

Some children who donate cells to a brother or sister have a lower quality of life and need extra support

What were researchers trying to learn?

Researchers wanted to learn how children who donated cells to a brother or sister were affected by the experience. They wanted to learn about the children's physical, emotional, and social health. This is called their quality of life (QOL). The researchers also wanted to learn whether parents knew how donation affected their child.

Donating cells for transplant is very safe, but it's not completely risk-free for the donor. It's important to find out how children who donate to an ill brother or sister may feel.

The researchers talked to more than 100 donors and their parents by phone. They talked to them at 3 different times:

- Before donating
- 4 weeks after donating
- 1 year after donating

Each time they asked questions about the donor's QOL, including their physical and emotional health and school life. The donors were all between 5 and 18 years old.

What did they find?

The researchers found that at each time about 20% of donors (1 in 5) had very poor QOL. But very few children (5%, or 1 in 20) had poor QOL at all 3 times.

They also found that parents overestimated their child's QOL each time. In other words, parents thought that their children who donated were doing better than they actually were.

Finally, the researchers learned that younger children (5-7 years old) were more likely to have a lower QOL compared to older children (8-18 years old).

Important Points:

- **About 20% of donors (1 in 5) at each time point had very poor QOL.**
- **Parents tended to overestimate their child's QOL.**
- **Younger children were more likely to have a lower QOL.**

Why is this important?

The results of this study will help doctors and parents understand how children might feel after donating to a sibling. It may also help doctors know when children need extra support.

What else should I keep in mind about this study?

The results of research studies are always limited in what they can and can't tell you. With this study, the researchers couldn't tell what caused a child's poor QOL. It may have been from the stress of having a seriously ill sibling, the physical effects of donating cells, or a combination of each.

Also, the researchers only studied the QOL of children up to 1 year after transplant. So we don't know if the children who donated had better, worse, or similar QOL more than 1 year later.

Questions to ask your doctor

If your child donates cells for a sibling's transplant, you may want to ask:

- What signs or symptoms of stress could my child have after donating for a sibling?
- Does this transplant center have resources, like a donor advocate, to help support my child?
- How can I support my child before and after donating cells?

Learn more about

- [This research study](#)
- [Blood and marrow donation](#)

Source:

Switzer GE, Bruce J, Kiefer DM, et al. Health-related quality of life among pediatric hematopoietic stem cell donors. *The Journal of Pediatrics*. 2016 Nov 30; 178: 164-170. Epub 2016 Aug 10. PMC5085860.

About this research summary

Ground-breaking research into blood and marrow transplant is happening every day. That research is having a significant impact on the survival and quality of life of thousands of transplant patients. But the research is written by scientists for scientists. By providing research news in an easy-to-understand way, patients, caregivers, and families have access to useful information that can help them make treatment decisions.

This information is provided on behalf of the Consumer Advocacy Committee of the CIBMTR[®] (Center for International Blood and Marrow Transplant Research[®]). The CIBMTR is a research collaboration between the National Marrow Donor Program[®]/Be The Match[®] and the Medical College of Wisconsin.
