



## Aminoff Suffering Syndrome: A Challenge for Medical and Nursing Staff during End-of-Life Care: Open Letter and Proposals

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### **Author's contribution**

*The sole author designed, analyzed, interpreted and prepared the manuscript.*

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### **ABSTRACT**

The diagnosis of Aminoff Suffering Syndrome in advanced dementia determined by measuring the suffering level of patients according to the Mini Suffering State Examination (MSSE) scale — facilitates acceleration and intensity of care by the nursing staff in order to prevent and relieve suffering. Relief of Suffering Units for patients with Aminoff Suffering Syndrome should be an integral part of any medical department or nursing home that specializes in caring for elderly people. Aminoff Suffering Syndrome at the end of life could, and should be diagnosed, prevented and diminished. The treatment of patients with Aminoff Suffering Syndrome at the end of life is a genuine challenge for medical and nursing personnel. Our proposals for further experimental studies at the end of life are the diagnosis of Aminoff Suffering Syndrome in dying patients with cancer, AIDS, cardiac, pulmonary, kidney, liver and other terminal diseases. We recommend that such studies should be performed at all medical settings.

*Keywords: End of life; Aminoff Suffering Syndrome; Relief of Suffering Units; palliative care.*

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## ABBREVIATIONS

ASS : Aminoff Suffering Syndrome  
MSSE : Mini Suffering State Examination  
SM-EOLD : Symptom Management in End-of-Life in Dementia  
CAD-EOLD : Comfort Assessment in Dying with Dementia

## 1. INTRODUCTION

### 1.1 Epigraph of Paper

*Suffering of patients is not a function of disease, suffering of patients is a function of inadequate medical and nursing care [1].*

During the latter half of the last century, human society and the medical profession have appraised the founding of St Christopher's Hospice in 1967 by Dame Cicely Saunders [2,3,4], who made an extraordinary contribution to alleviating human suffering. In the 1960s, Dame Cicely Saunders introduced the concept and term *total pain*. Saunders and Baines [5] described this as an integrated, multidimensional experience, including physical, psychological, social, and spiritual aspects that contrasted with the limited consideration of pain as a physiological response, which was the view held by numerous medical professionals at that time.

Several important questions await experimental evidence from well-validated clinical studies performed on patients at the end-of-life. Such issues include:

- 1) How to measure the suffering level of patients who are enrolled in palliative care?
- 2) Does palliative care successfully diminish and alleviate human suffering until demise?
- 3) Which are the best validated tools to evaluate the suffering level at the end of life, i.e. from diagnosis of suffering before and during palliative care, and until demise?
- 4) What is the best approach to diagnose short survival at the end of life?

Undoubtedly, additional questions still remain to be answered.

According to the results of a prospective clinical study on measuring the level of suffering at the end of life, we defined a new clinical and pathological entity, i.e. Aminoff Suffering

Syndrome. The data were presented at world and international congresses in Madrid [6], Saint-Petersburg [7], Trondheim [8], Paris [9], Honolulu [10], Athens [11], Copenhagen [12], Seoul [13,14,15], and Edinburgh [16].

The Aminoff Suffering Syndrome in advanced dementia is characterized by a high Mini Suffering State Examination (MSSE) scale score, <6 months' survival, irreversible and intractable aggravation of suffering and actively dying medical condition until demise [17,18,19,20].

In the year 1907, Dr Alois Alzheimer published a famous case report on Mrs Auguste Deter [21]. In our article published in 2013, we were able to establish that Mrs Deter suffered from Aminoff Suffering Syndrome [22]. Last months, weeks and days of life of Mrs Auguste Deter was in high suffering level by MSSE and definitely were in Aminoff Suffering Syndrome by description of her medical history and follow up which was wrote Dr. Alois Alzheimer in 1906.

The MSSE (Table 1) scale [23,24] developed by us, is the first objective clinical tool for evaluation of suffering level in advanced dementia. The MSSE scale is available in English, Hebrew, Dutch [25], German, Italian and Spanish, and covers 10 items (range 0-10). A high MSSE scale score with range 7-10 indicates a high level of suffering, and reflects the severity of the medical condition in advanced dementia.

The MSSE Score Interpretation:

Low level of suffering: range 0-3  
Intermediate level of suffering: range 4-6  
High level of suffering: range 7-10

The MSSE scale was tested using the Cronbach  $\alpha$  model, which demonstrated its *significant reliability* ( $\alpha = 0.798$ ). A  $\kappa$  agreement coefficient of 0.791 between two observers was found. Both observers found significant association between the three MSSE levels and age ( $P = 0.02$ ), haemoglobin ( $P = 0.02$ ), albumin ( $P < 0.001$ ), cholesterol ( $P = 0.04$ ), use of analgesics or antipsychotics ( $P = 0.04$ ).

**Table 1. Mini Suffering State Examination (MSSE)**

<b>Date</b>					
Not calm					
Screams					
Pain					
Decubitus ulcers					
Malnutrition					
Eating disorders					
Invasive action					
Unstable medical condition					
Suffering according to family opinion					
Suffering according to medical opinion					
Total MSSE score					

*Convergent validity* of the MSSE scale was proven by Pearson correlation with Symptom Management in End-of-Life in Dementia (SM-EOLD) scale ( $r = 0.574$ ,  $P < 0.0001$ ), and Comfort Assessment in Dying with Dementia (CAD-EOLD) scale [26,27] ( $r = -0.796$ ,  $P < 0.0001$ ). The mean survival of end-stage dementia patients with a low MSSE scale score (MSSE =  $2.24 \pm 0.99$ ) was  $57.76 \pm 9.73$  days, and with a median MSSE scale score (MSSE =  $4.92 \pm 0.83$ ) the mean survival was  $44.70 \pm 5.99$  days. In the high MSSE scale score group (MSSE =  $8.06 \pm 1.00$ ) mean survival was much shorter ( $27.54 \pm 4.16$  days) [28].

The differences between the survival times of the three MSSE scale score groups was evaluated by Kaplan-Meier analysis (Log Rank,  $P = 0.0018$ , Breslow,  $P = 0.0027$ ) and were significant. The results of the Cox proportional Hazard model of survival showed a high correlation between high MSSE scale score and high risk of mortality, and short survival of end-stage dementia patients during the last 6 months of life with *significant predicting validity* ( $P = 0.013$ ) [29].

MSSE scale could measure suffering of advanced dementia patient as such same scales and methods performed by any medical or nursing staff and in any setting.

According to the MSSE scale, it has been confirmed that patients with end-stage dementia represent a heterogeneous group and have different levels of suffering, and accordingly proved a *significant concurrent validity*. The results of our research showed that hospitalization in geriatric department in tertiary hospital in Israel fail to decrease the high level of suffering of such patients. The total score of MSSE scale of advanced dementia patients on

the day of admission to geriatric department was  $5.62 \pm 2.31$ , and increased to  $6.89 \pm 1.95$  on the last day of life with a *significant test-retest reliability* ( $P < 0.0001$ ) [30].

Despite traditional medical and nursing care, a large proportion of dying patients with dementia experience increased suffering as they approach death. According to the MSSE scale, 63.4% and 29.6% experienced high and intermediate levels of suffering, respectively, with only 7% having a low level of suffering upon their demise [31].

On the last day of life, 71.8% of dying patients with dementia with Aminoff Suffering Syndrome were not calm, 71.4% had decubitus ulcers, 94.4% suffered from malnutrition, 95.8% had eating disorders, 90.1% experienced invasive procedures, and 90.1% were in an unstable medical condition. The suffering level in advanced dementia has a significant correlation with short survival, advancing age, more severe illness, malnutrition, the existence of decubitus ulcers, and the administration of medications [31]. Thus, the life of patients with end-stage dementia is filled with grief, secretion and stench, suppuration and wounds, crying, screaming, or silent pain. This appears to be the natural and essential path of end-stage disease and aging.

In the modern humane Western world, despite advanced medical science, society at large is not always aware of the terrible suffering of elderly people in the last stage of life [17].

The world outside the confines of the hospital is unaware of what transpires in the wards of hospitals and nursing homes.

This also applies to other tragic circumstances. A healthy person may think "*This is not happening to me and it will not happen to me*".

Physicians and nursing staff are faced day and night with a difficult and exhausting task. Despite the hardship of coping, it appears that the medical personnel accept this appalling process of doom. The patients' families are not always aware of this reality. Those who are in fact aware of the seriousness of the patient's condition, often distance themselves from the reality of the hospital and its environs. Others may engage in harsh altercations with the treating medical staff.

Medicine today facilitates extended longevity at a high price of suffering to the patients, their families, and even to the medical professionals. [17] It is easy to calculate the daily and annual costs of hospitalization. The maintenance costs are enormous over such an extended period. In the future, with increasing successes in the treatment of heart diseases and tumors, patients with dementia may well be in the majority in hospital departments. One of proposals is preventing avoidable hospital admissions for people with advanced dementia [32].

Perpetual and increased agony of an end-stage dementia patient is reminiscent of the suffering of patients prior to the era of anesthesia, or antibiotics. The main causes of suffering at the end-of-life are *inadequate medical and nursing care, overprotection phenomenon with dying patients* [33,34] and *Geriatrics D refusal phenomenon* [35].

Possible solutions for suffering at the end of life are the measurement level of suffering, and enrolment of patients diagnosed with Aminoff Suffering Syndrome to home or hospital palliative care settings, or alternatively to Relief of Suffering Units [36,37] within hospitalization departments. Relief of Suffering Units that can perform daily medical practice without any new pecuniary or equipment expense should switch from futile intensive medical care to *intensive nursing care*. Intensive nursing care could prevent and relieve suffering at the end-of-life by a more meticulous approach to symptoms of not calm, screams and pain, decubitus ulcers, malnutrition and eating disorders, and thus obviate futile invasive action. Special vigilance and tenderness, warm hands, constant surveillance of the dying patient and intensive professional nursing care are challenges for nursing staff, and are a guarantee for relief and prevention of suffering at the end of life.

The suffering assessment [38,39,40,41,42,43] and quality of dying evaluation [44,45] are

important at the end of life. Some available instruments developed for suffering assessment in end of life: Initial assessment of suffering [46], Pictorial Representation of Illness and Self Measure [47], Suffering Assessment Tool [48] State of Suffering-V [49], The Suffering Scales [50], and Structured Interview for Symptoms and Concerns Scale [51].

The outcomes assessed in palliative care involve symptoms, physical signs, laboratory tests, evaluation scales, questionnaires for activities of daily living, or quality-of-life in order to interpret the quality of provided care [52,53].

Unfortunately, the overall reporting rate for *validation* articles in palliative care journals is only 1.43%, and there is a paucity of studies on patient-centered validation methods [54].

This clinical practice development article is an open letter as well as proposals to the medical and nursing staff at all palliative and hospice settings:

We appeal to all medical researchers involved in geriatric care to perform experimental prospective studies in their respective clinical settings:

1. Diagnosis of Aminoff Suffering Syndrome in end-of-life patients with cancers and other malignant neoplasms;
2. Diagnosis of Aminoff Suffering Syndrome in end-of-life patients with AIDS, heart, kidney, pulmonary, and liver diseases;
3. Measurement of suffering level by diagnosis of Aminoff Suffering Syndrome on day of admission and on last day of life to evaluate effectiveness of treatment in a hospice setting;
4. Routine diagnosis of Aminoff Suffering Syndrome in Geriatric, Internal Medicine, Surgery and other departments for subsequent enrolment of patients to palliative treatment, or Relief of Suffering Units.

## 2. CONCLUSION

Aminoff Suffering Syndrome waits to its wide use in medicine [55]. Diagnosis of Aminoff Suffering Syndrome could diminish suffering of patients at the end of life by *adequate medical and nursing care* [56]. Dealing with Aminoff Suffering Syndrome at the end of life provides a genuine challenge to nursing and medical personnel.

The definition of Aminoff Suffering Syndrome is an important step in clinical scientific research of dilemmas and diverse challenges at the end-of-life. In clinical practice, diagnosis of Aminoff Suffering Syndrome can be performed in any setting that specializes in the treatment of end-of-life patients.

The diagnosis of Aminoff Suffering Syndrome opens new horizons in the approach to anguish at end-of-life and provides a novel method for identifying which patients require immediate palliative treatment.

### CONSENT

It is not applicable.

### ETHICAL APPROVAL

It is not applicable.

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### COMPETING INTERESTS

Author has declared that no competing interests exist.

### REFERENCES

1. Aminoff BZ. Prognosis of short survival in patients with advanced dementia as diagnosed by Aminoff Suffering Syndrome. *Am J Alzheimers Dis Other Demen.* 2014; 29(8):673-7.  
DOI: 10.1177/1533317514539543  
[PubMed PMID: 24939003].
2. Du Boulay S, Saunders C. The founder of the modern hospice movement (revised edition). London: Hodder and Stoughton; 1994.
3. Clark D. Originating a movement: Cicely Saunders and the development of St Christopher's Hospice, 1957-1967. *Mortality.* 1998;3(1):43-63.  
DOI: <http://dx.doi.org/10.1080/713685885>
4. Clark D. Religion, medicine, and community in the early origins of St. Christopher's Hospice. *J Palliat Med.* 2001; 4(3):353-360.  
DOI: 10.1089/109662101753123977  
[PubMed PMID: 11596547].
5. Saunders C, Baines M. Living with dying: The management of terminal disease. Oxford: Oxford University Press; 1983.
6. Aminoff BZ. Aminoff Suffering Syndrome: A new pathological entity in end-stage dementia. 10<sup>th</sup> International Conference on Alzheimer's Disease and Related Disorders, Madrid, Spain, July 15-20, 2006 [abstract]. *Alzheimer's & Dementia.* 2006; 2(Suppl. 1):S258-259.
7. Aminoff BZ. Aminoff Suffering Syndrome: A new pathological entity in end-stage dementia. VI European Congress of the International Association of Gerontology and Geriatrics, St. Petersburg, Russia, 5-8 July, 2007 [abstract]. *Adv Gerontol.* 2007; 20:80.
8. Aminoff BZ. Aminoff Suffering Syndrome: A new pathological entity in end-stage dementia. 5<sup>th</sup> Research Forum of the European Association for Palliative Care (EAPC), Trondheim, Norway, 28-31 May, 2008 [abstract]. *Palliat Med.* 2008;22:462.
9. Aminoff BZ. Aminoff Suffering Syndrome (ASS): A new pathological entity in end-stage dementia. XIX IAGG 2009 World Congress of Gerontology and Geriatrics, Paris, France, 5-9 July 2009 [abstract]. *J Nutr, Health Aging.* 2009;13(Suppl 1): S221.
10. Aminoff BZ. Aminoff Suffering Syndrome and decubitus ulcers in advanced dementia. 10<sup>th</sup> Alzheimer's Association International Conference on Alzheimer's Disease, Honolulu, Hawaii, July 10-15, 2010 [abstract]. *Alzheimer & Dementia.* 2010; 6(Suppl 1):3-436.
11. Aminoff BZ. Entropy definition of human happiness and suffering. Abstract Book for the 6th Annual International Conference on Philosophy, 30-31 May & 1-2 June 2011, Athens, Greece: P2 [abstract]. First Published in Athens, Greece by the Athens Institute for Education and Research.
12. Aminoff BZ. Suffering and pain in end-stage dementia. 21<sup>st</sup> Nordic Congress of Gerontology. Dilemmas in Ageing Societies, Copenhagen, Denmark, 2012, June 10-13, [abstract] 06.1-2. Published in Copenhagen, Denmark; 2012.
13. Aminoff BZ. Aminoff Suffering Syndrome and pain in end-stage dementia. The 20<sup>th</sup> IAGG World Congress of Gerontology and Geriatrics, Seoul, Korea, June 23-27, 2013 [abstract]. *J Nutr, Health Aging.* 2013; 17(Suppl1):PS312.

14. Aminoff BZ. End-of-life anguish: Aminoff Suffering Syndrome and Relief of Suffering Units. The 20<sup>th</sup> IAGG World Congress of Gerontology and Geriatrics, Seoul, Korea, June 23-27, 2013 [abstract]. *J Nutr, Health Aging*. 2013;17(Suppl 1):PS616.
15. Aminoff BZ. Aminoff Suffering Syndrome and anti-entropy deficiency phenomenon in advanced dementia. The 20<sup>th</sup> IAGG World Congress of Gerontology and Geriatrics, Seoul, Korea, June 23-27, 2013 [abstract]. *J Nutr, Health Aging*. 2013;17(Suppl 1):PS404.
16. Aminoff BZ. Entropy definition of human suffering and happiness and Aminoff Suffering Syndrome. 2015a International Congress on Arts, Communications, Science and Technology. 29<sup>th</sup> June-6<sup>th</sup> July at the Hilton Edinburgh Grosvenor Hotel. Edinburgh, Scotland.
17. Aminoff BZ. Measurement of suffering in end-stage Alzheimer's disease. *Tel Aviv: Probook, Dyonon*; 2007.
18. Aminoff BZ. Aminoff Suffering Syndrome: A new pathological entity in end-stage dementia.' 10<sup>th</sup> International Conference on Alzheimer's Disease and Related Disorders, Madrid, Spain, July 15-20, 2006. In: *Alzheimer's Disease: New Advances, Medimond International Proceedings*. 2007;55-59.
19. Aminoff BZ. End-stage dementia: Aminoff Suffering Syndrome and Relief of Suffering Units. *The Open Geriatr Med J*. 2008;1: 29-32.
20. Aminoff BZ. End-stage dementia: Aminoff Suffering Syndrome and decubitus ulcers. *Dementia*. 2012;11(4):473-481. DOI: 10.1177/1471301211421224
21. Alzheimer A. Uber eine eigenartige Erkankung der Hirnrinde. *Allgemeine Zeitschrift fur Psychiatrie*. 1907;64:146-8.
22. Aminoff BZ. Mrs. Auguste D{eter} demise in 1906 was in Aminoff Suffering Syndrome. *Am J Alzheimers Dis Other Demen*. 2014;29(3):199-200. DOI: 10.1177/1533317513511288 [PubMed PMID: 24211868].
23. Aminoff BZ. Mini-suffering state examination. 4<sup>th</sup> European Congress of Gerontology, Berlin. Germany, July 7 – 11, [abstract]. *Gerontol und Geriatr*. 1999; 32(2):238.
24. Aminoff BZ, Purits E, Noy Sh, Adunsky A. Measuring the suffering of end-stage dementia: Reliability and validity of the mini-suffering state examination. *Arch Gerontol Geriatr*. 2004;38(2):123-130. DOI: 10.1016 [PubMed PMID: 14698490].
25. Schols R, Schipper R, Brabers A, Schols J. De Mini-suffering State Exam (MSSE) onderzocht in een Nederlands verpleeghuis. *Dementie (Nederlands)*. 2003;27(5):14-19.
26. Volicer L, Hurley AC, Blasi ZV. Scales for evaluation of end-of-life care in dementia. *Alzheimer Dis Assoc Disord*. 2001;15(4): 194-200. [PubMed PMID: 11723370].
27. Volicer L, van der Steen J. Outcome measures for dementia in the advanced stage and at the end of life. *Adv Geriat*; 2014. Article ID 346485, 10 pages.
28. Aminoff BZ. Mini-suffering state examination scale: Possible key criterion for 6 months' survival and mortality of critically ill dementia patients. *Am J Hosp Palliat Med*. 2008;24(6):470-704.
29. Aminoff BZ, Adunsky A. Their last six months of life: Suffering and survival of end-stage dementia patients. *Age Ageing*. 2006;35(6):597-601. [PubMed PMID: 16926196].
30. Aminoff BZ, Adunsky A. Dying dementia patients: Too much suffering, too little palliation. *Am J Alzheimers Dis Other Demen*. 2004;19(4):243-247. [PubMed PMID: 15359563]. DOI: 10.1177/153331750401900402
31. Aminoff BZ, Adunsky A. Dying dementia patients: Too much suffering, too little palliation. *Am J Hosp Palliat Med*. 2005;22(5):344-348. [PubMed PMID: 16225356]. DOI: 10.1177/104990910502200507
32. St John K. Preventing avoidable hospital admissions for people with advanced dementia. *End Life J*. 2015;5:1e900005 DOI: 10.1136/eoljnl-2015-900005
33. Aminoff BZ. Overprotection phenomenon with dying dementia patients. (Editorial). *Am J Hosp Palliat Med*. 2005;22(4):247-248.
34. Aminoff BZ. Family overprotection phenomenon of dying dementia patients. 10<sup>th</sup> International Conference on Alzheimer's Disease and Related Disorders, Madrid, Spain, July 15-20, 2006. In: *Alzheimer's Disease: New Advances, Medimond International Proceedings*. 2007;687-691.

35. Aminoff BZ. Geriatrics D refusal phenomenon. 10<sup>th</sup> International Conference on Alzheimer's Disease and Related Disorders, Madrid, Spain, July 15-20, 2006, Madrid, Spain. In: Alzheimer's Disease: New Advances, Medimond International Proceedings. 2007;631-635.
36. Aminoff BZ. The new israeli law "The dying patient" and relief of suffering units. *Am J Hosp Palliat Med.* 2007;24(1):54-58. DOI: 10.1177/1049909106295299 [PubMed PMID: 17347506].
37. Aminoff BZ. Relief of suffering with dementia units. *Innovations in care - the Israeli Perspective. Dementia (Special Issue).* 2009;8:407-15. DOI: 10.1177/1471301211421224
38. Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med.* 1982; 306(11):639-645. [PubMed PMID: 7057823].
39. Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, Volicer L, Givens JL, Hamel MB. The clinical course of advanced dementia. *N Engl J Med.* 2009;361(16):1529-38. [PubMed PMID: 19828530].
40. Mitchell SL, Black BS, Ersek M, Hanson LC, Miller SC, Sachs GA, Teno JM, Morrison RS. Advanced dementia: State of the art and priorities for the next decade. *Ann Intern Med.* 2012;156 (1 Pt 1):45-51. DOI:10.7326/0003-4819-156-1-201201030-00008. [PubMed PMID: 22213494].
41. Krikorian A, Limonero JT, Corey MT. Suffering assessment: A review of available instruments for use in palliative care. *J Palliat Med.* 2013;16(2):130-142. DOI: 10.1089.
42. Van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, Cohen LW, Munn J, Achterberg WP, Ribbe MW, de Vet HC. Measuring the quality of dying and quality of care when dying in long-term care settings: A qualitative content analysis of available instruments. *J Pain Symptom Manage.* 2011;42(6):852-563. DOI: 10.1016. [PubMed PMID: 21620642].
43. Aminoff BZ. Entropic definition of human happiness and suffering. *Philosophy Study.* 2013;3:609-618.
44. Cohen LW, van der Steen JT, Reed D, Hodgkinson JC, van Soest-Poortvliet MC, Sloane PD, Zimmerman S. Family perceptions of end-of-lifecare for long-term care residents with dementia: differences between the United States and the Netherlands. *J Am Geriatr Soc.* 2012; 60(6):316-322. DOI: 10.1111. [PubMed PMID: 22288500].
45. Van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, Cohen LW, Klapwijk MS, Bezemer M, Achterberg WP, Knol DL, Ribbe MW, de Vet HC. Psychometric properties of instruments to measure the quality of end-of-life care and dying for long-term care residents with dementia. *Qual Life Res.* 2012;21(4):671-84. DOI: 10.1007/s11136-011-9978-4 [PubMed PMID: 21814875].
46. MacAdam DB, Smith M. An initial assessment of suffering in terminal illness. *Palliat Med.* 1987;1:37-47.
47. Buchi S, Sensky T. PRISM: Pictorial representation of illness and self measure. A brief nonverbal measure of illness impact and therapeutic aid in psychosomatic medicine. *Psychosomatics.* 1999;40(4):314-320. DOI: [http://dx.doi.org/10.1016/S0033-3182\(99\)71225-9](http://dx.doi.org/10.1016/S0033-3182(99)71225-9)
48. Baines BK, Norlander L. The relationship of pain and suffering in a hospice population. *Am J Hosp Palliat Care.* 2000; 17(5):319-326. DOI: 10.1177/104990910001700509 [PubMed PMID: 11886056].
49. Ruijs KD, Onwuteaka-Philipsen BD, van der Wal G, Kerkhof Ad JFM. Unbearability of suffering at the end of life: The development of a new measuring device, the SOS-V. *BMC Palliat Care.* 2009;8(1): 16.
50. Schulz R, Monin JK, Czaja SJ, Lingler JH, Beach SR, Martire LM, Dodds A, Hebert RS, Zdaniuk R. Measuring the experience and perception of suffering. *Gerontologist.* 2010;50(6):774-784. DOI: 10.1093/geront/gnq033 [PubMed PMID: 20478899].
51. Wilson KG, Graham ID, Viola RA, Chater S, de Faye BJ, Weaver LA, Lachance JA. Structured interview assessment of symptoms and concerns in palliative care. *Can J Psychiat.* 2004;49(6):350-358. DOI: 10.1177/070674370404900603
52. Parker D, Hodgkinson B. A comparison of palliative care outcome measures used to assess the quality of palliative care

- provided in long-term care facilities: A systematic review. *Palliat Med.* 2011; 25(1):5-20.  
DOI: 10.1177/0269216310378786.  
[PubMed: 20817748].
53. Krikorian A, Roma JP. Current dilemmas in the assessment of suffering in palliative care. *Palliative and Supportive Care.* 2014; 9.  
DOI: 10.1017/S1478951514001102
54. Kumar SP, Sisodia V. Reporting of validation studies: A systematic review and quantitative analysis of research publications in palliative care journals. *Saudi J Health Sci.* 2013;2(3):161-168.  
DOI: 10.4103/2278-0521.127048.
55. Aminoff BZ. On mechanisms of human behaviour: The "Mind blindness phenomenon" in philosophy, religion, science and medicine. *Philosophy Study.* 2015b;5:167-77.  
DOI: 10.17265/2159-5313/2015.03.007
56. Aminoff BZ. Not calm and Aminoff Suffering Syndrome in advanced Alzheimer's disease. *Am J Alzheimers Dis Other Demen.* 2016;31(2):169-180.  
DOI: 10.1177/153331751559885  
[PubMed PMID: 26294697].

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