

Symptom Assessment in Hospitalized Older Palliative Patients With Cancer: Agreement Among Patients, Nurses, and Proxies

Aurélie Van Lancker, MSc, RN, Stephanie Cypers, MSc, RN, Elke Vanwynsberghe, MSc, RN, Sofie Verhaeghe, PhD, RN, Ann Van Hecke, PhD, RN, and Dimitri Beeckman, PhD, RN

Palliative care is defined as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organization [WHO], 2002, pp. 15–16). Cancer remains one of the leading causes of death (Ferlay et al., 2010); therefore, patients with cancer represent an important proportion of the patients in the palliative care setting.

Palliative patients with cancer suffer from multiple symptoms and, at times, with high prevalence (Teunissen et al., 2007; Van Lancker et al., 2014). Subsequently, symptom management is seen as the most important aspect of palliative care (WHO, 2002). This requires adequate symptom assessment, which allows identification of symptoms in multiple domains, such as physical, psychological, social, functional, and existential (WHO, 2002). Like palliative care, care of older adults requires a multifaceted approach. Older adults often are confronted with comorbidities, polypharmacy, functional decline, cognitive problems, and loss of homeostatic reserve, which can result in symptoms in multiple domains (Depp & Jeste, 2006; Marengoni et al., 2011). Adequate symptom assessment is essential to be able to implement appropriate interventions to control symptoms.

Patient self-reported symptoms are seen as the gold standard in symptom assessment (Pautex, Berger, Chatelain, Herrmann, & Zulian, 2003). However, patients are not always able to report their symptoms because of a variety of reasons that are particularly relevant for older adult patients in palliative care (Kaye, Baluch, & Scott, 2010). Patients are, for instance, not able to report their symptoms if they experience cognitive problems, confusion, and weakness (Kaye et al., 2010;

Purpose/Objectives: To evaluate the level of agreement of symptom assessment among older adult palliative patients with cancer, nurses, and patients' proxies.

Design: A cross-sectional study.

Setting: Two general hospitals in Flanders, Belgium.

Sample: 120 palliative patients with cancer, aged 65 years and older.

Methods: A validated 36-item instrument developed to assess physical, psychological, functional, social, and existential symptoms in older palliative patients with cancer was independently completed by patients, the nurses, and proxies.

Main Research Variables: Frequency and intensity of 36 symptoms.

Findings: The study indicates that nurses and proxies tend to underestimate physical and social symptoms and overestimate psychological, functional, and existential symptoms. Agreement scores between patients and nurses and patients and proxies were only significantly different in 39% and 20% of the cases, respectively. Higher intraclass correlation coefficients were measured between patients and proxies compared to patients and nurses. Agreement was associated with demographic and clinical factors, such as gender and prognosis.

Conclusions: This study indicates discrepancies among patient, nurse, and proxy in the assessment of symptoms.

Implications for Nursing: Patients should be encouraged to report their true experiences. Nurses and proxies should be taught to recognize and assess symptoms and to communicate about them with patients.

Key Words: signs and symptoms; palliative care; symptom assessment; neoplasms

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Nekolaichuk et al., 1999). For those patients, symptoms can only be assessed indirectly or estimated by a formal (nurse and physician) or informal (proxy) caregiver. The validity and reliability of those assessments are

unclear. As a result, underreporting may result in undertreatment and overreporting may lead to unnecessary interventions, such as high doses of medication (Kaye et al., 2010; Winn & Dentino, 2005). This may reduce the quality of life of the patient and lead to discomfort.

Studies on the agreement of symptom assessment among the patient, the healthcare provider, and the proxy have been performed in different settings and populations (Higginson & Gao, 2008; Laugsand et al., 2010; Pautex et al., 2003; Yip, Wilber, Myrtle, & Grazman, 2001). To the authors' knowledge, only one study focused on a population of older adult palliative care patients (Pautex et al., 2003). Overall, healthcare professionals and proxies have a tendency to under- and overreport symptoms, respectively. Lower agreement has been observed for more subjective symptoms, such as depression, and less prevalent symptoms, such as poor sleep (Laugsand et al., 2010; Pautex et al., 2003). In a population of older palliative patients, Pautex et al.

(2003) used the Edmonton Symptom Assessment Scale (ESAS) and confirmed that healthcare providers tend to underestimate physical and objective symptoms and overestimate physiological and subjective symptoms. However, Pautex et al. (2003) assessed only a limited number of symptoms with a small sample size (N = 42). Therefore, the aim of the current study was to evaluate the level of agreement of symptom assessment (physical, psychological, functional, social, and existential) among older palliative patients, nurses, and proxies.

Methods

A cross-sectional study was performed from November 2012 to May 2013. The study was conducted in two general hospitals in Flanders, Belgium: General Hospital Groeninge, Kortrijk, and General Hospital OLV Lourdes, Waregem. Patients were recruited from eight internal medicine units and one geriatric ward.

A convenience sample of older palliative patients with cancer participated in the study. Patients were eligible for the study if they met following criteria: (a) aged 65 years or older; (b) a palliative patient as defined by Desmedt et al. (2011), "A patient suffering from an incurable, progressive, life-threatening disease, with no possibility of obtaining remission, stabilization or improvement of this illness" (p. 3); (c) having a current diagnosis of a malignant disease; (d) being able to interact with the interviewer; (e) being able to provide written, informed consent; and (f) being hospitalized for at least one week so that the nurses could make an adequate estimation of the occurrence of symptoms. The patient indicated a proxy who was able to provide an accurate estimation of the occurrence of symptoms. Patients were excluded if they had not received any visits in the past week and if they were in a terminal phase of illness (defined as the last phase of life and characterized by general organ failure).

Instruments

Symptoms were assessed using a validated 36-item instrument specifically designed for older palliative patients with cancer (Van Lancker et al., 2012). The instrument was developed based on an extensive literature review. Face and content validity were evaluated using a double Delphi procedure with 11 clinical and/or research experts in oncology, palliative care, geriatric care, and nursing. The item content validity index (I-CVI) ranged from 89.9%–100%. Lynn (1986) recommended an I-CVI of 80% or greater. The scale content validity index (S-CVI) was 93%. Polit and Beck (2011) recommended a S-CVI of 90% or greater. The instrument was pilot tested for clarity and ambiguity in a sample of 10 hospitalized older adult patients. Changes were made following the Delphi and pilot study. The

Table 1. Sample Characteristics (N = 120)

Characteristic	\bar{X}	SD
Age (years)	77.5	0.7
Characteristic	n	%
Gender		
Male	78	65
Female	42	35
Marital status		
Married	77	64
Widow or widower	32	27
Unmarried	8	7
Divorced	3	3
Cancer type		
Gastrointestinal	55	46
Lung	21	18
Breast	12	10
Prostate	11	9
Urogenital	9	8
Hematologic	7	6
Other types of cancer	5	4
Metastases		
Yes	98	82
No	22	18
Life expectancy		
Weeks	19	16
Months	69	58
Years	32	27
Cognitive status^a		
Normal	97	81
Deficit	23	19

^a For the Clock Drawing Test, a score of 2 or greater represented a cognitive deficit, whereas a score of 0 or 1 was considered to be normal. For the Mini Mental State Examination, a score of less than 23 represented a cognitive deficit, whereas a score of 23 or greater was considered to be normal.

Note. Because of rounding, percentages may not total 100.

Table 2. Frequency and Intensity of Symptoms Rated by Patients, Nurses, and Proxies

Symptom	Symptom Frequency ^a										p ^b	Symptom Intensity ^a								p ^b
	Never		Rarely		Sometimes		Often		Always			Not		Somewhat		Moderate		Very Serious		
	n	%	n	%	n	%	n	%	n	%		n	%	n	%	n	%	n	%	
Physical																				
Lack of appetite																				
Patient	23	19	5	4	17	14	36	30	39	33		6	6	16	17	29	30	46	47	
Nurse	19	11	21	17	32	27	25	21	23	19	0.00**	3	3	22	22	51	51	25	25	0.13
Proxy	26	22	3	3	16	13	40	33	35	29	0.29	5	5	8	9	39	42	42	45	0.44
Fatigue																				
Patient	17	14	4	3	23	19	35	29	41	34		3	3	13	13	48	47	39	38	
Nurse	11	9	10	8	36	30	39	33	24	20	0.16	2	2	22	20	70	64	15	14	0.00**
Proxy	10	8	4	3	23	19	47	39	36	30	0.32	4	4	12	11	55	50	39	36	0.98
Pain																				
Patient	34	28	10	8	21	18	33	28	22	18		2	2	4	5	33	38	47	55	
Nurse	26	22	19	16	31	26	35	29	9	8	0.2	2	2	19	20	25	27	48	51	0.22
Proxy	30	25	4	3	33	28	29	24	24	20	0.55	3	4	6	7	16	19	58	70	0.06
Lack of energy																				
Patient	19	16	11	9	27	23	36	30	27	23		6	6	20	20	42	42	33	33	
Nurse	12	10	14	12	35	29	50	42	9	8	0.5	2	2	25	23	70	57	20	19	0.14
Proxy	16	13	6	5	29	24	40	33	29	24	0.21	2	2	15	14	48	46	39	38	0.07
Nausea																				
Patient	66	55	4	3	27	23	17	14	6	5		3	6	7	13	15	28	29	54	
Nurse	58	48	19	16	27	23	15	13	1	1	0.35	5	8	18	29	23	37	16	26	0.16
Proxy	63	53	15	13	2	21	12	10	5	4	0.21	1	2	11	19	16	28	29	51	0.39
Sleeplessness																				
Patient	70	58	7	6	24	20	32	27	7	6		3	4	9	13	32	46	26	37	
Nurse	52	43	20	17	37	31	8	7	3	3	0.00**	4	6	21	31	32	47	11	16	0.00**
Proxy	51	42	11	9	29	24	23	19	6	5	0.26	4	6	8	12	33	48	24	35	0.79
Vomiting																				
Patient	92	77	2	2	8	7	14	12	4	3		—	—	1	4	10	36	17	61	
Nurse	85	71	12	10	14	12	9	8	—	—	0.31	2	6	8	23	11	31	14	40	0.22
Proxy	87	72	8	7	11	9	12	10	2	2	0.83	—	—	4	12	12	36	17	52	0.76
Dizziness																				
Patient	82	68	9	8	18	15	6	5	5	4		2	5	12	32	12	32	12	32	
Nurse	69	58	21	18	20	17	10	8	—	—	0.41	8	16	22	43	16	31	5	10	0.00***
Proxy	68	57	14	12	27	23	9	8	2	2	0.16	4	8	18	35	18	35	12	23	0.97

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*p < 0.05; **p < 0.01; ***p < 0.001

^aSymptom frequency was assessed for all patients (n = 120). Symptom intensity was only rated when the symptom was not assessed. Therefore, the number of rating for symptom intensity varies per symptom and per rater.

^bWilcoxon signed rank test

^cThe item weight loss was a dichotomous variable: yes/no. This was transformed to never/always to allow representation in the table. Chi-square test was used to measure the difference between raters.

Table 2. Frequency and Intensity of Symptoms Rated by Patients, Nurses, and Proxies (Continued)

Symptom	Symptom Frequency ^a										p ^b	Symptom Intensity ^a								p ^b	
	Never		Rarely		Sometimes		Often		Always			Not		Somewhat		Moderate		Very Serious			
	n	%	n	%	n	%	n	%	n	%		n	%	n	%	n	%	n	%		
Physical (Continued)																					
Tension																					
Patient	79	66	12	10	19	16	7	6	3	3		3	7	11	27	19	46	8	20		
Nurse	55	46	31	26	22	18	11	9	1	1	0.06	–	–	28	43	31	48	6	9	0.14	
Proxy	55	46	12	10	36	30	11	9	6	5	0.00**	2	3	13	20	30	46	20	31	0.27	
Heartburn or belching																					
Patient	77	64	11	9	15	13	13	11	4	3		5	12	16	37	13	30	9	21		
Nurse	83	69	14	12	18	15	5	4	–	–	0.02*	1	3	22	60	14	38	–	–	0.56	
Proxy	85	71	3	3	21	18	8	7	3	3	0.31	3	9	11	31	13	37	8	23	0.42	
Constipation																					
Patient	72	60	5	4	15	13	16	13	12	10		4	8	8	17	21	44	15	31		
Nurse	71	59	13	11	17	14	15	13	4	3	0.16	3	6	20	41	15	31	11	22	0.54	
Proxy	75	63	6	5	18	15	11	9	10	8	0.34	2	4	13	29	13	29	17	38	0.28	
Diarrhea																					
Patient	83	69	8	7	13	11	12	10	4	3		–	–	6	16	10	27	21	57		
Nurse	83	69	17	14	9	8	10	8	1	1	0.05*	3	8	12	32	9	24	13	35	0.3	
Proxy	80	67	15	13	14	12	10	8	1	1	0.28	1	3	6	20	11	28	20	50	0.11	
Tingling in hands or feet																					
Patient	91	76	3	3	12	10	6	5	8	7		6	21	7	24	5	17	11	38		
Nurse	110	91	8	7	1	1	1	1	–	–	0.00***	1	10	6	60	3	30	–	–	0.16	
Proxy	101	84	6	5	3	3	4	3	6	5	0.02*	–	–	5	26	5	26	9	47	0.58	
Sore mouth or pain when swallowing																					
Patient	84	70	2	2	14	12	12	10	8	7		–	–	7	19	13	36	16	44		
Nurse	84	70	13	11	7	6	15	13	1	1	0.07	1	3	12	33	19	53	4	11	0.02*	
Proxy	86	72	6	5	6	5	14	12	8	7	0.53	1	3	5	15	13	38	15	44	0.53	
Shortness of breath																					
Patient	56	47	6	5	21	18	25	21	12	10		1	2	5	8	21	33	37	58		
Nurse	52	43	14	12	27	23	17	14	10	8	0.34	1	2	17	25	21	31	29	43	0.02*	
Proxy	53	44	4	3	30	25	16	13	17	14	0.5	2	3	3	5	20	30	42	63	0.15	
Dry mouth																					
Patient	25	21	3	3	26	22	40	33	26	22		5	5	31	33	35	37	24	25		
Nurse	51	43	21	18	25	21	19	16	4	3	0.00***	6	9	34	49	24	35	5	7	0.01*	
Proxy	31	26	7	6	34	28	36	30	12	10	0.00**	11	12	25	28	31	35	22	25	0.28	

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*p < 0.05; **p < 0.01; ***p < 0.001

^aSymptom frequency was assessed for all patients (n = 120). Symptom intensity was only rated when the symptom was not assessed. Therefore, the number of rating for symptom intensity varies per symptom and per rater.^bWilcoxon signed rank test^cThe item weight loss was a dichotomous variable: yes/no. This was transformed to never/always to allow representation in the table. Chi-square test was used to measure the difference between raters.

Table 2. Frequency and Intensity of Symptoms Rated by Patients, Nurses, and Proxies (Continued)

Symptom	Symptom Frequency ^a										p ^b	Symptom Intensity ^a								p ^b
	Never		Rarely		Sometimes		Often		Always			Not		Somewhat		Moderate		Very Serious		
	n	%	n	%	n	%	n	%	n	%		n	%	n	%	n	%	n	%	
Physical (Continued)																				
Cough																				
Patient	64	53	10	8	20	17	18	15	8	7		1	2	14	25	26	46	15	27	
Nurse	66	55	19	16	15	13	17	14	3	3	0.04*	3	6	25	46	23	43	3	6	0.00***
Proxy	69	58	8	7	17	14	21	18	5	4	0.32	7	14	10	20	19	37	15	29	0.09
Itching																				
Patient	80	67	2	2	10	8	8	7	20	17		4	20	6	30	5	25	5	25	
Nurse	101	84	10	8	5	4	4	3	—	—	0.16	2	11	11	58	4	21	2	11	0.27
Proxy	88	73	4	3	8	7	4	3	16	13	0.12	2	13	7	44	4	25	3	19	0.32
Changes in food taste																				
Patient	48	40	5	4	16	13	16	13	35	29		6	8	13	18	22	31	31	43	
Nurse	74	61	13	11	20	17	10	8	3	3	0.00***	2	4	18	39	21	46	5	11	0.27
Proxy	45	38	4	3	7	6	34	28	30	25	0.52	4	5	28	9	13	45	9	40	0.19
Airway mucus																				
Patient	62	51	8	7	22	18	17	14	12	10		3	5	18	31	22	37	16	27	
Nurse	67	56	11	9	24	20	15	13	3	3	0.03*	4	8	21	40	22	42	6	11	0.05*
Proxy	66	55	4	3	28	23	13	11	9	8	0.25	2	4	17	32	23	43	12	22	0.68
Urinary incontinence																				
Patient	97	81	4	3	11	9	5	4	3	3		—	—	3	13	3	26	14	61	
Nurse	99	83	4	3	8	7	4	3	5	4	0.89	1	5	4	18	8	36	9	41	0.06
Proxy	99	83	3	3	9	8	5	4	4	3	0.78	2	10	—	—	9	43	10	48	1
Fecal incontinence																				
Patient	105	88	2	2	7	6	3	3	3	3		—	—	2	13	—	—	13	87	
Nurse	103	86	6	5	3	3	4	3	4	3	0.89	—	—	5	29	6	35	6	35	0.19
Proxy	108	90	3	3	5	4	2	2	2	2	0.15	1	8	1	8	4	33	6	50	0.08
Weight loss ^c																				
Patient	34	28	—	—	—	—	—	—	86	72		—	—	—	—	—	—	—	—	
Nurse	44	38	—	—	—	—	—	—	76	63	0.00***	—	—	—	—	—	—	—	—	—
Proxy	35	29	—	—	—	—	—	—	85	71	0.00***	—	—	—	—	—	—	—	—	—

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^aSymptom frequency was assessed for all patients (n = 120). Symptom intensity was only rated when the symptom was not assessed. Therefore, the number of rating for symptom intensity varies per symptom and per rater.

^bWilcoxon signed rank test

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Symptom	Symptom Frequency ^a											p ^b	Symptom Intensity ^a								p ^b
	Never		Rarely		Sometimes		Often		Always		Not		Somewhat		Moderate		Very Serious				
	n	%	n	%	n	%	n	%	n	%	n		%	n	%	n	%	n	%		
Psychological																					
Brooding																					
Patient	42	35	10	8	23	19	33	28	12	10		4	5	14	18	37	47	23	29		
Nurse	21	18	22	18	46	38	25	21	6	5	0.56	—	—	25	25	67	63	12	12	0.34	
Proxy	18	15	11	9	39	33	37	31	15	13	0.00***	3	3	15	15	51	50	33	32	0.06	
Depressed mood																					
Patient	54	45	10	8	41	34	13	11	2	2		—	—	9	14	32	49	25	38		
Nurse	37	31	31	26	34	28	16	13	2	2	0.24	—	—	22	27	40	49	21	25	0.14	
Proxy	35	29	12	10	40	33	28	23	5	4	0.00***	2	2	7	8	31	37	45	53	0.02*	
Nervousness																					
Patient	56	47	11	9	26	22	19	16	8	7		2	3	20	31	26	41	16	25		
Nurse	60	50	25	21	21	18	11	9	3	3	0.02*	2	3	30	50	21	35	7	12	0.00**	
Proxy	44	37	7	6	30	25	24	20	15	13	0.00**	9	12	23	30	33	43	11	15	0.08	
Fear																					
Patient	72	60	9	8	21	18	11	9	7	6		2	4	6	13	17	35	23	48		
Nurse	41	34	28	23	34	28	15	13	2	2	0.01*	1	1	17	22	38	48	23	29	0.14	
Proxy	52	43	2	2	42	35	16	13	8	7	0.00***	1	2	6	9	23	34	38	56	0.02*	
Difficulties concentrating																					
Patient	63	53	7	6	30	25	18	15	2	2		3	5	15	26	22	39	17	30		
Nurse	60	50	16	13	34	28	9	8	—	—	0.33	3	5	23	39	27	46	6	10	0.31	
Proxy	55	46	12	10	34	28	14	12	5	4	0.33	7	11	19	29	24	37	15	23	0.15	
Anger																					
Patient	85	71	2	2	21	18	11	9	1	1		—	—	2	6	19	54	14	40		
Nurse	78	65	15	13	25	21	2	2	—	—	0.4	1	2	15	36	22	52	4	10	0.03*	
Proxy	63	53	19	16	34	28	2	2	1	1	0.12	3	5	15	27	22	39	16	29	0.00**	
Loneliness																					
Patient	76	63	6	5	24	20	12	10	2	2		—	—	5	11	15	34	24	55		
Nurse	58	48	21	18	32	27	9	8	—	—	0.4	4	7	12	19	26	42	20	32	0.13	
Proxy	68	57	13	11	25	21	14	12	—	—	0.49	1	2	2	4	17	33	32	62	0.16	

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*p < 0.05; **p < 0.01; ***p < 0.001

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Symptom	Symptom Frequency ^a										p ^b	Symptom Intensity ^a								p ^b	
	Never		Rarely		Sometimes		Often		Always			Not		Somewhat		Moderate		Very Serious			
	n	%	n	%	n	%	n	%	n	%		n	%	n	%	n	%	n	%		
Psychological (Continued)																					
Confusion																					
Patient	92	77	7	6	17	14	4	3	—	—	0.08	—	—	6	21	11	39	11	39	0.05*	
Nurse	98	82	9	8	10	8	3	3	—	—		3	14	7	32	11	50	1	5		
Proxy	89	74	7	6	20	17	3	3	1	1		0.4	4	13	4	13	18	58	5		16
Functional																					
Difficulties with self-care																					
Patient	32	27	3	3	11	9	19	16	55	46	0.04*	21	24	20	23	30	34	17	19	0.00**	
Nurse	14	12	11	9	20	17	25	21	50	42		23	22	47	44	32	30	4	4		
Proxy	22	18	7	6	17	14	20	17	54	45		0.16	21	21	28	29	34	35	15		15
Difficulties with moving																					
Patient	38	32	11	9	15	13	23	19	33	28	0.22	11	13	15	18	33	40	23	28	0.09	
Nurse	24	20	16	13	28	23	23	19	29	24		7	7	38	40	33	41	12	13		
Proxy	30	25	11	9	17	14	28	23	34	28		0.09	15	17	14	16	36	40	25		28
Social																					
Satisfied with social life																					
Patient	4	1	4	3	15	13	23	19	74	62	0.00***	—	—	10	9	28	24	78	67	0.00**	
Nurse	11	1	10	8	21	18	38	32	40	33		—	—	11	9	49	42	58	49		
Proxy	1	1	6	5	26	22	29	24	58	48		0.04*	1	1	9	8	37	31	72		61
Feeling supported																					
Patient	1	1	3	3	8	7	21	18	87	73	0.00***	—	—	4	3	23	19	92	77	0.00**	
Nurse	1	1	7	6	15	13	40	33	57	48		—	—	5	4	36	30	78	66		
Proxy	—	—	3	3	4	3	34	28	79	66		0.88	—	—	3	3	21	18	96		80
Existential																					
Experience life as meaningful																					
Patient	5	1	10	8	14	12	29	24	62	52	0.55	1	1	6	5	31	27	77	67	0.44	
Nurse	1	1	7	6	21	18	46	38	45	38		—	—	10	8	37	31	72	61		
Proxy	2	1	6	5	16	3	29	21	67	56		0.11	1	1	1	1	23	20	93		79

*p < 0.05; **p < 0.01; ***p < 0.001

^aSymptom frequency was assessed for all patients (n = 120). Symptom intensity was only rated when the symptom was not assessed. Therefore, the number of rating for symptom intensity varies per symptom and per rater.

^bWilcoxon signed rank test

^cThe item weight loss was a dichotomous variable: yes/no. This was transformed to never/always to allow representation in the table. Chi-square test was used to measure the difference between raters.

instrument assesses symptoms on five domains: physical, psychological, functional, social, and existential. The test-retest reliability (30-minute intervals) showed a weighted kappa from 0.53–1, with the majority of the items (88%) showing substantial (0.61–0.8) to almost perfect (greater than 0.8) agreement.

The symptoms are rated on a five-point Likert-type scale to assess frequency of symptoms which they encountered in the past week, ranging from 1 (never) to 5 (always), and a four-point Likert-type scale to assess intensity of the prevalent symptoms experienced in the past week, ranging from 1 (not serious) to 4 (very serious). One symptom, weight loss, receives a dichotomized answer category (0 for “yes” or 1 for “no”).

Additional demographics and clinical data were collected, including age, gender, marital status, and living status (see Table 1). Clinical data collected included cognition assessed by the Clock Drawing Test (CDT) (Shulman, Pushkar Gold, Cohen, & Zuccherro, 1993) or Mini Mental State Examination (MMSE) (Tombaugh & McIntyre, 1992), life expectancy (weeks, months, years), type of malignant disease, metastases (yes or no), and Flemish Triage Risk Screening Tool (TRST) (Deschodt et al., 2011).

Data Collection

Ethical approval was obtained by the ethics review committee of the two general hospitals. Eligible patients were identified by the attending physicians. The physicians provided oral information about the study to the patient. After consent, the patients, proxies, and nurses were approached by one of the two research assistants who explained the study more extensively. Patients who agreed to participate were asked to sign an informed consent. Proxies and nurses provided oral consent.

Patients, nurses, and proxies of the patients assessed the symptoms independently on the same day using the validated instrument. Patients completed the instrument by means of a standardized and structured interview with one of the two researchers. The nurses and proxies received the instrument in hard copy.

Data Analysis

The data were analyzed using SPSS®, version 20. Descriptive statistics and symptoms were presented in absolute numbers and frequencies. The level of agreement was examined using three different methods as described by Laugsand et al. (2010). First, agreement at the individual level was measured using the Wilcoxon Signed-Rank test to compare the frequency and intensity of symptoms as assessed by the three assessors. Second, differences in scores were measured for frequency and intensity of each symptom. The difference score

was computed by (a) subtracting the score of the patient from the score of the nurse and (b) subtracting the score of the patient from the score of the proxy. Patient assessment was seen as the gold standard. Difference scores (DS) were interpreted as follows: DS of ± 1 , good agreement; DS of -2 or lower, underestimation; DS of 2 or greater, overestimation. Third, agreement at the individual level was measured using the intraclass correlation coefficient (ICC), two-way mixed effect model, and the absolute agreement. The ICC was reported with its 95% confidence interval (CI). The strength of agreement was interpreted according to Landis and Koch (1977): 0–0.2, poor; 0.21–0.4, fair; 0.41–0.6, moderate; 0.61–0.8, substantial; and 0.81–1, almost perfect.

The DS were used to investigate the demographic and disease-related factors associated with under- and overestimation and good agreement. The chi-square test was used to measure this association. A *p* value of less than 0.05 was considered significant.

Results

A total of 120 hospitalized patients participated in the study. Patients had a mean age of 77.5 years (*SD* = 0.7). The five most prevalent symptoms were fatigue (86%), lack of energy (84%), lack of appetite (81%), dry mouth (79%), and difficulties with self-care abilities (73%). Agreement scores of symptom assessment at group level between patients, nurses, and proxies are provided in Table 2.

Nurses tended to report lower symptom frequency and intensity compared to patients; however, for 61% of the symptoms, no significant difference in agreement between patients and nurses was noted. Proxies tended to report higher symptom frequency and intensity compared to patients. However, this was not the case for all symptoms. No significant differences were noted between patients and their proxies for frequency (81%) and intensity (89%) of symptoms. The direct over- and underestimation of symptoms defined as a DS of -2 or less or 2 or greater are provided in Table 3.

The frequency of symptoms most underestimated by nurses were dry mouth (43%) and changes in the taste of food (39%). Best agreement was found for the assessment of fecal incontinence (93%), vomiting (92%), and diarrhea (92%). The intensity of symptoms most underestimated by nurses were fatigue (8%) and difficulties with self-care (8%). The frequency of the symptom most often overestimated by nurses was fear (19%). The intensity of the symptom most often overestimated by nurses was difficulties with self-care (5%).

The frequency of symptoms most underestimated by proxies were dry mouth (19%) and tingling in hands or feet (15%). Best agreement was found for

Table 3. Underestimation and Overestimation of Symptoms

Symptom	Symptom Frequency										Symptom Intensity									
	Underestimation				Good Agreement			Overestimation			Underestimation			Good Agreement			Overestimation			
	−4	−3	−2	%	0	±1	%	2	3	4	%	−3	−2	%	0	±1	%	2	3	%
Patients Versus Nurses																				
Physical																				
Lack of appetite	2	6	17	21	50	37	73	6	2	−	7	−	6	5	38	40	92	4	−	3
Fatigue	1	6	12	16	48	38	72	11	4	−	13	1	9	8	49	36	91	1	−	1
Pain	−	5	12	14	46	47	78	5	5	−	8	1	5	5	48	22	94	1	−	1
Lack of energy	−	5	9	12	49	43	77	11	3	−	12	−	3	3	37	51	95	3	−	3
Nausea	−	3	13	13	60	34	78	8	2	−	8	2	3	4	21	12	93	2	1	3
Sleeplessness	−	11	18	24	44	36	67	9	2	−	9	−	6	5	25	14	95	−	−	−
Vomiting	−	3	4	6	91	19	92	2	1	−	3	1	1	2	12	9	98	−	−	−
Dizziness	1	3	4	7	68	32	83	9	3	−	10	−	1	1	14	12	99	−	−	−
Tensions	1	4	7	10	49	39	73	13	6	1	17	−	2	2	9	15	98	−	−	−
Constipation	4	8	11	19	60	24	70	7	5	1	11	−	4	3	11	13	96	1	−	1
Diarrhea	−	2	7	8	83	27	92	1	−	−	1	1	1	2	17	4	98	1	−	1
Heartburn or belching	2	9	10	18	74	14	73	11	−	−	9	−	1	1	11	8	99	−	−	−
Tingling hands or feet	6	6	12	20	86	10	80	−	−	−	−	−	−	−	2	2	100	−	−	−
Sore mouth or pain when swallowing	1	8	8	14	77	20	81	5	−	1	5	1	2	3	8	9	98	−	−	−
Shortness of breath	−	4	8	10	60	39	83	6	3	−	8	−	6	5	28	17	95	−	−	−
Dry mouth	12	17	22	43	32	32	53	3	2	−	4	−	6	5	20	28	93	2	−	2
Cough	1	5	8	12	75	27	85	2	2	−	3	−	5	4	16	19	96	−	−	−
Itching	−	5	9	12	89	12	84	2	3	−	4	−	−	−	1	5	100	−	−	−
Change in food taste	22	10	15	39	44	21	54	3	5	−	7	1	3	3	11	14	96	1	−	1
Airway mucus	3	7	11	18	64	25	74	7	3	−	8	−	4	3	19	14	96	1	−	1
Urinary incontinence	1	1	6	7	92	12	87	4	2	1	6	−	2	2	8	2	98	−	−	−
Fecal incontinence	−	−	5	4	98	13	93	3	−	1	3	−	2	2	4	2	98	−	−	−
Psychological																				
Brooding	−	5	12	14	40	44	70	13	5	1	16	−	4	3	33	30	93	4	−	3
Depressed mood	−	3	9	10	55	26	68	14	3	−	14	−	3	3	32	20	97	1	−	1
Nervousness	1	10	19	25	44	31	63	9	3	3	13	−	5	4	19	13	96	−	−	−
Fear	1	2	8	9	46	40	72	17	5	1	19	−	2	2	22	14	98	−	−	−
Difficulties concentrating	−	9	12	18	61	22	69	13	3	−	13	−	4	3	13	18	96	1	−	1
Anger	−	3	11	12	75	22	81	8	2	−	8	1	2	3	11	8	98	−	−	−
Loneliness	−	1	13	12	65	27	77	12	2	−	12	−	3	3	17	11	98	−	−	−
Confusion	−	1	10	9	93	12	88	4	−	−	3	2	1	3	7	4	98	−	−	−
Functional																				
Difficulties with self-care	−	2	2	3	71	32	86	7	6	−	11	2	8	8	34	37	87	5	1	5
Difficulties with moving	−	3	7	8	64	29	78	14	3	−	14	1	3	3	29	39	93	3	1	3

(Continued on the next page)

Table 3. Underestimation and Overestimation of Symptoms (Continued)

Symptom	Symptom Frequency										Symptom Intensity									
	Underestimation				Good Agreement			Overestimation			Underestimation			Good Agreement			Overestimation			
	−4	−3	−2	%	0	±1	%	2	3	4	%	−3	−2	%	0	±1	%	2	3	%
Patients Versus Nurses (Continued)																				
Social																				
Satisfied with social life	2	5	12	16	59	37	80	3	1	1	4	−	2	2	73	39	98	−	−	−
Feeling supported	−	4	6	8	75	34	91	−	1	−	1	−	−	−	86	32	100	−	−	−
Existential																				
Experience life as meaningful	−	3	6	8	59	41	83	7	2	2	9	−	4	3	71	38	95	2	−	2
Patients Versus Proxies																				
Physical																				
Lack of appetite	−	1	5	5	76	33	91	1	4	−	4	1	1	2	50	34	93	4	−	3
Fatigue	−	4	6	9	55	40	79	7	6	2	13	1	5	5	50	39	93	3	−	3
Pain	2	6	8	13	57	29	72	12	3	3	15	−	−	−	51	16	98	3	−	3
Lack of energy	−	6	6	10	58	30	73	13	5	2	17	−	3	3	43	40	92	6	1	6
Nausea	1	1	11	11	76	27	86	4	−	−	3	−	2	2	27	11	96	3	−	3
Sleeplessness	1	6	9	13	52	40	77	8	3	1	10	1	3	3	27	20	95	−	2	2
Vomiting	−	3	2	4	97	15	93	1	2	−	3	−	−	−	13	11	100	−	−	−
Dizziness	−	2	9	9	71	26	81	8	4	−	10	−	2	2	11	14	96	3	−	3
Tensions	1	4	5	12	57	25	68	17	7	4	23	−	1	1	16	9	98	1	1	2
Constipation	4	7	5	13	70	22	77	9	1	2	10	−	−	−	13	17	99	1	−	1
Diarrhea	−	1	5	5	87	23	92	3	1	−	3	−	1	1	18	10	99	−	−	−
Heartburn/belching	1	3	10	12	78	18	80	4	6	−	8	−	2	2	9	12	98	1	−	1
Tingling hand/feet	2	4	12	15	88	10	82	0	1	3	3	−	1	1	8	2	98	1	−	1
Sore mouth/pain when swallowing	1	4	6	9	88	15	86	1	3	2	5	−	−	−	15	10	100	−	−	−
Shortness of breath	1	4	5	8	70	29	83	7	2	2	9	−	1	1	33	18	98	2	−	2
Dry mouth	4	6	13	19	51	36	73	7	2	1	8	2	4	5	39	32	93	2	−	2
Cough	1	3	6	8	78	24	85	4	2	2	8	1	1	2	26	14	98	−	−	−
Itching	−	4	5	8	97	10	89	4	−	−	3	−	1	1	3	5	99	−	−	−
Change in food taste	2	4	4	8	74	22	80	7	2	5	12	−	−	−	42	15	96	4	1	4
Airway mucus	2	3	9	14	77	19	80	6	2	2	8	−	2	2	18	23	96	3	−	3
Urinary incontinence	1	2	7	8	95	9	87	2	2	2	6	−	−	−	7	4	99	1	−	1
Fecal incontinence	1	−	6	6	105	6	93	2	−	−	2	−	−	−	4	3	100	−	−	−
Psychological																				
Brooding	−	3	3	5	48	37	71	23	5	1	24	1	1	2	35	31	94	5	−	4
Depressed mood	−	−	7	6	56	34	75	17	3	3	19	−	−	−	22	32	98	3	−	3
Nervousness	−	2	8	8	59	23	68	18	8	2	23	−	2	2	21	28	97	2	−	2
Fear	−	1	5	5	64	22	72	22	3	3	23	−	−	−	24	14	98	3	−	3
Difficulties concentrating	−	2	8	8	75	20	79	10	3	2	13	2	3	4	22	16	93	3	−	3

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Table 3. Underestimation and Overestimation of Symptoms (Continued)

Symptom	Symptom Frequency						Symptom Intensity					
	Underestimation			Good Agreement			Overestimation			Underestimation		
	-4	-3	-2	0	±1	%	2	3	4	-3	-2	%
Patients Versus Proxies (Continued)												
Psychological (Continued)												
Anger	-	2	5	8	22	82	15	1	-	13	8	93
Loneliness	-	1	5	5	26	88	6	2	-	7	18	98
Confusion	-	1	4	4	13	89	7	1	-	7	10	100
Functional												
Difficulties with self-care	2	-	3	4	21	88	6	-	3	8	40	93
Difficulties with moving	1	1	6	7	21	82	10	1	3	12	42	94
Social												
Satisfied with social life	1	1	8	10	35	87	3	2	1	5	79	98
Feeling supported	-	1	-	1	19	97	2	1	-	3	95	100
Existential												
Experience life as meaningful	-	1	5	5	35	88	4	4	1	8	78	98
											2	-

feeling supported (97%), vomiting (93%), and fecal incontinence (94%). The intensity of the symptom most underestimated by proxies (anger) was 7%. The frequency of the symptoms most often overestimated by proxies were 24% (brooding), 23% (tension), 23% (nervousness), and 23% (fear). The symptom intensity most often overestimated by proxies (lack of energy) was (6%).

Agreement of symptoms at individual levels between patients, nurses, and proxies is provided in Table 4. Higher agreement existed concerning the frequency of symptoms compared to the intensity of symptoms. In addition, better ICCs were identified between patients and proxies compared to between patients and nurses. The agreement between patients and proxies was for the frequency of all symptoms moderate to excellent, except for the symptom of tension (ICC = 0.18). Fifteen symptoms showed poor to fair agreement between patients and nurses for frequency. Agreement on the intensity of symptoms was low for both dyads.

The 120 patients, nurses, and proxies each assessed 35 symptoms. The symptom of weight loss was not included in the analysis on factors associated with the over- and underestimation of symptoms because a DS could not be calculated for this dichotomous variable. This yielded a total of 4,200 patient-nurse and patient-proxy observations for symptom frequency. Fewer dyads (range = 1,560–1,800) were measured for symptom intensity because the latter could only be rated for prevalent symptoms.

The agreement between patients and nurses on symptom frequency was associated with gender, marital status, living status, presence of metastases, expected prognosis, and treatment with radiation therapy (see Table 5). Nurses more often underestimated symptom frequency in female patients, patients living with both partner and other(s), and patients receiving radiation therapy. Overestimation of symptom frequency by nurses was more prevalent in male patients, divorced patients, patients living alone, and patients having metastases. The agreement between patients and nurses on symptom intensity was associated with gender, marital status, living status, cancer type, metastases, expected prognosis, and radiation therapy. Nurses more often underestimated symptom intensity in male patients, patients aged 75–79 years, patients living with both partner and/or other(s), patients with no metastases, patient with a life expectancy of years (compared to weeks and months), and patients receiving radiation therapy. Overestimation of symptom intensity by nurses was more prevalent in female patients, patients aged 70–74 years, and patients with breast cancer.

The agreement between patients and proxies on symptom frequency was associated with marital status, living status, cognitive status, cancer type, metastases,

expected prognosis, and chemotherapy. Proxies more often underestimated symptom frequency in patients living with both partner and other(s), patients with

impaired cognition, and patients with breast and hematologic cancers. Overestimation of symptom frequency by proxies was more prevalent in widowed patients,

Table 4. ICC of Patient-Nurse and Patient-Proxy Pairs of Symptoms

Symptom	Symptom Frequency				Symptom Intensity			
	Patient-Proxy		Patient-Nurse		Patient-Proxy		Patient-Nurse	
	ICC	95% CI	ICC	95% CI	ICC	95% CI	ICC	95% CI
Physical								
Lack of appetite	0.81**	[0.73, 0.86]	0.53**	[0.37, 0.65]	0.53**	[0.37, 0.67]	0.34**	[0.15, 0.51]
Fatigue	0.44**	[0.29, 0.57]	0.39**	[0.23, 0.53]	0.31**	[0.12, 0.48]	0.21*	[0.02, 0.38]
Pain	0.51**	[0.36, 0.63]	0.56**	[0.42, 0.67]	0.61**	[0.44, 0.74]	0.32*	[0.11, 0.51]
Lack of energy	0.43**	[0.28, 0.57]	0.46**	[0.3, 0.59]	0.32**	[0.13, 0.49]	0.33**	[0.14, 0.5]
Nausea	0.72**	[0.62, 0.8]	0.56**	[0.42, 0.67]	0.44*	[0.16, 0.65]	0.18	[-0.12, 0.45]
Sleeplessness	0.51**	[0.37, 0.63]	0.36**	[0.19, 0.5]	0.06	[-0.22, 0.33]	0.35*	[0.07, 0.58]
Vomiting	0.78**	[0.7, 0.84]	0.73**	[0.63, 0.8]	0.21	[-0.22, 0.57]	0.15	[-0.25, 0.52]
Dizziness	0.52**	[0.38, 0.64]	0.45	[0.3, 0.58]	0.25	[-0.13, 0.56]	0.61*	[0.09, 0.84]
Tension	0.18*	[0.01, 0.34]	0.13	[-0.42, 0.3]	0.31*	[-0.05, 0.61]	0.2	[-0.18, 0.53]
Constipation	0.5**	[0.35, 0.62]	0.34**	[0.18, 0.49]	0.56**	[0.27, 0.76]	0.2	[-0.19, 0.52]
Diarrhea	0.76**	[0.67, 0.82]	0.74**	[0.64, 0.81]	0.63**	[0.35, 0.8]	0.31	[-0.1, 0.63]
Heartburn or belching	0.48**	[0.33, 0.61]	0.25*	[0.07, 0.4]	0.38*	[-0.02, 0.68]	0.35	[-0.11, 0.68]
Tingling hands or feet	0.43**	[0.28, 0.57]	0.12	[-0.35, 0.28]	0.56*	[-0.003, 0.85]	0.63	[-0.2, 0.97]
Sore mouth or pain when swallowing	0.64**	[0.52, 0.74]	0.52**	[0.37, 0.64]	0.63**	[0.32, 0.82]	0.05	[-0.26, 0.41]
Shortness of breath	0.67**	[0.55, 0.76]	0.68**	[0.57, 0.76]	0.34*	[0.09, 0.56]	0.23*	[-0.03, 0.47]
Dry mouth	0.43**	[0.27, 0.57]	0.13*	[-0.3, 0.29]	0.45**	[0.26, 0.61]	0.28*	[0.03, 0.5]
Cough	0.65**	[0.53, 0.74]	0.64**	[0.52, 0.74]	0.61**	[0.38, 0.77]	0.19	[-0.07, 0.45]
Itching	0.49**	[0.35, 0.62]	0.18*	[0, 0.35]	0.62*	[0.02, 0.9]	0.62*	[0.02, 0.9]
Change in food taste	0.67**	[0.56, 0.76]	0.11	[-0.05, 0.26]	0.6**	[0.41, 0.74]	0.19	[-0.17, 0.51]
Airway mucus	0.61**	[0.48, 0.71]	0.47**	[0.32, 0.6]	0.27*	[-0.02, 0.52]	0.34*	[0.04, 0.58]
Urinary incontinence	0.47**	[0.32, 0.6]	0.55**	[0.41, 0.67]	-0.02	[-0.65, 0.56]	0.13	[-0.29, 0.59]
Fecal incontinence	0.67**	[0.56, 0.76]	0.69**	[0.59, 0.78]	—	[-0.38, 62]	0.1	[-0.51, 0.7]
Weight loss ^a	0.66**	[0.52, 0.8]	0.82**	[0.7, 0.93]	—	—	—	—
Psychological								
Brooding	0.5**	[0.33, 0.63]	0.37**	[0.21, 0.52]	0.25*	[0.02, 0.45]	0.15	[-0.09, 0.37]
Depressed mood	0.45**	[0.28, 0.6]	0.41**	[0.25, 0.55]	0.12**	[-0.12, 0.36]	0.36*	[0.11, 0.56]
Nervousness	0.5**	[0.34, 0.62]	0.16*	[-0.11, 0.33]	0.45**	[0.22, 0.64]	0.33*	[0.03, 0.58]
Fear	0.51**	[0.35, 0.64]	0.34**	[0.18, 0.49]	0.53**	[0.27, 0.72]	0.37*	[0.06, 0.61]
Difficulties concentrating	0.55**	[0.41, 0.66]	0.27*	[0.1, 0.43]	0.27*	[-0.01, 0.51]	0.21	[-0.13, 0.5]
Anger	0.51**	[0.36, 0.63]	0.41**	[0.25, 0.55]	0.06	[-0.18, 0.33]	-0.07	[-0.37, 0.31]
Loneliness	0.69**	[0.58, 0.77]	0.47**	[0.32, 0.6]	-0.17	[-0.47, 0.16]	0.18	[-0.16, 0.5]
Confusion	0.6**	[0.48, 0.71]	0.5**	[0.35, 0.62]	0.18	[-0.31, 0.59]	-0.14	[-0.48, 0.33]
Functional								
Difficulties with self-care	0.78**	[0.7, 0.84]	0.76**	[0.67, 0.83]	0.49**	[0.31, 0.63]	0.31**	[0.12, 0.49]
Difficulties with moving	0.73**	[0.63, 0.8]	0.71**	[0.61, 0.79]	0.56**	[0.38, 0.69]	0.36**	[0.15, 0.54]
Social								
Satisfied with social life	0.44**	[0.29, 0.58]	0.29**	[0.12, 0.45]	0.55**	[0.41, 0.67]	0.55**	[0.4, 0.67]
Feeling supported	0.66**	[0.54, 0.75]	0.48**	[0.28, 0.62]	0.57**	[0.43, 0.68]	0.54**	[0.38, 0.66]
Existential								
Experience life as meaningful	0.53**	[0.39, 0.65]	0.35**	[0.19, 0.5]	0.46**	[0.3, 0.59]	0.32**	[0.14, 0.47]

*p < 0.05; **p < 0.01; ***p < 0.001

^a The item weight loss was a dichotomous variable of yes or no. The Cohen's kappa statistic was used instead of the ICC.

CI—confidence interval; ICC—intraclass correlation

patients living alone and with others, patients with normal cognitive function, patients with urogenital and lung cancer, patients with no metastases, and patients treated with chemotherapy. The agreement between patients and proxies on symptom intensity was associated with gender, age, marital status, cognitive status, metastases, expected prognosis, radiation therapy, and chemotherapy. Proxies more often underestimated symptom intensity in male patients, patients aged 65–69 years, unmarried patients, patients with no metastases, patients with a life expectancy of years, and patients receiving radiation therapy. Overestimation of symptom intensity by proxies was more prevalent in female patients, patients aged 85–89 years, patients with impaired cognition, and patients not receiving chemotherapy.

Discussion

This study investigated the agreement between patients, nurses, and proxies with regard to symptom assessment. The results of this study indicate that nurses and patient proxies tend to underestimate physical and social symptoms and overestimate psychological, functional, and existential symptoms. However, agreement was for the majority (greater than 60%) of the symptoms not statistically significant ($p > 0.05$), which indicates that the observed differences might arise from chance only. The agreement of the frequency of symptoms between patients and proxies was better than the agreement between patients and nurses. Overall, agreement was better for less-subjective symptoms and symptoms that are less humiliating for patients to talk about (Brorsson, Lindblad, & Rastam, 1998; Dewar, Gregg, White, & Lander, 2009). Agreement between the intensity assessment of symptoms was, for most (greater than 50%) of the symptoms, rated as poor to fair between patient and nurse and patient and proxy.

Most previous studies were conducted in a population and setting different from hospitalized older palliative patients with cancer, except for Pautex et al. (2003). The findings of the current study confirm the results of Pautex et al. (2003). However, the current study included a larger number of patients and assessed symptoms in more domains.

The findings are somewhat in contrast with a large multicenter study of adult patients with cancer (Laugsand et al., 2010). Laugsand et al. (2010) indicated that healthcare providers underestimate symptoms in about 10% of the patients, regardless of the type of symptom. However, the adult patients with cancer included in a study by Laugsand et al. (2010) differs somewhat from the older palliative patients with cancer included in the current study because the latter is more

vulnerable to comorbidities, cognitive problems, and dependency. The current study measured a significant association between cognitive status and the agreement of symptom frequency and intensity between patients and proxies, indicating underestimation by proxies. This association was not significant between patients and nurses, but the absolute values suggest an underestimation by nurses. These findings are in contrast with the findings of Laugsand et al. (2010), who reported less agreement in patients with a normal cognitive status. Less agreement seems to be present in patients of younger age. However, no significant association was measured for frequency, in contrast to intensity.

Differences in scores could be the result of patient bias. In the current study, patient report was seen as the gold standard. However, one could question the true representation of the symptoms as reported by patients. Literature suggests that patients, particularly older adult patients, sometimes minimize their symptoms for a variety of reasons, such as not wanting to be a burden to others (McPherson, Wilson, Chyurlia, & Leclerc, 2010; McPherson, Wilson, & Murray, 2007), seeing symptoms as part of aging (Kaye et al., 2010), and denying symptoms as coping mechanism (Arraras, Wright, Jusue, Tejedor, & Calvo, 2002; Hauer et al., 2009).

This study has some strengths that enhance the validity of the results. First, this study is the first, to the authors' knowledge, to measure the agreement between patients and nurses and patients and proxies regarding symptom frequency and intensity on five domains (physical, psychological, functional, social, and existential) in older palliative patients with cancer. Second, patients had to be hospitalized for at least a week to allow nurses to build a relationship with the patient and to get to know the patient. In addition, patients had to receive a visit from at least one person in the past week to enable a good estimation of the symptoms by the proxy.

This study also has some limitations. First, no demographic information was gathered for the nurses and proxies. The collection of this data would have allowed the authors to identify if certain variables at nurse and proxy level could have explained under- or overestimation of symptoms. Bahrami, Parker, and Blackman (2008) reported that the clinical experience of an oncology nurse was a significant predictor of agreement between patients and nurses. Higginson and Gao (2008) reported that higher caregiver burden was significantly associated with agreement on symptom assessment. Second, the study was a cross-sectional study, which does not allow for the identification of a causal relationship. Third, generalization of the results could be limited because the study was performed in two non-randomly selected general hospitals in Belgium.

Table 5. Association at Univariate Level of Difference Scores and Demographic and Clinical Factors

Characteristic	Symptom Frequency								Symptom Intensity							
	Underestimation		Good Agreement		Overestimation		χ^2	p	Underestimation		Good Agreement		Overestimation		χ^2	p
	n	%	n	%	n	%			n	%	n	%	n	%		
Patients Versus Nurses																
Gender							13.984	0.00***							9.81	0.01**
Male	370	14	2,103	77	256	9			94	9	967	90	17	2		
Female	219	15	1,161	79	90	6			33	6	541	91	19	3		
Age (years)							16.831	0.08							28.607	0.00***
65–69	126	16	603	75	76	9			30	9	293	89	5	2		
70–74	83	12	567	81	50	7			7	3	262	93	13	5		
75–79	119	14	654	78	67	8			29	10	245	88	4	1		
80–84	179	15	913	77	98	8			42	9	431	90	7	2		
85–89	45	12	309	80	31	8			10	6	162	93	3	2		
90 or older	–	–	32	91	3	9			–	–	17	100	–	–		
Marital status							30.781	0.00***							5.362 ^a	0.45
Married	378	14	2,095	78	221	8			70	7	947	91	21	2		
Widower	168	15	869	78	83	7			41	8	429	89	13	3		
Divorced	8	8	74	71	23	22 ^a			5	11	41	87	1	2		
Unmarried	35	13	226	81	19	7			11	11	91	88	1	1		
Living status							34.274	0.00***							18.416 ^a	0.01**
Alone	154	15	758	75	103	10			38	10	343	88	10	3		
With partner	376	14	2,072	78	211	8			66	7	927	91	21	2		
With partner/others	29	21	98	70	13	9			8	14	50	85	1	2		
With children	16	7	215	88	14	6			3	2	119	96	2	2		
With others	14	10	121	86	5	4			12	15	69	83	2	2		
Cognitive status							5.059	0.08							2.931	0.23
Less than 2	457	14	2,651	78	296	8			93	7	1,177	91	25	2		
2 or greater	132	16	613	76	60	8			34	9	331	88	11	3		
TRST							0.056	0.97							0.895	0.64
Less than 2	234	14	1,309	78	137	8			45	7	565	91	11	2		
2 or greater	355	14	1,955	78	209	8			82	8	943	90	25	2		
Cancer type							20.688	0.06							27.5 ^a	0.01**
Gastrointestinal	260	14	1,521	79	144	8			64	8	713	91	8	1		
Lung	101	14	560	76	74	10			17	6	251	92	4	2		
Breast	68	16	324	77	28	7			12	7	147	86	13	8		
Prostate	58	15	300	78	27	7			12	7	145	90	5	3		
Urogenital	50	16	225	72	39	12			10	9	100	88	4	4		

(Continued on the next page)

*p < 0.05; **p < 0.01; ***p < 0.001

^aFischer's exact test

TRST—Triage Risk Screening Tool (Flemish version)

Table 5. Association at Univariate Level of Difference Scores and Demographic and Clinical Factors (Continued)																
Characteristic	Symptom Frequency								Symptom Intensity							
	Underestimation		Good Agreement		Overestimation		χ^2	p	Underestimation		Good Agreement		Overestimation		χ^2	p
	n	%	n	%	n	%			n	%	n	%	n	%		
Patients Versus Nurses (Continued)																
Cancer type (Continued)							20.688	0.06							27.5 ^a	0.01**
Hematologic	32	13	190	78	23	9			9	10	84	88	2	2		
Other	20	11	144	82	11	6			3	4	68	96	–	–		
Metastases							6.331	0.04*							14.478	0.00***
Yes	112	15	578	75	80	10			92	7	1,276	91	33	2		
No	477	14	2,686	78	266	8			35	13	232	86	3	1		
Expected prognosis							0.822	0.66							15.618	0.00***
Months	436	14	2,396	78	247	8			83	6	1,182	91	33	3		
Years	153	14	868	78	99	9			44	12	326	87	3	1		
Radiation therapy							8.039	0.02*							14.816	0.00***
Yes	179	17	813	75	93	9			50	11	389	86	15	3		
No	410	13	2,451	79	253	8			77	6	1,119	92	21	1		
Chemotherapy							3.087	0.21							0.195	0.91
Yes	316	14	1,817	79	177	8			68	7	838	91	20	2		
No	273	15	1,447	77	169	9			59	8	670	90	16	2		
Patients Versus Proxies																
Gender							2.19	0.34							7.291	0.03*
Male	204	8	2,251	83	275	10			52	5	1,049	92	36	3		
Female	128	9	1,202	82	140	10			20	3	608	92	35	5		
Age (years)							14.7	0.14							27.418	0.00**
65–69	75	9	634	79	96	12			24	7	321	90	13	4		
70–74	50	7	583	82	67	10			12	4	276	92	13	4		
75–79	73	9	687	82	80	10			12	4	280	94	7	2		
80–84	89	8	990	83	111	9			20	4	493	93	17	3		
85–89	24	6	333	87	28	7			1	1	163	91	16	9		
90 or older	2	6	31	89	2	6			–	–	15	100	–	–		
Marital status							16.152	0.01*							14.079 ^a	0.02*
Married	229	9	2,207	82	259	10			47	4	1,024	92	41	4		
Widower	86	8	906	81	128	11			14	3	487	92	29	6		
Divorced	2	2	96	91	7	7			2	4	44	96	–	–		
Unmarried	15	5	244	87	21	8			9	8	102	91	1	1		

(Continued on the next page)

*p < 0.05; **p < 0.01; ***p < 0.001
^aFischer's exact test
TRST—Triage Risk Screening Tool (Flemish version)

Table 5. Association at Univariate Level of Difference Scores and Demographic and Clinical Factors (Continued)

Characteristic	Symptom Frequency								Symptom Intensity							
	Underestimation		Good Agreement		Overestimation		χ^2	p	Underestimation		Good Agreement		Overestimation		χ^2	p
	n	%	n	%	n	%			n	%	n	%	n	%		
Patients Versus Proxies (Continued)																
Living status							28.164	0.00***							13.362	0.08
Alone	77	8	826	81	112	11			16	4	402	93	16	4		
With partner	214	8	2,189	82	257	10			47	4	1,014	92	41	4		
With partner/others	21	15	102	73	17	12			1	2	61	97	1	2		
With children	7	3	224	91	14	6			3	2	118	94	4	3		
With others	13	9	112	80	15	11			5	7	62	82	9	12		
Cognitive status							18.437	0.00***							7.749	0.02*
Less than 2	251	7	2,833	83	311	9			55	4	1,320	93	47	3		
2 or greater	81	10	620	77	104	13			17	5	337	89	24	6		
TRST							0.48	0.79							1.243	0.54
Less than 2	127	8	1,385	82	168	10			32	5	630	91	28	4		
2 or greater	205	62	2,068	82	247	10			40	4	1,027	93	43	4		
Cancer type							50.342	0.00***							19.051	0.07
Gastrointestinal	121	6	1,635	85	169	9			41	5	806	92	30	3		
Lung	53	7	591	80	91	12			13	4	279	90	17	6		
Breast	52	12	330	79	38	9			6	3	165	94	5	3		
Prostate	30	8	328	85	27	7			2	1	164	95	6	4		
Urogenital	30	9	240	76	45	14			6	5	104	93	2	2		
Hematologic	29	12	184	75	32	13			3	4	70	95	9	11		
Other	17	10	145	83	13	7			1	1	69	96	2	3		
Metastases							25.053	0.00***							18.838	0.00***
Yes	262	8	2,864	84	304	9			48	3	1,416	93	59	4		
No	70	9	589	77	11	14			24	9	241	87	12	4		
Expected prognosis							12.18	0.00**							20.025	0.00***
Months	251	8	2,554	83	275	9			42	3	1,300	93	62	4		
Years	81	7	899	80	140	13			30	8	357	90	9	2		
Radiation therapy							0.216	0.9							7.118	0.03*
Yes	84	7	897	83	104	10			30	6	453	90	21	4		
No	248	8	2,556	82	311	10			42	3	1,204	93	50	4		
Chemotherapy							20.723	0.00***							7.754	0.02*
Yes	150	7	1,953	85	207	9			40	4	953	93	29	3		
No	182	9	1,500	79	208	11			32	4	704	91	42	5		

*p < 0.05; **p < 0.01; ***p < 0.001

^aFischer's exact test

TRST—Triage Risk Screening Tool (Flemish version)

Implications for Nursing and Research

The results of this study indicate that proxies are somewhat better than nurses in estimating the symptoms that patients experience. However, the findings raise some concerns when treatment options and decisions are based on the estimation of symptoms made by nurses and proxies. The general underestimation of physical and social symptoms and overestimation of psychological, functional, and existential symptoms could result in under- and overtreatment. Undertreatment could lead to needless discomfort and decreased quality of life. In palliative care, overtreatment in terms of receiving holistic attention could be judged as unharmed. However, overtreatment in terms of higher doses of medication could have side effects, and painful interventions are equivalent to undertreatment.

As a result of the differences in assessment between patients, nurses, and proxies, it is advised to combine patient-, nurse-, and proxy-reported symptom assessment in clinical practice and research. Treatment decisions should be based on this combined evaluation to optimize care. However, in clinical practice, symptoms often are assessed by one party only. Patients should be encouraged to report their true experience, and misconceptions should be addressed through education. Nurses and proxies should be taught to recognize and assess symptoms and to communicate about it with patients. The literature implies that patients do not always report their true experiences, but strong evidence is lacking to support that implication. More research is needed on the reasons for symptom disagreements between patients, nurses, and proxies. This can be achieved by research focusing on (a) reasons why patients do or do not report their symptoms, (b) how nurses and proxies recognize and assess symptoms, and (c) the underlying thoughts of patients, nurses, and proxies regarding the report and assessment of symptoms. Those insights will

Knowledge Translation

Adequate symptom assessment is essential to allow attuned symptom management.

Patient-, nurse-, and proxy-reported symptom assessment should be combined in clinical practice and research.

Insight into the reasons why patients do or do not report their symptoms, and how nurses and proxies recognize and assess symptoms, will provide indications to improve symptom assessment and agreement.

provide indications to set up interventions to improve symptom assessment and symptom agreement.

Conclusion

The current study indicates that nurses and proxies tend to underestimate physical and social symptoms and overestimate psychological, functional, and existential symptoms. Agreement was associated with multiple demographic and clinical factors, such as gender and presence or absence of metastases. Treatment interventions should be based on a combined assessment of symptoms by the patient, a healthcare professional, and the patients' proxies. More insight is needed in reasons of disagreement on symptoms between patients, nurses, and proxies. These insights will provide indications to set up interventions to improve symptom assessment and symptom agreement.

Aurélien Van Lancker, MSc, RN, is a PhD student, Stephanie Cyfers, MSc, RN, and Elke Vanwynsberghe, MSc, RN, are students in Master Science of Nursing and Midwifery, and Sofie Verhaeghe, PhD, RN, Ann Van Hecke, PhD, RN, and Dimitri Beeckman, PhD, RN, are professors, all in the University Centre for Nursing and Midwifery in the Department of Public Health at Ghent University in Belgium. No financial relationships to disclose. Van Lancker can be reached at aurelie.vanlancker@ugent.be, with copy to editor at ONFEditor@ons.org. (Submitted August 2014. Accepted for publication October 6, 2014.)

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