

Complex decision making in patients with dementia in an internal medicine department

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Abstract: With the increase of polymorbidity, extending life expectancy and improving treatment options for chronic diseases, the care for dementia is moving into other areas of medicine. The length and quality of life with advanced dementia is directly dependent on the quality of medical and nursing care, early detection and treatment of complications, nutritional support and palliative care plan. Significant is also the support for family carers. The key coordinators of care for patients with dementia are general practitioners (GPs), geriatricians, psychiatrists, and an increasingly important role play internists. Case reports of patients admitted to an internal medicine department. Description of clinical experiences with caring on patients with dementia. In the internal departments of regional hospitals, there is a room for adjustment of the care plan, for comprehensive assessment of the patient and for making crucial decisions regarding nutrition, treatment of chronic diseases, consideration of previously expressed wishes in the context of the patient condition, and potential prognostic indicators. This assessment must result in a comprehensive documentation and communication with patients, and in the case of advanced dementia with their family members. The general internal medicine is very often the first place where the patient has a chance to hear about indication for palliative care. Without the availability of a multidisciplinary assessment, good communication and documentation, it is unrealistic to expect that the hospital would provide comprehensive care for patients with dementia.

Keywords: Dementia syndrome; life expectancy; palliative care; internal medicine; geriatrics; care plan; previously expressed wishes; polymorbidity

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Introduction

“It is useless to ask if life has meaning or not. It has a meaning which we give to it.”—Lucius Annaeus Seneca (4 BC–65 AD).

The issue of dementia is challenging contemporary medicine. There was a significant increase of life expectancy at birth in the last 20 years in developed countries. Therefore, the incidence of dementia increased and it is often combined with the consequences of metabolic syndrome. Polymorbidity of chronic diseases is shifting the care of patients with dementia into the acute medicine facilities since standard treatment by psychiatry is not

enough to create a comprehensive plan of care. Acceleration of problems, especially in moderate and severe dementia, requires emerging role of intensive care, internal medicine, geriatrics and practical medicine in management of the long-term patients with dementia. Previously expressed wishes, symptomatic treatment plan for palliative care, including withdrawal from treatment, family support and care for survivors, penetrate into the healthcare environment that is not often ready for them. The Czech Republic is in this sense only in the beginning of the arduous journey to reform of health and social systems.

World of a patient with dementia, situations and needs of carers

It is not easy to understand and yet it is the only way to help him. I ask my students to imagine a world with dementia, for example, by the method of visualization:

"You're 60 old, we know each other and you know that as a physician I am dealing with dementia. For about half a year, you observed ever-increasing difficulties—in decision making, with memory, when dealing with emotions, when trying to organize your time. You're very nervous, failing in roles that were previously well managed. You come to me and ask me the hard question: "Is it dementia?" At that moment, when my answer, unfortunately, is that all examinations indicate that, there is a cut and we stand together on a train station platform. Before us is a beautiful train with a lot of people, some with bags, others accompanying them, you have suitcases and board the train. The train is rolling. Moving ground beneath your feet, moving at its own pace, makes you unsure. Likewise, flickering landscape behind windows, especially when the train accelerates after the city. You put things into the coupe, which is beautifully furnished, and go to magnificent ballroom, theater, into cinema, and sitting at lunch in a nice restaurant. You are eating great food, you feel good. But then you spill the soup, because your hand is shaking and you cannot judge the distance. Waiter arrives, and although politely, he strongly advised you to eat in your coupe—there are those who already cannot handle everything perfectly. Your coupe from that day is your living space. And you feel more and more that your coupe is your body. You perceive a lot of stimulation coming from outside, audio, olfactory, visual, and from the inside, mainly feeling of pain and other, sometimes very uncomfortable, bodily sensations. Also anxiety. And you understand them less and less, they are still new to you, you cannot connect them with your experience. Subsequently, windows of your coupe became almost opaque. You are living longer mainly in a binary system: plus or minus, those are your worlds. Pleasant or unpleasant, painful or painless, soothing or scary. That way you will arrive at the destination."

Patients with dementia have different perceptions than the general population. Significant components of perception are speech and emotions. Stimulations from the outside environment are important factors causing uncertainty, incomprehension, anxiety or fear. Significant is the intonation, speed of speech, sound or noise, "atmosphere" or calm, nervousness and tension. A person with advanced dementia perceives like a child 1–3 years old. He can be defiant, in a panic, defensive and escaping.

Mrs. Eva, 77-year-old woman in the late stage of Alzheimer's dementia, was admitted to an internal department because of disorders of food intake and "collapse" condition of unknown etiology. During her first 3 days, family tried to stimulate her mentally, but the patient refuses to fully communicate. That occurs also with food and fluid intake; she must have infusion therapy but repeatedly removes the intravenous catheter. After team (nurses, doctors and caregivers) considers the situation, we conclude that Mrs. Eva should receive trazodone in the evening and midazolam at night, with subcutaneous hydration. During the day, especially in the presence of the family, she begins to regularly drink. The situation has slightly improved after next 3 days. We met several times with the family and talked about domestic conditions for care (Mrs. Eva was cared for by only by her husband, younger family members were not involved). The result was a decision to discharge Mrs. Eva home, contact the mobile hospice care, adding nurses and caregivers for 4 h/day on the family's request. For three weeks, the situation has considerably improved, the patient even begun to contact the surroundings, relaxed, and started little walking with rehabilitation nurse and her daughter.

Respect for the rights and dignity, ensuring safety in the hospital environment (1)

- ❖ Adequately addressing—the best salutation for which a person responds favorably, agreement with the legal guardian or next of kin, exclusion of psychosocial malignancies (ignoring, infantilization, objectification, ridicule, etc.).
- ❖ Dressing up—we do not insist on completely civilian clothes, suitable clothes are comfortable "sports" or homemade clothes that do not restrict movement of patients and are easy to maintain. We prefer custom or personalized clothing, and will avoid inappropriate labeling.
- ❖ Protected environment—an environment where patients reside together with a carer—in any case it is not possible to lock people with dementia in their own space without oversight and support by staff, and families.
- ❖ Restraints—any means of restraint may be used only on the basis of examination and doctor's prescription. This restraint use must be documented. If the restraint is used, it is necessary to increase the number of staff so that the person with dementia can be continuously monitored, until resolution of problem behavior (see

Recommendation Alzheimer Europe).

Conduct disorders are often referred to as agitation (physical or verbal, aggressive or non-aggressive) and lead to resistance in patient's care. Psychological symptoms include mood and psychotic symptoms, including sleep disorders. They occur during the development of dementia in almost all patients, mostly starting in moderate stages of dementia. If not effectively addressed, they significantly reduce quality of life of the patient and his relatives, significantly complicate care and may negatively influence the location of care. They significantly reduce the effectiveness of provided care.

Etiology

- ❖ Acute health problems—pneumonia, urinary tract infection (UTI), other infections, pain, febrile illness of unknown etiology, urinary retention, constipation, endocrine (hyperthyroidism and hypothyroidism) or electrolyte abnormalities.
- ❖ Drug toxicity—especially psychotropic drugs, opioids, anticholinergics.
- ❖ Environmental factors—not fulfilling physical needs, hunger, thirst, fatigue, cold, heat, pain, feeling the urge to defecate or urinate, constipation, retention of urine.
- ❖ Change of caring, change the time schedule of care, too much stimulation in the environment or vice versa, boredom, sleep disturbance, lack of stimuli, also visual ones.

Diagnosis

- ❖ Appreciation of the history, development of behavioral change—in terms of character and intensities, time of day, time course, any environmental change, very important is the view of the family of the patient and the observed relieving factors.
- ❖ Physical examination—dehydration, infection, heart failure, pain, constipation.
- ❖ Tests of cognitive condition of the patient, compared to the previous situation (Folstein Mini Mental Test Examination).
- ❖ Carefully monitor the appearance and behavior of the patient, rate of speech, mood, thought, perception, cognition, attention.

- ❖ Investigate the biochemistry, blood count, levels of administered drugs.
- ❖ In case of ambiguity can also help neurological evaluation, ECG, X-ray, CT scan or other tests according to the clinical picture.

Treatment options (1)

It is always necessary to treat potentially modifiable organic causes, as well as working with environmental influences and attitude of staff towards the patient.

In treatment of behavioral disorders, it is important to realize that:

- ❖ Forty percent of these situations resolve spontaneously.
- ❖ In certain cases associated with severe anxiety placebo can help [for example, subcutaneous (sc) saline administration with psychological support for the patient, empathy and sharing].
- ❖ In the case of anxiety which is difficult to deflect by the support and environmental modification, medication can be introduced in the evening, e.g., trazodone (75–150 mg dose according to the effect), or a short-acting benzodiazepine (oxazepam, or also alprazolam, midazolam which can be given sub-cutaneously/in off label indication in Czech Republic).
- ❖ Maintaining regular regime of the day—activities, hygiene and nursing procedures, eating or sleep.
- ❖ Physical activity should take place utilizing any patient potential, within which it enables him to perform those activities that he can handle. This is an important role for carers, occupational therapists, recreational activities coordinators and physiotherapists.
- ❖ In communication with patients speak more slowly and pronounce intelligibly, preferably with a good eye contact.
- ❖ Environment of care, keep quiet, comfortable, creating a sense of security.
- ❖ Keep in range of the visual field of the patient a clock and calendar.
- ❖ Monitoring news, television, and radio can help only patients with lower levels of cognitive deficit.
- ❖ It is useful to use pet therapy, aromatherapy, or art therapy, music—especially if the patient has the opportunity to participate.

Hospital environment is essential place for deciding on need for palliative care

“We need CPR”

Fifty-five-year-old Mrs. Mary is brought to an internal department. Admission diagnoses—long-term food intake disorder in Alzheimer's Dementia. The patient was cared for at home by a daughter and a husband for 4 years. Objectively seen severe loss of muscle mass, severe dysphagia.

The next afternoon, at the Department of Internal Medicine, her daughter and her husband are trying to feed the patient in the presence of staff. Mrs. Mary does not communicate and has much phlegm because of administration of excessive volume of enteral nutrition via gastrostomy. After a massive aspiration followed by shortness of breath a resuscitation team is called. At this time, the patient had not addressed previously expressed wishes, and did not set up a palliative care plan.

The patient is resuscitated, intubated, and admitted to the Department of Anesthesiology and Resuscitation (ARO) as a “hopeless terminal condition”. The biggest problem proves to be the inability of physicians from primary care, the internal department and ARO to clearly communicate the final phase of dementia to family, and to express support for the withdrawal of ineffective therapy. It is difficult to communicate at ARO, because the family of the patient did not have previous support, now feels guilty for the condition of their wife/mother and refuses to accept the final phase of the disease.

“Provision of care”

Peter is an 85-year-old man with documented symptoms of the Parkinson's disease and symptoms of organic brain syndrome. He is admitted to an internal department of a district hospital for a “worsening of health state”. He was brought by an ambulance which was called by the caregiving wife (as stated in the documentation).

Lab results show slight increase in inflammatory parameters and he is immediately given antibiotics. According to the attending physician, he has UTI. The head nurse tells me that he should be relocated. I wonder why? “He is very restless, and does not want to eat and drink.”

I'm going to evaluate the patient. This is obviously a very frail patient with significant muscle atrophy and with severe malnutrition (albumin 21 g/L), with onset of severe vascular dementia. He also has a chronic heart failure, stage C, an ejection fraction of 30%, the chronic renal insufficiency with a reduction in glomerular filtration of about one third. He is not well

hydrated and has strong psychomotor agitation. Resting supine blood pressure is 110/80. He has contractures of lower limbs at the knees. He has candidiasis in his mouth.

I invite the family of the patient; son comes the same day. He says that he lives 150 km away, takes once a month time off, so he can go to visit his parents. “You know sir chief physicians, my mother is demented, I cannot do more”. I find that the wife is very anxious. According to the son, although sister/daughter lives next door, “she was not involved in the care.” I call a social worker; home care is indicated and finally she finds a suitable home hospice care. The GP have not seen the patient physically for more than a year. Social investigation discovers that the patient lives in an unsuitable environment (Figure 1) and his overall condition requires a combination of intensive palliative care and nursing care, together with the provision of social support. After meeting with the whole family, day care is provided, which is paid by the family. An intensive ongoing surveillance of mobile palliative care team ensures health care and the patient lives in his home without the need for intensive care for 3 more months. Dies from heart and kidney failures at home, without the need for intensive hospital care. The family expresses feelings of satisfaction from participation in care.

Admission and discharge of dementia patients (2)

Admission of the patient to the internal medicine department represents usually acute hospitalization, which is often lasting only few days. How to ensure a multidisciplinary assessment within this time frame?

- ❖ Day 1—addressing acute health issues—finding the etiology of problems, whether it is treatable, initiate causal or symptomatic treatments.
- ❖ Must contact the family as soon as possible, personal meeting.
- ❖ Within 24 h establish long-term care plan (revision of the management plan—social aspects, interviews with family, including family support, evaluation of patient's cognitive status, options to stabilize chronic diseases, nutritional assessment).

Monitoring of five indicators (2):

- ❖ Ability to stabilize decompensated chronic diseases.
- ❖ Situations and the possibility to intervene with the nutritional status.
- ❖ Situations and the possibility to intervene with the state of cognitive and behavioral disorders.



Figure 1 The unsuitable environment.

- ❖ Situations and the possibility to intervene with other symptoms, especially pain, nausea, shortness of breath and so on.
- ❖ Patient's social condition and possible future scenarios care plan—medical and psychological decompensation of dementia resulting in ever worsening independence, maintaining the existing psychological and the social status often requires more support. Family of the patient is very often not prepared for that.

During hospitalization, it is necessary to contact the family and carry out social investigation to assess the compatibility of their home environment with the potential patient. We should think that the family will await the advice, support and understanding of their uncertainties. Prepare scenarios for different situations. Possibility of palliative care at home is the ideal solution for patients with dementia and their families—will be functional only if there is continuous medical support and available social services.

Risks of drug administrations (3)

- ❖ Antihypertensives—in patients with signs of frailty syndrome (all patients with advanced dementia) the target blood pressure is less than 140/80 value. Lower values may result in muscle, cerebral and renal hypoperfusion and subsequent nutritional, circulatory and metabolic complications.
- ❖ In diabetes—insulin therapy and most of the antidiabetics bring distinct benefits for patients with advanced dementia. It is necessary to carefully assess the control of diabetes, considering need for diabetic diet in case of deteriorating oral intake. It is important to sensitively communicate given situation with family of a patient and articulate potential risks of current treatments—always in the context of a palliative care

plan, which was previously discussed with the family (description of the real situation of the patient and appreciation of the possible development of disease/illness).

- ❖ Diuretics—especially in patients with heart or renal failure it is not easy to assess the cost/benefit of diuretic therapy. The route of administration of medications and their dosages must meet the possibilities of the patient and their family carers/staff.
- ❖ Neuroleptics—their dosage should be initiated in the evening and at night, where possible sedative effect is less risky for the patient. The treatment effects should be periodically re-evaluated.
- ❖ Analgesics—less mobile or immobile patients with pain visual analogue scale (VAS) four or more generally benefit from transdermal opioids (mostly buprenorphine or fentanyl). Treatment should be complemented by good hydration and constipation treatment. Untreated chronic pain is a major causative factor of delirium and significantly reduces quality of life.

How to set the care plan

Palliative care requires a good knowledge of the reasons why we administer specific medications, perform examinations, and recommend the location of care. Only in this way we can “tailor” the care to the needs of the patient and his relatives, and could avoid iatrogenic damage to the patient, or misunderstandings, tension, and unnecessary suffering. We are building a bridge across the chasm of incurable disease.

- ❖ What diseases and how much overall health, but also mental, social and spiritual condition of the patient has an impact on quality of life? What is the attitude of his family? What is modifiable?
- ❖ An important health factor in determining the prognosis and quality of life of patients with dementia in the late stages of the disease are nutrition, potential mental and physical condition to prevent delirium, quality medical and nursing care, and complicating comorbidities.
- ❖ In a plan of care, it is more important to define appropriate care than to think about prognosis. It should contain an early indication for palliative care.

Conclusions

- ❖ We should think in making our decisions more about what kind of life can be with the disease, than how long it will be.
- ❖ Consider in making decisions as partner not only your patient but also your colleagues and relatives of their patients.
- ❖ Try to adopt and apply in practice that even “bad news” can bring much good—especially if they bring the space and time for a better life with the disease.
- ❖ Respect, openness and honesty in the relationship with the sick, are much stronger than fears, ego considerations or loss of responsibility.
- ❖ Care for the neediest is a privilege that needs to be accepted and provided with responsibility and respect.

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Footnote

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