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Self-Reported Personality Traits are Prospectively Associated with Proxy-reported Behavioral and Psychological Symptoms of Dementia at the End of Life

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Abstract

Objective—Behavioral and psychological symptoms of dementia (BPSD) are among the most challenging aspects of Alzheimer’s disease for patients and their families. Previous studies have found associations between informant-reported retrospective personality and BPSD; we test whether prospective, self-reported personality predicts who will experience these symptoms.

Methods—Deceased participants from the Health and Retirement Study who had evidence of cognitive impairment at the end of life ($N=1,988$) were selected to examine whether self-reported five factor model personality traits, measured up to 8 years before death, were associated with proxy-reported BPSD.

Results—Neuroticism was associated with increased risk of the seven BPSD: got lost in familiar places, wandered off, were not able to be left alone, experienced hallucinations, suffered from depression, had periodic confusion, and an uncontrolled temper. These associations were not moderated by age, gender, race, or education. Conscientiousness was associated with fewer symptoms overall and especially with lower risk of getting lost in familiar places and not being able to be left alone.

Conclusions—The present research indicates that self-reported personality, particularly Neuroticism, is associated prospectively with risk for a wide range of behavioral symptoms for individuals who had cognitive impairment at the end of life. The use of self-reported personality traits can help aid in identifying who is most at risk for behavioral symptoms. Such information may be useful for non-pharmacological interventions tailored to the individual’s personality to reduce the prevalence and burden of these BPSD.

Keywords

Behavioral symptoms; neuropsychiatric symptoms; personality traits; neuroticism

Alzheimer’s disease (AD) and related dementias (ADRD) take a substantial emotional and economic toll on both the patient and the family of the person with dementia (Alzheimer’s

Association, 2015). Many aspects of the disease and its progression are difficult, but it is the behavioral and psychological symptoms of dementia (BPSD) that loved ones often report as the most problematic (Black and Almeida, 2004). Individuals who have BPSD need greater supervision (Okura and Langa, 2011), progress in the disease faster (Geda *et al.*, 2013, Lyketsos *et al.*, 2011), are more likely to be institutionalized (Gaugler *et al.*, 2009), and have a greater cost of care (Herrmann *et al.*, 2006) than individuals who do not have these symptoms. BPSD also contribute greatly to family and professional caregiver burden and are among the most challenging symptoms in the management of dementia (Rinaldi *et al.*, 2005, Shin *et al.*, 2005). As such, BPSD are a strong predictor of placement into a nursing home from living in the community (Gaugler *et al.*, 2009, Toot *et al.*, 2017). Identifying who is at greatest risk of these symptoms is critical to help caregivers understand and proactively manage potential symptoms. To that end, the purpose of the present research is to examine whether self-reported personality traits are associated with proxy-reported BPSD at the end of life.

BPSD, also referred to as neuropsychiatric symptoms of dementia, are heterogeneous and operationalized in various ways. In general, BPSD are typically described as disturbances in psychological functioning, perception, motor function, circadian rhythms, and eating behaviors (Cerejeira *et al.*, 2012). Common symptoms include depression, apathy, elation, and delusions (psychological disturbances), hallucinations (perceptual disturbances), wandering, repetitive purposeless behaviors, verbal aggression, and physical aggression (motor function disturbances also referred to as agitation), change in sleep patterns (circadian rhythm disturbances), and loss or increase in appetite (eating behavior disturbances) (Cerejeira *et al.*, 2012).

Personality traits have been implicated in both risk for AD and behavioral symptoms associated with dementia. Personality, as defined by the Five Factor Model, is operationalized into five dimensions (Costa and McCrae, 1992): Neuroticism (the tendency to experience negative emotions), Extraversion (the tendency to be outgoing and sociable), Openness (the tendency to be creative and open-minded), Agreeableness (the tendency to be trusting and compassionate), and Conscientiousness (the tendency to be organized and disciplined). These personality traits have been associated consistently with risk of Alzheimer's disease: Individuals who score higher in Neuroticism and lower in Conscientiousness have a three-fold increase in risk of AD compared to individuals who score on the opposite end of the spectrum of these traits (Terracciano *et al.*, 2014). Higher Openness and Agreeableness have been found to be protective against dementia (Terracciano *et al.*, 2014).

Personality traits have been associated with various aspects of behavioral symptoms (Low *et al.*, 2002, Tabata *et al.*, 2017). A systematic review of the literature up to 2010 found that of the five traits and across a range of BPSD, Neuroticism had the most associations with mood and aggression-related symptoms across the studies reviewed (Osborne *et al.*, 2010). Specifically, seven out of 18 studies found a significant association between Neuroticism and these symptoms. This association is consistent with the broader literature on Neuroticism that indicates that this trait is a strong risk factor for mood and other psychiatric disorders across the lifespan (Kotov *et al.*, 2010). Although the other four personality traits

were associated with behavioral symptoms in individual studies, when aggregated together, there was little evidence of consistent associations (Osborne *et al.*, 2010). The more recent literature continues to be mixed, with some studies finding no association between personality and BPSD (Pocnet *et al.*, 2013) and others findings associations for Neuroticism and Openness and the total number of symptoms (Mendez Rubio *et al.*, 2013).

Previous research on the relation between personality traits and BPSD has been critical for raising awareness of this issue and providing an initial evidence base for an association. This research has relied on proxy-reported, retrospective assessments of personality traits. In these studies, researchers ask a proxy, usually the caregiver or other knowledgeable informant, to report on the person with dementia's personality prior to the onset of dementia and, at the same time, to report on the person's current behavioral symptoms. Such retrospective reports are informative but may be subject to recall biases (Brewin *et al.*, 1993, Weinstock *et al.*, 1991). Given the significant changes in personality that take place with the onset of the disease (Robins Wahlin and Byrne, 2011), the proxy may rely partly on current personality in making retrospective assessments or may exaggerate pre-dementia personality characteristics in contrast to current behaviors and mood. Studies that use self-reported personality are needed to test whether these traits prospectively predict who will manifest specific behavioral symptoms.

To address this need, the present research uses a subsample of a large national panel study to examine whether self-reported personality traits are associated with risk of seven behavioral symptoms in the last year of life as reported by a knowledgeable proxy. Given that Neuroticism is a strong risk factor for psychopathology across the lifespan (Kotov *et al.*, 2010) and that some previous studies have found an association between Neuroticism and BPSD (Osborne *et al.*, 2010), we expect this trait to be associated with an increased risk of BPSD. Likewise, given that Conscientiousness is a consistent protective factor against Alzheimer's disease (Duberstein *et al.*, 2011) and cognitive decline (Luchetti *et al.*, 2016), we expect this trait to be associated with lower risk of BPSD. We do not make specific predictions for the other three traits. In addition to the main effect of personality on BPSD, we examine whether any of these associations are moderated by age, gender, race, education, baseline cognitive status, and interval between personality and BPSD assessments to determine whether the relations are similar or different across demographic groups, cognitive status, and interval between testing.

Method

Participants and Sample Selection

Participants were drawn from the Health and Retirement Study (HRS). HRS is a longitudinal study of Americans aged 50 years and older and their spouses. HRS data are publically available from here: <http://hrsonline.isr.umich.edu/>. Five factor model personality traits were first assessed on a random half of the HRS sample in 2006 as part of a leave-behind questionnaire; the other half of the sample completed the personality scale in 2008. These two assessments were combined as the baseline sample.

After the death of a participant, HRS staff attempt to interview a proxy informant who was knowledgeable about the panel member at the end of his/her life. This exit interview covers the same topics covered in the core HRS interview and also includes questions about the health and behavior of the panel member at the end life. Exit interviews between 2008 and 2014 (the most recent year with data available) were aggregated to identify all possible deceased participants with relevant data. Among those who had a proxy complete the exit interview ($N=5,205$), we selected participants who had evidence of dementia or other memory-related deficits at the end of life based on at least one of three criteria. First, we selected participants who scored in the range of either dementia or cognitive impairment not dementia (CIND) on the modified Telephone Interview for Cognitive Status (TICS_m) assessment (Crimmins *et al.*, 2011) either in the year of the personality assessment or in one of the follow-ups (see below). Second, we selected participants who either self-reported or had a proxy report of a diagnosis of dementia while was still alive. Third, we selected participants whose proxy indicated that the participant had a memory-related disease or significant memory problems at the end of life in the exit interview after the participant's death. There were 1,998 deceased HRS participants (54% female) with self-reported personality, evidence of a memory impairment, and information on behavioral symptoms, as reported by a knowledgeable proxy in the exit interview. Of the knowledgeable proxies, 33% were spouses of the deceased, 49% were children of the deceased, 17% were other relatives, and <1% were from outside the family.

Measures

Personality—Participants completed the Midlife Development Inventory (MIDI; (Lachman and Weaver, 1997) as part of the leave-behind questionnaire. The MIDI is a 26-item self-report adjective measure of Five Factor model personality traits. Specifically, the items measured Neuroticism (e.g., moody; $\alpha=.70$), Extraversion (e.g., talkative; $\alpha=.73$), Openness (e.g., creative; $\alpha=.80$), Agreeableness (e.g., helpful; $\alpha=.63$), and Conscientiousness (e.g., organized; $\alpha=.66$). Participants rated items on a scale from 1 (not at all) to 4 (a lot). Relevant items were reverse scored, and the mean was taken across items for each trait (range 1–4).

Behavioral symptoms—As part of the exit interview, the knowledgeable proxy of the deceased HRS participant reported on behavioral symptoms. Seven items were chosen based on their relevance to the most significant behavioral symptoms of dementia commonly identified (Cerejeira *et al.*, 2012, McKhann *et al.*, 2011). Specifically, the proxy was asked, “Was there a period of at least one month during the last year of his/her life when he/she had...” Proxies answered this question for depression, periodic confusion, and uncontrolled temper. Proxies were also asked, “Did he/she ever...” get lost in a familiar environment, wander off alone, and ever see or hear things that were not really there. Finally, proxies were asked, “In the last two years, could he/she be left alone for an hour or so?” For each item, proxies responded no (recoded as 1) or yes (recoded as 0). For each behavioral symptom, the item was set to missing when the proxy either did not know or refused to answer. We also took a sum across the seven symptoms as a measure of how many symptoms each participant exhibited (range 0–7).

Cognitive status—As part of regular assessments that occur in HRS every two years, participants completed the modified Telephone Interview for Cognitive Status (TICS_m). The total TICS_m score (possible 27 points) is the sum of performance on immediate and delayed recall of 10 words (range 0–20 points), serial 7 subtraction (range 0–5 points), and backward counting (range 0–2 points). Participants who scored ≤ 11 points were classified as cognitively impaired (52% of the sample). The TICS_m has been validated previously against a comprehensive neuropsychological assessment and clinical diagnosis of dementia (Crimmins *et al*, 2011; Langa *et al*, 2005) and used to track national trends in dementia (Langa *et al*, 2017).

Analytic Strategy

We used logistic (individual symptoms) and linear (BPSD sum) regression to test the association between baseline personality and behavioral symptoms of dementia reported in the exit interview. Specifically, we predicted each symptom and the BPSD sum from self-reported personality, controlling for age at the personality assessment, sex, race, education, and interval between the personality assessment and the exit interview. We then tested whether any of these associations varied by cognitive status at baseline, interval between the personality and BPSD assessments, age, sex, race, or education.

Results

Table 1 shows the descriptive statistics for all study variables. Participants completed the personality measure 2 to 8 years before death ($M=4.81$ years, $SD=2.06$), for a total of 9,620 person-years. The prevalence of behavioral symptoms ranged from 7% for wandering off to 62% for periodic confusion. The analytic sample ranged from $n=1,836$ to $n=1990$ due to missing data on the outcome measures. The most consistent association between personality and behavioral symptoms was for Neuroticism (Table 2): Participants who scored higher in Neuroticism were at a 22% to 58% greater risk of experiencing BPSD, including getting lost in familiar places, wandering off, not being able to be left alone, hallucinations, depression, periodic confusion, and an uncontrolled temper. Not surprisingly, this trait was also associated with a greater number of symptoms overall. Although Conscientiousness was only associated with lower risk of getting lost in familiar places and lower risk of not being able to be left alone, it was associated with fewer symptoms overall. Finally, two associations emerged for the other traits: Extraversion was associated with less risk of depression and Agreeableness was associated with less risk of getting lost in familiar places. Openness was unrelated to any of the behavioral symptoms. The overall pattern of results was similar when we excluded participants who self-reported on their personality within two years of their death. In addition, the pattern of results was similar when participants classified on the third criterion (proxy-reported memory problems at the end of life, which we could not differentiate from other conditions such as delirium) were excluded from the analysis, except that the association between Agreeableness and lost in familiar places was eliminated. The overall pattern was also similar regardless of baseline cognitive status, with one exception: Among participants who were apparently cognitively normal at baseline, Conscientiousness was associated with less risk of depression at the end of life, whereas there was no association between Conscientiousness and risk of depression among

participants who had evidence of impairment at the baseline personality assessment ($OR_{interaction}=1.43$, 95% CI=1.01–2.04, $p=.048$). There were also no interactions between personality and the interval between personality assessment and assessment of BPSD.

Although some significant interactions emerged, there was not strong evidence that the associations varied by the demographic factors. Higher Extraversion was associated with greater risk of wandering off for women but was unrelated to this symptom among men ($OR_{interaction}=2.03$, 95% CI=1.09–3.77). Higher Extraversion was also associated with less risk of being able to be left alone among the relatively younger participants ($OR_{interaction}=1.02$, 95% CI=1.00–1.05) and both Extraversion and Openness were associated with less risk of hallucinations among relatively younger participants ($OR_{interaction}=1.02$, 95% CI=1.00–1.05 for both associations). Conscientiousness was associated with less risk of getting lost in familiar places among both African American and white participants, but the association was stronger among African American participants ($OR_{interaction}=.56$, 95% CI=.32–.96). Extraversion was also associated with less risk of getting lost among African American participants ($OR_{interaction}=.54$, 95% CI=.31–.93). Finally, Openness was associated with a greater risk of an uncontrolled temper among African American participants but was unrelated to this symptom among white participants ($OR_{interaction}=1.69$, 95% CI=1.03–2.77). None of the associations was moderated by education. It is of note that none of the demographic factors moderated the relation between Neuroticism and the behavioral symptoms of dementia: across age, sex, race, and education, Neuroticism increased risk of each behavioral symptom measured in this study.

Discussion

The present study indicates that personality traits, measured by self-reports approximately 2–8 years before death, are associated with risk of behavioral symptoms of dementia at the end of life, as reported by a knowledgeable proxy. Across the seven behaviors measured, Neuroticism had the most consistent association with risk of BPSD: Those high in Neuroticism were more likely to get lost in familiar places, wander off, were not able to be left alone, had hallucinations, and experienced depression, periodic confusion, and an uncontrolled temper. These associations for Neuroticism did not vary across different demographic groups.

Across the lifespan, Neuroticism is a risk factor for psychiatric disorders. The DSM-V, for example, lists Neuroticism as a well-established risk factor for major depressive disorder and as a risk for worse long-term outcomes (American Psychiatric Association, 2013). Neuroticism has likewise been implicated in anxiety, substance use, and other depressive disorders (Kotov *et al.*, 2010). The literature on Neuroticism and BPSD has been somewhat mixed (e.g., Mendez Rubio *et al.*, 2013, Pocnet *et al.*, 2013), but a systematic review of the literature indicated that this trait has the most consistent association with BPSD (Osborne *et al.*, 2010). The present findings indicate that a tendency toward experiencing negative emotions, as self-reported by the individual, is a consistent predictor of symptoms across a range of behavioral domains. Individuals high in Neuroticism are emotionally reactive and do not respond well to stress (Leger *et al.*, 2016). This tendency appears to continue to shape behavior as individuals struggle with cognitive impairments at the end of life.

Conscientiousness was only associated with two of the five symptoms: Participants who scored high on this trait were less likely to get lost in familiar places and were less likely to not be able to be left alone. Across the lifespan, Conscientiousness is associated with better health and well-being (Sutin *et al.*, 2013, Weiss *et al.*, 2009) and greater self-control (Jackson *et al.*, 2010). Individuals who score high in Conscientiousness are less likely to develop Alzheimer's disease, relative to those who score low on this trait (Duberstein *et al.*, 2011) and are more resilient to the presence of neuropathology in the brain (Terracciano *et al.*, 2013). The negative association between Conscientiousness and the sum of behavioral symptoms suggests that individuals who score high in this trait have fewer behavioral symptoms in total rather than a protective effect for specific symptoms. And, as expected, the other three traits were not consistently associated with the BPSD in this study.

The self-report personality assessment was relatively close (i.e., within eight years) to the assessment of behavioral symptoms. It is possible that elevated Neuroticism or lower Conscientiousness could be an early symptom of the disease process and thus our assessment could be capturing the disease rather than the individual's premorbid personality. Recent research indicates, however, that personality remains stable even as cognition begins to decline (Terracciano *et al.*, 2017). As such, the personality assessment likely captures information about the individual's core psychological functioning. In addition, there was little indication that the associations varied by cognitive status as baseline or interval between testing and all participants had evidence of some memory impairment. Even among this impaired group, those who scored higher on Neuroticism or lower on Conscientiousness were at greater risk of more behavioral symptoms toward the end of life.

It is of note that the association between Neuroticism and the seven behavioral symptoms did not vary by gender, age, race, or education. This similarity across groups indicates that even if there are mean-level differences in Neuroticism across demographic groups (e.g., women tend to score higher in Neuroticism than men), the risk associated with this trait is similar. There were some significant interactions with the socio-demographic factors for the other traits. These interactions, however, were generally small in magnitude and a clear pattern across symptoms did not emerge. This finding suggests that an individual demographic group did not have a particular personality profile that increased risk of BPSD relative to other demographic groups.

The current findings have relevance for interventions to reduce and manage behavioral symptoms of dementia. BPSD are among the most difficult aspects of dementia, especially for caregivers (Gaugler *et al.*, 2009). These symptoms are often managed with pharmaceutical interventions (Sink *et al.*, 2005), with antipsychotic medications the most commonly prescribed to manage symptoms (Levinson, 2011). Yet, antipsychotics have limited efficacy and significant adverse effects, including accelerated cognitive decline and increased risk of death (Steinberg and Lyketsos, 2012). Effective non-pharmaceutical interventions are clearly needed to more effectively manage BPSD while protecting the health and well-being of the person with dementia and caregivers.

Many behavioral interventions for BPSD aim to prevent symptoms by managing aspects of the environment that trigger specific symptoms (Gitlin *et al.*, 2010). There is some evidence

that matching the intervention to the personality interests of the person with dementia is more effective than an intervention applied to everyone (Kales *et al.*, 2015). For example, Kolanowski and colleagues (2011) tested whether an intervention matched to the patient's personality style of interest would be more effective than the standard approach. They found support for their hypothesis: Patients had a significant reduction in agitation and passivity when the activities in the intervention were matched with their personality style. Personality-tailored interventions may thus be more effective than ones that do not consider the person's basic characteristic tendencies.

The present study had a number of strengths. In contrast to previous studies on personality and BPSD, for example, the present research used a prospective design with a self-report measure of personality and proxy-reported behavioral symptoms. The relatively large sample was also a strength especially compared with previous studies that often had fewer than 100 participants. The present research did have limitations. First, we did not have a comprehensive measure of BPSD. The available items measured important behavioral symptoms, but it would be worthwhile in future research to have a more standardized measure. A more standardized measure would also allow us to differentiate symptoms that are potentially from delirium rather than dementia, which we could not do in this study. We also did not have a verified diagnosis of dementia but rather relied on participants' test scores and proxy-reports of cognitive impairments. It would be worthwhile in future research to have a physician-diagnosis of dementia to ensure proper categorization of participants as having had dementia. Finally, it would also be worthwhile to get a more comprehensive measure of personality earlier in adulthood to both identify whether specific aspects of personality are stronger predictors of BPSD than the broad domains and to examine whether personality has similar predictive power when measured across a longer follow-up period. Despite these limitations, the present study indicates that self-reported Neuroticism and Conscientiousness are prospectively associated with who will display behavioral symptoms of dementia at the end of life.

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Key points

- Retrospective observer-reports of personality have been associated with behavioral and psychological symptoms of dementia (BPSD)
- Self-reported personality is a prospective predictor of who will experience BPSD
- Self-reported Neuroticism prospectively predicted seven symptoms; higher Conscientiousness was associated with less symptomatology

Table 1

Descriptive Statistics for Study Variables

Study Variable	Mean (SD) or %
Baseline age (years)	77.19 (9.86)
Sex (female)	54%
Race (African American)	16%
Race (Other/Unknown)	2%
Education (years)	11.44 (3.34)
Interval (years)	4.81 (2.06)
Self-reported Personality	
Neuroticism	2.10 (.64)
Extraversion	3.06 (.59)
Openness	2.77 (.59)
Agreeableness	3.44 (.54)
Conscientiousness	3.16 (.56)
Proxy-Reported Behavioral Symptoms	
Lost in familiar places	22%
Wander off	7%
Cannot be left alone	18%
Hallucinations	26%
Depression	56%
Periodic confusion	62%
Uncontrolled temper	20%
Sum of behavioral symptoms	2.06 (1.61)

N=1,998.

Table 2

Association between Self-reported Personality Traits and Proxy-Reported Behavioral Symptoms of Dementia

Personality trait	Behavioral Symptom				
	<u>Lost in familiar places</u>	<u>Wander off</u>	<u>Cannot be left alone</u>	<u>Hallucinations</u>	
Neuroticism	1.32 (1.10–1.58) **	1.48 (1.11–1.97) **	1.22 (1.01–1.48) *	1.30 (1.09–1.54) **	
Extraversion	.95 (.78–1.14)	1.23 (.90–1.67)	.91 (.74–1.11)	.98 (.82–1.18)	
Openness	.88 (.72–1.06)	1.01 (.74–1.37)	.82 (.67–1.01)	1.02 (.85–1.23)	
Agreeableness	.75 (.61–.92) **	.95 (.68–1.32)	.90 (.72–1.12)	1.04 (.85–1.28)	
Conscientiousness	.74 (.61–.90) **	.92 (.67–1.25)	.75 (.61–.93) **	.90 (.74–1.08)	
Sample <i>N</i>	1843	1864	1864	1836	
	Symptom Sum				
	<u>Depression</u>	<u>Periodic Confusion</u>	<u>Uncontrolled temper</u>		
Neuroticism	1.50 (1.29–1.74) **	1.31 (1.12–1.52) **	1.58 (1.32–1.89) **	.13 (.09, .18) **	
Extraversion	.84 (.71–.98) *	1.00 (.85–1.17)	1.15 (.95–1.40)	.00 (–.05, .05)	
Openness	1.01 (.86–1.18)	1.06 (.90–1.24)	1.15 (.95–1.40)	.01 (–.04, .06)	
Agreeableness	.98 (.82–1.17)	.95 (.80–1.14)	.87 (.71–1.08)	–.02 (–.07, .03)	
Conscientiousness	.85 (.72–1.00)	.95 (.80–1.12)	.83 (.68–1.01)	–.06 (–.11, –.01) *	
Sample <i>N</i>	1941	1984	1990	1740	

Note. Coefficients are Odds Ratios (95% Confidence Interval) from logistic regression predicting each behavioral symptom from personality, controlling for baseline age, gender, race, education, and interval between personality assessment and the exit interview. The coefficients for Symptom Sum are standardized regression coefficients predicting the sum of all behavioral symptoms controlling for the same set of covariates.

* $p < .05$.

** $p < .01$