A feminist study of the learning and educational activities of women unpaid caregivers in Newfoundland and Labrador

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Abstract

Although Canada has one of the best health care systems in the world, neo-liberalism is taking a toll and gender inequities abound. Using individual interviews and focus groups, this feminist study explored the complex education and learning strategies of seven female unpaid caregivers on the southwest coast of Newfoundland and Labrador. Findings show expansive skills in 'cross-disciplinary' communication, a sense of agency, a movement from learner to teacher, and admirable medical knowledge and technical skills. Yet the women work and learn predominantly in isolation which riddles the landscape with questions of power and control that have both positive and negative connotations.

Keywords

power, knowledge, unpaid women caregivers, communication, self-directed learning, health literacy

Introduction

Health care in Canada, as in many parts of the world, is highly politicised and ideologically driven. Introduced by a socialist government in the mid-1900s, the new universal health care system was to be publicly funded and available, equally and equitably, to everyone. Neo-liberalism, however, is solidly on the march in Canada and this has had major implications for a once robust system. Over the past few decades, federal governments have decreased funding to the health care system. Keeping abreast with these cuts are government-led discourses, supported by right-wing research (e.g. Irvine, Ferguson & Cackett, 2005), that persistently disparages the health care system, characterising it as non-entrepreneurial, riddled with out-dated technology, hindered by unions, and incapable of meeting the

demands of the aging population. By continually pointing out these deficits, some scholars suggest the goal is to shake Canadians loose from their extraordinarily high level of support for universal access and embrace a market-driven, 'for profit' scheme (e.g. Armstrong, Amaratunga, Bernier, Grant, Pederson & Wilson, 2002).

In the province of Newfoundland and Labrador on the east coast of Canada – the focus of our study – activities of economic health restructuring have been particularly intense due to the primarily rural nature of the province that makes health provision more expensive. Restructuring activities have ranged from the amalgamation of services and closing of clinics to the relentless downloading of care giving responsibilities to individuals and families. But the terms 'individuals' and 'families' are problematic because they obscure the very gendered nature of current economic restructuring policy and practice (Haslam, 1994; Botting, Neis, Kealey & Solberg, 2002). The majority of those onto whose shoulders health care is downloaded, are women. Feminist scholars have therefore, explored the complex impacts of neoliberalism on nurses, technicians and other paid health care employees (e.g. Heitlinger, 2003). Running abreast are studies that illustrate the plight the unpaid caregivers, the focus of our study (e.g. Armstrong, et al, 2002). However, what has received little attention is what and how women unpaid health care givers are being educated or are learning to play their roles as unpaid caregivers. This is an important focus not only because it contributes discourses of adult education and learning, but because it provides yet another piece of the problematic neoliberal health restructuring puzzle and broadens policy discussions.

Using individual interviews and focus groups, our study aimed to illuminate and problematise the health knowledge acquisition and self-directed learning strategies of seven women unpaid caregivers on the southwest coast of Newfoundland and Labrador. We begin this article by briefly contextualising our study within the neoliberal landscape of Canada today, and particularly, its impact on health care as seen by feminist scholars. This is followed by a discussion of self-directed learning and health literacy, the 'educational' lenses that frame this study. We then present the findings, followed by a discussion and conclude by offering suggestions for educational health policy changes for unpaid care givers.

Neoliberalism: The Political Context

Canada was built on a tradition of collectivism and socialism. Its people worked together to establish one of "the most generous and open-handed benefit provisions to be found anywhere in the world" (Clarke, 1997, p. 17). Although neo-

liberalism as an economic theory began having a distinctive influence on Canadian conservative parties in the mid-1970s, socially-oriented parties continued for many years to see it solely as “a form of anomalous political extremism” (Teeple, 1995, p. 3). However, it has become normalised to such an extreme that even when an electorate replaces a conservative party with more liberal or social democratic one, there remains the core expectation of maintaining or protecting these policies. The result has been the systematic “demise of long-established social… institutions” (p. 2). Canada’s socially envisioned universal health-care system is one of the victims.

The present health care system in Canada can be metaphorically described as a tree. The visible part – the branches, leaves and flowers – is the formal apparatus of doctors, nurses, clinics, and hospitals. Over the past two decades Canadians have witnessed the closure of publicly owned and operated hospitals and care centres. A study by Heitlinger (2003) illustrates the lack of institutional power the nurse have and suggests that since they are at the whim of market-forces, they are unlikely to gain power. The roots of our health care tree – fragile, vital and invisible – are the caregivers, described as *individuals* (our emphasis) who provide ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive, or mental health conditions (Canadian Caregiver Coalition, 2004). But, as argued in the introduction, feminists argue that discursive terms such as ‘individual’ and ‘caregiver’ problematically disguise the fact that the majority of these are in fact, women (e.g. Botting, 2002; Tudiver, 1994). Characterised stereotypically as naturally caring and nurturing, these women carry an increasingly heavy burden of administering to family members to keep them healthy and in many cases, alive, without the institutional support (problematic as it is), extensive training or resources paid health employees have access to. Studies show many unpaid care givers take time off work and thereby lose pay and benefit, become fatigued and vulnerable to injury or stress and even feel increasingly more isolated from friends (Botting, 2002; Morris *et al*, 1999; Richard, Kasuya, Polgar -Bailey & Takeuchi, 2000). Feminist scholars see this as a recipe for disaster, an inequitable situation that will ultimately prove unsustainable (Hay, 2005; Richard, Kasuya, Polgar -Bailey & Takeuchi, 2000). They call for more financial and policy support for these women. By way of contributing to these calls, we query how women unpaid care givers are learning and/or being educated to do play their roles and what support this aspect might require.

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Knowledge Power, Self-Directed Learning and Health Literacy

In addition to neoliberalism, theories of self-directed learning and health literacy provide lenses through which we can view the education and learning of women unpaid care-givers. Wilson (2010, p. 1) argues that everyone today lives at the centre of "a knowledge explosion." In terms of those attempting to navigate the current health care system, this translates into multiple and complex concepts and words coupled with rapid advancements in technology and treatments which can challenge even the most educated. Wilson goes on to suggest that the acquisition of knowledge – what he calls "knowledge power" – empowers people by enabling them to muster the requisite tools to function in today's complex information and technology saturated world, and underpins any ability to think critically. 'Knowledge power' is "*civilizing"*(emphasis his) and enables people to "know something about everything…and tackle the most difficult problems" (p.4). This means that "self-directed learners are likely to be the clear winners" in the knowledge mêlée of the 21st century (p. 225).

At its inception, self-directed learning was defined as "a process in which *individuals* take initiative, with or without the help of others, in diagnosing their learning needs, formulating learning goals, identifying human and material resources for learning, choosing and implementing appropriate learning strategies, and evaluating learning outcomes" (Knowles, 1975, p. 8). Inherent to this discourse are of inter-connected concepts of control, choice, autonomy, agency and power (Moulden, Peterson, Rinaldi, Charaniya, Malekpour, Churchill, Whitworth & Kostka, 2008; Rager, 2003; Taylor, 2009). Control is theorised as being in command of and over what and how one learns. Indeed, the innate perception here is of influence, the ability to challenge and change practices or policies. Autonomy, agency and choice carry many of the above connotations but also refer to a sense of independence and freedom to decide her own learning trajectory, differentiate, select amongst abundance and act within and upon the world as knowing, confident subjects. Lingering within the folds of control, autonomy and so forth are assertions of personal responsibility and issues of empowerment, defined as "a process by which oppressed persons gain some control over their lives by taking part with others in…activities and structures that allow people increased involvement in matters which affect them directly" (Rai, 2007, p.113). Scholars have also ascribed characteristics to competent self-directed learners: energetic, positive, self-assured and skilful (Collins, 2009; Levett -Jones, 2005). Indeed, the skilful self-directed learner is able, ready and willing to prepare, execute, and complete learning

independently. Moreover, he or she “is able to decide what needs to be learned next” (Jossberger a, Brand- Gruwela, Boshuizena and Wieb, 2010, p. 418). Within today’s complex world, what needs to be learned, according to Wilson (2010) is ‘requisite’ or “targeted knowledge power” that includes making meaning from core (old) knowledge, and acquiring new knowledge, and the ability to communicate.

A number of scholars, however, suggest caution and watchfulness vis-à-vis the enthusiasm for self-directed learning (Tusting & Barton, 2006). Candy (1991) and Taylor (2009) suggest, for example, that self-directed learning discourse tends to underestimate the power of social and cultural factors that curb freedom and autonomy. There are also structural and institutional factors, as in the case of the health care system, that can create their own restrictions and limitations. Feminists, and we count ourselves in this group, suggest that in addition, gender conditioning continues to have a negative impact on how much control, self-assurance, autonomy and ‘choice’ women actually have (Butterwick, 2003; Hayes & Flannery, 2000). They do not see women simply as victims of systems outside their control or that self-directed learning is fruitless (Rager, 2003) but they do acknowledge and problematise the gendered limitations, and challenges of the discourse of self-directed learning. Further, the issue of knowledge as power also needs to be problematised. When is knowledge real power and when can it be used to women’s disadvantage? When is and what knowledge, to borrow from Thompson (1997), really useful and when is it not? These questions lead us to contemporary debates around health literacy.

Health literacy is a term scholars use to try to untangle the maze of education, training and knowledge required in today’s complex health world (Nutbeam, 2006). It is defined “a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment” (Parker in Greenberg, 2001, p.69). Tacit to health literacy are also complex notions of control, practical knowledge, and autonomy that are, as with self-directed learning, equally contested. Particularly important is the concept of personal responsibility for one’s own health. While for some personal responsibility is nothing less than empowering, it problematised by others. Feminist scholars such as Chovanec and Foss (2006) and Greenberg (2001), for example, call for a movement away from approaches that favour individualism towards an emphasis on the political economy of health for two key reasons. Firstly, individual responsibility for health has become a smoke-screen for the reduction of funding to institutionalised care and secondly, has placed a disproportionate amount of responsibility on women who are expected

to stay healthy themselves and care for others (Haslam, 1994).

Research design

The purpose of this feminist study was to explore the educational and learning strategies of unpaid health care givers on the south west coast of Newfoundland and Labrador. We chose feminist research because it has an emancipatory and transformative intention. Moreover, it places women at the centre of the research process, beginning with their experiences and standpoints as subjects and bringing together from the margins their voices and visions (De Koning and Martin, 1996; Hesse-Biber & Leavy, 2007; Ironstone- Catteral, 1998).

Seven unpaid caregivers took part in the study. They responded to advertisements we placed in two local care and women's centres asking for volunteers with five or more years of care giving experience. One of the authors is also a long-time care giver. The women who responded to our advertisements were eager to share their experiences and saw the study as "a way to become more connected to a larger group" (Jackie).

Participant profiles

Noreen is in her early seventies. She and her husband have been married over 50 years and she has been caring for him for the past fourteen due to his kidney failure. They had saved a substantial amount of money but now just manage to pay their living expenses as all these savings are needed to cover additional medical costs. Noreen misses any sense of freedom.

Ida is a young retiree, remarried and the mother and caregiver to her twenty-four year old daughter. Nine years ago her daughter was diagnosed with schizophrenia, bipolar disorder tendencies and a mild form of developmental delay and since that diagnosis. Ida is a tireless advocate for her daughter but now must care for her mother who recently had a stroke and is now blind, paralysed on one side and tube fed. She describes her life as being constantly on call, 'available' and without spontaneity.

Maria is a divorced mother of three who works part-time. The eldest was born with severe mental and physical disabilities. He is hydrocephalic, has cerebral palsy and is tube fed. Maria was told her son would only live six months but through her self-sacrifice and care he will soon reach his twenty-fifth birthday. She notes that her

care situation has improved but shudders to think of any outcome if/when she were to fall ill.

Dorothy is single and never married and has no children. She has worked full time and for the past ten years and has lived with and cared for her mother in her mother's home. She notes how much gender plays out in our society and how she became her mother's primary caregiver as the only female with five brothers. Her brothers all have families so everything falls to her. Her mother had several strokes and needs full-time care. Dorothy has only had one ten-day holiday in 10 years because "I will not upset my mother for my own benefit." Like Noreen, she describes her life as one without freedom.

Jackie is 43 years old, a self-identified feminist and social activist. When her mother needed her because of her worsening arthritis Jackie packed up her 20 years of living in the city and returned to their small rural community to care for her. She worries she may not find work in the area, and knows she and her mother cannot survive on her mother's pension. She also expected more support from family and friends and admits to feeling alone and scared. However, Jackie is now getting involved in municipal politics.

Rona has been a caregiver for thirty-five years, since 1970 when her daughter was born with severe developmental and physical disabilities. Rona worked full time all late evening and night jobs because her husband worked all day jobs although in the beginning they took turns in terms of care giving. But then her mother became ill and her stepfather wouldn't allow anyone else into the home to care for her. Rona describes her life as very hard and wonders why she has to suffer so much to prevent her mother and daughter from suffering.

Lorna is in her mid-fifties. She spent 22 years caring for a severely handicapped daughter. After her daughter died, her mother moved in and needs care. Lorna is an adult educator who works full time in a women's centre. She talked of feeling exhausted but loved her child and mother too much to leave them to what she describes as "an uncaring system." In spite of the odds she recently undertook a Masters degree to get away from the "closed in feeling, with no freedom…I needed space, space for me."

The study began with a focus group that brought women together the seven women to help us to develop targeted questions around their education and learning strategies. Following this, we undertook individual face to face interviews where the

researchers probed the nature health knowledge, learning and education activities and the social and political contexts of the women unpaid caregivers. This was followed by a focus group held at the local women's centre where one of the authors worked. This location was easily accessible. The focus group allowed the women to build on the ideas they shared in the interviews but more importantly, to talk about advocacy and networking in more detail, something advocated for by feminists working in the health care (Tudiver, 1994). All interviews and the final focus groups were audio taped and transcribed. From the compilation of data, researchers analysed, codified, categorised and thematised participants experiences (Gubrium, Sankas, Luborsky, 1994).

Cross-Disciplinary Communication

Learning to communicate across disciplines was one of the key learning strategies in which the women engaged. This was always learned and seldom if ever taught. One aspect of this was learning to communicate across a diversity of bureaucracies, what Noreen referred to "as speaking across disciplines." None of the women really understood just how complex or frequent these communications would be, and the multiple roles it would take them into. For example, to deal with her disabled son, Maria is required to communicate with a social worker, a physiotherapist, a family doctor, several home care workers and specialists and even a home renovator. Others agencies included providers of medical equipment for the physically handicapped and rehabilitation staff. She argued that "the psychiatrist, the caseworkers, and the health care policy people", for example, seldom if ever communicated and therefore, "I was actually the conduit for this. I was the one who connected them." Jackie added that "everyone has their own specialised language", and she had to learn quite quickly how to switch from one "set of jargon to the next." Daley (2006) argues that keeping abreast with health care jargon is extremely difficult, even for the most highly medically educated. Yet these caregivers learned the communication thread that ran between different departments and "in a way, pulls the different people together. Well, someone needs to learn to do it!" (Lorna).

Self-confidence and the 'right' to question

Self-confidence, autonomy, control, assertiveness are all attributes of the self-directed learner and this was a second major theme in the study. Jackie provided an example of when she actually rang and spoke to the Premier of Newfoundland and

Labrador. She noted how “I’ve now learned pretty strong persuasive skills and I’m not afraid now to speak to anyone in terms of what I know I’m entitled to.” Rona described this activity as “learning to fight, ever and always “further up the chain! You just have to keep going higher and higher.” Ida argued that you need to continually muster persistence and to never give in because “All you hear is this is the policy. No! No! No! It is only an excuse not to look into it. If you speak up enough and often, they will give you a little bit so you will shut up.” Lorde (1984) describes this as “the transformation of silence into language and action” (p.40), a sense of agency that helps women to challenge a system by activating a power from within (Hayes and Flannery, 2000; Tisdell, 2001).

But there were many tearful moments during the study, partly from acute anger and partly from the extreme fatigue from what Ida called the “fire-walls that need to be scaled or ducked.” Moreover, the learning and acting were most often done individually. Sometimes there were impressive gains, someone would get some form of support, but it was a struggle in and of isolation. As Ida so aptly noted, unpaid and paid caregivers are not in fact, a team. No matter how sympathetic or caring paid staff may be, “a team implies cooperation for a common purpose and its not there for many reasons.”

From Learners to Teachers

Who is a learner and who is a teacher? When do learners become teachers? These questions introduce the third theme to emerge in the study and it is indeed, complex and troubling. To begin, it would be inconceivable in Canada for medical personnel to work the front lines of health care without a sound medical education. Professionals are trained extensively and regularly to, for example, recognise symptoms and administer medications. In other words, they are highly ‘health literate’. And yet a similar knowledge or level of literacy is expected of unpaid women caregivers without the training:

Well can you imagine someone giving you [a specific drug] and I can’t remember now the name….I got the books and there are two lots of medication that you’ve got to mix and you have to get that just right. Well gee, I am not a pharmacist and I felt that if anything happened to him [her husband] it would be my fault.

(Noreen).

Yet when Noreen rang the hospital staff for assistance, I was told I knew more about his case than the nurses at the hospital. They more or less said that knowledge made it my responsibility to keep him alive." Going further, Maria learned to change the gastrointestinal tubes (GI) in her son's abdomen. When questioned how she had learned to this, she said, "Oh, nobody ever trained me, everything I learned was on my own. I read some in books and checked online and what I didn't read I learned from experience." Once her son he had pulled out one of the tubes and when she took him to the hospital she discovered "the nurse couldn't put it in, the doctor on call couldn't put it in, it had to be a surgeon."

Other participants talked about learning all things technical. For example, in the focus group Noreen told this story:

Let me tell you about the [home dialysis] machine. I had to learn how to use that, you had to learn what to punch in and if it got a bubble then it would quit and you had to get it going again. And if something happened to the machine I just had to call this number and they would talk me through how to fix the machine. I had to fix it myself and they told me step by step how to fix the machine. *It's cruel.*

Some women did speak of brief training sessions they would receive in the hospital around machinery or re-dressing a wound. But the majority were performing technical and what they saw as risky procedures that at times, as noted above, only a surgeon was capable of doing. Government regulations call for paid home care workers to have extra training within six months of being hired but this does not seem to apply to the unpaid caregiver. Many women shared their extreme fears in their abilities because "after all, whether he lives or dies is really down to me. I'm in charge here so it matters what I learn, what I know."

The participants also lamented that lack of information available through the diverse agencies, about, for example, mental illness and talked of hours spent looking up information on the internet around medical apparati, medications, and diverse symptoms and diseases "in order to be prepared for emergencies *when,* not if, they arise" (Dorothy). Rager's (2003) study of women with breast cancer drew attention to the importance of the Internet "not only for information, but for moral

support” (2003, p.285) and it seems that at least for the former, many women rely on this technology to provide the answers they need. But some participants questioned these activities. For example, Ida noted, “I can learn a lot of things online and in the books or pamphlets. But you know what is missing here? The questioning, the human touch. It is not a real person who I can talk to. That makes it limiting and well, isolating.”

But these women did not stop at just learning for themselves. Many have now become the educators, propping up the health care system with their skill and ability. An excellent example comes from Noreen:

when the feeding pump arrived at my house I spent hours trying to get it set up. Neither public health nor the hospital was able to help me they had not used this type of pump before. I had to feed him [her son] so I had to learn. I now train all my home care assistants and that means for every change of person – and that happens a lot…The person who comes here needs to learn a lot, there is the pump, care for the g-tube, and medication. It takes a good two weeks for me to train them.

Networking and advocacy

There were some examples of networking and actions that reached beyond their own worlds and needs. However, this was confined, not surprisingly, to women who had activist backgrounds. Lorna, for example, engaged in much outreach to other unpaid caregivers “because they [the health care system] never tell you what is available and you have to find out on your own. And that is why when I see another parent who has a disabled child I find them and speak to them because I can help them.” The inability of health agencies to actually advocate on behalf of the women propelled them into roles such spokespeople for the disabled, the mentally ill, the aging and so on. Rona ultimately took her story to the media and through their support, received a health care worker for 40 hours a week. While this could be seen as simply an individual gain as we discussed above, by taking her story to the media she was able to provide information otherwise invisible to much of the public (many of whom could end up care givers) and embarrass a non-responsive system into action. The public in turn added their voices to her plea through letters to the editor so in fact, she created new knowledge from old and mobilised the knowledge (Wilson, 2010).

The focus group concluded with a discussion about how to develop a network of unpaid caregivers who could provide moral support, something invaluable as suggested by Rager (2003), but more importantly, to speak as a group and challenge the system together rather than constantly in isolation. Laura noted how taking part in this study “has lessened my sense of caregiver isolation. In the small network of unpaid caregivers my voice was heard, not only was my voice heard, my feelings and fears were validated. I felt supported and hopeful that together we could advocate for change.” Feminist researchers, and adult educators, see this as an important outcome of the group enquiry process – a greater understanding of one’s own reality as a stepping stone to knowledge about the larger context and a collective decision to work for change (Hesse-Biber & Leavy, 2007; Ironstone-Catteral, 1998; Montell, 1999; Tisdell, 2001; Preece, 2009).

However, the majority of the stories of learning and functioning were stories of individual struggle and action and this is not “going away to change in this system anytime soon.” While the women did not go so far as to say the government deliberately tried to keep them apart, they did suggest it felt as though this were an aim: “the more isolated you are, the less impact you have.”

Discussion and conclusions

The participants of this study have learned to be skilful, self-directed learners who have learned a number of strategies to learn their roles such as reading books, continually questioning and, although not often, attending training sessions. Other strategies included watching and trial and error. While experiential learning is a valuable practice, we must be cognisant of the fact that these women fully understand the practice of trial and error has lives at stake. A third strategy employed was the Internet. Although formal training to use equipment, mix and administer prescriptions and carry out other medical tasks such as changing pumps or inserting tubes was minimal, through autodidaxy the women gained what Wilson (2010) calls ‘targeted’ knowledge, in this case medical and technical, so much so they were transformed into instructors and spokeswomen, using what they had struggled to learn to help others and provide leadership (Taylor, 2009). The unpaid caregivers in our study have learned to perform tasks assumed to be the purview of only highly skilled surgeons or pharmacists. Without exaggeration, they are indeed keeping family members alive.

These self-directed activities must be seen as empowering in the sense of greater control of situations, the sense of agency and even the influence these women have

exerted on the system, although this often has only benefited the individual and we shall return to this shortly. Knowledge here is indeed power, “a capital resource”, as Wilson (2010, p.1) suggests, and these women are to be applauded for what they have learned, and the gains they have made. Through their self-directed learning practices, they have acquired a political consciousness manifest in crossing boundaries disciplines, developed strong communication skills and have learned what they need to know to keep family members healthy and alive. Although many studies suggest women are often too intimidated to ask questions, and this was echoed in our study, many of these are in fact mustering the knowledge which is leading to the courage to not only ask the health care system to ring the provincial Premier and the media if necessary. Feminists have long argued that women possess abilities often ignored, undermined or erased within the discourses of legitimised knowledge in society and even at times, by the women themselves (Hayes & Flannery, 2000; Preece, 2009). Although we did find the women were far too modest about their medical knowledge they did recognise their power and knowledge so much so that they would push care assistants aside to keep control of the situation. They move us well along the health literacy continuum of acquiring “the functional skills that individuals need to manage their own health” and towards what Chovanec and Foss call ‘critical health literacy” (p. 219) in so very many ways and this is powerful and important.

But are their situations always empowering? Taylor (2009) cautions that “at first sight, the concept of self-directed learning would appear to be an uncomplicated good as it puts the learner at centre stage and ensures her needs and interests are given the highest priority” (p. 207). There are indeed cracks in the lives of these women that reveal a complexity around power and knowledge.

Reading books and searching for information online is invaluable learning, but it is not always a good substitute for formal training and the kind of learning that happens when one discusses and shares their ideas with others and tests understandings and information against the knowledge of another person or a group. Moreover, caution must also be exercised in terms of the internet. As powerful a social information/networking tool as it is, much medical ‘trash’ also exists online and in health care, much is about making money by encouraging people to ‘purchase’, for example, diverse drugs. There is also the problem of people ‘taking on’ symptoms or seeing them in others due to what they have read (Authors, 2007). Health literacy is the ability to “reach understanding and, as an ultimate goal, achieve wisdom”, not simply the ability to read about symptoms

(Hawthorne and Klein, 1999, p. 140).

There is no real indication in the existing health care system on the southwest coast of Newfoundland and Labrador that the individual gains these women have made have translated into a shift in policy from which others will reap the rewards. Although they talked about beginning a network that could have a stronger, collective voice, the reality is they are often so occupied with care and so fatigued many had difficulty imagining where they would dredge up the time let alone the energy. They truly do act alone or in isolation as “care commitments” constrain them from being more active collectively and publicly more often than not (Preece, 2006, p. 426). In other words, a collective sense of power was all but missing and socio-political change also absent. Therefore, their targeted knowledge power does not seem to be able to do what Wilson (2010) suggests is most important: “provide the basis for solving *our* most difficult problems and rising to *our* most significant challenges” (p. 7). Our challenges are the destruction of our health care system and a gender blindness that is as palpable as it is invisible.

One participant’s skill put her in a position where she had to fix a dialysis machine. Showing spirit and commitment, she did just that but she felt it was “cruel” if not dangerous for the health care officials to expect this, as it was their equipment, after all. The harder reality is it is the personal responsibility of these ‘unpaid’ caregivers to be in daily in the ‘business’ of keeping people alive (Daley, 2006, p. 219). This negates the notion of choice in terms of their learning and the roles they must play thereby detracting much of what is called empowerment. Indeed, this is also not what Daley (2006) calls “equitable and sustainable access to health knowledge.” Going further, we should ask if paid health care providers in hospitals, clinics and other sites expected to perform these duties without pay? To both of these we would say ‘not yet’ in Canada. Although the assumption exists under a universal health care system that resources are evenly distributed, our study also supports the suppositions by feminist scholars and researchers that they are not (i.e. Chovanec and Foss, 2006; Morris et al, 1999; Hanson, 2001). ‘Skilful’ learning coupled with neo-liberal economic rationalisation around health care puts women into impossible situations of life and death that other learning may not. What we are suggesting here is a problematic interplay between a political ideology and a highly motivated self-directed learner that could have serious consequences. The accolades for what the participants know and can do are well founded; the downloading of responsibility is oppressive and takes advantage of the fact that these women love their family members and are willing to stretch themselves to the

limit to learn to care for them.

We conclude this article with some recommendations. Firstly, would recommend that a network of support of their peers be developed and sustained. As Holland (2005), Rager (2003) and Tudiver (1994) suggest, a network creates a safe space where women can learn from each other and provide a constant ear to rant about the health system and/or their situations. Coming together would also be a space for them to become a more collective voice, demanding changes that would be more likely to have an impact on the system, rather than solely the individuals. Given the personal constraints, meetings could be face to face, but also, virtual since all the women had access to computers. But this alone is insufficient and in many ways, simply adds to the overwhelming responsibility these women have in their lives. Moreover, as feminist scholars suggest and the women in this study alluded to, nurses and others in the healthcare system are also poorly paid and overworked. We call therefore for structured spaces for a dialogue between the paid and the unpaid care givers to discuss their 'common' needs and concerns vis-à-vis the health of the Canadian public. This way, they could work together to solve "health-related problems at the individual or community level" (Daley, 2006, p. 233). Thirdly, we suggest that better education and training mechanisms be developed. In order to reach this goal, an information campaign that alerts the public to the fact that so many women are caring for others, despite their powerful learning strategies and knowledge, without the medical training they may believe should be fundamental to this role.

Although Canada's universal health care system remains one of the best in the world, like so much else there is gender blindness and neo-liberal adjustments we must actively challenge and transform. If health literacy, self-directed learning and knowledge are truly power, then let us make them so across the board.

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