342 Infant/Child NICU/PICU Deaths: Subsequent Health and Functioning of Parents, Grandparents, & Surviving Siblings

JoAnne M. Youngblut, PhD, RN, FAAN
Dr. Herbert & Nicole Wertheim Professor
Florida International University
Nicole Wertheim College of Nursing & Health Sciences
Infant/Child Death: Life Changing Event

- Studies of parent health & functioning
  - Not easily translated to practice (timing)
  - Very few longitudinal studies, data collection in 1st year post-death
- Few studies of GP health & functioning
- Studies of children – data from parents
Our Studies: Parents, Grandparents, & Children in 1st Year after ICU Death

• Parent study: NINR, NIH, R01 NR009120

• Grandparent (GP) study: NIGMS, NIH, MBRS SCORE Individual Research Subproject S06 GM008205

• Sibling study – Data collected from School-age children & teens: NINR, NIH, R01 NR012675
Parent Study

188 families with deceased infant/child
- 176 mothers, Mean Age 32 (SD=8)
- 73 fathers, Mean Age 37 (SD=9)
- 44% Hispanic, 35% Black, 21% White
- Quantitative data: 1, 3, 6, & 13 mo
- Qualitative data: subset of 63 parents, 7 & 13 mo
Grandparent Study

• 136 GP, 36 – 77 years old, 35% > 60
• 115 deceased grandchildren: ≤ 6 yrs
• 73% GP female
• 24% Hispanic, 38% Black, 38% White
• 1 interview by telephone 2-6 months post-death (quantitative only)
Sibling Study

- 132, ages 6-18, from 71 families
- 96 School-age children, 36 Teens
- 58% female
- 30% Hispanic, 50% Black, 20% White
- Quantitative data: 2, 4, 6, & 13 mo
- Qualitative data: at 7 & 13 months for 31 School-age, 17 Teens
Sibling Study Parents

- 70 mothers, Mean Age 36 (SD=7)
- 26 fathers, Mean Age 39 (SD=7)
- 32% Hispanic, 41% Black, 27% White
- Quantitative data: 2, 4, 6, & 13 months after sibling death
- No qualitative interviews
Parent & Sibling Morbidity

• Date & type of:
  – Acute illnesses, chronic conditions
  – Hospitalizations, Health services
  – Medication changes
• Parent-rated Depression, PTSD
• Grandparent-rated Depression, PTSD
• Child-rated Depression, Anxiety
249 Parents’ Physical, Mental Health

• 404 acute illnesses, 98 hospitalizations, 132 newly diagnosed chronic health conditions
• Depression: 35% mothers, 24% fathers
• PTSD: 35% mothers, 30% fathers
• 2 mothers – newly diagnosed cancer
• *Pediatrics, 2013; Am J Hospice & Palliative Medicine, 2016*
136 GPs’ Physical, Mental Health

- 59 Acute Illnesses, 7 Hospitalizations
- 68% pre-existing chronic conditions
- 31% Depression; 35% PTSD
- Greater Depression if provided child care

- *Journal of Community Health, 2015*
132 Children’s Physical Health

- 207 illnesses, 2 hospitalizations
- 674 treatments/health services
- In 1st 6 months after sibling death
  - 64% illnesses &
  - 65% treatments

- J of Child & Family Studies, 2018
Child-rated Mental Health

• 43% Elevated Anxiety
• 6% Depression
• Anxiety higher: girls, Black vs White children
• Anxiety & Depression lower if child:
  – Saw sibling in ICU before/after death
  – Attended funeral
• Journal of Pediatrics, 2019
96 Sib Parents’ Physical Health

- 394 acute illnesses
- 17 hospitalizations
- 56% mothers had pre-existing chronic conditions
- 124 medication changes

- *Am J of Critical Care (AJCC)*, 2019
Acute Illnesses by Study Month

[Bar chart with data for parents (N=249), siblings parents (N=96), and children (N=132) over study months 1 to 13.]
Mothers’ Grief (parent study)

- Steady decrease: 1 through 13 months
- Grief greater for:
  - Hispanic vs White
  - Deceased Teens vs Infants
  - Child declared brain dead
- Not by whether death expected
Fathers’ Grief (parent study)

• Decreased from 3-6 months only
• Less Panic than mothers of same child
• No differences by Race/ethnicity, Deceased’s age group, Mode of death, Whether Death was expected

• Journal of Loss & Trauma, 2017
Grandparent Grief

• GP grief higher if provided child care
• No difference by time since death
• GPs vs Parents
  – Significantly higher Personal Growth
  – Significantly lower Grief than parents

• Journal of Community Health, 2015
Grief: School-age Children & Teens - Beginning analyses

• Grief higher for:
  – Teens at 4, 13 months
  – Girls at 2 months

• Growth higher for:
  – Black vs White children at 4 mo
  – Teens at 2, 13 months
  – Girls at 6 months
Parent Functioning

- 72% partnered at 1 & 13 months
- 18% mothers, subsequent pregnancy
- Return to Employment by 1 month
  - 50% mothers
  - 74% fathers – Median of 14 days
Grandparent Functioning

- GM & GF: Perceptions of couple relationships similar
- 91% returned to their jobs
- 86% by 14 days
- Black GP thought more often about deceased at work than white GP
Child School Functioning

• In 13 months:
  – 14 had 41 school detentions
  – 9 had 28 school suspensions
  – 59 had 123 requests for parent-teacher conferences

• Difficulty focusing on school work:
  – At 2 months for Boys
  – At 6 months if Didn’t see sibling in ICU
Qualitative Analyses
Child Responses to Sibling Death

• Themes: Circumstances of the death, Burial events, Thinking about/talking to deceased sibling, Fears, & Life changes

• School-age Fears:
  – Death, cancer, being snatched away - self, parents, other siblings
  – Decreased from 7-13 months

• J Child & Family Studies, 2016
Child Responses to Sibling Death

• Adolescents by 13 months
  – Changes in family life
  – Changes in themselves (more considerate, mature)
  – Fears (death, cancer, being snatched away - self, parents, other siblings) increased from 7-13 months

• *J Hospice Palliative Nursing*, 2017

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Nicole Wertheim College of Nursing & Health Sciences
Florida International University
Health Care Providers: What Parents Said Helped Most

- Compassionate, sensitive, caring staff
- Understandable explanations on child’s condition
- Experienced, competent nurses
- Providers did everything to help child
- Parent involvement in care, decisions
Health Care Providers: What Didn’t Help

- Conflict between parents & providers
- Communication problems
- Parents not understanding the child’s disease, care, & complications
- Insensitive, non-supportive staff
- Inexperienced, not knowledgeable providers

- *Am J Hospice & Palliative Care, 2013*
Parent: Wish I Had Done

• Mothers
  – Spent more time with their child
  – Held their child more
  – Chosen different treatment path

• Fathers
  – Spent more time with their child
  – Monitored their child more closely
Parent: Wish I Had Not Done

• Mothers
  – Taken poor care of themselves
  – Agreed to surgery/treatment

• Fathers
  – Left the hospital
  – Agreed to surgery/treatment

• J Am Assoc Nurse Practitioners, 2019
Sib Parent: Wish I Had Done

- Mothers
  - Spent more time with child
  - Chosen different treatment path
  - Advocated for changes in care

- Fathers
  - Spent more time with child
  - Gotten care earlier
  - Gone to a different hospital
Sib Parent: Wish I Had Not Done

• Mothers
  – Agreed to surgery/treatment
  – Taken own actions

• Fathers
  – Agreed with physicians/treatment
  – Been so hard on their child

• *Am J Hospice Palliative Nursing, 2019*
Children: Wish I Had or Had Not Done

• Wished they had:
  – Spent more time with sibling
  – Talked, played more with sibling

• Wished they had not:
  – Been mean or fought with sibling
  – Complained, argued with others about sibling
Parent: Coping with Child Death

• Mothers
  – Caring for self (keeping busy, job)
  – Remembering their child
  – Talking with friends, family, children

• Fathers
  – Caring for self (keeping busy, job)
  – Moving forward
  – Religious activities
Sib Parent: Coping w/ Child Death

• **Mother**
  – Religious activities
  – Care for self (keeping busy, job)
  – Talk about &/or with deceased

• **Father**
  – Religious activities
  – Care for self (keeping busy, job)
  – Things to Remember/Honor child
Children Coping with Sib Death

- Talking to parents, family, friends, teacher, & deceased sibling
- Playing with family, friends
- Quiet activities
  - Listen to music
  - Watch TV
  - Read
Lessons Learned
Lessons Learned

• Data from this body of research provides guidance for the type and timing of interventions for parents and siblings following infant/child death

• Shared results from only a few of the published papers
Lessons Learned – Physical Health

• Parents’ & Children’s Morbidity
  – Greatest in months 1 - 6
  – Very low in months 7 - 10
  – Increased again in months 11 - 13

• Many acute illnesses preventable

• Screen for diabetes, hypertension, angina, asthma, even in younger parents
Lessons Learned – Mental Health

• At 1 month, ~70% mothers & ~60% fathers had Depression, PTSD
• Fewer by 13 months (35% mothers, ~27% fathers)
• Screen parents for depression, PTSD in 1st through 6th months after death
• Black & Hispanic mothers at higher risk
Lessons Learned – Mental Health

• Children – almost half with Anxiety; very few with Depression

• Anxiety Higher in:
  – Girls, Teens
  – Black than white children initially
  – Didn’t see sib in ICU before death

• Allow/encourage children to see sib in NICU/PICU before death
Lessons Learned – Grief

• Grief greater for mothers than fathers; Hispanic than white mothers, mothers of deceased teens

• No difference in Grief by whether expected the death

• GP Grief higher if provided child care

• Provide time, space for GP to talk about deceased grandchild & ask questions
Lessons Learned

• Parents wished: Spent more time with child & Not agreed to child’s surgery/treatments

• Most frequent coping: Caring for self, Remembering their child

• Need information at levels & in languages they understand to avoid misunderstandings, potential liability
Lessons Learned

• Children wished:
  – Spent more time, played more w/ sib
  – Not been mean to sibling

• Most frequent coping:
  – Talk to family, friends, deceased sib
  – Playing with others
  – Some solitary activities
Lessons Learned

• Ask children how they are doing
• Probe for, respond to child’s regrets, misconceptions, & questions away from parents
• Children, regardless of age, aware of parents’ grief, tried to comfort them
• When parent(s) present, may hide or minimize feelings to protect parents
Lessons Learned – Child Fears

• Top fears: daily (dark, high places) and violent situations (robbed, shot, knifed, kidnapped), doctors’ offices, bugs, and animals across age, sex, race/ethnicity

• Girls – bugs, situations with parents & siblings

• Boys – daily (& violent) situations

• Help children identify ways to cope with their fears
Ongoing Work

• Death ritual practices in countries of origin or cultural/ethnic group
• Parent health and functioning 1, 3, 6, 13 months and 2-6 years after child death
• Infant and child ICU death: Sib Parent recall vs chart cause of death
• Children’s grief after sibling death
• Children’s relationships with parents, siblings, friends
Thank You