







Narrative for systemic map

Many families who consent to organ donation hope to find meaning in their decision. While awareness campaigns refer to donation as a *gift of life*, families may experience ambiguity when the decision is difficult and painful in addition to being an opportunity to help others. Viewing themselves as facilitating organ donation on behalf of the donor, can contribute to a sense of unity, a post-death psychological attachment to their relative and a sense of connection with recipients.

However, if the family struggles to accept death, the donor's preferences were unclear, or there was disagreement amongst family members, complications may emerge. Secondary losses may be experienced when transplants fail, or recipients die.

Before transplant, potential recipients experience progressive organ failure and reduced quality of life. Receiving a transplant offers hope but this may be diminished by a sense of guilt and unworthiness. Recipients may seek to address their crisis by acknowledging the donor family's grief and honouring the donor. Resolving these psychological stressors has been linked to recovery from surgery and adherence to their treatment regimen.

Regardless of how personality and behavioural changes experienced by recipients are interpreted, they may contribute to ambivalence and identity disruption. Recipients are unlikely to openly discuss these struggles when doctors view transplantation as an exchange of *spare parts*.

When parties trust that healthcare professionals understand the breadth and depth of their experience rather than viewing it in terms of the popular metaphors, a supportive environment can emerge where they feel free to express their concerns.

Recognising the relationship between donor families and recipients, healthcare professionals may provide anonymous information to each of the parties. Information about transplant outcomes and recipient progress would assist the donor's family to develop a conclusion to the deceased's biography, and a continuation of the family's narrative; while information about the donor as a person may assist recipients to resolve identity disruption and guilt.

For some, this anonymous information may be sufficient while others may feel that more is needed. Information about risks and benefits of options such as anonymous correspondence can be provided.

Each of the parties may require some encouragement before writing. Donor families often want to provide information about the donor as a person and receive information about

the ways that transplantation changed the lives of recipients, while recipients may write to acknowledge the family's grief and show gratitude.

After writing a letter it is possible that there will be a delay before a response is received or there may be no response. Healthcare professionals could assist by managing expectations. In time, a threshold may be reached, and parties may explore the possibility of meeting in person.

In the ways described, donor families and recipients often develop a sense of connection that assists them to develop a confident post donation / transplantation identity and positive psychological relationship with the deceased. This can have a positive influence on each party's ongoing adjustment, enabling them to attend to their respective challenges in ways that contribute to personal growth and a restructuring of priorities.

Regulating organisations and researchers are also active participants in the system. Researchers can contribute to improved understanding of risks and benefits leading to informed decisions. Regulating authorities have the responsibility of protecting not only the stakeholders, but the system as a whole. Their need to reduce the potential for harm may lead to cautious decisions attending to certain needs, such as comfort and support, rather than others, such as autonomy and empowerment.

Unfortunately, dividing the system in this way could contribute to an unexpected development. For example, while focussing on vulnerability, organisations may restrict contact and use the *gift* or *spare parts* metaphors. However, when recipients experience the need to explain and come to terms with post-transplant behavioural changes, express gratitude, or deal with guilt, or when donor families need concrete evidence of the value of their decision, these metaphors are inadequate and may contribute to ambivalence and distress.

In contrast to the aims of the organisations involved, this distress may increase each party's motivation to meet and for some, direct contact may become vital to the development of their identity, narrative and ongoing adjustment. Researchers and organisations whose findings and decisions inform the scope of healthcare professionals' practice and donor family and recipient options have a responsibility to explore this complex system and find paths that balance protection from harm with facilitation of benefit and consider principles such as autonomy and informed choice.