

Patients, families and caregivers need transplant info

Blood and marrow transplant (BMT) is a highly complex treatment that can affect health for years afterward. Patients, caregivers and families receive a lot of information throughout BMT.

What is the best way to provide information? And what are priorities for future researchers who want to study BMT patient education? A group of volunteers met regularly for 2 years to help answer these questions. They reviewed 230 articles on patient education and transplant. The group included:

- 8 BMT healthcare providers (2 doctors, 2 nurses and 1 social worker)
- 3 BMT recipients
- 1 BMT caregiver
- 2 staff from Be The Match[®]

The group found:

1. Education requires close attention the patient, caregiver, family, educator, the education material and the method.
2. Caregivers and family members need education that is tailored for them and their needs.
3. While the healthcare team may focus on education to increase patients' knowledge, patients also value education because it may help them feel less distressed and more confident that they can take an active role in their recovery.

The group advised making a standard BMT education program. Ideally, the program would:

- help people across all cultures, incomes and educations;
- provide reliable, up-to-date info on effects of BMT, sexual health and advanced care planning;
- offer an option for self-directed learning, so people with different needs can get the information they need at the time that is most appropriate for them.

Future research should focus on how patient and caregiver/family education impacts life after BMT.



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About this research summary

This information is provided on behalf of the Consumer Advocacy Committee of the CIBMTR[®] (Center for International Blood and Marrow Transplant Research[®]).

Source

Schoemans HM, Finn L, Foster J, et al. A Conceptual Framework and Key Research Questions in Educational Needs of Blood and Marrow Transplantation Patients, Caregivers, and Families. *Biology of Blood and Marrow Transplantation*. doi: 10.1016/j.bbmt.2019.02.017. Epub 2019 Feb 20. [Epub ahead of print]doi:10.3324/haematol.2018.203919. Epub 2018 Dec 4.

