

GFCF: Food, Autism, and Challenges to Scientific Motherhood and Neoliberalism

Shortly after deciding to put her daughter on a gluten-free/casein-free/soy-free (gfcfsf) diet, Lorena asked the online Dietary Intervention (DI) community for help “*navigating this strange new world.*” In particular she was having trouble finding a source of protein that her daughter, Rachel, was willing to eat and was frustrated that even on the gfcfsf diet, Rachel was continuing to exhibit behaviors associated with autism.¹

Rachel will not eat meat or beans so I am supplementing with brown rice protein powder but now I am worried about arsenic! Also, are there any safe yogurts? We had a coconut milk yogurt but I have discovered that the yogurt has carrageenan [which has been linked to inflammation, diabetes, and cancer]. So now the only meal she will actually eat is gf pasta that is made from rice (arsenic!) or corn (GMOs and pesticides!).

Lorena received nearly 30 responses, including some of the comments below, with details on how to approach the protein issue:

“You could buy gelatin from Great Lakes. 1 tbsp has 6 grams of protein. You can mix this into any cold drink and you can’t tell it’s there. 365 Organic almond milk from WFs doesn’t have carrageenan. Of course you can make your own almond milk; it’s the best. But I have a full time job so that is out of the question.”

“The protein powder likely has glutamines in it or something similar (look for anything that starts with gluta- or aspart- on the label). That could account for the increased behaviors. You can also get protein from quinoa and/or amaranth. These are fantastic gf ‘grains’ (quinoa isn’t technically a grain) that are WHOLE protein food sources.”

“We love chia seeds and hemp seed for protein. Spaghetti squash makes a great sub for noodles”

“Are you sure you are 100% gfcfsf? If not, that could be why she is still stimming.² We all make mistakes at first because there is SO much to learn...like d-alpha-tocopherols is made from soy”

Scholars have argued that when mothers of children with special needs spend their time, energy, and money on alternative care for their children, such as those involved in feeding practices like the gfcf diet, the politics of motherhood becomes individualized and ineffective. Rather than fighting for policy change, funding redistribution, consumer boycotts, equal rights, or other structural social changes, mothers largely focus their resources on individual children (Douglas; Sousa; Yochim & Silva). From this lens, the practice of implementing the diet and the discursive world of the online communities that support the diet serve to reproduce the kind of individualized, intensive mothering valued in a neoliberal economy (Giles 9).

However, as this virtual ethnography demonstrates, analyzing the actual communities of care allows for a shift in perspective. The social practices of mothers in online gfcf communities, revolving around the everyday sharing of recipes, observations about food reactions, and tips related to food selection and preparation, challenge medical/scientific epistemology as well as the deregulation and corporatization of food production in the United States. Through these seemingly commonplace communicative acts and the practice of implementing the diet, mothers position themselves as authoritative experts whose knowledge is founded on shared experience. In the acts of knowing and sharing, mothers engage in a maternal politics that in many ways challenges normative medical and capitalist discourses as well as the neoliberal push to individualize motherhood. This essay employs qualitative textual analysis to explore the complex and contradictory politics of mothers' implementation of the gfcf diet and participation in online community discussions of the diet and examines how the mothers work serves to disrupt traditional power relations between food producers and consumers, doctors and patients, and evidence-based and experiential knowledge.

Etiology of Autism, The Role of Mothers, and the GFCF diet

As early as the 1970s Dr. Benjamin Feingold proposed an additive-free and salicylate-free diet as a behavioral intervention for hyperactive children, and in the mid-1990s some in the autism community began focusing on diet as a key treatment tool (Eyal 21). While it is unknown how many children are being fed a gfcf diet, currently between a third and one half of all children diagnosed with autism will participate in complimentary or alternative interventions the most popular of which are special diets

(Adams; Perrin *et al.*). Though not every mother who participates in the two online communities analyzed in this essay has a child diagnosed with autism, many do, and those whose children have other “disorders” rely on the experiential knowledge of the autism community. Thus, a brief history of autism etiology and interventions is instructive in situating the gfcf diet and the role of mothers in shaping knowledge.

In 1943, Leo Kanner identified autism as a congenital disorder. At the same time, he was influenced by contemporary psychological theories of the day and, in subsequent publications – both medical and popular – he began engaging in mother-blaming, suggesting psychodynamic factors were causing autism (Raz 78-9). In 1960, Kanner told *Time* magazine that parents of children with autism were “cold and rational” individuals who “happened to defrost long enough to produce a child” (qtd. in Raz, 79). Later, in a continuation of holding mothers responsible for their children’s disorder, Bruno Bettelheim popularized the term “refrigerator mothers” and compared the behaviors of those who had undergone neglect and trauma in the concentration camps at the hands of SS guards with the behaviors of children with autism who, he believed, had undergone a similar neglect and trauma living with their unaffectionate mothers (Sousa 222).

Theories of maternal deprivation lost ground in the 1970s as gender relations and maternal work patterns shifted (Raz 91) and with an active coalition of parents and researchers, spearheaded by Bernard Rimland, a genetic neurological etiology became commonly accepted (Douglas 171). Like Kanner, who had gotten most of his data from parental reports, Rimland used a checklist, in his 1964 *Infantile Autism*, which parents

could fill out and send back to him; through these checklists, and subsequent conversations with parents, Rimland formulated the biogenetic theory of autism that is commonly accepted today. In addition, from the onset of his work on applied behavior analysis (ABA) with behavioral psychologist Ivar Lovaas, parents were included as integral elements in the study of the disorder and interventions. In a 2006 history of his research on autism, Rimland wrote, “As the years went on, I continued to find, repeatedly, that parents, especially the mothers, were remarkably effective at identifying treatments...” (qtd. in Eyal, 22).

Rimland also increasingly began to rely on parents to identify environmental factors – vaccinations, milk, wheat, and polluted ecosystems – that exacerbated their children’s autistic behaviors (Douglas 171; Eyal). In 1995 he helped form Defeat Autism Now! (DAN!), a research and training project focused on biomedical treatments for autism including diet, supplements, and heavy metal detoxification. Rather than embracing neurodiversity (the *acceptance* of all neurological variations) or focusing on the *management* of autism through behavioral interventions, those who implement biomedical interventions seek *recovery* from autism.³ Those who follow the gfcf diet, a cornerstone of the biomedical approach, believe that children with autism often have abnormal digestive systems resulting in the inability to fully absorb certain sugars, carbohydrates, and proteins as well as increased intestinal permeability. This allows opioids formed in the breakdown of gluten (the protein found in wheat) and casein (the protein found in milk) to enter the brain, causing “brain fog” and other autistic behaviors (Adams 12-13; Karnik 5). Thus mothers’ experiential knowledge was

instrumental in changing the conceptualization of autism and in identifying both therapeutic and biomedical interventions.

Neoliberalism, Intensive Mothering, and Mothers of Children with Special Needs

Neoliberalism offers a productive frame of analysis that has frequently been used to make sense of motherhood (Giles) and the practices of mothers with children who have special needs (Douglas; Yochim & Silva). These authors suggest that in our neoliberal era, as governments have reduced social and community services, such as funding for health and education, and deregulated food and pharmacological production and marketing, mothers have been called upon to pick up the slack. Indeed, as MacKendrick argues, government has failed “to properly evaluate the safety of synthetic chemicals and implement stringent regulations and legislative frameworks to govern chemical innovation, manufacture, and release” leaving mothers responsible for eliminating their children’s health risks (2). Moreover, neoliberalism, fundamentally in support of a free market, and therefore in service of the production of qualified laborers for the market, requires the ideal neoliberal mother to “maximize [her children’s] bodily and mental health potential” (Yochim & Silva 409) and raise children who will ultimately become human capital even as they are growing up in chemically-compromised environments. Since neoliberalism functions as an ideology, it stands to reason that the value of childcare and wellness would be leveraged so that mothers would accept the government’s off-loading of labor and cooperate in the raising of healthy consumer-citizen-employees. From this perspective, mothers come to believe that the provision of educational, health, and therapeutic services for their children with special needs is

their personal moral obligation rather than a fundamental element of social welfare (Giles 10).

Yet, the ideology of neoliberalism does not operate in isolation; it is augmented and amplified by the perpetuation of gendered based divisions of labor and the ideology of intensive mothering (Hays, 1996). Intensive mothering is a child-centric mode of care that relegates a mother's interests, desires, and personal development to less importance than those of her children. In this scenario, the good mother spends her time, energy, and income on children's activities, consumer goods, education, and enrichment rather than on those that would contribute to her self-actualization.

The growing body of research on mothering children with special needs identifies neoliberal intensive mothering as a profoundly pressure-filled position where mothers are encouraged to embrace the role of "warrior-heroes" in which they must wage battle "against social and political forces to gain medical and educational interventions for their children despite the high personal and financial costs to themselves and their families" (Sousa 220). These warrior-heroes face enormous pressure because they feel responsible for mastering medical knowledge and simultaneously relying on instinctual knowledge of their children to dismiss evidence-based research (Yochim and Silva 409). Supported by celebrity mom and activist Jenny McCarthy, these discourses are said to place mothering "in opposition to science and medicine" so that mothers must "feverishly negotiate" between maternal instinct and controlled studies (Yochim and Silva 407-410). From a neoliberal perspective, this process further privatizes the experience of mothering because a mother's focus is on

wading through a myriad of choices and making decisions about her own child's interventions rather than focusing her resources on advocating for social equality or structural changes in policy, funding allocations, social welfare practices, and research streams.

Indeed, mothers of children with special needs are asked to engage in an intensive mothering in which success is only possible for those with money, time, and advanced education (MacKendrick 18; Sousa 238). Yet, the active and involved mother of children with special needs exists within a complex and contradictory web of power relations. An alternative political agency, activism, and meaning can develop even as mothers engage in the decidedly gendered and intensive practices of cooking, creating recipes and negotiating over food (Cook; West). As the mothers in the online communities in this study implement and discuss the gfcf diet they are critically interacting with, and challenging, dominant ideologies of motherhood and neoliberal capitalism.

Case Study of two online communities

These complex power relations are explored through a virtual ethnography of member postings between 2001 and 2013 in two online communities (Hine). The Dietary Intervention (DI) Community is explicitly devoted to parents of children on the autism spectrum who are interested in a gfcf diet and the Sensory List is a community for parents whose children suffer from difficulties with sensory processing.⁴ The DI community has over 15,000 members and since 2000 has averaged 3,000 messages per month while the Sensory List, though much smaller, has over 4,000 members with an

average of 700 messages per month. As with most online communities, gathering demographic information on the women who participate in these communities is difficult. However, based on discussions of the financial burdens involved in implementing a gfcf diet, including discussion of how one might use WIC to pay for the foods that are “legal” on the diet, it can be determined that a range of mothers along the socioeconomic spectrum, with the largest concentration being in the middle classes, participate in these communities. This research is explicitly feminist in its value of women’s everyday experience and knowledge (Code).

Challenging Scientific Motherhood and Deregulation of Food Oversight

Whereas mothering was once a skill passed down through generations of women, scientific mothering is an ideology that, like intensive motherhood, structures family and social relationships. Scientific motherhood emerged as a result of mid-19th century medical advancement, urbanization, professionalization, and changes to extended family structures that demanded women learn mothering from male scientific and medical experts who, in turn, profited from imparting parenting advice (Apple 16). Today scientific motherhood is materialized in the parenting advice book market as well as pre- and post natal classes on how to care for newborns. For mothers with children who have special needs, this often translates into medical professionals who dismiss, patronize, or resist their efforts to participate in treatment plans (Schaffer *et al.*). In the case of autism, mothers who have questioned genetic etiology of autism and sought to direct the medical community to explore environmental causes have been ridiculed in media and the scientific community (Bumiller 884-885). By employing the gfcf diet as a

treatment for “recovering” their children from autism and other neurological disorders, the mothers in this study directly challenge scientific motherhood and the mainstream medical community who do not believe that autism is curable. Routinely, mothers in these communities turn to each other rather than medical professionals, and experience-based evidence rather than empirical, controlled studies, in order to make treatment decisions for their children. Because the gfcf diet is not a recognized treatment option within the medical community, and because research funding has not supported the study of biomedical interventions, mothers must rely on each other and their own evidence as proof that the diet is an effective treatment.

The mothers’ practice of sharing stories and recipes, and of raising gfcf children, insists on the validity of what I have previously called “feminine epistemology,” a (learned, non-essentialist) form of knowledge, culturally associated with women, which privileges experience, anecdotal evidence, and collaborative knowledge production (Zaslow 5-6). Feminine epistemology need not always be in opposition to science; in the case of the gfcf diet it aims to fill in where the institutional, political and economic structure of the medical establishment has stymied research. Though they are focused on treatment plans for their own children, their discourse is neither individualizing nor accepting of the power relations that govern medical, food industry and pharmacological superiority. Thus while their communication can be empathic or practical (recipes, lists of foods that are “legal” within the diets regulations, and strategies for getting children to eat), it also often decidedly challenges scientific and neoliberal motherhood.

When a new community member wrote to the DI community asking how she might convince her husband that going gfcf would be good for their son, Annette shared links to several of the few inconclusive studies of the diet. Most responders, however, agreed with Saskia who declared “*nothing [is] more powerful than testimonials*” and Lisa shared a story about the power of connected knowing:

I found it nearly impossible because there were few resources. I didn't understand cross-contamination. I didn't know that I couldn't give him small bites here and there. I also didn't realize that for our son we also had to rid the body of corn and soy. Once I found this group ten years later, we tried it again – the right way. Our son was non-verbal, aggressive, had seizures and sleeping issues. Today he speaks, he is not aggressive or self-abusive. He no longer has seizures. He sleeps through the night! Any question that it helped our son? This week his neurologist asked me if I thought that perhaps he has been misdiagnosed! I laughed. He was correctly diagnosed. He has just been improved due to years of work.

The privileging of food rather than pharmaceuticals as a primary treatment, when pharmaceuticals are an option, is also a challenge to normative medical approaches and to corporate/capitalist power. In one instance, Gloria reminds another mother that she must follow-through with the diet because,

You will never get back the lost time in your child's life. I did not hear the word “mommy” out of my daughter's mouth until she was 4 and it wasn't

because she was on Ritalin or Prozac or Haldol, it was because the source of toxins were removed from her body. It was because her gut was healing and it was because we started intense therapy. We are not powerless even when the medical professionals fail us.

It is not only the medical profession that they see as failing them but also the consumer food market. Both Lisa's choice to cut corn and soy, which are hidden additives in many processed foods, and Lorena's attempt to remove arsenic, pesticides and genetically modified foods from her daughter's diet demonstrate mothers rejection of conventional, corporatized feeding practices. Though not always overtly activist, the mothers in these communities do address the lack of government oversight on food production. In one example, Silvia writes,

For instance, there is actually blue dye in the nitrate portion of lunchmeat and bacon; the FDA does not require that disclosure on packaging. Another one: while there may not be any preservatives in string cheese, it is common practice to line the inside plastic with preservatives.

At other times, particularly in the DI community, discussions can be more directly critical of specific corporations that produce foods with genetically modified organisms, hidden preservatives, or unnecessary additives.

Many mothers on these sites discuss how difficult it is to start the diet though they commonly note that *"once you get the hang of it, it's not so bad."* Still, even as they are *"hanging in there,"* their discourse does not suggest that they are overwhelmed by pressure or struggling to navigate through a labyrinth of competing fields of

knowledge, none of which they can master. As seen in the introduction, there is a great deal of expertise on food preparation and how to take back the family (or child's) diet from corporate food producers. Instead of pain, mothers often express joy that they have been able to use the gfcf diet to sustain social connection and family life and to empower themselves and their children (DeVault 230).

Moreover, as members of this community of connected knowing, they are not experiencing this intensive mothering as individualized. Amanda captures the sentiment when she writes,

Being able to read and interact with people who speak the same language as I do, who understand what is happening in my household, who so generously give advice and share experiences, is nothing short of amazing.

In their private and shared implementation of the gfcf diet as a form of recovery for their children, the mothers in these communities affirm their ability to participate in the production of knowledge and to challenge the privatization of motherhood and the corporatization of food production.

Conclusion

Much of the research on mothers and health-related care has focused on the negative (Corman 439). Following this tradition, Douglas argues that mothers of children with autism are "self-governing and instrumental;" implying that mothers are complicit in sustaining neoliberal ideology and economy as they intensively mother, filling in where a free market economy has failed to provide adequate social welfare and

government regulation (17). While the mothers in this community *are* participating in intensive mothering, which is certainly easier and less oppressive for women who have the economic, educational, and cultural resources to actualize their intensity, this study of two online communities of mothers who implement and discuss the gfcf diet leads to a more nuanced analysis.

As we saw with Lisa and Gloria whose children now speak, sleep, and relate, an intensive focus on feeding sometimes alleviates daily challenges and makes living easier and more pleasurable for both child and parent. Additionally, as this essay has demonstrated, the very act of participation in the community can be seen as an activist challenge to market-driven medical and food industries rather than an acceptance of normative medical views on autism as a genetic rather than environmental disorder, as well as a challenge to food production that privileges cost over health risk. Just as one mother tells another that she must learn to “*separate food from love*” if she is to be successful on the gfcf diet, scholars must learn to separate mothering from patriarchal and consumerist ideologies if they are to critically analyze the complex and contradictory positions of mothers as they feed their children with special needs.

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¹ Gluten-free/Casein-free (gfcf) is standard for the diet. Many others add soy-free and corn-free making it the gfcfsfcf diet.

² Stimming is a colloquialism for self-stimulating behaviors such as hand flapping, rocking, and spinning in circles.

³ Defeat Autism Now! became the Autism Research Institute in 2011.

⁴ Both are email listservs; one is open to the public and the other requires acceptance by the moderator. To protect the participant's identities and the identity of their children, pseudonyms have been given to the name of the groups, the mothers, and the children. In addition, where a direct quote is used, minor changes may be made but the original intent has been maintained. For additional details, see Zaslow, 2012.