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Psychometric Properties of a Structured Interview Guide for the Rating for Anxiety in Dementia (RAID-SI)

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Abstract

OBJECTIVES—The Rating Anxiety in Dementia (RAID; Shankar et al, 1999)is a clinical rating scale developed to evaluate anxiety in persons with dementia. This report explores the psychometric properties and clinical utility of a new structured interview format of the RAID (RAID-SI), developed to standardize administration and scoring based on information obtained from the patient, an identified collateral, and rater observation.

METHOD—The RAID-SI was administered by trained master's level raters. Participants were 32 persons with dementia who qualified for an anxiety treatment outcome study. Self-report anxiety, depression, and quality of life measures were administered to both the person with dementia and a collateral.

RESULTS—The RAID-SI exhibited adequate internal consistency reliability and inter-rater reliability. There was also some evidence of construct validity as indicated by significant correlations with other measures of patient-reported and collateral-reported anxiety, and non-

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significant correlations with collateral reports of patient depression and quality of life. Further, RAID-SI scores were significantly higher in persons with an anxiety diagnosis compared to those without an anxiety diagnosis.

CONCLUSION—There is evidence that the RAID-SI exhibits good reliability and validity in older adults with dementia. The advantage of the structured interview format is increased standardization in administration and scoring, which may be particularly important when RAID raters are not experienced clinicians.

Keywords

dementia; anxiety; clinical interview; assessment; Rating for Anxiety in Dementia

Background

In older adults with dementia, anxiety is an emerging area of concern. Anxiety is common in dementia, with prevalence rates varying from 38% in Alzheimer's disease to as high as 72% in vascular dementia (Ballard, Neill, & O'Brien, 2000; Seignourel, Kunik, Snow, Wilson, & Stanley, 2008). When anxiety co-occurs with dementia, it has been associated with additional burden on patients and caregivers, since it can contribute to decreased independence, increased limitations on activities of daily living), increased behavioral problems, and a greater risk for nursing-home placement (Gibbons et al., 2002; Kraus, et al., 2008; Neville & Teri, 2011; Porter et al., 2003; Schulz et al., 2004; Teri et al., 1999).

With increased attention to prevalence and impact of anxiety in dementia comes the need for an ability to assess anxiety symptoms in people with cognitive impairment. The Rating Anxiety in Dementia (RAID; Shankar, Walker, Frost & Orrell, 1999)is a clinical rating scale comprising 18 items rated ona three-point scale, specifically developed to evaluate severity of anxiety in persons with dementia (PWD). Ten of the items rate somatic symptoms and five are about specific fears. The only published clinical rating scale of anxiety for use with persons with dementia, the RAID has been used in at least eight published studies to date (Cheston, Jones & Gilliard, 2003; Cooke, Moyle, Shum, Harrison, & Murfield, 2010; Gibbons, Teri, Logsdon & McCurry, 2006; Neville & Teri, 2011; Paukert, et al., 2010; Qazi, Shankar & Orrell, 2003; Selwood, Thorgrimsen & Orrell, 2005; Twelftree & Qazi, 2006; Spector, et al., 2003).

A score of 11 indicates excellent sensitivity (77% to 90%) and specificity (79% to 82%) for identifying a *Diagnostic & Statistical Manual, Fourth Edition* anxiety disorder or clinically significant anxiety as compared with separate clinician judgment. The original development study documented strong psychometric properties for the RAID: excellent internal consistency reliability (alpha = .83), adequate inter-rater reliability (item kappas from .51 to 1.00, with overall item agreement ranging from 84% to 100%), and evidence for its convergent/divergent validity (as indicated by higher correlations with measures of anxiety than depression). Data from three open trials support the ability of the measure to identify change following treatment (Paukert, et al., 2010; Cheston, et al., 2003; Qazi, et al., 2003).

The RAID was designed to use input from patients and caregivers, as well as any relevant clinical information available from medical records or other sources (Shankar et al., 1999). Discrepancies between patient and caregiver ratings are to be integrated based on clinical judgment. However, the RAID is presented as a one-page instrument with very brief instructions on rating and scoring, and no guidance regarding how to integrate these multiple and potentially discrepant sources of information. There is indication in the literature that researchers are using the RAID in different ways: two studies based RAID scores only on the report of the caregiver (Gibbons et al., 2006; Twelftree & Qazi, 2006), one study based

RAID scores only on the report of the person with dementia (Cooke, et al., 2010), others reported interviews with both the caregiver and the person with dementia (Cheston, et al., 2003; Selwood, et al., 2005; Spector, et al., 2003), and one study reported that the RAID scores were based on clinical notes and interviews with both the caregiver and the person with dementia (Qazi, et al., 2003). The original study included interviews of both caregiver and patient but rather ambiguously stated that the scale should be scored "based on all available information" (Shankar et al, 1999). Finally, of all the published work using the RAID, only the original study has reported on its inter-rater reliability.

As part of a recent treatment study (Paukert et al., 2010), our team elaborated upon the RAID instructions and modified the RAID format into a structured interview, thus standardizing administration, scoring, and information gathering and integration (see appendix. The structured interview guide includes detailed rater instructions regarding follow-up probes and other matters of administration; collection of frequency, distress, and severity information to improve scoring; and approaches for integrating information. The primary purpose of this project was to explore the psychometric properties and clinical utility of this structured interview format of the RAID (RAID-SI).

During a pilot study using the RAID-SI (Paukert et al., 2010), the trained clinical raters reported that their clinical confidence in RAID-SI scores varied across patients. That is, raters reported that in some instances they were less confident that the RAID-SI reflected the true clinical situation because, despite high confidence in the accuracy of their administration and scoring of the RAID-SI, the raters found the PWD and/or caregiver/ collateral informant to be poor informants. The secondary purpose of this project was to examine associations between the RAID-SI and rater clinical confidence and to examine predictors of clinical confidence ratings.

Method

Participants

Participants were 32 persons who qualified for an anxiety treatment outcome study based on the following inclusion criteria: age 50 or older; a dementia diagnosis confirmed by a medical provider and mild-moderate dementia severity (Clinical Dementia Rating [CDR] score = 0.5 to 2.0; Morris, 1993); a collateral who also consented to participate in the study (we defined collateral as a family member, paid caregiver, or close friend who spends at least 8 hrs/week with the patient and speaks fluent English); Neuropsychiatric Inventory (NPI) anxiety subscale ≥ 4 (completed by the collateral); and primary diagnosis not major depressive disorder.

Persons with dementia (n=32) were recruited from geriatric, neurology, psychiatry, and primary care clinics at a Veterans Affairs Medical Center, the geriatric and neurology clinics affiliated with a medical school, the county hospital, and community day centers for older adults with dementia. All persons with dementia were recruited in the context of a randomized clinical trial of cognitive behavioral therapy for anxiety in dementia (ClinicalTrials.gov NCT00596284).

Measures

Mental Health Diagnosis and Dementia Severity Assessment—Mental health diagnoses were determined using the Mini International Neuropsychiatric Interview (MINI; Sheehan et al., 1998). Dementia severity was determined using the CDR(Morris, 1993) scale and the Dementia Rating Scale-2 (DRS; Mattis, 2001). Information for both the MINI and CDR was collected from both the patient and collateral. The DRS (Mattis, 2001)was

administered to inform the cognitive functioning scores on the CDR. All interviews were audio recorded, and a random 20% of MINI assessments (n = 11) were rated by a second psychologist to obtain inter-rater agreement, which was adequate for all diagnoses (generalized anxiety disorder [GAD] kappa = .79; depression kappa = 1.00; other anxiety kappa = .61 (includes all anxiety diagnoses except GAD, including obsessive-compulsive disorder, panic, panic w/agoraphobia, post-traumatic stress disorder, social phobia, specific phobia, anxiety not otherwise specified).

Rating for Anxiety in Dementia-Scheduled Interview—RAID-SI items assess symptoms rated 0 (absent) to 3 (severe) in four categories: worry, apprehension and vigilance, motor tension, and autonomic hyperactivity (Shankar et al, 1999). The RAID has adequate inter-rater reliability, internal consistency, and evidence of convergent/divergent validity (Shankar et al., 1999; Cheston et al, 2003; Twelftree & Qazi, 2006).

Collateral reports of Anxiety, Depression, Quality of Life, and Relationship Quality of the Person with Dementia—Collaterals were asked to complete measures about the PWD's anxiety, depression, and quality of life as well as the quality of the relationship between the PWD and collateral; all measures were completed by the collateral in a self-report format, with the IE providing assistance with reading aloud items and/or responses if necessary.

Anxiety was assessed with the Penn State Worry Questionnaire–Abbreviated (PSWQ-A-collateral), the Neuropsychiatric Inventory anxiety subscale (NPI-A), and the Geriatric Anxiety Inventory (GAI-collateral). Depression was assessed with the Geriatric Depression Scale (GDS-collateral). Relationship quality was assessed with the Mutuality Scale. Quality of life was assessed with the Quality of Life in Alzheimer's Disease scale (QOLAD-collateral).

The PSWQ-A-collateral is an eight-item scale in which the collateral rates amount of agreement with worry-related statements on a Likert scale from 0 (not at all typical) to 5 (very typical). The original PSWQ-A has been shown to perform reliably (α = .87) and to exhibit strong psychometric properties with the full PSWQ in nondementia populations (Crittendon & Hopko, 2006; Hopko et al., 2003), and was used to assess worry in an open trial of CBT for late-life anxiety in patients with dementia (Paukert et al, 2010).

The GAI-collateral (Pachana et al., 2007) is a 20-item questionnaire developed to assess symptoms of generalized anxiety (such as fearfulness, worry, and physiological symptoms) in older adults. Items are worded as statements with which the respondent agrees or disagrees and refer to experiences during the past week. Pachana et al. reported high internal consistency (α = .91) in a sample of 452 community-dwelling older adults. The developers also reported excellent 1-week test-retest reliability in a clinic-based sample of older adults with psychiatric disorders (r = .91). The GAI was significantly correlated with NPI anxiety severity and NPI anxiety distress scores in a sample of 100 memory clinic patients, most of whom were diagnosed with dementia (Byrne, Pachana, Arnold, Appadurai, & Chalk, 2008).

The NPI-A is scored using the report of a collateral who knows the person well. Scripted screening questions ask whether anxiety symptoms have been present during the past month. If anxiety is present, as indicated by a positive response to the screening question, seven additional questions are coded as *present* or *absent*. Collaterals are then asked to rate the frequency and severity of overall anxiety symptoms. A composite score is derived by multiplying frequency by severity, resulting in positive scores of 1 to 12. The NPI-A is the most widely used psychological and behavioral scale for patients with dementia, and it is

used routinely in outcome trials (Burns, Lawlor & Craig, 2002). The measure is administered solely to the collateral to evaluate the patient's symptoms.

The GDS-collateral (Yesavage, Brink, Rose & Lum, 1983) is a 30-item self-report instrument designed to measure symptoms of depressed mood in older adults. Items describe recent mood-related symptoms, and choice of ratings is "yes" or "no." The GDS has high reliability indices and concurrent validity correlations across a multitude of studies and geriatric populations (Wancata, Alexandrowicz, Marquart, Weiss, & Friedrich, 2006).

The Mutuality Scale (Archbold, Stewart, Greenlick & Harvath, 1990) is a 15-item self-report scale that assesses closeness, shared activities, reciprocity, and other indicators of relationship quality between the collateral and the person with dementia. Items are rated on a four-point scale and averaged for a total score. Archbold et al. reported a Cronbach's alpha of 0.91 and a test-retest reliability coefficient of 0.79 across a 6-to 7-month period. The scale has been applied in studies of dementia caregivers (e.g., Gallagher-Thompson, Dal Canto, Jacob, & Thompson, 2001; Snow et al., 2009).

The QOL-AD consists of 13 items assessing quality of life domains. Items are totaled for a sum score. Concurrent validity evidence for this instrument includes significant correlations with measures of functioning, mood, and pleasant events (Logsdon et al., 1999), as well as the Dementia Quality of Life scale and the Euroqol-5D scale (Thorgrimsen et al., 2003). Persons with severe dementia and MINI scores as low as three are able to complete the scale validly (Thorgrimsen et al., 2003).

Person With Dementia Reports of Their Own Anxiety, Depression, and QOL— PWDs were asked to complete measures about their own anxiety, depression, and quality of life (PSWQ-PWD; GAI-PWD; GDS-PWD; QOLAD-PWD). A rater read each question aloud to the PWD, oriented and re-oriented him/her as necessary to the response choices using printed response cards, and recorded his/her responses.

Rater Clinical Confidence—Rater confidence in the accuracy of RAID-SI scores was measured with the following item, "How confident are you that the RAID-SI final scores reflect the actual clinical situation?," rated on a six-point scale from 0 (Not At all Confident) to 5 (Very Confident). Confidence ratings were begun part-way through the trial in response to the independent evaluators' (IEs') reports regarding the widely varying quality of information provided by patients and collaterals; these exploratory ratings were completed on a subset of 13 (41%) RAID-SI interviews.

Procedures

The MINI and CDR were administered to all participants by a trained graduate student during the diagnostic assessment. The interview was conducted with both the patient and collateral present.

The RAID-SI, the collateral self-report measures about the PWD, and the PWD self-report measures about the PWD were administered by an IE at the patient's home or in the clinic at a separate assessment appointment as part of a baseline evaluation in a larger clinical trial. The RAID-SI was administered as a clinical interview conducted jointly with the patient and collateral.

The patient and collateral each received $20 for completing the assessment. IEs were trained master's-level raters with no significant experience in dementia assessment. RAID-SI inter-rater reliability was examined in a randomly selected subset of 11 interviews (20% of the IE's first 20 assessments and 10% of all subsequent assessments), accounting for 34% of all

interviews. IE assessments were compared with those made by a licensed psychologist with expertise in dementia assessment (Snow).

Results

Descriptives

Descriptive data are presented in Table 1. Most patients were non-Hispanic Whites (65.1%), and the most frequent dementia diagnosis was Alzheimer's disease (60.5%). About half of the sample had mild dementia severity, and half had moderate impairment. Twenty patients (62.5%) had an anxiety disorder diagnosis, 12 (37.5%) did not have an anxiety disorder diagnosis (but qualified for the study due to the elevated anxiety symptomatology per the NPI-A). GAD was the most prevalent anxiety disorder diagnosed (n=14, 43.75%)

Reliability, Validity, and Diagnostic Accuracy

The RAID-SI yielded good internal consistency reliability (Cronbach's alpha = .75, $n = 32$) and inter-rater reliability (average weighted kappa = .71, $n = 11$). There was also evidence of convergent validity, as indicated by significant zero-order correlations with other measures of anxiety (PSWQ collateral $r = .36$, $p < .05$; PSWQ-PWD $r = .49$, $p < .01$; GAI-collateral $r = .46$, $p < .01$; GAI-PWD r = .48, $p < .01$; NPI anxiety-collateral $r = .38$, $p < .05$). Regarding discriminant validity, the RAID-SI was not correlated with a measure of collateral-PWD relationship quality (mutuality-collateral, $r = -.04$, $p =$ ns), a measure of quality of life (QOLAD-collateral, $r = -.18$, $p =$ ns), or a collateral report of depression (GDS-collateral $r = .26$, $p =$ ns). The RAID-SI was correlated with PWD reports of quality of life (QOLAD-PWD, $r = -.61$, $p < .001$) and depression (GDS-PWD, $r = .52$, $p < .01$).

The Wilcoxon Mann-Whitney test was used to determine whether RAID-SI scores differed as a function of the presence/absence of an anxiety diagnosis or, more specifically, the presence/absence of GAD. RAID-SI scores were significantly higher in PWD with any anxiety diagnosis ($n = 20$; $M = 17.99$, $SD = 7.15$) compared with those who did not qualify for any anxiety diagnosis ($n = 12$; $M = 10.17$, $SD = 5.62$), $z = -2.79$, $p < .01$. Similarly, RAID-SI scores were significantly higher in PWD with GAD (n=15; $M = 18.59$, $SD = 7.40$) than among PWD without GAD (n=17, $M = 11.94$, $SD = 6.42$), $z = 2.38$, $p < .02$.

As a further examination of construct validity, receiver operating curve (ROC) analyses were conducted to evaluate the diagnostic accuracy of the RAID-SI. The area under the curve (*AUC*) was .80 ($SE = .08$; 95% confidence intervals = .64–.96), indicating that the RAID performs well at distinguishing between those with any anxiety diagnosis and those with no anxiety diagnosis (an AUC of .50 indicates performance at chance level and an AUC of 1.00 would be perfect performance). See Table 2 for the sensitivity and specificity of the RAID at various cut-off points. The cut-point score that optimized diagnostic accuracy (simultaneously maximizing sensitivity and specificity) was 10, resulting in a sensitivity of .90 and specificity of .67.

Clinical Confidence

RAID-SI rater clinical confidence ratings were distributed across the range of confidence, although skewed toward the "more confident" range of the scale (very confident = 5 = 31%; 4 = 15%; 3 = 46%; 2 = 8%; 1 = 0%; not at all confident = 0 = 0%). Confidence ratings were not significantly correlated with number of hours per week that collaterals spent with the PWD, RAID-SI scores, other measures of anxiety, or most measures of depression. Confidence ratings were significantly correlated with the GDS-collateral score (spearman's $rho = -.73$, $p < .01$) and with dementia severity (spearman's $rho = .59$, $p < .05$). As collateral

ratings of the PWD's depression and dementia severity increased, RAID-SI rater clinical confidence declined.

Discussion

This study provides evidence that the RAID-SI is a useful psychometric instrument with good reliability and validity. The RAID-SI had moderately high inter-rater reliability. Further, there is evidence of concurrent and discriminant validity; the instrument correlated significantly and positively with other self-report measures of anxiety and seemed to tap into different constructs compared with collateral ratings of the relationship, PWD quality of life, and PWD depression. The RAID-SI was correlated with QOLAD and PWD reports of quality of life and depression; this finding emphasizes the importance of the joint PWD/collateral interview, as these results suggest it would be difficult to distinguish anxiety from depression by interviewing the PWD alone. Finally, the RAID-SI was able to distinguish persons with a clinical diagnosis of anxiety from those without a diagnosis, as well as patients with and without a diagnosis of GAD.

To our knowledge, this is the first study that has addressed the confidence of clinical ratings for persons with dementia. This is an important aspect of this study because it is a common occurrence for raters to find some persons with dementia and their collaterals to be poor informants. Our data suggest that evaluations of more cognitively impaired and depressed individuals (or at least individuals perceived to be more depressed by their collaterals) pose greater challenges. Adding a clinical confidence rating to the end of clinical interviews for persons with dementia might provide one quick indicator of the accuracy of those data. This might then serve as a prompt for the clinician to search for additional sources of information if possible, as well as a reminder to those using the RAID-SI ratings in clinical decision-making that these scores may not tell the whole story. Additional research with larger samples is needed in this area to understand whether psychometric indicators differ between those dyads rated with higher versus lower clinical confidence.

The challenge of clinical interviews with a PWD is that the PWD's report may be inaccurate due to language, memory, and abstract-thinking impairments that intensify over the course of the dementing disease. There is strong evidence that PWDs are able to respond accurately to questions about their mood, experiences, and preferences (Feinberg & Whitlatch, 2001; Fisher, Burgio, Thorn & Hardin, 2006; Menne & Whitlatch, 2007; Snow et al., 2009). However, previous studies have also consistently found that PWDs have an under-reporting bias (Davison, McCabe, & Mellor, 2009; Snow, Kunik et al., 2005), and although these self-report abilities have been shown to vary depending upon context, situation, and type of brain damage, there is not yet adequate information to reliably predict whether a specific individual with dementia will be able to accurately self-report (Chopra, Sullivan, Feldman, Landes & Beck, 2008; Snow, Cook et al., 2005). Given the existing evidence base, the National Alzheimer's Coordinating Center (NACC) requires that the presence of depression be assessed from both participants and their collateral sources (Beekly et al., 2004). In this study we chose to address this challenge by interviewing the PWD and collateral together. The joint clinical interview procedure was modeled on that of a large, methodologically rigorous epidemiologic study of depression in persons with dementia (Zubenko et al., 2003), and our own adaption of this joint interview technique that we successfully used in our epidemiologic study of the development of aggression in PWD (Kunik et al., 2010a; Kunik et al., 2010b).

The joint clinical interview gives the clinical rater the opportunity to directly assess the potential impact of the different types of factors that have evidenced a moderating effect on accuracy of self-report and collateral report (i.e., quality of PWD/collateral relationship;

level of PWD knowledge evidenced by caregiver; observable indicators of the PWD's mood, cognitive ability and judgment; observable indicators of the collateral's mood, cognitive ability, and judgment). The joint interview may also result in richer information because the PWD's and collateral's responses provide cues to each other that help elicit additional information, allowing the dyad to provide the most thoughtful and comprehensive response possible. It is also important consider possible detrimental effects of the joint interview. The joint presence of the dyad may influence one of the participants to hold back information to avoid disagreement. However, we do not know of any evidence to suggest that this may result in a particular direction of systematic bias based upon our experiences it seems as likely that the caregiver might hold back PWD symptom reports to avoid upsetting or disagreeing with a PWD who is adamant about underreporting as it would be for the PWD to seek to avoid disagreement by not protesting if the collateral reports symptoms that the PWD doesn't feel he/she is experiencing. Of course, conducting separate interviews of the PWD and collateral has its own effects–we suspect that a PWD with a tendency to underreport may be more likely to deny symptoms in an individual interview because the collateral would be present to cue the PWD with reminders of contradictory events and experiences. Perhaps it would be most ideal to conduct interviews separately and then conduct a final interview together, but this would be quite infeasible in most research and clinical settings due to the required time. Overall, we would argue that if choosing between joint versus separate clinical interviews, the joint interview is superior due to the extra clinical information available to the clinician.

In sum, the major contribution of the RAID-SI's structured-interview format is increased standardization in administration and scoring, which may be particularly important when RAID raters are not experienced clinicians or lack experience with the dementia population. The raters in this study, masters-level clinicians with limited experience with persons with dementia, were challenged by the task of integrating potentially discrepant information from the collateral and PWD and found the guidance of the RAID-SI to be very helpful, as indicated by the strong inter-rater reliability findings.

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Appendix. Rating Scale for Anxiety in Dementia Structured Interview

Acknowledgment: This appendix contains a structured interview that can be used to guide the administration of the Rating Scale for Anxiety in Dementia. The Rating Scale for Anxiety in Dementia Scale was developed by K. Shankar, M. Walker, D. Frost, and M. W. Orrell, and information on its development is available as follows: Shankar, K. K., Walker,

M., Frost, D., & Orrell, M. W. (1999). The development of a valid and reliable scale for rating anxiety in dementia (RAID). *Aging and Mental Health, 3*, 39–49.

General Instructions

Understanding the Goal and Development of the RAID

The purpose of this structured interview is to assist in the reliable assessment of anxiety severity by standardizing the method of assessment and providing clear anchor points for the assignment of severity ratings. The interview items and the anchor points are meant to supplement good clinical judgment, not replace it.

Using a Past WEEK Time Frame

The time frame for the RAID is **THE PAST WEEK** and should be consistent for all items.

Assessing Patient and Collateral

When possible, administer the RAID to the patient and to his/her collateral together. Inform the patient and collateral that you will first ask a set of questions of the patient (these will all be questions within one item) and then will turn to the collateral to ask whether he/she has anything to add or clarify about this set of questions.

Then use your clinical judgment to determine how to weigh the patient's answers and the collateral's answers to arrive at the best score for that item.

Ask About Presence/Absence First, Then Severity

Most items of the RAID ask about multiple symptoms/consist of multiple probes.

FIRST, ask each of the probes with the goal of just determining the *presence/absence* of each of those symptoms.

THEN list the symptoms that were endorsed and inquire abut *overall severity for the collection of endorsed symptoms* (see SEVERITY section below).

NEXT, turn to the collateral and ask whether he/she has anything to add or clarify about this set of questions.

Inquiring About Severity

The severity rating for each item concerns the collection of the endorsed symptoms for that item. Paraphrase the list of endorsed symptoms for that item; then ask the patient about severity for that group of symptoms overall. Ask about **frequency** of the collection of symptoms for that item (how much, how often) and then about how much **distress** and **interference** the collection of symptoms causes. *[NOTE: there may be some patients who are too memory-or attention-impaired to be able to complete this cognitive task. If you determine this is the case, then you can move to a procedure of asking about presence/ absence and then severity for each separate symptom rather than for the collection of endorsed symptoms.]*

- Possible follow-up probes to assess **frequency**: (ask only collateral these specific questions if the patient cannot estimate frequency)
  - Did you worry/have the symptom daily?
  - How often do *these symptoms* occur?
  - Do they happen daily?

- More days than not?
- If no, how many days in a week? (most, half, few, none, a lot, a medium amount, a little)
  - ♦ If yes, how much of the day?

- Possible follow-up probe to rate **distress**:
  - Did it bother/distress you a lot, a medium amount, or a little?
  - How much does the symptom bother you or your spouse/relative/friend?
  - How upset or uncomfortable does it make you or your spouse/relative/friend feel?
- Possible follow-up probe to rate **interference**:
  - How much does it interfere/keep you from/get in the way of your life or your spouse/relative/friend's life?
  - How much does it keep you from doing the things you want to do/doing the things you need to do/getting things done/living your life the way you want to/doing things you need to do during the day?
  - Are there things you aren't doing, or your spouse/relative/friend is not doing, because of your symptoms?
  - (specific to worry): Is it hard for you to stop thinking about <worry>? Does worrying about that get in the way of....
    - ♦ Other wording options besides *interfere*
      - How much does it keep you from…
      - How much does it get in the way of…
    - ♦ Other wording options besides *with your life*
      - …doing the things you want/need to do?
      - …getting things done?
      - …living your life the way you want to?
      - …doing things you need to do during the day?
      - …insert specific examples you've heard about during the interview…this is a great option for patients who need more concrete examples; but, remember, since these types of patients are already having trouble with abstract concepts and generalizing, you'll want to also ask one of the general questions, or give several specific examples, so you can be sure you understand how the symptom is interfering with their life overall.
- When assessing severity, avoid using the same words that are used as the anchors in the RAID (e.g., don't ask if the symptom was mild, moderate, or severe), and don't ask if the symptom was a 1, 2, or 3 *(because you can't be sure that you*

understand what the participant with dementia understood those numbers to mean when he/she responds back to you).

Quantity of Endorsed Symptoms and Severity

Severity is defined most readily by the frequency of occurrence and degree of distress and interference associated with the endorsed symptoms. The number of symptoms present is incorporated into your severity rating only as it impacts distress and interference. For example, a higher rating may be achieved for a *single* severe symptom than for *several* mild or moderate symptoms. Alternatively, *several mild* symptoms may lead to a *moderate* rating of severity because of their overall impact on distress.

Overlap Between Anxiety and Medical Symptoms

- If you're **absolutely sure** a symptom is due to a medical problem only, don't include it in your rating (such situations tend to involve acute medical symptoms). *If in doubt, rate it!*
- However, trembling is an item that we find is often related to medical situations, and so merits special follow-up. Merriam-Webster defines *trembling* as "(1) to shake involuntarily, as with fear or cold; (3) to be affected by fear or anxiety"; whereas a *tremor* is defined as "rhythmic, involuntary, oscillatory movement of body parts." Tremors are the most common type of neurologic movement disorder; thus, it is important to differentiate tremors from trembling, used in the RAID as a possible sign of fear or anxiety. Tremors can be caused by neurologic conditions (Parkinson's, multiple sclerosis), drugs, metabolic conditions (e.g., diabetic with low blood sugar) or may not have an identifiable cause ("essential tremor"). Essential tremors occur in more than 5% of people over age 60, so they are pretty common. Essential tremors occur most often in the hands, upper extremities, and head, and, sometimes, voice and tend to occur while the hands are being used (whereas hand tremors due to Parkinson's occur more often when the person is at rest or walking). **To help differentiate *trembling* from *tremors*, ask follow-up questions about conditions under which the symptom occurs and whether the participant is experiencing fear or anxiety when the symptom occurs.** Because essential tremors are undiagnosed in approximately 50% of the people who suffer from them, you'll often have to rely on your own clinical judgment to decide whether the symptom is a tremor or trembling. You may find it helpful to read the first couple of pages of this article: (Smaga, S. (2003). Tremor. *American Family Physician,* 68,1545–52. Available at http://www.aafp.org/afp/20031015/1545.pdf).

Using the Anchors to make the Final Rating

The rating scale is 0 – 3. You should use your best clinical judgment to make the determination as to which score best fits, based upon the verbal descriptors, which are consistent throughout the items (i.e., absent=0; mild or intermittent = 1; moderate = 2; severe = 3).

The following table may help you think about how you combine Frequency, Distress, and Interference information to determine the total score. Obviously, these are just guides to help give you an idea of the differences between a 1, 2, and 3. This table does not cover every possible combination of verbal descriptors you will hear in your assessments. Ultimately, you must use your own clinical judgment regarding what a Mild (1), Moderate (2), and Severe (3) score should be.

SCORING RULE: *If in doubt between two scores, always use the higher score.*

Distress/Interference	Frequency	Score
None.....AND:	None	0
Present/Mild .....AND:	Present/Less than 50%	1
Mild.....AND:	>50%	
Moderate.....AND:	<=50%	2
Moderate.....AND:	>75%	
Severe.....AND:	>50%	3

Here are some guides to show how some of the verbal descriptors commonly used by patients map on to frequency percentages:
100% Constantly
75% Several Times a Day
50% Every Day
<50% Several Times a Week
<25% 1–2 Times a Week

- Please note that it is very important to differentiate *every day* from *several times a day* to make accurate scoring decisions. Most individuals tend to use the words *every day*, so you'll have to make sure to always follow-up on this response by asking, "Does it happen several times a day, or just sometime every day?"
- Raters often find it more challenging to differentiate between mild/moderate and moderate/severe distress than to determine frequency or make other differentiations. Participants often describe distress in ambiguous terms, such as, "It upsets me a lot" (could be moderate or severe, depending upon the context), or "I do find that upsetting." Note that, at certain levels of frequency, making these distress differentiations is very important; and, at other levels of frequency, such differentiations are less important. Be sure to ask enough follow-up questions to be able to clearly determine when such differentiations are important.

Recording Scores

If the RAID is administered to the dyad together, you are required to record only a final score. If the RAID is administered independently to each member of the dyad, rate both the patient and collateral separately; and then determine the final score, using your clinical judgment to decide whose report gets more weight, based on whose report is probably the most accurate. There is a score summary page for the RAID. Please enter the final scores on these score summary pages.

A Note Regarding RAID Item #1, Worry about Physical Health—Be sure to make a distinction between physical health (rated in this item) and cognitive performance/abilitity/ capacity (rated in the next item).

A Note Regarding RAID Item #4, Worry Associated with False Beliefs or Perceptions—This is a tricky item! You may often get the sense that you're not getting as good information about this item as you would be able to if you were talking to the patient alone. This is true! So don't worry; it's not your skill – it's just a really tricky subject to discuss with the patient and collateral together. However, the Peaceful Mind team has decided that the time that would be required to inquire about this item separately is not

worth the extra information that might be gathered. So, just do your best; and don't worry about it. Be confident in the knowledge that, if patient worry around a delusion is really significant, the collateral will know what you are asking about and tell you; this has definitely been our experience!

A Note Regarding RAID Item #11, Motor Tension—Do not rate pain as causing "severe distress" just because the person has everyday pain and must take medication to control it. The amount of *distress* caused by the pain is separate from the suffering of the pain itself. A person could suffer from chronic pain but be able to control it with medication and exhibit *acceptance* of the chronicity of the pain and thus not be severely distressed; whereas another person could suffer from a lot of *fear of the pain* and describe feeling very burdened by knowing the pain will recur very frequently, even if he/she is mostly able to control the pain by medication; and this person would be severely distressed.

Notes on Challenges Around Assessing Patients with Dementia and Challenges Around Assessing Patients and Collaterals Together

The research literature clearly indicates that persons with dementia have an under-reporting bias: that is, when they report about their situation inaccurately, they tend to play down the presence/intensity/impact of their symptoms. This is probably due partly to memory problems and partly to social-desirability effects. Regarding the former, the patient may have difficulty remembering specific instances of the construct on which he/she is being questioned and, thus, may fail to report those instances of anxiety. Regarding the latter, as other cognitive abilities diminish, people with dementia rely particularly heavily on the social skills to get along in the world. Thus, people with dementia may be even more reluctant than a cognitively intact person to "complain" to a stranger about things that are not going well.

Thus, the assessor must rely on the collateral to provide indications as to when the person with dementia is under-reporting.

However, both you and the collateral are in a challenging position. If the collateral voices his/her disagreement with the patient too strenuously, the person with dementia may feel disregarded, infantilized, or persecuted. If the collateral, to keep the peace, says very little, you could end up with a really misleading assessment of the patient's symptoms.

There are two possible "tricky situations" that you might find yourself in:

(1) First Tricky Situation—The collateral is reluctant to add much information. In this situation, you as the assessor must help the collateral by saying things that set the stage for him/her to be able to provide the additional information you need without upsetting the patient.

You can help set the stage by:

- Making sure you check in with the collateral after checking in with the patient on each and every item.
  - The amount of time you take to do this can be diminished all the way to the short phrase, "Do you have anything to add?," once, in your clinical judgment, the collateral is comfortable with the process, is providing additional information as needed, and understands you need him/her to do this for each item.
  - But until that point, you'll need to say a little more.

- If you get the sense that the collateral is reluctant to contribute his/her view, you could say,
  - " Could I get your point on this, too?" It may be that you and [patient] see this issue differently; and, if so, that's important information for me." [You might be careful to make sure that collateral and patient know you are saying this next part to BOTH of them:] "It's not that you are wrong, and you are right...or that you are right and you are wrong...it's that we all see things in a different way. And it's important for me to get both of your views, even if you disagree? Is that OK with both of you?"

- Making sure that you are cognizant of using words and nonverbal gestures to check in with the patient/maintain rapport with the patient/(indirectly or directly) give the patient the message that his/her input is just as valuable as the collateral's. You can do this by...
  - Saying to the patient, after you have gotten input from both patient and collateral, "Good, now I've gotten input from both of you about that issue. Let's go on to the next item now...."
- The main point here is that you are constantly monitoring your rapport with *both* patient and collateral to try to make sure that both of them are getting the message (indirectly or directly) that the input of each is a valuable and necessary part of the interview

(2) Second Tricky Situation—The collateral has no problem stating his/her point of view. In fact, the collateral is so eager to add his/her contribution that he/she is talking over the patient, either leading to the patient's giving up and "shutting down" or creating an agitated and argumentative atmosphere.

In this situation, you as the assessor must help the patient by saying things that set strict boundaries as to when the collateral speaks. Of course, you have to do this in a skillful way that still affirms to the collateral that his/her information is valuable; so that you do get the collateral's point of view as well.

You can help set the stage by:

When the collateral interrupts the patient, break in and say, "It may be that you and [patient] see this issue differently; and, if so, that's important information for me." [You might be careful to make sure that collateral and patient know you are saying this next part to BOTH of them:] "It's not that you are wrong and you are right...or that you are right and you are wrong...it's that we all see things in a different way. And it's important for me to get both of your views, even if you disagree. FIRST, let me get [patient's] point of view. Then I'll get your point of view; is that OK?"

- If the collateral continues to interrupt, say..."Hold on, I need to do this in a certain way. I need to get [patient's] point of view first; then I need to get your input, OK?"

Table 1

Demographic and baseline characteristics of persons with dementia and their collaterals

	Persons with Dementia (N = 32)	Collaterals (N = 32)
Age, Mean (SD)	78.59 (9.68)	63.03 (12.92)
Women, N (%)	19 (59.38)	63.03 (12.92)
Race/ethnicity, N (%)		
White	21 (65.63)	23 (71.88)
Black	7 (21.88)	7 (21.88)
Multiracial	1 (3.13)	0 (0.00)
Other	3 (9.38)	2 (6.25)
Hispanic	4 (13.33)*	7 (22.60)†
Education level, N (%)		
High school or less	15 (65.63)	6 (18.75)
College or more	17 (53.13)	26 (81.26)
CDR score, N (%)		N/A
Mild (.5 or 1)	15 (46.88)	
Moderate (2)	17 (53.13)	
Dementia diagnosis, N (%)		N/A
Alzheimer's disease	20 (62.50)	
Dementia NOS	8 (25.00)	
Lewy Body	1 (3.13)	
Vascular	3 (9.38)	
Principal Psychiatric Diagnosis, N (%)		N/A
Any anxiety	20 (62.5%)	
Anxiety NOS	4(12.50)	
GAD	14.(43.75)	
PTSD	1(3.13)	
Panic disorder	1(3.13)	
Dysthymia	1(3.13)	
None	12(37.5)	
During the past month, number of hours/week spent on average with patient, Mean(SD)	N/A	94.78 (65.12)
Collateral relationship to patient	N/A	
Spouse		16 (50.00)
Child		13 (40.63)
Sibling		1 (3.13)
Paid caregiver		1 (3.13)
Other		1 (3.13)
Assessment scores, Mean(SD)		
PSWQ-A	17.41(7.39)	23.50(8.43)
GDS	10.05(6.80)	18.05(5.65)
GAI	5.84(5.58)	8.88(5.02)
QOL-AD	35.97(7.12)	29.37(5.89)

* Only N = 30 provided ethnicity;

† Only N = 31 provided ethnicity

NOS = not otherwise specified; GAD = generalized anxiety disorder; PTSD – post-traumatic stress disorder; PSWQ-A = Penn State Worry Questionnaire – Abbreviated; GDS = Geriatric Depression Scale; QOL-AD = Quality of Life – Alzheimer's disease

Table 2

Sensitivity and specificity of RAID-SI thresholds in predicting the presence of anxiety diagnosis in persons with dementia

Threshold	Sensitivity	Specificity
6	95%	25%
7	95%	42%
8	95%	50%
9	95%	58%
10	**90%**	**67%**
11	80%	67%
12	80%	67%
13	75%	75%
14	65%	75%

Note. Values in boldface represent optimal cut-off for maximum sensitivity and specificity.

RAID-SI = Rating for Anxiety in Dementia Structured Interview