

Coordinating the Youth Caregiver in the United States: Representation, Ambivalence and Slow Violence

Elizabeth Olson

Department of Geography
University of North Carolina at Chapel Hill
eaolson@email.unc.edu

Abstract

In this article, I reflect upon Nixon's (2011) charge to better represent slow violence through the context of youth caregivers in the United States. These youth are invisible in recent efforts to acknowledge the looming national 'care crisis'. Youth caregivers face a range of barriers to receiving supports, and professionals who interact with youth are largely unaware of the possibility that children and adolescents can be caregivers. I apply an autoethnographic lens to my role as a researcher and advocate, explaining my attempts to raise awareness about youth caregiving amongst multiple audiences and through various media. I also discuss how this process of representing and authoring is underpinned with an ambivalence, much of which emerges from creating and stabilizing categories of youth caregivers as a research object. I therefore conclude with a reflection on how ambivalence became a productive partner in representing slow violence through theories of multiplicity, coordination, and epistemic humility/responsibility.

Keywords

Youth; caregiving; young carer; slow violence; body multiple; health

Introduction

In his exploration of slow violence, Nixon (2011) emphasizes the importance of representing the violence that is enacted upon certain groups of people; violence often enacted by hiding and obscuring harms through elaborate techniques of responsabilization and neglect. His point is that our representations matter, perhaps especially when confronting forms of violence that take place over times and distances so vast as to temper the tangibility of harm. Slow violence afflicts places and people that are "unimagined



communities internal to the space of the nation-state, communities whose vigorously unimagined conditions become indispensable to maintaining a highly selective discourse of national development” (Nixon, 2011, 150). The phrase, “vigorously unimagined,” suggests an effort and intention so that the victims of this kind of structural, long, and extensive violence are materially and symbolically erased from state concern. Nixon encourages those who wish to counter slow violence to consider “how to devise arresting stories, images, and symbols adequate to the pervasive but elusive violence of delayed effects” (Nixon, 2011, 3). However, becoming an effective narrator of “unimagined communities” also brings with it intellectual histories saturated with colonial intent, patriarchy, and racist and gendered constitution of knowledge. Authorship is, as Haraway (1988) reminds us, implicated in the power to have a position and a viewpoint that removes some narrators from observation, while positioning others as embodied subjects selected for analysis.

The tension that arises from exposing slow violence through authorship is one that I have been grappling in my work as a researcher of, and advocate for, youth caregivers in the United States. The term youth caregiver (also known as “young carer”) refers to people under the age of 18 who assume caring responsibilities for a family member. Their caring roles might be directed towards a parent, guardian, sibling, or other relative, but the definition stipulates that the person who requires care or support must be living with a chronic illness, disability, mental health problem, or other medical condition that requires support in order to undertake everyday activities (Aldridge and Becker 1990; Evans 2014). Children’s caregiving work, similar to adult caregivers’, depends upon the needs of the care recipient and the kinds of additional support that is available. Therefore, like adults, their contributions can range from supporting activities of daily living (ADLs), such as dressing, bathing, and eating, to undertaking activities instrumental to daily living (AIDLs), such as shopping, transportation, or administering medicine (see Assaf et al. 2016).

In contrast to other countries, the U.S. does not recognize young people as caregivers in any federal legislation, which limits the age of a family caregiver to 18 years (Leu and Becker, 2016). This lack of recognition is echoed in youth and caregiving professional training, and there is no comprehensive training program in fields of social work, education, or pediatrics about youth caregiving and its impacts. Whereas the research community continues to invest in understanding the challenges facing adult caregivers, family caregiving research continues to exclude the collection of data on people under the age of 18, regardless of their level of responsibility in care (see National Academies, 2016). Meanwhile, the scant data that does exist from the U.S. suggests that for some youth, caregiving can impact education and learning (Siskowski, 2006), and can trigger isolation and stress that is different from that experienced by their non-caregiving peers (Greene et al., 2016). In short, the lives of youth caregivers are “vigorously unimagined” in the U.S., sidelined by large caregiver advocacy organizations with specified agendas, ignored in policy debates, excluded from agenda-setting research on caregiving, and largely unknown by professionals who work with children and adolescents. In the interim, news reports hail millennial caregivers as the “creative” solution to pressures facing adults caring for both their own parents and their children (Pinsker, 2017). I build from Nixon (2011; 151) who cautions that this kind of “administered invisibility” or the active maintenance of media and policy in order to not just obscure, but misrepresent the plight of groups, is key to the perpetuation of slow violence.

Since 2014, I have gradually become a local and national leader advocating for better research, policies, and practices that might improve conditions for youth caregivers. This role moves me fluidly from intimate conversations with groups of grandparents raising grandchildren in rural North Carolina, to schools where I explain the need for research collaboration, to conference calls with national organizations to strategize legislative campaigns. In spite of my commitment, integrating the category of “youth caregiver” into the U.S. political, cultural, social, and economic landscape leaves me with a deep feeling of ambivalence about my role as author and narrator. This ambivalence persists even as I embrace,

and fully believe in, a radical commitment to shift resources toward youth caregiving families, to remove everyday barriers to education and wellbeing, and to create policies that reject what is currently a racist, gendered, and age-biased landscape of caregiver support in the U.S.

The phrase “youth caregiving” is a symbol intended to confront slow violence, but it is also an unstable object that can be pathologized as it passes through diverse communities of research and practice (Cahill and Torre, 2007). Because most youth caregivers in this country do not know that there is a category which describes their position, researchers and advocates like me have an outsized influence in authoring who youth caregivers are in the U.S., and which strategies might be most useful for breaking through their administered invisibility. In my own work, this means that the category “youth caregiver” is being interpreted and translated by particular professional communities: researchers largely drawn from medicine, nursing, or clinical social work; caregiving advocates who seek to influence policy-makers, corporations, and other advocacy groups; aging services, or the network of service providers and aging professionals; and child and youth-oriented services, in which schools are especially influential. Each of these professional communities and their representative institutions have the potential to accept or reject the category of youth caregiver as requiring research or a change in practice. I have assumed the role of author to create of effective symbols and narratives to tell the story of youth caregiving, but with a constant concern about the research object that might be produced in the process.

For the remainder of this article, I use an autoethnographic approach - inspired by the potential to evoke critical reflexivity toward the research process (Butz, 2010) - to explore the process of representing slow violence among “vigorously unimagined” groups of caregivers. I focus on the action-oriented aspects of my work, including my decision to create and advocate for a new subcategory of youth caregiving that I call “bookend caregiving.” I use bookend caregiving to describe the growing number of children, adolescents and young adults who are primary or secondary caregivers for older adults such as grandparents and older parents.

I begin by explaining the neoliberal economic structures that produce the contemporary “care crisis,” and my reasons for conducting historical research in order to draw out the longer histories of racist and gendered imaginings behind youth caregiving in the United States. I then turn to the materials that I have produced for coordinating understandings of youth caregiving across different communities, and how I and my collaborators have balanced impulses to pathologize and objectify the youth caregiver with the desire to accurately represent the urgent need for recognition, visibility, and inclusion.

It is important to note from the outset that diverse voices will not be represented through direct quotations of research subjects in this article, nor will the circumstances and experiences of the young people and families that I work with be explained or described in detail. The reasons for this are both ethical and epistemological. Ethically, the information that I have gathered from conversations with youth caregivers and their families during the work described here has been for the purpose of building networks and not producing research outputs, and so our interactions are held in confidence. Epistemologically, the article aims to take a deep look at the practice of representation by drawing upon feminist geography’s expressed concern about the relationship between research, power and knowledge (Rose, 1997). My contribution includes a discussion of theoretical resources that have helped me improve my own understandings of the everyday, mundane decisions and responses that contribute to the practical ethics of representation.

Slow Violence midst a care crisis

Slow violence is “a violence that occurs gradually and out of sight, a violence of delayed destruction that is dispersed across time and space, an attritional violence that is typically not viewed as violence at all” (Nixon 2011, 2). Like Watt’s (2013) earlier articulations of silent violence, Nixon’s slow violence is generated across time and space in ways that make it both difficult to recognize in the temporal

and spatial scales of human experience. Thus, one of the key challenges is to narrate communities back into the history, present, and future of broader economic, political and social structures. In the case of youth caregivers, I have interpreted this task as reconstituting their history (Olson, 2017) in order to disrupt research and popular accounts that prefigure children as care recipients rather than caregivers. Situating and historicizing youth caregivers has led me to research key moments in which administered invisibility exposes itself and is therefore different from decisions made about framing (e.g. Lakoff and Ferguson, 2006), which I also discuss in detail below.

Claims of a “care crisis” in the U.S. are intended to draw attention to population-wide challenges in providing care to those who need it. Historically, the phrase has described a political moment when the problem of private care has been elevated into public consciousness, sometimes with the hope of spurring legislative action (England, 2010). The current care crisis revolves around a complex debate that can be simplified into the following key points: there are not enough formal (paid, professional) and informal (unpaid, family) caregivers to meet current and growing needs for caregiving for people with illness, disability, or other significant health issues in the United States; the aging of the population means that even more demands are being put on families to provide significant care; if not addressed in the next twenty years, this crisis could result in economic insecurity and medical disaster for the U.S. This particular care crisis dates back to at least 2008, when Roslyn Carter penned an editorial in *Preventing Chronic Disease*, warning that

...this blessing of long life presents us with a new set of formidable challenges: soaring rates of dementia and untreated mental health problems among the elderly, a growing burden of chronic illnesses that affects our communities, disturbing problems of elder abuse, and an unparalleled demand for the services of both professional and family caregivers. All progress comes with costs and challenges, but in the 21st century we will experience this burden on a scale and at a speed that we have never seen before. So, we must prepare ourselves. (Carter 2008, no page number)

The aging of the Baby Boomer generation, who are sometimes referred to by the controversial metaphor of the “aging tsunami” (Barusch, 2013), has moved this current care crisis into full view; unlike ongoing cases of slow violence, this care crisis has a built-in countdown clock. With more than 17 million people already caring for family members over the age of 65, all other indicators suggest this number of caregivers will rise rapidly over the next twenty years. The National Academy of Sciences report, “Families Caring for an Aging America” formalized the expert view that the growing proportion of older Americans will require dramatic reimagining of our economic, social, health, and built infrastructure (National Academies, 2016).

This crisis, like others, cannot be attributed only to a demographic population shift but rather to the complex outcomes of long-term neoliberalization of systems of care. The restructuring of health care that has been necessary with the hollowing out of the welfare state means that labor markets do not respond to those who require higher levels or greater skilled care, or to rising demands for more mainstream care (England and Alcorn, 2018; Kearns and Joseph, 1997). Meanwhile, the lucrative character of medical sciences and related improvements in diagnosis and treatment mean that certain forms of illness can be partly or fully repaired to extend life, often at a profit to some and resulting in new conflicts of interest (e.g. Spece et al., 1996). With these twinned changes - the possibility for repair, and the absolution of the state from care obligations - the responsibility for care shifts from the clinic to the patient and, increasingly, the family caregiver. In the context of aging, which plays an outsized role in the current care crisis, the requirements for older people to “age well” suggests a responsibility to keep bodies and minds in good order. Staying fit, emotionally engaged, and diligent about preventative health care are signs of an individual who takes their aging seriously and responsibly. The caregiver, in turn, is expected to practice “self-care” in this stage of late liberalism, caring for oneself so that she may

simultaneously care for someone else who is vulnerable (Dahl 2017, p. 50). Dahl (2017) argues that the current care crisis is not so much one of supply and demand, but of an inability to understand how neoliberalism has shaped our possibilities for care and what we think about it.

Against this backdrop, it is not surprising to see renewed concern about those caregiving individuals whose work is now essential for the future of the nation, but who lack sufficient resources to be held responsible as demanded by neoliberalized care - that is, being responsible for the wellbeing of others as well as for one's self. The RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act, which was signed into law by Donald J. Trump on January 22, 2018 following bi-partisan effort in both houses of the legislature, begins a process to plan for a future in which U.S. families take on greater burdens of caregiving. The resulting law is limited, as it creates an Advisory Committee to make recommendations to the Department of Health and Human Services but does not include funding to enact the recommendations. It also highlights the obscurity of young people in this ensuing crisis. The bill used a normalized definition of caregiver that excludes youth: "The term 'family caregiver' means an *adult family member* or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation" (Sec 2.2, italics added). Thus, what many caregiving advocates would argue to be the most significant family caregiving legislation of the 21st Century, already excludes youth caregivers in an act of definition.

This context underpins the key processes at play in my own attempts to create the symbols and narratives to represent youth caregiving. My approach is driven by a feminist praxis that is in constant iteration with the ethics of care and critical research on the political economy and geopolitics of caregiving in contemporary global capitalism. Fisher and Tronto's (1990) four phases of care designate caregiving as the act of providing care, or the material and embodied expressions that emerge from responsibilities for care (England and Dyck, 2012; Lawson, 2007; McEwan and Goodman, 2010). As the home is recognized as a key site for providing care through "family" or "informal" caregiving, it is also penetrated by the rules, policies and legislation that facilitate or regulate the provision of care in private spaces (England and Dyck, 2011). Those most vulnerable to slow violence within the contemporary care crisis are black and brown female caregivers who cross national borders for paid domestic work (Glenn, 2010; Raghuram, 2012). In critical approaches to global caregiving, care is often disaggregated as either waged or unwaged, with the former becoming represented as a commodity and the latter an affective relationship. This has been an important operational dichotomy in research, even when both affect and labor have been shown to defy a simple dichotomous relationship with waged and unwaged (e.g. Bastia, 2015).

Though scholarship produced around the ethics of care provides an opportunity for integrating youth caregivers into a broader critique of the politics and economies of caregiving, it provides few existing entry-points for analyzing unwaged young people as caregivers rather than care-recipients. As Robson (2004, 67) writes in reference to girl caregivers in Zimbabwe, youth who provide care are "invisible, unheard and unsupported," and even in countries like the United Kingdom where young carers have substantial protections, they can be vulnerable to diverse harms that are perpetuated by their invisibility (Aldridge and Becker, 1990). Evans (2011: 340) explains that "the idea of a child caring for a parent also disrupts norms of parenting, particularly motherhood, that define children as being dependent [...] for nurturing, care, and socialisation." Unlike other countries where young carers are already recognized or where concepts of "kinship care" include children (see Leu and Becker, 2016), the dominant childhood narrative in the U.S. is that children should be care recipients rather than producers of care or labor (Zelizer, 1994).

The U.S. government's vision of childhood ignores the country's long history of enlisting children in caregiving in ways that become tied to arguments about eugenics and the "American race"

(Olson, 2017), and the whiteness that is inherent in this version of U.S. childhood (Spillers, 1987). Because children are presumed to be care recipients, and because the moral judgements of parents who allow children to work are codetermined by race, class, immigration status, and family composition, conjuring the category “youth caregiver” runs the risk of perpetuating stereotypes. This may be true for both the young people themselves, and the people with whom they engage in mutual caregiving, including disabled adult parents (Olsen, 1996). It also risks fueling misunderstandings of cultural and economic characteristics of U.S. families that favor family caregiving over professional intervention, and could lead to these families, many of which belong to ethnic minority groups including Latinx, African-American, and African and Asian immigrant, as immoral or inadequate parents, thereby requiring intervention by the state.

The potential role of children in Carter’s challenge to prepare for the unknowable future of longer lives in the absence of care is unclear. Creating a better symbolic and narrative representation of youth caregiving is not a simple task of narrating children back into this story, because doing so presents risks, including the responsabilizing tendencies of accelerated austerity and reinforcing stereotypes of already marginalized families. These concerns have shaped how I’ve framed youth caregiving and have sharpened my attention to the long-term commitment and indirect pathways that might influence the relevance of my research (see Staeheli and Mitchell, 2005). To illustrate what this means in practice, I now turn to some of my efforts to represent youth caregivers within this context before proposing some approaches which have helped me to understand my own participation in this process.

Framing the youth caregiver across fields of care

The phrase “youth caregiver” was already established when I began working in the U.S., codified informally by the American Association of Caregiving Youth in 2007. In its headquarters in Boca Raton, Florida, it sustains an impressive school-based intervention program, the Caregiving Youth Project, and maintains partnerships that span a wide range of advocacy groups that focus on caregiver or youth wellbeing. In my own state and region - the “Research Triangle” of North Carolina - the category is still unfamiliar to most people and to most youth experts. It is also unfamiliar to youth caregivers themselves, who may not recognize themselves as caregivers, and to their families. Explaining what I mean by youth caregiving to a professional, a neighbor, or at an academic conference provokes a repertoire of questions that I’m now so familiar with, I have cultivated a list of responses such as:

- no, youth caregivers does not refer to children with disabilities who require additional care;
- no, we are not talking about children who are parents (though that is possible, some young parents are also caring for someone else);
- yes, we include the kinds of work that kids “just do for their families” because some of that work might be necessary because of family caregiving needs;
- yes, keeping company counts as caregiving because an adult doing the same activity would be considered a caregiver;
- no, caregiving you a child or adolescent does not automatically mean that the child is being neglected.

These informal and more formal conversations, and the many tried routines of explaining youth caregiving to a new audience, has had an outsized influence on the ways that we have chosen to frame the youth caregiver.

Given the dominance of the current care crisis in policy and national debate, I decided to initially situate my engagement with youth caregivers within the aging community. There is an empirical reason for this focus; unpublished data from a pilot survey at a local middle school and trends in Youth Caregiving Project enrolment suggest that the majority of youth caregivers are providing care for older adults. The prevalence of millennials providing care for older family members is beginning to capture the attention of popular media and powerful advocacy groups, such as Forbes Magazine (Gastfriend, 2018) and the AARP (Jenkins, 2018), in more nuanced ways than in the past. Aging service providers have also been sympathetic and effective partners from a very early stage of my work, because they understand the challenges facing caregivers in a way that many youth services providers do not.

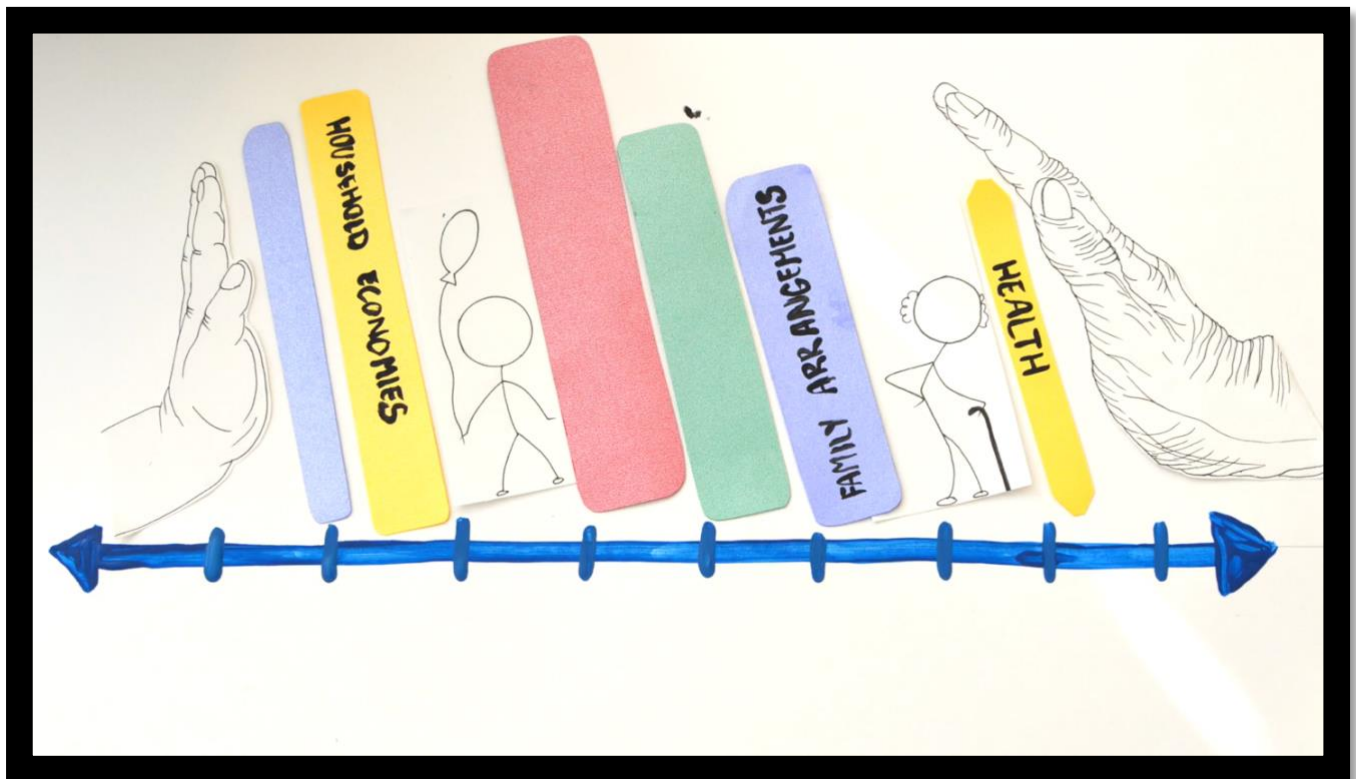


Figure 1: Still from Bookend Caregiving video illustrating how changes across multiple dimensions can influence a differential burden of family caregiving. Source: <https://vimeo.com/207876428>

I decided to use the phrase “bookend caregiving” because it suggests and imagery of change, much like the mutual and shifting care relationships that is part of relationships of caring for older adults (e.g. Fruhauf et al., 2006). It is a phrase that could both make sense and compliment the dominant imaginary of the “sandwich caregiver”, which is generally imagined as a (female, white) professional with children who is also caring for one or two parents with declining health, disability, or chronic illness. I hired Ms. Julianna Ritter, a student researcher and filmmaker on my project, and with the voices of friends, family, and other students, we created an educational short film that we hoped would be watchable, memorable, and efficient in its explanation of bookend caregiving (see figure 1).

Creating the video was not a directly participatory process with youth caregivers or bookend caregiving families (c.f. Cahill and Torre, 2007), but when creating the script, content, and feel, I incorporated the lessons and concerns that I had heard from youth in both the UK and the U.S.: caregiving can be both rewarding and difficult; remember that not everyone has a similar experience; and, as vigorously asserted by a group of youth caregivers participating in a day camp with the Caregiving Youth Project, encourage others to recognize that youth caregivers exist. My target thus became practitioners who might be working with youth caregivers across diverse practices, and youth caregiving families which may not have a referent for caregiving by children and adolescents in their family. The film took approximately three months to produce, with significant review to ensure that it did not stigmatize or pathologize youth caregivers and their families.

Rather than focusing on individual caregivers through emotional attachment, I hoped the film would clarify definitions and emphasize the importance of this role. The look was intended to be



Figure 2: Still from Bookend Caregiving video to illustrate the question, what counts as caregiving? The explanation tries to clarify that many things that children do may count as caregiving, even if it is considered to be “normal” household chores such as cooking and cleaning.

watchable for young people who might see the link on social media and recognize themselves, their families, or their friends and neighbors (figure 2). We diversified both images and voices so that age, race, gender, and ethnicity would not be normalized in the video (figure 3). The film differs from other documentaries of youth caregivers produced by some of my collaborators, and shows such as *The Doctor* and HBO's *Vice*, which trigger strong affective responses in viewers by showing both the love and the difficulties of care faced by specific families. The difference in responses to the *Bookend*

Caregiving film and documentary short films is significant: though ours serves an educational purpose, it does not produce strong emotions as do the other documentary accounts of care, a point that I return to later in my reflections.



Figure 3: Still from Bookend Caregiving video, with a deliberate diversity of age and ethnicity represented in the images. The script is narrated by people of different ages, accents and genders to reinforce the diversity of youth caregiving families. Voice contributors were volunteers.

With other collaborators, I've created various symbols and narratives, including logos, postcards with appeals for contacts and information, infographics about educational impacts, and PowerPoint slides and presentations for different communities. My audiences have included caregivers, kids, social workers, teachers, aging specialists, caregiver support specialists, grandparents raising grandchildren, and other groups that called upon us for information. All are strongly impressed by the orientation of our work toward recognition of youth caregiving and our reasons for engaging in our efforts to raise awareness. Some audiences were caregivers as children and are now in fields related to caregiving or youth, others continue to undergo difficult transitions into young adulthood, and yet others occupy the "sandwich" position in caregiving families. I've appeared with collaborators on a radio show (*The State of Things*, 2018), and co-authored an op-ed for *The Hill* (Olson and Siskowski, 2018) because a lobbyist suggested that it was the most efficient way to reach legislators immediately following the RAISE Act passage.

Each act of representation exhibits a careful curation of the story of youth caregivers: they are part of a family and all members provide some form of care; they are normal but not normalized, and so not talked about; they may be difficult to identify because of privacy concerns; they are in all different kinds of families, and some household circumstances are more supportive of wellbeing than others. Each output varies according to the particular arrangement of collaborators and audience, but they share the aim of explaining that existing systems and institutions are not responsive to youth caregivers and their families.

These attempts reveal the difficulty of better representing slow violence for the purpose of engagement and action. Audiences are frequently comprised of many individuals and organizations with different mandates and different positions in relation to the unimagined community. When meeting a new group, I'm often concerned about how the concept of youth caregiving will travel and how prejudice and implicit bias could close down conversation. For instance, in schools, I expect to be asked if caregiving families should be reported to the Department of Social Services, a system of protective services that is the subject of deep mistrust by racial minorities and those living in poor communities due to historical and contemporary racism and classism in child removal (Rivaux et al., 2008). Other times, I see youth caregiving re-articulated with a clarity that I then pick up myself and deploy in other contexts. For example, when presenting the idea in a hard-won meeting with an influential district-level school administrator, I noticed her quickly frame youth caregivers within her professional understanding. Her response followed this line of reasoning: she has many groups of kids - children of incarcerated parents, children with disabilities - that need institutional responses to remove barriers to learning. We had just told her about a group of kids that she didn't even know was a group, let alone one that required appropriate responses. If we have supports for these other kids, where are the supports for youth caregivers? I now repeat this story when meeting for the first time with school administrators, because it helps them envision the place of youth caregivers in their own work more effectively than my own framings could accomplish.

The symbols and narratives that we have used to represent youth caregiving are just one part of our work, and here I briefly offer insights into the creation of two networks that also serve in the role of representing youth caregivers. In 2015, I co-created a network of researchers, the Caregiving Youth Research Collaborative (CYRC), that brings together researchers from the fields of nursing, pediatric medicine, education, social work, psychiatry, psychology, and a single feminist scholar (me). We support each other, disseminate surveys, read articles, and communicate individual and collective progress, but we also disagree and speak past one another when we are unable to square our epistemological differences.

To sustain this work that I know is important, I accept that the framing of youth caregiver for this group is often viewed from a medical and health perspective, as reflected by the membership. This opens the youth caregiver himself to be the embodied site of the process of building knowledge that we require in order to effectively advocate on their behalf. We discuss prevalence studies that can convince policy makers that interventions are urgent; inquiries into awareness by educators or health practitioners; and clinical investigations in which the stress of caregiving might be proven through measures that are especially persuasive or cutting-edge. Sometimes we acknowledge the need to evidence what we already suspect: that caregiving can be difficult for children much in the way that it can be difficult for adults, that it can result in a lack of sleep, or in problems in school, or isolation and stress. Research focusing on medical questions also reveals dimensions of youth caregiving that have not been researched in other countries, and members of the network have produced important insights into young people's experiences of administering medicine (Nickels et al., 2018), and outreach materials that incorporate youth voices through creative resources (Kavanaugh and Howard, 2018), to name but a few. This network could be understood as producing the youth caregiver as a research object which can be known

and accounted for, but it could also be understood as an attempt to frame the youth caregiver as a critical subject for understanding and responding to contemporary conditions of family caregiving.

The second network is the Bookend Caregiving Network (<http://bookendcaregivers.web.unc.edu>), which connects researchers, politicians, school-based staff and administration, health navigators, pediatricians, gerontologists, community and regional government, and caregiving families in seven counties that comprise the Triangle J region of North Carolina. Initially funded by a Patient-Centered Outcomes Research Institute pipeline-to-proposal award with a community partner, Mr. Martin Hunicutt, and in collaboration with the American Association of Caregiving Youth and the regional Area Agency on Aging, it began as an initiative to create partnerships with diverse stakeholders for the purpose of improving the lives of bookend caregiving families. As the network evolved, it has assumed the task of raising awareness amongst diverse actors and organizations that are likely to be serving bookend caregiving families. The network has required substantial outreach to vastly different communities of practice, often with very different missions.

When I first began speaking with schools, social workers, and family caregiver specialists about young people who have caregiving responsibilities, I found that discussing the youth caregiver in North Carolina required me to stabilize the category in a way that felt simplistic and at times essentializing. It has taken a tremendous amount of learning, humility, and patience to find a balance between opening space for further conversation and allowing for complexity and heterogeneity, because the youth caregiver also generates new responsibilities for groups that are often already overburdened and underfunded. Clarifying the boundaries of the category gave professionals the conceptual tools needed to create a space for the youth caregiver within their missions and mandates. Within the school district that I have been working most closely with, for instance, the youth caregiver is most easily understood as a student who exhibits chronic absenteeism and tardiness, exhaustion, and distractions from stress or worry. Among the aging services communities, concerns about rising incidents of elder hunger require immediate remedies, and federal funds targeted for supporting caregivers can be constrained by age restrictions. Professionals in these systems justified involvement and action by fitting the child caregiver into a broader mission such as closing the “achievement gap” between very high and very low performers, or addressing the need for improved care of the elderly. Importantly, this often accompanies requests for evidence of need that can only be available if youth caregivers and their families become research subjects.

In each community of practice, representing youth caregiving requires stabilizing the subject while allowing for flexibility so that a new field of care can incorporate the concept into their own frame of reference. Some of my efforts have failed to frame youth caregivers convincingly; indeed, to date I have been unable to persuade key administrators within my own university to prioritize learning about the educational impacts of family caregiving by students, and my collaborators and I have yet to convince any national cohort studies on youth and wellbeing to include an effective module about caregiving. In sum, the ambivalence I feel towards these acts of representation reflect the cautionary successes and failures that are sometimes individual, sometimes shared with my collaborators. They also hint at the importance of having robust theoretical frameworks that can make use of ambivalence, which I turn to now as a kind of open-ended conclusion.

Narrating slow violence: theoretical tools for coordination, ambivalence, and humility

How might my reflections on representing youth caregivers inform the work of others who seek to represent slow violence? I believe that ambivalence has challenged me rethink framings, or to draw back from certain narratives in favor of others. But as Bhabha (1984) suggests in his consideration of postcolonial mimicry, ambivalence is a signal or a modifier of a normative bearing, not a functional theoretical framework. Though it may highlight a problem or tension in the way the youth caregiver is being constituted and held together across diverse communities, it does not provide guidance for the

“expert” author who represents unimagined communities in order to counteract slow violence. Identifying theoretical frameworks that can help me better understand my contributions as I move forward with research and advocacy has become increasingly important as my networks grow and change. In this final section, I highlight two scholarly interventions that have allowed me to make productive use of my ambivalence. The first is Mol’s (2002) exploration of the body multiple, and the second, theories of epistemic responsibility and humility advanced by Kittay and in the broader field of bioethics.

Mol’s (2002) elaboration of the “body multiple” suggests one way that concerns about power can remain at the forefront of praxis, particularly as they become expressed through an awareness of the work of coordination. Mol focuses on the emergence of disease (specifically, atherosclerosis in a Dutch hospital) through the synchronism of discursive and material practices of medical professionals and patients. Her ethnographic study considers how a single body, and even a single disease, becomes pieced together through blood pressure tests, laboratory results, and patient histories. In her analysis, each of these singular elements can exist alone, but the body itself is all of these, and so there must be a mechanism by which things that are apart can be brought together. In the hospital, this entails adding up disparate pieces in the patient’s file, or resolving discrepancies across different examinations. When the different singular expressions of the body are bundled, Mol (2002, 55) describes the body that “hangs together” through these “*forms of coordination*” (italics in original). The result is a body that is simultaneously singular and multiple. The form of coordination is the action or space which brings the different elements of the body multiple together, resolving differences in their reports, adding up and comparing, and ultimately proffering a version of disease that might in the future be undone or rearranged in a different moment of coordination.

I have come to use the idea of my work serving as a form of coordination, drawing together and resolving the various frames of youth caregiving that each community of practice creates. It references the kinds of power that I enact as an author, and the resulting responsibilities for increasing the visibility of some frames, or cultivating new ones when the body multiple of “youth caregiver” seems to be at risk of becoming mostly a research object. Producing better representations of slow violence may not refer to an obvious storyline or evident symbolic referent, because it can also entail navigating similarities and differences that emerge within and between fields of care, and providing the space and attention needed to coordinate multiple frames of unimagined communities. This task involves resolving disparate but necessary frames that often isolate (sometimes pathological) characteristics of the youth caregiver, including: overtired student, mental health risk, empathetic citizen, loving son, stressed granddaughter, and so on. To think of myself as a form of coordination allows me to reflect critically on the representations that I and others produce, and to use my ambivalence as a signal to critically analyze what has gone into any particular body multiple formation of the youth caregiver.

While the idea of the body multiple and forms of coordination has helped me to both explain and make choices about strategic alliances and collaborations, theories of epistemic responsibility and humility remind me that in many circumstances, I lack the expertise or knowledge to effectively narrate the youth caregiver for such diverse communities. Feeling ambivalent about how we should represent youth caregiving makes me mindful of the motivations for doing so, and the potential harms that can emerge from representation. This work as narrator of slow violence has carried with it different ethical concerns and responsibilities than other participatory work that I had done in the past. In contrast to well-considered dilemmas associated with understanding and responding appropriately to the communication expectations of participants in research (e.g. MacKenzie et. al, 2015), youth caregivers must also see themselves in the representations that we produce; the hope is that, if they do, they might offer other framings of the youth caregiver. This approach is, to be blunt, an ass-backwards way of doing participatory research, and many of the ethical frameworks that I’ve used in those contexts, including

ethics of care, do not grapple sufficiently with the twinning of representation and expertise for emancipatory purposes. Feminist theories of epistemic humility and epistemic responsibility have been essential for working through some of my dilemmas. Scholars like Ho (2011), writing in the field of bioethics, emphasize that groups which are considered vulnerable or subject to multiple disparities (like many of the families of youth caregivers) may experience even greater epistemic oppression when experts demand both respect and trust. This reminds me that the body multiple must remain open to influence and change, but it means that I put the tasks of education and communication - the cart - ahead of the research "horse." Though the students involved in the Caregiving Youth Project express their enthusiasm for being involved in research, and even insist upon its importance, this is because trust has emerged from a long community commitment and evidenced care by the people who have been working with them over a long period of time.

I have made mistakes and have had many failed attempts at connecting with caregiver communities, and though humbling, they are reminders that my role as author is not totalizing and can be disassembled or silenced as well. Kittay (2008) suggests a way to make use of humbling moments and resulting ambivalence in ambitious representational efforts like Bookend Caregiving through the concept of epistemic responsibility. She describes a conversation she had with the philosopher Peter Singer about his position regarding people with disabilities, and expressed astonishment when, after inviting him to visit a community that her own daughter participated in, he displayed a marked disinterest and refused the offer. This is epistemically irresponsible, she clarifies, because the formation of his knowledge about the subject of his philosophy is based on being willfully ignorant of the subject matter itself (Kittay, 2008). In representations of slow violence, it might be best to assume and anticipate ambivalence, and to take seriously the challenges of epistemic responsibility and the humility to recognize the limitations of idealizations, even those that might seek justice for suffering communities.

Conclusion

Nixon (2011, 9) laments that politics and science are often driven by "immediate self-interest, procrastination, and dissembling" which exacerbate the conditions of slow violence, and so better representations are intended to help relieve these tendencies. In this article, I've tried to do two things - to better represent the significance of youth caregivers in the United States, and to reflect on the kinds of decisions and engagements that I've undertaken as a researcher and advocate to expose this form of slow violence through a brief autoethnographic reflection. My purpose is to break the silence about youth caregiving in the U.S. so that we might come to terms with the past, present and future of care, but I'm also realistic about the limitations of this endeavor.

As Dahl (2017, 93) argues from a feminist understanding of aging and care, "silence points to two aspects of power: silence as normalization and silence as the forgotten/the unspeakable." Silence and slowness are effective bedfellows in the perpetuation of violence over long periods of time and space, but whereas the forgotten and unspeakable might be addressed better through the narratives and symbols that I have presented here, normalization implies something that travels from narrative to the structures of society. My work can be seen as trying to stabilize the category of youth caregiver into something that might counteract the slow violence of a dangerously neoliberalized existence that is brought on by the silence that surrounds these families, but it is also mundane, slow, partial, and even dissembling. Many of my efforts have gone toward easing the tension of the body multiple in order to construct an adequate figure of the youth caregiver that makes sense to fields and practices of care that might, in turn and eventually, offer care for the youth caregiver.

My experience suggests that representing slow violence can be charged with a fair amount of ambivalence, and so I've concluded by suggesting some theoretical frameworks that have helped me make this ambivalence a productive partner in my many collaborations. As I reach out to ever more

diverse groups of professionals - palliative care experts, school social workers, veterans caregiver service navigators - I add another dimension to the multiplicity that is the youth caregiver. I incorporate these insights and perspectives as I move amongst diverse fields of practice to explain why youth caregivers and their families should be seen and accounted for, supported, empowered, and understood.

By thinking of my role in this broader space of research activism as a form of coordination, I have been able to make use of ambivalence to reconsider my limits as expert and as a signal to reconsider the framing of the youth caregiver as it moves into different fields of care. The audience for our representations exceeds that which will read my academic publications, and the inputs are not confined to the time frame of a given research project. Epistemic humility and responsibility require diligence and patience which can slow the process of representing slow violence, but for me it is a welcome slowness that provides a space for ethical authorship.

Acknowledgements

My work has been made possible because of the many partners, formal and informal, in my work with youth caregivers. For the work discussed here, I'm especially indebted to Dr. Connie Siskowski, Martin Hunicutt, Twanna Monds, Emma Armstrong-Carter, Juliana DeSouza Ritter, Laura Kathryn Smith, and the advisory board of the Bookend Caregiving Network. Funding for the first two years of the network was provided by a PCORI Pipeline to Proposal Award titled: Building Networks for Comparative Research with Youth Caregivers of Older Adults (E. Olson, PI). I'm grateful to the blind reviewers who convinced me to pursue a different approach for this article, and for the supportive talent of Caitlin Cahill and Rachel Pain.

References

- Assaf, Raymen Rammy, Jennifer Auf der Sprunge, Constance Siskowski, D.A. Ludwig, M.S. Mathew, and J. Belkowitz. 2016. Participation Rates and Perceptions of Caregiving Youth Providing Home Health Care. *Journal of Community Health* 41, 326-333.
- Aldridge, Jo, and Saul Becker. 1999. Children as carers: the impact of parental illness and disability on children's caring roles. *Journal of Family Therapy* 21, 303-320.
- Barusch, Amanda. 2013. The Aging Tsunami: Time for a New Metaphor? *Journal of Gerontological Social Work* 56, 181-184.
- Bhabha, Homi. 1984. Of mimicry and man: The ambivalence of colonial discourse. *October* 28, 125-133.
- Butz, David. 2010. Autoethnography as Sensibility. In *The Sage Handbook of Qualitative Geography*, edited by Dydia DeLyser, Steve Herbert, Stuart Aitken, Mike Crang, and Linda McDowell, 138-155. Thousand Oaks, CA: Sage.
- Cahill, Caitlin and María Elena Torre. 2007. Beyond the journal article: Representations, audience, and the presentation of participatory research. In Sara Kindon, Rachel Pain and Mike Kesby (Eds.) *Participatory Action Research Approaches and Methods: Connecting People, Participation and Place*. London: Routledge. 196-205.
- Carter, Roslyn. 2008. Addressing the caregiving crisis. *Preventing Chronic Disease* 5. http://www.cdc.gov/pcd/issues/2008/jan/07_0162.htm. Accessed September 13, 2018.
- Dahl, Hanne Marlene. 2017. *Struggles In (Elderly) Care: A Feminist View*. London: Palgrave Macmillan.

- England, Kim. 2010. Home, Work and the Shifting Geographies of Care. *Ethics, Place & Environment*, 13, 131-150.
- England, Kim, and Caitlin Alcorn. 2018. Growing care gaps, shrinking state? Home care workers and the Fair Labor Standards Act. *Cambridge Journal of Regions, Economy and Society* 11, 443-457.
- England, Kim, and Isabel Dyck. 2011. Managing the body work of home care. *Sociology of Health & Illness* 33, 206-219.
- England, Kim, and Isabel Dyck. 2012. Migrant workers in home care: Routes, responsibilities, and respect. *Annals of the Association of American Geographers* 102.5 (2012): 1076-1083.
- Evans, Ruth. 2011. Youth Caregiving and HIV in the UK: Caring Relationships and Mobilities in African Migrant Families. *Population, Space and Place*, 17, 338-360.
- Evans, Ruth. 2014. Children as Caregivers. Ben-Arieh, A., Casas, F., Frones, I, Korbin, J.E. (Eds.) *Handbook of Child Well-Being*, (1893-1916). Springer.
- Fisher, Berenice, and Joan Tronto. 1990. Toward a feminist theory of caring. In, Emily K. Abel and Margaret K. Nelson (eds) *Circles of care: Work and identity in women's lives*. 35-62.
- Fruhauf, Christine A., Shannon E. Jarrott, and Katherine R. Allen. 2006. Grandchildren's Perceptions of Caring for Grandparents. *Journal of Family Issues* 27, 887-911.
- Gastfried, Jody. 2018 (July 25). The Cost of Caregiving: Meet the Millennials Taking A Second (Unpaid) Shift. *Forbes*. <https://www.forbes.com/sites/jodygastfriend/2018/07/25/the-cost-of-caregiving-meet-the-millennials-taking-a-second-unpaid-shift/#9fa572529ff7> Accessed August 13, 2018.
- Glenn, Evelyn Nakano. 2010. *Forced to Care: Coercion and Caregiving in America*. Cambridge, Mass: Harvard University Press.
- Greene, Jennifer, Donna Cohen, Constance Siskowski, and Peter Toyinbo. 2017. The relationship between family caregiving and the mental health of emerging young adult caregivers. *The journal of behavioral health services & research* 44: 551-563.
- Haraway, Donna. 1988. Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies* 14, 575-599.
- Ho, Anita. 2011. Trusting experts and epistemic humility in disability. *IJFAB: International Journal of Feminist Approaches to Bioethics* 4, 102-123.
- Jenkins, Jo Ann. 2018 (May 29) Millennials and Caregiving? Yes, It's a Thing. *Family Caregiving* <https://www.aarp.org/caregiving/home-care/info-2018/millennial-caregivers-work-life.html> Accessed August 13, 2018.
- Kavanaugh, Melinda and Megan Howard. 2018. *Real Kids Talk about ALS* ALS Society of America. <http://www.alsa.org/assets/pdfs/youth-guide1.pdf> Accessed 29 January 2019.
- Kearns, Robin A., and Alun E. Joseph. 1997. Restructuring health and rural communities in New Zealand. *Progress in Human Geography* 21, 18-32.
- Kittay, Eva Feder. 2008. Ideal Theory Bioethics and the Exclusion of People with Severe Cognitive Disabilities. In *Naturalized Bioethics: Toward Responsible Knowing and Practice*, edited by Hilde Lindemann, Marian Verkerk and Margaret Urban Walker, 218-37. Cambridge: Cambridge University Press.

- Lawson, Victoria. 2007. Geographies of Care and Responsibility. *Annals of the Association of American Geographers* 27, 1-11.
- Lakoff, George and Sam Ferguson. 2006. The Framing of Immigration. The Rockridge Institute, <https://escholarship.org/uc/item/0j89f85g> Accessed January 15, 2019.
- Leu, Agnes and Saul Becker. 2016. A Cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *Journal of Youth Studies* 20, 750-762.
- McEwan, Cheryl. and Michael Goodman. 2010. Place Geography and the Ethics of Care: Introductory Remarks on the Geographies of Ethics, Responsibility and Care. *Ethics, Place and Environment* 13, 103-112.
- MacKenzie, Catrina A., Julia Christensen, and Sarah Turner, 2015. Advocating beyond the academy: dilemmas of communicating relevant research results. *Qualitative Research* 15, 105-121.
- Mol, Annemarie. 2002. *The Body Multiple: ontology in medical practice*. Durham and London: Duke University Press.
- National Academies of Sciences, Engineering, and Medicine. 2016. *Families caring for an aging America*. National Academies Press.
- Nickels, Margaret, Connie Siskowski, Cynthia N. Lebron, and Julia Belkowitz. 2018. Medication administration by caregiving youth: An inside look at how adolescents manage medications for family members. *Journal of adolescence* 69: 33-43.
- Nixon, Rob. 2011. *Slow Violence and the Environmentalism of the Poor*. Cambridge, MA: Harvard University Press.
- Olsen, Richard. 1996. Young carers: challenging the facts and politics of research into children and caring. *Disability & society* 11, 41-54.
- Olson, Elizabeth. 2015. Geography and ethics I: Waiting and urgency. *Progress in Human Geography* 39: 517-526.
- Olson, Elizabeth. 2017. 'The largest volunteer life saving corps in the world': centering child caregiving in histories of U.S. human security through the Little Mothers' League." *Social & Cultural Geography*. Published on-line 17 August. DOI: 10.1080/14649365.2017.1362585
- Olson, Elizabeth and Connie Siskowski. 2018 (24 January). The U.S. needs to support and recognize youth caregivers. *The Hill* <https://thehill.com/opinion/healthcare/370578-the-us-needs-to-support-and-recognize-youth-caregivers> accessed January 29, 2019.
- Raghuram, Parvarti. 2012. Global care, local configurations: Challenges to conceptualizations of care. *Global Networks* 12, 155-174.
- Rivaux, Stephanie L., Joyce James, Kim Wittenstrom, Donald Baumann, Janess Sheets, Judith Henry, and Victoria Jeffries. 2008. The Intersection of Race, Poverty, and Risk: Understanding the Decision to Provide Services to Clients and to Remove Children. *Child Welfare* 87, 151-168.
- Robson, Elsbeth. 2004. Hidden Child Workers: Young Carers in Zimbabwe. *Antipode* 36, 227-248.
- Rose, Gillian. 1997. Situating knowledges: positionality, reflexivities and other tactics. *Progress in human geography*, 21(3), 305-320.
- Siskowski, C. (2006). Young caregivers: Effects of family health situations on school performance. *Journal of School Nursing*, 22(3), 163-169.

- Spece, Roy G. Jr., David S. Shimm, and Allen E. Buchanan. Eds. 1996. *Conflicts of interest in clinical practice and research*. New York, Oxford University Press.
- Spillers, Hortense J. 1987. Mama's baby, papa's maybe: An American grammar book. *Diacritics* 17, 64–81.
- Staeheli, Lynn A., and Don Mitchell. 2005. The complex politics of relevance in geography. *Annals of the Association of American Geographers* 95, 357-372.
- The State of Things*. 2018. WUNC Radio, May 17. <http://www.wunc.org/post/hidden-struggles-and-rewards-youth-caregiving> Accessed on 29 January.
- Watts, Michael. 1983/2013. *Silent Violence. Food, Famine, and Peasantry in Northern Nigeria*. Athens and London: University of Georgia Press.
- Zelizer, Viviana A. 1994. *Pricing the Priceless Child: The Changing Social Value of Children*. Princeton, NJ: Princeton University Press.