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The Evolution of Group & Online Perinatal Support Over 35 Years


Little to No Support Groups
↓
Face to Face Peer Support Groups
↓
One on One Telephone Support
↓
Online Support

“The telephone can’t reach the deceased but the internet can.”

~ unknown
9 in 10 Americans use the internet  (Pew Research Center)

Technology

Thanatology

Thanatechnology
Who Grieves Online (Varga 2018)

No Internet Use:
- Grief is private
- Not in need of support
- Disrespectful

Limited Internet Use:
- Grief online use okay in moderation
- Access memorials and remembrance sites
- Private groups
- Posts on special dates
- Lurkers (people who read but do not post) (Pector, Hsuing, Van Uden-Kraan)

Vast Internet Use:
- Acceptable to grieve online find it supportive
- Death announcements
- Grief and mourning tasks completed here
- Continued bonds - talking directly to deceased
Perinatal Loss Parents Who Grieve Online

- Women
- White (concerning due to African American women are twice as likely to experience pregnancy loss)
- Well-Educated
- Have Insurance
- Mothers more than Fathers (Pector 2012 & Gold, Normandin, Bogss 2016)

Where Perinatal Loss Parents Grieve Online
Where Grieving Happens Online

- **Static Content** (Varga, 2018)
  - Information (websites)
    - ex: Still Standing Magazine
- **Synchronous Support**
  - Online & Offline (real time)
    - ex: Star Legacy Foundation virtual groups
- **Asynchronous Support**
  - Forums, Memorial Sites, Blogs, & Social Media (24/7)
    - Twitter #babylosshour
    - Instagram #Ihadamiscarriage
    - Facebook - Pregnancy After Loss Support
    - Apps - S.O.B.B.S.
    - African American Loss Mom Specific - Sisters In Loss

Why Perinatal Loss Parents Grieve Online

- Pregnancy After Loss Support

![Pregnancy After Loss Support](image-url)
Why Grieve Online

All Types of Grievers

- Seek Information & Support
- Express Emotions
- Engage in Grief Work & Mourning Tasks  
  (Worden)
- Continuing Bonds with Deceased  
  (Varga 2018)

“Online world provides a place of others who validate, normalize, and provide a place where grief is accepted.”  
(Varga 2018)

Continued Bonds Online for Bereaved Parents

- Sharing Memories of Deceased
- Speak Directly to the Deceased  
  (Varga 2018)

- Declaring Identity:
  - As a Parent  
    (Capitulo 2004)
  - Completing Parenting Roles/Tasks
  - Making New Memories with Deceased
How Perinatal Loss Parents Grieve Online

Symbols:
- 🧼 - Angel baby or baby that died
- 🌈 - Rainbow baby or baby born after
- ☀️ - Sunshine baby or baby born before

Hashtags:
- #stillbirth, #miscarriage, #infantloss, #babyloss,
- #stillborn, #SIDS, #TFMR, #bereavement,
- #lifeafterloss, #pregnancyloss, #1in4, #griefjourney,
- #StillbornStillLoved, #Ihadamiscarriage,
- #rainbowbaby, #pregnancyafterloss

Sharing Memories & Emotions:
Photos, stories, momento, helping others

Asynchronous Support

How
- Instagram
- Facebook
- Twitter
- Personal Blogs
- Collective Websites
- Memorial Sites
- Apps
- Virtual Groups
- Online Grief Courses
- TalkSpace
Synchronous Support (real time)

* Facilitated same as if it was in-person
* See faces for emotional impact on others
* Everyone gets a chance to talk
* Sometimes others in background dad, sibling, grandparent

### Signs of a Well Functioning High Quality Online Group

<table>
<thead>
<tr>
<th>Discover</th>
<th>Groups</th>
<th>Create Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>PALS - Pregnancy After Loss of a Multiple</td>
<td>PALS - Pregnancy After Loss with No Support</td>
<td></td>
</tr>
<tr>
<td>PALS - Pregnancy After TFMR Loss Group</td>
<td>PALS - Pregnancy After Loss Support</td>
<td></td>
</tr>
<tr>
<td>PALS - Pregnancy After Infant and Toddler Loss</td>
<td>PALS - Pregnancy After Third Trimester Support</td>
<td></td>
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<tr>
<td>PALS - Pregnancy After Second Trimester</td>
<td>PALS - Pregnancy After First Trimester Support</td>
<td></td>
</tr>
<tr>
<td>PALS - Trying to Conceive After Loss</td>
<td>PALS - Parenting After Pregnancy or Infancy Support</td>
<td></td>
</tr>
</tbody>
</table>
Signs of a Good Online Group

Non-judgemental
Active
Caring with a sense of community & helpful support from multiple participants
Moderators
Stable core membership (Pector 2012)
Loss specific (Varga 2018)

Benefits & Risks of Grieving Online
## Benefits
- Increase access to support
- Increased access to shared experiences
- Increases to validate experiences (Varga 2018)
- Remedy for disenfranchised grief (Pector 2012)
- Empower members to access info
- Convenient

## Risks
- Safety
- Lack of site control (varies)
- Online social norms
- Knowledge where to find support (Varga 2018)
- Misinterpretation
- Anger
- Fraud
- Difficulty to manage crisis
Evolution of loss groups (Carlson, Lammert, O’Leary 2012)

“The Majority of today’s parents search for birth information and social support on the internet.” (Plantin, Darebrak 2009)

Online vs. In-Person Support
Online vs. In-Person Support in Perinatal Loss

- No difference in outcome or those who participate (Gold, Normandin, Boggs 2016)

- Psychological benefits over measurable change in grief process citing Yalom: (Pector 2012)
  - Major Therapeutic Factors Operative in Groups
    - Universality
    - Cohesiveness
    - Catharsis
    - Interpersonal Learning
    - Helping Others

  These factors occur as effectively online as in face-to-face settings (Pector and Hsiung 2011)

Current Resources

- Resolve.org
- Starlegacyfoundation.org
- Pregnancyafterlosssupport.com
- Missfoundation.org
- Stillstandingmag.com
- Firstcandle.org
- Compassionatefriends.org
- Sands.org.uk
- Petals.org
- Storiesofbabiesbornstill.org - App PARI-P
- Ericammcafee.com/community - Sisters In Loss
- #Ihadamiscarriage
- @Ihadamiscarriage
- #Babylosshour
“Grief must be witnessed to be healed.” ~ Elisabeth Kubler-Ross

References


