

DEMENTIA CARE AND ORGANIZATIONAL CULTURE:
CHALLENGES IN LONG TERM CARE

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TITLE: DEMENTIA CARE AND ORGANIZATIONAL CULTURE:
CHALLENGES IN LONG TERM CARE

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ABSTRACT

In the current climate of downsizing and cost cutting within the health care system in Ontario, the Long Term Care (LTC) sector is faced with the present and future challenge of providing care for a growing population of people afflicted with dementia. LTC facilities are generally regarded as a suitable location for people with dementia experiencing behavioural disturbances to live out the last years of their lives. Critics, advocates and researchers are concerned with the capacity of facilities to meet the complex care needs of this vulnerable population. Confronted by barriers such as staff shortages, increased workloads and acuity of resident care facilities are struggling. The purpose of this study was to explore what characterizes a LTC facility that allows the staff to receive and respond well to the care needs of their residents experiencing behavioural disturbances, to better understand the organizational culture and practices that distinguish them from facilities that are not as successful in their efforts to provide resident-centred care.

A small qualitative study of specialized geriatric outreach case managers working within a number of different LTC facilities was conducted using personal interviews to draw forward their experiences and observations. This group of professionals was uniquely positioned to witness the organizational cultures and practices within facilities associated with good and responsive care. Analysis of their accounts suggests that an organizational culture within a LTC facility that is able to create an environment that builds capacity among the staff to provide responsive care, was resident-centred, had an inclusive work culture, provided support and work flexibility was better able to be

responsive to the needs of residents with dementia experiencing behavioural disturbances. The findings also revealed the importance of not losing sight of the impact front-line staff can have on making changes and pushing back against the current social policy agenda and constraints in LTC.

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INTRODUCTION

Long term care (LTC) facilities are generally regarded as the most appropriate setting for the care of people affected by severe dementia to live out the last years of their lives. As well, they are the only facilities that provide a communal setting for people with dementia to reside (Gibson, Forbes & Conn, 2008). In the next 30 years, it is estimated that the demand for LTC beds will increase beyond the available resources: “Based on historical growth trends, the total number of long-term care beds in Canada is forecasted to grow from approximately 280,000 beds in 2008 to 690,000 in 2038. This leaves a projected shortfall of more than 157,000 beds in 2038” (Alzheimer Society of Canada, 2010, p.7). Over recent years a shift in social policy from public to private provisioning of health care services, coupled with federal and provincial governments failing to invest adequately in public infrastructure has produced large gaps between available resources and the demands of an aging population (Institute of Research on Public Policy, 2011).

The health care system is strained and ill equipped to meet the complex needs of this population; critics, advocates and researchers identify a number of specific and interrelated concerns about the LTC sector. Factors such as staff shortages, increased workloads and inflexible work schedules, increased acuity of resident care, decreased job satisfaction, increased injury and violence in the workplace are contributing to a growing concern regarding the quality of care received in LTC facilities (Armstrong and Daly, 2011 and Ontario Health Coalition, 2008). Care workers report feeling unprepared to provide appropriate care for residents with cognitive impairment and behavioural disturbances, “These residents have complex care needs that result in repeated reports of

inadequate training, inadequate staffing levels, improper placement and violence”

(Ontario Health Coalition 2008, p.8). Advocacy groups consistently endorse improved minimum standards for care and workers and are supported by best practice literature, but unfortunately there continues to be resistance from governments to implement these strategies.

However, there is variability within the LTC sector in that some facilities are able to offer more responsive resident-centred care. I was interested in examining the variability in quality of care as observed by specialized front-line care providers, case managers from a geriatric psychiatry outreach team working within LTC facilities. Through their experiences, I hoped to identify the organizational conditions that make possible good care for this growing and complex population. Case managers’ insights about good and promising practices that they see in the course of their work can, I anticipate, contribute to future discussions of policy and practice in the service of this often stigmatized population.

As a social worker, I have worked in various health care settings. Something that has become very apparent to me throughout the course of my work experience in health care, is the discrimination and stigmatization that people and families affected by dementia receive at all levels of the system. This vulnerable population is at the mercy of an unprepared health care system. At times requiring 24 hour supervision and care by numerous health care providers, these people require a sizeable commitment of resources from the health care system. Families are overwhelmed, frustrated and disillusioned by a health care system that often fails to provide adequate care in an appropriate setting.

There is system-wide tension at the boundary between the acute care hospital sector and the LTC sector in which this population gets caught. I am concerned about a health care system that lacks the resources to provide timely and appropriate care. People end up in hospitals taking up acute care beds because LTC facilities are no longer able to manage behaviours or in psychiatric facilities waiting months or even years for beds in LTC facilities that are reluctant to accept them, or in crisis in the community with inadequately supported families overwhelmed by stress and grief. Amid this broad problematic scenario however, some LTC facilities receive and respond well to the complex care needs of residents with dementia experiencing behavioural disturbances. For this thesis research, I was particularly interested in understanding the characteristics that enabled them to do so. To situate this, a review of several bodies of related literature follows.

LITERATURE REVIEW

Demographics and the Character of Dementia

In the constrained context of the health care system in Ontario, present and future capacity for responding to the needs of elderly people with dementia is a growing concern. It has become common knowledge that the population is aging. By 2041 it is estimated that 4 percent of Canadians, which is equivalent to 1.6 million people, will be 85 year or more (Institute for Research of Public Policy 2011). Given that aging is the predominant and unchangeable risk factor to developing dementia, the number of people that will receive a diagnosis is also predicted to increase. According to the Alzheimer Society of Canada, in 2008 103,000 new cases 65 years and older of dementia were diagnosed; that number is expected to be 257,800 by 2038. In 2008, 480,600 people in Canada had been diagnosed with dementia. The prevalence of dementia in 2008 was 480,600, equal to 1.5% of the population of Canada. That number will rise to 1,125,200, equal to 2.8% of the population by 2038. In economic terms, cost for care is estimated to reach \$153 billion by 2038, with a cumulative cost over the next 30 years of \$872 billion (Alzheimer Society of Canada, 2010). The numbers represent a challenge and obstacle to an already stressed and contested health care system. To illuminate the situation further, a brief description of the character of dementia is provided below.

Dementia refers to a class of progressive neurodegenerative diseases, of which Alzheimer's disease is the most common. Characteristics of the disease include progressive deterioration of cognition resulting in gradual decline of memory, judgment,

emotional instability, physical function and eventually the inability to care for ones self. Dementia not only impacts the individual afflicted but also their family and care providers (Alzheimer’s Society, 2010). This burden becomes particular pronounced when people experience behavioural and psychological disturbances, a common symptom of dementia and often the reason for institutionalization, “Difficult behaviours are relatively common challenges that can occur throughout the natural progression of dementia, but are particularly common in the mid to late stages of the disease” (Buhr and White 2007, p. E.101). Behavioural disturbances include a wide range of behaviours: wandering, pacing, increased agitation resulting in physical and verbal aggression, sleep disturbance, inappropriate sexual behaviours, and psychological disturbances such depression and psychosis (Buhr et al., 2007). Although not an inclusive list, these behaviours represent the challenges of providing person-centred care and the considerable distress created for the individual, families and care providers in the process. Given the prevalence, 60% to 80% of residents living in LTC facilities have some form of dementia (Ontario Health Coalition 2008), the care and management of these residents presents a significant challenge. For the purposes of this study, the focus will be on those residents with a diagnosis of dementia experiencing behavioural and psychological disturbances.

The LTC Policy Context

LTC facilities in Ontario are governed and funded by the Ministry of Health and Long-Term Care, “The most recently available figures show that in 2004 there were 70,850 long-term care beds in Ontario” (Banerjee 2009, p.45). The Long-Term Care Act was implemented July 1, 2007 (recently revised again July 1, 2010), replacing the previous Nursing Homes Act, Charitable Institutions Act and Homes for the Aged and Rest Homes Act (Ontario Ministry of Health and Long Term Care, 2010). The new act undertakes to improve the quality of care received by residents and enhance safety; an aim to be achieved by improving the protection of patients’ rights and providing resident-focused care. The Act includes inspection standards, operational provisions, criteria and polices that govern the functioning of facilities in the province of Ontario (Ontario Ministry of Health and Long-Term Care 2011). The Act also mandates that every facility establish a Residents’ Council, an independent body within the home to further advocate on the residents’ behalf (Banerjee 2009). The Community Care Access Centre (CCAC), the provincial agency that brokers community resources, is responsible for determining eligibility, managing wait lists and admission to LTC facilities. Briefly, LTC services are intended for those individuals 18 years and older, requiring assistance with activities of daily living and 24 hour nursing/care provider supervision (Ontario Ministry of Health and Long-Term Care 2011).

In Ontario, the majority of LTC beds are located in facilities owned by for-profit corporations, “More than half of these beds (38,057) are in for-profit homes, compared to

16,654 beds in municipal homes, 6,588 beds in non-profit homes and 8,841 beds in charitable homes” (Banerjee 2009, p.45). The residents represent a complex mix of chronic physical diseases and cognitive impairment, 76.6% of the residents are women and the average is 83 years (Banerjee 2009). Acuity of resident care within LTC facilities is increasing, “as a result of the redefinition of complex continuing care, shorter lengths of stay in hospitals, ageing, and the downloading of mental health patients form hospitals” (Ontario Health Coalition 2008, p.8). It is from this context of LTC, that advocates and researchers focus current debate and critique of the services and care provided and the work environment for staff. This will be discussed below.

Current Concerns and Conceptualizations of LTC

Critics, advocates, unions and researchers are concerned with the current state of the LTC sector, “Crushing workloads, stress, inadequate supports, lack of control, a punitive culture, rationing of supplies, and inadequate resources have contributed to conditions that are creating harm to residents, stress and undue financial burden families, and exacerbated staffing shortages across the sector” (Ontario Health Coalition 2008, p.4). These concerns are linked to poor employment conditions and, by implication, poor care for the residents of the LTC facilities. Often associated with profit-motive and structural critique of increased privatization and growth of the LTC market, these issues have been identified in the literature as negatively impacting on resident care. The Institute for Research on Public Policy (2011) explored whether the type of ownership of a facility impacts on resident care, concluded that for-profit facilities are more likely to provide inferior care, “the evidence suggests that, as a group, such facilities are less likely

to provide good care than nonprofit or public facilities” (Institution for Research on Public Policy 2011, p.34). The Ontario Health Coalition (2008) contends that by virtue of their intent to be profitable and by maneuvering certain envelopes of government funding and private fees from residents, the for-profit industry does not serve the public interest by providing affordable and accessible care (Ontario Health Coalition, 2008). Not for-profit facilities tend to provide more hours of direct patient care (Ontario Health Coalition, 2008) and to resort less to use of physical restraints (Institution for Research on Public Policy, 2011). Given that the majority of LTC beds in Ontario are found in for-profit facilities (Banerjee 2009), this presents concerns regarding the impact it has on the organizational structures of facilities. Staffing level is one such area that has been identified that could explain the differences between for-profit and not for-profit ownership (Institution for Research on Public Policy, 2011).

Consistently, staffing shortages are reported to be the most significant issue for workers. Staff report working short-staffed on a regular basis resulting in increased workloads and stress, “Inadequacies in formal staffing levels are exacerbated by a failure to replace absent staff members” (OHA 2008, p.12). When asked, staff reported, as a daily occurrence being unable, because of time constraints, to complete the required tasks (Ontario Health Coalition, 2008). Armstrong and Daly (2004), in *There are Not Enough Hands: Conditions in Ontario’s Long-Term Care Facilities*, surveyed workers in LTC to explore the conditions within the system that are undermining workers’ health and capacity to provide care. They found shortages in all areas of the workforce within LTC, impeding the cohesion of teams, staff turnover, and negatively impacting morale and job

satisfaction. Researchers found workers were most concerned and the greatest stress was created by the gap between the care they want to provide and what is actually happening, “Nearly 60 percent of the time workers don’t have the time to provide emotional support (59.8%), while walking and exercise of residents is not done more than half the time (52.3%)” (OHC 2008 p. 12). Along with shortages, the workforce in the LTC sector is aging which has implications for future development (Armstrong and Daly 2004 and OHC 2008). Another factor related to staff shortages was concern at high rates of injury and violence with LTC facilities.

In May 2008, the Ontario Health Coalition completed a report, *Violence, Insufficient Care, and Downloading of Heavy Care Patients: An evaluation of increasing need and inadequate standards in Ontario’s nursing homes*. The document highlights many concerns regarding high rates of injury and violence for both staff and residents, occurring at all points of interaction between staff and resident and, resident and resident. Care workers report feeling ill-equipped to provide appropriate care for residents with cognitive impairment and behavioural disturbances, “These residents have complex care needs that result in repeated reports of inadequate training, inadequate staffing levels, improper placement and violence” (Ontario Health Coalition 2008, p.8). This combination of staff shortages, increased workload, increased acuity and lack of adequate training has created a situation within the LTC sector that can be dangerous for residents and staff.

The practices of LTC facilities are shaped by these material factors of critics’ concern (financing, employment conditions, and physical facilities) and also by values,

philosophies, organizational practices and commitments. Within LTC facilities, it is this organizational culture that also impacts the staff, the care provided by staff and support received from management (Cohen-Mansfield and Jensen, 2008). The organizational culture is an integral part of the living and working environment of LTC facilities. This discussion follows.

The Cultures of LTC Facilities

Research into the culture of LTC facilities and the impact it has on residents and staff has been approached from various perspectives. The culture of an organization is influenced by the beliefs and attitudes shared by the members, as well as structures and practices that exist. A transition is occurring within the sector, in an effort to improve the quality of care, away from the medical model of care toward a more resident-centred model with emphasis given to the utilization of nonpharmacological approaches to care for residents experiencing behavioural disturbances (Cohen-Mansfield and Jensen 2008; Long Foley, Sudha, Sloane and Gold 2003). The literature documents a movement within the LTC sector toward a change in philosophy, a shift to deinstitutionalize the approach to care: "... culture change is a reaction to the oppressive, regimented life of traditional institutional environments entrenched in the biomedical model, which are organized to facilitate the efficient delivery of care while treating elders primarily as clinical entities and downplaying psychosocial and spiritual needs as well as overall quality of life" (Miller, Booth and Mor 2008, p. 456). Three themes characterizing a shift in culture toward much needed redevelopment with the LTC sector will be

discussed: care philosophy that is resident-centred, socialization of staff to a culture of teamwork and education for staff.

Miller, Booth and Mor (2008) surveyed experts in the field of LTC to explore the ideal attributes required for an organizational culture that will enable staff and managers to meet the increasing needs of an aging population and revitalize an under-achieving system. Two attributes with regard to culture are noted to be of particular interest – that it is person-centered and professionally rewarding. Person-centred refers to a culture that recognizes and supports the individual needs of people, a key concept when considering the changing care needs of residents with behavioural disturbances (Miller et al. 2008). Professionally rewarding refers to a culture that creates a positive work environment for staff, “we need a prepared workforce, trained and competent, that understands gerontological and geriatric principles. Everyone that touches the long-term care system should understand what it means to touch frail elderly people” (Miller et al. 2008, p.457). Compared to the current situation in Ontario of staffing shortages compromising quality care and poor morale among workers, the attributes identified represent a stark contrast and a goal to aspire to within the sector.

Scott-Cawiezell (2005) conceptualized a model to build organizational capacity, incorporating essential elements needed to improve the quality of care and sustain meaningful change. Culture is identified as playing a role: “A culture that values teamwork and risk taking for innovation is essential for high-performing teams to develop and produce sustainable improvement” (Scott-Cawiezell 2005, p204). Potential improvements identified with the model include staff retention, positive staff perception

of management and, improved communication and teamwork with the facility.

Meaningful and effective communication is another element identified to improve staff relationships and increase staff involvement in decision making (Scott-Cawiezell 2005).

Leadership that focuses on teamwork and communication, and management infrastructures that support quality improvement and the ability to build capacity are also recognized elements within an organizational structure required to create and sustain change (Scott-Cawiezell 2005).

Further to Scott-Cawiezell's (2005) model, Tyler and Parker (2011) compared LTC facilities with high and low levels of teamwork. They found staff working in facilities with high level teamwork have positive attitudes toward co-workers on other teams or units, extend that positive attitude to co-workers, were less likely to blame problems on other teams and less anxious to work on other teams. Facilities with high level teamwork were found to have managers that model positive attitude and behaviours: "... modeling was formalized in the training programmes found in high-teamwork facilities through the use of mentors. Essentially, new employees were socialized into the facility by working with a mentor" (Tyler and Parker 2011, p. 45). In comparison, in cultures with low level teamwork, both managers and workers spoke negatively about co-workers, reported that their units were busier with higher acuity resident care and held the other units responsible for the problems within the facility (Tyler and Parker 2011). Tyler and Parker (2011) conclude that to create and sustain cultural change at all levels of the organizational structure, all members of the staff, including management must be involved. Socializing staff to be effective team members within a person-centre culture

of care is a feature of the change movement advocating for improved quality of care with the LTC sector.

With regard to management, Barry, Brannon and Mor (2005) studied the relationship between management practices used to empower nurses' aides and the impact on residential care outcomes. Although unable to definitely conclude that such empowerment impacts on quality of care, the researchers did highlight its importance for future research in support of the current culture change movement. Leadership within the LTC sector has begun to recognize the important role played by nurses' aides within the overall effectiveness of facilities. It represents a shift in managerial structure toward a more participatory model involving the input of both staff and residents (Barry et al. 2005). This study lends support to Scott-Cawiezell (2005) and Tyler and Parker (2011) and the role of teamwork within a facility and moving away from the hierarchical management models.

Authors van Beek and Gerritsen (2010) surveyed nursing staff working in eleven Dutch nursing homes using a questionnaire and observation methods to study the relationship between organizational culture and the quality of care within the facilities. Quality of care was measured by the perception of nursing staff participating in the study and that of outside observers involved in the study. Researchers found differences in the culture of the facilities. Briefly, clan cultures characterized by shared values and goals focused on the internal functioning and participations of the members provided higher quality care both from the nursing staff surveyed and the outside observers. Market culture, differentiated by a for-profit focus and hierarchical in management structure, was

negatively associated with quality of care (van Beek and Gerritsen 2010). The results of this study lend support to the growing concerns related to the increase in privatization/for-profit of the LTC sector, and also highlight the benefits of a culture that is care-focused.

Touching on the role of education within the LTC sector, Hughes, Bagley, Reilly, Burns and Challis (2008), surveyed a large number of care staff employed in facilities in England using questionnaires and telephone interviews. In the context of increasing complexity and diversity of the population living in LTC facilities and recognizing the inadequacies of education provided for staff, the researchers examined factors that influenced the confidence and knowledge of staff caring for residents diagnosed with dementia (Hughes et al. 2008). The findings support, despite the current low levels of training provided with regard to the mental health needs of residents, the idea that training does impact on the felt confidence of staff. The researchers draw attention to the potential linkage of appropriate training and quality of care, suggesting increased training results in increased confidence of staff and improved quality of care (Hughes et al. 2008). How to put the findings into practice within an organizational structure is the question: “The challenge for managers of care homes is to identify and utilize the training opportunities for care staff along with providing a culture which values learning designed to enhance competence and confidence in the care of older people with dementia” (Hughes et al. 2008, p.236). A culture that identifies education for front-line staff as a priority creates opportunities to enhance quality of care through the expanded knowledge and confidence of the workers.

Complexities of Caring for Residents with Behavioural Disturbances

The features identified above characterized a shift in the organizational culture of the LTC sector in general terms. However, more specifically, the complexities of caring for people with dementia experiencing behavioural disturbances add additional challenges for the staff and managers of LTC facilities. Analyses that link individual workers' experiences and stress to organizational cultures are especially helpful. They shift the focus to the conditions created to support, or not support, caring relations, good care and supported employment. The nature and perception of challenging behaviours, the emotionally difficult work and stress are impacted by the conditions within LTC facilities. The literature provides some insight into this issue and this is discussed below.

A comparative study of nurses working in special care units (SCU) and traditional units (TU) revealed that interpretation of resident behaviour was influenced by the perceived intent to harm. Despite the higher exposure to disruptive behaviours, SCU nurses reported less distress than TU nurses, "The two groups of caregivers differed in their perception of intent to harm, with SCU staff more likely to attribute behaviours to a disease process" (Middleton, Stewart and Richardson 1999, p.18). Long Foley, Sudha, Sloane and Gold (2003) investigated staff perception of successful and unsuccessful management of residents with severe behavioural disturbances living in a dementia care unit. Researchers identified five factors perceived by staff to be most influential in their success or failure with a resident. More importantly, the staff experienced a sense of

helplessness when they were unsuccessful in caring for a resident with difficult behaviours: “Such helplessness must be addressed head on, in order to maintain unit morale and to achieve optimal resident management” (Long Foley et al. 2003, p.122). This lends support to Cohen-Mansfield and Jensen’s (2008) finding regarding physician perception of improved care for staff; physicians identified the most feasible strategy to improve care within LTC facilities is for managers to provide support for staff.

Kovach, Kelber, Simpson and Wells (2006) using Consequences of Need-Driven, Dementia-Compromised Behaviour (C-NDB) theory, investigated nursing responses to residents experiencing behavioural disturbances. In C-NDB theory, behaviour is understood as the result of unmet needs, when needs are unmet or misinterpreted it can lead to an escalation of behaviour or completely new behaviours. These behaviours have the potential to spiral out of control, negatively impacting the staff, resident and environment (Kovach et. all, 2006). This C-NDB theory focuses on the needs of the resident, and recognizes that to have success in meeting the residents’ needs, the nurse must understand that their response, or lack of response, can impact on behaviours. The purpose of this study was to examine the predictability of recurring behaviours based on variations in nursing intervention. The researchers were exploring more than perception, they were interested in the nurses’ actual response to behaviours, whether behaviours are predictable based on nursing intervention. This idea of predictability is extremely useful when conceptualizing a culture of care within a facility. Knowledge of predictability may decrease stress within the environment for staff and residents and is beneficial information to have for future development.

The literature reports consistently that front-line staff in LTC facilities providing care for residents with behavioural disturbances experience high rates of stress, staff turnover, burnout, emotional and physical abuse (Cohen-Mansfield and Jensen 2008; Long Foley, Sudha, Sloane and Gold, 2003; Kovach, Kelber, Simpson and Wells 2006; Lopez 2006; Middleton, Stewart and Richardson, 1999). Kovach et al. (2006) found that the basic fundamental nursing practice of assessment prior to treatment was not being completed when providing care for residents with disruptive behaviour.

Brazil, Kassalainen, Ploeg and Marshal, (2010) studied aspects of emotional care work, specifically from the perspective of community based health care workers providing palliative care. Researchers used a critical incident approach to examine the occurrence of “moral distress”, defined as: “...feelings and experiences which result from a moral conflict where one has a sense of the correct action to take but constraints prevent implementation of the act” (Brazil et al. 2010, p.1687). Moral distress is known to lead to increased levels of stress and burnout among staff and poor care. How systems are organized and the support or lack of support given to their staff during the process can lead to moral distress (Brazil et al. 2010). The Ontario Health Coalition (2008) highlights many incidents reported by staff that have not had the resources to provide adequate care and the emotional stress it creates: “Care workers are angry, or they end up in tears, when describing their feelings of guilt and inadequacy for providing less care than they know residents need” (Ontario Health Coalition 2008, p.7). Further studies investigating the occurrence of moral distress among staff in LTC facilities would be beneficial in better understanding the association between organizational culture and emotional stress.

Lopez (2006) offers an alternative strategy for managing the emotional stress associated with care provision in LTC facilities. Drawing from Hochschild's original theory of emotional labour, Lopez (2006) developed the concept of "Organized Emotion Care" as an alternative to conceptualizing the emotional aspects of care work. Directed at administrators and managers of LTC facilities, the concept focuses on the opportunity to create space within the structures and practices of the facility to manage emotional stress, "Organizational emotional care does not prescribe feeling states or display rules but rather consists of organizational attempts to create hospitable conditions for the development of caring relationships between service providers and recipients" (Lopez 2006, p.137). Rather than scripted interactions with residents or no interaction, staff are encouraged and afforded the time within the routine of their daily work to engage with and develop meaningful relationships with residents. This creates a culture of support for staff and residents to cope with the stresses associated with life in a LTC facility.

In order to explore the organizational conditions and cultural characteristics of LTC facilities providing responsive care to residents with dementia, a small qualitative study was undertaken as described in the methodology section.

METHODOLOGY

The purpose of this study was to explore the characteristics of long term care (LTC) facilities pertaining to how these organizations receive, respond, and react to the complex care needs of the residents with dementia who experience behavioural disturbances. The goal was to better understand the organizational culture and practices associated with positive responses within LTC facilities related to the needs of this population. Methodologically, this study drew on the elements of critical theory, specifically, the process of critical reflection and how the structures of power and dominance within the organizational structures of the LTC facilities relate to and connect with the care of this population: “In general, critical social science defines social science as a critical process of inquiry that goes beyond surface illusions to uncover the real structures in the material world in order to help people change conditions and build a better world for themselves”(Kreuger and Neuman, 2006, p.83). In order to delve into the organizational conditions and practices associated with good care, as witnessed by a key group of service providers, a qualitative study was undertaken, “Qualitative research aims to produce rounded and contextual understandings on the basis of rich, nuanced and detailed data” (Mason, 2002, p. 3). Specifically, the study was designed to draw forward the untapped knowledge and perceptions of a small sample size of geriatric mental health outreach team case managers.

Sample

A theoretical sample of specialized case managers was selected because of their relevant position within LTC facilities, “theoretical sampling means selecting groups or categories to study on the basis of their relevance to your research questions, your theoretical position and analytical framework, your analytical practice, and most importantly the argument of explanation that you are developing” (Mason 2002, p.124). This group of seasoned professionals work at the boundaries between acute, long-term and community care sectors and are uniquely positioned to observe the quality and conditions of care. Drawing on the experiences and observations of these providers working within LTC facilities, I hoped to gain insight into the organizational culture and the impact it has on the ability of staff to successfully provide responsive care to the residents.

The sample was recruited from a regional geriatric mental health outreach program that provides specialized case management services to older adults with complex mental health needs, behavioural disturbances and mental health problems associated with cognitive impairment and severe mental health illness developed later in life. The program is funded by the Ministry of Health and Long Term Care (MOHLTC), and is part of a regional mental health program and affiliated with a major university.

As a social worker employed by the same regional mental health program, my insider position and knowledge of the system was advantageous when deciding how and where to find a sample (LaSala, 2003). Conversely, this location also posed an ethical

risk. Participants may have been concerned about a breach of privacy or confidentiality or felt obligated to take part in this study. Care was taken to ensure recruitment of participants was conducted in a way that minimized possible feelings of coercion. I worked with the manager of the program, who distributed information letters (Appendix B) to the case managers during a routine staff meeting. Interested participants were invited to contact me through email or direct phone contact for further information. Recruitment began with one outreach team and if the response had been low, I would have moved to another team, but this turned out to be unnecessary, as five members of the first team came forward to participate. Participants were assured of their privacy and confidentiality throughout the research process.

Throughout the study, I was attentive to the impact that my role played in the research process. As a social worker who has recently worked in the field of geriatric psychiatry, I cannot be completely neutral or detached because I come to the process with previous experience and knowledge, “It is better to try to understand the complexities of the interaction, and to try to develop a sense of how context and situation work in interview interactions, than to pretend that key dimensions can be controlled for” (Mason 2002, p.65). Therefore, it was important for me to be vigilant and reflective of my actions, open to the examination and perhaps the unexpected that may occur during the research process (Mason, 2002).

The sample of five case managers was all female, white and ranged in age from approximately 40 to 60 years of age. Three had nursing backgrounds and two were occupational therapists. All were experienced in the field of mental health with an

expertise in geriatric psychiatry and behavioural disturbances associated with cognitive impairment. Four of them had been employed with the program for more than 5 years, and one case manager for 1 ½ years.

Data Collection and Analysis

To prevent any unnecessary inconvenience, the manager offered a private office space and all participants chose to be interviewed at the outreach program office. At a mutually agreed upon time, face to face individual interviews were conducted with participants, each lasting approximately one hour. With permission from the participants, all the interviews were audio recorded; this was done to accurately capture all the information that was shared. Prior to each interview, participants were provided with an information letter and consent form (Appendix B). The purpose, goals and potential risks of the study were clearly outlined and understood and written consent was obtained. Participants were reminded that they had the option to withdraw at any time from the study without any negative consequences. A signed copy of the consent form was given to each participant.

A semi structured interview format and interview guide (Appendix A) was used to elicit conversation and explore subject matter, “You will want to take cues from the ongoing dialogue with your interviewees about what to ask them next, rather than to go into the interaction entirely pre-scripted” (Mason 2002, p.64). This approach allowed the conversation to be flexible and change direction when something of particular relevance was mentioned by the interviewee that I wished to pursue. Questions were designed to explore the contextual and situational experiences of the participants working within

LTC; they were asked to reflect on successful and unsuccessful interventions with residents and staff, and to identify practices, barriers, organizational structures and how they impact on the care received by residents with behavioural disturbances.

During the interviewing process, I was very conscious of my position as a social worker who has worked in similar circumstances as the participants, and the bearing it may have had on my interpretations of their responses. Having an insider perspective has both advantages and disadvantages. On the positive side, the insider has a shared understanding of the participants' world and can use that knowledge to elicit in depth discussion. The disadvantage is that familiarity has the potential to create an insider bias that may cause the interviewer to assume the meaning without asking clarification or miss nuances within the participants' descriptions (LaSala, 2003), "Insider investigators might fail to adequately explore certain respondent perceptions because they take for granted that they understand how their informants view common cultural phenomena" (LaSala 2003, p19). While the interviews were being conducted, I was attentive and made a conscious effort to not assume the meaning and sought out clarification from the participants.

The audio tapes were transcribed into a written document by an independent transcriber. Once the audio recorded data was transcribed, downloaded and saved electronically, the data were deleted from the audio tapes. The transcripts were then read several times, searching for developing patterns and themes in the descriptions provided by the case managers:

In general, data analysis means a search for patterns in data-recurrent behaviours, or objects, or a body of knowledge. Once a pattern is identified, it is interpreted in terms of a social theory or the setting in which it occurred. The qualitative researcher moves from the description of a historical event or social setting to a more general interpretation of its meaning (Kreuger & Neuman, 2006, p.442).

The small sample of experience in which this study is based has the potential, like all qualitative work, to shed light conceptually on some of the dynamics and processes at play in LTC facilities. Given the particularity of the sample and its location in a particular region and province, the transferability of the results has of course, some limitations.

Findings

Participants entered the world of Long Term Care (LTC) in response to requests from facilities for consultation regarding a resident's care. As noted earlier, it can be challenging to respond effectively to the needs of residents experiencing behavioural disturbances resulting from dementia. In the current context of health care and LTC, they are often seen as burdensome: to LTC facilities without sufficient capacity or commitment to their care and to the acute hospital sector to which they are transferred if LTC facilities are unable to meet their needs. Although referrals are sent to the outreach team on a case by case basis, the accounts of this study's participants indicate that they have a wider developmental aspiration to enhance LTC facilities' ongoing ability to sustain good care for this vulnerable population. Their description of some elements of this capacity-building work are described first below, followed by their identification of some of the key themes that, in their experience and judgment, characterized responsive and unresponsive LTC culture: organizational features that supported building capacity for responsive care and organizational features that compromised it.

Case Managers' Entry Points: Building Capacity for Responsive Care

Case managers drew on examples and observations made from their particular positioning between LTC administration and everyday front line care, and their unique entry into facilities as consultants, clinicians and educators. This entry point into the LTC facilities affords them an opportunity to observe many different situations involving staff, residents and administration and to acquire insight into how organizations are able

to be responsive to the needs of residents suffering with behavioural disturbances and how they develop the capacity to do so successfully. One such insight identified by case managers as having an impact on responsive care, was the facilities' ability to successfully build capacity within the organization. More specifically, it was desirable to have the capacity to enhance staff's ability. Their accounts of successful capacity building and intervention involved staff with good problem solving and assessment skills and the ability to work effectively in a team. The goal of these interventions was that the facilities incorporated those skills and used them when responding to the ongoing and future needs of their residents.

For example, one case manager described a situation at a facility where, despite the final result being hospitalization for the resident, she perceived that good care had been provided, reflecting positive capacity in the facility as the staff had come together as a team to manage the resident's care:

So the success of it was that the staff were able to document and observe and respond and they really tried to use non pharmacological interventions at the facility, they used recreation staff a great deal. To me it was successful in that his needs were being met.

Another observed the evolution she had witnessed in a facility with which she had worked over time:

When I look at it now, a number of years later...this facility is much better...at looking at...assessing the risk and learning from their experiences or calling and saying...this is what is happening and we don't want to be sending them just to

the hospital, to ER because we know that's not necessarily going to be the most helpful...so what can we do?

In this particular account regarding building capacity, the case manager highlights the problem solving and assessment skills needed to make appropriate referrals to the outreach team. Teamwork is also mentioned:

And the facilities that do time it right...are more responsive in working with our team...when we do a risk screen, they're able to...they're not reactionary so much as they've tried these things...they're really trying to work in partnership and consultation.

The participants in this study believed it was part of their role as case managers working in LTC, to assist staff with this process of building capacity. Integrating this concept into their approach when working with staff, their commitment to improving skills was discernible in their accounts of their practice. One case manager summarized her goals:

You want people to focus on people, to be able to identify their learning objectives. You want people to learn how to manage themselves. You want people to...learn...know to develop insight into their own practice of how they are impacting on the patient and on their colleagues.

Another participant noted the importance of building relationships and developing a rapport with the wide range of care providers working in facilities. She reported fostering a feeling of equality and camaraderie with her colleagues at one facility, something she perceived to be beneficial:

Certainly when I was there, really feeling like I had a good relationship with both the staff and also with the nurses...getting input from everyone in terms of what was going on and staff feeling comfortable, even the PSWs...stopping me in the hall and saying, this is what's happening with so and so...that is good communication.

It is through this collaboration that case managers have been successful in engaging with LTC staff, creating opportunities for the development and transfer of skills. When this process is allowed to flow through the organizational structure and capacity can develop, case managers have noted a tendency among those facilities to have effective interventions with residents experiencing challenging behaviours:

You're skill building for them, so they may have another individual who presents similarly, where they don't need to refer to us because they'll say, well this worked with Mr. So and So, so we'll try that here.

Although the case managers recognized their roles as educators, they also noted that the ultimate responsibility for good care and the creation of an environment where building capacity is a priority lay with the facilities themselves. As one pointed out, the outreach team cannot possibly see every resident in a facility, facilities must appreciate this and they "...need to build that capacity within their own organization".

Participants described facility staff's perception of their own ability or skill level as playing a key role in organizational capacity building. For instance, one case manager elaborated this point in the context of making referrals to the outreach team. She noted that staff who have confidence in their abilities tend to take the initiative to problem solve

before referring to the outreach team for assistance, while staff with a lesser perception of their abilities tend to call for outside support. Staff lacked the confidence to proceed independently:

I think...the ones that have success in managing challenging care situations almost feel skilled so that they wait longer...Whereas some of the others who have a lower threshold...all the flags go up and they call for help earlier, almost before they try things internally themselves because they don't necessarily see themselves as being able or it's not within them, its external. Help has to come.

In the next section, the organizational features associated with such “success” are explored.

Organizational Factors Associated with Responsive and “Successful” Care:

In the interviews, I asked case managers to reflect on what distinguished facilities “that have success in managing challenging care situations” from those that do not. One participant articulated the organizational features associated with success in caring well for the residents experiencing behavioural disturbances in these terms:

They just seem to have a great pride in their quality of work. Like...this culture of...people, this is someone’s home now, we’re here to provide that care...it’s an intangible thing, it’s hard...to put your finger on...You can feel it when you’re there...and it’s everybody, the rec staff, it’s the cleaning lady, it’s the fellow that pushes the snack cart...they just have this sense of...what they’re doing is meaningful and helpful and they take pride in their work.

Layered in her textured observation were three elements that threaded through and were amplified in all the participants’ analyses of what characterized a facility with the capacity to meet the needs of residents: being resident centred, inclusive work culture and a culture of support and flexibility. These three elements are taken up and explored below.

Being Resident Centred: “It’s their home”

The observation in the words of the case manager quoted above that a LTC facility ‘is someone’s home’ had a powerful connotation. It implies a commitment to personalized care, to being attuned to each resident as a unique individual and to their belonging in the facility. To successfully meet the needs of residents living in LTC as if

it were their home, the care provided in facilities should include these attributes. Case managers' accounts indicated that when staff were able to empathize with residents experiencing difficulty, they were more successful at providing personalized care. The ability to empathize with another person's suffering seems to be a critical quality for an employee of a LTC facility. This case manager's account of a facility suggests the positive outcome empathy has with regard to care:

So I think that...with that facility, I think often you're looking at more positive results because there is...a real difference in terms of how they look at the clients and really...that understanding...an empathy comes across. When you speak to the staff there's an empathy for the client.

Appropriate education for staff was identified by case managers as playing a role in fostering empathy and insight into why residents may react or behave in certain ways. One case manager reflected on the importance of this insight noting that residents' sometimes challenging behaviours are understood not as motivated or intentional but rather as a symptom of their illness: "...this feeling, that...it's awful for us having to deal with this person but it's awful for that person as well." She reflected on an incident that highlighted the role empathy and education play in this crucial distinction:

So that was very impressive, in there was even some carry over in that at a later date another client actually hurt one of the staff in the night and the staff did not have an emotional reaction, in fact they followed through with a similar process so there was actually some learning.

Education allows staff to develop an understanding of the disease process and insight into the effects it has on the resident's emotions and behaviours. This combination of education and empathy was noted by case managers to be influential in the development of a resident-centred culture.

Another case manager reflected on the importance of staff taking a holistic approach to care. The facility's knowledge of a resident's personal history creates opportunities for the resident and staff to develop some degree of rapport and lessen the likelihood of staff perceiving residents as merely jobs to be completed. She expressed frustration at the absence of such knowledge in some facilities and its implications for care:

I'm amazed at how many...of the places that I go into...know nothing about this person's personal history and that's such an easy thing to be able to acquire and it can really give you a sense of that person as person...rather than...just someone who needs me to be doing all this personal care.

The ability to empathize and see the resident as a whole person to be cared for with dignity and respect was identified as essential to creating a resident-centred culture of care. It allowed staff to put the resident into a relatable social context; for example this man is a grandfather with grandchildren who had a career and a favourite sports team. The care provided is simply not just a task performed on an object but a personalized activity as noted. This issue will be explored later.

While case managers firmly underscored the significance of a resident-centred culture for residents, they also noted its complexity and potential challenges for staff. For

instance one case manager highlighted the importance of realistically acknowledging the possible stressors associated with resident-centred work:

I think that...acknowledging those feelings...looking at trying to help them see where you make a difference...because sometimes if you just sit there and think about it...overall it can feel completely overwhelming and disheartening. So how do you...maintain that hope...and feeling that you're making a difference? Where do you find those simple pleasures throughout the day...where you have made a difference.

She poses an important question, how does a care provider achieve job satisfaction? Acknowledgement and support certainly are two elements that have been recognized by the case managers as beneficial in establishing a culture that is supportive of staff in their efforts to be resident-centred. The literature supports the case managers' observations, "A nursing home that creates a culture that supports open communication and relationships, based on trust, respect, and leadership, ensures that staff members have the environment and resources to make and sustain improvement" (Scott-Cawiezell 2005, p.206). This last participant's observation also suggested, as did others, the importance of facility staff's morale and positive engagement in their work. This will be explored in the next section.

Inclusive Work Culture: "It's everyone"

Looking further into the organizational character of facilities that can meet the needs of their residents, a strong sense of teamwork and inclusion was identified by case managers to be a valuable feature. Referring back to the case manager's description of a

facility where a positive culture exists (p. 30), her response was “...it’s everybody”. In other words, effective teams are inclusive of everyone that is affiliated with the resident living in the facility from the Director of Care (DOC), to the family physician, housekeeping staff, all front-line care providers, the resident’s family, dietary staff and so on. One case manager recalled a consultation over a resident’s care: “So in this case the DOC called the maintenance person, he was there in no time at all, checking out, talking about, what he could do to help out” toward a common resident-focused goal. This shows inclusivity and a positive creation of culture. Scott-Cawiezell (2005) states that “culture is one of the elements that must be considered for nursing homes to support their high performing teams’ ability to make and sustain improvement”(p. 203).

According to participants, an inclusive work culture allows all staff to utilize their skills in a meaningful way to meet the challenges presented to them. One case manager reflected on the role of the personal support worker (PSW) in LTC. She believes that PSWs know residents best, they work directly with them every day and as such their input is invaluable. This case manager reflected on her practice of incorporating the knowledge of the PSWs by involving them in strategizing sessions with the team:

I think there’s more likely...changes if you do in-services and allow them to help come up with the strategies, then they feel they’re part of the process...it’s certainly more effective.

Being part of the process demonstrated to the PSW that their knowledge was valued, creating an opportunity to be inclusive of all the care providers. This case

manager was leading by example, revealing to the team how to achieve an inclusive work environment.

In contrast, case managers described the negative impact that less cohesive and inclusive teams can have on the culture of a facility. One case manager equated it to working in silos and splitting among the staff: “you spend a lot of time and energy trying to be politically correct, trying to deal with egos and things like that rather than focusing on the client.” When teams are disconnected and primacy is not given to the resident, the focus shifts away from meeting care needs to internal systems issues. She summarized it this way: “...what we saw was squabbling and power struggles and arguing amongst themselves”. Another participant noted the tensions produced in facilities that called attention to staff hierarchies:

That’s also a home where for Nursing Appreciation Week the registered staff get a luncheon, get flowers, nobody else gets anything. And so in that home I saw...a sign that was up saying thanks to all the charge nurses for their excellent work, something about Nursing Weeks and a PSW wrote, “what are PSWs, chopped liver?”

This same case manager went on to describe another facility that instead of Nursing Week, held a “Staff Appreciation Week”, an example of a culture that showcased everyone’s work and promoted a sense of teamwork and shared purpose among the staff.

Associated with an inclusive work culture were managers that were visible and engaged with staff, residents and their families. For example, one case manager reflected

on the management style found in a facility that she thought very successful in dealing with challenging behaviours skillfully and well. The style was less hierarchical and more focused on developing a team approach to resident-focused care:

Well frankly, the decision makers in the positive situation were very present in the clinical area...Actually the DOC...it appeared to me that they were simply present on the unit, interacting with the clients and the staff on an ongoing basis...I could go to the DOC, I could go to the administrator and they would all be able to tell me what was going on with certain clients and what their concerns were...actually maintaining an ongoing dialogue with me. I can't remember going in without being able to access any one of them directly and access them in relation to the specific needs.

In such organizational cultures, participants noted that there was a commitment by management to be aware and involved with the care of the residents, to lead by example and provide support to their staff when navigating challenging situations. This point is well illustrated in another participant's recollection of a particularly effective DOC's approach:

So the DOC knew the family, she knew the residents; she knew the approach to care. She came with me onto the home areas. We talked about some of the challenges and some possible strategies and she was right involved trying to get them implemented. And I think that message to the staff was, and it wasn't just telling staff, it was that we need to be creative, that we need to try these things ...it was actually being involved.

Another case manager highlighted the benefits of a management style that is supportive of an inclusive work culture:

How do you manage this...for in-servicing...you've got a room of 20 people ready 2 minutes ahead of time, unlike other places where it's like, did you know about today? And I mean their incentive...you attend 3 sessions and you get a certificate. So it's not food, it's not extra pay, it's not anything but the DOC sits in on the education. I think part of it, there is the visibility of the DOC more so than the administrator and so the DOC is visible but also engaged. And participating.

Participants also spoke of contrasting facilities in which they witnessed incoherent and un-informed approaches to residents' care:

On one occasion I brought the doctor, the geriatric psychiatrist in, we talked to three different staff and got three different answers to the same question...there's something essential problematic about that...I think some of it has to do with this lack of identified leadership and leadership with the ability to provide...support and organization and reinforcement of good team functioning.

In summary, a combination of teamwork and management style was thought by the case managers to produce an inclusive work culture characterized by a sense of unity, good morale and job satisfaction. In such facilities, they found that staff responded as a team, had more confidence in taking on challenging situations rather than focusing blame on one person or discipline when an intervention was not successful. They identified a

culture that has a resident-centred focus and an inclusive work environment as more responsive to needs of residents with behavioural disturbances.

Culture of Supports and Flexibility: “They take pride in their work”

The third characteristic of LTC facilities, that case managers considered cared well for residents with behavioural disturbances, was articulated by the participant quoted on p. 30 as ‘taking pride in their work’. While certainly related to being resident-centred and inclusive, analysis of the interview data suggested that such pride was also linked to an organizational culture of flexibility in care provision and employment practices that supported staff’s exercise of flexibility and discretion.

With respect to care provision, an example of such flexibility offered by one participant concerned a facility’s effort to ensure a resident was bathed in a way and at a time that she could accept:

And she is still a challenge...About three or four times...switching staff they got her dressed, they didn’t get her washed but about an hour later the person that does baths came in and the resident was agreeable to do a bath, even though it wasn’t her time to have a bath and they got her into the bathtub. There’s that kind of flexibility and...team work with the nursing, the PSW staff.

The example represents the positive results of a resident-focused team working collaboratively to engage a resident who was disturbed at the prospect of receiving personal care. It underscored the staff’s ability to be flexible in their approach as well, their support of each other’s efforts.

With respect to flexibility and support of staff, participants identified the importance of the organizations' acknowledgment and support of their good work at both the staff and management levels. Case managers noted consistently that when workers were supported in their efforts to show initiative and be resident-centred, morale was good. As with resident- focused care, it was important to also see the staff as individuals with specific needs. One case manager was very cognizant of the importance of acknowledgement and fostering a sense of pride and accomplishment among the staff:

Yes support for the charge nurse, the managers, from outside people just to say, I find that if you say, holy cow! I can't believe you've been managing him this well for this long...I think it goes a long way and helps decrease their frustration.

Participants consistently voiced awareness of the difficult and, indeed, inflexible environments in which LTC staff worked.

Generally they're caring people, it's just that they're working in an environment that's very regulated, that is pretty rigid. I mean because even for nursing to flex the meal time then dietary has to be engaged.

Like others, this case manager found that this rigid and regulated environment created barriers for staff in their efforts to provide care, an issue taken up below.

As noted earlier, LTC staff work in environments governed by regulations from within and from without: by individual facilities' organizational practices and commitments and by Ministry and policy requirements and standards. However, to be able to think outside the box and develop a plan of care that adjusts to the changing and complex needs of this vulnerable population, some flexibility in the interpretation of the

regulations is required. If utilized appropriately, this concept of flexibility was recognized as a useful practice. Participants noted a culture that allows staff the opportunity to be creative and responsive to the needs of residents was one that allowed a flexible interpretation of regulations.

Participants identified two areas where flexibility played a key role; the first involved the LTC facility's interpretation of regulations, the second involved the impact interpretation has on developing and implementing care plans for residents. One case manager acknowledged the necessity of regulations but also highlighted the practicality of being flexible with the interpretation:

The regulations, probably necessary. It's how we use the regulations creatively or follow them creatively...I mean people have to be...washed and dressed and cleaned however, what they were looking at was yes, over the course of the day we get that accomplished.

Case managers found that in those instances where facilities allowed for flexibility with regulations, individualized care plans and strategies to manage challenging situations tended to be more successful than those that did not. For example:

I think there's an acceptance from the management team...there's a culture that the PSWs are supported by the RPN's, by the RN's, by the DOC. There's a communication...not such a hierarchy of the DOC locked away in her office and the PSWs are afraid to try different things...they rationalize...if Mrs. Jones doesn't want to have a bath on a certain day...they're not going to force

her...they'll wait or they'll do different things because they know that their manager is not going to freak out on them.

The concept of flexibility effectively integrates the two previous organizational factors; being resident-centred and inclusive team work. A cohesive team was able to utilize its skills to flexibly interpret the regulations in such a way that created caring interventions that were responsive and resident-focused. Significantly, this case manager noted that flexibility in terms of regulations and case plans was possible when management and staff were not fearful of reprimand. When asked what characterized facilities that were not fearful and were willing to bend the rules to accommodate resident needs, she observed:

I think a facility that hasn't been cited by the Ministry...and isn't feeling fearful that every time they do something...they're going to have the Ministry look at them.

This idea is also supported in the literature, "Our data suggest that moving away from a punitive model would permit more mindful care to occur, while freeing facility resources to focus on resident health outcomes rather than citation prevention" (Colon-Emeric, Plowman, Bailey, Corazzini, Utley-Smith, Ammarell, Toles and Anderson, 2010, p.1292).

As they reflected on the organizational conditions they associated with flexibility, participants made interesting comparisons between older, more established facilities and newer ones. Typically, residents and families are attracted by new buildings and

additional amenities. However, participants reflected that newly built facilities were less likely to have experienced and cohesive staff:

One was highly new and desired and one is very old and not at all desired and the experiences at (facility name) is definitely superior, the older one, in terms of just their willingness, their readiness, their availability, their ability to problem solve even before they make a referral.

In this example, it appears that the facility staff was able ‘to take pride in their work’ and that the culture of care was far more powerful than a new building.

While participants elaborated on organizational characteristics that they associated with flexibility, they also described characteristics that compromised a culture of support and flexibility. One such characteristic consistently identified, was inadequate staffing levels. They provided many examples of staff forced to work short staffed, the result of cost saving practices such as not replacing absent staff. These practices are well documented in the literature. Armstrong and Daly (2011), confirm the case managers’ observations, failure to employ enough staff, as another practice utilized. McGregor and Ronald (2011) and Player and Pollock (2001) discuss the implications that privatization has had on the LTC sector in the U.K. ; increased dependence on casual, non-unionized labour, absence of benefits, all practices used to reduce staffing and cut costs. One participant’s recollection highlighted the increased risk potential for residents and staff when facilities are inadequately staffed:

I mean you can often see, I remember going into...one long term care and I was at the nursing desk which is by the dining room and there was not one single staff

around and all these residents...there were two residents and you knew that things were going to escalate because they were both invading each other's space and there was no staff around to intervene.

The case manager went on to explain that she was able to intervene and divert a potentially dangerous and completely preventable situation. She went on to say, "I think one of the huge barriers is just not having enough staff". It was the feeling of this participant that just one extra PSW per shift could lessen the number of violent incidents between residents living in LTC. In the next account, the case manager expressed her frustration with the lack of available staff in a facility and how it impacted on her work:

Another nursing home which I'm fairly new to in the last year, now you can never seem to find staff which I find very frustrating cause I spend my time roaming around the halls looking for bodies to help me, who know the person...have an awareness of that person and their fluctuations.

This case manager went on to draw a contrast with another older more established facility in the area where the staff were accessible and knowledgeable about the resident. This comparison between new and old was made by several case managers. The experience and stability of a seasoned team was seen as a positive asset to have when managing residents with behavioural disturbances, especially considering the staffing shortages most facilities face.

Lack of adequate staff was seen as a barrier to facilities' completion of even the basic activities of daily living. Going beyond those tasks proved to be far too challenging for staff feeling already overwhelmed and over worked. This is supported in the

literature, the Ontario Health Coalition(2008) found that, “Nearly 60 percent of the time workers don’t have the time to provide emotional support (59.8%), while walking and exercising of residents is not done more than half the time (52.3%). More than 40 percent of the time, recording, foot care, and providing support to co-workers is left undone...” (Ontario Health Coalition, 2008, p.12) One of the participants reflected on the impact of a culture where the workers lack time and feel fearful to be flexible with the regulations:

Time is often the issue...we’re too busy, we don’t have time to keep going back or don’t have time to change this. Or the Ministry says that we have to do it this way, I mean that’s often a big challenge...the rules and regulations or interpretation of the rules and regulations from the Ministry, in terms of making changes.

Another noted that, time-deprived front-line staff dealing with day to day demands of residents with challenging behaviours do not have the time or resources to respond with flexibility and can, as a result, disengage from residents and their environment:

I think sometimes the PSWs, who are...the recipient of the behaviour the most, are at times the most skeptic, skeptical because they’ve had to deal with it and they’ve, in order to...I think, you almost have to put up walls to continually take that and attempt and try to do your job, get them clean.

Such ‘putting up of walls’ demonstrates the results of a culture that has failed to provide the adequate support and leadership to build capacity and afford needed reassurance to their staff. The implications for resident care are grim:

From what I have seen, long term care, a lot of people are task oriented because there are limited resources...PSW ratio to client. You’ve got one floor, there’s a lot of clients that require perhaps a lot of care and the PSWs are torn in terms of you can’t help one person at the same time you’re helping another person. So they become task...focused on getting the person on the toilet.

The same case manager identified newer facilities as having less consistent staffing, less opportunity to build inclusive teams, more mistrust among the staff and poor morale. A stark contrast to the older established facilities mentioned earlier:

Some of the newer homes in particular tend to have a lot of agency staff, they have high rates of absenteeism so they’re relying on agency staff and they don’t know the clients and...might be the registered staff and they don’t know the PSWs and the PSWs don’t trust that person cause they’re agency and so for sure that affects morale.

Another participant likened these working conditions to a treadmill. The staff has become immersed in the day to day challenge of meeting unrealistic time lines for tasks to be completed; feeling too overwhelmed with no opportunity given to reflect back to what was happening. She saw them resorting to “survival mode”, with a focus entirely on completing the task, not on the resident. If unchecked, this has the potential to evolve into a dangerous situation. When the emphasis is on institutional needs rather than the

resident, this can lead to the depersonalization of the resident. As well, there is the potential for management to turn a blind eye and the situation to remain unchecked so long as the tasks are completed: “These pressures are exacerbated by lack of resources and the way the moral legitimacy of the work is undermined by the gap which separates the rhetoric of policy from the sharp reality of practice.” (Wardhaugh and Wilding 1993, p.16) This concept will be discussed further later in the paper.

This last example captured what participants witnessed when a culture within a facility is neither resident-centred, inclusive or flexible. Describing a situation in a facility where the culture and practices are detrimental to any kind of sustainable capacity, one participant gave an example of the regulation regarding diaper distribution; patients were allotted a certain number per day and if the resident’s needs exceeded that, the PSW had to justify to the charge nurse why more were needed before getting permission to retrieve more:

I think the regulations of diapers and wash cloths and all the things like that is so stringent and the PSW has to ask for 8 and then they say no you don’t get 8, you get 7 and it’s just bizarre...They’re not going to take it home. You know I understand not having a big open storage room where you can take whatever you want but give them at least one bag each...they’re trying to manage the cost but it just is, ...seems ridiculous.

Not only does this example demonstrate a lack of trust on the part of the administration toward the PSW but also a belief the PSW lacks the capacity to make a decision about residents’ care needs. The culture in this facility was not providing an

opportunity for the PSW to feel capacity in her work, as a matter of fact, it seems rather demoralizing. The narrow interpretation of the regulations allows no discretion; the PSW is unable to utilize any of her skills. It also illustrates how financial constraints imposed on LTC facilities either by funders' cuts or profit motives penetrate the day to day work of staff and the everyday details of residents' care.

DISCUSSION

This study and the interviews were framed to invite and conceptualize case managers' insights into the organizational conditions that enhance LTC facilities' care for residents with behavioural disturbances. Even so, accounts such as the last one, offered as negative counterpoints to positive organizational practices and cultures, took up a great deal of the interviews and, indeed, of participants' reports of their experiences of LTC facilities. This balance of attention and experience lend urgency to improving the conditions and resources that currently structure LTC in Ontario. However, it is also true that, despite what sounds rather grim, some LTC facilities in case managers' experiences were able to practice positively. These facilities were found to have organizational features that promoted a culture associated with responsive and supportive care, impacting both on the residents as well as the staff. Specifically, these features were as follows; an ability to build capacity within the organization and commitments to resident-focused care and an inclusive work environment. These factors combined to create a culture of support and flexibility where staff took pride in their work. The ability of the staff to manage challenging situations with residents seemed to improve when these features were integrated into the organizational structure of the facility, an integrated summarized below.

Summary: Building Capacity and Organizational Features

The ability to build capacity was present in facilities with a culture that is responsive to the needs of the residents. It was characterized by staff with good problem

solving and assessment skills and the ability to work as a cohesive team. Their goal was to enhance the skill level of staff, to learn from past experiences and use that knowledge reliably when responding to the ongoing and future needs of residents living in the facility. In a culture that encourages the development and transfer of skills, teams were found to be confident and able to independently take on challenging situations with residents experiencing behavioural disturbances. Ultimately, it is the responsibility of the facility to ensure good care and create an environment where building capacity is a priority. However, in the accounts of the case managers in this study suggested that they also acted as educators in the development of capacity: by engaging staff and leading by example and developing trusting relationship with their colleagues in the facility.

Being resident-centred represented, according to participants, a commitment to personalized care for each individual living in a facility; a facility considered to be their home. In such a culture, care is not a task but a personalized act. This organizational feature is at the heart of the “Cultural Change” movement supported by advocacy groups and scholars in an effort to deinstitutionalize LTC facilities (Miller, Miller, Jung, Sterns, Clark and Mor 2010; Tyler and Parker 201). Workers with the attribute of empathy are found to be more responsive and successful in meeting the needs of this population. Low empathy and negative attitudes among care providers toward dementia patients has been found to correlate with incidents of burnout (Astrom, Nilsson, Norberg, Sandman and Winblad 1991). Appropriate education regarding the disease process of dementia and the symptoms associated with it are vital to support staff in developing insight into why residents behave as they do. As mentioned earlier and is evident in the literature, training

and education for staff can also make a difference in the confidence they feel in caring for residents with dementia and behavioural disturbances (Hughes, Bagley, Reilly, Burns and Challis 2008). Having knowledge of a resident's past life gives staff a social context in which to relate to the individual, also beneficial in the provision of respectful and dignified care. This combination of empathy and insight, supported by meaningful education, enable staff to perceive residents as individuals with unique needs.

A strong sense of teamwork and inclusion was also identified as an organizational feature of LTC facilities responsive to the needs of their residents and echoes others' research. A team that is inclusive of all the people involved in the care of a resident allows staff to utilize their skills in a meaningful way to enhance the care received by the resident. It creates a sense of cohesion and equality among the members of the team, improving morale and job satisfaction: "good teamwork improves the attitude of employees toward one another, which in turn improves teamwork, which in turn improves attitude" (Tyler and Parker 2011, p.47). Management style was also identified as part of an inclusive work culture. A successful management team was seen as one that is involved and engaged with the staff and residents of the facility. This approach is less hierarchical, focused on teamwork, leads by example, modeling positive attitudes and beliefs, exhibits open communication and is respectful of the staff (Tyler and Parker, 2011). In contrast, a lack of teamwork and exclusion creates splitting among the staff, poor communication and tension. The focus is shifted away from the individual resident's needs to the internal system's needs.

A culture of support and flexibility was the final organizational feature identified by the participants in the study and by other contributors to the literature. In such a culture, staff are supported and acknowledged in their efforts to show initiative with respect to resident care. Given the challenging and changing nature of the care required by residents with behavioural disturbances, staff require some level of flexibility in their approach to remain responsive and resident focused. As well, a culture that allows teams the opportunity to utilize their skills with discretion, based on experience, creates a positive work environment for staff. The practice of flexibility, with regard to the interpretation of regulations found in LTC, is beneficial in maintaining a culture that is resident focused (Tyler and Parker 2011).

Along with the positive features, participants also identified negative practices that compromised a culture of support and flexibility. Inadequate staffing levels within LTC facilities is a well documented practice used to downsize and cut cost. “Legislating minimum staffing levels would be a key strategy for improving quality” (Institute for Research on Public Policy, 2011, p.30). This article goes on to state that “...high profits are generated in the residential care sector by instituting lower staffing levels, which result in inferior quality of care”(p.30). Unstable work environments, inconsistent staffing, use of outside agency staff are all barriers to a resident focused culture of care. Shortages in staffing result in overworked, stressed workers, increasing rates of injury and violence, unable to complete even the basic task required (Ontario Health Coalition, 2008). LTC facilities are subjected to numerous regulations that, strictly enforced by management teams, can become more concerned about completing the task and meeting

the targets than resident care and safety. In such organizational cultures, in order to cope with the increasing demands, workers can become disengaged from residents, focus on the completion of the task with the emphasis on survival. Noting the conditions that can lead to a “corruption of care” (Wardhaugh and Wilding, 1993) observe that this has the dangerous potential of depersonalizing residents. Given the vulnerability of the population of concern here, defined as less than fully persons, “the way is clear to forms of behaviour and treatment which would be unacceptable with those not so stigmatized” (Wardhaugh and Wilding 1993, p.27).

As mentioned, for every positive organizational practice, case managers were able to provide a negative counterpoint, highlighting the barriers faced by facilities in their efforts to provide care for this vulnerable population. Given the current neo liberal climate of diminished resources, privatization and downsizing, it is not surprising that facilities experience difficulty in overcoming the challenges presented by the rhetoric of social policy that fails to match with the realities of front-line work in LTC facilities (Wardhaugh and Wilding 1993). Realistically, it may not be the time to anticipate sweeping macro level social policy changes to address the issues in the LTC sector. Perhaps the path to improvement is not from the top down but rather from the bottom up. Facilities such as the ones identified by the participants in this study have the potential to lead by example and set a standard for resident focused care. A facility that is unique or exceptional in some way, that is able to cultivate a culture of support and flexibility, can be a catalyst for change.

John Clarke (2004), *Dissolving the Public Realm? The Logics and Limits of Neo-liberalism*, supports this notice of bottom up change. He reminds us that even in what can seem an overwhelmingly dominant neo liberal political climate where public services of all kinds are eroded, people do find ways and spaces to press back against the erosion (Clarke 2004). In this instance, to care well, to foster an organizational culture against the grain of pressure to regulate and standardize care, LTC facilities must give primacy to residents' needs not organizational needs. Care and organizational life are not all determined from above, people have an impact and make a difference from 'below': "For many reasons, the public realm (and the attachments that it mobilizes) is part of the 'grit' that prevents the imagined neo-liberal world system functioning smoothly" (Clarke 2004, p.44). Perhaps focusing on the successes at the front line has more potential for change than at a macro policy level or is, at least, an energizing complement to it. The thesis findings and Clarke's conceptualization of 'the grit' affirm the value of the study's approach. Two examples from the literature highlight such 'bottom up' successes.

Lopez (2006), *Emotional Labor and Organized Emotional Care, Conceptualizing Nursing Home Care Work*, studied three similar nursing homes to compare the organizational practices of emotional management among the staff within each facility. Lopez observed three distinct practices along a continuum of management. At one end, Hochschild's theory of emotion labour, inherently coercive in its requirement that workers to comply with a prescriptive set of rules developed by management. At the other end of the continuum, Lopez identified an alternative organizational model to emotional labour. 'Organized emotional care' (Lopez 2006), supportive in its approach

to workers attempts to create organizational spaces within the structure of the organization where caring relationship between staff and resident can develop (Lopez, 2006). Lopez (2006) describes a situation within a facility that highlighted the practice of organized emotional care. In this facility, instructional videos were utilized as educational tools for new staff, demonstrating techniques to transfer and mobilize wheelchair dependent residents. Along with the physical instructions, management used the video to encourage and promote social interaction between the staff and the resident: “it reminded workers of the basic humanity of nursing home residents: an elderly person in a wheelchair is not a thing to be moved here or there as the routines of care require but a human being who needs to be consulted, to the extent possible, about his or her wishes” (Lopez 2006, p.151). The routines established by this facility via the training video, created organizational space for staff and residents to develop meaningful relationships, potentially decreasing the occurrence of the dehumanizing situations that Wardhough and Wilding (1993) feared. This then created a moment and a space in time for coaching, mentoring and supporting staff. Lopez identified this particular facility as “an outlier” in the LTC sector that he studied in the U.S., not typical of what usually happens with the majority of homes (LTC facilities). However, it speaks to the idea of a local change from the bottom up and is an example of a facility that is exceptional, implementing strategies from within that positively impact front line resident care.

The second example highlights organizational practices used to manage compliance with regulations in LTC. Colon-Emeric, Plowman, Bailey, Corazzini, Utley-Smith, Ammarell, Toles and Anderson (2010) examined the impact of regulations on the

‘mindfulness’ of staff activities related to resident care. High levels of mindfulness are thought to enable staff to recognize early changes in resident behaviours and health, efficiently gather information and be able to respond in a flexible manner as the situation demands (Colon-Emeric et al. 2010). The researchers found that when regulations are used as a standard of care to achieve, care was more resident focused/mindful. If regulations are reinforced punitively, the focus of staff shifted from resident to regulations. As well, organizations with resident focused mission statements were found to foster mindfulness among staff; if the organization was more concerned about cost, less focused on the resident and less mindful and less able to respond to the changing needs of the residents (Colon-Emeric et al. 2010). Allowing space and practice to occur with the organizational culture of LTC to rethinking the way regulations are reinforced could set up regulations as a means, rather than a barrier, to resident-focused care. Again, this is an example of a strategy that occurs at the front line of service. Front line strategies such as this one highlighted, have the potential to improve the quality of care for residents in the LTC sector from the bottom up. This study also lends support to the idea of flexibility and teamwork as important organizational features of a resident focused culture of care.

In keeping with this notion of local bottom up change, the interpretive approach used in the study highlights the importance of front-line workers’ experiences. The case managers from their unique position as both insiders and outsiders in a number of different LTC facilities were able to capture through their observations, the challenges and successes of staff caring for this vulnerable populations. Although invested in the

well being of residents and front line staff, the case managers were not completely integrated in the fabric of the cultures and were able to observe with a somewhat objective eye the organizational features of each facility at work, “What is distinctive about interpretive approaches, however, is that they see people, and their interpretations, perceptions, meanings and understandings, as the primary data sources” (Mason 2002, p.56). From this perspective they were able to discern the features of facilities that enabled staff to be responsive to resident needs despite the barriers created by macro level social policy that is incongruent with everyday reality of LTC facilities. Not to take away from the importance of social policy reform, the focus of everyday successes, changes from the bottom up seem more meaningful and immediate for the staff working and residents living in LTC facilities.

Social Work has a particular contribution to make in this area given its distinctive attention to policy and systemic factors and front-line realities and to understanding the inter-relationships. The participants in this study were from other disciplines and, while frustrated by the insufficiencies of many LTC facilities’ care, did not in the interviews prominently link them to wider policy debates or issues. For example, few commented on the ownership of the facilities they described, a factor that the literature suggests has considerable impact on care and culture. With a professional claim to systems analysis of individual problems and to the practice of collective advocacy, Social Work researchers and practitioners in this arena can contribute by making the links between front-line care, organizational culture and its political and economic restructuring. Social work as a profession, “...respects the intrinsic worth of the persons she or he serves in her or his

professional relationships with them” (OCSWSSW, 2011). The college goes on to state that “A social worker or social service worker shall advocate change in the best interest of the client, and for the overall benefit of society, the environment and the global community” (OCSWSSW, 2011). This thesis has identified the organizational conditions in LTC facilities that make it possible to provide good care for this ever growing and complex population. The insights gained through this research have made it possible for me to distinguish the “grit” (Clarke, 2004), the good practices that exist within this neo liberal climate resulting in downsizing and erosion of the long term care sector. As a result, this research paper may contribute to future discussions of policy and practice in the service of social work for this stigmatized population.

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APPENDIX A

Interview Guide Questions:

1. In your experience as a case manager, can you describe a situation when a LTC facility responded well with positive results providing care for a resident with a diagnosis of dementia experiencing behavioural disturbance. Can you also describe a situation when a LTC facility responded poorly resulting in a negative outcome? Where there difference between the facilities? I will let you define positive and negative outcomes.
2. Reflecting on your experience, how do facilities that historically have managed behavioural disturbances well decide when a situation becomes too risky to manage independently and seek outside consultation? Do these facilities differ from those that don't seek consultation readily? Do facilities wait too long to seek out consultation? If yes, why do you think this happens?
3. Reflecting on your work experience with LTC facilities, are staff open to recommendations made by yourself and/or the team? Is there a willingness to integrate recommendations into the care? Are there differences between facilities, please explain? Is the staff supported in their efforts to integrate recommendations? What would that support look like?
4. What do you see as the barriers to effective care for people experiencing behavioural disturbance living in LTC?
5. Please describe the key features of a LTC facility that you find responsive to the needs of people experiencing behavioural disturbance. What do you think supports and strengthens these features with a facility?
6. In your role as a case manager, you are in a unique position to have access to a number of different facilities and those that live and work within. As we are all aware, the population is aging and the demand for appropriate care will only increase. Do you have any suggestions on how to manage the growing pressures on LTC facilities? What do you see as a resolution?

APPENDIX B



Appendix B: Information Letter and Consent Form

Title of Study: Long Term Care Facilities: Challenges in care of dementia patients, Insights from Case Manager's Experiences

Principal Investigator: Christine Stanzlik Elliot BA, BSW, RSW, MSW candidate
School of Social Work, McMaster University
Staff member (Social Worker) of St. Joseph's Healthcare,
Hamilton

Information Letter

As a Case Manager and member of the Halton or Niagara Geriatric Outreach Team, you are invited to participate in a research study. This is a student project conducted under the supervision of Dr. Jane Aronson, Professor and Director of the School of Social Work at McMaster University. The study will help the student learn more about the topic area and develop skills in research design, collection and analysis of data, and writing a research paper. In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate. Please take your time to make your decision. Thank you for taking the time to both read this letter, and to consider this invitation to participate.

Why is this research being done?

In the constrained context of public health services, elderly patients with dementia who experience behavioural disturbances are a particular concern. Long Term Care (LTC) facilities are generally regarded as the most appropriate site for their complex care but in practice they differ considerably in their reception of and response to such patients. This results in system-wide tensions at the boundaries between LTC facilities and hospitals. Better understanding of the organizational cultures and practices associated with positive response to the needs of this population can contribute to enhancing patient care and to understanding of system-level problems.

Date: _____ Participant's Initials: _____ Version Date: April 25, 2011

Information Letter and Consent Form – continued

What is the purpose of this study?

The purpose of this study is to reveal the characteristics (organizational culture, everyday frontline practices, resources, staffing, funding) that differentiate LTC facilities that typically assume care of this patient population readily and well and facilities that do not.

What will my responsibilities be if I take part in this study?

If you agree to participate in this study, you will be asked to participate in a face to face interview with the investigator. The estimated length of the interview is 60 minutes. The interview will occur at a mutually agreed upon time and location. With your permission, the interview will be audio recorded.

How many people will take part in the study?

5 to 8 Case Managers will be recruited for the study.

What are the possible risks to the participants? How will they be minimized?

There are no known risks associated with this research study. The investigator will not use your name or any other information that would allow you or the locations and service sites that you refer to, be identified. All of the data will be securely stored in a locked cabinet and on a secure server in the investigator's home office. The data for this research will be retained for 10 year.

What are the possible benefits to me and/or for society?

You may not benefit personally from your participation in this study. Although possible benefits may include having your experience heard and acknowledged. The information and insights gathered from Case Managers could serve to support change in policy and practice within LTC facilities that would benefit the residents. It could also serve to identify areas where future research is needed.

Date: _____ Participant's Initials: _____ Version Date: April 25, 2011

Information Letter and Consent Form – continued

What information will be kept private?

Your data will not be shared with anyone except with your consent or as required by law. All personal information will be removed from the data. A code number will be assigned to your data. The data, with identifying information removed will be securely stored in a locked office in St. Joseph's Healthcare, Charlton site, Hamilton on a secure server. For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the St. Joseph's Healthcare Hamilton Research Ethics Board may consult your research data. However, no records which identify you by name or initials will be allowed to leave St. Joseph's Healthcare Hamilton. By signing this consent form, you authorize such access. If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to the disclosure. Audio-recordings will only be listened to by the research and will be destroyed after 10 years.

Will the participant be paid to participate in this study?

You will not be paid to participate in this study?

Will there be any cost to the participant?

There will be no cost to you.

What if you decide not to take part in the study?

Participation in this study is voluntary. Nothing will happen if you decide not to participate. If you do decide to participate, you have the option to withdraw at anytime during the study. You may also refuse to answer any questions you don't want to answer and still remain in this study.

What if you decide to take part in the study?

Please contact the investigator, Christine Stanzlik Elliot, via email cstanzli@stjoes.ca or pager #905-974-7797.

If you have any questions or problems

If you have any questions regarding the study now or later, please contact the investigator, Christine Stanzlik Elliot pager # 905-974-7797. If you have any questions regarding your rights as a research participant, contact the office of the Chair of the Research Ethics Board, St. Joseph's Healthcare, Hamilton at 905-522-1155 ex. 33537. This study has been reviewed by the Research Ethics Board of St. Joseph's Healthcare, Hamilton.

Date: _____ Participant's Initials: _____ Version Date: April 25, 2011

Information Letter and Consent Form – continued

I have read the preceding information thoroughly. I have had the opportunity to ask questions, and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand I will receive a signed copy of this form.

Name of participant

Signature of Participant

Date

Consent form administered and explained in person by:

Name and Title

Signature

Date

Date: _____ Participant's Initials: _____ Version Date: April 25, 2011