Children as stem cell donors

- The ethics and beyond…

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Introduction

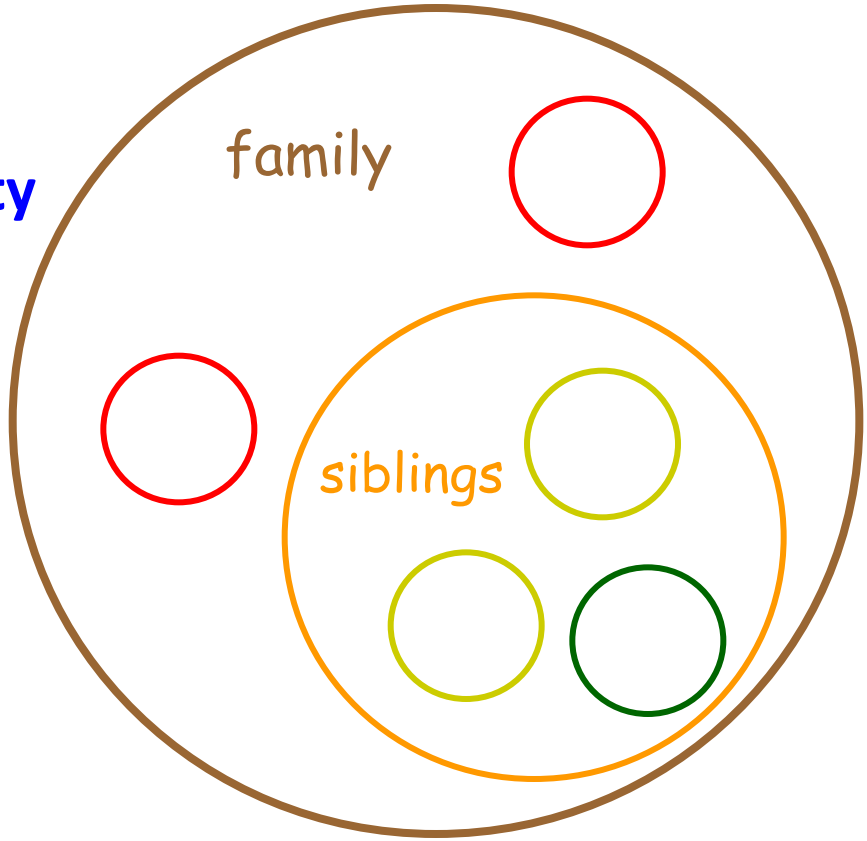
The majority of allogeneic transplants in Latin America are from family members

When the patient is a child…

…than the donor m/p would be his/her sibling – healthy child

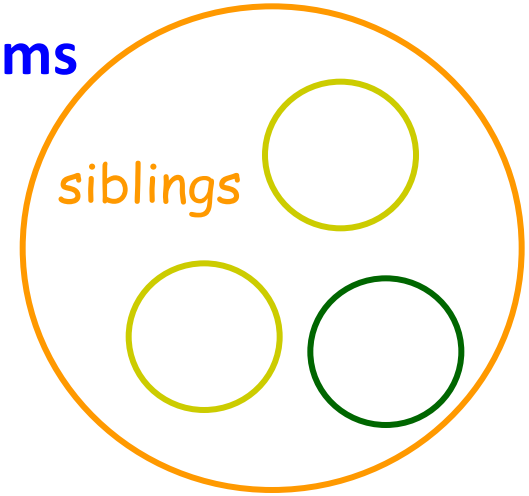
The family

- A social system
- Shared reality
- Shared conflicts and prosperity
- Dynamic system

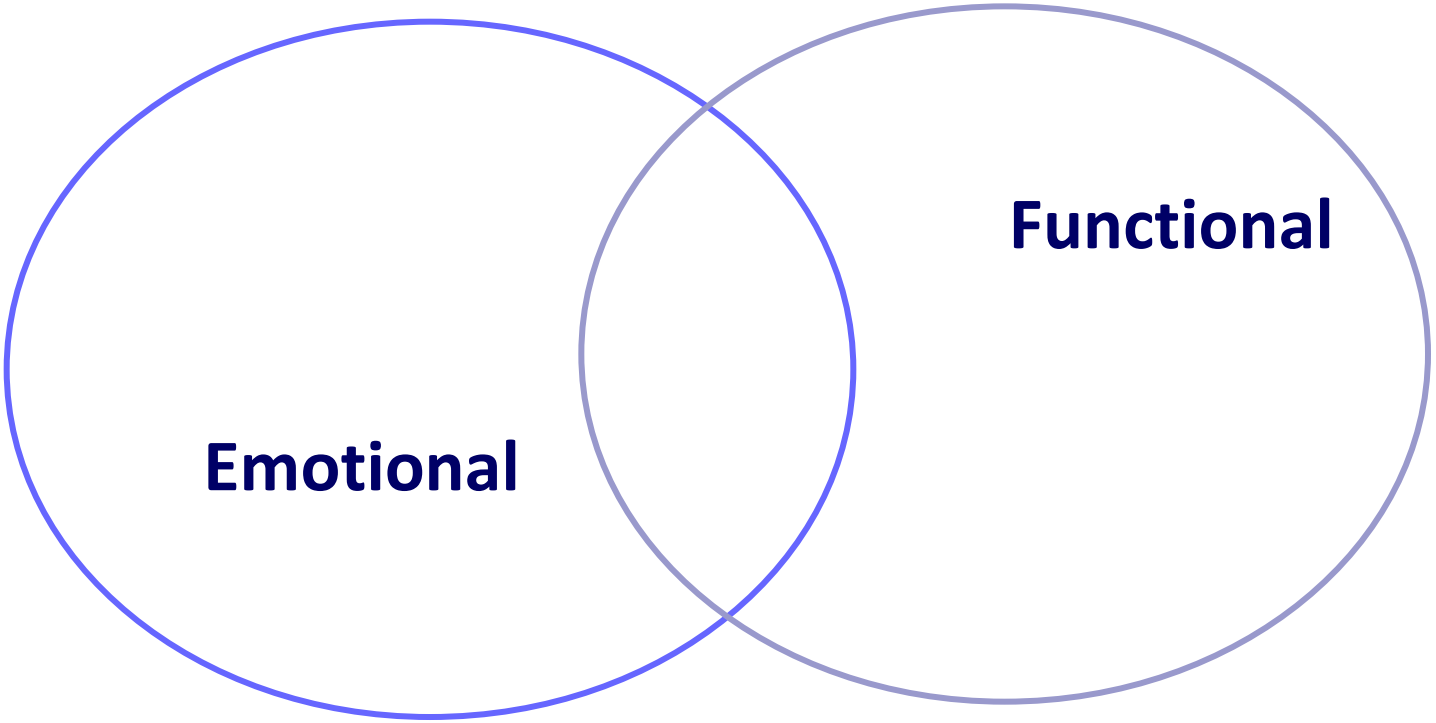


Siblings

- Shared genetic background
- Shared behaviors and feelings
- Mutual experiences
- Similarities in perceptions & value systems
- Emotional bonds



Siblings – cont.



Family relations

- Giving, receiving & asking for help.
- The background and the backup.
- Moral obligation.
- Sibling subsystem –
  - Expectations are not clear.
  - Depends on age of both siblings (donor and patient)

History and numbers…

- First pediatric sibling transplant – 1968 in Leiden, The Netherlands
- ~3000 annual worldwide sibling pediatric donations.
- 600-700 children in Europe donate for their siblings each year.
- 39%-48% of all childhood transplantations benefits from sibling donors donations.
- Bone marrow harvesting is still the major source for stem cells in pediatric transplantations, followed by peripheral blood and cord blood-derived.

Dilemmas…

- The exposure of a healthy child to a potentially harmful medical procedure with no direct clinical benefit, counterpoised by the positive emotional impact of saving a seriously ill sibling.

Delany L, et al. **Altruism by proxy: volunteering children for bone marrow donation.** BMJ 1996; 312: 240–243.

Dilemmas…

- **What is the minimum age for harvesting a child?**

- **Informed consent:**
  - **a. Young children are considered incapable of giving informed consent.**
  - **b. Informed consent procedures for child donors have only lately been specifically addressed.**
  - **c. Parents or legal representatives give proxy consent for BM harvest.**
    - **- leaving the donor no choice but to donate.**
  - **d. The notion that legal representative, an advocate, is required to protect the interest of young donors is still in its infancy.**

Dilemmas…

- **Donor follow-up:**
  - **a. Demands coming from donor registries.**
  - **b. Individual transplant centers presently develop pediatric donor care programs.**
  - **c. FACT–JACIE standards now mandate creation of a policy for minor donors.**

Dilemmas…

- **The donor experience:**
  - **a. In adult sibling donors –**
    - **physical side effects are outweighed by psychosocial gains.**
  - **b. Limited literature on –**
    - **immediate or long-term effects of childhood BM donation.**
    - **the use of hematopoietic growth factors in children.**
  - **c. Research has concentrated more on psychosocial effects than on physical outcome.**

Medical ⟷ **Psychological**

Clinical ⟷ **Ethical**

Medical risks and benefits…

- **No direct medical benefit from serving as a stem cell donor.**
- **Risks:**
  - **a. Complication rate – 1.1% (for adults and children)[1].**
  - **b. Estimated death incidence of 1 death per 10000 donations[1].**
  - **c. Most children younger than 12 years require central vascular access[2].**
  - **d. Exposure to blood products – pRBC, Thrombocytes[2].**
  - **e. Exposure to GCSF (affects myeloid cells, chromosomal integrity and gene expression)[3].**

1. Confer DL. Hematopoietic cell donors. In: Blume KG, Forman SJ, Appelbaum F, eds. *Thomas' Hematopoietic Cell Transplantation*. MA: Blackwell; 2004:538 –549 Vol 1.Malden.
2. Pulsipher MA, et al. *Bone Marrow Transplant*. 2005;35(4):361–367.
3. Anderlini P, Champlin RE. *Blood.* 2008;111(4):1767–1772.

Psychosocial risks and benefits…

- **Benefit of helping a sibling or other close family member.**
- **Risks:**
  - **a. Many children experience distress related to their role as a donor[1,2].**
  - **b. Believe that they did not have a choice[1,2].**
  - **c. Report being poorly prepared for the procedures[1,2].**
  - **d. Describe feeling responsible for the recipient's course after transplantation[1,2].**
  - **e. Until engraftment occurs, donors often feel neglected (..this is also true of non-donor siblings)[3].**

1. MacLeod KD, et al. *J Pediatr Psychol.* 2003;28(4):223–231.
2. Weisz V, et al. *Behav Sci Law.* 1996;14(4):375–391.
3. Shama WI. *Soc Work Health Care.* 1998;27(1):89 –99.

Sitting for setting

A need to set international criteria and recommendations for the treatment and benefit of pediatric donors.

On September 12th -13th –

The 3rd WBMT Donor Outcome Workshop
September 12-13, 2013
Vienna, Austria

First time – pediatric donor issues were addressed

The goal - to set international and global criteria for management of pediatric donors

Summary

- The patient and the donor are from the same family.
- The parents are biased between “what is good?” for the patient and the donor.
- The donor is a minor, and this causes unique medical and psychosocial problems.
- This in tern, needs special attention both for the clinical and the ethical aspects.
- The WBMT with its committee for donor issues is going to address this topic and is going to set criteria for how to manage and how to take care for pediatric donors, soon.

Obrigado

Thank you

Gracias