

# Palliative care quality indicators in Italy. What do we evaluate?

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## Abstract

**Purpose** In recent years, the number of palliative service providers has increased significantly. This expansion necessitates an evaluation in order to provide the basis for quality improvement of the care. Policymakers, managers of palliative care programs, and others committed to the improvement of end-of-life care need methods and criteria to measure and evaluate the care delivered. As quality measurement is expensive and difficult to undertake, it is fundamental that quality measures evaluate the right things. Quality evaluation in Italy is supported by health authorities who have developed some indicators of palliative care. The aims of this study were to give an overview of these indicators.

**Methods** We analyzed all palliative care indicators developed by Italian national authorities from 2000 to the present. These indicators have been divided into three different levels of analysis (structure, process, and outcome). Subsequently, two reviewers have independently compared their degree of concordance with domains, and guidelines developed by the

NCP for palliative care and after careful discussion an expert panel has elaborated a final consensus document.

**Results** Most of the quality indicators analyzed deal with the structure and process of palliative care, however they miss outcomes and do not cover domains mainly concerned with spiritual, ethical, cultural, or existential aspects of care. **Conclusions** More attention should be paid to the development of outcome indicators of palliative care. The attempt to identify a group of indicators which cover every domain of palliative care represents a challenge for the future in terms of finding new cognitive models more oriented toward subjectivity.

**Keywords** Palliative care · End of life · Quality indicators · Quality of care

## Introduction

In the last decades, medicine advancements have gradually led to a profound change in the characteristics of dying. A long time ago, death was an unexpected event often caused by infections or fatal illnesses affecting the young and the elderly to the same extent. Today, death is more commonly a late-life event, often occurring as a result of slowly progressive diseases characterized by disability and long duration [1]. Palliative care was developed with the goal to protect the dying from preventable suffering and to offer a support system that may help patients live as actively as possible until death [2].

Recently, palliative care services have grown steadily both in Italy [3] and around the world [4, 5], often as a result of increasing interest in this topic by the legislators. Parallel to the growth and to the general public interest, it is becoming necessary to develop a system for monitoring the quality and accuracy of the new services [6]. Evaluation constitutes a

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fundamental tool for the continuing improvement of services, interventions, and outcomes. It also offers the possibility to compare subjective impressions to objective benchmarks [7].

In general, the interest in evaluation methodology in health care has been greatly benefited from the development of the concept of the culture “of quality,” as first introduced by Donabedian [8]. It later became the fundamental model upon which the quality of health care is evaluated. This is an evaluation method based on three different types of indicators: structure, process, and outcome [9], which respectively represent the places, modalities, and consequences of the offered care.

Going back to the origins of palliative care, when Cicely Saunders claimed people’s quality of life to be the real goal to reach, it means dealing with a wide and difficult topic where dynamic concepts overcome static concepts and where subjectivity prevails over objectivity, so that measurability is brought into question [10, 11]. “Dynamism” means giving new priorities, such as giving new meaning to life and death as well as finding out new dimensions (such as the spiritual or transcendental dimension) [12]. Trying to develop and use appropriate indicators in order to estimate concepts which tend to be dynamic, subjective, and difficult to quantify is today a difficult and complicated challenge.

The National Consensus Project for Quality Palliative Care (NCP) [13] has developed an educational and evaluative model to promote the philosophy of palliative care with the aim of improving the quality of care. The model and relative guidelines have served as a foundation for the National Quality Forum Preferred Practices and have become a hallmark within the field guiding policy makers, providers, practitioners, and consumers in understanding the principles of quality palliative care. In 2007 the NCP Task Force became a formal subcommittee of the four national palliative care organizations “the Hospice and Palliative Care Coalition” [13]. The NCP model takes into consideration the eight dimensions delineated by the WHO’s definition of palliative care [2]. For each dimension, guidelines have been produced in order to promote the development of evaluation tools and operative models.

Each guideline explores different areas of professionalism and service, and provides specific criteria in order to determine whether or not specific goals are met. The aims of the National Consensus are development, experimentation, and implementation of palliative care quality indicators, amenable of continuing comparison and improvement [13].

In Italy, as a result of “The 1998–2001 National Health Program” as well as the development of a palliative care network, the national health authority committed itself to the identification of specific indicators of palliative care in order to monitor and evaluate the quality of service. This process implies the analysis of annual reports provided by the different Italian regions (administrative subdivisions of Italian territory),

and is aimed to create a dynamic process of monitoring and development that is capable of guiding the decision-making process of the different levels of political institutions.

Thirty-nine national indicators of palliative care quality have been identified [14, 15]. They will be monitored by the Italian Ministry of Health according to the criteria expressed by the current legislation [16].

In view of the importance on the policies of health at different institutional levels, this study is aimed to verify the robustness of these indicators as effective tools for monitoring and assessment of palliative care quality services. Specifically, this study is aimed at analyzing the types of indicators that have been chosen and their concordance with the eight dimensions, guidelines, and criteria established by the NCP, assuming the latter one as the golden standard of palliative care quality service [17].

## Methods

The indicators examined are extrapolated from the “2003 State-Regions agreement” [14] and the “2007 Ministerial Decree” [15], which constitute the Italian national source of legislation on palliative care [3] from 2000 to present. In order to better understand the multidimensional nature of quality, the indicators have been subdivided according to the most used model for quality measurement in Italy: the “Donabedian paradigm” [18]. The indicator subdivisions have been formulated in relationship to their typology and level of analysis as follows:

- Indicators of structure,
- Indicators of process, and
- Indicators of outcome.

Subsequently, two reviewers have independently compared the degree of concordance between Italian indicators and dimensions, guidelines and criteria developed by the NCP, assumed as the gold standard. The two concordance rates have been prepared by a third reviewer in order to be presented to the consensus conference [19] where the concordance rates were reviewed and disagreements were clarified. The consensus panel was made up of doctors and nurses with experience in quality evaluation and palliative care. After careful and thorough discussion on concordance rates, the panel elaborated a final consensus document at different levels of analysis.

The first analytical level focuses on the percentage of concordance of the Italian indicators in relationship to the criteria expressed within each dimension. The second analytical level focuses on the evaluation of the distribution of this concordance percentage within the specific guidelines related to the analyzed dimension. Table 1 shows the eight dimensions proposed by the NCP

**Table 1** The eight dimensions proposed by the NCP

Domains of quality palliative care
1. Structure and process of care
2. Physical aspects of care
3. Psychological and psychiatric aspects of care
4. Social aspects of care
5. Spiritual, religious, and existential aspects of care
6. Cultural aspects of care
7. Care of the imminently dying patients
8. Ethical and legal aspects of care

## Results

### Indicators typology (structure, process, outcome)

Among 39 analyzed indicators, there were 12 (30%) indicators of structure, 25 (64%) indicators of process, and 2 (5%) indicators of outcome. Table 2 shows in detail their distribution according to the three typologies. According to the panel's judgment, only five out of eight dimensions identified by the NCP are somehow addressed by the Italian palliative care indicators. Three dimensions are not addressed. Tables 3 and 4 highlight the degree of concordance for dimension and guideline.

The first dimension (structure and process of care) has been judged satisfied by 16.5 (33.7%) Italian indicators, with an uneven distribution among the guidelines ranging from 0% to 8.17%. The second (physical aspects of care) and third dimensions (psychological and psychiatric aspects of care) have been judged satisfied respectively by 3 (27.2%) and 6 (27.2%) Italian indicators. Their distribution is evenly distributed among the guidelines. The fourth dimension (social aspects of care) has been judged satisfied by two (33.3%) Italian indicators. No indicator satisfies the fifth and the sixth dimensions (spiritual, religious, and existential aspects of care, cultural aspects of care). The seventh dimension (care of the imminently dying patients) has been judged satisfied by one (10%) Italian indicator. Its degree of concordance is not evenly distributed among the guidelines. No Italian indicator satisfies the eighth dimension (ethical and legal aspects of care).

## Discussion

The indicators are variables with high informative content, they allow us to evaluate complex phenomena in a synthetic way and provide sufficient elements to guide the decisions. Particularly, structure and process indicators inform us of the quality of service while outcome indicators evaluate the effects of care on the patient's condition. The

analysis of the Italian palliative care indicators shows a higher attention toward the evaluation of care process appropriateness as compared to service outcomes.

Indicators of structure focus on the definition of service characteristics (indicators 6, 7, 8, 9) in relationship to the user population (indicators 1, 2, 3, 4, 5) and to the properties of the resources in use (indicators 10 and 11). Indicators of process analyze the volume of service provided to the potential population of the single patient (indicators 13 and 14, 18–19, 22–28, 32–36), their promptness (indicators 15 and 16, 20), appropriateness (indicators 17, 21, 30 and 31), and efficiency (indicators 29, 37).

Indicators of outcome are scanty. The only indicator of outcome taken into consideration is the location of death (indicators 38, 39). Methodological instruments for the identification of other types of outcome are not mentioned. Our analysis confirms the need, already described in international literature [5, 9, 11, 20, 21], to develop and implement outcome indicators.

In the most recent years, also the Joint Commission in the United States is in favor of developing indexes of outcome instead of indexes of structure and process, as preferred methods to monitor service efficiency [7]. Consequently, resources are increasingly shifted toward services providing a tangible level of effectiveness. We believe that more effort should be made in order to restore the correct equilibrium among the three different types of indicators (structure, process and outcome) for a more complete and effective monitoring of services [22].

Elements that may account for outcome indicators deficiencies are linked to patients who often are not able to complete long and complex questionnaires, so the only source of judgment is often proxies (e.g., family caregivers) or a member of the palliative care team. But the discrepancy between data reported by the patient and those of the medical or nursing staff is all too well known [5, 7].

Other difficulties could be related to the need to quantify, in the form of numbers, rates, percentages, and proportions (e.g., number of patients treated, number of daily encounters, type of disease, mortality or morbidity rates) [7, 23], the quality of service offered. Often authors use indicators from a medical chart review, but these measurements represented the direct action made by clinicians and does not incorporate the patient-reported perception [24].

Over the past decade, the ENABLE (Educate, Nurture, Advise, Before Life Ends) project has been affronting the challenges to establish relevant quality indicators to measure outcomes that are valuable to patients, family, and administrators. This project is trying to overcome the three major difficulties in palliative care evaluation: (1) the person whose perspective should be analyzed, (2) the

**Table 2** Distribution of the eight dimensions in detail according to the three typologies

## Structure

1. Number of hospice beds
2. Number of hospices meeting decree PCM 20/1/2000 and regional requirements/total number of hospices
3. Number of palliative care units or dedicated health care services offered to the resident population
4. Percentage of USL (territorial administrative subdivision of the Italian Ministry of Health) with at least one palliative care unit or dedicated health care service within the USL territory
5. Number of hospice beds/potential population
6. Utilization of multidimensional protocols of evaluation
7. Percentage of networks with Help-Line 12/24 h
8. Percentage of networks with 24 h availability of palliative care
9. Systematic use of satisfaction questionnaires
10. Number of employees that have attended training course/number of employees in the network
11. Percentage of employees with specific training on care
12. Availability of programs of communication directed to the citizen

## Process

13. Number of patients who died of cancer that received home and/or hospice palliative care/number of patients who died of cancer
14. Days per year of home palliative care offered to patients who died of cancer
15. Number of patients who were on a waiting list for less than 3 days between referral and enrollment in home care network programs/number of patients in home care network and with completed service
16. Number of patients who were on a waiting list for less than 3 days between referral and enrollment in hospice care network programs/number of patients admitted to the hospice and with completed service
17. Number of cancer patients in hospice with a length of stay of less or equal to 7 days/ number of cancer patients in hospice
18. Number of patients in the network/potential population
19. Number of patient in waiting list/patients assisted by the network
21. Percentage of enrolled patients with Karnofsky Performance Status  $\leq 50$
22. Number of hours of home palliative care assistance provided by physicians (working for the network)/potential population
23. Number of hours of hospice palliative care assistance provided by physicians (working for the network)/potential population
24. Number of hours of home palliative care assistance provided by nurses (working for the network)/potential population
25. Number of hours of hospice palliative care assistance provided by nurses (working for the network)/potential population
26. Number of hours of palliative care assistance provided by psychologists/potential population
27. Number of hours of palliative care assistance provided by social workers/potential population
28. Number of hours provided by other professionals in the network/potential population
29. "In hospice" bed utilization rate
30. Average length of hospice assistance
31. Average length of home specialized care
32. Average number of home visits by network nurses per patient
33. Average number of home visits by network palliative care physicians per patient
34. Intensity of care coefficient: (ratio between number of interventional care/total number of days in enrollment in palliative care unit or other dedicated team)
35. Number of home visits by primary care physician/patients assisted by the network
36. Number of patients in home care/total number of patients assisted by the network
37. Percentage of days of hospital acute stay/total days of provided assistance

## Outcome

38. Percentage of deceased patients in the network who died at home
39. Percentage of deceased patients in the network who died in hospice

person who will do the assessments, and (3) the tools that are valid, reliable, and sensitive to change to be able to gather the data from seriously ill patients [25].

With reference to Italian dimensions of palliative care, major deficiencies are noted in regard to cultural, ethical,

spiritual, and existential aspects of care, as evidenced by international literature [19, 26–28]. These aspects of care, being those whose characteristics of subjectivity are not quite suited to a mere quantitative evaluation highlighted the measurement difficulties of patient and family perspec-

**Table 3** Concordance of the Italian indicators per examined dimension

Dimension	Criteria per dimension	Criteria concordance per dimension, no. (%)
1. Structure and processes of care	49 criteria	16.5 (33.7)
2. Physical aspects of care	11 criteria	3 (27.2)
3. Psychological and psychiatric aspects of care	22 criteria	6 (27.2)
4. Social aspects of care	6 criteria	2 (33.3)
5. Spiritual, religious, and existential aspects of care	9 criteria	0 (0)
6. Cultural aspects of care	6 criteria	0 (0)
7. Care of the imminently dying patients	10 criteria	1 (10)
8. Ethical and legal aspect of care	14 criteria	0 (0)

tives on one hand, and the need of steering the efforts on the other.

In the palliative field, evaluation methods should not be based on elements which bypass cultural, existential, and spiritual context of the people. In this way, we may not understand the meaning that patients give to their illness and the time left to live [29, 30]. The lack of knowledge about their expectations, wishes, and personal aims makes it more difficult to carry out interventions to improve their quality of life [31].

In fact, it should be necessary to define evaluation methods that do not respond comprehensively to the

positivist model which, in the name of the experimental method, has led to a reductionistic approach to reality, ultimately leading to an analytic approach to the person as well as to its dissociation in different and separated domains of analysis [32]. We need new cognitive models oriented towards subjectivity which, based on the WHO definition of palliative care [2], introduce the holistic conception of the human being as a biopsychosocial entity as a common denominator of evaluations. Promoting the correct equilibrium between different types of indicators (structure, process, outcome) and measure outcomes in line with the philosophy of palliative care will provide the

**Table 4** Distribution of criteria concordance per guidelines

Dimension	Guidelines	Criteria concordance distribution among the guidelines, no. (%)
1.	1.1. Inter- and multidisciplinary assessment of pt. and families	3 (6.12)
	1.2. Pt and families' decision-making process	1 (2.04)
	1.3. Interdisciplinary team	4 (8.17)
	1.4. Training and supervision of volunteers	0 (0)
	1.5. Team training	1 (2.04)
	1.6. Service quality evaluation	1.5 (3.07)
	1.7. Team's emotional impact evaluation	0 (0)
	1.8. Settings continuity	3 (6.12)
	1.9. Environmental response to pt. and families' needs	3 (6.12)
2.	2.1. Symptoms management	3 (27.2)
3.	3.1. Psychological status evaluation	3 (13.6)
	3.2. Programs for grieving processing	3 (13.6)
4.	4.1. Evaluation of social aspects of patients and families	2 (33.3)
5.	5.1. Spiritual and existential dimensional evaluation	0 (0)
6.	6.1. Cultural and community dimensional evaluation	0 (0)
7.	7.1. Evaluation of symptoms and signs, development of appropriate plans of care	1 (10)
	7.2. Postdeath assistance	0 (0)
	7.3. Interdisciplinary service after death	0 (0)
8.	8.1. Respect of patient and families' will	0 (0)
	8.2. Plan of care addresses ethical questions	0 (0)
	8.3. Plan of care does not violate palliative care legislation	0 (0)



evidence to ensure that palliative care will continue to prosper in the area of health care reform.

### Strengths and limitations

This study focused on the indicators of palliative care developed by Italian health care authorities to monitor and evaluate the quality of palliative care services. It represents the first adequate analysis of national indicators, regarding palliative care in Italy, which are able to orientate the multidimensional development of the evaluation. By using the Donabedian model, we have been able to analyze the indicators in detail according to their different levels of analysis divided into structure, processes, and outcomes.

However, this study also has its limitations. Firstly, this study has only taken national (Italian) indicators into consideration without taking into account the various regions (administrative subdivisions of Italian territory). Secondly, we have not evaluated the methodological characteristics of the identified quality indicators, for example the presence of clearly defined numerators, denominators, and/or the performance standards.

### Conclusions

This analysis of Italian indicators evidences the need to develop and to use indicators that take into consideration all three major levels of analysis (structure, process, and outcome). The analysis of NCP dimensions' level of satisfaction displays the need for a more complete evaluation of care which must include the related ethical, cultural spiritual, and existential aspects of care.

It is possible that these difficulties arise from the lack of an explicit conceptual model of reference, which would make the complexity of palliative care more comprehensible. An approach that unites pathophysiological as well as psychological, social, and cultural components of the sick person would be able to address end-of-life issues in a more rational fashion, thus focusing on the person as opposed to the symptom.

It is worthwhile to mention Donabedian's definition of models and indexes as "servers and not masters" [33]. They should be regarded as working tools that facilitate researchers' and professionals' study and work. They should never rigidly limit their independent thinking and practice. Public health authorities, researchers, and professionals are all expected to participate in the unraveling of new methods of analysis, thus improving the quality of palliative care on the basis of the best scientific evidence [34].

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### References

1. NIH (2004) NIH state-of-the-science conference statement on improving end-of-life care. *Consens State Sci Statements* 21(3):1–26
2. WHO (2010) Definition of palliative care <http://www.who.int/cancer/palliative/definition/en/>. Accessed 13 Aug 2010
3. Zucco F (2010) Hospice in Italia, seconda rilevazione ufficiale. Medica editoria e Diffusione scientifica, Milano
4. Sepulveda C, Marlin A, Yoshida T, Ullrich A (2002) Palliative care: the World Health Organization's global perspective. *J Pain Symptom Manage* 24:91–96
5. Granda-Cameron C, Viola SR, Lynch MP, Polomano RC (2008) Measuring patient oriented outcomes in palliative care: functionality and quality of life. *Clin J Oncol Nurs* 12:65–77
6. Ahmed N, Bestall JC, Ahmedzai SH et al (2004) Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliat Med* 18(6):525–542
7. Peruselli C, Marinari M, Brivio B et al (1997) Evaluating a home palliative care service: development of indicators for a continuous quality improvement program. *J Palliat Care* 13:34–42
8. Donabedian A (1988) The quality of care. How can it be assessed? *JAMA* 260:1743–1748
9. Seow H, Snyder CF, Mularski RA et al (2009) A framework for assessing quality indicators for cancer care at the end of life. *J Pain Symptom Manage* 38:903–912
10. Aspinall F, Addington-Hall J, Hughes R, Higginson IJ (2003) Using satisfaction to measure the quality of palliative care: a review of the literature. *J Adv Nurs* 42:324–339
11. Jocham HR, Dassen T, Widdershoven G, Halfens R (2006) Quality of life in palliative care cancer patients: a literature review. *J Clin Nurs* 15:1188–1195
12. Teno JM, Byock I, Field MJ (1999) Research agenda for developing measures to examine quality of care and quality of life of patients diagnosed with life-limiting illness. *J Pain Symptom Manage* 17:75–82
13. National Consensus Project for Quality Palliative Care (2009) Clinical practice guidelines for quality palliative care, second edition <http://www.nationalconsensusproject.org>. Accessed 11 Sept 2010
14. Presidenza del Consiglio dei Ministri—Conferenza Stato Regioni (2003). Indicatori per la verifica dei risultati ottenuti dalla rete di assistenza ai pazienti terminali e per la valutazione delle prestazioni erogate. *Repertorio Atti N.* 1665
15. Ministero della Salute (2007) DM N. 43. Definizione degli standard relativi all'assistenza ai malati terminali in trattamento palliative
16. Legge N. 18 (2010) Disposizioni per garantire l'accesso alle cure palliative e alla terapia del dolore
17. Ferrell B, Connor SR, Cordes A et al (2007) The national agenda for quality palliative care: the National Consensus Project and the National Quality Forum. *J Pain Symptom Manage* 33:737–744
18. Rodella S (2010) La qualità dell'assistenza sanitaria secondo Avedis Donabedian. Il pensiero scientifico editore, Roma
19. Sistema nazionale per le linee guida (2009) Come organizzare una conferenza di consenso <http://www.snlg-iss.it> Accessed 17 March 2011
20. Seow H, Snyder CF, Shugarman LR et al (2009) Developing quality indicators for cancer end-of-life care: proceedings from a national symposium. *Cancer* 115:3820–3829
21. Pastrana T, Radbruch L, Nauck F et al (2010) Outcome indicators in palliative care—how to assess quality and success. Focus group and nominal group technique in Germany. *Support Care Cancer* 18:859–868

22. Lorenz K (2008) Progress in measuring and improving palliative and end-of-life quality. *J Palliat Med* 11:682–684
23. Peruselli C, Paci E, Franceschi P, Legori T, Mannucci F (1997) Outcome evaluation in a home palliative care service. *J Pain Symptom Manage* 13:158–165
24. Sato K, Miyashita M, Morita T et al (2008) Reliability assessment and findings of a newly developed quality measurement instrument: quality indicators of end-of-life cancer care from medical chart review at a Japanese regional cancer center. *J Palliat Med* 11(5):729–737
25. Bakitas M, Bishop MF, Caron P, Stephen L (2007) Developing successful model of cancer palliative care services. *Semin Oncol Nurs* 26(4):266–285
26. Ostgathe C, Voltz R (2010) Quality indicators in end-of-life care. *Curr Opin Support Palliat Care* 4:170–173
27. Pasman HR, Brandt HE, Deliens L, Francke AL (2009) Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage* 38:145–156
28. Mularski RA, Dy SM, Shugarman LR et al (2007) A systematic review of measures of end-of-life care and its outcomes. *Health Serv Res* 42:1848–1870
29. Marzano M (2004) *Scene Finali*. Mulino editore, Milano
30. Holland J, Weiss T (2008) The new standard of quality cancer care: integrating the psychosocial aspects in routine cancer from diagnosis through survivorship. *Cancer J* 14:425–428
31. Institute of Medicine (US) Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting (2008) *Cancer care for the whole patient: meeting psychosocial health needs*. National Academies Press, Washington
32. Battaglia L, Carpanelli I, Tuveri G (2010) *Etica nella cura oncologica*. Carocci Faber, Roma
33. Donabedian A (1981) Using decision analysis to formulate process criteria for quality assessment. *Inq Summer* 18:102–119
34. Lohr KN, Yordy KD, Thier SO (1988) Current issues in quality of care. *Health Aff* 7:5–18