

Caregiver Perspectives of Stigma Associated with Sickle Cell Disease in Adolescents

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Overview

- Discuss stigma and health-related stigma
- Provide rationale for current study
- Review methodology and results of current study
- Discuss implications, limitations, and future directions
- Questions and discussion

Stigma vs. Health-Related Stigma

- Stigma

- Labeling another group as different or undesirable
- Includes stereotyping, discrimination, devaluation, exercise of power
- May be based on numerous factors such as race, religion, sexual identity, intelligence, medical status
- May be a cause of chronic stress
- Can lead to physical or mental injury

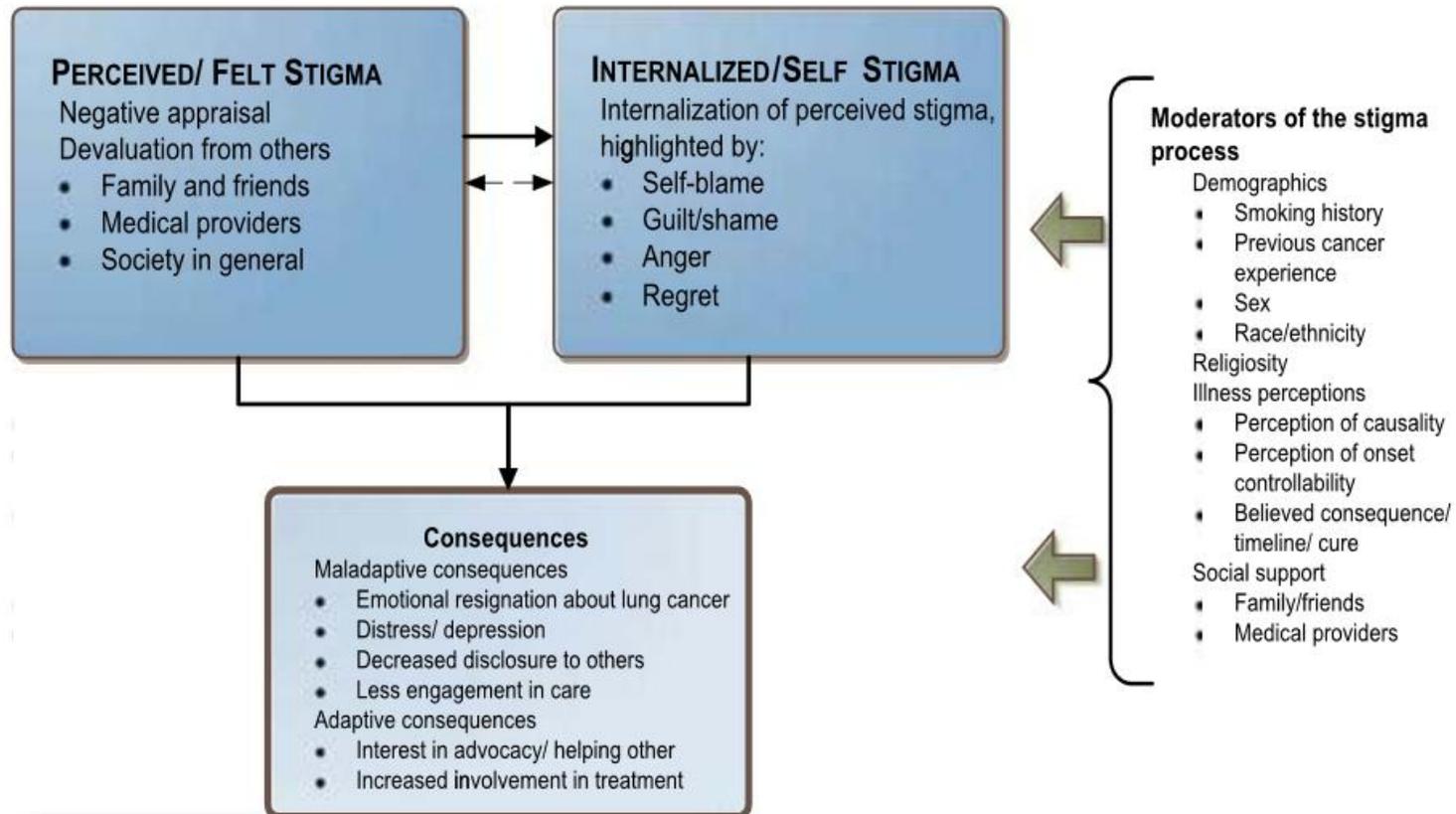
- Health-Related Stigma

- Devaluation, judgment, exclusion, or rejection on the basis of medical status
- May come from family, friends, community, healthcare providers, teachers
- Tends to become more apparent through late adolescence and early adulthood

Link & Phelan, 2006; Mukolo, Helfinger, & Wallston, 2010; Scrambler, 2009; Jenerette, et al., 2012; Slade, Molloy, & Keating, 2009; Jenerette & Brewer, 2010)

Models of Health-Related Stigma

- Conceptual model of patient-reported stigma (Adults with Lung Cancer; Hamann et al., 2014)



Models of Health-Related Stigma

- Childhood mental health stigma (Mukolo et al., 2010)
 - Public
 - Self
 - Institutions/service providers

Potential Effects of Health-Related Stigma

- May delay or avoid treatment due to fears of discrimination (e.g., labeled as “drug-seeking”)
- Feeling different or being excluded socially (e.g., “People think SCD is contagious”)
- Experiencing negative emotions in relation to diagnosis (e.g., feeling guilty or ashamed)
- Families feeling alienated from others
- Individuals with SCD may require hospitalizations, emergency department usage, and medications to manage pain, which increase the likelihood of experiencing health-related stigma
- Within SCD in U.S., risk is especially high for young adults due to pre-existing racial stigma, lack of understanding of SCD from adult medical providers, and social deprivation due to frequent hospitalizations
- For adults with SCD, stigma associated with inadequate medical care, decreased medical self-efficacy, premature hospital self-discharge, distrust of providers, and lower likelihood of participating in medical trials

Link & Phelan, 2006; Burnes et al., 2008; Weiss et al., 2006; Jenerette et al., 2005; Jenerette & Brewer, 2010; Latiimer et al., 2010; Haywood et al., 2010

Health-Related Stigma in SCD

- More research is focusing on assessing stigma related to SCD in adult populations
 - Using the Measure of Sickle Cell Stigma (e.g., Bediako, et al, 2016)
 - Using Stigma in Sickle Cell Disease Scale (e.g., Blake, et al., 2017)
- Pediatric research uses Child Stigma Scale
 - 28 youth with SCD aged 13-21: More health-related stigma associated with lower quality of life (Wakefield, et al., 2017)
 - 92 youth with SCD age 12-18: Higher stigma related to higher pain ratings lower quality of life, more loneliness during a hospitalization, and lower pain reduction (Martin et al., 2017)

Health-Related Stigma: Parent Perspectives

- Parents of patients with SCD in Canada (Burnes et al., 2008)
 - Perception of low public profile of SCD
 - Culture of silence around SCD
 - Sense of stigma related to lack of knowledge of SCD
 - Stereotypes and assumptions
 - SCD is contagious
 - SCD is the result of a curse on the family
 - Mothers are to blame for giving birth to a child with chronic illness
 - Internalized feelings of guilt and shame
 - Feeling stigmatized by health insurance companies

Health Related Stigma: Parent Perspectives

- SCD in Ghana (Dennis-Antwi, Culley, Hiles, & Dyson, 2011)
 - Mothers and fathers cope by denying that their child has an illness
- SCD in United States (Porter, Graff, Lopez, & Hankins, 2013; Graff et al., 2012)
 - Adult providers lack knowledge to treat SCD properly
 - Parents are sometimes hesitant to disclose illness to family members
 - Fear being judged
 - Emphasis on need to advocate

Seeking additional perspectives

- Review of the literature revealed lack of research exploring caregiver perspectives on the stigma of having a child with SCD
- No studies specifically examined parental perspectives of stigma related to SCD in US
- No models of stigma within pediatric medical populations
- General lack of research examining health-related stigma in pediatric (under 18) populations
- Need this information to identify areas for intervention and improvement

Methods

Procedure

- Institutional Review Board approved all procedures
- Participants recruited from outpatient clinic during clinic visits and through mailing letters to caregivers to participate in focus groups
- Completed measures packet (including demographics)
- Focus Groups
 - Audiotaped
 - Facilitated by licensed psychologist, postdoctoral psychology fellow
 - Assistant moderator present to take field notes/observational notes
 - 1.5 to 2 hours in duration
 - Facilitators provided a summary of topics at the end of the groups

Participants

- Eligibility: Primary caregiver of patient with SCD aged 12-18, currently receiving treatment at the institution
 - Caregiver Age: Mean 42.3 (range 28-69)
 - Number of Children: Mean 3.4 (range 1-8)

Variable	Total Participants (N = 20)	Percentage
Relationship to Child with SCD		
Mother	18	90%
Father	1	5%
Grandmother	1	5%
Marital Status		
Single	13	65%
Divorced	5	25%
Married	2	10%

Participants

Variable	Total Participants (N=20)	Percentage
Education		
<High School	2	10%
High School/GED	5	25%
Some College	8	40%
Bachelor's	4	20%
Unknown	1	5%
Annual Income		
<\$10,000	5	25%
\$10,000-19,999	3	15%
\$20,000-29,999	8	40%
\$30,000-39,999	1	5%
\$40,000-49,999	1	5%
\$50,000-59,999	2	10%

Data Analysis

- Exploratory qualitative methodology using both inductive and deductive approaches (Patton, 2002)
- Transcribed verbatim by independent party within research institution
- Coded independently by two team members (postdoctoral fellow, graduate student)
- Coders met to resolve disagreements, organize codes into categories, organize categories into themes
- Categories and themes examined against health-related stigma model (Hamann et al., 2014)
- Descriptive statistics conducted to describe demographic information

Results

Theme 1: Perceived Stigma

- Academic Settings
- Athletic Settings
- Medical Settings
- Social Settings

Theme 1: Perceived Stigma

- Academic Settings

- Lack of understanding, awareness, and accommodations
- Teachers not willing to comply with accommodations in education plan
 - Permission to carry water bottle, allowance of bathroom breaks
 - Teachers not understanding of frequent absences
- *“At high school she cannot take her water bottle, take it to class, and [teachers] say ‘Well, I can’t give her this special privilege, other kids are going to want to bring a water bottle to class’”*

- Athletic Settings

- Medical Settings

- Social Settings

Theme 1: Perceived Stigma

- Academic Settings
- Athletic Settings
 - Lack of understanding in terms of allowance of water breaks, time for resting, bathroom breaks
 - Poor understanding of patient's individual medical needs
 - *"I go to every coach and I'm like, look...this is what's going on with him. He needs to drink plenty of water. If he is injured, you know, you need to look at it and then in a few minutes you need to look at it again and ask him if he is in pain. See if it's swellings, I know my son. They [coaches] need to know."*
- Medical Settings
- Social Settings

Theme 1: Perceived Stigma

- Academic Settings
- Athletic Settings
- Medical Settings
 - Feeling that their children may be labeled as “drug seeking”
 - Believing that health care providers may dismiss pain experience of patients
 - *“They say, well, I’m in pain. It’s like a ten, and that doctor looking at ‘em [sic] like nah, it’s not a ten. It’s a two.”*
 - Believe that most medical doctors lack knowledge and expertise to treat patients with SCD, resulting in inadequate care
 - *“And that was just awful. I mean, how is it that a doctor did not know how to treat a sickle cell patient?”*
- Social Settings

Theme 1: Perceived Stigma

- Academic Settings
- Athletic Settings
- Medical Settings
- Social Settings
 - Difficult interpersonal relationships with family, resulting in withholding information due to fear of judgment or being misunderstood
 - *“Like, with my family, you can’t discuss that with them. ‘Oh, he’s not in pain.’ You know, that kind of stuff.”*
 - Perceived children at risk of being excluded or misunderstood, made fun of for being different
 - Some classmates and peers believe that SCD is contagious
 - General lack of SCD knowledge in greater society
 - *“They’re not familiar with it.”*

Theme 2: Internalized Stigma

- Emotional Distress of Caregiver
- Perception of Internalized Stigma of Children/Adolescents

Theme 2: Internalized Stigma

- Emotional Distress of Caregiver
 - Feeling guilty
 - Feel at fault for having a child with SCD
 - *"It's the parent's fault, right?"*
 - Own lack of knowledge and awareness of having sickle cell trait prior to having a child with SCD
 - *"I didn't even know that I had the trait until she was born. And when she was born and she had the disease and I said well how did she get the disease? ...I was never told I had the trait."*
 - Feeling frustrated, upset, or angry due to lack of awareness and understanding from others
 - *They didn't know he was supposed to drink water and I was fussing about it. I went up there and started fussing about it."*
- Perception of Internalized Stigma of Children/Adolescents

Theme 2: Internalized Stigma

- Emotional Distress of Caregiver
- Perception of Internalized Stigma of Children/Adolescents
 - Perceive their children as depressed due to their illness
 - *“He got depressed. He feels like he’s different, so he would try to make himself keep up with the other kids.”*
 - Perceive their children as embarrassed about their disease, choosing to not disclose disease to others
 - *“She was embarrassed and she didn’t want people to know, and she didn’t want to feel different.”*

Theme 3: Suggestions from Caregivers

- Provide SCD Education to School Personnel
- Provide SCD Education to Peers
- Greater Societal Education
- Take Ownership of Disease

Theme 3: Suggestions from Caregivers

- Provide SCD Education to School Personnel
 - Improve communication and provide education to teachers, administrators, and other school staff
 - *“Sometimes you just have to do the round table talk with them [school staff]. Because it works, it does work.”*
 - *“So as a parent, you have to go to the school, the guidance counselor, and everybody got to be aware. Pass out some books, let them have the little books like that, pass out them books.”*
- Provide SCD Education to Peers
- Greater Societal Education
- Take Ownership of Disease

Theme 3: Suggestions from Caregivers

- Provide SCD Education to School Personnel
- Provide SCD Education to Peers
 - Belief that educating peers will enhance acceptance and awareness of SCD
 - *“If they can in some kind of way bring out some literature where they will be able to, you know, read on it to try to break – you know – conversate [sic] with their friends about sickle cell, you know, to educate their friends and things about sickle cell.”*
- Greater Societal Education
- Take Ownership of Disease

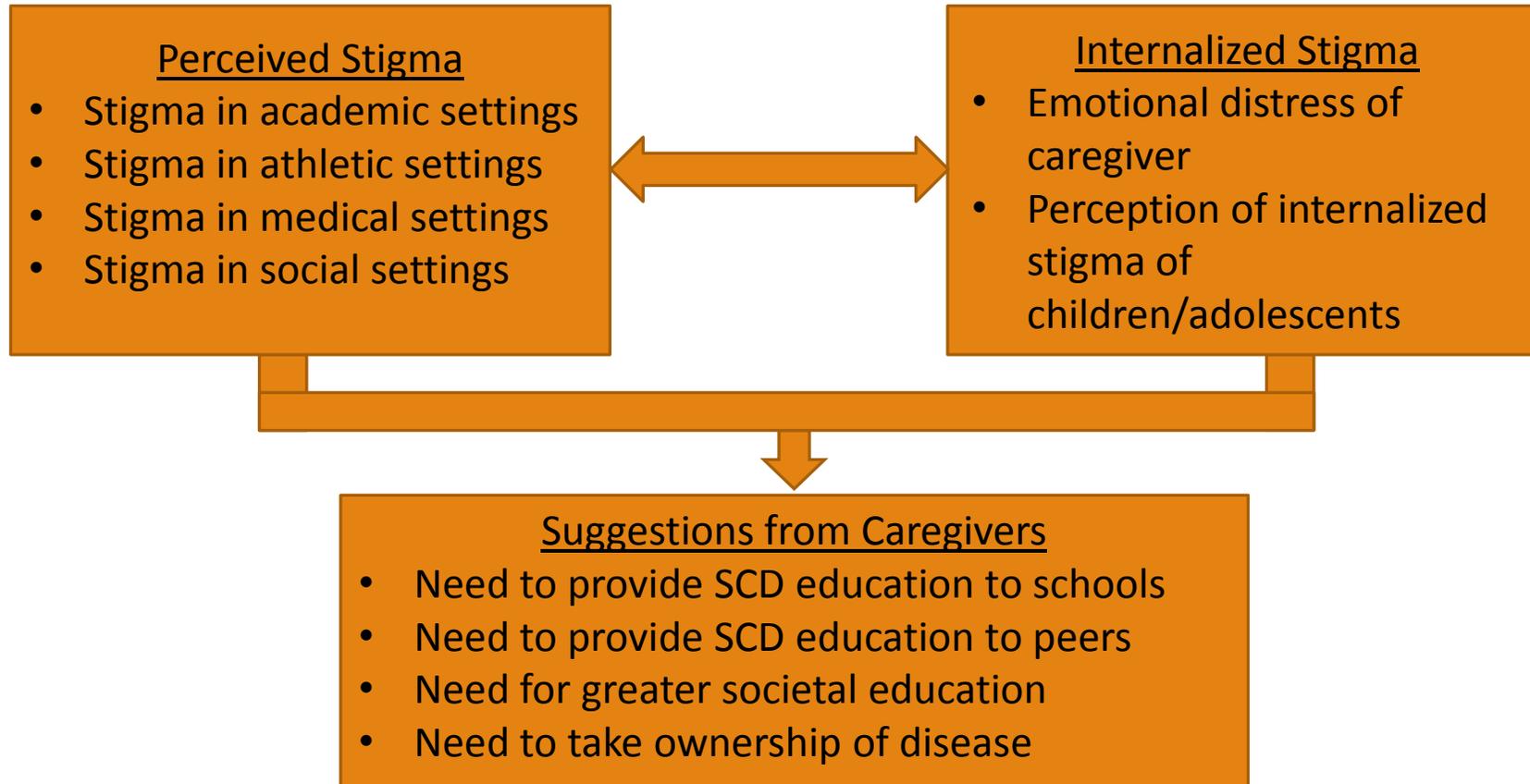
Theme 3: Suggestions from Caregivers

- Provide SCD Education to School Personnel
- Provide SCD Education to Peers
- Greater Societal Education
 - As caregivers believe that general public suffers from lack of knowledge about SCD, they encourage dissemination of information
 - *“Maybe you guys could do more advertising and let people know that this information is here.”*
- Take Ownership of Disease

Theme 3: Suggestions from Caregivers

- Provide SCD Education to School Personnel
- Provide SCD Education to Peers
- Greater Societal Education
- Take Ownership of Disease
 - Belief that children can combat stigma by taking ownership of their disease
 - *“You know, instead of just saying you know this is what I have. I’m gonna own it. I’m gonna deal with it. That’s it, and I don’t care who knows is a big thing.”*

Conceptual Model of Stigma



Discussion and Conclusions

Health-Related Stigma is a concern.

- Parents identify perceived stigma across contexts
- Perception that the general public is unaware of SCD
- Concerns extend to medical settings and health care providers
- Racism may also be a factor
 - May increase level of perceived stigma for patients and families, especially in medical settings (Royal, Jonassaint, Jonassaint, & DeCastro, 2011)

What can we do about it?

- Advocacy and awareness
 - Educate peers, teachers, coaches, medical professionals, and society
 - Brief intervention in schools to increase peer and teacher knowledge associated with improvement in regard to stereotyping and misconceptions about SCD (Koontz, Short, Kalinyak, & Noll, 2004)
 - Use of technology, social media, and advertisement campaigns
- Encourage increased communication between patients and providers to improve collaboration
 - Poor communication associated with mistrust and increased perception of stigma (Lattimer, et al., 2010)
- Cultural awareness training (Thomas & Cohn, 2006)
- Support groups and mentors to provide a safe environment, establish normalcy, and reduce stigma (Alonzo & Reynolds, 1995, utilized support groups for individuals affected with HIV)

EARLY INTERVENTION IS IMPORTANT

- Feelings of stigma begin in early childhood and become more evident across the lifespan (Jenerette & Brewer, 2010)
- Recommend support groups for children, adolescents, young adults, and caregivers
 - St. Jude offers monthly adolescent and caregiver support groups
- May also develop mentorship programs to match older individuals with younger patients to facilitate coping and adjustment

Limitations and Future Directions

- The themes reported in this study were not assessed directly, but rather were raised organically during a larger study
 - Future studies need to focus on this more directly
- Sample came from a single institution, and consisted of caregivers of adolescents, limiting generalizability of results
 - Need to include different ages and different perspectives
- Majority of participants were mothers
- Need to develop appropriate conceptual model of stigma
 - Some disagreement as to whether stigma is comprised of numerous factors (stereotyping, devaluation) or if it is a separate construct (Mukolo, 2010; Haywood et al., 2014)
- Identify needs of students, and whether those needs are met

Conclusions

- Health-related stigma seems to affect patients and caregivers of individuals with SCD
- Caregivers believe there is a lack of education and awareness
- Ideas for intervention focus on education on small and large scales
- Early intervention is key, as perception of stigma begins early and grows throughout the lifespan
- Stigma comes from multiple sources – it is important to combat stigma in all environments to improve outcomes for patients with SCD

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Questions and Comments
