Stories of Bereaved Parents: The Use of Religion/Spirituality to cope with their Infant’s/Child’s Death

Dawn Hawthorne, PhD, RN
JoAnne M. Youngblut, PhD, RN, FAAN
Dorothy Brooten, PhD, RN, FAAN
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Study Purpose

To explore how parents from diverse racial/ethnic population use religious/spiritual activities to cope with the death of their infant/child

Time point: 7 months after their infant’s/child’s death in the Neonatal/Pediatric ICU.
Background and Significance

In 2016 over 50,000 infants (0-1 year old) and children (1-18 years old) died annually in the US. Approximately 52% representing infant deaths. Approximately 80% of infant and childhood deaths within the hospital occur in the NICU/PICU. (Matthews et al., 2011)
Background and Significance

- NICU/PICU admission and stay are overwhelming and painful for parents.

- Faced with difficult end-of-life decisions

- The stress created by this traumatic event disrupts their mental and physical health

(Youngblut et al., 2013)
Some bereaved parents rely on their religious/spiritual beliefs to obtain comfort, create meaning from their loss and help with the healing process.

(Cowchock et al., 2010; Litchenthal, et al., 2010)
Religion & Spirituality

Religion:
- A specific framework of beliefs, values and practices a person holds and uses to guide his/her life (Schneider, 2004)

Spirituality:
- Broader than religion
- The core of human beings that gives meaning and purpose to each person’s existence irrespective of their faith (Koenig, 2009)

Spirituality for the individual can be religious or non-religious (Peri, 1997)
Similarities of Religion & Spirituality

Both provide guidance on how individuals live harmoniously with self, others, and the environment.
Religion/Spirituality as a Coping Strategy

Death of a child creates disequilibrium within the psychic and social world of bereaved parents (Klauss, 1999)

Religion/Spirituality

- Provide security and peace
- Equate the death of their child with God’s plan
- Hope for reunion in the afterlife
Recruitment

- Families identified by the clinical co-investigators of each unit
  - 4 level III NICUs and 4 PICUs

- Office of Vital Statistics, Florida Department of Health
Inclusion Criteria

NICU families
- Singleton pregnancy
- Neonate born alive
- Lived for > 1 hour

PICU families
- Patient in the PICU for > 1 hour
- Deceased child ≤18 years of age
Exclusion Criteria

- Multiple gestation pregnancy if deceased is newborn
- Child in foster home before hospitalization
- Injury suspected to be child abuse
- Death of a parent in the hospitalization event
Procedure

- PD sent a letter to bereaved parent
- Bereaved parent contacted @ 3-4 weeks
- Qualitative Interview in parent’s home in English or Spanish at 7 months post death
- Both parents when possible
Interviews

- Open-ended semi-structured interviews were recorded and transcribed

- Deductive content analysis was used to explicate themes
Theory used to Guide the Study

- Nancy Hogan –
  - Hogan’s grief theory (1996) defines grief as “a process of coping, learning and adapting” (p. 44) and was developed from qualitative grounded theory research. The model posits that irrespective of the relationship of the bereaved person to the deceased, the process of bereavement remains unchanged. The model consists of six phases.
Theory (cont)

- First Phase - “getting the news” (feelings of shock)

- Second Phase - “facing reality”

- The Third Phase - “becoming engulfed in the suffering”
Theory (cont)

- Fourth Phase – “begin to experience some good days”
- Fifth Phase – “getting on with their lives”
- Sixth Phase – “develop new perspectives”

- The model hypothesizes that these stages are not linear but cyclical (Hogan, Morse & Tason, 1996).
Results
Study Sample

• 33 bereaved parents
  – 12 died in the NICU
  – 21 died in the PICU
• Understand spoken English or Spanish
<table>
<thead>
<tr>
<th></th>
<th>Mothers (n = 32)</th>
<th>Fathers (N = 6)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age [M (SD)]</strong></td>
<td>32.4 (8.273)</td>
<td>38.0 (10.000)</td>
</tr>
<tr>
<td><strong>Race/ethnicity [n (%)]</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>9 (28.1%)</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>Black</td>
<td>13 (40.6%)</td>
<td>2 (28.6%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>10 (31.3%)</td>
<td>1 (14.3%)</td>
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<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;High School</td>
<td>2 (6.3%)</td>
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</tr>
<tr>
<td>HS graduate</td>
<td>9 (28.1%)</td>
<td>1 (14.3%)</td>
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<tr>
<td>Some college</td>
<td>14 (21.9%)</td>
<td>2 (28.6%)</td>
</tr>
<tr>
<td>College degree</td>
<td>7 (30%)</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>Religion [n (% )]</td>
<td>Mothers (n = 32)</td>
<td>Father (n = 6)</td>
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<tr>
<td>------------------</td>
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<td>--------------</td>
</tr>
<tr>
<td>Protestant</td>
<td>18 (56.3% )</td>
<td>3 (42.9% )</td>
</tr>
<tr>
<td>Catholic</td>
<td>8 (25% )</td>
<td>1 (14.3% )</td>
</tr>
<tr>
<td>Jewish</td>
<td>3 (9.4% )</td>
<td>1 (14.3% )</td>
</tr>
<tr>
<td>None</td>
<td>3 (9.4% )</td>
<td>1 (14.3% )</td>
</tr>
<tr>
<td>Total Annual Income</td>
<td>Families (N = 33)</td>
<td></td>
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<tr>
<td>--------------------</td>
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<td></td>
</tr>
<tr>
<td>&lt; $20,000</td>
<td>6 (4% )</td>
<td></td>
</tr>
<tr>
<td>$20,000 - 49,999</td>
<td>7 (21.2% )</td>
<td></td>
</tr>
<tr>
<td>≥$50,000</td>
<td>15 (45.5% )</td>
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</table>
### Deceased Child’s Characteristics

<table>
<thead>
<tr>
<th>Sex</th>
<th>Males = 17 (51.5%)</th>
<th>Females = 15 (48.5%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Infants (0 - 12.5 months)</td>
<td>16 (48.5%)</td>
</tr>
<tr>
<td></td>
<td>Preschooler (13 – 16 months)</td>
<td>7 (24.2)</td>
</tr>
<tr>
<td></td>
<td>School-age (61 – 144.5 months)</td>
<td>4 (12.1)</td>
</tr>
<tr>
<td></td>
<td>Adolescents 144.51 – 227.9 months)</td>
<td>5 (15.2)</td>
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Getting the News
Getting the News

- Feeling of shock
- Extreme pain
- Unacceptance of the death
Getting the News

- Receiving the news “No Hope”
- Open to Miracles
- Prayed for a Miracle and believed that their prayers would be answered
Open to Miracles

“I was praying for a miracle and I didn’t know what to think for a brain injury….I am a Christian and I believe in God so I was praying to God…through the night by telling him to choose for me because I wanted my daughter to be happy kinda give me peace in my heart. I trusted that my daughter will be in a better place…..even though I didn’t want him to take her I said I just wish that you can give me her but if she’s not you know take her with you.
“we thought God would have - was going to get a miracle from God (crying) that he would cure her, were she to hang in there long enough...If it’s God’s will that she passes today, tonight, she passes ......we’re not gonna put her on a ventilator machine...we are not going to revive her and shock her body and like I said hook her up to machines”
I was talking to God and was...God you are testing me right now...you just wanna see how faithful I am because I believe in your Lord, you’re testing me because she is gonna be okay. She didn’t make it....I didn’t give up thinking that he might save her...I all this stuff that she wanted to unhooked-like let me go, let me go and we did”. 
Facing Reality
Facing Reality

“I accept that my son is gone but deep down in my heart I don’t I sometimes I don’t want to accept it…sometimes I just be like you know Lord I wish it could be me you take and let him stay…I say that a lot of times because he was so young and innocent and did not deserve to die”
Facing Reality

“I miss him you know – I don’t miss him any less I miss him even more now you know… I don’t know if I will ever stop grieving you know – I grieve for him every day… I still cry for him every day... I still cry every day – I think about him every day, every moment almost all the time (crying).... so it’s always there – never going to go away”
Becoming Engulfed in the Suffering
Becoming Engulfed In The Suffering

- “When you loose a child you – let me tell you there is a thin line between sanity and insanity”

- “There is nothing you can say to ease the pain”

- “I feel like a lost a part of my soul”
Becoming Engulfed in the Suffering

Questioned God’s decision

Prayer - prayed for understanding

Support from family members, friends and religious leaders

Obtaining strength from other children

Angry with God
In coping with the death parents often asked “Why me Lord”? or “Why is this happening to me?”
Becoming Engulfed in the Suffering

- A few parents expressed anger and frustration at God
- At everyone
- At their ex partner
Becoming Engulfed in the Suffering

- “I’m just so angry all the time…I try to put it away but....by me I have no understanding why my baby passed and everything else”
Becoming Engulfed in the Suffering

- Parents who remained angry wanted answers as to why their infant/child died
Gradually Emerging from the Suffering

“I have good days and I have bad days you know I had a bad day yesterday you know some days I….I’m always thinking about him but some days it just make me very moody you know so I had a bad day yesterday so… I can’t tell you how often it …

I’ll always shed a tear… yesterday I cried all day long usually when I’m alone.
Getting On With Their Lives
Getting On With Their Lives

- Bereaved parents incorporated the deceased child into their daily lives
- Spoke constantly about the memories with the deceased child
- Looked at pictures and reminisced
Getting On With Their Lives

“talk about him as if he is living and it will make you feel better… talk about all the good things he did while he was living.”
Getting On With Their Lives

- Creating a showcase in the home
- Making a scrapbook
- Wearing the child’s rosary beads
Creating New Perspectives
Creating New Perspectives

- Looked at life differently

- Became stronger in their faith and personal life
Creating New Perspectives

“I look at life so differently; I thought I was living before but not until she came into my life and because my other two kids are healthy I never really maybe much just ask God for. I never had to lean on him so much so much so what she’s done is brought me close to God- help me just to look at life totally different- a different perspective …
Creating New Perspectives

- “I’ve grown as a human being. I think I’m more compassionate, more thoughtful of others who are enduring such a loss”

- Others started foundations
“Her sickness brought us back to our faith; to our religion which is what got us through the day and which is still ...and what is still keeping us going”. So if anything it actually brought us closer; not only to ourselves but to the Lord.

“The church and the Lord – we surrounded ourselves with believers, the bible and that’s it period.
“I knew I was a strong person before the death but she has made me stronger – I knew about God …but I know my relationship has gotten closer and um stronger and I have more interest in pursuing and keeping that close you know that relationship that I have with him because at the end of the day I realize that there is nobody on this earth could have helped that pain”.

Christine E. Lynn College of Nursing
...right now is about staying healthy, taking care of the kids, Um stronger in Christ “
Conclusion

- Parents were deeply affected by the death of their infant/child
- Prayer was an integral part of coping with their grief
- Most parents emerged from the suffering stronger
Thank you .... 

Questions ?