

End of life care for the frail Old – Communication and ethics

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We are born. We grow up. We get old. We die.

Some of us are born into privileged societies. We establish our life-projects, like education, occupation, family and friends.

For many the life-project is strongly limited, often to the question of food, housing, daily life survival, peace and family. In the poorer world regions numerous children are a central part of their planned life-project, and care when they are frail and old..

In most developed countries, we face a growing tendency of the expectation: “society will take care of us when we get dependent on care from others.”

We succeed and we fail. We grow older. We are in the older years more or less healthy and develop more or less dependency on others. Some develop dementia and cognitive failure. Few die healthy “with their boots on”. 75 % and more of us will in the last weeks, months or years before we die need care day and night.

Many expect a good quality of life and respect for their dignity, also in their years as old before they die. Some receive it. If they receive it or not, depend on a long variety of external and internal social and cultural factors.

We have learnt that central key factors to dignity are our personal life project and the freedom to make choices. To give strength to both these perspectives demands theoretical and practical competence in communication and ethics, both for the professional or non-professional carers.

Before we focus on these challenges, it is imminent to reflect on the question: What makes the conditions for good communication and ethics facing the frail old so special and important?

1. Because the frail old are more vulnerable than others.
2. Because they increasingly will face physical and psychosocial disability limitations, often connected with cognitive failure.
3. Because frail old often see death as a good solution. 4 out of 5 we meet tell us: “I trust you. When time has come, let me die.
4. Because death died. It disappeared into institutions, where it is well hidden from the family.

5. Because their frailty and illnesses make them dependent on care and the health care system.
6. Because the health care system are more interested in money making on old peoples diseases, than on quality of life and dignity in the their final years.
7. Because dying old are admitted to hospitals and kept alive with lack of respect for informed or presumed consent.
8. Because resources, competence, teaching and research with focus on long term care and palliative care for frail old is far from established.
9. Because death and dying comes closer every day.
10. Because doctors lack training in communication and ethics.
11. Because all of us contribute. Questions like frailty, dependency and death are denied, hidden and no longer communicated in our daily life.

The reality for the frail and dying old, in close future us, is often cruel. The societies are overwhelmed by the costs for long term care. Instead the health care systems have well established strategies to earn as much money as possible, fulfilling therapy with poor or absent benefit to health for the frail old.

The challenges of frail old people older than 75 in their final years of life can be described in four stages: 1. Healthy aging – age 75 to 100 and more. 2. The vulnerable old – last 2 to 10 years of their lives. 3. The dependent old – last weeks, months to 10 years. 4. The dying old – last days, weeks or months.

When we further discuss the practical perspectives of ethics and communication regarding the frail old, I wish all of us healthy aging. My focus will be on stage 2-4.

The key question in ethics is: *What is a good life?* Caring for frail old patients a second question arise: *What is a good decision to enable and support a good life for our patient?*

Following these two basic ethical questions a variety of new central questions arises, like: *Has the patient received proper information regarding his health, options for medical or caring interventions, probably benefit, costs and side effects, and consequences of these interventions? Did the patient understand the offered information? Are we withholding and hiding necessary information? Why? Is it in some (or most) end-of-life situations, ethical acceptable not to tell the patient the truth? Shall we remain silent about the prognosis? Is it morally and ethical acceptable to give information and to communicate on these matters with the relatives, and not with the patient? If the patient is more or less cognitive impaired, which strategy and action in decision making will show maximal respect for the patient's life-values, life-project and dignity? Who is responsible for the "in praxis" quality and ethics of these communication processes? Who protect the patient's dignity and basic human rights, when the patient no longer is able to speak for himself?*

The target of communication, the approach to these and other relevant ethical questions for the frail old, are dependent on the factors earlier described. Mostly the participants in this scenario are found in four groups: The patient, the relatives, the caring personal and the physician.

The frail old patient is the key person. To support and give strength to his or hers maximal autonomy and life project should be the central target for communication and ethics. That means that communication about the condition, situation, options for therapy and care, and prognosis for the patient, never should take place without the patient present.

There are some few, but important exceptions to this basic rule, like: Patients with severe dementia and/or cognitive impairment. The unconscious or psychotic patient. The dying patient in their final days and hours. These dying patients often give a signal: "Let me go. Talk to and support my family." At the average 60 % of the dying patients will be unconscious in the last hours, days or weeks before they die.

Prerequisite is not only the information to the patient, but even more information from the patient like: *What was the previous received information? (Patients and relatives will then not tell what the information was, but what they understood.) What are the patient's expectations and goals? What is the patient's life project? Who are important relatives and care givers? What are the important questions from the patient? What kind of support does the patient and relatives need to see and understand the situation and the options? What information should the doctor receive to enable optimal care in the remaining life—time?*

That the patient is the key person, does not mean that the relatives should be excluded in the communication processes. On the opposite. Most old patients live in or are connected to a family system, where spouse, children or other relatives have more or less close roles for the care and the important decision making. From the beginning important relatives should be invited to and included in the communication process, also supporting them to contribute to information, communication and questions from the patient.

Here we face major challenges. Different cultures and generations have different communication patterns and view autonomy differently. In North Europe it is developed and established a tradition to give open and frank information to patients about diagnosis, therapy and care options, also prognosis, and not to give sensitive information to relatives without the patient present. In south and east Europe the praxis and tradition is different. The family structures and boundaries are stronger. The target of information is more the relatives than the patient. Information and prognosis with negative consequences are withheld from the patient under the motto: "We must protect the patients from the truth, especially about the impending death. We must not destroy hope." But isn't it to destroy hope when the hope we present is based on lying? Whether the patient nor we can find the way in an unknown

landscape, if the road map is wrong. The strongest argument in favor of telling the truth is autonomy and ethics.

The caring staff, in home care and institutions: nurses, assistant nurses, physical therapists, occupational therapists and others, has a role which is major underestimated. Often they know and care for frail old patients over a long period. They often have unique information, observations, competence and experience regarding the patient and her situation. They know the actual large and small questions to be raised. Better than any, they often can review the physical and psychosocial and spiritual challenges. They should be included and participate in all communication processes and decision makings regarding frail old patients. In praxis they are mostly forgotten.

The physician is at the best a skilled, competent and compassionate conductor.

Frail old patients are frail because they are old and ill. These patients need proper medical and interdisciplinary assessment. At the average the patients in our nursing homes have 7 chronic and/or severe diseases. At an average nursing home patients in Norway daily receive 12 different drugs. Before we focus on care or psychosocial integration, strategic communication or ethical challenges, we must establish a map over the health and illnesses, over good and recommended medical interventions, restoring or contributing to health. The physician must also make up his mind what he should not recommend, like interventions or treatments with poor outcome and multiple side effects.

Like most of us, physicians like good results and grateful patients and relatives. Many physicians don't like frail, multimorbid and dying old patients. The strategies of these physicians towards the patients are: to avoid them, to overlook that they are dying, to lie to them, to support unrealistic hopes, to offer meaningless and burdensome interventions, to admit dying old patients to hospitals.

In general, we may like it or not, physicians are key factors in the end-of-life drama. Physicians can open or close doors: to the health care system, to adequate or misleading information or therapies, to proper or inappropriate long term care at home or in institutions. They can focus on details or the patient's life-project. They can be present or absent, skilled or amateurs, including or excluding.

How the physicians play their role as communicators and conductors in this drama, enable or disable a good communication process on the small and large ethical challenges for the patients remaining life.

Doctors often lie to frail old patients and their relatives. They withhold important information. The needed competence in ethics, communication, palliative care for the frail old, teaching and research on these matters, is poorly established. Long term care for frail and dying old means low budget, low status and lack of adequate competence.

Norway, Sweden and the Netherlands probably have the best professional standard in Europe for competence in nursing homes: caring staff and nursing home physicians. The Netherlands has a well established medical specialty for physicians in “Nursing –home-medicine”.

Let us hope that neither you nor I meet ignorant and incompetent physicians in our final stages of life. The good physician though, the ones we meet, among them the ones sitting in this audience, are caring, humble, skilled and compassionate, not lying. They are communication partners and conductors, with major competence in long-term and palliative care.

These perspectives on ethics and communication focus on the frail old patient with competence, the ones who are capable to understand choices and take their own decisions. We have to follow and respect the principles of informed consent.

A large number of frail old persons lack these abilities, especially the rapid increasing number of patients with dementia with cognitive failure. How do we communicate with them? And what are in these situations, the basic principles showing respect for their autonomy and life project?

It gets more complicated. The majority of patients with cognitive failure still can understand and make choices, but they need support from skilled persons who they trust, who listen and find the right words and explanations. Often a bargain is the task, with a “weak paternalism”, where we suggest and support the patient to find the good solutions.

But also patients with severe cognitive failure still have, although reduced autonomy. The strain is, their autonomy now increasingly is getting vulnerable and dependent on others. The main characteristic of these others is: They are close relatives or carers. Their knowledge and closeness to the patients can support us with vital information like: *What is the life-story and life-project of the patient? What were the central values? Are there, formal or non-formal advanced end-of-life directories?*

Advanced directory means written or verbal information or statements on end-of-life matters from the patient in advance, before they developed cognitive failure.

In the daily life of patients with cognitive failure, there will be numerous small ethical challenges, like: *Get out of bed? Shower or bath? Tooth brush? Company? Physical and psychosocial activity? A walk? Wheelchair? What to eat, and when? When go back to bed?*

But also large and basic ethical questions develop: *Home, nursing home or hospitals? Drugs: benefit/ side effects? By challenging problems due to behavioral disturbances: Locked doors, sedation, environment therapy, staff-competence? Artificial nutrition? Prolonging of the death-process? Access to competent caring staff and doctors?*

The communication now grows more complicated. Not the patient, the proxy need information and must face the ethical questions, speak for the patient and protect the patients autonomy. These proxies are mostly the relatives, the caring staff or the general practitioner (GP). Advanced directories are important and helpful, but often have limitations, especially when we have good reasons to doubt that our specific ethical challenge is addressed by the directory.

Again this communication process needs a responsible conductor. My hope is that the patients GP, the nursing home physician or the responsible hospital consultant take this role. Again the reality is cruel. More than often the patient's physician don't take the role, or take it with a destroying ignorance or incompetence, with the wrong focus.

In our North-European countries there is a growing tradition that a caring nurse take this responsibility and role, often with competence and success.

The goal is preparing communication, reviewing and discussing the patient's situation and challenges, now and in future, until she dies with optimal palliative care, without unnecessary hospital admission the last hours or days before death.

The important ethical questions needs assessment. The approach should be a combination of focus on: *What is a good decision for the patient? And: Presumed consent - Which decision would the patient take, if she could?*

The worst scenario is lack of planning, lack of, or varying information to different key persons, no preparation to the impending central questions.

The largest violation of dignity I can imagine, is that frail old in their last hours and days are left alone with their dying, that communication on and relief of the developing suffering is completely ignored, that they are sent to hospitals, dying in transport, or met by professional lunatics and strangers in the health care system, with therapeutic omnipotence, who don't address that a human being is dying.

Oddvar. A phone call, late Sunday evening. The nurse on the phone: Oddvar is severe ill. Fever 29. His wife is with him. She says: "Oddvar has pneumonia." In our nursing home, our doctors are on call 24 hours a day. I drive to the nursing home. Oddvar is 84 years old. He has been in the nursing home the last 2 years. He suffers from dementia with severe cognitive failure. The last 2 months bed-ridden, verbal communication no longer possible. His wife comes every day, and cares marvelous for him. I examine Oddvar. We sit down in the ward room: His wife, the nurse and I. His wife looks at me and says: "He has a pneumonia, right?" "Yes," I reply. "You are a good doctor." "Then we give him penicillin doctor Husebø, right?" "To give penicillin is one side... I have an important question for you. What would he have wanted in this situation?" After some seconds she replays: "He would have wanted to be dead, years ago. He used to be a proud man..." "That is the other side." "But isn't it a lot of suffering to die from pneumonia?" "Earlier we said: Pneumonia is the friend of old

people,” I answered. “And we can relieve his suffering sufficient if problems develop.” “Husebø, then we should not give him penicillin. But you must know, I love him, very deep.” Oddvar become palliative care and not penicillin. He dies peaceful four days later with his wife at his side. My question: “What would he have wanted?” – is presumed consent. She openly states that Oddvar would have wanted to die. On the other side she loves him, and is not quite ready to let him go. To ask her: “What do you want us to do?” probably would lead to action and penicillin. He might have lived for some more days.

Maria. 3 months ago Maria fell at home and fractured the lumbar spine (L5), and was admitted to the orthopedic ward in hospital. Fracture was stable, no indication for surgery. After 10 days in hospital she is referred to a nursing home for rehabilitation. She stays there for 3 weeks. The benefit of rehabilitation was absent. Then, 4 weeks ago, she is transferred as long-term patient to our nursing home. Her general condition by income is extremely poor. Weight 44 kilo. Her food and fluid intake is poor. Mobilization from bed is not possible. Severe cognitive failure. The last 3 previous years she was admitted to hospital and different specialists 8 times. The result from these referrals was 9 different diagnosis and 13 different drugs. One of the diagnoses from all specialists was consistent: dementia. She was never referred to assessment of her dementia... 4 weeks after her income, she is dying, unconscious with high fever and pneumonia. The situation is worsening, despite intravenous penicillin and nutrition. The nurse explains: “Marias husband is very difficult and demanding. He accuses us, that we are killing his wife. He threatens with lawyer and police.” We invite her husband and the daughter to a meeting, taking place next day. The dialog is open and challenging. Marias husband still demands that we restore Marias health and weight to the situation before she fell. He also demands transfer to the hospital, and totally neglects our statement that severe dementia is the main problem and that Maria is close to death. Threats with lawyer and police are dominant. We state that there is no indication for hospital admission. The next two days Maria health is further deteriorating despite intravenous penicillin and nutrition. We stop the death prolonging treatment and focus on palliative care. Two days later she dies peacefully in the nursing home without family members present. Two months later her husband goes to the police and accuses us: We have murdered Maria.

Nina, 91 years old, is by all means healthy, walking around, cheering other patients, despite her severe dementia. Then she falls and fractures her left hip. Due to her cognitive failure she is unable to understand and cope with the situation. Verbal communication is not possible. She is now bed-bound. She is admitted to orthopedic surgery. The next day she comes back to our nursing home. She had refused anesthesia and surgery.

Oddvar, Maria and Nina represent some of the main communication and ethical challenges in end of life care of the frail old. They all suffer from severe dementia. They need care day and night. Due to advanced cognitive failure they totally lack

ability to understand their choices or make decisions. Our professional competence tells us that Oddvar and Maria will die within the next days or weeks, and that the focus should be on optimal palliative care. If Nina don't undergo orthopedic surgery she also will slide into that situation.

Oddvars wife is prepared. She has over years seen and experienced the development of Oddvars dementia. She knows and trusts the caring staff and nursing home physician. There have been several open, preparing meetings, discussing the challenges for Oddvar and his relatives, in present and future. She loves him. She is caring for him. It is difficult for her to let him go. But with support she accepts this as the best solution. That evening we easily reach a consensus. Our answers to the basic questions: *What is a good life? What is a good decision to enable and support a good life for our patient?* are consistent. We also have the same understanding of Oddvars presumed consent.

Marias husband is not prepared. Several hospital admissions and specialist assessments kept the focus on a large variety of diagnosis and therapeutically options. These multiple options convinces him: There is a solution somewhere, a radical therapy yet not discovered or withheld, which will cure Maria, back to good health and good years together. This tragedy is a symptom of the modern health care system. They almost exclusive focus is on diseases and cure, with omnipotent therapeutically interventions. There is a basic lack of focus on and competence for optimal support for the patient's whole life project, especially facing chronic and incurable diseases, frail old and end of life care.

The autopsy of Maria showed severe Alzheimer disease, by no doubt the reason for almost all of her health problem over many years.

Despite our efforts and competence, we don't succeed. It is not possible to establish the needed trust and consensus in the short time left before Maria dies. The husband denies. He is fighting, not accepting her death. He keeps on fighting after her death. It is understandable that he needs enemies. We are his favorite target. The name of this denial and fight is grief. The strongest expression of love is grief.

In Marias situation the husband and we strongly disagree on the basic questions: *What is a good life? What is a good decision to enable and support a good life for our patient?* For Marias husband lack of appropriate medical assessment and interventions as the problem. He fights with the goal rehabilitation, to restore her health to her situation years ago. For us, as the caring team the key problem is irreversible, severe dementia and impending death. Competent palliative care is the solution. We are fare from reaching a consensus regarding Marias presumed consent and the goals for treatment. With good conscience we take the charge and responsibility.

In most European countries, Maria would have been admitted to hospital the last days before death. In most hospitals they would provide artificial nutrition, PEG-tube,

and active with all pharmacological and technical measures fight any life-threatening complications until she is stone dead.

In many countries a lawyer or the court would intervene for life prolonging measures. Through these interventions she might have lived some more days, perhaps weeks. But which costs, which life, which quality, which dignity?

In Nina's situation it could be respect for her remaining autonomy to accept her refusal of surgery. She has no close relatives as possible partners in the process of communication and decisions. Back to the basic questions: *What is a good life? What is a good decision to enable and support a good life for our patient?* And, what is presumed consent? The answer of the caring staff together with the physician is: A good life with quality and dignity is still possible. She probably would have wanted to be mobile and enjoy life for some more months and years. We decide to give surgery a second chance.

Next day she again is admitted to the hospital and hip surgery. This time she is accompanied of a practical nurse, who is her primary carer in the nursing home. With the practical nurse present, she accepts anesthesia and surgery. After 24 hours in hospital she comes back and is rehabilitated in the nursing home, thanks to our physical- and occupational therapists. This is a year ago. She is still walking around, cheering other patients and staff, and clearly enjoying her life.

Nina's challenges shows different perspectives. She is not quite close to death. It is easy to "let her go", due to her dementia and a severe medical accident. Nihilism is also a threat to the frail old, and gives us important attention for the need and availability of multidisciplinary competence.

Maria, Oddvar and Nina represent frail old patients with dementia and cognitive failure at the end of their life. Challenges, processes and outcome vary. They, their relatives, caring staff and physician need early and continuing processes with focus on preparing communication, the patients life-project, small and large ethical problems, in present and future.

The preparing, including communication is the starlight. The patient if possible, the close relatives, a representative of the caring staff, and the doctor, meet, several times. Challenges now and until the patient dies, and palliative care are reviewed, discussed and planned. A consensus, a preparing palliative plan for action is established, with clear, congruent written documentation, available day and night if emergencies develop.

Truth hurts. But deceit hurts more.