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Research Article

Nomenclature Used by Family Caregivers to Describe and Characterize Neuropsychiatric Symptoms

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Abstract

Background and Objectives: Neuropsychiatric symptoms (NPS) are a core feature of Alzheimer's disease and related dementias that are characterized by a fluctuating course. NPS are challenging to manage and contribute to high rates of burden among family caregivers. Successful information exchange between clinicians and family caregivers is critical for facilitating effective management of NPS. However, this communication is often challenging due to inconsistent terminology and classification of symptoms and limited understanding of how family caregivers recognize and describe symptoms. The objective of this study was to examine the language family caregivers' use to describe and contextualize NPS.
Research Design and Methods: Descriptive qualitative study of 20 family caregivers in a mostly urban county in the Midwestern United States using semistructured interviews. Caregiver descriptions of NPS were analyzed using directed content and text analysis to examine terminology, followed by a thematic analysis approach to examine contextualization of NPS.
Results: Caregivers employed shared terminologies to describe NPS that differed substantially from clinical terminology used to classify symptoms. Caregivers frequently engaged sense-making as a strategy to explain NPS. This sense-making served to contextualize patterns in behavior and was characterized by explanatory, situational, and strategy-oriented frameworks for understanding behavior in terms of its purpose and meaning. Caregivers' descriptions of NPS reflected broad overlap between individual NPS (i.e., agitation and care resistance) that would generally be considered clinically distinct symptoms.
Discussion and Implications: Nomenclature surrounding NPS may vary considerably between family caregivers and clinicians, and should be evaluated in partnership with people with dementia and their caregivers to ensure supportive interventions and resources are responsive to caregivers' interpretation of symptoms and sense-making.

Key words: Neuropsychiatric Symptoms, Dementia, Caregiving-Informal, Behavior

Neuropsychiatric symptoms (NPS)—a heterogeneous set of symptoms reflecting altered mood, behavior, perception, or thought content—are a core and nearly universal feature of Alzheimer's disease and related dementias (Gitlin, Kales, & Lyketsos, 2012). Varying in presentation and etiology, NPS are understood to have biopsychosocial and caregiving determinants (Kales, Gitlin, & Lyketsos, 2015; Kolanowski et al., 2017). Their fluctuating course complicates their management, most of which takes place at home through the work of unpaid family and friend caregivers (McCabe, You, & Tatangelo, 2016; Schulz & Martire, 2004).

NPS represent one of many daily challenges which family caregivers must manage (Oken, Fonareva, & Wahbeh, 2011). In addition to contributing to adverse psychological outcomes for family caregivers, poorly managed NPS are detrimental to the individual with dementia and hasten disease progression, increase risk for institutionalization, and reduce quality of life (Lyketsos, 2015; Tun, Murman, Long, Colenda, & von Eye, 2007; Wancata, Windhaber, Krautgartner, & Alexandrowicz, 2003; Yaffe et al., 2002). Effective management of NPS requires successful information exchange between clinicians and family caregivers to delineate symptom patterns, identify contributing factors, and incorporate targeted interventions (Holmes & Adler, 2005; Kales, Gitlin, & Lyketsos, 2014). Findings from prior qualitative research to understand dementia caregivers' information needs suggest that many caregivers do not initially identify NPS as being a symptom of dementia (Peterson, Hahn, Lee, Madison, & Atri, 2016). Caregivers have reported uncertainty regarding how to describe NPS served as a barrier in information seeking efforts to identify management strategies (Peterson et al., 2016). A recent review of dementia family caregiver needs highlighted the role of formal care providers in meeting informational needs in order to apply practical information to help them with NPS management—yet a lack of shared understanding with their care recipient's health care team was a barrier in meeting these needs and could contribute to inadequate or undesirable plans of care (Holmes & Adler, 2005; McCabe et al., 2016). Primary care providers, who often play a central role in the health care team for persons with dementia, have similarly identified a need for improved dementia-specific education regarding diagnosis, supportive services, and symptom management (Foley, Boyle, Jennings, & Smithson, 2017) and general discomfort in managing NPS (Jennings et al., 2018). Decisional support surrounding NPS management and "behavioral crisis" events have also been identified by family caregivers and clinicians as a determinant of acute care utilization and an important focus for caregiver and family communication, with stakeholders expressing a desire for more focused improvements in these areas (Jacobsohn et al., 2019; Jennings et al., 2015; Werner et al., 2017).

The effectiveness of clinician-recommended strategies to prevent and respond to NPS depends on the clinician's accurate understanding of distinct symptom trajectories in the home environment and, reciprocally, the caregiver's understanding regarding treatment plans. Despite the importance of ensuring bidirectional communication about symptoms and the complexity of NPS, there is little research on the role of NPS nomenclature in clinician-family communication and symptom management. Classification and terminology used to describe NPS have been informed almost exclusively by researcher and clinician-derived frameworks attempting to specify the broad range of symptomatology present in dementia. Even within scientific and lay-audience literature, these symptoms are referenced using a myriad of terms including behavioral and psychological symptoms of dementia, behavioral disturbances, behavioral symptoms, and responsive behaviors among others (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). Despite the critical importance of delineating specific symptom features for clinical management, these symptoms are often broadly grouped under major domains (i.e., mood disturbances and agitation), which also lack precise and consistent definitions (Cerejeira et al., 2012). Language used to describe specific symptom profiles also varies across standard measurement tools. Additionally, the manner in which caregivers understand NPS may differ, given differences in caregiver-care recipient relationships, cultural norms, and management needs, further hindering bidirectional communication between caregivers and clinicians (Brodaty, 2009, Stella et al., 2015).

Understanding caregivers' language for describing NPS also holds important ethical considerations, as current labeling of symptoms is viewed by some dementia advocacy groups as a negative, deficit-oriented characterization of common responses to cognitive impairment (Dementia Action Alliance, 2015). The National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers acknowledges these concerns through the development of key recommendations for developing improved nomenclature in dementia that highlight the views of caregivers and individuals with dementia regarding confusing and stigmatizing terminology (Gitlin, Maslow, & Khillan, 2018). These recommendations follow standards developed by national and international societies and organizations to address language used to describe aging and dementia that many find stigmatizing and unproductive ("Dementia Action Alliance, 2015; Lundebjerg, Trucil, Hammond, & Applegate, 2017; Stall, Campbell, Reddy, & Rochon, 2019).

To explore family caregivers' nomenclature surrounding NPS in dementia, we conducted semistructured interviews with family dementia caregivers focused broadly on their daily caregiving experiences. Our objective was to identify terminology employed to describe NPS and to examine contextual factors surrounding this nomenclature.

Methods

Study Design and Sample

This study used a descriptive qualitative approach with semistructured interviews to understand how caregivers describe and contextualize NPS. Major research questions, the interview guide, and the use of qualitative approaches were established a priori. Institutional Review Board (IRB) approval was also sought and given prior to commencement of study procedures. To reach the most diverse group of participants possible, a multipronged recruitment strategy was used, spanning several counties, communities, academic, and hospital settings. Participants were recruited through flyers posted online and in local community venues, such as coffee shops, libraries, community centers, Aging and Disability Resource Centers, and senior centers. Lastly, participants were recruited through an acute care recruitment mechanism, wherein a hospital-based study recruiter monitored patient/caregiver dyads enrolled in the transitional care services for eligibility and invited eligible caregivers who were present during the hospital stay to participate.

Inclusion criteria were broad; to participate, one had to provide unpaid, nonprofessional care for a person with dementia, be over 18 years old, and speak and understand English. The recruitment goal was 30, or whenever theoretical saturation was reached. In total, 20 participants were recruited into the study and all participants completed interviews. Participants received a US$25 honorarium.

Data Collection and Measures

Data collection involved a single, 60- to 90-min interview, which took place in a private location of the participant's choice and were conducted by two authors (AGB, NW) using a semistructured question guide (see Supplementary Table 1). Private interview locations included an office in the university, a reserved room in a public library or in the participants' home. Authors had no established relationship with participants prior to study commencement and participants were informed of the purpose of the study before interviews were conducted. The interview guide was developed based on the research questions at hand by two authors with training in qualitative methodology (AGB, NW) and was reviewed critically by the authors' respective study teams with disciplinary backgrounds in nursing and engineering. To expose natural language used to describe NPS and situations where NPS might arise, questions focused broadly on caregiving experiences and activities, caregiving role, network, strategies, resources, and challenges. Responses were probed to establish depth in examining how caregivers understood their experiences managing NPS. Caregivers were asked to complete a demographic questionnaire. Data collection took place over 1 year.

Data Analysis

Interviews were audio recorded, transcribed verbatim, and deidentified. Directed content analysis procedures were planned in advance of data collection with the study team and focused on identifying natural descriptions of NPS events and coding relevant language and context. Language was evaluated in the broader context of the conversation, often across several lines of text to ensure they represented a description of an NPS event. Following initial review of all interviews, the study team met to develop and finalize a data-driven coding framework (see Supplementary Table 2). Across each phase of coding and analysis, transcripts were coded line-by-line in Microsoft Excel by two independent coders (AJ and SM). Discrepancies were identified through duplicate review, after which two blinded coders (LB and AGB) reviewed text associated with discrepancies and served as an arbitrator by separately coding these text. In this arbitration process, there were no instances in which all three reviewers disagreed. All coders had some clinical training in care of persons with dementia and received training in coding procedures from AGB.

Data were analyzed in two separate phases, the first involved a directed content and text analysis of caregiver terminology employed to describe NPS, followed by a thematic analysis of these descriptions in order to elucidate the ways in which NPS were contextualized by caregivers. Directed content analysis was informed by established criteria in the Neuropsychiatric Inventory (NPI) through consultation with the entire study team (Braun & Clarke, 2006; Cummings et al., 1994). The NPI is a validated, reliable tool used with caregivers of people with dementia to assess severity and caregiver distress associated with the following NPS: delusions, hallucinations, agitation/aggression, dysphoria/depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behavior, nighttime behavior, and appetite/eating (Cummings et al., 1994). To facilitate comparison across terminology used to describe specific NPS events, major coding domains were organized by symptom type as in the NPI but adapted to best fit caregivers' naturally occurring descriptions of symptoms. For example, agitation, aberrant vocalization, and motor behaviors were broadly categorized as agitation or calling out. Irritability, elation, disinhibition, depression, and dysphoria were categorized as mood affect or changes and apathy. Hallucinations and delusions were grouped together and categorized as altered thoughts. Statements about cognitive changes or illogical thought content were categorized as general statements regarding cognitive changes. Final coding categories included agitation, repetitive questions, anxiety, resisting care, wandering, aggression, apathy, altered thoughts, and an "other" category which allowed coding of descriptions within the NPI that would require more context to map onto specific criteria, for example, specific statements about personality that would require context on premorbid personality to categorize as a change. All descriptions of NPS were then reviewed and analyzed using qualitative text analysis, which involved identification of common or salient key words and phrases within each major coding domain (Ryan & Bernard, 2000). These key descriptors were further reviewed to determine their frequency within and across symptom domains.

NPS descriptions were then analyzed using a thematic analysis approach to characterize major themes present in how caregivers' descriptions of NPS were contextualized (Braun & Clarke, 2006). Using line-by-line coding, we reviewed codes generated across each category to identify and organize major findings into emergent themes. All themes were compared to raw data to ensure accuracy.

Results

Participant Characteristics

All 20 caregivers were family members caring for a spouse (*n* = 9) or a parent/step-parent (*n* = 11). Ages ranged from 48 to 82 (mean = 63) with 7 participants not specifying age; 11 were female; 10 identified as Caucasian, 1 as African American, and 9 did not specify their racial/ethnic background. Fifteen participants reported having frequent support from other family or friends, and 11 caregivers used a source of formal support such as in-home care or skilled nursing facilities.

Specific Terminology and Phrases Used to Describe NPS

All caregivers spontaneously described NPS and collectively provided 265 accounts of NPS across interviews. Across all accounts of NPS, 132 distinct key descriptors were used to label and characterize symptoms, with the number of key descriptors used by a participant for a symptom ranging from 3 to 28 descriptions (mean = 12). The most common NPS mentioned were agitation, repetitive questions, and anxiety, representing 51% percent of all key descriptors (Table 1).

Caregivers' descriptions of NPS reflected broad overlap in terminology across clinically distinct symptoms, with little evidence of perceived distinction among specific NPS in complex scenarios (Figure 1). In many situations, caregivers described multiple NPS simultaneously as a singular event as one caregiver described anxiety and repetitive questions: "I think she started to feel the fear, she knows something is happening to her she just doesn't know what…it's like you tell her over and over." Shared terminology was most prevalent between descriptions of agitation and resisting care events, with four common shared descriptors. There was also frequent overlap for descriptors of anxiety and altered thoughts, with three common shared descriptors.

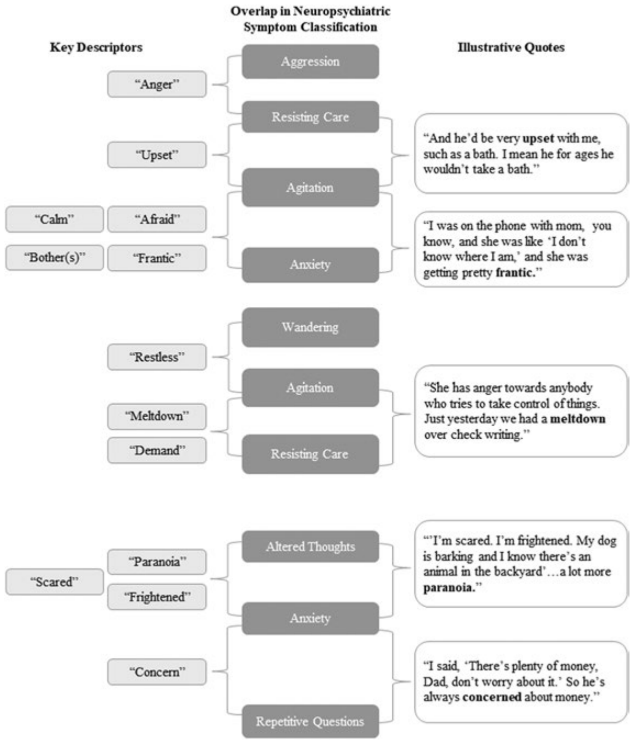
Context and Presentation of Caregiver Descriptions of NPS

The broader context within which caregivers presented NPS in their conversations was characterized into three major

Table 1. Key Terminology and Phrases Used by Family Caregivers to Describe Neuropsychiatric Symptoms

Symptom	Key Descriptors—Terminology and Phrases[a]	Frequency
Agitation	▪ "Anger," "Upset," "Meltdown," ▪ "Frantic," "Restless," ▪ "Calm," "Relax," ▪ "Demand," "Bothered"	▪ 40 different descriptors were used a total of 66 times, representing 25% of all NPS descriptions
Repetitive Questions	▪ "Always Asking," "Repeating," ▪ "Constantly," "Same Questions," ▪ "Again," "Remember," ▪ "Over and Over," "All the Time"	▪ 8 different descriptors were used a total of 41 times, representing 15% of all NPS descriptions
Anxiety	▪ "Frantic," "Upset," "Paranoia," ▪ "Scared," "Afraid," "Frightened," ▪ "Calm," "Relax," ▪ "Bother," "Concern"	▪ 24 different descriptors were used a total of 30 times, representing 11% of all NPS descriptions
Resisting Care	▪ "Anger," "Upset," ▪ "Meltdown," "Demand"	▪ 25 different descriptors were used a total of 29 times, representing 11% of all NPS descriptions
Altered Thoughts	▪ "Hallucinations," "Paranoia," "Hearing Voices," ▪ "Scared," "Frightened" ▪ "Convinced," "Thought"	▪ 12 different descriptors were used a total of 22 times, representing 8% of all NPS descriptions
Wandering	▪ "Got Out," "Walking Around," "Padding Around," ▪ "Wander," "Escape," "Leave," ▪ "Restless"	▪ 7 different descriptors were used a total of 13 times, representing 5% of all NPS descriptions
Aggression	▪ "Fly Off," "Afraid," "Roaring," ▪ "Unruly," "Pull," "Make Me," "Dragged," ▪ "Hurt," "Angry," "Settle Down"	▪ 10 different descriptors were used a total of 10 times, representing 4% of all NPS descriptions
Apathy	▪ "No Interest," "Doesn't Interact," ▪ "No Feelings," "No Emotions," ▪ "Opposite," "Isn't Social"	▪ 6 different descriptors were used a total of 7 times, representing 3% of all NPS descriptions
Other Symptoms	▪ "Not sleeping," "He was tired," ▪ "Confused at night," "Sundown" ▪ "Used to eat" "Wasn't eating" ▪ "Depressed"	▪ There were 47 instances of descriptions that represented other symptom domains in the NPI of dysphoria/depression, appetite/eating, and nighttime behavior - representing a total of 18% of all NPS descriptions

[a] Represents most common descriptors per category.



"And he'd be very **upset** with me, such as a bath. I mean he for ages he wouldn't take a bath."

"I was on the phone with mom, you know, and she was like 'I don't know where I am,' and she was getting pretty **frantic.**"

"She has anger towards anybody who tries to take control of things. Just yesterday we had a **meltdown** over check writing."

"'I'm scared. I'm frightened. My dog is barking and I know there's an animal in the backyard'…a lot more **paranoia.**"

"I said, 'There's plenty of money, Dad, don't worry about it.' So he's always **concerned** about money."

Figure 1. Examples of overlap in neuropsychiatric symptoms (NPS) classification of key descriptors with illustrative quotations.

themes that illustrated distinct sense-making patterns: explanatory, pattern-oriented, and strategy-orientation (Table 2). In many descriptions of NPS, more than one approach to contextualizing symptoms was identified.

Explanatory sense-making was common throughout caregivers' descriptions and reflected a proclivity to rationalize symptoms by providing explanations for their occurrence and contributing factors—often care recipient needs or emotions—instead of describing the symptom. Caregivers often described the importance of empathy when contextualizing NPS events through an explanatory lens: "[She is] striving to maintain control and grabbing for more control as it slowly seeps away, which is what I'm sure we all would do in that situation." In other situations, caregivers identified the care recipients' emotions (i.e., "frightened" and "concerned") or needs (e.g., "[to] calm down"). Upon further probing, caregivers were able to divulge specifics about the behavior or event, but often continued to engage an explanatory lens. Symptoms were often implicit in caregivers' response to questions about what a bad or good day looks like. Within their responses, explanatory sense-making reflected a desire to maintain normalcy and relationship dynamics as caregivers described difficulties with this, including interference in common tasks: "I'm trying to get dinner ready…and it's like having a four-year old around." As an exception, descriptions of apathy were infrequent (3% of all descriptions) and rarely focused on rationalizing the behavior, as most exclusively described changes in engagement including lack of emotion or interaction: "So she's not interested in anything really. And that's just the opposite of what she used to be."

Pattern-oriented sense-making focused on temporal or cyclic patterns of NPS as a way of understanding or predicting them as responses to events. Situating NPS descriptions according to broader patterns, caregivers often described symptoms as "episodes" or "events" and provided temporal structures. One caregiver framed her mother's agitation as brief confusion, "She would have some episodes because I would get phone calls…she thought that she needed to get my father who passed away." Another caregiver described a hospital visit causing sleep disturbances: "The night he was taken to the hospital…Well he was restless and walking around." Pattern-oriented sense-making was often presented as a description of the most common context which would elicit certain NPS, to support anticipation of the symptom event.

Strategy-oriented sense-making emphasized the need to employ certain strategies to alleviate a challenging situation, often without detailing the symptom and instead describing their response to the symptom: "And I'm like going, 'Well, dad, you're just going to have to relax' … I said, 'I'll be here.'" One caregiver described how he had to redirect his father while out in the community to avoid a challenging situation: "He'd get upset if the booth at the restaurant wasn't open for us…I'd have to divert him to a different one and say, this is going to be fine." Caregivers readily identified multiple strategies when describing challenging NPS that they routinely employed at home.

Discussion and Implications

Family caregivers of people with dementia use a wide range of terminology to describe specific NPS and demonstrate their approach to understanding NPS as forms of meaningful behavior, situational responses that are modifiable through different strategies. This nomenclature and sense-making appears to stand in contrast with clinical and research classification of NPS that is predominantly deficit-oriented. Our findings demonstrated broad overlap in the use of nonclinical terminology to describe NPS across individual symptom domains, suggesting that delineation of symptoms that present in similar ways (i.e., agitation/care resistance and apathy/depression) may not be intuitive to caregivers. Although many descriptions of NPS events included details about specific situations, caregivers often employed nonspecific terms (i.e., "meltdown," "upset," and "restless"). Some of this may share limitations with use of broad-umbrella clinical terminology such as "agitation" wherein the specific challenge is poorly delineated due to lack of precision in describing the actual actions of the person with dementia. Knowledge of these terms may be useful in informing a framework for dialogue between caregivers and clinicians as the presence of potentially challenging NPS may be overlooked using such broad terms as "upset" and "scared."

Table 2. Major Themes in Family Caregivers' Sense-Making and Contextualization of Neuropsychiatric Symptoms

Common Examples of Sense-Making	Illustrative Quote(s)
Theme 1: Explanatory Sense-Making	
▪ Care recipient is fearful or anxious	"And then I think she started to feel the fear, you know. She knows something is happening to her. She just doesn't know what."
▪ Care recipient is fixating on something	"I struggle with trying to explain things so as not to upset her. And I try to explain, well, I've only got so much time … She stays focused when she's on a point and won't let it go."
▪ Care recipient is confused or forgetful	"[H]e started forgetting how to get places, and that would cause an argument."
▪ Care recipient is frustrated with their situation	"And she's not happy with her current situation. And I think when I get to that, I think anyone who has ultimate freedom that you can come and go and go out to eat and enjoy all of the fruits and wonders of living freely, when you start getting locked down, who would enjoy that, you know? So I can understand the frustration. And as a part of frustration you may say things that you wouldn't normally say or think."
Theme 2: Pattern-Oriented Sense-Making	
▪ Caregiver situates onset of behavior temporally or around other major events	"A few weeks before he went in the hospital he wasn't allowing anything to get washed, or I finally would talk him into wearing a different pair of pants just so I could wash the article. And then he could put them back on if he wanted to. But very set in his ways of what he wanted done when he wanted it done."
▪ Caregiver anticipates responding cyclic behavior based on a consistent pattern of "early signs"	"She just, you know, I can just tell that her breathing will get really shallow. And it's just something, usually something that she wants to know. How's that going to work, you know, \$5,200. \$5,200, who's got \$5,200. How am I going to pay \$5,200? […] I'm going to have to tell her again today. But she asks, where am I going? How much does it cost? And I feel like I need to tell her."
▪ Caregiver contextualizes symptom based on the time of day it presents in relation to recent changes in environment	"And then with mom, I've been, because she's getting, you know, very agitated and stuff at night, I've been having her just, you know, do the ten breaths thing. And, okay, let's just stop and take ten deep breaths, and that works pretty good for her. […] That'll get her calmed down a little bit too. […] It's kind of like since the fall. And I'm hoping that it goes away, because I think it's unfamiliar surroundings even though she doesn't remember where she came from and, you know, she doesn't remember her apartment. But she knows that something is different, and she knows she's in a place."
Theme 3: Strategy-Oriented Sense-Making	
▪ Caregiver remains calm in response to urgent situation and as a de-escalation strategy	"And even though I was, you know, maybe five hours away at the most, I just can't instantly drop what I'm doing and get there. So it would be more of a calm voice, and don't, you know, this is not what's going on, Mom. It's okay. You're okay sort of thing."
▪ Caregiver uses distraction to address recurring requests care recipient has that cannot be met	"But then about a month later, you know, same thing. I need to go to the bank and stuff, but I managed to put her off."
▪ Caregiver encourages interaction to address lack of engagement	"She just isn't a social person anymore, whether it's because she feels left out, because when we do go, everybody, you know, interacts with her or tries to get her to interact, and she just doesn't."
▪ Caregiver uses visual reminders and other tools to address repetitive questions	"whenever she would ask the [same] questions, you'd be like, well, it's all written over here on the whiteboard"

Caregivers commonly described NPS through a sense-making lens focused on understanding the reason for the symptom. Often, this contextualization highlighted the importance of maintaining normalcy in relationships that may be disrupted through labeling of loved ones as "agitated" or "resistant." When describing NPS, caregivers also demonstrated sense-making by understanding the NPS as the care recipient's attempt to communicate feelings or as a consequence of frustration given changes in memory or thinking. Caregivers seemed to demonstrate a keen awareness that NPS could be related to the underlying disease, which is in contrast to other studies wherein caregivers often attributed NPS to causes other than Alzheimer's disease and related dementias (Hinton, Chambers, & Velasquez, 2009; Stella et al., 2015). It is likely that there are different patterns in sense-making, understanding, or attribution of NPS, and that this might be due to individual characteristics and the nature of their caregiving. Altogether, caregiver sense-making of NPS has implications for accurate recognition and reporting of NPS. Apathy was the least mentioned symptom which is an important finding as it is also known to be one of the most prevalent and pervasive NPS (Borsje, Lucassen, Wetzels, Pot, & Koopmans, 2018). As a symptom, apathy may be challenging for caregivers to identify and if noticed, it may be not present as bothersome as it often results in dampening of behavior, specifically a lack of motivation, rather than the addition of behaviors like in agitation (Gilmore-Bykovskyi, 2018; Gilmore-Bykovskyi, Block, Johnson, & Goris, 2019; Massimo, Kales, & Kolanowski, 2018). Caregiver education on the presentation, course, and implications of apathy may be helpful in improving recognition and appreciation of potential interventions. Collectively, the variation of key descriptors applied to NPS highlight varying degrees of ambiguity and complexity in individual domains.

These findings also highlight the difficulty clinicians may encounter in accurately assessing NPS, provided the heterogeneity, complexity, and in some instances, vague nature of caregivers' symptom descriptions. Several steps may help us to address these challenges in research and practice. First, there is a need for earlier and more frequent engagement of family caregivers and persons with dementia in the development and refinement of clinical tools, as there may be opportunities to better align descriptions of symptoms with caregivers' understandings. It is also possible that more specific descriptions of behaviors and the context in which they occur may prove to be more useful in designing individualized management strategies than symptom labels. To understand the utility of contextualized descriptions of NPS in assessing symptoms to inform individualized supportive care, prospective evaluation comparing these approaches to existing standardized assessment tools within clinician–caregiver communications may be required.

Although education around NPS management is merited and has frequently been identified as an unmet need among family caregivers (Jennings et al., 2015; McCabe et al., 2016; Steiner, Pierce, & Salvador, 2016), there is also an untapped opportunity to recognize, incorporate, and value the existing expertise of family caregivers. Relevant policy implications may include explicit requirements through major funders of dementia-related research to incorporate family caregivers or persons with dementia in informing and shaping the development of and refinement of clinical and research-related tools. This may enable earlier recognition of divergence between the perceptions and nomenclature of those living through and with dementia, and the views of clinicians and scientists. This may also accelerate the incorporation of more accessible, and potentially less stigmatizing nomenclature into practice, research, and the media. Finally, future work should be directed at synchronizing descriptors of NPS with the perspectives of the caregivers who most commonly respond to them.

This study was limited to a sample of caregivers residing in the Midwest and the participants were majority white. Future work directed at a more racially and geographically diverse sample size can provide greater insight into the sense-making and language used by family caregivers. Although many caregivers offered rich descriptions of the care recipient, detailed demographic information about the care recipient and caregiving relationship and types of supports used was not systemically collected, limiting its potential contributions to the analysis. This study also did not attempt to understand caregivers' motivations for using certain language to describe NPS, nor how caregivers' understanding of NPS may shape the language they select to use, which are important areas for further investigation. Future work might examine how caregiver sense-making and language differs between caregivers, dependent on their background, the nature of their caregiving, and the characteristics of the person for whom they care.

To the best of our knowledge, this is the first study that has examined family caregivers' nomenclature surrounding NPS in dementia. Our results suggest that the various deficit-oriented clinical nomenclature for NPS contrasts greatly with the broad, overlapping terminology and experiential sense-making family caregivers use in their daily lives. Reliance on effective communication between caregivers and their clinical teams for the effective management of NPS may require adoption caregivers' language, or explicit development of shared nomenclature. Further research examining family caregivers' interpretation of specific NPS is needed to ensure that supportive interventions are responsive and accessible, and promote effective caregiver–clinician communication regarding NPS.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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Authors' Contributions

Study conception: Andrea Gilmore-Bykovskyi; Study design: Andrea Gilmore-Bykovskyi; Data acquisition: Gilmore-Bykovskyi and Nicole E. Werner; Data analysis and interpretation: All authors; Drafting of manuscript: All authors; Critical revision and approval of final manuscript to be published: All authors.

Conflict of Interest

None reported.

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