



ORIGINAL ARTICLE

Systemic strengths and needs in palliative home care: exploring complexity

X. Busquet-Duran^{a,b,e,*}, B. Mateu-Carralero^a, J. Bielsa-Pascual^{b,c,e}, L. Milian-Adriazola^a, N. Salamero-Tura^a, P. Torán-Monserrat^{b,d,e}



^a Programa d'Atenció Domiciliària Equip de Suport (PADES), Servei d'Atenció Primària Vallès Oriental, Institut Català de la Salut, Barcelona, Spain

^b Unitat de Suport a la Recerca Metropolitana Nord (USR-MN), Institut Universitari per a la Recerca a l'Atenció Primària de Salut Jordi Gol i Gurina (IDIAPJGol), Barcelona, Spain

^c Instituto de Investigación Germans Trias i Pujol (IGTP), Badalona, Barcelona, Spain

^d Departamento de Medicina, Facultad de Medicina, Universitat de Girona, Girona, Spain

^e Grupo de Investigación Multidisciplinar en Salud y Sociedad GREMSAS, Barcelona, Spain

Received 17 April 2023; accepted 14 November 2023

Available online 13 December 2023

KEYWORDS

Palliative care;
Needs assessment;
Home care services;
Place on death;
Complexity

Abstract

Objective: We aimed to investigate the relationship between systemic strengths and complexity in home care of end-of-life patients.

Methods: Quantitative descriptive longitudinal study of patients cared for at home by a palliative care team. Place of death was analyzed in relation to complexity, as determined by the HexCom complexity model after the initial home assessment. We used Pearson's chi-square test to analyze the comparison of proportions.

Results: Forty-six hundred patients (74.4% oncologic) with a mean age of 76.2 years (SD 13.2) participated. Fifty-three percent had complete or severe functional dependence, 30.8% were already bedridden in the first assessment, and 59.7% died at home. Strengths influenced place of death, specifically exosystem (team) strength (OR: 4.07 [1.92–8.63]), microsystem (both patient 0.51 [0.28–0.94]) and caregiver (OR: 3.90 [1.48–10.25]), and chronosystem, related to prediction of progressive course (OR: 2.22 [1.37–3.60]).

Conclusions: To improve care for end-of-life patients and their families, a systemic view of dying and death that includes both needs and strengths is necessary. In this sense, the systemic framework proposed by Bonfrenbrenner can be useful for clinical practice.

© 2023 The Authors. Published by Elsevier España, S.L.U. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

* Corresponding author.

E-mail address: xbusquet@umanresa.cat (X. Busquet-Duran).

PALABRAS CLAVE
 Cuidados paliativos;
 Evaluación de
 necesidades;
 Servicios de atención
 de salud a domicilio;
 Lugar de muerte;
 Complejidad

Fortalezas sistémicas y necesidades en atención paliativa domiciliaria: explorando la complejidad

Resumen

Objetivo: Nos proponemos investigar la relación entre las fortalezas sistémicas y el lugar de muerte en atención domiciliaria de pacientes en final de vida.

Método: Estudio cuantitativo descriptivo longitudinal de pacientes atendidos por un equipo domiciliario de cuidados paliativos. Se analizó la ubicación de la muerte en relación con la complejidad detectada tras la primera valoración domiciliaria usando el modelo de complejidad HexCom. Para la comparación de proporciones utilizamos la prueba de ji cuadrado de Pearson.

Resultados: Participaron 464 pacientes (74,4% oncológicos), edad media 76,2 años (DE: 13,2). El 53% presentaban dependencia funcional total o severa, el 30,8% estaban ya encamados en la primera valoración y el 59,7% fallecieron en domicilio. Las fortalezas influyen en el lugar de muerte, sobre todo la fortaleza del exosistema (equipo) (OR: 4,07 [1,92-8,63]), la del microsistema (tanto la fortaleza del paciente (0,51 [0,28-0,94]) como de cuidador (OR: 3,90 [1,48-10,25]), y la del cronosistema, relativo a la previsión de un curso progresivo (OR: 2,22 [1,37-3,60]).

Conclusiones: Para mejorar la asistencia a los pacientes en situación de final de vida y sus familias es necesaria una mirada sistemática del morir y de la muerte que incluya tanto necesidades como fortalezas. En este sentido, el marco sistemático propuesto por Bonfrenbrenner puede ser de utilidad para la práctica clínica.

© 2023 Los Autores. Publicado por Elsevier España, S.L.U. Este es un artículo Open Access bajo la licencia CC BY-NC-ND (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Introduction

The goal of palliative care is to improve the quality of life of patients and their family members as they confront the problems inherent to a life-threatening illness.¹ In this situation, psychological, social, and spiritual health are considered equally important to physical health.² Based on the works of Ferris et al.,³ a model of care focused on needs with the ultimate aim of alleviating suffering has become established internationally. Care at the end of life is care for suffering; this suffering emerges when something is perceived as a major threat and, at the same time, one does not have sufficient resources to face it.^{4,5} In this sense, rather than focusing on threatened needs, attention should be focused on detecting and reinforcing the strengths of the system and, thus, increasing the sense of control. Focusing care only on people's needs promotes their infantilization.⁶ It has been suggested that this phenomenon be called "care blinders."⁷

Home care for severe and/or near-death patients is not only limited by the more or less sophisticated healthcare resources provided by the hospital and health centers, but also by the involvement of family and formal caregivers, who are often not available.⁷ In our setting, death has moved from a family and community setting to being primarily the domain of health systems.² Relationships and networks have been replaced by professionals and protocols which focus on needs, and primarily biological aspects.⁸ It is known that reductionism and compartmentalization can potentially be counterproductive in the challenge of managing complex problems.⁹

Following the conceptual model of complexity's role in the care of patients with multiple chronic diseases,¹⁰ complexity of care can be understood as the persistence of unease/suffering despite the care received. This depends on individual variables that arise from the patient's life experience and on the capacity for care of the healthcare team assessing him/her.¹¹ This means that in clinical practice, complexity would be equivalent to the team's difficulty in responding to the patient's specific needs at any given time. Previous studies have been able to objectify how complexity in home care is related to location of death such that probability of death in the hospital is greater in more complex cases¹² and that there is a linear association between complexity and location of death in the hospital.¹³

Among the palliative care complexity classification systems,¹⁴ only the HexCom-Clin model includes a specific section for the detection and assessment of strengths. It is based on the five ecological systems proposed by Bronfenbrenner¹⁵: microsystem (person, needs, and characteristics), chronosystem (dynamic influences of time), mesosystem (interactions with family/health professionals), exosystem (palliative care services/systems), and macrosystem (social influences) (Table 1). This categorization has undergone a qualitative¹⁶ and quantitative¹⁷ validation process.

This work aims to investigate the relationship between place of death and the strengths of the patient and his/her care environment. The specific objectives are: 1) link the place of death to the level of strength. 2) Determine which subtypes of strengths have the greatest influence on the place of death. 3) Link the place of death to the level of need.

Table 1 HexCom complexity model: needs and strengths.

NEEDS: identifies the patient's areas of discomfort and relates it to the possibility of a response by the department.

Levels of complexity and interpretation:

L — low (little difficulty). Guarantee of being able to address the situation with the department's resources.

M — medium (moderate difficulty). Guarantee of handling the situation with the support of other professionals and/or specialized teams.

H — high (refractory difficulty). Little possibility of change. Accompaniment and/or probable referral to another resource/level of care is required

Clinical	Physical discomfort due to symptoms (pain, dyspnea), refractory lesions (malignant ulcer), or therapeutic difficulty (adherence or access to drugs/techniques)
Psychoemotional	Maladaptive emotional unease (intense, persistent emotions that interfere with relationships and functionality), inflexible personality traits (poorly adaptive), psychopathological profile
Spiritual	Deep unease with a feeling of a biographical disruption, lack of meaning (personal, vital, suffering), loneliness (unwanted, isolation due to breakdown of relationships), feeling of guilt, impossibility to forgive (oneself, others), panic about the future (death itself or separation from loved ones), feeling of injustice
Social-family	Unease in the caregiver/patient relationship, insufficient care, no resources, no caregiver
Ethics	Unease due to information management, clinical decisions/adequacy of therapeutic effort (ATE), desire for hastened death (DHD)
Direct relationship with death/dying process	Unease due to problematic location of dying. Maladaptive denial of the final days of life (FDL), traumatic FDL difficult sedation (due to practice, indication, understanding). Risk factors for complicated grief

STRENGTHS: identifies the systemic source of strength and relates it to the possibility of reinforcing them by the department.

Levels of strength and interpretation:

L — Low (absent): There are no strengths or they are not used. Significant difficulty in being able to reinforce them.

M — Medium (precarious): Fragile support that must be validated, preserved, and strengthened as a priority.

H — High (consistent): Firm support that is unlikely to change during the course of the disease.

Microsystem	Individuals: the patient and his/her caregivers	PATIENT: strength of the patient (values, mental capacity, resilience/adaptability, preferences/priorities) CAREGIVER: strength of family caregivers (values, mental/physical capacity, resilience/adaptability, extensive network)
Mesosystem	Interactions: patient interaction with their relationship network and professional network	TIES: strength of family and/or community ties (tone of caring, organizational capacity, etc.) PROFESSIONAL TIES: strength of ties with referring professionals (primary care physician/nurse, specialist) FINANCES: financial strength
Chronosystem	Time: changes over time	PENDING ISSUES: having pending issues that cause concern (legacy, finances, bequest, ties, etc.) PROGRESSIVE COURSE: anticipating a progressive course of the disease without abrupt changes and without changes in the caregiving environment
Exosystem	Team: team competence	TEAM: the strength and competence of the team to meet the needs of the patient/family (interdisciplinary nature, training, communication, community integration, continuity, and consensus on the therapeutic objective)
Macrosystem	Resources: availability of health and social-health services/resources	SOCIAL-HEALTH RESOURCES: sufficient provision and accessibility to social-health services and/or resources to meet the patient's needs (continuity of care, home help service, dependency law, places in residential facilities, hospitalization or social-health admission, radiotherapy units, pain clinic, day hospital, etc.)

Patients and methods

This work is a quantitative, descriptive, longitudinal, cohort study.

Patients attended to by a home care support team in the period from January 1, 2019 to December 31, 2021

were analyzed. This team, created in 1992, comprises medical, nursing, psychology and social work professionals. Its coverage area includes a total of 193,520 inhabitants (urban and rural). It reports to the primary care management and does not have direct access to a palliative care unit.

Inclusion criteria

Patients at the end of life cared for at home and those already deceased in whom the HexCom-Clin model was used as a tool for assessing complexity after the first visit.

Exclusion criteria

Patients whose HexCom-Clin record was not completed. Patients cared for at nursing homes, patients in the bereavement program or volunteer program exclusively, and those attended to for a percutaneous gastrostomy replacement were excluded.

Definition of variables

- Sociodemographics: age, sex, partner as main caregiver (yes/no), family worker (yes/no) (Professional who cares for the patient and provides the care necessary for performing activities of daily living).
- Clinical: main diagnosis (oncologic/non-oncologic), performance status (degree of dependence: total/severe with Barthel ≤ 60), cognitive status (mild/moderate impairment: >2 errors Pfeiffer), prognosis (Palliative Performance Status ≤ 40 bedridden).
- Care: circumstances at discharge (death at home: yes/no).

Complexity variables

- Needs: clinical, psychoemotional, spiritual, social-familial, ethical, and in relation to dying (low (L), medium (M), or high (H) complexity). For the analysis, high and medium complexity were grouped and compared to low complexity.
- Strengths: patient microsystem, caregiver microsystem, family ties mesosystem, professional ties mesosystem, economic strength mesosystem, pending issues chronosystem, progressive course chronosystem, team exosystem, and social-health structure macrosystem (low (L), medium (M), or high (H)). For the analysis, low and medium strength were grouped and compared to high strength.

Data analysis

Pearson's chi-square test was used to determine independence or association between two variables through the comparison of proportions. On the bivariate logistic regression, the odds ratio (OR) with its corresponding confidence intervals and 95% significance was used to determine the weight of each variable in relation to the study variable (death at home: yes or no). On the multivariate logistic regression in a first saturated model, all factors that were found to be significant on the bivariate analysis or which had $p \leq 0.100$ were included. Next, those that were not significant were eliminated until the final model was reached. The level of significance was $p < 0.05$. All analyses were performed using the SPSS statistical package for Windows, version 25.0.

Ethics committee approval

The study was approved by the Clinical Research Ethics Committee of the Jordi Gol University Institute for Research on Primary Care (IDIAP, for its initials in Spanish) (registration number 4R19/125). All participants read and signed an informed consent form.

Results

Of the 930 new patients attended to during the study period, 464 patients met the inclusion/exclusion criteria (49.89%). The mean age was 76.2 (SD 13.2) years. Most were male (58%) and had oncologic disease (74.4%). Fifty-three percent had total or severe functional dependence (Barthel ≤ 60), 30.8% were already bedridden at the initial assessment (PPS ≤ 40), 70.9% had no cognitive impairment (Pfeiffer ≤ 2 errors), the main caregiver was the partner in 46.8% of cases, and 28.7% had the help of a family worker. A total of 277 patients (59.7%) died at home.

Table 2 shows that, regarding the general variables, patients who are young, male, and have cancer die in the hospital more often ($p < 0.001$). On the other hand, patients with functional or cognitive impairment and those who have a family worker died at home more often ($p < 0.001$). In regard to the needs detected in the first visit, it can be seen that all the areas of need are related to death in the hospital except for the area of psychological need ($p = 0.462$). In regard to strengths, strength in each of the subareas is related to death at home except for the strength of patient, which is related to death in the hospital ($p = 0.000$) and the strength of macrosystem, which appears to be unrelated to place of death ($p = 0.260$).

Table 3 shows the results of the bivariate analysis. As can be seen, performance status was the variable with the greatest weight in dying at home, both in relation to the Barthel Index OR 3.46 (2.34–5.10) and Palliative Performance Status (PPS) OR 4.53 (2.81–7.30), followed by cognitive impairment OR 2.54 (1.60–4.04, $p = 0.000$), and having a family worker OR 2.15 (1.39–3.33). On the other hand, it is observed that those who die at home less often are individuals with cancer OR 0.38 (0.24–0.61) or women OR 0.54 (0.37–0.79). Regarding the areas of need, it was found that the area related to death—which includes difficulties in planning the location, management of the final days of life, and the presence of risk factors for grief—was most related to dying outside the home OR 0.11 (0.06–0.19), followed by the area of social-familial need 0.45 (0.30–0.69). As for the strengths, the exosystem—that is, the team that cares for the patient itself—held the most weight, with OR 4.44 (2.53–7.78), followed by the strength of caregiver, OR 3.91 (1.88–8.12). The strength of the patient was the only subarea that behaved inversely, being linked to death outside the home OR 0.40 (0.26–0.61).

Table 4 shows the saturated and final logistic regression model: Dying at home was related to being bedridden (PPS ≤ 40) OR 2.68 (1.46–4.92), having cognitive impairment (Pfeiffer >2 errors) OR 1.93 (1.10–3.40), and female gender OR 1.63 (1.01–2.62). Regarding gender, it is important to mention that the interaction caused by the variables within the model inverted its β coefficient and, although it lost sta-

Table 2 Key characteristics stratified by patient. Place of death among patients in specialized home palliative care (N = 464).

	Total	Death at home		<i>p</i> Value
		No 187 (40.3%)	Yes 277 (59.7%)	
General variables				
Age (mean and SD)	76.2 (13.2%)	72.8 (13.0)	78.4 (12.8)	<0.001
Female gender	195 (42.0%)	62 (33.2%)	133 (48.0%)	0.001
Performance status (Barthel): total dependency, severe ≤60	247 (53.2%)	66 (35.3%)	181 (65.3%)	<0.001
Cognitive status (Pfeiffer): no cognitive impairment ≤2 errors	370 (79.7%)	132 (70.6%)	238 (85.9%)	<0.001
Prognosis (Palliative Performance Status) bedridden ≤40	143 (30.8%)	26 (13.9%)	117 (42.2%)	0.000
Caregiver: partner	217 (46.8%)	93 (49.7%)	124 (44.8%)	0.169
Family worker	133 (28.7%)	37 (19.8%)	96 (34.7%)	<0.001
Type of disease: oncological	345 (74.4%)	158 (84.5%)	187 (67.5%)	<0.001
Needs (high and medium complexity)				
Clinical need	231 (49.8%)	111 (59.4%)	120 (43.3%)	<0.001
Psychological need	263 (56.7%)	105 (56.1%)	158 (57.0%)	0.462
Spiritual need	194 (41.8%)	94 (50.3%)	100 (36.1%)	0.002
Social-familial need	311 (67.0%)	144 (77.0%)	167 (60.3%)	<0.001
Ethical need	102 (22.0%)	49 (26.2%)	53 (19.1%)	0.046
Death need	320 (69.0%)	171 (91.4%)	149 (53.8%)	<0.001
Strengths (high strength)				
Patient microsystem strength	324 (69.8%)	151 (80.7%)	173 (62.5%)	<0.001
Caregiver microsystem strength	427 (92.0%)	161 (86.1%)	266 (96.0%)	<0.001
Family ties mesosystem strength	435 (93.8%)	168 (89.8%)	267 (96.4%)	0.004
Professional ties mesosystem strength	429 (92.5%)	165 (88.2%)	264 (95.3%)	0.004
Financial strength mesosystem strength	404 (87.1%)	150 (80.2%)	254 (91.7%)	<0.001
Pending issues chronosystem strength	370 (79.7%)	127 (67.9%)	243 (87.7%)	<0.001
Progressive course chronosystem strength	289 (62.3%)	82 (43.9%)	207 (74.7%)	<0.001
Exosystem (team) strength	396 (85.3%)	139 (74.3%)	257 (92.8%)	<0.001
Macrosystem (social-health structure) strength	405 (87.3%)	166 (88.8%)	239 (86.3%)	0.260

Notes: Performance status (degree of dependence: total/severe with ≤60 Barthel). Cognitive status (no cognitive impairment ≤2 errors Pfeiffer). Prognosis (Palliative Performance Status: Bedridden with ≤40 PPS). Needs: for the analysis, high and medium complexity were grouped and compared to low complexity. Strengths: for the analysis, low and medium strength were grouped and compared to high strength.

tistical power in its *p* value, it continued to be statistically significant within the model. On the other hand, not dying at home was associated with cancer OR 0.47 (0.24–0.89). As for the areas of need, the only one that remained in the final model was the area in relation to death OR 0.19 (0.10–0.35), but with a very significant weight. Finally, the strengths that influenced the place of death were the strengths of exosystem (team) OR 4.07 (1.92–8.63), microsystem (both patient strength 0.51 (0.28–0.94) and caregiver strength OR 3.90 (1.48–10.25) but in an inverse manner), and chronosystem, regarding anticipation of a progressive course without abrupt changes OR 2.22 (1.37–3.60).

Discussion

These results suggest that systemic strengths strongly influence the complexity of care in palliative home care. Above all, the strength of exosystem (team) OR 4.07 (1.92–8.63), microsystem (both the strength of the patient 0.51 (0.28–0.94) and the caregiver OR 3.90 (1.48–10.25), and chronosystem, regarding anticipation of a progressive course OR 2.22 (1.37–3.60) had an influence.

The authors are not aware of any studies regarding strengths to support or refute these results. However, the data found in regard to the general variables related to the place of death seem to reinforce them. In this regard, various studies have shown how performance and cognitive status, age, and type of disease are related to dying at home or not.^{18–21} It seems obvious that the strength of team (exosystem) and the ability to anticipate a disease without abrupt changes (chronosystem) would favor death at home. In this regard, Alonso-Babarro, A et al. found that having a home palliative care team considerably decreased the risk of dying in the hospital (OR 0.4, 0.2–0.6).²² Furthermore, Gomes et al.²³ noted that abrupt changes in the course of a disease favored in-hospital death. As for the microsystem—that is the strengths of the patient and the caregiver—it seems that they would act inversely: if the strength is the caregiver, he/she will probably die at home, and if it is the patient, he/she will likely die in the hospital.

This could possibly indicate that we are in a setting that does not accept death and dying and that a patient with enough strength will continue to fight to the end.^{24,25} On the other hand, we are in a society in which information is still often withheld from the patient and the family member

Table 3 Bivariate logistic regression regarding circumstances at discharge (death at home) (N = 464).

	β	OR (95% CI)	p
General variables			
Age	0.033	1.03 (1.02–1.05)	<0.001
Gender: female	-0.622	0.54 (0.37–0.79)	0.002
Performance status (Barthel): total dependency, severe ≤ 60	1.240	3.46 (2.34–5.10)	<0.001
Cognitive status (Pfeiffer): Mild, moderate, severe impairment >2 errors	0.933	2.54 (1.60–4.04)	<0.001
Prognosis (Palliative Performance Status) bedridden ≤ 40	1.510	4.53 (2.81–7.30)	<0.001
Caregiver: partner	-0.199	0.82 (0.56–1.19)	0.293
Family worker	0.766	2.15 (1.39–3.33)	0.001
Type of disease: oncologic	-0.964	0.38 (0.24–0.61)	<0.001
Needs (high and medium complexity)			
Clinical need	-0.648	0.52 (0.36–0.76)	0.001
Psychological need	0.036	1.04 (0.71–1.51)	0.849
Spiritual need	-0.582	0.56 (0.38–0.82)	0.003
Social-familial need	-0.791	0.45 (0.30–0.69)	<0.001
Ethical need	-0.406	0.67 (0.43–1.04)	0.072
Death need	-2.217	0.11 (0.06–0.19)	<0.001
Strengths (high strength)			
Patient microsystem strength	-0.925	0.40 (0.26–0.61)	<0.001
Caregiver microsystem strength	1.362	3.91 (1.88–8.12)	<0.001
Family ties mesosystem strength	1.105	3.02 (1.37–6.65)	0.006
Professional ties mesosystem strength	0.996	2.71 (1.33–5.52)	0.006
Financial strength mesosystem strength	1.002	2.72 (1.56–4.76)	<0.001
Pending issues chronosystem strength	1.217	3.38 (2.11–5.41)	<0.001
Progressive course chronosystem strength	1.331	3.79 (2.55–5.63)	<0.001
Exosystem (team) strength	1.490	4.44 (2.53–7.78)	<0.001
Macrosystem (social-health structure) strength	-0.229	0.80 (0.45–1.40)	0.431

Notes: Performance status (degree of dependence: total/severe with ≤ 60 Barthel). Cognitive status (mild, moderate, severe impairment >2 errors Pfeiffer). Prognosis (Palliative Performance Status: bedridden with ≤ 40 PPS). Needs: For the analysis, high and medium complexity were grouped and compared to low complexity. Strengths: for the analysis, low and medium strength were grouped and compared to high strength.

is the one with more information and, thus, decision-making power. In this regard, Costa et al. found that coherence in decision making between the patient and caregiver was the strongest predictor of place of death.²⁶ Another explanation could be that if the strength is the patient, he/she would want to protect his/her care environment and therefore would prefer not to die at home. In any case, these results are preliminary and exploratory; they will need to be explored further, perhaps using qualitative methods.

This study has various limitations. The first limitation is that the opinion of the patient and his/her care environment was not considered, nor was that of the different actors in the system, such as the health and social primary care professionals involved or the professionals in the hospital units. However, the apparent validity demonstrated with the HexCom-Clin model¹⁶ and the corresponding reliability studies¹⁷ lend a certain degree of strength to the results. Likewise, the evaluation team is an interdisciplinary team with extensive healthcare and research experience.

The second limitation is more conceptual. Despite being a topic of growing interest, the conceptualization of complexity in palliative care is not well established.¹⁴ This work is based on the hypothesis that the greater the complexity of care, the easier it is to die in the hospital. Clinical practice and previous studies do indeed suggest this,^{12,27} but it remains a hypothesis and a simplification. The

paradigm of complexity focuses on the interaction of variables. These results suggest that more than one particular area of strength, it is the interaction between the different strengths that is more important.

Finally, this study encompasses the COVID-19 period, in which the pandemic severely compromised the various health services.^{28,29} At that point, home care was considerably limited and the location of the death was changed and determined by factors such as the availability of services and difficulties in social-familial accompaniment.^{30,31} One of the anomalies observed is the lack of a HexCom record in some of the patients in this period. It is also true that this opens up a future line of research into differences in regard to complexity and resources in the COVID-19 era.^{32,33}

Home teams providing end of life care for a patient must have a comprehensive, realistic vision,³⁴ and this reality includes both the needs, which will always be increasing, and the strengths, which must be reinforced.³⁵ The analysis of strengths in the first visit can help in planning the place of death. Assessing the strength of caregiver (microsystem), the team itself (exosystem), and foreseeing a progressive disease course without disruptions (chronosystem) may have a greater influence on planning for death at home than the needs detected at that time. However, complexity is a dynamic concept that will change over time as the disease progresses and is the result of the interaction among

Table 4 Logistic regression model regarding circumstances at discharge (death at home) (N = 464).

	Saturated model		
	β	OR (95% CI)	p
General variables			
Family worker	0.121834	1.13 (0.61–2.08)	0.695
Performance status (Barthel): total dependency, severe ≤ 60	0.483722	1.62 (0.92–2.86)	0.095
Cognitive status (Pfeiffer): mild, moderate, severe impairment >2 errors	0.601199	1.82 (1.02–3.28)	0.044
Prognosis (Palliative Performance Status): bedridden ≤ 40	0.951229	2.59 (1.32–5.08)	0.006
Age	0.008225	1.01 (0.99–1.03)	0.436
Gender: female	0.435489	1.55 (0.94–2.55)	0.088
Type of disease: oncological	-0.48355	0.62 (0.30–1.27)	0.189
Clinical need	-0.14354	0.87 (0.531.41)	0.562
Social-familial need	0.446881	1.56 (0.86–2.85)	0.145
Death need	-1.67685	0.19 (0.09–0.38)	<0.001
Ethical need	-0.1558	0.86 (0.48–1.51)	0.592
Spiritual need	0.351631	1.42 (0.84–2.40)	0.187
Strength patient microsystem	-0.56756	0.57 (0.29–1.11)	0.100
Caregiver microsystem strength	1.346329	3.84 (1.32–11.19)	0.014
Family ties mesosystem strength	-0.05389	0.95 (0.27–3.36)	0.933
Professional ties mesosystem strength	0.349969	1.42 (0.51–3.97)	0.505
Financial strength mesosystem strength	0.446376	1.56 (0.73–3.32)	0.246
Pending issues chronosystem strength	0.40626	1.50 (0.79–2.86)	0.217
Progressive course chronosystem strength	0.691044	2.00 (1.18–3.38)	0.010
Exosystem (team) strength	1.294698	3.65 (1.63–8.17)	0.002
Constant	-3.39814	0.03 (0.00–0.00)	0.012
Final model			
Cognitive status (Pfeiffer): mild, moderate, severe impairment >2 errors	0.659005	1.93 (1.10–3.40)	0.022
Palliative performance status: bedridden ≤ 40	0.986832	2.68 (1.46–4.92)	0.001
Gender: female	0.486768	1.63 (1.01–2.62)	0.045
Type of disease: oncological	-0.76062	0.47 (0.24–0.89)	0.021
Death need	-1.65019	0.19 (0.10–0.35)	<0.001
Patient microsystem strength	-0.66743	0.51 (0.28–0.94)	0.032
Caregiver microsystem strength	1.360469	3.90 (1.48–10.25)	0.006
Progressive course chronosystem strength	0.796464	2.22 (1.37–3.60)	0.001
Exosystem (team) strength	1.403538	4.07 (1.92–8.63)	<0.001
Constant	-1.1415	0.32 (0.00–0.00)	0.097

Notes: Performance status (degree of dependence: total/severe with ≤ 60 Barthel). Cognitive status (mild, moderate, severe impairment >2 errors Pfeiffer). Prognosis (Palliative Performance Status: bedridden with ≤ 40 PPS). Needs: for the analysis, high and medium complexity were grouped and compared to low complexity. Strengths: for the analysis, low and medium strength were grouped and compared to high strength.

the different variables. On the contrary, it would be advisable to have a bed in a palliative care unit in advance if the individual is a patient with cancer without functional dependence. Ultimately, the aim is to ensure that people can die at home, limiting transfers to hospitals as much as possible⁷ and preventing the patient's dying moments from occurring in the hospital to the extent it is possible.³⁴

In future studies, it is essential to include the different care resources where the patient may die and which intervene in the process (nursing homes, social-health care, acute care hospital) as well as the variable of time of care, which other studies have shown significantly influences the place of death.¹³ On the other hand, it would be interesting to delve deeper into the role of the gender variable in regard to strengths and its impact on complexity, taking into account both the strengths of the patient and the caregiver.

Conclusion

In conclusion, in order to improve care for patients at the end of life and their families, a systemic view of death and dying² that includes both needs and strengths is needed. In this sense, the systemic framework proposed by Bonfren-brenner may be useful in clinical practice.¹⁵

Ethical considerations

The study was approved by the Clinical Research Ethics Committee of the Jordi Gol University Institute for Research on Primary Care (CEIC IDIAP, for its initials in Spanish) (registration number 4R19/125). All participants read and signed an informed consent form.

Funding

This study received partial funding from the JGol University Institute for Research on Primary Care (IDIAP) (4R17/053) and a research grant for the principal investigator (XB).

Conflicts of interest

All authors declare that they have no known financial interests or personal relationships that may appear to influence the work presented in this article.

Availability of databases and material for replication

The Jordi Gol IDIAP has no mechanism in place to store anonymized databases in public repositories. The data are not publicly available due to privacy restrictions. However, the properly anonymized databases can be made available to individuals through express request made to the principal investigator of the project and corresponding author of this article, Dr. Xavier Busquet-Duran (xbusquet@umanresa.cat).

Acknowledgments

To Rosa María García, of GREMSAS, and to all the members of the PADES Granollers team who participated in the study: Joana Llobera-Estrany, Ana Isabel López-García, Eva María Jiménez-Zafra, Olga Bosch-de la Rosa, Anna Moragas-Roca, Susana Martín Moreno, Emilio Martínez-Losada, Silvia Crespo-Ramírez, Eda Sara Persentil Viure, and María Jesús Micó.

References

1. World Health Organization. Palliative-Care. Published 2022. [Accessed 31 August 2023]. Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.
2. Sallnow L, Smith R, Ahmedzai SH, Bhadelia A, Chamberlain C, Cong Y, et al. Report of the Lancet Commission on the value of death: bringing death back into life. *Lancet*. 2022;399:837–84, doi:10.1016/S0140-6736(21)02314-X.
3. Ferris FD, Balfour HM, Bowen K, et al. A model to guide patient and family care. *J Pain Symptom Manage*. 2002;24:106–23, doi:10.1016/S0885-3924(02)00468-2.
4. Bayés R, Arranz P, Barbero JBP. Propuesta de un modelo integral para una intervención terapéutica paliativa. *Med Paliativa*. 1996;3:114–21.
5. Maté J, Mateo D, Bayés R, Casas C. Elaboración y propuesta de un instrumento para la detección del malestar emocional en enfermos al final de la vida. *Psicooncología*. 2009;6:507–18.
6. Gilligan C. La ética del cuidado. Barcelona: Fundació Víctor Grífols i Lucas; 2013. Cuadernos Número 30.
7. González Ramallo VJ, Gallego Alonso-Colmenares MM. Dying at home, a reasonable alternative to hospitalization. *Rev Clin Esp*. 2018;218:296–7, doi:10.1016/j.rce.2018.05.001.
8. Díez-Manglano J, Isasi de Isasmendi Pérez S, Rubio Gómez M, et al. Cuidados en los últimos días de vida en los pacientes hospitalizados en medicina interna. *Rev Clín Esp*. 2019;219:107–15, doi:10.1016/j.rce.2018.06.010.
9. Halpern SD. Toward evidence-based end-of-life care. *N Engl J Med*. 2015;373:2001–3, doi:10.1056/NEJMmp1509664.
10. Grembowski D, Schaefer J, Johnson KE, et al. A conceptual model of the role of complexity in the care of patients with multiple chronic conditions. *Med Care*. 2014;52 Suppl 2:S7–14, doi:10.1097/MLR.0000000000000045.
11. Codorniu N, Tuca A. Complexity levels of interventions in a hospital support team: descriptive study about prevalence, clinical characteristics and team organisation for each level. 3rd European Association for Palliative Care Research Congress-Stresa, Italy 2004. EAPC Abstracts., ed. *Palliat Med*. 2004;18:303–93.
12. Tuca A, Gómez-Martínez M, Prat A. Predictive model of complexity in early palliative care: a cohort of advanced cancer patients (PALCOM study). *Support Care Cancer*. 2018;26:241–9, doi:10.1007/s00520-017-3840-3.
13. Busquet-Duran X, Jimenez-Zafra E, Tura-Poma M, Bosc-de la Rosa O, Manresa-Dominguez J, Toran-Monserrat P. Trayectorias de complejidad en final de vida: un estudio multicéntrico prospectivo observacional longitudinal. *Med Paliativa*. 2021;28:13–22, doi:10.20986/medpal.2021.1155/2020.
14. Grant M, de Graaf E, Teunissen S. A systematic review of classifications systems to determine complexity of patient care needs in palliative care. *Palliat Med*. 2021;35:636–50, doi:10.1177/0269216321996983.
15. Pask S, Pinto C, Bristow K, et al. A framework for complexity in palliative care: a qualitative study with patients, family carers and professionals. *Palliat Med*. 2018;32:1078–90, doi:10.1177/0269216318757622.
16. Busquet-Duran X, Jiménez-Zafra EM, Tura-Poma M, et al. Assessing face validity of the Hexcom model for capturing complexity in clinical practice: a Delphi study. *Healthcare*. 2021;9:165, doi:10.3390/healthcare9020165.
17. Busquet-Duran X, Esteban-Perez M, Manresa-Domínguez JM, Moreno SM, Leston-Lado L, Torán-Monserrat P. Intra-rater reliability and feasibility of the HexCom advanced disease complexity assessment model. *Aten Primaria*. 2022;54:102343, doi:10.1016/j.aprim.2022.102343.
18. Pividic L, Pardon K, Morin L, et al. Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. *J Epidemiol Community Health*. 2016;70:17–24, doi:10.1136/jech-2014-205365.
19. Cabañero-Martínez MJ. Lugar de fallecimiento de las personas con enfermedades susceptibles de cuidados paliativos en las diferentes comunidades autónomas de España. *An Sist Sanit Navar*. 2020;43:69–80, doi:10.23938/ASSN.0856.
20. Davies JM, Sleeman KE, Leniz J, et al. Socioeconomic position and use of healthcare in the last year of life: a systematic review and meta-analysis. *PLoS Med*. 2019;16:e1002782, doi:10.1371/journal.pmed.1002782.
21. Jordan RI, Allsop MJ, ElMokhallalati Y, et al. Duration of palliative care before death in international routine practice: a systematic review and meta-analysis. *BMC Med*. 2020;18:368, doi:10.1186/s12916-020-01829-x.
22. Alonso-Babarro A, Bruera E, Varela-Cerdeira M, et al. Can this patient be discharged home? Factors associated with at-home death among patients with cancer. *J Clin Oncol*. 2011;29:1159–67, doi:10.1200/JCO.2010316752.
23. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care*. 2013;12:7, doi:10.1186/1472-684X-12-7.
24. Schroepfer TA. Mind frames towards dying and factors motivating their adoption by terminally ill elders. *J Gerontol B Psychol Soc Sci*. 2006;61:S129–39, doi:10.1093/geronb/61.3.S129.
25. Saeed F, Hoerger M, Norton SA, Guancial E, Epstein RM, Duberstein PR. Preference for palliative care in cancer patients: are men and women alike? *J Pain Symptom Manage*. 2018;56:1–6, doi:10.1016/j.jpainsymman.2018.03.014, e1.

26. Costa V, Earle CC, Esplen MJ, et al. The determinants of home and nursing home death: a systematic review and meta-analysis. *BMC Palliat Care.* 2016;15:8, doi:10.1186/s12904-016-0077-8.
27. Busquet-Duran X, Jiménez-Zafra EM, Manresa-Domínguez J-M, et al. Describing complexity in palliative home care through HexCom: a cross-sectional, multicenter study. *J Multidiscip Healthc.* 2020;13:297–308, doi:10.2147/JMDH.S240835.
28. Gómez-Batiste X, Leiva JP, Tuca A, et al. Organización paliativa durante la pandemia de la COVID-19 y propuestas para la adaptación de los servicios y programas de cuidados paliativos y de atención psicosocial ante la posibilidad de reactivación de la pandemia y época pos-COVID-19. *Med Paliativa.* 2020;27:242–54, doi:10.20986/medpal.2020.1184/2020.
29. García Caballero R, Herreros B. Areas for improvement in end-of-life care. *Rev Clin Esp.* 2021;221:341–2, doi:10.1016/j.rce.2020.06.007.
30. Buscemi V, López M, Bosch O, et al. Aprendiendo de la experiencia del duelo en el contexto de la pandemia por el COVID-19. *Med Paliativa.* 2021;28:166–76, doi:10.20986/medpal.2021.1243/2021.
31. Bullich-Marín I, Costas-Muñoz E, López-Matons N. Cuidados paliativos al final de la vida en tiempos de pandemia: la experiencia del PADES-COVID. *Med Clin (Barc).* 2022;158:239–40, doi:10.1016/j.medcli.2021.02.016.
32. Sanz Peces EM, Vázquez Ramos V, Tejero González J, et al. Impacto de la pandemia por COVID-19 en pacientes con necesidades paliativas atendidos por un equipo de soporte de atención domiciliaria. *Med Paliativa.* 2022;29:88–95, doi:10.20986/medpal.2022.1313/2022.
33. Rubio YA, Jiménez-Rojas C, Gómez-Pavón FJ. Efectos de la pandemia por COVID-19 en la actividad de una unidad de cuidados paliativos. *Med Clin (Barc).* 2021;156:520–1, doi:10.1016/j.medcli.2021.01.001.
34. Conthe P. El médico clínico ante el paciente en el final de sus días. *Rev Clin Esp.* 2018;218:15–6, doi:10.1016/j.rce.2017.10.006.
35. Stajduhar KI, Funk L, Roberts D, et al. Home care nurses' decisions about the need for and amount of service at the end of life. *J Adv Nurs.* 2011;67:276–86, doi:10.1111/j.1365-2648.2010.05491.x.