

Palliative care for acute cerebrovascular disease: a survey of italian neurologists' opinions

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Introduction and objectives

In recent years increasing interest was addressed to palliative care (PC) in neurology, and several contributions are focused on cerebrovascular disorders. The Study Group " Bioethics and Palliative Care " of the Italian Neurological Society started in 2017 a discussion about the this topic, with particular reference to patients admitted in the stroke units.

The objective of this survey was to know the opinions of Italian neurologists about the need of PC in cases of severe stroke with potentially negative prognosis. The results coming from the survey will contribute to establish future specific recommendations

Methods and materials

Some members of the Study Group working in stroke units set up a committee, and with an appropriate consensus procedure drawn up a questionnaire reporting 12 statements about the planning of PC in stroke units, each of which provided for a reply (I agree or I disagree), and some questions about personal data and institutions. The survey was finally held in 2018 in a national context with the collaboration of the Italian Stroke Organization and in three Italian regions with the collaboration of the Italian Neurological Society.

Results

The questionnaire was answered by 183 neurologists, most of them working in stroke units and in general hospitals, coming from different geographic areas. The need to introduce PC in the stroke units was confirmed with a broad consent (159 / 183 positive answers), specially for an " end of life " condition defined on the basis of prognostic criteria. A general agreement emerged also about: 1) the neurologist must have an appropriate knowledge of PC; 2) PC must be included in a structured program, with preliminary evaluation of appropriateness and futility of diagnostic and therapeutic measures; 3) this approach is mandatory for invasive procedures as surgery, cardiopulmonary resuscitation, assisted breathing; 4) there is a imperative duty to provide adequate measures to exclude any patient's suffering, physical and psychological; 5) the patients' wishes when known (advanced directives, other instructions) must be taken in consideration, witnessed by their representatives in **absence of direct information**.

Conclusions

This is the first survey carried out in Italy about the need of PC in patients with severe stroke. Undoubtedly the survey suffered some methodological limitations, as the small dimension of the sample and the selection criteria. Nevertheless, our results lead to an univocal conclusion: PC must be always considered for patients admitted to the stroke units, entering the daily practice of neurologists.

SCHEMA RACCOLTA DATI	
DATI PERSONALI	
1	Nome, Cognome (Iniziali)
2	Specializzazione in: neurologia (1), altro (2)
3	Anno di specializzazione: pre 1990 (1); 1990/2000 (2); 2000/2010 (3); post 2010 (4)
ISTITUZIONE DI RIFERIMENTO	
4	Ospedale Generale (1); IRCCS (2); Università (3); altro (4)
5	In: Italia nord (1); Italia centro (2); Italia sud + isole (3)
SEDE DELL'ATTIVITA'	
6	Stroke Unit (1); Neurologia generale (2); altro (3)
QUESTIONARIO	
CONCORDI SULLE SEGUENTI AFFERMAZIONI ? (SI / NO)	
1	C'è spazio per l'applicazione delle cure palliative nelle stroke unit
2	Lo stroke team deve disporre di competenze acquisite ed adeguate per l'applicazione di cure palliative "primarie "
3	Uno "specialty palliative team" deve essere disponibile per consulto e per una presa in carico diretta del paziente quando le circostanze lo richiedano, all'interno o al di fuori dell'ospedale di riferimento.
4	Nel caso dell'ictus acuto le cure palliative si applicano principalmente in una condizione "end of life" da definire sulla base di criteri prognostici
5	Il parere esperienziale del personale di assistenza rappresenta un valido contributo alla valutazione prognostica e alle decisioni conseguenti
6	Occorre una preliminare valutazione di appropriatezza dei provvedimenti terapeutici causali da commisurare alle circostanze
7	In particolare va soppesata la opportunità di provvedimenti invasivi: atti chirurgici, tracheostomia e intubazione, rianimazione cardiopolmonare
8	Ogni provvedimento va inoltre assunto dopo un giudizio inerente alla sua futilità
9	L'interesse e le opzioni generali dal paziente sono da mettere in primo piano e vanno ricostruite con i suoi fiduciari nel caso in cui il paziente non sia in grado di comunicarle.
10	Occorre coinvolgere il paziente / fiduciario per ogni decisione, specialmente per la messa in opera di trattamenti invasivi e all'avvio / sospensione di provvedimenti di sostegno vitale
11	E' opportuno che le decisioni diagnostiche - terapeutiche siano condivise fra personale di assistenza e malati / fiduciari
12	Occorre provvedere al sollievo di ogni tipo di sofferenza dovuta o meno alla astensione da provvedimenti di sostegno vitale e/o alla loro sospensione.
ALTRE INFORMAZIONI	
CONCORDI SULLE SEGUENTI AFFERMAZIONI ? (SI / NO)	
1	In sede di esperienza personale di stroke unit o comunque di patologia cerebrovascolare acuta hai avuto problemi a decidere il tipo di approccio diagnostico - terapeutico ?
2	Hai mai avuto la sensazione di inappropriata e / o futilità delle cure applicate ?
3	Nella tua realtà esistono PDTA o procedure operative al riguardo ?
Further comments	
Statement 4 about the opportunity to consider PC mainly in a " end of life " condition received less unanimous consent: only 80% of positive responses. This reflects the ongoing debate about " end of life " palliative care vs. "early " or " simultaneous " palliative cares.	
The answers to the final part of the questionnaire (" altre informazioni "), were non reported in the section " results " and documented the absolute lack of structured procedures or local guidelines for a palliative approach to the patients with severe stroke. Obviously, this reflects the experience of the responders.	
References	
Provinciali L. et al. Need for palliative care for neurological diseases. <i>Neurol Sci</i> , 2016 Oct; 37(10):1581-1587	
Holloway G.H. et al. Palliative and End-of-Life care in Stroke: a statement for healthcare professionals from the AHA/ASA. <i>Stroke</i> , 2014 jun; 45(6): 1887-1916	
Alonso A. et al.. End-of-life decisions in acute stroke patients: an observational cohort study. <i>BMC Palliative Care</i> , 2016 apr; 5; 15:38	