NONPHARMACOLOGICAL INTERVENTIONS
FOR NEUROPSYCHIATRIC SYMPTOMS OF
DEMENTIA: A Modern Approach
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3. Introduction
4. Method
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6. Discussion
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8. Appendices

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Nonpharmacological Interventions for Neuropsychiatric Symptoms of Dementia: A Modern Approach

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Guest Editorial

The Interplay of Quality of Life Issues and the Clinical Care of Persons with Neuropsychiatric Symptoms related to Dementia

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Over the last 10 years Canadian provincial governments and healthcare providers have increasingly focused on older adults with neurocognitive disorders given the high rates of behavioural and psychological symptoms of dementia or neuropsychiatric symptoms (NPS) associated with dementia (Behavioural Supports Ontario). High prevalence rates of NPS mean that its impact is far reaching across society and the health care system, while often adversely affecting quality of life of those it affects and their caregivers. Years of clinical care and research has looked for interventions that will minimize the adverse impact of NPS without contributing poor health outcomes. In this current issue of Research Insights, three articles provide an in depth examination of nonpharmacological interventions as it relates to NPS of dementia.

The first article, a republication of a 1974 paper by Mendonça and Cowie, provides a historical perspective on the management approaches for older adults with psychiatric illness and associated behaviours. This article provides the acknowledgement that neuropathological and physiological differences impact the older adult’s ability to participate in psychiatric rehabilitation. Current rehabilitation and psychiatric activation strategies were being provided to a population of hospitalized older adults with dementia and/or major mental illness at the St. Thomas Psychiatric Hospital. This was occurring at a time when the merits of traditional institutional care were beginning to be questioned. These authors use examples and describe theories to use in psychiatric activation. It is interesting to note the timing of this article, several years after Kral’s (1966) groundbreaking work on classical conditioning. When considered in the current 21st-century healthcare context many similar paradigms can still be considered applicable. This article promotes concepts of team based rehabilitation and recovery which are now common place in mental health care. It references the importance of goal attainment scaling and individualized care planning for individuals expressing behaviour changes. Although the terminology has evolved, this article focusses on goals for individuals, strength-based approach, maximizing procedural memory reaction, and behavioural activation.

The second article by Gutmanis, Marlatt, and Burhan provides a well-rounded review of the current state of literature as it pertains to prevalence rates, definitions, aetiology, prognosis, and risks associated with NPS. The introduction sets the stage for an in-depth review on the literature related to nonpharmacological care strategies for those with neuropsychiatric symptoms of dementia. The authors take us through the literature of key meta-analyses and systematic reviews focused on the evaluation of nonpharmacological interventions. Ongoing challenges continue to plague this area of research such as variation in methodological design, measurements approaches, and lack of standardization of staffing and training. This article leaves us with the message that education combined with strategies to promote skill development and understanding amongst providers and caregivers continues to be a primary evidence-based strategy.

Finally the third article authored by Gutmanis, DeForge,
Jowarski, et al., provides some important insights into the contextual issues related to those who have cognitive impairment and neuropsychiatric symptoms when they enter the acute care medical system of a large general hospital. The authors provide a qualitative evaluation of a pilot project that uses therapeutic recreation to support those who have dementia and associated behaviours when they enter the emergency department (ED) of a large acute care hospital in Ontario, Canada. The pilot intervention consisted of involving this patient group in personalized ‘recreational’ activities and empathetic interactions, which served to prevent responsive behaviours from being elicited in a hectic, unfamiliar, and potentially distressing environment. In addition, it was identified that knowledge diffusion occurred as ED staff became familiarized with collaborative evidenced-based approaches in dementia care. Although a short trial with limitations in research methodology, this important pilot is a delving into an under-evaluated area of health care delivery.

In conclusion, the research and evaluation of nonpharmacological interventions on persons with dementia and associated neuropsychiatric behaviours continues to be a complex interplay of contextual issues of persons with dementia, their identities prior to illness onset, and the caregiving social environment. The challenges that impact this area of research reinforce the key point that the personal and social context - provided by the lived experience of the ill person - is of upmost importance when supporting those with dementia and their caregivers. Dr. David Conn (Conn, 2017) reminds us that although that this field has progressed in research, we are still struggling with the optimal evidenced based care strategy.

The strength of bringing these three articles together is that it highlights the growth and the breath of the literature. Language and description of behavioural changes has evolved significantly over the last 20 years, as many researchers are trying to combat barriers of stigma. In this new era of partnership between clinicians and caregivers who clarify the lived experience of illness, it behooves us to include them in our research and evaluation strategies, which would help further the work and the advocacy that is so much needed in this field.

References


Response Sets/Chains and Activation of the Elderly

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1. Adjunct Professor, Department of Psychiatry, Western University, London ON.
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This paper was presented at the Ontario Psychogeriatric Association Convention at Kingston, Ontario, on November 15-16, 1974.

ABSTRACT

This paper offers some conceptual considerations of activation therapy designed to counter disorientation and withdrawal. It was suggested that activation therapy with the brain-damaged elderly could increase in effectiveness if it were to elicit response sets or response chains already present in the participants’ previous learning history rather than rely only on new conditioning. An attempt was made to explain the eliciting effect with Pavlovian principles. The suggestions were based on experience with rehabilitative therapy on the psychogeriatric unit at St. Thomas Psychiatric Hospital.

Keywords: Elderly Rehabilitation, Activation Rehabilitation, Response Sets, Memory Loss

Besides emphasizing community responsibility in reducing unnecessary hospitalizations (Goldstein, 1973), current thinking in mental health has also concerned itself with the course of in-hospital therapy for the elderly. Methods of symptom control and rehabilitation that attend to biophysiological, cognitive-emotional, and social needs of the elderly are being emphasized. This is because under institutional conditions of isolation and stimulus deprivation, further deterioration in functioning of the elderly can occur even when good physical care and rest are provided. Hence while chemotherapy and behaviour therapy have been largely used for controlling symptoms, activation therapy is being increasingly recommended for rehabilitation purposes (Cautela, 1966; Linden, 1953; Wolfe, 1971).

Psychiatric activation can be defined as rehabilitative therapy consisting of social, psychological and physical stimulation and designed to counter disorientation and withdrawal. Disorientation is used here to refer primarily to deficits, of varying degrees in remote or recent memory, involving retrieval and/or acquisition of information along the dimensions of time, person, and place. It also includes attentional and information-processing disorders.

Withdrawal would refer primarily to a loss of affective tone and desocialization, disinterest, and even depression. Activation with these objectives could be brought about by a variety of techniques: occupational therapy activities, reality orientation, sensory training, remotivation training, and self-care training. In general, outcome studies of such stimulatory activation have been encouraging. There is research evidence (e.g., Loew & Silverstone, 1971) that, while organic and physiological changes are mostly irreversible, intensive psychological and physical stimulation does have rehabilitative potential. Along with the variety of techniques used, however, there has been some vagueness with respect to their rationale.

The purpose of this paper is to offer some conceptual clarification of a psychological strategy involved in activation therapy. It will be suggested that activation, especially of the elderly with chronic brain syndromes, could be made more efficient if it were to stimulate and elicit sets or chains of responses already present in the patient’s previous learning history, as well as, and to a lesser extent, stimulate or condition discrete responses. This suggestion is based on our experience with various rehabilitative procedures conducted at the psychogeriatric unit at St. Thomas Psychiatric Hospital.
Sample

The specific therapeutic procedure discussed in this paper has been used on a 25-bed female ward, whose residents range in age from 51-87. Activation therapy of a variety of forms has been tried with all but a few very demented elderly of this sample. The number of participants per week in activation therapy have ranged between 15 and 20. None of the participants on activation therapy are bedridden but they are all dependent on others for self-care in varying degrees and most of them severely deficient with respect to recent memory. Fifteen of them have been diagnosed as having brain syndromes and the rest psychoses.

Limitations due to Organic Damage

Aetiologically, organic and psychosocial factors are known to contribute to the aging process (Peterson, 1973). Of all these factors, the extent of irreversible brain involvement appears to be the important limiting to rehabilitation possible with the elderly. The ageing brain is progressively vulnerable. There occurs irreparable loss of nervous tissue due to ageing and infective, toxic or metabolic stress (Peterson, 1973). Concomitant with these changes, the behaviour of the elderly becomes less efficiently conditionable (Cautela, 1969; Jakubczak, 1973) and they become less able to learn and retain new information (Kral, 1966).

Information of organically based psychological deficits ought to guide the choice of rehabilitative methods and help form realistic expectations of outcome. For example, increases in spontaneity and alertness obtained through sensory retraining of the aged with brain syndrome have been reported (e.g., Richman, 1969). This improvement is probably not due to growth and development of brain cells through stimulation of sense receptors, as has been suggested, but due to the cueing of reflex sensory and social responses already learnt prior to the onset of social withdrawal. Again, Kral (1966) found that the severe kind of recent memory disorder involves an inability to acquire new learning as well as difficulty of retrieval while the benign kind involves only the latter. This would suggest that reality orientation therapy consisting of memory retraining may be of little use to the elderly with the severe type of recent memory disorder (excepting for reversible deficits associated with certain conditions, e.g., stroke, initial stages of cerebrovascular disease). Hence, the probability of irreversible cognitive deficits implies that more effort needs to be invested in rehabilitative strategies that do not necessarily rely on fresh conditioning. One such strategy should be devise activities that elicit response sets or response chains already learnt in the past but fallen into disuse due to lack of appropriate cueing.

Activation of response clusters

A response set or chain is a response cluster with general applicability as opposed to a discrete response. A set refers to a cognitive strategy or method according to which an individual consistently handles a class of similar events (D’Zurilla & Goldfried, 1971) e.g., a cluster of behaviours associated with shopping, which a person uses whenever he or she goes to a store. A chain refers to an identifiable series of responses occurring in succession where the completion of one response is the cue for the initiation of the next (Skinner, 1953) e.g. the steps involved in cooking a particular recipe or making tea. An individual’s behavioural repertoire ordinarily consists of discrete individual responses as well as these complex clusters, and both are considered to be manipulable units in planning for behaviour change.

The experience that has preceded the above thinking can best be described by the following three activities:

A. Sitting in front of an elderly person with a drink and some cookies and reinforcing every smile, verbal comment or self-feeding response with a positive reaction.

B. Sitting during a ward party in the same way as in activity A and with the same behavioural objectives.

C. The same activity as in A carried out with the same objectives, during and even following a cooking session with a group of elderly patients and staff. The session would involve handling cutlery, utensils and activeness, like greasing pans, beating eggs. The group might consist of ambulant and nonambulant patients. The cooking procedures might be conducted jointly by staff and patients or sometimes mostly by staff with patients sitting around performing simpler tasks like handing an egg to somebody, holding a spoon, slowly stirring something in a bowl.

We have found that elderly participants in ‘C’ type activities would generally show more social behaviour and task-relevant behaviour than they might in ‘A’ or ‘B’ type activities. We have also found that type ‘C’ activities are more effective in stimulating non-verbal participatory
behaviour like handling a spoon, passing the jam, sitting alertly than verbal behaviour. Activity ‘C’ differs from ‘A’ or ‘B’ by the absence of a systematic contingency for reinforcing discrete behaviours. It is also different in that it contained stimulus patterns and responses sets and chains associated with cooking, an activity, that occurred regularly in the patient’s past, more regularly than would a party, the setting of activity ‘B’. Activities similar to cooking seem to function as ‘setting’ variables. Admittedly, operant factors (like the reinforcing comments of staff) are at work, but they most likely server to maintain behaviours that are facilitated by the ‘setting’ activities themselves. It could be argued that cooking was more reinforcing and hence better able to modify behaviour. But changes in behaviour were observed during the cooking activity and not only consequent to it. An explanation of the role of possible behavioural contingencies would be an involved one.

A parsimonious explanation of the eliciting effect of ‘setting’ activities seems to be found within a classical conditioning framework. The activities contain response sets or chains previously conditioned and, on account of constant usage, very much a part of the aged individual’s learning history. The response set or response chain now acts as a powerful ‘unconditioned response’ evoked by an appropriate cluster of stimuli which acts as a complex ‘unconditioned stimulus’. Hence, no reinforcement is needed for the eliciting effect since the responses seem to be evoked in the manner of strong reflex responses. Cautela (1969) has pointed out that Pavlov’s (1958) views on the balance of excitation and inhibition in the ageing nervous system has practical relevance to therapeutic programs for the aged. According to Pavlov (1958), the ageing process brings about an impairment in the ability to extinguish previous conditioning, a greater need for stimulus variability (as opposed to monotonous activity for just keeping busy), a need to regulate the amount of stimulus intensity to avoid disorganization. Also, a stronger ‘conditioned stimulus’ and ‘unconditioned stimulus’ appear to be necessary in order to obtain conditioned responses.

**Examples**

The following are examples of activities that have been used as setting variables in the psychological strategy suggested in this paper.

1. **Baking:** Patients take an active part in this program by beating eggs, stirring batter and mixing ingredients together – greasing pans, rolling out cookies, breaking eggs, peeling tomatoes and onions, cutting up celery etc. and canning e.g. chilli sauce and putting it in jars – spreading on bread for sandwiches, decorating cookies, cupcakes, and cakes, also spreading cheese on crackers and decorating them.

2. **Mini-parties:** These are small gatherings of about 5-7 patients. The parties all have a theme, which is reflected in appropriate posters, snacks, cutlery and other accessories. They last for about one hour. Some examples are spring tea, St. Patrick’s Day, Easter party, May Day party, pizza party, candlelight party, strawberry festival.

3. **Shopping excursions:** Patients are taken shopping to Towers department store for clothing. They push the shopping carts and look at merchandise. Where possible, we have them tell us what dresses and shoes they like and are comfortable in. Again, where possible, we have them pay the cashier.

4. **Tending plants:** Our ladies grow potted plants and transplant slips. Some are assigned to look after and water them.

5. **Music sessions:** These are really ‘remotivation’ type therapy sessions with a central theme. For example, appropriate songs are used, interspersed with short periods of concrete orientation to objects connected with a theme: e.g. household tools, fruit and vegetables.

**Summary and Conclusions**

It was suggested that in view of the limitations imposed by brain damage in our hospitalized elderly in acquiring new learning and conditioning, rehabilitative procedures be devised to elicit and reactivate response sets or response chains regularly used in the past but now fallen into disuse. Activities containing these ‘sets’ or ‘chains’ could be used as setting variables in activating therapy procedures. It was suggested that operant procedures be used mainly to maintain responses that were elicited. It was also suggested that a parsimonious explanation for the eliciting of response ‘sets’ or ‘chains’ could be found along Pavlovian conditioning principles.

Following on our pilot efforts in using this rehabilitative strategy, the next step would be to evaluate its usefulness.
The evaluation would have to take into consideration the type of subjects since samples with different levels of organic and psychological impairment might be differentially responsive. The evaluation would also have to use measures sensitive to change in the elderly with declining functions. In this respect individual Goal Attainment Scaling and unobtrusive indices of change would prove useful (Kiresuk & Sherman, 1968; Webb, 1966).

**References**


Neuropsychiatric Symptoms of Dementia: Nonpharmacological Care Strategies

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ABSTRACT
The neuropsychiatric symptoms (NPS) of dementia can be challenging to manage and can pose a significant risk to the well-being of the person living with the behavioural issue, their care providers, and others who are in their care environment. While the precise etiology and pathology associated with NPS of dementia remains unclear, neurotransmitter changes as well as alterations to frontal-subcortical circuits, cortico-cortical networks, the monoaminergic system, and metabolic and vascular systems may be at fault. Psychosocial models have also been proposed including the “unmet needs” model, a behavioural/learning model, and an environmental vulnerability/reduced stress-threshold model. The development of targeted care strategies that take into account these many possible factors can be facilitated through the use of the DICE model (describe, investigate, create, evaluate). While caregiver knowledge interventions, changes to the physical environment, and communication skill improvement have been shown to be efficacious care strategies, the results from studies of the impact of other nonpharmacological approaches to care have been mixed. Current investigations of the impact of music therapy, pet therapy, massage/touch, Snoezelen therapy, exercise, recreation therapy, and aromatherapy have not consistently demonstrated impact due to measurement issues and varying study populations. Future large scale randomized controlled trials with adequate blinding and follow-up periods that use validated and responsive measures are recommended to examine efficacy, cost-effectiveness, safety, and feasibility of nonpharmacological approaches to care.

Keywords: Nonpharmacological Treatments, Neuropsychiatric Symptoms, Dementia, Individualized Approaches to Care

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Neuropsychiatric symptoms (NPS) of dementia can be defined as distortions of perception, thought content, behaviour, or affect (Finkel, Costa e Silva, Cohen, Miller, & Sartorius, 1996). NPS include a wide range of behaviours that have been clustered into five domains: depression (includes: sad, tearful, hopeless, guilty, anxious, irritable/screaming, suicidal), agitation (pacing, repetitive actions, dressing/undressing, restless/anxious), aggression (physical aggression, verbal aggression, aggressive resistance to care), apathy (withdrawn, lacks interest, amotivation), and psychosis (hallucinations, delusions, misidentification, suspicious) (McShane, 2000). Those living with NPS may also display other behaviours such as sleep disturbances, wandering, ingestion of non-edible/dangerous substances, and repetitive questioning. Among those living with dementia, NPS frequently co-occur and change over time. For example, someone who wanders and displays apathy may then experience delusions, which may be replaced by aggression. Further, symptoms often fluctuate in frequency, duration, and severity.

While cognitive deficits have a downward trajectory, NPS tend to fluctuate episodically, but may last for six months or more (Kales, Gitlin, & Lyketsos, 2015). Symptoms can be challenging to manage (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; Savva et al., 2009) and can pose a significant risk to the safety and well-being of the person living with behavioural issues, their care providers, and others in the care environment (Chan, Kasper, Black, & Rabins, 2003; Rodney, 2000; Rosen, Pillemer, & Lachs, 2008; Russ, Batty, & Starr, 2012; Toot, Devine, Akporobaro, & Orrell, 2013). NPS are associated with faster cognitive decline, accelerated progression to institutionalization and death, greater caregiver distress, and poor quality of life (Levy, Lancot, Farber, Li, & Herrmann, 2012; Lyketsos, Miller, Neuropsychiatric Syndromes Professional Interest Area of the International Society to Advance Alzheimer’s, & Treatment, 2012; Rabins et al., 2013). As well, it has been estimated that 30% of the cost of caring for community-dwelling individuals with dementia is directly attributable to NPS management (Beeri, Werner, Davidson, & Noy, 2002).

Among those living with dementia, NPS type and intensity are impacted by disease type, duration, and stage. For example, hallucinations are seen more often in Lewy body dementia than in Alzheimer’s disease (AD). As well, those living with frontotemporal dementia often exhibit behaviours typical of executive control loss (Bott, Radke, Stephens, & Kramer, 2014). While apathy is commonly reported by family members across all stages and tends to worsen over time, delusions, hallucinations, and aggression are more episodic and more common in moderate to severe stages of AD (Lyketsos et al., 2011).

Estimates of the prevalence of NPS vary considerably and may be impacted by stigma (Chapman, Williams, Strine, Anda, & Moore, 2006), government policies and funding (George-Carey et al., 2012), and setting (e.g., community vs. long-term care; http://www.statcan.gc.ca/pub/82-003-x/2016005/article/14613/tbl/tbl01-eng.htm). However, NPS are common among those living with dementia. For example, it is estimated that up to 80-97% of those living with AD will live with NPS at some point during their disease progression (Gauthier et al., 2010). In a recent meta-analysis, Zhao et al. (2016), reported that among those living with AD, the pooled prevalence of aggression was 40%, disinhibition 17%, irritability 36%, euphoria 7%, delusions 31%, hallucination 16%, sleep disorders 39%, depression 42%, anxiety 39%, apathy 49%, and appetite disorders 34%. While the prevalence of NPS varied widely across studies, the most frequently reported NPS in AD were apathy, depression, aggression, anxiety, and sleep disturbances, while the least frequently reported symptom was euphoria (Zhao et al., 2016).

**Etiology and Pathology**

NPS may be due to many factors. While some of these factors are modifiable, others are not. Progressive neurological damage from the underlying neurodegenerative disease is at the root of many behavioural issues. As well, concomitant sensory deficits (e.g., visual, auditory), physiologic deficits (e.g., dehydration), and medical issues (e.g., urinary tract infections; adverse effects of prescribed and over-the-counter medications) are also linked to behavioural issues. Additional causes discussed in the literature include: unmet needs; caregiver factors; environmental triggers; and frustrating interactions between the individual and their caregiver and/or their environment (Kales et al., 2015). Although the exact neurobiological changes that lead to expressive behaviours remains unknown, in 2013
Geda and colleagues (Geda et al., 2013) postulated a three-part hypothetical model. The first hypothesis is that at least three frontal-subcortical circuits (dorsolateral prefrontal circuit, orbitofrontal prefrontal circuit, and the circuit involved in motivated behaviour) mediate human behaviour. The second hypothetical model proposes that cortico-cortical networks, of which five have been frequently cited, mediate emotional as well as cognitive processing. Finally, the third model suggests that the monoaminergic system involving neurotransmitters such as serotonin, norepinephrine, and dopamine, along white matter projections from rostral to caudal brain regions, mediate complex behaviour.

Investigators have examined the impact of glutamatergic (Gauthier et al., 2010), neurotrophic (for example, brain-derived neurotrophic factor) (Zhao et al., 2016), and other neurochemical and neuroendocrine systems on NPS of dementia. For example, post-mortem studies that have looked at changes in brain structure and chemistry in patients with confirmed AD, have found evidence of serotonergic neuronal loss in the brain stem (Casanova, Starkstein, & Jellinger, 2011; Halliday et al., 1992; Mann & Yates, 1983). Further, research into genetic polymorphisms supports the involvement of the serotonergic system. In some studies, polymorphism in the 5-hydroxytryptamine (5-HT) transporter gene has been associated with behavioural symptoms of AD including agitation/aggression and psychosis (Pritchard, Pritchard, Bentham, & Lendon, 2007; Sukonick et al., 2001; Sweet et al., 2001). However, these findings are not consistent (Assal, 2004; Rocchi, 2003; Ueki, 2007). Serotonergic receptor polymorphisms, mainly 5-HT2A, but also 5-HT2A (Holmes, Arranz, Collier, Powell, & Lovestone, 2003), 5-HT1A, B, D, and 5-HT6 (Garcia-Alloza et al., 2004; Lai et al., 2003), have also been implicated.

Neuroimaging studies, such as the Alzheimer’s Disease Neuroimaging Initiative (ADNI), have demonstrated the disruption of large-scale networks including the salient network and central-executive networks among those with NPS. For example, delusions in AD have been associated with grey matter atrophy in the anterior insula (Fischer, 2016; Ting, 2015) and the anterior cingulate cortex (Rafii et al., 2014). Delusions also have been associated with abnormalities in the frontal and parietal cortices, areas that represent the central-executive network (Bruen, McGowan, Shanks, & Venneri, 2008; Rafii et al., 2014). A systematic review pointed to the association of paranoid delusions in AD with right frontal cortical areas, while misidentification delusions have been linked to temporal-area abnormalities (Ismail, Nguyen, Fischer, Schweizer, & Mulsant, 2012). Hallucinations have been associated with right anterior insula abnormalities in addition to bilateral prefrontal areas (Blanc et al., 2014). As well, supramarginal region thinning was predictive of hallucinations in another study (Donovan et al., 2014). Agitation has been associated with abnormalities in salient network structures, including the anterior insula, the anterior cingulate cortex, and connections to the prefrontal cortex (Balthazar et al., 2014; Bruen et al., 2008; Rosenberg, Nowrangli, & Lyketsos, 2015).

The impact of metabolic and vascular pathologies on expressive behaviours has also been examined. For example, deficits in blood flow and metabolism of prefrontal areas have been reported in those living with AD and depressive symptoms (Akiyama et al., 2008; Hohlfed et al., 2005; Kataoka et al., 2010; Levy-Cooperman et al., 2008; Terada et al., 2014), while apathy in AD has been associated with grey matter atrophy in the left and right anterior cingulate cortex (Bruen et al., 2008), hypoperfusion in the left anterior cingulate cortex and right orbitofrontal area, relative hyperperfusion in the hippocampi and temporal areas (Lanctot et al., 2007), and hypometabolism in the left orbitofrontal area (Hohlfed et al., 2005).

Other health issues can also trigger NPS. Given the propensity of those with dementia to develop delirium, expressive behaviours may be due to delirium superimposed on dementia. Pre-morbid psychiatric illnesses including depression due to unipolar or bipolar illness, mania due to bipolar or schizoaffective illness, and psychosis due to schizophrenia or related illnesses, can mimic features of...
the NPS of dementia (e.g., (Woudstra et al., 2014). Further, NPS can also be elicited through the use of substances such as alcohol (Kim et al., 2012), or neuroleptics such as benzodiazepines and anti-cholinergic drugs (Tune & Bylsma, 1991).

Nondisease related factors are also associated with the expression of NPS. Three psychosocial theoretical models have been proposed by Cohen-Mansfield (2000), the “unmet needs” model, a behavioural/learning model, and an environmental vulnerability/reduced stress-threshold model (Cohen-Mansfield, 2000). Persons living with neurocognitive disorders may have difficulty expressing medical and physiological needs (e.g., pain, hunger, thirst, need to void) as well as psychosocial needs (e.g., boredom, loneliness, fear, anxiety). In addition, some people living with dementia may experience a lower stress tolerance threshold and may react adversely to environmental triggers such as noise. Finally, an expressive behaviour can be inadvertently reinforced if the consequences reward the behaviour (e.g. screaming in the dining room results in getting meals in bed).

Other investigators have proposed models that include both disease-related factors as well as nondisease related factors. For example, Kitwood (1993) suggests that NPS are a function of personality (e.g., previous coping strategies, tendency to accept help from others), biography (e.g., spousal death, loss of personal resources, other challenges presented in life), health (e.g., sensory impairment), neuropathological impairment (e.g., disease type/severity), and social psychology (e.g., sense of safety, value, and personal being) (Kitwood, 1993).

An Approach to the Assessment of Neuropsychiatric Symptoms in Dementia: DICE

Once an expressive behaviour has been detected and prior to the selection of a care strategy, possible underlying and modifiable causes need to be identified. One such approach, DICE (describe, investigate, create, and evaluate), was developed by a panel of American dementia care experts. This model promotes the development of individualized assessment and care plans through a four-step process (Kales et al., 2015). The first step is to elicit a precise description of the symptoms through discussion with the person and both their formal and informal caregivers. Using standardized assessment tools, the specific behaviour and any antecedents/triggers are identified, as are the specific aspects that are the most distressing or potentially harmful and the consequences of the behaviour.

Once the symptoms have been well described, possible underlying and modifiable causes are identified. Patient factors (e.g., unmet needs, acute medical change, sensory deficits), caregiver factors (e.g., distress/burnout/depression, lack of knowledge/skills, communication challenges), and environmental factors (e.g., level of stimulation and noise, safety, level of activity/structure) are considered as possible triggers.

In the third step, the care team collaborates to co-create and implement a treatment plan for the person with the NPS that addresses the underlying cause(s) of the behaviours. Both medical and nonpharmacological approaches are considered (see Table 1).
Table 1. 
Identifying possible causes of NPS and possible nonpharmacological approaches to NPS

<table>
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<tr>
<th>Possible Cause</th>
<th>Examples of Possible Care Strategy</th>
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<td><strong>Personal Factors</strong></td>
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<tr>
<td>Undiagnosed medical issues</td>
<td>• Medical work up to discover and treat an undiagnosed health issue (e.g., provide fluids if dehydrated)</td>
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<td></td>
<td>• Medication review</td>
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<tr>
<td>Sensory deficits</td>
<td>• Supply corrective eyewear, hearing aids</td>
</tr>
<tr>
<td>Unmet needs</td>
<td>• Determine need (e.g., if thirsty, supply water)</td>
</tr>
<tr>
<td>Pain</td>
<td>• Pain medications</td>
</tr>
<tr>
<td><strong>Caregiver Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Lack of knowledge of factors</td>
<td>• Training and development</td>
</tr>
<tr>
<td>associated with NPS</td>
<td>• Courses such as Gentle Persuasive Approaches (GPA)©</td>
</tr>
<tr>
<td>Communication issues</td>
<td>• Eliminate open-ended questions</td>
</tr>
<tr>
<td></td>
<td>• Simplify; limit number of offered choices</td>
</tr>
<tr>
<td>Caregiver distress/</td>
<td>• Adult Day Programs</td>
</tr>
<tr>
<td>burnout/depression</td>
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<tr>
<td><strong>Environmental Factors</strong></td>
<td></td>
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<tr>
<td>Over/under stimulation</td>
<td>• Sensory enhancement/relaxation</td>
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<tr>
<td></td>
<td>• Massage and touch</td>
</tr>
<tr>
<td></td>
<td>• Music</td>
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<td></td>
<td>• Snoezelen therapy</td>
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<td></td>
<td>• Aromatherapy</td>
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<td></td>
<td>• Quiet areas</td>
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<tr>
<td>Lack of meaningful activity</td>
<td>• Promotion of meaningful leisure activities</td>
</tr>
<tr>
<td>Safety</td>
<td>• Camouflaged exit points</td>
</tr>
</tbody>
</table>

During the final step, evaluate, recommended strategies are evaluated. Clinicians are asked to consider: Have the strategies been attempted and effectively implemented? Has the target symptom changed? Have caregiver’s issues improved? Even after the symptom has resolved, ongoing monitoring is recommended. The frequency of symptom and care strategy efficacy monitoring is somewhat setting-specific, but the Canadian Consensus Conference on Dementia specifies this should occur at least every three months (Hogan et al., 2008).

**Nonpharmacological Approaches to Care for NPS of Dementia**

Because of the many disease-related and non-disease related issues that could lead to the expression of NPS, no one single evidence-based approach to care could effectively reduce all NPS in everyone living with dementia (Kales et al., 2015). While it is suggested that the first line of treatment usually be a nonpharmacological approach, unless there are imminent danger or safety concerns (Ouslander, 2003), the management of the NPS of dementia relies on the use of both nonpharmacological and selected pharmacological therapies (Gitlin, Kales, & Lyketsos, 2012). The following section will only review evidence supporting the use of nonpharmacological approaches to care. A number of investigators have conducted systematic reviews of nonpharmacological approaches to care for those living with the NPS of dementia. For example, Cohen-Mansfield (2000) conducted a review of published papers that examined the efficacy of specific interventions in decreasing expressive behaviours among older adults living with dementia or cognitive impairment (Cohen-Mansfield, 2000). Of the 83
papers that were reviewed, most studies (76%) involved nursing home residents while the remaining looked at hospitalized individuals or those living in the community. It was noted that most studies examined the presence of any expressive behaviour and did not examine specific expressive behaviours such as aggression or wandering. Cohen-Mansfield concluded that medical and nursing care that effectively addressed functional limitations (e.g., pain), sensory limitations (e.g., provision of hearing aids), sleep problems (e.g., light therapy, decreased nighttime noise), and limitations on autonomy (e.g., removal of physical restraints) should be optimized. As well, there was evidence to support the provision of social contact (e.g., pet therapy, one-on-one interaction, simulated presence therapy, an audiotape of a relative’s telephone conversation). It was also suggested that staff be offered training that improves care delivery (e.g., courses on the impact of dementia on social and self-care abilities, methods of assessing abilities and interventions that maintain or compensate for those abilities) and that long-term care homes consider reducing stressful stimuli or increasing relaxation during care activities using techniques such as massage, music, white noise, and aromatherapy. The review also concluded that structured activities should be tailored to the person and be personally meaningful (e.g., sewing for those who used to sew, nature walks for those who previously enjoyed going for walks).

A systematic review conducted by Livingston et al. in 2005 examined all published studies that dealt with psychological approaches to the management of NPS of dementia and classified the evidence according to the Oxford Centre for Evidence-based Medicine Levels of Evidence (Livingston et al., 2005). The evidence in published paper of the following strategies were assigned a grade of D (Level 5 evidence or troublingly inconsistent or inconclusive studies of any level): reminiscence therapy, validation therapy, reality orientation therapy, simulated presence therapy, therapeutic activity programs, Montessori activities, exercise, and increased social interaction. Four approaches (cognitive stimulation therapy, music therapy, Snoezelen therapy (a multisensory stimulation therapy), and specific staff education programs in managing NPS) were assigned a grade B (consistent level 2 or 3 studies or extrapolations from level 1 studies). Only teaching caregivers about how to change their interactions with patients was assigned a grade A (consistent level 1 studies).

Another systematic review of nonpharmacological strategies for the management of NPS among persons with dementia, conducted by Ayalon, Gum, Feliciano and Arean (2006), concluded that the most promising strategies seemed to be individually tailored behaviour interventions, but that further evidence of this approach was needed (Ayalon et al., 2006).

In a review of 21 systematic reviews of studies that examined a single intervention focused on reducing expressive behaviours among older adults with dementia and seven systematic reviews of combination interventions, O’Neil et al. (2011) found little evidence to support reminiscence therapy, simulated presence therapy, validation therapy, acupuncture, aromatherapy, and light therapy (O’Neil et al., 2011). There was limited evidence supporting massage and touch therapy, pet therapy, and behaviour management techniques such as cognitive-behavioural therapy. Although methodologically sound studies were lacking, the authors concluded that music therapy may have the potential for immediate and short-term reduction of agitation among those living with the NPS of dementia. Further, while there was no consistent evidence demonstrating a long-lasting effect, the authors suggest that future research into the effectiveness of Snoezelen therapy and transcutaneous electrical nerve stimulation (TENS) may be warranted. Finally, while exercise appeared to increase sleep duration and decrease nocturnal awakenings, exercise studies did not consistently demonstrate a significant reduction in expressive behaviours such as agitation.

Seitz et al. (2012) conducted a systematic review of all papers published between 1980 and 2010 of randomized, controlled trials evaluating nonpharmacological interventions for NPS of dementia conducted in long-term care home settings (Seitz et al., 2012). Findings from the 40 studies that met the inclusion criteria suggested that staff training in NPS management strategies, mental health consultation and treatment planning, exercise, recreational activities, and music therapy or other forms of sensory stimulation such as aromatherapy and Snoezelen therapy, were effective strategies. However, most interventions required resources that were beyond what long-term care home staff could offer. The authors note that a meta-analysis was not possible due to the heterogeneity of study design and outcome measures.

Brodaty and Arasaratnam (2012) conducted a meta-
analysis of studies that examined the effectiveness of nonpharmacological interventions delivered by family caregivers for community-dwelling adults living with the NPS of dementia. In the 17 studies that studied the effect of caregiver interventions on the NPS of those living with dementia, the pooled-estimate of Cohen’s effect size was 0.34. Among the 13 studies that looked the effect of caregiver interventions on caregiver reactions to the person with NPS, the pooled-estimate effect size was 0.15. The authors concluded that caregiver education, skills training (e.g., communication strategies, problem solving), social support, and environmental modifications (e.g., creating an uncluttered space) were effective care strategies. However, the authors note that the often-multicomponent interventions varied in dose, intensity, and delivery mode (telephone, mail, face-to-face, groups, computer-based) thereby making it impossible to identify which specific elements were effective for which behaviours. The authors concluded that strategies that are tailored to the needs of the person with dementia and their caregiver, that were delivered individually in the home, that used multiple components over a period of 3 to 6 months, and that were interspersed with telephone sessions and subsequent individual or group telephone follow-up, were the most successful.

In a systematic review by Gitlin, Kales, and Lyketsos (2012) of studies published between 1992 and 2012 that recruited community-dwelling persons with dementia, it was noted that studies on adult day services showed multiple benefits including reductions in behavioural symptoms and caregiver distress (Gitlin et al., 2012). These authors also noted that some studies of music therapy and other sensory strategies, such as massage and aromatherapy, reported increased agitation and physical aggression. They also pointed out that while some strategies may be effective for some symptoms (e.g., agitation), they may not be helpful for others (e.g., hallucinations), and that the best combination of strategies remained unknown.

A review paper by McClam, Marano, Rosenberg, and Lyketsos (2015) that examined the findings of randomized, controlled trials published between 2004 and 2014 that focused on strategies used to change behavioural symptom severity, concluded that exercise training when compared to social interactions or walking, may decrease depression, and daily personalized music therapy may decrease anxiety (McClam et al., 2015). However, they found that clients who were exposed to bright light therapy in the morning could experience increased agitation and aggression.

In a systematic review of 20 papers published between 2005 and 2015 on nonpharmacological interventions among those living with the NPS of dementia, de Oliveira et al. (2015) concluded that activity programs that were tailored to participants’ interests and skills reduced the incidence of NPS (de Oliveira et al., 2015). In addition, they found that programs where attendees listened to familiar songs resulted in reduced anxiety. As well, studies of bright light therapy demonstrated reduced agitation and sleep disturbance.

Several Cochrane reviews have examined the effectiveness of specific nonpharmacological approaches. For example, a review conducted by Forbes, Blake, Theissen, Peacock, & Hawranik (2014) found no effect of light therapy on cognitive function, sleep, or the NPS of dementia and concluded that there is insufficient evidence to justify the use of bright light therapy in this population (Forbes et al., 2014). Chung and Lai (2002) concluded that while there is no evidence demonstrating the efficacy of Snoezelen therapy for dementia, there is a need for more research-based evidence (Chung, Lai, Chung, & French, 2002). In a review of 10 papers that examined the impact of music therapy on the NPS of older adults with dementia (Vink, Birks, Bruinsma, & Scholten, 2004), Vink et al. (2004) concluded that the methodological quality and the reporting of the studies was too poor to draw any useful conclusions regarding any benefit.

Several formal caregiver education courses have been developed and evaluated. For example, Gentle Persuasive Approaches (GPA®), is a 7.5-hour, case-based, interactive educational training program that utilizes short-lecture format, experiential exercises, guided group discussion, dementia-specific videotapes, demonstration of appropriate techniques, and application by the participants through supervised role-play. Grounded in the principles of person-centered dementia care, expressive behaviours are interpreted as self-protective, defensive, or communicative strategies in response to unmet needs. A study of program efficacy showed that self-perceived competency and attitudes towards the clinical use of such strategies were significantly higher immediately following the curriculum and six-weeks later (https://www.ageinc.ca/wp-content/uploads/2017/01/GPA-Project-Final-Report-March-2005-rev-nov-1.pdf).
In a review of 12 papers, Eggenberger, Meimerl, and Bennett (2013) concluded that caregiver communication skills training improved the quality of life and well-being of people living with dementia and increased positive interaction (Eggenberger et al., 2013). The training sessions described in these papers included discussions of verbal skills (e.g., use of one-step instructions), non-verbal and emotional skills (e.g., make eye contact, show empathy), attitudes towards people with dementia (e.g., use a calm approach, avoid patronizing speech), behavioural management skills (e.g., avoid confrontation), usage of tools (e.g., create and use memory aids), self-individual experiences (e.g., need to reflect on your communication style), and theoretical knowledge (e.g., how to develop appropriate expectations of those living with AD). Communication skills training had a significant impact on both formal and informal caregiver communication skills, competencies, and knowledge.

NPS may also be evoked with medical issues such as constipation, incontinence and pain. Strategies aimed at relieving constipation and improving continence may decrease agitation. As well, acute and chronic pain, issues common to many older adults, may lead to agitation. Treatment with common analgesics may decrease agitation and, if taken prior to bedtime, may result in improved sleep quality (Habiger, Flo, Achterberg, & Husebo, 2016).

Health care settings, from hospitals to long-term care homes, have been challenged to recognize and address physical health issues common to older adults, such as decreased visual acuity, in their physical design. Elder-friendly built environments created through effective physical design may help older adults, both those living with dementia and those not living with dementia, who often cope with the same aging-related health issues, maintain or improve their level of physical function (http://www.fraserhealth.ca/media/Code_Plus_Physical_Design_Components_Elder_Friendly_Hospital_2nd_Edition_.pdf). Some long-term care homes have changed the built environment in an effort to decrease the expression of NPS (Waller, 2013). For example, meaningful activity has been encouraged by providing those living with the NPS of dementia with social spaces and places to walk. Orientation has been supported by large face clocks, natural lighting, and views of nature (Waller, 2013). However, while the efficacy of some of these design changes appears to be relatively self-evident, the literature supporting these claims is relatively scant.

In their review of the literature on the impact of built environment on the NPS of dementia, Livingston et al. (2005) found that according to the Oxford Centre for Evidence-based Medicine Levels of Evidence (http://onlinelibrary.wiley.com/doi/10.1111/j.1464-410X.2009.08936.x/pdf), the evidence supporting the concealment of exits was Grade C. Further, evidence supporting the efficacy of signposting, decreased sensory stimulation (e.g., turning off the television, lowering voices), and unlocking doors for short periods of time was only Grade D.

In a review of the 57 papers on physical environments for those living with dementia, Fleming, Crookes, and Sum (2008) concluded that while an over emphasis on safety may have detrimental effects such as the promotion of restricted activity and associated functional decline, unobtrusive safety features, such as control of unauthorized exiting and the provision of specialized equipment such as canes, increased resident well-being and decreased depression (Fleming et al., 2008). They also found good evidence for the provision of a variety of spaces with different functions (e.g., multi-purpose activity areas, kitchen/dining rooms). However, evidence supporting the benefits of gardens, without enhanced staff interaction, was weak. As well, they found that the evidence supporting both the beneficial effects of involving those living with the NPS of dementia in ordinary activities of daily living and the use of personal memorabilia, such as memory boxes located outside of bedrooms as orientation aids, was limited. While the evidence supporting the use of signage was not strong, they found that making the toilet very visible was beneficial. As well, as echoed in the Code Plus manual (http://www.fraserhealth.ca/media/Code_Plus_Physical_Design_Components_Elder_Friendly_Hospital_2nd_Edition_.pdf), the authors suggest that levels of illumination should be increased.

Another systematic review of five studies of built environments and their impact on NPS of dementia among those living in long-term care, Soril et al. (2014) concluded that there was inconclusive evidence to suggest a specific built environment that was clinically superior (Soril et al, 2014). In another overview of the literature, van Hoof, Kort, van Waarde, and Blom (2010) again concluded that there was little scientific evidence as to the efficacy of many home modifications but that many held promise (van Hoof et al., 2010).
Discussion

While not completely understood, many possible disease-related and etiological factors associated with the expression of the NPS of dementia have been described. Identification of care strategies that take into account these many possible factors can be facilitated through the use of the DICE model (describe, investigate, create, evaluate). Prior to the development of a care strategy co-created with the care team and the person living with an expressive behaviour, symptoms are characterized and probable underlying causes are identified. Once implemented, care strategies are continually evaluated and refined. Seitz et al (2012) confirmed the impact of a comprehensive mental health assessment wherein possible medical and well as other causes were thoroughly investigated prior to the implementation of a care strategy (Seitz et al., 2012). Reviews conducted by Cohen-Mansfield (2000) and Ayalon et al. (2006) also support an individualized approach to care, wherein potential causes of behavioural symptoms are first identified and then specifically addressed.

Meta analyses and systematic reviews as to the efficacy and effectiveness of various strategies have determined that caregiver knowledge interventions (often multiple components delivered over the course of a number of sessions interspersed with follow-ups) can significantly reduce NPS in persons with dementia as well as caregiver negative reactions to these symptoms. In addition, changes to the physical environment, such as increasing illumination and making sure that needed amenities, such as toilets, are easily identifiable, have been shown to be beneficial. Further, training sessions that focused on the development of both formal and informal caregiver communication skills significantly improved caregiver interactions with those persons living with the NPS of dementia.

The impact of other strategies such as music therapy, pet therapy, massage/touch, Snoezelen therapy, exercise, recreation therapy, and aromatherapy, has not been consistently demonstrated. There are a number of reasons for the limited support of these strategies. First of all, the study populations have varied from community-dwelling adults with some cognitive impairment to long-term care home-dwelling older adults with severe dementia. Further, investigators may have failed to enroll the target population, as those living with an acute illness or those who died are usually excluded. As the impact of an intervention may well vary by the disease stage, by type of symptom, the presence of co-occurring symptoms, as well as by symptom expression (frequency, intensity and duration), and setting (long-term care vs. community), further study regarding which intervention may be effective in which situation is needed.

Mixed results may also be due to numerous methodological issues. Caregivers often need to provide consent and may not be readily available to the study’s recruiters. As a result, recruitment may be low and the studies may be underpowered. As well, by comparison with the funding available for drug research, there is limited funding for nonpharmacological studies again limiting the ability to mount large-scale, multi-site studies. In addition, for most of the trialed interventions, allocation concealment was not possible, potentially resulting in biased effect sizes. Further, while some of the reviewed nonpharmacological interventions were specific (e.g., only music therapy) others were multicomponent (e.g., during adult day programs, attendees are offered a number of activities).

Measurement challenges may have also led to mixed study findings. While some studies used omnibus measures such as the Neuropsychiatric Inventory (Cummings et al., 1994), likely due to the fact that many people living with the NPS of dementia have co-occurring symptoms, others measured specific behaviours with specific tools (e.g., depression with the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). As well, while some tools measure symptom intensity, others measure frequency or duration. Further, most scales rely on information provided by caregivers, and reported results may be impacted by factors such as caregiver burden, potentially biasing the reported outcomes. Due to the variation in the behaviour rating scales that have been used, Brodaty and Arasaratnam (2012) concluded that it was impossible to identify which specific therapeutic elements were effective for which behaviours (Brodaty & Arasaratnam, 2012). As well, as noted by Livingston et al. (2005) and Ayalon et al. (2006), even if some therapies are not shown to be efficacious, they may provide pleasure for either the person with the NPS or for their caregivers, thereby decreasing caregiver distress or staff turnover and so may be worthwhile.

As noted by Seitz et al. (2012), although the outcomes
associated with staff training and education tend to be evaluated over a period of time, as it takes time for clinicians to change their behaviour, the impact of other interventions such as music therapy and sensory stimulation have generally been assessed over shorter periods of time and are probably most effective in reducing NPS while the participant is actively engaged in the activity. Future studies are needed to determine if ongoing implementation with a specific duration leads to long-term impacts. Also, as noted by Seitz et al., there were no studies evaluating the impact of adding more nurses or personal support workers, despite knowing that in Ontario, the average long-term care home resident only receives 2.9 hours of direct care per day (http://www.oltca.com/oltca/Documents/Reports/WhyNotNowFULL_March2012.pdf). With a low staffing complement and few hours of direct care, even efficacious nonpharmacological therapies may not be implemented in specific settings due to the need for staff training and time. Nonpharmacological interventions can be aimed at prevention, amelioration/reduction or the elimination of NPS. While most studies have investigated the impact of a specific intervention on symptom reduction, future studies are needed to determine which strategies can be used to prevent symptom occurrence. Future studies could also examine the long-term impact of prevention on the development and expression of NPS as it is unknown if screening and monitoring behavioural symptoms at an early stage alters the course of NPS. Future studies are also needed not only to determine when strategies should be started but when they should be stopped. As well, it is unknown which patients may find certain therapies pleasurable in terms of duration and frequency. For example, aromatherapy may be pleasurable when experienced for a short duration but may cease to have an impact when people are exposed to scents on a continual basis or too frequently.

Conclusions

While the positive impact of increasing caregiver knowledge of strategies aimed at reducing the NPS of dementia as well as the positive impact of activities tailored to the person have been demonstrated, additional studies are needed to validate the use of other nonpharmacological approaches such as music therapy, Snoezelen therapy and exercise. Future large scale randomized controlled trials with adequate blinding and follow-up periods that use validated and responsive measures could examine efficacy, cost-effectiveness, safety, and feasibility.

References


NPS IN DEMENTIA


Rabins, P. V., Schwartz, S., Black, B. S., Corcoran, C., Fauth, E., Mielke, M., . . . Tschanj, J. (2013). Predictors of progression to severe
Alzheimer’s disease in an incidence sample. *Alzheimers Dementia, 9*(2), 204-207. doi:10.1016/j.jalz.2012.01.003


Optimizing the Care of Older Adults Living with Cognitive Impairment and Neuropsychiatric Symptoms: A Preliminary Assessment of Therapeutic Recreation in the Emergency Department

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Going to an emergency department (ED) is an anxiety-provoking experience for everyone but can be especially difficult for those living with cognitive impairment due to mental health concerns, addictions, dementia, or other neurological conditions. ED admissions for those living with cognitive impairment are not rare. Calculations derived from population prevalence estimates (Ng et al., 2015) and 2016 census data (Statistics Canada, 2016), suggest an estimated 4,018 people over the age of 40 are currently living with dementia in Middlesex-London. Further, with an annual ED visit rate of 556.5 per 1,000 (Canadian Institute for Health Information, 2010), an estimated 2,236 Middlesex/London residents living with dementia will attend an ED annually. As well, among the 3,361 people who are in a long-stay Middlesex/London long-term care (LTC) home bed (personal communication), an estimated 90% or 3,025 are living with some kind of cognitive impairment (Ontario Long-Term Care Association, 2017). As approximately one-quarter of all LTC home residents will attend an ED over a six-month period (Grunier et al., 2010), an estimated 756 Middlesex/London LTC home residents with cognitive impairment will go to an ED every six months.

An ED visit is especially challenging for those living with cognitive impairment who are also living with neuropsychiatric symptoms (NPS). NPS can include withdrawal from social activities, restlessness, repetitive motions, pacing, exit-seeking, calling out or screaming, hitting, kicking, or biting. NPS frequently occur among those living with vascular and neurodegenerative disease. For example, it is estimated that up to 80-97% of those living with Alzheimer’s Neurocognitive Disorder (NCD) will live with NPS at some point during their disease progression (Gautier et al., 2010). In a recent meta-analysis, Zhao et al. (2016) reported that among those with Alzheimer’s NCD, the pooled prevalence of aggression was 40%, disinhibition 17%, irritability 36%, euphoria 7%, delusions 31%, hallucinations 16%, sleep disorders 39%, depression 42%, anxiety 39%, apathy 49%, and appetite disorders 34%. While NPS may be due to many factors, including progressive neurological damage from an underlying neurodegenerative disorder, pre-existing psychiatric illness, physiologic deficits (e.g., dehydration), and medical issues (e.g., urinary tract infections) (Kales, Gitlin, & Lyketsos, 2015), such symptoms can also be interpreted as manifestations of unmet or misunderstood needs, especially among those living with both cognitive deficits and limited communication abilities (Cohen-Mansfield, 2000; Kunik et al., 2010). Sometimes termed “responsive” or “expressive” behaviours, NPS can put the person, care providers, and others at risk of harm (Rodney, 2000; Rosen, Pillmer, & Lachs, 2008).

Based on research findings and a push to promote a culture of healthcare that embraces personal control, dignity, and quality of life, strategies that promote healthcare providers’ understanding of the feelings and actions of those living with cognitive impairment and NPS continue to proliferate in Ontario and across Canada (Dyck, Kontos, Angus, & McKeever, 2005; Gutmanis, Snyder, Harvey, Hillier, & LeClair, 2015; Gutmanis et al., 2016; Mitchell, Dupuis, & Kontos, 2013). Knowing that strategies that increase care partner knowledge of possible causal
antecedents of responsive behaviours as well as their skills in reducing the frequency and expression of these behaviours (e.g., Seitz et al., 2012), numerous courses have been designed to help clinicians and care partners understand what is most meaningful to a person living with NPS and to assist them in the identification and implementation of strategies that could mitigate both the expression of NPS and the impact of factors that could exacerbate NPS (e.g., Putting the P.I.E.C.E.S. Together™ (P.I.E.C.E.S. Canada), Gentle Persuasive Approach (Speziale, Black, Coatsworth-Pusposky, Ross, & O’Regan, 2009), U-First! (Alzheimer Society Ontario, 2011).

A whole-person approach that includes the incorporation of psychosocial elements into care should be used across the healthcare continuum, including the ED (Mattu, Grossman, & Rosen, 2016). However, issues such as time constraints (Bolster & Manias, 2010) and a lack of understanding and awareness about responsive behaviours (Kontos, 2005) often preclude such practices from being implemented, especially in the ED. Further, while person-centred care is considered the gold standard (Han, Radel, McDowd, & Sabata, 2016), medical care, especially in a location where life and death issues are being managed, can often be centred on biomedical issues, that is to say on “cure” instead of “care”. Especially when a person is unable to clearly communicate their needs, a serious lapse in personalized care may arise (Fries, 2014).

Care in the Emergency Department

Often chaotic and overcrowded, EDs are a critical point of access to the healthcare system and provide essential care 24 hours a day, seven days a week. ED staff are tasked with rapidly identifying those who are critically ill, while efficiently diagnosing the underlying etiology, and promptly initiating life-saving therapies. An environment designed to focus on a single acute healthcare issue with a goal to rapid disposition is often not attuned to older adults who frequently present with acute-on-chronic complex medical issues (Kadam, Croft, & North Staffordshire GP Consortium Group, 2007) and who need continuity of care (Bayliss et al., 2015).

Unscheduled ED visits universally increase distress and anxiety, but are especially difficult for those living with dementia, who have twice as many visits to the ED as older adults without dementia (Ng et al., 2014). Unfamiliarity with the environment and routines, combined with the stress of whatever illness led to the ED visit (Dementia Initiative, 2013), as well as lack of ED staff knowledge of dementia care (Kelley, Parke, Jokinen, Stones, & Renaud, 2011) can lead to the emergence or exacerbation of NPS. Further, older adults with cognitive disorders may be at increased risk for escalating NPS due to a longer ED length of stay (Canadian Institute for Health Information, 2005) that may place them at increased risk for dehydration and infection (Cunningham & McWilliam, 2006), factors known to be associated with the expression of NPS. A recent literature review found that for every 10 additional hours in the ED, the risk for an adverse event increased by 20% among older adults living with NPS (Rhodes et al., 2016). In addition, people often arrive at the ED by ambulance, unattended by anyone who knows them. Being alone in an undesirable situation for prolonged periods of time can increase agitation (Buettner, Lundeberg, Lago, Farrell, & Smith, 1996). Cognitively impaired agitated older adults who wander may pose a particular problem in the ED. For safety reasons, they may be restrained (McBrien, 2007), which, in turn, may result in increased agitation (Werner, Cohen-Mansfield, Braun, & Marx, 1989), which may lead to hospital admission and/or refusal of readmission to the person’s prior living location (e.g., retirement or LTC home). Despite a trend of increasing numbers of older adults attending EDs (Wilber et al., 2006), a recent systematic review concluded that there is limited research on interventions that could improve the quality of care of older ED patients with cognitive impairment (Schmittk, Martin-Khan, Beattie, & Gray, 2013).

Efficacy of Leisure Activities in the Reduction of NPS

While there is limited research into strategies that could reduce the expression of NPS among older adults with cognitive deficits who are attending an ED, there is considerable evidence supporting the use of leisure activities as an effective strategy to mitigate the expression of NPS and to increase overall happiness among older adults in other settings. Although happiness is a fundamental human need that is integral to quality of life, those with dementia may be especially challenged to experience this emotion (Schreiner, Yamamoto, & Shiotani, 2005). Studies have found that leisure activities may play a very important role in stimulating positive affect and improving quality of life among those living with the NPS of dementia. For example, Albert et al. (1996) found that positive affect declines with increasing
dementia severity. As well, Hayaski et al. (2016) found that decreased positive affect was significantly correlated with decreased cerebral blood flow in the left premotor and superior frontal gyri and was inversely related to apathy and depression, symptoms common to those living with dementia (Levenson, Sturn, & Hasse, 2014). Further, those with dementia may lack the cognitive skills needed to independently and actively pursue pleasure-enhancing experiences (Lawton, Van Haitsma, & Klapper, 1996).

A number of studies have demonstrated the impact of specific recreational activities on the expression of NPS. For example, a 2005 systematic review found support for the effectiveness of music therapy (Livingston, Johnston, Katona, Paton, & Lyketsos, 2005). Another systematic review, conducted by Seitz et al. (2012), concluded that recreational activities, as well as music therapy and some types of sensory stimulation, such as aromatherapy and Snœzelen therapy, significantly reduced the expression of NPS.

**Individualized Approaches to Care**

While many of the systematic reviews of specific leisure-based strategies summarize the findings from studies that examined how a specific approach, on average, could reduce NPS among those with cognitive impairment, few reviews have examined the impact of individualized approaches to care. One systematic review of nonpharmacological strategies for the management of NPS among persons with dementia concluded that the most promising strategies seemed to be individually-tailored interventions, but that further evidence of this approach was needed (Ayalon, Gum, Feliciano, & Arean, 2006).

A systematic review conducted by Han et al. in 2016 focused on the benefits of individualized leisure and social activities among those living with dementia. Of the 11 studies that examined leisure and social activities that were tailored to the person based on performance factors, these authors concluded that such activities significantly decreased agitation and other NPS when compared to usual care or standardized activities (e.g., attending a group singalong). Specific activities were selected on the basis of information collected during interviews with a family member of the person living with dementia and were tailored to personal preference, cognitive or functional abilities, current needs, lifelong habits and roles, and current health status. Positive effects were also noted in duration and levels of participation, attention, and sleep. Greater benefits were found when activities were matched to both interests and functional levels or to interests alone. Further, negative outcomes, such as increased swearing and screaming, were observed in persons who were asked to do a standardized activity versus an individualized activity or during usual care.

Han et al. (2016) also reviewed six studies that examined the impact of leisure and social activities that were individualized based on self-identity. Self-identity, often measured by the Self-Identity Questionnaire, can be estimated from occupational or social roles, personal attributes/achievements, and lifelong leisure activities (Cohen-Mansfield, Parpura-Gill, & Golander, 2006). This tool is completed with information gathered through interviews with the person living with cognitive impairment and/or their care partners. Examples of activities associated with self-identity include past/present interest in art, music, pets, reading, television, and office work. Those living with dementia showed greater levels of engagement and pleasure and less agitation when provided with individualized stimuli than nonindividualized stimuli, except live social stimuli (e.g., one-on-one interactions with a research assistant or interactions with a live animal such as a dog). Further, greater levels of engagement were found when people were engaged in leisure activities that matched their current preferences more so than past preferences.

TR Specialists are in an ideal position to skillfully engage those living with NPS and get them to actively participate in individually-tailored leisure activities that could both promote the enhancement of a positive attitude and mitigate the expression of NPS. TR Specialists are healthcare professionals whose goal is to enable persons living with physical, cognitive, emotional, and/or social limitations to acquire and/or maintain skills, knowledge, and behaviours that will, in turn, promote leisure time enjoyment, increase functional independence, and foster participation as fully as possible in society (Therapeutic Recreation Ontario, nd).
evaluation, community practice, research, communication and inter-professional collaboration, professional accountability, and professional development (Therapeutic Recreation Ontario b, nd). Despite this standardized post-secondary school training, skepticism regarding the impact of TR on patient outcomes exists. For example, a recent American survey of healthcare administrators showed that TR may not be fully accepted as a legitimate therapy by the larger medical community, that TR was not well recognized by healthcare administrators who did not appreciate the level of education and training required to be a TR Specialist. As well, many felt that TR services could be provided by other healthcare professions (Harkins & Bedini, 2013). Such skepticism may impact healthcare leaders’ decisions to trial the services of TR Specialists in acute care.

Further, even when TR services are trialed, new care strategies may not be readily incorporated into patient care plans. Many factors influence the adoption of new approaches to care. Based on Rogers’ Diffusion of Innovation Theory (1995), it has been suggested that to be adopted, innovative practices need to demonstrate the degree to which: the change in practice is seen as being better than the idea it supersedes (relative advantage); the new practice fits with existing values, past experiences, and health care provider needs (compatibility); the new practice is difficult to understand and use (complexity); the healthcare providers can experiment with the new strategy (trialability); the benefits of the innovation are readily visible (observability); the healthcare providers can adapt, refine or modify the innovation to suit circumstances (reinvention); and the new knowledge can be readily transferred from one situation to another (ease of use) (Greenhalgh, Robert, MacFarlane, Bate, & Kyriakidou, 2004; Scott, Plotnikoff, Karunamuni, Bize, & Rodgers, 2008). This framework provides criteria by which the examination of TR in ED settings could be examined.

A Trial of Therapeutic Recreation in the ED: Preliminary Qualitative Results

The purpose of this qualitative program evaluation was to describe the impact of TR Specialists, who work as members of a local Geriatric Mental Health Outreach Team (GMHOT), on care provided to older persons exhibiting NPS who have been admitted to an ED. Funded by and based in the region’s acute care system, the formation of the inter-professional GMHOT was based on evidence that showed that inter-professional teams provide better and more integrated care than individual care providers, notably for those living with complex medical, psychological and social needs (Blewett, Johnson, McCarthy, Lackner, & Brandt, 2009). The GMHOT includes geriatric psychiatrists, a psychologist, nurses, social workers, occupational therapists, and, notably, TR Specialists who contribute to the provision of outpatient geriatric psychiatry consultation, assessment, and treatment within a teaching environment to rural and urban-dwelling older adults and their family members who are living in London, Ontario and the surrounding region.

The described ED offers tertiary/quaternary services to people living in the same geographic area and is the lead trauma centre for this region. This ED also specializes in acute mental health, oncology, critical care, medicine, cardiology, and general surgery services. An inter-professional team that includes nurses, emergency medicine consultants, medical residents, orderlies, social workers, and Home and Community Care case managers (in Ontario, Home and Community Care staff coordinate access to Adult Day Programs, assisted living, supportive housing, and LTC, and provide access to care options such as in-home nursing and personal support) provides emergency care for more than 59,000 patients annually.

Methods

Using a semistructured interview guide (Appendix A), the two TR Specialists on the London-Middlesex GMHOT were asked to reflect upon their work experience as team members and as members of an inter-professional team providing services in the ED. This key informant interview was recorded with permission. The audio-recorded interviews were analyzed along with field notes to create analytic memos that, when assembled, were iteratively reviewed and refined by IG, RD, LJJ, and ND. The authors acknowledge their position as authors co-constructing an account of this particular program. Formal ethics approval was not required and was not obtained for this program evaluation.

Preliminary Results

While a quantitative strategy that measures the impact of TR Specialists on client outcomes attending the ED using standardized tools has yet to be implemented, noteworthy impacts have been observed. TR Specialists are self-
reflective and routinely critically analyze their impact on and reaction to their clients (Millar & Pedlar, 2006; Gilbert, 2010). Self-reflection is especially important to TR practice as care strategies are developed within the context of leisure and recreation, which can promote a more informal person-therapist relationship (Briscoe, 2012).

Four key themes emerged: 1) the need for comprehensive inter-disciplinary assessment and care in the ED; 2) the benefits of meaningful activities based on self-identity; 3) changing the culture of care in the ED through knowledge diffusion; and 4) implementation challenges.

**Comprehensive Inter-Disciplinary Assessment and Care in the ED**

Drawing on best practices, a TR Specialist’s assessment of a person living with NPS is typically based on the P.I.E.C.E.S.™ framework, a tool designed to identify possible causes for NPS (P.I.E.C.E.S., 2016). Each letter of the acronym cues assessors to identify possible Physical, Intellectual, Emotional, Capabilities, Environment and/or Social factors that could trigger NPS (e.g., under “physical”, the assessor determines if any physical issues, such as pain, sensory loss, difficulty walking, ambient temperature, or medication utilization, might be triggering the expressed behaviour (Baycrest, nd). Participation and interest in leisure activities is usually assessed through ongoing observation and collaboration with the patient and their care partner(s). Information such as music preferences, favorite foods, personal achievements, and past and present pets is collected. This, as well as information specific to medical issues, usually gathered from the nursing/medical assessment and the person’s psychosocial history, often pulled from social worker or occupational therapy notes, is used to develop a comprehensive, holistic picture of the person and their life story. TR Specialists then develop a care plan, implement it, and evaluate the impact. Effective interventions are documented in progress notes and verbally shared with staff. A formal report, based on the Leisure Competence Measure (Kloseck, Crilly, Ellis, & Lammers, 1996), is added to the patient’s chart to ensure that all staff who are providing care and/or interacting with the person are aware of possible approaches to care (Appendix B).

Patients never remain in the ED; they are either transferred to an in-patient bed or return to their prior living situation. However, some discharge destinations, such as LTC homes, may be hesitant to take back someone whose NPS have led to an ED admission. In an effort to support successful transitions, promote continuity of care, reduce recidivism, and ensure that the person goes to their optimal care setting, assessment findings and a list of effective strategies are shared with care providers at the discharge location.

**Benefits of meaningful activities based on self-identity**

The TR Specialists were able to recount with ease specific times when meaningful activities based on self-identity successfully mitigated the expression of NPS.

The disruptive behaviours of a male patient with dementia – whose professional background included being a mechanic and a builder – decreased when offered a dry paint brush. With initial cueing and encouragement, he became interested in utilizing the brush and began to “paint” the hand railings and vents in the corridor.

On her way to see a patient in the emergency room, a TR Specialist was warned by a registered nurse to pay special attention to a patient who had been screaming and hitting and consequently restrained. Knowing the patient loved stuffed animals, the TR Specialist brought one with her, requested and obtained permission to remove one of the patient’s hands from the restraints, and observed the patient’s behaviours transform such that soon thereafter she was less agitated and able to take her medications without resistance or restraint use.

In these and other similar instances, the ability to become attuned to a person’s identity and to intervene with an activity that preserves or otherwise gives meaning to that person’s identity effectively mitigated the NPS that were being exhibited.

**Changing the culture of care in the ED through knowledge diffusion**

TR Specialists noted that their presence in the ED promoted a more holistic view of the patient. As well, the TR Specialists were able to recount situations that depicted a care culture that is becoming more adept at integrating TR care practices and, more broadly, at providing effective
interdisciplinary care. The following narrative shows that the impact of the TR Specialist suggested strategies can bereadily observed, that the strategies can be reinvented and trialed, and that the knowledge can be readily used by the inter-professional staff. In keeping with the tenets of Rogers’ Diffusion of Innovation Theory (1995), these characteristics suggest that there may be considerable potential for the uptake of this new approach to care.

The TR Specialist was asked to see someone in the ED who was becoming increasingly agitated. She found out that the person really loved to walk. After walking the hallways, they then engaged in a sorting activity. Later on, when the TR Specialist came back to see how the patient was doing, she noted that the ED nurse had the patient, who was now far less agitated, sorting bottles.

Having watched the de-escalation of NPS among some older ED patients following a walk with the TR Specialist, rather than calling security, ED staff are now seen walking with patients, allowing them to vent their frustration and anger.

ED staff are also sharing their experiences of how meaningful activities based on self-identify can mitigate the expression of NPS.

Security staff were monitoring a patient for safety reasons in the emergency room. The TR Specialist had previously assessed and completed a report for staff on this particular patient. As the TR Specialist went back to do a follow up visit in the ED, security staff, having already read her report but not recognizing the TR Specialist as its author, shared with the TRS the information they had gathered from the report – “Just so you know, he likes fishing and hunting.”

However, culture change and the diffusion of innovation takes time. As an estimated three people are seen each week in the ED, a culture shift, from a biomedical model to one that includes a holistic assessment of a patient’s life, will likely take time.

Implementation challenges

A number of barriers to the implementation of person-specific leisure-based strategies were identified. Information on past occupational or social roles, personal achievements, and lifelong leisure activities may be very challenging to obtain from a person exhibiting NPS, especially when there are no family present and the person is unable to verbally express their personal story. As well, ED staff may not have the time needed to get to know a person and any behavioural/environmental/other triggers in such a fast-paced environment. Further, to get a leisure-focused assessment, a physician order is needed, and TR Specialists are not available on a 24/7 basis. Moreover, not all suggested strategies work all the time; some do initially and then stop working as the person’s needs/health condition change. This constant need to adapt suggested strategies can sometimes lead to staff frustration. Finally, it was noted that some ED staff may feel that TR Specialists are there “to play games with patients.” Although both formal and informal education sessions that provide staff with more accurate information on the TR role are regularly offered, not all ED staff are able to attend.

At a very practical level, space in the ED is at a premium and the TR Specialists described some challenges in accessing, storing, securing, and cleaning recreation supplies. For example, ED staff might ask ‘Can you leave that here?’ (e.g., knitting supplies, an iPod™), but TR Specialists have learned from experience that doing so might lead to recreation supplies becoming lost, misplaced, ruined, or contaminated. Yet, to not make the supplies available may heighten the risk of ED staff not taking ownership of, implementing, or making use of TR Specialist recommended strategies.

Discussion

Despite challenges to implementing TR Specialist practices in an ED setting, this trial has shown that positive impacts have been observed in terms of preventing and/or mitigating NPS among ED patients with underlying cognitive impairments. Although few other studies have examined the impact of TR Specialists on NPS in ED settings, these findings that feature the incorporation of meaningful activities into effective care strategies support previously reported conclusions. For example, a recent study at North York General Hospital in Toronto as to the effectiveness of Montessori-based activities on the reduction of NPS among older adults attending the ED found that among the 49 enrolled patients who were living with a diagnosis of dementia and who exhibited NPS, behaviours resolved in 61% and improved in 34% of study patients after engaging in Montessori-based activities such
as sorting cards and looking at a laminated book that showed scenes that a person might encounter in the ED (Adams, 2014). An additional 34% experienced a reduction in NPS. One person’s NPS did not change and in one case there was an escalation in NPS.

These findings also highlight that the assessment of a cognitively impaired person’s leisure interests may be very challenging with a patient who is facing an unfamiliar ED environment and dealing with the stress of whatever led to the ED transfer and the consequent heightened emotional state. While the TR Specialist’s assessment of skills, strengths, and abilities may not truly reflect the person’s baseline level, the selection of an activity nonetheless ought to be based on something that is meaningful to the person’s self-identity, a findings that reinforces the notion that the impact of an intervention may be person-specific: an intervention such as painting might agitate a passive subject, while for an agitated subject, the same intervention may be calming (Fitzsimmons & Buettner, 2002).

Quantification of the impact of person-specific leisure activities in the ED is challenging but possible. The addition of TR Specialists to the ED care team may save hospital dollars. Strategies that reduce the expression of NPS among those living with cognitive impairment who are attending an ED may reduce stress among ED staff, restraint use, length of ED stays, hospitalization rates, and may promote successful return to a prior living setting thereby increasing system capacity and flow. Although more research is required to further validate these value propositions, it is clear that the potential to leverage significant value from the addition of a TR Specialist in the ED should be considered and evaluated.

The described program evaluation has several limitations. Only two TR Specialists from one tertiary care setting were interviewed. Future studies describing the experiences of other TR Specialists working in similar environments across Ontario are needed to gather broader insights. However, this may prove to be very challenging because, to the best of our knowledge, there are no other TR Specialists who provide care in any Ontario EDs. Further research is also needed to identify context-specific measures of symptom reduction that could then be used to assess the costs and outcomes associated with the implementation of TR Specialist identified leisure activities. Additional research into factors associated with ED clinician uptake of evidence-based TR Specialist suggested practices is also needed.

Conclusions

Building on the literature that supports the impact of person-specific identity-based leisure activities on decreasing NPS among those living with cognitive impairment, TR Specialists, members of an inter-professional GMHOT who are working in a busy ED that provides tertiary/quaternary services, have changed the way ED clinicians provide care to those living with NPS. TR Specialists noted that comprehensive, inter-professional assessment and care planning promotes holistic, patient-centered care. Further, meaningful activities based on self-identity often successfully mitigated the expression of NPS. Diffusion of TR knowledge and the application of strategies that have countered implementation challenges have led to the integration of suggested leisure activities into individualized care plans and cultural change. Future pan-Ontario research will promote broader insights into quantitative impacts associated with individualized leisure activities and NPS.

References


Appendix A

Key Informant Interview Guide

During the audio-recorded interview, conducted on October 16, 2015, both TR Specialists were asked to describe:

1. Their approach to care in the acute care sector
   - How does TR work within the Geriatric Mental Health Outreach Team’s model of care?
   - How was this practice innovative?

2. Success stories:
   - What enabled any successes? What worked for whom in what circumstances?
   - What have you learned from any failures and under what circumstances?
   - How are you assessing and measuring success?
   - Describe your relationship with other Geriatric Mental Health Outreach Team members.
Appendix B

Therapeutic Recreation Initial Assessment

Client’s Name: ________________________  Preferred Name: _____________  Age: ____  ID: ____  Date: ________________

Diagnosis: _____________________________________________________________________________________________________________

Social History

Marital status: ________________ Name of Spouse: __________________ (If deceased, when?): ________________________________

Children: _____________________________________________________________________________________________________________

Grandchildren: _______________________________________________________________________________________________________

Siblings: _____________________________________________________________________________________________________________

Significant People: ____________________________________________________________________________________________________

Place of residency (Past and Present): ____________________________________________________________________________________

Occupation: __________________________________________________________________________________________________________

Education: ___________________________________________________________________________________________________________

Language(s) spoken: ________________________________________________________________________________________________

Religion/Spiritual Beliefs: ______________________________________________________________________________________________

Music Preferences: _________________________________________________________________________________________________

Pets (Past and Present) (Names and types): ______________________________________________________________________________

Significant places, experiences, travelled: ______________________________________________________________________________

Personal achievements: ______________________________________________________________________________________________

Past and Present Routines: Is being helpful and/or productive important? Was there time for leisure activities? (e.g., caring for children, pets, cleaning, working, etc): __________________________________________________________________________

Fears or Phobias: ________________________________________________________________________________________________

Favourite foods: ____________________________________________________________________________________________________
**Participation Preferences:**

- Large Group ☐
- Small Group ☐
- Common Area ☐
- 1:1 ☐
- Alone ☐
- Own Room ☐
- Community ☐

In the past, how would you describe yourself?

- Very Social ☐
- Social ☐
- Somewhat Social ☐
- Prefers to spend time by him/herself ☐
- Private ☐

In present-day, how would you describe yourself?

- Very Social ☐
- Social ☐
- Somewhat Social ☐
- Prefers to spend time by him/herself ☐
- Private ☐

**Additional Information:**
____________________________________________________________________________________________________________
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**Leisure Profile:**

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<th>Past</th>
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<th>Past</th>
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<td>Cards</td>
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<td>Computer/Internet</td>
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<td>Chess/Checkers</td>
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<td>Crocheting/Knitting</td>
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<td>Home Repairs</td>
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<tr>
<td>Organizing/Sorting</td>
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<td>Puzzles (jigsaw or word)</td>
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<td>Reading</td>
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<td>Woodworking/Home Repairs</td>
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<td>Sewing/Needlepoint</td>
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<td>Baking/Cooking</td>
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<td>Ceramics/Pottery</td>
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<td>Children</td>
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<td>Cleaning/Folding</td>
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<td>Collections</td>
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<td>Crafts</td>
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<tr>
<td>Drawing/Sketching</td>
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<td>Flower Arranging</td>
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<td>Humour/Comedy</td>
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<td>Painting</td>
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<td>Plays an instrument</td>
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<td>Shopping</td>
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**PHYSICAL**

Bicycling  ☐ ☐
Boating/Water sports  ☐ ☐
Bowling/Shuffleboard  ☐ ☐
Exercises  ☐ ☐
Fishing/Hunting  ☐ ☐
Gardening  ☐ ☐
Sports _______________  ☐ ☐
Swimming  ☐ ☐
Walking/Hiking  ☐ ☐
Winter Activities___________  ☐ ☐

**SOCIAL**

BBQ’s/Picnics  ☐ ☐
Dancing  ☐ ☐

Future Leisure Interests: __________________________________________________________

Leisure Dislikes: __________________________________________________________

*Therapeutic Recreation Specialist will fill out the following* Goals (Client’s, Family, GMHOT):

Functional Intervention (Improve Functional Ability) ☐ _______________________________________
Leisure Education (Leisure Knowledge and Skills) ☐ _______________________________________
Leisure Participation (Organized Participation, Community Involvement) ☐ __________________

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<th>Strategies/Plan</th>
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Discussion Groups  ☐ ☐
Socializing/Family Visits  ☐ ☐
Special Events/Parties  ☐ ☐
Cultural Program  ☐ ☐
Devotional/Reading Material  ☐ ☐
Meditation/Yoga  ☐ ☐
Pastoral Care  ☐ ☐
Religious  ☐ ☐
Rituals/Items  ☐ ☐
Spiritual Television/Show  ☐ ☐
Singing  ☐ ☐
Other _______________  ☐ ☐