

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

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# **Infant/Child Death: Life Changing Event**

- **Studies of parent health & functioning**
  - **Not easily translated to practice (timing)**
  - **Very few longitudinal studies, data collection in 1<sup>st</sup> year post-death**
- **Few studies of GP health & functioning**
- **Studies of children – data from parents**



# **Our Studies: Parents, Grandparents, & Children in 1<sup>st</sup> 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 1<sup>st</sup> 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***

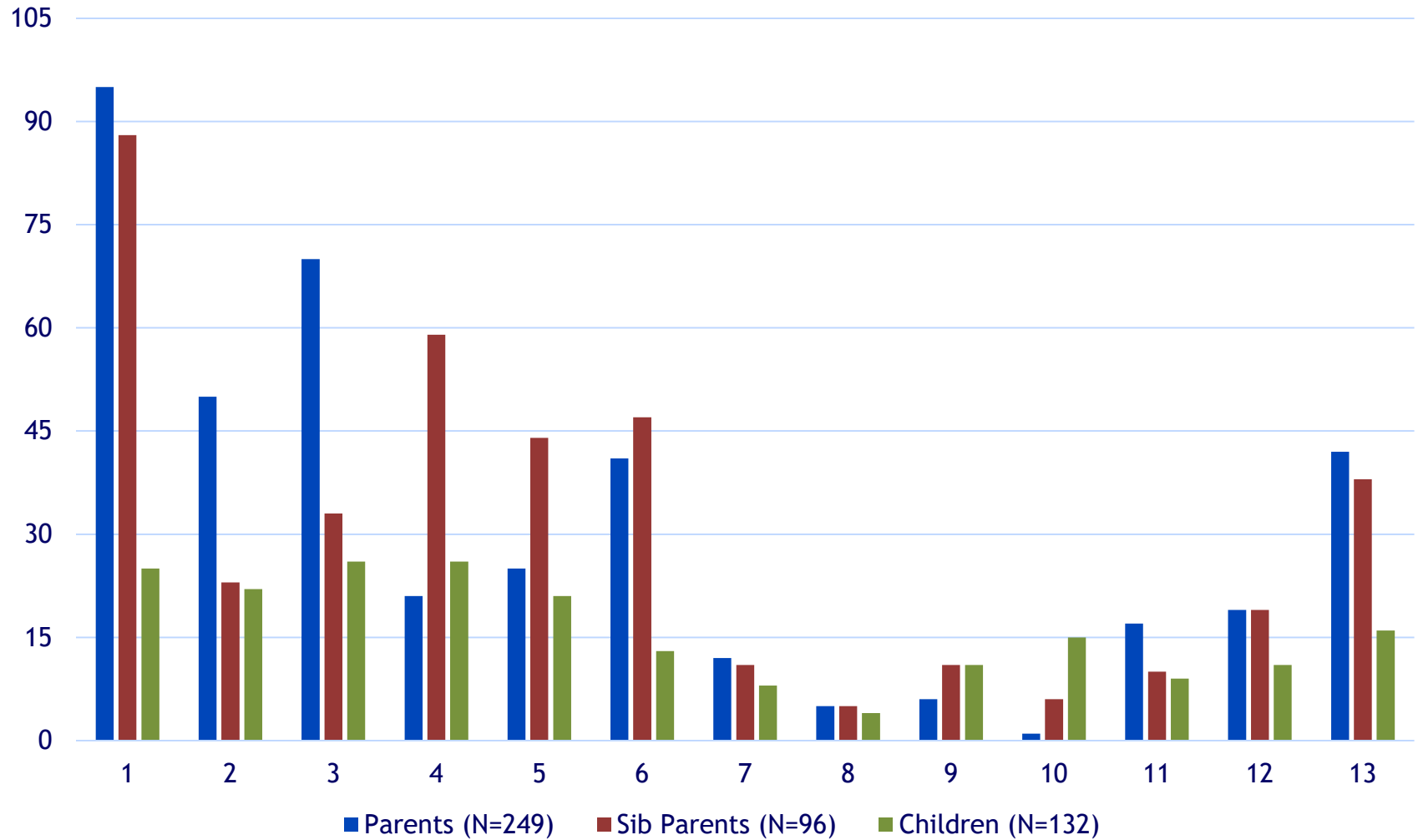


# 96 Sib Parents' Physical Health

- 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



# **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***





# 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 1<sup>st</sup> through 6<sup>th</sup> 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



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