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Family Caregiving as Health Work: A Critical Perspective on the Value of Supporting a Loved One Aging at Home

by Mary Rita Holland

Abstract: This paper uses the example of family caregivers in Atlantic Canada to shed light on the invisible emotional labour—or health work—required to maintain the home as a site of care and manage disrupted meanings of home space and family relationships. It provides an overview of feminist political economics perspective to illustrate the history of women's exploitation, the extent of their invisible health work, and the impact of private home care and aging-in-place policies on their experiences of home. A critical perspective on gendered, familial care providers and their relationship to the care environment contributes to knowledge of the impact of imposing long-term care policy on domestic relationships and places.

Keywords: Canada; family caregiving; feminist political economy; home care

Résumé : Cet article s'appuie sur l'exemple des aidants familiaux dans les provinces de l'Atlantique canadien pour illustrer le travail émotionnel invisible – ou travail en santé – qu'implique le maintien du domicile comme lieu de soins et la gestion des bouleversements liés à l'espace domestique et aux relations familiales. Il offre un aperçu du point de vue féministe à l'égard de l'économie politique pour montrer l'exploitation historique des femmes, l'ampleur de leur travail invisible en santé, ainsi que les répercussions des soins à domicile privés et des politiques de vieillissement à domicile par rapport à leur expérience du foyer. Pour comprendre les conséquences de l'imposition d'une politique de soins de longue durée sur les relations et les milieux familiaux, il faut poser un regard critique sur les aidants familiaux selon leur genre et sur leur rapport à l'environnement de soin.

Mots clés : aidant familial; économie politique féministe; soins à domicile; Canada

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Introduction

When health problems are chronic due to age or disability, family caregivers must take on the long-term work of supporting a loved one at home. Family members who find themselves caring for a loved one either at close proximity or from a distance over the long-term are an integral part of the health care system yet, because their efforts are based on

the private realm of the home, their contributions remain largely invisible and undervalued.

In 2019, I began an inquiry into the question: What do family caregivers do to maintain the home as a site of care and how are they supported? The project took place in rural New Brunswick and consisted of interviews with family caregivers and frontline health and social services staff. Participants spoke of the interior and exterior work involved in maintaining the home as a site of care. While housekeeping, administrative tasks, and property maintenance are not factored into home care policy, participants portrayed this work as "critical to care," similar to findings of feminist political economists who study care in institutional settings (Armstrong, Armstrong, Scott-Dixon 2008).

The research used the example of family caregivers of rural older adults in New Brunswick to shed light on the invisible health work required to maintain the home as a site of care and manage disrupted meanings of home space and family relationships. Findings suggest that structural forces like government policies and income inequality create and perpetuate new forms of health work for family caregivers.

While presenting findings from the research, I encountered the perspective of people who supported family members living with chronic illness or disability living at a distance. It was clear that while the health work they engaged in looked different from that of family caregivers living in the home or nearby, those caring at a distance also played a significant role in the form of home care "without walls." A critical perspective on gendered, familial care providers and their relationship to the care environment is necessary to understand the impact of imposing long-term care policy on domestic relationships and places.

Positioning Myself in the Research

My interest in the contributions of family caregivers began when I noticed contradictions inherent in the cancellation of the Primary Informal Caregiver Benefit (PICB) program in New Brunswick. In 2018, Premier Gallant's government introduced a monthly, non-taxable benefit of $106.25 to eligible informal caregivers, the PICB. The stated purpose of the benefit was twofold, first to "recognize the vital role informal caregivers play in supporting and assisting seniors and adults with a disability to remain safely in their own homes" and second "to help offset some of the costs associated with caregiving" (Government of New Brunswick 2017). The discourse suggested that the government recognized the contributions of family caregivers and the "home" as part of the health care system. Less than a year after the PICB was introduced, the newly-elected Progressive Conservative government of Premier Blaine Higgs cancelled the program, arguing that it had not proven effective as only half of those eligible had applied for the benefit (CBC News, April 5, 2019).

I have a personal connection to the research because my mother cared for my father full-time during this period. My mother experienced the cancellation of PICB as a personal insult and disregard for her work, caring for my father at home and "keeping him out of a nursing home." The decision to direct funds to increase the pay of home care workers did not address my mother's needs as my father did not qualify for subsidized home care hours. I endeavoured to learn more about the impact of the policy and the lives of people caring for loved ones at home in response to lingering questions over how government policy for informal care did not reflect my mother's needs and experience.

Care is Health Work, not Housework

"Caring" is broadly defined as "the mental, emotional, and physical effort involved in responding to and supporting others" (Evans and Neysmith 1998, 11). A number of scholars have explored the negative economic and health impacts on family caregivers (Duxbury, Higgins, Schroeder 2009; Duxbury and Higgins 2017; Turcotte 2013). The research question "what do family caregivers do to maintain the home as a site of care" developed in response to the work of Armstrong, Armstrong, and Scott-Dixon (2008) who have shed light on ancillary health care work in long-term care. They found that by privatizing aspects of care like laundry and meal service, governments re-categorized this work as ancillary, or "outside of care." Doing so meant they could cut costs by offering contracts for housekeep

ing and food service to the lowest bidder. The deleterious effects on care—standardization of personal care and poor quality food, to name a few—are compounded by the poor working conditions of non-unionized, low-waged contract employees. High turnover in the ancillary care work sector has become the norm as precariously employed laundry and food service workers may opt for hotel or restaurant work with better pay. Armstrong, Armstrong and Scott-Dixion (2008) argue that the work involved in feeding and clothing residents in long-term care facilities is fundamental to care, should be compensated accordingly and, most importantly, should be categorized as skilled care work to ensure its social value is upheld.

Armstrong, Armstrong, and Scott-Dixon's theoretical contribution to research on long- term care can easily be extended to home care, particularly in areas where there is a private provision like New Brunswick. Subsidized home care supports are available for some forms of ancillary care work but homemakers, or home support workers, are employed by private, for profit-agencies and are poorly trained and low paid. Government policy states that homemaker support is meant to supplement the work of family members and restrict homemaker activities through guidelines and strict, means-tested eligibility criteria. Therefore, I argue that family caregivers have become an essential workforce, providing laundry and meals similar to the ancillary workforce in the long-term care setting.

No matter where it is provided or by whom, care is work. According to Armstrong and Day, "unlike many other forms of labour, the timing and duration of care needs are often unpredictable and vary significantly over time of day and of life" (Armstrong and Day 2017, 10). Care involves two people and is therefore relational work; "doing the work well requires conditions that make relationships possible" (Armstrong and Day 2017, 11). In other words, policymakers must go beyond the atomized version of caregivers and task-oriented, for-profit model of service delivery to prioritize fundamental aspects of care.

Feminist Political Economy

Debates over women's activities in relation to space are the hallmark of feminist scholarship. Feminist political economists move beyond discussions of "public" and "private" spheres to categorize women's unpaid labour in relation to the institutions and social structures that shape their experiences. A comprehensive feminist political economics perspective can help to illustrate the history of women's exploitation, the extent of their invisible care work, and the impact of private home care and aging-in-place policies on their experiences of home. While not all research participants in the study discussed here were women, the scholarly field of caregiving and the social organization of the home are gendered, thus feminist political economy is a good theoretical fit for the research.

While gendered expectations of women as caregivers constitute long-standing social norms, the relationship between unpaid care and the state has evolved over the past century in Canada. The post-war period of capitalism in Canada was based on a model of social reproduction; this period marked the institutionalization of unpaid care within the welfare state. Feminist political economists have fought against this gender bias in policy for years yet it has proven enduring. Their proposals have varied. Some argue unpaid labour should be commodified as a means of creating market value and material benefit. Others argue against market-oriented solutions in favour of social programs to decommodify care.

Prior to determining in which direction policy should proceed, it is vital to conceptualize care in relation to where it is performed. Armstrong, Armstrong, and Scott-Dixon (2008) provide a framework that helps with commodifying family caregiving by demonstrating that care is more than units/tasks and medical services but skilled work requiring compassion and human interaction. This view of care necessitates a broader understanding of context, skills, and relationships with space (e.g., the home) than what currently exists in policy. Family caregivers want to be visible; this requires some way of reversing institutionalized invisibility of their work.

The Value of Care Work

Feminist political economists understand care as work and argue that there is a need to make it visible for the purpose of drawing attention to its value. Marilyn Waring (1988, 1999) challenges the assumptions of neo-classical economics in her critique of the general accounting of paid versus unpaid work in the global economy. Waring argues in favour of commodifying, or assigning a monetary value to, women's activities in the home in order to make their work visible. Work happens regardless of whether it is paid and must therefore be understood from beyond narrow economic constructs, otherwise, as Waring points out "my grandmother did not work, and those mothers I see with their infants are not working" (Waring 1988, 21). Donath (2000) and Folbre (2001) argue the best solution is to categorize care work according to what its substitutes would cost in the marketplace. Waring (1999), Braedley (2010), and Luxton (2010) call for assigning monetary value to care work in The National System of Accounts which measures global economic activity. Such commodification strategies dedicated to solving the practical problem of how best to measure the value of unpaid care are helpful in framing family caregiving as a form of unpaid labour.

The practice of valuing work according to where it is performed is institutionalized through labour categorization codes like the North American Industry Classification System (NAICS) and National Occupation Classification (NOC). Armstrong, Armstrong, and Scott-Dixon point out that the codes measure and categorize work based on the activity type (NAICS) and employer (NOC) rather than the location meaning that, for example, laundry services, housekeeping, or food preparation are grouped according to activity (i.e. housekeeping or food service) and whether an individual worker is employed in a hotel or a hospital (Armstrong, Armstrong, and Scott-Dixon 2008, 16). As a result, nearly half of health care workers in hospital and long-term care settings are not classified as such. Breaking up care into units of activity gives the impression that it consists of a series of low-skill tasks. The associated low rates of pay have brought less care and poorer health outcomes, particularly for older adults and persons living with a disability care (Armstrong, Armstrong, and Scott-Dixon 2008, 9). These same researchers further argue that activities categorized as "ancillary" in hospitals and long-term care—those that are classified as "out of care" and often contracted out to the private sector—require skill and are every bit as "critical to care" as the work of physicians and nurses.

The unpaid domestic work involved in maintaining and supporting the household's inhabitants is referred to as "social reproduction." Bezanson describes the concept as a set of processes involved in "providing for social, emotional and physical needs and efforts to secure an income" (Bezanson 2006, 26). Women in Canada have been involved in social reproduction since Confederation, yet the development of the welfare state has reinforced rather than mitigated the effects of women's unequal burden of care.

Scholars continue to draw attention to our lack of understanding of the price women pay in terms of time and energy devoted to social reproduction. Whether for no pay in the home or low pay in the market, women have buttressed the family, market, and society against the exploitation of labour. Luxton expands the definition of social reproduction to include "the complementary work (also often done by women for pay) provided by state services such as education and health care or in the market" (Luxton 2010, 36). By combining the paid and unpaid activities of women's caring, Luxton enhances our understanding of women's roles in social provisioning, and points out that state support for caring through investments in public services is one way to lessen the burden. Yet, as we can see with the Canadian example, the policy direction is toward greater individualization and privatization of social reproduction as governments reduce investment in care in the name of fiscal responsibility (Bezanson 2006, 11).

Unpaid caregiving is increasing in Canada while the concept of gender is disappearing from government policy (Morris et al. 2017). Policymakers have re-framed care as a "family" concern, and, as Braedley points out, promote their "presumption that households and communities should and will actively provide services formerly offered by the state or third sector organizations" (Braedley 2010, 216). Low-income women who are informal caregivers have fewer options for supports and services. As Braedley (2010) argues, women are less likely to have employee benefits that would support their care activities and are less likely to have the financial resources available to contract out their domestic work (e.g., cleaning services). Moreover, low-income women are more likely to receive some form of government assistance and be subjected to surveillance by the state because of their circumstances (Braedley 2010, 225).

Debates on the Commodification of Care

Key to understanding the ways in which women have been systemically disenfranchised through assumptions about their willingness to provide care is the fact that it is not the burden of labour in the physical sense but the social relations involved that perpetuate women's subordination to capitalism (Luxton 2010, 34). Donath (2000) argues that it is possible to characterize the economy as a masculine entity and calls for a separate, or "other economy" to draw attention to women's experiences. While Donath's argument is clearly based on a concern for gender parity, it is also a call to improve the study of economics which has hitherto focused on an incomplete model of the economy. She argues that "in order to be able to investigate empirically the relationship between the other economy and the market economy, it is vital that feminist economists devise ways of measuring the other economy" (Donath 2000, 121).

Nancy Folbre is similarly dedicated to solving the practical problem of how best to measure the value of unpaid care. She argues that the most straightforward approach is to look at the cost of substitutes, like purchasing home care outside the home. While she admits that "purchased services are only partial substitutes for personal services from a family member or friend ... the cost of purchased substitutes provides at least a lower-bound estimate of the value of socially important activities" (Folbre 2001, 66). Folbre acknowledges that the first step toward computing such information is to develop instruments other than opportunity cost to account for the time and energy women devote to caring for others. While Donath (2000) focuses on the broader issue of including women's economic experiences, Folbre (2001) seeks to incorporate mechanisms from the market economy to explain women's caregiving in terms of its market value. Folbre argues for greater integration of women in the market economy through "valuing" unpaid work while Donath argues that integration is not only impossible but undesirable.

A combined approach—one that simultaneously compensates care work in market terms and includes state support for an "other economy"—would balance out the hitherto unequal roles for the market and state, vis-à-vis care work. The starting point for such a shift is to assign care work a value in the National System of Accounts (Braedley and Luxton 2010, 14). My research will contribute to the broader goal of accounting for unpaid care by gaining insights from family caregivers on the kinds of activities involved in maintaining the home as a health care setting and the costs associated with such work when outside help is necessary. By making the full extent of family caregiver work visible, it is possible to bring the social structures that systematically oppress women into focus for the purpose of reform.

Neoliberalism and Familialization of Long-term Care

In the present Canadian policymaking context, neoliberalism prevails in public discourse and social-political organization. Politicians argue that public spending must be curtailed and offer the competitive market as the means to lower taxation levels while maintaining services. Moreover, the virtues of capitalism are promoted; competition is depicted as "natural" and ideally suited to maximize social good (Braedley and Luxton 2010, 8). Thus, the state receives its mandate not from citizens but from the market. Rather than the state staying out of the economy, "neoliberalism activates the state on behalf of the economy, not to undertake economic functions or to intervene in economic effects, but rather to facilitate economic competition and growth, and to economize the social (Brown 2015, 62).

The rationalization for inequality in the neoliberal era is expressed through "the assumption that what we get is what we deserve as a result of our efforts" (Armstrong and Armstrong 2010, 187). The neoliberal trend toward relying on families to provide social welfare, families who obtain financial means through the market, has consistently dominated Canada's policies vis-à-vis women's care work. The effect is the suppression of social citizenship rights for women in the name of individual responsibility. As Brodie and Bakker argue, "the language of choice elevates the goal of individual liberty—the right to choose—over all other goals, including gender equality" (Brodie and Bakker 2008, 34). State provision of social welfare has become less popular over time, based on what Armstrong and Armstrong (2010, 187) refer to as "privatization of responsibility." In the citizen-as-consumer society, individual choice is considered not only a right but an imperative.

Welfare state scholars have fought tirelessly against downsizing government and against placing the onus on vulnerable populations to improve their circumstances. In more recent years, scholars have pointed out health impacts of social policies based on an individualized model of citizenship. As Polzer and Power argue, the technique of encouraging citizen-consumers "to maintain their health through their own 'free choices' and informed decisions" not only commodifies health but increases demand for health-related products as individuals must seek their own, market-based solutions for poor health and disease (Polzer and Power 2009, 4). The neoliberal backdrop of privatizing government functions has led health departments and hospitals to subcontract care services from agencies that operate like private businesses (Ferguson 2009, 168). Faced with declining levels of government funding, formerly publicly funded services in hospitals, like laundry and food preparation, have become privatized. Such a change is based on the thinking that care activities can be separated into those requiring trained health professionals and those who are low-skilled and whose work resembles services available in hotel and hospitality sectors.

Neoliberal approaches in the health sector—individualization and privatization—are inconsistent with the goals and nature of caregiving. Breaking up care into assembly-line units of activity has brought less care and poorer health outcomes, particularly for elderly and disabled individuals who rely on access to home care (Armstrong, Armstrong, Scott-Dixon 2008, 8). The current discourse around aging populations and the sustainability of public health care in Canada has supported the current model, one that is based on business practices in the name of efficiency. Yet, health care is "a relationship between health care workers and those with health care needs that cannot easily be reduced to a series of unspecified tasks and allotted to narrow time frames" (Armstrong, Armstrong, Scott-Dixon 2008, 8). By categorizing the work of caregivers as similar to the activities that take place in the home, governments have effectively found a way to keep pace with the neoliberal project of reducing the role of the state.

While scholars have acknowledged the increased burden on family members that accompanies private delivery of home care (Skinner and Rosenberg 2006; England 2010), the fact that their efforts are categorized in the same way as ancillary health work in an institutional setting suggests limited understanding of the way their work is socially organized. Invisibilizing the labour and costs of home care are hallmarks of a liberal welfare state.

Care at Home is Health Work, not Housework

The distinction between "health care" and "ancillary health work" articulated by Armstrong, Armstrong and Scott-Dixon (2008) illustrates the creep of privatization in health and long-term care at an institutional level. Mykhalovskiy and McCoy's (2002) definition of "health work" captures the invisible labour involved in managing health at an individual level. The trend toward reprivatizing care to the home through aging-in-place home care policy frames the need for long-term care as an individual and family responsibility. England (2010, 141) describes the result as "a privatised safety net" that "reveals how neoliberalism is far from self-sufficient, and depends on cultural assumptions about home and the hard work of women in the private sphere." Combining the critiques of feminist political economists on privatization in health care with critical geography of home provides a means of making visible not just the extent of "health work" involved in a rural setting but the gendered, neoliberal context that makes it so.

As illustrated in the rural findings from New Brunswick presented above, qualitative research with family caregivers and frontline staff demonstrates the complex nature of health work involved in care for older adults aging at home in an era of familialization. Family caregivers—particularly those who live-in—are tasked with navigating the material conditions of the home as well as its meaning, trying to preserve family relationships and traditions while operating within the constraints of everyday life. Such constraints are particularly challenging for family caregivers who are women and/or living on low income for whom the home can seem like a confined space, both literally and metaphorically.

Managing the home as a site of care involves a multitude of activities and constant coordination of space and relationships. The complex health work of family caregivers must be identified and counted rather than taken for granted. Recent debates on the future of long-term care in New Brunswick, as illustrated in the policy change from investing in the PICB to private home care agencies, focus on the need for higher levels of staffing. Yet governments are

aware that well-paid, unionized, full-time home care roles demand exponentially higher operating budgets for home care that can only be achieved through tax increases. The true costs of care, in other words, are human labour. Keeping those costs inside the home through familialization of home care has created new forms of health work for family caregivers who have few community and government resources to draw on.

Prospective Research: Long-distance Caregivers in Halifax, Nova Scotia

Location is central to my research in a number of ways. A number of scholars have provided insight into the unique relationship between caregivers and their physical surroundings, or workspace. Wiles argues that the geography of caregivers can provide researchers with "a sense of the physical, material and social constraints that operate on daily life and the strategies people use to negotiate these" (Wiles 2003, 1301). What is most significant about this line of research is that it will contribute to a more comprehensive view of the costs of home care—costs that are borne by family caregivers.

Place-based responses to aging assume the availability of a) a safe home environment and b) human labour to support healthy aging in the home space. Such requirements are often met by the adult children of parents living in a city or country that is far from the care recipient. While considerable scholarly attention has been directed at caregivers and their "burden" of providing assistance to a loved one living with chronic illness or disability, less has been devoted to the forms of health work long-distance caregivers are involved in that ensures the home is maintained as a site of care. Such forms of health work go beyond administrative and emotional support and can include the maintenance of culture, family relationships, and memories—vital aspects of health that are invisible in neoliberal (e.g., Canada) and authoritarian (e.g., China) welfare states.

Long-distance caregiving to aging people has been a common phenomenon in modern society. In Canada, according to Vézina and Turcotte (2010), 22 per cent of caregivers provide help for a parent living more than an hour away. Research has documented the caregiver "burden" (Adelman et al. 2014) emphasizing the physical, emotional, and financial strains faced by those who care for relatives with chronic illnesses or disabilities (Pinquart, Sörensen, Light 2003; Sambasivam et al. 2019). A secondary data analysis by Li and Wister (2023) shows that in Canada, greater caregiving intensity leads to more restriction to social life of family caregivers, causing worse social isolation.

In order to build on research of long-distance caregiving in Canada, I have designed a qualitative study to provide a comparative analysis between Halifax residents who are Canadian citizens caring for a loved one at a distance (over 1 hour away) in Canada and residents who are Chinese immigrants/newcomers caring for a loved one in China. The purpose of the comparison is to further develop an understanding of the types of health work related to supporting a loved one at home, albeit from afar. The difference between caregiving traditions in Canada, which emphasize individual responsibility for caregiving, and that in China, where adult children caregivers hold more responsibility (Lai 2008) poses unique challenges and coping strategies for the caregivers. Compared to caregivers who are taking care of

their loved ones in Canada, Chinese-Canadian long-distance caregivers may face cultural differences and language barriers affecting long-distance caregiving, as well as societal expectations to avoid formal caregiving services, due to a strong adherence to traditional values, such as filial piety, and the pressures of immigration (Lai and Surood 2008).

Using semi-structured interviews with long-distance family caregivers residing in Halifax, Canada, while caring for a loved one in Canada or China, the prospective research project will respond to the question: What does family caring entail for long-distance family caregivers and how are they supported? The research will provide a comparative analysis of two distinct experiences of sociocultural norms, citizenship status, and caregiving responsibilities.

The objectives of the research are to: (1) Identify invisible forms of health work involved in providing care at a distance; (2) Compare/contrast the feelings of familial responsibility in China and Canada; (3) Determine how Halifax-area family caregivers can be better supported in managing their role.

As discussed above, significant rationale for the study is that earlier research on family caregivers did not lend itself to gaining an understanding of the diversity of experiences of family caregivers. Rural areas of New Brunswick in the studies discussed above were demographically homogenous, with the exception of linguistic/cultural differences between Anglophone and Francophone populations.

For the prospective study, long-distance caregiver participants will be recruited through social media posts. However, to ensure recruitment materials reach marginalized communities, outreach emails will also be sent to organizations representing specific populations, including caregiver support groups (Alzheimer's Association) and marginalized communities such as urban Indigenous people (Mi'kmaw Native Friendship Centre) and Black Nova Scotians (Health Association of African Canadians) and Nova Scotia Community Health. With a diverse immigrant population from within and outside of Canada, Halifax provides a unique setting to study these differences.

By analyzing the experiences of caregivers in different cultural backgrounds, this research will contribute to a deeper understanding of the intersection between culture, family dynamics, and caring practices. It will also build out the scope of research on the health work of family caregivers to include those providing care from afar, both in another country and across Canada. As such, it has the potential to benefit both the scholarly community and long-term care practitioners. The research also has the potential to increase knowledge of the resources used to support long-distance caregivers living in Halifax and in the area in which the study participants provide care (China and Canada).

Conclusion

At the conceptual level, there is work to be done in making visible the "invisible heart" of the care economy. Folbre argues this is possible through a commitment to measuring the value of care work and promoting our success as a society on the basis of how that number reflects "the kinds of success we care about," including the values of caring, sharing, duty, and responsibility (Folbre 2001, 79). State support for policies that reward caregivers and, in particular, the sharing of care commitments between genders, would be a way to begin to shift the balance away from individualization and toward the state ameliorating the effects of patriarchy and capitalism on health care at home. The contributions of long-distance family caregivers in Canada remain invisible because it occurs beyond jurisdictions (municipally, provincially, and federally). Family caregivers require recognition and encouragement to mitigate distress and burnout. Whether they are providing meals, administrative support, care coordination, or home maintenance, family caregivers are "critical to care." The needs of caregivers should be addressed regardless of where they live in relation to the care recipient due to the fact that the work they do is time-consuming, financially and emotionally burdensome, and beneficial to a health/social system elsewhere that faces reduced costs.

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