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Volume 2 | Page 56-65 Copyright CC BY NC SA 4.0 **Original Article**

Assessing the Content Validity of the EORTC QLQ-C15-PAL in Advanced Cancer Patients and Health Care Providers from Chilean Palliative Care Services

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Abstract

Monitoring quality of life (QOL) is a central part of evaluating outcomes in palliative care. Yet, in Chile, there are no validated tools specifically designed to measure QOL and symptom burden in patients under palliative care. This study aimed to examine the relevance and clarity of the EORTC QLQ-C15-PAL among Chilean patients with advanced cancer and palliative care professionals, following the same methodological approach previously used to adapt the EORTC QLQ-C30. A descriptive, cross-sectional design was used across four palliative care centers between October and November 2017. Individual interviews were conducted with patients and health care professionals to explore their views on the importance, appropriateness, and usefulness of the 30 items in the QLQ-C30 for assessing palliative care outcomes. Participants were also encouraged to identify additional topics they believed were important to include. Forty-eight patients with advanced cancer and thirty-five health professionals participated. The domains viewed as most relevant were pain, physical functioning, fatigue, sleep disturbance, emotional functioning, nausea and vomiting, social interaction, appetite loss, constipation, and role functioning. Participants also emphasized aspects not covered in the tool, such as satisfaction with care, emotional and psychological support, and linguistic concerns in the dyspnea and constipation items. The findings support the content validity of the EORTC QLQ-C15-PAL for assessing quality of life and symptom experiences among advanced cancer patients in Chile. Therefore, its use is recommended in palliative care practice within this context. Following these results, the EORTC group refined the dyspnea and constipation items. Further research is warranted to incorporate a social dimension that captures a more complete view of patient well-being.

Keywords: Advanced cancer, Palliative care, EORTC QLQ-C15-PAL, Quality of life, Symptom burden, Patient-reported outcomes

Introduction

Palliative care focuses on enhancing patients' quality of life (QOL) by identifying and managing symptoms early in the disease process [1]. Therefore, QOL assessment is a key indicator of the effectiveness of palliative interventions. However, evaluating QOL in patients with advanced cancer can be challenging due to the number and intensity of symptoms they experience. To minimize the burden of data collection, patient-reported outcome (PRO) instruments used in palliative settings should be concise, address the most significant symptoms and concerns, and exclude items with limited clinical relevance.

The European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core 15 Palliative Care (QLQ-C15-PAL) is a shortened, 15-item adaptation of the original 30-item QLQ-C30—a well-established, validated, and widely translated tool for assessing QOL in cancer populations [2]. The QLQ-C15-

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PAL includes items from the QLQ-C30 that were identified as most pertinent for palliative care based on patient and clinician interviews [3] and psychometric analyses using item response theory [4, 5]. This process ensures comparability between results derived from the QLQ-C15-PAL and studies using the full QLQ-C30 [3]. The instrument has been successfully validated and translated in multiple countries [6–14], including several Spanish-speaking contexts [15, 16].

Although a Chilean-Spanish version of the QLQ-C30 and some of its modules have been validated [17, 18], research using these tools in oncology settings remains limited [19–22], and no validated instruments currently exist to assess symptoms and QOL among palliative care patients in Chile. When the QLQ-C15-PAL was initially developed, its content validity was tested among patients and professionals from six European countries [3]. However, given differences between European and Chilean health systems—particularly in the organization and availability of palliative care—re-examining its content validity in the Chilean context is necessary.

In Chile, most palliative care units operate within the public health system, with a smaller number of private facilities. Although Chile has the highest density of palliative care services in Latin America [23], the overall availability remains lower than in Western Europe. In 2013, the country had one service per 808,000 inhabitants, compared with ratios ranging from 1:48,000 in the United Kingdom to 1:122,000 in Denmark [24]. Consequently, the present study aimed to assess the content validity of the QLQ-C15-PAL among Chilean patients with advanced cancer and palliative care professionals, replicating the approach used in Europe to refine the original QLQ-C30 [3].

Materials and Methods

Participants

A cross-sectional study was carried out between October and November 2017 in four public hospitals in Santiago, Chile, all of which provide palliative care services. The recruitment goal was a minimum of 10 patients and 10 health care professionals (HCPs) per site.

Eligible patients were outpatients with advanced cancer who were aware of their diagnosis, receiving palliative care, and willing to provide informed consent. Exclusion criteria included being too unwell to participate or not being a native Spanish speaker. HCPs were eligible if their primary role was in palliative care. For patients, primary tumor site was recorded; for HCPs, professional background and years of experience were noted. Demographic data were collected for all participants.

Ouestionnaires

This study utilized the Chilean-Spanish version (version 3) of the EORTC QLQ-C30, obtained from the EORTC Quality of Life Department in Brussels. The QLQ-C30 includes 30 items grouped into five functional domains—physical, emotional, role, cognitive, and social functioning—along with three symptom scales (fatigue, pain, nausea/vomiting), one global health/QOL scale, and six single items addressing sleep disturbance, dyspnea, constipation, appetite loss, financial strain, and diarrhea. All items are rated on a 4-point Likert scale from 1 ("not at all") to 4 ("very much"), except for the global health/QOL scale, which ranges from 1 ("very poor") to 7 ("excellent") [25, 26].

The QLQ-C15-PAL was derived from the QLQ-C30 to meet the needs of palliative care populations while maintaining the core advantages of the original instrument. The reduction process eliminated items judged by patients and professionals to be less relevant for palliative contexts [3] and utilized item response theory to condense multi-item scales [4, 5]. Four domains—physical functioning, emotional functioning, nausea/vomiting, and fatigue—were shortened by retaining the most informative items. Due to limited perceived relevance, the global QOL scale was reduced from two to one item (removing overall health), and several domains—social, role, and cognitive functioning, along with the diarrhea and financial difficulty items—were excluded entirely.

Procedure for interviews

To examine the content validity of the QLQ-C15-PAL, semi-structured interviews were conducted following both the procedure originally applied in the development of the shortened QLQ-C30 for palliative care [3] and the EORTC Quality of Life Group's module development guidelines [27]. The primary goal of these interviews was to identify which aspects of the QLQ-C30 were most relevant for palliative care patients in Chile and to assess whether the QLQ-C15-PAL adequately captures these dimensions.

Each patient completed the Chilean-Spanish version of the QLQ-C30 during an individual session with a trained interviewer. Following completion, participants were asked to reflect on how well the questionnaire items represented the quality and outcomes of the palliative care they received. Specifically, they were invited to evaluate each item's relevance, appropriateness, relative importance, and breadth of coverage.

Relevance was rated on a four-point scale (1 = "not at all," 2 = "a little," 3 = "quite a bit," 4 = "very much"). When a participant assigned a score of 1 or 2, they were prompted to explain their reasoning (e.g., "Why do you find this question not or only slightly relevant?"). Appropriateness was assessed by identifying any items



participants perceived as inappropriate or distressing. To evaluate relative importance, each participant was asked to choose the ten items they considered most critical for evaluating palliative care outcomes. Finally, to assess coverage, participants were encouraged to mention additional issues they felt were important but not included in the questionnaire.

A similar procedure was followed with health care professionals (HCPs), except that their comments referred to how well the QLQ-C30 items represented palliative care outcomes in general, rather than for specific patients. HCPs were asked to assess each item's relevance, appropriateness, importance, and completeness using the same response and evaluation structure.

Statistical analysis

Descriptive statistics were used to summarize participant characteristics, with categorical data expressed as proportions and continuous variables reported as means, standard deviations, medians, and ranges. For each QLQ-C30 item, the mean relevance score was calculated by converting raw responses to a 0–100 scale, where 0 corresponded to "not at all" and 100 to "very much" [26].

The proportions of participants who rated an item as "inappropriate or upsetting" and those who included it among the ten most important items were determined. For multi-item scales, the percentage of participants selecting at least one item from each scale as among the ten most important was also computed. Items and scales were then ranked according to this measure of importance, termed the *importance percentage*, defined as the average of the percentage of patients and HCPs selecting each item [(% of patients + % of HCPs)/2]. Despite unequal sample sizes, both groups were given equal weight in this ranking. These rankings were compared with those reported in the original European study [3] to explore similarities or differences in perceived importance.

Health care professionals were further divided into two subgroups—physicians and other HCPs—to examine potential differences in their relevance and importance ratings. Comparisons were performed using the Mann—Whitney U test. Qualitative responses were organized into categories reflecting either (1) reasons for items being considered less relevant, or (2) suggestions for additional topics to include. A *p*-value below 0.05 was considered statistically significant. All analyses were conducted using SPSS version 23.

Results and Discussion

Participation

In total, 48 patients with advanced cancer and 35 health care professionals participated in the interviews. The patients' median age was 60 years, with the most frequent diagnoses being prostate cancer (14.6%), stomach cancer (10.4%), and multiple myeloma (10.4%). Among the HCPs, the median age was 39 years. The professional distribution included physicians (34.3%), nurses (20.0%), and psychologists (20.0%), among others. Additional demographic and clinical details are presented in **Table 1**.

Table 1. Profile of 48 Patients and 35 Health Care Professionals Involved in Interviews

| Category | Patients | Health Care Professionals |
|---------------------------------|-----------------|----------------------------------|
| Sex | N (%) | N (%) |
| Male | 16 (33.3%) | 9 (25.7%) |
| Female | 32 (66.7%) | 26 (74.3%) |
| Age | | |
| Mean (SD) | 59.2 (13.1) | 40.9 (12.7) |
| Median (Range) | 60 (29–86) | 39 (23–70) |
| Hospitals | | |
| Sotero del Rio | 27 (56.3%) | 12 (34.3%) |
| San Juan de Dios | 4 (8.3%) | 5 (14.3%) |
| Salvador | 13 (27.1%) | 11 (31.4%) |
| Felix Bulnes Cerda | 4 (8.3%) | 7 (20.0%) |
| Diagnosis (Cancer Site, ICD-10) | | |
| Prostate (C61) | 7 (14.6%) | - |
| Stomach (C16) | 5 (10.4%) | - |
| Multiple Myeloma (C90) | 5 (10.4%) | - |
| Breast (C50) | 4 (8.3%) | - |
| Colorectal (C18-C20) | 3 (6.3%) | - |
| Melanoma Skin Cancer (C43) | 3 (6.3%) | - |



| Uterine (C54-C55) | 3 (6.3%) | - |
|--|-----------|---------------------|
| Ovarian (C56, C570-C574) | 3 (6.3%) | - |
| Liver (C22) | 2 (4.2%) | - |
| Sarcoma (C46-C49) | 2 (4.2%) | - |
| Cervical (C53) | 2 (4.2%) | - |
| Kidney (C64-C66) | 2 (4.2%) | - |
| Lymphoma (C81-C85) | 2 (4.2%) | - |
| Other Cancer (All Other C Codes) | 5 (10.4%) | - |
| Discipline of Health Care Professionals | | |
| Physician | - | 12 (34.3%) |
| Nurse | - | 7 (20.0%) |
| Psychologist | - | 7 (20.0%) |
| Paramedic | - | 6 (17.1%) |
| Physiotherapist | - | 1 (2.9%) |
| Social Worker | - | 1 (2.9%) |
| Nutritionist | - | 1 (2.9%) |
| Years of Experience of Health Care Professionals | | |
| Mean (SD) | - | 13.9 (11.9) |
| Median (Range) | - | 11 (1–42) |
| CD C: 1 1D ::: 1CD 10 1: :: 1C:::: 1Cl | | . 177 11 2 11 101 2 |

Notes: SD = Standard Deviation, ICD-10 = International Statistical Classification of Diseases and Related Health Problems 10th Revision

Interviews

Evaluation of relevance, suitability, and perceived importance of the EORTC QLQ-C30

Table 2 presents the quantitative findings from participants' ratings of each item's relevance, appropriateness, and importance. Qualitative explanations for items judged as "not" or "only slightly relevant" are summarized in **Table 3**. Both sets of results are discussed together for each dimension of the QLQ-C30 to provide an integrated interpretation.

The sequence of discussion follows the order of importance established in **Tables 2 and 3**. Based on participants' perspectives, the aspects most valued in assessing outcomes of palliative care were pain, physical functioning, sleep disturbance, emotional well-being, nausea and vomiting, fatigue, social engagement, loss of appetite, role performance, and constipation.

Table 2. Relevance, inappropriateness and importance of items reported by 48 patients and 35 health care professionals

| Domain | Item No. | Mean Relevance Score | | % Rated Unsuitable | | % Ranked as Top Item | | % Domain in Top 2 | |
|----------------------------------|----------|-------------------------|------|-----------------------|------|-------------------------|------|-------------------|--|
| | | Pts. | HCPs | Pts. | HCPs | Pts. | HCPs | | |
| Pain (PA) | 9 | 100 | 97 | 0 | 0 | 96 | 77 | | |
| | 19 | 97 | 80 | 2 | 6 | 27 | 54 | | |
| Any PA Item | - | - | - | - | - | 98 | 94 | 96 | |
| Physical Functioning (PF) | 1 | 77 | 64 | 6 | 9 | 40 | 3 | | |
| | 2 | 78 | 63 | 2 | 0 | 25 | 3 | | |
| | 3 | 76 | 73 | 4 | 3 | 17 | 9 | | |
| | 4 | 83 | 85 | 6 | 3 | 23 | 51 | | |
| | 5 | 98 | 95 | 0 | 0 | 60 | 71 | | |
| Any PF Item | - | - | - | - | - | 98 | 80 | 89 | |
| Sleep Disturbances (SL) | 11 | 97 | 95 | 0 | 0 | 75 | 86 | 80 | |
| Emotional Well-Being (EF) | 21 | 95 | 63 | 0 | 3 | 19 | 6 | | |
| | 22 | 93 | 68 | 0 | 2 | 21 | 11 | | |
| | 23 | 92 | 73 | 0 | 0 | 21 | 17 | | |
| | 24 | 98 | 89 | 0 | 0 | 38 | 60 | | |
| Any EF Item | - | - | - | - | - | 73 | 83 | 78 | |
| Nausea/Vomiting (NV) | 14 | 96 | 88 | 0 | 0 | 25 | 54 | | |

| | 15 | 97 | 87 | 0 | 0 | 35 | 46 | |
|--------------------------------------|----|----|----|---|---|----|----|----|
| Any NV Item | - | - | - | - | - | 46 | 69 | 57 |
| Fatigue (FA) | 10 | 97 | 67 | 2 | 3 | 50 | 6 | |
| | 12 | 92 | 73 | 0 | 3 | 31 | 20 | |
| | 18 | 92 | 74 | 2 | 3 | 42 | 14 | |
| Any FA Item | - | - | - | - | - | 77 | 34 | 56 |
| Social Functioning (SF) | 26 | 93 | 89 | 2 | 3 | 31 | 54 | |
| | 27 | 88 | 83 | 4 | 0 | 8 | 31 | |
| Any SF Item | - | - | - | - | - | 38 | 60 | 49 |
| Appetite Loss (AP) | 13 | 99 | 86 | 0 | 0 | 35 | 57 | 46 |
| Role Activities (RF) | 6 | 95 | 79 | 0 | 0 | 50 | 23 | |
| | 7 | 82 | 57 | 2 | 6 | 31 | 6 | |
| Any RF Item | - | - | - | - | - | 60 | 26 | 43 |
| Constipation (CO) | 16 | 92 | 83 | 0 | 0 | 29 | 54 | 42 |
| Economic Strain (FI) | 28 | 93 | 81 | 4 | 3 | 35 | 49 | 42 |
| Overall Health/Quality of Life (QOL) | 29 | 97 | 90 | 0 | 0 | 8 | 23 | |
| | 30 | 95 | 89 | 0 | 3 | 15 | 49 | |
| Any QOL Item | - | - | - | - | - | 23 | 54 | 39 |
| Shortness of Breath (DY) | 8 | 70 | 70 | 2 | 3 | 46 | 17 | 31 |
| Mental Clarity (CF) | 20 | 90 | 54 | 0 | 3 | 21 | 6 | |
| | 25 | 97 | 67 | 0 | 0 | 15 | 14 | |
| Any CF Item | - | - | - | - | - | 33 | 17 | 25 |
| Diarrhea (DI) | 17 | 93 | 79 | 2 | 0 | 17 | 20 | 18 |
| | | | | | | | | |

The Domain are ranked according to importance. Items in bold form were extracted from the EORTC QLQ-C30 to form the EORTC QLQ-C15-PAL questionnaire

Table 3. Categorized reasons why some items were rated as little or not relevant by the participants

| Domain | Item No. | Relevance Issues ^a | Technical Issues ^b | $In appropriate^{\mathfrak{c}}$ | Relative Unimportance ^d | Not Important ^e | Difficult | Total Issues |
|-----------------------|----------|-------------------------------|-------------------------------|---------------------------------|---------------------------------------|----------------------------|-----------|--------------|
| | | Pts. | HCPs | Pts. | HCPs | Pts. | HCPs | Pts. |
| Pain | 9 | - | - | - | 1 | - | - | - |
| | 19 | - | 3 | - | 1 | - | 2 | 1 |
| Physical Functioning | 1 | 5 | 5 | - | - | 3 | 3 | 1 |
| | 2 | 4 | 6 | 1 | 1 | 1 | - | 1 |
| | 3 | 4 | 6 | 1 | 2 | 1 | 1 | 1 |
| | 4 | 3 | - | - | - | 2 | 1 | 1 |
| | 5 | - | - | - | - | - | - | - |
| Emotional Functioning | 21 | 1 | 5 | 1 | 2 | - | 1 | - |
| | 22 | 1 | 5 | 2 | 1 | - | - | 1 |
| | 23 | - | 1 | 4 | 5 | - | 1 | - |
| | 24 | - | 2 | - | 3 | - | 1 | - |
| | 10 | - | 5 | - | 1 | - | 1 | 1 |
| | 12 | - | 3 | 2 | 3 | - | 1 | 2 |
| | 18 | 1 | 4 | 1 | - | - | 1 | 2 |
| Nausea and Vomiting | 14 | 1 | 2 | - | 2 | - | - | - |
| | 15 | - | 2 | - | 1 | - | - | - |
| Sleep Disturbances | 11 | - | - | - | 1 | - | - | - |

^a The mean of the values for patients (Pts.) and health care professionals (HCPs)

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| 26 | 1 | - | - | - | 1 | 1 | 1 |
|----|---|---|---|---|--|--|--|
| 27 | - | 1 | - | 2 | 2 | - | 1 |
| 8 | 3 | 5 | 14 | 13 | 1 | - | 1 |
| 6 | 2 | 1 | - | 3 | - | - | - |
| 7 | 4 | 11 | - | 1 | 1 | 2 | 1 |
| 16 | - | 1 | 10 | 7 | - | - | - |
| 13 | - | 1 | - | - | - | - | - |
| 28 | 1 | 2 | - | 1 | 2 | 1 | - |
| 29 | - | 2 | 1 | - | - | - | 1 |
| 30 | - | 1 | 2 | 3 | - | 1 | 1 |
| 20 | 4 | 11 | - | 1 | - | 1 | - |
| 25 | 1 | 8 | - | 1 | - | - | - |
| 17 | - | 3 | - | - | 1 | - | - |
| | 27 8 6 7 16 13 28 29 30 20 25 | 27 - 8 3 6 2 7 4 16 - 13 - 28 1 29 - 30 - 20 4 25 1 | 27 - 1 8 3 5 6 2 1 7 4 11 16 - 1 13 - 1 28 1 2 29 - 2 30 - 1 20 4 11 25 1 8 | 27 - 1 - 8 3 5 14 6 2 1 - 7 4 11 - 16 - 1 10 13 - 1 - 28 1 2 - 29 - 2 1 30 - 1 2 20 4 11 - 25 1 8 - | 27 - 1 - 2 8 3 5 14 13 6 2 1 - 3 7 4 11 - 1 16 - 1 10 7 13 - 1 - - 28 1 2 - 1 29 - 2 1 - 30 - 1 2 3 20 4 11 - 1 25 1 8 - 1 | 27 - 1 - 2 2 8 3 5 14 13 1 6 2 1 - 3 - 7 4 11 - 1 1 16 - 1 10 7 - 13 - 1 - - - 28 1 2 - 1 2 29 - 2 1 - - 30 - 1 2 3 - 20 4 11 - 1 - 25 1 8 - 1 - | 27 - 1 - 2 2 - 8 3 5 14 13 1 - 6 2 1 - 3 - - 7 4 11 - 1 1 2 16 - 1 10 7 - - 13 - 1 - - - 28 1 2 - 1 2 1 29 - 2 1 - - - 30 - 1 2 3 - 1 20 4 11 - 1 - 1 25 1 8 - 1 - - |

Pain (PA) scale

Pain was selected as the most important dimension of the QLQ-C30 and both items were rated as highly relevant.

Physical functioning (PF)

Within the physical functioning scale, participants identified the item on needing help with self-care as the most critical, followed by staying in bed. In contrast, items addressing the ability to take short or long walks were generally rated as less relevant, with respondents noting that walking capacity is often not applicable for patients in palliative care. Among HCPs, the item on strenuous activities was most frequently marked as inappropriate (9%).

Sleep disturbances (SL)

Difficulty sleeping was widely recognized as highly relevant, with 80% of participants ranking it among the top priorities for evaluating palliative care outcomes.

Emotional functioning (EF)

Patients rated emotional functioning items as more pertinent than HCPs did, yet 83% of HCPs and 73% of patients still included this domain among the ten most important. The item "feeling depressed" received particular attention, especially from professionals. Nine participants suggested rewording "feeling irritable" to "feeling angry" to improve comprehension and clarity.

Nausea and vomiting (NV)

Both nausea and vomiting were considered key symptoms, with 69% of HCPs selecting them as important for monitoring patient well-being in palliative care.

Fatigue (FA)

A majority of patients (77%) identified fatigue as a critical symptom, whereas only 34% of HCPs did so. Within this domain, "feeling weak" was seen as less important by professionals, who considered it redundant with other items. "Needing to rest" also received lower relevance ratings.

Social functioning (SF)

Nearly half of respondents (49%) highlighted social functioning as an important domain. Both items, concerning the impact of physical condition or treatment on family life and social activities, were considered highly relevant, with family interference being rated slightly higher.

Loss of appetite (LA)

HCPs emphasized lack of appetite more than patients, with 57% versus 35% selecting it as an important issue.

Role functioning (RF)

Patients rated role functioning as significant (60%), particularly the item regarding limitations in work or daily activities.

Constipation (CO)

Constipation was identified as important by 42% of participants. Approximately 20% (n = 17) suggested modifying the wording, noting that patients sometimes had difficulty understanding the item (**Table 4**).



Table 4. Categorized comments about linguistic issues found in the dyspnea and constipation items of EORTC OLO-C30

| Domain | Item No. | Participant Comments and Suggestions (Quotation Marks) | Pts. | HCPs |
|--------------|----------|--|------|------|
| Dyspnea | 8 | Not well formulated | 1 | 2 |
| | | "Ran out of air" | 1 | 2 |
| | | "Lack of air" | 3 | 4 |
| | | "Ran out of breath" | 5 | 2 |
| | | "Difficulty breathing" | 2 | 1 |
| | | "Maximum tiredness" | - | 2 |
| | | Did not understand "short of breath" | 2 | - |
| | | Total | 14 | 13 |
| Constipation | 16 | "Difficulty defecating" | 3 | 6 |
| | | "Troubles defecating" | 2 | 1 |
| | | "Bowel movements" | 1 | 2 |
| | | Did not understand "constipated" | 1 | 1 |
| | | Total | 7 | 10 |

Pts Patients, HCPs health care professionals

Financial issues

When asked about financial difficulties, nearly half of the healthcare professionals (49%) and about one-third of patients (35%) considered it an important aspect of palliative care. Only a few participants raised concerns about the appropriateness of this question in the palliative context.

Global health and quality of life

Both items within the global health/QOL domain were viewed as meaningful by participants. Healthcare professionals were more likely than patients to identify this domain as critical for evaluating care outcomes (54% vs. 23%). Some respondents, however, questioned the clarity of item 30, noting that the concept of "quality of life" may not be easily understood by all patients in palliative settings.

Dyspnea

A number of participants from both patient and HCP groups reported that the item on dyspnea was difficult to understand. About one-third of respondents (33%, n = 27) recommended revising the language to make it clearer (Table 4).

Cognitive functioning

Cognitive functioning was perceived as less essential compared to the other functional domains, with only one-quarter of participants rating it as important. Within this domain, the item regarding concentration problems (item 20) received the lowest relevance scores.

Diarrhea

Although diarrhea was acknowledged as a symptom of concern, it was the least frequently selected item in terms of importance.

No statistically significant differences were observed when comparing physicians (n = 12) and other HCPs (n = 23) in terms of how they rated relevance or importance; therefore, these results are not separately reported in **Table 2**.

Additional issues not covered by the QLQ-C30

Participants were invited to suggest any topics they felt were missing from the questionnaire but important for evaluating palliative care outcomes. In total, 91 issues were reported and subsequently organized into ten overarching categories. The three most frequently mentioned areas were satisfaction with care, emotional wellbeing, and psychological support. Satisfaction with care primarily reflected patients' views on the quality of healthcare providers and effectiveness of treatments. Emotional wellbeing encompassed concerns such as loss of social roles and changes in mood. Psychological support included mental health needs and coping strategies for living with advanced cancer. Additional details can be found in **Table 5**.



| Table 5. Additional issues that would be relevant to include when evaluating the outcome of palliative care | | | | | | | |
|---|--|------|------|--|--|--|--|
| Issue Category | Examples/Aspects | Pts. | HCPs | | | | |
| Satisfaction with Care | Satisfaction with health care professionals, satisfaction with information received, adherence to treatment, effectiveness of medication, side effects | 8 | 4 | | | | |
| Emotions | Role loss, mood changes, sadness, anhedonia, fear | 5 | 7 | | | | |
| Psychological Support | Psychological needs, significant lifestyle changes, facing life with advanced cancer, measuring psychological distress, personality disorders | 6 | 6 | | | | |
| Sexuality | Sexual satisfaction, sexual activity | 1 | 10 | | | | |
| Social Support | Support from family/relatives, caregivers' distress, cohabitation (e.g., whom do you live with?) | 4 | 5 | | | | |
| Symptoms and Problems | Visual problems, slurred speech, eating/swallowing difficulties, drowsiness, dementia/delirium, urinary problems | 2 | 7 | | | | |
| Existential Issues | Thoughts about death, uncertainty about the future, transcendence | 1 | 8 | | | | |
| Spiritual Issues | Spiritual pain, spirituality | - | 6 | | | | |
| Physical Difficulties | Ability to move independently at home, toileting independence | 3 | 3 | | | | |
| Economic Problems | Delays in sick leave payments, transportation expenses (e.g., travel to hospital) | 1 | 4 | | | | |
| Total Number of Issues | | 31 | 60 | | | | |

Pts Patients, HCPs health care professionals

This study examined the content validity of the EORTC QLQ-C15-PAL among 48 patients and 35 healthcare professionals across four palliative care services in Chile, using a methodology similar to a prior European investigation [3]. Overall, the findings support the questionnaire's relevance, while also highlighting specific observations unique to the Chilean context.

Eight of the ten function and symptom domains included in the QLQ-C15-PAL—pain, physical functioning, sleep difficulties, emotional functioning, nausea/vomiting, fatigue, lack of appetite, and constipation—were consistently recognized by participants as key areas for assessing palliative care outcomes. Patients tended to prioritize physical functioning and fatigue, whereas healthcare professionals emphasized emotional functioning, nausea/vomiting, and global health status/QOL. Most of the items retained in the QLQ-C15-PAL aligned with those identified as relevant by participants, supporting the appropriateness of the shortened questionnaire for use in Chile.

Pain emerged as the most critical domain, endorsed by 96% of participants, which aligns with existing literature identifying it as a prevalent symptom among advanced cancer patients in palliative care [28, 29]. Other frequently cited domains included physical functioning (89%), sleep disturbances (80%), emotional functioning (78%), nausea/vomiting (57%), fatigue (56%), and social functioning (49%). Notably, although social and role functioning were excluded in the original QLQ-C15-PAL due to limited relevance in Europe [3], a substantial proportion of respondents in Chile—49% and 43%, respectively—considered these dimensions important. Social functioning was highlighted mainly by HCPs in relation to patients' family interactions, while patients emphasized role functioning as it pertains to daily activities and work. Previous qualitative research in Chile has similarly identified family roles, social support, and occupational limitations as significant concerns for palliative care patients [30].

When asked about additional issues not addressed by the QLQ-C30, HCPs identified nearly twice as many topics as patients. This may reflect HCPs' broader perspective across multiple patients, compared with the individual focus of patients themselves. Fatigue or cognitive load at the end of the interview may also have limited some patients' responses. Among the most frequently reported gaps were satisfaction with care, emotional well-being, and psychological support. In contrast to the European study, existential or spiritual concerns were less commonly mentioned [3]. These findings suggest that further research is needed to evaluate potential modifications to the QLQ-C15-PAL, such as incorporating a social functioning dimension, to capture the full spectrum of QOL for Chilean patients. Despite national and international recommendations for social support in palliative care [1, 31, 32], only one of the four services in this study included a social worker, highlighting a gap in current care provision.

Qualitative feedback also revealed language issues in two items: dyspnea and constipation. Approximately 33% and 20% of respondents, respectively, found these questions unclear. The suggested revisions were submitted to



the EORTC Translation Unit, leading to modifications in the Chilean versions of both the QLQ-C30 and QLQ-C15-PAL.

Limitations of this study include the absence of psychometric testing within the Chilean population. However, prior international studies have established the questionnaire's reliability and validity [6–13]. Recruitment challenges were also present, as some palliative care services had fewer than the targeted ten HCPs. Nonetheless, no data were missing, as participants were supported throughout the self-assessment process.

Conclusion

The EORTC QLQ-C15-PAL demonstrates strong content validity for measuring symptoms and QOL in advanced cancer patients receiving palliative care in Chile. Linguistic concerns identified in the dyspnea and constipation items were addressed through revisions by the EORTC. The instrument offers a practical means for clinicians and researchers to evaluate patient outcomes and guide interventions aimed at improving quality of life. Its implementation in Chilean palliative care is recommended, and future research should explore the inclusion of a social dimension to achieve a more comprehensive assessment of patient QOL.

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