

# Balancing the Tension in Long-Term Residential Care

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**Abstract** Although high income countries increasingly emphasize care at home, long-term residential care is and will remain the place where some of our most vulnerable live and work. Based on over 500 interviews with the entire range of actors in long-term residential care, intensive observations by interdisciplinary teams of at least 12 in 27 different sites in six countries and on background documents that take context into account, this paper explores tensions in long-term residential care. It argues that recognizing and balancing these tensions is critical to care and constitute promising practices. However, multiple pressures are shifting the balances in these tensions, with for-profit, chain ownership and the increasing pressure to emphasize clinical care among the most powerful forces.

**Keywords** Nursing homes · Social care · Risk · Equity · Regulations

## Introduction

Long-term residential care (ltrc) is where many of the most vulnerable live and, in spite of moves towards aging in place, where many will continue to live in the future. It is also a workplace for thousands of paid and unpaid providers, most of whom are women and many of whom are from racialized communities. It is a barometer of values and practices; a signal of economic, cultural and social perspectives, raising issues that go

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beyond specific services and practices; issues such as human and social rights, the role of the state, responsibilities of individuals, families and governments, work organization and skills; and notions of care. For all these reasons, long-term residential care deserves not only study but reimagining.

This paper is based on an international project which seeks to identify promising practices for conceptualizing and organizing long-term care, learning from and with other countries. Funded for seven years by the Social Science and Humanities Research Council of Canada and with additional funding from the European Research Area in Aging project, we are searching for promising practices that will help us reimagine long-term residential care. For our purposes, long-term residential care refers to facilities that provide 24 h nursing and personal support and have some form of public funding. With researchers from Norway, Sweden, Germany, the UK, the US and Canada, the project includes all three types of Esping-Andersen's (1990) welfare state. Centered around four overlapping themes (accountability and governance, work organization, funding and ownership, and approaches to care), our interdisciplinary team that includes an architect, physicians, nurses, historians, a cultural theorist, sociologists, social workers, an economist, an anthropologist and a political scientist is structured to continually learn from, and with, each other. Our union, employer and community partners help ensure that our search is grounded and shared.

## Methods

Our methods are complex, layered and evolving in new ways.

Our analytical mapping provides descriptions and analysis of how long-term residential care looks in our many jurisdictions. Building on the small number of articles explaining rapid ethnography, we designed tools and approaches for rapid site-switching ethnographies. Using this complex strategy that constantly developed over time and through collective analysis of our methods, we sought to capture rich complexity rather than strictly comparative, single factor data. We have visited sites in all the countries involved in the project, covering a wide variety of models such as Eden,<sup>1</sup> Dementia Care Matters<sup>2</sup> and Gentle Persuasive Approaches.<sup>3</sup>

Key informants from government, union and community groups in all jurisdictions provided advice on what homes, based on what criteria, we should use as a way of studying promising practices. With this advice, we approached specific care homes for access. Most of the homes identified as promising were non-profit although we also visited some for-profit ones and many of the non-profit homes included forms of privatization. We researched the context and structure of the selected homes, conducted pre-interviews, and then took in a team of 12 researchers to observe and interview over a week, from 7 am until midnight. Six different people spent four days on each of the two units under study. The interdisciplinary teams, some of whom have not worked in this area, bring fresh eyes to the study. Mid-visit the entire team met to discuss what we

<sup>1</sup> See Eden Alternative <http://www.edenalt.org/about-the-eden-alternative/>

<sup>2</sup> See Dementia Care Matters <http://www.dementiacarematters.com/>

<sup>3</sup> See Alzheimer Society <http://www.alzheimerlondon.ca/public-education-programs/gentle-persuasive-approaches-in-dementia-care>

thought we have learned, what we need to explore further and what we missed, and we did the same again at the end of the visit. We developed an additional day-long visit at a second and sometimes third site which we call a flash ethnography. Prepared with our background material and our information from the previously visited sites, we met with managers (and others), and then fanned out to do interviews (both prearranged and serendipitous) and observation before meeting again with the managers to give feedback, ask questions and clarify our interpretations. Each team included faculty and students from multiple countries, with a significant number from the local area to help us understand not only the language but also the culture. The point was to share different perspectives while developing a detailed portrait from which we could all learn about promising practices.

We shared and analyzed the data together, and together developed new approaches to gathering and analyzing data. In doing so, we sought to recognize rather than camouflage the rich complexity in Itrc, and to do so in new ways that emphasize differences in perspectives. While we worked to provide consistency in our data gathering, we were also flexible in keeping with our search for promising practices. These can be singular practices found in only one location, they may be ideas not yet fully applied, or they may be broader approaches to care worth sharing, examining further and imitating. Our purpose was to identify good ideas worth developing further in specific contexts, while asking for who do they work and in what ways. Although we coded the data in multiple ways, this article is based on our collective discussions about what we saw in the places we studied.

Guided by feminist political economy, our objective was to identify promising practices that encourage dignity and respect for both providers and residents. For us, this means practices that understand care as a relationship with multiple players, practices that support differences and equity, and practices that promote active, healthy aging based on the recognition of different capacities. It also means paying attention to power and the search for profit, recognizing that context matters. The project as a whole has ethics approval from the Principal Investigator's university and from individual institutions which have approval processes.

## Why Promising Practices?

There are three basic reasons why we searched for promising rather than best practices. First, we sought positive strategies rather than a single, right way because we understand both populations and conditions as varied. Second, context matters and matters on multiple levels from global rules governing markets to local means of measuring and recording medications. While research often seeks to remove context, we sought to embrace it. Conditions of work create the conditions for care but conditions combine in different ways that can have different consequences, and we wanted to identify both those ways and those consequences. Third, recognizing that there are multiple players at multiple levels, we asked what works for whom, where and under what conditions.

Our search for promising practices meant attending to relationships among different categories of workers, rather than examining groups in isolation. It also meant asking about gender, racialization, class, sexuality—for residents, workers, families, organizations. We paid attention to time, not only time for tasks but also time of day, of life and

of job tenure because all have significant consequences for care. Exploring the conditions of work involved including methods for reporting and the regulations that govern daily practices as well as issues such as security, scheduling, and predictability. We examined the physical and social space as well as the community location and both the policy and the economic context, looking for how each shapes and is shaped by the other. We considered both what was there and what was missing, listening for both noises and silences. Finally, we identified negative practices, asking for whom they were not promising, under what conditions. All of this meant recognizing tensions and contradictions within and outside residences. It is these tensions that are the focus here.

## **Tensions in Long-Term Residential Care**

Significant tensions in long-term residential care have gradually become evident to us in our research, tensions we see as central to reimagining long-term residential care. Others connected to our project, such as Vabø and Næss (Næss et al. 2013) and Storm (2013) have also emphasized tensions and there is increasing discussion of tensions in the literature. We are both adding to the list of tensions previously identified, bringing them together and detailing them. We see these as tensions to be recognized and balanced rather than ignored, eliminated or shifted in a direction that has negative consequences for care.

## **Clinical vs Social Care; Home vs Institution**

The tension between medical and social care is a familiar issue in the literature, especially in the social work and feminist literatures (see, for example, Gerard 2010; Finch and Groves 1983; The King's Fund 2014; Waerness 1984). While social care has multiple meanings at different levels of analysis (see, for example, Bostock and Humphries 2011, Daly and Lewis 2000), in *ltc* it usually refers to personal care that includes everything from assisting with bathing, eating, dressing and toileting to leading recreation, chatting and offering social support. It is distinguished from clinical care which usually refers to interventions such as administering medicine or treating skin ulcers. The extent to which medical and social care are balanced is reflected in and reflects how workers are educated and regulated, in how care is practiced and organized, and in how buildings are designed and care financed, among other physical and social factors. This tension between clinical and social care is closely linked to that between home and institution, with all countries in our project claiming these are homes or at least home-like, which implies a focus on and commitment to social care. But often these homes emphasize the clinical, constructing and organizing residences as institutions of the sort Goffman (1961) described long ago.

According to Canada's Ontario Government (Ontario Ministry of Health and Long-Term Care 2014), for example, "Long-Term Care Homes are places where seniors can live and receive support services". They "offer higher levels of personal care and support." Yet in many we visited, the clinical was clearly the visible priority. Medication carts dominating hallways, prominent nursing stations mimicking hospital designs, and brackets for rubber gloves outside rooms all indicated the presence and importance

of clinical care. Long hallways that look like hospital corridors and ringing bells leave little doubt this is not a home. Medications play a central role. In Canada, for example, two-thirds (68.7%) of the residents in long-term care homes are on some form of antidepressants (CIHI 2014: Table 11, p. 29), medications that are dispensed throughout the day from large medical carts sometimes surrounded by yellow tape to prevent disruption from residents or other staff. A clear division of labour, often signified by different coloured uniforms, restricts many practices to those defined and educated as clinical professionals. When only licensed nurses are allowed to dispense medications and fill in charts on residents, such work becomes their priority and consumes much of their time. This clinical work is often done at nursing stations, blocked from residents by a counter too high to see over from a wheelchair. Funding models are based on diagnostic groups, further emphasizing the clinical. Meanwhile social care is often devalued and defined as unskilled, in part because it has long been associated with women and been hidden in the household (Armstrong et al. 2008).

In Canada, most of the social care is provided by female health care aides (HCAs) or by men from racialized groups who report they have to focus on essential, measured tasks like bathing, toileting and feeding, often even neglecting things like foot and mouth care (Armstrong et al. 2009: Table 14, p. 101). In a survey conducted for an earlier study, we found that one in five of these workers said emotional support, walking and exercise are often left undone while a third said they often have no time to chat (Armstrong et al. 2009: Table 16, p. 106). Observations and interviews for our current study reinforce this finding.

We studied places that worked to make social care the visible priority. In a UK home, nursing stations were removed to break up corridors, replaced by lounging areas allowing residents to sit and engage with the many objects scattered there or to talk with visitors. Reporting on residents is done in a separate room and nurses spend time on direct care, reflecting a less rigid division of labour compared to Canada. Most medications are kept in fridges in residents' rooms, thus avoiding the medication cart's constant presence. Some medications can be provided by any worker. Halls are occupied more by decorations than by signs of medical care.

In a Norwegian home, the music therapy program goes well beyond giving residents ipods, involving staff singing with residents in their individual rooms as well as in groups such as the choir for residents with dementia who are usually non-verbal. This home claims to have dramatically reduced both reliance on medications and levels of violence from residents in ways that ease care providers' work, confirming research in other countries (Fukui et al. 2012; Music and Memory 2014). The single rooms are homelike (Ringard et al. 2013, p. 112), accommodating personal furnishings and allowing residents to lock the door. In another Norwegian home, all residents have direct access to a garden. The global budget in a Norwegian nursing home allowed the management to experiment with new approaches to palliative care which focused on social support rather than on clinical care.

In the Swedish homes we visited, all residents have a small kitchen to not only remind them of home but also to allow them to live more like they did at home. One Swedish home had circular hallways, avoiding the long hallway look and allowing workers to move among the small units if additional help is required. Another Swedish home used protruding walls with colourful wallpaper to interrupt hallways. Each unit of 11 had a large common area that included a kitchen, where residents gathered as they do at home. Some meals are prepared for them there.

In a German home, the residents even participate in preparing the meals and women in particular can do what they did at home. They empty dishwashers and set tables on a regular basis as well. The women we saw cutting onions as they sat together around a table could have been meeting in someone's kitchen. Some are paid for the work as a way of recognizing their contribution.

Clinical care is obviously important in long-term care and both structures and practices need to accommodate such care. However, lack of time too often means a focus on essentials and essentials are defined as medical. Yet both governments and management stress that these are homes, not clinical institutions, for good reasons. Although research indicates that length of stay varies by country as well as with gender and resources (Hjaltadóttir et al. 2011; Kelly et al. 2010), these are called long-term residential care because people live there for a long time and do so with many health issues that cannot be effectively treated with medical interventions. A senior manager we interviewed in Ontario explained to us that the “average length of stay or living in the home is 18 months and every day I say ‘If you had only 18 months to 24 months of life left what do you want it to be?’ And it’s our job to make that the best it can be and so it’s a very empowering and enriching thing to do.” “Putting life in their years”, as one German manager we interviewed put it, means creating structures and practices that emphasize the social at least as much as the clinical. We saw multiple examples of how this can be done. We also saw examples where it is not done, reflecting the growing pressure to provide clinical care that comes from the increasing medical needs of the residents and the increasing budget constraints that reduce staffing levels, especially in for-profit chains (Harrington 2013; Harrington et al. 2012a; b; Stolt et al. 2011).

## Detailed Regulations vs Trust

Scandals popularized in the media in many countries have exposed ways we have failed to make it “the best it can be.” A primary response to these scandals, especially in North America, has been more detailed regulations focused at the facility level (Lloyd et al. 2014), indicating the growing tension between basic trust and detailed regulations. Trust here is understood to mean assuming that homes and workers are acting in the best interests of residents, based on some shared principles, guidelines, and education. Detailed regulations refer to specific legal requirements and their enforcement that assume the opposite of trust. The latter means rules about procedures for everything from medications to where, when and how residents should eat as compared to trusting workers, institutions, residents and families to act appropriately with some oversight (Banerjee and Armstrong 2015).

While trust alone can be problematic, the balance is increasingly shifting to more and more detailed regulations, reporting requirements and enforcement techniques. In the US, for example, federal regulations set detailed standards, survey requirements and enforcement prescriptions (Harrington 2001, p. 508). The survey “requires that residents be interviewed or assessed and that observations be made to evaluate whether some 185 quality requirements (in 17 different categories) and ‘life safety’ requirements have been met.” States can add additional regulations. Some states, such as Illinois, have as many as 5000 quality of care standards (Braithwaite et al. 2007, p. 223). In our US interviews, we repeatedly heard that nursing homes had more

regulation than the nuclear industry. Our research on scandals suggests that such regulations have grown significantly along with for-profit, chain ownership (Lloyd et al. 2014). Although there is US research suggesting these regulations, when enforced, can help ensure specific practices such as a reduction in the use of psychotropic drugs (Mukamel et al. 2012), there is also research indicating that violations of staffing and quality standards had minimal impact and, in the case of California at least, succeeded only after lengthy and expensive litigation (Harrington et al. 2014).

Ontario provides another example of increasingly detailed regulations. The provincial ombudsman (Marin 2010, p. 1) observed, “compliance staff must apply over 450 standards during inspections” leading to considerable “inconsistencies.” An overhaul of the system failed to reduce the complexity. According to a key informant, “Because the regulations are so byzantine they can’t afford to properly implement [them]. So homes aren’t being inspected with their comprehensive inspection protocol. The level of detail is coming back to haunt them”. As an administrator put it, “If hospitals ever had to deal with this regulation they would fail miserably and they have many more resources than a long-term care home.” Some regulations around dining provide one indication of how regulations rather than a reliance on trust and knowledge prevail: “Resident maintains 90 degree angle of hips, knees and ankles... maintains head in upright position with chin tipped forward... maintains stability of trunk... does not slip forward, lean sideways, or lean back in chair; ... is positioned close to table with table level between waist and midchest... will have eye contact with person providing assistance who is seated at the same level that residents’ needs are anticipated (Ontario Ministry of Health and Long-Term Care 2012, p. 3). Yet there is evidence indicating that the detailed documentation resulting from such regulations is often inaccurate and frequently overestimates what is actually eaten (Simmins and Reuben 2000). An administrator gave us the example of regulations requiring specific coded doors, which meant replacing their current coding systems and spending all the money that would have gone to repair the roof on redoing door codes.

Although regulations are certainly not absent in other jurisdictions, such detailed regulations are less common. In a UK home, they rely on staff to judge when people have enough to drink and eat and do not require that either be done at fixed times or recorded in detail. One example we were given was of a woman who was anorexic all her life but her family was insistent that the home ensure she gained weight. The Director responded in two ways. First, she told the relatives that the home could not fix a life-time of practices and would not try. Second, the staff observed the resident at meal times and realized that she was turned off by the sight of a whole plate of food. So they allowed her to eat while walking and ensured that there was food available that could be eaten on the go and when she was hungry rather than at fixed times or places. This resident then gained weight. This place was full of things stuffed in railings and hanging from ceilings. When we asked about whether inspectors objected on health and safety reasons to the clutter, the Director said yes but after the rationale for such clutter was explained, the home was allowed to keep what is a central piece in their approach to dementia care.

According to Szebehely and Meagher (2013, p. 267) “the Nordic countries have shared a long-standing tradition of trust in the professionalism of public sector workers, and democratic steering and oversight of services at the local level”. A national body develops basic quality guidelines and binding guidelines on how systems of quality

assurance should be developed (Szebehely and Meagher 2013, p. 267). In a presentation to us by a former inspector, we were told that their model is school inspectors. This approach means encouraging homes to construct their own methods for evaluating quality, based on shared principles. While there are both announced and unannounced inspections, in general the inspectors are welcomed because staff members are proud of their facilities and happy to get advice on improvements. Multiple methods are used by inspectors to focus on formative evaluations that are followed up to ensure advice was heard. We could find no evidence demonstrating that Swedish residential care provides lower quality care compared to countries with much more detailed regulations.

It has become obvious that regulation and effective enforcement are required in Itrc. However, increasingly detailed regulations at the level of the home have not been shown to result in significantly better quality and often result in more time for documentation, resulting in less time for care. Accountability is too often defined in terms of counting with a resulting focus on what can be counted as a way to measure and assure quality, a process that implies little trust in the skills of workers or the approaches of managers. But “not everything that can be counted counts, and not everything that counts can be counted” (Cameron 1963, p. 13). As an Ontario administrator put it, “I mean the minimum standard for the Ministry is a blessing and a curse”. Some are able to work around the rules in keeping with their philosophy, even in rule-bound Ontario where an administrator offered an example.

“By law, one of the requirements actually is it’s a professional staff that’s doing the MDS assessments and doing any adjustments but we try and integrate the PSW [care aides] as much as possible because in fact the PSW is the one that’s with the resident all the time and they’re the ones that notice a significant change and can highlight those things to the RN or RPN.”

But too many rules can mean a focus on the test rather than on care.

## Safety vs Risk

What residents, workers, families and institutions are allowed to do depends on how risk is viewed and regulated. We saw significant variation in what was defined as risks for residents, staff, and families.

A doctor at an Ontario site summed up the approach in many homes when she said, “My job is to keep people safe and comfortable”. The emphasis on safety and comfort means avoiding real or anticipated risks, with policies often developed in response to accidents or complaints. For example, in one home even visitors were not allowed to use the microwave because one of them had caused a fire heating up food. The small kitchen was locked and, as a result, residents could not even get themselves a glass of water. In another, caffeine was not allowed because residents might get excited. Many homes prohibited alcohol or allowed it only on very special occasions. With falls widely used as an indicator of quality in care, it is often understood as safer to place residents in wheelchairs or even leave them in bed to avoid the risk of falling. A family member in British Columbia complained that his mother walked into the home but was put in a wheelchair immediately, with the result that she no longer walked. A nurse explained this was the safest approach when there is not enough staff to ensure a safe walk. Moreover, as workers in more than one home explained to us, they do not have



time to walk residents to meals and fear being blamed for falls if they do encourage exercises.

Risks to resident health can also include such dangers as malnutrition, choking and isolation. While these are real dangers, a focus on risk can mean pureed food for too many. It can mean what feels like forced feeding, especially when staff have little time and too many residents to help eat. We saw such pressured eating in too many North American sites we visited, as care aides worked hard to meet the regulations. A risk focus can mean putting everyone in bibs to protect their clothes and many in diapers because there is a danger of ‘accidents’ and no time to respond quickly when residents need to use the toilet. A focus on risk can also mean, as we saw in a Western Canadian home, a prohibition against soya sauce based on the argument that it contained too much salt. Half the residents were Asian in origin and had been eating soya sauce all their lives.

Yet we visited homes in Eastern Canada where residents could vary where they sit to eat, whether they eat in their rooms, when they eat and with whom. In a Western Canadian home, residents were given a choice about whether or not they preferred a bib and their choice was indicated on their chair to ensure that their choice was respected. Hot meals were presented in warming carts at the table and residents allowed to eat what and how much they wished that day. We saw workers with enough time to allow residents to chew their meals and, as was the case in a UK home, to choose how much they wanted to eat that day.

We saw women using knitting needles in the UK and using sharp knives to cut onions for dinner in Germany, just as women would at home. According to our information, such practices did not lead to significant injury. Some male residents made their own tea in the UK and we were told that the only accident with hot liquids happened to a care worker. Coffee with caffeine was common as was alcohol consumption, without any clear evidence that either led to serious negative physical or social consequences.

An occupational therapist in Norway told us she sees her job as pushing people to their physical limits. When we asked if this resulted in falls, she said sometimes it does. If this happens, they examine the reasons but without the intent of establishing blame related to either the workers or the home but rather in order to understand the factors involved. Their approach is based on the recognition that life without risk is boring and that exercise itself can prevent falls. Given that research indicates that boredom is a major problem in nursing homes (Slama and Bergman-Evans 2000) and that a “systematic review provides strong evidence that exercise programs can reduce fall rates in older people”, it seems worth some risk in order to maintain health and reduce boredom (Sherrington et al. 2008, p. 2240).

Increasingly regulations are designed to keep residents safe and facilities protected, but there has not been the same level of concern for the comfort and safety of workers. Some strategies to reduce risks for workers have been introduced. For example, Ontario regulations require two people to use the mechanical lifts. However, some workers tell us that the lifts do not fit in some spaces and workers are often too rushed to find a second person to help. In Manitoba, for example, we visited homes where the lifts were not placed over the beds, causing considerable strain for both workers and residents. In Eastern Canada, more than one site had toilets placed in corners in ways that put considerable strain on workers seeking to assist residents who needed help getting on

and off the toilet. Although the risk of violence towards workers has increased, workers are often told that little can be done because it is just part of the dementia or the fault of the worker (Armstrong et al. 2009). Like attitudes towards health and safety in many female-dominated workplaces, the primary notion is that the work is not dangerous or that the danger is inevitable given the population, even though health care has the highest rates of absences due to illness and injury of any industry (Association of Workers Compensations Boards of Canada 2013; Messing 1998).

It is important to avoid unnecessary risk. However, there is a real risk that risk avoidance for residents becomes the priority rather than a life lived. Such risk avoidance is more likely to be the priority when the emphasis is on clinical care, counting incidents and meeting detailed regulations. Autonomy requires some willingness to allow residents to take risks, although many regulations, insurance company rules, and family pressures often encourage a focus on safety over autonomy. This tension is linked in turn to the tension between ability and disability. How can we balance the need to allow people to live to the full extent of their capacities and maintain or even improve those capacities while recognizing that they have significant incapacities? This is an issue long struggled over in the disability community, producing innovative approaches to defining and supporting people in terms of what they can do rather than in terms of what they cannot do (Chouinard et al. 2010). In the social model of disability, it is not the disability but the social barriers that must be overcome. Balancing the two becomes harder when care and funding are defined in terms of disability, and when both time constraints and regulations encourage a focus on impairment.

## **Autonomy vs Management and Community Control**

To what extent are managers and workers, as well as families, allowed to make decisions about care and how can this be balanced in ways that ensure resident safety, management control, and worker health? Since Karasek (1979) published his research on the importance of exerting some influence over work, there have been multiple studies demonstrating that providing workers with some autonomy can protect workers' health while lack of control can undermine it. A literature survey on nurse aides employed in Itrc found they had "feelings of humiliation, vulnerability, insignificance, invisibility, uncertainty and insecurity" as a result of their lack of power in a hierarchical organization (Andersen 2009). Since Grandjean et al. (1976) began investigating autonomy in care, research has also demonstrated that health care workers' right to decide can have a positive impact on those for whom they provide care (Barry et al. 2005). Indeed, it can be argued that resident-focused care requires that workers be allowed to make decisions in relation to specific residents. At the same time, care providers' right to decide may conflict with the needs of the broader community in and outside of the home, with the calls for accountability, with ensuring providers have appropriate skills, with the emphasis on team work, and with the wishes of residents, not to mention the search for profit or just cost control.

In keeping with other research (Andersen 2009), only a quarter of the Canadian respondents in our survey of HCAs for an earlier project said they can affect the planning of each day's work all or most of the time (Armstrong et al. 2009, p. 75). Few

can determine their schedules, making it harder especially for women to plan their domestic work. North American workers in the sites we visited had very little formal power and were frequently excluded from reporting meetings or family consultations. As one HCA put it, “We’re not machines. We’re not robots. Sometimes they expect you to be...”. There is often a clear, hierarchical division of labour that is shaped by regulations, ownership, organizational and reporting practices, supervisory policies, and individuals. In an Ontario home, for example, regulations require that residents be at breakfast by 8.30. The contracted-out food service delivers the food trays at 8 and picks them up at 9. The care staff rush to get residents up, dressed and at the table, spend some time recording their food intake and start packing up by 8.45, leaving little opportunity for either decision-making or resident-focused care (Lowndes et al. 2015).

In contrast, half of the Swedish workers in our survey for the earlier project said they could influence care planning and their own schedules all or most of the time (Armstrong et al. 2009, p. 75). We visited homes where breakfast was a much more relaxed affair. Workers prepared breakfast in the kitchen as residents joined them, with both workers and residents having a say in what was done when and in what food was put on the table. A German home had residents and care staff working together to set the table and consult on other aspects of the labour involved, creating an opportunity for shared decision-making. Our Ontario field notes record very little breakfast conversation either among residents or between residents and workers while those from Sweden indicate considerable animation.

In a Norwegian home, regular meetings to discuss policies and residents included the full range of workers and, from our observations, allowed everyone to confidently express their view. We also saw examples of other areas where these workers participated in decision-making. In a Norwegian home, the care staff was centrally involved in the decision about how to decorate the home when a donation made it possible to make major changes. They decided to purchase modern furniture and brightly coloured art, based on the argument that residents and families should be proud of the home and think about living in the present rather than in the past. Similarly, staff did the gardening, choosing plants and their location based on their knowledge of residents and their families. Because the care staff at this home worked in both residential and home care on a daily basis, they knew what kinds of gardens were preferred. In another Norwegian home, staff also had a say in the selection of art. The result was stunning photos of older people, photos revealing residents’ strength and presence. A Philipino chef in a UK home carefully researched British cooking and consulted with residents before he developed trays of small helpings which allowed residents to get a greater variety as well as smaller portions that fit their appetites. He was going outside the past practices and even the usual rules, but the residents ate more than they had in the past when presented with whole plates of food. When an Eastern Canadian home was building a new facility, the management involved the kitchen staff in planning. In our visit to the kitchen, these workers made it clear that they were proud of a kitchen that worked well for them and for the residents they served. The women who had been doing the cooking in the old place were sponsored to take a cooking course in a nearby city and guaranteed a job on return. The kitchen staff develops the meal plans in consultation with the dietician, gets creative with left-overs and negotiates with local farmers for fresh produce. By contrast, in contracted out services, we saw an emphasis on control.

One argument against allowing decision-making on the part of those at the bottom of the care hierarchy is lack of skill. Indeed, these workers themselves often report that they need more training for the increasing complexity in care needs (Andersen 2009, p. 6) and for the growing diversity of the residents. In looking for promising practices, however, it is often hard to distinguish between the skills, capacities and personalities of individuals that contribute to dignity and respect and the structures that promote the kinds of skills, capacities and personalities that encourage appropriate care (Armstrong 2013). The balance is important when it comes to issues such as stressing training, selection and reporting over promoting structures that encourage residents and providers to act appropriately. We have been repeatedly told by workers that close supervision, tight schedules and heavy workloads prevent them from applying the skills they have. Continence care is frequently offered as an example (Armstrong et al. 2012). In some North American homes we visited, the number of diapers per resident was severely restricted and workers were told they could not change the diaper until the urine reached the blue line on the diaper. A focus on cost reduction, and strategies taken from business, promoted this approach. However, workers know their residents and also know when a change is required but are prevented from using these skills by the rules.

Especially with more of these workers coming as immigrants or migrants, culture and language differences may also be used as the basis for arguing against greater autonomy for care providers. In Norway, we saw a program that used peer-to-peer sessions to familiarize workers not only with language related to tasks but also with social relations. Such formal sessions simultaneously recognized workers' knowledge while offering practical training that enhances the capacity to make appropriate decisions. As in Denmark, the focus is on "developing and realizing the potential of the individual in order to create value for others" (Kamp 2012, p. 65).

Variability in the right to decide is not restricted to those who provide most of the personal care. A UK manager talked about the difference between working for the previous chain owners and the current situation, with one owner. She said that she had very little leeway in the chain situation, with most protocols and decisions made by the head office in ways that often conflicted with local needs. Now she has a say in how the home is organized as well as opportunities to innovate. For example, she approached a local training group and offered them free parking in exchange for them doing their practices where residents could see the action. She started a playground for children who come to visit their grandparents or great-grandparents, so the children can look forward to coming and have something to do while they are there. She also organized with other small homes to share ideas and services in ways that both reduced costs and provided support for managers. Similarly, the Ontario non-profit homes we encountered could take the initiative and develop shared services in areas that a single home could not easily afford or organize while still retaining local control. However, the non-profit Ontario home that hired a for-profit management company found that decisions were taken away from the managers who remained, with the result that injury rates increased and families mutinied against the new meal restrictions which altered years of traditional ethnic food options.

Funding models also shape the extent to which managers can decide. In Ontario, for example, the public funding comes in envelopes for nursing and personal care, raw food, program and support services and other accommodation, with strict requirements

that the money be spent in these areas or sent back to the government. While this can help ensure that this money goes to care rather than profit, we were told by various managers that it creates rigidities and limits innovation. In Norway, on the other hand, the secure global budgets allowed the management to introduce specialized palliative care services.

Those care providers with the highest formal qualifications also had quite different degrees of autonomy, depending on the owners, the regulations, the funding and traditional practices. In Norway, we saw one person named the responsible nurse. This gave the resident, the family, other workers and the management someone to call on for questions, information and complaints while also providing this nurse with some say over the residents' care.

Efficient and responsive organizations do have to ensure that appropriate care is provided and this requires both some structured authority and some supervision. Schedules are necessary and tasks must be done. Work involves coordination to function smoothly and it is necessary to ensure that decisions are based not only on skilled assessments but also on recognizing multiple differences and the need for team work. But these ends can be accomplished in ways that balance autonomy for care providers, managers, and families with the need for safe care. We witnessed teams, especially in the Nordic countries that, through shared work and decision-making, were able to ensure quality by allowing some autonomy and drawing on the full range of staff knowledge. This is just one example of how decision-making can be shared effectively to improve both care and working conditions.

## Choice vs Equity

In the interests of equity, governments have adopted multiple strategies to protect the rights of individuals and communities. But sometimes these rights clash. Two kinds of rights that were in particularly obvious tension in our research were those related to care provider and those related to selecting a LTC home.

The countries in our study prohibit discrimination in hiring related to gender, race and ethnicity. In all the countries, the overwhelming majority of the residents and workers were women. In most of the homes we visited, the majority of residents were Caucasian. Increasingly, however, men are applying for work in these homes and a growing number of workers in all of our countries increasingly relied on immigrant labour, many of whom were from racialized communities. Moreover, more residents are men and more are from a variety of cultural backgrounds.

The most obvious tension involves opposition raised to male care workers looking after women. Opposition often comes from the family. One member of a family council in Ontario made it very clear to us that he would not have a man bathing his wife or taking her to the toilet. The staff and management try to accommodate resident and family concerns by switching workers, although the female staff members told us this too often means they have extra work loads because no extra staff is hired. Sometimes even this strategy is not available. A male worker in another Ontario home gave the example of a woman refusing to have him change her diaper but he is the only person on the unit at night and the relief person is also male. He has to provide the care over her opposition or risk the consequences of the residents spending long hours in a very

wet diaper. A Manitoba home has a different approach. A female staff member accompanies male staff when either the resident or the worker is new, and the women have the men slowly increase the range of tasks they perform.

Interestingly, we did not hear of men objecting to women workers although we did hear about men objecting to some male workers they feared were homosexual. Although all the homes we visited had formal policies against such discrimination as well as against racism, we did hear from both workers and managers in several homes that the residents were old and often suffered from dementia so workers should not take it personally and should simply ignore racism and homophobia. In a UK home, however, the manager said she talked to residents who spoke or acted in racist ways and if they did not stop, she asked them to leave the home. This strategy does require management's right to make residents leave.

Language also emerged as a source of tension. In all countries, we heard workers, families, residents and families complaining about workers who did not understand the language and culture of the residents. If we are to stress social support, communication is critical and yet it is also important to have equity in hiring, which can mean staff that are not from the dominant culture in the home. But we also heard from workers who saw such complaints as a cover for racism. The only example we saw of attempts to address such issues directly was the Norwegian example of workers teaching other workers language skills on work time. The tensions are bound to increase, however, as the population in ltrc becomes more diverse.

Another, perhaps less obvious tension related to choice has to do with admission to ltrc. All of the homes we visited were heavily subsidized by government and government policies made it clear that residents could be refused only on the grounds that the home did not have the required equipment or staff to provide needed care. But homes are often structured to cater to a particular language, ethnic or religious group and some are clearly identified with a particular class. For example, a Western Canadian home run by the Jewish community kept a strictly kosher kitchen and prohibited non-kosher food from entering. However, with rules about admitting those who applied and a shortage of beds, a growing number of residents were not Jewish, creating considerable tensions. Moreover, the staff was almost entirely non-Jewish and when a worker brought a non-kosher birthday cake into the staff room she was threatened with firing. In order to maintain their coherent communities, facilities often develop strategies to go around them. A posh US home recruited from an expensive private hospital in the region as a means of avoiding Medicaid-funded residents and of maintaining their preferred class composition.

Tensions around gender, culture, race and class are not of course exclusive to ltrc. However, they do take a particular form when intimate care is being provided, social support is critical and interaction is frequent. Balancing the choices of residents with equity in hiring and workloads also takes a particular form when so many of the residents have some form of dementia. Tensions around balancing community cohesion with equity are also not exclusive to ltrc. Living with those who share your language and culture can provide critical social support but can also mean exclusion for others outside that culture, a tension that is particularly obvious when there is a shortage of alternatives.

## Concluding Comments

Our research is based on the notion that there is no single, right way to provide care that respects the dignity of both residents and those who provide care. This partly because we are convinced that context matters and that tensions are both integral to care and to effective change. We saw little open discussion of such tensions and a growing imbalance, with a shift towards the more clinical and institutional, more detailed regulations, risk avoidance, and increasing control, to the detriment of both residents and staff. A major factor in this shift is the growing search for profit and the application of methods taken from the for-profit sector. Only some of the tensions we encountered are discussed here. Based on our research, we argue that these and other tensions need to be explicitly recognized and balanced, and have identified some promising practices for doing so.

### Compliance with Ethical Standards

**Conflict of Interest** Pat Armstrong declares no conflict of interest.

**Informed Consent** As there is no person or personal data appearing in the paper, there is no one from whom a permission should be obtained in order to publish personal data.

**Ethical Treatment of Experimental Subjects (Animal and Human)** This research received ethics approval from York University as well as from specific homes studied, where this was required.

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