Understanding and Mitigating Social Support Barriers for Young Adults with Cancer

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OVERVIEW

The Need:
For Adolescents and Young Adults (AYAs) with cancer, social support plays a vital role in hope, coping, quality of life, and health outcomes.

The Challenge:
A majority of young adults with cancer have experienced nonsupport from someone they would have expected to provide support.

STUDY QUESTIONS

• Why do some people choose not to offer support to someone they know with cancer?
• What are cancer survivors’ perceived reasons for nonsupport?
• How do the two sets of reasons compare?
• What resources and interventions could help mitigate nonsupport?

METHODS / ANALYSIS

Method:
Recruited Young Adults (18-39)
- Survivors who experienced nonsupport
- Young adults who struggled with or never offered support
- Demographics/Eligibility checks. Participants list up to 5 nonsupport reasons

Analysis:
- Participants:
  - Patients (N=111) Nonsupporters (N=131)
  - 13 Reasons:
    - Patients (284) Nonsupporters (438)
    - 22 reason categories --> 4 higher level categories
    - Identified exemplars

RESULTS

NONSUPPORT REASONS

Supporter-Focused
• Low self-efficacy
• Lack of emotional control or self-coping
• Feeling uncomfortable
• Other priorities / concerns
• Support is not useful
• Misinformed about cancer
• Support would be insincere or self-serving
• Indifference
• Cancer is a burden on the supporter
• Character flaw

Receiver-Focused
• Support not deserved
• Support not desired, needed, or used
• Support would generate negative emotions
• Adequate support already being provided

Context-Focused
• No opportunity
• Unable to contact
• Physical distance
• Health + safety concerns
• Lack of resources

Relationship-Focused
• Relational closeness
• Relational norms

POSSIBLE STRATEGIES & TOOLS FOR INTERVENTION

• Low self-efficacy - Encourage/facilitate conversations; examples of what to say/not say.
• Lack of emotional control - Improve understanding about diagnosis; Tools for coping with emotional support groups.
• Feeling Uncomfortable - Tips and scripts for offering support; practice supporting in non-cancer contexts.
• Other Priorities - Tools to assess capacity to support on the basis of support needs.
• Not Useful - Information on multifaceted health benefits of support; Tools to identify best support based on needs.
• Cancer misinformation - Information to improve cancer understanding and the range of patient experiences.
• Insincere / Self-serving - Education on support perceptions and expectations; Comm tips on why support offered.
• Indifference - Strategies for sensemaking and with potential supporters to address concerns; Tools to help patient reach out, invite support, be vulnerable.
• Burdensome - Tools to identify personal strengths and authentic support aligned with relationship needs.
• Character Flaw - Tools to self-assess support capacity; Strategies to recognize/address toxic relationships.

• Not deserved - Counsel on how supporting others can create better present and future instead of placing blame on past; Self-assess perceptions / emotions toward patient.
• Not desired - Help understand support needs and options; De-stigmatize accepting help as a weakness.
• Generate negative emotions - Self-assess what leads to upsetting situations; tips to navigate/avoid triggers.
• Already Adequate Support - Information on how needs and support change over time - need for consistency.
• No Opportunity - Tools to identify barriers; Strategies to notify important people to the support network.
• Unable to contact - Resources to help patients connect with support system (e.g., financial, tech).
• Physical Distance - Education on the range of support opportunities not requiring physical presence.
• Lack of Resources - Strategies for cost-effective ways to support someone; Financial assistance resources.
• Safety / Health Concerns - Information on support options that don’t require physical presence.
• Relational Closeness - Education perceptions, expectations; support options based on relationship.
• Relationship Norms - Tools to offer relationally and culturally sensitive support.

FINDINGS

• Patients and supporters generate their own reasons to explain support barriers.
• These stories don’t always align.
• These reasons are the “Problems to be Solved” regarding supportive communication.
• Proposed resources and interventions can help manage expectations, mitigate support barriers and misperceptions, and facilitate problem-solving.

NEXT STEPS

• Conduct interviews to baseline care team social support practices and gaps.
• Develop resources + training to establish patient social support best practices.
• Measure impact within a clinical setting.

COMMUNITY IMPACT

• Consistent social connection and support assistance across treatment centers.
• Improved support and connection through clear communication and understanding of community needs and challenges.
• Improved quality of life and health outcomes.

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