

“This Rural Thing is a Big Deal” Community Stakeholders’ Perceptions of Cancer-Related Financial Toxicity in Rural Settings

Rose, M.,¹Park, S.,¹Sloss, E.,¹Kirchhoff, A.,^{2,3} Mooney, K.,^{1,3} Brooks, P., Pannell, S., Pannell, D., Ellis, C., Patronas, E., Patronas, J., Scott, R., Bradshaw, E.,⁴ Gallagher, K.,⁴ Steinbach, M.,³ Bellerive, C.,⁵ Fausett, A.,³ Fowles, J.,³ Stephens, J.,⁶ & Tay, D. L¹

¹College of Nursing, University of Utah
²School of Medicine, University of Utah
³Huntsman Cancer Institute
⁴Patient Advocate Foundation
⁵Memorial Sloan Kettering
⁶School of Nursing, University of Wyoming

Introduction

- Rural cancer patients and caregivers face added challenges, including limited access to local healthcare services and providers
- These barriers contribute to the indirect costs of cancer care and overall financial toxicity
- Self-advocacy (developing skills and confidence to meet personal needs) can support resilience in navigating these challenges
- Few proactive interventions exist to help rural patients and caregivers build self-advocacy skills to combat financial toxicity

Methods

- This study was approved by the University of Utah Institutional Review Board
- **Community Advisory Board:** 14 members including rural cancer patients/survivors (4), caregivers (3), nurses/NPs (4), and financial advocates (3)
- **Parent Study:** Needs assessments with focus groups and interviews, 6 Zoom-based CAB meetings (Aug 2024–April 2024) to map priorities, Strengths, Weaknesses, Opportunity and Threats analysis, and user-centered design principles
- **This study focused on needs assessment phase of the research**
- **Analysis:** Focus group and interview transcripts were transcribed verbatim
- An inductive codebook was developed and two coders thematically analyzed the transcripts to identify key themes related to financial challenges and resource gaps associated with cancer care for rural patients and families

Rural cancer patients and caregivers experience unseen financial burdens from travel and limited healthcare access, often compounded by stigma, inconsistent community resources, and a need for self-advocacy to navigate complex care decisions.

Theme 1: Community As Safety Net - Strong social networks helped some patients manage hardship through informal supports (rides, meals, emotional support).

“There could have been a lot of worry if it hadn’t been for the kindness of our community.” - Rural cancer caregiver #1



Theme 2: Unseen Costs of Traveling for Care - Patients experienced financial toxicity from gas, lodging, missed work and long travel times.

“We figured it up that it was going to cost us about \$7500 to stay out there in a hotel or try to find an Airbnb or something.” - Rural cancer survivor #3

Themes Identified By Community Stakeholders

Theme 3: Self-Advocacy As a Tool to Support Resilience - Participants emphasized the importance of asking questions, understanding their financial options, and speaking up about need during care planning.

“If they don’t know how to reach out for help or what resources are available, they’re stuck.” - Financial Advocate #1



Theme 4: Overcoming Stigma in Seeking Financial Assistance - Many patients/caregivers felt the need to keep their financial struggles private or expressed discomfort talking about money.

“In our society and our culture in North America, it is taboo to talk to your neighbor about money.” - Rural cancer survivor #2

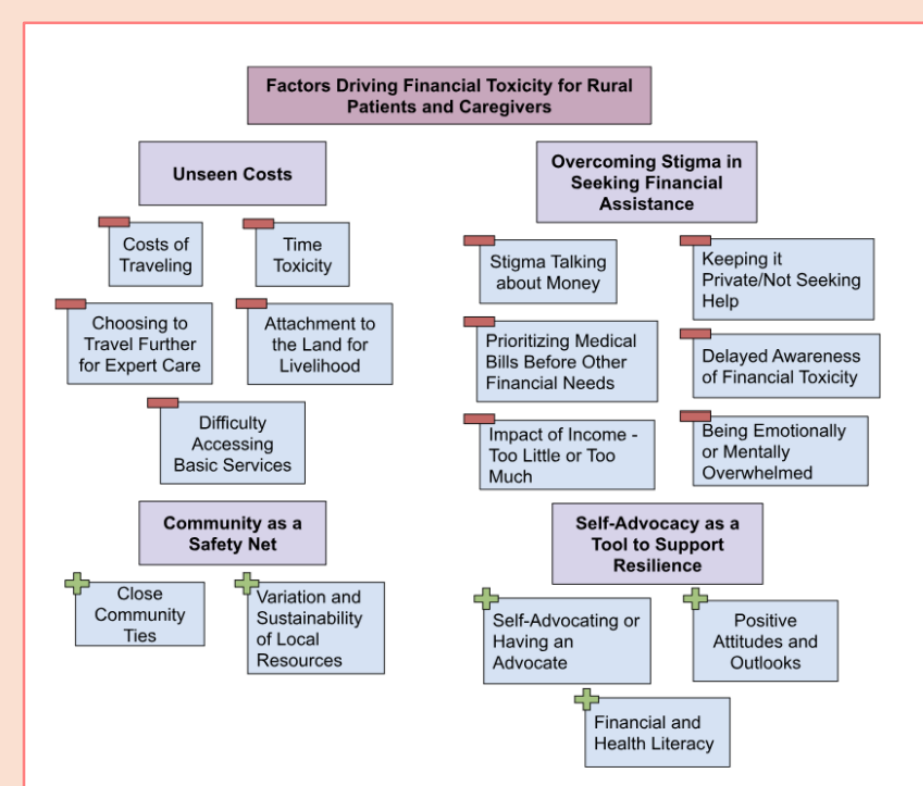


Figure 1: Factors affecting financial toxicity for rural patients and caregivers as identified by community stakeholders

Differing Priorities:

- **Patients/caregivers** prioritized developing practical tools and resources for self-advocacy
- **Healthcare providers and financial advocates** prioritized supporting emotional distress linked to financial toxicity

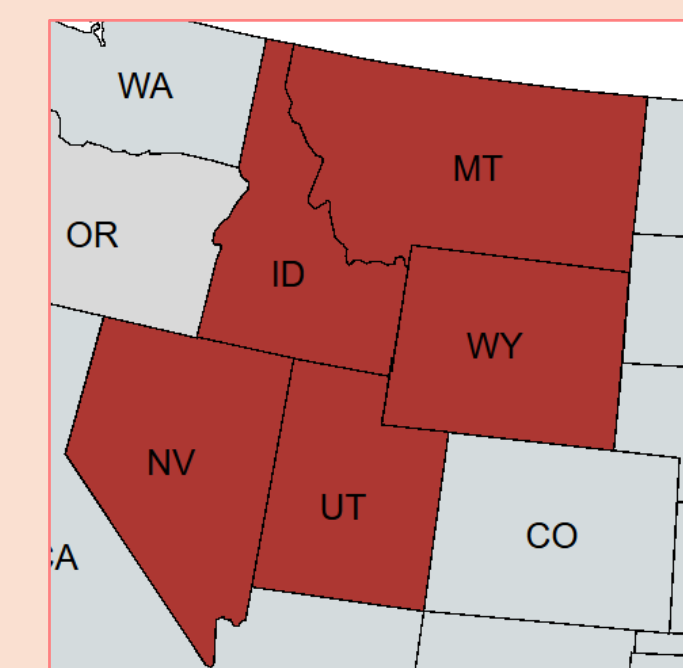


Figure 2: The Huntsman Cancer Institute 5 state catchment area

Discussion

- Empowering patients and caregivers to speak up, ask questions, and understand their options can build long-term resilience
- Some rural perspectives (e.g., non-English speakers, underrepresented communities) may not have been fully captured
- Because of the stigma around discussing finances, there may have been underreporting or discomfort in sharing experiences
- Unlike many other interventions, this approach was developed using a user-centered design process and guided by rural community stakeholders

References



Acknowledgement

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- We acknowledge Mackenzie Mitchell for her help in coding the transcripts

Themes Identified By Community Stakeholders

Theme	Description	CAB Member Quotes
1. Unseen Costs of Traveling for Care	Patients experienced financial toxicity from gas, lodging, missed work, and long travel times	<i>“We figured it up that it was going to cost us about \$7500 to stay our there in a hotel or try to find an Airbnb or something.” – Rural cancer survivor #3</i>
2. Community as a Safety Net	Strong social networks helped some patients manage hardship through informal support (rides, meals, emotional support)	<i>“There could have been a lot of financial worry if it weren’t for the kindness of our community”. – Rural cancer caregiver #1</i>
3. Overcoming Stigma in Seeking Financial Help	Many patients/caregivers felt the need to keep their financial struggles private or expressed discomfort talking about money	<i>“In our society and our culture in North America, it is taboo to talk to your neighbor about money.” – Rural cancer survivor #2</i>
4. Self-Advocacy as a Tool for Resilience	Participants emphasized the importance of asking questions, understanding their financial options, and speaking up about needs during care planning.	<i>“If they don’t know how to reach out for help or what resources are available, they’re stuck”. – Financial Advocate #1</i>

