AN EMPIRICAL STUDY OF HEALTH PROVIDERS’ BELIEFS ABOUT PERSONHOOD IN DEMENTIA AND THEIR INFLUENCE ON INTENDED PATIENT CARE

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In Partial Fulfilment of the Requirements
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by
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Paulette Vanessa Hunter, candidate for the degree of Doctor of Philosophy in Clinical Psychology, has presented a thesis titled, *An Empirical Study of Health Professionals' Beliefs about Personhood in Dementia and Their Influence on Intended Patient Care*, in an oral examination held on June 25, 2012. The following committee members have found the thesis acceptable in form and content, and that the candidate demonstrated satisfactory knowledge of the subject material.

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Abstract

Three studies were conducted to measure health providers’ beliefs about the personhood of long-term care residents with dementia, and the influence of these beliefs on health providers’ intended actions toward patients in the long-term care contexts. In Study I, a Likert-format measure of health providers’ beliefs about the personhood of long-term care residents with dementia (the Personhood in Dementia Questionnaire) was created after reviewing relevant literature and consulting with health providers. In Study II, this questionnaire was administered to a pilot sample of nurses and continuing care assistants. Psychometric analysis and subject matter expert review were used to reduce the length of the questionnaire to 20 items by deleting items that were less desirable from either theoretic or psychometric standpoints. The revised questionnaire demonstrated good internal consistency reliability, and preliminary tests of external validity revealed a stronger correlation with a measure of beliefs about person-centred care than with a measure of beliefs about cancer treatment. Study III tested the criterion validity of the Personhood in Dementia Questionnaire by examining its significance as a predictor of health providers’ responses to a health care vignette series. The Personhood in Dementia Questionnaire, together with the cognitive status of the patients described in the vignette series, was a significant predictor of all three intervention strategies identified as possible responses to the vignettes. Specifically, higher Personhood in Dementia Questionnaire scores were associated with an increased likelihood of considering pain medication and non-pharmacologic methods as intervention strategies. They were also associated with a decreased
likelihood of considering anxiolytic medications. Overall, results from this study series show that it is possible to identify and measure health providers’ beliefs about personhood in dementia. The results also provide initial evidence of the internal consistency reliability and of the external validity, including the criterion validity, of the Personhood in Dementia Questionnaire. The Personhood in Dementia Questionnaire can be used to evaluate components of person-centred dementia care interventions that target health providers’ beliefs about the personhood of patients with dementia.
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AN EMPIRICAL STUDY OF HEALTH PROFESSIONALS’ BELIEFS ABOUT PERSONHOOD IN DEMENTIA AND THEIR INFLUENCE ON INTENDED PATIENT CARE

1. Overview

*Personhood* is a social status that affords human beings moral status (Kitwood, 1997). Over the last two decades, a great deal of attention in the nursing literature has been devoted to the possibility that the personhood of individuals with dementia is unfairly compromised, with negative effects on emotional and physical well-being. This attention has led to an emphasis on the development of person-centred care frameworks. Although frameworks for person-centred care are now being evaluated in order to determine the nature of their influence on the social dynamics of long-term care facilities, the basic premise behind the development of these frameworks has never been tested.

The contemporary movement toward person-centred dementia care is based on the premise that a health provider’s *attitudes* toward (including their *beliefs* about) the personhood of the individual with dementia result in *actions* that either support or undermine that individual’s personhood, and that those actions (including the type of health care that is provided) in turn predict health *outcomes*. To this end, there is a small body of evidence to suggest that health providers’ attitudes toward individuals with dementia to some degree inform their actions (e.g., Normann, Asplund, & Norberg, 1999). There is also some work that demonstrates positive outcomes of intervention programs for individuals with dementia (e.g., Gibson, Marley & McVicker, 1995; Kitwood, 1995a; Netten, 1993; Romero & Wenz, 2001). As a result of these two bodies of evidence, it is tempting to hypothesize links among attitudes, actions, and outcomes,
even though these links have not been demonstrated empirically where attitudes toward patient personhood are concerned. Until beliefs about patient personhood can be studied empirically, there is no way to demonstrate empirically that these beliefs predict health providers’ actions or patient outcomes. Therefore, the major goal of this study series was to develop a questionnaire to measure beliefs about personhood and to examine whether questionnaire responses predict a criterion measure of health providers’ intended actions toward patients. Strauss and Smith (2009) commented that the validity of questionnaires and theoretical constructs is interdependent; thus, to the extent that the criterion-related validity of the new measure is supported, the theory that beliefs about personhood may influence the nature of health services provided to individuals with dementia is also supported.

In this thesis, biological, psychological, and social aspects of dementia are explored. Models that emphasize the social-environmental problems that contribute to dementia symptoms are given particular attention. Since these models emphasize personhood, philosophical literature on the subject of personhood is first explored in order to establish a foundation for the further study of personhood. After this, the idea that personhood can be viewed as the attitude (or, more specifically, the belief) of one person about another is explained. The theory that health providers may treat those with dementia differently than those without dementia, to the extent that dementia affects personhood, is also described. Person-centred care frameworks are then discussed as an effort to improve the attitudes (e.g., beliefs and feelings) of health providers toward patients with dementia. Finally, the construction of a questionnaire to measure health providers’ beliefs about personhood in dementia is described. This construction effort
will rely heavily on the exploration of the meaning of personhood to health providers themselves, and is intended as a step toward defining and validating this construct. In addition, to explore the validity of theories about the implications of health providers’ beliefs about personhood in dementia, a study of the correspondence of these beliefs to intended patient care behaviour in typical health care scenarios is discussed. Finally, vignettes describing patient characteristics and behaviour are described as a means of further examining the possibility that health providers may treat those with dementia differently than those without. Health providers’ intended actions with respect to pain management are of particular concern in these vignettes, since large discrepancies in pain management between patients with dementia diagnoses and patients with no dementia diagnoses (other conditions equal) are well-documented (see, e.g., Adunsky, Levy, Mizrahi & Arad, 2002; Forster, Pardiwala & Calthorpe, 2000; Morrison & Siu, 2000).

2. Dementia in the Context of Long-Term Care

Nearly 10% of Canadians over the age of 65 currently have some form of dementia (Alzheimer Society of Canada, 2009). Over the next 25 years, the number of people living with dementia in Canada could double, reaching greater than 1 million (Alzheimer Society of Canada, 2009). Analysis of data from the Canadian Study of Health and Aging (CSHA) indicates that approximately half of newly diagnosed individuals entered long-term care facilities within five years of diagnosis (Hébert, Dubois, Wolfson, Chambers & Cohen, 2001). Since the prevalence of dementia in long-term care facilities is about 50 percent (Mendez & Cummings, 2003), providing appropriate care for individuals with dementia is an important clinical concern for health providers who work in long-term care settings. Similarly, the quality of the care provided
in the long-term care environment is an important concern of patients and their families (Morgan & Stewart, 1999; Train, Nurock, Manela, Kitchen, & Livingston, 2005).

In Canada, there is limited public funding for long-term care (e.g., funding for nursing and personal services, but not for meals, accommodations, and recreational services). For the consumer, this translates into an income-based subsidy for long-term care that ranges from no coverage to full coverage. Depending on the province, these and other aspects of long-term care facilities may be administered directly by health regions or by private agencies or community/religious groups. To monitor and improve quality and consistency across these administrative groups and across provinces, many Canadian long-term care facilities have adopted research-based standardized assessments (i.e., Minimum Data Set or MDS). These assessments are administered to each resident at regular intervals, and the results (e.g., rates of psychotropic medication use, physical restraint use, or falls) can be monitored at the individual, facility, and provincial levels. In some provinces (e.g., Ontario), provincial inspections are conducted annually as another measure of quality. Additionally, publicly funded facilities are encouraged by provincial associations and provincial ministries of long-term care to become accredited by organizations such as Accreditation Canada or Commission on Accreditation of Rehabilitation Facilities. Both organizations provide an independent external peer review to assess service quality across several domains of care. For instance, Accreditation Canada (2009) measures service quality across the following seven domains: culture, communication, medication use, workforce, infection control, falls prevention, and risk assessment.
Despite these measures to ensure quality of care, long-term care residents with dementia diagnoses do not receive the same standard of care that other patients do, at least where pain management is concerned (e.g., Adunsky et al., 2002; Forster et al., 2000; Morrison & Siu, 2000). Malloy and Hadjistavropoulos (2004) have hypothesized that a possible explanation for these discrepancies in health service is that the personhood of individuals with cognitive impairment is not fully recognized. This hypothesis is supported by the impressions of long-term care residents themselves. In one Canadian study that included residents with mild to moderate cognitive impairment, residents were interviewed directly about the aspects of care they perceived to be most important to the quality of their care. Two main themes emerged from their responses: (1) residents’ lives are given meaning by relationships and (2) residents felt a sense of waiting for attention and, for some, waiting for the end (Coughlan & Ward, 2007). This waiting was in sharp contrast with their previous sense of independence, and was also related to the “loss of a sense of personhood and value” (p. 52).

The reasons for this loss of a sense of personhood and value are likely to be complex. For example, Astrom, Nilsson, Norberg, and Winblad (1990) have suggested that patients’ behavioural disturbances can “make it difficult for the nursing staff to understand and place themselves in the patient's world” (p. 1237). However, these behavioural symptoms are themselves related to a complex interplay of staff, patient, and environment factors (see Cohen-Mansfield, 2001). Thus, although this study series examines the influence of health providers’ beliefs about the personhood of individuals with dementia on their intended approach to health care, it is recognized that many factors come to bear on these beliefs and intentions (e.g., routinization of care in the
service of organizational efficiency; see Malloy & Hadjistavropoulos, 2004), and that the theoretical model on which this study is founded will not be complete until further study of these variables can be accomplished.

3. Dementia

There is increasing recognition that health is not a purely physical phenomenon, but is influenced by psychological and social variables. The relationship between health and social factors is bidirectional: an individual’s health status also influences the social world (Hadjistavropoulos, Craig, & Fuchs-Lacelle, 2004). Take chronic pain as an example. A physical pathology such as rheumatoid arthritis may be at the root of the pain condition. However, psychological variables (e.g., level of depression) and social conditions (e.g., level of social support) are known to influence the intensity of pain (Hadjistavropoulos & Craig, 2004). In turn, the person with chronic pain exerts an influence on the social world; for example, he or she may request increased assistance performing tasks such as shopping if mobility is compromised. The resulting new social dynamic is tolerated well by some social partners and poorly by others. In cyclical fashion, this social dynamic influences psychological variables, which in turn influence physical processes; this results in a complex interplay of social-environmental, psychological, and physical variables. The complexity of interactions among biological, psychological, and social processes is not limited to pain conditions, of course, and biopsychosocial models of disease are now well-accepted. For example, the World Health Organization (WHO, n.d.) now recognizes the multidimensionality of all health conditions, and considers anatomical, physiological, social participation, and environmental variables as important health and disability indicators. In the context of
dementia, the adoption of a biopsychosocial approach is extremely important: since there is no known treatment to effectively address the physical pathology of dementia, at this time, interventions are better focused on psychological and social aspects of the disorder. Accordingly, biopsychosocial models specific to dementia (e.g., Kitwood, 1997) criticize the traditional emphasis on the physical pathology of dementia, and consider psychological and social processes important to both the etiology of dementia and to the treatment of individuals with dementia.

3.1. Classification of Dementia

Grabowski and Damasio (2004) defined dementia as, “an acquired and persistent impairment of intellectual faculties, affecting several cognitive domains, that is sufficiently severe to impair competence in daily living, occupation, or social interaction” (p. 2). Many neurological disorders are encompassed within this description; these include Alzheimer’s disease, vascular dementia, Parkinson’s Dementia, and demyelinating diseases such as multiple sclerosis (Mendez & Cummings, 2003). A number of other health conditions can result in dementia for some individuals if left untreated. Examples include tumours, drug toxicity, nutritional imbalances, and infections (Clarfield, 1989).

Clinicians rely on the results from neuroimaging, laboratory tests, and clinical neurological and neuropsychological tests to classify dementia according to diagnostic criteria. Over the last decades, the number of types of dementia that can be clinically distinguished with relatively good sensitivity and specificity has increased (Gold et al., 2002; Kantarci & Jack, 2003). Criteria for Alcohol-Related Dementia (ARD), Dementia with Lewy Body (DLB), Frontotemporal Dementia (FTD) and its subtypes, Vascular
Dementia, and Alzheimer’s Disease (AD) have been developed and continue to be refined (e.g., American Psychiatric Association, 2000; McKeith, Galasko & Kosaka, 1996; McKhann et al., 1984, 2001; Neary et al., 1998; Roman et al., 1993). Although the Diagnostic and Statistical Manual for Psychiatric Disorders (American Psychiatric Association, 2000) currently classifies dementia into just two categories (Dementia of the Alzheimer’s Type and Dementia Due to Other Medical Condition), this is likely to change as recent developments in the dementia literature are incorporated into future revisions. Common across all dementias, and emphasized in the DSM-IV-TR diagnostic criteria, is that dementia is marked by deterioration of multiple cognitive functions. This level of deterioration is sufficient to interfere with regular occupational and interpersonal functioning. Memory is most frequently one of the cognitive functions that must be impaired to meet diagnostic criteria. However, memory impairment is not required to meet criteria for a dementia diagnosis, for instance, in the case of FTD (McKhann et al., 2001; Neary et al., 1998). Language disturbances, motor disturbances, and altered patterns of behaviour are also commonly observed in dementia. Disturbances in these areas of functioning vary across dementia subtypes. Many of the symptoms or changes identified as important to dementia diagnosis (i.e., social dysfunction, memory impairment) overlap criteria that are considered by philosophers as definitive of personhood. This may explain why discussion of personhood in dementia has been a growing area of emphasis in the dementia literature (e.g., Malloy & Hadjistavropoulos, 2004; O’Connor et al., 2007; Touhy, 2004).
3.2. Stages of Dementia

The idea that it becomes more difficult to recognize personhood as dementia progresses is persistent in professional discussions of dementia (Tappen, Williams, Fishman, & Touhy, 1999). To the extent that memory and independent functioning are considered important to personhood, it does follow that personhood is diminished as dementia progresses through stages. Staging systems are used to describe the progression of dementing illnesses and are frequently applied as descriptors of dementia in the clinical research literature (e.g., mild, moderate, or severe). A popular staging system is the Clinical Dementia Rating (CDR; Morris, 1993), a questionnaire in which a clinician rates cognitive problems across six domains of function. The clinician’s ratings are combined into a global rating of dementia as absent, questionable, mild, moderate, or severe (Morris et al., 1997). This mapping system is more accurate once a dementia diagnosis has been confirmed (i.e., in the mild to severe ranges). In this system, mild refers to moderate difficulties with memory and other cognitive functions, with increased dependence at home and in the community; moderate implies severe memory loss and severe impairment in other cognitive functions, with very little independent function; severe implies profound memory loss and dependence. This staging system emphasizes memory functions and level of dependence in describing the advancement of dementia. Once again, these are two criteria that are sometimes considered by philosophers as definitive of personhood; thus, it seems that both the presence of symptoms that meet criteria for dementia, and the severity of these symptoms, may be important to developing an understanding of health providers’ beliefs about personhood in dementia.
3.3. Effects of Dementia on the Person and the Social Environment

3.3.1. Neurobiological correlates of dementia. The cognitive profiles of each of the known dementias can be discussed in terms of their neuroanatomical correlates. The neuroanatomical changes observed in dementia include: intracellular changes (e.g., neurofibrillary pathology, granulovascular change, and Hirano bodies in AD; Pick bodies in FTD; Lewy bodies in DLB), extracellular deposits (senile amyloid plaques in AD), and neuronal loss (Grabowski & Damasio, 2004). These pathological changes often involve specific regions (e.g., the entorhinal cortex and hippocampus in AD or the prefrontal regions in FTD; Grabowski & Damasio, 2004). Thus, the traditional idea that dementia was a global encephalopathy is no longer accepted (Grabowski & Damasio, 2004). For example, in earlier stages of so-called primary dementias (e.g., AD, FTD), higher cognitive functions (i.e., functions that are served by the cerebral cortices) are disrupted and motor functions (i.e., functions related to sub-cortical brain structures) are preserved (Grabowski & Damasio, 2004). Even within a particular diagnostic category, different cognitive profiles appear to be adequately explained by the specific patterns of damage involved (e.g., specific areas of atrophy) (Grabowski & Damasio, 2004).

Nonetheless, puzzling cases exist in which there does not seem to be a direct relationship between the cognitive and behavioural manifestations of dementia and either the region or the degree of neuropathology. For instance, post-mortem examinations reveal neurological correlates of dementia (e.g., extensive neurofibrillary plaques and tangles) in the brains of some individuals, although these individuals did not meet criteria for dementia in their lifetimes. In contrast, it occasionally happens that the brains of individuals who met criteria for dementia during their lifetime have none of the expected
neuropathological changes (Grabowski & Damasio, 2004; Lezak, Howieson & Loring, 2004). No satisfying explanation for these findings exists. Although it is important to develop a further understanding of physical processes that might explain such findings, it also remains possible that social and psychological factors may help to explain some of these observations. Further study of psychological and social processes that influence dementia would contribute to an improved understanding of the disorder and effective treatment of associated behavioural symptoms.

3.3.2. Psychological correlates of dementia. In an analysis of data from the European Alzheimer Disease Consortium (2254 patients across 12 centres), clinically relevant neuropsychiatric symptoms had a point prevalence\(^1\) ranging from 4.9% (euphoria) to 55.2% (apathy) (Aalten et al., 2007). Symptoms of agitation, depression, anxiety, irritability, and apathy were observed to be at the higher end of this range, while delusions, hallucinations, euphoria, disinhibition, night-time behaviour disturbances, and eating or appetite abnormalities were observed to be at the lower end of the range (using 25% as an approximate cut-off). These prevalence rates may be skewed by the inclusion of participants from memory clinics, as these individuals are more likely than individuals from the general population to show a complex symptom profile (Aalten, de Vugt, Jaspers, Jolles, and Verhey, 2005). Nonetheless, other studies of neuropsychiatric symptoms have confirmed both a high prevalence (Lyketsos et al., 2000) and a high persistence (Steinberg et al., 2004; Aalten et al., 2005) among individuals who have been diagnosed with dementia; thus, these symptoms represent an important clinical concern. Martin and Whitehouse (1990) stated that psychological symptoms and behavioural

\(^1\) Point prevalence refers to the proportion of people in a population who have a symptom or condition at a particular point in time.
changes may result either directly from brain damage or from understandable reactions to
the loss of cognitive abilities.

3.3.3. Social correlates of dementia. Neuropsychiatric and behavioural
disturbances are highly prevalent in long-term care facilities (Aalten et al., 2007;
Lyketsos et al., 2000). These symptoms are significant and their etiology is complex
(Martin & Whitehouse, 1990), at once influencing and being influenced by social-
environmental conditions. There are data to suggest that characteristics of those in close
relationship with a diagnosed individual exert an influence on the severity of
neuropsychiatric and behavioural symptoms (e.g., Marriot, Donaldson, Tarrier, & Burns,
2000). Evidence of the influence of the physical environment and general social
conditions on the neuropsychiatric symptoms of dementia is also developing (e.g.,
Morgan & Stewart, 1999). In addition, there is an abundance of literature discussing the
contribution of the neuropsychiatric symptoms of dementia to the experience of caregiver
burden among those in relationship with an individual who has dementia (e.g., Hébert et
al., 2001). Taken together, these different lines of research make clear that we need a
multidimensional approach to understanding the psychological/behavioural disturbances
of individuals with dementia, which are related to a complex interplay of staff, patient,
and environment factors (Cohen-Mansfield, 2001).

The mutual interplay of patient and caregiver factors is illustrated well by the
research of Teri and colleagues (1992), and Zarit (1996). These authors have commented
that the most frequently occurring behavioural and psychiatric disturbances reported by
those in relationship with an individual with dementia include repeating questions, losing
things, forgetting things, concentration difficulties, anxiety, and sadness. The behavioural
and psychiatric symptoms of dementia that were reported as most distressing to those in relationship with an individual who has dementia include threatening to hurt others, expressing suicidal thoughts or thoughts of dying, sadness, dangerous behaviour, and arguing (Teri et al., 1992; Zarit, 1996). Still, Zarit (1996) found that such symptoms predict institutional placement only to the extent that a caregiver feels trapped by his or her experiences caring for an individual with dementia. That is, mental and behavioural disturbances do not themselves appear to increase the likelihood of institutionalization. It is possible to generalize too much from the results of a single study; however, the suggestion that caregiver beliefs (i.e., the belief that one is trapped) predict the institutionalization of individuals with dementia more accurately than the symptoms of dementia themselves is profound. If this is true, then it is not a far leap to theorize that health providers’ beliefs about the personhood of individuals with dementia will likewise influence specific actions taken in the provision of health services to an individual with dementia.

3.4. Conclusion

Dementia is a disorder of cognition that is thought to be caused by neuropathological processes which are usually observable at autopsy. A range of psychiatric and behavioural disturbances is present in a large proportion of individuals with dementia. These disturbances persist throughout the course of the disorder, although in some cases their severity may increase (e.g., depression, apathy) or decrease (e.g., psychotic symptoms) with time. For some people in relationship with individuals who have dementia, the psychiatric and behavioural disturbances of dementia contribute to feelings of being trapped, which, in turn, predict institutionalization. In institutional
settings, psychiatric and behavioural disturbances continue to exert effects on the social environment and contribute to caregiver burden (Hallberg, Norbergh, & Eriksson, 1990). At the same time, there is also evidence that social and environmental factors contribute to psychiatric and behavioural disturbances (e.g., Morgan & Stewart, 1999). Thus, a biopsychosocial understanding of dementia best accounts for the influence of dementing processes on biological, psychological, and social systems and the reciprocal influence of social systems on the psychological symptoms of dementia.

4. Sociocultural Accounts of Dementia

4.1. Social Constructionist Accounts of Dementia

According to some authors, the language used to describe and discuss dementia from a biomedical perspective often implicates the individual with dementia as the source of the pathology that so frequently arises in the social system (Sabat, 2003). This argument is substantiated by the sheer number of studies devoted to the topic of caregiver burden, and the relative absence of studies devoted to the way the social environment burdens the individual with dementia. The profound social implications of dementia cannot be discounted; at the same time, the social system cannot be disregarded as the context in which the behavioural symptoms of dementia take on their significance. Social constructionist accounts of dementia, such as those offered in Sabat’s (2003) discussion of the *positioning* of individuals with dementia and in Kitwood’s (1997) discussion of the *social psychology of dementia*, assign a much greater etiological role to the social system than do biomedical accounts of dementia.

have defined as “patterns of beliefs in the members of a relatively coherent speech community…. a loose set of rights and duties that limit the possibilities of action” (pp. 4-5). According to Sabat (2003), awareness of both interactive positioning (the positioning of one person by another through speech) and reflexive positioning (attempts to position oneself in a more desirable way) is important to understanding the way that dementia is socially constructed. Sabat’s (2003) textual analysis of the discussion of dementia in sources ranging from the DSM-IV (American Psychiatric Association, 1994) to the popular press offers several examples of malignant positioning, a type of interactive positioning that is dangerous because of its negative effects on the individual who is positioned. According to Sabat (2003), the numerous ways in which members of society either explicitly or implicitly malignantly position individuals with dementia, taken together with word-finding difficulties and other cognitive correlates of dementia, place individuals with dementia at a severe disadvantage with respect to their ability to use reflexive positioning (i.e., to reposition themselves) effectively. Thus, commonly accepted storylines about dementia attain a certain level of face validity. Sabat (2003) offers the following text as an example of one such storyline: “Nurses reported that patients receiving validation therapy were less physically aggressive, less depressed, but more nonphysically aggressive in terms of increased wandering, pacing, and repetitive movement” (Benjamin, 1999, p. 124). Sabat (2003) comments:

The loving and devoted relatives and friends of a person who is undergoing major surgery may pace about the waiting room and walk up and down hallways, due to a combination of being anxious and not wanting to sit in one place for hour after hour. This behaviour would hardly be labelled ‘nonphysically aggressive’ (p. 90).
To Sabat, the end result of positioning an individual with dementia in this manner is that he or she “will receive co-operation from others only in the construction of a [self] that can be called the ‘burdensome/dysfunctional patient’” (p. 86). His criticisms suggest that negative beliefs about individuals with dementia (e.g., beliefs that symptoms such as pacing are a form of aggression) are widely held and influence individuals with dementia in negative ways.

4.1.2. Kitwood’s social constructionist perspective. One of the most often-cited works in the dementia care literature is Kitwood’s (1997) text, *Dementia Reconsidered*. In this text, Kitwood (1997) criticizes the biomedical understanding of dementia for its implications regarding the *personhood* of diagnosed individuals, and offers a social constructionist perspective. Kitwood (1993a, 1997) disputes the idea that neuropathology fully accounts for the spectrum of symptoms observed in dementia, and argues instead that to fully understand dementia, one must also attend to other factors. In contrast to the prevailing model of dementia, which appeals almost exclusively to physiological changes to explain the spectrum of changes (e.g., cognitive, behavioural, emotional, social) observed in dementia, Kitwood outlines a model in which biological and neurobiological factors, personal history, personality, and social environment all interact to determine outcomes that may or may not include dementia. Thus, Kitwood argues that the biomedical understanding of dementia overemphasizes neuropathology and underemphasizes the contribution of personal history and the present social environment to the symptom profile of the person who is diagnosed with dementia.

Although Kitwood (1997) refers to his account of dementia as a social psychological model, the account has also been labelled a social constructionist account
For example, like many social constructionist theoretical efforts, Kitwood’s (1997) account has a moral emphasis: it is rather explicitly a moral project aimed at stimulating change in long-term care cultures. Additionally, Kitwood (1997) alludes to the social construction of dementia in three different ways: (1) he advances ideas about the social construction of the diagnostic category of dementia; (2) he writes about the social construction of the day-to-day, lived experience of dementia; and (3) he hypothesizes that social factors contribute to the neurobiological correlates of dementia. His ideas about the social construction of dementia as a diagnostic category and about the social construction of the day-to-day, lived experience of dementia are, arguably, less controversial than ideas that social factors contribute to the neuropathology of dementia.

With respect to his more controversial argument, Kitwood (1997) argues that brain structure is not determined by developmental and pathological factors alone, but is also being determined (i.e., in the present) by the social context of the individual. This perspective is reflected in Kitwood’s (1997) theory that when an individual’s social environment is characterized by respect and support, or positive person work, the neurobiological environment is one that is conducive to nerve growth; for instance, new synaptic connections that compensate for neuron loss. In contrast, when an individual’s social environment is characterized by malignant social psychology (i.e., responses from others that include rejection, control, avoidance, and the like), the health of the nervous system may be compromised.

By this standard, Kitwood’s work was a resounding success. It had substantial influences on policy changes in long-term care in the UK, and stimulated international developments in gerontology.
It is clear that Kitwood (1997) did not intend this account to supplant the biomedical model, but rather to expand it. This is evidenced by his ready acknowledgement of the tandem roles of social and neurobiological factors in the progression of dementia. Still, there are difficulties with accepting this account at face value. Kitwood provides a reasonably specific model for the dialectic interplay of social and neurobiological factors in the progression of dementia, but offers little direct evidence for his model. Most of the case evidence he does provide suggests the possibility that negative social factors contribute to a faster progression of dementia. Some limited case and survey data (e.g., Kitwood, 1995) suggested a possible contribution of positive social factors to rementing (i.e., reductions in the severity of dementia symptoms), but this phenomenon was characterized as temporary maintenance or improvement rather than a true interruption or reversal of dementia.

Kitwood’s (1997) assertions that positive environmental conditions are associated with nerve growth are testable and have some literature support in non-human populations (e.g., Brown et al., 2003; Iso, Simoda, Matsuyama, 2007; Kempermann, Kuhn & Gage, 1997; Olson, Edie, Ernst & Christie, 2006; Van, Kemperm & Gage, 1999). Likewise, Kitwood’s (1997) assertion that the health of the nervous system is compromised under negative social conditions has empirical support in non-human populations (e.g., Ferdman, Murmu, Bock, Braun & Leshem, 2007; Leasure & Decker, in press; Stranahan, Khalil, & Gould, 2006). Overall, however, Kitwood’s (1997) theory of a dialectic interplay of social and neurobiological factors continues to be plagued by a lack of empirical support from research in human populations. In human populations, one of the best sources of evidence for environmental effects on human neurological health is
the study of cognitive rehabilitation. So far, the majority of controlled trials have concluded that these interventions do not lead to improvements in general cognitive functioning for individuals with dementia (Clare & Woods, 2003; Clare, 2003). However, the current state of research evidence does permit the conclusion that social environmental conditions have a prophylactic effect (Fratiglioni, Paillard-Borg, & Winblad, 2004). Therefore, in light of current evidence, the contribution of social factors to the improvement of dementia once an individual has been diagnosed seems more limited than Kitwood’s (1997) work suggests. For obvious reasons, there has been no experimental study of the effect of negative social-environmental conditions on neuropathology; thus, Kitwood’s theory that social factors contribute to neuropathology remains unsubstantiated. Non-experimental approaches to research will be necessary to clarify whether or not this aspect of Kitwood’s theory has merit. This study series can be viewed as a step toward clarifying the media through which these neuropathological changes take place. More specifically, this study series emphasizes behavioural intentions; it is behaviours toward the individual with dementia that, in Kitwood’s theory, contribute to neuropathological decline.

Surprisingly, Kitwood’s (1997) idea that the diagnostic category of dementia is socially constructed and, in some sense, arbitrary may be less palatable than the controversial idea that social events have neurobiological sequelae. It is difficult to accept the view that dementia is purely a socially constructed category in light of relatively strong neurobiological evidence (e.g., the neuroimaging of lesions and atrophy or the microscopic study of neurofibrillary tangles) that dementia reflects identifiable

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3 There is evidence that rehabilitation strategies can improve specific cognitive abilities for individuals who have dementia (Clare, 2003). As yet, there is no evidence to suggest that this represents an improvement of dementia; rather, it demonstrates that new learning can take place in dementia.
pathological processes (e.g., Binder, Guillozet-Bongaarts, Garcia-Sierra, & Berry, 2005; de Leon et al., 1997). Of course, given Kitwood’s (1997) consistent reference to the neurobiological correlates of dementia, it is unlikely that he intends to describe dementia merely as a social phenomenon. This aspect of his theory is best viewed in connection with the related idea that the lived experience of dementia is dependent on the social context. That is, the particular classifications of dementia that have developed over time are frequently distinguished by the cognitive and behavioural aspects, and related social consequences, of dementia rather than by neurological sequelae (which remain difficult to assess until autopsy). Thus, as social values and practices change over time, ideas about dementia, including the terminology used to define and describe dementia, are also likely to change. The merit of this approach to understanding dementia is most apparent in anthropological and cross-cultural studies of dementia.

4.2. Anthropological and Cross-Cultural Accounts of Dementia

Recent anthropological and cross-cultural studies have supported social constructionist accounts by illuminating the role of the social system in dementia. An individual with dementia lives in a context that includes not only his or her immediate physical and social environment, but also a broader socio-cultural context. This context includes the values, beliefs, norms, and assumptions that shape how the experience of dementia is understood and acted on by individuals with dementia and by those who interact with them (O’Connor et al., 2007). It includes organizational cultures and practices as well as local and governmental health policies. For these reasons, Henderson (2002) has criticized the strictly biomedical account of dementia for being too narrow in scope:
Dementia is not universally considered a ‘devastating disease’ as is alliteratively forwarded as immutable fact in medical texts. The fact is that everyone notices that the person has changed, but the change is viewed as a part of the elastic fabric of culture that is incorporated within the bounds of reasonable experience (p. 195).

If dementia is understood as part of the fabric of culture, then it is possible that there are many ways to understand and experience dementia. Studies of the socio-cultural context of dementia provide examples of the ways that “cultural understandings of health and illness mediate the interpretation of disease symptoms and the status afforded to the ill person” (O’Connor et al., 2007, p. 141). A case example from Henderson and Henderson (2002) is illustrative. These authors studied an American Indian family in which an 84-year old woman was experiencing symptoms including memory loss, confusion, and hallucinations. The authors described the family’s reaction to these symptoms as having a tone of “mystical awe” even in the face of the woman’s potentially upsetting social behaviour (p. 206). Many of the woman’s symptoms were interpreted as signs that she was communicating with “the other side” or the supernatural world (p. 206).

Anthropological and cross-cultural studies suggest that the social response to symptoms of memory loss and dependence is not consistent from one cultural group to another. The response to such symptoms relates to various practices and values of the social system, including the extent to which the social system accepts symptoms that might otherwise be associated with dementia as normal, considers longevity a social asset, emphasizes interdependent functioning over independent functioning, and emphasizes stable residence versus mobility (Ikels, 2002). The social response to symptoms of memory loss and increasing dependence may also relate to the degree to
which psychosocial factors (such as the experience of a painful loss) are thought to contribute to these symptoms (Leibing, 2002) or the degree to which the individual is held responsible for his or her situation (Traphagan, 2002).

The central theme that emerges from anthropological and cross-cultural studies of cognitive impairment is that certain symptoms are commonly accepted as associated with dementia in Westernized cultures, but are not necessarily considered pathological in non-Westernized cultures. Moreover, these differences in beliefs influence the extent to which individuals are valued. If individuals with dementia are valued differently on the basis of differing beliefs about their symptoms, it follows that these valuations will be associated with differential treatment. For example, one might expect positive beliefs, or higher valuations of individuals with dementia, to be associated with prosocial behaviour (e.g., inclusion in conversations or social events) and negative beliefs, or lower valuations, to be associated with avoidance. This study series is an effort to evaluate this hypothesis empirically by studying the hypothesized interconnections between beliefs about individuals with dementia and intended behaviours toward them.

4.2.1. Criticisms of Social Constructionist and Anthropological Understandings of Dementia. Social constructionist and anthropological understandings of dementia can be criticized for oversimplifying the biomedical account of dementia and the biomedical approach to the patient and for seeming to minimize the significance of clinical, laboratory, and neuroimaging results indicative of severe pathology. These accounts of dementia also seem to underestimate the significance of the changes introduced to family systems (and other social systems) as the severity of dementia-related neuropathology increases. Although social constructionist accounts of dementia
have served as a stimulus for discussion of dementia care in the gerontological nursing literature and have contributed directly to policy change in the United Kingdom (Brooker, 2007), policy changes have lagged in North America. It may be the case that in North America, empirical data are more likely than cogent theoretical arguments to stimulate clinical practice guidelines and policy changes. Concerted efforts to evaluate the merit of specific aspects of social constructionist theories, especially through empirical study, may be necessary to stimulate the changes these works seem designed to inspire. This research addresses a gap in the literature by empirically evaluating certain aspects of influential social constructionist theories of dementia (i.e., the work of Kitwood, 1997).

4.2.2. Contributions of Social Constructionist and Anthropological Understandings of Dementia. Despite the dearth of empirical support for social constructionist approaches to dementia at the present time, the theoretical and practical contributions of this approach should not be underestimated. Social constructionist accounts of dementia, along with anthropological and cross-cultural studies of dementia, have stimulated a great degree of discussion in the contemporary gerontological literature at an international level. As a result of these publications, there is an increasing acceptance of the idea that the social environment is important to the holistic well-being of the individual with dementia and an increasing adoption of biopsychosocial frameworks in dementia care practice (Brooker, 2007). The advancement of a social constructionist understanding of dementia by Kitwood (1993a, 1997) has directly informed policy changes affecting long-term care in the United Kingdom. In the long-term care environment, where many individuals with dementia spend the latter years of
their lives, the development of a more holistic (i.e., less problem- or pathology-oriented) approach to dementia care may represent a substantial contribution to patient well-being.

In a related way, this project recognizes the social context of dementia, particularly in the long-term care environment. The measure that was developed in this series of three studies was intended to contribute to an understanding of the social dynamics of long-term care by exploring health providers’ attitudes toward patients with dementia and the influence of these attitudes on intended actions in situations that commonly arise in long-term care settings. Attitudes specific to personhood in dementia are of particular importance to this research, since these attitudes are considered as centrally important to the wellbeing of patients with dementia diagnoses (Kitwood, 1997).

5. Dementia and the Problem of Personhood

As dementia progresses, profound changes in the affected individual’s social and occupational functioning occur, and the social significance of these changes frequently results in questions about the personhood of the affected individual. For example, doubts about the personhood of individuals with dementia are reflected in the familiar phrases: “he is not the same person he used to be” and “she is only a shell of the person she used to be”. Many authors have theorized that individuals with dementia are vulnerable to poorer health care and poorer health outcomes precisely because of this decreased recognition of their personhood. Kitwood’s (1997) view is perhaps the most extreme example of this perspective: he theorized that the rate or pattern of neurological decline in dementia is a function of a failure (both within and outside the long-term care context) to recognize the personhood of individuals with dementia. Others have offered more
specific variants of this theory. For instance, Malloy and Hadjistavropoulos (2004) have posited that in some instances, undermanagement of pain in dementia (see, e.g., Adunsky et al., 2002; Forster, Pardiwala & Calthorpe, 2000; Morrison & Siu, 2000) may occur because health providers fail to fully appreciate patients’ personhood as cognitive decline becomes more pronounced. Others have argued that some of the behavioural problems observed among people with dementia may result from the failure of health providers and others in relationship with someone who has dementia to provide for the social status, respect, and basic needs of the person (Pulsford, 1997).

It is challenging to evaluate the merit of these theories, and this is largely related to the problem of describing the nature of personhood. Although the word person has been in common use in the English language for centuries, it has proven difficult to define it in a satisfying way. Over the centuries, personhood has been defined variously as species membership, a quality conditional on a specific ability or set of abilities, and a moral status. All of these conceptions of personhood (and others) continue to inform mainstream debate about the meaning of personhood. As one philosopher of the Renaissance period stated,

If you should try and grasp what Man's being is, it would be exactly like trying to hold a fistful of water: the more tightly you squeeze anything the nature of which is always to flow, the more you will lose what you try to retain in your grasp (de Montaigne, 1576/1987, p. 186).

5.1. Criterion-Based Theories of Personhood

According to Bourgeois (1995), a relatively recent trend in philosophy’s long history has been to conceive of personhood in a moral sense. In this sense, certain rights
and duties are due to those who qualify as persons. This perspective has its roots in Kant’s (1785, cited in Bourgeois, 1995) statement that, “Only rational agents or persons can be ends in themselves. As they alone can have an unconditioned or absolute value, it is wrong to use them simply as means to an end whose value is only relative” (p. 104). In Kant’s view, a human being is considered a person who is worthy of esteem and protection from harm precisely because of the quality of rationality. Thus, rationality is a criterion for personhood, which denotes a status associated with increased esteem and reduced potential for harm. Over the centuries, philosophers have applied the criterion of rationality, as well as other criteria, to define personhood by answering to the question: ‘Just who are we morally obligated to?’

5.1.1. Personhood as rationality. Kant’s (1785, cited in Bourgeois, 1995) appeal to rationality as the critical measure of personhood dates back to Aristotle, who considered reason an essential property of the psuche (self) and the distinguishing feature of persons as compared to animals (Bourgeois, 1995). French philosopher René Descartes is also well-known for his influence on contemporary perspectives on personhood and specifically for the idea that persons are comprised of both material and immaterial substances, (i.e., a body accompanied by a non-physical, conscious, rational mind; Bourgeois, 1995). Descartes highlighted the importance of rationality in the famous words, cogito ergo sum (Descartes, 1644/2004).

Since the ability to reason and to communicate reasoning is thought to be lost in advanced dementia, the idea that rationality determines personhood has important implications. Autobiographical reports from those who have dementia describe intermittent periods of losing the ability to think clearly (e.g., Graboys & Zheutlin, 2008;
Henderson, 1998). Thus, for those who accept any definition of personhood that relies on rationality, personhood is either lost or compromised at some stage of dementia. The widespread influence of Cartesian dualism, particularly in Westernized countries, is expected to contribute to an emphasis on rationality as a criterion for personhood in dementia. To Descartes, the brain was the point at which the mind exerted influence on the body. In this view, the types of behavioural changes that accompany dementia, including loss of ability to communicate, signify the disconnection of mind and body (e.g., as expressed in the belief that the mind is locked within the body or the belief that only the shell of the person remains).

**5.1.2. Personhood as psychological continuity.** Philosopher John Locke was concerned with changes in personhood and, in particular, one’s culpability on Judgment Day for acts committed either before or after such changes (Bourgeois, 1995). Locke (1689) wrote that in order to be the same person, one must experience psychological continuity: “as far as this consciousness can be extended backwards to any past action or thought, so far reaches the identity of that person” (Chapter 27: 9). By consciousness, Locke seems to have meant self-awareness (Bourgeois, 1995). Two important implications of this view are that: (a) consciousness is a prerequisite of personal identity, and (b) personal identity is firmly rooted in memory (in the interpretation of Moody, 2003). In this view, personhood (insofar as it relates to personal identity) is compromised by loss of memory. The implications for individuals with dementia are relatively straightforward, as Moody (2003) states, “If we adhere to this view of personhood, the individual with dementia who can no longer maintain psychological continuity would be regarded either as a non-person or as a different person from the one they were before”
The Lockean perspective has contributed to Western thought for centuries and is likely to influence contemporary thinking about the personhood of individuals with dementia, among laypersons and philosophers alike.

5.1.3. Personhood as bodily continuity. Some have proposed that personhood is not a quality of all human beings, but is linked to bodily continuity (Bourgeois, 1995). In this view, substantial change or damage to the body results in loss of personhood. In the case of dementia, physical change is largely limited to the brain, where neuron structure and function is compromised. It is difficult to argue that these changes are not contiguous; therefore, this particular way of examining personhood has few implications for those with dementia. Nonetheless, in cases in which neuropathy results in changes to muscle tone (e.g., affecting facial expression and posture in Parkinson’s Disease), these physical changes may call into question the personhood of an individual with dementia, or may at least prompt questions about whether that individual is the *same* person.

5.1.4. Personhood as emotional capacity. For many, *sentience*, or the ability to experience pleasure and pain, provides the definitive standard of personhood (Moody, 2003; Tulloch, 1996). More rarely, personhood is conceived of as relying on emotional capacity, a more complex capability than sentience (Dewing, 2008). From either standpoint, the personhood of most individuals with dementia is upheld until the end of life. For example, McFadden, Ingram, and Baldauf (2000) assert that individuals with dementia retain emotional capacities, even in the final stages of dementia. Autobiographical reports of individuals with dementia (e.g., Henderson, 2002) similarly suggest that emotional functioning outlasts cognitive functioning. The possibility that sentience could be an important determinant of health providers’ attitudes toward patient
personhood is suggested by the finding by Norbergh, Helin, Dahl, Hellzén, and Asplund (2006) that an important dimension of health providers’ attitudes toward a patient with dementia was the patient’s ability to experience various emotions.

5.1.5. Personhood as agency. Bourgeois (1995) wrote that in ancient Rome, “the concept of freedom became closely linked with that of a person” (p. 81) and observed that the Stoics (ancient philosophers in Greece and Rome) considered that we must play the role assigned to us by providence. Although we have the freedom to either accept or fight our fate, it has been pre-determined. Other understandings of agency have emerged since the time of the Stoics (Hughes, 2001). For example, in the situated-embodied-agent (SEA) view of personhood, a person is a “being that acts and interacts in the cultural and historical context in which it is embedded” (Moody, 2003, p. 20). The set of actions available to a person is broad enough to allow for the persistence of personhood even in cases of severe dementia (Harré, 1998; Hughes, 2001):

The SEA view holds out the possibility that the person might survive into severe dementia. For whilst the person’s agency might be whittled away (albeit gestures and behaviour can act as continuing manifestations of agency), if personhood is embedded in the individual’s life history and engagement with others, as well as in his or her bodily form, then it makes sense still to talk of the person even in severe dementia (Hughes, 2001, p. 91).

Moody (2003) argues that situated-embodied-agent accounts of personhood help to promote positive attitudes and care practices in dementia care, whereas definitions based on psychological continuity or cognitive abilities may promote negative attitudes and care practices. Nonetheless, this perspective is a recent one and is less likely than other
criterion-related theories of personhood to have wide acceptance among laypersons. In addition, signs of agency may be increasingly difficult to recognize as dementia progresses to more severe stages.

5.1.6. Personhood as human being. The early humanists and religious thinkers like Augustine promoted a moral sense of personhood in their consideration that all human beings are worthy of dignity and respect (i.e., regardless of their possession of the quality of rationality; Bourgeois, 1995). Of all criterion-based discussions of personhood, this perspective has the widest scope and the fewest negative implications for those who have dementia. For those who adopt this view, individuals with dementia remain persons until the moment of death. Augustine’s view closely parallels this philosophy:

“Augustine makes the dignity and value of persons dependent simply on their being loved by God, rather than on the possession of abilities” (Bourgeois, 1995, p. 92). The perspective of Canadian philosopher Jean Vanier (1998) also exemplifies this view. Within secular humanism too, the worth of a person is independent of his or her abilities (Bourgeois, 1995). Since a substantial proportion of Canadians report affiliation with a religious denomination (Statistics Canada, 2001), this perspective on personhood is likely to inform the attitudes of at least some health providers toward patients with dementia. However, it is important to note that both religious and non-religious individuals are vulnerable to enacting discrimination, however unintentional (e.g., Darley & Batson, 1973). Thus, this perspective on personhood may be less predictive of health providers’ actions toward patients with dementia than beliefs that certain criteria, such as sentience or psychological continuity, are necessary for personhood.
5.2. An Alternative to Criterion-Based Approaches to Personhood

Kitwood (1997) is heralded for circumventing traditional criterion-based definitions of personhood by writing that personhood is “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being… implying recognition, respect, and trust” (p. 8). Kitwood’s definition of personhood emphasizes the idea of moral status and therefore represents an extension of Kant’s idea that personhood is associated with moral duties and with individual rights. In contrast to other definitions of personhood, many of which also rely on a Kantian ethic, Kitwood’s definition is broad enough to encompass all individuals with dementia, who are considered by this definition as recipients of rights rather than possessors of capabilities. Kitwood’s definition is widely cited and has been extremely influential in the field of gerontological nursing. Nonetheless, a critical perspective is beginning to emerge in this literature. For example, Dewing (2008) comments that the definition inadvertently accomplishes what it set out to avoid; that is, relegating individuals with dementia to a different moral status than others:

There is a tension in Kitwood’s definition of personhood, where moral concern for others is emphasized but as a consequence, he inadvertently draws attention to those without dementia placing a conferred secondary status of personhood on persons with dementia (p. 6).

In spite of its philosophical problems, Kitwood’s (1997) definition continues to inform the direction of theory and research in dementia care. It has generated discussion of perception of patient personhood as an important consideration in the development and evaluation of nursing practice, and it has also stimulated the development of person-
centred frameworks for nursing practice. This project, a study of health providers’ beliefs about personhood, is an extension of the literature stimulated by Kitwood’s work. Kitwood’s definition of personhood suggests that beliefs about the rightful status of individuals with dementia will be an important subset of such beliefs.

5.3. The Study of Personhood in Dementia

At the present time, there is adequate evidence to support the idea that individuals with cognitive impairment, including dementia, are treated differently than individuals without cognitive impairment, and this is especially well-documented in literature about pain management (e.g., Adunsky et al., 2002; Forster et al., 2000; Morrison & Siu, 2000); however, there is not sufficient evidence to conclude that these differences in treatment result from beliefs about personhood. Despite the popularity of discourse about personhood in dementia and the adoption of person-centred models of dementia care, particularly in the United Kingdom (Dewing, 2004), there has been very little empirical study of the question of personhood. This study series was an initial attempt to contribute to the literature in this manner. The primary goals of this study were to measure health providers’ beliefs about personhood, and then to examine whether these beliefs inform the quality of intended actions; in other words, to examine whether beliefs about personhood have practical consequences in the long-term care environment. Pain management is an important practical concern given that significant discrepancies in analgesic use for patients with dementia versus those without have been documented (e.g., Adunsky et al., 2002; Forster et al., 2000; Morrison & Siu, 2000).

The philosophical foundations of dialogue about personhood (in dementia or otherwise) are essential to an understanding of both the premises of and the controversies
surrounding the contemporary literature on person-centred dementia care. Although this research brings personhood further into the domain of empirical study, philosophical conceptions of personhood cannot be cast aside. It is not possible to quantify beliefs about personhood without first appealing to a common language, and it is well-known that many commonly shared ideas, reflected in language, have their roots in philosophy’s long history (for example, the ubiquitous Western idea of mind-body dualism can be traced back to Descartes). This review of philosophical theories of personhood contributed to the construction of a measure of beliefs about personhood (i.e., item generation) in this study series. It was expected that health providers would adopt, to a greater or lesser degree, one or more of the criterion-based ideas about personhood outlined above. It was also expected that beliefs about the rightful status of individuals with dementia diagnoses would be reflected in health providers’ beliefs about personhood.

6. Health Providers’ Attitudes toward Older Patients and Patients with Dementia

The research question that guided this project (do beliefs about personhood in dementia influence health providers’ behaviours?) could be rephrased as one about stereotypes: “Do learned stereotypes regarding the personhood of patients with dementia lead to inadvertent prejudicial actions by health providers, and so reduce the quality of health care?” The word inadvertent is important: a large volume of research in the area of social psychology has led to the conclusion that people inevitably rely to some degree on stereotypes to guide impressions of others (Macrae & Bodenhausen, 2001). Initial conclusions about (and actions toward) social partners are based on knowledge of category memberships; for example, whether the social partner is male or female, young
or old, or of First Nations or Caucasian ancestry. Frequently, the effects of stereotype activation are subtle. For example, those who have studied stereotype activation have observed that indirect effects of stereotype activation can influence how new information is encoded and interpreted. According to a review by Quinn, Macrae, and Bodenhausen (2003), people tend to: (1) notice information that confirms existing stereotypes; (2) interpret ambiguous data as confirming existing stereotypes; and (3) seek information that confirms existing stereotypes. Stereotypes, whether positive, negative, or neutral, are perpetuated through each of these human tendencies.

The implication with respect to this study series is that stereotypes about individuals with dementia must be present simply because dementia exists as a social category. Extrapolating from the well-researched conclusion of Macrae and Bodenhausen (2001) that stereotyping is a natural human tendency, it is likely that health providers will think and act on the basis of these stereotypes without awareness that they are doing so (e.g., by noticing information that confirms stereotypes). There is no body of research in this area that directly assesses stereotypes about dementia or their effects on health providers’ actions. On the other hand, there is a small body of literature on person perception in other health care contexts. This literature emphasizes that various observable personal qualities (e.g., physical attractiveness) influence the behaviour of health providers. For instance, Hadjistavropoulos, Ross, and von Baeyer (1990) found that physicians’ ratings of pain were influenced by the physical attractiveness of the patient. These studies of the influence of person perception on provider behaviour suggest that additional exploration of the relationship between the attitudes and intended behaviour of health providers is important.
In particular, attitudes toward the personhood of individuals with dementia are important to this research. Because *personhood* is a construct that is difficult to define adequately, it is important to differentiate beliefs about personhood from other types of attitudes; for example, attitudes about appearance in older adulthood or beliefs about cognition in older adulthood. At present, there is no literature that differentiates beliefs about personhood in dementia (or the consequences of these beliefs) from other types of attitudes toward patients with dementia. However, several studies of attitudes toward older persons and attitudes toward individuals with dementia exist, and understanding differences in health providers’ attitudes toward these distinct (but overlapping) groups is useful for distinguishing beliefs about personhood from other constructs.

### 6.1. Health Providers’ Attitudes toward Older Persons

Attitudes toward older persons have been studied extensively and meta-analytic results are now available. In a large meta-analytic review of attitudes toward older and younger adults, Kite, Stockdale, Whitley, and Johnson (2005) observed that attitudes toward older adults were more negative than attitudes toward younger adults. Nonetheless, these authors also observed that this effect depended on which aspects of general attitudes were of interest: “this bias was largest when stereotypic beliefs and perceptions of attractiveness were assessed; the bias was reduced when behaviors/behavioral intentions or affective evaluations were measured” (p. 254). In other words, although negative stereotypes about older people are present in the general population, prejudicial behaviour toward older adults is not of the magnitude that might be expected on the basis of prevalent stereotypic beliefs.
In the context of long-term care, attitudes toward older persons appear to be generally positive: nurses who work in long-term care have neutral to positive attitudes toward older patients (Slevin, 1991; Treharne, 1990); they also have more positive attitudes than health providers with less years of training (e.g., licensed practical nurses and nursing aides; Smith, Jepson, & Perloff, 1982). Attitudes toward older and younger patients were not compared in these studies; thus, it remains possible that nurses’ attitudes toward older patients are more negative than those toward younger patients, as the work of Kite et al. (2005) suggests. Nonetheless, overall, health providers’ attitudes toward their older patients appear to be more positive than findings from the general population would suggest.

Despite these generally positive findings, there is variability in health providers’ attitudes, and relationships between attitude valence and certain aspects of professional nursing practice (i.e., restraint use, social interaction with patients, and general nursing care) have been observed (Armstrong-Esther, Sandilands & Miller, 1989; Helmuth, Lookinland, Anson & McCabe, 1995; Wilkes, LeMiere & Walker, 1998). For instance, more negative attitudes toward older adult patients are associated with positive attitudes toward restraint use. Work toward extending these studies of attitudes and behaviour to long-term care residents with dementia, as a specific sub-group of older adults residing in long-term care, has begun and these efforts were continued in this series of studies.

6.2. Health Providers’ Attitudes toward Patients with Dementia

Knowledge of health providers’ attitudes toward patients with dementia lends an important foundation to this research. Over the last several years, a number of studies have measured the attitudes of health providers toward patients with dementia. For
example, Brodaty, Draper, and Low (2003) measured attitudes toward work using the Swedish Strain in Nursing Care Assessment Scale (Strain scale) and the Swedish Satisfaction with Nursing Care and Work Assessment Scale. The Strain scale has dementia-specific content (e.g., “In daily care, people with dementia often are stubborn/resistive.”) and has two subscales: one measures attitudes and the other measures strain. Brodaty and colleagues (2003) found that of the items listed on the Strain scale, the most prevalent perceptions about persons with dementia were that they have little control over difficult behaviour and are anxious, unpredictable, lonely, and frightened. However, many of those surveyed believed that the atypical behaviours of individuals with dementia were “deliberate rather than a consequence of the dementia” (p. 588). This work suggests that health providers do have specific beliefs about the emotional state of individuals with dementia. Although these beliefs appear to be negative, it is unclear whether they reflect observations of the actual emotional state of long-term care residents with dementia (e.g., as reflected in Coughlan and Ward’s [2007] qualitative study) or whether they are stereotypes.

Norbergh and colleagues (2006) used the semantic differential technique to examine the attitudes of nurses toward patients with dementia diagnoses. Their semantic differential scale had 57 bipolar pairs of adjectives that estimated an unknown number of dimensions of nurses’ attitudes towards an identified patient. A statistical analysis of the responses indicated a four-dimensional structure in which the following characteristics were important in defining a positive or negative attitude toward patients with dementia: a combined ethical and aesthetic dimension (e.g., good-evil; clean-dirty); an ability to understand (e.g., wise-stupid; knowledgeable-ignorant); an ability to experience (e.g.,
joyful-sad; satisfied-painful); and a capacity for social interaction (e.g., active-passive; alert-tired). Nurses’ attitudes were reported to have fallen at the positive to neutral end of a positive to negative attitude continuum. These results suggest that important domains of attitudes toward patients with dementia include aesthetic concerns, cognitive capacity, emotional expressiveness, and social abilities. These domains overlap many of the criteria for personhood in the philosophical literature and may also be important to the measurement of attitudes toward personhood in dementia.

Astrom, Nilsson, Norberg, Sandman, and Winblad (1991) examined the relationships of scores on a scale that measured the positive-negative valence of their attitudes toward long-term care residents with dementia and scores on measures of burnout and empathy levels among health professionals. These authors found that registered nurses (RNs) had more positive attitudes toward patients with dementia than did licensed practical nurses (LPNs) and that burnout predicted less positive attitudes toward patients with dementia as well as lower empathy. These results suggest that both burnout and professional role/qualifications may account for some of the variance in attitudes toward patients with dementia.

Further assessment of health providers’ attitudes toward individuals with dementia was conducted by Zimmerman and colleagues (2005). These authors used structured interviews to obtain data about attitudes, stress, and job satisfaction. They found that levels of stress were higher among male workers, younger workers, and those who had worked for less than two years. They also found that positive attitudes towards patients with dementia were more common among health providers who had worked for less than two years, were better-educated, felt their training was good, or worked in new
facilities. In this study, positive attitudes towards patients with dementia were associated with job satisfaction, replicating the results of Brodaty and colleagues (2003). These results, like those of Astrom and colleagues (1991), suggest that education level may moderate the extent to which health providers believe that individuals with dementia are persons. Further, on the basis of these results, it appears that after more time in the work force, attitudes toward patients with dementia become more negative.

In summary, measurement of health providers’ attitudes toward patients with dementia is an emerging area of research. Some findings from this body of research (e.g., Norbergh et al., 2006) align well with studies of health providers’ attitudes toward older adult patients, which suggest that these attitudes are neutral to positive in valence. Other studies (e.g., Brodaty et al., 2003) indicate that health providers hold negative beliefs about individuals with dementia, and these contrasting results suggest that the literature must develop further before general conclusions may be drawn as to the nature of health providers’ attitudes toward patients with dementia. Nonetheless, a finding that emerges from this literature is that variability in attitudes can be effectively predicted. The measurement of burnout, stress, job strain, job satisfaction, empathy, and demographic variables in studies of attitudes toward patients with dementia has validated the idea that these variables account for some of the response variability in attitude measures. In particular, burnout, stress, and reduced job strain are associated with more negative attitudes whereas job satisfaction is associated with more positive attitudes. Demographic variables (e.g., professional qualifications, duration of career, and age) have also been observed to influence attitudes toward patients with dementia. Although this study series had an explicit focus on beliefs about personhood in dementia as a variable that
distinguishes attitudes toward individuals with dementia from attitudes toward other older adults, work-related variables that predict attitudes toward patients with dementia (e.g., professional qualifications, years of work experience) were also assessed.

6.3. Summary and Conclusions

Research on attitudes toward older adults suggests that, in the general population, attitudes toward this group are generally less positive than attitudes toward younger adults. Nonetheless, in long-term care settings, nurses’ attitudes toward older adult patients appear to be neutral to positive in valence. As a group, registered nurses appear to have more positive attitudes toward older patients than do their colleagues with less training (i.e., licensed practical nurses and nurses’ aides). Still, there is some variability in the attitudes of health providers, including registered nurses, and negatively valenced attitudes are associated with behaviours that are potentially harmful to patients’ quality of life (e.g., increased restraint use, less discussion with patients). Regardless of the average valence of attitudes toward long-term care residents, the study of relationships between the attitudes and intended behaviour of health providers has potential to inform the literature in this area.

To date, only a small body of research on health providers’ attitudes toward older adults with dementia exists. This research is inconclusive about the valence of attitudes toward this population (findings vary depending on how attitudes are measured). Like the body of research on attitudes toward older adult patients in general, research on attitudes toward patients with dementia has been concerned with the relationships between attitudes and other variables. For instance, relationships among the work-related characteristics of health providers (e.g., education, burnout, satisfaction with work) and
attitudes toward patients with dementia have been explored. However, there are dissimilarities in these two bodies of research; specifically, the former is more concerned with the influence of attitudes on intended or actual behaviour toward patients and the latter is more concerned with the influence of work-related factors on attitudes. These differences in emphasis are unfortunate; it is as important to understand what variables affect the attitudes of health providers as it is to understand the implications of these attitudes for the care of patients. For this reason, several work-related characteristics of health providers were assessed in this project in order to assess their relationship with attitudes toward patients with dementia. In addition, since relationships between health providers’ attitudes toward patients with dementia and their intended or actual patient care behaviour are under-researched, one of the major goals of this project was to study those relationships. In particular, the relationship between health providers’ beliefs about personhood in dementia and their intended patient care behaviour was assessed.

7. Person-Centred Dementia Care Frameworks

Theoretical literature suggesting that health providers and others have negative attitudes toward older adult patients with dementia has been greatly influential in stimulating change. In particular, Kitwood’s (1987a, 1987b, 1988, 1989, 1990a, 1990b, 1993a, 1993b, 1993c, 1995a, 1995b) works on the topic of personhood in dementia, summarized in the book *Dementia Reconsidered: The Person Comes First* (Kitwood, 1997), stimulated considerable work in the field of gerontological nursing. In the United Kingdom, this work included the development of several person-centred dementia care frameworks (see Dewing, 2004), or guiding principles for professional dementia care. An examination of content of these frameworks and the context from which they emerged is
important to the proposed study, since these frameworks reflect the actions that are to be expected when health providers believe that their patients are full persons. It is also important to recognize that person-centred care frameworks have grown in popularity on moral but not empirical grounds. This study series can also be considered as a step toward validating the theoretical rationale for these frameworks.

7.1. History of Movements to Improve Dementia Care

As Kitwood (1997) observed, concerted movements toward the consistent provision of positive interventions in the care of individuals with dementia have been under development since the 1960s, in the form of such interventions as reminiscence therapy (Butler, 1963), reality orientation (Taulbee & Folsom, 1966), quality standards and evaluation methods for use in long-term care (e.g., Brooker, 2007; Kitwood & Bredin, 1992); validation therapy (Feil, 1993), biographical and identity-based approaches (e.g., Gibson et al., 1995); a sensation-based therapy called Snoezelen (Benson, 1994; Threadgold, 1995); and counselling and psychotherapy groups (Kitwood, 1997). Person-centred care frameworks incorporate many aspects of these previously-established psychosocial interventions (e.g., by emphasizing individuality, relationship, and the social needs of the individual with dementia), but differ in their holistic approach to the provision of service. Although person-centred care frameworks are borrowed from earlier psychosocial interventions for dementia, these frameworks had their origin in Kitwood’s work on the subject of personhood in dementia.

7.2. The Humanistic Beginnings of Person-Centred Care

The term person-centred, as it was used by Kitwood (1997), “was intended to be a direct reference to Rogerian psychotherapy with its emphasis on authentic contact and
communication” (Brooker, 2007, p. 14). Rogers’ (1961, 1980) works emphasized that under ideal conditions, the climate of psychotherapy ought to be one of empathy, congruence, and prizing (i.e., unconditional positive regard). Rogers (1980) described these conditions as attitudes of the professional toward the patient. Like their precursor, person-centred dementia care frameworks are intended to foster the development of particular attitudes of the health provider toward the patient. These attitudes are thought to be beneficial to maintaining the personhood of the patient. However, person-centred dementia care frameworks differ from the Rogerian approach in their greater emphasis on particular types of actions.

7.3. Person-Centred Dementia Care Frameworks

Several person-centred care frameworks have been established as an attempt to translate the values of the person-centred care movement into recommendations for practice. These include: (1) authentic consciousness, (2) positive person work, (3) the Burford Model of nursing, (4) the Senses Framework, and (5) the VIPS framework. In the most generic sense, what these person-centred care frameworks have in common is that they attempt to foster a set of positive attitudes and actions toward patients with dementia. In a more specific sense, each framework has its own unique areas of emphasis but there is a common emphasis on the recognition of the unique needs and qualities of each patient in the context of a patient-professional relationship characterized by mutuality.

7.3.1. Authentic consciousness. The authentic consciousness framework challenges nurses to examine their own values about older people and calls for the necessity of making the values of the nurse and the older person transparent in order to
develop a successful negotiated relationship (Dewing, 2004; McCormack, 2001). Emphasis is shifted from \textit{doing to} patients in the course of care to \textit{doing with} patients, or in other words enabling patients to continue to do as much as they can for themselves (Dewing, 2004). The five moral duties of nurses operating from this framework are: informed flexibility, sympathetic presence, negotiation, transparency, and mutuality (Dewing, 2004). These duties are described as follows (McCormack, 2001):

1. \textit{Informed flexibility} involves “the facilitation of decision-making through information-sharing and the integration of new information into established perspectives and care practices” (p. 269).

2. \textit{Sympathetic presence} involves valuing the individual, understanding his or her unique attributes, and responding to cues that indicate what is important to the individual, all in order to maximize coping.

3. \textit{Negotiation} involves an appreciation of the patient’s right to participate in decisions that concern him or her, even if it is not appropriate for the patient to make the final decision in some instances.

4. \textit{Mutuality} is “the recognition of the others’ values as being of equal importance in decision-making” (p. 273).

5. \textit{Transparency} involves making the intentions and motivations for action, and the boundaries of care decisions, explicit to the patient (p. 275).

Each of the moral duties outlined in McCormack’s (2001) framework for person-centred care is described in terms of several corresponding attributes and enabling factors, which include nurses’ values, beliefs, and behaviours.
7.3.2. **Positive person work.** Kitwood (1997) theorized that dementia is not simply a neurological condition but rather, as Dewing (2004) summarized, “a dialectical interplay between neurological and psychosocial factors” (p. 40). In Kitwood’s (1997) perspective, some modes of relating to individuals with dementia contributed to loss of personhood and further cognitive decline, while other modes enhanced treatment and prevented cognitive decline. Drawing from his own observational work in long-term care facilities, Kitwood identified 17 processes that commonly undermine the personhood of individuals with dementia: treachery, disempowerment, infantilization, labeling, stigmatization, outpacing, invalidation, banishment, objectification, ignoring, imposition, withholding, accusation, disruption, mockery, and disparagement. He referred to these processes as a form of *malignant social psychology*. He did not consider malignant social psychology to represent the faults of individual health providers, and instead viewed it as an inheritance held over from the beginnings of institutional care. *Positive person work* is the complement of Kitwood’s theory of the contribution of malignant social psychology to dementia, and represents efforts to uphold personhood. Examples of *positive person work* include: recognition (i.e., acknowledging and affirming a person), negotiation (consulting a person about his or her preferences), collaboration (working together on tasks including personal care), play (participating in an activity for the sake of enjoyment), timalation (providing sensory stimulation), celebration (facilitating the experience of joy), relaxation (being nearby, if helpful, to reduce anxiety), validation (acceptance of another person’s subjective reality), holding (providing a safe psychological environment), and facilitation (enabling a person to do what he or she otherwise could not).
Kitwood’s work has been highly influential in the field of gerontological nursing, and has stimulated the development of other frameworks of person-centred care. It has also played a role in policy change in the UK (i.e., a shift toward person-centred frameworks of gerontological nursing care). However, Dewing (2004) argues that Kitwood’s work is insufficiently developed and offers little in the way of practical advice. Nonetheless, Dewing concluded that Kitwood’s work rings true for many practitioners and can be related to their everyday experiences. Therefore, it has relatively high utility as a framework for nursing practice.

7.3.3. The Senses Framework. The Senses Framework described by Nolan, Davies, and Grant (2001) emphasizes the importance of facilitating older individuals’ security, belonging, continuity, purpose, achievement and significance in the care environment (Nolan & Davies, 2002). There is an explicit focus on the subjective experience of the older individual, but there is also an emphasis on the importance of nurses and others who relate to the patient participating in this experience (Dewing, 2004). Although this framework has the advantages of being empirically derived and not unduly complex, it has been criticized for its lack of specificity (for instance, in informing nurses of the ways in which they might attend to the identified senses; Dewing, 2004). It has also been criticized for having a limited, mainly environmental, focus (Dewing, 2004).

7.3.4. The Burford Model. The Burford Model of nursing (Johns, 1994) is a framework that suggests ways of developing a relationship with an older individual in the context of nursing care (Dewing, 2004). The framework relies on the following skills and values:
1. **Holism:** The patient is seen as a whole person, the environment of the patient is attended to, and the nurse collaborates with the patient.

2. **Situated meaning:** The patient’s perspective on the meaning of a health event is considered important to his or her care. The patient’s wishes (e.g., for collaboration versus dependence) are respected as part of this perspective.

3. **Working with:** A collaborative relationship with the patient is sought in each care situation. The nurse may operate out of a paternalistic mode when the patient, for some reason, cannot achieve this relationship (so long as he or she is acting in the best interests of the patient).

4. **Concern:** Includes self-concern, concern for the patient, and the actions taken to address each type of concern. Regular self-reflection facilitates concern; emphasis on perfectionism and efficiency depletes it.

5. **Being available:** Involves attention to the patient, awareness of the here and now interaction with the patient, and active efforts to communicate availability.

6. **Being involved with patients:** This is described as the art of relating closely with a patient and family without overextending oneself.

7. **Mutual understanding:** Knowledge of personal characteristics, concerns, and expectations that arises from being open and authentic.

This framework “facilitates (sic) the nurse to consider the lived experience of the person and … to reflect on how the person is affecting the nurse and how the nurse’s feelings about the person might influence the relationship” (Dewing, 2004, p. 41). It has been criticized for its failure to address clinical elements of health and illness that are also important to nursing care (Dewing, 2004). There is also substantial overlap in the
meanings of the skills and values considered important in this framework (e.g., all of the seven listed skills and values emphasize collaborating with the patient to one degree or another). Finally, some definitions are unclear. For example, holism is more likely to be considered a value than a skill, but is described in a skills-based fashion.

7.3.5. The VIPS Framework. According to Brooker (2007), person-centred care involves a value base in which people are respected, regardless of their age, diagnosis, or cognitive status. It also involves learning about and remembering the individuality of the person; for instance, acknowledging unique histories, personalities, and resources. Further, it involves an empathetic perspective, or an effort to try to comprehend what the person with dementia might be experiencing or trying to communicate. Empathy relies on initiating conversation with individuals with dementia (to find out about them), listening to them, asking or reading about them, and using imagination based on one’s own experiences (e.g., of being in unfamiliar places or feeling disoriented). Finally, the VIPS Framework involves a recognition that individuals with dementia continue to exist as part of a social environment and to have social needs and the potential for personal growth. Thus, the acronym VIPS represents a respectful value base, a concern for individuality, an empathetic perspective, and recognition of the social environment. Like Kitwood’s (1997) positive person work, the framework from which it is drawn, the VIPS framework has an intuitive appeal (Dewing, 2004). It also establishes a clear set of values and behaviours for person-centred gerontological nursing that is likely to be useful to beginning and advanced practitioners alike (i.e., it does not require advanced practice knowledge; Dewing, 2004). For these reasons, the VIPS framework is likely to have relatively high utility (Dewing, 2004).
7.4. Common Factors in Frameworks for Person-Centred Care

Although Dewing (2004) observed that those who developed person-centred care frameworks rarely offer practical suggestions for implementation, these frameworks nonetheless provide a rudimentary sketch of the characteristics of a person-centred health practitioner. Among these characteristics, the foremost in importance is the ability to establish relationships with individuals with older adults that are characterized by mutuality, respect, and empathy. Another characteristic common to all of these frameworks is awareness of one’s own and others’ values. Additionally, the ability to negotiate the patient’s interests when met with conflicting demands (or at minimum, to be transparent when one cannot) appears to be important in some frameworks of person-centred care. These common factors in person-centred care frameworks suggest that a range of beliefs about personhood is possible, and that important beliefs about the personhood of patients with dementia may include beliefs: (a) that it is possible to have a relationship with a person with advancing dementia; (b) that a person with advancing dementia has a right to make his or her own decisions in the long-term care setting; and (c) that a person with advancing dementia can communicate meaningfully. The ideals reflected in these frameworks also suggest that psychosocial interventions (e.g., conversations with patients) are more likely to be adopted when health providers believe that an individual with advancing dementia is a person.

7.5. Effects of Person-Centred Care on Health Outcomes

This project focused on the relationship between health providers’ attitudes toward patient personhood and their intended actions toward patients with dementia. Ultimately, the development of studies to explore relationships between attitudes, actions,
and patient outcomes will be necessary to test the merit of Kitwood’s (1997) theory and
to test the frameworks for person-centred care that have been developed as a result of its
influence. Person-centred care frameworks are designed to positively influence the
beliefs and actions of health care providers, resulting in improvement in patient
outcomes. Evaluating the nature of any associations between person-centred care and
mental and physical health outcomes is an important step toward understanding the
validity of these frameworks. At the present time, the ability of the facility or unit at large
to meet specific quality indicators associated with person-centred care approaches is the
most common way to evaluate person-centred care frameworks, and studies of patient
outcomes after implementation of person-centred dementia care frameworks are limited.
Nonetheless, some empirical and qualitative studies of person-centred care or similar
approaches exist, and examples are reported in the following text.

7.5.1. Early research. Kitwood (1995a) asked 10 persons who “have a rich
experience with long-stay care and who have adopted a strongly person-centred approach
to those with dementia” (p. 138) to provide information about experiences with
individuals with dementia who had experienced positive long-term change. The 10 health
professionals who were surveyed provided data on a total of 49 cases. Kitwood asked the
professionals to rate the degree of positive change on a two-point scale (1 indicating
slight change and 2 indicating marked change). The following dimensions were
measured: assertion of desire or will, warmth/affection, overcoming shame, increase in
trust, spontaneity, transcending depression, and acceptance of limitation. Scores were
summed along each dimension so that the total score for each dimension could reach a
maximum of 98. Scores ranged from 58 (overcoming shame) to 84 (warmth/affection).
Scores for the increase in trust and acceptance of limitation dimensions totalled above 80 points each. The results suggest the possibility that individuals with dementia can experience positive changes in some areas of psychosocial functioning after admission to long-term care. The generalizability of these results is, of course, limited by the methodology Kitwood chose; for instance, he did not discuss the manner in which categories were selected for use in this questionnaire, he chose a convenience sample, and the survey results are likely to be skewed by demand characteristics. Kitwood admitted that the proportion of individuals with dementia who experience positive long-term changes is uncertain and probably quite small, that disease factors (e.g., a slow-moving or benign neurodegenerative process) may account for these variations, and that individual strengths (rather than caregiver abilities) may account for the differences. Nonetheless, he asserted, on the basis of this survey, that positive outcomes are possible results of person-centred care.

7.5.2. Controlled trial evaluations of interventions of patient and staff outcomes. Kitwood’s (1995a) study has notable methodological limitations, but new approaches to assessing the outcomes associated with person-centred care rely on much sounder approaches. Randomized controlled trials (RCTs) of interventions described as promoting person-centred care have begun to emerge. For example, Sloane et al. (2004) completed an RCT of two person-centred interventions for use in dementia care. The first intervention (person-centred towel bath) involved training certified nursing assistants to attend to resident comfort and preferences while delivering a towel bath to a patient who is in bed. This intervention also involved: (1) using problem-solving approaches to identify causes of any difficulties with bathing and possible solutions; (2) education about
behavioural symptoms as a manifestation of unmet needs; and (3) adjusting communication strategies based on dementia severity. The second intervention (person-centred showering) involved providing choices to a resident who is assisted to the shower; for example, offering extra towels for warmth, adjusting the shower spray, providing food as a distraction, using products suggested by family and staff, or using no-rinse soap. Sloane and colleagues found that residents who were assisted in bathing or showering using person-centred strategies were 53% to 60% less likely than residents in a waitlist control group to display agitated or aggressive behaviours, and were also less likely to display signs of discomfort. Moreover, both interventions improved skin conditions and neither had disadvantageous results. Finally, a report by Hoeffer et al. (2006) showed that staff behaviours and perceptions changed as a result of the intervention. Specifically, staff displayed more gentleness and verbal support, and reported perceiving the experience of bathing or showering residents as easier.

Another program focused on the effects of staff education and inter-professional communication on the prescription of antipsychotic medications to patients with dementia. Fossey et al. (2006) delivered a 10-month training and support intervention focused on providing nursing home staff with non-pharmacologic approaches to manage agitated behaviour of residents with dementia. This intervention also involved a series of medication reviews, accompanied by written and telephone recommendations about the prescription of antipsychotics. These recommendations were made by psychiatrists and communicated to general practitioners, and usually involved the discontinuation of antipsychotic medications in accordance with best practice guidelines. This cluster randomized trial showed that it was possible to reduce the proportion of residents taking
antipsychotics and that the symptoms of patients with dementia were not worsened as a result.

Dementia Care Mapping (DCM; Bradford Dementia Group, 1997) involves using an observational measure to assess the level of ill-being or well-being for each individual living in long-term care based on his or her experiences, behaviour, and mood. Brooker (2005) reviewed 34 papers published between 1993 and 2005, and identified seven reports of controlled trial studies using DCM to assess outcomes. Of these, five reports documented statistically significant changes after the implementation of psychosocial interventions. The interventions were diverse, and included aromatherapy, horticultural therapy, intergenerational programs, discontinuation of antipsychotic medications, and increased outdoor activities. The interventions were not necessarily defined as person-centred; however, the evaluation method, DCM, is explicitly rooted in the tradition of promoting person-centred dementia care.

Chenoweth et al. (2009) compared a person-centred care intervention with Dementia Care Mapping (DCM) and with usual care, using a cluster randomized trial (i.e., random assignment of groups rather than individuals). DCM involves adjusting clinical practice based on observations collected using the DCM measure (described above). In this study, person-centred care involved staff education about the potential meanings of unwanted behaviour displayed by patients with dementia, an emphasis on the persistence of emotions despite cognitive impairment, and a discussion of staff interactions that may contribute to behaviours of residents with dementia. Both DCM and the person-centred care intervention were implemented on an individual basis as much as possible, and this was facilitated by telephone communication with long-term care staff.
Patient outcomes included agitation, quality of life, falls, neuropsychiatric status, hallucinations, and cost of treatment. DCM and person-centred care were each effective in reducing agitation relative to care as usual. DCM was also effective in reducing falls (the person-centred care intervention increased falls). Jeon and colleagues (2011) reported on staff outcomes from the same study using the Maslach Burnout Inventory – Human Services Scale (MBI; Maslach & Jackson, 1981) and the General Health Questionnaire. The emotional exhaustion scores (a subscale of the MBI) of staff who participated in DCM declined over the intervention period.

The Eden Alternative™ is an approach related to person-centred care that involves adopting ten principles in an effort to decrease boredom, loneliness, and helplessness in long-term care. The approach includes enriching the environment with plants, animals, and children; promoting companionship; encouraging spontaneity; facilitating meaningful activity; ensuring that medical treatment facilitates holistic well-being; putting more authority into the hands of long-term care residents; creating opportunities for long-term care residents to contribute; and recognizing the importance of continual change in an effort to realize these aspirations. A number of studies have evaluated the Eden Alternative™ but only one controlled trial could be identified. Coleman et al. (2002) compared the Eden Alternative (EA) to traditional care, collecting data on the following primary outcomes: cognition, survival, immune function, functional status, and cost of care. One year post-implementation, the EA group did not differ from the control group (after adjusting for baseline differences). Moreover, when secondary outcomes were examined, the EA group had experienced more falls, nutritional problems, hypnotic prescriptions, and staff terminations. They also required more skilled nursing
care. The only positive outcome was a lower rate of anxiolytic prescriptions for the EA group. Nonetheless, staff and residents reported that participating in EA was a positive experience.

7.5.3. Other effects of programs that promote person-centred care. The Gentle Persuasive Approaches™ program (Schindel-Martin & Dupuis, 2005) attempts to improve staff responses to behavioural and psychological symptoms of dementia through education and skills (e.g., crisis response) training. No peer-reviewed studies of the approach are available at present, but program evaluation research presented by Schindel-Martin and Dupuis (2005) suggests that this program is effective in enhancing a number of staff competencies that are directly related to the content of the training program. Patient outcomes were not examined in this study.

Another program that promotes person-centred care is called ‘Putting the P.I.E.C.E.S. Together’ (P.I.E.C.E.S.; Ontario Ministry of Long-Term Care, 1999). P.I.E.C.E.S. involves staff education with the goal of improving responses to behavioural and psychological symptoms of dementia. The acronym ‘P.I.E.C.E.S.’ represents an algorithm for assessing the potential functions of these symptoms and for generating interventions by examining physical, intellectual, emotional, environmental, and social factors, as well as capabilities that may be involved. After a province-wide implementation described by McAiney et al. (2007), participants rated themselves as better able to recognize and understand mental health problems and to use a variety of recommended assessment tools. Patient outcomes were not examined in this study.

7.5.4. Conclusions. Empirical research in the area of personhood and person-centred care frameworks, particularly as these are applied to dementia, is only beginning
to develop. Many additional studies were not reported here because of serious methodological limitations (e.g., failure to use a control condition). To date, controlled investigations suggest that person-centred care frameworks sometimes lead to clinically and statistically significant outcomes, but the present evidence base is too small to draw sound conclusions. As the construct of person-centred care becomes better-defined, a more specific focus on the outcomes of implementing particular frameworks or specific aspects of care that are promoted within these frameworks would help to demonstrate the validity of these frameworks and may help to distinguish the results from those obtained in the study of other psychosocial interventions for dementia.

As yet, it has not been demonstrated that an increased focus on personhood (i.e., as opposed to some other construct, such as increased attention) contributes to the hypothesized and not yet demonstrated success of these frameworks for nursing practice. For example, one difficulty with the current base of evidence is that most studies of person-centred care assess staff or patient outcomes without directly examining person-centredness (Edvardsson & Innes, 2010, have previously commented on this shortfall). Therefore, one aim of this project series was to study health providers’ beliefs about the personhood of patients with dementia and to evaluate the hypothesis that these beliefs have practical consequences. A positive relationship between these two constructs would suggest a need for the further development of outcome research to explore the practical effects of adopting person-centred care frameworks (e.g., as opposed to other psychosocial interventions).
8. Measuring Beliefs about Personhood and their Influence on the Intended Behaviour of Health Providers

The above discussion focused on the challenges of long-term care practice for both patients and health providers, including particular challenges that may arise when providing health services to individuals with cognitive impairment due to dementia. Some of these challenges were discussed as a product of social systems that foster the devaluing of individuals with dementia, as opposed to symptoms of disease. Kitwood (1997), in particular, was explicit in outlining the interplay between social conditions and the progression of dementia. He observed that the personhood of individuals with dementia was regularly reduced in the course of day-to-day interactions, and encouraged health providers to notice and alter this pattern. His views have been extremely influential in long-term care practice in the United Kingdom and, increasingly, worldwide. Although his work has occasionally been criticized on philosophical grounds (e.g., Dewing, 2008), little work has been done to empirically substantiate or refute his claims. For instance, it remains unclear whether some health providers are more likely to uphold personhood than others, and to what degree this variation is linked to beliefs about personhood in dementia. It is also unclear whether beliefs about personhood in dementia influence the actions of health providers toward long-term care residents with dementia (i.e., the extent to which beliefs about personhood help to explain discrepancies in the quality of health care provided to individuals with and without dementia). An empirical justification for Kitwood’s theory could increase its influence on policy and practice change outside the United Kingdom. On the other hand, if this theory is not substantiated, then increased
effort can be put into understanding other potential reasons for any observed inadequacies in health services provided to individuals with dementia.

The purpose of the series of studies described in the following sections was to begin to establish an empirical basis to test Kitwood’s (1997) influential theory by examining whether providers’ beliefs about the personhood of individuals with dementia influence their actions toward long-term care residents with dementia. To this end, the major aim of this study series was to create a measure of beliefs about personhood in dementia. Additional research goals included examining the reliability and validity of the measure and examining the measure’s potential as a predictor of health care providers’ intended care behaviour. With respect to intended behaviour, the focus was on pain management. This is a major contemporary issue in dementia care given the observation of clinically important discrepancies in analgesic medication use among patients with dementia diagnoses as compared to those with no dementia, other factors equal (e.g., Adunsky et al., 2002; Forster et al., 2000; Morrison & Siu, 2000).

9. Study I: Generating a Measure of Beliefs about Personhood in Dementia

9.1. Purpose

The main purpose of Study I was to develop a face-valid initial item pool for a measure of beliefs about personhood in dementia. Related goals included: first, summarizing the foregoing literature review related to personhood in dementia; second, generating an operational definition of beliefs about personhood in dementia to guide item generation efforts (see Loevinger, 1957); and third, generating questionnaire items from the literature review and from consultations with key informants (i.e., health providers who provide care to patients with dementia).
9.2. Participants

Participants in Study I were recruited from a health region that was in the process of rolling out a program to promote person-centred care. The program (i.e., P.I.E.C.E.S.; Ontario Ministry of Long-Term Care, 1999) is delivered in a train-the-trainer format, and during the period in which Study I was completed, a small number of trainers were receiving or had recently received training. However, no participants in Study I were involved in the program.

9.2.1. Focus groups. Thirty-five health providers (11 nurses and 24 special care aides or SCAs) participated in five focus groups. To facilitate discussion, focus groups for SCAs and nurses were held separately (there were three SCA focus groups and two nurse focus groups). Most focus group participants were female (only one male participated).

9.2.2. Interviews. An additional eight health providers took part in individual interviews. All individual interviewees were female.

9.2.3. Participant survey. Twenty-three of those who participated in an interview or focus group (53% of the total number of participants) also completed a brief paper-based survey about the validity of the results.

9.3. Measures

9.3.1. Interview schedule. The interview schedule used in the consultations with key informants appears in Appendix A. Interview questions were framed as a general exploration of the experiences of health providers who work in dementia care. Direct questions about beliefs about personhood in dementia were not included in the interview
by design, to minimize the risk that participants would answer in ways they perceived to be socially desirable, and thereby bias the results.

9.3.2. Member checking questionnaire. Consistent with qualitative research guidelines (Crabtree & Miller, 1999) and research precedent (e.g., Kaasalainen et al., 2010), a member check was completed. Specifically, a questionnaire was used to evaluate the extent to which each participant agreed with the themes identified during the Study I consultations. Participants were asked to respond to the question, “To the best of your knowledge, is this summary consistent with the spirit of the views of long-term care staff in your facility?” They rated the consistency of the summary with the views of staff at their facility on a scale of 1 to 6 (ranging from not consistent at all to very consistent). They were also given an opportunity to comment on the results and to add information they perceived to be missing. A copy of the survey is provided in Appendix B.

9.4. Procedure

9.4.1. Focus groups and interviews. Following approvals by the Regina Qu’Appelle Health Region Research Ethics Board and the University of Regina Research Ethics Board, long-term care facility administrators in Regina Qu’Appelle Health Region recruited staff participants for Study I using the recruitment script provided in Appendix C. At three facilities, health provider participants were invited to attend a focus group held during the day at their place of work. At two facilities (one of which had also participated in focus groups), participants were invited to attend individual interviews. Individual interviews were scheduled flexibly. Some participants attended before, during, or after their shift; some attended on a day off.
Prior to participating in a focus group or interview, each participant was given the opportunity to read a description of the purpose of the research and a summary of relevant details including risks and benefits, measures to protect anonymity, and limits of confidentiality. Each participant consented to participate before the interview or focus group began by signing a consent form (see Appendix D).

9.4.2. Member Checking. After the interview and focus group data were analyzed, a description of the results was drafted. Facility administrators were asked to circulate this to those who had participated in the study. A brief anonymous survey was included with the results (see Appendix B), and participants were asked to return the survey in a sealed envelope addressed to the researcher. Facility administrators were asked to communicate that completing the survey was optional.

9.4.3. Item development. Questionnaire items are ideally derived from interviews with key informants and from literature review (Kline, 2005). Thus, Personhood in Dementia Questionnaire items were derived from themes and statements synthesized from the transcribed interviews with health providers. Items were also generated to correspond to themes reflected in the foregoing literature review on the subject of personhood. They were constructed in accordance with principles for good design (e.g., brief, easily understandable, grammatically correct; Kline, 2005).

All items were formatted as brief statements accompanied by a Likert response scale. Cox (1980) recommends providing five, seven, or nine response choices, taking into account the influence of the number of responses on various psychometric qualities of a scale. Increasing the number of points on the Likert scale improves psychometric properties of the scale (Diefenbach, Weinstein, & O’Reilly, 1993; Jenkins & Taber, 1977;
Russell and Bobko, 1992); however, increasing the number of points beyond seven makes it difficult to appropriately label the points and is not likely to confer meaningful psychometric advantages (Diefenbach, Weinstein, & O’Reilly, 1993; Jenkins & Taber, 1977). Therefore, a seven-point Likert scale was chosen to accompany Personhood in Dementia Questionnaire items, as in the following example:

Residents with dementia have a sense of purpose.

0 1 2 3 4 5 6 7

Disagree strongly Agree strongly

Personhood in Dementia Questionnaire items are listed in Appendix E.

9.4.4. Review of items by subject matter experts. A group of five reviewers with academic interests in areas such as psychology of personhood, philosophy of personhood, or dementia care reviewed the original pool of 64 items. This review team included the researcher and three research committee members. To minimize the possibility of introducing bias, responses were completed independently using an e-mailed survey, with no comparison of opinion or results until all responses were received. In the survey, reviewers were asked to identify the major theme each item reflected in each item using one of four pre-defined categories (biological, psychological, social, and moral). Items for which agreement was 80% or higher were retained; others were flagged for deletion.

9.5. Analysis

9.5.1. Thematic content analysis of transcript data. Thematic content analysis (Burnard, 1991) was used to code focus group and interview data. This type of qualitative analysis is an approach derived from Glaser and Strauss’ (1967) grounded theory method
and from works on content analysis (Burnard, 1991). It involves a series of stages that the researcher undertakes in order to generate categories that comprehensively describe the textual data being analyzed. The stages are briefly outlined as follows (Burnard, 1991):

1. After each interview, make notes about topics discussed in interviews.
2. Review transcripts and make notes about general themes.
3. Review transcripts to identify unrelated content. Freely record category headings to describe all other units of text.
4. Survey the resulting list and collapse similar headings into broader categories, retaining the sub-headings.
5. Remove similar categories to produce a final list. Retain all sub-headings, but collapse them under a single category.
6. To guard against researcher bias, invite others to generate categories independently. Make adjustments to the categories as necessary to correct for bias.
7. Re-read the transcripts with the finally agreed list of categories and re-code the transcripts according to the list of categories and sub-headings.
8. Request interviewee feedback on results to ensure validity.

There are a number of software options for thematic content analysis. These programs provide a convenient way to store transcript data and conduct analyses. The researcher conducts the analyses himself or herself, using the software as a medium. NVivo (Version 1.3, 2000) was used to facilitate the content analysis in Study I. NVivo provided the necessary flexibility for data coding and allowed for visualization of relationships among units of text and coded categories (Richards, 1999).
A thematic analysis of the full transcript from each interview and focus group was conducted to provide interviewees with the opportunity to give feedback on the validity of the results (Step 8). During this process, a second rater who has extensive experience in qualitative analysis coded a portion of the data to confirm the categories reflected in the full transcripts (Step 6). Since content directly related to personhood was of primary interest, this content was identified and analyzed separately (Step 3).

9.5.2. Analysis of participant member checking questionnaire. Results of the participant survey were analyzed by calculating the mean and mode of the participants’ agreement scores. Participants’ comments were listed, unless they could be classified as reflecting one of the themes listed in the research summary.

9.6. Results

9.6.1. Identification of personhood-related themes from the literature review. The foregoing literature review was used to identify important themes to guide questionnaire development. Themes identified in the foregoing literature review are illustrated in Figure 1. Thus, Figure 1 does not necessarily represent all dimensions of personhood; however, it does represent many of the themes that have been discussed in dementia care literature.

9.6.2. Full analysis of transcript data. Categories and sub-categories that were generated during the full analysis of transcript data are reprinted in Appendix B (these categories were provided to Study I participants during the participant survey). The focus of this study was specifically on the results pertaining to personhood.

9.6.3. Identification of transcript themes related to personhood. Transcript themes that directly reflected beliefs about personhood in dementia were identified and
analyzed separately. These were reframed as general statements of the kind, “An individual with dementia is a person…”]. Nine such statements were identified, and these are listed in Table 1. These statements were then categorized using the themes generated in the foregoing literature review (as summarized in Figure 1). As can be seen by comparing Table 1 to Figure 1, there was an imperfect correspondence between the themes generated during the literature review and the themes generated during consultations with key informants. In particular, two new themes emerged from the consultations with key informants and were added to Table 1: Individuality/Uniqueness and Social Identity.

9.6.3.1. Individuality/uniqueness. Key informants emphasized the individuality/uniqueness of residents with dementia of long-term care residents with dementia during Study I, as in the following statements:

   Interviewee 1: And some people like are very aggressive and physical. ... And other people get very sweet and you know there is quite a difference in personality. ...

   Interviewee 2: And you wonder what the difference is. Why one... is docile and content and the other one is not.

The idea that individuality is important to personhood is also expressed in an emerging psychological literature on the topic of personhood. For example, Martin, Sugarman, and Hickinbottom (2010) state, “… selfhood, identity, and agency all figure prominently in our conceptualization of persons.... Identity is a person’s recognition by others and, through others, by one’s self as a unique individual, with a particular biography (autobiography) and personality” (p. 157).
Figure 1. Themes about personhood identified in a literature review.
Table 1

*Statements about personhood and corresponding themes*

<table>
<thead>
<tr>
<th>Statement about personhood</th>
<th>Corresponding theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>(“An individual with dementia is a person...”)</td>
<td></td>
</tr>
<tr>
<td>• as opposed to an old body</td>
<td>• Bodily continuity</td>
</tr>
<tr>
<td></td>
<td>• Moral status</td>
</tr>
<tr>
<td>• because he or she can sense or feel</td>
<td>• Sentience</td>
</tr>
<tr>
<td></td>
<td>• Emotional capacity</td>
</tr>
<tr>
<td>• because he or she has a unique personal history</td>
<td>• Individuality / Uniqueness</td>
</tr>
<tr>
<td>• because he or she is living</td>
<td>• Social identity</td>
</tr>
<tr>
<td>• because he or she is has thoughts or cognitive processes</td>
<td>• Human being</td>
</tr>
<tr>
<td>• because he or she expresses free will</td>
<td>• Sentience</td>
</tr>
<tr>
<td>• because he or she is an individual rather than a member of a generic group (e.g., residents, the demented)</td>
<td>• Rationality / Cognitive capacity</td>
</tr>
<tr>
<td>• even though family members may not see them as the <em>same</em> person.</td>
<td>• Agency</td>
</tr>
<tr>
<td></td>
<td>• Individuality / Uniqueness</td>
</tr>
<tr>
<td></td>
<td>• Moral status</td>
</tr>
<tr>
<td></td>
<td>• Psychological continuity</td>
</tr>
</tbody>
</table>

*Note.* Statements about personhood were generated on the basis of statements about personhood made by one or more health provider during interviews and focus groups. Themes in boldface were generated from interviews with key informants; all other themes were derived both from literature review and key informant interviews.
9.6.3.2. Social identity. The emphasis that several key informants placed on the past accomplishments of individuals with dementia suggested that one’s past social identity were also considered to be an important aspect of personhood, regardless of one’s memory of that identity:

Interviewee 4: But that helps us relate too to them that at one time all that they did and all that they were, you know.

Interviewee 3: And I find looking at like the wedding picture and the wedding dresses they were so beautiful the women and the men, oh, they were so, oh very nice, I love that.

Interviewee 4: Reading their history, you know that all helps... it’s a person just in an older body or a bit of a mixed up head.

For Bourgeois (1995), social identity is contingent on embodiment. In Bourgeois’ discussion, he acknowledges the difficulty presented by change over time, using the example that a boxer “as an old man may include in himself everything that was or will be taken in along the viewline associated with the body that grows from that of the boy to the body of the old man” (p. 267). He notes that at different stages of life a person may adopt viewpoints that are inconsistent with those of earlier life. He does not consider it necessary to accept that one person has ceased to exists, and instead suggests that it may be possible to consider one’s personhood at a specific moment in time as being a stage of the “overall person” (p. 267). In this view, personhood may include some, though not necessarily all, past attributes of the embodied individual. This argument takes on special significance in the case of dementia because of the changes in social identity that often accompany the progression of the disease.
The idea that past attributes of an embodied individual are important to personhood is found elsewhere in literature on the topic of dementia. For example, After her diagnosis, she was no longer a pilot, a high-ranking law enforcement officer, a locomotive engine driver, the organizer of her husband’s life, or homemaker for a family. Still, all of these social personae were part of the life she lived for decades and reflected long-held qualities and beliefs she still possessed. As a result, Mrs. E. wanted to be treated with the respect and deference rightfully due to a woman of considerable substance and achievement, in spite of her diagnosis (Sabat, Napolitano, & Fath, 2004, p. 181).

The idea that social identity is significant is also expressed in the writing of individuals with dementia. For instance, Cary Smith Henderson wrote, “Sometimes we miss being important” (p. 74). Thus, social identity also appears to be an important dimension of personhood in dementia.

9.6.4. Further categorization of themes derived from literature review and consultation. After consulting with subject matter experts, a decision was made to further summarize the themes generated in the literature survey and in interviews with key informants as members of four higher-level, or basic, categories: biological, psychological, social, and moral (see Table 2). The first three categories are very commonly used in psychological research. For example, biopsychosocial models, now ubiquitous, provide conceptualizations of various diseases and disorders that are based on this three-category system. Lasher and Faulkender (1993) used a similar four-category system (i.e., physical, psychological, social, and transpersonal categories) as they constructed a scale to measure anxiety about aging. The addition of a fourth category was
Table 2

*Themes identified in a literature review and interviews with key informants*

<table>
<thead>
<tr>
<th>Higher-level theme</th>
<th>Lower-level theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Biological</td>
<td>• Bodily continuity</td>
</tr>
<tr>
<td></td>
<td>• Human being</td>
</tr>
<tr>
<td>• Moral</td>
<td>• Moral status</td>
</tr>
<tr>
<td>• Psychological</td>
<td>• Agency</td>
</tr>
<tr>
<td></td>
<td>• Emotional capacity</td>
</tr>
<tr>
<td></td>
<td>• Individuality / Uniqueness</td>
</tr>
<tr>
<td></td>
<td>• Psychological continuity</td>
</tr>
<tr>
<td></td>
<td>• Rationality / Cognitive capacity</td>
</tr>
<tr>
<td>• Social</td>
<td>• Sentence</td>
</tr>
<tr>
<td></td>
<td>• Social identity</td>
</tr>
</tbody>
</table>

*Note.* Personhood-related themes identified in the literature review and following interviews with key informants were collapsed into four higher-level categories.
considered important in Study I because moral status had been identified as a dimension of personhood. However, rather than using a “transpersonal” category, which has spiritual connotations, the term “moral” was selected to allow for a broader range of content.

9.6.5. Member checking. Level of agreement with the overall results from the consultations was assessed by survey. The average agreement rating was 4.9 (on a six point scale), and the modal rating was 5. This demonstrates strong but not perfect agreement with the results. Perfect agreement was not expected, considering that the summary of results was an aggregate across all focus groups and interviews and there was, naturally, some variation in the content of each interview and focus group. Participants were given the opportunity to add to the results. Some of their comments could be classified within existing themes; however, new themes were also mentioned. Further discussion of these new themes is beyond the scope of this text, since no new personhood-related themes were mentioned. However, a summary of the participant survey results, including new themes, is provided in Appendix F.

9.6.6. Operational definition of beliefs about personhood in dementia. After the literature review and qualitative analyses were completed, the following operational definition of beliefs about personhood in dementia was generated to guide item development. Beliefs about personhood in dementia may include:

1. An evaluative statement about an individual/group with dementia (e.g., Mrs. Jones is not the person she once was);
2. An evaluative statement about the way dementia affects or does not affect an individual/group (e.g., Dementia has not affected Mr. Smith’s interest in farming); or

3. A statement assigning or limiting the rights of an individual/group with dementia (e.g., Residents with dementia should not be allowed to make decisions about their care).

9.6.7. Questionnaire items. Sixty-four questionnaire items that met the operational definition of beliefs about personhood in dementia were generated from the themes identified in the literature review and transcript analysis. This initial version of the Personhood in Dementia Questionnaire is reprinted in Appendix E.

9.6.8. Review of items by subject matter experts. Five subject matter experts reviewed each item and decided whether each item best reflected biological, psychological, social, or moral themes. Twenty-three of the original 64 questionnaire items were flagged for removal because of less than 80% agreement on the theme associated with each item.

10. Study II: Pilot Study of a Measure of Beliefs about Personhood in Dementia

10.1. Purpose

The purpose of Study II was to develop a questionnaire with good psychometric properties using the pool of questionnaire items generated in Study I. More specifically, the primary goal of Study II was to ensure that the Personhood in Dementia Questionnaire had good psychometric properties. This was accomplished by deleting items that detracted from internal consistency and items that were substantially influenced by attempts to respond in a socially desirable manner. A second goal of Study
II was to conduct a preliminary study of the convergent and discriminant validity of the improved questionnaire.

It was expected that, following psychometric item analysis, an internally consistent questionnaire, minimally affected by social desirability responding, would be generated. It was hypothesized that:

1. There would be a statistically significant and moderate to strong positive association between beliefs that personhood persists in dementia and beliefs about the use of person-centred care strategies in a long-term care setting (convergent validity).

2. Beliefs that personhood persists in dementia would not predict attitudes toward other patient groups; specifically, there would not be a strong negative association between beliefs that personhood persists in dementia and beliefs favouring an aggressive approach to the treatment of patients with cancer (discriminant validity).

10.2. Participants

Sixty health providers (14 nurses and 46 special care aides) participated in Study II. The average amount of long-term care work experience for this sample was 13.2 years ($SD = 9.0$). Sample demographics are further described in Table 3. As in Study I, participants in Study II were recruited from a health region that had partially rolled out a program to promote person-centred care (i.e., P.I.E.C.E.S.; Ontario Ministry of Long-Term Care, 1999) delivered in a train-the-trainer format.
Table 3

*Percentage of sample by demographic characteristic*

<table>
<thead>
<tr>
<th>Demographic characteristic</th>
<th>Percent of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1.7</td>
</tr>
<tr>
<td>Female</td>
<td>98.3</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
</tr>
<tr>
<td>Nurse (LPN, RN, RPN, or trainee)</td>
<td>23.3</td>
</tr>
<tr>
<td>Special Care Aide</td>
<td>76.7</td>
</tr>
<tr>
<td>Education level</td>
<td></td>
</tr>
<tr>
<td>Bachelor’s degree in nursing (B.Sc.N.)</td>
<td>10.0</td>
</tr>
<tr>
<td>Diploma in nursing / Enrolled in B.Sc.N.</td>
<td>15.0</td>
</tr>
<tr>
<td>Certificates / On-the-job training</td>
<td>75.0</td>
</tr>
<tr>
<td>Country of origin</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>91.7</td>
</tr>
<tr>
<td>Other</td>
<td>8.3</td>
</tr>
<tr>
<td>Spiritual traditions</td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>71.7</td>
</tr>
<tr>
<td>None or Unspecified</td>
<td>25.0</td>
</tr>
<tr>
<td>Other</td>
<td>3.3</td>
</tr>
</tbody>
</table>

*Note.* One additional person did not meet criteria for participation (her occupation was listed as “other” rather than nurse or care aide). Her information was not included in the sample demographics reported here.
10.3. Measures

10.3.1. Social desirability responding. The Balanced Inventory of Social Desirability Responding (BIDR; Paulhus, 1991) was chosen to assess the social desirability bias in Personhood in Dementia Questionnaire items. The BIDR has 40 items, each rated on a 7-point Likert scale. A total scale score and two subscale scores (self-deceptive enhancement [SDE] and impression management [IM]) are derived using scoring rules. Examples of items on the SDE scale include, “I never regret my decisions” and “I am not a safe driver when I exceed the speed limit”. Examples of items on the IM subscale include, “I have said something bad about a friend behind his or her back” and “I always obey laws, even if I’m unlikely to get caught”. The subscale scores each range from 0 to 20, and the full scale score ranges from 0 to 40. The test has reasonably good psychometric properties that compare well to other measures of social desirability responding. According to Paulhus (1991), Cronbach’s alpha, a measure of the full scale’s internal consistency, is 0.83, and test-retest correlations for each subscale at five weekre-administration are \( r = .69 \) (SDE) and \( r = .65 \) (IM). The full scale correlates well with two other measures of social desirability (Paulhus, 1991), supporting its concurrent validity. Factor analytic studies support the subscale structure (Paulhus, 1991).

10.3.2. Beliefs about person-centred care. The Person-Directed Care and Environmental Support for Person-Directed Care (PDC; White, Newton-Curtis, and Lyons, 2008) was chosen to study the convergent validity of the Personhood in Dementia Questionnaire. The PDC has a seven-item personhood subscale that assesses retrospective self-reports of actions thought to represent person-centred care. Each item is rated on a 5-point Likert scale. Examples of items on this subscale include: “Thinking
about the people in your care, how often do you focus on what they can do, more than
what they can’t do?” and “Thinking about the people in your care, how often do you ask
them about their wishes?” This PDC subscale has good internal consistency despite a low
number of items (α= .86; White et al., 2008). No psychometric information about the
external validity of the PDC is available, although the authors have indicated that in
preliminary analyses, the tool discriminated between long-term care settings, disciplines,
and staff levels.

The personhood subscale of the PDC was modified for use in this study by
changing the item stems from “For how many do you…” or “How often do you…” to
“How important is it to….”. For instance, one item reads, “For how many do you see the
experience of living here through their eyes” and another reads, “How often do you help
them give back to others”. These items were changed to read, “How important is it to see
the experience of living here through their eyes” and “How important is it to help them
give back to others”. The remaining items were modified in similar fashion. These
modifications allow the measure to be interpreted as a measure of beliefs rather than a
measure of self-reported actions, and facilitates interpretation of convergent validity.

10.3.3. Attitudes toward patients with cancer. The Cancer Attitudes
Questionnaire measures beliefs about cancer treatment; for example, beliefs about the
role of patient and family attitudes, the role of physician attitudes, outcomes, viability of
outpatient treatment, and importance of a multidisciplinary approach to treatment. It was
originally intended to be administered to medical students or physicians to assess beliefs
about cancer treatment. The eight-item physician attitudes subscale of the Cancer
Attitudes Questionnaire (Lebovits, Groen, & Goetzel, 1984) was administered as a
measure of the discriminant validity of the Personhood in Dementia Questionnaire. This subscale contrasts attitudes favouring aggressive cancer treatment against attitudes reflecting the emotional and social needs of the patient. For example, “To give good cancer therapy, the physician should focus on the disease itself, rather than its emotional consequences for the patient”. Cronbach’s alpha for this subscale is adequate at $\alpha = 0.69$ (Lebovits et al., 1984). Scale scores are obtained by reverse-scoring negatively worded items, adding the scores for each item within a subscale, and dividing this sum by the number of items on the subscale to allow for direct comparison of results across subscales. Since only one subscale was used in this study, the total score on the physician attitudes subscale was used in all analyses, as opposed to the average item score.

The physician attitudes subscale of the Cancer Attitudes Questionnaire was chosen to test the discriminant validity of the Personhood in Dementia Questionnaire for three reasons. First, it measures attitudes about a different patient group (i.e., patients with cancer as opposed to patients with dementia). Secondly, it measures a construct that is, at face value, different from beliefs about personhood in dementia (i.e., beliefs about the appropriate focus of cancer treatment). Finally, both the physician attitudes subscale and the Personhood in Dementia Questionnaire can be broadly classified as measures of patient-centred attitudes. This allows for the potential to draw meaningful conclusions about measuring patient-centred attitudes in distinct patient groups.

**10.3.4. Demographics questionnaire.** The demographics questionnaire used in Study II is reprinted in Appendix G. Each participant’s age, sex, occupation, education, years of work experience in long-term care, country of birth, and spiritual tradition was
requested. Providing information about one’s country of birth and spiritual tradition was optional.

10.4. Procedure

After this series of studies was approved by the Regina Qu’Appelle Health Region Research Ethics Board and the University of Regina Research Ethics Board, participants were recruited at long-term care facilities in the Regina Qu’Appelle Health Region (RQHR). Long-term care facility administrators were asked to co-ordinate a convenient time for interested health providers (i.e., nurses and SCAs) to leave the unit, at their option, in order to participate in the study. Recruitment posters were provided (see Appendix H). Health providers who opted to participate in Study II first reviewed a brief description of the purpose of the research, including information about risks and benefits and limits of confidentiality. If they remained interested, they signed consent forms (see Appendix I). When the consent forms were submitted, they were asked to complete a battery of questionnaires, including the Personhood in Dementia Questionnaire. To facilitate honest responding, questionnaires were completed anonymously.

After the results were received, one case (14) was discarded because of violation of the eligibility criteria. Physician attitudes subscale data for one additional case (43) was discarded because approximately half of the responses to this subscale were missing. Otherwise, missing data were accounted for by occasionally missed or double-scored items. The percentage of questionnaire data missing ranged from 0.13 for the personhood subscale of the PDC to 2.47 for the physician attitudes subscale of the Cancer Attitudes Questionnaire. All missing data were replaced using two-way imputation (Sijtsma & van

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4 A subscale of the Cancer Attitudes Questionnaire (Lebovits, Groen, & Goetzel, 1984).
der Ark, 2003; van Ginkel & van der Ark, 2005). This method is an improvement over replacement of missing data with series means in that it takes into account both the responses of other participants on the item that is being imputed (as in replacement with the series mean) and the response pattern of the participant whose data are being imputed. After missing data were replaced, the data were screened for outliers by visually inspecting histograms of total score data and also by examining whether total scores for individual participants fell at least three standard deviations above or below the mean total score for the scale. Using this process, the Personhood and Dementia Questionnaire and the physician attitudes subscale of the Cancer Attitudes Questionnaire were each found to have one outlier (case 8 and 17, respectively). These data were removed.

10.4.1. Psychometric refinement of the Personhood in Dementia Questionnaire. A stepwise process was used to refine the item content of the Personhood in Dementia Questionnaire. First, items flagged for removal after review by the subject matter expert team were eliminated. Next, the item-total correlations of the remaining 41 items were calculated. Two items (1 and 18) were immediately identified as problematic because of negative correlations with the total score; thus, they were deleted. This left a pool of 39 items ($\alpha = .88$).

To reduce vulnerability to social desirability responding, the correlations of each of the 39 remaining items with the BIDR total score were calculated, and any items that had statistically significant correlations with the BIDR total score were deleted. This resulted in the deletion of six items (16, 19, 31, 34, 51, and 64). The remaining 33 items on the questionnaire continued to have good internal consistency ($\alpha = .86$).
The item-total correlations of the Personhood in Dementia Questionnaire were then examined. First, five items with item-total correlations less than 0.20 were deleted (items 2, 24, 27, 37, 38). This left 28 items ($\alpha = .87$). Then, items with the lowest item-total correlations less than 0.30 were sequentially deleted (items 3, 13, 48). This left 25 items; again, these had good internal consistency ($\alpha = .87$). The average inter-item correlation was .19, and this falls within the target range recommended for homogeneity of questionnaire items (see Briggs & Cheek, 1986; Clark & Watson, 1995).

Since such significant revision to a questionnaire can influence score calculations, the data were checked for outliers again, using a three standard deviation difference from the average score for the 25-item version of the questionnaire as a cut-point. Two outliers were identified (cases 9 and 17) and excluded from further analysis. This exclusion influenced the correlations of questionnaire items with the BIDR total score, and items 50 and 60 were removed because of statistically significant correlations. Since use of the revised dataset also influenced internal consistency of the 25-item questionnaire ($\alpha = .78$), items 59 and 29 were removed to improve reliability. The resulting Personhood in Dementia Questionnaire had 21 items ($\alpha = .79$).

The data were once again checked for outliers, this time using a three standard deviation difference from the average score for the 20-item version of the questionnaire as a cut point. The score for case 17 no longer fell beyond three standard deviations from the mean and was re-included in the dataset. This inclusion resulted in a small improvement to the Cronbach’s alpha coefficient for a 21-item Personhood in Dementia Questionnaire ($\alpha = .81$). Further improvement was obtained by deleting item 14. This resulted in a finalized 20-item questionnaire ($\alpha = .81$) (see Appendix J). The average
inter-item correlation for this questionnaire on the newly revised set of data was .21 (again within a range that demonstrates homogeneity; Briggs and Cheek, 1986; Clark & Watson, 1995). The development process is summarized in Figure 2.

10.5. Analysis

Descriptive statistics for all scales used in Study II are provided in Table 4. All scales had at least acceptable internal consistency (Cronbach’s alpha for the BIDR full scale was 0.81; alpha coefficients for other scales are reported in Table 5). All scale scores were tested using a one-sample Kolmogorov-Smirnov test and a Shapiro-Wilks test, and only the personhood subscale of the PDC was found to deviate ($p < .05$) from a normal distribution. Since the statistical significance test for the Pearson product-moment correlation is relatively unbiased using non-normal data (Edgell & Noon, 1984) and most data in Study II were normally distributed, the Pearson product-moment correlation was used in the following analyses.

10.5.1. Convergent validity. To test Hypothesis 1, that the convergent validity of the Personhood in Dementia Questionnaire would be supported by a statistically significant, moderate to strong, positive relationship with the modified personhood subscale of the PDC (White et al., 2008), the correlation of the two scales was calculated.

10.5.2. Discriminant validity. The correlation of the Personhood in Dementia Questionnaire with the physician attitudes subscale of the Cancer Attitudes Questionnaire (Lebovits et al., 1984) was also calculated. This calculation was to test Hypothesis 2, that the discriminant validity of the Personhood in Dementia Questionnaire would be supported by the failure to observe a strong positive relationship between the two measures.
Figure 2. Flow chart depicting design of the Personhood in Dementia Questionnaire.
### Table 4

*Means and standard deviations for six scales*

<table>
<thead>
<tr>
<th>Scale</th>
<th>$M$</th>
<th>$SD$</th>
<th>$n$</th>
</tr>
</thead>
<tbody>
<tr>
<td>PDQ full scale</td>
<td>116.804</td>
<td>11.338</td>
<td>58</td>
</tr>
<tr>
<td>PDC subscale</td>
<td>33.125</td>
<td>1.898</td>
<td>58</td>
</tr>
<tr>
<td>CAQ subscale</td>
<td>17.589</td>
<td>5.637</td>
<td>56</td>
</tr>
<tr>
<td>BIDR full scale</td>
<td>12.857</td>
<td>6.169</td>
<td>58</td>
</tr>
<tr>
<td>BIDR SDE subscale</td>
<td>6.554</td>
<td>3.697</td>
<td>58</td>
</tr>
<tr>
<td>BIDR IM subscale</td>
<td>6.304</td>
<td>3.727</td>
<td>58</td>
</tr>
</tbody>
</table>

*Note.* PDQ = Personhood in Dementia Questionnaire; PDC subscale = Personhood subscale of the Person-Directed Care and Environmental Support for Person-Directed Care measure (White et al., 2008); CAQ subscale = Physician attitudes subscale of the Cancer Attitudes Questionnaire (Lebovits et al., 1984); BIDR = Balanced Inventory of Desirable Responding (Paulhus, 1991); SDE subscale = Self-Deceptive Enhancement subscale; IM subscale = Impression Management subscale.
Table 5

Coefficient alphas, reliability-corrected intercorrelations, and uncorrected intercorrelations for scores on three measures of person-centred care

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PDQ</td>
<td>.808</td>
<td>.521</td>
<td>-.238</td>
</tr>
<tr>
<td>2. PDC subscale</td>
<td>.395*</td>
<td>.711</td>
<td>-.297</td>
</tr>
<tr>
<td>3. CAQ subscale</td>
<td>-.170</td>
<td>-.199</td>
<td>.630</td>
</tr>
</tbody>
</table>

*Note. Cronbach’s alpha coefficients for each questionnaire are printed in bold font along the diagonal. Correlations corrected for reliability are printed above the diagonal and uncorrected correlations are printed below the diagonal. PDQ = Personhood in Dementia Questionnaire; PDC subscale = Personhood subscale of the Person-Directed Care and Environmental Support for Person-Directed Care measure (White et al., 2008); CAQ subscale = Physician attitudes subscale of the Cancer Attitudes Questionnaire (Lebovits et al., 1984).

* This correlation is statistically significant at the 0.01 level (1-tailed).
10.6. Results

10.6.1. Convergent validity. The Personhood in Dementia Questionnaire and the modified personhood subscale of the PDC were observed to have a statistically significant moderate positive correlation, $r (58) = 0.40, p < .01$, see Table 5. This result supports Hypothesis 1, and provides initial evidence of the convergent validity of the Personhood in Dementia Questionnaire.

10.6.2. Discriminant validity. The correlation between the Personhood in Dementia Questionnaire and the physician attitudes subscale of the Cancer Attitudes Questionnaire was not statistically significant, $r (58) = -.17, p = .11$, see Table 5. Failure to observe a statistically significant correlation between the Personhood in Dementia Questionnaire and physician attitudes subscale provides support for Hypothesis 2 and gives evidence of the discriminant validity of the Personhood in Dementia Questionnaire with measures of beliefs pertaining to other patient populations.

10.6.3. Post-hoc analysis and results. During the course of the analyses completed in Study II, it was observed that the physician attitudes subscale of the Cancer Attitudes Questionnaire (Lebovits et al., 1984) had a statistically significant correlation with the BIDR total score and the BIDR IM subscale score. To control for possible effects of social desirability bias on the results of the test of discriminant validity, the partial correlation of the Personhood in Dementia Questionnaire and the physician attitudes subscale was calculated, using the BIDR total scale score to control for the influence of social desirability responding. After controlling for social desirability bias in this manner, the partial correlation between the Personhood in Dementia Questionnaire
and the physician attitudes subscale was lower than the unadjusted correlation between the two measures and did not reach statistical significance, $r (58) = -0.11, p = .21$.

11. Study III: Assessing the Validity of the Personhood in Dementia Questionnaire

11.1. Purpose

The examination of a new scale’s relationships with existing scales and other measurable variables is an important (and ongoing) task (Loevinger, 1957; Simms & Watson, 2007). This work began in Study II with an examination of the scale’s convergent and discriminant validity. In Study III, the scale’s discriminant validity was further tested, factorial validity and criterion-related validity were examined, and relationships with other constructs and demographic variables were further explored.

Criterion-related validity is the extent to which a test predicts one or more “practical” criteria (Strauss & Smith, 2009, p. 4). With respect to measures of attitudes, the practical criteria of interest are behaviours that are theoretically linked to the respondents’ attitudes. In health care, it can be labour-intensive and costly to directly observe behaviours of interest, especially when large sample sizes are required. There is also a high potential for observer effects and for ethical dilemmas when direct observation is used to assess criterion validity in clinical settings (Gould, 1996). Given these circumstances, questionnaires that assess self-reported behaviours or behavioural intentions are a reasonable alternative to direct observation of behaviour. Questionnaires assessing behavioural intentions have been used successfully to estimate the real-world behaviour of health providers (e.g., Arslanian-Engoren, 2004; Braspenning & Sergeant, 1994; Murray, Del Mar, & O’Rourke, 2000; Tabak, Bar-Tal, & Cohen-Mansfield, 1996), and vignette-style questionnaires have been used to assess external validity in scale
validation research (e.g., DeCotth, 1977; Hill & Willoughby, 2005). Thus, a measure of
the behavioural intentions of health providers after reviewing a clinical vignette was
employed to test criterion validity in Study III. The vignettes’ emphasis on behavioural
intentions surrounding medication use reflects current debates about the use of certain
classes of medications in long-term care. For example, the under-use of analgesics among
patients with dementia diagnosis is well-documented (Feldt, Ryden, & Miles, 1998;
Horgas & Tsai, 1998; Kaasalainen et al., 1998; McCaffery, Ferrell, & Pasero, 2000;
Morrison & Siu, 2000; Sengstaken & King, 1993).

Confirmatory factor analysis, exploratory factor analysis, and principal
components analysis are techniques that can assist in evaluating aspects of factorial
validity. Given that the measurement of person-centred care is a new area of research, an
exploratory factor analysis was completed to better understand the dimensionality of the
Personhood in Dementia Questionnaire. One of the central questions about beliefs about
personhood, as measured by the Personhood in Dementia Questionnaire, is whether these
beliefs reflect the same fundamental meaning (e.g., respect for personhood in dementia)
or whether they reflect multiple domains of meaning. For example, if there are multiple
domains of beliefs about personhood, these might include beliefs about physical, social,
psychological, and moral attributes of persons with dementia (thereby corresponding to
the themes used by subject matter experts to assess the items). Alternatively, these
domains might include the themes generated in the literature review and in interviews
with key informants, which connote a number of capabilities and attributes that have been
associated with personhood throughout the centuries (e.g., sentience, rationality,
individuality, and others). It is also possible that a different set of domains, unrelated to these theoretically salient possibilities, could be observed.

To further assess the external validity of the Personhood in Dementia Questionnaire in Study III, analyses of the Personhood in Dementia Questionnaire’s relationships with several other measurable variables were planned. These were: years of education, years of work experience, burnout, and job satisfaction. Other research has shown that a higher level of education (or a job title that requires a higher level of education) is associated with more positive attitudes toward patients with dementia (Astrom et al., 1991; Zimmerman et al., 2005). However, with respect to years of work experience, previous results are mixed. For example, Kada, Nygaard, Mukesh, and Geitung (2010) reported that more years of work experience is associated with more hopeful and person-centred attitudes. In contrast, Zimmerman et al. (2005) found that positive attitudes toward patients with dementia were more prevalent among health providers with two or fewer years of work experience. The relationship of job satisfaction with attitudes toward patients with dementia has also received some attention in the literature. Brodaty et al. (2003a) found that lower levels of satisfaction with work were associated with worse attitudes towards residents with dementia. Zimmerman et al. (2005) found that health providers who work at newer facilities (a variable that may be associated with job satisfaction) tend to have more positive attitudes toward patients with dementia. Finally, the relationship between burnout and attitudes toward dementia has also been tested previously, and burnout was associated with less positive attitudes toward patients with dementia (Astrom et al., 1991). Given that previous literature has shown that education, work experience, job satisfaction, and burnout are variables that
bear a relationship to attitudes toward patients with dementia diagnoses, it was important to test the relationship between each of these variables and the Personhood in Dementia Questionnaire.

11.1.1. Hypotheses. In Study III, it was hypothesized that:

1. Health providers’ beliefs about personhood in dementia would help to explain their intended approach to patient care, as reflected in responses to patient vignettes. Specifically, higher scores on the Personhood in Dementia Questionnaire would be associated with:

   a. Greater likelihood of recommending/using pain medication, based on the importance assigned to the development of empathy, or understanding of another person’s subjective experience in literature describing person-centred care frameworks (e.g., Brooker, 2007; Johns, 1994; Nolan, Davies, & Grant, 2001).

   b. Greater likelihood of recommending/using anxiolytic medications, based on the importance assigned to holistic care in literature describing person-centred care frameworks (e.g., Brooker, 2007; Johns, 1994; Nolan, Davies, & Grant, 2001).

   c. Greater likelihood of recommending/using non-pharmacologic strategies, based on the importance assigned to holistic care in literature describing person-centred care frameworks (e.g., Johns, 1994).

2. The presence or absence of a dementia diagnosis would influence health providers’ intended approaches to patient care, as reflected in responses to patient vignettes. Specifically, a dementia diagnosis would be associated with:
a. Reduced likelihood of recommending/using pain medication, based on literature documenting an under-use of pain medication in this population (Feldt, Ryden, & Miles, 1998; Horgas & Tsai, 1998; Kaasalainen et al., 1998; McCaffery, Ferrell, & Pasero, 2000; Morrison & Siu, 2000; Sengstaken & King, 1993).

b. Reduced likelihood of recommending/using anxiolytic medication, based on evidence (such as that noted above) of a discrepancy in the provision of other interventions, such as pain medication, to those with cognitive impairment as opposed to those without.

c. Reduced likelihood of recommending/using non-pharmacologic strategies, based on evidence (such as that noted above) of a discrepancy in the provision of other interventions, such as pain medication, to those with cognitive impairment as opposed to those without.

3. The presence or absence of a dementia diagnosis would moderate the relationship of health providers’ beliefs about personhood in dementia and their intended approach to patient care as reflected in:

   a. The likelihood of recommending/using pain medication.

   b. The likelihood of recommending/using anxiolytic medication.

   c. The likelihood of recommending/using non-pharmacologic strategies.

4. There would be a statistically significant positive association between participants’ years of education and their scores on a measure of beliefs about personhood.
5. There would be a statistically significant positive association between participants’ years of work experience and their scores on a measure of beliefs about personhood.

6. There would be statistically significant associations between participants’ scores on three scales representing aspects of burnout and scores on a measure of beliefs about personhood; specifically:
   a. Beliefs about personhood would be negatively associated with depersonalization.
   b. Beliefs about personhood would be negatively associated with emotional exhaustion.
   c. Beliefs about personhood would be positively associated with personal accomplishment.

7. There would be a statistically significant positive association between participants’ scores on a measure of job satisfaction and their scores on a measure of beliefs about personhood.

8. There would be statistically significant associations between participants’ scores on three scales representing aspects of burnout and scores on a measure of job satisfaction; specifically:
   a. Job satisfaction would be negatively associated with depersonalization.
   b. Job satisfaction would be negatively associated with emotional exhaustion.
   c. Job satisfaction would be positively associated with personal accomplishment.
In addition, it was expected that it would be possible to use exploratory factor analysis to generate a factor model of the Personhood in Dementia Questionnaire.

11.2. Participants

A minimum sample size of 140 was required for Study III, based on an *a priori* power analysis using G*Power* (Faul, Erdfelder, Lang & Buchner, 2007) with a desired statistical power level of 0.8, a medium effect size (0.15), and the use of up to eight predictor variables in a multiple regression.

After removing four questionnaire sets completed by people who did not meet criteria for participation (i.e., recreation therapists and managers) and one questionnaire set that contained a high number of missing and double-scored responses, the sample for Study III comprised 178 participants, including 41 nurses and 137 special care aides. Nine males (5.1% of the sample) and 165 females (92.7%) participated. An additional four participants (2.2%) did not disclose their sex. Sample demographics, including years of experience in long-term care, religious faith, and country of origin, are further described in Table 6. As in Studies I and II, participants in Study II were recruited from a health region that had partially rolled out a program to promote person-centred care (i.e., P.I.E.C.E.S.; Ontario Ministry of Long-Term Care, 1999).

11.3. Vignettes

Vignette Series A and B were developed for the purposes of this study using methods drawn from Taylor’s (2006) work on factorial surveys. To ensure the relevance of the vignettes to contemporary issues in dementia care, the vignette responses emphasize behavioural intentions surrounding medication use, including the use of analgesics, anxiolytics, and non-pharmacologic alternatives. The written text of each
Table 6

*Percentage of sample by demographic characteristic*

<table>
<thead>
<tr>
<th>Demographic characteristic</th>
<th>Percent of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7.3</td>
</tr>
<tr>
<td>Female</td>
<td>92.7</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td></td>
</tr>
<tr>
<td>Nurse (LPN, RN, RPN, or trainee)</td>
<td>23.0</td>
</tr>
<tr>
<td>Special Care Aide</td>
<td>77.0</td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
</tr>
<tr>
<td>Bachelor’s degree in nursing (B.Sc.N)</td>
<td>14.6</td>
</tr>
<tr>
<td>Diploma in nursing / B.Sc.N. trainee</td>
<td>8.4</td>
</tr>
<tr>
<td>Certificate / On-the-job training</td>
<td>77.0</td>
</tr>
<tr>
<td><strong>Country of origin</strong></td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>69.7</td>
</tr>
<tr>
<td>Other</td>
<td>30.3</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>68.5</td>
</tr>
<tr>
<td>None or Unspecified</td>
<td>7.3</td>
</tr>
<tr>
<td>Other</td>
<td>24.2</td>
</tr>
</tbody>
</table>
vignette describes a situation in which a patient is in pain and displaying agitated
behaviour. Vignette Series A (see Appendix K) describes cognitively intact patients with
pain conditions. The sex of the patients is systematically varied within the series in order
to control for any possible influences of sex on the results. The age of the patients is held
within a restricted range (i.e., 82 to 86 years) in order to closely match the average age of
patients in long-term care facilities in Canada (e.g., see Jensen, Fraser, Shankardass,
Epstein, & Khera, 2009). After reading each vignette, the participant is asked to rate, on a
7-point Likert scale, the likelihood of implementing or recommending each of 12 clinical
interventions if faced with a situation similar to that described in the vignette. The list of
possible interventions includes four pharmacological interventions (two involving
anxiolytic medications and two involving analgesic medications), four alternative
interventions (physical and psychosocial), and four interdisciplinary interventions (i.e.,
initiating requests for consultation/intervention from a specialist from a discipline outside
nursing). Vignette Series B (see Appendix J) is identical to Vignette Series A, with the
exception that each patient is clearly identified as having a dementia diagnosis.

Since the vignettes had not been tested previously, the following series of steps
was used to ensure their adequacy for use in the criterion validity study. First, to ensure
sufficient face validity, space was provided for participants to write comments about the
vignettes on the questionnaire form, and these comments were examined. Several
participants noted that the response options associated with Vignette 2, a vignette about
constipation as a source of pain, did not include the most appropriate interventions for
this condition. Vignette 2 was discarded for this reason. Next, the internal consistency of
the 12 response choices (i.e., items) for each of the remaining vignettes in the series was
examined, first for Series A and then for Series B. The first four items on Vignettes 1, 3, and 4, all relating to the use of medication, tended to have poor item-total correlations (e.g., $r < .20$) when results across both series were compared. Thus, each Vignette Series was divided into two subscales: a pharmacologic interventions subscale and a non-pharmacologic interventions subscale. However, the pharmacologic interventions subscale showed higher reliability and better item-total correlations when it was further sub-divided into an Anxiolytic Intervention Scale and an Analgesic Intervention Scale. Scale scores for the resulting Analgesic, Anxiolytic, and Non-Pharmacologic Intervention Scales were derived by adding the Likert scores associated with the appropriate items (items 1-2, 3-4, and 5-12, respectively) from each of three vignettes. Scale intercorrelations and Cronbach’s alpha statistics for the three new scales for Vignette Series A and B are provided in Table 7.

11.4. Measures

In addition to the Personhood in Dementia Questionnaire and the vignette series, three brief pencil-and-paper questionnaires were administered during Study III: a measure of anxiety about aging, a measure of burnout, and a measure of job satisfaction. A brief demographics questionnaire was also administered.

11.4.1. Measure of Job Satisfaction. The Measure of Job Satisfaction (Traynor & Wade, 1993) has 37 items across five subscales (Personal Satisfaction, Satisfaction with Workload, Satisfaction with Professional Support, Satisfaction with Pay and Prospects, and Satisfaction with Training). These five subscales were derived from factor analysis, and internal consistency by subscale is very good, with Cronbach’s alpha

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5 This scale was included to permit exploratory analyses, but to limit the scope of this document, it is not further discussed.
Table 7

*Intercorrelations and coefficient alphas for three intervention scales across two subsets of the sample*

<table>
<thead>
<tr>
<th></th>
<th>Vignette Series A</th>
<th>Vignette Series B</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>1. Anxiolytic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Analgesic</td>
<td>.171</td>
<td></td>
</tr>
<tr>
<td>3. Non-Pharmacologic</td>
<td>.191*</td>
<td>.334**</td>
</tr>
</tbody>
</table>

*Note.* Vignette Series A and B are identically phrased, except that Vignette Series A describes patients who do not have dementia diagnoses. Each series is divided into three scales: the Anxiolytic Interventions Scale (6 items), the Analgesic Interventions Scale (6 items), and the Non-Pharmacologic Interventions Scale (24 items). Cronbach’s alpha coefficients for each subscale are in boldface.

* This correlation is statistically significant at the 0.05 level (1-tailed).

** This correlation is statistically significant at the 0.01 level (1-tailed).
ranging from 0.84 to 0.88. Internal consistency for the full scale is excellent ($\alpha = .93$).

Test-retest reliability coefficients for each subscale range from 0.76 (Personal Satisfaction) to 0.91 (Satisfaction with Pay and Prospects). Concurrent validity with another measure of job satisfaction is high ($r = .83$).

Chou, Boldy, and Lee (2002) examined the reliability, validity, and factor structure of the Measure of Job Satisfaction when used to assess health providers who work in long-term care settings. Chou and colleagues identified five factors (personal satisfaction, workload, professional support, training, and team spirit/co-workers). Four of these factors correspond to those identified by the authors of the scale, but one (team spirit/coworkers) differs, suggesting the possibility that some Measure of Job Satisfaction items function differently when completed by staff who work in long-term care settings. Nonetheless, internal consistency for each factor identified in this study was very good (lowest subscale $\alpha = .86$) and full scale reliability was, again, excellent ($\alpha = .86$). Thus, the Measure of Job Satisfaction was chosen for its excellent psychometric properties when used in a long-term care workplace setting.

11.4.2. Maslach Burnout Inventory – Human Services Scale. The Maslach Burnout Inventory (MBI; Maslach & Jackson, 1981) was developed to measure emotional exhaustion, or burnout, among employees who work in highly relational jobs (e.g., police, health care workers, teachers). It has three subscales that measure emotional exhaustion, depersonalization, and reduced personal accomplishment, respectively. Maslach and colleagues later developed three versions of the scale; one for human services workers (such as health care workers), another for teachers, and a third for people employed in jobs that are not clearly relational in nature. The scales have been
subject to several analyses of validity since their inception, but MBI – Human Services Scale (MBI-HSS) items have not changed since 1981 (Maslach, Jackson, & Leiter, 1996).

Reliability of the MBI-HSS subscales is good. Cronbach’s alpha coefficients for the Emotional Exhaustion, Depersonalization, and Personal Accomplishment scales are .90, .79, and .71, respectively (Maslach & Jackson, 1996). Two- to four-week test-retest reliability coefficients for the MBI-HSS subscales were .82, .60, and .80, respectively, in a sample of health administrators and graduate students in social welfare (Maslach & Jackson, 1996). Test-retest reliability at other time intervals and with other samples has been reported. The general pattern is that Emotional Exhaustion has the best stability. In addition, MBI-HSS subscales demonstrate reasonably good stability over time periods as long as one year (Maslach & Jackson, 1996).

The validity of the MBI-HSS is well-supported in several studies. Discriminant validity is supported by low correlations of the MBI-HSS subscales and measures of job satisfaction, and by low correlations of the MBI-HSS subscales with a measure of social desirability (Maslach & Jackson, 1996). Tests that discriminate MBI-HSS subscale scores from scores on scales measuring depression have had less ideal results, but factor analysis has been used to demonstrate that “subscales for burnout and for depression loaded on separate second-order factors” (Leiter & Durup, 1994, as cited in Maslach & Jackson, 1996, p. 16).

Maslach and Jackson (1996) have provided numerous other data to support the scale’s external validity. For example, the convergent validity of the MBI-HSS is supported by a positive correlation between scores on the JDS measure of growth satisfaction and scores on the Personal Accomplishment subscale, and negative
correlations between JDS scores and scores on the Emotional Exhaustion and Depersonalization subscales, respectively (Maslach & Jackson, 1996).

11.4.3. Demographics Questionnaire. The demographics questionnaire used in Study III is reprinted in Appendix L. Each participant’s age, sex, occupation, education, years of work experience in long-term care, years of work experience in other health care positions, type of other health care positions, country of birth, and spiritual tradition was requested. Providing information about one’s country of birth and spiritual tradition was optional.

11.5. Procedure

As in Study II, participants were recruited at long-term care facilities, after seeking approval from the Regina Qu’Appelle Health Region (RQHR) research ethics board and facility administrators. The recruitment methods were the same as those used in Study II: facility administrators informed staff about the study in person and/or with recruitment posters (see Appendix M), refreshments were provided, and funds for relief staff were provided as needed, through a research grant. Staff who elected to participate reviewed information about the study, including a description of the research, associated risks and benefits, and measures taken to protect confidentiality. Then they signed a consent form (see Appendix N) and completed a survey comprised of five questionnaires.

A between-groups design was used to assess whether participants’ responses to the Vignette Series were influenced by patient diagnoses. That is, Vignette Series A and Vignette Series B were randomly allocated among the participant surveys so that half the participants were asked to respond to vignettes describing patients with dementia, and the
other half were asked to respond to vignettes that described patients in the same manner, except that there was no mention of a dementia diagnosis.

11.6. Analysis

Before completing the analyses, data were examined for the presence of outliers on full scale or subscale scores (i.e., scores at least three standard deviations above or below mean scale scores). On this basis, the following questionnaire data were removed: Measure of Job Satisfaction (case 1); Vignette responses (case 8); MBI-HSS Depersonalization subscale data (MBI-DP; case 46); MBI-HSS Personal Accomplishment Subscale data (MBI-PA; cases 78 and 149); and Personhood in Dementia Questionnaire data (case 92). In the following additional cases, a full set of questionnaire data was missing, either because the respondent had not completed most or all of that questionnaire or because the respondent gave the same response for each item: Vignette responses (cases 7, 150, 168); MBI-HSS (cases 22, 54, 109, 137, 166); Personhood in Dementia Questionnaire (case 182). All remaining missing data were replaced using two-way imputation (Sijtsma & van der Ark, 2003; van Ginkel & van der Ark, 2005). In these cases, data were missing because a participant occasionally missed or double-scored items. Table 8 provides the percent of missing data for each questionnaire used in Study III.

Descriptive statistics for all scales used in Study III are provided in Tables 9 and 10. All scales except the MBI-HSS Depersonalization subscale had at least acceptable reliability (see Tables 7 and 11). All scale scores were tested using a one-sample Kolmogorov-Smirnov test and a Shapiro-Wilks test, and only the MBI-HSS
Table 8

*Percent missing data for five full scales*

<table>
<thead>
<tr>
<th>Scale</th>
<th>% Missing Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vignette Series A &amp; B combined</td>
<td>1.42</td>
</tr>
<tr>
<td>PDQ</td>
<td>1.39</td>
</tr>
<tr>
<td>MJS</td>
<td>0.75</td>
</tr>
<tr>
<td>MBI</td>
<td>0.58</td>
</tr>
</tbody>
</table>

*Note.* PDQ = Personhood in Dementia Questionnaire; MJS = Measure of Job Satisfaction (Traynor & Wade, 1993); MBI = Maslach Burnout Inventory Human Services Scale (Maslach & Jackson, 1981).
Table 9

*Means and standard deviations for five scales*

<table>
<thead>
<tr>
<th>Scale</th>
<th>$M$</th>
<th>$SD$</th>
<th>$n$</th>
</tr>
</thead>
<tbody>
<tr>
<td>PDQ</td>
<td>116.394</td>
<td>13.131</td>
<td>175</td>
</tr>
<tr>
<td>MJS</td>
<td>83.354</td>
<td>23.404</td>
<td>175</td>
</tr>
<tr>
<td>MBI – EE</td>
<td>27.717</td>
<td>10.960</td>
<td>173</td>
</tr>
<tr>
<td>MBI – DP</td>
<td>9.169</td>
<td>4.062</td>
<td>172</td>
</tr>
<tr>
<td>MBI – PA</td>
<td>-19.906</td>
<td>8.631</td>
<td>171</td>
</tr>
</tbody>
</table>

*Note. PDQ = Personhood in Dementia Questionnaire; MJS = Measure of Job Satisfaction (Traynor & Wade, 1993); MBI = Maslach Burnout Inventory Human Services Scale (Maslach & Jackson, 1981); EE = Emotional Exhaustion subscale; DP = Depersonalization Subscale; PA = Personal Accomplishment subscale. PA is interpreted in the opposite direction as other MBI subscales (high scores indicate less burnout).*
Table 10

Means and standard deviations for Vignette Series A and B

<table>
<thead>
<tr>
<th>Scale</th>
<th>Vignette Series A</th>
<th>Vignette Series B</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 86)</td>
<td>(n = 88)</td>
</tr>
<tr>
<td>Anxiolytic Interventions Scale</td>
<td>19.093</td>
<td>22.068</td>
</tr>
<tr>
<td></td>
<td>8.325</td>
<td>8.156</td>
</tr>
<tr>
<td>Analgesic Interventions Scale</td>
<td>36.012</td>
<td>34.125</td>
</tr>
<tr>
<td></td>
<td>5.290</td>
<td>6.789</td>
</tr>
<tr>
<td>Non-Pharmacologic Interventions Scale</td>
<td>135.058</td>
<td>134.318</td>
</tr>
<tr>
<td></td>
<td>17.831</td>
<td>19.923</td>
</tr>
</tbody>
</table>

Note: Vignette Series A and B are identically phrased, except that Vignette Series A describes patients who do not have dementia diagnoses. Each series is divided into three scales: the Anxiolytic Interventions Scale (6 items), the Analgesic Interventions Scale (6 items), and the Non-Pharmacologic Interventions Scale (24 items).
Table 11

*Coefficient alphas for five scales*

<table>
<thead>
<tr>
<th>Items</th>
<th>α</th>
</tr>
</thead>
<tbody>
<tr>
<td>PDQ</td>
<td>.772</td>
</tr>
<tr>
<td>MJS</td>
<td>.948</td>
</tr>
<tr>
<td>MBI – EE</td>
<td>.870</td>
</tr>
<tr>
<td>MBI – DP</td>
<td>.563</td>
</tr>
<tr>
<td>MBI – PA</td>
<td>.763</td>
</tr>
</tbody>
</table>

Note: PDQ = Personhood in Dementia Questionnaire; MJS = Measure of Job Satisfaction (Traynor & Wade, 1993); MBI = Maslach Burnout Inventory Human Services Scale (Maslach & Jackson, 1981); EE = Emotional Exhaustion subscale; DP = Depersonalization Subscale; PA = Personal Accomplishment subscale. PA is interpreted in the opposite direction as other MBI subscales (high scores indicate less burnout).
Depersonalization and Personal Accomplishment subscales were found to deviate \((p < .05)\) from a normal distribution.

**11.6.1. Criterion validity.** The extent to which a test predicts one or more practical criteria is called criterion validity. Study III involved assessing the criterion validity of the Personhood in Dementia Questionnaire by measuring its relationship to Vignette Series responses. This was accomplished by using moderated multiple regression to test Hypothesis 1 (that beliefs about personhood in dementia help to explain long term care workers’ intended patient care strategies), Hypothesis 2 (that the presence or absence of a dementia diagnosis influences intended care strategies), and Hypothesis 3 (that the presence or absence of a dementia diagnosis moderates the relationship between beliefs about personhood in dementia and intended patient care strategies). Because each Vignette Series was divided into three subscales, each Vignette subscale (i.e., Anxiolytic Interventions Scale, Analgesic Interventions Scale, and Non-Pharmacologic Interventions Scale) was modelled separately. To create these models, vignette scores were first regressed on Personhood in Dementia Questionnaire scores and dummy variable scores representing presence or absence of dementia diagnosis (as stated in the vignette series), as specified by the following equation:

\[
\text{Vignette score} = b_0 + b_1 \text{Personhood in Dementia Questionnaire Score} + b_2 \text{Diagnosis}
\]

Then, the cross-product of the centred Personhood in Dementia Questionnaire scores and the values representing presence or absence of dementia diagnosis was added to the regression model (i.e., as a second step in a hierarchical regression), as follows:
b) Vignette score = $b_0 + b_1$Centred Personhood in Dementia Questionnaire Score + $b_2$Diagnosis + ($b_1$Centred Personhood in Dementia Questionnaire Score) ($b_2$Diagnosis)

To test Hypothesis 1, the hypothesis that health providers’ beliefs about personhood in dementia help to explain their intended patient care behaviour, the statistical significance of the co-efficient for Personhood in Dementia Questionnaire Score, or $b_1$ in model (a) above, was examined. Statistical significance of $b_1$ was taken as evidence that beliefs about personhood help to explain a portion of the variance in health care decisions. In similar fashion, statistical significance of $b_2$ in the model (a) was taken as evidence that the presence or absence of dementia diagnosis affects intended patient care behaviour (i.e., in a test of Hypothesis 2).

To test Hypothesis 3, that the presence or absence of a dementia diagnosis would moderate the relationship of health providers’ beliefs about personhood in dementia and their intended patient care behaviour, the statistical significance of the change in $R^2$ as a result of adding an interaction term (as specified in model [b] above), was examined. The interaction term was specified as the cross-product of centred Personhood in Dementia Questionnaire scores and dummy scores representing presence or absence of dementia diagnosis (see Keith, 2006, pp. 132-141). A statistically significant increase in $R^2$ as a result of adding the interaction term to the model was taken as support for the hypothesis that that dementia diagnosis moderates the relationship of health providers’ beliefs about personhood in dementia and their intended patient care behaviour.

11.6.2. Relationship with demographic variables. To test Hypothesis 4, that there would be a statistically significant positive association between participants’ years of education and their scores on a measure of beliefs about personhood, the correlation of
the Personhood in Dementia Questionnaire and participants’ years of education was calculated. A statistically significant positive correlation was taken as evidence that education is associated with positive beliefs about personhood in dementia. Similarly, to test Hypothesis 5, that there would be a statistically significant negative association between participants’ years of work experience and their scores on a measure of beliefs about personhood, the correlation of the Personhood in Dementia Questionnaire and participants’ years of work experience was calculated. A statistically significant positive correlation was taken as evidence that the more years of work experience one has, the greater likelihood that one will have positive beliefs about the personhood of individuals with dementia.

11.6.3. Relationships with other constructs: Burnout. To test Hypotheses 6a, 6b, and 6c, the correlations among participants’ scores on the Personhood in Dementia Questionnaire and each MBI-HSS subscale (i.e., Emotional Exhaustion, Depersonalization, and Personal Accomplishment) were calculated. Statistically significant negative correlations between the Personhood in Dementia Questionnaire and the Emotional Exhaustion and Depersonalization subscales, respectively, were taken as evidence that the more a long-term care worker feels “burnt out”, the greater the likelihood that he or she will have negative beliefs about the personhood of individuals with dementia. In contrast, a statistically significant positive correlation between the Personhood in Dementia Questionnaire and the Personal Accomplishment subscale was taken as evidence that the less a long term care worker feels “burnt out” (as reflected by higher Personal Accomplishment scores), the greater the likelihood that he or she will have positive beliefs about the personhood of individuals with dementia.
11.6.4. **Relationships with other constructs: Job satisfaction.** The correlation of the Personhood in Dementia Questionnaire and the Measure of Job Satisfaction was calculated to test Hypothesis 7. The observation of a statistically significant positive correlation was considered as evidence that a higher level of job satisfaction is associated with more positive beliefs about the personhood of individuals with dementia.

11.7. **Results**

11.7.1. **Criterion validity: Analgesic Intervention Scale.** Assumptions for regression were met. There was no multicollinearity since the point-biserial correlation between Personhood in Dementia Questionnaire scores and dementia diagnosis was near zero, \( r (169) = -.005, p < .001 \). Normality was assumed, since points on a normal probability plot of the residuals fell close to the diagonal (see Figure 3). Independence of residual terms could be assumed because the Durbin-Watson test value of 1.63 was in a range that is considered acceptable compared to an ideal value of 2.00, taking into account a sample size greater than 100 and the three predictor variables used in the model (Durbin & Watson, 1951). The assumption of homoscedasticity, or the same level of variance in the predicted variable at each level of the predictor variable, was evaluated by examining a plot of standardized residual values against standardized predicted values (see Figure 4). This assumption was also met, given that standardized residual values do not increase as standardized predicted values increase. Finally, the assumption of a linear relationship was evaluated by examining a plot of standardized residual values against standardized predicted values (see Figure 4), and this assumption was met given that there was no evidence of a non-linear pattern.
Figure 3. Normal probability plot for the Analgesic Intervention Scale. The close proximity of the graphed points to the diagonal line suggests that these data sufficiently meet the assumption of normality of error variance.
Figure 4. Scatterplot of standardized residuals and standardized predicted values for the Analgesic Intervention Scale. Given that standardized residual values do not increase as standardized predicted values increase, the assumption of homoscedasticity is met. Given that there is no evidence of a non-linear pattern in the graphed points, the assumption of linearity is also met.
Together, Personhood in Dementia Questionnaire scores and dementia diagnosis accounted for 6.7% of the variance in Analgesic Intervention Scale scores, $F(2, 168) = 6.04, p < .01$. This represents a small effect. The influence of Personhood in Dementia Questionnaire scores and dementia diagnosis on vignette scores is reflected in the coefficients reported in Table 12. The coefficients show that if the patient described in the vignette had dementia, the likelihood that the respondent would express the intention to use analgesics was lower (confirming Hypothesis 1a). In contrast, stronger beliefs about patient personhood were associated with a greater likelihood of expressing the intention to use analgesics (confirming Hypothesis 1b). When an interaction term reflecting the cross-product of centred Personhood in Dementia Questionnaire scores and a dummy variable representing dementia diagnosis was added to this model, the change in variance explained as compared to the original model was not statistically significant, $\Delta R^2 = .006, \Delta F(1, 167) = 1.103, p = .30$. Therefore, Hypothesis 3a was rejected; in other words, dementia diagnosis does not alter the extent to which Personhood in Dementia Questionnaire scores are useful in predicting Analgesic Intervention Scale scores.

11.7.2. Criterion validity: Anxiolytic Intervention Scale. Assumptions for the hierarchical regression of predictor variables on Anxiolytic Intervention Scale scores were met. There was no multicollinearity, as evidenced by a very low point-biserial correlation between Personhood in Dementia Questionnaire scores and dementia diagnosis, $r (169) = -.005, p < .001$. Normality was also assumed since points on a normal probability plot of the residuals fell close to the diagonal (see Figure 5). The Durbin-Watson statistic, an indicator of the independence of residual terms, had a value of 1.61, and was therefore in a range that is considered acceptable compared to an ideal
Table 12

*Moderated multiple regression analysis summary: Beliefs about personhood and cognitive status as predictors of the likelihood of considering analgesic interventions*

<table>
<thead>
<tr>
<th>Model</th>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>ß</th>
<th>p</th>
<th>r²</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Beliefs about Personhood ⁶</td>
<td>.091</td>
<td>.035</td>
<td>.196</td>
<td>.009</td>
<td>.197</td>
</tr>
<tr>
<td></td>
<td>Cognitive Status ³</td>
<td>-2.041</td>
<td>.906</td>
<td>-.168</td>
<td>.026</td>
<td>-.169</td>
</tr>
<tr>
<td>2</td>
<td>Beliefs about Personhood ⁶</td>
<td>.054</td>
<td>.050</td>
<td>.116</td>
<td>.282</td>
<td>.197</td>
</tr>
<tr>
<td></td>
<td>Cognitive Status</td>
<td>-.2059</td>
<td>.906</td>
<td>-.169</td>
<td>.024</td>
<td>-.169</td>
</tr>
<tr>
<td></td>
<td>Interaction Term ⁷</td>
<td>.073</td>
<td>.069</td>
<td>.112</td>
<td>.295</td>
<td>.194</td>
</tr>
</tbody>
</table>

*Note.* Models 1 and 2 represent steps in a hierarchical regression. Model 1 was used in hypothesis testing. The change in variance explained by Model 2 was also used in hypothesis testing. This change in variance was not statistically significant; nonetheless, Model 2 results are presented for completeness. Model 1 $R^2 = .067 \ (N = 170, p < .01)$. Model 2 $R^2 = .073 \ (N = 170, p < .01)$.

⁶ The zero-order correlation of predictor variables with the Analgesic Intervention Scale scores; ⁷ Personhood in Dementia Questionnaire scores; ³ Cognitive status (1 = diagnosed with dementia; 0 = not diagnosed with dementia); ⁷ The cross-product of cognitive status (1 or 0) and centred Personhood in Dementia Questionnaire scores.
Figure 5. Normal probability plot for the Anxiolytic Intervention Scale. The close proximity of the graphed points to the diagonal line indicates that these data sufficiently meet the assumption of normality of error variance.
value of 2.00, for a sample size greater than 100 and three predictors (Durbin & Watson, 1951). The assumption of homoscedasticity was also met, given that standardized residual values did not increase along with increments in standardized predictive values (see Figure 6). Finally, the assumption of a linear relationship was met given that there is no evidence of a non-linear pattern of relationship between standardized residual values and standardized predicted values (see Figure 6).

Together, Personhood in Dementia Questionnaire scores and dementia diagnosis accounted for 13.7% of the variance in Anxiolytic Intervention Scale scores, $F(2, 168) = 13.38, p < .001$, and this represents a small to moderate effect. The influence of Personhood in Dementia Questionnaire scores and dementia diagnosis on vignette scores is reflected in the coefficients reported in Table 13. The coefficients show that stronger beliefs about patient personhood are associated with a weaker inclination to use anxiolytic medication, whereas dementia diagnosis is associated with a stronger inclination to use anxiolytics. Although both coefficients were statistically significant (see Table 13), neither contributed to the model in the expected direction; thus, Hypotheses 2a and 2b are each rejected.

The interaction between Personhood in Dementia Questionnaire scores and dementia diagnosis was evaluated by adding an interaction term to the original model using hierarchical regression. Contrary to Hypothesis 3b, when this interaction term was added to the model, the change in variance explained by the new model as compared to the old was not statistically significant, $\Delta R^2 < .001, \Delta F(1, 167) = .06, p = .81$. This means that the strength of the observed association between Personhood in Dementia
Figure 6. Scatterplot of standardized residuals and standardized predicted values for the Anxiolytic Intervention Scale. Given that standardized residual values do not increase as standardized predicted values increase, the assumption of homoscedasticity is met. Given that there is no evidence of a non-linear pattern in the graphed points, the assumption of linearity is also met.
Table 13

*Moderated multiple regression analysis summary: Beliefs about personhood and dementia diagnosis as predictors of the likelihood of considering anxiolytic interventions*

<table>
<thead>
<tr>
<th>Model</th>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>ß</th>
<th>p</th>
<th>r²a</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Beliefs about Personhood¹</td>
<td>-.210</td>
<td>.046</td>
<td>- .328</td>
<td>.001</td>
<td>- .329</td>
</tr>
<tr>
<td></td>
<td>Cognitive Status</td>
<td>2.862</td>
<td>1.201</td>
<td>.171</td>
<td>.018</td>
<td>.173</td>
</tr>
<tr>
<td>2</td>
<td>Beliefs about Personhood</td>
<td>-.199</td>
<td>.066</td>
<td>-.310</td>
<td>.003</td>
<td>-.329</td>
</tr>
<tr>
<td></td>
<td>Cognitive Status</td>
<td>2.868</td>
<td>1.205</td>
<td>.171</td>
<td>.018</td>
<td>.173</td>
</tr>
<tr>
<td></td>
<td>Interaction Term</td>
<td>-.022</td>
<td>.092</td>
<td>-.025</td>
<td>.810</td>
<td>-.246</td>
</tr>
</tbody>
</table>

*Note.* Models 1 and 2 represent steps in a hierarchical regression. Model 1 was used in hypothesis testing. The change in variance explained by Model 2 was also used in hypothesis testing. This change in variance was not statistically significant; nonetheless, Model 2 results are presented for completeness. Model 1 $R^2 = .137$ ($N = 170, p < .01$). Model 2 $R^2 = .138$ ($N = 170, p < .01$).

¹ The zero-order correlation of predictor variables with the Anxiolytic Intervention Scale scores; ² Personhood in Dementia Questionnaire scores; ³ Cognitive status (1 = diagnosed with dementia; 0 = not diagnosed with dementia); ⁴ The cross-product of cognitive status (1 or 0) and centred Personhood in Dementia Questionnaire scores.
Questionnaire scores and Anxiolytic Intervention Scale scores does not vary according to the cognitive status of the patient.

**11.7.3. Criterion validity: Non-Pharmacologic Intervention Scale.** All relevant assumptions for the hierarchical regression of Personhood in Dementia Questionnaire scores and dementia diagnosis on Anxiolytic Intervention Scale scores were met. There was no multicollinearity, as evidenced by a very low point-biserial correlation between Personhood in Dementia Questionnaire scores and dementia diagnosis, \( r(169) = -.005, p < .001 \). Normality was also assumed since points on a normal probability plot of the residuals fell close to the diagonal (see Figure 7). The Durbin-Watson statistic, an indicator of the independence of residual terms, had a value of 1.84, and was therefore in a range that is considered acceptable compared to an ideal value of 2.00 (Durbin & Watson, 1951). The assumption of homoscedasticity was met, given that standardized residual values did not increase along with increments in standardized predictive values (see Figure 8). Finally, the assumption of a linear relationship was met given that there is no evidence of a non-linear pattern of relationship between standardized residual values and standardized predicted values (see Figure 8).

When entered together into a moderated multiple regression model, Personhood in Dementia Questionnaire scores and dementia diagnosis accounted for 9.9% of variance in Non-Pharmacologic Intervention Scale scores, \( F(2, 168) = 9.26, p < .001 \), and this represents a small effect. Judging by statistical significance tests of the standardized coefficients for the model, Personhood in Dementia Questionnaire scores explained a statistically significant amount of the variance in Non-Pharmacologic Intervention scores, confirming Hypothesis 1c. That is, stronger beliefs about patient personhood were
Figure 7. Normal probability plot for the Non-Pharmacologic Intervention Scale. The close proximity of the graphed points to the diagonal line indicates that these data sufficiently meet the assumption of normality of error variance.
Figure 8. Scatterplot of standardized residuals and standardized predicted values for the Non-Pharmacologic Intervention Scale. Given that standardized residual values do not increase as standardized predicted values increase, the assumption of homoscedasticity is met. Given that there is no evidence of a non-linear pattern in the graphed points, the assumption of linearity is also met.
associated with a stronger inclination to use non-pharmacologic strategies. In contrast, dementia diagnosis did not help to explain variance in Non-Pharmacologic Intervention scores. Thus, Hypothesis 2c is rejected. The influence of Personhood in Dementia Questionnaire scores on vignette scores can be seen by examining the coefficients reported in Table 14.

The interaction between Personhood in Dementia Questionnaire scores and dementia diagnosis was evaluated by adding an interaction term to the original model using hierarchical regression. Contrary to Hypothesis 3c, when this interaction term was added to the model, the variance explained by the new model did not differ from the variance explained by the previous at a level that reached statistically significance, $\Delta R^2 = .001, \Delta F(1, 167) = .16, p = .69$. Thus, the strength of the observed association between Personhood in Dementia Questionnaire scores and Non-Pharmacologic Intervention Scale scores does not vary based on the cognitive status of the patient, and Hypothesis 3c is rejected.

11.7.4. Association of Personhood in Dementia Questionnaire scores with education and work experience. A weak but statistically significant positive correlation between participants’ years of education and beliefs about personhood was observed, $r(173) = .13, p < .05$, confirming Hypothesis 4. Contrary to hypothesis 5, there was no correlation between participants’ years of work experience and their beliefs about personhood in dementia, $r(176) = .10, p = .10$, meaning that more experience working in long-term care was not associated with higher levels of positive beliefs about personhood in dementia. Intercorrelations between the Personhood in Dementia Questionnaire, years of education, and years of work experience are reported in Table 15.
Table 14

*Moderated multiple regression analysis summary: Beliefs about personhood and dementia diagnosis as predictors of the likelihood of considering non-pharmacologic interventions*

<table>
<thead>
<tr>
<th>Model</th>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>β</th>
<th>p</th>
<th>( r^a )</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Beliefs about Personhood(b)</td>
<td>.452</td>
<td>.105</td>
<td>.314</td>
<td>.001</td>
<td>.314</td>
</tr>
<tr>
<td></td>
<td>Cognitive Status(c)</td>
<td>-1.108</td>
<td>2.760</td>
<td>-.029</td>
<td>.689</td>
<td>-.031</td>
</tr>
<tr>
<td>2</td>
<td>Beliefs about Personhood</td>
<td>.408</td>
<td>.152</td>
<td>-.284</td>
<td>.008</td>
<td>.314</td>
</tr>
<tr>
<td></td>
<td>Cognitive Status</td>
<td>-1.129</td>
<td>2.767</td>
<td>-.030</td>
<td>.684</td>
<td>-.031</td>
</tr>
<tr>
<td></td>
<td>Interaction Term(d)</td>
<td>.084</td>
<td>.212</td>
<td>.042</td>
<td>.693</td>
<td>.245</td>
</tr>
</tbody>
</table>

*Note.* Models 1 and 2 represent steps in a hierarchical regression. Model 1 was used in hypothesis testing. The change in variance explained by Model 2 was also used in hypothesis testing. This change in variance was not statistically significant; nonetheless, Model 2 results are presented for completeness. Model 1 \( R^2 = .099 \) (\( N = 170, p < .01 \)). Model 2 \( R^2 = .100 \) (\( N = 170, p < .01 \)).

\( a \) The zero-order correlation of predictor variables with the Non-Pharmacologic Intervention Scale scores; \( b \) Personhood in Dementia Questionnaire scores; \( c \) Cognitive status (1 = diagnosed with dementia; 0 = not diagnosed with dementia); \( d \) The cross-product of cognitive status (1 or 0) and centred Personhood in Dementia Questionnaire scores.
Table 15

Means, standard deviations, and intercorrelations of Personhood in Dementia Questionnaire, years of education, and years of work experience

<table>
<thead>
<tr>
<th></th>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PDQ</td>
<td>116.394</td>
<td>13.131</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Years of education</td>
<td>1.964</td>
<td>1.608</td>
<td>.125*</td>
<td></td>
</tr>
<tr>
<td>3. Years of work experience</td>
<td>12.724</td>
<td>9.201</td>
<td>.096</td>
<td>-.171*</td>
</tr>
</tbody>
</table>

* Correlation is statistically significant at the .05 level (1-tailed).

** Correlation is statistically significant at the .01 level (1-tailed).

Note. PDQ = Personhood in Dementia Questionnaire.
11.7.5. The Personhood in Dementia Questionnaire’s correlations with other measures. The intercorrelations of the Personhood in Dementia Questionnaire, Measure of Job Satisfaction, and MBI-HSS subscales are reported in Table 16. Hypotheses 6a and 6b predicted that Personhood in Dementia Questionnaire scores would decrease as burnout (i.e., Emotional Exhaustion and Depersonalization) increased. Contrary to hypotheses, there was no correlation between Personhood in Dementia Questionnaire scores and MBI-HSS Emotional Exhaustion subscale scores, or between Personhood in Dementia Questionnaire scores and Depersonalization subscale scores (see Table 15). However, a positive correlation between Personhood in Dementia Questionnaire scores and MBI-HSS Personal Accomplishment scores was observed, confirming Hypothesis 6c. The statistically non-significant correlation between the MBI-HSS Depersonalization subscale and Personhood in Dementia Questionnaire scores is not interpreted further, given the low reliability of the six-item MBI-HSS Depersonalization subscale in this study (see Table 11). Thus, it appears that stronger beliefs about personhood in dementia are associated with a sense of personal accomplishment at work, but not with one’s level of emotional exhaustion.

Table 16 shows that the correlation of Personhood in Dementia Questionnaire and Measure of Job Satisfaction scores was not statistically significant. Thus, contrary to Hypothesis 7, higher levels of job satisfaction were not associated with more positive beliefs about personhood.

11.7.6. Additional correlational results. Intercorrelations among the Measure of Job Satisfaction and other variables are presented in Table 16. The observed relationship between the Measure of Job Satisfaction and Emotional Exhaustion is strong and
Table 16

*Intercorrelation of Personhood in Dementia Questionnaire and five other scales*

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PDQ</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. MJS</td>
<td>.041</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. MBI – EE</td>
<td>-.052</td>
<td>-.615**</td>
<td>.380**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. MBI – DP a</td>
<td>-.094</td>
<td>-.261**</td>
<td>.256**</td>
<td>.488**</td>
<td></td>
</tr>
<tr>
<td>5. MBI – PA</td>
<td>.244**</td>
<td>.173*</td>
<td>-.211**</td>
<td>-.108</td>
<td>-.240**</td>
</tr>
</tbody>
</table>

*Note. PDQ = Personhood in Dementia Questionnaire; MJS = Measure of Job Satisfaction (Traynor & Wade, 1993); MBI = Maslach Burnout Inventory Human Services Scale (Maslach & Jackson, 1981); EE = Emotional Exhaustion subscale; DP = Depersonalization Subscale; PA = Personal Accomplishment subscale. PA is interpreted in the opposite direction as other MBI subscales (high scores indicate less burnout). a MBI-DP correlations are reported for completeness; however, reliability of MBI-DP was inadequate (α < .6).*

*Correlation is statistically significant at the .05 level (1-tailed).*

**Correlation is statistically significant at the .01 level (1-tailed).*
negative, indicating that people who are more satisfied with work are less likely to feel Emotionally Exhausted (and vice versa). Moreover, higher levels of job satisfaction were associated with a sense of personal accomplishment at work. These results support Hypothesis 8b and 8c, respectively. Although the correlation between the MBI-HSS Depersonalization subscale and Measure of Job Satisfaction scores was statistically significant and negative (in line with Hypothesis 8a), this result is not discussed further given the low reliability of the six-item MBI-HSS Depersonalization subscale in this study (see Table 11).

11.7.7. Exploratory factor analysis. Principal axis factoring (PAF) of the Personhood in Dementia Questionnaire was completed. The Kaiser-Maier-Olkin measure was used to confirm sampling adequacy; KMO = .76 (good; Hutcheson & Sofroniou, 1999). KMO values for individual items ranged from .55 to .89, and all values were above the acceptable limit of .5 (Hutcheson & Sofroniou, 1999). Correlations among the items were sufficiently large for PAF using Bartlett’s test of sphericity, \( \chi^2(190) = 723.25, p < .001 \). An initial PAF was run to obtain eigenvalues for each component of the data. Seven components had eigenvalues over Kaiser’s criterion of 1 and a scree plot showed inflexions that could justify retaining two, four, or six components.

Best practice guidelines (Osborne, Costello, & Kellow, 2008) and simulation research (summarized by Hayton, Allen, & Scarpello, 2004) suggest that Parallel Analysis is more accurate than either Kaiser’s criterion or the scree plot for determining the number of factors to retain for the analysis. Parallel Analysis involves generating eigenvalues from several normally distributed sets of random data that have the same number of items and cases as the research data (Fabrigar, Wegener, MacCallum, &
Simulated eigenvalues are compared to those generated by an initial factor analysis of the research data. The predicted mean or the predicted 95\textsuperscript{th} percentile eigenvalues from the simulation may be used as criteria for comparison; however, Hayton and colleagues (2004) recommend using the 95\textsuperscript{th} percentile criterion to limit the potential for over-factoring. Using this approach, any factors generated from the research data that have eigenvalues higher than those of the corresponding 95\textsuperscript{th} percentile eigenvalues from the simulation are retained. Thus, the Parallel Analysis reported in Table 17 (and depicted graphically in Figure 9) shows that three factors should be retained for PAF of Study III data.

When the data were reanalysed, a three-factor solution explained 38.99\% of the variance. Factor 1 comprised all of the positively phrased items on the questionnaire; Factor 2 comprised all of the negatively phrased items on the questionnaire; and a single item (‘1. Residents with dementia have a sense of purpose’) represented Factor 3. Two items did not have loadings above 0.30 on any of the three factors (‘7. All residents with dementia should be treated with respect’ and ‘8. Residents with advanced dementia are no longer true participants in life; instead, they watch from the sidelines’). Given the instability of the third factor, a two-factor solution was specified and PAF was applied again. This solution explained 32.08\% of the variance. Items 1, 7, and 8 did not have substantial (i.e., >.30) loadings on either factor. Table 18 shows the factor loadings after oblique (direct oblimin) rotation.

12. Discussion

Kitwood’s definition of personhood as, “a standing or status that is bestowed upon one human being, by others” (1997, p. 8), and his accompanying discussions of
## Table 17. Parallel Analysis of Study III data and simulated data

<table>
<thead>
<tr>
<th>Eigenvalue #</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>A – C</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3.61</td>
<td>0.76</td>
<td>0.88</td>
<td>2.73</td>
</tr>
<tr>
<td>2</td>
<td>1.45</td>
<td>0.64</td>
<td>0.73</td>
<td>0.72</td>
</tr>
<tr>
<td>3</td>
<td>0.68</td>
<td>0.54</td>
<td>0.64</td>
<td>0.04</td>
</tr>
<tr>
<td>4</td>
<td>0.52</td>
<td>0.46</td>
<td>0.53</td>
<td>&lt;0</td>
</tr>
<tr>
<td>5</td>
<td>0.41</td>
<td>0.39</td>
<td>0.46</td>
<td>&lt;0</td>
</tr>
<tr>
<td>6</td>
<td>0.35</td>
<td>0.33</td>
<td>0.38</td>
<td>&lt;0</td>
</tr>
<tr>
<td>7</td>
<td>0.30</td>
<td>0.27</td>
<td>0.32</td>
<td>&lt;0</td>
</tr>
<tr>
<td>8</td>
<td>0.19</td>
<td>0.20</td>
<td>0.26</td>
<td>&lt;0</td>
</tr>
<tr>
<td>9</td>
<td>0.13</td>
<td>0.15</td>
<td>0.20</td>
<td>&lt;0</td>
</tr>
<tr>
<td>10</td>
<td>0.05</td>
<td>0.09</td>
<td>0.13</td>
<td>&lt;0</td>
</tr>
</tbody>
</table>

Note. $N = 175$. A = Eigenvalues from Principal Axis Factoring of Study III data (non-iterated solution); B = Mean of simulated eigenvalues from 100 sets of randomly generated data; C = 95th percentile of simulated eigenvalues. A – C = difference of Study III eigenvalues and 95th percentile of simulated eigenvalues. Eigenvalues less than 0.01 from Study III data are not reported, nor are the corresponding simulated eigenvalues. Three of the eigenvalue differences were greater than zero (in boldface); thus, three factors were retained for Principal Axis Factoring.
Figure 9. Scree plot and cut-points determined using Parallel Analysis. The solid line represents a scree plot of the eigenvalues generated from Study III data. The intersection of the dashed lines with the scree plot shows the cut-points suggested by Parallel Analysis. The uppermost line shows the mean eigenvalues generated from 500 sets of random, normally distributed data. The lowermost line represents corresponding 95th percentile eigenvalues from the simulation. These points of intersection suggest either a three-factor or a seven-factor solution.
Table 18

Summary: Principal Axis Factoring of the Personhood in Dementia Questionnaire

<table>
<thead>
<tr>
<th>Item Number and Abbreviated Item Content</th>
<th>Rotated Factor Loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Factor 1</td>
</tr>
<tr>
<td>12. Have had an important role in my life</td>
<td>.64</td>
</tr>
<tr>
<td>19. Have feelings about their experiences</td>
<td>.61</td>
</tr>
<tr>
<td>6. Contribute to a sense of community here</td>
<td>.61</td>
</tr>
<tr>
<td>9. Connect with each other in meaningful ways</td>
<td>.59</td>
</tr>
<tr>
<td>2. Are still capable of making informed choices</td>
<td>.48</td>
</tr>
<tr>
<td>11. Continue to play important roles in families</td>
<td>.48</td>
</tr>
<tr>
<td>20. Feel the same range of emotions as I do</td>
<td>.45</td>
</tr>
<tr>
<td>15. Have some awareness of daily events</td>
<td>.41</td>
</tr>
<tr>
<td>3. Have a right to make choices about their care</td>
<td>.41</td>
</tr>
<tr>
<td>13. Find stimulation such as music very helpful</td>
<td>.39</td>
</tr>
<tr>
<td>10. Want to socialize</td>
<td>.36</td>
</tr>
<tr>
<td>1. Have a sense of purpose</td>
<td>.27</td>
</tr>
<tr>
<td>8. Are no longer true participants in life</td>
<td>.26</td>
</tr>
<tr>
<td>4. Are low-functioning and no longer persons</td>
<td>-.10</td>
</tr>
<tr>
<td>17. We should prioritize the most aware residents</td>
<td>-.03</td>
</tr>
<tr>
<td>16. Those who whine a lot should be isolated</td>
<td>.03</td>
</tr>
<tr>
<td>18. Do not think and reason logically</td>
<td>.12</td>
</tr>
<tr>
<td>5. Can no longer contribute in a meaningful way</td>
<td>.22</td>
</tr>
<tr>
<td>14. No longer experience pleasure</td>
<td>.20</td>
</tr>
<tr>
<td>7. Should be treated with respect</td>
<td>-.04</td>
</tr>
</tbody>
</table>

Eigenvalues | 4.28 | 2.14 |
% of variance | 21.39 | 10.69 |
α | .75 | .68 |

Note. Factor loadings above .30 appear in bold.
actions that demonstrate success or failure in extending this status to persons with dementia, had an extraordinary influence on dementia care in the United Kingdom. This influence gradually spread to other parts of Europe and to North America, and the movement toward person-centred care continues to expand. Over the last decade, person-centred dementia care became an increasingly important focus for Canadian long-term care facilities. For example, in 2011, the Alzheimer’s Society of Canada published a document titled, *Guidelines for Care: Person-centred care of people with dementia living in care homes*. By 2012, of the 13 Regional Health Authorities in the province of Saskatchewan, where this series of studies took place, four had broadly introduced large-scale programs with a person-centred care focus (i.e., P.I.E.C.E.S. or Gentle Persuasive Approaches™).

Movements to adopt person-centred care practices in long-term care have greatly outpaced empirical research. Although frameworks and models for person-centred care have existed for some time now (e.g., see Dewing, 2004) it is only possible to identify a few peer-reviewed studies of patient outcomes associated with frameworks or models for person-centred care (Brooker, 2005; Chenoweth, 2009; Coleman et al., 2002; Fossey, 2006; Hoeffer et al., 2006; Sloane et al., 2004). So far, the reported outcomes are positive, but this knowledge base needs considerable development. Moreover, Edvardsson and Innes (2010) have observed that a sole focus on patient outcomes can hamper the development of an understanding of the capacity of person-centred care.

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6 P.I.E.C.E.S. (Ontario Ministry of Long-Term Care, 1999) and Gentle Persuasive Approaches™ (Schindel-Martin & Dupuis, 2005) are Canadian programs designed to enhance behavioural support for individuals with dementia living in long-term care.

7 Many programs with overlapping content have been evaluated in long-term care settings, but these have had a narrower focus, such as preventing delirium (Siddiqi et al., 2008), effectively managing behavioural and psychiatric symptoms of dementia (e.g., Santmeyer, Serafini, & Larson, 1992), improving mood or quality of life (e.g., Teri et al., 2003), preventing falls (e.g., Nowalk et al., 2001; Heyn, Abreu, & Ottenbacher, 2004), or managing pain effectively (e.g., Jones et al., 2004; Leone, Standoli, & Hirth, 2009).
interventions to change care behaviours. So far, the person-centredness of care providers has not been an outcome in studies of interventions that are designed to promote person-centred care, likely because measures of person-centred care have not existed until very recently (Edvardsson & Innes, 2010). Thus, another improvement in empirical justification for person-centred care has been the recent development of a number of measures of person-centred dementia care. As these measures begin to be integrated into intervention studies, there is better potential to demonstrate that interventions designed to facilitate person-centred care do change the behaviour of care providers in meaningful ways, and that this is what improves patient outcomes.

Like other recently developed measures, the Personhood in Dementia Questionnaire was created to address the evaluation gap that Edvardsson and Innes (2010) observed. However, the Personhood in Dementia Questionnaire was not designed to measure person-centred behaviours, but rather person-centred attitudes. This distinguishes it from other recently developed measures, and helps to address another problem with existing empirical support for person-centred approaches to dementia care. To explain further, Kitwood’s (1997) definition of personhood as “a standing or status” implies that personhood is reflected not only in one’s actions, but also in one’s attitudes toward a person with dementia. In this respect, the movement toward person-centred care relies on a theory that closely parallels Ajzen’s (1988) theory of planned behavior, which posits that attitudes, along with contextual factors, guide actions. That is, although Kitwood’s (1997) writing does assign specific importance to person-centred actions (i.e., positive person work), the very idea that these actions reflect a standing or status implies that attitudes are central to the theory. Despite the noted advances in empirical
justification for person-centred approaches to dementia care, the idea that behaviours that are defined as person-centred are fundamentally linked to acknowledgement of personhood, or beliefs about the status of another individual, remains unexamined. Thus, the major contribution of this study series is that it was the first to analyze the relationship between attitudes and actions reflected both in Kitwood’s work and in the continuing development of person-centred approaches to care.

In this study series, Kitwood’s definition of personhood as a standing or status was operationalized for application in the context of dementia care, as a set of beliefs about: (1) dementia, (2) the way dementia affects people, and (3) the rights of people with dementia. Study I showed that it was possible to identify a set of such beliefs. Study II demonstrated that this set of beliefs was internally consistent and homogeneous, and could therefore be considered to represent a single construct (i.e., beliefs about personhood in dementia). Study III showed that these beliefs have consequence because, in tandem with dementia diagnosis, they predict a statistically significant proportion of the variance in responses to clinical vignettes. Given that responses to clinical vignettes relate to actual clinical practice (e.g., Arslanian-Engoren, 2004; Braspernning & Sergeant, 1994; Murray, Del Mar, & O’Rourke, 2000; Tabak, Bar-Tal, & Cohen-Mansfield, 1996), Study III offers the first empirical support for the theory that beliefs about personhood in dementia influence behavior (although it remains to be seen whether similar results will be obtained in real-world clinical settings). Findings from Study I, II, and III relied on the development of a measure of beliefs about personhood in dementia. Thus, the central purpose of this study series was to develop and validate a measure called the Personhood in Dementia Questionnaire.
12.1. Psychometric Quality of the Personhood in Dementia Questionnaire

In order to provide a context in which to explore the validity and reliability of the Personhood in Dementia Questionnaire, it is useful to summarize the results of a critical review of similar measures, all developed in the period extending from 2001 to 2010\(^8\), overlapping the period in which this study series took place. Each of 12 measures reviewed by Edvardsson and Innes (2010) has in common a focus on person-centred care; nonetheless, the intended use for the measures is diverse. For example, one of the measures was designed for use in dementia care, seven for use in long-term care, three for use in hospitals, and one for use in a home care setting. The measures assess person-centred care from various perspectives, including those of staff members, family caregivers, and cognitively unimpaired patients. Of the 12 measures Edvardsson and Innes (2010) reviewed, 11 are research-oriented, and reliability and validity evidence had been presented for 10. The psychometric quality of these 10 measures is summarized here alongside a discussion of the reliability and validity of the Personhood in Dementia Questionnaire.

12.1.1. Reliability of the Personhood in Dementia Questionnaire. Internal consistency estimates for existing measures of person-centred care range from adequate to excellent ($\alpha = .64$ to $.94$ at the level of the total scale; Edvardsson & Innes, 2010). Consistent with the internal consistency of other measures of person-centred care, the internal consistency of the Personhood in Dementia Questionnaire is good ($\alpha = .808, N = 60$). Moreover, this reliability estimate closely approximated the estimate obtained when

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\(^8\) Although twelve measures were developed during the period during which this study series took place, most were not appropriate for this study because they are not self-report measures. In addition, several of the measures were not published when the research was proposed. Some were published but were not identified, perhaps because of a distinct research focus (e.g., a focus on family observation of staff behavior as opposed to health provider’s attitudes).
the Personhood in Dementia Questionnaire was delivered to a larger sample ($\alpha = .772$, $N = 176$), suggesting that these results are robust.

12.1.2. Content validity of the Personhood in Dementia Questionnaire.

Content validity of the Personhood in Dementia Questionnaire was supported by subject matter expert agreement rates of 80% or higher for each of the 20 Personhood in Dementia Questionnaire items (items with lower agreement ratings were screened out early in the design process).

12.1.3. Construct validity of the Personhood in Dementia Questionnaire.

Studies of person-centred care scales have emphasized construct validity. The construct validity of most scales reviewed by Edvardsson and Innes (2010) was supported by evidence that a literature review or observational study was completed, and key informant perspectives had been included as the scale was constructed. In addition, construct validity of six of the measures reviewed by Edvardsson and Innes was supported by a description of the interpretable factor structure of the questionnaire. In similar fashion, adequacy of construct validity for the Personhood in Dementia Questionnaire is supported by the use of literature review, consultations with key informants, and consultations with subject matter experts during the questionnaire design process. Exploratory factor analysis was also completed to investigate the underlying factor structure of the questionnaire.

Factor analysis showed that variance in Personhood in Dementia Questionnaire scores is explained best by two factors. The first factor is made up of 11 positively worded items reflecting beliefs about the contributions and capabilities of a resident with dementia, or *positive beliefs* about personhood in dementia. For example, one item reads,
‘it is possible for residents with dementia to connect with each other in meaningful ways’. A twelfth item (‘Residents with dementia have a sense of purpose’) has non-substantial loading (i.e., < .3) on this factor. The second component is made up of six negatively worded items that were reverse scored prior to component analysis (e.g., ‘residents with dementia who whine a lot should be isolated’). This factor may be said to reflect the absence of negative beliefs about personhood in dementia. Of note, one positively worded item about respect (‘All residents with dementia should be treated with respect’) has a non-substantial loading (i.e., < .2) on this factor and approximately zero loading on the positive beliefs factor.

There are two competing interpretations of this result. First, it seems likely that this component structure implies a method effect related to the differential functioning of positively and negatively worded items. For example, negatively worded items may be confusing for some respondents (Podsakoff, MacKenzie, & Podsakoff, 2012), resulting in a different pattern of responding to these items than to positively worded items. Alternatively, these two components may have substantive meaning. To use an example from other research, positively and negatively worded items on the State-Trait Anxiety Inventory (Spielberger, 1983) perform differently, but Spielberger has argued that these differences are theoretically meaningful. For example, negatively worded items better differentiate anxious from non-anxious individuals under conditions of high stress whereas positively worded items better differentiate anxious from non-anxious individuals under conditions of low stress (Spielberger, 1983). Some of the negatively worded items in the Personhood in Dementia Questionnaire are quite disparaging (e.g.,
‘residents with dementia who whine a lot should be isolated’), and this may suggest that reverse-scored negatively worded items reflect something more than a method effect.

If the observed two-component structure does have substantive meaning, one possibility is that beliefs about personhood is a two-dimensional construct that includes positive beliefs about the capabilities of a person with dementia as well as an absence of prejudicial attitudes. On the other hand, if the two-component structure is not meaningful, this has important implications for further questionnaire design efforts. For example, it may be helpful to reframe the negatively worded items as positively worded items and re-examine the factor structure of the questionnaire. Approaches to further development of the Personhood in Dementia Questionnaire are offered in the Limitations and Future Directions section.

12.1.4. Criterion and concurrent validity of the Personhood in Dementia Questionnaire. Assessment of a scale’s validity is ongoing, and typically includes examinations of convergent validity and discriminant validity. Another important form of validity assessment is criterion validity, or assessment of a scale’s ability to predict real-world phenomena. With the exception of White and colleagues’ (2008) evidence that the Person-Directed Care (PDC) questionnaire discriminates among LTC settings, disciplines, and staff job levels, no external assessments of validity are available for person-centred care measures (see Edvardsson & Innes, 2010). It was necessary to assess the convergent validity of the Personhood in Dementia Questionnaire in relative terms since there is no other measure of beliefs about personhood in advanced dementia. Discriminant validity and convergent validity studies examined how closely the Personhood in Dementia Questionnaire compared to more similar and less similar
constructs, respectively. Discriminant validity was supported by a statistically non-significant correlation with the physician attitudes subscale of the Cancer Attitudes Questionnaire and convergent validity was supported by a moderate size correlation with the personhood subscale of the PDC (White et al., 2008).

The criterion validity of the Personhood in Dementia Questionnaire was also supported in the results from this series of studies. In Study III, health providers’ scores on the new Personhood in Dementia Questionnaire, together with the diagnostic status of patients described in vignettes (i.e., dementia or non-dementia), explained a statistically significant percentage of the variance in the likelihood that staff would consider anxiolytic and analgesic interventions for hypothetical elderly long-term care patients experiencing problems with pain. The direction of the effect of dementia diagnosis was such that if the patient described in the vignette had dementia, health providers were less likely to recommend analgesic medication. This result is in line with existing literature reports that document less pain medication use for patients who have dementia relative to patients who do not have dementia in clinical practice settings (Feldt, Ryden, & Miles, 1998; Horgas & Tsai, 1998; Kaasalainen et al., 1998; McCaffery, Ferrell, & Pasero, 2000; Morrison & Siu, 2000; Sengstaken & King, 1993). In contrast, beliefs about personhood in dementia, as reflected in scores on the Personhood in Dementia Questionnaire, appeared to counteract this effect. That is, the higher a health provider’s scores on the Personhood in Dementia Questionnaire, the more likely it was that he or she would recommend use of analgesic medications for a patient with pain, regardless of the patient’s dementia diagnosis. This combination of results seems to confirm the suggestion
in the literature that more favourable beliefs about personhood have a positive influence on intentions regarding patient care.

Similar results were observed when likelihood of using anxiolytic medications was the criterion variable; however, the effects were in the opposite direction. That is, health providers were more inclined to recommend the use of anxiolytic medications if the patients described in the vignettes had dementia. These effects are in line with normative practice in long-term care; for instance, Wang, Brookhart, Setoguchi, Patrick, and Schneeweiss (2006) state that approximately one third of patients with dementia who live in American nursing homes have prescriptions for benzodiazepines and two thirds have prescriptions for psychotropic medications. However, there is considerable controversy over the use of psychotropic medications to treat behavioural disturbances associated with dementia (e.g., see McDonald, Carpenter, Box, Roberts, & Sahu, 2002 and Wang et al., 2006 for contrasting perspectives). Beliefs about personhood in dementia, as reflected in scores on the Personhood in Dementia Questionnaire, offset the tendency to consider anxiolytics. That is, those with stronger beliefs about personhood in advanced dementia were less likely to recommend the use of anxiolytic medications for patients with pain, regardless of cognitive status. This may reflect a greater awareness of the potential for side effects and adverse effects of medications (see Wang et al., 2006), or perhaps a greater sensitivity to the core clinical problem, among other possibilities. Once again, these results seem to confirm that beliefs about personhood influence intentions regarding patient care.

Finally, Personhood in Dementia Questionnaire scores explained a statistically significant amount of variance in the likelihood that health providers would consider
using non-pharmacologic (e.g., psychosocial and alternative medicine) interventions for patients described in vignettes. The direction of this effect was such that stronger beliefs about personhood were associated with a greater likelihood of using non-pharmacologic strategies to care for patients with pain conditions, regardless of a patient’s dementia status. The alternative interventions mentioned in the vignettes were either activity-based (e.g., talking with the patient to distract him or her from pain) or assessment-based (e.g., requesting a physiotherapy consultation). Activity-based interventions such as exercise, music, and distraction have shown promise in reducing pain (see reviews by Kelley, Kelley, Hootman, & Jones, 2010; Nilsson, 2008; Malloy & Milling, 2010) and there is increasing attention in the literature to the importance of interdisciplinary collaboration in pain assessment and management (e.g., Hadjistavropoulos et al., 2007). Perhaps participants with higher Personhood in Dementia Questionnaire scores are more aware of these developments. However, given that the majority of respondents were care aides, it is more likely that the participants simply have more access to non-pharmacological approaches than to pharmacological approaches, and are more likely to choose to employ these with all patients (regardless of cognitive status) when they have stronger beliefs about personhood in dementia. For example, beliefs about personhood in dementia may be associated with beliefs about personhood in a more general sense.

Overall, the Personhood in Dementia Questionnaire performed well in criterion validity studies, in that it helps to predict the use of three important intervention strategies for patients with co-morbid dementia, pain conditions, and behaviour changes. Nonetheless, some questions about the criterion validity of the Personhood in Dementia Questionnaire remain. For example, the ability of the Personhood in Dementia
Questionnaire to predict a statistically significant amount of variance in scores on scales measuring the likelihood of recommending analgesic, anxiolytic, and non-pharmacologic intervention strategies was independent of dementia status (i.e., a statistically significant interaction between dementia status and Personhood in Dementia Questionnaire scores was not observed). It may be the case that responses to the dementia-specific Personhood in Dementia Questionnaire reflect general beliefs about personhood (i.e., personhood regardless of dementia status). Alternatively, it may be the case that the health providers who responded to the Series A (no dementia) vignettes relied on their experiences with older adults in long-term care, a large portion of whom have dementia. Another possibility is that the interaction test was insufficiently sensitive, partly because the interaction test “focuses on the unique effects attributable to the interaction after the variation due to the original variables has been statistically removed” (Keith, 2006, p. 137). Some have argued that substantial interaction is infrequently observed in the real world (Darlington, 1990, as cited in Keith, 2006).

In summary, Study III provided initial evidence of the convergent and discriminant validity of the Personhood in Dementia Questionnaire. Study III also showed that Personhood in Dementia Questionnaire scores predict the likelihood of a health provider considering three different intervention strategies (i.e., analgesic, anxiolytic, and non-pharmacologic strategies) in response to a series of vignettes about patients who display pain conditions accompanied by behaviour changes. All effects were independent of the cognitive status of the patients described in the vignettes, although cognitive status acted as another determinant of the likelihood of favouring analgesic and anxiolytic strategies (and the direction of this effect was opposite to that of the
Personhood in Dementia Questionnaire). These observations provide initial evidence of the external validity of the Personhood in Dementia Questionnaire, including its criterion validity.

12.1.5. Additional psychometric advantages of the Personhood in Dementia Questionnaire. Social desirability bias, or the tendency to respond to questionnaires in a socially desirable way (i.e., as opposed to being fully honest), deserves special attention during the construction of scales that measure patient-centred attitudes. Results from the assessment of discriminant validity completed in Study II demonstrate the importance of either controlling for these effects or choosing measures that are minimally influenced by social desirability during studies of person-centred care. More specifically, in Study II, a statistically significant correlation between the physician attitudes subscale of the Cancer Attitudes Questionnaire and the Balanced Inventory of Desirable Responding was observed. Controlling for the effects of socially desirable responding altered the relationship between the Personhood in Dementia Questionnaire and the physician attitudes subscale substantially. Thus, a further psychometric advantage of the Personhood in Dementia Questionnaire is that social desirability bias was addressed in the scale’s design phase by removing vulnerable items and by testing the questionnaire to ensure that scale scores were not statistically significantly associated with scores on a measure of social desirability responding.

The 7-point Likert-type response scale of the Personhood in Dementia Questionnaire may represent a further psychometric advantage. Although there is considerable debate about the number of items required in order to use Likert scales appropriately in parametric analyses, several authors have used empirical results to
demonstrate that 5- to 7-point Likert scales can be appropriately used in parametric analyses (e.g., Carifio & Perla, 2007, 2008; Norman, 2010). Although most of the measures reported by Edvardsson and Innes (2010) also had a 5- to 7-point Likert-type response scale, two measures had four-item response scales (e.g., Chappell, Reid, & Gish, 2007; Reid, Chappell, & Gish, 2007).

12.2. Significance of the Personhood in Dementia Questionnaire

Long-term care intervention research involves a vulnerable population. Intervention researchers are compelled to address persistent problems including levels of restraint use, delirium, depression, behaviour change, decreased quality of life, and off-label prescription of anti-psychotics and neuroleptics, among others. Most studies of person-centred care interventions appropriately assess either these types of outcomes or changes in employee knowledge, and promising results have been observed (e.g., Brooker, 2005; Chenoweth, 2009; Coleman et al., 2002; Fossey, 2006; Hoeffer et al., 2006; McAiney et al., 2007; Schindel-Martin & Dupuis, 2005; Sloane et al., 2004). However, in most of these studies, outcomes are not directly related to person-centred care (Edvardsson & Innes, 2010). If improving person-centredness is the primary goal of an education program or other intervention, then assessments of the outcome of that program or intervention should include measures or indicators more directly related to person-centredness (Edvardsson & Innes, 2010). Outcomes that are more directly related to the spirit of person-centred care frameworks might include health providers’ beliefs about personhood in dementia, the number of meaningful daily interactions patients have with health providers, the degree to which care is individualized, family members’ satisfaction with observed patient-provider interactions, and the kinds of choices made
available to a patient, among others. Thus, like other measures of person-centred care that emerged in the last decade (Edvardsson & Innes, 2010), the Personhood in Dementia Questionnaire addresses an asymmetry between intervention goals and current measurement practices.

In his much-cited writing about person-centred dementia care, Kitwood (1997) highlighted the importance of health providers’ attitudes by discussing stigma about age and cognitive disability that pervade society and also influence dementia care environments. Kitwood advocated for a form of dementia care based on the humanistic attitudes advanced by psychotherapist Carl Rogers (1961). Contemporary person-centred care interventions follow the spirit of Kitwood’s work by including a dual focus on attitudes and skills. For example, the Gentle Persuasive Approaches™ program (Schindel-Martin & Dupuis, 2005) attempts to foster a belief that behavioural and psychological symptoms of dementia are responses to internal and environmental stimuli, but also works to develop health providers’ skills in choosing strategies that diffuse challenging behaviors and in using appropriate self-protective techniques when necessary (Schindel-Martin & Dupuis, 2005). The Personhood in Dementia Questionnaire is uniquely positioned to assess changes in individual staff members’ attitudes toward patients with dementia when frameworks or interventions to promote person-centred care are introduced. Other measures associated with the person-centred care dementia movement emphasize retrospective reports of behaviour or assessment of a facility-wide culture of care (see Edvardsson & Innes, 2010).

12.2.1. Use of the Personhood in Dementia Questionnaire outside research contexts. Personhood in Dementia Questionnaire items solicit individual health
provider’s beliefs about the residents they work with. Several participants in Study II and Study III commented positively that the measure helped them to reflect on their work in a meaningful way. Therefore, an ideal use of the Personhood in Dementia Questionnaire outside a research context is as an instrument for personal reflection. The questionnaire could be a valuable addition to change promotion strategies that focus on person-centred care. For example, it could be used to facilitate self-assessment and personal reflection, or group discussion about the meaning of the phrase “person-centred care”.

12.3. Significance of the Study Series

Beyond developing the Personhood in Dementia Questionnaire, an overarching goal of the study was to determine the extent to which beliefs about personhood in dementia influence a health provider’s intended approach to care. A better understanding of the influence of beliefs about personhood in dementia on staff-patient interactions and quality of care is important as person-centred care frameworks continue to be translated into practice. Researchers have demonstrated that person-centred care interventions lead to statistically significant changes in patient outcomes (Brooker, 2005; Chenoweth, 2009; Coleman et al., 2002; Fossey, 2006; Hoeffer et al., 2006; Sloane et al., 2004). However, these programs are typically multi-faceted, including several points of intervention and, as Edvardsson and Inness (2010) noted, measures of person-centred care have not been included in these studies. Thus, as yet, there is very little direct evidence that the observed changes in outcome are related specifically to person-centredness. Inclusion of

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9 There is one exception. Dementia Care Mapping (DCM; Brooker & Surr, 2005) has been used in person-centred care interventions. DCM is a measure designed for use in quality improvement efforts. It was not designed for outcome research and, although it has good interrater reliability, other reports of its validity and reliability are not available (Edvardsson et al., 2010).
person-centred care measures would help to demonstrate that changes are at least partly related to changes in person-centred attitudes and behaviours.

In Study III, the relationship between the Personhood in Dementia Questionnaire and intended care behaviour was assessed. Moderated multiple regression was used to test whether scores on the Personhood in Dementia Questionnaire predicted the likelihood of using certain interventions for hypothetical patients described in a vignette. Scores on the Personhood in Dementia Questionnaire, in combination with the diagnostic status of the patients described in the vignettes, explained between 6.7% and 13.7% of the variance in staff members’ approaches to three different types of clinical interventions. Intended behaviour is known to predict real-world behaviour in a variety of situations (Ajzen, 1988); thus, components of person-centred care interventions that influence attitudes or beliefs about patient personhood may also have the potential to influence care providers’ approaches to care.

The observation of a statistically significant (though small; i.e., $r^2 < 0.15$) correlation between that Personhood in Dementia Questionnaire scores and years of education is also encouraging. Most respondents with higher levels of education had nursing degrees. The content of nursing degree programs is diverse and not likely to include a specific focus on personhood in advanced dementia as a major theme (see Berman et al., 2005 for a survey of curriculum content in American nursing programs). A small association between education and scores that reflect beliefs about personhood in dementia is unsurprising on this basis. Nonetheless, the existence of a small association may suggest that targeted staff education programs could help long-term care facilities progress toward a culture of person-centred care. In other areas of clinical intervention,
targeted education has been shown to influence nurses’ attitudes and several studies have shown sustained results (see Aylward, Stolee, Keat, & Johncox, 2005 for a recent review).

It should be acknowledged that an attitude-focused intervention is not the only way (nor necessarily the best way) to introduce a change in practice. Researchers are increasingly turning their attention to systemic factors, including barriers to the implementation of recommendations made in education programs. For example, Caspar and O’Rourke (2008) demonstrated the important role of organizational dynamics in determining the provision of person-centred care by showing that various forms of structural empowerment (e.g., power, information, resources, support, opportunities) explained close to half the variance in the provision of individualized care. In the Western Canadian provinces, a multi-centre collaboration initiative called the translating research in elder care (TREC) research program (Estabrooks, Squires, Cummings, Teare, & Norton, 2009) is currently being conducted to better understand the magnitude of organizational effects on the translation of knowledge into practice.

Systemic factors may influence behaviour directly, as suggested by Caspar et al. (2008), but results from the current series of projects suggest that systemic factors may also play an indirect role in determining the person-centredness of health providers. More specifically, certain work-related variables bear relationships to beliefs about personhood in dementia and these, in turn, predict the likelihood of implementing various intervention strategies for patients described in clinical vignettes. For example, Study III demonstrated that a work-related variable, sense of personal achievement (a dimension of burnout), was associated with beliefs about personhood in dementia. In addition, although
job satisfaction was not found to be associated with beliefs about personhood, it was associated with all three dimensions of burnout examined in Study III, which suggests that it may play an indirect role in mediating attitudes toward patients with dementia. It is acknowledged that the relationships mentioned here are correlations, and the direction of any cause-effect relationships is unknown. Nonetheless, these results demonstrate a relationship between employee and workplace factors. Further study on the potential effects of organizational factors on employee attitudes and behaviours, especially in interactions with patients, is important as work in this area continues.

These findings support the need for increased attention to workplace dynamics as efforts to foster a person-centred culture in long-term care continues to develop. The results also suggest that scores on the Personhood in Dementia Questionnaire may be responsive to efforts aimed at improving employee experiences of workplace culture; for instance, to the extent that such efforts act to enhance a sense of personal achievement. This hypothesis is in line with Caspar and O’Rourke’s (2008) observation that structural empowerment is associated with provision of individualized care. Thus, the Personhood in Dementia Questionnaire may be useful in evaluating initiatives that are broader in scope than providing education about person-centred care.

13. Limitations and Future Directions

13.1. Additional Psychometric Evaluations of the Personhood in Dementia Questionnaire

Studying the validity of a scale is not a single event but rather an ongoing process over the course of years (Strauss & Smith, 2009); thus, the development and initial testing of the Personhood in Dementia Questionnaire is considered a first step. It is
important to continue to evaluate and improve the Personhood in Dementia Questionnaire in ways that fall outside the scope of the present set of studies.

13.1.1. Test-retest reliability. Continued evaluation of the Personhood in Dementia Questionnaire should include an examination of its test-retest reliability, which was not assessed in the present series of studies.

13.1.2. Factorial validity. Given that Exploratory Factor Analysis of the Personhood in Dementia Questionnaire suggested the possible presence of a method effect related to the use of negative items in the questionnaire, confirmatory factor analysis (CFA) with a new large data set is needed to better understand whether positively and negatively phrased items have substantive importance (i.e., whether they best reflect method effects or meaningful, interpretable factors). In Confirmatory Factor Analysis (CFA), competing factor structure models, including hierarchical models, can be tested. For instance, it would be possible to test hierarchical alternatives to better understand the relative contribution of method effects (DiStefano & Motl, 2006). This can be done by modelling a single factor (e.g., reflecting positive beliefs about personhood) along with a smaller sub-factor of reverse-scored negatively worded items. If this model explains the structure of the questionnaire better than alternative structures such as a two-factor model, the implication would be that although there is a method effect, both groups of items are measuring the same overarching construct; i.e., respect for personhood in dementia. This is a worthwhile question to pursue from the standpoint of factorial validity. An alternative would be to redesign the questionnaire so that all items are phrased positively rather than negatively, and to re-examine the factor structure of the revised questionnaire.
13.1.3. **Construct validity.** It will also be important to continue to study the construct validity of the Personhood in Dementia Questionnaire by examining its relationships with other measures. In particular, it will be useful to conduct additional convergent validity studies using newer measures that are more closely related to the Personhood in Dementia Questionnaire than those that could be identified at the time of this study (see Edvardsson and Innes, 2010). Related to this, the choice of measure for the current convergent validity study (i.e., the personhood subscale of the PDC; White et al., 2008) may have attenuated the observed results. The PDC is not dementia-specific. It was designed for use in long-term care environments, but not specifically for work with patients with dementia. In addition, the modified version of the personhood subscale of the PDC that was used in Study II measures beliefs about person-centred care, rather than beliefs about personhood in dementia.

13.1.4. **Criterion validity.** Study III relied on a newly created measure of behavioural intentions to assess the criterion validity of the Personhood in Dementia Questionnaire. Validation of this new measure was limited to a focus on internal consistency and content validity. A related limitation concerning the use of this measure is that the degree to which the results from the criterion validity study generalize to actual clinical practice situations remains unclear. Thus, conducting additional criterion validity studies with *in situ* patient care behaviour as the criterion of interest will also be important.

13.1.5. **Social desirability.** A limitation of the approach used in Study II was that the internal consistency of the Personhood in Dementia Questionnaire was compromised somewhat in order to enhance other psychometric properties of the measure; in particular,
to reduce its vulnerability to social desirability responding. Social desirability bias could undermine the construct validity and external validity of a measure like this; thus, it was considered essential to remove items that were influenced by social desirability bias. At the same time, it is recognized that lower levels of reliability attenuate observed correlations with other scales, and these are often used to evaluate validity.

13.2. Developing a Better Understanding of Variables that Influence Person-Centred Care

Several frameworks for person-centred care have been designed (e.g., Brooker & Surr, 2005; McAiney et al., 2007; Schindel-Martin & Dupuis, 200), and both published (Brooker, 2005; Coleman et al., 2002; Chenoweth et al., 2009; Fossey, 2006; Hoeffer et al., 2006; McAiney et al., 2007; Sloane et al., 2004) and unpublished (Schindel-Martin & Dupuis, 2005) evaluations of these frameworks are now emerging. The basic premise that stimulated the development of these frameworks is that beliefs about personhood in dementia influence patient care. However, person-centred care interventions are typically multi-component, and efforts to change beliefs or attitudes about personhood are just one aspect of these interventions. It is important to understand how each component of person-centred care interventions contributes to changes in patient outcomes, in order to focus efforts for change on these components. For example, individualized behavioural assessment and intervention appears to be a consistent focus of person-centred care interventions. Other possible examples of content in person-centred care interventions and frameworks include effective use of communication and conflict dissolution strategies (Schindel-Martin & Dupuis, 2005) and close attention to a resident’s level of engagement and emotional well-being (Brooker & Surr, 2005). Developing an
understanding of how each area of focus contributes to changes in attitudes and
behaviours would do a great deal to advance a base of knowledge about the patient and
staff outcomes associated with person-centred long-term care cultures. As a measure of
beliefs about personhood in dementia, the Personhood in Dementia Questionnaire is well
positioned as a direct measure of the effectiveness of intervention components in
improving person-centredness.

13.3. Expanding the Focus of Research to Better Address Systems Factors

In a context of increased need for dementia care associated with an aging
population that is more vulnerable to this disease (Alzheimer Society, 2010) and the
associated pressure on health care budgets, there is a risk that the current emphasis on
person-centredness care may too greatly emphasize the importance of individual attitudes
and practices, acting as a smokescreen for problems that are systemic in nature. Several
current assessments of person-centredness already focus on attributes of long-term care
environments rather than on attributes of health providers within those facilities
(reviewed by Edvardsson & Innes, 2010). In light of Caspar and O’Rourke’s (2008)
observation that structural empowerment is highly associated with the provision of
individualized care, it seems quite appropriate to measure outcomes at the facility level.

However, as efforts to examine contextual factors in care continue to develop, it is
also worthwhile to examine the effects of person-centred care initiatives on staff. For
example, incorporating a focus on both patients and staff as these interventions are
designed and implemented may enhance understanding of contextual factors. Patient-
centred results are likely to be better achieved by recognizing the needs of employees and
the dynamics of organizational systems. For instance, a staff-focused initiative to
improve care called ‘the productive ward’ or ‘Releasing time to care™’ (Wilson, 2009) provided a set amount of funding for external consultative support and staff planning time. This allowed staff flexibility to identify organization-specific changes to increase the time staff spent in direct care. Strategies like this ensure that health providers have the required resources and support to work toward change. The Personhood in Dementia Questionnaire could be used as part of a battery that examines employee outcomes associated with efforts to improve workplace cultures in long-term care.

14. Conclusion

The Personhood in Dementia Questionnaire was developed for use in research (especially the evaluation of person-centred care interventions that include a focus on attitude change). Compared to other measures of person-centredness, the Personhood in Dementia Questionnaire is unique in two main ways. First, no other measure of person-centred care assesses person-centredness through self-reports of attitudes (other measures focus on health providers’ behaviours or on attributes of a facility that suggest a culture of person-centred care). Secondly, compared to other measures, the external validity of the Personhood in Dementia Questionnaire, including its criterion validity, is better-studied. Nonetheless, the Personhood in Dementia Questionnaire is a new instrument, and additional examination of its reliability and validity must be undertaken in order to better understand its psychometric properties. Based on current evidence, the Personhood in Dementia Questionnaire shows initial promise as a measure of person-centred attitudes toward patients with advanced dementia, and its psychometric properties compare very well to those of similar instruments. In particular, the external validity of the Personhood in Dementia Questionnaire is comparatively well supported.
A series of studies that tested the relationship of beliefs about personhood with other constructs demonstrated that beliefs about personhood are positively associated with years of education, a sense of personal accomplishment at work, and beliefs about person-centred care. This study series also showed that beliefs about personhood are not associated with years of work experience, job satisfaction, and emotional exhaustion (an aspect of burnout). Furthermore, this research confirmed that beliefs about personhood predict intended care behaviours, including the likelihood of choosing anxiolytic medications, analgesic medications, and non-pharmacologic methods as intervention strategies for patients with pain conditions and concomitant behaviour changes. These results appear to indicate that beliefs about personhood in dementia are influenced by education and a sense of personal accomplishment, but are resistant to some work-related influences. These beliefs predict health providers’ intended approaches to dementia care (for example, they appear to counteract a tendency toward over-utilization of psychotropic medications and under-utilization of pain medications in this population).

Overall, this work suggests that there may be potential to use beliefs about personhood to predict health provider’s intervention choices when working with patients who have dementia. Although the evidence base needs further development, this study series provides direct empirical support for the inclusion of attitude-focused content in person-centred care intervention programs.
15. References


Toronto, ON: Penguin Books. (Original work published 1576)


Saskatoon Star Phoenix (2008, October 18). *SIAST adds nursing seats, expands space.*


Steinberg, M., Tschanz, J. T., Corcoran, C., Steffens, D. C., Norton, M. C., Lyketsos,


Teri, L., Gibbons, L. E., McCurry, S. M., Logsdon, R. G., Buchner, D. M., Barlow,


Appendix A: Interviewer/Moderator Guide for Study I

Brief introduction (following written consent procedures): I am conducting research on dementia care as a dissertation project in psychology, and I am meeting with you because I want to better understand the experiences of nurses and special care aides who work extensively with people who have dementia. I would like you to speak as freely as possible about your experiences, and I want to assure you that your responses are confidential, and that any identifying information you share about you, other staff, or patients will be protected. Do you have any questions before we begin?

1. I understand that the type of work you do can be rewarding, but also very challenging.
   (a) What things make it easier for you to work with someone with dementia?
   (b) What things make it difficult for you to work with someone with dementia?

2. In your work, have you noticed that some staff members treat people with dementia differently than other patients?
   (a) In what ways?
   (b) Why do you think this might be?

[If issues surrounding personhood arise, continue to discuss these issues as thoroughly as possible; otherwise use the following additional questions to explore this issue further.]

3. Do you think it is true that patients with dementia get treated like objects instead of people sometimes?
   (a) How so?
   (b) What things make it easier for you to see an individual with dementia as a person?
Prompt for work-related and other

(c) What things make it more difficult?

Prompt for work-related and other

4. There is a lot of research now that says patients with dementia do not receive as much pain control as other patients. For example, if a patient without dementia has bad arthritis, she will probably have a prescription for it. If a patient with dementia has bad arthritis, she might not have a prescription for it or the prescription might be a lot lower. No one is 100% sure why this happens, but it is not just a coincidence. Do you have any ideas about this from your own work?
Appendix B: Member Check Survey for Study I

Experiences of Health Professionals in Long-term Care

This is a summary of information collected in focus groups and individual interviews in winter of 2009. It contains information from all of the interviews that were conducted, and is not based on a single interview or focus group. Please take some time to review the notes and answer the questions at the end of the summary, in order to help us ensure that our summary is consistent with the views of staff. You do not need to record your name on this summary and anything you add will be kept confidential. You may write as much or as little as you wish. Thank you for your valuable feedback!

1. Challenges of working with long-term care residents who have dementia:
   • The following behaviours are difficult to manage: grasping, inappropriate behavior, resisting help with personal care, physical or verbal aggression, repeated questions or requests, restlessness/sundowning, wandering into other residents’ rooms, wanting attention, wanting to leave, and calling out
   • The effects of cognitive impairment can make it difficult to understand and meet residents’ needs
   • Many residents are fearful, and need reassurance
   • It is sometimes easy to forget about residents who don’t say or do much

2. Workplace factors that act as facilitators (or barriers) to providing good care:
   • (Lack of) sufficient time to spend with residents
   • (Lack of) effective teamwork/communication
   • (Perceived lack of) support from other staff or management
   • (Poor) continuity of care
   • (Insufficient) activity programming
   • (Insufficiently) trained staff

3. Effective strategies for working with patients who have dementia:
   • Learn about the patient’s personal and medical history
   • Ensure all basic physical needs are met (hunger, temperature, need to use the toilet, etc.)
   • Get to know the patient’s usual patterns, and follow up on behavioural changes
   • Address the patient's emotional needs (e.g., promote a feeling of safety)
   • Provide activities and stimulation
   • Request medication for pain/anxiety as needed, but avoid over-medicating
   • Acknowledge the patient’s reality (don't argue with the patient)
   • Pay attention to your approach to the patient (e.g., eye contact, explanations during personal care)
   • Be flexible, creative, patient, and persistent
   • When necessary, distract or redirect the patient
   • When necessary, trade tasks with someone else or leave and come back later
4. Rewards of working in long-term care:
- Personal connections with residents and staff
- Variety, challenge, and humour in the workday
- Being appreciated by residents
- Sense of personal satisfaction from providing good care and/or engaging the resident
- Personal growth (e.g., learning to be more patient; learning things from patients)

5. Challenges of working in long-term care:
- Let-down/difficulty adjusting in the first few days of long-term care work
- Feel unappreciated at times by residents, families, and superiors
- Wanting more “quality time” with residents
- The work can be physically demanding
- Grief when a resident dies
- Worry about residents when at home

6. What is important to person-centred care:
- Knowing about a resident’s history, including current previous preferences and activities
- Accepting the resident as he or she is right now
- Including the resident in conversations or activities
- Respecting the resident’s choices, provided this does not compromise health or safety
- Protecting the residents’ dignity (e.g., ensuring they are nicely groomed, protecting privacy)
- Treating others as I would like to be treated
- “Going the extra mile” for a resident (e.g., a focus on relationships rather than tasks)

7. Perspectives on personhood in dementia:
- All residents with dementia deserve respect
- Many residents with dementia have a sense of purpose (e.g., concern for family or farm)
- Many residents with dementia still care about their appearance and making a good impression
- Many residents with dementia are capable of indicating some preferences/choices
- Residents with severe dementia remain aware of the most basic feelings (pleasure and pain)
- Residents with dementia contribute to a sense of family or community in long-term care
- It is possible to connect with residents who have dementia (e.g., by speaking with them, learning about personal history)
- Some staff may feel that a patient with severe dementia is a body; no mind left
- Some staff may feel that a patients with severe dementia have lost their purpose, or a part of themselves
To the best of your knowledge, is this summary consistent with the spirit of the views of long-term care staff in your facility?

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<td>Not consistent at all</td>
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<td>Very consistent</td>
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1. If this summary is not consistent with your experience, what would you change or delete?

________________________________________________________________________
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2. Is there anything else you would like us to know about your experiences working with long-term care residents who have dementia?

________________________________________________________________________
________________________________________________________________________
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Appendix C: Recruitment Script for Study I

“Dr. Thomas Hadjistavropoulos and his graduate student, Paulette Hunter, are researchers at the University of Regina. They are going to be conducting a study about health professionals’ experiences caring for patients with dementia. They want to learn more about your thoughts about the rewards and challenges of working with patients who have dementia, and your thoughts about your patients and your work. They are going to be doing a focus group at our facility, and I am wondering if you would like to participate. We haven’t settled on a day and time yet (OR STATE DATE AND TIME), but it will likely take place within the next two weeks. It would be held on your regular shift, and there would be about 5-10 other people from our facility in the group. If you want to participate but would rather not be in a focus group, the researchers are also willing to meet with you individually.

You do not have to participate in this research if you are not interested – it is entirely up to you. Would you please let me know by DAY OF THE WEEK whether you would like to participate? If I don’t hear back from you by then, I will assume you weren’t interested. (IF PARTICIPANTS REQUEST FURTHER DETAILS ABOUT THE RESEARCH, SUCH AS HOW THEIR RESPONSES WILL BE USED, THEY MAY CALL THE RESEARCHER, PAULETTE HUNTER, AT 585-4428).
Appendix D: Consent Form for Study I

Consent to Participate in an Interview / Focus Group

Title: Special Issues in the Care of Persons with Dementia

You are being invited to participate in a study. Before you decide whether or not to participate, please take a few moments to read the following information (continued on the reverse of this page). Please ask a member of the research team to explain any information that is not clear to you.

Principal Investigator: Paulette Hunter, M.A.
Graduate Student, University of Regina
Supervised by Dr. Thomas Hadjistavropoulos
(306) 585-4428

Co-investigator: Thomas Hadjistavropoulos, Ph.D., R. D. Psych., ABBP, FCAHS
Research Associate, Regina Qu’Appelle Health Region
Professor of Psychology,
Centre on Aging and Health
University of Regina
(306) 585-4428

Sponsor: The Canadian Institutes of Health Research (CIHR) and the Saskatchewan Health Research Fund (SHRF) provided support for this project

What is the purpose of the study?
Special issues can arise in the care of patients with dementia as compared to other patients. In the study you are invited to participate in, we want to understand some of the issues you have encountered and how you approach these issues. We are also interested in staff perceptions of patients with and without dementia.

What will I be asked to do?
You are being asked to participate in either an individual interview or a group interview with about 5-10 other healthcare professionals from your facility. In either case, the session will take place during your regular work hours, will last between 1 and 2 hours, and will be digitally recorded. During the interview, we will discuss some of the special issues that you encounter in caring for patients with dementia. Randomly selected participants will be contacted by telephone after the interview to provide feedback on the results (the results will be mailed, and the follow-up phone call will take approximately 15 minutes).

Who is conducting the study?
This study is being conducted by Paulette Hunter who is a researcher with the University of Regina. This research is being supervised by Thomas Hadjistavropoulos, Ph.D., R. D. Psych., ABBP, FCAHS, Director of the Centre on Aging and Health at the University of Regina. If you have any questions about this study, you may contact Paulette at (306) 585-4428 in the Health Psychology Laboratory at the University of Regina.
**Why is the interview being recorded? Will the interview be confidential?**

Rather than try to write down your thoughts and opinions during the interview it is much easier (and more accurate) to record the interview. Your responses will be stored securely in the Health Psychology Laboratory at the University of Regina (i.e., on a CD in a locked file cabinet). No one except the researchers and other employees and volunteers of the Health Psychology Laboratory will have access to this data. After the interviews are complete we will transfer the recordings into written form. Your responses will be rendered anonymous in all written transcripts. Only group results or anonymous quotations will be used when we present the reports or summaries of this study.

Your manager will know that you are a participant in this study, but no information linking responses to any individual will be released by us. This is necessary in order to provide workload relief while you are involved in the study.

By law we are required to break our promise of confidentiality if any of the participants share information that suggest that someone may be in real physical danger (e.g., threats of physical abuse or suicide). Also, we cannot guarantee that other volunteers who have participated in the group interview format will keep the discussion confidential. By signing this form you agree to respect everyone’s right to not have his or her personal thoughts spread outside the interview.

**Are there any risks to participating?**

There are no known risks aside from the possibility that (although we ask participants to keep all group discussion confidential) a member of the group may disclose aspects of the discussion to others.

**How will I benefit from this study?**

It is hoped that the results from these interviews will help us understand some special issues that health professionals encounter in caring for patients with dementia and will contribute to improvements in training and care planning in this area.

**Will I get a copy of the study results?**

We will be conducting two other related studies in the same 12-month period. You are not required to participate in the other studies. When all three studies end, those who participated in any of the studies will be invited to attend a paid, catered coffee break. During this session, all details of each study, including findings, will be presented. Written copies of the study results will also be available on request.

**Am I required to participate?**

No - your participation in the interview is entirely voluntary. You may choose not to participate or may withdraw from the interview at any time without consequence. You are also free to answer only the questions you choose.

**Who can I contact if I have any concerns about my rights as a research volunteer?**

This study was approved by the Research Ethics Boards of the Regina Qu'Appelle Health Region and the University of Regina. This process ensures that the study applies current standards of good research and helps to protect the rights of research volunteers. If you have any additional questions about your rights as a research participant, or if you would like to discuss your participation in this study with someone other than the researcher(s) listed on the previous page, please contact the Chairperson of the Regina Qu'Appelle Health Region Research Ethics Board, Dr. Elan Paluck, at (306) 766-5451, or contact the Chair of the University of Regina Research Ethics Board at (306) 585-4775.
Consent Statement
I have read the above information and have been provided the opportunity to ask questions. I agree to participate in the interview knowing that it is voluntary. I may choose to end my participation in the interview at any time without affecting my current or future employment status. I understand that the group interviews are confidential and I agree to keep confidential the discussion and comments made by other people in the interview. I have received a copy of this consent form. I am agreeing to the following interview format (check one): Individual  Group

Participant name (print)  Signature of Participant  Date

Signature of Researcher  Date
## Appendix E: Personhood in Dementia Questionnaire (Initial Item Pool)

**Instructions:** Consider how true each statement is, and choose the rating that best applies. Remember that your response can only be used if you mark one and only one scoring circle per item.

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<tr>
<td>1. Residents with dementia should have freedom to do as they wish.</td>
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<td>2. Most residents with advanced dementia are not capable of taking responsibility for themselves in any meaningful way. (R)</td>
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<td>3. A resident gradually loses his or her soul as dementia progresses to the end stages. (R)</td>
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<td>4. It is important to ask or inform a resident with dementia before taking him or her to an activity.</td>
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<td>5. Residents with advanced dementia are unique individuals.</td>
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<td>6. Residents with end-stage dementia have lost an essential part of their humanity. (R)</td>
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<td>7. Residents with dementia lose their perception of pain as dementia advances. (R)</td>
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<td>8. Before a resident with dementia dies, the person they were gradually ceases to exist. (R)</td>
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<td>9. Residents with advanced dementia can still express themselves through non-verbal communication.</td>
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<td>10. Residents with dementia have a sense of purpose.</td>
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<td>11. Most residents with dementia are still capable of making some informed choices about their lives.</td>
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<td>12. It is important to treat each resident with dementia the way I want to be treated if I ever have dementia.</td>
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<td>13. Some residents with dementia are like extended family members to me.</td>
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<td>14. Residents with dementia who resist care are demanding respect in their own way.</td>
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**Instructions:** Consider how true each statement is, and choose the rating that best applies.

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<thead>
<tr>
<th></th>
<th>Disagree extremely</th>
<th>Disagree quite a bit</th>
<th>Disagree Slightly</th>
<th>Neither agree nor disagree</th>
<th>Agree slightly</th>
<th>Agree quite a bit</th>
<th>Agree extremely</th>
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<tr>
<td>15. Residents with dementia have a basic right to make any choices they can about their care.</td>
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<td>16. All residents with dementia continue to make meaningful contributions to life at the long-term care facility.</td>
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<td>17. Dementia takes away the beauty of those who are affected by it. (R)</td>
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<td>18. Residents with dementia who can still socialize should be given priority when activities are scheduled. (R)</td>
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<td>19. A resident with end-stage dementia is essentially a body that is kept alive. (R)</td>
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<td>20. It's not really possible to get to know a resident with severe dementia as a person. (R)</td>
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<td>21. Residents with very advanced dementia are so low-functioning that they are no longer persons. (R)</td>
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<td>22. Residents with severe dementia have personally meaningful experiences.</td>
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<td>23. Making conversation with a resident with end-stage dementia is pointless because he or she cannot reply. (R)</td>
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<td>24. A person can learn a lot from residents with dementia.</td>
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<td>25. Residents with dementia who can have a conversation are more fully human than those who can no longer speak. (R)</td>
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<td>26. Residents with severe dementia would like to participate in personally meaningful activities.</td>
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<td>27. Learning about what a resident with dementia accomplished in earlier periods of life helps me grow in respect for that resident.</td>
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**Instructions:** Consider how true each statement is, and choose the rating that best applies.

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<tr>
<th>Statement</th>
<th>Disagree extremely</th>
<th>Disagree quite a bit</th>
<th>Disagree Slightly</th>
<th>Neither agree nor disagree</th>
<th>Agree Slightly</th>
<th>Agree quite a bit</th>
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</thead>
<tbody>
<tr>
<td>28. Residents with end-stage dementia can no longer contribute to the world in any meaningful way. (R)</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>29. A resident with dementia who can still play piano is a more valuable member of the long-term care community than a resident who is immobile. (R)</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
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</tr>
<tr>
<td>30. Residents with dementia contribute to a sense of community within our long-term care facility.</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>31. Most residents with dementia have shown me that they care for me in one way or another.</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
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</tr>
<tr>
<td>32. Learning about what a resident with dementia accomplished earlier in life reminds me that he or she is a person just like me.</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
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</tr>
<tr>
<td>33. All residents with dementia should be treated with respect.</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
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</tr>
<tr>
<td>34. Even in dementia, a person remains a person until the moment of death.</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
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</tr>
<tr>
<td>35. Residents with advanced dementia are no longer true participants in life; instead, they watch from the sidelines. (R)</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
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</tr>
<tr>
<td>36. Residents with very advanced dementia no longer have an interest in relationships. (R)</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
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</tr>
<tr>
<td>37. Most residents with severe dementia have a sense of community within the long-term care facility.</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
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</tr>
<tr>
<td>38. Residents with severe dementia have lost their capacity to relate to other people. (R)</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
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</tr>
<tr>
<td>39. It is possible for residents with dementia to connect with each other in meaningful ways.</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
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</tr>
<tr>
<td>40. Residents with dementia want to socialize with the people around them.</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
</tbody>
</table>
**Instructions:** Consider how true each statement is, and choose the rating that best applies.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree extremely</th>
<th>Disagree quite a bit</th>
<th>Neither agree nor disagree</th>
<th>Agree slightly</th>
<th>Agree quite a bit</th>
<th>Agree extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>41. Residents with dementia can continue to play an important role in their families.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
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<tr>
<td>42. Some residents with dementia have had an important role in my life.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>43. Residents with advanced dementia have a purpose, even when we can't see what it is.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
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<tr>
<td>44. Residents with end-stage dementia are more content when staff members talk to them.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
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<tr>
<td>45. There is always some way to connect with a resident who has dementia, even if he or she cannot communicate.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>46. Providing stimulation such as music is very helpful for a resident with end-stage dementia.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>47. As dementia advances, residents with dementia no longer experience basic feelings such as pleasure. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>48. There should be negative consequences for residents with dementia who strike out or swear at staff. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>49. A resident with severe dementia is just as much a person as someone with normal cognitive abilities.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>50. Residents with dementia who ask the same question repeatedly need a higher dose of medication. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
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<tr>
<td>51. Residents with dementia can have important roles in life at the long-term care facility.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>52. Residents with end-stage dementia have some awareness of what is happening around them.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
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<tr>
<td>53. Residents with dementia who whine a lot should be isolated. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
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<td></td>
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</tr>
</tbody>
</table>
**Instructions:** Consider how true each statement is, and choose the rating that best applies.

<table>
<thead>
<tr>
<th></th>
<th>Disagree extremely</th>
<th>Disagree quite a bit</th>
<th>Disagree Slightly</th>
<th>Neither agree nor disagree</th>
<th>Agree slightly</th>
<th>Agree quite a bit</th>
<th>Agree extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>54. The needs of residents who still have awareness of their environment should take priority over the needs of those who have less awareness. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>55. The less aware a resident is, the less important it is to offer care according to personal preferences. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>56. Most residents with dementia are unable to connect with the real world. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>57. It is important to ensure the privacy of residents with end-stage dementia, even if they do not seem aware of privacy.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>58. Residents with advanced dementia are no longer persons like you and me, because they do not think and reason logically. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>59. Residents with dementia are not as fully human when they reach a stage in which they do not recognize their surroundings. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>60. Residents with dementia are not as fully human because of their severe memory loss. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>61. Reading or inquiring about the personal history of a resident with dementia is a way to get to know that resident as a person.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>62. Residents with dementia have feelings about their experiences.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>63. Most residents with dementia feel the same range of emotions as I do.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>64. For most residents with dementia, there is something in life that gives them joy (e.g., a food, activity, person, or possession).</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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</tbody>
</table>

(R) = Reverse coded item
Appendix F: Responses to Member Check Survey Questions 1 and 2

1. If this summary is not consistent with your experience, what would you change or delete?

The respondents who answered this question usually interpreted it as a question about changes they would like to see in long-term care. The following changes were recommended:

• "Staff not to feel residents with severe dementia have no mind left or lost their purpose or part of themselves because they won't care for them as normal persons with due respect."
• "More change in educating family members to accept and understand their loved one’s needs."
• "If I would change anything it would be patience and understanding."
• "In providing care, we also need more time to spend with residents. Teamwork and communication is also a key to provide good care to the resident and sometimes it is not consistent."
• “Workload varies from group to group. It seems residents are placed in a group based on their location rather than their care needs.”
• “Caring approach - ongoing consistent, pleasant explanation of what and how something is being done... language barrier (staff speaking poor English - mispronouncing words)...really connecting with residents by self-disclosure and genuine interest in them and their history. Respect on equal level.”

One respondent interpreted the question as intended, and provided this feedback:

• “Rewards of working in long-term care: personal connections with residents and staff and families (families are very important too!) - being appreciated by residents and family and staff / our own peers too.”
2. Is there anything else you would like us to know about your experiences working with long-term care residents who have dementia?

Two comments about paying attention to a person’s approach to a resident were deleted, because these were reflected in the listed themes. A statement that the job is a challenge was deleted because it was reflected in the listed categories. Finally, a book recommendation was deleted. New themes revolved around wages, uncertainty about the benefits of medication, taking time with the residents, the emotional demands of the work, and the strains associated with increasing complexity of care:

- "We're not paid enough for what we do! I make what a Safeway clerk makes and I am responsible for people's lives. (Sad)"
- "I would like to know if medication given for dementia helps to recover because my experience is that most of them are worse than when they were not on medication."
- "Time given to the residents is the best gift to them. Time allows them the opportunity to smile / to make their own choices."
- "Working in dementia unit is very difficult. You need to be patient, loving, and have self-control and know how to manage stress. I had an experience a few months ago and I was so stressed that time when I came to work [describes experience with patient care]."
- "Dementia can be emotionally 'taxing' on resident and caregiver."
- Needs of residents in long-term care increasing - admitted (i.e., numerous diagnoses, frailer, need constant supervision...). Our staffing levels have not increased at the same level [describes effects of increasing complexity of care on time spent with patients]"
Appendix G: Demographics Questionnaire for Study II

Demographic Information

Age: _______

Years of experience in long-term care: _______

Occupation:
- [ ] Registered nurse
- [ ] Registered psychiatric nurse
- [ ] Licensed practical nurse
- [ ] Special care aide
- [ ] Other: ____________________________

Degrees or certificates held: ___________________________________________
- [ ] Master’s of Nursing
- [ ] Bachelor’s of Nursing
- [ ] Practical Nursing Diploma
- [ ] Continuing Care Assistant or equivalent certificate (e.g., for Special Care Aides)
- [ ] Other: ____________________________

When interpreting questionnaire results, it can be helpful to know about cultural and religious heritage. If you feel comfortable doing so, please indicate:
(a) What country you were born in: _______________________
(b) The religion or other spiritual tradition you follow: _______________________


CATERED COFFEE BREAK FOR RESEARCH

The University of Regina Health Psychology Laboratory is looking for RNs, LPNs, RPNs, and Special Care Aides who are willing to complete 4 brief questionnaires during an extra paid break today.

The questionnaires are about your approaches to cancer and dementia care. There are also some questions about your personal qualities. Your responses will be anonymous.

You must notify the nurse in charge when you take this break, so that he/she can co-ordinate relief.

Free snacks and beverages are available to thank you.

11:00 a.m. - 1:00 p.m.
LOCATION
Appendix I: Consent Form for Study II

Consent to Participate in Survey Research

Title: Developing a Questionnaire to Assess Health Professionals’ Perceptions of Patients

You are being invited to participate in a study. Before you decide whether or not to participate, please take a few moments to read the following information (continued on the reverse of this page). Please ask a member of the research team to explain any information that is not clear to you.

Principal Investigator: Paulette Hunter, M.A.
Graduate Student, University of Regina
Supervised by Dr. Thomas Hadjistavropoulos
(306) 585-4428

Co-investigator: Thomas Hadjistavropoulos, Ph.D., R. D. Psych., ABBP, FCAHS
Research Associate, Regina Qu’Appelle Health Region
Professor of Psychology,
Centre on Aging and Health
University of Regina
(306) 585-4428

Sponsor: The Canadian Institutes of Health Research (CIHR) and the Saskatchewan Health Research Fund (SHRF) provided support for this project

What is the purpose of the study?
A questionnaire is being developed as part of a continuing effort to understand health professionals’ perceptions of long-term care residents with and without dementia. This study is being conducted to help improve the questionnaire. During this study, the new questionnaire will be administered, along with three other brief questionnaires. The three other questionnaires will be used to study the properties of the newly developed questionnaire. The improved version of the questionnaire will be used in future studies that will help us develop a better understanding of caregiver perceptions of patients with and without dementia.

What will I be asked to do?
You are being asked to respond to four brief questionnaires during regular work hours. This will take approximately 15-30 minutes. After you complete the questionnaires, you may return them directly to the researcher. If you would like extra time, you may request a stamped addressed envelope so that you can mail the questionnaires in at a later date.

Who is conducting the study?
This study is being conducted by Paulette Hunter who is a researcher with the University of Regina. This research is being supervised by Thomas Hadjistavropoulos, Ph.D., R. D. Psych., ABBP, FCAHS, Director of the Centre on Aging and Health at the University of Regina. If you have any questions about this study, you may contact Paulette at (306) 585-4428 in the Health Psychology Laboratory at the University of Regina.
Will my responses be confidential?
Your responses will be stored securely in the Health Psychology Laboratory at the University of Regina. No one except the researchers and other employees and volunteers of the Health Psychology Laboratory will have access to this data. Your responses will be rendered anonymous after we receive your questionnaire.

Are there any risks, costs, or benefits related to my participation?
There are no known risks from participation in this study. The only cost to you is the time required to complete the questionnaire (about 15-30 minutes). In return, you are being offered a catered coffee break while you complete the questionnaire during your shift. It is hoped that the results from these interviews will help us develop a questionnaire that can be used to better understand some of the experiences of health professionals who work in long-term care.

Will I get a copy of the study results?
We will be conducting two other related studies in the same 12-month period. You are not required to participate in the other studies. When all three studies end, those who participated in any of the studies will be invited to attend a paid, catered coffee break. During this session, all details of each study, including findings, will be presented. Written copies of the study results will also be available on request.

Am I required to participate?
Your involvement in this study is completely voluntary and you may decline participation or withdraw at any time without affecting your current or future work situation.

Who can I contact if I have any concerns about my rights as a research volunteer?
This study was approved by the Research Ethics Boards of the Regina Qu'Appelle Health Region and the University of Regina. This process ensures that the study applies current standards of good research and helps to protect the rights of research volunteers. If you have any additional questions about your rights as a research participant, or if you would like to discuss your participation in this study with someone other than the researcher(s) listed on the previous page, please contact the Chairperson of the Regina Qu'Appelle Health Region Research Ethics Board, Dr. Elan Paluck, at (306) 766-5451, or contact the Chair of the University of Regina Research Ethics Board at (306) 585-4775.

Consent Statement
I have read the above information and I understand that if I wish to, I may contact the researcher to ask questions before I agree to participate. I agree to complete this questionnaire knowing that it is voluntary and that I may choose to end my participation at any time without affecting my current or future employment status. I understand that my responses to this survey will be kept confidential. I have retained a copy of this consent form for my records.

<table>
<thead>
<tr>
<th>Participant name (print)</th>
<th>Signature of Participant</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
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<table>
<thead>
<tr>
<th>Signature of Researcher</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

Please keep one copy of this consent form for your own records (e.g., in case you have questions at a later date).
Appendix J: Personhood in Dementia Questionnaire

**Instructions:** Consider how true each statement is, and choose the rating that best applies. Remember that your response can only be used if you mark **one and only one** scoring circle per item.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree strongly</th>
<th>Disagree quite a bit</th>
<th>Disagree Slightly</th>
<th>Neither agree nor disagree</th>
<th>Agree slightly</th>
<th>Agree quite a bit</th>
<th>Agree strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Residents with dementia have a sense of purpose.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>2. Most residents with dementia are still capable of making some informed choices about their lives.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>3. Residents with dementia have a basic right to make any choices they can about their care.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>4. Residents with very advanced dementia are so low-functioning that they are no longer persons. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>5. Residents with end-stage dementia can no longer contribute to the world in any meaningful way. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>6. Residents with dementia contribute to a sense of community within our long-term care facility.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>7. All residents with dementia should be treated with respect.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>8. Residents with advanced dementia are no longer true participants in life; instead, they watch from the sidelines. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>9. It is possible for residents with dementia to connect with each other in meaningful ways.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>10. Residents with dementia want to socialize with the people around them.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
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<td></td>
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</tbody>
</table>
**Instructions:** Consider how true each statement is, and choose the rating that best applies.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree extremely</th>
<th>Disagree quite a bit</th>
<th>Disagree Slightly</th>
<th>Neither agree nor disagree</th>
<th>Agree slightly</th>
<th>Agree quite a bit</th>
<th>Agree extremely</th>
</tr>
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<tbody>
<tr>
<td>11. Residents with dementia can continue to play an important role in their families.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>12. Some residents with dementia have had an important role in my life.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>13. Providing stimulation such as music is very helpful for a resident with end-stage dementia.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>14. As dementia advances, residents with dementia no longer experience basic feelings such as pleasure. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>15. Residents with end-stage dementia have some awareness of what is happening around them.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<td>16. Residents with dementia who whine a lot should be isolated. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>17. The needs of residents who still have awareness of their environment should take priority over the needs of those who have less awareness. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<td>18. Residents with advanced dementia are no longer persons like you and me, because they do not think and reason logically. (R)</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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<tr>
<td>19. Residents with dementia have feelings about their experiences.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
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<tr>
<td>20. Most residents with dementia feel the same range of emotions as I do.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
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</tbody>
</table>

(R) = Reverse scored
Appendix K: Vignettes

Series A
Pain Vignettes
In this section, there are four paragraphs that describe patients living in long-term care. Please read these paragraphs carefully. To respond to the questions, indicate how you would most likely respond to this situation on a typical day. If you wish, you may explain your answer further in the “comments” section following each paragraph.
1. Mr. S. is an 83 year-old man who does not have dementia. He has chronic pain in his lower back and legs. As a result, he is very restless. He will sit for a brief period to eat a meal or watch a television program, but he is usually up and walking within a few minutes. He spends much of his day walking back and forth in his room or elsewhere on the unit. During mealtimes and group activities on the unit, this sometimes distracts and agitates some of the other residents.

Using the scale below as a guide, write a number beside each statement to indicate how likely you would be to implement each intervention in this situation:

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<tr>
<th>Definitely not</th>
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1. Suggest a prescription for anti-anxiety medication to the attending physician/nurse: __________
2. Suggest a prescription for additional pain control to the attending physician/nurse: __________
3. Provide/suggest a pain medication, such as Tylenol, as needed: __________
4. Provide/suggest an anti-anxiety medication, such as Ativan, as needed: __________
5. Engage the patient in physical activity, when you have time to do so: __________
6. Informally monitor this patient’s behaviour to help identify causes/solutions: __________
7. Provide an enjoyed activity such as music to distract the patient: __________
8. Use conversation to distract the patient from this problem, as time provides: __________
9. Suggest/request an occupational therapy assessment: __________
10. Suggest/request physiotherapy assessment/treatment: __________
11. Suggest/request assessment by a behavioural consultant: __________
12. Discuss your observations with other members of the care team: __________

☐ Other:
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

☐ Comments:
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
2. Mrs. H. is an 86 year-old woman who does not have dementia. She frequently becomes constipated. During these episodes, she continuously wrings her hands and appears distressed. She appears particularly distressed at mealtimes. This can upset other residents who are seated with her.

Using the scale below as a guide, write a number beside each statement to indicate how likely you would be to implement each intervention in this situation:

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6. Informally monitor this patient’s behaviour to help identify causes/solutions: ____
7. Provide an enjoyed activity such as music to distract the patient: ____
8. Use conversation to distract the patient from this problem, as time provides: ____
9. Suggest/request an occupational therapy assessment: ____
10. Suggest/request physiotherapy assessment/treatment: ____
11. Suggest/request assessment by a behavioural consultant: ____
12. Discuss your observations with other members of the care team: ____

☑ Other:
________________________________________________________________________________________
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________________________________________________________________________________________

☑ Comments:
________________________________________________________________________________________
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________________________________________________________________________________________
3. Mrs. C. is an 82 year-old woman who does not have dementia. She is no longer mobile and frequently experiences pressure sores as a result of her loss of mobility. When she experiences bouts of pain, she groans for much of the day, rings the call bell several times per hour, and calls out for help to staff that pass her room en route to other tasks. This can be extremely disruptive to other patients.

Using the scale below as a guide, write a number beside each statement to indicate how likely you would be to implement each intervention in this situation:

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6. Informally monitor this patient’s behaviour to help identify causes/solutions: ______
7. Provide an enjoyed activity such as music to distract the patient: ______
8. Use conversation to distract the patient from this problem, as time provides: ______
9. Suggest/request an occupational therapy assessment: ______
10. Suggest/request physiotherapy assessment/treatment: ______
11. Suggest/request assessment by a behavioural consultant: ______
12. Discuss your observations with other members of the care team: ______

☐ Other:
________________________________________________________________________
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☐ Comments:
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4. Mr. G. is an 85 year old man who does not have dementia. He has severe arthritis. He is unhappy most of the time, and it is difficult to encourage him to participate in activities on the unit. He simply repeats, “I’m not much good for anything anymore”. During mealtimes, he complains that the food is “not the same” (as at home). During personal care, he either complains of pain or complains about other staff and residents.

Using the scale below as a guide, write a number beside each statement to indicate how likely you would be to implement each intervention in this situation:

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7. Provide an enjoyed activity such as music to distract the patient: _____
8. Use conversation to distract the patient from this problem, as time provides: _____
9. Suggest/request an occupational therapy assessment: _____
10. Suggest/request physiotherapy assessment/treatment: _____
11. Suggest/request assessment by a behavioural consultant: _____
12. Discuss your observations with other members of the care team: _____

☐ Other:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

☐ Comments:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Series B
Dementia Vignettes
In this section, there are four paragraphs that describe patients living in long-term care. Please read these paragraphs carefully. To respond to the questions, indicate how you would most likely respond to this situation on a typical day. If you wish, you may explain your answer further in the “comments” section following each paragraph.
1. Mr. S. is an 83 year-old man who has been diagnosed with dementia. He has chronic pain in his lower back and legs. As a result, he is very restless. He will sit for a brief period to eat a meal or watch a television program, but he is usually up and walking within a few minutes. He spends much of his day walking back and forth in his room or elsewhere on the unit. During mealtimes and group activities on the unit, this sometimes distracts and agitates some of the other residents.

Using the scale below as a guide, write a number beside each statement to indicate how likely you would be to implement each intervention in this situation:

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3. Provide/suggest a pain medication, such as Tylenol, as needed: __________
4. Provide/suggest an anti-anxiety medication, such as Ativan, as needed: __________
5. Engage the patient in physical activity, when you have time to do so: __________
6. Informally monitor this patient’s behaviour to help identify causes/solutions: __________
7. Provide an enjoyed activity such as music to distract the patient: __________
8. Use conversation to distract the patient from this problem, as time provides: __________
9. Suggest/request an occupational therapy assessment: __________
10. Suggest/request physiotherapy assessment/treatment: __________
11. Suggest/request assessment by a behavioural consultant: __________
12. Discuss your observations with other members of the care team: __________

☐ Other:
________________________________________________________________________
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2. Mrs. H. is an 86 year-old woman who has been diagnosed with dementia. She frequently becomes constipated. During these episodes, she continuously wrings her hands and appears distressed. She appears particularly distressed at mealtimes. This can upset other residents who are seated with her.

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10. Suggest/request physiotherapy assessment/treatment: ____
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12. Discuss your observations with other members of the care team: ____

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3. Mrs. C. is an 82 year-old woman who has been diagnosed with dementia. She is no longer mobile and frequently experiences pressure sores as a result of her loss of mobility. When she experiences bouts of pain, she groans for much of the day, rings the call bell several times per hour, and calls out for help to staff that pass her room en route to other tasks. This can be extremely disruptive to other patients.

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11. Suggest/request assessment by a behavioural consultant: _____
12. Discuss your observations with other members of the care team: _____

☐ Other:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

☐ Comments:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Appendix L: Demographics Questionnaire for Study III

Age: _______

Sex: _______

Years of experience in long-term care: _______

Years of other health care experience: _______

Type of other health care experience: _______

Other degrees or certificates held: _______

Occupation:
q Special care aide
q Licensed practical nurse
q Registered psychiatric nurse
q Registered nurse
q Other: _______________________

When interpreting questionnaire results, it can be helpful to know about cultural or religious heritage. If you feel comfortable doing so, please indicate:

(a) What country you were born in: __________________________________________

(b) The religion or other spiritual tradition you follow: _________________________

Were you in a focus group or interview about dementia care at your facility in fall 2009?
  r Yes  r No

Did you complete questionnaires very similar to these at your facility in summer 2010?
  r Yes  r No
CATERED COFFEE BREAK
FOR RESEARCH

The University of Regina Health Psychology Laboratory is looking for RNs, LPNs, RPNs, and Special Care Aides who are willing to complete 5 brief questionnaires during an extra paid break today.

The questionnaires are about patient care, burnout, and job satisfaction. There are also some questions about your personal qualities. Your responses will be anonymous.

You must notify the nurse in charge when you take this break, so that he/she can co-ordinate relief.

Free snacks and beverages are available to thank you.

11:00 a.m. - 1:00 p.m.
LOCATION
Appendix N: Consent Form for Study III

Consent to Participate in Survey Research

Title: Assessing the Influence of Health Professionals’ Beliefs about Dementia on Patient Care Choices

You are being invited to participate in a study. Before you decide whether or not to participate, please take a few moments to read the following information (continued on the reverse of this page). Please ask a member of the research team to explain any information that is not clear to you.

Principal Investigator: Paulette Hunter, M.A.
Graduate Student, University of Regina
Supervised by Dr. Thomas Hadjistavropoulos
(306) 585-4428

Co-investigator: Thomas Hadjistavropoulos, Ph.D., R. D. Psych., ABBP, FCAHS
Research Associate, Regina Qu’Appelle Health Region
Professor of Psychology,
Centre on Aging and Health
University of Regina
(306) 585-4428

Sponsor: The Canadian Institutes of Health Research (CIHR) and the Saskatchewan Health Research Fund (SHRF) provided support for this project.

What is the purpose of the study?
The purpose of this study is to determine the nature of the relationship between health professionals’ beliefs about dementia and choices made in providing care to long-term care residents with dementia. The way workplace satisfaction and burnout levels affect beliefs and choices will also be examined.

What will I be asked to do?
You are being asked to respond to five brief questionnaires during regular work hours. This will take approximately 20 minutes. After you complete the questionnaires, you may return them to the person coordinating the study at your facility. If you would like extra time, you may request a stamped addressed envelope so that you can mail the questionnaires in at a later date.

Who is conducting the study?
This study is being conducted by Paulette Hunter, a researcher with the University of Regina. This research is being supervised by Thomas Hadjistavropoulos, Ph.D., R. D. Psych., ABBP, FCAHS, Director of the Centre on Aging and Health at the University of Regina. If you have any questions about this study, you may contact Paulette by calling the Health Psychology Laboratory at the University of Regina at (306) 585-4428.

Will my responses be confidential?
Your responses will be stored securely in the Health Psychology Laboratory at the University of Regina. No one except the researchers and other employees and volunteers of the Health Psychology Laboratory will have access to this data. Your responses will be rendered anonymous after we receive your questionnaire.
Are there any risks, costs, or benefits related to my participation?
There are no known risks from participation in this study. The only cost to you is the time required to complete the questionnaire (about 20 minutes). In return, you are being offered a catered coffee break while you complete the questionnaire during your shift. It is hoped that the results from these interviews will help us develop a questionnaire that can be used to better understand some of the experiences of health professionals who work in long-term care.

Will I get a copy of the study results?
We will be conducting two other related studies in the same 12-month period. You are not required to participate in the other studies. When all three studies end, those who participated in any of the studies will be invited to attend a paid, catered coffee break. During this session, all details of each study, including findings, will be presented. Written copies of the study results will also be available on request.

Am I required to participate?
Your involvement in this study is completely voluntary and you may decline participation or withdraw at any time without affecting your current or future work situation.

Who can I contact if I have any concerns about my rights as a research volunteer?
This study was approved by the Research Ethics Boards of the Regina Qu’Appelle Health Region and the University of Regina. This process ensures that the study applies current standards of good research and helps to protect the rights of research volunteers. If you have any additional questions about your rights as a research participant, or if you would like to discuss your participation in this study with someone other than the researcher(s) listed on the previous page, please contact the Chairperson of the Regina Qu’Appelle Health Region Research Ethics Board, Dr. Elan Paluck, at (306) 766-5451, or contact the Chair of the University of Regina Research Ethics Board at (306) 585-4775.

Consent Statement
I have read the above information and I understand that if I wish to, I may contact the researcher to ask questions before I agree to participate. I agree to complete this questionnaire knowing that it is voluntary and that I may choose to end my participation at any time without affecting my current or future employment status. I understand that my responses to this survey will be kept confidential. I have retained a copy of this consent form for my records.

___________________________
Participant name (print)
___________________________
Signature of Participant
___________________________
Date

___________________________
Signature of Researcher
___________________________
Date

Please keep one copy of this consent form for your own records (e.g., in case you have questions at a later date).