Palliative and Supportive Care (2017), **15**, 98–109.

doi:10.1017/S1478951516000857

Enhancing psychosocial and spiritual palliative care: Four-year results of the program of comprehensive care for people with advanced illnesses and their families in Spain

XAVIER GÓMEZ-BATISTE, M.D., PH.D.,[1] DOLORS MATEO-ORTEGA, PH.D. PSYC.,[1]
CRISTINA LASMARÍAS, R.N., B.A., M.SC.,[1] ANNA NOVELLAS, B.A. SOC.W.,[1]
JOSE ESPINOSA, M.D., M.SC.,[1] ELBA BEAS, C.N.A.,[1] SARA ELA, B.A.,[1]
JAVIER BARBERO, PH.D. PSYC.[2] AND FOR THE "LA CAIXA" FOUNDATION[3]

[1]The Qualy End-of-Life Observatory–WHO Collaborating Center for Palliative Care Programs, Catalan Institute of Oncology. Barcelona, Spain
[2]Hematology Unit, Hospital Universitario La Paz. Madrid, Spain
[3]Area of Social Integration, La Caixa Foundation. Barcelona, Spain

(RECEIVED August 2, 2015; ACCEPTED October 7, 2016)

ABSTRACT

Objective: We aimed to describe the overall quantitative and qualitative results of a "La Caixa" Foundation and World Health Organization Collaborating Center Program entitled "Comprehensive Care for Patients with Advanced Illnesses and their Families" after four years of experience.

Method: Qualitative and quantitative methods were employed to assess the program. Quasiexperimental, prospective, multicenter, single-group, and pretest/posttest methods were utilized to assess the quantitative data. The effectiveness of psychosocial interventions was assessed at baseline (visit 1) and after four follow-up visits. The following dimensions were assessed: mood state, discomfort, anxiety, degree of adjustment or adaptation to disease, and suffering. We also assessed the four dimensions of the spiritual pain scale: faith or spiritual beliefs, valuable faith or spiritual beliefs, meaning in life, and peace of mind/forgiveness. Qualitative analyses were performed via surveys to evaluate stakeholder satisfaction.

Results: We built 29 psychosocial support teams involving 133 professionals—mainly psychologists and social workers. During the study period, 8,964 patients and 11,810 family members attended. Significant improvements were observed in the psychosocial and spiritual dimensions assessed. Patients, family members, and stakeholders all showed high levels of satisfaction.

Significance of Results: This model of psychosocial care could serve as an example for other countries that wish to improve psychosocial and spiritual support. Our results confirm that specific psychosocial interventions delivered by well-trained experts can help to ease suffering and discomfort in end-of-life and palliative care patients, particularly those with high levels of pain or emotional distress.

KEYWORDS: Palliative care, Advanced disease, Integrated care, Psychosocial care, Comprehensive care

INTRODUCTION

The growing prevalence of chronic illness in developed countries presents a significant challenge. Chronic illness—and its treatment—negatively impact the physical and emotional well-being of both

---

Address correspondence and reprint requests to: Xavier Gómez-Batiste, The Qualy Observatory–WHO Collaborating Center for Palliative Care Public Health Programs, Catalan Institute of Oncology, Avenida Gran Via 199–203, 08908 l'Hospitalet de Llobregat, Barcelona, Spain. E-mail: xgomez@iconcologia.net.

patients and family members, particularly caregivers. Despite the growing acceptance of palliative care (PC) for end-of-life care, it has become increasingly clear that patients and their families require not only physical care but also comprehensive emotional care. Although all aspects of PC—including the emotional and social support components—have steadily evolved and improved over time, in most cases this improvement has been ad hoc rather than systematic (Kamal et al., 2013). As a result, psychosocial and spiritual needs are often overlooked or considered secondary to physical and treatment-related needs.

Several studies have demonstrated the importance and value of psychosocial support for terminally ill patients (Goodwin et al., 2001; Bruera & Yennurajalingam, 2012). Given the complexity of such patients and the substantial resources required for their care, a comprehensive approach to meeting the multidimensional needs of these patients and their families is urgently needed. Many studies have investigated the value of community-based PC programs (Aiken et al., 2006; Brumley et al., 2007; Hughes et al., 2010; Rabow et al., 2004; Zimmer et al., 1985; Bakitas et al., 2009; Jordhøy et al., 2000), although, as Seow and colleagues (2014) observed, the psychosocial aspects of PC generally receive little or no attention in such studies due to financial limitations and, perhaps more importantly, because PC remains an evolving concept. Despite the aforementioned development of local community-based PC models, to our knowledge, no truly comprehensive programs have been implemented on a national or regional basis.

According to a recent qualitative analysis carried out in Spain, the main aspects of PC most in need of improvement lie within the spiritual, psychosocial, and bereavement domains (Gómez-Batiste et al., 2008*a*; 2012; 2016). In this context, a recent proposal called for development of a comprehensive model of care to address the multidimensional needs of patients with chronic illness (Maté-Méndez et al., 2013). The present report found that patients with advanced conditions have numerous essential (i.e., nonphysical) needs, including the following: spiritual-existential necessities, dignity, autonomy, love, tenderness, and hope.

In short, the psychosocial needs of patients and their families comprise an important but largely ignored component of PC. Recent studies of psychological therapies have yielded relevant results in terms of effectiveness and have demonstrated improvement regarding life meaning and well-being in end-of-life patients (Rosenfeld et al., 2016; Breitbart, 2003; Breitbart et al., 2015; Chochinov et al., 2011; Gil Moncayo & Breitbart, 2013; Breitbart et al., 2010).

The idea for the need to develop a new approach to psychosocial care of terminally ill patients and their families arose from two previous studies carried out to assess the status of PC programs in Spain (Gómez-Batiste et al., 2008*b*; 2008*c*). These studies identified several key but underserved areas in the public health and PC realms in need of improvement: the emotional, social, and spiritual aspects of care, as well as care during the bereavement process. Such an innovative approach was developed in Spain under the auspices of the Spanish National Strategy for Palliative Care.

The first step in developing this program was to identify the main psychosocial care needs of the population. Once these were determined, a program was specifically designed to meet those needs as efficiently and effectively as possible. The primary aims of this program—managed jointly by the "La Caixa" Foundation (LCF) and the World Health Organization Collaborating Center for Palliative Care Public Health Programs (WHOCC) (Ela et al., 2014)—were to improve the psychosocial and spiritual aspects of PC for both patients and families. Importantly, given the lack of existing models for delivery and organization of this type of care within a PC model, this program was created from the ground up. Although the primary objective of the project was to improve patient care, an important secondary aim was to accumulate evidence about the interventional and organizational models that work best in this population (Mateo-Ortega et al., 2013).

The LCF–WHOCC program involves a total of 29 psychosocial support teams (PSTs) comprised of psychologists, social workers, nurses, and other professionals (primarily physicians, but in some cases physiotherapists and chaplains). Early results in terms of psychological and spiritual well-being were promising, with significant improvements on numerous parameters—including anxiety, emotional distress, life meaning, peace of mind, and forgiveness (Gómez-Batiste et al., 2011).

We report herein the updated qualitative and quantitative results obtained through patient medical records and satisfaction surveys of relevant stakeholders (patients, relatives, and PC teams). To our knowledge, this is the first large-scale program of its kind. The only other psychosocial initiative on this scale that we are aware of—"Improving Access to Psychological Therapies" (IAPT)—was developed in the United Kingdom (Clark et al., 2009) but with a very different focus (the general emotional care of patients with anxiety or depression), rather than specific care for advanced chronically ill patients. The LCF–WHOCC organizational model presented here, in which highly specialized and well-trained PSTs were created specifically to coordinate and deliver care in cooperation with existing palliative or conventional care services, is completely novel and unique in terms of its size (more than 100,000 individuals), its model of organization based on support teams, and its national scope (Figure 1). Briefly, our study was a collaborative effort funded by the LCF (a private foundation) and the WHOCC, which in Spain includes the Qualy End-of-Life Observatory at the Catalan Institute of Oncology in Barcelona. This program and the use of data were approved by the ethics committee of the Bellvitge University Hospital in Barcelona, Spain.

METHODS

A theoretical model of care and organization was developed. This model first defined the psychosocial dimensions of care and then created a systematic approach to meet those specific psychosocial and spiritual dimensions. The main focus—and the novelty of the approach—was the creation of specialized dedicated teams of specialists (i.e., the PSTs), whose role was to complement preexisting PC services. The PSTs were given the task of providing emotional support, spiritual care, and bereavement assistance for patients and their families. The program was led by a full-time management team of five professionals from the LCF and the WHOCC, supported by an expert group of experienced PC professionals.

Each PST was composed of three full-time professionals, one of whom acted as the team leader (on either a full- or part-time basis). A total of 133 professionals were appointed and assigned to 29 different PSTs, which were tasked with providing support to 61 PC teams (mean = 3.58 PC teams per PST). Later, when PSTs had gained more experience and efficiency, they also provided support for an additional 134 PC teams. Each PST was organized by a variety of not-for-profit organizations. Table 1 describes the primary duties of the PSTs.

Training of PST Members

All members received comprehensive training on the key aspects of psychosocial PC. The training program consisted of 12 on-site two-day sessions, covering all topics and methodologies relevant to the psychosocial approach. A member of the core team was responsible for monitoring each PST and for individualizing improvements when necessary. The staff also received online training to complement the in-person training. The PST teams began their initial activity, in most cases, during January of 2009.

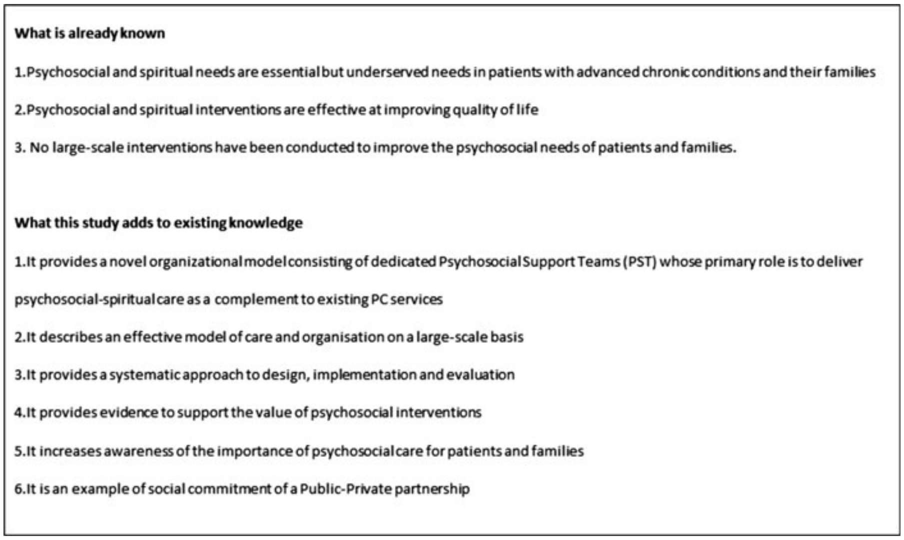
Quantitative Data Collection and Analysis

All data were entered into a computer database, including the following: patient and family data (characteristics, types, number); output data (duration of visits, first follow-up, place of care, etc.); and intervention (assessment/follow-up, number of assessments). The majority of the data for the present report was retrieved from an intranet created to allow the care teams to systematically enter all relevant data. Access to this platform was fully confidential and restricted to professionals involved in the program.

Clinical Variables and Outcome Measures

Patients and Families

For the purposes of the present prospective study, we evaluated all data from January 1 to September 30, 2012. This study period was selected for two reasons: (1) changes were made to the online platform and the



What is already known

1.Psychosocial and spiritual needs are essential but underserved needs in patients with advanced chronic conditions and their families

2.Psychosocial and spiritual interventions are effective at improving quality of life

3. No large-scale interventions have been conducted to improve the psychosocial needs of patients and families.

What this study adds to existing knowledge

1.It provides a novel organizational model consisting of dedicated Psychosocial Support Teams (PST) whose primary role is to deliver psychosocial-spiritual care as a complement to existing PC services

2.It describes an effective model of care and organisation on a large-scale basis

3.It provides a systematic approach to design, implementation and evaluation

4.It provides evidence to support the value of psychosocial interventions

5.It increases awareness of the importance of psychosocial care for patients and families

6.It is an example of social commitment of a Public-Private partnership

Fig. 1. Key points of this article.

Table 1. *Main activities of the psychosocial support teams*

Primary activities	
Support palliative care units	Training sessions, and support for preventive care team Case analysis meetings and interventional planning Individualized intervention in specific cases Informal support actions in specific situations and promotion of mutual support between the PC team and the PST Help the PC team in making difficult decisions (primarily ethical)
Provision of patient-centered care	Assessment of discomfort and helping patients and families with adjustment difficulties Spiritual care Supportive psychotherapy Help in resolving practical issues (financial, public assistance programs, wills, paperwork to obtain support with wheel chairs, finding household help outstanding issues Short-term individual psychotherapy sessions Apply specific psychological techniques (counseling, cognitive behavioral therapy, narrative therapy, life review therapy, redefinition, dignity therapy or legacy, and search for meaning) depending on the needs of each patient
Family-centered care	Assessment of family needs Psychoeducation regarding the relationship between the patient and family members Capacity building to help caregivers organize care Mediation of interpersonal relationship problems Provide advice about available community resources Psychotherapeutic interventions in cases of distress
Bereavement care	Detect risk factors for complicated grief Mental healthcare for bereavement Intervention in complex situations Care for most vulnerable family members Advice and/or referral to community resources
Registration platform	Input data (on assessments and interventions) into computerized platform
Administrative	Processing pensions, financial aid, legal documents, etc. Coordination with other centers
Training	Attend courses conducted by the program and other external related to the subject
Knowledge contribution	Contribute knowledge to community entities; courses, conferences, workshops, etc.
Volunteer management	Selection, coordination, and monitoring of volunteers

variables after September 30, 2012, thus making future comparisons more difficult; and (2) the aim of this project was to achieve continuous improvement, thus necessitating regular assessments and modifications to the program. In this case, our goal was to evaluate the data collected during the first nine months of the year, with the intention of assessing the data in order to develop and implement modifications at the start of the next year.

Patient data were retrieved from clinical records. The effectiveness of the intervention was assessed by comparing the score at the baseline visit (visit 1) to, at least, the next two successive visits (visits 2 and 3). The sample included subjects with at least three interventions. Analysis was performed up to the fifth follow-up visit. Not all subjects supplied answers for every evaluated dimension, but to those which applied in each case.

The following parameters were assessed at admission and at all follow-up visits for patients: mood, discomfort, anxiety (on a numerical scale from 0 to 10), degree of adjustment or general adaptation to disease (on a numerical-verbal scale from 1 to 5), and suffering (on a categorical scale from short to long). The four dimensions of the spiritual pain scale are those that were used at the San Diego Hospice/Institute of Palliative Medicine (Ferris et al., 2002; 2007). The scale assessed relationships, peace of mind, hope, and meaning in life using a Likert-type scale methodology, ranging from “not at all” to “very much.”

Regarding family members, the following psychosocial dimensions were assessed: discomfort, anxiety, depression, and insomnia (on a numerical scale from 0 to 10). Assessment was also performed using a Likert-type scale methodology, ranging from “not at all” to “very much.”

Organizational Audits

A leadership team (LT) tasked with overseeing program implementation was created. This team was staffed jointly by the LCF and the WHOCC. The LT regularly performed in-situ visits to all teams. During these visits, a semistructured survey was administered to collect data on the following: clinical activity, quality of care, team training, and relationships with PC teams and other stakeholders. In addition to interviewing PST members, the LT also interviewed the directors and managers of these teams.

External Audits

A professional auditor (Pricewaterhouse Coopers [PWC], London, United Kingdom) carried out an external organizational audit to assess the following areas: management, coordination, activity, and services. The audit also involved in-situ visits to all teams, a review of a random sample of clinical charts, the clinical activity of the teams, and an economic and budgetary follow-up analysis.

Qualitative Measurements

Numerous qualitative assessments were performed, including a randomized chart review, stakeholder survey, and satisfaction surveys for patients and families. The assessments and instruments utilized in these assessments are described below.

An expert social worker (senior psychosocial care professional) and a data manager were tasked with evaluating a random sampling ($n = 348$) of patient and family clinical psychosocial records. The social worker qualitatively assessed the following dimensions: needs assessment, objectives, therapeutic plan, and use of correct terminology. The objectives of this qualitative assessment were to identify the patient's main concerns and problems, to determine the psychosocial diagnosis used to establish the therapeutic plan and objectives, and to assure coherence between initial assessment and case follow-up. These assessments were performed for all individuals who received care from the PST (i.e., both patients and family members).

The following were identified as stakeholders in the PST program: (1) members of PC teams supported by PSTs, (2) managers of both providers and PC teams, (3) policymakers from regional departments of health, and (4) key professional leaders (e.g., leaders of related medical societies and the Spanish Association of Psychologists). A total of 506 stakeholders were identified, and a structured survey (>100 questions on various domains) was sent to all these individuals by post. The survey questions included the following domains: (1) knowledge of the program; (2) knowledge of the functions of PSTs; (3) program acceptance; (4) relationship and degree of coordination between PSTs and PC teams; (5) evaluation of the care delivered by PST professionals; (6) assessment of PST professionals (training/preparation, competence, commitment); (7) contribution of PSTs to the care of patients/family members (psychological support, detection of mental health problems, reduction of anxiety or depressive symptoms, spiritual support, improvement in quality of life); (8) overall satisfaction with the program; (9) continuity of the program (likelihood, necessity); and (10) value added by the program. In most cases, these domains were assessed on an 11-point scale (from 0 to 10).

When a patient death occurred, a survey was sent to the family (600 families) three months after the death to assess: (1) the perceived quality of the psychosocial care for the patient, (b) the quality of care received (by patient and family), and (c) suggestions for service improvement.

Statistical Analysis

All study variables were analyzed at the baseline visit and again at follow-up visits using the appropriate descriptive statistics depending on the nature of the variable. The continuous variables included number of observations, mean, standard deviation (*SD*), standard error of the mean (*SEM*), minimum, median, and maximum. Categorical variables included number of observations and column percentages (n, %).

Training

After the initial postgraduate course on psychosocial palliative care, other formal training activities and follow-up were instituted. The directors were trained in how to improve managerial and mentoring skills, and clinical and methodological training were reinforced. Additionally, all teams had ongoing access to the LT for consultation and support for both the organizational and clinical aspects of the program.

RESULTS

A total of 29 PSTs involving 133 professionals were created. Most teams included at least one psychologist and one social worker, and usually either a nurse or doctor, or both (less commonly, a physiotherapist or chaplain). Each team comprised a mean of 3.6 professionals (2.5 psychologists, 0.83 social workers, and 0.27 nurse/doctor/other [chaplain, physiotherapist]). These 29 PSTs served a total of 134 PC teams: 74 based in hospitals and 60 PC home units.

Quantitative Results: Patients and Families

During the inclusion period, a total of 8,964 patients (54.8% male) attended. The mean age was 70.4 years (range = 1–103 years). Most patients (77.9%) had a cancer diagnosis (primarily lung, colorectal, or breast cancer), while the remaining 22.1% had other chronic diseases or conditions (mainly geriatric frailty, multimorbidity, dementia, or cardiac/respiratory failure) (Table 2). A total of 92 pediatric patients (excluded from the effectiveness analysis) received care from PSTs, primarily for cancer, including leukemia, brain cancer, bone cancer, and lymphoma.

A total of 11,810 family members attended during the inclusion period. The average age of family caregivers was 55.3 years ($SD = 15.8$). Most caregivers were female (70.2%). After first contact, 45.9% had at least one follow-up visit, and 24.3% had two or more. By relationship with the patient, most family members were either children (42.5%) or spouses (28.1%). Retired family members made up 21.6% of the sample.

A total of 23,436 patient and family consultations were performed. The mean duration of each intervention was three weeks. Slightly more than half (51.8%) of patients required at least one follow-up intervention (31.5% required ≥ 2). A mean of two follow-up interventions were performed per patient, with a median length of seven days between visits. Most interventions (64.4%) were performed at an institutional unit, with the remaining interventions occurring at home (23.7%) or in an outpatient clinic (9.6%) (data missing for 2.3% of cases).

Effectiveness of Interventions

For analysis of effectiveness, a total of 2,823 patients were included. Figure 2 shows a mixed-effects model adjusted by gender and age in 2,069 patients who answered questions about anxiety on three or more visits. The PST visit effect was significant (likelihood ratio [LR] $= 657.64$, $p < 0.0001$). Anxiety decreased by 7% between the first and second visits and by 12% between the first and third.

Figure 3 shows a mixed-effects model adjusted by gender and age in 2,104 patients who answered questions about emotional distress on three or more visits. We employed a visual analog scale (0–10). The visit effect was significant ($LR = 757.44$, $p < 0.0001$). Emotional distress decreased by 9% between the first and second visits and by 14% between the first and third.

Figure 4 shows that the 2,296 patients were twice as likely ($OR = 2.03$, $CI_{95\%} = 1.98–2.15$) to have a good or average mood state at the second versus the first visit. At the third PST visit, the corresponding OR was three times that of the first.

Figure 5 shows a mixed-effects model adjusted by gender and age in 1,234 patients who answered questions about meaning on three or more visits. The visit effect was significant ($LR = 248.30$, $p < 0.0001$), with life meaning scores decreasing by 4% between the first and second visits and by 7% between the first and third.

Table 2. *Main patient pathologies*

Oncological	77.9%	Non-oncological	22.1%
Lung	16.1%	Geriatric comorbidities	16.1%
Colorectal	10.6%	Dementia	3.7%
Breast	6.2%	Heart failure	2.7%

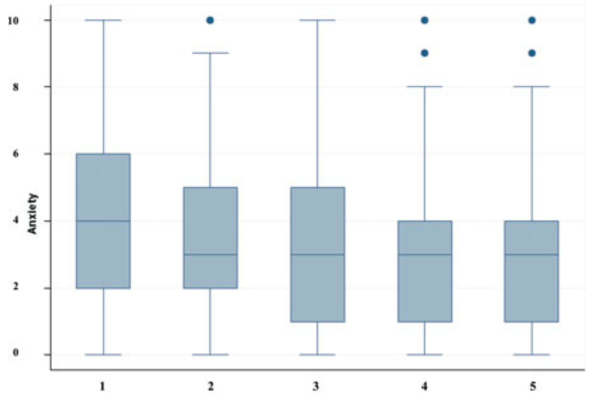


Fig. 2. Anxiety in patients: changes from first to fifth PST visit.

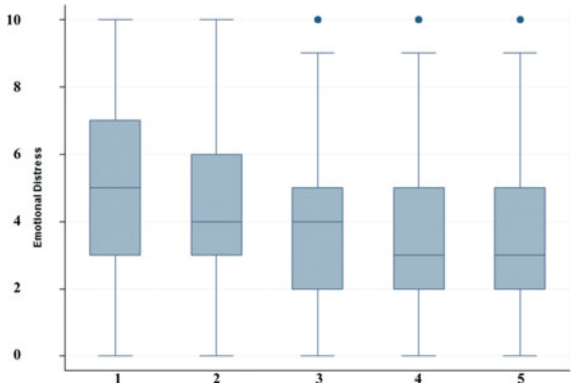


Fig. 3. Emotional distress in patients: changes from first to fifth PST visit.

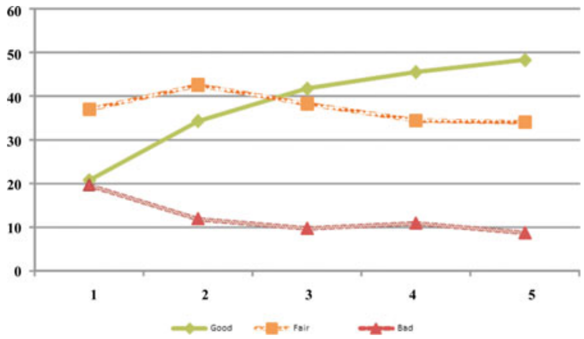


Fig. 4. Mood state in patients: changes from first to fifth PST visit.

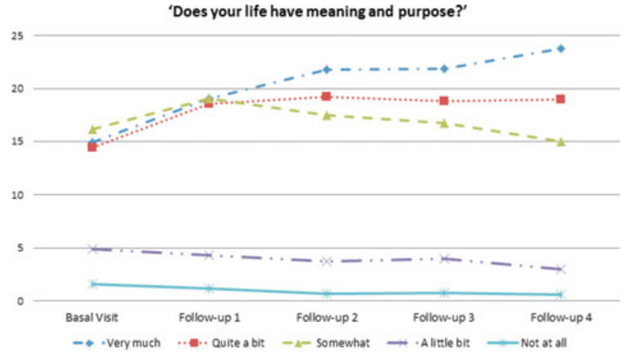


Fig. 5. Meaning in life for patients: changes from first to fifth PST visit.

In 1,175 patients who were interviewed on three or more visits, the visit effect was significant for peace of mind/forgiveness ($LR = 190.94$, $p < 0.0001$), decreasing by 3% between the first and second visits and by 6% between the first and third (Figure 6).

In 2,229 patients who were interviewed on three or more visits, the visit effect for general adaptation was significant ($LR = 653.09$, $p < 0.0001$), decreasing by 4% on the adaptation score between the first and second visits and by 7% between the first and third (Figure 7).

Regarding relatives, a total of 2,802 family members were included for the analysis of effectiveness. Figure 8 depicts a mixed-effects model adjusted by gender and age in 2,537 relatives who answered questions about emotional distress on three or more visits. The visit effect was significant ($LR = 1138.78$, $p < 0.0001$), with emotional distress decreasing by 10% between the first and second visits and by 14% between the first and third.

Figure 9 shows a mixed-effects model adjusted by gender and age in 2,535 relatives who answered questions about anxiety on three or more visits. The visit effect was significant ($LR = 1123.74$, $p < 0.0001$), with anxiety scores decreasing by 9% between the first and second visits and by 14% between the first and third.

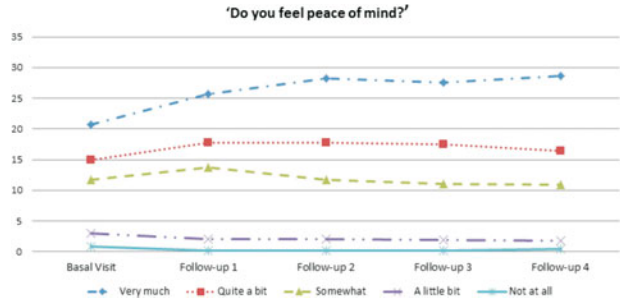


Fig. 6. Peace of mind and forgiveness for patients: changes from first to fifth PST visit.

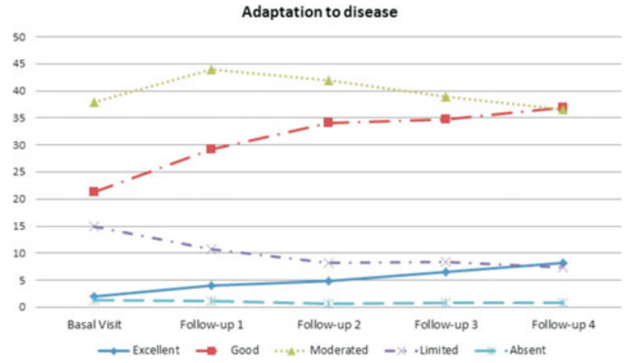


Fig. 7. General adjustment or adaptation to disease in patients: changes from first to fifth PST visit.

Figure 10 shows a mixed-effects model adjusted by gender and age in 265 relatives who answered questions about depression on three or more visits. The visit effect was significant ($LR = 16.99$, $p < 0.0002$), with the depression score decreasing by 4% between the first and second visits and by 8% between the first and third.

Figure 11 shows a mixed-effects model adjusted by gender and age in 189 relatives who answered questions about insomnia on three or more visits. The visit effect was significant ($LR = 8.32$, $p = 0.0156$), with insomnia in family members decreasing by 0% between the first and second visits and by 5% between the first and third.

Overall, significant improvements were observed on all follow-up assessments, and changes were significant for both patients and family members.

External Audit

The external audit team (PWC) visited all PC departments, interviewed the directors and managers of PC teams, and reviewed clinical and organizational documentation. The audit team carried out a total of 1,268 checks to assess 10 areas related to the

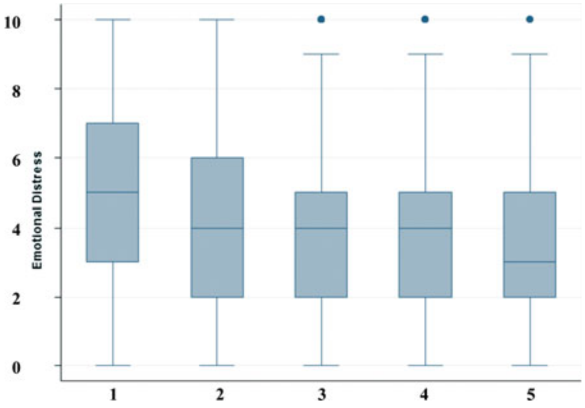


Fig. 8. Emotional distress in family members: changes from first to fifth PST visit.

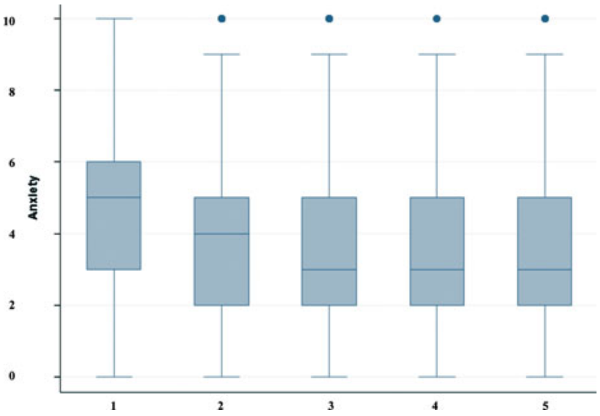


Fig. 9. Anxiety in family members: changes from first to fifth PST visit.

following: availability of clinical guidelines, compliance with data protection laws, economics, the structure of the PST, volunteer management, and administrative data. The auditors found some minor deviations from standard procedures (e.g., lack of compliance with patient/family visit timetable, incompletely justified expenses, and minor administrative errors) in 199 cases (15.7% of checks). In addition, of the 892 managerial aspects evaluated (financial, structural, procedural, volunteer management), 74 (8%) were considered in need of improvement. A total of 163 specific recommendations for improvement were made.

Random Psychosocial Chart Review/ Qualitative Analysis

Of the 348 clinical records reviewed, qualitative analysis showed that 62% met the overall quality criteria. In most cases (79%), the clinical record described and prioritized patient issues in a clear and specific manner. However, only 53% used appropriate terminology, while 62% defined "clear and specific" intervention objectives. Based on these results, we proposed improvements to individual teams and staff.

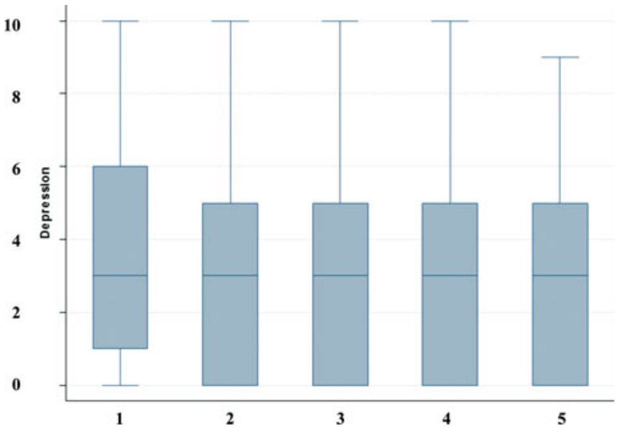


Fig. 10. Depression in family members: changes from first to fifth PST visit.

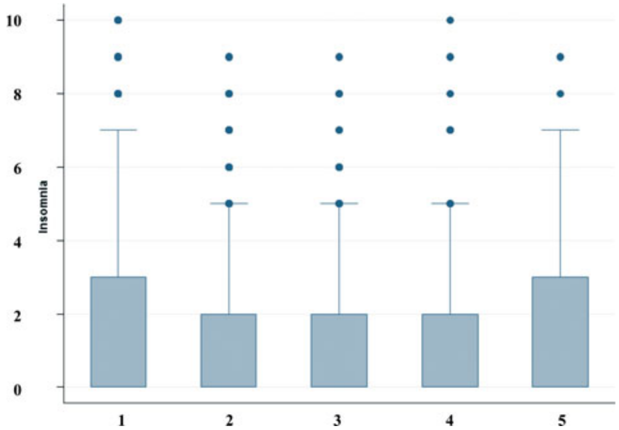


Fig. 11. Insomnia in family members: changes from first to fifth PST visit.

Stakeholder Survey

Overall, stakeholders reported a strong (8.1 out of 10) positive perception of the project in terms of both qualitative and quantitative measures. Stakeholders were surveyed about seven different dimensions (100 questions), providing responses on a numerical scale ranging from 0 to 10. An inferential analysis was performed using the Kruskal–Wallis method ($p \leq 0.05$ considered significant). The most important quantitative results of the survey of stakeholders are summarized in Table 3.

Satisfaction

A total of 85 professional leaders of PC departments (78% of the PC teams in the program) responded to the 25-question survey (numerical scale ranging from 0 to 5, in which 0 was "absolutely disagree" and 5 "absolutely agree"). The main results are shown in Table 4.

DISCUSSION

The main objectives of the present study were to describe the structure and main outputs and assess the effectiveness of an innovative model of palliative care focused on the psychosocial and spiritual needs of patients (and their families) with an advanced chronic disease. We found that this program is both feasible for and effective in improving the psychosocial and spiritual care of both patients and family members. To our knowledge, this is the first program of its kind and scope (29 dedicated full-time teams

Table 3. *Main significant results: stakeholders' survey*

Dimension	Domain	Aspect	*p* value
Awareness and acceptance of the program	Awareness of the main functions of PSTs	Improving PCT training in the psychosocial management of patients and families	0.028
Program effectiveness	Professional training of PCT	Psychosocial and spiritual care of patients and family with high complexity	0.03
Efficiency	Attention model	PST adds value to the current model of palliative care	0.00
Added value of the program	Type of coverage	The care given has given priority to patients and family members in complex situations	0.00
	Type of coverage	The care given has given priority to patients and family members in complex situations	0.00
Future focus of the program.	Type of coverage	The care given has given priority to patients and family members in complex situations	0.00

and >100,000 individuals attended throughout Spain). Moreover, the model of psychosocial support—highly trained PSTs working in close concert with medical PC teams—developed here provides a template that can be adopted by other regions and countries.

Our study was carried out in Spain, where approximately 300,000 people die each year from a chronic illness. The large number of patients with chronic illnesses indicates a strong demand for PC services, which may last for months or even years due to the chronic nature of such diseases. Palliative care itself is a relatively new specialty, emerging over the past 20 to 30 years as a consequence of the growth in the prevalence of chronic illness due to population aging and other health-related factors (Clark, 2007). Traditionally, the primary focus of PC has been to deliver palliative treatments to reduce the physical burden of disease. Although the need for psychological support has also long been recognized, this aspect of care has received far less attention until relatively recently. Various studies have demonstrated the value of psychological interventions in this population (Rosenfeld et al., 2016; Breitbart, 2003; Breitbart et al., 2015; Chochinov et al., 2011; Gil Moncayo & Breitbart, 2013; Breitbart et al., 2010); however, most such interventions have been organized on an ad-hoc basis. To our knowledge, ours is the first study to systematically investigate and demonstrate the effectiveness and value of a large-scale program for patients and families in a large Western European nation.

Table 4. *Satisfaction of palliative care professionals with the psychosocial support teams*

Dimension	Average score (5-point scale)
Relationship between PST and PCT	4.68
Team support	4.44
PST–PCT coordination	4.58
Psychosocial care	4.63
Communication	4.13
Satisfaction with PST	4.13
Overall satisfaction with program	4.51

In the United Kingdom, a large-scale initiative called "Improving Access to Psychological Therapies" was developed to improve depression and anxiety disorders (Clark et al., 2009). There, large numbers of patients were successfully treated with low-intensity interventions (e.g., guided self-help). Importantly, more than half of the patients who received at least two treatment sessions (including the assessment interview) were considered to have recovered. Crucially, treatment gains were largely maintained at 10-months follow-up. These findings support the benefit of such approaches and served to help inspire our own efforts in Spain.

Rabow et al. (2004) carried out a controlled trial involving 50 patients with advanced chronic illnesses with a life expectancy ranging from 1 to 5 years and compared these to a control group of 40 patients. All of their intervention patients were treated by an interdisciplinary palliative medicine team called the "comprehensive care team," composed of a social worker, nurse, chaplain, pharmacist, psychologist, art therapist, volunteer coordinator, and three physicians who addressed physical, emotional, and spiritual issues. All team members (except for the volunteer coordinator) had expertise in PC. The program integrated various interventions, including consultation with the primary care physician (PCP), case management, volunteer and group support, chaplaincy consultation, and artistic expression. In the intervention group, PCPs received multiple PC team consultations, and patients received advance care planning, psychosocial support, and family caregiver training. Those authors found significant post-intervention improvements in the treatment group, which had significantly less dyspnea, less anxiety, and improved sleep quality and spiritual well-being. However, no significant differences in terms of pain, depression, quality of life, or, surprisingly, satisfaction with care were observed. Overall, this small trial showed that consultation with a palliative care medical team that included psychosocial support led to improved patient outcomes on certain important measures of well-being but failed to improve pain or depression. Although the study by Rabow and colleagues (2004) was conducted on a much smaller scale than the one reported herein, it does demonstrate the potential benefits of comprehensive PC and the growing interest in such models. However, as the authors noted, there are multiple barriers to implementation, not the least of which is the cost and complexity of such a program.

Model of Care

The major achievement of the LCF–WHOCC program described herein is that we developed a successful model of care that responds to the essential needs of patients. To develop this model, we first defined the psychosocial dimensions of clinical care (see Barbero Gutierrez et al., 2016) using a systematic approach for each of these psychosocial dimensions. Similarly, the model of organization of services was based on the concept of "support teams," involving a specialized psychosocial support team acting in support of preexisting PC services (Gómez-Batiste et al., 2010). The role of the support teams was clear and did not conflict in any way with the medical/nursing PC team. The primary emphasis of the PST interventions was to provide emotional support for patients and their families, as well as spiritual care, bereavement process assistance, and support for the PC team. We carefully reviewed the existing knowledge on spirituality and provided extensive training to PSTs. Some of the highlights in terms of achievements in advancing our understanding of spirituality with regard to end-of-life care include the development of a book on end-of-life spiritual care that summarizes the specific aspects of end-of-life care for most common religions (Sobrevia & Torradeflot, 2013) and organization of a symposium on the essential needs of end-of-life care held in Barcelona during March of 2014 (with around 400 attendees).

Another important, yet uncommon, aspect of the model of care developed herein was the focus on providing psychosocial support not only for patients but also for their caregivers. As Noble et al. (2015) recently reported, home-based care can result in substantial emotional, social, and physical demands on informal caregivers. Consequently, there is an acute need for new models of specialist PC provision at home. For that reason, Noble and colleagues (2015) developed a novel specialized hands-on PC model delivered in a community setting in England, with the important aim of supporting both patients and home-based caregivers. As we have shown in our study, it is possible to improve the psychosocial well-being of both patients and family members, and it seems probable that interventions with both groups are mutually reinforcing, as improvements for patients and caregivers further improve outcomes.

As is evident from the preceding discussion, several studies and small-scale interventions have been carried out, but none with the wide scope of ours. In many ways, the program described herein represents the first wide-scale effort to greatly expand the role of psychosocial and spiritual care to palliative care services to encompass both patients and their families. However, this program and approach are still being perfected as we attempt to identify the most effective model. Nevertheless, as our results demonstrate, we have learned much from this ongoing program, and the benefits for patients and families are clear. In terms of clinical outcomes, improvement was observed on all measured parameters. The most significant changes were produced between the first and third interventions, suggesting that at least three interventions are necessary to achieve maximum benefit in most cases. The fact that these improvements were achieved in patients previously treated by existing PC services underscores the added benefit of psychosocial care delivered by trained specialists, particularly considering that PC interventions are typically more effective than generalist interventions. In terms of qualitative results, it is clear that satisfaction is high among patients, families, and PST staff. The stakeholders also confirm that this model has improved the quality of existing PC and is a value-added service worth incorporating. This proposed model of psychosocial care, developed to address the essential needs of patients and their families, is based on well-established existing models, as well as on the experience of senior pioneers in Spain involved in the training and monitoring of PSTs.

STRENGTHS AND LIMITATIONS OF THE STUDY

Our study describes an innovative program implementing 29 full-time psychosocial/spiritual support teams with a nationwide scope in Spain; involving common training, policies, and documentation; and with a comprehensive and systematic evaluation of results. The methodology to explore effectiveness with a quasiexperimental pre/post survey needs to be complemented with other methods (randomized trials), which are currently ongoing. In addition, variability among the interventional approaches and data registration practices of the various PSTs could be a limitation. However, to minimize this variability, we attempted to standardize procedures to the greatest possible extent, but because part of the aim of our study was to gain experience, there were likely differences among the teams in terms of composition (i.e., varying mixes of professionals from different fields [psychologists, social workers, nurses, physicians, chaplains]) and the specific approach to psychosocial care. Finally, neither efficacy nor cost-effectiveness was evaluated.

CONCLUSIONS

The present paper describes the organization and outcomes of a comprehensive national psychosocial support program for patients with advanced chronic illness and their families. Overall, our results demonstrate the effectiveness of the program and confirm the general satisfaction of patients, family members, and other stakeholders. These results are in agreement with preliminary findings reported previously.

This model of psychosocial care could serve as a template for other regions or countries that wish to further improve psychosocial support for this highly vulnerable and often underserved population. However, it is clear that we are still in the early stages of developing this model of care, and more research is needed to develop greater standardization to ensure the replicability and consistency of such programs. Nevertheless, this model has already begun to spread beyond Spain, with two trials currently underway in Mexico and China (Hong Kong).

According to a growing body of literature, psychosocial interventions play a key role in improving outcomes in patients with advanced chronic illnesses. The benefits are myriad, including reduced symptom burdens, improved quality of life, better survival outcomes, improved satisfaction with care, and reduced healthcare resource utilization. The importance of the present project is that it provides a proven model for operationalizing delivery of psychosocial support in conjunction with existing outpatient palliative care services.

ACKNOWLEDGMENTS

The authors hereby certify that they have no conflicts of interests to declare. We would like to express our deep gratitude to the staff of the Area of Social Integration at LCF (Barcelona, Spain)—Marc Simón, Montserrat Buisan, Verónica de Pascual, Marta González, Lidia Albert, and Mireia Guardiola—for their commitment and support in the implementation of our program. We are also thankful for all the healthcare professionals who worked on the psychosocial teams. We would also like to specifically thank the following institutions for their support in the implementation of the program: the Spanish Ministry of Health, the general management of the Catalan Institute of Oncology, and the Catalan Department of Health. The authors would also like to thank Mr. Brad Londres for his support in reviewing, providing final language editing, and improving this document.

FUNDING

This study received no additional funding.

REFERENCES

Aiken, L.S., Butner, J., Lockhart, C.A., et al. (2006). Outcome evaluation of a randomized trial of the PhoenixCare intervention: Program of case management and coordinated care for the seriously chronically ill. *Journal of Palliative Medicine*, *9*(1), 111–126.

Bakitas, M., Lyons, K., Hegel, M.T., et al. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial. *The Journal of the American Medical Association*, *302*(7), 741–749. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3657724/.

Barbero Gutiérrez, J., Gómez Batiste, X., Maté Méndez, J., et al. (eds). (2016). *Manual para la atención psicosocial y espiritual a personas con enfermedades avanzadas: Intervención psicológica y espiritual* [in Spanish]. Barcelona: Obra Social La Caixa. Depósito legal: B 8914-2016.

Breitbart, W. (2003). Reframing hope: Meaning-centered care for patients near the end of life. Interview by Karen S. Heller. *Journal of Palliative Medicine*, *6*(6), 979–988.

Breitbart, W., Rosenfeld, B., Gibson, C., et al. (2010). Meaning-centered group psychotherapy for patients with advanced cancer: A pilot randomized controlled trial. *Psycho-Oncology*, *19*(1), 21–28. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3648880/.

Breitbart, W., Rosenfeld, B., Pessin, H., et al. (2015). Meaning-centered group psychotherapy: An effective intervention for improving psychological well-being in patients with advanced cancer. *Journal of Clinical Oncology*, *333*(7), 749–754. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3648880/.

Bruera, E. & Yennurajalingam, S. (2012). Palliative care in advanced cancer patients: How and when? *The Oncologist*, *17*(2), 267–273. Epub ahead of print Jan 17. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3286176/.

Brumley, R., Enguidanos, S., Jamison, P., et al. (2007). Increased satisfaction with care and lower costs: Results of a randomized trial of in-home palliative care. *Journal of the American Geriatrics Society*, *55*(7), 993–1000.

Chochinov, H.M., Kristjanson, L.J., Breitbart, W., et al. (2011). Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: A randomized controlled trial. *The Lancet. Oncology*, *12*(8), 753–762. Epub ahead of print Jul 6. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3185066//.

Clark, D. (2007). From margins to centre: A review of the history of palliative care in cancer. *The Lancet. Oncology*, *8*(5), 430–438.

Clark, D.M., Layard, R., Smithies, R., et al. (2009). Improving access to psychological therapy: Initial evaluation of two UK demonstration sites. *Behaviour Research and Therapy*, *47*(11), 910–920.

Ela, S., Espinosa, J., Martínez-Muñoz, M., et al. (2014). The WHO Collaborating Centre for Public Health Palliative Care Programs: An innovative approach of palliative care development. *Journal of Palliative Medicine*, *17*(4), 385–392. Epub ahead of print Jan 16.

Ferris, F., Balfour, H.M., Bowen, M.D., et al. (2002). A model to guide patient and family care: Based on nationally accepted principles and norms of practice. *Journal of Pain and Symptom Management*, *24*(2), 106–223. Available from http://www.jpsmjournal.com/article/S0885-3924(02)00468-2/abstract.

Ferris, F., Gómez-Batiste, X., Fürst, C.J., et al. (2007). Implementing quality palliative care. *Journal of Pain and Symptom Management*, *33*(5), 533–541. Available from http://www.jpsmjournal.com/article/S0885-3924(07)00129-7/pdf.

Gil Moncayo, F.L. & Breitbart, W. (2013). Psicoterapia centrada en el sentido: "Vivir con sentido." Estudio piloto [in Spanish]. *Psicooncologia*, *10*(2–3), 233–245. Available from http://revistas.ucm.es/index.php/PSIC/article/view/43446.

Gómez-Batiste, X., Ferris, F., Paz, S., et al. (2008*a*). Ensure quality public health programmes. A Spanish model. *European Journal of Palliative Care*, *1515*(4), 195–199.

Gómez-Batiste, X., Nabal Vicuna, M., Trelis Navarro, J., et al. (2008*b*). Evaluación cualitativa del desarrollo del Proyecto Demostrativo OMS de Cuidados Paliativos de Cataluña a los 15 años de su implementación y propuestas de mejora del programa [in Spanish]. *Medicina Paliativa*, *15*(5), 293–300.

Gómez-Batiste, X., Ferris, F., Picaza, J.M., et al. (2008*c*). Ensure good quality palliative care: A Spanish model. *European Journal of Palliative Care*, *15*(3), 142–147.

Gómez-Batiste, X., Espinosa, J., Porta-Sales, J., et al. (2010). Modelos de atención, organización y mejora de la calidad para la atención de los enfermos en fase terminal y su familia: Aportación de los cuidados paliativos [in Spanish]. *Medicina Clinica*, *135*(2), 83–89.

Gómez-Batiste, X., Buisan, M., González, M.P., et al. (2011). "La Caixa" Foundation and WHO Collaborating Center Spanish National Program for enhancing psychosocial and spiritual palliative care for patients with advanced diseases, and their families: Preliminary findings. *Palliative & Supportive Care*, *9*(3), 239–249.

Gómez-Batiste, X., Caja, C., Espinosa, J., et al. (2012). The Catalonia World Health Organization Demonstration Project for Palliative Care Implementation: Quantitative and qualitative results at 20 years. *Journal of Pain and Symptom Management*, *43*(4), 783–794.

Gómez-Batiste, X., Blay, C., Martínez-Muñoz, M., et al. (2016). The Catalonia WHO Demonstration Project of Palliative Care: Results at 25 years (1990–2015). *Journal of Pain and Symptom Management*, *52*(1), 92–98.

Goodwin, P.J., Leszcz, M., Ennis, M., et al. (2001). The effect of group psychosocial support on survival in metastatic breast cancer. *The New England Journal of Medicine*, *345*(24), 1719–1726. Available from http://www.nejm.org/doi/pdf/10.1056/NEJMoa011871.

Hughes, P.M., Bath, P.A., Ahmed, N., et al. (2010). What progress has been made towards implementing national guidance on end-of-life care? A national survey of UK general practices. *Palliative Medicine*, *24*(1), 68–78. Epub ahead of print Oct 16, 2009.

Jordhøy, M.S., Fayers, P., Saltnes, T., et al. (2000). A palliative-care intervention and death at home: A cluster randomised trial. *Lancet*, *356*(9233), 888–893.

Kamal, A.H., Currow, D.C., Ritchie, C.S., et al. (2013). Community-based palliative care: The natural evolution for palliative care delivery in the U.S. *Journal of Pain and Symptom Management*, *46*(2), 254–264. Epub ahead of print Nov 15, 2012. Available from http://www.jpsmjournal.com/article/S0885-3924(12)00462-9/pdf.

Maté-Méndez, J., González-Barboteo, J., Calsina-Berna, A., et al. (2013). The Institut Català d'Oncologia (ICO) model of palliative care: An integrated and comprehensive framework to address essential needs of patients with advanced cancer. *Journal of Palliative Care*, *29*(4), 236–242.

Mateo-Ortega, D., Gómez-Batiste, X., Limonero, J., et al. (2013). Efectividad de la intervención psicosocial en pacientes con enfermedad avanzada y final de vida [in Spanish]. *Psicooncología*, *10*(2–3), 299–316. Available from http://revistas.ucm.es/index.php/PSIC/article/viewFile/43451/41100.

Noble, B., King, N., Woolmore, A., et al. (2015). Can comprehensive specialised end-of-life care be provided at home? Lessons from a study of an innovative consultant-led community service in the UK. *European Journal of Cancer Care*, *24*(2), 253–266. Epub ahead of print Apr 15, 2014. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4359037/.

Rabow, M.W., Dibble, S.L., Pantilat, S.Z., et al. (2004). The comprehensive care team: A controlled trial of outpatient palliative medicine consultation. *Archives of Internal Medicine*, *164*(1), 83–91. Available from http://jamanetwork.com/journals/jamainternalmedicine/article-abstract/216477.

Rosenfeld, B., Saracino, R., Tobias, K., et al. (2016). Adapting meaning-centered psychotherapy for the palliative care setting: Results of a pilot study. *Palliative Medicine*, pii: 0269216316651570. Epub ahead of print.

Seow, H., Brazil, K., Sussman, J., et al. (2014). Impact of community-based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: A pooled analysis. *BMJ*, 348, g3496. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4048125/.

Sobrevia, X. & Torradeflot, F. (eds). (2013), *Atención religiosa al final de la vida: Conocimientos útiles sobre creencias y convicciones* [in Spanish]. Barcelona: Obra Social La Caixa. Depósito legal: B-12.141-2013.

Zimmer, J.G., Groth-Juncker, A. & McCusker, J. (1985). A randomized controlled study of a home health care team. *American Journal of Public Health*, *75*(2), 134–141. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1645992/.