



- Spirituality and religiosity are common among adolescents
- Spirituality and religiosity increase coping and positively correlates with health outcomes (Cotton, Zebracki, Rosenthal, Tsevat, & Drotar, 2006)
- Research is limited with regards to spirituality and health among adolescents

#### Purpose

 The purpose of the current study was to examine how adolescents with sickle cell disease describe and experience spirituality and religiosity (S/R).



#### Aims

- Examine how adolescents living with sickle cell disease describe their spirituality and religiosity.
- Examine the process of spiritual and religious development in adolescents with sickle cell disease
- Examine the role of spirituality and religiosity in shaping beliefs about health and illness for adolescents with sickle cell disease.
- Provide adolescents a voice in describing their experiences of spirituality and religiosity.

  Page 4

### Spirituality and Religiosity

- Spirituality-Innate capacity to transcend and experience meaning and purpose in life beyond one's material, temporal, existence through contemplation and action aimed toward the sacred (Benson, Roehlkepartain, & Rude, 2003).
- Religiosity-Commitment to an organized way of knowing and orienting to the religious community's subject of worship (Schaefer, 2010).



 Spiritual Development - The process of growing the innate human capacity for selftranscendence, leading one to discern and experience meaning and purpose in life beyond their material, temporal, existence through contemplation and action aimed ultimately toward the sacred (Benson, Roehlkepartain, & Rude, 2003; Miller & Thoresen, 2003; Pargament, 1997).

#### Spiritual Development Framework Social Contexts (e.g., family, peers, school, congregation, neighborhood) **Culture** (e.g., media, ethnicity, nation) Awareness A Way of Living Meta-Narratives (e.g., scripture, stories) Outcomes Healthy Interconnection Harmful Other Dimensions of Development Change: Time, Growth, Significant Life Experiences

Page 7

## Spiritual Development Framework

Awareness- Being or becoming aware of or awakening to one's self, others, and the universe (which may be understood as including the sacred or divine) in ways that cultivate identity, meaning, and purpose

(Roehlkepartain, Benson, Scales, Kimball, and King, 2008)



Interconnecting- Seeking, accepting, or experiencing significance in relationships to and interdependence with others, the world, or one's sense of the transcendent (often including an understanding of God or a higher power); and linking to narratives, beliefs, and traditions that give meaning to human experience across time (Roehlkepartain, Benson, Scales, Kimball, and King, 2008, p.40)

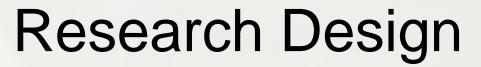
# Spiritual Development Framework

 A Way of Living- Expressing one's identity, passions, values, and creativity through relationships, activities, and/or practices that shape bonds with oneself, family, community, humanity, the world, and/or that which one believes to be transcendent or sacred

(Roehlkepartain, Benson, Scales, Kimball, and King, 2008)

#### Methodology

- Research Design
- 2 Research Questions
- Recruitment and Setting
  - **Participants**
- Data Collection
- Data Analysis



- Qualitative Descriptive Study (Sandelowski, 2000)
- Constructivist-Interpretive Paradigm
  - Reality is subjective
  - Interaction with environment
     determines how meaning created
  - Researcher and participant engaged in dialogue



- 1. How do adolescents living with sickle cell disease (SCD) describe their spirituality and religiosity?
- 2. What is the process of spiritual and religious development like for adolescents with SCD?
- 3. What is the role of spirituality and religiosity in shaping beliefs about health and illness for adolescents with SCD?

  Page 13

#### Recruitment and Setting

- Participants were recruited by the researcher
- Parental consent and participant assent were obtained at the time family agreed to participate in the study
- Sickle cell comprehensive clinic
- Support group organization
- Large midwestern city in the United States



- 9 Participants
- Inclusion Criteria:
  - Diagnosis of SCD, English-speaking,
     and 15-19 yrs.
- Exclusion Criteria:
  - Significant cognitive delay or communication impairment, active pain episode, or other urgent medical crisis



- Demographic Surveys (Appendices I and J)
  - -Parent, teen
  - Interview Guide (Appendices K, L)
    - Appendix K- participants indicate having religious beliefs
    - Appendix L- participants indicate not having religious beliefs

# Data Analysis

#### Concurrent Iterative Process

Verified

Transcripts and entered into Nvivo 10

Initial coding

template,

additional codes arose from data

(1st set of transcripts)

**Data Reduction** 

Committee

member used

template

(.8 inter-rater

reliability)



Looked within/

across codes for themes, coded



Data summaries created for each code



List of codes revised, coded remaining transcripts

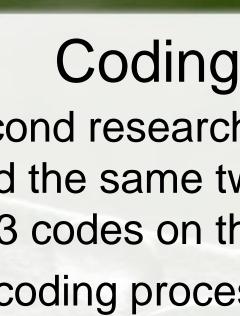
**Conclusion Drawing** 

**Data Display** 

# **Initial Coding Template**

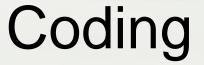
Theory Driven Codes - Three core developmental processes of spiritual development as described in the Spiritual Development Framework

- Awareness
- Interconnecting
- A Way of Living
- Additional codes were added as they arose form the data (13 codes)

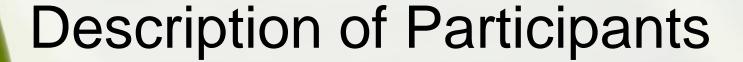


- A second researcher independently coded the same two transcripts with the 13 codes on the template.
- This coding process led to a revised list of 21 codes.
- At the end of each coding session, the PI reviewed codes, checked for redundancy, and combined codes to reduce data describing similar information and reorganized previous codes as needed.

Page 19



- Resulted in final coding template of 24 codes
- Final template was applied to the remaining transcripts (see Appendix A).
- Constructs taken for the SDF and used as codes:
  - Awareness, Interconnecting, A Way of Living, and Metanarratives
- Interconnecting classified as Interconnecting (General), Interconnecting (God, Higher Power. transpersonal), and Interconnecting (Others, Creative Arts, Interpersonal)



- 8 African American, 1 African American and Sicilian descent
- M=16.2 yrs, 3-Male, 6-Female
- Most (n=8) were 15-17 yrs-Middle Adolescence
- Hemoglobinopathies
  - -6 had Sickle Cell Anemia HbSS
  - 2 had hemoglobin S-beta-zerothalassemia (Hbβº/S)
  - 1 had sickle cell with hemoglobin C (HbSC)

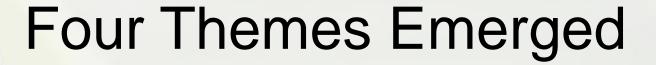
#### Results

Theme 1
S/R as
Coping
Mechanisms

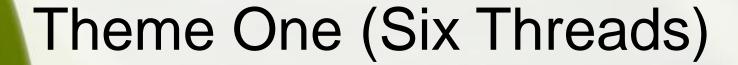
Theme 2
Shaping of Identity

Theme 4
Expectations
of Health
Providers

Theme 3
Influence of
Beliefs on
Health and
Illness

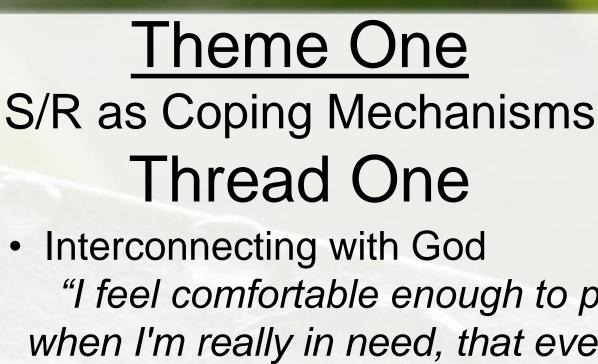


- Theme One- Spirituality and Religiosity as Coping Mechanisms (6 threads)
- Theme Two- Shaping of Identity
- Theme Three- Influence of Beliefs on Health and Illness
- Theme Four- Expectations of Health Providers (2 threads) Page 23



Spirituality and Religiosity as Coping Mechanisms

- Interconnecting with God
- Interconnecting with others
- Interconnecting with creative arts
- Scriptural metanarratives
- Transcendent experiences
- Acceptance and finding meaning



"I feel comfortable enough to pray when I'm really in need, that even like my best friend... I can't talk to her about it or I don't feel comfortable. So I feel like pretty strong in praying and just letting out all of my problems or whatever is bothering me or my feelings to Him." (17 y.o. female) Page 25 -Interconnecting with others

"I often reflect on the wonder of God in others." (16 y.o. female)

"My family reminds me that I am never alone." (17 y.o. male)

# Theme One S/R as Coping Mechanisms Thread Three

Interconnecting with creative arts

"I will just think about dancing and it helps me feel better." (16 y.o. female)

#### Theme Two

Shaping of Identity

Participants described their spirituality and religiosity as impacting how they lived their lives and responded to others, to be "grateful," "successful," "calm," "patient," "wise," "mature," "forgiving," "nice," and "good."

### Theme Three

Influence of Beliefs on Health and Illness

"Without my religion I don't think I would be alive." (17 y.o. male)

"....if you are trying to live upright before God and actually try to keep yourself healthy, then sure, sure you're gonna be healthy and live a good life." (16 y.o. female)

Page 29

# Theme Four

#### **Expectations for Health Providers**

- Thread One
  - Religiosity is personal, private, communal
  - Thread Two
    - Sharing spiritual/religious beliefs is risky
    - "No, because that would be like getting into my personal life or they might just, like, go around and spread rumors saying that oh, my God, he's this or he's that, and they shouldn't." (15 y.o. male)



#### Limitations

 Predominantly Christian, religious, and representing mostly one ethnic group

 Participants received specialized care

Response bias

# **Implications**

#### Research

- Solidifies S/R language
- Lays the ground work for greater exploration of the adolescent population in the context of spirituality and health
- Potential to facilitate and improve methods in which we examine S/R in the adolescent population

# **Implications**

#### **Practice**

- Promote conversations among practitioners engaged in caring for children and adolescents
- Facilitate understanding of the diverse ways spirituality impacts health
- Enhance spiritual assessment and support, and provision of culturally appropriate spiritual care

# **Implications**

#### **Theory**

 Contributes to further advancement of the theory of spiritual development

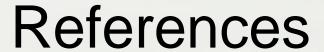
#### Education

Integration of holistic care



# Thank you

- Study funded in part by the Nurses
   Foundation of Wisconsin
- Email: <u>Dora\_Clayton-Jones@Baylor.edu</u>
- Questions???



- Benson, P. L., & Roehlkepartain, E. C. (2008). Spiritual development: A missing priority in youth development. *New Directions for Youth Development,* 118, 13-28.
- Cotton, S., Grossoehme, D., Rosenthal, S.L., McGrath, M.E., Roberts, Y.H., Hines, J., Yi, M.S. & Tsevat, J. (2009). Religious/Spiritual coping in adolescents with sickle cell disease. *Journal of Pediatric Hematology Oncology, 31* (5), 313-318.
- Cotton, S., Zebracki, K., Rosenthal, S.L., Tsevat, J. & Drotar, D. (2006). Religion/spirituality and adolescent health outcomes: A review. *Journal of Adolescent Health*, 38, 472-480
- Miles, M.B. & Huberman, A.M. (1994). *Qualitative data* analysis (2<sup>nd</sup> edition). Thousand Oaks, CA: Sage Publications.
- Miller, W.L., & Crabtree, B.F. (1992). Primary care research: A multimethod typology and qualitative road map. In B.F. Crabtree & W.L. Miller (Eds.), Doing qualitative research (pp. 3±28). Newbury Park, CA: Sage.



- Nonnemaker, J.M., McNeely, C.A., & Blum, R.W. (2003). Public and private domains of religiosity and adolescent health risk behaviors: Evidence from the National Longitudinal Study of Adolescents Health. *Social Science & Medicine*, 57(11), 2049-2054.
- Roehlkepartain, E. C., Benson, P. L., Scales, P. C., Kimball, L., & King, P. E. (2008). With their own voices: A global exploration of how today's young people experience and think about spiritual development. Minneapolis, MN: Search Institute.
- Schaefer, J. (2010). Theology 6995 Independent Study in Adolescent Spirituality and Religiosity, Personal discussion with Jame Schaefer, PhD, Director, Marquette University, Milwaukee, Wisconsin.
- Wulff, D. (1997). *The psychology of religion:* Classic and contemporary views. New York, NY: Wiley.