Suffering with advanced stage dementia/NCD, he seemed removed, by several degrees, from present moment of reality. Approaching a co-patient, he proceeded to throw his beverage upon him. It was a witnessed event. Staff intervened, controlling the situation. This unassuming elderly man had triggered a cascade of events. What followed was routine; in this case and in similar clinical scenarios across old aged residential facilities. Discourse amongst staff ensued to attempt to ascertain the meaning for the seemingly “unprovoked aggression”. This resident spoke only French, his primary language, as his previous mastery in English had eroded. He spent most of the day wandering the LTCF unit, “lost” in his own singular reality. Staff who understood what the resident was mumbling revealed him to be misidentifying the residential facility as the chapel where he worked as a janitor all his life. Amnestic and disorientated, the meaning behind his aggressive expressions weren’t overtly understood. The clinical staff and the doctor were left to wade through the mire of confusion in his expressions and navigate a plan and safe outcome by attempting to understand his reality in order to unveil the *meaning* inherent in his behavior.

Many varied and hypothetical meanings potentially underlying the aggressive expressions were placed forth; all plausible. They spanned the biological, (was he medically unwell? ‘does he have a UTI’?); psychological, (was he missing his wife, sad or depressed?), physiological ( was he uncomfortable due to constipation) and social (did he see the co-resident as an unwelcomed guest in his ‘chapel’. All equally valid perceptions, but staff found themselves again without a means to clarify. For clinicians lacked a comprehensive, comprehensible and concise tool to assess the presenting behavior whereby the findings would be consistent and assist in formulating a treatment plan. This is not atypical. On the contrary, rather typical, depicting the current landscape in assessment and management of residents with NCD exhibiting behavioral expressions in LTCF.

The prevalence of behavioral expressions, ‘agitation’ being one of its ubiquitous manifestation, is present in up to 90% of the residents in advanced stages of NCD residing in LTCF (Liperoti et al., 2008). As an example, ‘agitation’ is a manifestation in an acute confusional state of delirium which is also characterised by other symptoms of disorganised thinking, delusions and hallucinations, irritability, aggression and sleep disturbances. In acute onset psychotic episodes or acute exacerbation of chronic psychotic states, symptoms of delusions and hallucinations are often associated with disorganized speech, changes in emotions to include lability and volatility and aggression including ‘agitation’. An altered emotional state such as chronic severe depressive illness or a manifestation of an ‘anxiety disorder’ will present itself with symptoms of emotionality or irritability, being very needy or clingy and with a degree of restlessness and ‘agitation’. Unmet innate physiological needs in the form of need to void or defecate or seeking comfort for pain can produce a similar spectrum of symptoms ranging from emotional distress or irritability to restlessness and ‘agitation’.

The definition of the term ‘agitation’ in mental health literature, a symptom manifestation of various psychiatric illnesses is; “excessive motor activity associated with a feeling of inner tension” (American Psychiatric Association, 2000)).  Similarly, the Comprehensive Textbook of Psychiatry identifies agitation as, “severe anxiety associated with motor restlessness” (Kaplan & Sadock, 1995). Both of these definitions of ‘agitation’ are based in description of psychiatric disorders in general adult psychiatry and not specific to behavioral expressions in residents with NCD. Due to these inconsistencies around the definition of ‘agitation’, Cohen-Mansfield made a valiant effort to put some order in the use of this concept in dementia population. According to Cohen-Mansfield behavioural expressions in dementia can only be labelled as *agitation* once the following conditions have been ruled out:

* *Delirium* is a syndrome of impairment of consciousness and attention with disorganised thinking and abnormalities in mentation and behaviours. It is relatively rapid in onset with a characteristically fluctuating course,” (Caine, Grossman, & Lyness, 1995, p. 729). There are numerous causes of delirium and often a consequence of disturbance in individual’s medical condition.
* *Psychosis* is a state of breakdown in reality testing in an individual of any age including those experiencing cognitive impairment. Symptoms of psychosis are as described above.
* An individual’s *emotional state* refers to their internal emotions influencing behaviours. Internal emotional states may include symptoms of or syndrome of depression and/or anxiety and feelings of pain (Cohen-Mansfield, 2003).
* *Unmet needs* refer to any need of a person with dementia which may not be identified or attended to by the caregiver (CG) or care provider (CP). Common unmet needs may include hunger, thirst, pain, the need to use the washroom, as well as environmental needs (e.g. social stimulation or need for change of environment).

Hence, if an observer can attribute the manifestation of the behavioural expressions due to the resident’s innate physiological needs or secondary to any of the aforementioned clinical syndromes, then they cannot nor should they get labelled as *agitation*.  In fact, the diagnostic criteria for Behavioral Symptoms in NCD in DSM 5 and, all previous DSM books, have been built around the construct of ‘agitation’ put forth by Cohen-Manfeild. In everyday clinical practice, the labelling of behavioral expressions as ‘agitation’ invariably is done based on definitions put forth by Kaplan and Sadock (1995). Yet, the paradigm used to *quantify* the frequency and severity of the identified behavioral expressions is with *Cohen-Mansfield Agitation Inventory* (Morandi et al*.*, 2012).  Hence, there exists an obvious disconnect between the paradigm used to label and the one used quantify behavioral expressions in residents with NCD. This represents the current state of everyday clinical practice in the area of assessing and managing behavioral expressions in residents with NCD.

As has been mentioned earlier, the criteria to diagnose behavioral expression in DSM is structured around the construct of *agitation* put forth by Cohen-Mansfield. The diagnosis of behavioral expressions in NCD is one of exclusion in that all medical, mood, anxiety, psychotic disorders as well as unmet needs have to be ruled out prior to labelling symptoms as behavioral expressions in NCD.

In the early stages of dementia when it is possible to obtain a history from the patient, conduct a formal mental state examination with an appropriate physical examination, distinguishing amongst different clinical states, using established DSM criteria, can be achieved. However, as there is advancement in cognitive impairment into the late stages of NCD, engaging them in a clinically meaningful history taking and mental state examination becomes increasingly challenging as well as limited in its reliability and validity. Under these conditions, greater emphasis is put upon obtaining collateral information from all sources and on clinical observations of the family and the staff, instead of a formal clinical examination of the resident with NCD. Under these circumstances, it is not surprising at all that it becomes difficult not only to identify a given clinical diagnosis but also to distinguish amongst various clinical diagnosis. Such was the clinical dilemma with our French-speaking resident in the advanced stages of NCD.

A few standardised scales are available for use in these clinical scenarios to help in distinguishing amongst many of the aforementioned clinical conditions in residents with NCD. One example of these scales includes Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young, & Shamoian, 1988) and Dementia Mood Assessment Scale (Sunderland, Alterman, Yount, Hill, & Tariot, 1988). These two scales are frequently used to assess clinical depression in NCD. However, the primary role of these scales is to measure the severity of clinical depression and not to screen for and diagnose the presence of clinical depression in these residents (Visser, Verhey, Ponds, Kester, & Jolles, 2000), a common misuse of these scales in clinical practice. Alexopoulos et al (1988), in their original article, stated “The Cornell scale is a quantitative measure of depression. Although, its total scores correlate with the presence of depressive syndromes classified by RDC, the Cornel scale is not designed for the use as a diagnostic instrument”.

Another example of a scale used to screen for delirium in residents with NCD is the Confusion Assessment Methodology (CAM). This scale has a high validity and reliability in diagnosing acute confusional states in non-cognitively impaired patients. Adaptations of CAM scale have been validated such as CAM-ICU for non-verbal, ventilated patients. This and other adaptations include a cognitive and functional assessment or detailed descriptors of the target population and not the CAM criteria themselves (Ely, et al., 2001; Lewis, Miller, Morley, Nork, & Lasater, 1995; Marcantonio, Machaels, & Resnick, 1998; McCusker, Cole, Bellavance, & Primeau, 1998). CAM has not been validated in residents with advanced NCD( ). In residents with advanced stages of NCD, there are very often significant expressive language abnormalities inclusive of disorganised thinking and speech and detecting changes in them, from baseline, can be extremely challenging even for the most experienced clinicians. Furthermore, fluctuations in the course of behavioral expressions in the course of each day, day after day, in the form of diurnal variations (sundowning) occur in residents with NCD as well as those experiencing delirium. It is also the case with abnormalities in attentional abilities in the two cohorts.

Neuropsychiatric Inventory (NPI) was developed to measure neuro-psychiatric symptoms in residents with NCD as well as caregiver burden. There are twelve (12) different disturbances measured in this scale; delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behaviors, night-time behavior disturbances and appetite and eating abnormalities. There have been further modifications of NPI to include Neuropsychiatric Inventory-Clinician Rating scale (NPI-C) and Neuropsychiatric Inventory- Nursing Home (NPI-NH) to assess in residents dementia. In the NPI-C, of the total 128 dyads (‘caregiver/patients), 107 were mild to moderate dementia and only 21 were with severe dementia. In the NPI-NH, 41 patients were recruited for the reliability study and the severity of dementia was …………. Lai (2014) conducted a meta-analysis of the published paper which used NPI to assess symptoms in dementia and other neurological disorders between 1995 and 2013. Whereas, there were many strengths associated with NPI (content and concurrent validity, intra-and inter-rater reliability, test-retest reliability), one of the most pressing limitations of the tool was its inability to discriminate between different disorder. The paper concluded with stipulating ‘the clinical utility of the NPI also needs to be further explored’. The validity and reliability of many of the sub-scales of NPI (delusions, hallucinations, dysphoria and irritability) in advanced stages of NCD, when clinical examination becomes increasingly unreliable, needs questioning. Behavioral Pathology in Alzheimer’s Disease (BEHAV-AD) Rating Scale was specifically developed to overcome the identified limitations of all the existing measurement scales for lumping behavioral, cognitive and functional impairments. BEHAV-AD was focused on measuring the behavioral manifestations in Alzheimer’s disease with specific attention to identification of sensitivity of response to treatment with conventional psychotropic medications, in addition to non-pharmacological interventions. BEHAV-AD consisted of seven sub-scales; Paranoid and delusional ideation, Hallucinations, Activity Disturbances, Aggressiveness, Diurnal rhythm disturbances, affective disturbances and Anxiety and Phobias. It is, by far, the most comprehensive behavioral assessment scale in use in clinical practice. It offered the most comprehensive evaluation of the varied sub-types psychotic symptoms in individuals with Alzheimer’s disease. Its limitation has been the inability of BEHAV-AD to assist with identification and distinguishing amongst different disorders to guide pharmacological treatments. Finally, the inability of the residents with advanced stages of NCD to engage in clinical assessments would also apply to several subsections of BEHAV-AD as well.

For therein lays a broad reach of uncertainty magnified by a lack of confidence in available assessment tools for identifying behavioral expressions in residents with advanced stages of NCD. Indeed literature consistently demonstrates a relative paucity of reliable and valid assessment scales for patients with moderate to advanced stages of NCD (Morandi et al*.,*2012). This struggle has been further validated by World Health Organization (2012) in that the diagnosis of specific clinical states psychiatric co-morbidity or distinguishing amongst clinical states, in accordance with DSM is increasingly difficult and challenging in moderate to advanced stages of NCD (World Health Organization, 2012). Similarly, the Ontario Association of Non-Profit Homes and Services for seniors, in there 2005 Position paper, advocated for “better assessment tools, more coordinated services, more resources to support creative models within communities and increased funding to support the needs of those with complex mental health issues” (Alzheimer Society, 2005).

In light of the identified limitations in the application of all of the aforementioned clinical paradigms, literature started moving in a different direction. This direction seems to have emerged once there was acceptance of the paradigm of behavioral expressions being a ‘mode of communication’ for residents in advanced stages of NCD. It was proposed the residents in the advanced stages of NCD were no longer able to communicate or express themselves through language but were doing so through their behavioral expressions. The same would apply to residents with significant language abnormalities, both receptive and expressive, regardless of the stage or aetiology of NCD. The next natural step in this approach was developing approaches to understand the ‘meaning’ of this ‘mode of communication’ through the behavioral expressions. What are these residents with advanced stages of NCD saying to their family members and health care professional through their behavioral expressions? As a way forward, all recent literature is encouraging health care professionals to find “meaning” in the presence of behavioral expressions in residents with advanced NCD. Understanding the “meaning” of behaviors has been determined to be the essential step in order to make substantive progress in the assessment and management of behavioral expressions in dementia; both, advancement of non-pharmacological and pharmacological interventions. Yet, there has been a conspicuous absence of any direction for clinician in understanding the ‘meaning’ of behaviors in the advanced stages of dementia; when the reliability and validity clinical examination is highly questionable.

**All published literature is identifying the need to develop clinical paradigm, which will assist in understanding the “meaning” for the presence of behaviors in patients with D/NCD.**

**With this as the identified goal, guidance sought from existing published literature with a view to:**

1. Understand the reasons for paucity in the current state of affairs, and
2. Develop a comprehensive **Biopsychosocial Model** and a novel approach to labeling and **Classifying Behaviors** in moderate to advanced stages of D/NCD; in order to better understand their ‘meaning’.

The first step in this journey was a comprehensive review of the published literature in the field over the last three decades on the existing *terminology* and *models* put forth in understanding the presence of behaviors in D/NCD. The results revealed that literature was fraught with inconsistencies with respect to definitions of commonly used *terminology,* inconsistent and heterogeneous application of *terminology* for different sets of behaviors, in different clinical contexts in different clinical environments. Furthermore, all published *models* for understanding the occurrences of behaviors in patients with D/NCD were dichotomized along biological or psychosocial paradigms.

**A comprehensive biopsychosocial (BPS) model is yet to be developed!**

Acknowledging these deficits and adhering to the basic academic definitions of *Reference Terminology and Classification Systems* (3)*,* a sequential approach developed, as the way forward to address the identified deficits in the field. The first step was to posit a **Biopsychosocial Model** for the presence of behaviors in NCD. Literature identified multifaceted factors contributory to the occurrence of behaviors in patients with D/NCD:

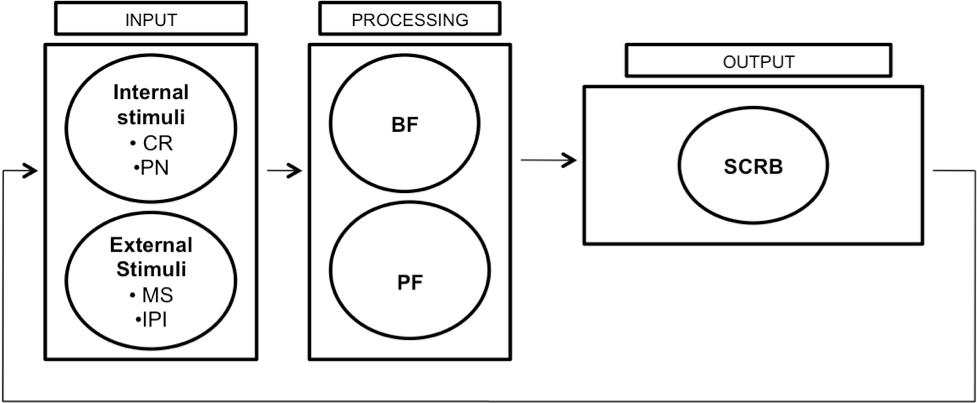
* **Biological Factors** [stage of the disease with or without the presence of premorbid presence or absence of co-morbid mental illness **(SOD),** inherent Circadian Rhythms **(CR)** and Innate Physiological Needs (**IPN**)],
* **Personal Factors** (pre-morbid personality and acquired coping strategies), and
* **Environmental Factors** [Milieu Structures (**MS**) and Interpersonal Interactions **(IPI**)].

A complex interplay amongst each of these variables hypothesized to justify the generation of a comprehensive **Biopsychosocial (BPS) Model** and the appointment of new *terminology* to label behaviors in D/NCD: ***Stage Congruent Responsive Behaviors (SRCB) (pronounced, “scrub”).*** Figure 1 describes how the **Biological**, **Personal**, and **Environmental Factors** interact dynamically amongst each other to result in generation of behaviors. **Internal Factors (CR or IPN)** and **External Factors (MS or IPI)** are inputted into the **Information Processing Module** [**Biological** (Stage of Disease) and **Personal (pre-morbid personality and acquired coping mechanism) Factors**].

The internal and external factors are assimilated, proccessed and integrated into meaningful bites of information and outputted as behavioral expressions. The quality of behavioral expressions chnages with the progression of the disease and its interplay with pre-morbid personality and acquired coping mechanisms thereby resulting in coining of the term Stage Congurent Responsive Behaviors (SCRB). The emergence of the behaviors are congruent, and responsive to, the chnages in the brain functioning witht the disease advancement. Please refer to the book for details on the functionaing of the model.

Figure 1.

Functional model of Stage Congruent Responsive Behaviors



The next obvious step was to seek direction, from published literature, on identifying an approach to classify behavioral expressions. The criteria put forth by Davis, Buckwater and Burgio (1997) selected to justify the methodology to classify behavioral expressions. This criteria and format chosen due to its relevance in classifying behavioral symptoms in D/NCD and its widespread acceptability. It is commonly cited and used in research regarding behaviors in persons with dementia/NCD or related mental health disorders.

**New Classification for SCRB**

Davis et al*.* (4) proposed a set of criteria, based upon these definitions, as a way of developing a more reliable and valid measure of classification of behaviors in D/NCD.  These criteria are as follows:

1. Identification of the target population,
2. Construction of items into categories which adequately represent the domain,
3. Definition of the ‘purpose’ and ‘meaning’ of the doamin, and
4. Specification of the construct of the category or domain.

Identification of target population.

Individuals with NCD who are unable to engage in a reliable and valid clinical assessment (history and mental state examination).

Construction of items into categories.

Collection of vast and heterogeneous phenotypic symptoms into a database. Manually stratifying the behavioral symptoms into ‘alike’ or similar’ categories. The chosen title of each of these ‘alike’ or similar’ categories adequately reflects the collective ‘meaning’ of the behavioral symptoms represented therein.

Definition of the purpose of the measure.

Defining the ‘purpose’ and ‘meaning’ of each established behavioral category; what is the individual with dementia communicating through their expressions. Family members and health care professionals need a framework to apply to the observed behavioral expression to interpret the reasons for their presence, in that context, the purpose it is serving the individuals with dementia. Defining ‘purpose’ and ‘meaning’ is essential to developing a fitting behavioral care plans to address the identified ‘needs’ being expressed through the behaviors.

Specification of the construct of each category.

Justification was sought from existing psychology literature to support the collection of ‘alike’ or ‘similar’ behavioral symptoms into individual behavioral categories, representing by an appropriate title, towards representation of their ‘purpose’ and ‘meaning’. To this end, extensive review of the literature in neuropsychology, behavioral psychology, general psychology and social psychology undertaken. Neuropsychology literature offered Theories on Regulation of Sensorium and Information Processing Theories, Behavioral psychology offered Motivational Theories, General psychology offered Theories on Regulation of Emotions and Social Psychology offered Theories on Principles of Compliance and Aggression.

Five theoretical psychological constructs were used to justify classification of individual behavioral symptoms into specific behavioral categories and each category reflecting a meaning herein. 1. Theories on Regulation of Sensorium 2. Information Processing Theories 3. Motivational Theories 4. Theories on Regulation of Emotions 5. Theories on Compliance and Aggression

**Behavioral Category justified by Theories on Regulation of Sensorium**

* Disorganized Expressions.

**Behavioral category justified by Information processing Theories**

* Mis-Identification Expressions.

**Behavioral Categories justified by Motivational Theories**

* Goal-Directed Expressions,
* Apathy Expressions,
* Importuning Expressions, and
* Motor Expressions.

**Behavioral categories justified on Theories in Regulation of Emotions**

* Emotional Expressions
* Fretful-Trepidated Expressions.

**Behavioral categories justified on Theories of Compliance and Aggression**

* Oppositional Expressions, and
* Physical Expressions.

**Heterogeneous Behavioral categories**

* Vocal Expressions, and
* Sexual Expressions

Behavioral categories of Vocal and Sexual Expressions required each of the three psychological constructs of Information Processing, Motivational and emotional regulation theories for their justification. Vocal and Sexual Expressions consist of six (6) subtypes under each of the two categories.

Individual behavioral categories emanating under this classification system led to their collation into a new dementia behavioral tool titled:

Luthra’s Behavioral Assessment and Intervention Response (LuBAIR™) Inventory

The validity and reliability study for the LuBAIR™ Inventory published in 2016.