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Developing a national quality register in end-of-life care: The Swedish experience

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Abstract

Background: The complexity of end-of-life care, represented by a large number of units caring for dying patients, different types of organizations and difficulties in identification and prognostication, signifies the importance of finding ways to measure the quality of end-of-life care.

Aim: To establish, test and manage a national quality register for end-of-life care.

Design: Two questionnaires were developed with an attempt to retrospectively identify important aspects of the care delivered during the last week in life. An internet-based IT platform was created, enabling the physician and/or nurse responsible for the care during the last week in life to register answers online.

Setting: Units caring for dying people, such as hospital wards, home care units, palliative in-patient care units and nursing facilities.

Results: The register received status as a National Quality Register in 2006. More than 30,000 deaths in nursing facilities, hospital wards, palliative in-patient units and private homes were registered during 2010, representing 34% of all deaths in Sweden and 58% of the cancer deaths.

Conclusions: We have shown that it is feasible to establish a national quality register in end-of-life care and collect data through a web-based system. Ongoing data analyses will show in what way this initiative can lead to improved quality of life for patients and their families. There is an ongoing process internationally to define relevant outcome measures for quality of care at the end-of-life in different care settings; the registry has a potentially important role in this development.

Keywords

Cancer, end-of-life care, palliative care, quality register

Introduction

Palliative care is about preventing and relieving suffering for patients and families facing the problems with life-threatening illness, thereby aiming to improve quality of life. Traditionally, palliative care has centred on patients with cancer, but increasing efforts during recent years have focused on providing palliative care to a broader range of patients with serious illnesses, in accordance with statements from the World Health Organization.[1] The latest report from the US shows that cancer diagnoses account for approximately 40% of all hospice admissions.[2] In contrast, the corresponding figure in many European countries is approximately 90%.[3] While cancer patients often experience a fairly predictable decline during their disease trajectory, patients with non-malignant diseases like congestive heart failure or chronic pulmonary disease can experience stable but impaired function suddenly interrupted

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by severe illness and rather sudden death. This less well-defined terminal phase, leading to an increased risk of late identification of terminally ill patients, represents a challenge to health care professionals providing care to patients with non-malignant diagnoses.[4] Limited access to palliative care services and high turnover rates of staff in facilities caring for patients with chronic severe illness, e.g. nursing homes, are other challenges in providing high quality care in end of life.

Faced with these challenges, it is important to develop ways of measuring the quality of end-of-life care that patients receive, regardless of where this care is given. A set of key domains define together the concept of quality of end-of-life care: physical comfort, spiritual and psychological well-being, shared decision making, communication, support to family members and access to care.[5–7] To examine these different dimensions, it has been suggested that mixed methods (e.g. both prospective and retrospective studies) and multiple data sources (e.g. administrative data, family satisfaction surveys and population-based surveys) have to be combined to achieve best possible information. This information could then be used on a national level to identify areas in need of improvement, effectiveness of existing programmes and demographic trends affecting future needs and priorities.[6–8]

Sweden has a population of approximately nine and a half million inhabitants. The life expectancy for women is 83 years, men 79 years; around 90,000 people die annually. The most common places of death are acute care hospitals (47%), residential care facilities (42%) and private homes (9%).[9] The health care system is a socialized, public system that is tax funded and mainly managed by 21 self-governing county councils and regions. The country is further divided into 290 municipalities, and these are responsible for care of the elderly in their homes or in resident care facilities. Palliative care is part of the health care system and was initially developed in the 1970s. Since the mid 1990s there has been a continuous expansion of palliative care units providing advanced home care, care in in-patient units (e.g. hospice) or consulting services.

Sweden has a long tradition of keeping national individual-based registers; the population register, today administered by the Swedish Tax Agency, has complete archives from the 18th century and forward. The personal identity number was introduced in 1947 and covers the total population. The number is used by health care in all medical records and provides secure identification of all individuals. Since the 1970s, there has been continuous development of nationwide registries to assess quality in health care. Today there are 71 different national quality registries in the health care sector. These registries contain individual-based data on problems or diagnoses, treatment interventions and outcomes. In addition to being used at the local level, they are used for general planning and management, providing unique opportunities to monitor and improve health care. Local authorities and regions (e.g. county councils) have the primary responsibilities for continuing operation and financing, but the registries are developed and managed by representatives of the professional groups that use them. While significant results have been achieved through the efforts of registries covering single disease entities in somatic care, there are important fields with a higher level of complexity that until recently has not been monitored through quality registries. End-of-life care represents such a field, where the complexity can be referred to, for example the large number of units caring for dying patients, different types of organizations providing this care, difficulties in identification of the dying phase as well as the difficulties in defining appropriate quality outcomes.

A government commission proposed in 2001 that palliative care should be improved in Sweden and available on equal terms for all people needing it.[10] A review by The National Board of Health and Welfare published in 2006 noted that there was a lack of knowledge about palliative care among health care professionals and an uneven distribution of resources. In addition, the need for monitoring quality of end-of-life care was highlighted.[11] In an attempt to improve monitoring, with the ultimate goal of improving quality of end-of-life care for all dying people in Sweden, an initiative to start a register was taken by the Swedish Association for Palliative Medicine in late 2004. In this article we describe the process of establishing a nationwide quality register in end-of-life care, the registration procedure, results from a pilot study and present coverage, together with the current development of the register.

Methods

A working group was formed in late 2004, with four members having long experience in palliative care and expert knowledge in different aspects of quality improvement. The initial efforts concentrated on specifying criteria for high quality end-of-life care. By adopting the 12 principles constituting a ‘good death’ that have been highlighted in guidelines from the British Geriatrics Society,[12] two different questionnaires were developed with the intent to retrospectively identify important aspects of the care delivered during the last week in life, on both the individual patient level and on the level of the care unit. In accordance with the aim of the register, the goal was set to ultimately achieve details about every death in Sweden, except for cases where a forensic post mortem examination was planned.

Questionnaires

The first questionnaire (Q1) consisted of 22 questions and concerned information provided to patient and family, decision-making capacity, symptom relief, prescribed drugs, preferred place of death and support to the family. The nurse and/or the physician responsible for the care during the last week in life should answer the questionnaire as soon as possible after the death of a patient. If the patient had been moved during the last week, the staff on the unit where the death occurred should complete the questionnaire. In response to feedback from users and ongoing development of the register, Q1 was revised in 2007 and five questions were added. A further revised version is scheduled for release in 2011. Table 1 shows the current version of the questionnaire.

The second questionnaire (Q2) consisted of 23 questions and concerned basic facts about the care unit, availability of staff, existing documented routines around end-of-life care and accessibility to injectable drugs for pain, nausea, anxiety and death rattles (Table 2). The manager of the unit should answer the questionnaire when the unit joined the register and then update the answers annually. In response to feedback from users, one question in Q2 was revised in 2007.

Approval from authorities

It was identified early in the process that support from both local, regional and national authorities was necessary to achieve sustainability in the register. Meetings with representatives from The Swedish Association of

Table 1. Questions in the current version of questionnaire Q1

Number	Question	Reply alternatives
1	Unit identification code	
2	Personal identity number of patient	
3	Patient name	
4	Zip code	
5	Gender	Man/woman
6	Date when the deceased was enrolled at the unit where the death occurred	
7	Date of death	
8	The place of death is best described as:	Resident care facility–permanent stay/resident care facility–short term stay/hospital ward (not palliative)/palliative in-patient care unit/private home with support from advanced home care/private home with support from basic home care/other
9	Disease that caused the death:	Cancer/heart disease/respiratory disease/dementia/stroke/other neurological diseases/infection/diabetes/other (to be specified)
10	Will there be a forensic post mortem examination?	Yes/no (if yes, no further completion is needed)
11	Based on the individual disease trajectory, the death was:	Expected/unexpected/do not know
12	At what latest date before death did a physician visit/examine the patient?	
13	Has the patient, during the final period in life, received articulated verbal information about the imminent death?	No/yes, by a physician/yes, by a nurse/yes by a nurse and physician/do not know
14	Has the family received verbal information about the imminent death of the patient?	No/yes, by a physician/yes, by a nurse/yes by a nurse and physician/do not know
15	How long before death did the patient lose his/her decision-making capacity?	Hours/days/weeks/months/years/do not know
16	Has an NRS-scale (0–10) been used during the last week in life to assess pain?	Yes/no/the patient cannot cooperate/do not know

(continued)

Table 1. Continued

Number	Question	Reply alternatives
17	Indicate the symptom(s) that was not completely relieved during the last week in life:	Shortness of breath/rattles/confusion/pain/nausea/anxiety/ no troublesome symptoms/other/do not know
18	Has a specialist outside the team been consulted concerning the patient's non-relieved symptoms?	No/yes (specify what kind of specialist)
19	Did the patient have pressure ulcers during the last week in life?	Grade 1/grade 2/grade 3/grade 4/no/do not know
20	Did the patient have injectable PRN drugs prescribed during the last 24 h in life?	Yes or no for each of pain/rattles/nausea/anxiety
21	Who was present at the time of death?	Staff/family/staff and family/no one
22	Did the patient die in his/her preferred place?	Yes/no/do not know
23	At how many other places apart from the place of death did the patient receive care during the last 2 weeks in life?	0/1/2/3/>3/do not know
24	Has bereavement support been offered to the family?	Yes/no/do not know
25	Are you satisfied with the end-of-life care that was delivered to the patient?	A scale from 1 to 5 representing not at all (1) to completely (5)
26	Date of completion:	
27	Name, e-mail address of registrant, occupation	Physician/nurse

Table 2. Questions in the current version of questionnaire Q2

Number	Question	Reply alternatives
1	Name of the unit	
2	Code name (provided from the register)	
3	City	
4	Principal	County council/municipality/private
5	Type of unit:	Hospital ward on university hospital/regional hospital/ community hospital, department:/primary care unit/ basic home care within municipality/resident care facility–permanent stay/resident care facility–short term stay/advanced home care/palliative in-patient care unit/palliative consulting team
6	Number of beds (specify number of single rooms)/ number of enrolled patients:	
7	Number of employees, proportion of employees that has been employed more than 2 years:	
8	Number of deceased patients on the unit during last 12 months:	
9	On average, how long does it take during day time to get an acute assessment of a dying patient from a:	0–2 h/<24 h/1–3 days/not available. For each of: Physician/nurse/chaplain/social worker/physiotherapist/occupational therapist
10	On average, how long does it take during night/weekend to get an acute assessment of a dying patient from a:	0–2 h/<24 h/1–3 days/not available. For each of: Physician/nurse
11	Can there be arrangements made for families to stay over night in the patient room?	Yes/no
Do you have written routines on the unit for:		
12	How physicians should document that the patient has been assessed as being in the dying phase?	Yes/no

(continued)

Table 2. Continued

Number	Question	Reply alternatives
13	Regular symptom assessment of dying patients concerning pain/nausea/anxiety?	Yes/no for each symptom
14	How the family should be informed about the imminent death of the patient?	Yes/no
15	Information about economic benefits for caregivers?	Yes/no
16	How staff should acknowledge special requests based on the patient's ethnic background?	Yes/no
17	How staff should acknowledge spiritual/religious needs?	Yes/no
18	Which PRN drugs that should be prescribed for dying patients?	Yes/no
19	During nighttime and weekends, do the unit have access to injectable drugs for pain/nausea/anxiety/rattles?	Yes/no for each symptom
20	Do you have written routines for necessary actions at the time of death?	Yes/no
21	Do you have written routines for how bereavement support should be offered to the family?	Yes/no
22	After the death of a patient, does the staff have time to reflect around the care given?	Yes/no
23	Date of completion, name, title, e-mail address	

Local Authorities and Regions (SALAR) and the National Board of Health and Welfare resulted in economical support, enabling a pilot study during 2005. Since 2006 the register has been fully functioning and has received annual financial support from the executive committee of the National Quality Registries. In 2010, the government allocated special funds to the register in order to improve care for multi-ill elderly all over the country.

Information technology issues

Simplicity, user friendliness and security are key issues when creating an information technology (IT) system that should handle data entries, retrieval and analyses of patient data. Collaboration was established early in the process with an IT management company that operated another national quality register in the country. Based on combined experiences, an internet-based IT platform was created consisting of two databases and a website.[13] The website contains general information about the register, links to the data entry interface where users enter patient data and links to automatically generated reports. Registered patient data is initially validated concerning the accuracy of the personal identity number of the deceased patient and the dates entered by the user. All data are stored in a primary database and subsequently transported to a secondary database. Standardized reports are immediately created from the secondary database and made accessible from the website, enabling transparent comparisons down to the level of single care units. However, the information based on personal ID numbers of individual patients is protected by rigorous standards regarding confidentiality and data handling. Stored data is matched weekly with the central population register and annually with the Cause of Death Register at the National Board of Health and Welfare for validation purposes.

Pilot study and recruitment of units

Members of the working group recruited units consisting of hospital wards, home care units, palliative inpatient care units and resident care facilities in order to conduct a pilot study. The aim was to test the feasibility of the registration procedure. Both questionnaires together with general information about the register were sent to participating units, and registration of deceased patients took part during three months in 2005. Data from the pilot study was analysed and compiled in a report that was distributed to all participants. The units were encouraged to continue reporting patients after the completion of the pilot study.

During 2005, a steering committee was formed with representatives from different professions and from different parts of the country. Contacting local authorities and key persons in different health care institutions, and participating in conferences and meetings around the country, were different ways of recruiting new units. An executive committee with a register manager and two coordinators was created within the steering committee in the beginning of 2006, facilitating the process of recruitment and daily work in the register. This was further enhanced by establishing a secretariat with permanent staff during 2010. The executive committee meets regularly; work within the steering committee is maintained through telephone conferences, bi-annual meetings and e-mail conversations.

Registration procedure

When a unit wants to join the register, the secretariat is contacted through the website and a unique identification code is created for the care unit. The manager at the unit is requested to answer Q2 before registration with Q1 can start. After the death of a patient, the physician and/or the nurse responsible for the care answer the questions in Q1 either on paper or at the website. Logging in to the registration pages on the website requires the unit identification code. Answers on paper are ultimately registered on the website by the local unit.

Feedback to units and access to data

Online reports provide immediate feedback to users. These reports present the results over time for single units (requires the unit to be logged in) and also a comparison with the total results of equivalent units in the country. The steering committee produces an annual report with analyses and comments that is presented on a yearly conference arranged by the register. The report can be downloaded from the register's website. Members of the executive committee and the steering committee also participate in local conferences and visit units to give feedback and information.

Local authorities, patients and the public can access online reports and view data over time from counties/regions and/or municipalities separated on different types of care units. All gathered data belong to the register, but external researchers can access data after formal request and approval from the steering committee.

Results

The pilot study conducted during May to July 2005 resulted in 283 registered deaths, representing 1.2% of all deaths in the country during that period. One hundred and twenty-two different units received an identity code and were able to participate with registrations.

During 2010, 30,894 (34% of all deaths) deaths were registered on 2888 different units. Table 3 shows the development of the register from 2006 to 2010.

Table 3. Development of different aspects of the quality register from 2006 to 2010

Parameter	2006	2007	2008	2009	2010
Number of registered deaths in the quality register (per cent of all deaths in the country)	4962 (5%)	9955 (11%)	15546 (17%)	21,441 (24%)	30,894 (34%)
Proportion of all cancer deaths reported to the quality register	16%	30%	39%	48%	58%
Number of units registering deaths in the quality register	319	583	957	1632	2888
Proportion of units that have answered questionnaire 2	44%	83%	100%	100%	100%
Number of county councils/regions that have reporting units	18/21	21/21	21/21	21/21	21/21
Number of municipalities that have reporting units	78/290	130/290	166/290	207/290	288/290
Proportion of registered deaths occurring in private homes	24%	18%	16%	15%	13%
Proportion of registered deaths occurring in residential care facilities	27%	29%	36%	43%	50%
Proportion of registered deaths occurring at palliative in-patient care units	35%	36%	28%	23%	16%
Proportion of registered deaths occurring at hospital wards	13%	16%	19%	18%	20%

The proportion of deaths reported from residential care facilities and hospital wards as part of the whole material is increasing over the years. During the first 2 years, palliative in-patient care units were the largest contributors of data. In 2008, the number of deaths registered at residential care facilities exceeded that of palliative in-patient care units.

The proportion of deaths reported to the register from different counties during 2010 varied between 20% and 60% of all deaths. The corresponding figures for the 290 municipalities were 0% and 100% respectively, with 146 municipalities reporting between 40% and 69% of all deaths. All counties and 288 municipalities have reporting units 5 years after the establishment of the register.

Fifty-eight per cent of all cancer deaths in the country were registered during 2010. Fifty-five per cent of all deaths are currently reported to the register within a week after the death date. The executive committee has received feedback from participating units on how local quality improvement projects have been launched as a result of register data. Examples of this concerns improved routines for pain assessment in palliative care teams, increased attention to the presence of pressure ulcers in patients on hospital wards, increased prescribing of essential drugs used as needed for symptom control and enhanced attention to patients' reflections around preferred place of death.

Discussion

When introducing the register in 2005, our aim was to present a user-friendly web-based register that would allow participating units, local authorities, patients and the public to have immediate online access to the results, thereby supporting development and quality improvement of end-of-life care. Further, the design should be simple enough to stimulate continuous reporting of deceased patients and facilitate further expansion of the register. The continuous growth of the register, with a gradual increase in the number of participating units and registered deaths, now exceeding one third of all deaths, together with increasing coverage among counties and municipalities, shows that the principles behind the working method have been feasible. It is possible to retrospectively assess important aspects of end-of-life care in a standardized way in different care settings and present the data online.

Parallel to establishing and developing the register, there has been continuing analyses of incoming data, recognized in the annual reports. Local quality improvement projects have been launched as a result of register data and the register hopes that mere use of the questionnaires will increase awareness among staff, ultimately leading to improved quality of end-of-life care. It is not until signs of this improved quality can be shown in the collected data that the register can be deemed successful. The proportion of registered deaths coming from residential care facilities and hospitals is increasing, and further expansion of the register must focus on these types of care units to better reproduce the actual demographics of deaths in Sweden in the registered data. To facilitate the growth of the register, a group of regional managers has been established across the country that will help the executive committee to spread information and recruit new units. Registration of cancer deaths in the quality register has recently been established as one of the national quality indicators for cancer care in Sweden.[14] This must be seen as an important general step to improve the quality of end-of-life care. Further, some of the specific indicators in the registry, such as the use of pain assessment and drugs used as needed during the last week of life and offering of bereavement support to family, is currently used by providers of and purchasers of palliative care. There is still no international or national Swedish consensus on outcome measures of palliative care. The registry may play an important role in this critical development.

The major concern about the working method in the register is the question of validity. How do we know that answers registered in the questionnaire really reflect the actual care given during the patient's last week in life? We chose a retrospective design with staff answering the questionnaire using data from medical records and personal knowledge of the patient, focusing on the last week of life. This is in accordance with recommendations in the literature.[15,16] An alternative way of monitoring quality of end-of-life care would have been to prospectively record data, if possible including patient ratings on topics such as symptom severity, and obtained information about the disease and prognosis. Considering the large number of units caring for dying patients, the different types of organizations providing this care with different levels of knowledge and skills, and the difficulties in identification and prognostication, the working group agreed early in the process to use a retrospective approach. To test the validity of data, the register has recently conducted two studies to compare the documentation in medical records with the answers in Q1, and data is in press. The studies include comparisons between existing medical records and newly developed computerized records containing prospective patient generated data. In extension, using computerized medical records with prospective data capture could be one way of integrating quality registries with patient records, avoiding duplicate entries in records and quality registries. The domains of quality measured in the registry include structure (Q2) as well as process and outcome (Q1) as measured by patient (symptoms) or staff. These domains were chosen on the basis of patient needs as expressed by British Geriatrics Society.[12]

Further expansion of data collection in the future could include proxy ratings obtained from families.

Some questions in Q1 necessitate subjective judgments by the registrant and the answers will depend on level of knowledge and skill as well as personal attitudes. While the data recorded must be used cautiously, having these questions in the form can hopefully stimulate local discussions around quality of end-of-life care.

There is today in Sweden an increasing use of integrated care pathways in palliative care, such as the Liverpool Care Pathway (LCP).[17] While these pathways provide standardization of end-of-life care, promoting best practice and raising awareness of the needs of dying patients and their families, there has so far been less focus on measurement of outcomes.[18] By comparing documentation from pathways with registered data in Q1, additional validation could be obtained. Ideally, this combination of prospective and retrospective data collection could help understand the complex field of end-of-life care and ultimately improve quality of life for patients and families.

There are initiatives outside Sweden, besides the integrated care pathways, aiming at improving end-of-life care at a national level. In Australia, the Palliative Care Outcomes Collaboration (PCOC) assists palliative care services in measuring the quality of symptom control and in developing a national benchmarking system.[19] Clinicians collect data at the time of clinical service provision, not solely confined to end-of-life. In contrast to the Swedish quality register, the Australian initiative is restricted to palliative care services. In the US, the Veterans Affairs (VA) health care system has initiated a programme to develop a nationwide system of measuring quality of care at the end of life.[20] Multiple data sources will be used in this programme.

In conclusion, we have shown that it is feasible to establish a national quality register in end-of-life care and collect data through a web-based system from a large number of units and in different care settings. Ongoing data analyses will show in what way this initiative can lead to improved quality of life for patients and their families. There is an ongoing process internationally to define relevant outcome measures for quality of care at the end-of-life in different care settings; the registry has a potentially important role in this development.[21,22]

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Conflict of interest

The authors declare there is no conflict of interest.

References

1. World Health Organization. *Palliative care: the solid facts*. Copenhagen, Denmark: WHO, 2004.
2. National Hospice and Palliative Care Organization. *NHPCO facts and figures: hospice care in America* NHCPO, September 2010, Alexandria, VA.
3. European Association for Palliative Care. *EAPC task force on the development of palliative care in Europe*. EAPC, 2005. Available from: http://www.eapc-taskforce-development.eu/country.php
4. Brandt HE, Deliens L, Ooms ME, van der Steen JT, van der Wal G and Ribbe MW. Symptoms, signs, problems, and diseases of terminally ill nursing home patients: a nationwide observational study in the Netherlands. *Arch Intern Med* 2005; 165: 314–320.
5. Ferrell B, Connor SR, Cordes A, et al. The national agenda for quality palliative care: the National Consensus Project and the National Quality Forum. *J Pain Symptom Manage* 2007; 33: 737–744.
6. Casarett DJ, Teno J and Higginson I. How should nations measure the quality of end-of-life care for older adults? Recommendations for an international minimum data set. *J Am Geriatr Soc* 2006; 54: 1765–1771.
7. Teno JM. Measuring end-of-life care outcomes retrospectively. *J Palliat Med* 2005; 8(Suppl 1): S42–S49.
8. Bainbridge D, Brazil K, Krueger P, Ploeg J and Taniguchi A. A proposed systems approach to the evaluation of integrated palliative care. *BMC Palliat Care* 2010; 9: 8.
9. Jakobsson E, Johnsson T, Persson LO and Gaston-Johansson F. End-of-life in a Swedish population: demographics, social conditions and characteristics of places of death. *Scand J Caring Sci* 2006; 20: 10–17.
10. Döden angår oss alla – värdig vård vid livets slut (SOU 2001:6). Stockholm: Statens offentliga utredningar, 2001.
11. Vård i livets slutskede – Socialstyrelsens bedömning av utvecklingen i landsting och kommuner. *SoS rapport 2006-103-8*. Stockholm: Socialstyrelsen, 2006.
12. British Geriatrics Society. *Palliative and End of Life Care for Older People*, Good Practice Guides 26, available at: www.bgs.org.uk 2006.
13. Svenska Palliativregistret. Available from: www.palliativ.se.

14. Nationella riktlinjer för bröst-, kolorektal- och prostatacancer. Beslutsstöd för prioriteringar. Stockholm: Socialstyrelsen, 2007. Contract no.: 2007-102-9.
15. Earle CC and Ayanian JZ. Looking back from death: the value of retrospective studies of end-of-life care. *J Clin Oncol* 2006; 24: 838–840.
16. Patrick DL, Engelberg RA and Curtis JR. Evaluating the quality of dying and death. *J Pain Symptom Manage* 2001; 22: 717–726.
17. Ellershaw J and Ward C. Care of the dying patient: the last hours or days of life. *BMJ* 2003; 326: 30–34.
18. Luhrs CA and Penrod JD. End-of-life care pathways. *Curr Opin Support Palliat Care* 2007; 1: 198–201.
19. Currow DC, Eagar K, Aoun S, Fildes D, Yates P and Kristjanson LJ. Is it feasible and desirable to collect voluntarily quality and outcome data nationally in palliative oncology care? *J Clin Oncol* 2008; 26: 3853–3859.
20. Finlay E, Shreve S and Casarett D. Nationwide veterans affairs quality measure for cancer: the family assessment of treatment at end of life. *J Clin Oncol* 2008; 26: 3838–3844.
21. Claessen SJ, Francke AL, Belarbi HE, Pasman HR, van der Putten MJ and Deliens L. A new set of quality indicators for palliative care: process and results of the development trajectory. *J Pain Symptom Manage* 2011; [Epub ahead of print].
22. Pasman HR, Brandt HE, Deliens L and Francke AL. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage* 2009; 38: 145–156.