Quality assessment of palliative home care in Italy

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Abstract

Rationale The complexity of end-of-life care, represented by a large number of units caring for dying patients, of different types of organizations motivates the importance of measure the quality of provided care. Despite the law 38/2010 promulgated to remove the barriers and provide affordable access to palliative care, measurement, and monitoring of processes of home care providers in Italy has not been attempted.

Aims and objectives Using data drawn by an institutional voluntary observatory established in Italy in 2013, collecting home palliative care units caring for people between January and December 2013, we assess the degree to which Italian home palliative care teams endorse a set of standards required by the 38/2010 law and best practices as emerged from the literature.

Methods The evaluation strategy is based on Rasch analysis, allowing to objectively measuring both performances of facilities and quality indicators’ difficulty on the same metric, using 14 quality indicators identified by the observatory’s steering committee.

Results Globally, 195 home care teams were registered in the observatory reporting globally 40 955 cured patients in 2013 representing 66% of the population of home palliative care units active in Italy in 2013.
Rasch analysis identifies 5 indicators (“interview” with caregivers, continuous training provided to medical and nursing staff, provision of specialized multidisciplinary interventions, psychological support to the patient and family, and drug supply at home) easy to endorse by health care providers and 3 problematic indicators (presence of a formally established Local Network of Palliative care in the area of reference, provision of the care for most problematic patient requiring high intensity of the care, and the percentage of cancer patient dying at Home).

Conclusions The lack of Local Network of Palliative care, required by law 38/2010, is, at the present, the main barrier to its application. However, the adopted methodology suggests that a clear roadmap for health facilities to afford future quality and normative challenges.

KEYWORDS
evaluation, home palliative care, Italian National Law 38/2010, quality challenges, quality standards, Rasch analysis

1 | INTRODUCTION

In many developed countries, national policies have been introduced to incentivize and implement the provision of palliative care for patients with complex needs and their families and by allowing them to choose their right place of care.

Palliative care incorporates both end-of-life care (incurable patients) and hospice care (for patients who are terminally ill and expected to have less than 6 months life expectancy), and it expands traditional disease model by increasing goal’s focus on enhancing quality of life, optimizing functions, fostering end-of-life care with decision making, and providing emotional and spiritual support to patients and their families.¹

Accordingly, palliative care may be delivered at the patient’s house or in inpatients’ dedicated structures such as hospices, hospitals, or nursing homes.

Evidence shows that by promoting the provision of home palliative care to people approaching the end-of-life, it leads to better outcomes, improving quality of life, reducing symptoms, or even
prolonging survivals also in widening patient’s choice of care and to the most cost-effective use of resources.\textsuperscript{2–4}

In Italy, palliative care is provided by the National Health Service and, although since the mid-2000s, there has been a continuous expansion of palliative care units providing advanced home care (normed by institutional guidelines on essential levels of assistance\textsuperscript{5} and normative standards\textsuperscript{6} for home care and care in inpatients facilities [hospice] or consulting services) and palliative care officially initiated since the National Law 38/2010 (NL 38/2010).\textsuperscript{7}

Such law, officially recognizing the right of every citizen to have access to pain therapy, includes advices and guidelines to governments on how to implement national palliative care programs and to remove barriers within the current healthcare system.

The Ministry of Health promoted, in relation to a certified possession of minimum standards, related to organizational and normative features of the structure (established in 2012 within the “Intesa Stato-Regioni,”\textsuperscript{16} an official agreement between Ministry of Health and Italian Regions) and the creation of regional and national networks of palliative care and pain therapy for both adults and children to assure the continuity of care from hospitals to home by creating multidisciplinary clinical pathways.

The law pioneered recommendations to integrate palliative care into the National Health Service and to provide affordable access to home palliative care units (HPUCs). HPUCs are health units that composed of integrated multiprofessional teams, which guarantee, in a defined area, medical, nursing, rehabilitation, psychosocial, and spiritual support, in favor of people with chronic and progressive diseases who approach the end-of-life, without inadequate/ineffective or inexistent evidence-based treatments able to stabilize their disease.\textsuperscript{8} An HPCU may belong to either public or private organizations (both for profit and not for profit) and could be headed by hospitals, local health authorities, or private institutions.

Furthermore, an HPCU may deliver primary palliative care, coordinated by general practitioners (GPs) or specialized palliative care with the intervention of multidisciplinary teams composed of physicians and nurses with specialist training, psychologists, and social workers and with a medical availability 24 hours a day, collaborating together to face the complexity, higher nearing the end-of-life. Basic interventions, delivered by GPs and nurses, provide a palliative approach through optimal symptoms management and adequate communication with the patient and family, whereas specialized care, mainly dedicated to patients with complex needs, clinical instability, and difficulty in symptom management, requires a high level of competence and inter-disciplinary work. The individual care plan guarantees the continuity of care by scheduling the interventions 7 days a week.

The NL 38/2010 includes also guidelines to provide adequate drug supply, to guarantee professional requirements to be respected by palliative care doctors and nurses, and to annually control the development and the quality of the activities of Local Networks Palliative Care in the different Italian Regions (each year, the Ministry of Health must present to the Parliament a report).

Although many national agencies/institutions\textsuperscript{9–14} or literature\textsuperscript{2, 15} has identified palliative care guidelines, standards, and quality domains, the monitoring of health services to patients with life-threatening disease is still difficult to implement in many countries; it causes a lack of official data, especially for outpatients and community settings.\textsuperscript{2, 15, 16}

Recent reports\textsuperscript{16–20} were focused on the efforts and experiences countries have made in improving affordable access to palliative care, monitoring advances, challenges, and gaps in policies and infrastructures. However, some exceptions apart,\textsuperscript{21} these experiences were focused mainly at country level, and rarely, there were examples of monitoring systems to publish information on health facilities and on the service assessment.

In Italy, although public engagement to measure and monitor quality of the care through the provision of high-quality palliative care has gained momentum after the promulgation of the NL 38/2010, practices followed by palliative care services (the real application of the law in health care facilities) are still unevenly monitored.\textsuperscript{16} Moreover, in Italy, the scientific literature on palliative care services is still limited.\textsuperscript{22, 23}

What is becoming imperative in the Italian context is the development of monitoring systems based on measurement of outcome/process indicators and the dissemination of timely and accurate data.\textsuperscript{24, 25}

To address these challenges, since 2012, the Italian Ministry of Health has promoted the comprehensive and national data collection program “Observatory of Best Practices in Palliative Care” (OBPPC), inspired by international standards and best practices in palliative care, that has been designed to provide quality, reliable, and timely data on HPUCs and to assess the objectives defined by the NL 38/2010, to assist Italian palliative care services to improve practice and define a common clinical language to streamline intercommunication between palliative care providers.

The aim of the present paper, related to the call 2014, is to assess the quality of the care provided by Italian HPUCs registered in OBPPC by means of a comparative analysis. It has been examined the adherence of HPUCs to standards required by the NL 38/2010 (“standard indicators”) and other quality dimensions (“quality challenges”), suggested by the literature, by using a reliable set of items (quality indicators).

In this regard, it has been used a robust statistical method that allowed rigorous measurements: (1) to examine whether quality indicators, specified in the study, fit the expectations to show if the below construct (quality of the provided care) could be quantified and obtained to measure the overall performance of HPUCs; (2) to assess how far Italian HPUCs are in agreement with the law standards and quality challenges in daily practice; and (3) to suggest a future quality roadmap.

\section{Methods}

The OBPPC program, under the supervision and coordinated by the technical-scientific Agency of the Italian Ministry of Health (Agenas), started in 2012 as scientific research project aimed to identify all HPUCs active since 2011 on the Italian territory. Specifically, Agenas and the Ministry of Health identified health structures using both administrative registers of local health authorities (for public facilities) and institutional registers of scientific societies (Italian Society of palliative care and Italian Society of General Medicine) and honored and representative not-for-profit associations (Italian Federation for Palliative care and Floriani Foundation) for private facilities.
Later, the OBPPC continued in 2014 mainly as data collection program using an institutional web portal.

In the OBPPC call 2014, an institutional scientific steering committee (composed of palliative care experts such as regional and national stakeholders, managers, academics, GPs, and members of the executive committees of the Italian and European Association of palliative care), under the supervision of Agenas, has proposed guidelines and methodologies.

Participation, exclusively addressed to HPCUs, was voluntary by registering the unit in the web portal. An institutional internet-based IT platform was created, enabling the institutional legal responsible of HPCUs (identified on Italian territory and directly contacted by Agenas) to register answers online in 3 forms: the first consists in an identity record to register relevant information of HPCUs; the second is a detailed questionnaire describing clinical, structure, and processes data (settings and services provided, staff, continuity of care, and outcomes assessment); and the third, instead, collects all relevant activity data (patients, admissions, diagnosis, nurses/physician visits, and place of death) in the fiscal year 2013.

All information, filled by institutional legal representatives of each HPCU, were collected at HPCU level (aggregate data) and were officially certified and transmitted to Agenas.

Moreover, the steering committee established a subset of core activity data (minimum dataset) for 2013 including assisted patients, cancer patients, and deceased cancer patients; number of palliative care physicians and nurses (and their 2013 workload); days of assistance and total effective days of home care (both cancer and deceased cancer patients); and total amount of home visits per palliative care physician and nurse.

Only those units able to provide the minimum dataset and gave consensus to analyze/disseminate their data were evaluated.

Because this is the first Italian attempt to implement a national monitoring of HPCUs, the approach has followed the principle of simplification and identification of few basic standard/quality domains: the steering committee identified 14 dichotomous indicators (Table 1), of which the first block (1-8) collects standard indicators drawn by the NL 38/2010 (or other institutional guidelines of the Ministry of Health), whereas the last 6 indicators (9-14) were suggested by experts of the steering committee as quality challenges.

Among quality challenges, the last 4 indicators (11-14), resting on the evidences that high volumes and more complicated patients are associated to better expertise and, that, dying at home is the most important outcome measured in home care, being quantitative in nature required explicit thresholds. Precisely, the specified thresholds ("Intensity," " Beds," and "NCancer" inspired, although not formally established, by Ministerial guidelines, "PoD_Home" by the literature qualify high quality care in the Italian context, under the outlook of the steering committee.

The database on evaluated units, which fulfilled the minimum dataset, resulted complete for 14 quality indicators.

2.1 Methodology

In the implementation of monitoring systems, other than to determine which performance measures are appropriate to the specific domain under investigation, policy makers and organizational managers must address the important task to decide what metrics should be used to measure the construct of interest.

The amount of quality indicators (items) each HPCU achieved does not coincide with the measurement of the true (latent) construct, such as the quality of the provided care: cumulative score were not measured themselves. Raw scores, typically prone to floor and ceiling effects, represent discontinuous observations, which can only indicate ordering at best, and differences in raw scores represent true differences in the construct only in case of unidimensionality (items represent a single construct) and proportionality (between raw scores and "quantity" of the construct).

Rasch models (RM) provided a powerful and effective approach to the construction of latent constructs with optimal properties, among all, specific objectivity, estimating observations parameters (abilities of HPCU) and item parameters (difficulties of quality indicators).

In the RM, it is expected that each HPCU possesses varying levels of ability to obtain quality indicators, that each quality indicator provides varying degrees of challenge/difficulty, both estimated in a logit scale, and that the probability of an HPCU to pass an indicator is governed only by the difference among ability and difficulty: HPCUs that "accumulate" achieved indicators demonstrated to be "better," because the more "difficult" indicators the HPCUs' obtain, the better they are.

The RM proposed that indicator’s difficulty is used to locate quality indicators along a continuum of HPCUs ability, and their ability to achieve a particular indicator is used to locate these performances along the same continuum of indicators difficulty. A quality indicator becomes "difficult" when the ability of the HPCUs (quality) is not enough to surpass/endorse it.

In practice, an item’s difficulty is estimated as that level of HPCU’s ability required to have 50% of probability to obtain that indicator. Thus, when an HPCU is in the same position of an indicator, the HPCU has exactly 50% of probability to achieve it.

Essentially, the RM prescribes what the response should be (to have specific objectivity), thus examining whether the data correspond to a specific below the basic structure, by essentially checking the item fit and dimensionality.

Specifically, the statistical fit of an item indicates which items have poor fit to the model and why the lack of fit has occurred: differences between observed and expected values were subjected to conventional chi-square statistics and significance testing. Other alternative item fit statistics (infit- outfit mean square (MSQ) and infit/outfit t-statistics) were proposed to assess item misfitting or predictable items. Overall, misfitting indicators were those with low P values (usually, < .05), infit MSQ ≥ 1.3, and infit t-statistics > 2, whereas predictable items (overfitting) had low outfit MSQ (< .05) and infit t-statistics <-2.30

Moreover, dimensionality may be evaluated using principal components analysis on the Rasch standardized residuals (PCAR): after the contribution of the measure (Rasch factor) to the data is removed, a PCAR is not expected to extract any principal components and the first eigenvalue (v1) greater than a proposed fixed cut-point (1.40) signifies a violation of unidimensionality. PCAR also helps to examine item local independence, signifying that item correlations should be small (under a suggested threshold, < .30), once the underlying Rasch factor has been accounted for.
# TABLE 1  Quality (standard and challenges) indicators adopted in the OBPPC

<table>
<thead>
<tr>
<th>Quality indicators</th>
<th>Question</th>
<th>Responses</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Network (38/2010 law)</td>
<td>Is the local network of palliative care formally established within the ASL (local health authority) of reference?</td>
<td>No/yes</td>
<td>Yes</td>
</tr>
<tr>
<td>2. PrimaryPC (38/2010 law)</td>
<td>Does the HPCU provide primary PC with at least specialist-certified PC nurses and general practitioners?</td>
<td>No/yes</td>
<td>Yes</td>
</tr>
<tr>
<td>3. SpecializedPC (38/2010 law)</td>
<td>Does the HPCU provide specialized PC at least with specialist-certified PC physicians and nurses?</td>
<td>No/yes</td>
<td>Yes</td>
</tr>
<tr>
<td>4. Continuity (38/2010 law)</td>
<td>Does the HPCU guarantee assistance 24 h a day, 7 d a week at least with specialist-certified palliative care physicians or nurses?</td>
<td>No/yes with planned care/yes with promptness availability or phone</td>
<td>All except from &quot;no&quot;</td>
</tr>
<tr>
<td>5. PsySupp (38/2010 law)</td>
<td>Does the HPCU guarantee psychological support to the patient and his or her family?</td>
<td>No/yes with volunteering/yes with dedicated psychologist within the team</td>
<td>All except from &quot;no&quot;</td>
</tr>
<tr>
<td>6. Training (38/2010 law)</td>
<td>Does the HPCU guarantee continuous educational and training activities on palliative care to its medical and nursing staff?</td>
<td>No/yes and organized by HPCU educational plan/yes, but outside the HPCU educational plan</td>
<td>All except from &quot;no&quot;</td>
</tr>
<tr>
<td>7. Drug supply (38/2010 law)</td>
<td>Does the HPCU guarantee drug supply (directly or indirectly, through standardized procedure with the ASL/hospital of reference)?</td>
<td>No/only opioids drugs/all drugs, excluded &quot;nonlife saving&quot;/all drugs, included &quot;nonlife saving&quot;</td>
<td>All drugs, excluded or included &quot;nonlife saving&quot;</td>
</tr>
<tr>
<td>8. Promptness (38/2010 law and 7)</td>
<td>Indicate the number of deceased cancer patients (assisted and deceased within 31/12/2013) according to the time passed between the signalling and start of the service</td>
<td>≤ 1 d/1-2 d/2-3 d/&gt;3 d/unknown</td>
<td>% of deceased cancer patients within 3 days ≥80%</td>
</tr>
<tr>
<td>9. NSupport (steering committee)</td>
<td>Is the HPCU supported by formalized activities of nonprofit organizations?</td>
<td>No/yes, within the local network of palliative care/yes, outside the local network of palliative care</td>
<td>All except from &quot;no&quot;</td>
</tr>
<tr>
<td>10. Interview (steering committee)</td>
<td>Does the HPCU provide an &quot;interview&quot; with caregivers before the taking charge of the patient at home? If yes, does it follow a standardized procedure?</td>
<td>No/yes, without a standardized procedure/yes, with a standardized procedure</td>
<td>All except from &quot;no&quot;</td>
</tr>
<tr>
<td>11. Intensity (steering committee and 1 study)</td>
<td>Average care intensity coefficient (days with at least one home visit/days of enrolment) for deceased cancer patients</td>
<td>Average care intensity coefficient for deceased cancer patients (CIA)</td>
<td>CIA &gt; 0.5</td>
</tr>
<tr>
<td>12. Beds (steering committee and 1 study)</td>
<td>Number of &quot;home bed equivalent&quot; (total amount of days of assistance in the year 2013, divided by the number of days in the year)</td>
<td>1-10/10-20/20-30/30-40/40-50/50-60/60-70/70-80/80-90/90-100/100-120/&gt;120 beds</td>
<td>Equivalent home beds ≥30</td>
</tr>
<tr>
<td>13. NCancer (Steering Committee and 1 study)</td>
<td>Number of cancer patients cared for within year 2013</td>
<td>No. of cancer patients cared for</td>
<td>Cancer patients cared for ≥200</td>
</tr>
<tr>
<td>14. PoD_Home (steering committee)</td>
<td>Number of deceased cancer patients according to the place of death (PoD)</td>
<td>Home/hospice/hospital/other (geriatric facilities, retirement home, and nursing home)/unknown</td>
<td>% of deceased cancer patients at home ≥75%</td>
</tr>
</tbody>
</table>

Abbreviations: ALS indicates the Italian acronym of local health authority; HPCU indicates home palliative care unit; OBPPC, Observatory of Best Practices in Palliative Care; PC, primary care.
Hence, the RM furnished various statistics used to evaluate the extent to which the data were conformed to the model; thus, it aided further decisions concerning the exclusion of certain items to improve the measurement properties of the questionnaire.

Rasch measures for item, and observations have their reliabilities (R), ranging between 0 and 1, and separation indices (S). High R for HPCU means that HPCUs were well separated according to their ability to obtain quality indicators. Separation index, ranging between 0 and infinity, describes the number of statistically different performance strata that the items/observations can identify in the sample. Low-item reliability/separation (R < 0.80, S < 2) implies that the items may not be not sensitive enough to distinguish between high and low performers.29,32,33

Rasch models have been used in a wide variety of applications in health care and specifically in the development of de novo health status instruments (see 1 study34 for a review).

As preliminary analysis, we control if activity indicators related to 14 quality indicators present in implausible/unusual values for a HPCU; to this end, we use leverage as a measure, quantifying how far away each activity indicator value of an observation is from those of the other observations, and typically high-leverage points are those with leverage value higher than the average leverage.

In case of high-leverage point for an activity indicator, the corresponding quality indicator value for an HPCU was left as a missing value.

After this formal check, a Rasch dichotomous model was applied to assess HPCUs within the specified 14 quality indicators. Items misfit, degree of reliability and separation, and unidimensionality were assessed.

The main result of the analysis, if data confirm Rasch expectations, was an overall continuous measure of HPCUs’ "quality," where HPCUs were calibrated along an ideal ruler where their ticks are difficulties of quality indicators.

<table>
<thead>
<tr>
<th>TABLE 2</th>
<th>Distribution of main activity data year 2013 (N = 97 HPCUs)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Min</td>
</tr>
<tr>
<td>Assisted patients</td>
<td>27.0</td>
</tr>
<tr>
<td>% of &lt;18 years old on assisted patients</td>
<td>0.0%</td>
</tr>
<tr>
<td>Cancer patients</td>
<td>13.0</td>
</tr>
<tr>
<td>% cancer patients on assisted patients</td>
<td>35.1%</td>
</tr>
<tr>
<td>Deceased cancer patients</td>
<td>10.0</td>
</tr>
<tr>
<td>% deceased cancer patients on assisted cancer patients</td>
<td>25.2%</td>
</tr>
<tr>
<td>Deceased cancer patients x palliative physician</td>
<td>17.0</td>
</tr>
<tr>
<td>Deceased cancer patients x palliative nurse</td>
<td>3.0</td>
</tr>
<tr>
<td>Length of care in days (deceased cancer patients)</td>
<td>25.0</td>
</tr>
<tr>
<td>Care intensity coefficient (deceased cancer patients)</td>
<td>0.0</td>
</tr>
<tr>
<td>Weekly home visits by PC physicians (x deceased cancer patient)</td>
<td>0.0</td>
</tr>
<tr>
<td>Weekly home by PC nurses (x deceased cancer patient)</td>
<td>0.1</td>
</tr>
</tbody>
</table>

Place of death (% on deceased cancer patients)

| Home | 19.9% | 75.9% | 72.8% | 100.0% |
| Hospice | 0.0% | 9.6%  | 13.5% | 51.5% |
| Hospital | 0.0% | 9.2%  | 12.7% | 54.6% |
| Nursing home | 0.0% | 0.0%  | 1.0%  | 17.2% |

Abbreviations: HPCU indicates home palliative care unit; PC, primary care.
In the sample, there was only 1 HPCU able to satisfy all quality domains, supporting the absence of ceiling effects. The first 3 columns of Table 3 illustrate the surpass rate (percent of HPCU surpasses each indicator) and the indicator’s difficulty.

Regarding the quality indicators (last 5 columns in Table 3), all of them fit both for significance ($P < .05$) and magnitude of misfit (infit MSQ < 1.3 and infit $t$-statistics < 2). Globally, over the entire set of indicators, the model fits the RM (Andersen Likelihood Ratio test = 10.613 and $P = .388$). Concerning the dimensionality based on PCAR, the first 2 eigenvalues ($v_1 = 1.17$ and $v_2 = 0.47$) exhibited unidimensionality and any local dependence was found.

Based on these results, the data showed a good fit to the RM, thus revealing the existence of a unidimensional construct that can be used to describe and benchmark the HPCUs’ quality of care.

Regarding institutional typology, HPCUs managed by private hospitals have better performance than public HPCUs and not-for-profit organizations, although (adjusted Bonferroni) multiple contrasts demonstrated only one significant performance’s difference between HPCU in private hospital vs HPCU in public local health authorities ($P = .002$). Furthermore, crudely dividing public and private HPCUs, the institutional typology (2-side $t$ test) was found not significant ($P = .321$).

The general key form of Table 3 reveals 5 quality indicators often achieved (“Interview” is the most achieved) and two mostly unachieved, such as case mix of patients in need of high intensity of care (“Intensity” is the less achieved) and the percentage of cancer patients dying at Home (“PoD_Home”).

Almost all of the HPCUs enrolled in the study guarantee an interview with the patient’s family before the start of the assistance, provide specialized care (at least minimum setting with primary care [PC] physicians and nurses), and offer continuous training to their professionals.

Concerning most difficult dimensions, in the 37.1% of the HPCUs, the local network of palliative care is not formally established, contrary to the provisions of the current legislation.

Only 58% of HPCU cared annually more than 200 cancer patients and even if the biggest part of the cancer patients die at home (average

### Table 3: Rasch statistics for the 14 quality indicators

<table>
<thead>
<tr>
<th>Quality Indicator</th>
<th>Response Rate</th>
<th>Difficulty</th>
<th>Std. Error</th>
<th>Chi-square $P$ value</th>
<th>Outfit MSQ</th>
<th>Infit MSQ</th>
<th>Outfit $t$</th>
<th>Infit $t$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview</td>
<td>99.0%</td>
<td>-3.15</td>
<td>0.940</td>
<td>1.00</td>
<td>0.29</td>
<td>0.83</td>
<td>-0.33</td>
<td>0.08</td>
</tr>
<tr>
<td>SpecializedPC</td>
<td>97.9%</td>
<td>-2.44</td>
<td>0.674</td>
<td>.300</td>
<td>1.06</td>
<td>0.90</td>
<td>0.37</td>
<td>0.04</td>
</tr>
<tr>
<td>Training</td>
<td>94.8%</td>
<td>-1.48</td>
<td>0.445</td>
<td>1.00</td>
<td>0.42</td>
<td>0.80</td>
<td>-1.14</td>
<td>-0.49</td>
</tr>
<tr>
<td>PsySupp</td>
<td>92.8%</td>
<td>-1.11</td>
<td>0.386</td>
<td>1.00</td>
<td>0.43</td>
<td>0.74</td>
<td>-1.45</td>
<td>-0.90</td>
</tr>
<tr>
<td>Drug</td>
<td>85.6%</td>
<td>-0.31</td>
<td>0.296</td>
<td>.961</td>
<td>0.75</td>
<td>0.93</td>
<td>-0.84</td>
<td>-0.31</td>
</tr>
<tr>
<td>Continuity</td>
<td>82.5%</td>
<td>-0.07</td>
<td>0.278</td>
<td>.979</td>
<td>0.72</td>
<td>0.84</td>
<td>-1.16</td>
<td>-0.99</td>
</tr>
<tr>
<td>Beds</td>
<td>77.3%</td>
<td>0.28</td>
<td>0.257</td>
<td>.739</td>
<td>0.89</td>
<td>1.04</td>
<td>-0.47</td>
<td>0.36</td>
</tr>
<tr>
<td>Promptness</td>
<td>71.1%</td>
<td>0.62</td>
<td>0.242</td>
<td>.858</td>
<td>0.84</td>
<td>0.93</td>
<td>-1.02</td>
<td>-0.57</td>
</tr>
<tr>
<td>NSupport</td>
<td>69.1%</td>
<td>0.73</td>
<td>0.238</td>
<td>.826</td>
<td>0.85</td>
<td>0.92</td>
<td>-0.97</td>
<td>-0.80</td>
</tr>
<tr>
<td>PrimaryPC</td>
<td>64.9%</td>
<td>0.93</td>
<td>0.233</td>
<td>.529</td>
<td>0.97</td>
<td>0.98</td>
<td>-0.17</td>
<td>-0.16</td>
</tr>
<tr>
<td>Network</td>
<td>62.9%</td>
<td>1.02</td>
<td>0.231</td>
<td>.668</td>
<td>1.21</td>
<td>1.16</td>
<td>1.65</td>
<td>1.75</td>
</tr>
<tr>
<td>NCancer</td>
<td>57.7%</td>
<td>1.25</td>
<td>0.227</td>
<td>.176</td>
<td>1.12</td>
<td>1.09</td>
<td>1.11</td>
<td>1.13</td>
</tr>
<tr>
<td>PoD_Home</td>
<td>46.4%</td>
<td>1.73</td>
<td>0.225</td>
<td>.509</td>
<td>0.98</td>
<td>1.01</td>
<td>-0.17</td>
<td>0.09</td>
</tr>
<tr>
<td>Intensity</td>
<td>40.2%</td>
<td>1.99</td>
<td>0.228</td>
<td>.127</td>
<td>1.16</td>
<td>1.10</td>
<td>1.37</td>
<td>1.23</td>
</tr>
</tbody>
</table>

Bold identifies standard indicators, required by 38/2010 law (N = 97).

$a$Items identifying overfitting.
domains, whereas HPCUs are separated by approximately 3.7 logits, suggesting a well-resolution of more than 5 logit; it would be twice difficult to achieve it rather than a quality indicator located at the same level of such HPCU.

If an HPCU at the top of the Figure 1 (Rasch ruler) is situated 1 logit lower than a particular quality indicator (that they would like to achieve), it would be twice difficult to achieve it rather than a quality indicator located at the same level of such HPCU.

Moreover, the Rasch Ruler helps to comprehend if quality indicators are well defined or targeted in respect of the analyzed HPCUs. The difficulties of achievement have a range of more than 5 logit; it suggests a well-defined hierarchical structure among the quality domains, whereas HPCUs are separated by approximately 3.7 logits, which underlines that HPCUs’ variability is not excellent but acceptable anyways. This is confirmed by reliability/separation indices, acceptable for HPCUs ($R = 0.8$ translating to 3 significant separated strata of ability) and slightly better for items ($R = 0.86$, 3.6 strata of difficulty).

The degree of overlapping among HPCU and indicators (measures) is satisfactory only in the right part of the Rasch ruler, meaning that, overall, quality indicators are easier than selected HPCUs, given the predominance of HPCU at the upper end of the ability dimension; however, such misalignment mainly depends on the different typology of specified items: coherently (apart “Interview”), the quality standards (required by the law) are the most achieved ones, whereas the less achieved indicators resulted the quality challenges which, as expected, better contribute to the identification of low/top performers.

4 | DISCUSSION

The performance analysis proposed in the current paper has revealed the main strengths and limits of the Italian HPCUs surveyed by the study.

The study registered a good representativeness of existing HPCUs on the Italian territory: the response rate (66%) is quite in line with other studies (64% for community care facilities in England in 2014–2015).

Concerning the description of activity data, the extension of PC services to frail noncancer patients (mean 7.1%) and pediatric patients (mean 1.2%) in complex and advanced chronic conditions, as confirmed internationally, it is still inadequate, as demonstrated by the described data.

The length of care observed (mean 62 days and median 49 days) for deceased cancer patients corresponds to the ones reported by the experiences of the other observers in palliative care, with an intermediate value between those recorded by the Australian Palliative Care Outcomes Collaboration (mean 38.3 days), a large population study on deceased palliative care users in Ontario (mean 47 days), and the National Council for Palliative Care for England (about 100 days) home-based PC project in a Medicare Shared Savings Program (median 56 days and mean 109 days).

Overall, 52% of palliative care days for deceased cancer patients were delivered in the last 2 months of life. Although few studies have assessed the intensity of palliative home care delivery over time of a patient’s survival, our result is quite consistent with one recent finding in Ontario (where 49% of care days for deceased patients delivered in last 2 months of life).

Moreover, among deceased cancer patients, 50% was seen by HPCU professionals nearly once every 2 days (median care intensity coefficient = 0.48) while receiving end-of-life homecare services, for a median of 1.5 physician visits per week and 2.7 nurse visits per week.

The intensity of care reported in this study appears to be consistent with Italian regulatory standards and higher than recent international experiences (in Ontario, less than 1 of 10 decedents received palliative care home visit from a physician, whereas in England only one-third of deceased patients are seen by palliative and hospice community teams).

Moreover, analyses have shown that the most important outcome in home care, the deceased at home, is mainly guaranteed to a large quota of patients cared for (mean 72.8%), value larger than those reported from recent meta-analyses (ranging from 24% to 69%, but lower than 81% reported for England). However, a nonnegligible quota deceased in hospital (mean 12.7%), an intermediate value between those reported in literature (ranging from 3.3% to 22.5%), from a recent meta-analysis using high-quality randomized controlled trials.

As far as quality analysis is concerned, the study registered a good compliance of HPCUs to normative aspects, but still, there is a lack of satisfying the quality challenges indicators, particularly in 4 quality areas.

The main difficult quality areas (development of the Palliative Care Networks, provision of adequate intensity of care and guarantee the home as place of death) belong to operational and organizational aspects linked with the inability to develop structures able to ensure integrated governance of pathways and continuity of care.

As internationally recognized, this basically depends on a difficult management of the unpredictable trajectory of the disease and to the difficulty in identifying a terminal stage, resulting in the principal barriers for appropriate and holistic palliative care settings.

To this end, strategic directions have to be addressed to foster the organizational plan and to create, develop, and strengthen its dedicated and specialized teams to guarantee and integrated management and an adequate response to the needs.
Concerning possible agreement of the presented quality results with other contexts, literature on organizational quality of the care and their determinants in PC is very heterogeneous, because indicators often cover one specific setting or target group, making difficult international comparisons.43,44

Notwithstanding, the empirical analysis and the Rasch ruler have large policy implications at organization level providing concrete answers to support the continued development of HPCU roadmap toward quality in the analyzed context. As much as an indicator is difficult to achieve, there is a lower probability of success and greater organizational efforts are needed to ensure a successful fulfillment of such indicator.

Concretely, if an HPCU is located at the quality level of indicator “Continuity” (thus having 50% of probability to obtain it), this unit has 27% of probability to successfully achieve the “Primary PC” indicator (located 1 logit higher) or if the indicator is located 2 logits higher (eg. “Intensity”), the chances of success decrease at 12% of probability, and so on.

Hence, the Rasch analysis can effectively identify HPCU’s stages of quality growth, by showing their own level of capability, thus suggesting the right sequence of further quality domains not already implemented to minimize the probability of future failure.

For example, concerning the “home death” indicator as well established,45 factors increasing its likelihood included (other than a worse functional status and social aspects such as not living alone and presence of an informal caregiver) intensity of nurse and physician home visits, multidisciplinary home palliative care teams, and timing of referral to palliative care.

Last 3 factors were retrieved and processed in the presented analysis, giving information on how improve the likelihood that the patient’s preferences will be met.

Specifically, from the indicators’ hierarchy, each HPCU should be motivated to promote strategies increasing the likelihood of home death, such as increasing home visits, and improving timeliness of charge and favor multidisciplinary teams involving also nonclinical professionals (psychological and spiritual support), using as support the information on the difficulty of such managerial strategies.

By understanding these relationships, HPCU can foster a more effective decision making and more effective allocation of resources to be able to ensure the quality improvement or specific objectives such as met patient’s preferences about place of death.

In conclusion, presented analyses are able to provide information to institutions and providers to implement improvements in public health policies, foster dialogue between professionals, and raise awareness of patients and their families on the quality of services and the ability of access to palliative care programs.

This analysis, limited to the examination of the units that voluntarily joined the portal, should be extended to all Italian HPCUs and, especially, to all type of care settings within the Network of Palliative Care, also correlating clinical conditions with care settings.

One main limitation of the present paper is the lack of outcome measures, only involving process measures on PC units. However, there is no complete consensus on agreed selection and use of outcome measures in palliative and end of life care daily practices.46

More evidence and interdisciplinary research studies on outcomes are essential to palliative care development and continuous improvement.42

CONFLICT OF INTEREST

The authors declare no conflict of interest.

REFERENCES


