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Review

Problems Associated with the Measurement of Neuropsychiatric Symptoms of Dementia

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Abstract

Neuropsychiatric symptoms (NPS) affect nearly all persons living with dementia (PLWD) at some point during the course of the disease. Given the absence of a cure or effective pharmacotherapy for dementia, it is particularly important to prevent, measure, track, and manage NPS in dementia care. Unfortunately, these efforts are hindered by inconsistent operational definitions and measurement tools for numerous neuropsychiatric symptoms. This review examines agitation, aggression, restlessness, and rejection of care as examples of NPS that are not consistently measured across research studies and scales. The results of a computerized search of peer-reviewed published studies of assessment tools measuring these NPS are reported. The differences in operational definitions and conceptual underpinnings of the four NPS are highlighted through comparisons of seven agitation measurements and four aggression measurements, and through a discussion of the inappropriate nesting of restlessness and rejection of care within co-occurring – but distinct – NPS. Universally-accepted consensus definitions of NPS are needed in order to develop accurate measurements around these definitions. Until that time, inconsistent nosology, conceptualization, and measurement will continue to confound our understanding of the prevalence and disease burden of these behaviors and hinder the development of effective interventions.

Keywords
Neuropsychiatric symptoms; dementia; assessment; definition; agitation; aggression; restlessness; rejection of care

1. Introduction

Neuropsychiatric symptoms (NPS) are a common feature of dementia and affect nearly all persons with the disease at some point [1, 2]. Also termed behavioral symptoms, behavioral and psychological symptoms of dementia (BPSD), or neurobehavioral symptoms, these clinical phenomena represent a heterogeneous group of non-cognitive symptoms and behaviors occurring in persons with dementia [3]. Often cited by caregivers as one of the most distressing aspects of dementia care [4], NPS lead to adverse outcomes for caregivers including higher caregiver burden and increased depressive symptomatology [5], reduced caregiver employment income [6], and adverse physical health and psychosocial consequences [7]. For persons living with dementia (PLWD), NPS are associated with more rapid disease progression [8], poorer quality of life [9], earlier long-term care placement [6, 10], and greater healthcare utilization and costs [11].

NPS are generally categorized into five primary clusters: depression, agitation, aggression, apathy, and psychosis [2, 12]. However, there are longstanding and growing questions as to whether measurement tools reinforcing these clusters are truly capturing the full range of NPS [13-15]. Furthermore, research finds that certain NPS long considered symptoms of another behavior may actually be distinct, thus requiring their own measurement items and interventions [15-19]. In other words, researchers have identified several behaviors that should be differentiated from rather than subsumed by other NPS as solely a symptom or indicator of those NPS.

There are numerous factors underscoring the need for precise measurement of neuropsychiatric symptoms. First, the capacity to assess, track and monitor, and manage NPS hinges on being able to accurately measure them at the outset. It is exceedingly difficult to evaluate the effectiveness of an intervention targeting a specific NPS if the measurement design is inexact. Second, the underlying cause of an NPS, such as an unmet need, may be missed or misidentified if the behavior itself is poorly understood. Research finds that accurate assessment of NPS may help identify and address potential unmet needs [20, 21]. Third, conceptual and operational discrepancies across measurement tools have led to poor understanding of the prevalence of various NPS. Prevalence is considered one of the most fundamental measures in epidemiology and can inform differential diagnosis as well as comparison of disease or symptom burden across locations or time periods [22].

Fourth, inaccurate measurement of NPS may not detect comorbidities or capture patterns of symptoms. Identification of comorbid NPS can elucidate the underlying neuropathology of those symptoms, including shared risk factors and causal mechanisms. Finally, most existing measures decontextualize behaviors and do not consider situational characteristics or the ecosystem in which behaviors occur [15]. This is unfortunate, as research suggests that NPS may result from the interaction of intrapersonal factors, unmet needs, neuropathology, and environmental conditions, among other variables [23, 24], and this contextual interplay should inform NPS interventions.

An additional concern with the NPS measurement tools currently available is the variability in time periods assessed. As NPS can fluctuate throughout the week, inconsistency in patterns and frequencies of symptoms can make accurate assessment as well as evaluation of intervention effectiveness challenging. For example, a measure that considers a single point in time or a period of three days may yield a very different symptom profile as compared to a measure that considers a one-month time period or more. Naturally, this can lead to errors or other issues when attempting to elucidate a symptom profile on from a single measurement tool. This problematic fluctuation in NPS and the variability of definitions of behaviors and their measurements may also be associated with the instability of NPS clusters over time [13]. For example, a recent systematic review of NPS clusters in persons with Alzheimer's disease found that no two studies reported the same factor composition [25].

While there are a number of neuropsychiatric symptoms for which researchers have identified inconsistent measurement, this manuscript focuses on four: agitation, aggression, restlessness, and rejection of care.

2. Methods

A systematic search for peer-reviewed published studies (January 1, 1980-December 1, 2019) was conducted in PsycInfo, CINAHL, CINAHL Plus, Google Scholar, Ovid, EBSCO, and Medline using the following terms: *neuropsychological tests, neuropsychological measurements, rating scale, instrument, dementia, Alzheimer's disease, behavior, neuropsychiatric symptoms, agitation, aggression, rejection of care, and resistiveness to care.* Additionally, a comprehensive search of book chapters, review papers, and meta-analyses of neuropsychological measures was performed and the reference sections were cross-checked with the initial computerized search. Papers identified through this process were further searched for additional references related to relevant assessment scales or studies. Studies and behavioral scales were selected with the following criteria: (1) published or available in English; (2) presented or utilized a behavioral scale or definition that either directly addressed agitation, aggression, rejection of care, or similar neuropsychiatric symptoms, (3) were developed for or tested in persons living with dementia, and (4) one or more psychometric properties were reported. As a recent, exhaustive literature search for dementia-related restlessness was previously conducted by this author [15], and new restlessness scales have not been published since that time, restlessness was not included in the systematic review.

3. Results

The initial search yielded 1,180 papers related to agitation, 430 papers related to aggression, and 27 papers related rejection of care. Manual searches of these papers led to the identification of an additional 14 papers on agitation and 13 papers on aggression. Among these 1,207 papers, 17 potential measures were identified for agitation, seven for aggression, and one for rejection of care. Of the measures included in this review, seven were focused exclusively on agitation, four focused on aggression, and one focused on rejection of care. As noted in the aforementioned systematic review [15], there are currently no scales that singularly target dementia-related restlessness. Findings related to the measurement of the four NPS of interest in this manuscript are described below.

3.1 Agitation

Agitation is a particularly challenging neuropsychiatric symptom to measure. It has become something of an umbrella term encompassing many different symptoms, some of which research suggests are distinct [15-18, 26, 27]. Consequently, there are a broad range of operational definitions for agitation across the literature. In one of the most commonly-used reference points, agitation is operationally defined as "inappropriate verbal, vocal, or motor activity that is not judged by an outside observer to result directly from the needs or confusion of the agitated individual." [28]

Additional definitions include agitation as "overt behavior that includes restlessness, hyperactivity, or subjective distress…[as well as] verbal or physical aggressive behavior not directed at a specific target," [29] agitation as behavioral manifestations representative of agitation, specifically "vocal and oral/facial movements, upper torso and upper extremity movements, and lower extremity movements," [30] and "vocal or motor behavior that is either disruptive, unsafe, or interferes with the delivery of care in a particular environment." [31] Inconsistency in terminology has resulted in varying incidence rates, data misinterpretation, and ineffective treatment approaches [26, 30].

In an effort to resolve the clinical and research challenges stemming from non-specific, variable definitions of agitation, an Agitation Definition Work Group (ADWG) was convened by the International Psychogeriatric Association (IPA) [32]. A consensus definition of dementia-related agitation was reached through a process of surveys, electronic communications, and face-to-face meetings with members of the IPA, its affiliates, and "other organizations involved in the care and research of neuropsychiatric disorders in patients with cognitive impairment." [32] This consensus defines agitation as (1) occurring in patients with a cognitive impairment or dementia syndrome; (2) exhibiting behavior consistent with emotional distress; (3) manifesting excessive motor activity, verbal aggression, or physical aggression; and (4) evidencing behaviors that cause excess disability and are not solely attributable to another disorder (psychiatric, medical, or substance-related) [32]. While this type of consensus work is an important first step towards promoting a universally-accepted definition of agitation in PLWD, the definition proposed by the ADWG includes aggression as a symptom of agitation, which is not supported by the literature. Furthermore, neither this definition nor a modified definition that recognizes agitation as distinct from aggression have been validated in assessment form. As such, established agitation measurement tools with discrepant items and underlying definitions continue to be used in dementia behavior research.

A comprehensive review of measures for agitation in dementia [33] found eight assessments solely targeting this NPS: the Cohen-Mansfield Agitation Inventory (CMAI) [34], the Disruptive Behavior Rating Scales (DBRS) [29], the Brief Agitation Rating Scale (BARS) [35], the Pittsburgh Agitation Scale (PAS) [36], the Overt Agitation Severity Scale (OASS) [30], the Scale for the Observation of Agitation in Persons with Dementia of the Alzheimer type (SOAPD) [37], the Agitated Behavior in Dementia Scale (ABID) [38], and the Cohen-Mansfield Agitation Inventory-Observational Version (CMAI-O) [39]. It is important to note that, while these eight assessments are included due to their intent to measure agitation alone, their symptom checklists may not be supported by current literature (e.g., may include items that were later recognized as being distinct rather than symptomatic of another NPS).

Across scales, there was a wide range of specificity in terms of the types of agitated behavior assessed, from the broad (e.g., "increased psychomotor activity") to the precise (e.g., "tapping toes, clenching toes, tapping heel, extending/flexing/twisting foot"). There was surprisingly low overlap among the items on each scale (Table 1), with the greatest overlap between the items on the CMAI and the BARS (11 items in common), primarily due to the fact that the BARS was derived from the CMAI [35]. The greatest overlap between two unrelated scales was the 10 items in common on the CMAI and OASS: pacing, wandering, cursing, verbal aggression, hitting, kicking, strange or disruptive vocalizations, handling/rummaging, repetitive mannerisms or motions, and inappropriate physical sexual behavior. In contrast, the DBRS and SOAP-D had only one item in common (increased psychomotor activity).

Table 1 An overview of instruments that exclusively measure agitation in dementia.

Behavior	CMAI	DBRS	BARS	PAS	OASS	SOAPD	ABID	CMAIO
Pacing	X	X	X	X	X			X
Wandering	X	X	X	X	X		X	X
Dressing/Disrobing	X			X				X
Spitting	X	X						X
Cursing	X	X			X			X
Verbal aggression	X	X			X		X	X
General aggression				X				
Requests for help	X							X
Repetitive questioning	X		X	X				X
Hitting	X	X	X		X			X
Kicking	X	X			X			X
Grabbing	X		X					X
Pushing	X		X					X
Throwing things	X	X						X
Strange/disruptive vocalizations	X		X	X	X	X	X	X
Screaming	X	X	X					X
Biting	X					X		X
Scratching	X							X
Eloping	X							X
Intentional falling	X							X
Complaining	X		X					X
Negativism	X					X		X
Inappropriate food/drink intake	X							X
Hurting self or others	X						X	X
Threatening physical harm		X						
Handling/rummaging	X				X			X
Hiding things	X							X

Hoarding things	X							X
Destroying property	X						X	X
Repetitive mannerisms or motions (e.g., rocking, picking at objects)	X		X	X	X	X		X
Inappropriate verbal sexual behavior	X							X
Inappropriate physical sexual behavior	X				X		X	X
General restlessness	X		X				X	X
Using weapons		X						
Physical aggression		X			X		X	
Criticizing		X						
Scolding		X						
Hand wringing		X			X			
Unable to be still		X						
Rapid speech		X						
Increased psychomotor activity		X				X		
Expressions of distress		X						
Banging on things				X				
Stealing				X				
Resisting care				X			X	
Repetitive mouth movements (e.g., lip smacking)					X			
Tapping fingers or feet					X			
Arguing							X	
Anxiety							X	
General agitation		X					X	
Waking caregiver							X	
Delusions							X	
Hallucinations							X	
Inappropriate social behavior							X	

Note: CMAI = Cohen-Mansfield Agitation Inventory; DBRS = Disruptive Behavior Rating Scales; BARS = Brief Agitation Rating Scale; PAS = Pittsburgh Agitation Scale; OASS = Overt Agitation Severity Scale; SOAPD = Scale for the Observation of Agitation in Persons with Dementia of the Alzheimer type; ABID = Agitated Behavior in Dementia Scale; CMAIO = Observational Cohen-Mansfield Agitation Inventory

Five scales were developed for use with nursing home or long-term care residents living with dementia [29, 34-37], two were applicable to inpatient settings or units [30, 36], and two could be used with community-dwelling PLWD [34, 38].

Psychometric properties of the agitation scales were assessed, specifically reliability and validity. With regard to reliability data, 75% reported internal consistency (i.e., Cronbach's α) [30, 34-39], 75% reported interrater reliability [29, 30, 34-37], and only one reported test-retest reliability [38]. In terms of validity, only one scale reported convergent validity [30], 37.5% reported concurrent validity [29, 35, 37], 25% reported content validity [30, 37], one scale reported discriminant validity [37], 37.5% reported an unspecified validity indicator [34, 36, 38], and one scale reported criterion, incremental, and discriminant validity [39].

In addition to the eight agitation-specific scales, there are at least ten general dementia behavior scales in the literature that include items intended to measure agitation [33, 40]. These include the Consortium to Establish a Registry for Alzheimer's Disease Behavior Rating Scale for Dementia (CERAD-BRSD) [41], the Behavior and Mood Disturbance Scale (BMDS) [42], the Columbia University Scale for Pathology in Alzheimer's Disease (CUSPAD) [43], the Behavioral Syndromes Scale for Dementia (BSSD) [44], the Comprehensive Psychopathological Rating Scale (CPRS) [45], the Dementia Behavior Disturbance Scale (DBDS) [46], the Alzheimer's Disease Assessment Scale (ADAS) [47], the Dysfunctional Behaviour Rating Instrument (DBRI) [48], the California Dementia Behavior Questionnaire (CDBQ) [49], the Neurobehavioral Rating Scale (NBRS) [50], and the "gold standard" in NPS research, the Neuropsychiatric Inventory (NPI) [51]. Scale comparisons can be found in previous research [15, 33, 39] and, as with the agitation-specific scales, there were a variety of terminologies and items aimed at capturing this NPS.

3.2 Aggression

Aggression is a common clinical manifestation in dementia that poses great challenges for PLWD as well as caregivers [52]. Most dementia caregivers find aggressive behaviors difficult to manage, emotionally distressing, and often dangerous, which leads to feelings of powerlessness, sadness, and a sense of being ineffective [53]. A frequently-used general definition of aggression describes this as "overt behavior of animals or humans involving intent to harm another organism or inanimate object." [54] Another operational definition of this NPS describes it as "an overt act, involving the delivery of noxious stimuli to (but not necessarily aimed at) another object, organism or self, which is clearly not accidental." [55] Dementia-related aggression is usually characterized by either verbal insults and shouting or physical acts (e.g., hitting, biting, throwing objects) as well as sexually aggressive behavior, and often occurs during the provision of personal care [56].

As with several other dementia behaviors, aggression is often measured as a symptom of agitation rather than a distinct NPS. However, research suggests that these NPS should be differentiated, do not always co-occur, and have differential effects on caregivers and unique treatment routes [57, 58]. In contrast to agitation, aggression is related to a greater likelihood of caregiver depression and perceived burden [49, 59]. Furthermore, defining aggressive behavior as a type of agitation precludes the development and implementation of targeted interventions for behaviors that require different approaches [59]. While aggression and agitation are overlapping NPS, they are not identical [60]. As noted by the ADWG, agitation can occur in the absence of aggression, and predatory aggression can occur without agitation [32].

Further complicating the measurement and treatment of aggression, resistiveness to/rejection of care is often referred to in the literature as a symptom or type of aggression. As detailed below, a type of aggressive behavior known as reactive aggression is caused by rejection of care and occurs when PLWD do not understand the need for care or misconstrue the intention of the care provider [61]. Due to executive dysfunction, PLWD rarely exhibit proactive aggression, which involves using aggressive behavior as a means to achieve a particular goal and is usually premeditated [61-63].

A review of measures for aggression in dementia [33] found four assessments solely targeting this NPS: the Overt Aggression Scale (OAS) [64], the Ryden Aggression Scale (RAS) [65], the Rating Scale for Aggressive Behavior in the Elderly (RAGE) [55], and the Aggressive Behavior Scale (ABS) [66]. Items on these four scales varied widely (Table 2) and there were substantially less commonalities as compared to the agitation scales. The greatest overlap was between the OAS and RAGE, with the following 10 items in common: shouting, insulting others, cursing, threatening self or others, throwing or kicking objects, acts leading to mild-moderate self-harm, physically threatening others, hitting, kicking, pushing, and causing mild-moderate injury to others. The ABS had the lowest overlap with any scales, as it had only one item in common with the RAGE (resistance to care) and no items in common with the other three aggression scales.

Table 2 An overview of instruments that exclusively measure aggression in dementia.

Behavior	OAS	RAS	RAGE	ABS
Loud noises	X			
Shouting	X		X	
Insulting others (e.g., name calling, being critical)	X	X	X	
Accusatory language		X		
Cursing	X	X	X	
Demanding/arguing			X	
Threatening self or others	X	X	X	
General verbal abuse				X
Slamming doors	X			
Making a mess	X			
Throwing or kicking objects	X	X	X	
Breaking objects or destroying property	X	X		
Setting fires	X			
Picking or scratching at self	X			
Mild-to-moderate self-harm (e.g., banging head, throwing self to floor)	X		X	

Cutting self	X			
Severe self-harm (e.g., self-mutilation, internal injury)	X			
Physically threatening others (e.g., gesturing, lunging)	X	X	X	
Pinching		X		
Hitting others	X	X	X	
Kicking others	X	X	X	
Pushing others	X	X	X	
Tackling others		X		
Elbowing others		X		
Slapping others		X		
Scratching		X		
Spitting		X		
Brandishing weapon		X		
Biting		X	X	
Using a weapon		X		
Causing mild-moderate injury to others	X		X	
Striking others with object		X		
Causing severe injury to others	X			
General physical abuse				X
Unwanted hugging		X		
Unwanted kissing		X		
Touching others' body parts		X		
Making obscene gestures		X		
Intercourse		X		
Disobeying rules			X	
Resisting care			X	X
Irritability			X	
Impatience			X	
Antisocial acts			X	
Angry with self			X	
Socially inappropriate behavior				X
Overall aggression			X	

Note: OAS = Overt Aggression Scale; RAS = Ryden Aggression Scale; RAGE = Rating Scale for Aggressive Behavior in the Elderly; ABS = Aggressive Behavior Scale.

The type of aggression, object of the aggressive acts, and context of the aggressive behavior were important specifiers that did not always align across scales. For example, only the RAS directly measured sexual aggression. Severe self-harm, such as self-mutilation, was only measured by the OAS, and (unspecified) antisocial behavior was only measured by the RAGE. Resistance to care was assessed by both the RAGE and the ABS. The OAS and RAS provided very specific examples of each type of aggression measured, while the ABS was a summary scale of four items on the Minimum Dataset (MDS) 2.0: verbal abuse, physical abuse, socially inappropriate or disruptive behavior, and aggressive resistance of care using verbal or physical methods [66].

Regarding the target population, two scales can be used with nursing home residents living with dementia [55, 66], two can be used with hospital patients [64, 65], and one can be used with psychiatric inpatients [64]. Only the RAS was designed for use with community-dwelling PLWD [65].

Reliability and validity of the aggression scales were assessed. With regard to reliability data, 75% reported internal consistency (i.e., Cronbach's α) [55, 65, 66], 75% reported interrater reliability [55, 64, 65], and 50% reported test-retest reliability [55,65]. Regarding validity, 50% reported concurrent validity [55, 66], and one scale reported construct validity and content validity [65].

In addition to the four aggression-specific scales, there are at least seven general dementia behavior scales in the literature that include items intended to measure aggression [33]. These include the Behavioral Pathology in Alzheimer's Disease (BEHAVE-AD) scale [67], the BSSD [44], the CERAD-BRSD [41], the DBDS [46], the Dementia Signs and Symptoms Scale (DSS) [68], the Nursing Home Behavior Problem Scale (NHBPS) [69], and the NPI [51]. Comparisons can be found in previous research [15, 33], and the problem of varying operational definitions persists across these scales.

3.3 Restlessness

Restlessness appears to be a particularly common NPS, and preliminary research indicates that it affects more than 64% of persons with dementia [16]. This research also suggests an association between restlessness and adverse outcomes for the caregiver-person living with dementia dyad. Unfortunately, as is characteristic of the field, restlessness is often classified as a form of agitation and remains poorly understood, ambiguously described, and measured with varying definitions in studies on NPS in persons with dementia. The continued lack of a clear and consistent conceptualization of dementia-related restlessness has significant implications for treatment, as appropriate treatment is guided by diagnosis. Nesting restlessness within agitation inventories prevents researchers from understanding its specific contribution to disease burden, both for PLWD and caregivers. In addition, the effectiveness of interventions for restlessness behaviors cannot be gauged without valid and reliable measurement of the this NPS. Regarding research consequences, as with agitation and aggression, the prevalence of restlessness has not been accurately recorded due to inconsistent nosology, measurement, and conceptualization.

A systematic literature review found no scales specific to dementia-related restlessness [15]. Scales specific to other NPS and general NPS scales assign numerous labels to these behaviors, including "restlessness/restless/general restlessness" [34, 38, 69-71], "nighttime/sleep restlessness" [72-74], "motor restlessness" [75], "agitation" [29, 48-50, 76], "motor agitation"

[36], "physical agitation" [74], "activity disturbance" [77], "noncognitive behavior" [47], "limb movements" [46], "anxiety" [72], "disinhibition" [44], "mechanical/motor" [78], "behavioral disturbances" [43], "fidgets/unable to sit still" [69], "excessive motor activity" [50], "aberrant motor behavior" [51], "overactive behaviors" [68], "defective self-regulation" [41], and "walking behaviors" [79]. As is evident from this list, conceptual and operational confusion regarding restlessness is pervasive throughout the dementia literature.

The ambiguous and varied definitions of restlessness were first noted more than 20 years ago [80, 81]. At that time, initial efforts were made to develop a unified definition of this NPS. However, problems with these proposed definitions included a lack of accounting for the effects of dementia on cognition [80], lack of specificity to the manifestation of restlessness within the dementia course [81], and insufficient distinctions between restless behaviors and other, related NPS [81]. Recently, a renewed research focus on the measurement of restlessness yielded a new proposed definition based on: a review of the literature for existing definitions and measures of restlessness, identification of common elements across existing definitions, assessment of fit with relevant theoretical frameworks, and an exploration of the relationship between restlessness and other behavioral symptoms [15].

Regier and Gitlin [15] proposed that dementia-related restlessness consists of three key attributes: 1) diffuse motor activity or motion subject to limited control that is judged by a clinician, caregiver, or observer to be excessive and/or inappropriate to the circumstances, 2) non-productive or disorganized behavior that fails to appropriately address or target potential underlying causes, and 3) subjective distress communicated by the person with dementia or extrapolated from the behavior itself. The authors further emphasize that restlessness should be "differentiated from and not confused with wandering or elopement, pharmacological side effects, a (non-dementia) mental or movement disorder, or behaviors occurring in the context of a delirium or at end-of-life." [15] As compared to restlessness, agitated behaviors are typically better organized, can be motor or verbal (vs. solely psychomotor), and may be aggressive or non-aggressive in presentation [82]. Early restlessness researchers also described agitation as a discontinuous episodic motor or verbal behavior that required intervention to prevent harm to self or others, whereas restlessness was viewed as a continuous, harmless behavioral state [83, 84].

The definition proposed by Regier and Gitlin [15] represents the first step towards advancing a definition of restlessness for use in clinical and research settings. However, as this definition is still provisional, additional steps must be taken and are in process in order to fully adopt this definition within the field. For example, validity studies, reliability of the provisional definition, and its utility in pilot studies and subsequent clinical trials must be examined in order to empirically validate the definition.

3.4 Rejection of Care

Also referred to as resistance to care, uncooperative behavior, and noncompliance [85], rejection of care (RC) in PLWD has been defined as "the repertoire of behaviors with which persons with dementia withstand or oppose the efforts of a caregiver [86]." RC behaviors can occur during activities of daily living, when diagnostic or therapeutic interventions are provided, or when the caregiver attempts to redirect the PLWD [86]. RC, like restlessness, has long been couched within the definitions of other neuropsychiatric symptoms; specifically, agitation and

aggression. For more than a decade, however, research findings have indicated that agitation, aggression, and RC are related but not equivalent [18, 19].

Several key features differentiate RC from other co-occurring NPS. In contrast to aggression, the posited underlying intent of RC is to reject or refuse needed care but not to harm others [85, 87]. RC may lead to aggressive behavior, however, when the PLWD is depressed [88] or misunderstands the intentions of the care provider [58]. In contrast to agitation, RC does not communicate unmet needs [89] and is therefore not decreased through stimulation and meaningful activity. Furthermore, agitation and RC are related to dementia severity in different ways. Agitation is present at very early stages of dementia, doubles in prevalence in the moderate stage, and decreases as dementia progresses to severe/end stages, whereas RC is infrequent in early stages and increases eightfold by severe dementia [19].

A review of the literature revealed one scale specific to RC [86], and at least three general dementia behavior scales in the literature that include items intended to measure this NPS [33, 51, 78, 90]. The Resistiveness to Care Scale-Dementia of the Alzheimer Type (RTC-DAT) [86] is a 13-item scale measuring the duration and intensity of the following behaviors: “turning away, pulling away, pushing away, pushing/pulling, grabbing an object, grabbing a person, adducting, hitting/kicking, saying no, crying, threatening, screaming/yelling, and clenching mouth.” The scale also specifies the care context of RC. The authors of this scale reported acceptable reliability (internal consistency, inter-rater reliability) and validity (content validity, construct validity). Since its inception, the RTC-DAT has been used in numerous research studies, and the primary author has presented detailed recommendations for conducting research on RC [86]. However, the publication of the RTC-DAT does not preclude the use of established general NPS assessment scales that miscategorize RC as a form of agitation or aggression.

4. Conclusions

Neuropsychiatric symptoms affect nearly all persons living with dementia [1, 2], regardless of etiology, and are associated with poor patient and caregiver outcomes [4-11]. Management of these symptoms presents significant challenges for both formal and informal caregivers and is therefore a critically important aspect of dementia care.

The first step towards managing NPS is identifying when they occur [91], which cannot be done without accurate measurement tools. Furthermore, accurate measurement is built upon a sound operational definition. Unfortunately, there are numerous neuropsychiatric symptoms for which there is either no commonly accepted consensus definition, or for which the utility of a consensus definition continues to be hampered by ongoing use of problematic assessment tools. Agitation, aggression, restlessness, and rejection of care, described herein, are several examples of NPS that are not consistently measured across research studies and scales.

As noted by Mahoney [86], research does not progress efficiently when different terms are used for NPS. Indeed, inconsistent nosology, measurement, and conceptualization have confounded our understanding of the prevalence and disease burden of dementia-related agitation, aggression, restlessness, and rejection of care. In addition, intervention development, evaluation of intervention effectiveness, and assessment of dementia caregivers’ needs are adversely impacted.

It is vital that researchers in this field acknowledge, promote, and endeavor to remedy the need for better measurement of neuropsychiatric symptoms. This review was undertaken in order to spotlight the myriad issues with the current methods of measuring neuropsychiatric symptoms and provide recommendations for future directions in research and measurement development in this area. Suggestions generated by this review include modifying the consensus definition of agitation [32] to exclude aggression as a symptom, developing assessment scales that incorporate this modified definition, distinguishing aggression from rejection of care in future scales, validating the provisional definition of restlessness [15], and increasing the utilization of the RTC-DAT [85]. Future researchers may also consider whether the operational definitions of NPS should remain stable over time, or if criteria should be modified according to dementia staging. As it is estimated that there will be 152 million persons living with dementia worldwide by 2050 [92], and up to 90% of PLWD experience NPS [93], it is critically important that the measurement and management of neuropsychiatric symptoms remain a top priority in the field of dementia research.

Author Contributions

Natalie Regier conceived, planned, researched, and wrote the manuscript independently.

Competing Interests

The author has declared that no competing interests exist.

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