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Why them?: The Informal Caregiver’s Transition to Cancer Diagnosis

Rebecca Hoppe¹, Marcia A. Winter¹, & Tara A. Albrecht²
¹Virginia Commonwealth University ²Duke University



BACKGROUND

Hematologic malignancies (HM; acute leukemia or lymphoma¹) are life-threatening cancers

- Associated with high mortality, numerous symptoms, and lengthy hospitalizations¹
- Required hospitalization for intensive chemotherapy treatment²
- Affects family & one member takes role of informal caregiver

Informal Caregivers (IC) assist with pragmatic needs & help manage treatment symptoms, while navigating healthcare system³⁻⁴

- Distress levels are similar or higher than HM patients⁹⁻¹⁰
- Distress may have a ripple effect on aspects of IC’s life, impact relationships¹¹ and physical well-being¹²
- Experience low quality of life and psychological well-being⁵⁻⁸

There is scant research exploring the experiences of ICs of HM patients, although that information would be helpful in addressing their needs

SPECIFIC AIM

Describe the complex experiences of informal caregivers of patients with HM, particularly with regard to adaptation and caregiver role preparation in the midst of diagnosis and treatment

METHODS

- Recruited from NCI-designated Cancer Center in US mid-Atlantic region within 3 months of the HM diagnosis
- Longitudinal descriptive design was used
- Here we analyzed and report on the qualitative data collected from semi-structured interviews¹³
- Content analysis conducted to generate common themes ¹⁴

RESULTS

Demographics of Informal Caregiver (IC) (N=28)

Age range	29-76 years (M=54.29, SD=15.19)	
Gender	67.9% Female	
Race & Ethnicity	67.9% Caucasian	3.6% Asian
	21.4% Black or African American	3.6% Other
Relationship to patient	67.9% Spouse/Significant other	14.3% Child
	10.7% Parent	7.1% Other (sister in-law)
Patient’s HM diagnosis	85.7% Acute Leukemia	7.1% Other
	10.7% Lymphoma	

PSYCHOLOGICAL ADJUSTMENT

Theme

Exemplar

Accepting Help	“It’s easy to help other people, but to accept help it’s not always so easy.”
Protection	“I’m staying here with him because [I am] trying to make sure he's telling [medical team] when he has pains and asking questions he needs to ask.” “I come out here in this waiting room a lot and cry, pretty hard, because I have to stay positive for him. [I] don’t want to let him see how scared I am. I need him to stay strong and positive.”
Powerlessness	“You work your whole life to get to the point that you retire and we had all these plans to do things. All that’s on hold. The future plan, you work, get your house so it doesn’t need maintenance, get the cars paid off, house paid off, all these, you know, bills so you can do some travelling and not worry. So [cancer] just robs you of things.”
Discomforting Thoughts	“Without him, I don’t know how I would possibly manage. I am terrified of what could happen.”
Illness Transition	“I think about it every day because there’s nothing I can do. I’m like, ‘Why are you giving up? It seems like you’re giving up. You don’t want to sit up, you don’t want to eat, you don’t want to talk, you don’t want to do anything.’ And I said, ‘And to me that’s giving up.’”
Caregiver Role Preparation	“I’m very prepared. I’ve actually worked in this hospital as a care partner. I’ve been in the medical field for twenty years. I’m a caregiver at heart naturally. I just never thought it would be for my husband this early.”
Empowerment	“I’ve actually learned that I could do a lot more than I thought I could.”
Hope	“I really think we will get through this and be over with by the summer. I am really looking forward to him retiring. We have big plans for doing different things.”

RESULTS

Informal caregivers endorsed both adaptive and maladaptive psychological adjustment

- **Adaptive adjustment** included accepting help from others and feelings of empowerment, control, and hope
- **Maladaptive adjustment** included feelings of powerlessness, protectiveness, and rumination of discomforting thoughts

CONCLUSIONS

- Findings highlight the complexities of caregiver burden as they adapt to their HM’s diagnosis and new caregiver role
- IC’s would benefit from receiving structured guidance and support as they adjust and manage the challenges inherent of a new complex HM
- Apprising healthcare personnel of caregivers’ experiences can inform interventions aimed at caregiver role preparation, burden prevention, acceptance, and empowerment in role
- Future research should explore the benefit of tailored supportive care interventions that enhance adaptive adjustment for IC

ACKNOWLEDGMENTS

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Powerlessness	“You work your whole life to get to the point that you retire and we had all these plans to do things. All that’s on hold. The future plan, you work, get your house so it doesn’t need maintenance, get the cars paid off, house paid off, all these, you know, bills so you can do some travelling and not worry. So [cancer] just robs you of things.”
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DEMOGRAPHICS

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RESULTS

Informal caregivers endorsed both adaptive and maladaptive psychological adjustment

- **Adaptive adjustment** included accepting help and feelings of empowerment, control, and hope
- **Maladaptive adjustment** included feelings of powerlessness, protectiveness, and discomfoting thoughts

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CONCLUSIONS

- Findings highlight the complexities of caregiver burden and adjustment
- ICs would benefit from receiving structured guidance and support
- Palliative care can be leveraged to support ICs
 - Apprising oncology clinicians of caregivers' experiences can inform interventions aimed at caregiver role preparation, burden prevention, promoting acceptance, and empowerment in their new supportive role
- Testing efficacy of tailored supportive care interventions for both the patient with HM and their IC are needed to support adaptive adjustment

REFERENCES

- ¹Noone, A. M., et al. (2018). SEER Cancer Statistics Review, 1975-2015. Bethesda, MD.
- ²Tallman, M. S., et al. (2019). NCCN Clinical Practice Guidelines in Oncology: Acute Myeloid Leukemia, Version 3.2019. *Official Journal of the National Comprehensive Cancer Network*, 17(6), 721-749.
- ³Frambes, D., et al. (2018). Informal caregivers of cancer patients: Review of interventions, care activities and outcomes. *Western Journal of Nursing Research*, 40, 1069-1097.
- ⁴Kent, E. E., et al. (2016, Jul 1). Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer*, 122(13), 1987-1995.
- ⁵Bevans, M. F., et al. (2016). Documenting stress in caregivers of transplantation patients: Initial evidence of HPA dysregulation. *Stress*, 19, 175-184
- ⁶Ferrell, B. R., & Kravitz, K. (2017, Jul-Aug). Cancer Care: Supporting Underserved and Financially Burdened Family Caregivers. *Journal of the advanced practitioner in oncology*, 8(5), 494-500
- ⁷Reblin, M., et al. (2018, Feb). Mediating burden and stress over time: Caregivers of patients with primary brain tumor. *Psycho-Oncology*, 27(2), 607-612.
- ⁸Shaffer, K. M., et al. (2017). Effects of caregiving status and changes in depressive symptoms on development of physical morbidity among long-term cancer caregivers. *Health Psychology*, 36(8), 770-778.
- ⁹Beattie, S., & Lebel, S. (2011). The experience of caregivers of hematological cancer patients undergoing a hematopoietic stem cell transplant: a comprehensive literature review. *Psychooncology*. 20(11):1137-1150. Epub 2011/03/23.
- ¹⁰Langer, S., Abrams, J., & Syrjala, K. (2003). Caregiver and patient marital satisfaction and affect following hematopoietic stem cell transplantation: a prospective, longitudinal investigation. *Psychooncology*. 12(3):239-253.
- ¹¹Bishop, M., et al. (2007) Late effects of cancer and hematopoietic stem-cell transplantation on spouses or partners compared with survivors and survivor-matched controls. *Journal of Clinical Psychology*. 25(11):1403-1411
- ¹²Simoneau, T., et al. (2013). Elevated peri-transplant distress in caregivers of allogeneic blood or marrow transplant patients. *Psychooncology*. 22(9):2064-2070.
- ¹³Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health*, 33(1), 77-84.
- ¹⁴Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15(3), 398-405.

