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

Bechor Zvi Aminoff¹,²*

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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 the St Christopher’s Hospice and all other settings.

Keywords: End of life; Aminoff suffering syndrome; relief of suffering units; palliative care.

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

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. Dame Cicely Saunders defined the concept of total pain as the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles. Coyle also wrote that a diagnosis of a life threatening illness jars open a door of awareness, the same door that, for most of our lives, comfortably allows us to keep thoughts about death in the background [6].

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

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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. Aminoff suffering syndrome (ASS) in advanced dementia is the new proposed term for a pathological symptomatology and entity that is characterized by a high Mini Suffering State Examination (MSSE) scale score, <6 months survival, irreversible and intractable aggravation of suffering and medical condition until demise [7]. The data were presented at world and international congresses in Madrid [8], Saint-Petersburg [9], Trondheim [10], Paris [11], Honolulu [12], Athens [13], Copenhagen [14], Seoul [15, 16, 17], and Edinburgh [18].

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 [19, 20, 21, 22].

In the year 1907, Dr Alois Alzheimer published a famous case report on Mrs Auguste Deter [23]. In our article published in 2013, we were able to establish that Mrs Deter suffered from Aminoff Suffering Syndrome [24]. 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 [25, 26] 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 [27], 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.

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

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

**Mini-Suffering State Examination (MSSE) – Dutch version:** Aminoff BZ, Gerontologie und Geriatrie 1999; Aminoff BZ, Purits E, Noy S, Adunsky A. Measuring the suffering of end-stage dementia:

Suffering items Yes (1)/no (0)

1. Not calm
2. Screams
3. Pain
4. Decubitus ulcers
5. Malnutrition
6. Eating disorders
7. Invasive action
8. Unstable medical condition
9. Suffering according to medical opinion
10. Suffering according to family opinion

MSSE score, total

MSSE score interpretation:

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

Zorgverlener versie

Nederlandse vertaling en aanpassing: Schols R, et al. (Schipper RJ, Brabers A, & Schols J. [The Mini Suffering State Exam (MSSE) has been studied in a Dutch nursing home]. Tijdschrift voor Verpleeghuisgeneeskunde 2003;27(5):14-18.)

Kwamen onderstaande verschijnselen of situaties in de laatste week van het leven voor?

Nee Ja

a. Rusteloos (niet kalm)

b. Roepen/schreeuwen

c. Aanwijzingen voor pijn

d. Decubitus (doorligwonden)

e. Toestand van ondervoeding of ongewenst gewichtsverlies

f. Regelmatige medisch technische behandelingen

g. Eetproblemen

h. Onstabiele medische toestand

i. De bewoner leed naar het oordeel van de behandeld arts

j. De bewoner leed naar het oordeel van de verzorging

k. De bewoner leed naar het oordeel van de familie

* De originele versie omvat slechts een enkel item “medical opinion”

** Niet opgenomen in de versie van Schols et al.

Familie versie

Schriftelijke vragenlijst; verkregen uit vertaling en terugvertaling van de Engelstalige aanpaste versie op de volgende bladzijde. Had uw familielid/naaste ervaring met onderstaande verschijnselen of situaties in de laatste week van het leven?

Nee Ja

a. Was uw familielid/naaste rusteloos (niet kalm)?
b. Schreeuwde uw familielid/naaste of riep hij/zij om hulp? □ □ 
c. Had uw familielid/naaste pijn? □ □
d. Had uw familielid/naaste doorligwonden? □ □
e. Had uw familielid/naaste problemen met eten, zoals weigeren om te eten, moeilijkheden of ongemak met slikken, verlies van eetlust, of was sondevoeding nodig? □ □
f. Leek uw familielid/naaste ondervoed, door gewichtsverlies, ingevallen ogen en wangen? □ □
g. Kreeg uw familielid/naaste vaak onderzoeken of behandelingen die voor hem/haar de rust verstoorden, zoals afname van bloed, inbrengen van een katheter of voedingssonde of een ademhalingsbuis? □ □
h. Had uw familielid/naaste een nieuw medisch probleem dat hij/zij niet eerder had, zoals een longontsteking, urineweginfectie of uitdroging? □ □
i. Had de arts of verpleegkundige de indruk dat uw familielid/naaste leed? □ □
j. Had u de indruk dat uw familielid/naaste leed? □ □

Aangepaste familie versie - vertaling © EMGO Instituut voor onderzoek naar gezondheid en zorg, VU medisch centrum Amsterdam, 2007

Family version

Interview; ten opzichte van de originele zorgverlener versie zijn items in vraagvorm gezet en is uitleg toegevoegd.

These questions ask for ‘No’ or ‘Yes’ responses. Did [RESIDENT] experience these conditions or treatments or display these behaviors in the last week of life, from _ _ / _ _ / _ _ [date 1 week prior] until the time [HE/SHE] died?

No Yes

a. Was [RESIDENT] restless or not calm? □ □
b. Did [RESIDENT] scream or cry out for help? □ □
c. Was [RESIDENT] in pain? □ □
d. Did [RESIDENT] have bedsores or pressure ulcers? □ □
e. Did [RESIDENT] have problems with eating, such as refusing to eat, difficulty or discomfort with swallowing, loss of appetite, or need a feeding tube? □ □
f. Did [RESIDENT] appear malnourished, including having weight loss, sunken eyes or cheeks? □ □
g. Did [RESIDENT] have frequent tests or treatments that caused [HIM/HER] disturbance, such as drawing blood, inserting catheters or feeding or breathing tubes? □ □
h. Did [RESIDENT] have any new medical problems that [HE/SHE] didn’t have before, such as pneumonia, urinary tract infections, or dehydration? □ □
i. Did the doctor or nurse believe that [RESIDENT] was suffering? □ □
j. Do you believe that [RESIDENT] was suffering? □ □

MSSE Family version - © UNC Interdisciplinary Center for Aging Research, The University of North Carolina at Chapel Hill, USA, 2007.


Verdere informatie bij dr.ir. J.T. van der Steen, j.vandersteen@vumc.nl
### Mini Suffering State Examination (MSSE) scale – Hebrew version:

<table>
<thead>
<tr>
<th>Date</th>
<th>Suffering items</th>
<th>Yes-1</th>
<th>No-o</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>לא ردון</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>עצ değil</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>כאב</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>יישע חום</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>חום תחתון</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>הפרעת אכילה</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>הפרעת תזונה</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>מ@Before</td>
<td>ueil</td>
<td>רפואית</td>
</tr>
<tr>
<td>9</td>
<td>סבל לפי דעת צוות רפואי או סיעודי</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>סבל לפי דעת בני משפחה של חולה</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**MSSE score**

<table>
<thead>
<tr>
<th>MSSE score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–3</td>
<td>Low suffering</td>
</tr>
<tr>
<td>4–6</td>
<td>Moderate suffering</td>
</tr>
<tr>
<td>7–10</td>
<td>High suffering</td>
</tr>
</tbody>
</table>

### Slovenia version of MSSE

Tabuľ ka 1. Krátke vyšetrenie miery utrpenia – Mini Suffering State Examination (MSSE) (7)
Sledované príznaky Áno (1)/Nie (0)

1. Nepokoj
2. Výkriky
3. Bolest
4. Dekubity
5. Malnutrícia
6. Poruchy príjmu potravy
7. Invazívne interвенціє
8. Nestabilný klinický stav
9. Utrpenie podľa názoru lekára
10. Utrpenie podľa názoru rodiny

**MSSE skóre spolu:** Hodnotenie: nízka miera utrpenia 0 – 3, stredná miera utrpenia 4 – 6, vysoká miera utrpenia 7 – 10

### Germany version of MSSE

Welche der folgenden Zustände oder Umstände treffen **aktuell** auf den/ die Bewohner/in zu?

<table>
<thead>
<tr>
<th>a. Unruhe</th>
<th>Ja</th>
<th>Nein</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Ist die früheste wesentliche Ausdrucksweise, die bei Menschen, die sich verbal nicht ausdrücken können, auf Leiden hinweist. Ruhe / Gelassenheit an sich schliesst Leiden nicht aus, jedoch kann ein Mangel an Ruhe / Gelassenheit und andauernde Agitation auf Leiden hinweisen.</em></td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>b. Schreien / Rufen</th>
<th>Ja</th>
<th>Nein</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Ein Zeichen der Verzweiflung und ein Hilferuf, der auf Leiden hinweist.</em></td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>c. Schmerzen</th>
<th>Ja</th>
<th>Nein</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Im Endstadium der Demenz ist jeder Schmerzausdruck schwierig zu erkennen.</em></td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Um in der Praxis Schmerz besser feststellen zu können, ist es hilfreich, bewusst eine Reaktion hervorzurufen und gleichzeitig die Veränderungen des Gesichtsausdrucks zu beobachten (z.B. durch Abtasten, Abklopfen oder Umlagern der Person).

d. Dekubiti / Druckulzera
Können in jedem Krankheitsstadium Leiden hervorrufen und zu einem schlechteren Zustand führen.

e. Mangelernährung
Von objektiven Laborwerten ausgehend (Gesamteiweiss, Albumin, Cholesterin, Hämaglobin etc.).

f. Essstörungen
Nahrungsumverweigerung, Schluckstörungen oder andere Zustände, die den Einsatz einer Magensonde oder einer PEG (Perkutane entero- und gastrostomische Gastrostomie) erforderlich machen.

g. Invasive Massnahmen
z.B. Blutuntersuchungen, Katheterisierungen, mechanische Fixierung, Wundreinigung, ständige Flüssigkeitszufuhr (i.v.), Hämodialyse, Intubation, künstliche Beatmung.

h. Instabiler medizinischer Zustand
Nimmt Bezug auf den aktuellen medizinischen Zustand (u.a. Pneumonie, Harnwegsinfekt, Störungen des Elektrolythaushalts).

i. Leiden aus medizinischer / professioneller Sicht
Eine subjektive Einschätzung des 'Krankseins' durch behandelnde Ärzte oder durch Pflegende. Diese Einschätzung muss nicht identisch sein mit der aktuellen Diagnose oder Symptomatik.

j. Leiden aus Sicht der Familie / Angehörigen
Ist häufig die erste Information über das mögliche Leiden eines Patienten.

The MSSE scale was tested using the Cronbach α model, which demonstrated its significant reliability (α = 0.798). A κ 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).

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 [28, 29] (r = -0.796, P < 0.0001). The mean survival of end-stage dementia patients with a low MSSE scale score (MSSE = 2.24 ± 0.99) was 57.76 ± 9.73 days, and with a median MSSE scale score (MSSE = 4.92 ± 0.83) the mean survival was 44.70 ± 5.99 days. In the high MSSE scale score group (MSSE = 8.06 ± 1.00) mean survival was much shorter (27.54 ± 4.16 days) [30].

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) [31].

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
± 2.31, and increased to 6.89 ± 1.95 on the last day of life with a significant test-retest reliability ($P < 0.0001$) [32].

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 [33].

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 [33]. 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 [19].

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. [19] 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 [34].

Perpetual and increased agony of an end-stage dementia patient is reminiscent of the suffering of patients prior to the era of anaesthesia, or antibiotics. The main causes of suffering at the end-of-life are inadequate medical and nursing care, overprotection phenomenon with dying patients [35, 36] and Geriatrics D refusal phenomenon [37].

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 [38, 39] 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 [40, 41, 42, 43, 44, 45] and quality of dying evaluation [46, 47] are important at the end of life. Some available instruments developed for suffering assessment in end of
life: Initial assessment of suffering [48], Pictorial Representation of Illness and Self Measure [49], Suffering Assessment Tool [50] State of Suffering-V [51], The Suffering Scales [52], and Structured Interview for Symptoms and Concerns Scale [53].

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 [54, 55].

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 [56].

This clinical practice development article is an open letter as well as proposals to the medical and nursing staff at St. Christopher's Hospice, and medical personnel at other 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 [57]. Diagnosis of Aminoff Suffering Syndrome could diminish suffering of patients at the end of life by adequate medical and nursing care [58]. Dealing with Aminoff Suffering Syndrome at the end of life provides a genuine challenge to nursing and medical personnel.

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COMPETING INTERESTS

Authors have declared that no competing interests exist.

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He was born in the former Soviet Union, in Uzbekistan, Samarkand on 5 June. He studied medicine and in 1970 graduated with MD degree from the Samarkand Medical Institute, Uzbekistan, and received his PhD degree from Stavropol Medical Institute, Russia, in 1974. In 1982 he emigrated from the USSR to Israel, where he specialized in Geriatric Medicine and Gerontology. He was the Chairman of the Geriatrics D Department at the Sheba Medical Center, Tel-Hashomer since 1993 until 2005. He is or has been an Editorial Board Member of 28 international journals. He was awarded an Honorary Doctor degree of the Yorker International University, Firenze, Italy, 2009. On 16 February, 2015, he was awarded a Research Professor Degree from the International Biographical Centre, Cambridge, England. Results of his studies have been generalized in 4 recently published books, 123 published articles in renowned professional scientific journals and have been presented at World and Regional congresses. His research interests are development of and research on the first objective tool Mini Suffering State Examination [MSSE] scale for evaluation of suffering in advanced Alzheimer's disease and at End-of-Life. Definition of a new medical and pathological entity in advanced Alzheimer's disease and at End-of-Life, coined Aminoff Suffering Syndrome (ASS), Development of the new theory and entropy definition of human happiness and suffering, in addition to the entropic theory definition, further investigations in philosophy and psychology include the Mechanisms of Human Behaviour: Legends of Desirable Anti-Entropy Deficiency Phenomenon Theory and the Mind Blindness Phenomenon in Philosophy, Religion, Science, and Medicine. Among his many scientific publications are articles on: Overprotection phenomenon of dying dementia patients; Geriatrics "D" refusal phenomenon pertaining to advanced dementia patients; Proposal of new approach to dying patients and establishment of Relief of Suffering Units for patients diagnosed with Aminoff Suffering Syndrome.

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