The “Good” Mother: Ritualized Negotiations As a Form of Disability Self-Advocacy
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Abstract:

This paper brings forth the important contribution of mothers of an online illness discussion group who tell intimate narratives as a way to reconstruct their identity and give voice to their post-diagnosis world. There is a sense of ritual engagement, that is, a communal reiteration of shared understandings, identities, and beliefs that offers existential affirmation and, as Carey (1989) argues, enacts a shared faith in the wisdom of the group and the portrayal of a symbolic order that grants agency to participants.

Using thematic coding analysis, this paper focuses on the affirmation of good mothering through a communal enactment of maternal anxiety as they struggle over what it means to put their children before their own needs. This does not only affect one mother, but other member’s decisions as well—the whole community participating in this narrative is affected and are communally advocating for cultural acceptance. They grapple with what it means to be a “good” mother by making tough choices to medicate their symptoms and continue to breastfeed and thus possibly putting their child at risk from (unknown) exposure; or making the choice not to medicate their symptoms and breastfeed, thus exacerbating the disease and rendering parenting extremely difficult. The ritual is the maternal struggle of self-value that puts the child’s welfare above the welfare of the mother’s own health—a ritualized negotiation of
dominant cultural notions of what it means to be a good mother as they self-advocate and weigh health risks as requisite to enacting “good mothering.”
Introduction

Now, more than ever, disability studies scholarship must re-examine practices of self-advocacy especially through digital venues where those with disabilities and families who support them can speak for themselves. As Michele Wates and Rowen Jade (1999) offer in Bigger Than The Sky: Disabled Women on Parenting, mothers who are disabled need a safe venue to “explore where [they] are now, where [they] have come from and where [they] are going as disabled women,” (p. 7). This article brings forth the important contributions of mothers with autoimmune arthritis diseases in an online illness discussion group who, while they have never met one another, tell intimate and detailed illness narratives of breastfeeding while on toxic medicines as a way to help them learn to reconstruct or re-map their identity, form new relationships, challenge stigmas, and give voice to and navigate their parenting in their post-diagnosis world.

In ongoing online communicative interactions, I find a sense of ritual engagement; that is, a communal reiteration of shared understandings, identities, and beliefs that offers existential affirmation and, as James Carey (1989) puts it, enacts a shared faith in the wisdom of the group and the portrayal of a symbolic order that grants agency to participants. Further, many online support groups are committed to

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self-advocacy; that is, participants produce meanings of self-identity and cultural membership as an intentional effort to alter prevailing social perceptions and public policies about their illness and its consequences, not just for each other, but for their own identities and quality of life.

Not all self-advocacy needs to draw overt attention to a cause and sometimes the individual may not necessarily realise they are advocating in their enactments. Just as the public voices of the disability rights movement advocate for change, so do the interpersonal voices uttered in quieter settings, among peers in conversation or in online forums for example. While these utterances may not necessarily be affecting strategic activism as directly as a lawsuit per se, they are still enacting a form of advocacy, especially as they discuss experiences of oppression or injustice, support each other’s right to dignity and well-being, and recommend measures large or small to improve their conditions relative to their own (dis)ability. That is, self-advocacy is a way for people with disabilities to “speak for [their] rights” and suggest, support, or recommend change (Shapiro, 1993, p. 184). Before public action on behalf of the rights and change that Joseph Shapiro emphasizes, there must be local and personal recognition and reflection. Tellingly, Shapiro describes self-advocacy as a means for people to speak up for themselves and “make them think” critically about their situations, where individuals are more inclined to “take control” of their own decisions (p. 204). Sometimes self-advocacy happens in the most intimate of conversations, when
individuals reveal very personal stories about their lived experiences. Self-advocacy is about self-representation as much as about public arguments for political change.

This article represents a portion of a broader research project to reframe autoimmune arthritis self-representations as ritual communication in order to shift the ground for self-advocacy. Within the framework of the broader research project, I choose to examine the communicative interactions of an online forum among mothers who have a disability. Participants produce the forms and meanings of (self) identity and cultural membership, particularly of what it means to have autoimmune arthritis, ritually as customary, standardised, and communal. Within the context of mothering with a disability, the questions guiding this study are: How does the group enact self-advocacy? What are the implications of framing this self-advocacy as ritual communication?

To answer these questions, this article will detail rheumatoid arthritis (one type of autoimmune arthritis disease), establish the conceptual framework that guides the analysis, and then analyze the most prominent theme present in the data. The women’s questions and responses about mothering with rheumatoid arthritis provide a compelling example of self-advocacy as ritual communication.
**Rheumatoid Arthritis: A Case in Point**

Autoimmune arthritis offers a particularly apt focus for a study of ritual communication because representations of those who suffer these diseases are so explicitly contested. There are over 100 different forms of arthritis (Arthritis Foundation, *About Us*). Each type involves pain or discomfort posited in one or more joints. To combat stigma and false representation of the disease, there is a current push from various arthritis awareness advocates (such as *Show Us Your Hands!*, International Autoimmune Arthritis Foundation, RAGuy, CreakyJoints, RAChicks) to distinguish among each of these forms. Different forms of arthritis signify different meanings in society and these differences can have a direct impact the identity of the person with arthritis.

Rheumatoid arthritis is a type of autoimmune arthritis that is caused by the ravages of an overactive immune system (as opposed to osteoarthritis which is degenerative and typical in older adults). Rather than protecting the health of the individual, the immune system attacks the synovium lining surrounding the joints, causing fluid buildup, swelling, and severe pain (Arthritis Foundation, *Living With Arthritis*). No one is certain of the cause of this form of arthritis, but it is speculated that it can be either genetically acquired or “triggered” by environmental factors such as viruses or traumatic development to the body like birth. Onset most typically occurs in females who are in their 30s, although it is also found in males, juveniles, and infants. Often in society autoimmune arthritis conditions are mistakenly represented as
osteoarthritis. This mistake not only misrepresents an autoimmune disease, but also stigmatises and complicates the representation of those who suffer from autoimmune arthritis. For example, some may be perceived as not “old enough” to have arthritis; others may be held at fault for their condition (i.e. because they are too heavy, putting stress on their joints); still others may not be believed by their spouses or family members since often young mothers are diagnosed with this often invisible painful, chronic condition. Most mothers with an autoimmune arthritis disease are often confronted on their abilities (i.e. anxiety from others over basic caregiving), constantly questioned (i.e. that they may not have the endurance to care for their children), or perceived as “less than” their more normative able-bodied counterparts.
Ritual communication as self-advocacy

According to James Carey (1989) ritual communication is the shared and negotiated experiences of the participants where “a particular view of the world is portrayed and confirmed,” by way of structured communicative acts which are imbued with larger socio-cultural awareness (p. 20). Thinking of communication as ritual draws attention “toward the social consequences of communication” that possesses cultural significance and illustrates the understood assumptions that are reproduced in everyday patterns and practices in community life (Rothenbuhler, 2006, p.14). The ritualistic view of communication in this sense, according to Carey (1989), is not solely concerned with the transmission of messages or in this case, the medical accuracy or validity of opinions and advice, but rather with communication as a way to reproduce communal beliefs and advance a sense of social order that empowers members and affirms their value and agency.

Examining communication as cultural allows us to comprehend the social forces and underlying assumptions of shared meanings that are often unreflectively reproduced (Carey, 1989). From a ritual perspective, self-representations are embedded in a disability community’s communal self-advocacy; that is, the effort to acknowledge suffering, confront oppressive conditions, and advance positive shared identities; hence, individuals participating in the ritual communication of the community advocate for
themselves by reproducing the ritualized claims and arguments that enacts their community.

The ritual view of communication is complemented by Arthur Frank’s (1995) conception of the way we “think with stories” (p. 23). This is a process that not only combines reasoning and memory, but also requires a certain level of collaboration and affective evocation (Morris, 2001, p. 55). To think with (and respond to) stories is a process that can be a powerful form for “expressing suffering and experiences related to suffering” (Hyden, 1997, p. 49). Participants “learn by hearing themselves tell their stories, absorbing others' reactions and experiencing their stories being shared” (Frank, 1995, p. 1). Empowered by ritual enactments, illness narratives are a way for individuals diagnosed with an autoimmune arthritis disease to self-advocate using their collective voice to challenge societal perceptions and damaging stigmas.

Illness narratives were so convincingly identified by Frank (1995) in his now classic work, The Wounded Storyteller. He couches the significance of wounded storytelling against medical language that is too distant from the immediacy of embodied suffering (Frank, 1995, p. 25). Frank (1995) describes illness narratives as a way for the affected person to use their own personal voice to tell, “what illness has imposed on her and [to] seek to define for herself a new place in the world” (p. 7). I would like to add “and among each other” to suggest that the person with the illness or impairment is now a part of a new group, a type of sub-group that communicates
among others by sharing and negotiating experiences that are situated within a
dominant able-bodied society. Frank (1995) describes three different types of
(wounded) storytelling: the restitution narrative are the stories that see the illness as an
interruption, where “the expectation [is] that other people want to hear restitution
stories” and reflect a desire to “get well and stay well” even if the outcome of the illness
may eventually be fatal (Frank, 1995, p. 77); chaos narratives “imagine life never getting
better” and are often told out of sequence of actual events where “the teller of the
chaos story is not heard to be living a proper life” (Frank, 1995, p. 97); and quest
narratives told by people who “meet the suffering head on; they accept illness and seek
to use it” where “the quest is defined by the ill person’s belief that something is to be
gained through the experience” (Frank, 1995, p. 115). In this sense, Frank (1995) argues
that stories are told through the wounded body, where through storytelling the
individual is negotiating their connection to their impairment, society, other intimate
relationships, as well as to other individuals who may be experiencing similar difficulties.

It is important for me to distinguish between Frank’s (1995) work and the way in
which these categories are used throughout this study. I take these narrative types or
categories to be ritualized patterns reproducing oppressive or empowering meanings
and relations. These patterns are produced and reproduced within the fellowship of
disability communities. The larger sociopolitical struggles over the oppression and rights
of those with disabilities appear within the collective stories between members of
online disability groups, specifically exhibited when narrative types emerge from ritually produced enactments within the cultural fellowship.
Research Site and Method

Award winning BabyCenter© provides an especially rich site for the focus of this study. It is a global parenting network that claims to “nurture more than 100 million parents since its launch in 1997... [that] reaches over 78 percent of new and expectant moms online in the United States” (BabyCenter RA). BabyCenter makes available hundreds of experts, doctors, and board-approved information to mothers who seek support, friendship, and advice (BabyCenter RA). Not surprisingly, people often find themselves seeking advice from others who share their condition; individuals who are living, coping, and struggling through similar experiences. Along with thousands of discussion forums, BabyCenter hosts a Rheumatoid Arthritis community forum that is open to any mother who either suffers herself or has a child who suffers with this chronic illness.
A thematic narrative analysis\(^2\) was the primary approach used to code\(^3\) data.

According to Catherine Kohler Riessman (2008), a thematic narrative analysis generally identifies and theorizes common thematic elements across data or participants, events that are reported, and actions in established traditions (or are more ritualistic in nature, as in the case of this study) (p. 74). Information was collected between January 2011 and July 2013 (including performing research searches in the forum online archives from March 2008 – August 2013). As of 2013 there were approximately 600 members (the number changes daily), 3500 comments, and almost 900 forum posts.

The most prominent theme\(^4\) was included in this essay and represents a common culturally fraught struggle that mothers living with this chronic illness typically

\(^2\) Data was analyzed by separating stories (or posts) into like categories or thematic clusters by looking at post titles, which are typically very descriptive. When ambiguity of the primary theme (i.e. if there was a question regarding the nature of the post) arose I opened the post to read the detailed description. During this stage I also made note of posts that contained more than 10 group-member comments, which indicated a high rate of interest in the topic. This was done so I could revisit the most popular posts in the second stage of the coding analysis. The focus of the inquiry was kept in mind when coding the emergent themes, continuously oscillating from the emergent themes back to the theoretical framework (e.g. narrative, communication, disability) to affirm the data and their socio-cultural implications.

\(^3\) Once a particular post was noted it was then further coded to note ritualized messages and narrative types. Frank’s (1995) three illness narrative types (i.e. Restitution, Chaos, and Quest) served as initial guides to complicate the analysis of the poster’s comments although given the comparative inductive approach, other narrative types emerged.

\(^4\) While posts usually focused on one particular topic, almost all of them contained more than one (overlapping) theme. Occasionally, there were several primary themes (e.g. breastfeeding AND medicine concerns).
endure. The highlighted post in this essay serves as an example of how the group enacts self-advocacy and encapsulates many of the shared concerns of side-effects of taking toxic medication, in this case while nursing an infant.

In the following sequence, mothers with rheumatoid arthritis are grappling with tough choices: whether to medicate their symptoms and continue to breastfeed and thus possibly put their child at risk from (unknown) exposure; to medicate their symptoms and not breastfeed, though this is not a typical topic; or choose to not medicate their symptoms and breastfeed, thus exacerbating the disease and rendering parenting extremely difficult. I contend that they are engaged in a *ritually produced* narrative that enacts a socio-cultural struggle over what it means to be a “good mother” and what it means to put children before a mother’s own needs.

**The Medicated Breastfeeding Mother**

One of the most extended and intense themes in my data set concerned the medicated breastfeeding mother, yielding 81 different comment threads. The following online narrative is an example of mothers who are grappling with ingesting medications that contain potentially harmful side effects while breastfeeding their infant children. The exchange below is part of a 15 post dialogue in response to a member seeking advice on taking medications while breastfeeding, a decision not to be taken lightly.
Post Topic: “Prednisone/Enbrel and Breastfeeding”

Initial Post

Screen Name: SuciaGirl, Posted 04/17/2009

...I have had RA for 6 years and (thankfully) it went fully into remission during pregnancy. My daughter is now 8 weeks old and I'm starting to feel all the lovely symptoms of a flare. ...Anyway, I'm now at the point of figuring out if I should do prednisone for a while so I can keep breastfeeding, or if it is time to switch my little girl to formula and go back on Enbrel.

My questions for those of you who have gone through this:
1. How bad was your flair [sic] after you delivered and did it get better on its own?
2. If you used prednisone and were BFing, did it effect your LO?
3. Did you BF on Enbrel?...

In this post SuciaGirl asks three important questions to experienced mothers in the group. She indicates she is eight weeks post-delivery and beginning to have the expected postpartum flare. In addition to consulting her doctor, which is the conventional way of coping with a severe medical condition, she seeks insights from the shared experience of RA and motherhood within the group. She is interested in
garnering a better understanding of her options for medicating her symptoms while breastfeeding her newborn baby.

Screen Name: scrpbkqueen, Posted 04/17/2009

I wasn't on prednisone while I was BFing ...each [flare] was worse until I almost fell getting out of the chair with him one night. That scared me enough that I stopped BFing and went onto MTX ASAP and started him on formula. I still pumped until I started MTX, so he was getting some breastmilk until then, but I decided it was better to be able to care for him like I should than hurt and breastfeed and risk dropping him. ...

This post represents a pattern in responses posted by concerned breastfeeding mothers where their described experience is offered as a suggestion, they mention a specific medicinal treatment, and they close by describing the repercussions of their choices. Here, Scrpbkqueen responds to SuciaGirl’s questions and offers a suggestion concerning the medications she took to treat her RA while she was breastfeeding. Then she describes the extent of her condition by taking Prednisone (a corticosteroid used to treat inflammation) and the unhelpful ways the medication treated her condition which led to her almost dropping her child. She indicates that because she was frightened by
this incident, she began taking Methotrexate (a.k.a. MTX, a disease-modifying anti-rheumatic drug or DMARD). The important point is that this drug is toxic but it is a particularly common form of treatment. Finally, she implies that SuciaGirl should consider caring for herself rather than breastfeeding, so that in the end she can care for her child. Both being frightened by the close call she had when she almost hurt her child and the priority of caring for the child properly reproduce the negotiation of what it means to be a “good mother.”

Screen Name: SuciaGirl, Posted 04/17/2009

... how scary! Just the idea of almost falling terrifies me. It is such a real possibility when we are weak. It sounds like you made the absolute best decision for both of you.

...I just got a call back from my Rheumy and he said that I am ok to take Enbrel while BFing. It does not, according to him, go into the breast milk. Everything I have read disagrees with this, but I'm assuming that since I'm not a doc and he is, he is going to know more about it than I do (REALLY hoping that belief doesn't bite me in the ass later!)... Honestly, I'm feeling so horrible though that as soon as I got off the phone with him I gave myself an injection. Before I got
the phone call I had made up my mind to go back on Enbrel and stop BFing. Now I think I will BF for as long as it makes sense, but my main focus is for both of us to be healthy.

Unfortunately, this narrative of struggle is very common among mothers who post about breastfeeding within the group. SuciaGirl struggles and before she hears from her doctor she resists her instincts to breastfeed and does not give herself the Enbrel injection (Enbrel is a biologic TNF-inhibitor used to treat autoimmune diseases). She learns from her physician that it is “ok” to take Enbrel while breastfeeding, even though she had already made the decision to take the injection. This is a good example of what Frank (1995) argues of restitution narratives which require “recovery or triumph” of medicine – she has triumphed both by taking medicine to treat her RA and by continuing to breastfeed.

Screen Name: IndyKaren, Posted 04/17/2009

...I can tell you that I used both prednisone and Enbrel throughout my entire pregnancy (with the approval of my rheumy, my OB/GYN, and maternal/fetal medicine specialist); I also breastfed my son for 11 1/2 months while on both prednisone and Enbrel... this is just my own experience, but ... if you choose to
BF while using Enbrel, you should feel reasonably sure that it will not have an ill effect on your child...

Screen Name: Leo309, Posted 04/18/2009

... I ...was on pred[nisone] the whole pregnancy. I continue to take it while BFing. I'm not going to take Enbrel and BF, I feel there is too much mixed info (even thought it will probably turn out to be just fine)...I do agree though that it's better to be able to care for your LO and yourself than to suffer in pain just so you can BF. It really stinks that we have to make these decisions though, doesn't it?

Participants are struggling over how to reconcile the culturally hegemonic definition of the good mother with what it means to be a medicated breastfeeding mother. They negotiate what it means to be a “good” mother – choosing to breastfeed while medicated may put the baby at risk; conversely, choosing not to medicate their autoimmune arthritis may cause them to suffer to the point where they may not be able to care for their child (example of dropping the child). Either way, they agree the choice “really stinks.” In the next set of posts, the participants negotiate their own struggles as a way to navigate their oppression as members of the larger society. Their exchange
negotiates the conflict between the baby’s needs and the mother’s needs by choosing to take particular medicines while breastfeeding (versus being in severe pain).

Screen Name: SuciaGirl, Posted 04/21/2009

... I agree, it totally stinks to have to worry about caretaking versus breastfeeding. I try to find the silver lining as often as possible, but frankly having this disease just bites...I totally understand not wanting to BF while on Enbrel. I'm honestly torn about it as well...

BabyZuewski, Posted 10/03/2010

...I am trying to suffer through the pain rather than take meds... Shortly after I gave birth ...I started to feel this tremendous weakness and then pain all over my body.... I only took [Prednisone] for a week because I am BFing and I am not going to stop. ...I cannot stop BFing because I cannot afford formula. I know it's crazy but I'm choosing to endure the pain (going on and off prednisone as needed) until my baby is a year old. He is 5 1/2 months old now...I don't know what else to do other than suffer at this point.
In this excerpt community members talk through their struggles, collaborate with each other’s lived experiences, and make decisions based upon the community story. While it should be acknowledged that many storytellers in this post tell a restitution narrative, they also tell a story of coping and trying to survive – one member even remarks that she has “too much stiffness and pain right now to type much more,” a resistance to the “I’m fine” narrative associated with Frank’s (1995) restitution type.

By reframing the interactions on this mothering forum as ritual communication, disability self-advocacy can be understood as deeply invested in an alternative understanding of the dominant moral order that negotiates what “good mothering” can be and assures these women of their right to be valued and their capacity for agency. Together they are reaffirming value and agency which is developed by legitimising concern, expressing empathy, and validating their experiences. This type of disability self-advocacy should not just be understood as individuals standing up for themselves, but also as a collective action as together they reaffirm a narrative of self-worth and value.

The women presented in this group are not activists, but are working through their lived experiences and (self) advocating for their own agency and self-worth. Their stories are important because they illustrate that they can live through their diagnosis and mother well, that they have the power to decide how to best care for themselves
and their babies, and that even though they are in despair they are worth something to their family and society – that they are valued and deserve love.

I turn now to the implications of framing disability self-advocacy as ritual communication.
Ritually Constituting the Meaning of Good Mother

Recognizing the way these mothers advocate for themselves among each other and in the context of hegemonic cultural definitions that disadvantage them is important. Yet this is not the most critically significant aspect of my data. Rather, it is as ritual communication that the power of this communal narrative of self-advocacy can be recognized. The initial post prompts a validating exchange as a ritualized pattern of storytelling to affirm a communal value and unite as a community around their desire to be a “good mother.” Importantly, this sequence implicitly critiques the binary demands of the larger social moral order; as one poster put it, it “bites” to have to make these tough decisions about their own health and the health of their children. This exchange both provides communal support for the mother and affirms the group’s determination to advocate for a more complex understanding of mothering and autoimmune arthritis. They seek fairness and compassion, traits they find empowering through their shared ideas. While expressing empathy they also advocate resisting disabled stereotypes and offer advice for the poster to view this process of being different as something inherently acceptable. The message seems to be that just because it is different (or rather not the norm within society) does not mean it is bad.

The members of this forum struggle over what it means to be a “good mother” and how to live within their family unit. By confronting stigmas they are promoting compassion and care by having faith in a moral order that allows for and even values
their mothering and bodies. This collective knowledge engages participants to critically examine their role in the larger moral order—eliciting questions and raising concerns regarding oppressing bodies that matter—especially as they work within the larger societal pressures of what it means to be a “good” mother or wife. The members are constantly questioning their own self-worth, challenging dominant social norms of an able bodied woman and mother.

The ritual is about the reaffirmation of a kind of maternal struggle and anxiety that puts the child’s welfare above the welfare of the mother’s own health; that is, an affirmation of good mothering though a communal enactment of maternal anxiety. The ritual is also about advocating for “good” mothering, as they are encouraged to consider their own health over the minimal risk to the child. These women are tapping into the shared wisdom of the group, empowering each other to resist counter-demands requiring maternal self-sacrifice in the reaffirmation of self-value and agency. Participants are constantly grappling with tough decisions that assure them a place or put them at odds with the “grand social order” as Carey (1989) puts it.

To paraphrase Carey (1989), these rituals invite participants to frame their own lives in terms of mothering with a disability (p. 21). By doing so, the members affirm the underlying cultural assumptions and routine practices of what it means to mother with rheumatoid arthritis and question the way it is understood in society. Fellowship emerges in mutual self-recognition and collective empathy as members describe what it
means to mother with a disability, breastfeed while on toxic medications, or coping with pain and the difficulties that arise within intimate relationships. Further, the ritually communicated understandings in this forum both empower members to advocate among themselves for their own agency and well-being as they counter oppressive stigmas that put into question their “good mothering.” At the same time, members may unreflectively reproduce oppressive socio-cultural restrictions and social stigmas as they post and assert damaging messages about their own bodies and experiences. This imbrication of empowerment and reproduction demonstrates the complexity of collective storytelling. The respondents offer support in different ways, address social oppression in different ways, and utilize narrative types in various ways, sometimes by following the storyline of Frank’s illness narrative types and sometimes by fragmenting these types or precipitating alternative trajectories (as in stories of navigation or coping).

Frank’s (1995) restitution narrative type clearly plays a part in these stories. He defines the restitution narrative as the talk of medical tests, treatments, competency of physicians, and alternative treatments, all of which can be seen in abundance throughout the online group. This narrative type also requires that storylines emphasize talk of recovery and a triumph of medicine—concepts that are rarely, if ever, idolized in the telling of a chronic illness narrative. No one with RA ever says “I’m fine” or “I’ll be healthy again” – more like “I’m okay” because members of the group know that able-
bodied people living in an ablest culture will not truly understand what it is like to mother having RA. While certain aspects to the restitution narrative type can be seen in the online community members know that there is no cure for rheumatoid arthritis and instead seek stories from the experience of others in the online community to help them reconstitute their post-diagnosis world. The ritual forms through the telling of the story over and over again by different members, where shared experiences are confirmed, supported, justified and act to empower women into taking action for their own health, affirming a moral vision of a valued life, and perhaps ultimately creating social change.

The example presented in this essay illustrates the way in which disability narratives continuously situate themselves within a larger cultural context. By telling and re-telling personal stories while at the same time offering support and advice, participants draw on the communal wisdom of the group for assurance that they are making the “right” decisions for themselves (while supporting one another) and their children. More importantly, they feel their choices are morally justified. There is a communal affirmation of self-worth and agency that locates these women within a larger moral order. As participants admit despair and resentments of feeling (unjustly) unloved and struggle with self-worth and the desire to be valued despite their disability, they come together by communicatively reframing the meaning of “good mother” and negotiating the oppressive normative notions of the disabled body’s worth or value.
References


