

A Lost Population: How to Create a Safe Harbor in the Online Community for Teens Coping with Parental Cancer

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Abstract

How, as oncology social workers, can we ensure the safety of this population that often gets “lost” among their parents’ medical issues? Facilitated online support groups can offer a rare means of support to teens coping with parental cancer.

Some of the challenges working with this population directly relate to their sometimes limited ability to verbalize their thoughts in an in-person setting. Creating an invulnerable online environment for teens is the first step towards a new perspective on clinical outreach.

By providing the space for teens to explore their experiences among like-minded individuals, this online support group becomes a safe harbor. There are many components of this model including; a professionally-led (licensed oncology social worker) group, group screener (completed by both teen and parent/legal guardian), a written consent form, terms/conditions/ privacy policy and a set of safety guidelines for the group space. The group screener is unique in that it is meant to detect “red flags” to prevent future crises; it also helps the moderating social worker assess the writing skills of the teen to determine if they are appropriate. The purpose of this space is to facilitate conversations on topics such as identity formation, managing family conflict and emotional well-being. This professionally-facilitated group aspires to decrease feelings of isolation and inspire hope by expression of written word in various mediums. Teens feel protected by the anonymity of this online group; they can be who they choose and express themselves in a way that is most comfortable to them.

A novel online support group model for teens coping with parental cancer will be highlighted in detail in poster presentation format. Guidelines for developing safety features, current research and plans for the future will also be addressed.

Background

Research shows that on a national level, there is a gap in clinical services for adolescents coping with parental cancer. There are many challenges in providing in-person group services for this age population; they may be limited by geographic location or the services may not exist. It seems that in this era, online support is the most tangible means to connect. However, many online teen communities exist but lack the structure and safety procedures that parents seek. Is there a solution to this problem? How can we, as oncology social workers, create a safe environment for teenagers struggling to connect?

Psychosocial issues for teen caregivers

- Feelings of:
 - Anger, confusion, isolation, sadness etc.
- Lack of adaptive coping mechanisms
- Inability to identify and express emotions
- Desire for independence and autonomy

Goals of Project

- Create a safe online community for teens affected by parental cancer
- Provide emotional support through written word in order to allow teens to explore their identities while finding camaraderie with their peers who are struggling with a similar situation
- Decrease feelings of isolation and increase sense of empowerment for this population
- Encourage the use of written word as an adaptive coping mechanism



Benefits

- Offers a safe, shared space for teens to connect
- Population specific
 - Teen caregivers coping with parental cancer
- Professionally moderated
 - Facilitators can give guidance, support & resources while maintaining a safe online environment both physically and emotionally
- Flexible platform allows for 24/7 access
- Encourages the use of written word to better express emotions
 - Creative writing prompts and exercises
- Encourages autonomy and independence in a unique group setting
- Offers support regardless of geographic location
- Safety guidelines that are population and age specific
- Services are free of charge

Limitations

- Recruitment is challenging
 - Organizations are unaware of the scope of our services
- Limitations set by group platform
 - Only accessible via computer
- Consistency of posts
 - Due to school and extracurricular activities, teens may have trouble posting consistently
- No live chat function
 - Teens struggle with the inability to talk to each other in “live time” in a way that is similar to Facebook messaging or texting
- Not diagnosis specific

Method

THE PROGRAM:

- 15 week cycles (summer, fall and winter)
- Rolling admission during the first two months
- Flexible message board format
- Password protected group accessible 24/7
- Facilitated by a licensed oncology social worker

THE PROCESS:

- Teen completes online registration and screener through our website
- Oncology social worker uses screener to assess writing level/appropriateness/red flags
- Oncology social worker reaches out to parent/guardian
- Oncology social worker uses screener to assess appropriateness/red flags with parent/guardian
- If teen is appropriate, oncology social worker obtains written consent from parent/guardian (downloadable form)
- Oncology social worker approves teen group member; sends out welcome e-mail with group link

Plans for the future

- Offer live chat function
- Start group cycle with either teleconference call or video call where all members can join (and continue monthly throughout the cycle)
- Offer diagnosis specific teen caregiver groups
- Expand recruitment in order to increase size of online groups



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