

LONG-TERM CARE PERSONAL SUPPORT:  
“THERE’S A SYSTEM AT WORK”

LONG-TERM CARE PERSONAL SUPPORT: “THERE’S A SYSTEM AT WORK”

By

EFFIE GALANIS, B.S.W.

A Thesis

Submitted to the School of Graduate Studies

in Partial Fulfilment of the Requirements

for the Degree

Master of Social Work

McMaster University

© Copyright by Effie Galanis, August 2007

MASTER OF SOCIAL WORK  
(2007)

McMaster University  
Hamilton, Ontario

TITLE: Long-Term Care Personal Support: "There's a System at Work"

AUTHOR: Effie Galanis  
B.S.W. (Ryerson University)

SUPERVISOR: Dr. Jane Aronson

NUMBER OF PAGES: vii, 88

## ABSTRACT

The purpose of this research is to examine front line practices in long-term care (LTC) facilities and the conditions which variously preserve, enhance and constrain workers' efforts to provide personalized and identity supporting work with older adults deemed cognitively impaired. This interest derived from my experience as a student in a long-term care facility setting and matured through subsequent years of practice experience with cognitively impaired older adults.

A modified form of institutional ethnography was employed to explore how personal support work in long-term care settings was "socially organized" by local and extra-local forces (Campbell & Gregor, 2002). A qualitative study was conducted, involving semi-structured interviews with personal support workers employed in long-term care facilities. Participants were recruited from two, non-profit long-term care facilities in Southern Ontario. While small, this sample of front line experience can illuminate current practices in long-term care and stimulate conceptualization of its challenges and possibilities.

A predominant theme in the findings is the constraint of 'time', which is exacerbated by factors, such as: staff shortages; Ministry standards, and demands of care; and performing underappreciated and undervalued tasks. Participants' accounts of their work with cognitively impaired older adults revealed their commitment to personalize care. Participants also described how they strove to negotiate time and organizational constraints in order to facilitate identity-supporting work. Lastly, participants offered suggestions for proposed changes to the organizational culture of long-term care and to improving their work conditions.

In conclusion, the possibilities of organizational change efforts aimed at enhancing personalized care are considered, along with their policy and resource implications.

## ACKNOWLEDGEMENTS

This research was not entirely an independent effort, and was influenced and supported by several others whom I would like to acknowledge and thank.

I would like to recognize the valuable contribution of all participants involved in this study, not only for their cooperation, but for their ongoing and daily efforts in providing quality care to older adults in long-term care. I would like to thank them for candidly sharing their experiences, joys and frustrations with their work. Also, I am extremely grateful to the long-term care facilities that were involved in supporting the recruitment process for participation of this research.

I want to acknowledge the encouragement and criticisms of each professor this past year, but particularly to Dr. Chris Sinding and Dr. James Gladstone for the many informal conversations about my research topic that assisted in shaping and guiding my research purpose and intentions. It is with great pleasure and much appreciation that I thank, Diane Allen, Darlene Savoy and Lorna O'Connell for their numerous efforts in supporting the graduate students this past year and ensuring a comfortable transition into, and throughout, the program.

As a thesis supervisor, Dr. Jane Aronson, offered guidance, encouragement and commitment to the thesis process, which exceeded my expectations for a supervisor. As a researcher and an academic I am inspired by her compassion and research efforts. I would like to, especially, thank you for your comforting words and calm demeanour, which helped control and minimize my fears and anxieties and facilitated the success of this project. Thank you!

Lastly, I would like to acknowledge my family and friends for their patience and understanding throughout the year, and their encouragement and support for making the completion of the thesis (and program) a reality.

## TABLE OF CONTENTS

### *Preliminaries*

Descriptive Note	ii
Abstract	iii
Acknowledgements	iv
Table of Contents	v

### *Text*

<u>INTRODUCTION</u>	1
Establishing a Problematic	1
A Social Justice Issue	4
Rationale	6
<u>LITERATURE REVIEW</u>	9
Organizational Culture of Long-Term Care	10
Organization of Personal Support Work	13
Cognitive Impairment and Autonomy	15
Theoretical Perspectives	18
Political-Economy Theory	19
Social Constructionist Perspective	20
<u>METHODOLOGY</u>	23
Methodology	23
Method	25

Sample Recruitment	25
Sample	26
Data Collection	28
Data Analysis	29
<u>FINDINGS</u>	31
Personal Support Work and its Organization	31
“It Doesn’t Mean They’re Not There”: Understandings of Cognitive Impairment	34
“You’re There for Them”: The Importance of Personalizing Care	38
“Getting to Know” Residents as Individuals: Sources of Knowledge	40
Institutional “Getting to Know”	40
Worker “Getting to Know”	44
Institutional Constraints and Residents’ Needs: Conflicting Demands	46
“It All Boils Down to the Time the Dining Room Opens”: Everyday Work Organization	47
“We Need More Hands”: Insufficient Staff	50
Ministry Standards of ‘Care’	52
Getting our Work Done: Working with Time Constraints	54
The Low Status of Primary Care Workers’ Knowledge: “You’re Looked Down On”	56
Putting Workers’ Knowledge to Use: Ideas and Barriers	59
<u>DISCUSSION</u>	62
Organization of Personal Support Work	63
Organizational Culture Change	66

Concerns for Conceptualizing Cognitive Impairment	69
<u>APPENDIXES</u>	73
Appendix A – Information Letter	73
Appendix B – Recruitment Flyer	76
Appendix C – Interview Guide	77
Appendix D – ‘Eden Alternative’ Principles	78
<u>REFERENCES</u>	79

## INTRODUCTION

The purpose of this research was to explore the ways in which front-line practices in long-term care (LTC) facilities can variously preserve, enhance and limit the individual autonomy and identity of cognitively impaired residents.

### Establishing a Problematic

My brief experience in a long-term care facility brought about the problematic of this research, which was the nature of how primary care provisions were made for older adults, particularly when there was an assumption of cognitive impairment. My initial practice discomfort arose when I was asked to conduct a cognitive assessment for a new resident. I was immediately aware of the inherent power embedded in making a determination of capacity or incapacity, and the ways in which care may be compromised for residents based on ‘blanket assumptions’ and inaccurate conceptualizations of cognitive impairment. For instance, I recall an occasion from my practice when I devoted some extra time to sit with a resident who was verbally non-communicative, at which point I was told by a primary care staff that I was ‘wasting my time’ with a resident that was unable to benefit from my interaction. I was troubled. I wondered how it could be that non-verbal communication ability translated into incapacity for human emotion and comfort or rendered an individual undeserving of respectful social relations. I recognized that cognitive impairment was not a state that was rigid across time and context. I was also concerned that, in this particular setting, the identification of cognitive impairment resulted from the application of a very limited standardized

assessment tool. This particular tool was only expected to take 15 to 20 minutes to administer, a time pressure that heightened my anxiety. How could I determine after only 20 minutes of speaking with somebody for the first time, what that individual was capable of? I spent an hour conducting that first assessment. I established that, by using the right combination of words, time and patience, the resident concerned was capable (during our interaction) of comprehension and expressing preferences and therefore, should be able to, at least, contribute to decisions regarding his own care.

As time passed, I became aware that the policy for assessing decisional capacity in my practice setting was conducted with all new residents upon admission, regardless of medical diagnoses that may suggest the presence of cognitive impairment. Recognizing the apparently stereotypical and ageist assumptions attached to this organizational work process, as well as the disorienting effects of placement, I speculated that the standardized assessment tool served an organizational purpose; if residents' decision-making capacity was restricted, perhaps their care could be accomplished faster. Setterlund and Wilson (1989) confirmed this speculation when they found that within long-term care "power is distributed so that control of residents is seen as important, while autonomy for residents is seen as disruptive....choice is limited to expedite staff routines" (p. 34).

Fortunately, my role allowed for flexibility of time and patience during interactions with residents. I could, thus, attempt to facilitate opportunities for self-determination and autonomous decision-making. However, the organization of primary care practices was characterized by routinized relations, structured activities and task-

oriented roles (Diamond, 1992), which constrained the time allotted for primary care work to be performed. I realized that residents who were deemed cognitively impaired were at greater risk of becoming depersonalized as a result of the way the facility was organized. When choices were available regarding care preferences, such as selecting clothes to wear or choosing from meal options in the dining room, residents who were deemed cognitively impaired were often not given a choice; their voices were silenced. There were assumptions that a label of cognitive impairment provided justification to perform care without promoting autonomous decision-making, because this was viewed as a more timely and efficient approach towards service provision – consistent with the presence of neo-liberalist ideologies in the public service sector. Efficiency and attention to costs were dominant organizational concerns in this setting and, indeed, they are given primacy in all public services as a result of state restructuring and the dominance of neo-liberal ideology (Brodie, 1999).

Neo-liberalism was, and still is, the current dominant paradigm of public management which “emphasizes the primacy of the capitalist market as the steering force in society, deregulation of the economy and the displacement of public goods onto the market” (Brodie, 1999, p. 37). The organization of caring labour has transformed within the restructured welfare state (Aronson & Sammon, 2000) and has been influenced by privatization, cost-cutting, downsizing, contracting external employment (Baines, 2004) and the application of managerialist technologies that are market-driven (Lawler, 2000). These changes have resulted in the development of new imperatives in service delivery which are concerned with resource allocation, efficiency, power, control and

accountability (Lawler, 2000), often eroding or jeopardizing client-centered models of service.

In light of this context and my observations in practice, I wondered how primary care workers negotiated providing caring labour amid the tensions and constraints of institutional work processes and the operating principles of the current welfare state. This research problematic emerged from my practice experience; it is also grounded in a commitment to the pursuit of social justice.

### A Social Justice Issue

Literature has suggested that elder care responsibility has become a social justice issue (Johnson, 2002), and the prevailing social work ideology on the matter is founded on principles of fairness, equal opportunity, and acknowledged needs of rights (Rawls, 1971).

The Social Work *Code of Ethics* principle of social justice contends that

Social workers promote social fairness and the equitable distribution of resources, and act to reduce barriers and expand choice for all persons, with special regard for those who are marginalized, disadvantaged, vulnerable, and/or have exceptional needs. Social workers oppose prejudice and discrimination against any person or group of persons, on any grounds, and specifically challenge views and actions that stereotype particular persons or groups

(Canadian Association of Social Workers, 2005, p. 5).

The problematic of this research is consistent with the social work principles of social justice. Interpreting and enacting these values and principles with populations that are vulnerable to their compromise is complex and requires care and vigilance. Historically, for example, people with developmental disabilities, young people and people with mental health problems have suffered erosions of their rights and dignity in the delivery

of services. With respect to the population of concern to me in this research – older adults – it is important to recognize that we live in a systemically ageist society. Palmore (1992) identified that societal perceptions of old age and ageing are more often negative than positive. Further, Palmore (1990) suggested that older adults are commonly perceived as “senile, rigid, old-fashioned, sick, disabled, sexless, unproductive, isolated, lonely and depressed” (p. 38). It is, therefore appropriate to be alert to the possibility that their self-determination and rights may be more readily compromised than that of groups not similarly marginalized. Legislation codifies definitions of incapacity and its assessment in the practices of health professionals and services (Hiltz & Szigeti, 2006). My interest lies in better understanding how capacity and incapacity are construed and responded to in the ordinary, day-to-day practices of long-term care facilities and with what implications for the day-to-day care of elderly residents.

This research is also consistent with the social work principle of respecting the inherent dignity and worth of persons and the value of self-determination: “social workers respect the client’s right to make choices based on voluntary, informed consent (Canadian Association of Social Workers, 2005, p. 4). As an undergraduate social work student I was led to believe that, “no matter where they are employed...social workers are influence by the social work value of self-determination” (Hepworth, Rooney, Rooney, Strom-Gottfried & Larsen, 2006, p. 3). Sanctioning this value in practice with populations whose capacity is thought to be compromised is complex and troubling. How ‘incapacity’ is determined and construed requires very critical attention, in case individuals’ rights and dignity be over-ridden or damaged. In a culture characterized by

systemic ageism, careful attention to understandings of the capacity of older adults is crucial.

### Rationale

Justification for exploring this research issue at this time is based on statistical prevalence rates of aging and cognitive impairment, the current public debate and political agenda regarding standards of care in long-term care settings and the apparent gap in the literature that invites additional attention.

In 2001, 3.92 million Canadians were 65 years of age or older, which is two thirds more than in 1981 (Health Canada, 2002). In this same year, the proportion of seniors in the overall population was 1 in 8, a number which was projected to increase to 1 in 5 by 2026 (Health Canada, 2002). Moreover, the Canadian Study of Health and Aging (1994) indicated that there were 364,000 people in Canada with Alzheimer's disease or a related dementia, representing 8% of the population over the age of 65 and 35% of the population over 85 years of age. According to the Ontario Health Coalition (2007), between 60% and 80% of residents in long-term care are cognitively impaired. These sources highlight the realities of population aging and the anticipated growth of older adults with dementia or a cognitive impairment, and suggest the merit of examining the quality of care and services available to support older adults. Since cognitively impaired residents in long-term care appear to be the greatest users of this support, this area is particularly relevant for examination.

This research was also timely because it coincided with public debate in Ontario regarding Bill-140: *Long-Term Care Homes Act, 2006*. This Bill proposes minimum care

standards of 3.5 hours of practical care per resident and suggests that facilities should receive sufficient resources for nursing and personal care to support these standards (Ontario Health Coalition, 2007). Debate on Bill-140 has established growing political and public interest in standards of care in long-term care facilities. Indeed, during the process of this research, one of the care facilities involved was under scrutiny of Ministry inspection and was publicly criticized in the media for providing ‘inadequate’ care.

Although my research purpose was informed by an extensive review of the literature, which will be identified in greater detail in the next chapter, there was an apparent gap in the literature that justified exploration of this problematic. Previous research has examined the organizational conditions for nurses in acute health care settings (Ahmadi, Speedling & Kuhn-Weissman, 1987); the efforts and skills of personal support workers in home care (Neysmith & Aronson, 1996); the importance of ensuring autonomy and opportunities for self-determination among older adults in general (Checkland & Silberfield, 1993); and specifically, older adults in long-term care (Jang, 1992; Brocklehurst & Dickinson, 1996). There also exists a growing body of literature identifying the benefit of autonomy among cognitively impaired older adults (Woods, 1994; Knapman & Waite, 1995; Zarit & Downs, 1999; Cohen-Mansfield, Parpura-Gill & Golander, 2006). As opposed to simply examining the benefits of autonomy, I was interested in exploring the organizational conditions and practices which enabled and constrained identity-supporting work with residents who were deemed cognitively impaired.

Before discussing the methodology employed for the purposes of this research and presenting the findings, the next chapter reviews the literature to provide a more detailed and descriptive context for the research purpose.

## LITERATURE REVIEW

Research indicates that the population of nursing home residents is predominantly made up of either frail elderly people who have no family or services available to support them in the community or older adults with extreme cognitive impairment who are least appropriate for community based care. For many, therefore, nursing homes are often ‘facilities of last resort’ (Vladeck, 2003). Institutional living is marked by physical and social discontinuity from autonomous community living (Tobin & Lieberman, 1976). This discontinuity requires a significant amount of adjustment on the part of older adults, specifically in terms of giving up control over their lives to an institutional routine and structure. Kane and West (2005) suggest that even ‘good’ nursing homes are institutions which operate according to fixed rules and accepted regulations. They suggest that while all institutions have their own ways of doing things, procedures can readily tend to give primacy to organizational priorities (Kane & West, 2005). Research identifies the importance of choice and control in improving quality of life for older adults in institutional care (Hofland, 1994), highlighting the value of examining the environment and opportunities for promoting resident autonomy.

In order to set the scene for this study’s focus, I drew on research and literature related to a number of areas: the current culture of long-term care; the organization of personal support work; and the importance and benefits of autonomy with cognitively impaired older adults. Two theoretical perspectives informed the direction of my research: political-economy theory and social constructionist perspective. The

substantive literature is drawn largely from U.S. and Canadian sources. While there are clearly differences in the organization and founding of elder care in the two countries, their population demographics, broad histories and patterns of response to older people's needs are comparable.

### Organizational Culture of Long-Term Care

Historical shifts in ideologies for caring and curing those deemed dependent in society, moved from maintaining criminals and 'dependents' within their communities to separating them from the rest of society into almshouses, workhouses, insane and orphan asylums, and penitentiaries (Lidz, Fischer & Arnold, 1992). This history, most fully documented in the U.S. and Britain, was also evidenced in Canada (Whalen, 1972). Almshouses were originally "designed to house the poor and ill of all ages... [but] by the nineteenth century, became a warehouse for the old" (Holstein & Cole, 1995, p. 16). With increased specialization of the function of these institutions, the almshouses' population became increasingly older, and little distinction was made between the "healthy, but indigent and the poor disabled elderly" (Lidz, Fischer & Arnold, 1992, p. 25). Almshouses came to assume the familiar shape of present day nursing homes (Holstein & Cole, 1995) and from the beginning these facilities were structured by professionals who perceived old age as a medical problem requiring expert attention (Holstein & Cole, 1995). Although relatively little health care is provided, and the primary form of care is 'social care', long-term care facilities continue to be organized as health care facilities (Vladeck, 2003).

Redfoot (2003) argues that the nursing home “epitomizes the most obvious example of the extent of control exerted by medical professionals over the lives of those who enter our long-term care systems” (p. 98). The dominance of medical control and assumptions shapes the experiences not only of residents entering the organizational system through placement, but also of the staff employed within long-term care organizations – by defining priorities in medical rather than social terms.

The ‘total institution’, as identified by Goffman (1961), also characterizes the culture of long-term care: all activities are conducted in the same place and under the same authority; the residents’ daily activities are carried on in the immediate company of other residents; and daily activities are tightly scheduled and imposed from above, with one activity beginning at a scheduled time and leading into the next (Goffman, 1961). This institutional design characterizes many institutional settings (e.g. prisons, mental health wards, hospitals, boarding schools).

Translated to long-term care in particular, this standardizing imagery of the institution suppresses attention to the heterogeneity of the older adult population, assuming that daily structures, routines and activities will be beneficial for all residents alike. Clearly, however, older adults’ lives and years of experiences have uniquely shaped each of them. There is, therefore, a tension between the inevitable presence of difference and variation among residents and the drive of “total institutions” (Goffman, 1961) to homogenize and standardize. Consider, for example, the potential difficulties involved for residents, in adjusting to the institutional routine of having to wake up early regardless of previous sleep activity. An individual’s biorhythms are difficult to change,

so someone who has habitually slept in late in the morning is unlikely to adjust to the rigid schedule in an institution that starts the day early (Kane & West, 2005). The rigidity of institutional organization varies, of course, from place to place and it is possible to establish more flexible cultures and work practices (Lopez, 2006). For example, the Eden Alternative is an emerging client-centered model of holistic service provision in long-term care facilities; it aims to foster de-institutionalized environments through the adoption of principles and philosophies that enhance the choice and power of older adults (Eden Alternative, 2007). Such initiatives offer useful models and challenge the assumed practices of long-term care institutions which, in general, still tend toward quite tightly institutionalized care.

Institutions' general tendency to standardize, coupled with the dominant medical model of care and its attention to deficits (rather than strengths) can be reinforced, too, by well-intentioned legal and policy standards. For instance, I am aware from my practice experience, that the Ontario Ministry of Health and Long-Term Care standards require all residents, at minimum, to receive supervision during their bath or shower, regardless of their mobility or ability. As a result, residents have to succumb to 'total care' due to nursing home placement, rather than having the opportunity to carry out their activities of daily living independently and privately. Residents who are able and interested could be presented with opportunity to continue to contribute to their care, for instance by doing laundry or helping with meal preparation. During my experience in long-term care, there was a resident who was a retired nursing professional who was interested in maintaining that social identity. She assisted the nursing staff during 'medication rounds' by pushing

the trolley of medication behind the head nurse. Such a simple gesture contributed to the preservation of her social identity (Shuttlesworth, Rubin & Duffy, 1982) and sense of purpose. Literature contends that care must be provided which “is rehabilitative whenever possible, prosthetic whenever necessary, and at all times humane, identity-preserving, and ego-supporting” (Tobin, 2003, p. 61).

Studies examining older adults’ institutionalization and relocation into long-term care facilities indicate that the quality of psychosocial environments was more predictive of ‘successful’ outcomes than were individual attributes (Lieberman & Tobin, 1983). Specifically, Lieberman and Tobin (1983) found that beneficial psychosocial qualities included: warmth expressed in interpersonal relations between residents and staff; tolerance for difficult behaviours, such as aggression, drinking, wandering, complaining and incontinence; and the extent to which residents are perceived and treated as individuals, in being allowed and encouraged to express individuality.

This review of the literature suggests the importance and the difficulty of delivering personalized, identity-supporting care in institutional environments, thus, has implications for personal support work – the front-line, closest caring worker with the resident.

### Organization of Personal Support Work

Researchers in the U.S. and Canada note that the personal support labour force is comprised, primarily, of women from culturally diverse backgrounds. Although, they may be employed full-time, their low wages often render them below the ‘poverty line’, requiring them, out of financial necessity, to maintain dual employment (Diamond, 1992;

Armstrong & Armstrong, 1999). Additionally, within long-term care facilities, there is a workforce crisis characterized by high staff turnover and absenteeism, low morale, and difficulty in recruiting skilled professionals (Martin, 1992; Armstrong & Armstrong, 1999).

The fundamental and instrumental tasks of personal care work include bathing, dressing, toileting, feeding and managing personal hygiene or grooming of residents. Such work is understood culturally to require little skill, is associated with women's innate capacities and is accorded relatively low status and reward (Aronson & Neysmith, 1996). The organization of long-term care workers' labour is characterized by routines, schedules and task-oriented work. The relational aspect of their work with residents is found to be seldom articulated or officially built into their days (Diamond, 1992). Instead, long-term care settings are often structured around the physical, functional and medical needs of residents, attending little to the psychosocial dimensions of need and the work performed. Although, unnamed, and often unrecognized by the institution, personal support workers do provide, arguably the majority, of emotional and relational care to residents (Ross, Carswell & Dalzeil, 2002). This care demands skills in forming and sustaining relationships with residents and navigating the instrumental tasks of providing care in a personalized way. Research conducted by Neysmith and Aronson (1996) regarding the skills required for home care workers to negotiate the organization of their care found that "*help* turns out to be a complex, negotiated phenomenon – accomplished by means of observation, particular knowledge of the individual, a careful according of self-determination to clients and a large degree of flexibility on the part of the home care

worker” (*original emphasis*; p. 8). Diamond (1992) further acknowledges the complicated skills involved when providing care, specifically within an institutional setting, through his articulation and understanding of the intricate act of feeding residents: “delicate, sometimes frightening process of feeding a frail, sick person....[is a] refined and complicated skill, but unnamed and suppressed when forced into a forty minute task” (p. 134).

The relationship developed between caregivers and residents are considered the most important element of care in long-term care (Kane & West, 2005). Diamond (1992) suggests that task-orientation in long-term care conceals and demeans the formation of bonds over time within care dyads, which are essential to the elements of personal care provided. In addition, Lopez (2006) asserts that “the requirements of social justice and dignity for the elderly and infirm who are institutionalized cannot be realized without genuinely caring and nurturing relationships between nursing home aides and residents” (p. 136). There is an apparent acknowledgement within the literature and among those knowledgeable about long-term care that relationships are not something distinct from the work, but integral to how it gets accomplished (Diamond, 1992).

### Cognitive Impairment and Autonomy

“Nursing home residents today are significantly older, sicker, and more likely to be demented than they were 25 years ago” (Vladeck, 2003, p. 2); a trend that is projected to continue with population aging. For older adults, the conditions that often bring them into long-term care – confusion, dementia, wandering – are such that the capacity for choice and rational decision-making is compromised, if not absent (Agich, 1995). Kane

and West (2005) further suggest that older adults are regularly excluded from the decision making process, and the more urgent the matter, the less the older adult's preferences are considered. However, research concludes that 'identity supporting' work and respecting autonomy are critical concepts for improving *quality of life* with older adults (Hofland, 1994; Wellin & Jaffe, 2004; Cohen-Mansfield, Parpura-Gill & Golander, 2006).

Participation and choice regarding medical and treatment decisions are, regulated for older adults with cognitive impairment through legislative constructions of 'decisional capacity'. However, autonomy and control remain important concepts for elder care. Agich (1995) identifies the concept of 'interstitial decision making', which he describes as the actions that are not usually experienced as matters that require explicit decisions to be made and rather are habitual ways of acting and interacting. This form of decision making is concerned with the day-to-day decisions that older adult residents *were* making when living in the community, such as when they would like to take a shower (in the morning, in the evening, etc.). Hofland (1994) contends that even people with advanced dementia are often able to make simple decisions such as choosing clothes or expressing food preferences, thus personalizing daily routines. Nursing home residents place substantial importance on these small everyday decisions, because they give expression to the functioning sense of self (Kane & Caplan, 1993; Agich, 1995).

In addition to autonomy and choice, the literature supports increased understanding of the importance and need for preservation of *personhood* with cognitively impaired older adults, particularly within institutionalized residential settings,

where the risk of depersonalization is greatest. Personalized care is an important aspect for providing care to older adult residents, and particularly those with cognitive impairment, when capacity for maintaining identity may be threatened by physical appearance or health conditions. Participants in research conducted by Wellin & Jaffe (2004) defined personal care as including both an awareness of residents' current lives and emotional losses, as well as the attempts to preserve dignity despite cognitive impairment. Lopez (2006) acknowledges the importance of connecting with residents and building relationships, and further draws on his own experience of being able to view older adult residents not only as they are now – wrinkled, immobile, dependent – but with glimpses of the younger people they once were. It can be easy to forget that there is an autobiographical history attached to the older adult resident with cognitive impairment, particularly since this impairment may be marked by communication disorders or severe physical decline. This analysis underscores the need for personalized care attached to an understanding of the resident as a whole person with a social history and multiple social role identities. This kind of holistic, identity-supporting approach to practice with older adults further detaches residents from the master identities often conferred on them by their current health diagnoses and physical decline.

In addition to promoting personalized, identity-supporting care respectful of human dignity, research demonstrates the importance of acknowledging older adults' strengths and capacities, even in the advanced stages of dementia. Tappen, Williams, Fishman and Touhy (1999) cautioned that failure to identify a resident's continuing awareness can lead to low expectations for therapeutic intervention, and result in mere-

task oriented interactions. In long-term care, it is the personal support workers who are most frequently involved with residents on a regular basis and as a result have the greatest opportunity for developing genuine relationships and providing identity-supporting work (Ross, Carswell & Dalzeil, 2002). There is also growing evidence to support that even among individuals with late stage dementia the capacity for displaying affect and maintaining their social identity persists. Rovner, German, Burton, and Clark (1996) contend that the capacity to experience emotion remains intact into the late stages of dementia. Sabat and Harre (1992) assert that personal identity can persist far into the end stages of dementia although social identity requires interaction with others in order to be materialized otherwise it will be diminished and even lost over the course of the illness. Basting (2002) acknowledges that the 'self' is situated on a continuum of memory and creativity that exists in a social context, and although the person suffering from memory loss might suffer a gradual decline of personal control over their identity, this does not consist of a complete loss of self. These findings underscore the need for personal support workers – the most involved staff with residents – to establish social relationships and support individual identity, and long-term care facilities to enable and foster the development of these relationships.

### Theoretical Perspectives

The identification of the research problematic and the development of the research purpose were informed by both political-economy and social constructionist perspectives. The following section will briefly describe the key tenets and premises of these theories as they apply to this research.

*Political Economy Perspective*

A political economy perspective on aging and old age emphasizes the implications of economic structures for the aged and for society's treatment of the elderly, with specific considerations for variation in social location (Estes, 1991). Townsend's (1981) formulation of the political economy perspective on aging highlights the way in which meaning and experiences of old age, and the distribution of resources to the aging are influenced by economic, political and sociocultural factors. In considering the restructured Canadian state and privatization of social services broadly, but more specifically long-term care services, these changes will be experienced differently by older adults in different social locations. The political economy perspective attends particularly to the impact of social class. For the 'working poor' and elders on low incomes, the decentralization of federal responsibility for funding social programs and cuts in provincial social spending download the costs of community and support services to individuals, making them private rather than public costs (Lawler, 2000). Without being able to afford community support services or to survive on the thin public services that remain, the only option for long term care and support in later life may become nursing home placement (Aronson, 2006). However, an older adult of higher socioeconomic status may be less affected by these changes, as a result of services being affordable to them. The divide in long-term care, as a result, may soon take form of middle and high income seniors benefiting and utilizing community support to remain in their homes, while, low-income seniors requiring support are placed in institutions – similar to the days of the almshouses.

Poverty means not only a lack of material resources, which creates malnutrition, ill-health, disability and other forms of deprivation, but also prevents participation in all aspects of life: social, economic, cultural and political....older people living in poverty suffer from social exclusion that detaches them from...decision-making processes and thereby reinforces their isolation and insecurity by taking away their ability to change their circumstances

(Walker, 2005, p. 821).

The political-economy theory created a shift from previous victim-blaming approaches and fosters recognition of external influences affecting the social conditions experienced by the aging population. This theory offers an awareness of the effects of public policy on individual experiences of aging that are separate from older adult's personal control: social service provisions (program needs, eligibility, costs, subsidies); federal pension plans and retirement income (contributions, rates, 'claw-backs'); and housing options (availability; affordability; accessibility; location; type of accommodation). As older adults have historically been accorded relatively low status in society, and consequently have also been a relatively low political priority, they are becoming one of the greatest consumers of service within the market-driven, privatized, welfare state - changing the relationship, and possibly the redistribution, of power and economic organization in society (Estes, 1991).

### *Social Constructionist Perspective*

Vivien Burr's (1995), conceptualization of the social constructionist perspective offers two valuable contributions to the focus of this research. First, she asserts that knowledge is sustained by social processes, stating that "our current accepted way of understanding the world, is a product not of objective observation of the world, but of the social processes and interactions in which people are constantly engaged with each other"

(Burr, 1995, p. 4). In our society, aging and old age have been constructed in a way which emphasizes the powerlessness and dependency of the elderly population and opens the way to restricting autonomy. Being old in society has been equated with 'dependency' and 'helplessness', however there is increasing recognition by gerontologists that dependency is socially created and empowerment of older adults is both possible and beneficial (Clark, 1989).

Second, Burr (1995) suggests that

all ways of understanding are historically and culturally relative...specific to particular cultures and periods of history...seen as products of that culture and history...dependent upon the particular social and economic arrangements prevailing in that culture at that time

(Burr, 1995, p. 4).

A historical examination of 'old age' would demonstrate that the construction of dependency and helplessness was a result of urbanization, industrialization and commercialization of agriculture (Hendricks & Hendricks, 1986), which was encouraged in order to serve the interests of the 'dominant class' of society. Furthermore, a cultural approach to understanding 'old age' would reveal that Western perceptions and ideologies about aging and old age are not universal and vary considerably among cultures, insofar as the level of respect and value accorded to the elderly (Novak & Campbell, 2001).

Of particular relevance to the direction of this research is the social construction of dementia. Restrictions on autonomous decision-making among older adults diagnosed with dementia or deemed cognitively impaired flow from these seemingly objective medical definitions and diagnostic criteria. *The Diagnostic and Statistical Manual of*

*Mental Disorders (DSM-IV)* defines dementia based on medically constructed diagnostic criteria, which include: the presence of memory impairment *and* cognitive disturbances which affect *either* language, recognition, motor activities or executive functioning (American Psychiatric Association, 1994). With respect to the decision making capacity and autonomy of individuals with a dementia or Alzheimer's diagnosis, the only symptom which may logically inhibit decisional capacity is 'cognitive disturbances regarding executive functioning'. However, based on the medical criteria, that symptom does not need to be present in order to make an accurate diagnosis, but the label of 'cognitively impaired' when applied to older adults, is frequently associated with assumptions of 'incapacity'.

In summary, political economy and constructionist perspectives framed my approach to the study. Together, they provide a structural analysis of the social positioning of older people (political economy), and direct attention to the local making of meaning and power of language in shaping social realities (social constructionism). To pursue my questions about the delivery of long-term care to elderly nursing home residents deemed to be cognitively impaired, I used a modified form of institutional ethnography. This methodological approach permits exploration of the interweaving of broad power structures and particular local experience and its organization; it is introduced in the next chapter.

## METHODOLOGY

### Methodology

In order to explore the character of front-line, long-term care practices with cognitively impaired residents, I employed a modified form of Dorothy Smith's institutional ethnography (Smith, 1990). This approach addresses the intricate interrelationships between social and work processes in local contexts and the wider social and power structures that surround and organize them. Campbell and Gregor (2002) describe institutional ethnography as a method designed to unravel "how things happen" – in this case with personal support work in long-term care facilities – and to uncover how the relationships and activities of personal support work are "socially organized". This methodological approach was well-suited to explore how the work of personal support workers may be shaped by the local forces (internal work processes and individualized care efforts) and extra-local forces (dominant discourses related to old age and ageism, political priorities and Ministry of Health and Long-Term Care standards for practice, etc). Specifically, I sought to examine how the organization of personal support work within an institutional setting was arranged in ways that constrained or facilitated the workers' efforts for ensuring that resident care was not depersonalized. The benefit of incorporating ethnographic research is that it was particularly suitable for understanding individuals within their own context and environment, as well as their "beliefs, attitudes, values, roles, social structures, and norms of behaviour" (Yegidis, Weinbach & Morrison-Rodriguez, 1999, p. 134).

The methodology of this study was a combination of critical and interpretive social science research. “Institutional ethnographers generally have critical or libratory goals; they undertake research in order to reveal the ideological and social processes that produce experiences of subordination” (DeVault & McCoy, 2006, p. 19). In this research I was interested in exploring the positioning and “subordination” of older adults in long-term care, particularly those deemed cognitively impaired, as well as the “subordination” of personal support workers in long-term care based on their relatively low power and status within the organizational hierarchy. Critical epistemology extends beyond simply understanding why things are as they are to exploring how they are maintained this way and grasping for alternative forms of understanding (Neysmith, 1995).

Neuman (1997) defines interpretive methodology as “the systematic analysis of socially meaningful action through the direct detailed observation of people in natural settings in order to arrive at understandings and interpretations of how people create and maintain their social worlds” (p. 68). The critical approach to institutional ethnography looks beyond subjective accounts of participants’ experiences in order to understand how they are structured and socially organized (DeVault & McCoy, 2006). With this overarching methodological framework, I undertook a qualitative study: interviewing a small sample of personal support workers in long-term care facilities and analyzing their accounts of their work with elderly residents as a point of entry into the wider dynamics at play.

## Method

### *Sample Recruitment*

I recruited a sample of personal support workers from two long-term care facilities in Southern Ontario. This convenience sample (Yegidis, Weinbach & Morrison-Rodriguez, 1999) of two facilities was obtained as a result of distant ties to one, through my own past practice background, and my supervisor's connection to another. The two facilities were in many respects typical of long-term care facilities in urban areas of the province and were similar on most dimensions. Both were non-profit long-term care homes that primarily relied on funding support from the Ministry of Health and Long-Term Care (MOH & LTC). Their principles of services were consistent with the goals, objectives and purpose of my research, which highlighted the importance of concepts such as self-determination, independence, dignity, and personalized care to older adults. Each of the facilities employed front-line care workers that were unionized however a significant difference did exist in that one facility employed personal support workers directly within the organization and the other organization contracted workers from an external agency.

From these two facilities, a purposive sample of front-line care providers was recruited. Purposive sampling is "concerned with constructing a sample which is meaningful theoretically, because it builds in certain characteristics or criteria which help to develop and test [the researcher's] theory and explanation" (Mason, 1996, p. 94). Accordingly, I sought personal support workers with a significant base of experience (minimum of two years) of front-line care provision with older adults deemed cognitively

impaired. My reason for selecting personal support workers for this research, as opposed to other long-term care staff, was that personal support workers provide the majority of the practical assistance for immediate daily needs of residents' in long-term care facilities, such as dressing and bathing (Ross, Carswell & Dalziel, 2002). In addition, literature suggests that health care aides are significantly more involved with residents than Registered Nurses or Registered Practical Nurses (Ross, Carswell & Dalziel 2002). The request for two years of experience was dual purposed: it ensured that participants would have a sufficient base of knowledge and examples to draw from during interviews and that they would be familiar with the organizational culture of long-term care settings.

### *Sample*

Specific recruitment strategies were negotiated with each facility, in order to accommodate their particular structures. One of the facilities authorized access to individual worker folders so that information letters (Appendix A) could be randomly distributed. In the other, flyers were created and posted (Appendix B) on each floor of the facility and in the staff lounge to invite workers to participate in the research. It was clarified for potential participants that, although recruitment was conducted through the long-term care facility which employed them, the research was not being conducted on behalf of or for their employer, and that confidentiality of their participation would be maintained. Clarifying that the research was independent from their organization was done to ensure that participation was voluntary and not a result of obligation or coercion. Participants were notified that this research, including all written correspondences to participants, had been approved by the McMaster University Research Ethics Board, and

contact information was made available if there were any questions or concerns regarding the details of the research project. Participants signed written consent prior to the research being conducted to acknowledge all aspects of the research parameters, including understanding confidentiality, anonymity and the release of the honorarium. Participants were given a \$20 honorarium in recognition of their time and knowledge.

The final sample for this research consisted of four (4) participants. Participants ranged in age from 35 to 45 years, and had between five to eight years of experience as personal support workers. Their accumulated educational experience and training included certification as: a personal support worker, palliative care worker, restorative care worker, and developmentally handicapped services worker. Three of the participants were born in Ontario, while only one was born outside of Canada, in Africa. Only one participant reported working more than one job and disclosed that it was not out of financial necessity. Interestingly, in addition to their formal employment responsibilities, all of the participants disclosed *informal* caregiver responsibilities to either parents or children and in one instance to both. In the interest of preserving anonymity of participant identity and confidentiality of the information provided, findings are reported without reference to the facility in which participants were employed. Further, the gender of participants is not reported; since personal support work is a female-dominated occupation, all participants are referred to with a feminine pronoun.

The labour force of personal support workers in Ontario includes a high representation of people from diverse cultural and racialized communities and a

significant proportion work at more than one job in order to generate a living wage (Armstrong & Armstrong, 1999). The relative lack of cultural diversity in the sample of personal support workers who came forward to participate in this research may be a result of information letters and flyers posted only in English. It is possible that workers who did not speak English as a first language may not have been comfortable engaging in a conversation or may have felt that they would not be able to articulate themselves adequately. In future research, closer attention should be paid to arrange for interpretation services and to communicate that possibility within the recruitment strategy.

### *Data Collection*

During interviews with participants I used a semi-structured interview guide (Appendix C). The interview guide included questions designed to explore participants' understanding and experience of sustaining elderly residents' identities; the potential challenges of sustaining identity of cognitively impaired residents and; the organizational processes that enabled or restricted the workers' efforts towards identity supporting work. From the perspective of institutional ethnography "the interviewer's goal is to elicit talk that will not only illuminate a particular circumstance but also point toward next steps in an ongoing, cumulative inquiry into translocal processes" (DeVault & McCoy, 2006, p. 18). The use of semi-structured qualitative interviewing enabled me to uncover the individual meaning behind the work processes of 'front line' staff in long-term care and their individual interpretations of their work. The interviews that I conducted followed the lead of participants in terms of what they identified as relevant to discuss about their

work and work settings; I requested elaboration and clarification through the use of probes. “Each interview provides an opportunity for the researcher to learn about a particular piece of the extended relational chain, to check the developing picture of the coordinative process, and to become aware of additional questions that need attention (DeVault & McCoy, 2006, p. 23). When an unanticipated theme emerged in one interview, I explored it in subsequent interviews, which allowed me to check and compare the consistencies and contradictions among participant responses.

### *Data Analysis*

Each interview was audio recorded and transcribed in order to assist the process of data analysis with accurate and detailed accounts of participant narratives. Transcripts were initially reviewed for content and then emerging themes and signals were identified regarding the ‘social organization’ of participants’ work (DeVault & McCoy, 2006). While reviewing transcripts I schematically organized themes and drew upon comparisons, as well as identified the contradictions among participant discourses (Ristock, 2002). Transcripts were read through a critical, deconstructive lens which enabled consideration of the discursive conditions of participants’ work by: first, acknowledging the voice of participants as authoritative; second, understanding participant accounts as constructions of individual subjectivities of their selves and their relation to the world (Ristock, 2002).

The analysis was also loosely informed by Mauthner and Doucet’s (1998) “voice-centered relational method” of analysis which:

Represents an attempt to translate this relational ontology into methodology and into concrete methods of data analysis by exploring individuals' narrative accounts in terms of their relationships to the people around them and their relationships to the broader social, structural and cultural contexts within which they live

(p. 8).

The findings are presented in the next chapter, moving from participants' descriptions of the character of their work and its organization to analysis of themes that structured their activities and their understandings of them. The transferability (Lincoln & Guba, 1985) of these findings requires qualification on a number of grounds. As noted above, the small sample of participants was not typical of the wider work force in terms of culture, race and dependence on more than one job. It is possible that they represented a relatively privileged portion of the personal support workforce and possibly, that enabled them to participate in the research. In considering transferability, too, it is important to note that the two facilities sampled were both from large Southern Ontario cities. Experience in rural or remote areas may be quite different. Even as the study results should be read with these qualifications in mind, the experience of this small group of participants does provide a useful window through which to map and conceptualize front line work with residents in long-term care facilities.

## FINDINGS

At the beginning of interviews, I asked participants to describe their work, its organization and their understandings of cognitive impairment as context for my subsequent exploration of their practice with residents. A summary of their responses is briefly presented below, followed by their articulation of the importance of personalizing residents' care and their commitment to doing so. I was eager to understand how they accomplished personalized or identity supporting care and how that accomplishment was 'socially organized' (Campbell & Gregor, 2002) by processes both local to the facility settings and external to them. Accordingly, the subsequent section of the analysis addresses: the institutional and individual practices that enabled participants to develop the knowledge of residents which was considered necessary for personalizing care; work and organizational processes that constrained its provision; and their approaches to negotiating those constraints. Finally, participants' observations about how care might be improved are drawn together, along with articulations of their consciousness that because of their low status, their front-line, practice-derived knowledge was seldom put to use.

### Personal Support Work and its Organization

The organization of front line work was very similar in the two facilities from which participants were recruited and, indeed, typical of long-term care facilities more generally. Personal support work was structured in shifts that ranged from five to eight hours, in which workers could be either the only worker assigned to the shift, or one of up to five workers during a shift. Workers were assigned to a particular floor or unit to

provide care for between 30 to 50 residents. Each shift was associated with particular routines and responsibilities, reflecting the highly scheduled character of residents' days. When asked to describe the content of their work, participants placed varying degrees of emphasis on its instrumental and psychosocial dimensions:

As a personal support worker our *main objective* is to attend to their personal care, getting them up in the morning, getting them ready for breakfast, giving them their care, brushing their teeth, making sure they are washed, they are clean....It is a holistic approach we use for them. We do cater to their emotional needs, sense of security, that's also belonging, it's all part of it, but in the morning that's the *main objective*...to get them ready (#3)

Everything! It is basically everything. Of course with all the care that they can't do for them self, its emotional support....if it's just sitting and holding their hand...that's comfort for them you know. Feeding and...it's everything that they would do on a day-to-day basis...some of them cannot do it any more (#4)

Participants' accounts of how they actually performed this practical and emotional work revealed the multiple skills involved in providing personal care. These skills are used to ensure the residents' comfort with the environment and the worker providing the care. One participant articulated succinctly the inseparability of tasks from their relational contexts:

You just can't go in and strip somebody...it's humiliating (#2)

Sometimes the thinking and skill involved in this work was expressed as empathy, as participants reflected on how they would like to receive care, and incorporated that information into their work with residents.

Well, how would you like it done for you? You have to think...I look at everybody there as my own parent. And you have to look at it like that and how would you like things done for you....I don't want to be woke up with somebody coming in with a really loud voice and too bubbly, you know? You go in calm and you don't be flipping on all the lights (#4)

Other notable skills that were emphasized included caring and compassion, which were entwined with the prevailing trait of *common sense* and what *felt natural* for participants.

‘common sense’, I mean...the air conditioning’s on so some of these residents they’re cold, they need a sweater on their arms...some of the other ones...are sweating in their beds, so they don’t need the blankets on, they don’t need a sweater on they just need a t-shirt and they are happy. So, sometimes ‘common sense’ when getting dressed is applied... it’s just natural. It’s not something that I think about (#2)

People skills! I mean you have to be able to read people a little bit and....it has to come natural at some point....you have to talk a lot. I’m more comfortable, I think, with older people than I am with a lot of younger people. You have to be a happy person....if I’m suffering something they don’t need to know it, you go in with a smile on your face, right? People skills! And you have to be gentle, compassionate, caring, but for the most, I think it just comes that way (#4)

Not surprisingly, patience was also cited as a pivotal skill and time as the critical resource in performing personal care duties and approaching older adult residents.

Basically, you want to be as friendly as you can and not try to be so fast with them, because you’ve got to think you’re getting them out of bed at that time in the morning, you don’t want to rush them. You know, I know it has to be a rush, rush situation, but you want to give them some space too in that time. Now there’s [staff] that will just rush too fast, kick them out and that’s not right...give them that time (#1)

I think, you know, you have to be slow. If you’re fast and rushing around it only gets rubbed off on them. You’re going to have 20 upset people because you look upset. You’re rushing; they feel rushed (#4)

Interestingly, participants were able to suggest that patience and taking their time with residents’ care was an important aspect of their work, but also maintained that the nature of the facility structure fosters a fast-paced environment in which workers felt ‘rushed’. Before this underlying tension in their work is explored, attention is given to participants’ understandings of cognitive impairment among long-term care residents.

### “It Doesn’t Mean They’re Not There”: Understandings of Cognitive Impairment

Significantly, participants suggested that there was a very high prevalence rate of residents with cognitive impairment and dementia in their facilities.

We don’t have too many that aren’t, to some point, impaired. On our floor of 30, there’s probably 3 that I can say are not...to some point (#4)

If you look at the resident in a nursing home almost all of them, yes we have the locked unit, yes, but working on the other floors it looks like almost all of them have something to do with memory...I am referring to the whole building, because at times you see people who are mobile who are really independent, but you walk in one morning, they are so confused. So we figure that almost all of them have something to do with memory. Bits of memory loss somewhere, so we can’t really treat them like you and I (#3)

Presumed prevalence rates for cognitive impairment further generated dialogue during interviews about how personal support workers distinguished residents who had dementia from those residents who did not, and where their understandings of cognitive impairment were developed. Verbal communication and comprehension were highlighted as principal indicators for determining cognitive impairment among long-term care residents.

School, school taught me all the steps [or stages of Alzheimer’s disease]...basically, I have to say they’re right dead on because you see it, you see it happening always, and its scary....like in step 1, they’re normal, but then you know something is wrong, the communication levels aren’t right up to par. And then, when it comes to step 2, you know that now their communication is way off...they’re slurring, they don’t really know what they’re speaking about. They’ll be talking about something then all of a sudden talking about something else (#1)

I would just say ‘common sense’, I hate to say that, but it is ‘common sense’, if you talk to them, they’re talking, babbling about something that you can’t link words together, you know that they are not there (#2)

Zarit and Downs (1999) argue that a primary goal for dementia care is to give voice to people with dementia and focus on understanding their approach to communication and how to enhance their personhood by addressing their basic humanity. At times, participants revealed this kind of nuanced appreciation of cognitive impairment, aware of its variability between people and over time.

Even though they may be very, very confused once you get that toothbrush in their hand, get it directed towards their mouth they know what to do....get them started, they can do it (#4)

Just because a person has dementia or Alzheimer's *doesn't mean they're not there*, I mean, it runs in my family so I have had to deal with it, so, there are moments of clarity and you never know when they are going to pop-up.... you can't approach them as, as um, old people, people who are mentally ill or not with it enough because they are, they're all there on some level (#2)

These articulations for describing the complexities of cognitive impairment exhibited fragile conceptualizations and, initially, a seemingly contradictory statement from, at least, one participant. In one account the participant suggested that through efforts to communicate 'common sense' informs her that cognitively impaired residents "are not *there*" and in the next account acknowledged the fluidity of resident awareness: "doesn't mean they're not *there*....they're all *there* on some level". Upon reflection and discussion of this participant's 'contradictions', I recognize that her accounts *do* acknowledge the fluidity of cognitive impairment and recognize her expertise and the possibility of the resident actually "not there" in that moment.

Participants identified lack of verbal communication skills as the predominant indicator of cognitive impairment among residents, but did not acknowledge the various other symptoms associated with dementia, such as loss of memory, judgment and

reasoning or changes in mood and behaviour (Alzheimer Society, 2007). Significantly, too, none of them identified the possibility that difficulty in verbal communication could stem from another, unrelated condition, notably strokes, and may not be an indicator of cognitive impairment. In one instance, I asked a participant if her efforts to promote autonomous decision making and accommodate resident preferences would be greater for a resident who had survived a stroke when compared to a resident who was deemed cognitively impaired. The participant asserted again verbal communication and comprehension as a determining factor.

Probably yes, because you're going to get a more clear answer to "do you want the bed pan or do you want to get up and go on the toilet?" and with dementia you're going to do what probably is *easiest for you* but also what's better for them (#4)

This particular account for affording greater efforts for promoting autonomy and choice of residents, who survived a stroke, appears to ignore the likelihood of aphasia as a symptom of stroke, which impacts verbal ability and may, potentially, affect cognitive ability. Aphasia is a symptom following a stroke that results in the survivor being unable to speak or speaking in a 'new language', which the Heart and Stroke Foundation (2006) reported affects one-third of all survivors of stroke. This, in addition to participants' apparently inflated reports of prevalence rates of cognitive impairment suggests that there may be misplaced assumptions that *competent* residents (such as residents who had survived a stroke) are cognitively impaired due to lack of verbal ability. Also, the last-quoted participant's account suggested that care provided to a resident thought to be cognitively impaired may be driven more often by limits to workers' physical efforts, as opposed to individual resident preferences.

Despite the apparent difficulties with comprehension and poor verbal communication, another approach was offered for engaging cognitively impaired residents which was primarily through the worker's ability to identify resident strengths and the importance of respecting their dignity.

Even though they don't communicate to me, I still talk to them like they're there...because I know somewhere it will filter down...and for some reason, you know even though they have dementia it sounds weird, but they know who we are, each individual, by our voices or the way we move or something, they seem to know who each of us individuals are (#2)

This participant's perception echoed previously cited research by Vladeck (2003) who contends that there is a growing recognition that even individuals with significant cognitive impairments may be more responsive to a range of stimuli than had previously been believed, and "even the most demented patient can not only benefit but in some ways respond to care that is more compassionate and expert" (p. 8). However, at times, the fluidity and subjectivity in the degree of comprehension that residents displayed appeared to get lost as it seemed as though work was performed *on the residents* as opposed to *with the residents*.

So if you have to give care [here] you go to some rooms, they are not even talking. They don't talk at all. Only you do everything for them, you clean them, I take them to the dining room, give them a wash...they don't talk at all (#3)

Sometimes participants did feel that there was not anyone there, with the attendant consequence that residents became merely bodies that were objectified during care. This risk might be heightened if – as seemed the case among these participants – there was limited appreciation that lack of verbal communication skill might not reflect impaired cognition but, rather, the impact of strokes or other medical and social

conditions. That cognitive impairment was described in a rather homogenous way and thought present in most residents may warrant further exploration. For present purposes, however, it was striking that participants generally sought and responded to the person they cared for, whether verbally or physically.

#### “You’re There for Them”: The Importance of Personalizing Care

Participants emphasized the importance of individualized and personalized care and described the characteristics that, they felt, embodied personalized care in their work settings. The need to respect individual worth and dignity of residents was particularly emphasized by supporting their strengths and minimizing the degree of ‘total care’ provided.

Letting them do what they can do for themselves. Try to give that time too. Because somebody’s gone from a walker and now in a wheelchair doesn’t mean that they can’t still get in that bathroom in front of a sink to brush their own teeth....it’s just to let them do the things for themselves that they still can do (#4)

What I do is, I will let her [a specific resident] do [pause]...she can’t do peri care, she’s total peri care...but there’s other things like washing her face, her underarms, her hands she can do. So I do the peri care, meanwhile, while I’m busy it’s all conversation...when I’m done the peri care she sits herself up, I give her the deodorant, because I incorporate the restorative, make her do as much as she can do, she will apply the deodorant lightly, she will try to do her own brassiere at the back (#3)

Another aspect of personalized care that participants noted was allowing for individual choice and accommodating for personal preferences, also indicative of promoting autonomy.

If you turn on a big bright light first thing in the morning on some person you won’t be getting them out of bed, anyways, because you’re just going to shut them down for the day. So it’s a couple of minutes as you’re getting things and then “What shirt would you like to wear?” You have to ask, you know, give them something to pick and choose from (#4)

There's this one lady...she used to have that thing, where I would say "hello there" and she will trust me, so I always say, to make her focus on me, "I'm always going to take care of you". "I know dear, I know". And then I'll come back in the next 2 hours..."What are you doing? Don't touch me!" I now try to tell her, "It's me darling, how are you?" And then I'll try and get her comfortable, and then she'll remember me again, but I have to wait until it clicks in before I can touch her, because if I touch her, you're going to get a spark and you're going to get into a fight, so I try to slowly get her to think about me. If it doesn't work I can't do her care...I have to get the other PSW to come in (#1)

Although the importance of socialization with residents was perceived as essential when working towards a personalized method of care, it was also not always possible.

Sometimes during the day you just sit with them and hold their hand after a meal, get your hug....it's more difficult in some ways but...just make it simpler. And it's more just sitting with them (#4)

I'm very talkative with our residents, this is what gets me in trouble with some of our other nurses is they want peace, peace, peace in the morning, me...I was a social butterfly and that's what residents want. They want you to talk to them and tell them about their day....they want to be talked to, they want to be joked around (#1)

While outlining the complicated details and tasks involved in personal support work, participants explained that the skills and approach they applied during their work were not rigid and must remain flexible in order to adjust to and accommodate individual residents' preferences and particularities.

Each resident is totally different they all have their own different personalities so you just feed off the personality....all individuals have their own needs and their own wants and how they want to be dressed, how they want this and that...if you want to help them go and do it. *You're there for them* (#1)

It depends on the individual...so, you can find out very soon the way they like things done...and then do it...we have one in particular...and you have to do everything a certain way or she will stop you, and tell you "NO!" She gets quite upset, and the rest of the day goes downhill from there (#2)

The above example addresses the importance of personalized care, but also suggests that for some residents ‘depersonalized’ care posed consequences and had the potential to shape an individual’s behaviour for the remainder of the day. The effect of depersonalized care highlighted the significance of identity supporting work for, at least one, resident, in addition to workers. Studies in this area have demonstrated that supporting individual identities and autonomy enhances the quality of life for older adults (Woods, 1994; Knapman & Waite, 1995; Brocklehurst & Dickinson, 1996). Research further indicates that autonomy and control can be the primary determinant in psychological and emotional well-being as well as a critical variable in physical health for the elderly (Rodin, 1986; Bowsher, 1990; Moye, 1996).

#### “Getting to Know” Residents as Individuals: Sources of Knowledge

In highlighting the significance of personalized care and exploring workers’ varying approaches to enacting it with residents, the question arose as to how participants gathered knowledge about individual residents in order to facilitate identity supporting, personalized care work. Participants described two dominant avenues for accessing information: first, the institutionally communicated information through personal support workers’ documentation, verbal reports, care plans and conference meetings, and second, the knowledge workers derived from their own observations.

#### *Institutional “Getting to Know”*

Personal support workers were responsible for some documentation practices within long-term care. I was interested in understanding the purpose of their documentation and the type of information that was included in flow sheets and

communication logs completed at the end of every shift. The kind of information that was considered “something that really has to be communicated” (#2) to other personal support workers was centrally concerned with the functional ability of residents and the instrumental tasks performed by workers.

Each person has a flow sheet and the personal support workers are expected to fill out the flow sheets...how much fluid they drink; how much food they ate for breakfast, lunch, dinner and the two snacks; and bedtime...and then we have to write whether it was...just washing in the sink, if we did peri-care, if it was a bath day, if they got a shower, oral care, if they have dentures, if they were cleaned, mouth swab, for the men if they were shaved, finger nails cut, toe nails cut, oh, a really significant [one], if they were in the wheelchair or if they have a walker...[it's a] checklist, it's a standard, and every floor has the exact same flow sheet (#2)

It is for hygiene...can they do their own hair? Do they have their own teeth? Do they wear glasses? For toileting...can they do it themselves? What products do they wear? It's going to have...pretty much *everything* in there (#4)

I asked whether the standardized, checklist format included any attention to the psychosocial tasks and personalized care efforts that were embedded in their work processes and which they had described to me at some length. All participants affirmed that they were not.

No we don't report that....it's not important....the basics are important, feedings, making sure that people are dry, clean, if they've had bowel movements they're incontinence products are changed (#2)

No, because it doesn't require...us to say anything like that, it's always the negative. Write about whatever you know. You don't ever report stuff like that. Nurses don't want to hear that, they want to hear about 'Oh, by the way she's got a bruise on her left arm or stuff like that' (#1)

The 'textual reality' (Paré, 2004) thus created, did not, then, include many aspects of residents' complexities and workers' efforts. As Diamond (1992) found in his ethnographic research in a nursing home “if it wasn't charted, it didn't happen, but much

more happened than got charted” (p. 137). Dorothy Smith (1974) conceptualized this point further and explained that the “socially organized practices of reporting and recording work upon what actually happens or has happened to create a reality in documentary form, and though they are decisive to its character, their traces are not visible in it” (p. 257). This analysis appears to accord with the personal support work documentation, described by study participants, which created a ‘reality’ of residents through their functional and dependent ‘needs’, erasing the significance of the psychosocial dimension of the person and the psychosocial care provided.

In addition to these documentation expectations, at the beginning of each shift, personal support workers received a verbal report from the nurse to update them on individual residents’ needs.

Once we get in we get the report from our RPN or our RN and then the night nurse will tell us exactly what happened for the night, say if it’s the day shift....So we get the report, then we start doing the care (#1)

The nurses pass the information on to us. It is verbally communicated. If we need anything we go find a nurse. Is he on this diet? Is he regular? What product is he? They relay that information to us (#3)

Something that really has to be communicated, we have a communication book, and then, also the RPNs will tell us at report....they would do that at report....they’ll put it on their report sheet, so it would be noted and then they will tell us, but usually, it would be communicated (#2)

With nursing staff as the primary source of the verbally reported information, there may be a tendency to focus on professionally-defined, or medically and functionally determined, needs of the resident. Research suggests that within medical reporting “a different type of language is favoured, one closer to scientific discourse, supposedly more objective, and focused on details, ‘evidence’, and signs of dysfunction” (Paré, 2004,

p.87). The communication of resident 'need' and 'dependencies' exposed deficits and minimized the residents' strengths and capacities.

An emphasis on deficit emerged in participants' descriptions of the resident care plans. Care plans were designed for each resident in order to specify individual care needs. Participants noted that care plans were important in enabling them to get to know individual residents, yet, also acknowledged the limitations of their use.

Their care plan tells us exactly what their needs are....if we don't have the care plan then we don't know anything, basically, so we have to read through the care plan (#1)

One way we would know some of the things that their likes and dislikes, is through their care plan....over time too, you get to know the likes and dislikes, but it's not always the best way to find out that you've done it, set them off, you know you've done something that they don't like or they prefer to wear t-shirts rather than button down shirts like they have in the closet. That's not written in the care plans anywhere, usually. But it's a lot of trial and error (#4)

The information in these care plans were generated based on the *professional* assessments of internal staff and from the initial care conference meetings conducted during resident admission. Despite ongoing, hands-on involvement with residents, personal support workers were not part of these institutional processes.

Doctors, nurses, everybody that knows the individual, they write up the care plan of what [the residents'] needs are....it doesn't really give any history of where [they] worked or nothing...it just tells you their limitations...it doesn't really help a care provider....so care plans only basically tell us the limitations of the residents and how to take care of them and their care. It doesn't give us insight of what they like to do or what their hobbies are (#1)

[Who is present for the care conference meetings?] The Director of Care, there would be the RN, there'd be the RPN, there may or may not be a PSW, sometimes, I am not sure if physio attends, I think that's all...it's usually the RN, RPN, the family...depending on the cognitive, you know, how aware the person is, they will attend (#2)

Participants' accounts of the care plan, and relative lack of resident involvement, accorded with previous research conducted by Brocklehurst and Dickinson (1996) who evaluated the extent of autonomy in long-term care and found "that in two-thirds of cases residents did not contribute to the care plan nor were important preferences included" (p. 331). I was struck by how participants identified the development of care plans as designed by 'everybody that knows the individual', but remained seemingly unconcerned that the primary care workers – those who know residents most closely – and the residents themselves, were often uninvolved in this process. By excluding residents and their primary care workers from the development of care plans, the institutionally communicated format for 'getting to know' residents' was skewed to instrumental and functional issues, and participants needed to learn and respond in practice to individual residents' preferences and particularities.

*Worker "Getting to Know"*

Participants cited time and the development of individual relationships with residents as key resources for 'getting to know' residents, and thus, being able to personalize resident care.

Basically you have to give the time to get to know that person, if you want. It's up to the PSW, okay, to get to know that person. If you don't want to, that's your own business, okay, but it's up to that individual to find out about the resident....you learn their behaviours as a routine, basically, of each resident. Once you get to know them...you get to beat up your own way of dealing with them too, and know their needs a lot better. You're in that field where you're doing one-on-one with them, you know exactly what they want, you know exactly their needs, their wants, and then even socialize too, you start to get that relationship.... You have some residents that will actually open [up] and tell you what they want (#1)

With time you get to know how to deal with each individual. With time the care becomes individualized....what we do is we come to know them individually and get to know how to approach them (#3)

Participants also gathered information from families regarding the particularities for providing resident care.

We would probably just talk to the family or talk to the resident, depending on how competent they were... [And if they weren't competent?] we would probably ask the family...and then we'd just figure it out over like, a week or so (#2)

When the resident first comes in and the families bring them in, there is a meeting and...the families discuss kind of what they want done, and if the resident is 'cognitive enough' they might state....as PSWs, because we do their care, we talk to the families and find out what their routine was...were they a morning person? Do they not want to get up until ten? You know, were they a night owl? (#2)

These information gathering processes seemed to rely heavily on family members, rather than residents and were greatly influenced by assessments of residents' cognitive status. Getting to know the residents deemed cognitively impaired was seen as particularly challenging in regard to participants' efforts to offer choice and promote autonomy.

If you're working on a floor where they're all locked in, let's say you're not going to offer too many choices. You're going to upset them...when you're working on a locked unit...if you can spend more time with one you might get off a little bit better but...if the whole floor is like that, you're asking questions that they don't care (#4)

Those that aren't [cognitively impaired], we give them a choice and we give them time to do as much as they can do....we try, but most of the time it doesn't work out. We give them a choice. Especially in this way, we ask them what they want to wear, yes, makeup, everything. With the cognitively impaired, it looks like we have to do everything for them (#3)

This last observation suggests the tension between striving to 'get to know' and personalizing care, and working with residents as if they had no preferences or

particularities. Besides being emotionally demanding, participants noted that this work could also be physically demanding due to the possibility of complex behaviours associated with the dementia, such as agitation or aggression.

It's very hard, and then they'll get mad....so, it's real hard work, working in a mental or Alzheimer's unit because there's a lot more work to it (#1)

When we're providing [a resident's] personal care, and change her products, her briefs, you know, when she's fighting us we just explain, you know, we need to get you clean, we need to wash you, you know, you don't want to smell. It's hard because she's fighting us but...I know she's uncomfortable being wet and you can just tell, but you just work through it, you let her fight and sometimes kick...but *we have to change her*...you can't have a person smell or wet (#2)

In summary, participants described the channels for the official, textual information about residents to which they had access and, less frequently, to which they contributed, stressing its predominantly functional nature. In their own processes of getting to know residents, it seemed that greater attention was given to their emotional states and preferences. Their accounts revealed the complexity of personalizing work with cognitively impaired residents and suggested the tendency – found in other research (Wellin & Jaffe, 2004) – to relate only to bodies and physical tasks if residents' identities seemed inaccessible or if there was insufficient time to reach for them and thus, to personalize their care. In the next section, the challenges of personalizing care, particularly of insufficient time, are explored.

#### Institutional Constraints and Residents' Needs: Conflicting Demands

Participants indicated that within their settings, institutional expectations and their desire to provide client-centered care were sometimes insufficient. A considerable tension existed in participant responses regarding the conditions that were identified as

constricting and those that were facilitating of personalized care. While participants seemed well-intentioned in the care that they provided to residents, it was clear, as one participant observed, that there was ‘a system at work’ (#1) that guided and shaped the organization of their labour. Study participants referred explicitly to the constraints to personalized care work generated by the organization of their particular facilities and by Ministry standards for practice. The resulting limit on the time available to them was the predominant theme.

*“It All Boils Down to the Time the Dining Room Opens”: Everyday Work Organization*

The amount of time that participants felt they were able to dedicate to residents for providing personal care varied, depending on the time of day and the level of care that the resident required.

Total care in the morning is [pause] we probably spend 10 minutes, 15 minutes max...’cause we’re so rushed (#4)

In long-term care...there has to be 20 minutes per resident, ok, we have to get these people up in 20 minutes flat....Some people are being done in 15 minutes because they’re...more easier care, then you can ship them out (#1)

five minutes?...you could take ten, fifteen minutes because they’re a lot heavier care...but probably five minutes (#2)

As participants spoke of the routines and schedules of their facilities, a dominant emphasis was placed on the pressure imposed by the organization of meal times. This was decidedly true for breakfast, which participants described as ‘hectic’ and ‘chaotic’.

It all boils down to the time the dining room opens....for example, one girl does two dining rooms. One dining room opens at 8:00 and at 8:30 she should be in the other dining room. So, if we don’t cut down what we do for the residents as PSWs, she will run late and then everything will be thrown in chaos....so, we have a problem of cutting things short and wrestling in the morning, literally wrestling in the morning to get them ready for breakfast (#3)

Sometimes, you can't be there at 8:30, it's a bit later, but we don't start work until seven, we come in and have report, which sometimes takes a bit longer than other times. And we have to try every effort to be down at the dining room ready to start breakfast at eight-thirty....it is very rushed (#2)

The other day...we were running late, and most mornings we do run late to the dining room, supposed to be there by 8:30....our floor has the most wheelchairs out of the building, so we've probably got, I think, 20 wheelchairs. So, how do you get there by 8:30? (#4)

'Wrestling' to get residents ready combined with the 'built in' pressure to move fast, constrained participants' aspirations to not rush residents and to personalize their care.

What happens is we're so consumed with getting them up, getting them up, getting them up, routine, routine, boom, boom, boom, that the residents get left out and they don't get socialized....I learned, you know, they need that extra time or extra little 5 minutes of your quality time, it doesn't take much. Of course a lot of [staff], in their head think, it's too much 'cause I don't have that time. It's already built in their system, fast, fast, fast, instead of slow pace. Slow pace yourself....'there's a system at work' and we have to get them up so darn fast (#1)

We don't have time to stop and talk to them and that's something that really bugs me. If we would have the extra time to just talk to them I think it would make a difference in their day. And...even with the personal care, if we had time we could do more for them.... A lot of them, quite a number of them would prefer having showers and baths before breakfast. But we don't have time to do that (#3)

These accounts of how care was provided highlighted the facilities' emphasis on the functional tasks to be completed – 'getting them up' – and a "system at work", producing a rushed and hurried provision of care. Similarly, Diamond (1992) describes personal support work as "organizationally produced as menial and mechanical, industrially streamlined to complement the making of patients" (p. 166). Participants communicated their frustrations with the rigidity of the schedules and routines of long-term care facilities, recognizing them as a direct hindrance to the development of

relationships and the conditions for personalized care – identified, primarily, as opportunities for socialization with residents.

It would be nice, but we just don't have the time, um, the only time we have to sit with residents is if they are a total feed and you feed them at lunch and you could talk to them about their husbands or their children, um, if you are feeding them during the nourishment break, um, if you are giving them a bath, is about the only time you have, personal time to spend with them (#2)

Sometimes they do want to talk in the morning but unfortunately we are always pressed for time so after breakfast is the time you meet that need too. Come on what did you want to talk about? Let's sit down and have a little conversation (#3)

Considering the evident time constraints surrounding the dining room and meal times, participants did find ways to negotiate providing personal care within the organizational structure and routine of the day-to-day activities.

Most of our dining rooms open at 8:00 or 8:30, so at most, all you have is an hour and a half to get them, 8 to 10 residents, ready. So that makes a big push. So, what we do is we get the ones we really can get ready for breakfast, get them up, dress them up and the ones we can't...we were given the choice...to let them go to the dining room in their housecoat...it is their home. So, if some of them are comfortable doing that we just tidy them up, make them look presentable, and they go to breakfast in their housecoats, and then when breakfast is over we get them ready, clean them up, let them change into their street clothes, ready for lunch (#3)

Between 7:00 and 8:00 when we serve breakfast, we do not have a lot of time, it is rush, rush, rush, go, go, go, so we try and do things as *quickly* as possible...as *easy* as possible (#2)

Participants were asked to consider how organizational conditions could support their efforts to provide the personalized element of care in long-term care settings. Not surprisingly, time, once again, emerged as a central theme.

To give them [residents] more time....To be honest with you, it is very sad when a resident wants to talk and we have to 'cut them short' and go. That is something that really bugs me in this job (#3)

It looks like a home [but]...care isn't given like a home! You should be able to sit with somebody, take more time to give the care, personalize it a little bit more, which I think takes more time. We don't have it! (#4)

Participants' descriptions of providing care against the tensions of satisfying organizational routines and time constraints indicated that resident care could often be compromised in the process. There was, as participants identified, "a system at work" which has "built in pressures" and resulted in workers feeling the organizational pressure of "rush, rush, rush" and "go, go, go" with the ensuing discourse regarding this particular time of day illustrated as 'chaotic' and 'hectic'. For residents, this meant that they were 'cut short' and care was provided as 'quickly' and 'easily' as possible.

*"We Need More Hands": Insufficient Staff*

Aligned with the concerns about insufficient time to perform their work, participants highlighted the importance of adequate staffing for facilitating personalized care. This included staff coverage or availability, skills, consistency and support within the organization. First, they identified the nature of how worker coverage was organized in their facilities to explain the heavy demands of their work.

What happens is, after breakfast two PSWs will go off for their break, leaving two other PSWs doing all the care, the peri care, trying to get the showers, getting the call bells. Then those two come back from break then the other two go off....I think it's 11:00 when all of us are back on the floor, but at that time, now it's lunch break so we now have a half an hour....one [PSW]...leaves at 11:00 now so now we've got that extra feeder she's gone...so now we're short in that area....[one] person will go on her lunch break for half an hour, the other [PSW] will leave at 11:15 leaving one nurse now for 15 minutes if there are any call bells and trying to get them down to the dining room...which sometimes is hectic. After that there's a nurse that comes in at 11:30, she takes over, now she's alone for 15 minutes and we rotate right till about 12, then all three of us are there at the dining room finally, and now we're doing the [meal] service again (#1)

There's a lot of staff shortage. The main thing, I would have to say is there's a lot of staff shortages....I know a lot of facilities too, they're shorter than us, I don't know how they all do it (#1)

Each time that there was a shift change, or a personal support worker was providing care to a resident for the first time, the 'getting to know' process began over again. Staff turnover combined with the shift nature of personal support work in long-term care, posed concerns and consequences for the continuity of resident care.

The residents suffer from the new faces, the new voices, the new approaches and of course we all do things differently even if we have to follow a routine, the way we tend them is different....it is something they put up with. They don't like that, but then again it has to happen (#3)

During interviews, participants also captured the nature of problems related to job demands and workload pressures as a result of shift work and scheduling problems. Due to the relatively low pay rates for personal support work in long-term care, participants noted that many personal support workers in their settings needed other jobs to secure a living wage. As a result, they were sometimes unable to accommodate the regular shift rotations expected of staff employed in these facilities.

At times, the consequences of insufficient staff coverage and support created a direct conflict between care that was respectful of a resident's dignity, that was possible within organizational pressures of time and routine, and that was abiding by the Ministry of Health and Long-Term Care regulated standards of practice for personal support workers.

What happens too is, let's say we're short, like I was telling you for the lunches we have somebody on a chair lift or that person's sitting down already on a chair lift, on a toilet and I'm the only one now left. Now my responsibility is actually to get the RPN but most of the time a [PSW] will just go, you know what, I have no time looking and searching for an RPN because the RPN is mostly busy doing her med rounds or whatever cause it is one of the busiest times too, I'm going to do that chair lift and that's what will happen (#1)

The accumulation of constraints and competing interests resulted in participants' compromising 'care standards' to provide care in a timely manner, which may have placed residents and workers at 'risk'. The following section further details participants' opinions of the Ministry standards and the organizationally imposed expectations of personal care work.

### *Ministry Standards of 'Care'*

Abiding by Ministry's standards was identified as an additional pressure on the already complicated and demanding nature of personal support work. Participants noted the standards and demonstrated concern with questions of 'liability' and 'accountability'.

We have...so many policies now, so *we don't lift anymore*. We have to use machines, okay, it's all for the interest of the residents and the ethics team. So these are things, this is something we can't go against now so whether that will take your time now or not you have to go for the machine and come use it for the resident cause if you break your back or something happens you are to blame (#3)

The Ministry does some good things, I'm not saying it's bad, but it does put a lot of pressure on us. Call bells, whether they can work a call bell or not, has to be out on top of the bed. They've come in and pushed a call bell then timed us to see how long does it take to get there. They do put a lot of pressure...they tape seatbelts that are locked seatbelts; they put a tape and a time on that. They'll come back 2 hours later to see if that's been removed because it should be. Now we've got 20 wheelchairs with seatbelts so sometimes somebody has to come off the floor from doing care and toileting and bath to check the belts and reposition people (#4)

Ministry regulations, even if seen as sensible and supportive of good care, were also seen to generate extra work. Some participants saw some of these regulations as trivial and diverting their attention from more important work.

They come in and make the dumbest demands, they want to ensure that there's a hand towel on the little towel rack in their rooms, like they don't care that these people aren't cold, they don't smell, they seem to be happy, they worry about these hand towels, and that the toothbrushes can't be touching the hairbrush. But if you have a person with dementia who uses a toothbrush to brush their hair, you know, you can't ensure that (#2)

We have towel rings in the bathroom. We have to have a towel hanging in the ring. Come on, that's just a decorative thing. You know no briefs in the cupboard. You can't see them when they're in the cupboard, why can't we leave an extra brief for later on in the day, you know, just think. And I'm sure with time when we change our routine and change the way we do it it's going to fall right into place, but we're so used to doing it that way (#4)

Two participants referred to the current media coverage regarding Bill-140, proposed legislation to introduce a minimum standard of 3.5 hours of care per resident per day in long-term care facilities. They voiced different perspectives about this initiative, but both were sceptical, one about the possibility of standardizing what has to be individualized and one at the meagreness of the time proposed.

I wonder how they worked that [number] out...it's too low! From the time you walk in, you get that person up, take them to the dining room, you make sure they eat. After the meal, you toilet them, then comes the shaving, the men, the nails, if it is a person's shower day...some of them do go for physio some of them we do exercise on the floor. Then comes lunch time, you have to take them to the dining room. The same routine, make sure they eat, take them back, toilet them, if they have an afternoon nap you put them in bed, get them up, take them to the dining room for supper, make sure they eat, take them back, toilet them. These days we are not even allowed to put them in bed before 8:00 (#3)

If you turn on the radio you hear something about...how there is supposed to be so much time per person, but if it depends on how much care is, that's the thing, you can't regulate because this person is a total mechanical lift whereas this person walks, so I just have to get this person dressed, this one I have to do everything for them...so you can't regulate how much time we spend (#2)

In sum, participants described how they understood the limits to their abilities to provide personalized care. In the next section, their accounts of how they negotiated those limits in their everyday work are explored.

### Getting Our Work Done: Working with Time Constraints

Participants described how, at times, they persisted in giving time-consuming, personalized attention to residents despite pressures not to do so. One participant in particular described how she resisted jeopardizing residents' fragile autonomy or dignity.

You know what it is, it's, we had a worker come from another floor...it's a big time thing for them, that we don't have time to toilet. If they are wearing a product that means they're incontinent...but it's not. They may not be able to hold all their urine, but if you put them on [the toilet], they're going to evacuate everything. Like, people feel, if you are wearing a product, you don't have to go on a toilet. They have to go on a toilet! If you can get them there they should be there (#4)

In the morning, providing mouth care, some people will say don't do their mouth in the morning, do it after breakfast. Well, I know as well as you do, if you don't do it before breakfast, it's not getting done because you're not taking them back to do it. Maybe some would, but I don't see it. And how would you like to get up and eat your breakfast with, you know, not cleaning your mouth...until I'm told not to do it before breakfast, I'm doing it (#4)

They also described instances of performing work 'above and beyond' what was expected of them, seemingly in an act of resistance to their organizational constraints. As other research has also found (Aronson & Neysmith, 1996), the just-quoted participant and others would on occasion, work extra unpaid time in order to attend to residents' emotional (rather than physical) needs.

Now, 10 after 3, I'm off the clock, there's some, 2 minutes to 3:00 it doesn't matter what's done, not done. It's just not right...I know you have to not make it too personal, but come on, you know, you can't leave a lady that's crying....and I've been told "Go home!", but if I'm doing or seeing something that needs to be, like that lady yesterday, I'm not leaving. Like it doesn't matter, I'm not...I do what's right for me (#4)

These kinds of integrity-preserving responses were simply not always possible however, and participants described how, at times, they over-rode residents' wishes in order to manage their time efficiently.

Not everybody has to be dressed [to go to the dining room] but most of those people don't want to come in a housecoat....that's sort of our argument right now, one lady doesn't want to come in a housecoat, wants her shower before breakfast, now she can't have it, and I'm not about to dress her twice, you know what I mean? And because she's not sick shouldn't be having a tray in her room (#4)

On evenings, sometimes, right after supper we're putting some residents right into bed, right after supper. Do these residents really want to go to bed? Oh, we put them to bed because we've got to get these residents into bed and then get our work done (#1)

Sometimes, their way, it takes much longer, it's much harder on us, and well, for example, if they wanted to get their bra on in bed, it is very hard to get a bra on a woman or a blouse in bed, but sitting up on the side of the bed or in the wheelchair then they could move their arms (#2)

This last quoted participant alludes to the limits not only of her time, but also her physical strength. While the physical demands of the work were not often elaborated on by participants, their overall fatigue was.

You don't stop, and if they [nurses] see you sitting they make you feel like you shouldn't be sitting, to even do your book work [documentation]. That's the only time we sit. It's ridiculous, that's the only time we sit, truly....you're always going to have the achy legs and I don't know if everybody does, it might be just me, I'm drained at the end of the day (#4)

Sometimes, care was provided in the manner which was requested by the nurses, without consulting or accounting for preferences of the resident. One participant reported how such a decision was made in the ‘best interest’ of a resident.

We have another [resident]...she’s deteriorating...we found that she just sleeps through breakfast, so now we just leave her in bed, and we don’t go to her until 10....but they do have a choice. No...we never asked her, well we sort of did but we took it upon ourselves and thought that this was in her ‘best interest’ to leave her in bed until 10, then when she gets up at 10:30 she’s more alert to eat her lunch (#2)

This apparently unconsultative decision-making process can be understood as a way for over-taxed staff to reconcile themselves to the limits of their resources and abide by the decisions made by their ‘superior’ staff. However, this could also be reflective of the power and status dynamics within long-term care facilities. In the final section, the consequences regarding personal support workers’ low status in the division of labour in long-term care facilities is considered for its implications for the personalizing of care.

#### The Low Status of Primary Care Workers’ Knowledge: “You’re Looked Down On”

Personal support workers in long-term care are paraprofessional workers on a team predominantly consisting of ‘professional’ staff, such as doctors, nurses, physiotherapists, dieticians, and social workers. The low status of personal support workers on the multidisciplinary team, despite the closeness of their relationships with residents and their detailed knowledge of them, was a source of frustration.

We’re doing everything and we get treated like crap....it’s like, we’re doing their personal care, we know exactly what their needs are then we report it to the RPN...I remember one time I reported something...we know these residents, we know it’s something....“she’s a little depressed!”, “Oh, it’s nothing”. We know this person, we talk to her every day, something’s wrong so look into it, please, before it’s too late...we know that they’re really sick or down, you know? So, it bothers us (#1)

Lack of appreciation and recognition for the work performed by personal support workers was particularly articulated related to the divide between personal support workers and nursing staff.

We hear all the negatives, and we may have a meeting now and then, but you always get in the beginning, doing a great job, blah, blah, blah, and then all the negatives. Well let's just get the negatives out of the way and work on them, keep your positives to yourself...there have been family members going to head nurses with positive feedback and you don't hear it. Why aren't they passing that on? Then you hear later that nurse told one person out of eight of us (#4)

We always find you hear the negative instead of the positive, which irks us a lot too in the facility that we're always hearing, "Oh, we could do a better job here and there", instead of saying "Wow, that was good of you guys"....let me tell you we would like to hear some positive instead of negative (#1)

Participants knew, too that residents and their families recognized their low status, and minded the, sometimes, demeaning way in which they were treated.

Coming from us, we're nobody to them, we're not upper management, we...how do I say this? They're thankful that you're there, but then when it comes to the bigger things, no, you're just the, you're looked down on. You know the maid, the waitress, you know, you're looked down on (#4)

There were various areas of work that were affected by the power and status differentials felt by participants working on a team in a medical setting. This was most evidenced by participants' concerns that their work was associated with menial work and not recognized as a valuable contribution to residents' care:

When it comes to management I think they value what we do because at the end of the day...we are doing the job. Sometimes we go the RN, 'could you please help, they tell us 'I don't know anything about that'....when I started this job...I have to work this catheter but I have no idea how to open "Could you help me?" She said, "No...I don't know how to help you" (#3)

[The RPNs] do the medications, they call us to help them do dressings, but some of them won't try to sit down and help feed somebody at meal time or help clear dishes. We have to clear the dishes. You know, we should be removing people and starting their care not cleaning the dining room, you know, not...things like thicken soup, why can't the cook be thickening all the soups, you know. I mean it's simple and you know how to do it, but now you're thickening a soup that's too hot to serve, it could have already been done (#4)

We are not allowed to go into their charts as PSWs (#3)

In addition to the lack of support participants perceived by nursing staff in regards to assistance with completing the instrumental tasks of their work, there were also contentions regarding lack of emotional support.

If you need support you go to them, but you shouldn't have to. If you need help, I feel I can go to my nurses, most of them, and ask for a hand with something if I need help yes, but I think the emotional support maybe that's where we're lacking as workers. Some of them can just put a wall up and go and go through the motions of it, of their job, but I think it's going to be a high burn out job, burn out rate (#4)

Participants were asked, in light of not feeling supported by their supervisors, to identify the internal support systems that they felt comfortable accessing from their work settings.

Each other...period! (#4)

I think that the staff room is mainly the place we all get to meet from different floors and...it is, I'm sure it has been said that we shouldn't even do that, but how can you not do that when we are looking after human beings....so, when we meet there...we always talk about the shift, the present shift. Oh, this morning this happened, someone had a fall so we had to stop this and we got so late and this one was upset, this one passed away and the whole floor was in chaos, you know?....once you start that someone says well what did you do? What happened? What did the RN say? Did the ambulance come on time? So that is where we share our views, we learn from each other...we get attached to people, and that's one big issue too, and they pass away, I mean, if you don't get that support you end up with a very, very bad day (#3)

One RPN who I do work with on the floor...she's a very good nurse and she helps out on the floor and she will praise you....that's what you need to hear and there's only a few that will do that. It's more negative than positive and it hurts (#1)

#### Putting Workers' Knowledge to Use: Ideas and Barriers

Participants articulated practical and creative suggestions for improving their work conditions and residents' care. Without any verbal prompting, suggestions were offered, which indicated that they had previously considered solutions to the frustrations and constraints of their work. Participants were able to consider potential solutions for personalizing care; enhancing organizational approaches for 'getting to know' residents, and specifically cognitively impaired residents; increasing accountability and reducing professional status barriers within the organization; and improving the development of Ministry of Health and Long-Term Care standards of care. They expressed ideas for enhancing workers' time and for the organization of their work:

Maybe increase the hands, yes when we have more hands then we would have more time to do these things (#3)

The best thing, like, we would love to have is a bath team, that would actually help out. I remember at a facility I used to work in, where there was a bath team and it helped out...where their responsibility was just taking them into the shower, giving them a bath, and then it was much better (#1)

Suggestions for improving the psychosocial aspects of care were also discussed, which were ultimately related to the manner in which the instrumental and functional components of care were provided.

First, we make sure that some, like family members or somebody who will take the time, talk to a family member, get a whole whack of their information for us so that we'll have something to work on, especially in [dementia] units (#1)

It looks like with the PSW job, when you go in all the work is all you see if you're going to take out the person. At times we forget...the background, all we want to do is get the person up, clean them up, make sure they eat, make sure they are clean a little bit of time, one way or the other....maybe they can increase staff, but when it comes to the time I doubt it very much. So, maybe if we are educated on how to incorporate these things as we worked with them or give them the care it will benefit them a lot (#3)

One participant was able to draw upon her wealth of experience with cognitively impaired older adults and their families and propose several creative solutions for enabling workers to personalize interactions with residents. The following suggestion was made to increase the information available through the organizational 'getting to know' process.

What one family did was a video with them [the resident] and how it used to be. So, when you come into a dementia unit...you see a video of them and say "oh my gosh, he was a caring man before, instead of this rude guy"....that's what we need is people like family members to come in, and write his log, you know what he use to do and then we get to realize what kind of person he was....and then we'll probably actually treat him a lot better too...some [PSWs] will start to realize, you know, he's a human being better start giving him some dignity (#1)

In an effort to minimize the status barriers in long-term care, and increase the personal support workers' accountability for residents' care, the concept of allowing personal support workers greater autonomy in care decisions was introduced.

We can make a lot of decisions. Now, if something has to be changed [in the resident care plan] you then have to take it to the nurse. I mean, changes, you have to assess each resident, too. As you're going, let's say, in to see them, they're sitting in their room and it's time for their toilet and now they're not helping to get up or they don't have the strength to help you get up, you make that decision to let's try a machine, you know, to help them to stand. Now that...we're allowed to do that! I mean you have to assess them all the time. And so, if you use the machine once, okay, but now if you find you're using a machine a couple of times you'd better be telling somebody that the state of this person is starting to change so they can change the care plan. So that somebody who's not always on that floor doesn't try to do something, you know, that they shouldn't be, alone and possibly getting hurt (#4)

Participants also offered suggestions for the type of assistance the Ministry of Health could offer to the long-term care industry to support worker's efforts pertaining to personalized care.

More money means more staff, I mean, I know some of the places don't have the staff ratios that we have and if we're short one person then we're struggling to get all our stuff done...and yeah, the baby boomers are aging and they need more cash (#2)

I think that the Ministry needs to go in and work, or work side by side with people who do the work to get a clue about the day to day activities (#2)

In analyzing the data gathered in interviews with study participants, a number of themes and concerns emerged that have been presented above. In the process of the analysis, it became evident that the research questions initially posed were, in some respects, not possible to pursue. My initial focus had been on understanding how personal support workers engaged in identity-supporting work with cognitively impaired residents. The study participants certainly shed some light on this, illuminating their commitments to that process, despite seemingly unrefined understandings of cognitive impairment, the actual work and skill of doing so. However, the more striking theme in their accounts concerned how time pressure constrained their ability to engage in such work, whether with cognitively impaired or cognitively healthy residents. "The system at work" (#1) – a complex interplay of organizational, political and economic factors – frustrated them and limited the capacity of the facilities in which they worked.

## DISCUSSION

The research findings from this study have some implications for the organization of front-line care practices in long-term care facilities and the institutional environment of nursing homes. Although the study participants articulated compassionate and skilled approaches to their work, they also expressed frustration with the time pressures and rigidity in daily routines that restricted their ability to personalize the care of residents, whether deemed to have cognitive impairment or not. While other research and literature have demonstrated the importance of identity-supporting work with older adults, and specifically older adults deemed cognitively impaired, this research suggested that the institutionalized and routinized environment of nursing homes pose specific constraints on workers' efforts to provide personalized care with residents. Brechin (1998) argues that successfully sustaining 'good care' is reliant on care processes being mutually rewarding for the care giver and the care receiver. As one participant from this study described, the pace and demeanour in which primary care staff provide care is inextricably linked to how care is received by residents – "you're rushing; they feel rushed" (#4). Based on Brechin's (1998) analysis and this study's findings, I conclude by drawing out some implications about areas of needed change in nursing homes.

Specifically, I consider – in Brechin's (1998) terms - how conditions may be made more 'rewarding' for both workers and residents and, thus, the quality of care enhanced. In particular, I will address the value of enhancing personal support workers' sense of their status and of being appreciated for their work. I also consider how a client-

centered philosophy of care in nursing homes may be actualized and, finally, address the implications of participants' conceptualizations and understandings of cognitive impairment for performing identity-supporting work. In considering the possibilities for change in long-term care, I will draw upon principles and approaches adopted from the 'Eden Alternative', which aims to create a 'human habitat' for older adults – "a place where they can live, rather than wait to die" (Eden Alternative, 2007). The principles of the Eden Alternative (Appendix D) are based upon the belief that "aging should be a continued stage of development and growth, rather than a period of decline" (Eden Alternative, 2007) by enhancing resident choice and autonomy. This approach proposes efforts to de-institutionalize the culture and environment of nursing homes and to maximize growth in resident's experiences and lives.

### Organization of Personal Support Work

Participants in this study identified aspects of long-term care and the organization of their labour that could be usefully changed: their experience of their low status as personal support workers, its reinforcement in their exclusion from decision making regarding resident care, and lack of expressed appreciation for the work that they performed. As previously noted, personal support workers have the most direct front-line knowledge of residents' well-being and preferences (Ross, Carswell & Dalzeil, 2002) and, logically, have much to contribute to the personalizing, and quality, of residents' care. Participants in this research made valuable suggestions to maximize personal care efforts and minimize the depersonalizing effects of their long-term care facilities. One way to value and draw forward their experience and suggestions may be by instituting

regularly scheduled personal support worker meetings in long-term care facilities.

Participants noted the benefit they derived from meeting and talking with each other in passing or in their short breaks in the staff rooms and structuring such opportunities more thoughtfully may enable workers to share experiences, concerns and expertise regarding constraints in their work processes, personal approaches to negotiating care amid those constraints, and potential solutions for organizational change.

This approach would be successful if workers' voices are acknowledged and supported as valuable at organizations' administrative, decision making levels and if there is openness for creating organizational change. In addition, the implementation of this idea, or a similar one, would demonstrate the recognition and value of personal support workers' voices and suggestions, and serve to reduce the hierarchical status barriers. Such initiatives would, of course, also require time – a resource, as the study indicates, that is in very short supply under current institutional and funding arrangements. Conceptually, however, the idea is sound and compelling, even as it may imply a radical reorganization of long-term care. The Eden Project offers a model of a way forward. It proposes replacing the medical model approach to nursing homes – which operate with top-down administrative decision making procedures – with a 'human habitat' model, giving real responsibility to the primary care workers (National Center on Accessibility, 2001).

In addition, the organization of primary care work within the 'Eden Alternative' is comprised of permanent care teams for a small number of residents in which workers must 'apply' to be a part of the community, rather than be 'assigned' to it. This fosters

consistency of staff which, in turn, promotes the development of authentic and knowledgeable relationships between staff and residents - potentially rewarding for residents as they reap the benefits of familiar faces and environments, greater opportunity for personalized care and less disruption to their daily lives. In addition, personal support work as an occupation has been characterized by high burnout rates (Ross, Carswell & Dalziel, 2002), which indicates the importance for improving worker morale.

Implementation of the Eden principles within other long-term care homes has demonstrated reduced staff turnover (National Center on Accessibility, 2001). Lastly, this model encourages personal support workers to prepare their own schedules and daily assignments, providing a greater amount of autonomy to a historically undervalued staff group (National Center on Accessibility, 2001).

The accounts of participant in this study also indicated that personal support workers were infrequently involved in the formal organizational processes for ‘getting to know’ residents. Including personal support workers in care conference meetings would enable them to receive relevant information from the resident and their family about the preferences and particularities of care. In the facilities accessed here, participants communicated that this information was received verbally and second-hand from nursing professionals, who, they felt, were often unfamiliar with the complexity of personal support work and the skills involved. This inclusion would also allow the resident to discuss all aspects of care with one of the workers who will be providing the most practical, day-to-day activities of care. Although this would not lessen the importance of worker efforts to ‘get to know’ individual residents, it might serve to enrich the context of

their work with individual residents and to communicate acknowledgement and appreciation of the value of personal support work. Nursing homes that have adopted the principles of the ‘Eden Alternative’ schedule weekly meetings with the permanent care team, including any staff who come into contact with residents – housekeepers, activity, laundry, maintenance, rehab staff – in order to make decisions regarding care and ‘individualized resident need’, with all members working towards *that* common goal (National Center on Accessibility, 2001) regardless of their positioning in the traditionally accepted hierarchy of status and power. Changes such as these would effectively include personal support workers more fully in the delivery and organization of care and would contribute to making their work more ‘rewarding’ in lifting morale. Other organizational changes would also be needed to reduce the institutional character of nursing homes to further improve quality of care for residents and working conditions for staff which are considered below.

### Organizational Culture Change

Participant accounts of organizational processes and imperatives that constrained personalized care centered on lack of time and the routinization of their labour. The level of emphasis placed on what I heard as the apparent ‘tyranny’ of the dining room offered particular insight into these tensions. The scheduling and regulation of meal times dictated the shape of residents’ and workers’ days. Participants’ efforts to work with the dining room schedules resulted in hurried and limited time with residents who, in turn, were offered little or no flexibility. These patterns and practices are not unique to the facilities sampled here (Diamond, 1992) and are rooted in constraints and assumptions

related to employment practices, shift structures and costs (among other things).

However, it is possible to envision a more flexible and less standardized organizational culture, on what – in Brechins' (1998) terms – would be more 'rewarding' for both workers and residents.

Again, the Eden Alternative offers a model in its emphasis on enhancing the flexibility and spontaneity of the environment for residents and personal care workers: "an Elder-centered community imbues daily life with variety and spontaneity by creating an environment in which unexpected and unpredictable interactions and happenings can take place" (Eden Alternative, 2007). With respect to meal, for example:

Once awake, a person might choose to have a cup of coffee, or tea. Or they might decide to have breakfast in the dining room. Many Eden Alternative homes have open hours for dining. The homes may offer a buffet, so residents have a choice of when and what they eat

(Action Pact, Inc., 2007).

The Eden Alternative identifies other dimensions of flexibility, addressing what are termed the 'three plagues' which account for suffering among older adults in residential care: loneliness, helplessness and boredom (Eden Alternative, 2007). The cure for loneliness lies in companionship, and Eden Homes encourage: the presence of pets (parakeets in nearly every room, cats and dogs, aquariums and fish, etc.); intergenerational and community involvement through on-site child care facilities; 'inviting and available' parks and playgrounds for children and other members of the community; and flower and vegetable gardens (National Center on Accessibility, 2001). These features also serve to cure the plague of helplessness. Through helping children and caring for pets and plants, residents maintain some responsibility for making

decisions about their environment and living beings around them, overcoming the sense of helplessness and complete dependency on the environment. Furthermore, ‘Edenized’ homes operate from independent communities as opposed to wards or units, which include their own kitchen, dining room and living room and residents are actively involved with meal preparation and assisting staff which stresses independence and responsibility (Action Pact, Inc., 2007). Lastly, incorporating children and pets into the environment fosters an environment of spontaneity (the behaviours and actions of children and pets are not easily controlled) which creates flexibility to account for residents’ individuality and preferences. Within these environments, residents are not restricted by rigidity of routines and schedules, and are able to decide to either, visit children in the child care centre, go outside to the playground or stroll through the paved walks of the garden (National Center on Accessibility, 2001), truly accounting for each individual residents’ preferences and particularities.

These descriptions of Edenized facilities’ approaches offer useful models, ideas and practices. In the two facilities sampled in this study, some elements of these practices were taken up; for example, one sought to organize physical space into smaller sections or ‘pods’, so that the institution felt smaller and was partnered with programs incorporating pet therapy. Initiatives and designs such as these are important and accord with the literature on how to achieve personalized care in institutional environments. Importantly, though, they beg questions about the different base of resources available to Edenized homes and to non-profits in contemporary Ontario.

Currently, in Canada there is only one home for the aged that is planning to operate, when open later this year, from the Eden model (Eden Alternative, 2007). This facility, however, is a privately owned retirement home - not a publicly funded nursing home. Such care is, then, accessible only to seniors with sufficient economic resources. Long-term care facilities such as those sampled from here must struggle against daunting material odds to enhance the conditions of their care.

### Concerns for Conceptualizing Cognitive Impairment

How cognitive impairment is understood in the provision of care in long-term care facilities was a focus of particular interest in this study. From my own practice, I was concerned at the base for its determination and the consequences of it for residents. As described in the findings sections, study participants strove to work responsively with residents they deemed cognitively impaired, but also seemed to labour with some misconceptions about the prevalence and indicators of cognitive impairment. These misconceptions suggest implications for practice and education.

Participants appeared to overestimate the prevalence of residents who were cognitively impaired in their long-term care settings. It was likely, therefore, that long-term care residents without a cognitive impairment were presumed to be cognitively impaired and may have been treated as though they were unable to communicate particularities and preferences of care. As previously indicated, it has been estimated that between 60-80% of residents in long-term care facilities have some form of cognitive impairment (Ontario Health Coalition, 2007) – an estimate that corresponded with both facility administrators' reports that approximately 70% of their residents had, not a

diagnosed cognitive impairment, but ‘memory impairment’. One administrator explained that this label encompassed residents with mild cognitive impairment, stroke and residents who demonstrated symptoms of memory loss, without a formal diagnosis ever being made. If the apparent ‘over’-identification of cognitive impairment among this study’s participants is typical, clarification regarding the assessment and the determination processes for labelling residents cognitively impaired may be warranted.

Participants’ emphasis on communication and comprehension as the key signals for determining cognitive impairment suggests areas for educational and professional development. This narrow conceptualization does not take into account three other phenomena that may also affect a resident’s ability to communicate comprehensively: aphasia due to stroke; hearing impairment; and speaking English as a second language (or not at all). The Heart and Stroke Foundation (2002) notes that the risk of stroke doubles every ten years after the age of fifty-five, rendering the older adult population at least twice as likely to suffer a stroke. Approximately, one-third of individuals who experienced a stroke will have difficulty with their use of language, unable to speak or speak in a “new language”, also known as aphasia (Heart & Stroke Foundation, 2006). With respect to hearing loss as an inhibitor of communication, the Canadian Association of Speech-Language Pathologists and Audiologists (2000) report that 20% of those 65 years and over and 40% of those over 75 have significant hearing difficulty. In addition, at least 80% of older adults in nursing homes have impaired hearing (Canadian Association of Speech-Language Pathologists and Audiologists, 2000). And, lastly, some older adult immigrants in long-term care may speak English minimally or not at all.

Statistics Canada reports that in 2001, 29% of individuals aged 65 to 74 and 28% of those aged 75 to 84 were immigrants - not born in Canada and/or did not have Canadian citizenship at birth - compared to 17% of the non-senior population (Turcotte & Schellenberg, 2007, p. 271). With a high percentage of older adults who have immigrated, English may not be the older adults' first language, and could be characterized by difficulty with verbal communication or comprehension. In addition, Statistics Canada (1996) census reported that 4% of seniors were unable to speak *either* of Canada's official languages.

For all of these reasons, residents may be misidentified as cognitively impaired. If so labelled, staff may limit their efforts to draw them out and get to know them and, thus, the possibilities of personalizing their care may be compromised. Accordingly, personal support workers may benefit from additional education and training regarding: the complicated nature and symptoms of cognitive impairment and approaches for personalizing resident care. Indeed, one participant affirmed the value of such training, concerned about misconceptions about residents' capacities not translated into fixed assumptions about their incapacity and, hence, into unresponsive and potentially depersonalized care.

These research implications and suggestions for change – in the organization of personal support work, organizational cultures and staff development – are tentatively offered as ways of enhancing the conditions of personal support work and the quality of resident care. As noted repeatedly above, all are contingent on the availability of time

and resources. In closing, I note very briefly the role that social work can play in pressing for increased resources and enhanced care.

In their roles inside long-term care facilities, social workers promote client-centered models of care and encourage greater involvement for personal support workers within the organization. They can also encourage management and decision-making authorities to consider change in organizational cultures and provide evidence and examples of others' practices to inform such change. Lastly, political advocacy is necessary to improve resources and services for older adults. Social workers can support the efforts of existing organizations that advocate for passing Bill-140 for minimum care standards (i.e. Ontario Health Coalition, Ontario Association of Social Workers, etc.) and similarly, lobby political organizations, such as the Ministry of Health and Long-Term Care, Local Health Integrated Networks (LHINs), and the provincial Health Minister.

Progress toward the changes discussed here will be contingent on resources and the public commitment to long-term care facilities in Ontario. Social work has a part to play in advocating for improved funding and sufficient staffing, as well as in engaging the public, policy makers and service providers in envisioning improved and alternate approaches to care. It is hoped that this small study contributes to these endeavours.



## Appendix A – Information Letter

July 3<sup>rd</sup>, 2007

### INVITATION TO PARTICIPATE IN RESEARCH

Supporting the Identities of Older Adults Deemed Cognitively Impaired: Challenges for Long Term Care

**Investigator:** Effie Galanis, M.S.W. candidate, McMaster School of Social Work

**Principal Investigator:** Dr. Jane Aronson  
Department of Social Work  
McMaster University  
Hamilton, Ontario, Canada  
(905) 525-9140 ext. 23783

#### **Purpose of the Study:**

With population aging and the increased incidence of cognitive impairment among older adults, we are facing new challenges in long-term care (LTC). It is particularly challenging to find ways of delivering care that preserve elderly residents' identities and senses of themselves – ways of ensuring that they do not get 'lost' or depersonalized in the routines of institutional life.

As a social worker, my practice experience has been with older adults in long-term care, community and palliative care settings. As a Masters student in a social work program, I have the opportunity to conduct my own research. I am interested in asking care workers employed in front line, long-term care positions – those most involved and knowledgeable about day-to-day care – how they go about their work in ways that personalize care and sustain identity. As well, I am interested in hearing about the organizational conditions that enable and restrict identity supporting care.

#### **Potential Participants:**

For the purpose of this study I am interested in personal support workers who have a minimum of 2 years experience in long-term care work.

#### **What will happen during the study?**

Participation in this research involves **an interview** with me that will last for approximately one hour, including questions about how you work with residents in ways that are personalized and supportive of their identities. For instance, I will ask participants to describe examples from their work of ways that they personalize and individualize care provided to cognitively impaired older adults and to identify the conditions that they believe

allow or prevent this work from occurring in their practice setting. Interviews will be scheduled to take place at a location convenient for you (e.g. at the university, a library, coffee shop) at an equally convenient time. With your permission, interviews will be audio-taped and transcribed so that I can have an accurate record of your comments and thoughts. Following completion of the interview, I may contact participants by phone in order to clarify information and comments made during the interview.

**Payment or Reimbursement:**

A \$20 honorarium will be awarded to participants in appreciation of their time and knowledge through their contributions to this research.

**Who will know what I said or did in the study?**

This research is **not** being conducted on behalf of, or for, your place of employment and you will remain anonymous. I will not disclose your participation in this research to your employer. I am accessing research participants from two separate facilities and, in reporting the study, will refer simply to ‘two LTC facilities in southern Ontario’ – further ensuring the anonymity of participants and the facilities that assisted me accessing participants.

Throughout the research process, every care will be taken to respect your privacy: no identifying information will appear in written reports generated, and all the information you provide will be kept in a locked filing cabinet in my home office. Following completion of the study, I will destroy all records of participation including consent forms, audio recorded interviews and interview transcripts.

Your employer has offered the use of work space to conduct interviews either during, before, or after your shift, if this is the most convenient option for you. In addition to the research honorarium, your employer has proposed that interviews completed during your work hours will still receive full pay for the length of the interview (1 hour). This option requires participants to make arrangements for coverage with their employer, and therefore, if you chose to be interviewed at this location during work hours, your anonymity cannot be assured as your employer will be aware of your participation in this research. Although complete anonymity is not possible under these circumstances, I will still maintain confidentiality of information shared and eliminate any identifying information from my report. Please be advised that interviews do not need to be conducted at your place of employment and can be scheduled for a more convenient and private location.

**What good things could happen if I participate?**

The primary benefit of this research is to the scholarly community through the increased understanding of the skills and conditions that facilitate identity supporting work with cognitively impaired older adults. Participants’ experiences and knowledge are valuable and will contribute to informing best practices for working with older adults deemed cognitively impaired.

**Will anything bad happen during the study?**

Participants will be asked to talk about the opportunities and constraints in their work with elderly residents and to reflect on what they are able to accomplish in their caring work. These topics will have personal and perhaps emotional significance for them, possibly

generating feelings ranging from a sense of satisfaction and optimism to frustration, disappointment or self-criticism. Should any participant become upset as they reflect on their work, I will check in to ensure that they wish to continue and, if indicated, suggest resources they may find supportive. In addition, participants may be making observations about their work or work place setting that, if generally known, could embarrass them. In order to alleviate this potential risk I propose that participants exercise caution in who they select to notify of their participation.

**What if I change my mind about participating in the study?**

Participation in this study is voluntary, and participants will maintain the right to withdraw participation in this research at any time without facing any consequences from the researcher or their employer. If participants do not want to answer some of the questions, they do not have to but can still participate in the study if they choose. In the event that you choose to withdraw participation, all information you have provided will be returned to you or destroyed.

**Study Debriefing:**

Participants will be provided with a summary of the research when it is completed and, if interested, invited to contact me for elaboration.

**Rights of Research Participants**

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

**McMaster Research Ethics Board Secretariat**  
**Telephone: 905-525-9140, ext. 23142**  
**c/o Office of Research Services**  
**E-mail: [ethicsoffice@mcmaster.ca](mailto:ethicsoffice@mcmaster.ca)**  
**McMaster University**

If you would like to participate and schedule an interview, or if you have any further questions regarding participation in this research, please contact me at [galanii@univmail.cis.mcmaster.ca](mailto:galanii@univmail.cis.mcmaster.ca) or (long distance) 416-579-4100, otherwise leave a (local) message with Darlene Savoy at 905-525-9140 ext. 24596 (please leave name, phone number and a convenient time to return your call).

Effie Galanis, B.S.W.

Principal Investigator & M.S.W. candidate, McMaster School of Social Work



## Appendix B – Recruitment Flyer

### **Supporting the Identities of Older Adults Deemed Cognitively Impaired: Challenges for Long-Term Care**

#### **AN INVITATION TO PARTICIPATE IN A RESEARCH PROJECT**

I am conducting some research on the work of health care aides and personal support workers in Long Term care facilities. The project is part of my master's program in the School of Social Work at McMaster University.

I am interested in asking workers employed in front line long-term care positions – **those most involved and knowledgeable about day-to-day care** – how they go about their work in ways that personalize residents' care and sustain their identities.

☞ ☞

#### **Who Can Participate?**

Are you a health care aide or a personal support worker employed in long-term care?

Do you have at least two years of experience?

Would you be interested in participating in my research?

☞ ☞

Participation in this research would involve an interview with me. It will last approximately one hour and be scheduled at a location convenient for you (e.g. coffee shop, public library).

This research is **not** being conducted on behalf of your employer. If you take part, you will remain anonymous and any information you provide will be treated as confidential.

**An honorarium of \$20 will be provided for your participation, in appreciation of your time and knowledge.**

☞ ☞

If you are interested in participating or would like more information about the project, please contact me, Effie Galanis, **by Friday, July 13th** at [galanii@univmail.cis.mcmaster.ca](mailto:galanii@univmail.cis.mcmaster.ca) or by phone at 416-579-4100.

\* Due to my thesis and program time constraints, please notify me regarding your interest to participate **by Friday, July 13<sup>th</sup>** in order to schedule an interview at your earliest convenience.

### Appendix C - Interview Guide

- 1) Can you briefly describe what is involved in the work that you do with residents in the long-term care facility?
- 2) A widely accepted goal in institutional LTC is to ensure that residents' senses of themselves – their identities and particularities – are supported. As you go about your work, can you think of specific ways that you attempt to support residents in that way? How you personalize your care? (probe for examples, specifics)
- 3) I am particularly interested in how the care of residents deemed cognitively impaired can be personalized and can support identity. Could you tell me about your work with residents in this group? Do you see differences in your approach (between residents with cog impairments and without)? (probe for examples, specifics)
- 4) Where did you learn how to offer care that's personalized in this way? Is this kind of care noticed or valued by others e.g. residents, families, co-workers, supervisors? (probe for specifics).
- 5) What makes your personalized care of residents easier or more difficult? (probe for challenges and supports – individual resident characteristics, own experience/skill, organizational issues e.g. time, conditions, support/ supervision).
- 6) What would enable you to do more work of this kind – personalized, attentive to residents' individuality?
- 7) I'm interested in knowing what a 'rewarding' or 'good' day at work would look like to you? Can you describe what such a day would be like?

## Appendix D – ‘Eden Alternative’ Principles

1. The three plagues of loneliness, helplessness and boredom account for the bulk of suffering among our Elders.
2. An Elder-centered community commits to creating a Human Habitat where life revolves around close and continuing contact with plants, animals and children. It is these relationships that provide the young and old alike with a pathway to a life worth living.
3. Loving companionship is the antidote to loneliness. Elders deserve easy access to human and animal companionship.
4. An Elder-centered community creates opportunity to give as well as receive care. This is the antidote to helplessness.
5. An Elder-centered community imbues daily life with variety and spontaneity by creating an environment in which unexpected and unpredictable interactions and happenings can take place. This is the antidote to boredom.
6. Meaningless activity corrodes the human spirit. The opportunity to do things that we find meaningful is essential to human health.
7. Medical treatment should be the servant of genuine human caring, never its master.
8. An Elder-centered community honors its Elders by de-emphasizing top-down bureaucratic authority, seeking instead to place the maximum possible decision-making authority into the hands of the Elders or into the hands of those closest to them.
9. Creating an Elder-centered community is a never-ending process. Human growth must never be separated from human life.
10. Wise leadership is the lifeblood of any struggle against the three plagues. For it, there can be no substitute.

Source: Eden Alternative. (2007). *The Eden Alternative*. Retrieved on August 11, 2007 from <http://www.edencan.com>.

## REFERENCES

- Action Pact, Inc. (2007). *Culture Change Now*. Retrieved on August 22, 2007 from <http://www.culturechangenow.com/#about>.
- Agich, G.J. (1995). Actual autonomy and long-term care decision making. In L.B. McCullough & N.L. Wilson (Eds.), *Long-Term Care Decisions: Ethical and Conceptual Dimensions* (pp. 113-136). London: The John Hopkins University Press.
- Ahmadi, K.S., Speedling, E.J., & Kuhn-Weissman, G. (1987). The newly hired hospital staff nurse's professionalism, satisfaction and alienation. *International Journal of Nursing Studies*, 24(2), 107-121.
- Alzheimer Society. (2007). *What is Alzheimer's disease?* Retrieved on August 9, 2007 from <http://www.alzheimer.ca/english/disease/whatisit-intro.htm>.
- American Psychiatric Association. (1994). *Diagnostic Criteria for DSM-IV*. Washington, D.C.: American Psychiatric Association.
- Armstrong, P., & Armstrong, H. (1999). *Women, Privatization and Health Care Reform: The Ontario Scan*. Toronto: National Network on Environments and Women's Health.
- Aronson, J. (2006). Silenced Complaints, Suppressed Expectations: The Cumulative Impacts of Home Care Rationing. *International Journal of Health Services*, 36(3), 535-556.

- Aronson, J., & Neysmith, S.M. (1996). "You're not just in there to do the work": Depersonalizing policies and the exploitation of home care workers' labor. *Gender & Society*, 10(1), 59-77.
- Aronson, J., & Sammon, S. (2000). Practice amid social service cuts and restructuring: Working with the contradictions of 'small victories'. *Canadian Social Work Review*, 17(2), 167-187.
- Baines, D. (2004). Seven kinds of work – only one paid: Raced, gendered and restructured work in social services. *Atlantis*, 28(2), 19-28.
- Basting, A.D. (2002). Looking back from loss: Views of the self in Alzheimer's disease. *Journal of Aging Studies*, 17, 87-99.
- Bowsher, J.E. (1990). Behavioural competency as a predictor of perceived control in nursing home elders. *Issues in Mental Health Nursing*, 11, 361-374.
- Brechin, A. (1998). What makes for good care? In A. Brechin, J. Walmsley, J. Katz & S. Peace (Eds.), *Care Matters: Concepts, Practices and Research in Health and Social Care* (pp. 170-187). London: Sage Publications.
- Brocklehurst, J., & Dickinson, E. (1996). Autonomy for elderly people in long-term care. *Age and Ageing*, 25, 329-332.
- Brodie, J. (1999). The politics of social policy in the twenty-first century. In D. Broad & W. Anthony (Eds.), *Citizens or Consumers? Social Policy in a Market Society* (pp. 37-46). Halifax, Nova Scotia: Fernwood Publishing.
- Burr, V. (1995). What is social constructionism? In V. Burr (Ed.), *An Introduction to Social Constructionism* (pp. 1-16). London: Routledge.

- Campbell, M., & Gregor, F. (2002). *Mapping Social Relations: A Primer in Doing Institutional Ethnography*. Aurora, Ontario: Garamond Press.
- Canadian Association of Social Workers. (2005). *Code of Ethics*. Ottawa, ON: Canadian Association of Social Workers.
- Canadian Association of Speech-Language Pathologists and Audiologists. (2000). *Adult Hearing Disorders – Fact Sheet*, Retrieved November 17, 2006, from <http://www.caslpa.ca/PDF/fact%20sheets/adult%20hearing%20disorders.pdf>.
- Canadian Study of Health and Aging Working Group. (1994). Canadian Study of Health and Aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150, 899-913.
- Checkland, D., & Siberfield, M. (1993). Competence and the three A's: Autonomy, authenticity, and aging. *Canadian Journal on Aging*, 12(4), 453-468.
- Clark, P.G. (1989). The philosophical foundation of empowerment. *Journal on Aging and Health*, 1(3), 267-285.
- Cohen-Mansfield, J., Parpura-Gill, A., & Golander, H. (2006). Utilization of self-identity roles for designing interventions for persons with dementia. *The Journals of Gerontology*, 61B(4), 202-212.
- DeVault, M.L., & McCoy, L. (2006). Institutional ethnography: Using interviews to investigate ruling relations. In D.E. Smith (Ed.), *Institutional Ethnography as Practice* (pp. 15-44). New York: Rowman & Littlefield Publishers, Inc.
- Diamond, T. (1992). *Making Gray Gold*. Chicago: The University of Chicago Press.

Eden Alternative. (2007). *The Eden Alternative*. Retrieved on August 11, 2007 from

<http://www.edencan.com/>.

Estes, C.L. (1991). The new political economy of aging: Introduction and critique. In M.

Minkler & C.L. Estes (Eds.), *Critical Perspectives on Aging: The Political and*

*Moral Economy of Growing Old* (pp. 19-36). Amityville, New York: Baywood

Publishing Company Inc.

Goffman, E. (1961). *Asylums: Essays on the Social Situation of Mental Patients and*

*Other Inmates*. Garden City, N.Y.: Doubleday.

Health Canada, Division of Aging and Seniors. (2002). *Canada's Aging Population*.

Canada: Minister of Public Works and Government Services Canada. Retrieved

on August 14, 2007 from

[http://www.hcsc.gc.ca/seniorsaines/pubs/fed\\_paper/pdfs/fedpager\\_e.pdf](http://www.hcsc.gc.ca/seniorsaines/pubs/fed_paper/pdfs/fedpager_e.pdf)

Heart and Stroke Foundation. (2002). *Statistics & Background Information-Stroke*

*Statistics*. Retrieved November 7, 2006, from

<http://ww2.heartandstroke.ca/Page.asp?PageID=33&ArticleID=1078&src=news&>

[From=SubCategory](http://ww2.heartandstroke.ca/Page.asp?PageID=33&ArticleID=1078&src=news&)

Heart and Stroke Foundation. (2006). *StokeLine: Support for Survivors and Caregivers*,

*Issue 3*. Retrieved November 17, 2006 from

[http://ww2.heartandstroke.bc.ca/images/English/BC\\_SL\\_Spring06.pdf](http://ww2.heartandstroke.bc.ca/images/English/BC_SL_Spring06.pdf)

Hendricks, J., & Hendricks, C.D. (1986). *Aging in Mass Society: Myths and Realities*, 3<sup>rd</sup>

*edition*. Toronto: Little, Brown and Company.

Hepworth, D.H., Rooney, R.H., Rooney, G.D., Strom-Gottfried, K., and Larsen, J.A.

(2006). *The Challenges of Social Work. Direct Social Work Practice: Theory and Skills*, 7<sup>th</sup> edition. Canada: Thomson Brooks/Cole.

Hiltz, D., & Szigeti, A. (2006). *A Guide to Consent and Capacity Law in Ontario*.

Markham, ON: Lexis Nexis Butterworths.

Hofland, B.F. (1994). When capacity fades and autonomy is constricted: A client-centered approach to residential care. *Generations*, 18(4): 31-36.

Holstein, M., & Cole, T.R. (1995). Long-term care: A historical reflection. In L.B.

McCullough & W.L. Wilson (Eds.), *Long-Term Care Decisions: Ethical and Conceptual Dimensions* (pp. 15-34). London: The John Hopkins University Press.

Jang, G. (1992). Autonomy of institutionalized elderly: Resident and staff perceptions.

*Canadian Journal on Aging*, 11(3), 249-261.

Johnson, J. (2002). Taking care of later life: A matter of justice? *British Journal of*

*Social Work*, 32(6), 739-750.

Kane, R.A., & Caplan, A.L. (1993). *Everyday Ethics: Resolving Dilemmas in Nursing*

*Home Life*. New York: Springer Publishing Co.

Kane, R.L., & West, J.C. (2005). *It shouldn't be this way: The failure of long-term care*.

Nashville: Vanderbilt University Press.

Knapman, C., & Waite, H. (1995). Dementia care: Time to ask new questions. *Social*

*Alternatives*, 14(2), 41-44.

- Lawler, J. (2000). The rise of managerialism in social work. In E. Harlow & J. Lawler (Eds.), *Management, Social Work and Change*. Hampshire, England: Ashgate Publishing Ltd.
- Lidz, C.W., Fischer, L., & Arnold, R.M. (1992). *The erosion of autonomy in long-term care*. New York: Oxford University Press.
- Lieberman, M.A., & Tobin, S.S. (1983). *The experience of old age: Stress, coping, and survival*. New York: Basic Books.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park: Sage.
- Lopez, S.H. (2006). Emotional labor and organized emotional care: Conceptualizing nursing home care work. *Work and Occupation*, 33(2), 133-160.
- Martin, J. (1992). *Cultures in Organizations*. New York: Oxford University Press.
- Mason, J. (1996). *Qualitative Researching*. London: Sage Publications.
- Mauthner, N., & Doucet, A. (1998). Reflections on a voice-centred relational method. In J. Ribbens & R. Edwards (Eds.), *Feminist Dilemmas in Qualitative Research* (chapter 8). London: Sage Ltd.
- Moye, J. (1996). Theoretical frameworks for competency in cognitively impaired elderly adults. *Journal of Aging Studies*, 10(1), 27-42.
- National Center on Accessibility. (2001). *An Eden Alternative: A Life Worth Living*. Retrieved on August 22, 2007 from <http://www.ncaonline.org/ncpad/eden.shtml>.
- Neuman, L. (1997). The meanings of methodology. In *Social Research Methods: Qualitative and Quantitative Approaches* (pp. 60-87). Boston: Allyn & Bacon.

- Neysmith, S.M. (1995). Feminist methodologies: A consideration of principles and practice for research in gerontology. *Canadian Journal on Aging*, 14(1), 100-118.
- Neysmith, S., & Aronson, J. (1996). Home care workers discuss their work: The skills required to “use your common sense”. *Journal of Aging Studies*, 10(1), 1-14.
- Novak, M., & Campbell, L. (2001). *Aging & Society: A Canadian Perspective*, 4<sup>th</sup> edition. Scarborough, ON: Nelson Thomas Learning.
- Ontario Health Coalition. (2007). Why is a minimum care standard so important? *Issues in Long-term Care facilities: Briefing Note*. Retrieved January 16, 2007, from <http://www.web.net/~ohc/LongTermCare/LTCBriefingNoteOnMinimumStandards1.pdf>
- Palmore, E. (1990). *Ageism: Negative and Positive*. New York: Springer Publishing Co.
- Palmore, E.B. (1992). Knowledge about aging: What we know and need to know. *The Gerontologist*, 32(2), 149-150.
- Paré, A. (2004). Texts and power: Toward a critical theory of language. In L. Davies & P. Leonard (Eds.), *Social Work in a Corporate Era: Practices of Power and Resistance* (pp. 76-90). Aldershot, Hants, England: Ashgate Publishing Ltd.
- Rawls, J. (1971). *A Theory of Justice*. Cambridge, Massachusetts: The Belknap Press of Harvard University Press.
- Redfoot, D.L. (2003). The changing consumer: The social context of culture change in long-term care. In A.S. Weiner & J.L. Ronch (Eds.), *Culture Change in Long-Term Care* (pp. 95-110). New York: The Haworth Social Work Practice Press.

- Ristock, J.L. (2002). Troubling tales: Telling stories, exposing language, raising questions. *No More Secrets: Violence in Lesbian Relationships* (page 27-45). New York: Routledge.
- Rodin, J. (1986). Aging and health: Effects of the sense of control. *Science*, 233, 1271-1276.
- Ross, M.M., Carswell, A., & Dalziel, W.B. (2002). Staff burnout in long-term care facilities. *Geriatrics Today: Journal of the Canadian Geriatrics Society*, 5, 132-135.
- Rovner, B.W., German, P.S., Burton, L.C., & Clark, R.D. (1996). A longitudinal study of participation in nursing home activity programs. *The American Journal of Geriatric Psychiatry*, 2(2), 169-174.
- Sabat, S.R., & Harre, R. (1992). Construction and deconstruction of self in Alzheimer's disease. *Ageing & Society*, 12, 443-461
- Setterlund, D., & Wilson, J. (1989). Social work with the elderly: Residential care as an example. *Australian Social Work*, 42(3), 31-39.
- Shuttlesworth, G.E., Rubin, A., & Duffy, M. (1982). Families versus institutions: Incongruent role expectations in the nursing home. *The Gerontologist*, 22(2), 200-208.
- Smith, D. (1974). The social construction of documentary reality. *Sociological Inquiry*, 44, 257-268.
- Smith, D.E. (1990). *Texts, Facts, and Femininity: Exploring the Relations of Ruling*. London: Routledge.

Statistics Canada. (1996). *Visible minority population by age, 1996 Census*. Retrieved on January 10, 2002 from

<http://www.statcan.ca:80/english/Pgdb/People/Population/demo41.htm>.

Tappen, R.M., Williams, C., Fishman, S., & Touhy, T. (1999). Persistence of self in advanced Alzheimer's disease. *Image – Journal of Nursing Scholarship*, 31, 121-125.

Tobin, S.S. (2003). The historical context of "humanistic" culture change in long-term care. In A.S. Weiner & J.L. Ronch (Eds.), *Culture Change in Long-Term Care* (pp. 53-64). New York: The Haworth Social Work Practice Press.

Tobin, S.S., & Lieberman, M.A. (1976). *Last Home for the Aged*. London: Jossey-Bass Publishers.

Townsend, P. (1981). The structured dependency of the elderly: A creation of social policy in the twentieth century. *Ageing and Society*, 1(6), 5-28.

Turcotte, M., & Schellenberg, G. (Eds.). (2007). *A Portrait of Seniors in Canada, 2006* (Catalogue no. 89-519-XIE). Ottawa: Minister of Industry, Statistics Canada. Retrieved on August 22, 2007 from

<http://www.statcan.ca/english/freepub/89-519-XIE/89-519-XIE2006001.pdf>

Vladeck, B.C. (2003). Unloving Care revisited: The persistence of culture. In A.S. Weiner & J.L. Ronch (Eds.), *Culture Change in Long-Term Care* (pp. 1-9). New York: The Haworth Social Work Practice Press.

Walker, A. (2005). Towards an intergenerational political economy of ageing. *Ageing and Society*, 25(6), 815-839.

- Wellin, C., & Jaffe, D.J. (2004). In search of “personal care”: Challenges to identity support in care for elders with cognitive illness. *Journal of Aging Studies*, 18, 275-295.
- Whalen, J.M. (1972). Social Welfare in New Brunswick, 1784-1900. *Acadiensis*, 54-64.
- Woods, B. (1994). Management of memory impairment in older people with dementia. *International Review of Psychiatry*, 26(2/3), 153-162.
- Yegidis, B.L., Weinbach, R.W., & Morrison-Rodriguez, B. (1999). *Research Methods for Social Workers*, 3<sup>rd</sup> edition. Toronto: Allyn & Bacon.
- Zarit, S.H, & Downs, M.G. (1999). State of the art for practice with dementia. *Generations*, 23(3), 6-9.