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Instruments to measure behavioural and psychological symptoms of dementia

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Abstract

Reliable and valid measurement of behavioural and psychological symptoms of dementia (BPSD) is important for research and clinical practice. Here we provide an overview of the different instruments and discuss issues involved in the choice of the most appropriate instrument to measure BPSD in research. A list of BPSD instruments was generated. For each instrument Pubmed and SCOPUS were searched for articles that reported on their use or quality. Eighty-three instruments that are used to measure BPSD were identified. Instruments differ in length and detail, whether the interview is with participants, informants or by observation, the target sample and the time frames for use. Reliability and validity is generally good, but reported in few independent samples. When choosing a BPSD instrument for research the research question should be carefully scrutinised and the symptoms of interest, population, quality, detail, time frame and practical issues should be considered.

Introduction

Behavioural and psychological symptoms of dementia (BPSD) affect almost all people with dementia (Savva *et al.*, 2009). It has been suggested that the prevalence of most symptoms increases with worsening cognitive impairment (Purandare *et al.*, 2000), with fewer symptoms in the final stages of dementia (Lovheim *et al.*, 2008). BPSD are associated with an increased risk of long-term hospitalisation and medication use and decreased quality of life of persons with dementia and their caregivers (Shin *et al.*, 2005). At a time when these aspects of dementia are being recognised for their potential importance (Department of Health, 2009; National Institute for Health and Clinical Excellence, 2006), reliable and valid measurement of BPSD is needed for research and clinical practice. To date, 83 different instruments have been used to measure BPSD in demented or older populations. To help researchers choose the most appropriate instrument to measure BPSD in their study, here we will give an overview of the nature of instruments used to measure BPSD, discuss their performance and highlight common issues that may affect the measurement of BPSD.

Methods

From reviews, books and previous literature a list of BPSD instruments developed for use in people with dementia, the older population (persons aged 65 years and over) or all adults irrespective of age and diagnosis was generated (Burns *et al.*, 2004; Weiner *et al.*, 1996). For each instrument the literature databases Pubmed and SCOPUS were searched in April 2011 for articles that reported on the use or quality of these instruments. Search terms used in Pubmed included the name of the instrument (text search in title or abstract) and at least one of the following: "reproducibility of results" (mesh term), "validation study" (mesh term), validity (text), validities (text), reproducibility (text), reliability (text), or reliabilities (text). In SCOPUS the citations of the original article first describing the instrument were searched using the name of the instrument and validity, validities, reliability, reliabilities or reproducibility (text search in title, abstract or keyword).

Characteristics of the tests were extracted and summarised by one of the authors (RvdL), including which symptoms are measured, if it is based on interviews with the person with dementia or an informant, who conducts the interview, if observation is included, the number of items, the scale, if severity and/or frequency was measured, the time frame, the country where the instrument has been developed, if it includes measures of cognitive aspects of dementia and the population the instrument has been developed for. The wording of the questions used to measure the symptoms was compared for the most commonly used instruments. In addition, the reliability and validity of the most commonly used instruments were summarised. Characteristics of the studies investigating quality were extracted, including if authors were independent from the research group that developed the instrument, number of participants, recruitment, methods, and characteristics of the population. Because our main focus is on instruments for symptoms of dementia, the question wording and reliability and validity were not described for the instruments that were developed for use in all adults, but only for instruments developed for use in those with dementia or the older population, in which dementia is more common. The reliability and validity were not summarised for instruments that included measures of cognitive function as most did not report separate results for the cognitive and non-cognitive parts of the instruments.

Results

In total, 83 instruments that are used to measure BPSD were identified (see Supplementary Material, Additional File A). We have previously described the number of citations of these instruments (van der Linde *et al.*, 2013). Based on the number of citations, 32 instruments that were most commonly used were included in the summary Tables 1–6, including instruments that measure several BPSD, symptom-specific instruments and instruments that include a measure of cognitive function. In Tables 1 and 2, we have indicated whether the instruments were developed to measure symptoms in people with dementia, older people, or all adults irrespective of age and diagnosis. Tables 3–6 present results limited to demented or elderly populations as indicated in each table.

BPSD that are measured

There is large variability in symptom inclusion across BPSD assessment instruments (Table 1; Supplementary Material, Additional File A). Depressive symptoms are most often included ($n = 46$) in the 83 BPSD instruments that were identified, followed by irritability ($n = 37$), non-aggressive agitation ($n = 26$), anxiety ($n = 22$), hallucination ($n = 21$), delusion ($n = 20$), wandering ($n = 22$), apathy ($n = 17$), sleep problems ($n = 14$) and elation ($n = 6$). Symptom specific instruments are available for depressive symptoms ($n = 22$), anxiety ($n = 6$), non-aggressive agitation ($n = 6$), irritability ($n = 6$), apathy ($n = 2$) and wandering ($n = 2$).

Of the most commonly used instruments ($n = 32$) (Table 1), 27 measured depressive symptoms, 15 irritability, nine non-aggressive agitation, 11 anxiety, 11 hallucination, 12 delusion, six wandering, 10 apathy, nine sleep problems, and four elation.

Characteristics of instruments

Table 2 shows the characteristics of the most commonly used instruments for BPSD. Information on the characteristics for all instruments is available in the Supplementary Material, Additional File A. Of the 83 instruments, 38 measure several BPSD, whereas 45 are specific for one or two symptoms. Symptom specific instruments usually include more questions per symptoms, ranging up to 413 questions with most instruments including 10–20 questions, while instruments measuring several BPSD often include only one to three questions per symptom.

Instruments have been developed for demented ($n = 35$), elderly ($n = 25$) or adult ($n = 22$) populations. Some of the scales developed for elderly or adult populations have been standardised for use in dementia, including the personality inventory (Petry *et al.*, 1988; Petry *et al.*, 1989), the Brief Psychiatric Rating Scale (Overall and Gorham, 1962) and the Apathy Evaluation Scale (Marin *et al.*, 1991).

Table 1. Overview of BPSD that are measured by the most commonly used instruments

Name	Dep	Anx	Apa	Hal	Del	Agi	Sle	Wan	Irr	Ela
All BPSD										
Dementia										
NPI (Cummings *et al*., 1994)	●	●	●	●	●	●	●[1]		●	●
BEHAVE-AD (Reisberg *et al*., 1987)	●	●		●	●		●	●	●	
CERAD/BRSD (Tariot *et al*., 1995)	●	●	●	●	●	●	●	●	●	
BMDS (Greene *et al*., 1982)	●	●	●		●	●	●	●	●	
Personality Inventory (Brooks and McKinlay, 1983)	●		●						●	
CUSPAD (Devanand *et al*., 1992)	●			●	●	●		●	●	
CPRS (Asberg *et al*., 1978)	●		●	●	●	●	●		●	●
DBDS (Baumgarten *et al*., 1990)			●			●	●	●	●	●
All										
BPRS (Overall and Gorham, 1962)	●	●	●	●	●	●			●	
MINI (Sheehan *et al*., 1998)	●	●		●	●					
Including cognition										
Dementia										
RMBPC (Teri *et al*., 1992)	●	●							●	
ADAS (Mohs *et al*., 1983)	●			●	●	●				
Elderly										
CAMDEX (Roth *et al*., 1986)	●	●	●	●	●		●		●	
GMS/AGECAT (Copeland *et al*., 1976)	●	●	●	●	●	●	●		●	●
All										
DSM-IV SCID (American Psychiatric Association, 1994; Spitzer *et al*., 1992)	●	●		●	●		●			
Irritability/aggression										
Dementia										
RAS (Ryden, 1988)									●	
All (psychiatric settings)										
OAS (Yudofsky *et al*., 1986)									●	
Agitation										
Elderly										
ABMI/CMAI (Cohen-Mansfield *et al*., 1989)						●			●	
Apathy										
Elderly										
AES (Marin *et al*., 1991)			●							
Anxiety										
All										
STAI (Spielberger *et al*., 1970)	●									
HSC (Derogatis *et al*., 1974)	●	●								
ASIS (Zung, 1971)	●									
SPAI (Turner *et al*., 1989)	●									
Depression										
Dementia										
Cornell (Alexopoulos *et al*., 1988)	●									
Elderly										
GDS (Yesavage *et al*., 1982)	●									
All										
BDI (Beck *et al*., 1997)	●									
Hamilton (Hamilton, 1960)	●									

(*Continues*)

Table 1. (Continued)

Name	Dep	Anx	Apa	Hal	Del	Agi	Sle	Wan	Irr	Ela
HADS (Zigmond and Snaith, 1983)	●									
MADRS (Montgomery and Asberg, 1979)	●									
Zung (Zung, 1965)	●									
PHQ (Spitzer *et al.*, 1999)	●									
CES-D (Radloff and Teri, 1986)	●									

BPSD, behavioural and psychological symptoms of dementia; Dep, depressive symptoms; Anx, anxiety; Apa, apathy; Hal, hallucinations; Del, delusions/persecution; Agi, non-aggressive agitation; Sle, sleep problems; Wan, wandering; Irr, irritability/aggression; Ela, elation.
[1]12-symptom instrument (1997) only.

Most instruments measured only BPSD, while others include a cognitive assessment ($n = 10$) or other components including measures of disability or physical health ($n = 7$) or other psychiatric or psychological symptoms ($n = 9$).

Twenty-eight instruments are based on interviews with the participant, 27 are informant based and 11 include both. Observational data alone ($n = 17$) or in combination with questionnaires is used in 32 instruments. The interview can be conducted by a trained interviewer ($n = 31$), a clinician ($n = 13$) or can be self-administered ($n = 21$).

The instruments measure severity ($n = 24$), frequency ($n = 16$) or both ($n = 14$), change ($n = 3$), presence/absence only ($n = 13$) or other ($n = 3$) (not reported for $n = 8$). Symptom scoring ranges from dichotomous to visual analogue scales (VAS), with most instruments using categorical scales with three to five options. Time frames used in questionnaires range from the last day or the last one or two weeks to the last month, while observational instruments measure the symptoms only when the behaviour occurred, during 10–15 minute intervals, three days or 1–2 weeks.

The most commonly used instruments show a similar range of characteristics, including instruments that are based on interviews with the participant ($n = 9$), an informant ($n = 9$) or both ($n = 4$), or measured by observation ($n = 9$, of which $n = 3$ observation only), number of items ranging from 10 to over 400, measuring severity ($n = 8$), frequency ($n = 9$), both ($n = 1$) or neither ($n = 7$), using time frames ranging from currently present to four weeks. Most instruments (22 of the 32 most commonly used instruments) have been developed in the United States.

Question wording

In 1996 a consensus meeting [International Psychogeriatric Association (IPA), 2002] suggested the following symptom definitions: *delusions*: "simple and unsystematised paranoid beliefs, such as frequently accusing caregivers of stealing or being insincere or deceitful"; *hallucination*: visual or auditory, e.g. seeing people who are not there; *depressive symptoms*: "a pervasive depressed mood and loss of pleasure, self-deprecatory statements and expressed wishes to die, or a family or personal history of depression prior to the onset of dementia"; *apathy*: "lack of interest in daily activity and personal care and a decrease in different types of interaction, including social interaction, facial expression, vocal inflection, emotional responsiveness and initiative"; *anxiety*: "previously non-manifest concerns about their finances, future and health (including their memory) and worries about previously non-stressful events and activities like being away from home", including Godot syndrome (repeatedly asking questions about an upcoming event) and fear of being left alone; *wandering*: including checking, trailing or stalking, pottering or rooting, aimless walking, nighttime walking, walking directed towards an inappropriate purpose, excessive activity, wandering off, needing to be brought back to the house and repeatedly attempting to leave the house; *agitation*: including inappropriate verbal, vocal or motor activity that is not judged by an outside observer to result directly from the needs or confusion of the person; *physically non-aggressive agitation*: including general restlessness, repetitive mannerisms, pacing, trying to get to a different place, handling things inappropriately, hiding things, inappropriate dressing or undressing and repetitive sentences; *aggressive behaviours*: including hitting, pushing, scratching, grabbing things or people, kicking and biting, screaming, cursing, temper outbursts and making strange noises. Table 3 shows the BPSD definitions of the instruments for older or demented populations that have been cited most frequently. Specific definitions and question wording differs across instruments measuring the same symptom. For example, the Neuropsychiatric Inventory

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

Table 2. Characteristics of the most commonly used BPSD instruments

Name	*N* Cited	Interviewer	Interviewee	Observation	*N* Items[1]	Scale (*n* options)	Severity or frequency	Time frame	Country[2]
All BPSD									
Dementia									
NPI (Cummings *et al.*, 1994)	2134	CLI	INF	No	12	3–5	SEV/FRE/DIS	4 weeks	USA
BEHAVE-AD (Reisberg *et al.*, 1987)	642	CLI	INF	No	25	4	SEV	2 weeks	USA
CERAD/BRSD (Tariot *et al.*, 1995)	263	INT	INF	Yes	48/46	2–5	SEV	4 weeks	USA
BMDS (Greene *et al.*, 1982)	224	SELF	INF	No	34	5	FRE	NS	UK
Personality Inventory (Brooks and McKinlay, 1983)	146	INT	INF	No	18	5	CHA	Onset	UK
CUSPAD (Devanand *et al.*, 1992)	129	INT	INF	No	29	2–5	SEV	4 weeks	USA
CPRS (Asberg *et al.*, 1978)	113	INT	PAR	Yes	65	4	FRE	NS	Sweden
DBDS (Baumgarten *et al.*, 1990)	104	INT/ SELF	INF	No	28	5	FRE	1 week	Canada
All									
BPRS (Overall and Gorham, 1962)	[3]	INT	PAR	Yes	16	7	SEV	Current	USA USA France
MINI (Sheehan *et al.*, 1998)	2586	INT	PAR	No	83	2	—	Current	UK
Including cognition									
Dementia									
RMBPC (Teri *et al.*, 1992)	416	SELF	INF	No	24	5	FRE	1 week	USA
ADAS (Mohs *et al.*, 1983)	170	—	OBS	Yes	10	2–6	SEV	-	USA
Elderly									
CAMDEX (Roth *et al.*, 1986)	981	INT	PAR/INF	No	333 436	2	—	NS	UK USA
GMS/AGECAT (Copeland *et al.*, 1976)	283	INT	PAR/INF	Yes		2	—	NS	UK
All									
DSM-IV SCID (American Psychiatric Association, 1994; Spitzer *et al.*, 1992)	1940	CLI	PAR/INF	Yes	297 disorders			Current	USA
Irritability/aggression									
Dementia									
RAS (Ryden, 1988)	146	—	OBS	Yes	25	6	FRE	Past year	USA
All (psychiatric settings)									
OAS (Yudofsky *et al.*, 1986)	447	—	OBS	Yes	16	2	SEV/DUR	Current	USA
Agitation									

(*Continues*)

Table 2. (Continued)

Name	*N* Cited	Interviewer	Interviewee	Observation	*N* Items[1]	Scale (*n* options)	Severity or frequency	Time frame	Country[2]
Elderly									
ABMI/CMAI (Cohen-Mansfield *et al*., 1989)	443	–/INT	OBS/INF	Yes	14/29	6–7	FRE	1 week	USA
Apathy									
Elderly									
AES (Marin *et al*., 1991)	247	SELF	PAR/INF	No	18			NS	USA
Anxiety									
All									
STAI (Spielberger *et al*., 1970)	[3]	SELF	PAR	No	40	4		NS	USA
HSC (Derogatis *et al*., 1974)	1305	SELF	PAR	No	58	4	SEV	NS	USA
ASIS (Zung, 1971)		SELF	PAR	No	20	4	SEV	1 week	USA
SPAI (Turner *et al*., 1989)		SELF	PAR	No	32	7	SEV/FRE	NS	USA
Depression									
Dementia									
Cornell (Alexopoulos *et al*., 1988)	858	CLI	INF	Yes	19	3	SEV	1 week	USA
Elderly									
GDS (Yesavage *et al*., 1982)	3428	SELF	PAR	No	30	2	—	1 week	USA
All									
BDI (Beck *et al*., 1997)	11,252	SELF	PAR	No	21	4	SEV	1 week	USA
Hamilton (Hamilton, 1960)	9740	INT	PAR	No	21	3–5	SEV	NS	UK
HADS (Zigmond and Snaith, 1983)	7995	SELF	PAR	No	14	5	SEV	1 week	UK
MADRS (Montgomery and Asberg, 1979)	3741	INT	PAR	No	10	7	FRE	NS	UK
Zung (Zung, 1965)	2288	SELF	PAR	No	20	4	FRE	NS	USA
PHQ (Spitzer *et al*., 1999)	1425	SELF	PAR	No	11	2–4	FRE	NS	USA
CES-D (Radloff and Teri, 1986)	416	SELF	PAR	No	20	4	FRE	1 week	USA

BPSD, behavioural and psychological symptoms of dementia; CLI, clinician; INT, interviewer; SELF, self-administered; INF, informant; PAR, participant; OBS, observation only; FRE, frequency; SEV, severity; CHA, change; DIS, distress; DUR, duration; NS, not specified.

[1]Number of items of the total instrument is presented.

[2]Country in which the instrument has been developed.

[3]First published in book form.

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

Table 3. Comparison of BPSD definitions

Name	Dep	Anx	Apa	Hal	Del	Agi	Sle	Wan	Irr	Ela
All BPSD										
Dementia Neuropsychiatric Inventory (NPI) (Cummings *et al.*, 1994)	*Screening:* Sad or depressed *Sub-questions:* Tearfulness; sad or in low spirits; feels like a failure; deserves to be punished; no future; family better off without him/her; wish for death; other signs of depression or sadness	*Screening:* Very nervous, worried or frightened; very tense or fidgety; afraid to be apart *Sub-questions:* Worried about planned events; feeling shaky; unable to relax; tense; shortness of breath; butterflies in stomach; racing or pounding of the heart; avoid situations that makes him/her nervous; nervous or afraid when separating; other signs of anxiety	*Screening:* Lost interest; lacks motivation; more difficult to engage *Sub-questions:* Less spontaneous; less active; less likely to initiate conversation; lacking in emotions; contributes less to household chores; less interested in plans of others; lost interest in family; less enthusiastic; other signs of not caring about doing new things	*Screening:* visual, auditory, experience things that are not present *Sub-questions:* auditory, talks to people who are not there, visual, olfactory, tactory, tastes, other unusual sensory experiences	*Screening:* Beliefs that you know are not true; family members are not who they say they are; home is not their home *Sub-questions:* beliefs is in danger, others planning to hurt, stealing, spouse having affair, unwelcome guests living in the house, spouse not who they claim to be, house is not one's home, abandonment, television figures present in home, other unusual things	*Screening:* Pacing, doing things over and over *Sub-questions:* Pacing; rummaging around; put on and take off clothes; repetitive activities; fidget excessively, unable to sit still; other activities done over and over	*Screening:* Difficulty sleeping; up at night; wandering at night *Sub-questions:* Difficulty falling asleep; gets up during the night; wanders or inappropriate activity at night; awakens others; wakes up in the night thinking it is morning; awaken too early; sleeps excessively during the day; other night-time behaviours	—	Irritability *Screening:* Irritated and easily disturbed; moods changeable; abnormally impatient *Sub-questions:* Bad temper; rapidly changes mood; sudden flashes of anger; impatient; cranky and irritable; argumentative, difficult to get along with; other signs of irritability Aggression *Screening:* Refuses to cooperate; won't let people help; hard to handle *Sub-questions:* upset with carers, resists; stubborn; uncooperative; hard to handle; shouting or cursing; slamming doors, kicking or throwing; hurt or hit others; other aggressive behaviours	*Screening:* Too cheerful or too happy for no reason *Sub-questions:* Feels too good or too happy, different from usual self; laughs at things that others do not find funny; childish sense of humour; childish pranks; claiming to have more wealth than is true; other signs of feeling too good

(*Continues*)

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

Table 3. (Continued)

Name	Dep	Anx	Apa	Hal	Del	Agi	Sle	Wan	Irr	Ela
BEHAVE-AD (Reisberg *et al*., 1987)	Tearfulness and other depressed mood (e.g. death statements) with or without clear affective or physical components	Anxiety about upcoming events; other anxieties; fear of being left alone; other phobias	—	Visual; auditory; olfactory; haptic; other hallucinations	People are stealing things; one's house is not one's home; spouse or caregiver is an imposter; abandonment; infidelity; other suspiciousness or delusions	Purposeless (repetitive) activity (including pacing)	Day/night disturbance	Wandering away from home or caregiver	Verbal outbursts; physical threats and/or violence; other agitation	—
CERAD/ BRSD (Tariot *et al*., 1995)	Sad, blue or depressed; feelings of hopelessness or pessimism; cried; feels life is not worth living/ wish to die	Feelings of anxiety; physical signs	Loss of enjoyment; loss of initiative; social withdrawal	Auditory; visual hallucinations	Threatened, suspicious; unfaithful; abandoned; spouse is imposter; television characters are real; people are in house; dead people still alive; house is not home	Agitated or upset; repetitive behaviour; restlessness; purposeless behaviour	Tiredness; change in sleeping pattern; trouble falling asleep	Wandering; trying to leave home	Easily irritated or annoyed; uncoopera-tiveness; verbal aggression; physical aggression	—
BMDS (Greene *et al*., 1982)	Unhappy and depressed; cries for no obvious reason	Looks frightened and anxious	Keeps busy; sits around doing nothing; shows interest in news friends and relatives	—	Accuses people of things	Restless and agitated; paces up and down wringing hands	Gets up unusually early in the morning	Gets lost in the house; wander outside the house at night; gets lost outside	Irritable and easily upset; angry and threatening	—
Personality Inventory (Brooks and McKinlay, 1983)	Unhappy; listless	—	Lifeless; listless	—	—	—	—	—	Quick-tempered; irritable; cruel; mean	—
		—	—				—			—

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

CUSPAD (Devanand *et al.*, 1992)	Sad, depressed or down in the dumps			Auditory (voices or sounds), visual (visions), olfactory (unusual smells), tactory (things crawling on skin) or other hallucinations	Strange ideas or unusual beliefs; Follow-up questions: unfaithful; caregiver plotting to leave; beliefs of physical illness	Agitated or restless		Wandered away from home/ caregiver	Verbal outbursts; physical threats and/or violence	
CPRS (Asberg *et al.*, 1978)	Sadness; pessimistic thoughts; suicidal thoughts; fatigability	—	Slowness of movement; lassitude; inability to feel	Auditory, other hallucinations; hallucinatory behaviour	Ideas of persecution	Overactivity; agitation	Reduced sleep; increased sleep; sleepiness	—	Hostile feeling; hostility	Elation; elated mood
DBDS (Baumgarten *et al.*, 1990)	—	—	Lack of interest daily activities	—	—	Paces up and down; repeats the same action; moves arms or legs in a restless or agitated way; asks the same question repeatedly	Wakes up at night; sleeps excessively during the day	Wanders in the house at night; gets lost outside; wanders aimlessly	Verbally abuses, curses; refuses to be helped; physical attacks; screams; destroys property or clothing; throws food	Cries or laughs inappropriately
Including cognition										
Dementia										
RMBPC (Teri *et al.*, 1992)	Sad or depressed; hopelessness or sadness about the future; crying and	Appearing anxious	—	—	—	—	—	—	Verbal aggression; threats to hurt others; destroying property; arguing	—

(*Continues*)

Table 3. (Continued)

Name	Dep	Anx	Apa	Hal	Del	Agi	Sle	Wan	Irr	Ela
	tearfulness; commenting about death of self or others; feeling worthless or being a burden to others; feeling like a failure or no worthwhile accomplishments									
ADAS (Mohs *et al.*, 1983)	Tearfulness; sad, discouraged, down; ability to respond to encouragement and jokes.	—	—	Visual; auditory; tactile hallucinations	Belief in ideas that are almost certainly not true	Pacing; increased motor activity	—	—	—	—
Elderly										
CAMDEX (Roth *et al.*, 1986)	Appetite; weight change; difficulty coping; difficulty decision making; less pleasure; less energy; feels alone; lack of concentration; slowed speech; slowed thought; feeling depressed; loss of interest; blames self; depressed	Worry more; anxious; physical symptoms	Loss of interest; slowed speech/ thought	Auditory; visual hallucinations	Watched or spied on, hypochondriacal delusions; persecution	—	Getting to sleep; restless at night; waking early	Wandering	Irritable; irritable or angry	—

GMS/ AGECAT (Copeland *et al.*, 1976)	Depressed mood; future seems bleak; life is not worth living; would like to be dead; sad; tearful; gloomy; thoughts of suicide	Worrying; tense and worried; subjective fear or anxiety; physical symptoms including tension headaches, autonomic symptoms, palpitations, sweatiness; fear;	Slowing in thinking; slowed movements; listlessness; lack of energy; less interest; nothing enjoyed; lack of interest	Visual; auditory hallucinations	Suspicious; anyone deliberately trying to annoy them; belief has been attacked, harassed, cheated or persecuted; conspiracy; someone can read thoughts	Restlessness	Sleep disturbance; difficulty falling asleep; sleep interrupted;		Hostile or irritable; angry with self; uncooperative; starts arguments; angry; hatred; sarcastic; irritability; lost temper; rages of anger; heated arguments	Elated, euphoric
Irritability/ aggression *Dementia* RAS (Ryden, 1988)	—	—	—	—	—	—	—	—	Pushing/shoving; slapping; hitting/ punching; pinching/ squeezing; pulling hair; scratching; biting; spitting; elbowing; kicking; tackling; making threatening gestures; throwing an object; striking a person with an object; brandishing a weapon; damaging property	—

(*Continues*)

Table 3. (Continued)

Name	Dep	Anx	Apa	Hal	Del	Agi	Sle	Wan	Irr	Ela
Agitation/ irritability *Elderly* ABMI/CMAI (Cohen-Mansfield *et al*., 1989)	—	—	—	—	—	Pace, aimless wandering; general restlessness, repetitious mannerisms; repetitive sentences	—	—	Cursing or verbal aggression; hitting, kicking pushing, biting, scratching, spitting; grabbing onto people, throwing, tearing, destroying things; other aggressive behaviours; screaming	—
Apathy *Elderly* AES (Marin *et al*., 1991)	—	—	Interested; gets things done; start on their own; interested in new experiences; little effort; intensity; initiative; motivation; friends	—	—	—	—	—	—	—
Depression *Dementia* Cornell (Alexopoulos *et al*., 1988)	Sadness, sad expression, sad voice, tearfulness; lack of reactivity to pleasant events	—	—	—	—	—	—	—	—	—

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

Elderly								
GDS (Yesavage *et al*., 1982)	Less satisfaction with life, has dropped activities and interests, life empty, bored, not hopeful about future, bothered by thoughts, not in good spirits, afraid, not happy, helpless, restless, not going out, worry, memory problems, down hearted and blue, worthless, less excited, less energy, upset, crying, difficulty concentrating, does not enjoy getting up, avoids social gathering, less decisive, less clear mind	—	—	—	—	—	—	—

BPSD, behavioural and psychological symptoms of dementia; Dep, depressive symptoms; Anx, anxiety; Apa, apathy; Hal, hallucinations; Del, delusions/persecution; Agi, non-aggressive agitation; Sle, sleep problems; Wan, wandering; Irr, irritability/aggression; Ela, elation.

Table 4. Summary of the reliability and validity of the most commonly used BPSD instruments

	Reliability			Validity		
Name	Test–retest reliability	Interrater reliability	Internal consistency	Comparison with clinician rating/consensus	Construct validity (comparison with other tests)	Internal structure
All BPSD						
Dementia						
NPI (Cummings *et al.*, 1994)	3 weeks – overall frequency: 0.79, severity: 0.86 (Cummings *et al.*, 1994)	Frequency: 93.6–100%, severity: 89.4–100% (Cummings *et al.*, 1994)	Alpha = 0.88 (0.87–0.88) (Cummings *et al.*, 1994)	Content rated as valid by Delphi panel (Cummings *et al.*, 1994)	Not significantly different from BEHAVE-AD or HDRS (Cummings *et al.*, 1994). Similar prevalence rate of psychosis to BEHAVE-AD, lower prevalence than CUSPAD (Cohen-Mansfield and Golander, 2011)	22% of items significantly related, 78% unrelated (Cummings *et al.*, 1994)
BEHAVE-AD (Reisberg *et al.*, 1987)		Kappa = 0.619–1.00 (Patterson *et al.*, 1997) Kappa = 0.295–1.00 (median 0.697) (Mack *et al.*, 1999) ICC consistency = 0.65–0.91 (English), 0.80–0.99 (French). ICC agreement = 0.65–0.91 (English), 0.78–0.99 (French) (Sclan, 1996)			Higher interrater agreement than BPRS (Mack *et al.*, 1999). Similar prevalence rate of psychosis to NPI-NH, lower prevalence than CUSPAD (Cohen-Mansfield and Golander, 2011)	
CERAD/ BRSD (Tariot *et al.*, 1995)	1 month – AD: $r = 0.70–0.89$	Kappa = 0.77–1.00 (Tariot *et al.*, 1995)		Both anxiety and depression scores discriminated	Associated with CMAI total ($r = 0.759$), ABID frequency ($r = 0.658$),	

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

	Control: $r = 0.62$ (Patterson *et al.*, 1997)			between depressed and non-depressed subjects ($F = 15.15$; $P < 0.001$ and $F = 18.5$; $P < 0.001$) (Jacobs *et al.*, 1998)[2]	ABID reaction ($r = 0.561$), RMBPC ($r = 0.620$) (Weiner *et al.*, 2000)	
BMDS (Greene *et al.*, 1982)	3 weeks – total $r = 0.84$ (0.73–0.90) (Greene *et al.*, 1982)				Strongly correlated to DBDS $r = 0.73$ (Baumgarten *et al.*, 1990)	
Personality inventory (Brooks and McKinlay, 1983)[1]						
CUSPAD (Devanand *et al.*, 1992)		Lay interviewer versus psychiatrist, Conjoint: kappa = 0.74–1.0, Back to back: kappa = 0.54–0.73 (Devanand *et al.*, 1992)			Higher prevalence of psychosis than BEHAVE-AD, NPI-NH and CERAD-BRSD (Cohen-Mansfield and Golander, 2011)	Weak correlation between items $r = 0.07$–0.21 (Devanand *et al.*, 1992)
CPRS (Asberg *et al.*, 1978)		Kappa = 0.79 (van der Laan *et al.*, 2005); $r = 0.33$–0.99 (Montgomery *et al.*, 1978a); $r = 0.27$–0.96 (Montgomery *et al.*, 1978b). Agreement: reported 30–100%, observed 36–100% (Amati *et al.*, 1978)				
			Coefficient of internal consistency		Strongly correlated to BMDS $r = 0.73$	Correlation between individual

(*Continues*)

Table 4. (Continued)

	Reliability		Validity			
Name	Test–retest reliability	Interrater reliability	Internal consistency	Comparison with clinician rating/consensus	Construct validity (comparison with other tests)	Internal structure
DBDS (Baumgarten *et al.*, 1990)	2 weeks – $r = 0.71$ (Baumgarten *et al.*, 1990)		alpha = 0.83 (Baumgarten *et al.*, 1990)		(Baumgarten *et al.*, 1990)	items and total score = 0.20–0.64 (average 0.44) (Baumgarten *et al.*, 1990)
Irritability/ aggression						
Dementia						
RAS (Ryden, 1988)	8–12 weeks: – overall scale: $r = 0.86$ (Ryden, 1988)		Alpha = 0.91, overall sample: alpha = 0.88 (Ryden, 1988)		Higher prevalence than MDS (Bharucha *et al.*, 2008)	
Agitation						
Elderly						
ABMI/CMAI (Cohen-Mansfield *et al.*, 1989)	1 month – Test–retest correlation: AD: $r = 0.830$ ($p < 0.001$), control $r = 0.826$ ($p < 0.001$) (Koss *et al.*, 1997)				Associated with ABID $r = 0.62$, $p < 0.001$ (Logsdon *et al.*, 1999). Association between ABMI (observed) and CMAI (informant), $r = 0.17$–0.56, ($p < 0.05$–0.001) (Cohen-Mansfield and Libin, 2004)	
Apathy						
Elderly						
AES (Marin *et al.*, 1991)	Mean interval 25.4 days – $r = 0.76$–0.94 (Marin *et al.*, 1991)	ICC = 0.94, mean kappa = 0.58 (Marin *et al.*, 1991)	Clinician: apathy, alpha = 0.91; interest, alpha = 0.86. Informant: apathy, alpha = 0.90; interest, alpha = 0.88.	Se = 92.9%, Sp = 56.6%, PPV = 0.50, NPV = 0.94 (Clarke *et al.*, 2007)	Total scores and scores for apathy factor of AES significantly correlated with the	

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

			Subject: apathy, alpha = 0.88; other, alpha = 0.41 (Clarke *et al.*, 2007)		frequency × severity score of the apathy subscale of the NPI (Clarke *et al.*, 2007)	
Depression						
Dementia						
Cornell (Alexopoulos *et al.*, 1988)		Kappa = 0.67 (Alexopoulos *et al.*, 1988)	Internal consistency = 0.84 (Alexopoulos *et al.*, 1988)		Satisfactory validity when comparing to Hamilton (Alexopoulos *et al.*, 1988)	
Elderly						
GDS (Yesavage *et al.*, 1982)	1 week – $r = 0.85$ (Yesavage *et al.*, 1982)		Internal consistency = 0.95 (Yesavage *et al.*, 1982)	Correlated well with the number of research diagnostic criteria for depression. Cutoff of 11: Se = 84%, Sp = 95% cutoff of 14: Se = 80%, Sp = 100% (Brink *et al.*, 1982)	Internal consistency higher for GDS than for Hamilton and Zung. (Yesavage *et al.*, 1982)	Mean intercorrelation among items = 0.36 (Yesavage *et al.*, 1982)

BPSD, behavioural and psychological symptoms of dementia.
[1]No reliability or validity studies found.
[2]Depression diagnosed with Behavioural Symptoms Interview, BSI, by use of Research Diagnostic Criteria, RDC.

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

Table 5. Characteristics of studies reporting on the reliability or validity of instruments

Name	Study	Independent	N	Recruitment	Dementia	Age – sex distribution	Country	Longitudinal results
Dementia								
NPI (Cummings *et al.*, 1994)	Cummings 1994 (Cummings *et al.*, 1994)	No	40; 45	Concurrent validity: Family members of outpatients attending a university or a Veterans Affairs dementia clinic or of subjects participating in a clinical trials programme; Interrater reliability: caregivers of outpatients in a dementia clinic or of patients who were on stable doses of medication in a clinical trials programme	Yes	Concurrent validity: 18/40 women, Mean age: 75.7, 56–90 Interrater reliability: 19/45 women	USA	NR
BEHAVE-AD (Reisberg *et al.*, 1987)	Patterson 1990 (Patterson *et al.*, 1997)	Yes	34	Research registry of the University Hospitals of Cleveland Alzheimer Centre	Yes	Mean age, 72.7 (SD 6.1) 62–89, 24/34 female	USA	NR
	Sclan, 1996 (Sclan, 1996)	No	18	New York University Ageing and Dementia Research Centre	Yes	Mean age 73.9 (SD 7.5) 59–85, 12/18 women	USA	NR
	Mack 1994 (Mack *et al.*, 1999)	Yes	61 (AD), 20 (control)	Research registry of the University Hospitals of Cleveland Alzheimer Centre	Yes	Mean age AD: 72.0 (SD 6.7) 59–89, control: 69.3 (5.8) 58–79	USA	NR
CERAD/BRSD (Tariot *et al.*, 1995)	Patterson 1997 (Patterson *et al.*, 1997)	No	64 (control), 241 (AD)	Existing research populations of 27 participating ADCS sites	Yes	147/242 women, Mean age 72.3 (SD = 9)	USA	12 month follow-up: total score over time significantly different only

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

							for control group and MMSE 16–20	
Tariot 1995 (Tariot *et al*., 1995)	No	104	16 medical centres within the United States	Yes	Of total sample n = 303: 52.5% female, Mean age: 73.5 (SD = 7.8) 50–91	USA		NR
Jacobs 1998 (Jacobs *et al*., 1998)	No	29 (dep), 41 (non dep)	Research registry at the Alzheimer Centre of University Hospitals of Cleveland and Case Western Reserve University. Adults over the age of 40 with dementia who are living in the community at the time of assessment	Yes	Mean age 71	USA		NR
Weiner 2000 (Weiner *et al*., 2000)	No	148	Community-dwelling persons with AD in a multisite study of the treatment of agitation in AD that was conducted by the Alzheimer's Disease Cooperative Study Subjects were drawn from 21 sites	Yes	Mean age: 74.8 (SD = 7.1) 55% female	USA	Changes in BRSD score correlated more weakly to changes in two other instruments (CMAI and RMBPC) than correlations between baseline scores	

(*Continues*)

Table 5. (Continued)

Name	Study	Independent	N	Recruitment	Dementia	Age – sex distribution	Country	Longitudinal results
BMDS (Greene *et al.*, 1982)	Greene 1982 (Greene *et al.*, 1982)	No	18 (38 total)	Main caring relative of day hospital patients	Yes	Total sample ($n = 38$) Mean age: 76 (59–87) 29/38 females	UK	NR
	Baumgarten 1990 (Baumgarten *et al.*, 1990)	No	52; 46	Sample 1: community-residing patients seen at a geriatric assessment unit located in a Montreal teaching hospital; Sample 2: community-residing patients who were participating in the titration phase of a study of the effectiveness of THA in the treatment of AD	Yes	Mean age 77.8 (SD = 6.2)/68.9 (SD = 8.2) 46/63% female	Canada	NR
Personality inventory (Brooks and McKinlay, 1983)	[1]							
CUSPAD (Devanand *et al.*, 1992)	Devanand 1992 (Devanand *et al.*, 1992)	No	20	Outpatients attending a memory disorders clinic	Yes	Mean age 72.1 (SD 9.8), 65% women	USA	NR
	Cohen-Mansfield 2011 (Cohen-Mansfield and Golander, 2011)	Yes	74	Nursing home residents aged 65 and above from nine nursing homes in Israel	Yes	Mean age: 85.5, 76.7% female	Israel	NR
CPRS (Asberg *et al.*, 1978)	(Montgomery *et al.*, 1978a)	No	49	Depressed patients in England and Sweden during ongoing treatment	No (Dep)	NR	UK Sweden	NR
	Montgomery 1978 (Montgomery *et al.*, 1978b)	No	106	Hospitalised patients diagnosed as primary depressives participating in clinical trials at the end of the placebo wash out	No (Dep)	Sweden: 34/52 female, mean age 44.6 (SD = 14.5) 18–68 England	UK Sweden	NR

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

				period in England and Sweden		39/56 female, mean age: 44.1 (15.3) 21–69		
	van der Laan 2005 (van der Laan *et al.*, 2005)	Yes	62	Patients who were consecutively admitted to an acute ward (open and secluded) for elderly patients with functional psychiatric problems	No (MMSE > 16)	Mean age: 70 years (SD 6) 59–84 68% women	Netherlands	NR
	Amati 1978 (Amati *et al.*, 1978)	Yes	2	Admitted to the department of psychiatry	NR	NR		NR
DBDS (Baumgarten *et al.*, 1990)	Baumgarten 1990 (Baumgarten *et al.*, 1990)	No	52; 46	Sample 1: community-residing patients seen at a geriatric assessment unit located in a Montreal teaching hospital; Sample 2: community-residing patients who were participating in the titration phase of a study of the effectiveness of THA in the treatment of AD	Yes	Mean age 77.8 (SD = 6.2)/68.9 (SD = 8.2), 46/63% female	Canada	NR
Irritability/ aggression *Dementia*								
RAS (Ryden, 1988)	Ryden, 1988 (Ryden, 1988)	No	31; 15; 166	Minneapolis/St Pauls Chapter of the Alzheimer's Disease and Related Disorders Association (ADRDA) and from the rosters of five dementia clinics in the metropolitan area.	Yes	54% female	USA	NR
	Barucha 2008 (Bharucha *et al.*, 2008)	Yes	15	Nursing home residents of a non-profit community LTC facility in suburban Pittsburgh, PA	Yes	NR	USA	Temporal instability of symptoms (over 25 days)

(*Continues*)

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

Table 5. (Continued)

Name	Study	Independent	N	Recruitment	Dementia	Age – sex distribution	Country	Longitudinal results
Agitation								
Elderly								
ABMI/CMAI (Cohen-Mansfield *et al.*, 1989)	Koss 1997 (Koss *et al.*, 1997)	No	114 (AD), 32 (control)	Existing research populations of 27 participating ADCS sites	Yes	147/242 women, Mean age 72.3 (SD = 9)	USA	Agitation increased over one year in all but controls and those with mild dementia
	Logsdon 1999 (Logsdon *et al.*, 1999)	No	148	Recruited for a multisite controlled treatment study, 21 sites across the United States, the AD cooperative study	Yes	Mean age: 74.8 (SD = 7.1), 55% female	USA	NR
	Perlman 2008 (Perlman and Hirdes, 2008)	No	214	Patients residing in a CCC hospital in Ontario, Canada	No (elderly hospital patients)	Mean age 82.0/83.5/76.8 (SD = 11.3/9.9/12.9)	Canada	NR
Apathy								
Elderly								
AES (Marin *et al.*, 1991)	Marin 1991 (Marin *et al.*, 1991)	No	123	Residents from a private or community dwelling that did not restrict their activities. Rehabilitation programmes of Harmarville rehabilitation centre (stroke), AD research centre of the University of Pittsburgh School of Medicine (AD), inpatient and outpatient programmes of Geriatric Health Services, University of Pittsburgh School of Medicine (depressives), volunteers (control)	Yes	Age range: 55–85	USA	NR
	Clarke 2007 (Clarke *et al.*, 2007)	Yes	121	Outpatient multidisciplinary clinic: Behavioural Neurology Clinic at Baycrest Centre for Geriatric Care in Toronto	Yes	Mean age: 73.7 (SD = 9.4) 52.9% female	Canada	NR

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

Depression								
Dementia								
Cornell (Alexopoulos *et al.*, 1988)	Alexopoulos 1988 (Alexopoulos *et al.*, 1988)	No	83 (26 interrater)	Psychiatrically hospitalised or in nursing home (no details)	Yes	Interrater: Mean age: 81 (range 63–93) Internal consistency: Median age 79 (range 63–89)	USA	NR
Elderly								
GDS (Yesavage *et al.*, 1982)	Yesavage 1983 (Yesavage *et al.*, 1982)	No	100 (test retest 20)	Local senior centres and housing projects. Inpatients and outpatients of country and private treatment setting for depression	No	NR	USA	NR
	Brink 1982 (Brink *et al.*, 1982)	No	71	Local senior centres and housing projects. Inpatients and outpatients of country and private treatment setting for depression	No	NR	USA	NR

BPSD, behavioural and psychological symptoms of dementia; NR, not reported.
[1]No reliability or validity studies found.

Table 6. Summary of the characteristics and quality of the instruments

Name	BPSD	Detail	Length	Quality investigated[1]	Setting	Interview	Severity/ frequency
All BPSD							
Dementia							
NPI (Cummings *et al.*, 1994)	Broad	Low	Short	Low	3	Informant	Both, distress
BEHAVE-AD (Reisberg *et al.*, 1987)	Medium	Medium	Medium	High	3	Informant	Severity
CERAD/BRSD (Tariot *et al.*, 1995)	Broad	High	Long	Low	2, 3	Informant	Severity
BMDS (Greene *et al.*, 1982)	Medium	Medium	Medium	Low	2	Informant	Frequency
Personality inventory (Brooks and McKinlay, 1983)	Narrow	Low	Short	NR	NR	Informant	Change
CUSPAD (Devanand *et al.*, 1992)	Medium	Medium	Medium	Medium	1	Informant	Severity
CPRS (Asberg *et al.*, 1978)	Medium	High	Long	High	2	Informant	Frequency
DBDS (Baumgarten *et al.*, 1990)	Medium	Medium	Medium	Low	2	Informant	Frequency
All							
BPRS (Overall and Gorham, 1962)	Medium	Medium	Short	—	—	Participant	Severity
MINI (Sheehan *et al.*, 1998)	Medium	Low	Long	—	—	Informant	Dichotomous
Including cognition							
Dementia							
RMBPC (Teri *et al.*, 1992)	Narrow	Medium	Medium	—	—	Informant	Frequency
ADAS-noncog (Mohs *et al.*, 1983)	Medium	Medium	Short	—	—	Observation	Severity
Elderly							
CAMDEX (Roth *et al.*, 1986)	Medium	Low	Long	—	—	Informant	Dichotomous
GMS/AGECAT (Copeland *et al.*, 1976)	Broad	Low	Long	—	—	Participant or informant	Dichotomous
All							
DSM-IV SCID (American Psychiatric Association, 1994; Spitzer *et al.*, 1992)	Medium	High	Long	—	—	Participant	Not specified
Irritability/aggression							
Dementia							
RAS (Ryden, 1988)	Narrow	High	Medium	Medium	1, 3	Observation	Frequency
All (psychiatric settings)							

(*Continues*)

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

Table 6. (Continued)

Name	BPSD	Detail	Length	Quality investigated[1]	Setting	Interview	Severity/ frequency
OAS (Yudofsky *et al*., 1986)	Narrow	High	Short	High	Actors	Observation	Severity, duration
Agitation							
Elderly							
ABMI/CMAI (Cohen-Mansfield *et al*., 1989)	Narrow	High	Short/ medium	Low	1, 2, 3	Observation	Frequency
Apathy							
Elderly							
AES (Marin *et al*., 1991)	Narrow	High	Short	Medium	3	Informant or participant	Not specified
Anxiety							
All							
STAI (Spielberger *et al*., 1970)	Narrow	High	Long	—	—	Participant	Not specified
HSC (Derogatis *et al*., 1974)	Narrow	High	Long	—	—	Participant	Severity
ASIS (Zung, 1971)	Narrow	High	Long	—	—	Participant	Severity
SPAI (Turner *et al*., 1989)	Narrow	High	Long	—	—	Participant	Both
Depression							
Dementia							
Cornell (Alexopoulos *et al*., 1988)	Narrow	High	Short	Low	1, 2	Informant	Severity
Elderly							
GDS (Yesavage *et al*., 1982)	Narrow	Medium	Medium	Low	1, 2	Participant	Dichotomous
All							
BDI (Beck *et al*., 1997)	Narrow	High	Medium	—	—	Participant	Severity
Hamilton (Hamilton, 1960)	Narrow	High	Medium	—	—	Participant	Severity
HADS (Zigmond and Snaith, 1983)							
MADRS (Montgomery and Asberg, 1979)	Narrow	High	Short	—	—	Participant	Frequency
Zung (Zung, 1965)	Narrow	High	Short	—	—	Participant	Frequency
PHQ (Spitzer *et al*., 1999)	Narrow	High	Short	—	—	Participant	Frequency
CES-D (Radloff and Teri, 1986)	Narrow	High	Short	—	—	Participant	Frequency

BPSD, behavioural and psychological symptoms of dementia.

BPSD: narrow: 1–3 symptoms, medium 4–8 symptoms, broad 9–10 symptoms; Detail: Low: dichotomous or only one question per symptom, Medium: more than one response option and more than one question per symptoms, High: more than one response option and consistently more than 2/3 question per symptom; Length: of total instrument, short: ≤ 20, medium 21–35, >35 long; Quality: Low: Reliability and/or validity not investigated by independent researchers, Medium: one independent study investigated reliability and/or validity, High: $>$ 1 independent study investigated reliability and/or validity; Setting: Reliability and/or validity studied in 1: primary care, 2: secondary care, 3: tertiary care.

[1]The quality is only reported for the most commonly used instruments developed for use in elderly or dementia that do not include cognitive function.

(NPI) (Cummings *et al.*, 1994) uses only two questions to measure depressive symptoms, "Does the patient seem sad or depressed? Does he/she say that he/she feels sad or depressed?", followed by further questions if the symptom is present. In contrast, BEHAVE-AD (behavioural symptoms in Alzheimer's disease; Reisberg *et al.*, 1987) uses a more severe definition of depressive symptoms, which emphasises suicidal symptoms and tearfulness. The RMBPC (revised memory and behaviour problems checklist; Teri *et al.*, 1992) has a higher number of questions about depressive symptoms, including appearing sad or depressed, feelings of hopelessness, crying, commenting about death, feeling worthless and feeling like a failure. Instruments specific for depressive symptoms often use more than 20 questions. Their questions are more detailed, including questions regarding satisfaction with life, activities and fulfilment, lack of energy, hopefulness, feeling upset and worthless, crying, concentration and memory.

Reliability and validity

Table 4 shows the results of studies that have investigated the reliability of the most commonly used instruments. Although there are small differences between the instruments, reliability and validity studies show acceptable results for all instruments. Generally, the studies report good reliability, with an inter-observer reliability of kappa = 0.5–1.0 and an internal consistency coefficient alpha above 0.80 when reported. Results from different instruments are correlated, suggesting good construct validity. However, not many studies have investigated reliability and/or validity ($n = 1$–4 per instrument). More detailed information about the characteristics of the studies investigating the reliability or validity of the instruments can be found in Table 5. Often the quality of instruments is measured by the research group who developed the instrument, possibly introducing bias. Study samples are often small ($n = 18$–214) and mostly recruited from secondary settings including hospitals or memory clinics and tertiary settings including dementia specialised hospitals. Few instruments ($n = 2$) are validated in more than one setting. All instruments except CPRS (comprehensive psychopathological rating scale; Asberg *et al.*, 1978) and GDS (geriatric depression screening; Yesavage *et al.*, 1982) have been tested in demented populations. Longitudinal results have only been reported for the CERAD/BRSD (consortium to establish a registry for Alzheimer's disease/behavior rating scale for dementia; Tariot *et al.*, 1995), RAS (Ryden Aggression Scale; Ryden, 1988) and CMAI (Cohen-Mansfield Agitation Inventory; Cohen-Mansfield *et al.*, 1989). No studies validating the instruments in a population-based sample were found. Study samples are often older and more severely impaired than seen in the population. Therefore, even for the most commonly used instruments, data on their quality is surprisingly limited, and this should be borne in mind before using them in practice.

Discussion

Summary – choosing a scale for research

When choosing the most appropriate measure for research, the specific question should be carefully scrutinised to ensure that the outcome of interest is adequately captured. Table 6 summarises the characteristics and quality of the most commonly used instruments.

Broad instruments measuring many symptoms are very useful to provide a general overview of BPSD as they are easy to use and are often shorter and less time consuming. In studies where more detail is required, narrow scales may be more appropriate, as they often provide more detail about individual symptoms. Broad scales measuring at least nine symptoms include the NPI (Cummings *et al.*, 1994), CERAD (Tariot *et al.*, 1995) and GMS (geriatric mental state; Copeland *et al.*, 1976). Of these, NPI and GMS provide less detail and are short, while the CERAD is longer and provides more detail. There are a range of narrow instruments measuring 1–3 symptoms in dementia available for irritability, non-aggressive agitation, apathy and depressive symptoms, including the Personality Inventory (depressive symptoms, apathy, irritability) (Brooks and McKinlay, 1983), RAS (irritability) (Ryden, 1988), Agitated Behaviour Mapping Instrument (ABMI, agitation) (Cohen-Mansfield *et al.*, 1989), Apathy Evaluation Scale (AES, apathy) (Marin *et al.*, 1991) and Cornell Scale for Depression in Dementia (depressive symptoms) (Alexopoulos *et al.*, 1988). These provide high detail and include a larger number of questions per symptom.

The results of studies investigating the reliability or validity of the instruments were similar and were therefore of limited use in comparing the instruments. Therefore, we summarised the quality of the instruments as the number of studies investigating the reliability or validity of the instrument and if these included studies by independent researchers. Of the instruments measuring several BPSD, the quality of the BEHAVE-AD (Reisberg *et al.*, 1987) has been investigated by three studies of which two were independent. The quality of other instruments is often only investigated by the researchers who developed the instruments. Further, most instruments have been validated in secondary or tertiary care, with few primary care validation studies.

Some instruments have been developed specifically for use in dementia, while others are aimed at general older people or adult populations. While some of these have

Int. J. Methods Psychiatr. Res. 23(1): 69–98 (2014). DOI: 10.1002/mpr

been validated for use in dementia and are widely used, generally the use of dementia specific scales is preferred in demented populations. Most instruments developed for use in dementia are based on interviews with an informant or on observation, while instruments aimed at adult populations are often based on interviews with the participant. In the early stages of dementia an instrument including patient report may be appropriate, but later in the disease course informant-based questionnaires or observational data are preferred. Interviewing informants overcomes potential problems with report by the person with dementia and the fact that when interviewed they may not exhibit abnormal behaviour. However, factors such as the living situation of informants and persons with dementia and the relationship between the person with dementia and their informant may influence the results (Ready *et al.*, 2004).

Differences between instruments may influence the results. For example, it has been suggested that the large differences in prevalence of BPSD in mild cognitive impairment that have been reported may partly be due to differences between instruments (Monastero *et al.*, 2009). With over 2100 citations, the NPI has been the most widely used instrument (Cummings *et al.*, 1994; van der Linde *et al.*, 2013). Using an instrument that has been commonly used, such as the NPI and others as shown in Table 2, improves comparability between studies. However, in some cases, one of the less frequently used instruments (see also Supplementary Material, Additional File A) may be more appropriate for the specific research question. For example, observational instruments including the non-cognitive subscale of the Alzheimer Disease Assessment Scale (ADAS) (Mohs *et al.*, 1983), RAS (Ryden, 1988) or ABMI (Cohen-Mansfield *et al.*, 1989) could add valuable information when a more in-depth study of symptoms is required.

Issues when measuring BPSD

Several issues exist when measuring BPSD. Firstly, there are differences between symptoms. Some may be more visible than others and therefore easier to measure, for example irritability is difficult to cope with by caregivers and is likely to be noticed, while caregivers may not be aware of depressive symptoms.

There are no clear definitions of symptoms and they may overlap. A test should include no content that is irrelevant, for example BPSD measures should not include questions measuring cognitive function, and measure for depressive symptoms should not include questions measuring apathy, anxiety or sleep problems. However, distinguishing between BPSD and cognitive symptoms and between individual BPSD is not always clear. Measures for depressive symptoms may include "anxious expression, rumination, worrying" (Cornell scale for depression in dementia) (Alexopoulos *et al.*, 1988) or "retardation" (Hamilton depression rating scale) (Hamilton, 1960) that may be used in other instruments to measure anxiety or cognitive function.

Little information is available on cutoff points that should be used to decide if a symptom is present or absent. Some definitions of BPSD set a different threshold of severity compared with those used in other instruments. Furthermore, BPSD are often unstable over time and may be present on some days but not on others. Potential problems with report by the person with dementia and factors such as the living situation of informants and persons with dementia and the relationship between the person with dementia and their informant may also influence the results (Ready *et al.*, 2004).

Conclusions

Choosing an instrument

When choosing the most appropriate measure for research, the specific research question should be carefully scrutinised. The decision depends on a number of factors including the symptoms of interest, the population, the quality of the instrument, the amount of detail that is required, the time frame, other components of the instrument that are of interest and practical issues such as time restrictions. These factors should be taken into account to ensure that the research question is adequately captured. When reporting the results, researchers should report characteristics of the instrument as these can influence results.

Further research

Some BPSD are included in instruments much more often than other symptoms. Depressive symptoms have been included in 46 of the 83 instruments, while elation was measured by only six. Symptoms that are not included in instruments will be studied less frequently. However, in addition to depressive symptoms, aggression, psychosis and wandering have been identified as the behavioural and psychological symptoms that are most difficult to cope with by caregivers (International Psychogeriatric Association (IPA), 2002). Better measurements of these symptoms are needed to improve knowledge of their prevalence, associations and management.

Currently, the reliability and validity of instruments has not been sufficiently addressed with the need for independent replication of quality measures. Study populations

are small and often recruited from secondary or tertiary centres. More studies investigating the quality of instruments in a variety of populations are needed. When using an instrument in a population in which it has not been validated, researchers should be encouraged to test the instrument in the population of interest.

A better understanding of the occurrence and causes of BPSD and clearer definitions of these symptoms are needed to improve measurement and to overcome issues including the overlap between symptoms and differences in visibility.

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Declaration of interest statement

The authors have no competing interests.

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