

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

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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).¹⁻⁴ The very nature of end-of-life circumstances (which are ever-changing, unpredictable and full of contradictions, ambiguities, surprises, and insecurities)⁵ makes end-of-life care a paradigmatic situation of complexity.^{6,7} 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.^{8,9}

Based on the definition of complexity levels and the inclusion and referral criteria of patients,¹⁰ a model for the care of people with advanced illness and/or

at the end-of-life (the Hexagon of Complexity, HexCom) has been published¹¹ and partially validated,¹² with an inter-observer Kappa of 0.92

This model^{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 health-care services,”¹³ or rather, a mismatch between patient needs and services.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.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.^{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.^{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.¹⁸ It also describes varying needs according to the different pathologies that result in death.¹⁹ These most prevalent of these diseases can be grouped into five categories: cancer, organ failure, neurological disorders, dementia, and frailty/multimorbidity.^{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.

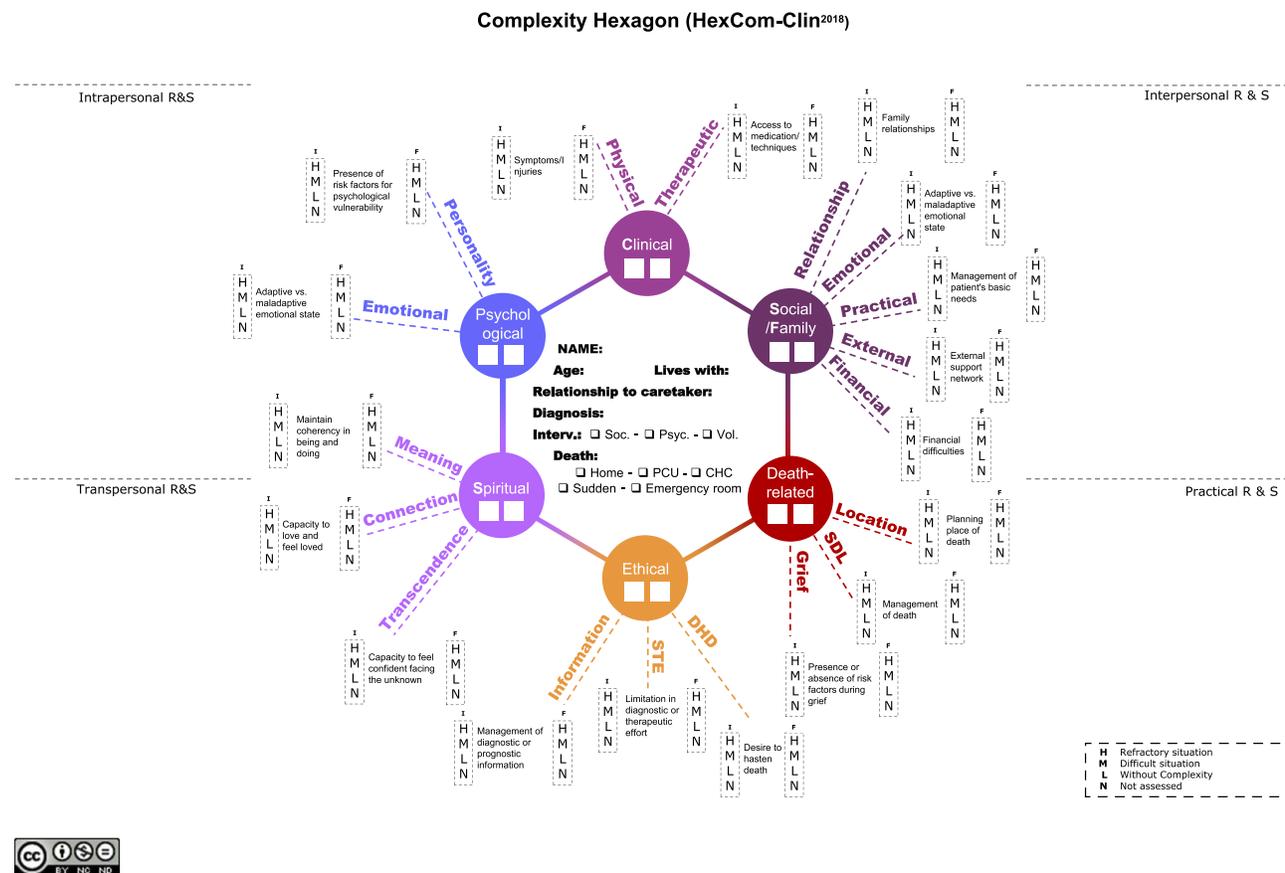


Figure 1 HexCom form (previous page): analysis of needs. **Notes:** Collects information about the Complexity observed in each domain and subdomain of Necessity, at the beginning (I) and at the end (F) of the Follow-up, with 3 complexity levels: High (H) (Refractory situation), Medium (M) (Difficult 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; Psyc: Psychologist; Vol: Volunteer; PCU: Palliative care unit; CHC: Hospital.

Intrapersonal R&S

- 1 Has the capacity for reinvention and resilience
- 2 Values autonomy
- 3 Uses humor
- 4 Has a strong/consistent personality
- 5 Takes an active role in facing his/her illness
- 6 Has good emotional control in threatening situations/the capacity to express emotions naturally
- 7 Practices assertiveness when making requests of those around him/her
- 8 Takes initiative in decision-making

Interpersonal R&S

- 1 Capacity to love and feel loved
- 2 Relationship with partner
- 3 Relationship with sons / daughters
- 4 Relationship with grandchildren
- 5 Relationship with family
- 6 Strength of the caretaker
- 7 Has a large network of family and friends
- 8 Relationship with pet
- 9 Is able to rebuild important relationships
- 10 Communicates openly with the people around him/her
- 11 Builds trusting relationships with medical professionals
- 12 The family supports the patient's decisions (maintains his/her self-autonomy)
- 13 Has a close family
- 14 Has the capacity for preservation and adaptation of roles
- 15 The caretaker finds meaning in this role
- 16 Feels recognized by others

Resources & Strengths

Transpersonal R&S

- 1 Finds meaning in having fighting spirit
- 2 Has hope
- 3 Feels confident and determined in the face of uncertainty
- 4 Feels connected to nature
- 5 Has faith (regardless of religious practice)
- 6 Practices a religion
- 7 Maintains a spiritual practice (prayer, meditation, etc.)
- 8 Feels sustained by love
- 9 Is grateful
- 10 Does not fear death
- 11 Is able to find meaning in the face of adversity
- 12 Is able to say goodbye/prepare funeral
- 13 Lives in the present moment
- 14 Is able to leave a legacy
- 15 Has the capacity for reconciliation
- 16 Has the capacity for self-preservation and self-protection
- 17 Is satisfied with his/her life

Practical R&S

<ul style="list-style-type: none"> <input type="checkbox"/> 1 Builds trusting relationships with medical professionals <input type="checkbox"/> 2 Receives good support from medical professionals <input type="checkbox"/> 3 Organizational ability <input type="checkbox"/> 4 Family has the capacity for caring <input type="checkbox"/> 5 Has a support network <input type="checkbox"/> 6 Has a private caretaker <input type="checkbox"/> 7 Is financially stable <input type="checkbox"/> 8 Has an oxygen concentrator <input type="checkbox"/> 9 Uses space as a resource <input type="checkbox"/> 10 Reads 	<ul style="list-style-type: none"> <input type="checkbox"/> 11 Writes <input type="checkbox"/> 12 Practices self-care <input type="checkbox"/> 13 Practices hobbies <input type="checkbox"/> 14 Uses TV/radio for entertainment <input type="checkbox"/> 15 Hobbies <input type="checkbox"/> 16 Takes cares of plants/garden <input type="checkbox"/> 17 Takes walks <input type="checkbox"/> 18 Has a pet <input type="checkbox"/> 19 Goes out for a coffee, to buy lottery tickets, etc. <input type="checkbox"/> 20 Uses new technology
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Figure 2 HexCom form (later page): analysis of resources and strengths.

Notes: Collects information about Resources and Strengths observed in the home and that help sustain the actual situation. It is indicated if resource determination is detected.

Abbreviation: R&S, resources and strengths.

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.²² PADES teams have demonstrated effectiveness, efficiency, and user satisfaction.^{23,24} 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 teams²⁵ as well as the impact of budget cuts to health care.²⁶

Inclusion/exclusion criteria: Patients with advanced disease and/or at the end-of-life attended by PADES teams at their home. Patients who received care in a residential institution are excluded. We used consecutive sampling during the recruitment period (15/02/6 to 15/12/16) to assign patients that met inclusion requirements to one of the PADES teams that agreed to participate in the study.

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%)	P
Average age ^a Range	74.5 (12.3) 22–100	85.1(8.8) 53–105	77.7(17.9) 24–101	89.5(7.8) 66–107	90.12(8.6) 70–101	78.7(13.0) 22–107	<0.001 ^e
Female	213(41.8%)	80(47.6%)	30(63.8%)	56(71.8%)	15(57.7%)	394 (47.6%)	<0.001 ^f
Caretaker:							<0.001 ^f
Partner	253(49.9%)	49(29.3%)	11(23.4%)	17(21.8%)	3(11.5%)	333 (40.4%)	
Children	181(35.7%)	77(46.1%)	23(48.9%)	46(59.0%)	19(73.1%)	346(41.9%)	
Other Fam	35(6.9%)	17(10.2%)	7(14.9%)	7(9.0%)	1(3.8%)	67(8.1%)	
Other	38(7.5%)	24(14.4%)	6(12.8%)	8(10.3%)	3(11.5%)	79(9.6%)	
External caretaker							<0.001 ^f
No	385(75.6%)	94(56.0%)	21(44.7%)	40(51.3%)	14(53.8%)	554(66.9%)	
Part time	82(16.1%)	42(25.0%)	18(38.3%)	20(25.6%)	9(34.6%)	171(20.7%)	
24 hrs	42(8.3%)	32(19.0%)	8(17.0%)	18(23.1%)	3(11.5%)	103(12.4%)	
Functional status (Barthel Index) ^a	61.9(27.3)	48.3(28.9)	13.1(15.5)	6.2(12.8)	19.8(27.7)	49.8(32.4)	<0.001 ^e
Cognitive impairment							<0.001 ^f
No	419(82.2%)	113(67.3%)	18(38.3%)	0(0.0%)	14(53.8%)	566(68.3%)	
Mild	46(9.0%)	21(12.5%)	9(19.1%)	1(1.3%)	6(23.1%)	83(10.0%)	
Moderate	26(5.1%)	18(10.7%)	2(4.3%)	7(9.2%)	3(11.5%)	56(6.8%)	
Severe	19(3.7%)	16(9.5%)	18(38.3%)	68(89.5%)	3(11.5%)	124(15.0%)	
Medical diagnosis ^b	C34: 123 (24.1%) C18: 68 (13.3%)	I50: 58(34.5%) J44: 51(30.4%)	G31: 26(55.3%) G12: 8(17.0%)	G30: 46 (59.0%) G31: 25 (32.1%)	R54: 12(46.2%) I70: 4(15.4%)		
Dementia ^c	33 (6.5%)	25(14.9%)	20(42.6%)	75(100%)	5(19.2%)	158 (19.1%)	<0.001 ^f
Total days ^d	31(14–65)	37.5(16.25–104.00)	35(13–116.25)	37.5(9–68.5)	13.5(4.75–60.75)	33(14–74)	0.064 ^g
PADES visits ^d	5(3–9)	5(3–10)	5(2–9.25)	4(2–7)	3(2–7.25)	5(2–9)	0.240 ^g
Social worker visit	337(66.7%)	120(71.9%)	37(80.4%)	49(63.6%)	13(50.0%)	556(67.7%)	0.055 ^f
Psychologist visit	135(26.7%)	17(10.3%)	11(23.9%)	8(10.7%)	2(7.7%)	173(21.2%)	<0.001 ^f
Complexity Score ^d	51(24–201)	33(23–132)	32(22–213)	23(11.5–111)	32.5(21–122)	42(23–141)	<0.001 ^g

Notes: N(%): number of patients in each disease group and their percentage with respect to the total. PADES: Home care support team program. ^aMean and Standard Deviation; ^bICD-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. ^cConcomitant dementia. ^dMedian, 25th and 75th percentiles; ^et Student test; ^fChi-square test; ^gKruskal–Wallis test.

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).

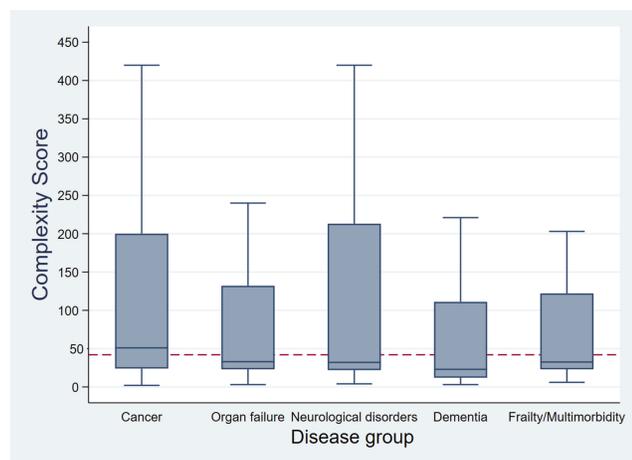


Figure 3 Comparison of complexity scores of each disease group. **Note:** The dashed line represents the median Complexity Score of all participants.

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

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(10.5%)	33(4.2%)
Ethical	554(70.4%)	169(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%)

Abbreviations: STE, suitability of treatment efforts; DHD, desire to hasten death; SLD, situation during last days of life.

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.

Table 3 compares “Moderate or high complexity” across disease groups: clinical and physical complexity were highest in the organ failure group and lowest in the dementia group.

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%)^a	30 (63.8%)	36 (47.4%)^b	17 (65.4%)	522 (63.7%)	0.004
Physical	292 (57.9%)	114 (69.1%)^a	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%)^b	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 (55.3%)	15 (27.3%)	9 (39.1%)	333 (44.3%)	0.055
Spiritual	149 (33.6%)	38 (29.7%)	9 (33.3%)	1 (3.7%)^b	4 (23.5%)	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	4 (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%)	13 (20.0%)	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%)^a	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: ^aGreater 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

Table 4 Resources and Strengths Used to Face the End-of-Life Across Disease Groups

Domain/Subdomain	Cancer	Organ Failure	Neurological Disorders	Dementia	Frailty Multimorbidity	Total	P
Intrapersonal	410(80.1%)^a	120(71.4%)	27(57.4%)^b	32(41.0%)^b	17(63.0%)	606(72.8%)	<0.001
Strong and resilient personality	221(43.2%)^a	61(36.3%)	13(27.7%)	15(19.2%)^b	11(40.7%)	321(38.6%)	0.001
Self-decision making	327(63.9%)^a	94(56.0%)	20(42.6%)	7(9.0%)^b	10(37%)^b	458(55.0%)	<0.001
Self-emotional control	311(60.7%)^a	81(48.2%)	19(40.4%)	20(25.6%)^b	10(37%)	441(53.0%)	<0.001
Interpersonal	439(85.7%)^a	126(75.0%)^b	35(74.5%)	53(67.9%)^b	17(63.0%)^b	670(80.5%)	<0.001
Capacity to feel loved	305(59.6%)	98(58.3%)	27(57.4%)	39(50%)	15(55.6%)	484(58.2%)	0.620
Positive relationships	387(75.6%)^a	107(63.7%)	26(55.3%)^b	37(47.4%)^b	16(59.3%)	573(68.9%)	<0.001
Family & Roles: caring family environment	258(50.4%)^a	69(41.1%)	20(42.6%)	26(33.3%)^b	13(48.1%)	386(46.4%)	0.028
Transpersonal	359(70.1%)^a	111(66.1%)	21(44.7%)^b	17(21.8%)^b	16(59.2%)	524(63.0%)	<0.001
Future-focused: confident about the future	273(53.3%)^a	85(50.6%)	14(29.8%)^b	3(3.8%)^b	12(44.4%)	387(46.5%)	<0.001
Present-focused: living the here & now	263(51.4%)^a	77(45.8%)	13(27.7%)^b	14(17.9%)^b	9(33.3%)	376(45.2%)	<0.001
Religiosity and rituals	86(16.8%)	34(20.2%)	6(12.8%)	6(7.7%)	7(25.9%)	139(16.7%)	0.083
Practical	364(71.1%)	131(78%)^a	32(68.1%)	33(42.3%)^b	19(70.4%)	579(69.6%)	<0.001
Organization: organizational capacity	289(56.4%)	105(62.5%)	29(61.7%)	33(42.3%)	15(55.6%)	471(56.6%)	0.052
Capacity to entertain oneself	214(41.8%)^a	79(47.0%)^a	12(25.5%)	3(3.8%)^b	9(33.3%)	317(38.1%)	<0.001

Notes: The significant differences according to the standardized residuals for Pearson's Chi-square test are marked in bold: ^aGreater than 1.96 (observed frequency is greater than expected); ^bLess than -1.96 (observed frequency is less than expected).

desired to hasten death.³⁴ A recent systematic review yielded great variability in results for this subdomain, ranging from 3.3% to 28%.³⁵ Lastly, prevalence of moderate to high complexity indicators of grief was 32%³⁶ and prevalence of pathological grief was 28%.³⁷

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.³⁸ The higher level of psychological (emotional) complexity observed in the neurological disorders group is perhaps related to the expectation of loss over a longer period of time.^{39,40}

The low level of complexity in the dementia group may be related to cognitive impairment presented by patients.⁴¹⁻⁴³ The lower level of ethical and spiritual complexity observed may be related to the difficulty that health-care professionals had in detecting these needs.⁴⁴ 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.⁴⁵ Thus, by promoting team consensus and communication, the instrument fulfills an important role. In our analysis of other tools, we found that PCPSS⁴⁶ does not include an ethical or death-related domain, nor does it differentiate between the spiritual and psychological/emotional domains that PC-NAT does;^{47,48} NAT-PD-C⁴⁹ is exclusively used for cancer cases and NAT-PD-HF⁵⁰ for advanced heart disease; CSNAT⁵¹ is specifically aimed at caretakers; NA-ACP⁵² and NEST13⁵³ test patient response; and, lastly, IDCPAL is focused more on management than clinical practice.⁵⁴ 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 ($Kappa=0.92$).¹² 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.⁵⁵ 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.⁵⁶

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^{57–63} 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.^{64–68}

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.^{45,69}

We also recommend further analysis of complexity as observed in non-cancer groups, and it will be interesting to see the evolution of complexity. Future research should focus on specific validation studies of this instrument.

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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Author Contributions

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Disclosure

The authors report no conflicts of interest in this work.

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