Answering the Call: Equity in Grief, Considerations & Approaches to Inclusive Grief Support

Alesia K. Alexander, LCSW, CT
Heartlight Grief Center Signature Series, 2022
Agenda

• Overview & Perspectives on Child/Adolescent/Young Adult Grief Experience
• Grief Support with Youth & Communities of Difference
• Beyond Cultural Competency & Self-Care
• Professional Development in Grief Support
• Inviting in & Putting it all Together
Professional Personal Professional Professional Professional Personal
Behind you, all your memories.

Before you, all your dreams.

Around you, all who love you.

Within you, all you need.

I Did it, Daddy! Keep watching me...
Scavenger Hunt
Beyond Diversity: Inclusion

• Just another buzzword?
• Who do we mean?
• Requires higher level investment
• Deeper engagement
• Infrastructure inherent
• Liability Killer
• Spirit and Morale Lifter
"If you are silent about your pain, they’ll kill you and say you enjoyed it."

ZORA NEALE HURSTON
Syphilis Victims in U.S. Study Went Untreated for 40 Years

By JEAN HELLER
The Associated Press

WASHINGTON, July 25—For 40 years the United States Public Health Service has conducted a study in which human beings with syphilis, who were induced to serve as guinea pigs, have gone without medical treatment for the disease and a few have died of its late effects, even though an effective therapy was eventually discovered.

The study was conducted to determine from autopsies what the disease does to the human body.

Officials of the health service who initiated the experiment have long since retired. Current officials, who say they have serious doubts about the morality of the study, also say that it is too late to treat the syphilis in any surviving participants.

Doctors in the service say they are now rendering whatever other medical services they can give to the survivors while the study of the disease's effects continues.

Dr. Merian H. DuVall, Assistant Secretary of Health, Education and Welfare for Health and Scientific Affairs, expressed shock on learning of the study. He said that he was making an immediate investigation.

The experiment, called the Tuskegee Study, began in 1932 with about 500 black men.
Reflection# 1
Overview & Perspectives on Child/Adolescent Young Adult Grief Experiences

What We Know, What We Miss…
Grief

- Has been described as a PROCESS,
- As TASK oriented
- As an EXPERIENCE
- As a JOURNEY
- As PATHOLOGY...

It matters how YOU describe it, in order to inform how you SUPPORT and FACILITATE it…
Grief & Loss

The grief experience includes the physical and emotional reactions experienced following the *perceived* loss of someone or something of value. This unique and individual experience can affect body, mind, feelings, spirit, attitudes, relationships, and daily living. Its’ duration and intensity is determined by the person’s age, background, life experience, relationships, and type of loss.
Perception As Inclusive Practice Anchor

How a person “sees, describes, and experiences” their loss is a practical touchpoint for all clinical interventions engaging grief, especially with young people.

Engaging and empowering this in your spaces creates safety, respect and can support the rapport necessary for inclusive grief support.
COVID Grief

Multi-faceted

Plastic/Dynamic

Connects us beyond the virus

Unique Journey

Our Goodbyes have changed…

Impacts how we view/perceive time, connections, self, community
Reflection# 2
Development Considerations & Grief

• No hard, and fast rules here.
• Diversity/Unique qualities exist in experiencing.
• ACEs/trauma history can impact experience/needs.
• Start where the child/teen/young adult is…
• Avoid generalizing to “blanket” grief responses/interventions
<table>
<thead>
<tr>
<th>Age</th>
<th>Understanding of Death</th>
<th>Expressions of Grief</th>
<th>What You Can Do</th>
</tr>
</thead>
<tbody>
<tr>
<td>INFANTS</td>
<td>▪ May experience loss as an absence, particularly of a primary caregiver.</td>
<td>▪ Changes in normal patterns of eating, sleeping, bowel and bladder habits, and interacting.</td>
<td>▪ Offer physical comfort. &lt;br&gt; ▪ Maintain a routine. &lt;br&gt; ▪ Provide stable environment. &lt;br&gt; ▪ Monitor your own self care.</td>
</tr>
<tr>
<td>AGES 0-2</td>
<td>▪ Death is temporary and/or reversible. &lt;br&gt; ▪ Dead person continues to live and function in some ways. &lt;br&gt; ▪ May feel responsible for death because of wishes and thoughts.</td>
<td>▪ Grief expressed primarily through play. &lt;br&gt; ▪ May reenact the death. &lt;br&gt; ▪ May ask questions about the death over and over again. &lt;br&gt; ▪ Cycle between activity, routine, and need for care or “time out”.</td>
<td>▪ Allow “death play.” Join in and offer guidance. &lt;br&gt; ▪ Answer questions honestly and simply. &lt;br&gt; ▪ Use drawings and stories to help children express feelings. &lt;br&gt; ▪ Memory making/experiences</td>
</tr>
<tr>
<td>PRESCHOOLERS</td>
<td>▪ Beginning to see death as permanent. &lt;br&gt; ▪ Death happens to others. &lt;br&gt; ▪ May see death as a person or spirit—a ghost or the bogeyman.</td>
<td>▪ Curious about death. Will ask specific questions and want details. &lt;br&gt; ▪ Concerned with how others are responding. &lt;br&gt; ▪ May exhibit aggressive behavior (s), attention-seeking.</td>
<td>▪ Use “older kid” play therapy, especially for 10-12 year olds. &lt;br&gt; ▪ Answer questions honestly and simply. &lt;br&gt; ▪ Offer constructive “venting” activities. &lt;br&gt; ▪ Communication skill building, ventilation opportunities</td>
</tr>
<tr>
<td>AGES 3 – 5</td>
<td>▪ A more “adult or evolved” understanding of death as permanent and universal. &lt;br&gt; ▪ Just beginning to explore spiritual aspects of death.</td>
<td>▪ Heightened emotions of anger, guilt, and shame. May exhibit depression, denial behaviors, and repression. &lt;br&gt; ▪ May act out, withdraw, exhibit mood swings and/or engage in impulsive behaviors, including sexual behaviors. &lt;br&gt; ▪ May idealize the deceased, especially if deceased is friend, sibling, or parent.</td>
<td>▪ Tolerate acting out behaviors if teen or others are not being harmed. &lt;br&gt; ▪ Be available, but do not take control. &lt;br&gt; ▪ Encourage search for meaning—questions about life and death—as long as teen or others are not harmed. &lt;br&gt; ▪ Empowerment focused, future facing activities and support builds</td>
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<td>GRADE SCHOOLERS</td>
<td>▪ Just beginning to explore spiritual aspects of death.</td>
<td>▪ Heightened emotions of anger, guilt, and shame. May exhibit depression, denial behaviors, and repression. &lt;br&gt; ▪ May act out, withdraw, exhibit mood swings and/or engage in impulsive behaviors, including sexual behaviors. &lt;br&gt; ▪ May idealize the deceased, especially if deceased is friend, sibling, or parent.</td>
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Adapted from: Wolfelt, A. 1996 Healing the Bereaved Child: Grief Gardening, Growth through Grief and Other Touchstones for Caregivers
Children and Grief: Grief and Developmental Stages
National Cancer Institute – Loss, Grief, and Bereavement
http://www.cancer.gov/cancertopics/pdq/supportivecare/bereavement
Stroebe, Schut, 1999

Dual Process Model

Oscillation

Loss Oriented Activities
- Remembering loved one(s)
- Memory making
- Reminiscing
- Funerals/Ceremonies
- Estate Business
- Legacy Building
- Cleaning/Purge of Home/Property

Restoration Oriented Activities
- Cooking
- Cleaning
- Exercise
- Meditation/Prayer
- Ritual
- Creativity
- New Schedules/Habits
- Self-Care
- Social

Oscillation

Oscillation
Mourning Tasks - Worden

- Accept the loss.
- Acknowledge the pain of the loss.
- Adjust to new environment and identity.
- Reinvest in the reality of life without loved one/reality of the loss.
Communities, Youth of Difference & Grief Support
Considerations for Inclusive Practice
Reflection# 3
Intersectionality

Initially introduced as a Feminist ideology/construct.

Created by Kimberle Crenshaw, JD to describe disenfranchisement of Black women from social justice, and equality work/movements.

Useful in grief work as a tool for engaging narrative building and identity clarification for self, professional and community awareness.
Grief of Difference

These experiences may be impacted by additional layers of narrative around:

• Poverty
• Racism
• Oppression/Privilege
• Trauma
• Abandonment
• Insecure Attachment Styles
• Kinship & Community Care, ACCESS
• Community Narratives around Shame, or Distrust
• Stigmas or Disenfranchisement
Grief & Trauma

- **Trauma** Informed Care
- **Grief** Informed Care
  - **NOT** the same. No competition, just different focal points, narrative angles, and perspectives engaging individuals and a system **FULLY**. A prompt to all professionals to get ALL of the stories impacting a child/teen/family, or community.

- TRAUMA first, Grief onward…
Cumulative Loss

Losses do not happen in a vacuum.

Additional losses may bring up previous loss reactions, or trigger new reactions or behaviors from unresolved grief.

In Communities of Difference, the impact of unresolved histories of loss may be a huge barrier to support.

Do not be afraid to explore what worked before as a way of finding new ways to support coping.
The Work Of Diversity, Inclusion Intersectionality in Grief

Responds to:

• What do you have questions about?
• Your Values
• Your Beliefs
• Your Biases
• What you want reflected back to you in any interaction.
• Affirms, Confirms, Opens you up to more, & DIFFERENT Questions
• Keeps you alert, PRESENT…
BOTH : AND

-Kris F.
Barriers to Diversity

- Media imagery/messages about who people of color are, who gay/lesbians are, etc.
- Skewed perception of what family is, what “functional” is.
- Getting over ourselves enough to let go of long-held ideas about difference, who we are.
- Fear of offending.
- Fear of appearing prejudiced, or racist.
- Shame, or no- to low - self awareness of our own privilege, and/bias.
Equality vs. Equity

EQUALITY

- Everyone being treated the same.

EQUITY

- Everyone being given all the access and resources to engage, participate and succeed.
Girls often are given more permission to grieve— but because of hostility in environment; many are choosing not to take it.

Being “hard” or untouchable by pain is more accepted than traditional roles and stereotypes.

More girls are exhibiting anger in their grief journeys than sadness.

Requires practitioners to revamp approaches to support to meet these “new” needs.
Gender Issues

Boys have a full range of emotion, and the ability and desire to share and express themselves fully.

Unfortunately, they learn early on to distrust this desire for deep connection and expression.

There are clear messages about feelings and intimacy not being acceptable or “manly”

• Media
• Families
• Attachment & Parenting styles
• Culture reinforces these messages

This happens across demographics, and can have lasting effects on total functioning, regardless of loss hx., or presenting issues.
Othering...

Non-binary, gender nonconforming youth and individuals are not fully represented in our grief support constructs, and ways of ascribing the modern loss experience. Neurodiversity is also underrepresented.

Research and inclusive practice must be aligned to engaging the uniqueness of these grief journeys as a part of identity formation, resources, living in the queer body, coping, safety, and losses more specifically experienced as a part of these communities/identities.
Groups

Create a safe and non-judgmental space for sharing, and for creating “story”

Group is a resource for helping kids and their families put their story and history in perspective.

Should intrinsically support whatever that storyline is.

Loss is a defining factor in how a child/teen creates their identity, and develops a script for resilience and for finding their place in the world at large.
In Group...

- Protect the space.
- Ask about/Use desired pronouns, names, nick-names.
- Set clear boundaries.
- Know the losses.
- Set members up for success in communicating with each other, and across Difference.
- In the beginning, explore myths, and messages members have about each other, if a mixed group.
- Build in appreciation for the Difference(s).
Listening Inclusively

• Listen with attention, and not *intention*.
• Acknowledge feelings shared with a word-
  • “Oh…”
  • “I see,…”
  • “Mmm…”
  • “Tell me more.”

• Ask questions.

• Acknowledge discomfort around disclosing/sharing.

• Give feelings names. Ask how they describe/experience feeling identified.

• Pay attention to your body language. (ex. Don’t demand eye contact, etc.)

• Pay attention to their body language. (Notice discomfort, closing body language)

• Check limitations that you may have placed on sharing in previous directives, “rules”.
Jamal in Group

Appearance and affect may mask true feelings.

May appear defensive, guarded and hostile even though the prevalent feeling(s) are really fear, anxiety, desire to belong, be seen.

Gets messages and cues from all sides that indicate how damaged and “unmanageable” he/they is/are.

Understands the threat he presents to a “therapeutic setting”, society.

Has desire to live up to this until given other, more accurate cues from group, and from the facilitator.
Families in Therapy

Goal: Create a safe and non-judgmental space for sharing, and for creating “story”.

Group work is a resource for helping kids and their families put their story and history in perspective.

Should intrinsically support whatever that storyline is.

Loss is a defining factor in how a child/teen creates their identity, and develops a script for resilience, and for finding their place in the world at large.
What Do Kids/ Families of Color & Difference Want?

- Authenticity
- Voice
- Validation
- Respect
- Inclusion
Beyond Cultural Competency & Self-Care

More than CEUS & Bubble Baths…
The Tough Stuff...

- In group we must prepare and train staff and volunteers to deal with the function and dysfunction of all groups.
- We must give a context to what we see and hear that is slow to pathologize and quick to respond in sensitive, and relevant ways.
- We not only have to listen to what is being said in group, but also to what is not.
<table>
<thead>
<tr>
<th>Keep</th>
<th>Keep it simple.</th>
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<tbody>
<tr>
<td>Make</td>
<td>Make it sooner, rather than later.</td>
</tr>
<tr>
<td>Answer</td>
<td>Answer what you know, say what you don’t know.</td>
</tr>
<tr>
<td>Give</td>
<td>Give time for the emotion, or lack of.</td>
</tr>
<tr>
<td>Open</td>
<td>Open the door for opportunities for revisiting news later.</td>
</tr>
<tr>
<td>Allow</td>
<td>Allow for space, time in processing information.</td>
</tr>
</tbody>
</table>
# Social Media & Grief

- Allows for connection beyond immediate proximity
- Can be inclusive and lend creativity/free expression across platforms.
- Uses existing networks/lends itself to generating other ideas for support and connection.
- Can be a barrier to access/create comparative, biased, or hostile environment for feeling ventilation.
- Relevance not widely agreed upon construct online. Can promote isolation, exclusion, othering, abuse.
- Can be a meaning making/legacy promoting tool
- Can create portals for support not possible due to inequity/access issues.
- Requires oversight/engagement beyond our current infrastructure, rapid change in platforms and popularity shifts regularly.
Social Media & Grief

Provides alternative approaches/platforms of access for neurodivergence in grief practices, support/rituals.

Creates tools for deeper research, collation of information about grief.

Robust digital community of youth living with loss online.

Creates a common language for young people living with loss.

Extends ability to create education/training more frequently for grief professionals.

Can be a tool for group/activity generation.

Can support Client engagement around family narrative builds, genealogy support for fleshing out grief narratives.

Sharing of creative outputs in grief work.
OM

“Calm Zone”

“No mud, no lotus...”
Ritual

The symbolic has an important role in how people can heal from loss.

Many traditions we observe after a death are deeply rooted in ritual.

Kids and BIPOC/D are familiar with the role of ritual in their everyday lives.

Plays a huge part in how we interact with the world.

Incorporating the element of ritual can be a very helpful step in interacting with a grieving individual or system.
Resources

Use of self
What is around you?
Use existing networks.
What is important to the kids/communities you are working with?
Relevance
Meaning
Cements your commitment to understanding them.
Shows respect.
Inviting in & Putting it All Together...

Engagement & Strategies
Barriers to Inclusive Community Engagement

- Funders
- Board of Directors
- Strategic Plan
- Staff Competency
- Your “Public”
- Community of Choice/Population to be Served
- Self
Conscious Community Engagement

- Involves your stakeholders at every phase
- Delivers clear and respectful messaging
- Plans for multiple ways of reaching the community
- Is sustainable, and consistent
Programming Considerations

COMMUNITY & SCHOOL ACCESS

COLLABORATION & OUTREACH

TRAINING

PROGRAMMING TIMELINES
Program Development

What do you want to accomplish?

Have you answered the hard questions?

How can you diversify existing materials and activity plans?

Are existing materials/supplies safe and inclusive?

What are the physical/cognitive/accomodational changes that need to be made to plans?

Extra logistical considerations?

Plan B?
### Connecting...

<table>
<thead>
<tr>
<th>Role of connection</th>
<th>Role of responsibility and accountability to the larger community</th>
<th>Role of culture and of individual history</th>
<th>Role of males</th>
<th>Role of elders</th>
<th>Role of ritual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Take it back to the village...</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>
Action Plans

MAKE AN ASSESSMENT, HOW GREAT/BAD IS IT?
ANSWER THE HARD QUESTION(S) FIRST.
WORK WITH THE END IN MIND.
BUILD IN OPPORTUNITIES FOR COMMUNICATION.
BUILD IN OPPORTUNITIES FOR RESPECT.
GO BEYOND THE SURFACE.
## Considerations for Inclusion

### CURRICULUM

**Considerations:**
- Where did it come from?
- Specificity to Community/clients served
- Empowerment Based
- Strengths Focused
- Historical/Cultural Context
- Does it ask the right questions?
- Flexible?
- Responsive?

### OUTREACH

**Considerations:**
- Are you the right ambassador?
- What are the collaborations/partners that you need to ID, engage?
- What is intent?
- Sustainable?
- Authentic?
- Answers a call
- Responsive
- “Real”
- Organization Perception in Community

### GROUP FACILITATION

**Considerations:**
- What are your triggers?
- Plan B
- Strengths
- Empowerment
- Offers Choice
- Teachable
- Mediation Skills
- Active Listening Skills
- Behavior Management

### VOLUNTEER RECRUITMENT/TRAINING

**Considerations:**
- Who do you need?
- Why?
- Recruitment Strategies Specific to Need
- Authenticity
- Specific Training Modules
- Open Dialogue
- Transparency
- Competency
- Supervision

### INCLUSION PRACTICES

**Considerations:**
- How Serious are you?
- Leadership?
- Resources
- Open
- Has Buy-In from Stakeholders
- Everyone Participates
- Integration vs. “Celebration or Appreciation”
- Mission & Values reflect Commitment
Community Outreach

- **Identify** the “true” leaders
- **Gatekeepers** are key. **Earn** their respect.
  - Their identities are not always obvious.
- Go to the **source**, cut out the middle man.
- **Enlist** unlikely allies.
- Be **clear** about your goals.
- **Restate** agendas and goals often.
- Be **alert** to the “politics” of the community of interest.
- **Reassess** often, and throughout the process.
Professional Development in Grief Support

Baselines & Accountability
The Skin You Are In...

- How well-defined is your grief journey?
  - What are your questions?
  - Challenges?
  - Triggers?
  - Where are you at peace?
- How do you define your family of origin?
  - Choice/Curated Community or Family
- What stereotypes or beliefs do you hold?
  - General
  - Specific
Barriers to Self-Care in Grief

• Belief that we are not “supposed to share our struggles/conflicts”
• Unclear feelings about our own grief/loss history
• No room for a comprehensive Self-Care Strategic Plan that is ongoing, flexible in our development as Professionals
• Concern about Competency
• Your “Public Facing Self vs. Private You”
• No identified Support System
• Self imposed exile(s)
Self-Care

- Play
- Creativity
- Courage
- Self-Advocacy
- Supervision
- Collegiality/Connection in the field
- Continuing Education/Training
- Respite
- Boundaries
Why Should I Care about Self-Care?

- Guides Behavior & Practice
- Spirituality Alignment
- Sets Multiple Compasses
- Identifies & Clarifies Boundaries
- Supports Self-Care Goal - setting/Maintenance
- Allows Support of Others
- Allows for Goal Setting
- Prioritizing Needs
- Informs Resilience
- Identifies Barriers & Biases
Why Should WE Care?

- Grounds Foundation for INterventions & Models of Support
  - Guides Hiring & Training
  - Builds in support and safety for staff
  - Shows gaps in Service, Research, Core Competencies
  - Identifies & Engages stakeholders
  - Can guide mission/professional development...
Considerations for the Future

1. Diversity of Peer & Family Centered Models & Approaches to Practice/Support
2. Leadership Development, Retention, & Identification of Legacy Opportunities
3. Advocacy Focus for Policy, Protection of Young People, Communities & Advancement of Field
4. Research with Diverse Groups
5. Recruitment/Training Focus around Diversity & Inclusion
6. Neurodiversity & Grief

Diversity of Peer & Family Centered Models & Approaches to Practice/Support
Conclusions

We must begin to look at themes and patterns of behavior that we collude with consciously and subconsciously. As we show up to support young people and communities.

We must reject some of the easy conclusions that come out of skewed evaluation, and limited research about how young people, Communities of Color/Difference grieve, and what their support needs are.

We must become vigilant within our communities and programs about what our stakeholders say it is that they need.
thank you

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