

# Palliative care quality measures: an exploratory study

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## ABSTRACT

**Objectives** The aim of this study was to investigate how palliative care service structures and processes correlate with their outputs and outcomes, measuring the latter respectively in terms of intensity of care and death at home.

**Methods** The Veneto Regional Health Authorities collected a set of 37 quality indicators for the year 2016, covering the following five dimensions: service integration, service structure, accessibility, professional processes and organisational processes. Their validity was assessed by a panel of 29 palliative care experts. A score was assigned to each indicator on the basis of its relevance. Non-parametric correlations between the care quality indicators and the measures of the palliative care outputs and outcomes were investigated, along with the presence of a monotonic trend in the performance of the local health units (LHU) grouped by 'low', 'medium' or 'high' scores and differences between these groups of LHUs.

**Results** The data showed that palliative care service structure and professional processes were the dimensions correlating significantly with the intensity of care coefficient. An increasingly significant statistical trend was found in both the intensity of care coefficient and the proportion of deaths at home for the three groups of LHUs in terms of the professional processes dimension.

**Conclusions** Despite its limitations, this study brought to light some statistically significant findings that are worth investigating in larger samples. To achieve improvements in the quality of palliative care, it is important for healthcare providers to know which variables most affect the output and especially the outcomes of the services offered.

## INTRODUCTION

The goal of palliative medicine is to prevent or relieve suffering and to support the best quality of life for patients and their families and also to improve the quality of a patient's remaining life

in terms of providing care and respecting their wishes and preferences.<sup>1</sup>

The increasing professionalisation of palliative care raises some questions concerning the quality of the services provided. It has become important to establish professional standards and develop guidance on best practices to orient the commissioning of services, the organisation of palliative care and the allocation of resources.<sup>2</sup> To ensure that palliative care is of the highest quality, various scientific commissions have envisaged systems for measuring and reporting its quality relating to these crucial areas.<sup>3,4</sup> A framework commonly used in health service research was developed by Avedis Donabedian, who discussed the service structures, processes and outcomes of care.<sup>5</sup> The quality of these various aspects is likely to be interdependent to some degree. A good-quality service structure and good-quality professional and organisational processes will probably give rise to good-quality outcomes. Patients' outcomes concern their personal characteristics and are affected by what healthcare providers do for them or on their behalf. For example, several studies have demonstrated that the perceived quality of palliative care is associated with the place of death. People with cancer dying at home reported perceiving a lower burden of symptoms, and a better end of life than those dying elsewhere.<sup>6</sup> The quality of the palliative care provided for people who die at home is rated more highly by their relatives too.<sup>7</sup> It has been demonstrated, moreover, that patients often opt to receive palliative care at home because it satisfies their wish to receive appropriate care while preserving a more 'normal' family life.<sup>8</sup> Death at home can, therefore, be considered a valid outcome in terms of the quality of palliative care, which indirectly expresses the feasibility of access to treatment.

Despite an abundance of literature on the assessment of palliative care quality based on the different Donabedian dimensions, there has been a paucity of research on the empirical validity of this framework.<sup>9</sup> This shortcoming particularly concerns the relative impact of palliative care service structures and processes on their outputs and on the outcomes for terminally-ill patients. A previous study on Donabedian's model applied to a large sample suggested that the quality of elderly care is determined primarily by factors pertaining to process, that is, to how caregivers behave towards their patients. The authors concluded that continuing improvement in the quality of elderly care should be encouraged, with a particular focus on process variables.<sup>9</sup>

The aim of the present study was to investigate how palliative care service structure and process factors correlate with their outputs and outcomes, measured in terms of intensity of care and death at home, respectively.

## METHODS

### Context

In Italy, regional authorities plan and organise health-care facilities and activities through their regional health departments in accordance with a national health plan designed to assure an equitable provision of comprehensive care throughout the country. The regional authorities coordinate and control local health units (LHU), each of which is a separate component of the national health system that plans and delivers healthcare services to its local community (based on a regional health plan). The history of palliative care in Italy is rather recent. It was only in 2010 that the importance of palliative care was recognised, with law n. 38/2010 establishing the right of citizens to have access to palliative care and pain treatment as part of the essential healthcare services and that each LHU should organise services to guarantee palliative care at home and in hospices. A LHU coordinating arrangement, the '*centrale operativa territoriale*' (COT) (continuity of care provider), provides a link between primary care and hospital services, thus strengthening the intermediate care sector.<sup>10</sup>

### Relevance and scoring of quality indicators

The Veneto Regional Authority collected data on a set of 37 palliative care quality indicators for the year 2016, concerning the following five dimensions: (1) service structure; (2) professional processes, defined as what healthcare providers do for patients; (3) organisational processes, meaning how the resources are developed and organised; (4) integration, a particular organisational process that takes action to ensure a genuine coordination among health personnel across settings and continuity of care and (5) accessibility, in terms of the resources available and the population served.

The survey was conducted in June 2016, by interviewing the heads of palliative care units at all the 21 LHUs in the Veneto Region.

The content validity of the indicators was assessed by a panel of 29 palliative care experts from the Veneto Region (chosen so as to obtain a balanced representation of the whole range of professional profiles), who were asked to say whether each indicator was a relevant measure of one of the above-mentioned dimensions, scoring it as: 'irrelevant', 'scarcely relevant' or 'highly relevant'. The distribution of the experts' opinions was then used to assign a weight to each indicator (see online supplementary table 1S).

The same importance was assigned to all five dimensions in the framework, each of which could be awarded a score of up to 10 (each dimension was associated with a set of single and composite indicators, weighted as explained above and rescaled to obtain a maximum of 10). As regards indicators for which the answer could be 'yes' or 'no', a score equating to the indicator's weight was awarded for 'yes' and assigned to each LHU and a score of zero for 'no'. For indicators with continuous responses (eg, 'Palliative care physician's average daily working hours'), a score from 0 up to the indicator's weight was awarded (eg, its full weight for 24 hours, half its weight for 12 hours).

### Statistical analyses

Kendall's tau non-parametric rank correlation was used to correlate the scores for the different dimensions and test the construct validity. The convergent validity was tested too, by estimating the correlations between each dimension and the LHU outputs and patient outcomes using Kendall's tau rank correlation.

For each LHU, the scores obtained for each dimension were labelled as 'low' (below the 25th percentile), 'medium' (between the 25th and 75th percentiles) or 'high' (above the 75th percentile). Kendall's tau test was used to check for the presence of a monotonic trend for the LHU outputs and patient outcomes among the three groups of LHUs, while the Mann-Whitney test was used to test the differences between the three groups.

Given the small number of LHUs (21) involved in the study, we opted to consider all correlations and differences between groups with p values below 0.10 as significant.

### Ethical considerations

The data analysis was performed on anonymised aggregate data with no chance of individuals being identifiable. The study complied with the Declaration of Helsinki and with Italian Law n. 196/2003 on the protection of personal data. The recent resolution n. 85/2012 of the Italian Guarantor for the Protection of Personal Data confirmed the allowability of processing personal data for medical, biomedical and epidemiological research and that data concerning

health status may be used in aggregate form in scientific studies. Permission to use data extracted from administrative databases was granted by the Veneto Regional Authority.

## RESULTS

Online supplementary table 2S shows each LHU's score for each dimension. Online supplementary table 3S shows the correlations between the palliative care quality dimensions. Correlations emerged between the service integration and accessibility dimensions (Kendall's  $\tau=0.387$ ,  $p=0.023$ ). Service structure also correlated with accessibility (Kendall's  $\tau=0.297$ ,  $p=0.069$ ), professional processes (Kendall's  $\tau=0.596$ ,  $p=0.001$ ) and organisational processes (Kendall's  $\tau=0.356$ ,  $p=0.037$ ). Finally, a significant correlation emerged between professional processes and organisational processes (Kendall's  $\tau=0.378$ ,  $p=0.040$ ). Online supplementary table 4S shows that service structure and professional processes correlated significantly (at 10%) with the intensity of care coefficient, while none of the dimensions correlated with the proportion of patients dying at home.

Figure 1 shows an increasingly significant statistical trend for the intensity of care coefficient among the three groups of LHUs for the professional processes dimensions and the total scores. In terms of the proportion of patients dying at home, figure 1 shows a significant monotonic trend at 10% for the three groups of LHUs as regards the professional processes dimension ( $p<0.10$ ).

## DISCUSSION

The data indicate that palliative care service structure and professional processes were the dimensions correlating significantly with the intensity of care coefficient. An increasingly significant statistical trend was found in both the intensity of care coefficient and the proportion of deaths at home for the three groups of LHUs in terms of the professional processes dimension.

This study is the first to have focused on performing a content validation of the indicators used to measure different quality dimensions of palliative care. This is the most rigorous approach for assessing the content validity of healthcare quality indicators, since it requires agreement or near-consensus among professionals from different disciplines and different practice environments.<sup>11</sup> The overall framework tested here revealed a high content validity.

We also tested the indicators for construct validity, which addresses the extent to which a purported quality measure correlates with other measures according to the conceptual framework underpinning quality in palliative care,<sup>11</sup> and a strong correlation emerged between the dimensions examined. The overall positive correlation among the different dimensions goes to show that all

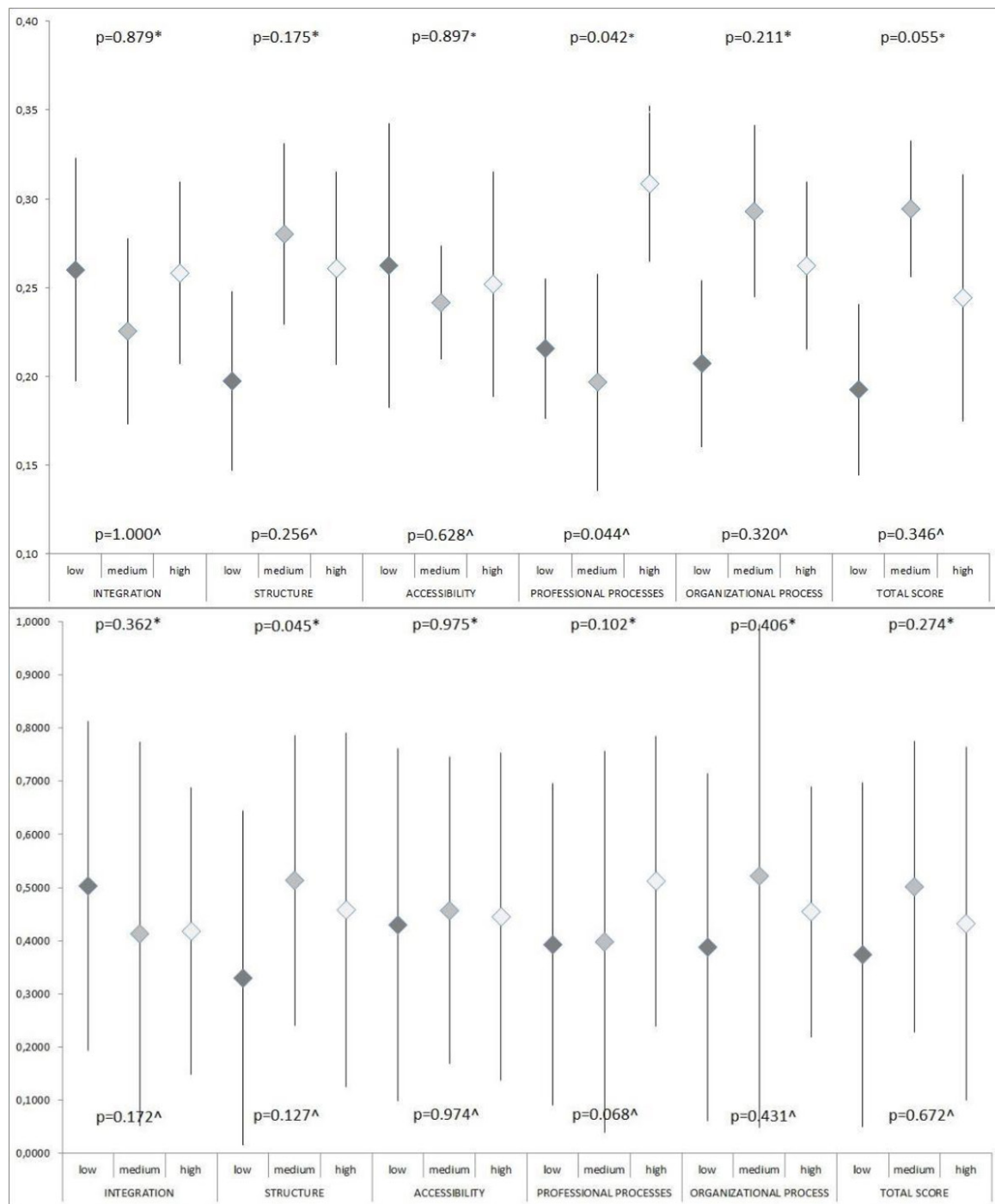
these dimensions are interrelated in their influence on quality.<sup>12</sup>

Finally, we tested for convergent validity. In particular, service structure was found significantly correlated with the intensity of care coefficient, which is hardly surprising, since a greater availability of staff and facilities (as measured by the service structure dimension) makes it easier to provide a more intensive care service. Professional processes also correlated significantly with the intensity of care coefficient. This finding is also easy to interpret: in order to deliver better elective professional care processes to patients and caregivers, health professionals need to provide their services more intensively.

The paucity of research investigating the associations between palliative care service structure and processes and their outputs or patient outcomes makes it difficult to compare our findings with other reports. A previous study correlating such quality dimensions (process and structure) with the patient satisfaction outcome in the setting of Sweden's elderly care services found that the patient satisfaction outcome was largely accounted for by process-related or interpersonal aspects of care—in terms of respect, information and influence—whereas structural variables were unrelated to patient satisfaction.<sup>9</sup> Our results seem to underscore instead that the proportion of people dying at home is an outcome related to the professional process. This seems to suggest that helping families to prepare for the scenarios that accompany death affects patients' trust, and their conviction that the healthcare services will be able to address their needs right until the end of their life. Evidence from systematic reviews suggests that palliative care at home meets with higher caregiver and patient satisfaction.<sup>13 14</sup> Such care should strive to preserve the patient's dignity, provide compassionate and effective individually tailored responses sensitive to a patient's needs, bolster hope, enhance meaning and lessen the suffering of patients nearing death.<sup>15</sup> In accordance with the vision of the late Dame Cicely Saunders, palliative care should 'do all [it] can, not only to help you die peacefully, but also to live until you die'.

Our results concerning the correlations between process indicators and outcomes seem to demonstrate that assessing the conduct of palliative care units (eg, the use of pain assessment scales and systems for monitoring care provision) could be a fundamental step towards improving healthcare outcomes.<sup>16</sup> Several studies have demonstrated that it is important to measure the quality of healthcare because it tells us how a health system is performing and leads to better care.<sup>17</sup>

The main limitations of the present study concern the small sample size: data were only collected on 21 LHUs, so the analysis has limited power. Some significant findings nonetheless emerged and warrant further investigation in larger samples in future studies. Other limitations concern the choice of specific indicators for assessing the different dimensions, although the relevance of each indicator was judged by a panel of experts.



**Figure 1** CIs for (A) the intensity of care coefficient and (B) proportion of decrease at home by LHU group ('low', 'medium', 'high'). The p values related to test for trend are marked as '^' and the p values related to the Mann-Whitney tests as '\*'.

In conclusion, optimising the quality of palliative care services demands their valid and systematic measurement. Quality indicators are important in giving health-care providers access to clear information on the quality of their services and thus continue to improve them.<sup>18</sup> In particular, there are often many factors contributing to the outcomes—in palliative care as in any other health-care service—including: organisational culture, leadership, teamwork,<sup>19</sup> resources and structural features and professional standards of care. Hence, the need

to understand which phenomena are more associated with outcomes in order to monitor them more closely, without wasting resources on monitoring factors with no influence on outcomes. To give an example, it may be preferable from an accountability perspective to use process indicators to assess performance because these measures could theoretically have several beneficial effects on outcomes (process indicators are often quicker to measure while an activity is ongoing, whereas capturing other outcome measures takes longer). But

the demonstrable association between process indicators and outcomes may be weak, or only indirect, in other healthcare services.<sup>10</sup> Our data indicate that measures of palliative care process indicators correlate strongly with outputs and also with outcomes for patients. The challenge of palliative care for healthcare policy-makers is to create the right conditions for quality process indicators to be effectively integrated in day-to-day practice. The findings of the present exploratory study need to be confirmed by larger studies on palliative care quality assessment, which should define and calculate validated indicators for measuring quality and analyse the interrelations among the various aspects of care.

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