Assessing Apathy in Long-term Care Residents with Dementia: Who Should be the Rater?

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Abstract

Background: Apathy is prominent in persons with dementia and apathy assessment is challenging. It remains unclear who should conduct apathy assessments in long-term care settings for residents with moderate to advanced dementia. The Apathy Evaluation Scale (AES) is a widely used instrument and its use for long-term care residents with dementia needs to be further established. This study explored the relationship among apathy assessments conducted by family and clinical caregivers using the original AES (AES-18) and the nursing home version (AES-10).

Methods: This study used a cross-sectional, descriptive design and enrolled 15 quartets of participants recruited from long-term care settings. Each quartet consisted of one resident with dementia, one family member, one certified nursing assistant (CNA), and one licensed practical nurse (LPN) or activity staff. Family, CNAs, and LPNs/activity staff rated the resident's apathy level on the AES independently. Bivariate Pearson correlation coefficients were used for analysis.

Results: The results revealed that ratings conducted by CNAs and LPNs/activity staff were moderately correlated for the AES-18 and the result approached statistical significance ($r=0.47$, $p= .08$). None of the other AES ratings among family, CNAs, and LPNs/activity staff were significantly correlated.

Discussion: Family and clinical caregivers were incongruent on their AES ratings of apathy. It remains undetermined which rater provides the most valid AES rating for residents with dementia. Findings from this study further highlight challenges in rating apathy in this population. Future

research is needed to determine best practices for accurate apathy assessment for residents with dementia in long-term care.

Keywords

dementia; Alzheimer's disease; apathy; neuropsychiatric symptoms; long-term care

Introduction

Apathy in dementia

Nearly half of nursing home residents live with dementia (Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013) and apathy is one of the most prevalent symptoms in this population (Holtta et al., 2012). Specifically, 84% of nursing home residents with dementia live with apathy (Wood, Cumming, & Hsu, 2000). Apathy is a disorder of motivation, clinically characterized by a lack of interest, initiative, voluntary activity, and responsiveness to environmental stimuli and a blunted mood (Robert et al., 2009). Apathy is associated with adverse consequences for persons with dementia (PWD), including faster cognitive and functional decline, poorer quality of life, and higher mortality (Starkstein Jorge, Mizrahi, & Robinson, 2006; Samus, et al., 2005; Vilalta-Franch, Calvo-Perxas, Garre-Olmo, & Lopez-Pouse, 2013). Despite the potential for these negative outcomes, apathy is often overlooked for residents with dementia in long-term care (Landes et al., 2001; Starkstein et al., 2006).

Challenges of apathy assessment in people with dementia

Residents with apathy are not well-identified or addressed in long-term care in part due to the fact that apathy is a seemingly innocuous symptom and does not result in acute disturbances as do other behavioral symptoms of dementia. Apathy is often underdiagnosed or misdiagnosed as depression due to the symptom overlap of lacking motivation (Tagariello, Girardi, & Amore, 2008). In addition, apathy is a relatively abstract and subjective symptom. People with dementia and apathy may not be able to explicitly articulate their thoughts and feelings. Research reveals that PWD with apathy show less awareness on their cognitive changes and apathy symptoms as compared to their family caregivers and PWD without apathy (Starkstein, Petracca, Chemerinski, & Kremer, 2001). Moreover, the clinical manifestations of apathy are subtle and negative (e.g., no interest, lack of initiative, lack of engagement of activities, social withdrawal, and no facial expression), making it challenging for caregivers to recognize apathy as compared to the more conspicuous symptoms of dementia, such as agitation and aggression.

The nature of long-term care further complicates apathy assessment for PWD. First, residents in long-term care tend to have more advanced dementia and are more likely to have difficulty with self-reporting symptoms of apathy. Individuals with more advanced dementia often have more difficulty understanding and answering questions for apathy assessment; for example, with questions such as, "do you have motivation?" or "are you interested in things?" (Marin, Bierdrzycki, & Firinciogullari, 1991). Family members are knowledgeable about residents' baseline personality and characteristics to detect behavioral and affective changes but they are not always up-to-date with residents' conditions at the care facility nor always accessible for apathy assessment.

Clinical caregivers have varying levels of training and contact with residents. For example, certified nursing assistants (CNAs) typically have the most contact with residents during caregiving activities but they have lower levels of healthcare training. Nurses have regular contact with the residents and have more training in assessment. However, assessment of apathy is not a routine nursing practice. Nurse practitioners and physicians have more advanced healthcare training, but relatively limited contact with residents. A number of studies have shown assessment discrepancy and varied measurement psychometrics among different raters (self-report, family, LPN and CNA) for commonly used apathy assessment instruments, including the neuropsychiatric inventory (NPI) and the Apathy Evaluation Scale (Wood et al., 2000; Clarke et al., 2007). Who the best person among family and various care providers to conduct apathy assessments in long-term care remains undetermined.

Apathy evaluation scale

The Apathy Evaluation Scale (AES-18) was developed over two decades ago (Marin et al., 1991) and has been widely used for apathy assessment for various neuropsychological disorders (Radakovic, Harley, Abrahams, & Starr, 2015). The AES-18 consists of 18 items and includes self-report, informant, and clinician versions of said items. The AES-18 was initially designed to use in psychiatry clinics and has been validated in clinic and community settings (Radakovic et al., 2015). Clarke et al. (2007) validated all three forms of the scale in a sample of largely community-dwelling PWD and revealed that the informant version had the most sensitive, valid assessment with an area under the curve (AUC) of 0.82, followed by 0.72 for the clinician version and 0.65 for the self-report version. However, the AES-18 has not been well validated in long-term care settings.

Prior research has identified limitations for the use of the AES-18 in long-term care because several items of the AES-18 were determined by individuals' cognitive function and the nursing home care model and not necessary directly relevant to residents' apathy symptoms; this is reflected in items such as "sh/e has an accurate understanding of his/her own problems" and "someone has to tell him/her what to do each day" (Lueken et al., 2007). Thus, an abbreviated, nursing home version of the AES (AES-10) was developed by eliminating eight items from the AES-18, item 5 and items 10 through 16, to facilitate the use of the AES for nursing home settings (Lueken et al., 2007).

The AES-10 was validated and highly correlated (r=0.97) with the AES-18 (Lueken et al., 2007). Notably, in that study, the AES-10 was administered by experienced geriatric psychiatrists with formal training of the scale administration. It is unclear if the validity would remain consistent when administered by family or other clinical caregivers. Leontjevas et al. (2012) further validated the scale against the apathy diagnostic criteria and revealed that the scale performed well for residents with and without dementia (AUC=0.88, *p*=.0001). However, when examining its performance for the residents with dementia alone, the AES-10 showed poor differentiation between apathy and non-apathy. In this study, the AES-10 was administered by researchers interviewing primary professional caregivers without specifying the role of caregivers. To our knowledge, the usefulness of the AES-10 utilized by professional caregivers and family has not been examined. It is essential to

explore the use of the AES-10 by different raters in order to further establish its psychometrics and extend its implications for clinical practice and research in long-term care.

The purpose of this study was to explore the agreement of apathy assessment using the AES, both the AES-18 and AES-10, among family and clinical caregivers for long-term care residents with dementia. Specifically, this study examined the relationships among AES ratings for three raters: 1) family, 2) CNA, and 3) licensed practice nurse (LPN) or activity staff.

Design

Samples

This was a cross-sectional, descriptive study which employed a convenience sample. Study participants involved 15 quartets recruited from one assisted living facility and one nursing home in Pennsylvania, USA. Each group consisted of 1) one resident, 2) one family member, 3) one CNA, and 4) one LPN or activity staff.

Resident inclusion criteria were: 1) age of 65 or older, 2) English speaking, 3) diagnosis of dementia, 4) admission to the facility for at least 1 month, and 5) no terminal illness or other neuropsychiatric or neurodegenerative disorders. The study participants could be at any stage of dementia with or without apathy. Potential residents were initially identified by the staff and administrators of the facilities. Chart review screening was conducted by the research team to confirm that participants met inclusion criteria.

Family participants had to be English speaking and age 18 or older. Potential family participants were initially identified by staff of the facilities. Participants could be any family relationship and were not required to be the residents' legally authorized representative.

Inclusion criteria of clinical caregivers (i.e., CNA, LPN, and activity staff) included: 1) age of 18 or older, 2) English speaking, 3) work experience in the care setting for at least one month, and 3) direct care provider for the enrolled resident at least four times over the previous month. The study protocol was approved by the Institutional Review Board (IRB) of the Pennsylvania State University (#STUDY00004518). Prior to each resident enrollment, written consent was obtained from their legally authorized representative and verbal assent was obtained from the resident. Family and clinical caregivers also provided written consent to their participation.

Study procedures

Family, CNAs, and LPNs/activity staff were each asked to fill out a survey that included demographic information and then rated the resident's apathy level on the AES-18 independently. The AES-18 was rated on a 1-4 Likert scale (1=not at all characteristic, 2=slightly characteristic, 3=somewhat characteristic, and 4=a lot characteristic). The AES-10 consists of 10 items, directly derived from the AES-18 (eliminating item 5 and items 10 through 16) and used the same rating method. Family members used the informant version of the AES, while CNAs, LPNs, and activity staff used the clinician version. They

were required to rate the resident's apathy level, based on their observation of the resident's thoughts, feelings, and activity over the previous four weeks. Prior to their ratings, the research team provided brief verbal and/or written instruction about the use of the AES-18 and encouraged participants to ask questions. Each of the three raters' assessments were completed within a one week time frame.

Data analysis

Statistical analysis was conducted using the Statistical Package for the Social Science version 24 (SPSS 24, IBM Corporation, New York, NY, USA). The total scores of the AES-18 and AES-10 were calculated. Based on the AES administration guideline, except for three of the items (6, 10, and 11), the scores were reversed as 1=4, 2=3, 3=2, and 4=1. The possible total scores of the AES-18 and AES-10 were 18-72 and 10-40, respectively. The higher AES score indicates greater levels of apathy. Descriptive statistics were used to explain participants' characteristics and AES ratings. Bivariate Pearson correlation coefficients were used to examine the agreement of AES ratings among family, CNAs, and LPN/activity staff. Due to the small sample size, we also examined the magnitude of the correlations using the guidelines from Cohen which describe correlations between .1 and .3 as weak, correlations between .3 and .5 as moderate and correlations above .5 as large (Cohen, 1988).

Results

Sample characteristics

A total of 15 quartets were enrolled. Participants' characteristics are reported in tables 1-3. Resident participants were aged 86 years on average. All residents were Caucasian and 60% were female. Among the residents, 60% lived in an assisted living. A total of 40% of the residents were diagnosed with Alzheimer's disease. Family participants were 65 years old on average and were primarily Caucasian and female. More than half of the participants were the resident's daughters. On average, family visited the resident 11 times over the past 4 weeks.

CNA participants were 46 years old on average and were predominantly Caucasian and female. They had an average of 5.8 years of work experience at the facility and 73% of them had a high school education. CNAs provided direct care for the resident for 12.9 days on average over the past 4 weeks. LPN/activity staff participants were 31 years old on average and were all Caucasian and female. Activity staff comprised two-thirds of the participants. Two-thirds of the LPNs/activity staff had some college education and the rest of them completed college degrees. They had approximately 4.2 years of work experience at the facility and provided direct care for the resident for approximately 19.9 days over the past 4 weeks.

Correlations of AES ratings among family, CNAs, and LPNs/activity staff

No outliers were identified in any of the ratings. None of the bivariate correlations on AES-18 ratings among family, CNAs, and LPNs/activity staff were statistically significant. The results for AES-10 were similar. Given the small sample size, we also considered the

magnitude of the correlations as an indication of effect size. Though non-significant, correlations between CNAs and LPNs/activity staff were moderate in size (r=0.47, *p*= .08) using the AES-18. The correlation was weaker for the AES-10 (r=0.35, *p*= .21). Notably, family members' ratings were poorly correlated with either CNAs or LPNs/activity staff for both AES-18 and AES-10.

Discussion

This study revealed that apathy ratings using the AES (both AES-10 and AES-18) among family, CNAs, and LPNs/activity staff were not significantly or even consistently correlated. Potential explanations include that the raters received different extent of dementia training (if any), had different levels of involvement with the residents, and played different roles in caregiving. In addition, the nature of their interactions with the residents, the frequency of interactions, and time of day for their interactions may influence residents' affect and behaviors and raters' perceptions. The findings did not provide evidence to support the reliability of the AES rated by CNAs, LPNs/activity staff, or family for long-term care residents with dementia.

Given that this is a pilot study with a small sample size, the non-significant results are not surprising. The results do correspond to a prior study reporting inconsistent ratings among different version of the AES-18 (Clarke et al., 2007). The rating disagreement was also observed in the Neuropsychiatry Inventory (NPI; Cummings et al., 1994). Wood and colleagues (2000) compared the behavior symptom assessment between LPNs and CNAs using the NPI-Nursing Home version (NPI-NH) and revealed that their ratings on apathy were significantly different. This study further reported that LPNs apathy ratings were moderately correlated with standardized observations conducted by researchers (r=0.351); whereas CNA's ratings were poorly correlated with the observations. They concluded that LPNs are better raters than CNAs for apathy assessment, but that neither CNAs nor LPNs/activity staff are ideal for rating apathy in the nursing home setting (Wood et al., 2000). Our pilot study results lend to similar conclusion.

Limitations and suggestions for future research

This is a pilot study with a small, homogeneous sample, so there is insufficient power to detect statistical significance and the generalizability of results is limited. It would be beneficial to replicate this study on a larger scale, not only to further examine the aforementioned relationships, but also to explore key factors influencing the validity of apathy assessment, for instance, frequency of contact, time of contact and assessment, familiarity with the residents, and caregiving role. In addition, this study did not compare the apathy rating against any standardized criteria. It is essential to examine the validity of apathy assessment among these different raters. For example, future research should validate the AES ratings completed by different raters against the apathy diagnostic criteria.

Conclusion

As one of the very few studies that compared apathy assessment across family and various caregivers, the findings highlight the issues of apathy assessment from different

perspectives. Most apathy assessment tools collect information from family and/or clinical caregivers, suggesting this lack of reliability may also exist for other tools. It is important not to assume a valid and reliable apathy scale functions the same way in different populations, care settings, and when completed by different people using varied assessment procedures. Establishing validity and reliability of the scale is critical prior to use for large-scale assessments in research and clinical practice in the long-term care setting.

In summary, apathy assessment is challenging. Family, CNAs, and LPNs/activity staff were incongruent on apathy assessment using AES ratings. It remains undetermined who can provide the most valid rating of apathy using the AES for long-term care residents with dementia. This study points out an important issue that needs to be addressed in order to accomplish accurate apathy assessment for long-term care residents with dementia.

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Table 1.

Resident Demographics and Baseline Characteristics

Characteristics	n (%)/ Mean ± SD (range)
Age (years)	85.8±5.1 (75-93)
Facility Type	
Assisted Living	9 (60.0%)
Nursing Home	6 (40.0%)
Gender, Female	9 (60.0%)
Race, Caucasian,	15 (100.0%)
Type of Dementia, Alzheimer's disease	6 (40.0%)
Diagnosis of Depression	8 (53.3%)
AES-18 total score	
Family	57.5±8.1(44-68)
CNAs	56.0± 8.4(36-68)
LPNs/activity staff	49.5±14.2(30-72)
AES-10 total score	
Family	31.8±4.7(24-38)
CNAs	31.5±5.0 (20-39)
LPNs/activity staff	27.3±8.9(13-40)

Table 2.

Family Characteristics

Characteristics	N (%)/ Mean ± SD (range)
Age (years)	65.5±11.7 (51-90)
Number of visits over the past 4 weeks	11.1±12.6 (0-40)
Gender, Female	11 (73.3%)
Race, Caucasian	15 (100.0%)
Relationship with the resident	
Spouse	4 (26.7%)
Daughter	7 (46.7%)
Son	2 (13.3%)
Others	2 (13.3%)
Education	
High school	2 (13.3%)
Some college	1 (6.7%)
College	5 (33.3%)
Some graduate education	2 (13.3%)
Graduate education	5 (33.3%)

Table 3.

Clinical Caregiver Characteristics

Characteristics	N (%)/ Mean ± SD (range)	
	CNAs	LPNs/activity staff
Age (years)	45.9±13.4 (20-62)	30.7±11.3 (21-52)
Number of years working at the facility	5.8±3.0 (0.5-10)	4.2±4.9 (1-21)
Number of days providing care for the resident over the past 4 weeks	12.9±5.3 (4-20)	19.9±6.5 (4-15)
Gender, Female	14 (93.3%)	12 (100.0%)
Race, Caucasian	15 (100.0%)	15 (100.0%)
Education		
High school	11 (73.3%)	0 (0%)
Some college	0 (0%)	9 (60.0%)
College	3 (20.0%)	6 (40.0%)
Some graduate education	1 (6.7%)	0 (0%)

Table 4.

Correlations among AES ratings

	AES-18		AES-10	
	CNAs	**LPNs/activity staff**	**CNAs**	**LPNs/activity staff**
Family	−0.16 (*p*=.57)	0.19 (*p*=.49)	−0.14(*p*=.61)	0.28 (*p*=.32)
LPNs/activity staff	0.47 (*p*=.08)		0.35 (*p*=.21)	