



# **Social Determinants of Grief:**

*The Impact of Black  
Infant Loss*





Happy  
to Host!

NICHQ  
National Institute for  
Children's Health Quality



# **Social Determinants of Grief:**

*The Impact of Black  
Infant Loss*





**A Time of Grief**

# Social Determinants of Health

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- Income level
- Educational opportunities
- Occupation, employment status, and workplace safety
- Gender inequity
- Racial segregation
- Food insecurity and inaccessibility of nutritious food choices
- Access to housing and utility services
- Early childhood experiences and development
- Social support and community inclusivity
- Crime rates and exposure to violent behavior
- Availability of transportation
- Neighborhood conditions and physical environment
- Access to safe drinking water, clean air, and toxin-free environments
- Recreational and leisure opportunities

# Another Social Determinant: COVID 19

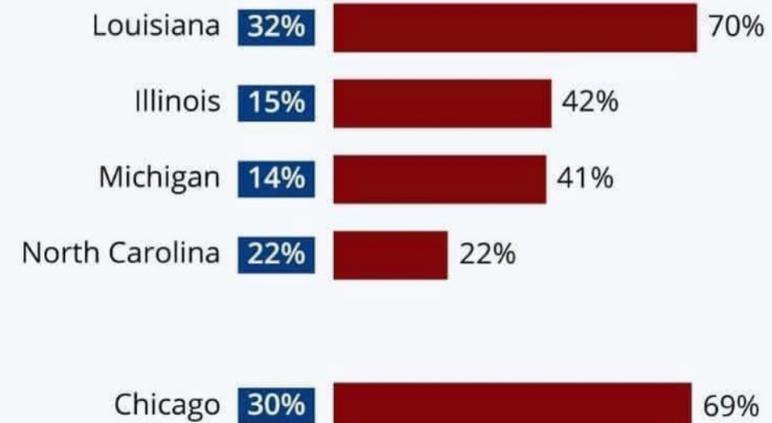


*The CDC has been requested to collect and publicly report racial demographics of patients affected by COVID-19 from a national perspective.*

## COVID-19's Devastating Impact On African Americans

African American share of state/city populations and COVID-19 deaths (as of Apr 06, 2020)

■ Share of state/city's population ■ Share of COVID-19 deaths



Sources: 2010 Census, respective state/city health departments



Forbes statista

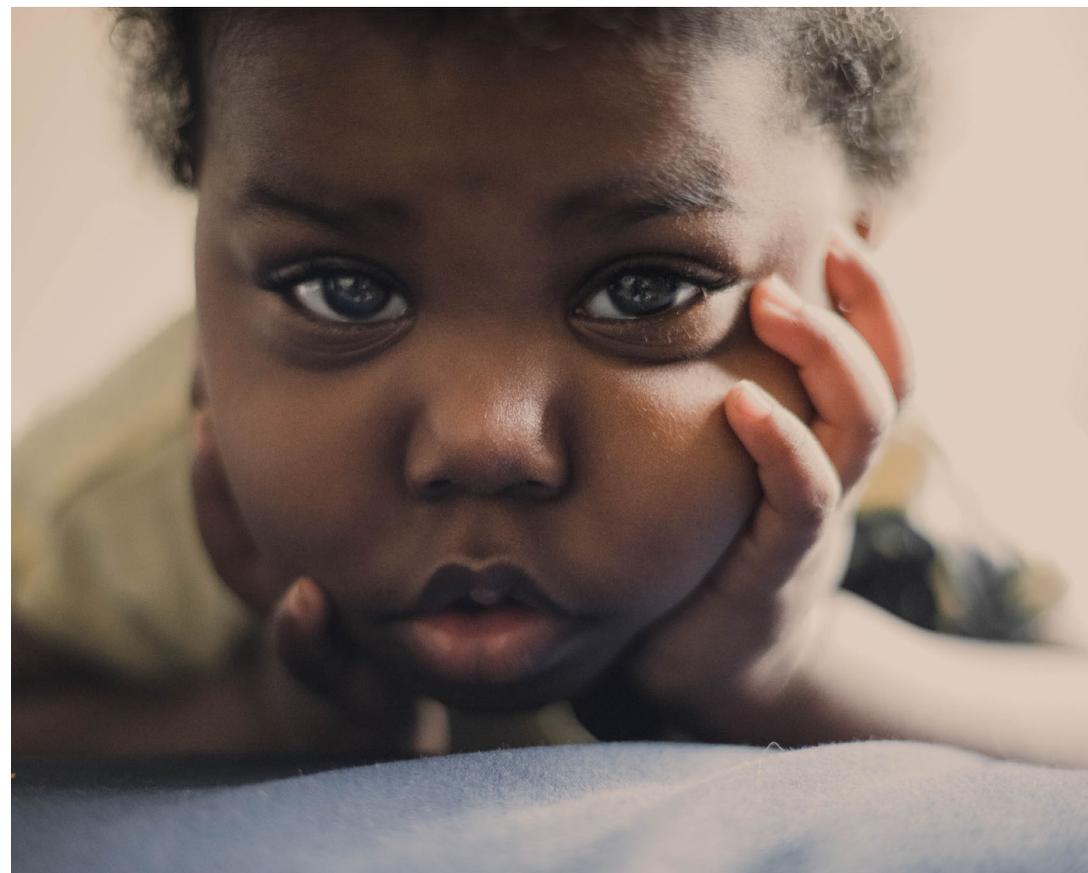
# COVID-19 is not causing the disparities, it further exposes a bias health care system

*“...unemployment, food insecurity and unstable or substandard housing conditions may further perpetuate disparities in health outcomes for people infected by the coronavirus, most specifically among low-income communities of color.”*



**BABY 1ST**

NETWORK



# Baby 1<sup>st</sup> Network

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Baby 1st Network is committed to providing the tools necessary to empower and engage communities to keep their infants safe

## PROFESSIONALS

A leading resource for information and training; a valued collaborator in community efforts to reduce infant mortality

- Education and Training
- Nurses and Social Workers
- Child Care Providers
- Clergy
- EMT/Paramedics
- Funeral Directors
- Facts and Figures

## COMMUNITY OUTREACH

We strive to inform the community on the disparate statistics and the impact infant mortality has on the nation, state and community as a whole

- Community Health Forums
- Community Mini-Grants
- Community Resource Toolkit
- Infant Safe Sleep Advocacy Training

## LOSS SUPPORT

The Baby 1st Network provides bereavement support services through volunteer contacts throughout the state, referral resources and a library of grief materials for families, free of charge

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Community focused



# Our Webpage

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# Ohio Infant Mortality Report 2018

- In 2018, Ohio's infant mortality rate was 6.9 per 1,000 live births compared with 7.2 in 2017.
- From 2009 through 2018, Ohio's infant mortality rate decreased at an average of 1.1% per year.
- After a five-year increase, black infant mortality rate went from 15.6 per 1,000 live births in 2017 to 13.9 in 2018.

Black infants still die at a rate  
2.5 to 3 times higher than  
white infants



# Reporting sudden unexpected infant deaths in Ohio, and bereavement support services

- In 2002, the Ohio Department of Health (ODH) created the Sudden Infant Death Syndrome (SIDS) Program
- Ensures compliance with **Ohio Revised Code 313.121** – reporting of sudden and unexpected infant deaths and providing support and bereavement services
- Working with ODH, Ohio Coroner's Association and local health departments, Baby 1st Network alerts service providers of sudden infant deaths in a community



Completed form  
should be submitted  
within 72 hours

**Ohio Department of Health  
Notification of Infant Death**

Infant's Name		Last	First	Middle	Date of Birth		Date of Death											
Gender		Age	Hispanic Ethnicity	Race (Check all that apply)														
<input type="checkbox"/> Male	<input type="checkbox"/> Female	<input type="checkbox"/> Unknown	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> White	<input type="checkbox"/> Black / African American	<input type="checkbox"/> American Indian / Alaskan Native	<input type="checkbox"/> Hawaiian Native / Pacific Islander	<input type="checkbox"/> Asian <input type="checkbox"/> Unknown <input type="checkbox"/> Other _____										
County of Death			County of Residence			County of Autopsy												
Father's Name		Last	First	Middle	Area Code and Phone Number		Age											
Residence		Street Address			City	State	Zip											
Mother's Name		Last	First	Middle	Area Code and Phone Number		Age											
Residence		Street Address			City	State	Zip											
<p>The <b>Preliminary</b> diagnosis of this death is:</p> <table border="0"> <tr> <td><input type="checkbox"/> SIDS</td> <td><input type="checkbox"/> Undetermined (Natural)</td> </tr> <tr> <td><input type="checkbox"/> Unintentional Injury / Accident</td> <td><input type="checkbox"/> Undetermined (Not Natural)</td> </tr> <tr> <td><input type="checkbox"/> Asphyxia</td> <td><input type="checkbox"/> Undiagnosed Disease / Natural</td> </tr> <tr> <td><input type="checkbox"/> Other Unintentional Injury</td> <td><input type="checkbox"/> Other (Please Explain)</td> </tr> <tr> <td><input type="checkbox"/> Inflicted Injury / Homicide</td> <td></td> </tr> </table> <p><input type="checkbox"/> Circumstances dictate that <b>NO</b> contact with the family should be made until final diagnosis</p>									<input type="checkbox"/> SIDS	<input type="checkbox"/> Undetermined (Natural)	<input type="checkbox"/> Unintentional Injury / Accident	<input type="checkbox"/> Undetermined (Not Natural)	<input type="checkbox"/> Asphyxia	<input type="checkbox"/> Undiagnosed Disease / Natural	<input type="checkbox"/> Other Unintentional Injury	<input type="checkbox"/> Other (Please Explain)	<input type="checkbox"/> Inflicted Injury / Homicide	
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<p>Form Completed by: _____</p> <p>Area Code and Phone Number: _____</p> <p>County: _____</p>																		

Please send this report to:

Baby 1st Network  
P.O. Box 403  
Toledo, OH 43697-0403  
Or Fax (330) 929-0593

HEA 7721 - Revised 07/18 If you have questions regarding this form, please call Stacy Scott, PhD at (330) 929-9911



# Sudden Unexpected Infant Death

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## Sudden Infant Death Syndrome (SIDS)

A medical cause of death. Sudden death of infant less than 1 year that remains unexplained after investigation, including autopsy, death scene examination, and review of health history.

# Sudden Unexpected Infant Death

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## Sleep-related death:

### Death of infant while sleeping

Characteristics of or elements in the sleep environment appear to play a role in the sudden, unexpected death.

SIDS

Asphyxia

Undetermined causes

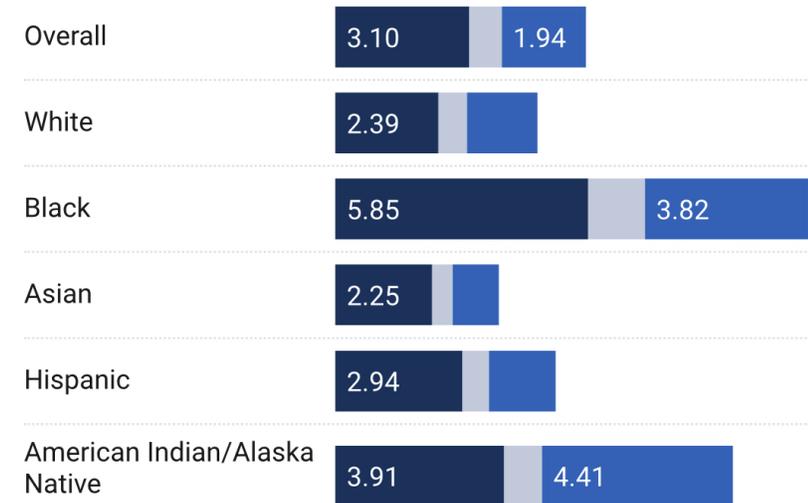
# National Disparities



## Infant Death Rates Vary by Race

Mortality rate by age of infant's death, 2017

■ Less than 7 days ■ 7-27 days ■ 28 days-under 1 year



The infant mortality rate measures the number of deaths per 1,000 live births

Chart: Gaby Galvin for USN&WR

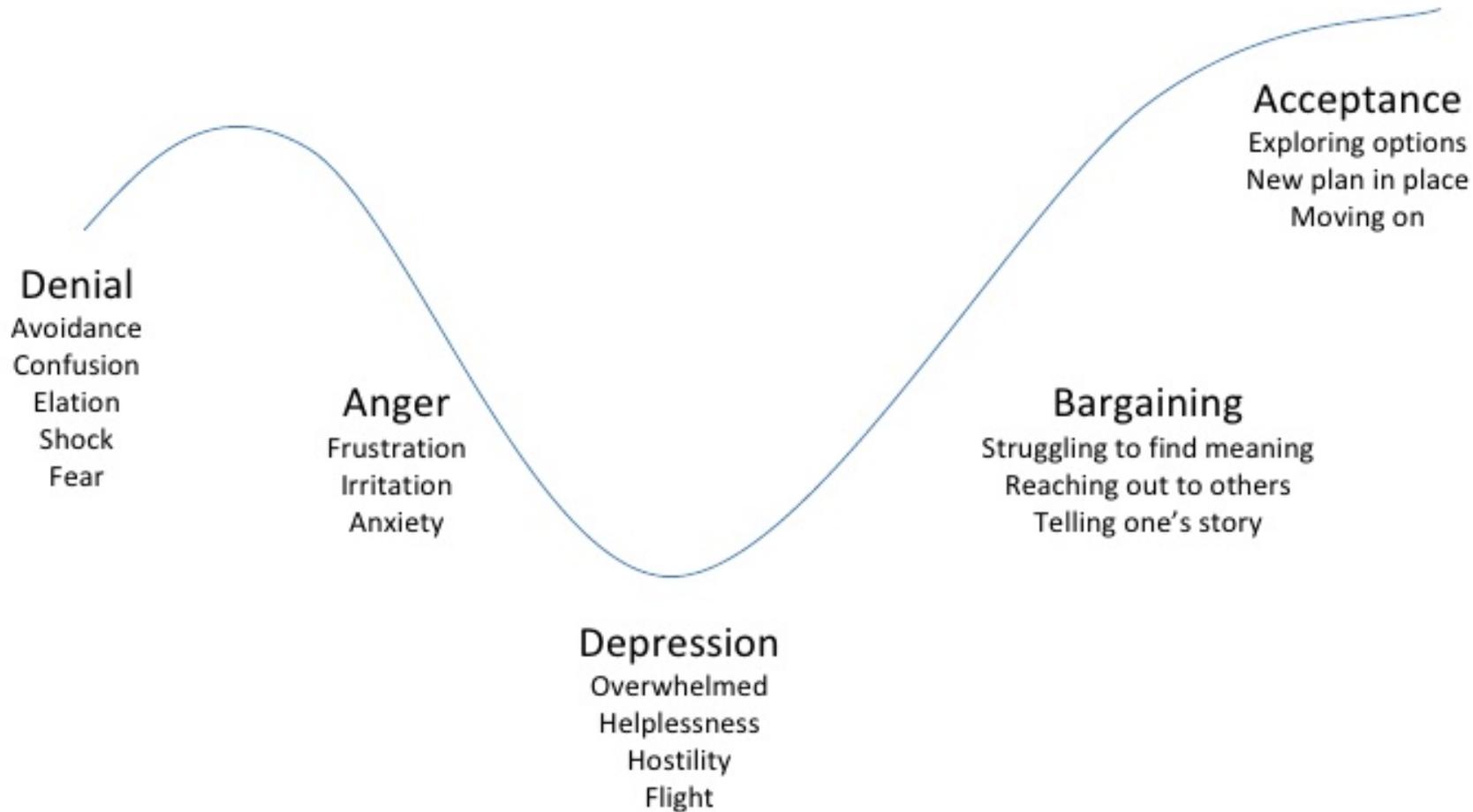
• Source: [Centers for Disease Control and Prevention](#) • [Get the data](#)

• Created with [Datawrapper](#)

A woman with dark, curly hair is sitting on a bed, looking down with a somber expression. Her right hand is pressed against her forehead, suggesting emotional pain or stress. She is wearing a white tank top. The background is a dimly lit room with a bed and some furniture visible.

# Stages of Grief and the New Normal

# Kübler-Ross Grief Cycle



Information and  
Communication

Emotional Support

Guidance and  
Direction

# What will be the new normal

During the COVID-19 Pandemic:

- Funeral professionals and religious leaders must weigh a family's need to mourn against community safety and potential legal consequences of violating state orders
- Loved ones are being denied access to hospitals and care centers; they are not able to say good-bye or accept the illness
- Loved ones stored in a climate-controlled trucks or temporary morgues for days
- Prolonged Stage One – Shock and Denial – of the Stages of Grief



**Understanding African  
American Grief**

# Understanding African American Grief

Understanding African American grief requires:

- Taking a long look at the historical and contemporary experience around the issue of death
- Recognizing a troubling fact:

**There's very little research on Black grief and its connection to racism and social injustices**

# Evidence Based vs. Evidence Informed

*Although African Americans make up 13% of the population, out of thousands of studies on grief, only 31 published papers focused exclusively on African Americans' experiences of loss.*

Granek, Leeat, (2016, September 4) Psychology, Grief and African Americans, Retrieved from [https://www.huffpost.com/entry/psychology-grief-and-afric\\_b\\_8076238](https://www.huffpost.com/entry/psychology-grief-and-afric_b_8076238)

# Why the neglect of African American grief?

“One way to think about it is that many who write about grief may assume that African American grief is no different from that of Euro-American grief.”

“African American grief may be aversive for some whites to study, because understanding African American grief could draw whites into understanding the pain and the premature deaths caused by white oppression and indifference to that oppression.”

Rosenblatt, Paul C., Wallace, Beverly R, African American Grief, (2005). New York, NY:  
Taylor & Francis Group

# Historical Perspective

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**1619**  
Slavery

**1865**  
Emancipation

**1870**  
Jim Crow Laws/  
Segregation

**1960s**  
Civil Rights Era

**1970 to present**

- Racism (Individual/Systems)
- Implicit/Explicit Bias
- Inequities in Health Care
- High Infant Mortality Rates
- High Prematurity Rates
- High Maternal Morbidity.

*“African Americans have experienced compounded loss and trauma beginning with slavery in this country 400 years ago... and may play a significant role in how some cope with further loss and trauma.”*  
(Pinderhughes, 2004)

*“...present-day realities of high rates of poverty, single parent families, incarceration, educational disadvantage, and health disparities have been part of the experience of African Americans in the United States.”*

Boyden, J. Y., Kavanaugh, K., Issel, L. M., Eldeirawi, K., & Meert, K. L. (2014). Experiences of african american parents following perinatal or pediatric death: a literature review. *Death studies*, 38(6-10), 374–380. <https://doi.org/10.1080/07481187.2013.766656>

# According to the Article *Experience of African American Parents Following Perinatal or Pediatric Death: A Literature Review*.

*“A child’s death is one of life’s most difficult experiences. Little is known about the unique factors that influence the grief experience for bereaved African American parents. Through an integrative review of 10 publications, the authors describe the grief responses, outcomes, and implications for African American parents who experience the death of a child.”*



# Four themes emerged:

- Emotional response to loss
- Factors that added to the burden of loss
- Coping strategies
- Health consequences of grief

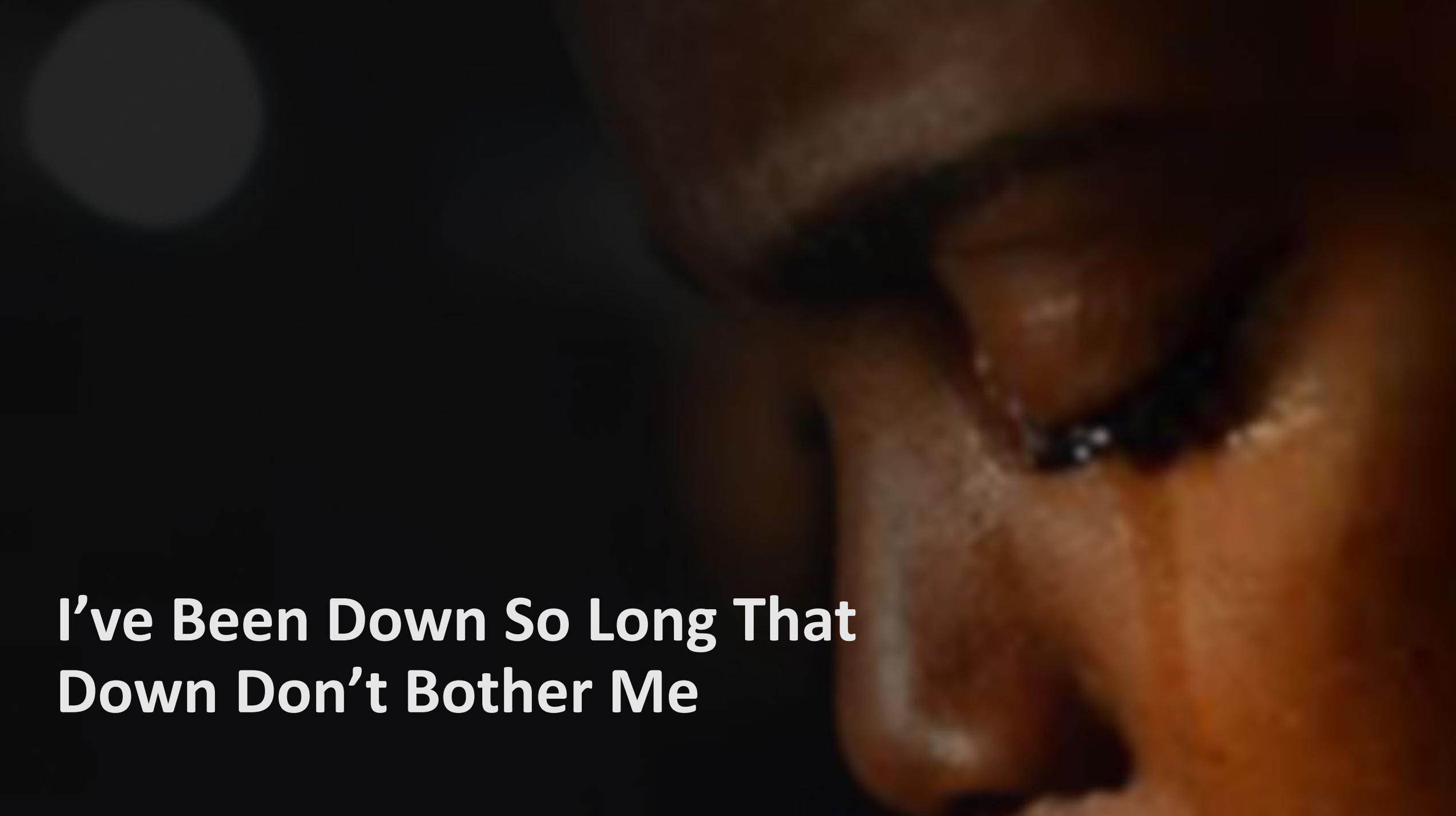
# Health Consequences of Grief

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## Two different perspectives:

- One study found no association between level of grief and perception of general health (Patterson, 2000), which the researcher attributed to the women defining health solely within the context of physical symptoms and functioning.
- Paradoxically, in another study, the better mothers perceived their health to be, the higher their level of depression (Page Edwards, 1998), which the researcher interpreted as because African Americans may view mental illness as a sign of weakness, not as a part of overall health. Consequently, many denied needing professional support. (Page Edwards, 1998)

Boyden et al.



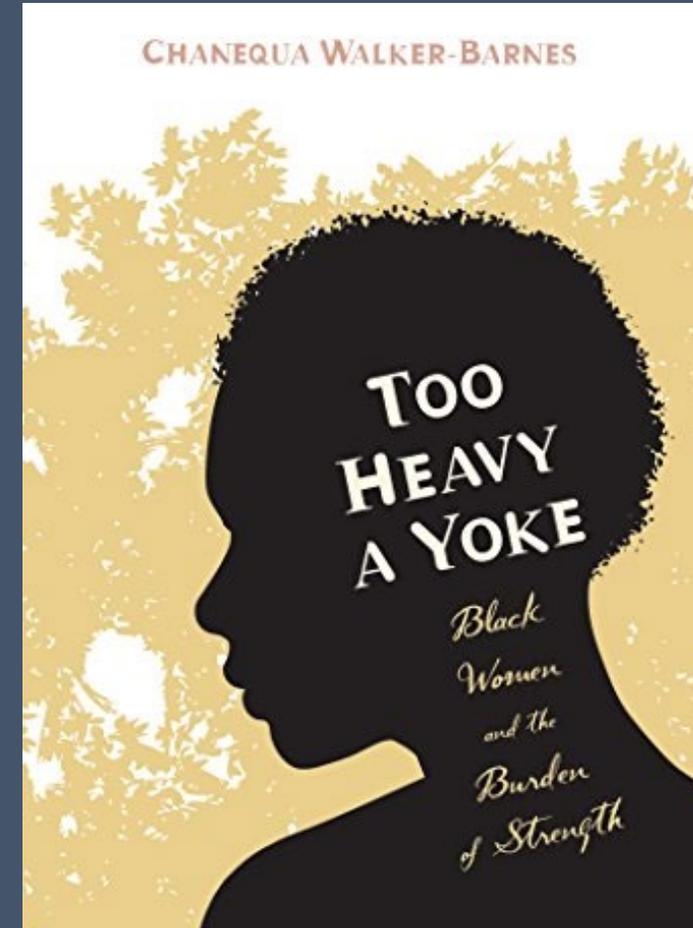
**I've Been Down So Long That  
Down Don't Bother Me**

# The Myth of Strength

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*“While both Black men’s and Black women’s identities have been bound by cultural mandates to be strong, the manifestation of strength that has become normative for Black women is uniquely racialized and gendered. “*

*“Strong is a racial-gender codeword. It is the verbal and mental shorthand for the three core features of the **StrongBlackWoman** – caregiving, independence and emotional strength/regulation”*



Walker-Barnes, Chanequa, *Too Heavy A Yoke: Black Women and the burden of strength*, Eugene, Cascades Books (2014)

# Who are these StrongBlackWomen?

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- Diverse backgrounds
- All ages
- Students from HBCUs to Ivy League schools
- Minimum wage workers who struggle to make ends meet
- Corporate employees
- Management level professionals
- Married, single, with or without children

Despite the great social economic diversity, they are similar in many respects. Regardless of their station in life, each has a high sense of responsibility and consequently serves as a load bearer.

# Social Determinants of Grief

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- Constantly extends herself to others
- Driven by a deeply ingrained desire to be seen as helpful and caring
- Incapable of saying no to requests without experiencing feelings of guilt and worthlessness
- Incapable of asking for “help” as she is saying no
- Since childhood, she has been taught that a good black woman is independent, a giver of help, including emotional, financial or instrumental support
- Dealing with stressful life events
- Racism
- Receiving unfair treatment
- Experiencing other’s serious illness or untimely deaths

# Strong and Dangerous

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*“Whereas being a Black woman who is strong may be commendable, being a StrongBlackWoman may be dangerous. The mythological strength of Black women often masks the very real vulnerabilities of their lives. There is a largely ignored health crisis confronting Black women in America.”*

*“During and since slavery, then the “strength” of Black women has been a backhanded compliment, a convenient rationalization for the oppressive circumstances under which Black women lived and labored.”*



# Infant Loss

# Perinatal Loss In Low-income African American Parents: The Lived Experience

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## Study Objective:

To examine the experience of low-income, African American parents surrounding perinatal loss and to describe how other life stressors influenced the parents' responses and caring needs.



Kavanaugh, K, Hershberger, P. Perinatal loss in low-income African American parents. Journal of Obstetrics, Gynecologic, & Neonatal Nursing, 2005; 34(5):595-605.10.1177/2884217505280000

# Four themes emerged

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- a. Recognizing problems and responding to the loss
- b. Dealing with stressful life events
- c. Creating and cherishing memories of their infant
- d. Living with the loss

Kavanaugh & Hershberger, 2005

# Misreading symptoms of pregnancy complications —

*One father said:*

*“Not even with the water being broken, I guess for a week prior, you know, we thought the baby was just sitting on her bladder and that she had no control of that, but, you know, that’s the kind of stuff that comes with being first time parents and really not knowing what happens.”*

Kavanaugh & Hershberger, 2005

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# Maintaining Hope During Medical Treatment

*One of these mothers said:*

*“They said there was no guarantee that she would live, not unless there was a miracle. I was believing in a miracle because I do believe in God and I had faith.... But then there was really nothing else more they could do for her because she wasn’t getting better.... The next day when I went to see her, she was real blowed (sic) up. I couldn’t see that was her. So I told them, I guess it’s time to take her off the machines because they said that her organs were so damaged, and there was nothing else they could do for her.”*

Kavanaugh & Hershberger, 2005

# Feeling Intense Emotions After the Death

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*One mother said:*

*“When she found out I lost the baby, she just held me like I was a baby, rubbed my back and everything. She just was real helpful. I don’t know if I would have made it. I will never forget her name. I know their job is to be a nurse, but she didn’t have to be that nice. She was really nice. She stayed there until my mother came. She sat in the room until my mother came. I felt much better.”*

Kavanaugh & Hershberger, 2005

# Dealing with Stressful Life Events

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- Feeling abandoned or unsupported
- These feelings cause stress. Some mothers argue with family members so intensely that the mothers relocated to other housing
- Several mothers explained that they were deserted by the father of the baby when they became pregnant
- Several mothers felt abandoned by their own parents separated from them because of substance abuse or incarceration and were not there during the pregnancy
- One of these mothers had the extra responsibility of raising her three younger siblings because of her mother's substance abuse

# Suffering Economic Hardship

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*Mom said:*

*“I was still stressed out. I wasn’t getting any rest. It was eight long laboring hours. When I would go to the clinic, they were like you are doing too much. You have to stop. You aren’t giving the baby enough rest.... I didn’t really say to them what I was really going through, I had to have this job. It was the only way to support the kids and keep eating. ... The money I was getting from public aid was barely enough just to pay the rent... So it would be two or three days I went without eating, just drinking water and eating crackers. One of them days I felt the baby move. I said, “Oh, you still surviving in there?”*”

Kavanaugh & Hershberger, 2005

# Experiencing Other's Serious Illness or \_\_\_\_\_ Untimely Deaths

- Many mothers had close relatives who were seriously ill and/or hospitalized during their pregnancy
- Parents experienced deaths of other close family members or friends
- Also included untimely deaths of infants, nieces and nephews, siblings, parents, grandparents, and young male cousins or friends
- One father, a substitute high school teacher, experienced the deaths of three students in one year. Even if the death had not been recent, the current loss triggered painful memories of the other deaths

# Receiving Unfair Treatment

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- Parents perceived they received unfair medical treatment
- One mother reported unfair treatment by a funeral director who buried her son sooner than she was told and without her presence
- According to the mother, the funeral director said that he did not know she wanted to be present for the burial. She said,

**“I was mad with them because they buried my son without me being there .... How did he not know that I wanted to go.... My heart just dropped. ... Like I didn’t even get a chance to say goodbye to him.”**

Kavanaugh & Hershberger, 2005

# Receiving Unfair Treatment

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*One mother whose baby died after being in the neonatal intensive care unit said:*

*“I feel they didn’t do the best that they could. I think it was because of financial. I was on public aid and so much that certain doctors will only do so much for people on a medical card. ... But if I had a better insurance, they would have put their heart and soul into it and I feel they didn’t.”*

Kavanaugh & Hershberger, 2005

# Receiving Unfair Treatment

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*One father said:*

*“I know she (his wife) was not in a private room and was not a VIP patient, but, to me she was a VIP patient.” This father also perceived unfair treatment with regards to paternity establishment. He shared that his name did not appear on his son’s birth certificate even though he provided the requested documentation that he was married to the mother of his son.”*

Kavanaugh & Hershberger, 2005

# Creating and Cherishing Memories of Their Infant

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Parents created memories of their infant by:

- Being physically close
- Observing family resemblances
- Collecting keepsakes of their infant
- Making decisions on infant burial, including a memorial or prayer service



Kavanaugh & Hershberger, 2005

# Being with their Infant

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One mother recalled:

*“And I held him until about four hours. I said I loved him. I don’t want him to go, but God knows best. Maybe I’m struggling so much that it would be just another burden and He knows best. Well I was just holding him and crying. I said, somewhere you get a chance to see your grandma. I tell him when you get there when you get old enough you think about me.”*

Kavanaugh & Hershberger, 2005

# Living with the Loss

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- Encountering difficult situations
- Relying on their spirituality
- Seeking diversions and support
- Making sense of the loss
- Contemplating future pregnancies



Kavanaugh & Hershberger, 2005

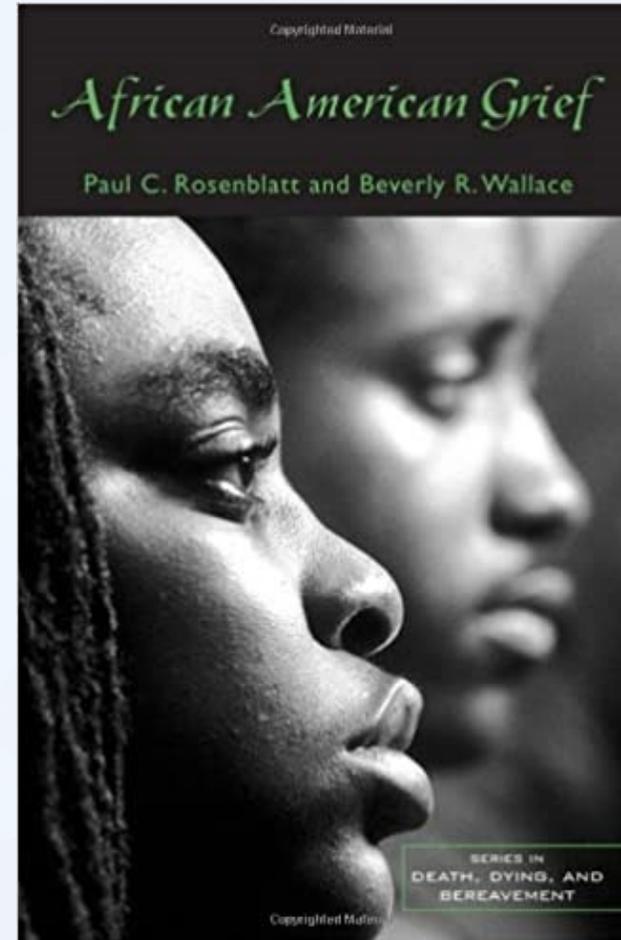
# **How to help bereaved African Americans**



# Understanding African American Grief

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- African American Grief is and is not like white grief
- Cultural Grief and the Pileup of Losses
- Grief Therapy/Support for African Americans
- African American Diversity
- Revising How We Think about Grief



Rosenblatt, Paul C., Wallace, Beverly R, African American Grief, (2005). New York, NY: Taylor & Francis Group

# African American grief is and is not like white grief

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- Be supportive and helpful to a bereaved African American women and their families
- Be attuned to and knowledgeable about racism in the United States
- Become broadly familiar with and knowledgeable about African American culture

Rosenblatt & Wallace, 2005

# Cultural Grief and the Pileup of Losses

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- Explore the concept of cultural grief that goes beyond a death, recognizing and addressing that both past and present losses may contribute to the grieving process
- Understand African Americans may be impacted by losses related to centuries of racism, discrimination, and oppression

Rosenblatt & Wallace, 2005

# Grief Therapy/Support for African Americans

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- Counselors and support group facilitators need to be well grounded in dealing with racism and discrimination in African American lives
- Not being able to deal with sensitive issues could be unhelpful or even hurtful to grieving African Americans
- It is important to be able to move beyond the rudimentary level in dealing with issues such as race, class, racism, discrimination, and related matters
- It could mean having to confront one's own complicity in the racial system, and the way one benefits from that system

# African-American Diversity

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- Knowledgeable support of African Americans who are grieving will always require attention to the uniqueness of the individual, situation, and community.

**Remember: African Americans differ in social class, religion, spirituality, cultural identification, or other ways.**

Rosenblatt & Wallace, 2005

# Revising How We Think about Grief

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- It is important that our country and communities be understood not as a homogenous society but a mixture of different cultures, with many different ways of understanding and dealing with dying, death, and grief

**We must not assume that everyone shares a common culture when it comes to loss.**

Rosenblatt & Wallace, 2005

# Always Remember

One person's grief does not invalidate another person's grief  
All loss is relevant and impactful

“We Must Keep Hope Alive”



# Discussion

- Considering infant mortality rates in the United States being what they are, why is it not commonplace to provide bereavement support services to families who have lost an infant?
- What are some of the barriers that prevent African American families from utilizing the limited bereavement support services that do exist?
- How can one find financial support for bereavement services?



**Thank You for Joining Us!!!!**

[www.baby1stnetwork.org](http://www.baby1stnetwork.org)