

2014-09-29

Engaging at a Garden Vignette: The Effect on Neuropsychiatric Behaviour in Moderate to Severe Dementia

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Marcy-Edwards, D. (2014). Engaging at a Garden Vignette: The Effect on Neuropsychiatric Behaviour in Moderate to Severe Dementia (Doctoral thesis, University of Calgary, Calgary, Canada). Retrieved from <https://prism.ucalgary.ca>. doi:10.11575/PRISM/25890

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Engaging at a Garden Vignette: The Effect on Neuropsychiatric Behaviour in Moderate to
Severe Dementia

by

Donna Lee Marcy-Edwards

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE
DEGREE OF DOCTOR OF PHILOSOPHY

INTERDISCIPLINARY GRADUATE PROGRAM

CALGARY, ALBERTA

September, 2014

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Abstract

Neuropsychiatric behaviour is common in all those with dementia (1). Approaches to behaviour management have been both pharmacologic and nonpharmacologic. This study explored a nonpharmacologic intervention designed to reflect the understanding of behaviour as guided by: Need-driven Dementia-compromised Behaviour, Self-determination, Biophilia and Attention Restoration Theories. It was hypothesized that engaging at a garden vignette would reduce both neuropsychiatric behaviour and psychoactive medication given. A quasi-experimental within-subject repeated measures design was used. The five-phase design included baseline and two-week intervention and washout phases that were repeated. The study was set in a long-term care facility specializing in ‘difficult to manage’ behaviour. Participant admission criteria were limited to proxy consent, and moderate to severe dementia severity with no pain limitations. The garden vignettes included all materials required to ‘garden’ and create a feeling of a ‘garden’. Each vignette was easily accessed, centrally located, open to self-determined visits and available twenty-four hours per day during the intervention phases. The Mini-Mental State Exam and the Geriatric Dementia Scale were used to determine dementia severity. Measurement of neuropsychiatric behaviour was completed during the last week of each phase using the Neuropsychiatric Inventory –Nursing Home (NPI-NH), Cornell Scale for Depression in Dementia (CSDD), Single Question Depression Test (SQDT), Apathy Inventory (AI) and the Ryden Aggression Scale 2 (modified)(RAS2). Chart review recorded psychoactive PRN medication use. Activity at the garden vignette was video recorded twenty-four hours per day, seven days per week for the two weeks of each intervention phase. Significant neuropsychiatric behaviour changes were primarily between baseline and all other phases for the NPI-NH, NPI-NH-OD, CSDD and the RAS2. Greater neuropsychiatric behaviour and caregiver distress at

baseline was associated with spending more time at the vignette. Spending significantly more time at the vignette in phase 2 was associated with spending more time in phase 4. Removal of the vignette created greater neuropsychiatric behaviour and caregiver distress in phase 3. A greater level of depression in phase 4 was associated with spending more time at the vignette and being self-determined was associated with less depression. There was no evidence of effect on apathy, self-assessed depression or psychoactive PRN medication administration.

Acknowledgements

I would like to express my sincere gratitude to all those who participated in the thesis process with me. Dr. Ron Wardell, my supervisor, who while experiencing extreme intrusions into his retirement, sweltering in the shade of Saguaro cactus, spent numerous hours reading and rereading, questioning and clarifying. His patience and calm demeanour are a testament to the sage that he is. Special thanks also to the members of my committee Drs. Nancy Grant, David Hogan and Colleen Maxwell, for their willingness to engage with me in this developmental learning process. To Dr. Tak Fung the dedicated long-suffering statistician who consumed numerous pots of tea as he selflessly helped me ‘understand’ statistics. To Dr. Luz Palacios-Derflinger whose emergency statistical consultations were gratefully appreciated. To Dr. Sheila Evans and Judy Hanson who spent hours patiently watching videos, marveling with me at the exposure of hidden abilities and talents in those with moderate to severe dementia during their interactions at the garden vignette.

A special thank you is extended to all those who supported the actual research process. Thank-you to the Bethany Care Society who agreed to offer a clinical environment in which to conduct the research; to the Unit Manager, Jennifer Simon and Educator Ann Warnock-Matheron who courageously supported the research process; to all unit staff members who spent hours gathering consent, completing assessments and bringing residents to engage with the vignette; and especially to the residents and their families who participated in the research process, often with a hope that we might learn more about living with dementia.

Thank you also to the Canadian Nurses Foundation Dr. Ann Beckingham Scholarship and the Alberta Registered Nurses Educational Trust Scholarship for their financial support. Without

these very important groups of supportive individuals none of this research could have been completed.

Finally, to my ever supportive and tolerant family who cheered me on when I was down, listened unwaveringly when I was excited and who by their mere presence reminded me everyday of how fortunate I am to have them in my life.

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List of Symbols, Abbreviations and Nomenclature

Symbol	Definition
AI	Apathy Inventory
CSDD	Cornell Scale for Depression in Dementia
FAST	Functional Assessment and Staging Tool
GDS	Global Deterioration Scale
MMSE	Mini Mental State Exam
MOET	Modified Observation of Engagement Tool
NPI-NH	Neuropsychiatric Inventory- Nursing Home
NPI-NH-OD	Neuropsychiatric Inventory-Nursing Home Occupational Distress
PRN	Pro re nata, meaning medication given as needed [determined necessary by nursing staff/by nurse is how you describe this on p.36?] and Latin for ‘as the circumstances arise’ on p.164
RAS2 (modified)	Ryden Aggression Scale 2 (modified)
SQDT	Single Question Depression Test

Chapter One: **Introduction**

As our population ages so the number of individuals affected by dementia increases. As a clinical nurse specialist in gerontology one of the greatest challenges I face is the management of behavioural and psychological symptoms arising from changes related to dementia. From mood disorders to psychotic symptoms, aggression or impulsivity, 80% of individuals diagnosed with dementia and 50% of those diagnosed with mild cognitive impairment will express one or more of such neuropsychiatric symptoms (1). There are currently two distinct recommended approaches to symptom management: pharmaceutical and nonpharmaceutical. Budget cuts, reduced staff ratios and the replacement of professional staff with less qualified workers has led to the favouring of pharmaceutical prescription (2-4). Research on psychoactive medication use to manage behaviour has identified modest benefit but at risk of a potential for severe adverse effects from cerebrovascular events to extrapyramidal symptoms (5, 6). Nonpharmaceutical interventions while devoid of serious side effects have also produced only modest benefits with a litany of confounders to analyzing the impact (7-9). Many nonpharmaceutical interventions have been described but few have been subject to the rigors of research evaluation and few have included people with moderate to severe dementia. The intervention of gardening is known to offer pleasurable, physical and social benefit to individuals with dementia (10). What was unknown was whether a garden vignette located within a dementia care unit could attract the attention of residents, facilitate engagement in gardening activities and provide measurable benefit to individuals in individuals with moderate to severe dementia.

The intervention described in this thesis was applied in a quasi-experimental, within-subjects, repeated measures design to determine the effect of interaction at a garden vignette on both neuropsychiatric behaviour and psychoactive pro re nata (PRN or as determined necessary

by the nurse) use in individuals with moderate to severe dementia living in a long-term care setting. The five 2-week phases included baseline, insertion and removal of the vignette, and a repeat of the insertion and removal phases. Twenty-four hours per day video recording of the vignette site during the two intervention phases provided interaction data. To reflect 'real' care unit experiences, interaction with the vignette was not prescribed and direct caregivers were the primary assessors of behaviour. Engagement with the vignette was open to curiosity and exploration, dependent on self-determined behaviour or mediated by others as the occasion arose. Staff and visitors were not subjected to a formalized gardening protocol nor taught the process of gardening.

Resources, both financial and human, limited the context for the study to a single site but included two nursing units that shared common management, similar staffing patterns and similar dementia populations. The sample specifically included those with known expressions of neuropsychiatric behaviour, difficult to manage behaviours and moderate to severe dementia. The degree of participant cognitive impairment dictated a greater dependence on third-party assessment tools, but the inclusion of participant response to a single question depression test and participant behaviour captured in video recordings offer a valid and reliable means of understanding vignette interactions and give participant voice to the study.

The information in this thesis is presented in six chapters. Chapter One briefly outlines the importance of the topic and the research hypotheses that arose from not knowing the potential for a garden vignette to affect behaviour, and offers a brief outline to navigate the document. Chapter Two reviews historical, current, developing, and theoretical understandings of dementia, related neuropsychiatric behaviour and interventions to manage that behaviour. Philosophical concepts from Nursing (Need-Driven Dementia-Compromised Behaviour Theory),

Environmental Design (Attention Restoration Theory and Biophilia) and Behavioural Psychology (Self-determination Theory) are presented as the foundational framework for development of the intervention, creation of the hypotheses and methods of evaluation. Chapter Three describes the research process including ethics approval, sample selection, instruments, procedures, and data analyses. Chapters Four and Five describe and summarize the statistical analyses and the significant findings from the measures of neuropsychiatric behaviour (Chapter Four) and the video observations (Chapter Five). Chapter Six, the final chapter, analyzes and interprets the findings in relation to the hypotheses, and their congruence or divergence from the literature. Factors affecting the assessment of neuropsychiatric behaviour were noteworthy and are addressed separately from the discussion of confounding factors, limitations, strengths, implications for practice, and directions for future research.

Chapter Two: **Review of the Literature**

2.1 Background to the Study

Dementia refers not to a single disease, but to a clinical syndrome typified by a cluster of signs and symptoms. Memory difficulties, language disturbances, difficulty learning, psychological and psychiatric changes, altered social behaviour and impairments in activities of daily living are characteristics of the clinical syndrome (11, 12). Dementia subtypes described by Burns include Alzheimer disease (~ 50% of cases), vascular dementia (~ 25%), mixed Alzheimer and vascular dementia (may be included in either of the previous two categories), Lewy body dementia (~ 15%). Frontotemporal, subcortical (e.g., Parkinson's disease dementia), focal dementias (e.g., Progressive aphasia), normal pressure hydrocephalus (potentially reversible dementia) and dementia resulting from intracranial lesions constitute the remaining 5% of dementia cases (11). Current Canadian dementia subtype statistics quantify only Alzheimer disease and vascular dementia at 63% and 20% respectively. (13) Henceforth this group will be referred to singly as 'dementia'. In Canada, dementia currently affects 500,000 individuals, and within the next 25 years the number is predicted to be between 1-1.3 million (13). By 2038 the annual cost of dementia care is predicted to be 872 billion dollars (13). The prevalence of severe cognitive impairment in those living in nursing homes in Canada in 2011 was 60% (14). This rate is seriously affected by the availability of long-term care beds and by changes in health care system beliefs. Current care models shift the care for dementia patients from long-term care to community but a predicted shortfall of 157,461 long-term care beds by 2038 remains (13). The 2007 Dementia UK Report (15) recorded the prevalence of dementia in UK nursing homes at 72%-74%. Increasing numbers of individuals experiencing dementia concentrated in care centres creates increasing challenges to providing care.

2.1.1 Challenging Behaviours

Disruptive or challenging behaviours in clients experiencing dementia are caregivers' greatest challenges (16). At some time during the course of their illness up to 80% of individuals experiencing dementia will demonstrate challenging behaviours such as impaired socialization, hitting, shouting, throwing, spitting, biting, continuous motion, apathy, and/or sleep disturbance (1) these will hence forth be referred to as 'neuropsychiatric' symptoms. Care-giving staff in long-term care report managing more challenging behaviours than in the past (17). While disease processes are a major factor in the development of these behaviours (18), Stokes (19) suggested that understanding the aetiology of 'challenging behaviours' should include consideration of not only biogenic but psychogenic and environmental factors. It is the complex environmental contributors to the development of neuropsychiatric behaviours that are the focus of this research.

Caregivers as part of the environmental context may contribute to the development of neuropsychiatric behaviours. Significant reductions in Registered Nurse staffing, increasing numbers of direct care staff with limited educational preparation (2), "astounding nursing assistant turnover rates, heavy workloads, a dwindling labour supply of low income workers, limited recognition of the important nature of the work and stigma associated with working in a nursing home" (p.31) (20) all impact care and resident responses to that care (21).

While these care environment descriptions are primarily American and Australian, the Canadian context is not dissimilar. To reduce budgets, professional staff have been replaced with those who are less qualified (2). Only 11 % of all Canadian RN's work in long-term care settings (22) while lower paid unregulated nursing aids and orderlies (NAO) are becoming the common care providers (23). Alberta ratios of regulated RN/LPN staff to NAO's in long-term

care are not currently available but 2009 Alberta Health Services recommendations for staffing levels call only for increases in unregulated workers and increasing LPN/RN ratios in favour of LPNs (24). The 2005 National Survey of the Work and Health of nurses identified that 47% of long-term care nurses attributed quality of care problems to inadequate staffing levels (25).

The problem however is not just inadequate staffing. Two recent Canadian studies have identified relationships between levels of staff knowledge and ability to manage neuropsychiatric behaviour in dementia as ‘problematic’, potentially resulting in increased use of pharmaceuticals (3, 4). Challenging behaviour research has also identified that level of education/knowledge of caregiver affects interpretation of challenging behaviour. Validity tests of care aide observations showed they were valid for only 3 of 11 behaviour domains tested and LPN level caregiver observations were only moderately correlated with researcher observations (26). As a result, Wood et al. (26) questioned the ability of poorly educated staff to recognize the subtle changes in behaviour that may take place. If only high levels of disturbance are recognized behaviour is allowed to escalate. This then raises the question as to the benefit of merely increasing unregulated staff levels when the complexity of the situation demands so much more than increased numbers.

Such a difficult work environment coupled with the increasing number of neuropsychiatric behaviours in residents leads to staff behaviours that foster dependency, are often paternalistic (27), mechanical or coercive (28). These staff behaviours are reflected in the use of physical or chemical restraints (16, 28, 29), frequently resulting in escalation of challenging behaviours (30). Seeking assistance with behaviour management, caregivers often turn to pharmaceuticals.

2.1.2 Pharmaceutical Management of Dementia and Dementia Behaviours

Current pharmaceutical approaches using Cholinesterase inhibitors (ChEIs) for improving and stabilizing cognitive function demonstrate modest success in early Alzheimer disease (31). Late stage effects on dementia are controversial (32-34). While it has been suggested that ChEIs are not useful in managing challenging behaviours (35) others argue the slowing of cognitive decline through the use of ChEIs effectively reduces challenging behaviours (36). Another perspective has been to suggest that it is not cognition that is improving but specifically an increase in attentional capacity that improves cognition (37). Rodda's (38) fourteen study systematic review of ChEIs in the management of neuropsychiatric behaviours found only three studies demonstrated significant effect in behavioural and psychological symptoms. In the face of these data Rodda concluded that the evidence base for the efficacy of ChEIs on neuropsychiatric behaviours was limited but in the absence of alternatives recommended their use (38). Others counter that halting symptom progression for 3 months is not clinically significant enough to warrant claims of effective management (39). Another challenge with ChEI treatment research is the loss of subjects due to adverse side effects. A Cochrane review of 10 randomized double-blind placebo controlled trials identified that a full 29% of participants in the treatment group withdrew as a result of adverse events with nausea, vomiting and diarrhea being the most significant (31).

Antipsychotics and anxiolytics have been proposed as useful for behaviour management, but Ryden et al. (29) found that the side-effects of the drugs were a serious hazard to patients with dementia and demonstrated little or no effect on challenging behaviours. Subjects receiving antipsychotics showed significantly more physical aggression than nonusers (29). Recent systematic reviews (5, 6, 40) of placebo controlled trials examining the efficacy of antipsychotics

in the management of neuropsychiatric symptoms have concluded that while both risperidone and olanzapine continued to show usefulness in the reduction of aggression and psychosis (risperidone) modest efficacy and serious adverse cerebrovascular events and extrapyramidal symptoms suggest cautious use for only those in severe distress. Gill's (41) examination of the association between antipsychotics and all-cause mortality in dementia patients found a statistically significant increase in the risk for death after thirty days of atypical antipsychotic use versus non-use in community-dwelling individuals. Findings such as these have led to recommendations of severely restricted use of antipsychotics for dementia patients with neuropsychotic behaviour in the UK (42), Canada (43) and the US (44). These recommendations have shown mixed responses to prescribing patterns. While some authors have demonstrated reduced prescription of antipsychotics for behavioural symptom control in specialist practice (45), others have found that antipsychotic prescription practices were not necessarily related to clinical indication but permissiveness about antipsychotic use in the nursing home environment (46). This variation in prescription practice is thought to reflect the debate surrounding the appropriateness of the therapy (46). Across Canada prescribing rates for antipsychotic medications in long-term care were found to vary from 23%-37% (average 30%) (47).

Pharmaceutical therapy controversy arises from challenges in understanding the efficacy of pharmaceuticals. This controversy results from serious methodological concerns. The following have been identified as methodological issues of concern: lack of definitions of clinical significance in improvement of neuropsychiatric symptoms, the habit of comparing results across studies using different measurement tools, incomplete reporting of or missing data (48), not identifying clinically useful outcomes or agreed upon outcomes (49), use and comparison of multiple scales and subscales and not defining significant findings within

subscales versus total scale scores, only reporting positive outcomes, treatment studies of short duration (31), and finally the primary research funding source being pharmaceutical companies (35). These controversies have led to uncertainty around the application of national drug safety recommendations and prescribing practices (49).

Pharmaceuticals alone cannot address the management of neuropsychiatric behaviour in Alzheimer disease and related dementias (35). While pharmaceuticals can play an important role in the management of neuropsychiatric behaviours, difficulty in understanding efficacy and changing prescribing patterns support and offer opportunity to examine nonpharmaceutical interventions in the management of neuropsychiatric behaviour.

2.1.3 Nonpharmacologic Interventions

Many systematic reviews of nonpharmaceutical intervention in the management of neuropsychiatric behaviour have been published (7-9, 50, 51). Criteria for inclusion are often varied, with thousands of studies identified but only 12 to 23 actually analyzed. All have found mixed modest effects on neuropsychiatric behaviour. Few studies have specifically chosen to examine these effects on moderate to severely demented individuals. Kverno et al. (8) found 91.2% of studies were conducted on individuals with mild to moderate cognitive impairment and only 11 of 143 studies described interventions developed for moderately to severely cognitively impaired individuals. These findings confirm the practitioner's perceived lack of evidence-based knowledge in the application of interventions for the moderate to severely impaired individual with dementia. Unfortunately mild to moderate cognitive impairment progresses and residents with late stage dementia should be afforded equable evidenced-based care and treatment.

Limited efficacy in all systematic reviews was related to small sample sizes (n=5 to 148), Hawthorne effects, and multiple tools with limited data to recommend a preference, variable

timing, extreme variability in symptom expression and multiple confounding environmental features. Together these studies highlight challenges related to availability, vulnerability, funding and complexity inherent in real-world research that explores behaviour responses to nonpharmaceutical interventions with moderate to severely demented participants (52). Recommendations for more research into hands-on therapies tailored to balance individual arousal patterns (such as might be experienced during self-determined activity at a garden vignette) have been made (8).

Non-pharmacologic interventions are many and varied. Emotion-oriented approaches, simulated presence, behavioural and environmental treatments, sensory-oriented treatments including aroma, bright light, movement, music, multi-sensory stimulation, touch, and balancing arousal therapy have all been researched with varying degrees of success (8, 53-56) (57, 58) (59)]. Behavioural and environmental treatment studies are limited. Three studies, two from Italy and one from Canada, examined changes in behaviour resulting from care strategies designed for Special Dementia Care Units. One study did not describe the actual intervention, a second examined the effects of gentle care with a reduction of auditory stimuli and the third study examined the effect of moving from areas of higher to lower density living spaces. Findings showed a reduction in behavioural disturbance with diminished psychotropic drug and restraint use but no study received a high score in the strength and quality research schema used (60-62). Activity based studies are equally limited. A systematic review of the benefits of gardening for older people (10) analyzed 14 studies from a variety of disciplines. The findings showed evidence of enjoyment and benefits to quality of life, physical ability and activeness. None had specifically examined the effect of a garden vignette on neuropsychiatric behaviour,

nor the effect of self-determined activity on that behaviour in moderate to severely demented individuals (8).

While the development of non-pharmacological interventions along with respectful, compassionate, autonomous care philosophies (63-66) is highly recommended, the efficacy and cost effectiveness (67) of these interventions is often not clearly understood (59, 68, 69). A problem is that intervention studies appear most often to be single attempts at describing an activity that is thought to affect behaviour, with little thought given to the theoretical constructs of the intervention and thus the development of knowledge. Indeed, Kolanowski (70) suggested that nursing science has few effective interventions for managing neuropsychiatric behaviours because there have been few links between intervention development and causal theory.

2.1.4 A Pilot Study

A descriptive exploratory pilot study conducted by the author and colleagues described the actions of residents with dementia during interactions at vignette sites. A vignette was defined as a designated area within the residential care setting containing clusters of objects designed to attract attention and encourage interaction/exploration. Twenty-four hours per day video recording for the 2-week intervention phases identified a statistically significant finding that residents with moderate to severe dementias were most likely to engage in activity at vignettes. It was also found that there was no statistically significant relationship between pre-dementia hobbies, interests or employment histories and time spent at vignettes or vignette chosen for activity (71). The unexpected nature of these findings has prompted the current theoretical discussion and questions proposed by this research.

2.2 Theoretical Frameworks for Understanding Dementia Behaviour Interventions

2.2.1 Need-driven Dementia Compromised Behaviour (NDB)

Links between intervention and theory have often been weak, but the Nursing metaparadigm has always included the physical environment as a contributor to health (72). Problematic to Grand Theories of Nursing is their limited understanding of environmental constructs on which intervention research may be based (72), but nursing researchers continue to seek assistance from a broad conceptual base including psychological and environmental theory. A current Nursing understanding of neuropsychiatric behaviour that includes recognition of the importance of environment in the construction of behaviour is the Need-driven Dementia-compromised Behaviour (NDB) model (73). NDB, a mid-range nursing theory, recognizes that while behavioural responses from individuals with dementia may be interpreted by caregivers as challenging, they are, given the complexity of the disease state and environment, the most integrated and meaningful response possible. NDB theory seeks to alter the caregiving environment by altering caregiver's negative perceptions of behavioural symptoms. Rather than labeling behaviours as challenging or disruptive, behaviours are conceptualized as indicating unmet need. Further, if needs are responded to appropriately, quality of life for individuals experiencing those unmet needs is meant to improve (73). Using this perspective the caregiver becomes open to multiple interpretations and interventions. The result is hopefully an environment that is less controlling and less dominated by the institutionalized responses of physical and chemical restraint.

Conceptually within NDB, behavioural symptoms are explained as resulting from complex interactions between 'proximal' and 'background' factors (73). Background factors, stable or more slowly changing, are the characteristics that predispose the individual to

neuropsychological symptoms; e.g., premorbid personality, health status, neurological and cognitive status, physical ability and psychosocial factors (70). Proximal factors are much more fluid and dynamic, including the immediate physical and social environment, and the changing physiological and psychological need states of the individual (70). Neuropsychological behavioural symptoms may be directly influenced by background factors alone or they may be mediated by the interaction of proximal and background factors. In all instances, neuropsychological behaviour is thought to be the most integrated response possible given both proximal and background factors (70).

NDB identifies ‘activities’ as proximal factors created to enrich both physical and social environments through matching an individual’s background factors (70, 74). It is here that some of the assumptions in the theory are questioned. Difficulty arises when little or no knowledge of previous interests exists or when cognitive/functional ability prohibits engagement in activities previously enjoyed. A pilot conducted by this author found that in moderate to severe dementia, the relationship between previous recreational interests, occupation and choice of activity or interaction was not significant (71). This finding, at odds with the theory, prompted a closer look at why individuals choose to interact at activity vignettes and what benefit might be gained by the interaction. These questions prompted an examination of self-determination theory, biophilic design theory and attention restoration theory to establish theoretical support for why activity at a garden vignette is not merely a residual function of pre-dementia interest and why that activity would have an effect on behaviour.

2.2.2 Self-determination Theory (SDT)

Self-determination Theory (SDT) is a “macrotheory of human motivation” (75). As such, SDT encompasses multiple issues of motivation, but its application in this study facilitates an

exploration of the potential effect of self-determined behaviour in residents with moderate to severe dementia on affect and behaviour. It was proposed that for residents experiencing dementia, offering an opportunity for self-selected activity that promotes a sense of power and control may enhance well-being and be demonstrated through changes in behaviour (63). Indeed, following an extensive review of SDT research from multiple countries Deci and Ryan (75) suggested that both competence and autonomy are universal psychological needs and that the satisfaction of these needs can predict psychological well-being. SDT enhances the nursing understanding of need-driven behaviour by truly exploring the complex relationships between proximal and background factors from a client motivational perspective. Current SDT research has shown a preference for younger, cognitively aware participants. Apart from Custer et al.'s (76) 2010 nursing home study examining the associations between need fulfillment, caring relationships and subjective assessments of well being, no previous studies applying SDT to older populations had been found. The role of self-determination in dementia remains unexplored and unknown.

The relationship between a sense of well-being and self-regulation is clearly described in SDT (77) where it is proposed that seeking out novel and challenging experiences is inherent in human nature and that the quality or type of motivation promoting those experiences is more important than the amount of motivation (75). Ryan and Deci (77) suggested that “natural inclination toward assimilation, mastery, spontaneous interest and exploration is so essential to cognitive and social development that it represents a principal source of enjoyment and vitality throughout life” (p.70). The unknowns are at what level self-determination exists within the context of dementia and dementia care settings and what does self-determination in dementia look like in residents living in long-term care settings where loss of autonomy, control and

restraint are the norm. If, as proposed in SDT, predisposition to exploration and spontaneous interest is more than a biological endowment, with social context being a catalyst for motivation and personal growth (77), it becomes pertinent to explore the relationship between environmental interventions and the consequent behaviours of residents with dementia living in long-term care settings. Key to understanding these relationships are the concepts of intrinsic and extrinsic motivation.

Intrinsically motivated individuals engage in an activity because it is interestingly novel, offers an opportunity for challenge and exploration and is spontaneously satisfying (78). For dementia sufferers living in institutions, an opportunity for the expression of internal motivation may be problematic. Meals, medications, and activity are all routinely scheduled. Indeed personal experience has shown that staff may even attempt regimented sleep and wake times. Under the code of 'safety', objects with a potential for interaction are either removed or glued in place. Entrances and exits are locked or closely monitored further reducing opportunity for exploration. The result is a bleak uninspiring physical environment where spontaneity and novelty create concern. Individuals who engage in internally motivated pursuits such as escape, exploring others' property and refusing to eat at scheduled times and places are labeled uncooperative, challenging and problematic (79), a testament to the concepts identified by the NDB model.

In an attempt to manage the challenging behaviours extrinsic motivations are offered. Restraint (physical or chemical), restriction (movement limited to room or nursing unit) and distraction are commonly used (80). In the cognitively intact, the use of threats and punishments creates pressure, a sense of being controlled and contributes to a loss of autonomy satisfaction (81). For clients with moderate to severe dementia the observed response may be anger, verbal

explosiveness and physical aggression. When SDT is applied to clients with dementia, the experience described above is one of *controlled motivation* where one's behaviour is a function of the external contingencies of reward or punishment (75). For those with moderate to severe dementia the basic human need of the experience of autonomy is often ignored (82), thus the social context of institution has the opportunity to limit severely, both internal and external motivation. It is the extent to which the environment fosters a sense of competence, relatedness and autonomy that supports a person's motivation to engage in a task (83) and when social environments interfere with motivational development there is a serious effect on well-being (78). Indeed Vallerand et al.'s (83) review of Self-determination Theory (SDT) research identified that environments supportive of autonomy lead to increased levels of motivation and self-determination producing greater adaptive affective, cognitive and behavioural outcomes. Thus it was proposed that providing an opportunity for self-determined activity for dementia patients would support adaptive behaviours as evidenced by a reduction in emotional outbursts, improved sleep patterns, and reduced apathy. In this context activity participation is no longer limited by the memory of past activity experiences but becomes an in-the-moment response to novelty and opportunity for exploration offered by an intervention that supports autonomy and competence.

The relationship between environment and the creation of behaviour is complex, and the SDT proposition that it is not merely the environment that matters but the extent to which the environment supports the individual in experiencing feelings of autonomy and competence (83) offers insight into engagement in activity at vignettes. Cohen-Mansfield's (84) research on 'stimulus attributes' and 'engagement supports' for activity reported that "study participants showed a preference for a work-related stimuli because these activities tapped into a past role

identity and felt familiar to the residents” (p.5). The application of SDT challenges that perspective and offers an alternative explanation for these findings. In short, participating in work-related activities such as sorting, stuffing and stamping envelopes is much more engaging, detailed and explorative than the intervention of manipulating children’s blocks, the two activities Cohen-Mansfield et al. compared (84).

From this perspective, for those with dementia and altered memory, engagement at activity vignettes may not be related to the remembering of past pleasures from the activity, but the ability of the vignette, in the moment, to offer novelty and an opportunity for exploration while fostering feelings of competence and autonomy. Carpenter et al. (85) in researching personal preference in cognitively intact adult child-parent dyads offers support for the competence and autonomy argument. Findings demonstrated that while adult children showed good overall accuracy at overall predictions of their older parent’s psychosocial preferences, they *underestimated* parent preferences for engaging in growth activities, particularly the desire to seek new experiences and to be challenged in their life. Also underestimated were preferences regarding diversionary activities, (exercise, reading and attending cultural activities) and self-dominion (autonomy). It was also found that adult children *overestimated* a parent’s desire to spend time in large groups and participate in organizations and clubs. Perhaps researchers tend to make similar under/over estimations.

Extending preference analysis to older adult caregiver-mild dementia dyads, Whitlach et al. (86) found significant difference between caregiver and care-recipient values on the autonomy subscale of the Values and Preferences Scale. Caregivers reported the following items as significantly less important than did care-recipients: ‘having time to self’, ‘coming and going as one pleases’, ‘doing things for oneself’ and ‘having something to do’. Caregivers are thus

challenged to remember their role is not merely one of ‘pill-pusher’ or stimulator of memories but one who offers the opportunity to create new experiences that are relevant to the individual.

2.2.2.1 Apathy, Self-determination Theory and Dementia

Although caregivers may desire docility in residents with dementia (87), it is only recently that ‘apathy’ has been identified as a challenging behaviour. The prevalence of apathy, a persistent “disorder of the initiation, direction and intensity of goal-directed behaviour” (88, 89) in dementia has been identified as being anywhere from 37% to 86.4% (90). Unlike depression and anxiety that have been shown to decrease across the disease trajectory, the presence of apathy has been shown to increase as the disease progressed (91). Apathy prevalence appears less common in community samples of Alzheimer disease (AD) with prevalence rates from 29% to 52.4% (90). This disparity has been explained by noting that by the time apathy becomes problematic those individuals were already in care (90). While there clearly exists for some residents a relationship between cerebral blood flow and the presence of apathy (88), van Reekum’s (90) review of the literature offers that the presence of trauma, frontal lesions, lesions of the inferior genu of the internal capsule, Lewy bodies, HIV, and multiple sclerosis also demonstrate a relationship with apathy. Older age, the presence of pre-existing depression, and increased severity of dementia have also been related to apathy in patients with AD but for each of those categories none are necessary nor sufficient conditions for the production of apathy (92). It is also noteworthy that the greatest prevalence of apathy is not found in a single diagnostic category but in the category of ‘nursing home residents’ where fully 84.1% of 69 residents were identified as apathetic when assessed using the Neuropsychiatric Inventory (26). van Reekum (90) suggested that both severity of illness and the context of institutionalized chronic care settings are contributing factors in these findings. Thus it is that

findings from apathy research and the propositions of SDT lead to the consideration that non-engaging environments (77) in long-term care centres may contribute to apathy. The argument in support of this statement arises from differing understandings of ‘need’.

In the Need-driven Dementia-Compromised Behaviour model the concept of need is very generally defined as an innate physiological requirement for success deeply rooted in the lifetime developmental history of the individual where neuropsychological behaviours arise as an expression of unmet need or in pursuit of a goal (73). This perspective would seem to emerge from drive theory where needs are described as “physiological deficits that disturb the organism’s quiescence and push the organism to behave in ways that were learned because they satisfied the needs and returned the organism to quiescence”(p.230) (81). Problematic with the NDB perspective is the limited understanding of need in relation to psychological drivers of behaviour such as motivation. Also of concern is NDB’s strong adherence to ‘history’ as a component in expressions and interpretations of behaviour. With memory loss an outstanding feature of dementia, the loss of history to the extent that individuals no longer recognize close family members, provides a very weak link to understanding behaviour. In offering a limited definition of need, NDB ignores the complexity of need-driven behaviour. Concern with NDB arises from the potential to create caregivers focused on physiological need with limited understanding of retained autonomy and competence needs, already problematic in long-term care settings (82). In attempting to define need I am again drawn to the explanations of SDT.

SDT acknowledges physiological need as a drive mechanism but advances thinking to include psychological processes where behaviour is not just the result of physical need satisfaction but may be a natural inclination to act by engaging in activities that are interesting (81). In other words, human behaviour does not result solely from physiological need deficit, but

may arise from an ability or inability to engage in the inherent psychological needs of engagement and the maintenance of personal coherence or competence (81) (93). Where there is no opportunity to engage in activities of self-interest and competence while other needs are being met, there may be dysfunctional or challenging behaviours expressed (81). One such behaviour may be that of apathy or as described in SDT, amotivation “a state in which people lack the intention to behave, and thus lack motivation” (p.237). Within SDT amotivation arises when individuals lack a sense of control or a sense of effectiveness. Indeed researchers have demonstrated that exposure to controlling situations is also capable of depleting energy stores (94). Thus it is proposed that for demented individuals whose cerebral blood flow is not in question living in care situations where all aspects of activity are highly controlled and self-determined activity curtailed, neuropsychiatric behaviour may result. While apathy has been described as a feature of dementia affecting some 36%-90% of dementia patients (92, 95), what is not clearly understood is the power of environment to precipitate or maintain apathy in individuals with dementia.

Together SDT and NDB assist in understanding how environments may contribute to neuropsychiatric behaviour, but the philosophical basis for understanding treatment options for managing this behaviour remain unclear. Pharmacologic treatments aspire to enhance, inhibit or replace neurochemicals (96) but the potential role of environmental activity as treatment for individuals with dementia expressing neuropsychological symptoms is less clear. What has been proposed, however, is that an environment has the capacity to be restorative. To understand how environments are restorative it is necessary to understand the concept of biophilia.

2.2.3 Biophilic Design Theory

It has been suggested by Wilson (97) that restorative environments arise as a result of biophilic design. Biophilia refers to the “inherent human inclination to affiliate with natural systems and processes, especially life and life-like features of the nonhuman environment” (98). An extensive review of biophilia research led Wilson to suggest a biophilia hypothesis (97) that proposed a genetic basis for both positive and negative human responses to nature that have evolved over time as a result of complex learning. Wilson (97) further offered that this evolutionary development has resulted in a modern human who appears to retain a biological readiness for positive responses to nature. It is proposed that as humans have moved from natural to built environments these biophilic responses can be elicited through environmental design (97).

Positive human biophilic responses are thought to have arisen from biologically prepared learning or evolution resulting from general adaptation to non-threatening natural landscapes. The premise is that we humans have evolved to like, attend to and seek out certain types of environments; that those environments act to restore or enhance recovery from stress, and indeed may even enhance high order cognitive function.

Research in the area of liking, attention and approach shows that humans are not only predisposed to liking, but attend to and readily approach natural elements that promote survival; e.g., water and food sources and spaces that offer security in a manner that is also persistent (99, 100). In modern humans Wilson’s (97) review of cross-cultural studies identified a preference for park-like landscapes with scattered trees and green vegetation, partial openness, uniform ground surfaces and water.

Wilson (97) proposed that humans have evolved to respond to natural environments in a manner that is restorative. This suggestion arose from his conceptualization of the evolutionary development of sympathetic and parasympathetic responses to events. The function of these two systems with their complex neural circuitry and neuroendocrine pathways are the preparation for and neutralization of external threats. The sympathetic system prepares humans for fight or flight, while the mediating parasympathetic system acts to reduce the negative effects of stress inducing situations (101, 102). Wilson (97) suggested that in reducing sympathetic nervous system stimulation the parasympathetic system facilitates energy restoration. From an evolutionary perspective, these restorative responses enhanced early chances for survival by promoting recovery from fatigue when adapting to a demanding situation. This early biological preparedness to respond arose from adapting to life in natural environments, but as the movement of humans from natural to built environments has occurred in a relatively short time frame, there are no biologically evolved mechanisms to respond to the built or urban environment (97). The result being that modern humans have retained a positive preference for environments that include the elements described previously.

Research supporting the restorative hypothesis has examined the affective human response to built/urban environments and natural environments in both simulated and natural contexts. Exposure to both contexts has produced the physiological responses of decreasing heart rates, blood pressure and muscle tension (103). Employing only simulations of natural landscapes through photos, slides and/or videos, researchers have also invoked positive emotions, and reduced the negative emotions of fear and aggression (104, 105).

While all physiologic response research exploring the concepts of biophilia has been conducted on cognitively intact subjects, Duggan et al.'s (106) qualitative study explored the

relationship between the outdoor environment and individuals with early to moderate dementia (MMSE scores from 15-29). The ‘voices’ of the interviewees shared that not being able to go out was associated with feelings of depression and that their enjoyment of the environment was aesthetic and social, rather than functional. The authors further state that ‘the enjoyment of being out of doors was maintained in the early and moderate stages of dementia and that going outdoors appeared to be an important contributory factor in maintaining quality of life.’ (p.196). These findings suggest that individuals with early to moderate to severe still retain the capacity to respond to biophilic environments.

Equally, the physiological research findings allow the postulation that because individuals with moderate to severe dementia retain a gross physiological capability to respond reflexively at the sympathetic and parasympathetic level, the evolutionary response relationship between environmental scenes/natural features and physiological restoration would persist. Indeed aging and novelty research exposing older adults to novel visual stimuli demonstrated that for older adults autonomic responses of skin conductance, heart rate changes and EEG brain activity while lower to all stimuli than responses of younger subjects, they did not produce habituated responses to the stimuli as quickly but the response lasted longer (107). Within the context of dementia the prevalence of autonomic neuropathy has been found to be more common in all dementia subtypes compared with controls, with some of those changes specifically linked to cholinergic dysfunction and related drug usage in Lewy body and Parkinsonian dementia (108). While older demented adult autonomic responses to a visual stimulus may be reduced, their continued existence and prolonged response supports the possibility for physiological restoration from environmental scenes/natural features. Thus it is proposed that biophilic elements incorporated into built environments housing moderate to severely demented

individuals should have an impact on feelings of restoration as evidenced by reduced instances of challenging behaviours such as aggression or apathy.

While Wilson (97) identified evolutionary environmental preferences, Ulrich and others (99) sought to articulate the preferential characteristics of the preferred natural landscapes. Preferred environments were found to require a moderate to high level of complexity, including elements that could be attended to and independently perceived. There needed to be structure within the complexity with a focal point or patterning present. A moderate to high level of clearly defined depth or perspective was required with curving sightlines that created a sense of something unknown in the distance. The ground surfaces needed to be relatively even or smooth to support ease of movement and the scene had to be judged as safe with little or no sense of threat. While it was found that together, the previously described properties elicited liking, the addition of water to a scene created an even stronger sense of liking. Ulrich (103) proposed that together these features create an environment that is not only universally preferred but is thought to influence recovery from stress.

2.2.4 Attention Restoration Theory (ART)

While the characteristics of natural environments are shown to play a role in restorative processes, so too is the cognitive function of attention. The role of attention in restoration has been described by Kaplan in the Attention Restoration Theory (ART) (100) which stated that continued use of direct attention reduces the capacity to attend which results in irritability, committing errors on tasks, or showing attentional fatigue (e.g., being easily distracted). Our human capacity for directed attention is restored through the distinct properties of being away, fascination, extent/coherence and compatibility (100). 'Being away' is the creation of psychological distance from our routine mental context. 'Fascination' is effortless attention

sustained when the scope of the environment is orderly. 'Extent/coherence' is the ability to support interpretation and exploration and when there is a match between the individual's inclinations and environmental demands including supports for the intended activity, 'compatibility' is said to exist (100). Links between attentional fatigue, restoration and environmental preference have been made by Purcell, Peron and Berto (109) who have shown that attentional fatigue increased preference for natural environments. Hartig and Staats (110) examined the effect of psychological states on environmental preference and showed that the greater the attentional fatigue, the greater the level of perceived restoration in response to exposure to a simulated nature environment. While these concepts were developed and understood in the world of the cognitively intact, it is not clear how they might be understood in the context of the cognitively impaired. To date a literature search has revealed a single application to those with dementia. A conference presentation by Diaz Moore (111) discussed the content analysis of an expert panel's opinions on the restorative features of restorative gardens for people with dementia. Unfortunately the opinions and responses of the people with dementia were not a part of the study.

Living with dementia is a constant struggle to maintain attention, indeed for those with Lewy body (DLB) dementia attentional dysfunction is a distinguishing neuropsychological attribute (112, 113). Directed attention (DA) is defined as the effort required to focus and support challenging mental activity. While most often under voluntary control, DA is susceptible to fatigue and uses inhibition to control distraction (114). Research in the area of attention has found that recovery from testing activity demands is slower in DLB groups as compared with normal controls and DAT subjects and that task conditions influenced not only the degree of impairment, but also the variability of attentional performance (112).

Neurophysiological changes associated with dementia also lead to a loss of executive function or the ability to carry out sequenced activities to achieve a goal (115). In dementia the simultaneous loss of directed attention and executive function results in diminished problem solving, high levels of distraction, inability to follow a plan, loss of patience and endurance, less appropriate behaviour and irritability (116, 117). Bradshaw (112) further suggested that if situational factors cause increased demand on impaired higher cortical function clinically observable changes in behaviour and functional ability would occur. In dementia, when environmental, social or psychological demands exceed ability, the result is often the expression of challenging behaviours (21, 68). Responding to the potential for harm created by challenging behaviours, caregivers and administrators create, perhaps inadvertently, sterile highly controlled environments that may not be restorative.

Cohen-Mansfield et al. (118), in their work with personal characteristics and engagement in activity in nursing homes, identified that not only does cognitive status play a role in activity engagement, but so to do levels of sensory functioning, demographic variables, medical status and physical functioning. From this body of research has come the Comprehensive Process Model of Engagement (119) in which the authors suggested that engagement is affected not only by personal characteristics but by the attributes of the stimulus and environmental characteristics. Findings such as those described in attention and engagement research offer significant support for including in the dementia sufferers environment elements that support self-determined interactions with natural elements as a means of attention restoration (119).

A garden centre is a means of applying ART in the built environment. It creates an opportunity to conceptually 'be away'. While natural settings are the preferred "away" opportunity (100) living on the 7th floor in a locked institutional unit with extreme seasonal

climate constraints limits the availability of that experience. Research with cognitively intact subjects has demonstrated that photos and videos of landscapes are capable of embodying meaning (110, 120), thus it was felt that interactions with actual plant material and soil may create authentic “away” experiences with the power to affect behaviour (121).

Using ART the creation of fascination through use of a garden centre was readily accomplished. Scented, colourful, edible plants, glossy magazines with engaging pictures, the texture and smells of soil/vermiculite, watering cans and garden tools offered an array of sensations that were not merely novel but were easily attended to, requiring minimal cognitive expenditure. The garden center expanded the environmental context from minimalist hallways and barren seating areas to a context where objects fostered links to previously experienced activity or in the absence of memory afford the opportunity to explore and create new experiences. Thus was the concept of fascination supported.

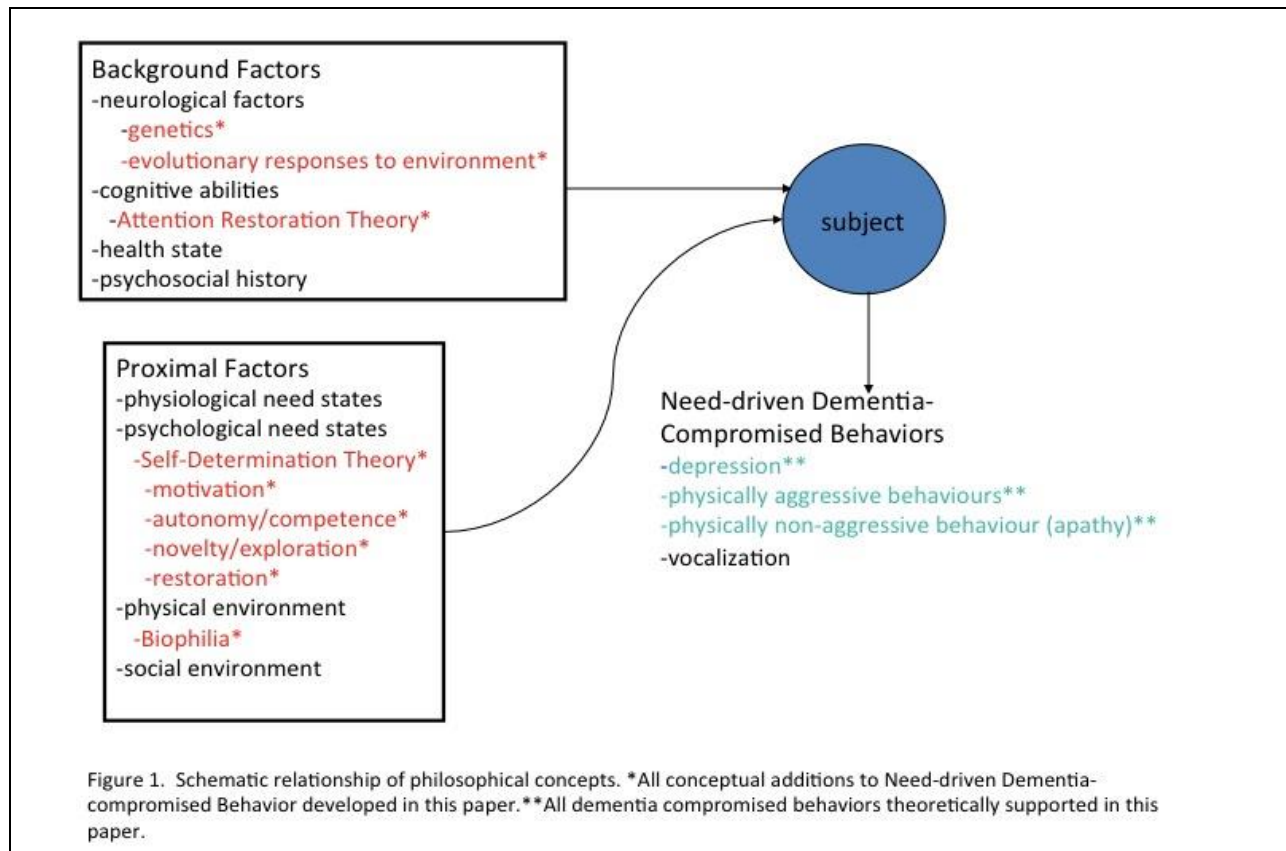
Extent/coherence in ART (100) was created by developing a garden centre offering sufficient variety of materials to sustain not only exploration but recognition and coherent interpretation of the objects and their intended use. In clustering objects for interaction, a composite of materials that support a variety of understandings about the activity of gardening was created (122). Plants on a window ledge are less engaging than the opportunity to manipulate the gamut of materials involved in the process of gardening.

Compatibility, the match between environmental supports or demands, and the individual’s inclination to engage in activity is the final concept described in ART (100) and when applied to the garden centre presented a significant challenge. In a pilot study examining activity participation in demented individuals at activity vignettes, participant interest in activities pre-dementia did not influence activity preference for the cognitively impaired (71),

and in another study familiarity was not found to be restorative or preferred in normal subjects (109). On the other hand, environmental supports for the activity and environmental constraints on action were key to understanding engagement in activity at vignette sites. Previous experience has shown staff support of the project to be a more powerful influence on activity at the vignette than intrinsic motivation in the resident.

Kaplan and Kaplan's (100) theory of attention restoration is an interpretation of environmental preference data that has evolved from the assumption that preferred environments support effective functioning and well-being. Ulrich et al. (103) added to the conceptualization of attention restoration by showing that it is not always variations in stimulation levels that account for restoration, but the content of man-made versus natural properties of the stimulus, with natural features providing greater restoration. In developing these concepts, Hartig (110) has challenged that not only must the preferential features of environments be evaluated but also the characteristics of individuals interacting within those environments must be examined to explain environmental preference. For those with moderate to severe dementia the reality of institutional living is 24 hours per day/7 days a week exposure to an unchanging built environment; regimented control of eating, sleeping, eliminating; difficulty communicating and way finding; exposure to the challenging behaviours of others and no possibility of escape. In such an environment the potential for psychological distress is high, thus exposing a need to incorporate this conceptual understanding of environments into the development of an intervention that seeks to promote restoration and reduce psychological distress.

Figure 1. Conceptual Map of Theoretical Relationships



2.3 Summary

As the number of individuals with dementia rises so too rises the number of challenging behaviours caregivers will be expected to manage. Pharmaceuticals, while appropriate for some, will not be appropriate for others and it is for those ‘others’ that alternative intervention strategies are sought. Changing caregiving environments including diminished education levels of direct care staff, heavy workloads and rapid staff turnovers also affect care responses to challenging behaviour, thus, providing further reason to seek care strategies that do not tax the caregiving system in terms of personnel and material resources.

Understanding neuropsychiatric behaviour and caregiver responses is complex and challenging. Four theoretical perspectives help inform the design, development and

understanding of an activity intervention for residents experiencing moderate to severe dementia living in a care setting. Need-driven dementia behaviour (NDB), Self-determination Theory (SDT), Biophilic Theory, and Attention Restoration Theory (ART) all contribute to understanding why neuropsychiatric behaviours are present and how this understanding influences the construction of an intervention that may reduce those behaviours.

NDB offers caregivers a means of understanding neuropsychiatric behaviour from the perspective of an expression of need but is limited by its focus on physiological need as the creator of behaviour and its reliance on memory of past-experience as a guide to activity construction. SDT enhances the understanding of need-driven behaviour by identifying that behaviour results not merely from physiological need states, but from a universal psychological need for autonomy and competence. These inherent needs are expressed by seeking out novel and challenging experiences and the action of doing so is mediated by both internal and external motivation. What is not clearly known in dementia is the level of internal motivation that exists, as apathy is a symptom of the disease process. While the presence of apathy may be attributed to vascular decline that is not the case for all who present with apathy. Thus SDT has been identified as offering insight into how external controlled motivation present in institutional caregiving settings such as restraint and restricted movement may precipitate neuropsychiatric behaviour. It is further suggested that it is the extent to which environments offer support for autonomy, competence and relatedness that supports an individual's motivation to engage in a task. The type of stimulus offered for engagement is also significant. Indeed Biophilic Design Theory assists in understanding the type of stimulus intervention that would be most supportive of engagement with the dementing population.

Biophilia is our innate human inclination to be with nature. Biophilic responses are the result of evolutionary development but human movement from natural to built environments has taken place in such a short space of time that human responses continue to reflect early evolutionary nature responses. While human responses to the environment may result from our exposure to nature, institutional caregiving environments are monotonous, controlling and in northern climates limited in their exposure to preferred natural features. These limitations in conjunction with a reduction in the ability to meet the psychological needs of autonomy and competence promote the expression of neuropsychiatric behaviour. Thus it was proposed that an environmental activity intervention could be designed to support the following features: a) biophilic design including natural elements with high levels of complexity but easily attended to and independently perceived, b) a clearly defined depth or perspective, c) moderate to high levels of safety and little or no sense of threat and d) ease of movement. It is proposed that together these features will act to reduce stress, influence restoration and as a result diminish neuropsychiatric behaviour.

Attention Restoration Theory further enhances our understanding of restorative environments by clearly defining the cognitive features of restorative environments. The distinct environmental properties of 'being away', fascination, extent-coherence and compatibility when linked with elements of nature are proposed as being capable of reducing attentional fatigue thereby reducing potential for the development of neuropsychiatric behaviour. As residents living in locked environments have no opportunity for 'being away' the offering of novel and engaging self-determined activity with natural elements seeks to create an opportunity for restoration.

With this in mind, it was proposed that a garden vignette created by using clusters of objects that reflect the process of gardening would offer an opportunity to engage in activity when a resident was personally inclined, not when institutionally programmed. This proposition is reflective of Korpela and Hartig's (120) research demonstrating that motivation and self-regulation are integral to the development of restorative environments and advances the notion that offering residents an opportunity to engage in self-determined activity at a vignette site could be restorative, resulting in fewer episodes of challenging behaviour. It was further suggested that a garden vignette would also meet the need for exploration in a constrained and limiting environment while supporting the innate human restorative response to natural environments. In a locked, long-term care setting housing individuals with moderate to severe dementia the garden vignette could act as a nonpharmaceutical intervention. While there exists theoretical and in the case of normal subjects research evidence describing behavioural change in response to biophilic environmental components, what is unknown is the impact of a garden vignette intervention on behaviour in residential subjects with moderate to severe dementia.

Chapter Three: **Methods**

This chapter is divided into the following sections: hypotheses, study design, population and sample, study setting, outcome measures, study procedures, and data analyses. Rationale for the design choice, design features and a detailed description of the intervention are included. The population and sample are described including eligibility, inclusion and exclusion criteria. The setting description includes both physical and human components that contribute to the understanding of context. A discussion of the psychometric properties of the outcome measures is followed by a detailed description of procedures related to: ethics, participant recruitment, preparation of staff, and data collection processes. A description of both proposed and post-hoc data analyses completes the chapter.

3.1 Hypotheses

The complexities uncovered by the literature review, professional practice experience and the results of a pilot study all led to the development of a study designed to evaluate the effects of resident interactions with a garden vignette on neuropsychiatric behaviours among individuals suffering with dementia living in a long-term care setting. It was hypothesized that time spent engaged with a garden vignette over a four-week period would be associated with:

1. A decrease in the frequency of challenging behaviours (e.g., impaired socialization, hitting, shouting, throwing, spitting, biting, continuous motion, apathy, sleep disturbance, depressive symptoms); and,
2. A decrease in medication used to control behaviour.

3.2 Study Design

To test the hypotheses a quasi-experimental, within-subjects, repeated measures design was used. The study was divided into five phases: 1) baseline, 2) intervention 1, 3) washout 1,

4) intervention 2, and 5) washout 2. Each intervention and washout phase was two weeks in duration. This design was chosen because: a) the study was an exploratory examination of the potential effects of the intervention on behaviour with particular interest in both intra-individual (i.e., within-subjects) and time-effect changes in behaviour (123); b) the intrinsic heterogeneity in the expression of dementia supported a within-subjects design when there are a small number of participants (124); and c) randomization was not feasible given the size, time and financial limitations of the study. A quasi-experimental repeated measures design both acknowledged and responded to the complexities of the question and the limitations of the study, while fully accepting the changeable nature of neuropsychiatric behaviours. As progression of neuropsychiatric symptoms does not occur at a uniform rate there was a need not only to repeat measures over time but to include multiple indicator variables (123, 125). The nature of the sample population, including its gender mix and range and severity of neuropsychiatric behaviours, was not reproducible in any other location in the city, thus eliminating the possibility of a multiple site design. The relative homogeneity of the sample with respect to severity of dementia (moderate to severe) and the documented presence of difficult to manage neuropsychiatric symptoms reduced concerns about lower internal consistency and reliability that may arise with a more diverse population (126).

The measures used to quantitate behaviour in the moderately to severely demented individual were of moderate validity, reliability and sensitivity to change (125). Tools assessing a single behavioural domain (Cornell Scale for Depression in Dementia (CSDD), Single Question Depression Test (SQDT), Apathy Inventory (AI), and a modified Ryden Aggression Scale 2 (RAS2)) were used in conjunction with a multi-symptom instrument (Neuropsychiatric Inventory-Nursing Home (NPI-NH)) to increase reliability and validity in measuring

neuropsychiatric behaviour outcomes (7). While neuropsychiatric symptoms are rarely chosen as the primary outcome measure in dementia studies, their importance to the delivery of quality nursing care argues that they should be assessed (127). Tools used to establish eligibility for the study were the Global Deterioration Scale/Functional Assessment Staging (GDS/FAST) (128) and the Mini-Mental State Examination (MMSE) (129). A full explanation of the psychometric properties and procedures employed for all measurement tools are discussed in later sections.

Chart review produced sociodemographic and medication use data. Baseline chart data included: date of birth, sex, diagnoses, previous occupation, and previous hobbies and interests. The small sample size limited occupation classification to four sectors: primary, secondary, service, and unknown (see Appendix A for category components). Hobbies and interests were classified into the five categories of needlecraft, gardening, sedentary activities, athletic activities, and activities outside the home (see Appendix B for category components). Previous hobbies, interests and occupations were included to support both the NDB theory construct (73, 130) that proposed a role for past experience in the creation of behaviour, and other bodies of work that suggest in moderate to severe dementia the retention of procedural memory (131) and activity-dependent neuroplasticity (132) may impact participant interest and willingness to engage in an assisted or independent manner at the garden vignette. Although the pilot study showed no correlation between occupation and previous hobbies and interests, the sample size was small and a repetition of this type of analysis could be used to corroborate pilot findings.

The second hypothesised outcome, a reduction in medication use to manage neuropsychiatric behaviour, was measured by chart review of daily psychoactive medication administration. Psychoactive medication data collection noted regularly scheduled (daily prescription) or pro re nata (PRN) (given as determined necessary by nursing staff). The

regularly scheduled cognitive enhancers such as cholinesterase inhibitors (ChEI) and N-methyl-D-aspartate-agonist (NMDA) were noted as part of the general psychoactive medication profile. While cognitive enhancers are used primarily to delay the progression of Alzheimer disease symptoms, their chemical action may have an effect on neuropsychiatric behaviour (6, 37, 133) thus their use may be a contributing factor to changes in neuropsychiatric behaviour. Their presence is only noted as a potential confounder to behaviour expression. PRN medications were the primary focus of medication management for neuropsychiatric behaviour and included: typical antipsychotics, atypical antipsychotics, antidepressants, anti-anxiety agents, nighttime sedation, mood stabilizers, and anticonvulsants (see Appendix D for a complete list of medications as approved in the proposal). Regularly scheduled and psychoactive PRN medication use data were collected for each participant across all phases of the study.

3.2.1 Description of the Intervention

Figure 2. Photograph of the Garden Vignette on Unit 2



Clinical practice, theory and a pilot study were the basis for the selection of a garden vignette as the intervention. A garden vignette offered gender and culturally neutral activity not dependent on language skills for success. The garden vignette (134) was a designated area that contained clusters of gardening and nature related objects designed to both attract attention and encourage self-determined interaction and exploration. Identical vignettes were established on each unit directly opposite each other but separated by a five-foot high wall. This formation was designed to provide similar and equal access for residents on each unit. However, as the data from both vignettes are considered as an amalgamation, the two vignette set-ups are considered and referred to as one. Positioned in a highly visible, high traffic space, the location supported ease of accessibility and increased visibility (135), reducing the cognitive work of wayfinding (attention fatigue) associated with dementia-related impaired environmental navigation skills (136). The vignette itself was also designed to support the Attention Restoration theoretical constructs of ‘being away’, ‘fascination’, ‘extent/coherence’, and ‘compatibility’. This was done by incorporating a cluster of garden-related objects with the potential to: produce a sense of being in a garden rather than an institution (being away); providing novelty through the use of bright colours, objects not normally found in locked environments (e.g., garden trowels), and unusual plant material (e.g., palm and citrus trees) (fascination); the contents of the vignette were easily understood as being related to gardening (extent/coherence); and 24 hours per day availability at one’s own choosing (compatibility).

The vignette included all objects required to accomplish the activity of gardening: a sturdy garden centre table; soil, plastic pots, garden seeds, light plastic garden tools, and a plastic watering can; scented, colourful, edible plants; glossy gardening magazines with engaging pictures; and large artificial flowers to attract attention.

To support the concept of biophilia, the garden vignette included living trees, shrubs, herbs, and flowers. A small garden umbrella, a storage trolley and small table in combination with the biophilic components were intended to create a ‘sense’ of garden. To enhance the visual prominence and potential stimulation/attention effect plant size varied from small to large (135) and included both natural and artificial flowering plants (137) (see Figure 1 for visual presentation and Appendix D for detailed lists of objects). The garden vignette became the hub for the garden activities of planting, supervised watering, manipulation of seeds and seed packets, trowels, pots, soil, clean up with a whisk broom and dust pan, or turning the pages of magazines. Light exposure for the plants was limited by the physical design of the environment, but seeds germinated and plants maintained their leaves during the intervention period. Water and nutrient needs for the plants were met either by the researcher, interested staff or resident interactions at the site.

Resident safety when manipulating objects at the vignette was always a focus of attention. The garden vignette offered the greatest number of ‘safe’ objects with which to interact. All objects available to ingestion were vetted by consultation with poison control and horticulture experts (e.g., seeds, plants, soil). Staff were consulted with regard to safety of tools, pots and the soil products for planting as well as preference for living or artificial plants. Concern over spillage of water with a potential for slipping was met with the provision of an empty watering can for use under supervision. To support vignette intervention fidelity and reduce the potential for confounding effects related to vignette changes, daily checks of the vignette contents were completed with replacements or removals as necessary (e.g., replacing magazines, refilling the dirt bin).

The garden vignette was introduced on the first Monday after completion of baseline data collection and remained in place for 14 days. The vignette was then removed for 14 days. This process was repeated once.

When the garden vignette was in place, all residents had unobstructed exposure and access, 24 hours per day. The intervention design did not mandate or control vignette interaction, but instead relied on either self-determination to be at the vignette or spontaneous interaction mediated by others (staff, family, significant others). This process was chosen as it better reflected the reality of the nursing units where activity and engagement of residents may be dependent upon the completion of required tasks such as bathing, feeding, bed making, or medication administration before time is available to stimulate residents, and the potential for participant resistance to programmed activity.

3.3 Study Population and Sample

The target population included individuals diagnosed with dementia living in long-term care settings who exhibited challenging behaviours. The sample was drawn from a population of institutionalized individuals exhibiting a high number of challenging behaviours. Participants were recruited from two special care dementia units, chosen because their specific mandate was to manage complex behaviours in the dementia population. With an increased concentration of neuropsychiatric behaviours in the sample, there was a greater opportunity to measure the effect of the garden vignette on those behaviours (7).

As there were no previous data available on the effect of a garden vignette on behaviour, it was not possible to conduct a sample size calculation. However, knowing that the study included control and intervention phases and desiring a power of 0.8 with an $\alpha = 0.05$, a two-

tailed test would require between 25 and 32 participants per group. If the proxy decision-makers of residents in the units who were candidates for the study agreed to participation, the anticipated study sample in the selected special care dementia units ranged from a minimum of 28 participants to a maximum of 49.

Eligibility criteria for the study included: a) a diagnosis of dementia; b) the presence of one or more difficult to manage behaviours; c) living in a long-term care setting and d) consent from their legal guardian to participate. Inclusion criteria were: a) moderate to severe dementia as indicated by Global Deterioration Scale/Functional Assessment Staging (GDS/FAST) (138, 139) scores of 5 to 7 and Mini Mental State Exam (MMSE) (139, 140) score of less than 20; b) residence on the unit for a minimum of four weeks; and c) a minimum of one difficult to manage behaviour such as delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviour, sleep and nighttime behaviour disorders, and appetite and eating disorders. The selection of moderate to severe dementia as the target sample arose from: a) a need for evidence-supported nursing interventions for the care of individuals with moderate to severe dementia (52, 141); b) post-pilot study awareness of the challenges inherent in managing neuropsychiatric behaviour in individuals with moderate to severe dementia; c) a dearth of evidence for nonpharmaceutical nursing management of neuropsychiatric behaviour in this population, particularly in the realm of activity as an intervention (142-144); and d) awareness of the relationship between increased expression of neuropsychiatric behaviours and dementia progression (18, 140). Use of the GDS/FAST in combination with the MMSE arose from: a) the need to accurately stage dementia severity for sample selection, b) awareness of the loss of language skill in severe dementia leading to reduced ability to respond to verbal testing (140), and c) the need to reduce

the potential for sociocultural bias inherent in psychometric descriptors and mental status testing (139). Used together it was believed that the GDS/FAST and MMSE would identify accurately individuals with moderate to severe dementia. These tools were used at baseline for categorization and sample selection purposes only. Detailed psychometric information for both measures can be found in the 3.5.1 Tests for Study Admissibility section. The four-week unit residency requirement was set to reduce the potential for behaviour exacerbation in response to a personal experience of environmental change unrelated to the intervention (145). A single exclusion criterion was the presence of intractable pain. Pain has the capacity not only to reduce interest in activity but also increase restlessness and feelings of fatigue while contributing to isolation (146), all behaviours not supportive of activity engagement at a vignette.

The pilot study (71) identified walking residents as more likely to engage in the vignette, therefore being wheelchair bound was initially proposed as an exclusory criterion. It became apparent that exclusion of the wheelchair bound from the sample would not be appropriate as many residents used the wheelchair intermittently. Wheelchairs were used to enhance mobility when gait instability with fall risk and/or limited walking endurance was present. Many residents, although capable of walking, spent part of the day in a wheelchair or wheeled Broda chair in an effort to restrain them from uninvited invasions of another resident's personal space. Therefore, use of a wheelchair was removed as an exclusion criterion.

Forty-seven residents in the two units were considered eligible to participate in the study and their guardians were approached for consent. Thirty-six guardians (77%) granted approval to participation. No potential participants were excluded from the study as a result of intractable pain. MMSE scores excluded two potential participants. Thirty-four participants (n=34) or 94% of those who were eligible and for whom consent was obtained were entered into the study. One

resident enrolled in the study died during baseline data collection in an event unrelated to the intervention study. Thirty-three participants (n=33) or 92% completed the study.

3.4 Study Setting

The setting for this study was a long-term care facility in a Western Canadian city. The facility provided around-the-clock professional care services to individuals with complex health care needs who were unable to remain at home or in a supported living environment. Within the facility, the two nursing units offering specialized care for dementia were selected as the study setting. To provide anonymity, the nursing units that participated in the study will be referred to as Unit 1 and Unit 2.

Unit 1 could accommodate 22 residents while Unit 2 housed 27. In practice, the number of beds available for occupancy on the unit varied in relation to the behaviour expressed by the current occupants of the room. Most resident rooms were shared accommodation. If a resident living in a double room demonstrated behaviour that was too unpredictable with the potential to harm a roommate, that individual became a single occupant of a double room reducing the number of potential residents. During the research period two beds were not filled because the room occupant was unable to tolerate shared accommodation, reducing the total number of potential participants to 47.

Admission to the units required a physician's diagnosis of dementia, unpredictable aggressiveness, or complex behaviour requiring two or more staff to intervene. To ensure the mandate of the unit was met, all potential admissions were reviewed and interviewed by the unit manager in consultation with a physician. Unit 1 was considered to house residents expressing more acute/problematic neuropsychiatric behaviours. The residents on Unit 2 were generally perceived by the caregiving team to be more stable with fewer or diminished challenging

behaviours. If behaviour became more easily managed, patients from Unit 1 could be transferred to Unit 2, but there were also residents who were admitted directly to Unit 2 from acute care or community settings. If behaviour escalated, residents could also be transferred from Unit 2 to Unit 1. No study participants transferred across units during the study. This steady state reduced the potential for participant behaviour change resulting from personal experience of environmental change. There were, however, two new admissions to Unit 1 and one new admission to Unit 2 during the study. New admissions were not included in the study.

The complexity of resident behaviour on the two nursing units led to higher than usual caregiver to resident ratios for a long-term care setting which may vary from 1 care aide per 4 to 15 residents depending on country and care setting (147). On day shift, Unit 1 had 1 registered nurse (RN), 2 licensed practical nurses (LPN) and 5 care aides, while Unit 2 had 1 RN, 1 LPN, and 5 care aides. On afternoon shift, Units 1 and 2 had identical staffing complements (1 RN, 1 LPN, and 5 care aides). During night shift, 1 RN was shared between the units with each unit staffed by 1 LPN and 1 care aide. A unit clerk, unit manager, social worker, and unit educator were all physically located on the unit, shared by both units and worked a day shift that overlapped with the day and evening shifts of the nursing and care aide staff. Other staffs that made periodic visits to the unit were pharmacists (daily), occupational therapists (daily), recreation therapists (daily), physiotherapists (as required), physicians (as required and for weekly conferences), dietitians (daily), and a chaplain (daily or as required). The degree of involvement with participants was dependent on the clinical role of the individual. Ancillary staff stated that time spent on the unit was dependent on workload. Dietary support and maintenance staffs appeared at various times throughout the day. Family members frequently came at mealtime to assist with the feeding of loved ones. While the two nursing units had more

direct care staff per resident than other nursing units in the institution, it is not known whether the increase in staff led to greater levels of therapeutic interaction and stimulation.

The nursing unit was divided into two separate care units. The layout of each care unit included long double corridors with sleeping rooms on both sides, centrally located shower/bathing and service rooms, and a large open dining room/sitting/activity area. Each care unit also had one smaller dining room and a small staff/quiet room with half glass walls. The nurses' station was shared, centrally located between the two units, enclosed by a four-foot high wall and overlooked the large activity/dining room. Access to the care units and the nurses' station were lock controlled. The large dining/sitting/activity room contained large round tables for eating with the perimeter lined with all manner of chairs (Broda chairs, wing-back or lounge chairs, wheelchairs, padded geriatric reclining chairs, stackable chairs, and stools). Also present in this space were wheeled trolleys used by dietary staff for the provision of snacks and meal service. One unit had a piano and the other unit had a television. The small dining room in each care unit had a television mounted on the wall, large round dining tables and an assortment of chairs from padded recliners to stacking chairs. Both large activity/dining rooms had natural lighting through large windows and overhead florescent panels in a drop ceiling. Self-determined exploration or interaction was limited to the confines of the nursing unit and the objects described above.

3.5 Measures

Measurement instruments were selected in relation to: a) their ability to identify severity of dementia for study participation; b) their appropriateness for the characteristics of the study population; c) their potential to identify behaviour change; and d) their congruency with the theoretical constructs illustrated, evaluated and/or discussed by Biophilic Design theory, Need-

Driven Dementia-compromised Behaviour (NDB) theory, Attention Restoration Theory (ART) and Self-determination Theory (SDT).

NDB theory propositions include the suggestion that neuropsychiatric behaviour may arise from unmet need and that the behaviour being expressed is the best response possible given the current cognitive state (73). While the contributions of disease pathology to the expression of neuropsychiatric behaviour are acknowledged in the theory, a link between caregiving and the expression of neuropsychiatric behaviour (73) was also proposed. NDB theory would thus support the measurement of neuropsychiatric behaviour to understand response to care interventions. In moderate to severe dementia the most commonly expressed neuropsychiatric behaviours (140) are: a) the psychomotor disorders of pacing and agitation, b) the psychobehavioural disorders of aggressiveness and inappropriate shouts, and c) the psychiatric disorders of hallucination, depression, anxiety, and delusions. The tools selected for the study reflected these patterns of behaviour.

The following tools were used as primary outcome measures of neuropsychiatric behaviour change: the Neuropsychiatric Inventory-Nursing Home (NPI-NH) (148), the Ryden Aggression Scale 2 (RAS2) (149), the Cornell Scale for Depression in Dementia (CSDD) (150), the Apathy Inventory (AI) (151), and the Single Question Depression Test (SQDT) (152). They are described in detail in the primary outcome measures section (3.5.2).

The NPI-NH was chosen for its ability to measure a wide range of neuropsychiatric disturbances that may be expressed by different dementia types and to measure caregiver distress in managing those behaviours (125). The finding that depressive syndromes increase in dementia identified the need to measure depression (153). The inclusion of both the CSDD and AI was based on the knowledge that the presence of depressive symptoms may impact the apathy

score (89) and that as dementia severity increases depression is replaced by apathy as the neuropsychiatric behaviour more commonly expressed (154). The decision to use the RAS2, a tool for the measurement of aggression, arose from the knowledge that: a) there is a high incidence of low-impact aggression in people with dementia, b) that aggression is more common in patients with dementia, c) that the experience of aggression is very subjective and underreported, and d) that aggression is a major challenge and burden to caregivers and their work (154, 155). The use of highly focused behaviour tools offered an opportunity to gather more precise and specific details about the most commonly expressed and challenging behaviours. With the exception of the SQDT, third-party respondents (i.e., the assigned caregiver for the participant) completed all the primary outcome measures tools.

Inclusion of the SQDT as a primary outcome measure was a special case. It was selected to offer a participant voice because all other tools were measures of third-party perceptions of mood and behaviour. Previous studies have shown that those with dementia are capable of accurately reporting feelings of depression. (156). The SQDT had not previously been used in populations with severe dementia but met the criteria for tools of potential use in moderate to severe dementia in that it does not demand sophisticated cognitive thinking or acting (125). The participant was asked the single question by the primary researcher on the same day other behaviour measurements were completed for that participant.

While pathophysiological change and caregiver actions contribute to the expression of neuropsychiatric behaviour, the physical environment in which those processes take place also contributes to the expressions of behaviour. The theoretical concepts of biophilia, attention fatigue and self-determination were described in the literature review as being related to the expressions of aggression, irritability, apathy, and depression. Philosophically it was important

to understand the vignette as a context for self-determined behaviour. It had been proposed that a well-designed vignette could not only attract attendance, but also instigate behaviour and support the individual's ability to engage in the behaviour without assistance (self-determined). Further it was proposed that self-determined engagement at the vignette could affect the individual's ability to relate to others and serve as a means to regulate their own behaviour (77). To understand these complex relationships participant activity at the vignette was video recorded 24 hours per day, 7 days per week for each week of the intervention phases.

Video-recorded data collection at the vignette site was chosen to reduce the challenges found with other methods. The significant deterioration of verbal cognition and expression in the dementia population renders interview techniques highly unreliable (157). Single-day-time budget data collection where activity is observed and recorded manually during short time frames throughout the working day is troubled by researcher availability. Observations conducted only during regular work hours may not be truly reflective of activity patterns observed in dementia (158, 159). Additionally there is the risk of reactive effects created by the presence of the researcher (160). Proxy interviews with family or staff offer a third-party interpretation of life in an institution, not an understanding of life as it is truly lived (161).

The Modified Observation of Engagement Tool (MOET) was used to record participant activity observed in the video recordings (see Appendix E for the tool and Appendix F for tool category descriptions). A full description of the tool can be found in the primary outcome measures section (3.5.2.6).

3.5.1 Tests for Study Admissibility

To meet the criteria for study participation and sample characteristics, the GDS/FAST and the MMSE were completed for potential participants at baseline. Awareness of 'floor

effects' in the MMSE (139) led to the inclusion of the GDS/FAST to reduce the potential for mislabelling the severity of dementia. The following descriptions offer detailed psychometric information.

3.5.1.1 Global Deterioration Scale (GDS)/Functional Assessment Staging (FAST) System

The GDS/FAST designed by Reisberg et al. (138) is a global scale used to identify clinically meaningful progressive changes in dementia most often of the Alzheimer type (see Appendix G for the GDS and Appendix H for the related FAST). In this study these tools were completed once at baseline for use in participant categorization only. The results were used in conjunction with the MMSE to confirm the degree or severity of dementia and thus admissibility to the study. The scale is based on validated clinical markers of dementia progression. Three advantages to using a global assessment have been proposed: availability to greater severity range; reduction in the potential influencing factors of language skills, education, occupation, culture, personal background, and practice effects; and, although not commonly used in this manner, to sensitivity to treatment effect (139, 162, 163). GDS (128) describes “seven clinically distinguishable global stages of dementia” (p.167) from stage 1 where individuals are free from both clinical and subjective complaints of cognitive deficit to stage 7 where continuous assistance is required for survival. FAST is used in conjunction with the GDS to further delineate functional decline in the individual. FAST stages are concordant with the GDS stages from which they were developed. The FAST scale is a hierarchical scale consisting of 16 items. Scores range from normality (FAST stage 1) to severe dementia (FAST stage 7). The stages are further subdivided into five and six sub-stages (in stages 6 and 7 respectively). No times for administration of the tools were suggested. The staging system has been used in multiple studies from correlating pathophysiological decline (164) to multi-centre studies examining the efficacy

of Alzheimer disease medications (163, 165). Interrater reliability has been reported as ranging from 0.82 (166) to 0.97 (167).

In this study both the GDS and the FAST were completed to categorize severity of dementia for inclusion in the study. GDS/FAST scores were assigned following a caregiver interview with chart verification (see Appendix J). A team of three (the researcher (RN, PhD candidate) and two research assistants (one RN master's prepared clinician and the other RN retired)) used the interview data, the chart nursing notes, occupational/physiotherapist notes, and institution assessment tool data as well as physician notes to assign a GDS/FAST score. Only GDS findings were reported as the fine-grained information from the FAST subcategories did not add to the study findings.

3.5.1.2 Mini-Mental State Exam (MMSE)

The MMSE (129) is a commonly used 30 item assessment of cognition (168). In this study it was used in conjunction with the GDS/FAST at baseline only to determine severity of dementia and thus admissibility to the study. The MMSE questions are grouped in the following 7 categories: orientation to time, orientation to place, registration of three words, attention and calculation, recall of three words, language, and visual construction (see Appendix J). The assessment can generally be administered in 10 to 15 minutes. The MMSE score is a total of the number of correct answers, with a perfect score being 30. A score of 23 or below may indicate the presence of cognitive impairment (169). A 26-year review of MMSE studies (169) comparing multiple populations found reliability alphas from 0.68-0.96; test-retest reliability kappa scores of 0.80-0.95; sensitivity scores ranging from 82-100%; and construct validity ranging from 0.70 to 0.90 when compared with other cognitive screening tests (169). Differences in reliability and validity were attributed to hospital versus community sample

populations, level of education, heterogeneity of the samples in relation to neurological or psychiatric diagnoses, and degree of cognitive impairment. Ceiling effects in mild cognitive impairment and floor effects in severe Alzheimer disease have been identified as drawbacks to using the MMSE for individuals within those disability categories (139). While other tools have been identified as more appropriate for use in severe dementia (e.g., Severe Impairment Battery (170, 171) or Clinical Evaluation of Moderate-to-Severe Dementia (KUD) (172)), the MMSE was used merely to assist in determining baseline dementia severity for inclusion in the study, not intervention effect on dementia severity. Inter-rater reliability between the two Master's prepared researchers who administered the tool was 100% agreement.

3.5.2 Primary Outcome Measures

It was proposed that interactions with a garden vignette would change neuropsychiatric behaviour and reduce psychoactive PRN medication. The primary outcome, change in neuropsychiatric behaviour, was measured by the NPI-NH, the AI, the CSDD, the RASD2, and the SQDT. The administration of psychoactive PRN medication was measured using chart review. All measurement tools and strategies are described below.

3.5.2.1 Neuropsychiatric Inventory-Nursing Home Version (NPI-NH)

The NPI-NH is a modified version of Cumming's Neuropsychiatric Inventory (NPI) (148) designed to measure a wide range of neuropsychiatric behaviours as perceived by the institutional caregiver and the impact of those behaviours on the on caregiver's work (see Appendix K for complete tool). In this study the NPI-NH was used to measure participants' neuropsychiatric behaviour pre-intervention at baseline and in response to each intervention and washout phase. Specifically the tool measures the caregiver's perception of the presence, frequency, severity, and occupational disruptiveness of twelve neuropsychiatric symptoms

(anxiety, delusions, hallucinations, agitation/aggression, depressed mood, euphoria, apathy, disinhibition, irritability, aberrant motor behaviour, nighttime behaviour, and eating changes). Frequency (F) is rated on a 4-point Likert scale. Severity (S) is rated on a 3-point Likert scale. Multiplying F x S produces a specific distinct score for each symptom. The score per symptom can range from 1 to 12. Summing the twelve F x S scores produces a total score that can range from 12 to 144. A symptom score ($F \times S \geq 4$) is considered a clinically relevant neuropsychiatric behaviour (26) but statistically meaningful change may vary according to subscale; for example, meaningful change for apathy was felt to be shown by a 'shift' of 4+ points while change in euphoria/elation would be indicated by a 'shift' of 5.13+ points (173). Occupational distress is determined by asking the caregiver to rate on a 5-point scale the experienced level of disruption caused by the behaviour identified. No estimates of administration time are present in the tool's instruction manual or on its website but others have suggested a time of 30 minutes (173).

Internal consistency reliability ranged from $\alpha = 0.67$ (126) to $\alpha = 0.88$ (148). Seventy-two hour test-retest reliability ranged from $r = 0.51$ to $r = 0.88$ (173, 174). Inter-rater reliability was 89.4-100% (174) with no trends shown as a result of different types of training. Concurrent validity compared the original NPI to the BEHAVE-AD and the Hamilton Depression Rating Scale (HDRS) where all correlations reached $p = 0.05$ (174). The NPI-NH continues to be evaluated and, while reliability may diminish with advancing dementia, the original NPI was identified by the European Consensus on Outcome Measures for Psychosocial Intervention Research in Dementia Care as the measurement tool of choice (175). Subsequent to this data collection further work with the NPI has identified the following weaknesses (176):

1. Caregiver reports may be influenced by caregiver mood, cultural beliefs, minimization of symptoms, and caregiver's level of education,

2. Limited knowledge of reliability ratings for individual dimensions,
3. Few items specific to severe or mild dementia,
4. Inability to use individual domains in a stand-alone fashion as a result of limited depth of questions in each domain (e.g., depression), and
5. Limited sensitivity to change as compared to measures incorporating clinician assessment.

The result has been revision of the NPI and the creation of the NPI-C (clinician) (176) with the addition of 78 new items, the creation of a new domain for aberrant vocalization and the separation of agitation/aggression into separate domains. The clinician-administered instrument has shown improved convergent validity between the NPI-C depression domain and the CSDD ($r = 0.61$), and the NPI-C agitation domain and the Cohen-Mansfield Agitation Inventory (CMAI) improving from ($r = 0.19$) to ($r = 0.40$) (177). Zuideman et al. (178), comparing the NPI-NH and CMAI inter-observer and test-retest reliability, concluded that the NPI-NH might be best used in individuals with moderate to severe symptoms or when effect sizes are large (change greater than 11 points). Given the context of knowledge available at the time of this study proposal and data collection, the NPI-NH was the most appropriate multi-domain measurement tool given the small sample size, the majority of participants having Alzheimer disease and the resources available to complete the assessments.

Administration of the NPI-NH posed methodological challenges in the long-term care setting. Common practise is to complete the tool once per determined measurement period. For the purposes of this study, it was believed that this would not produce data truly representative of the behaviour as expressed by the participant or as experienced by the caregivers. Having only one shift complete the NPI-NH would not offer an accurate representation of resident behaviour. Experiences of the individual and their behaviours could be extremely different given the time of

day; time-of-day-related (temporal) expressions of neuropsychiatric behaviour may or may not be present on one staff member's shift. Acknowledgement of the behaviour, severity rating and occupational distress scores would need to be filtered through groups of staff over the course of three shifts in a day. Institutional processes for recording behaviour and shift change information exchanges did not support a detailed discussion with all shifts to summarize daily behaviour. As it was unrealistic to expect a single measurement of behaviour to produce a valid and reliable assessment of behaviour, each of the three working shifts (days, evenings and nights) completed the NPI-NH for each resident during each phase. Wood et al. (26) used a similar day/evening shift data collection process using the NPI-NH when working with nurse caregivers as informants. The data from each shift were analyzed separately. A full description of tool completion is documented in the procedures section (3.6.3.2).

3.5.2.2 Cornell Scale for Depression in Dementia (CSDD)

The CSDD is a 19-item screening tool designed to differentiate between mood and cognitive symptoms (179) (see Appendix L). It has been identified by the European Consensus on Outcome Measures as the measure of choice for determining patient mood (175), and was chosen for this study because of its sensitivity to treatment effects across a wide range of depression severity and because it is mostly caregiver rated. The tool was used to examine the intervention effect on depressive symptoms across the phases of the study. The scale measures 5 characteristics of depressive behaviour: mood-related signs, behavioural disturbance, physical signs, cyclic functions, and ideational disturbance. There are 3 to 4 subcategories for each major characteristic. The caregiver is asked to recollect behaviour observed during the week prior and rate that behaviour as being: absent (0), mild to intermittent (1), severe (2), or unable to evaluate. The range of possible total score is 0-38.

In this study the institutional caregiver and researcher together reviewed the signs and symptoms as they appeared on the scale. The caregiver was reminded only to include behaviour observations from the past week to answer questions. The researcher used additional descriptors to assist in understanding the meaning of each item as allowed by the administration instructions. A score was assigned to each item (179). A second component of the CSDD is an interview with the individual. As only three participants were able to engage in the interview process, the interview portion was not done and caregiver assessments of depressive behaviours were the sole score used in analysis. Total time of administration is approximately 30 minutes (20 minutes with caregiver and 10 minutes with individual).

Scores > 10 indicate probable depression. Scores > 18 indicate definite major depression. Alexopoulos' (179) original work demonstrated an interrater reliability of $k_w = 0.67$, internal consistency of $\alpha = 0.84$ and a total CSDD score correlation of 0.83 with depressive subtypes classified by Research Diagnostic Criteria (179). CSDD reliability was similar between mild and severe dementia, indicating it can be used for either population group ($k_w = 0.63$ for the severely demented group and $k_w = 0.62$ for the less demented group) (179).

3.5.2.3 Single Question Depression Test (SQDT)

The Yale Task Force on Geriatric Assessment developed the SQDT (152, 180), wherein the individual is asked, 'Do you often feel sad or depressed?'. A response of yes is rated as presence of depression. Administration time is generally short, less than 1 minute. Criterion validity showed sensitivity of 0.69 and specificity of 0.90. Psychometric evaluation comparing the Geriatric Depression Scale (GDS) and the SQDT demonstrated high convergent validity with the GDS specificity 0.93 and sensitivity 0.54 (152). It has been noted that if a screening test

meets the time and resource demands of the practice environment, then it is more likely to be implemented (180).

In this study, the SQDT was used to ‘give voice’ to participants with moderate to severe dementia. The findings were used to compare participant response to staff evaluations of depression. The researcher conducted the SQDT with the participants.

3.5.2.4 Ryden Aggression Scale 2 (RAS2)

The Ryden Aggression Scale (149) is a 26-item Likert-type caregiver-completed scale that retrospectively measures the frequency and nature of aggression. Three subscales measure physically aggressive behaviour (PAB) (17 behaviours), verbally aggressive behaviour (VAB) (4 behaviours) and sexually aggressive behaviours (SAB) (5 behaviours). The respondent notes the behaviour and the frequency with which it occurs during a shift on a log sheet. The aggression score is calculated by summing the number of documented aggressive behaviours in a 24-hour period. An accompanying description sheet allows for documentation of times, location, events preceding each incident of aggression and caregiver response to the behaviour.

For this study, the measurement of aggression was suggested as a means of understanding the restorative aspect of the garden vignette. It was proposed that if the garden centre offered an opportunity for self-determination and/or a restorative effect, levels of aggression (i.e., the number of aggressive incidents) would diminish. Use of the RAS2 did not however prove to be successful. The daily checklist for the identification of behaviours expressed, the details required by the description sheet and the number of other behaviours being measured became burdensome to staff. Therefore, RAS2 data collection was changed. The description of behaviour sheet was removed and only the checklist of aggressive behaviours observed per shift was retained (see Appendix M). To increase compliance in completing the RAS2 checklist, the

list was placed in the chart right next to the daily caregiving checklist. These data were gathered for five days during the measurement week in each phase (see outcome measures procedures in section 3.6.3.2) and the total number of aggressive incidents were calculated for each day then summed for the week. The weekly summed data were used in statistical analyses to identify change. Because of the reduction of tool data to the number of aggressive behaviours per day, the reliability and validity data available for the RAS2 do not apply to its use in this study.

3.5.2.5 Apathy Inventory (AI)

Developed by Robert (151), the Apathy Inventory (AI) assesses the emotional, behavioural and cognitive aspects of apathy and was designed to measure the behaviours presented by moderate to severely demented residents who received care from others. It was used in this study to increase the reliability and validity of the apathy findings by the more global NPI-NH (127). The clinician version using third-party interpretation of behaviour and designed for use in institutional settings was chosen (see Appendix N for complete tool). The care aide, who was the primary caregiver in this long-term care setting, was asked to complete the tool. The frequency and severity of emotional blunting, lack of initiative and lack of interest was assessed. A score > 2 in any of the dimensions was considered clinically significant and an indicator of the presence of apathy. Internal consistency using Cronbach's alpha coefficient was $\alpha = 0.84$. Strong interrater correlations (Kappa = 0.99) and test-retest reliability scores (Kappa = 0.99 for all categories) support the use of this tool (151). The authors also offer that the tool is useful in measuring change occurring over specific time frames (151). No administration time was given.

The AI proved problematic for care aides unused to not only identifying apathy as a symptom but also quantifying that behaviour. As a result, the researcher added the tool author's

descriptions of behaviour to the scoring sheet to clarify what was being asked without changing the intent or purpose of the score (see Appendix N). It was the care aides' intimate knowledge of the residents' expressions of behaviour and responses to social interactions, care and treatments that made them the primary and most available source for behavioural data collection.

3.5.2.6 Modified Observation of Engagement Tool (MOET)

Video recording offered the opportunity to understand intervention effect as related to the degree of engagement in the activity. A tool to record the amount and degree of engagement was required. The Observational Measurement of Engagement (OME) tool designed by Cohen-Mansfield et al. (119) and used for researcher-controlled exposure to stimuli was originally proposed for use. It was found, however, that the fine-grained detail and participant interaction categories used in the OME were not completely appropriate for this study and some modifications were made to make it more useful in the context. Appendix E contains the complete tool and Appendix F contains the detailed description of the categories listed in the tool.

The original OME measured five dimensions of engagement: rate of refusal, duration, attention, attitude, and activity. The self-determined nature of the study intervention did not support a rate of refusal of stimuli category, but a refusal to engage (yes/no) category was maintained for when an individual was brought to the vignette by another and refused to participate. To understand self-determined or mediated activity, the new categories of self-determined arrival (i.e., arrives at the vignette by own volition) and brought by others were created. Leaving the vignette was documented in the following categories: left by self, other leaves resident stays, other and resident leave together, and removed by other. Duration was the amount of time in seconds spent by the participant at the vignette.

Level of attention was also modified from the original OME. To determine the ability of the vignette to initially attract resident attention, a ‘purposeful’ category was created, indicating the participant was intentionally coming to the vignette. The categories of somewhat or very attentive were removed as they were found to be too susceptible to rater interpretation. Attentiveness became a measure of the use of senses (i.e., sight, touch, taste, smell); not attending, one, two, or three senses. Any combination of senses could be noted and recorded. These categories were found to be reliable with interrater agreement rising to 100% agreement versus 50% to 75% with the previous attentiveness categories when independent recordings were compared. The ‘time spent at the vignette’ category also offered insight into the ability of the vignette to retain attention and/or the ability of the visitor to attend the vignette.

The attitude category in the original OME was deleted, because it was not possible to determine attitude from distant camera vision and without actual interaction with the participant. For activity, the original OME subcategories were altered to better reflect this study’s engagement activities, including: touching, holding, manipulating, being disruptive, and inappropriate manipulation (Appendix F presents a full description of measurement dimensions). The modified tool also included lists of the objects on the vignette and observers notation of the objects used in interaction. Noting the objects of interactions assisted in identifying the type of object or activity that drew or retained participant attention and whether it was the objects that supported the concept of biophilia (e.g., plants, flowers, trees) that attracted their attention or inanimate objects (e.g., flower pots, trowels, magazines). The addition of the category ‘wheelchair noted whether or not participants were wheelchair bound and created data related to physical accessibility of the vignette.

A final change from the original OME was the scoring dimension. A numeric score was not calculated in any of the categories. The data in the modified tool are scored as binary (i.e., observed or not observed). When behaviour was observed, a check mark was placed in the corresponding box (Appendix E contains the complete tool). The modifications to the OME tool and creation of the MOET were responsive to the needs of the study; the video data available and the ability of the tool to maintain interrater reliability; therefore the test statistics for the original OME tool are not reported.

During use of the MOET a single challenge arose when video footage did not facilitate the clear determination of the activity of sleep. The inability to conclusively distinguish between whether eyes were closed, downcast, or ‘just resting’ limited the observers’ capacity to be certain the participant was asleep. This resulted in the conclusion that the individual was just ‘not attentive’. The result may be the inaccurate classification of sleeping individuals as merely inattentive, but in analysis, both are considered low activity levels at the vignette.

3.6 Study Procedures

3.6.1 Ethics Approval

The Institutional Ethics Review Board of the University of Calgary granted ethics approval (see Appendix O). Proxy, registered caregiver and general caregiver consent to participate forms can be found in Appendices P through R. The research site required a separate consent to access the chart for chart review (see Appendix S). Signage drawing attention to the video cameras and the recording process was required by the Ethics Board and can be found in Appendix T.

Thirty-two staff signed consent for participation forms. The consenting staff included all levels of caregiver and ancillary staff as described in 3.4 Study Setting. Non-consenting staff

members were not asked to complete any of the measurement tools. Signage on the entry door to the large dining/activity room where the vignette was located and at the vignette itself offered staff who did not wish to be video recorded the opportunity not to come or bring residents to the vignette, or alternately contact the researcher about having their features removed from the video. No one contacted the researcher.

3.6.2 Participant Recruitment and Sample

Using a convenience sample influenced both recruitment and sampling processes. Formalized guardianship, an institutional admission criterion for both units, afforded clear identification of legal guardians to approach for proxy consent. All guardians responsible for dependent adults on nursing units 1 and 2 were approached for consent to participate in the study. In accordance with the institution's privacy policy, consent packages were sent by the institution's business office. Documents provided by the researcher included: letter of introduction; surrogate consent form; separate consent form for access to medical records as required by the institution's Privacy Commissioner; and a stamped and addressed return envelope. Two weeks after mailing, if no response had been received, a phone call from the unit manager, clerk or educator was made to the guardian. Unit staff communicated to the researcher that a number of follow-up calls revealed guardians had either not received the documents or had assumed them to be receipts for bill payments and did not attend to them. In these cases, a second letter was sent after ensuring the address was correct.

While an in-person information session with guardians had originally been proposed to enhance recruitment, the unit manager did not believe that it would draw many attendees, as older guardians would be reluctant to come. A second strategy of approaching guardians when they were visiting the units was initiated. The unit manager, clerk or educator facilitated most of

these connections. When guardians had questions that staff could not answer, they were directed to the researcher or research assistants. The two research assistants were both Registered Nurses (one prepared at the Master of Nursing level). The concerns most commonly expressed to the researcher were related to potential benefits for their loved one and/or the potential that participation would increase agitation. Only one guardian phoned the researcher directly to refuse participation, indicating their perception that benefit for their dependent adult was unlikely (this person did die near the start of the study).

3.6.3 Data Collection Processes

3.6.3.1 Preparation of Staff

In consultation with the unit manager and educator, a series of information sessions were designed to introduce the research project to unit staff. The unit manager and educator required that all staff attend the sessions. The information sessions took place in the small resident dining room on Unit 1.

Information sessions included a statement of the research question, reasons for asking the question, a brief explanation of the theoretical reasoning behind the garden vignette design, function and purpose, the research process, and measurements to be completed. The roles and responsibilities of staff in the research project were clearly outlined. Forty-five minute sessions were offered close to shift change times with the intent to expose as many staff as possible to the information offered. Two presentations per day were given over the course of three consecutive days. The unit manager determined the days and times of the presentations. To create maximum exposure she considered staff rotations, on-off work periods and shift changes. All direct care staff (i.e., dietitians, pharmacists, physiotherapists and occupational therapists, chaplains, volunteers, RNs, LPNs, and care aids) were invited to the sessions. Cleaners and dietary aids

were also included if available. Night staff received a separate orientation at 2300 hrs on two separate occasions. Only two presentations were required, as many night staff had already been exposed to the project during the day or evening rotation presentation.

The staff consent form for participation were given out and discussed at these meetings. The unit clerk collected the completed consent forms. The focus for consent collection was staff with positions where they spent large amounts of time on the unit (i.e., RN, LPN and care aides).

3.6.3.2 Outcome Measures Procedures

Baseline data collection began on consent of the proxy to participate in the study. The MMSE and GDS/FAST were completed and if the study admission criteria of moderate to severe dementia and no pain limitation to participation were met, the resident became a participant. Measures of neuropsychiatric behaviour were then completed and retained as baseline measures of neuropsychiatric behaviour. Recruitment lasted for 4 weeks and baseline measures of behaviour were completed on admission to the study.

Intervention and washout phase outcome measures were completed Monday to Friday in the final week of each phase. The selection of the order for resident measurement was done in the following manner: participant names were written on individual slips of paper and placed in a labeled brown paper lunch bag (each unit had their own bag); then the unit clerk drew names from each bag. For Monday through Wednesday, it was three names from the bag for Unit 1 and four for Unit 2; Thursday and Friday it was 3 names for both units. The number of names drawn reflected the unequal number of participants on each unit (Unit 1, n=15, Unit 2 n=18) and attempts to balance the evaluation process over the five-day measurement period, lessening the workload at the end of the week when staff may feel more fatigued. The testing order determined this way was used for phase 2 (intervention 1) data collection was maintained for

each measurement period throughout the remainder of the study. In other words, participants originally tested on a Monday were always tested on the Monday, exactly two weeks from the previous measurement. This approach ensured standardized time periods of exposure for both the intervention and washout prior to measurement.

3.6.3.3 Procedures to Minimize Third-Party Tool Completion Effects

The use of third-party informants to complete measurement tools creates challenges to reliability and validity. Recent emotional reaction to problematic behaviours immediately prior to assessment (173), fragmentation of caregiver respondent's memory of behaviour as a result of shift changes and days off (125) and clinician awareness of previous levels of deficit (156) may all contribute to achieving only moderate reliability and validity in measurement tools (125, 126, 173). In an effort to reduce these potential effects, multiple measurements across time were collected (see Table 1). The tools selected to measure behaviour change were originally thought to be short and easily administered, requiring caregiver observation or interviews rather than participant interaction. Use of participant questionnaire testing was limited to the single question of the SQDT. To reduce potential reactions to strangers and enhance reliability, the researcher completed the SQDT during each measurement period. The presence of temporary staff on weekends and their reduced familiarity with residents and the study led to the decision that no measurements would take place on weekends.

Table 1. Schedule of Testing Events Repeated in each Measurement Period

Day of Week	Shift	NPI-NH	CSDD	RAS2	AI	SQDT	Med Audit
Monday Unit 1 (3)	Days	X	X	X	X	X	RA
Unit 2 (4)	Evenings	X		X	X		
	Nights	X		X			

Tuesday Unit 1 (3) Unit 2 (4)	Days	X	X	X	X	X	RA
	Evenings	X		X	X		
	Nights	X		X			
Wednesday Unit 1 (3) Unit 2 (4)	Days	X	X	X	X	X	RA
	Evenings	X		X	X		
	Nights	X		X			
Thursday Unit 1 (3) Unit 2 (3)	Days	X	X	X	X	X	RA
	Evenings	X		X	X		
	Nights	X		X			
Friday Unit 1 (3) Unit 2 (3)	Days	X	X	X	X	X	RA
	Evenings	X		X	X		
	Nights	X		X			

Note. (3) or (4) refers to number of residents tested per day; Days = day shift; Evenings = evening shift; Nights = night shift; RA = research assistant

3.6.3.4 Maintaining Reliability with Outcome Measures

No formalized training sessions were used to familiarize the care aids with the tools for the following reasons: a) difficulty removing staff from their caregiving duties to practice with the tools; and b) the need for adult learners to be fully engaged in the skill, to practice the skill in the moment and to experience one-to-one instruction and feedback (181). To ensure valid and reliable completion of measurement tools, collaborative participatory education teaching methods were used. Education scholars have identified that these methods are the most successful means for adult learners in clinical settings to acquire skills, knowledge or attitude (181, 182) and would be key to promoting accurate measurement tool completion. The choice to use one-on-one tool introduction and completion sessions arose from: a) knowledge of adult learning theory, b) level of caregiver knowledge, c) the logistics of covering staff to create learning opportunities, and d) the research time frame. Guiding completion of the tools in the

natural setting supported adult learning principles in clinical practice arenas. Once it became apparent that proficiency in English was also a concern, the use of one-on-one sessions was clearly validated in the attainment of reliable test data. To increase reliability throughout the data collection period the researcher sat with individuals (and/or caregiving groups) while they were completing the forms for the first time to assist in understanding the descriptors and the criteria for decision-making. To increase validity of the assessment, input from multiple levels of caregiver (RNs, LPNs, care aids) was sought, and initial rounds of measurements took place in a group setting where all members of the caregiving group participated in determining the existence of the behaviour, as well as frequency, severity and occupational disruptiveness.

During the second phase of data collection (intervention 1), it became apparent that one-on-one (researcher and caregiver) completion of tools was an inefficient use of both staff and researcher time. To complete data collection within 5 days for each of the next 4 periods of data collection, it was determined that a single caregiver would be responsible for completing the NPI-NH, AI and CSDD based on group consultation. To ensure accuracy when completing the forms the researcher was present at charting time and available to answer questions and offer guidance regarding definitions of terms and clarity in decision-making.

The NPI-NH and the AI were repeated on evening shifts but only the NPI-NH was completed on night shift, as detecting depression and apathy during sleeping hours was not possible. Aggression, hallucinations, agitation and irritability, however, could be expressed during nighttime awakenings and were easily identified using the NPI-NH and RAS2. The CSDD was completed only once during each measurement period as depression develops and presents over longer periods of time and may be less amenable to short-term activity exposure (183).

Staff orientations to the measurement tools on days, evening and night shifts were similar. The researcher went over the tools with all grades of staff and then in a group worked through a minimum of three evaluations. The process was simpler on night shift as there was fewer staff in the group and they were required to complete fewer tools. All shifts were provided with coffee and/or food (selected by staff on that shift the day before) was used to assist in the completion process and proved to be a successful means of engaging staff. For times when the researcher was not present, the complete description and protocol for administration of the tools were kept in folders for each shift.

The researcher was always present for the weekday overlap of afternoon shift and evening shift. When the researcher had completed the orientation of night staff, evening staff would communicate to night staff all new admissions to the study and give night staff the researcher-prepared measurement tool package (the NPI-NH form and the reminder to complete the RAS2 form located in the chart next to the shift record of care). During the remaining measurement periods a similar pattern of communication was maintained with night shift staff. The researcher would meet with night staff on the first measurement day of each measurement period to familiarize and re-establish the protocol. After the first night, evening shift would then give the night staff the measurement documents requiring completion on that particular night.

3.6.3.5 Video Recording Procedures

Participant interactions with the garden vignette were observed 24 hours per day using four visible ceiling-mounted video cameras. The camera positions offered four different angles (two per each vignette) creating 360° visual access to the vignettes. Video data were recorded on a GE Truvision DVR 30 and then saved to external hard drives.

The pilot study showed that multiple researchers viewing the recording reduced observer bias through increased objectivity in determining frequency, type and depth of interaction of each participant with the vignette. Except for nighttime recordings, the researcher and a member of the research team observed the video data together. Limited interactions between 2400 hours and 0600 hours led to committee members granting permission for the researcher alone, to view those interactions. While watching the video, researchers would note observations of the indicators of the MOET classifications, the development of which was described previously in section 3.5.2.6.

3.6.3.6 Chart Review

Sociodemographic information (see Appendices A and B for tools used) and psychoactive medication use data were gathered using chart review. A Licenced Practical Nurse, a member of the unit staff, familiarized the research assistant (a Registered Nurse) with the medication administration documents on the nursing units. A list of medications approved in the study proposal was used to collect data specific to psychoactive medication use. The research assistant noted all regularly scheduled psychoactive medications administered on a daily basis. Each drug was then entered into its pharmaceutical category and the number of participants receiving that drug was counted. This information was then used to identify general use of psychoactive medication in the sample population. Administration of pro re nata (PRN) medication (given as determined necessary by nursing staff) was recorded on a daily basis for each participant. Drug name, dose and explanation for administration (if available) were noted. A single administration dose of a PRN medication was coded as 1 and the numbers then totalled to produce the number of times a PRN medication was given to each participant on each day of the study. The total number of times a medication was given was then totalled for each phase of

the study. The number of times a PRN medication was given per phase was then used in correlational data analysis to explore potential relationships between neuropsychiatric behaviour test scores and the frequency of PRN medication administration, a study outcome measure.

3.7 Data Analysis

The complexity and differing types of data led to the creation of two separate data analysis chapters. The psychometric outcome analyses are presented in Chapter 4 and the video data analyses are found in Chapter 5.

The primary outcome measures of incidence, frequency and severity of behaviour were measured by the NPI-NH, CSDD, AI and RAS2 and produced continuous data. The SQDT produced categorical data. The analyses of each data type will be described separately below.

3.7.1 Data Analyses of Continuous (Interval) Variables

The continuous variables were first analyzed by examining scatterplots of data from each test in each measurement period. Scores appeared to be normally distributed. To determine if a time (phase) effect existed for the continuous (interval) variables, the one-way repeated measures ANOVA (184) was performed. To determine where the significant phase differences existed, the paired *t*-test was computed. The multiple pair-wise comparisons led to application of the Bonferroni correction (185). In this instance the Bonferroni adjustment divided the original $\alpha = .05$ by 10, the total number of comparative pairs among the five phases.

The small sample size and the possibility of the presence of outliers led to the use of the one-way repeated measures ANOVA's corresponding nonparametric Friedman's test. Friedman's test is a ranking test that does not take into account the large scores attained by some individuals. If the conclusions of both the one-way repeated measures ANOVA and the Friedman's test are the same then the results from one-way repeated measures ANOVA are

reported. This is done because the parametric score is the measure of the actual behaviour, and is more informative than the ranked score (186). The data analysis in the following two chapters will show all of the processes.

3.7.2 Data Analyses for Categorical Variables

The SQDT produced categorical data. The expected responses were either ‘yes’ or ‘no’, but limited language skills associated with moderate to severe cognitive impairment led to the creation of a further four potential response categories: nonverbal, refused, ‘I don’t know’, and ‘sometimes’. Coding of the responses was 1 = yes, 2 = no and as the data provided by the final four categories were not a clear indication of either being depressed or not they were coded as 3 = nonverbal. To make the data more meaningful the data were re-coded with a value attachment assigning the larger number to the known depressed response. The data were then coded as follows: 1 = no, 2 = neutral and 3 = yes. The neutral category included the refused, ‘I don’t know’, ‘sometimes’ and nonverbal groups. Rather than treating those who were unclear in their feeling of depression as missing data it was of interest to see if the presence or removal of the vignette could change those who were identified as neutral to being either distinctly positive or negative. To determine if there was a time (phase) effect, Friedman’s test was then completed. As no statistical significance was demonstrated, no further phase analysis was done. As there was no phase effect on the neutral group further analyses using the SQDT data used only the true yes/no response data.

3.7.3 PRN Medication Administration Data Analysis

Chart audit provided the data for the psychoactive medication administration analyses. Descriptive statistics only were applied to the regularly scheduled psychoactive medication data. PRN psychoactive medication data were subjected to procedures similar to the neuropsychiatric

test data. Each time a PRN medication was given it was counted as 1. The total number of PRN medications given each participant during a measurement period was then totalled. The ANOVA, the paired *t*-test (Bonferroni corrected) and Friedman's test were applied. No significance led to a deeper look at the data. Scatterplots showed a high degree of variance in the number of medications given to participants. To reduce the variance in the raw scores the data were grouped into two categories: those who received medication and those who did not. The *t*-test was then used to examine the mean differences between the two groups and their scores from the neuropsychiatric tests.

To examine the strength of the relationship between being given a PRN medication and scores on the interval data from the neuropsychiatric tests, Pearson *r* correlations were also completed. For the SQDT data, chi-square was calculated. Then crosstabulation of the grouped data for having received a PRN medication (1 = received PRN medication and 0 = no PRN medication) with the SQDT data (yes/no) for each phase was computed.

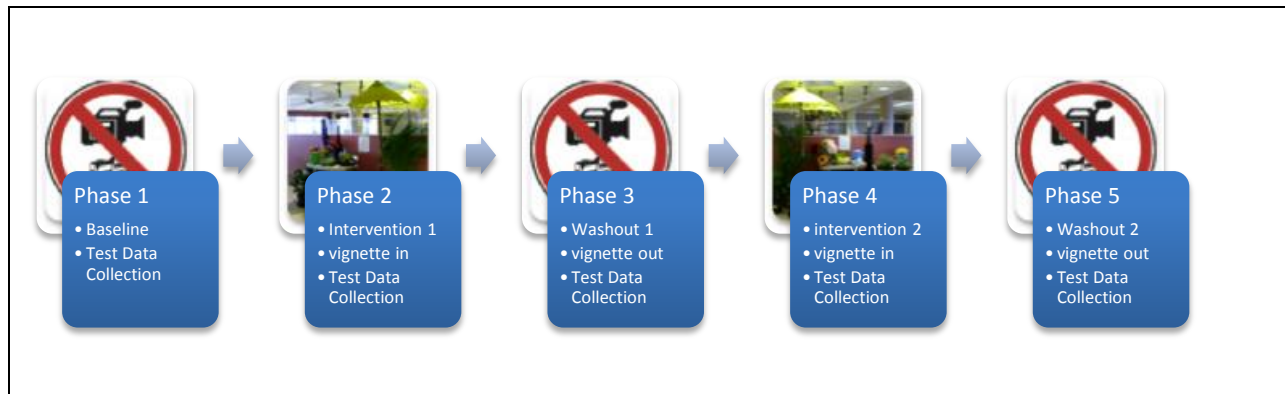
Limited PRN medication findings led to a descriptive examination of the data and the inclusion of two case studies that illustrated the challenges to understanding PRN medication administration in a long-term care setting.

3.7.4 Video Data Analysis

To understand the relationship between participant interactions at the garden vignette and neuropsychiatric behaviour, data collection at the vignette required a focus on detail and continuous observation. There was 24-hours per day video recording for the two 2-week intervention phases (phases 2 and 4); video data were not collected at baseline, or during the phase 3 and 5 washout phases. (See Figure 3 for clarification of phase and associated activity.)

For the purposes of analysis, the video data from both vignettes were combined and are referred to in the singular as ‘vignette data’.

Figure 3. Video Data Collection Process



The Modified Observation of Engagement Tool (MOET) allowed for recording observed engagement for a number of variables (see Appendix E for the tool and Appendix F for a detailed description of the measurement variables). Data produced by the MOET was binary, coded ‘1’ if engagement was observed and ‘0’ if not. The number of observations in each category for each participant in each phase was summed and this data were used in all analyses. Video rating reliability was checked throughout the viewing process. Midway through each phase of video data observation, a single day of video viewing was randomly selected and video observations were recorded a second time. From those observations, 12 time frames were randomly selected and the measure of agreement between the two observation periods was calculated using the Kappa statistic (187). The Kappa statistic was excellent, ranging from .94 to .96.

3.7.4.1 Analyses for the Effect of Time Spent at the Vignette and the Neuropsychiatric Test Variables

Time spent at the vignette is the independent variable that assists in understanding the relationship between exposure to the vignette and the potential effect of the vignette on

behaviour. Technical difficulties resulted in two days of missing video data for phase 2 (intervention 1), resulting in only 12 days of accessible video data. Phase 4 (intervention 2) had 14 days of video data. To standardize the raw scores phase 2 data were divided by 12 and phase 4 data were divided by 14, arriving at a mean score per phase.

The standardized time data were examined for potential trends and patterns. The presentation and analyses of these data are organized in relation to how data from either phase 2 or 4 relate to all other phases. A histogram of total time spent at the vignette (see Figure 16 section 5.1) revealed a bimodal distribution with a split in the data at 1000 seconds of total time spent at the vignette. The bimodal nature of the data was not a normal distribution therefore the use of parametric statistics was not appropriate. It was determined that for the group that spent < 1000 seconds at the vignette the lack of interaction at the vignette would provide limited detail as to how the vignette affected their behaviour. O'Connor et al. (69) suggested that depending on the proportions, if those who respond to the treatment and those who do not are considered as a single group, the treatment may be inadvertently rated a failure. Given that, it was important to create groups separated by time exposure to the vignette. Two new data groups were created: participants who spent ≤ 1000 seconds at the vignette and participants who spent > 1000 seconds. The data from these two time groups were used to examine if differences existed between the two groups with respect to their neuropsychiatric test scores. The continuous score data were explored using the *t*-test. Participants who never attended the vignette were excluded from this analysis. No exposure to the vignette produced data irrelevant to understanding the effect of the vignette on behaviour.

3.7.4.2 Analyses for the Effect of Time Spent at the Vignette and the Sociodemographic Data

Not all data could be examined using the two time groups. The sociodemographic data groups became too small, so all sociodemographic data were analysed using the mean 'total time spent at the vignette' score. The data were skewed with small numbers in each group therefore the nonparametric analogue of the *t*-test, the Mann-Whitney U, was calculated.

The comparison of previous occupation and total time spent at the vignette was originally examined using a one-way repeated measures ANOVA, but the sample size in one of the categories was only one, so a *t*-value was computed on the two larger number groups, secondary sector (*n*=3) and service sector (*n*=25) to explore the potential for difference between the groups and total time spent at the vignette.

3.7.4.3 Analyses for the Effect of Time Spent at the Vignette and the Single Question Depression Test Data

Analyzing for the effect of time spent at the vignette on SQDT data only the binary data (1 = yes, 2 = no) categorizations were used. These data were explored using chi-square, a nonparametric method of testing the significance of a relationship between two categorical variables (185).

3.7.4.4 Pearson *r* Correlation Analyses Exploring Video Variable Relationships

Pearson Correlation Coefficients were used to explore video data correlations between dependent and independent variables. The independent variables used in these calculations were: total time spent at the vignette, the number of times a participant was given a PRN medication and arriving at the vignette by self (the variable identifying self-determined behaviour). Colton's (188) interpretations of correlation size were used to identify significant correlations for inclusion in the findings:

“Correlations from 0 to .25 (or -.25) indicate little or no relationship; those from .25 to .50 (or -.25 to -.50) indicate a fair degree of relationship; those from .50 to .75 (or -.50 to -.75) a moderate to good relationship; and those greater than .75 (or -.75) a very good to excellent relationship.” (p.54)

Polit (184) provided further guidance in interpreting *r*-values by offering that when variables are of a psychosocial nature, as in this study, correlations rarely exceed .50, therefore, expectations of *r*-values greater than .50 would be unrealistic. Correlations below .25 were not reported in the findings.

3.7.4.4.1 Analyses for the Effect of Time Spent at the Vignette and Being Given a PRN

Medication

To examine the strength of the relationship between the number of times a psychoactive PRN medication was given and total time spent at the vignette, the Pearson *r* correlation was used.

3.7.4.4.2 Pearson *r* Correlation Analyses Exploring Video Variable Relationships with Being Given Psychoactive PRN Medication

To determine the strength of the relationship between the video activity variables and being given a PRN psychoactive medication, the Pearson *r* correlation was used. Each time an activity was observed it was recorded as 1 event. For each participant, the number of events in each activity category was then totalled for each measurement phase. The number of events in each activity category was then correlated with the number PRN psychoactive medications the participant had been given during the phase.

3.7.4.4.3 Analyses for the Variable Self-determination

The design of the study facilitated self-determined activity by creating a vignette that was open and available for self-determined interaction 24 hours per day/7 days per week for two 2-week phases. The video data variable ‘arrived by self’ identified times of self-determined activity. The data were coded ‘1’ if yes arrived by self and ‘2’ if no.

The number of self-determined visits for each participant varied greatly with a skewing of that data toward one or two unassisted visits. While categorized as self-determined, the individuals with lower numbers of self-determined visits may have arrived at the vignette by happenstance. This thinking led to the creation of two groups representing self-determined activity with the median number of visits used to define the groups. Those with less than or equal to the median number of unassisted visits were categorized as being not self-determined and those with greater than the median number of unassisted visits were categorized as being self-determined in their behaviour. The *t*-test was then used to compare the two groups’ diagnoses, neuropsychiatric test scores and video data variables. Crosstabulation and chi-square were used to examine the relationship between being self-determined and MMSE scores, diagnoses and the SQDT. To understand the strength of the relationship between being self-determined at the vignette and the type of engagement at the vignette as well as the preferred objects of interaction a Pearson correlation was calculated.

3.7.5 Summary of Data Analyses

The type of data and sample size determined the analyses. Continuous interval variables were analyzed using the one-way repeated measures ANOVA and the *t*-test (Bonferroni corrected). The non-parametric Friedman’s test and the chi-square were used with ordinal variables. To understand the strength of the relationships the Pearson *r* correlation was

calculated. PRN medication administration findings were counterintuitive and were thus examined from a descriptive stance. The complete findings are presented in chapters 4 and 5.

Chapter Four: **Analyses of Neuropsychiatric Test Data**

Selection of a quasi-experimental time-series within-subjects repeated measures design arose from a specific interest in determining the intraindividual (within-subjects) and time-effect changes in behaviour that may arise from interaction with a garden vignette. Data analyses reflect the type of data and the need to determine whether within-subject and time-effect behaviour changes were the result of interaction with the garden vignette. The findings reviewed in this chapter will be limited to: demographics; the neuropsychiatric test data; the neuropsychiatric test data as they relate to the administration of neuropsychiatric medications; and two individual case examples. The data from the Neuropsychiatric Inventory-Nursing Home (NPI-NH) and the Neuropsychiatric Inventory Nursing Home – Occupational Distress (NPI-NH OD) are presented for three measurement time frames defined by work shifts (days, evenings and nights) across all five phases. The Cornell Scale for Depression in Dementia (CSDD) and the Single Question Depression Test (SQDT) data are from a single measurement across all phases. The Apathy inventory data were derived from two measurement time frames defined by the two work shifts, days and afternoons, across all phases. Video data and its relationship to the neuropsychiatric test and medication administration data will be described in the following chapter.

4.1 Sociodemographic Data

Thirty-six potential participants were recruited to the study. Two were ineligible as their MMSE scores were greater than 19. One participant died during baseline data collection (two weeks prior to the introduction of the intervention). Of the 33 participants enrolled who provided data, 22 were males (67%) and 11 were females (33%). Ages ranged from 54 to 92. The average age was 77.78 years with the median being 81 years.

4.1.1 Occupation History

The potential for past experience and the retention of procedural memory to affect personal preference and activity enjoyment (131) led to the inclusion of occupational history e.g., did a past history of farming influence the potential to engage in self-determined gardening experiences. Statistics Canada's labour force sector definitions were used to categorize the previous work lives of participants. Primary sector workers (i.e., mining, forestry, fishing, farming, oil and gas drilling) made up 3% (n=1) of the sample. Secondary sector workers (i.e., construction, manufacturing) accounted for 9% (n=3) of the sample. Most of the sample (n=25, 76%) were service sector workers (i.e., banking, insurance, education, recreation, health, real estate, hotels and restaurants). The occupations of 12% (n=4) individuals were unknown.

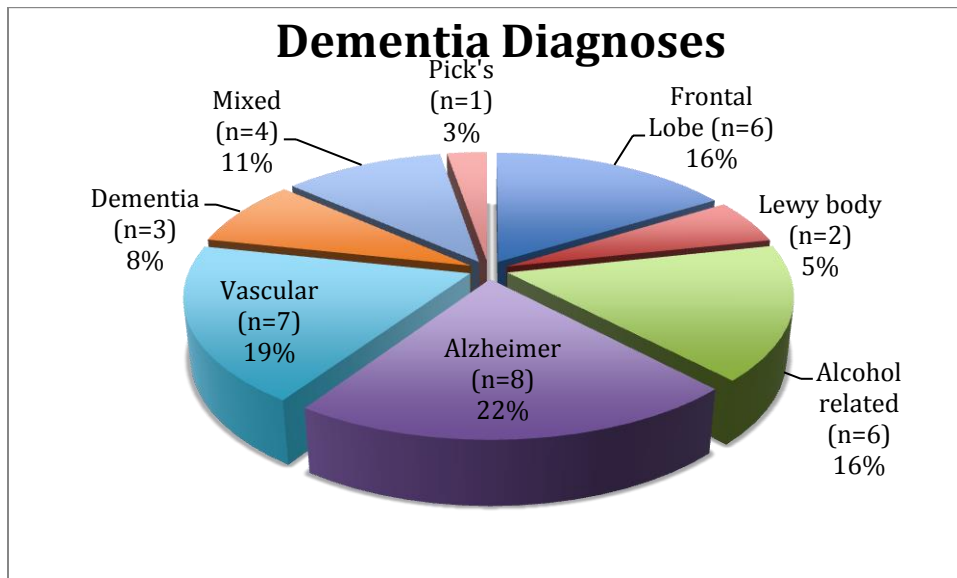
4.1.2 Previous Hobbies and Interests

The assumptions of Need-driven Dementia-compromised Behaviour Theory supported the collection and inclusion of previous hobbies and interest data. Prior to their dementia, participants had participated in the following hobbies and recreational interests: 87.9% (n=29) sedentary activities (cards, reading, painting, TV, movies, bingo, writing, gambling, puzzles or music), 72.7% (n=24) athletic activities (walking, sports, swimming, exercise, hockey, boating, coaching, dancing, fishing), 45.5% (n=15) activities outside the home (outings, camping, politics, community involvement, travel, dining out, church, service clubs), 27.3% (n=9) gardening, and 9.1% (n=3) needle craft (knitting, crocheting, embroidery, sewing, and needlepoint). Three (9.1%) had no hobbies or interests identified.

4.1.3 Dementia Diagnosis

Data on the type of dementia as recorded in the files of participants are presented in Figure 4.

Figure 4. Clinical Diagnosis of Dementia Type



4.1.4 Cognitive and Functional Status

The cognitive status of all participants was determined through administration of the mini mental state exam. At baseline MMSE scores ranged from 0 to 19. The distribution is shown in Figure 5. The mean score was 7.6 (median 8).

Figure 5. Baseline MMSE Scores

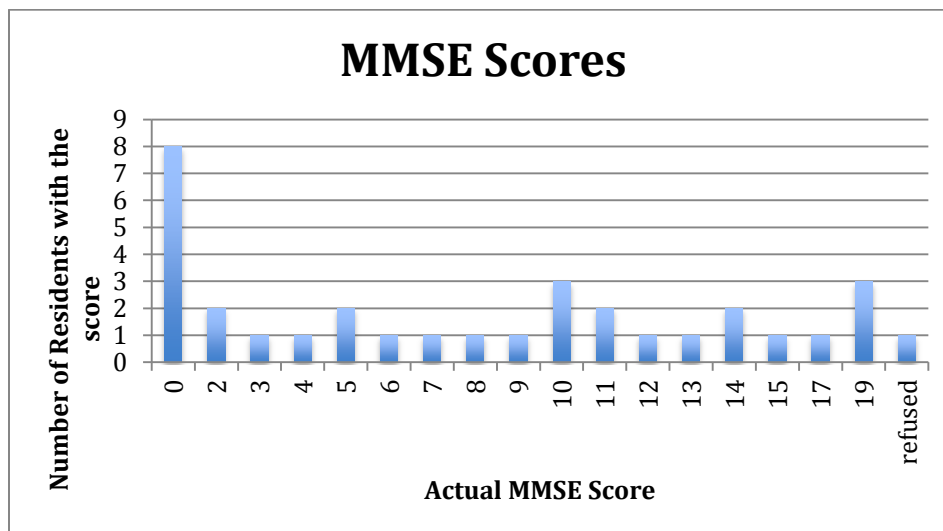
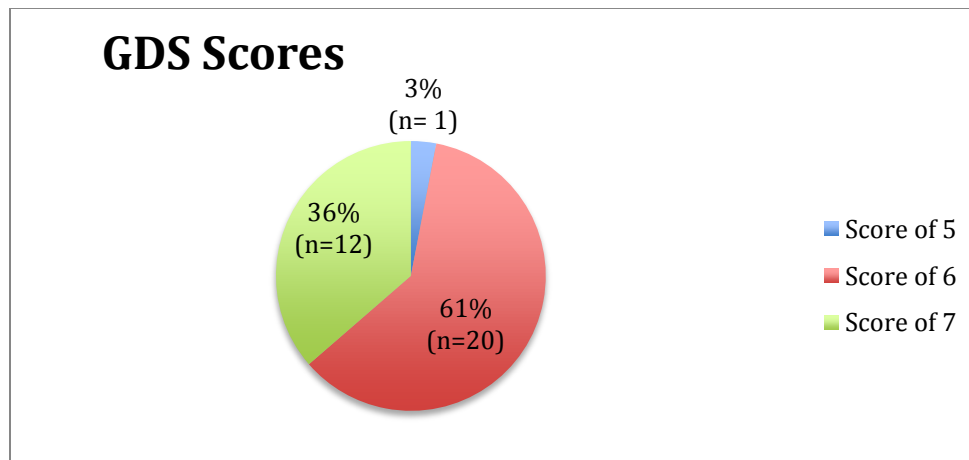


Figure 6 shows the percentage (number) of participants by GDS score at baseline. The sample had moderate to severe dementia They were dependent in activities of daily living and at a stage when behavioural disturbances are common (128).

Figure 6. Global Deterioration Scale (GDS) Data at Baseline



4.2 Neuropsychiatric Inventory-Nursing Home Data Analyses

All participants demonstrated at least one of the behaviours captured by the NPI-NH. Tables 1 and 2 in Appendix U graphically present the NPI-NH data in Table 2 below. Tables 1 and 2 in Appendix V graphically present the NIP-NH-OD data in Table 2 below. Appendices W to Y provide the NPI-NH score data across all shifts and phases in a scatterplot format. Appendices Z to BB show the scatterplot data for the NPI-NH occupational disruptiveness (OD) scores across all shifts and phases.

The repeated measures ANOVA results presented in Table 2 show that over time there is a significant difference in NPI-NH day and evening shift scores. There were no significant differences between the scores across the night shift phases. The ANOVA also showed that over time there were statistically significant differences in the mean NPI-NH-OD (occupational

distress) scores for day and evening shifts between phases 1 and 2, 3, 4, and 5 (see Table 2).

There were no significant findings for the NPI-NH-OD night shifts across the phases.

Table 2. Neuropsychiatric Inventory-Nursing Home Phase Effect ANOVA Results

Outcome	n	P1 Mean	P2 Mean	P3 Mean	P4 Mean	P5 Mean	<i>F</i>	df	<i>p</i> -value (sig)
NPI-NH days	33	31.24 (19.92)	23.42 (16.774)	26.42 (24.621)	21.82 (15.171)	17.15 (18.495)	4.246	4,128	.003*
NPI-NH evenings	33	40.58 (15.597)	26.03 (20.082)	24.85 (14.563)	27.58 (12.865)	23.58 (16.638)	12.297	4,128	<.001*
NPI-NH nights	33	10.39 (13.763)	7.30 (10.082)	6.21 (10.848)	11.61 (17.787)	6.42 (9.226)	2.140	4,128	.08
NPI-NH OD days	33	9.39 (6.118)	7.61 (6.005)	7.91 (7.226)	6.36 (4.285)	5.88 (6.986)	2.622	4,128	.04*
NPI-NH OD eves	33	16.15 (5.227)	9.94 (7.044)	7.58 (5.062)	9.91 (5.246)	8.42 (6.230)	22.283	4,128	<.001*
NPI-NH OD nights	33	4.67 (6.014)	2.58 (3.289)	2.36 (3.380)	3.82 (5.670)	2.73 (3.752)	2.582	4,128	.04*

Note. P1 is Phase 1 Baseline; P2 is Phase 2 Intervention 1; P3 is Phase 3 Washout 1; P4 is Phase 4 Intervention 2; P5 is Phase 5 Washout 2; (....) is the standard deviation; * denotes significance at the 0.05 level.

The NPI-NH paired *t*-values (Bonferroni corrected) results in Table 3 show a statistically significant difference in the means indicating a phase effect for: day shift scores between phase 1 and phases 2 and 5; and evening shift scores between phase 1 and phases 2, 3, 4 and 5 but no statistically significant mean differences across phases 2 through 5. There were no significant mean score differences across the phases during night shift (see Table 3). Significant phase differences persisted for the NPI-NH with the Friedman's test for both day and evening shift (see Table 5).

Table 3. Neuropsychiatric Inventory-Nursing Home Paired *t*-values Across All Phases for All Shifts (Bonferroni Corrected)

Phase	1(D)	1(E)	1(N)	2 (D)	2(E)	2(N)	3(D)	3(E)	3(N)	4(D)	4(E)	4(N)	5(D)	5(E)	5(N)
1	1.000	1.000	1.000	0.05* (p<.005)	<.001* (p<.001)	1.000 (p=.19)	1.000 (p=.23)	<.001* (p<.001)	1.000 (p=1.4)	0.07 (p=.007)	<.001* (p<.001)	1.000 (p=.68)	0.02* (p=.002)	<.001* (p<.001)	1.000 (p=.13)
2				1.000	1.000	0	1.000 (p=.44)	1.000 (p=.68)	1.000 (p=.60)	1.000 (p=.56)	1.000 (p=.56)	.33 (p=.03)*	.69 (p=.07)	1.000 (p=.5)	1.000 (p=.56)
3							1.000	1.000	1.000	1.000 (p=.21)	1.000 (p=.25)	.8 (p=.08)	.66 (p=.07)	1.000 (p=.66)	1.000 (p=.92)
4										1.000	1.000	1.000	1.000 (p=.16)	1.000 (p=.16)	.35 (p=.04)*
5													1.000	1.000	1.000

Note. D represents day shift; E represents evening shift; N represents night shift; (...) indicates *p*-value before Bonferroni correction; *indicates significance at the 0.05 level.

The NPI-NH-OD paired t -values (Bonferroni corrected) showed there were statistically significant mean differences between phase 1 and phases 2, 3, 4, and 5 (see Table 4) for evening shift, but only between phase 1 and 4 for day shift. There were no significant findings for the NPI-NH-OD night shift across the phases. Significant phase differences persisted for the NPI-NH-OD with the Friedman's test for evening shift only (see Table 5).

Table 4. Neuropsychiatric Inventory-Nursing Home Occupational Distress Paired t -values Across All Phases for All Shifts Comparisons (Bonferroni Corrected)

Phase	1(D)	1(E)	1(N)	2(D)	2(E)	2(N)	3(D)	3(E)	3(N)	4(D)	4(E)	4(N)	5(D)	5(E)	5(N)
1	1.000	1.000	1.000	1.000 ($p=.12$)	<.001* ($p<.001$)	1.000 ($p=.03$)*	1.000 ($p=.22$)	<.001* ($p<.001$)	1.000 ($p=.03$)*	.04* ($p=.004$)	<.001* ($p<.001$)	1.000 ($p=.41$)	.21 ($p=.02$)*	<.001* ($p<.001$)	1.000 ($p=.09$)
2				1.000	1.000	1.000	1.000 ($p=.79$)	.29 ($p=.03$)*	1.000 ($p=.77$)	1.000 ($p=.19$)	1.000 ($p=.97$)	.33 ($p=.08$)	1.000 ($p=.14$)	1.000 ($p=.24$)	1.000 ($p=.81$)
3							1.000	1.000	1.000	1.000 ($p=.19$)	.21 ($p=.02$)*	.8 ($p=.14$)	1.000 ($p=.22$)	1.000 ($p=.47$)	1.000 ($p=.62$)
4										1.000	1.000	1.000	1.000 ($p=.69$)	1.000 ($p=.17$)	.35 ($p=.13$)
5													1.000	1.000	1.000

Note. D represents day shift; E represents evening shift; N represents night shift; (...) indicates p -value before Bonferroni correction; *indicates significance at the 0.05 level.

When the data were examined in relation to shifts (days, evenings and nights), the initial analysis suggested difference across the shifts. On night shifts, 9 participants scored zero, as they were asleep. Nighttime means varied between 10.39 and 11.61 compared to 17.15 - 31.24 for day shift means (186). The large amount of variance led to performance of the Friedman's test. The results shown in Table 5 present statistically significant findings similar to those of the repeated-measures ANOVA for the NPI-NH and NPI-NH OD.

Table 5. Friedman's Test Scores for the NPI-NH and the NPI-NH-OD Across All Shifts

Outcome	n	χ^2	d.f.	p-value
NPI-NH days	33	18.6	4	.001*
NPI-NH evenings	33	33.4	4	<.001*
NPI-NH nights	33	4.4	4	.36
NPI-NH OD days	33	8.6	4	.07
NPI-NH OD evenings	33	55.3	4	<.001*
NPI-NH OD nights	33	3.35	4	.50

Note. NPI-NH = Neuropsychiatric Inventory-Nursing Home; NPI-NH-OD = Neuropsychiatric Inventory-Nursing Home Occupational Distress; days = day shift; evenings = evening shift; nights = night shift; * denotes significance at the 0.05 level.

4.3 Cornell Scale for Depression in Dementia (CSDD) Analyses

The CSDD was administered once to each resident during the measurement phases. CSDD scoring classifications are as follows: below 6 - probable absence of depression; above 10 - probable major depression and scores above 18 indicating definite major depression (189). The outcome means at baseline indicated probable major depression. After intervention 1 the depression means dropped to a probable absence. At the first washout and for the remainder of

the phases the means increased and lay between probable absence and probable major depression. Graphic presentation of these findings is found in Figure 7. One-way Repeated Measures ANOVA data in Table 6 show a statistically significant difference in CSDD scores across time indicating time (phase) effect. Table 7 paired *t*-values show statistically significant differences between phase 1 and phases 2, 3, 4, and 5; and phase 2 and 5. Friedman's test also showed a statistically significant time (phase) effect (see Table 8).

Figure 7. Cornell Scale for Depression in Dementia (CSDD) Outcome Means Across All Phases

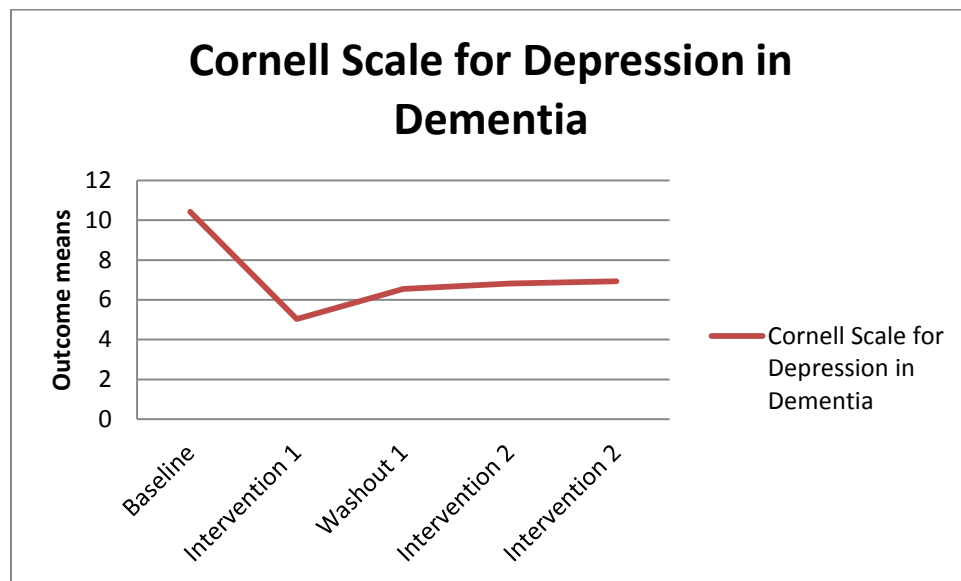


Table 6. One-way Repeated Measures ANOVA Results from the Cornell Scale for Depression in Dementia Scores

Outcome	n	P1 Mean CSDD score	P2 Mean CSDD score	P3 Mean CSDD score	P4 Mean CSDD score	P5 Mean CSDD score	F	df	<i>p</i> -value (sig)	Friedman's test
CSDD	33	10.42	5.03	6.55	6.82	6.94	8.363	4	<0.001*	.002*

days		(5.256	(4.134)	(5.050	(3.988)	4.860				
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Note. CSDD = Cornell Scale for Depression in Dementia; P1 is Phase 1 Baseline; P2 is Phase 2 Intervention 1; P3 is Phase 3 Washout 1; P4 is Phase 4 Intervention 2; P5 is Phase 5 Washout 2; (...) is the standard deviation; * denotes significance at the 0.05 level.

Table 7. Cornell Scale for Depression in Dementia Paired *t*-values (Bonferroni Corrected)

Phase	1 Baseline	2 Intervention	3 Washout	4 Intervention	5 Washout
1	1.000	<0.001* (p<.001 *)	0.006* (p=.001*)	0.04** (p=.004*)	0.01* (p=.001*)
2		1.000	1.000 (p=.12)	0.28 (p=.03)*	0.26 (p=.03)*
3			1.000	1.000 (p=.78)	1.000 (p=.69)
4				1.000	1.000 (p=.90)
5					1.000

Note. CSDD = Cornell Scale for Depression in Dementia; (...) indicates *p*-value before Bonferroni correction; * denotes significance at the 0.05 level.

Table 8. Friedman's Test (nonparametric)

Outcome	n	χ^2	d.f.	<i>p</i> -value
CSDD	33	17.431	4	.002*

Note. CSDD = Cornell Scale for Depression in Dementia; * denotes significance at the 0.05 level

4.4 Single Question Depression Test (SQDT) Analyses

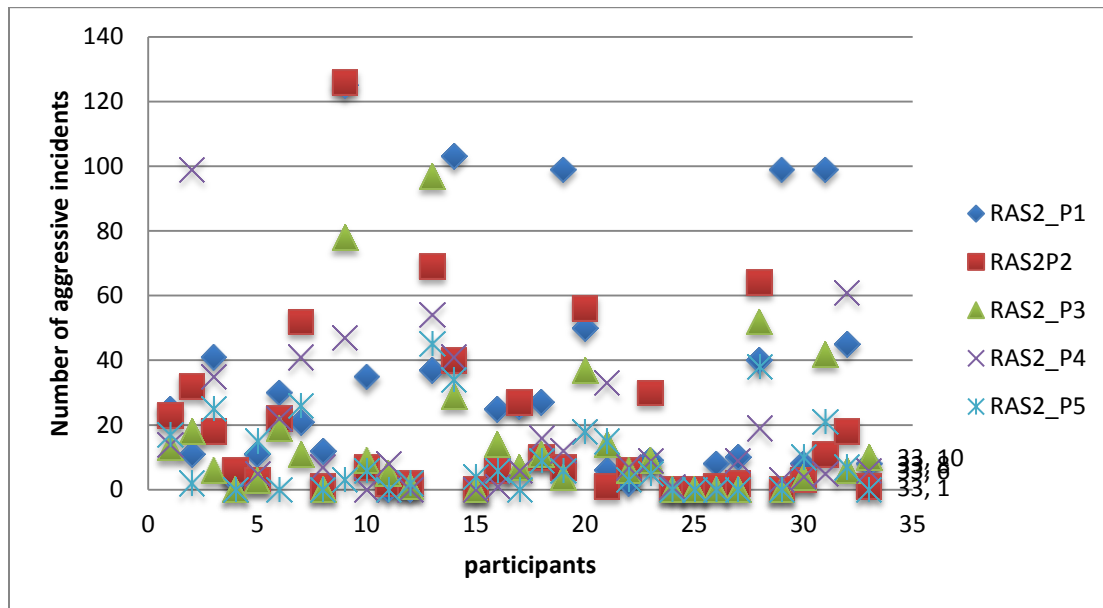
The SQDT data were analysed using the nonparametric ANOVA equivalent, Friedman's test. No statistically significant phase effect was demonstrated. As there was no significant difference there was no need to do the Wilcoxon Sum Rank test.

4.5 Ryden Aggression Scale 2 Statistical Analyses

The Ryden Aggression Scale 2 (RAS2) was modified considerably for use in the study. The revisions are described in detail in the method chapter. The result was a score that recorded only the presence of the listed types of aggression during all three shifts over 5 days.

The Figure 8 scatterplot shows that the data was skewed toward 0 with several outliers. Figure 9 graphically presents the mean number of aggressive incidents across all phases and shows a decrease in the number of aggressive incidents across all phases except for intervention 2. Table 9 presents the one-way repeated measures ANOVA and shows a statistically significant time (phase) effect. The paired *t*-values (see Table 10) showed statistically significant pairwise differences, which disappeared after the Bonferroni correction. Non-parametric Friedman's Test was statistically significant indicating that the time effect remained (see Table 11).

Figure 8. Scatterplot Showing Ryden Aggression Scale 2 (RAS2) Data Across All Phases



Note. RAS2 = Ryden Aggression Scale Version 2; P1 is Phase 1 Baseline; P2 is Phase 2 Intervention 1; P3 is Phase 3 Washout 1; P4 is Phase 4 Intervention 2.

Figure 9. Ryden Aggression Scale Outcome Means Across All Phases

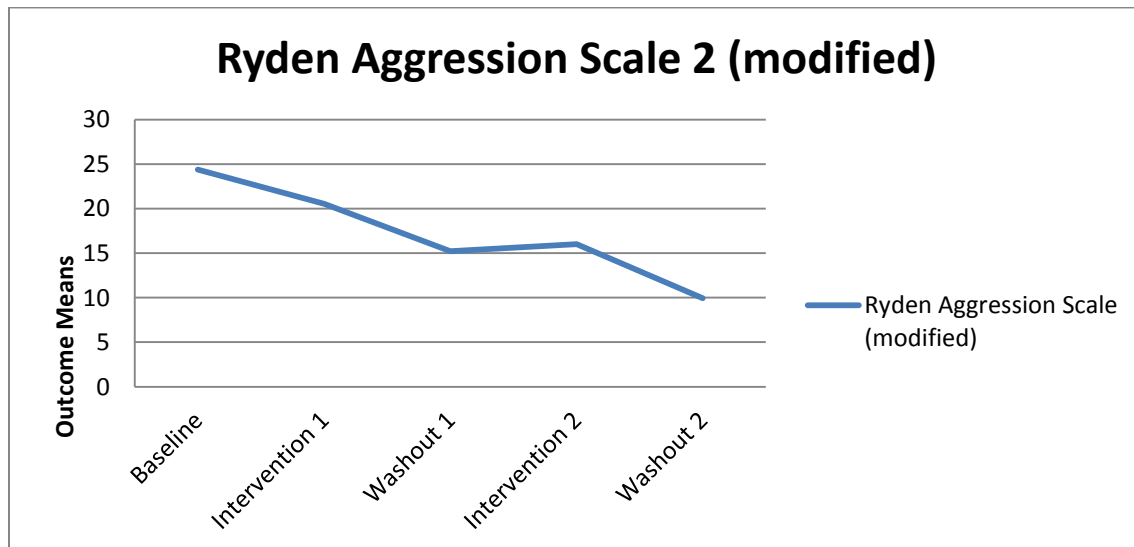


Table 9. RAS2 One-way Repeated Measures ANOVA Tests for Phase Effect

Outcome	n	P1	P2	P3	P4	P5	F	df	p-value
		Mean	Mean	Mean	Mean	Mean			(sig)

RAS2	29	24.38 (29.33)	20.55 (28.97)	15.21 (23.40)	16.00 (18.09)	9.93 (12.67)	4.054	4,112	0.004*
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Note. RAS2 = Ryden Aggression Scale Version 2; Mean = mean number of aggressive events; P1 is Phase 1 Baseline; P2 is Phase 2 Intervention 1; P3 is Phase 3 Washout 1; P4 is Phase 4 Intervention 2; P5 is Phase 5 Washout 2; n=29 indicates that there were four residents for whom data were incomplete; (...) is the standard deviation; * indicates significance at the 0.05 level.

Table 10. Ryden Aggression Scale 2 (modified) Paired *t*-values (Bonferroni Corrected)

Phase	RAS 1 (Baseline)	RAS 2 (Intervention)	RAS 3 (Washout)	RAS 4 (Intervention)	RAS 5 (Washout)
1	1.000	1.000 (p=.28)	0.37 (p=.04)*	0.52 (p=.05)*	0.07 (p=.007)*
2		1.000	0.628 (p=.06)	1.000 (p=.28)	0.311 (p=.03)*
3			1.000	1.000 (p=.82)	1.000 (p=.14)
4				1.000	0.355 (p=.03)*
5					1.000

Note. RAS2 = Ryden Aggression Scale Version 2; * denotes significance at the 0.05 level; (...) indicates *p*-value before Bonferroni correction.

Table 11. Ryden Aggression Scale 2 (modified) Friedman's Test (nonparametric) Results

Outcome	n	χ^2	d.f.	<i>p</i> -value
RAS2	29	13.447	4	.009*

Note. RAS2 = Ryden Aggression Scale Version 2; *denotes significance at the 0.05 level

4.6 Apathy Inventory (AI) Analyses

Figure 10 graphically presents the AI mean scores across the phases. One-way repeated measures ANOVA showed no statistically significant time (phase) effect across all phases for either day or evening shifts (see Table 12). The paired t -values showed a single statistically significant difference on day shift between phase 1 and 2 (see Table 13), which disappeared after the Bonferroni correction. Evening shift data showed a statistically significant difference between phase 1 (baseline) and phase 3 (washout 1) and phase 5 (washout 2) (see Table 14). Friedman's test also showed no time (phase) effect across the phases on either day or afternoon shifts (see Table 14).

Figure 10. Apathy Inventory (AI) Outcome Mean Across All Phases and During Two Separate Work Shifts

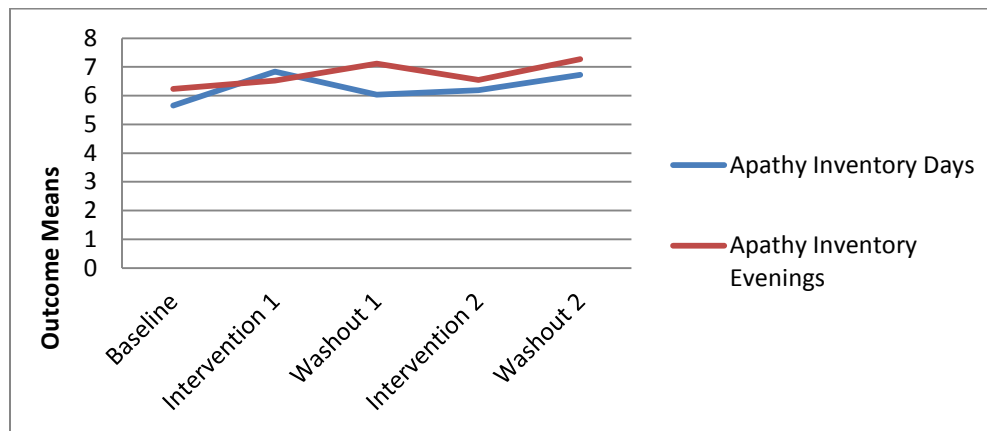


Table 12. Apathy Inventory One-way Repeated Measures ANOVA Test for Phase Effect

Outcome	n	P1 Mean AI score	P2 Mean AI score	P3 Mean AI score	P4 Mean AI score	P5 Mean AI score	F	df	p-value (sig)
AI days	3 2	5.66 (2.824)	6.84 (2.653)	6.03 (2.834)	6.19 (2.596)	6.72 (2.899)	1.923	4	.111

AI	3	6.24	6.52	7.12	6.55	7.27	2.222	4	.07
eves	3	(2.807)	(3.374)	(3.110)	(2.927)	(2.649)			

Note. AI = Apathy Inventory; P1 is Phase 1 Baseline; P2 is Phase 2 Intervention 1; P3 is Phase 3 Washout 1; P4 is Phase 4 Intervention 2; P5 is Phase 5 Washout 2; (...) is the standard deviation; * denotes significance at the 0.05 level

Table 13. Apathy Inventory Day Shift Paired *t*-values (Bonferroni Corrected)

Phase	1 (Baseline)	2 (Intervention)	3 (Washout)	4 (Intervention)	5 (Washout)
1	1.000	.19 (<i>p</i> =.02)*	1.000 (<i>p</i> =.46)	1.000 (<i>p</i> =.22)	.88 (<i>p</i> = .09)
2		1.000	0.707 (<i>p</i> =.07)	1.000 (<i>p</i> =.19)	1.000 (<i>p</i> =.81)
3			1.000	1.000 (<i>p</i> =.7)	1.000 (<i>p</i> =.21)
4				1.000	1.000 (<i>p</i> =.363)
5					1.000

Note. * denotes significance at the 0.05 level; (...) indicates *p*-value from the paired *t*-test before Bonferroni correction.

Table 14. Apathy Inventory Evening Shift Paired *t*-values (Bonferroni Corrected)

Phase	1 (Baseline)	2 (Intervention)	3 (Washout)	4 (Intervention)	5 (Washout)
1	1.000	1.000 (<i>p</i> =.55)	.45 (<i>p</i> =.05)*	1.000 (<i>p</i> =.51)	.17 (<i>p</i> = .02)*

2		1.000	0.936 (<i>p</i> =.09)	1.000 (<i>p</i> =.94)	1.000 (<i>p</i> =.13)
3			1.000	.84 (<i>p</i> =.08)	1.000 (<i>p</i> =.71)
4				1.000	.75 (<i>p</i> =.08)
5					1.000

Note. * denotes significance at the 0.05 level; (...) indicates *p*-value from the paired *t*-test before Bonferroni correction.

Table 15. Apathy Inventory Friedman's Test (nonparametric)

Outcome	n	χ^2	d.f.	<i>p</i> -value
AI days	32	4.35	4	.36
AI eves	33	5.98	4	.20

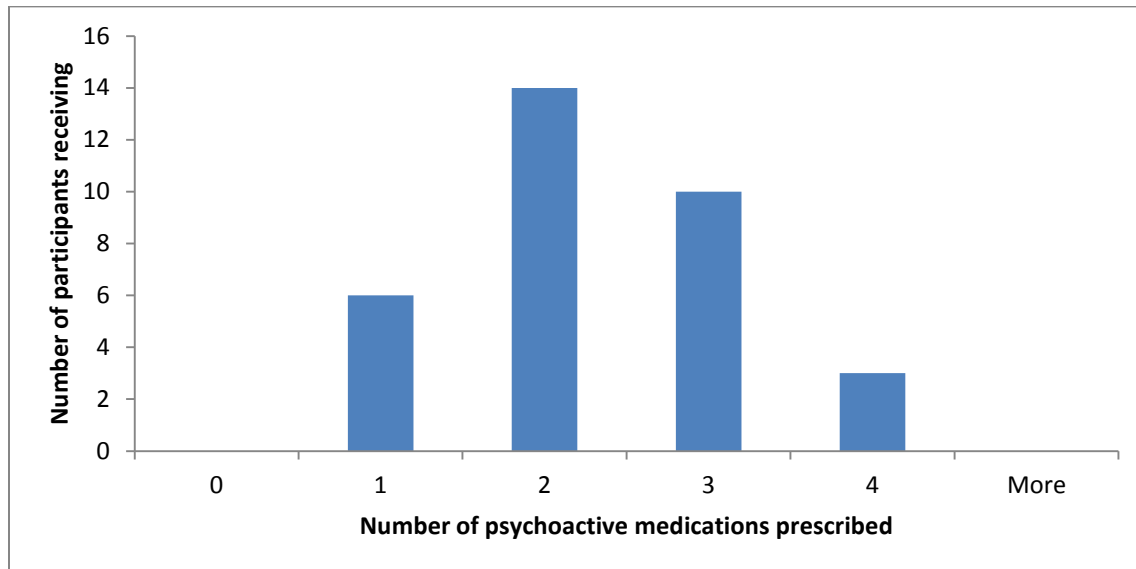
Note. AI = Apathy inventory; Days = day shift; Eves = evening shift; * denotes significance at the 0.05 level

4.7 Medication Use: Regularly Scheduled and PRN

Regularly scheduled psychoactive medications used in the management of dementia symptoms were as follows: 5 (15%) participants were on cholinesterase inhibitors (ChEI), 21 (64%) antidepressants, 23 (70%) atypical antipsychotics, 1 (3%) typical antipsychotics, 11 (33%) mood stabilizers and anticonvulsants, 4 (12%) antianxiety agents, and 3 (9%) on a night-time sedative. Eight (24%) took an N-methyl-D-aspartate-agonist (NMDA). The psychoactive medications used on a PRN basis included antidepressants, atypical and typical antipsychotics, mood stabilizers and anticonvulsants, antianxiety agents and night-time sedatives. (See Chapter 3 Methods 2.6.3.6 Chart Review for a detailed account of medication data inclusion and collection.) Figure 11 illustrates the number of regularly scheduled neuropsychiatric medications

prescribed to individual participants in the study population. Six individuals received one, fourteen two, ten three and three persons received 4 psychoactive medications.

Figure 11. Histogram of Regularly Scheduled Psychoactive Medication



4.7.1 PRN Medications Given

Figure 12 illustrates the mean number of times a PRN medication was given during each phase. One-way repeated measures ANOVA showed there was no statistically significant difference in the within-subjects dependent groups across the phases. The paired *t*-values showed there were no statistically significant differences between the phases (see Table 16). Friedman's test showed no statistically significant time (phase) effect.

Figure 12. Mean Number of PRN Medications Administered in each Phase of the Study

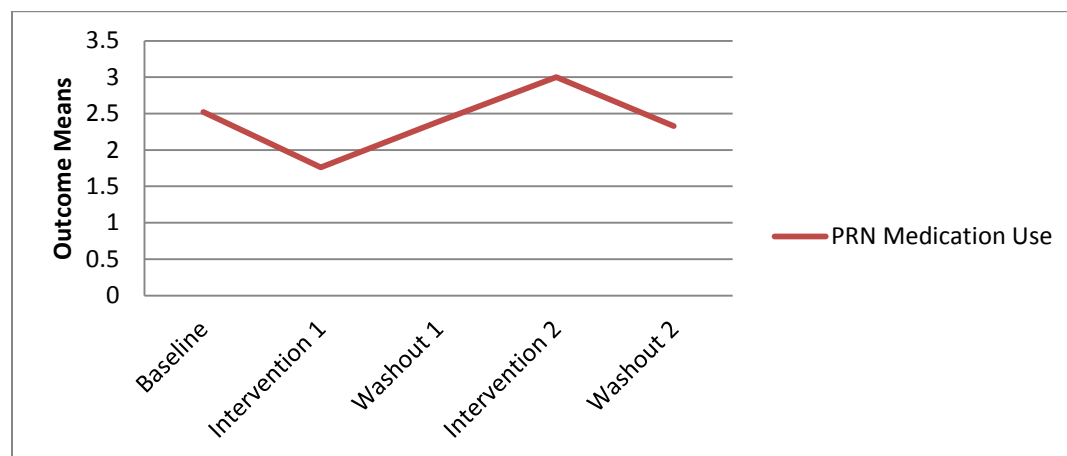


Table 16. PRN Medication Paired *t*-values for All Phases (Bonferroni Corrected)

Phase	1 (Baseline)	2 (Intervention)	3 (Washout)	4 (Intervention)	5 (Washout)
1	1.000	1.000 (p=.125)	1.000 (p=.849)	1.000 (p=.594)	1.000 (p=.868)
2		1.000	0.634 (p=.063)	0.695 (p=.069)	1.000 (p=.476)
3			1.000	1.000 (p=.355)	1.000 (p=.934)
4				1.000	1.000 (p=.223)
5					1.000

Note. PRN is pro re nata (given as determined necessary by the nurse); * denotes significance at the 0.05 level; (...) indicates *p*-value before Bonferroni correction.

4.7.1.1 PRN Medication and the Dependent Variables

To determine if a difference in neuropsychiatric tests scores existed between those who received PRN neuropsychiatric medication and those who did not, a grouped *t*-test was calculated. To determine the degree of association between the number of PRN medications given and scores on the NPI-NH, NPI-NH-OD, the CSDD, the AI and the RAS2 neuropsychiatric tests the Pearson product-moment correlation (Pearson's *r*) was calculated. The findings are presented below.

4.7.1.1.1 Correlation Analysis of the Relationship Between PRN Medication Data and the NPI-NH and NPI-NH-OD Mean Scores

Significant *r*-values are presented in Table 17 below. In phase 1, only the day shift NPI-NH and NPI-NH-OD means scores show a significant correlation with being given a PRN medication. The phase 2 NPI-NH and NPI-NH-OD mean scores showed no significant correlations with being given a PRN medication across all shifts. The phase 3 analysis showed a significant correlation between being given a PRN medication and both NPI-NH and NPI-NH-OD scores on evening and night shifts. In phase 4 the day shift and evening shift NPI-NH data produced a significant correlation and the NPI-NH-OD correlations were significant for evening shift only. The phase 5 analysis showed a significant correlation between being given a PRN medication and both the NPI-NH and NPI-NH-OD scores for all three shifts.

Table 17. Pearson Correlations Between the PRN Medication Given and the Neuropsychiatric Inventory-Nursing Home and the NPI-NH Occupational Distress Scores

Phase	Neuropsychiatric test variable	<i>r</i>	<i>p</i>	n
P1	NPI_days	.430	.01	33
	NPI_ODdays	.374	.03	33

P3	NPI_eves	.567	.001	33
	NPI_ODeves	.463	.007	33
	NPI_nights	.442	.01	33
	NPI_ODnights	.451	.008	33
P4	NPI_ODeves	.377	.03	33
P5	NPI_days	.807	.001	33
	NPI_ODdays	.778	.00	33
	NPI_eves	.564	.001	33
	NPI_ODeves	.670	.0002	33
	NPI_nights	.620	.001	33
	NPI_ODnights	.644	.0005	33

Note. NPI = Neuropsychiatric Inventory-Nursing Home; NPI_OD = Neuropsychiatric Inventory – Nursing Home Occupational Distress; P1 = Phase 1; P3 = Phase 3; P4 = Phase 4; P5 = Phase 5; days = day shift; eves = evening shift; nights = night shift; *p* is significant at .05.

4.7.1.1.2 Grouped (Yes received /No did not receive) PRN Medication and the NPI-NH

To determine if a difference in NPI-NH scores existed between those who received a PRN medication and those who did not, a paired *t*-test calculation was completed. Table 18 presents the significant findings. Participants with higher NPI-NH scores on evening shift and night shift during washout 1 (phase 3) were significantly more likely to be given PRN medications. During intervention 2 (phase 4) participants with higher NPI-NH scores on day and evening shifts were more likely to be given PRN medications. In phase 5, the final washout phase, participants with higher NPI-NH scores were more likely to be given PRN medication on all three shifts. There were no significant results for phases 1 and 2.

Table 18. The Neuropsychiatric Inventory-Nursing Home Scores and PRN Medication Grouped *t*-values

Outcome Measure		Mean	SD	<i>t</i>	<i>p</i>
NPI_evesP3	Yes meds	30.40	15.17	-3.42	.002 (<i>df</i> =31)
	No meds	16.31	8.42		
NPI_nightsP3	Yes meds	9.75	12.79	-3.12	.006 (<i>df</i> =20)
	No meds	.77	1.30		
NPI_daysP4	Yes meds	28.71	12.1	-3.01	.005 (<i>df</i> =31)
	No meds	14.50	4.80		
NPI_evesP4	Yes meds	34.47	12.65	-3.82	.001 (<i>df</i> =28)
	No meds	20.25	8.44		
NPI_daysP5	Yes meds	23.24	23.67	-2.1	.05 (<i>df</i> =19)
	No meds	10.69	6.84		
NPI_evesP5	Yes meds	32.24	17.669	-3.68	.001 (<i>df</i> =24)
	No meds	14.38	9.07		
NPI_nightsP5	Yes meds	10.53	11.07	-3.01	.007 (<i>df</i> =19)
	No meds	2.06	3.38		

Note. NPI = neuropsychiatric inventory; days = day shift; eves = evening shift; nights = night shift; P1=baseline;P2=intervention 1; P3=washout 1; P4=intervention 2; P5=washout 2; *p* is significant at .05.

4.7.1.1.3 Apathy Inventory and PRN Medications

t-Test results from the grouped (yes/no received a PRN medication) data analyses showed no statistically significant results in any phases. The Pearson correlation analysis to examine the strength of any relationships between the AI score and being given a PRN medication revealed that in phase 4, there existed a fair relationship ($r = .365$, $p = .04$) between the number of times a

participant would be given a PRN medication and the score they received on the apathy inventory (see Table 19).

Table 19. Pearson r Correlations Between Apathy Inventory Scores and PRN Medication

Phases	Neuropsychiatric test variable	r	p	n
P4	AI_eves	.365	.04	33

Note. PRN is pro re nata (given as determined necessary by the nurse); AI = Apathy Inventory; eves = evening shift; P4 = Phase 4; p is significant at .05.

4.7.1.1.4 The Cornell Scale for Depression in Dementia and PRN Medication

Pearson Correlation analyses of the relationship between being given a PRN medication and CSDD scores show that in phase 1 there existed a fair significant correlation between having a higher score on the CSDD and being given a PRN medication (see Table 20 below). In phase 4 the CSDD score showed a fair correlation with being given a PRN medication but it was not statistically significant. No other significant correlations were found with the CSDD and PRN medication.

Table 20. Pearson Product-Moment Correlations Between PRN Medication Given and the Cornell Scale for Depression in Dementia

Phases	Neuropsychiatric test variable	r	p	n
P1	CSDD	.41	.02	33
P4	CSDD	.32	.07	33

Note. PRN is pro re nata (given as determined necessary by the nurse); P1 = Phase 1; P4 = Phase 4; CSDD = Cornell Scale for Depression in Dementia

t -values from the CSDD and grouped data (yes/no received a PRN medication) analysis revealed only phase 1 had significant results. Findings in Table 21 show that individuals who received more PRN medication were more likely to have a higher CSDD score than the ones that did not receive medication. For all other phases there was no difference between the groups.

Table 21. PRN Grouped Data (yes medication/no medication) and the Cornell Scale for Depression in Dementia *t*-values

Outcome Measure		Mean	SD	<i>t</i>	<i>p</i>	Mean difference (no—yes)	95% CI of difference	
							lower	upper
CSDD_P1	No meds	8.55	4.25	-2.799	.009 (df=31)	-4.758	-8.225	-1.291
	Yes med	13.31	5.498					

Note. CSDD = Cornell Scale for Depression in Dementia; P1 = Phase 1 Baseline; Yes med = PRN medication given; No med = no medication given; CI = confidence level. Equal variance was assumed.

4.7.1.1.5 Ryden Aggression Scale 2 (modified) and PRN Medication

The *r*-values presented in Table 22 show that there was no relationship or association between the score a participant received on the RAS2 and the number of times a PRN medication was given during phase 1 (baseline). In phases 2 and 4 (interventions 1 and 2) and phase 5 (washout 2) there existed a significant fair degree of relationship between having a higher RAS2 score and being given a PRN medication. In phase 3 (washout 1) a moderate to good significant relationship existed between having a higher RAS2 score and being given a PRN medication.

Table 22. Significant Correlations Between PRN Medication Given and the Ryden Aggression Scale 2 (modified)

PRN Medication Given	Neuropsychiatric test variable	<i>r</i>	<i>p</i>	<i>n</i>
P1	RAS2 Nothing significant			
P2	RAS2	.39	.03	33
P3	RAS2	.54	.001	33
P4	RAS2	.43	.01	33
P5	RAS2	.42	.02	33

Note. P1 = Phase 1; P2 = Phase 2; P3 = Phase 3; P4 = Phase 4; P5 = Phase 5; RAS2 = Ryden Aggression Scale (modified); PRN = pro re nata (given as determined necessary by the nurse)

The grouped *t*-values (yes/no received a PRN medication) presented in Table 23 below show that in phase 1 a participant with a higher RAS2 (modified) score was significantly more likely to receive a PRN medication. Phases 2 and 3 data showed no statistically significant difference between being given a PRN medication and the RAS2 score. Both phases 4 and 5, however, showed that a participant with a greater number of aggressive incidents as identified by the RAS2 was statistically significantly more likely to be given a PRN medication.

Table 23. Significant *t*-values from PRN Grouped Data (yes medication/no medication) and the Ryden Aggression Scale 2 (modified) Analyses

Outcome Measure		Mean	SD	<i>t</i>	<i>p</i>
RAS2_ P1	Yes meds	38.69	36.52	-2.43	.03 (<i>df</i> =15)
	No meds	12.65	14.25		
RAS2_2		<i>Nothing significant</i>			
RAS2_3		<i>Nothing significant</i>			
RAS2_ P4	Yes meds	24.81	20.09	-3.74	.002 (<i>df</i> =17)
	No meds	5.44	5.046		
RAS2_ P5	Yes meds	15.18	13.84	-3.08	.005 (<i>df</i> =23)
	No meds	3.69	6.52		

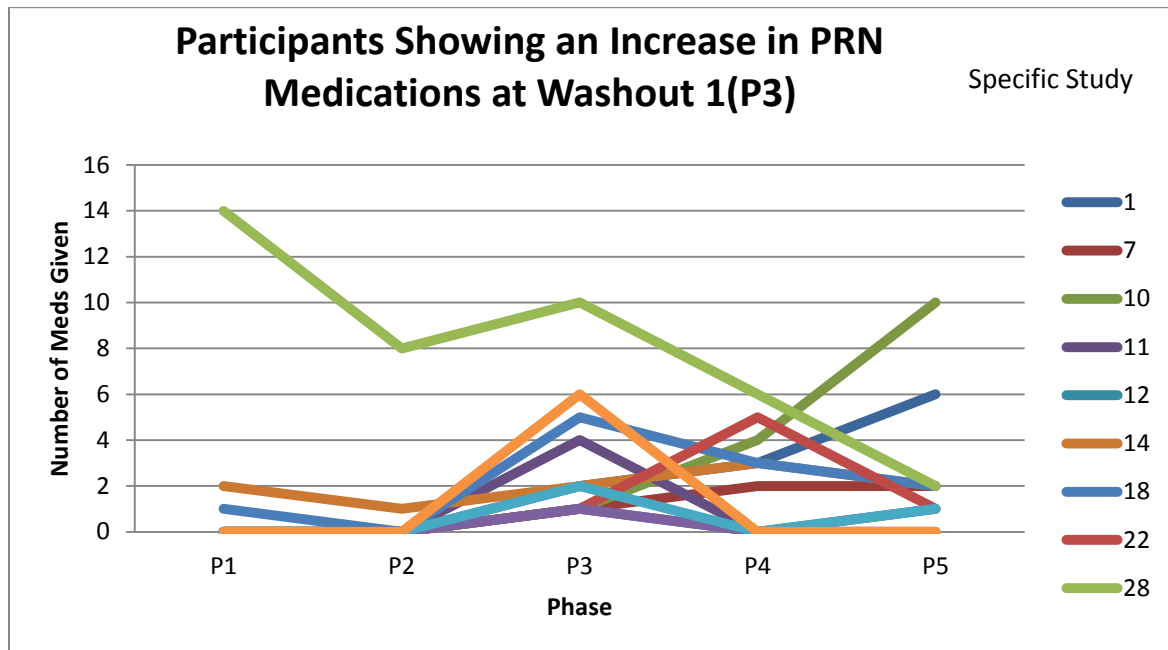
Note. RAS2 = Ryden Aggression Scale 2 (modified); P1 = baseline; P2 = intervention 1; P3 = washout 1; P4 = intervention 2; P5 = washout 2; Yes meds = received PRN medication; No meds = did not receive PRN medication

4.7.2 Descriptive Data Arising from PRN Medication Administration Analyses

The administration of PRN medication is a complex process. The small sample size and the unpredicted relationship between medication administration and time spent at the vignette led to further exploration of the data. The raw data showed 10 distinct patterns in the medication administration data. The most common pattern of response (*n*=12) was for PRN medication administration to show an increase during phase 3 (washout 1) from baseline and intervention 1 (see Figure 13 below). There is an overlap of participants in this category with the group who received ever-increasing amounts of PRN medication (continuous escalation group). Following

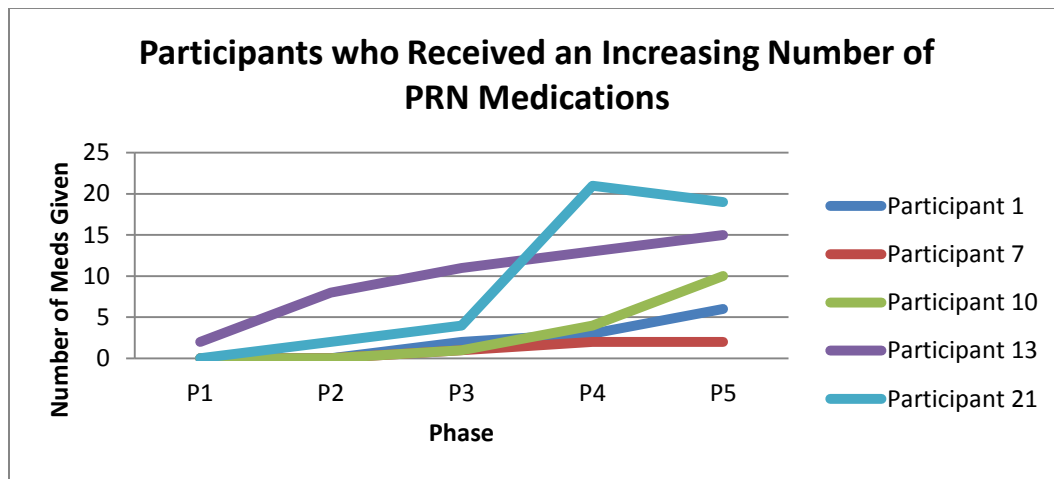
this increase at phase 3 (washout 1), 8 participants received fewer medications during the following phase 4 (intervention 2) while 4 received more.

Figure 13. Participants Who Received an Increasing Number of PRN Medications During Washout 1 (Phase 3)



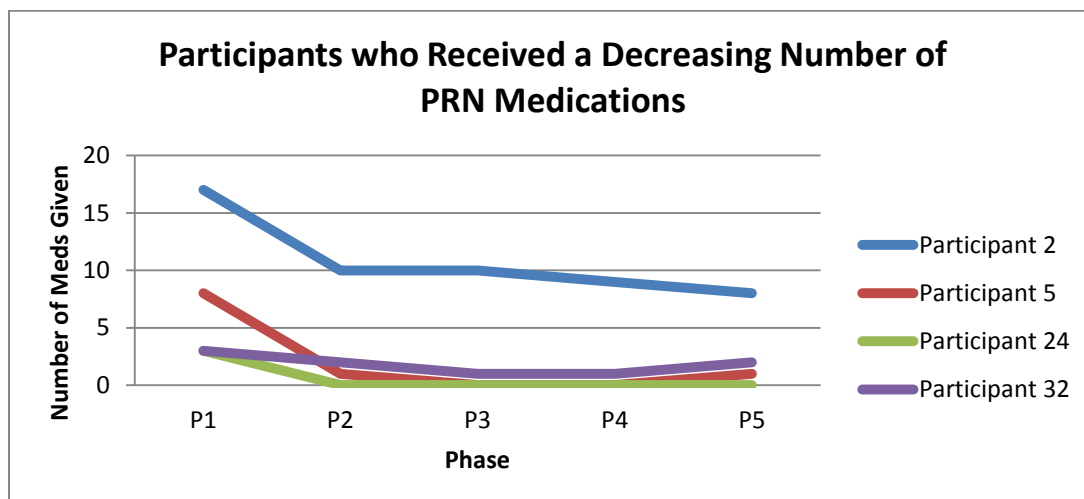
The second most common pattern of medication administration was those individuals who showed a continual increase in medications across all phases of the study (n=4). A fifth individual showed increases across the first 4 phases and decreased by only one medication in phase 5 so has been included in this group (see Figure 14).

Figure 14. Participants Who Received a Continually Increasing Number of PRN Medications Across All Phases



The third pattern was a decrease in medication administration with participants (n=4) showing a reduction in PRN medications across 4 of the 5 phases. Two participants in this group showed an increase of one more PRN medication in phase 5 (washout 2), otherwise that pattern was one of decline (see Figure 15 below).

Figure 15. Participants Who Received Decreasing Number of PRN Medications Across the Phases



The fourth pattern observed (n=3) was an increase of PRN medication administration during intervention 1 then a steady decline. The remaining patterns were multiple variations

with only one or two participants with a particular pattern of medication administration. The predicted pattern of high baseline, decrease at intervention 1, increase at washout 1, decrease at intervention 2 and increase at washout 2 was not seen at all.

The relationship between medication administration and time spent at the vignette is potentially very complex. Possible explanations for these findings will be discussed in detail in the discussion section.

To further demonstrate the complexity of PRN medication administration two short descriptive case studies are included Appendices K and L.

4.8 Summary of Findings

Thirty-three participants with moderate to severe dementia, a history of aggression and surrogate-consent were the sample population. Dementia diagnoses were mixed. Occupations were primarily from the service sector, with a variety of hobbies and interests. Psychoactive medication use was present in both regularly scheduled and PRN formats. Participant neuropsychiatric behaviour as measured by the NPI-NH, CSDD, SQDT, AI, and the RAS2 (modified) was collected across five phases. The findings are summarized as follows:

4.8.1 The NPI-NH and NPI-NH-OD

1. For the NPI-NH scores the repeated measures ANOVA and Friedman's test showed that a statistically significant difference existed between the day and evening shifts, but not for night shift. Paired *t*-values after the Bonferroni comparison showed statistically significant mean differences for day shift between phase 1 and phases 2 and 5; and for evening shift between phase 1 and phases 2, 3, 4, and 5.
2. For the NPI-NH-OD scores the repeated measures ANOVA showed a difference between all shifts and across all phases. Friedman's test however only supported the difference on

evening shift across all phases. Paired t -values after the Bonferroni correction, showed statistically significant mean differences for day shift between phase 1 and phase 4 only; and for evening shift between phase 1 and phases 2, 3, 4, and 5. No statistically significant findings for the NPI-NH-OD for night shift across all phases.

3. Pearson r Correlations between being given a PRN medication and having higher NPI-NH and NPI-NH-OD scores showed fair to moderate correlations for day shift in phase 1; evening and night shifts in phase 2; evening shift in phase 4 and for all three shifts in phase 5.
4. Paired t -test analyses showed that participants were significantly more likely to be given a PRN medication in; phase 3 on evening and night shift; phase 4 on day and evening shift and for all three shifts in phase 5 if you had a higher NPI-NH score.

4.8.2 The Cornell Scale for Depression in Dementia (CSDD)

1. The repeated measures ANOVA and Friedman's test showed that a statistically significant difference existed between phase 1 and all other phases.
2. The paired t -values after Bonferroni correction showed statistically significant mean differences between phase 1 and all other phases. No statistically significant difference existed between the other phases.
3. Pearson r Correlations between being given a PRN medication and having a higher CSDD score existed in phases 1 and 4 (fair correlation).
4. Grouped (yes/no PRN medication) t -test findings showed that in phase 1 the participant was more likely to receive a PRN medication if their CSDD score was higher.

4.8.3 The Apathy Inventory (AI)

1. The repeated measures ANOVA and Friedman's test showed no statistically significant mean differences across the phases for either day or evening shift.
2. The Paired t -values initially showed a statistically significant mean difference between phases 1 and 2 on both day and evening shift, but did not persist with the Bonferroni correction.
3. Only in phase 4 did a fair significant r -value exist between having a higher AI scores and being given a PRN medication.
4. No significant t -values in the grouped (yes/no PRN medication) analyses with the AI.

4.8.4 The Ryden Aggression Scale (modified) (RAS2)

1. Data were skewed toward zero, with the majority of aggressive incidents related to 6-10 participants depending on the phase.
2. The repeated measures ANOVA showed a statistically significant mean difference existed between phase 1 and phases 3, 4 and 5, but after the Bonferroni correction only approached significance between phases 1 and 5.
3. Statistically significant Pearson r Correlations between being given a PRN medication and having a higher RAS2 score were fair to moderate during phases 3 to 5.
4. Paired t -test findings for the grouped data (yes given a PRN medication and no not given a PRN medication) showed that higher RAS2 scores in phases 1, 4 and 5 led to being more likely to be given a PRN medication.

4.8.5 The Single Question Depression Test (SQDT)

1. There were no statistically significant findings with any data analyses for this test.

4.8.6 PRN Medication Administration Findings

1. Repeated measures ANOVA and Friedman's test showed no statistically significant difference in the within-subjects dependent groups across the phases.
2. Paired t -values (Bonferroni corrected) showed there were no statistically significant differences between the phases.
3. A range of PRN medication administration patterns existed but their relationship to neuropsychiatric test scores was not always evident.

The data presented show that changes from baseline neuropsychiatric behaviour did occur for some participants. The following chapter explores the video data and offers adjunct information to complete the understanding of the effect of a garden vignette on neuropsychiatric behaviour.

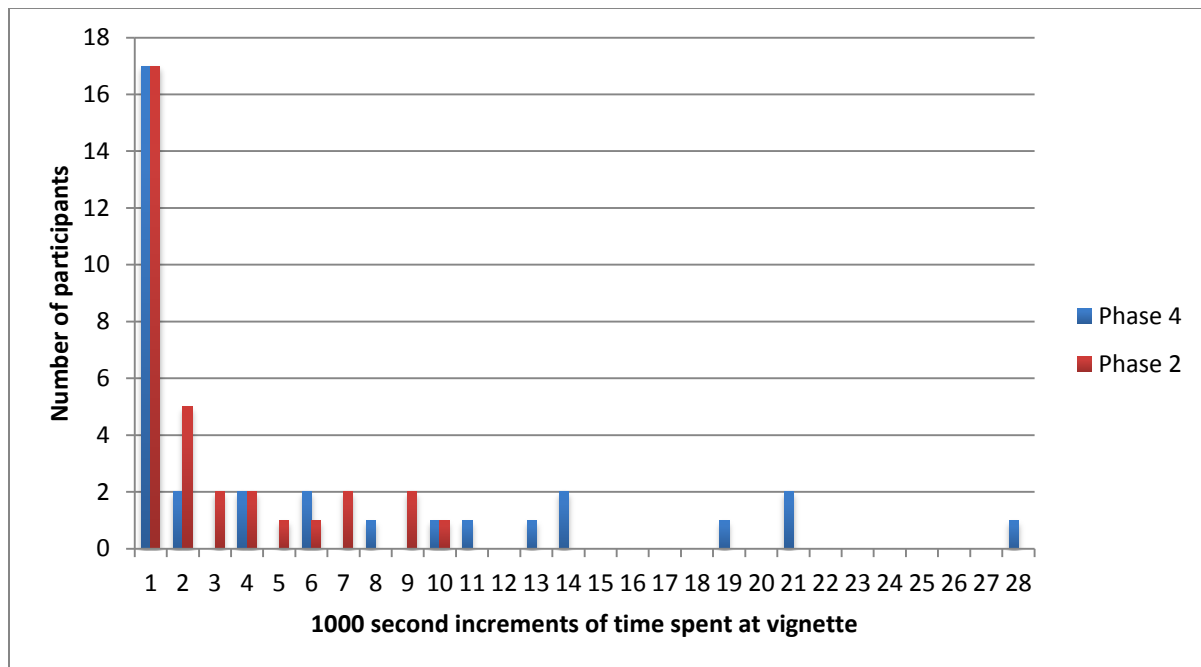
Chapter Five: **Video Data Analyses**

Phases 2 and 4 provided the four weeks of 24 hours per day digital video data (two weeks each phase). Data were coded using the MOET (see method chapter for a detailed description). The coded data were then examined for potential vignette engagement effects arising from the amount of time and how it was spent. Relationships between the time spent, vignette activity variables, neuropsychiatric test scores and PRN psychoactive medication administration (henceforth referred to as PRN medication) were analyzed using the *t*-test and Pearson *r* correlations. Potential relationships between sociodemographic characteristics and spending time at the vignette were also explored. The following discussion presents the video data in five sections: 1) *t*-test analyses of the time-grouped data (>1000 seconds or ≤ 1000 seconds) for the intervention phases, 2) analyses of the Single Question Depression Test (SQDT) data, 3) PRN medication analyses of both grouped and non-grouped time data, 4) correlational analyses of video variables and neuropsychiatric test scores by phase, 5) correlational analysis of self-determined behaviour and video variables.

5.1 *t*-Test Analyses of Time-grouped Data for the Intervention Phases

Time spent at the vignette was the MOET category that recorded exposure to the intervention (dose). The histogram (see Figure 16) revealed a bimodal distribution of time that led to a grouped-time *t*-test analysis. Explanation of the grouping rationale and process are found in the methods chapter.

Figure 16. Histogram of Total Time Spent at Vignette Comparing Intervention Phases 2 and 4



5.1.1 Analyses of Phases 2 and 4 ‘Total Time Spent at the Vignette’ and Sociodemographic Data

Time-grouped *t*-test analyses of sociodemographic data resulted in time-group sizes that were too small to offer any understanding of the relationships between time spent at the vignette and participant sociodemographic characteristics. It was decided to use mean ‘total time spent at the vignette’ (in seconds) as the dependent variable to examine potential relationships with the sociodemographic variables (rationale in method section). A *t*-test analysis demonstrated a significant relationship between having a diagnosis of vascular dementia ($n=6$) ($M = 1158.38$, $SD = 947.96$) and total time spent at the vignette ($n=25$) ($M = 485.68$, $SD = 568.83$) conditions $t(29) = 2.276$, $p = 0.03$. These data showed that individuals who had a diagnosis of vascular dementia spent significantly more time at the vignette than the mean total time spent by all participants. The small sample size and skewed nature of the data then led to calculation of the nonparametric Mann-Whitney U. No statistical difference between the median time spent at the

vignette and diagnostic categories was found although the Vascular dementia does trend toward significance at $p = 0.09$.

The t -values comparing those individuals with histories of a previous interest in gardening [yes ($n=9$) ($M = 247.28$, $SD = 303.22$)] and no previous gardening interest [($n=22$) ($M = 766.67$, $SD = 755.61$)] showed significantly greater mean ‘total time spent at the vignette’ by those with no previous history of gardening [$t(29) = -1.982$, $p = 0.011$]. However, the Mann-Whitney U calculation showed no statistical significance between ‘total time spent at the vignette’ and any categories of previous hobbies and interests.

The comparison of previous occupation and total time spent at the vignette was originally examined using a one-way repeated measures ANOVA, but the sample size in one of the categories was only one, so a t -value was computed using the two larger number groups, secondary sector ($n=3$) and service sector ($n=25$). The t -values showed no significance between total time spent at the vignette and previously having worked in the secondary sector ($n=3$) ($M = 669.89$, $SD = 543.14$) or having worked in the service sector ($n=24$) ($M = 670.5$, $SD = 744.42$), $t(27) = .001$ $p = .999$. Again the small sample and skewed nature of the sample may have played a role in these findings.

5.1.2 t-Test Analyses of Phase 2 Time- Grouped (≤ 1000 seconds and >1000 seconds) and Dependent Neuropsychiatric Inventory-Nursing Home (NPI-NH) and Dependent Neuropsychiatric Inventory-Nursing Home Occupational Distress (NPI-NH-OD) Variables Data

The t -test was used to determine if a difference existed between the mean scores on the NPI-NH and NPI-NH-OD and spending ≤ 1000 seconds or >1000 seconds at the vignette. The grouped time data showed statistically significant findings for only 2 time periods: 1) the phase 1 night shift NPI-NH and NPI-NH-OD scores, and 2) the phase 3 day shift NPI-NH scores. No

other neuropsychiatric scores showed a statistically significant difference between the mean test scores and the grouped time spent at the vignette across all phases (see Appendix A for data table). The following is a description of those findings.

The NPI-NH night shift phase 1 variable findings (NPI_nightsP1) indicated that individuals who spent >1000 seconds at the vignette ($M = 15.94$, $SD = 16.67$), were significantly more likely to have a higher NPI-NH score on night shift than those who spent ≤ 1000 seconds ($M = 3.21$, $SD = 3.36$), $t(16) = -2.985$, $p = .009$. The NPI-NH-OD score on night shift in phase 1 (NPI_OD_nights P1) finding indicated that the individuals who spent >1000 seconds at the vignette ($M = 7.13$, $SD = 6.44$) were significantly more likely than those who spent ≤ 1000 seconds at the vignette ($M = 1.07$, $SD = 1.5$), $t(17) = -3.651$, $p = .002$ to have higher NPI-NH-OD scores at baseline. In other words, individuals who cause greater occupational distress to caregivers on night shift at baseline were more likely to spend time at the vignette in phase 2 (intervention 1) of the study.

The NPI-NH score on day shift in phase 3 (NPI_daysP3) finding shows that individuals who spent >1000 seconds at the vignette ($M = 30.81$, $SD = 23.95$) during phase 2 (intervention 1) were significantly more likely than those who spent ≤ 1000 seconds at the vignette ($M = 16.50$, $SD = 9.55$), to have higher NPI-NH scores ($t = -2.091$, $p = .05$) on day shift during phase 3 (washout 1).

In summary, participants who spent > 1000 seconds at the vignette during phase 2 (intervention 1) expressed greater neuropsychiatric behaviour on night shift at baseline, caused the greatest occupational distress on night shift at baseline and were more likely to have expressed greater amounts of neuropsychiatric behaviour following removal of the intervention on day shift in phase 3.

5.1.3 t-Test Analyses of Phase 2 Time-Grouped (≤ 1000 sec and >1000 sec) and Modified Observation of Engagement Tool (MOET) Dependent Variables Data

The *t*-test was used to analyze the difference between the two time-groups and how participants engaged at the vignette. The video variables were described in the method chapter and can be found in table format in Appendix E. During phase 2 (intervention 1), participants who spent >1000 seconds at the vignette were significantly more likely to: leave the vignette with another, have their attention interrupted by another, not attend to the vignette although spending time at the vignette, and sleep at the vignette. Descriptions of those findings are below and Appendix GG presents the findings in table format.

The findings for the variable ‘departs with other’ (phase 2) show that participants who spent >1000 seconds at the vignette during intervention 1 ($M = .21$, $SD = .18$) were significantly more likely to be removed from the vignette by others than those who spent ≤ 1000 seconds ($M = .10$, $SD = .11$), ($t(28) = -2.03$, $p = .05$). This finding relates to the variable ‘attention interrupted’ finding that participants who had their attention interrupted when at the vignette during phase 2 and spent >1000 seconds at the vignette ($M = .16$, $SD = .18$) were significantly more likely to have their attention interrupted when at the vignette than those who spent ≤ 1000 seconds at the vignette ($M = .01$, $SD = .03$), $t(16) = -3.21$, $p = .005$.

The variable ‘does not attend to the vignette in phase 2’ finding shows that participants who spent >1000 seconds ($M = .08$, $SD = .11$) at the vignette in phase 2 although spending more time at the vignette, were more likely than those who spent ≤ 1000 seconds at the vignette ($M = .02$, $SD = .05$), $t(21) = -2.16$, $p = .04$ not to attend to any of the items on the vignette.

The previous finding relates to the ‘sleeping at the vignette’ variable in phase 2 (amb_sleep2) finding that shows a statistically significant amount of time was spent sleeping at

the vignette site. Participants that spent >1000 seconds at the vignette ($M = .05$, $SD = .08$) were more likely than those who spent ≤ 1000 seconds at the vignette ($M = .00$, $SD = .00$), $t(15) = -.23$, $p = .03$ to be seen sleeping at the vignette.

Findings that trended toward statistical significance at $p = .06$ and $p = .07$ were included in Appendix GG as they offer further insight into understanding engagement behaviour at the vignette from a clinical perspective. Participants who spent >1000 seconds at the vignette were more likely to touch, hold and attend to the stimulus using two senses.

The remainder of the findings in the phase 2 grouped-time data explored the differences between the time-groups and the objects of engagement. The data showed that individuals who spent >1000 seconds at the vignette were statistically significantly more likely to interact with the garden trowel and fork ($M = .04$, $SD = .06$), the seed packets ($M = .08$, $SD = .14$) and the gardening magazines ($M = .04$, $SD = .07$) than the individuals who spent ≤ 1000 seconds ($M = .01$, $SD = .02$), $t(19) = -2.19$, $p = .04$; ($M = .08$, $SD = .00$), $t(15) = -2.27$, $p = .04$; ($M = .00$, $SD = .00$), $t(15) = -2.150$, $p = .05$ respectively (see Appendix HH for the findings table).

The use of the watering can and the pots and trays, while not statistically significant offered clinical significance in helping to understand a degree of preference for other objects. Those individuals who spent >1000 seconds at the vignette were more likely to engage with the watering can ($M = .07$, $SD = .12$) and the pots and trays ($M = .10$, $SD = .14$) than those who spent ≤ 1000 seconds ($M = .01$, $SD = .05$), $t(16) = -2.27$, $p = .06$; and ($M = .02$, $SD = .04$), $t(19) = -2.01$, $p = .06$ respectively.

In summary, individuals who spent >1000 seconds at the vignette during phase 2 (intervention 1) were significantly more likely to not only be interrupted while at the vignette but to be removed from the vignette by someone else; to touch and hold items on the vignette using

two senses; and they were more likely to be found sitting at the vignette not paying any attention to the vignette itself. When individuals spent > 1000 seconds at the vignette the objects they chose to interact with were significantly more likely to be the: garden trowel and fork, seed packets, gardening magazines, with a smaller interest in the watering can and pots and trays.

5.1.4 t-Test Analyses of Phase 4 Time- Grouped (≤ 1000 seconds and >1000 seconds) and Dependent Neuropsychiatric Test Variables Data

Time-grouped data *t*-test analyses examining the difference between the two time groups and the neuropsychiatric test scores produced statistically significant results for only the Cornell Scale for Depression in Dementia (CSDD), the Neuropsychiatric Inventory-Nursing Home (NPI-NH) and the Neuropsychiatric Inventory-Nursing Home Occupational Distress Scale (NPI-NH-OD). The CSDD findings show that individuals who spent >1000 seconds ($M = 7.69$, $SD = 5.5$) at the vignette in phase 4 were significantly more likely to have higher depression scores during the phase 3 (washout 1) than those who spent ≤ 1000 seconds ($M = 3.8$, $SD = 3.05$), $t(24) = -2.054$, $p = .05$. In other words, individuals who experienced greater levels of depression prior to the reintroduction of the vignette were more likely to spend more time at the vignette when it was reintroduced. (See Appendix II for table format *t*-values.)

The NPI-NH score on night shift in phase 1 (NPI_nightsP1) indicates that those who spent >1000 seconds at the vignette in phase 4 were more likely to have had a higher NPI-NH score ($M = 16.19$, $SD = 16.44$) on night shift in phase 1 than those who spent <1000 seconds ($M = 4.50$, $SD = 4.42$), $t(18) = -2.692$, $p = .02$. The NPI-NH-OD score on night shift in phase 1 (NPIOD_nightsP1) indicates a similar pattern with the NPI_nightsP1 score. Those individuals that spent >1000 seconds at the vignette in phase 4 ($M = 7.19$, $SD = 6.37$) were identified as

having created greater occupational distress for caregivers during phase 1 than those who spent ≤ 1000 seconds at the vignette in phase 4 ($M = 1.70$, $SD = 2.26$), $t(20) = -3.143$, $p = .005$.

The NPI-NH score on day shift during phase 3 (NPI_daysP3) findings suggest that those that spent >1000 seconds at the vignette in phase 4 were more likely to have expressed neuropsychiatric behaviours ($M = 31.69$, $SD = 23.5$) during phase 3 than those participants who spent ≤ 1000 seconds at the vignette in phase 4 ($M = 17.3$, $SD = 9.04$), $t(20) = -2.202$, $p = .04$. (See Appendix II for t -values in table format.)

In summary, participants who spent >1000 seconds at the vignette in phase 4 were more likely to: have a higher depression score in phase 3 (washout 1); have had higher baseline NPI-NH and NPI-NH-OD scores on night shift; and have had higher NPI-NH scores on day shift in phase 3 (washout 1).

5.1.5 t-Test Analyses of Phases 2 and 4 Time-Grouped Data (≤ 1000 sec and >1000 sec) and Modified Observation of Engagement Tool (MOET) Dependent Variables

The phase 2 and 4 time-grouped data were examined for differences between the time-groups and type of engagement and objects interacted with at the vignette. This stage of video data analysis included both phase 2 (intervention 1) and phase 4 (intervention 2) video data.

Time-grouped data t -test analyses data produced statistically significant results for the following phase 2 variables: departing with another, being in a wheelchair and sleeping at the vignette.

The phase 4 significant findings were for: being brought by another but being left on their own, engaging by manipulating the stimulus, leaving with another, not attending to the vignette, sitting quietly and having their attention interrupted. A verbal description of the statistically significant findings is found below. Significant findings can be found in table format in Appendix JJ.

The findings for the variable ‘departs with another’ (Dpt_other2) indicate that individuals who spent >1000 seconds at the vignette in phase 4 (intervention 2) ($M = .23$, $SD = .18$) were more likely to have left the vignette with someone else during phase 2 interactions than those who spent ≤ 1000 seconds ($M = .10$, $SD = .08$), $t(23) = -2.17$, $p = .04$. In other words, they may have stayed longer at the vignette in phase 2 if someone had not removed them. In phase 4 those same individuals spent more time at the vignette.

For the variable ‘in a wheelchair’ (Wchair2) individuals who spent >1000 seconds at the vignette were more likely to be sitting in a wheelchair ($M = .66$, $SD = .68$) than those who spent ≤ 1000 seconds at the vignette ($M = .04$, $SD = .08$), $t(23) = -2.19$, $p = .04$.

The findings for the variable ‘ambience –sleeping’ (amb_sleep2) indicate that individuals who spent >1000 seconds at the vignette in phase 2 ($M = .05$, $SD = .08$) were more likely than those who spent ≤ 1000 seconds ($M = .00$, $SD = .00$), $t(15) = -2.33$, $p = .03$ to be found sleeping at the vignette in phase 2. This finding was repeated in phase 4 data where those who spent >1000 seconds at the vignette ($M = .02$, $SD = .03$) were more likely to be observed sleeping at the vignette than those who spent ≤ 1000 seconds ($M = .00$, $SD = .00$), $t(15) = -2.24$, $p = .04$.

The ‘arrives with other-other leaves’ (arr_other_other_L4) variable findings indicate the individuals who spent >1000 seconds at the vignette during phase 4 ($M = .23$, $SD = .2$) were more likely to be brought to the vignette by someone else, but the other person would leave them to engage in the vignette on their own. Those who spent ≤ 1000 seconds ($M = .01$, $SD = .03$), $t(24) = -4.11$, $p = .001$ were less likely to have been brought by someone else and left at the vignette.

The ‘engages by manipulating the stimulus’ (engage_ms4) in phase 4 finding indicates that individuals who spent >1000 seconds at the vignette ($M = .27$, $SD = .24$) were more likely

than the individual who spent ≤ 1000 seconds ($M = .06$, $SD = .13$), $t(15) = -2.84$, $p = .009$ not to just look at or touch the stimulus but actually manipulate or do something with the stimulus.

The variable ‘departs with other’ (Dpt_other4) in phase 4 finding indicates that individuals who spent >1000 seconds ($M = .30$, $SD = .23$) were more likely than those who spent ≤ 1000 seconds ($M = .07$, $SD = .05$), $t(17) = -3.8$, $p = .001$ to leave the vignette with someone else.

The variable ‘not attending when at the vignette’ (atten_no4) finding indicates that individuals that spent >1000 seconds ($M = .18$, $SD = .18$) at the vignette in phase 4 were more likely not to pay attention to the objects at the vignette than those who spent ≤ 1000 seconds at the vignette ($M = .01$, $SD = .03$), $t(16) = -3.63$, $p = .002$. This finding, which was definitely the case for certain participants, most likely arose as a result of residents falling asleep at the vignette and being left sleeping for long periods of time.

The phase 4 variable ‘attention interrupted (atten_in4) finding indicates that individuals who spent >1000 seconds ($M = .25$, $SD = .23$) at the vignette were significantly more likely to experience an interruption during their time at the vignette than those who spent ≤ 1000 seconds ($M = .02$, $SD = .05$), $t(17) = -.39$, $p = .001$. An example of this is the individual quietly sitting reading a garden magazine when a staff member comes by to give a medication, remove a bib, or just talk to the individual. The researchers observed but were not able to categorize that after interruption the participants often did not go back to doing what they had been doing previously. At times the individual would even leave the vignette and follow the person who had interrupted him/her.

The phase 4 variable ‘ambience sitting quietly’ (amb_sq4) finding indicates that individuals who spent >1000 seconds ($M = .51$, $SD = .31$) at the vignette were statistically

significantly more likely than those who spent ≤ 1000 seconds ($M = .03$, $SD = .04$), $t(16) = -5.99$, $p = .001$, to spend that time sitting quietly at the vignette. This would appear related to the previous finding that they were not attending to the vignette or articles at the vignette.

The phase 4 grouped-time data analyses identified only 3 statistically significant objects of interaction: the watering can, the living plants and herbs and the pots and trays. The orange and white bag containing seeds and planting material approached significance ($p = .07$). The statistically significant findings are described below and are in table format of the findings in Appendix JJ.

The phase 2 variable ‘object-watering can’ (obj_sc2) findings suggests that participants that spent >1000 seconds ($M = .07$, $SD = .12$) were significantly more likely than those who spent ≤ 1000 seconds ($M = .00$, $SD = .00$), $t(15) = -2.28$, $p = .04$, to interact with the watering can.

The phase 4 variable ‘objects –living plants and herbs’ (obj_LPH4) finding suggests that participants who spent >1000 seconds at the vignette in phase 4 ($M = .24$, $SD = .27$) were significantly more likely than those who spent ≤ 1000 seconds ($M = .09$, $SD = .08$), $t(19) = -2.12$, $p = .05$, to interact with the living plants and herbs that were available at the vignette.

The variable ‘objects – pots and trays (obj_pots_trays4) finding indicates that participants who spent >1000 seconds ($M = .16$, $SD = .24$) at the vignette in phase 4 were significantly more likely than those who spent ≤ 1000 seconds ($M = .03$, $SD = .05$), $t(17) = -2.19$, $p = .05$, to choose the pots and trays to interact with.

The findings for the ‘object-white and orange bag’ (obj_bagwo4) variable in phase 4 do not indicate significance, but a trending toward significance. The participants who spent >1000 seconds ($M = .04$, $SD = .07$) at the vignette in phase 4 were more likely than those who spent

≤ 1000 seconds ($M = .00$, $SD = 00$), $t(15) = -1.94$, $p = .07$, to explore the orange and white bag that contained a planting container and seeds.

5.1.5.1 Cross Tabulation Analyses of the Two Time-Groups and Two Intervention Phases

The final consideration was whether there was any relationship between the two time groups in the two intervention phases. A cross tabulation analysis and chi-square calculation showed a statistically significant relationship between the two time groups.

Table 24. Crosstabulation of Grouped-time Phase 2 and Grouped-time Phase 4

		Grouped-time Phase 4		Total
		≤ 1000 seconds	> 1000 seconds	
Grouped-time Phase 2 ≤ 1000 seconds	n	7	2	9
	% within Grouped-time Phase 4	77.8%	12.5%	36%
> 1000 seconds	n	2	14	16
	% within Grouped-time Phase 4	22.2%	87.5%	64%
Total	n	9 (100%)	16 (100%)	25 (100%)

Note. n is the number of cases; Grouped-time Phase 2 is the category of time data from phase two that was divided into two categories: those who spent ≤ 1000 seconds of time at the vignette and those who spent > 1000 seconds at the vignette; the Grouped-time Phase 4 data represent the same data for phase 4.

Individuals who spent > 1000 seconds at the vignette during phase 2 (intervention 1) were statistically significantly more likely to spend more time at the vignette in phase 4 (intervention 2) ($\chi^2 = 10.65$, $df = 1$, $p = .002$). Indeed, 87.5% returned and spent > 1000 seconds at the vignette during phase 4 (intervention 2) (see Table 24).

In summary, the video data for phase 4 showed that individuals who spent greater than 1000 seconds at the vignette were more likely to: have been removed from the vignette by someone else during the first intervention; be in a wheelchair, be found sleeping at the vignette

during the first intervention; and were more interested in the watering can during the first intervention. As participants in phase 4 (intervention 2), the individuals who spent more than 1000 seconds at the vignette were more likely to have been: brought by someone else and left to interact at the vignette on their own, taken from the vignette by someone after having been brought by someone else, and when they were engaging were more likely to manipulate the objects on the vignette demonstrating a higher level of engagement. When not engaging at the vignette the individuals who spent more time in phase 4 were likely to be sitting quietly at the vignette, possibly even sleeping which would account for the category of no attention being significant. When they were attending to the vignette though they would both look at and touch the objects on the vignette. A problem that arose for this group also seemed to be that when they were at the vignette they were also more likely to have their attention interrupted by others.

Individuals who spent >1000 seconds at the vignette in phase 4 (intervention 2) interacted most often with the following objects: living plants and herbs, the pots and trays and the orange and white bag that contained a planting medium and seeds.

Crosstabulation of time groups two and four in a 2 x 2 table (see Table 24) showed a statistically significant relationship between the amount of time spent at the vignette in phase 2 and phase 4, suggesting that those who spent a greater amount of time at the vignette in phase 2 were statistically significantly more likely to spend a greater amount of time at the vignette in phase 4.

5.2 Data Analyses of the Single Question Depression Test (SQDT)

The binary (yes/no) data produced by the Single Question Depression Test (SQDT) were analyzed using chi-square (185). The relationship between the amounts of time spent at the vignette in phase 2 (intervention 1) and the SQDT results in phases 1 through 5 were not

statistically significant. The phase 4 (intervention 2) time-grouped data showed a single statistically significant relationship between responding yes ($\chi^2 = 6.49$, $df = 1$, $p = .04$) to ‘Do you often feel sad or depressed?’ and spending greater than 1000 seconds at the vignette. Phase 5 showed no statistically significant relationship with phase 4 time-grouped data.

Table 25. Chi-Square Crosstabulation of Intervention 2 (Phase 4) Grouped-time Data

		Grouped-time Phase 4		Total
		≤1000 seconds	> 1000 seconds	
SQDT Phase 4	Yes count	0	6	6
	% within Grouped-time Phase 4	0%	60%	35.3%
	No count	7	4	11
	% within Grouped-time Phase 4	100%	40%	64.7%
Total	Count	7 (100%)	10 (100%)	17 (100%)

Note. SQDT = Single Question Depression Test

The phase 4 time group data did however show a relationship with the SQDT in phase 2 ($\chi^2 = 6.491$, $p = .035$) indicating that when the participant spent more time at the vignette in phase 2 (intervention 1), that individual was more likely to answer yes to the question “Do you often feel sad or depressed” in phase 4 (intervention 2).

5.2.1 Analysis of the Mean Differences between SQDT Scores in All Phases and across All Dependent Variables

The Single Question Depression Test (SQDT) produced participant response data. Not all participants were able to respond verbally across all phases, thus the sample size for this test was smaller and more varied than for the other neuropsychiatric tests. The numbers of respondents for phases 1 to 5 are 26, 23, 21, 23 and 19 respectively. The percent of individuals responding yes to the SQDT question “Do you often feel sad or depressed” for Phases 1, 2, 3, 4,

and 5 respectively are as follows: 46.2% (n=12), 56.5% (n=13), 38.1% (n=8), 43.5% (n=10) and 56.2% (n=10). These findings show that from baseline (n=26) to the final phase (n=19) fewer individuals were able to respond to the question. Participants self-identified as depressed during phase 2 (intervention 1) and the final washout in phase 5. The first washout phase produced the least number of individuals who stated they felt depressed and was followed by a steady increase in numbers to the conclusion of the study. Noting these changes, the *t*-test was used to explore whether a relationship existed between the SQDT and dependent video variables across all phases of the study. For phases 1 and 2, there were no statistically significant relationships between SQDT scores and all video variables. In phase 3 (washout 1) the only statistically significant finding was the variable *atten_no2*, which indicated that individuals who answered no (n=11) to the SQDT question, indicating they did not feel sad or depressed ($M = .11$, $SD = .13$), $t(11) = -2.37$, $p = .037$ were significantly more likely not to attend to the vignette than those who answered yes ($M = .01$, $SD = .03$). This finding may be expected in that individuals not feeling depressed may be more likely to seek out and engage in regular unit programming (190). In phase 4 the *t*-test analysis of SQDT (yes/no response) and video variables in phase 4 yielded the results described below and are presented in table format in Appendix KK.

The *t*-test findings for the variable ‘engages by holding the stimulus’ (*engage_hs4*) and responses to the SQDT show that the mean number of times a participant held a stimulus and answered no they were not depressed ($M = .12$, $SD = .17$) was statistically significantly different from individuals who responded yes and held the stimulus ($M = .42$, $SD = .29$), $t(15) = 2.7$, $p = .007$). For the variable ‘engages by manipulating the stimulus’ (*engage_ms4*) individuals who replied yes, (n=6) they felt sad or depressed were statistically significantly more likely to be observed manipulating ($M = .32$, $SD = .20$), $t(15) = 3.1$, $p = .007$) objects at the vignette than

those who said no ($M = .08$, $SD = .12$) they were not sad or depressed. This would indicate that when at the vignette, individuals who were sad or depressed engaged in more complex activity.

For the phase 4 'ambience sitting quietly' (amb_sq4) variable, the t -test finding indicates that the number of times a participant was observed sitting quietly at the vignette and answered yes to the SQDT indicating that they felt sad or depressed ($n=6$) ($M = .55$, $SD = .41$), $t(15) = 2.13$, $p = .05$ was statistically significantly greater than the number of times an individual was observed sitting quietly at the vignette having responded no ($M = .19$, $SD = .27$). While it may seem contradictory to the previous paragraph, perhaps those who feel sad and depressed may do so because there is nothing for them to do and those who sit quietly at the vignette are more content to do so because they do not feel they are missing something and are merely enjoying the ambience created by the garden centre rather than experiencing lack of motivation. What is not known is whether these are the same individuals.

The t -values for the variable 'object trowel and fork' (obj_t_f4) in phase 4 indicated that the mean number of times that a participant was observed interacting with the trowel or garden fork and who responded yes to the SQDT ($M = .14$, $SD = .09$) was statistically significantly greater than the mean number of times a participant who responded no was observed interacting with the trowel and fork ($M = .02$, $SD = .03$), $t(5.8) = 4.1$, $p = .02$.

The phase 4 variable 'object-soil bins' (obj_soilbins4) t -test finding indicates that the mean number of times a participant was observed interacting with the soil bins ($M = .03$, $SD = .04$), having responded no to the SQDT was statistically significantly less than the mean number of interactions with the soil bin for those individuals who responded yes to the SQDT ($M = .11$, $SD = .06$), $t(15) = 2.78$, $p = .01$.

The variables ‘whiskbroom and dust pan’ (Obj_wbb4) and ‘pots and trays’ (Obj_pots_trays4) in phase 4, while not statistically significant, were understood as having clinical importance in that they were the next most commonly chosen articles for interaction and could be included in vignette development. *t*-Test results for these two are found in Appendix KK.

In phase 5 (washout 2), the only dependent variable that achieved statistical significance was that of ‘attends with three senses’ (atten_3s4) where yes ($n=7$) ($M = .05$, $SD = .05$) and no ($n=7$) ($M = .00$, $SD = .00$), $t(6) = 2.5$, $p = .028$. The mean and standard deviation for the no group result from those individuals never attending to the vignette with three senses. This finding shows that those who said yes to the SQDT question in phase 5 (washout 2) were significantly more likely to have engaged at the vignette using 3 senses in phase 4. It also indicates that individuals who said no they were not feeling sad or depressed in phase 5 did not use three senses at any time during the intervention phase, indicating that their level of engagement may have been less. Those individuals who self-identified as feeling sad or depressed in phase 5 had been more engaged in the vignette in phase 4 and were perhaps ‘missing’ the opportunity for activity when it was removed. The presence of this result only in phase 5 and not phase 3 may have been related to the fact that this was now the second time the vignette had been ‘taken away’.

5.3 Analyses of PRN Medication Administration Data

5.3.1 Non-grouped Data Analyses for ‘Total Time Spent at the Vignette’ and The Number of Times a Neuropsychiatric Medication was Administered

Pearson *r* correlation analyses explored the strength of the relationships between the total time a participant spent at the vignette and the number of times a PRN medication was given. A

fair significant degree of relationship (188) was found to exist between total time spent at the vignette during phase 2 (intervention 1) and the number of times a participant was given a PRN medication ($r = .36$ $p = .05$). Phase 3 (washout 1) produced a fair but not significant relationship between being given a PRN medication and total time spent at the vignette ($r = .31$ $p = .09$).

5.3.2 Time-Grouped Data Analyses of PRN Medication Administration

Examining the time-grouped (>1000 seconds and ≤ 1000 seconds) data for relationships with the PRN medication administration data the t - value showed no significant differences in the means between the two time groups for phases 2 and 4 and the number of times a PRN medication was given across all phases.

5.4 Pearson Correlations Between Neuropsychiatric Test Scores and Dependent Intervention 1 (Phase 2) Video Data Variables

To ascertain the strength of the relationships between neuropsychiatric behaviour measured by the NPI-NH, NPI-NH-OD, CSDD, RAS2 and the AI, and the phase 2 (intervention 1) dependent video variables, the Pearson Correlation Coefficient was used. Significant data are presented in the text that follows, but all Pearson $r \geq .25$ or $-.25$ can be found in table format from Appendices LL through XX.

5.4.1 Pearson Correlations Between the Baseline NPI-NH and NPI-NH-OD Mean Scores and Phase 2 Video Variables

The NPI-NH scores for day shift at baseline show only a fair relationship with the NPI-NH score and using three senses ($r = .31$, $p = .001$) indicating that those individuals with higher NPI-NH scores would be fairly likely to be attending to the vignette using a greater level of engagement by engaging with 3 senses. The remaining variables showed no correlation with the NPI-NH scores on day shift.

Having a higher baseline NPI-NH scores on night shift showed a moderate to good correlation with spending time at the vignette ($r = .51, p = .004$) and being interrupted when at the vignette ($r = .60, p = .001$). Only a fair correlation is found between having higher NPI-NH scores on night shift during phase 1 and manipulating the stimulus when at the vignette ($r = .35, p = .001$) and sleeping at the vignette ($r = .37, p = .04$). Object interactions that showed good to moderate correlations with having a high NPI-NH score on night shift in phase 1 were: interactions with the white and orange bag ($r = .54, p = .002$), the tin metal planting kit ($r = .633, p = .001$) and the potted tulips ($r = .59, p = .001$). A fair degree of relationship with having a higher NPI-NH score was demonstrated with the following objects for interaction: seed packets ($r = .43, p = .02$), soil bins ($r = .49, p = .01$), pots and trays ($r = .40, p = .03$), magazines ($r = .48, p = .007$), grey garden centre ($r = .36, p = .05$). Higher NPI-NH scores on night shift during phase 2 showed a moderate to good correlation with interacting with the tin metal planting kit (see Appendix LL).

Having a higher Neuropsychiatric Inventory Occupational Distress Score (NPI_OD) (see Appendix OO) on night shift during phase 1 (baseline) correlated moderately with not being attentive when at the vignette ($r = .56, p = .001$). Only a fair correlation existed between total time spent at the vignette ($r = .39, p = .03$), being interrupted when at the vignette ($r = .47, p = .009$), and sitting quietly at the vignette ($r = .47, p = .009$) and having higher NPI_OD scores on night shift during phase 1. Examining the correlation between the NPI_OD night shift phase 1 scores and objects for interact revealed only fair correlations with the soil bins ($r = .38, p = .04$), the white and orange bag seed kit ($r = .40, p = .03$), the tin metal planting kit ($r = .49, p = .006$) and the potted tulips ($r = .41, p = .02$) (see Appendix LL). Three of the four objects chosen for interaction offer a more complex level of interaction and opportunity for exploration.

5.4.2 Pearson Correlations Between the Phase 2 NPI-NH and NPI-NH-OD Mean Scores and the Phase 2 Video Variables

The Pearson correlations between the video variables and the NPI-NH scores on day shift in phase 2 show a tendency to negative correlations although only a fair rating for correlation (188), most of which were not statistically significant. The statistically significant correlations are listed in text but all correlations $r \geq +$ or $-.25$ can be found in Appendix LL. The higher the NPI-NH score, the less likely the individual was to: engage with the soil bin ($r = -.37, p = .04$), or the pots and trays ($r = -.42, p = .02$). The only positive correlation showed that as NPI-NH scores increased the individual was more likely not to be attentive at the vignette ($r = .33, p = .08$) but was not significant. The correlations between the video variables and the mean NPI-NH-OD score in phase 2 also produced several ‘fair’ negative correlations but they were not significant. High NPI-NH-OD scores on evening shift were closer to statistical significance and showed a fair correlation (188) between being more likely to refuse to engage at the vignette ($r = .35, p = .06$) and not attending to the vignette when at the vignette ($r = .34, p = .06$). On night shift, a higher NPI-NH-OD scores was statistically significant and correlated moderately with interacting with the tin metal planting kit ($r = .58, p = .003$).

5.4.3 Pearson r Correlations Between the Phase 3 NPI-NH and NPI-NH-OD Mean Scores and Phase 2 Video Variables

Higher NPI-NH-OD mean scores on day shift during phase 3 were only fairly negatively correlated (188) and were not statistically significant. Participants with higher NPI-NH-OD mean scores on evening shift were also more likely to refuse to interact with the vignette ($r = .45, p = .01$) and be inattentive when at the vignette ($r = .38, p = .04$) in phase 2. Higher NPI-NH scores on evening shift during phase 3 correlated positively with only looking at objects at the vignette ($r = .43, p = .02$). There were, moderate to good correlations (188) between high

NPI-NH scores on night shift and not being attentive when at the vignette ($r = .56, p = .001$) or choosing the white drawer trolley ($r = .53, p = .003$) to interact with when there (see Appendix LL) for complete listing of $r \geq .25$).

5.4.4 Pearson r Correlations Between the Cornell Scale for Depression in Dementia (CSDD) Mean Scores (Phases 1 to 3) and Intervention 1 (Phase 2) Video Variables

The only video data variable that correlated fairly with having a higher CSDD mean score was found in phase 1. The correlation was with using the watering can ($r = .35, p = .06$) but was not significant. All CSDD and video variable Pearson $r \geq .25$ correlations across all phases are listed in Appendix MM. None were statistically significant.

5.4.5 Pearson r Correlations Between the Apathy Inventory Mean Scores (Phases 1 to 3) and Intervention 1 (Phase 2) Video Variables

The Apathy Inventory correlation data show statistically significant negative correlations between having a higher apathy score and refusing to engage at the vignette ($r = -.40, p = .03$) suggesting that individuals with higher apathy inventory scores were less likely to refuse to engage at the vignette. The correlation is only fair (188). The remaining correlations while not statistically significant do show that a fair degree of relationship may have existed (184). The evening shift AI correlation was similar to that of day shift. Higher apathy scores on evening shift in phase 2 showed a negative correlation between refusing to engage ($r = -.37, p = .04$) meaning that those with high evening shift apathy scores were significantly less likely to refuse to engage when at the vignette. No other statistically significant correlations were found although the phase 3 AI mean score produced a fair correlation with interacting with the white plastic covered table ($r = .35, p = .06$). All correlations where $r \geq .25$ or $-.25$ are listed in table format in Appendix NN.

5.4.6 Pearson r Correlations Between the Ryden Aggression Score 2 (modified) (Phases 1 to 3) and Intervention 1 (Phase 2) and Video Variables

Data from the RAS2 were a record of the number of aggressive events expressed by individuals throughout the day. The only video variable that correlated significantly with the RAS2 score was the phase 2 ‘refuses to engage’ variable ($r = .40, p = .03$), indicating that individuals with higher RAS2 scores during phase 4 were more likely to have refused to engage at the vignette in phase 2.

5.5 Pearson Correlations Between Neuropsychiatric Test Scores and Intervention 2 (Phase 4) Video Variables

5.5.1 Pearson Correlations Between the NPI-NH and NPI-NH-OD Mean Scores and the Intervention 2 (Phase 4) Video Variables

The findings are presented for each work shift (days, evenings and nights) and Appendix OO shows all r -values $\geq .25$ or $-.25$ in table format. There were no significant Pearson correlations between the day shift phase 4 NPI-NH and NPI-NH-OD mean scores and the phase 4 (intervention 2) video variables.

Higher NPI-NH scores on evening shift were significant and moderately correlated (188) with: greater time spent at the vignette, being in a wheelchair and sitting quietly at the vignette (see Appendix OO). A higher NPI_OD score also indicated moderate and significant correlations with total time spent at the vignette, being in a wheelchair, sitting quietly at the vignette, engaging with magazines. Fair but not significant correlations existed with purposefully arriving at the vignette, but also not paying attention to the objects, engaging with the white table, the orange bag with seeds and the potted tulips when at the vignette.

Individuals with higher NPI-NH-OD scores on night shift were significantly more likely to have spent time sleeping at the vignette ($r = .41, p = .04$). Higher NPI-NH scores also

correlated fairly although not significantly with being more likely to have been sleeping at the vignette and less likely to leave the vignette with another. There is a fair negative correlation between being removed from the vignette by someone and having a higher NPI-NH or NPI-NH-OD score, but it is not significant (see Appendix OO for a complete listing of r -values $\geq .25$ or $-.25$).

5.5.2 Pearson Correlations Between the Cornell Scale for Depression in Dementia Mean Scores (Phase 4) and Intervention 2 (Phase 4) Video Variables

All but one of the fair Pearson correlations between having a higher score on the CSDD and phase 4 video variables were negative. Appendix QQ presents all r -values $\geq .25$ or $-.25$ in table format. Only two r -values were significant; being less likely to sleep at the vignette ($r = -.40, p = .05$) and interacting with the white trolley ($r = -.39, p = .05$). The single positive correlation was between having a higher score on the CSDD and leaving the vignette with someone else ($r = .31, p = .12$). These findings indicate that the greater the depression as identified by the higher score the more likely the individual would be to leave the vignette with someone else, either by being taken away by someone or by following someone away from the vignette. The most common scenario was that of being removed by a caregiver from the vignette. The higher the CSDD score the less likely the individual would be to come to the vignette by him/herself and the less likely they would be to leave by their own selection. The higher the CSDD score, the less likely the individual would be found sleeping at the vignette. Objects for interaction that were negatively correlated to higher scores on the CSDD were the living plants, storage trolley and the grey garden centre itself.

5.5.3 Pearson Correlations Between the Apathy Inventory (AI) Mean Scores (Phase 4) and the Intervention 2 (Phase 4) Video Variables

The AI variable presented data from two shifts, days and afternoons. The findings will be presented separately for each shift. Four of the five day shift phase 4 Apathy Inventory fair correlations between the video variables were negative and none were significant. Appendix RR presents the r - values $\geq .25$ or $-.25$ in table format. A higher AI score on day shift presented a fair negative correlation with the following video variables: having their attention interrupted, and engaging with living plants and herbs, the magazines and the white table. These findings indicate that an individual with a high apathy score would be less likely to interact with the living plants and herbs, magazines and the white table. The single positive fair correlation was with not attending when at the vignette. If the individual is doing nothing, there is no reason for the caregiver to interrupt; therefore, the individual will be left alone at the vignette. Given the characteristics of apathy, these results are a potentially predictable response.

The phase 4 afternoon shift AI correlations produced a single fair correlation that was significant. A higher apathy score on evening shift was significantly correlated with being in a wheelchair ($r = .38, p = .05$). Higher apathy scores on evening shift produced fair positive correlations with being brought to the vignette by another and being left ($r = .31, p = .13$), sitting quietly at the vignette ($r = .27, p = .18$). These findings suggest that those individual who are apathetic are more likely to be in a wheelchair, more dependent on others bringing them to the vignette and are more likely to sit quietly at the vignette. Higher apathy scores on afternoon shift were also negatively correlated with the garden centre itself ($r = -.30, p = .14$) and the potted tulips ($r = -.29, p = .15$), suggesting that apathetic individuals were less likely to interact with the grey garden centre or the potted tulips.

5.5.4 Pearson Correlations Between the RAS2 (modified) Mean Scores (all phases) and the Phase 4 Video Variables

Significant phase 4 video variable correlations with the RAS2 data showed that individuals in wheelchairs at the vignette were more likely to have a greater number of recorded aggressive incidents during phases 3 and 5 (see Table 3). It was also found that individuals with higher RAS2 scores during phase 5 were significantly more likely to attend to the vignette using only one sense, be sitting quietly at the vignette and show a preference for the real living plants (see Table 26).

Table 26. Significant Pearson *r* Correlations Between RAS2 (modified) Scores and Phase 4 Video Variables

RAS2 (modified)	Phase 4 Video Variable	<i>r</i>	<i>p</i>	n
RAS2_P3	Wchair	.45	.02	26
RAS2_P4	Obj_cpp4	.41	.04	26
RAS2_P5	Atten_1s	.52	.006	26
	Amb_sq4	.45	.02	26
	Obj_LPH4	.46	.02	26

Note. RAS2 is Ryden Aggression Scale; Wchair is wheelchair; Obj_cpp4 is compressed peat pellets; atten_1s is attention 1 sense; Amb_sq4 is using for ambience sitting quietly; obj_LPH4 is living plants and herbs; 4 refers to phase 4; P3, 4 and 4 refers to phases 3, 4 and 5; n is number of participants.

5.5.5 Pearson Correlations Between Day Shift Phase 5 (Washout 2) NPI-NH and NPI-NH-OD Scores and Phase 4 Video Variables

The NPI-NH and NPI-NH-OD data were collected on all three work shifts (days, evenings and nights). Appendices SS and TT present all shift data in table format including all Pearson *r* correlations $\geq .25$ or $-.25$. Both the NPI and NPI_OD day shift scores during phase 5 (washout 2) showed very similar correlations. The higher day shift NPI and NPI_OD scores expressed in phase 5 (washout 2) showed a fair degree of correlation (188) with several phase 4 video variables. The significant correlations indicated that individuals with higher NPI-NH scores on day shift were more likely to have come to the vignette with another and left with

another, engaged visually, turned their body toward the vignette and held the stimulus. They were also more likely to be sitting quietly at the vignette and their preferred objects for interaction were the whiskbroom and dustpan, seed packets, the white and orange bag with seeds and the tin metal planting kit. Participants with higher NPI-NH-OD scores were significantly more likely to leave the vignette with another, engage by holding an object, be in a wheelchair and be sitting quietly. The significant correlations with objects of engagement were the same as for the NPI-NH except for the orange bag and seeds (see Appendix SS). Fair, but not significant correlations between the day shift NPI-NH and the NPI-NH-OD and the video variables can be found in Appendix SS.

5.5.6 Pearson Correlations Between Evening Shift Phase 5 (Washout 2) NPI-NH, NPI-NH-OD Scores and Phase 4 Video Variables

Higher NPI-NH scores on evening shift showed a fair, significant degree of correlation with a single video variable, that of sitting quietly at the vignette ($r = .42, p = .03$). Fair nonsignificant r -values existed between having a higher NPI-NH score and attention at the vignette using one sense ($r = .36, p = .07$), and interest in the seed packets ($r = .25, p = .21$). These findings indicate that individuals with higher NPI-NH scores on evening shift during phase 5 (washout 2) were more likely to have sat quietly at the vignette, using only a single sense (most likely vision) with the seed packets attracting the greatest interest.

Higher NPI-OD scores on evening shift during washout correlated in a fair and significant manner with the following video variables: sitting quietly at the vignette ($r = .50, p = .01$), looking at ($r = .40, p = .04$) and turning the body toward the vignette ($r = .41, p = .04$). A good to moderate correlation existed between having a higher NPI-NH-OD score on evening shift during washout and having interacted with the following vignette objects: whisk broom and

dustpan ($r = .42, p = .03$), watering can ($r = .39, p = .05$), seed packets ($r = .41, p = .04$), metal planting kit ($r = .38, p = .05$), and magazines ($r = .30, p = .05$). Fair but nonsignificant correlations existed between higher NPI-NH-OD scores on afternoon shift and the following video variables: being more likely to come to and leave the vignette independently, touching and manipulating the objects (see Appendix TT). Significant correlations between higher NPI-NH-OD scores and objects of interaction were: the whisk broom and dust pan, the watering can, seed packets, magazines and the metal planting kit.

The findings indicate that during phase 5, individuals that created greater occupational distress for caregivers on evening shift were fairly independent in their arrivals and departures from the vignette in phase 4. They engaged visually, most often using only one sense when at the vignette. They would have been found sitting quietly at the vignette possibly looking at magazines but when they chose to interact with objects on the vignette were most likely to choose active engagement objects; e.g., the whisk broom and brush, the watering can, seed packets and the metal planting kit.

5.5.7 Pearson Correlations Between Night Shift Phase 5 (Washout 2) NPI, NPI-NH-OD Mean Scores and Phase 4 Video Variables

Fair, significant Pearson correlations between higher NPI-NH scores and phase 4 video variables on night shift during phase 5 (washout 2) were: being in a wheelchair ($r = .40, p = .04$), and attending to the vignette using 1 sense ($r = .44, p = .03$). Although not statistically significant, fair r -values were found between higher NPI-NH night shift scores and the following video variables: engaging visually, being interrupted when at the vignette, sitting quietly at the vignette, and compressed peat pellets (see Appendix UU).

Higher NPI_OD scores (occupational distress) on night shift during the final washout phase showed a moderate correlation (188) with being in a wheelchair ($r = .53, p = .005$). Lower levels of engagement complexity indicated by attending with one sense only, ($r = .46, p = .02$), sitting quietly ($r = .46, p = .02$) and having your attention interrupted ($r = .41, p = .04$) when you were at the vignette were significant correlations with producing greater occupational distress for staff on night shift in phase 5. The correlation with higher NPI_OD scores and objects of interaction showed that the correlations were only fair and not statistically significant. The strongest of these were with the living plants and herbs, the compressed peat pellets and magazines (see Appendix UU).

5.5.8 Pearson Correlations Between Phase 5 (Washout 2) Apathy Inventory (AI) and Day Shift Data and Phase 4 Video Variables

The apathy inventory scores on day shift during the second washout period in phase 5 and the phase 4 video variables correlated negatively with the following; being in a wheelchair ($r = -.31, p = .18$), attending to the vignette with one sense only ($r = -.25, p = .22$), being interrupted at the vignette ($r = -.25, p = .23$) and interacting with living plants and herbs ($r = -.38, p = .06$) (see Appendix VV). Although not statistically significant, the negative r -values indicate that the individual with higher apathy scores were much *less* likely to: be in a wheelchair; attend using one sense and be interrupted when at the vignette during the intervention phase. A single positive phase 5 day shift fair r -value was not significant. The correlation was between having a higher AI score and not being attentive to anything when at the vignette ($r = .33, p = .06$) (see Appendix VV).

Fair and significant r -values (188) were found between having higher evening shift AI score during phase 5 (washout 2) and being brought to the vignette by someone else and being

left on their own at the vignette ($r = .47, p = .02$), interacting with the soil bins ($r = .41, p = .04$) and the grey garden centre itself ($r = .48, p = .01$). Higher apathy inventory scores negatively correlated with the type of engagement that occurred at the vignette. Although not significant, those individuals with higher AI scores were less likely to touch or manipulate the stimulus ($r = -.28, p = .17$), inappropriately manipulate the stimulus ($r = -.37, p = .06$) or be in a wheelchair ($r = .29, p = .15$) (see Appendix VV).

5.5.9 Pearson Correlations Between Phase 5 (Washout 2) Cornell Scale for Depression in Dementia and Phase 4 (Intervention 2) Video Variables

The phase 5 Pearson correlation analyses between the Cornell Scale for Depression in Dementia score and video variables produced the following two fair significant r -values (188); leaving the vignette with another ($r = .48, p = .01$) and sleeping at the vignette ($r = -.42, p = .03$). Fair but not significant r -values were found between having a higher CSDD score and total time spent at the vignette, arriving at the vignette and being left, not being attentive when at the vignette and interacting with the white storage drawer trolley (see Appendix WW for r -values). These data offer that individuals with higher CSDD scores, while being more likely to spend more time at the vignette, appear to require a greater level of caregiver involvement. They are brought by another and while spending more time are not sleeping but are still not attending to the objects on the vignette.

5.6 Pearson Correlations Between Self-determined Behaviour, Neuropsychiatric Behaviour and PRN Medication

Thirty participants engaged in self-determined arrivals at the vignette during phase 2 and 26 during phase 4. The difference in the number of self-determined visits per phase and the skewed nature of the data (a full description of reasoning is found in the method chapter) led to the creation of two groups per phase. In phase 2 the groups compared were; participants with \leq

2 self-determined visits and participants with > 2 visits. In phase 4 the groups compared were: participants with ≤ 4 visits and participants with > 4 visits. Twelve of thirty participants made two or more self-determined visits in phase 2 and twelve of twenty-six participants made four or more self-determined visits in phase 4. Almost half of all visitors to the vignette were self-determined. The difference between the numbers of self-determined arrivals in the two phases was not statistically different. The number of self-determined visitors and the increase in the mean number of self-determined visits as the study progressed may reflect the need to develop familiarity(191) to achieve a level of comfort to support self-determined activity.

The grouped crosstabulation and chi-square analyses showed there were no significant relationships between the groups (self-determined or not self-determined) for MMSE scores and diagnoses. The diagnoses for the most common self-determined visitors were as follows: Alzheimer, vascular, alcohol-related and frontal lobe dementia. The t -test was then used to examine the data for mean score differences between being self-determined or not and the neuropsychiatric test scores. During phase 2 at the vignette, there were no significant findings between self-determined arrival and the SQDT or the number of PRN medications given across all five phases of the study.

A single significant t -value was found for the phase 2 self-determined arrival data. This finding indicated that the group who were more self-determined ($n=12$) ($M = 4.67$, $SD = 2.87$) were significantly more likely to have lower CSDD scores in phase 4 than the group who were not self-determined ($n=18$) ($M = 8.56$, $SD = 3.88$), $t(28) = -.296$, $p = .004$. The phase 2 self-determined arrival data approached significance with the Apathy Inventory evening shift (AI) data in phase 5. Participants who were self-determined in their arrival ($n=12$) ($M = 6.17$, $SD =$

2.62) were more likely to have lower AI scores than those who were not self-determined (n=18) (M = 8.11, SD = 2.63) on evening shift in phase 5, $t(28) = -.199, p = .057$.

Phase 4 self-determined arrival data showed that once again there were no significant relationships between SQDT scores or number of PRN medications given and being self-determined in visiting the vignette. Phase 4 self-determined arrival data indicated that participants who were self-determined (n=12) (M = 12.75, SD = 16.66) were more likely to have higher NPI-NH scores on night shift during phase 3 than those who were not self-determined (n=14) (M = 2.79, SD = 3.76), $t(12) = .215, p = .05$. A second significant relationship with the phase 4 self-determined arrival data and the phase 4 CSDD scores was found. Participants who were self-determined (n=12) (M = 5, SD = 3.52) were more likely to have lower CSDD scores in phase 4 than those who were not self-determined (n=14) (M = 8.43, SD = 3.72), $t(24) = -2.42, p = .02$. The phase 5 *t*-test data showed no statistically significant differences between the mean neuropsychiatric test scores and self-determined arrival at the vignette.

Pearson correlations to understand the strength of the relationship between self-determined behaviour and the video variables are documented in table format for both phases 2 and 4 in Appendices XX and YY respectively. For phase 2 there were significant excellent *r*-values between being self-determined and being purposeful in arrival, leaving by oneself, engaging visually and turning the body toward the stimulus. Significant moderate to good *r*-values existed between being self-determined and: touching and holding the stimulus, attending with one and two senses, sitting quietly, and objects for interaction including: the grey garden centre, and living plants and herbs. Fair, significant *r*-values existed between being self-determined and: being in a wheelchair, manipulating the stimulus, having attention interrupted, and interacting with the garden trowel and fork, garden gloves, the watering can, whisk broom

and dustpan, seed packets, and pots and trays. The phase 4 correlation analysis presented very similar data, but often with higher *r*-values and greater significance (see Appendix YY).

5.7 Summary of Findings for Video Variables

The findings from the video data analyses revealed a complex interaction between time spent at the vignette, the expression of neuropsychiatric behaviour and participant interactions with objects at the garden vignette. Diagnoses and disease-type analyses indicated limited relationships with activity at the vignette. Vascular dementia was the only diagnosis to present a hint of relationship with being more likely to spend time at the vignette. Only gardening as a previous hobby showed a relationship with spending time at the vignette. The use of PRN medication and vignette activity showed no correlation with being a frequent attender and being given more PRN medication. Not filtering for frequent attendance did show a fair correlation between spending more total time at the vignette and being given more medication in phase 2.

The video data analyses also offered the opportunity to describe with greater confidence the strength of the relationship between being self-determined, not only the type of activity that this facilitated, but also the type of objects preferred by individuals who were self-determined. The presence of depression and apathy were found to affect self-determination but there was no relationship with being self-determined and being given more PRN medication. To facilitate greater understanding of the effect of activity at a garden vignette on the expression of neuropsychiatric behaviour and PRN medication administration, these findings and their relevance to practice will be explored in the discussion section.

Chapter Six: **Discussion**

The research question was whether engaging at a garden vignette would have an effect on the neuropsychiatric behaviour expressed by individuals with moderate to severe dementia living in a long-term care setting. It was hypothesized that time spent engaging at a garden vignette with biophilic characteristics would decrease the frequency and severity of neuropsychiatric behaviours and reduce PRN psychoactive medication use. To say unequivocally that the hypotheses were supported by the findings of this study is not possible. Significant findings that support the hypotheses include:

1. Significant differences, primarily between baseline and all other phases, for the expression of general neuropsychiatric behaviour, caregiver distress, and third-party assessed depression and aggression.
2. Participants who in phase 2 spent significantly more time at the vignette spent significantly more time at the vignette in phase 4.
3. Participants who expressed greater neuropsychiatric behaviour and created greater caregiver distress at baseline spent more time at the vignette in phase 2.
4. Expressions of neuropsychiatric behaviour and caregiver distress on evening shift in phase 3 (washout 1) were significantly greater than those in phase 1.
5. Participants with greater levels of third-party assessed depression spent significantly more time at the vignette in phase 4.
6. Return of the vignette in phase 4 showed that participants who expressed greater expressions of neuropsychiatric behaviour and caregiver distress at baseline and on day shift during the first washout spent more time at the vignette.
7. An absence of significant increases in neuropsychiatric behaviour during both intervention phases except on evening shift in phase 4.
8. Significant correlations between how time was spent at the vignette and the expression of neuropsychiatric behaviour including: being in a wheelchair, spending quiet time, being autonomous and the complexity of activity engaged in.

Findings that do not support the hypotheses:

1. No significant differences between the phases for self-identified depression, apathy and PRN psychotropic medication administration.
2. No significant relationships between 'time spent at the vignette' and PRN psychotropic medication administration.

The following discussion explores the findings in relation to both hypotheses. The discussion proceeds from a general understanding of effect of the garden vignette on neuropsychiatric behaviour as evidenced by differences between the phases, through increasing levels of specificity including total time, grouped time and how time was spent. All are discussed in relation to context and with reference to the current literature. The methodological challenges related to study design, including phase and time effects, sample size, sampling criteria, measurement tools and the use of caregiving staff to evaluate behaviour are examined with suggestions for improvement. Implications of the study findings for clinical practice, future research and theory development are also highlighted.

6.1 The Phase Effect on Neuropsychiatric Behaviour

It was hypothesized that engaging in activity at a garden vignette would reduce both neuropsychiatric behaviour and PRN psychoactive medication use. The significant findings showing phase effect only partially supported the hypotheses. Participants showed a significant decrease in neuropsychiatric behaviour during the first intervention phase but this was not repeated to the same extent in the second intervention phase. Participant neuropsychiatric behaviour during the washout phases never returned to baseline levels, potentially indicating a carryover effect. The effect of the garden vignette was greatest between phase 1 and phase 2 for both day shift and evening shift, although for evening shift the significant difference was retained across all phases. The significance of the evening shift behaviour responses may be complicit with temporally related changes in behaviour (sundowning) (192, 193) or different levels of staff for evening shift resulting in assessments or expectations of greater neuropsychiatric behaviour (193). The failure to demonstrate significant differences for night shifts might be expected because the majority would be sleeping.

No significant phase differences for the AI and the SQDT may reflect that apathy and depression are not typical responses to short-term environmental change (194), and/or fewer of participants expressed apathy or were able to answer the yes/no “Do you often feel sad or depressed?” question. No significant phase differences for the number of times a PRN psychoactive medication was given may be reflecting habituated staff responses to a particular resident’s behaviour (195) or general habituated behaviour to a symptom type (196). Insufficient time and limited resources are often cited as reasons for using psychotropics to manage neuropsychiatric behaviour rather than psychosocial interventions (142). Challenges with measurement tool completion and interpretation of behaviour may also have affected the results; these are discussed later in the chapter. The small sample size and the large standard deviations indicate poor statistical power, meaning that it is difficult to say with certainty that no difference existed.

Previous studies have shown that environmental change may trigger neuropsychiatric behaviour (197-199). The fact that the vignette did not appear to increase neuropsychiatric behaviour over the duration of the study may be encouraging for activity therapists hesitant to change environments for fear of inciting significant neuropsychiatric behaviour.

6.2 ‘Time Spent at the Vignette’ and Neuropsychiatric Behaviour Response

Initial analyses showed that insertion of the vignette created a significant difference between the phases on some neuropsychiatric behaviour scores and only for certain shifts but did not answer the question of whether actual time spent at the vignette had an effect on neuropsychiatric behaviour. To address that question, video data using ‘total time spent at the vignette’ were analyzed for relationships with neuropsychiatric behaviour and being given a PRN psychoactive medication.

The findings again present mixed support for the hypotheses. The bimodal distribution and related analysis showed that participants who spent the most time at the vignette in phase 2 were significantly more likely to return and spend the most time in phase 4, potentially indicating: 1) simply a retention of interest in the vignette, or 2) the activity met the needs of those who initially participated and sought a similar experience on its return (73).

Those who spent the most time at the vignette in phase 2 had shown a greater degree of neuropsychiatric behaviour and were more problematic to staff on night shift at baseline. When the vignette was removed in phase 3 they were also significantly more likely to cause staff occupational distress on day shift, potentially indicative of ‘missing’ the vignette. When the vignette was returned in phase 4, the phase 2 pattern of behaviour was repeated. Participants who expressed greater neuropsychiatric behaviour at baseline on night shift were significantly more likely to spend more time at the vignette. These relationships considered in conjunction with the absence of a significant increase in neuropsychiatric behaviour at nighttime during the intervention phases may be indicating that engaging at the vignette had a positive effect on neuropsychiatric behaviour. That the effect did not repeat in the final washout phase may be attributed to research fatigue and organizational change; these are discussed in detail later in the chapter. Others have also produced unpredicted or few findings of behaviour change in later phases of intervention studies with attributions to disease progression effects on negative rather than positive behaviours (200) and enduring effects of treatment (201).

It was also shown that when the vignette returned in phase 4 participants who spent the most time at the vignette had significantly higher levels of depression during phase 3 (washout 1) (as determined by others using the CSDD) and self-identified as being depressed in phase 2. That the SQDT and CSDD findings are not always reflective of each other as measures of

depression is not surprising. Differences in self-report versus informant assessments with respect to quality of life in dementia are well known (85, 86, 202), but ‘emotional well-being’ ratings are garnering more interest. Self-report versus informant differences in this field have been attributed to intraindividual variability and living in the ‘here and now’ often associated with memory impairment (203). Self-report is more likely to be an ‘in the moment’ assessment of feeling rather than a weekly assessment of emotional well-being (200). Given that Kolanowski et al. (200) found negative emotions were more susceptible to environmental manipulation, it may be that individuals who self-identified as depressed sought interactions at the vignette because they were depressed and responded to vignette removal by being so obviously depressed, it was reported by staff. Others have reported finding a decrease in pleasure related to withdrawal of activities (201).

6.3 How Time Was Spent and Effect on Neuropsychiatric Behaviour

To further understand how ‘time spent at the vignette’ might affect behaviour, the type of activity and level of engagement during time spent were examined. Correlational analyses identified the activity variables significantly related to neuropsychiatric behaviours as: ‘being in a wheelchair’, spending quiet time at the vignette, being self-determined at the vignette, and the degree of complexity engaged in at the vignette.

The Pearson correlations across all phases and all shifts showed a variety of relationships. An increase in the number of fair correlations was noted as the study progressed, perhaps indicating the role of familiarity and increased comfort in exploring the vignette (191, 204). The majority of Pearson correlations were in the fair to moderate range ($r = .25$ to $.75$) (184, 188). The use of third-party assessments of psychological symptoms that may be less well defined does not produce the excellent Pearson r correlations ($r = .75$ or greater) found in bench science

(184). Lower r -values in psychosocial research are not uncommon (184) and current thinking proposes the acceptance of lower r -values as indicators of importance when examining psychological symptoms as found in this study (184, 188). The following discussion highlights the significant correlations between the video variables and neuropsychiatric test scores with a focus on: ‘being in a wheelchair’, quiet time at the vignette, role of autonomous activity, and the effect of level of engagement.

6.3.1 Being in a Wheelchair

The video variable ‘being in a wheelchair’ presented strong correlations across phases 3, 4 and 5 with all but one neuropsychiatric test. Participants in wheelchairs during phase 3 were significantly more depressed. In phase 4 on evening shift, wheelchair bound participants had significantly higher expressions of neuropsychiatric behaviour, created significantly greater caregiver distress and were significantly more apathetic. This trend continued in phase 5 on both day and night shifts but not evening shift. These correlations between being in a wheelchair and having higher neuropsychiatric test scores also correlated significantly with spending the most time sitting quietly at the vignette and being dependent on others to bring and remove them, indicating a relatively high level of dependence.

The absence of any neuropsychiatric test score correlations with being in a wheelchair in phases 1 and 2 seems to be an anomaly, but was likely the result of fewer observations of individuals in a wheelchair interacting at the vignette. During the first intervention, being brought to the vignette was associated with the participant expressing less severe neuropsychiatric behaviour or creating less distress for the caregiver. Antithetical were participants in wheelchairs. They expressed greater neuropsychiatric behaviour and created greater caregiver distress which may have led to staff reluctance to include them in vignette

activity (205), resulting in fewer observations of them during the first intervention phase. These findings may also be reflecting the creative use of the wheelchair as a means to manage behaviour. Being in a wheelchair reduced opportunities for close interaction and the potential for assertive or aggressive interactions with other residents. Several participants were able to walk, but were nonetheless maintained with lap belts in a wheelchair. Other authors have corroborated that difficult to manage residents were less likely to be brought by staff to the vignette (79, 206). These authors also describe a reluctance of staff to encourage those with the least functional ability, agitation or apathy to engage in activity. If not assisted to the vignette, it may have taken some time for individuals in wheelchairs to notice and/or position themselves for comfortable engagement at the vignette. The video recorded many instances of persistent individual struggle by those in wheelchairs to access the objects in the vignette. The increase in correlations after the first intervention may also be attributable to both staff and residents' feelings of increased familiarity (191, 204) and a sense of safety as there had been no experience of untoward incidents occurring during the first intervention.

The following example illustrates the ability of those who may be disruptive and in wheelchairs to seek out and engage in activity. During the first intervention a participant was observed on the periphery always watching but never engaging. Only 4 of 22 of this participant's visits occurred during intervention 1. During the second intervention this individual spent more and more time coming progressively closer to the vignette and eventually reaching out and touching an object. The participant's interactions were varied, from visual engagement only to the more complex activity of picking up a magazine and thumbing through the pages, turning the page over top of the toast that had been left by the aide. This same individual had been asked to participate but would refuse and rapidly roll away in the wheelchair. Nineteen of

twenty-two visits were self-determined. During the 3 assisted visits the participant was wheeled to the vignette and left there. On two of these three occasions the participant showed no attention when at the vignette. During MMSE testing the participant's single verbal response of "I want to go home" and inability to complete any of the required tasks led to a score of zero. Although seriously limited in ability to engage with others, the vignette had piqued this participant's curiosity and the self-determined nature of the activity afforded an opportunity to engage in a manner that met personal needs and ability. For this individual the vignette seemed to fulfill the need for uniquely self-determined engagement and activity.

It is known that individuals with severe cognitive and functional disability are often excluded from activity (79, 206). Others have shown the benefit from one-on-one activity matched to cognitive and functional ability (143), personality (196), and previous interests (201); however, the retention of interest and ability in those who are wheelchair bound with severe cognitive impairment and significant expressions of neuropsychiatric behaviour is less understood. The demonstration that a garden vignette created an opportunity for such an impaired individual to reconnect with the external environment shows the potential for environmental enhancement to engage individuals with dementia. The capacity to reduce expressions of neuropsychiatric behaviour in the wheelchair bound is less clear and requires further investigation.

6.3.2 Quiet Time at the Vignette

As noted previously, participants who spent the greatest amount of time at the vignette did so in a passive state, sleeping (phase 2) or sitting quietly or being inattentive (phase 4). The effect of this passivity was noted primarily in the later phases of the study. The hypothesis proposed that time spent engaged at the vignette would reduce expressions of neuropsychiatric

behaviour. The findings showed that passivity at the vignette correlated significantly with nighttime expressions of neuropsychiatric behaviour, depression and apathy.

There were no significant correlations between spending greater amounts of time sleeping at the vignette and expressing greater neuropsychiatric behaviour or creating greater distress for caregivers on night shift during the intervention phases. Phases 1 and 3, however, showed significant correlations between the phase 2 vignette variables of 'sleeping' and 'not attending' and greater expressions of neuropsychiatric behaviour on night shift (phase 3) and greater caregiver distress (phases 1 and 3). It is possible that, together, these correlations may be indicating that time spent sleeping was less when the vignette was present than when it was removed. No video recording took place during non-intervention phases so there is no means of establishing whether this was indeed the case. There may already have been established patterns of behaviour related to boredom (207), medication (208) or dementia-related pathological sleep changes (209) which accounted for increases of neuropsychiatric behaviour on night shift when the vignette was absent and the observations of sleeping at it when it was present.

It is not just daytime sleep, however, that increases nighttime wakefulness. The lack of engagement in daytime activity has also been associated with greater nighttime wakefulness (210-214). It may be that the vignette offered just enough stimulation, novelty, difference or opportunity for activity to enhance activity rhythms, which Martin et al. (212) have identified as having the potential to improve disrupted sleep/wake patterns. The absence of any significant correlations between greater neuropsychiatric behaviour and passivity during the intervention phases may be reflecting enhanced activity rhythms or disrupted sleep/wake patterns (215), but given the sample size, not to the extent of statistical significance.

Participants who expressed greater neuropsychiatric behaviour on day shift at baseline were more likely to be found sleeping at the vignette, but were also more likely to engage in complex activity. These findings indicate that novelty and curiosity may not always be able to counter the daytime sleep effects of medication, pathology or nighttime wakefulness. When the individual is alert, however, their engagement in more complex activities (206, 211) may affect activity rhythms (212), leading to the reduced expressions of neuropsychiatric behaviour on night shift observed during the intervention phases.

The findings related to daytime sleep and nighttime wakefulness may also be explained by staff responses to wakefulness. Wakefulness during the night may facilitate or even precipitate the expression of neuropsychiatric behaviour, e.g., aggressiveness in wanting or trying to get up. Staff may be inclined to interpret nighttime wakefulness as inappropriate, categorizing restiveness and inability to sleep as neuropsychiatric behaviour. Yamakawa (216), comparing nighttime movement in dementia patients using integrated circuit tag monitoring, found that nurse documentation of movement behaviour at night occurred only when the behaviour exceeded their expected norm for the patient or if the patient had travelled far enough to be noticed by the staff. The nurse's interpretation of the expected nature of the behaviour thus played a role in what was known and recorded about that patient's sleep behaviour. It is possible then that the caregivers in this study expected the participants to sleep during the night and when they did not, it was noted as neuropsychiatric behaviour.

Being asleep at the vignette and not being attentive also correlated with CSDD scores. In phase 5, participants who had slept at the vignette in intervention phases were determined to be less depressed, but those who were 'inattentive' at the vignette were determined to be more depressed. It may be that sleeping in the presence of biophilic components was restorative (217)

or that biophilic components facilitated sleep thereby affecting mood (218). Whatever the mechanism, the potential for activity intervention to have a carryover effect on mood has also been described by Kolanowski et al. (201). Inattention at the vignette may be highlighting the subgroup of individuals with dementia described by Daffner et al. (219) who do not appear to be able to spontaneously initiate or activate attentional resources and are unable to respond appropriately to objects in the environment. Even though inattentive, these participants may have experienced some ambience effect which was missed when the vignette was removed and resulted in behaviour that caregivers determined as expressions of depression. The differences found between sleeping and being inattentive may also be an artefact of video data categorization where it was difficult to determine if downcast eyes were sleeping eyes or merely periods of inattention.

A similar pattern of behaviour might also be expected with the AI correlations. Participants with higher apathy scores in phases 4 and 5 showed fair correlations with being inattentive and sitting quietly at the vignette, a reflection of Daffner et al.'s (219) work described previously. Being asleep, however, did not correlate with higher AI scores during any phase on any shift. The absence of correlation between higher AI scores and the video variables of not being attentive, sitting quietly and sleeping at the vignette in phases 1, 2 and 3 are inconclusive findings and may be related to methodological challenges of understanding the concept of apathy or AI tool design, which is geared to measures of motivation rather than general symptomology.

Given the above findings and discussion it would appear that even passive encounters with the vignette created an experience that may have affected nighttime sleep, depression and apathy scores. The small sample size, medication effects and disease pathology may also have contributed to these findings and confound the interpretation.

6.3.3 Autonomous Engagement in Activity

While the hypotheses did not identify autonomous activity as a variable, it was proposed that seeking out novel and challenging experiences is inherent to human nature, is a basic human need and that the ability to do so in an autonomous manner creates a sense of well-being (78). The intervention was deliberately designed to support autonomous activity. It was proposed that this autonomous behaviour would reduce the expression of neuropsychiatric behaviour. It was measured by the video variable ‘arrived by self’ and was described as self-determined behaviour.

Self-determination, a characteristic of human nature, includes the seeking of novel and challenging experiences influenced by internal and external motivations (75, 78). Environments that support autonomous behaviour lead to increased levels of both motivation and self-determination, which in turn foster greater adaptive cognitive and behavioural outcomes (83). The self-determination findings from this study reflect self-determined behaviour patterns found in non-demented individuals whose opportunities for autonomous activity are restrained. Some participants, even with dementia, retained self-determined behaviour. An increase in the median number of self-determined visits from two during phase 2 (intervention 1) to four during phase 4 (intervention 2) reflects Vallerand et al.’s (83) assertion that environmental support of autonomous behaviour increases levels of self-determination. Showing more self-determination in the two intervention phases was associated with lower apathy and depression test scores, perhaps a reflection of the intricate relationship between motivation, opportunity and self-determination or a carryover effect from two experiences with autonomous activity that contributed to a greater sense of well-being (78, 204). When the opportunity for autonomous activity was removed a significant increase in global neuropsychiatric behaviour was noted on day shift (phase 3), a behavioural outcome that may be related to attempts at extending

autonomous activity to other contexts (220). Indeed Lavigne and Vallerand (220) offered that small changes at a situational level, e.g., vignette activity, may be internalized and have a broader contextual effect, such as engaging in autonomous activity in other contexts.

Autonomous activity in a highly controlled environment, however, may be construed as challenging or uncooperative behaviour and recorded as such on measurement tools. The return of the vignette and its offer of autonomous activity showed that individuals who expressed greater levels of neuropsychiatric behaviour on day shift during washout were more likely to be self-determined in their activity when the intervention returned, a possible consequence of the role of autonomous activity on behaviour.

Being self-determined in arrival at the vignette also correlated moderately with spending more time at the vignette. This finding, when considered with the grouped time analysis that showed participants who spent the most time at the vignette were significantly more likely to have expressed greater levels of neuropsychiatric behaviour on both day and night shift before the vignette was introduced, may indicate that any activities offered on the Unit prior to the vignette's introduction did not satisfy the exploration, novelty, and autonomous behaviour needs of some residents. The absence of appropriate daytime activity may have fostered daytime sleep, which, in turn, could have precipitated nighttime wakefulness. Greater expressions of global neuropsychiatric behaviour on day shift during the first washout may also be reflecting a loss of self-determined activity. The absence of similar relationships in phase 5 may be the result of carryover effect, research fatigue and the small sample size.

Together the findings show that opportunity for self-determined activity during interactions at the vignette had an effect on behaviour during the middle phases of the study. They also show that self-determination continues to exist in dementia and that being self-

determined in interactions at the vignette are associated with lower levels of apathy and depression and conversely that interference with autonomous activity may increase expressions of neuropsychiatric behaviour on night shift. It is also evident that experiencing autonomous activity perpetuates itself and the restoration of autonomous activity leads to reinforcement of that behaviour. These findings contribute to understanding the behaviour effects that result from interacting at the vignette. Engaging in autonomous activity, however, did not produce any significant relationships with the frequency of administration of PRN psychotropic medications.

6.3.4 Engaging with the Vignette

The hypothesis proposed that time spent engaged with a garden vignette would reduce neuropsychiatric behaviour. The type of activity engaged in at the vignette in turn, may affect this finding. Video variables related to activity type and level of complexity included: use of one, two or three senses; looking at, touching, holding, manipulating, inappropriately manipulating and being disruptive in relation to the stimulus. Self-determined activity was discussed previously. Significant findings in this analysis are few.

First exposure to the vignette showed that greater expressions of neuropsychiatric behaviour at baseline correlated significantly with the participant using three senses, and engaging with objects that required a more complex level of activity, e.g., the metal planting kit, the orange bag with seeds, soil bins, pots and trays, and seed packets. This may be an indication that prior to the intervention, the need to engage in more varied and complex activity was not being met and was expressed in a greater degree of neuropsychiatric behaviour (201). This interpretation of these findings is in accord with the assumptions of the Need-driven Dementia Compromised Behaviour theory (NDB) where neuropsychiatric behaviour is proposed to be a response to unmet need (73).

Another significant finding was that participants who engaged with more complex objects at the vignette in the final intervention phase created greater occupational distress for the caregiving staff when the vignette was removed in the final washout. Such findings suggest a need for familiarity with the vignette before complex engagement takes place (191, 204); reduced opportunity for self-determination; or staff response to the loss of an intervention previously used to distract or engage residents.

Instances of disruptive or inappropriate behaviour at the vignette were very uncommon. During the four weeks of 24 hours per day video observation there were only two observations in the MOET categories of ‘being disruptive in relation to the stimulus’ and ‘inappropriately manipulating an object’, so participants were appropriate in their use of the objects at the vignette. Staff fears that participants would use nonessential objects as weapons has resulted in the environment of residential dementia care units being devoid of interesting objects for interaction. Clustering objects into a vignette also, perhaps, creates a more coherent, easily understood representation of the expected activity (221) resulting in appropriate use of the objects.

By exploring the relationships between activity complexity engaged in at the vignette and expressions of neuropsychiatric behaviour, we are able to identify that some individuals may not be engaged to a level of activity that is appropriate to their needs, resulting in increased expressions of neuropsychiatric behaviour and causing caregiver distress. The vignette may have offered support for both staff and participant by providing opportunities for engagement at levels that could be modified to meet the participant’s unique personal interest, skill and functional needs (201). The hypothesis is supported by the identification that engaging in activity at the vignette that meets the needs of the participant (be it guided by staff or self-

determined) may influence the expression of neuropsychiatric behaviour. The absence of any significant relationships between expressions of neuropsychiatric behaviour and type and complexity of behaviour during the intervention phases at the very least demonstrates that vignette activity did not increase neuropsychiatric behaviour, but may also result from the inability of the small sample size to demonstrate the significant amounts of favourable change required when using the NPI-NH.

6.4 Summary of the Effect on Specific Neuropsychiatric Symptoms

Three of the commonly expressed neuropsychiatric behaviours in moderate to severe dementia are depression, aggression and apathy. The following sections describe and summarize the effect of the garden vignette on each of those behaviours with support from current literature.

6.4.1 The Effect of the Garden Vignette on Levels of Depression

The hypothesis was that time spent engaged at a garden vignette would reduce symptoms of depression. The research findings are mixed. The presence and degree of depression was evaluated using both self (SQDT) and third-party (CSDD) assessment tools. Self-admission to depression showed no change, but depression rated by others showed a significant reduction on introduction of the vignette, and for those who spent the most time in phase 2, a significant increase during washout 1, phase three. Depression scores plateaued 'below probable major depression' for the remainder of the phases. The findings from each method of evaluation will be explored individually, together and with reference to the literature to show how engagement at a garden vignette affected depression.

Depression in dementia is not uncommon, with prevalence rates varying from 20% (154) to 26.5% (222-224), but in those who self-admit to depression, prevalence increases to 50% (225). Study participants reflect those findings, where 12 of 26 (46%) who were able to respond,

admitted to feeling depressed. Those who admitted to depression showed no significant change in self-perception of depression between the phases. Participants who self-admitted to depression were more likely, however, to spend the most time at the vignette in both intervention phases and when they spent more time at the vignette in phase 2, they were more likely to say yes, they were depressed in phase 4. The reverse was also found. Participants who said no, they were not depressed in phases 1 and 2 were less likely to attend the vignette. In phase 4, participants who self-identified as depressed were more likely to engage in complex levels of activity, e.g., holding and manipulating objects with a preference for objects that required greater complexity to use (e.g., trowel, fork, soil bins). A single correlation between ‘feeling sad or depressed’ and using three senses when at the vignette existed in washout 2, phase 5.

For self-identified depressed residents spending more time at the vignette was a significant response to feelings of depression. Depression has been attributed not only to pathological changes in dementia (91), but also to stale programming, lack of meaningful activities, a loss of autonomy (225), and not being able to go outdoors (106). The vignette, designed to reflect a garden environment may have offered autonomous activity in a new, different and aesthetically pleasing format that appealed to individuals feeling sad or depressed. ‘Level of awareness’ in dementia has also been attributed to depression in nursing homes, with higher levels of awareness in vascular dementia associated with greater depression (222). Study participants with vascular dementia were found to spend significantly more total time at the vignette. Although interaction at the vignette did not lead to a change in the self-perception of being depressed, spending more time at the vignette and engaging in complex activity with objects that require more complex interaction may be reflecting greater awareness and cognitive

ability in this group and that their depression may be related to an activity programming need that is not being met (74, 79, 143, 206, 226, 227).

Third-party assessment of participant depression at baseline showed mean scores at the level of probable major depression. During the first intervention, participants were rated as significantly less depressed with their depression test scores decreasing to probable absence of depression. On removal of the vignette participants who had spent more time engaging with it became more depressed but not to the levels seen during baseline. The return to greater levels of depression may stem from a complex mixture of effects. They could be ‘missing’ the esthetic features of the vignette, as little active engagement was noted. Being in a wheelchair, which may limit easy access to the vignette, could have frustrated them leading to feelings of helplessness. In this group, for whom reduced ability and motivation may be the greater determinants, they may be missing their interactions with staff as they are brought to and removed from the vignette. This explanation is not dissimilar to Garland et al. (228) whose research findings showed that in a nursing home no matter how banal or artificial the interaction, it represents an improvement. It is however very difficult to isolate the effect of personal interaction from the characteristics of activity interventions (7, 210, 228). In truth, it is most likely a combination of many effects.

Following the first washout phase, the level of depression in participants plateaued with depression scores remaining virtually unchanged but ‘below probable major depression’ across the final stages. These findings are similar to those of Kolanowski et al. (201) who found enduring positive effects on mood following removal of activity interventions individualized to personality style of interest. The vignette offered participants the opportunity to engage whenever they so desired and at the level that reflected their personal interest, skill and ability.

In the later phases of the study, a third-party assessment of ‘more depressed’ was associated with being in a wheelchair, spending significantly less time sleeping at the vignette (but not actively engaging), and requiring assistance in being brought to and taken from the vignette. Participants deemed more depressed following removal of the vignette were significantly more likely to spend time at the vignette when it was returned, as found in those who self-identified as depressed. Those participants who were less depressed were also significantly more likely to be self-determined in coming to the vignette. These findings may be attributable to participant levels of awareness (222), increased familiarity of both staff and residents with the vignette (204), and lack of ability or loss of motivation (229).

Together, the different methods of depression assessment confirmed the presence of depression in the participant sample. There were however differences in the engagement with the vignette and its effects according to the type of assessment. Self-identified depressed subjects showed no change across the phases as they sat quietly but engaged in more complex activity. Those determined by others as depressed, showed a significant reduction in depression when the vignette was introduced, and those who had spent the most time at the vignette showed a return to significant depression when it was removed. Those defined as depressed by others were also not actively engaged at the vignette, and showed greater dependence in arriving at or departing from the vignette. The differences between the two depressed groups may exist because of diminished cognitive ability and loss of motivation. It is also possible that what others have described as a ‘decreased staff sensitivity to lower levels of behaviour symptoms’ results in diminished recognition and response to depression in nursing homes (26, 230). While it may be that only severe symptoms of depression were noted, the staff did bring those they

determined to be depressed to the vignette, though it might require more than being delivered to the vignette without encouragement to engage for depression to be affected.

6.4.2 The Effect of the Garden Vignette on Aggressive Behaviour

The hypothesis that aggression, a common neuropsychiatric behaviour (155, 231), would decrease if participants spent time engaging at a garden vignette was only partially supported. The number of aggressive events expressed by each participant was recorded daily on the modified Ryden Aggression Scale 2 (RAS2). The findings showed a high degree of individual variability in participants, with the majority having no record of aggression. While a significant difference in aggressive behaviour between phase 1 and phases 3, 4 and 5; phases 2 and 5; and phases 4 and 5 was shown, these disappeared with the Bonferroni correction. Although no significant relationships were found between the amount of time spent at the vignette and changes in aggressive behaviour, the mean number of daily aggressive events showed a steady decline from 24 at baseline to 10 during phase 5. As expected, there was a moderately significant correlation between participants expressing more aggressive behaviour and being given PRN psychoactive medications (68, 232, 233), which is discussed in greater detail in relation to the second hypothesis.

For those participants who showed aggression, the presence of the garden vignette may have created a restorative ambience. Hartig et al.'s (104, 234) present research shows that not only field experiments in natural environments, but pictures of natural settings can reduce psychological stress. A garden vignette may possess the capacity to diminish stress-induced aggression thereby reducing the number of aggressive incidents seen in the study. The restorative capacity of the vignette may have then led to a carryover effect with continued reductions and fewer aggressive events recorded. Others (18, 91) have identified that increasing

severity of dementia is associated with an escalation of aggressive behaviour with time so the study findings of a steady decline in the number of daily aggressive events over time in the moderate to severely demented participants in this study might not be expected.

Factors that may have moderated the findings include: methodological alterations to the tool that reduced it to being merely a record of the number of aggressive events that occurred for each participant; the small numbers of participants who expressed aggression; the conservative nature of the Bonferroni comparison (184); and research fatigue for recording aggressive events.

6.4.3 The Effect of the Garden Vignette on Apathy

Apathy, as a neuropsychiatric behaviour, was also hypothesized to diminish with time spent engaging at the garden vignette. The Apathy Inventory (AI) (235) measured the presence and degree of apathy in study participants. The hypothesis was not supported by the findings. Participants showed no significant differences in presence or degree of apathy across the phases. Significant differences were found only on day shift between phases 1 and 2, and on evening shift between phases 1 and 3; they did not remain with the Bonferroni correction and were likely hampered by the small sample size and the conservative nature of the Bonferroni comparison (184).

The limited nature of these findings makes it difficult to reach any conclusions as to the effect of the garden vignette on apathy.

As might be expected with a disorder of motivation, when the strength of the relationships between video variables and being apathetic was examined, there were no significant correlations between the amount of time spent at the vignette, or being self-determined in arriving at or leaving the vignette. The few correlations of note created a picture of the participant with apathy as one who would not refuse to engage if the process was initiated,

who was in a wheelchair, and who was more likely to have been brought to the vignette by someone and then left. Each of those features reflected a loss of motivation or capacity to explore by oneself. Participants who were more apathetic were also significantly less likely to interact with the more complex of the objects such as the living plants and herbs and soil bins, potentially a reflection of disease progression (91, 222).

Although the findings do not support the hypothesis that engaging with a garden vignette would reduce apathetic behaviour, there are, however, important considerations for nursing practice. Participants with higher apathy scores, while less likely to refuse or initiate the activity, may still retain some interest if assisted by others. This behaviour may also be reflecting limitations brought about by disease process (91, 222).

Earlier in the discussion it was suggested that those who enjoy sitting quietly might enjoy the biophilic nature of the garden vignette and the ambience it creates. However, sitting quietly as a manifestation of apathy would be viewed as a negative rather than positive behaviour trait. Kolanowski et al. (142) found that nurses did not view passivity as important and suggested that the resident who is withdrawn or passive will most likely not receive any treatment or intervention. It is, of course, impossible to determine to what degree passivity reflects apathy or enjoyment of the environment created by the vignette or combinations thereof. It is critical to identify those individuals with apathy and explore caring interventions designed to supplement their pathologically diminished motivation in an attempt to maintain or enhance their quality of life (142, 143). Apathy is more prevalent with increasing severity of dementia (91, 222) and may mean participants with apathy may actually require greater nursing support than others who are capable of self-determination. Perhaps those who are apathetic would benefit more from therapeutic activities tailored to the individual rather than group intervention (236). The onus on

nurses is to develop skills in not only determining the presence of apathy but to understand how to engage, support and foster individual expression in those who are apathetic. Receptivity to their need to withdraw and their response to engagement would be key to developing interventions.

6.5 The Vignette Effect on PRN Medication Administration

The second hypothesis was that psychoactive PRN medication administration would diminish if participants spent time engaging at the garden vignette. The hypothesis was predicated on the understanding of *pro re nata*, the Latin for ‘as the circumstances arise’. It was assumed that increases or decreases in neuropsychiatric behaviour would be reflected in changed neuropsychiatric test scores and would ultimately be reflected in the number of times psychoactive PRN medication (henceforth to be referred to in this section only as PRN medications) was administered to manage those changes.

Five levels of analyses produced limited support for the hypothesis. Initial analysis identified that all participants received at least one regularly scheduled central nervous system active medication. The sample’s psychoactive medication profile showed higher antipsychotic and mood stabilizer use, similar antidepressant use and lower cognitive enhancer usage rates than those of a recent American study (232). 70% of participants in the study sample were taking regularly scheduled atypical antipsychotics which may have contributed to the limited evidence of effect from engaging with the garden vignette, a finding also noted by others (196, 236).

A second analysis of PRN medication use showed no significant differences between the phases for PRN medication administration (see Table 16). Thus it may be suggested that introduction and withdrawal of the vignette had no effect on PRN medication administration.

A third analysis explored the relationship between spending time at the vignette and being given a PRN medication. During the first intervention greater amounts of total time spent at the vignette correlated significantly with being given a PRN medication, although the grouped time data examining only those who spent the most time at the vignette did not show that frequent attendees were more likely to receive PRN medications. The significant increase in PRN medication given during phase 2 (intervention 1) but during no other phase might be explained by the role of familiarity (191, 204) where, once accustomed to the vignette, the participants did not require more PRN medications or that a Hawthorne effect (237) may have led staff to administer more medication in anticipation of a neuropsychiatric behaviour in response to environmental change.

A fourth analysis determined the strength of the relationship between expressions of neuropsychiatric behaviour and being given a PRN medication. During the two intervention phases only a single significant correlation between greater expressions of any neuropsychiatric behaviour and being given a PRN medication was found. That correlation appeared for evening shift and did *not* include greater caregiver distress.

The non-intervention phases showed that at baseline participants received PRN medication in correlation with expressions of neuropsychiatric behaviour and creation of caregiver distress only on day shift. During the first washout, on afternoon and night shifts, significant strong correlations were found between being given a PRN medication and participant expressions of neuropsychiatric behaviour and causing caregiver distress. The final washout phase repeated the first washout phase findings, but on all three shifts. The correlation findings were supported by the grouped *t*-values that showed participants who received PRN medication in the final three phases were more likely to have greater expressions of

neuropsychiatric behaviour during the phases and shifts described above (Table 17, Chapter 4 provides the detail).

The existence of these correlations in phases without the vignette, juxtaposed with the absence of correlations in intervention phases may indicate a favourable effect, albeit weak. Temporally associated neuropsychiatric behaviours (sundowning) may have been exacerbated by the loss of the vignette, contributing to these findings (193, 238). The absence of a significant reduction in PRN medication during the intervention phases may be influenced by any or a combination of the following: a neutral effect, a blunting of effect by regularly scheduled medication (196, 236), the inability to detect change given the sample size, the tendency for caregiving staff to report only extremes in behaviour (155) or the complexity of positive behaviour change in the presence of a disease that potentiates negative behaviour. As in this study, Kolanowski et al. (201) also found it difficult to produce a treatment effect during the intervention.

The unpredicted findings in relation to PRN medication administration led to a fifth level of analysis. To understand the complexity of medication administration in an institutional setting with a small sample size, patterns of PRN medication administration were examined. Ten different patterns emerged, three of which incorporated 18 of 25 individuals receiving PRN medications. The primary patterns included participants who received ever-increasing amounts of PRN medication across all phases (n=5), those who received decreasing numbers of PRN medications across the study (n=4) and those who received increasing amounts of PRN medication from washout 1 to the conclusion of the study (n=9). The characteristics of these groups are explored within the context of the disease process, the participant's unique manifestations of the disease and being given PRN medications.

The provocation of neuropsychiatric behaviour by environmental change has been reported in specific dementia types and so it would seem important to determine if study participants exposed to eight weeks of environmental change exhibited similar findings. Those with Alzheimer disease (AD) and frontal lobe dementia (FLD) were described as being predisposed to agitation in the presence of environmental change (197). If sensitivity to environmental change produced agitation then it might be expected that participants would in turn receive more PRN medication to manage the behaviour. Five participants received increasing numbers of PRN medications across all five phases of the study. In this group only two had a diagnosis of AD and none had FLD. Nine participants received increasing amounts of PRN medication at the first washout with continued increases throughout the remaining phases. In this group only one had AD and two had FLD. The group that showed a decrease in receiving PRN medications across the study contained two participants with AD and no one with FLD. While very small, the study sample does not reflect the findings of the larger study (197). Increases in NPI-NH, RAS 2 scores and PRN medication administration did not show a relationship with expected expressions of behaviour in relation to disease type.

The one participant characteristic that did show a relationship with being given more PRN medication was the degree of cognitive impairment. The group receiving ever-increasing amounts of PRN medication was severely cognitively impaired (MMSE scores from 2 to 5). Eight of nine participants who received increasing amounts of PRN medication from the first washout to completion of the study scored 10 or greater on their MMSE. Three of four participants who received decreasing amounts of PRN medications across the study recorded MMSE scores between 8 and 14. It may be that the degree of cognitive impairment plays a more

significant role in the expression of neuropsychiatric behaviour (197, 239) and the administration of PRN medications than expected expressions of behaviour for disease type.

It is possible that the group who received increasing PRN medication during the first washout in phase 3 had retained cognitive ability and were able to compensate for the initial environmental changes of new faces asking questions in phase 1 and the introduction of the vignette in phase 2, but the third change, removal of the vignette that may have been a turning point. This understanding is further complicated by consideration of the role of self-determination and/or loss of self-determined activity with the removal of the vignette. It may not be just environmental change, but the experience of psychological distress resulting from a reduction in self-determined activity with the accompanying attention restoration that leads to increases in PRN medication administration. Several studies by Cohen-Mansfield (84, 119, 240-242) and Kolanowski (201, 206, 243) have examined the role of stimulation and engagement in a variety of activities to reduce agitation or neuropsychiatric behaviour. Their study activities have, however, always been researcher led with timed dose control. The Cohen-Mansfield results have been mixed but it is this researcher's belief that activities chosen in their studies on engagement (e.g., interacting with children's wooden blocks) lack the requirements of novelty, curiosity and meaningful stimulation. Kolanowski's (201) work, while offering much more engaging activities related to past experience and personality, still used researcher-controlled interactions and have produced data that only partially support behaviour change related to the interventions. What is perhaps missing or what is difficult to tease out from such a complex context is the role self-determination and attention restoration play in need-driven compromised behaviour in dementia.

6.6 Sociodemographic Characteristics and the Relationship with Time Spent at the Vignette

Sociodemographic characteristics that might influence attention and functional ability were explored because of their potential to affect engagement at a garden vignette. Total time spent at the vignette was examined for relationships between diagnoses, previous occupation, and previous hobbies and interests. Participants with vascular dementia and a previous history of gardening spent significantly more time at the vignette (t -values), but no significant differences in time spent at the vignette were found for the different occupations. Although the sample size was small, the t -value was preferred over the nonparametric ranking of the Friedman's test because the loss of information about the quantity of time spent at the vignette was considered too great.

6.6.1 Discussion of Sociodemographic Findings

The small sample size and further reductions produced by the grouped data are the most likely explanations for limited significance in the sociodemographic findings. The relationship simply cannot be assessed because the study was underpowered to examine this issue. The findings may, however, still have relevance (185). Previous studies examining the relationship between dementia pathology and behaviour were used to develop an understanding of the participants' potential to seek out, engage in and produce a behaviour response to activity at a vignette. Similarities and differences to those studies are highlighted below.

Study participants with a diagnosis of vascular dementia (VAD) and those with a history of recreational gardening were found to spend significantly more time at the vignette, a finding similar to that outlined by Desmond (244). Individuals with VAD were described as having 'patchy', unpredictable, fluctuating patterns of strengths and weakness in cognitive function, and

memory superiority to those with Alzheimer disease, with the greatest impairment being in executive function. A tremendous inconsistency between patients was also noted. It was suggested that this type of cognitive change would result in greater retained capacity in some areas and reductions in others. In spending more time at the vignette study participants with VAD may be demonstrating a greater capacity or retained ability to respond to curiosity, explore or recollect gardening and so interact with the garden objects.

Damage to the frontal lobes in dementia may also have contributed to the findings. Daffner et al. (245), investigating the effects of infarction damage to the frontal lobes, found that the individual's natural tendency to seek stimulation from novel or unusual stimuli was damaged. The novel stimuli they used were line drawings and the outcome measure was length of time participants looked at the drawing before pressing a button to change the picture (245). In this study the novel stimulus was much more robust, a three dimensional, interactional cluster of objects that altered the usual physical living environment for fourteen days with participants who were moderate to severely demented. Participants with a diagnosis of frontal lobe dementia (n=6) showed the greatest number of observations of 'not attending' (n=18) when at the vignette.

Participants with frontal lobe dementia were twice as likely as any other diagnostic group except those with VAD not to be attentive when at the vignette. When they did pay attention, they were more likely to use two or three senses. The common feature of limited attention to the novel stimulus was present with four of six participants with a diagnosis of frontal lobe dementia. The majority of their visits to the vignette were recorded as no attention or using one sense only. For example, in the FLD group the individual who spent the greatest amount of time at the vignette sat with her back to the vignette using it as ambience and interacting with the

objects at the vignette on only 3 of 16 visits (MMSE 2). The individual who spent the least time at the vignette made only one 11-second visit briefly looking at the vignette (MMSE19).

Study participants with AD and VAD were very similar in their patterns of attendance at the vignette with only 8 and 9 instances respectively of being at the vignette and not attending. Their engagement behaviours did however differ. AD participants were almost twice as likely to use two senses when at the vignette than VAD participants (AD 45 observations, VAD 26 observations). AD participants were also more likely than VAD participants to use three senses when at the vignette (4:1). Four of seven participants produced the majority of the 'use of two senses' observations. A graph representing the diagnostic groups and attention data can be found in Appendix ZZ. Participants with AD and VAD were drawn to new and novel stimuli and engaged in complex activity using two and three senses even in the presence of moderate to severe dementia. These behaviours reflect the earlier work by Daffner et al. (2019) who suggested that AD patients who are less engaged by or attracted to novel visual stimuli may merely be a subset of individuals who were less curious rather than an all encompassing symptomatic feature. Testing this hypothesis using experimental tasks and eye movement measures, Daffner et al. (2019) identified that within the AD groups there were indeed those who were curious (n=9) and those who were not (n=8). The two groups were not statistically different in dementia severity, presence or treatment for depression (none were depressed or taking antidepressants), novelty identification, attentional eye movements, or pattern of eye movements. The only statistically significant difference arose from scores on the Personality and Behavioural Inventory. Both Daffner et al. (2019) and Kolanowski and Litaker (196) found no support for the hypotheses that AD patients may be overwhelmed by and/or withdraw from novel stimuli. Thus it would seem that while the small sample size of this study limits the ability to

generalize, it did produce findings that are concordant with larger sample studies. This data also indicated that participants with AD, FLD and VAD fully engaged using two senses when at the vignette, supporting the belief that novelty and the seeking out of novelty may continue to be retained in moderate to severe dementia and a range of underlying diagnoses.

Acknowledgement that individuals with AD are drawn to novel experiences, that individuals with frontal dementia although more likely to not attend to objects in the environment will still engage at complex levels and that individuals with VAD will spend more time at a vignette than other diagnostic groups, all in the context of moderate to severe dementia, provides support for significant theory and intervention development. These findings open the door to greater creativity in offering activity for those individuals. The exploration of diagnostic types and attention at the vignette suggests that, while neuropsychiatric behaviours may be present in 80% of individuals experiencing dementia (1), the presence of those symptoms does not preclude the individual from continuing to seek out and engage in novel environmental features. This examination also indicates the need to consider the type of diagnosis in the development of individualized care and activity strategies that are appropriate to retained ability.

6.7 Limitations and Strengths of the Study

Several authors and systematic reviews indicate that activity-based intervention studies conducted in long-term care settings (8, 9, 50, 51, 124, 246) suffer from multiple barriers and limitations. In that respect, this study was not unique. The following discussion identifies limitations within the method: study design, sample size, factors affecting judgements about neuropsychiatric behaviour, and measurement tools. General confounders such as sedative medication and human contact are also discussed. Strategies to mitigate confounders and improve method are identified in relation to each topic. Study strengths identified and discussed

below include the five-phase design, a unique approach to dose exposure (self-determination), the use of a single study site to reduce confounding factors, analysis of both intra and inter-subject data, analysis of PRN medication administration, participant selection criteria focused on the presence of neuropsychiatric behaviour, and the use of video data to improve the reliability and validity of the vignette interaction data.

6.7.1 Repeated Measures Design Limitations

The five-phase repeated-measures design, while reducing the potential bias effects of not being able to blind participants or treatment professionals to the intervention, was susceptible to effects related to the passage of time: a) unpredicted and unknown major institutional change, b) carryover effect, c) interval ‘thinking’ and third-party assessments, and d) the ability to identify change within the phase. Each of these and their effects on this study are discussed below.

6.7.1.1 Unknown Institutional Change and the Effects on the Research Process

During the final two phases of the study two site management projects were begun: a) implementation of the Minimum Data Set (MDS) Resident Assessment Instrument (RAI) and b) preparation for accreditation. Unaware that these projects were pending, the researcher was unable to predict or prevent potential challenges to the study method and was only able to respond in the moment. Staff members familiar with the study’s assessment tools were readily engaging in the ‘extra work’ created by the research; however, the institutional requirement to learn a second ‘new’ method of evaluating behaviour and the focus on improved documentation for accreditation proved daunting for caregiving staff. Although it was hoped a focus on behaviour assessment by both research and institution would enhance behaviour assessment, this was not necessarily the case. Both sets of documents competed for caregiver assessment time; timely completion of forms became the focus. Group completion of the research tools became

impossible on one unit. An example may be found in the RAS2 findings where regardless of intervention or washout, a continual decrease in aggressive incidents was noted across the phases. While these results may be considered evidence of a carryover effect specific to aggressive behaviour, a similar response could be expected in the NPI-NH, which was not the case. The study protocol of daily notation of aggressive behaviours in conjunction with the institutional changes in documentation and assessment may have contributed to a fall-off of recorded observations rather than an actual reduction in aggressive events.

Large system changes (e.g., the process of accreditation or major assessment and documentation changes) may affect research. A strategy to reduce the challenges presented by institutional change would be to inquire as to the potential for such a change to take place during the term of the study. Meetings with administrative leaders to facilitate the research should include inquiries about both the unit and the larger institutional context.

6.7.1.2 Time and the Potential for Carryover Effect

The decision to use a two-week phase interval arose from experience with the pilot, in which participants tolerated the two-week environmental change with little observable response. It was also believed that the two-week interval would be less susceptible to disease progression effects and memory loss in participants would potentially reduce carryover effect. A continuous reduction in the RAS2 means and the plateauing of the NPI-NH, the NPI-NH-OD and the CSDD score means in the later phases show that some carryover effect may have been present. For the AI, repeated evaluation may have improved awareness of the concept of apathy, a neuropsychiatric symptom not commonly evaluated by caregivers, and resulted in AI scores increasing across the phases. In this instance the carryover effect may have been on the evaluators, not necessarily participants.

Other intervention studies have used varying time frames from a single week to months (7) with no clear indication of the most appropriate time for phasing. It has been suggested, however, that future intervention studies consider the treatment effect on the symptom, short or long term, and measure outcomes in phases that reflect that time expectation (7). A more detailed discussion of this perspective occurs below in relation to the ability of the intervention to change behaviour.

6.7.1.3 Interval ‘Thinking’ and Third-Party Assessment

A second feature of time as a limitation related to the third-party caregiving assessor group. The study tools asked the caregiver to recall behaviour ‘during the week prior’ or ‘in the past two weeks’. Caregivers identified that they found it very difficult to ‘think’ in weekly intervals; it was difficult to remember if particular behaviours occurred in the past two days, weeks or the previous month. This remembering activity is possibly easier for caregivers of single participants (e.g., when family caregivers are respondents for a single person), but institutional caregivers are charged with the care of eight to ten residents which may confound their memory of events (237). Daily notes describing behaviour may be required to produce more reliable data. The extra detail required to note reliably behaviour change would most likely be considered extremely onerous by caregiving staff. The challenge lies in creating a balance between tapping the wealth of knowledge about the participant’s behaviour that resides in the minds and experiences of the caregiving staff and the actual ability and opportunity for staff to share that knowledge without being burdensome.

6.7.1.4 Time and the Identification of Change

A third concern related to time arose when considering the ability of an intervention to not only affect, but also sustain a change in neuropsychiatric behaviour. O’Connor et al.’s (69)

systematic review of psychosocial treatments of behaviour symptoms in dementia suggested that short-lived expressions of behaviours such as anxiety, agitation or moments of aggression may produce only short-lived intervention effects. Measurement at two-week intervals may not capture the full effect of the intervention on short-term expressive behaviours and may be even more diluted by third-party assessor memory of events. Given the previous discussion of factors influencing caregiver assessment of behaviour, it is possible that only major events would be noted, thus, the impact of the intervention on smaller yet equally important expressions of neuropsychiatric behaviour may be missed (155, 195, 230, 247). For behaviours that are expressed in a more enduring manner (e.g., depression and apathy), the time frame of two weeks may be too short to identify treatment effect. These behaviours may require a more intense level of treatment over a period greater than two weeks before behaviour change is demonstrated (201). It has also been suggested that staff are less likely to report the withdrawn and passive behaviours considered less ‘troublesome’ or ‘obvious’ (144), complicating understanding of effect. Perhaps studies examining intervention effect on neuropsychiatric behaviour should separate short-term and longer-term effects. Short-term outcome measures could be used to focus on agitation and aggression responding to in-the-moment expression of symptoms, while tools such as the AI and CSDD could be used to measure seemingly longer-term effect responses as seen in apathy and depression (7). In doing so, the study design would reflect the behaviour and its response to the intervention rather than the intervention waiting for a response. To produce reliable data, study costs for in-the-moment intervention and evaluation would increase considerably.

6.7.2 Sampling Limitations

Sampling criteria and sample size produced limitations in the study. The small sample size was a considerable limitation to effect size and power to generalize to the broader population. The need to generalize to the broader population is, however, questioned by Campbell (248) who offers that to determine degree of applicability, ‘proximal similarity’ where researchers and consumers consider the context similarity to the situation of extrapolation rather than external validity may be more valid. Detailed descriptions of the context are found in the methods chapter. To increase validity, statistical analyses designed for small sample sizes were used: the Bonferroni correction, grouped phase data analysis using the *t*-test for continuous data and the chi-square for binary data, reporting confidence intervals, repeated measures and the creation of more homogenous groups (e.g., time groups and PRN medication groups). The challenge with small sample sizes is that they are limited to detecting large differences only and are underpowered to conclusively establish null effects. The small sample size ranking analyses also produce challenges by reducing the detail that may be required to understand the response, e.g., actual time spent versus a ranking of time spent.

A second sampling limitation was the participant criteria of moderate to severe dementia. While producing a more homogenous sample with respect to cognitive and functional ability, the restricted sample created a reliance on third-party assessment of neuropsychiatric behaviour. The challenge for others to accurately measure and grade psychiatric symptoms such as anxiety, apathy and depression are well known (69) and, although the tools used presented reasonable reliability, face validity and sensitivity to change (see methods chapter), caregiving staff found the Ryden Aggression Scale 2 (RAS2), the Apathy Inventory (AI) and the Cornell Scale for Depression in Dementia (CSDD) difficult to use. The care staffs’ characteristics (see 6.7.3

Factors Affecting Judgements About Behaviour) also had the potential to affect scores, but whether it was an increase or decrease in the score is not known and could not be controlled. It is, however, known that broader, more heterogeneous samples of individuals with dementia have the capacity to produce lower scores on neuropsychiatric tests (7), so limiting the sample to individuals known to express neuropsychiatric behaviour offered the opportunity to specify for whom the intervention may apply. While sample selection for the presence of neuropsychiatric behaviour should reduce the potential for low ratings on neuropsychiatric test scores (7), the expression of certain domains of neuropsychiatric behaviour in dementia on active treatment nursing units appears to present more frequently in short triggered bursts rather than sustained expressions of psychopathy (7, 50, 69). This then results in large ranges in neuropsychiatric test scores and the creation of outliers depending on the day of measurement.

When considering the intervention effect on neuropsychiatric behaviour, the selection of specific samples that reflect the behaviour being studied would require a much larger population from which to select in order to attain a larger sample. To access the larger population, multiple-sites would be required. Besides requiring increased funding support, a multiple-site study brings a new set of complications such as different staff mixes, physical environments or existing programs all of which could confound intervention results.

6.7.3 Factors Affecting Judgements About Behaviour

In this study a third party completed four of the five neuropsychiatric behaviour measurement tools. In measuring behaviour the recognition, naming and assignment of a numerical value to degree and severity require a complex integration of experience and interpretation. The following factors have been identified as having the potential to affect third-party judgement about behaviour and thus the findings of this study:

- time of and for assessment,
- degree of exposure to the behaviour,
- level of knowledge about the behaviour and/or disease processes,
- consequences of reporting the behaviour,
- cultural and sex filters,
- sociolinguistic skill,
- staff relational behaviours,
- caregiver health status,
- reporting processes,
- available staff support, and
- the institutional context including beliefs systems and staffing levels.

The following discussion examines the implications of these factors in the understanding staff measurement of neuropsychiatric behaviour and administration of PRN medication.

6.7.3.1 The Influence of Time and Exposure

When recalling events measured by the study tools, caregiving staff identified difficulty in separating behaviour events into two-week measurement intervals. The ability to accurately recall behaviours attributable to a particular individual when caring for multiple individuals may contribute to recall bias (177, 249). It has been shown habituation and/or normalization of repeated experiences of neuropsychiatric behaviour result in only ‘substantial changes’ in care recipient behaviour being noted by caregivers (155, 230, 250). As a result, measurement tools may suffer from reliability issues resulting in reduced severity and occupational distress ratings (230).

6.7.3.2 Repeated Exposures to Violence and Aggression

For caregivers, repeated exposure to care home resident violence and aggression has been found to produce cumulative effects such as distorted thinking, depersonalization, and/or emotional and physical withdrawal (247). Job insecurity and fear of being accused of provoking the aggressive incident have been identified as reasons for not reporting violence. The combined result is an acceptance of violent behaviour and a belief that it is just part of the job, resulting in reduced reporting of incidents (247). In this study, staff reported that it “didn’t matter what the resident was doing, the work had to get done.” Stockwell-Smith et al. (251) when exploring staff perceptions of their ability to manage behaviour and the needs of individuals living with dementia found a similar response.

The tendency for staff to ‘normalize’ neuropsychiatric behaviour, the cumulative effects of depersonalization, and/or emotional and physical withdrawal by caregivers may all lead to a blunting of behaviour assessment and reduced scores on the measurement tools. The caregivers who completed the study measurement tools were seasoned employees on the unit and their exposure to neuropsychiatric behaviour was not new. This may have contributed to reporting only the most egregious events. A continued reduction in the number of aggressive incidents recorded across the study may be reflecting this process of ‘normalization’.

6.7.3.3 The Influence of Knowledge and Education

Behaviour assessment and inevitably PRN psychoactive medication administration are also challenged when staff levels of knowledge about disease processes, neuropsychiatric behaviours, and medications to manage the behaviour are insufficient (251, 252). Inadequate monitoring of medication response in long-term care settings has been found with caregivers being unaware of the pharmaceutical treatment most appropriate to the neuropsychiatric

behaviour (230). Staff knowledge or interpretation of knowledge about the disease process and related behaviours may also affect medication administration (253). If staff perceived participants with dementia as highly susceptible to change and anticipated an increase in neuropsychiatric behaviour, increases in PRN medication administration may be unrelated to actual behaviour change. The study findings showed that some participants did receive ever-increasing numbers of PRN psychotropic medication across the study phases with no associated change or increase in neuropsychiatric behaviour expression as measured by the tools. In some instances, increased PRN medication administration occurred in the face of diminishing NPI-NH and NPI-NH-OD scores.

Level of education also plays a role in both awareness of neuropsychiatric behaviour and response to that behaviour (254). Research examining the ability of caregiving staff to recognize neuropsychiatric behaviour has primarily focused on the detection of depression (193). It has been shown that varying levels of education lead to varying levels of ability and confidence in both recognizing and monitoring depression in nursing home residents with 37%-45% of depression cases diagnosed by psychiatrists not identified by caregiving staff (230, 255, 256). If the most commonly present neuropsychiatric behaviour is not readily identified and monitored, the presence or absence of neuropsychiatric behaviours associated with mood and personality (apathy and anxiety) may be difficult to identify and rate as well (239). The ANOVA, paired *t*-tests and Friedman's test all showed no significant differences in AI scores across all phases indicating that apathy scores did not respond to the presence of the vignette. The lack of significant findings and the methodological challenges experienced with AI tool administration suggest the degree of apathy and its response to the vignette remains unclear, but based on other studies (89, 92, 257) was likely present and possibly increasing (91). With the symptoms of

apathy often being considered a subset of the symptoms of depression (258), it may be that asking the bedside caregiver, often the least educated of the caregivers, to distinguish between apathy and depression is unrealistic.

6.7.3.4 The Influence of Ethno-Cultural Filters and Sex

Caregiver cultural beliefs or perceptual filters may result in different interpretations of behaviour (252). Participants may also have differing perception of behaviour and/or expectations of caregivers (193). During the study staff reported residents responded differently to staff in ways they felt were related to their ethnicity and gender. Staff and residents with similar ethno-cultural backgrounds were said to “experience fewer problems with the patients”. Stockwell-Smith et al. (251) also found that culture and ethnicity played a role in understanding the appropriateness of care strategies for individuals with dementia. In Australia, caregivers who were recent immigrants (<5 years) from South and Central Asia (e.g., India and Nepal) were less likely to understand appropriate care strategies for individuals with dementia than those who had lived in Australia for >5 years or were from other ethnic and cultural groups (252). It has also been suggested that if negative attitudes have developed from resident use of racially charged language during interactions with caregivers, care decisions may be affected (259). Alternatively, others have found that racist language in the presence of dementia may soften the caregivers’ response with attributions to not being “in the right state of mind” (260).

Sex, in combination with ethnic beliefs, may also affect behaviour assessment. Pope and Ripich (261) report that when sex and ethnicity differences exist between caregiver and residents with dementia, social interactions are limited and responses to cues are either altered or impaired. While they did not identify the interactions as having a potential to precipitate aggressive or agitated behaviour, my personal observations found there was the potential to do so. Together,

sex and ethnicity differences between caregiver and resident may result in an increase or decrease in behaviour events recognized and recorded.

6.7.3.5 Sociolinguistic Influences

General societal understandings of dementia also create a means by which we interpret dementia-related behaviours. Hamilton's (262) review of the sociolinguistic aspects of language and dementia explored how the nuanced understanding of individuals with dementia can be created through social interaction. Hamilton (262) offered that when the individual with dementia is defined by the western world of neuropsychiatry and underlying brain disease, communication with those individuals becomes distorted. Because the western world highly values intellect and reasoning, relational and aesthetic aspects of 'knowing' the individual become neglected. Descriptions of 'loss of self' and being an 'empty shell' come to the fore and so alter relational practices. If there is no 'self' to manage 'self control' then others must take on the role of controller. In the institutional context the controller becomes the professional caregiver and imposes the institutional agenda. Related research has also shown that highly controlling communication significantly correlated with increased resident resistiveness to care (263). It has also been shown that institutional speaking practices resulting from institutional agendas seriously alter and limit social interaction between caregiver and care recipient (264). Professional white monoracial encounters in a nursing home were marked by a greater number of yes/no questions, evaluative comments and requests for information. Such an interrogational style was felt to limit narrative memories and storytelling (264). The absence of a shared common cultural or ethnic experience acts to limit the sharing of narrative memories and storytelling. Conversations become acts of information acquisition rather than social exchange. These altered conversational styles may also lead to expressions of neuropsychiatric behaviour

through frustration or inability to communicate at a human level. Caregivers and participants in this study represented several cultures and different gender perspectives, each of which may have affected not only the perception of neuropsychiatric behaviour, but also the expression of neuropsychiatric behaviour and responses to that behaviour.

6.7.3.6 Reporting and Acknowledging Behaviour

The manner of reporting changes in behaviour may also contribute to staff perception of the behaviour (254). Typically at the research site, the non-licensed caregiver reported their care activities and resident responses to the licensed caregiver in an informal verbal format. Verbal reports of behaviour change did not often include measures of severity nor were they specific to symptom criteria that delineate the disease. The licensed caregiver response to the reports passed on by the unlicensed caregiver communicated which information was valuable and action worthy. The non-licensed caregiver interprets the response of the licensed caregiver and assigns significance to the information. The interpreted degree of significance is then reflected in the type of information shared in the verbal report. If verbal reports are not responded to or acted on, the reporter might interpret this as the observations being insignificant and no longer report the finding (254). The resulting effect is that symptoms might go unreported, and additionally, undocumented in the health record. Voyer et al. (265) found that the proportion of symptoms verbally reported versus those recorded in the nurses notes ranged from 1.9% to 53.5%.

Reduced reporting of findings or concerns could result in reduced identification of neuropsychiatric behaviour but also appropriate interventions or treatment (230). Furthermore, the complexity created by concurrent behaviours (e.g., agitation, irritability, aberrant motor behaviour) (197) for care staff not used to rating behaviours (e.g., aides), causes difficulty in both filtering out and rating the individual behaviours (26).

When English is not the primary language spoken by the rater, the measurement tool descriptions of the behaviour (which are written in English) may also be less readily understood. This creates challenges not only in relating the verbal description of the behaviour that is observed, but also to assigning a degree of severity and caregiving distress level required in measurement tools. de Medeiros et al. (177) suggested that caregivers may also deny the presence of the symptom or minimize the degree of severity in response to cultural belief systems. In identifying a resident as being ‘difficult to manage’, the caregiver exposes him/herself to potential criticism about their ability to manage the expected level of care, resulting in reluctance to report. The concept of habituated exposure may also be at play here, which results in minimization of severity or disruption (230).

6.7.3.7 The Influence of the Care Provider’s Relational Behaviours and Participant Response

McGilton et al. (266) have proposed that the relational behaviours of staff have an effect on the mood and affect of individuals living in residential care. While this interaction was not the focus of this study, relationships between staff and care recipient may have had an effect on both the expression and interpretation of neuropsychiatric behaviour (247). Negative caregiver “banter and demeanour” (p.726) has been shown to produce aggressive behaviour during bathing (267), while the presence of depression in caregivers has been shown to affect their ratings of neuropsychiatric behaviour (177, 249, 268). One American study found rates of depression at 48.5% in nursing assistants at 49 long-term care facilities across three states (269). If this is a generalized finding it could well affect care by reducing interpersonal interactions and lack of interest in identifying health changes. It also could lead to differences in data or diagnosis depending on who was caring for the individual on the day that the assessment was done. Again these behaviours are influenced by culture and gender.

6.7.3.8 The Influence of Available Support

Staff support available at the time of expression of neuropsychiatric behaviour may also have an effect on the interpretation of the behaviour. When staff feel confident in their ability not only to recognize but also manage the behaviour, they may be more likely to intervene and be successful in moderating the severity of the behaviour. This in turn would result in reduced scores for severity and occupational distress during evaluation (270). Evers (270) also found that staff might complete questionnaires in a manner that offers the 'socially desirable' answer when aggressive behaviour and the ability to manage aggressive behaviour is the point of enquiry.

Levels of staffing are also considered to be 'available support', thus, caregiver-resident ratios may have the ability to affect PRN psychotropic medication administration. The trend to reduced caregiver-resident ratios and the replacement of professional staff with less qualified workers has been purported to cause diminished patient safety and a potential for increased use of pharmaceuticals to manage resident behaviours and a means of providing relief to overburdened staff (47). While an American study has linked fewer RN hours to increased use of psychotropic drugs (271), this was not confirmed in the only Canadian study examining staff-resident ratios and antipsychotic medication use (272). The two units in which this study was conducted were considered to have low caregiver-resident ratios with a single Registered Nurse on each unit during day shift. The institutional introduction of the RAI-MDS did create anxiety about the potential use of that data to determine caregiver-resident ratios and the possibility for a change in those ratios. This too may have been a factor in medication administration and recording of neuropsychiatric behaviour.

Ethnicity, sex, knowledge level, education, and personal health of the caregiver have the potential to affect acknowledgement, categorization, levelling, and response to neuropsychiatric

behaviour. Repeated exposure to varying degrees of assault on personal safety, level of staff support, unit information reporting styles, and communication style further complicate the interpretation of behaviour and responses to it. The measurement of neuropsychiatric behaviour is much more complex than anticipated during the design and development of this study.

The complexity in judging behaviour may also have contributed to the mixed and varied effects shown for PRN psychotropic medication administration. The premise for PRN psychotropic medication administration is that it reflects distinct characteristics defining the patient need for medication. Awareness of this need and subsequent medication administration should be driven by an understanding of the behaviour being expressed, patient level of distress created by the behaviour, how the medication works, and what behaviours the medication can be expected to alter. At times however there seemed little relationship between behaviour as measured by neuropsychiatric behaviour tools and the administration of a PRN psychotropic medication. The ‘influencing factors’ described above may have contributed to this apparent dissociation between behaviour assessment and PRN psychotropic medication administration.

6.7.4 The Impact of Multiple Measurement Tools and Research Fatigue

As noted previously, ‘research fatigue’ was felt to be a limiting factor in this study. The five phases of measurement, the number of measurement tools used and the institutional changes in documentation were thought to have contributed to this fatigue. The application of multiple tools reflected the need to enhance reliability and validity of findings by supporting the large multi-domain tool (NPI-NH) with single domain tools (CSDD, SQDT and the RAS2) (127). Authors of numerous systematic reviews (7) have suggested enhancing methodology through the use of a “suite of clinically relevant outcome measures (e.g., behaviour, affect, mood, medication use, caregiver stress) to maximize the value of their endeavours” (p.248). The original study

premise was to supplement the lack of depth identified by others in some of the NPI-NH domains (e.g., depression and apathy (176)) with stand-alone measures CSDD, AI and SQDT. The SQDT specifically was included to offer a ‘voice’ to individuals with moderate to severe dementia in data collection.

The question of who should carry out the suite of assessments is to be considered in the matter of research fatigue. The NPI-NH, CSDD, AI, and RAS2 all have ‘caregiver’ versions, each with the expectation that a caregiver could complete the tool. What is difficult to define is which caregiver is in the best position to complete the tool with the most reliable report about the participant’s neuropsychiatric behaviour: the master’s prepared research assistant who spends 15 minutes with the participant; the RN or LPNs who supervise the care; or the caregiver who provides intimate care to the individual over a period of eight hours and experiences the aggression, agitation, apathy, and depression first hand.

The NPI-NH, CSDD, AI and RAS2 each presented challenges for non-licensed caregivers, which may have contributed to research fatigue. The most obvious challenges arose from the language used in the tools. The language of neuropsychiatry was difficult for care aides to understand and respond to. Knowledge of symptomology presented a second stumbling block and, although the NPI-NH presented a simpler descriptive presentation of the behaviour, the practice specific expectations of the caregiver did not match the degree of expectation in the tool, leaving the caregiver feeling challenged to complete the tool. In practice, care aides were never asked to decide on or label behaviour. They reported on their work with very basic descriptions of their experiences, often summing up their day with the patient by saying ‘good for care’. The tools, on the other hand, required a much higher level of participation, understanding and judgement, which had the potential to be fatiguing for those not used to that type of practice.

An associated challenge was the element of time. More tools require more caregiver time. Direct care expectations for care aides did not change during the research process. This left little time to note and record their experiences. A caregiver would complete four tools for each resident for whom they cared and four to five residents would be assessed on a single day during the measurement phase. In the final two phases when study tool completion in the context of institutional change became onerous, a personal strategy was used to create time. The researcher (upon completion of the institutional feeding course) fed patients at lunchtime while a direct caregiver completed the research measurement tools.

When the number of tools, time and language concerns began to impede the group completion of measurement tools in phases 4 and 5, single caregivers who spoke and read English became the sole respondent. The continued presence of the researcher during tool completion continued to support language and understanding needs, a pragmatic approach supported by O'Connor (7).

While the use of multiple tools may be recommended, the cognitive complexity, the daily time requirements to complete each tool during each measurement phase for five phases may all have contributed to research fatigue in caregivers who completed the assessments. The nature of nurses' work is fatiguing. The addition of research participation while initially inciting excitement and engagement may in the later stages create fatigue. Factors most likely to create nurse fatigue described by Stegge et al. (273) are clearly present in this study. The physical demands of caring (e.g., lifting, pushing, pulling) and the time and multitasking demands and the mental demands related to time management, the large quantity of tasks, time pressures, interruptions, memory, and concentration all contribute to nurse fatigue and were present in this study. Using fewer or different tools may ease some of the fatigue, but O'Connor et al.'s

systematic review, which identified a vast number of scales and tools, described little compelling advantage of one tool over the other and concluded that challenges to measuring neuropsychiatric behaviour in quantitative studies will continue. Perhaps the use of the broader multi-domain tool at baseline to identify the predominant neuropsychiatric behaviour domains expressed by the individual, followed by assessment of those prominent domains only during the different phases would reduce some fatigue. The newly revised NPI tool with its enhanced domains may offer an opportunity to reduce the number of tools used in intervention research.

Studies in Canada examining the makeup of institutional caregivers have found that the majority of nonregistered institutional caregivers are immigrant women, (274) with varying levels of knowledge and education about neuropsychiatric behaviour. The neuropsychiatric assessment tools designed for caregiver assessment do not appear to reflect the skill, knowledge and ability of an institutional caregiver, rendering them difficult to use and understand. Until tools are developed that can be more reliably used and understood by the individuals with day-to-day care interaction knowledge of the participant (e.g., the care aide), or funding for intervention studies increases to educate and support the level of staffing required to sustain detailed observation, multiple tool data collection will continue to present methodological challenges.

6.7.5 The Confounders

6.7.5.1 Psychoactive Medication

A potentially significant confounder in this study was that all participants received some form of regularly scheduled psychotropic medication. Scores on neuropsychiatric behaviour tests may be seriously affected by the psychotropic medication. Sedation effects may blunt agitation or aggression scores while depression and apathy scores may increase. Other

researchers attempting to assess neuropsychiatric behaviour responses to intervention have noted similar limitations (55, 144, 196). Measurement tools used in the study make no reference to medicated responses. Cut-off scores that indicate the presence or absence of neuropsychiatric behaviour are not related to psychoactive medication use in the populations. The neuropsychiatric behaviour scores in this study may all be blunted by medication and thus the change in behaviour as a result of the intervention may not be detected as statistically significant. A 4 to 5 point change in the behaviour domain score or a 22 point total score change as suggested by Iverson et al. (173) to be an indication of statistical significance may be too great to be achieved in the presence of regularly scheduled antipsychotics (173). Although baseline scores were also determined in the presence of psychoactive medication, expectations that behaviour scores should return to baseline may also be unrealistic given that medication administration was not controlled by the study and medication schedules were open to change.

6.7.5.2 Human Contact

A second confounder is that of human contact. Several authors have documented the paucity of human interaction between residents with dementia and caregivers (142, 196, 207, 226, 275-277), which suggests that the mere presence of human interactions within the intervention have the potential to alter behaviour. Many interactions at the vignette had an element of human interaction. Participants may have been brought to and/or taken away by another person or interrupted when at the vignette. Each of these actions may have had an effect. Most certainly it was noted that interruption at the vignette altered activity by stopping the engagement with no resumption of the activity or in extreme cases following the interrupter away from the vignette. The MOET (Modified Observation of Engagement Tool) could be further modified to include response to interruption variables to understand the effect of

interruption on activity engagement. The identification of self-determined behaviour, however, did show a pure interaction experience. Those who were self-determined in arrival and/or exit from the vignette were responding not to human interaction but to interaction with the vignette.

6.7.6 *Strengths of the Study*

While the literature raised the expectation of many limitations, this study does offer advantages over other studies: a) a five-phase study design (278), b) unique theoretical underpinnings for the management of dose exposure (self-determination), c) a single site of study which reduced confounding factors arising from diverse staffing and institutional activity programs present in multi-site studies, d) analysis of both intra and inter subject data, e) analysis of PRN medication administration in relation to neuropsychiatric behaviour, f) participant selection criteria related to documented expression of neuropsychiatric behaviour (7), and g) the use of video data to improve the reliability and validity of the vignette interaction data (201). Several of these methodological enhancements have been recommended by systematic reviews of dementia activity research as means to improve reliability and validity (7, 9, 50, 51).

The creation of a five-phase design increased reliability not seen in other activity intervention studies (55, 201, 210, 275). Repetition of the phases sought to reduce the placebo and Hawthorne effects that may result from a single intervention phase.

Analysis of intra and inter subject data afforded an opportunity to look at intervention response at both the group and individual level. The heterogeneity of dementia with its unique individual responses to differing dementing processes suggests that one size may not fit all. The philosophical underpinning of NDB theory requires reflection on the unique nature of the response. Kolanowski et al.'s series of works (130, 143, 201, 279) applying NDB theory to activity research provides many examples of the need for individualization of activity and

understanding individual response to interventions. Thus both inter- and intra-subject data analysis enhances internal validity. Inclusion of individual case study data as related to PRN medication analysis offers depth to understanding the unique nature and presentation of dementia in the study sample.

The use of self-determination as a means of considering dose is new to the field of activity research in dementia. In efficacy trials, dose has always been prescribed in terms of when, how much time and the type of activity that is offered for engagement (143). The use of self-determination offers the individual an opportunity for greater control and an element of empowerment. Self-determination also provides a glimpse at the true effect of vignette activity. The individual chooses when to engage, how to engage, what to engage with, and exits based on the extent to which the chosen engagement meets his/her need for novelty and stimulation. The finding that self-determination continues to exist in the presence of moderate to severe dementia is key to understanding the potential for new strategies and opportunities for activity. Self-determination as a means of stimulating neuroplasticity in dementia and its potential to maintain or enhance functional ability (132) opens opportunity for new fields of dementia research.

The use of a single site to conduct the research reduced the challenges presented by differences in: a) case mix, e.g., higher cognitive ability or reduced levels of neuropsychiatric behaviour, b) administrative management of behaviours, e.g., less use of psychotropic medication and/or wheelchair restraint, c) large system administrative change, e.g., another site may not have been changing to the MDS RAI system of documentation at the same time, d) staff education differences, e) staffing levels and ethnic diversity, and f) onsite programming. Each of these cannot be controlled for but have the potential to impact validity. Conducting the research within the same institutional context and constraints served to strengthen internal validity.

The video data were not affected by research fatigue nor was it limited by the challenges present with care aide assessment data. PhD and Masters prepared Registered Nurses analyzed the data. Their level of knowledge and understanding of research methods, evidence of strong inter-rater reliability and clear definitions of MOET categories enhanced the internal reliability of the video data analyses.

Repetition of the intervention phase and video data collection supported a comparison of responses. It showed that residents returned to engage with the objects. Indeed, in individual cases, familiarity with the vignette increased (more time spent) with a greater complexity of activity taking place. In the second intervention phase of the study two patient interactions were observed that had not been seen previously. These interactions while not statistically significant were significant in the fact that they actually occurred. Both were observed during the final week of intervention and were instances of participant-participant interactions about objects on the vignette. During the first intervention phase no participant-participant interactions were observed. Repeating the intervention phase (and subsequent washout phase) showed the effects of familiarity, repeated exposure and change. The use of video data strengthened internal validity and reliability by affording the opportunity to view and review all decisions in relation to engagement at the vignette.

A further strength was acknowledgement of the presence of regularly scheduled psychotropic medication and the examination of PRN medication administration in conjunction with behaviour assessment. Many studies explore behaviour responses to an intervention and, while several acknowledge the presence of psychotropic medications in their samples (55, 144, 201, 228, 280), only a few include the use of PRN medication in their analysis (55, 144). Some merely note the presence of psychotropic medications (201, 280) while others restrict the giving

of a PRN psychotropic before intervention (228). Still others do not mention either PRN or regularly scheduled medication in their dementia intervention studies (196, 210, 275) at all. Given that an American one-year cross-sectional study (232) of Medicare recipients (n=395,131) found 84% of the cohort had received at least one medication for controlling the symptoms of dementia, it would seem important to acknowledge the role of psychotropic medication in the mediation of behaviour. Although current cross-sectional data on Canadian use are not known, a 2007 administrative database study (n=47,322) in the province of Ontario (46) identified antipsychotic medication rates between 20% and 40%. A 2011 study for a single large metropolitan Canadian city examining psychotropic medication use in Canadian long-term care patients who were referred for psychogeriatric consultation (n=69) found 98.5% of the study patients were on psychotropic medication (281) with many on multiple psychotropics. Regularly scheduled psychotropic medications were present for 100% of this sample. That neuropsychiatric behaviour in dementia is present and creates challenges is known. It is also known that the use of psychotropics in their care is extensive. Activity intervention research designed to reduce neuropsychiatric behaviour needs to identify clearly, examine and describe the role or potential role of psychotropics in the production of research findings about changes in neuropsychiatric behaviour. This was done in this study and acts to increase the validity of the findings.

A final strength was the use of purposive sampling, selecting individuals already known to express neuropsychiatric behaviour, which was a systematic review recommendation to increase the power to demonstrate treatment effect (7). While the sample was focused, there were still outliers with extreme behaviour or individuals whose behaviour may have been diminished through medication administration, a protected environment, and progression of the

disease process or possibly better management of co-morbid illness. Nonparametric statistical analyses were used to reduce the effect of outliers and repeated measures sought to increase reliability of measurement data.

6.8 Implications of the Study for Practice, Theory and Method

The findings of this study, considered within the context of past research, have implications for the provision of a nonpharmaceutical, activity intervention for managing neuropsychiatric behaviour in individuals with moderate to severe dementia, the development of theory in relation to activity intervention research in dementia, and the advancement of activity intervention research methods. The following discussion explores each of these areas.

6.8.1 Practice Implications

6.8.1.1 Activity at a Vignette is a Valid Means to Engage Individuals with Moderate to Severe Dementia

While mixed, the findings of this study show that engaging at a garden vignette may be a valid nonpharmaceutical adjunct to behaviour management in individuals with moderate to severe dementia. Implications are discussed as they relate to socio-demographics, time spent at the vignette, neuropsychiatric behaviours and self-determination.

Participants with vascular dementia and a history of previous gardening may be the most likely to spend time at the vignette. Retained cognitive reserve and primed memory may prompt engagement at the vignette, but it does not preclude others from interest or engagement. While no significant relationships were found to exist between ‘time spent at the vignette’ and MMSE scores, previous occupation or functional ability, patterns of attendance indicated the vignette was used by participants with varying degrees of cognitive impairment and functional capacity.

The following grouped-time (≤ 1000 seconds and > 1000 seconds) findings show that the vignette had an effect on both participant and caregiver. 1) When the vignette was removed in phase 3, participants who had spent > 1000 seconds at the vignette were more likely to cause occupational distress for caregivers on day shift. 2) Participants who spent > 1000 seconds at the vignette in phase 2 were significantly more likely to spend > 1000 seconds at the vignette in phase 4. Together these findings show that participants who spent the most time at the vignette appeared to make a connection with the vignette. Response to vignette removal may indicate effect by different means: participants missed activity at the vignette and expressed greater neuropsychiatric behaviour, which was experienced by the caregiver as increased occupational distress; or caregivers missed the vignette and struggled to find alternatives to meet the activity needs of their residents, potentially experienced as occupational distress in the participant. That individuals returned to the vignette and continued to spend > 1000 seconds is a significant indicator that the vignette offered an activity opportunity that was valued by a group of participants and in turn by staff. Research has identified that residential environments are predominantly ‘boring’ with the most prevalent activities being television, background media or no activity at all (282). The presence of the vignette changed the environment and offered an alternative. The implication is that a garden vignette may be used to support the needs of both resident and caregiver. It may fulfill the activity needs of residents who do not respond to regular programming and provide caregivers with a readily available adjunct to engage residents.

Together the findings showed that changes in specific types of neuropsychiatric behaviour did occur in relation to the insertion and removal of the garden vignette. A significant reduction in the expression of neuropsychiatric behaviour as measured by the NPI-NH, NPI-NH-OD was noted primarily between baseline and intervention one, and although NPI-NH and NPI-

NH-OD scores increased during washout phase 3 day shift, they never returned to baseline levels. This pattern was also shown with the CSDD and the RAS2. These findings imply that the first intervention had a significant effect on the reduction of some types of neuropsychiatric behaviour but that the level of effect was not retained over the course of the study. As presented earlier, potential influences on these findings included Hawthorne effect, carryover effect, organizational change, tool challenges, phase timing, caregiver characteristics, research fatigue and ultimately the small size of the sample. The implication for practice is, however, that the introduction of a garden vignette to the dementia care environment will not produce catastrophic increases in neuropsychiatric behaviour and may for some individuals have a positive, or at the very least neutral, effect on their behaviour. Such findings are important to understanding the role of activity in providing a sense of connection, identity and autonomy while maintaining psychological well being and quality of life (204).

Measuring behaviour for different time frames (day, evening and night shifts) reflected the experiences of caregivers in institutional settings and their need to respond to exacerbations in behaviour that may be temporally related (26, 196). Examples of daytime sleep affecting nighttime neuropsychiatric behaviour clarified the relationship between what was observed and what staff experienced and recorded. Measuring behaviour on each work shift identified with greater specificity and sensitivity how activity levels had the potential to affect levels of neuropsychiatric behaviour throughout the 24-hour period. The findings suggest a need for recognition of the degree to which regular programming engages or activates participants with a goal of reduced daytime sleep, thereby reducing challenges for night shift caregivers. Highlighting exacerbations in neuropsychiatric behaviour with respect to work shifts offered an

opportunity to better present evidence of the power of activity on one shift to affect the work of others on another shift.

A vignette effect on depression was evident in both the CSDD and SQDT findings. Scores diminished from a level of probable major depression at phase 1 (baseline) to probable absence of depression during phase 2 (intervention 1) and for the remainder of the study. The observation of a plateau in the scores for phases 3 to 5 suggests a potential carryover effect, an intervention mood-response effect identified by others (201). Comparisons between the personal identification of depression (SQDT) and the third-party attribution of depression (CSDD) showed differences in the degree of activity engaged in at the vignette. The individuals who self-identified as depressed, which would indicate greater self-awareness, engaged in far more complex activities (e.g., using three senses and holding and manipulating the objects), while those with third-party attributions of depression were more likely to be inattentive at the vignette. The presence of self-awareness has been identified by others as not only being germane to the identification of personal need, but also as having a reciprocal relationship with positive environmental stimuli (283, 284). It may then be suggested that for individuals who are self-aware enough to respond to the SQDT and whose choice of activity includes complex manipulations the vignette may be meeting a perceived need for activity and is functioning as intended. A practice implication arising from these findings is the need to distinguish between those who are self-aware and those who are less so and provide activities that respond to the unique activity level needs of the individual in an effort to reduce feelings of sadness and depression (74, 285). Others (284, 286) have emphasized the potential for those with greater awareness to benefit from engaging in psychosocial interventions and activity participation to prevent affective problems or maintain a positive affect in moderate dementia.

Even those who were less self-aware appeared to have experienced some benefit from exposure to a biophilic ambience or activity initiated by others. The action of ‘sitting quietly’ at the garden vignette was linked with having significantly lower CSDD scores. Individuals who spent > 1000 seconds at the vignette when it was first inserted were significantly more likely to have higher CSDD scores during the following washout phase, and when the vignette was returned they were more likely to spend > 1000 seconds at the vignette again. Individuals who were self-determined in their arrivals were also more likely to have a lower CSDD score. The implication is that spending time at the vignette, either sitting quietly or engaged in complex activity, had the capacity in some residents to change behaviour to the extent that they were determined by others to be less depressed when the vignette was in place and more depressed when it was removed. Considered in conjunction with the findings of others, the CSDD and SQDT findings indicate that the vignette could be used as a nonpharmaceutical adjunct to the management of depressive symptoms.

The effect of the vignette on aggressive behaviour also had implications for nursing. Significant reductions in recorded aggressive behaviour across the study phases showed that the vignette intervention appeared successful in reducing aggressive behaviour as recorded by the RAS2 (modified). Significant correlations between higher RAS2 scores and the frequency of being given a PRN medication indicated that pharmaceuticals were still prevalent in the management of escalating aggressive incidents but the continued reduction in aggressive incidents across the phases may indicate a carryover effect. The practice implication arising from this effect is that the presence of the vignette with its offering of self-determined activity and restorative ambience may act as a moderating influence on general aggressive tendencies in deepening dementia. A second nursing implication arose from the video observation of only two

nonaggressive incidents of inappropriate object use at the vignette. Given the well-founded concerns for safety and the resulting absence of objects for interaction on dementia units, the appropriate use of garden trowels and forks, plant pots and dirt is clinically important. A complete explanation as to how and why this occurred can be found in the theoretical implications section in relation to Attention Restoration Theory (see 6.8.2.2) (287).

Although no significant effects on apathy scores were found in relation to the vignette, the presence of apathy would by its very nature have reduced self-determined interactions at the vignette and thus exposure to the intervention. Observations of only 12 of 30 (phase 2) and 12 of 26 (phase 4) participants engaged in greater than two self-determined behaviour events would lend support to the previously stated belief of the relationship between apathy and self-determined behaviour. The AI and video data analyses did however show that individuals with higher apathy scores did not refuse to interact at the vignette when brought by others. A practice implication for these findings is the need for staff education programs to enhance awareness of apathy as a disorder of motivation and the development of nursing strategies appropriate to engage individuals who present with passivity (142). The presence of apathy should not mean relegation to a chair on the sidelines, but an opportunity to continue engagement, initiated by others, that responds to the unique personal skill, ability, personality, interest, and need of the individual (243).

Video data analyses showed that self-determination continued to exist in the presence of dementia and seemed to be linked with familiarity, given that phase 4 produced more self-determined visits than phase 2. Those who were more self-determined were more likely to spend time at the vignette and were less likely to have high CSDD scores. When the vignette was first removed some self-determined participants expressed significantly greater neuropsychiatric

behaviour as measured by the NPI-NH and CSDD in phase 3; self-determined participants returned to the vignette when it was reinserted. It would seem that for some individuals, offering self-determined activity opportunity might support the reduction of neuropsychiatric behaviour. The maintenance and fostering of autonomy has been shown to have great significance for those with dementia living in care as they struggle to respond to their sense of isolation and maintain connections with the real world (288).

Given the findings demonstrating vignette interaction effect on neuropsychiatric behaviour it may be suggested that the garden vignette could be used as a nonpharmaceutical adjunct to the management of neuropsychiatric behaviour in individuals with moderate to severe dementia. To attain the greatest effect for apathetic and/or depressed individuals nursing staffs would need to identify those who express those traits and develop strategies that support their engagement at the vignette, e.g., identification of skill level, ability and personality traits. Those who are self-determined will find their own way and will return unassisted if the degree of novelty and extent/coherence is appropriate. Even those who are self-determined may require personal assistance at the vignette, not only to increase their enjoyment of the vignette but also to facilitate activity as dementia deepens or ideational apraxia limits initiation. Caution in accepting these findings and their implications is suggested as the small sample size, the degree of individual variance and caregiver assessment and quantification of behaviour may have affected these findings.

Future research to enhance the application of the garden vignette as a nonpharmaceutical intervention could include: a) an exploration of the type of interactions that are most supportive of resident interaction, b) an exploration of how vignette interaction may be actively

incorporated into a care regimen and c) examination of caregiving strategies to promote engagement in individuals expressing apathy in activity.

6.8.1.2 Implications Related to Pro Re Nate (PRN) Medication Administration

The study hypothesis that PRN psychoactive medication use would be reduced in conjunction with a reduction in neuropsychiatric behaviour showed mixed results. The ANOVA, Friedman's test and paired *t*-test showed no significant difference in the phases in relation to PRN psychoactive medication administration. Time spent at the vignette produced no significant difference between the two time groups (> 1000 seconds or ≤ 1000 seconds) for being given a PRN psychotropic medication. The implications are that neither insertion nor removal of the vignette or spending time at the vignette triggered increased PRN medication administration. This would support that staff could institute a garden vignette with little worry as to the potential for increased PRN psychotropic medication administration.

Examining relationships between neuropsychiatric test scores and being given a PRN psychoactive medication produced very mixed findings which prevents any conclusions from being drawn. Early study phases showed few significant results and only during the later phases did the grouped (yes/no medication given) data show significant relationships between the NPI-NH and RAS2 scores, an expected finding. PRN psychoactive medication administration patterns identified that individuals with the lowest MMSE scores were given ever increasing amounts of PRN psychoactive medication as the study progressed, potentially indicating either progression of the disease or reduced cognitive ability to respond to the environmental changes that were occurring every two weeks. Patterns also identified that withdrawal of the intervention in phase 3 seemed to be the point at which PRN medication administration was most likely to be triggered, but this did not necessarily coincide with increased documentation of neuropsychiatric

behaviour. Indeed aggressive events recorded decreased as the study progressed. The reasons for PRN psychoactive medication administration remain unclear in relation to expressions of neuropsychiatric behaviour as measured by the tools in this study.

Further study would be required to understand how staffs interpret and respond to neuropsychiatric behaviour in their determination to medicate, and may be addressed best through the use of qualitative methods. Questions designed to explore the decision-making processes associated with administering a PRN neuropsychiatric medication could enhance our understanding of why there were mixed correlation findings between neuropsychiatric test scores, patterns of PRN medication administration and being given a PRN psychotropic medication. Important questions to explore might include: What are nurses seeing and responding to that creates that difference? What specific behaviours are to be resolved by giving the medication? What guides psychotropic PRN medication administration?

6.8.1.3 Implications Related to Wheelchair Participants

The absence of any Pearson correlations between ‘being in a wheelchair’ and all of the neuropsychiatric tests in phases 1 and 2, followed by fair to good significant Pearson correlations between ‘being in a wheelchair’ and all but one of the neuropsychiatric tests (SQDT) for phases 3, 4 and 5 may be related to limited access. Being in a wheelchair may require longer periods of time to both notice the vignette and find ways to access it. Participants in wheelchairs who were brought by others to sit quietly at the vignette showed significant fair correlations with having higher NPI-NH, NPI-NH-OD and AI scores during phase 4 (intervention 2). The significance of these findings is that staff did appear to use the vignette as one option to manage behaviour, but for this group the ambience did not appear to improve neuropsychiatric behaviour. Perhaps this group, rather than being left to sit quietly, required a guided interaction with the vignette or the

activity of gardening did not match this group's unique interests, both possible contributors to increased expressions of neuropsychiatric behaviour. The presence of apathy may require a more focused staff intervention than exposure to ambience. Progression of the disease or unknown co-morbid physiological change may also have contributed to these findings.

In phase 5 (washout 2) participants with significant correlations between being in a wheelchair and having higher NPI-NH and NPI-NH-OD scores were more likely to have been actively engaged when at the vignette in intervention phases. This finding may be showing that those more actively engaged missed the opportunity for activity when it was removed. Together the significance of these findings is four-fold: a) being in a wheelchair may reduce accessibility (visual and physical), affecting opportunities for interaction at the vignette; b) even in wheelchairs, individuals are capable and interested in engaging at vignette sites; c) individuals in wheelchairs may express greater neuropsychiatric behaviour when a desired activity is not accessible; and d) when opportunities exist for engaging residents, staff will encourage residents to make use of those opportunities by placing them in the vicinity of the vignette, but for some it may require more than being brought and left. Vignette design should incorporate these understandings by placing vignettes in wheelchair accessible sites, and improving staff recognition of who might benefit from the vignette and how that benefit might be instigated.

Future research directions could be directed at both staff and residents in a qualitative exploration of staff interpretation of vignette use by residents in wheelchairs. Limited early use of the vignette could be examined through the ease of accessibility or through the more complex understanding of familiarity (191) and engagement.

6.8.2 Theoretical Implications

Philosophically, this study acknowledged the complex relationship between not meeting basic human needs and the expression of neuropsychiatric behaviour (73). Previous to this study self-determination had not been proposed or recognized as a basic human need in dementia populations and intervention research methods had always predetermined intervention dose (84, 119, 201, 206, 210, 243, 289, 290). Unknown were: whether self-determination was retained in moderate to severe dementia and whether the offering of self-determined activity could have an effect on the expression of neuropsychiatric behaviour in a highly controlled environment with limited opportunity for self-expression.

6.8.2.1 Self-determination as a Basic Human Need

This study clearly demonstrated that for some individuals self-determination was retained. From thirty-three participants, thirty in phase 2 and twenty-six in phase 4 engaged in self-determined behaviour with the mean number of self-determined visits doubling in phase 4. No pathological disease process was significantly associated with being more self-determined. Dementia diagnoses were represented in almost equal numbers in those who were self-determined. There were also no statistically significant relationships between MMSE scores and being self-determined, suggesting that regardless of pathology or cognitive ability individuals with moderate to severe dementia engaged in self-determined behaviour at the vignette.

The NPI-NH evaluated a broader spectrum of neuropsychiatric behaviour, which may explain why only a single statistically significant relationship with self-determination was found. Individuals who had higher NPI-NH scores on night shift during the first washout phase were statistically significantly more likely to be self-determined when at the vignette in phase 4. The lack of any statistical relationship between being self-determined and NPI-NH scores during both

intervention phases may indicate that being self-determined had a neutral effect on the NPI-NH score, neither increasing nor decreasing neuropsychiatric behaviour. The washout phase finding may indicate that participants missed the opportunity for self-determined behaviour and their expressions of self-determination on night shift may have been interpreted as neuropsychiatric behaviour, a response to not having a basic human need met.

6.8.2.1.1 Curiosity and Novelty as Related to Self-determination

To be self-determined is to exhibit a degree of curiosity and a response to novelty (75), two characteristics not commonly associated with moderate to severe dementia. When presented with a change in the physical environment, participants who were self-determined demonstrated curiosity in their surroundings by going to and interacting with objects that were part of a new and strange environmental feature. Indeed, participants with AD who visited the vignette were more likely to use three senses and twice as likely to use two senses than individuals with VAD. Even participants with frontal dementia, who had the greatest number of observations of 'not attending to the vignette', showed greater use of two and three senses when engaging at the vignette, indicating a retained sense of curiosity.

Together these findings enhance our understanding of basic human needs and their relationship to neuropsychiatric behaviour. Knowledge of the retention of ability is extremely important (172) to develop activities that may: (a) be more responsive to the unique needs of the individual by including opportunity for self-exploration and engagement, (b) act to encourage recognition of retained ability in activity planning and (c) inspire caregiving staff to include elements within activities that are novel and arouse curiosity.

Future research opportunities could include an exploration of the role of premorbid personality in the expression of self-determination. Theissen et al. (291) identified that the

personality characteristics of antagonism, whimsical and impulsive behaviour, rigid behaviour and being vulnerable in social interactions were retained even in stage 6 of the Reisberg Global Deterioration Scale. Similar personality characteristics may also be the basis for self-determined behaviour. Kolanowski and Buettner (243) further suggested that the use of personality profiling may enhance nursing's ability to match activity to person, improving on meeting the unique activity needs of the individual. Personality profiling was not used in this study but such an inclusion may further assist in understanding the meaning of self-determination in dementia.

6.8.2.2 Attention Restoration Theory and Biophilia Theoretical Implications

Attention Restoration Theory (221) had not previously been applied to activity development for individuals with moderate to severe dementia. Theory authors proposed that continued use of direct attention reduced the capacity of an individual to respond resulting in irritability, attentional fatigue and task errors (221). It was thus anticipated that increased cognitive demand, the result of progressive dementia and the cognitive stressors arising from large group institutional living could together produce attention fatigue and increased irritability. Further, it was offered that creating a psychological distance from our routine mental context (being away), effortless attention (fascination), the ability to interpret and explore (extent/coherence) and engaging in activity where individual preference and environmental demands supported the intended activity (compatibility) combined to reduce attention fatigue. Natural environments were presented as the preferred means of meeting those criteria and the goal of restoration (109). Consequently it was proposed that a garden vignette could be restorative and attention restoration criteria were used for its design. Features included strongly biophilic elements such as large palms, small orange trees, flowering plants and herbs. The

hardscape included a colourful Thai umbrella, a planting centre, large artificial flowers and gardening aids from seeds to a whiskbroom for clean-up.

6.8.2.2.1 Activity Versus Ambience in Attention Restoration

The vignette elements were intended to create a ‘sense of garden’. Some participants engaged in gardening activities while others selected the vignette for ‘ambience’. The mood created by the vignette appeared to support sleep. Being asleep at the vignette correlated significantly with spending >1000 seconds at the vignette and in the final washout (phase 5), having a lower CSDD score. Being asleep at the vignette did not correlate, however, with higher AI scores during any phase on any shift, offering that sleeping at the vignette may not be just the product of reduced motivation to remove oneself from the environment. Being ‘inattentive’ also correlated significantly with spending >1000 seconds at the vignette but in contrast to sleeping, participants had higher CSDD scores. Individuals who were more depressed spent more time at the vignette, but did not actively engage with vignette objects. These observations may be reflecting participant use of the garden vignette as ambience. What is not clearly known is whether the lower CSDD scores in the final washout that were correlated with spending more time at the vignette were the results of the long-term effects of a restorative environment on behaviour.

A second finding that offers evidence to support the importance of the attention restoration constructs of extent/coherence and compatibility was the absence of any correlation with being disruptive in relation to the stimulus and inappropriate manipulation of the stimulus. On the surface it suggests that the objects for interaction did not present a safety hazard. Given there were garden trowels and forks available to individuals with a high level of neuropsychiatric behaviour, assumptions of safety are challenged. Understanding can be found in the constructs

of attention restoration. Presentation of garden trowels and forks in the context of a vignette is key. The clustering of multiple objects into a vignette enhanced the understanding and interpretation of the objects as related to ‘gardening,’ meeting the criteria of extent/coherence. Self-determination reflected the inclinations of the individual by affording either acceptance or refusal of the offered activity thereby meeting the criteria of compatibility. Level of engagement reflected the individual’s capacity and was evidence of ability. This form of natural compatibility may have reduced the potential stress created by mismatches between personal preference, capacity and caregiver managed activity (74) observed in other research formats. It is offered that together these elements contributed to enhanced environmental comprehension and appropriate behaviour.

The constructs of extent/coherence and compatibility in Attention Restoration Theory do appear to be applicable to the creation of garden vignettes. Clustering objects to create a sense of garden assists with environmental cognition, which in turn may act to facilitate appropriate use of objects. Clustering biophilic objects also appears to create an ambience that facilitates sleep and may over the long term have an effect on depression. Further study is needed in this area to understand the relationship between ambience and depression in dementia. What is also unclear is how participants experienced the vignette. Observations of activity, measures of time spent and test scores relay little information about the ‘experience’ of the vignette. Future research might explore in more verbally competent individuals: what the vignette offers them; how engaging with the vignette makes them feel; what do they like or not like, how could we improve the experience; is it worth improving? For severely impaired individuals asking a simple question such as ‘did you enjoy this gardening experience?’ may offer some insight into their experience of the vignette. Expansion of the concept of experience could be extended to staff as

well, asking what their experiences with the vignette were including supports and barriers to use; if and how they incorporated the vignette into care practices; what did or did not work for them; what changes might they like to make to the vignette; and how might the vignette be better utilized.

6.8.3 Methodological Implications

This study has methodological implications that may serve to strengthen nonpharmaceutical intervention research. A methodological purpose of this study was to strengthen the philosophical foundation for activity-based intervention research in individuals suffering with moderate to severe dementia. This was accomplished by: (a) examining the concept of self-determination as it relates to activity, the expression of neuropsychiatric behaviour and as an alternative to timed intervention dose protocols; and (b) applying attention restoration and biophilia theory to the development of a garden vignette. Challenges to method were also experienced in relation to measurement tool limitations.

6.8.3.1 Self-determination as Intervention Dose Control

In this study Need-Driven Dementia-Compromised Behaviour (73) provided the core philosophical stance. In the presence of reduced verbal communication behaviours such as neuropsychiatric behaviour were considered an expression of need. Further it was offered that meeting needs would reduce behavioural symptoms. This study is the first to identify and apply ‘opportunity for self-determination’ as a basic human need for individuals with dementia. In doing so it recognized the retention of ‘person’ and ‘ability’ thus reducing paternalistic attitudes sometimes seen in dementia study designs especially for individuals with moderate to severe dementia. Previous authors have found that intervention dose protocols are extremely difficult to maintain achieving only 61% of the planned interventions due to participant reluctance to

participate (56). Findings also suggest that timed dose protocols may result in the production of aggression and agitation (56). Still other authors do not note refusals or exclude those who are 'uncooperative' from their findings (201, 210).

The maintenance of treatment fidelity in long-term care settings presents a significant challenge (292). Researchers attempt to control and reduce potential confounding factors such as pain, hunger, thirst, elimination needs and environmental conditions (201, 275), but all admit potential for deviation and unintentional effect. Attempts to design activities that reflect skill level, previous style of interest or functional capacity involve enormous amounts of time spent in data collection, sifting through the data and attempting to match activity to the individual (201). Limited success has been shown with third-party matching (201). To apply self-determination as a concept relevant to research method in dementia means to understand that self-determination inevitably produces matches to activity and treatment fidelity. Individuals who are hungry, tired, thirsty or needing to void do not engage in self-determined activity at an activity centre. They may be expressing neuropsychiatric behaviour as a result of unmet need. Individuals who are not interested in what is offered at the vignette will not attend. Equally important is that standard care is not reduced or altered when using self-determination as a means of offering engagement.

Challenges to the use of self-determination as a reliable means of increasing treatment fidelity do exist however. One such challenge is the presence of apathy. These findings showed that individuals who are more self-determined are less likely to have high apathy scores. When using self-determination as a method for dose control, it would be necessary to determine degree of apathy present in all participants. Recognition of the presence of apathy does not preclude interaction at a vignette nor in the study did apathy prevent individuals from interacting with the objects once they were started at the activity. While self-determination as initiating activity may

be affected in the presence of apathy, exposure to novelty may engage the attentional system thereby facilitating a sustained response (132). Perhaps key to understanding why self-determination would work when the activity does not necessarily match previous hobbies or interests (a consideration that is in opposition to Need-driven Dementia-compromised Behaviour (NDB) theory) is that in moderate to severe dementia, loss of memory for what was previously enjoyed may be replaced by a retention of human curiosity and an inherent ability to respond to novelty within the physical environment (132).

6.8.3.2 Attention Restoration to Assist in Intervention Design

Combined with self-determination, the research findings of this study suggest that it is possible to design environmental features that attract, sustain and potentially restore attention. Attention restoration constructs were applied to the design of the vignette and may have contributed to the following findings: a) clustering objects together enhanced understanding of the object's use, resulting in only two harmless instances of inappropriate object use recorded on video which supported the construct of 'extent/coherence'; b) the creation of an ambience that was supportive of sleep supported the construct of 'being away', that is, creating a psychological distance from the routine mental context; c) self-determined exploration in the process of gardening was evidence of the construct of 'fascination' (effortless attention), where engagement was facilitated by retained novelty and curiosity; and d) video observations that some participants stayed for > 1000 seconds using three senses to interact with garden objects supported the construct of 'compatibility'.

Together the new philosophical constructs and the study findings of how these applied to the dementia population add a new dimension to understanding NDB theory. It is not always necessary to rely on past positive activity experiences. In moderate to severe dementia, loss of

memory or lack of habituated response does not preclude activity engagement, but it does challenge those providing activity to incorporate elements of self-determination and activities that incorporate elements of attention restoration into their programs. Enhanced understanding of the philosophical constructs produced by the additions of self-determination and attention restoration acts to strengthen the content validity of the study.

6.8.3.3 Measurement Challenges

As previously identified in the limitations section (6.7), major challenges to the reliability and validity of the study findings were both the measurement tools available for use and the resources to complete the tools. The number of tools, reliance on caregiving staff to complete third-party tools and five phases of measurement potentially resulted in research fatigue. The complexity of the tools, the unaccustomed requirement to make decisions, a need for English fluency to complete the tools, changes to the work environment, frequent exposure to neuropsychiatric behaviour, differing cultural filters, and interactional processes all demonstrated the complexity and ubiquitous confounders to reliability and validity experienced in real-world research. The implication may be the use of a more pragmatic approach to research design (293). This may require: a reduction in the number of tools used; a more focused approach to measuring neuropsychiatric behaviours by clustering behaviours to be studied in response to short or long-term outcomes, e.g., responses to depression and apathy may require a greater length of time to identify change (69); improved efforts to increase the knowledge levels of caregivers as assessors of behaviour; and a provision of release time to support thoughtful evaluation of behaviour.

External validity was challenged by the small sample size. Limiting the sample to those participants diagnosed with neuropsychiatric behaviour, but including all dementia diagnostic

categories and all types of neuropsychiatric behaviours strengthened clinical applicability with the possibility of maximizing applicability to usual care settings rather than those that are tightly controlled with little relevance beyond the immediate setting (7, 293). Future research to include a larger focused sample would serve to enhance external validity.

That neuropsychiatric test scores never returned to baseline during the washout phases may indicate the presence of a baseline Hawthorne effect (237), where merely being engaged in the research process produced higher than expected scores. For caregivers, evaluation apprehension may have arisen from: a) being asked their opinion, b) being afforded the opportunity to evaluate their daily work experiences of their resident's difficult to manage behaviours, and c) personal caregiver needs to be engaged in something other than the 'everyday'. All of these factors may have contributed to the initial high neuropsychiatric test scores. It follows that the washout scores may be a reflection of a regression to the mean (237). It may be possible to reduce the extent of this bias by creating tool learning experiences separate from actual evaluation experiences. For this study learning about the tools and application to participants was completed simultaneously to afford one on one teaching, to enhance understanding and to improve retention. The reasons for this included limited research personnel, staff time constraints, and caregiving staff learner characteristics (294). Creating separate learning experiences about the tools would seek to increase internal reliability and validity.

The measurement tools themselves presented further difficulty. The language of neuropsychiatry is complex and difficult for lower qualified caregivers (care aides) to understand. This population of caregivers receives limited if any instruction on the identification and management of psychiatric behaviour (295). A further complication is many individuals in

these positions have English-as-an-alternate language which adds another layer of complexity to understanding the language of neuropsychiatry. Assumptions that longstanding staff, minimal staff turnover and institutional continuing education on special care units would produce a knowledgeable worker skilled in neuropsychiatric assessment were, in hindsight, not reasonable. What remains reasonable, however, is the belief that it is precisely the individuals whose time is spent at the bedside providing direct care that are best suited to know, through intimate experience, the behaviour of their charges. It is recommended that to enhance caregiver knowledge of neuropsychiatric symptom assessment a series of 15 to 20 minute education sessions be held on a daily basis prior to beginning the actual research process. Video clips demonstrating the behaviours measured by the NPI-NH, supported by unit specific examples and a single page written description of behaviour for future reference would provide better knowledge support. On completion of the twelve behaviours measured by the NPI-NH, four follow-up sessions using case study and tool application would then be completed. On completion of all sessions caregivers would be awarded a certificate of completion to publicly acknowledge their contribution. The certificate could be used at performance review or for future employment opportunities. Dellefield's (296) literature review of strategies to maintain best practices in long-term care suggests that the approaches described above may offer more hope of maintaining best assessment practices throughout the research process. Increases in research cost and time would be very significant and best supported by larger grant research projects. An alternative approach may be to re-examine measurement tools with caregiver characteristics and ability as a focus rather than the ability of the researcher; tools that are understood and can be completed properly have the potential to provide fuller data collection. The need for caregivers at the bedside to be able to not only identify but act on the expressions of

neuropsychiatric behaviour is key to both better behaviour management strategies and safe caring environments, and would facilitate improved research participation.

To counter research fatigue and thereby improve reliability the number of tools used could be decreased. The difficulty with this proposal is that some of the data show that the broader NPI-NH score did not necessarily reflect the findings of the single behaviour measure tools, such as for depression (CSDD, SQDT), apathy (AI) and the simple single counting of aggressive incidents (RAS2). Only if future research demonstrated convergent validity between the NPI-NH behaviour categories and validated outside measures could the NPI-NH be used exclusively. Individual behaviours sheets could then be isolated from the total score and used in the same manner as the CSDD or AI, but within the time constraints of completing a single tool. Recent changes to the NPI (NPI-C) through the addition of 78 new items and a deliberate focus to improve the depression and apathy score pages may be able to meet those needs (176). Staff education programs could then be designed to specifically reflect the tool descriptions, potentially increasing both reliability and validity of the results.

6.9 Summary of Discussion

The ANOVA and Friedman's test showed that removal of the vignette did not produce effects on neuropsychiatric outcomes. No phase effect was shown for the AI, the SQDT or the number of PRN psychoactive medications given. The paired *t*-test analyses showed that the difference between the phases was primarily between baseline and intervention one and most often for evening shift. Inability to demonstrate a significant effect between each insertion and withdrawal phase could be attributed to multiple factors: carryover effect resulting from inadequate phase time differences (potentially too short or too long depending on the type of behaviour); intraindividual variability in the expression of neuropsychiatric behaviour; small

sample size impacted by grouping of data, further reducing the size; organizational change that impacted the final two phases; reduced staff sensitivity to neuropsychiatric behaviour; staff characteristics that impacted assessment of neuropsychiatric behaviour; and regular daily psychoactive medication administration.

The effect of time spent at the vignette showed mixed findings but individuals who spent > 1000 seconds at the vignette were significantly more likely to return to the vignette when it was reinstated, have higher NPI-NH and NPI-NH-OD scores at baseline on night shift prior to insertion of the vignette and have higher CSDD and NPI-NH scores during the first washout phase. In phase 4, participants who self-identified as depressed (SQDT) were significantly more likely to spend > 1000 seconds at the vignette during that phase. No significant 'time spent at the vignette' effects were associated with the AI or RAS2 for either phases 2 or 4. Spending time at the vignette also significantly correlated with being self-determined. The mixed findings may be attributed to the small sample size, excessive daytime sleep prior to the insertion of the vignette or a negative response to the loss of activity in the washout phases.

How time was spent at the vignette also presented a mixed effect on neuropsychiatric behaviour. Significant *t*-values showed that individuals who were identified by staff as being more depressed in phase 3 were brought and left by staff and spent more time at the vignette when it was returned in phase 4. This was interpreted as staff awareness of not only a need to engage these individuals but also their willingness to take action based on their assessment when the opportunity existed. Individuals who spent more time at the vignette were also significantly more likely to be asleep or not attentive (phases 2 and 4), in a wheelchair (phase 2) and sitting quietly (phase 4). It was suggested that daytime sleep as a prime activity might be related to nighttime neuropsychiatric behaviour. Although sleep at the vignette was recorded, increases in

neuropsychiatric behaviour on night shift during intervention phases did not rise to the significant levels shown at baseline and phase 3 (washout 1). These findings may be demonstrating that time spent sleeping at the vignette may not be as great as time spent asleep in non-intervention phases when there is no other form of activity. It may be that even small amounts of self-determined activity or activity other than regular programming reduce daytime sleep. By phase 4, spending more time at the vignette also meant being significantly more likely to engage in higher levels of activity (e.g., manipulating the stimulus), including those who self-identified as depressed (SQDT). Spending more time also meant greater opportunity for interruption and when interrupted participants often did not resume their activity or followed the interrupter away. In non-intervention phases 1, 3 and 5, significant Pearson correlations between the NPI-NH and NPI-NH-OD scores and being in a wheelchair, asleep, being inattentive, or sitting quietly supported the significant *t*-values. While it seems a large amount of time at the vignette was spent in sleep, the opportunity for interaction during times of wakefulness appeared to reduce nighttime neuropsychiatric behaviour to a greater extent than having no opportunity at all. Reductions in daytime sleep may always prove difficult in the face of sedative medications and disease progression effects.

Examining the complexity of engagement also offered insight into how the vignette might affect behaviour. Individuals with higher NPI-NH scores at baseline on day and night shifts correlated significantly with engaging in more complex activity in phase 2 (e.g., using two or more senses (day shift) and manipulating the stimulus (night shift)). Several significant Pearson correlations also existed between objects that required a greater level of interactive complexity and having higher NPI-NH scores on night shift at baseline. The greatest number of significant correlations occurred between higher NPI-NH-OD scores and vignette variables in

phase 5 (washout 2). Individuals who in phase 4 were engaged in more complex activity at the vignette showed a good significant correlation with higher NPI-NH-OD scores in phase 5. The non-intervention phases 1, 3 and 5 produced t and r -values that showed a relationship and fair to good correlation between increased neuropsychiatric behaviour and occupational distress scores, and spending quiet time at the vignette yet still engaging in complex activity. These findings provide support for the original hypothesis that vignette activity would have an effect on neuropsychiatric behaviour. For some individuals the vignette provided either an ambience that was felt to be restorative or met their need for activity, and when removed the vignette was missed and neuropsychiatric behaviour increased.

The PRN psychoactive medication data analyses using ANOVA, Friedman's test and the paired t -test showed no significant differences between the phases, indicating that installation and removal of the vignette had no measurable effect on giving PRN psychoactive medication. The implication is that environmental change was unlikely to be the catalyst for giving PRN medications. PRN psychoactive medication administration was also not affected by the amount of time spent at the vignette. Other findings were mixed. Using grouped (yes/no received PRN psychotropic) data examining for specific relationships between neuropsychiatric test results and PRN medication administration showed an absence of relationship with the AI and CSDD, which could be expected as apathy and depression are not commonly treated with PRN psychotropics. The presence of significant t -values during the later phases of the study showing significant relationships between having higher NPI-NH, NPI-NH-OD and RAS2 scores and PRN medication administration could indicate that individuals were being given PRN psychotropics in response to escalating behaviour. However, PRN psychotropic medication use showed administration patterns that did not always reflect escalating neuropsychiatric behaviour. These

mixed findings may be the result of challenges in understanding neuropsychiatric behaviours responsive to psychotropics and/or the need for a quiet and cooperative resident. A staff review of nonpharmaceutical strategies to prevent the escalation of behaviour including early recognition of agitation and related behaviours, with the inclusion of strategies for early intervention, may assist in limiting PRN psychoactive medication use.

Self-determination findings showed self-determination was retained in the presence of moderate to severe dementia and that the number of self-determined visits doubled during the second intervention phase, a potential consequence of familiarity. Those most likely to be self-determined were participants with lower CSDD and AI scores, neither of which are unexpected findings. The significant relationship between increased night shift neuropsychiatric behaviour during phase 3 (washout 1) and being more self-determined when the vignette returned showed a potential for increased neuropsychiatric behaviour in the absence of self-determined activity. These findings may be attributable to the potential for self-determined behaviour to carry over from small situational change (e.g., activity at the vignette) to the larger context (e.g., being more self-determined in wanting to get up at night) and/or to the reductions in the amounts of daytime sleep during the intervention. Staff interpretations of nighttime wakefulness were also thought to potentially contribute to increased indications of neuropsychiatric behaviour on night shift.

Self-determination as a means of ‘dose’ control is new to dementia intervention research and was suggested as a means of improving method. The participant chooses to visit, self-selects objects for interaction, engages with the objects in the manner of their choice, and determines when the intervention no longer meets their engagement needs and then leaves. Self-determined behaviour as a measurement variable reduces the effect of confounders such as human contact and challenges to treatment fidelity such as refusal to participate and related behaviour

exacerbations. It also challenges researchers to construct activities that stimulate curiosity with a balance of novelty and familiarity that will promote self-motivated visits to the intervention. The ability of the vignette to attract attention and hold that attention in return visits was significant. A single significant relationship between having higher NPI-NH scores on night shift in phase 3 and being more self-determined during phase 4 is inconclusive for behaviour change effect. How self-determination was understood by caregivers may have affected behaviour assessment and also contributed to these findings. Together these findings imply that: 1) individuals with moderate to severe dementia are capable of self-determined activity, and 2) in the absence of self-determined activity, expressions of greater neuropsychiatric behaviour are followed by an increase in self-determined activity when the opportunity returns.

That curiosity and self-determination are retained behooves all who engage with individuals with moderate to severe dementia to identify its presence and to respond through developing activity opportunities that meet this significant need. That means rather than regularly scheduled programming, creating/providing vignettes (e.g., gardening, or others like crafts or office) that support self-determined activity. Those in whom self-determination is absent may require staff assistance to engage with the vignette; this was a significant finding observed for those with higher CSDD and SQDT scores.

The application of Attention Restoration Theory (ART) to design and develop the vignette was also new to intervention research in dementia. Clusters of objects related to gardening created a biophilic ambience that was proposed to reduce neuropsychiatric behaviour. The video variables ‘purposeful positioning’, ‘sitting quietly’ and ‘asleep’ at the vignette were used as indicators of the ambience. Ambience findings were mixed but indicated that a significant activity at the vignette was sleeping. The sleep effect may have been enhanced by

stage of dementia and psychoactive medication. Time spent sleeping at the vignette during intervention phases (phases 2 and 4) did not however increase nighttime neuropsychiatric behaviour to levels apparent in the preceding non-intervention phases 1 (baseline) and 3 (washout 1). During no phase did being asleep at the vignette correlate with higher AI scores, suggesting that reduced motivation may not be a constituent of sleep in dementia. Individuals who were depressed did spend more time at the vignette, but they were more likely to be inattentive rather than sleeping. Indeed having a lower CSDD score was significantly more likely to be related to sleeping at the vignette. It cannot be definitively stated that the vignette created an environment that was conducive to sleep, but the potential for the garden vignette to have created conditions that facilitated an environment that supported sleep is evident.

ART also led to the proposition that the clustering of objects would enhance environmental interpretation. This too was new to dementia intervention research. The video variables ‘disruptive in relation to stimulus’ and ‘inappropriately manipulated the stimulus’ were thought to reflect the ability of participants to understand expectations at the vignette. Only two instances of inappropriate manipulation of the stimulus and no disruptive incidents occurred throughout the total four weeks of intervention. This lack of inappropriate behaviour at the vignette in moderate to severely demented individuals may indicate that the clustering of related objects at the vignette facilitated a deeper understanding of expected behaviour, potentially triggering memories of past gardening experiences. Those who were self-determined chose the activity and were not corrected or organized by others in their behaviour, which may also reduce opportunities for conflict and aggression. Together these understandings of vignette interactions imply that Self-determination Theory (SDT) and ART might be used to support the development

of activities that reduce opportunities for conflict, engage and fascinate through novelty, and use of clusters of objects that stimulate remembering or trigger activity processes.

Limitations to the study included a small sample size, participants acting as their own controls, reliance on care aides for completion of measurement tools, challenges to the application of tool protocols, the potential for phase effect carry over, research fatigue, and the inevitable potential for Hawthorne effect when research is conducted in a site not previously exposed to the research process.

Recommendations to improve method include: a) increasing sample size while maintaining a focus on the known presence of neuropsychiatric behaviour; b) limiting dementia type and symptom profile (e.g., activity at a garden vignette may be more appropriate for those individuals with depression or apathy rather than explosive bouts of aggression or agitation); c) adjusting phase lengths to reflect treatment times appropriate for the type of behaviour being measured (e.g., mood change versus acute expressions of aggression); d) development and use of tools that may be understood and used effectively by direct caregivers, instead of tools at a level suited to masters prepared clinicians; and e) an enhanced protocol to teach caregiving staff about dementia and the neuropsychiatric symptoms associated with dementia. A major implication for engaging any of these strategies would be a significant increase in the cost of doing the research.

Suggested areas for future research included: a) exploration of caregiver experiences of vignette use (e.g., ease of use, how it was used, what factors facilitated or impeded use, when it was used and why); b) examination of the effect of garden vignette self-determined activity on quality of life; c) exploration of the role of premorbid personality on self-determination; d) exploration of the relationship between ambience, depression and dementia; e) qualitative research to understand the decision making processes involved in the giving of PRN

psychotropic medication; f) exploration of the type of interactions that are most supportive of resident interaction; and g) exploration of how vignette activity may be actively incorporated into a care regimen.

Implications for practice included: a) a need for greater depth of knowledge among caregivers about dementia, neuropsychiatric behaviours in dementia and medication knowledge regarding indication, expected response and side effects to set the stage for safer medication administration; and b) improved identification of the presence of apathy and depression with emphasis on lack of motivation as a symptom to encourage caregivers to offer interventions to initiate activity. It is important to maintain links with the institution to create environments that enhance practice knowledge, improve care and are receptive to research and research activity.

This study was a first look at a potential nonpharmaceutical intervention designed to reduce the expression of neuropsychiatric behaviour in individuals with moderate to severe dementia. Considered within the context and sample size, the data can be used to generate hypotheses around the following: how best to engage individuals at the vignette; who benefits most from engagement at the vignette; the most appropriate time-frame for intervention phases; other types of activity that could be incorporated into a vignette format; the applicability of self-determination as a basic human need and as a means of exploring intervention dosing; the role of biophilia in vignette construction and the creation of ambience; and the means by which attention restoration theory and the concept of extent/coherence can be used to create activity settings that are not only comprehended but acted upon by people with the other levels of dementia. In summary this study offers the following conclusions:

1. A garden vignette can be created that attracts the attention of moderate to severely impaired individuals with a diagnosis of dementia.

2. If available, staff will use the garden vignette as an adjunct to other nursing care strategies.
3. Environmental change through garden vignette insertion and removal may not affect neuropsychiatric behaviour to the degree proposed or expected.
4. The vignette may be used to encourage engagement in the activity of gardening.
5. The vignette may also be used as a means of creating ambience.
6. Participants who used the vignette for ambience were more likely to have higher depression scores but lower apathy scores.
7. Removal of the vignette was significantly related to increases in neuropsychiatric behaviour on some shifts.
8. Participants who spent greater amounts of time at the vignette engaged in more neuropsychiatric behaviour on night shift when the vignette was removed, but returned to spend greater amounts of time when the vignette was restored, suggesting that some individuals may have ‘missed’ the vignette and perceived some type of positive experience from interacting at the vignette.
9. Some moderate to severely demented individuals retained a need for self-determination and those individuals may be less likely to be depressed and may engage in more complex activity when at the vignette.
10. Individuals with vascular dementia may be more likely to come to the vignette, but individuals with Alzheimer dementia may spend longer periods of time once at the vignette.

11. Individuals in wheelchairs may take a longer period of time to notice and engage with the vignette and those individuals, while expressing greater neuropsychiatric behaviour, are more likely to be self-determined.
12. PRN medication administration did not always relate to neuropsychiatric behaviour scores as determined by the NPI-NH, CSDD, RAS2, and the AI.
13. Neuropsychiatric behaviour assessments may be modified by caregiver characteristics (personal mood; knowledge of dementia, medications and medication side effects; cultural and societal belief systems; interactional patterns; gender; and language skills), organizational characteristics (reporting methods, available support during challenging episodes, and need to ‘fit in’) and participant characteristics (stage and type of dementia).
14. PRN psychotropic medication administration may be affected by neuropsychiatric assessments.

The answer to whether participants who were moderate to severely cognitively impaired experienced a change in neuropsychiatric behaviour and a reduction in PRN psychoactive medication in response to activity at the garden vignette is inconclusive. The expression of neuropsychiatric behaviour results from a complex amalgam of environmental, personal and organizational features. Third-party measurement of those behaviours is equally complex. To understand behaviour change in such an environment presents multiple challenges. Some participants engaged repeatedly while others showed no interest at all. Some showed increases in neuropsychiatric behaviour while others showed decreases. Some slept while others dug, potted and played. No one was violent. That individuals present with unique expressions of dementia is known, that they present with unique responses to vignette activity is now also known. Dementia-informed responses to a garden vignette show that some individuals respond

to novelty, they retain a sense of curiosity and are capable of self-determination. They can understand the intent of clusters of objects and they may enjoy just sitting and taking in the ambience. These unique responses will hopefully inform unique solutions. This study acknowledges the work of many who have previously taken on this task, and to those who follow, it offers a new look at activity intervention research with individuals with moderate to severe dementia.

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APPENDIX A: PREVIOUS OCCUPATION CATEGORIES

Previous Occupation:

Please circle previous occupation of research participant

Resident Name: _____ Participant Code # _____

Previous Occupation

Primary Sector (code 1)

Mining

Forestry

Fishing

Farming

Drilling for oil and gas

Secondary Sector (code 2)

Construction

Manufacturing

(Blue-collar)

Service Sector (code 3)

Insurance

Banking

Education

Recreation

Health

Real estate

Hotels

Restaurants

(White-collar)

Unknown (code 4)

APPENDIX B: PREVIOUS HOBBIES AND ACTIVITIES

Previous Hobbies and Activities

Resident Name _____ Participant Code# _____

Circle all activities that are indicated in the resident chart that were previously enjoyed by the resident.

1. Needle craft (code 1)
 - a. Knitting
 - b. Crocheting
 - c. Embroidery
 - d. Sewing
 - e. Needlepoint
2. Gardening (code 2)
 - a. Any activity involving the care of plant life indoors or outdoors
3. Sedentary activities (code 3)
 - a. Cards
 - b. Reading
 - c. Painting
 - d. TV
 - e. Movies
 - f. Bingo
 - g. Writing
 - h. Gambling
 - i. Puzzles
 - j. music
4. Athletic activities (code 4)
 - a. Walking
 - b. Sports
 - i. Hockey
 - ii. Golf
 - iii. Basketball
 - iv. Soccer
 - v. Skating
 - vi. Swimming
 - vii. Skiing
 - c. Exercise –home gym or exterior gym
 - d. Boating
 - e. Dancing
 - f. Coaching
 - g. Fishing
5. Activities outside the home (code 5)
 - a. Outings
 - b. Camping
 - c. Politics
 - d. Community involvement
 - e. Travel
 - f. Dinning out
 - g. Church
 - h. Service clubs
 - i. Volunteering

APPENDIX C: LIST OF PSYCHOACTIVE MEDICATIONS NOTED FOR CHART REVIEW

List of Medications to be Recorded During Chart Audit (297, 298)

Resident Name: _____ Code: _____

Generic Name	Trade Name	Dose	Scheduled	PRN	PRN Date dose	Med with- held	Noted side effects
Cholinesterase Inhibitors (code 1) (improve cognition)							
Donepezil	Aricept						
Rivastigmine tartrate	Exelon						
Galantamine HBr.	Razadyne or Reminyl						
Tacrine (rarely used)	Cognex						
N-Methyl D-aspartate (NMDA) antagonist (code 2) (delay progression in mod-severe AD)							
Memantine	Namenda						
Buspirone HCl	BuSpar (anxiety)						
Antidepressant (code 3)							
Trazodone HCl (for sleep also)	Desyrel						
For complete list see below table. Enter resident's prescription in blanks below.							
Combination Antipsychotic & Antidepressants (code 4)							
Fluoxetine & Olanzapine	Symbyax (Prozac & Zyprexa)						

Atypical Antipsychotics (code 5) (Reduce delusions, hallucinations)							
Aripiprazole	Ability						
Clozapine	Clorazil						
Olanzapine	Zyprexa						
Paliperidone	Invega						
Quetiapine	Seroquel						
Resperidone	Resperdal						
Typical Antipsychotics (code 6) Reduce delusions, hallucinations							
Chlorpromazine	Thorazine						
Fluphenazine	Fluphenazine						
Haloperidol	Haldol						
Iloperidone	Fanapt						
Loxapine	Loxitane						
Molindone	Moban						
Perphenazine	Perphenazine						
Thioridazine	Thioridazine						
Thiothixene	Navane						
Trifluoperazine	Stelazine						
Mood Stabilizing & Anticonvulsant medication (code 7)							
Divalproex sodium (valproic acid)	Depakote						
Lithium carbonate	Eskalith						
Lamotrigine	Lamictal						
Lithium Citrate	Lithium citrate						
Lithium carbonate	Lithobid						
Gabapentin	Neurontin						
Carbamazepine	Tegretol						
Topiramate	Topamax						
Oxcarbazepine	Trileptal						

Anti-anxiety Medications (code 8) (agitation)							
Lorazepam	Ativan						
Buspirone (not a benzodiazepine all others in list are)	BuSpar						
Clonazepam	Klonopin						
Chlordiazepoxide	Librium						
Oxazepam	oxazepam						
Clorazepate	Tranxene						
Diazepam	Valium						
Alprazolam	Xanax						
Disinhibition Medications (code 9)							
Propranolol HCl (aggression)	Inderal						
Medroxyprogesterone acetate (sexual disinhibition)	Depro- Provera						
Leuprolide acetate (sexual disinhibition)	Lupron						
Sleep disturbance (code 10)							
Temazepam	Restoril						
Zolpidem tartrate	Ambien						
Zaleplon	Sonata						
Melatonin	Melatonin						

Generic Name, Trade Name

Antidepressant Medications (also used for anxiety disorders)

amitriptyline (tricyclic) Elavil
 amoxapine Asendin
 bupropion Wellbutrin
 citalopram (SSRI) Celexa
 clomipramine (tricyclic) Anafranil
 desipramine (tricyclic) Norpramin
 doxepin (tricyclic) Sinequan
 duloxetine (SNRI) Cymbalta
 escitalopram (SSRI) Lexapro (for major
 depressive disorder)
 fluoxetine (SSRI) Prozac
 fluoxetine (SSRI) Sarafem (PMDD)
 fluvoxamine (SSRI) Luvox (for OCD only)
 imipramine (tricyclic) Tofranil
 imipramine pamoate (tricyclic) Tofranil-PM

isocarboxazid (MAOI) Marplan
 maprotiline (tricyclic) Ludiomil
 mirtazapine Remeron
 nortriptyline (tricyclic) Aventyl, Pamelor
 paroxetine (SSRI) Paxil
 paroxetine mesylate (SSRI) Pexeva
 phenelzine (MAOI) Nardil
 protriptyline (tricyclic) Vivactil
 selegiline Emsam 18 and older
 sertraline (SSRI) Zoloft
 tranlycypromine (MAOI)
 trazodone Desyrel
 trimipramine (tricyclic) Surmontil
 venlafaxine (SNRI) Effexor

APPENDIX D: LIST OF CONTENTS FOR GARDEN VIGNETTE

1 large plastic gardening table with drawers, shelving and wheels for mobility

Vermiculite/soil for planting, compressed peat pellets

Bin for soil storage at vignette

Gardening gloves

Variety of seed packets for planting

Variety of living edible plants including herbs and flowers such as marigolds, and pansies

Non-poisonous tropical plants e.g., palms and citrus

Variety of sizes and shapes of plastic pots

A plastic watering can

A gardening fork and trowel

A dustpan and brush

Plastic storage trolley on wheels for extra supplies

Multiple copies of glossy gardening magazines

Large bouquet of artificial flowers to attract attention

Colourful umbrella, table and two chairs for beneath the umbrella (as available on site)

APPENDIX E: MODIFIED OBSERVATION OF ENGAGEMENT TOOL (MOET)

Modified Observation of Engagement Tool (Part 1)

	Timing			Arrivals & Departures						Behaviours Observed								Attention				
											physically occupied by stim											
Participant	entry - time on video clock	exit- time on video clock	total time	self-determined arrival	brought by other, other leaves-resident stays	brought by other, leaves with other	removed by others	left by self	wheelchair	refusal to engage	visually focuses on stimulus	turning body toward stimulus	touched the stimulus	held the stimulus	manipulated the stimulus	disruptive in relation to stimulus	inappropriately manipulated stimulus	not attentive	attentive 1 sense	attentive 2 senses	attentive 3 senses	

Modified Observation of Engagement Tool (Part 2)

[illegible]

APPENDIX F: MODIFIED OBSERVATION OF ENGAGEMENT TOOL (MOET) CATEGORY DESCRIPTIONS

Arrivals and Departures

1. Entry time: this is the time on the clock that is recorded when you first observe an individual approaching and demonstrating interest in the vignette. Look for body language such as the position of face, head, neck, eyes, body, feet toward the vignette that would indicate the individual is connecting with the objects at the vignette. Sometimes the connection is very small as when the individual only glances at the vignette, while at other times, the individual will stare for long periods of time at the objects. It is important to note even the glances at the vignette as they are an indication that the vignette has been 'seen' and 'attended' to.
2. Exit time: this is the time when the individual disconnects from the vignette. Please note if their connection has been interrupted or continuous. For example: A resident may be sitting at the vignette and looking at a magazine, but is interrupted by a staff member who comes to remove their bib, give them medication or talks with them about the vignette. Do not stop or restart time calculation, just note that the time was interrupted by ticking the 'interrupted during' box and continue to observe until the resident shows a definitive break from the vignette by walking or moving away from the vignette. There may be times when the resident falls asleep at the vignette site. Please continue to monitor time, but check the box that says 'asleep at vignette'. The same applies to a resident who is just 'sitting quietly at the vignette' and not interacting with the objects at the vignette.
3. Total time: This is the total time that the resident spends at the vignette and is measured in seconds to accommodate the short glances or walk by looks that residents make at the

vignette site. Even if the resident spends one hour at the vignette, please convert to seconds.

Behaviours Observed

Physical Occupation with Stimulus

1. Self-determined arrival: this refers to how the resident has come to be at the vignette.
Self-determined means that the resident has come of their own volition, under their own steam, without any help from others.
2. Brought by other, other leaves-resident stays: This category means that someone has brought the resident to the vignette, has initiated the contact, but leaves the resident at the vignette by themselves to explore the objects.
3. Brought by other, leaves with other: This category is used when a resident is brought to the vignette by someone and then leaves with that same person when they leave.
4. Removed by others: In this category the resident is already at the vignette and someone comes and takes them from the vignette. Someone else has influenced their leaving.
5. Left by self: This category is used when the resident leaves the vignette under his or her own volition.

Level of Engagement:

This category explores the level of interest or attraction the vignette objects create for the resident

1. Refusal to engage: This category is used when a resident is brought to the vignette by someone else, but refuses to look at or interact with the objects at the vignette. For example: the nurse walks with a resident to the vignette and picks up some objects to

show the resident. The resident turns his/her back to the vignette and does not visually engage with the object being offered, may push away the object, or even struggles against the nurse to leave the vignette.

2. Visually focuses on the stimulus: This category is used when residents actively engage in looking at the objects on the vignette.
3. Turning the body toward the stimulus: In this category the turning of the body toward the object demonstrates a more intense level of interest rather than just visually glancing at the object.
4. Touched the stimulus: In this category the resident uses the sense of touch to denote engagement at the vignette. The resident may touch any of the objects on the vignette, including the grey cart, umbrellas, plants etc.
5. Held the stimulus: The resident is observed actually picking up an object or is given an object to hold by someone else.
6. Manipulated the stimulus: The behaviour is observed when the resident uses an object in the manner that is intended by the object itself. For example: the resident uses the whisk broom to brush soil off the surface; the resident puts soil in a pot; a resident picks up a magazine and begins to turn the pages; a resident puts seeds in a pot; the resident opens a seed packet to explore the contents.
7. Disruptive in relation to stimulus: The resident uses the objects in the vignette in an aggressive manner. For example: the resident throws a pot; uses a trowel to hit something or someone

8. Inappropriately manipulated the stimulus: The resident uses the objects in the vignette in a manner in that is not expected. Pulls plants out of their pots, tears leaves off of the plant; hammers with the trowel; tries to eat the peat puck, seeds or soil.

Level of Attention: this category examines the degree to which the individual takes notice.

1. Not attentive: This category is used when the resident comes to the vignette, but uses it as environmental ambience. For example: The resident comes to the vignette, positions a chair directly in front of the vignette and sits with his/her back to the vignette itself. There is no interaction between the resident and the vignette, other than the deliberate creation of close proximity to the vignette. Nurses may also be seen bringing a resident in a wheelchair and leaving them deliberately close to the vignette, but not able to visually or physically interact with the vignette objects.
2. Attentive 1 sense: In this category the resident uses only one sense to engage at the vignette. For example: The resident may walk up to the vignette, but only looks at the objects, never touching or manipulating anything.
3. Attentive 2 senses: For this category the resident uses two or more senses to engage with the objects at the vignette. For example: the resident looks at the objects and then picks up a trowel (both vision and touch are used here); the resident tastes a peat puck (vision, touch and taste are used here).
4. Interrupted attention: This category is chosen when the resident is at the vignette, engaging with the vignette and something happens in the background to 'interrupt' the resident's attention. For example: A resident may be standing quietly looking at the objects at the vignette, when a staff member comes along and begins to talk with them; a

resident is reading a magazine and the staff member comes and removes the toweling bib;
a resident is manipulating the seed packets and a staff member comes to give them a medication.

Ambience: refers to a gestalt (set of things that when considered as a whole amount to more than the sum of its parts) created by the objects within the space. It is the overall effect created by the features within the vignette to offer as ‘sense’ of garden. The question becomes, are the residents or staff using the vignette for the ambience the objects create. Without the objects there, would the resident have come or positioned him or herself in that position.

1. Purposeful positioning at vignette: The resident is purposeful in their approach to the vignette. For example: The resident walks directly toward the vignette. Body language including focus of eyes on the vignette is definitive to get them to the vignette as opposed to someone who walks by and glances at the vignette because it happens to be near them. The resident organizes furniture around the vignette in such a way as to communicate that proximity to the vignette and its objects offers a special sense or setting in which the individual has chosen to remain.
2. Sitting quietly at the vignette: the resident is not interacting with the objects at the vignette, but sits quietly near the vignette. They can be brought by others or come by themselves
3. Asleep at the vignette: The resident may proceed from sitting quietly to sleeping at the vignette, or may be brought by family or staff already asleep and be left to experience the ambience of the vignette.

APPENDIX G: THE GLOBAL DETERIORATION SCALE

GLOBAL DETERIORATION SCALE (GDS)

(Choose the most appropriate global stage based upon cognition and function, and CHECK ONLY ONE.)

- ☐ 1. **No subjective complaints of memory deficit.** No memory deficit evident on clinical interview.
- ☐ 2. **Subjective complaints of memory deficit**, most frequently in following areas:
(a) forgetting where one has placed familiar objects;
(b) forgetting names one formerly knew well.
- No objective evidence of memory deficit on clinical interview.
 No objective deficit in employment or social situations.
 Appropriate concern with respect to symptomatology.
- ☐ 3. **Earliest clear-cut deficits.**
- Manifestations in more than one of the following areas:
(a) patient may have gotten lost when traveling to an unfamiliar location.
(b) co-workers become aware of patient's relatively poor performance.
(c) word and/or name finding deficit become evident to intimates.
(d) patient may read a passage or book and retain relatively little material.
(e) patient may demonstrate decreased facility remembering names upon introduction to new people.
(f) patient may have lost or misplaced an object of value.
(g) concentration deficit may be evident on clinical testing.
- Objective evidence of memory deficit obtained **only with an intensive interview**.
 Decreased performance in demanding employment and social settings.
 Denial begins to become manifest in patient.
 Mild to moderate anxiety frequently accompanies symptoms.
- ☐ 4. **Clear-cut deficit on careful clinical interview.**
- Deficit manifest in following areas:
(a) decreased knowledge of current and recent events.
(b) may exhibit some deficit in memory of one's personal history.
(c) concentration deficit elicited on serial subtractions.
(d) decreased ability to travel, handle finances, etc.
- Frequently no deficit in following areas:
(a) orientation to time and place.
(b) recognition of familiar persons and faces.
(c) ability to travel to familiar locations.
- Inability to perform complex tasks.**
 Denial is dominant defense mechanism.
 Flattening of affect and withdrawal from challenging situations.

- ☐ 5. **Patient can no longer survive without some assistance.**

Patient is unable during interview to recall a major relevant aspect of their current life, e.g.:

- (a) their address or telephone number of many years.
- (b) the names of close members of their family (such as grandchildren).
- (c) the name of the high school or college from which they graduated.

Frequently some disorientation to time (date, day of the week, season, etc.) or to place.
An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s.
Persons at this stage retain knowledge of many major facts regarding themselves and others.
They invariably know their own names and generally know their spouse's and children's names.
They require no assistance with toileting or eating, but may have difficulty choosing the proper clothing to wear.

- ☐ 6. May occasionally forget the name of the spouse upon whom they are entirely dependent for survival.
Will be largely unaware of all recent events and experiences in their lives.
Retain some knowledge of their surroundings; the year, the season, etc.
May have difficulty counting by 1s from 10, both backward and sometimes forward.

Will require some assistance with activities of daily living:

- (a) may become incontinent.
- (b) will require travel assistance but occasionally will be able to travel to familiar locations.

Diurnal rhythm frequently disturbed.
Almost always recall their own name.
Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment.

Personality and emotional changes occur. These are quite variable and include:

- (a) delusional behavior, e.g., patients may accuse their spouse of being an imposter; may talk to imaginary figures in the environment, or to their own reflection in the mirror.
- (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities.
- (c) anxiety symptoms, agitation, and even previously non-existent violent behavior may occur.
- (d) cognitive abulia, e.g., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.

- ☐ 7. **All verbal abilities are lost over the course of this stage.**
Early in this stage words and phrases are spoken but speech is very circumscribed.
Later there is no serviceable speech at all - only unintelligible utterances with rare emergence of seemingly forgotten words and phrases.

Incontinent; requires assistance toileting and feeding.

Basic psychomotor skills (e.g. ability to walk) are lost with the progression of this stage.
The brain appears to no longer be able to tell the body what to do.
Generalized rigidity and developmental neurologic reflexes are frequently present.

¹ Reisberg, B., Ferris, S.H., de Leon, M.J., & Crook, T. The global deterioration scale for assessment of primary degenerative dementia. *Am.J.Psychiatry*, 1982;139:1136-1139.

APPENDIX H: THE FUNCTIONAL ASSESSMENT STAGING SYSTEM (FAST)

FUNCTIONAL ASSESSMENT STAGING (FAST)^{1,2} (Check highest consecutive level of disability.)

1. ☐ No difficulty, either subjectively or objectively.
2. ☐ Complaints of forgetting location of objects. Subjective work difficulties.
3. ☐ Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.*
4. ☐ Decreased ability to perform complex tasks, e.g., planning dinner for guests, handling personal finances (such as forgetting to pay bills), difficulty marketing, etc.*
5. ☐ Requires assistance in choosing proper clothing to wear for the day, season, or occasion, e.g. patient may wear the same clothing repeatedly, unless supervised.*
6. ☐
 - (a) Improperly putting on clothes without assistance or cuing (e.g., may put street clothes on over night clothes, or put shoes on wrong feet, or have difficulty buttoning clothing) occasionally or more frequently over the past weeks.*
 - ☐ (b) Unable to bathe properly (e.g., difficulty adjusting bath-water temperature) occasionally or more frequently over the past weeks.*
 - ☐ (c) Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.*
 - ☐ (d) Urinary incontinence (occasionally or more frequently over the past weeks).*
 - ☐ (e) Fecal incontinence (occasionally or more frequently over the past weeks).*
7. ☐
 - (a) Ability to speak limited to approximately a half a dozen intelligible different words or fewer, in the course of an average day or in the course of an intensive interview.
 - ☐ (b) Speech ability limited to the use of a single intelligible word in an average day or in the course of an intensive interview (the person may repeat the word over and over).
 - ☐ (c) Ambulatory ability lost (cannot walk without personal assistance).
 - ☐ (d) Cannot sit up without assistance (e.g., the individual will fall over if there are no lateral rests [arms] on the chair).
 - ☐ (e) Loss of ability to smile.
 - ☐ (f) Loss of ability to hold up head independently.

* Scored primarily on the basis of information obtained from a knowledgeable informant and/or caregiver.

¹ Adapted from Reisberg, B., Functional assessment staging (FAST). *Psychopharmacology Bulletin*, 1988;24:653-659.

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APPENDIX I: RESIDENT PROFILE OF INDEPENDENCE AND FUNCTION

Name: _____

Code: _____

Category of Behaviour	Totally Self-determined, chooses activities by self and follows through completing choices	Minimal assistance, needs options clarified but able to choose between two or more options and follows through	Difficulty making choices when presented with two options. Requires direction from staff or does not complete task	Total direction by staff. No options offered, not able to choose.
Meal choices				
Hygiene choices (brushing teeth, washing)				
Grooming choices (clothes selection, combing hair)				
Toileting				
Night time sleep				
Daytime napping				
Attendance at activity programming				

APPENDIX J: THE MINI MENTAL STATE EXAMINATION (MMSE)

Mini-Mental State Exam

Resident: _____ Code # _____

Date: _____

Orientation to Time		Response	Score Circle one	
What is the....	Year?		0	1
	Season?		0	1
	Month of the year?		0	1
	Day of the week?		0	1
	Date?		0	1
Orientation to Place				
Where are we now? What is the	Province?		0	1
	Country?		0	1
	City/town (or part of city or neighborhood)?		0	1
	Building (name or type)?		0	1
	Floor of building (room number or address)?		0	1
Registration: I am going to say three words that I would like you to remember and will ask you to repeat them later in our conversation. Please repeat them after me now. Ready? Here they are....Apple or Orange (pause), Penny (pause), Table (pause). Now please repeat those words back to me. Remember them for later. (Show the object that you are referring to. Repeat up to 5 times but score only the first trial)				
	Apple or Orange		0	1
	Penny		0	1
	Table		0	1
Attention and Calculation: When you were in school, were you better at spelling or math? (If the answer is Math, do the Serial 7 test. If spelling do the Spell World Backward.)				
Serial 7 test: Now I would like you to subtract 7 from 100. Then keep subtracting 7 from each answer until I tell you to stop. What is 100 take away 7? (If needed, say: Keep going.) 93 (1 or 0), 86 (1 or 0), 79 (1 or 0), 72 (1 or 0), 65 (1 or 0) <div style="text-align: right;">Total: /5</div>				
Spelling World Backwards: Spell 'WORLD' forward. (correct any spelling errors) then say, Now spell WORLD backwards). Only score the backward spelling. (D=1) (L=1) (R=1) (O=1) (W=1) <div style="text-align: right;">Total: /5</div>				
Recall: What were the three words that I asked you to remember? (Do not offer hints)				
	Apple or Orange		0	1
	Penny		0	1
	Table		0	1

Naming:				
What is this?	(point to pen or pencil)		0	1
What is this?	(point to watch)		0	1
Comprehension:				
I am going to ask you to do something for me. Would you please take this paper in your right hand (pause), fold in half (pause) and put it on the floor.				
Take this paper in your right hand			0	1
Fold it in half			0	1
Put on the floor			0	1
Repeat after me: 'No ifs ands or buts'			0	1

Reading: Please read this and do what it says. (Show participant the words written below)

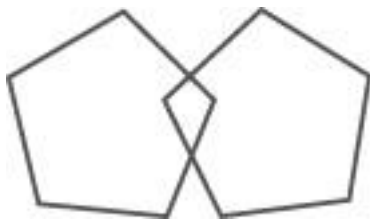
CLOSE YOUR EYES

Score: 0 1

Writing: Can you please write a sentence? (if the participant does not respond, say: Write about the weather. Place this piece of paper in front of him/her, provide a pen or pencil and indicate the space where you would like him/her to write the sentence. Score 1 point if the sentence is understandable, containing a subject and verb. Ignore errors in spelling or grammar.)

Score: 0 1

Drawing: Please copy this design. (show the diagram and ask to draw beside the original. Score 1 point if the drawing consists of two 5-sided figures that intersect to form a 4-sided figure.)



Score: 0 1

Total Score: /30

SQDT: Do you often feel Sad or Depressed?

Adapted from Folstein MF, Folstein SE, McHugh PR. Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*. 1975;12:189-98.

APPENDIX K: THE NEUROPSYCHIATRIC INVENTORY-NURSING HOME (NPI-NH)

npiTEST

Neuropsychiatric Inventory (NPI)

Comprehensive Assessment of Psychopathology in
Patients with Dementia

By Jeffrey L. Cummings, MD

Neuropsychiatric Inventory

Neuropsychiatric Inventory

**Comprehensive Assessment of Psychopathology in
Patients with Dementia**

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INTRODUCTION

The Neuropsychiatric Inventory (NPI) was developed to provide a means of assessing neuropsychiatric symptoms and psychopathology of patients with Alzheimer's disease and other neurodegenerative disorders. The NPI has been used to characterize the neuropsychiatric symptom profiles in a variety of neurological diseases. It has proven to be sensitive to change and has been employed to capture treatment related behavioral changes in patients receiving cholinesterase inhibitors, antipsychotic agents, melatonin and a variety of other antidementia and psychotropic compounds. The NPI is available in many languages, has been shown to be reliable in cross-cultural studies, and allows study of neuropsychiatric symptoms of dementia patients in different countries and cultures.

The NPI is valid and reliable. It has been integrated into studies with neuroimaging techniques (magnetic resonance imaging, single photon emission computed tomography, and positron emission tomography) to help explicate the neuroimaging correlates of behavioral changes in patients with Alzheimer's disease and other dementias, and to explore the relationship between treatment-related changes in regional brain function and altered behavior. Autopsy studies provide further convergent validity of the NPI.

This manual provides administration and scoring instructions for the NPI. It contains the standardized script for administering the questions to be asked of patients when performing the NPI. The background articles that establish the psychometric properties of the NPI and of the related caregiver distress scale are referenced. Master copies of the worksheets and scoring summaries that can be copied for your convenience are provided. This material constitutes the administration manual for the NPI.

A version of the NPI has been developed and validated for use in nursing homes (the NPI-NH), where information is collected from professional caregivers. The NPI-Questionnaire (NPI-Q) version of the NPI has been developed and cross-validated with the standard NPI to provide a brief assessment of neuropsychiatric symptomatology in clinical practice settings.

Thank you for your interest in the NPI. I hope that these instruments and their manuals and related information prove to be helpful to you in characterizing behavioral and neuropsychiatric symptoms in your patients, understanding the distress experienced by caregivers, and following treatment related changes in behavior. Neuropsychiatric symptoms are a key manifestation of dementias, and understanding and treating them is a major advance in improving the quality of lives of patients and their caregivers.

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NPI | Neuropsychiatric Inventory (NPI): INSTRUCTIONS FOR USE AND ADMINISTRATION

I. Purpose of the NPI

The purpose of the Neuropsychiatric Inventory (NPI) is to obtain information on the presence of psychopathology in patients with brain disorders. The NPI was developed for application to patients with Alzheimer's disease and other dementias, but it may be useful in the assessment of behavioral changes in other conditions. Ten behavioral and two neurovegetative areas are included in the NPI:

Delusions
Hallucinations
Agitation/Aggression
Depression/Dysphoria
Anxiety
Elation/Euphoria
Apathy/Indifference
Disinhibition
Irritability/Lability
Aberrant motor behavior

Sleep and Nighttime Behavior Disorders
Appetite and Eating Disorders

II. Administration of the NPI

A. NPI Interview

The NPI is based on responses from an informed caregiver, preferably one living with the patient. A caregiver can be defined as a person spending at least 4 hours per day at least 4 days per week with the patient and who is knowledgeable about the patient's daytime and nighttime behaviors. If an informed observer is not available, this instrument cannot be used or must be modified. The interview is best conducted with the caregiver in the absence of the patient to facilitate an open discussion of behaviors that may be difficult to describe with the patient present. Several points should be made when you introduce the NPI interview to the caregiver:

- Purpose of the interview
- Ratings - frequency, severity, distress
- Answers apply to behaviors that are new since the onset of the disease and have been present for the past four weeks or other defined period
- Questions can usually be answered with "Yes" or "No" and responses should be brief

When beginning the inventory, say to the caregiver "These questions are designed to evaluate your (husband's/wife's/etc) behavior. They can usually be answered "yes" or "no" so please try to be brief in your responses." If the caregiver lapses into elaborate responses that provide little useful information, he/she may be reminded of the need to be brief. Some of the issues raised with this scale are very emotionally disturbing to caregivers and the interviewer should reassure the caregiver that they will discuss the problems in more detail after completion of the inventory.

Questions should be asked exactly as written. Clarification should be provided if the caregiver does not understand the question. Acceptable clarifications are restatements of the questions in alternate terms.

B. Changes in Behavior

The questions pertain to changes in the patient's behavior that have appeared since the onset of the illness. Behaviors that have been present throughout the patient's life and have not changed in the course of the illness are not scored even if they are abnormal (e.g., anxiety, depression). Behaviors that have been present throughout life but have changed since the illness are scored (e.g., the patient has always been apathetic but there has been a notable increase in apathy during the period of inquiry).

The NPI is typically used to assess changes in the patient's behavior that have appeared in a defined period of time (e.g., in the past four weeks or other defined interval). In some studies, the NPI may be used to address changes occurring in response to treatment or that have changed since the last clinic visit. The reliability and validity studies of the NPI were conducted using the 4-week time frame. The time frame of the question would then be revised to reflect this interest in recent changes. Emphasize to the caregiver that the questions pertain to behaviors that have appeared or changed since the onset of the illness. For example, the questions might be phrased "Since he/she began treatment with the new medications..." or "Since the dosage of _____ was increased"

C. Screening Questions and Subquestions

The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, mark "No" and proceed to the next screening question without asking the subquestions. If the answer to the screening question is positive or if there are any uncertainties in the caregiver's response or any inconsistencies between the response and other information known by the clinician (e.g., the caregiver responds negatively to the euphoria screening question but the patient appears euphoric to the clinician), the category is marked "Yes" and is explored in more depth with the subquestions. If the subquestions confirm the screening question, the severity and frequency of the behavior are determined according to the criteria provided with each behavior (below).

In some cases, the caregiver will provide a positive response to the screening question and a negative reply to all subquestions. If this happens, ask the caregiver to expand on why he/she responded affirmatively to the screen. If he/she provides information relevant to the behavioral domain but in different terms, the behavior should be scored for severity and frequency as usual. If the original affirmative response was erroneous, leading to a failure to endorse any subquestions, then the behavior is changed to "No" on the screen.

Some sections such as the questions pertaining to appetite are framed so as to capture whether there is an increase or decrease in the behavior (increased or decreased appetite or weight). If the caregiver answers "Yes" to the first member of the paired questions (such as has the patient's weight decreased?), do not ask the second question (has the patient's weight increased?) since the answer to the second question is contained in the answer to the first. If the caregiver answers "No" to the first member of the pair of questions, then the second question must be asked.

D. Frequency and Severity Ratings

When determining frequency and severity, use the behaviors identified by the subquestions as most aberrant. For example, if the caregiver indicates that resistive behavior is particularly problematic when you are asking the subquestions of the agitation section, then use resistive behavior to prompt judgments regarding the frequency and severity of agitation. If two behaviors are very problematic, use the frequency and severity of both behaviors to score the item. For example, if the patient has two or more types of delusions, then use the severity and the frequency of all delusional behaviors to phrase the questions regarding severity and frequency.

When assessing frequency, say to the person being interviewed “Now I want to find out how often these things (define using the description of the behaviors noted as most problematic on the subquestions) occur. Would you say that they occur less than once per week, about once per week, several times per week but not every day, or every day?” Some behaviors such as apathy eventually become continuously present, and then “are constantly present” can be substituted for “every day.”

When determining severity, tell the person being interviewed “Now I would like to find out how severe these behaviors are. By severity, I mean how disturbing or disabling they are for the patient. Would you say that (the behaviors) are mild, moderate, or severe?” Additional descriptors are provided in each section that may be used to help the interviewer clarify each grade of severity. In each case, be sure that the caregiver provides you with a definite answer as to the frequency and severity of the behaviors. Do not guess what you think the caregiver would say based on your discussion.

We have found it helpful to provide the caregiver with a piece of paper on which is written the frequency and severity descriptions (less than once per week, about once per week, several times per week, and once or more per day for frequency; and mild, moderate, and severe for severity) to allow him/her to visualize the response alternatives. This also saves the examiner from reiterating the alternatives with each question.

E. “Not Applicable” Designations

In very impaired patients or in patients with special medical circumstances, a set of questions may not be applicable. For example, bed-bound patients may exhibit hallucinations or agitation but are unable to exhibit aberrant motor behavior. If the clinician or the caregiver believes that the questions are inappropriate, then the section should be marked “NA” (upper right corner of each section), and no further data are recorded for that section. Likewise, if the clinician feels that the responses are invalid (e.g., the caregiver did not seem to understand the particular set of questions asked), “NA” should be marked. Analytically, “NA” responses must be treated as missing values.

F. Neurovegetative Changes

Items 11 (sleep) and 12 (appetite) were added after the original publication of the NPI (Cummings et al, 1994). They were included because they are common problem areas in Alzheimer’s disease and other dementias. They form part of the depression syndrome in some patients and were specifically excluded from the dysphoria subscale of the NPI in order to allow that subscale to focus on mood symptoms. These two symptoms may not be included in all protocols.

G. Caregiver Distress (NPI-D)

When each domain is completed and the caregiver has completed the frequency and severity rating, ask the associated caregiver distress question if your protocol includes the distress assessment. To do this, ask the caregiver how much, if any, “emotional or psychological” distress the behavior he/she just discussed causes him/her (the caregiver). The caregiver must rate his/her own distress on a five point scale from 0 - not at all, 1 - minimal, 2 - mildly, 3 - moderately, 4 - severely, 5 - very severely or extremely. The distress scale of this instrument was developed by Daniel Kaufer, M.D. (Kaufer et al., 1998).

III. Scoring the NPI

Frequency is rated as:

- ☐ 1. Rarely – less than once per week
- ☐ 2. Sometimes – about once per week
- ☐ 3. Often – several times per week but less than every day
- ☐ 4. Very often – once or more per day

Severity is rated as:

- ☐ 1. Mild – produces little distress in the patient
- ☐ 2. Moderate – more disturbing to the patient but can be redirected by the caregiver
- ☐ 3. Severe – very disturbing to the patient and difficult to redirect

The score for each domain is: domain score = frequency x severity

Distress is scored as:

- ☐ 0. Not at all
- ☐ 1. Minimally (almost no change in work routine)
- ☐ 2. Mildly (some change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

Thus, for each behavioral domain there are four scores:

- Frequency
- Severity
- Total (frequency x severity)
- Caregiver distress

A total NPI score can be calculated by adding the scores of the first 10 domain scores together. If the two neurovegetative items are included, specify that the 12 item score is being used rather than the 10 item score. The distress score is not included in the total NPI core.

The total distress score is generated by adding together the scores of the individual NPI distress questions; specify whether the 10 or 12 item score is being used.

IV. NPI-NH and NPI-Q

A nursing home version of the NPI (the NPI-NH) has been developed for use with professional caregivers in institutional settings. The instrument is identical to the original NPI but the questions have been rephrased to reflect the fact that the professional caregiver will not have known the patient prior to the onset of the illness and cannot know if the current behaviors represent changes from premorbid behaviors. The caregiver distress questions have been rephrased to assess the “occupational disruptiveness” of the behaviors. The NPI-Q version of the NPI has been developed and cross-validated with the standard NPI to provide a brief assessment of neuropsychiatric symptomatology in clinical practice settings. The NPI, NPI-NH, and NPI-Q are all available through the website (NPITest.net).

V. Translations

The NPI is available in a variety of languages for Asia, Europe, and the Americas and more translated versions are currently being developed. These are available through the MAPI Institute Nice, France.

VI. Copyright and Use of the NPI

The NPI, NPI-NH and NPI-Q, and all translations and derivations are under copyright protection with all rights reserved to Jeffrey L. Cummings. They are made available at no charge for all noncommercial research and clinical purposes. Use of the instrument for commercial purposes (clinical trials, screening for commercial projects, application by for-profit health care providers, etc) is subject to charge and use of the instrument must be negotiated with Dr. Cummings. (E-mail [jcummings@mednet.ucla.edu](mailto:jcumings@mednet.ucla.edu) or NPItest.net).

It is requested that a copy of all published papers and abstracts using the NPI or NPI-NH be provided to Dr. Cummings at the address shown above. This allows construction of a comprehensive bibliography of studies and investigators using these instruments.

VII. Key References

Cummings JL. The Neuropsychiatric Inventory: Assessing psychopathology in dementia patients. *Neurology* 1997; 48 (Supple 6): S10-S16.

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Wood S, Cummings JL, Hsu M-A, Barclay T, Wheatley MV, Yarema KT, Schnelle JF. The use of the Neuropsychiatric Inventory in nursing home residents, characterization and measurement. *Am J Geriatr Psychiatry* 2000; 8: 75-83.

Neuropsychiatric Inventory Questions

A. DELUSIONS**(NA)**

Does the patient have beliefs that you know are not true (for example, insisting that people are trying to harm him/her or steal from him/her)? Has he/she said that family members are not who they say they are or that the house is not their home? I'm not asking about mere suspiciousness; I am interested if the patient is convinced that these things are happening to him/her.

- ☐ Yes (If yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient believe that he/she is in danger - that others are planning to hurt him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient believe that others are stealing from him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient believe that his/her spouse is having an affair? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient believe that unwelcome guests are living in his/her house? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient believe that his/her spouse or others are not who they claim to be? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient believe that his/her house is not his/her home? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient believe that family members plan to abandon him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 8. Does the patient believe that television or magazine figures are actually present in the home?
(Does he/she try to talk or interact with them?) | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 9. Does the patient believe any other unusual things that I haven't asked about? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If the screening question is confirmed, determine the frequency and severity of the delusions.

Frequency:

- ☐ 1. Rarely – less than once per week
☐ 2. Sometimes – about once per week
☐ 3. Often – several times per week but less than every day
☐ 4. Very often – once or more per day

Severity:

- ☐ 1. Mild – delusions present but seem harmless and produce little distress in the patient.
☐ 2. Moderate – delusions are distressing and disruptive.
☐ 3. Severe – delusions are very disruptive and are a major source of behavioral disruption. (If PRN medications are prescribed, their use signals that the delusions are of marked severity.)

Distress: How emotionally distressing do you find this behavior?

- ☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

B. HALLUCINAIONS**(NA)**

Does the patient have hallucinations such as seeing false visions or hearing false voices? Does he/she seem to see, hear or experience things that are not present? By this question we do not mean just mistaken beliefs such as stating that someone who has died is still alive; rather we are asking if the patient actually has abnormal experiences of sounds or visions.

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient describe hearing voices or act as if he/she hears voices? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient talk to people who are not there? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does he/she describe seeing things not seen by others or behave as if he/she is seeing things not seen by others (people, animals, lights, etc)? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does he/she report smelling odors not smelled by others? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does he/she describe feeling things on his/her skin or otherwise appear to be feeling things crawling or touching him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does he/she describe tastes that are without any known cause? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does he/she describe any other unusual sensory experiences? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If the screening question is confirmed, determine the frequency and severity of the hallucinations.

Frequency:

- ☐ 1. Rarely – less than once per week.
- ☐ 2. Sometimes – about once per week.
- ☐ 3. Often – several times per week but less than every day.
- ☐ 4. Very often – once or more per day.

Severity:

- ☐ 1. Mild – hallucinations are present but harmless and cause little distress for the patient.
- ☐ 2. Moderate – hallucinations are distressing and are disruptive to the patient.
- ☐ 3. Severe – hallucinations are very disruptive and are a major source of behavioral disturbance. PRN medications may be required to control them.

Distress: How emotionally distressing do you find this behavior?

- ☐ 0. Not at all
- ☐ 1. Minimally (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

C. AGITATION/AGGRESSION**(NA)**

Does the patient have periods when he/she refuses to cooperate or won't let people help him/her? Is he/she hard to handle?

- ☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient get upset with those trying to care for him/her or resist activities such as bathing or changing clothes? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Is the patient stubborn, having to have things his/her way? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Is the patient uncooperative, resistive to help from others? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient have any other behaviors that make him/her hard to handle? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient shout or curse angrily? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient slam doors, kick furniture, throw things? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient attempt to hurt or hit others? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 8. Does the patient have any other aggressive or agitated behaviors? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If the screening question is confirmed, determine the frequency and severity of the agitation/aggression.

Frequency:

- ☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – once or more per day.

Severity:

- ☐ 1. Mild – agitation is disruptive but can be managed with redirection or reassurance.
☐ 2. Moderate – agitation is disruptive and difficult to redirect or control.
☐ 3. Severe – agitation is very disruptive and a major source of difficulty; there may be a threat of personal harm. Medications are often required.

Distress: How emotionally distressing do you find this behavior?

- ☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

D. DEPRESSION/DYSPHORIA**(NA)**

Does the patient seem sad or depressed? Does he/she say that he/she feels sad or depressed?

- ☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

- | | | |
|--|------------------------------|-----------------------------|
| 1. Does the patient have periods of tearfulness or sobbing that seem to indicate sadness? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient say, or act as if, he/she is sad or in low spirits? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient put him/herself down or say that he/she feels like a failure? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient say that he/she is a bad person or deserves to be punished? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient seem very discouraged or say that he/she has no future? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient say he/she is a burden to the family or that the family would be better off without him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient express a wish for death or talk about killing himself/herself? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 8. Does the patient show any other signs of depression or sadness? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If the screening question is confirmed, determine the frequency and severity of the depression/dysphoria.

Frequency:

- ☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – essentially continuously present.

Severity:

- ☐ 1. Mild – depression is distressing but usually responds to redirection or reassurance.
☐ 2. Moderate – depression is distressing; depressive symptoms are spontaneously voiced by the patient and difficult to alleviate.
☐ 3. Severe – depression is very distressing and a major source of suffering for the patient.

Distress: How emotionally distressing do you find this behavior?

- ☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

E. ANXIETY**(NA)**

Is the patient very nervous, worried, or frightened for no apparent reason? Does he/she seem very tense or fidgety? Is the patient afraid to be apart from you?

- ☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient say that he/she is worried about planned events? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient have periods of feeling shaky, unable to relax, or feeling excessively tense? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient have periods of [or complain of] shortness of breath, gasping, or sighing for no apparent reason other than nervousness? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient complain of butterflies in his/her stomach, or of racing or pounding of the heart in association with nervousness? (Symptoms not explained by ill health) | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient avoid certain places or situations that make him/her more nervous such as riding in the car, meeting with friends, or being in crowds? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient become nervous and upset when separated from you (or his/her caregiver)? (Does he/she cling to you to keep from being separated?) | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient show any other signs of anxiety? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If the screening question is confirmed, determine the frequency and severity of the anxiety.

Frequency:

- ☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – once or more per day.

Severity:

- ☐ 1. Mild – anxiety is distressing but usually responds to redirection or reassurance.
☐ 2. Moderate – anxiety is distressing, anxiety symptoms are spontaneously voiced by the patient and difficult to alleviate.
☐ 3. Severe – anxiety is very distressing and a major source of suffering for the patient.

Distress: How emotionally distressing do you find this behavior?

- ☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

F. ELATION/EUPHORIA**(NA)**

Does the patient seem too cheerful or too happy for no reason? I don't mean the normal happiness that comes from seeing friends, receiving presents, or spending time with family members. I am asking if the patient has a persistent and abnormally good mood or finds humor where others do not.

- ☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient appear to feel too good or to be too happy, different from his/her usual self? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient find humor and laugh at things that others do not find funny? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient seem to have a childish sense of humor with a tendency to giggle or laugh inappropriately (such as when something unfortunate happens to others)? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient tell jokes or make remarks that are not funny to others but seem funny to him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does he/she play childish pranks such as pinching or playing "keep away" for the fun of it? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient "talk big" or claim to have more abilities or wealth than is true? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient show any other signs of feeling too good or being too happy? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If the screening question is confirmed, determine the frequency and severity of the elation/euphoria.

Frequency:

- ☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – essentially continuously present.

Severity:

- ☐ 1. Mild – elation is notable to friends and family but is not disruptive.
☐ 2. Moderate – elation is notably abnormal.
☐ 3. Severe – elation is very pronounced; patient is euphoric and finds nearly everything to be humorous.

Distress: How emotionally distressing do you find this behavior?

- ☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

G. APATHY/INDIFFERENCE**(NA)**

Has the patient lost interest in the world around him/her? Has he/she lost interest in doing things or does he/she lack motivation for starting new activities? Is he/she more difficult to engage in conversation or in doing chores? Is the patient apathetic or indifferent?

- ☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient seem less spontaneous and less active than usual? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Is the patient less likely to initiate a conversation? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Is the patient less affectionate or lacking in emotions when compared to his/her usual self? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient contribute less to household chores? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient seem less interested in the activities and plans of others? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Has the patient lost interest in friends and family members? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Is the patient less enthusiastic about his/her usual interests? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 8. Does the patient show any other signs that he/she doesn't care about doing new things? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If the screening question is confirmed, determine the frequency and severity of the apathy/indifference.

Frequency:

- ☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – nearly always present.

Severity:

- ☐ 1. Mild – apathy is notable but produces little interference with daily routines; only mildly different from patient's usual behavior; patient responds to suggestions to engage in activities.
☐ 2. Moderate – apathy is very evident; may be overcome by the caregiver with coaxing and encouragement; responds spontaneously only to powerful events such as visits from close relatives or family members.
☐ 3. Severe – apathy is very evident and usually fails to respond to any encouragement or external events.

Distress: How emotionally distressing do you find this behavior?

- ☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

H. DISINHIBITION**(NA)**

Does the patient seem to act impulsively without thinking? Does he/she do or say things that are not usually done or said in public? Does he/she do things that are embarrassing to you or others?

- ☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient act impulsively without appearing to consider the consequences? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient talk to total strangers as if he/she knew them? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient say things to people that are insensitive or hurt their feelings? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient say crude things or make sexual remarks that he/she would not usually have said? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient talk openly about very personal or private matters not usually discussed in public? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient take liberties or touch or hug others in way that is out of character for him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient show any other signs of loss of control of his/her impulses? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If the screening question is confirmed, determine the frequency and severity of the disinhibition.

Frequency:

- ☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – essentially continuously present.

Severity:

- ☐ 1. Mild – disinhibition is notable but usually responds to redirection and guidance.
☐ 2. Moderate – disinhibition is very evident and difficult to overcome by the caregiver.
☐ 3. Severe – disinhibition usually fails to respond to any intervention by the caregiver, and is a source of embarrassment or social distress.

Distress: How emotionally distressing do you find this behavior?

- ☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

I. IRRITABILITY/LABILITY**(NA)**

Does the patient get irritated and easily disturbed? Are his/her moods very changeable? Is he/she abnormally impatient? We do not mean frustration over memory loss or inability to perform usual tasks; we are interested to know if the patient has abnormal irritability, impatience, or rapid emotional changes different from his/her usual self.

- ☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient have a bad temper, "flying off the handle" easily over little things? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient rapidly change moods from one to another, being fine one minute and angry the next? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient have sudden flashes of anger? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Is the patient impatient, having trouble coping with delays or waiting for planned activities? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Is the patient cranky and irritable? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Is the patient argumentative and difficult to get along with? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient show any other signs of irritability? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If the screening question is confirmed, determine the frequency and severity of the irritability /lability.

Frequency:

- ☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – essentially continuously present.

Severity:

- ☐ 1. Mild – irritability or lability is notable but usually responds to redirection and reassurance.
☐ 2. Moderate – irritability and lability are very evident and difficult to overcome by the caregiver.
☐ 3. Severe – irritability and lability are very evident; they usually fail to respond to any intervention by the caregiver, and they are a major source of distress.

Distress: How emotionally distressing do you find this behavior?

- ☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

J. ABERRANT MOTOR BEHAVIOR**(NA)**

Does the patient pace, do things over and over such as opening closets or drawers, or repeatedly pick at things or wind string or threads?

- ☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

- | | | |
|--|------------------------------|-----------------------------|
| 1. Does the patient pace around the house without apparent purpose? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient rummage around opening and unpacking drawers or closets? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient repeatedly put on and take off clothing? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient have repetitive activities or "habits" that he/she performs over and over? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient engage in repetitive activities such as handling buttons, picking, wrapping string, etc? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient fidget excessively, seem unable to sit still, or bounce his/her feet or tap his/her fingers a lot? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient do any other activities over and over? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If the screening question is confirmed, determine the frequency and severity of the aberrant motor activity:

Frequency:

- ☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – essentially continuously present.

Severity:

- ☐ 1. Mild – abnormal motor activity is notable but produces little interference with daily routines.
☐ 2. Moderate – abnormal motor activity is very evident; can be overcome by the caregiver.
☐ 3. Severe – abnormal motor activity is very evident, usually fails to respond to any intervention by the caregiver and is a major source of distress.

Distress: How emotionally distressing do you find this behavior?

- ☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

K. SLEEP AND NIGHTTIME BEHAVIOR DISORDERS**(NA)**

Does the patient have difficulty sleeping (do not count as present if the patient simply gets up once or twice per night only to go to the bathroom and falls back asleep immediately)? Is he/she up at night? Does he/she wander at night, get dressed, or disturb your sleep?

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient have difficulty falling asleep? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient get up during the night (do not count if the patient gets up once or twice per night only to go to the bathroom and falls back asleep immediately)? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient wander, pace, or get involved in inappropriate activities at night? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient awaken you during the night? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient wake up at night, dress, and plan to go out, thinking that it is morning and time to start the day? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient awaken too early in the morning (earlier than was his/her habit)? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient sleep excessively during the day? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 8. Does the patient have any other nighttime behaviors that bother you that we haven't talked about? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If the screening question is confirmed, determine the frequency and severity of the nighttime behavior.

Frequency:

- ☐ 1. Rarely – less than once per week.
- ☐ 2. Sometimes – about once per week.
- ☐ 3. Often – several times per week but less than every day.
- ☐ 4. Very often – once or more per day (every night).

Severity:

- ☐ 1. Mild – nighttime behaviors occur but they are not particularly disruptive.
- ☐ 2. Moderate – nighttime behaviors occur and disturb the patient and the sleep of the caregiver; more than one type of nighttime behavior may be present.
- ☐ 3. Severe – nighttime behaviors occur; several types of nighttime behavior may be present; the patient is very distressed during the night and the caregiver's sleep is markedly disturbed.

Distress: How emotionally distressing do you find this behavior?

- ☐ 0. Not at all
- ☐ 1. Minimally (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

L. APPETITE AND EATING CHANGES**(NA)**

Has he/she had any change in appetite, weight, or eating habits (count as NA if the patient is incapacitated and has to be fed)? Has there been any change in type of food he/she prefers?

- ☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Has he/she had a loss of appetite? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Has he/she had an increase in appetite? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Has he/she had a loss of weight? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Has he/she gained weight? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Has he/she had a change in eating behavior such as putting too much food in his/her mouth at once? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Has he/she had a change in the kind of food he/she likes such as eating too many sweets or other specific types of food? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Has he/she developed eating behaviors such as eating exactly the same types of food each day or eating the food in exactly the same order? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 8. Have there been any other changes in appetite or eating that I haven't asked about? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If the screening question is confirmed, determine the frequency and severity of the changes in eating habits or appetite.

Frequency:

- ☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – once or more per day or continuously.

Severity:

- ☐ 1. Mild – changes in appetite or eating are present but have not led to changes in weight and are not disturbing.
☐ 2. Moderate – changes in appetite or eating are present and cause minor fluctuations in weight.
☐ 3. Severe – obvious changes in appetite or eating are present and cause fluctuations in weight, are embarrassing, or otherwise disturb the patient.

Distress: How emotionally distressing do you find this behavior?

- ☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

(05/27/09: JLC)

NPI	Neuropsychiatric Inventory
	Worksheet

Directions: Read all items from the NPI "Instructions for Administration of the NPI". Mark Caregiver's responses on this worksheet before scoring the Frequency, Severity, and Caregiver Distress for each item.

<p>A. DELUSIONS: <input type="checkbox"/>Yes <input type="checkbox"/>No <input type="checkbox"/>N/A Frequency _____ Severity _____ Distress _____</p> <p><input type="checkbox"/> 1. Fear of harm <input type="checkbox"/> 2. Fear of theft <input type="checkbox"/> 3. Spousal affair <input type="checkbox"/> 4. Phantom boarder <input type="checkbox"/> 5. Spouse imposter <input type="checkbox"/> 6. House not home <input type="checkbox"/> 7. Fear of abandonment <input type="checkbox"/> 8. Talks to TV, etc. <input type="checkbox"/> 9. Other _____</p>	<p>B. HALLUCINATIONS: <input type="checkbox"/>Yes <input type="checkbox"/>No <input type="checkbox"/>N/A Frequency _____ Severity _____ Distress _____</p> <p><input type="checkbox"/> 1. Hears voices <input type="checkbox"/> 2. Talks to people not there <input type="checkbox"/> 3. Sees things not there <input type="checkbox"/> 4. Smells things not there <input type="checkbox"/> 5. Feels things not there <input type="checkbox"/> 6. Unusual taste sensations <input type="checkbox"/> 7. Other _____</p>
<p>C. AGITATION/AGGRESSION: <input type="checkbox"/>Yes <input type="checkbox"/>No <input type="checkbox"/>N/A Frequency _____ Severity _____ Distress _____</p> <p><input type="checkbox"/> 1. Upset with caregiver; resists ADL's <input type="checkbox"/> 2. Stubbornness <input type="checkbox"/> 3. Uncooperative; resists help <input type="checkbox"/> 4. Hard to handle <input type="checkbox"/> 5. Cursing or shouting angrily <input type="checkbox"/> 6. Slams doors; kicks, throws things <input type="checkbox"/> 7. Hits, harms others <input type="checkbox"/> 8. Other _____</p>	<p>D. DEPRESSION/DYSPHORIA: <input type="checkbox"/>Yes <input type="checkbox"/>No <input type="checkbox"/>N/A Frequency _____ Severity _____ Distress _____</p> <p><input type="checkbox"/> 1. Tearful and sobbing <input type="checkbox"/> 2. States, acts as if sad <input type="checkbox"/> 3. Puts self down, feels like failure <input type="checkbox"/> 4. "Bad person", deserves punishment <input type="checkbox"/> 5. Discouraged, no future <input type="checkbox"/> 6. Burden to family <input type="checkbox"/> 7. Talks about dying, killing self <input type="checkbox"/> 8. Other _____</p>
<p>E. ANXIETY: <input type="checkbox"/>Yes <input type="checkbox"/>No <input type="checkbox"/>N/A Frequency _____ Severity _____ Distress _____</p> <p><input type="checkbox"/> 1. Worries about planned events <input type="checkbox"/> 2. Feels shaky, tense <input type="checkbox"/> 3. Sobs, sighs, gasps <input type="checkbox"/> 4. Racing heart, "butterflies" <input type="checkbox"/> 5. Phobic avoidance <input type="checkbox"/> 6. Separation anxiety <input type="checkbox"/> 7. Other _____</p>	<p>F. ELATION/EUPHORIA: <input type="checkbox"/>Yes <input type="checkbox"/>No <input type="checkbox"/>N/A Frequency _____ Severity _____ Distress _____</p> <p><input type="checkbox"/> 1. Feels too good, too happy <input type="checkbox"/> 2. Abnormal humor <input type="checkbox"/> 3. Childish, laughs inappropriately <input type="checkbox"/> 4. Jokes or remarks not funny to others <input type="checkbox"/> 5. Childish pranks <input type="checkbox"/> 6. Talks "big", grandiose <input type="checkbox"/> 7. Other _____</p>

CONTINUES ON NEXT PAGE

NPI

Neuropsychiatric Inventory

Worksheet

<p>G. APATHY/INDIFFERENCE: <input type="checkbox"/>Yes <input type="checkbox"/>No <input type="checkbox"/>N/A Frequency _____ Severity _____ Distress _____</p> <ul style="list-style-type: none"> <input type="checkbox"/> 1. Less spontaneous or active <input type="checkbox"/> 2. Less likely to initiate conversation <input type="checkbox"/> 3. Less affectionate, lacking emotions <input type="checkbox"/> 4. Contributes less to household chores <input type="checkbox"/> 5. Less interested in others <input type="checkbox"/> 6. Lost interest in friends or family <input type="checkbox"/> 7. Less enthusiastic about interests <input type="checkbox"/> 8. Other _____ 	<p>H. DISINHIBITION: <input type="checkbox"/>Yes <input type="checkbox"/>No <input type="checkbox"/>N/A Frequency _____ Severity _____ Distress _____</p> <ul style="list-style-type: none"> <input type="checkbox"/> 1. Acts impulsively <input type="checkbox"/> 2. Excessively familiar with strangers <input type="checkbox"/> 3. Insensitive or hurtful remarks <input type="checkbox"/> 4. Crude or sexual remarks <input type="checkbox"/> 5. Talks openly of private matters <input type="checkbox"/> 6. Inappropriate touching of others <input type="checkbox"/> 7. Other _____
<p>I. IRRITABILITY/LIBILITY: <input type="checkbox"/>Yes <input type="checkbox"/>No <input type="checkbox"/>N/A Frequency _____ Severity _____ Distress _____</p> <ul style="list-style-type: none"> <input type="checkbox"/> 1. Bad temper, "flies off handle" easily <input type="checkbox"/> 2. Rapid changes in mood <input type="checkbox"/> 3. Sudden flashes of anger <input type="checkbox"/> 4. Impatient, trouble coping with delays <input type="checkbox"/> 5. Cranky, irritable <input type="checkbox"/> 6. Argues, difficult to get along with <input type="checkbox"/> 7. Other _____ 	<p>J. ABERRANT MOTOR BEHAVIOR: <input type="checkbox"/>Yes <input type="checkbox"/>No <input type="checkbox"/>N/A Frequency _____ Severity _____ Distress _____</p> <ul style="list-style-type: none"> <input type="checkbox"/> 1. Paces without purpose <input type="checkbox"/> 2. Opens or unpacks closets or drawers <input type="checkbox"/> 3. Repeatedly dresses and undresses <input type="checkbox"/> 4. Repetitive activities or "habits" <input type="checkbox"/> 5. Handling, picking, wrapping behavior <input type="checkbox"/> 6. Excessively fidgety <input type="checkbox"/> 7. Other _____
<p>K. SLEEP AND NIGHTTIME BEHAVIOR DISORDERS: <input type="checkbox"/>Yes <input type="checkbox"/>No <input type="checkbox"/>N/A Frequency _____ Severity _____ Distress _____</p> <ul style="list-style-type: none"> <input type="checkbox"/> 1. Difficulty falling asleep <input type="checkbox"/> 2. Up during the night <input type="checkbox"/> 3. Wanders, paces, inappropriate activity <input type="checkbox"/> 4. Awakens others at night <input type="checkbox"/> 5. Wakes and dresses to go out at night <input type="checkbox"/> 6. Early morning awakening <input type="checkbox"/> 7. Sleeps excessively during the day <input type="checkbox"/> 8. Other _____ 	<p>L. APPETITE/EATING CHANGES: <input type="checkbox"/>Yes <input type="checkbox"/>No <input type="checkbox"/>N/A Frequency _____ Severity _____ Distress _____</p> <ul style="list-style-type: none"> <input type="checkbox"/> 1. Loss of appetite <input type="checkbox"/> 2. Increased appetite <input type="checkbox"/> 3. Weight loss <input type="checkbox"/> 4. Weight gain <input type="checkbox"/> 5. Change in eating habits <input type="checkbox"/> 6. Change in food preferences <input type="checkbox"/> 7. Eating rituals <input type="checkbox"/> 8. Other _____

APPENDIX L: THE CORNELL SCALE FOR DEPRESSION IN DEMENTIA (CSDD)

Cornell Scale for Depression in Dementia

NAME _____ AGE _____ SEX _____ DATE _____

Cornell Scale for Depression in Dementia

Ratings should be based on symptoms and signs occurring during the week before interview. No score should be given if symptoms result from physical disability or illness.

SCORING SYSTEM

Unable to evaluate 0 = Absent 1 = Mild to Intermittent 2 = Severe

A. MOOD-RELATED SIGNS

1. Anxiety; anxious expression, rumination, worrying
2. Sadness; sad expression, sad voice, tearfulness
3. Lack of reaction to pleasant events
4. Irritability; annoyed, short tempered

B. BEHAVIORAL DISTURBANCE

5. Agitation; restlessness, hand wringing, hair pulling
6. Retardation; slow movements, slow speech, slow reactions
7. Multiple physical complaints (score 0 if gastrointestinal symptoms only)
8. Loss of interest; less involved in usual activities (score 0 only if change occurred acutely, i.e., in less than one month)

C. PHYSICAL SIGNS

9. Appetite loss; eating less than usual
10. Weight loss (score 2 if greater than 5 pounds in one month)
11. Lack of energy; fatigues easily, unable to sustain activities

D. CYCLIC FUNCTIONS

12. Diurnal variation of mood; symptoms worse in the morning
13. Difficulty falling asleep; later than usual for this individual
14. Multiple awakenings during sleep
15. Early morning awakening; earlier than usual for this individual

E. IDEATIONAL DISTURBANCE

16. Suicidal; feels life is not worth living
17. Poor self-esteem; self-blame, self-depreciation, feelings of failure
18. Pessimism; anticipation of the worst
19. Mood congruent delusions; delusions of poverty, illness or loss 4-8

1. The same CNA (certified nursing assistant) should conduct the interview each time to assure consistency in the response.
2. The assessment should be based on the patient's normal weekly routine.
3. If uncertain of answers, questioning other caregivers may further define the answer.
4. Answer all questions by placing a check in the column under the appropriately numbered answer. (a=unable to evaluate, 0=absent, 1=mild to intermittent, 2=severe).
5. Add the total score for all numbers checked for each question.
6. Place the total score in the "SCORE" box and record any subjective observation notes in the "Notes/Current Medications" section.
7. Scores totaling twelve (12) points or more indicate probable depression.

Score

Score greater than 12 = Probable Depression

NOTES/CURRENT MEDICATIONS: _____ Assessor: _____

APPENDIX M: RYDEN AGGRESSION SCALE 2 (RAS2) DAILY LOG SHEET

Participant: _____ Pre _____ Inter _____ Post _____

Record **every** aggressive behaviour of this resident which occurred during your shift by placing an 'x' opposite the behaviour in the appropriate column for the shift you worked.

D=days or 7-3 E=evenings or 3-11 N= nights or 11-7

Date	Mon March 14			Tues March 15			Wed March 16			Thurs March 17			Friday March 18			Saturda y March 19			Sunday March 20			TOT AL
Shift	D	E	N	D	E	N	D	E	N	D	E	N	D	E	N	D	E	N	D	E	N	
Physically aggressive behaviours																						
Biting																						
Elbowing																						
Hitting/punching																						
Kicking																						
Pinching/squeezing																						
Pushing/shoving																						
Pulling hair																						
Scratching																						
Slapping																						
Spitting																						
Tackling																						
Making threatening gestures																						
Throwing an object																						
Waving a weapon																						
Using a weapon																						
Damaging property																						
Verbally Aggressive Behaviours																						
Cursing/obscene/vulgar language																						
Hostile language																						
Making verbal threats																						
Name calling																						
Sexually Aggressive Behaviours																						
Hugging																						
Intercourse																						
Kissing																						
Making obscene gestures																						
Touching body parts of another																						
Total:																						
Initials of caregiver																						

APPENDIX N: THE APATHY INVENTORY (AI)

Apathy Inventory (AI) – Clinician

Name / Code: _____

Date: _____

____ Pre-Intervention ____ Intervention

____ Post-Intervention

The Apathy Inventory (AI) is based on clinician (member of care staff) point of view following the observation of a day for the patient living in an institution. It also includes a global evaluation.

Emotional Blunting: Does the patient show affection? Does s/he show emotion?

Take into account:

- Facial expression and gestures appropriate to conversation.
- The capacity of the patient to express an emotional reaction during the course of a humorous conversation, or on the other hand, a sad conversation.
- Reaction to presentation of a new medical diagnosis or medical test results.
- The capacity of the patient to express an emotional reaction when proposed a reward eg. Offering a candy for being helpful.

Evaluation: score out of /4

Score: ____ / 4

0 No problem (always shows emotion)

1 (frequently shows emotion)

2 (moderate problem (sometimes shows emotion))

3 (severe problem (seldom shows emotion))

Loss of Initiative: Does the resident initiate a conversation and or make decisions?

Take into account:

- Spontaneous capacity to speak and to integrate oneself into a conversation, to ask for details
- The relationship with the caregiver (when a question is posed directly to the patient, does the patient turn their head towards the caregiver, asking for s/he to respond?)
- Their response at requests to do things (the fact of doing something only after being stimulated or asked to do so indicating a lack of spontaneity of initiative and should be taken into account in the evaluation.
- Do not count as initiatives repetitive behaviors (pacing, stereotype questions).

Evaluation: Score out of /4

Score: ____ /4

0 No problem (always engages) 290

1 (frequently engages)

2 Moderate problem (sometimes engages)

3 (seldom engages)

4 (severe problem (never engages))

Loss of Interest: Does the resident have interests? Is s/he interested in the activities or projects of others? Does s/he show interest in friends and family members or visitors?

Take into account:

- The level of interest of the subject in the interview/ care giving process. Mimicking the caregiver's activities eg. Brushing own teeth after shown, feeding self after shown, washing or dressing self (tries to do these things but needs assistance with the task)
- Level of interest in staff. Does s/he know first names of staff?
- Level of interest in other residents.
- Type of questions resident asks throughout the day re: every day activities, meal times and outings, wanting to do something, family.
- Quality and quantity of details provided by the patient when asked about their personal interests.
- The desire to participate in activities and their level of active participation.

Evaluation: Score out of /4

Score: ____/4

0 No problem (always interested)

1 (frequently interested)

TOTAL SCORE (of 12)

Total Score: ____/12

*The
tool

format has been modified to include the behaviour descriptors to enhance ease of use and assist assessors in their determination of behaviour.

APPENDIX O: SURROGATE CONSENT FORM

Surrogate Consent Form

TITLE: The Effect of Vignette Activity on the Challenging Behaviors Expressed by Individuals with Dementia, Living in Long-term Care

SPONSOR: Canadian Nurses Foundation and the Alberta Registered Nurses Education Trust

Investigators: Dr. Ron Wardell (PI- supervisor)

Donna Marcy-Edwards (PhD Candidate)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

This research is a continuation of a previous pilot study designed to describe how individuals with dementia interact with objects at activity vignettes, which were clusters of objects that residents could interact with whenever they wanted. Currently I am studying whether or not activities at a garden centre have an effect on the challenging behaviors that are sometimes shown by people with dementia living in a nursing home e.g. Aggression, depression, agitation and apathy. Because the presence of dementia reduces a person's ability to make decisions, your surrogate consent for your significant other or ward's participation in this study is being sought. If at any time during the research process your significant other or ward regains competency, personal consent will be attained.

We already know that up to 90% of people with dementia will experience one or more of the challenging behaviours mentioned above. It is also known that these behaviours do not always respond well to drug therapy and cause the most stress for caregivers. We also know that when people are admitted to long-term care many decisions are made for them, which may take away their sense of independence and autonomy. Another feature of living in long-term care is that residents often have to wait for activities to be arranged by staff before they can get busy doing things. Other research has shown that people with dementia living in long-term care often spend a lot of time sitting, doing nothing and that boredom and loss of self-direction can lead to some of the challenging behaviours that we see.

To try and understand the relationship between activity and behaviour a blocked time-series research study has been developed. A small garden vignette will be set up on the MDE and SCU units where residents can do gardening if they want, with whom they want, and when they want 24 hours per day, 7 days a week for two weeks. The garden vignette has a lot of objects that help guide the activity of gardening. Residents can handle the objects, plant seeds, water, taste herbs and enjoy a sense of garden in the indoor setting of the nursing unit. Residents can use the tools at the garden centre or sit at a table under an umbrella surrounded by plants and look at garden magazines. To understand the possible effect of the vignette on behaviour, the vignette will be in place for two weeks then it will be removed for two weeks. This pattern will be repeated.

I do not know what will happen to resident behaviour when I put the vignette in place or take it away. There may be more agitation, or there may be more interest and curiosity. Because resident response is not known, all care giving staff will be asked to look for possible changes in behaviour. All usual treatments for managing challenging behaviours will continue to be implemented if and as necessary.

You may notice several other research activities will taking place when the vignette is available and when it has been removed. Information will be gathered in three ways; video recording all interactions at the garden vignette, interviewing the resident and caregivers, and reading the chart.

All activity at the garden centre will be video recorded. The videos will be examined to see how often a resident came to the vignette, if they came by themselves or were brought by someone and how engaged in the activity they were. I will use this information to see if there is a relationship between level of interest and time spent at the vignette and the number and severity of challenging behaviours in the person visiting the vignette.

Resident interviews will be completed during weeks 1, 2, 4, 6, 8 and 10. A detailed description is given below in describing what the research participant has to do.

All activity at the garden centre will be video recorded. The videos will be examined to note how often a resident came to the vignette, whether they came by themselves or were brought by someone and how engaged in the activity they were. I will use this information to look at whether or not there is a relationship between level of interest and time spent at the vignette and the number and severity of challenging behaviours in the person visiting the vignette.

Taking information from the chart is another means of gathering study data. Things like age, gender, previous occupation and previous hobbies will be recorded to help look for any possible relationships between those items and level of activity or enjoyment of the vignettes. Medication use will also be recorded.

As a family member or guardian, your time is not required to assist with this project. If you are visiting and wish to explore the vignette with your family member or ward you

are encouraged to do so, but it is not a requirement for your family member or ward's participation. Your consent for your family member or ward to participate in the study means that throughout the study time your family member or ward will be interviewed 6 times. These interviews will take place during weeks 1 and 2; 4 and 5; 8 and 9 and will be conducted by my research assistant or myself. If you do not consent to participation, your family member or ward will not be prevented from using the garden vignettes, they will not be interviewed and any appearance on the video will not be included in our data collection activities.

The minimum number of subjects that we are hoping to enroll in the research study is 34 but the potential number of subjects on both the Maximizing Dignity with Expertise Unit and the Special Care Unit is 49. It is easier to determine the effect of the intervention with a larger number of subjects. Only the MDE and the SCU will be used for the study. No patients on the nursing unit will be prevented from interacting at the garden vignette. The research process will not contribute to any changes in treatment or activity experiences designed for your significant other.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose is to find out the effect of interactions at a garden vignette on the behaviours of agitation, aggression, depression and apathy as well as the use of medication to manage those behaviours. A garden vignette is a group of objects designed to attract the attention of residents with dementia and to encourage handling and using any of the objects for the process of gardening.

WHAT WOULD THE SUBJECT HAVE TO DO?

A garden oasis containing gardening materials and tools necessary for gardening and a garden seating area will be located in the main dining/common area of the nursing unit. The participant is encouraged to visit the garden vignette and to handle the objects at the vignette. It is important to know however, that going to the vignette is not a scheduled event or a requirement. The study is designed such that the participant visits the vignette when they want to and does what they want without any expectation of spending specific amounts of time or doing specific tasks. Family or unit staff can encourage visits to the vignette, but this is also not a requirement.

Participation Expectations: Each participant will be interviewed by the research staff six times; once before the research begins and at intervals thereafter.

Interview 1 will take place prior to the placement of the vignette. During this interview the participant will be asked questions about their memory and thinking. This will include answering questions from a test called the Mini Mental State Exam. This is a 30-question test that takes about 30 minutes to complete. During week 2 the participant will be interviewed about their current emotional feelings. The Cornell Scale for Depression in Dementia will guide this interview. This 19-question document takes 20 minutes to

complete. It uses both caregiver and resident responses to determine if depression is present. The Single Question Depression Test (taking less than 1 minute to complete) will also be used to compare reliability and validity with the more complex Cornell Scale. If the participant wishes to withdraw during the measurement process, they will be able to do so and approached at a later time or date to complete the process. Any single interview will not take longer than 30 minutes, so staggering of the measurement process will be used to meet the reduced attention ability present in dementia.

Measures of agitation, aggression, and apathy will be completed by conversations with care giving staff using the Neuropsychiatric Inventory-Nursing Home, the Apathy Inventory and the Ryden Aggression Scale. Conversations with staff and observations of the subject will also be used to determine ratings on the Global Deterioration Scale (GDS) and Functional Assessment Staging System (FAST) which are measures of thinking and functioning ability.

After the vignette is in place, four participant interviews will take place using only the Cornell Scale for Depression in Dementia and the Single Question Depression Test, as thinking ability is not expected to change in such a short time frame.

The participant will be video taped whenever he/she visits the garden vignette, as video recording will be continuous 24 hours per day, 7 days per week. Cameras will not be hidden and signs at the vignette site will state that videotaping is in progress. Recording of activity at the vignette helps to know both how independent and how active the participant is at the vignette. Each of which may have an effect on behavior change.

Information from the participant's chart is required as well. What we would like to know from the chart are gender (male or female), diagnosis, previous occupation, previous hobbies and interests, medications and medication use patterns during the research process. Each of these may have an effect on the behaviour we see. Below is a chart that outlines the research process.

Phase	1 Control (no vignette)	2 Intervention (vignette in place)	3 Control (no vignette)	4 Intervention (vignette in place)	5 Control (no vignette)
Time Frame	Weeks 1 & 2	Weeks 3 & 4	Weeks 5 & 6	Weeks 7 & 8	Weeks 9 & 10
Data collected	NPI scores Q shift x 2 Wk 2 only	NPI scores Q shift x 2 Wk 4 only	NPI scores Q shift x 2 Wk 5 only	NPI scores Q shift x 2 Wk 8 only	NPI scores Q shift x 2 1 Wk 10 only
Interview	IA scores Wk 2	IA scores Wk 4	IA scores Wk 6	IA scores Wk 8	IA scores Wk 10
Interview	SQDT wk 1	SQDT wk 4	SQDT wk 6	SQDT wk 8	SQDT wk 10
Interview	CSDD wk 2	CSDD wk4	CSDDwk 6	CSDD wk 8	CSDD wk 10
Interview	RAS2 wk 2	RAS2 wk4	RAS2 wk 6	RAS2 wk 8	RAS2 wk 10

Researcher	Medications	Medications	Medications	Medications	Medications
Researcher	MMSE & GDS/FAST Wk 1				
Video data Researcher Assistants	Time spent at vignette (no wk 3)	Time spent at vignette	Time spent at vignette (no wk 7)	Time spent at vignette	Time spent at vignette (no wk 11)
Researcher Assistants	Self-determined or no	Self-determined or no	Self-determined or no	Self-determined or no	Self-determined or no
Researcher Assistants	OME tool data	OME tool data	OME tool data	OME tool data	OME tool data

WHAT ARE THE RISKS?

The risks for taking part in the study include exposure to gardening objects and the gardening process with minimal supervision. The participants may ingest any object at the vignette, but all objects will be vetted by poison control for safety. All living plants will be safely edible. All seeds will be non-treated. All garden tools will be plastic.

There may be increased agitation noted as a result of environmental change, both at the time of insertion of the garden vignette and on removal of the garden vignette.

WILL THE SUBJECT BENEFIT IF THEY TAKE PART?

It is hoped that offering self-determined/autonomous activity will decrease the frustration that exists when living in environments with high levels of control and loss of autonomy. In creating the activity as an interaction with materials found in nature rather than just the built environment, it is hoped that participants may feel less depressed, less agitated, less apathy or less need to express aggression. In feeling less stress there may be reduced need for prn medications or restraint.

If you agree for the subject to participate in this study there may or may not be a direct medical benefit to the subject. The subject's *behaviour* may be improved during the study, but there is no guarantee that this research will help them. The information we get from this study may help us to provide better treatments in the future for patients with *dementia*.

DOES THE SUBJECT HAVE TO PARTICIPATE?

Alternatives:

As there is no change in the subject's treatment regimen there is no need for an alternative. Individuals not enrolled in the study will not be prevented from interacting at the vignette. The recording of their actions will not be used as data in the research.

VOLUNTARINESS AND WITHDRAWAL OF CONSENT

Participation in this study is voluntary and you may withdraw your consent at any time without jeopardizing the health care of the subject. To withdraw from the study please phone to speak with a researcher about your wish and/or concerns. All data collected prior to withdrawal from the study will be included in the study. The researcher may withdraw a participant if serious changes in health occur, including the discovery of severe and continuous pain, falls resulting in serious injury or death. If new information becomes available that might affect your willingness to have the subject participate in the study, you will be informed as soon as possible.

WHAT ELSE DOES PARTICIPATION INVOLVE?

Participation involves an opportunity to assist caregivers in better understanding 'challenging behaviours'. When caregivers focus on recording challenging behaviours, they become more sensitive to identifying potential triggers to behaviour, which may lead to better understanding of challenging behaviour. Observations of individuals doing things at the vignette offers an opportunity to better understand what interests your significant other and what affords care gives an opportunity to look at better ways of encouraging activity.

WILL WE BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?

There are no costs to the participant and equally there is no payment for participation.

WILL THE RECORDS BE KEPT PRIVATE?

To ensure confidentiality, all participants will be assigned an identification number and all data collected about that participant will be entered using the identification number. The list of names and corresponding identification numbers will be kept in a locked filing cabinet in my supervisor's office. All working data collected including video recordings, chart audit and measurement test data will be kept in a locked filing cabinet in the researcher's office. The only people with access to the files will be the Supervisor, PhD candidate, research assistant and statistician. All data will be destroyed 5 years after the defence of the thesis.

IF THE SUBJECT SUFFERS A RESEARCH-RELATED INJURY, WILL WE BE COMPENSATED?

In the event that the participant suffers injury as a result of participating in this research, no compensation will be provided to the subject by the University of Calgary, the Alberta Health Services or the Researchers. The research subject still has all their legal rights. Nothing said in this consent form alters their right to seek damages.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to allow the person you represent to participate. In no way does this waive the subject's or your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw the subject from the study at any time without jeopardizing their health care. If you have further questions concerning matters related to this research, please contact:

Donna Marcy-Edwards
Or
Dr. Ron Wardell

If you have any questions concerning your rights as a possible participant in this research, please contact: The Director, the Office of Medical Bioethics, University of Calgary.

Participant's Name

Surrogate's Name

Signature and Date

Investigator/Delegate's Name

Signature and Date

Witness' Name

Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

APPENDIX P: REGISTERED CARE-GIVING STAFF CONSENT FORM

Registered Care-giving Staff Consent Form

TITLE: The Effect of Vignette Activity on the Challenging Behaviours
Expressed by Individuals with Dementia, Living in Long-term Care

SPONSOR: Canadian Nurses Foundation and the Alberta Registered Nurses
Education Trust

INVESTIGATORS: Dr. Ron Wardell (PI- supervisor)
Donna Marcy-Edwards (PhD Candidate)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

This research is a continuation of a previous pilot study designed to describe how individuals with dementia interact with objects at activity vignettes, which are clusters of objects that residents could interact with whenever they wanted. Currently I am studying whether or not activities at a garden centre have an effect on the challenging behaviors that are sometimes shown by people with dementia living in a nursing home e.g. Aggression, depression, agitation and apathy.

Currently 500,000 individuals in Canada are living with dementia with numbers predicted to increase to 1-1.3 million by 2035 (13). The cost by 2038 is expected to be 872 billion dollars (13). Prevalence of dementia in Canadian nursing homes in 2008 was 45.4% (13). The greatest challenges for caregivers and contributors to rising costs are neuropsychiatric / challenging behaviors (299, 300). Current pharmaceutical approaches using Cholinesterase inhibitors demonstrate only modest success and questions of clinical significance arise (32, 35). Antipsychotics and anxiolytics are used in severe cases, but serious side effects and limited responses to the modification of challenging behaviors has led to severe use restrictions (41, 43).

Research examining the relationship between activity and challenging behaviors in normal participants demonstrates a relationship between a sense of well-being and the opportunity to engage in autonomous/self-determined activity (77). When autonomy does not exist, depression, agitation and aggression may result (81). The ability to engage in autonomous/self-determined activity in a locked nursing home unit where meal times, sleep times and activities are highly programmed is severely restricted with a potential result being increased agitation, aggression or apathy (90).

The ability of the environment to impact behavior for both normal and dementia residents has clearly been established by Lawton (53, 301), Cohen-Mansfield (54, 119), Wilson (98,

302) and Hartig (234, 303). Living in a nursing home where movement out of the building is prohibited by locks; where diminishing thinking ability reduces independence in activities of daily living and where objects for interaction are limited by safety concerns seriously limits normal experiences of engagement, exploration and independence. Studies have shown that individuals with dementia living in a nursing home spend between 65%-85% of their time doing nothing (304, 305). Research has also shown that fully 45% of individuals with dementia living in a nursing home receive little or no facility activities; 20% receive occasional activities and while 12 % receive daily activities, those activities were deemed inappropriate for functional level and stated interests (79, 157). It is during unoccupied time that most residents display neuropsychiatric / challenging behaviors (79). Empty environments contribute to the neuropsychiatric / challenging behavior that is expressed by those living with dementia in institutions (306).

A previous pilot study conducted at a different nursing home found that residents with moderate to severe dementia were more likely to interact with objects at a vignette than those without dementia and that the most frequent attendees to the vignette had identified frequent feelings of sadness or depression. What was not researched was the effect of the garden vignette on behavior.

To try and understand the relationship between activity and behaviour a blocked time-series research study has been developed. A small garden vignette will be set up on the MDE and SCU units where residents can engage in the activity of gardening if they want, with whom they want, and when they want 24 hours per day, 7 days a week for two weeks. The garden vignette contains a cluster of objects that help guide the activity of gardening. It offers an opportunity to handle the objects used for gardening, to actively plant seeds, water, taste herbs and enjoy a sense of garden in the indoor setting of the nursing unit. There will be an opportunity to use the tools at the garden centre or sit at a table under an umbrella surrounded by plants and look at garden magazines. To understand the possible effect of the vignette on behaviour, the vignette will be in place for two weeks then it will be removed for two weeks. This pattern will be repeated.

We do not know what effect the vignette placement or removal will have on the residents. There may be increases in agitation, or there may be increased interest and curiosity. Because resident response is not known, all care giving staff will be asked to look for possible changes in behaviour. As a staff member your observations will be guided by questionnaires that direct your attention to noticing the presence of any behaviours, the type of behaviour, how frequent and how severe they are as well as how much impact they have on your practice. All usual treatments for managing challenging behaviours will continue to be implemented if and as necessary.

Several other research activities will take place when the vignette is available and when it has been removed. Information will be gathered in three ways; video recording all interactions at the garden vignette, interviewing the resident and caregivers, and reading the chart. Interviews will be completed during weeks 1, 2, 4, 6, 8 and 10. A detailed description is given below.

All activity at the garden centre will be video recorded. The videos will be examined to note how often a resident came to the vignette, whether they came by themselves or were brought by someone and how engaged in the activity they were. I will use this information to look at whether or not there is a relationship between level of interest and time spent at the vignette and the number and severity of challenging behaviours in the person visiting the vignette.

Taking information from the chart is another means of gathering study data. Things like age, gender, previous occupation and previous hobbies will be recorded to help look for any possible relationships between those items and level of activity or enjoyment of the vignettes. Medication use will also be recorded.

As a staff member, your potential participation is described in greater detail in the “What would I have to do” section below.

The minimum number of subjects that we are hoping to enroll in the research study is 34 but the potential number of subjects on both the Maximizing Dignity with Expertise Unit and the Special Care Unit is 49. It is easier to determine the effect of the intervention with a larger number of subjects. Only the MDE and the SCU will be used for the study. No patients on the nursing unit will be prevented from interacting at the garden vignette. The research process will not contribute to any changes in treatment or activity experiences designed for the residents.

WHAT IS THE PURPOSE OF THE STUDY?

To find out the effect of interactions at a garden vignette on the behaviors of agitation, aggression, depression and apathy as well as the use of medication to manage those behaviors. A garden vignette is a group of objects designed to attract the attention of residents with dementia and to encourage handling and using any of the objects for the process of gardening.

WHAT WOULD I HAVE TO DO?

Your work as a staff member of the MDE and SCU may lead you into the camera recording range at the garden vignette. You are not required to do anything at or with the garden vignette, but if you wish to engage a resident who is standing there or nearby you are encouraged to do so. You may also bring a resident to the vignette if you feel they would be interested. Your presence in the video is not used to evaluate your care giving. Your presence in the video is not recorded as who you are, but that ‘someone’ facilitated resident activity at the vignette. All events are merely recorded as self-determined activity (came by themselves) or facilitated activity (brought by someone).

The presence of dementia requires that researchers gather third-party observations of behaviour as residents with dementia are often considered unreliable sources of information. The individual with the greatest knowledge about the resident is you, the caregiver. As caregivers on this unit work in teams, the measurement tool data will be gathered from the team.

As a member of the care giving teams you will be asked to participate in the completion of several behaviour measurement tools. The Neuropsychiatric Inventory – Nursing Home, is a tool completed at the end of your work shift on specified days only to document the presence, frequency and severity of 12 neuropsychiatric behaviours as well as the level of disruption caused to you by the behaviour. If the resident has exhibited neuropsychiatric behaviours during your shift this tool may take 15-20 minutes to complete. If there has been no such behaviour the tool is completed in seconds. The following tools will be also completed at the end of each two-week intervention period and each two-week ‘no’ intervention period on specified days. The Ryden Aggression Scale is a 26-item Likert-type scale that retrospectively measures the frequency and nature of aggression and the Apathy inventory assesses emotional blunting, lack of initiative and lack of interest as well as frequency and severity taking approximately 15 minutes to complete. Aggression and apathy are both subscales of the Neuropsychiatric Inventory so you will have already thought about these two behaviours thereby reducing the amount of time required to complete the form. An opportunity to work with the tools and the researcher before the research begins will be provided.

The Cornell Scale for Depression in Dementia will also be completed. It is a 19- item tool where the researcher interviews the caregiver (yourself) to determine the presence of signs and symptoms of depression in the residents you care for (20 minutes). Following this interview, the researcher will interview the resident for 10 minutes asking similar questions. While the times given are an estimate, users have found that as they become more familiar with the use of the tools, time taken to complete the measurement tools is shortened.

The following is an outline of the measurements and their time frame.

Phase	1 Control	2 Intervention	3 Control	4 Intervention	5 Control
Time Frame	Weeks 1 & 2	Weeks 3 & 4	Weeks 5 & 6	Weeks 7 & 8	Weeks 9 & 10
Data collected	NPI scores	NPI scores	NPI scores	NPI scores	NPI scores
Interview team	Q shift x 2 Wk 2	Q shift x 2 Wk 4	Q shift x 2 Wk 6	Q shift x 2 Wk 8	Q shift x 2 Wk 10
Interview team	IA scores Wk 2	IA scores Wk 4	IA scores Wk 6	IA scores Wk 8	IA scores Wk 10
Interview of resident	SQDT Wk 1	SQDT Wk 4	SQDT Wk 6	SQDT Wk 8	SQDT Wk 10
Interview resident & team	CSDD Wk 2	CSDD Wk 4	CSDD Wk 6	CSDD Wk 8	CSDD Wk 10
Interview team	RAS2 Wk 2	RAS2 Wk 4	RAS2 Wk 6	RAS2 Wk 8	RAS2 Wk 10
Researcher	Medications	Medications	Medications	Medications	Medications
Researcher	MMSE & GDS/FAST				
Video data	Time spent at	Time spent at	Time spent at	Time spent at	Time spent at

Researcher Assistants	vignette (no wk 3)	vignette	vignette (no wk 7)	vignette	vignette (no wk 11)
Researcher Assistants	Self-determined or no	Self-determined or no	Self-determined or no	Self-determined or no	Self-determined or no
Researcher Assistants	OME tool data	OME tool data	OME tool data	OME tool data	OME tool data

WHAT ARE THE RISKS?

The risks include:

1. Challenges to time management when completing the behavior measurement tools.
2. If the video camera records you engaging in criminal behavior or abusive treatment of a resident or staff member the researchers are required to report abusive behavior to management.
3. There are no known side effects.

WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study there may or may not be a direct benefit to you. If you are in the study because you have been identified as having the potential to be video taped or because you are a member of the team who will be assessing resident behaviour there is no guarantee that this research will directly help you. The information we get from this study may help us to provide better treatments in the future for patients with dementia.

A potential benefit to your taking part in this study may come from a greater in-depth understanding of the behaviour of your residents. Tools used to understand levels of dementia as well as frequency and severity of neuropsychiatric behaviour offer opportunities to better understand triggers to behaviour with the potential to develop trigger specific responses to those behaviours. Greater knowledge also assists in the ability to predict when a behaviour may be expressed fostering the use of early intervention to prevent escalation of the behaviour. The presence of the vignette materials offers all levels of staff opportunities to explore new ways to interact with residents. The opportunity to interact with residents in a pleasant activity rather than always direct care giving develops improved relationships between residents and staff.

The behavioural data produced by these tools may also be used by nurse managers to demonstrate the prevalence of these behaviours and the challenges to care giving when planning staffing levels.

DO I HAVE TO PARTICIPATE?

You do not have to participate in this study, but your special individual knowledge of the residents you care for is highly valued. If you have concerns about how you might

participate, please contact the primary investigator to discuss these concerns and potential solutions.

The possibility to change your work assignment is limited by the knowledge that staff changes affect the behaviour of those with dementia and by replacement staff availability.

Voluntariness and Withdrawal of Consent

Your participation in this study is voluntary and you may withdraw from the study at any time without jeopardizing job. You may withdraw by contacting the field researcher. All study data collected prior to your withdrawal will be included in the study. You may be withdrawn from the study by the researcher if you are engaging in criminal or abusive activity in the unit setting.

If new information becomes available that might affect your willingness to participate in the study, you will be informed as soon as possible.

WHAT ELSE DOES MY PARTICIPATION INVOLVE?

Your participation in this study is to engage residents in activity at the vignette if you feel so inclined (not a mandatory requirement but a personal interest perspective) and to assist in the evaluation of behaviours expressed by residents twice a week, every other week over a total of ten weeks. You may also be asked to participate in education sessions that provide in-depth information about the study and how to use the behaviour measurement tools.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

There is no payment for participation in this study, but the MDE and SCU nursing units will be allowed to keep the garden centres and most of the materials on them.

WILL MY RECORDS BE KEPT PRIVATE?

All recorded activity at the vignette site will be kept private by ensuring that only the researcher and the research assistants will have access to the raw data. Data will be stored in a locked filing cabinet in the researcher's office. As staff are not the focus for observation at the vignette, written data collection includes only resident level of activity, what they interact with and how, and whether they came by themselves or were brought by someone will be recorded. No information about staff is noted on data collection tools. Staff and researcher interviews about resident behaviour do not contain any information about the staff member.

IF I SUFFER A RESEARCH-RELATED INJURY, WILL I BE COMPENSATED?

In the event that you suffer injury as a result of participating in this research, the University of Calgary, the Alberta Health Services or the Researchers will provide no compensation to you. You still have all your legal rights. Nothing said in this consent form alters your right to seek damages.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Ron Wardell

Or

Donna Marcy-Edwards

If you have any questions concerning your rights as a possible participant in this research, please contact: The Director, the Office of Medical Bioethics, University of Calgary.

Participant's Name

Signature and Date

Investigator/Delegate's Name

Signature and Date

Witness' Name

Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

APPENDIX Q: GENERAL STAFF CONSENT FORM

TITLE: The Effect of Vignette Activity on the Challenging Behaviors Expressed by Individuals with Dementia, Living in Long-term Care

SPONSOR: Canadian Nurses Foundation and the Alberta Registered Nurses Education Trust

INVESTIGATORS: Dr. Ron Wardell (PI- supervisor)

Donna Marcy-Edwards (PhD Candidate)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

This research is a continuation of a previous pilot study designed to describe how individuals with dementia interact with objects at activity vignettes, which are clusters of objects that residents could interact with whenever they wanted. Currently I am studying whether or not activities at a garden centre have an effect on the challenging behaviours that are sometimes shown by people with dementia living in a nursing home e.g. Aggression, depression, agitation and apathy.

We already know that up to 90% of people with dementia will experience one or more of the challenging behaviours mentioned above. It is also known that these behaviours do not always respond well to drug therapy and cause the most stress for caregivers. We also know that when people are admitted to long-term care many decisions are made for them, which may take away their sense of independence and autonomy. Another feature of living in long-term care is that residents often have to wait for activities to be arranged by staff before they can get busy doing things. Other research has shown that people with dementia living in long-term care often spend a lot of time sitting, doing nothing and that boredom and loss of self-direction can lead to some of the challenging behaviours that we see.

A previous pilot study conducted at a different nursing home found that residents with moderate to severe dementia were more likely to interact with objects at a vignette than those without dementia and that the most frequent attendees to the vignette had identified frequent feelings of sadness or depression. What was not researched was the effect of the garden vignette on behaviour.

To try and understand the relationship between activity and behaviour a blocked time-series research study has been developed. A small garden vignette will be set up on the MDE and SCU units where residents can do gardening if they want, with whom they want, and when they want 24 hours per day, 7 days a week for two weeks. The garden vignette has a lot of objects that help guide the activity of gardening. Residents can handle the objects, plant seeds, water, taste herbs and enjoy a sense of garden in the

indoor setting of the nursing unit. Residents can use the tools at the garden centre or sit at a table under an umbrella surrounded by plants and look at garden magazines. To understand the possible effect of the vignette on behaviour, the vignette will be in place for two weeks then it will be removed for two weeks. This pattern will be repeated.

I do not know what will happen to resident behaviour when I put the vignette in place or take it away. There may be more agitation, or there may be more interest and curiosity. Because resident response is not known, all care giving staff will be asked to look for possible changes in behaviour. All usual treatments for managing challenging behaviours will continue to be implemented if and as necessary.

You may notice several other research activities will taking place when the vignette is available and when it has been removed. Information will be gathered in three ways; video recording all interactions at the garden vignette, interviewing the resident and caregivers, and reading the chart.

All activity at the garden centre will be video recorded. The videos will be examined to see how often a resident came to the vignette, if they came by themselves or were brought by someone and how engaged in the activity they were. I will use this information to see if there is a relationship between level of interest and time spent at the vignette and the number and severity of challenging behaviours in the person visiting the vignette.

As a staff member, your potential participation is described in greater detail in the “What would I have to do” section below.

The minimum number of subjects that we are hoping to enrol in the research study is 34 but the potential number of subjects on both the Maximizing Dignity with Expertise Unit and the Special Care Unit is 49. It is easier to determine the effect of the intervention with a larger number of subjects. Only the MDE and the SCU will be used for the study. **No** residents on the nursing unit will be prevented from interacting at the garden vignette. The research process will not contribute to any changes in treatment or activity experiences designed for the residents.

WHAT IS THE PURPOSE OF THE STUDY?

To find out the effect of interactions at a garden vignette on the behaviours of agitation, aggression, depression and apathy as well as the use of medication to manage those behaviours. A garden vignette is a group of objects designed to attract the attention of residents with dementia and to encourage handling and using any of the objects for the process of gardening.

WHAT WOULD I HAVE TO DO?

Your work as a staff member of the MDE and SCU may lead you into the camera recording range at the garden vignette. You are not required to do anything at or with the garden vignette, but if you wish to engage a resident who is standing there or nearby you are encouraged to do so. You may also bring a resident to the vignette if you feel they

would be interested. Your presence in the video is not used to evaluate your care giving or the performance of your job. Your presence in the video is not recorded as who you are, but that ‘someone’ facilitated resident activity at the vignette. All events are merely recorded as self-determined activity (came by themselves) or facilitated activity (brought by someone).

The following chart identifies the various research data collection activities that you may see taking place on the MDE and SCU units during the research process.

Phase	1 Control	2 Intervention	3 Control	4 Intervention	5 Control
Time Frame	Weeks 1 & 2	Weeks 3 & 4	Weeks 5 & 6	Weeks 7 & 8	Weeks 9 & 10
Data collected	NPI scores Q shift x 2 Wk 2	NPI scores Q shift x 2 wk 4	NPI scores Q shift x 2 wk 6	NPI scores Q shift x 2 Wk 8	NPI scores Q shift x 2 wk 10
Interview team	IA scores Wk 2	IA scores Wk 4	IA scores Wk 6	IA scores Wk 8	IA scores Wk 10
Interview of resident	SQDT Wk 1	SQDT Wk 4	SQDT Wk 6	SQDT Wk 8	SQDT Wk 10
Interview resident & team	CSDD Wk 2	CSDD Wk 4	CSDD Wk 6	CSDD Wk 8	CSDD Wk 10
Interview team	RAS2 Wk 2	RAS2 Wk 4	RAS2 Wk 6	RAS2 Wk 8	RAS2 Wk 10
Researcher	Medications	Medications	Medications	Medications	Medications
Researcher	MMSE & GDS/FAST				
Video data Researcher Assistants	Time spent at vignette (no wk 3)	Time spent at vignette	Time spent at vignette (no wk 7)	Time spent at vignette	Time spent at vignette (no wk 11)
Researcher Assistants	Self-determined or no	Self-determined or no	Self-determined or no	Self-determined or no	Self-determined or no
Researcher Assistants	OME tool data	OME tool data	OME tool data	OME tool data	OME tool data

WHAT ARE THE RISKS?

The risks include:

1. Challenges to time management if there are increased objects to clean or move on site.

2. If the video camera records you engaging in criminal behaviour or abusive treatment of a resident or staff member the researchers are required to report abusive behaviour to management.
3. There are no known side effects.

WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study there may or may not be a direct benefit to you. If you are in the study because you have been identified as having the potential to be video taped or because you are a member of the team who will be assessing resident behavior there is no guarantee that this research will directly help you. The information we get from this study may help us to provide better treatments in the future for patients with dementia.

A potential benefit to your taking part in this study may come from helping develop a greater in-depth understanding of the behaviour of the residents. The presence of the vignette materials offers all levels of staff opportunities to explore new ways to interact with residents. The opportunity to interact with residents in a pleasant activity rather than always direct care giving develops improved relationships between residents and staff.

DO I HAVE TO PARTICIPATE?

You do not have to participate in this study, but your special individual knowledge of the residents you work with is highly valued. If you have concerns about how you might participate, please contact the primary investigator to discuss these concerns and potential solutions.

The possibility to change your work assignment is limited by the knowledge that staff changes affect the behaviour of those with dementia and by replacement staff availability.

Voluntariness and Withdrawal of Consent

Your participation in this study is voluntary and you may withdraw from the study at any time without jeopardizing job. You may withdraw by contacting the field researcher. Data collected prior to your withdrawal from the study will be included. You may be withdrawn from the study by the researcher if you are engaging in criminal or abusive activity in the unit setting

If new information becomes available that might affect your willingness to participate in the study, you will be informed as soon as possible.

WHAT ELSE DOES MY PARTICIPATION INVOLVE?

If, through your daily, work you notice objects from the vignettes in resident rooms could you please notify the researcher they are there.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

There is no payment for participation in this study, but the MDE and SCU nursing units will be allowed to keep the garden centres and most of the materials on them.

WILL MY RECORDS BE KEPT PRIVATE?

All recorded activity at the vignette site will be kept private by ensuring that only the researcher and the research assistants will have access to the raw data. Data will be stored in a locked filing cabinet in the researcher's office. As staff are not the focus for observation at the vignette, written data collection includes only resident level of activity, what they interact with and how, and whether they came by themselves or were brought by someone will be recorded. No information about staff is noted on data collection tools. Staff and researcher interviews about resident behaviour do not contain any information about the staff member. All data will be destroyed 5 years following the thesis defense.

IF I SUFFER A RESEARCH-RELATED INJURY, WILL I BE COMPENSATED?

In the event that you suffer injury as a result of participating in this research, no compensation will be provided to you by the University of Calgary, Alberta Health Services, or the Researchers. You still have all your legal rights. Nothing said in this consent form alters your right to seek damages.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Ron Wardell

Or

Donna Marcy-Edwards

If you have any questions concerning your rights as a possible participant in this research, please contact: The Director, the Office of Medical Bioethics, University of Calgary.

_____ Participant's Name	_____ Signature and Date
_____ Investigator/Delegate's Name	_____ Signature and Date
_____ Witness' Name	_____ Signature and Date

If you have any questions concerning your rights as a possible participant in this research, please contact: The Director, the Office of Medical Bioethics, University of Calgary.

APPENDIX R: BETHANY CARE CONSENT FORM

Bethany Care Society Release of Personal Information



☐ BAI ☐ BCOL ☐ BLL
☒ BCA ☐ BCS ☐ BSL
☐ BCO ☐ BHH Other Facility: _____

CONSENT FOR RELEASE OF PERSONAL INFORMATION

I, _____, consent to the release of

(Name)

Age, gender, previous occupation, previous hobbies and interests, presenting and current neuropsychiatric behaviours, current level of wellness, current levels of activity and medication information from the chart of

(Resident Name)

to Donna Marcy-Edwards (PhD candidate) nurse researcher at the University of Calgary, for the purpose of supporting research that is examining the effect of self-determined activity at a garden vignette on behaviours for those with moderate to severe dementia living in a nursing home. Information gathered will be examined for its relationship to the amount of time spent at the vignette, level of engagement at the vignette, and preference of objects for interaction. This information will then be used to evaluate the effect of the vignette on neuropsychiatric behaviours pre and post vignette placement by examining the relationship between each of these variables and presenting behaviours.

I acknowledge that I have been made aware of the reasons for the disclosure of the above information, and the risks and benefits associated with consenting to its release.

I understand that I may revoke my consent at any time, by providing a signed, written statement to that effect.

Date: _____ Valid Until: May 13, 2011

Signature: _____ Print Name: _____

309/71110 00-05 Rev. 02-01

MAINTAIN ON RESIDENT'S HEALTH CARE RECORD /

EMPLOYEE FILE

Inventory # 109686

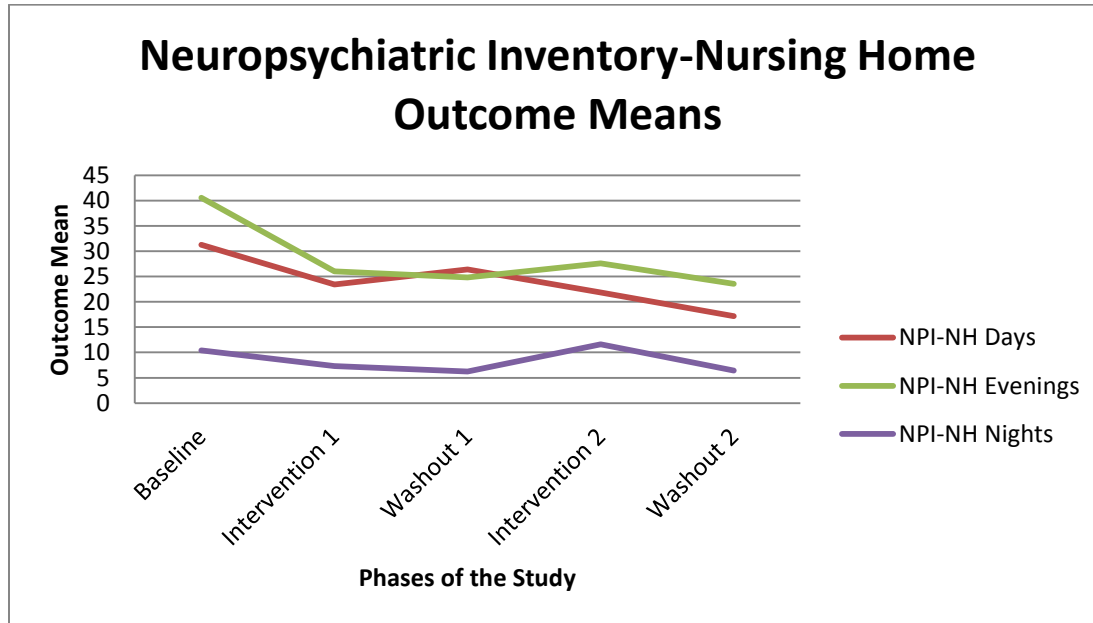
RIM MANUAL

Attention: Video Recording in Progress

This garden centre is the focus of a Doctoral research project. A video recording of all activities at the garden centre will be recorded 24 hours per day, 7 days per week for two months. All those who enter the area around the centre will be captured on video. If you do wish to be recorded, please avoid this area. If you are inadvertently captured on the video and do not wish to be identified, please contact the Donna Marcy-Edwards [researcher] identifying when you were in the area including day and time and your facial features will be blurred. The research is not focused on identifying individuals, but on activity at the centre.

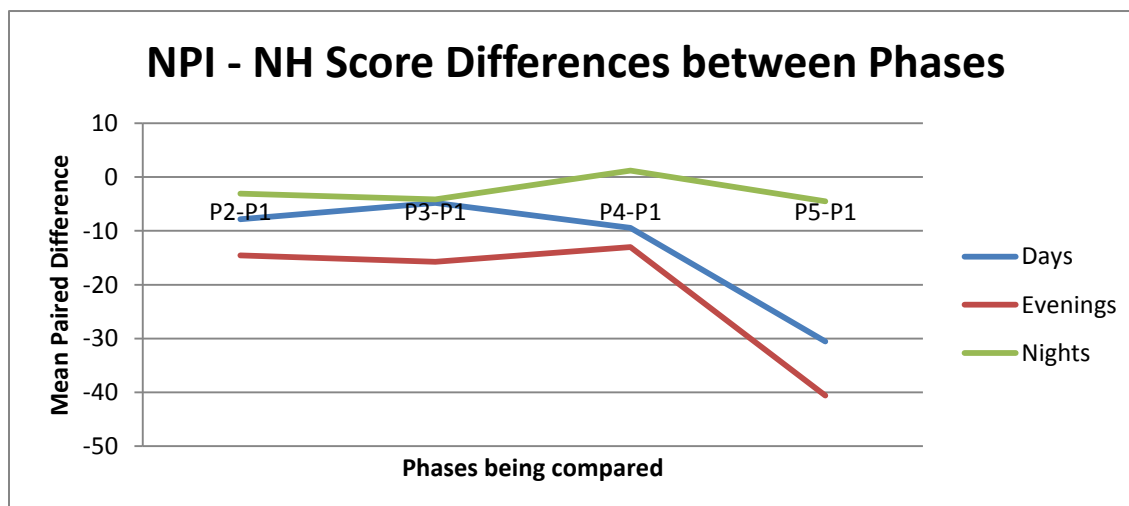
APPENDIX T: NPI-NH MEAN SCORES AND DIFFERENCES ACROSS ALL PHASES

Table 1: NPI-NH Severity of Behaviour Graphic and Table Data



Note. NPI-NH = Neuropsychiatric Inventory-Nursing Home; days = day shift; evenings = evening shift; nights = night shift.

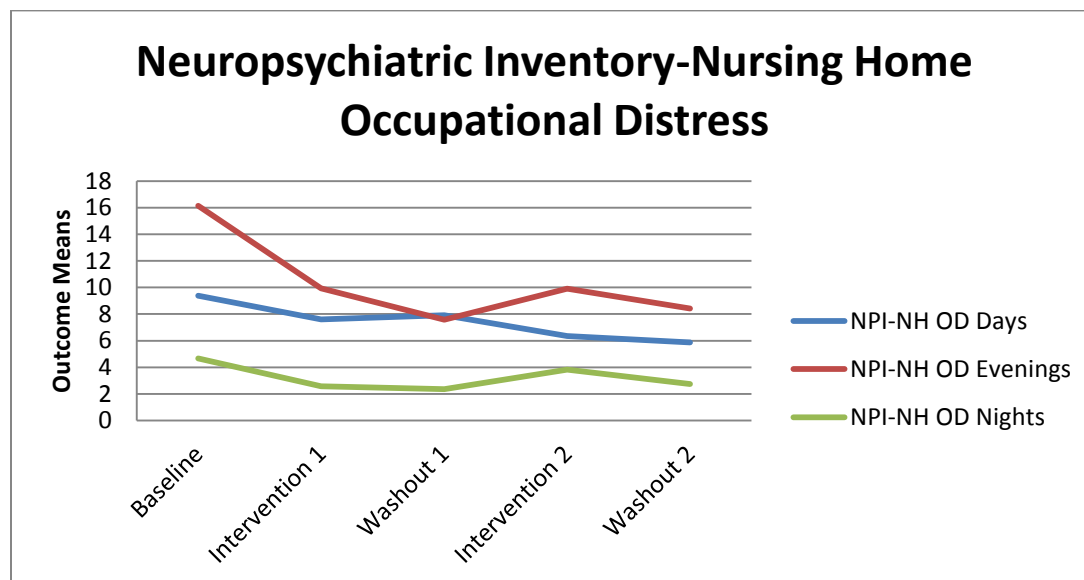
Table 2: Phases Paired-Mean Differences for the Neuropsychiatric Inventory-Nursing Home



Note. P1 is Phase 1 Baseline; P2 is Phase 2 Intervention 1; P3 is Phase 3 Washout 1; P4 is Phase 4 Intervention 2; P5 is Phase 5 Washout 2

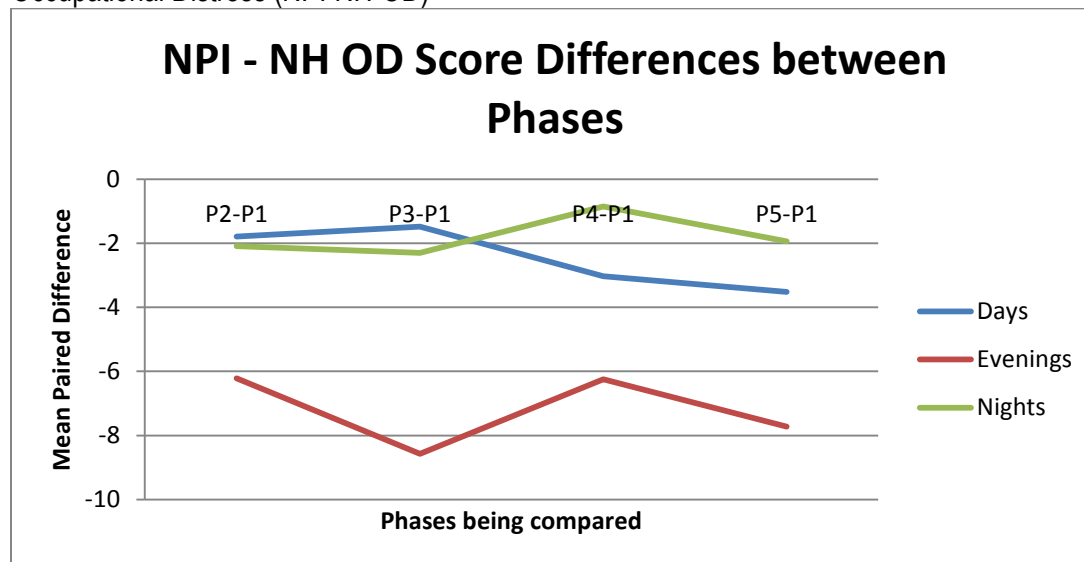
APPENDIX U: NPI-NH-OD MEAN SCORES AND DIFFERENCES ACROSS ALL PHASES

Table 1: NPI-NH-OD Scores for the Three Working Shifts Across the Five Phases of the Study



Note. NPI-NH-OD = Neuropsychiatric Inventory-Nursing Home Occupational Distress; days = day shift; evenings = evening shift; nights = night shift.

Table 2: Study Phases Paired-Mean Differences for the Neuropsychiatric Inventory-Nursing Home Occupational Distress (NPI-NH-OD)



Note. P1 is Phase 1 Baseline; P2 is Phase 2 Intervention 1; P3 is Phase 3 Washout 1; P4 is Phase 4 Intervention 2; P5 is Phase 5 Washout 2; days = day shift; evenings = evening shift; nights = night shift.

APPENDIX V: DAY SHIFT SCATTERPLOTS OF NPI-NH DATA MEAN SCORE DIFFERENCES BETWEEN ALL PHASES

Table 1: Day Shift NPI-NH Mean Score Differences Between Baseline and Intervention 1

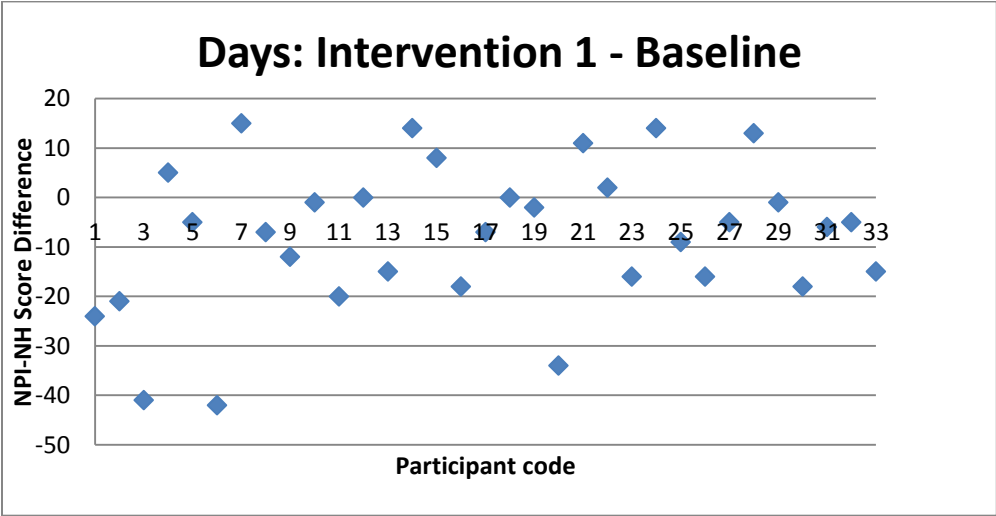
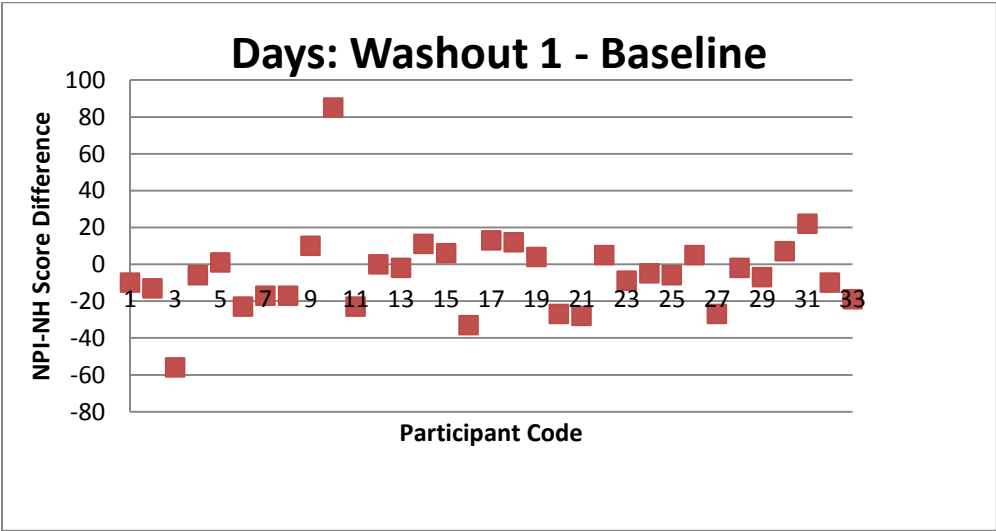


Table 2: Day Shift NPI-NH Mean Score Differences Between Baseline and Washout 1



Appendix W (cont'd): Day Shift Scatterplots of NPI-NH Mean Score Differences Between all Phases

Table 3: Day Shift NPI-NH Mean Score Differences Between Baseline and Intervention 2

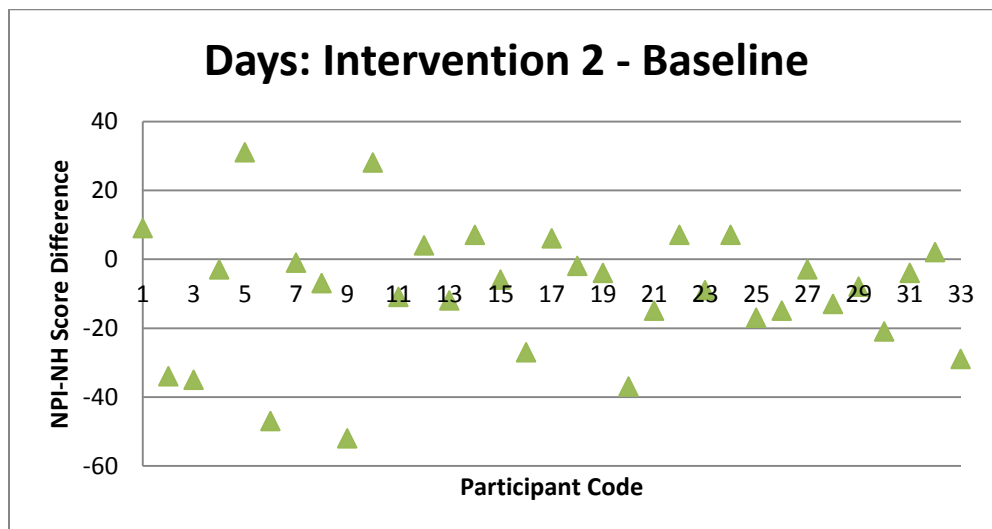
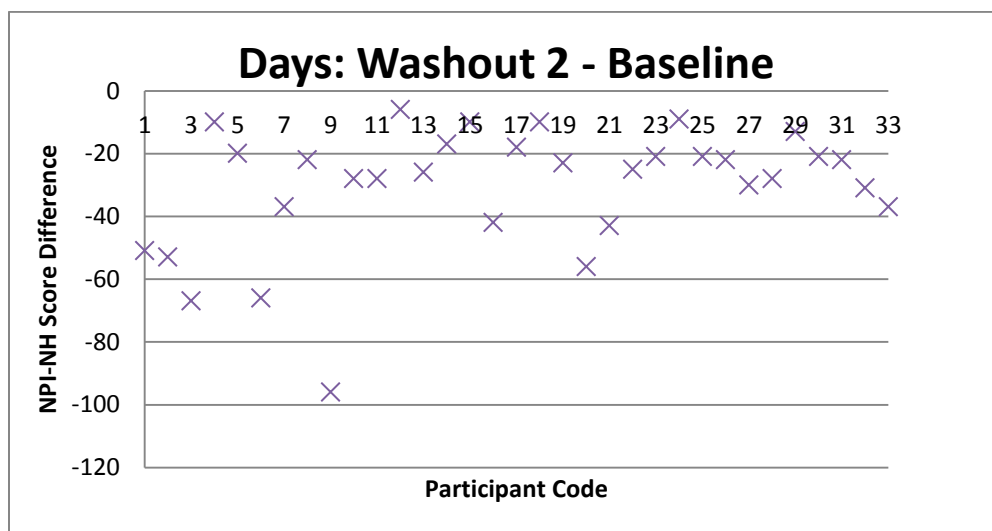


Table 4: Day Shift NPI-NH Mean Score Differences Between Baseline and Washout 2



APPENDIX W: EVENING SHIFT SCATTERPLOTS OF NPI-NH MEAN SCORE DIFFERENCES BETWEEN ALL PHASES

Table 1: Evening Shift NPI-NH Mean Score Differences Between Baseline and Intervention 1

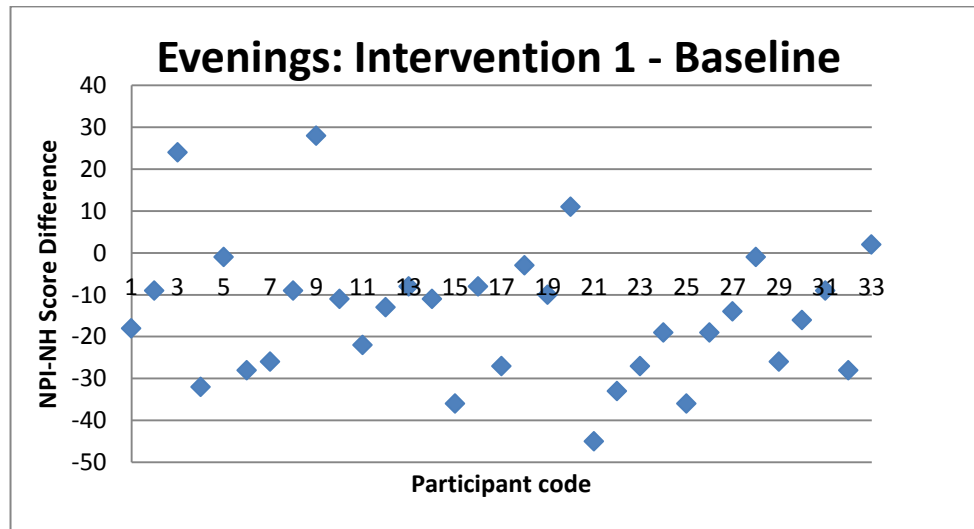
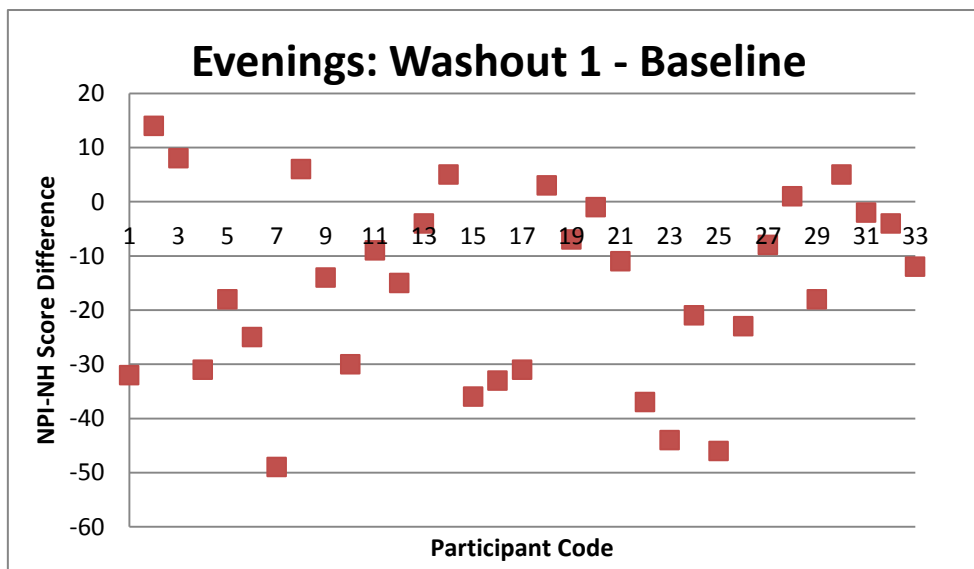


Table 2: Evening Shift NPI-NH Mean Score Differences Between Baseline and Washout 1



Appendix X (cont'd): Evening Shift Scatterplots of NPI-NH Mean Score Differences Between All Phases

Table 3: Evening Shift NPI-NH Mean Score Differences Between Baseline and Intervention 2

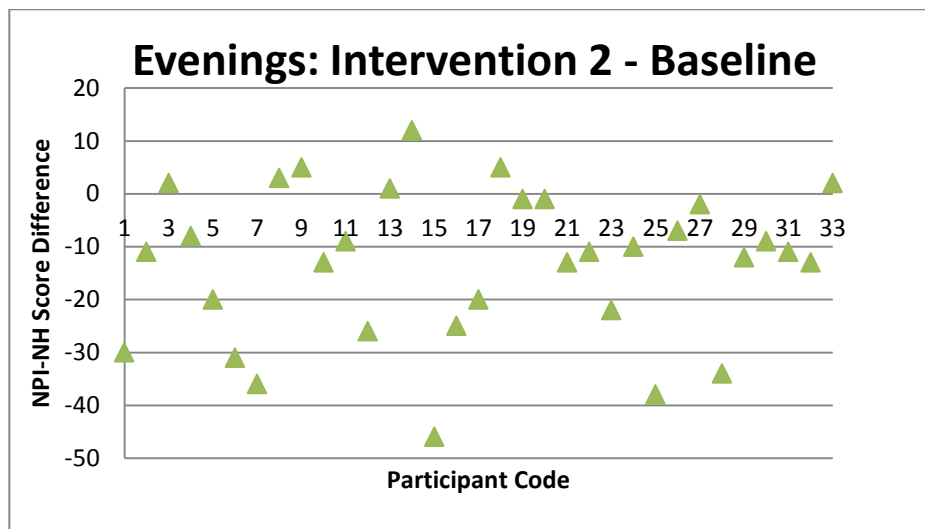
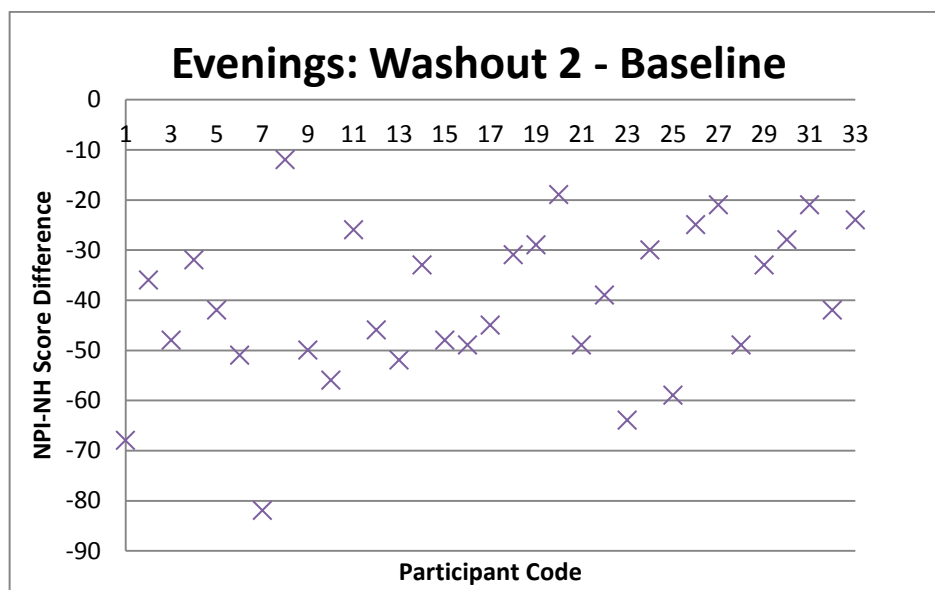


Table 4: Evening Shift NPI-NH Mean Score Differences Between Baseline and Washout 2



APPENDIX X: NIGHT SHIFT SCATTERPLOTS OF NPI-NH MEAN SCORE DIFFERENCES BETWEEN ALL PHASES

Table 1: Night Shift NPI-NH Mean Score Differences Between Baseline and Intervention 1

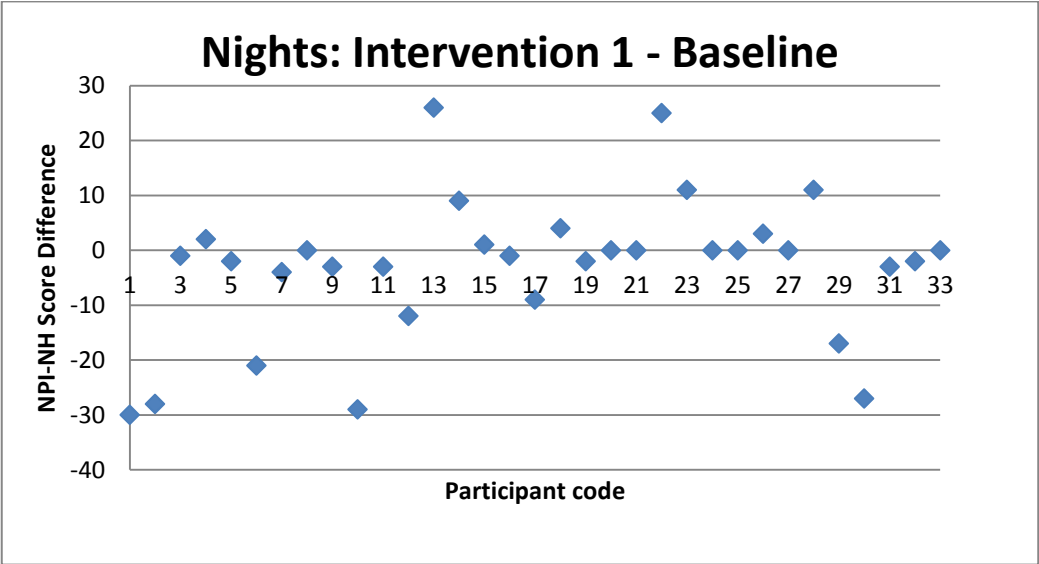
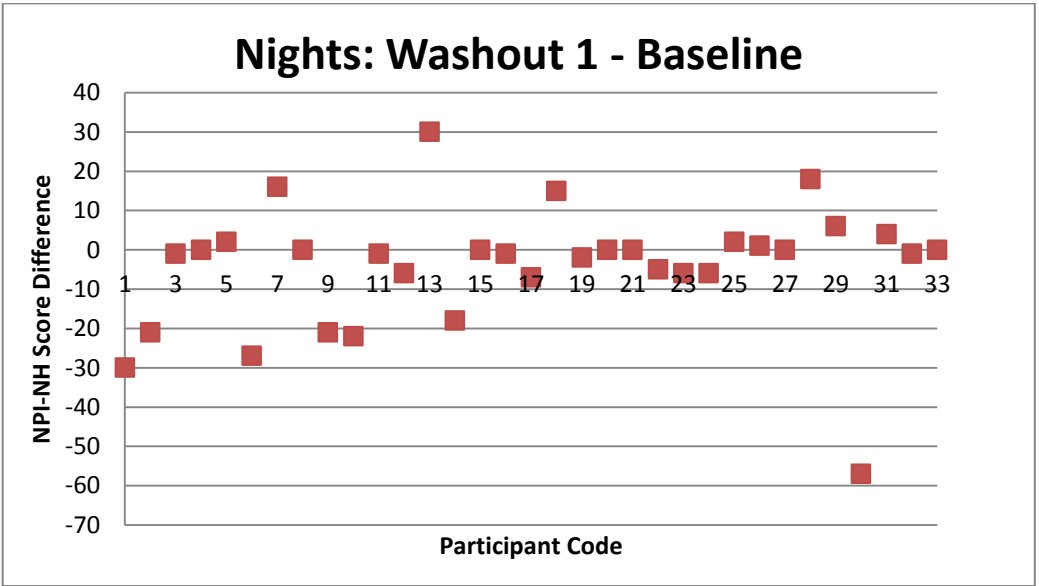


Table 2: Night Shift NPI-NH Mean Score Differences Between Baseline and Washout 1



Appendix Y (cont'd): Night Shift Scatterplots of NPI-NH Mean Score Differences Between All Phases

Table 3: Night Shift NPI-NH Mean Score Differences Between Baseline and Intervention 2

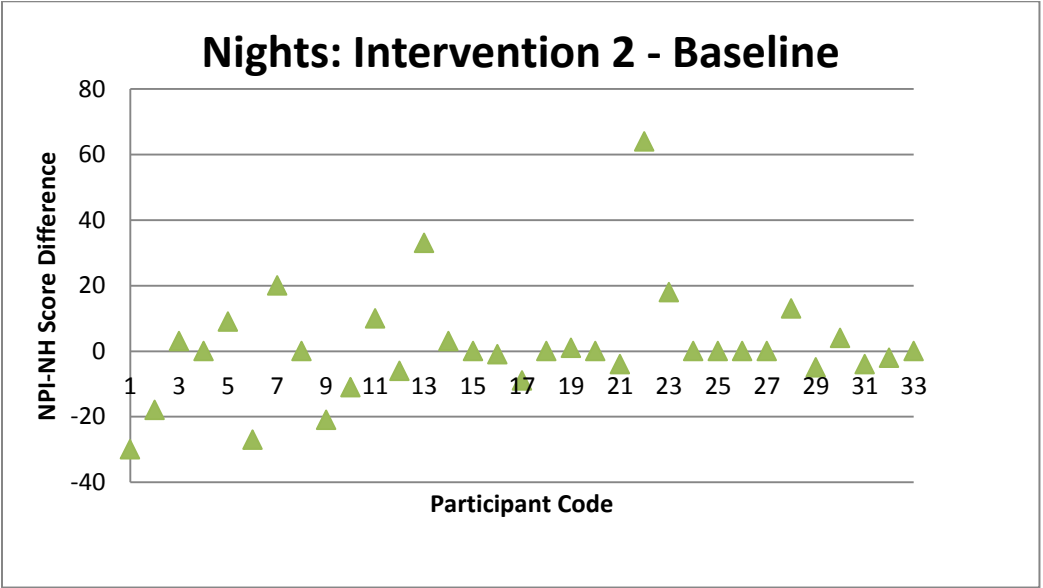
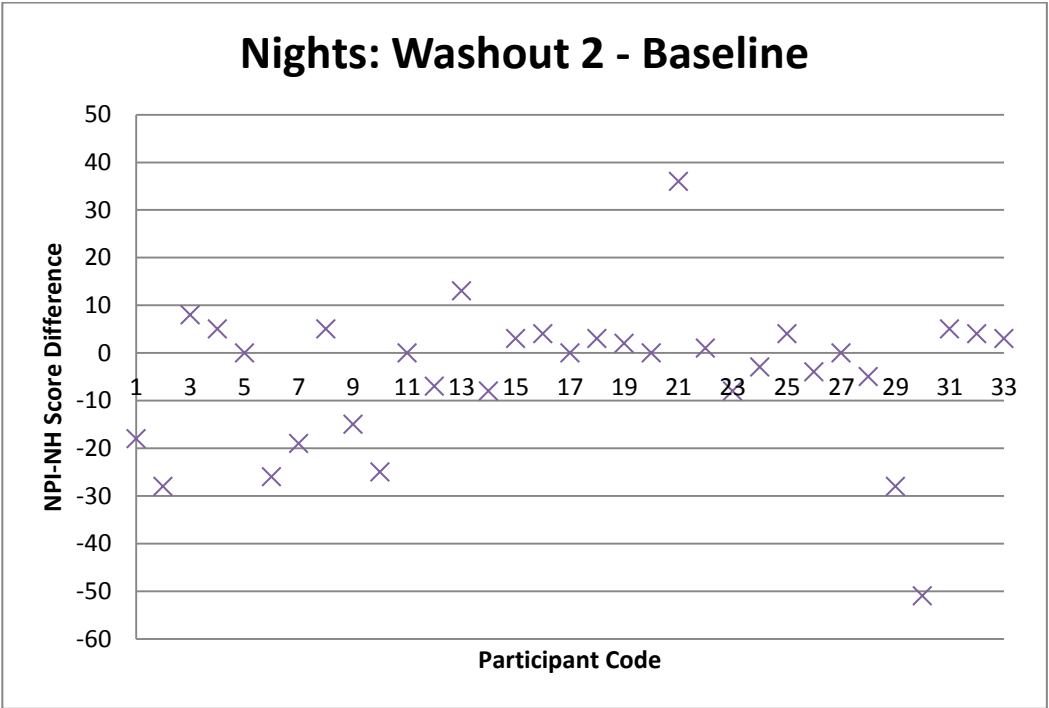


Table 4: Night Shift NPI-NH Mean Score Differences Between Baseline and Washout 2



APPENDIX Y: DAY SHIFT SCATTERPLOTS FOR NPI-NH OCCUPATIONAL DISRUPTIVENESS MEAN SCORE DIFFERENCES ACROSS ALL PHASES

Table 1: Day Shift NPI-NH-OD Mean Score Differences Between Baseline and Intervention 1

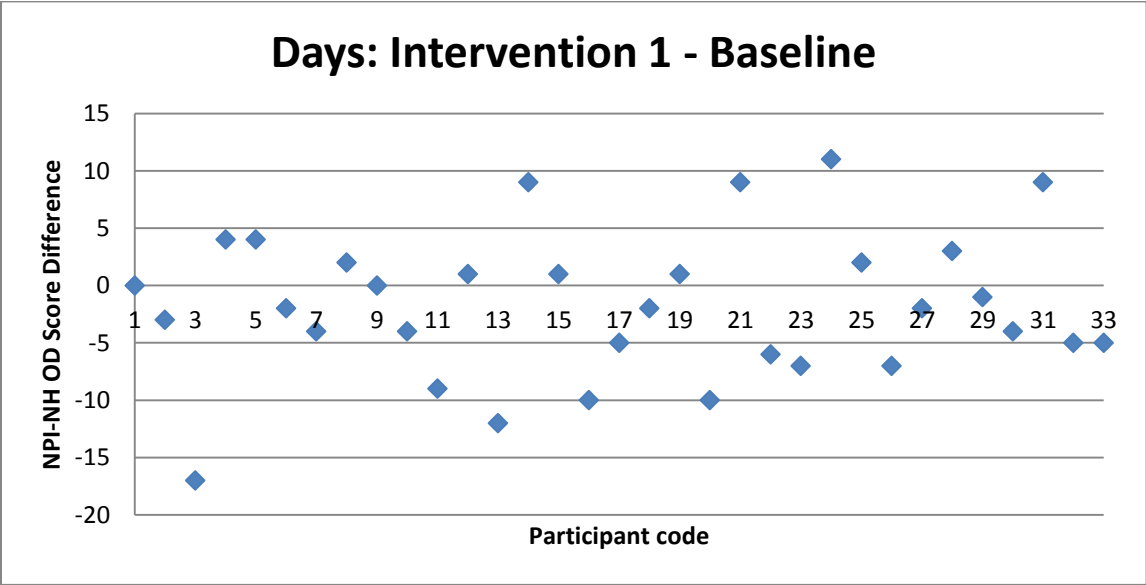
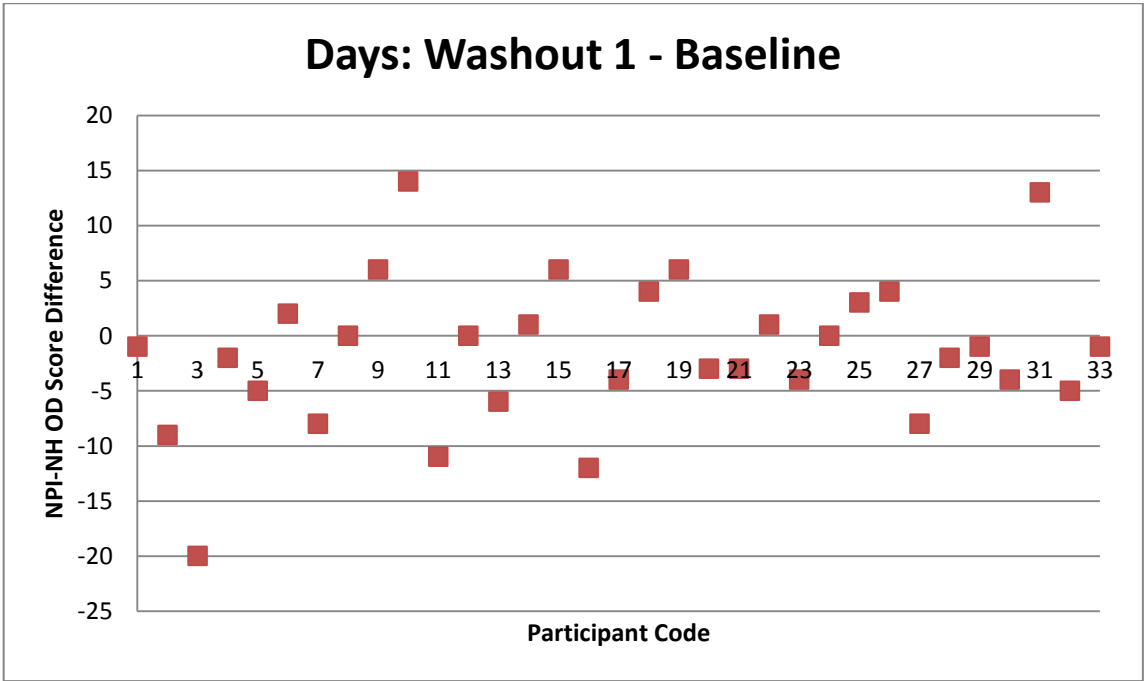


Table 2: Day Shift NPI-NH-OD Mean Score Differences Between Baseline and Washout 1



Appendix Z (cont'd): Day Shift Scatterplots for NPI-NH Occupational Disruptiveness Mean Score Differences Across all Phases

Table 3: Day Shift NPI-NH-OD Mean Score Differences Between Baseline and Intervention 2

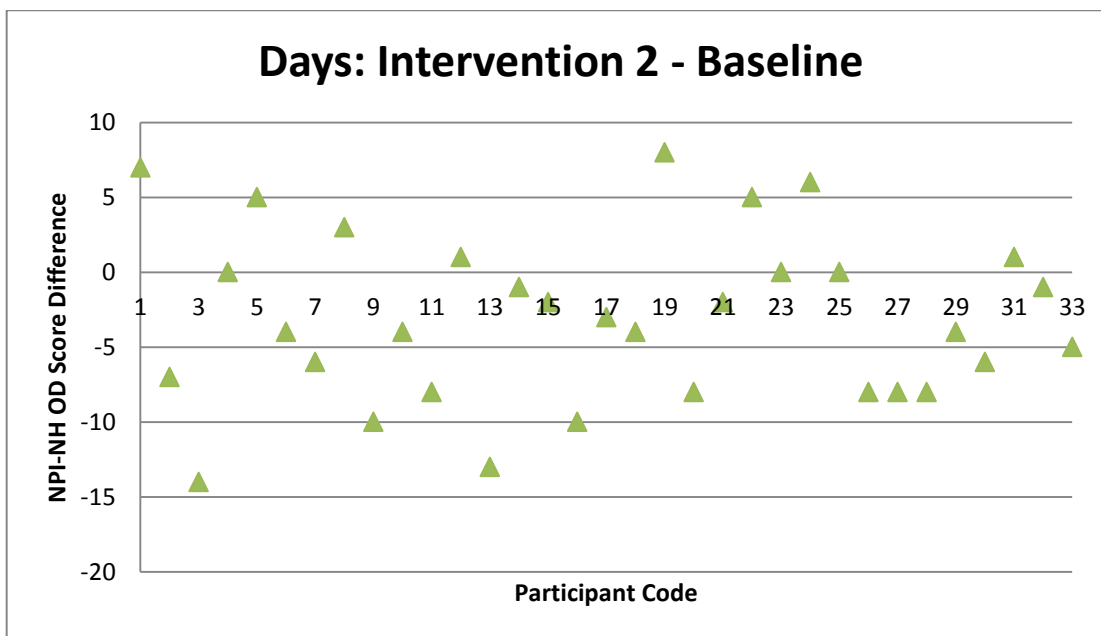
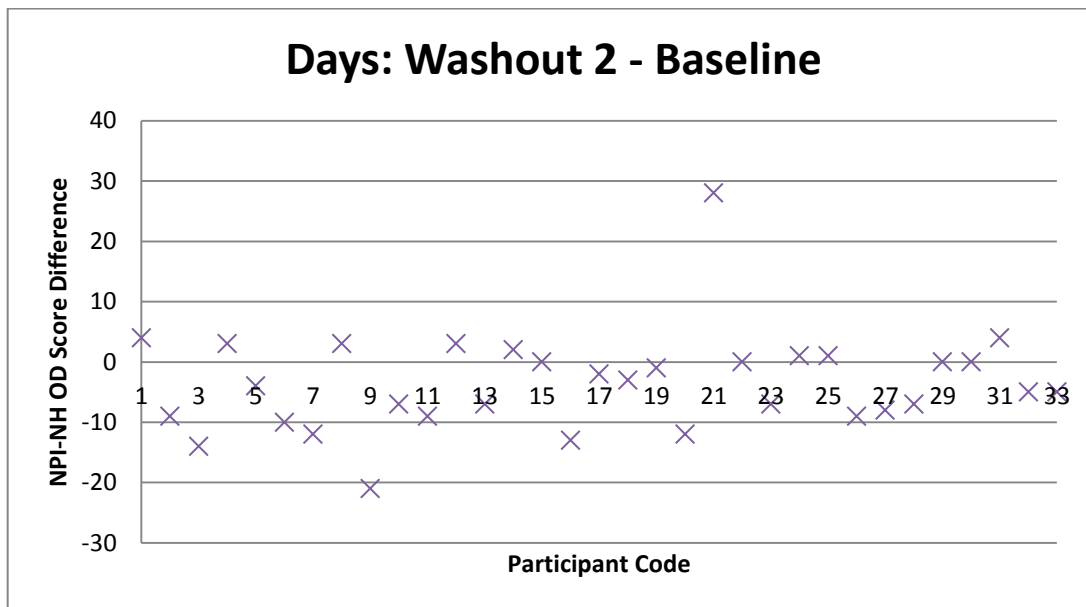


Table 4: Day Shift NPI-NH-OD Mean Score Differences Between Baseline and Washout 2



APPENDIX Z: EVENING SHIFT SCATTERPLOTS FOR NPI-NH OCCUPATIONAL DISRUPTIVENESS MEAN SCORE DIFFERENCES ACROSS ALL PHASES

Table 1: Evening Shift NPI-NH-OD Mean Score Differences Between Baseline and Intervention 1

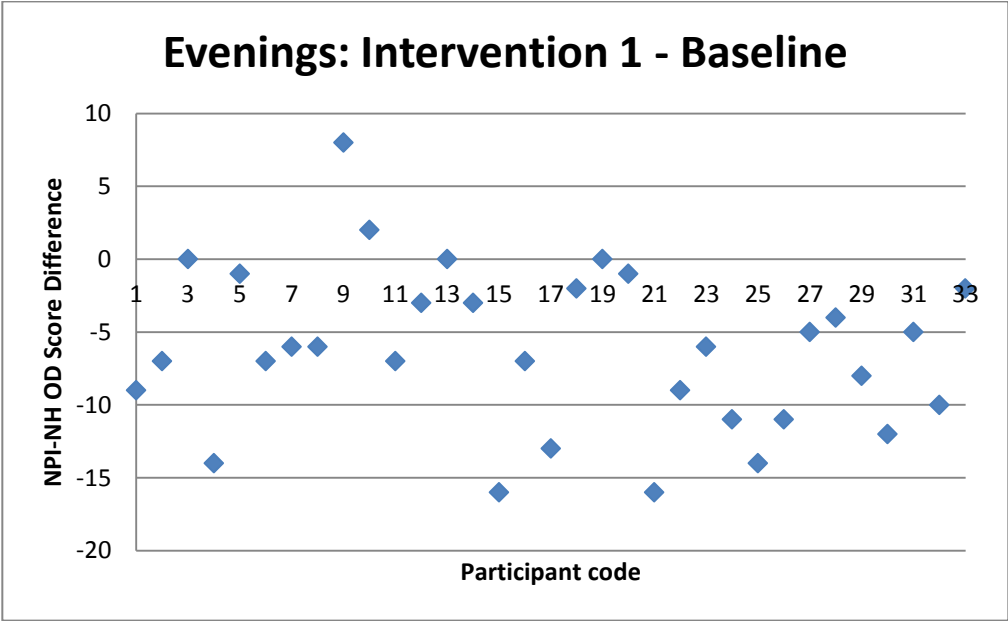
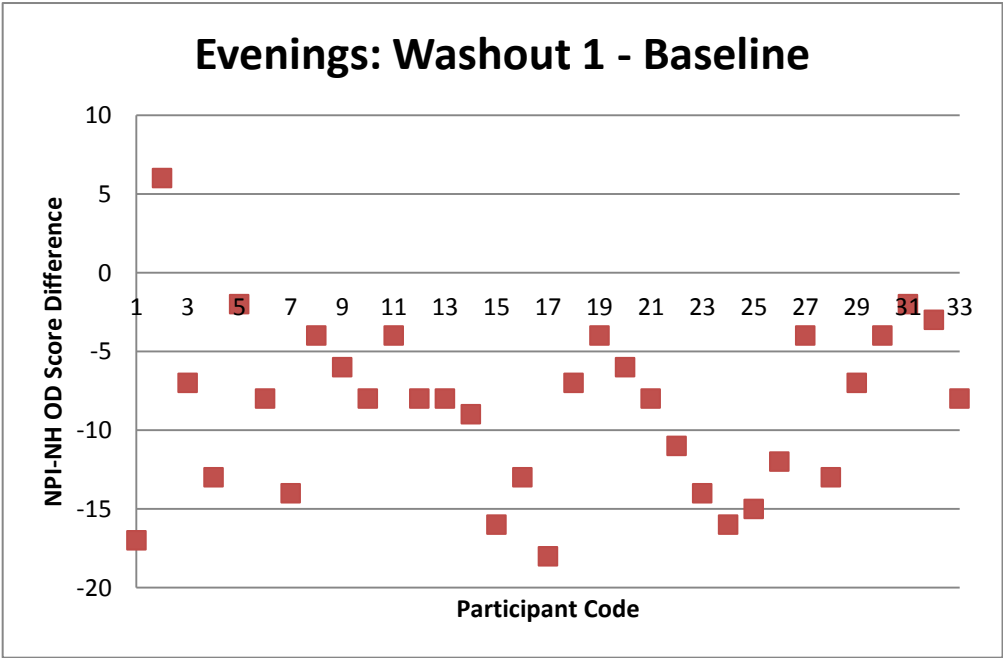


Table 2: Evening Shift NPI-NH-OD Mean Score Differences Between Baseline and Washout 1



Appendix AA (cont'd): Evening Shift Scatterplots for NPI-NH Occupational Disruptiveness Mean Score Differences Across all Phases

Table 3: Evening Shift NPI-NH-OD Mean Score Differences Between Baseline and Intervention 2

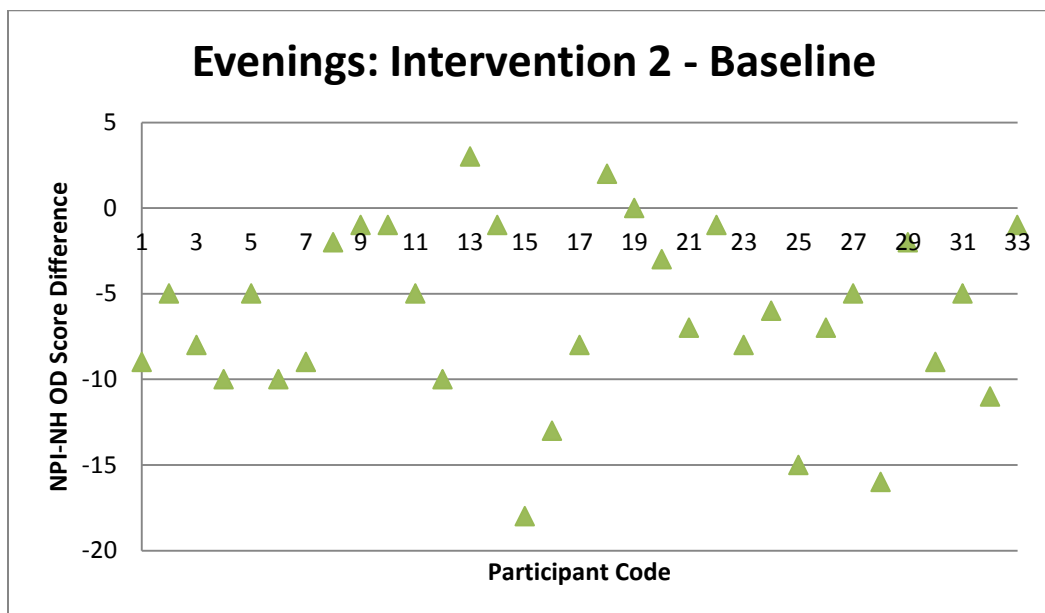
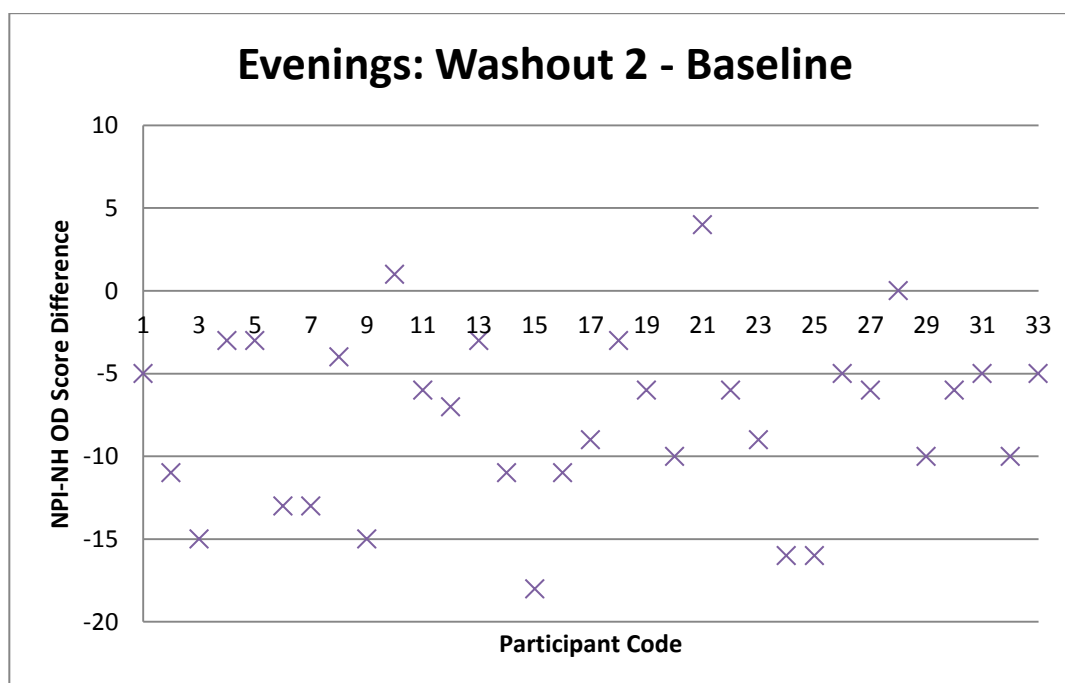


Table 4: Evening Shift NPI-NH-OD Mean Score Differences Between Baseline and Washout 2



APPENDIX AA: NIGHT SHIFT SCATTERPLOTS FOR NPI-NH OCCUPATIONAL DISRUPTIVENESS MEAN DIFFERENCE SCORES ACROSS ALL PHASES

Table 1: Night Shift NPI-NH-OD Mean Score Differences Between Baseline and Intervention 1

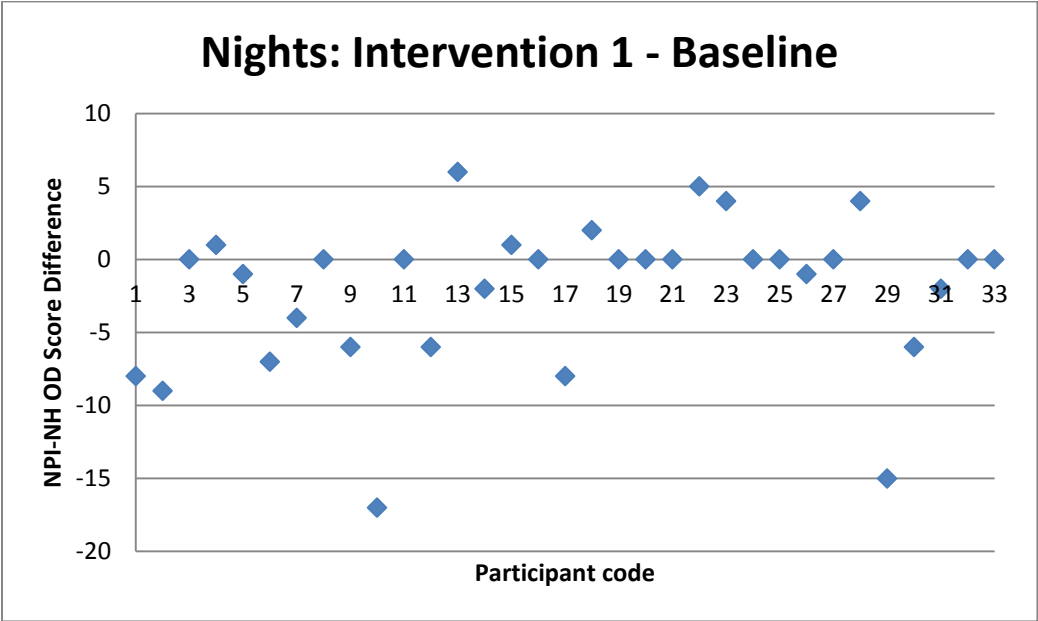
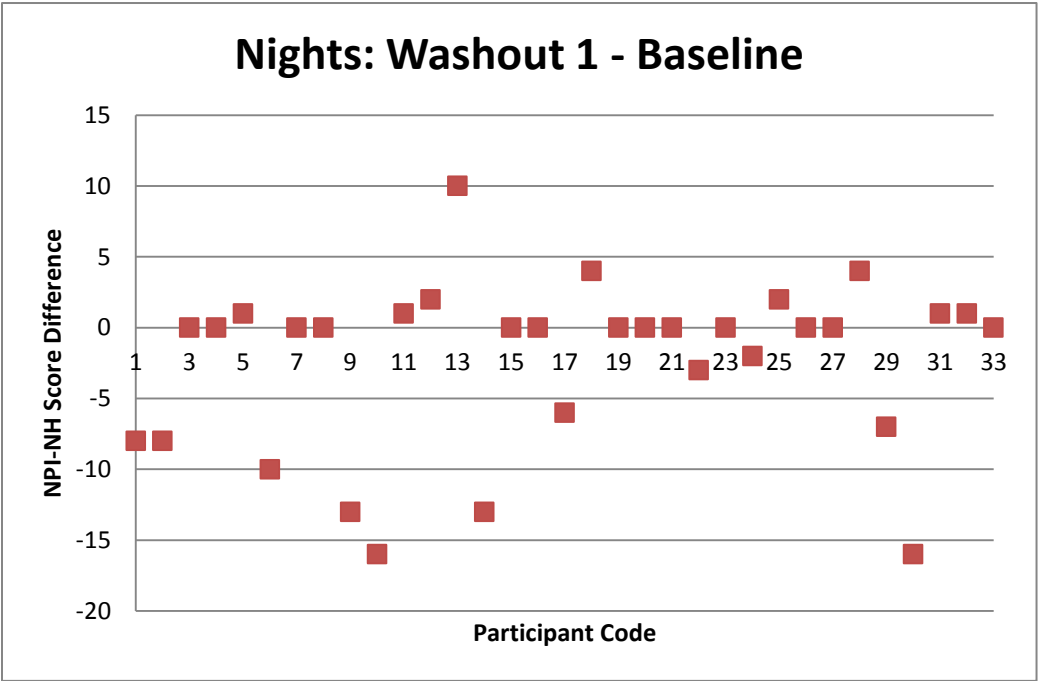


Table 2: Night Shift NPI-NH-OD Mean Score Differences Between Baseline and Washout 1



Appendix BB (cont'd): Night Shift Scatterplots for NPI-NH Occupational Disruptiveness Mean Score Differences Across all Phases

Table 3: Night Shift NPI-NH-OD Mean Score Differences Between Baseline and Intervention 2

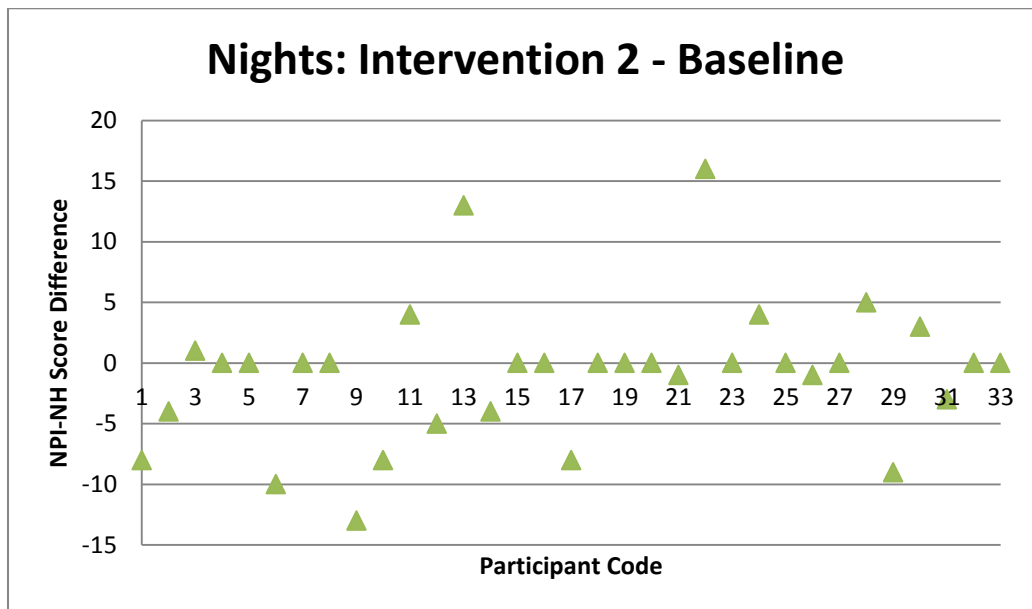
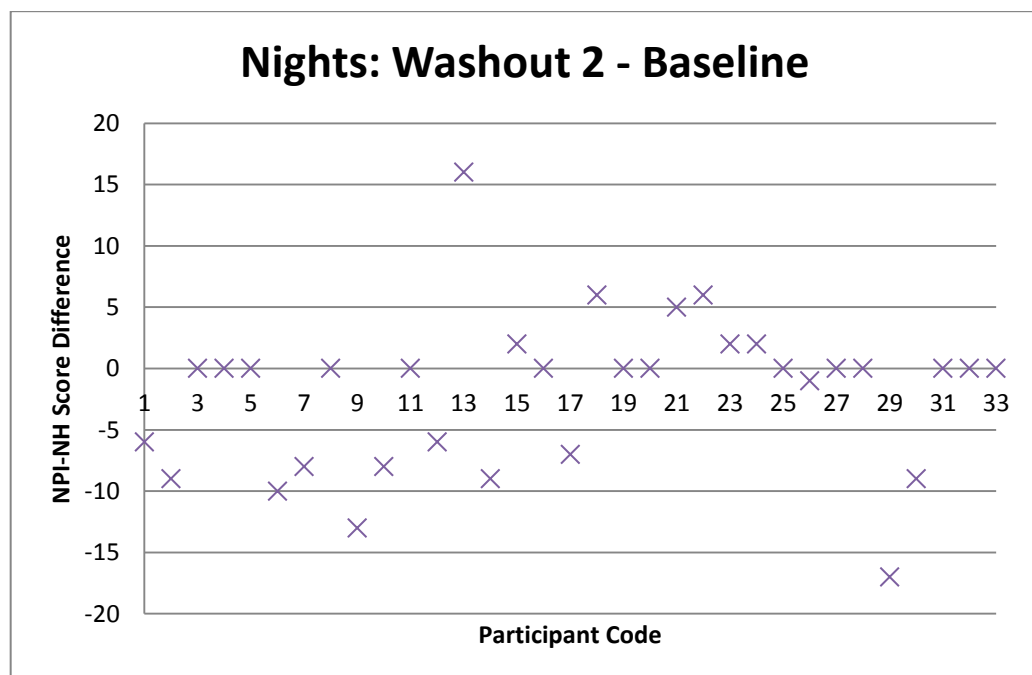


Table 4: Night Shift NPI-NH-OD Mean Score Differences Between Baseline and Washout 2



APPENDIX BB: SCATTERPLOTS FOR CORNELL SCALE FOR DEPRESSION IN DEMENTIA (CSDD) MEAN SCORE DIFFERENCES ACROSS ALL PHASES

Table 1: CSDD Mean Score Difference Between Baseline and Intervention 1

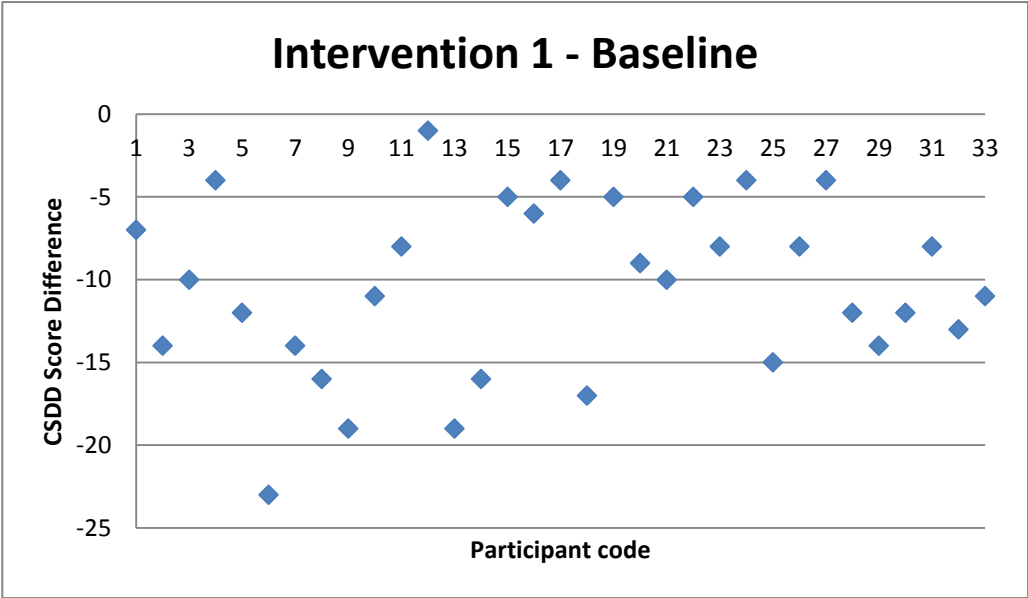
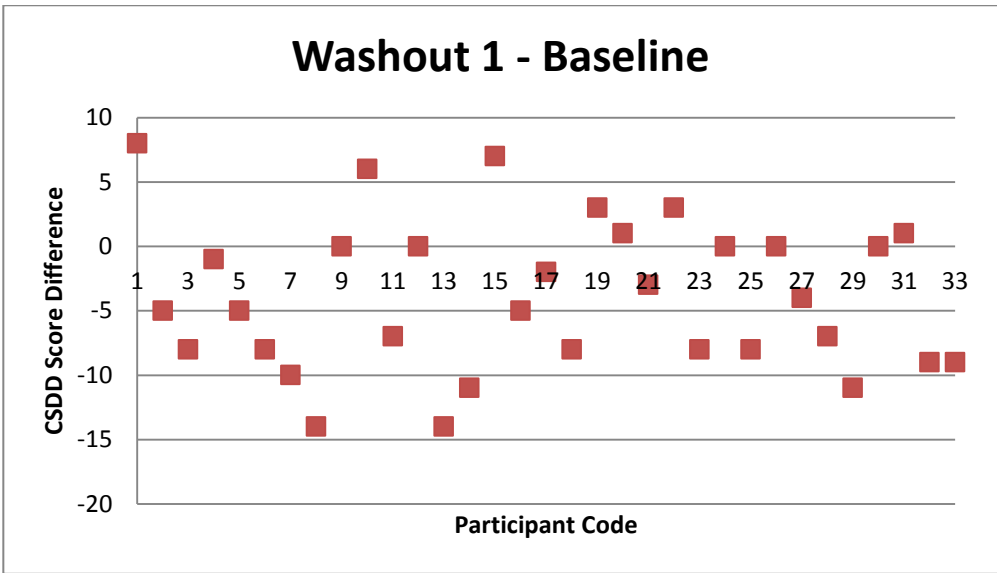


Table 2: CSDD Mean Score Difference Between Baseline and Washout 1



Appendix CC (cont'd): Scatterplots for CSDD Mean Score Differences Across All Phases

Table 3: CSDD Mean Score Difference Between Baseline and Intervention 2

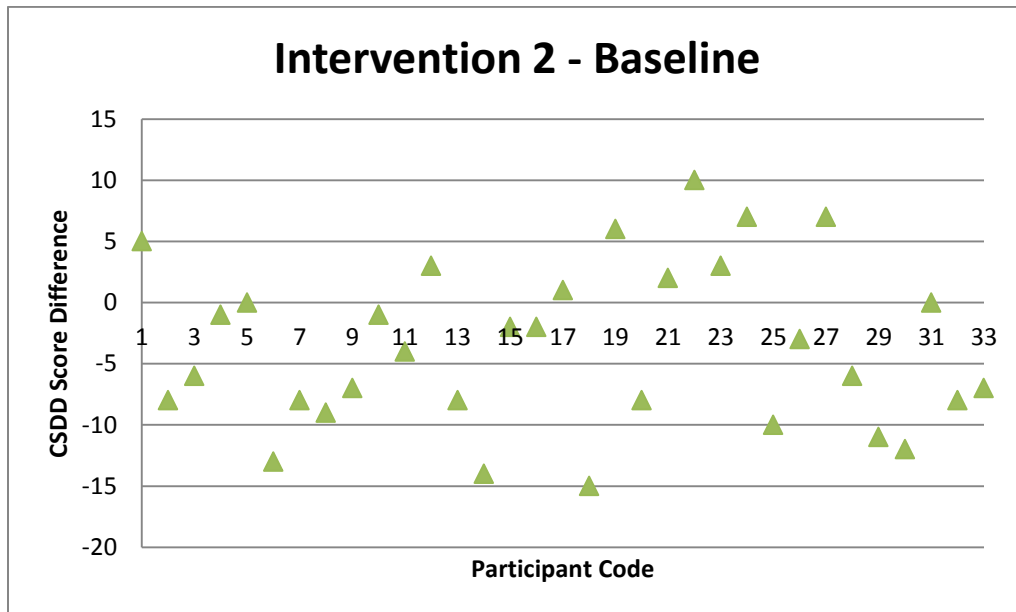
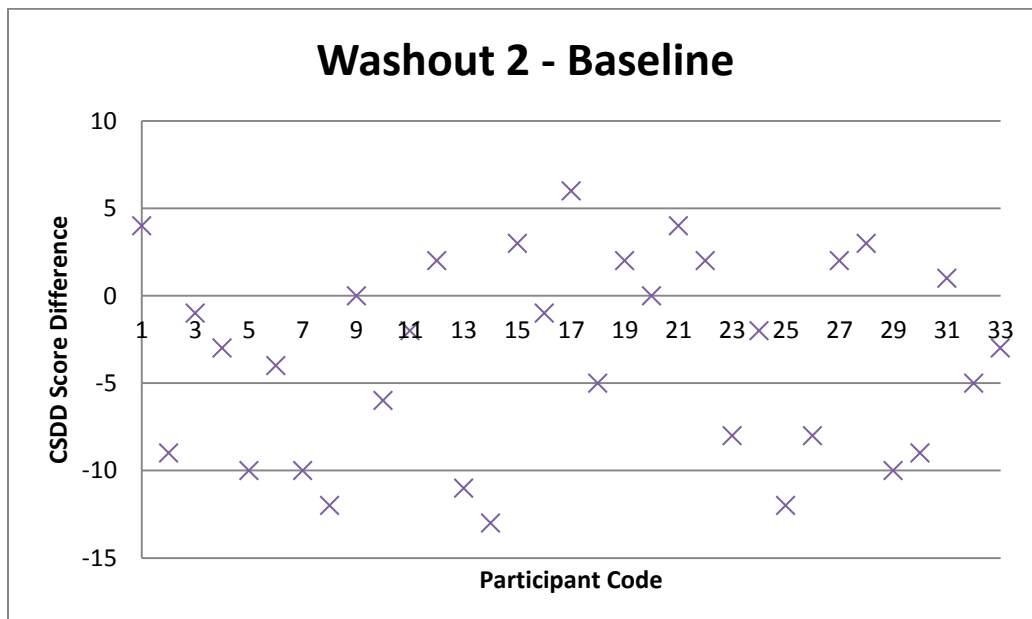


Table 4: CSDD Mean Score Difference Between Baseline and Washout 2



APPENDIX CC: SCATTERPLOTS FOR RYDEN AGGRESSION SCALE 2 (MODIFIED) (RAS2) MEAN SCORE DIFFERENCES ACROSS ALL PHASES

Table 1: RAS2 Mean Score Difference Between Baseline and Intervention 1

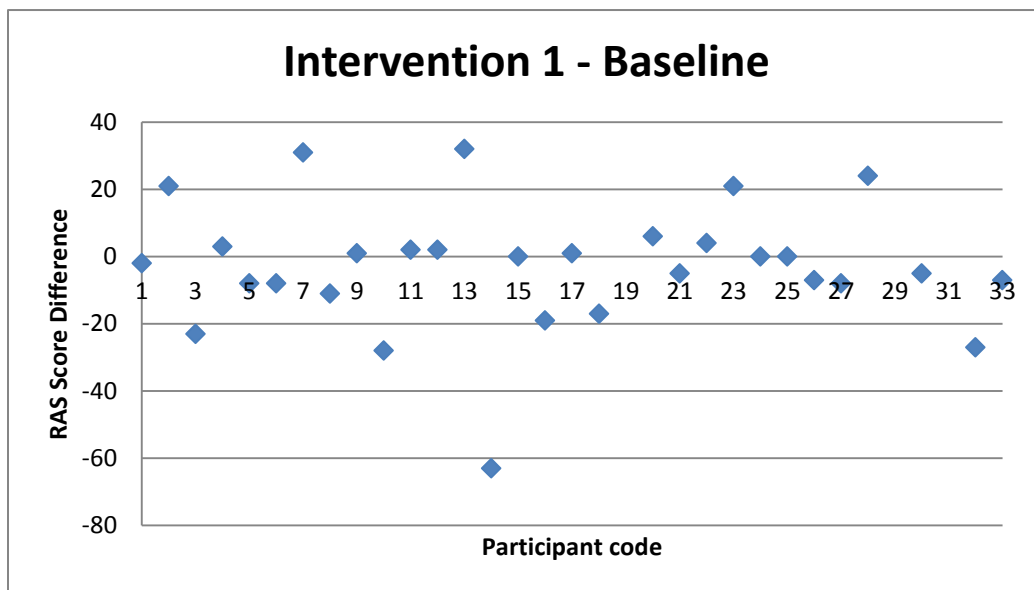


Table 2: RAS2 Mean Score Difference Between Baseline and Washout 1

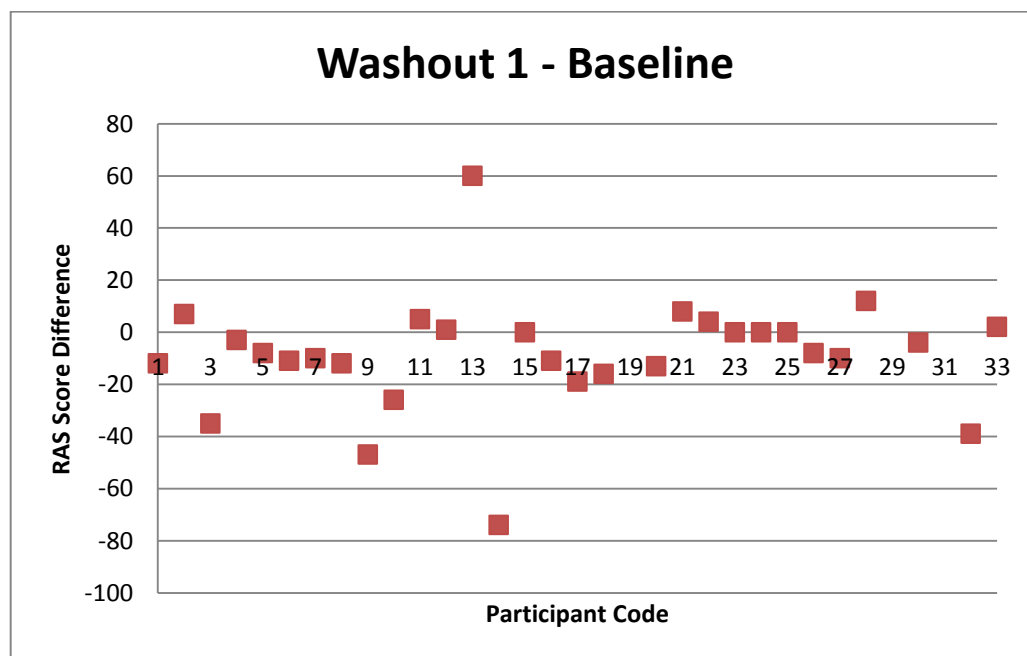


Table 3: RAS2 Mean Score Difference Between Baseline and Intervention 2

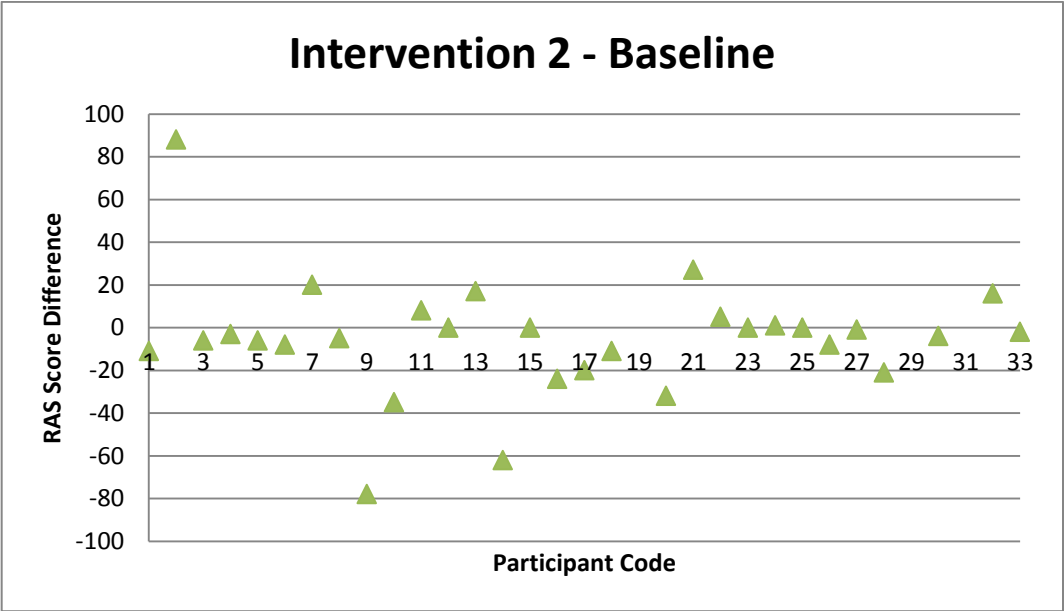
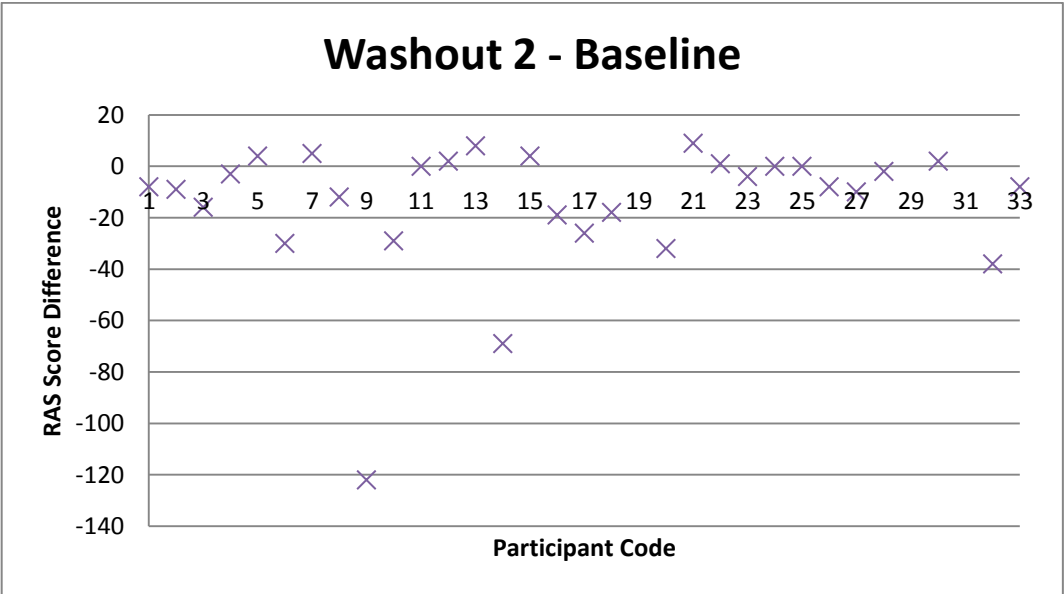


Table 4: RAS2 Mean Score Difference Between Baseline and Washout 2



APPENDIX DD: CASE STUDY 1

Participant 1 was male, aged 74 with a diagnosis of Alzheimer disease complicated by sport injuries (concussion) who had previously worked in the service sector. Participant 1 received no PRN medications during baseline (phase 1) and the first intervention (phase 2) of the study.

During the first phase of intervention (phase 2) he made 4 visits to the site. During phase 3 (washout 1) he twice had PRN olanzepine 2.5 mg (atypical antipsychotic) prior to care for aggression. During the second intervention phase (phase 4) the participant received 1 dose of trazodone (for agitation) and 2 doses of olanzepine (for aggression). The bracketed descriptions are directly from the nurses' notes as rationale for administration. During this second intervention phase, participant 1 visited the vignette 18 times, a fourfold increase in activity from intervention 1. Following removal of the vignette in the second washout phase (phase 5), participant 1 began to receive PRN olanzepine daily starting on day 2 of the vignette removal for 3 consecutive days, missed 1 day then again was given olanzepine for two consecutive days. Reasons for administration were noted as 'agitation' and prior to care, 'aggression'. No further prn medications were given to the end of the study.

Participant 1 had two medication changes during the study. Both changes however, occurred later in the study and were to increase the dose of the antidepressant Trazodone. The medication increases occurred on April 15, the 25th day of intervention with only 4 days left in the second phase of intervention and April 19, the first day of the second washout phase. There were no notable changes in the number of vignette visits as a result of the medication change. These medication changes appear to be unrelated to the apparent increase in aggressive behaviour over the course of the study unless they are responding to a potential side effect of Olanzepine, which is increased depression.

Examination of the neuropsychiatric data for participant 1 found that at baseline neuropsychiatric behaviour was being expressed at a moderate level on day shift with an NPI-NH score of 51, 68 on evening shift and 30 on night shift. The maximum score is 144. The NPI-NH-OD scores for day, evening and nightshifts were 8, 23 and 8 respectively. When the vignette intervention phase is in place, the NPI scores for days, evenings and nights reduced to 27, 50 and 0 respectively. These score changes should be the result of a noticeable change in behaviour. The AI dayshift score decreased from 12 to 9, the RAS2 from 25 to 23 and the CSDD score from 7 to 5. The AI evening shift score increased from 11 to 12. None significant enough to produce noticeable behaviour change.

When the vignette is removed and the first washout phase begins, the NPI-NH days score increases to 41, but did not return to the high of 51 at baseline (see table below for details). The NPI-NH-OD scores remain similar during baseline, intervention 1 and washout 1 at 8,8, and 7 respectively. At washout 1 the Cornell score increases from 5 (intervention1) to 15, but the RAS2 drops to 13 from 23 during intervention. The decrease in RAS2 is contradictory to the change in NPI-NH score, which is puzzling, as the RAS2 should be reflected in the NPI-NH. When the vignette is once again returned, the NPI days score increases to 60 with the NPI-NH-OD increasing to its highest level yet at 15. On evening shift, the NPI-NH increases minimally from 36 to 38, but the NPI-NH-OD more than doubles from 6 to 14. Night shift rates both the NPI-NH and the NPI-NH-OD at 0. The AI days increases from 5 to 10, but the AI evening shift score remains at 12. The RAS2 increases by one to 14 and the CSDD decreases from 15 to 12. When the vignette is removed for the second time for washout 2, the NPI-NH days score reduces to 52, and is back to baseline. The NPI-NH-OD days is 12 (4 more than baseline) the NPI-NH eves is 48 (20 less than baseline) and the NPI-NH-OD eves is 18 (5 less than baseline). Night

shift NPI-NH is 5 and Nights NPI-NH-OD is 2. The AI days and eves remain similar to the intervention phase at 10 and 11, but the RAS2 increases to 17 from 14 at intervention 2. The CSDD decreases to 11 from 12 at intervention 2. Table 1K presents a compilation of all test data with PRN medications administered across the phases.

Figure 1: Participant 1 NPI-NH, NPI-NH-OD and PRN Medications

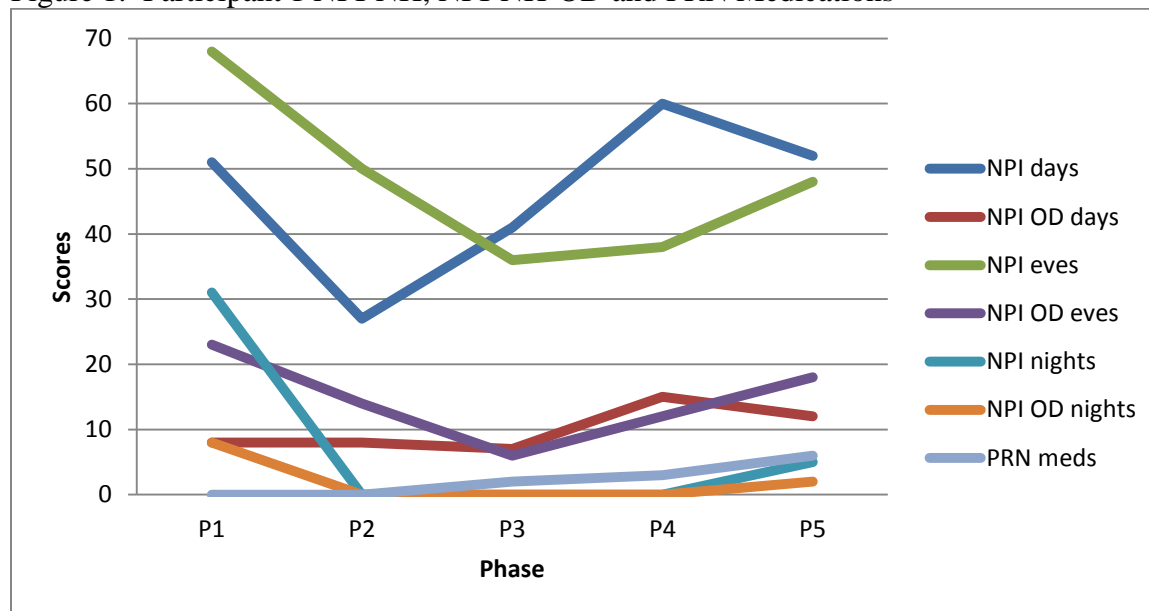


Figure 2: Participant 1 CSDD, AI and PRN Medications

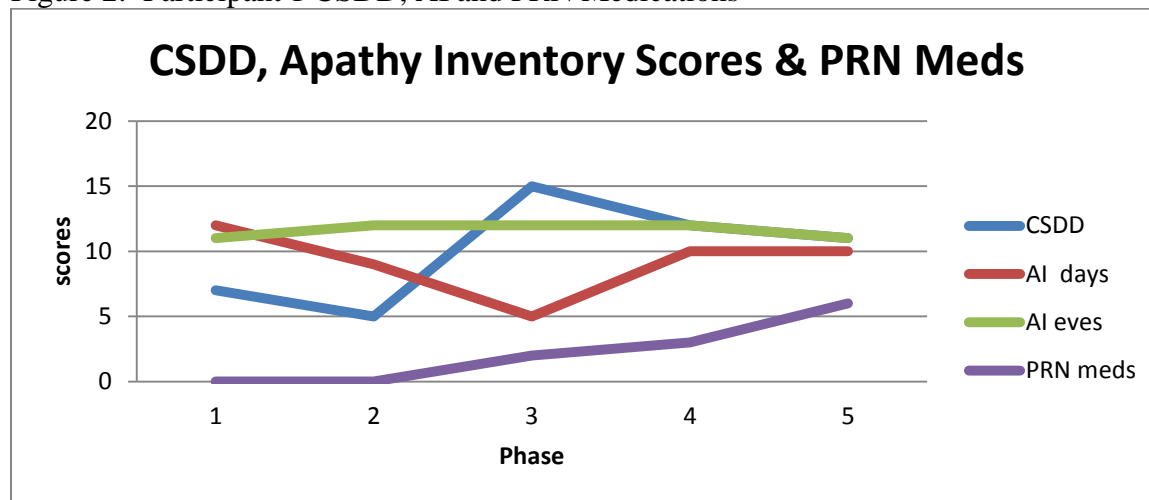


Figure 1 presents data that seems to identify the reinstatement of the vignette in phase 4 as a trigger to increased neuropsychiatric behavior as measured by the NPI-NH. Behaviours however, did not reach the higher level recorded at baseline. In phase 4, the change in behavior also triggered the giving of atypical antipsychotics (Olanzapine) and an increase in the amount of antidepressant and anti-anxiety agent (Trazadone) given. The increase in neuropsychiatric behaviour in phase 4 and the reasoning behind the giving of Olanzapine would be expected to be reflected in the RAS2 scores, but the RAS2 score increased by only a single event.

Figure 2 presents data from the CSDD and AI. The AI day shift score doubled from phase 3 (AI score 5) to phase 4 (AI score 10) indicating an increase in apathy, which contradicts the video data that identified the number of visits to the vignette increased from 5 to 18 in phase 4. These observations are not consistent with what is known about apathetic behaviour and the concept of 'lack of interest' or 'initiative'. The AI includes variables that are dependent on verbal skill and with moderate to severe dementia, and a loss of language ability, the IA may not be an appropriate tool to determine the degree of apathy that exists. These individuals may always be determined to be apathetic, but the video data showing an increase in the number of visits would perhaps indicate that the vignette was offering the individual an opportunity to engage in self-determined activity which did not require verbal skill, but which afforded an opportunity to 'do something' other than wheel around and around the unit in a wheelchair. This triggers a question around the use of the AI score to determine apathy in individuals with diminished verbal skill or the ability of care staff to assess apathy when reduced language capacity exists. Eighteen visits to the vignette suggest curiosity in one's environment, but whether the presence of curiosity negates the presence of apathy is not known. For this individual, vignette visits did not increase

until the vignette had been removed and then reinstated which would seem to suggest a need for familiarity/comfort with the vignette before exploration/engagement at the vignette could begin.

The participant's pattern of vignette interactions also constitutes an important part of understanding the participant's behaviour responses. The variable 'time spent at the vignette' was the indicator for dose exposure to the vignette and critical to understanding the effect of the vignette. During the first intervention only 4 visits were made recording a total time of 4404 seconds. One of the time frames was very long (4249 seconds) during which time only viewing and touching occurred. Time was also spent just sitting quietly at the vignette. During intervention 2, 18 visits were made with a total time of 3066 seconds being spent touching, holding and manipulating the stimuli. A higher level of engagement with the objects was observed during those 18 visits. It is important to note that at no time did someone else ever bring the participant. His presence at the vignette was always self-determined, he always left on his own and he was always in a wheelchair. The participant's first long visit could be an example of attention restoration and the power of biophilic environments to have an effect on certain individuals. The stress relieving effect of 'nature' or environments contrived to represent nature may have led to the decrease in NPI, NPI OD, AI day shift, RAS2 and Cornell scores. The increase in NPI scores during the second intervention may be the result of his needs moving from attention restoration to curiosity, action or participation and a return to the need for autonomy and self-determination which was interpreted by staff as being uncooperative, making their work harder and requiring medication to return to the previous docile state (307). Irving (307) suggests that when staff identify individuals as being unable to 'self govern' as in being out of control, unpredictable, irrational and disturbing, they require outside governance and that this governance contributes to the use of restraint. Staff beliefs about the attribution of cause to

the behaviour being expressed, the expectation for change in the behaviour and the emotions experienced by staff as a result of the behaviour may also play a role in staff responses to behaviour and the request for chemical or physical restraint (308).

For this single individual the pattern of behaviours measured by third-party neuropsychiatric tests did not always correspond with the number and type of PRN medications given. Nor did they always reflect observed video data. Both offer acknowledgement for the complexity inherent in human responses to behaviour, behaviour responses to interventions and the administration of PRN medication.

Table 1 K: Compilation of All Phase, All Test and PRN Medication Data for Participant 1

Phase of Study	PRN Meds	Intervention Day of Study	Number of visits to vignette	NPI days	NPIODday	NPI eves	NPIODeve	NPI night	NPIODnig	IA days	IA eves	RAS2	Cornell
Phase 1 Baseline	None		none	51	8	68	23	30	8	12	11	25	7
Phase 2 Intervention 1				27	8	50	14	0	0	9	12	23	5
	None	0-3	None										
	None	4	2										
	None	11	3										
Phase 3 Washout1	Olanzapine 2.5 mg (for aggression)	12		41	7	36	6	0	0	5	12	13	15
	Olanzapine 2.5 mg prior to care in am	13											
Phase 4 Intervention 2	None	16	2	60	15	38	14	0	0	10	12	14	12
	50 mg trazodone prn given Increase trazadone to 250 mg QAM	17	2										
	None	19	2										
	None	20	1										
	None	21	None										
	2.5 mg Olanzapine	22	None										
	None	24	1										
	2.5 mg olanzepine	25	1										

	None	26	5										
	None	27	1										
	None	28	3										
Phase 5 Washout 2	First day washout 2 increase AM trazodone to 300 mg			52	12	48	18	5	2	10	11	17	11

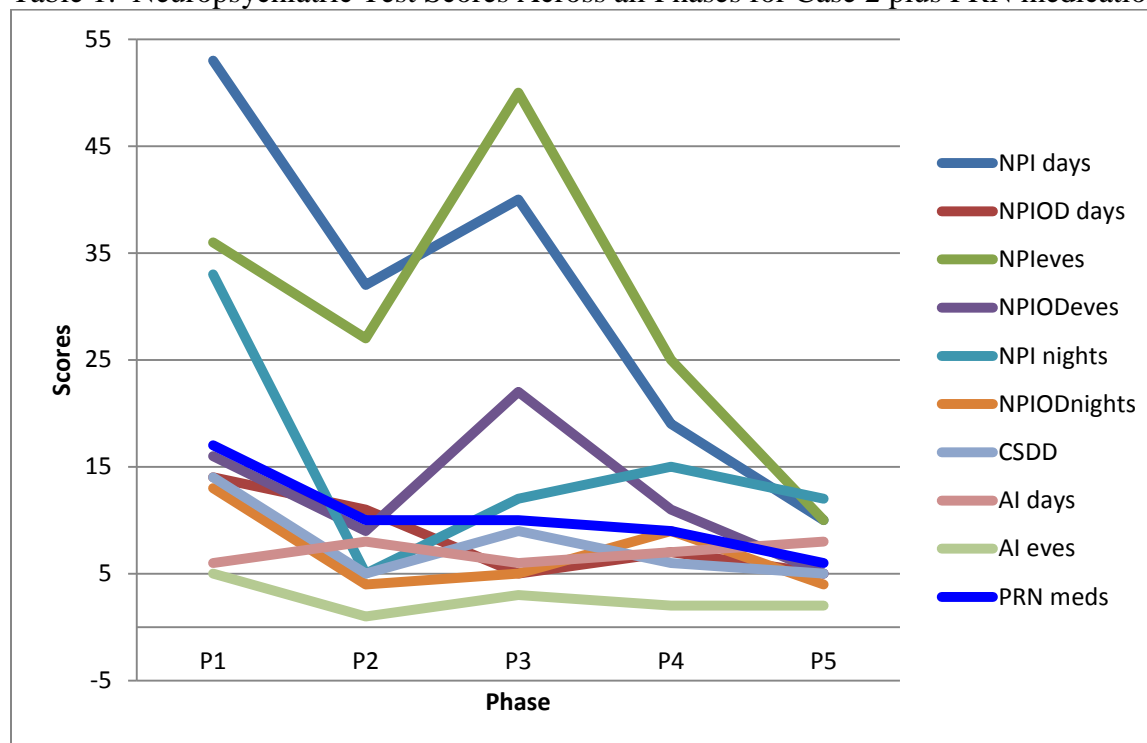
APPENDIX EE: CASE STUDY 2 DECELERATION IN PRN MEDICATION USE

Participant 2 (P-2) is the antithesis to case 1. Throughout the research process P-2 received ever-decreasing amounts of neuropsychiatric medications. P-2 is also opposite to case 1 in that P-2 was totally dependent upon staff to come to the vignette and interacted in a very limited way with the objects at the vignette. What the two cases do have in common is that they both spent more time at the vignette in phase 4 than in phase 2. P-2 spent a total time of 28,351 seconds at the vignette: 8554 seconds in phase 2 and 19807 seconds in phase 4, more than double that of phase 2.

P-2 had a diagnosis of Lewy Body dementia, an MMSE score of 8 and was wheelchair bound with significant dystonia, rigidity, and hallucinations. During the research phases P-2 received 16, 10, 10, 9 and 6 doses of PRN neuropsychotics across phases 1-5 respectively demonstrating a decreasing number of PRN medications given across the data collection period. He experienced no changes to his regularly scheduled medications. The following graph illustrates the changes in his neuropsychiatric test scores across all phases as correlated with his PRN medications. The graphic visuals demonstrate a pattern of decreasing PRN medications that seem to be unrelated to P-2's neuropsychiatric test scores. At baseline P-2 has the highest range of neuropsychiatric scores from 53 to 13 depending on the shift and has the highest number of PRN medications given (n=17). The neuropsychiatric test scores drop across all tests in intervention phase 2 along with the number of PRN medications given (n=10). During washout phase 3 where the vignette was removed, the neuropsychiatric test scores increased in all categories except the day shift apathy inventory. During phase 4 where the vignette was returned, neuropsychiatric test scores show a mixed response with some scores dropping significantly (NPI-NH days drops from 40 to 19), while others rise minimally (NPI-NH-OD days raises from 5 to 7). PRN medications drop to 9. In phase 5, the final washout phase all

neuropsychiatric scores drop from phase 4 except the apathy inventory on day shift, which rises from 7 to 8. PRN medications given are now only 6.

Table 1: Neuropsychiatric Test Scores Across all Phases for Case 2 plus PRN medication



When at the vignette P-2 was most likely positioned for ambience as his rigidity and dystonia created limited ability to physically manipulate many of the vignette objects. During phase 2 he was not observed to touch, hold or manipulate any objects. During phase 4 on one occasion he was offered and interacted with the following objects: the trowel, whiskbroom and brush, soil bin, pots and trays and a magazine. On a second visit he was offered magazines only. For all remaining visits he was positioned in his wheelchair by staff near the vignette to experience the ‘ambience’ of the vignette. In four of seven visits he slept at the vignette.

The interpretation of these results is challenging. It was expected that increasing neuropsychiatric behaviour scores would lead to increasing amounts of neuropsychiatric

medication administration. Participant 2 demonstrates the textbook expectation of behaviour response to the insertion and removal of the intervention until the final two phases where the responses in phase 4 are mixed and the responses in washout phase 5 continue a decreasing trend for both behaviour and PRN medication which are opposite to what would be predicted if the vignette was having an effect. A possible explanation for the behavioural response is that during phase 4 where the results are mixed but with major declines in NPI scores, it was the only time the resident actively engaged with objects at the vignette.

Tests	P1	P2	P3	P4	P5
NPI days	53	32	40	19	10
NPIOD days	14	11	5	7	5
NPI eves	36	27	50	25	10
NPIOD eves	16	9	22	11	5
NPI nights	33	5	12	15	12
NPIODnights	13	4	5	9	4
CSDD	14	5	9	6	5
AI days	6	8	6	7	8
AI eves	5	1	3	2	2
PRN meds	17	10	10	9	6

P-2's NPI scores dropped markedly across all shifts and it was only the NPIOD scores on days and nights and the Apathy inventory days score that showed increases from phase 3. One potential explanation is that the opportunity for stimulation in the form of gardening created an

increase in occupational distress scores by changing the level and degree of interaction that was offered thus the participant may have expected more engagement in care aspects.

In phase 3 when a change of 23 points in the NPI-NH score, and 13 points in the NPI-NH-OD score did not elicit an increase in PRN medication, the complexity of PRN medication is highlighted. This individual showed an important change in behaviour, but medication was not used. The diminishing scores on most neuropsychiatric tests in phases 4 and 5 in the absence of regularly scheduled medication changes or PRN medication administration offers the optimist an opportunity to suggest that time spent at the vignette affected this individual in a very positive way. However, the complexity inherent in measuring neuropsychiatric behaviour, administering medication in response to that behaviour and the potential for a progressive disease effect on behaviour all provide multiple alternative explanations. Further exploration of the concepts will take place in the discussion chapter.

APPENDIX FF: T-TEST ANALYSES OF PHASE 2 TIME- GROUPED (≤ 1000 SECONDS AND >1000 SECONDS) AND DEPENDENT NPI-NH AND NPI-NH-OD VARIABLES DATA

Outcome Measures	Mean NPI Score	SD	<i>t</i> value	<i>p</i> *	95% CI Mean NPI Score	
					Lower Limit	Upper Limit
NPI_nights P1						
≤ 1000 (n=14)	3.21	3.355	-2.985	.009*	-21.7	-3.7
>1000 (n= 16)	15.94	16.667		(<i>df</i> =16)		
NPI_OD_nightsP1						
≤ 1000 (n=14)	1.07	1.492	-3.651	.002*	-9.6	-2.6
>1000 (n=16)	7.13	6.438		(<i>df</i> =17)		
NPI_daysP3						
≤ 1000 (n=14)	16.50	9.547	-2.091	.05*	-28.3	-.294
>1000 (n=16)	30.81	23.945		(<i>df</i> =28)		

Note. *two-tailed $p = .05$ values; NPI =Neuropsychiatric Inventory; OD = Occupational Distress Score; AI = Apathy Inventory; Nights = night shift; Eves = evening shift; Days = day shift

APPENDIX GG: T-TESTS ANALYSES OF PHASE 2 TIME-GROUPED (≤ 1000 SEC AND >1000 SEC) AND MODIFIED OBSERVATION OF ENGAGEMENT TOOL (MOET) DEPENDENT VARIABLES DATA

Video Outcome Measure	Mean Event Score	SD	<i>t value</i>	<i>p</i>	95% CI Mean Event Score	
					Lower Limit	Upper Limit
Dpt_other2 ≤ 1000 (n=14) >1000 (n=16)	.1012 .2135	.10928 .17994	-2.029	.05* (<i>df</i> = 28)	-.23	.001
Atten_no2 ≤ 1000 (n=14) >1000 (n=16)	.0179 .0833	.04824 .10971	-2.160	.04* (<i>df</i> =21)	-.13	-.001
Atten_int2 ≤ 1000 (n=14) >1000 (n=16)	.0119 .1563	.03026 .17710	-3.207	.005* (<i>df</i> =16)	-.24	-.05
Amb_sleep2 ≤ 1000 (n=14) >1000 (n=16)	.0000 .0469	.00000 .08033	-.2334	.03* (<i>df</i> =15)	-.09	-.004
Obj_t_f2 ≤ 1000 (n=14) >1000 (n=16)	.0060 .0417	.02227 .06086	-2.186	.04* (<i>df</i> =19)	-.07	-.002
Obj_sp2 ≤ 1000 (n=14) >1000 (n=16)	.0000 .0781	.00000 .13767	-2.270	.04* (<i>df</i> =15)	-.15	-.005
Obj_mag2 ≤ 1000 (n=14) >1000 (n=16)	.0000 .0365	.00000 .06783	-2.150	.05* (<i>df</i> =15)	-.07	-.0003

Note. Mean Event Score is the mean number of times a participant was seen at the vignette participating in the outcome measure; Dpt_other2 =Departs with other; Atten_no2 = Does not attend to stimulus; Atten_int2 = attention interrupted; Amb_sleep2 = sleeping at vignette; Obj_t_f2 = object -trowel/fork; Obj_sp2 = Object – seed packets; Obj_mag2 = Object magazines; MOET = modified observation of engagement tool; *two-tailed *p* values, *p* =.05

APPENDIX HH: T-TEST ANALYSES OF PHASE 4 TIME- GROUPED (≤1000 SECONDS AND >1000 SECONDS) AND DEPENDENT NEUROPSYCHIATRIC TEST VARIABLES DATA

Outcome Measure	Mean Score test score	SD	<i>t value</i>	<i>p</i> *	95% CI Mean test Score	
					lower	upper
CSDD_P3 ≤1000 (n=10) >1000 (n=16)	3.80 7.69	3.048 5.499	-2.054	.05* (<i>df</i> =24)	-7.8	.02
NPI_nights P1 ≤1000 (n=10) >1000 (n=16)	4.50 16.19	4.428 16.441	-2.692	.02* (<i>df</i> =18)	-20.8	-2.6
NPIOD_nightsP1 ≤1000 (n=10) >1000 (n=16)	1.70 7.19	2.263 6.369	-3.143	.005* (<i>df</i> =20)	-9.1	-1.9
NPI_days P3 ≤1000 (n=10) >1000 (n=16)	17.30 31.69	9.044 23.497	-2.202	.04* (<i>df</i> =20)	-28	-,80

Note. *two-tailed *p values*, *p* =.05; CSDD = Cornell Scale for Depression in Dementia; NPI =Neuropsychiatric Inventory; OD = Occupational Distress Score; Nights = night shift; Days = day shift

APPENDIX II: T-TESTS ANALYSES OF PHASE 4 TIME-GROUPED DATA (≤ 1000 SEC AND >1000 SEC) AND MODIFIED OBSERVATION OF ENGAGEMENT TOOL (MOET) DEPENDENT VARIABLES

MOET Video Outcome Measure	Mean Event Score	SD	<i>t value</i>	<i>p</i> *	95% CI Mean Event Score	
					Lower Limit	Upper Limit
Dpt_other2 ≤ 1000 (n=9) >1000 (n=16)	.0926 .2292	.07733 .17873	-2.165	.04* (df=23)	-.27	-.006
Wchair2 ≤ 1000 (n=9) >1000 (n=16)	.0429 .6563	.07678 .68025	-2.194	.04* (df=23)	-.44	-.01
Amb_sleep2 ≤ 1000 (n=9) >1000 (n=16)	.0000 .0469	.00000 .08033	-2.334	.03* (df=15)	-.10	-.004
Ojb_wc2 ≤ 1000 (n=9) >1000 (n=16)	.0000 .0677	.00000 .11871	-2.283	.04* (df=15)	-.13	-.004
Arr_other_other_L4 ≤ 1000 (n=9) >1000 (n=16)	.0143 .2277	.03012 .20407	-4.112	.001* (df =24)	-.32	-.10
Dpt_other 4 ≤ 1000 (n=9) >1000 (n=16)	.0714 .2946	.04762 .22719	-3.799	.001* (df=17)	-.35	-.10
Engage_ms4 ≤ 1000 (n=9) >1000 (n=16)	.0571 .2679	.13384 .24398	-2.838	.009* (df=15)	-.36	-.06
Atten_no4 ≤ 1000 (n=9) >1000 (n=16)	.0143 .1786	.03012 .17690	-3.632	.002* (df=16)	-.26	-.07
Atten_int4 ≤ 1000 (n=9) >1000 (n=16)	.0214 .2500	.04821 .22887	-3.860	.001* (df=17)	-.35	-.10
Amb_sq4 ≤ 1000 (n=9) >1000 (n=16)	.0286 .5045	.03689 .31458	-5.986	.001* (df=16)	-.65	-.31
Amb_sleep4 ≤ 1000 (n=9) >1000 (n=16)	.0000 .0179	.0000 .03194	-2.236	.04* (df=-15)	-.04	-.001
Obj_LPH4						

≤1000 (n=9)	.0857	.08109	-2.120	.05*	-.30	-.002
>1000 (n=16)	.2366	.26563		(df=19)		
Obj_pots_trays4						
≤1000 (n=9)	.0286	.04994	-2.190	.05*	-.26	-.001
>1000 (n=16)	.1607	.24258		(df=17)		
Obj_bagwo4						
≤1000 (n=9)	.0000	.00000	-1.936	.07	-.08	-.004
>1000 (n=16)	.0357	.07377		(df=15)		

Note. Mean Event Score is the mean number of times a participant was seen at the vignette participating in the outcome measure; 2 = phase 2; 4 = phase 4; Dpt_other2 = Departs with other; Wchair2 = in wheelchair; Amb_sleep2 = ambience-sleeping; Obj_wc2 = Object-watering can; Arr_other_other_L4 = Arrives with other; other leaves; Dpt _ other 4 = Departs with other; Engage_ms4 = engages by manipulating stimulus; Atten_no4 = No attention to vignette; Atten_int4 = Attention interrupted; Amb_sq4 = Ambience-sitting quietly; Amb_sleep4 = Ambience-sleeping; Obj_LPH4 = Living plants & herbs; Obj_pots_trays4 = pots and trays; Obj_bagwo4 = orange bag with seeds; MOET = modified observation of engagement tool; *two-tailed p values, $p = .05$

APPENDIX JJ: MEAN DIFFERENCES BETWEEN SQDT SCORES IN ALL PHASES AND ACROSS ALL DEPENDENT VIDEO VARIABLES

MOET Outcome measure	Mean Event Score	Sd	t-value	p*	95% CI Mean Event Score	
					Lower Limit	Upper Limit
Engage_hs4 Yes (n=6) No (n=11)	.42 .12	.29 .17	.23	.02* (df=7)	.06	.53
Engage_ms4 Yes (n=6) No (n=11)	.32 .08	.21 .12	2.65	.007* (df=7)	.07	.40
Amb_sq4 Yes (n=6) No (n=11)	.55 .2	.41 .28	1.89	.05* (df=8)	-.001	.71
Obj_t_f4 Yes (n=6) No (n=11)	.14 .02	.09 .03	3.23	.02* (df=6)	.03	.22
Obj_wbb4 Yes (n=6) No (n=11)	.13 .01	.12 .03	2.31	.07 (df=5)	-.01	.25
Obj_soilbins4 Yes (n=6) No (n=11)	.11 .03	.06 .05	2.78	.01* (df=15)	.02	.13
Obj_pots_trays4 Yes (n=6) No (n=11)	.13 .05	.1 .09	1.89	.08 (df=15)	-.01	.18

Note. Mean Event Score is the mean number of times a participant was seen at the vignette participating in the outcome measure; Engage_hs4 = Engages- holding stimulus; Engage_ms4 = Engages-manipulates stimulus; Amb_sq4 = Ambience-sitting quietly; Obj_t_f4 = Garden trowel & fork; Obj_wbb4 = Whisk broom & dust pan; Obj_soilbins4 = Soil bins; Obj_pots_trays4 = Pots & trays; a 2 or 4 in the descriptor refers to phase 2 or 4; MOET = modified observation of engagement tool; *two-tailed *p* values, *p* = .05

APPENDIX KK: PEARSON CORRELATIONS BETWEEN VIDEO VARIABLES AND NPI-NH AND NPI-NH-OD SCORES ACROSS ALL SHIFTS AND PHASES 1 TO 3

Table 1

Pearson Correlations Between the Baseline NPI-NH and NPI-NH-OD Mean Scores and Phase 2 Video Variables

Neuropsychiatric variable	Video variables (MOET)	<i>r</i>	<i>p</i>	<i>n</i>
NPI_daysP1	Atten_3s (attention 3 senses)	.31	.001*	30
NPI_ODdaysP1	Atten_3s (attention 3 senses)	.34	.07	30
NPI_nightsP1 (Neuropsychiatric Inventory – night shift phase 1)	time (total time spent in seconds)	.51	.004*	30
	engage_ms (manipulates stimulus at vignette)	.35	.06	30
	atten_int (attention is interrupted)	.60	.001*	30
	amb_sleep(sleeping at the vignette)	.37	.04*	30
	obj_sp (seed packets)	.43	.02*	30
	obj_soilbins (soil bins-green or blue)	.49	.01*	30
	obj_pots_trays (plant pots or trays)	.40	.03*	30
	obj_bagwo (white and orange bag)	.54	.002*	30
	obj_metalkit (tin metal planting kit/pot)	.63	.001*	30
	obj_mag (magazines)	.48	.007*	30
	obj_gardenc (gray garden centre)	.36	.05*	30
	obj_tulips (potted tulips)	.59	.001*	30

Note. NPI = neuropsychiatric inventory; Days = day shift; OD = occupational distress score; P1 = phase 1; MOET = modified observation of engagement tool; *two-tailed *p* values, *p* = .05

Table 2

Statistically Significant Pearson *r* Correlations Between Baseline NPI-NH-OD Mean Scores and Phase 2 (Intervention 1) Video Variables

Neuropsychiatric variable	Video variables (MOET)	<i>r</i>	<i>p</i>	<i>n</i>
NPI_OD_nightsP1 (Neuropsychiatric Inventory Occupational Distress Score – night shift. phase 1)	time (total time spent in seconds)	.39	.03*	30
	atten_no (is not attentive at vignette)	.56	.001*	30
	atten_int (attention is interrupted)	.47	.009*	30
	amb_sq (sitting quietly at the vignette)	.47	.009*	30
	Obj_soilbins (soil bins-green or blue)	.38	.04*	30
	Obj_bagwo (white and orange bag)	.40	.03*	30
	Obj_metalkit (tin metal planting kit/pot)	.49	.006*	30
	Obj_tulips (potted tulips)	.41	.02*	30

Note. NPI = neuropsychiatric inventory; Days = day shift; OD = occupational distress score; P1 = phase 1; P2= phase 2; MOET = modified observation of engagement tool; * statistical significance

Table 3.

Pearson Correlations Between the Phase 2 NPI-NH and NPI-NH-OD Mean Scores and the Phase 2 Video Variables

Neuropsychiatric variable	Video variables (MOET)	r	p	n
NPI_daysP2	Arr_other_other_L(arrives with other, other leaves them at vignette)	-0.27	.15	30
	Engage_ts (touches stimulus at vignette)	-0.26	.17	30
	atten_no (is not attentive at vignette)	.33	.08	30
	atten_3s (attentive 3 senses)	-0.34	.07	30
	obj_t_f (gardening trowel or fork)	-0.26	.17	30
	obj_soilbins (soil bins-green or blue)	-0.37	.04*	30
	Obj_pots_trays (plant pots or trays)	-0.42	.02*	30
	Obj_bagwo (white and orange bag)	-0.28	.15	30
	Obj_tulips (potted tulips)	-0.25	.18	30
NPI_evesP2	Engage_r (refuses to engage)	.34	.06	30
	atten_no (is not attentive at vignette)	.40	.03*	30
NPI_NightsP2	obj_metalkit (tin metal planting kit/pot)	.52	.001*	30
NPI_ODdaysP2	Arr_other_other_L(arrives with other, other leaves them at vignette)	-0.32	.08	30
	obj_soilbins (soil bins-green or blue)	-0.27	.15	30
	Obj_tulips (potted tulips)	-0.25	.18	30
NPI_ODevesP2	Arr_other_other_L(arrives with other, other leaves them at vignette)	-0.27	.15	30
	Engage_r (refuses to engage)	.35	.06	30
	Atten_no (is not attentive at vignette)	.34	.06	30
NPI_ODnightsP2	Atten_int (attention interrupted)	.26	.16	30
	Obj_metalkit (tin metal planting kit)	.58	.003*	30
	Obj_tulips (potted tulips)	.29	.12	30

Note. NPI = Neuropsychiatric Inventory; OD = Occupational distress score; Days = day shift; eves = evening shift; nights = night shift; P1 = phase 1; P2 = phase 2 MOET = modified observation of engagement tool; * statistical significance

Table 4.
Pearson Correlations Between the Phase 3 NPI-NH and NPI-NH-OD Mean Scores and Phase 2 Video Variables

Neuropsychiatric variable	Video variables (MOET)	r	p	n
NPI_ODdaysP3	Engage_v (engages visually)	-.26	.17	30
NPI_ODevesP3	Dpt_self (departs vignette by self)	-.31	.10	30
	Engage_r (refuses to engage)	.45	.01*	30
	Atten_no (is not attentive at vignette)	.38	.04*	30
	Amb_sleep	.25	.18	30
NPI_evesP3	Engage_v (engages visually)	.43	.02*	30
	Atten_no (is not attentive at vignette)	.34	.07	30
NPI_nightsP3	Atten_no (is not attentive at vignette)	.56	.001*	30
	Atten_3s (attentive 3 senses)	.25	.18	30
	Amb_sleep(sleeping at the vignette)	.29	.11	30
	Obj_trolley (white drawer storage trolley)	.53	.003*	30
NPI_OD_nightsP3	Atten_no (is not attentive at vignette)	.51	.004*	30
	Atten_3s (attentive 3 senses)	.29	.116	30
	Amb_sleep	.40	.03*	30
	Obj_trolley (white drawer storage trolley)	.55	.002*	30

Note. NPI = Neuropsychiatric Inventory; OD = Occupational Distress Score; Days = day shift; eves = evening shift; nights = night shift; P1 = phase 1; P2 = phase 2; P3= phase 3; MOET = modified observation of engagement tool; * statistically significant.

APPENDIX LL: PEARSON CORRELATIONS BETWEEN THE CSDD SCORES AND INTERVENTION 1 (PHASE 2) VIDEO VARIABLES ACROSS ALL PHASES

Neuro-psychiatric variable	Video variables (MOET)	<i>r</i>	<i>p</i>	n
CSDD_P1	Obj_wc (watering can)	.35	.06	30
CSDD_P3	Arr_self (arrived by self)	-.28	.14	30
	Dept_self (left by self)	-.29	.12	30
	Engage_v (visually engages at vignette)	-.29	.13	30
	Engage_bt (engages by touching)	-.27	.15	30
	Wheelchair	.29	.13	30
	Amb_purp (purposeful positioning at vignette)	-.27	.15	30

Note. CSDD = Cornell Scale for Depression in Dementia; P1 = phase 1; P3 = phase 3; MOET = modified observation of engagement tool; * statistical significance

APPENDIX MM: PEARSON CORRELATIONS BETWEEN THE AI SCORES AND INTERVENTION 1 (PHASE 2) VIDEO VARIABLES ACROSS ALL PHASES

Neuropsychiatric variable	Video variables (MOET)	<i>r</i>	<i>p</i>	n
AI_daysP1	Engage_r (refuses to engage)	-.40	.03*	30
AI_daysP3	Obj_t_f (gardening trowel or fork)	-.25	.19	30
	Obj_soilbins	-.25	.19	30
	Obj_pots_trays (plant pots or trays)	.27	.16	30
AI_evesP2	Engage_r (refuses to engage)	-.37	.04*	30
	Atten_1s (attention 1 sense)	-.28	.14	30
AI_evesP3	Engage_ms (manipulates stimulus)	-.25	.18	30
	Obj_LPH (living plants and herbs)	-.28	.14	30
	Obj_table (white table)	.35	.06	30

Note. AI = apathy inventory ; P1=phase 1; P2= phase 2; P3 = phase 3; Days = day shift; eves = evening shift; MOET = modified observation of engagement tool * statistically significant.

APPENDIX NN: PEARSON CORRELATIONS BETWEEN THE NPI-NH, NPI-NH-OD SCORES, AND INTERVENTION 2 VIDEO VARIABLES FOR PHASE 4

Neuropsychiatric variable	Video variables from Intervention 2 (phase 4) (MOET)	r	p	n
NPI_daysP4	Atten_no (not attentive at vignette)	.28	.17	26
	Amb_sq (sitting quietly at vignette)	.28	.16	26
	Amb_sleep (asleep at the vignette)	-.28	.17	26
NPI_ODdaysP4	Amb_sleep (asleep at the vignette)	-.27	.18	26
NPI_evesP4	Time (total time spent in seconds)	.44	.02*	26
	Wheelchair (resident in wheelchair)	.39	.05*	26
	Amb_sq (sitting quietly at vignette)	.38	.05*	26
	Obj_tulips (potted tulips)	-.27	.19	26
NPI_ODevesP4	Time (total time spent in seconds)	.53	.005*	26
	Wheelchair (resident in wheelchair)	.54	.005*	26
	Atten_no (not attentive at vignette)	.27	.19	26
	Amb_purp (purposeful positioning at vignette)	.26	.21	26
	Amb_sq (sitting quietly at vignette)	.57	.002*	26
	Obj_mag (magazines)	.39	.05*	26
	Obj_table (white table)	.29	.16	26
	Obj_tulips (potted tulips)	-.35	.09	26
	Obj_bagwo (orange bag with seeds)	.38	.06	26
NPI_nightsP4	Dpt_other (leaves vignette with other)	-.37	.06	26
	Amb_sleep (asleep at the vignette)	.27	.19	26
NPI_ODnightsP4	Dpt_other (leaves vignette with other)	-.32	.11	26
	Amb_sleep4 (asleep at the vignette)	.41	.04*	26

Note. NPI = Neuropsychiatric Inventory; OD = Occupational Distress Score; Days = day shift; eves = evening shift; nights = night shift; P1 = phase 1; P2 = phase 2; P3= phase 3; P4 = phase 4; MOET = modified observation of engagement tool;* statistically significant.

APPENDIX OO: PEARSON CORRELATIONS BETWEEN THE SQDT AND THE INTERVENTION 2 VIDEO VARIABLES FOR PHASE 4

Neuropsychiatric variable	Video variables (MOET)	<i>r</i>	<i>p</i>	n
SQDT_P4	Time (total time spent in seconds)	-.29	.27	17
	Arr_other_otherL (arrives at vignette with other, other leaves)	-.43	.08	17
	Arr_other (arrives at vignette with other)	-.30	.24	17
	Dpt_other (leaves vignette with other)	-.49	.05*	17
	Dpt_self (leaves vignette by self)	-.25	.33	17
	Engage_v (engages visually)	-.34	.19	17
	Engage_bt (body turns to stimulus)	-.35	.17	17
	Engage_ts (touches stimulus at vignette)	-.42	.09	17
	Engage_ms (manipulates stimulus at vignette)	-.62	.007*	17
	Engage_ims (inappropriately manipulated stimulus at vignette)	-.34	.18	17
	Wheelchair (in wheelchair)	-.28	.28	17
	Atten_no (not attentive at vignette)	-.35	.17	17
	Atten_2s (attentive 2 senses)	-.43	.09	17
	Atten_int (attention is interrupted)	-.36	.15	17
	Amb_purp (purposeful positioning at vignette)	-.37	.15	17
	Amb_sq (sitting quietly at vignette)	-.48	.05*	17
	Obj_t_f (garden trowel or fork)	-.73	.001*	17
	Obj_gg (garden gloves)	-.30	.24	17
	Obj_wbb (whisk broom and dustpan)	-.63	.007*	17
	Obj_sp (seed packets)	-.27	.30	17
	Obj_pots_tray (plant pots and trays)	-.44	.08	
	Obj_bagwo (white and orange bag)	-.30	.24	17
	Obj_metal kit (tin metal planting kit)	-.36	.16	17
	Obj_gardenc (grey garden centre)	-.37	.15	17
	Obj_tulips (potted tulips)	.30	.25	17

SQDT = Single Questions Depression Test; P4 = phase 4; MOET = modified observation of engagement tool;
 *statistically significant.

APPENDIX PP: PEARSON CORRELATIONS BETWEEN THE CSDD SCORES (PHASE 4) AND INTERVENTION 2 (PHASE 4) VIDEO VARIABLES

Neuropsychiatric variable	Video variables (MOET)	<i>r</i>	<i>p</i>	n
CSDD_P4	Arr_self (arrives by self)	-.28	.17	26
	Dpt_other (departs vignette with other)	.31	.12	26
	Dpt_self (departs vignette by self)	-.27	.19	26
	Arr_other (brought by another)	.34	.09	26
	Atten_1s (uses 1 sense only)	-.26	.20	26
	Amb_sleep (sleeping at the vignette)	-.40	.05*	26
	Obj_LPH (living plants and herbs)	-.34	.09	26
	Obj_trolley (white drawer storage trolley)	-.39	.05*	26
	Obj_gardenc (grey garden centre)	-.29	.15	26

CSDD = Cornell Scale for Depression in Dementia; P4 = phase 4; MOET = modified observation of engagement tool; *statistically significant.

**APPENDIX QQ: PEARSON CORRELATIONS BETWEEN AI SCORES (PHASE 4)
AND INTERVENTION 2 (PHASE 4) VIDEO VARIABLES**

Neuropsychiatric variable	Video variables	<i>r</i>	<i>p</i>	n
AI_daysP4	Atten_int (attention is interrupted)	-.37	.06	26
	Atten_no (does not attend to vignette)	.32	.12	26
	Obj_LPH (living plants and herbs)	-.32	.11	26
	Obj_mag (magazines)	-.29	.16	26
	Obj_table (white table)	-.31	.12	26
AI_evesP4	Arr_other_otherL (arrives with other, other leaves)	.31	.13	26
	Wheelchair	.38	.05*	26
	Amb_sq (sitting quietly at vignette)	.27	.18	26
	Obj_gardenc (grey garden centre)	-.30	.14	26
	Obj_tulips (potted tulips)	-.29	.15	26

AI = apathy inventory; days = day shift; eves = evening shift; P4 = phase 4; MOET = modified observation of engagement tool; *statistically significant.

APPENDIX RR: PEARSON CORRELATIONS BETWEEN THE DAY SHIFT NPI-NH, NPI-NH-OD SCORES AND INTERVENTION 2 (PHASE 4) VIDEO VARIABLES FOR PHASE 5

Neuropsychiatric variable	Video variables (MOET)	<i>r</i>	<i>p</i>	n
NPI_daysP5	Arr_other_otherL (arrives with other, other leaves)	.348	.08	26
	Arr_other (brought by other)	.45	.02*	26
	Dpt_other (leaves with other)	.49	.01*	26
	Engage_v (engages visually)	.39	.05*	26
	Engage_bt (turns body toward vignette)	.40	.05*	26
	Engage_ts (touches stimulus at vignette)	.35	.08	26
	Engage_hs (holds stimulus at vignette)	.50	.01*	26
	Engage_ms (manipulates stimulus at vignette)	.35	.08	26
	Wheelchair (in wheelchair)	.57	.002*	26
	Atten_1s (attention 1 sense)	.30	.14	26
	Atten_2s (attention 2 senses)	.36	.07	26
	Amb_purp (purposeful positioning at vignette)	.36	.07	26
	Amb_sq (sitting quietly at vignette)	.57	.002*	26
	Obj_LPH (living plants and herbs)	.26	.20	26
	Obj_t_f (garden trowel or fork)	.32	.11	26
	Obj_gg (garden gloves)	.36	.07	26
	Obj_wbb (whisk broom and dustpan)	.44	.03*	26
	Obj_wc (watering can)	.38	.06	26
	Obj_sp (seed packets)	.48	.01	26
	Obj_pots_trays (pots and trays)	.31	.12	26
	Obj_bagwo (white and orange bag)	.43	.03	26
	Obj_metalkit (tin metal planting kit)	.48	.01	26
	Obj_mag (magazines)	.36	.07	26

Neuropsychiatric variable	Video variables (MOET)	<i>r</i>	<i>p</i>	n
NPI_OD days P5	Arr_other_otherL (arrives with other, other leaves)	.34	.09	26
	Dpt_other (leaves with other)	.55	.003*	26
	Engage_v (engages visually)	.32	.11	26
	Engage_bt (turns body toward vignette)	.33	.10	26
	Engage_ts (touches stimulus at vignette)	.35	.08	26
	Engage_hs (holds stimulus at vignette)	.52	.007*	26
	Engage_ms (manipulates stimulus at vignette)	.38	.06	26
	Wheelchair (in wheelchair)	.47	.02*	26
	Atten_2s (attention 2 senses)	.35	.08	26
	Amb_purp (purposeful positioning at vignette)	.31	.13	26
	Amb_sq (sitting quietly at vignette)	.52	.007	26
	Obj_LPH (living plants and herbs)	.25	.20	26
	Obj_t_f (garden trowel or fork)	.32	.11	26
	Obj_gg (garden gloves)	.36	.07	26
	Obj_wbb (whisk broom and dustpan)	.53	.005*	26
	Obj_wc (watering can)	.40	.04*	26
	Obj_sp (seed packets)	.50	.01*	26
	Obj_pots_trays (pots and trays)	.31	.12	26
	Obj_bagwo (white and orange bag)	.36	.07	26
	Obj_metalkit (tin metal planting kit)	.60	.001*	26
	Obj_mag (magazines)	.32	.12	26

Note. NPI = Neuropsychiatric Inventory; OD = Occupational Distress Score; Days = day shift; eves = evening shift; nights = night shift; P1 = phase 1; P2 = phase 2; P3 = phase 3; P4 = phase 4; P5 = phase 5; MOET = modified observation of engagement tool; *Statistically significant; Only Pearson correlations (*r*) of .25 or greater (suggesting a minimum fair correlation) were included in the table data.

APPENDIX SS: PEARSON CORRELATIONS BETWEEN THE EVENING SHIFT NPI-NH, NPI-NH-OD SCORES AND INTERVENTION 2 (PHASE 4) VIDEO VARIABLES FOR PHASE 5

Neuropsychiatric variable	Video variables (MOET)	<i>r</i>	<i>p</i>	<i>n</i>
NPI_evesP5	Atten_1s (attention 1 sense_)	.36	.07	26
	Amb_sq (sitting quietly at the vignette)	.42	.03*	26
	Obj_sp (seed packets)	.25	.21	26
NPI_ODevesP5	Arr_self (arrives at vignette by self)	.28	.16	26
	Dpt_self (departs vignette by self)	.33	.10	26
	Engage_v (engages visually)	.40	.04*	26
	Engage_bt (turns body toward vignette)	.41	.04*	26
	Engage_ts (touches stimulus at vignette)	.27	.19	26
	Engage_hs (holds stimulus at vignette)	.35	.08	26
	Engage_ms (manipulates stimulus at vignette)	.28	.16	26
	Wheelchair (in wheelchair)	.38	.06	26
	Atten_1s (attention 1 sense)	.48	.01*	26
	Atten_2s (attention 2 senses)	.29	.15	26
	Atten_int (attention is interrupted)	.27	.18	26
	Amb_purp (purposeful positioning at vignette)	.35	.08	26
	Amb_sq (sitting quietly at vignette)	.50	.01*	26
	Obj_gg (garden gloves)	.29	.16	26
	Obj_wbb (whisk broom and dustpan)	.42	.03*	26
	Obj_wc (watering can)	.39	.05*	26
	Obj_sp (seed packets)	.41	.04*	26
	Obj_bagwo (white and orange bag)	.38	.06	26
	Obj_metalkit (tin metal planting kit)	.38	.05*	26
	Obj_mag (magazines)	.39	.05*	26

Note. NPI = Neuropsychiatric Inventory; OD = Occupational Distress Score; Days = day shift; eves = evening shift; nights = night shift; P1 = phase 1; P2 = phase 2; P3 = phase 3; P4 = phase 4; P5 = phase 5; MOET = modified observation of engagement tool; *Statistically significant; Only Pearson correlations (*r*) of .25 or greater (suggesting a minimum fair correlation) were included in the table data.

APPENDIX TT: PEARSON CORRELATIONS BETWEEN THE WASHOUT 2 (PHASE 5) NIGHT SHIFT NPI-NH, NPI-NH-OD MEAN SCORES AND PHASE 4 VIDEO VARIABLES

Neuropsychiatric variable	Correlated video variable (MOET)	<i>r</i>	<i>p</i>	n
NPI_nightsP5	Engage_v (engage visually)	.24	.25	26
	Wheelchair	.40	.04*	26
	Atten_1s (attention using 1 sense)	.44	.03*	26
	Atten_int (attention interrupted)	.30	.13	26
	Amb_sq (sitting quietly at vignette)	.30	.13	26
	Obj_cpp (compressed peat pellets)	.33	.10	26
NPI_ODnightsP5	Arr_other_other_L (arrives with other, other leaves)	.32	.12	26
	Engage_v (engages visually)	.30	.14	26
	Engage_bt (turns body toward vignette)	.28	.17	26
	Engage_hs (holds stimulus at vignette)	.25	.23	26
	Wheelchair	.53	.005*	26
	Atten_1s (attention 1 sense)	.46	.02*	26
	Atten_int (attention interrupted)	.41	.04*	26
	Amb_sq (sitting quietly)	.46	.02*	26
	Obj_LPH	.34	.09	26
	Obj_cpp (compressed peat pellets)	.37	.06	26
	Obj_mag (magazines)	.36	.07	26

Note. NPI = neuropsychiatric inventory; OD = occupational distress score; Nights = night shift; P5 = phase 5; MOET = modified observation of engagement tool; *statistically significant; only Pearson correlations (*r*) of .25 or greater (suggesting a minimum fair correlation) were included in the table data.

APPENDIX UU: PEARSON CORRELATIONS BETWEEN PHASE 5 DAY AND EVENING SHIFT AI SCORES AND PHASE 4 (INTERVENTION 2) VIDEO VARIABLES

Neuropsychiatric variable	Video variables (MOET)	<i>r</i>	<i>p</i>	n
AI_daysP5	Wheelchair	-.31	.18	26
	Atten_no (not attentive at vignette)	.33	.10	26
	Atten_1s (attention 1 sense)	-.25	.22	26
	Atten_int (attention interrupted)	-.25	.23	26
	Obj_LPH (living plants and herbs)	-.38	.06	26
AI_evesP5	Engage_ims (inappropriately manipulated stimulus at vignette)	-.37	.06	26
	Arr_other_otherL (arrive with other, other leaves)	.47	.02*	26
	Engage_ts (touches stimulus)	-.28	.17	26
	Engage_ms (manipulates the stimulus)	-.28	.17	26
	Wheelchair	.29	.15	26
	Atten_no (not attentive at the vignette)	.37	.07	26
	Obj_soilbins (green or blue soilbins)	.41	.04*	26
	Obj_gardenc (grey garden centre)	.48	.01*	26

Note: AI = Apathy Inventory; P5 = phase 5; days= dayshift; eves = evening shift; MOET = modified observation of engagement tool *statistically significant; only Pearson correlations (*r*) of .25 or greater (suggesting a minimum fair correlation) were included in the table data.

APPENDIX VV: PEARSON CORRELATIONS BETWEEN THE PHASE 5 CSDD SCORES AND PHASE 4 (INTERVENTION 2) VIDEO VARIABLES

Neuropsychiatric variable	Video variables (MOET)	<i>r</i>	<i>p</i>	n
CSDD_P5	Time (total time spent in seconds)	.32	.11	26
	Arr_other_otherL (arrives with other, other leaves)	.33	.11	26
	Dpt_other (leaves with other)	.48	.01*	26
	Atten_no (is not attentive at vignette)	.36	.07	26
	Amb_sleep (sleeping at vignette)	-.42	.03*	26
	Obj_trolley (white drawer storage trolley)	-.23	.25	26

Note. CSDD = Cornell Scale for Depression in Dementia; P5 = phase 5; MOET = modified observation of engagement tool *statistical significance; Only Pearson correlations (*r*) of .25 or greater (suggesting a minimum fair correlation) were included in the table data.

APPENDIX WW: PEARSON CORRELATIONS BETWEEN PHASE 2 SELF-DETERMINATION VIDEO VARIABLES AND ALL OTHER PHASE 2 VIDEO VARIABLES

Variable: Self-determination	Video variables (MOET)	<i>r</i>	<i>p</i>	n
Phase 2: Arrives by self	Dpt_self2 (departs by self)	.99	.001	30
	Wchair (in wheelchair)	.39	.03	30
	Engage_v2 (engages visually)	.94	.001	30
	Engage_bt2 (engage, turns body toward stimulus)	.93	.001	30
	Engage_ts2 (engages by touch)	.57	.001	30
	Engage_hs2 (engages by holding the stimulus)	.54	.002	30
	Engage_ms2 (manipulates stimulus)	.48	.007	30
	Atten_1s2 (attends with one sense)	.78	.001	30
	Atten_2s2 (attends with two senses)	.57	.001	30
	Atten_int2 (attention interrupted)	.49	.006	30
	Amb_purp2 (purposeful in arrival)	.94	.001	30
	Amb_sq2 (ambience sitting quietly)	.57	.001	30
	Obj_LPH2 (living plants and herbs)	.5	.005	30
	Objt_f2 (garden trowel and fork)	.39	.03	30
	Obj_gg2 (garden gloves)	.42	.02	30
	Obj_wc2 (watering can)	.47	.009	30
	Obj_wbb2 (whisk broom & dust pan)	.46	.01	30
	Obj_sp2 (seed packets)	.38	.04	30
	Obj_pots-trays2 (pots and trays)	.40	.03	30
	Obj_gardenc2(grey garden centre)	.5	.006	30
	Obj_tulips (potted tulips)	.37	.05	30

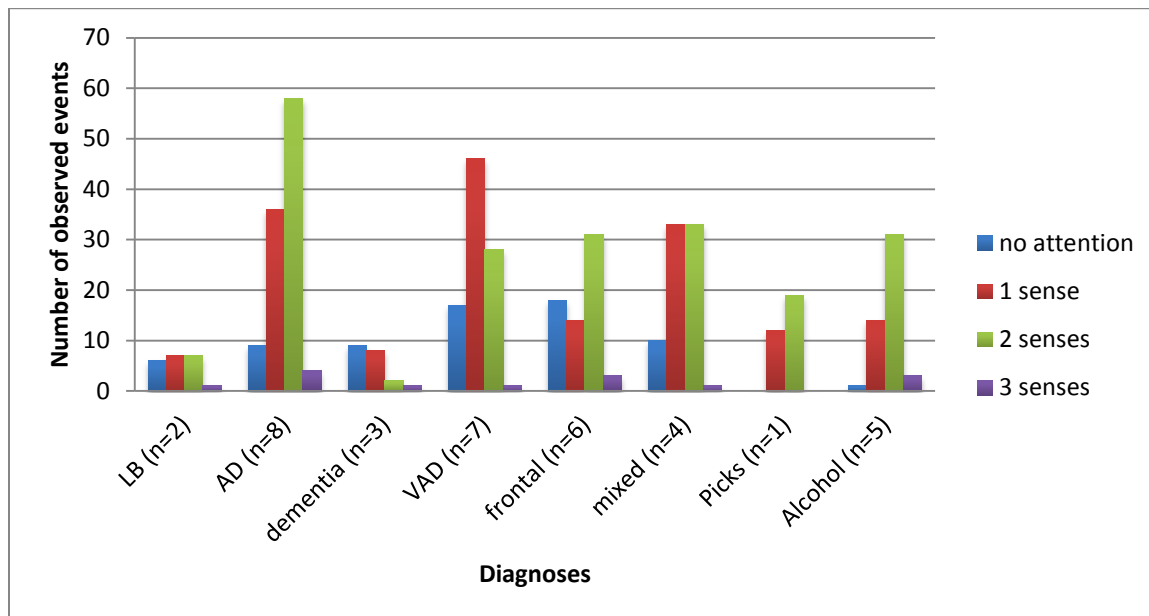
Note: MOET = modified observation of engagement tool; n = number of participants; Only Pearson correlations (*r*) of .25 or greater (suggesting a minimum fair correlation) were included in the table data; *p* = .05 is significant.

APPENDIX XX: PEARSON CORRELATIONS BETWEEN PHASE 4 SELF-DETERMINATION VIDEO VARIABLES AND ALL OTHER PHASE 4 VIDEO VARIABLES

Variable: Self-determination	Video variables	<i>r</i>	<i>p</i>	n
Phase 4: Arrives by self	Dpt_self4 (departs by self)	.98	.001	26
	Wchair (in wheelchair)	.39	.05	26
	Engage_v4 (engages visually)	.93	.001	26
	Engage_bt (engage, turns body toward stimulus)	.93	.001	26
	Engage_ts4 (engages by touch)	.87	.001	26
	Engage_hs4 (engages by holding the stimulus)	.71	.001	26
	Engage_ms4 (manipulates stimulus)	.71	.001	26
	Engage_ims4 (inappropriately manipulates stimulus)	.42	.03	26
	Atten_1s4 (attends with one sense)	.87	.001	26
	Atten_2s4 (attends with two senses)	.89	.001	26
	Atten_int4 (attention interrupted)	.78	.001	26
	Amb_purp4 (purposeful in arrival)	.92	.001	26
	Obj_bagwo4 (white & orange bag with seeds and jar)	.73	.001	26
	Obj_LPH4 (living plants and herbs)	.67	.001	26
	Objt_f4 (garden trowel and fork)	.5	.009	26
	Obj_gg4 (garden gloves)	.77	.001	26
	Obj_wc4 (watering can)	.58	.002	26
	Obj_soilbins4 (soil bins)	.7	.001	26
	Obj_sp4 (seed packets)	.5	.01	26
	Obj_pots-trays4 (pots and trays)	.7	.001	26
	Obj_gardenc4(grey garden centre)	.4	.04	26
	Obj_mag4 (magazines)	.69	.001	26
	Obj_table4 (table)	.74	.001	26

Note. MOET = Modified Observation of Engagement tool; n = number of participants; Only Pearson correlations (*r*) of .25 or greater (suggesting a minimum fair correlation) were included in the table data; *p* = .05 is significant.

APPENDIX YY: DIAGNOSES AND LEVELS OF ATTENTION



Note: LB = Lewy Body; AD = Alzheimer Disease; VAD = Vascular Dementia; Frontal = Frontal Dementia; Mixed = Mixed Dementia; Pick's = Picks Dementia; Alcohol = Alcohol-related Dementia