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Finding beauty in the struggle: Using relational dialectics theory to analyze discourses that influence what it means to be both mom and caregiver to a child with medical complexities

Children with CCCs and their mothers

- One in four chronically ill children in the United States has a complex chronic condition (CCC) (Rezaee & Pollock, 2015).
- Most parental caregivers for children with CCCs are mothers as they work to meet societal expectations of what “good mothering” entails (Israr, 2019; Benjamin et al., 2019).
- “Good” mothers must be “committed, ever available, [and] deeply involved” while caring for their child in a “seamless, ... natural, and organic” way (Musick et al., 2016).
- Relational dialectics theory (Baxter, 2008) analyzes how communication is ripe with contradictions, or discourses. Our study focuses on how dominant centripetal discourses interplay with each other to create transformative instances.

Research Questions

What is the synchronic interplay between the primary centripetal discourses about what “good” mothering entails for parenting a child with a medical complexity?

How do these discovered discourses engage in discursive transformations and aesthetic moments as they emerge in within mother’s talk about their caregiver experiences?

Mothers are emotionally strong

“It’s physically exhausting, and mentally exhausting ‘cause of the grief of losing your son, the way he was. So, I guess I would say grief and pain, that’s what my life has been like for the last four years.” (Julie, son has a neurological condition)

“Oh, they talk a lot about my strength and give me a lot of kudos for being strong. Except behind closed doors, honestly, I’m not as strong as I appear. I just do it for [my daughter]. Because I don’t want her to see her mommy falling apart, so I’m strong for her. And when she’s somewhere safe, I kind of just have my meltdown.” (Carrie, daughter has a congenital condition)

Mothers are mentally capable

“I think in the beginning, the thing I struggled the most with, because he had so many different things, but he didn’t have a specific diagnosis we were being bounced from doctor to doctor to problem to problem. And there was nobody who was helping me to coordinate that. So, I had to learn really fast how to be the go between and we weren’t just at one place.” (Jennifer, son is undiagnosed)

“We are here and the neurologist we were working for – he just kind of got at the end of the rope, he’s like I don’t know what else to do for you. We have tried all these medicines. Nothing is making the seizures stop.” (Molly, daughter has a neurological condition)

Methods

- Interviewed 17 mothers affiliated with a pediatric palliative care program in the Midwestern U.S (see *Table 1*).
- Participants’ ages ranged from 25 to 52 years old ($M=36.64$, $SD=7.34$).
- 15 self-identified as White/Caucasian, one as Black/African American, and one as Hispanic.
- All mothers completed a semi-structured, in-depth interview that lasted between one to two hours.
- All interviews were analyzed using contrapuntal analysis (Baxter, 2011).

Table 1. *Demographics*

Mother Pseudonym	Total Number of Children	Age of Child with Complex Condition (in years)	Child’s Diagnosis (as categorized by Primary Medical Doctor)	Child’s Prognosis (as determined by the mother)
1. Anna	2	14	Neurological	Not a progressive or terminal disease
2. Julie	6	21	Neurological	Improving, but continued uncertainty
3. Jennifer	2	7	Neurological	Unknown
4. Amelia	1	2	Neurological with pulmonary comorbidity	Chronic health problems
5. Sammy	1	20	Congenital	Uncertain
6. Angie	1	7	Neurological	Terminal
7. Naomi	2	2	Congenital	Uncertain
8. Carrie	2	4	Congenital	Uncertain
9. Tori	1	2	Neurological	Uncertain
10. Morgan	4	5	Congenital with renal and hepatic comorbidities	Uncertain
11. Molly	2	5	Neurological	Almost complete recovery-some developmental delays
12. Bailey	2	5	Neurological	Lifelong care
13. Alicia	2	1	Congenital	Premature death, lifelong care
14. Tracy	2	2	Congenital with neurological comorbidity	Uncertain
15. Katie	2	2	Congenital	Uncertain
16. Alice	3	5	Congenital with autoimmune comorbidity	Uncertain
17. Sandra	3	3	Congenital	Uncertain

Aesthetic moment of redemptive suffering

“But, the normal day to day can be absolutely exhausting and I think I’m just permanently tired and I think I always will be. My hair is turning gray and that’s just how it is. I wouldn’t trade him for the world. That’s an interesting place to be. I guess he’s taught me to see beauty in pain.” (Jennifer, son has a neurological condition)

“I’m so grateful, I don’t know. We lost a child in 2011. At the [specialized hospital], so now having a special needs child that has as much issues as she has going on, it’s just, (crying) I’m just beyond grateful to have her. Life is not easy (crying), but she’s just such a joy. She’s perfect. I wouldn’t want to have it any other way to be honest.” (Carrie, daughter has a congenital condition)

Findings

- The centripetal discourse discovered illustrated the tension between mothers feeling the need to be emotionally strong *and* mentally capable to be a maternal caregiver for their child with a CCC (see quotes included).
- These two centripetal discourses are not mutually exclusive.
- Both discourses exist simultaneously and sometimes at the suspension of both.
- Through moments of transformative hybridity, aesthetic moments of redemptive suffering existed, or the notion that there is a deeper meaning behind challenges associated with caregiving.

Significance & Practical Implications

- Our findings support the theoretical concept of transformative aesthetic moments in relational dialectics theory (Baxter, 2011) as we show evidence of mothers creating moments of peace through perspective-taking and reframing their redemptive suffering.
- Our findings contribute to the literature on social support and its connection to relational dialectics theory scholarship.
- We offer insights to information that could be used in parental educational programs for parents of children with CCCs.

References

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