

Feasibility of providing bereavement care via a social media platform to parents who have lost a child to cancer



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Disclosures

No disclosures to report



Outline

- Background
- Method
- Results
- Discussion



Background

- Caregivers who have lost a child to cancer are at-risk for poor outcomes
- Desire for ongoing communication with medical team
- Lack of access to oncology-specific bereavement resources

Psychosocial Standards of Care: Bereavement

A member of the health care team should contact the family after a child's death to assess family needs, to identify those at risk for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support.

Lichtenthal et al., 2015; Wiener et al., 2015



Technology and Social Media

- **Psychosocial support via technology**

- Telephone → Internet

- **Facebook platform**

- Varied levels of security
- 24/7 access

- **Technology Acceptance Model (TAM)**

- Usefulness
- Ease of use



Davis, 1986, 1989; Facebook, 2013; Fox & Brenner, 2012



Background

- Community-based organization started by a bereaved caregiver contacted hospital staff
- Identified unmet psychosocial need
- Request was made to initiate an online support group for bereaved caregivers
- Hospital support



Study Aim

To determine the feasibility of a hospital-based online bereavement support group for caregivers who have lost a child to cancer



Method

• Demographics

- 118 families were initially contacted
- Caregivers included had lost a child to cancer over the past four years

• Recruitment

- Initial recruitment
 - The Psychosocial Manager mailed letters to the 118 identified caregivers
 - Scripted follow-up phone calls were made by social workers
 - 45 families were reached by phone
 - 73 families could not be reached, despite multiple attempts
 - 6 families opted out of communication (1 post-mailing; 5 post-phone calls)
- Ongoing recruitment
 - Approximately 1 month after a child's death, families are mailed an invitation to join the group (*clinical judgment*)



Method

• Social media platform

- Facebook
 - Popular and accessible
 - Only 1 caregiver without active FB profile prior to group
 - "Secret" group created
 - Group facilitators created official FB pages
- Caregivers review and acknowledge a disclaimer



Disclaimer: *"By joining this group I acknowledge that Levine Children's Hospital (LCH) and the Prayers for Elijah Foundation (PEF) are in no way offering professional psychological support services in the group and that my participation in the group does not create a provider-patient relationship. I understand that by joining the group, I am entering a peer support group for bereaved individuals and that anything I post or disclose is not private or subject to any duties of confidentiality. I understand that I will not hold either LCH or PEF liable for my mental health care or privacy."*



Method

- **Group structure**

- Monthly, 60-minute groups are held on a fixed day/time
- Caregivers can engage in the Facebook group at *any* time

- **Facilitators**

- Two psychosocial staff members lead each group remotely

- **Examples of topics**

- Personal stories from group members
- Coping
- Holidays
- Impact of losing a child



Results

- **Number of sessions: 7 (August 2017-present)**

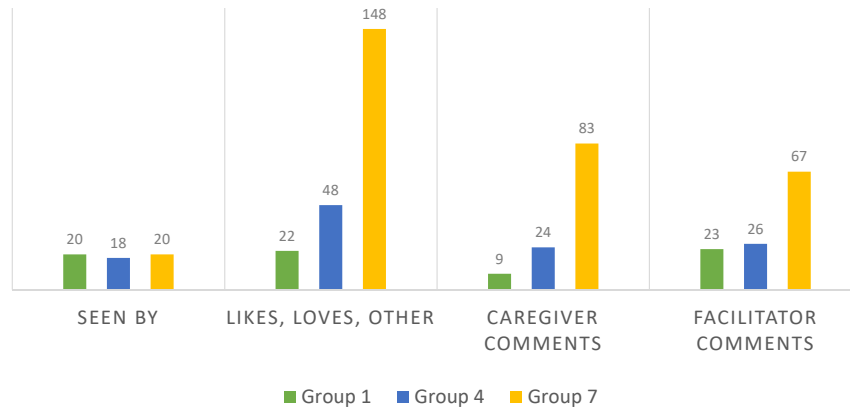
- **Number of caregivers in group: 22**

- **Statistics for caregiver and staff engagement from 3 groups:**

- August (group 1)
- November (group 4)
- February (group 7)



Results



Examples from Facebook



Examples from Facebook

Elijah's Place at Levine Children's Hospital

August 29, 2017

I am having a difficult time with school starting yesterday. The milestones are the toughest. This year was supposed to be [redacted] freshman year at college. Living his fun filled college days.

When he was born in 1999 I thought 2017 seemed so far away, and now it's here and he isn't. He made it through the 9th grade had plans to go to MIT or Virginia Tech to be come an engineer and in his words 'do cool stuff for a living'.

I hope everyone made it through the last couple of weeks with school starting back. ❤️

Like Comment

You and 1 other

Seen by 18 people.

I had a really really bad day yesterday too. It was supper to be the first day of high school .. we have a lot of dreams a lot of goals to reach ... I feel so down .. I still have all this angry, sadness, disappointment [redacted] want to be a architect. The life is very unfair 😞😞😞

24w Like Reply

Sorry for your day as well. It is unfair and I have no idea how we were chosen for the 'Grieving Mothers (Fathers too) Society' we were tossed in. I try to think of all the things he would be doing; enjoying himself.

24w Like Reply



Examples from Facebook

Seen by 18 people.

Thank you for sharing 🙏🙏 we're all in this together and i love how we can "re-write our address books". I need to hear that so thank you 🙏🙏

13w Like Reply

Ahh, thanks. Thanks for watching the video without judgement. I had three takes because the first two I started crying. I could talk for hours on my [redacted] and our year long story but I knew it needed limiting. 😞

13w Like Reply

You did wonderful! I was so impressed how you kept it together! It's so hard to 🙏🙏

13w Like Reply

Came across this truth in a book I was given called "Brave Enough" by Cheryl Strayed. 🙏

If, as a culture, we don't bear witness to grief, the burden of loss is placed entirely on the bereaved, while the rest of us avert our eyes and wait for those in mourning to stop being sad, to let go, to move on, to cheer up. And if they don't—if they have loved too deeply, if they do wake each morning thinking, *I cannot continue to live*—well, then we pathologize their pain; we call their suffering a disease. We do not help them; we tell them that they need to get help.

4 Comments Seen by 18



Discussion

- **Limitations**

- Difficulty recruiting and establishing contact with bereaved families
- Technological barriers

- **Strengths**

- Provides peer support at any time
- Maximizes hospital resources
- Useful and easy to use (TAM)
- *Fulfills the Psychosocial Standards of Care: Bereavement*
- *Disseminable to other hospitals*



Food for Thought

- **Ideal time to recruit bereaved caregivers**

- Recruit closer to time of death, but *not too close*
- When do you contact families if they are not interested during first contact?

- **Real therapeutic interactions *can* happen online, even if folks have never met and never seen one another**

- ...Just be patient!

- **Little to no ethical or risk management concerns have surfaced**

- **Excellent use of resources: acceptable to caregivers and also to staff**

- **Helpful to have two leaders, as opposed to one**

- Group leaders communicate offline (e.g., via text) with each other live during the group to coordinate



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Questions or comments?



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Ethical Concerns



Comment: "I wouldn't share this with anyone else...I just picked up my prescriptions from CVS, and it just made me realize how screwed up I really am. I've joked around and said I'll probably be crazy the rest of my life. X's death took a toll on me emotionally, physically—I'm sad, depressed, anxious, gained a ton of weight, get shingles about once a month from the stress, can't sleep, and the list goes on and on.

Is it just me? Am I abnormal? Again, I am only opening up to you guys because I know you're standing right where I am and because I trust that our conversations will stay here."



Results

Group #	Seen By	Likes, Loves, Other	Caregiver Comments	Facilitator Comments
1	20	22	9	23
4	18	48	24	26
7	20	148	83	67