

Not Calm and Aminoff Suffering Syndrome in Advanced Alzheimer's Disease

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Abstract

We studied 183 patients with advanced dementia who had been admitted to the Geriatric-Internal Medicine Department of a general hospital, with a 1 year follow-up evaluated by Mini-Suffering State Examination (MSSE) scores on first days after admission. The *not calm* compared to calm patients with advanced dementia had a high suffering level (6.12 ± 2.16 versus 3.21 ± 1.71) with a statistically significant difference ($P = 0.001$). The *not calm* patients were sicker, a higher percentage had fever ($P = 0.005$), elevated levels of white blood cells WBC ($P = 0.003$) and C-reactive protein (CRP) ($P = 0.020$). The Kaplan–Meier function analysis showed a shorter survival of *not calm* versus calm advanced dementia patients, with a statistically significant difference (Log Rank [Mantel–Cox] $P = 0.002$). *Not calm* in advanced dementia patients is the first item of the MSSE and is a very important symptom of Aminoff Suffering Syndrome.

Keywords

not calm, advanced dementia, end of life, Aminoff suffering syndrome

Introduction

The first manifestation and visual sign of suffering in advanced dementia is that of being *not calm* and is the first item of the Mini-Suffering State Examination (MSSE) scale developed by Aminoff¹ and described 11 years ago.²

Physicians are familiar with medical attempts to define the behavior of patients with dementia: agitation,³⁻⁵ behavioral and psychological symptoms of dementia,⁶ behavioral and psychological disturbances,^{7,8} psychosis,^{9,10} restlessness,¹¹ discomfort,¹² delirium,¹³ twilight,¹⁴ resistance to care,¹⁵⁻¹⁷ obstreperous behavior,¹⁸ catastrophic reactions,¹⁹ aggressiveness,²⁰ and other common terms that are of assistance in guiding decision making regarding treatment strategies.^{21,22}

The brain of a patient with advanced dementia, despite severe cognitive impairment, is still emotionally effective. Cognitive decline in the patient with dementia does not necessarily denote that there is also emotional impairment. Conversely, already in the first clinical stages of Alzheimer's disease, patients are concerned and aware that they are undergoing some form of change and their emotional level increases. Patients are unhappy, become despondent, and thus their suffering increases.

The high level of suffering in advanced dementia defined by us as the Aminoff suffering syndrome²³⁻²⁵ is characterized by a high MSSE scale score, less than 6 months' survival for terminal patients and less than 1-month survival for dying patients, irreversible and intractable aggravation of medical condition, and suffering until demise. Our aim was to study possible interrelations between *not calm* and Aminoff suffering syndrome in advanced Alzheimer's disease.

Methods

Study Population

Over a 1-year period, we studied all patients with advanced dementia admitted to a Geriatric-Internal Medicine Ward of a tertiary general hospital. Diagnosis was based on the *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition) revised criteria for dementia.²⁶ Inclusion criteria were severe dementia interference in verbal communication (Mini-Mental State Examination 0/30),² complete dependence in activities of daily living and functional movement (Functional Independence Measure 18/126),²⁷ and stage 7c or higher of the Functional Assessment Staging (FAST) scale.²⁸ We recruited patients diagnosed as having Alzheimer's disease, multi-infarct and poststroke dementias, and dementia of unknown origin. The final analysis was composed of 183 patients (73 males and 110 females), age range 56 to 102 years. The study was authorized by the local Hospital Helsinki Committee.

When observing a patient with severe dementia, initially one should note whether the patient is suffering or not. Is the patient

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calm or agitated? A patient who can speak is not under discussion, but only one who is unable to carry out oral communication. Is the patient in fact suffering?

We would like to emphasize that when a patient is distraught, this is obvious from facial expression. One should learn to make a diagnosis by observing that something is amiss from the patient's facial expressions, body language, movements, linked hands, eyes, corners of the mouth, wrinkles on the forehead and on the face, heavy breathing, and body and facial perspiration that are all visible signs of torment.

On the first days of admission (2.9 ± 4.3 days) to the Geriatric-Internal Medicine Department, patients were evaluated with the MSSE scale. For each patient, the demographic and following data were collected: total protein, albumin (AL), cholesterol (Ch), hemoglobin (Hb), white blood cells (WBCs), total lymphocyte count (TLC), C-reactive protein (CRP), body mass index, use of nasogastric tube, and percutaneous endoscopic gastrostomy (PEG; Table 1). The use of medications, such as antipsychotics, antidepressants, narcotics, analgesics, antibiotics, and infusions, was recorded. Diagnosis of Parkinson's disease, space occupying lesion, and cerebral vascular accident (CVA) was also recorded in the medical history (Table 1).

The MSSE

The MSSE scale, developed in 1999 by Aminoff¹ and described by us,² is the first objective clinical tool for evaluation of suffering level in advanced dementia. The MSSE scale is available in English, Hebrew, and Dutch,^{29,30} and the translation and validation of Spanish and German versions are in progress. The MSSE scale comprises 10 items relating to the patients' characteristics as well as the perception of their condition by medical staff and families. Each item scores 0 (no) or 1 (yes). The total score ranges between 0 and 10, with higher scores reflecting elevated degrees of suffering levels. Based on clinical experience, the following items were included in the MSSE: *not calm, screams, pain, decubitus ulcers, malnutrition, eating disorders, invasive action, unstable medical condition, suffering according to medical opinion, and suffering according to family opinion.*

The MSSE scale was tested using the Cronbach α model, which demonstrated its significant reliability ($\alpha = .798$). A κ agreement coefficient of .791 between 2 observers was found. Both observers found significant association between the higher MSSE levels and older age ($P < .02$), low levels of Hb ($P < .02$), AL ($P < .001$) and Ch ($P < .04$), and higher/increased use of analgesics or antipsychotics ($P < .04$). Convergent validity of the MSSE scale was proven by Pearson's correlation with the Symptom Management in End-of-Life in Dementia scale ($r = .574$, $P < .0001$) and the Comfort Assessment in Dying with Dementia scale³¹ ($r = -.796$, $P < .0001$).

A high MSSE scale score with range 7 to 10 indicates a high level of suffering and reflects the severity of the medical condition in end-stage dementia. According to the MSSE scale, it has been confirmed that end-stage dementia patients (ESDPs)

Table 1. General Characteristics of Calm and *Not Calm* Patients With Advanced Dementia Upon Admission to a Geriatric Internal Medicine Ward.

	Calm (n = 101)	Not Calm (n = 82)	P Value
Age, mean \pm SD, years	84.6 \pm 7.4	86.4 \pm 7.4	.117
Males/females, %	39.6	60.4	.930
Married, %	49.5	39.02	.158
Divorced, %	15.8	6.1	.354
Widowed, %	42.6	51.2	.246
Holocaust survivor, %	23.8	17.1	.270
Ashkenazi origin, %	64.4	51.2	.074
Sephardic origin, %	36.6	48.8	.248
Cerebral vascular accident, %	42.6	25.6	.017
Depression, %	24.8	21.9	.659
Parkinson's disease, %	15.8	19.5	.518
Space occupying lesion, %	16.8	20.7	.503
By orally feeding, %	79.2	78.1	.850
Per zonda feeding, %	16.8	20.7	.503
Percutaneous endoscopic gastrostomy feeding, %	2.0	2.4	.834
Narcotic treatment, %	3.0	4.9	.506
Analgesic treatment, %	2.0	3.7	.491
Antidepressant treatment, %	26.7	31.7	.463
Antipsychotic treatment, %	25.7	40.2	.037
Hypnotic treatment, %	14.9	18.3	.534
Use of restraints, %	0.0	1.2	.268
Fever, %	30.7	51.2	.005
Infusion treatment, %	58.4	82.9	.0001
Antibiotic treatment, %	49.5	70.7	.004
White blood cells (\pm SD)	9237 \pm 3301	11 176 \pm 5341	.003
Total lymphocyte count (\pm SD)	1454 \pm 693	1480 \pm 980	.835
Hemoglobin (\pm SD), g/dL	11.5 \pm 1.5	11.3 \pm 1.8	.607
Cholesterol (\pm SD), mg/dL	155.6 \pm 38.5	150.3 \pm 45.3	.463
Total protein (\pm SD), mg/dL	6.2 \pm 0.65	6.1 \pm 0.69	.635
Albumin (\pm SD), mg/dL	3.11 \pm 0.48	3.03 \pm 0.56	.307
Body mass index (\pm SD) kg/m ²	23.7 \pm 4.0	23.2 \pm 5.3	.735
C-reactive protein (\pm SD), mg/L	56.5 \pm 56.7	82.2 \pm 78.1	.020

Abbreviation: SD, standard deviation.

represent a heterogeneous group and have different levels of suffering and accordingly proved a significant concurrent validity. The results of our previous research showed that care in a geriatric department fails to decrease the high level of suffering of patients with end-stage dementia. The total MSSE scale score on the day of admission was 5.62 ± 2.31 and increased to 6.89 ± 1.95 on the last day of life with a significant test-retest reliability ($P < .0001$).³²

The group differences among the survival times of the 3 MSSE scale scores was evaluated by Kaplan-Meier analysis (log rank, $P < .0018$, Breslow, $P < .0027$) and were significant. The results of the Cox proportional Hazard model of survival showed a high correlation between high MSSE scale score, high risk of mortality, and short survival of ESDPs during the last 6 months of life with significant predicting validity ($P < .013$).³³

Table 2. Comparison Between Items (%) in the Mini-Suffering State Examination (MSSE) Scale Score of Calm and Not Calm Patients With Advanced Dementia.

Items Measured by the Mini-Suffering State Examination	Calm (n = 101)	Not Calm (n=82)	P Value
Not calm	00.0	100.0	
Screams	00.0	25.6	.0001
Pain	23.8	45.2	.002
Decubitus ulcers	25.7	26.8	.869
Malnutrition	82.2	75.6	.279
Eating disorders	56.4	64.6	.262
Invasive action	61.4	82.9	.001
Unstable medical condition	22.8	56.1	.0001
Suffering according to medical opinion	24.7	76.8	.0001
Suffering according to family opinion	23.8	58.5	.0001
MSSE score	3.21 ± 1.71	6.12 ± 2.16	.001

Statistical Analysis

Comparison between the 2 groups of patients with advanced dementia using the following parameters (fever, Hb, WBC, TLC, CRP, Ch, use of antibiotics and infusions, and among others) and each of the MSSE scale items (*not calm*, screams, and so forth) was performed using the *t* test for independent samples and chi-square or Fisher exact test.

Survival functions for the 1-year follow-up were evaluated by the Kaplan-Meier method. The log rank (Mantel-Cox) tests were used to compare survival functions between the 2 groups. The SPSS for Windows software, version 21.0, was used for the analysis.

Results

A follow-up of 183 patients (73 males and 110 females) diagnosed with advanced dementia who were admitted to a Geriatric-Internal Medicine Ward is depicted in Table 1. During the first days of admission, these patients were diagnosed as calm (n = 101) and *not calm* (n = 82). We evaluated 43 items of demographical, medical, and laboratory features (Tables 1 and 2) and in 33 items found no statistical significant differences between the groups.

The main results of our study revealed that the *not calm* patients with advanced dementia were sicker and diagnosed with Aminoff suffering syndrome.

The MSSE scale scores of the calm and the *not calm* patients with advanced dementia were 3.21 ± 1.71 (low suffering level) and 6.12 ± 2.16 (high suffering level), respectively, with a significant statistical difference (*P* = .001; Table 2).

More *not calm* than calm individuals were diagnosed as having pain (45.2% vs 23.8%, *P* = .002), had an unstable medical condition (56.1% vs 22.8%, *P* = .0001), fever (51.2% vs 30.7%, *P* = .005), high WBC (11 176 ± 5341 vs 9237 ± 3301, *P* = .003) and CRP levels (82.2 ± 78.1 vs 56.5 ± 56.7, *P* = .020), and had undergone more invasive procedures (82.9% vs 61.4%, *P* = .001). Fewer of the *not calm*

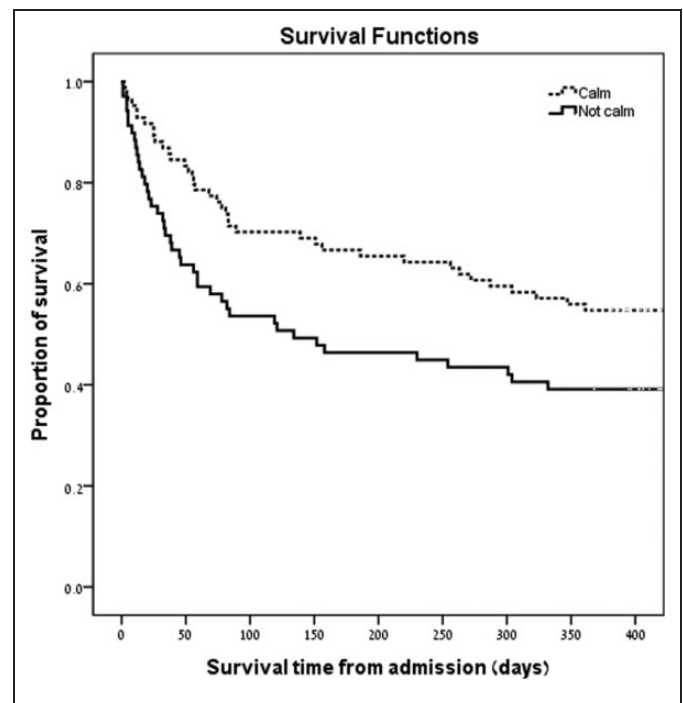


Figure 1. Kaplan-Meier curves: 1-year survival of calm and not calm patients with advanced dementia. Log rank (Mantel-Cox); chi-square 5.428; *P* = .020.

patients with advanced dementia had a history of CVA (25.6% vs 42.6%, *P* = .017).

However, *not calm* patients with advanced dementia were treated with more antipsychotic drugs (40.2% vs 25.7%, *P* = .037), antibiotics (70.7% vs 49.5%, *P* = .004), and infusions (82.9% vs 58.4%, *P* = .0001).

The difference between a 1-year survival Kaplan-Meier function analysis of both groups was statistically significant with log rank (Mantel-Cox; *P* = .002; Figure 1) with shorter survival of *not calm* patients with advanced dementia.

Discussion

Human behavior is characterized by prominent tendencies and drives to achieve pleasure, satisfaction, and happiness and to avoid suffering, pain, and sorrow.^{34,35} The suffering assessment³⁶⁻⁴⁰ and quality of dying evaluation^{41,42} are important in advanced dementia. Some available instruments developed for suffering assessment are Initial assessment of suffering,⁴³ Pictorial Representation of Illness and Self Measure,⁴⁴ Suffering Assessment Tool,⁴⁵ State of Suffering-V,⁴⁶ The Suffering Scales,⁴⁷ and Structured Interview for Symptoms and Concerns Scale.⁴⁸ The MSSE scale remains the first objective valid tool for suffering assessment in advanced dementia.

Difficulty in diagnosing short survival is a known problem for enrolling patients for palliative and hospice treatment,⁴⁹⁻⁵¹ eligibility for Medicare and Medicaid insurance companies in the United States,⁵² establishing “The Dying Patient Act” in Israel,^{53,54} and also in performing the “Oregon’s project.”^{55,56}

National Medicare Guidelines for determining prognosis in dementia,⁵⁷ stage 7c of the FAST scale,²⁸ the Karnofsky performance scale,⁵⁸ and the Charlson Comorbidity Index⁵⁹ are some available cutoff points for enrollment in a hospice. The FAST scale is not associated with survival in a long-term follow-up study of dementia.⁶⁰ The results of another study suggested that the Hospice Medicare Guidelines for predicting survival of patients were invalid.⁶¹ The increased risk score on a dementia rating scale, such as FAST, Mitchell Novel Risk Score (MDS/Mitchell score), and the Advanced Dementia Prognostic Tool scales, was a commonly identified risk factor for short survival in the majority of literature.^{62,63}

Diagnosis of Aminoff suffering syndrome could prove beneficial in the prognosis of short survival in advanced dementia.⁶⁴ The first description of advanced dementia by Dr Alois Alzheimer is a reminder of the reality of the torment and anguish of these patients.⁶⁵ The medical, functional, cognitive and emotional condition of Mrs Auguste D{eter} during her last months and days are characteristic of Aminoff suffering syndrome.⁶⁶ In fact, in our previous studies, most patients with end-stage dementia had a high suffering level upon their demise.⁶⁷

Results of our study show that *not calm* in patients with advanced dementia, which is the first item of the MSSE scale, is an important symptom of Aminoff suffering syndrome.

A higher suffering level was found in the *not calm* (6.12 ± 2.16) than in the calm patients with advanced dementia (3.21 ± 1.71) with a statistically significant difference ($P = .001$).

Not calm patients with advanced dementia were sicker with a higher percentage suffering from fever and elevated levels of WBC and CRP. More of these individuals were treated with antibiotics, infusions, and antipsychotics.

Individuals with advanced Alzheimer's disease with a symptom of *not calm* should be properly diagnosed, treated, and the condition prevented. Aminoff suffering syndrome should be correctly diagnosed to facilitate adequate medical and nursing care to prevent the futile suffering of terminal and dying patients. In order to relieve their suffering, these individuals should receive intensive treatment in palliative settings or alternative Relief of Suffering Units.^{68,69}

It should be borne in mind that high suffering level and *not calm* is not a marker of disease severity in advanced Alzheimer's disease. High suffering level of a patient is an indicator of inadequate nursing and medical treatment.⁶⁵

We would like to add causes of not calm in advanced dementia, which we defined in our monograph²⁴:

The reasons for not calm in advanced dementia are numerous, but it is essential and important to be aware that *most can be helped and treated!*

Causes of Being Not Calm in End-Stage Dementia

Helplessness

The ESDPs, who are bedridden, in a wheelchair and sometimes with tied hands and legs, are totally incapacitated. Some

patients are impulsive and perform acts that could endanger themselves, that is, fall from their beds, or wheelchairs. Undoubtedly, being helpless causes psychomotor distress and therefore a lack of composure.

Their suffering is similar to that of persons who are in solitary confinement in prison, or any small area, the size of which is comparable to that of a bed or a wheelchair. Prisoners are hopeful that they will be liberated from solitary confinement. An ESDP has no hope of release and the only solution is death.

A baby's state is also helpless. It is satisfying to take care of delicate babies with gentle hands when they cry and see the consequent reduction in suffering. Not always does an ESDP receive loving attention, warm hands, an embrace, or a kiss and caress. A neonate is able to perform certain actions and movements that ESDPs are incapable of: A newborn of just a few hours can move hands and legs, and occasionally even the entire body. They cry, emit sounds, and, most importantly, they can swallow.

An elderly person in an embryonic position with all limbs contracting, and who lacks a swallowing reflex, is in a far worse condition than that of a newborn, as the ability to move is nonexistent, and even swallowing of spittle is impossible. In this situation, patients cannot scratch themselves, wave away a fly, change position, cover themselves, complain of pain or feeling bad, or of any disturbing problems. They suffer and therefore are in a state of restlessness.

Unfortunately, for the patient and those in close proximity, the aforementioned state can persist for many years. The patient's dependence on another individual requires the caregiver to observe and determine the cause of suffering, and the action to be taken, both physically and emotionally. If the caregiver meets with success, the patient relaxes.

In a patient with ESD, as with babies, the cause for any unrest should be sought, and the patient should not be abandoned until placidity has been acquired.

An Uncomfortable Position

Initially, a patient with dementia is able to walk and function normally. It is only in advanced stages of the illness that this becomes problematic. Despite a serious cognitive decline, lack of awareness of time, and distance orientation, the patient can be moved. When behavior becomes impulsive or violent, changing position is a difficult problem for the patient and becomes extremely difficult for the caregiver. Immobilization is then achieved by tying the patient physically to a wheelchair or by the use of sedatives.

The cognitive decline is accompanied by movement changes, which appear as an extrapyramidal syndrome. Gradually, the handicap increases, the patient develops contractions in the limbs, and finally the body forms a fetal position, with knees raised toward the abdomen and chest. Not only are ability to walk and equilibrium lost but also the ability to sit or even lie in a functional and comfortable manner.

Because of the fetal position, muscle inflexibility, and articular contractures, ESDPs remain in the same position in

which they are placed by the caregiver, until the next change of posture. Certain areas of the skin need protection to avoid decubitus ulcers. Immobility in the confines of a bed over a long period causes a great deal of suffering. It is not always possible to settle the patient in a comfortable position; therefore, a few hours out of bed in a wheelchair are extremely important. This prevents development of ulcerations, aspiration when eating, pulmonary embolism, and provides some change in the daily routine, not merely lying in bed hour after hour. If sitting in a wheelchair becomes unbearable, the patient should be returned to bed. It is of utmost importance to find a comfortable position for the patient. In order to change position, they are reliant upon the staff that tends to their needs. Some positions in bed or in a wheelchair often cause much discomfort and can often be a nightmare. This can cause serious breathing difficulties, changes in blood supply, and can even lead to wheelchair death.

The procedure for changing positions is complicated, and inexperienced or indelicate hands can cause pain, tearing of the skin, and subcutaneous bleeding. Occasionally, fragile bones can be broken during turning and altering positions. Positions should be changed every 2 to 3 hours. Good lighting should be available near the patient to inspect pressure spots, and if redness or irritation is evident, appropriate massage should be performed and ointment applied. It is essential that soiled diapers, due to defecation or urination, be changed when required.

Areas with a risk of pressure ulcers should be protected, particularly the buttocks, trochanters, ankles, heels and ears. Prevention of pressure sores on the heels and soles of the feet is not problematic, as several devices for this purpose are available. The most appropriate method is to place pillows in the area under the ankles so that there is no contact between the soles and heels of the feet and the bed. Bed sheets should never have folds, as these cause intensive friction and this can result in severe bedsores.

To all those who say, "Nothing new has been written here," I ask, "Why then has this *not* been carried out? Is it because caregivers are insufficiently qualified? Is it because they are unable to perform their duties or is it because they are unwilling to perform the tasks that are already familiar to them?"

Moving the Patient From the Bed

On waking in the morning, rising, going to the bathroom to wash and brush teeth, and of course using the toilet are most natural functions that are taken for granted. The ESDPs are unable to move, and shifting them from the bed is a formidable undertaking.

The first consideration is whether one can, or should, move the patient from bed. Many patients are bedridden for weeks and months. The pretexts are insufficient attending staff, heavy patient, or inability to sit in a wheelchair. It is true that sitting in a wheelchair can cause profound pain and suffering, and therefore, the duration of sitting in the wheelchair should be adjusted accordingly. Only a few institutions move such patients from

their beds more than once a day, and in no hospital are patients moved from bed twice before noon.

Trained personnel are capable of moving patients effortlessly, without causing pain or discomfort and without injury during the process. Conversely, a staff member who is inexperienced in transferring patients with severe dementia from the bed may cause fractures, tearing of the skin, or other injuries, thus adding to the pain they already endure.

A mechanical device can be used to move a patient. Physically, it is much easier for the staff to use a hoist, but it is most distressing to observe an older adult and stooped person in the hoist pouch—naked, blue, and helpless.

Bathing

Bathing ESDP is essential, and most families do not consent to bed baths. When bathing a person in bed, the water is stagnant and the body is not suitably cleansed. Only partial washing of the torso and limbs can be accomplished in bed, and not all crevices are accessible. Therefore, patients are washed on an iron or plastic chair with a hole in the middle. Sitting on a bathing chair is so problematical that a 97-year-old lucid woman remarked that she felt as though she was sitting on a chair from the time of the inquisition. Bathing in this fashion is a source of extreme discomfort to the patient.

A problem may arise when patients are seated and awaiting their turn to be bathed. The distress is 2-fold—severely incapacitated patients need to be cleansed gently so as not to add to their anguish. It should be mentioned that in most geriatric departments patients are washed regularly and there are no bad odors in the room or corridor or in the proximity of the patients.

Grooming

Daily shaving, periodic manicure and pedicure as well as a haircut should be carried out to ensure that the patients appear presentable and have a feeling of well-being. These are all part of the treatment regime. The same applies to dressing patients. An unshaven patient with long finger and toenails and dressed in pajamas is a repulsive sight and an insult to dignity. Thus, the patient's unrest may be partly due to a feeling of being neglected and subsequent degradation.

Oral Excretion and Treatment

It is difficult to comprehend how the attending staff can pass patients and not consider them emergency cases, especially when the patients are obviously distressed due to excretion, or suppuration in the oral cavity, and occasionally may even be experiencing breathing difficulties almost to suffocation.

The ESDPs have eating, mastication, and deglutition (swallowing) disturbances. Therefore, morsels of food are discharged from the oral cavity and spill onto the chin and clothes. In a baby, this may be regarded as endearing, but a dirty, food-covered face is totally repugnant in the elderly individuals.

Unswallowed food that remains in the mouth can sometimes lead to asphyxiation. In addition, patients who cannot eat by mouth and have a feeding tube or PEG often were emitting contents from the mouth. It is well known that a human discharges more than 1000 cm³ of saliva a day, while in a patient who cannot swallow, saliva accumulates in the oral cavity and it becomes dense and purulent, resulting in a possible mass that adheres to the mucous membranes and pharynx, blocking the respiratory tract. In the absence of regular contractions of the muscles and mucous membranes in the oral cavity, microbes and fungus reproduce in large quantities. The tongue becomes coated, dry, and sometimes brownish in color. Manifestations of bleeding crusts in the mucous membranes, mainly in the pharynx and throat regions, are a serious prognostic sign.

Several daily treatments of the mouth are of utmost importance. Management should be active but delicate, in order to avoid damaging the mucous membranes, and it is necessary to cleanse all discharge, crusts, and masses from the oral cavity.

It is imperative that oral treatment be administered not only at regular intervals determined by the therapeutic program but whenever discharges, crusts, or masses are manifest.

Defecation and Enema, Rectal Investigation, and Glove Procedure

In a competent geriatric department, there are no patients with constipation, although there may be several with spontaneous defecation. No devices are used, such as a bag with a catheter, or defecating bag. It is extremely humiliating, also for lucid patients who suffer from incontinence, to defecate in diapers. The ESDPs experience this same humiliation when defecating in a diaper. Frequently, one hears patients requesting toilet assistance, with a reply from a staff member that "you have a diaper on, do it in there," or when patients defecate in a diaper and request a clean one, the reply is that "it is not yet time for a change," or that "the nurse or caregiver is busy."

The ESDPs seldom have regular defecation routines. Therefore, a rectal examination is performed periodically in order to ascertain that the ampulla of the rectum is empty. It is occasionally constipation that exacerbates the situation and fecal stones appear.

Severe constipation is a source of great suffering to the patients. Some are treated by using gloves and removing the excrement with a gloved finger. This practice is essential but painful; the patient is in distress and is agitated, and the method is most unpleasant for patients, attending physicians, or nurses who perform the glove procedure.

Follow-up of patients with constipation is essential. If the condition is not diagnosed, followed up, and treated, serious problems may ensue. Accumulation of fecal stones may result in an acute abdomen, or perforation, that will require surgery and naturally profound suffering.

Some patients may require an enema via a rectal tube. All these procedures are invasive, painful, and even more so to ESDP. It is also difficult to choose the correct, suitable medication with effective response. A complex issue! Indeed, how

very difficult it is to treat defecation of an elderly person, and how different this is compared to a mother or caregiver changing a baby's diaper!

Insertion of a Feeding Tube

A decision has been made to insert a feeding tube! The patient is, of course, unable to participate in this decision. In principle, the decision is taken following the failure to feed orally and aspiration. The nurse introduces a feeding tube in accordance with the doctor's orders. The family should provide their formal consent for this procedure, and when they do not concur, the problem becomes an ethical issue: whether to allow the patient to starve to death, that is, using passive euthanasia or to try to force the issue with the family.

An intensified procedure always causes much anguish. A patient who objects to introduction of a foreign object needs to be restrained. A tube introduced through the nasal cavity causes feelings of suffocation, nausea, the urge to vomit, and pain; excretion from the nose and throat regions; suction; occasional bleeding from the nose, respiratory, and digestive systems; and at times asphyxiation.

A feeding tube alters the external facial appearance of the patient. A person with a feeding tube is always a disturbing sight. However, this is the only way in which to maintain nourishment, sometimes for months and years, until the demise of the patient. A feeding tube causes breathing difficulties, aspiration, and occasionally decubitus ulcer when it comes into contact with the mucous membranes. The majority of patients need to have their hands bound indefinitely. The patient suffers and is compelled to pay a heavy price in order to survive.

Insertion of a Catheter

In a patient with urinary incontinence, it may be preferable to avoid insertion of a catheter, to ensure fewer foreign bodies, less invasive procedures, and fewer infections of the urinary tract. However, the need to change diapers is more frequent. Patients lie saturated for many hours in a urine puddle, the skin becomes more vulnerable, with increased irritation and tearing, and decubitus ulcer occur. Insertion of a catheter is a rapid procedure, sometimes painful, but it appears that patients can be unaware of the catheter and are more comfortable with a tube.

Liquid Infusions

This process is frequently the only connection between patients and the outside world, especially when their condition is serious and it is impossible to feed solids or liquids orally or by means of a feeding tube and PEG. Occasionally, the problem is lack of and difficulty in finding veins. This results in more jabbing, infusions in uncomfortable areas, and endangering patients with infusions in the neck and femoral veins.

Unnecessary torment is inflicted because patients do not understand and refuse further invasive procedures. It then becomes necessary to restrain the patient by tying the hands.

In order to maintain an inserted infusion line, it is often common practice for the patient to be confined to bed and immobilized for days, or weeks.

Stoma

Unfortunately, many patients have tubes inserted in various organs, for example, a gastrostoma, stomas in the lung gap—trocar, gallbladder, in the kidney—nephrostoma. Overall, stomas themselves are not felt. However, patients with serious dementia locate and remove every tube from their body, thus the *modus operandi* should be repeated and, similar to any invasive procedure, is a source of particular misery, as once again movement should be restricted and the patient restrained.

Bandages

A bandage may have a calming effect; lessen the level of sensitivity and pain and not the antithesis. Removing and changing a bandage often causes excruciating pain. However, leaving a bandage on for a prolonged period in accordance with medical instructions, and then finding that the bandage is subsequently full of suppuration and excretion, with a stench, and not having the bandage changed “because it is not yet time”—is a source of endless suffering.

Injections and Drawing Blood

Injections, particularly of insulin, do not cause specific pain due to the small size of the needles. However, drawing blood from certain geriatric patients can occasionally be a nightmare for them as well as the physician. When veins are not easily accessible and several attempts must be made to insert the needle, or, while drawing blood from an artery or femoral vein, patients become restless and resist any procedure, physical restraint may be required until the blood sample has been drawn. It is extremely difficult to take blood from patients who are in a fetal position with stiffness in all 4 limbs. Traumatic puncturing causes subcutaneous bleeding and swelling at the site. Difficulties in drawing blood can cause coagulation and hemolysis, erroneous blood results, and may require repeat withdrawal.

Binding of Hands and Legs to a Wheelchair or Bed

Liquid infusions, feeding or PEG tubes, catheters, stomas, and bandages are often provided for ESDP. As a result of serious confusion and a natural human impulse to remove any foreign protuberance, restlessness prevails and binding hands and occasionally also the legs is required. Because there is a danger of falling out of the wheelchair or bed, it is common practice to secure patients to the bed or wheelchair.

The methods for securing patients to a wheelchair do not ensure that they will not rise together with the wheelchair and fall over, thus endangering themselves. End-stage patients vehemently object to being tied, leading to restlessness,

shouting, and the desire to untie knots and leave the chair. The torment they endure is obvious to any passerby.

Unfortunately, cruel binding of hands is often essential to ensure administration of the required treatment, due to lack of cooperation. An alternative is to anesthetize, or sedate the patient, but this is not always effective. Medications for total sedation are nonexistent, and an anxiolytic is not always feasible. Antipsychotic treatment causes a decline in the general and functional condition of an ESDP. Furthermore, a calm patient can easily remove a feeding or liquid infusion tube. Although there are directives in the daily instructions of a doctor, even a senior physician, to bind hands, this does not sanction the tying of every case. Nevertheless, it is essential for some patients in geriatric departments, or geriatric institutions to have their hands tied, sometimes for months or even years, until their demise.

Immobilization by strapping the hands is an insult to dignity, causes frustration and anger, and increases restlessness and feelings of helplessness. The procedure is frequently painful and causes cyanosis of fingers, swelling of the palms, and tearing of the skin. Alternative methods are sought, that is, a brand of bandage in the form of gloves on the palms of the hands. However, this too is frustrating and is not always the solution.

If healthy individuals would be asked whether they would agree to have their hands bound for a prolonged period and be maintained with a feeding tube for the purpose of survival, they would not acquiesce.

Tying of both feet and hands is rare, but this only occurs when a patient is agitated and there is a possible danger of falling out of bed. Then there is no alternative but that of securing the patient to the bed. A substitute for this could be personal, 24-hour supervision by the attending staff. However, this is not a feasible arrangement in any institution, and it is economically expensive and staff is insufficient for such vigilance.

It is difficult to describe the helplessness and torment of tied patients who are immobilized, unable to wave away a fly, cover themselves, or turn over in bed, day after day, night after night until death.

Scratching

Dermatological conditions that are difficult to diagnose and treat induce scratching. Often scabies causes itching, and because it is contagious, it affects not only one specific individual but can be transmitted to others.

Other irritations of the skin may be due to atrophy, dryness, a process of infections, or side effects of drugs, cleaning products, and various allergies. As patients are unable to complain, or scratch themselves, this finds expression in suffering and restlessness.

Fever

This is *the* foremost hazard in ESD. Not a day can be recalled in a geriatric department when no high temperature has been

recorded. This is a dilemma exhausting both patients and physicians alike. According to every geriatric, or internal medicine text, there are numerous rationales for a fever. However, the main source is usually an infection.

An infectious disease specialist needs a definite diagnosis for the high temperature, evidence that infection is the cause, the source of the infection, and name of the microbe and its sensitivity to antibiotics. If a definite diagnosis is determined, this simplifies the situation, at least regarding initiation of antibiotic treatment. If an infection is manifest, response to antibiotic treatment is approximately 60%.

It is, however, a problem to define the source of fever and infection in ESD. Microbes are cultivated in the urine, decubitus ulcers, and diverse wounds. The source of the infection could be pulmonary, abdominal, or in other organs. In the hospital, it is technically and logistically complicated and difficult to implement examinations and tests, especially when there is little or no cooperation from the patients. There may be dire consequences if an accurate diagnosis is not determined promptly, and precious time may elapse until initiation of therapy.

It is known that the general physical condition and cooperation of ESDP change rapidly upon manifestation of an infectious disease. Their condition deteriorates, they stop eating and drinking and become dehydrated, thus requiring frequent infusions and may develop malnutrition. Blood cultures are the best method for diagnosing infections. A positive culture identifying the microbe and its sensitivity can be a good indication for correct treatment.

However, broad-spectrum antibiotic treatment initiated immediately a fever is detected could be most effective, despite the ambiguity of the infection. It is true that this approach is unscientific, but it does induce relief. Of course, such treatment is intended to alleviate suffering, and the superfluous need for imaging.

It may be suggested that antibiotic treatment is unwarranted as is the investigation of the source of a high temperature in ESD. It is facile to allow such patients to reach a state of septic shock and demise. Undoubtedly, in the majority of such cases we refer to passive euthanasia but disagree with this concept. When patients are critically ill and there is absolutely no prospect that their condition will alter, or improve, it is futile to continue antibiotic treatment, but this cannot always be halted. This does not mean that the patient has been abandoned, and the family should be informed accordingly that the staff has not stopped taking care of their loved ones.

Hypothermia

Hypothermia occurs frequently in the elderly population, and patients with dementia may be susceptible to cold rigors even at a room temperature of +17°C. It is essential to measure the temperature of patients with dementia with a special thermometer, when there has been a change in their condition and there is suspicion of cold rigors that are a serious illness and warrant hospitalization. It should be remembered that in winter,

when patients cannot complain that they are cold, undressing and later dressing in a cold bathroom, or allowing them to lie naked waiting to be washed with cold water, is cruel. Neglecting to dress them warmly with a sweater or socks and to cover them occurs frequently, and although the patients feel the cold they cannot express their discomfort.

A warm or cold room, controlled by air conditioners, is essential for the treatment of ESDP. In a hot room they exude moisture, dehydrate quickly, and unpleasant perspiration sets in. In a cold room, they may become hypothermic. The air conditioners themselves, if not adjusted correctly, may be a source of discomfort as the patients are unable to move or complain.

Mattresses

Although there are several recommended mattresses for geriatric patients, most are uncomfortable and do not prevent pressure ulcers. Lying on such a mattress is agony for the patients. Clinical experience has shown that an air mattress with bubbles is more comfortable. However, these mattresses are not readily available in institutions or in hospital departments. The families are usually requested to purchase one and often there is opposition and altercations arise between the families and the nursing staff. The families feel that the hospital or institution should provide such mattresses as part of their treatment program.

It has not been proven that a sand mattress with automatic bed movements is more effective in the prevention of decubitus ulcers. Without the caregiver's qualified hands to turn the patients, examine, and treat the skin every 2 hours, bedsores cannot be prevented.

Odors

The ESDPs have double incontinence. According to the work schedule they are examined by a nurse, diapers are changed, and they are cleaned and washed when necessary. During all these procedures, a putrid odor is inhaled, not only by the patient and the attending staff but also by others in close proximity. The stench of pressure sores, bandages, and various wounds, gangrene of the feet, vomiting, bleeding, and suction, urine, and excretion are all beyond description. This is part of the daily routine in ESD.

Noise and Shouting

The essential tranquility required in the department and wards is not maintained; the sound of air conditioners and suction, screaming, restlessness of other patients, shouting of attending staff, a radio on high volume with disturbing background music, and all add to the cacophony. Frequently, all this transpires as though the patients are inanimate objects and are non-existent. It is not realized that the noise disturbs and frightens them and they consequently become agitated and restless. This clamor is an accepted part of the routine in treatment of such patients.

Draught

Pure air is good and healthy, and a ward should be well ventilated several times a day. A naked patient or a patient who has just been bathed should not be in a draft, as they are unable to complain of cold, or that they want to be moved, or covered.

Prolonged Delay for Every Procedure

Unfortunately, personal and individual treatment for each ESDP is nonexistent. In all geriatric departments, or institutions, only a limited number of nurses and assistants are on duty in the mornings, fewer in the late afternoon and even less at night. Thus, it is impossible to attend to the needs of every patient simultaneously. Patients have to wait their turn to be washed on a washing chair, moved from bed and even more importantly, to be returned to bed when they are already tired and in profound anguish because of prolonged sitting.

When waiting at the X-ray unit, various clinics, hours in corridors, and in the wards, time seems eternal. In this state, the patient becomes an object, that is, a tool to be examined regardless of the circumstances, without considering the duration of waiting and the subsequent strenuous check-up. The human aspect seems to have been forgotten or dismissed.

A patient who is obviously feeling very bad is in a perpetual waiting state—for a cup of tea, a glass of water, food, medicines, activities, aid with changing positions, or even when calling for help. Occasionally, it seems that the attending staff feel it is beneath their dignity to provide a patient with immediate attention. They assume that the families, rather than the staff, are there to answer to the needs. When patients ring, call, or shout, who cares about their suffering?!

Sharing a Room With Other Patients

Others sharing a room with an ESDP are obviously disturbed by shouting, treatments, and odors. From a cognitive point of view, there is no awareness of surrounding activities, but the patients are emotionally aware of disturbances. If someone screams in the room, the other occupants obviously become irritated.

Lack of privacy

Patients, even when lucid, often do not appear to care and do not always obey rules of self-respect and personal dignity. Frequently, intimate body parts remain uncovered, and their naked bodies can be viewed by passersby. The level of dignity and embarrassment of such patients is hard to judge. In the case of those in a state of confusion and unaware of their condition, with regard to exposure the staff does not share the embarrassment of the relatives or visitors.

Cleanliness

The same embarrassing situation as that of dignity and self-respect arises repeatedly, that is, respectable and clean

individuals who were previously particularly fastidious with their hygiene, in advanced age and state of dementia, suffer from double incontinence. They lie in excrement for several hours, until the schedule calls for a diaper change.

In those who are placid and resigned to this situation, a level of brain damage may be evident. The majority are more vocal in such instances. It is erroneous to think that patients are indifferent to lying in a urine and excrement-soiled diaper. If the attendant or nurse would just soak a diaper in water and wrap this around themselves for a few hours, they would better comprehend the feeling of discomfort. Perhaps they would stop admonishing lucid patients by saying “do it in the diaper that you have on” when they ask to be taken to the toilet.

Hunger

Can ESDP be hungry? How is it possible to know? Apparently some have anorexia and eventually reach a state of cachexia and sarcopenia. It is even more difficult to know whether hunger exists in those with a feeding tube or PEG, who are fed intravenously throughout the day. The instinct to suckle is the only inherent sense already developed in a newborn. This urge gradually diminishes and disappears with aging and dementia.

Thirst

Thirst and the impetus to drink are more profound than the impulse to eat. Therefore, dehydration is prevalent in ESD. Through the goodwill of caregivers, an exaggerated quantity of liquid is sometimes given to elderly individuals who are known to drink insufficient quantities. This may have serious consequences for older persons who are unable to discharge a large quantity of liquid and may lead to water poisoning, or hyponatremia, which could even endanger their lives.

Fear and Anxiety

Prolonged lack of verbal communication and with no comprehension of what they are experiencing contributes to feelings of fear and anxiety, to which almost every cause of restlessness can be attributed.

Fear of Dying

It is difficult to know whether ESDP are aware that death is imminent. Even lucid individuals, during their last moments of life, are usually unaware that the end is near.

Boredom

The ESDPs have nothing to keep them occupied, time seems endless and life very boring. They desire and require emotional stimulation and perpetual inactivity adds to their disquiet.

Lack of love

Few individuals in a state of ESD have the privilege of feeling truly loved. Undoubtedly, a feeling of being loved by a spouse, children, or a lifelong partner enhances positive emotions and reassures the patient.

Concern

If not love, then concern should be one of the professional qualities of physicians and nurses. Unfortunately, this attribute is nonexistent in the attitude of most physicians toward ESDP. In addition, most attending nurses are unaware of the actual condition and prognosis of their patients. They perform their duties in a strictly professional manner, which is how they perceive their vocation. Patients assuredly sense this indifference, which of course is reflected in their restlessness.

Disregard

Disregard is a more serious trait than lack of concern. Indifference toward ESDP often borders on actual negligence. Patients can perceive this change in attitude which only heightens their frustration.

As quintessential, quality treatment is not provided when needed, the significance of the treatment is lost.

Discrimination of an ESDP

It is true that ESDPs are difficult, frustrated, and need prolonged treatment until their demise. The condition of these patients is more exacting than that of patients either having terminal cancer or in a critical condition. This does not justify the apathetic attitude of medical staff who regard these patients, just because they are also elderly patients, as society outcasts. In some departments, physicians simply ignore such patients. Medical staff omit examinations, prescribe expensive medicines, and referrals are made for hospitalization in nongeriatric departments.

Discrimination and inappropriate treatment are the main reasons for the source of torment in ESD. However, they are not the direct reasons for the suffering, but these traits are sensed by the patients and find emotional expression in restlessness and shouting.

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