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Family Caregiver Issues



Objectives

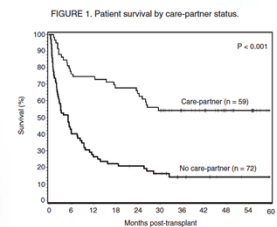
1. Explain the unique needs of those caring for adult and pediatric HCT patients.
2. Describe the most current evidence-based strategies nurses use to support caregivers of adult and pediatric HCT patients.

Psychosocial sequelae of the patient during the transplant trajectory

- Fears about the future
- Approximately 1 in 3 patients will suffer from depression in the first year following a HSCT
- Reduced quality of life
- Difficulty re-establishing social, occupational and family roles

Relevance

- The consistent presence of a caregiver during hospitalization for an allogeneic transplant was found to predict longer 5-year survival rates
- Quality of support offered by caregivers may influence survival



Psychosocial Needs of Adult HSCT Caregivers

Psychosocial Experience of Caregivers

1. Distress among HSCT caregivers
2. Needs of HSCT caregivers
3. Caregiver burden: a balancing act
4. Caregivers and patients as dyads
5. Benefits of the care-giving role
6. Long-term effects of care-giving

Distress among HSCT caregivers

- Distress among HSCT caregivers is **highest pre-transplant** and then decreases over the transplant trajectory
- **Caregivers** may experience **more distress** than HSCT patients
- Predictors of caregiver distress include being a **female** caregiver, higher levels of **subjective burden**, and **patient symptom distress**

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Needs of HSCT Caregivers

- Care-giving
 - Patient care needs
 - Ability to communicate with the health care team
- Psychological
 - Fear of the future
 - Ineffective coping
- Social
 - Difficulty adapting to role changes
 - Lack of time to themselves and for leisure activities

Needs of HSCT Caregivers: Most Difficult Care-giving Activities

Mean Difficulty of the Ten Most Difficult Caregiving Activities			
	Item	Mean ^a	SD
1	Listen when feeling very sad or scared	2.36	1.39
2	Listen to concerns about cancer/treatment	2.29	1.39
3	Help with emotional ups and downs	2.19	1.48
4	Talk about feelings related to cancer	2.00	1.56
5	Talk about the possibility of death	2.00	2.03
6	Discuss the future	1.93	1.27
7	Deal with mood swings	1.83	1.81
8	Keep other family members informed	1.78	1.15
9	Handle his or her anger	1.69	1.69
10	Protect from exposure to microbes	1.63	1.40

^a Scale = 1–5; with 5 = very difficult.

Cooke et al., 2011, *European Journal of Oncology Nursing*, 15(5), 500-507

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Caregiver Burden: A Balancing Act

- Objective burden
 - Time and financial commitments
 - Decreased energy
- Subjective burden
 - Difficult to watch their relative suffer
 - Uncertainty about the future
- Caregivers learn to balance the needs of the patient, their own needs, and their relationship

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HSCT Patient-Caregiver Dyads



- Caregiver marital satisfaction was significantly lower than patient marital satisfaction six months and one year post-transplant
- Female caregivers experience more distress and lower marital satisfaction
- Caregivers **hide their own fears and worries** related to the cancer and HSCT in an attempt to not cause any added distress to the patient
 - Has high intrapersonal costs on the caregiver

Psychosocial Experience of Caregivers



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Benefits of the care-giving role



1. Personal Growth
2. Improvement of relationships
3. Increased perception of rewards was associated with:
 - Younger age
 - Preparedness for the care-giving role

Psychosocial Experience of Caregivers



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Long Term effects of Care-giving



- 36 survivor-caregiver dyads
- 1-6 years from BMT
- Ongoing care-giving demands
 - Continued role changes and new responsibilities
 - Social support decreased over time
 - **Unmet expectations** that the survivor would "return to normal" after the acute transplant phase

Long-term Care-giving Demands

- Multi-site study
- 177 HSCT survivor-caregiver dyads
- 133 married couples (controls)
- Cross-sectional design
- Mean time since diagnosis: 6.7 years

Role

- Survivors and caregivers had more clinically significant cases of depression than controls
- Partners were less likely to seek intervention than survivors
- Compared to survivors and controls, partners endorsed:
 - lower social support
 - increased loneliness
 - lower dyadic satisfaction

Caregiver Gender

- Compared to males, female partners were more likely to report:
 - **Negatives**
 - Poorer mental health
 - Increased depressive symptomatology
 - Decreased social functioning
 - Sexual problems
 - Cognitive dysfunction
 - Social constraint
 - **Positives**
 - Post traumatic growth
 - Higher social support

Predictors of Quality of Life

- Over the first year
 - Increased predictability of care-giving
- Long-term
 - Survivor depression
 - Caregiver health problems
 - Coping
 - Female gender
 - Social constraint
 - Depression
 - Multiple life changes
 - Social support

Psychosocial Needs of Pediatric HSCT Caregivers

Trajectory of Parental Distress

- 151 parental caregivers
- Longitudinal design:
 - Weekly from week -1 to week +6
 - Monthly from week +6 to month +6
- Highest at admission through week +3
- Distress levels out at 4-6 months post

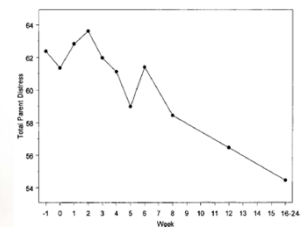


Fig. 1. Global parent distress over time.

Predictors of Pediatric Caregiver Distress

- Family environment
- Lower socioeconomic status
- Younger mothers
- Previous distress associated with child's medical illness
- Mothers pre-transplant depressive symptoms
- Child's pre-transplant distress
- Avoidant coping
- More frequent hospitalizations or transfers to ICU

Pediatric Caregivers Needs

- Purpose: To identify needs and resources of family caregivers of pediatric HSCT patients in the first year following transplant
- Design: Cross-sectional study
- Recruitment: Online survey
- Sample: 161 parents (87.6% mothers)
- Child had received a transplant a median of 4 years prior (1-20 years)

Top 5 problems identified over the first year

1. Personal needs
2. Meeting family's emotional needs
3. Managing household
4. Assisting child with emotional needs
5. Addressing family's physical needs

Caregiver recommended resources

- The resource wish list:
 1. Emotional/social issues for child undergoing HSCT
 2. Post-transplant care and follow-up
 3. Practical strategies
 4. Emotional issues of care-giving
 5. Insurance issues
- Less needed:
 1. How to connect with other parents
 2. Legal issues of care-giving

Nursing Strategies and Caregiver Interventions

Psychosocial Interventions for HSCT Caregivers

- Four intervention studies to date:
 1. Massage therapy/healing touch
 - RCT: control, healing touch, or massage intervention
 - Caregivers in the massage therapy intervention reported significantly less anxiety, depression, and fatigue post-intervention
 2. Dyadic intervention
 - 4 session problem-solving education intervention
 - COPE
 - Feasibility study

Psychosocial Interventions for HSCT Caregivers

3. Group format (caregivers only)
 - Adult and pediatric caregivers
 - Feasibility study
4. RCT of one 90 minute pre-admission intervention versus standard of care
 - Education, communication, relaxation
 - Pediatric caregivers
 - Intervention = feasible
 - No difference in reported stress between groups

Intervention Studies- Single Arm

1. Problem-Solving Education for Caregivers and Patients During Stem Cell Transplant. NIH; NCT00766883
2. Study of the Emotional Needs of Caregivers of Stem Cell Transplantation Patients. FHCRC; NCT00082654

Intervention Studies- Randomized

1. Nursing Intervention in Supporting Family Caregivers of Patients Undergoing Stem Cell Transplant. City of Hope Medical Center; NCT01341873
2. Relieving Distress in Parents Caring for a Child Undergoing a Hematopoietic Stem Cell Transplant. NCI; NCT00953082
3. Facilitating Parent Adaptation to Pediatric Transplant: The P-SCIP Trial. Fox Chase Cancer Center; NCT00939380

Cancer Caregivers

- Meta-analysis of cancer caregiver interventions
- To evaluate the efficacy of caregiver interventions using multiple caregiver outcomes:
 - illness appraisal factors (e.g., burden, needs)
 - coping resources (e.g., self-efficacy, coping strategies)
 - quality of life (e.g., distress, marital relationship, physical functioning)

Cancer Caregivers: Results

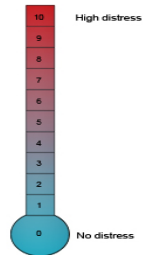
- 29 RCTs of cancer caregiver interventions
 - Psycho-educational
 - Skills training
 - Therapeutic counseling
- Key Findings:
 1. Interventions demonstrated a significant positive effect on multiple outcomes
 2. Mixed finding regarding intervention duration
 3. Caregiver only interventions resulted in viewing the caregiver role as more positive

Screening for Caregiver Distress

Screening Tools

Distress Thermometer

- Good validity for patients and caregivers
- Diagnostic utility for patients = good
- Diagnostic utility for caregivers = poor



Screening Tools

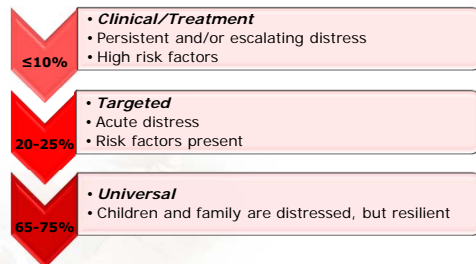
- Psychosocial Assessment Tool (PAT)
 - Brief parent-report screening tool
 - 15 items (5-10 minutes to complete)
 - 7 subscales
 - Structure/resources
 - Family problems
 - Social support
 - Stress reactions
 - Child problems
 - Sibling problems
 - Family beliefs

Screening Tools

- Psychosocial Assessment Tool (PAT)
 - Feasible
 - Useful tool → links with Pediatric Psychosocial Preventative Health Model framework
 - Identifies “risk level”
 - Could potentially guide teams to appropriate resources to provide families
 - Provides health care team with increased psychosocial information about the family

Suggested Interventions

Pediatric Psychosocial Preventative Health Model



Suggested Interventions

- Module approach:
 - Educational module
 - Caregiver mastery
 - Preparedness
 - A psychosocial module
 - Coping
 - Problem solving strategies
 - Self-care module
 - Exercise
 - “Down time”

Our Recommendations

1. Psycho-education
 - Provide information on psychosocial sequelae
 - Reduce uncertainty by discussing role transitions
 - Increase coping strategies
 - Self-care
2. Restoring equity within the relationship
3. Improve patient and caregiver communication

What Strategies Can Nurses Use Now?

1. Check-in with the caregivers
 2. Reflect
 3. Normalize that it is a difficult experience
 4. Validate
1. Identify vulnerable caregivers

What Else Can Nurses Do?

- Education on transplant trajectory, including:
 - Information on the physical aspects of care-giving
 - Information on the psychosocial aspects of care-giving
 - Resources available
 - Make a resource library (relaxation CDs)
- Referral to psychosocial resources
 - Distress screening
 - Keep in mind which caregivers are the most vulnerable
 - Learn when to refer
- Emphasis on caregiver self-care

Resources for Caregivers

- Websites and Societies
 - American Cancer Society/Canadian Cancer Society
 - Cancercare
 - Leukemia and Lymphoma Society
 - National Cancer Institute
 - National Alliance for Caregiving
 - National Bone Marrow Transplant Link
- Books
 - 100 Questions and Answers about Caring for Family or Friends with Cancer; Susannah Rose 2005
 - Supportive Cancer Care: The Complete Guide for Patients and Families; Rosenbaum 2001

Conclusions

1. Family care-giving responsibilities frequently persist long after HSCT
2. The HSCT care-giving experience is one of uncertainty, adaptation to changing roles, and emotional distress
3. There are limited evidence-based nursing strategies and/or psychosocial interventions for caregivers to guide clinical practice
4. Future interventions should include:
 - Psycho-education
 - Self-care
 - Distress screening
 - Referral of caregivers in need of more psychosocial support

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