



9-3-2019

When Black and White Medicine Turns Gray: Exploring the Interplay and Meaning of Discoursing about Parenting a Child with a Complex Chronic Condition

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Recommended APA Citation

Rafferty, K. A., & Hutton, K. (2019). When Black and White Medicine Turns Gray: Exploring the Interplay and Meaning of Discoursing about Parenting a Child with a Complex Chronic Condition. *The Qualitative Report*, 24(9), 2102-2121. Retrieved from <https://nsuworks.nova.edu/tqr/vol24/iss9/1>

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When Black and White Medicine Turns Gray: Exploring the Interplay and Meaning of Discoursing about Parenting a Child with a Complex Chronic Condition

Abstract

Parents of children diagnosed with complex chronic conditions (CCCs) face many challenges with managing their child's health. As parents are tasked with competing demands and the constant changes required to provide the best care possible for their child, talk about contradictions regarding their dual, and oftentimes competing, roles and responsibilities as both parent and caregiver is likely to occur. Using relational dialectics theory (Baxter, 2011) as a framework, we conducted a contrapuntal analysis to analyze 35 White, mostly Christian parents' narratives about their experiences managing their child's healthcare. Two primary discourses emerged: the centripetal discourse of normal health and the centrifugal discourse of difference. The interplay between these two primary discourses led to a hybrid discourse: difference is our new normal. Within this discourse, parents discussed previous speech encounters where they relied upon the co-construction of a new normal with others who were living or willing to live in their new reality. Our findings emphasize how an assessment of parents' talk conveys their discourse-dependence with navigating the inevitable uncertainties associated with managing their child's CCC. In addition, we discuss how parents co-construct their new normal in the face of unique family functioning that is structurally different from societal expectations and social norms about parenting and pediatric health care management.

Keywords

Relational Dialectics Theory, Contrapuntal Analysis, Pediatric Chronic Illness, Parental Caregivers, Health Communication, Family Communication, Complex Chronic Conditions

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Acknowledgements

We would like to thank the families who shared their stories with us. We would also like to thank The Ronald McDonald House Charities for their help and support with recruitment and data collection. Last, we want to thank Sarah Heller, Nicole Miller, and Madison Schwenneker for their assistance with data analysis.

When Black and White Medicine Turns Gray: Exploring the Interplay and Meaning of Discouraging about Parenting a Child with a Complex Chronic Condition

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Parents of children diagnosed with complex chronic conditions (CCCs) face many challenges with managing their child's health. As parents are tasked with competing demands and the constant changes required to provide the best care possible for their child, talk about contradictions regarding their dual, and oftentimes competing, roles and responsibilities as both parent and caregiver is likely to occur. Using relational dialectics theory (Baxter, 2011) as a framework, we conducted a contrapuntal analysis to analyze 35 White, mostly Christian parents' narratives about their experiences managing their child's healthcare. Two primary discourses emerged: the centripetal discourse of normal health and the centrifugal discourse of difference. The interplay between these two primary discourses led to a hybrid discourse: difference is our new normal. Within this discourse, parents discussed previous speech encounters where they relied upon the co-construction of a new normal with others who were living or willing to live in their new reality. Our findings emphasize how an assessment of parents' talk conveys their discourse-dependence with navigating the inevitable uncertainties associated with managing their child's CCC. In addition, we discuss how parents co-construct their new normal in the face of unique family functioning that is structurally different from societal expectations and social norms about parenting and pediatric health care management. Keywords: Relational Dialectics Theory, Contrapuntal Analysis, Pediatric Chronic Illness, Parental Caregivers, Health Communication, Family Communication, Complex Chronic Conditions

Today, one in four children in the United States is diagnosed with chronic illness (Children and Adolescent Health Measurement Initiative, 2016). Such conditions include diabetes, cancer, cerebral palsy, cystic fibrosis, heart disease and mental illness (e.g., eating disorders, depression). While each condition may vary in its severity, prevalence, or stigma, the rigorous caregiving demands placed on parents of these children has resulted in consistent reports of experiencing poor levels of quality of life, regardless of a child's specific diagnosis (Cohen, Vowles, & Eccleston, 2010). This is because parents must dramatically reconfigure their roles and responsibilities (e.g., balancing daily life alongside caregiving tasks; Haskell, Mannix, James, & Mayer, 2012) as they seek to become educated advocates (Rafferty & Sullivan, 2017) and serve as conversational proxies for their child (Goldsmith, Wittenberg-Lyles, Ragan, & Nussbaum, 2011).

An emerging population within pediatric chronic illness is young people diagnosed with complex chronic conditions (CCCs). CCCs are "any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or one organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center" (Feudtner, Christakis, & Connell, 2000, p. 206). Today, approximately 10% of pediatric admissions are

young people living with a CCC. The most frequent types of CCCs are cardiovascular, congenital, neuromuscular, respiratory, and oncologic (Simon et al., 2010).

Parents are the primary caregivers of children living with CCCs and must continuously negotiate their roles and responsibilities with managing their child's care (Rafferty, Hutton, & Heller, 2019). This task can be daunting as young people with CCCs have high rates of hospitalization, readmissions, use of technology-dependent devices, use of prescribed medications, and inpatient mortality rates (Simon et al., 2010). As such, many parents report feelings of uncertainty and negative emotions (e.g., fear, frustration; Barakat & Alderfer, 2011); they also experience recurrent sorrow as they watch their child struggle to achieve developmentally appropriate skills and milestones (e.g., learning to walk, attending school; Coughlin & Sethares 2017). In total, parents report spending an average of 30 hours per week tending to their child's medical needs (National Alliance for Caregiving & American Association for Retired People [AARP], 2009). Thus, parents who raise children with a CCC experience demands that go beyond the normal tasks of parenting (Daire, Munyon, Carlson, Kimemia, & Mitcham, 2011).

Alongside the labor associated with managing a child's CCC, parents must also discursively construct and sustain their family's new identity, functionality, and sense of normality (Canary, 2012; Hays & Colaner, 2016). "Normal," in particular, is a weighted term suggesting that a societal standard exists for family structure and functioning (Buzzanell, 2010). By definition, parents with medically complex children defy these expected societal standards, and thus, must communicatively craft normalcy in new ways through every day talk and routines (Hays & Colaner, 2016). This can be seen as a type of "communication work," which is defined as the labor and resources for managing talk about illness (Donovan-Kicken, Tollison, & Goins, 2012). As parents talk about their child's illness, it is likely that parents rely upon discourse-dependent practices when constructing their new personal and family identity. Thus, for this research study, we analyzed parents' talk about caregiving for their medically complex child and the larger proximal (i.e., within a relationship or interaction) and distal (i.e., larger cultural meanings) already-spoken discourses that are evident within parents' talk. Next, we discuss scholarship on the role of discourses within health, followed by the rationalization for using Baxter's (2011) relational dialectics theory as a framework for analyzing parents' narratives.

The Role of Discourses about Normal Health in Families

Language and our talk-in-interaction about normality is "embedded within cultural formations or societal macrodiscourses" where the term normal is regarded as both an outcome and process (Buzzanell, 2010, p. 2). In the context of family, the valence of the word "normal" is a weighted term suggesting that a societal standard exists for family structure and functioning (Hays & Colaner, 2016). Because centripetal discourses privilege normal health (see Harter, Quinlan, & Ruhl, 2013; Holladay, 2017), families that have a member with an illness must communicatively craft normalcy through routines and everyday talk (Hays & Colaner, 2016).

Society's privilege to those individuals with normal health is both socially and contextually constructed. As Davies (2000) highlights, "social competence is... fundamentally to do with appearing as normal or 'unpassremarkable' within the terms of available, apparently transparent, categories" (p. 23). Therefore, words such as "normal," "average," "healthy," or "typical" are terms that describe bodies or physical states that one desires based on culturally dominant representations; yet, these words often conjure a multitude of images based on contextually specific articulations of what is "normal" for that individual (e.g., height, body type, achievement of developmental milestones, skin complexion; Holladay, 2017).

Illnesses and disabilities reflect an underlying disease or disorder of “normal” physiology in an individual. Therefore, the language that we, as a society, use to define and characterize illnesses and disabilities is situated within a cluster of ideological categories that include words, such as “sick, deformed, crazy, ugly, old, maimed, afflicted, mad, abnormal, or debilitated—all of which disadvantage people by devaluing bodies that do not conform to cultural standards” (Garland-Thomson, 2002, p. 5). Such negative connotations refer to these individuals as an *other*, or outside of the social norm simply because of their disability or illness.

The expansive and overwhelming growth of medical knowledge in the 20th century has led to its broad cultural power of defining what is true about the human body and mind, advancing what scholars in disability studies call the “medical model” (Holladay, 2017). According to the medical model, there is some distinction between the *normal* body/mind and the abnormal difference that constitutes disorder. Part of this model includes the “jurisdiction of medicine” (Clarke, Shim, Mamo, Fosket, & Fishman, 2003, p. 161), where individuals become objects of medical categorization and statistical analysis since they possess and manifest disease and abnormality. As Clarke et al. (2003) states, this perspective targets the individual:

...health itself and the proper management of chronic illnesses are becoming individual moral responsibilities to be fulfilled through improved access to knowledge, self-surveillance, prevention, risk assessment, the treatment of risk, and the consumption of appropriate self-help/biomedical goods and services. (p. 162)

As patients and their family caregivers manage illness and disability, tensions between scientific and humanistic assumptions about responsibility for health care management (Zoller & Kline, 2008), as well as rule following (i.e., defined do’s and don’ts that one ought to engage in or avoid; Ranjbar, Mickinlay & Mcvittie, 2014) become more pervasive. Rules, which are often determined by societal norms (i.e., assumptions that children are generally healthy, and parents rely upon scientific evidence) or powerful medical institutions (Holladay, 2017), reinforce ideologies that all health can be managed by an individual’s character and lifestyle. Thus, within the context of pediatric illness, the responsibilities and rules to monitor and control a child’s health and bodily normativity are oftentimes placed on parents who are regarded as a child’s primary caregiver and conversational proxy during healthcare interactions (Goldsmith et al., 2011; Rafferty & Sullivan, 2017; Rafferty et al., 2019). Therefore, it is important to understand parents’ experiences with managing their child’s health, particularly when these experiences involve medically complex children who are outside of the “normal” realm of pediatric health care.

Theoretical Framework: Relational Dialectics Theory

Relational dialectics theory (Baxter, 2011) proffers a framework for assessing parents talk about caring for their child with a CCC, and in particular how “[m]eaning-making emerges from the struggle of competing discourses” (p. 123). By examining competing discourses (e.g., a cultural system of meaning), researchers may identify different discursive struggles that are apparent within and across different utterance chains. An utterance is a turn in someone’s talk (Baxter, 2011) that connects utterances at four links: *distal already-spoken*—utterances reflecting the cultural meaning and discourses that cultural members give voice to in their talk; *proximal already-spoken*—utterances conveying past meanings and discourses within a given relationship; *proximal not-yet-spoken*—immediate response from the hearer in the interaction;

and *distal not-yet-spoken*—anticipated responses of a generalized other within the culture. Thus, distal links are culturally influenced, and proximal links pertain to idiosyncratic relationships.

One key charge to scholars undertaking relational dialectics theory (RDT; Baxter, 2011) is to determine the primary discourses that guide the construction of meaning through talk within a specific context (Suter, Seurer, Webb, Grewe, & Koenig Kellas, 2015). Our current analysis focuses on parents talk about caregiving for their medically complex child(ren). In particular, we focus on the proximal and distal already-spoken discourses to examine how these discourses affect parents' meaning and identity. Another goal for scholars employing the RDT framework is to understand how meaning is constructed from the interplay of power among unequal discourses. Baxter (2011) refers to power as a "characteristic of discourses" (p. 18) that affects meaning-making. In an attempt to explore how power shapes our talk, researchers must map out both *centripetal discourses*—those central and dominant discourses that are considered to be "normative, typical, and natural" (Baxter, 2011, p. 123), and *centrifugal discourses*—those peripheral and marginalized discourses, which are often categorized as "nonnormative, off-center, unnatural, and somehow deviant" (Baxter, 2011, p. 123).

For this study, we use RDT as a framework to understand parents' narratives about caregiving for their medically complex child, and the discourses that are evident in their talk. This research is important because maintaining the quality of life for children with CCCs is largely contingent upon parental caregivers' ability to successfully coordinate their child's treatment across different health care professionals, while simultaneously attending to daily life responsibilities (Haskell et al., 2012; Rafferty et al., 2019). As a growing number of parents become tasked caring for medically complex children (National Alliance for Caregiving & AARP, 2009), research is needed to understand the ways in which families, and parents in particular, communicatively construct meaning and identity in their new roles. Such scholarship may also be useful for health care professionals, as parents of medically complex children, on average, must coordinate care between 13 outpatient physicians and six subspecialists (Carosella, Snyder, & Ward, 2018). Hence, health care providers have the time and abilities to work with parents to help generate new possibilities and discourses surrounding their roles as caregivers (Harter et al., 2013; Hays & Colaner, 2016; Rafferty et al., 2019). Thus, the following research question guides our analysis: *How do discourses compete to make meaning of parents' identity as a parent and caregiver to their medically complex child?*

Method

Participants

For this study, we interviewed 35 parents (28 mothers, 7 fathers). The average age of parents was 41 (ranging from 25 to 57, $SD = 9.96$), and all parents self-reported White/Caucasian. Ninety-one percent of the parents were married, 6% were divorced/not remarried, and 3% were single/never married. The majority of parents reported being Christian (74%). Overall, 63% of parents earned a Bachelors, Masters, or Professional degree. In most instances, only one of the parents to a chronically ill child was interviewed ($N = 23$); there were six pairs of parents (both mother and father) who participated. Most parents ($N = 30$) had only one child living with a complex chronic condition; five parents had two chronically ill children.

Across the interviews, parents discussed 33 children diagnosed with CCCs that included: genetic conditions (39%), oncologic conditions (21%), neurologic disorders (12%), heart conditions (9%), mental illness (9%), endocrine disorders (6%), and a hematologic disorder (3%). Parents described each of these conditions as complex due to its severity,

comorbidity, or rarity. In fact, 19 children were hospitalized for medical procedures at the time of the interview, and 10 of the children (30%) had co-morbid health issues (i.e., presence of two or more chronic conditions). There was a range of prognoses, as reported by the parent: 39% of the children required lifelong care, 34% had an uncertain prognosis, 18% were undergoing medical interventions (e.g., chemotherapy, bone marrow transplant, heart transplant), and 9% of the children received a terminal prognosis. Twenty-one of the children were male and 12 were female. Children ranged in ages from 3 months to 21 years, with the average age 8.9 years ($SD = 6.9$). Most children ($N = 24$, 73%) had been living with their condition for at least 3 years.

Interview Procedure and Data Collection

The data used in this paper is a secondary analysis of existing data (Cheng & Phillips, 2014) for a larger grounded theory study that examined parents' caregiving experiences related to uncertainty, hope, and hopelessness. Interview and data processing methods we describe in the following section refer to the primary research; these results are reported in Rafferty (2015). Upon receiving IRB approval, parents were recruited in two different ways and from two different research locations. Twenty parents were recruited from a local chapter of The Ronald McDonald House, a non-profit 501(c)(3) corporation that provides housing and other services (e.g., food, art therapy) for families with hospitalized children; 15 parents were recruited from the local and regional community via snowball sampling and online websites (e.g., juvenile diabetes chapter). We continued data collection to ensure that no new themes emerged.

Any parent or parental surrogate with a chronically ill child receiving ongoing medical or pharmacological treatment was eligible to participate; other family relationships (e.g., aunt/uncle, grandparent, sibling) were excluded. In the case of dual-parent households, both parents could participate; however, these parents were each interviewed separately. Finally, to adhere to the focus on parental caregiving during a child's treatment period, a child must have been diagnosed for a minimum of six months (i.e., parents may have received their child's diagnosis while (s)he was in utero) and currently receive ongoing medical or pharmacological treatment.

Once eligibility was confirmed, parents signed informed consent and then participated in a narrative interview that included general questions about their caregiving experiences (e.g., *What has your life been like since your child's diagnosis?*) and recollection of significant conversations that occurred and/or information received throughout their child's diagnosis and treatment (e.g., *What has it been like talking with other people about your child's illness and treatment needs?*). Most interviews lasted for 60 to 90 minutes and were conducted in a private location; parents were compensated \$30. All interviews were transcribed by the first author and a team of undergraduate research assistants.

Data Analysis

We re-analyzed the interview transcripts for this secondary analysis research using contrapuntal analysis (Baxter, 2011). This approach involved three steps when analyzing the interview transcripts: (a) identifying discourses, (b) locating competing discourses, and (c) examining how the interplay of discourses constructs meaning (Baxter, 2011). This process began by having both authors and three undergraduate research assistants independently read all 35 transcripts and listen to the audio files. Next, we each independently completed line-by-line coding of the transcripts to identify initial coding categories. Examples of such categories included *recognition* (e.g., acknowledging challenges and hardships; articulating necessary steps for feeling supported by others), *difference* (e.g., what makes their personal experience

unique), *power* (e.g., experiencing conflict with medical professionals; being assertive with family), *uncertainty* (e.g., coping with an unknown future; highlighting what is yet to be understood), *normality* (e.g., talk about expectations and original desires; comparisons to other parents with healthy children). For five months we sorted through the initial coding categories, refining, re-categorizing, and combining them. Eventually, our coding categories cohered into two primary discourses (Baxter, 2011): the centrifugal discourse of *normal health* and the centripetal discourse of *difference*. Each discourse characterizes aspects of what it means to be a parental caregiver for a child with a CCC. The interplay between the two primary discourses led to the hybridization of a discourse about *new normal*, which included the sub-discourse of co-constructing a new normal.

We analyzed how the primary discourses of *normal health* and *difference* were co-created by scrutinizing parents talk, using three forms of discursive markers (i.e., negating, countering, entertaining; Baxter, 2011). *Negating* (i.e., discourse marker that plainly rejects or dislocates another discourse), was often made apparent in words such as, “not,” “no way,” and “never.” Parents used negating when talking about “typical childhood development” or “normal healthy children,” and stating what their child could *not* do. *Countering* (i.e., discourse marker that displaces a discourse with a different one) was evident in words such as, “although,” “yet,” and “on the other hand.” For example, many parents used the term “new normal” to show differences or changes in their new family identity and lifestyle. The last discourse marker was *entertaining* (i.e., suggests a discursive position is one among many possibilities), which was often evidenced in phrases such as “perhaps,” and “it could be.” Parents used this language when talking about their child’s future and the uncertainties associated with it. By analyzing parents talk through the use of discursive markers allowed us to remain sensitized to instances of contested discourse.

Credibility and Confirmability. Lincoln and Guba (1985) outline several criteria that qualitative scholars can use to assess the credibility and confirmability of their research. Throughout data collection and analysis, we ensured the rigor and trustworthiness of our findings by each writing detailed memos as we analyzed interview transcripts and using individual and group constant comparison as we discussed our coding decisions (Charmaz, 2006). This approach allowed us to maintain an exhaustive audit trail that outlined our conversations during weekly coding meetings where we engaged in investigator triangulation (Lincoln & Guba, 1985). Finally, the first author had prolonged engagement in the area of study. She spent two years as a weekly house volunteer for The Ronald McDonald House, prior to conducting the interviews. Then, the interviews were conducted over the course of a year. Data analysis was completed over several months with all authors listening to all of the audio files and reading the transcripts several times. During data analysis we identified the discourses and contradictions evident within parents talk. Theoretical saturation was achieved when both authors and all research assistants agreed that the properties and dimensions of the discourses were sufficiently comprehensive.

Findings

The reported speech encounters discussed in parents’ narratives provide evidence of dialogic expansion (i.e., presence of multiple discourses in a text; Baxter & Braitwaite, 2008). Specifically, we identified two primary discourses where parents enacted the synchronic practice of direct interplay by expressing a centripetal discourse of *normal health* (which included a sense of order, structure, and predictability), while also acknowledging the inevitability of the centrifugal discourse of *difference* resulting from having a child with a CCC. Both discourses and their interplay are discussed using exemplars.

Centripetal Discourse of Normal Health

Centripetal discourses privilege normal health (e.g., Harter et al., 2013). The discourse of normality is about the interplay of presence and absence in terms of what parents and their families are capable of doing and how their daily life functions amidst complex illness. When talking about their experiences as a parental caregiver, many parents acknowledged the prevalence of this discourse and how others regarded normal health as a gold standard from which their child was compared. For example, parents used the word normal when forming comparisons between their child and other typical children. These comparisons were often initially discussed with doctors as a way to comprehend their child's diagnosis. One mother stated: “[The doctor] told us what a normal heart looks like and what our baby's heart's gonna look like” (Monica, daughter has congenital heart condition). Beyond their child's diagnosis, language about normality was embedded within subsequent conversations with other health care providers as parents discussed treatment options and identified ways to improve their child's quality of life. For example, one mother said:

It's been for the last almost two years now a total discovery of what it is that's going on with her. And she's had a little bit of genetic work done that hasn't really shown anything. So, I don't have a clear label for her because the doctors don't know. And that is to me okay because it gives me that hope that okay she's gonna someday be a very normal person. (Amy, daughter has unknown congenital condition)

In this particular example, this mother explained how uncertainties about her daughter's diagnosis and treatment has culminated into feelings of hope that someday her daughter may “be a very normal person.” However, for other parents, a lack of certainty from medical professionals made normality seem untenable because parents had nothing to compare.

The discourse of normality was also evident when parents discussed their daily life routine, which included attending to their child's medical needs alongside more typical life responsibilities (e.g., paying bills, working, disciplining children). In these narratives, parents would highlight the ways in which their child acted like other normal children. Parents also discussed parenting challenges they faced that were comparable to the challenges that parents with healthy typical children experience. For instance, one mother stated:

She has all these medical needs, but I also have to be a very normal parent with her. She's a toddler. She's totally pushing my boundaries right now and trying to figure out what behaviors she can get away with: throwing temper tantrums and needing time outs. It's really hard sometimes to not give in to her because first of all she's got medical issues. She throws a temper tantrum; she has her speaking valve on at the time. And that's a hugely complex situation right there. I can't walk away from her because she's got her speaking valve on and that's, she has to have one-on-one supervision with it. I don't want to take it off because then I'm like removing her voice and that's not fair. She's in the middle of expressing something to me right now and so it's just it's a very complicated. On the one hand, when she does something naughty part of me is like yes (laughs) 'cause it's great to see that normalcy from her. (Eva, daughter has genetic condition)

As this mother expressed, parents with medically complex children still experience many “normal” parenting challenges, such as learning how to discipline their child. However, these

annoyances (e.g., children acting out) were often welcomed parenting trials because they served as beacons of hope that their child was developing in similar ways as other healthy children. Nonetheless, these glimpses of normality created new challenges as parents had to creatively develop responses that met both their child's developmental stage and current medical needs.

Part of parents' narratives that privileged the discourse of normality included talk about typical family experiences (e.g., family vacations, child's participation in sports). Parents expressed a sincere desire to give their children the same opportunities as normal children. Although these opportunities often required extensive planning or modifications, parents, like this mother, found it necessary for their children to have normal life experiences:

We treat [my daughter] like a normal kid as often as we can. We take her on vacation and people are like, "you took her in the water, are you crazy?" "Yep we are! Her five thousand dollar ventilator is by the water." (Mary, daughter has congenital condition)

This mother, like many other parents, expressed in her interview that it was important to let her daughter "feel normal" and not place too many restrictions on her life. Thus, normality was both a desire and goal that parents had for their medically complex child.

In order to understand what normality entailed within the confines of a particular diagnosis, parents sought out efficacious narratives from other children living with similar conditions. These stories allowed parents to see examples of children living positive, fulfilling lives like other normal children their age. For example, one father stated:

We wanted to see people, how they're acting, and how they're doing so we could get hope. And we did, we found them ... One in particular, she's probably 25, but man she loves life. She goes skiing and snowboarding, and all these cool things that other normal kids like to do... People like that give us hope. (Pat, daughter has congenital condition)

In addition to seeking out online stories from other children, parents were also consulting with other parents like them who openly shared their experiences with living normal lives. To highlight this, one mother recounted a conversation that she had with another mother who had a child with the same genetic condition as her two sons:

We just don't know how [our sons are] going to manage. We don't know if they will be able to go to a birthday party and whether he can have a hot dog and birthday cake like other normal kids... But, I remember I talked to this mother. She had a teenager with [the same diagnosis]. She was like, "yeah [my son's] fine. He plays baseball. He's a great athlete and he goes out with his friends and has pizza. He just takes the cheese off." It was so comforting. (Becky, two sons have genetic condition)

Both reported speech encounters articulate the expectations of normality that parents have for their children, even if they have a medically complex illness. Such expectations include activities of daily living like what they will eat, attendance at other children's birthday parties, participation in sports, and having annual family vacations. Yet, depending on a child's condition and prognosis, these normal events may require ongoing adaptations and/or modifications that deviate from parents' original expectations for their child and his or her

normal life. For children with more severe conditions, such normal experiences will never occur (i.e., the child will never walk, talk, be an independent adult).

Finally, a parent's need and desire for some semblance of normality was expressed when their child was in the hospital for in-patient treatments or complications with surgeries. For example, one mother said:

There have been several parents walking around with Bluetooths. We are trying to maintain a normal life outside of being here because this is not supposed to be forever. You have to make sure that life happens outside of here. (Ruth, daughter has mental illness)

As this mother stated, living at the hospital was not a part of their family's normal daily life. As such, maintaining daily responsibilities (e.g., working, caring for other children) alongside being at the hospital made everyday normality inconceivable at the present moment. While their child was hospitalized, parents also discussed the new responsibilities they had: bringing the comforts of home to the hospital in order to help their child feel normal. For example, one mother said:

As traumatic and scary as [the pediatric intensive care unit] is, it doesn't mean [my son] can't do things. This is home. I'm going to make it as normal as I can for him. He watches the Lorax Movie at home, so I got the Lorax here and I put that on for him. (Ann, son has genetic condition)

However, being displaced in a different city or state for their child's medical treatment, or having multiple children to care for made it more difficult to achieve normality, as one mother expressed:

[My son] has frequently felt like [his] life is to accompany [his sister]. So making the other [sibling] feel a sense of normal, a sense of home, or this is something special. But, not trying to mask over the fact that this is disruptive. (Ruth, daughter has mental illness)

Thus, achieving some semblance of normality was both a desire and family goal. However, for the 19 children who were hospitalized for medical procedures at the time of their parents' interview, normality was challenged and oftentimes deemed improbable at the present moment.

Centrifugal Discourse of Difference

The discourse of difference encompasses parents' talk about unique, distinguishing features of their medically complex child that is often presented as a comparison to the average, typical healthy child. Parents who raise children with a disability or illness experience caregiving demands that go beyond the typical demands of parenting (Daire et al., 2011). For instance, most of these parents must coordinate care between 13 outpatient physicians and six subspecialists to manage their child's illness and maintain her or his quality of life (Carosella et al., 2018). As such, parents must surrender their previous conceptualizations and expectations about what it means to parent and/or care for their child. One mother noted this abandonment by saying, "Normally a parent has all the ability to say 'I love you,' hold her, she'll stop crying. But for [our daughter] we can't do that; we need the doctors to help" (Monica, daughter has congenital heart condition). Similarly, another mother said: "You are unable to be the same person you were before because now you are part of a community that

you didn't ask to join" (Gianna, son has neurological condition). As both mothers expressed, parenting looks different when a child has a CCC. Parents must immerse themselves and their families in a new world of acronyms, medical treatments, hospital stays, medications, and meticulous planning, while also accepting the inevitable uncertainties associated with parenting a medically complex child (Rafferty, 2015). Parents explicitly talked about the differences in their parenting roles by using statements like: "my child's not typical," "our life is different than other people," and/or "we can't do that." Thus, the discourse of difference negates and counters the centripetal discourse of normal health.

After receiving their child's diagnosis, parents noted how life immediately became different. As one father stated: "with a kid like this it's different. Her diagnosis was a game changer for our family. We look at things completely differently now" (Dan, daughter has congenital condition). Ongoing demands associated with providing constant medical care resulted in the need for continual changes, which varied from relocating to a new city for an indefinite amount of time as their child completed in-patient medical treatments to altering a family's dietary pattern. Whether in the hospital or at home, parents had to restructure their family's life in order to keep the focus on their sick child and attend to his or her needs first. These changes made their family life different, which one mother discussed by saying:

Our schedule and our focus has definitely changed. Our schedule being that we don't have a whole lot of extracurriculars going on. We used to be in ballet; we used to go to the Y. We always had something. Well, everything's off the schedule. It is pretty much day by day, and [my daughter] has become a big part of our family's focus. (Nancy, daughter has oncologic condition)

As this mother recounted, the entire family's life now operated on a day-to-day basis, as other parents similarly expressed. This lifestyle was different from their life pre-diagnosis. Parents also described how they had to discard or re-evaluate previous goals that they had for their child because of the limitations stemming from their child's condition. One mother stated:

It's a lot different than what we thought... I mean, even schools. I remember when we were in our [marriage preparation class] and we thought our kids are being brought up going to Catholic schools... Well, that was shot out right away because the school administrators told us he was better off in public [schools]. (Clare, son has congenital condition)

Most of the parents were married and reported having frequent speech encounters with their spouse that included talk about the necessary adaptations that now made life different than before. For instance, one mother referenced this by saying:

[My husband and I] will be talking about [our daughter]. I give him updates twice a day from [the hospital]. And so we'll try to make a plan for the future: maybe it's this, let's talk to these people, we'll do this. But then she starts to take ten more steps further in fifty million directions. And, I have to remind him "you know what, you're wasting so much time. Don't even bother. We can't plan like that anymore. Our lives are different" ... so my husband and I have to remind each other to be patient and just wait and see. (Rebecca, daughter has oncologic condition)

As this mother stated, having a child with a CCC is different from the norm and requires a sense of abandonment to their life pre-diagnosis. Thus, all parents' offered insight into how

they wrestled with the discourse of difference as they attempted to restructure daily living, abandoned future goals and aspirations that they had for their family, and also negotiated and navigated these differences collectively with their spouse.

Parents also discussed previous speech encounters where they were exposed to the centrifugal discourse of difference, particularly noting its prevalence when recounting conversations with medical professionals, as well as other parents and their children traversing similar health experiences. For example, one father said: “We now live in a whole new world with different acronyms. The doctors keep on creating new labels for my son and kids like him” (Dave, father, son has neurological condition). Thus, conversations with medical providers and other parents with similarly diagnosed children reminded parents that their child was different from the norm. Because of these differences, parents highlighted the need to assert themselves to ensure that their child received the care that they desired. Often times, this occurred when their child was needing urgent or emergent care because of side effects from new treatments or colds and other illnesses that created complications. For example, one mother said:

[In the U.S.], we base our health care around revenue; so, it is very difficult to get care like normal kids. [My two children] have a disease that although not rare in numbers, at this point it’s rarely known... When we bring our kids in to [the hospital] and [the doctors] are like “what’s their diagnosis?” They look at my kids with like a myriad of issues, and yet really look pretty amazing, and they’re like “what in the world?” We tell them [the name of the disease]. [The doctors] don’t have any idea and they go out and consult doctor Google and come back and think they are an authority. (Annie, two children have genetic condition)

This mother’s example highlights how the rarity of her children’s condition (which makes them different) exacerbates the tension that exists between scientific and humanistic assumptions in healthcare management (Zoller & Kline, 2008), which is not always about competing goals, but sometimes differences in meaning and power. In this case, because her children were different than most children who visit the emergency room, and the doctors were not experts in their particular condition, this mother struggled with the emergency doctors about who had the most informed authority and insight about how to best help her children. She needed doctor’s assistance, but also struggled with their lack of expertise in her children’s specialized medical needs. Other parents discussed facing similar challenges where they shared the same goal as their child’s medical providers (e.g., wanting to best manage a child’s condition), yet the means for achieving a particular health goal differed. For instance, one mother said:

I talked to the nurse practitioner and I said, “what can we do about this?” And she says, “the only thing we can do is put her on the pill.” And I said, “I’m not putting her on the pill.” And she said, “well, we are the doctors here and we say she needs to go on the pill” ... I asked them to take a lab, or basically include in the blood draws that she’s getting to find out what her levels are so we know if we have to supplement with progesterone. They said, “if you are not in agreement to put her on the pill, we are not going to take that lab for you... it’s either my way or no way.” (Ursula, daughter has oncologic condition)

Thus, navigating differences with medical providers about how to best manage and treat a child’s particular condition often involved contentious debates and power struggles, as this mother described above. In order to be the best advocates for their child, parents had to become

health literate and assert their role as advocates to ensure their child received the care they desired. This was not an easy task and left many parents with uncertainties and questions. In these moments, parents often relied upon veteran parents who had children with similar conditions and could provide access to informational resources about which medical experts could help them.

Hybridization: Difference Is Our New Normal

We found that the two discourses of normal health and difference were often positioned together where the only thing normal about having a child with a CCC is that life is different than they anticipated and will require ongoing changes for an undetermined time. In these cases, transformative interplay led to the creation of a hybrid discourse, where two or more identifiable discourses are repositioned as compatible (Baxter, 2011; Baxter & Norwood, 2015). In this case, the clash between the two primary discourses (i.e., normality and difference) warranted the potential and need for a new hybrid discourse, which parents referred to as their new normal. When talking about this hybrid discourse parents utilized discursive markers of countering and entertaining as they recounted previous speech encounters with other people who were affirming and also living (or willing to live) within their new normal. Across these instances, parents highlighted how accepting both discourses of normality and difference could expose the aesthetic moments (“often emotion-laden experiences characterized by deep pleasure or stimulation;” Baxter, 2011, p. 141) in their dual roles as parents and medical caregivers for their medically complex child. In these aesthetic moments, parents could redefine and co-construct new meanings for their families (with the buy-in of others) where they discussed the need to rely upon both their head and heart in a way that revolutionized their understanding and knowledge of parenting and “normal” family life in the present moment. For example, one mother stated:

One year ago a single word [i.e., cancer] changed our normal reality. In one year, [our family] has redefined “pain” and “hard” and “scary” over a dozen times with each definition heavier than the last. But we’ve also redefined “commitment” and “strength” and “love,” with each definition more powerful. (Erica, son has oncologic condition)

Parents like this mother redefined language in new ways that acknowledged the now-known-fragility of life. This intentional act allowed parents to transform their original perspectives of difference as a negative thing into meaningful constructions of lessons learned and gratitude experienced since their child’s diagnosis. As all parents noted, the entire story of what it means to be a parental caregiver for a medically complex child is a story of *both* suffering and redemption; either part of the story by itself is incomplete. One father affirmed this by saying:

[My wife and I] are lucky because we get the opportunity to really live life. I mean I would rather be sitting on the couch watching football, rather than being at a dogfight for my kid’s life, but this is real life. You are out there on a hospital ward with all these other families and kids and it is the real deal. In a bizarre way we are lucky. (James, son has oncologic condition, relapsed for the third time)

This father details how caring for his son’s oncologic condition has taught him impactful life lessons. Parents’ ability to utilize this new language and adopt a similar more hope-filled perspective involved participation from others who could help co-construct their new normal.

Co-constructing a new normal. Parents relied upon others to help them co-construct a new normal. The phrase new normal had multiple meanings and referents: (a) acknowledging the changes and differences with their current life compared to their previous lifestyle; (b) highlighting the challenges with how life functions at the hospital compared to home life; and (c) discussing differences with their child compared to societal discourses privileging “typical” childhood development. In sum, new normal served as a discursive term that represented parents’ tenuous state of having made some sense of their child’s illness, but because it is new and constantly changing it cannot be taken-for-granted in the way the old normal was. One mother recounted this by saying:

It’s beyond devastating. By the time they actually gave us the real diagnosis it had been over a year trying to figure this out... And on a clear day someone said to me, “you have to give yourself the opportunity and be kind to yourself and mourn the loss of your child because you no longer had the child you thought you had. You have a totally different child.” And it’s true. As soon as I really did get over the guilt of mourning her – because she’s still there and she’s still vibrant and beautiful and loving – but you have to mourn those expectations that you had and the future you thought you were gonna have as a family. You have to mourn the relationship that you had wanted two sisters to have. And as soon as we did that – and that wasn’t easy – that probably took three years. It is only then that you can accept your new normal. (Shannon, daughter has genetic deletion)

Here, this mother emphasizes the importance of time and patience in the process of co-constructing a new normal. She also conveys how the advice given to her about mourning the loss of her previous expectations was an instrumental proximal discourse in her acceptance of her own family’s new normal.

A second critical factor to co-constructing a new normal was seeking helpful information from other people who were willing to live and sustain parents’ new normal. Within conversations and online searches, parents became health literate, were able to make more informed medical decisions, and discovered new ways to restructure their day-to-day lives based upon others’ past shared experiences. Parents were dependent upon others living in their alternative reality (i.e., new normal) who could help them discover their own new stability, expertise, or practices about how to best traverse their own family’s new normal. In particular, Facebook groups allowed parents to form equitable comparisons between their child and other similar children. Within these online communities’ parents could assess what was “normal” for that condition and garner important resources and support from other parents like them. For instance, one mother stated:

A comparison to normal kids is hard... One of the side effects of [his medication] is hair growth, and I felt like if I asked on my general mom’s group, “okay, should I shave my child?” I would get this negative response. But, I brought it up on the other Facebook group and people were like, “no we do.” (Grace, son has hematologic condition)

All parents belonged to at least one Facebook group specific to their child’s condition. Within these groups, parents asked questions and provided responses to one another. Thus, parents were able to collectively cultivate communities where they could redefine normality in novel ways.

Medical professionals also helped parents construct their new normal. However, the process to find the right medical experts who could assist in these constructions was oftentimes a laborious process. Parents discussed traveling across the country several times to find specialists and enroll in clinical trials. Parents often sought out these professionals on their own or were encouraged by other medical professionals to seek more advanced help. For example, one mother detailed how her son's pediatrician asked her to identify a medical specialist who could better assist them:

[The doctor] said, "Mrs. Drew if you have an expert for us to interface with, we'd appreciate that. You know, we don't mind interfacing with someone, another doctor." That kind of lit a fire under me and I thought I need somebody who knows what to do. So, I went online and searched until I found the one. (Erin, son has genetic condition)

Accounts like Mrs. Drew's are so different from how most parents typically access health care for their children. However, this assertive process of advocacy became a significant part of their new identity. Without this assertiveness, parents noted the difficulties with cultivating their own new normal because of limited knowledge and access to specialized health care resources.

Finally, other family members (e.g., grandparents, siblings) were mentioned as helpful resources in facilitating parents' constructions of a new normal. Family relationships provided critical social support that included coordinating a child's care, serving as a sounding board, and receiving continuous encouragement. As an example, one mother recounted a conversation with her dad that transformed her understanding about the purpose of parenthood:

Something my dad told me was that it is not my job to get you into Harvard or make sure you have this fantastic job. My only job is to get you into heaven. And so the easiest way for me to deal with [my son] is remembering that, 'cause he is the easiest kid I could have. While it seems really hard sometimes thinking he needs to learn to eat a cookie or something normal like that... But, when you step back and you say my only job as a parent is to get him into heaven—I have won the lottery. Our new normal will bless him for all eternity. (Catherine, son has genetic condition)

These conversations challenged parents to look beyond normal societal expectations and focus on the eternal reward. Parents were also reminded that it is okay to not be normal. In this case, the grandfather suggests that his grandson's illness is able to witness to others in a way that normal healthy children would not be able to do. Thus, this example conveys an aesthetic moment that suggests a type of super normal comparison (i.e., trailblazer).

In sum, parents relied upon others (e.g., doctors, nurses, family members, friends, other parents with medically complex children) who were living or willing to live in their new normal. These people helped parents cultivate and sustain their family's new normal by offering critical social support, encouragement, access to resources, and affirmation. Without access to these people and the information and encouragement they provided, parents would not be able to create and accept this new hybrid discourse that difference is their new normal. It is through this hybrid discourse that parents were able to identify aesthetic moments since their child's diagnosis where they experienced blessings and expressed gratitude about living their new normal.

Discussion

Healthcare systems and family relationships “only exist because of the interaction of opposing voices exposed through communication” (Pecchioni & Keeley, 2011, p. 367). In our study, we convey how larger systems of meaning and discourses influence parents talk about their identity surrounding their dual roles and responsibilities as both parents and medical caregivers. In particular, we identify two discourses: (1) centripetal discourse of *normality*, and (2) centrifugal discourse of *difference*. Within parents’ narratives we found that they often positioned both discourses together to create a hybrid discourse: *difference is our new normal*. In this hybrid discourse, parents’ talk about normality and difference shows a transformative struggle (Baxter, 2011; Baxter & Norwood, 2015) where both discourses are no longer oppositional, but rather integral and dependent upon the other. It is through this hybrid discourse that parents are able to experience aesthetic moments where they express gratitude about their new normal.

After receiving their child’s diagnosis, all parents shared that they had initial conceptualizations of normality and health because of pre-eminent social meanings assigned to certain conditions, such as information about a condition’s severity, prognosis, genetic components, lifestyle alterations, and treatment options. In addition, societal macro-discourses about “health,” “disability,” and “stigma,” with society privileging the biological, healthy, intact, nuclear family (Baxter, 2011) also affected parents’ understanding of their new identity. Albeit the definitions of words such as “healthy” being contested and muddled (Tulloch, 2005), the World Health Organization defines health as a state of complete physical, mental, and social wellbeing, and not merely the absence of disease or infirmity (WHO, n.d., para. 1). Within disability studies (Oslund, 2015) and chronic illness (Holladay, 2017) scholarship, the enduring, yet erroneous correlation, linking disability and illness to poor health transmits the courtesy stigma that originated from dominant stories in religious and popular texts (Bauer, 2011). Because of these larger dominant discourses, parents must claim and redefine normality and health for them and their family in novel ways in order to experience aesthetic moments. We provide insight into the communicative practice of normalizing, and the many way that parents use language and talk co-construct hybrid discourses within pediatric health contexts (Buzzanell, 2010).

For many of the parents, normality was described as being a desire, expectation, and standard that is socially constructed. In an attempt to create a new normal, parents had to realign and re-envision new possibilities and potentials with new community members who were also living or willing to live in their current reality. Thus, parents talked their “new” normal into being through the daily maintenance and rituals involved in caring for their child (Buzzanell, 2010). Parents reclaimed the word “normal” by pointing to the family functioning that unites them with all others who are “doing family” in similar ways, while also noting salient differences between them and outsiders (but often regarding differences as blessings of gratitude). Thus, our findings mirror other scholars (Buzzanell, 2010; Canary, 2012; Hays & Colaner, 2016) by illuminating the degree to which communication practices (i.e., messages and discourses) preserve family relationships and allow parents to talk their new normal into being. Parents’ acceptance and enactment of this hybrid discourse had the potential to foster aesthetic moments where parents discussed experiencing gratitude amidst suffering, as well as discovered new meanings for their “new” identity and parenting responsibilities that are different from definitions of parenting as outlined by societal standards. This knowledge is important because talking about “disability within the family and with others is effective for moving the family system forward into productive transformations” (Canary, 2012, p. 171), as well as sustains family’s abilities to effectively construct their “new” normal (Hays & Colaner, 2016).

Theoretical and Practical Implications

Our work contributes to the theoretical development of RDT (Baxter, 2011) in important ways. Through an examination of discursive tensions apparent in parents' talk about their experiences, we were able to identify aesthetic moments within the hybrid discourse: difference is our new normal. This knowledge adds to other scholars (see O'Hara & Shue, 2018; Scharp & Thomas, 2017) who have also studied discursive hybridity and aesthetic moments within relationship talk. We also contribute to the limited research employing RDT (Baxter, 2011) in the health care context (e.g., O'Hara & Shue, 2018; Wolf, 2014), albeit discourses significantly influencing the content within health conversations among patients, families, and medical professionals. Finally, ours is the first study to examine discourses of parental caregivers for children living with CCCs, despite the continued growth of this population (1 in 5; Children and Adolescent Health Measurement Initiative, 2016), and the potential that more families will need to navigate these discursive struggles as they accept new identities.

Our work may be influential in helping family members and friends understand the identity struggles and challenges parents of medically complex children face, as well as the larger societal discourses influencing parents' talk. As many family members and friends seek to provide helpful social support to parents of medically complex children, it is important to be mindful and sensitive to their language choices, and in particular, how they talk about normality and difference. In addition, health professionals are in a unique position to help parents understand, assess, identify, and support their "reauthorizing process" (Frank, 2004). On average, parents of medically complex children must coordinate their child's care between 13 outpatient physicians and six subspecialists (Carosella et al., 2018). Hence, parents 30 additional hours a week tending to their child's medical needs (National Alliance for Caregiving & AARP, 2009) are spent interacting with a variety of specialists and subspecialists. Although the current findings did not specifically focus on the role of health care providers and parents, health care professionals do spend a lot of time with these parents, and thus have a significant impact on parents' language choices about normality (Davis, Mayo, Picora, & Wimberley, 2013; Harter et al., 2013). In considering the hybridization discourse of *difference is our normal*, medical providers may recognize the full range of emotions and capabilities that encompass the complexities of parenting a medically complex child, and as such, they may be able to help parents craft messages about creating their new normal. These tenets of narrative medicine (Frank, 2004) are particularly important communication skills that have been equated with optimal interactions between health care providers and parents of children with CCCs (Davies et al., 2017).

Limitations and Directions for Future Research

As with any research, there are limitations to consider. Most significantly, the sample is highly homogenous: All parents self-reported as White/Caucasian, and the majority were married Christian mothers staying at the Ronald McDonald House as their child was in the hospital receiving in-patient medical treatment. Here, parents had access to supportive resources (e.g., food, lodging, access to therapy programs). Almost all parents had children with CCCs that involved physical health issues. In addition, there are limitations surrounding important questions about family finances, employment, and/or access to health insurance that were not directly discussed in the interview protocol nor mentioned in the demographic survey. While some of these topics did organically emerge in a few of the interviews (e.g., talk about having to work because of health insurance coverage, quitting job to stay home full-time with

their child), a more comprehensive understanding of a family's financial situation would have added greater insight about one's financial abilities to construct normalcy.

All of these limitations present multiple avenues for future research. One direction is the examination of different types of parental caregivers across a spectrum of different pediatric complex diagnoses. One particular focus could examine parents whose medically complex children have mental health diagnoses. Parents' experiences may be different since mental illness is sometimes invisible (e.g., high-functioning autism) and/or stigmatized (e.g., eating disorders), and these perceptions have historically been influenced by larger societal discourses where people with mental illness were removed from society (Bauer, 2011). Second, because pediatric chronic illness is a "family affair," (Haskell et al., 2012) other family compositions (e.g., single mothers) need to be studied. Researchers may compare differences between mothers and fathers parenting the same child or interview other family members, such as siblings. Siblings are often not the focus of scholarship, and as a result, siblings often feel overlooked and experience compromised psychosocial wellbeing (Kwolek, Wilson, & Hall, 2014). Third, researchers should study conversations that parental caregivers have with other family members or health care providers, and the discourses present within these exchanges. Studying these interactions would allow for an examination of *enacted speech* between relational partners, which enables deeper insights into how meanings are constructed within actual speech encounters (Baxter, 2011; O'Hara & Shue, 2018).

Conclusion

In sum, health plays a central role in family functioning. Families and health are intertwined in meaningful ways, and communication is central to these processes. Our research highlights how larger systems of meaning and already-spoken discourses influence parents' talk about their identity as a parent to a medically complex child. By using RDT (Baxter, 2011), we identify the complexities associated with being a parental caregiver to a medically complex child, and the interplay of discourses that affect parents' talk about "normal" family life, day-to-day family functioning, and family identity.

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We would like to thank the families who shared their stories with us. We would also like to thank The Ronald McDonald House Charities for their help and support with recruitment and data collection. Last, we want to thank Sarah Heller, Nicole Miller, and Madison Schwenneker for their assistance with data analysis.

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Article Citation

Rafferty, K. A., & Hutton, K. (2019). When black and white turns gray: Exploring the interplay and meaning of discourses about parenting a child with a complex chronic condition. *The Qualitative Report*, 24(9), 2102-2121. Retrieved from <https://nsuworks.nova.edu/tqr/vol24/iss9/1>
