

Running Head: PERSON CENTERED CARE FOR ELDERLY WITH DEMENTIA

Implementing Person Centred Care Strategies for those with Dementia in Residential Care: An Integrative Review of the Literature

By

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Abstract

Many people with dementia in the moderate to later stages require around the clock nursing care in a residential care facility. Nursing homes or residential care facilities have developed from a past that focused on the physical care rather than the needs of the whole person. Person centered care (PCC) is a holistic model of care that recognizes all the needs of a person including, physical, psychological, social and spiritual. It is the preferred model of care for those with dementia in residential care. The transition from an institutionally based nursing home to a person centered home is not an easy one. There are many changes that need to take place and the literature has lessons to be learned that can be shared. This project is an integrative literature review on research on person centered care initiatives with the goal of providing a “how to” guide for other facilities making this change. The research provides insights into successful implementation of person centred care including style of management, methods of knowing the person in care, education strategies, and practical strategies in using multi-sensory environments and bathing. While the journey of moving to a person centered model is not an easy one, it is a journey towards improving the quality of life for those who live in residential care and as such it is well worth the effort.

Introduction: Statement of the Problem

In my position at a residential care facility for 90 people with dementia I often hear that the person coming into care once stated that they would rather die than come to a nursing home. I also learn about spouses or other family members' who promised their loved ones they would never take them to a home however after struggling for months or years, realize they can no longer be the caregiver. They are then faced with the guilt of placing their loved one into care. I also hear profound sadness in the voice on the other end of the phone when I offer a room to a family who has put their loved one on "a list" for care. Despite what has been taking place, this phone call in most cases seems to come too soon. I have to believe that we can do better than provide places that most people hope they will never reside.

The facility where I work is embarking on moving our facility from an institutional model to a "human habitat" where every resident can live lives that are full and abundant. We are, therefore, in the process a profound change in our model of care delivery. The literature is filled with research and lessons to be learned for ours and other facilities to improve care for those with dementia. This purpose of this project is to pull these lessons together to provide a comprehensive guide for best practice in dementia care.

Population Trends and Prediction: Dementia

The media and journal literature reveals that Canada, including BC, is unprepared for the number of people who will be diagnosed with dementia in the years to come. In 1991, just over a quarter of a million (252,600) elderly Canadians were afflicted with some form of dementia. Nearly two thirds (64%) of those with dementia were diagnosed as having Alzheimer's disease, the remainder being almost equally divided between vascular (19%) and other forms of dementia (17%). Because women tend to outlive men, the majority of seniors with dementia were women (68%) (Statistics Canada, 1996, p. 8). A new report entitled "Rising Tide: The Impact of Dementia on Canadian Society" written by the Alzheimer Society of Canada in 2010 states that Canada "can expect a several fold increase in dementia in the coming decades" (Alzheimer Society of Canada, 2010, p. 8).

Turning our spotlight onto B.C., the British Columbia Medical Association (BCMA) refers to dementia as "a 'sleeping giant' that our health care system is not prepared for" (BCMA, 2004, p. 5). The statistics are alarming as BC projects an increase in numbers by the year 2011 to be up by 22% to reach "at least 55,000 people" (BCMA, 2004). "Today people over age 85 are the fastest growing segment of BC's population. Unfortunately, one third of this age group also suffers from some form of dementia" (BCMA, 2004, p. 9). Vancouver Island and the Okanagan area have the "highest proportion of seniors in their population" (BCMA, 2004, p. 15). A major reason for the concern is related to the cost of providing care for this population. "The annual cost of dementia increases dramatically as the severity of the disease progresses. Mild Alzheimer's cost is an estimated \$9,451 per year, but this increases to \$36,794 per

year for people with severe Alzheimer's. The primary reason is as severity increases, so does reliance on nursing homes" (BCMA, 2004, p. 17). This raises the issue of resources which are insufficient to meet the current need. Indeed, "there are long waiting lists for public long term care facilities, limits on the number of hours available for home and nursing care, and limited ability for Health Authorities to help families work through the system" (BCMA, 2004, p. 22). This is not meant to promote fear, rather, it is to acknowledge that we need to begin to prepare for the future with the knowledge that dementia will be an increasing challenge to the health care system. For many people who have dementia, residential care is eventually a reality. "Nursing home placement (NHP) is a common, major event in the natural history of Alzheimer's Disease (AD). Approximately 75% of AD patients eventually reside long term in nursing homes" (Knopman, Berg, Thomas, Grundman, M, Thai, & Sano, 1999, p. 714).

The BCMA's document "Building Bridges" calls for the government to make dementia a priority in BC. "Given our aging population and the implications for the health care system, dementia should be a higher priority issue for the BC government, as it has been in other provinces such as Ontario, Manitoba and Alberta. Currently this is not the case" (BCMA, 2004, p. 20). It is true that BC does not have a "dementia lens" on health care developments. If it did, we would be ensuring that all staff who work in long term care have education in the area of dementia, we would make all acute care centres 'elder friendly' (they are not at the present time) and we would be carefully reviewing the staffing needs for this population which are unique from the staffing needs of other populations. Another issue identified as a challenge by BCMA is the fact that dementia is a chronic disease that requires a great deal of time and follow up, this fact and the fact that there is a lack of family physicians in the province is a concern.

While this is not a nursing issue, it has implications for the role of the Advanced Practice Nurse (APN) with the elderly with dementia.

Dementia and the Need for Residential Care

People require residential care for a variety of reasons, however, many people need twenty four hour nursing care due to cognitive decline that meets the definition of dementia. It is estimated that two thirds of the population living in residential care had a form of dementia (Nazarko, 2009; Gaspard, 2009). Dementia is a devastating condition that presents clients and their families with a series of losses with nursing home placement often viewed as a major loss for all. Dementia is defined as “a complex, degenerative condition that erodes an individual’s cognitive abilities. It is a vicious disease that over time steals people’s memories, talents and even their identities” (BCMA, 2004, p. 5). Dementia is relentless, irreversible, and considered a terminal disease. It steals a person’s cognitive abilities and makes them a stranger with their loved ones and in their own home and neighbourhood. Dementia results in “impairment in higher brain functions such as memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgement and executive function to a degree sufficient to affect daily activities” (Provincial Dementia Service Framework Working Group, 2007, p. 3). Although dementia is not a normal part of aging, the “chance of developing dementia increases significantly with age” (Provincial Dementia Service Framework Working Group, 2007, p. 3). Therefore, as the population’s ages the number of people with dementia will increase. Dementia progresses through the stages of mild, moderate and severe and the amount and type of care that is needed changes throughout the stages. Once a person has reached the severe

stages they “cannot be left unsupervised and require total assistance in all activities of daily living” (Provincial Dementia Service Framework Working Group, 2007, p. 19). Caring for a person with dementia can be extremely difficult due to a person with moderate to advanced dementia being unable to perform their own activities of daily living. In addition, care is often difficult when various behaviours associated with dementia occur such as “sleep-wake cycle disturbance, screaming, crying, repeated calling out, and pacing. These behaviours are difficult for family members to manage and can lead to carer distress and placement of people in residential care” (Chenoweth et. al. 2009, p. 317). The job of caregiving is “hard – physically, emotionally, and financially. Caregiver stress has been shown to be a significant predictor of early institutionalization for the person with dementia” (Alzheimer Society of Canada, 2010, p. 53). Nursing homes offer a host of benefits for people with dementia including “twenty-four-hour supervision, emotional relief for families, safety and fewer restrictions for wanderers and increased opportunities for social stimulation” (Zimmerman & Sloane, 1999, p. 63). While these benefits exist, there are number of flaws with the way residential care is provided to those with dementia.

The Problems with “Nursing Homes”

When a person commits a criminal offence such as murder they are given a trial and if found guilty, they are secured in a locked environment and their needs are managed within an inflexible and efficient routine. Unfortunately something very similar happens to many frail elderly whose only crime is developing moderate to advanced staged dementia. Residential care or nursing homes are often extensions of hospitals with rigid schedules and rules with the medical model in the forefront. “Unfortunately, the image projected in many nursing homes, despite providing good care, is institutional, cold, regimented and dominated by daily life activities. The focus in most nursing homes is on treatment with little emphasis placed on helping the residents cope with loneliness, helplessness and boredom” (Robinson, 2007, p. 121). This is due to the fact that “like hospitals, nursing homes are currently organized around providing medical and supportive services” (Thomas, 1996, p. 25). In fact, the typical nursing home is institutionally based and as a result “focus on nursing tasks, medication administration, care routines, policies and a hierarchical structure” (Gaspard & Garin, 2009, p. 23). There are a number of explanations as to why residential care provides care in this way including the historical origins of nursing homes, organizational focus and the tendency to objectify people with dementia

Historical origins of nursing homes:

How residential care settings operate today are largely based on how nursing homes have evolved over the years. In the early 1900’s some elderly with Alzheimer’s Disease were institutionalized in mental hospitals but the majority were housed in almshouses or poorhouses (Lacey, 1999). Those in hospitals were the more fortunate as

“almshouses were notorious for their unsanitary, crowded conditions, inadequate food and abusive care” (Lacey, 1999, p. 105). The elderly with dementia remained in almshouses longer than other populations who were transitioned to other forms of care. During the time period between 1900 and 1940, many elderly people with dementia were transitioned to mental hospitals. It was during this time that the “medicalization of institutional care” occurred (Lacey, 1999). Out of this came the focus of medical conditions, chemical and physical restraints to manage people with behaviours in larger numbers than seen before. In the period between 1940 and 1950, the “nursing home” was born (Lacey, 1999; Morris, 1995-1996). “For better or worse, nursing homes were encouraged to adopt a “hospital based system of health care” (Lacey, 1999, p. 108). By the 1960’s and 70’s the focus of care changed somewhat from “warehousing” the elderly with dementia to trying to find methods of rehabilitation and improving the quality of life. It was during this time period that therapies such as music and horticultural therapy for the elderly with dementia began (Lacey, 1999). While there were strides made at this time, the central focus in care homes was on the medical problems and ways to focus on these in an efficient manner. Residential care as we know it today has a somewhat sad beginning from poorhouses to mental institutions to nursing homes. Many of the problems we experience to this day are related to the impoverished history that led to what we know today as long term care centres for the elderly with dementia.

Focus on the biomedical or medical model of dementia

Nursing homes are founded on the biomedical model. With this positivistic care model the caregiver relates to a person through their diagnoses or disease and tends to

focus on the appropriate therapy, usually pharmacological as their primary care delivery (Hill, 2008; Penrod, 2007). The biomedical model focus is on “disorder, dysfunction or deformity that is located within an individual. This has been termed the “pathology orientation” or “deficit orientation”. In this model, disability can be classified, quantified, measured and standardized” (Smart, 2009, p. 4). “The traditional focus of nursing on physical features of activities of daily living has been derived from the biomedical model of acute care, and the resulting neglect of psychosocial needs means that many people with dementia spend long hours alone and emotionally distressed in residential care” (Chenoweth et al., 2009, p. 317). The biomedical model, while perhaps strong in the physical realm, fails to address the elements of social involvement, psychological or spirituality factors that often play a very important role in one’s life. The history of the current residential care home is based on the medical or biomedical model which “is a form of colonial patronage that is becoming more and more influential in nursing. Such colonization takes the forms of powerful discourses...that pervade all spheres of nursing: research, education, administration, and practice (Holmes, Roy & Perron, 2008, p. 42). Indeed “nursing homes have represented the medical model since the 1950’s” (Lacey, 1999, p. 124). Those who live in nursing homes are generally there due to a health problem and therefore “many people find themselves at the mercy of providers in facilities that focus on maintenance of the physical condition, to the neglect of the person with that condition” (Coker, 1998, p. 435). As we turn our lens to dementia, which has been “understood as a biomedical phenomenon, a disease with a trajectory of irrevocable decline resulting primarily from neurodegenerative changes” (O’Connor et al, 2007, p. 122) one needs to know that the focus of care in dementia has been largely biomedical rather than holistic. The

biomedical model, while perhaps addressing the physical needs of a person, is an inappropriate model for residential care. Researchers have realized that the trajectory of dementia is not as clear cut as they once thought. They now realize that the social and physical environment plays a role in the progression of the disease and can be adapted to optimize a person with dementia's life (O'Connor, 2007). In addition, while residential care employs a very strong biomedical model, "people living with the disease and their caregivers are the experts on what quality of life means to them, and how they are functioning in their normal environment, and they are often the first to notice changes in function throughout all stages of the disease" (Provincial Dementia Service Framework Working Group, 2007, p. 20). Therefore while the medical or biomedical model of care in residential care addresses the physiological area of a person, it ignores the social, psychological and spiritual areas which play a very important role in one's quality of life. If we focus on our illness only, we lose sight of the "person" with dementia and factors which also play a role in that persons quality of life.

Institutional focus

Nursing homes are designed to be efficient, routine based and focussed on institutional goals rather than the unique needs and preferences of each individual resident (Bergman-Evans, 2004). Residential care facilities that employ the "institutional model of care often fail to meet the emotional, social and spiritual needs of elderly residents with dementia (Gaspard & Garm, 2009; Hancock, Woods, Challis & Orrell, 2005, Nazarko, 2009). This is largely due to the fact that those with advanced dementia lack the cognitive and verbal skills needed to communicate their needs and therefore inappropriate care practices are a potential and real risk (Kontos & Naglie,

2007). Nazarko (2009) notes that nursing care can be well meaning but “disabling”. “Sometimes a person deteriorates rapidly when he or she enters a home, and the person’s abilities can deteriorate to the level of nursing care given” (Nazarko, 2009, p. 296). In an effort to get the work done to meet the goals of the institution, disabling care is a very real risk in long term care. While it is a fine balance, staff need to provide opportunities for residents in long term care do as much as they can for their physical wellbeing but equally important, their sense of self. When nurses provide disabling care which is care that goes beyond the true needs of their residents, they encourage dependence and in fact disempower those who need every opportunity to retain what they are able to do to remain as independent as possible.

Objectification of people

Those who provide care in dementia care residential settings are challenged to provide care to people whose functional ability deteriorates as the dementia process progresses. Functional ability decline affects one’s ability to carry out the activities of daily living such as eating, dressing, toileting and transferring. In addition, those with dementia lose the ability to communicate. In a care environment where there are many people with a similar disease process, there is great potential for the dominant views that a person with dementia is an object to perform tasks on. This view or approach is in direct contrast with person centred care and is extremely dehumanizing. I have worked in residential care homes where I have heard the staff refer to the Residents as “tasks”. Phrases such as “we have four feeds to do” or “make sure you “do” Mrs. ...” are, unfortunately, not unheard of. It is the type of language, attitude and care practices such as these are extremely detrimental to a person’s sense of self or personhood. If the

person with dementia is regarded as inadequate, confused and helpless, she or her will take this position and care providers may interpret her or his behaviour in a way that confirms this view (Graneheim & Jansson, 2006, p. 1400). This presents to a person with dementia a vicious cycle. If a caregiver treats individuals as though they are an object to be taken care of, they further detach from themselves and participate less in their own life and care. This dependence has a further effect as “dependence becomes equated with asexuality; the more dependent and impaired the individual, the less credence is given to sexual or intimacy needs” (Ballard, 1998, p. 240). Thus exhibiting how dependency further places the person with dementia to be perceived as an object by caregivers. It is very interesting that while dementia is a disease of the brain, it affects the entire body and results in body image changes. “Dementia’s impact upon the patients body image is progressive [as the cognitive decline], though insidious in the first instance...concern for appearance may rapidly deteriorate later extending to poorly managed hygiene” (Jenkins & Price, 1996, p. 86). Phinney & Chesla (2003) carried out a qualitative study intending to “understand the meaning of dementia symptoms in terms of how breakdown is embodied in everyday habits and practices” (p. 285). Several themes were articulated including the “breakdown of bodily smooth flow”, “being slow”, “being lost” and “being blank” (p. 288). These feelings translated into feeling disconnected with the physical world and their own body. Dementia causes an individual to become detached from their own physical body, a form of disembodiment or disconnection. There are some who believe that the distressing behaviours in dementia such as agitation and aggression, are related to this process of detachment and lack of control of the body (Jenkins & Price, 1996). With this in mind, it is very important that the caregivers of those with dementia recognize them of a person with

worth and uniqueness in this world. It is true that “the personalising of care for each older person must be a fundamental principle in care” (McMinn, 1996, p. 20).

Inappropriate care may include practices that objectifies, dehumanizes or infantilizes a resident in an effort to meet time lines or cost containment in terms of reduced staffing (van Weert, 2006). Agitation and aggression are resident behaviours that are often associated with this type of care (Egan et al., 2007; Sloane et al, 2004; van Weert et al., 2006). Fortunately, there is currently a shift taking place in long term care that places the person first and foremost in focus and it is called “Person Centered Care”.

Person Centered Care

Person centered care (PCC) is a model of care that shifts the focus from institutional and biomedical goals to the unique needs of the person in care and is viewed as a preferred model for residential dementia care (Brooker, 2004; Chenoweth et al., 2009; Gaspard & Garm, 2009; Nazarko, 2009; Price, 2006; Robinson, 2007). While the medical model focuses on a persons' pathology, diagnosis and subsequent treatment, PCC is a "powerful concept in nursing, which developed in response to the need for a more patient-sensitive health care service" (Price, 2006, p. 56). Person centred care has also "become synonymous with good quality care" (Brooker, 2004, p. 215) and promises "enhanced relationships and quality of life for residents, family and staff (Gaspard & Garm, 2009, p. 23). The recent document published by the Alzheimer Society of Canada states that a priority policy option for Canada is to "create national person-centered standards for care facilities" (Alzheimer Society of Canada, 2010, p. 51). The earliest author of the concept of "person centered care in dementia" was Thomas Kitwood who defines person centred care as the following:

Person-centered care encompasses four major elements, all of which have been defined as person centred care in and of themselves by some writers. These elements include: 1. Valuing people with dementia and those who care for them. 2. Treating people as individuals. 3. Looking at the world from the perspective of the person with dementia. 4. A positive social environment in which the person living with dementia can experience relative wellbeing. (Brooker, 2004, p. 216).

Thomas Kitwood was a pioneer in dementia care. Kitwood 's "person centered care offered hope to the person with dementia, and also to the carers who could now see a

role beyond that of caretaker. His ideas dramatically changed the thinking and the talk around dementia care” (Hill, 2008, p. 21). Crandall et al. (2007) further identifies PCC as encompassing the elements of: personhood, knowing the person, maximizing choice and autonomy, quality care, nurturing relationships, a supportive physical and organizational environment. Nazarko (2009) expands on the concept of person centered care and identifies key elements as: personal worth, a sense of agency, social confidence and hope. Fossey (2006) found that a person centered care delivery model reduced the need for psychotropic medications which is extremely positive as these medications offer a host of risks for people with dementia including increased confusion, risk of falls and subsequent injury and over sedation. Chenoweth et al. (2009) also concluded that “agitation, a major symptom of distress and need-driven dementia compromised behaviours, was lower with both person-centered care” (p. 323).

Studies that have evaluated person centered care have shown that it results not only in better patient outcomes, but also in increased satisfaction with care. While this approach is being put forward as the preferred paradigm for the health care systems’ interaction with all consumers, it is considered of special importance in working with older persons, especially those in long term care. By incorporating lifelong practices and preferences into care routines, elements of roles, activities and environments familiar to the person can be perpetuated, a situation that is of particular value for older persons. (Cohen-Mansfield & Parpura-Gill, 2007, p. 133).

“Personhood” is a concept that emerges in the literature with respect to PCC. Thomas Kitwood viewed the “preservation of personhood as the central issue in the care of people with dementia” (Adams, 1996, p. 951). Chenoweth et al. (2009) defined personhood as “the recognition, respect and trust bestowed upon one human being by

others in social relationships” (p. 317). And another perspective of personhood is explained in the following:

The concept of personhood provides a lens for conceptualizing care of people with dementia. It affords the rationale and language for improving care and for raising consciousness about the status of people with dementia as people, intrinsically worthy of respect. Personhood is what makes each of us a unique human being. It includes all the dimensions of a person that make the person feel whole, including life history and family” (Gaspard & Garm, 2009, p. 23).

Throughout the literature on PCC, Kitwood’s framework emerges strongly. This framework identifies behaviours on the part of the caregivers and categorizes them as either Positive Person Work (PPW) or Malignant Social Psychology (MSP). Kitwood identifies PPW behaviour as actions that are therapeutic and helpful in maintaining a person’s sense of self and include behaviours such as: recognition, negotiation, collaboration, validation and stimulation. Malignant Social Psychology, on the other hand, are those behaviours that erode the residents’ sense of self and examples of these are: disempowerment, infantilization, intimidation, labelling and objectification (van Weert, 2006).

Unfortunately some health professionals deny their residents personhood (Coker, 1998).

Role performance, relationships with families, and personal control are de-emphasized as anxious professionals get on with the business of managing the illness. Personhood, which is the very root of one’s vulnerability, reflects one’s values, spirituality, history, and strengths, welded

together through years of living. When personhood is honoured, one feels comfortable; when it is not taken into account, one feels depersonalized” (Coker, 1998, p. 436).

Personhood therefore is the true “core”, true nature and history of a person and it is critical that a persons’ personhood is honoured in the care that they receive.

While the definition and rationale for personhood and PCC is clear, the implementation into residential care is not as evident and “little attention has been devoted to staff members and their needs in implementing person-centered models” (Cohen-Mansfield & Parpura, 2007, p. 133). Hill (2008) notes that there are many barriers to the implementation of PCC into care largely because of the embedded values and beliefs associated with the biomedical focus. Changing values and beliefs and the “way it has always been done” is very difficult in health care. With this in mind, how does a residential care facility which is largely focussed on efficiency and cost containment, shift its focus to person centered goals? What strategies or organizational changes must be made? What education should be provided to staff? With these questions in mind, the literature was searched, synthesized and summarized to identify practical strategies that were necessary for successfully implementing PCC into residential care. The research question to be answered in this project is, therefore: What are the organizational changes and practical strategies for implementing PCC successfully into residential care?

Methodological Approach: The Integrative Literature Review

The research method employed in this work is an integrative literature review. The creation and use of systematic, organized, diligently researched literature reviews can provide a connection between research and evidence based practice. (Evans & Pearson, 2001; Harrison, 1996; Polit & Tatano, 2008). Systematic literature reviews are viewed as important methodologies in the “advancement of a discipline, because they accumulate past endeavours, summarise major issues and are an important way to disseminate the information generated by a large number of individual studies” (Evans & Kowanka, 2000, p. 33). The integrative literature review is one example of a systematic literature review and is considered a research methodology in its own right (Polit & Tatano, 2008). An integrative literature review allows a researcher to survey and summarise a vast body of research in order to inform practice or policy development (Whittemore & Knafl, 2005). The aims of an integrative literature review are very broad and include objectives such as “to define concepts, to review theories, to review evidence, and to analyze methodological issues” (Whittemore & Knafl, 2005, pp. 547-548). There are important steps involved in an integrative literature review process including: identification of a problem, literature search, data evaluation and analysis (similar to qualitative research looking for emerging themes) and comparison, presentation and conclusion (Whittemore & Knafl, 2005). Systematic methods for combining evidence in nursing such as integrative reviews can play a key role in the advancement of nursing knowledge and “are replacing primary research as the source of evidence on which decisions are based” (Evans & Pearson, 2001, p. 593). Integrative reviews have the power to enhance nursing practice by providing overviews of

experimental and theoretical knowledge in addition to identifying areas where further research is needed. With these factors in mind, the research methodology of an integrative review is an appropriate methodology for the research question posed with the benefit of summarizing the knowledge to date on the topic of successful implementation of person centred care into residential care for those with dementia.

Literature Search

A search of the literature using CINAHL EBSCO database (1982 – present) and Medline (1966 – present) was conducted on November 1, 2009; followed by a search of the database Ageline (1978 – present) and Web of Science on December 20, 2009 using the search terms “person centred care” and “dementia”, and limited to peer reviewed research journals, English language articles. Out of the 77 articles found with this search strategy, those that related directly to incorporating person centered care initiatives into practice were chosen for review for this integrative literature review. This subset resulted in 19 research articles. The articles that centered on the implementation of a person centered care technique in care were critiqued and included in the “sample” for review. Articles that were not included were those that focussed on: clients home, day care or acute care settings, palliative care or the research conducted on the attitudes of staff towards people with dementia. The articles were critiqued using a systematic methodology reviewing the substantive and theoretical, methodologic and ethical qualities (Polit & Beck, 2004). Findings from the research will be synthesized to provide a guide for the successful implementation of person centered care into practice in dementia focussed residential care. One limitation that was discovered when reviewing the references of key articles was the searching language and lack of uniformity between CINAHL and MEDLINE subject headings.

The medical research, while appropriate to this topic does not consistently index their research using the term “person centered care”. However if an article was deemed to be about person centered care then it was included.

Data Evaluation or the “Individual Article Critique”

There are two important steps in data evaluation in an integrative review. The first step is a critique of each article to evaluate its merit and the second step is the summary or synthesis of all of all of the articles that flows into recommendations for best practice based on legitimate studies.

For the first part of the process, while the researcher will include many different forms of research and theoretical works, the research quality of each article is evaluated by examining validity, bias and appropriate methodology (Whittemore, 2005). In an ideal situation, two independent people will code the studies for quality using a scoring mechanism and the amount of “agreement” is measured as inter-rater agreement (Whittemore, 2005). Whittemore (2005) further provides details into the scoring criteria of quantitative research including:

- Sample: size, description and presence of rational inclusion and exclusion criteria.
- Protocol or intervention: systematic and well explained, detailed enough to understand what treatment intervention took place, whether subjects were blinded or randomized and discussion about group comparisons is evaluated..
- Measurement: data collection tools are well explained, allow for reliability and validity and any threats to validity are explained.

- Attrition: if any participants are not included in the study results the researcher explains their absence.
- Statistical analyses are well explained and the significance is reported with accurate assumptions.
- Discussion: the conclusions are well explained and any weaknesses such as bias are discussed.

The criteria for evaluating qualitative research is somewhat different and includes (Beck, 2009):

- Clear statement of the problem, research question, sample origin, qualities and size.
- Logical and well researched literature review.
- Conceptual underpinnings – concepts are clearly explained and defined.
- Methodological considerations: participants rights are protected; research follows design and tradition, sample and setting are well described.
- Data collection is well described.
- Data analysis strategy is clearly defined.
- Findings and interpretations and implications are articulated.

While these criteria are presented as a guideline, there are no established “gold standard” assessment tools yet available to evaluate research for an integrative review. However the researchers must use some methodology consistently to evaluate the individual articles (Evans, 2007; Kirkevold, 1997; Polit and Beck, 2008). Whatever methodology is utilized the studies which are stronger should be given “more weight

than weaker ones in coming to conclusions about a body of evidence” (Polit & Beck, 2008, p. 670). The challenge in the integrative review is evaluating the various forms of literature including qualitative, quantitative, theoretical literature. Another factor in the data analysis stage is noting variability between studies and accounting for this variability as well as evaluating the studies for validity and reliability and if there are problems in these areas, making sure that data summaries reflect this.

Because this was a student project, requiring demonstration of independent work, it was not feasible to have two researchers score the articles. Thus, the articles were scored independently, to determine variations between studies and evaluate validity and reliability. More weight will be given to studies that meet criteria of a “good” study and the weaknesses of other papers may be noted. For the purposes of the qualitative and quantitative research, Polit and Beck 2004, Chapter 26 was utilized to evaluate each article. See Appendix B for the criteria utilized in this project.

Data Analysis or the “Synthesis” of the Data

After critiquing and evaluating each article, the second phase begins – this is referred to as the synthesis phase. With defined criteria, “an innovative synthesis of the evidence, are the goals of the data analysis stage” (Whittemore & Knafl, 2005, p. 550). While there are a variety of data analysis methods that can be employed, one methodology is “constant comparison” which is a methodology employed in qualitative research. In a constant comparison methodology, the “extracted data are compared item by item so that similar data are categorized and grouped together. Subsequently, these coded categories are compared which further the analysis and synthesis methodologies” (Whittemore, 2005, p. 550). The methodologies utilized in qualitative research have

been applied into the methodologies in the integrative literature review with the benefit of reducing error and potential bias (Whittemore & Knafl, 2005). The methodologies include data reduction, data display and data comparison (Whittemore, 2005). Data reduction refers to classifying topics in articles to various pre-determined subject groups; data display refers to the process of putting the data extracted into some form of visual aid such as a chart or table; and data comparison refers to comparing and contrasting the data extracted from the articles. While there are a variety of methodologies available for data analysis for the integrative review “the proposed method of data analysis and synthesis should be documented in the review protocol before commencing the review” (Evans, 2007, p. 145).

In the research project of investigating person centered care implementation, one would look for recurring themes and draw those out for the discussion phase of the project. In the case of the implementation of PCC into practice may include themes such as organizational changes required, tools to assist in the implementation, barriers to implementation and so on.

Synthesis of Findings

The articles that focussed on PCC implementation, summarized in Appendix A, were carefully reviewed in this literature review. Collectively the articles provide many insights into a variety of themes relating to the successful implementation of this care model into residential care. These themes include organizational and educational factors, methods of knowing a person, as well as very practical interventions for bathing

and use of a multisensory environment. An overview of the findings in the articles reviewed will be presented in the following pages.

Organizational Factors

One theme that emerged strongly throughout the literature was the fact that in order for PCC to be implemented there needed to be a strong base of support stemming from the organization's management team. This belief needed then to flow to the manifestation of outward signs of support such as PCC reaching all levels of the organization, flexibility, the implementation of PCC into the documentation tools as well as a recognition that PCC may not save time and in fact, it may at times, take longer. The literature indicates that all of these factors are very important for PCC to become successfully implemented.

The importance of strong, caring leadership which is comfortable with decentralized decision making

“As management does unto staff, so shall staff do unto Elders” (Eden Alternative Inc., 2007, p. 37). A fundamental element that emerged from the literature was that of the importance of support and caring being shown by management towards staff in order for PCC to be successfully implemented (Crandall, 2007; Tellis-Nayak, 2007; van Weert, 2006). While this element was subtle in some research, it was clearly shown in the study conducted by Tellis-Nayak (2007). Tellis-Nayak (2007) utilized surveys for both families and caregivers at 156 nursing facilities and evaluated the response for both. The analysis looked for the type of management style that correlated to families perception of staff providing person centered – engaged care. Their results

were insightful in that they provide a guide for managers who aim to implement person centered care into their facility. The literature supports the findings that in order for person centered care to become a reality, the people who provide care need to know that they are valued, appreciated and cared for.

A cultural transition to person centred caregiving calls for caring managers who know that the well being of the residents is inseparable from the welfare of the caregiver, and that the needs of the caregiver transcend mere bread and butter considerations. Such managers fashion a workplace that recognizes the person behind the CNA role; challenges and supports her; and helps her to achieve, to relate, and to enjoy her work. They turn workers into loyal and devoted caregivers. Families and state surveyors bear witness to how a person-centred work setting positively affects the residents well being” (Tellus-Nayak, 2007, p.g 53).

How an organization shows caring will vary from one organization to another but if this is understood from the beginning, it allows for growth and freedom within an organization. Tellus-Nayak, (2007) found that CNA satisfaction, loyalty and commitment increase when their managers care about them and when their managers listen to them: “Our findings show that CNA’s indeed perceive their managers exerting a pervasive influence in their work life” (Tellus-Nayak, 2007, p. 52). In “low turnover facilities, managers create, by example and tactic, a “care culture” that values caregivers; respects them; and gives them recognition, and feedback....A quality workplace is nurtured by kind managers. A joyous and compassionate workplace presided over by an uncaring manager is an unsustainable contradiction” (Tellus-Nayak, 2007, p. 53). While some may believe that money is the major motivator in performance, this was not supported by the study: “Our data suggests that material

incentives do not principally drive CNA satisfaction. CNA's are dissatisfied with their wages, but higher wages alone will not win their commitment" (Tellus-Nayak, 2007, p. 53). With this starting point in mind, we will now look at other important elements that are key for the implementation of person centered care into residential settings.

While PCC must be adopted by all in order to be successful, policy needs to be set and supported by management. In other words, there needs to be direction "from the top" in order for PCC to be successful (Dowling, 2007). Through a quantitative study that evaluated staff behaviour following PCC education, Boettcher et al. (2004) emphasized the importance of good leadership in the effective implementation of person centered care where "good leaders" are defined as those who are able to empower staff; provide educational opportunities; provide access to resources and support; reduce stress; and consult frequently with their staff about resident care. Crandall et al. (2007), in their evaluation study that looked at the effect of a Best Practice Initiative for PCC in a number of facilities, further noted that in order for PCC to be incorporated into practice, the leaders of the facilities needed education on the importance of PCC, so that they could support their staff on this initiative. Crandall et al. (2007) also noted that successful organizations empowered the care staff that were in contact with the residents the most. This, then, represents a shift in decision making from the top down to the person closest to the resident – in other words a decentralized system of power is necessary for PCC to truly happen. If PCC is to be genuinely adopted, then change needs to stem from the resident and their family to the direct care staff and outwards (Chenoweth et al. 2009). This was corroborated by van Weert et al. (2006) who noted in their quantitative study evaluating the effect of multisensory environments on PCC practices, and previous research which has shown that organizational support was

critical to successful adoption of PCC practices. Sloan et al (2004), in their quantitative study on the effect of PCC with residents in residential care, also noted that it was imperative that continued efforts in PCC practices need to be sought after in order to support the very difficult and important work that caregivers provide to those with dementia. Underlying all the research in this paper was the critical importance that those who provide direct care have on the lives of those with dementia was present. With this in mind, when the resident becomes the focus, those who are closest to the resident need to become empowered to make changes that affect care. This, while perhaps obvious, represents a shift in organizational structure and decision making; However, support such as education and resources are essential in order for this paradigm shift to be successful. Cohen-Mansfield & Parpura (2007), in their study that evaluated the effect of PCC through a case study analysis, discuss the need for resources and how simply by having items such as large towels or very soft face cloths brought in, care is dramatically affected. Staff need to feel that they have the tools to do their work and so it is critical that they are supported not just theoretically but with tangible goods to be able to do their job to the best of their ability. One way that management can “walk the talk” is to integrate PCC into performance appraisals of employees (Boettcher, 2004). In order for any education intervention to be sustaining, it has to be incorporated into the expectations of performance by supervisors. “LTC staff members with effective supervisors have more work empowerment, greater opportunity for professional development, more information to do their job successfully, greater access to support and resources, less stress, and more job satisfaction. In addition, highly effective staff report that their charge nurses frequently consult them for input about the resident” (Boettcher et al, 2004, p. 189).

The research overwhelmingly identified the importance of strong, supportive, caring leaders who are comfortable with a decentralized decision making process and provide their staff with the tools that they need to carry out care that is truly person centred.

Person centered care needs to be adopted by all areas of an organization

Crandall et al. (2007) through careful analysis of organizations where PCC was successfully implemented after education and support noted that “culture change is not possible without commitment at all levels of staff” (p. 48). This finding was reiterated by Chenoweth et al. (2009) in their quantitative study where they measured changes in staff behaviour after PCC education was provided and found that “person centred care encourages all staff to initiate, become involved in, and take ownership of changes in practice” (p. 324). The concept of person centered care being well integrated into the facility fits very well with the notion of person centered care. All team members need to “buy in” as person centred care is a movement away from meeting the goals and objectives of the facility and therefore has to be adopted by all in order to be successful. “Person centered care encourages all staff to initiate and become involved in, and take ownership of changes in practice” (Chenoweth, 2009, pg. 324). Dowling et al. (2007) corroborated this finding in their integrative literature review that reviewed PCC in a disabled population. They noted that breaking down the barriers of departments, and hierarchical structure is important in the successful implementation of PCC in residential care (Dowling, 2007).

Flexibility in an organization

Historically and into the present, residential care has been highly regimented and structured. In their study on person centered bathing, Sloane et al. (2004) found that one barrier to change to a person centered approach was rigidity in an organization. In the implementation of PCC, “the influence of time pressure and rigid institutional policies cannot be underestimated” (Sloane et al., 2004, p. 1802). These researchers found that where institutional policies were inflexible, the adoption of person centred bathing was unsuccessful. Indeed a key element in implementation of PCC is for the organization to adopt a culture of flexibility. Dowling et al. (2007) in their integrative literature search summarized their findings when they stated “flexible support, developed collaboratively, built on people’s abilities, ambitions and hopes for the future, and based on principles of choice, empowerment and inclusion, are some of the factors that enable a person centred approach” (Dowling et al., 2007, p. 71). Flexibility makes sense if the direction for care stems from the Resident, then the organization must be able to flex and flow according to the needs and preferences of residents as much as possible.

Integration of PCC into documentation and communication tools

Crandall et al. (2007) in their research where they compared organizations that were successful adopters of PCC versus those who weren’t, learned that that the facilities that were successful in implementing PCC into practice changed their documentation tools (nursing assessment, observation sheets) so that they were PCC oriented. They also found that successful organizations had policies and procedures in place that were in line with the model of PCC. In addition the researchers identified a

need for people to document information about a resident. Coker (1998) explored this in her very interesting study that began with a chart review in a long term care setting which revealed no information on “personhood” for those being cared for. Coker met with the nurses and challenged them to find out information about a resident and discuss various aspects of this process including methods and barriers of obtaining this information. The study was revealing in that it highlighted the importance of families as well as the need for a place in the chart to record this important information:

Nurses initiated contact with residents and their families and used guided questioning to learn about and document the values, spirituality, history, and strengths that make their residents persons. The pilot project demonstrated that data about an individuals’ personhood is likely to be documented for potential use by others when there is a designated place on the health record for that purpose.” (Coker, 1998, p. 451).

Nurses may feel constrained by their own documentation tools which do not expand into these areas of concern. “Not having a specific location to record ongoing personhood data that is accessible to all caregivers was seen as a barrier by nurses” (Coker, 1998, p. 448). This was very much supported in Crandalls’s research which concluded that the facilities which were best able to adopt PCC into practice made changes in “mission statements, policies and procedures, job descriptions, and training materials. Although such documents do not guarantee sustainability of person-centred care, they do help reinforce the “this is the way we do things here” mentality and provide important structures to help ensure that practice changes are not lost when key staff leave the facility” (Crandall, 2007, p. 55). The walk the talk, therefore, needs to be evident in the important documentation along with areas for PCC information to be captured and retrieved easily.

Patient centred care may or may not save time

The studies varied in their conclusions about time saving with person centered care. Kontos and Naglie (2007) in their qualitative research design that combined research-based drama with focus groups and assessed the participants (i.e. caregivers) knowledge of the meaning of non-verbal communication and therefore ability to “read” their patients and provide person centred care. These researchers found that the respondents found time to be saved and used more efficiently as a result of knowing the Resident and responding uniquely to each person based on their needs. “Participants agreed that taking the time to figure out the reason for specific behaviours that they interpreted as bodily expressions of personhood, and how to respond positively to such expressions, can render the provision of care more time efficient in the long term” (Kontos & Naglie, 2007, p. 560). On the other hand, Sloan et al. (2004) in their research on PCC bathing where different approaches were utilized, found that person centred bathing itself took longer than the regular type of bathing but they did not discuss the nursing care involved if a person is agitated after a bath without PCC interventions. Therefore the research is inconclusive as to whether PCC increases or decreases time efficiency however time saving should not be the end goal in any care. (Dowling et al., 2007). Staff may very well need time to provide care that is person centered and it is important that management takes this into consideration when determining budgets for staffing.

Methods of Learning about the Person

While organizational changes are necessary in order for PCC to be implemented, another critical component is for the staff to know the resident extremely well. The research findings offer many insights into how this can be achieved including learning to relate to a person with dementia, continuity of staff, involving family and the use of life histories.

Embodiment of dementia to gain an understanding of the behaviours seen in dementia

Kontos and Naglie (2007), in their participatory research, aimed to learn about the use of imagination of care providers in their efforts to understand the meaning of behaviour in late stage of dementia. Their study focuses on the residents bodily expressions as a means of communication thereby providing insight to the person behind the dementia process. They explored the use of imagination as a strategy in person centered care through the use of videotaped vignettes of observed events on a dementia unit (using actors) and then created six focus groups to discuss the drama. After the participants had viewed the vignettes, the researchers, asked a “series of semi-structured questions about participants reactions to the production, specifically their understanding of self expressions by persons with severe cognitive impairment through bodily habits, gestures, and actions and the response or lack of response by the care practitioners depicted in the production” (Kontos & Naglie, 2007, p. 551). Using grounded theory methods, five themes emerged from the discussion including the fact that through the use of imagination: *sympathetic connections were present, shared*

bodily experience, socially acquired habits of the body, time efficiency and non-pharmacological behaviour management. Although the use of imagination is not a strategy that is often discussed in health care, Kontos and Naglie (2007) provide rationale for its use with those with later staged dementia in gaining an understanding of what that person is experiencing.

By the imagination we place ourselves in [a sufferer's] situation, we conceive ourselves enduring the same torments, we enter as it were into his body, and become in some measure the same person with him, and thence form some idea of his sensations, and even feel something which, though weaker in degree, is not altogether unlike them. (Kontos & Naglie, 2007, p. 562).

While it may be an unusual nursing intervention to employ, it appears that being able to understand the experience of a person with dementia is a very important component of being able to implement PCC into practice. Rasin and Kautz (2007) supported this claim stating: “Person centered knowledge included the recognition that residents behaviour was influenced not only by the disease process of dementia, but also by their feelings, social and emotional needs and past experiences.” (Rasin & Kautz, 2007, p. 34). Therefore PCC calls upon the caregivers to see beyond the behaviour into the meaning behind it, armed with knowledge of the person to provide care that is understanding and responsive to that persons individual needs.

Continuity of care

Consistent staffing is a critical element in the implementation of PCC. This is very important if staff are ever to “know the residents like you know the back of your hand” (Rasin & Kautz, 2007, p. 34). A number of studies noted that continuity of care

assisted with knowing the resident well (Dowling, 2007; Rasin & Kautz, 2007). One caregiver stated, “You need to know your residents...well enough that you might not be able to put your finger on it, but when you see them walking down the hall, you know instantly there’s something not right” (Rasin & Kautz, 2007, p. 34). This is an organizational issue that has a major impact on the care that residents receive. (Dowling et al. 2007). Therefore continuity of care is an important element of PCC with the understanding that a relationship between the caregiver and the client emerges when consistency in staffing occurs.

Involving the family

Coker (1998) found that one of the key barriers to the nurses not being able to find key information about a person was the fact that family were not present at admission or throughout the residents’ time in the residential care facility. Families are critically important in order for the staff to learn important information about the individuals who were unable to share due to cognitive deficits (Crandall, 2007). Crandall et al. (2007) in their evaluation research that identified qualities of successful organizations found that these facilities “emphasized communication with individuals, even those who were non-verbal, in their care to better understand what was important to individual residents. Family members were enlisted to support this process” (p. 52). Families play a key role in the sharing of information about a person when they are no longer able to communicate with the staff. There are benefits for the resident and the family when they are approached as a team member and source of background information for a person in residential care. Research has shown that overall, family members appreciated being consulted about the resident (Coker, 1998, Egan, 2007). As

mentioned earlier this is where families play a key role and often families find this exercise positive and rewarding (Egan et al, 2007). The research indicates that families play a key role in the life of residents with dementia. They are important members of the care team in a variety of ways as they are often the key to the residents past life and as such are invaluable in planning their care.

The use of life histories

Every person has a unique life story and in order to provide true PCC, caregivers need to learn these stories (Clarke, Hanson & Ross, 2003). The value of story is that “to be a caring, compassionate healer, one must appreciate story. Story is an ongoing narrative of events – a history-that includes the meanings a particular person gives to lived events” (Coker, 1998, p. 450). It is through the use of a persons “story” that true person centered care can be given that honours a persons values, preferences and beliefs (Coker, 2003). Four of the research studies reviewed, explored strategies to learn important facts about the residents that reflect the residents’ unique personality, background and life history (Egan et al, 2007 ; Coker, 1998; Clark, Hanson & Ross, 2003; Hansebo & Kihlgren, 2000;).

Egan et al. (2007) aimed to explore in a quantitative and qualitative study the impact of life histories on the frequency of aggressive behaviour as well as explore the perception of staff of the life histories impact on behaviour as well as find out if families found the sharing of life histories to be acceptable. Clarke et al. (2003) also examined the effect of life histories, however, used a different approach as they carried out a qualitative study that evaluated staff’s and residents response to the process of creating and the presence of resident biography information. The study concludes through

grounded theory analysis of the focus group conversations that biographical sketches help the staff see the person behind the patient and enhance relationships between staff and families of residents. The study also found that the process of creating a life history was not always appropriate for all due to the negative feelings for some relating to their past which was insightful and respectful. Hansebo & Kihlgren (2000) conducted a similar study in that they asked staff to provide a narrative on a person and then provided the staff with an “intervention” which consisted of education on an assessment tool (Resident Assessment Instrument) and then asked for a post intervention narrative on the resident. Similar to Egan, the researchers found that the intervention increased the caregivers knowledge of the resident however we are not informed if this had any impact on resident outcome or care. Likewise Coker (1998) wanted to investigate the barriers for nurses who had not previously gathered key “personhood” information about a resident. Coker (1998) used a qualitative approach of interviewing the nurses and analyzing the content of their rationale as to why this information had not been collected in the past and this research highlighted many interesting elements that are important for gathering “personhood” information. Coker’s research highlighted the need for a “place” to put this information so that the nurses were prompted to collect the information and knew also where to locate it once it was complete.

The use of life histories is very valuable in gaining knowledge about a person as “memories make up the framework of a person’s life story” (Hansebo & Kihlgren, 2000, p. 260). Unfortunately as dementia progresses, one’s ability to retrieve these memories and communicate them to others diminishes. Egan et al (2007) also noted that that the use of life histories has the potential to increase quality of care for those with dementia and may decrease aggression and notes that further research should focus

on ways to transmit and maintain this information among staff and investigate more closely the changes to care and resident behaviours. Clarke et al. (2003) found that life histories were very positive in seeing the person instead of the patient as well as strengthening ties between staff, residents and families. The process of obtaining a life history is also therapeutic in that “listening to someone else’s story is a powerful way of showing that they are valued as an individual” (Clarke et al., 2003, p. 698). “From birth to death, people live through many struggles, joys, relationships, dreams, and disappointments that structure the meanings assigned to their lives” (Hansebo & Kihlgren, 2000, p. 261). Therefore there is therapeutic value simply in spending time with a person obtaining the life history in addition to learning key information that can contribute to PCC implementation.

In addition to the benefits already mentioned life histories also contribute to:

- Understanding why families did not visit after they had learned more about the family dynamics (Hanesbo & Kihlgren, 2000).
- An increased willingness to engage the residents in their ADL’s much more than before (Hanesbo & Kihlgren, 2000).
- Cognitive status was understood much more afterwards (Hanesbo & Kihlgren, 2000).
- Carers made an increased effort to involve families in learning more about the residents (Hanesbo & Kihlgren, 2000).
- The importance of consistency and continuity of care was closely linked to being able to obtain a life history as this takes time and happens when you have

developed a trusting, therapeutic relationship with the person (Clarke et al., 2003; Hanesbo & Kihlgren, 2000).

- The importance of listening well to a person in order to learn their history was highlighted in the research (Hanesbo & Kihlgren, 2000).
- Photographs were important for “bringing the persons biography alive for all concerned and provoked strong memories” (Clarke et al., 2003, p. 702).
- Talking with residents about their life story was a positive experience for both the resident and the caregiver – a win-win. (Clarke et al., 2003).
- Negative experiences that the resident had lived through were not linked to negative judgement by the staff but rather appreciation for the lives that they had lived. Negative, traumatic experiences seem to surface for a person with dementia or depression so understanding a person’s life experience is very important for caregivers (Egan et al., 2007).

With the benefits that are inherent in knowing a person well, “it is important to give carers opportunities for detailed assessment ... which will help to improve care quality for the frail and vulnerable elderly patients in nursing homes as well as in other living environments (Hanesbo & Kihlgren, 2000, p. 276). Therefore management needs to be aware of the time commitment needed for staff to conduct life histories that are meaningful, valuable and ultimately necessary for the successful implementation of PCC into practice.

Educational Considerations for Implementation of PCC into Residential Care

Many people who work in health care experienced and survived a rigorous biomedically focused education. As a result of this background and the inherent frame of reference or biomedical lens that results from this education, education in PCC is critical (Boettcher, 2004). Education is the key in shifting the focus from “tasks” to overall care is critical in changing from a traditional model to a PCC model of care (Dowling, 2007; Saltmarche, Kolodny & Mitchell, 1998; Sloane et al., 2004). Support such as education is considered vital to the success of PCC as evidenced by previous research that shows that “only those nursing homes that gave intensive support to caregivers were able to effect enough change in clinical practice to improve resident outcomes significantly” (van Weert, 2006, p. 667). Crandall et al. (2007) employed an evaluation research method to evaluate the Best Practice Initiative of introducing PCC for nine different residential facilities in Oregon. Crandall described the process undertaken by the team which included a kick off meeting for many facilities followed by a call for interest in facilities who were interested in working towards the implementation of PCC into care. The researchers described the specific PCC strategies used by the successful facilities and also summarized the characteristics of the highly, moderately, and minimally successful organizations thereby providing rich information for other facilities looking at implementing PCC. Boettcher, Kemeny, Deshon and Stevens (2004) used a very similar type of design to evaluate the effect of a dementia orientated person centered care curriculum on the pre and post outcomes of CNA’s and nurse mentors in their care of people with dementia. Kemeny et al. (2004) also evaluated a dementia and person centered care educational program in terms of outcome on behaviours of CNA’s and nurse mentors while Gaspard and Garm (2009) also evaluated an educational program provided for nurses that aimed to shift attitudes and

practice towards a person centered care approach. Saltmarche, Kolodney & Mitchell (1998) evaluated an educational program that aimed to change values and beliefs of nurses towards elderly people with dementia. In their research they provided four vignettes which were presented at the first class and then again at the last class and the nurses overall showed, at the end of the course, a desire to understand what was happening from the patients' perspective rather than assuming to know what was best for the patient. Focus groups were conducted at the beginning and end of the course. Some outcomes of this included frustration with other peers who had not received the same education and provided care in the "old" way, frustration with systems that did not support person centred care and relief that they were not responsible for solving problems rather they were there to understand the problems from the patients perspectives. Managers noted the nurses who participated in the course were more relaxed with people, took their time, and did not complain about how things were done. Many felt more relaxed spending time with residents and not just doing "tasks" for them. "I felt I always had to do things – orders, medication, oxygen and now I am comfortable just sitting, talking with patients" (Saltmarche, Kolodny & Mitchell, 1998, p. 85).

As mentioned earlier, it is important for the concept of PCC to be adopted by all areas of an institution and the way that this can be done is through education. The literature, therefore, overwhelmingly indicates that education is a key factor in the successful implementation of PCC into practice in residential care. Crandall, however, notes that "because educational approaches alone are often not effective in accomplishing change in institutional settings, a coaching consultation model was used. Research has shown that the addition of advanced practice nurse consultation is

important in effectively translating research knowledge into practice” (Crandall, 2007, p. 50). Therefore while education is very important in the implementation of PCC, there is also a role for the advanced practice nurse as will be discussed later in this project.

Curriculum content for Person Centered Care Education

The literature reviewed in this integrative literature review was rich in insights into educational curriculum content and methodology. Topics included in the research reviewed were:

- Discussion about aging (Saltmarche, Kolodny & Mitchell, 1998)
- Knowledge of dementia and behaviours and psychological symptoms associated with dementia (BPSD) (Boettcher et al, 2004; Cohen-Mansfield & Papura-Gill, 2007; Hoeffner et al., 2006; Kemeny, 2004 & Sloane et al. 2004).
- The impact of staff behaviours and attitudes affecting residents behaviour. With the intention of supporting a shift in nurse’s knowledge and attitudes towards older clients by helping nurses learn and integrate the principles of person focussed care and the standards that support these principles (Chenoweth, et al, 2009; Fossey, 2006; Saltmarche, Kolodny & Mitchell, 1998).
- Person centered view of care with a focus on the work of Thomas Kitwood (Fossey, 2006; Hoeffner et al., 2006; Kemeny, 2004;)
- Development of individualized interventions (Fossey, 2006; Hoeffner et al., 2006; Kemeny, 2004)
- The importance of a gentle, caring approach for those with dementia
“Approaches that are insistent, task-focused, impersonal, painful and intrusive

on the residents personal space appear particularly likely to provoke agitated or aggressive responses” (Sloane et al. 2004, p. 1800).

- Techniques for establishing person centered care bathing (Crandall et al. 2007; Hoeffner et al., 2006)
- Active listening, communication skills, initiating the interaction, conversation, using unique details in conversation (Boettcher et al, 2004, Fossey, 2006; Kemeny, 2004)
- Reminiscence techniques (Fossey, 2006)
- Involvement of family caregivers (Fossey, 2006).
- Understanding that behaviour is a form of communication and unmet needs, use of antecedent behaviour consequence models (Chenoweth et al., 2009; Fossey, 2006; Hoeffner et al., 2006 Kemeny, 2004; Cohen-Mansfield & Papura-Gill, 2007; Sloane et al., 2004)
- The recognition that feelings persist despite cognitive impairment (Chenoweth et al. 2009) This included discussions and explorations into how the nurses felt about aging, how they felt about their clients aging (Saltmarche, Kolodny & Mitchell, 1998) which resulted in themes emerging such as: independence versus safety; being with others versus solitude; quality of life versus longevity. (Saltmarche, Kolodny & Mitchell, 1998).

With these curriculum topics, a residential care home could develop a course on PCC and provide this to their staff at all levels.

Teaching Methodologies for Person Centered Care Education

The literature sheds a great deal of light on the methods of providing this education. The methods were diversified but all were methods of reinforcing the principles of PCC in long term care. Some of these techniques included:

- Classroom settings (Sloane et al, 2004; Boettcher, 2004; Fossey, 2006)
- Practice homework (Boettcher, 2004)
- Supportive mentoring (Boettcher, 2004; Fossey, 2006)
- On the job coaching (Boettcher, 2004)
- Skills modelling (Fossey, 2006)
- In house training (Cohen-Mansfield & Papura-Gill, 2007)
- Role playing (Gaspard & Garm, 2009) and experiential learning (Boettcher et al. 2004).
- Activities (Gaspard & Garm, 2009)
- Discussions and videos (Gaspard & Garm, 2009).
- Appropriate clinical pathways and standards are taught throughout the three days as well (Gaspard & Garm, 2009).
- Reviewing tapes where person centered care what utilized (Hoeffner et al., 2006).

- Non-traditional style of education was utilized with the rationale that as the model was non-traditional, the style should also be non-traditional and more free flowing than the usual style of teacher – student methodology (Saltmarche, Kolodny & Mitchell, 1998).

Evaluation of education

The literature offers insights into the importance of education on both short and long term effects on behaviour on the part of those who provide close care of the residents. Hoeffner et al. (2006) found that “the results of our study reinforce that education of even experienced CNA’s in person centered approaches can improve their performance and experience when they are assisting cognitively impaired residents who exhibit agitated and aggressive behaviour during bath time” (p. 532). Egan et al. (2007) noted that one of the drawbacks of their research was the lack of education and introduction of the life histories to the direct care staff. It is important that education and support are provided with any change, and the introduction of PCC is no different. Crandall et al. (2007) identified the role of the advanced practice nurse as a change agent and a coach to assist facilities to change their practice from institutional based to person focussed thereby also validating the importance of educational support for the process of adoption to be successful. How can we expect care providers to change their long standing practice if they are not provided education, rationale, tools, practical examples all which provide a “road map” to providing person centered care? We cannot and that is why education is such a key part of the implementation of person centered care strategies in long term care.

Practical Ideas for Implementing PCC into Practice

In addition to providing key information such as organizational and educational changes and methods of knowing a person the literature provided very concrete insights into two areas. One included the use of a multi-sensory environment and the other was ways to improve bathing for those with dementia in residential care.

Incorporating multi-sensory environments (MSE)'s into care

The use of multisensory environments emerged in the PCC literature as a means to enhance or enable optimal care. Snoezelin or multi-sensory environments (MSE's) are defined as a “psychosocial intervention that combines a person centered approach with the integration of sensory stimuli in daily care for nursing home residents suffering from moderate or severe dementia” (van Weert et al., 2006, p. 656). By providing sensory stimulation in the form of familiar or preferred scents (i.e. a favourite perfume), sounds (i.e. classical music), tastes and touch, the caregivers can enhance a person with dementia's interaction with the world which for many results in an improved quality of life or at least a moment of joy (Van Weert et al., 2006). In their research on MSE's for those with dementia, Hope (2004) explains that “multisensory environments represent an approach for improving the quality of life for people of all ages who have sensory impairments” (Hope et al., p. 554, 2004). MSE's are characteristically a purpose built area which contain equipment that stimulates primary senses such as sight, hearing, and touch. Research demonstrates that MSE's affect behaviour of the elderly in positive ways. Van Weert et al. (2006) presented a valid but rather complex quantitative study aimed to measure the effect of the implementation of snoezelin therapies on the quality

of behaviour on the part of the care providers. This was captured on video and analyzed by independent observers who were not told if the care givers were in the control or experimental group. Kitwood's dialectic model was used to categorize behaviour displayed by care staff and this was correlated to snoezelen therapies in a Chi correlational test. The methodologies and measures were appropriate and the findings were valid as result. While Hope et al. (2004) also looked at the use of snoezelin rooms in the care of people with dementia, they took a very different slant towards their subject and conducted qualitative research that evaluated the utilization of a multisensory room. They used focus groups as their methodology and were able to derive rich information relating to the utilization and benefits of a snoezelin room for people with dementia.

From these studies, practices that care staff can incorporate include: (1) encouraging the resident to smell the soap, lotion or perfume, or after shave, talking about the scent and waiting for a response; (2) using visual sensory stimulus such as providing a mirror for the resident to look at themselves, or talking about colours or design of clothing; (3) utilizing auditory stimuli such as individual music, and tactile stimulation such as encouraging residents to touch various textures such as linen or a soft stuffed animal. All of these strategies encourage the resident to be aware of their senses and acknowledge that the resident is able to experience and appreciate the world around them. Hope et al. (2004) found three central themes emerged from the focus groups of the staff after they had received education and incorporated the use of MSE's into practice. These themes included: *Being reminded* or surprised in that staff noted that they discovered something new about their residents when in the MSE. The residents had behaviours in the MSE that they normally did not show ie. One resident

tapped his finger on his chair. “Seeing something new or unexpected or being reminded of the person’s capabilities was something that varied in intensity. Two respondents used the metaphor of seeing the person in a ‘new light’ which seems to capture the essence of what was being said and suggests there is a reconfiguration in perceptual set for some staff” (Hope et al., p. 557, 2004). *Realignment*: Staff realized that their role was important and they had something to contribute to the residents life “realizing therapeutic potential and a perceived adjustment in the relationship” (Hope et al, p. 557, 2004) were the highlight of this theme. A third effect of the MSE was “*Overflow*”. Overflow refers to the fact that the caregivers realized that their residents were interested in various things i.e. visual or otherwise and this overflowed into their caregiving outside the MSE. “One participant mentioned how she would seek to stimulate her resident in the day room by showing her a book, rather than leave her to sleep, recognizing by virtue of the MSE that the lady in question could look at and be entertained by visual stimulation” (Hope et al., 2007, p. 558). As a result of Hope et al.’s study, (2004) some staff described the MSE is a “safe little box” where many residents felt safe and care givers had an opportunity to literally see them in a new light that influenced how they felt about their own role and what they could do with the resident when back in the other parts of the building. “The data suggest that the MSE offers a way to spend meaningful time with a person with dementia and this time is characterized by its propensity to promote communication at a level commensurate with the fundamentals of a caring relationship. It counters to some extent the forces extant in the caring relationship related to differential power relationships and by virtue of the diagnosis. The conceptual model offered proposes that there is a change in the staff’s perception of the patient as a consequence of new information being revealed” (Hope et

al, 2007, p. 559). While a MSE may or may not be feasible for all facilities, strategies can be introduced to highlight the senses in resident care paying close attention to resident preferences throughout the exercise.

Bathing strategies

If one spends enough time in long term care in many facilities, it is not long before one hears screams from the tub room where a terrified resident with dementia is forcibly being bathed. Bathing is one of the first Activities of Daily Living (ADL) that causes extreme agitation in people with dementia. It is often bathing that results in agitation and aggression and then the administration of psychotropic medications (Cohen-Mansfield & Parpura-Gill, 2007). This is likely due to the invasion of a person's privacy as well as the fear of being submerged into a tub. One resident at the facility I work in told the staff that they were trying to fry her in a vat of oil. One can only imagine the fear that this would invoke. The practice of forced bathing has long been in place with the belief that this was essential and no alternative was available. Thankfully, research is showing this not to be the case. Sloane et al. (2004) and Hoeffner et al (2006) employed an experimental methodology with a randomized controlled design which evaluated two person centered forms of bathing to determine if resident aggression would be reduced as a result. Sloane et al. (2004) looked at person centered showering which included showering that provides choices, covering with towels to maintain warmth and modesty, techniques to distract (i.e. with food), using preferred bathing products, and no rinse soap. Person centered bathing is a towel bath that is done in bed which uses two bath blankets, two bath towels, no rinse soap and 2 quarts of warm water, ensuring the resident is covered at all times and the caregiver uses a gentle

massage to clean the resident. The methodology included a control group and two experimental groups where the experimental group received the person centered shower for six weeks followed by six weeks of the person centered bathing. Video taping was used to collect the data and the behaviour was coded by unbiased coders who utilized two tools to measure resident behaviour and discomfort. Skin cleanliness was also assessed using an objective tool as was the use of psychoactive and analgesia medications. Hoeffner et al. (2006) conducted a similar study as Sloane et. al. (2004) however this research team wanted to find out if agitation was reduced due to caregiver behaviours such as being relaxed and smiling and allowing the resident to perform as much of the bath as possible. Chenoweth et al. (2009) also conducted a quantitative study that evaluated the effect of person centered care practices and dementia care mapping on the levels of behaviours and quality of life for people with dementia and Cohen-Mansfield and Parura-Gill (2007) conducted case study research that examined how a woman with a history of aggression during bathing changed as PCC techniques were utilized in her care. The research conducted in these studies provide sound evidence that the practice of forced bathing is not necessary as there are person centered techniques that are just as effective without causing stress and trauma to the resident.

Some very practical advice for bathing was mined from the literature including:

- Crandall et al (2007) note the importance of the use of a “bathing success portfolio” for each resident where each worker records what was tried and what works best for these residents. “In this way, hard won wisdom was not lost when new or different staff cared for the resident (although consistent assignments are the norm). Direct care staff were empowered to make bathing decisions” (Crandall, 2007, p. 51).

- Showering rather than tub soaks for those who were afraid of the bath tub or had a history of showering rather than bathing (Cohen-Mansfield & Parpura-Gill, 2007).
- Use of the towel bath in bed (Sloane et. al., 2004).
- Use of non-rinse soap to avoid rinsing water over a person's head (Sloane et al. 2004).
- Using bathing products recommended by family or other staff members who had successfully bathed resident (Sloane et al., 2004).
- Towel bath in the room rather than bath in the "tub room" which is much more homelike and non-institutional (Cohen-Mansfield & Parpura-Gill, 2007)
- Preferences regarding the time of day and an accommodation of these preferences with the acknowledgement that evening bathing is helpful for some to get to sleep (Cohen-Mansfield & Parpura-Gill, 2007; Crandall, et al. 2007)
- Using products that were familiar for the person (Cohen-Mansfield & Parpura-Gill, 2007; Crandall et al. 2007)
- Ensuring that the frequency of bathing matches with the patterns of the person as much as possible (Cohen-Mansfield & Parpura-Gill, 2007)
- Coloured walls in the tub room to enhance "warmth" (Cohen-Mansfield & Parpura-Gill, 2007)
- Coloured towels (less institutional) (Cohen-Mansfield & Parpura-Gill, 2007)

- Plants (Cohen-Mansfield & Parpura-Gill, 2007)
- Pictures (Cohen-Mansfield & Parpura-Gill, 2007)
- Curtains (Cohen-Mansfield & Parpura-Gill, 2007)
- Use of warm water, with a room that is also warm (Cohen-Mansfield & Parpura-Gill, 2007)
- Soft light and reduction of glare (Cohen-Mansfield & Parpura-Gill, 2007)
- Relaxing music (Cohen-Mansfield & Parpura-Gill, 2007)
- Warm blankets (Cohen-Mansfield & Parpura-Gill, 2007)

It is interesting to note that most of these interventions are inexpensive and highly possible in long term care settings. It is important that staff are supported to enact these changes to change the bathing experience from frightening to enjoyable and comforting, thus enhancing the lives of those with dementia in residential care.

In summary, this integrative literature review provided valuable findings in the successful implementation of PCC into practice. Insights into key elements of the organization were highlighted particularly the need for a supportive management team, flexibility in workplace, integration of PCC into documentation and communication tools and an acknowledgement that PCC needs to be adopted by all areas of an organization. In addition, the literature provided many helpful findings in ways to learn more about the person in care including life histories, embodiment or imagination, continuity of care and incorporating the wisdom of families into the care of those with dementia. Finally, the literature offered valuable insights into the importance and

means of providing education along with practical incorporation of PCC in the area of bathing and the use of multisensory environments.

Links to Nursing Practice

The literature also provided some clarity into the role of nursing in the implementation of PCC into practice. Nurses play a pivotal role in long term care and as a result in order for PCC to become a reality, nurses need to be committed to this model of care. Boettcher et al (2004) noted that “in order for CNA’s to provide PCC to meet residents needs, they also must be supervised in a person-centered way. Nursing management and leadership contribute beneficially to quality care” (p. 189). Crandall (2007) noted that “not having a staff nurse on the team in the beginning led to some undermining of the team’s efforts, in part because nursing staff was not knowledgeable or fully committed to the practice changes identified to support person-centered care” (p. 54). Barriers to person centered care in several studies was shown to be due to the fact that many nurses are not prepared to supervise in a person-centered manner during their formal training (Boettcher et al., 2004; Kemeny et al. 2004) which further advocates for education for all staff including the nurses who work in residential care. When care is truly person centered, nurses roles change from that of rule enforcer to leaders, team-builders and supporters of those closest to the residents including families and care aids or CNA’s (Crandall et al. 2007). Kemeny et al. (2004) also summarized that it was critical that nurses were educated on how to mentor the CNA’s so it is important that staff who support the CNA’s are also provided with instruction. Nurses may also act as advocates for their residents and families, other care staff and they can

act as advocates and team players with other areas that play important roles in long term care from housekeeping to maintenance to dietary services.

The role of the Advanced Practice Nurse

The literature identifies a role for an advanced practice nurse in the area of implementation of PCC in residential care for those with dementia. One of the five recommendations that arose from a recent report from the Canadian Alzheimer's Society (2010) identifies the need to increase the availability of specialists such as advanced practice nurses with specialized knowledge of dementia. In order for an advanced practice nurse to provide real person centered care there are essential elements that are needed and these include:

- Awareness of best practice of dementia care and are able to implement these practices into care [clinical competency] (Crandall et al., 2007).
- Advocacy for this population as their disease removes their cognitive ability to advocate for themselves in the moderate to later stages [leadership and clinical competency].
- Provide support and ongoing education for staff that provide the day to day care in residential settings. [Leadership competency]. Leadership skills are very important for nurses who work in the areas of practice. In the study that looked at the positive effects of PCC on bathing, “during bedside consultation, a clinical nurse specialist worked directly with a nursing assistant for 2-4 weeks during three to eight baths to develop effective strategies and an individualized bathing care plan” (Hoeffler et al., 2006, p. 525).

- Consultation and collaboration were also highlighted as key areas for nurses who lead PCC initiatives. “Gerontological nurses could play a primary role in teaching how to individualize care and could serve as role models by working directly with caregivers. They can develop educational materials and provide consultation” (Rasin & Kautz, 2007, p. 36).
- Education development that is PCC focused. As described by Saltmarche et al. (1998) a course was developed by a clinical nurse specialist in gerontological nursing, facilitated by the co-ordinator, chief nursing officer and two other advanced practice nurses who were knowledgeable about person centred care and Parse’s Theory of Human Becoming. (Saltmarche, Kolodny & Mitchell, 1998). Crandall et al., (2007) noted that “research has demonstrated that the addition of advanced practice nurse consultation is important in effectively translating research knowledge into practice” (p. 50). [Leadership, Collaboration].
- Ensure that ethical care is provided and the needs and preferences for those with dementia are honoured and respected by implementing and supporting person centred care [Leadership].

Another key role for the advanced practice nurse is team building. Nurses need to take a lead in the development of all team members so that PCC initiatives are not lost when staff members leave. Encouragement may be needed for “new caregivers, who did not know the residents, to ask co-workers how the residents might react. Caregivers learned that an approach might vary by person and that one resident might need a different approach than others”(Rasin & Kautz, 2007, p. 34).

There is undoubtedly a role for an advanced practice nurse in the implementation of PCC into care for those with dementia in residential care.

Links to Nursing Theoretical Knowledge

While PCC is in itself a “framework”, it is helpful to look at nursing theory for further insights into implementing this model into practice. The theoretical models examined for relevance are Parse’s Theory of Human Becoming and Newman’s Theory of Expanding Consciousness.

Parse’s Theory of Human Becoming

Parse speaks to the notion of encouraging and inviting the client to explain how they envision their health, their own circumstances and how they define quality of life or what is important to them. With Parse’s theory, residents are viewed as co-participants in their own health and as experts as to how things should happen to meet their definition of quality of life (Parse, 1997). “In the human becoming perspective, nursing is not defined by knowledge but is, instead, focused on the nurse-person relationship. The person, rather than the nurse, is the expert concerning health and quality of life because only the person living the life can define its quality” (Saltmarche, Kolodny & Mitchell, 1998, p. 81). In terms of person centered care “Mathews (1962) defined person-centeredness as nursing action that encourages the patient to disclose how he sees the world, what he is experiencing, and the meanings these experiences have for him” (Coker, 1998, p. 439). One may wonder how this theory could be appropriate for those with dementia, as their cognitive competency is in question. In my

experience in working with those with dementia, I have gained some insights on this issue. I feel very strongly that people with dementia retain the right to make the choices that they are still able to make. This may include whether they want to eat a particular food or not, whether they accept or refuse medication, whether they want to have a tub or bed bath. As such, policies and procedures need to reflect this right and this is a further role for the advanced practice nurse to incorporate these rights into the day to day operation of a facility. Person centered care fits nicely with Parse's theory. If we truly listen to the person and adapt our care to meet their individual needs we are much better able to provide good care. I believe that Parse's Theory of Becoming relates to the issue of quality of life better than any other theory I have found as it defines quality of life according to each person's definition and in the end there is no better means to determine this.

Newman's Theory of Expanding Consciousness

Newman "describes human being as open energy systems in constant interaction with environment which also is an open system. The only way for nurses to understand an individuals' health status is to understand the individuals patterns of relating to the environment" (Weingourt, 1998, p. 27). In the context of PCC implementation it is critical that the nurse and others who provide care need to be aware of a person's life approach, preferences, history, and patterns in order to provide effective care. An underlying premise of this theory is that "human beings are continually moving toward expanded consciousness" (Weingourt, 1998, p. 27). Expanded consciousness refers to "insight and the recognition of patterns" (Vandemark, 2006, p. 606). Weingourt (1998) further explains expanded consciousness as a time

when a person discovers that their familiar patterns of reacting to the world are no longer effective and a new approach to life must be found. This leads to a period of disorder and chaos in that person's life. The person is now faced with the "choice point" where they can decide to change or revert back to a way of living that is no longer effective but is familiar and therefore considered "safe". If a person chooses to change then they have the potential to progress to a higher level of consciousness. The role of nursing is to assist the client during the period where uncertainty exists and the role of the nurse is to "help the client cope with the choice point and strengthen the new choices" (Weingourt, 1998). It is interesting to note that "the role of the nurse in this experience is to help clients recognize their own patterns. Intervention is a form of non-intervention whereby the nurse's presence assists clients to recognize their own patterns of interacting with the environment. Insight into these patterns provides clients with illumination of action possibilities, which then opens the way for transformation to occur" (Witucki, 2002, p. 585-586). If we relate this to residential care, Newmans model seeks to assist a person in care to "work together and, over time, create new patterns, enabling the client to move to a higher level of consciousness and satisfaction" (Weingourt, 1998, p. 27). With those with dementia which progresses this may be challenging however this highlights the need to really know a person well to understand and anticipate their patterns and provide understanding and support when new patterns emerge. Both nursing theories are in parallel with the notion that care must be responsive to the individual person and as a result, and both theories are relevant to person centered care.

Future Research

There are many areas where further research into PCC into residential care would be beneficial.

Sustainability

While the studies reviewed the effects of implementation of various methods they did not explore ongoing sustainability for long term integration into residential care. As an example, longitudinal research is needed to find out how biographical work can be done on an ongoing basis and how it can become standard practice in care. There is also a need to find other methods of obtaining this information as formal situations may not be the most practical. It may be worthwhile, as an example, to explore means of obtaining the same information during the care at other times. In addition it would be very worthwhile to explore the sustainability for ongoing education, in terms of best methods and the cost associated with this. It makes sense for this model of care to be incorporated into the education that all health care providers receive.

Other practical strategies to incorporate PCC into care

While research into PCC bathing, and use of the MSE, are well covered in the literature it would be beneficial to see more research in the area of other practical strategies to incorporate PCC into practice for example in the area of dining. A research study, as an example, into the effects of flexible dining times and weight monitoring

would be very worthwhile. This would seek to address the concerns that rigid, fixed dining times are the only way to maintain a normal weight in the elderly.

Studying facilities who have implemented PCC into care

Future research into implementation of PCC in Canadian residential care facilities would also be beneficial. It would be ideal if pre and post implementation data was available on clinical indicators such as weight loss, depression, use of psychotropic medications and restraints. It is my belief that while we have identified PCC as the ideal to aim for in Canadian residential care facilities, the rate of adoption and implementation is very slow. Research into the barriers in each setting would be useful so that we, as a sector of the health care continuum, can work towards removing these barriers to ensure that every person in residential care has the right to care that is personalized to their needs, preferences and values.

Summary

With the inherent belief that “years spent in long term care facilities are for living, not merely for physical safekeeping” (Coker, 1998, p. 439) it is critical that those who provide care for people in residential care strive to improve the quality of life in these settings. Quality of life as defined by Parse is what a person sees as important to them and this also resonates with Newman’s Theory of Expanding Consciousness. It seems ethical then that it is our duty as care providers to provide care in a manner that is person centered. This model of care has been shown to have positive effects in the form of reduced need for psychotropic medication, care that maintains a person’s “selfhood” and reduces resident agitation and aggression (Chenoweth et al, 2009; Fossey et al., 2006; Hoeffler et al., 2006). The integrative literature review completed for this project synthesized research in this area to offer a variety of strategies and “lessons learned” for successfully implementing PCC into practice including implications for leadership support, methods of learning about a person, education strategies and practical changes in the form of MSE’s and in PCC bathing. It is my hope that PCC becomes the standard of care rather than the exception in long term care in the very near future.

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Appendix A: Table of Research Reviewed for this Integrative Literature Review

Citation	Primary type of research	Study Descriptions with [Critique]
<p>Boettcher, I.F., Kemeny, B., Deshon, R.P. & Stevens, A.B. (2004). A system to develop staff behaviours for person centered care. <i>Alzheimer’s Care Quarterly</i>, 5(3), 188-196.</p>	<p>Quantitative research</p> <p>This study investigated the outcome of an intensive staff development program for the Certified Nursing Assistants and nurses as well as evaluated the impact of person centered care mentoring (PCM) on changes in CNA behaviours that are considered to be person centered care behaviours.</p>	<p><u>Substantive and Theoretical Dimensions:</u> Dementia caregiving is often challenging: physical, emotional exhaustion; grief over the losses that the person with dementia presents with. CNA’s who provide care for those with dementia report that caring for people with dementia is stressful due to behaviours exhibited by people with dementia. They also state that they need education on working with people with dementia. This kind of education has been associated with higher levels of job satisfaction.</p> <p><u>Methodologic Dimensions:</u> This research was conducted in a 165 bed, nonprofit, private nursing home in West Michigan. Participants included 46 CNA’s, 38 nurses and 50 Residents. A curriculum was developed and delivered to CNA’s and nurse mentors in 5 sessions on the topics of: i. Dementia and person centered view of care ii. Communication skills; iii. Individualized care; iv. Knowledge of need driven behaviour; v. skills to be part of a caring organization. Training was provided in a variety of ways including role playing and homework. Mentoring training was provided for the nurses (in four additional training sessions). These focused on observation, feedback, goal setting and problem solving. So mentoring was a big part of this process as well as the education. Outcomes were measured by independent trained observers measuring pre-training and post training behaviours in the areas identified to be “person centred care behaviours” in the areas of nonverbal communication, assistance with tasks, conversation, initiating activities, responding to calls, using unique details and interaction with families. The statistical “t” test was used to compare the means of the pre and post behaviours. Outcomes: The post-training means were significantly higher than the pre-training means in 4 of the 7 dimensions. Areas where improvement was seen were: non-verbal initiation of PCC; assisting residents with independence-oriented tasks; verbal conversations; using unique details of the residents life in conversation Also seen was an increase in offering the resident choices to promote autonomy as much as possible. The study showed that the implementation of an intensive staff development program (that included experiential techniques) and the implementation of reinforcing performance evaluation, reinforced the skills learned during the education. Also, after two months another observation was done and the PCC methods were still being used.</p> <p><u>Ethical Dimensions:</u> The study was approved by the Institutional Review Board. Informed consent was obtained from residents or their legal authorized representative, CNA’s and their mentors according to the federal Policy for the protection of Human Research Subjects.</p> <p>[A very well done study – good pre and post evaluation; good summary; excellent rationale for the study; only problem was the lack of explanation regarding the way in which the observation was conducted – was it videotaped or on the job – in which case the observers presence would undoubtedly affect the action of the caregiver].</p>
<p>Chenoweth, L, King, M.T., Jeon, Y, Brodaty, H., Stein-Parbury, J., Norman, R., Haas, M. & Luscombe, G. (2009). <i>Caring for aged</i></p>	<p>Quantitative</p> <p>(Pre and Post intervention, with an analysis between 3 “sites” which included 15</p>	<p><u>Substantive and Theoretical Dimensions:</u> This study, situated in Australia, called Caring for Aged Dementia Care Resident Study (CADRES), aimed to evaluate the effectiveness of person centered care versus using Dementia Care Mapping versus conventional dementia care on outcomes such as: Behavioural Psychological Syndrome associated with Dementia (BPSD) which includes agitation and aggression, reduction of psychotropic drugs, restraints, rates of accidents or injuries. They also looked at the cost of</p>

Citation	Primary type of research	Study Descriptions with [Critique]
<p>dementia care resident study (CADRES) of person centered care, dementia care mapping, and usual care in dementia: A cluster-randomized trial. <i>Lancet Neurology</i>, 8, 317-325.</p>	<p>nursing homes).</p>	<p>each strategy for feasibility in application.</p> <p><u>Methodologic Dimensions:</u> 15 sites with a total of 289 residents participated in this study. 5 homes were designated to a “Site”. Inclusion criteria included: medical diagnosis of dementia; over 60 years of age, rated high on the Australian resident classification system for dependence; had low cognitive function (as indicated by C or D on the resident classification system). Had experienced some need driven behaviours in the past [not indicated how this was measured]; had written informed consent by their representative or by themselves [were they considered competent to make this decision?]; and were in permanent residential care. Exclusion criteria included lack of consent; serious co-morbidities that would mask or complicate dementia; palliative care; unremitting pain; distressing physical symptoms or respite placement. Three sites (with 15 total homes) participated: Site 1: was taught person centred care and dementia care mapping. (5 homes); Site 2: was taught dementia care mapping, however usual care was provided to the residents (5 homes); Site 3: taught person centered care; usual care (5 homes). Training on PCC (a two day course) was provided to two staff members [this is unusual as only two people is a very small number] in each of the 5 sites (they were selected by managers). 2 researchers carried out DCM at the five sites and taught care staff to do the same. Outcomes were measured before the intervention, directly after the 4 months of intervention and then 4 months follow up. Various tools were used to measure behaviour including the Cohen-Mansfield agitation inventory (CMAI) which is a valid tool for assessing agitation; Quality of Life in late-stage dementia (QUALID) was also used. [not familiar with this tool] which looks at levels of discomfort; activity engagement and interactions with others; restraint use was monitored and counted; incidents with transfer to hospitals were counted and these included falls, fractures, lacerations, bruises, med errors, and behavioural incidents; antipsychotic medication use. Statistical analysis was the Chi Square test for the variables between the three groups. Results: In the homes with no PCC intervention, “usual” care took place and which was characterized by: custodial and physical task oriented practices that included use of physical restraints, tendency to neglect the psychosocial needs of residents, little attention paid to residents choices. Antipsychotic drug use was higher in person centered care group than in either the DCM or the usual care group [this is curious – is it possible that those people more sensitive to the suffering of people responded with more medications?]. The number of falls was increased in the group that provided PCC [but it was already established that “usual” care included physical restraints. People who are restrained do not fall].</p> <p><u>Ethical considerations:</u> Inclusion criteria included written informed consent given on their behalf by their guardian or had given verbal assent themselves. Funding source had no role in study design, data collection, analysis or writing of report.</p> <p>[Overall a very well done study; good outcomes but I wish the authors had explained why PCC lead to an increase in falls and psychotropic medications more than they did – I think it may be possible to interpret the findings to show that PCC increases the risk to an individual. The fact that agitation was decreased in the PCC group was the reason the authors summarized that PCC should be implemented into care for those with dementia in residential care so there was enough weight attributed to this outcome].</p>
<p>Clarke, A., Hanson, E.J. & Ross, H. (2003). Seeing the person behind the patient: enhancing the care of older people using a biographical approach. <i>Journal of Clinical</i></p>	<p>Qualitative (Grounded Theory)</p>	<p><u>Substantive and Theoretical Dimensions:</u> The authors recognize the need for improvement in care of the elderly (from reports that caregivers hold negative views of the elderly and are is deficient in some areas). Biographical sketches are a way for staff to come to know a patient thereby provide care that is more responsive to that persons needs (PCC). Life story was viewed as a low cost method to incorporate PCC into practice and former studies have shown that this method has increased respect, understanding and acceptance of patients by staff. Barriers to biographical sketches include: time involved, the emotional investment involved in speaking to a person about their life. The researchers acknowledge that not all people will want to talk about their lives as it may stir</p>

Citation	Primary type of research	Study Descriptions with [Critique]
Nursing, 12, 697-706.		<p>up painful memories. The purpose of this study was therefore to determine if the use of biographical approaches would be used for: a. gaining greater understanding and empathy for the elderly and b. encourage person centered care.</p> <p><u>Methodological Dimensions:</u> a practice development initiative where researcher investigate a specific intervention in a setting. [not described well in the article] <u>Criteria:</u> patients who were expected to remain on the transitional care unit for a longer period of time [time period not specified] were included in the study. Convenience sampling as it was fully voluntary and people had to come forward as participants and all patients were asked [in this type of research this is okay but a convenience sample is weak with quantitative research; this sample was the qualitative component of the study]. Staff were provided with education about biography taking in paid time educational sessions and a literature file was maintained and made available for all staff. While no formal mechanism of taking a biographical sketch was provided, staff were given colourful folders for stories, photographs and other memorabilia could be kept. It was noted later that the more structured approach was more beneficial to capture all the areas and pictures were seen as beneficial to spark memories. [we are not told if the biographies are in a public place or if education is provided to the other staff not involved in taking the life story; nor are we told what information went into the biographies and what would be helpful for care]. Focus groups were used of those who had used life biographies in the past and also those who had never used them. Staff were asked: about their understanding of biographical work, how they could use it in their every day work; and advantages and disadvantages of this strategy [the limitation of only asking staff if it changed care was dealt with by asking the patients as well as shown next]. Patients were asked: how they felt about telling their story, and whether they felt that the biographical sketches affected their care.[not told what went into the biographies] Patients: semistructured interviews were done with patients and relatives pre and post biographical sketches.[would have been better see the interview questions in a table]. The interviews were transcribed and two members of the research team thematically analysed the transcripts for similarities and differences using constant comparative technique. The project got off to a slow start as the nursing staff were facing workload issues but when a care attendant was identified to take on the project, the project moved forward. <u>Findings:</u> biographical sketches allow staff to: - see the person behind the patient (They also were able to see the patient in a much broader context than as a person who needed care) and – build stronger relationships with the patients and their families. But the researchers also realized that biographical sketches are not for everyone (including those who are very private, those with painful past experiences, those who have not yet established a trusting relationship with care staff yet). [insightful themes that emerged with the notion that life biographies are not for everyone reflecting respect for the elder].</p> <p><u>Ethical considerations:</u> consent was obtained from representatives or residents themselves. Funding source had no role to play in the study design, data collection or writing of the report.</p> <p>[Some deficits seen: the authors first line was “Although much has been written about person – centred care of older people, commentators have recently questioned whether it actually occurs in everyday practice” (pg. 698). While the researchers interview staff and patients after the introduction of the biographies is done, they do not detail what is in the biographies nor do they never provide concrete ways that identify how PCC is implemented. They do note that staff see the person rather than the patient, but the reader is not provided with examples of this occurring. Presentation: very clearly laid out, easy to understand and the rationale for study is well presented. Title is reflective of content and the abstract is clear and well written]</p>
Cohen-Mansfield, J., Parpura-	Case Study	<u>Substantive and Theoretical Dimensions:</u> Bathing is one of the first Activities of Daily Living that causes extreme agitation in people

Citation	Primary type of research	Study Descriptions with [Critique]
<p>Gill, A. (2007). Bathing: A framework for intervention focusing on psychosocial, architectural and human factors consideration. Archives of Gerontology and Geriatrics, 45, 121-135.</p>		<p>with dementia. It is often bathing that results in the administration of psychotropic medications. The authors aimed to test a operational framework that aimed to reduce the use of pharmacological interventions. The authors describe TREA (Treatment Routes for Exploring Agitation) which is a systematic algorithm for providing non-pharmacological interventions for agitated behaviours. This framework focuses on the resident as well as the staff members focussing on the underlying rationale for behaviour, looking at environmental modifications, staff training and providing institutional support. This framework consists of Staff, Support, Resident based interventions and Environmental factors where the environment was enhanced as much as possible to make the resident feel comfortable.</p> <p><u>Methodologic Dimensions:</u> Case Study: One resident, Mrs. A., was the subject of the intervention. Mrs. A. has a reputation of displaying aggressive behaviour particularly during personal care including verbal aggression, screaming, kicking, throwing food. Bathing required 3 people – two people to hold her down and one to wash her. The process included: A baseline assessment of her medical status. Diagnosis: dementia and depression; anxiety, delusions and psychosis; history included sexual abuse by her father. Other diagnosis include asthma, hyperthyroidism, kyphosis, osteoporosis and cardiovascular disease; interviews with staff – revealed that the resident had distinct periods of agitation (with verbal aggression) several times an hour with the more physical behaviours several times of day; observation of the resident – were done with the Agitation Behaviour Mapping Instrument (ABMI) and more pronounced aggression was present during bathing; observations of the staff – used inappropriate techniques such as using boxing mitts and encouraging her to “box” with them; patronizing tone, sarcastic remarks were also used; self identity: her husband provided some insights into this residents previous likes and dislikes including music, socialization, visits with family and friends, eating, spending time with her dog. Underlying reason for behaviour: through all of the assessments, it was determined that this resident had been bathed by the same caregiver and was handled very roughly, was cold during the bath, lacked privacy, was receiving multiple psychoactive drugs which could all contribute to her discomfort. Loneliness: her incompatibility with current caregiver; boredom from staying in bed all the time. Intervention: primarily staff training and direct resident intervention. resident: psychoactive medications were reduced; resident: needed to develop trust with caregivers so the researcher actually spent time with her exploring the things that she could still enjoy; staff: primary care giver was changed to someone who did not have the negative history that the current caregiver had; resident and staff: resident was not submerged in a tub or taken to shower room rather a towel bath was done in her bed with extra soft cloths and no rinse shampoo and soap. Also, having her face washed, was very distressful to Mrs. A. so this was left until the end so that she wasn’t distressed for the entire bath; staff: changes in communication – staff were coached on how to respond to people with agitation in a way that did not further escalate their agitation. The staff did not force care but rather stopped what they were doing and came back later; Environment – Mrs. A’s husband supplied her favourite music – music was played when care was not being provided and then later when care was provided as a means to calm Mrs. A. down. Results: Staff: behaviour change in care; better understanding of the resident; realizing that her behaviour was her means of communicating; staff learned new bathing techniques and much better communication skills with the resident. Resident: had much less agitated behaviour (statistically significant). Discussion: The TREA model is resident centered and provides a framework to look beyond the behaviour associated with dementia and find causes to remedy the persons experience in care.</p> <p>Ethical Considerations: Informed consent was collected from resident’s husband and staff participants.</p> <p>[A good study but inherent in the case study is the lack of generalizability beyond the person however it is very important for the person in question and can form a good basis for hypothesis for subsequent studies].</p>

Citation	Primary type of research	Study Descriptions with [Critique]
<p>Coker, E. (1998). Does your care plan tell my story? Documenting aspects of personhood in long term care. <i>Journal of Holistic Nursing</i>, 16(4), 435-452.</p>	<p>Qualitative Interviews with RN's who were challenged to find out Personhood information on residents in their care.</p>	<p><u>Substantive and Theoretical Dimensions:</u> The author begins by explaining the critical importance of maintaining a persons sense of "self" in long term care. She acknowledges that in health care, the focus is on the physical ailments and the rest of the person is ignored. Further discussion talked about the fact that long term care is not just for physical safe keeping but for living and the importance of this very fundamental belief. In order for living to happen "it is necessary for residents to be known and responded to as individual people who have unique life experiences, different daily patterns, and who therefore have different sources of meaning in their later years" (Coker, 1998, p. 439). A chart review of the unit under review, revealed that no documentation about the residents personhood existed on the chart (in this case personhood was defined as the persons preferences, strengths or background). Purpose: This study is a pilot project that aims to identify some of the barriers that interfere with nurses collecting and documenting data that reflects a residents personhood in long term care.</p> <p><u>Methodologic Dimensions:</u> This study took place in a residential care unit at a university affiliated teaching hospital. 3 primary and 3 associate nurses participated in this study [we are not told if the sample is self selected or if they were recruited by their manager or any other means]. On this unit RN's were the primary nurses and 24 hour RN care was provided. An hour long session was conducted (twice to accommodate the scheduling of nurses) to ask the nurses what information relating to personhood they felt was important to have in the patients chart. After the two sessions the information was collected and 6 themes emerged including: respect, preferences, interests, family, background and hopes and dreams. Each nurse was asked to choose one resident to gather information relating to personhood during the next month. A month later the nurses met to discuss and share their experiences. They had to report on 1. the source of the information that they obtained; 2. share those sources as some of these sources may not have been used in the past; 3. hypothesize as to why this information was not historically gathered 4. discuss how this information could impact on care in the future. <u>Sources of information</u> – various sources used; primarily families who enjoyed being interviewed; telephone interviews set up for some who were not in town; social workers notes; residents typically were not a source of this information. <u>Data collected</u> – all nurses were very excited about this process and enjoyed learning more about the residents who they provided care for. <u>Hypothesized reasons</u> for not having collected data routinely – 1. family members not present at the initial interview 2. there had not been a place to document this information until now 3. no family and resident was uncommunicative. Impact on nursing care situations – comments were very general but some specifics included: if they don't like coffee, don't continue to offer it; if they prefer solitary activities, don't push group activities; they all felt that this information provided inroads into better communicating with the resident (i.e. ideas for conversations) *this was felt to be the most beneficial outcome*</p> <p><u>Summary:</u> nurses must know their patients as persons to help them achieve well being or even to understand what well being means to them.</p> <p><u>Ethical Considerations:</u> Prior to the study, approval was granted by the local ethics committee, all participants were informed about the study (written and verbal information provided) and confidentiality was maintained throughout. From the start of the project, it had been agreed that the older person or family member would have ownership of their life storybook and their permission had to be sought to gain access to the material. The ethical value of choice was recognized when the authors surmised that biographies are not for everyone. They realize that for some, the process would be painful and they may chose to decline.</p> <p>[This pilot showed that nurses were able to overcome some of the barriers to documenting an individuals personhood in long term care. "Nurses initiated contact with residents and their families and used guided questioning to learn about and document the values, spirituality, history, and strengths that make their residents persons. The pilot project demonstrated that data about an individuals</p>

Citation	Primary type of research	Study Descriptions with [Critique]
		<p>personhood is likely to be documented for potential use by other when there is a designated place on the health record for that purpose.” (Coker, 1998, p. 451).]</p>
<p>Crandall, L., White, D.L., Schuldheis, S. & Talerico, K.A. (2007). Initiating person-centered care practices in long term care facilities. <i>Journal of Gerontological Nursing</i>, 33(11), 47-56.</p>	<p>Evaluation Research (Outcome Evaluation)</p>	<p><u>Substantive and Theoretical Dimensions:</u> PCC is seen as critical to quality care in long term care. Elements of PCC include: knowing the person, maximizing choice and autonomy, comfort, nurturing relationships, and supportive environment.</p> <p><u>Methodologic Dimensions:</u> This paper is an evaluation of a program initiated by the Oregon Health & Science University Hartford Center of Geriatric Nursing Excellence and the state agency that monitors long term care facilities in that area. The project was initiated through a program called “Best Practice Initiative” which aimed to integrate scientific evidence into practice for those with dementia and others in residential care with person centered care principles being the “best practice”. The project had 3 components including: 1. A kick off conference: where they described the project and asked for volunteers for participants 2. A selection process to identify facilities that wanted to participate in ongoing person centered care; 3. Educational retreats; 4. Individualized coaching for the facilities involved. Coaching came from an Advanced Practice nurse who worked with the participants to 1. develop a structure for change 2. assist teams to respond to resistance 3. work through the change process and 4. make change occur (narrow gap between wanting change and making it happen). Each facility was to chose an area where they wanted to focus on to implement patient cared care such as bathing or dining changes. After the kick off and selection process, 9 facilities participated in the initiative. After the facilities were chosen, they received coaching onsite and then by e-mail or telephone for ongoing support. All facilities who participated in this project were able to make progress in implementing patient centered care practices. 3 of the facilities made significant changes, 4 made moderate changes and 2 others made minimal changes.</p> <p>The author then examined each facility and identified what they did to become either successful, moderately successful or minimally successful in implementing patient centered care.</p> <p>Results: Successful organizations or those facilities that were able to affect significant practice change: changed documentation tools in their facility to accommodate PCC, policies and procedures were rewritten with this model in mind, a bathing success portfolio was created that communicated the personal information that would allow for successful bathing, they created a book where staff could communicate what PCC has meant for me as a means to capture the change; planning and education were key to successful implementation as was communication with the residents and their families to better understand the residents likes and dislikes; greater flexibility with a focus on the resident rather than on the facilities and staff routines. Maximizing the control by the Residents and developing and nurturing relationships with family members was viewed as very important. Also, these organizations, while only focussing on one area noticed where other areas of their facility were not PCC and changes in those areas began. Direct care staff were also fully involved in decision making and designing ways to make PCC occur. Moderate organizations: had an interest the project but did not consider PCC core work; project activities were put aside during stressful times (staff shortages, state surveys etc.). Minimally successful organizations: administrative turnover; did not have a strong understanding of PCC principles and did not have a strong commitment to the project; little support given to the PCC team; some undermining of success occurred. [insightful reflections – very thorough evaluation of the program]</p> <p>[An excellent evaluation article that reviews a program and draws conclusions that are very useful for others to learn from].</p>

Citation	Primary type of research	Study Descriptions with [Critique]
<p>Dowling, S., Manthrope, J. & Cowley, S. (2007). Working on person-centered planning: From amber to green light? <i>Journal of Intellectual Disabilities</i>, 11(1), 65-82.</p>	<p>An integrative literature review of the literature on Person Centered Care for the learning disabled in England.</p>	<p><u>Substantive and Theoretical Dimensions</u>: Person centered care in England for those with learning disabilities aimed to provide services tailored to the unique needs and wishes of their clientele. This study aimed to determine the bridges and barriers to the implementation of person centered care in adult social care. Barriers included: funding structures, staffing deficits, ambiguity about the approach or desire to change. PCC is assisted by: policy encouragement, practitioner enthusiasm and positive evaluations.</p> <p><u>Methodological Dimensions</u>: Scoping review by a team of consultants who were paid for their work. This integrative review sought clarity and consensus and papers that were empirical, opinion, evaluation or review were included [this is nice in a way as I know I had to eliminate many papers who I thought were excellent resources because they were neither quantitative or qualitative works]. The search strategy was defined and many databases were searched. Data management – citations were entered and retrieved into Reference Manager. Data extraction and analysis – a framework was utilized including: general information; antecedents to PCC planning, contextual and structural issues, process in implementation; issues for service workers and their families, factors relevant to a particular population, issues for frontline staff, outcomes and evidence of best practice. Interestingly they found many articles on people with learning disabilities but not many on the elderly or elderly with mental health issues. Although the authors note that “the articles were discussed in detail before a final decision as to whether to include them was taken” (p. 68) it is not stated what criteria was used to evaluate quantitative or qualitative research articles. [this is a problem with integrative literature reviews as there is no gold standards in article evaluations].</p> <p>[Overall, nice in that my paper is similar but with a different population; very sketchy on the details however; no explanation of critiquing of articles took place for this work].</p>
<p>Egan, M.Y., Munroe, S., Hubert, C., Rossiter, T., Gauthier, A., Eisner, M., Fulford, Neilson, M., Daros, B. & Rodrigue, C. (2007). Caring for residents with dementia aggressive behaviour: Impact of life history knowledge. <i>Journal of Gerontological Nursing</i>, 33(2), 24-30.</p>	<p>Quantitative and Qualitative research (Experimental and Interviews)</p>	<p><u>Substantive and Theoretical Dimensions</u> : Aggressive behaviour is highly correlated with dementia. There is research that indicates that aggressive tendencies decrease when individualized person centered care is provided. Therefore, it is important for those who are caring for people with dementia in the later stages, when they are unable to verbalize their needs, to know and understand the individuals they are taking care of. One way to learn more about a person is through life histories [rationale for study clearly explained]. <u>Objectives of this study</u>: 1. To determine the incidence of residents “problem behaviours” decrease if staff were aware of these residents life histories 2. to determine if there is a change in staff’s perception of the residents as a result of learning their life history 3. to learn if the process of learning life history and sharing this information acceptable to families? [objectives clear but very ambitious]</p> <p><u>Methodologic Dimensions</u>: Single subject, repeated measure design and qualitative interviews were used. A repeated measure design is defined as “an experimental design in which one group of subjects is exposed to more than one condition or treatment in random order; sometimes referred to as a crossover design” (Loiselle et al., 2004, p. 482). Quantitative data was collected on the residents behaviour but qualitative data was collected from staff. Eligibility criteria for resident participation included: diagnosis of dementia; been a resident for 2 months or longer; judged as having “problem behaviour” and in the end, four female residents in an age range of 77 – 93 years of age who had a history of aggressive behaviours that included slapping, biting, head butting, kicking, pushing and spitting and yelling (both physical and verbal aggression) participated in the project [not generalizable to others outside of this description] [we are not told if these individuals were assessed for other sources of aggression such as pain or delirium]. Graduate nursing students met with families and asked about key life history information including: birthplace; members of present</p>

Citation	Primary type of research	Study Descriptions with [Critique]
		<p>family and family of origin; location where resident grew up and lived; education; work experiences, known traits and any interesting life events. These were then summarized into a one page summary and placed on the chart and in some cases where the care staff could easily access them i.e. over the bed. [different from Clarke et al. who had the nursing assistants complete the life histories – possibly greater buy in if staff collect it rather than someone from outside of the organization] [what introduction was done for staff to know about life history availability? If family didn’t want personal information over the bed, how accessible were the charts to the care staff (very often care staff do not access the charts)…therefore access and background to this resource is an issue that is not explained in this study]. Data collection: For the quantitative part of the study: A resident behaviour monitoring tool was used [definitions of aggression were formulated by the researchers with input from staff and then staff monitored behaviour on a daily basis] to evaluate behaviour of the four residents prior to the life histories being available and then throughout the time when the life histories were readily available. A graph was created and celeration line analysis were used to observe for trends (either increasing or decreasing in incidences of aggression). For the qualitative part of the study: After the data was collected, the researchers interviewed the staff [did they interview them alone or in a group? Not told and this may influence response either positively or negatively] asked the staff open ended questions in order to determine if they read the life histories, how informative they were; and accessibility of this information and if their perception of the Resident changed as a result of reading the life history [so possibly answering my questions about methods but would have made sense to provide formal introduction to the life histories rather than ask them post facto]. <u>Also for the qualitative part of the study:</u> Families were also asked as to their feelings towards the process of documenting and sharing life histories. The interviews were transcribed verbatim and analyzed by the first author of the paper and this was verified by co-authors [this isn’t very clear – we don’t know if they also read the interviews and made their data analysis independently of knowing the first authors opinion or did they just review what the first author wrote with nothing to compare their results to?]. Results: 1.Quantitative data: Aggressive frequency was inconclusive. Only four residents took part in this study [sample size too small for any statistical analysis]. Resident 1 had a decrease in verbal aggression but no change in physical aggression. Resident 2 decrease in both physical and verbal aggression. Resident 3 had decrease in physical and verbal aggression however this resident was also ill during the observation period so her change in behaviour may have been due to the illness rather than any care changes [should she be included in the results?] and Resident 4 showed little aggressive behaviour at baseline and there was no change throughout the observation period. [while there appears to be some overall net reduction in physical and verbal aggression, it is difficult to know if it is due to the interventions in the study, sample size is too small, resident who is ill should not be included in the results at all…therefore, inconclusive results from this study. The authors note that the reduction in aggression could also be due to increased attention as they were required to check in on the residents every two hours, they also note that staff may have not recorded aggressive behaviour when it occurred, both are good points to note]. Qualitative results [staff]: from the 10 staff interviews completed (7 care attendants, 1 LPN and one RN), it was determined that having access to life histories “helpful” in providing resident centered care. Qualitative results [Families]: Three out of four families felt that the exercise of writing their family members life history was a positive experience while one family found the experience painful as it brought back sad memories of the past but this family member felt that it would improve care so felt it worthwhile. Conclusions: the authors are cautious with their conclusions but recommend that future research is needed to examine the best ways to transmit and maintain this biographical information among staff and the relationship of this knowledge on relationships between care staff and residents [authors recognize the limitations of this study and made valid recommendations for future research].</p> <p><u>Ethical Dimensions:</u> met with consent prior to involvement with study.</p>

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<p>Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R. & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomized trial. <i>British Medical Journal</i>, 332, 756-761.</p>	<p>Quantitative Cluster trial design</p>	<p><u>Substantive and Theoretical Dimensions:</u> The authors realize that many people with dementia receive major tranquilizers or neuroleptics for behaviours such as agitation and aggression. “Good practice” recommends that other methods (psychological or environmental) are attempted first prior to the use of these drugs and the authors hypothesize that the amount of psychotropic medication will decrease or have less of a chance of being initiated if person centered strategies are implemented to manage behaviours. Therefore this study aimed to change practice in nursing homes using person centered care methods.</p> <p><u>Methodologic Dimensions:</u> 170 eligible residents from nursing homes which have many dementia care residents. [there is a very complex method used to arrive at this number which will enable the researchers to show statistical significance, the authors acknowledge that cluster sampling is a weaker sampling than other methods however talks about practicality and also increases the size of the sample to compensate for the design]. 12 nursing homes, “six care homes were randomised to the training and support intervention and six to treatment as usual” (p. 757). 4 in each from London, Newcastle and Oxford were the locations of the study. Neuroleptic use was measured with 2 in each area having low use and 2 having high use. Procedure: Cluster trial design (cluster – random sample of a group of units) was used For the 6 “treatment groups” a “consultant old age psychiatrist” and a senior member of the nursing department reviewed the medications of each resident in the study and advised the prescribing MD’s to d/c meds if they had been in use for more than 3 months if the behaviour was no longer present. For the control groups: usual treatment and prescribing took place. The consultant wrote to the prescribing physician with their recommendations and telephoned if no action had been taken in 2 weeks as a follow up. Intervention: for the 6 treatment groups, a learning package, taught by a psychologist, OT or nurses at each center over the period of 10 months, was delivered to the treatment groups that focussed on person centered skills in training and supervision. [very extensive curriculum; not sure if a psychologist would ensure the nursing related information would be translated for care staff in a way that would be practical]. Measures: medications were translated to units of chlorpromazine; the Cohen-Mansfield agitation inventory was used; Dementia Care Mapping was used to measure quality of intervention by staff and a psychology research assistant who is blind to the intervention group (i.e. does not know if they are observing the intervention or non intervention group) observed behaviour at 12 months [we aren’t told how the this person observes behaviour – just by being present or by video or ?...this is not well described] ; Baseline and then at one year data was collected. Primary outcomes were the number of neuroleptics given and the secondary outcomes was the agitation level. Results and discussion: The treatment group had significantly less use of neuroleptics than the control group. This lead the authors to conclude: “an intervention offering support with individualized psychological intervention as part of a programme promoting person centered care and good practice provides a viable alternative to neuroleptics for treating behavioural symptoms in patients with dementia” (Fossey et al., 2006, p. 758).</p> <p><u>Ethical Dimensions:</u> Consent was obtained from the management of the nursing homes. Family carers of residents were asked to give consent for involvement of their relatives.</p>
<p>Gaspar, G. & Garm, A. (2009). The caring journey. <i>Nursing BC</i>, 41(1), 22-26.</p>	<p>Evaluation research</p>	<p><u>Substantive and Theoretical Dimensions:</u> This paper discusses and evaluates a program called “The Caring Journey” which was a project in two residential are settings in the Fraser Health Authority. The origins of this program are linked to the Dementia Service Framework, a program called Caring Journey from Alberta, the Chronic Care Model and the Model for Improvement.</p> <p><u>Methodologic Dimensions:</u> The Caring Journey: Is an educational program that promotes the use of a person centered model of care and supports staff to modify their behaviour. The goal is to strengthen’s staff ability to provide appropriate care for those with dementia. The program: A 3 day onsite educational program that takes nurses and other staff through experiences about dementia.</p>

Citation	Primary type of research	Study Descriptions with [Critique]
		<p>Teaching methodologies include role playing, activities, discussions and videos. Appropriate clinical pathways and standards are taught throughout the three days as well. During the 3 days, staff develop care plans and problem solve behaviours that they are familiar with those with dementia. Evaluation of the program in terms of learning outcomes: The program was evaluated using Kirkpatrick's evaluation construct, using 4 basic constructs to evaluate change. [not described here]. Through the evaluation process the authors state staff demonstrated a significant improvement in their knowledge of dementia and appropriate care strategies. Learning evaluation demonstrates that staff increased their knowledge of dementia by 10% when using a post test; 94% of staff said they found the education worthwhile; 100% said they would recommend it to other health professionals.</p> <p><u>Ethical Dimensions:</u> Consent for participation was obtained from the management of the homes where the study was taking place and the family carers of the residents involved.</p> <p>[Sounds like a wonderful program but is not very descriptive about the specifics – I found myself wanting to contact the authors to see if we could attend or have them come to our facility to teach *may try to do this* ..good measured outcomes however long term follow up not done. With respect to those who took the course we don't know the details – how long had they worked with people with dementia, did they come to the class on their own time or paid time, how many took the course. And in terms of plans, will this be an ongoing program for new employees or periodically offered].</p>
<p>Hansebo, G. & Kihlgren, M. (2000). Patient life stories and current situation as told by carers in nursing home wards. <i>Clinical Nursing Research</i>, 9(3), 260-279.</p>	<p>Qualitative Research</p>	<p><u>Substantive and Theoretical Dimensions:</u> The authors describe the importance of memories and the fact that a person's life story is very individual and unique. They feel that better care planning can happen and therefore better care if staff who care for these residents have a better idea of what their life stories are. The aim of the present study was to compare patients' life stories and current situations, as told by carers, before and after 1 year of supervision when the RAI/MDS was used as a basis for individualized care planning. The RAI/MDS or Resident Assessment Instrument/Minimum Data Set is an assessment tool that has been developed as a means to assess elderly people's physical, psychological and psychosocial status – the residential RAI tool was used. The first part of any nursing assessment is the assessment of patient needs and resources.</p> <p><u>Methodologic Dimensions:</u> This research was a part of a larger project in 3 nursing homes in different locations in Sweden with people with cognitive impairments. Of the sample, 28% were men and 72% female. Pre-intervention: Before the "intervention" took place the caregivers were asked to narrate the life story and current situation of the patient best known to them. The intervention included: One day training took place of the RAI/MDS for all carers. Each team was supervised by one of the authors for 2 hours once a month during the intervention year. The focus was on the needs of the residents and special attention was paid to the patients' remaining abilities and resources. Gradually the RN's took over the "supervisory" role of this assessment. [the intervention seems lacking something, maybe the description is poor but I am surprised that they got the outcome with this intervention – I have to wonder if the staff didn't take it upon themselves to do more when they realized they were being assessed about their knowledge of their residents. The RAI offers a certain amount of information but life story, family dynamics, previous occupation and many other interesting elements in a person's life are not included so I have to think that the staff went beyond the scope of the RAI to learn more about their residents]. Post intervention: After the "intervention", the carers gave an account of the life story for whom they were the contact person and the RN told about one of the patients cared for by her team. Findings: The main finding was that most carers gave a fuller, more detailed account of their patients after the intervention. Themes that emerged after the intervention were family situations, children, lifestyle, relationships, childhood, professions, ADL ability, personality and behaviour, psychosocial wellbeing.</p>

Citation	Primary type of research	Study Descriptions with [Critique]
		<p><u>Ethical Dimensions</u>: - Study was approved by the Regional Research Ethical Committee of Karolinska Institute, Stockholm, Sweden.</p>
<p>Hoeffler, B., Talerico, K.A., Rasin, J., Mitchell, M., Stewart, F.J., McKenzie, D., Barrick, A.L., Rader, J. & Sloane, P.D. (2006). Assisting cognitively impaired nursing home residents with bathing: Effects of two bathing interventions on caregiving. <i>The Gerontologist</i>, 46(4), 524-532.</p>	<p>Quantitative Two interventions were evaluated pre-post.</p>	<p><u>Substantive and Theoretical Dimensions</u>: Many residents with dementia display aggressive episodes during bathing. It is noted that bathing is the most intimate of care provided in residential care and the behaviour is believed to be a self protected response when they feel threatened and feel that caregivers aim to harm them rather than help them. The hypothesis is that CNA's who exhibit qualities associated with person centered care are effective in reducing behaviour by residents during bathing and it is the approach rather than the method used that is more important.</p> <p><u>Methodologic Dimensions</u>: Randomized controlled trial using a cross over design with 15 nursing homes. In one treatment group: CNA's received training in PCC techniques first with showering and then with towel bath; This was reversed in the other treatment groups. No intervention changed in the control group. The study collected data observational data of CNA's assisting residents with bathing. Sample [Caregivers]: A lot of thought went into recruiting the CNA's and they had to be people who would be consistent and they had back up's in the event they were away from work. Sample [Residents]: Inclusion criteria: 55 years of age and older; requiring assistance with bathing; having dementia (moderate to severe cognitive impairment); frequently exhibiting agitated or aggressive behaviours during bathing. Exclusion criteria: having other diseases other than dementias; primary diagnosis of psychotic disorder, primary language other than English; being palliative or acutely ill. Both treatment groups received training in PCC, behavioural assessment and problem solving; reviewed tapes of bathing and coaching on how to implement person centered approaches with showering and towel bathing. Measurements: Caregiving outcomes were measured and these were: gentleness and verbal support; representing behaviour; confidence and ease; preparedness; hassles (distress). The baths were videotaped at the end of the first 3 weeks; at the end of 6 weeks and then again after another 6 weeks. <u>Analysis</u>: ANOVA statistical analysis between the 3 groups: control, treatment group 1 and treatment group 2. Results: Improvements were seen in both treatment groups for: gentleness, verbal support, confidence and ease but not hassles. The treatment group did not in any of these areas. "Overall, person centered approaches resulted in more positive observed caregiving behaviour when CNA's assisted residents with bathing. Hassles may have been due to the fact that "verbal skills may be more difficult to learn when new bathing methods are introduced, and may require practice and reinforcement to be implemented consistently" (Hoeffner et al. 2006, p. 530). Therefore there is evidence for PCC techniques and education in LTC for those with dementia.</p> <p><u>Ethical Dimensions</u>: Researchers got written consent from the CNA's and consent from the residents [although we aren't told that the representatives gave consent].</p> <p>[Well done study that looked at the impact of behaviours rather than tasks on outcomes..good study in support of PCC for LTC for those with dementia].</p>
<p>Hope, K.W., Easby, R. & Waterman, H. (2004). 'Finding the person the disease has' – the case for multisensory environments. <i>Journal of Psychiatric and</i></p>	<p>Qualitative Focus Groups</p>	<p><u>Substantive and Theoretical Dimensions</u>: The authors contend that multisensory environments (MSEs) provide opportunities for an increased understanding of the people that they care for. The study: Took place in 3 phases over 4 years and was a part of a study being carried out by the National Health Service in the U.K.</p> <p><u>Methodologic Dimensions</u>: Phase one: problem identification: involved learning what the problem was and this was the identification of the fact that MSE's were under-utilized. The rationale for this was that staff forgot about it's presence and therefore</p>

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<p>Mental Health Nursing, 11, 554-561.</p>		<p>did not utilize it. Phase two: aimed at mediating factors at the individual level of the staff. Educational innovation was designed and delivered to the staff over a 5 month time frame. The education looked at the theory and practice of MSE's. 29 staff members attended these sessions. Phase three: a validation exercise to explore how the MSE could be improved and this included improving the physical environment; structure of care planning around MSE. Interviews were audiotaped and then transcribed and edited and then put into a computer analysis software package called CAQDAS which indexed the data using NUDIST or Non numerical unstructured data.indexing.searching and theorizing. 3 central themes emerged from the focus groups. 1. Being reminded or surprised. 2. Realignment: 3. Overflow. Discussion: Some staff described the MSE is a "safe little box" where many residents felt safe and care givers had an opportunity to literally see them in a new light that influenced how they felt about their own role and what they could do with the resident when back in the other parts of the building.</p> <p><u>Ethical Dimensions:</u> Consent for residents was obtained from family member or legal guardian. Staff consented by agreeing to the study. Not mentioned in the article if this went through a institutional review board but likely did in order to allow videotaping for bathing.</p> <p>[Interesting study with interesting implications for Multi-sensory Environments].</p>
<p>Kemeny, B., Boettcher, I.F., DeShon, R.P. & Stevens, A.B. (2004). Post intervention focus groups: Toward sustaining care. Journal of Gerontological Nursing, 30(8), 4-9.</p>	<p>Evaluation Research</p> <p>The purpose of this study was to evaluate the effectiveness of the intervention from the article by Boettcher.</p> <p>A follow up study to the previous article.</p>	<p><u>Substantive and Theoretical Dimensions:</u> This study is a part of a larger research study called Project RELATE (Research and Education for Living With Alzheimer's and Related Dementias: Therapeutic Elder Care). Purpose was to determine if education on person centered care and mentoring were effective and maintained post intervention.</p> <p><u>Methodologic Dimensions:</u> Focus groups were used to evaluate the interventions lasting effect. The author notes that "even when there is an initial change in staff behaviour, it is important to determine whether the change "sticks" beyond the end of the training phase" (Kemeny et al., 2004, p. 4) and explains the importance of the use of focus groups to elicit responses. The person centered curriculum provided. Focus groups (with a facilitator) were created according to the role so that the member of the focus group were not affected by status or power issues (i.e. RN's versus CNA's).[I thought that this was a good decision as CNA's may not be free to express themselves if those in a power relationship were present] [the authors provide a concise but good overview of the positives and negatives of focus groups with the positives being: focus groups allow for verbal sharing so literacy levels are not that important; focus groups provide rich details of shared experiences (the interaction between participants, confirmation or reinforcement of ideas is very valuable); they allow the participants to speak and be heard. The disadvantages of focus groups are that in this case, the participants know each other well and there may be status issues that influence the exchange of information]. Findings: Overall all focus groups (CNA's, nurses and administrators) found that person centered skills were being used 2 months after the intervention. The CNA's were very positive about the change in their behaviours and reported using all the behaviours with the residents however had problems with time limitations and encouraging individual activities. With respect to families, CNA's did not feel comfortable involving family in the care of the resident as they perceived the family not wanting to play a role in direct care of their family member. Barriers for nurses in using the skills they learned included time constraints and not wanting to intimidate the CNA's. Overall most found that the skills were being used but one area that was noted was that the CNA's did not think the nurses communicated any better after the intervention and the researchers concluded that the curriculum needed to be improved in the area of mentoring. Also more involvement was found to be needed from administration to support the nurses in their mentoring role.</p>

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		<p><u>Ethical Dimensions:</u> While Kemeny et al. (2004) did not articulate their ethical methodology, one may assume, since their study was a part of a larger study, that the ethical considerations were made however, as they are not mentioned, this is a deficit in this study.</p> <p>[This study was very useful in that it evaluated longer term outcomes than immediate changes; however one strong limitation was the fact that the changes were “self reported” rather than objectively observed. The finding of the need for mentoring for nurses was very valuable for those implementing person centered care into practice].</p>
<p>Kontos, P.C. & Naglie, G. (2007). Bridging theory and practice: Imagination, the body, and person centred dementia care. <i>Dementia</i>, 6(4), 549-569.</p>	<p>Qualitative study (Grounded Theory Research)</p>	<p><u>Substantive and Theoretical Dimensions:</u> Factors that may impact on care that those with dementia receive including: budget constraints, increased acuity and complex clinical care requirements of residents, reduced number of health care workers therefore higher workloads and care hours are defined in terms of what tasks are done. All of these factors could lead to depersonalized care of those with dementia. The care that dehumanizes and demoralizes a person with dementia is related to the notion that people with dementia lose their “self” or “self-hood” when they lose their cognition. The authors argue that achieving PCC is dependent on the care providers use of imagination to recognize selfhood despite the loss of cognitive abilities. The theoretical framework was that of Kitwood’s work on person centred care with the identified practices that should be avoided in care of those with dementia (infantilization, intimidation, stigmatization and objectification). The background of Hamington’s notion of caring imagination and Kontos theory of embodied selfhood also influenced the study.</p> <p><u>Methodologic Dimensions:</u> A qualitative research design that combines research-based drama with focus groups, the researchers assessed the participants (i.e. caregivers) knowledge of the meaning of non-verbal communication in order to assess the nurses ability to “read” their patients and provide person centred care. The researchers “argue that achieving person centered dementia care is dependent upon health practitioners imagination to recognize that selfhood persists despite the presence and progression of cognitive impairment” (Kontos & Naglie, 2007, p. 551) and imagination is informed by empathy for their residents. Six focus groups were established in three academic health care facilities in where dementia care is provided Ontario, Canada (and included facilities such as acute care, outpatient care, rehabilitation and long term care). Each group had the same moderator [therefore consistency in how the information is presented and discussed – optimal]. A research assistant with qualitative research training was also present to audiotape the sessions and document important points of the discussion [the way this is described it sounds like it was a consistent person as well although this is not explicitly stated]. A live performance of a production called “Expressions of Personhood in Alzheimer’s” was done in 5 vignettes illustrating five actual observed events on a dementia care floor and were chosen as they depicted emotions and illustrations of “self hood” and they also illustrated some of the de-personalizing ways that health care workers provide care to people with dementia. The production provided the topic of discussion of <u>non-verbal self expression</u> for those with cognitive loss. The sessions took 30 minutes for the production and 60 minutes for the discussion and semi-structured questions were asked to the group who watched the production. Sampling: purposive sampling technique [i.e. the researchers chose the participants based on their criteria]: Needed to have experience in providing care to those with dementia; had to be a nurse, care aide, occupational therapist, physiotherapist or recreational therapist; provided practice in accordance with person centered care principles [thus was a means to assess how people who practice in accordance with PCC principles, read their patients or residents]; were identified by administrators or supervisors who recommended these people based on them meeting the criteria. Participant description: Each focus group had 6-8 participants with 2 focus groups/facility. All 43 participants were women, 16 were nurses, 10 occupational therapists, 8 physiotherapists, 7 recreation therapists, 2 health care aides. 29 worked in long term care, 11 worked in behavioural management units and 3 worked on geriatric rehabilitation units [interesting that only 2 were care aides as care aides are</p>

Citation	Primary type of research	Study Descriptions with [Critique]
		<p>generally the group who provide the hands on physical care]. As above and all focus groups were audiotaped and transcribed.</p> <p><u>Analysis:</u> Data was analyzed according to standard thematic analysis techniques. Descriptions were attached to text and then these were grouped into categories and then the text in the same category was compared. As a result 5 themes emerged including: 1. Sympathetic connection (i.e. identifying that the person with a life story that affects who they are today; respecting that individual; and providing care that shows dignity; imagining that the client is her or her mother and thinking about the kind of care that she would like to receive is a powerful tool); 2. Shared bodily experience: knowing from our own experiences of embarrassment or discomfort; how bitter a crushed pill is will help to find something that masks the taste; keeping a resident warm after a bath is recognition of the sense of discomfort that comes from being cold after a bath and knowing how a hug can provide comfort and support are all ways of staff showing person centered care as a result of sharing a bodily experience 3. Socially acquired habits of the body - and this was described as the way people are as a result of their life history for example, a former farmer that got up in the early hours of the morning and looked as though he was planting seeds stems from his own life history; another resident stacked chairs and moved furniture as his employment had been as a cleaning person. 4. Time efficiency: if the time is taken at the outset to determine the need, time can be used more efficiently. 5. Non pharmacologic behavioural management: the participants suggested that practitioners who recognize and support bodily expressions of personhood can reduce the use of pharmacotherapies for management of behaviours often associated with dementia. [like Sloane et al (2004), found that PCC may reduce the use of psychotropics].</p> <p><u>Discussion:</u> Some of the participants identified the technique of thinking of a resident as a family member or themselves while others found this much too emotional and therefore crippling.</p> <p>[Excellent unique study where the researchers found that practitioners can provide person centered care much better if they have the opportunity or tendency to imagine what the person with dementia is thinking/feeling or what life history may be affecting their behaviour. In severe dementia, very often the resident is unable to verbalize to communicate so being cued into the non-verbal messages that the resident is providing is critical to being able to provide person centered responsive care. The authors conclude that this “technique” may reduce the time it takes to provide care and may also reduce the medication currently given as chemical restraints. The authors note that behaviours that are related to pain must be treated with analgesics].</p>
<p>Rasin, J. & Kautz, D.D. (2007). Knowing the resident with dementia: Perspectives of assisted living facility caregivers. <i>Journal of Gerontological Nurses</i>, 33(9), 30-36.</p>	<p>Qualitative research</p>	<p><u>Substantive and Theoretical Dimensions:</u> To identify the information that caregivers in assisted living utilized for those with dementia. Most of the knowledge of dementia for the long term care aides who work in A/L comes from “on the job” knowledge or their personal life experience.</p> <p><u>Methodologic Dimensions:</u> Qualitative, explorative research that utilized “focus groups” as a method of data collection. Purposeful sampling was used to ensure that a range of values were represented in the focus group. Recruitment letters were sent out and there was a postage paid envelope to return “if they did not want to participate”. Follow up phone calls, letters and meetings were set up after people had agreed (by default, i.e. they didn’t send in their postcard) to participate in this study. The principal investigator was an African American woman and the researchers note that focus group work occurs more successfully if the person running the group is of the same ethnicity and gender to the majority of the attendees who were obviously also African American. 5 focus groups were created with a total of 23 participants (all CNA’s). In each focus group – ground rules such as being respectful, allowing everyone to talk, use of audiotape and written consent were discussed. The questions asked were: Describe how you work with</p>

Citation	Primary type of research	Study Descriptions with [Critique]
		<p>people with dementia; Are there behaviours or actions of residents that you or staff have trouble dealing with? And How do you handle them? A moderator took notes and then summarized key points and requested clarification before the end of each session. Each session lasted about 1hr with the final 10 minutes used for verification. Refreshments were provided and each participant received a \$25 certificate to a national retail store [nice reward, good they didn't tell them about it before as it may have skewed the participants who were interested in the "gifts"]. Analysis: Kreuger's focus group data prep [good use of an existing focus group analytical tool] and analysis was utilized and all focus group meetings were transcribed. Themes development was initiated by each researcher and then corroborated by a 2nd researcher before consensus on themes was achieved. Two themes emerged from the data analysis: Behaviour centered knowledge i.e. agitation and how to avoid it (i.e. speak slowly and calmly, if they are reacting to a task such as bathing then back away and try again later); Person centered knowledge - the caregivers spoke about the residents in a way that showed they knew them very well. They looked beyond the behaviours and really knew the person and understood where the behaviours were stemming from. Encouraged new staff members to find out what works with "that person" acknowledging that all people are unique. A recognition that life histories may influence the behavioural aspects of dementia. And the caregivers stated that they used the information about life histories to anticipate clients' needs and prevent behavioural symptoms of dementia. Being able to pick up when there is "something wrong" because they know them so well.</p> <p>[Summary: strong qualitative study; clear research problem and fit to methodology; focus group methodology used and explained well; limitation in sample as those who agreed to participate may have just been those who didn't mail back the postcard (somewhat of a default approach to creating a sample group) and they may also not be representative of the whole group. Interpretative methodology explained well and data was genuine. Nice elements to this study: actual quotes of the care providers; an acknowledgement of the critical important of life histories in providing care; a nice overview of the role of the Gerontological nurse; an acknowledgement of the different kinds of information being used – nice distinction : behavioural and person centered. An acknowledgement that person centred care can often thwart behaviours.]</p>
<p>Saltmarche, A., Kolodny, V. & Mitchell, G. (1998). An educational approach for patient-focused care. <i>Journal of Nursing Staff Development</i>, 14 (2), 81-86.</p>	<p>Evaluation research</p>	<p><u>Substantive and Theoretical Dimensions:</u> In the past, caregivers thought that they could prescribe care to others without finding out what was important to them. The shift in thinking is towards a person centered approach that is reflected in Parse's Theory of Human Becoming where the person in care is the "expert" on their own experience and how it is affecting their life. Purpose of this study: discuss and evaluate a program of education that was provided for person centered care education for RN's.</p> <p><u>Methodologic Dimensions:</u> The course was intended to support a shift in nurses' knowledge and attitudes towards older clients by helping nurses learn and integrate the principles of person focussed care and the standards that support these principles. The goal was to help nurses approach the older people with the intent to understand their situations and work through options for care, as guided by the patients' perspective. A course was developed by a clinical nurse specialist in gerontological nursing, facilitated by the co-ordinator [not sure if the CNS is the co-ordinator], chief nursing officer and two other advanced practice nurses who were knowledgeable about person centred care and Parse's theory of Human Becoming. A non-traditional style of education was utilized with the rationale that as the model was non-traditional, the style should also be non-traditional and more free flowing than the usual style of teacher – student methodology. Objectives of the course: to promote awareness of what it is like to be elderly and be in an institution; to learn specific means of incorporating PCC methods into practice; to explore means of communicating that is person focussed; to focus on the priorities of the elderly and provide care for those areas. Course implementation: offered to RN's from 3 medical units, limited to 10 learners at a times (to promote discussion as much as possible), Each class lasted for 3 hours and the</p>

Citation	Primary type of research	Study Descriptions with [Critique]
		<p>course ran for 10 weeks. Some highlights included: discussion about aging; how the nurses felt about aging, how they felt about their clients aging; themes emerged such as: independence versus safety; being with others versus solitude; quality of life versus longevity; they talked about how they would feel if they became ill, lost their independence, experienced restraints; they had an opportunity to talk to residents to find out what was important to them – this occurred during daily practice and was reflected upon in the class. They learned to ask open ended question to obtain patient feedback such as: What is it like to be in this situation? What are your concerns? What are you hoping for? And s on. The WHY questions were avoided as people tend not to know why they feel a certain way but they will generally know what they feel. Course evaluation – several methods were used.</p> <p><u>Ethical Dimensions:</u> Consent is not discussed however if a nurse chose to participate in the course it could be assumed that they chose willingly although the “power over” issues were not discussed (i.e. if they were asked by a supervisor, were they given the choice to decline or accept without any consequences?).</p> <p>[Good study with great ideas for education for PCC].</p>
<p>Sloane, P.D., Hoefter, B., Mitchell, M., McKenzie, D.A., Barrick, A.L., Rader, J., Stewart, B.J., Talerico, K.A., Rasin, Rasin, J.H., Zink, R.C. & Koch, G.G. (2004). Effect of person centered showering and the towel bath on bathing associated aggression, agitation, and discomfort in nursing home residents with dementia: A randomized controlled trial. Journal of the American Geriatrics Society, 52(11), 1795-1804.</p>	<p>Quantitative research (Positivistic/Experimental)</p>	<p><u>Substantive and Theoretical Dimensions:</u> Agitation and aggression are common (cited as being as high as 86% of those with dementia) forms of behaviour during personal care. This is not only distressing to the resident but also to the care staff who are on the receiving end. Psychotropic medication is often given as a result to calm a person with these behaviours down however this medication is associated with delirium, increase in behaviours, reduced cognition. A non-pharmacological method of reducing agitation and aggression is proposed to be through person centered bathing. This study evaluated non-pharmacological interventions of providing hygiene using person centered care and focussed bathing measuring aggression.</p> <p><u>Methodologic Dimensions:</u> Randomized controlled trial with the pre-existing care control group and two experimental groups (with cross over in that the group received a person centered shower for a time period of six weeks, followed by a person centered shower for six weeks and the other group was in reverse order). [good design] Study conducted in 15 nursing homes (multi site study). [accounting for different cultures in different homes]. Two interventions were evaluated for six weeks for the two experimental groups (with a cross over at six weeks) and each incident was videotaped (as well as the control intervention being videotaped): person-centered showering or a towel bath which were person centered, in bed bath with no rinse soap. The CNA’s were provided with education on how to do the person centered showering and towel bath by a clinical nurse specialist or a psychologist. Other than consent and monitoring of behaviours, the control sites did not receive any education or intervention (until after the study was complete). Monitoring of the results was done by undergraduate and graduate students who watched videotapes and coded behaviours [unbiased viewers]. Agitation was evaluated using a tool called: Care Recipient Behavior Assessment (CAREBA) which monitored for aggression, agitation and resistance to care [validity of tool not mentioned but the authors state that it is a modified version of “Cohen-Mansfield Agitation Inventory” which is a well researched and accepted tool for measuring agitation]. Resident discomfort was also measured using a modification of the discomfort scale for dementia of the Alzheimer type [validity for this scale was not discussed but it is based on a previous scale]. Skin cleanliness was evaluated using the “Hardy Skin Condition Data Form” which looked for any form of skin breakdown or lesion. Medications were also monitored during the intervention period particularly the psychoactive and analgesic medications [therefore decreased medications]. Results: Agitation and aggressive responses were statistically reduced for the experimental groups but not for the control group 32-38% for all behaviours and 53-60% for bathing. Resident discomfort reduced as well for the two experimental groups. The towel bath duration increased by 3.3 minutes</p>

Citation	Primary type of research	Study Descriptions with [Critique]
		<p>and the person centered shower took 2.4 minutes longer than the control techniques. Skin condition improved for the two person centered techniques and there was no significant difference in the two groups with respect to microbial flora growing on the skin. <u>Discussion:</u> reflects that the practice of forced bathing needs to be questioned as there are alternatives to this. Didactic training and hands on coaching were used which were seen as pivotal to the success of this intervention. Barriers included: rigid institutional practices, the belief that a lot of water was needed for cleanliness is present (and unfounded) and objectification of residents needs to be avoided. The same change in practice that made restraints become almost obsolete in residential care needs to occur now with PCC. The authors take the position that this form of bathing reduces behaviours and thereby enhances the job for the care attendants increasing job retention and lessening burnout.</p> <p><u>Ethical Dimensions:</u> Recruitment occurred after an institutional review board approval was received and consent obtained prior to involvement in study.</p>
<p>Tellus-Nayak, V. (2007). A person-centered workplace: The foundation for person-centered caregiving in long-term care. Journal of the Medical Directors Association, 8, 46-54.</p>	<p>Quantitative</p> <p>Satisfaction scales for caregivers and families based on management style.</p>	<p><u>Substantive and Theoretical Dimensions:</u> PCC is a cultural shift that is being promoted in LTC that affirms the dignity of residents and staff, respects their individuality, maximizes their choice and empowers them. This study looks at the culture of long term care facilities to see if a management styles influence the adoption of PCC into practice. The hypothesis are: Managers play a critical role in satisfaction, loyalty and commitment of their staff. Managers are responsible for constructing a person centered environment that deepens staff engagement. Engaged staff promote better care that is person centered. Purpose : To understand the role of managers and how the work place culture interacts with the implementation of person centred care in long term care. The question to be answered is: Does a humane work environment promote caregiving whose outcomes are noted by visiting families and by state inspection surveyors?</p> <p><u>Methodologic Dimensions:</u> using a human relations framework, this study tests the idea that managers play a critical role in the implementation of PCC in long term care. Measurement was done through the use of satisfaction scales. 2 sets of nursing facilities, situated in similar economic markets and facing similar challenges, vary significantly in quality because of their different cultures and management approaches. *Eaton*'s framework [the authors do not introduce Eaton, just refer to the principles that are applied to this study – also not listed in references] states that organizations are SOCIAL not merely ECONOMIC. This social environment involves a web of involvement, interdependencies, formal hierarchies, informal bonds, conformity and non verbal communication. Managers and workers seek out their needs for security, self actualization, affiliation and transcendence [this sounds remarkably like Parse's theory!]. The design of this study is based on these foundations – that the LTC environment is a social environment that meets the social needs of individuals and this must be in place if good care i.e person centered care, can be provided. Data collection: data was from two sets of data collection sources. 2 satisfaction surveys in 324 nursing facilities in Nov. 2003 in south-eastern state in the US. One satisfaction survey was completed by nursing staff and one was completed by families of residents. [surveys were well researched and based on focus groups and used for a larger study later]. Staff were sent their surveys with pre-paid return envelope; were kept anonymous and were sent to a place away from the workplace [called My Inner View" which would encourage honesty on the part of the staff – good design consideration]. Response rate for staff was 36%. Families were sent their surveys in a similar way – the rate of return for families was 33%. [the author goes into the rationale as to the poor return rate but in fact, this is not that unusual – they state: no incentive to participate; a co-current state inspection survey may have redirected attention; and high staff turn over]. Due to anonymity, non-responders were not analyzed. Data analysis: staff and family surveys data was analyzed with ANOVA looking for correlations. CNA satisfaction, loyalty and commitment increase when their</p>

Citation	Primary type of research	Study Descriptions with [Critique]
		<p>managers care about them; when their managers listen to them; “Our findings show that CNA’s indeed perceive their managers exerting a pervasive influence in their work life” (Tellus-Nayak, 2007, p. 52).</p> <p><u>Ethical Dimensions:</u> The study design of using anonymous surveys was ethically done.</p> <p><u>Summary:</u> PCC is largely dependent on management support. The approach that management takes has a very large impact on the satisfaction of the CNA’s as well as the perception of quality in a workplace.</p> <p>[This is very important to show the link between kind and caring management and kind and caring care givers...I almost think this may be the most important study of all because it is so vital to the success of PCC into a residential care setting].</p>
<p>Van Weert, J.C.M., Janssen, B.M., van Dulmen, a.M., Spreeuwenberg, P.M.M., Bensing, J.M. & Ribbe, J.W. (2006). Nursing assistant’s behaviour during morning care: Effects of the implementation of snoezelen, integrated into 24-hour dementia care. <i>Journal of Advanced Nursing</i>, 53(6), 656-668.</p>	<p>Quantitative (Positivistic/Experimental)</p>	<p><u>Substantive and Theoretical Dimensions:</u> Dementia is an irreversible condition that is often associated with behaviours such as aggression and agitation. There is research that indicates that their behaviour is positively correlated to the behaviour and emotions of their caregivers. Snoezelen is an intervention which is based on sensory stimulation and has been shown to have calming tendencies for those with dementia. Kitwood’s dialectical framework includes a description of dementia based five factors: a. personality, b. biography, c. physical health, d. neurological impairment and e. social psychology. Kitwood believes that there is an interplay between neurological impairment and social psychology (where social psychology refers to a persons sense of safety, value and personal well being). The work that relates to maintaining a person’s personhood relates to the social psychology of that individual and the work that contributes to the maintenance of a persons’ personhood is termed by Kitwood as “Positive Person Work” (PPW). The behaviours that are associated with Positive Person Work include: recognition, negotiation, collaboration, facilitation, play, stimulation, celebration, relaxation, validation and holding. Behaviors that are damaging to a persons sense of self are termed “Malignant Social Psychology” and these are: treachery, disempowerment, infantilization, intimidation, labelling, stigmatization,. Objectification, outpacing, invalidation, ignoring, banishment, imposition, withholding, accusation, disruption, mockery and disparagement. The aim of this study is to study the behaviour of the Certified Nursing Assistants (CNA’s) 18 months after the implementation of Snoezelen in dementia care. The researchers aimed to determine the effect of a Snoezelen interventions were on the quality of the CNA’s behaviour during morning care</p> <p><u>Methodologic Dimensions:</u> 12 wards total in The Netherlands for people with dementia: 6 wards received training on the use of the Snoezelen and 6 wards did not and continued with normal practice. The control wards signed an agreement that they would refrain from implementing the Snoezelen on their wards during the research. Morning care was captured on video as morning care was identified as one of the peak times for Residents to exhibit behaviours associated with dementia (such as agitation and aggression). Implementation time was 18 months. Video was taken pre-implementation and at the end of the 18 months and then evaluated for change in behaviours. Therefore the study population in this study are the CNA’s who provide direct care. 120 CNA’s and 120 Residents (60 for treatment and 60 for control). All CNA’s that worked on the wards were recruited except for temporary staff, those who worked nights only and students. Residents needed a diagnosis of moderate to severe dementia and moderate to severe according to Care Dependency Scale. [Excellent description of sample size and criteria]. Data collection; videotaped morning care of Residents with CNA’s who knew them well. Total videotapes: 124 for pre-test and 126 videos post test. Video assessment was done by independent observers who were blinded to whether the CNA’s were in the experimental/control group. They assessed the quality of behaviour of the CNA’s. They developed an observation tool as there were no such tools available. Data was analyzed</p>

Citation	Primary type of research	Study Descriptions with [Critique]
		<p>and put into the categories of PPW or MSW. Some of the categories were not used as they did not apply to morning care and others were grouped. A Likert scale was utilized to measure how a behaviour was carried out (i.e. 1. not at all...4. maximally). And interobserver reliability was tested. Descriptive statistics (Chi Square test) were used to measure the difference in the behaviours of the CNA's pre and post implementation of Snoezelen techniques [appropriate]. There was a statistically significant display of negative behaviours (on the part of the caregivers) were demonstrated by the control group compared to the experimental group (Kitwoods Dialectal Framework) and the mean number of explicitly offered sensory stimuli increased for the experimental group from .67 (pre-test) to 3.22 (post-test). However there was no measurable change in the control group. Implementation of snoezelen in dementia care increases person centered care; there was a strong positive correlation between Kitwoods' scale and the use of snoezelen strategies in care. This is new research as no research to date has looked at the effect of introducing snoezelen into care on Kitwood's framework. The authors note that the organizations that provide intensive support (in the form of education and emotional support) had positive results and this study was no different, therefore education and a strong belief in PCC is imperative for practice changes. No recommendations for future research was discussed.</p> <p><u>Ethical Dimensions:</u> Conducted the study as a means to provide evidence to end forced bathing (promoting the ethical value of choice). Sought informed consent from each CNA who participated. Informed consent obtained from each representative. Verbal consent obtained from each resident at the time of videotaping.</p>

Appendix B: Polit and Beck: Evaluating Research Reports

This integrative literature review utilized Polit and Beck's chapter from

Polit, D.F. & Beck, C.T. (2004). Evaluating research reports. In *Nursing research: Principles and methods* (7th ed., pp. 655 – 672).

Philadelphia: Lippincott Williams and Wilkins.

The following summarizes the key areas used in this literature review the criteria with areas of critique highlighted during the process of the integrative literature review.

Summary of Critique Criteria:

Substantive and Theoretical Dimensions:

In the area of substantive and theoretical dimensions, the foundation for the work is evaluated.

Areas critiqued are:

1. Identification of the study question. Is it clear? Does it make sense?
2. Evaluation of the purpose or relevance of the work. Where does it fit within the body of knowledge.
3. What is the congruence between the study question and the methods used to address it?
4. Is context of this study discussed. Do we understand where it is in the scheme of the knowledge in this area. i.e are the theoretical underpinnings identified and discussed?
5. Is there a formal hypothesis?
6. Does the literature review appear to be thorough?

7. Are the ideas that are put forward logical and succinct?
8. Is there a strong foundation communicated that explains the rationale for this study?
9. Is there a conceptual or theoretical framework clearly (i.e. concepts are described well) discussed?
10. Do the findings support or rebuke the theory if one is proposed.

Methodological Dimensions:

In the Methodological Dimensions, the research is evaluated as to *how* the question was answered. The questions asked in this section include:

1. What would the most rigorous method be to answer the research question being asked and is this the method used?
2. What methodology is used? Is it well described?
3. What comparisons are being made in the study i.e. pre and post; between groups and are these comparisons fair and without bias?
4. If the design was longitudinal or cross sectional – were their sufficient data collection points?
5. Does the study have validity and reliability? i.e. in terms of scales used – are they well defined and tested for validity?
6. Is the population of the study well described?
7. How were the subjects recruited?
8. What is the sample size and is this a sufficient number of participants for the design?
9. To whom can the study results be generalized?
10. How was data collected? What methods were used – are these well explained and are they appropriate for the research question being asked?
11. Data collection tools: if interviews were used – were you provided with the questions asked? Do the questions asked answer the question appropriately? If a scale was used, is the scale valid? If observation was used, how might the presence of the researchers affect the behaviours? Is this addressed in the research discussion as a limitation? If observation, what method was used for data collection? I.e. video camera? For biophysical collection – were appropriate instruments utilized? Was care taken to ensure accuracy?

Ethical Dimensions

In the ethical dimensions analysis, the reviewer is looking for the following information:

1. Were the participants subjected to any harmful intervention that would cause pain, discomfort, embarrassment?
2. Did the benefits outweigh the risks?
3. Were the participants invited to join the study or co-erced? Were they free to decline?
4. Were any particular groups omitted from the research?
5. Did the participants or their representatives sign or give verbal consent for treatment?
6. Were safeguards taken to ensure safety and privacy of the participants?
7. Was the study approved and monitored by an Institutional Review Board or a similar ethics committee?