



Congresso Regionale
SIN SICILIA

LE CURE PALLIATIVE NELLA SCLEROSI MULTIPLA

Dott. Edoardo Sessa

COKE INITIATIVE

«Trattamento finalizzato a migliorare la qualità di vita dei pazienti e dei loro parenti, in presenza di una malattia mortale, ricercando attivamente e precocemente, rilevando ripetutamente e trattando adeguatamente i dolori e i problemi fisici, psicosociali e spirituali» (National Council for Hospice and Palliative Care Services WHO-OMS 1990 modificata dalla Commissione ministeriale per le cure palliative 1999)



CURE PALLIATIVE

Legge 15 marzo 2010, n.38 "Disposizioni per garantire l'accesso alle cure palliative e alla terapia del dolore" G.U. n. 65 del 19 marzo 2010.

Art.1 e 2: “La presente legge tutela e garantisce il diritto del cittadino ad accedere alle cure palliative e alla terapia del dolore, così come previsto nei L.E.A., al fine di assicurare il rispetto della dignità e dell'autonomia della persona umana, il bisogno di salute, l'equità dell'accesso all'assistenza, la qualità delle cure e la loro appropriatezza rispetto alle specifiche esigenze.”

Ai fini della presente legge si intende per:

«cure palliative»: l'insieme degli interventi terapeutici, diagnostici e assistenziali, rivolti sia alla PERSONA malata sia al suo nucleo familiare, finalizzati alla cura attiva e totale dei pazienti la cui malattia di base, caratterizzata da un'inarrestabile evoluzione e da una prognosi infausta, non risponde più a trattamenti specifici.

CURE PALLIATIVE

- ❑ Specificità delle cure palliative, ovvero presa in carico globale della persona e della famiglia
- ❑ Distinzione tra “cure palliative” e “terapia del dolore”
- ❑ Tutela il diritto alle cure palliative e alla terapia del dolore del malato **non solo oncologico** e non solo adulto

CURE PALLIATIVE

Articolo 5, Comma 2, Legge 38/2010

La Rete Locale di Cure Palliative è una aggregazione funzionale e integrata delle attività di Cure Palliative erogate in ospedale, in Hospice, a domicilio e in altre strutture residenziali, in un ambito territoriale definito a livello regionale.

La Struttura Organizzativa di Cure Palliative dell'Azienda Sanitaria: garantisce l'accoglienza, la valutazione del bisogno e l'avvio di un percorso di Cure Palliative, assicurando la necessaria continuità delle cure, la tempestività della risposta e la flessibilità nell'individuazione del setting assistenziale appropriato.

Effettua il monitoraggio quantitativo e qualitativo delle prestazioni erogate, verificandone anche gli esiti ed i relativi costi promuove ed attua programmi obbligatori di formazione continua rivolti a tutte le figure professionali operanti nella Rete.

CURE PALLIATIVE

Testo aggiornato al 6 luglio 2012

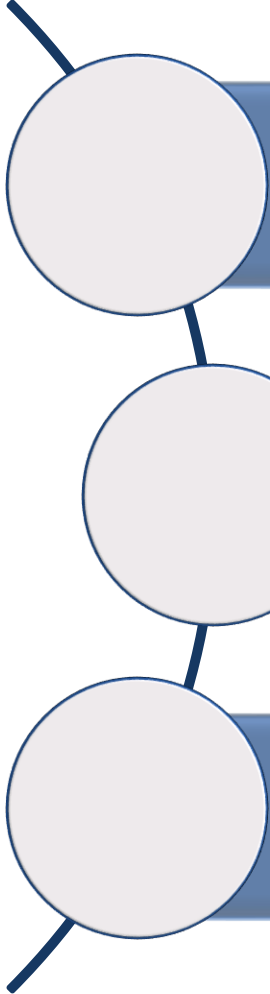
Accordo 16 dicembre 2010, n. 239/Csr
Gazzetta Ufficiale 18 gennaio 2011, n. 13

Accordo, ai sensi dell'articolo 4 del decreto legislativo 28 agosto 1997, n. 281, tra il Governo, le Regioni e le Province autonome di Trento e Bolzano sulle linee guida per la promozione, lo sviluppo e il coordinamento degli interventi regionali nell'ambito della rete di cure palliative e della rete di terapia del dolore

Accordo Stato-Regioni 25 luglio 2012

Cure Palliative per qualunque patologia ad andamento cronico ed evolutivo per la quale non esistono terapie o , se esse esistono, sono inadeguate o sono risultate inefficaci ai fini della stabilizzazione della malattia o di un prolungamento significativo della vita (L. 38/2010, art. 2, comma 1).

CURE PALLIATIVE

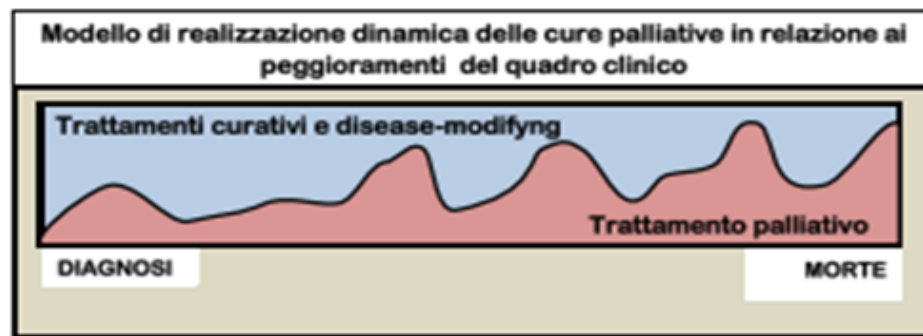
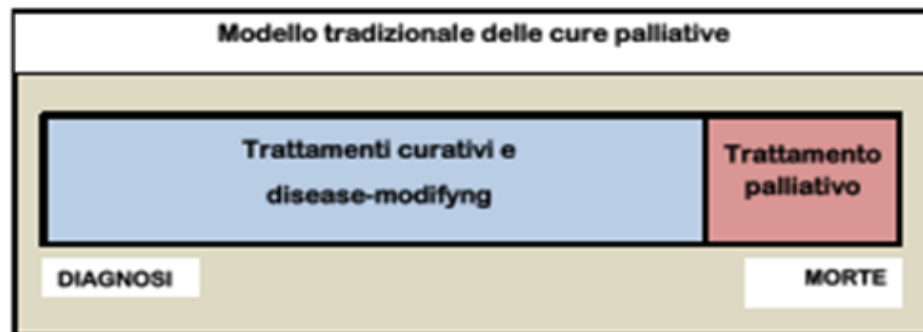


Le cure palliative sono rivolte a malati di qualunque età e non sono prerogativa della fase terminale della malattia.

Possono affiancarsi alle cure attive fin dalle fasi precoci della malattia cronico-degenerativa, controllare i sintomi durante le diverse traiettorie della malattia, prevenendo o attenuando gli effetti del declino funzionale.

Per soddisfare i bisogni dei malati e delle famiglie è necessario garantire il passaggio graduale dalle cure attive alle cure palliative, attraverso la condivisione degli obiettivi di cura, evitando così i rischi di una dolorosa percezione di abbandono.

APPROCCIO PALLIATIVO PRECOCE



Adattato da Bede et al. 2009

APPROCCIO PALLIATIVO PRECOCE

Miglioramento dello stato di salute mediante il controllo dei sintomi



Potenziamento dell'assistenza orientata alla qualità della vita della persona assistita e dei suoi caregivers



Ricerca dell'appropriatezza e dell'efficienza degli interventi assistenziali



CURE PALLIATIVE NEI DISTURBI NEUROLOGICI

REVIEW ARTICLE

A consensus review on the development of palliative care for patients with chronic and progressive neurological disease

D. J. Oliver^{a,b}, G. D. Borasio^c, A. Caraceni^{d,e}, M. de Visser^f, W. Grisold^g, S. Lorenzl^h, S. Veroneseⁱ and R. Voltz^{j,k}

During the appraisal of the literature seven main areas were developed from the evidence found on the management of palliative care for neurological disease.

There is limited evidence to support the recommendations but there is increasing evidence that palliative care and a multidisciplinary approach to care do lead to improved symptoms and quality of life of patients and their families.

*Oliver et al, European Journal of Neurology
2016, 23: 30–38*

CURE PALLIATIVE NEI DISTURBI NEUROLOGICI

MAIN AREAS

Palliative care and multidisciplinary approach (Level C)
Symptom management (Level B)
end of life care (Level C)
carer support and training (Level C)
education for all professionals involved in the care of these patients and families (Good Practice Point).

CURE PALLIATIVE NEI DISTURBI NEUROLOGICI

Research

Specialist palliative care improves the quality of life in advanced neurodegenerative disorders: NE-PAL, a pilot randomised controlled study

A phase II randomised controlled trial (RCT) was undertaken comparing an immediate referral to the service (FT, fast track) to a 16-week wait (standard track (ST), standard best practice) using a parallel arm design.

Results 50 patients severely affected by neurodegenerative conditions and their informal family carers were randomised: 25 FT, 25 ST. At baseline (T0), there were no differences between groups. After 16 weeks (T1), FT participants scored significant improvement in the SEIQoL-DW index, pain dyspnoea sleep disturbance and bowel symptoms.

This study analysed the impact on palliative care outcomes of a new specialist palliative care service for patients severely affected by amyotrophic lateral sclerosis, multiple sclerosis, Parkinson's disease and related disorders (multiple system atrophy progressive supranuclear palsy, MSA-PSP).

There was an improvement in quality of life and physical symptoms for neurological patients in palliative care. Caregiver burden was not affected by the service.

CURE PALLIATIVE

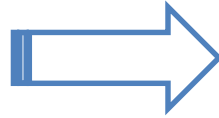
Anonymized personal information	Patient age Gender Living situation
Disease-related items	Diagnoses Date of respective main diagnosis Disease severity Need of special nursing care
Multidimensional, validated symptom, and problem checklist (Stiel, 2012)	Physical (8 items) Special nursing (2 items) Psychosocial (4 items) Social symptoms and problems (2 items)
Medication	Current medication in groups aiming at symptom relief (see Figure 2 for medication group overview)
Therapeutic procedures	Nursing efforts (including drug application by parenteral route, pumps, catheters), feeding and purging, embedding and wound care Physiotherapy (massage, edema drainage, mobilization, respiratory therapy) Psychosocial support (including advance care planning and psychosocial family support) Therapeutic measures (sedation, transfusion, punctures, catheter or stoma insertion, radiation, surgical, or chemotherapy)
Outcome	Outcome near discharge or death (including symptoms and problems) Team satisfaction score

CURE PALLIATIVE NELLE MALATTIE NEUROLOGICHE

- ❑ La pianificazione anticipata delle cure (*advanced care planning*): definire un preventivo accordo con il paziente e i familiari atto a definire gli eventuali interventi da realizzare prima dell'eventuale impossibilità di ricevere un consenso informato da parte del paziente .
- ❑ Le cure di fine vita (*and-of-life care o terminal care*): finalizzate al trattamento del paziente in fase terminale.
- ❑ L'approccio di ordine palliativo (*palliative care*): indirizzato a un miglioramento nella qualità di vita del paziente e delle persone a lui vicine (caregiver) nel corso di malattie in grado di limitare la sopravvivenza.

CURE PALLIATIVE NELLE MALATTIE NEUROLOGICHE

Malattie neurologiche



Andamento peggiorativo
per via dei meccanismi
patogenetici di tipo
degenerativo

- demenze e malattie cerebrovascolari;
- malattia di Parkinson e altri disturbi del movimento;
- esiti dei gravi traumi cranici;
- sclerosi multipla;
- malattie neuromuscolari (SLA, miopatie);
- tumori cerebrali

SCLEROSI MULTIPLA

100000

PERSONE AFFETTE DA SM IN ITALIA

20 - 40

RANGE DI ETÀ IN CUI VIENE GENERALMENTE
DIAGNOSTICATA



2 : 1

IL RAPPORTO TRA LE DONNE COLPITE
RISPETTO AGLI UOMINI

CURE PALLIATIVE NELLA SCLEROSI MULTIPLA

PALLIATIVE CARE IN PATIENTS WITH MULTIPLE SCLEROSIS

Aliza Bitton Ben-Zacharia, RN, CRRN, ANP, MSN,
and Fred D. Lublin, MD

Table 3. PROGNOSTIC FACTORS IN MS

Favorable Prognostic Factors	Unfavorable Prognostic Factors
Female gender	Male gender
Young age at onset	Old age at onset
Few symptoms at onset	Multiple symptoms at onset
Optic neuritis or sensory deficits at onset	Motor or cerebellar/brain stem symptoms at onset
Long intervals between the initial attacks	Short interval between the initial and the second attack
Low relapse rate in early years	High relapse rate in early years
Complete recovery after the initial attacks	Incomplete remission after the first relapses
No disability in early years	Early disability, clinical progressive course
Few lesions on MR imaging of the brain	High lesion load detected by early MR imaging of the brain

Ben-Zacharia & Lublin, 2001,
Neurologic clinics, 19(4),
801-827.

SCLEROSI MULTIPLA

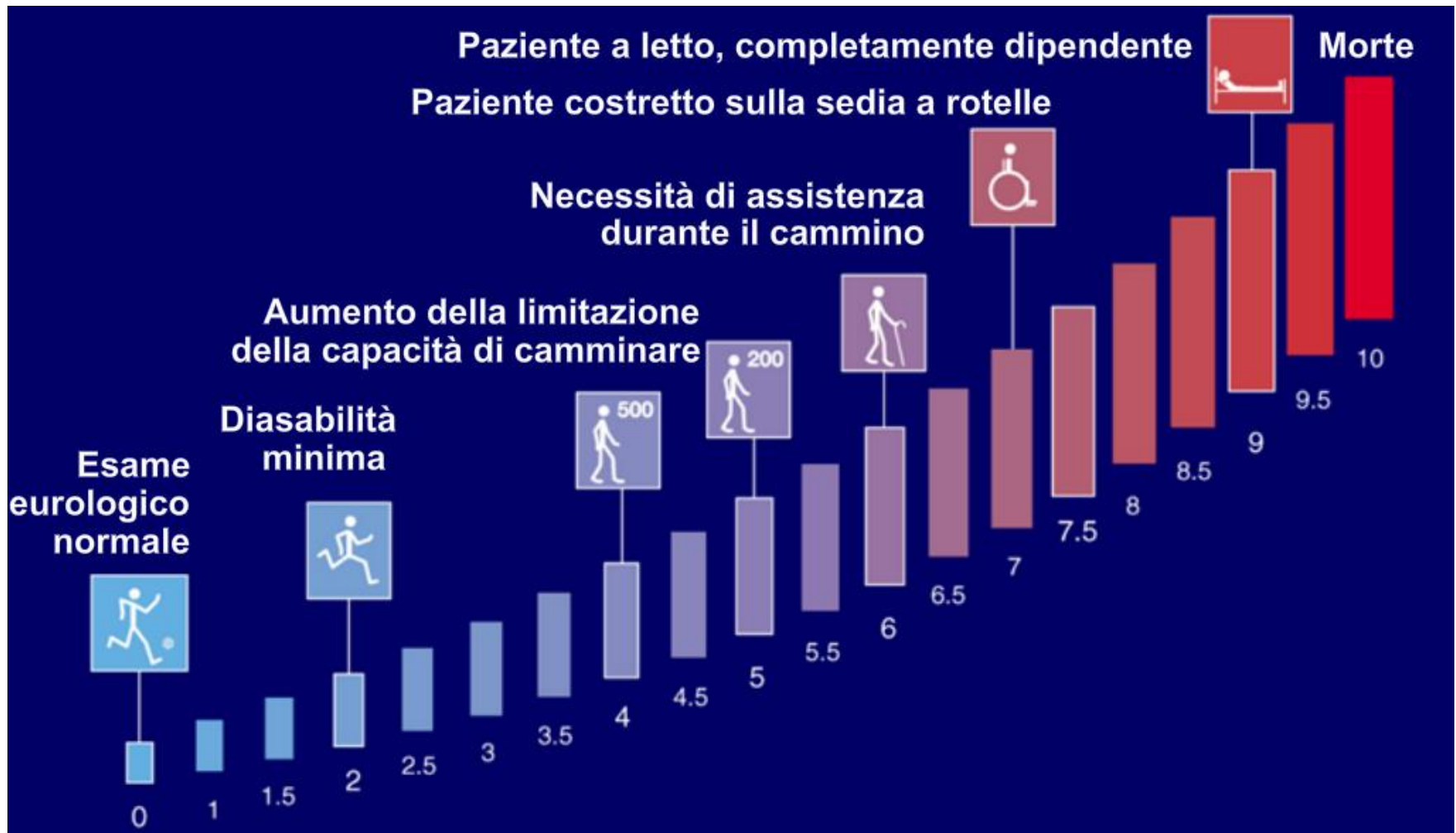
802 BEN-ZACHARIA & LUBLIN

Table 1. THREE MS DOMAINS: PHYSICAL, COGNITIVE, AND PSYCHOSOCIAL

Physical	Cognitive	Psychosocial
Loss of motor function	Decreased short-term memory	Depression
Loss of sensory function	Disorganization	Dementia
Loss of vision	Decreased thought processing	Bipolar disease
Dysarthria	Decreased speed of information processing	Impaired affect
Dysphagia	Decreased attention	Mood changes
Fatigue	Decreased judgment	Stress
Pain	Decreased decision making	Loss of partner
Spasticity/decreased coordination	Decreased concentration	Social isolation
Loss of bladder control	Decreased abstract reasoning	Decreased finances
Loss of bowel control	Decreased visual/spatial organization	Unemployment
Sexual dysfunction	Altered executive function	Role changes

SCLEROSI MULTIPLA

SCALE EDSS (EXPANDED DISABILITY STATUS SCALE)



CURE PALLIATIVE NELLA SCLEROSI MULTIPLA



**Le Cure Palliative precoci
outcome rilevabili**

25000 persone con SM grave, circa 6200 persone con SM in Italia presentano EDSS > 8.5 (*AISM 2017*). *Alti costi sanitari e sociali costo annuo circa 84.000 euro a persona (Barometro SM 2017)*

- Miglioramento dello stato di salute mediante l'attenzione al controllo dei sintomi (rilevabile, ad esempio, con la Palliative care Outcome Symptoms Scale MS, POS-S-MS – *Solari 2015*);
- Approccio proattivo all'identificazione dei bisogni del malato e della famiglia (numero di PAC attivate);
- Potenziamento dell'assistenza orientata alla qualità della vita della persona assistita e dei caregiver;
- Ricerca dell'appropriatezza e dell'efficienza degli interventi assistenziali (utilizzo di DMT non giustificati dalla fase di malattia; ricorso agli accessi in Pronto Soccorso e ricovero in letti per acuti).

SCLEROSI MULTIPLA

PERCORSO ASSISTENZIALE

la diagnosi
tempestiva di
malattia

il trattamento
secondo un
progetto
personalizzato

il
monitoraggio
clinico-
strumentale

- trattamento degli eventi acuti;
- trattamenti farmacologici;
- terapie sintomatiche;
- cure palliative

CURE PALLIATIVE NELLA SCLEROSI MULTIPLA

Applicabilità

(European Multiple Sclerosis Platform, 2014)

- ☐ EDSS score superiore a 7
- ☐ Sintomi complessi, importanti con complicanze mediche
- ☐ Disfagia e/o diminuito stato nutrizionale
- ☐ Difficoltà della comunicazione (ad. es. disartria con stanchezza)
- ☐ Deterioramento cognitivo

“Palliative care in MS is directed at symptom management, psychosocial support and rehabilitation”.

Obiettivi

Trattamento del dolore, dei disturbi psichici e del sonno, dei problemi sfinterici, della disfagia e dalla spasticità e delle complicanze infettive.

CURE PALLIATIVE NELLA SCLEROSI MULTIPLA

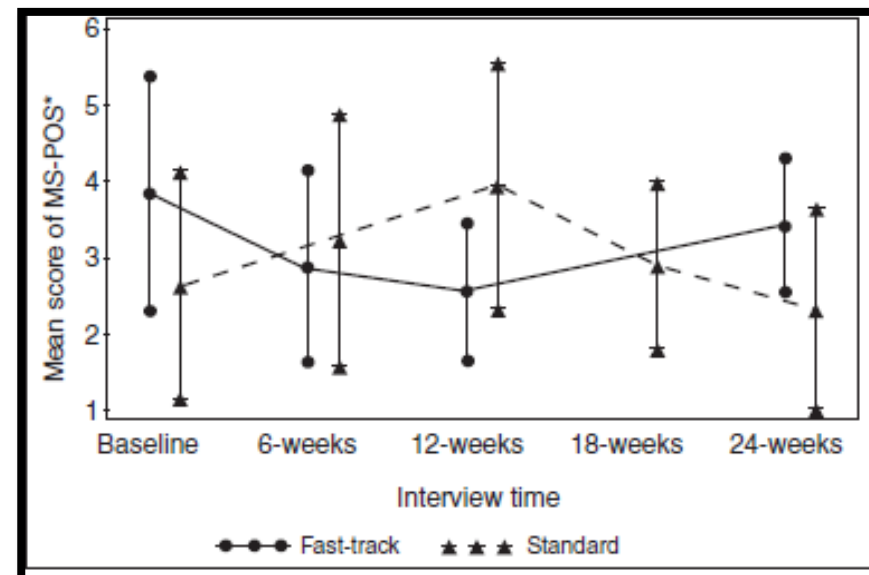
Palliative care for people severely affected by multiple sclerosis: evaluation of a novel palliative care service

Polly Edmonds¹, Sam Hart², Wei Gao², Bella Vivat³, Rachel Burman¹, Eli Silber⁴ and Irene J Higginson²

The intervention group was offered the team immediately (fast track, FI); the control group continued best standard care and then offered the team after 3 months (standard intervention, SI). 52 patients were eligible to be randomized (26 to the FI and 26 to the SI groups).

At 12 weeks people in the FI group had an improvement in the total score of the MS-POS whereas there was deterioration in the SI group. There was an improvement in caregiver burden in the FI group and a deterioration in the SI group.

Randomized controlled trial to explore whether a new palliative care service improved outcomes for people severely affected by multiple sclerosis.



Unmet Needs of People with Severe Multiple Sclerosis and Their Carers: Qualitative Findings for a Home-Based Intervention

Claudia Borreani¹, Elisabetta Bianchi¹, Erika Pietrolongo², Ilaria Rossi³, Sabina Cilia⁴, Miranda Giuntoli⁵, Andrea Giordano⁶, Paolo Confalonieri⁷, Alessandra Lugaresi², Francesco Patti⁴, Maria Grazia Grasso³, Laura Lopes de Carvalho⁵, Lucia Palmisano⁸, Paola Zaratin⁹, Mario Alberto Battaglia⁹, Alessandra Solari^{6*}, on behalf of the PeNSAMI project[†]

Objective: To identify unmet needs of people with severe MS living at home by qualitative research

Method: Data were collected from: at least 10 personal interviews with adults with severe MS (primary/secondary progressive, EDSS>8.0); three focus group meetings (FGs) of carers of people with severe MS; and two FGs of health professionals (HPs).

Results: 22 MS patients, 30 carers and 18 HPs participated. Patients had difficulties expressing needs; experiences of burden and loneliness were prominent, chiefly in dysfunctional, less affluent families, and among parent carers. Needs differed across Italy with requirements for information and access to services highest in the South. All participants voiced a strong need for qualified personnel and care coordination in day-to-day home care. Personal hygiene emerged as crucial, as did the need for a supportive network and preservation of patient/carer roles within family and community.

PeNSAMI PROJECT...

STUDY PROTOCOL

Open Access

Home-based palliative approach for people with severe multiple sclerosis and their carers: study protocol for a randomized controlled trial

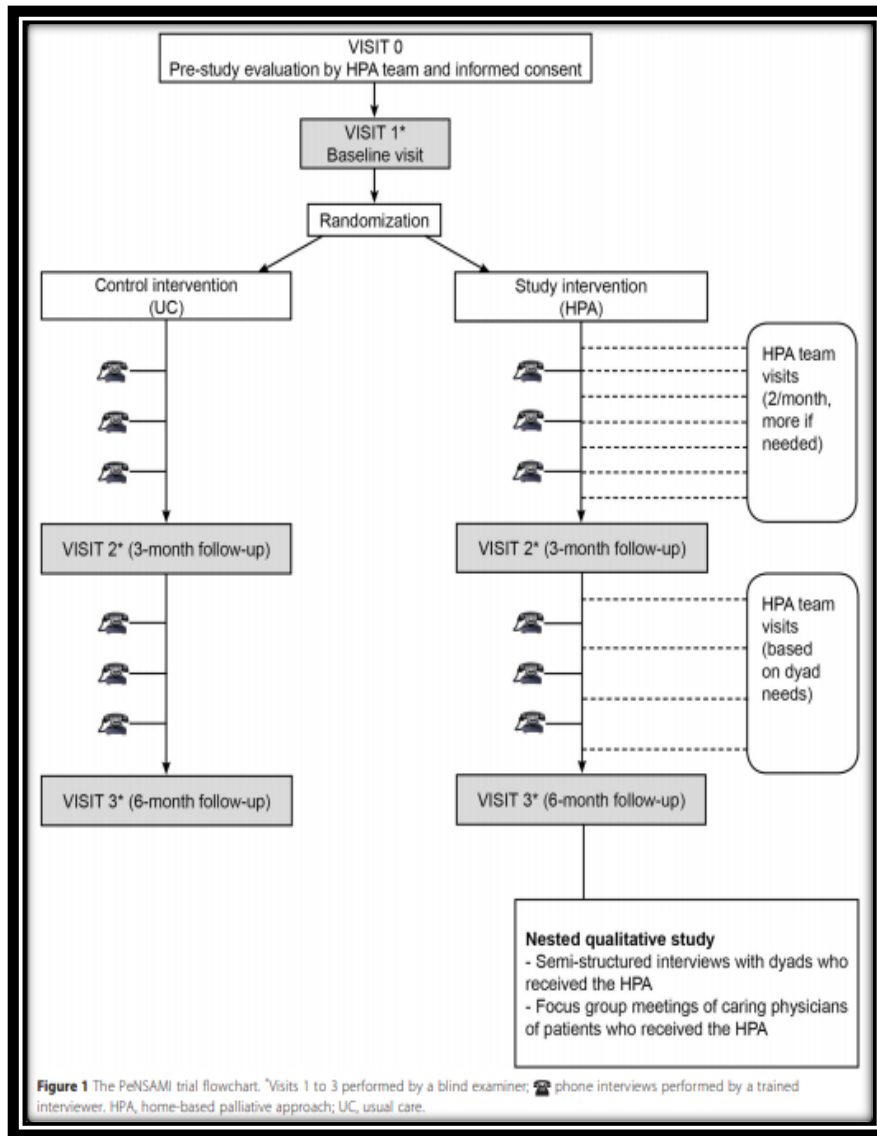
Alessandra Solari^{1*}, Andrea Giordano¹, Maria Grazia Grasso², Paolo Confalonieri³, Francesco Patti⁴, Alessandra Lugaesi⁵, Lucia Palmisano⁶, Roberta Amadeo⁷, Giovanni Martino⁷, Michela Ponzio⁸, Giuseppe Casale⁹, Claudia Borreani¹⁰, Renzo Causarano¹¹, Simone Veronese¹², Paola Zaratini⁸, Mario Alberto Battaglia⁸, on behalf of the PeNSAMI project

This is a single-blind randomized controlled trial with a nested qualitative study. Seventy-five severe MS-carer dyads are being randomized (at three centers, one in each area of Italy) to HPA or usual care (UC) in a 2:1 ratio. Each center has a specially trained team consisting of four professionals (physician, nurse, psychologist, social worker).

Inclusion and exclusion criteria... At least two unmet care needs among the categories identified in the *PeNSAMI Phase 1 qualitative study*.

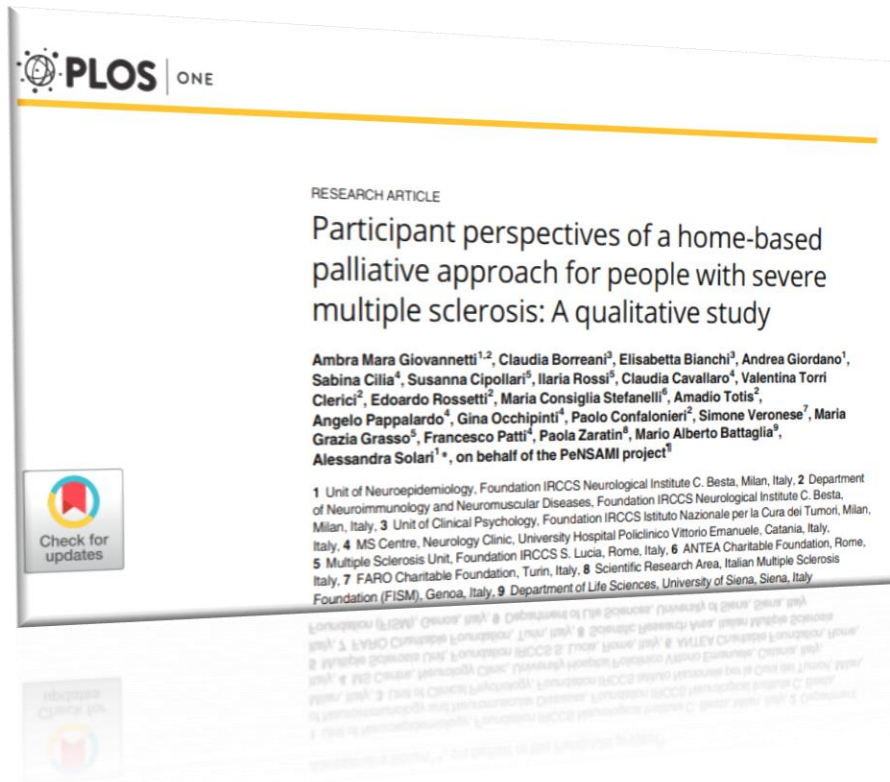
The primary aim of the present study is to determine the effectiveness of a home-based palliative approach (HPA) on MS symptoms and HRQOL of people with severe MS. Secondary outcomes are changes in patient functional status and mood; changes in carer HRQOL, mood and caregiving burden; costs; incorporation with standard care; unplanned hospital admissions; referrals to hospice; and deaths over the six-month intervention.

PeNSAMI PROJECT...



Primary outcome measures are changes in symptoms (Palliative care Outcome Scale-Symptoms-MS, POS-S-MS), and quality of life (the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW), not assessed in patients with severe cognitive compromise) at three and six months. Other outcomes are changes in patient functional status and mood; changes in carer quality of life, mood and caregiving burden; costs; incorporation with standard care; unplanned hospital admissions; referrals to hospice; and deaths.

PeNSAMI PROJECT...



A qualitative study to investigate the experiences of participants in a multicenter randomized controlled trial on a home-based palliative approach (HPA) for adults with severe multiple sclerosis (MS) and their caregivers.

Aim: to explore the strengths and challenges of the intervention, and circumstances that may have influenced its efficacy.

Participants were the 12 patients and 15 informal caregivers.

Intervention benefits were improved control of symptoms and reduced sense of isolation of the patient-caregiver dyads.

PeNSAMI PROJECT...

MULTIPLE
SCLEROSIS
JOURNAL

MSJ

Original Research Paper

Randomized controlled trial of a home-based palliative approach for people with severe multiple sclerosis

Alessandra Solari, Andrea Giordano, Francesco Patti, Maria Grazia Grasso, Paolo Confalonieri, Lucia Palmisano, Michela Ponzio, Claudia Borreani, Rosalba Rosato, Simone Veronese, Paola Zaratini and Mario Alberto Battaglia; on behalf of the PeNSAMI Project*

To assess the efficacy of a home-based palliative approach (HPA) for adults with severe MS and their carers.

Between January and November 2015, 78 dyads randomized, 76 (50 HPA, 26 UC) were analyzed.

Participants were non-institutionalized adults (age ≥ 18 years) with severe MS and their primary carers. Other patient inclusion criteria were primary or secondary progressive MS, Expanded Disability Status Scale (EDSS) score ≥ 8.0 , complex symptoms, and ≥ 2 unmet care needs.

PENSAMI PROJECT...

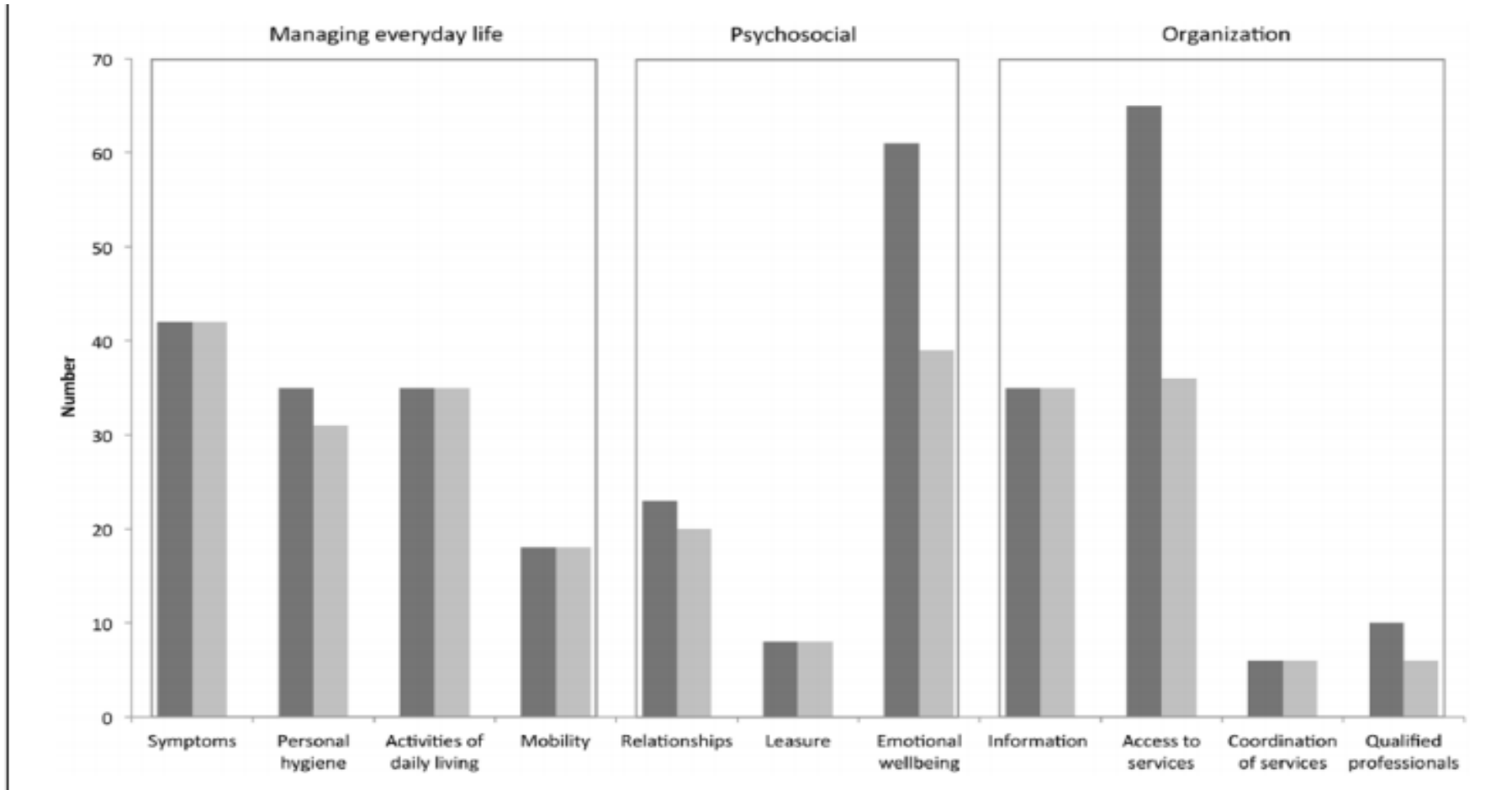
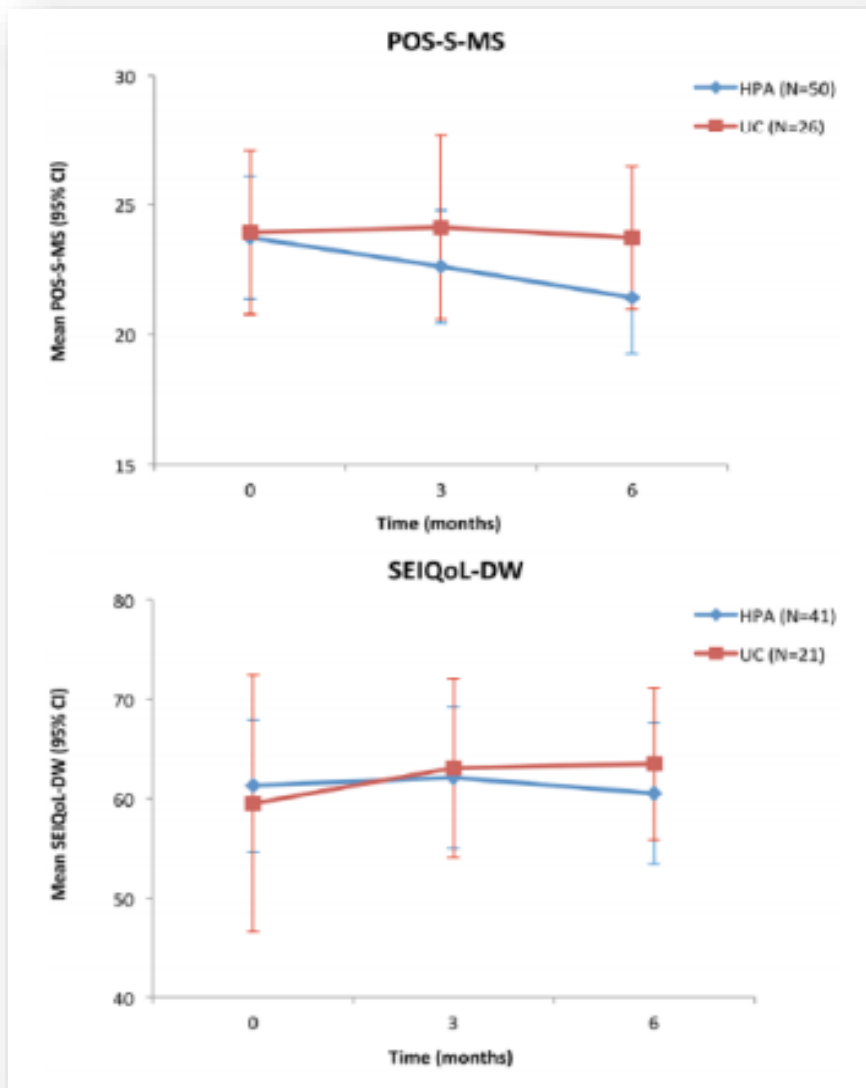


Figure 2. The care needs addressed (dark gray, overall $n=338$) and fulfilled (light gray, $n=276$) as reported by the home-based palliative approach (HPA) teams. Care needs are grouped into 11 pre-set categories and 3 domains.¹⁶

PENSAMI PROJECT...



Symptom burden (POS-S-MS) significantly reduced in HPA group compared to UC ($p = 0.047$). HPA slightly reduced symptoms burden. No evidence of HPA efficacy on patient quality of life and on secondary outcomes were found.

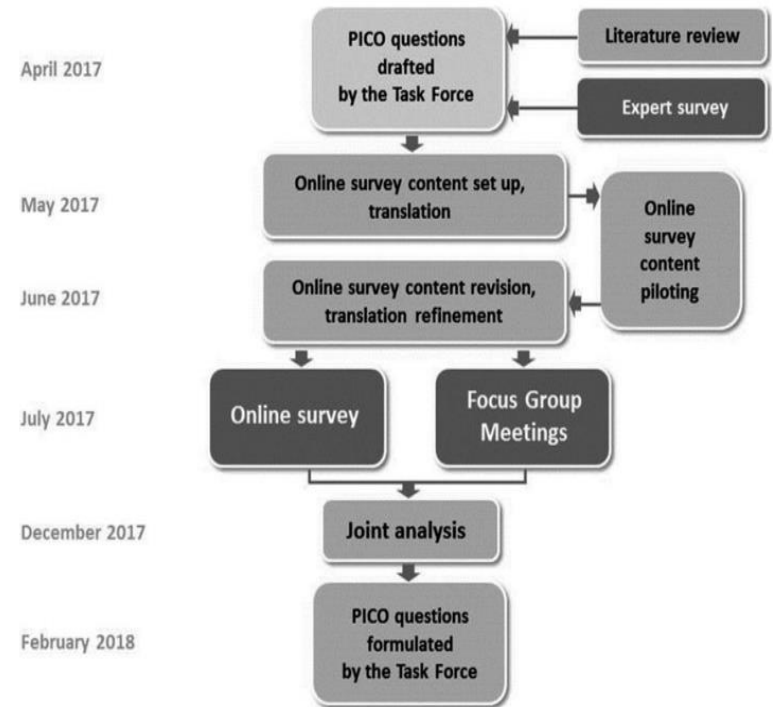
CURE PALLIATIVE, NEUROLOGI IN PRIMA LINEA. LINEE GUIDA SPECIFICHE PER I PAZIENTI CON SM. #EAN2018

ORIGINAL ARTICLE

Patient and caregiver involvement in the formulation of guideline questions: findings from the European Academy of Neurology guideline on palliative care of people with severe multiple sclerosis

S. Köpke^a, A. Giordano^b, S. Veronese^c, A. Christin Rahn^d, I. Kleiter^e, B. Basedow-Rajwicz^e, A. Fornari^b, M. A. Battaglia^f, J. Drulovic^g, L. Kooij^h, J. Koops^h, J. Mens^h, E. R. Meza Murilloⁱ, I. Milanov^j, R. Milo^{k,l}, F. Patti^m, T. Pekmezovicⁿ, J. Sastre-Garriga^l, J. Vosburgh^o, R. Voltz^p, J. Bay^q, D. J. Oliver^r and A. Solari^b

Definition of the key questions to be answered



CURE PALLIATIVE, NEUROLOGI IN PRIMA LINEA. LINEE GUIDA SPECIFICHE PER I PAZIENTI CON SM. #EAN2018

569 free comments, categorized into 4 domains:

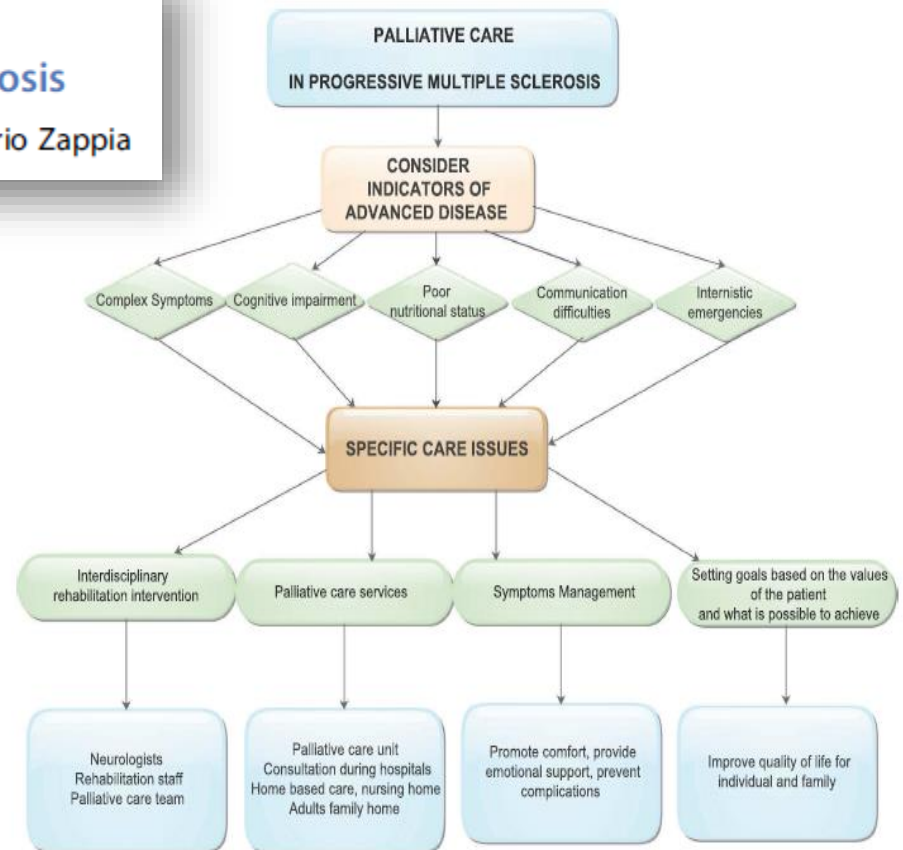
Guideline pre-specified topics (182 comments, 32%)	Symptoms management and multidisciplinary rehabilitation (topics 1 and 2), 59/182 comments (32%); palliative care (topics 4 and 5), 41 (23%); emotional and practical support for caregivers (topic 7), 29 (16%); advance care planning (topic 3), 19 (10%); education for caregivers (topic 6), 18 (10%); education and training in palliative care for MS health professionals (topic 8), nine (5%); education and training in MS for palliative care professionals (topic 9), seven (4%).
Additional topics, pertinent to the guideline (16 comments, 3%)	Voluntary euthanasia, 15/16 comments; sheltered housing/assisted living, one comment.
Additional topics, not pertinent to the guideline (211, 37%)	Welfare (104/211 comments, 49%): access/coordination of care/services (43, 20%), rights (28, 13%), employment (13, 6%), economic support for MS patients and caregivers (13, 6%), housing and environmental adaptations (7, 3%). Empowerment (54 comments, 26%): MS information for patients, relatives, caregivers and health professionals (49, 23%), decisional autonomy (4, 2%). Disease management (31 comments, 15%): competent professionals (15, 7%), patient emotional support (11, 5%), relative emotional support (5, 2%). Lifestyle (23 comments, 11%): diet (8, 4%), sexuality (8, 4%), leisure (7, 3%).
Outcomes (160, 28%)	Patient participation (36/160 comments, 22%), functioning (21, 13%), symptom burden (17, 11%), emotional well-being (14, 9%), advance directive/living will (14, 9%), service coordination (10, 6%), caregiver emotional well-being (10, 6%), quality of life (8, 5%), quality of death/dying (8, 5%), satisfaction with care/services (8, 5%), patient–clinician relationship (5, 3%), caregiver burden (4, 2%), complicated bereavement (3, 2%), costs (2, 1%).

CURE PALLIATIVE NELLA SCLEROSI MULTIPLA

SPECIAL REPORT

Palliative care in progressive multiple sclerosis

Emanuele D'Amico, Aurora Zanghì, Francesco Patti and Mario Zappia



CONCLUDENDO

Garantire una buona qualità della vita e il rispetto della dignità del paziente dovrebbe rimanere l'obiettivo della gestione palliativa. Ciò richiede una collaborazione attiva tra paziente, personale sanitario e medico con chiarezza linee di comunicazione aperta su tutte le questioni importanti. Discussioni periodiche del piano di assistenza dovrebbero consentire i correttivi necessari nell'evolvere del quadro clinico al fine di garantire che l'autonomia del paziente sia sempre rispettata.

RECAP

- HPA non sostituisce i servizi esistenti ma li integra;
- Carenza nelle risposte territoriali con frammentazioni delle cure in differenti settori dell'assistenza sanitaria (organizzazione in rete);
- Formazione delle Competenze Professionali;
- Necessità di creare spazi di cura nei servizi già esistenti (approccio palliativo che risponda ai bisogni specifici delle persone con SM);
- Presa in carico globale con valutazione dei bisogni del paziente e del caregiver, che non sempre sono soddisfatti dai servizi esistenti.
- Identificare su come e quando integrare le cure palliative nel corso del trattamento rimane difficile soprattutto per la complessità dei sintomi e l'eterogeneità della SM



GRAZIE

"The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychologic, social, and spiritual problems is paramount" (Jankovic and Tintner 2018).

CURE PALLIATIVE NELLE MALATTIE NEUROLOGICHE

Stadi di malattia molto protratti con disabilità crescente e importante comorbidità correlata all'età avanzata;

Possibilità di morte improvvisa, come può avvenire nella SLA e nell'atrofia multisistemica

Complicanze molteplici che interessano diversi sistemi come può avvenire negli stadi più severi della Sclerosi Multipla

CURE PALLIATIVE NELLE MALATTIE NEUROLOGICHE

Le peculiarità dell'assistenza palliativa in neurologia

Malattie neurologiche con decorso prolungato e fluttuazioni cliniche possono portare a un improvviso e imprevedibile declino, con conseguente accumulo di disabilità

La prognosi della fase terminale delle malattie neurologiche non si avvantaggia di solidi indicatori predittivi e spesso non consente di identificare in anticipo gli ultimi mesi di vita

Le fasi avanzate delle malattie neurologiche sono spesso caratterizzate da condizioni quali la difficoltà di comunicazione e il deterioramento cognitivo per cui è fondamentale la pianificazione anticipata delle cure

CURE PALLIATIVE NELLA SCLEROSI MULTIPLA

Approccio multidisciplinare e multiprofessionale all'assistenza con diversificazione di intervento "di base/generale" (personale esperto ma non dedicato) e "specialistico" (Unità di CP).

(Linee guida European Academy of Neurology (EAN), 2018)



CURE PALLIATIVE NELLA SCLEROSI MULTIPLA



Increase of receiving palliative care from 0.2% in 2005 to 6.1% in 2014 ($p < 0.001$) particularly with the dramatic single-year increase between 2010 (1.5%) and 2011 (4.5%)

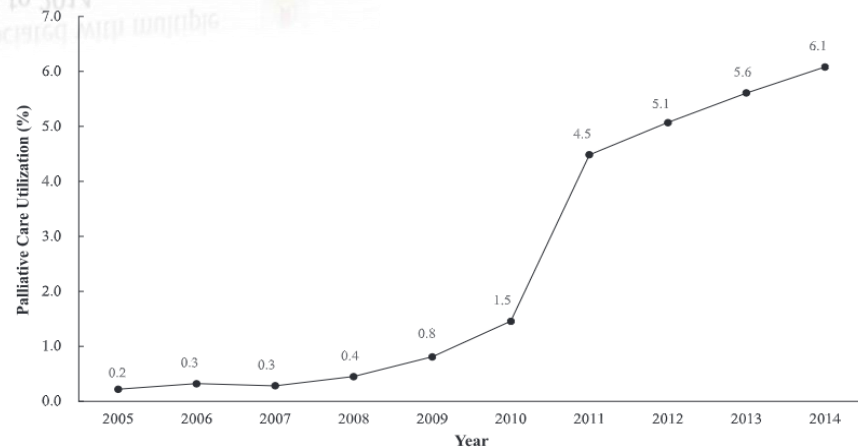
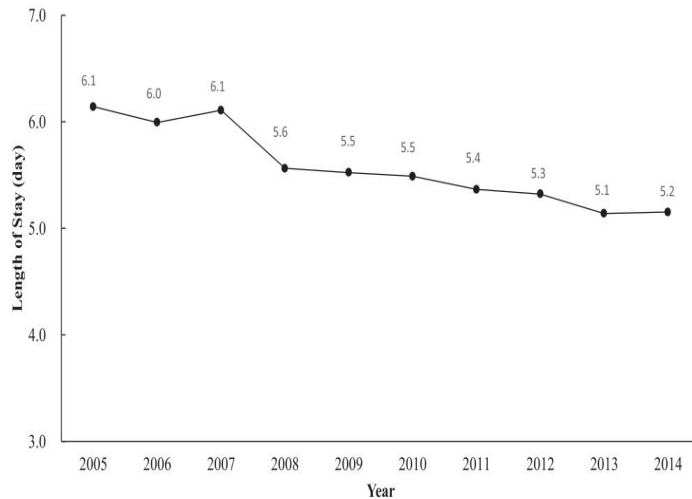


Fig. 1. The temporal trends of palliative care utilization among hospitalized patients with multiple sclerosis in U.S., 2005–2014 p-Value for trend < 0.001 . Source: NIS.

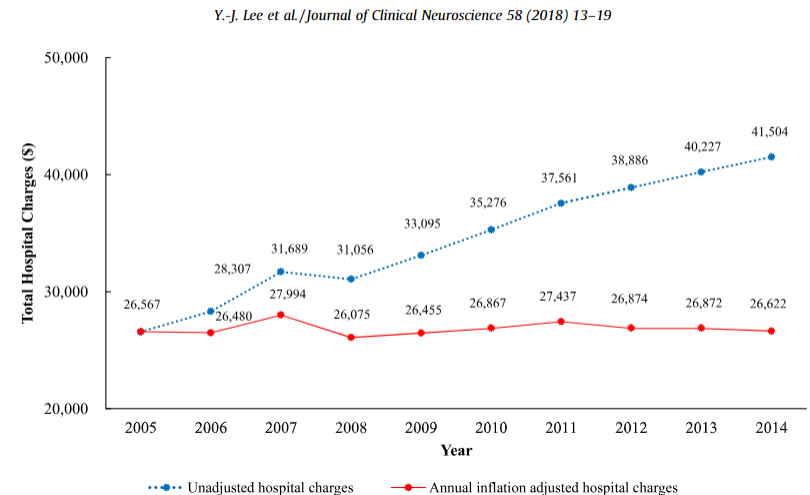
CURE PALLIATIVE NELLA SCLEROSI MULTIPLA



The temporal trends of the average length of stay among hospitalized patients with multiple sclerosis in U.S., 2005–2014 p-Value for trend <0.001. Source: NIS.

The crude hospital charges per MS patients appeared to be increased annually, but, after annual inflation adjustment during the 10 years, there was no significant change in hospital charges

The annual temporal trends of the average length of stay among patients with a significant decrease from 6.1 days in 2005 to 5.2 days in 2014 ($p < 0.001$).



Lee et al, Journal of Clinical Neuroscience 58 (2018) 13–19

APPROCCIO PALLIATIVO PRECOCE

Modifica il concetto tradizionale delle cure palliative riservate solo alla fase finale della vita suggerendone la realizzazione lungo l'intero percorso terapeutico di ogni malattia di cui non si prevede la guarigione

(Parikh et al 2013).

Il nuovo modello sottolinea l'importanza di interventi precoci nell'ambito delle cure palliative mirati al **miglioramento della qualità di vita.**



CURE PALLIATIVE NELLA SCLEROSI MULTIPLA

PALLIATIVE CARE IN PATIENTS WITH MULTIPLE SCLEROSIS

Aliza Bitton Ben-Zacharia, RN, CRRN, ANP, MSN,
and Fred D. Lublin, MD

Table 3. PROGNOSTIC FACTORS IN MS

Favorable Prognostic Factors	Unfavorable Prognostic Factors
Female gender	Male gender
Young age at onset	Old age at onset
Few symptoms at onset	Multiple symptoms at onset
Optic neuritis or sensory deficits at onset	Motor or cerebellar/brain stem symptoms at onset
Long intervals between the initial attacks	Short interval between the initial and the second attack
Low relapse rate in early years	High relapse rate in early years
Complete recovery after the initial attacks	Incomplete remission after the first relapses
No disability in early years	Early disability, clinical progressive course
Few lesions on MR imaging of the brain	High lesion load detected by early MR imaging of the brain

Ben-Zacharia & Lublin, 2001,
Neurologic clinics, 19(4),
801-827.

CURE PALLIATIVE NELLE MALATTIE NEUROLOGICHE

Definizione della fase di malattia che richiede un approccio palliativo nel caso in esame, tenendo conto dei fattori individuali quali l'età, le comorbidità, le complicanze e le disponibilità assistenziali.

Verifica delle risorse assistenziali disponibili nel contesto in termini di terapie farmacologiche , di modalità di assistenza o altro.

Identificazione delle modalità di comunicazione al caregiver e ai familiari interessati nonché delle possibilità di organizzazione assistenziale individuale.

Analisi delle risorse e delle competenze disponibili nella fase avanzata di malattia.

CURE PALLIATIVE NEI DISTURBI NEUROLOGICI

Research

Specialist palliative care improves the quality of life in advanced neurodegenerative disorders: NE-PAL, a pilot randomised controlled study

A phase II randomised controlled trial (RCT) was undertaken comparing an immediate referral to the service (FT, fast track) to a 16-week wait (standard track (ST), standard best practice) using a parallel arm design.

Results 50 patients severely affected by neurodegenerative conditions and their informal family carers were randomised: 25 FT, 25 ST. At baseline (T0), there were no differences between groups. After 16 weeks (T1), FT participants scored significant improvement in the SEIQoL-DW index, pain dyspnoea sleep disturbance and bowel symptoms.

This study analysed the impact on palliative care outcomes of a new specialist palliative care service for patients severely affected by amyotrophic lateral sclerosis, multiple sclerosis, Parkinson's disease and related disorders (multiple system atrophy progressive supranuclear palsy, MSA-PSP).

There was an improvement in quality of life and physical symptoms for neurological patients in palliative care. Caregiver burden was not affected by the service.

CURE PALLIATIVE NEI DISTURBI NEUROLOGICI

Palliative care for people severely affected by multiple sclerosis: evaluation of a novel palliative care service

Polly Edmonds¹, Sam Hart², Wei Gao², Bella Vivat³, Rachel Burman¹, Eli Silber⁴ and Irene J Higginson²

The intervention group was offered the team immediately (fast track, FI); the control group continued best standard care and then offered the team after 3 months (standard intervention, SI). 52 patients were eligible to be randomized (26 to the FI and 26 to the SI groups).

At 12 weeks people in the FI group had an improvement in the total score of the MS-POS whereas there was deterioration in the SI group. There was an improvement in caregiver burden in the FI group and a deterioration in the SI group.

Randomized controlled trial to explore whether a new palliative care service improved outcomes for people severely affected by multiple sclerosis.

