3 (33.3)	6 (50.0)
Children	1 (11.1)	2 (16.7)
Spouse	2 (22.2)	1 (8.3)
Other	1 (11.1)	0 (0.0)

Data presented as n (%), unless otherwise specified.

suicide is associated with higher rates of depression and anxiety disorder compared to other sudden deaths.¹⁵

Nevertheless, in a recent qualitative study, patients with bipolar disorder reported that they were willing to reflect on the subject of organ donation for research, considering it a good thing and that they could save lives by helping advance medicine.¹⁶ Altruism is an established reason to justify donations for research.⁴ A Scottish study revealed a unanimous view of organ donation as a good thing, and found that reasons for agreeing to brain donation were altruistic.¹² A Swedish survey showed through interviews made after the donation process that ethically sound studies do not cause harm to suicide-bereaved parents, and found that the great majority of participants reported gratitude for participating in the study.¹⁷

The present study did not set out to conduct an epidemiological assessment on the subject, and one limitation is the relatively low number of requests. The fact that the research group was only able to approach individuals for donation on a limited number of weekdays may have offered a limited view of the process. Moreover, when no next of kin or legal representative could be identified before autopsy, the case was excluded. This can lead to bias, as the profile of these individuals may have differed from that of cases whose families were promptly located. Nevertheless, according to the latest data from the Brazilian Ministry of Health, there were 107 suicides in the catchment area of the study in 2013. Of these, 67% were by hanging. Thus, estimating 143 suicides in the period of analysis, the 56 reported cases would represent around 40% of the total, which is consistent with the presence of staff on site.

Obtaining consent for donation for research purposes is an essential process for establishing relevant brain banks and repositories and, ultimately, elucidating the neurobiology of suicide and severe mental illness. Understanding factors specific to this situation is crucial, as these donations are most likely to be made by family members after a violent and unexpected death. In the present study, we report on the feasibility of brain tissue donation for research purposes. That acceptance rates for such donations were similar to those reported for neurodegenerative diseases is a relevant fact for the development of tissue biobanking in Brazil and, specifically, brain banking in mental health.

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Disclosure

The authors report no conflicts of interest.

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