

RELATIONSHIPS AS REMEDY: MEETING THE SOCIAL AND EMOTIONAL NEEDS OF  
ELDERS LIVING IN RESIDENTIAL CARE

by

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### Abstract

Person-centred care arose as a model of residential elder care in response to the lack of attention given to the social and emotional needs of elders under a traditional medical model. However, both the critical literature and my research project studying social workers' experiences of providing person-centred care in extended care facilities demonstrate that factors such as organizational culture, the particular considerations of frail and cognitively impaired elders, and lack of staff 'buy in' can impede its application. As a result, there are continued gaps in meeting the social and emotional needs of elders in care. This paper uses the framework of an ecological perspective to propose the application of relationship-centered care and community development approaches to bridge this gap.

## Introduction

The provision of residential long-term care for elders in Canada is located within the medical system. Critics of this service delivery model argue that this leads to an overemphasis on the medical and physical care needs of elders, and not enough attention to their continuing social, spiritual, and emotional needs (Kane & Kane, 2001; Kaufman, 1980; Kaufman, Shim & Russ, 2004; Kitwood, 1997; Ronch, 2004). Research in residential care facilities suggests that priorities for care are focused around the fulfillment of nursing duties, the priorities of the staff, and organizational routines (Deutschman, 2005; Henderson, 1995). In order to mitigate the dominance of the medical focus, the current philosophy of ideal care for elders in residential facilities revolves around the concept of ‘person-centred’ care (Clemens, Wetle, Feltes, Crabtree & Dubitzky, 1994; Hofland, 1994; Kitwood, 1997; Ronch, 2004; Sampsell, 2003). Principles involved in person-centered care have been defined in terms of the right of clients to self-determination (Clemens et al, 1994) and autonomy (Agich, 2003); in terms of policies and practices that enhance independence, dignity, fairness, participation and security (Division of Aging and Seniors, 1998); and in terms of supporting clients’ values and preferences (Eales, Keating & Damsma, 2001). Research on quality of life indicators and on the preferences of older adults demonstrates that psychosocial considerations are highly important in providing care to this population. Whether the care is provided in the community or in a residential setting, elders frequently mention having caring, interactive social relationships with family, friends and caregivers as a key factor in life satisfaction (Eales, Keating & Damsma, 2001; Kane & Kane, 2001; Wilhelmson, Andersson, Waern, & Allebeck, 2005). Other key factors include choice over physical surroundings, decision-making and routines (Eales et al, 2001), having a sense of

“home”, and having the functional abilities to be independent or to pursue favourite pastimes (Wilhelmson, et al, 2005).

The philosophy of person-centred care has therefore been widely embraced as a means to support such psychosocial needs within residential facilities for elders; however, there are several practical and theoretical constraints that make it difficult to realize. In this paper, I argue that while person-centred care is a positive shift away from the medical model of aging and elder care, in itself it has not been sufficient to overcome the structural barriers of the long term care system to create widespread cultural change in residences. Nor has it been able to consistently and meaningfully support the social and emotional needs of the ‘person’ in person-centred care – the elder. I will draw on my own research as well as critical literature in order to discuss the assumptions and limitations of person-centred care and to propose several approaches that may better serve to address the needs of elders who live in residential facilities. Borrowing from the ecological perspective, I will discuss how employing principles of relationship-centred care and community development can increase the degree of social and emotional “fit” between elders and their environment. Specifically, by building relationships at an interpersonal and community level, there is a great opportunity to create a larger community of care that meets the social and emotional needs of staff and residents alike.

### The Current Context of Residential Care for Elders

#### *The Biomedical Model of Care*

The Western model of medicine “assumes disease to be fully accounted for by deviations from the norm of measurable biological...variables. It leaves no room within its framework for the social, psychological, and behavioural dimensions of illness” (Engel, 2004, p. 53). Further, its roots can be traced to a period in history where the political influence of the Christian Church,

which claimed sole stewardship for a person's spiritual and moral well being, intersected with the growing field of rational scientific inquiry, which emphasized the study of an entity via its isolated parts. This intersection fostered the evolution of a separated, dualistic concept of mind and body that has persisted in the Western model of disease and treatment (Engel, 2004, p. 54). The language of science and medicine is also constructed on terminology that is linear, mechanistic and reductionist; medical diagnosis often lies in the use of measurements and machines and medical treatment lies in controlling and regulating the errant part (Birke, 2000).

A major critique of placing responsibility for elder care within the medical system is that funding for supportive and residential services becomes inherently tied to medical goals of care, which stress the importance of medical treatment over psychosocial needs. Henderson (1995, p. 37) asserts that this care model "neglects the fact that most placements are made due to lack of community resources, not actual need for constantly supervised medical attention." Further, innovation to improve "quality" within the medical model of elder care is made within a narrow framework that continues to emphasize structural standards of things such as staff inputs, weight loss, bedsores or falls, and that places a "low priority [on] bad quality of life outcomes (such as general misery)" (Kane and Kane, 2001, p. 5).

As a result of this narrow focus, the template for staffing in residential elder care is similarly structured on the medical model. According to Ronch (2004), nursing homes "are still organized, staffed, regulated and reimbursed according to the acute medical model of care" (p. 67), which relies on a "top-down" system of service delivery that places the highest level of authority and staffing in the "departments responsible for treating physical illnesses and caring for the biological and activity needs of daily living"(p. 68), and places less emphasis on staff who care for residents' social, interpersonal, creative or symbolic well-being such as social workers, occupational therapists, and activity programmers. The separation between medical and

non-medical staff and their individual goals for the resident can result in a person being treated “as a collection of separate and disconnected needs” (Ibid cit., p.69).

This medical model may be appropriate when a person is experiencing an acute illness requiring specific treatment; however, the implication of this model for elders who often live for years in residential care is that aging is viewed primarily as a chronic illness and not an active life process with the potential and need for continued social and emotional involvement. As observed by Henderson (1995) in his ethnography of a nursing home, nursing stations and procedures dominated the physical environment of the residential facility; he describes the “rapid, task oriented nature” of nursing care as “derived from medical values of time conservation and care focused on physical tasks” (p. 38). As a result, residents formed closer relationships with cleaning staff - who spent more actual time in the residents’ rooms - than they did with the nurses who performed the most intimate physical care. Further, residents were delegated to certain wings according to their care levels, not according to personal preference or social relationships. The décor of the facility changed dramatically between these wings, with those housing the most frail or demented elders also being the most stark and institutional as though the functional aspects of care had completely subsumed the aesthetic and personal ones.

A common example of nursing priorities conflicting with the psychological well being of elders is the experience of bathing in the residential care home. Especially in the cases of elders with dementia or cognitive impairments, being bathed can be a frightening and dreaded activity. Typically, baths are scheduled by the facility according to nursing and functional priorities, without consideration for the intimate and personal nature of the act. The bathing room in the facility where I worked was sterile, cold, functional, and a completely public space – there were doors on each side of the large room and residents and staff alike could walk through at any time. The activity is the site of many struggles between care staff and residents (Crandall, White,

Schulhweis, and Talerico 2007; Singer Edelson and Lyons, 1985, p. 17) and it is not uncommon for staff resort to administering a tranquilizing medication beforehand (Crandall et al., p. 52). An interpretation of such a model for bathing is that the bodies of individual residents belong to the nurses who are responsible for their maintenance. By entering into the residential facility, the personal knowledge of one's body is forfeited to the 'expertise' of the professional.

In recent decades, there have also been major medical advances in 'treatments' for aging (Kaufman, Shim and Russ, 2004), which further emphasize the dominance of medical considerations over social and emotional ones. This has resulted in a proliferation in complex medical and surgical procedures such as renal hemodialysis, kidney transplants, and cardiac surgeries for individuals at increasingly higher ages. Kaufman et al (2004, p. 731) assert that these treatments have been "normalized as necessary and appropriate" for elders; that "medicine today is considered the right (and perhaps only) tool for managing the problems of aging." Speaking with social work colleagues employed in long-term care, I have heard a number of disturbing cases where family members and doctors insist on sending frail elders in their eighties and nineties to acute care in the event of cancer, heart attack or pneumonia, despite the fact that treating the elder will not improve quality of life and may, in fact result in more physical damage like broken ribs from performing CPR. Such emphasis on 'treatments' for aging again shifts our focus away from the emotional and social aspects of aging and from models of care that support the psychosocial needs of the elderly.

All of the above factors combined mean that the primacy of a medical focus is conceptually and bureaucratically embedded in the structure of many residential care facilities. In other words, creating a homelike environment for elders is less of a priority than caring for their medical and bodily needs. Ronch (2004, p. 64) mentions the "almost universal but unaddressed" tendency to "demonize the family and label as 'dysfunctional' the family members

who strive to bring the values of the family culture into the health care setting.” Having worked in a long-term care residence, I know how hard it is for families to assert their preferences for care over those of the medical staff. For example, it is often important to families and residents that the resident be able to enjoy satisfying and familiar food, but this can mean contravening the care plan of the facility physician, whose own goal is to reduce the resident’s sodium levels and prolong his or her life. Even routine organizational procedures in some residential care homes mimic the procedures of the acute care ward – residents in many intermediate and maximum care level facilities must wear hospital style identification bracelets from the moment they move in. Such medicalized trappings make plain the roots and structures of our system of elder care.

#### *Person Centred Care: Promise and Prescription*

In recognition of the psychosocial needs of elders in residential facilities, a body of literature and public policy has been developed that seeks to legitimize and operationalize more holistic and respectful models of elder care. Often referred to as ‘person-centered’ care, there is increased emphasis on involving elders in their own care, supporting autonomy, and encouraging those activities that enhance meaning for the individual. Crandall et al. (2007) state that person-centred care “requires health care professionals to plan with the individuals who require daily assistance in such a way that clients are honored and valued and are not lost in the tasks of caregiving” (p. 48). While there is no singular definition of this practice philosophy, the authors’ review of the literature identified six common elements of person-centred care: recognition of the personhood of the elder, knowing the person, maximizing choice and autonomy, quality care, nurturing relationships, and a supportive physical and organizational environment (Crandall et al., 2007, p. 48).

The Eden Alternative ([www.edenalt.org](http://www.edenalt.org)) is perhaps the most popular lay philosophy related to the culture change in long term care and it speaks to both person-centered care and

whole system reform. The Eden Alternative is a set of principles designed to improve the quality of life for persons in care homes, by encouraging active participation in directing their own care as well as opportunities to nurture and mentor (Appendix A). In line with Ronch's concept of 'humanization' of care (2004) where the relationship between care staff and residents takes priority, the Eden Alternative involves training of staff to become better partners in caregiving. Much of the focus is directed towards making the facility more like a home; part of the model involves creating neighbourhoods and overall there is an emphasis on maintaining a connection with the wider community through visits from schoolchildren as well as from pets and families. While not a prescriptive model for intervention or facility change, it has nevertheless become quite popular as a way of reframing elder care to include psychosocial considerations, and has several internationally affiliated homes and an online community of support ([www.edenalt.org](http://www.edenalt.org)).

Insofar as the discussion around person-centered care provides the possibility to balance the medical and psychosocial caregiving of elders who live in residential facilities, this philosophy is valuable. As stated above, however, there is no set definition of what exactly person-centred care comprises. Predictably, there is also a body of literature that describes the difficulty of actually practicing in this manner. Clemens et al (1994) studied nurse and social worker case managers for elders in the community, and discovered that even when the participants espoused client-centred practice, "inconsistencies were noted in what case managers said they did in general, and what they reported they did with specific clients in practice" (Clemens et al, 1994, p. 78). The authors suggest that these contradictions arise from attempting to balance their professional practice ethics with the realities and pressures of the long term care system.

Even the widely adopted Eden Alternative can be difficult to operationalize. One facility found that their large size prevented them from training all their staff in a timely manner

(Sampsell, 2003). As a result, the ratio of front-line staff with training was significantly lower than the middle and upper managers with training, which is inherently contradictory to a person-centered approach. This example speaks to the structural difficulty in successfully implementing truly individualized care, even when an organization initiates that change. Nursing and social work codes of ethics ostensibly encourage a client-centred approach (Clemens et al, 1994), but this becomes increasingly difficult in a fully institutionalized setting where residents' menus, mealtimes, activities, hygiene, personal space and finances are dictated by staffing levels, service contracts, and scheduling. Crandall et al. (2007) studied nine long-term care homes that were offered training, coaching and support to implement their person-centred goals of care and found that the degree of success varied considerably between facilities. The important point to be made is that person-centered care is a philosophy and not a practice model, meaning that even if a facility agrees to adopt such a philosophy of care, Eden or otherwise, there is no guarantee that it will be carried out consistently within and between care homes.

Another issue is the emphasis on personal choice and autonomy that seems to dominate the person-centred care literature. The reality is that residential facilities care for large numbers of elders who are physically frail or cognitively impaired, and practicing in a person-centred way in an institutional setting gives rise to difficult ethical dilemmas around personal choice versus the safety of staff and other residents. The work of Kitwood (1992, 1997) has been a major influence in the field of dementia care not only because it draws attention to the social and emotional aspects of what has typically been defined as a medical condition, but also because it challenges health care providers to consider how they will support such things as 'autonomy' in individuals who are no longer capable of independent decision-making or who exhibit behaviours such as aggression as part of their condition. Agich (2003) similarly argues that traditional liberal notions of autonomy, around which the concept of person-centred care

revolves, is not particularly useful or suited to application in the long-term care setting. “As a cultural ideal, autonomy usually involves a vision of individuals freely living their lives according to their own beliefs and values, with little interference by the state or others” (Agich, 2003, p.14). “Simply to rely on the core liberal understanding of autonomy...without inquiring into its practical implications for frail or disabled elders demonstrates a questionable apathy or insincerity at best” (Agich, 2003, p. 23). Lloyd (2004) provides an additional critique that is particularly relevant to the difficulty of realizing person-centred care in extended care facilities. She argues that the current emphasis on values such as autonomy and independence in gerontological care actually inhibits quality care as we age, for two reasons. First, the language promotes an idealistic image of aging that dissociates elders who are frail or dependent. Second, emphasizing liberal notions of *independence* neglects the reality and necessity of *interdependence* at all ages of life. “Thus the needs of older people at the end of life should be considered, not only in relation to their individual rights and claims but also in relation to their connectedness with others and the ethics of practices [sic] concerned with their care and well-being” (Lloyd, 2004, p. 247).

To summarize then, the current context of elder care in facilities involves the interplay between the physical structures and practice priorities of the medical model and the more recent ideals of a person-centered philosophy such as autonomy, choice, respect, and individualized care. The elder care community has embraced the notion of person-centred care, especially the Eden Alternative, which has been useful in refocusing attention on the social and emotional needs that are not accounted for in a strictly medical model of care. But the examples given above demonstrate that there are still some difficulties to be addressed in terms of implementing person-centred *practice*. Important debates about the assumptions of person-centred care, like the conceptualization and primacy of autonomy, have not been taken up widely thus far. Also, a

major methodological gap in the literature on person-centred care is the paucity of primary research on the barriers and supports to carrying out person-centred care in residential facilities. The few that have been conducted reveal the importance of organizational considerations when implementing Eden or other person-centred approaches (Chenowith & Kilstoff, 2002; Crandall et al, 2007; Deutschman 2005) but Canadian literature on the topic is limited. Further, research into the experiences of long-term care workers themselves is limited, which makes it difficult to speculate on how to overcome barriers in improving care for elders, or even what those barriers might be. To this end, I studied the experiences of social workers as they attempt to carry out person-centred care in extended care residences.

### Person Centred Care for Elders Research Project (PCC for Elders)

#### *Background*

My intention for this research was not to come to a set definition of person-centred care describing specific, measurable, interventions, nor to assert that this paradigm is the only way to provide optimal care for elders. Rather, I sought to explore the experiences of social workers in providing care to residents in an extended care setting, in order to identify the supports and challenges they faced in implementing a philosophy of care that has been embraced by the elder care community but has no explicit model of practice. I chose social workers specifically, because of their professional promotion of client self-determination as a core value (Canadian Association of Social Workers, 2005). My assumption was that social workers in residential care facilities would find the concept of person-centred care congruent with their orientation to practice, so reflecting on and articulating its application would not be an unfamiliar topic. Further, social workers play a key role in supporting the non-medical needs of elders and integrating those needs into the wider care provided by residential care staff. They are trained

outside the medical model but work within it, providing them with a unique vantage point from which to comment on the larger system of residential care.

I also chose to base my research in facilities that care specifically for elders who need the maximum amount of support due to physical or cognitive decline. In British Columbia, these are known as extended care facilities. I felt that this setting would provide the opportunity to illuminate any particular strategies that care staff use to address the complexities of autonomy and choice that are so central to person-centred care but that the literature has expressly critiqued.

This qualitative case study involved four female social workers employed in four extended care facilities in an urban centre in British Columbia; each facility identified as having adopted the Eden Alternative. To provide a wider context for their experiences, it also included one psychiatrist who had a key role in the system wide implementation of the Eden Alternative in a health organization in the same urban centre (henceforth known as a contextual interviewee). Both the social workers and the contextual interviewee participated in semi-structured interviews, and the social workers also completed a short journal exercise where they described self-chosen anecdotes, success stories, and observations of person-centred care in relation to their practice. The primary research question guiding the data collection was: How do social workers conceptualize and operationalize person-centered care within the context of their workplaces? The subquestions were: What do they identify as the supports and barriers to practicing in a manner congruent to this ideal? Are there considerations specific to extended care that influence how person-centered their practice can be?

*Person-centred care: The ideal and the real*

Participants were easily able to define how they conceptualize person-centred care; these definitions identified four interrelated aspects that were mentioned by all social workers. The

first aspect involves the related notions of choice, independence and individuality. Comments on this aspect spoke to the importance of “working with the resident and having them at the heart of the decision-making”, respecting individuality in preferences and decisions, providing support to make choices happen, having items accessible to increase independence, having personalized care plans and routines for residents, and working according to the resident’s schedule as opposed to that of the care staff. Related to routines, a considerable number of comments spoke to the ideal for flexibility and freedom within them, in terms of toileting, food choices, activity and getting up/going to bed. As one participant summed up, person-centred care involves “...allowing them to have that little bit of independence in an environment where they have actually lost a lot of control.”

A second aspect that social workers mentioned repeatedly in their interviews and journals is the importance of communicating directly with the resident to find out preferences and to solve problems. While this is similar to the above ideals of choice, independence and individuality, it is also something the participants identified as being a particularly crucial practice approach in the extended care setting where many elders have communication barriers related to medical conditions or dementia. One participant stated, “It’s one of those things that social work is a little bit adamant about...let’s make an effort to communicate with the person if we can, whatever level we can.” This sentiment was echoed by another participant: “...I think, even if they are deemed mentally incapable, or incompetent, you still have to approach them as though they are capable.” Several social workers gave examples of how they take extra effort with elders who have communication barriers, such as using translators, employing sign cards, modifying questions to yes/no format, or even creating a system of eye blinking to use with an immobilized resident. Further, the examples the participants gave demonstrate the effectiveness of direct communication in resolving a number of scenarios with residents who were otherwise

pathologized by care staff for behavioural problems. It was clear that social workers feel a personal and professional responsibility to ensure that the resident's perspective is continually sought, and that care staff do not make unfounded assumptions because of communication barriers.

Linking to this is the third aspect of person-centred care mentioned by interviewees - the notion of caring for the whole person. Statements related to this aspect spoke of the need to “[provide] care with respect and [talk] to them with respect”, to make the environment homey and comfortable, to support aspects of individuals that are beyond the physical body such as emotional, spiritual, social, expressive and sense-related needs, seeing people as more than their behaviours and disabilities, and ensuring culturally appropriate care. Many comments involved the importance of hearing residents' histories to help contextualize them as whole persons with experiences and personalities. As one social worker commented:

I think it's easier to be kind a person when you know them better, and so if you don't have the opportunity to get to know them better by, either them telling you, or by the people around them telling stories about them...it's harder to know them as a person; it's harder to see them as a person, and it's easier to neglect them in a way.

The final aspect of person-centred care mentioned by participants acknowledges the importance of relationships and engagement in the lives of residents. According to the Eden Alternative, this means “addressing loneliness, helplessness, and boredom in the facility.” Also commonly mentioned was another Eden principle - creating consistency in care staff assignments so that residents have the ability to create trusting relationships. In terms of engagement, two participants described the involvement of residents in things like collecting and folding bibs after meals, or in helping to decorate for special occasions. One participant stressed, however, that it should be activity meaningful to residents, “not forced activity according to the

activity calendar.” Similar sentiments mentioned creating “the opportunity for experience” and “the chance to give back.” Commenting on a charity fundraiser held at her facility, one participant described the change in residents: “...I’ve never seen the happiness the way the residents *owned*...the project. It was so good. When they have to give something they want to give their fullest. And it gives them a lot of happiness” (original emphasis). Another participant spoke of the incredible need to provide “long lasting companionship” in a residential setting, either by encouraging families, setting up volunteer programs, or by “reaching out and building the community. To say, you can come in! You’re welcome!”

Overall, the social workers demonstrated a common conceptualization of person-centred care as well as a professional and personal commitment to approaching practice this way and promoting it in their workplaces. However, many of their comments reflected a disjuncture between their articulations of the ideal verses the reality of the system. One participant summed up person-centred care at her facility by saying, “I think just because we say we do it doesn’t mean we always can.” Similarly, another stated, “We...accept that we should be doing it that way, but whether it is possible or not is...another question. Other participants described compromise, weighing, prioritizing, not being able to please everybody, and “bringing [families’] expectations down to...what we can [actually] provide.” Attempts to initiate volunteer partnerships were sometimes seen by direct care staff as either falling outside their job descriptions or as violating union codes. The journal entries speak to the personal effects of not being able to practice according to their values; the language and tone of the writing reflects feelings of being overwhelmed, frustrated, isolated, helpless, pressured and being the lone voice in a crowd. At the same time, the entries demonstrate a deep commitment to the residents and a drive to continually bridge the gap between the ideal and the real.

*Barriers to person-centred care*

As previously stated, social workers are uniquely positioned within their worksites to speak to both the structural and interpersonal context of providing person-centred care. This was evident in both the interviews and the journals; social workers offered many insights into the barriers that prevent a complete realization of person-centred care and the Eden Alternative in their respective facilities. These barriers and challenges can be grouped by those related to the institutional environment and those that are more structural and bureaucratic. Both of these aspects in turn relate to the specific challenges of the extended care environment.

All the social work participants mentioned the physical environments of their facilities as a major barrier to providing person-centred care – “it’s like going from home to a permanent hospital.” In fact, all the facilities where participants worked either were originally built to be, or still are, hospitals. This means that rooms are generally multi-bed “ward” rooms with little privacy and very restricted space for residents to personalize with their belongings. The private and semi-private rooms are often waitlisted and coveted. Residents coming into the facility have no choice over rooms or roommates – the beds are assigned according to care level. One social worker lamented the contradiction between encouraging new residents to feel at home while at the same time informing them of the restrictions on how many outfits will fit in their cupboard. Another social worker commented how little space they have in general at her facility; all functional, recreational and social activities must take place in one large, open room. There is nowhere for residents and families to visit privately and there is a lack of proper chairs or tables at which to visit. She commented: “We’re just fighting for the basic things in the environment to make this place, you know, look home-like so that people could feel comfortable and cozy.” Eden also involves dividing residential facilities into “neighbourhoods” to facilitate socialization and relationships, but one social worker described it as somewhat “artificial.” “It’s basically just

draw[ing] a magic line and saying, ok...this is one neighbourhood...” The contextual interviewee confirmed the challenge of the pre-existing physical limitations in implementing the Eden model given that there was no money in the budget for physical restructuring or upgrades during the conversion, but from her perspective she did feel that the shift to a neighbourhood system had produced positive results overall in terms of activity planning and socialization in the different facilities.

The other aspect of this institutional environment is the routinization of intimate tasks. Toileting, for example, was mentioned several times as a key area of struggle, where continent residents’ requests to be aided to the washroom are constantly negotiated with care staff who have a set number of tasks to complete and a routine in which to complete them; those who want to go frequently are often seen as difficult for disrupting this routine. Residents who use incontinence products must also wait for their allotted time to be changed. The ability to rise and go to bed according to residents’ own preferences is also curtailed in the institutional environment. One social worker imitated the care staffs’ reaction to a resident who liked to go out in the garden on summer evenings: “Oh my God, it’s seven o’clock and he’s not going to bed yet!” He resorted to “sneaking” downstairs in order to continue this enjoyable pastime, despite the risk of setting off the programmed alarms. This last point is reminiscent of Goffman’s concept of “total institutions” (Lemert and Branaman, 1997, p. 55), where “the barrier that total institutions place between the [individual] and the wider world marks the first curtailment of self.”

The issue of food and food quality was raised by all social workers. One participant observed:

It’s one of the biggest...losses they have when they come into a big facility like that, is the choice of when to eat, what to eat, food that goes along with your culture, foods

that you prefer, going to the fridge any time and getting a snack, eating when you're hungry...

The decision by the regional health authority to contract out food services was viewed as a deplorable move that directly impacts the residents' quality of life. Food was described as "bland", "yucky", and generally monotonous. Some facilities now have plastic or Styrofoam utensils and dishes, and condiments come in packages that are difficult for elders who have physical disabilities to open independently. The contextual interviewee commented that now the food services "are probably more institutional than they ever were." Further, she pointed out that food services staff are not facility employees and, as such, they do not have to participate in any Eden focused training. One social worker stated, "...they're working from a different perspective than we are, so they've got different goals...we have been trying to come to some sort of agreement with them; it's been quite difficult." These examples of the institutional atmosphere demonstrate a gap between the organizational goals of person-centred care and the most fundamental aspects of daily life that have the potential to transform the 'facility' into more of a home.

While routinization and an institutional model of care are general aspects of the structural system in which long-term care is located, participants also identified specific ways in that regulation, bureaucracy and policies create obstacles for person-centred practice. For example, there are regulations that govern food services, health and safety, admission to facilities, levels of care, staffing, and transfers between facilities. Each of these regulations was identified by at least one participant as operating in contrast to the values of person-centred care. In particular, the policy mandating that elders in acute care be placed into the first available bed in any facility in the metropolitan district having a vacancy at the appropriate care level was seen as infringing not only on the right of elders to choose where they want to live, but also as affecting the elders'

families who might then have difficulty getting to the facility to continue their caregiving roles. Further, social workers pointed out that it has an impact on both the established and incoming residents who are placed together regardless of personality, habits, or possible racism. The residents have the ability to apply for transfers to other facilities, but this in turn creates a large amount of paperwork for social workers and restricts their time with elders and families. This paperwork currently involves a standardized assessment form that categorizes elders into levels of care and medical conditions, another aspect that social workers find anathema to their professional values and the ideal of person-centred care.

Other, well-meaning regulations can also be a barrier to providing person-centred care. One social worker relayed the story of a couple that came to the facility and wanted to be in the same room; one needed a mechanical lift for transfers and the other did not. The room had two mechanical lifts, and because occupational health and safety decided it was a “waste” to not use the other lift for a resident who needed it the couple had to reside in different rooms. As the participant pointed out, this was a difficult scenario because of the need to balance a couple’s wishes against the need of another resident for a lift, and against the equally valid need to prevent staff injuries from unsafe transfers.

Finally, the staffing model in residential care was identified as creating obstacles to person-centred care. The ratio of care aides to residents directly influences how personalized and flexible the care plans can be. One participant acknowledged that, “[a] lot of the problems and compromises we have had to make with our residents and our staff is to balance a resident’s needs with a staff’s workload.” Two social workers commented on the fact that residential care is promoted to families on the basis of 24-hour care for their frail loved ones. However, this does not mean one-to-one care for all of the 24 hours; staff at one facility are responsible for six to seven residents per shift, which “makes the staff very, very stressful.” So while neighbourhoods

may have been created to build staff/resident relationships, there is actually little time to do so. (An interesting counterpoint is that in one facility, staff ratios have actually been reduced but the social worker feels that instead, staff use the time to “do their sudoku, or crossword, or their magazines.” This observation relates more to the attitude of staff, which will be discussed in the subsequent section.)

As mentioned, the staffing structure of the health authority places emphasis on the front line medical care staff, which means that allied health disciplines such as occupational therapy, physiotherapy, rehabilitation therapy, music therapy and activity programming positions are often part-time or minimally staffed. Social workers are extremely busy: a ratio of close to 200 residents to one or one and a half full time social work positions was common across participants’ worksites. The result of these combined factors is that the medical and physical needs of residents continue to take priority over social and emotional needs, despite the ostensible organizational attempts to shift the balance by adopting the Eden Alternative. One participant observed, “...the system...doesn’t understand the use of these people, those disciplines when it comes to nursing home[s].”

The environmental and structural challenges to providing person-centred care as described are also overlaid with additional considerations that are unique to the context of an extended care facility. The simple fact that many residents have restricted mobility due to any number of physical conditions means that their ability to act spontaneously or independently pursue activity is severely restricted. Acts like toileting or even getting out of bed become much more involved tasks for all parties because they often require careful transfers and special equipment. One social worker pointed out that even porting people to activities is more work intensive, because the elevators only accommodate so many wheelchairs at once and staff need to make several trips. Many of the social workers’ examples of practice challenges spoke of

residents with cognitive impairments resulting from brain injuries, strokes, and dementia.

Communication barriers and difficult behaviours often accompany these impairments, and social workers spend a fair amount of time collaborating with families, staff and residents themselves to resolve the issues in a way that is respectful. One participant identified this scenario as a “main struggle” in extended care, involving “a lot of moral dilemma” as well as the “clash” of “paternalism...and...autonomy.” While family are often called upon to speak on behalf of residents, this was recognized by one social worker to be moving a step away from truly person-centered care. She spoke to the fact that families often have different expectations and goals than do residents, so staff must be cautious in circumventing the resident in the interest of easier communication and expedient decision-making. Finally, the contextual interviewee identified the difficulty of realizing the full philosophy the Eden Alternative in extended care because, as a result of these physical or cognitive restrictions, “it’s harder to find the opportunities to give back. That’s where the real challenge is, right?” This sentiment was echoed by one social worker, who pointed out the need to create relationships between staff and residents – “not only [elders] receiving care, but giving care...It is so hard for staff to embrace that.”

#### *“Buy In”, Leadership and Organizational Culture*

Comments from the social workers both explicitly and implicitly identified the interrelated concepts of “buy in”, good leadership and healthy organizational culture as fundamental to how person-centred a residential facility can be. They gave examples of how absence or presence of these factors can either “sabotage” or greatly enhance the practice of person-centred care. One participant clearly captured the relationship between all three aspects, as well as the constant struggle to attain the ideal:

And that filters down from the resident services manager, because I think she really, really, truly believes even though, there are a lot of pressures and a lot of stresses and

people are tearing their hair out all the time, she really does believe that the person-centred approach is real and right and true and do-able at the individual level and so, that filters down through the leadership team and also then hopefully to the front line staff.

Similarly, the contextual interviewee made an observation on the organization-wide implementation of the Eden alternative: “probably the key principle in the whole thing is wise leadership. And leadership that *really* understands the degree of commitment to culture change and is willing to lead that” (original emphasis). The relationship between good leadership and organizational culture seems to be bi-directional in that one does not tend to exist without the other. One social worker described how Eden was easier to implement in her facility because the positive environment was pre-existent: “If you ask them they’ve always said they’ve always had it, they just brought a name to it...they brought the Eden philosophy in but we were using it *way* before it came in here” (original emphasis). In that facility, staff also commonly bring Chinese food in for the Chinese Canadian residents who are not catered to by food services. An activity worker also bakes bread with residents and passes it out among residents, families and staff. These staff view the facility as “their community.” Speaking further to the notion of organizational culture, the contextual interviewee said “if we’re not nurturing our staff, they can’t or don’t nurture the elders they look after. And again, the bigger the organization, quite frankly, the harder it is.”

The difficulty lies in the fact that these aspects are, at their core, dependent on individual attitudes, relationships, priorities, and values of the people who work in residential care, described as “buy in.” As the contextual interviewee pointed out, “you can’t really mandate attitude.” One participant quoted a thought-provoking question from the Eden Alternative to illustrate the different attitudes of staff that affect care: “do you live where I work, or do I work

where you live?” Staffing models in some facilities have been changed to allow front line staff more time for engagement with residents, but the reality as identified by social workers is that some staff simply do not want to work according to an external ideal.

While facilities have committees, guiding principles, reflexive activities and refresher courses related to the Eden Alternative, there is no set method for working through problems in a person-centred way beyond making every possible effort to accurately represent and support the preferences of a resident. Eden is used as a “filter” through which problems are examined and approaches are suggested. Again, this relies on the attitudes of leadership and staff and their openness to move beyond traditional approaches and structural barriers. For example, one success story involved being able to move in a resident as well as his two cats, who were his “livelihood” and his only close companions. This would not have been possible without a willingness to look creatively at the situation and figure out how to move beyond resistance and the routine. On the other hand, one social worker described her frustration over the management’s decision to disband the family council in reaction to some criticism. She saw this council as a key avenue for advocacy and engagement that she worked very hard to promote and support. As she stated, Eden should be implemented according to a “community organization approach. It needs to come from the grassroots up. It should not be thrust from up to down.”

### *Interpretation of Results*

The findings of the PCC for Elders research project indicate that social workers view their interventions as successful when they are able to meet the social, emotional and spiritual needs of residents. Their conceptual ideals of person-centred care closely match the six elements presented by Crandall et al (2007, p. 48): recognition of the personhood of the elder, knowing the person, maximizing choice and autonomy, quality care, nurturing relationships, and a supportive physical and organizational environment. The findings also support the literature’s

identification of philosophical, structural and organizational difficulties in implementing person-centred care. In bridging the gap, social workers often use their personal and professional skills, creativity, and empathy. Themes from their stories of success point to their consistent emphasis on communication with the resident or the next closest person to that resident in the case of cognitive or communication barriers. Further, social workers advocate for residents to be seen as whole persons; they use their psychosocial assessments and their interpersonal skills to uncover the stories of the elders and put them in a wider context. This is viewed as especially important in the extended care setting; having this context allows other care staff to see residents as more than their behavioural problems and their disabilities. As one social worker said, it is important to approach all elders as if they are capable, to hold this in mind and search for solutions and meaningful engagements that speak to that person's preferences. During the interviews and in the journal entries I noticed that all the social workers made use of empathetic positioning to guide them in their interventions. That is, when reflecting on specific examples or even the overall atmosphere of their facilities, the participants' narratives styles demonstrated that they place themselves 'in the shoes' of others as a matter of course when working with elders and their families. I think this holds a clue as to why social workers feel such a resonance with the concept of person-centred care and why they are such consistent advocates for its application in their worksites.

However, an underlying theme of the data seemed to be one of working within the constraints of a system that is structured in fundamental opposition to the fulfillment of social and emotional needs, and that simply ascribing to Eden or person-centred care has not quite been able to rectify that particular lack in a consistent way. As a result, person-centred care in residential facilities often consists of a series of compromises between residents, families, and the facility. While the Eden Alternative provides the philosophical mandate and permission for

social workers and other staff to justify particular interventions and strategies and to think creatively in problem solving, actually carrying out person-centred care is inherently tied to good leadership, healthy organizational culture, and the attitude of individual workers. Further, these creative measures are still essentially “band-aids” as one participant pointed out, because the larger system “dictates” where people go, what funds are available to improve the physical environment or how many social workers, music therapists and activity workers will be hired, and even the fact that elders are collected together and housed away from the larger community. The medical and economic model of the larger system continues to promote the binary definition of health and the primacy of budgets as the bottom line.

#### Beyond Person-Centred Care: Relationships as Remedy

The slow pace of change within large organizations means that while the system can make a shift in policy towards person-centred care, the positive effects may take a long time to be felt consistently at the individual level. As explained by Germain and Bloom (1999), in the course of meeting their objectives complex organizations are required to create rules and regulations to deal with both internal and external contingencies. These regulations require the hiring of administrators and the formalization of policies. “Because of their nature, rules and regulations may become more rigidly interpreted over time, so that the original intent of the bureaucracy is transformed into maintaining the status quo, rather than serving avowed goals, a process known as goal displacement” (Germain and Bloom, 1999, p. 76). The PCC for Elders research project illustrated that despite the health authority’s adoption of a person-centred approach, the process of culture change in these extended care facilities has not consistently been able to reach the real root of the problem – the need for meaningful engagement and reciprocal relationships where elders have a chance to give back and staff also feel personal rewards. This

interpersonal requirement is, arguably, the aspect of person-centred care that is hardest to encourage and enforce, because it relies on the attitudes and motivations of individuals. As a result, it means that person-centred care has a tenuous position in the health care organization, because changes in leadership can easily equate to changes in the way that Eden is interpreted and supported.

The question then is how to both foster the social and emotional aspects of care in ways that can reach through the layers of medical and bureaucratic structures to genuinely alter the experience of the elder living in residence. To do this, I believe we first need to widen the scope of our interventions beyond the individual elder to include the community in which caring takes place – both the relational community of care staff, families, volunteers, and social networks, and the physical community where the care facility is located. Second, I believe there is great potential to employ a grassroots model of community development where interventions grow upwards from the level of the residents in order to circumvent the bulky machinery of policy and to address the residents' non-medical needs more expediently. Expanding the scope of elder care beyond individual residents and the liberal definition of autonomy recognizes the reality that society is constructed from relationships, and taps into the potential for creative, nurturing and responsive approaches to care.

### *Through an Ecological Lens*

Before presenting the concepts of relational care and community development and how they can enhance our models of care for the elderly, I would like to briefly outline some major aspects of an ecological perspective, in order to frame a theoretical approach to changing the culture of long-term care.

An ecological perspective assumes that people and phenomena are best understood in the context of their wider environment. It “rests on an evolutionary, adaptive view of human

beings...in continuous transactions with the environment...[T]he ecological perspective provides insights into the nature and consequences of such transactions both for human beings and for the physical and social environments in which they function” (Germain, 1979, p. 7). Consequently, the ecological perspective emphasizes analysis within the physical and social environments based on spatial and temporal constructs. The “anthropology of space highlights... the way people respond to space and the arrangement of objects in space, and how their spatial behaviors influence and are influenced by the physical and social environments” (Germain, 1979, p. 15). Biological rhythms, social cycles, and temporal constructs in different social settings are also key environmental considerations. Both spatial and temporal constructs are themselves mediated by factors such as age, gender, culture, experiences, emotion and physical condition (Germain, 1979).

Another key concept is the notion of adaptation versus adjustment. “Adaptations may be directed to changing oneself in order to meet environmental opportunities or demands, or they may be directed to changing the environment so that physical and social settings will be more responsive to human needs, rights, capacities and aspirations” (Germain & Bloom, 1999, p. 20). Adjustment, on the other hand, occurs when an individual passively accommodates the environment, despite any detrimental psychological, social, emotional, or physical effects on the individual. “What makes the critical difference in respect to the active (adaptation) or passive (adjustment) distinction is whether or not the individual is in control of the decision-making process or is controlled by either internal or environmental forces” (Germain & Bloom, 1999, p. 21). Adaptation and adjustment then determine the “degree of fit” between a person and their environment; it is this degree of fit that forms the major point of focus and intervention in the ecological perspective.

In analysing the degree of fit, the ecological perspective also draws attention to the interaction between systems. “The model may...be visualized as ever-widening concentric circles of environment that surround the individual, moving from the nearest to the remotest” (Greene, 1994, p. 204). Bronfenbrenner (1979, in Greene, 1994, p. 204) described them as: the microsystem, which comprises the interpersonal roles and activities of face-to face interactions in the immediate setting (i.e. the family); the mesosystem, which encompasses linkages between two or more settings where the individual is involved (i.e. the family and the school); the exosystem, which encompasses linkages between two or more settings, one of which does not ordinarily contain the individual (i.e. the workplace of one’s parents); and the macrosystem, which “consists of overarching patterns of a given culture or broader social context.” The quality and availability of these interactions are again mediated by the social/historical location, life experience, gender and culture of the individual, as well as by the particular qualities of the institutions and systems with which they interact. The influence is seen as dynamic and bi-directional, where the individual and the system both shape, and are shaped by, each other. This emphasis on interaction and spheres of influence between systems is a useful tool for approaching culture change in long-term care, where the building blocks of ethical and compassionate care are the relationships individuals have with one another – coworkers, residents, families, managers, health teams, etc. Understanding how each echelon of relationships relates and interacts with the next concentric ring is valuable in understanding where the barriers are to fully carrying out person-centred care.

At a direct social work practice level, the ecological approach requires social workers to improve the level of fit for their clients not only at an individual level, but also at the larger system level. In this approach, “...professional function includes: *mobilizing community resources* to improve community life; *influencing organizations* to develop responsive policies

and services; and *politically influencing* local, state, and federal legislation and regulations” (Gitterman, 1996, p. 396, emphasis in original). Further, the responsibility of the social worker is to “create general discomfort with the status quo” in cases where an organization is unwilling to “bend an agency policy, make an exception, or stretch service boundaries” (Germain and Gitterman, 1996, p. 161).

As self-contained communities, residential care facilities are well suited for analysis based on environmental considerations. The institutional constructions of time and space, the interactions of staff, residents and families, the support or restriction of autonomy – all these things inform the experience of the elder living in residential care. Examples from the literature and from the PCC for Elders research project clearly demonstrate a “lack of fit” for many elders - and even for staff - in care facilities. Meaningful reform, using an ecological lens, would necessarily involve changes to the physical *and* the social /emotional environment. It would involve interventions that recognize the influences of social location, culture and gender of residents to mitigate passive adjustment to programs that do not quite meet their needs. It would require simultaneous monitoring of both the individual experience and the wider organizational culture. Instead of approaching care from an individualized and disconnected way, ecologically inspired care would view the individual in the dynamic context of the overall environment to see where meaningful interactions are blocked and where incongruent practices arise.

Arguably, the goal of altering the environment for a better fit for residents is also the goal of the Eden Alternative – its principles speak to the need for a nurturing environment, interaction from the community, and the importance of supporting care staff (Appendix A). But the literature and the PCC for Elders research project demonstrate that during implementation, the relational and interactive aspects of care can be lost in the machinery of the organization and its culture. As a result, person-centred care becomes more about helping the elder adjust to the

rigidly structured environment than about changing the environment itself. So while the goals of person-centred care and those of an ecological approach are quite similar, the benefit of the latter is that it contains within it two aspects that hold the potential for redressing the social and emotional gaps in elder care that have emerged in the application of person-centred care; namely, an emphasis on relationships, and the interaction between social systems.

### *Relationship-Centred Care*

As stated by Abel (1995, p. 42), “All caregiving involves emotions and relationships.” In a facility where the entire premise for existence is the care of elders, this statement speaks to a web of relationships connecting residents, front line care staff, social workers, occupational therapists, activity workers, physiotherapists, rehabilitation assistants, doctors, volunteers, families, management, laundry and food service workers, cleaners, porters, administrative staff, and paid companions. Consequently, the emotions and relationships that arise between these various individuals and teams contribute greatly to the underlying social environment of a care home. Echoes of this sentiment were clearly voiced by the participants in the PCC for Elders research project: they recognized that simply mandating an Eden Alternative staffing or programming model is not enough to overcome the barriers of poor organizational culture or care staff who are motivated only by a paycheque. The contextual interviewee also spoke to the effects of promoting a model of care that is only ‘person-centred’ – she acknowledged that focusing so much attention on the residents and their priorities in some ways marginalizes the legitimate needs of the carers, who have an incredibly difficult job. In her study of three long-term care facilities, Deutschman (2005) heard similar reports from managers and administrators, who commented on how improvements in job quality for staff led to an overall motivation for better resident care.

In addressing these types of observations, Ronch (2004) proposes a movement of 'humanization' in elder care that

...requires that the 'how' of care to take priority over the 'what' of care. A further extension of this idea is that the 'how' of care directs our attention to the relationship between those who participate in the act of care, i.e. provider and recipient...That transition...makes it crucial to consider the needs of the care provider of equal importance to the needs of residents in the institution if the culture is to be humanized. (p. 63).

Part of this humanization would need to come from management and the health care authority, in the form of wage and benefit incentives, outlining clear expectations for conduct, and obvious demonstrations of the organization's support for its staff. As well, it would need to include exercises in team building, collaboration, and other initiatives that are part of fostering good organizational culture. But another integral aspect of this movement towards humanization would involve creating space within the structure of the organization and practice where staff have the ability to connect or reconnect with the idea of "care".

As an example, Bulfin (2005) describes a project undertaken as a partnership between a college of nursing and a community hospital in Florida. The goal of the project was to translate a nursing theory, nursing as caring, into practice in the emergency and oncology units. "The first and most basic premise of the theory is that all persons are caring and that caring is an essential feature of being human...Knowing self and other as caring, then, directs one's actions and enables one to live caring moment to moment" (Bulfin, 2005, p. 314). Further, "caring is uniquely expressed in nursing as the nurse who is intentionally and authentically present with another who is recognized as a person living caring and growing in caring" (Bulfin, 2005, p. 314). The project first garnered the support and collaboration of the administrators and nurse leaders before leading the nurses in a series of reflective activities that encouraged them to

describe and share expressions of their caring in their practice. The process also supported them in learning how to hear their patients' specific requests for care and to see them as whole and caring persons in their own right. Eventually, the terminology of the nursing as caring theory was incorporated into the change of shift reports, which served to legitimize this approach to caring in the overall structure of nursing in the units. Qualitative and quantitative data reveal the genuine effects of this project; patient satisfaction scores improved and comments from staff indicated that the reflection on caring not only awoke them to the internal reward of caring but strengthened their feelings of care for one another.

This emphasis on recognizing the humanity in the other is reminiscent of the work of Martin Buber (1970). For Buber, there are two central ways of being in the world: I-It and I-You (in some translations referred to as I-Thou). Relating in an I-It manner is unidirectional – one is detached from the other, the individual actor views and judges the other only in terms of what effect the other may have on oneself. The other is an external variable in one's own experiences. Relating in an I-You manner, however, requires engagement, presence, and authenticity. "The basic word I-You can only be spoken with one's whole being. The basic word I-It can never be spoken with one's whole being" (Buber, 1970, p. 54). Further, he asserts that, "the longing for relationship is primary" (Buber, 1970, p. 78) and that we only become ourselves through our reciprocal encounters with You.

Building on some of these tenets of Buber as well as arguments from psychology, philosophy and ethics, the late Kitwood (1992, 1997, 1998) constructed a body of work around the notion of 'personhood' and the moral component of care for elders with dementia. Personhood, as he has defined it, is "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect, and trust" (Kitwood, 1997, p. 8). Therefore it has less to do with what the individual knows of him or

herself, but whether the other chooses to recognize and share in that individual's humanity. In the case of persons with dementia, this is a crucial factor, since late stages of the disease require that others actively maintain the personhood of that individual – his or her life story, preferences, and intrinsic worth – in the face of a “shattered” sense of self. “The self that is shattered in dementia will not naturally coalesce; the Other is needed to hold the fragments together” (Kitwood, 1992, p. 285). The social workers in the PCC for Elders research project demonstrated an innate sense of personhood as they described how they approached elders with cognitive impairments “as if they are capable”, and how they actively sought to integrate personal history and family knowledge in the care of such elders. In the face of behavioural challenges or other issues, these social workers used their knowledge of that person to guide and contextualize the interventions they chose, and in several cases it was persistent reflection and exploration with a particular elder about his or her preferences that led to successful resolutions.

As Kitwood (1998) points out, this kind of caregiving is more involved than the traditional physical nursing and bodily care in most care homes; it is more the realm of broad “moral education.” However, he states, “it is remarkable how little attention has been given as yet to the topic of providing a moral education for those who will work, or who are already working in the so-called caring professions...Many people enter these professions very poorly prepared for the tasks that they will face” (¶ 5). To counter this, he and his colleagues at the Bradford Dementia Group in the UK created experiential learning exercises for careworkers working with elders who have dementia. Like the nursing as caring project, one type of exercise involves reflection and discussion of cases, and is further meant to demonstrate the dangers of oversimplifying situations or making assumptions about the elderly characters. A second exercise involves taking a personal history of a resident and relating some aspect of it to practice – again this is similar to the nursing as caring project in that it involves both getting to know the

unique and personal qualities of another, as well as translating that knowledge into the work of caring. A third and very powerful exercise employs role plays meant to simulate life as a person with dementia.

“An exercise of this kind has much to contribute to a careworker’s moral development, principally along two lines. i) It is a powerful way of transcending the existential divide which so often separates people with dementia from the rest of humankind: for developing a deeper level of empathy...ii) This exercise is an encounter with the defence processes that so often get in the way of authentic moral engagement, creating a distance and impersonality. (Kitwood, 1998, ¶ 31-33).

This is not to say that careworkers are solely responsible for the state of care in residential facilities - Kitwood recognizes that there is tension between the moral imperatives of care and the structural restraints and responsibilities of employees. The benefit of these exercises though, as with the nursing as caring project, is that they have the potential to create reflexive and authentic carers, to foster a personal reason *to* care, and further, that they focus attention on the bi-directional *relationship* of caring. In other words, they can be an important part of getting employees to ‘buy in’ to the idea of person-centred care and perhaps experience the personal reward of engaging with residents in a humanistic way. To use Buber’s (1970) language, the elder then becomes You and not It. The same can be said of the elder’s view of his or her carer – thereby completing the circle of the relationship. Putting myself ‘in the shoes’ of an elder, I can imagine that it would be easier to accept all manner of intimate caring if I were to know my care aid as more than It - as a multidimensional person with a family and hopes and fears. Recent scholarship has termed this approach ‘relationship-centred care’, and views it as an evolution of person-centred care (Nolan, Keady and Aveyard, 2001; Nolan, Ryan, Enderby & Reid, 2002).

The value of relationship-centred care and related exercises is not only that they can improve the overall culture of the care home, but also that they strengthen the ability and willingness of staff to support residents in their preferences and their decision-making. As pointed out by the social workers in the PCC for Elders research project, having a sense of an elder's history, preferences, personality and unique circumstances is extremely valuable in being able to offer appropriate choices for care, and it also enhances the staff's desire to collaborate rather than dictate. "Dependency in some aspects of life does not lead to dependency in all aspects of life" (McCormack, 2001, p. 437), meaning that a positive relationship between elder and carer allows for the elder to take control in those areas where they are still independent. A resident may not be able to dress him or herself, but s/he may still have strong preferences of what to wear. The process, however, is relational, in that it involves negotiation and collaboration within an "interconnected" relationship (McCormack, 2001) between the elder and the care staff. Of course, these choices must be meaningful and be supported by the wider structural environment so that 'choice' is not simply reduced to choosing between unsavoury options such as going to bed at six or going to bed at six-thirty because of staff shift changes. The promise I see in relationship-centred caring is that eventually residents, front-line and administrative staff would begin to relate to each individual other as You, creating an environment more like a natural community where all members feel that their social and emotional needs are met and respected.

*Community Development: Inviting the Outside In*

The decision to move to residential care is not a decision most elders relish. Imagine for a moment that you are an 86-year-old woman who has recently lost the use of her legs and one arm to a stroke. After a period of recovery in the hospital, it is determined by medical staff that you will probably not recover functional use of your limbs and you will require 24-hour care

because of your new difficulty with simple tasks, like using the toilet, bathtub, and manoeuvring around your home. Reluctantly you agree to move to a facility, and because you are moving directly from the hospital you must follow the provincial stipulation to move to the first available appropriate bed. Your new 'home' is located in an area of the city you are not familiar with. There are no shops, parks, or attractions nearby and you cannot leave the facility without the assistance of your daughter, who works full time and cares for her own children. Prior to your stroke you lived alone but were an active member of your local seniors' centre, and you enjoyed visiting friends there almost daily. Your social worker looks into booking a special bus for you to continue to attend it, but the company does not prioritize social visits and the care staff seem reluctant to get you ready on the days when it is available. She suggests hiring a paid companion, but you are on a fixed income, and besides – what would you talk about with someone so young? The idea of attending a seniors' day program does not appeal to you – all the elders look so frail! - so you decline the offer. Your friends are uncomfortable visiting you in this institutional environment, and the bus route to your new neighbourhood is unfamiliar. In the seconds it takes for a stroke, you have lost your familiar routines, pleasures, and most importantly, your network of social support. You are now isolated in a 'ghetto' of frail elders; an island surrounded by busy intersections and noisy streets. Without assistance, you are essentially cut off from the wider community, where you have lived for over 40 years.

This narrative illustrates several ideas. First, it demonstrates a decided 'lack of fit' between an independent-minded elder and the institutional facility she finds herself in. It also speaks to the complex period of transition and adjustment/adaptation that many elders face when having to move to residential care. Finally, it illuminates the 'lack of fit' between institutional care and the wider communities where they are associated. The discussion on relationship-centred care provides some direction on how the quality of care can help to ease the transition

and make a better interpersonal fit for elders in residential care, but I also see a potential role for community development initiatives to make links between care facilities and the external community, thereby increasing the flow of support and mutual benefit between social systems.

According to Ife (2002, p. 2), community development “is seen as the process of establishing, or re-establishing, structures of human community within which new ways of relating, organising social life and meeting human need become possible.” In his conceptualization, it contains principles of both ecological and social justice approaches.

The social justice perspective provides a vision of what is socially *desirable*; a society based on equity, empowerment, the overcoming of structural disadvantage, freedom to define needs and have them met, the definition and guaranteeing of rights, and so on. The ecological perspective provides a vision of what is *feasible*, and outlines the kind of society that will be viable in the long term, namely a society based on the principles of holism, sustainability, diversity, and balance (Ife, 2002, p. 79, emphasis in original).

Ife (2002, pp 80-81) goes on to describe five characteristics of community. First, there is the human scale of interaction; that is, interaction on the micro level where it can be controlled and shaped by individuals. Second, there is a sense of membership, identity and belonging, which becomes part of a person’s self-concept. Third, there is obligation in the form of the expectation for at least some participation in and contribution to the ‘life of the community’ for its maintenance and survival. Fourth, the quality of interactions is such that people have a greater variety of roles than in the structures of mass society, which allow them to engage more as ‘whole people’ than as limited and discrete categories (i.e. my co-worker John from accounting is also a coordinator at my community garden project). Finally, community is “an opportunity for an antidote to the phenomenon of ‘mass culture’...[It] enables the valuing, production and expression of a local community-based culture” which has unique characteristics and

opportunities for active production rather than passive consumption (p. 81). The benefit of community *development* is the potential for organic, responsive and empowering initiatives that are defined by the community's self-identified needs and that maximize the positive attributes and strengths inherent in that community.

Returning to the concentric rings of the ecological perspective, residential long-term care facilities can be seen as a system within a larger system or, I propose, communities within a community. A shift to relationship-centred care could be seen as a community development approach, in that it promotes increased feelings of membership and the expansion of roles from I-It to I-You. It also works to promote empowerment via a dynamic and collaborative approach to decision making. Turning our attention to the larger community, I propose that a community development approach could also be used to invite the outside in, to connect or reconnect elders with supports and services that fill the social and emotional gaps in institutional living. To illustrate using the above narrative, a community development project in this case might involve a program to link seniors' centre members and volunteers in any number of programs – peer visits, quilting, exercise, gardening et cetera. Or, like the example given by a participant in the PCC for elders study, initiatives could also include charity campaigns where elders raise funds with their handicrafts and donate this money to a cause of their choice. Such a campaign would foster feelings of empowerment, connectedness and usefulness among the elders, and possibly the facility as a whole as the campaign progressed. Because of the physical frailty of many elders in extended care facilities, it would be more likely that the seniors from the centres would be coming into the care homes, but this 'cross-pollination' of elders would expand the social and geographical horizons of both groups. Some facilities already encourage visits from schoolchildren, but I think there is a particular opportunity to invite the participation of elders from the outside community, given the similar age cohort and potential for friendships.

A criticism of this approach might be that elders on the ‘outside’ may not feel comfortable attending programs ‘inside’ a residential facility where, truthfully, the biomedical atmosphere can overwhelm social events and where they are confronted with very real examples of disabilities and decline associated with aging. But what are the roots of this argument? What is to be gained by keeping certain groups of elders isolated in their biomedical ‘ghettos’? Frankly, I think this criticism is based in ageism. As described by the PCC for Elders participants, the physical environment is still very hospital-like; wheelchairs and medical supplies are sometimes stored in hallways because of a lack of space, meals often come from external contractors on plastic trays, and there is very little room for elders’ personal belongings. But continuing to encourage a distinction between community members outside a facility and community members within it means that any sort of recognition and reform of the conditions within long-term care will be slow and disjointed. The isolation of elders in care homes means that they are politically and socially marginalized, making it easy to overlook this population when drawing up health care budgets and priorities. In line with an ecological perspective, inviting the outside in would create a dynamic flow of resources, information and connection between systems, so that the care home both influences, and is influenced by, the larger environment.

In general, the idea of community development with elders in residential care speaks to the concept of citizenship. While advocates in the field of elder care are moving towards a notion of personhood as outlined by Kitwood (1997) to promote the relational aspects of care, “one of the main boundaries of personhood is its lack of political dimension. In cognate literatures, including social gerontology, critical psychiatry and disability studies, a citizenship lens is used to promote the status of discriminated groups of people to that of an equal citizen, with the same entitlements as everyone else” (Bartlett & O’Connor, 2007, p. 108). By opening

up the confines of the care home to the wider community, the residents have the opportunity to exercise their rights as citizens and to have their needs recognized as legitimate.

Ranzijn (2002, p. 31) asserts that “the potential of older people to influence individual and community quality of life is unknown and relatively unexplored.” His work demonstrates that older people make numerous contributions to benefit their individual and community networks through activities such as caregiving, mentoring, volunteering, and providing informal help to friends and family when formal services fall short. As a result, he asserts “[a] paradigm shift in attitudes to older people is required, towards viewing them as a resource rather than a burden” (p.30). During my employment at a local seniors’ centre, I was privileged to meet and work for several inspiring and deeply political older adults who are strong advocates for the rights of elders. They have a wealth of connections, experience, and talent that they use to apply political pressure from their various positions as coalition members, board chairpersons, and activists. Examples such as these show that elders are *already* involved in their communities – applying a community development approach would not be a foreign or difficult concept for this group. Extending this opportunity to those who are not already involved increases community capacity to creatively meet the needs of its members.

### Conclusion

I began this paper with a critique of the biomedical model of elder care and its ‘treatments’ for aging. From the critical literature on this model of care, it is clear that structuring our system of elder care around this model overlooks the need for a more holistic approach that includes continued opportunities to grow, to nurture, and to participate in life. In response, ‘person-centred care’, including the Eden Alternative, has emerged as a care philosophy that has been widely embraced as a new ‘gold standard’ for residential facilities. However, both the

critical literature and my research project studying social workers' experiences of providing person-centred care in extended care facilities demonstrate that factors such as organizational culture, the particular considerations of physical frail and cognitively impaired elders, and lack of staff 'buy in' can impede its application. The concept of 'autonomy' as employed in person-centred care does not recognize the dynamic and interconnected ways people make decisions, and it does not address the realities for persons with cognitive impairments. Essentially, adopting a person-centred approach does not guarantee that the social and emotional needs of residents will be met – reforms often have difficulty reaching down through the machinery of bureaucracy to significantly impact residents' quality of life. Therefore we must remain critical of the current state of care for elders, not only in terms of the medical model, but also in terms of person-centred practice. There is a danger in becoming too attached to a popularized model of practice such as Eden without ongoing reflexivity, and person-centered practice is likely only the first step away from the traditional medical model.

There is a growing body of critical literature that proposes a shift towards a relationship-centred model of care. I have argued that this shift is appropriate because it supports quality care for elders at the same time as it works toward improving organizational culture through valuing the care staff. I also proposed that principles of community development be applied to residential care facilities in order to create bi-directional linkages to the wider community that support the emotional and social needs of elders in care and that legitimize them as political citizens. Both relationship-centred and community development initiatives are congruent with an ecological perspective, where the emphasis is to creating a better fit for individuals within systems. As the population of baby boomers ages, and as many of us move ever closer towards old age, we cannot afford to ignore the necessary reforms to our system of long-term care.

### Appendix A: The 10 Principles of the Eden Alternative

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

From: <http://www.edenalt.org/about/our-10-principles.html>

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