Patching Up the Holes: Analyzing the Work of Home Care

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ABSTRACT

Objective: Through close, critical readings of everyday practice of homecare case managers in Canada and Iceland, we demonstrate how contemporary neo-liberal policy that focuses on enhancing efficiency in the health care system has the effect of undermining forms of flexibility that previously enabled the delivery of home-based care and respected the unique needs of older adults.

Method: A case study method is used, drawing on a single case from Canada and another from Iceland to undertake an ethnomethodological analysis of how assessments of older adults’ needs for homecare support that is largely performed by women are accomplished.

Results: The interpretation of data illustrates both individual and collective strategies for the conduct of care in homes and communities. The effects of such strategies in terms of their effects in diminishing resistance to further shifts of responsibility for care over to individuals are demonstrated. Professional imperatives are shown to be effective in repairing and even extending the effects of responsibilization.

Discussion: This paper explores the effects of a variety of strategies employed by health care organizations as they both shape and respond to a changing care provision landscape. We illustrate how gendered organizational policies and professional practices support wider political interests in performance management and efficiency and, in so doing, further the effects of individualization in what could otherwise be mobilized collective responses to aging, poverty, illness and isolation.

Key words: Home care; neo-liberalism; gender; ethnography; Canada; Iceland

La traduction du résumé se trouve à la fin de l'article.

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Acknowledgements: The authors thank Dr. Cecilia Benoit and Dr. Helga Hallgrimsdottir for organizing the conference for which this paper was developed. Their commitment and assistance through the publication process has been much appreciated. Funding assistance from the Social Sciences and Humanities Research Council (SSHRC) for Dr. Ceci’s study and from the Icelandic Science Foundation for Dr. Bjornsdottir’s study is gratefully acknowledged.

Health care provided in the community, within people’s homes, is variably viewed as a key component of a fully functioning public health system,² as an unwelcome intrusion into a living space full of private decisions about how to live a life,³ and as a form of underpaid, undervalued work that has become a gendered ghetto for marginalized women.⁴-⁵

In confronting the significant challenges posed by home-based care, we hope to encourage critical reflection on the sorts of strategies that we have observed being incorporated into homecare practice.⁶-¹⁰

Through our various individual and joint field studies of homecare practice in Canada (Ceci and Purkis) and in Iceland (Bjornsdottir) we have observed relentless pressure being applied to nurses and allied health workers to increase the “efficiency” of their practices by making use of standardizing processes. These standardizing processes incorporate a task orientation into the work of caring for older people that shifts responsibility for work previously understood as professional to non-professional staff and to clients and family members themselves. We show later that such practices tend to work against supports and structures that would “hold” the dignity of the work in place by undermining the worth of the work, the workers and those in need of assistance.

In this paper we investigate the ways in which efficiency strategies serve to distract managers and policy-makers from formulating and addressing core questions that we believe precede those of how to safeguard efficiency of service delivery. The questions we refer to here are ones that address the goals of a contemporary homecare service, questions such as: What sort of effective and respectful partnerships could be built between state-supported health service delivery and the care provided by private citizens, such as family members and/or neighbours, to support the care of older adults now and into the long-term future? How can an effective service be developed when the needs of the older adult population are not regulated by times of the day but, rather, by circumstances that can change at a moment’s notice? What kind of system supports the dignity of this sort of health work, currently largely performed by women?
Sites in Canada and Iceland have been chosen to explore these questions because there are two countries that have traveled along a similar path, though at different speeds. Both have historical roots as welfare states, committed to using political power to mitigate socially produced dangers to individual and collective existence. Their respective health systems are one example of this. Recent decades, however, have witnessed the withdrawal of the state from areas of collective concern such as home care. For Canadians, consideration of the Icelandic context reveals what has been altered, at a very practical level, through globalization and the implementation of a neo-liberal agenda. For Icelanders, the comparison offers a glimpse of future possibilities.

We begin with a brief overview of the policy contexts within which homecare service delivery is currently emerging in both countries. We then present two case examples from separate field studies undertaken in Canada and Iceland that offer access to the everyday worlds of homecare practice in these two countries. Our aim is to demonstrate, through a close reading of homecare practice, how gendered political and organizational contexts influence the way in which practitioners assess and respond to the situations that older adults live in.

Caring for people in their homes: The policy context of Canada and Iceland

Canadian Context

Most high-income countries have developed systems for providing home-making and health-related supports to people who require such assistance – often seniors or those with chronic illness and/or disability – to continue to live in their own homes. Though home has always been the principal site of care of the sick or frail by family members and other informal caregivers, it has over the past two decades become an increasingly important location for the delivery of professional health services. As more people are either being treated or recovering from treatment at home, the acuity traditionally associated with institutions is transferred to these home settings. At the same time, changing demographic factors, including an aging population, means that the number of traditional clients of homehealth care, the frail elderly and the chronically ill is also increasing.

This shift in location of care must also be recognized as a cost shift. As Baranek et al. observe, more than simply a change in the site of care the move out of hospitals and other institutions “results in an increasing proportion of care moving beyond the collective ‘logic’ and institutionalized boundaries of the ‘Medicare’ mainstream.” Unprotected by the auspices of the Canada Health Act of 1984, home care is governed by neither federal legislation nor national standards. Although most provinces/territories fund some components of home care, local policy-makers have been preoccupied with questions of cost-sharing and base levels of services. In general, the further one moves from traditionally conceived health or medical services and from professional to non-professional services, the more attenuated are the arguments for public provision of services. As Duncan and Reutter have observed, with an increasing neo-liberal policy preoccupation with the acute or substitution (for institutional care) functions of home care, those who have benefitted from longer-term maintenance and preventive services become further disadvantaged in the competition for what have come to be seen as scarce resources.

The Icelandic Context

Since the 1980s, the explicit policy context in Iceland has stated that people should be helped to continue living in their own homes for as long as possible, despite decreased functional ability due to chronic illnesses or advanced age. This policy emphasis is reflected in the 1983 Act on the Affairs of the Elderly, revised in 1999. The health and well-being of the elderly was also a main focus in the “Health for All” document entitled The Icelandic National Health Plan to the Year 2010, which was passed by Parliament in 2001. One objective of this report was to ensure that at least 75% of people aged 80 years or older would be able, with appropriate help, to live in their own homes. In the summer of 2006 the Minister of Health and Social Security issued another policy statement, A New Vision – New Emphasis, in which numerous improvements in services for the elderly were promised. Homecare services, such as nursing and social services, were identified as being of central importance.

Despite what seems a clear policy directive, homecare services in Iceland have only recently become widely available. Institutionally based services had previously been the norm, and lobby groups and politicians in their calls for reform have primarily focused on the need for more institutional capacity. One of the main obstacles to the development of comprehensive homecare services has been an undeveloped organizational structure and unclear responsibility for service provision. Another major complaint has been the poor coordination between health care and social services. Health care services are organized and administered at the federal level, whereas social services are the responsibility of the municipalities. Recent policy documents have suggested a restructuring health and social services to enhance integration.

Methods

Two separate studies provided the data for this analysis. Both were ethnographic, involving an analysis of the context of health care as represented in policy documents and organizational structures; interviews with practitioners, patients and family members; and observations of nursing practice in the home environment. They were similarly analyzed using a constant comparison method. Following Yin’s method of explanatory, single-case study, this paper draws out the specifics of the constraints and possibilities of the work done by nurses in Canada and Iceland as they visit a typical client of homecare service delivery. Rather than arguing for the generalizability of the cases we aim to illustrate what nurses treat as necessary information to look for during a home visit and how they use that knowledge to create a network with family and wider community resources in the provision of care. This ethnographic, methodological approach allows us to offer an analysis of the work that always links back to an instance of typical practice.

The actual fieldwork for the Canadian study took place over approximately nine months in 2004. Seven case managers, all women and all experienced nurses with baccalaureate preparation, were the central participants in the study, allowing observation of their practices of screening clients,
determining eligibility, making referrals, monitoring clients’ status and re-evaluating over time. These practices were both the entry point and the centre of the analysis of the study, offering access to the field of care and the dilemmas currently shaping it. The study received ethical approval from the University of Victoria and the Vancouver Island Health Authority.

The Icelandic study involved 30 households in which one individual was assessed as in need of considerable assistance with daily activities and/or specialized treatment. This assistance was provided by Registered Nurses, most of whom had a diploma education, as well as lesser trained auxiliary nurses* and relatives when available. All the nurses were female, but the relatives were both men and women. The data collection took place in Reykjavik and neighbouring municipalities from 2001 until 2004. The project involved semi-structured interviews with patients, caregivers and nurses, in addition to field observation recorded by the researcher during nurses’ visits to the patients’ homes. The study was approved by the National Bioethics Committee for Iceland.

RESULTS

The Canadian case

The Canadian case study is developed in some detail in order to illustrate what health work looks like when circumscribed by discursive practices that emphasize efficiency and an imperative to enrol family members in its conduct. The Icelandic data suggest an alternative way to conceptualize the work, with practice organized around an idea of “flexibility” that contrasts with the Canadian example.

We begin with the Canadian case study and a typical case manager activity – the assessment-oriented home visit. The case manager explains her task to the researcher:

“I have to go and see Mrs. Watson … I am going to go in and do a review with the daughter at 0930 … the last time this woman has seen a doctor was 69 years ago. She’s 94 or 5 years old now … the family’s really ralled, lots of help going in there. I think I am going to reassess her because she needs more hours … The family’s asking for 3 hours in the evening, I have to go and justify it … I can’t do her assessment level. She lived for a time in Brookside House a [faith-based] assisted living place … They said they couldn’t keep her because she was too sick. (Ceci, fieldnotes, 2004; note: names have been changed to safeguard anonymity.)

The information provided in this account points to a variety of policy structures that shape the work of this case manager. She identifies her main purpose in making the visit as determining whether there is a “justification” for additional home support hours for Mrs. Watson in the evening. The information contained in Mrs. Watson’s file would not currently permit the case manager to approve additional time for evening support. However, if she can reassess Mrs. Watson, there is a sense of expectation that such reassessment will generate sufficient additional information to enable her to alter the level of support (measured in hours) that Mrs. Watson is eligible for.

The case manager knows that Mrs. Watson did try living in a more supportive environment: an assisted living facility run by her church. However, she required too much from that facility, which deemed her “too sick” to remain there, and so she was sent back home again. The situation described by the case manager seems incongruous: Mrs. Watson is too sick for an assisted living placement, and so she is returned home, where, except for the fact that her family has “rallied”, there would be little support for her beyond the two hours of paid home support she receives each day. If we juxtapose this situation against the scope of the solution that is being considered by the case manager, that is, the addition of one more hour of paid support, it is hard to comprehend how this solution might actually be considered helpful and how a highly paid, intelligent professional could engage in this as legitimate and rewarding work, i.e., as “good” work. However, this is not the case manager’s work. Instead, as we will see, she understands her work as a form of professional coordination.

When the case manager gets to Mrs. Watson’s home, a woman who appears to be in her early 70s greets her at the door. This is Mrs. Watson’s daughter. The implications of elderly children being the “family that rallies” to the aid of an even older parent are effectively hidden in the earlier discussion with the researcher. Of course, at closer proximity, much more is revealed:

“The smell of urine is very strong on entering the house and the daughter says, “I left everything as I found it this morning when I arrived.” Aside from the smell of urine the home appears clean and tidy. Mrs. Watson is seated at the dining room table. She is very small woman, appears well-groomed, alert but frail. She greets the case manager cheerfully. The case manager sits at the table with Mrs. Watson, and [the daughter] sits in the living room. (Ceci, fieldnotes, 2004.)

The case manager begins the process of reassessment. She asks a series of questions, such as whether Mrs. Watson has pain, what time she arises in the morning and goes to bed at night, and whether she wakes up during the evening. Mrs. Watson responds to each question in a way that suggests her hearing is very good and that she clearly understands the questions. It is only when her daughter, who is some distance away, contradicts nearly every response that a more complex picture begins to take shape.

Mrs. Watson claims that she has no pain, arises each morning at approximately 7:00 am, goes to bed at approximately 9:30 pm and does not awaken at all through the night. Her daughter directly contradicts the claim regarding pain, telling the case manager “that’s not true.” She also reiterates her central concern that has been behind getting the case manager to visit today; apparently, Mrs. Watson has been waking regularly at 4:00 or 5:00 a.m. and phoning members of the family, complaining about being cold. When they come to check on her, she has most often been incontinent of urine in the bed or while trying to get to the commode that is kept near her bedside.

A walk down the hallway to determine how steady Mrs. Watson is reveals precisely what the daughter meant when she said she had “left everything as I found it this morning when I arrived.” In addition to urine, there were small amounts of stool
on the floor between the bed and the commode. At this moment, the case manager sees both “front stage” and “back stage” regions of this home. Mrs. Watson provides a version of the front stage of her life; her daughter directs the case manager to see the back stage areas of her mother’s life and, at the same time, her own life. At that point we can see the precise “rigid polarities between the economic and personal spheres with rationality on one side and sentiment on the other” proposed by Zelizer.23 Benoit and Hallgrímisdóttir in this issue describe this polarity as setting up a false distinction between sentiment and caring on one hand in contrast to rational economic activity on the other. In the particular situation we highlight here, the dichotomy between caring and economics is demonstrated to be much more complex than such a simple and false distinction would suggest. While Mrs. Watson’s capacity to live independently remains unresolved by the rationalities imposed on the situation by the case manager, the daughter is being called upon to bolster a perception that Mrs. Watson is living independently. The longer this situation persists and the daughter’s health deteriorates as she seeks to meet her mother’s increasing dependencies, the more likely it is that ultimately the case manager will have two clients to provide for rather than just one. If this were a “purely” rational process, one might expect that a more “efficient” response (e.g., supportive housing) might be advanced by the case manager in order to avoid further deleterious impacts on both Mrs. Watson and her daughter. This does not occur.

As the hour and a half long visit draws to a close, Mrs. Watson has visibly faded. The conversation has turned away from her and is more actively being conducted between the case manager and the daughter. Sensing that the discussion has shifted focus, Mrs. Watson tries to reassert herself: “I’ve never been so disgusted in my life … people making such a fuss, making it a big reality that it’s hard to rise above.” (Ceci, Fieldnotes, 2004.)

The “reality” of home care
The case manager now talks about having a picture of Mrs. Watson’s life. The case manager reminds Mrs. Watson and her daughter that “they [the home support workers] are doing laundry, cleaning, emptying the commode … There’s no personal care being done … so we’ll be doing personal care … We have a lot happening here; we just have to coordinate it.” Referring to Mrs. Watson, she says to the daughter, “it’s just not there, her memory is like swiss cheese, there’s gaps … She’s always been someone to direct traffic, your family can’t leave her anymore to direct you … You are going to have to step in.”

It is significant that this statement is made at this stage in the visit. Before the visit, the case manager described the family’s contribution in quite positive ways. They had rallied to provide care for Mrs. Watson, and there was, apparently, “lots of help going in there.” Now that the formal reassessment had been conducted, the case manager underlines that the rallying is not going to be just for a short time. The efforts currently being made by the family may not be sufficient. Increased involvement by the family is now recognized as part of the formal coordination of services.

Against this emerging picture of how things are, according to the case manager, the daughter resists. According to her, Mrs. Watson has not been the organizer in the family: “She couldn’t even organize herself to wash the dishes everyday.” The case manager brings the conversation back to what, for her, is more relevant with respect to the coordinating work that she is there to accomplish: “Well she’s slipping and it’s harder and harder for her to hold on … You’ve stepped in, and now it’s a matter of coordinating things.” It appears that it does not matter who takes on the organizational work. By “stepping in”, the daughter has signaled that she is available to be enrolled as part of the gendered network of coordination that the case manager is making explicit.

Individualizing practices
There are some key pieces of information that have been created through this home visit. Most noticeable in this last exchange between the case manager and the daughter is that, as much as the daughter is looking for relief from this situation she has “stepped in”, and now the case manager needs her to remain “in” – despite the many clues offered by the daughter that the relationship between mother and daughter may not be positive – she must play a part in the coordination. The daughter is the person to whom the coordinated services are going to be attached. The case manager does not ask about other responsibilities the daughter may also carry. In not asking, the daughter is positioned as the most efficient rational response to this situation. There will be no collective option, such as supportive housing, offered. Instead, the case manager proposes to “coordinate” family members to serve the interests of a rationalized, neoliberal health care system.

The “old” way of providing home care
The early data (2001-2002) collected for the Icelandic study offer a clear contrast to the current Canadian situation. The provision of care is referred to as “old” because it has not yet been infiltrated by a neoliberal economic discourse demanding a clear differentiation of the kind of work each worker is allowed to do – the sort of differentiation that is clearly embedded in the Canadian case study, in which the case manager will engage the services of a range of different workers, each of whom will only be able to come for specified periods of time and to undertake very particular aspects of the caring work. By contrast, the main characteristic of homecare work in Iceland at present is flexibility. Nurses decide upon the services to be provided on the basis of patients’ needs. If a patient’s condition deteriorates, they increase services with visits up to eight or nine times a day. In many cases, they also turn to the family for more participation, as does the Canadian case manager, but with a different awareness, as one nurse said, “families differ as to how much they are willing to or can offer.” (Björnsdóttir, interview with nurse, 2001.)

At the time of the study, homecare nursing in Iceland was organized by neighbourhood community health care centres. The care provided by the nurses involved personal care, such as bathing, assistance with mobility and getting dressed, assistance with taking medications, symptom monitoring and management, wound care, incontinence care and various psychological supports. Many of the responsibilities described earlier for case managers in Canada, such as coordinating services and applying for additional services, were also part of the Icelandic nurse’s work.
In the interviews, both patients and their relatives expressed satisfaction with the services provided through home care. The nurses were seen as knowledgeable and resourceful. Many of the patients, particularly those who were living alone and did not have much contact with friends or family, said that it was nice to have someone come to visit who was leading an active life, raising children, travelling and going to the theater or the movies. Relationships between nurses, patients and caregivers were casual and relaxed. The nurse would sit at the kitchen table and talk when filling the medicine boxes for the week or have a cup of coffee and chat after completing a bath or wound dressing. They asked questions about how things had been going and usually had a pretty good overview of people’s situations.

The nurses said they liked their work. They felt that they were of considerable help to the patients and that their services made it possible for patients to remain at home. Most days nurses could easily manage the workload and give the patients the time they needed. The nurses did not hesitate to go “back stage” and get involved in matters that people look upon as private but that cause them difficulties. Many of the nurses even saw it as their role to do so in order for the patient and relatives to spend high-quality time together.

The family caregivers interviewed were generally pleased with the services provided by the nurses. However, the caregivers were also often overwhelmed by the responsibilities involved in their role. Many described how they had no time for themselves: they were always on call and felt that it was not easy to get out of the house. They also described how difficult it had been to obtain access to homecare services. They said that in the initial phases, when it was becoming apparent that the patient was beginning to need more help than they could provide, no one seemed to know where to turn for assistance.

A good example of this was Anna and her husband Bjorn who lived in an apartment building for the elderly. They had been married for 60 years, and their marriage had been a happy one. Their four children visited frequently. Bjorn’s cognitive function had become seriously impaired as a result of transient ischemic attacks. He needed assistance with dressing and bathing, and had suffered from incontinence for many years. An auxiliary nurse came in the morning to help him get dressed and also in the evening to prepare him for bed. Bjorn spent the day at a day centre for the elderly. Between these times, Anna tried to manage the incontinence, supervising him constantly, assisting him to the bathroom, cleaning him and changing his clothing. Anna’s capacity to continue this unpaid care work, however, was a significant concern:

At the interview Anna seemed confused and told me that she had nothing to tell me. I asked her if she wanted me to leave, but she told me that her daughter would be coming to talk to me. A few minutes later three of her children arrived … She [the daughter] told me that “something had to be done.” Her mother could not go on like this any longer. “She spends all of her waking hours cleaning and washing, and she is about to break. It is just too much for her.” (Björnsdóttir, fieldnotes, 2002.)

Anna’s daughter felt that her mother was entitled to more formal help, which in this case would mean a permanent placement for Bjorn in a nursing home. She said that the homecare nurses were very helpful and she was happy with their services, but she now felt that the time had come for her father to go into a nursing home. When the nurse in charge of Bjorn’s care was interviewed, she said she was surprised to hear that Anna’s daughter had been trying to get her father into a nursing home “behind the curtains”; “the relatives have a very difficult time understanding that there are no easy solutions. Respite care and permanent nursing home placements are so few, and you have to wait for a long time until your turn comes.” (Björnsdóttir, interview with a nurse, 2002.) She described her efforts to provide respite time for Bjorn, without success as yet, so that Anna could have the eye operation she required.

DISCUSSION AND CONCLUSIONS

Home care involves the sort of activities that are very often identified as domestic – non-intellectual, task-oriented, to do with bodies and other private or personal matters. Even the professional roles associated with home care, the work of case managers illustrated in this paper, remain primarily identified with ideas of women’s work, focused as case managers tend to be on (merely) coordinating the caring activities of others. This is the kind of work commonly perceived to be involved in the supportive care of older people and treated as though it is accomplished naturally and in a straightforward manner, particularly since it continues to be undertaken, for free, by family members.

Both of the case examples presented here refute this assumption. The case studies exemplify how challenging and complex the work – determining what to do for people who have become frail – actually is. In both cases the family does not know what to do any more or no longer has the capacity or desire to cope. It turns to the safety net of a publicly funded health care system for assistance. That system, in turn, redirects family members to continue to provide the same sort of assistance that they have been providing and that now exhausts them.

The market-based vocabulary of neoliberalism – efficiency, choice, competition – and associated ideals of individual autonomy, self-help and personal responsibility seem to have little to do with what is going on in these situations, but policy and practices shaped by such values will certainly have effects, and these will often be gendered effects. When the care of frail elders is expected to be taken up by the family, there is ample evidence that it is female family members who experience increased responsibilities for caregiving, yet many families are simply no longer organized in ways that support women in easily taking on this additional work. It can no longer be assumed that women are “at home” and able to provide care.

The situation in the Canadian example underlines the dilemmas of home-based care for those who are frail and elderly, including aging family caregivers and care needs beyond the capacities of these informal carers. The Canadian case study illustrates that it is women, and increasingly elderly women, who are actually doing the work of caring in highly individualized situations, largely unsupported by the heavy, rationalized system of modern health care. In acknowledging this, we can trace the normative assumptions that are being made in these everyday practices about gender, social roles and, increasingly, eth-
nicity and demonstrate that neo-liberal family policies have effects that tend to undermine the equality of all women.28

The Icelandic study, on the other hand, provides an example of home care that in most ways meets the needs of individuals who require assistance. Although there are similarities in the organization of home care in Canada and Iceland, there are also important differences that seem to stem from each system’s underlying philosophy. In Canada, home care is a highly structured and scarce commodity, shaped by a client base that has increasingly acute care needs because of policies that enable the discharge of people from acute care hospitals (“sicker and quicker”), narrow eligibility requirements for services and reduce the absolute number of long-term care beds available. Responding to these constraints has meant ensuring that there is a formal kind of equity in the system – service maximums, time-task management strategies, strict eligibility requirements. Within a system that institutes scarcity in this way and encourages people to remain in their own homes rather than moving to institutionalized care facilities, interventions are aimed at rationing care so that everyone has more or less equivalent access to the limited resources available. Yet the fairness of a care system that demands, indeed relies on, the experience of receiving long-term home care: Restructuring at work. Work, Employment and Society 2006;20:27-45.


RÉSUMÉ

Objectif : Au moyen d’une lecture critique et approfondie des pratiques quotidiennes des gestionnaires de soins à domicile au Canada et en Islande, nous montrons que les politiques néolibérales contemporaines qui cherchent à améliorer l’efficience du système de santé portent atteinte à la souplesse qui permettait auparavant d’offrir des soins à domicile aux personnes âgées en respectant leurs besoins particuliers.

Méthode : Nous avons utilisé une étude de cas au Canada et une autre en Islande pour mener une analyse ethnométhodologique de l’exécution des évaluations des besoins des personnes âgées qui requièrent des soins à domicile, une tâche effectuée en grande partie par des femmes.

Résultats : L’interprétation des données montre qu’il existe à la fois des stratégies individuelles et collectives pour la prestation des soins à domicile dans la communauté. Nous démontrons que ces stratégies ont pour effet de diminuer la résistance à de nouveaux transferts de responsabilité vers les particuliers en matière de soins. Les imperatifs professionnels s’avèrent efficaces pour réparer, et même prolonger, les effets de la responsabilisation.

Discussion : Dans cet article, nous explorons les effets de diverses strategies employées par les organismes de soins de santé pour orienter l’évolution de l’environnement de prestation des soins et pour s’y adapter. Nous montrons par des exemples que les politiques organisationnelles et les pratiques professionnelles sexospécifiques apportent des intérêts politiques plus vastes, axés sur la gestion du rendement et l’efficience, et que ce faisant, elles affermissent les effets de l’individualisation au détriment d’une riposte collective et mobilisée au velliumissime, à la pauvreté, à la maladie et à l’isolement.

Mots clés : soins à domicile; néolibéralisme; sexospécificité; ethnographie; Canada; Islande

REFERENCES


