

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Study protocol on advance care planning in multiple sclerosis (ConCure-SM): Intervention construction and multicenter feasibility trial
AUTHORS	De Panfilis, Ludovica; Veronese, Simone; Bruzzone, Michela; Cascioli, Marta; Gajofatto, Alberto; Grasso, Maria; Kruger, Paola; Lugaresi, Alessandra; Manson, Leigh; Montepietra, Sara; Patti, Francesco; Pucci, Eugenio; Solaro, Claudio; Giordano, Andrea; Solari, Alessandra

VERSION 1 – REVIEW

REVIEWER	Latorraca, Carolina Universidade Federal de São Paulo
REVIEW RETURNED	05-Jun-2021

GENERAL COMMENTS	Dear authors, Congratulations. I believe this study is extremely important to the future of multiple sclerosis patients and to facilitate advance care planning use. I only suggest to use less abbreviations throughout the abstract and the role text.
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REVIEWER	Vanopdenbosch, Ludo AZ Sint-Jan Brugge-Oostende AV, Neurology
REVIEW RETURNED	07-Jul-2021

GENERAL COMMENTS	<p>This is an excellent research project on ACP in MS. Timely because of the new Italian legislation and renewed interest in neuropalliative care identifying the need for knowledge about the process of ACP in specific neurological diseases. The trial is well planned and in depth. The qualitative methods are very meticulously described and to the highest standards. MRC recommendations on trials with complex interventions were incorporated. Maybe you can refer to Higginsons Evaluating complex interventions in End of Life Care: the MORECare statement (BMC Medicine 2013,11:111).</p> <p>The pitfalls in this kind of research identified in the post hoc analysis of the negative multimillion dollar SUPPORT trial of ACP in ICU in the 1990's were addressed, especially the idea that ACP is a dynamic process: this trial has expertly chosen a 'ACP-E questionnaire developed and validated to measure the complex behavior of ACP'. The consideration to 'train health care providers other than physicians in order to promote ACP knowledge within the caring team' is welcomed, however ACP should be embedded in primary care as well, I miss this aspect a bit. A lot of misunderstandings have arisen when ACP is hospital or specialist</p>
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	<p>focused. The involvement of GP's in the care of pwMS is of course country and culture dependent.</p> <p>A major hindrance in ACP in MS is to find the appropriate moment, this is nicely addressed in the eligibility criteria 'one or more of the following conditions that would make ACP relevant must be present: ...'</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1 - Mrs. Carolina Latorraca, Universidade Federal de São Paulo

- I only suggest to use less abbreviations throughout the abstract and the role text. Following reviewer's advice, we have removed some abbreviations from the abstract, and from the manuscript.

Reviewer: 2 - Dr. Ludo Vanopdenbosch, AZ Sint-Jan Brugge-Oostende AV

- Maybe you can refer to Higginsons Evaluating complex interventions in End of Life Care: the MORECare statement (BMC Medicine 2013,11:111). We have now quoted this consensus document (ref. 59) at the end of the Discussion: 'Finally, our pilot trial lacks long-term outcomes, chiefly the concordance between preferred and received EOL care and treatments [57]. However, the MS trajectory further challenges the collection of this outcome in the typical timeframe of a clinical trial. In line with the principles of ACP, we agreed not to narrow the inclusion criteria only to pwPMS in the late stage of the disease, deserving this relevant outcome to future studies.'
- ... however ACP should be embedded in primary care as well, I miss this aspect a bit. A lot of misunderstandings have arisen when ACP is hospital or specialist focused. The involvement of GP's in the care of pwMS is of course country and culture dependent. We agree that the involvement of GPs in the process of ACP is an important issue. However, it depends on the organization of the local healthcare system (as anticipated by the reviewer) and on the medical condition. We have added the following sentence (Discussion): 'We will not enroll from primary care practices as in Italy MS patients are followed in tertiary care centers. Moreover, previous attempts to involve the family physicians in the care of PwPMS were challenging [55].'