

The emotional and psychological impact of blood and marrow transplant

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Incidence of Psychological Disorders during transplant

- Rates of depression among general cancer patients range from 10%–25%
- Whereas in some studies, rates of depression among the transplant population are higher, ranging from 25% to 50%.
- From time of admission to discharge, anxiety symptoms decrease, and depressive symptoms increase.

Incidence of Psychological Distress following HCT transplant

- 26–28% of allogeneic transplant recipients report significant depressive symptoms at 1 year post-transplant.

The impact of psychological distress

- Psychological morbidity is associated with significantly increased LOS.
- Higher levels of depression among transplant patients affect post transplant physical health symptoms, increase symptom-related distress, and contribute to a higher suicide rate.
- Depression predicts mortality following transplant.

Predictors of psychological distress in transplant patients.

- Patient Factors:
 - Previous psychiatric morbidity
 - Pre-transplant compliance issues
 - Younger age
 - Female sex
 - Avoidant coping strategy (escape-avoidance, distancing and denial)
 - Recent smoking cessation
 - Lower functional status upon admission

Predictors of psychological distress in transplant patients.

- Environmental Factors:
 - Problems with presence, quality and perception of social support
 - The presence of difficult relationships
 - Professional reintegration concerns

Predictors of psychological distress in transplant patients.

- Transplant Factors:
 - Persistent symptoms such as chronic pain
 - Increased regimen-related toxicity
 - Slower physical recovery
 - Chronic graft-versus-host disease (cGVHD)
 - Negative appraisal of the transplant experience
 - Body image disturbance
 - Fears of relapse and secondary malignancies
 - Sexual function disruption

Coping

- Protective buffering
 - Defined as ‘hiding one’s concerns, denying one’s worries, concealing discouraging information, trying not to discuss the cancer and yielding in order to avoid disagreement.
 - “I suppose like anything in life there’s probably a lot of pretending . . . we pretend an awful lot and you have to, like, put on the good face at home”

Coping

- Avoidance
 - “I mean I did my degree while I got leukaemia so that took me through three years. I hadn’t it on my mind all the time—I was too busy at college to think about it really, so I thought that was a big help.”

Coping

- Balancing optimism and realism

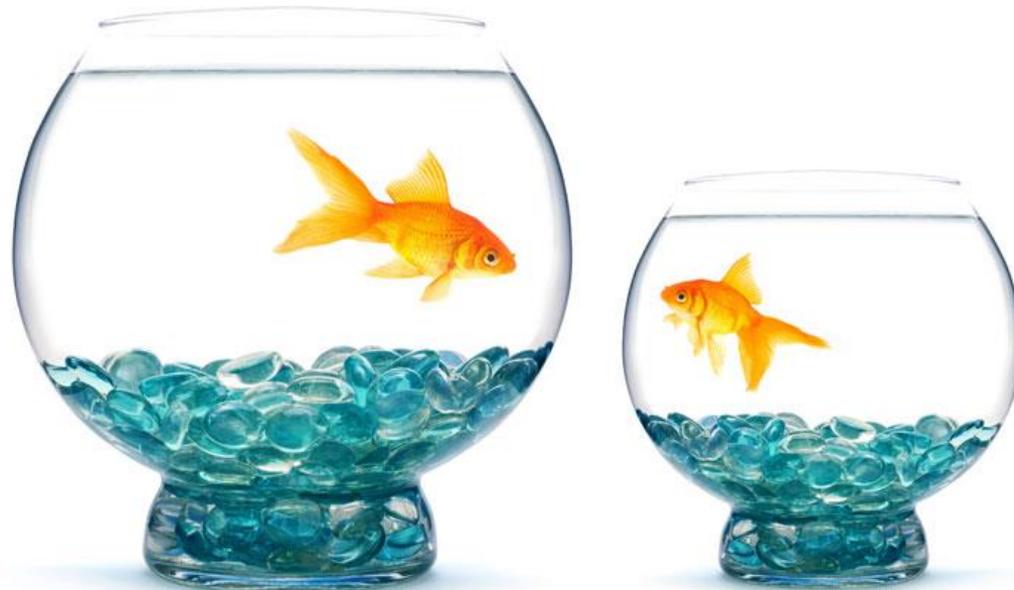


Coping

- Expectation shift
 - “rather than think I wish I could be doing this, I wish I could be doing that. I don’t, I just say right, I’m not going to be able to do this, I’ll shrink it...so you cope that way really.”
 - “I enjoy the simple pleasures in life more, don’t expect too much, which is nice, it means you can be easily satisfied.”

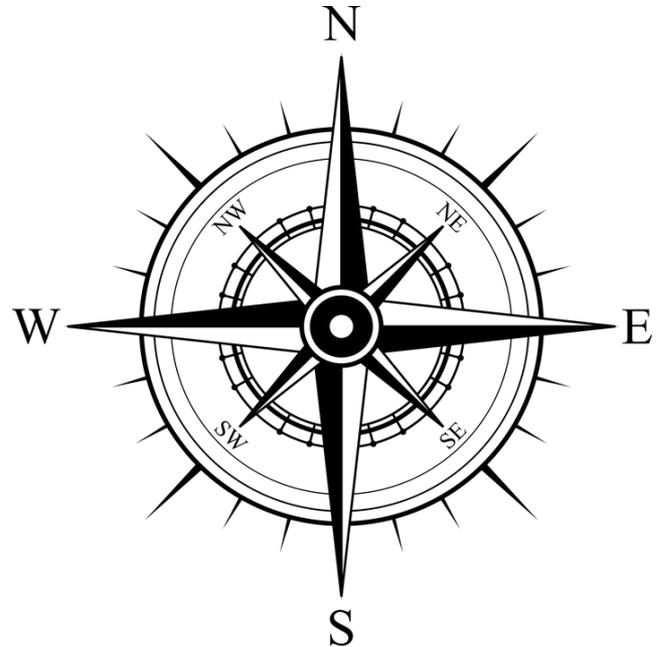
Coping

- Social comparison (up and down)



Coping

- Values clarification or shift
 - “I always said I would have money but I’m not bothered about it now.”



Donors

- “He became very ill and that was a time of very high anxiety and uncertainty as to whether he would survive. I guess at that point I felt some sense of responsibility. My head knows that I am not responsible, but my heart felt ‘wouldn’t it be awful (if) I was part of that process?’”

Relationships

- Cancer must be viewed in the family context.
- Transplant couples are largely satisfied and divorce is uncommon.
- Female spouses/caregivers consistently report lower relationship satisfaction, and satisfaction decreases over time.

Relationships

“Listen, I tell you, as much as I suffered, [my wife] suffered just as much. It was very hard for her. She also lost a year of her life.”

“It’s getting too hard for her to be looking after everything . . .she’s trying to be the lady of the house, the caregiver, the wife, the goal person, the shopper . . . to do everything here.”

Relationships

- The relationship intimacy model of couple adaptation to cancer:

- Relationship enhancing behaviours:
 - Reciprocal self-disclosure
 - Partner responsiveness
 - Relationship engagement
- Relationship compromising behaviours:
 - Avoidance
 - Criticism
 - Pressure-withdraw

Paediatric Considerations: Patients

- 40% of children experience significant anxiety before transplant.
- 40% children experience increased depression, peer isolation and behaviour problems during the 6 months post-transplant period.
- Extended hospital stays associated with worse depressive symptoms.
- Younger age (<7 years) associated with more severe withdrawal and loss of adaptive skills.

Paediatric Considerations: Patients

- 80% of children meet criteria for moderate PTSD 3 months post-transplant. 35% of children continue to experience PTSD symptoms 12 months post-transplant.
- Survivors described by peers as more withdrawn, less attractive, less athletic and less likely to be chosen as a best friend.
- Older age at the time of transplant is associated with better cognitive and educational outcomes. Older maternal age, and less maternal anxiety and depressive symptoms predict better patient outcomes.

Paediatric Considerations: Siblings

- Siblings of transplant patients are at risk of developing emotional reactions such as post-traumatic stress disorder, anxiety, and overall low self-esteem.
- New behaviour problems occur far more frequently among siblings who are donors than among non-donors.

Paediatric Considerations: Siblings

- Sibling donors often feel an overwhelming sense of responsibility for their sibling's survival; this often leads to psychological distress.
- Donor and non-donor siblings report loneliness, limited comprehension of the transplant procedure and a lack of attention from their parents. Furthermore, siblings who donate their marrow have reported a lack of choice when asked to donate.

Paediatric Considerations: Parents

- High prevalence of depression and anxiety in parents, who then become less responsive to their children's needs, resulting in poorer psychological and social outcomes for the children.
- Parental stressors include relocating to the transplant centre, living in two separate households, commuting between the home and the transplant centre, concurrently caring for other family members, work-related changes, lengthy hospital stays, financial burdens, parental informed consent for the transplant procedure, dealing with medication compliance and other medical complications.

Paediatric Considerations: Parents

- Emotional stress may stem from worry, concern and guilt regarding a child undergoing the transplant procedure, apprehension regarding losing a child and fear of relapse once the transplant procedure is completed.
- Mothers tend to be the ones to quit their job, relocate, and assume the care and support of the child. Fathers are also present during the long hospital stays, however, they tend to keep their job, and usually come in and out of the hospital. This may lead to a disproportionate amount of strain on the part of the mother and considerable guilt on the part of the father.

Impact on Nursing Staff

- Emotional labour
- Compassion fatigue
 - Communities of caring
 - Clear professional boundaries
 - Cultivating an enriched personal life

Survivorship

- Physical
 - Pain
 - Fatigue
 - Sleep
 - Sexual function
 - Physical function

Survivorship

- Psychological
 - Emotional distress
 - Depression
 - PTSD
 - Fear of recurrence
 - Psychological functioning in paediatric survivors
 - Neurocognitive functioning
 - Post-traumatic growth?

Survivorship

- Social
 - Social support
 - Work
 - Carers/donors
 - Financial toxicity

Resources

- Cancer Council
- Leukemia Foundation
- Treat me treasure me
- Support groups (e.g. look good feel better)
- Carers Australia
- Enrich
- Canteen
- 'Psychosocial Care of Cancer Patients' book