Abstract

A growing body of research examines the intersections between sibling relationships and disability. However, much of this research focuses on non-disabled siblings and how the disabled sibling affects them, thereby continuing to center able-bodiedness while further marginalizing disabled people. This research centers the voices of two siblings who are both disabled. Using duoethnography, the researchers engaged in a dialog interrogating how disability has played a role in our sibling relationship. Our dialog demonstrated the complexity of our experiences as siblings and as disabled people. We found that physical disability, a status we do not share, created role asymmetry and power differentials in our relationship. Conversely, we discussed how our shared experience of having psychiatric disabilities had a positive influence on our closeness, and enhanced our ability to provide mutual support and engage in reciprocity. This duoethnography has important implications for the inclusion of disabled siblings in future research.

**Keywords:** siblings, sibling relationships, family, disability, duoethnography
Sibling relationships are a unique aspect of kinship, as they have the potential to be the longest-enduring familial bonds, which creates the potential for a meaningful relationship with shared experiences that lasts throughout the life course (Connidis, 2001; Morgan & Kunkel, 2007). A growing body of literature seeks to better understand sibling relationships, and a sub-set of this research examines how disability affects sibling relationships. However, the majority of this research focuses on the experiences of non-disabled (or “typical”) siblings, thereby centering ability and further marginalizing people with disabilities. As a result, little is known about the experiences of disabled siblings from their perspective. Additionally, there is a dearth of research exploring how the sibling relationship is experienced when multiple siblings have disabilities. The purpose of our study was to begin to explore how disability influences sibling relationships when both siblings are disabled. Using duoethnography and disability studies perspectives, we interrogated how disability has played a role in our sibling relationship throughout our life courses.

**Literature Review**

The majority of research on siblings and disabilities seeks to better understand how the presence of disability affects sibling relationships. Studies focus on the dimensions of sibling relationships, how disabled siblings negatively or positively influence the non-disabled siblings, and how the relationships between disabled siblings and non-disabled siblings differ from the relationships of siblings without disabilities (Stoneman, 2005). A select number of studies also include or focus on the perspectives of disabled people regarding their sibling relationships.

**Dimensions of Sibling Relationships**

The sibling relationship has been characterized in the developmental psychology and family studies literature along four dimensions: (1) warmth/closeness, (2) conflict, (3) rivalry,
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and (4) relative status/power (Furman & Buhrmester, 1985). It bears repeating that these dimensions have been studied primarily for non-disabled children who have a disabled sibling.

**Warmth/Closeness.** Warmth and closeness in the sibling relationship manifest through qualities such as intimaecy, prosocial behavior, companionship, admiration, nurturance, perceived similarity, and affection (Furman & Buhrmester, 1985). Generally, research has shown that relationships between non-disabled siblings and disabled siblings are positive, nurturing, and fulfilling (Stoneman, 2005). Some research has also demonstrated that the relationships between disabled and non-disabled siblings are more positive than the relationships between non-disabled siblings (Stoneman, 2005).

**Conflict.** Conflict consists of features such as quarreling, antagonism, competition, and perceived parental favoritism (Furman & Buhrmester, 1985). Some studies have reported less conflict between non-disabled children and their disabled siblings (Fisman, Wolf, Ellison, Freeman, & Szatmari, 1996; Floyd, Purcell, Richardson, & Kupersmidt, 2009; Kaninsky & Dewey, 2011), whereas others have reported more conflict (Bagenholm & Gillberg, 1991; Ross & Cuskelly, 2006).

**Rivalry.** Rivalry comprises of competition and parental partiality (Furman & Buhrmester, 1985). Generally, non-disabled children have perceived mothers to be more partial to their disabled sibling (Bagenholm & Gillberg, 1991; Bischoff & Tingstrom, 1991; Cicirelli, 1994; McHale & Harris, 1992; Pit-ten-Cate & Loots, 2000; Sanders, 2004). This finding is likely due to the fact that parents often direct more attention to disabled children than their non-disabled siblings (McHale & Pawletko, 1992), which is referred to as differential parenting. This parenting technique is perceived as justified by some non-disabled siblings, while other non-
disabled siblings view it as favoritism and respond negatively (McHale & Gamble, 1989; McHale & Pawletko, 1992).

**Relative Status/Power.** Relative status/power includes dynamics such as nurturance of/by siblings, admiration of/by siblings, and dominance over/by siblings (Furman & Buhrmester, 1985). Parents have perceived a greater status/power differential when one sibling has a disability, compared to when neither sibling has a disability (Bischoff & Tingstrom, 1991; Floyd et al., 2009). Related to the concepts of status and power are sibling role relationships. Research has indicated that non-disabled and disabled siblings may experience role asymmetry. As Stoneman (2005) explained:

> Siblings of children with disabilities frequently assume dominant roles as they help, teach, and manage their [siblings]. Both older and younger siblings of children with disabilities assume expanded childcare roles as compared to their peers…As a result, role relationships between children with disabilities and their siblings are more asymmetrical. (p. 341)

Some studies have reported that the roles non-disabled siblings engage in with their disabled siblings are positive and carry developmental benefits (Stoneman & Brody, 1982). However, other studies have suggested that these roles result in role strain (i.e., the demands of the role become too intense), leading to negative outcomes (Stoneman, Brody, Davis, & Crapps, 1987).

**Influence of Disabled Sibling on Typical Sibling**

The influence of the disabled sibling on the non-disabled sibling has also been studied, with an emphasis on how the disabled siblings may have a negative influence on the non-disabled child. Consequently, a great deal of research in this area appears to be guided by the assumption that having a disabled sibling is detrimental to non-disabled children. For example,
research has posited that non-disabled children who have disabled siblings may have more behavioral problems (Ishizaki et al., 2005), social problems (Sharpe & Rossiter, 2002), and academic problems (Sanders, 2004).

In terms of positive influence, Taunt and Hastings (2002) reported that many non-disabled siblings who have disabled siblings thrive in their families. Other studies have found that non-disabled children who have disabled siblings show increased tolerance for differences, higher levels of empathy, greater sense of responsibility, more self-confidence, and a greater appreciation for their own health and intelligence (Cicirelli, 1994; Grossman, 1972; Powell & Ogle, 1985). Interestingly, while having a greater appreciation for one’s own health and intelligence is cast as a positive outcome in the literature, it contains prejudicial undertones and suggests that the non-disabled sibling pities or looks down on the sibling with a disability.

**Support Needs of Non-Disabled Siblings**

Arnold, Heller, and Kramer (2012) took a unique approach in their study of non-disabled people who had siblings with developmental disabilities by exploring their support needs for providing care and serving as advocates for their disabled sibling. They found that support needs for siblings of people with disabilities included: (1) obtaining disability-related information, (2) getting support for their caregiving role, and (3) enhancing the formal support system to address sibling needs. These needs are particularly important to meet, as many non-disabled siblings provide caregiving for their disabled siblings once their aging parents are no longer able to do so.

**Experiences of the Sibling with a Disability**

Very few studies have included the experiences of disabled siblings. Stalker (2002) reported that disabled siblings’ relationships with their non-disabled siblings were diverse and complex. They found evidence of “robust relationships with fun and conflict in equal measure,”
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which was reflective of the literature on non-disabled sibling relationships (p. 43). Serdity and Burgman (2012) studied disabled siblings who were the oldest siblings and found that participants showed engagement in their older sibling roles, which positively influenced their sense of self. Burbridge and Minnes’ (2014) study included people with developmental disabilities, who reported enjoying numerous activities with siblings and a desire to spend more time with siblings. Davis and Salkin (2005) engaged in a dialogic case study methodology to examine disability in their relationship and broader familial context. Davis, who is non-disabled, included Salkin in the research in order to ensure her voice, as a disabled sibling, was heard and validated.

Using the Social Model of Disability to Understand Sibling Relationships

In an effort to counter research on siblings and disability that views disability as an individual medical problem, Connors and Stalker (2003) and Stalker and Connors (2004) engaged in studies of disabled children and their siblings using the frameworks of the social model of disability (Oliver, 1990) and the social relational model of disability (Thomas, 1999), which challenges medical or individual models of disability by exploring how socially constructed barriers have disabled people with impairments. They reported that many siblings did not categorize their experience of having a disabled sibling as inherently negative or positive, but rather viewed their relationships as ordinary within the context of their families. In cases in which the sibling did perceive difference, they often attributed it to factors such as unequal treatment and oppressive attitudes of others. Hence, some disabled siblings and non-disabled siblings recognized that disability is a social construction that is imposed on them culturally and societally rather than the result of a medical issue or individual limitations (Connors & Stalker, 2003; Stalker & Connors, 2004).
Overview of the Current Literature on Siblings and Disability

An overwhelming majority of research has focused on the experiences of non-disabled siblings who have a disabled sibling (Stoneman, 2005). There is an emphasis on sibling relationships in childhood, with less scholarship examining how these relationships are experienced in adulthood. Most studies have examined the relationship between a non-disabled sibling and a sibling with an intellectual or developmental disability. Physical impairments, psychiatric impairments, and chronic illnesses are studied less frequently. Furthermore, to our knowledge, there are no studies that have examined the relationships of siblings who both have disabilities.

One possible reason there is a dearth of scholarship that includes the experiences of siblings with disabilities or that explores the relationships of siblings who both have disabilities is negative bias toward disability, which appears to be quite pervasive in a significant body of research concerning sibling relationships and disability. As Stoneman (2005) observed, “Conceptual models of families too often view children with disabilities as stressors rather than family members…Having a sibling with a disability is viewed as a problem to be understood and then solved” (p. 347). Meltzer and Kramer (2016) connect the emphasis on the non-disabled sibling and the “problems” disability may cause in the sibling relationship to the history of institutionalization, in which families were often encouraged to institutionalize disabled children for their own well-being and the well-being of the siblings. Embedded in this assertion was the belief that disability strains and harms familial relationships. This bias is reflective of compulsory able-bodiedness, which is a hegemonic (i.e., dominant and oppressive) ideological system that holds able-bodiedness as natural, normal, and desirable (McRuer, 2006). By focusing primarily on the experiences of able-bodied siblings, with a special concern for how disabled
siblings may be affecting able-bodied children, much of the family studies literature is implying that the able-bodied (or “normal”) sibling is the foremost (and in some cases, only) person worthy of exploration in the context of the sibling relationship and family system.

The purpose of this study is to center our voices as disabled people and interrogate how disability has a played a role in our sibling relationship. Given this, the research questions were: (1) How do disabled siblings experience their relationship when both siblings have disabilities, particularly in regards to the dimensions of sibling relationships: warmth/closeness, conflict, rivalry, and relative status/power? (2) How do our different salient identities (age, impairment type, and educational background) influence siblings with disabilities’ perceptions of their relationship?

We also seek to answer Meltzer and Kramer’s (2016) call for research on siblinghood that draws on disability studies approaches in order to center disability and open up new way to understand and study siblings. While Meltzer and Kramer (2016) were focusing on relationships between siblings with and without disabilities, we contend that disability studies can also inform research on multiple siblings with disabilities, particularly due to its emphasis on disability as a social, political, cultural, and economic phenomenon.

**Methodology**

**Duoethnography**

Duoethnography is a research methodology that emphasizes dialogue between researchers as a site of interrogation, discovery, and meaning-making. Norris and Sawyer (2012) stated, “Duoethnography is a collaborative research methodology in which two or more researchers of difference juxtapose their life histories to provide multiple understandings of the world” (p. 9). According to Norris (2008), duoethnography emerged out of two narrative
research traditions: storytelling and Pinar’s (1975) concept of currere, or “curriculum of life.” Norris (2008) explained, “Whereas currere examines an individual’s perspective on a concept, duoethnography extends currere by employing multiple voices in dialogue. Its purpose is to explore how the life histories of different individuals affect the meanings they give to experiences” (pp. 233-234). The emphasis on dialogue is essential in duoethnography, as the conversation that occurs between researchers allows them to create new meanings and interpretations of shared experiences (Nicolazzo & Harris, 2014). Then, from these shared experiences, researchers can (re)interpret new cultural understandings. In this sense, duoethnography is similar to autoethnography as it analyzes experiences within a broader social and cultural context (Chang, 2008).

Norris (2008) discussed four basic tenets of duoethnography. The first tenet is duoethnography should remain open as a methodology, rather than becoming prescriptive. The second tenet is that the individual’s voices should remain distinguishable in the dialogue. This format allows readers to experience each researcher’s voice as they discuss and share their experiences. It also allows readers to better understand how the researchers’ experience converge and diverge. The third tenet is that changes in views or perspectives are key in duoethnography. Thus, unlike methodologies that may seek to create a conclusive or final text, duoethnography embraces fluidity and an emerging sense of understanding. The fourth tenet is that differences in points of view are embraced. Hence, in duoethnography, differences in perspectives are encouraged, although similarities are not omitted. These four tenets of duoethnography serve as a guide for researchers as they construct the specific methods they will use to engage in dialogue.

As researchers, we selected duoethnography for our study because it allowed us to
engage in a dialogue about our sibling relationship. Had we separately explored our personal experiences, the data would have been singular and individualistic, rather than relational. Additionally, duoethnography centered our voices as people with disabilities.

**Data Collection**

Guiding questions were constructed to focus the dialogue on the connection between our sibling relationship and disability. The guiding questions were not strictly followed, as we wanted the dialogue to evolve and ensure there were opportunities for tangents to be explored. Our guiding questions included: (a) How has disability influenced our sibling relationship? (b) How does our sibling relationship look different regarding physical disability versus psychiatric disability? (c) How do you see disability playing a role in any relative power or status differentials in our sibling relationship? (d) How do you see disability influencing the closeness of our sibling relationship? (e) How do you see disability creating conflict in our sibling relationship? (f) How do you see disability resulting in any rivalry in our sibling relationship?

[Author 1] responded to the guiding questions first in writing, and then [Author 2] responded orally. We initially responded in distinct ways based on our personal preferences and time constraints. As [Author 2] answered, [Author 1] shared her response with [Author 2] and we engaged in a dialogue about each question. This conversation was recorded and transcribed. These data were then inserted into a common, shared document in order for us to reflect on our responses and edit or expand on the dialogue. Because duoethnographic inquiry focuses on the multiple influences between the dialogic relationship of participants and the cultural context in which they are embedded, our discussion of extant literature has been incorporated into our dialogue.
Situating Our Selves

[Author 1]: I am 30 years old and the first born of four siblings: [Author 2], Elena, and Alex. I have a psychiatric disability, and my current diagnosis is Bipolar Disorder, Type II and PTSD (Post-Traumatic Stress Disorder). I am currently a Ph.D. Student in Disability Studies, and thus have an academic as well as personal understanding of disability. I view my psychiatric disability as a part of my identity. I recently made the decision to go off pharmacological medications and am currently trying to manage my Bipolar II through exercise, nutrition, and holistic approaches. I see an individual therapist regularly and am also involved in group therapy specifically for women.

[Author 2]: I am 26 years old and the second born in our family. I earned a Bachelor of Arts in Sociology and currently work as a Mental Health Worker in an inpatient psychiatric hospital. I was born with two congenital heart conditions: Wolff-Parkinson-White (WPW) Syndrome and Ebstein’s Anomaly. As a result, I have had numerous hospitalizations and surgeries to treat tachycardia (a faster than normal heart rate). I also had open-heart surgery at the age of 20 to repair my tricuspid heart valve. Like [Author 1], I also have a psychiatric disability, although my diagnoses are major depression and generalized anxiety disorder.

Situating our Relationship

Although one can never provide full context for any given relationship, it is important to situate our relationship within our broader familial context and history. Our relationship is characterized by intense closeness, in part due to forces of circumstance. We were raised in a verbally, emotionally, and at times physically, abusive household. Our father targeted [Author 1] more than the other children, whereas our mother’s abuse was less focused and affected all of us. Our parents were frequently absent, physically and emotionally. In particular, our father was
largely missing from our upbringing. His absence resulted in our mother, as a single parent with four children, being out of the home regularly due to the pressure to earn income. This situation necessitated [Author 1] fulfilling a parental role for [Author 2], Elena, and Alex. Ultimately, the traumatic nature of our childhoods caused us to form a deep connection.

A Dialogue on the Intersections between a Sibling Relationship and Disability

The dialogue that follows elucidates our sibling relationship among the dimensions of: relative status/power, warmth/closeness, conflict, and rivalry. We focus on these individualized and psychologized outcomes present in much sibling literature, but incorporated disability studies perspectives in our discussion of these dimensions as a way of politicizing, rather than de-individualizing, disability (Meltzer & Kramer, 2016). Furthermore, at the end of each section of our dialogue, we collectively discuss how our conversation relates to existing literature, and how we might use disability studies perspectives to inform and enhance the ways we made meaning of our sibling relationships, and vice versa.

Status/Power: Role Asymmetry vs. Interdependence

[Author 1]: One of the key differences between us is that while we both have psychiatric disabilities, you also have a physical disability. How does our sibling relationship look different regarding physical disability versus psychiatric disability?

[Author 2]: I can relate to you on the psychiatric level, but we cannot relate to each other on the cardiac disability area. That is kind of something that I have felt...not necessarily alone in…but you cannot truly understand until you have been in the situation. Like with my open heart surgery, I was feeling really overwhelmed but I did not want to talk to people about it because they did not understand. I think my physical disability definitely did affect our relationship. Mom was not around, so you stepped in, in her place.
After my open-heart surgery, I just felt like I needed help with everything, and that was frustrating because not only did I feel horrible, but I also had to depend on others for everything. That stressed me out. I felt like you were doing so much for me, and I felt kind of uncomfortable. With my bandages, I remember being embarrassed because I did not want to be 20 years old, naked in a bathtub, having you clean a hole in my chest from tubes. I had to have help, but I felt pretty uncomfortable. Everything hurt so bad that I knew that if I tried to do it by myself, it would be a huge mistake. I knew how much energy you were pouring into helping me...and it felt like it was too much. I felt like you should not have had to be in that position. I guess it goes back to our mother - I never felt like you were annoyed with me, but I felt bad because you were constantly tending to me instead of our parents. I just wish it had not been so hard for both of us. I did not consider how dependent I would have to be on other people, especially you.

After a certain amount of time had passed, I remember being aggravated. I guess I thought, soon I will be able to take care of myself and then I will not be a problem...but that time came a lot later than I thought I would. And I knew you would take good care of me but it was weird because I was like, obviously you are my sister so you are going to help me, but I think it was the amount of support you had to provide. It was pretty excessive. It got kind of uncomfortable and I just felt super helpless and guilty that you had to be the person taking care of me.

[Author 1]: I think that your physical impairment created a hierarchy and a power differential between us in some ways. It set up a dichotomy between us of caregiver/care recipient, helper/helped, independent/dependent. While providing care for you was incredibly important to me, I cannot deny that this experience emphasized this difference, and it seems like
you experienced it similarly since you felt helpless and disempowered. I never realized you felt this way. I think your physical impairment resulted in role asymmetry and power differentials in our sibling relationship, particularly when I was providing care for you after your open-heart surgery. During this time, I should have expressed more to you how meaningful the experience was, how it was helpful to me to have your companionship in terms of my own mental well-being, and how much I cherished the opportunity for us to spend time together. I wish now that the experience could have been a little different – that we could have acknowledged our interdependence more throughout the process.

[Author 1 and 2]: Our dialogue began with a focus on how our experiences with different impairments influenced our sibling relationship. Similar to previous work on siblinghood and disability, there is some evidence of role asymmetry, in which one sibling is providing care for the other. However, much of the research on care between non-disabled siblings and disabled siblings focuses primarily on the provision of care as a “burden” (Meltzer & Kramer, 2016; Stoneman, 2005).

However, a disability studies framework challenges us to think about how social and cultural factors play a role in this construction. The value of independence and the need to take care of oneself strongly influenced our experience of caregiving across different impairments. Wendell (1996), a feminist disability studies philosopher, argued that we need to alter the individualistic narrative and embrace interdependence in our society in order to fully integrate people with disabilities. Our dialogue suggests that [Author 1] felt a strong sense of interdependence, due to her own experience with disability. As Rohrer (2005) wrote, “Living with a disability or relating to someone with a disability clarifies how interrelated our lives really are, how much we socially and politically need each other” (p. 48). However, [Author 1] did not
realize [Author 2] was not experiencing the act of care in the same way, and we lacked the ability at the time to express and discuss it. This finding reflects Connors and Stalkers (2007) assertion that children with disabilities often do not have access to counter-narratives of disability, such as the social model of disability.

Hence, role asymmetry was experienced mostly due to the limiting language and cultural discourses available to us as siblings with disabilities. Reflecting on how we perceived and experienced care contrarily due to our different impairments highlights the need for narratives of care and sibling relationships that emphasize interdependence. In the next section of our dialogue, we explore how our shared experience of psychiatric disability has allowed us to experience interdependence, mutual support, and reciprocity.

**Interdependence, Mutual Support, and Reciprocity**

[Author 1]: In regards to our psychiatric disabilities, we are equals in many ways, and our interdependence is much more apparent in that aspect of our lives. We support each other. Our relationship is mutual and reciprocal. When I experience a stressor, you are often the first person I turn to in order to receive comfort, commiseration, empathy, and encouragement. When I have tried to talk to some non-disabled family and friends about my psychiatric disabilities, I often receive sympathy, pity, judgment, and unhelpful or unsolicited advice. You know the advice I am talking about: try looking on the bright side; maybe you should try yoga; my cousin started acupuncture and it totally changed her life. (Shared Laughter). In our relationship, I know I can turn to you and you will understand where I am coming from due to sharing similar feelings and experiences. This allows us to connect on a deeper level and also allows me to receive a more meaningful form of support.
[Author 2]: Yes, as far as mental disability, we can relate to one another, we understand what each other is going through. We have talked so much about medicine, therapists, different diagnoses…a lot of times when people are dealing with mental illness, I guess it’s like they either have to seek out a community to relate to or don’t have anyone to relate to and I guess I just think it’s cool I can just call you! Our siblinghood is like a mental health community in itself.

[Author 1]: How would you define “mental health community”?

[Author 2]: In my personal experiences, I will feel isolated or lonely or like other people do not understand me...I think with mental illness, a lot of people feel misunderstood except by other people who have experienced it. I mean like a support system.

[Author 1]: I think as we have aged, we have moved away from the emphasis on “curing” our psychiatric disabilities and now focus more on incorporating disability into our identities and viewing it as part of our lives. And part of this process has been providing mutual support and thereby being in community with each other.

[Author 1 and 2]: The shared experience of psychiatric disability influenced our sibling relationship significantly. As previously mentioned, many studies of siblings with and without disabilities have focused on how the non-disabled sibling provides care to the disabled sibling, and how that may result in developmental benefits or negative effects due to role strain (Stoneman & Brody, 1982; Stoneman, Brody, Davis, & Crapps, 1987). However, as siblings with disabilities, our relationship highlights the reciprocity and mutual support often experienced by people with disabilities. Hillyer (1993) reflected on reciprocity and disability, claiming:

Disabled people force us to face the problem of reciprocity, the investment in a relationship by both participants. Reciprocity involves the difficulty of recognizing each
other’s needs, relying on each other, asking and receiving help, delegating responsibility, giving and receiving empathy, and respecting boundaries. (p. 18)

We strongly relate to this conception of reciprocity in regards to our relationship.

Furthermore, [Author 1] appreciated and agreed with [Author 2’s] conceptualization of our sibling relationship as a community. This characterization is similar to Chandler’s concept of crip communities. Chandler (2012) is interested in interrogating:

how disability can be understood differently, specifically, how disability can be taken up as communally binding and desirable, and how communities bound together by disability—crip communities—can “crip” community…[by enacting community] through mutual motivation or desire to dwell with disability, a desire which is antagonistic to the normative desire to cure or kill disability. (para 2)

As we recognized in our dialogue, our experience of psychiatric disability has become less individualized and concerned with “cures” over time, and more focused on how we can embrace our disabilities are a part of our identities, life experiences, and sibling relationship. In the next part our dialogue, we further explore how interdependence, mutual support, and reciprocity affected our warmth and closeness.

Warmth/Closeness

[Author 1]: Given that mutual support is such an important part of our relationship, I am curious if you see disability influencing how close we are?

[Author 2]: Definitely, because if we did not have similar psychiatric disabilities, we would not understand each other nearly as well or understand what we are going through. I have had a lot of people who ask, “Oh so you’re just really sad?” They do not understand. I think if one of us had mental illness, and others of us did not, we would not be as close. It probably
changed things a lot. But it makes it easier for us to connect and understand one another and know how to support each other.

[Author 1]: I agree. The stigma against psychiatric disability is so pervasive in our culture, and it is likely that if we did not each personally experience psychiatric disability, we would carry that stigma against each other and that would separate us rather than draw us closer together.

[Author 1 and 2]: Our dialogue emphasizes the ways in which the shared experience of disability (even though our specific diagnoses and impairment types differ) have influenced our closeness. Although some research has demonstrated the ways in which non-disabled siblings and disabled siblings experience closeness (Stoneman, 2005), other research indicates that closeness can be impacted by non-disabled siblings’ lack of understanding about disability. De Caroli and Sagone (2013) explored the attitudes of non-disabled siblings toward siblings with intellectual or developmental disabilities, and some non-disabled siblings described their siblings as “unfortunate,” “incomprehensible individuals,” and “a limit for their own family.” Similarly, Litzelfelner (1995) found that non-disabled siblings lacked an understanding of their sibling’s disability or felt stressed because of their sibling, resulting in a lack of closeness. Since we share the experience of psychiatric disability, our sibling relationship is characterized by understanding, interdependence, mutual support, and reciprocity. Thus, we did not experience attitudinal barriers; rather, disability brought us closer together. Again, from a disability studies perspective, our relationship sibling highlights the ways in which crip communities may form within families in which multiple members are disabled and have access to counter-narratives regarding the ways in which disability is socially constructed and relationally situated (Kafer,
Our dialogue now turns to the ways in which disability may have possibly created conflict.

**Conflict**

[Author 1]: So we have talked quite a bit about how disability has had a positive influence on our sibling relationship, but I am wondering about how disability might have created conflict in our relationship?

[Author 2]: I do not know. This is obviously a mixture of things, like me being young, me being depressed. But I remember when I attempted suicide as a teenager, you were just so pissed at me. And obviously I get why you were so pissed at me...it was so weird because I just felt like, if I die, I die. No consequences for me. But then you were like super pissed at me and I was kind of frustrated because I felt like the way you were treating me was not really what I needed at that time. I was feeling misunderstood and lonely. That was just a really bad time in my life...so when everyone was angry about it, I was frustrated.

[Author 1]: Looking back on that situation, I know I handled it badly. We were both young, and knew so little about mental illness outside of our day-to-day struggles. I never told you this because I was so focused on being strong for you and Elena and Alex, but one of the reasons I was angry with you was because I was also suicidal at the time but every time I would even consider attempting, I was always held back by the fact that I was raising you and Elena and Alex. Honestly, I envied the fact that you felt free enough to even try. I also had a lot of misplaced anger. I really was not mad at you, I was mad at Mom because I kept telling her over and over again that you needed help, that someone needed to do something, and she did nothing. So that was really hard for me.
[Author 2]: Another way I think conflict has come up is when Elena started having anxiety issues, and then I felt like the doctor she was seeing was not doing the right thing in regards to her prescriptions, that really frustrated me. I remember thinking, “This is not right, this is not okay.” I just knew what the doctor was doing was not the answer. Obviously she was new to the experience, but we were telling her, “This is not right.” But it was Elena’s first experience with it, and I am sure it was overwhelming for her.

[Author 1]: In that situation, it was great that we could support Elena in many ways, but it was also hard because she just was not in the same place as us in terms of her approach to psychiatric disability. I perceived that our insistence that Elena demand certain types of care and treatment or switch psychiatrists was a little perplexing for her, because it was not something she had been dealing with throughout most of her adolescence and young adulthood, like you and I had. I think it has taken us time to learn that we can use this system and still navigate and negotiate our care.

[Author 2]: Yes, and we recognize the ways in which our disabilities have positive influences on our lives.

[Author 1]: Definitely. Sometimes it is difficult when I am in pain or become very irritable with people around me, but it also has positive aspects, like it's made me more caring and empathetic, I have better coping and stress management strategies, I am more self-aware, and I have periods of extreme productivity and focus.

[Author 2]: Sometimes I do worry that since our diagnoses differ, I do not fully understand your experiences.

[Author 1]: But I do not think your lack of understanding of the specifics of my experience has compromised the support and reciprocity. For instance, you have been fully
supportive of my decision to quit taking psychiatric medications and to try and manage my care and access needs in other ways. I think the greatest conflict I experience is when I am having a hard time and then you or Elena reach out to me for support. I do not always feel like I can support you during those times.

[Author 2]: If we are all struggling and we are all freaking out about how we are struggling, it’s a tug and pull thing. I will rank what is going on in our lives sometimes. If I know what you are going through, and if I think you are going through a harder time than I am, I will try to be more supportive.

[Author 1]: Right. We are very capable of supporting each other, but if we are having our own crises, that makes it a lot harder. When I was younger, I used to be much more self-sacrificing and always put you and Elena and Alex above my own needs, even if it was detrimental to my own well-being. But now I feel like we are at a place where I can say, I cannot talk right now or I cannot do this right now, but we can connect later. I believe our ability to set and respect boundaries is only improving as we age.

[Author 1 and 2]: This part of our dialogue expresses how our experiences with disability in some cases created conflict within our sibling relationship. Prior research has shown mixed results in regards to conflict between siblings with and without disabilities, yet only a select number of studies include the disabled siblings’ experiences in regards to conflict. The limited research that does exist found that conflict between siblings with and without disabilities were similar to conflict between non-disabled siblings (Petalas, Hastings, Nash, & Duff, 2013; Seredity & Burgman, 2010).

Interestingly, in our dialogue, our shared experiences of psychiatric disability sometimes caused conflict due to competing needs or different approaches to care and treatment. For
instance, we discussed how our approach to psychiatry differed from our sister Elena’s initial approach, which caused conflict. Psychiatric care automatically sets up a power differential between providers and patients, but as our dialogue indicates, we view ourselves as active and empowered in our care. As Price (2011) noted, “I make regular use of the psychiatric system, and I consider myself the agent and director of my treatments; for example, I interviewed and discarded psychiatrists until I found one who agrees with my approach to my bodymind” (p. 11). Such an approach aligns with disability studies perspectives and the neurodiversity and mad pride movements (McWade, Milton, & Beresford, 2015), but not all of us have had equal exposure and access to alternative ways of understanding and approaching psychiatric disability.

However, in some regards, the conflict ultimately resulted in a closer and more stable sibling relationship. For example, we discussed our need to establish boundaries when our care or access needs conflicted. This practice of forming, communicating, and respecting boundaries relates back to Hillyer’s (1993) discussion of reciprocity. This perspective challenges the idea that conflict is inherently negative in sibling relationships when one sibling is disabled and the other is not. Rather, it pushes us to consider the ways in which conflict may be productive and result in a stronger sibling relationship. In the next part of our dialogue, we discuss another seemingly negative aspect of sibling relationships, rivalry.

Rivalry

[Author 1]: How do you see disability resulting in any rivalry in our relationship?

Rivalry often relates to competition and parental favoritism, which I feel like we experienced differently. It seemed that Dad favored you, whereas Mom favored me.

[Author 2]: I think for Mom, when I was born, having two kids was hard enough but then having a kid with a serious health problem was too much. To her, I was just more stress,
more bills, more problems. It was almost like my physical disabilities inconvenienced her. I remember if we had to go to the hospital really late at night, she was pissed or frustrated. It just felt weird to be like, we have to go to the hospital and Mom is mad at me. Mom has said Dad gave me extra attention, and she felt like that was because of my heart. He doted on me more. If I was not feeling well, he was right there, and supportive, and would take my pulse and freak out. That is what you would normally expect a parent to do, but Mom and Dad did not do a lot of things you expected a parent to do.

[Author 1]: I always felt strange about the way Dad treated you because as a child I never could understand why he abused me much more than you. I wonder if your physical disability was a significant factor in the disparate treatment. But it was strange because the feeling I had was not really rivalry—it was more like I just wanted to understand why I was the target of much of his anger and you were not. I would not consider being abused “less” favoritism. Our childhoods were traumatic for both of us. However, it also seems that Mom has also favored me in part due to my educational achievements and educational attainment, and she has often tried to create rivalry between us based on that.

[Author 2]: I agree, though it many ways I think our educational backgrounds and your involvement in disability studies has had a positive impact on how we perceive disability and our sibling relationships.

[Author 1]: How do you see our different educational backgrounds playing a role in how we view disability and our sibling relationship?

[Author 2]: Well, sometimes when I am giving my opinion or what I think might be right or I have an idea, I can talk about it, but I think you probably know more about it from an academic perspective. But I also think if we did not have the education we have, chances are
good I would not be the same. And if you were not getting a PhD in Disability Studies, I probably would have never critically thought about our disabilities. I think our educations have been really beneficial. And some people would not believe that depression is a disability. There are probably people with mental illness who say, “I am not disabled!” because of the negative connotation. But if any of us did not have the education we had, and specifically you, things would be a lot different...probably really different! I guess if I did not learn so much, then my depression would not be something I accept and embrace. It would just be a big messy thing. You and I are actively working on our mental health and actively taking care of ourselves.

[Author 1]: We are empowered through education and disability studies! To know ourselves, to recognize we live in a society that oppresses disabled people, and to engage in self-care.

[Author 1 and 2]: The final portion of our dialogue focused on rivalry in the sibling relationship and how that related to disability. Our family is interesting in this regard, because most of the literature reports that parents favor or provide more time and attention to children with disabilities, which was not the case in our family. Rather, it seemed that our mother absorbed the dominant cultural narrative of disabled children being burdens. From a disability studies perspective, we can also consider how economics and lack of community-based services played a role in this dynamic (Shakespeare, 2006). Our mother’s view of [Author 2’s] disability as a burden may have been exacerbated by the fact that our family lived in poverty after our Dad left, and our family lacked community-based resources and support.

This part of the dialogue also took a surprising direction, as we transitioned from discussing rivalry to unpacking how our educational backgrounds have played a role in the ways we understand disability and experience our sibling relationships. Specifically, [Author 1’s]
background in disability studies and her desire to share disability studies theories, perspectives, and frameworks with her siblings has had a profound impact on how we both view our identities related to disability and how we experience disability in cultural and societal contexts.

**Implications**

In this article, we have modeled how siblings with disabilities might engage in dialogue around how disability and sibling relationships intersect. Furthermore, this research project was cathartic in many ways for us. Norris and Sawyer (2012) highlighted how duoethnography can be transformative, noting, “Rather than uncovering the meanings that people give to their lived experiences, duoethnography embraces the belief that meanings can be and often are transformed through the research act” (p. 9). In this case, duoethnography provided a constructive way for us to reflect on our sibling relationship throughout our life courses, discuss family trauma openly, and engage in healing through the dialogic process. Thus, this research could open up possibilities for other disabled siblings who may benefit (singularly and collectively) from discussing their relationship in a structured way that considers the significance of their relationship within the context of their family and broader culture.

This duoethnography also answered Meltzer and Kramer’s (2016) call for research on sibling relationships to draw from disability studies perspectives. Our dialogue also revealed the way that disability studies can influence, transform, and inform the relationships of siblings with disabilities (and siblings without disabilities). Again, this supports Connors and Stalkers’ (2007) assertion that disabled children and family members may benefit from counter-narratives of disability. It also aligns with Ne’eman’s (2012) call to take disability studies outside the academy and make disability studies accessible. Our dialogue and discussion demonstrate the ways in
which disability studies has enhanced our understanding of and even transformed our sibling relationship.

This duoethnography was important because it centered the voices of two individuals with disabilities and explored how we perceived our sibling relationship. The research on siblings and disability to date seems to preclude the possibility that some families have multiple siblings with disabilities, and that their experiences should be valued. It is our hope that this exploration might serve as a starting point for a new turn in the literature and encourage researchers in family studies, developmental psychology, and disability studies to engage in research that incorporates the voices of siblings with disabilities.

However, as a duoethnography, this research was limited to a single sibling relationship between two disabled people. Future research is needed to explore the diverse and varied relationships of multiple sets of disabled siblings. Practitioners in family studies, counseling, and related applied fields should also be sure to consider, respect, and validate the perspectives of disabled siblings in broader familial systems. Additionally, more sibling research that considers multiple identities and is intersectional in nature is needed. One of the strengths of duoethnography is the dialogue occurs over axes of difference, but space constrained us to focus on three differences: age, impairment type, and education. We were not able to adequately explore the ways in which we perceive our mixed race (White/Asian) identifies differently, or that [Author 1] identifies as queer, while [Author 2] identifies as straight. Like disability, these identities influence our relationship. Furthermore, the focus on axes of difference limited our ability to discuss how being women with disabilities has also influenced our experience, particularly given the gendered nature of disability in households and the dynamics of providing and receiving care (McGraw & Walker, 2007). Thus, more work is needed in this area,
particularly regarding the experiences of multiple women siblings with disabilities. Furthermore, while we occupy several marginalized positionalities as mixed race disabled women, we also recognize our privilege, as we are both white passing, cisgender, and have high educational attainment. Future work should include disabled people in sibling research who also hold other marginalized positionalities, such as non-passing people of color, lower-income people, people with limited educational attainment, and queer and trans people.

Lastly, in addition to ensuring the inclusion of siblings with disabilities, scholarship is needed that centers disability as an analytical tool. Much of the current literature on siblings and disability does not consider disability as a category of analysis, but rather views it as an individual or medical problem, which contributes to the subordinated status of disabled people (Tremain, 2013). Using a disability analytic and incorporating disability studies perspectives opens up possibilities for researchers interested in the intersections of siblings relationships and disability to consider how attitudinal, environmental, and social barriers affect sibling relationships in which one or more sibling has a disability (Meltzer & Kramer, 2016). It also encourages researchers to explore how the presence of disability in a sibling relationship may influence aspects of the relationship such as pride, community, interdependence, and support.

**Conclusion**

Our dialogue about how disability influences our sibling relationship demonstrated the complexity of our experiences as siblings and as people with disabilities. For example, we discussed how we experienced physical disability, which we do not share, differently than psychiatric disability, which we do share (though our specific diagnoses differ). In regards to [Author 2]’s physical disability, we discussed how role asymmetry occurred and that a power differential emerged between us in some ways. [Author 1] expressed some regret that she did
not emphasize her interdependence with [Author 2] after [Author 2]’s open-heart surgery. Conversely, we viewed our psychiatric disabilities as having a positive influence on how close we are, and also discussed how the shared experience of psychiatric disabilities allows us to provide mutual support and engage in reciprocity in our relationship. This research was significant because it moved our perspectives as disabled people in a sibling relationship from the margins to the center. It encourages researchers to consider the ways that disabled siblings engage in unique, meaningful, interdependent, and empowering relationships because of (rather than in spite of) their disabilities. Furthermore, this research demonstrated how critical and dialogic inquiry expands academic fields, as this interdisciplinary project centered the experiences of disabled siblings and thus encourages future research in and across family studies, developmental psychology, and disability studies that explores the relationships between disabled siblings.
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