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The Role Of Digital Spaces in Caring For Children With Feeding Tubes: Home, Family, and Community Reconsidered

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The Role of Digital Spaces in Caring for Children with Feeding Tubes: Home,
Family, and Community Reconsidered

Sara Gilbert Loftus

Dissertation submitted
to the Eberly College of Arts and Sciences
at West Virginia University
in partial fulfillment for the degree of
Doctor of Philosophy
In
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**Keywords: family caregiving, children with feeding tubes, relational
approaches, feminist STS**
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Abstract

The Role of Digital Spaces in Caring for Children with Feeding Tubes: Home, Family, and Community Reconsidered

Sara Gilbert Loftus

This dissertation draws from feminist geographic research to critically examine the landscapes of care traversed by family caregivers of children with feeding tubes and complex medical and long-term care needs. Drawing from theories and methodologies from feminist disability and digital geographies, in combination with feminist science technology studies (STS), I explore the impact of neoliberal policy changes on daily caregiving tasks and how families, in response to these policy changes, (re)create digital spaces and relationships to satisfy their unmet needs. This research examines the growing and shifting roles of digital spaces in the everyday lives of marginalized and/or vulnerable communities to determine how digital spaces are (re)created by family caregivers and reflect how community relationships and digital activities impact family caregivers' ability to give care within precarious situations. A comprehensive examination of the Feeding Tube Awareness Foundation's (FTAF) online resources accessed by family caregivers serves as a case study for this project. I argue that digital spaces, like FTAF, are essential places in family caregivers' everyday geographies and are constituted by co-constructed relationships shaped and maintained by the digitally mediated activities of community actors (human and non-human) across multiple spaces and times. By incorporating Science and Technology Studies' theoretical and methodological insights, rare in the digital geography literature, this project attends to the diversity, structure, and internal dynamics within and among digital relationships in maintaining and transforming these digital communities, particularly deep web places like FAFT's Facebook group and the fluidity of user subjectivity across multiple digital places.

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List of Abbreviations

AI - Artificial Intelligence
ANT - Actor-Network Theory
ADA - Americans with Disabilities Act
BMA - Bureau of Medical Affairs
BOT - Artificial Intelligence Algorithm
CMS - Centers for Medicare and Medicaid Services
DME - Durable Medical Equipment
FB - Facebook
FTAF - Feeding Tube Awareness Foundation
G-Tube - A gastrostomy feeding tube inserted into the stomach also known as a PEG tube or a Mic-key or a Button.
HCBS - Home and Community-Based Services Program
HCBW - Home and Community-Based Waiver Programs
HEN - Home Enteral Feeding
HPN - Home Parenteral Nutrition
IDEA - Individuals with Disability Education Act
IRB - Institutional Review Board
J-Tube - A Jejunum feeding tube inserted into the small intestine (Jejunum)
MIC-KEY - A brand of feeding tube
NG Tube - Nasogastric Feeding Tube (inserted through the nose into the stomach)
PEN - Parenteral Nutrition Feeding through a vein
PEG - Percutaneous endoscopic gastrostomy tube
SA - Situational Analysis
STS - Science and Technology Studies
WVDHHR - West Virginia Department of Health and Human Resources

Chapter 1. Introduction

1.1 Problem Statement

More than 43.5 million caregivers in the United States provided direct unpaid care to an adult or child in 2015 because of changes in federal policy in the United States over the last decade (Family Caregiver Alliance, 2015; AARP, 2015). Many of these caregivers are family members of children with complex medical needs who are enteral (HEN) or intravenous (HPN) nutrition dependent (i.e., feeding tubes), medically fragile¹ and require long-term care (Baumgardner, 2019; McDonald et al., 2017). Because of their unique needs, these family caregivers and children with feeding tubes can be isolated within medical and disability communities, require complex and expensive medical interventions, and struggle to find care networks to support their daily needs (Green et al., 2019). In the United States, social service agencies, funded by Federal and State Governments, are intended to provide a critical safety net to help family caregivers navigate the often-fraught care landscapes they encounter. The implementation of neoliberal changes in government policies, reductions in funding, service provision, and reimbursement rates for social services and hospital stays have shifted the responsibility of care to family members in gendered ways (Holloway & Pimlott-Wilson, 2016; Power & Hall, 2018). This shift, I argue throughout this dissertation, transforms the family home into a medical home (Kelly et al., 2002) where family caregivers, primarily mothers (Macedo et

¹Many medically fragile children have orphan diseases which are defined as having less than 200,000 cases nationwide and presenting unique clinical characteristics and significant and complex medical and developmental needs.

al., 2015), are expected to meet the medical, developmental, and parental needs of the child under the intrusive eye of the state, in social and geographic isolation and increasing precarity (Kuo et al., 2011; Lindahl & Lindblad, 2013; Toly et al., 2019). In my research, I will show how family caregivers create and maintain digital spaces, like Facebook support groups (Cappellini & Ai-wan Yen, 2016; Johnson et al., 2022; Obst & Stafurik, 2010) to provide support, information, validation, witnessing, and affirmation of their caregiving efforts and to counter structural barriers they meet in the various social service delivery systems they depend upon (Baumgardner, 2019; Dabrowska, A & E. Pisula, 2010; Finlay & Kobayashi, 2018; Henning-Smith et al., 2019; Lavoie et al., 2021; Menec et al., 2019; Thyen et al., 1998).

Family caregiving, specifically for children with feeding tubes, is at the heart of my geographic inquiry, understanding how, where, and when it occurs and the ways that family caregivers actively work to (re)solve conflicts and barriers they encounter daily. The most direct impact that my research has on these family caregivers is validating their experiences. To be clear, this community does not need an outsider's validation for the kind of care work that they are engaged with on a day-to-day basis. I am not an outsider but am part of this community through my own caregiving of my child, who is dependent on feeding tubes and has complex medical and developmental needs. But at the same time, my engagement with this community as a researcher offers additional validation that our experiences have something to teach people beyond our community. In these digital spaces, we find knowledge, support, and caring that is lacking in other places. Together we work through pain, joy, and the perpetual challenges and contradictions of a system that overlooks and, at times, explicitly flattens the complexities of our experiences. But alongside being a caregiver of a child with complex medical care needs, I am also an investigator drawing from diverse disciplines, and through my work, I articulate what

caring looks like in spaces and relationships that previously have been overlooked. Lessons drawn from these families' experiences, along with the structural contexts in which they occur, advance and, at times, constructively critique geographic, feminist, and STS theories. Insights drawn from this research open opportunities to inform and hopefully transform policy. By listening and validating family caregivers' stories and experiences, my research connects theory and practice that could result in improvements in policy that directly affect this/my community. Even more so, family caregivers' experiences have commonalities with other marginalized communities. Explicitly elevating these commonalities has the potential to build solidarity and shared benefits from policy changes.

Extending the social care literature from disability and health geographers (Hall & Wilton, 2017; Lin et al., 2022; Macpherson et al., 2021; Milligan & Wiles, 2010; Power, 2010; Power & Hall, 2018; Powers & Gaete-Reyes, n.d.), who have provided detailed landscapes of care for family caregivers in the global north and elsewhere (for examples, see Andrew Power, Edward Hall, and Powers & Gaete-Reyes), my dissertation uses a feminist geographic perspective to engage with digital spaces that family caregivers create, maintain and occupy. My goal is to better understand why and how these digital spaces contribute to existing care landscapes by offering vital alternative places where family caregivers can build relationships that help satisfy their unmet needs (Loftus, 2022). This research provides empirical examples of how family caregivers move from passive recipients of social services to central agents of change through their actions, decisions and relationship-building with other family caregivers. Digital spaces and the relations forged therein are a critical part of this story.

The experiences shared by more than one hundred and sixteen family caregivers (who self-identified as mothers) allowed me to articulate the concept of an unpaid mother-expert as the

lynchpin for the implementation of neoliberal long-term care policies in the United States. Even though my research provides examples within specific contexts and experiences and is not intended to represent all family caregivers, it does illuminate the impact of long-term care policies and the assumptions that undergird them. Accordingly, the results of my research point to some of the unremarked casualties of these policies and assumptions, such as that of the mother-expert role that I describe in detail in Chapter 2. As I elaborate in my conclusion, future work needs to be done in this area. This research has only touched on aspects of ongoing complex trauma and post-traumatic stress to the family caregiver resulting from fulfilling these myriad roles while also dealing with the medical crisis of their child and under situations of persistent precarity caused by neoliberal policies. This trauma is not limited to the caregiver but also affects the child, the family, and the entire interdependent care team.

I also recognize and articulate the extension of the medical home model into the family home. Especially the resultant unintended and potentially harmful ways that the intrusion of the medical-industrial complex and social service complex (as extensions of the state) create an environment where there is no ‘private’ space for families. Because of this, digital spaces, for some caregivers who can access them, become a refuge. More importantly, there is unrecognized structural violence from this intrusion as families navigate through daily life in situations where they are powerless because saying ‘no’ means losing the services that they desperately need. Finally, I have opened another conversation *writ large* about our social and cultural values in the United States, deeply rooted in western liberal values of autonomy and individualism and ask where families like mine belong.

As a scholar-activist, my ambition is to make positive changes for my community while also contributing to the scholarship of my discipline. As a feminist geographer working in both

digital and disability geography, my work builds a bridge between these subdisciplines by showing how family caregivers of children with feeding tubes utilize digital spaces to meet their unmet needs. Moreover, my dissertation contributes to broader discussions within digital geography about digital media in social life and the varied content and structures of digital spaces by providing specific examples of how family caregivers (re)create spaces and how human and nonhuman actors influence those spaces over time (Alirezabeigi et al., 2020; Alper, 2014; Ash et al., 2018; Elwood & Leszczynski, 2018). To accomplish this, I bring methods from feminist science and sechnology studies (see A. Clarke et al., 2018) that enrich the methodology toolbox that feminist disability and digital geographers can use to explore the complex assemblages of human and nonhuman actors (i.e., actants, a term I will describe below²) populating digital spaces.

This dissertation presents a comprehensive examination of the growing and shifting roles of digital spaces in the everyday lives of marginalized and/or vulnerable communities with a particular focus on how federal and state policy changes impact daily caregiving tasks, how digital spaces are (re)created by family caregivers in response to these policy changes, and the myriad ways that diverse and often unaccounted for human and nonhuman actants (including seemingly mundane technologies) are involved in developing and sustaining community relationships in these digital spaces. Further, this research reexamines assumptions in feminist methodologies. It contributes empirical examples of the ‘doing’ of relational approaches that focus on the entangled relations of human and nonhuman actors to show the spatial and temporal dynamics of digital spaces as part of broader geographies of care.

² Actants is a term used in relational approaches to mean something that acts or is given permission to act by another (Latour, 2005).

In a broad sense, this research advances geographic theory on how supportive communities are created in digital spaces by examining participation, relationships, and temporality in less visible spaces like deep web groups. A comprehensive examination of the Feeding Tube Awareness Foundation's (FTAF) Facebook (FB) support group, created and sustained by family caregivers and other actants, serves as a case study for this research and provides, among other things, examples of how family caregivers go over, around and sometimes through barriers they encounter during daily caregiving in the United States.

Further, my analysis of the shift to home-based care and the assemblages that allow for this reconfiguration illustrates the contradictions of the "home is best" ideology, which argues that home is the natural and most appropriate setting for caregiving. Using ethnographic descriptions developed from family caregivers' comments in FTAF FB and interviews, I extend Andrew Power's key concepts of landscapes of care and demonstrate how neoliberal policies perpetuate unintended and unremarked structural violence to the family (Cassiman, 2011). I also explore the ways that "the structures and values of government itself" impact care (Power, 2010, p. 213) by expanding the existing concept of the medical home (Kelly et al., 2002) as an intrusion of the neoliberal medical-industrial complex into the family home and illustrate the reliance on unpaid mother experts as pseudo-professional team members (Mitchell, 2015). More so, while conducting feminist digital ethnography, I reexamine established feminist methods like proxy voice (see Karlawish, 2003; Kim et al., 2004) and problematize the assumptions of autonomy and individualism that undergird notions of ethical-decision making (Bell, 2014) for populations deemed incapacitated. I also demonstrate how family caregivers navigate uneven power relations across their care landscapes (see Macpherson et al., 2021). Drawing from Children's Geography, I build on previous discussions about uneven power relations and

elevating the voices of marginalized children (see Holloway, 2014; Holt, 2004; Stafford, 2017; Elwood & Leszczynski, 2018) and provide examples of the tensions between the emancipatory goals of feminist scholarship (Nagar, 2014) and the operationalization of those goals within marginalized populations. These contributions are likely valuable to researchers working with marginalized communities or those addressing societal problems beyond family caregivers in the United States. In other words, my research advances important theoretical and methodological debates in geographic and kindred social science scholarship well beyond the digital and/or the landscapes of care of families caring for children with feeding tubes.

1.2 Research Aims

Victoria Lawson (Lawson, 2007) uses the term “landscapes of care” to visualize care networks that are uneven, interdependent, and relational. Within this landscape, an extensive exploration of the everyday lives of family caregivers of children with feeding tubes has yet to be done (Giesbrecht et al., 2016; A. G. Hall et al., 2014; Loftus, 2022). The shift from institutional to home-based care has resulted in an uneven landscape where the family home is transformed into a “medical home,” and family caregivers, typically mothers, are expected to meet the medical, developmental, and parental needs of the child (Kelly et al., 2002; Macedo et al., 2015). As a result, family caregivers rely on formal and informal networks to help with daily caregiving tasks. There is a lack of empirical research by geographers about the lived experiences within medical homes, the impacts on family caregivers, and ultimately the people needing care (Gleeson, 1996; Chouinard et al., 2016; Garland-Thompson, 2004).

Accordingly, my research provides an empirical example of how family caregiving, as an identity and a doing (Ruddick, 1995), has been constructed and enacted within specific historical, material, and spatial contexts in the United States. It also explores the ethical challenges of using

ethnography to understand decision-making in family caregiving networks. It examines the structures in the FTAF FB group to understand better how assemblages of actants (human and nonhuman) in the community contribute to or hinder relationship formation.

Building on insights from critical ethnography and Science and Technology Studies (STS), which in turn have been informed by feminist epistemologies, I address three specific aims:

1. First, this research examines how long-term care is currently organized, provided, and funded in the United States and explores how these laws and policies impact family caregivers' ability to perform their daily care activities and might contribute to their (re)creation of digital spaces.
2. Second, this research examines the difficulties of implementing feminist ethics and practice when researching family caregiving networks, especially those involving children with complex medical and developmental needs and the imperfect and pragmatic realities of decision-making within complex caregiving networks.
3. Third, my research examines the role of both hosts and users (human and nonhuman) in building, maintaining, and transforming the FTAF FB community as an example of caregiving networks forged and maintained in digital spaces.

While the use of feminist frameworks in digital geography, institutional ethnography, and disability geography is widespread, my work draws from feminist STS approaches, like Situational Analysis, because it is best suited to study the inner workings of the FTAF FB community. This approach also illustrates hidden and unspoken work by members and identifies and upends some ablest assumptions undergirding feminist methods. Specifically, I present—in

line with a Science of Technology Studies (STS) tradition—a useful “how-to” methodological approach for identifying, analyzing, and understanding how humans and nonhuman actants create or harm relations in communities forged within the complex interface between online and offline worlds.

1.3 Research Approach

Drawing from feminist methodologies, this research uses digital ethnography, institutional ethnography, and Situational Analysis to explore the three research AIMs (Clarke et al., 2018; Elwood, 2009; Johnston et al., 2007). During my digital ethnography, I used the same methodological approaches found in traditional ethnography (e.g., participant observation, interviews, and ethnographic descriptions) to collect data from the FTAF FB support group between the summer of 2019 and 2021³. Research questions were posted every month in the FB group by the moderator, and responses were concurrently analyzed to create a “thick description” (Gertz, 1973) picture of how FAFT digital communities are (re)created by the human and non-human actors (actants) within them. Again, in line with an STS sensibility, these actants include seemingly mundane technologies—virtual or otherwise—that play a role in the making, unmaking, and/or transforming home, family, and community.

The following section introduces the Feeding Tube Awareness Foundation and provides some insight into who the community members are. I then introduce preliminary data that helped shape my thinking about digital spaces and inform my research questions.

³ This time period coincided with the peak of the Covid pandemic, a time in which many families were dealing with dependents at home and trying to figure out work responsibilities without being able to go into the office, which presented a window into the everyday realities of these family caregivers.

1.4 The Feeding Tube Awareness Foundation

The Feeding Tube Awareness Foundation (FTAF) is a U.S.-based family support organization established in 2010 with the stated mission to “support parents of children who are tube-fed while raising positive awareness of tube feeding as a lifesaving medical intervention” (Feeding Tube Awareness Foundation, 2020). The FTAF is a 501(c)3 not-for-profit founded by Tracy Nagi after the birth of her child, who required a feeding tube. The Feeding Tube Awareness Foundation (FTAF) self-identifies as the largest caregiver support group for pediatric feeding tube users. As of this writing in Spring 2023, it has more than 59,000 followers on its Facebook group. During keyword analysis, FTAF consistently ranks first in search engine optimization (SEO) placement and maintains a number one position in parent support linkages from surface web disability sites. The organization is in three deep web spaces: Facebook, Twitter, and Instagram. A snapshot taken on July 28th, 2021, of the membership statistics provided by Facebook about the FTAF FB group indicates that at that time, the group (consisting of 62,100 followers) was 91.1% women, with the majority ranging between 25 - 45 years, predominantly from the United States (75.4%), United Kingdom (9.9%), Australia (3.4%), Canada (3.3%), Ireland (.8%), New Zealand (.7%), South Africa (.6%), Mexico (.4%), Philippines (.4%), India (.3%), with other countries aggregated together. Between July 28, 2020 - July 28, 2021, Facebook reports that the main group page reached 1,592,022 users, with significant peaks in March 2020 and January 2021.

My relationships with the FTAF FB group began around 2011 when I became a member in response to challenges I was having being a family caregiver of my feeding tube-dependent child. At the time, I struggled with caregiving responsibilities for all three of my children. Like many others in the group, I joined the FTAF community looking for pragmatic solutions to my everyday problems of

raising my middle child, a medically complex feeding tube-dependent eleven-year-old. Even though by this time, I was a veteran *tubie*⁴ mom⁵, I still struggled to find a community that understood my experiences. Like many other family caregivers, the internet was not only a key strategic companion in my feeding tube journey, it was also a space where I felt visible and understood.

1.5 Preliminary Data

My dissertation builds on work that I began in the fall of 2017 when I examined how disability was represented in digital spaces, particularly in two contexts, the surface web and the deep web. Again, while geographers have and continue to examine the role of the digital in many contexts (Elwood, 2021; Elwood & Leszczynski, 2018; Longhurst, 2016), detailed attention to the structures and dynamics of these two kinds of spaces is rare. Presenting my preliminary work at geography conferences confirmed a great interest in this kind of work. Using several search engines (Google, DuckDuckGo) from different locations over three months (United States: West Virginia, Washington DC, and New York state and Canada: Ottawa and Montreal), I performed keyword searching for four keywords (disability, mothering, feeding tube children, mothering children with feeding tubes) every two weeks and returned four hundred and thirty-six (436) segments from these sites. The segments were open-coded by “site type” and analyzed using word frequency to develop ten (10) thematic codes (e.g., government, family support, news articles, definitions, other information, academic journal, blogs). The top five returned sites during the summer of 2017 were government websites (22%), news articles (16%), definitions

⁴ ‘Tubie’ is a self-identifying term used within the community by both parents of children with feeding tubes and children with feeding tubes themselves. The term, depending on the context, refers to the person, the tube or the experience.

⁵ My child was diagnosed as ‘Failure-to-Thrive’ and medically formula dependent from birth due to an inborn error of metabolism and a rare mitochondrial disease and comorbid Chromosomal deletion syndrome. My Ichabod had a Mickey Button placed at five months and continues to be feeding tube dependent as a young adult.

(12%), support organizations or services (10%), and academic journals (7%). Blogs, which represent personal narratives of experiences, were only 6% of the returned results. The majority of sites returned from the surface web (84%) were about financial resources, social support programs, industry advertisements (DME, Hospitals, Clinics), descriptions or definitions about feeding tubes, disabilities, other medical aspects of care, or news and academic articles describing aspects of the keywords. Only sixteen (16%) of returned responses were from the perspective of the family caregiver or individual with a feeding tube and shared their stories and experiences.

From this preliminary research, I identified that eighty-four percent (84%) of returned sites reflect industry-specific language about feeding tube diagnosis, medical or therapeutic interventions, durable medical supply (DME) advertisements, or other medical information using normative language reflecting ablest disability frameworks derived from the medical model⁶. Family support sites represent only sixteen percent (16%) of the SEO-returned locations from keyword analysis. The predominance of industry-sponsored sites instead of family support sites demonstrated a lack of digital spaces on the surface web that reflect family experiences. More so, it shows the unique positioning of the FTAF FB group, whose membership includes people from industry, medical, social services, government, family caregivers, and people with feeding tubes, as an “in-between” space where family caregivers find important information they need and a community of people with similar experiences. The multiplicity of members (who are also actants) prompted my interest in understanding how the diverse members in the FTAF FB group coexisted, given often conflicting perspectives and interests. I also wondered about issues of voice and representation and the difficulty in finding digital spaces created by family caregivers.

⁶ The medical model reflects a bias towards a “fix” or “cure” for disability in contrast to other social models of disability which reflect a view of disability as being socially constructed.

Finally, the preliminary research validated my experiences trying to find help on the internet, that the surface web could only partially meet my needs. While I found plenty of sites from government agencies, supply companies, doctor's offices, and hospitals, I realized that the family voices were missing and wondered if they were somewhere else, somewhere more hidden and secret. After joining FTAF, I realized there were deep web groups on Facebook and other places that could only be accessed through relationships with existing members. I wanted to know more about what caregivers received from these groups that they couldn't get anywhere else. Even more so, I wanted to know how and why these groups are formed and maintained, how family caregivers use them within the everyday materiality of their caregiving responsibilities, and where these groups fit into the broader landscapes of care that families traverse. These secret spaces hinted at more complex geographies of care that resonated with my experiences and how I used digital spaces to get through my day.

Again, while geographers have and continue to examine the role of the digital in many contexts (Barns, 2019; Elwood, 2021; Ergler et al., 2016; Richardson, 2018), less common is a detailed exploration of the structures and dynamics of digital caregiving support spaces, like the FTAF FB group.

1.6 Research Design

Even though this research is situated at the intersection of feminist digital and disability geographies, with a key focus on geographies of care, my integration of feminist STS methodologies to examine the mechanics of how communities of care⁷ are formed and sustained by family caregivers in these digital spaces is novel. I argue that using these approaches provides ways of examining how assemblages of human and nonhuman actants form or impact relations in the community and the materiality of care by family caregivers. To accomplish this, I use

⁷ I recognize my use of the term communities of care, and the term communities in general, implies a homogenous, cozy term that leaves untroubled bias, uneven power relations and gendered roles that is unchallenged and unremarked so far.

three approaches: 1) Critical Digital Ethnography, 2) Institutional Ethnography, and 3) Situational Analysis (SA).

1.6.1 Critical digital ethnography

Lassiter (2005) writes that while all ethnographic work is, at some point, collaborative, critical ethnographies explicitly engage research respondents as participants in the formulation and production of knowledge (Lassiter, 2005). In this way, my work exemplifies what Madison (2005) calls critical theory in action. Critical ethnography focuses on change mechanisms that challenge the dominant structures at multiple scales and identities from a critical framework, particularly feminist and postmodern methodologies (Bhattacharya, 2010; Madison, 2005; Smith, 2006). While critical ethnographic approaches are widely used in human geography (Banerjea, 2014; Bhattacharya, 2010; Faria et al., 2020; Madison, 2005), this is less the case in studies examining the role of the digital in everyday lives, not just of family caregivers but of a wide variety of communities (for examples in food studies see Leer & Krogager, 2021; and for ethical considerations see Lester, 2020).

As part of my ethnography, I collected responses to a series of questions from the FTAF FB group, which are listed in Appendix 1. While group interviews are an established method of data collection in qualitative research, one of the key methodological contributions of this research is my use of novel approaches for group interviewing in response to the practicalities and constraints found in the digital environment (Barratt & Maddox, 2016; Caliandro, 2014; Kennedy, 2008). For example, unlike in-person group interviews, a digital group interview can be synchronous and asynchronous. Following Athanasiadis et al. (who posted questions in a bariatric Facebook support group), my research questions were posted by the FTAF moderator FB group discussion thread (Athanasiadis et al., 2020) and were visible and open for a response

from any group member. My six group interview questions were posted in the FB group, three questions per month for two months (See Appendix 1). The posts remained in the group discussion feed and are open for (re)engagement by existing and new group members. Also, the FTAF moderator posted my request for interviews for follow-up questions each time the group research questions were posted (Appendix 1).

My approach can be viewed as a hybrid group interview, which is both individual and collective (Chase & Alvarez, 2000). Software like Zoom allowed me to connect with respondents from all over the world, and I recorded the audio for later transcription and review as I coded and analyzed. In addition, my research posts in the group allowed for asynchronous interviews via the post-conversation thread. This conversation reflected a range of actants (human and nonhuman) who dynamically interacted with current group members but also left a public record that could influence future respondents. This approach created a novel experiment of participatory research that engages, creates, and recreates data collection in ways that are unique to digital spaces. Additionally, this approach allowed for real-time member checking of research question responses in the discussion threads (Koelsch, 2013). Member checking is an iterative process where research findings are presented to the research participant for validation and accuracy (Cho & Trent, 2006). In this way, research participants can agree with or change their previous responses by deleting, amending, or adding to their previous posts.

In addition to hybrid group interviews, I was also a participant observer in the FTAF FB conversations, as I, too, responded and posted to my own and other community members' comments. The conversations that originated from my moderated research question prompt are woven into the ethnographic descriptions I developed from the narratives of daily life posted in the group (Curtis et al., 2000). Even though these conversations are posted in the public domain,

I have maintained the confidentiality and anonymity of all posts and responses in keeping with my Institutional Research Board (IRB) approval WVU #2102246119 and the informed consent practices posted with each research question. For community members who responded to my call for follow-up zoom interviews, I asked open-ended questions (Appendix 1) and then audio recorded (with respondent permission) and transcribed their responses verbatim (Oliver et al., 2005). I expected follow-up interviews to last about 15 minutes each, but in the end had more than fifty hours of recorded audio, with most interviews averaging between one and a half to two hours. From the stories that emerged from my various ethnographic approaches, I developed a robust picture of the daily lived experiences of the family caregivers and their children with feeding tubes (Cho & Trent, 2006; Curtis et al., 2000). In Chapters 2, 3, and 4, I provide narratives and ethnographic descriptions from the perspective of two characters: Jane and Ichabod. These characters are a combination of many different narratives collected from the FTAF FB group and the follow-up interviews⁸. In subsequent discussions of my analysis, I refer to Jane or the Janes interchangeably, both are meant to reflect the multiple voices of the one hundred and sixteen respondents in my data set.

1.6.2 Institutional ethnography

Understanding the inner workings of the FTAF FB group is an important part of explaining how and why family caregivers come to this digital space to meet their needs. Examining the FTAF FB group as an entity itself and as a part of larger organizations (which traverse multiscale and multitemporal contexts) is needed. Approaches drawn from institutional ethnography provide a way to look at and understand how local actions (e.g., by individuals)

⁸ Developing these composite characters is an important part of maintaining anonymity for my research respondents.

are impacted by the social organization (and the bias, perspectives, and agendas that constitute them)(Balcom et al., 2021; Ferdinands et al., 2021; Lund & Nilsen, 2019; Meuleman & Boushel, 2014). The use of Institutional Ethnographic approaches has been widely adopted by geographers, including feminists (see Billo & Mountz, 2016; Lohnes & Wilson, 2018). My research contributes to this literature by exploring how institutional policies (e.g., federal, state, agency) inform practices (e.g., eligibility, criteria, services) that affect family caregivers' ways and doings across their care landscapes. More so, using this approach foregrounds “problems in the system” (for examples, see Chapter 4) that directly affect the materiality of caregivers' experiences and ability to care for their children with feeding tubes (Billo & Mountz, 2016, p. 200).

Organizations, regardless of size, are not neutral, objective bodies but are reflections of the people that comprise them, creating a subculture that develops an institutional consciousness (Billo & Mountz, 2015; Ley D, 1983). From this perspective, power is understood within social and spatial relationships and manifests through actants (actors) inside and outside the organization (Smith, 2006). Furthermore, organizations can influence and be influenced by the daily lives of people intersecting with those institutions and the communities where they are active. Studying institutions offers the potential to understand how institutions impact structures, relationships, and identities within communities, including digital organizations like the FTAF (Billo & Mountz, 2015; Ley D, 1983). Feminist methodology underpins Institutional Ethnography, including the commitment to include the participant community in the research instead of only being about them (Smith, 2006). Like other feminist practices, interviews and text analysis are key components of analysis used in “bringing the institution into view”(Balcom et al., 2021). To help understand the way that FTAF, as an organization, impacts

this community, I conducted interviews with the founder and key organization volunteers (see Appendix for research questions). I also collected and analyzed conversations in the FTAF FB feed to better understand the organization's role and impact on the community. However, human actors are not the only institutional influence. Facebook, as an institution and an actant, impacts the experience, flow, and visibility of other actants in the community. Understanding these impacts, particularly those by the combined human and nonhuman actants in the FTAF FB community, contributes to the broader discourse about posthuman sensibilities within geography (see Chapter 3 for examples).

After the verbatim transcription of my interviews, I used an open and iterative coding process and developed themes and threads that opened avenues for further reflection and reevaluation. As shown in Chapters 2 - 4, my ethnographic approaches (critical and institutional) offer a window into the daily lives of family caregivers and their children with feeding tubes and expose the ways that neoliberal practices, across many different systems and organizations, penetrate their homes and lives in complicated and often uncontested ways. In response, family caregivers extend their landscapes of care into the digital to satisfy their unmet needs (Loftus, 2022), including ways to subvert uneven power relations and other inequities. To better understand the configurations of these digital spaces, particularly the nonhuman actants, I turn to theoretical and methodological approaches in feminist science of technology studies (STS).

1.6.3 Situational Analysis (SA)

While geographers have both adopted and elaborated on STS (including feminist STS) approaches (see Das & Das, 2021; Jackson & Neely, 2015; Leurs, 2017; Prouse, 2021), their work rarely considers how family caregivers (re)create digital spaces or how assemblages of human and nonhuman actants form the mechanisms that sustain or hinder digital community

relations and the resultant socio-materiality of care practices by caregivers. Given that advancing some of the feminist STS approaches at the intersection of feminist disability geography and digital geography is emergent, I go into detail about what these approaches entail, emphasizing benefits that might be gained from their application widely while also speaking specifically to landscapes of care scholarship and the way these approaches can provide a more nuanced understanding of the complexities of caregiving under neoliberal systems. To that end, I will provide a window into my process to help illustrate the ways of ‘doing’ this type of work.

Within STS scholarship, there are several overlapping and hybrid relational/ecological approaches, “theory-methods packages” (Clarke & Fiese, 2007. p 363), which overlap to some degree, beginning with

“Bourdiesian field theories; interactionist social worlds/arenas theory, then Foucauldian theories of discourse and the dispositive; actor-network theory (ANT); and later Deleuze and Guattari’s Assemblage and rhizome theories” (Fletcher & Clarke, 2018, p. 230).

Building from these earlier approaches, Feminist STS scholars recognized the importance of questions rooted in the pragmatic realities of everyday life and understanding how and what people do together and searched for other approaches that incorporate feminists' focus on context, intersectionality, and situations. (Clarke et al., 2022; Morse et al., 2016; Star, 2015).

As part of the postmodern turn, feminist STS scholars and others (like Strauss, Clarke, Casper, Star, and Fujimura) expanded the canonical grounded theory approach established by Strauss through social world/arenas/discourse analysis where the goal was to understand how multiple actors (social worlds) entered into a shared space (a social arena) and engaged in all sorts of actions (negotiations, conflicts, discourses) to accomplish something. SA is rooted in this expanded work and shifted the focus to understanding social actions and explicitly grounding analysis into the project's situation. In other words, this approach explicitly addresses

the context (the situation) and the recognition that all actors in the social worlds/arenas have their perspectives and worldviews that permeate the situation (Clarke, 2018).

As such, digital spaces, like the FTAF FB group, are constituted by uneven social and cultural forces that replicate marginalization and oppression from non-digital spaces (Ash et al., 2018). As a feminist geographer, ‘staying with the trouble’ and understanding the “difficulty, challenge, and messiness – of attending to the interplays of digitality, intersectionality, and marginalization on the ground” is important work that needs to be done (Elwood & Leszczynski, 2018, p. 12; Haraway, 2016). My research contributes to this by examining the relationships within the FTAF digital community and understanding how this community formed and maintains itself.

To accomplish this, I used an open, exploratory approach (Star et al., 2016) to illustrate various community actants, mainly focusing on the articulation work in the FTAF FB community. In keeping with Star and Clarke, my research recognizes the articulation work that occurs in digital spaces as “work, labor, as effortful and potentially fraught, however hopefully it may be undertaken” (Clarke, 2016, p. 85). In Chapter four, I provide examples of this by examining hidden articulation work by several actants (human and nonhuman) in the FTAF FB group.

In keeping with Star & Clarke’s reflexive process of getting to know my data deeply, I started the SA approach by developing my first “messy situational map” (Clarke, p. 14) at a meso-level of analysis to understand the overall situation of caregiving for a child with a feeding tube. This process involved trying to identify all the actants (human and nonhuman, analog and digital) that are (or could be) engaged in this situation across multiple temporalities and spatialities (minutes to years, bodily to global).

1.6.3.1 Figure 1. Messy Situation Map: Caring for a child with a feeding tube.



Through an open coding process of community actants (text, images, videos, emojis, shares, replies, posts), I implemented an abductive, situational approach as a first step in data exploration (Charmaz, 2008; A. Clarke et al., 2018; Star, 2016). During a “back and forth” process of coding and densifying coded data, I developed an understanding of different situations (themes, threads, and concerns) in the group as codes became saturated. This approach required an openness to new data that undergoes repeated evaluation and changes through constant re-evaluation. As I reevaluated, stepping through my process, new situations (e.g. going to school) were created and abandoned, reconfigured and reevaluated as interesting and warranting further exploration. The following figure (Figure 2) was one of three situations of interest that emerged through my ‘working with’ the messy situation in Figure 1 and provided more specificity about

the actants and materiality of educating a child with a feeding tube and complex medical needs. For children, education in the United States is mandatory. Schools and parents engage in intense negotiations about where, how, and what that education looks like for children needing medical interventions at the Intermediate Level of Care (ICF).⁹ During my analysis, I arranged the messy situation map into thoughts that became more organized around key ideas that eventually formed columns.

1.6.3.2 Figure 2: Educating a child with a feeding tube and complex medical needs



⁹ Intermediate Level of Care means people (e.g, children or young adults) that require long-term medical care that previously would be provided in a long-term medical care facility (e.g. nursing home).

Part of this reevaluation process required that I simplify the situation into ideas that made sense. In Figure 2, I started arranging elements (actants) into relational columns under three main groupings; child with a feeding tube, family caregiver, and educational elements. This regrouping allowed me to quickly see the overlap of actants between my columns, like laws that impacted the individuals (family caregivers and children with feeding tubes) and also the institutions (education provision, school boards across several scales and temporalities). In this way, I was engaging in articulation work and emergent theorizing, which Adele Clarke identified as inherently political and which I recognize as a situated and partial truth that (re)engages theory in a way that “keeps theorists in play” (2016, p. 95). During this simplification process, contradictory experiences were captured and made invisible as I merged responses into other categories for analysis. An advantage to this type of approach is the ability for marginalized (outliers) and mainstream perspectives to coexist in the data allowing for multiple perspectives to move forward without resolution (or consensus) (e.g., in this situation, I collapsed home-based nursing and school-based nursing into ‘nursing’). In addition, initially, I viewed human and non-human actants with the same potential importance (e.g., medical formula, American Disabilities Act, Special Education Teachers, Family Caregivers), which allowed some actants to become more important than others over the course of my continued analysis. As my focus shifted as new ideas and situations emerged (Clarke et al., 2018), I was able to explore relationships through cartographies of situations; situation maps, arena maps of social worlds and their relationships. These situational approaches ‘open up’ the data rather than produce a final result, although that can also happen (Clarke et al., 2018). In keeping with Clarke’s recommendation that researchers ‘wallow in the data’, I repeatedly coded, recoded, analyzed, and revisited my research posts, audio interviews, coded segments, and the FTAF FB group creating new memos

and notes along the way (Ibid). Through ongoing participant observation in the FTAF FB group, I observed interactions between community members, postings, and conversations within the FTAF group that supported the importance of the situations (see Figure 2 for examples) that I identified in my initial messy situational analysis. In this way, I've begun to make the connections between the materiality of everyday caregiving of children with feeding tubes, the various organization that they encounter in day-to-day caregiving, the digital spaces, the assemblages of human and nonhuman actors, the mechanisms that form and hinder relationships, and the ways these digital spaces help them traverse the complexities of their landscapes of care. More examples of the day-to-day materiality of caregiving are illustrated later through ethnographic descriptions derived from my interviews and research questions (see chapters 2 and 3).

As a result, by drawing from critical ethnographic and feminist STS approaches, I am able to give examples of the materiality of family caregiving (e.g., the need for nursing at home and school, seen in Figure 2) and the ways in which family caregivers become mother-experts (also seen in Figure 2) and the digital spaces they (re)create and use for knowledge, support, validation, and community.

1.6.4 Connecting all the lines, including my own experiences.

Bringing theories and methodologies from feminist disability geography and feminist STS approaches through an examination of a digital space like the FTAF FB support groups allows me to examine the FTAF FB group as a digital space and also a place that impacts change in my community. As a feminist scholar/activist, my use of critical digital ethnography and SA could provide the catalyst for opening conversations within my community and others that ultimately lead to policy change that could materially improve day-to-day caregiving for technology-

dependent loved ones. Explicitly attending to marginalized and othered communities is central to feminist geographic scholarship. As such, ethical and reflexive writing needs to be accountable to research participants while also allowing engagements between scholars and research participants that could result in positive changes (Banerjea, 2014). Feminist geographers are especially attentive to the spatiality of everyday experiences across multiple scales: globally, nationally, locally, at home, and in the body (England & Lawson, 2005; Gleeson & Kearns, 2001; Hamraie, 2013; Jampel & Bebbington, 2018; Milligan & Wiles, 2010) As such, feminist geographic research on how caregiving occurs, including in digital spaces, offers insights for feminist scholars, and other social scientists, to better understand the multi-directional and reciprocal nature of these landscapes of care (Lawson, 2007; Milligan & Wiles, 2010). In addition, Worth (2008) argues for the importance of including personal narratives, including my own, as a way of confronting ableism in research, “the personal political, using the emotions and experiences of disability to create critical research”(2008, p. 307).

My own experiences as a long-standing participant of the FTAF FB and my own stories are folded into this research as part of the ethnographic descriptions from the FTAF FB group, through my field notes from my participation in the FTAF group and my family’s experiences as participants in the Home and Community Based Waiver (HCBW) program in West Virginia. In this way, I become an actant who (re)creates the community when I post about my own tubie family experiences, successes, and failures of navigating the various medical and social service systems and engage through emojis, shares, and interactions with FTAF FB community members.

1.6.5 Ethical Issues and Other Methodological Considerations

Ethical discussions about social media research need to be situated within the context of the nature of public vs. private discourses, openness, and expectations of privacy. While some geographers have addressed some aspects of this issue (Elwood & Leszczynski, 2018; Ergler et al., 2016; Leurs, 2017), my work goes further in its methodical analyses of the complex structures of the internet. Finding guideposts for this analysis required me to draw from other disciplines, such as new media studies and emerging critical scholarship in computer and information sciences (Coughlan & Perryman, 2015; Gelinias et al., 2017; Haigh & Jones, 2007; Shaw, 2016; Wakeford, 2000). In the design and implementation of my research, I implemented practices established by other researchers of deep web spaces, like Facebook and other hidden and secret spaces like the silk road drug trade in deep and dark web spaces (Aldridge & Décary-Héту, 2014; Ferguson, 2017). Rene Batard et al. (2018) examined the ethical use of Facebook groups by Cubans during Hurricane Irma, finding that these groups “constituted a virtual space of care for citizens to exercise their care and solidarity by organizing rescue activities” (2018, p. 3). In their analysis, they maintained the anonymity of respondents in the Facebook groups by randomizing and aggregating responses. Tony Coughlan and Leigh-Anne Perryman also address the ethical issues of collecting data from social media (Facebook) and explore issues of privacy and ethical research practices for social media data (Coughlan & Perryman, 2015), describing the use of both traditional research practices and guerrilla research in Facebook groups, with a focus on the challenges of consent, whether its needed and how to acquire it when required. In my research, I grappled with the implications of informed consent and call for a reexamination of both the concept and practice, particularly for feminist scholars engaging in work with marginalized populations where practices to mitigate potential harm create tensions with

emancipatory goals of giving voice, participatory goals, and risks of further erasure or making invisible the communities we are trying to help.

Within a digital context, important discussions about the ethics of Facebook research continue, with cautionary warnings about the potential for exposure through machine learning and AI algorithms that can triangulate data from Facebook groups with other datasets and reveal identifiable information and members outside of these secret groups (Zimmer, 2010). Coughlan and Perryman conclude that a “responsible, reflexive researcher can conduct ethically defensible research in such spaces as long as they look closely at what might constitute public and private communication in itself” (2015, p. 153). In response to these risks, in later chapters, you will be introduced to Jane and Ichabod ^[12], the two characters I have developed as compiled figurations¹⁰. These two characters voice composite narratives created from the one hundred and sixteen data respondents. These figurations combine actual events with summations of the shared experiences of community members in the form of narratives and ethnographic descriptions (Jacobson & Larsen, 2014). I use they/their pronouns to recognize the multi-gendered and multivoiced respondents and explicitly acknowledge the difficulties in separating family caregiver experiences from their children's, especially when there are complex medical and developmental delays. As such, Jane's experiences reflect a collective experience while leaving unremarked individual experiences that could potentially expose respondents to unintended harm or those which can not be understood in isolation (Loftus, 2022). I acknowledge the loss of specificity about my individual respondents, valued in feminist scholarship, by my use of a

¹⁰ In the spirit of Donna Haraway, I am creating imaginary figures to “root people in the stories” of the family caregivers in my research and my figurations “collect up hopes and fears and show possibilities and dangers” (D. J. Haraway, 2004, p. 1),

figuration but contend that telling partial stories is an important step in bringing forth the experiences of the Janes.

In addition, my work includes sampling bias from the onset because of my focus on digital spaces¹¹. As such, my research leaves unchallenged the multiplicity of subjectivity and identity of the various actants and takes the digital objects as they are presented, acknowledging that they might contain truths, partial truths, twistings, and turnings or complete untruths. As with all qualitative research, my ethnographic descriptions only reflect what actants choose to share through comments, emojis, shares, or through absences and silence. Nagar writes of the importance of understanding the silences in the data and what is left unspoken (Nagar, 2014). In this way, my research does not reflect the silent or “lurker” in digital spaces that watch without speaking. As such, there could be an amplification of particular views or perspectives that are unintended, erroneous, and uncountable.

Finally, the FTAF FB group is hosted by Facebook, a US company that utilizes North American and European server locations. FTAF staff speak English, and posts and responses are predominantly in English, embedding a global-north bias that reflects western values and ideas about care and caregiving. Facebook has a global reach, and as you will see later, FTAF community members from every continent in the FB group share their experiences and perspectives. Even so, my work reflects biases inherent in the data divide and overrepresent global-north perspectives as the norm.

¹¹ Left unremarked are family caregivers that are not in these digital spaces because of lack of access to mundane technologies (e.g. computers & smart phones) and the internet (e.g. the digital divide).

Moving forward, I describe the structure of my dissertation and the three papers I have written and submitted to peer-reviewed journals (one is already published, one is being revised for publication, and the third is submitted).

1.7 Dissertation Structure

Paper 1: *Beyond the Institution vs. Home Care Dichotomy: Lessons from a Feeding Tube Home.*

(Currently revising for resubmission to Gender, Work, and Organization)

Provided in Chapter 2, this paper describes my ethnographic examination of the provision of Intermediate-Care-Facility (ICF) level care at home, where I illustrate the contradictions of the "home is best" ideology by focusing on three interwoven themes: structural dependency on unpaid mother-experts, spatio-temporal erasure through decentralization, and invasive surveillance structures. I also attend to how home-based care, as a practice and a place, reflects broader patriarchal, gendered, and neoliberalized concepts of autonomy and individual rights as expressed through policies like 'person-centered' care and the medical home model. Further, I provide a less explored perspective grounded in a digital examination of caregiving experiences in the context where it occurs. I start with an overview of the shift to home-based care and a reframing of the medical home model. I then provide ethnographic descriptions from my digital ethnography of family caregivers of children with feeding tubes. These digital ethnographic descriptions reflect the three themes and illustrate ideologies of liberal legalism that, on the surface, transfer power to caregivers through 'home is best' policies and procedures while masking unrecognized adverse outcomes to both the family caregiver and the cared-for (de Lange, 2018). In particular, my paper advances the Landscape of Care scholarship by thoroughly analyzing how digital spaces are woven into everyday care work through countless digitally mediated activities and positioning these digital spaces as places of care and caregiving. Also, I

contribute to feminist disability scholarship by illustrating how reliance on an ‘expert mother’ articulates the further infusion of neoliberalism into every aspect of the expanded ‘medical home’ concept and demonstrating how the political, social, cultural, and economic forces impact, and at times harm, both the family caregiver and child with a feeding tube in gendered and oppressive ways. I also contribute to feminist geographers' ongoing discussion about gendered and ableist assumptions of care work by illustrating how the ‘home is best’ ideology contributes to unrecognized and unremarked structural violence on family caregivers and replicates problematic mothering narratives.

My analysis has theoretical, methodological, and demonstrates policy implications that expose the imaginaries of care that often erase the actual care experiences. In a broader context, this focus also allows a fresh reexamination of the shifting imaginaries of care that undergird other populations and society.

Paper 2: Re-examining ethical challenges of using ethnography to understand decision-making in family caregiving networks of children with feeding tubes.

(Loftus, S. (2022). Re-examining ethical challenges of using ethnography to understand decision-making in family caregiving networks of children with feeding tubes. *Children's Geographies*, 0(0), 1–13. <https://doi.org/10.1080/14733285.2022.2026882>)

Provided in Chapter 3, this paper builds on previous discussions of ethics and feminist methodology by examining the tensions between the emancipatory goals of feminist scholarship and the operationalization of those goals within marginalized populations like children and youth dependent on medical technology. It starts with a discussion on family caregiving in the United States, then reviews current literature related to the othering of people deemed unable to make decisions for themselves, either through decision-making practices or incapacitation, and the resulting exclusion of voices in multivocal care networks and the ways that ethical practices and

standards might exclude vulnerable communities in the literature. I focus on the concept of “do no harm” pertaining to families making everyday decisions and provide detailed examples of how decision-making and subjectivity are entangled for family caregivers and the person receiving care. Indeed, these issues potentially impact research practices with individuals and communities everywhere, not just those deemed vulnerable.

Paper 3: *Relationships In A Digital Feeding Tube Community: Caring Across Space and Time.*
(Submitted to)

This paper, provided in Chapter 4, builds on digital geography and feminist STS literature, using relational approaches, like Situational Analysis, to examine the articulation work (visible and invisible) of human and nonhuman actants that enable the forming of meaningful relations in these digital communities. These approaches also contribute to a more nuanced way of understanding how spatial and temporal fluidity in these digital communities enables the forming of meaningful relations. This is a significant contribution to how feminist disability geographers have considered family caregivers and landscapes of care because my work explicitly attends to the human and nonhuman ways that actants in digital spaces form and harm relations in digital communities and demonstrates how these relationships, and the digital communities, impact the materiality of care for family caregivers of children with feeding tubes, an often-invisible community within this scholarship. Drawing from feminist STS approaches, I show the ‘doings’ of my situational analysis of caregiving children with feeding tubes and the accompanying situational, social arena, and positional maps. My analysis of the visible and invisible articulation work in the FTAF FB group contributes to a more nuanced way of understanding spatial and temporal fluidity in these digital communities. I conclude with a

discussion of how using relational approaches like Situational Analysis¹² provides insight into the assemblages that transform the Facebook group into a place where people know each other, interact and build relationships.

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Chapter 2. Beyond the Institution vs. Home Care Dichotomy: Lessons from A Feeding-Tube Medical Home.

(Invited for revisions from *Gender, Work, and Organization*).

2.1 Abstract:

Decades of rights-based advocacy for people with disabilities have transitioned long-term care in the United States from institutional settings to home-based care provided by interdependent care networks. This paper argues that policies and practices within these home-based care systems unintentionally produce and often perpetuate unrecognized structural violence on the recipients of care and the caregivers through practice and legal frameworks. This research has a critical digital component because of the distributed spatial experience of care work. Understanding caregiver experiences expose the geographic realities and ableist underpinnings of the home-based care model that undergird this violence. An ethnographic examination of the provision of Intermediate-Care-Facility level care at home is central to this analysis. I illustrate the contradictions of "home is best" ideology by focusing on three interwoven themes: structural dependency on unpaid mother-experts, spatio-temporal erasure through decentralization, and invasive surveillance structures. This research attends to how home-based care, as a practice and a place, reflects broader patriarchal, gendered, and neoliberalized concepts of autonomy and individual rights as expressed through policies like 'person-centered' care and the medical home model. In addition, this paper provides a less explored perspective grounded in a digital examination of caregiving experiences in the context where it occurs. While this analysis has theoretical, methodological, and policy implications, more important is the contextualization of family experiences that sometimes impact life and death.

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2.2 Keywords

feminist digital ethnography, family caregiving of child with a feeding tube, care work, technology-dependent caregiving, feminist geography

2.3 Introduction

The "homebound" phenomena experienced by billions during the Covid-19 pandemic starkly exposed women's disproportionate responsibility for caregiving (Aslam and Adams,

2022). However, for some caregivers, the isolation experienced by Covid-19 restrictions was very familiar. Family caregivers of children with feeding tubes, who are predominantly mothers or female relatives, have long dealt with the geographic isolation that comes with their caregiving responsibilities. The geographic story is central to understanding the contradictions and ideological underpinnings of their experiences and crosses between their physical and digital caregiving spaces. An understanding of the geographies of care for family caregivers would be remiss without an examination of the digital landscapes in addition to the physical landscapes of care.

Using ethnographic approaches, I examine home-based caregiving of children with feeding tubes. My research illustrates the contradictions of the "home is best" ideology by focusing on three themes: systemic dependency on gendered caregiving practices reified as the mother-expert, community erasure/atomization/fragmentation from decentralization; and unrecognized structural violence from various surveillance apparatus. In particular, I attend to how normative policies and practices reify uneven power and social relations that sustain precarity and crisis for these families at home and in the community. My digital ethnographic examination uses several ethnographic methods (e.g., participant observation, interviews, and ethnographic descriptions) combined with personal experience within a digital feeding tube support group (Boellstorff et al., 2012).

As I will show, "home" for these families can be filled with complex relationships built on shared needs that create dynamic geographies of care. To illustrate this, I critically examine how family caregiving, as an identity and a doing (Ruddick, 1995), has been constructed and enacted across spatio-temporal contexts in the United States, focusing on "home is best" ideology and the resultant medical home. Data for this research comes from several sources.

First, I conducted a historical review of shifting legal and institutional frameworks, followed by interviews and surveys with family caregivers of children with feeding tubes who participate in a digital feeding tube support group. An auto-ethnographic sensibility informs my understanding of how these Facebook digital interactions fit together, given my positionality as a family caregiver for my feeding tube-dependent son. Finally, an analysis of laws and policies impacting family caregivers' ability to perform their daily caregiving activities and the problem-solving strategies used by families provides context to this research.

This paper starts with an overview of the shift to home-based care and a reframing of the medical home model and then provides ethnographic descriptions drawn from my digital ethnography of family caregivers of children with feeding tubes. These digital ethnographic descriptions reflect the three themes and illustrate ideologies of liberal legalism that, on the surface, transfer power to caregivers through 'home is best' policies and procedures while masking unrecognized adverse outcomes to both the family caregiver and the cared-for (de Lange 2018). This analysis has theoretical, methodological, and policy implications that expose the imaginaries of care that often erase the actual care experiences. In a broader context, this focus also allows a fresh reexamination of the shifting imaginaries of care that undergird other populations and society in general.

2.4 Geographies of Care

Geographers have examined the experiences of caregivers across several contexts, from domestic workers and home health aides to gendered roles, mothering practices, and identities within different spatialities and landscapes (Boyer, 2018; Collins, 2002; England, 2003; Gaston, 2014; Longhurst, 2008; Pratt, 2012). Much of this work focuses on understanding who cares for whom, where, and why. Within this broader research, Victoria (Lawson 2007) uses the term

'landscapes of care' to visualize care networks that are uneven, interdependent, and relational. Within this landscape, an extensive exploration of the everyday lives of family caregivers of technology-dependent¹³ children (e.g., feeding tubes) has yet to be done (Giesbrecht et al., 2016; A. G. Hall et al., 2014; Loftus, 2022).

Caregiving and care work must be understood within the context of the particular places where it occurs and reflect an understanding that care landscapes are interconnected across local and global scales (Milligan and Wiles, 2010). Globally, the number of children requiring long-term medical care has increased as advanced treatments decrease mortality for children with complex medical needs (Foster, Agrawal, and Davis, 2019). Care practices differ across cultural, social, and political contexts. In the United States, home-based care is the standard practice for technology-dependent children with long-term care needs and reflects socioeconomic values of home as loving, stable, and inhabited by family caregivers willing and able to provide unpaid quality care (Gulla, Sahoo, and Sachdev 2020; Parks, 2003). Improvements in medical interventions (like enteral and parenteral nutrition¹⁴) have prolonged life for many children with rare and orphan diseases¹⁵, allowing them to live outside of hospitals even though they require significant care and medical intervention (Halliday et al., 2017). Even so, there still needs to be more attention by researchers on the impacts of home-based care for the caregiver, the family, and the cared-for, beyond the clinic evaluation of care (Cohen et al., 2011).

Children with complex medical needs transition from a hospital setting into home-based care, often without adequate support and services to meet the child's and family's needs (Kuo et

¹³ Technological interventions to sustain life like feeding pump dependencies, enteral tubes, parenteral nutrition, tracheostomies, colostomies, ventilation. (Okido et al., 2015).

¹⁴ Parenteral nutrition is the medical term for infusing specialized nutrition through a vein.

¹⁵ Orphan diseases are defined as having less than 200,000 cases nationwide and presenting unique clinical characteristics and significant and complex medical and developmental needs.

al. 2011; 2016). Medical literature frequently uses the 'medical home' concept to represent a coordination of care through a patient-centered primary care doctor (Sia and Taba 2004). My research extends this concept to reflect the experiences of family caregivers that provide ICF-level-of-care¹⁶ within a home setting (Keim-Malpass, Letzkus, and Constantoulakis 2019; Kelly et al. 2002). As I will show, the family home is transformed into an extension of the medical-industrial complex through policy and practice that scales from local to global.

In response to decades of disability rights advocacy, caregiving shifted from institutional settings to the home (Foster et al. 2019). More than 3.5 million families in the United States provide home-based care for a child/adult needing long-term care, of which more than 600,000 are technology-dependent children (Toly, Blanchette, and Musil 2019). For these families, caregiving is both a mundane and extraordinary practice that requires the incorporation of the everyday materiality of hospital life at home (Asiedu et al., 2018). I argue that a new model of care emerged that blurs the lines between the public and private home. This new "medical home" extends the medical-industrial complex into family homes through home care services funded by federal and state Medicaid programs. Expanding Medicaid fueled this shift from institutions to the home by providing home and community-based services. This expansion was in response to litigation, advocacy, and bipartisan legislation (like Katie Beckett Laws¹⁷ and *Olmstead vs. L.C.*, 527 U.A.581 1999) and laid the groundwork for home-based care under state-based Home and Community-Based Waiver programs (HCBW) (Keim-Malpass, Letzkus, and Constantoulakis 2019; Swartzell, Fulton, and Crowder 2022). While HCBW was a significant victory for

¹⁶ ICF level of care means twenty-four-hour care provided in an intermediate care facility that requires skilled nursing under the direction of a medical physician (i.e., nursing home care).

¹⁷ Katie Beckett was a technology-dependent child who was institutionalized due to a lack of home-based nursing care.

disability rights, some unseen and unremarked casualties of this shift, especially for family caregivers, are left unchallenged in the literature (AARP and Caregiving, 2022.; Stajduhar et al., 2020; Weaver et al., 2018). My research examines some of these negative aspects within the context of family caregivers of children with feeding tubes. Through a critical lens, this research attends to the ways that home-based care, as both a practice and a place, reflects broader patriarchal, gendered, and neo-liberalized concepts of autonomy and individual rights as expressed through policies like 'person-centered' care and the medical home model (Kelly et al. 2002). Importantly, this work is not a criticism of self-determination or an argument for returning to institutionalization but instead provides an examination of the unrecognized casualties of a system reliant on unpaid family caregivers and the neo-liberalization of home-based care that shifts the state's responsibility for care to families under the guise of 'home is best' ideology.

The topographies of where, when, and how family caregivers and their children navigate through everyday spaces, including private spaces like homes, are created and constrained by policies, ideologies, and sociocultural practices that can be gendered and reflect uneven power relationships (England & Lawson, 2005; Hall & Wilton, 2017). These topographies can reflect disablist ideas informed by human and non-human factors like materiality, policy, and practice that connect care work and advocacy (Boyer, 2018). In this way, politics and caregiving are entwined across scales and within systems while also being deeply personal (Worth, 2008). Understanding the 'where' of everyday caregiving is critical to understanding the care landscapes for these families, as is recognizing how policies are reified as natural and fixed and are deeply embedded within home-based caregiving experiences (Soldatic, Morgan, and Roulstone, 2014).

The structures and systems for caregiving support are situated within frameworks of normative space and time that can be mismatched with the needs of family caregivers (Lewiecki-

Wilson and Cellio, 2011). Maybee (2011) suggests that scholarship about caregiving of children with disabilities has historically focused on the personal, sociocultural, and economic aspects of caregiving while ignoring the structural, including spatial, aspects. For example, family caregivers depend on service delivery systems (e.g., formal education, home-based care, insurance, medical care), which are multiscalar and multitemporal and deeply entrenched with ideologies that can negatively impact care work¹⁸. As such, many technology-dependent children move through crip time¹⁹ and out of step with normative markers and could be denied access to needed supports and services (Kafer, 2021).

Across different scales, the particular aspects of everyday caregiving practices illustrate the connections between specific places and health (Gatrell & Elliott, 2014; Gleeson & Kearns, 2001). A family's caregiving landscape reflects both the embodiment and materiality of disability that undergird their ability to access resources, community life, and necessary services within the place and space most appropriate for their needs. The legal contours of this landscape have been significantly impacted by disability rights-based movements like the Americans Disabilities Act²⁰ (ADA) and the Social Security Act. These laws focused on ensuring that people with disabilities have equal access to daily services by requiring reasonable accommodations for people with recognized disabilities²¹. Through the ADA, people with disabilities cannot be discriminated against in activities of daily life, and it requires that reasonable accommodations

¹⁸ Many service programs use developmental milestones or administrative eligibility criteria based on normative chronological or developmental markers.

¹⁹ A term used by Allison Kafer to reflect that people with neurodiversity/chronically ill/disabilities experience time differently than linear, chronological time.

²⁰ The American Disability Act was passed in July of 1990.

²¹ The policies and processes embedded in the concept of recognized disabilities require interrogation of how and by whom disabilities are recognized.

be made to include them within the 'fabric of communities', including being able to live in a setting of their choosing.²² Within this context, institutional settings for long-term care were further destabilized. Court decisions like *Olmstead v. L.C.*²³ held that institutionalization of people with disabilities "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life," adding that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment" (*Olmstead v. L.C.*, 527 U.S. 587 1999). Resulting from the *Olmstead* decision, additional regulations originated from the Department of Justice to ensure that integration occurred (the Integration Mandate), requiring disability services and programs to be delivered "in the most integrated setting appropriate to the needs of qualified individuals with disabilities" (28 C.F.R. § 35.130(d)).

The ADA transformed community living by improving access to public spaces, including schools and other government buildings; addressing explicit discrimination in employment and society against people with disabilities; and requiring that public and private entities accommodate the needs of people with disabilities. As a result, ADA, combined with Medicare/Medicaid²⁴ changes, shifted people with long-term care needs from institutional settings to home-based caregiving (Parks, 2003; Power, 2010). This shift has resulted in varying and often contested implementation of services at the local level (e.g., uneven state and regional

²² In the ADA, congress states the "Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, [and] independent living...." 42 U.S.C. § 12101(a).

²³ 527 U.S. 581 (1999).

²⁴ 1983 implementation of Diagnosis Related Groups (DRGs), ICD-10 Codes and fixed payments for in-hospital care.

caregiving infrastructures) (Kuo et al., 2011). Nevertheless, disability rights activists successfully increased resources and services to help with daily life. They established that the state was responsible for providing services through social support mechanisms like Title XVIII and Title XIX of the Social Security Act, which created the Medicare and Medicaid programs, respectively²⁵ (Francis and Silvers, 2015).

These programs are critical components of the institutional apparatus by which caregiving in the United States occurs. Vellani (2016) argues that institutions' *what, who, how, and where* matter. Family caregiving experiences provide specific examples of how institutional policies are shaped and formed in practice and reflect broader assemblages of procedures, policies, ideologies, and inequities (Campbell, 2015; McNeil, 1993; Tremain, 2006). For example, the Social Security Act of 1935 does not explicitly address the needs of the disabled population other than providing an exception process that creates special categories of people entitled to support and services (Campbell, 2015; Tremain, 2006). Instead, it was crafted to provide for the general welfare of U.S. citizens and legal residents by setting up a system of federal programs to meet the needs of an aging population retiring from work (Martin and Martin, 2005). Healthcare needs for seniors are met through the Medicare program (Title XVIII of the Social Security Act), with targeted programs for some individuals with disabilities and specific kidney diseases²⁶. Non-senior health care needs are served by the Medicaid Program

²⁵ In the 1950's, legislation was introduced to "improve access to medical care for needy persons who were receiving public assistance" (www.cms.gov). Two insurance-based programs-- Medicare and Medicaid--were created.

²⁶ Social Security and Medicare (and subsequently Medicaid) are deeply entrenched in political and ideological frameworks vs responding to needs-based assessments.

(Title XIX of the Social Security Act), which provides insurance for individuals based on financial need, with some exceptions for individuals with disabilities and specific diseases or extensive medical costs. In 2001, the Centers for Medicare and Medicaid Services (CMS) was created to manage the Medicare and Medicaid programs. Additional changes to the Social Security Act, in response to Ronald Reagan's defunding of institutional health care settings, prompted the creation of Home and Community-Based Services (HCBS), section 1915(c) of the Social Security Act. This Act allows states to receive a waiver of Medicaid rules governing institutional care.

HCBS are implemented through waiver programs, like 1915c, which are also known as the "home and community-based services waiver" (HCBW). HCBW programs allow individual states to treat specific Medicaid populations in the home or other community-based settings rather than in institutional or long-term care facilities, such as hospitals or nursing homes (Keim-Malpass, Letzkus, and Constantoulakis 2019). Significant changes to HCBW have occurred since the 1990s because of ongoing advocacy and litigation by family caregivers and others. For example, the United States Supreme Court in the 1999 *Olmstead Decision*²⁷ determined that a lack of actual community placement options for ICF long-term care was discriminatory under the ADA. As a result, significant changes were implemented to how HCBW are practiced but left unchallenged how 'home is best' ideologies embedded in HCBW shift caregiving responsibilities from the state to the individual and their unpaid family and informal caretaker networks (Tremain, 2006). In addition, it created a sophisticated and broad-reaching surveillance apparatus that infringes on family and individual civil rights, privacy, and self-determination, as a trade-off for receipt of the necessary supports and services (Campbell 2015).

²⁷ *Olmstead v. L.C.* 527 U.S. 581 (1999)

Fundamentally, there are inequities around who is eligible for Medicaid and how HCBW funding and services are distributed nationally and within states (Hall et al., 2014; Perkins and Agrawal 2018; Segelman et al., 2017; Wang, 2019). HCBW programs are the only mechanism for long-term care outside an institutional setting²⁸. While income-based programs like Medicaid, Social Security Income (SSI), and other programs under the Social Security Act, offer limited financial and insurance support, they do not provide daily caregiving services like respite or skilled nursing. In addition, several social justice issues related to income eligibility, participant identification, and access and allocation of resources still need to be examined. For example, to be eligible for HCBW, applicants must meet both medical (e.g., ICF level of care) and income requirements, creating a system that excludes help for people based on income limitations.²⁹ More problematic is the reliance on two (2) areas of significant deficits in daily functioning, often tied to cognitive abilities determined through normative IQ and functional skills testing. This requirement links long-term care needs with cognitive deficits and significantly impacts policy by embedding normative categorical disability identities into

²⁸ Due to the closures of state hospitals, there are few institutional settings available to children and young adults. There is also a lack of funding and available beds for long-term care in nursing homes. In the United States nursing homes, in general, are not structurally capable of providing care over the lifespan (50+ years) of a child or young adult.

²⁹ Income limitations for support systems negatively impact families that earn too much to qualify without taking into account expenses for care. This can result in extremely negative outcomes like divorce, bankruptcy and suicide by caregivers. These limitations are deeply embedded within neoliberal ideologies about who needs help and who doesn't and undergird the false narratives about self-determination, individualism, and stigmatization of needing social support.

practice. As a result, significant stress and service gaps can occur for people who need long-term care but are not "disabled enough (i.e., cognitively disabled)" or "poor enough" to qualify for services (Crossley 2000). This gap is wider for people requiring home enteral nutrition (HEN) or home parenteral nutrition (HPN) because they are dependent on expensive and complicated medical procedures typically provided in ICF settings and often don't neatly fit into Medicaid eligibility criteria.

In addition, because HCBW services are state-based, eligibility, quality, and type of services differ between individual states resulting in disparities and geographic mobility limitations for people needing these supports (Falvey et al., 2020; Zablotsky, Maenner, and Blumberg, 2019). Under the state-based system, if someone moves to a different state, eligibility has to be redetermined under potentially different criteria regardless of previous eligibility status.

Decentralized services have resulted in an uneven landscape of haves/have-nots in the United States, with some states offering a comprehensive menu of services for long-term care and others having limited services (Moore, 2020). States have broad authority to decide which aspects of the HCBS policy they will offer, the form those policies will take, how services are delivered, and who is eligible to receive them. This decentralized approach embeds into policy spatial inequities that scale from institution to home, from federal to state, and the intersections in between. The "medical home" resides in this uneven landscape, reflecting a liminal space where public and private are co-mingled, and gendered divisions of labor are entrenched (Lewiecki-Wilson and Cellio, 2011; McRuer, 2016; Mitchell, 2015; Parks, 2003; Foster, Agrawal, and Davis, 2019).

As a result, the landscapes of care for family caregivers have been transformed, both positively and negatively. A key driver of these transformations prioritizes economic efficiency

over patient care (Foster et al., 2019), marked by an ever-widening reliance on unpaid family caregivers to provide services previously restricted to hospital settings and licensed medical personnel (Williamson et al., 2018). In this way, hospitalization extends into the family home as a hybridized 'medical home', resulting in neo-liberalized medical services that are explicitly emotional and insidious while being rendered benign.

2.5 Family Caregiving at home

When formal social support systems fail to meet the needs of these children, family caregivers are expected to fill the gap in their medical home (Macedo et al., 2015). In order to do this, family caregivers rely on formal and informal networks to help with daily caregiving tasks. Despite 'needs-based' rhetoric, HCBW systems, policies, and practices are underpinned by economic models reliant on unpaid family caregivers who are co-opted into the system as quasi-professional care team members. I argue that this creates a 'mother-expert' who has been trained in specific medical tasks for systemic economic efficiencies and to overcome direct care labor shortages (Cataldo et al., 2017). In practice, this mother-expert (or professional mother) becomes a member of the 'medical care team', replacing other licensed medical personnel. As a result, mother-caregivers are placed in untenable situations of caring for children, often without the necessary support, training, and resources, within a sociocultural framework of ideology that values self-sacrifice and obligation (Cataldo et al., 2017; Christopher, 2012; Douglas, 2016; Elliott, Powell, and Brenton, 2015; Henderson, Harmon, and Newman, 2016). This leads to comorbidities, including post-traumatic and ongoing complex stress, for the expert mothers and other caregivers, because of social and physical isolation, physical illness, mental health crisis, and other casualties that are unremarked and unaddressed by the systems they depend on (Alfheim et al., 2019).

To offset the resulting imbalances, caregivers developed alternative systems to meet their needs in the physical world (support networks) and as digital support groups on Facebook and other online platforms. These online support groups provide vital connections and information that 'mother-experts' use to fill gaps in knowledge as they attend to the daily needs of their children within their medical homes (Loftus, 2022). An understanding of the landscapes of care for family caregivers would be remiss without examining these digital landscapes in addition to the physical landscapes of care. This research connects these two landscapes through a digital ethnography of caregivers' experiences as shared in a feeding tube family support group on Facebook.

2.6 Case Study: Examples of life in a medical home

This ethnographic research follows the stories of family caregivers of children with feeding tubes and the precarious world of the medical home. In this precarious world, a complex structure of interwoven networks of health care professionals, therapists, early interventionists, teachers, social service agencies, caregivers, families, and children with feeding tubes all bump along in a daily dance of caregiving tasks (Gulla, Sahoo, and Sachdev, 2020; Okido, Zago, and de Lima, 2015).

This space is filled with children who, at another time and place, would have spent their life in a hospital or died early. Instead, their lives have been sustained and extended to the edges of personhood with increasingly sophisticated technologies and home-based caregiving (Svendsen et al., 2018; Rishworth, 2022). Narratives from caregiving families offer a glimpse into this alternative landscape and provide powerful illustrations of the inherent contradictions and unrecognized tensions produced at the intersection of structural supports intended to promote individualism and autonomy and the realities of dependency, crimp time, and neoliberalism. These

narratives reflect individual stories from my ethnographic research of a digital feeding tube support community, The Feeding Tube Awareness Foundation (FTAF). FTAF's primary mission is to connect family caregivers of children with feeding tubes. These ethnographic descriptions offer powerful glimpses into the teller's experiences; emotional, intimate, and vulnerable (Behar, 2014; Tsing, 2015; Desmond, 2016; Holmes, 2013).

As a scholar gathering data and a mother/caregiver of a son dependent on a feeding tube with complex medical needs, my positionality in this research is complex and multifaceted. I am also a long-time member/user of the FTAF Facebook group, and a scholar/advocate involved in various disability spaces in my community. I'm working toward ethical, emancipatory research that advocates for a better understanding of the needs and experiences of my community (Nagar, 2014; Chalachanova et al., 2020; Macpherson et al., 2021; Douglas, 2016).

In this case study, the experiences reflect the point of view of family caregivers of children and young adults (ranging from infants to twenty-two) with feeding tubes and other complex medical needs. Research data³⁰ was collected between the Summer of 2019 and the Summer of 2021 using digital ethnographic approaches (e.g., participant observation, digital focus groups), where I posted questions in a social media group, and members responded (Barratt and Maddox, 2016). I also conducted twenty (20) open-ended zoom video interviews (more than fifty collective hours) with family caregivers, all mothers of children^[11] with feeding tubes. During the interviews, interruptions were limited to clarification of terms or details. Verbal consent was requested, and a prompt was given to share their feeding tube journey with

³⁰ West Virginia University Institutional Research Board Approval was received for this research. WVU IRB Protocol # 2102246119

FTAF. More than one hundred and sixteen (116) family caregivers responded to at least one of the research questions posted in the Facebook group.

2.7 Meet Jane and Ichabod

To share the family experiences of my respondents while preserving anonymity, I have developed two characters as composite figurations³¹ named Jane and Ichabod^[12] to reflect the posts and interview excerpts from the individual respondents. These figurations reflect events that actually happened combined in ways that summarize the shared experiences of many different respondents from the FTAF FB community while also recognizing the partial and opaque nature of people's stories (Jacobson and Larsen, 2014).

When referencing Jane/Ichabod, I use they/their pronouns to reflect the multiplicity of gender preferences of the individual respondents. The narratives also reflect the intertwined voices of the family caregiver and the child with a feeding tube due to the imprecise, challenging, and at times, impossible task of disentangling individual voices due to complex medical or developmental delays³². In this context, Jane could be sharing her own experiences or might have juxtapositioned herself with the voice of Ichabod as a way to give voice to their shared feeding tube story. Neither Jane nor Ichabod are intended to be representative of nor generalized to a population but instead reflect the collective experiences as expressed during the particular time and place of my interviews and research from the FTAF FB group.

³¹ Following the spirit of Donna Haraway, where figurations “collect up hopes and fears and show possibilities and dangers” (D. J. Haraway, 2004, p. 1), I am creating imaginary figures to “root people in the stories” of the family caregivers in my research.

³² This study received Human Institutional Research Board Approval (WVU # 2102246119). All the respondents were over 18 and self-identified as the mother and primary caregiver of a child with a feeding tube and complex medical needs. No children with feeding tubes were interviewed.

Jane and Ichabod currently live in their family medical home, where Ichabod receives total care from Jane and a respite provider, with the support of an extensive medical team at their regional children's hospital. Ichabod received Early Intervention Services from birth and applied for and received an HCBW when Ichabod was young. This waiver provides financial and direct caregiving support, including paid respite staff that is available for an average of twenty hours a week. For the most part, Jane has learned to care for Ichabod through trial and error, with only limited training and support from medical professionals. Jane relies heavily on the FTAF Facebook group to help her solve every day caregiving problems (Loftus, 2022). Jane shares that they often feel underprepared to care for Ichabod at home and unsure about some aspects of their care. During interviews, Jane repeatedly talks about how the FTAF Facebook group helped problem-solve specific feeding-tube care issues and offered strategies for fighting for what they needed.

An example of the contradiction of the 'home is best' model is the assumption of a level of skilled caregiving that requires expert knowledge and training to keep Ichabod medically stable without providing funding or resources for caregivers to acquire the necessary training. Even more problematic is the underlying assumption that mothers want to (or should be capable of) providing this level of care and that failure to do so equals failure as a caregiver or, more fundamentally, as a mother. The case study data reflected caregivers' struggle with unrealistic expectations in narrative after narrative. In one example, even though the hospital didn't train Jane on the daily procedures and caregiving tasks of cleaning and maintaining a peg tube, NG tube, or specialized feeding techniques, these tasks were necessary as part of daily care for Ichabod. As a coping strategy, Jane turned to the FTAF to acquire the necessary information from other parents and FTAF online resources, to become the 'mother-expert' to meet Ichabod's

medical needs. The 'mother-expert' role is an additional layer of expectation beyond the 'intensive mothering' that has characterized motherwork in western liberal cultures (Arendell, 2000; Christopher, 2012; Edgley, 2021).

From a specific example, in order to leave the hospital with Ichabod, Jane needed to successfully 'feed' Ichabod. With minimal help from medical personnel in the hospital, Jane developed a solution of their own so they could leave.

So eventually, we found [a pacifier] that worked, and we managed to get [Ichabod] sucking on a bottle, which meant that the NG tube could come out. OK, so we had the NG tube for over 30 days. We then managed to get [Ichabod] to drink enough, which was still not what a normal baby, a neurotypical baby, would be drinking at like a month old. But [Ichabod] managed to get a suck and then keep sucking, and they were happy to send us home. So then [Ichabod] was, ah, all fit. We managed to get [Ichabod] drinking more and more.-- Jane.

To become the 'mother-expert' that was required to leave the hospital, Jane needed to look for other resources to supplement the information that they received from their medical team.

I mean, I don't know per se what they are, but I'm really, really good at, like finding what I need, though. If I needed it.-- Jane.

Even though the system requires Jane to become the 'mother-expert' and requires them to be part of the medical team within a medical home model, they expressed frustration and conflict with actual medical personnel who do not recognize nor value their caregiving experiences. This mother-expert role is both nominal in one sphere (within the medical-industrial complex) and very real within another (as replacement medical personnel in the HCBW team). This contradiction undergirds systemic inequities and results in families feeling they are constantly

'fighting' for what they need. As a result, families again turn to digital spaces for strategies and solutions to meet their needs (Loftus, 2022).

For example, Jane disagreed with Ichabod's specialist about a problem that was repeatedly sending them back to the hospital. In this interview excerpt, Jane describes their strategies to overcome this recurring problem.

So a lot of the stuff we found was because I was online all the time. I was going to this doctor. Thinking this doesn't seem right. So, like, what I figured out was [Ichabod] had a volume intolerance because I was online, and I told [the doctor] that that's what it was. And [the doctor] was like, oh, that's just a thing. And I was like, no, I think [Ichabod's] got a volume³³ intolerance. And that's pretty common with this particular formula to have a volume intolerance. I was looking up anything that had any kind of like studies. If I could find peer-reviewed studies. I was looking those up. -- Jane.

This narrative demonstrates Jane's ability to code-switch easily in and out of medical jargon and reflects their becoming the required 'mother-expert'. To be successful in their caregiving, Jane had to acquire expert language and engage with medical personnel as a peer to be valued as credible. Speaking the expert language provided power, access and, more importantly, elevated the mother-expert as a co-worker in the various service delivery systems, further reifying the reliance on unpaid 'mother-experts' as a long-term care solution.

This 'mother-expert' role extends into other support systems that are needed to integrate technology-dependent children into everyday life, like going to school and into the community. In addition to being a 'mother-expert' in medical caregiving, Jane also needed to become an expert in special education law. As a result, Jane researched special education law and policy and

³³ Volume in this quote refers to the amount of enteral feeding Ichabod can tolerate without negative physiological responses.

found themselves becoming a disability advocate in order to acquire or maintain their needed services in the face of constant cultural, social, and economic pressures.

With the return to physical school after COVID-19, Jane was told that Ichabod would have to remain on homebound services because of staff shortages in the school district that prevented a nurse from attending to Ichabod's needs. This response is contrary to the 'needs' based mandate of laws governing special education, which require services and accommodations for children based only on their needs, not the needs or resources of the school or school system.

They told me that they didn't have staff to do it [feedings] because they needed a nurse and that I could come to school and do [feedings] every day, or [Ichabod] would have to stay homebound.-- Jane.

Successfully navigating this barrier required Jane to rely on her 'mother-expert' knowledge of state education policy and federal special education law and experience 'fighting' against systemic barriers. After several contentious (fighting/advocacy) meetings, Ichabod returned to school, and the district provided the required nursing. Throughout this 'war' with the school, Jane received advice, support, and knowledge from the other 'mother-experts' in the FTAF community. In this way, FTAF becomes a professional peer space for 'mother-experts' to problem solve, similar to what happens in other professional work networks.

Mother-experts have become a central aspect upon which the 'home is best' ideology rests. For children with feeding tubes, mother-experts switch between various para-professional roles, including becoming social workers for their children. For example, Jane learned to navigate the different systems and structures that control their needed services, like special education, private insurance, Medicaid, and the HCBW systems. Narratives about these

structures continue the 'fighting' and 'war' language and describe Jane sometimes receiving help and other times finding solid barriers that seemed impenetrable to overcome.

Most state-supported programs have age, income, or disability identity categories as qualifiers for eligibility. These arbitrary qualification categories, often rooted in liberal ideologies, are one example of these impenetrable barriers. Income restrictions are another example of an underlying structural barrier. Caregiving social service programs rely on Medicaid billing codes. Because Medicaid is an income-eligibility program, families over income cannot access those services regardless of need. This is another example of the contradictions between ideology, policy, and practice. HCBW programs are 'person-centered' and thus need-based, but only within the tight constraints of overarching normative categories (e.g., chronological age, disability category, income, or state residency). Jane, as a mother-expert, either struggled on their own or hunted for and sometimes fought to get needed resources. For example, Jane could access the Katie Beckett program in their state while waiting for approval for the HCBW, but recognized that they were fortunate enough to have access to the resources (e.g., computer, internet, support groups) and the knowledge of where to look.

And I think we were privileged. That's part of our privilege, is that because we have, I don't know, because we have enough income that we've grown up with technology and stuff like that, we could research and do that sort of thing. And then, with my husband's education and my education, we knew how to research and find those services. Right? Which I'm sure other people that don't have that kind of thing ...it was such a big process.-- Jane.

At times, Jane found themselves fighting for their own needs and others in the community with the knowledge they gained. They did this in a volunteer capacity, without 'official' education or direction, based on their hard-won experience and expertise. As mother-experts, they translate their experiences into strategies to accomplish their own needs and

provide peer support for others. This was a common theme across many of the interviews, the need to share their experiences and help other families have an easier time.

My [Ichabod] is on Medicaid waiver in our state that provided all of [Ichabod's]... *was*³⁴ sorry. I get my tenses wrong sometimes. ... *was* on a Medicaid waiver that provided all of our nursing and filled in the financial gaps in care. And our state decided, 'oh, we're just going to get rid of that program. We don't need that program anymore'. And of course, for a kid like mine and most of the kids in the program, I mean, that's either a death sentence or permanent hospitalization.-- Jane.

Instead of accepting that decision, Jane led a group of other caregivers to advocate for maintaining the program. Constant attacks on HCBW programs illuminate another contradiction within ideology and practice where home-based services are rhetorically valued but are chronically underfunded. Even more critical is the atomization of political power resulting from the dispersion and fragmentation of this community. Within a centralized institutional setting, the legal framework, policy, and practice were under constant surveillance across many scales, which provided nexus points for individuals and institutions to organize advocacy and political power. This was demonstrated by the broader disability movement's successful advocacy, which led to significant systems changes across cultural and institutional settings. But under a decentralized system, the community has been dispersed, and advocating and organizing for political change requires new approaches, like using online groups. Even online, the state attempts to surveil what families are doing and saying. Jane describes how they organized in opposition to cuts in HCBW services in their state.

So when we first started out, [our online group was] completely secret. You couldn't find the group. And we're actually no longer completely secret. And it's still a closed group. But you can find the group now. But for those first few years, when we were fighting the

³⁴ Ichabod in this case is deceased.

state, they tried to infiltrate our group. We've been infiltrated at least three times that I know of, once by the state and twice by nurses or nursing agencies. And that's actually a huge issue that we have because, I mean, we still do a bunch of advocacy, but a lot of it is also support now, you know, supporting each other just through this life, which is so challenging. And so people have to be able to talk about this nurse just sucks. And, you know, this nurse stole our narcotics, or this nurse did, blah, blah, blah. And so we have unfortunately been infiltrated a couple of times. And then we had an agency threaten to sue us. And yeah, I mean, it's been really challenging. -- Jane.

Beyond surveillance, there are other unintended casualties of deinstitutionalization, particularly because the long-term care community was disassembled into uneven, decentralized services that are fragmented across scales and arbitrary identity categories (e.g., children, adults, poor, moderately disabled, physical vs. cognitive disabled, etc.) within neoliberal health care structures (Rishworth, 2022).

Within this atomization of care, the technology-dependent child becomes an 'orphan' across multiple systems (e.g., medical, education, social, cultural) where they might be the only person with complex medical needs and can't find or access appropriate services. This can lead to severe isolation and negative comorbidities for the child, parent, and family (Stajduhar et al., 2020; Weaver et al., 2018). An example of this can be found in the use of chronological age for eligibility/service delivery for feeding-tube children with complex medical needs. By age twenty-one, they must transition from pediatric care (or K-12 education) and move into adult systems regardless of their needs, which can be traumatic for everyone involved.

I put it off, and COVID helped because [Ichabod] turned 22 under COVID - so their pediatrician saw them but said I had to change doctors right away to med-ped because of licensing and insurance. Ichabod is only 89 pounds-they are tiny, and the thought of going to an adult doctor-it makes me sick to think about. I'm going to have to start all over - all the work I did to get a good team is just gone from one day to the next. It's terrifying.-- Jane.

In this example, Jane is caught in criptime, where the needs of Ichabod are being sublimated by normative developmental milestones, programmatic timelines, and outside administrative rules that don't reflect the needs of the community they are supposed to serve. Many Janes expressed that they feel traumatized by the systems they have to function within, and the movement from one system to another because of chronological age exacerbates this ongoing trauma (Alfheim et al., 2019). HCBW systems are riddled with age-related inconsistencies, like when services can begin, who can receive certain services, and in what settings. Some services are home-based, and some are clinic-based, depending on the participant's age.

Ichabod required suctioning since a baby. They would stop breathing all the time. I had a nurse come at home under a waiver. We had that from birth until they were fifteen. We had to resuscitate Ichabod all the time and use the suction machine to keep Ichabod alive. Then the state decided that only people over 21 could have a nurse. Why? So my nurse went away, and I had to stop working. Who could I leave Ichabod with like that? Nobody, not even my mother felt she could do the suctioning.-- Jane.

Jane's reliance on a nurse at home introduces another unintended consequence of decentralization of care and illustrates another contradiction of 'home is best' ideology. While Jane expressed that the home health nurse allowed her to work outside the home, it also created problems.

It's hard to have a stranger in your house all the time. They are there to help and I needed help. But they are always watching. No matter how nice they were, I just always felt they were watching. We couldn't be real, even in our own homes. Sometimes when my partner came home from work, if the nurse was still there, I had to remind him to watch what he said or how he played with the children. We didn't know who they [the nurses] were talking to back at the office. Or what they were saying in their notes. Sometimes we didn't like the person they sent, but it was them or nobody. It was uncomfortable, and we pretended a lot. Sex, arguing, disciplining the children, all the normal stuff had to wait until they [the nurse] were gone. I refused to have a night nurse, even though I needed more sleep, because then we would have someone watching us 24/7.-- Jane.

Jane was aware that the home health nurse was a 'mandatory reporter' and that they were watching everything while in Jane's home. The nurse observed all aspects of Jane's family life, well beyond the care of Ichabod. They had a front-row seat in the day-to-day family dynamics, from listening to and watching interactions between Jane and her partner, other children, family members, and Ichabod. However well-meaning, these nurses were not neutral nor objective but came with their own biases and cultural values. By being in Jane's home daily, the wall between public and private is shattered- the medical home is a public space at all times, and worse, a public space with a one-sided surveillance gaze that reports back to unaccountable health and social service structures. Jane would have severe consequences to themselves and their family based on anything negative reported by the nurse but had no control over who came into their 'private space'.

The nurse comes from an agency. There are only so many- and they talk - so if you cause trouble or ask for a different one because they just don't fit your family life- you become 'that mother'. I'm that mother - by the way. I only want certain people in my house. I'm not going to take anyone who shows up at the door just because they are a nurse. I'd rather stay home.-- Jane.

As family caregivers become 'mother-experts' across the different systems they navigate, they better understand the various state surveillance systems and learn strategies to maintain their privacy while also getting the needed services. As a result, there are performative aspects of family caregiving, where families engage in ritualized, mandatory processes that have nothing to do with how they meet their day-to-day needs. Many of these mandatory processes are formal interactions with various paid professionals within the support systems (e.g., social workers, teachers, medical personnel, and therapists). Through policy and regulation, the family caregiver and child must participate to maintain services regardless of whether they want, need, or have chosen the professional they are interacting with.

Undermining the empowerment promised through person-centered, rights-based advocacy of home-based ideologies, many of the Janes felt violated by having to accept unwanted people into their homes and their lives. They understood that some of those mandatory visits were really 'safety checks' predicated on the assumption that Ichabod was inevitably being abused because of the 'burden' of caring for them. Many Janes expressed frustration about how much money was spent to watch them instead of helping them directly.

So anyway, the waiver system is very, very important. But I also feel stuck. I want to move closer to my family, but we can't get away. Where I live, the waiver is better, but if we move, we lose [waiver] and have to go on the waiting list. So we have to stay here. -- Jane

The lack of program mobility and accessibility to other state HCBW programs is a significant issue for many Janes and Ichabods. The disjointed state-by-state program further isolates and subjugates families into accepting their current systems with little ability to challenge or change a program they rely on. Many Janes spoke about a lack of resources, especially respite services. In addition, many indicated that their state HCBW budgets continue to decrease yearly, and services are being eliminated because of funding cuts. There are waiting lists for services in the United States despite *Olmsted* injunctions requiring states to provide services to eligible people. For example, on the West Virginia HCBW FAQ page, the following answer is provided: How long is the waiting list in West Virginia?

The length of time a person is generally on the wait list for I/DD Waiver varies depending on slots that become available through attrition each year. Typically 125-175 slots can be awarded throughout each fiscal year. Persons with developmental disabilities have reported a wait of three or more years before receiving waiver services in West Virginia.³⁵-

³⁵ http://medicaidwaiver.org/state/west_virginia.html

The FAQ also reports³⁶ that there are 850 people on the waiting list and that assistance for people that are waiting for HCBW services (services that they are eligible to receive and are entitled to under federal and state law) might be available through other programs (Early Intervention for children birth to three, or Medicaid Grants if Medicaid eligible) for limited services. Finding funding for necessary services and equipment can be difficult for everyone—even 'mother-experts' who know how to advocate for their children.

These states are making millions of dollars off my child. And then all of these agencies make money too. And then they're going to fight over whether [Ichabod] can have a five-thousand-dollar wheelchair. When they literally have had, you know, they've billed three hundred thousand dollars that year on the back of this kid. Mm-hmm. Oh, that just kills me. But. No, no, I mean, we're doing that fight every day here, so I'm in that fight here in [home state]. So yeah. -- Jane.

Despite Janes' impression that the 'system' is earning money from Ichabod, there is limited empirical research that follows how the money flows within the system beyond calculating the cost savings of home-based waiver programs compared to institutional settings. The studies that have been conducted focus on the loss of employment, and programmatic and medical costs without incorporating family experiences and often further reify the 'burden to society' rhetoric (Buescher et al. 2014). Quantifying the cost of care without understanding the complexities of care within this expanded concept of a medical home presents a false and misleading representation of family caregivers' experiences caring for their feeding tube-dependent children. More importantly, a cost-based approach further separates families (as consumers) and care work (as service providers) within neoliberal service delivery models that "result in the susceptibility of [crip] bodies to myriad bureaucratic onslaughts" (Mitchell 2015, 42). Contrary to 'home is best' ideology, care decisions remain outside of the individual and

³⁶ Reviewed in September 2022.

families' hands, instead resting in 'regulatory domains where payment is actually debated and negotiated among third parties" (e.g., medical services organizations, DME, and service provider agencies) and where many of the costs of actual care rest on the shoulders of unpaid family caregivers (Ibid).

2.8 Discussion

Jane frequently talks about fighting to acquire what they need or maintain what they have. These narratives have exposed contradictions within the 'home is best' ideology by focusing on three themes: structural dependency on unpaid mother-experts, spatio-temporal erasure through decentralization, and invasive surveillance structures. All of these themes, at the root, speak to the ideological underpinnings of what constitutes good mothering and how mothers in this context develop alternative strategies to accomplish their everyday caregiving tasks. What is left unspoken and often unrealized by even the mothers themselves are the casualties of this system and these 'make do' strategies. These costs are unaccounted for within the system, the family, and even for individuals. Cultural narratives try to frame these costs within economic frameworks about the burden of caregiving. However, that hides the reality that some 'burdens' are necessary components of the current system (e.g., unpaid caregivers) (Chung, Young, and Bezner Kerr, 2019; Foster, Agrawal, and Davis 2019; Weaver et al., 2018). In contrast, many Janes talk about the benefits their tube-dependent children bring to the family and actively work to create a positive, meaningful community for themselves and their children.

Fundamentally, the cultural assumptions that mothers or other family members should be doing this work out of a responsibility rooted in gendered, ableist, and neoliberal ideologies result in problematic structural implications. Further, the uneven distribution of labor and the

elevation and expectation of self-sacrifice as a basic responsibility of mothering children with complex medical needs leads to unintended and unrecognized casualties to the mother-expert.

I better be dead if I'm not at Ichabod's bedside at the hospital, even though their father hadn't been there for days because of work. I had been sitting with Ichabod for more than four days straight, sleeping and eating in the room with no change of clothes and washing up in the room sink. Ichabod stabilized, and the weekend attending doctor told me to go to the Ronald McDonald house to rest and clean up. They would contact me if anything changed. While I was gone, the shift changed. When I came back to the room, the new doctor questioned where I had been and said that the nurses hadn't seen me and that I needed to be with my child. Nobody asked where their father was or why he wasn't there. I was so angry.-- Jane.

Cultural values like this undergird policy decisions that reify expectations that unpaid caregiving is not only expected but the responsibility of families and more specifically mothers. This expectation has been codified into policy and practice around the rhetoric of 'natural family settings' that is deeply embedded into the 'home is best' ideology.

In my research, the overwhelming response to my interview requests by the Janes' reflects their need to be witnessed and to have positive affirmations that they are doing a good job when they might be feeling or experiencing doubts or negative feelings about their capacity or desire to perform as the mother-expert that the home-based model relies upon.

Looking back at the Janes who fought to save waiver in their state, they found themselves directly confronting structural violence as representatives of the state attempted to undermine their efforts by infiltrating the different advocacy and support groups they'd organized. Because of Ichabod's death, Jane was no longer dependent on HCBW for survival and was in a unique position to advocate for the community without the threat of reprisal. In this instance, Jane's role had transformed into a community advocate because of her mother-expert knowledge of the community's needs and the system's laws, policies, and procedures. Interference from the state

wasn't limited to policy, as demonstrated by Jane's example of the state infiltrating their advocacy group. Many Janes also felt the tension of needing help but not wanting to give up control or the role of mother or wanting the intrusion of 'strangers' in their homes.

In addition, underlying assumptions that abuse is inevitable are problematic. The state's response to potential abuse is building an elaborate surveillance system to monitor abuse instead of providing more direct funding to families. Increasing direct funding to families could help decrease causes of the underlying antecedents (e.g. lack of adequate respite care, high medical costs, etc.) that cause abuse. Instead, the state underfunds direct care service hours, caps family hardship payments³⁷, and relies on unpaid 'natural family supports' to fill the service gaps.

This research extends the medical home concept by arguing that family homes become, through policies and practices, offsite hospital rooms embedded within the 'medical/social service industrial complex' and that there are unrealized and unrecognized consequences. These spaces are simultaneously an offsite hospital room, a social worker's office, and a theater where the family is performing caregiving in front of an audience that has the power to put them in jail.

The only people that have it worse, as far as people getting into my business, are people wearing ankle bracelets.-- Jane.

2.9 Conclusion

As a scholar-activist, I'm uniquely positioned to effect change for my community.

Drawing from specific examples from family caregivers, my research exposes unintended

³⁷ Some states will allow family members to be paid at minimum wage for 40 hours a week of care that they provide for their child receiving HCBS Waiver. The amount of hours and if payments are made at all vary on a state-by-state basis. These hours are deducted from the total budget of other services available to the waiver recipient.

casualties from the 'home-is-best' ideology that could allow for new conversations about how and where caregiving occurs. For example, recognizing the duality of the family home as a medical home opens opportunities for reframing policies to incorporate interdependent care networks instead of only focusing on the individual (e.g., person-centered). Pragmatically, this type of research can illuminate how policy and practices work within specific contexts and offers potential new legal interventions that could address inequities and structural barriers.

Further, the atomization of care into the home has rendered invisible the experiences of some families who find it too challenging to leave home and rely on systems that come into their private spaces. It is important to reiterate that a critique of 'home is best' ideology, and home-based practices is not advocating for a return to institutional settings. Instead, it is essential to expose unrecognized casualties within a home-based model, often most felt by the 'mother-expert' caregiver.

There is space for other alternative approaches that recognize the inequalities and casualties of home-based caregiving that could significantly improve the experiences and outcomes of family caregivers and their children. What would it feel like to live in a medical home with more of the tools and services needed to provide the best care possible for the entire family?

Definitions of home are being upended as life returns to 'normal' in our post-COVID age. While extreme in some ways, Jane and Ichabod's experiences are not just specific to their community but are broader and reflective of aspects of different life cycles.

2.10 Works Cited

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Chapter 3. Re-examining ethical challenges of using ethnography to understand decision-making in family caregiving networks of children with feeding tubes.

(Loftus, S. (2022). Re-examining ethical challenges of using ethnography to understand decision-making in family caregiving networks of children with feeding tubes. *Children's Geographies*, 0(0), 1–13. <https://doi.org/10.1080/14733285.2022.2026882>)

3.1 Abstract

Researching the experiences of children reliant on family caregivers is methodologically and ethically challenging. Conducting feminist digital ethnography within this context requires rethinking established feminist methods, including problematizing the assumptions of autonomy and individualism that undergird notions of decision-making. In this paper, I explore ethical decision-making within the context of multi-voice care teams for children with feeding tubes who require long-term care. Within geography, my work builds on previous discussions of ethics and feminist methodology by examining the tensions between the emancipatory goals of feminist scholarship and the operationalization of those goals within marginalized populations like children and youth dependent on medical technology.

3.2 Keywords:

capacity, decision-making, feminist ethics, feminist ethnography, family caregiving of child with a feeding tube, autonomy

West Virginia University, Office of Human Research Protections. Approval
Number:2102246119

3.3 Introduction

This paper explores the ethical challenges of using ethnography to understand decision-making in family caregiving networks of children with feeding tubes. Conducting feminist

ethnographic research in a multivocal caregiving network³⁸ requires rethinking some established feminist methods which rely on the problematic assumptions of individualism and autonomy (Bell, 2014). Because of these assumptions, some people are excluded as legitimate research subjects because they are labeled as too vulnerable, resulting in their experiences being made invisible (Beazley et al., 2009; Wolpert, 1980). This erasure occurs both at the individual level, with stories and experiences not being shared within critical research and institutionally, as ethics boards and methodologies codify practices that exclude these voices.

This case study draws from my doctoral research of a digital feeding tube support community, The Feeding Tube Awareness Foundation (FTAF), which connects family caretakers of children with feeding tubes. This research aims to explore the difficulties of implementing feminist ethics and practice when researching family caregiving networks, especially those involving children with complex medical and developmental needs that are dependent on medical technology to sustain life (i.e. feeding tubes or intravenous nutrition). It also examines the imperfect and pragmatic realities of decision-making within complex caregiving networks. This research is still ongoing and involves collecting data through participant observation and digital focus groups in which I post questions in a social media group and members respond, and open-ended video interviews of members of the FTAF online community between Summer 2019 and Summer 2021. In this paper, an ethnographic description offers examples of decision-making practices within complex family caregiving situations that challenge assumptions of subjectivity and autonomy and pose ethical questions about decision-

³⁸ A team of caregivers, professional, medical, familial, and unpaid who collaborate to care for someone with complex medical and developmental needs, each with their own goals, objectives, and perspectives.

making where there are multiple voices and interdependence between the cared for and caregiver (Power, 2010a).

My positionality in this research is complex, as I have multiple roles. I am a scholar gathering dissertation data, a mother/caregiver of a son dependent on a feeding tube with complex medical needs, a long-time member/user of the FTAF Facebook group, and an advocate involved in various disability spaces in my community. As a member of the feeding tube caregiver community that I am researching, I aim to engage in ethical, emancipatory research that advocates for a better understanding of our needs and experiences (Nagar, 2014). Sharing our experiences safely and ethically is an essential part of making a difference for our community and requires fluid decision-making and consent practices that push against normative values that prioritize individual autonomy.

In this paper, I examine the assumptions and implications of feminist ethics of care and practice (Hauskeller, 2020). Specifically, I focus on the concept of “do no harm” pertaining to families making everyday decisions. I present for reflection an ethnographic description gathered from my fieldwork with family caregivers, primarily mothers, who provide daily care for their children (ranging from infants to seventeen) with feeding tubes. I attempt to better understand the strategies used by caregivers to navigate their daily lives, as expressed in their postings and interactions in the FTAF Facebook support group. Employing digital ethnographic approaches (Barratt & Maddox, 2016), I aim to move beyond “doing no harm” to actively making a difference in my community by sharing experiences and positively influencing policy and practices (Chalachanova et al., 2020; Macpherson et al., 2021; Douglas, 2016). I focus on families of children/youth/young adults unlikely to traverse the intangible line from dependent childhood to autonomous individual because of technology dependency (e.g. feeding tubes,

ventilators, intravenous interventions) and legal/cultural/social structures in the United States. This discussion does not preclude or foreclose the potential futures of these children; instead, it reflects current restrictions that families live with due to the medical-industrial complex, structural barriers in the legal, political, and service delivery system, the devaluation of human life on the edges of personhood (Svendsen et al., 2018) and the reliance on unpaid care work as a mechanism of long-term care (Campbell, 2015; Cassiman, 2011; Mitchell & Snyder, 2018; Tremain, 2005).

I start with a discussion on family caregiving in the United States, then review current literature related to the othering of people deemed unable to make decisions for themselves, either through decision-making practices or incapacitation, and the resulting exclusion of voices in multivocal care networks and the ways that ethical practices and standards might exclude vulnerable communities in the literature. I focus on the concept of “do no harm” pertaining to families making everyday decisions and provide detailed examples of how decision-making and subjectivity are entangled for family caregivers and the person receiving care. Indeed, these issues potentially impact research practices with individuals and communities everywhere, not just those deemed vulnerable.

3.4 Family Caregiving of Children with Feeding Tubes

In the United States, many children and young adults with enteral³⁹ and intravenous nutrition needs (feeding tube or IV dependency) are medically fragile, often with orphan diseases,⁴⁰ and require long-term care (Halliday et al., 2017; Nelson et al., 2015). Improvements

³⁹ Enteral feedings are given via Gastrostomy tube (G-tube), Jejunum tube (J-tube), Gastro-jejunal tube (GJ tube) or Nasojejunal (NJ tube) depending on placement.

⁴⁰ Orphan diseases have less than 200,000 cases in the US with unique clinical characteristics and significant, complex medical and developmental needs.

in medical interventions have prolonged life for many with rare and orphan diseases, placing them in a unique interspace, living outside of hospitals but still requiring significant medical care. As a result, the family home is transformed into a “medical home” (Kelly et. al, 2002) where family caretakers, most often mothers (Macedo, et al. 2015) are expected to provide extensive medical caregiving without compensation⁴¹. They rely on both formal and informal care networks to accomplish daily tasks in states of extreme precarity and ongoing crisis (Greer et al., 2007; Heyman et al., 2004; Power & Hall, 2018). While not all feeding tube users require long-term care, children with a poor prognosis⁴² and the most significant medical and developmental needs often do (Clifford Simplican, 2015; Gulla et al., 2020; Kittay, 2019; Nishigaki et al., 2016; Okido et al., 2015). Because of a lack of empirical research about technology-dependent children and their family caregivers, the geographic literature is virtually silent on the experiences and needs of this community (Jenkin et al., 2020; Stafford, 2017).

3.5 Dependency and Individualism

Children with feeding tubes who need long-term care often have large care networks⁴³ that they depend on for intimate and mundane care. These networks are filled with tensions, contradictory perspectives, and uneven power structures, often complicated by economic, political, legal, and social expectations (Hauskeller, 2020; Young, 2002). Understanding caregivers' experiences in this context require unpacking these tensions, particularly around decision-making practices. Across many settings, family caregivers make mundane and life-

⁴¹ This practice is embedded at the policy level via support programs using neoliberal discourse around natural family supports.

⁴² In medical terms, a prognosis is used to describe the likely recovery, outcome, or course of a disease.

⁴³ Networks of care include family, friends, doctors, paid caregivers, and representatives from various social service agencies (Lawson, 2007; Macedo et al., 2015)

altering decisions for their children without their input due to severe medical, communication, or developmental delays. Even as social, cultural, and legal structures accommodate this process, through parental rights mechanisms, there is an uneasy tension that increases as youth approach the legal age of majority when parental rights end.

Regardless of the child's age, conflicts can occur as different opinions emerge around issues. Resolutions depend on several factors, including beliefs about dependency and competency, two concepts that are socially constructed, culturally variable, and situated within temporal frameworks that are grounded in normative assumptions (Kafer, 2013). For example, the dependency of a child upon a parent is generally acceptable in an American context, while the dependence of an adult upon a parent is not. The first is situated as natural, the second as a problem that needs to be solved, shamed, hidden, managed, or legislated away as the case may be (Katzman et al., 2020; McRuer, 2005; Mitchell, 2015; Samuels, 2017).

Destabilizing identity categories (like child and adult) across space and time (Puar, 2009) and re-examining the way we understand subjectivity, agency, and situated knowledge (Haraway, 1991; Judge, 2018) could prevent differentiated *Othering* (Hyndman, 2007), where people with cognitive impairments are more *Other* than some. This *othering* creates exceptions and differing practices (e.g. proxy voice⁴⁴, incapacitation⁴⁵, surveillance) that otherwise would be unacceptable, both in theory and practice. Similarly, destabilizing temporal categories (e.g.

⁴⁴ Proxy voice is the use of a 3rd party to make decisions for a person that has been deemed incapacitated and unable to decide for themselves.

⁴⁵ In practice, incapacitation removes agency from the individual and places it in the hands of a third party (a guardian), sometimes a family member, other times an institutional representative, or the State (Glen, 2015).

childhood and adulthood) offers a way to challenge assumptions and approaches that marginalize people who do not conform to normative constructs of time (e.g., developmental milestones, chronic illness, prognosis) (Kafer, 2013). Even so, normative temporal categories like childhood and adulthood cannot be rejected or theorized away, regardless of how arbitrary, because needed systems and structures (like education, health care, and legal rights) embed temporal categories as determinants for access, eligibility, and service provision.

These necessary support systems are deeply rooted in humanist values of individualism and autonomy (Jenkin et al., 2020; Dowling et al., 2019; Breitzkreuz, Rhonda, et al., 2014). Discourses of empowerment constructed through neoliberalism reify states of dependency (Dowse, 2009) for those failing to meet idealized norms (Ellis, 2018). Against the backdrop of individualism, children/youth/incapacitated adults needing long-term care with technology dependencies are positioned to be undervalued, unable to be economically productive (and subsequently requiring economic support), perpetually vulnerable, incompetent, and requiring protection against their own bad decisions (Goodley et al., 2014; Lewiecki-Wilson & Cellio, 2011).

In contrast, decentering individualism, epistemologically and in practice, challenges this view of dependency and recognizes that everyone has been/will be dependent at some point in their lifecycle (Kittay, 2019). As Kafer (2013) suggests, able-bodiedness is a temporary category. This reframing makes room for a relational perspective (Clifford Simplican, 2015) which situates dependency within a nested set of relations based on care needs that are neither fully transparent (Kittay, 2011) nor opaque (Butler, 2005) but instead consists of reciprocal relationships, both positive and negative, within the care network (Milligan & Wiles, 2010; Power, 2010b, 2010a; Wiles, 2003). In capitalist neoliberal societies, educational and political resources for children

and young adults with disabilities prioritize independent living skills, autonomy, and self-advocacy while neglecting concepts of relational autonomy (Dowling et al., 2019) and alternative ways of living based on interdependency and supported living (Hall, 2019) with scaffolding provided by networks of care.

Care networks still have challenges, especially relative to internal power dynamics. For example, tension within the team is compounded by complex care tasks where less-than-perfect situations develop that require fluid and flexible strategies for decision-making (J. M. Bell, 2013; Toly et al., 2019; Weaver et al., 2018). Also, an unrecognized plurality in decision-making requires detangling the multiple voices within care teams, the ways they interact, and how some voices are elevated and some subjugated based on the speaker's identity and perceived value.

3.6 Subjectivity and Agency

While elevating marginalized voices is a central part of feminist emancipatory scholarship, often unchallenged, is the positioning of *self* as a rational, autonomous individual (Butler, 1988; Collins, 2002; Hartsock, 1983) able to make decisions, perform independently, and express autonomy and self-consciousness (Mitchell, 2015). Western morals and ethics⁴⁶, including feminist ethics, offer an incomplete conceptualization of the rights and justice for people needing long-term care (Beaudry, 2021; Davis, 2007; Freeman, 2018; Hartley, 2020). As a result, western socio-cultural values construct some people with cognitive disabilities as 'human non-persons' because of their lack of demonstrable agency who require decision-making

⁴⁶ Social contract theory, Theory of the Mind, Hume's 'Law of Humanity', Locke, Kant, Hobbes, Rawls are all predicated on assumptions of self-awareness, rationality, reciprocity, regulation, executive function, or some other degree of capacity (as demonstrable through common sense means).

practices like proxy voice, guardianship, and incapacitation (Campbell, 2015; Grech, 2011; Kittay, 2011).

Incapacitation, as a mechanism, justifies *othering* and operationalizes the State's intrusion into the intimate affairs of disabled people using the language of protection and "best interest" (Cuddeback-Gedeon, 2020; Daly et al., 2019). Dinerstein (2012) describes guardianship as 'civil death' because the protected individual is no longer "permitted to participate in society without mediation through the actions of another if at all" (p. 3). The use of incapacitation, which Sabatino & Wood (2012) call a legal fiction, reflects "society's prevailing belief concerning individual autonomy and social order" and as such is highly contextualized (2012, pp. 35–36).

Evolving definitions of incapacitation reflect shifts in policy at the United Nations⁴⁷ and suggest that societies provide supported decision-making instead of substituted decision-making (e.g. guardianship) (Murray, 2018). However, less clear is how supported decision-making differs from guardianship in practice because in both policies, western liberal ideology remains uncontested, and the operationalization of "best interest" remains unclear.

Regardless of whether framed in a rights-based model or through supported decision-making (Murray, 2018), the goal of feminist ethical practice is to include the research participant in the process through reciprocal relationships that respect the subjectivity and voice of the individual (Judge, 2018). In practice, this is challenging for people with severe medical, communication, and developmental needs, especially in multi-voice care networks, and when the guardian and the 'protected person' might disagree (Cuddeback-Gedeon, 2020). Both feminist

⁴⁷ Convention on the Rights of Persons with Disabilities: Legal Capacity and Supported Decision Making.

and children's geography literature offer resources for resolving differences and recognizing multiple voices.

3.7 Ethical Methodologies and Practices

Children's Geographers and Feminist scholars attend to uneven power relations and elevate the voices of marginalized people. For example, Children's Geographers have centered children and their experiences, including those with disabilities (Holloway, 2014; Holt, 2004; Stafford, 2017). They have developed practices (like child-centered, participatory, emancipatory, and inclusive approaches) that shifted the child from being the object of research to being an actor with agency and subjectivity (Beazley et al., 2009, Chalachanova et al., 2020; Holt & Holloway, 2006; Jenkin et al., 2020; Douglas, 2016; Macpherson et al., 2021; Nind et al., 2015). However, including children's voices in research required challenging adultism and the failure to recognize that children have their own geographies and subjectivities (Holt, 2004; Stafford, 2017) and that positioning children within subordinate and dependent positions denies their voice in the research process (Holt, 2010; Hopkins & Bell, 2008). In this way, children should decide "whether to participate in research and what aspects of their stories to divulge" (Holt, 2004, p. 14). Further, some research methodologies and practices, particularly "research by proxy, where teachers and parents are asked to speak for children with disabilities and account for their experiences in various aspects of their lives" (Stafford, 2017, p. 602), rendered children, particularly those with disabilities, invisible as legitimate research participants.

Similarly, Feminist researchers embrace the use of participatory and emancipatory approaches to include voices previously marginalized or silenced (Elwood, 2009; Elwood & Leszczynski, 2018). Emancipatory research calls for the research respondent to be involved in the design and process of data collection (Caretta & Riaño, 2016) and utilize informed consent to

ensure participants are aware of the potential uses and risks of participation. Mietola, et al. (2017) argue for emancipatory research to acknowledge how ableist cultural and institutional practices within Institutional Review Boards (IRB), research ethics committees, and methods in the field, marginalize and reify ableist and paternalistic/infantile⁴⁸ representations of people deemed unable to speak for themselves. For example, the use of proxy voice (for examples, Karlawish, 2003; Kim et al., 2004; Luce, 2003; Silverman et al., 2004) to understand decision-making in a multi-voice context complicates established feminist validity techniques like member checking and self-reflexivity (Caretta & Pérez, 2019). Operationalizing inclusion practices remains challenging and requires re-examining the meaning of participation within the context of multi-voice subjectivity and potential unintentional consequences (Clark & Richards, 2017; Goodley et al., 2014; Goodley & Runswick-Cole, 2016; Holloway, 2014; Holt, 2004; Runswick-Cole et al., 2018; Stafford, 2017). For example, I argue that pragmatically the ‘voice’ of my research is necessarily multi-vocal; at a minimum, there is the voice of the family caregiver who provides the daily caregiving tasks, the voice of the child/youth/ incapacitated adult with a feeding tube; the voice of the support apparatus (e.g. the State, medical network, paid caregivers), or even the forum owner (FTAF) who moderates which questions are posted and has the power to delete or elevate responses. In addition, there are many other voices of members of the care network, which might or might not “officially” speak for the individual but are still important actors in the everyday decision-making process.

⁴⁸ This process of failing to recognize the agency and subjectivity of people with disabilities parallels similar lack of visibility of children in some literature.

While there is a clear directive to ‘do no harm’ in feminist practice, it is less clear what harm looks like in the context of a complex network of caregivers. The following case study explores the complexities of these issues in practice.

3.8 Case Study

Drawing from a case study, I present examples of difficult decision-making that family caregivers encountered within multi-voiced care networks and are drawn from data collected between 2019-2021 as part of a digital ethnography of a Facebook support group for family caregivers of children with feeding tubes, The Feeding Tube Awareness Foundation (FTAF). Facebook posts and interviews illustrate problematic aspects of decision-making family caregivers encountered in both day-to-day physical and virtual places relative to their caregiving tasks. Excerpts were compiled into ethnographic descriptions in support of the figurations used in this paper.

Respondents are members of a global family support group on Facebook with sixty-five thousand (65,000) followers. To date, twenty (20) open-ended video interviews have been conducted with family caregivers, all mothers of children⁴⁹ with feeding tubes, sharing their stories unprompted and with limited interruptions for clarification of terms or details. In addition, fifty (50) other family⁵⁰ caregivers have responded to the posted research questions. The interviews were open-ended and began with requesting verbal consent and a prompt to share how they became involved with the Feeding Tube Awareness Foundation. Jane and Ichabod are

⁴⁹ The children ranged in age from infant to seventeen (17) years old.

⁵⁰ By the end of the research period, more 116 individual respondents had posted to at least one research question.

compiled figurations⁵¹ of posts and interview excerpts from more than fifty (50) hours (collectively) of zoom interviews with family caregivers of tube-dependent children/youth ranging from infancy to seventeen (17) years old. Drawing from ethnographic fiction, the case study recognizes the partial and opaque nature of people’s stories and incorporates events that actually happened combined in ways that summarize the shared experiences of many members of this community (Jacobson & Larsen, 2014).

Disentangling the experiences of the family caregiver from the person receiving care is imprecise, challenging, and at times impossible because of complex medical or developmental delays and requires shifting from an individual voice to multivoiced accounts. Jane, in the interview, is speaking about their (mother and child) shared feeding tube story and trying to relay individual experiences. Jane and Ichabod currently live in their⁵² family home. Jane provides total daily care for Ichabod with support from family members and an extensive medical team they see regularly. Jane works part-time from home and has found more flexibility from her employer since Covid. Ichabod receives financial and other support through a state waiver program⁵³. Jane and Ichabod spent significant time in the regional children's hospital throughout his childhood and had several traumatic experiences⁵⁴ during those stays. Jane’s partner helps with caregiving when he can, but he works full-time outside of the home. There are family

⁵¹ In the spirit of Donna Haraway, where figurations “collect up hopes and fears and show possibilities and dangers” (D. J. Haraway, 2004, p. 1), I am creating imaginary figures to “root people in the stories” of the family caregivers in this research.

⁵² I speak in the plural form to recognize the multiple subjectivities of the figuration, the care networks, and the various gender identities of the respondents.

⁵³ Katie Becket Waiver and Home and Community Based Waiver are two State based programs intended to provide services to children with significant medical and cognitive needs to allow them to remain at home.

⁵⁴ Many of the mothers described their experiences as traumatic. In some cases, they were referring to encounters with insurance companies, medical personnel, social service support systems, painful procedures, near-fatal complications, harassment, and discrimination.)

members who help periodically and limited paid staff occasionally. In practice, Jane is responsible for making everyday decisions, including life-and-death interventions. Ichabod does not clearly express his wants or needs using spoken language, verbalizations, or gestures. Ichabod's prognosis is poor, and he requires total daily care (e.g. feeding, dressing, toileting) due to congenital abnormalities and "failure to thrive⁵⁵".

Jane received minimal training before bringing Ichabod home from the Intensive Care Unit and has figured things out through trial and error, resulting in both positive and negative experiences for them both. She asks for guidance from doctors, nurses, and other care team members but finds it difficult to get help from them. Jane described the importance of being in the Feeding Tube Awareness Facebook group and having other digital support spaces to go to.

"Before getting a diagnosis, my experience was one of isolation, of being scared, struggling to find a community, because you don't know any person in real life that has ever experienced anything like this" (Jane, Interview 1).

For example, in her everyday caregiving, she needed the FTAF Facebook support group or her other digital support places to get the information she wasn't getting in other offline places. In the physical world, her decision-making was often challenged or even disregarded by other members of the care network, particularly doctors and specialists. Jane expressed that she felt discounted and ignored and like her experience with Ichabod didn't matter. In contrast, the practical information she needed was online in the FTAF group.

⁵⁵ Failure to Thrive is a diagnosis given when height and weight are significantly below other children of similar age and sex based on normative height/weight/sex charts.

“they [forum group members] already understanding [*sic*] how to do certain things or they already have ways to figure it out...you know, it's 2:00 a.m. on a Friday night that something happens, and you have to figure it out, or it's a holiday [laughter] ... And these are [*sic*] things, like everybody experiences, but you don't know that at first and nobody tells you when you first go home with the tube. I remember running to the ER the first time there was granulation tissue and running to the ER the first time the NJ(Nasojejunal tube) was pulled out. And had I known that every child, even those with severe fine motor skill deficiencies, poor eyesight, whatever, will be able to pull it... that would have helped a lot...” (Jane, Interview 1).

Jane's identity and the community became entwined with her role as Ichabod's caregiver. Even though she didn't have a tube herself, her daily life was filled with the realities of tube dependency. The feeding tube community became her community, where she went to solve problems, to help her make decisions through the precarity and crisis of raising children in a medical home:

“I could just go on Facebook or whichever group and say like, listen, okay, this is happening. What do I do next, quick, instead of checking up with the doctor, I'd have like ten people answering my posts and saying, do this, and I'd post videos and pictures and ask what to do next. So we can solve the problem” (Jane, Interview 2).

Outside of the FTAF support group, Jane and Ichabod are present in other social media spaces through Instagram and a blog, which focuses on the challenging aspects of daily living. Jane created and maintained these digital spaces and uses plural language (e.g. our story) that reflects their entwined experiences. Both the blog and Instagram accounts are popular with significant followings.

Even though Jane had been sharing details about their daily lives for years in the hope of receiving help with feeding tube-related problems, as Ichabod grew older, Jane started to worry about sharing information on social media. For Jane, having a community online where people shared stories and asked questions was invaluable, but, recently, she'd started thinking about

privacy. For example, she hadn't realized that by asking questions in the FTAF Facebook group (which is public), her "non-tubie" friends on Facebook would get notifications of her post.

"I've had some of my posts, some of my friends can see if I have posted, and I don't necessarily want the world to know. Yeah. Like they get notified with that. Right. And so I would have people comment on that group that I didn't realize they could see my post. And I was like, whoa, like I didn't... you didn't need to know that we were in the hospital again. "(Jane, Interview 3)

This bleeding of information, of both her own and Ichabod's intimate experiences into areas of her life that she hadn't intended, is one of the unintended consequences of her decision to share information online. Ethically, the issue is that she is also sharing Ichabod's experiences without a way to clarify whether Ichabod agrees, which is problematic. Jane has expressed her need to connect, find a community that understands her, and have a place to problem-solve everyday issues she faces. She has found her place online, in the FTAF Facebook group and other online communities, in ways she did not find in the physical world. Jane expressed that without her online resources, she cannot provide the necessary care to Ichabod.

But would Ichabod want all these details shared? Without the ability to ask Ichabod, as Sarkadi et al. (2020) suggest, Jane is left with having to decide for them both. Is she doing "no harm"? Do the benefits outweigh the risks? Overall, Jane believes so. She describes her digital communities as a "lifeline" and a "lifesaver." She credits the solutions from the FTAF group with solving problems, especially when there is a conflict with medical members of the care team.

"I kept telling the GI [Gastroenterologist] that it's the formula, that Ichabod wasn't tolerating that type...but he wouldn't listen, just dismissed my concerns and changed the feeding rate. The doctor said to me...to my face...' oh, so you're the doctor now after

googling it'...he was very rude, very disrespectful to me...basically saying...sit down and shut up." (Jane, Interview 4)

Jane explained that she had googled 'severe and frequent vomiting' many times. Still, help only arrived after posting her experience in FTAF, and she felt validated after receiving many responses and suggestions from other caregivers. From there, after an intense conflict within the care team (existing doctors and insurance), Jane found a new specialist who diagnosed a missed rice allergy (the previous formulas were all rice-based).

"And I should tell you, he [the previous doctor] was so angry when we were able to switch ...He [the original doctor] sent us a letter that said he could no longer accept us as a patient. And he sent a certified letter, a certified letter! And I wanted to be like, I fired you first. But I didn't because, you know, you kind of had to just shut up and deal with it." (Jane, Interview 4))

On the other hand, she also expressed that she started to receive negative comments about her posts over time, which bothered her. She felt like people, particularly people outside of the feeding tube community, in the "real world" that she "had to friend" on Facebook, didn't understand her caregiving responsibilities and were insensitive to their experiences as a feeding tube family. She felt people are judgmental.

"They were talking about me like, oh, she put so much medical stuff. I'm like because I use my Facebook to post medical stuff. If you don't want to look at it, then don't. I'm really like, what is on my Facebook wall is my Facebook wall. So and I thought that maybe people shouldn't know, things that are private and ever since then...but it's very important ... So I am fine...I'm open to it... And we have an open like...oh...I don't care. Why would it bother me? It's fine to me. And I had to be able to effect things, to change what wasn't working" (Jane, Interview 2).

As Jane spoke, she was conflicted, torn between needing to draw on her FTAF community to help solve her day-to-day problems but worried about people criticizing her. More importantly, she doubted her use of these spaces, second-guessing herself and her decisions to post to the group. But, in the end, she decides that her need to find answers and solve her everyday problems outweighed the negative aspects.

As time progressed and Ichabod aged chronologically, Jane's unease grew. Ultimately, Jane decided to try and separate her own experiences from Ichabod's. She created a separate blog where she chronicles her own experiences as a caregiver and another blog that reflects Ichabod's story.

“[Ichabod] is getting older and it just felt that I needed to add some separation. That Ichabod's story and mine are different. That seemed more important now than before when they were younger.”

She wasn't sure if this approach was the right decision, but she feels that Ichabod needed his own voice to tell his own story. Jane also wanted to tell hers, and she thinks that their stories might diverge at this stage. To be true to both, and given Ichabod's inability to speak for himself, she struggles with telling both stories and respecting each of their subjectivities.

Jane's dilemma delves to the heart of the issue; if she is speaking, then whose story is being told? Can Jane and Ichabod's stories be untangled, or are they too intertwined? Jane and Ichabod feel *crip time*⁵⁶ and the growing schism between normative chronological and

⁵⁶ Crip time reflects the complex way that time and space are experienced by people with disabilities because of normative temporal and spatial frameworks (Kafer, 2013; McRuer, 2005; Samuels, 2017).

developmental age and the ever-increasing feeling that he needs privacy (Atwell et al., 2019; Kafer, 2013). As Jane and Ichabod age, Jane performs as herself and Ichabod in separate (but not) voices online in reaction to the child/adult binary and normative assumptions that comprise their crip, non-normative journey.

Neurotypical children can be asked what (if anything) they want to share (Sarkadi et al., 2020), but that is not the case for Ichabod. Previously, Jane felt confident that she was giving and receiving help by sharing their story, but now she was unsure about “sharenting” on her blog (Holiday et al., 2020). Even without “verbal” permission from Ichabod (Lipu & Siibak, 2019), she thinks he approves based on reading his body language when they skim comments on the page (Chalklen & Anderson, 2017; Moser et al., 2017). For Jane, this process is unclear because she cannot receive a definitive answer from Ichabod about his wishes. There is no declarative mechanism for Ichabod to express his decision. Jane’s decision process must rely on her interpretation and contextualization of Ichabod’s every day. Eventually, Jane decides to close Instagram and create a virtual ‘separation’ between herself and Ichabod as they move through crip time, the end of an atypical childhood, and the unrealized expectation of independence and adulthood (Kafer, 2013).

The previous excerpts describe how FTAF, and other online spaces, influence Jane’s ability to provide care to Ichabod and inform her decision-making. These decisions are complicated by the reality of her multi-voiced care team, which sometimes has different perspectives and resultant tensions between members about final decisions. These tensions demonstrate the nested relations of power discussed by Kittay (2011) and the relational and interdependency of caregiving (Milligan & Wiles, 2010). In addition, Jane is guided by feelings

about the ‘right thing to do’ in her everyday context and worries about the unexpected and potential harm from her decisions.

More importantly, these examples demonstrate uneasy tension around embedded concepts of subjectivity and agency in constructs of the western autonomous individual and paternalistic ideas of protection. For some, decision-making reflects an expression of desire, will, and agreement that can be straightforwardly asked and answered. But for others, decision-making is fraught with tensions, uneven power relations, anxiety, and uncertainty where a yes or no requires negotiation, reflection, and fluidity in response to changing circumstances, precarity, and crisis.

3.9 Conclusion

This paper focused on the concept of “do no harm” pertaining to families making everyday decisions and provided examples of how decision-making and subjectivity are entangled for family caregivers and the person receiving care. Jane’s experiences expose a blurring of subjectivities, both online and within the care network, where contested decision-making examples illustrate wider questions about multi-vocal consent. Feminist scholars are challenged to disentangle the various threads of voices within interdependent care networks to better understand whose voice belongs to whom and the power relationships that impact the everyday experiences of family caregivers and technology-dependent people. Ethnography, particularly ethnographic approaches attentive to the complexities of virtual spaces such as social media sites, allow the beginnings of these conversations that follow the threads of these networks.

Incorporating the stories of people with feeding tubes (and their care networks) requires a reexamination of problematic assumptions of individualism and autonomy in feminist practices.

Jane's entwined subjectivity with Ichabod raises questions about who is being researched while also illustrating the difficulties of decision-making in real-life and death situations where imperfect choices are made in moments of extreme uncertainty and stress. Jane described how the online feeding tube community helped her and expressed the desire to help other parents navigate a twisty road of uncertainty filled with decision-making potholes and complex forks with no clear indication of which way to go. Even so, family caregivers of children with feeding tubes move forward to accomplish their day-to-day tasks, making decisions that are ugly when compared to rigid ethical practices but meet their own needs. They do this by sharing their stories online, giving voice to their experiences, and solving their problems through complex strategies that go around, through, and sometimes over barriers they encounter along the way.

The case studies presented in this paper also demonstrate how the concept of ethics and ethical practices rely on the problematic assumptions of individualism and autonomy embedded in western liberalism. Moreover, some ethical research practices might result in the marginalization and erasure of vulnerable communities. As a result, there is a need to reexamine these practices against the lived realities of respondents (e.g., family caretakers making difficult decisions) through empirical research like this case study. Within the context of some vulnerable populations, ethical and emancipatory research necessitates a fluid, grounds-up approach that allows a frank and necessary discussion about "who" is being protected, how and why, while encouraging new practices that include vulnerable communities. Feminist ontology and epistemology provide storytelling, bringing voice, as a primary way for emancipatory change. Researchers must continue to gather stories that are difficult to tell even with the challenges of multiple voices and understanding who is speaking and making decisions.

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Chapter 4. Relationships in a Digital Feeding Tube Community: Caring across space and time.

(To be submitted to Progress in Geography or other methods journal)

4.1 Abstract

Family caregivers of children with feeding tubes utilize digital support groups to form relationships that help them in their daily caregiving tasks. Building on digital geography, and STS literature, this research uses relational approaches, like Situational Analysis, to examine the articulation work (visible and invisible) of human and nonhuman actants that enable the forming of meaningful relations in these digital communities. These approaches also contribute to a more nuanced way of understanding how spatial and temporal fluidity in these digital communities constitute these relations and what care looks like across spatial, temporal, and even technological divides. My comprehensive examination of the Feeding Tube Awareness Foundation's (FTAf) online resources serves as a case study for understanding how family caregivers build and maintain digital relationships to support their daily caregiving. More so, this paper provides a window into the black box of deep web groups to illuminate the assemblages of human and nonhuman actors, the mechanisms that form and hinder relationships, and the resultant socio-materiality of caregiving practices.

4.2 Keywords: assemblages, anticipatory work, family caregivers, children with feeding tubes

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4.3 Introduction

Family caregivers of children with feeding tubes rely on formal and informal relationships to provide support, information, validation, witnessing, and affirmation of their caregiving efforts and to counter structural barriers they encounter within the various social service delivery systems they depend upon. These family caregivers sometimes turn to digital support groups to build relationships and fulfill needs they cannot satisfy in the physical world (Loftus, 2022). These relationships are as genuine for these families as those developed in the physical world, especially for family caregivers who might feel physically and socially isolated.

This paper explores how family caregivers form and maintain relationships in digital environments using two approaches: digital ethnography and situational analysis. While geographers have contributed to our understanding of the embodied practices of caregiving, the isolation of caregivers, and also intimacy and caregiving practices across distances, less is known about how family caregivers use digital spaces as part of their caring responsibilities (Boccagni, 2012; Douglas, 2016; Dyck, 2005; Parreñas, 2014; Power, 2010; Pratt, 2012). As such, there is a critical need to examine the growing and shifting roles of digital spaces in the everyday lives of family caregivers. This paper presents my case study of the Feeding Tube Awareness Foundation (FTAF) Facebook (FB) feeding tube support group and ethnographic descriptions of the role of both hosts and users (both human and nonhuman) in building, maintaining, and transforming this digital community. In this case study, I use feminist STS-informed relational methodological approaches in unique ways to examine the structures and dynamics in the FTAF FB feeding tube community to better understand how assemblages of actants (human and nonhuman) contribute to or hinder relationship building across space and time. These approaches also contribute to a more nuanced way of understanding how spatial and temporal fluidity in these digital communities enables the forming of meaningful relations. This is a significant contribution to how feminist disability geographers have considered family caregivers and landscapes of care because my work explicitly attends to the human and nonhuman ways that actants in digital spaces form and harm relations. Also, I demonstrate how these relationships, and the digital communities, impact the materiality of care for family caregivers of children with feeding tubes, an often invisible community within this scholarship.

Although the case study is based in the Global North, the ubiquity of smartphones brings digital communities like FTAF into the global sphere. As I will show later, the membership of

the FTAF community reflects this geographically diverse. Digital spaces⁵⁷ and their enabling technologies (e.g., mobile phones, social media) have been well studied by social scientists, with many papers examining the complex changes in cultural and social behaviors resulting from the embedding of technology in our everyday activities (Barratt & Maddox, 2016; Batty, 1997; DeLanda, 2013). Some digital spaces, like deep web communities⁵⁸, emerge as alternative, often creative spaces for counter-narratives, alternate discourses, and non-dominant cultural activity to flourish (Rose, 2016). These deep web communities join seemingly disconnected or even conflicting social arenas⁵⁹ to satisfy a variety of needs. Even though researchers have investigated the actions and motivations of individual users of digital spaces (see Alirezabeigi et al., 2020; Alper, 2014; Longhurst, 2016), more attention is needed to understand relationships forged among community members and the ways these relationships co-construct the spaces themselves (Simon, 2016). My research attends to this gap in the literature by exploring how member actants (both human and non-human actors) constitute digital communities and examines how relationships fluidly form and reform through simultaneous and asynchronous digitally mediated activities. The term *digital mediated activities* emerged from critical scholarship to reflect the varied ways technology permeates our everyday lives and challenges broader geographic conceptualizations of space and place (Lasén, 2015). Understanding how individual digital activities constitute digital communities requires relational approaches to

⁵⁷ The term digital space includes the internet, social media sites, websites, deep web, dark web, chats, and groups. I use the term internet interchangeably with the term online.

⁵⁸The deep web is a distinct digital space constituted by digital entities (e.g. Facebook, Twitter, Tik Tok, groups, chats) that are not indexed by mainstream search engines like Google.

⁵⁹Following Susan Leigh Star's use of social arenas as communities that overlap and intersect otherwise unconnected social worlds (Star, et al. 2016) membership of the FTAF FB community includes Doctors, Nurses, Family Caregivers, People with Feeding Tubes, Insurance Companies, Medical Equipment Suppliers. In this paper, my focus is on caregivers of children with feeding tubes (a diverse social world itself) and does not explicitly attend to these other social worlds.

explore interaction, reformulations, and relationships across diverse temporalities and what they mean to the people who co-create them. Further, this research contributes empirical examples of the ‘doing’ of relational approaches that focus on the entangled relations of human and nonhuman actors to show the spatial and temporal dynamics of digital spaces as part of broader geographies of care.

The ways caregivers and people with chronic illness use digital spaces to gather information, find resources, and share their stories have been well documented (Atwell et al., 2019; Colvin et al., 2004; Johnson et al., 2022; Kennedy, 2008). Less is known about how family caregivers use deep web groups like Facebook as part of their caregiving network. This omission has important consequences for how geographers conceptualize, methodologically design, and study the shifting dynamics of the digital in the lives of vulnerable populations worldwide. It also has implications for key concepts that undergird digital and human geography, like the role of technology in everyday lives, especially related to being present “in” a particular place at a particular time, how communities are developed and maintained in different contexts, and reframes isolation within the context of both physical and digital spaces (Dabrowska, A & E. Pisula, 2010; Findler et al., 2016; Lawson, 2007; Thyen et al., 1998; Yantzi & Rosenberg, 2008). Even though social science research about digital spaces increased after COVID-19, there continues to be a lack of attention to the methodological approaches and implications necessary to do this research. To address this, my paper develops ethnographic descriptions from the participant community while also exploring both the hidden and visible mechanics that form and sustain the digital community, including my interventions as a researcher-participant.

Digital spaces have moved beyond the “sharing and caring” roles previously studied, as seen through social media posts, illness narratives, online support groups, mourning/memorial

pages, and other digitally mediated activities that demonstrate how patients and family caregivers use digital spaces to stay connected and become active in political, social, and entertainment spaces (Jacobson, 2018; Murray & Steinberg, 2018). Understanding these communities also invites a reexamination of how we understand agency and power from a relational perspective.

Relationships in digital communities can be examined and understood as both infrastructure (that holds the community together) and connections (between members) that are formed by millions of daily interactions (Brinkerhoff, 2009). Within the FTAF FB support group, patients, caregivers, researchers, practitioners, hospitals, and other human and non-human actants (actors) form relationships and engage in sociality and activism that is meaningful to them (Brinkerhoff, 2009; Fortun et al., 2014; Postill & Pink, 2012).

Research that focuses on sociality and recognizing the importance of relationships within digital communities, like the FTAF FB feeding tube support group (Alper, 2014; Banks, 2017; Banks & Bowman, 2014; Ringland, 2018), challenges the privileging of in-person social interactions in the literature, especially for family caregivers, who are often socially and spatially isolated. Drawing from Jessica Brophy, digital spaces are *between* spaces where participation is recognized as both present and absent, as “the space occupied by the self-online is an interior (mind) made exterior (visible and/or present to others)” (2010, p. 940). In the context of these digital communities, it is important to explore how these digital spaces unravel how we think about the self, being visible, and being included.

As such, digitally mediated living occurs within liminal spaces filled with complex interrelationships of people, structures, and institutions that are (re)created--but sometimes also challenged--by millions of interactions (Smelik & Lykke, 2010). These interactions are

simultaneously unique and commonplace, creating shared experiences while enabling intensely personal and intimate reflections of individuality and collectivities. For many family caregivers, the entwining of digitally mediated living (e.g., tweets, posts, emojis, memes) at home (which is also potentially a contested site of resistance) results in fuzzy public/private boundaries (Blunt & Dowling, 2006; Fekade, 2019). For feeding tube families, where technology is also embedded within the body, issues of intimacy, proximity, and interdependency must be understood within the context of the interconnected relationships that form around the daily rituals of technology use (Ash et al., 2018; Elwood & Leszczynski, 2018). An analysis that considers the full implications of bodily technological assemblages is beyond the scope of this paper, but I recognize that it is a critical element of understanding the scope of the experiences of this community.

Rather, for this paper, I focus on the articulation work, both visible and invisible, that has been identified by feminist STS scholars as a key component of forming and maintaining relations and illustrate numerous “unsettled relations” (Thornham, 2000) that trouble preconfigured identities and locations, including the idea that digital spaces are neutral and equalizing (McNeil, 2008; Noble, 2018; O’Neil, 2017). Adele Clarke, following Strauss, describes articulation work as “tasks that facilitate efforts of people to do things together” (Clarke, 2016, p. 99). This work is often invisible and situational and reflects uncertainties of particular contexts, and is linked through translations by the mediators and intermediators in the actor-network (Star & Griesemer, 2016). Clarke identifies the visible articulation work as the “things, the objects, stuff, bodies, machines, wires” that occur during translations (Clarke, 2016, p. 85). Some examples of invisible articulation work are the classifications, simplifications, and regrouping of time and space that occur in order to create, understand and process visible work.

Situational Analysis (SA), and its precursor, Actor-Network Theory (ANT), have addressed the role of things and other non-human actants in so-called “social” analyses, challenging the primacy and ubiquity of social construction frameworks (Baron & Gomez, 2016; Callon & Latour, 1981; Clarke, 2005; Latour, 2005). SA and ANT suspend the *a priori* definition of ‘what is or isn’t social’ and instead focus on networks, assemblages, and/or ecologies of relations to examine “how” relations assemble or don’t” (Law, 2009, p. 141). They do this while also recognizing that agency is distributed among actants. In these approaches, non-human and human actants are initially considered equally when explaining how the community (re)forms and exists (Deleuze & Guattari, 2018; DeLyser, 2010; Latour, 2005). Further, these communities acquire shape and characteristics as human and nonhuman actants assemble (Delanda, 2016). Understanding how actants interact requires moving beyond traditional methods that reflect individual actions to focusing on the web of relationships that are formed (Law, 2009). Inspired by Foucault’s attention to techniques, dispositions, and maneuvers used to discipline bodies (Delanda, 2016), part of what STS scholars provide is a detailed autopsy of the workings of power at a micro level, which includes the material artifacts and nonhuman actants as part of these processes. In doing so, STS approaches have not only helped open up the inner workings and black boxes of power, especially relative to the use of everyday technologies but also highlighted overlooked opportunities for collective action and transformation (Latour, 2005).

4.4 From ANT to Situational Analysis: A Feminist and Ecological Approach to Relations

Building on, but also critiquing from a feminist perspective, this genealogy of relational analysis in STS studies, Adele Clarke introduces Situational Analysis (SA) as another methodological approach that considers the situatedness, variation, and differences of all kinds.

SA expand the canonical grounded theory approach established by Strauss through social world/arenas/discourse analysis, where the goal was to understand how multiple actors (social worlds) entered together into a shared space (a social arena) and engaged in all sorts of actions (negotiations, conflicts, discourses) to accomplish something. SA is rooted in this expanded work, contributing by shifting the focus to understanding not just the social actions but explicitly grounding analysis into the particular situation being examined. In other words, this approach explicitly addresses the context (the situation) and the recognition that all of the actors in the social arena have their own perspectives and worldviews (social worlds) that permeate the situation (Clarke et al., 2022). This is an important advancement because it incorporates a feminist epistemological focus on context and grounding in everyday realities and experiences.

Drawing from Star (1999) to develop an “ethnography of infrastructure” of the FTAF FB community, I use Situational Analysis to explore how relationships are assembled within fluid spatial and temporal contexts. In a SA approach, analysis and data collection occur concurrently, beginning as soon as data is available, with a focus on the complexities of relationships rather than the necessity of simplification, although some simplification does occur through the process of densifying and collapsing codes into areas of concern. The power of SA is that marginalized (outliers) and mainstream perspectives can coexist in the assemblage allowing for multiple perspectives to move forward without consensus. In addition, human and non-human actants coexist through the relationships they form. In this way, decentered approaches emerge, where the subject of knowledge/practice can shift and move in response to the analysis. As a result, ecologies of relationships can be explored through cartographies of situations and social arena⁶⁰

⁶⁰ Social arenas are communities that overlap and intersect otherwise unconnected social worlds (Star, et al. 2016).

maps of social worlds and their relationships. These situated material relationships necessitate methods that allow for multi-sited and multimodal research to best evaluate such differences (Clarke, 1995; Haraway and Goodeve, 2018).

Situational Analysis provides the techniques necessary to be able to combine these data into social arenas for comparison without requiring them to conform to each other. Relations that emerge from interactions among different actants across perspectives allow for an ongoing process of exploration and analysis (Clarke et al., 2018; Mead et al., 1934). There are three types of techniques in SA: situational maps, social worlds/arena maps, and positional maps.

Situational maps help articulate the actants and elements in a particular situation being explored. The situation that I am exploring in this paper is the family caregivers of children with feeding tubes utilize digital support groups to form relationships that help them in their daily caregiving tasks, including my own intervention into the community as a researcher and a family giver.

Social worlds/arena maps visualize the “collective comments, relations and sites of action” (Clarke, p 4). Social worlds can be understood to be a group committed to a shared identity, meaning, and actions to meet their goals (Clarke et al., 2018). Social worlds focus on social action within particular communities of practice (which can be constituted by multiple social worlds). Social worlds reflect the collective actions of individual activities, not the individuals themselves (Clarke, 2018). As a result, social worlds can have identities that are more than the individual identities alone, a type of sum-of identity which allows for individual variations, “significantly, social worlds are actor-defined, permitting identification and analysis of collectives construed as meaningful by the actors in the situation themselves” (Clarke, 2018, p 150). Analysis using social worlds/arenas can be understood as “a relational ecological form of

organizational analysis, dealing with how meaning-making and commitments are organized and reorganized” across different boundaries and borderlands (*Ibid*, p. 150). A social worlds/arena map is one type of situational map that demonstrates the relationships between arenas within a social world. In my research, the social arena is the Feeding Tube Awareness Foundation FB group, which is constituted by different social worlds, including family caregivers, medical personnel, social service representatives, and many more.

At times these social worlds can reflect contradictory and/or oppositional world views, which can be visualized and analyzed by positional maps. Positional maps provide “simplification strategies for plotting positions articulated or not articulated” in particular situations (*Ibid*). All three types of SA can be used together or independently and can be applied flexibly and fluidly, as needed in the particular situation. As such, my case study of the FTAF FB feeding tube support group uses these three techniques to explore the role of both hosts and users (both human and nonhuman) in building, maintaining, and transforming this digital community. More so, this research describes how relationships in the digital community shape and inform the materiality of caregiving practices. Following Situational Analysis frameworks, which in turn build on STS approaches, my research examines not only how, where, and why family caregivers interact in the community but also how articulation work extends across space and time to shape and form the relationships themselves.

In what follows, I will introduce my case study of the FTAF Facebook Feeding Tube group, explain the main situation I explore, and provide examples of how human and nonhuman actors in the group help and hinder the formation of relationships using situational maps and social arena maps. My analysis of the articulation work and the visible/invisible work that occurs from human and nonhuman actant’s digital interactions contribute not only to a more nuanced

way of understanding spatial and temporal fluidity in these digital communities but also how investigating such interactions itself generates new relations. I finish with a discussion about how relational approaches like Situational Analysis⁶¹ provide insight into the assemblages that transform the Facebook group into a place where people know each other, interact and build relationships, relationships that, in turn, impact their capacity, not only to care for others but to feel visible and cared for themselves. This insight has implications for researchers studying other digital communities as well.

4.5 Case Study

The Feeding Tube Awareness Foundation (FTAF) is the largest feeding-tube family caregiver support organization in the United States, with a diverse membership consisting of family caregivers, people with feeding tubes, service providers, and the medical community. Similar to many other chronic illness family support organizations, FTAF is primarily an online-only organization with the stated mission of helping parents of children with feeding tubes. Data for this research was collected through survey questions and interviews conducted between the summers of 2019 and 2021. From these sources, I developed descriptions that are both specific to the family caregivers' experiences and common among many caregivers, including myself.

As a scholar-activist and a mother/caregiver of a son dependent on a feeding tube with complex medical needs, I hope to positively influence policy and practice. I am also a long-time member/user of the FTAF Facebook group and an advocate involved in various disability spaces in my community (Chalachanova et al., 2020; Douglas, 2016; Macpherson et al., 2021; Nagar, 2014). One objective of this paper is to describe the ways that the interactions between

⁶¹ Situational Analysis builds on genealogy of ANT and grounded theory.

community members with each other and with non-human actors assemble to (re)create the community.

Through my process, I provide examples from the assemblages of actants in the FTAF FB social arena from my analysis of actants in the group (which is partial and influenced by my role as a family caregiver) and influenced by the perspective of the family caregivers and the stories they relayed to me. Even as I articulate the social world of the family caregivers in this analysis, I recognize that I have not attended to the heterogeneity within this ‘family caregiver social world’. I also do not attend to the perspectives of other social worlds in the social arena, like the medical community, social service providers, and government representatives, who might also interject as actants. I use the term “assemblage,” as defined and understood by Clarke, as the combination of actants that create something more than the sum of the parts (2018). In the FTAF FB feeding tube group, the actants are diverse social worlds (both human and nonhuman), consisting of caregivers, children with feeding tubes, internet hosting companies, Facebook engineers, Facebook algorithms, DME companies, doctors, nurses, hospitals, direct care staff, medical feeding tube formula, delivery companies, siblings, family members, schools, agencies, state, the hardware; tube and internet, computers, wires, feed poles, backpacks, adaptive clothing, tubie pads, mickey-keys, and even the beeping of the feeding pumps. The situation I am exploring is how family caregivers of children with feeding tubes utilize digital support groups, particularly the FTAF FB group, to form relationships that help them in their daily caregiving tasks.

As you will see from my data and analysis of articulation work (hidden and visible) in the group, my research has implications on understanding the formation/maintenance/dynamics of these digital communities and methodological implications on their research.

4.6 Methods

I gathered family caregivers' experiences, mainly mothers of children and young adults (ranging from infants to twenty-two), with feeding tubes and other complex medical needs, by posting questions in the FTAF FB group resulting in more than one hundred and sixteen (116) family caregivers' responses⁶² to posted research questions. Additionally, I conducted follow-up video interviews with twenty (20) mothers producing more than fifty (50) hours (collectively) of unprompted stories⁶³. Family caregivers gave verbal consent and open-ended responses when asked how they became involved with the Feeding Tube Awareness Foundation. After collecting post responses from the FB group and transcribing the audio from my follow-up interviews, I used electronic qualitative data software (MAXQDA) to begin a thematic analysis of the data. Thematic analysis is a method used to identify interesting patterns in the data that can be organized as threads or themes for further exploration (Braun & Clarke, 2014). I coded my data using an exploratory, interactive process with a concurrent analysis of emerging ideas (Charmaz, 2008; Clarke, 2005).

A challenging aspect of this work is identifying research tools that allow for both specificity and commonality. While it is important not to 'abstract out' the detailed accounts from the family caregivers and situate each within the context of their feeding tube journey, the realities of doing research that could harm the respondents require extraordinary attention to confidentiality and anonymity. These concerns inform my criteria about inclusion/assembling the following examples of relations/interactions within the community. To this end, I am using

⁶² One hundred and sixteen (116) individual family caregivers responded to at least one of the seven posted research questions, with some of these family caregivers responding to more than one question and/or participating in a follow-up interview.

⁶³ With only limited interruptions for clarification of terms or details.

compiled figurations⁶⁴ (Jane and Ichabod ^[12]) as characters who voice composite narratives from the one hundred and sixteen (116) respondents⁶⁵. People’s stories are partial and opaque, and these figurations combine actual events and summations of the shared experiences of community members (Jacobson & Larsen, 2014). Using they/their pronouns for Jane/Ichabod recognizes the multiplicity of voices and explicitly acknowledges the difficulties in separating family caregiver experiences from their children's, especially when there are complex medical and developmental delays. As such, Jane’s experiences reflect *their* collective experience while leaving unremarked individual experiences that can not be understood in isolation (Loftus, 2022).

Using an iterative practice of exploration and refinement (Clarke, 2003), I identified commonalities in the experiences shared by family caregivers, looking for similarities with the goal of increasingly refined aggregation. Using a relational approach, I also wanted to understand how this Facebook Feeding Tube Community is (re)created by interactions between human and nonhuman actants.

4.7 Case Study: The Situation to be explored

Following a SA approach, I started my research by developing a messy situational map of the meta-level situation (caregiving for children with feeding tubes) that I am interested in exploring. Following Adele Clarke (2018), the first analytical tool I used was a Situational Map (Map 1), which helped me organize my thoughts about the narratives I had collected from the FTAF group. As you can see in Map 1, this first cut of the situation is very complex, with many

⁶⁴ Following the spirit of Donna Haraway, where figurations “collect up hopes and fears and show possibilities and dangers” (D. J. Haraway, 2004, p. 1), I am creating imaginary figures to “root people in the stories” of the family caregivers in my research.

⁶⁵ Jane and Ichabod do not represent one person, but instead are composite figurations formed from various narratives from the FTAF FB groups posted responses and follow-up interview questions. These two characters are an important technique to maintain respondent anonymity.

different actors (actants) identified by family caregivers. The actants in Map 1 are human (teachers, students, nurses, doctors, patients, family) and nonhuman (laws, equipment, supplies, services) actants that might (or not) represent different social worlds (schools, doctors' offices, hospitals, family, providers).



4.7.1. Map 1: Messy Situational Map: Caring for a child with a feeding tube with complex medical needs.

This situational map (Map 1) helps visualize the many different actants (human and nonhuman) involved in the caregiving of children with feeding tubes in the family home. Caregiving outside of an institutional setting is reliant on an unpaid family caregiver (usually a mother) willing to provide daily care while also navigating the various social worlds (doctors,

hospitals, insurance companies, government agencies, social service agencies, education agencies, etc.) that constitute their family's landscape of care. During daily caregiving tasks, the mother⁶⁶ functions as a "mother-expert" who is expected to function as a professional across several disciplines, often without any training or support. And yet, despite its messiness and complexity, this visual provides only a *fraction* of the social worlds that this mother finds herself navigating. As such, this very broad META situation was my first slice into a relational analysis of caregiving for children with feeding tubes. One of the persistent data points that arose, both visualized in the situation map and in narratives in my interviews, was the need for help with caregiving. While caregiving is a common problem for all parents, there are unique aspects of caring for a tube-dependent child. As visualized in Map 1, the scope and breadth of all of the 'pieces' involved in providing care for a medically complex child can pose significant challenges. For example, typical daycare settings might not accept the child, requiring the family to find private daycare. Here are some examples reported by Jane in the FTAF group showing how Jane struggles with finding other carers so they can work, attend to other children, or have respite for themselves.

We also have never left [Ichabod] with anyone. I even went to school with [Ichabod] 😞.
- Jane

I am an attorney and work from home during the day doing paperwork, and then when the hubs gets home from work, I go into the office in the evening and meet with clients. I make my schedule work around his. We do this partly because we need the money and mostly because I need a break. 😞 - Jane

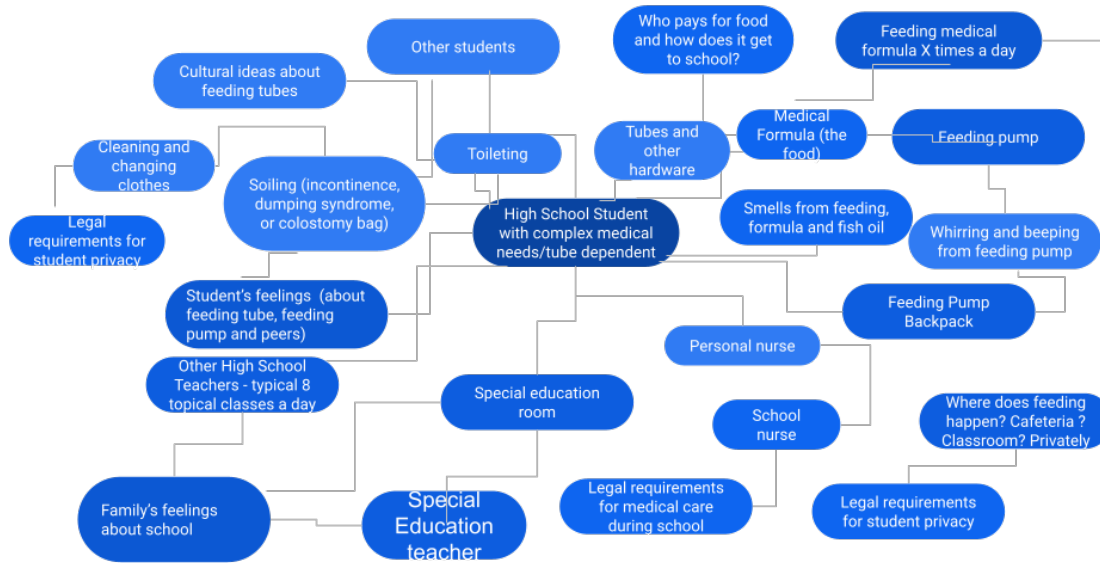
I waited until my [Ichabod] started school, and then I became a substitute teacher. You don't need a teaching certificate for that, just a certain number of college credit hours. Now I only work when [Ichabod's] in school. - Jane

⁶⁶ In my data set of 116 individual respondents, everyone self-identified as the 'mother' of a child with a feeding tube. I use the word mother to reflect this self-identification outside of specific gender identities.

In these narratives, Jane talks about the importance of school as part of their daily caregiving.

Figure 1a provides a more refined situational map of some of the human and nonhuman actants that reflect a day at school for a high-school-age student that requires total care⁶⁷.

Unpacking: Here's your lunchbox, have a great day at school.



What does a successful day at school look like?

Who is responsible for making sure all these things happen? What happens when things go wrong?

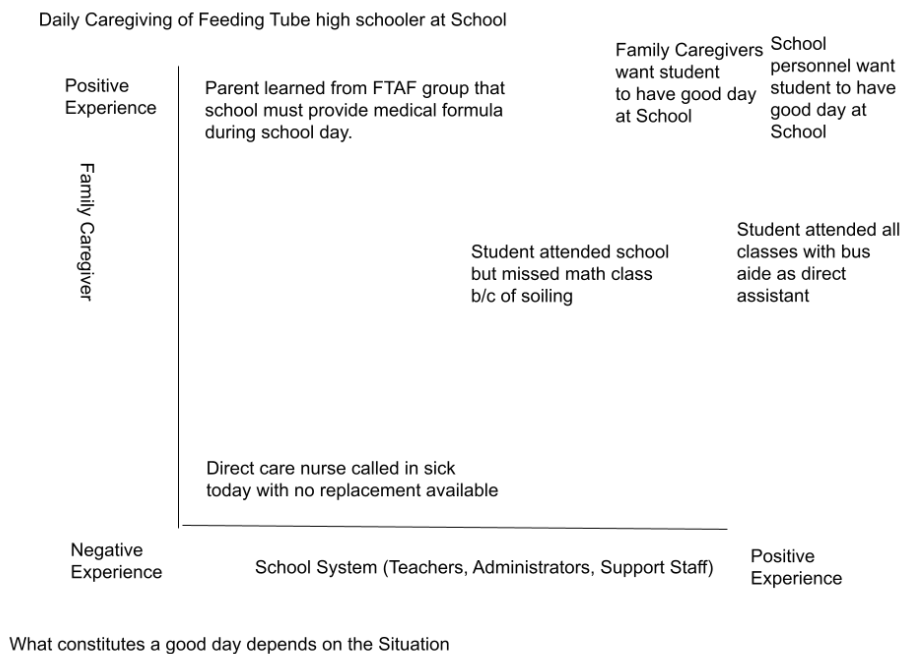
4.7.1a. Figure 1a: A Relational Map of one element (going to school) from Map 1 (See above).

A visual like this allowed me to move through the data and think about various interesting threads for further exploration and contributed to my thinking about the mother-expert and the overwhelming knowledge she must acquire to fulfill her daily caregiving tasks (in this case, the mundane task of ‘packing your child's lunchbox’). In addition, many of the elements in Figure 1a reflect the invisible articulation work that is a vital part of everyday care

⁶⁷ In this context, I use the word total care to mean a student that does not independently dress, feed, or toilet themselves and has significant supervisory requirements. This student could have a Global Assessment of Functioning (GAF) score of 40 or below.

for children with feeding tubes (e.g., the delivery of feeding tube supplies- medical tube formula, bags, syringes, etc.).

This relational map also illustrates the impetus for some family caregivers to look for resources to help them navigate these complexities. For example, one of the questions posed in Figure 1a is, who pays for medical formula at school? Another question is how and where does toileting occur, an especially difficult situation to address for high school students that might be incontinent and frequently soil or students with colostomy bags or dumping syndrome. Many family caregivers are overwhelmed and unsure of the answers and find themselves in a relationship with the school systems with different positions depending on particular situations (see the Positional Map in Figure 1b).



4.7.1b. Figure 1b: Positional Map of Family Caregiver and School System of High School Students

From the interviews and responses to my research questions in the FTAF FB group, situations like this (and others) are the reason that many family caregivers value and participate in the FTAF community.

Using situational approaches helped illustrate some of the complexities of the broad situation I was interested in (family caregiving of children with feeding tubes) and also underscore the specificity of the materiality of caregiving (e.g., daily feeding for a high schooler at school). These visual and relational approaches also help explain both the visible and hidden articulation work that is involved in the materiality of daily care (the arranging and coordination of all the parts and pieces involved in getting through the day).

4.7.2 My intervention as a researcher and community member.

My intervention as a researcher of the FTAF FB group presents another point of inflection where articulation work is made visible. While preparing to introduce the first research question, Traci Nagy⁶⁸ (the founder of FTAF) and I discussed the various ways that conversations occur in the community and the best way for me to engage with the community (as a researcher instead of a member). Our back-and-forth conversations (see Table 1) reflect the type of articulation work that Adele Clarke identifies as critical to creating and maintaining relationships (Clarke, 2005). As such, I visibly entered the FTAF FB arena as a new actant when my research questions were posted. However, before that, the FTAF Moderator and I interacted as actants making decisions about when, where, and how to post the research questions (see Table 1) and chronicles the mechanics of distributing my research questions to the group through a moderated post. My email interactions with Traci (who acted as the FB moderator for my

⁶⁸ Tracy gave consent to use her real name, and her founding of the Feeding Tube Awareness Foundation is public knowledge.

posts) occurred right before she posted my first research question to the group. This exchange captures a moment of hidden articulation work that undergirds the inner workings of the Facebook group. The FTAF staff person, acting as the group moderator, is a crucial node in the network of relationships because all group conversations start with a moderated post. In this example, the moderated post is my research introduction letter and my first Research Question, which asks, ‘Describe how long and in what ways you are involved in the Feeding Tube Awareness Facebook group.’

Through email correspondence in the days leading up to this first moderated post, Traci and I discussed the mechanisms of asking the research question (invisible work) and strategized a Plan B if no one within the community responded to my question. We were texting each other back and forth on the eve of the posting, both of us feeling anxious. Within minutes of posting the first research question, we had the following exchange:

4.7.2a. Table 1.

FTAF	9:05 pm	“I posted the intro/IRB information/first question tonight. I also scheduled a duplicate post for Friday morning. We have a better shot of reaching more people with more than one post. Fingers crossed. “
SL	9:29 pm	“Thank you! I’ve had two mothers volunteer for interviews in the first five minutes!!!”
FTAF	9:32 PM	“I love the internet.”

SL	9:34 pm	“Holy cow....and I was worried about crickets! We’ve got 22 responses in the first 15 minutes. I need to capture that somehow...”
FTAF	9:42 pm	“I will cancel the Friday post if you are overrun!”
SL	9:52 PM	“No, that is absolutely perfect! It will be great to have a big response because it just shows how powerfully people want to tell their stories. I love it! “

Another example of articulation work can be seen in Figure 5, where I take a different analytical slice of the moderated post referenced in Table 1. Figure 5 is a snapshot (taken at a particular point in time, in this case, January 18th, 2023) of the original moderated post. It captures the human and non-human actants engaging with each other while creating another

relationship node within the feeding tube community.

Describe how long and in what ways you are involved with the Feeding Tube Awareness Foundation (FTAF) Facebook group?

WVU IRB Protocol # | 2102246119

Principal Investigator: Dr. Maria Alejandra Perez, Contact information is 304-293-5603 and maria.perez@mail.wvu.edu.
Doctoral Candidate: Sara Loftus, sloftus@mix.wvu.edu

To whom it may concern:

I'm writing to invite your participation in a study of the use of digital family caretaker support groups. The specific study area is the online public Facebook group managed by the Feeding Tube Awareness Foundation. I am studying how family caregivers create and use digital groups as part of their daily caretaking routines.

Between the Spring of 2021 through the Summer of 2022, I will post a series (6) questions in the FTAF Facebook related to family givers use of and participation in the Facebook group. I will also recruit participants for follow up interviews with caregivers and Facebook group organizers at the Feeding Tube Awareness Foundation. I am a doctoral candidate in the Geography Department at West Virginia University. Participation in the research is limited to family caregivers 18 years and older. Data collected and follow-up interview responses will be kept confidential and anonymous, unless you give your explicit consent.

During the follow-up interview, you may choose to not answer any question. You may also discontinue the interview and your participation in the research project at any time. Focus groups and interviews should take no longer than 10 minutes and can be conducted at a time convenient to you. All interviews will be scheduled over ZOOM.

I welcome your interest in being interviewed. For more information, or to arrange for an interview, please contact me at sloftus@mix.wvu.edu.

Sincerely,

Sara Loftus
Doctoral Candidate
Department of Geology & Geography
West Virginia University
Morgantown, WV 26506

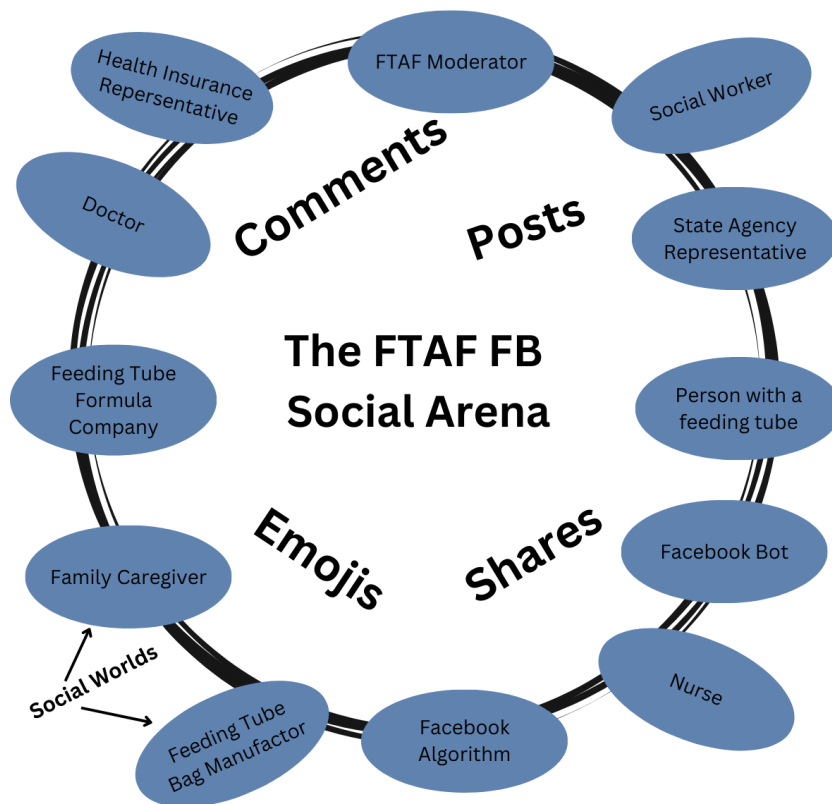
  55

64 comments 9 shares

4.7.2b. Figure 2.

This relationship node reflects articulation work by multiple actants, some human and some non-human. The original actant was me, as an external researcher, requesting the FTAF moderator to post my IRB information and the first research question. The moderated post, upon creation, becomes a nonhuman actant that brings together other actants from different social worlds within the FB feeding tube community.

For example, Map 2 visualizes the diverse social worlds that could engage as actants in the FTAF FB Group (the social arena).



4.7.3. Map 2. The FTAF Facebook support group social arena and diverse actants

This social arena map illustrates different social worlds that could assemble within the FTAF FB Social arena. In this context, the actants retain their identities (even if those identities might be contradictory to others in the group) while building relationships around mutually beneficial interactions (commenting, sharing, posting, emojis). These actants engage with the moderated post (nonhuman actant⁶⁹) in several ways, creating or responding to new human and nonhuman actants. Through this ever-expanding process of digitally mediated activities, new

⁶⁹ Once the moderated post is uploaded to the FTAF FB group, the post itself becomes a nonhuman actant that can engage with other community actants. The post has become separated from the human moderator that created it.

relationships are formed, broken, and reformed within the community. These actions occur across space and time in fluid ways as actants engage and disengage with each other in the FTAF FB social arena. This one social arena (the FTAF group) is just one of many social arenas, all gathering within the larger social arena of Facebook, which in turn is a social arena within a deep web digital space. Composed of billions of digitally mediated activities across multiple scales, geographies, and temporalities, these social arenas and the relationships within them are constantly readjusting and recreating themselves into communities.

To explain further, I will break down the actant interactions in Figure 2, which is a snapshot of my first research question post. As a network node, this post becomes another network meeting point that helps articulate diverse spatial temporalities. This node connects me, the FTAF moderator, and the community at large while also doing invisible articulation work of providing legitimacy for my questions and a site for aggregating individual experiences.



4.7.4. Figure 3: Snapshot of actants captured in January 2023 of Moderated Post_RQ1

The post itself is a non-human actant that elicits a response from additional human and non-human actants and becomes not only a node but also performs care work by legitimizing values and concerns of the community and makes members feel visible as evidenced by the fast and significant engagement. For example, this node links fifty-five (55) other human actants who expressed approval through emojis and sixty-four additional actants who responded to the original post. When shared, this actant was connected to nine (9) additional actant networks. In other words, the articulation of diverse spatial temporalities *is* care work.

There are also non-human actors reflected in Figure 3. The sixty-four (64) comments posted become non-human actors that could prompt additional human interaction. In addition, a

Facebook Bot (a non-human algorithm) engages in invisible aggregation work to determine which of those 64 comments are ‘most relevant’ and should be prominently displayed at the top of the post feed. Finally, the image of my IRB letter (Figure 2c) with the West Virginia University credentialing becomes another non-human actant that lends legitimacy and formality to the post and establishes my credibility.

WVU IRB Protocol # | 2102246119
Principal Investigator: Dr. Maria Alejandra Perez, Contact information is 304-293-5603 and maria.perez@mail.wvu.edu.
Doctoral Candidate:: Sara Loftus, sloftus@mix.wvu.edu

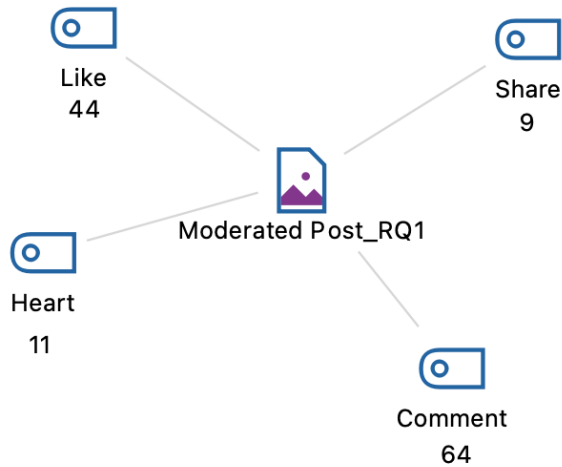
To whom it may concern:

I'm writing to invite your participation in a study of the use of digital family caretaker support groups. The specific study area is the online public Facebook group managed by the Feeding Tube Awareness Foundation. I am studying how family caregivers create and use digital groups as part of their daily caretaking routines.

4.7.5. Figure 3a. IRB Credentials (nonhuman actant).

Relationships formed during the actant's engagement with the moderated post can also be analyzed using a Relational Map (Map 3) that articulates the connections between actants within the network.

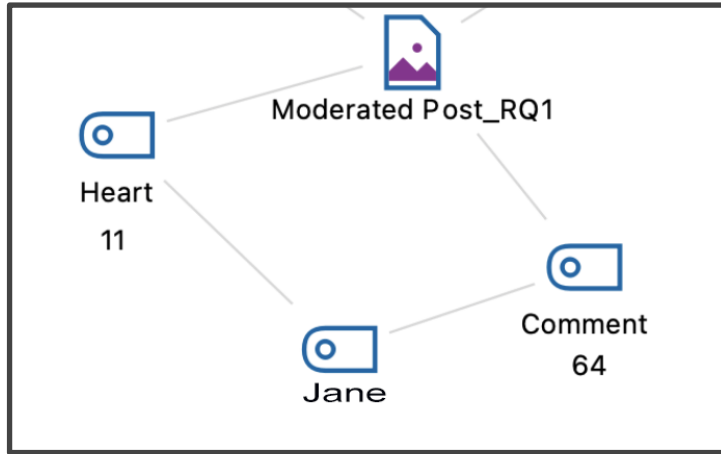
4.7.6. Map 3: Relational Map of Moderated Post of RQ 1



Map 3 depicts another way to look at the human and nonhuman actant interactions in response to the FTAF moderated posting of the first research question (Figure 2). In this relational map, the moderated post (a nonhuman actant) has elicited 44 like emojis (nonhuman actant) and 11 heart emojis (nonhuman actant) and moved 64 human actants to post comments which then become nonhuman actants that elicit further interaction. Finally, nine human actants shared this moderated post into their additional social arenas, thus connecting this social arena to the broader geography of this digital space (Facebook). These actions/interactions form the relationships that constitute the community and make the connections (materialized as comments, emojis, and shares) across the diverse actants within the social arena.

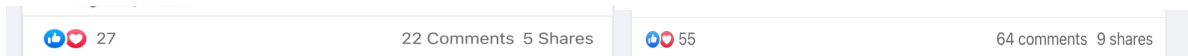
Taking a deeper dive, Figure 4 shows the multiplicity of actants, as one of the human actants (Jane), is both a nonhuman actant (as a heart emoji) and also a human actant (by a posted comment) within this digitally mediated activity. This multiplicity can occur simultaneously or asynchronously as actants react to other actants' actions within the group. For example, Jane

interacted initially with an emoji and then reengaged with a comment - in response to another Jane's comment.



4.7.7. Figure 4: Multiple roles of actants in relationships (human and nonhuman)

One of the overarching questions of this research is how digital communities are formed and maintained. In my case study, I have described a situation where the FTAF Staff person provides a prompt (in this case, my call for research participants) through a moderated post, which in turn became a non-human actant in the community that translates between actants from different social worlds in the community.



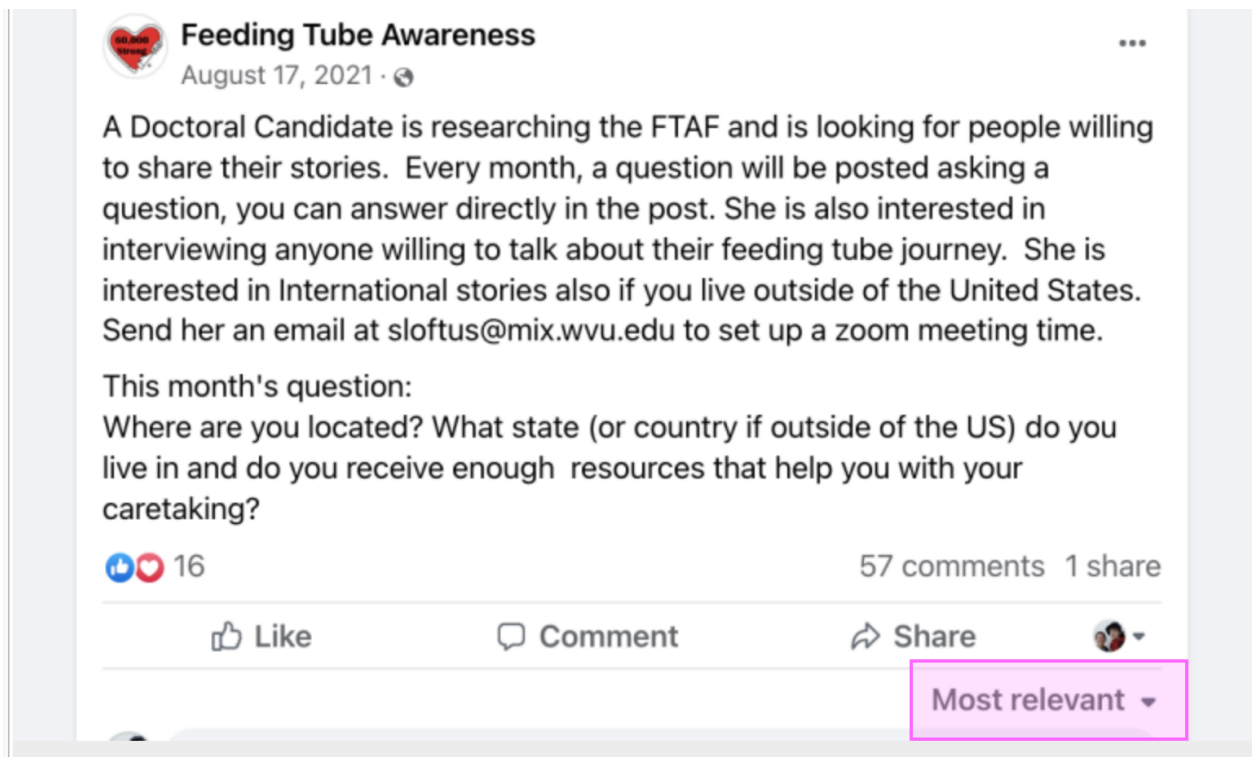
4.7.8. Figure 5: Comparison of responses from different times. Snapshots from July 2021 & January 2023

In Figure 5, the evolution of the ongoing conversation provoked from the original moderated post (July 2021), which had 27 Emoji responses, and a second snapshot (January 2023) which shows 55 emoji responses. These responses are nonhuman actants that contribute to and influence the community's conversation - as human/nonhuman actants engage with and react

within the community relationships. Similarly, the number of Janes that commented increased from 22 initially to 64 comments in the January 2023 snapshot.

Despite my original concern about whether people would be interested in my research, by the end of the data collection period, more than one hundred and sixteen (116) individuals had responded to at least one posted question. I conducted twenty (20) follow-up interviews with respondents, including three FTAF founding members who are also family caregivers, with the intended fifteen-minute interview extending at times to more than two hours (on average). All one hundred sixteen (116) respondents identified themselves as mothers of a child with a feeding tube (some mothers had more than one child with a tube).

Because the follow-up interview was open-ended based on a single prompt (“Is there anything more you would like to share about your feeding tube journey?”), specific demographic information was not collected. Even so, some mothers shared information about their family characteristics, like race, economic status, religion, and gender. Some respondents (in posts or follow-up interviews) self-identified as Roman Catholic, Hindu, Muslim, Christian, and Jewish. Some respondents self-identified (in posts or follow-up interviews) as White, African American, Middle Eastern, South African, Indian, South American, Pacific Islander, and Native American. Nevertheless, the Jane composite figure incorporates the feeding tube experiences as expressed within each person’s specific context. Respondents were from all over the United States and in several international locations like Canada, South Africa, Guatemala, Malaysia, England, Ireland, Austria, Guernsey Channel Islands, and Italy.

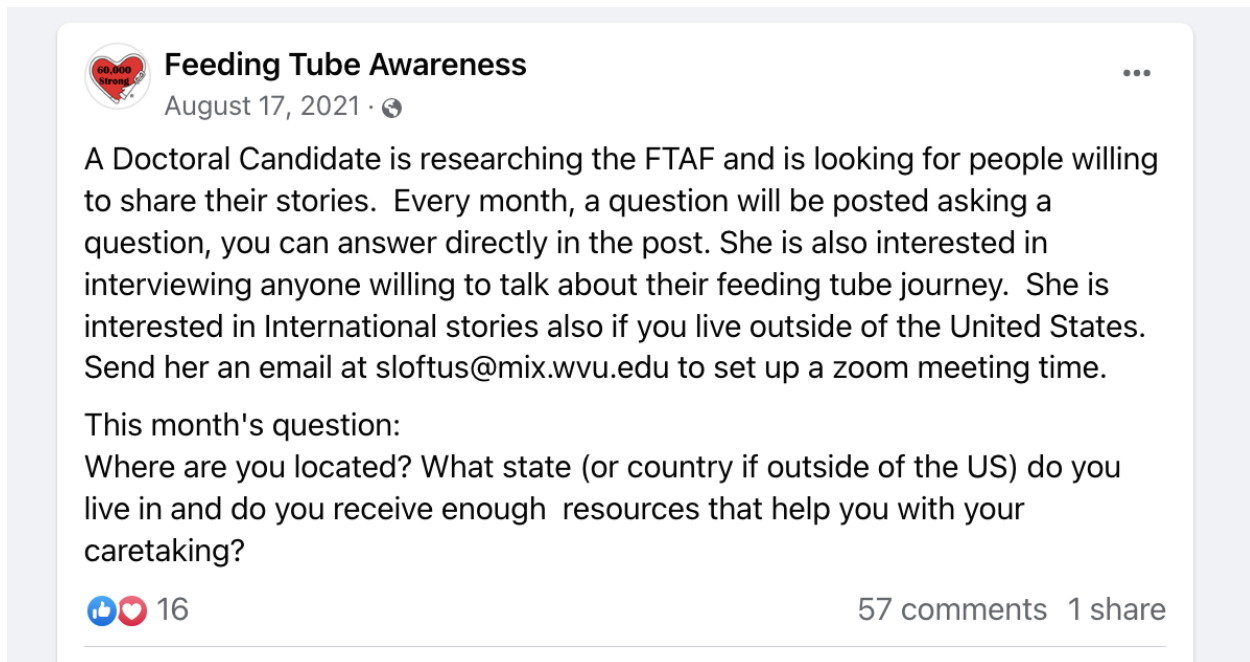


4.7.10. Figure 6: Facebook Algorithm as non-human actant.

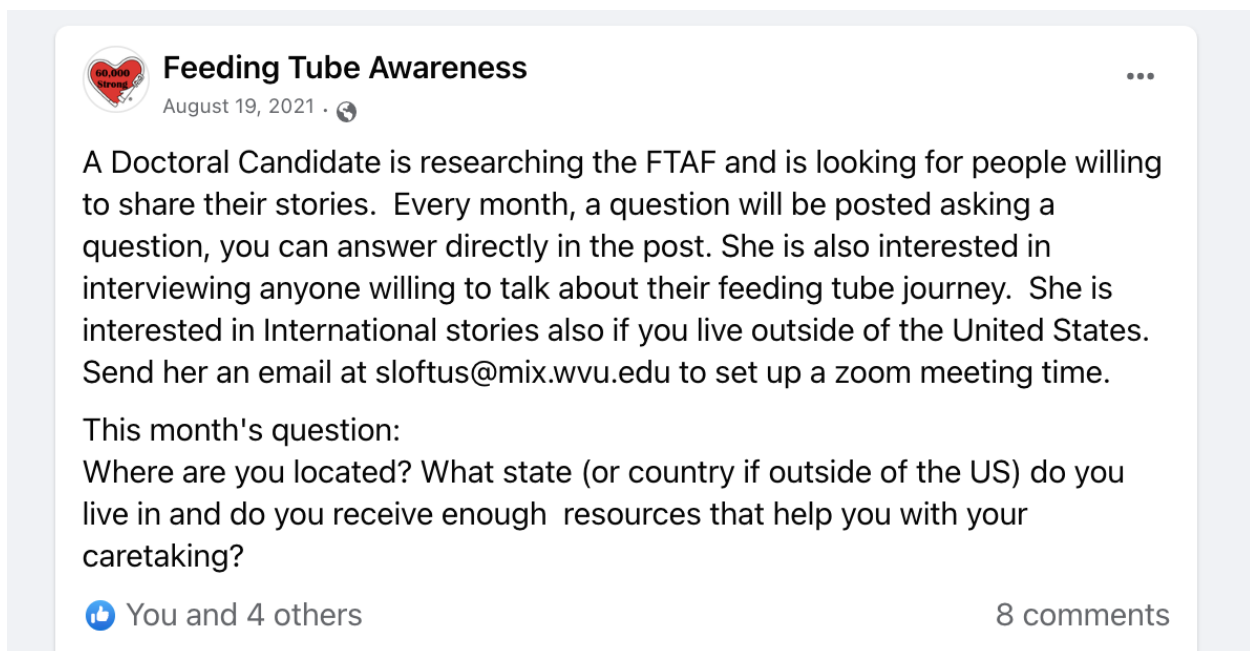
Facebook (FB) has developed algorithmic approaches to manage the millions of simultaneous digital interactions that occur every second of the day. The magenta box in Figure 6 shows one of these approaches, the aggregation of posts/comments into the ‘most relevant’ designation. The abstraction of all the responses into the category ‘most relevant’ is an important actant in the group. Identification of ‘most relevant’ - is tied to temporality - the most recent comments are promoted to ‘most relevant’ with the last two comments being shown above the ‘more’ actant. Engagement with a post by group members is influenced by which responses they see in their feed, and the default position is only to show the two most relevant responses underneath a post. As we saw in Figure 1, Emojis (non-human actants) also play a critical role in the conversation and, similar to the ‘most relevant’ actant, influence the perception of the importance of a particular post or response. In some ways, emojis present validity and validation as participations can quickly express agreement or disagreement with particular comments. Even

more important is that FB algorithms (non-human actant) recognize and prioritize posts (and comments) with high engagement scores, which are calculated based on clicks, emojis, and text comments. For the non-human algorithm, the context of the post/response is not as important as the engagement it creates. In this way, images, memes, and videos can become more important to the algorithm than human-human interaction, depending on engagement levels.

A group member might not post at all but is very active by clicking/emojis and could be recognized by the algorithm as an important contributor to the community. An example of this was demonstrated in two of my research question posts. One of the posts receives 300 engagements (likes, emojis), and the other only 16. The post with 300 engagements was returned first when I searched for my name or the keyword 'dissertation research'. This elevated ranking reflects FB's perspective that the group user would rather see a more engaged post than a less engaged one, regardless of the specific content in the post. In this way, the algorithm is very much an actant in my conversation about FTAF within the group. This also demonstrated a flaw in my research design, as the posts with some of the research questions became 'buried' in the feed as other posts deemed more interesting or relevant were given priority placement. This can be seen in Figure 7a and Figure 7b. The response from the community to the first post was higher than the repeat post a few days later. This could represent a level of saturation with the content, which in turn influences the various actants' engagement with the conversations.



4.7.11. Figure 7a: Original post of the research question on August 17, 2021.



4.7.12. Figure 7b: Same research question posted two days later, on August 19, 2023.

These two posts also offer a chance to consider how time itself is an actant that influences the conversation. In this example, the first moderated post entered the community on August

17th, 2021. Sixteen nonhuman actants entered the conversation (visualized as emojis) in addition, fifty-seven human actants (from potentially different social worlds) made fifty-seven comments, which in turn remain as nonhuman actants that could evoke further conversations at later times and dates. The later post only had five emoji responses and eight comments.

Nonhuman actants like feed placement, other conversations in the group, and time of day could have affected the relationships. More so, the process is fluid and cyclical, where the algorithm evaluates and reevaluates interactions, and posts that receive little engagement are lowered in rank, thus ensuring that they will continue to receive little engagement. Once a post is buried in the feed, the only way to find it is to know that it was there and complete a search query (with its own constraints) for it. So, in the end, moderation of conversations in the group occurs through human (FTAF staff) and non-human (algorithms) actants.

4.8. Inclusion v.s. exclusion

Beyond algorithmic aggregation, the FTAF staff also made decisions about their mission and intended audience. For example, FTAF is ‘a’ feeding tube support group, not ‘the’ feeding tube support group. FTAF Staff members frequently have to remind users of the specific mission of their group and that while they don’t intend to exclude anyone, they also are very specific about their intended audience. For example, this image posted to coincide with the Olympics elicited a significant response from the community (more than 1000 emojis, 119 comments, and

309 shares) but also generated conflict among G-tube users who were not parents.



4.8.1. Figure 8. MEME posted by FTAF Staff

This nonhuman actant (MEME) elicited more than one thousand emoji responses (including my own as a community member prior to my research), one-hundred nineteen human actants who posted comments, and three hundred and nine human actants that shared this meme into their networks. This meme also bridges differing social arenas within this FB community, creating tensions requiring articulation work from the FTAF moderators. In response to community member responses to the MEME expressing that they feel excluded, FTAF moderators posted the following:

“We are a pediatric organization, so that is why our materials are aimed at parents. You can certainly share your own feats. It isn't meant to exclude. Our audience is mainly parents because of the nature of our organization.” FTAF Staff Post

Others in the community also felt compelled to comment in support of the organization.

“This entire organization is run by moms who have dedicated hundreds of hours of their time — FOR FREE — for over a decade. They created the educational materials you will find at pediatric hospitals. The organization is called Feeding Tube Awareness because it was the first of its kind. Not because it is exclusionary. And if you have a feeding tube issue, it doesn’t matter your age, these wonderful ladies (some of whom I am privileged to know IRL) will help you.” Jane.

FTAF Staff indicated during their interviews that deliberate decisions had been made about the intended audience and the value of having the group ‘open’ to others, including adult feeding tube users, members of agencies, therapists, DME, and medical facilities. They shared that they have other secret spaces⁷⁰ that are ‘safe’ spaces for family caregivers to speak more freely, but the primary Facebook Group would not be hidden or secret by design and intention. As a result, FTAF staff occasionally have conflicts spill into the open.

The feeding tube awareness Facebook page was also kind of a catalyst for some of the private groups where we can talk more openly about things that we don’t want to share publicly. So it’s a secret group - Jane.

This FTAF group is just one of many different digital spaces that family caregivers frequent. They often find other digital spaces through their relationships in the FTAF community. The relationships they form in their digital groups impact the materiality of their caregiving, sometimes through information, support, or solutions to a problem that changes their caregiving practice and sometimes through physical resources that they cannot acquire in other ways.

⁷⁰ Facebook groups can be open, hidden or secret. All three types of groups are deep web groups in that they are behind the Facebook firewall and not indexed by Google. The difference is that open groups are ‘open to the public’ with no expectation of privacy, while hidden and secret groups are relational groups. Hidden groups can be found by internal query and permission to join can be made by non-members. Secret groups can not be found by search query and are only accessed through a relationship with a known member.

And that group [non-FTAF group], I help with that group too. I think we've got several hundred people in there, and that has been a huge resource as well because you can say, "Hey, I need help. I need an extension tube, or formula, or something else and someone will help - Jane.

4.9. Concluding Remarks

In this analysis, I have examined the shared experiences of family caregivers of children with feeding tubes, leaving unremarked the many potential differences (like socio-economics, religion, geography, gender, race, and (dis)ability) as expressed through their digitally mediated activities. Even more so, this digital place, the FTAF FB group, provides the social arena where family caregivers are visible and find affirmation and other benefits precisely because they have so much in common. I would argue that this digital space offers temporalities and spatialities for these different caregivers and many other actants to come together and form the community. They can do this because of the assemblage's capacity to enable/manage/articulate the multiplicity/fluidity of space-time.

In addition, part of what I am doing with this paper is to remind geographers that revisiting unresolved debates in the literature can contribute to good research in today's context. Expanding from Guattari's observation of the varied nature of subjectivity, a Situational Analysis of the FTAF FB group helps decenter family caregiving from a fixed here and now by situating it within a network of relationships (Deleuze & Guattari, 2018). Moreover, where these relationships take place and whether or not they are technologically mediated, and how is critical to consider. Digital spaces, like FTAF FB, are between spaces where participation is recognized as both present and absent in material and situational ways while also multi-temporal and multidimensional (Brophy, 2010). This was reflected in how different actants engaged and

disengaged with each beginning with the moderated post but then transforming into new engagements resulting from their own and other actants' interactions. All of these elements constitute relations, including my own; I, too, am part of the community.

Part of the contribution of this paper to the concept of community and social worlds is that my analysis shows the powerful articulation work that goes on to address and remedy the spatio-temporal fluidity, hence the power of the digital space. As such, deep web spaces like the FTAF FB feeding support group are assembled, formed, and reformed through digitally mediated activities that stretch beyond geographic and temporal boundaries. Temporal flexibility, as a concept, reflects the fluidity of time (and space) within digital communities (Valentine & Hassoun, 2019) as it reaches backward and forwards within a complex network of overlapping objects ⁷¹ (e.g., retweeting and reposting), which allows different actants to supersede the specificity of time and place. These objects are not aspatial or atemporal but re-emerge within new spatio-temporal contexts.

The importance of this paper, and my research more broadly, is not limited to understanding how family caregivers use a deep web space like FB to find resources, share their experiences, or build community. Instead, by examining the structures and assemblages of human and nonhuman actants within this FB group, I contribute to the geographic literature by providing an empirical example that connects assemblage theory, relational approaches like SA, and machine learning/artificial intelligence (FB Bots and Algorithms) with geographic and STS

⁷¹ Following Star and Clarke, I define objects as all the “stuff and things, tools and techniques, ideas, stories, memories and other material and nonmaterial things which are treated as “things” by community members (Clarke, 2016, p. 153).

sensibilities. My work takes a small step in breaking open the ‘black box’ of deep web groups to illuminate the ways that actants assemble and the resultant expressions of power, privilege, and exclusions that occur as a result. Further, my broader work demonstrates how these assemblages carry over into the materiality of everyday care work done by family caregivers of children with feeding tubes.

Accordingly, this paper calls for a more nuanced approach to what geographers mean when they study assemblages. As I have shown, there are detailed and consequential epistemological and ontological underpinnings to assemblages that are rarely explored in geographic literature. This paper has contributed to the broader caregiving literature by providing ethnographic descriptions and relational approaches like situated analysis to understand the role of both hosts and users (both human and nonhuman) in building, maintaining, and transforming this digital community. More so, I describe how relationships in the digital world shape and inform the materiality of caregiving practices. Group members visit the FTAF FB group to find answers to specific questions related to their caretaking. They also join to help other feeding tube families, share their stories, and reciprocate support and validation they might have received- to give back or pay it forward.

4.10. Works Cited

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Chapter 5. Concluding Remarks

Why do family caregivers go to the Feeding Tube Awareness Foundation's Facebook group? This research suggests that this digital place provides a community where family caregivers find other people who have shared their experiences, who 'get it' without necessitating long explanations or justifications, and who have real and practical solutions to everyday problems that could mean the difference between life and death for their children. Further, this community offers a supportive environment where family caregivers can express themselves to people who care, sometimes in ways that are unacceptable in society.

As I've described, the implementation of neoliberal changes in government policies, reductions in funding, service provision, and reimbursement rates for social services and hospital stays have shifted the responsibility of care to family members in gendered ways. This shift has transformed the family home into a medical home where family caregivers (mothers) are expected to not only meet the parental needs of their child but also become a mother-expert who is a pseudo-professional team member of countless medical, social and educational systems which control, surveil, penalize and criticize them under the guise of empowerment discourses (e.g., person-centered, natural family supports) and 'home is best' ideology.

Through composite narratives and ethnographic descriptions, I have shared the collective experiences of one hundred and sixteen 'Janes'. I am one of the Janes. My family's story is part of these collective stories that reflect how, where, and when our caregiving occurs. By telling the Janes' stories, I share how we actively work to (re)solve conflicts and barriers that we encounter daily and the ways that we use digital spaces like the FTAF (among others) to validate, encourage, advocate, commiserate, educate and overcome barriers we encounter every day. My positionality as a researcher offered additional validation, as reflected by the outpouring of Janes

wanting to share their experiences, that we have something to say to an audience wider than ourselves. Digital spaces like FTAF provided us with vital links to others that shared our experiences, allowing us to create and share knowledge, support, and caring that is lacking in other places. Together we work through the challenges and contradictions of a system that often overlooks our experiences.

The Janes' eager participation in my research confirmed that we want to be heard, our grievances, and our successes, because we have hard-fought knowledge to share that is invaluable to others who might be struggling and to the wider community. In my dual role as an academic researcher/community member, I bring together the threads of conversation and connect theory and practice through listening, witnessing, and validating family caregivers' stories and experiences. In this way, family caregivers' experiences, theirs and mine, become examples where other marginalized communities can find commonality and solidarity.

This research advances geographic scholarship on how supportive communities are created in digital spaces by sharing ethnographic descriptions that illustrate the materiality and affective dimensions of every caregiving experience in spaces where digital and non-digital domains coexist. My examination of the inner workings of a digital community focused on the relationships between human and nonhuman actants and how digital communities are formed, shaped, and maintained through an ever-increasing number of digitally mediated activities. In addition, my use of a particular relational approach grounded in a feminist STS tradition has broader significance in theorizing agency and power *as* caring both within geography and beyond.

A tremendous amount of hidden anticipatory and articulation work goes into creating and maintaining this digital place. The FTAF staff and other community members engage in this

articulation work, through myriad digitally mediated activities, for no financial compensation (everyone, from FTAF Staff to moderators to individual members, are unpaid) while also accomplishing their daily caregiving activities, sometimes during prolonged precarity and at times crisis. They do this because of the reciprocal caring relationships formed in the groups, not with individuals per se, but within the community as a whole. As a result, this community has become a location where knowledge is produced, introducing epistemological diversity (Fletcher & Clarke, 2018) as family caregivers (whom I theorize as mother-experts) share and receive information that they acquired through experience rather than traditional (more established? formal?) sites of knowledge production.

Geography and spatiality are central to this work, and essential conceptualizations about space and time are challenged by the way digital spaces allow for more flexible temporalities and spatialities. While some geographers are advancing these topics (Bowlby, 2012; Doucet, 2022; Dyck, 2005; Forlano, 2017), my research examines how family caregivers utilize online places in response to isolation and precarity. By examining the complex relationships between humans and non-human actants in digital spaces, I demonstrate how these digital communities might counter some of the adverse outcomes resulting from the isolation that family caregivers experience as they fulfill their daily care work. Moreover, I do this with a methodological framework that unpacks the relationships and assemblages that (co)constitute these communities as meaningful places for family caregivers of children with feeding tubes, something rarely done with this degree of detail in the geographic scholarship. As seen in Chapter 2, these groups provide bridges for family caregivers that span both geographic boundaries and reflect temporal flexibility.

This project addresses temporality in less visible spaces like deep web groups and other digital spaces within interdependent relationships and networks. This contribution is significant because it recognizes how digital spaces are entangled in everyday caregiving practices and relationships. My research defines communities as reflective practices that people do together and entails a multi-faceted joining process along a continuum of belonging (Lave & Wenger, 1991). Communities come together for a variety of reasons in a variety of places. For caregivers, who are often geographically, and socially isolated, digital spaces provide opportunities for community building, which they might not otherwise have because of their caretaking responsibilities and mobility limitations. In addition to being places to gather information, share information, and build solidarity with others experiencing similar things, digital spaces (e.g., social media groups) are dynamic actors in various social and political movements (Mattoni, 2017). People gather around shared experiences and political needs to rally for collective action (Baer, 2016; Barassi, 2017; Barratt & Maddox, 2016; McLean et al., 2019; Mclean & Maalsen, 2013). Building community and relationships with others in digital spaces is one of the ways that caring is expressed. Care and caretaking, however, are complex phenomena that challenge assumptions of individuality, self, and the role of the digital in people's lives. My work critically illustrates the political implications of care work and how communities form around shared goals and experiences.

In my research, I argue that the FTAF FB group is an important place in family caregivers' everyday geographies and that these digital communities are relationally shaped and maintained by the myriad digitally mediated activities of actants (human and nonhuman) across multiple spaces and times (Madianou, 2016). As such, my work contributes to an emerging conversation at the intersection of feminist geography (digital and disability) and feminist STS

that includes complementary theoretical and methodological approaches for exploring the impact of human and non-human actants in underrepresented communities. Within the FTAF FB community, representation and subjectivity are less fixed and fluid as actants move from an individual to a networked self that is connected through digital relationships (Brophy, 2010; Papacharissi, 2011). As such, respondents engage in the community within a context of multiples: multiple selves, multiple identities, and multiple communities, that are all situated within a nested framework of social worlds, all interconnected and co-constituted through overlapping social arenas which contain objects and actions that on the surface seem contradictory and oppositional.

Digital communities offer the possibility of political change that could emerge from articulation in these places (Raman & Komarraju, 2017). Additionally, my work offers opportunities for conceptualizing relationality (and a networked self) that is socially mediated and distributed (Papacharissi, 2011; Baym & Boyd, 2012) and also utilizes digital spaces “in the service of their own creative and instrumental objectives” (Baym & Boyd, p. 312). The ethnographic descriptions presented here provide examples of how community members traverse “multiple layers and kinds of audiences, bringing into being multiple and diverse kinds of publics, counterpublics, and other emergent social arrangements” (*Ibid*, p. 322). Through membership in digital communities, family caregivers engage in interactions that blur traditional conceptualizations of the public and create relationships and networks that debate, form and shape broader public issues within their community and society.

Finally, I used established relational approaches in unique ways to examine actants in the FTAF FB feeding tube community to understand better how these assemblages contribute to or hinder relationship building (Clarke & Fujimura, 2014; Star & Griesemer, 2016; Star & Strauss,

1999). I suggest that neoliberal policies and practices, as well as unchallenged "home is best" ideology, have resulted in unintended and unremarked casualties, like systemic dependency on gendered caregiving practices reified as the mother-expert, community erasure/atomization/fragmentation from decentralization, and unrecognized structural violence from various surveillance apparatus.

Activism and empowerment are fundamental goals for many Feminist scholars. Digital geography informed by Feminist theory and methodology and improves the understanding of the entanglement of the home, care work, and the digital. My research pushes further by examining digital spaces within the context of family caregiving responsibilities for technology-dependent people with long-term care needs and how digital spaces facilitate activism and change through interconnected networks.

At its core, my research is about understanding the care landscapes of children with feeding tubes and complex medical and developmental needs. Through the experiences of Jane and Ichabod, I have described a long-term care system that relies on unpaid caregiving by 'mother-experts' built on Western ideologies of independence, autonomy, and gendered caregiving roles. I've also discussed how the medical-industrial complex intrudes into the private home via my theoretical extension of the medical home concept and explored how and why family caregivers create digital spaces to acquire things they need.

Specifically, as a feminist geographer and a family caregiver, I've brought Jane and Ichabod into a conversation about the realities of everyday caregiving for children with complex medical and developmental needs that builds on previous scholarship about care work. Jane and Ichabod's collective, interdependent, spatiotemporally diverse, and technologically mediated experiences are a call to geographers and feminist scholars alike to take greater care of not

further establishing new ‘normative’ categorical identities built around autonomy and individualism. These concepts have a way of sneaking back into otherwise critical analyses, thus perpetuating an ableism that, at minimum, renders invisible the lives of a growing vulnerable community. In my work, I have introduced another perspective on autonomy and agency in practice for a community often excluded and made invisible even by feminist disability scholars.

To conclude, I’ll return to the three keywords in my title and highlight how my research examined these terms. My work asks everyone---scholars, activists, and fellow members of our communities---to recognize that home for caregivers of children with feeding tubes is not just an intimate place but also an extension of the hospital room, which I examine in my work by unpacking the medical home. Also, that family and relationships reflect family practices that might challenge notions of autonomy and individualism and non-normative lifecycles that problematize established feminist ethics and practice. And finally, communities include both physical and digital landscapes of care and are complex places where meaningful relationships are formed.

5.1. Works Cited

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Author's Note:

I began my doctoral studies at West Virginia University in 1995 fully intending to graduate within the requisite time allotted to me. I failed to do so.

As with many of the other Janes presented in this research, one of my children, my Ichabod, failed to thrive from birth and started us on our twenty-three-year journey as a tubie family. In 2001, I recognized that I could not write a dissertation and meet the needs of my family, so I left my Ph.D. program. Fast forward to 2017, and with the urging of my ailing mother, I reopened the door to finishing my Ph.D. Thankfully, my original advisor, Dr. Greg Elmes, answered my call and facilitated my reintroduction to the West Virginia University Geography Department, and the graduate committee reaccepted me into the Ph.D. program.

Again, like many of the other Janes, our Ichabod has brought us many, many good things, along with some very difficult things. We are not special, extraordinary, or blessed for having successfully navigated our journey so far, and by success, I mean that my Ichabod has exceeded their life expectancy by twenty-three years. Instead, this happened because of the hard work of hundreds of people (including my family) that have been part of Ichabod's interdependent care team over the years. We all collectively worked together in imperfect and, at times, really horrible situations to provide the best care we could. My Ichabod (who is now an adult but still my child), by normative scales, has the adaptive skills of a kindergartener, and by our family values and those of the State, will not (in fact legally cannot) live alone. As my husband and I age, we worry about who will take care of Ichabod; how do we plan for his care after we are gone, without Ichabod ending up in the State's hand? (state with a capital S) Twenty-three years into this experience, we now understand that, because of neoliberal policies and the persistent myopic focus on individualism and autonomy, the State (and all of its tentacles) does not have the capacity to care for our Ichabod in the way we, as a family, desire. Even though I have no regrets about my decision to be the primary caregiver of my Ichabod, I do worry about my other children having to navigate the same broken care systems that we did. If, through my work, I have opened possibilities for change for myself, my children, or others experiencing what we have, then the answer to the oft-asked question of *what am I going to do with this Ph.D.* has been answered to my satisfaction.

Appendix 1: Research Questionnaires

WVU IRB Protocol # | 2102246119

Principal Investigator: Dr. María Alejandra Pérez, Contact information is 304-293-5603 and maria.perez@mail.wvu.edu.

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Digital Caretaking: Relationships in a Feeding Tube Community --
Questionnaire

Questionnaire A – Survey questions for FTAF Executives, Staff

1. How long have you been involved with the Feeding Tube Awareness Foundation (FTAF)?
2. Why did you get involved with FTAF?
3. What state do you live in?
4. What do you know about caretaking services for people with feeding tubes and long-term care needs?
5. Have you ever had any communication with users of the Feeding Tube Awareness Foundation's digital spaces?
 - a. When/Where?
 - b. Only in FTAF online spaces or also in non-FTAF spaces
6. Does FTAF collaborate with family caretaking or feeding tube organizations in other countries or American counterparts?
 - a. Why/Why not?
 - b. Which organization are they and where are they?
7. Which of the FTAF digital spaces is most utilized by family caregivers?
 - a. Why do you think that is the most utilized space?
8. Why did you decide to create a Facebook group?
 - a. What are the positives and negatives of the FTAF Facebook group?

Questionnaire B - Monthly research questions for group members of FTAF Facebook group

1. Describe how long and in what ways you are involved with the Feeding Tube Awareness Foundation (FTAF) Facebook group?
2. Why did you get involved with FTAF?
3. Do you have all the help you need in your caretaking?
4. What help do you receive? Federal or State programs you utilize. Organizations? Other support networks?
5. Why did you join the FTAF Facebook group?
 - a. Do you go to other feeding tube-related sites? If yes, which ones?
6. Have you communicated with anyone from FTAF staff or other participants in the FTAF Facebook group?
 - a. In the group via posts, comments, or PM?

- b. Outside of the group via email, messaging, phone, or in person.
- 7. Do you care-take by yourself or do you have other people help you with your caretaking?
 - a. If yes, who are the people that help you (e.g. spouse/partner, siblings, children, neighbors, paid care staff, friends, relatives, volunteers?)

Questionnaire C - Follow-up online survey questions for FTAF Facebook group

- 1. Can you tell me what the FTAF group means to you?
- 2. Is there anything more you want to tell me about your participation in this group?
- 3. Can you tell me more about what other digital groups you belong to?

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Appendix 2: Confidentiality and Anonymity

During my research informed consent process, research respondents were assured confidentiality and anonymity in order to protect them from any unintended harm or reprisals from telling their story. To this end, I developed a figuration named Jane to represent a compilation of all family caregivers who participated in the research via interview, posted a response, or emailed. Because of this, I have not included details about with whom, when, or where interviews occurred.

116 unique respondents (Janes) across all 7 research questions.

Follow Up Interviews =
20

Average Interview = 2
hours

	Q1	Q2	Q3	Q4	Q5	Q6	Q7
Unique comments	32	55	51	55	9	9	23

These numbers represent the FIRST posting of the research question. There were several repeat postings of each question at the FTAF FB group Moderators discretion.

Additional interactions continued to occur after the initial post and are unremarked in this study.

Likewise, actants could have removed their interactions after data was collected .

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