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Background

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Describing Complexity in Palliative Home Care Through HexCom: A Cross-Sectional, Multicenter Study

**Background**: Complexity has become a core issue in caring for patients with advanced disease and/or at the end-of-life. The Hexagon of Complexity (HexCom) is a complexity assessment model in the process of validation in health-care settings. Our objective is to use the instrument to describe differences in complexity across disease groups in specific home care for advanced disease and/or at the end-of-life patients, both in general and as relates to each domain and subdomain.

**Methods**: Cross-sectional study of home care was conducted in Catalonia. The instrument includes 6 domains of needs (clinical, psychological/emotional, social/family, spiritual, ethical, and death-related), 4 domains of resources (intrapersonal, interpersonal, transpersonal, and practical), and 3 levels of complexity (High (H), Moderate (M), and Low (L)). Interdisciplinary home care teams assessed and agreed on the level of complexity for each patient.

**Results**: Forty-three teams participated (74.1% of those invited). A total of 832 patients were assessed, 61.4% of which were cancer patients. Moderate complexity was observed in 385 (47.0%) cases and high complexity in 347 (42.4%). The median complexity score was 51 for cancer patients and 23 for patients with dementia (p<0.001). We observed the highest level of complexity in the social/family domain. Patients/families most frequently used interpersonal resources (80.5%).

**Conclusions**: This study sheds light on the high-intensity work of support teams, the importance of the social/family domain and planning the place of death, substantial differences in needs and resources across disease groups, and the importance of relationship wellbeing at the end-of-life.

Keywords: home care services, palliative care, terminally ill, terminal care, non-cancer patient, complexity, interdisciplinary research

**Background**

Complexity has become a core issue in caring for patients with advanced disease and/or at the end-of-life (AD/EOL patients). The very nature of end-of-life circumstances (which are ever-changing, unpredictable and full of contradictions, ambiguities, surprises, and insecurities) makes end-of-life care a paradigmatic situation of complexity. Applying traditional approaches (such as reductionism or compartmentalization) to complex situations may be counterproductive, which means it necessary to establish conceptual frameworks that accommodate the multiple dimensions of complexity through comprehensive and pragmatic approaches.

Based on the definition of complexity levels and the inclusion and referral criteria of patients, a model for the care of people with advanced illness and/or
at the end-of-life (the Hexagon of Complexity, HexCom) has been published\textsuperscript{11} and partially validated,\textsuperscript{12} with an inter-observer Kappa of 0.92.

This model\textsuperscript{10,11} was created to address complexity in Catalonia (Spain). It is based on the conceptual framework of the Multiple Chronic Conditions Research Network of the University of Washington, which defines complexity as the “gap between patient needs and healthcare services,”\textsuperscript{13} or rather, a mismatch between patient needs and services.\textsuperscript{4} The instrument defines situations that are refractory to treatment options as “high complexity,” and situations that are difficult to resolve as “moderate complexity.” In this sense, classifying patients according to the level of complexity they present helps distinguish between those who need specialized palliative care and those who do not.\textsuperscript{14}

Based on the work of Ferris, the model (Figures 1 and 2) offers six domains of need (clinical, psychological/Emotional, social/family, spiritual, ethical, and death-related), which are broken down into 18 subdomains.\textsuperscript{2,15} The level of complexity for each domain or subdomain can be low, moderate, or high. The model also includes four domains of resources or strengths (intrapersonal, interpersonal, transpersonal, and practical) based on a consensual model of spirituality by Puchalski and which is applied in our clinical practice.\textsuperscript{16,17}

The literature provides information on the relevance of the family in home care, as both the caregiver and recipient of care, which clearly distinguishes home care from institutional care.\textsuperscript{18} It also describes varying needs according to the different pathologies that result in death.\textsuperscript{19} These most prevalent of these diseases can be grouped into five categories: cancer, organ failure, neurological disorders, dementia, and frailty/multimorbidity.\textsuperscript{3,20,21}

Our objective is to use the instrument to describe differences in complexity across disease groups in specific home care for AD/EOL patients, both in general and as relates to each domain and subdomain.

\textbf{Complexity Hexagon (HexCom-Clin\textsuperscript{[20]}\textsuperscript{[16]})}

![Image of Complexity Hexagon](image_url)

\textbf{Figure 1} HexCom form (previous page): analysis of needs.

\textbf{Notes:} Collects information about the Complexity observed in each domain and subdomain of Necessity, at the beginning (I) and at the end (F) of the Follow-up, with 3 complexity levels: High (H) (Refractory situation), Medium (M) (Difficult situation), Low (L) (Without Complexity), or N if it cannot be assessed. R&S: Resources & Strengths; STE: Suitability of treatment efforts; DHD: Desire to hasten death; SLD: Situation during last days of life. Interv: interveners. Soc: Social worker; Psy: Psychologist; Vol: Volunteer; PCU: Palliative care unit; CHC: Hospital.
Methods
Design: Cross-Sectional Study
Study Population: AD/EOL Patients Treated by PADES Teams at Catalonia (Spain)

In Catalonia, home care is shared between primary care services and home care support teams (PADES teams). PADES teams support primary and community care by visiting the homes of patients with complex cases who may benefit from interdisciplinary and specialized intervention. Generally, they are made up of medical, nursing, and social-work staff, although some teams also include physiotherapists, occupational therapists and/or psychologists. In 2015, PADES teams treated 15,337 patients, thus providing coverage for 34.8% of patients at the end-of-life. PADES teams have demonstrated effectiveness, efficiency, and user satisfaction. There are 1.15 PADES teams per 100,000 inhabitants. However, it is worth pointing out the significant differences in structure, dedication, and training across these teams as well as the impact of budget cuts to health care.

Variables
Level of Complexity (Outcome)

The instrument includes six domains of needs (clinical, psychological, spiritual, social/family, ethical, and death-related) and 18 subdomains (Figures 1 and 2). Each domain and subdomain may be classified according to three qualitative levels of complexity:

- High (H): Refractory situation, in which suffering occurs
- Moderate (M): Difficult situation that requires shared care
• Low (L): Low-level complexity
• Not Assessed (NA): Domain cannot be assessed.

The PADES team of each patient came to a consensus on the level of complexity she/he presented for each subdomain. Then, each domain takes its score from the highest degree of complexity observed in any of its subdomains. The overall level of complexity is, in turn, based on the highest level of complexity observed in any of the six domains.

Both high and moderate complexity require intervention from a PADES team. This is why we established the dichotomous variable “high/moderate complexity” vs “low complexity.”

**Complexity Score**

We calculated complexity scores by first determining the total number of domains classified as H, M, and L. These totals were then multiplied as follows: Hx100, Mx10, and Lx1 (the NA category was excluded). The result is an ordinal variable that constitutes a complexity score for each patient in which the hundredth place represents the total number of Hs, the decimal place represents the total number of Ms and the ones place represents the total number of Ls. Therefore, a patient with a score of 231 has 2 Hs, three Ms, and one L (and no NAs). In this way, we were able to obtain a complexity score for each patient.

**Resource and Strength Domains**

These domains address the values, attitudes, and beliefs that promote adaptation and/or the potential for transformation (change) as demonstrated by the patient/family in facing the end-of-life situation. They are divided into four domains (intrapersonal, interpersonal, transpersonal, and practical).

Disease groups: Medical diagnosis (ICD-10) and advanced disease groups: cancer, advanced chronic organ failure, neurological disorders, dementia, or geriatric frailty. Concomitant diagnosis of dementia (Yes/No). The PADES team came to a consensus about which diagnosis most greatly contributed to the process of death for each patient and classified him or her accordingly.

**Another Information**

• Socio-demographic data (age, gender, relationship to caretaker, family support worker).
• Patient’s status: functional status (Barthel Index) and mental status (SPMSQ).

• Health-care data: duration (total days) of home care; total number of visits during home care, psychologist, social worker, and volunteer visits.
• Location of death and cause of PADES team discharge.
• PADES team characteristics.

Training and data collection process: The Department of Health of the Government of Catalonia invited all 58 Catalan PADES teams to participate in this study. In total, 52 of these teams (89.6%) participated in one or two in-person training sessions at the Department of Health headquarters. The sessions lasted 5 hrs each and participants watched four videos of clinical cases to learn how to use the instrument and standardize data collection and compilation. Participants received a user’s guide and were offered a phone number to call should they have doubts during fieldwork. PADES teams assessed complexity using the instrument during interdisciplinary meetings after at least one home visit. They used an online formula to enter information into a centralized database, which contained no personal data that could reveal patient identity.

**Statistical Analysis**

Categorical variables are expressed as the absolute frequency and percentage. The Kolmogorov–Smirnov test was used to determine the normality of the quantitative variables and their frequency histogram, skewness, and kurtosis were inspected. Quantitative variables are described as the mean and standard deviation or the median and first and third quartiles (Q1–Q3) for those with a non-normal distribution. We used Pearson’s Chi-square test to compare proportions, the Student’s t-test for continuous variables, and the Kruskal–Wallis test for ordinal variables or non-normal variables.

Complexity was evaluated by combining “moderate” and “high” into one category, thus establishing a dichotomous variable (“high/moderate complexity” vs “low complexity”).

We used the Chi-square test to compare the prevalence of “moderate/high complexity” across disease groups and analyzed the standardized residual as a measure of the strength of the difference between observed and expected values: if the residual was less than −1.96, the observed frequency of the cell was less than the expected frequency; if it was greater than 1.96, the observed frequency was greater than the expected frequency.

Statistical significance for comparisons was $p \leq 0.05$. All analyses were performed with SPSS for Windows, version 23.0.
Ethics Committee Approval
The study was approved by the Clinical Research Ethics Committee of the University Institute of Research in Primary Care (IDIAP) Jordi Gol (registration number P15/171) and by the clinical research ethics committees of all participating centers. All participants read and signed an informed consent form.

Results
A total of 43 PADES teams (74.1% of those invited) participated in the study. We recruited 832 AD/EOL patients for the study: 511 (61.4%) had cancer and 321 had non-cancer diseases (38.6%) (Table 1). The mean age was 78.73 (SD=13.0) and 394 (47.6%) participants were female. Patients’ partners took on the role of caretaker in 40.4% of cases and their sons/daughters did so in 41.9%. In 554 (66.9%) cases there was no involvement of a family support worker. Patients presented moderate functional dependency (Barthel Index mean: 49.83), and a total of 566 (68.3%) participants presented no cognitive impairment.

We observed differences in socio-demographic data as well as status between groups as regards age, gender,

Table 1 Main Variables: Total and per Disease Group

|                | Cancer | Organ Failure | Neurological Disorders | Dementia | Frailty/ Multimorbidity | Total |
|----------------|--------|---------------|------------------------|----------|------------------------|-------|
| N(%)           | 511(61.4%) | 168(20.1%) | 47(5.6%) | 78(9.3%) | 26(3.1%) | 832(100%) |
| Average age    | 74.5(12.3) | 85.1(8.8) | 77.7(17.9) | 89.5(7.8) | 90.12(8.6) | 78.7(13.0) |
| Range          | 22–100 | 53–105 | 24–101 | 66–107 | 70–101 | 22–107 |
| Female         | 213(41.8%) | 80(47.6%) | 30(63.8%) | 56(71.8%) | 15(57.7%) | 394 (47.6%) |
| Caretaker      | Partner | 253(49.9%) | 49(29.3%) | 11(23.4%) | 17(21.8%) | 3(11.5%) |
|                | Children | 181(35.7%) | 77(46.1%) | 23(48.9%) | 46(59.0%) | 19(73.1%) |
|                | Other Fam | 35(6.9%) | 17(10.2%) | 7(14.9%) | 7(9.0%) | 3(11.3%) |
|                | Other | 38(7.5%) | 24(14.4%) | 6(12.8%) | 8(10.3%) | 3(11.5%) |
| External caretaker | No | 385(75.6%) | 94(56.0%) | 21(44.7%) | 40(51.3%) | 14(53.8%) |
|                | Part time | 82(16.1%) | 42(25.0%) | 18(38.3%) | 20(25.6%) | 9(34.6%) |
|                | 24 hrs | 42(8.3%) | 32(19.0%) | 8(17.0%) | 18(23.1%) | 17(68.1%) |
| Functional status | (Barthel Index) | 61.9(27.3) | 48.3(28.9) | 13.1(15.5) | 6.2(12.8) | 19.8(27.7) |
| Cognitive impairment | No | 419(82.2%) | 113(67.3%) | 18(38.3%) | 0(0.0%) | 14(53.8%) |
|                | Mild | 46(9.0%) | 21(12.5%) | 9(19.1%) | 1(1.3%) | 6(21.3%) |
|                | Moderate | 26(5.1%) | 18(10.7%) | 2(4.3%) | 7(9.2%) | 3(11.5%) |
|                | Severe | 19(3.7%) | 16(9.5%) | 18(38.3%) | 68(89.5%) | 3(11.5%) |
| Medical diagnosis | C34: 123 (24.1%) | J44: 51(30.4%) | G31: 26(55.3%) | G30: 25 (32.1%) | G30: 46 (59.0%) | R54: 12(46.2%) |
| Dementia | C18: 68 (13.3%) | I50: 58(34.5%) | G12: 8(17.0%) | G12: 25 (32.1%) | G12: 25 (32.1%) | G12: 4(15.4%) |
| Total days | 33(6.5%) | 35(14–45) | 20(42.6%) | 35(13–116.25) | 35(13–116.25) | 5(19.2%) |
| PADES visits | 5(3–9) | 35(13–116.25) | 20(42.6%) | 35(13–116.25) | 35(13–116.25) | 5(19.2%) |
| Social worker visit | 337(66.7%) | 35(13–116.25) | 20(42.6%) | 35(13–116.25) | 35(13–116.25) | 5(19.2%) |
| Psychologist visit | 135(26.7%) | 170(71.9%) | 113(23.9%) | 113(23.9%) | 113(23.9%) | 113(23.9%) |
| Complexity Score | 51(24–201) | 33(23–132) | 32(22–213) | 32(22–213) | 32(22–213) | 32(22–213) |

Notes: N(%) number of patients in each disease group and their percentage with respect to the total. PADES: Home care support team program. *Mean and Standard Deviation; †ICD-10 Code: C34: Neoplasm of lungs; C18: Neoplasm of colon; I50: Heart failure; J44: Chronic obstructive pulmonary disease; G31: Degenerative diseases of the nervous system; G12: Motor neuron disease; G30: Alzheimer’s disease; R54: Senility; I70: Atherosclerosis. aConcomitant dementia. bComplexity Score.

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relationship to caretaker, family support worker, and cognitive and functional status (p<0.001) (Table 1). The cancer group had the youngest mean age and the greatest number of participants. Cancer patients’ partners usually took on the role of caretaker and patients presented the best mental and functional status. Other groups consisted predominantly of older (except for the neurological disorders group, which was younger) females (except for the organ failure group, in which gender was equally distributed). Patients in these groups were mostly cared for by their sons/daughters with the aid of a family support worker and presented worse functional and mental status. Neoplasm of the lungs, advanced heart failure, degenerative disorders of the central nervous system, Alzheimer’s disease, and senility were the most common diagnoses for each group. We observed a high prevalence of concomitant dementia (42.6%) in the neurological disorders group.

Patients received home care for a total of 33 days on average, during which they received an average of 5 visits, without much variance across groups. The majority of patients received visits from social workers (67.7%), especially those in the neurological disorders and organ failure groups (80.4% and 71.9%; p=0.05). Psychologists treated 173 (21.2%) patients, above all those in the cancer and neurological disorders groups (26.7% and 23.9%; p<0.001). Volunteer support was less than 1.5%.

Most patients presented either moderate 385 (47.0%) or high 347 (42.4%) complexity. We observed the highest level of complexity (Score 51) in the cancer group and the lowest level (Score 23) in the dementia group (p<0.001) (Table 1, Figure 3).

| Domain/Subdomain | Complexity |
|------------------|------------|
| **Low** | **Moderate** | **High** |
| Clinical | 297(36.3%) | 387(47.3%) | 135(16.5%) |
| Physical | 336(41.1%) | 365(44.6%) | 127 (14.3%) |
| Therapeutic | 502(61.5%) | 243(29.8%) | 71(8.7%) |
| Psychological | 415(52.3%) | 279(35.2%) | 99(12.5%) |
| Personality | 594(76.4%) | 130(16.7%) | 53(6.8%) |
| Emotional | 419(55.7%) | 251(33.4%) | 82(10.9%) |
| Spiritual | 441(68.7%) | 150(23.4%) | 51(7.9%) |
| Meaning | 420(74.5%) | 105(18.6%) | 39(6.9%) |
| Connection | 530(84.1%) | 73(11.6%) | 27(4.3%) |
| Transcendence | 384(73.1%) | 110(21.0%) | 31(5.9%) |
| Social/Family | 257(31.4%) | 364(44.4%) | 198(24.2%) |
| Relationships | 534(65.5%) | 210(25.8%) | 71(8.7%) |
| Emotional | 425(52.5%) | 289(35.7%) | 96(11.9%) |
| Practical | 454(55.7%) | 267(32.8%) | 94(11.5%) |
| External | 420(54.6%) | 254(33.0%) | 95(12.4%) |
| Financial | 668(85.3%) | 82(10.3%) | 33(4.2%) |
| Ethical | 554(70.4%) | 162(21.5%) | 64(8.1%) |
| Information | 601(81.5%) | 91(12.3%) | 45(6.1%) |
| STE | 556(80.3%) | 112(16.2%) | 24(3.5%) |
| DHD | 540(87.7%) | 59(9.6%) | 17(2.8%) |
| Death-related | 313(42.2%) | 272(36.7%) | 156(21.1%) |
| Place | 290(48.5%) | 175(29.3%) | 133(22.2%) |
| SLD | 171(62.6%) | 61(22.3%) | 41(15.0%) |
| Grief | 459(62.8%) | 201(28.6%) | 44(6.3%) |
| Global complexity | 87(10.6%) | 385(47.0%) | 347(42.4%) |

Table 2 presents a summary of complexity observed in all patients. High complexity was most frequent in the social/family domain (24.2%) and in the place-of-death subdomain (22.2%), while it was least frequent in the ethical (8.1%) and spiritual (7.9%) domains.

### Figure 3
Comparison of complexity scores of each disease group.
Note: The dashed line represents the median Complexity Score of all participants.

### Table 2 Level of Complexity per Domain, Subdomain, and Global

**Psychological Complexity Was Lowest in the Dementia Group**

Spiritual complexity was lowest in the dementia group and the subdomain of transcendence was lowest in the organ failure group. Social/family complexity was lowest in the frailty/multimorbidity groups. Ethical complexity was lowest in the organ failure group. Death-related complexity and its...
Table 3 Differences in Complexity Across Disease Groups: Patients with Moderate or High Complexity (N%)

| Domain/Subdomain        | Cancer                  | Organ Failure | Neurological Disorder | Dementia                  | Frailty/ Multimorbidity | Total | P     |
|-------------------------|-------------------------|---------------|-----------------------|---------------------------|-------------------------|-------|-------|
| Clinical                | 318 (63.0%)             | 121 (73.3%)*  | 30 (63.8%)            | 36 (47.4%)b               | 17 (65.4%)              | 522 (63.7%) | 0.004 |
| Physical                | 292 (57.9%)             | 114 (69.1%)*  | 28 (59.6%)            | 31 (40.8%)b               | 17 (65.4%)              | 482 (58.9%) | 0.001 |
| Therapeutic             | 192 (38.2%)             | 73 (44.2%)    | 17 (37.0%)            | 22 (28.9%)                | 10 (38.5%)              | 314 (38.5%) | 0.258 |
| Psychological           | 252 (50.5%)             | 71 (44.9%)    | 24 (54.5%)            | 22 (32.8%)                | 9 (36.0%)               | 378 (47.7%) | 0.037 |
| Personality             | 119 (24.3%)             | 38 (24.5%)    | 8 (18.6%)             | 14 (21.9%)                | 4 (16.0%)               | 183 (23.6%) | 0.790 |
| Emotional               | 224 (46.0%)             | 64 (43.0%)    | 21 (53.5%)            | 25 (16.0%)                | 9 (39.1%)               | 333 (44.3%) | 0.055 |
| Spiritual               | 149 (33.6%)             | 39 (27.9%)    | 9 (33.3%)             | 1 (3.7%)b                 | 2 (11.1%)               | 201 (31.3%) | 0.023 |
| Meaning                 | 103 (26.4%)             | 29 (24.2%)    | 8 (38.1%)             | 1 (6.3%)                  | 3 (17.6%)               | 144 (25.5%) | 0.222 |
| Connection              | 71 (16.2%)              | 24 (19.0%)    | 3 (11.5%)             | 0 (0.0%)                  | 2 (11.8%)               | 100 (15.9%) | 0.191 |
| Transcendence           | 110 (30.5%)             | 20 (17.2%)b   | 7 (36.8%)             | 0 (0.0%)b                 | 2 (23.5%)               | 141 (26.9%) | 0.010 |
| Social/Family           | 348 (68.9%)             | 121 (73.3%)   | 34 (72.3%)            | 47 (61.8%)                | 12 (46.2%)b             | 562 (68.6%) | 0.045 |
| Relationships           | 172 (34.1%)             | 64 (39.3%)    | 18 (38.3%)            | 20 (26.7%)                | 7 (26.9%)               | 281 (34.5%) | 0.323 |
| Emotional               | 236 (47.0%)             | 80 (49.4%)    | 27 (58.7%)            | 32 (43.2%)                | 10 (38.5%)              | 385 (47.5%) | 0.409 |
| Practical               | 222 (44.0%)             | 80 (48.8%)    | 23 (48.9%)            | 28 (37.3%)                | 8 (32.0%)               | 361 (44.3%) | 0.312 |
| External                | 210 (44.0%)             | 83 (52.9%)    | 19 (47.5%)            | 28 (39.4%)                | 9 (37.5%)               | 349 (45.4%) | 0.232 |
| Financial               | 74 (15.2%)              | 25 (16.0%)    | 3 (7.5%)              | 8 (10.7%)                 | 5 (20.0%)               | 115 (14.7%) | 0.477 |
| Ethical                 | 156 (31.6%)             | 42 (26.3%)    | 14 (31.8%)            | 12 (30.1%)                | 8 (33.3%)               | 233 (29.6%) | 0.295 |
| Information            | 109 (23.0%)             | 16 (10.5%)b   | 4 (10.5%)             | 4 (7.7%)b                 | 3 (13.6%)               | 136 (18.5%) | 0.001 |
| Suitability of treatment efforts | 78 (18.7%) | 27 (18.6%) | 12 (29.3%) | 12 (18.5%) | 7 (29.2%) | 136 (19.7%) | 0.384 |
| Desire to hasten death | 50 (12.9%)              | 16 (12.2%)    | 3 (9.1%)              | 3 (7.0%)                  | 4 (20.0%)               | 76 (12.3%)  | 0.618 |
| Death                   | 283 (61.9%)             | 82 (58.2%)    | 21 (46.7%)            | 28 (38.9%)b               | 14 (53.8%)              | 428 (57.8%) | 0.003 |
| Location                | 215 (58.9%)             | 59 (54.1%)    | 10 (30.3%)b            | 15 (22.7%)b               | 9 (36.0%)               | 308 (51.5%) | 0.000 |
| Situation of last days  | 67 (42.7%)              | 18 (36.0%)    | 5 (29.4%)             | 6 (18.8%)                 | 6 (35.3%)               | 102 (37.4%) | 0.128 |
| Grief                   | 169 (38.9%)             | 39 (29.5%)    | 17 (38.6%)            | 14 (20.6%)b               | 6 (24.0%)               | 245 (34.8%) | 0.015 |

Notes: N(%): number of patients in each disease group and their percentage with respect to the total. The significant differences according to the standardized residuals for Pearson’s Chi-square test are marked in bold. *Greater than 1.96 (observed frequency is greater than expected); bLess than −1.96 (observed frequency is less than expected).

subdomains of location, situation of last days and grief were lowest in the dementia group, while the location subdomain was highest in the cancer group.

Regarding resources used to face the situation, cancer patients most frequently used all three types of resources, whereas dementia patients used them least frequently (Table 4). Patients with organ failure most frequently used practical resources and those with neurological disorders used transpersonal resources least frequently.

Discussion
There are significant differences in needs and resources across disease groups: cancer patients presented the greatest complexity, while dementia patients made the least use of resources.27

Complexity was greatest in the social/family domains and place of death. Interpersonal resources (positive relationships) were the type most frequently employed to cope with the end-of-life situation.28

In specialized home care, the situations professionals attend to are highly complex and transitory.

Our results corroborate those found in the bibliography. In one study, a home hospitalization team found that 79% of patients presented highly complex situations.29 We also know that the needs of cancer patients are radically different from those of terminal patients with organ failure.19,20,30,31 Waller observed physical complexity in 51% of participants, practical social/family complexity in 33%, and high spiritual complexity in 8.8%.32 Waller also observed high psychological/emotional complexity in 38.8% of patients. Both Waller’s figures and ours are greater than those found by Potash, who noted that between 20% and 35% of patients required specific psychological care.33 Regarding the ethical domain, Chochinov found that 8.5% of patients persistently
A recent systematic review yielded does not include an ethical or death-related domain, is speci
Lastly, prevalence of moderate to high com-
Thus, by promoting team

The lower level of ethical and spiritual com-
None of the aforementioned

| Domain/Subdomain | Cancer | Organ Failure | Neurological Disorders | Dementia | Frailty Multimorbidity | Total | P     |
|------------------|--------|---------------|-------------------------|----------|------------------------|-------|-------|
| Intrapersonal    | 410(80.1%) | 120(71.4%)   | 27(57.4%)                | 32(41.0%)| 17(63.0%)              | 606   | <0.001|
|                  | 221(43.2%) | 61(36.3%)    | 13(27.7%)                | 15(19.2%)| 11(40.7%)              | 321   | 0.001 |
|                  | 327(63.9%) | 94(56.0%)    | 20(42.6%)                | 7(9.0%)  | 10(37%)                | 458   | <0.001|
|                  | 311(60.7%) | 81(48.2%)    | 19(40.4%)                | 20(25.6%)| 10(37%)                | 441   | <0.001|
| Interpersonal    | 439(85.7%) | 126(75.0%)   | 35(74.5%)                | 53(67.9%)| 17(63.0%)              | 670   | <0.001|
|                  | 305(59.6%) | 98(58.3%)    | 27(57.4%)                | 39(50%)  | 15(55.6%)              | 484   | 0.620 |
|                  | 387(75.6%) | 107(63.7%)   | 26(55.3%)                | 37(47.4%)| 16(59.3%)              | 573   | <0.001|
|                  | 258(50.4%) | 69(41.1%)    | 20(42.6%)                | 26(33.3%)| 13(48.1%)              | 386   | 0.028 |
| Transpersonal    | 359(70.1%) | 111(66.1%)   | 21(44.7%)                | 17(21.8%)| 16(59.2%)              | 524   | <0.001|
|                  | 273(53.3%) | 85(50.6%)    | 14(29.8%)                | 3(3.8%)  | 12(44.4%)              | 387   | <0.001|
|                  | 263(51.4%) | 77(45.8%)    | 13(27.7%)                | 14(17.9%)| 9(33.3%)               | 376   | <0.001|
|                  | 86(16.8%)  | 34(20.2%)    | 6(12.8%)                 | 6(7.7%)  | 7(25.9%)               | 139   | 0.083 |
| Practical        | 364(71.1%) | 131(78%)     | 32(68.1%)                | 33(42.3%)| 19(70.4%)              | 579   | <0.001|
|                  | 289(56.4%) | 105(62.5%)   | 29(61.7%)                | 33(42.3%)| 15(55.6%)              | 471   | 0.052 |
|                  | 214(41.8%) | 79(47.0%)    | 12(25.5%)                | 3(3.8%)  | 9(33.3%)               | 317   | <0.001|

Notes: The significant differences according to the standardized residuals for Pearson’s Chi-square test are marked in bold: *Greater than 1.96 (observed frequency is greater than expected); †Less than –1.96 (observed frequency is less than expected).

desired to hasten death. A recent systematic review yielded great variability in results for this subdomain, ranging from 3.3% to 28%. Lastly, prevalence of moderate to high complexity indicators of grief was 32% and prevalence of pathological grief was 28%.

The fact that the highest level of clinical (physical) complexity was observed in the organ failure group is likely related to a less predictable trajectory and development of crises in these diseases. The higher level of psychological (emotional) complexity observed in the neurological disorders group is perhaps related to the difficulty that health-care professionals had in detecting these needs. Based on the open comments collected in the survey, it is clear that teams had a heavy workload and some difficulty in clearly defining some of the contents of the assessment tool, especially those related to spiritual needs. While clinical complexity is described as undeterminable in 0.2% of cases, this percentage reaches 22.6% in the subdomain of connection, 29.7% in meaning, and 35.5% in transcendence.

We know that unmet needs in end-of-life care are mostly related to communication issues. Thus, by promoting team consensus and communication, the instrument fulfills an important role. In our analysis of other tools, we found that PCPSS does not include an ethical or death-related domain, nor does it differentiate between the spiritual and psychological/emotional domains that PC-NAT does. NAT-PD-C is exclusively used for cancer cases and NAT-PD-HF for advanced heart disease; CSNAT is specifically aimed at caretakers; NA-ACP and NEST13 test patient response; and, lastly, IDCPAL is focused more on management than clinical practice. None of the aforementioned tools specifically examines resources and strengths.

**Limitations**

These results are a reflection of regular specialized home care and allow us to analyze complexity based on different disease groups. The concept of end-of-life complexity used for this study is based on clinical judgment, which is controversial and awaits consensus. The subjectivity that comes with making such clinical judgments is mitigated to...
some extent by prior training and the entire evaluation team coming to an agreement on complexity levels.

This tool is currently in the process of validation. However, partial validations not yet published in English have been conducted and have demonstrated high inter-rater reliability (Kappa=0.92). Based on these results, the Department of Health of the Government of Catalonia has decided to implement the tool in the management of such patients.

The sample size of neurological and frailty/multimorbidity patients was lower than necessary and might have affected statistical power in these groups. However, due to the larger size of the other groups, important differences were detected in frailty/multimorbidity patients and the trends observed are plausible.

Generalizations and Perspectives

The results of our study can be extrapolated to the field in question, or rather, to AD/EOL patients treated by specific home care teams, regardless of population differences.

The patterns observed suggest that specialized palliative home care should be focused mainly on cancer, neurology, and organ failure rather than fragility and dementia. Specifically, in the case of patients with cancer or organ failure, quick access to palliative care beds must be available and preferences regarding place of death must be taken into consideration. Our results also show that the role of the social worker on these teams and their integration in the social and community network must be reinforced and that, due to the intensity of this type of care (refractoriness, changing circumstances and short duration), health-care teams and professionals must be encouraged to practice self-care.

These findings highlight the importance of the presence of a skilled caregiver in the home, as well as the need for assessment of all areas included in the model due to the heavy burden that the psychosocial field can have on suffering at the end-of-life.

Conclusions

This study sheds light on the high-intensity work of support teams, the importance of the social/family domain and planning the place of death in home care, substantial differences in needs and resources across disease groups, and the importance of relationship wellbeing at the end-of-life.

Abbreviations

“Organ failure”, Advanced chronic organ failure; AD/EOL, Advanced disease and/or end-of-life; HexCom, Hexagon of Complexity; PADES, Home care support team program.

Consent for Publication

Not applicable, as the manuscript does not contain personal data.

Data Sharing Statement

While the IDIAP Jordi Gol does not plan on storing anonymous data in a public database, it will provide access to files should reviewers request it.

Ethics and Consent Statement

This study was conducted in accordance with the Declaration of Helsinki. This project was assessed by the Clinical Research Ethics Committee (CEIC) of the IDIAP Jordi Gol. Participating patients gave their informed consent. All participants read and signed an informed consent form.

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The authors report no conflicts of interest in this work.

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