

La gestione dei pazienti cronici con tumore cerebrale

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*La richiesta di competenza
neurologica nel prossimo futuro*

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Conflitti di Interesse

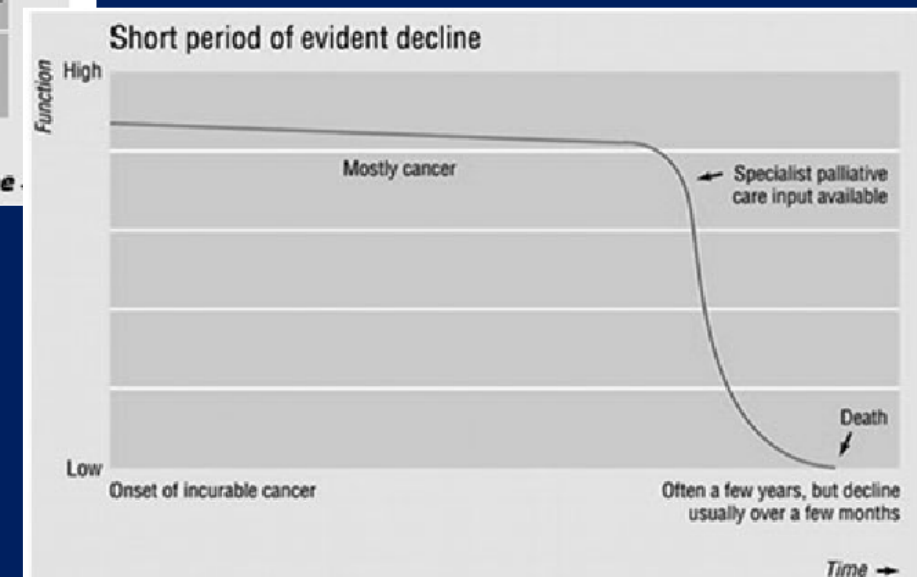
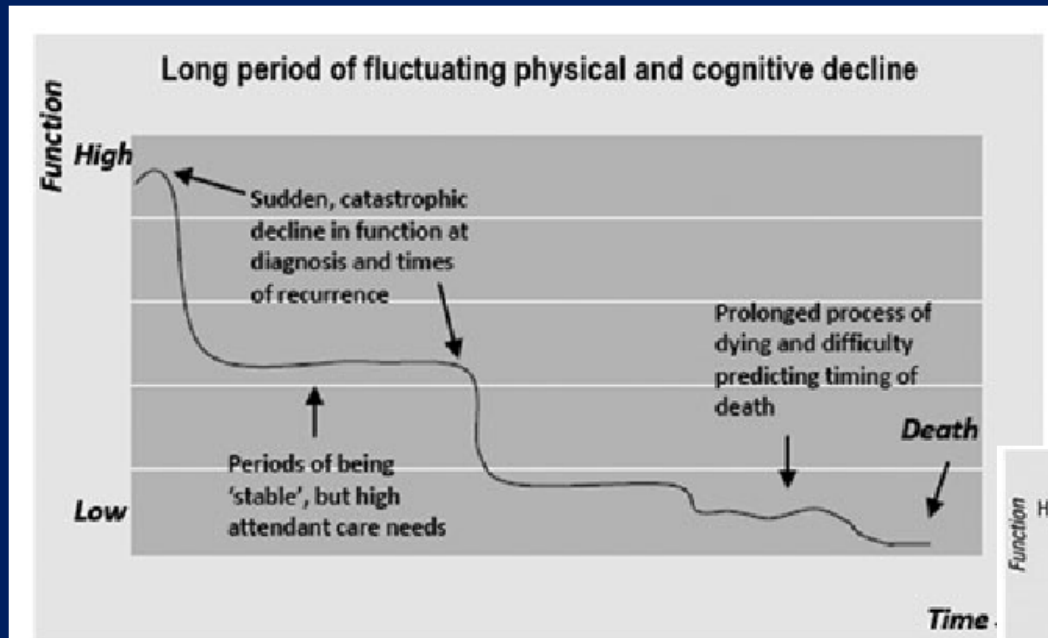
Pace, Andrea

- Nessun conflitto di interesse

Outline

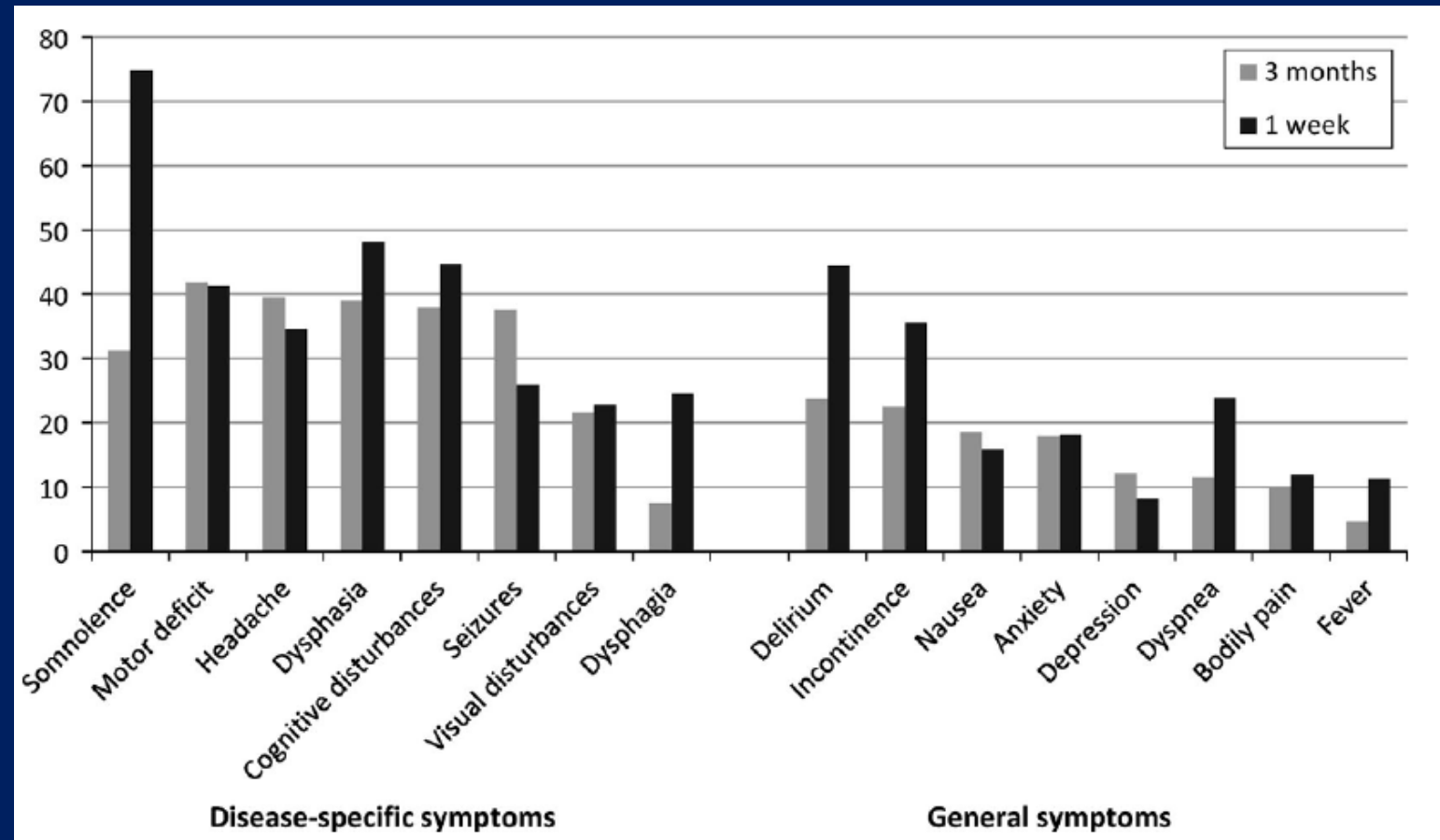
- Traiettorie di malattia nei tumori cerebrali
- Sintomi, Supporto e Palliazione
- Disturbi cognitivi e Capacità Decisionale
- Cure palliative simultanee
- Qualità delle cure alla fine della vita
- Linee Guida sulle Cure palliative Italiane (SIN-AINO-SICP)

Health care professionals' perspectives of living and dying with primary malignant glioma: Implications for a unique cancer trajectory



Symptoms and medication management in the end of life phase of high-grade glioma patients

J. A. F. Koekkoek · L. Dirven · E. M. Sizoo · H. R. W. Pasman · J. J. Heimans ·
T. J. Postma · L. Deliens · R. Grant · S. McNamara · G. Stockhammer ·
E. Medicus · M. J. B. Taphoorn · J. C. Reijneveld



Chronic symptoms in neurological diseases

	MOTOR	PAIN	INFECTION	DYSPNOEA	EPILEPSY	DYSPHAGIA	COGN
Stroke							
MS							
PD							
DEM							
MND							
BT							

MS=Multiple Sclerosis ;PD= Parkinson Disease; DEM= Dementia; MND=Motor Neuron Disease;
BT= Brain Tumor

Palliative care and neurology

Time for a paradigm shift

Neurology® 2014;83:561-567

DO NEUROLOGY PATIENTS HAVE UNIQUE PALLIATIVE CARE NEEDS?

Patients with a life-limiting neurologic illness often have a long and variable disease progression punctuated by cognitive impairment, behavioral issues, and communication problems, in addition to motor symptoms

WHAT PALLIATIVE CARE SKILLS NEUROLOGISTS NEED?

All neurologists, should have familiarity and comfort with several fundamental palliative care skills including communicating bad news, nonmotor symptom assessment and management, advance care planning, and caregiver assessment.

EANO guidelines for palliative care in adults with glioma

Andrea Pace, Linda Dirven, Johan A F Koekkoek, Heidrun Golla, Jane Fleming, Roberta Rudà, Christine Marosi, Emilie Le Rhun, Robin Grant, Kathy Oliver, Ingela Oberg, Helen J Bulbeck, Alasdair G Rooney, Roger Henriksson, H Roeline W Pasman, Stefan Oberndorfer, Michael Weller, Martin J B Taphoorn, for the European Association of Neuro-Oncology palliative care task force

To define the “state of the art” in palliative and supportive care as well as end of life care in neuro-oncology

- Symptoms management
- Patients and caregivers needs of care
- EoL issues

Mood and behavioural disorders

Evidence of several pharmacological interventions (eg, methylphenidate, donepezil) for mood disorders in patients with glioma is limited ¹⁶⁻²¹	++
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Multimodal psychosocial intervention might improve depressive symptoms in patients with brain tumours ²²	+++
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Rehabilitation for neurological deficits

Patients with brain tumours might benefit from early rehabilitation after surgery, as well as rehabilitation after tumour-specific treatment ²³⁻²⁵	++
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Cognition

Medical treatment to prevent or treat cognitive decline in patients with brain tumours is not recommended ^{16-18,26-28}	+++
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Cognitive rehabilitation has modest positive effects and should be considered especially in young patients with glioma who have a relatively favourable prognosis ²⁹⁻³¹	+++
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Stable glioma patients with cognitive complaints, deficits, or both might benefit from cognitive rehabilitation	Expert opinion
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Reduction of supportive medication should be considered in patients with glioma because they might be a potential cause of cognitive complaints or deficits	Expert opinion
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++++=high quality. +++=moderate quality. ++=low quality. +=very low quality. *Expert opinion was formulated by task force members.

Table 1: Quality of evidence for each recommendation concerning the treatment of the symptoms of glioma

Quality of evidence	
Patient needs	
The need for ongoing support might best be served by having one dedicated point of contact for continuity of contact with a health-care professional (most likely a specialist nurse) ³²	+
Early referral to palliative care and psychosocial support should be implemented ³²⁻³⁴	+
Caregiver needs	
Psychoeducation and cognitive behavioural therapy can increase feelings of mastery of caregivers and result in maintenance of their quality of life ³⁵	++
Medical professionals can mitigate caregiver stress by including the caregiver in medical consultations, requesting their feedback, and acknowledging their role ³⁶	+
Caregiver anxiety relating to the future death of the patient can be alleviated by more open communication ³⁶	+
++=low quality. +=very low quality.	
Table 2: Quality of evidence for each recommendation concerning needs of patients and caregivers	

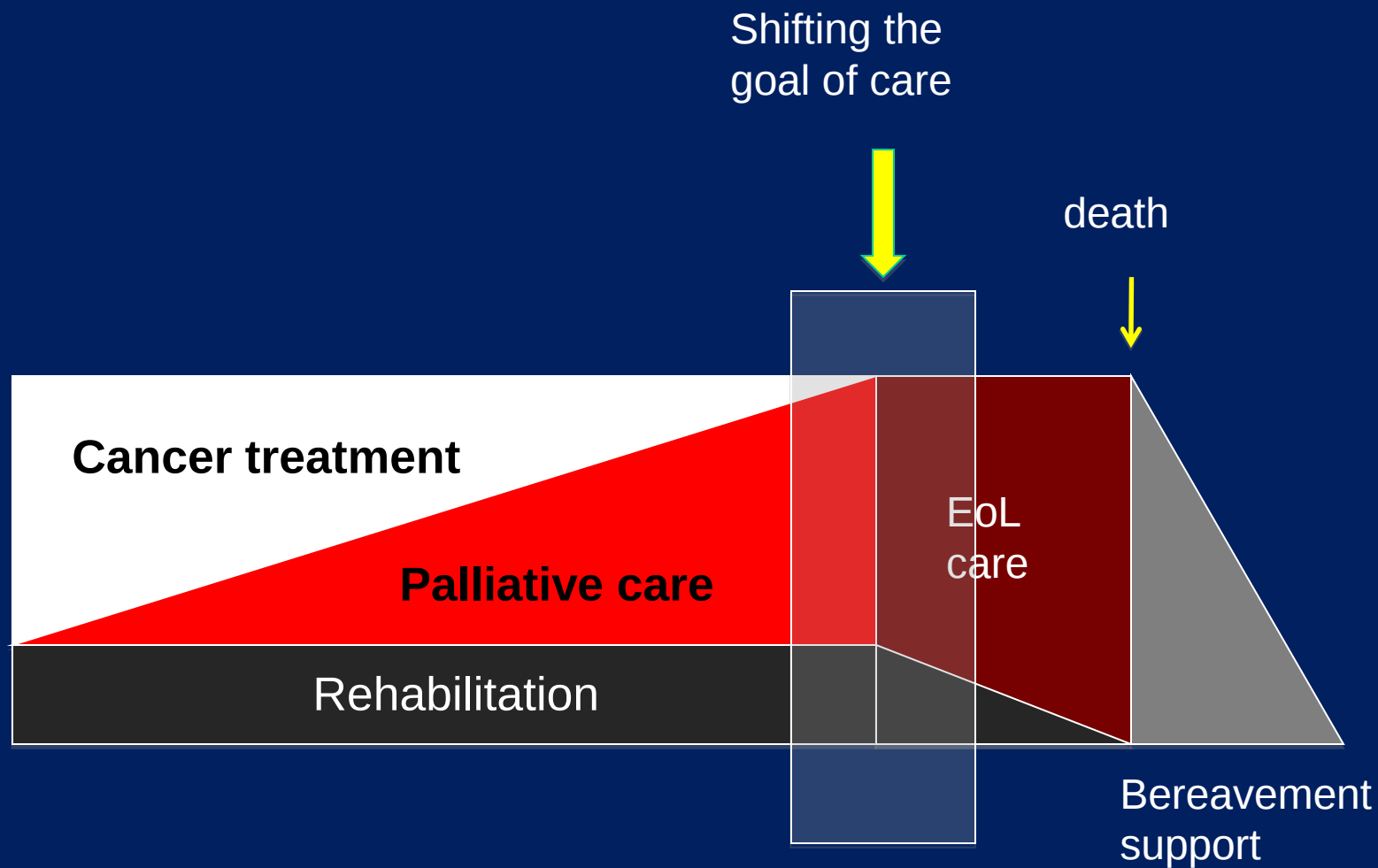
Neuro-Oncology Practice

Determining medical decision-making capacity in brain tumor patients: why and how?

Andrea Pace, Johan A.F. Koekkoek, Martin J. van den Bent, Helen J. Bulbeck, Jane Fleming, Robin Grant, Heidrun Golla, Roger Henriksson, Simon Kerrigan, Christine Marosi, Ingela Oberg, Stefan Oberndorfer, Kathy Oliver, H. Roeline W. Pasma, Emilie Le Rhun, Alasdair G. Rooney, Roberta Rudà, Simone Veronese, Tobias Walbert, Michael Weller[©], Wolfgang Wick[©], Martin J.B. Taphoorn, and Linda Dirven; on behalf of the European Association of Neuro-Oncology Palliative Care Task Force

Primary Brain Tumors: 38-50% of decisional incapacity at diagnosis

Metastatic Brain tumors: 60% of patients with impaired with impaired understanding



Integrating curative + palliative care in neuro-oncology
«*simultaneous care*»

**Pattern of care in the last 2 months of life in brain tumors in the lazio region (Italy):
analysis of a cohort of 3045 patients in the last 10 years (2010/2019).**

	last 2 months (%)	last month (%)
H readmission	43	33
ICU admission	4,5	3,7
ER access	38	24
Chemotherapy	24,5	11,4
Radiotherapy	12,1	6

Strategie assistenziali nei tumori cerebrali

Cure domiciliari

Rispetto della Qualità di Vita del paziente

Umanizzazione del rapporto di cura

Riduzione del tempo trascorso in ospedale

Riducono il carico assistenziale sulle famiglie

Riduzione dei costi a carico del SSN

Modelli di continuità assistenziale

Favoriscono l'integrazione tra ospedale e territorio

Mettono in rete le risorse sanitarie

Facilitano l'accesso del malato ai servizi

Migliorano la qualità e l'omogeneità delle cure

Palliative care delivery models in Neuroncology

- Neuro-Oncology Palliative care units
- Palliative care consultation teams
- Out-of-hours telephone support services
- Telehealth models

Aims:

- Coordination and continuity of care between N-O center and patient home
- Early provision of palliative care
- Optimal symptoms control
- EoL treatment decisions preparation (ACP)



Attività

Struttura

- **3 infermieri**
- **3 fisioterapisti**
- **1 neurologi**
- **2 psicologi**
- **1 ass sociale**

- Riabilitazione domiciliare
- Assistenza medica e infermieristica
- Terapie di supporto
- Supporto psicologico per pazienti e familiari
- Assistenza sociale
- Integrazione con i servizi territoriali
- Cure palliative alla fine della vita
- Supporto al lutto
- Reperibilità 24h – centrale d'ascolto telefonica dedicata

Home care for brain tumor patients (activity 2000 / 2020)

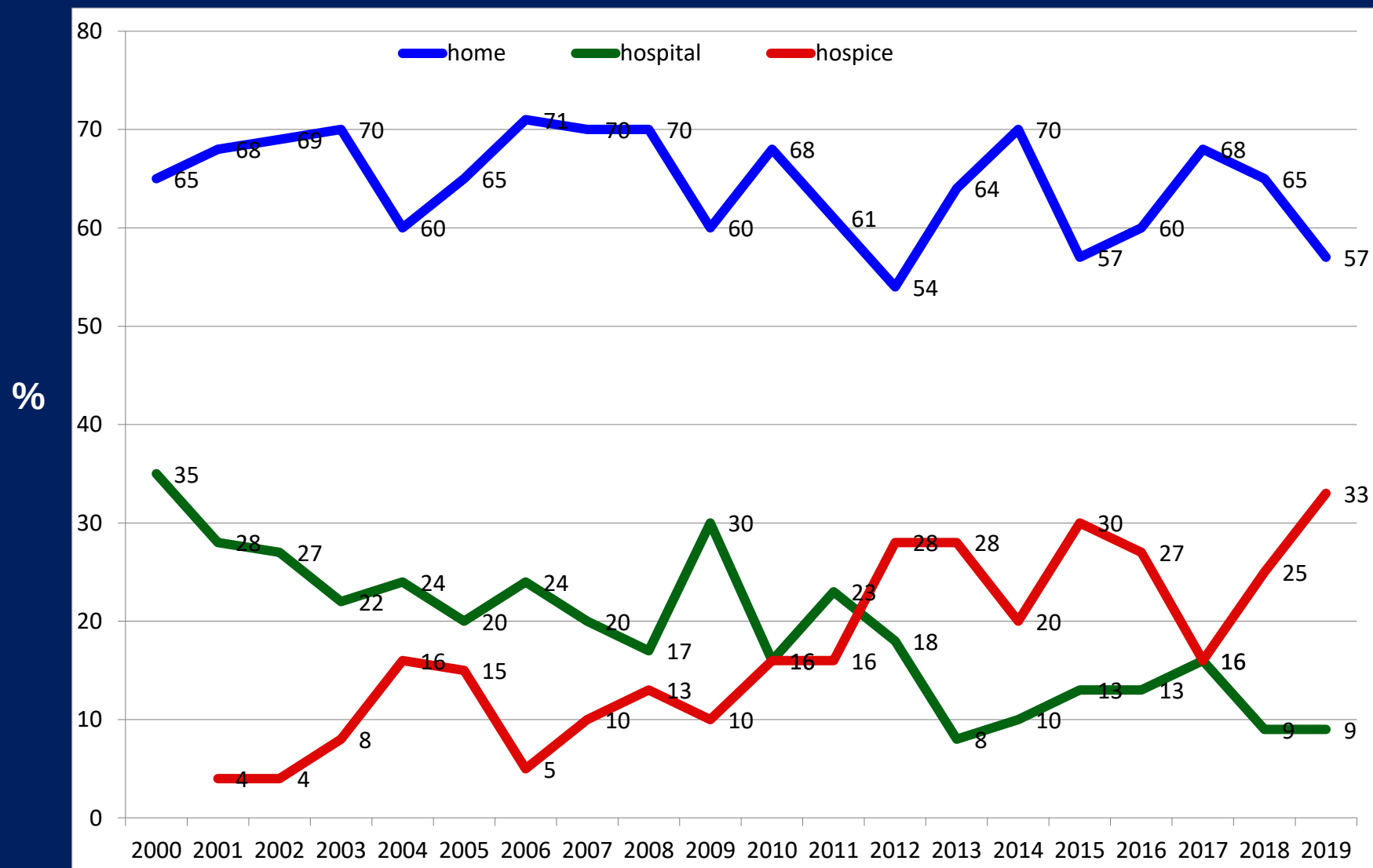


- **1166** patients (median age = 57 y)
 - 992** malignant gliomas
 - 182** other histology (MDB, Ependymoma, PCNSL..)
- **702** deaths
 - 449 (63%) at home, 126 (19% hospital, 127 (18%) in hospice

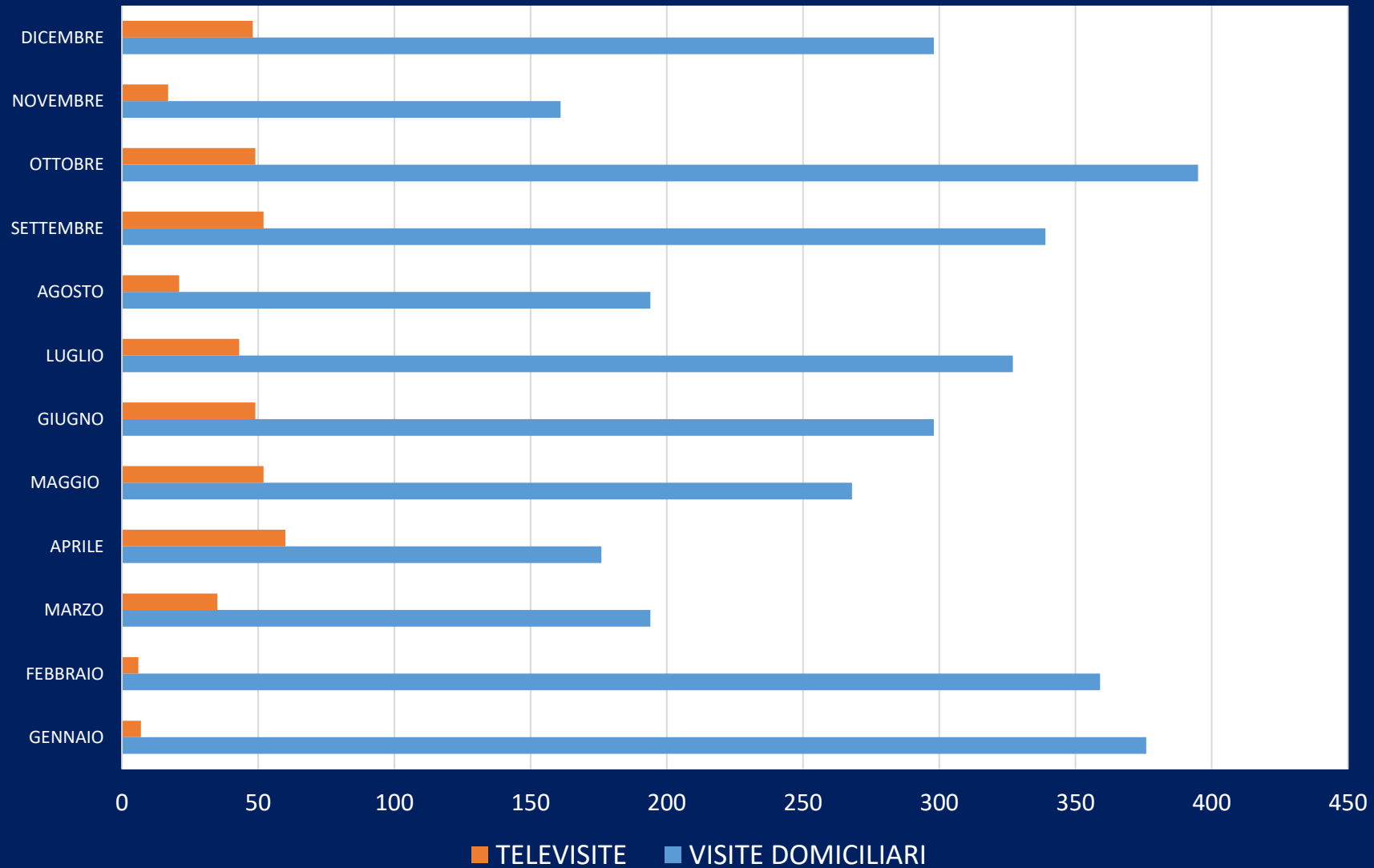
Days of assistance for patient (mean): 170 days

Place of death in 662 patients

Palliative home care Unit for BT patients

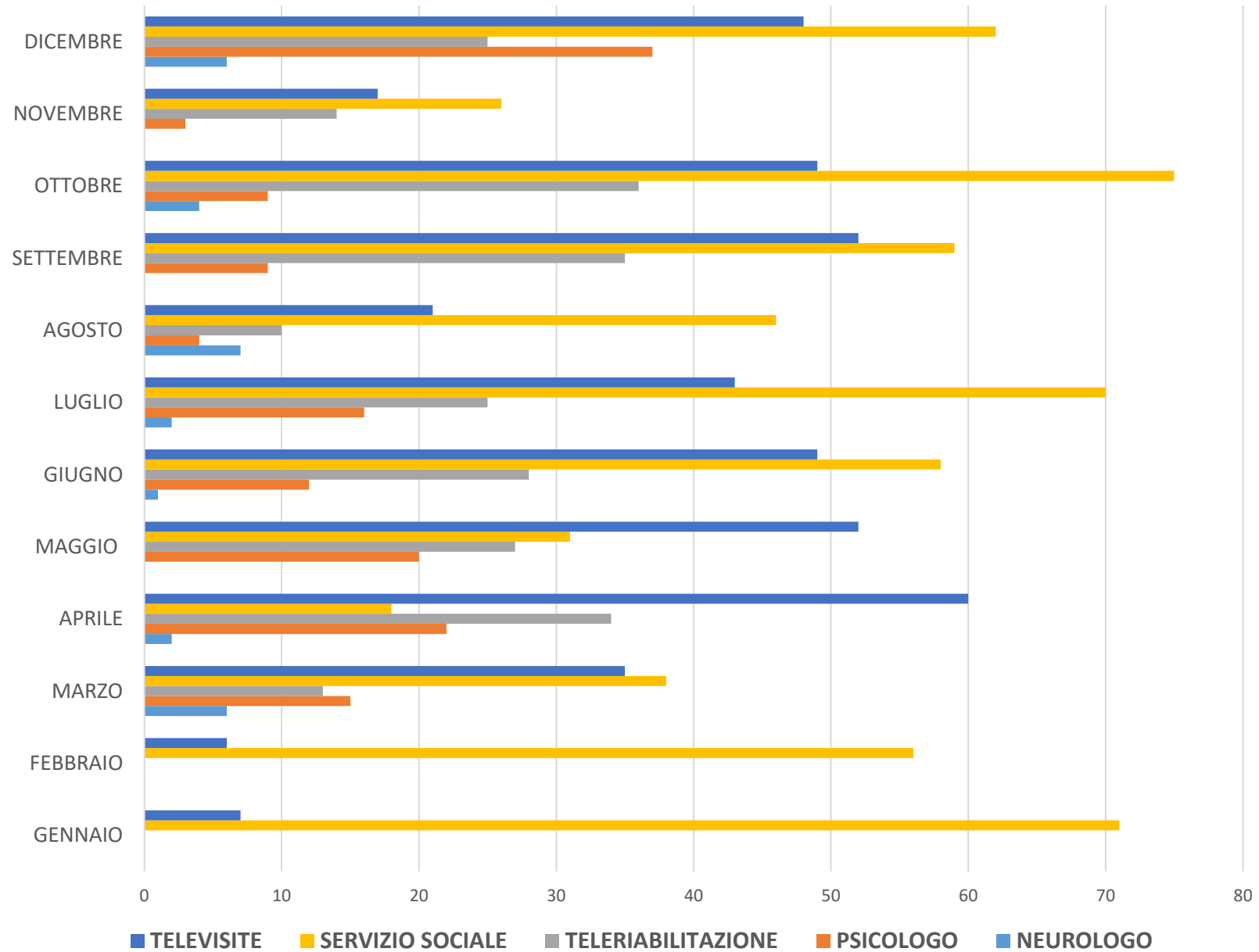


prestazioni domiciliari gennaio/dicembre 2020



Accessi domiciliari= 3246 Prestazioni di telemedicina= 431 (13,3%)

PRESTAZIONI DI TELEMEDICINA



Componenti, riforme e investimenti della Missione 6 Salute del PNRR

Componente 1: Reti di prossimità, strutture intermedie e telemedicina per l'assistenza sanitaria territoriale

Investimento 1.2: Casa come primo luogo di cura e telemedicina

Linee Guida Italiane sulle Cure Palliative In neurooncologia (AINO-SICP-SIN)

A. Pace¹, A. Solari², L. De Panfilis³, B. Lissoni⁴, E. Pronello⁵, R. Rudà⁶, A. Silvani⁷, A. Salmaggi⁸, R. Merli⁹, U. De Paula¹⁰, E. Bertocchi¹¹, M. Verza¹², S. Veronese¹³;

¹IRCCS Regina Elena Cancer Institute, Rome, Italy, ²Unit of Neuroepidemiology, Fondazione IRCCS Istituto Neurologico Carlo Besta,, Milan, Italy, ³Bioethics Unit, Azienda USL-IRCCS di Reggio Emilia, Reggio Emilia, Italy, ⁴Unit of Clinical Psychology, Niguarda Hospital, Milan, Italy, ⁵Department of Neuro-Oncology, City of Health and Science Hospital, Turin, Italy, ⁶Department of Neuro-Oncology, City of Health and Science University of Turin, Italy, ⁷Neuro-Oncologia Clinica, IRCC Istituto Neurologico Carlo Besta, Milan, Italy, ⁸Neurology and Stroke Unit, ASST, Lecco, Italy, ⁹Neurosurgery Unit, ASST PGXXIII, Bergamo, Italy, ¹⁰Radiation Oncology, San Giovanni-Addolorata Hospital, Rome, Italy, ¹¹Azienda USL-IRCCS di Reggio Emilia, Reggio Emilia, Italy, ¹²IRENE BT Patients Association, Rome, Italy, ¹³Fondazione FARO, Turin, Italy

Definizione dei temi rilevanti per le cure palliative nei pazienti affetti da neoplasia cerebrale e loro caregivers attraverso un questionario semi-strutturato e focus group

- *Intervista ai Pazienti* - *Focus group con familiari di pazienti affetti da neoplasia cerebrale* - *Survey on-line per operatori sanitari*

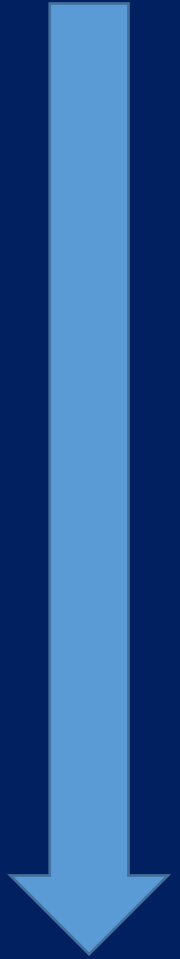
Data collection

- Patients interview
- Focus Group with Caregivers of patients death
- Neuroncology Health Professionals Survey

Results

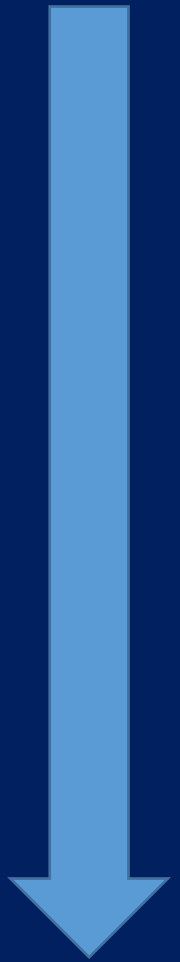
- 20 patients in 5 Italian Neuroncological Centers participated to the interview
- 40 Caregivers were involved in the Focus Groups
- 244 HP (Neuroncologists, Psychologists, Nurses, PC specialists) answered to the WEB Survey

Most treated topics (patients)



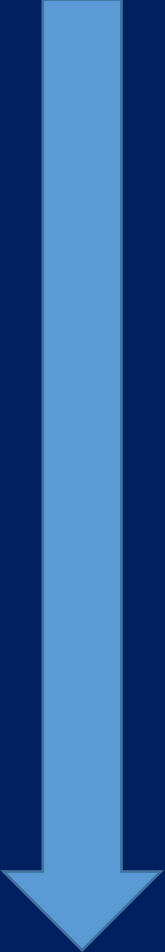
- **Communication**
- **Relationship with care team**
- **Symptoms control (cognitive symptoms)**
- Psychological support
- Advance Care Planning
- Motor Symptoms
- Activity Daily Living Limitations

Most treated topics (caregivers)



- **Communication**
- **Rehabilitation**
- **Psychological support for patients and caregivers**
- **Bereavement**
- **Symptoms control**
- **Spiritual Support**
- **Advance Care Planning**
- **Rehabilitation**
- **Models of care**

WEB Survey topics for health professionals

- 
- **Communication**
 - **Rehabilitation**
 - **Psychological support for patients and caregivers**
 - **Bereavement**
 - **Symptoms control**
 - **Spiritual Support**
 - **Advance Care Planning**
 - **Rehabilitation**
 - **Models of care**

Conclusioni

Il percorso di malattia del paziente neuroncologico richiede modelli di presa in carico caratterizzati da **continuità tra ospedale e territorio** e modulazione delle prestazioni assistenziali sui reali bisogni dei pazienti, analogamente ai pazienti affetti da patologie neurologiche degenerative

La pandemia COVID ha richiesto (e richiede) lo sviluppo di strumenti adeguati per potenziare l'assistenza sul territorio e migliorare i percorsi assistenziali dei pazienti affetti da malattie neurologiche croniche