Dying with dementia: most frequent symptoms. A review of the literature

Sterben mit Demenz: die häufigsten Symptome. Eine Literaturübersicht

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Abstract

Sensing, observing and interpreting the symptoms of persons suffering from dementia is very challenging. The difficulties lie in their restricted capacity to communicate and irregular transitions from a chronic-stable to an acute-critical condition both in the course of their symptoms and in the slow but continuous process of deterioration.
The aim of this integrative literature review was to identify the symptoms dementia patients present in the final twelve months of their lives and to identify instruments for symptom assessment. To this end, a comprehensive literature search within the electronic databases Medline® (PubMed), Cinahl® (EBSCO), PsycINFO® (OVID) and Cochrane Library for systematic reviews® and for clinical trials® in both German and English was performed including publications from January 2000 to July 2012.
Six symptoms were identified as frequent and common in the end-of-life phase of people with dementia: respiratory distress, pain, mood swings, restricted mobility, restricted food and fluid intake and behavioural and psychosocial symptoms. Knowledge of atypical symptom manifestation requires critical reflection about perceptions and observations, interpretation of these observations, development of assumptions and location within the context of everyday life in the meaning of clinical reasoning.

Abstract

Das Wahrnehmen, Beobachten und Interpretieren von Symptomen bei Personen mit Demenz in ihrer letzten Lebensphase ist herausfordernd. Die Schwierigkeiten liegen in der eingeschränkten verbalen Kommunikation, in wechselnden Übergängen von chronisch-stabilen zu akut-kritischen Symptomverläufen und in der langsamen aber stetigen Krankheitsverschlechterung.
Das Ziel dieser integrativen Literaturübersicht war es Symptome demenzerkrankter Personen in ihren letzten zwölf Lebensmonaten zu erfassen. Hierzu wurden die elektronischen Datenbanken Medline® (PubMed), Cinahl® (EBSCO), PsycINFO® (OVID), Cochrane Library für systematischeReviews® und für klinische Studien® von Januar 2000 bis Juli 2012 in Deutsch und Englisch systematisch durchsucht.
Es konnten sechs häufig und gemeinsam vorkommenden Symptome identifiziert werden: Atemnot, Schmerzen, Stimmungsschwankungen, eingeschränkte Mobilität, Ernährungsschwierigkeiten und herausforderndes Verhalten. Das Wissen um eine atypische Symptommanifestation erfordert ein klinisches Urteilsvermögen, das Wahrnehmungen und Beobachtungen kritisch reflektiert und interpretiert, die Entwicklung von Hypothesen und eine Einordnung in den Alltag ermöglicht.

INTRODUCTION

Approximately 1.5% of the people living in Switzerland are suffering from dementia (Bundesamt für Statistik (BFS), 2012; Schuler & Burla, 2012). An estimated 10% of new diagnoses of dementia involve persons aged 90 years or older. Equal numbers confirm this development for other German-speaking countries (Bickel, 2012; Gleichweit & Rossa, 2009). Ninety-five percent of the patients in advanced stages of dementia are dependent on full-time care and require institutional placement (Meeussen *et al.*, 2012; World Health Organization, 2011).

Patients with advanced dementia die over the course of 2–3 years (Shuster, 2000). Due to the incurable nature

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of this progressive, chronic disease, palliative measures are highly recommended for care (World Health Organization, 2011). Management of symptoms plays a key role in palliative care. However, the detection of symptoms in advanced stages is particularly challenged by the fact that patients are no longer able to communicate their complaints verbally (Herr, Bjoro, & Decker, 2006; Smith, 2005; World Health Organization, 2011). The risk for misperception and misinterpretation of symptoms is increased (Schumacher & Schneider, 2010). However, for advanced care planning and further therapeutic decision making, the observation of the course of symptoms is essential (Schafirovits-Morillo & Suemoto, 2010). Thus, the effectiveness of measures to relieve the symptoms needs to be based on a targeted and timely assessment of all symptoms occurring simultaneously. Therefore, the aim of this article is to give an overview of the most common symptoms of persons suffering from dementia in their last phase of life and to describe assessment instruments that are useful for the screening and assessment of these symptoms. The following research questions guided the study:

1. What are the most common symptoms that persons with advanced dementia suffer from in the final 12 months of their lives?
2. Which assessment instruments are useful for the detection of symptoms that persons with advanced dementia suffer from in advanced stages?

METHOD

This study expands on earlier work that aimed to explore end-of-life care of patients suffering from advanced dementia in nursing homes (Koppitz, Dreizler, Waldboth, & Imhof, 2014). The method for the current investigation is an integrative literature review. This method was chosen in order to gain a comprehensive overview and synthesis of the literature on symptoms of persons suffering from advanced dementia and on assessment instruments for symptom assessment (Torraco, 2005). A guiding framework was the concept of 'Quality of Dying', in which the patient's experience of symptoms and burden is in the focus of care (van Soest-Poortvliet et al., 2011). Symptoms are understood as subjective experiences that can be detected by the patients or by persons in their surroundings (Dodd et al., 2001). Related signs can be interpreted as indicators of a disease that can be detected by the patients themselves or others.

In June 2012, a comprehensive literature search was performed within the databases Medline® (via PubMed), Cinahl® (EBSCO), PsycINFO® (OVID), Cochrane Library for systematic reviews® and Cochrane Library for clinical trials® (Table 1: Search terms). Additionally, grey literature and articles identified in reference lists were searched. Moreover, an expert in the care of people suffering from dementia was consulted to identify further studies.

Table 1: Search terms

Population	Setting		Intervention		Outcome
Dementia OR	Nursing homes OR		End-of-life care OR		Symptom* OR
Dementia* OR	Home care OR		Palliative care OR		Sign*
Alzheimer	Elderly home	AND	Terminal care OR	AND	
			Scale OR		
			Assessment OR		
			Instrument OR		
			Measure		

The following aspects were defined as criteria for inclusion: persons suffering from dementia, symptoms appearing in the last 12 months of life, description of symptom frequency and characteristics and availability of assessment instruments. The period of the last 12 months of life was chosen as frame of reference since the deterioration of the health condition and related symptom manifestation in this phase of life is most evident (Bausewein, 2005; Kiely, Shaffer, & Mitchell, 2012; Testad, Aasland, & Aarsland, 2007). The focus on the last 3 months of life that was the frame of reference in earlier work and a focus on the last 6 months of life that was the basis for similar studies are closely related to the admission requirements of institutions offering palliative care and is not typical for the course of the disease (Shuster, 2000). Further criteria for inclusion were that the studies had to be written in German or English language and published between January 2000 and July 2012 (see Figure 1: results of the literature review).

All articles included were analysed and evaluated by two researchers working independently. Quantitative studies were evaluated methodically according to Brodaty (2003), qualitative studies according to Flemming (2010) and literature overviews according to the criteria of the Joanna Briggs Institute (2000) (see Table 2: Quality rating of included studies). Grey literature and literature reviews were included in this study as they contributed significantly to the gain in knowledge and can be used under this premise (Joanna Briggs Institute for Evidence Based Nursing and Midwifery, 2000; Torraco, 2005).

With regard to the literature reviews, 8 of the 10 criteria of the Joanna Briggs Institute (2000) had to be fulfilled for inclusion. Each included paper was analysed, abstracted
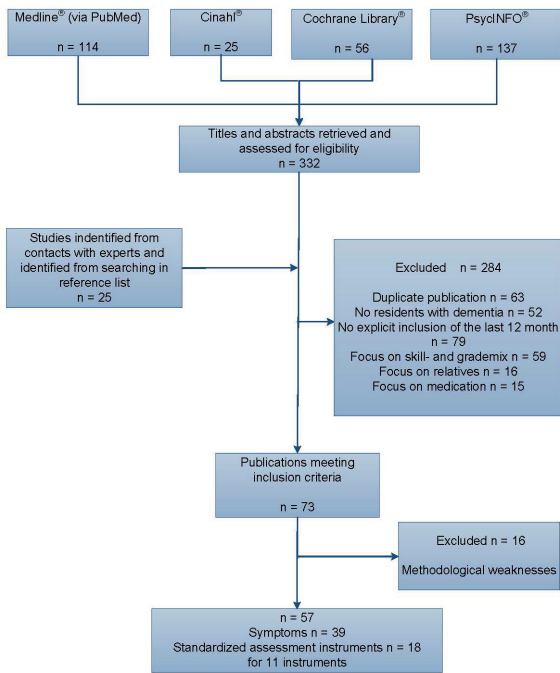
Fig 1. Results of the literature review

and synthesised according to Torraco (2005). In a tabular overview, the aim of the research, participants, design and method and key results were reviewed. The key results were then transferred into the analysis software Atlas-ti®. The synthesis of the different methodological approaches was undertaken by the method of critical interpretive synthesis (CIS) (Flemming, 2010; Flemming & McInnes, 2012). CIS allowed for integrating quantitative, qualitative and theoretical papers with the aim of transforming the evidence in a new conceptual framework.

RESULTS

A total of 57 individual publications, 39 for symptoms and 18 for 11 standardised assessment instruments, were included in this integrative literature review (Torraco, 2005).

Where no definition of the symptoms described could be identified in the publications, literature contributing to the characterisation and differentiation of the symptoms and their characteristic features was added. The selection was made in accordance with the criteria of the nomenclature of the NANDA nursing diagnoses (Doenges, Moorhouse, & Murr, 2013).

Table 2: Quality rating of included studies

Quantitative studies: Brodaty (2003)	Qualitative and mixed-method studies: Flemming (2010), using data from Hawker (2002)	Literature reviews: Joanna Briggs Institute (2000)
1. Design	1. Abstract and title	1. Review question
a. Randomised	2. Introduction and aims	2. Search strategy
b. Controlled (or comparison group used)	3. Method and data	3. Inclusion criteria
2. Subject	4. Sampling	4. Critical appraisal
a. Use of standardised diagnostic criteria	5. Data analysis	5. Data synthesis
b. All subjects accounted for/withdrawal noted	6. Ethics and bias	6. Similarity of studies
3. Outcomes	7. Findings and results	7. Reporting of findings
a. Well-validated, reliable measures	8. Transferability/generalisability	8. Conclusions and recommendations
b. Objective outcomes	9. Implications and usefulness	
c. Questionable unreliable outcome measures		
4. Statistics		
a. Statistical significance considered		
b. Adjustment for multiple comparison		
c. Evidence of sufficient power		
5. Results		
a. Blind ratings		
b. Follow-up assessment 6 months beyond		
5-item rating with very poor, poor, middle-range, good, very good quality.	Rating with good, fair, poor, very poor.	No explicit score rating was mentioned.
Summed score, which ranges from <5 (very poor) to >7, maximum 11 (Goodman et al., 2010).	Summed score, which ranges from 9 (very poor) to 36.	

This study resulted in a description of the most common symptoms, their occurrence, their characteristic features and related complications and in the identification of a symptom manifestation that is characteristic of patients with dementia in the last year of their life. Moreover, we identified assessment instruments that can be used for the symptom assessment in persons suffering from advanced dementia.

Symptoms in people with dementia in the dying phase

In the last phase of life, differentiation of dementia types is no longer relevant, since the types and prevalence of symptoms are identical in all forms of dementia at this point in time (Lussier, Bruneau, & Villalpando, 2011). In their last year of life, patients with dementia manifest a characteristic clinical picture that, according to the literature, is based on six symptoms often occurring concurrently (Table 3: Indicators of dying with dementia): 1) respiratory distress, often combined with respiratory infections leading to pneumonia; 2) pain; 3) mood swings; 4) mobility restriction leading to confinement to bed followed by pressure ulcers; 5) impaired food and fluid intake, often caused by dysphagia; and 6) behavioural disturbances, especially agitation, restlessness and disorientation (Cervo, Bryan, & Farber, 2006; Chang et al., 2005; Di Giulio et al., 2008; Fabbro, Dalal, & Bruera, 2006; Förstl, Bickel, Kurz, & Borasio, 2010; Hughes, Jolley, Jordan, & Sampson, 2007; Mitchell et al., 2009; Reynolds, Henderson, & Shulman, 2002; Roger Stieber, 2006; van der Steen, 2010; Wowchuk, McClement, & Bond, 2006).

Behavioural disturbances play a significant role with regard to the manifestation of symptoms in the last phase of life (Robert et al., 2010; Smith, 2005; Treloar, Crugel, & Adamis, 2009). A common cause of behavioural disturbances is pain (Aminoff & Adunsky, 2004; Lussier et al., 2011; Powers & Watson, 2008; Volicer & Hurley, 2003). Thus, Husebo (2011) came to the conclusion that agitation in people with dementia can be significantly reduced by adequate pain treatment. Furthermore, behavioural disturbances need to be seen in connection with ill-humour, depressive symptoms or depression (Durand, James, Ravishankar, Bamrah, & Purandare, 2009).

Behavioural disturbances, impaired food intake, the occurrence of pneumonia and restricted mobility can be interpreted as indicators for the beginning of the last phase of life (van der Steen, 2010). The frequent and common occurrence of respiratory distress, pain, behavioural disturbances, depressive moods, mobility restrictions and impaired food intake and the complications associated therewith, as well as the overlapping symptoms of challenging behaviour, can be referred to as characteristic of the dying process in persons with dementia. The key in

the perception of symptoms is behavioural disturbances. Often their behaviour is the only opportunity for people suffering from advanced-stage dementia to draw attention to them and possible problems (see Figure 2: symptom manifestation (Koppitz et al., 2014)).
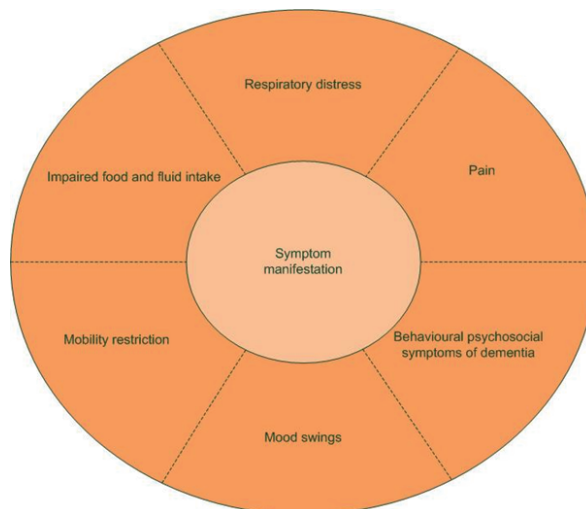

Fig 2. Symptom manifestation

Standardised instruments for the assessment of symptoms

There are several instruments for the assessment of individual symptoms of patients in the last phase of life with dementia. In the following, instruments will be introduced, which have proven sufficient validity and match the above-described typical symptoms of the dying phase in people with dementia, and which can be used in the palliative treatment of dementia patients who have limited or no longer existent verbal communication skills. Eleven instruments in total could be assessed as appropriate (see Table 4: Assessment instruments).

In addition to the instruments for the assessment of individual symptoms or symptom clusters, there are assessment instruments aimed at an overall assessment of all symptoms occurring simultaneously, namely the 'Mini-Suffering State Examination Scale' (MSSE) of Aminoff (2008) and 'The Symptom Management End-of-Life in Dementia Scale' (SM-EOLD) of Kiely, Shaffer & Mitchell (2012). The SM-EOLD does not subsume the behavioural symptoms into the umbrella term 'behavioural disturbances' like Volicer & Hurley do (2003). There is no segmentation like in Cornegé-Blokland (2012), too.

DISCUSSION

Knowing the symptoms that are accompanied by a poor prognosis is considered to be a precondition for initiating

Table 3: Indicators of dying with dementia

Quantitative studies			Symptoms						Quality score according to Brodaty (2003)
First author (year) country	Design	Sample	Respiratory distress	Pain	Mood swings	Mobility restriction	Impaired food and /or fluid intake	Behavioural disturbances	
Aminoff (2004), Israel	Prospective study	n=71, end-stage dementia patients admitted to the long-term geriatric ward		X	X	X	X	X	7
Chung (2006), China	Descriptive study	n=197 participants			X	X	X	X	7
Cornegé-Blokland (2012), Netherlands	Descriptive quantitative study	Structured single interviews; physicians (n=30, face-to-face), nurses (n=23, telephone interviews) and relatives (n=23, telephone-interview), 23 nursing homes.						X	6
Di Giulio (2008), Italy	Retrospective-explorative study	n=141, 7 nursing homes	X	X		X	X	X	6
Durand (2009), United Kingdom	Descriptive study	n=50 patients with a diagnosis			X				7
Husebo (2011), Norway	Randomised controlled trial	n=352 residents with moderate-to-severe dementia and clinically significant behavioural disturbances		X				X	9
Meeussen (2012), Belgium	Retrospective study	n=1108 cases of death			X	X	X	X	8
Mitchell (2010), USA	Retrospective cohort study	n=22,405, residents with advanced dementia	X			X	X		6
Mitchell (2009), USA	Secondary analysis of a prospective cohort study	n=323, 22 nursing homes, 18 months	X	X		X	X	X	8
Mitchell & Morris (2004), USA	Retrospective cohort study	n=2730 residents nursing home, n=290 home care clients	X	X	X	X	X	X	9
Mitchell & Kiely (2004), USA	Retrospective cohort study	n=6799 derivation cohort, n=4631 validation cohort; nursing home residents	X			X	X		8
Morrison (2000), USA	Prospective cohort study	n=111, with hip fracture		X					7
Neville (2007), Australia	Descriptive study	n=100 residents						X	7
Nourhashemi (2012), France	Observational prospective study	n=112, after hospitalisation in one of the two geriatric wards		X		X	X		7

Quantitative studies			Symptoms						Quality score according to Brodaty (2003)
Pieper (2011), Netherlands	Study protocol of a cluster-randomised study	n=168, no information of the participants	X	X		X	X		8
Reynolds (2002), USA	Quantitative-descriptive study	n=176, 2 nursing homes	X	X	X			X	6
Sampson (2010), United Kingdom	Randomised controlled study	n=33, emergency hospital admission		X					10
Skovdahl (2008), Sweden	Cross-sectional studies	n=1187 (1993) and n=1017 (2002)						X	8
Testad (2010), Norway	Descriptive study	Baseline data of three different intervention studies in Austria (n=38), England (n=302), Norway (n=163) collected in 2003 to 2005						X	7
Testad (2007), Norway	Descriptive quantitative study	n=211, 4 nursing homes			X			X	8
van der Steen (2002), Netherlands	Prospective cohort study	n=662, 61 nursing homes	X						7
Zwakhalen (2009), Netherlands	Observation study	n=117, 3 dementia-specialised nursing homes		X					8

Qualitative study				Symptoms						Quality score according to Flemming (2010)
First author (year) country	Design	Design	Sample	Respiratory distress	Pain	Mood swings	Mobility restriction	Impaired food and /or fluid intake	Behavioural disturbances	
Treloar (2009), UK	Exploratory retrospective study	Exploratory retrospective study	n = 14 interviews with key carers of dementia people, 3 months after death					X		25

Mixed-method study			Symptoms						Quality score according to Flemming (2010)
First author (year) country	Design	Sample	Respiratory distress	Pain	Moods swings	Mobility restriction	Impaired food and /or fluid intake	Behavioural disturbances	

Continued Table 3: Indicators of dying with dementia

Qualitative study		Symptoms					Quality score according to Flemming (2010)
Powers (2008), USA	Mixed-method study (chart analysis of the last 365 days of life and ethnographic field study)	quantitative part: n=30 qualitative part: n=30, 3 nursing homes				X	27

Reviews			Symptoms						Critical appraisal according Joanna Briggs Institute (2000)
First author (year) country	Design	Sample	Respiratory distress	Pain	Mood swings	Mobility restriction	Impaired food and /or fluid intake	Behavioural disturbances	
Alexander (2007), USA	Overview; definition and description of two symptoms	Women with anxiety and mood swings			X				No detailed information about including criteria and critical appraisal of the studies
Cervo (2006), USA	Overview of the literature: benefits of PEG, ethical considerations	Feeding tubes by people with severe dementia					X		No detailed information about including criteria and critical appraisal of the studies
Förstl (2010), Germany	Overview of the literature: treatment situation, pain assessment instruments and risk factors of epidemiology	studies between 1999 to 2009 were included	X			X	X		No detailed information about including criteria and critical appraisal of the studies
Goodman (2010), United Kingdom	Integrated review	68 publications		X					Criteria fulfilled
Hughes (2007), United Kingdom	Overview of the literature	Four studies about efficacy of palliative care to people with dementia: treatment of people with dementia		X	X		X		No detailed information about including criteria and critical appraisal of the studies

Reviews			Symptoms						Critical appraisal according Joanna Briggs Institute (2000)
Husebo (2011), Norway	Systematic review	Three RCT studies of pain medication efficacy in the treatment of patients diagnosed with dementia and agitation		X				X	Criteria fulfilled
Lussier (2011), Canada	Overview and consensus document about symptoms of end-stage dementia	No detailed information	X	X	X	X	X	X	No detailed information about including criteria and critical appraisal of the studies
Robert (2010), France	Review of literature	n=68 Alzheimer's disease scales			X	X	X	X	Criteria fulfilled
Sampson (2010), United Kingdom	Overview of the literature	199 articles, inclusion from 1985 to 2010	X	X		X	X	X	No detailed information about including criteria and critical appraisal of the studies
Sampson (2009), United Kingdom	Cochrane review about the efficacy of enteral tube feeding	Seven cohort studies, inclusion from 2005 to 2008					X		Criteria fulfilled
Smith (2005), USA	Overview of the literature	Seven assessment methods		X					Criteria fulfilled
van der Steen (2010), Netherlands	Overview of the literature	Fourteen observation- and (quasi-) experimental studies from 1994 to 2010	X	X			X	X	Criteria fulfilled
Volicer (2001), USA	Overview of the literature	Overview of the management of severe Alzheimer's disease and end-of-life issues	X	X	X	X	X	X	-
Volicer (2003), USA	Overview of the literature of behavioural symptoms	Overview about the management of behavioural symptoms		X				X	-
Wowchuk (2006), Canada	Overview of the literature	Studies from 1983 to 2004	X	X				X	No detailed information about including criteria and critical appraisal of the included studies

RCT: Randomised controlled trial

Table 4: Assessment instruments

Instruments	First author (year) country	Quality score	Shortness of breath	Pain	Mood swings	Mobility restriction	Impaired food and/or fluid intake	Behavioural disturbances	Reliability	Feasibility
PACSLAC (Pain Assessment Checklist for Seniors with Limited Liability to Communicate)	Fuchs-Lacelle (2004) Canada	8		X					α = 0.92; n = 40 subscales: α = 0.55 to 0.73	Described as feasible in practice, but information about expected time is missing (Mosele *et al.*, 2012; Warden, Hurley, & Volicer, 2003)
	Zwakhalen (2007) Netherlands	8		X					α=0.82-0.86; n=128; subscales α= 0.72-0.82	
PAINAID (Pain Assessment in Advanced Dementia Scale)	Warden (2003) USA	8		X					α> 0.70; n=19	
	Mosele (2012) Italy	8		X					α= 0.90; n=310	
PMAS (Patient Mood Assessment Scale)	Edberg (2000) Sweden	8			X				Overall: α 0.85; n=75 Each factor: α= 0.74	Information regarding the needed time for the use of the scale in clinical practice is missing.
CSDD (Cornell Scale of Depression in Dementia)	Müller-Thomsen (2005) Germany	8			X				α= 0.81; n=16; α= 82; n=31	With 19 items it can be assumed that the use of the scale in clinical practice is associated with a reasonable amount of time, though relevant information is missing.
	Kørner (2006) Denmark	8								
SMA (Southampton Mobility Assessment)	Pomeroy (1990) United Kingdom	7								
	Pereira (2006) Brazil, only abstract in English	6				X			No data to Cronbachα; Kappa test: mild to moderate 0.79–0.89; for severe dementia 0.49–0.53; n=107	Information regarding the needed time for the use of the scale in clinical practice is missing.
EdFED (Edinburgh Feeding Evaluation in Dementia Scale)	Watson (1996) Scotland	6					X		α 0.87; n=196	
	Stockdell (2008) USA	6					X			About 5 minutes are mentioned to be needed for the use.
BEHAVE-AD (Behavioural Pathology in Alzheimer's Disease Scale)	Reisberg (1996) USA	6						X	No data to Cronbach α; ICC 0.96, n=18 outpatients; ICC 0.95-0.96, n=20 nursing home patients	Approximately 15–20 minutes.
	Seignourel (2008) USA	6						X	No data to Cronbach α; inter-rater reliability 0.60-0.89	

Instruments	First author (year) country	Quality score	Symptoms						Reliability	Feasibility
			Shortness of breath	Pain	Mood swings	Mobility restriction	Impaired food and/or fluid intake	Behavioural disturbances		
NPI (Neuropsychiatric Inventory)	Cummings (1997) USA	7						X	No data to Cronbach α ; Test-retest reliability 0.64–0.71; inter-rater-reliability 0.93–1.00, n=199, (Mahon & Sorrell, 2008) in (Seignourel et al., 2008)	Approximately 15–20 minutes.
	Seignourel (2008) USA	6								
	Aalten (2003) Netherlands	8							α 0.64–0.72, n=199	
MMSE (Mini-Suffering State Examination Scale)	Aminoff (2008) Israel	8		X		X	X	X	α 0.73; n =103	Information regarding the needed time for the use of the scale in clinical practice is missing.
EOLD-SM (Symptom Management End-of-Life in Dementia Scale)	Kiely (2012) USA	8	X	X	X	X		X	α 0.68–0.78; n=323	Information regarding the needed time for the use of the scale in clinical practice is missing.
EPCA (Elderly Pain Caring Assessment)	Morello (2007) France	8		X					α 0.79, n=340	To rate takes on average 5 minutes (Morello et al., 2007).

palliative care (Schweizerische Gesellschaft für Palliative Medizin Pflege und Begleitung, 2012). The following six symptoms were identified: respiratory distress, pain, mood swings, mobility restrictions, impaired food and fluid intake and behavioural disturbances. In comparison with an earlier literature review (Koppitz, Dreizler, Waldboth, & Imhof, 2014) that was limited to the onset of symptoms in persons with dementia living in nursing homes, there is no ascertainable difference in the symptoms identified. This makes it clear the six symptoms identified occur irrespective of the setting in both their frequency and in the timing of onset.

Definition, categorisation and correlations of symptoms

If there is no clear definition of a symptom, this makes identification difficult, as well as whether or not to initiate treatment actions (undertake treatments?) or to evaluate the success of actions taken (Ackley & Ladwig,

2011). During this study, a lack of clarity in symptom definitions and categorisation of symptoms and signs was noticed. This can be demonstrated in the example of behavioural disturbances. Volicer and Hurley (2003) make a rough classification of challenging behaviour as agitation, aggressiveness, catastrophic reaction and unruly and belligerent behaviour, while Cornegé-Blokland & colleagues (2012) work with 12 categories of behavioural disturbances. The diversity of terms in the category of behavioural disturbances shows a lack of differentiation from one term to another. In addition, the question arises of what is actually meant by the single terms. Furthermore, it is unclear from which perspective these terms have been chosen. Agitation is probably formulated from a health expert's point of view, but not from a patient's perspective. For the patients, agitated behaviour is experienced as drawing attention to a problem like pain. This is also demonstrated by the study of Husebo (2011), where agitation could be significantly reduced by the treatment of pain.

When comparing the medical definition of dementia in ICD 10, the International Statistical Classification of Diseases and Related Health Problems (Deutsches Institut für medizinische Dokumentation und Information (DIMDI), 2013, with the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) (Sass, Wittchen, Zaudig, & American Psychiatric, 1998), it is noticed that behavioural disturbances do not exist in the ICD 10 definition. The DSM IV differentiates at least between forms of dementia with and without behavioural disturbances. A clear definition and classification of these phenomena in medical nomenclature is necessary for clinical judgement. None of the studies discuss whether mood swings are dependent on the experienced loneliness of the patient.

Sadness and loss of appetite in the last weeks of life established by Meussen (2012) can be evaluated as an indication of people suffering from dementia feeling their impending death. What is noticeable concerning the symptom of pain is that the increased risk of pain for women, as established by Zwakhalen and colleagues (2009), has not been examined any further. However, for the clinical examination and the assessment of pain, this influencing factor has to be taken into consideration.

Detection of symptoms

The symptoms of people with advanced-stage dementia do not differ in principle from those of other diseases. In the dying phase of cancer patients, for instance, breathlessness, pain, decreased sensation of thirst, lack of appetite and the occurrence of pressure ulcers are described (Bausewein, 2005). The only exception is unusual behaviour. This can be designated a typical symptom of dementia, even in the terminal phase (van der Steen 2010, Mitchell 2009), and occurs in more than 90% of patients (Aminoff 2004, Cornegé-Blokland 2012, Lussier 2011, Volicer 1989).

The challenge in the care and support of people with dementia is the detection of symptoms. On the one hand, external assessment of the symptoms and their intensity is necessary for patients with limited verbal communication skills (Schumacher & Schneider, 2010; van der Steen, 2010; Volicer & Hurley, 1998). On the other, the special feature of persons with dementia compared to patients suffering from cancer is the persistent but irregular and unpredictable change from chronic - stable to acute - critical symptom courses, combined with a lengthy and slowly progressive process of deterioration (Givens, Kiely, Carey, & Mitchell, 2009; Koppitz *et al.*, 2014; J. R. Lunney, Lynn, Foley, Lipson, & Guralnik, 2003; Lussier *et al.*, 2011; Miller, Teno, & Mor, 2004). This complex disease progression makes it difficult to identify the one crisis out of the many that could signal the coming end of life. This results in symptoms not being detected or being detected too late, or possibly being wrongly interpreted.

What is needed is clear, careful, balanced methods of problem detection that allow timely, relevant and multi-modal responses; this can only be achieved through attentive perception, observation and examination of the patient and interviewing their relatives (Jarvis, 2008; M. Lunney, 2010).

Particularly noticeable in the instruments identified is the inadequate or missing systematic link between pain and other concurrently occurring symptoms. Without this systematic link between pain and other symptoms, there is a danger of pain not being adequately treated. This undertreatment can, in turn, trigger or aggravate other symptoms.

Perceiving symptoms and signs using all human senses (seeing, hearing, smelling, tasting, feeling) to notice if something that does not correspond to the habits of the person suffering from dementia, observing (being attentive, collecting information and being able to differentiate), naming (describing, using terms, language) and communicating verbally and non-verbally with the patients, their families and colleagues serves health professionals in the process of explaining and understanding the symptoms and signs (Jarvis, 2008).

The validation and prioritisation process of the observable symptoms is more than an official act of categorisation (Jarvis, 2008). It requires critical reflection about perceptions and observations, interpretation of these observations, development of assumptions and the implementation in the context of everyday life (Jarvis, 2008). The combined effect of all signs and symptoms occurring simultaneously becomes significant and not the course of the disease, the prognosis or the pathological causes, influences and backgrounds of dementia (M. Lunney, 2010). Therefore, in order to be an expert in clinical judgement, professionals need to be not only qualified, but also trained on a regular basis.

Standardised assessment instruments can be helpful for the evaluation of physical, functional, psychosocial, emotional, mental, sexual, cultural, age-related, environmental and spiritual symptoms and signs (Wilkinson, 2011). Eight individual scales and two scales suited for the assessment of several symptoms occurring simultaneously have proven to be reliable standardised assessment instruments. For most of the scales, information with regard to use in clinical practice is missing. In this regard, it is not only the criterion of the time needed for scale completion that should be clear, but also the level of expertise required to be able to use the scale appropriately. The skill- and grade-mix plays an important role in home care and nursing homes. This is why information with regard to the qualification levels of the persons using these scales would be helpful in practice, but is often lacking.

Different assessment instruments are available for retrospective assessment of the burden of symptoms

as well as for assessment of the severity of individual symptoms (Kiely *et al.*, 2012; Volicer, Hurley, & Blasi, 2001; Zwakhalen *et al.*, 2009). However, both assessment types have disadvantages in terms of interpretation and decision making in the current situation. Additionally, the use of an overall assessment scale like the SM-EOLD only allows limited prediction of the future or of the changing course of symptoms typical of dementia. Therefore, standardised assessment instruments can only be used to support the validation process of the symptoms and signs that have been observed. The validation and prioritisation of symptoms and signs aiming at alleviating ailments is up to nursing experts, for whom scales are additional assessment tools. Especially in palliative care, nursing experts find themselves challenged by the holistic perception of the person and his or her ailments. Scales can support human observation; however, they are only one element of decision or action. Assessment tools can facilitate an interpretation of what has changed, but they cannot make decisions or take action. Health professionals are the crucial factor in the detection and identification of symptoms. With the use of standardised assessment instruments, the question arises as to how it is possible to achieve the expectation of a holistic approach despite the use of such instruments.

Relevance for practice

Health professionals and especially nurses with advanced clinical competencies are required for clinical practice. They should not just know the specific, common and rare symptoms in patients suffering from advanced dementia, but they should also be able to detect, observe and interpret them. In order to ensure this, annual refresher training courses on systematic documentation and evaluation are to be recommended. These training courses are necessary for staff of all qualification levels and could be further supported by training family members. Family members know the person with dementia very well and are able to compare the behaviour with that of other situations. The observations of family members could serve as an external evaluation for the observations made by the health professionals. This is a precondition for acting in a careful, evaluated, problem-relevant manner as well as for assessing complex situations, providing prognoses and making situation-specific advanced care planning. Thus, complications can be considered early and family members are involved in decisive processes.

Relevance for research

If unusual behaviour is the key for the identification of symptoms in people with dementia, then a clear categorisation and symptom definition is needed. This literature review made clear that there are up to 12 different categories of deviations in the definition of unusual behaviour. Therefore, a clear and precise representation of symptoms is necessary in order to allow clinical assessment. Furthermore, it is necessary to examine nursing experts' interpretations of symptom patterns occurring concurrently and repeatedly.

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