

REFLECTIONS

A human perspective on body donation: A case study from a psychosocial perspective

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Using a case study of how a son consented to his mother becoming a body donor, the factors that may have contributed to that decision are outlined. Social and psychological considerations about body donation in general are presented. These are followed by suggestions for organisational improvements for healthcare facilities and medical schools, including ease of access to accurate information for both medical professionals and members of the public. Finally, it is recommended that medical school staff dealing with potential donors and their families should be trained to communicate empathically and with compassion.

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While helping family members prepare for the imminent death of a loved one, there may be discussion around procedures to be followed after death in a hospital ward or at home, such as appointment of an undertaker. The family situation described below (names changed) highlights the importance of a compassionate response to discussion around the topic of body donation, and the relief that adequate information can provide to the family.

Case study

In 2012, Mrs X signed a Living Will, including a gentle preamble and some instructions to her family that requested that her body be donated to medical science. She was 78 years old at the time, and apart from some arthritic pains, was living an independent life.

In early 2015, Mrs X died of metastatic lung cancer, having outlived her husband and one of her sons. She had been in pain, and had experienced a partial spinal cord compression which required hospitalisation. Her remaining son, John, had numerous conversations with the oncology social worker about his mother's quality of life and symptom management. While in hospital Mrs X became aggressive and confused; brain metastases were diagnosed, and John and the oncologist made the joint decision not to treat these, as the patient's overall condition was deteriorating.

John had already discussed his mother's wish to die peacefully with his mother's oncologist, the medical officer caring for her in the ward, and the social worker. She was nursed in a private ward until her death.

During the preterminal phase of his mother's illness, John found the Living Will document and discussed the contents with the social worker five days before his mother's death. He was conflicted regarding its content – he wanted to honour his mother's wishes, but had reservations about whether he wanted her body to be used by medical science. He had discussed the situation with a trusted friend, who had advised him to pursue the directive and did not have any religious or cultural objections. John felt that he would be reassured if he knew what process to follow, and how the logistics would be

organised. This would reduce his stress, and allow him to focus on his own grief and that of his family.

On exploration of John's quandary, the social worker learned that he felt alone in his decision, without any siblings to share the responsibility, and was uncertain about how to make the necessary arrangements if he proceeded with his mother's directive. Following enquiry at the local university's medical school, the necessary paperwork was obtained. Both John and the social worker were provided with clear instructions that were shared in turn with the medical attendants and ward staff. He was required to forward the Living Will document to the medical school contact, along with his signed consent on his mother's behalf and a copy of her identity document. Information was obtained about which undertakers would be used to remove Mrs X's body, and John was able to decide whether or not he wanted the body to be available for a funeral, or whether he would like the ashes returned to him after cremation.

During conversations in the remaining few days, and after the death of his mother, John expressed gratitude and reassurance that he had clarity about the arrangements, and that he had had personal contact with a very pleasant and professional person at the medical school. This contact gave John the confidence that he had made the correct decision, after discussion with his family, who had supported him in this.

Discussion

On reflecting on this case, the social worker wondered what factors may encourage family members to support a decision on body donation. There are many academic articles about organ donation that explore cultural and religious factors, and the influences on family members to proceed with such donations. However, there appears to be little formal information to assist the family members of body donors, or the potential donors themselves.

What follows is a brief observation of some possible factors that may encourage body donation.

Honouring the wishes of the deceased

This is likely to be a primary driver for families to support a loved one's decision to donate their body to medical research. It has been

suggested in the academic literature that an individual's desire to become a body donor suggests an autonomous character in life, and a relatively unconventional approach towards disposal of his/her own remains after death.^[1] If a person has displayed such strength of character and opinion, family members are likely to feel duty bound to honour their wishes after the person is dead.

Ease of access to information regarding logistics after death

The period leading up to the death of someone who is terminally ill is frequently a time of some disorganisation within the family system, and confusion about roles, responsibilities and rights of family members. If they are aware of the dying person's intention to donate their body, the family may have little or no knowledge of how to act on this intention. Medical school websites are designed for students and academics to navigate, and simply accessing information about who to contact and what paperwork is required calls on investigative skills and time that family members may not have. In the case of Mrs X, this process was facilitated by the social worker, thereby reducing additional stress on the decision-maker.

Trust in the logistical arrangements

There is a very real human need to trust that the deceased's body will be respectfully removed and handled by professionals.^[2] Details of reputable undertakers who work with the relevant medical school are therefore helpful. Likewise, having 24-hour contact numbers for the undertakers alleviates concern about arrangements after death. For John, this certainty permitted him to move in and out of his mother's room, without a desperate need to be there 'at the end' or to oversee arrangements after she had died.

Sense of purpose/need in the donation

This factor may seem self-explanatory, but in a culture where urban mythology suggests that medical schools have 'too many bodies' (whereas in fact there is a paucity of cadavers in certain medical schools in South Africa, and elsewhere in the world^[1-3]), it was helpful and encouraging for John to know that his mother's body would be welcomed and would be of use to the university. There are exclusion criteria for body donations, which may vary between medical schools; these criteria are understandable in the context of academic study of the body, and obtaining clarity about them ahead of time can once again reduce stress for the family.

Altruism

For many people, motivation for requesting donation of their body is based on a sense of altruism – of making a contribution to the learning of students, or to the body of medical knowledge in general.^[2-4] John may have found some comfort in this aspect, as he recalled that his mother had been treated with a new medication several years previously, and had been diligently followed up by her doctor over the subsequent years to monitor its effect. John informed the liaison person at the university of these details, with the thought that there might be evidence of the response/treatment when her body was examined. There is no way of knowing whether the medical school used that specific information, but for John there was a possibility that his mother's experience in life could aid the development of medical treatments after her death, and confirm

that her body donation could make a contribution to medical knowledge.

In South Africa the family members of body donors are not financially rewarded, but the costs of removal of the body to the medical school (within a certain radius) and cremation are covered by the university.

Support and guidance

What information and structures could support and guide people facing decisions about body donation?

Ideally, the prospective donor should discuss their intention with the family before illness or frailty sets in – debate and discussion at this stage should facilitate easier and smoother decision-making in future.

Hospitals and other places of care where death commonly occurs should have current information readily available for family members who may make enquiries. Staff such as social workers, psychologists and nurses should be able to access this information with ease. Even if it is not a common situation, the request for body donation could be included in the institution's standard operating procedures. This access to information is described by Valderrama-Canales *et al.*^[5] as 'transparency of data' (p. 165), with the implication that easier access to information regarding body donation would lead to an increased number of donations.

Medical students should be made aware of the process of body donation, so that they are able to pass this information on to patients once they are practising as doctors.^[2]

University medical schools and their websites could have details or links that are easy to find and navigate, bearing in mind that many would-be donors will not know which department works with cadavers, and may therefore battle to find the correct person to assist them.

Personnel at medical schools who are likely to encounter such enquiries should be equipped with current information, should have easy access to the necessary paperwork, and should possibly receive training in working with members of the public in an empathic and compassionate manner, rather than in a clinical fashion that could be perceived by family members as emotionally cold or unfeeling.

Conclusion

It is suggested that clear communication between family members and ease of access to information about body donation would considerably assist people in the decision to commit to being body donors. Staff involved in receiving such donations should be professional in their approach, with excellent insight into the dilemmas faced by families as they move towards consenting to the donation.

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