Terminal Care in Older Patients in Hospital: Development of a Quality Indicator Set and its First Application in a Retrospective Comparison of Patients Treated in an Acute Geriatric Unit and a Palliative Care Unit of a Belgian University Hospital

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Abstract

Background: Care at the end-of-life of geriatric inpatients is of increasing importance. Nevertheless, limited research has been conducted on this subject so far.

Objectives: To compose a set of quality indicators (QIs) which measure the quality of terminal care for geriatric inpatients and to compare the quality of end-of-life care between the Acute Geriatric Unit (AGU) and the Palliative Care Unit (PCU).

Design: Retrospective case study.

Setting: Belgian university hospital.

Participants: Patients >75 years, who died an expected death between January 1st 2009 and December 31st 2010 at the AGU or the PCU.

Measurements: QIs collected through systematic literature search and the Delphi method.

Results: A set of 17 QIs was composed. At the AGU, 58 patients were included (QI score generally varying between 0 and 70%) and at the PCU 59 (QI score generally varying between 50 and 100%). The PCU scored significantly higher for 5 of the 17 QIs: pain screening, oral care and anxiety screening (all *p* < .001), prescription of rescue medication (p < .01), and pain treatment (*p* < .05). Both units scored low on delirium screening, spiritual care, and involvement of the general practitioner (GP) in care planning.

Conclusion: In-hospital care for the dying geriatric patient could be optimized further. Both departments should pay more attention to delirium screening, spiritual care, and the involvement of the GP in the care planning. At the AGU it is recommended that items regarding pain screening and treatment, oral care, and anxiety screening should routinely be included in the dying patients' records.

Keywords

End-of-life care, Elderly, Geriatric patient, Palliative care, Quality indicators, Quality of care

Introduction

During the last decades, there has been growing interest in high quality end-of-life care for the geriatric patient. This can be explained by the aging of the population, which leads to an increased number of frail, older patients who die in hospitals as a result of one or more chronic condition(s) [1].

The quality of end-of-life care for the geriatric patient is not optimal, characterized by inadequately treated symptoms and poor communication between health care professionals, patients and their families [2-4]. Geriatric care is too often only focused on optimizing the health and rehabilitation of the patient [5,6]. Consequently, palliative care is frequently provided too late or is not granted at all [7]. The quality of care (QoC) of older patients dying in hospitals can therefore be put into question.

However, little research regarding the quality of end-of-life care for the geriatric inpatient has been carried out. To date, research has focused mainly on patients with cancer (although the number of older people who die as a result of a non-malignant disease is higher) and non-acute settings such as nursing homes and home care [8,9].

This study had two main objectives: firstly, to compose a set of

Table 1: Quality Assessment of the 11 Included Articles by means of the Appraisal of Indicators through Research and Evaluation (AIRE) Instrument [21], Expressed as a Percentage, per Domain

	Article										
	Schenck et al. [18]	Walling et al. [20]	Wenger et al. [21]	Lorenz et al. [16]	Twaddle et al. [19]	Wenger & Rosenfeld [21]	Dy et al. [12]	Dy et al. [13]	Sato et al. [17]	Grunfeld et al. [15]	Earle et al. [14]
Domain 1 Purpose, relevance and organizational context	93.3	90.0	93.3	93.3	96.7	93.3	93.3	93.3	93.3	93.3	93.3
Domain 2 Stakeholder involvement	72.2	77.8	77.8	77.8	61.1	77.8	66.7	66.7	72.2	55.6	77.8
Domain 3 Scientific evidence	66.7	66.7	66.7	66.7	38.9	66.7	50.0	50.0	44.4	44.4	72.2
Domain 4 Additional evidence, formulation and usage	53.6	58.9	42.9	42.9	46.4	42.9	60,7	60,7	55.4	55.4	60.7

Quality Indicators (QIs) measuring the QoC for the dying geriatric inpatient and secondly, to explore and compare the quality of end-of-life care between the Acute Geriatric Unit (AGU) and the Palliative Care Unit (PCU).

Methods

The *first* part of the study included the composition of the set of QIs, based on a systematic literature search and followed by the validation using the Delphi method. For the systematic literature search, the databases PubMed, Web of Science and Cinahl were consulted using following search key terms: 'end-of-life', 'palliative', 'terminal', 'care', 'quality', 'indicator' and 'criteria'. Only articles published between 2001 and 2011, which focused on the end-of-life care of inpatients and which contained the description or development of QIs were included. Articles pertaining to patients in critical care services and paediatrics were excluded.

The methodological quality of the QIs was assessed using the AIRE (Appraisal of Indicators through Research and Evaluation) instrument. The AIRE instrument has been designed and validated in the Netherlands. It consists of 20 quality criteria divided into four quality domains: (1) Purpose, relevance, and organizational context, (2) Stakeholder involvement, (3) Scientific evidence, and (4) Additional evidence, formulation, and usage [10]. The instrument was applied by two researchers independently.

Four experts in geriatric and/or palliative care (three physicians and one nurse) participated in the Delphi process. They judged the QIs for their relevance with regard to the value of the QI for efficient judgement of the QoC at the patient's end-of-life through a visual analogue scale (0-10). The experts could add new QIs that were missing in the list according to them and that were essential to measure the QoC at the patient's end-of-life.

It was agreed that only QIs with the highest scores could be retained and that the main domains of palliative care (physical, psychological, spiritual, care planning, and family care) had to be represented.

The *second* part of the study consisted of the evaluation of the QoC (using the set of QIs) by conducting a retrospective case study based on records of patients deceased in a Belgian university hospital. Patients older than 75 years, who died an expected death at the AGU (40 beds) or at the PCU (8 beds) between January 1st 2009 and December 31st 2010 were included.

The methodology of Gearing was applied to maximize the objectivity of data collection by the two researchers. Gearing et al. (2006) have developed a systematic and scientifically based method to perform retrospective case studies. Following this method, nine steps were taken during the preparation and implementation of the data collection. This implies that a data collection instrument and specific guidelines were applied. By the application of clear protocols and guidelines, both researchers performed data collection and interpretation of the data in a similar way, which increased the inter-rater reliability [11].

The results for both departments were calculated separately per QI: ((number of patients for which the indicator is positive / the group of patients being evaluated) x 100).

The statistical analyses were carried out with the Statistical Package for the Social Sciences 19 program in which the Fisher's exact test, the Pearson chi-square test and the Mann-Whitney U-test were applied.

Results

The literature search resulted in 11 relevant articles [12-22], published between 2001 and 2011. The overall methodological quality of the QI sets, as assessed by the AIRE instrument, was similar and the domain scores varied within a limited range (Table 1). The total set of QIs was assessed instead of each QI separately, because the articles contained only general information about the development of the total set of QIs. In total, 83 QIs were collected.

After eliminating the doubles and the QIs that were not measurable through retrospective case study, 59 QIs were presented to the expert panel using the Delphi method. Since the experts assigned a high score to most of the QIs, a stringent cut-off score of eight was used. This resulted in a set of 17 QIs of which one was proposed by an expert ('if a patient is admitted to a hospital, then the chart should document that there has been phone contact with the general practitioner about the care planning'). All domains of palliative care were represented by the 17 QIs. Only two Delphi rounds were needed to achieve a consensus. All members of the expert panel agreed that the list of 17 QIs contained sufficiently relevant QIs and could be used in a retrospective case study to examine the QoC at the end-of-life of the geriatric inpatient.

In the retrospective case study 58 patients were included at the AGU and 59 at the PCU. Demographic and clinical characteristics are shown in table 2. The AGU and PCU were similar in terms of gender and hospitalization days, but were significantly different in terms of age and trajectory of dying [23]. At the AGU the average age was 86 years and at the PCU 82 years. The significant difference of age was considered of little importance, since the target population of the study consists of patients older than 75 years and both groups meet this criterion. In the AGU, 'organ failure' prevailed, in contrast to the PCU in which 'cancer' was the most common cause of death.

The scores of the AGU and the PCU for the applied QIs are

Table 2: Demographic and clinical characteristics of the study population

	Acute Geriatric Unit (n = 58)		Palliative Care Unit (n = 59)		
	n	%	n	%	p
Gender					.854
- Man	29	50.0	28	47.5	
- Woman	29	50.0	31	52.5	
Trajectory of dying					**<.001**
- Cancer	14	24.1	56	94.9	
- Organ failure	36	62.1	3	5.1	
- 'Frailty'	4	6.9	0	0.0	
- Others	4	6.9	0	0.0	
Age°	84.6	85.8 – 5.91	81.9	81.9 – 4.39	**.001**
Length of stay°	10.8	16.9 –15.39	13.4	18 – 14.40	.534
Number of days between DNR[1] status and decease°	8.0	15.5 – 17.77			

(Footnotes)

[1] Do Not Resuscitate

°(Median – Mean – Standard deviation instead of "n" and "%")
Significance level: $p < .05$

shown in table 3. The AGU scored high on a limited number of QIs, specifically on the QIs concerning dyspnoea, involvement of the patient's family in care planning and informing the family about the impending death of the patient. On the QIs concerning involvement of the patient's family in care planning and involvement of the GP, the AGU scored significantly higher than the PCU.

The PCU scored high on the QIs concerning pain, dyspnoea, oral care, anxiety, and informing the family about the impending death of the patient. The PCU scores were significantly higher than those of the AGU for five QIs, i.e. for pain screening, pain treatment, prescription of emergency medication, oral care, and anxiety screening.

Five QI scores were low in both departments, i.e., the QIs regarding delirium screening, spiritual care, discussion of the goals of care with the patient, involvement of the GP in the care planning, and communication between patient/family and health care professionals.

Discussion

In this study a set of 17 QIs was composed through literature review and the Delphi method.

This set was applied in a retrospective case study which revealed that the end-of-life care approach for the geriatric inpatient could be further optimized. Delirium screening, spiritual care, discussion of the goals of care with the patient, involvement of the GP in the care planning, and the communication between patients, family, and health care professionals were found to be shortcomings in both departments.

Terminal delirium is a distressing symptom, both for the patient and the family, and is very often undiagnosed [24-27]. This study affirms that underassessment of delirium is a core problem as none of the patient records contained information on delirium.

Also, more attention has to be paid to the spiritual needs of the patients. Palliative care literature supports patient's spirituality as a very important component of a good death [22,28,29].

A third focus of attention is communication. Communication with the patient, with the GP, and communication between the patient, his/her family and the health care professionals in hospital. Although GPs are key professionals in providing continuity of care at the end-of–life and are a good choice for third party intervention in making difficult end-of-life decisions [30], only one in five GPs of patients dying on the AGU were contacted. This was even less the case on the PCU. Other studies confirm that the GP is frequently not involved [31-33]. The AGU also scored significantly higher than the PCU on the QI concerning involvement of the family in care planning. This could be explained by the fact that such discussion took place before the admission at the PCU.

The PCU scored significantly higher with regard to pain screening, pain treatment, the prescription of rescue medication, oral care, and anxiety screening. These findings reflect the expectations of a service focused on palliative care compared to a service in which both curative and palliative care goals are to be reached. However, the higher scores of the PCU regarding pain and oral care could be partly explained by the different registration methods of both departments. These items are routinely included in the patient records at the PCU, while at the AGU; they have to be added manually in the record by the staffs, which are often neglected.

For the AGU it is recommended that palliative items concerning pain, oral care, and anxiety screening should routinely be added to the patient's record. Consequently, there seems to be an important need for a systematic approach concerning end-of-life care at the AGU. In order to achieve these goals, guidance such as the Gold Standards Framework and the Liverpool Care Pathway could be used [34,35]. Another possible strategy could be the involvement of multidisciplinary in-hospital palliative care teams [36].

This study has a number of strengths and limitations. Its main strength is the systematic approach and the application of the methodology of gearing [11] to maximize the objectivity of the data collection. In general, process indicators were used because they provide exhaustive information about the care process and they are the most appropriate type of QIs with regard to the assessment and improvement of quality [37].

However, there are also several limitations of the study. Firstly, the number of experts who participated in the Delphi process was limited. Secondly, multicentre research is preferable to investigate the transferability of the results. Furthermore, the study relies on the accurate recording of care providers, which involves the risk that the quality of the recording is limited. Although the researchers used a data collection instrument and although specific protocols and guidelines were applied in order to judge whether QIs were fulfilled, difficulties for interpreting information found in the charts (e.g. jargon, abbreviations) could still occur, which means that some information may have been missed. Also, a performance standard for the QIs is almost systematically missing in literature. Lastly, more QIs are probably needed to achieve a complete picture of care quality, but because of feasibility, preference was given to a limited set.

Currently, scientifically based QIs are scarce. Therefore, more research with regard to the development of QIs is necessary. Moreover, QIs focussing on the older population need to be developed, given their specific palliative needs [6,8].

Conclusion

This study revealed some shortcomings in the in-hospital end-of-life care for the geriatric patient, namely delirium screening, spiritual care, communication with patients/families, and the involvement of the GP in the care planning.

Table 3: Quality indicator scores of the acute geriatric unit and the palliative care unit

QI	Description	AGU[2] % (n)	PCU[3] % (n)	*p*
A. Physical domain				
Pain				
1	IF a patient is admitted to a hospital, THEN there should be screening for the presence or absence of pain within 48 hours of admission. This should be documented in the patient chart.	45.6 (26/57)	98.3 (58/59)	**<.001**
2	For patients who screened positive for pain, the percent who had a reduction or relief of pain within the 48 hours of admission (a pain score of 3 or less on a 10-point scale is considered equivalent to relief or reduction).	42.1 (8/19)	77.8 (28/36)	**.008**
3	IF a vulnerable elder (VE) with end-stage metastatic cancer is treated with opiates for pain, THEN the medical record should document a plan for management of worsening or emergent pain.	62.5 (5/8)	98.0 (49/50)	**.007**
Dyspnoea				
4	IF a patient has dyspnoea on admission, THEN s/he should be offered symptomatic management or treatment directed at an underlying cause within 24 hours.	92.9 (26/28)	86.7 (13/15)	.602
Gastrointestinal tract				
5	IF a patient is admitted to a hospital with affected gastrointestinal (GI) tract or abdomen, THEN the presence or absence of nausea or vomiting should be assessed within 24 hours.	60.0 (6/10)	84.2 (16/19)	.193
6	IF a VE has obstructive GI symptoms, THEN the medical record should document a plan for management of worsening or emergent nausea and vomiting.	100 (1/1)	100 (4/4)	-
7	IF a VE with persistent pain is treated with opioids, THEN one of the following should be prescribed or noted: (1) stool softener or laxative; (2) increased fibre, stool-softening foods; (3) documentation of the potential for constipation or why bowel treatment is not needed	55.6 (15/27)	66.0 (33/50)	.367
Other				
8	Percent of patients for whom the observation and if necessary the oral health care was documented.	60.3 (35/58)	98.3 (58/59)	**<.001**
9	Percent of patients for whom the presence or absence of delirium or agitation was documented.	0.0 (0/57)	0.0 (0/59)	-
B. Psychological domain				
10	IF a patient is admitted to a hospital, THEN the chart should document the presence or absence of anxiety.	29.8 (17/57)	83.1 (49/59)	**<.001**
11	For patients who screened positive for anxiety, the percent who received treatment within 24 hours of diagnosis.	94.4 (17/18)	75.8 (25/33)	.134
C. Spiritual domain				
12	IF a VE who was conscious during the last 3 days of life died an expected death, THEN the medical record should contain documentation about spirituality or how the patient was dealing with death or religious feelings.	43.9 (25/57)	54.5 (30/55)	.258
D. Domain 'information and care planning'				
13	IF a patient is admitted to a hospital, THEN the chart should document that the goals of care were discussed with the patient.	44.9 (22/49)	43.9 (25/57)	.915
14	IF a patient is admitted to a hospital, THEN the chart should document that there has been phone contact with theGP about the care planning.	19.0 (11/58)	1.7 (1/59)	**.002**
E. Domain 'family care'				
15	IF a patient is admitted to a hospital, THEN the chart should document that the goals of care were discussed with the family.	80.7 (46/57)	51.7 (30/58)	**.001**
16	IF a patient is admitted to a hospital, THEN the chart should have documentation of a meeting during the first week of hospital stay between patient/family and members of the healthcare team to discuss the patient's treatment preferences or the plans for discharge disposition.	35.1 (20/57)	22.4 (13/58)	.135
17	IF a patient is expected to die, THEN the chart should document that the family had been explained about the impending death of the patient.	91.4 (53/58)	96.6 (57/59)	.272

(Footnotes)

[2] Acute Geriatric Unit

[3] Palliative Care Unit

Significance level: *p*<.05

QI 1, QI 9 and QI 10 were not applicable for one patient at the AGU because this patient was unconscious within 48 hours of admission. QI 12 was not applicable for one patient at the AGU and for four patients at the PCU because they were unconscious during the last three days of life. QI 13 was not applicable for nine patients at the AGU and for two patients at the PCU because they were unconscious or refused to discuss the goals of care. QI 15 and QI 16were not applicable for one patient at the AGU and for one patient at the PCU because they didn't want their health status and goals of care to be discussed with their family.

Comparison between the AGU and the PCU gave new insights for improving quality of end-of-life care at the AGU, indicating that the AGU can improve its policy regarding pain screening and treatment, oral care, and anxiety screening.

Further development of QIs may be of importance to pinpoint shortcomings in the QoC and to indicate focuses of attention, which consequently might improve the quality of end-of-life care for geriatric patients.

Author Contributions

Annelies Cools and Delphine Vaneechoutte, as principal investigators, contributed equally and developed the study concept and design, and prepared the manuscript. Ruth Piers, Nele Van Den Noortgate, Mirko Petrovic, Karen Versluys and Martine De Laat supervised the study and reviewed and revised the manuscript.

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