

Hospice at Home- Article In the Hand Book “Palliative Care in the Community”

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Summary

The author defines the basic principles of hospice / palliative care organizations achieved by leading countries in this area. Trying to get into the essence of the problem in our environment, she also provides a number of concrete examples from her own practice.

Introduction

Social life is based on dialogue. The foundation for a successful dialogue understands what the other person is saying. And the interlocutor's understanding can only be possible if the same contents appear under the same name. It is particularly important to understand the terminology in pedagogical and scientific work. Therefore, in this text, the focus will be on clearer presentation of the basic concepts on which the organisation of a new profession is founded - hospice palliative care / palliative medicine. We wish to finally develop it in my country as well.

Why hospice at home?

Because it is:

- A. The most desirable form, especially for children and the elderly.**
- B. The cheapest and the fastest form of assistance, appropriate for a large number of people, if there is a possibility of regular co-operation at the level of primary health care.**

Ad A. To those who have a home it is ideal to end life at home. Changing the environment is often a great stress, especially for the helpless dying, to whom small details are very important. Families need help if they want to keep a dear member at home. Unfortunately due to the unsatisfactory reorganization of Croatian primary health care, the number of their simple home visits has drastically decreased. At the same time they emphasized their competence for hospice home visits under the parole: we know all this, we do all this. However, the basic problem is “when”. Primary health care doctors do not even have time to deal with, for example, febrile conditions at home, but patients need to come to the infirmary ... And visits to the dying, if they are to be implemented according to the rules of a new specialist profession, could last for hours, especially if the family is upset, and the patient's living conditions are only superficially known.

Ad B. At the primary health care level, there must be a unit that will be shaped at least partially within the scope of the Croatian Health

Care Act of 2003. It should involve three components at least: 1. A multi professional, interdisciplinary, mobile team for hospice home visits. It should have in its competence also 2. The outpatient department for pain and palliative care, for still mobile end-of-life patients and 3. The day hospice where partly mobile patients could be resocialized more easily, assuring at the same time some free time for the family members.

The initiative to start a hospice team would be in the first place in the hands of an elected general practitioner, when the condition of the patient becomes overwhelming.

The team that goes out “on the field” assesses the situation and makes plans achieving co-operation in the first place with family members helping them in necessary changes. The field team also includes specially educated volunteers who help primarily the family, but also the patient directly, enabling him to re-socialize. The patient's loneliness is often the biggest problem in home care, especially in families where the close family members work.

The mobile team urges consultative healthcare professionals or triggers “circulation” if necessary - short-term accommodation at specialist secondary or tertiary health care facilities. The reason may be: immobilization of pathological fracture, analgesic radiation, titration of symptomatic therapy of unbearable pain and other symptoms, or the accommodation - in stationary hospice when hospice at home becomes impossible. High quality hospice certainly has the capacity for a limited number of patients, who often must wait for admittance.

Education

Mentored practical training is the most important. The dying process needs to be experienced in its many different forms. Not even the best handbook can substitute one's own experience and objective descriptions of other colleagues. One needs to build his own attitude towards the death, and access fearless to what is natural destiny of every living being. In 2001, as a collaborator of Croatian Health Ministry project, financed by MMF, Jeremy Keen, an English expert for palliative medicine asked for: an interdisciplinary palliative team leader to go through an initial training of: 6 months of mentored practice in English Hospice and after that a two-year long distance learning course in Leeds. For nurses he asked for 6-week hospice training. In Germany, for a specialist of palliative

medicine, among other things, 180 diaries of dying are required!

Of course, we need to lower our bar significantly. Yet a minimum, which is far above the current maximum, has to be achieved if we want at least to get closer to our models abroad in the next future.

Which patients are not for hospice care?

1. Chronic curable and incurable patients who are being rehabilitated for better quality of life in special institutions. Occasionally, they need both supportive and also symptomatic therapy.

2. Geriatric patients who are treated and rehabilitated for better life. Only in the last months of their lives, as well as patients of the previous group, they become patients of palliative / hospice care.

3. Acute patients, from febrile conditions to pains of different aetiology and so on. This is the area of curative medicine, aimed at healing. They need besides the disease specific therapy, supportive and symptomatic therapy, but not palliative / hospice care. This is only indicated in medical failure.

What are the indications for hospice care?

All the states of clear failure of vital organs, regardless of etiology, patient's age or duration of illness. It is a new group of patients defined by this common feature.

Ethical dilemmas related to the end of life

Unfortunately, in our contemporary legislation, we are forced to black and white solutions. The moral principles of the sanctity of life and the right to personal autonomy come into conflict from time to time. Decisions on advising or interrupting procedures must be made with extensive debate about the nature and the expected outcome of the procedures. It should not be forgotten that the medical obligation, which should always have the priority – is to make suffering easier. Supporting a prohibition of killing could maximize the welfare of the society. If the ban "let to die" remains in effect, all the patients should have to die in intensive care units, with maintaining the life, which is equal to senseless torture. Otherwise, the health team would be charged with an act equal to murder. Competence is needed to realize autonomy, which is something that varies greatly, especially when deciding on the future I have dealt with this topic in the article cited below which has been of special interest abroad [1].

Regional Hospice Centre, Zagreb, Hirčeva 1, as a volunteers attempt to organize hospice at home.

Location

The Regional Hospice Centre was opened in 2002 in the large laundry, on the ground- floor of the modern building for the specialist in school medicine, medical specialization desintegrated during the unsuccessful health reform during the early nineties. Empty space for new contents was adapted primarily by the voluntary work of people with different professions, donations and money from foreign and domestic projects.

It included three rooms. Meetings were held in the largest, with an entire wall in glass, viewing at the schoolyard. Health professionals / volunteers meetings were held on Wednesdays. The purpose of these meetings was to exchange experiences and mutual support of participants to prevent "combustion syndrome" and develop practical knowledge. On

Tuesdays, the meetings of non-health volunteers were held, where they discussed their experiences on the practical training course at the Home for the elderly and the helpless in Crnatkova Street under the guidance of social worker. Later, they turned into discussions about experiences from hospice home visits. Numerous lectures were held in this area during the multi-day courses in Croatian and English language, for different profiles of health workers or non-health volunteers. Events for groups of over thirty members were held at the Croatian Medical Home, Šubićeva 9.

The "accordion" divided the smaller room into two parts: one part was used for orthopaedic aids to be borrowed (electronically controlled beds, wheelchairs, etc.) And a handy pharmacy, supervised by a pharmacist. In the second part there was an outpatient clinic, a place for small meetings or relaxation.

In the corridor just after the entrance, the administration was located on the left: computers, telephones, facsimiles. On the shelf on the right, (where the ironed clothes used to be placed), were the administrative registers, books, and propaganda material left behind, after the courses, symposiums and congresses, copies of BILTEN, as well as unsold objects from charity auctions.

Activity

The phone call would be answered by an administrator who often had to act as a psychotherapist in case of desperate calls for help. Her role was to put together as soon as possible the volunteer team (at least two people) who would go to the hospice home visit, preferably the same day. Of course, some calls were directed to "Home visits" or "Emergency health service".

At the home the situation would be analysed and a plan of specific assistance and involvement of other team members or consulting specialists (again volunteers) would be created, as well as the frequency of further visits planned. It happened repeatedly that we had to include material support (laundry, food, interventions of competent institutions etc) or assistance in sending the children to the seaside etc. Others were involved in important conversations / arrangements about what should be done at the end of life according the priorities defined by the patient himself. It was an activity that requires specially developed empathy and patience, reached only by practice.

It was supposed the team leader would make the report about what was found and planned, in triplicate. One copy was supposed to stay with the patient, the second copy was to be sent to the primary health care physician, and the third one should go to the archive. In order to facilitate the recording, a manual Dictaphone was added to the physician's bag. The text should be written by the administrator. There was a need to create a habit of noticing what was found and experienced, an obligation to which great importance was paid in many related institutions in the world, I have visited. Transport to the destination was most often by a private car of a volunteer physician, (expenses compensated by the "Centre"), less frequently by a taxi or the patient's car. Only the administrator and the leader of the volunteers, the social worker, were full employed.

Non-health volunteers

In all mentioned above the help from the non-health-care volunteers

was crucial. Looking at England and Poland, but also Germany and Austria as models, we were aware that they cover up to 50% of all hospice / palliative activities. Naturally, the people who are interested should go through the following: firstly, they should be selected (it is not enough to have good will, but also appropriate personality features), profiled according to preferences and qualifications, and finally their motivation should be sustained by meetings and joint excursions.

Examples of home hospice practice

After forty years of teaching activities I can, as I have always done, promote the teaching principle – from elementary practice to theory and literature data. I was firstly introduced to it in 1965, during the Alexander von Humboldt scholarship in Muenich, in professor Bodechtel's classes. By describing several examples from practice, I would like, after defining the basic principles of the new expertise, bring the reader closer to the core problem of helping those who are approaching the end of life [2].

What it is like to die

A 90 year old patient with myeloproliferative disease for over 13 years. She was always very calm, nice, polite; sometimes childlike spiteful. In the last weeks she was changing: she disliked to eat or drink, just lying peacefully. She asked me "What is it like to die?" And I said "Tell me what you want." "What I want..." she suddenly stopped and said in an angry voice: "death". I told her: "You shouldn't be afraid of death, for those who were good in life; death is usually also good. They say, you enter a tunnel with a light at the end, which doesn't allow you to go back. "That's crazy..." she replied and then she became quiet... and didn't say anything more.

Second time she welcomed me with a question "Why so early?" - I thought she had mistaken me for a nurse. I brought her a rose, but she did not like it. We were both quiet. I was tapping lightly on her bended knee... she took my other hand firmly and held it for a long time... "Are you sad?" "Sad, that's to nicely said. I'm lonely, abandoned, forgotten..." She would quickly forget someone's visit. She wanted an all-time companionship...

During the visit of her single sister she disliked otherwise, she said "Why are you here? I don't need you...". Turning around she continued: "but, you know, don't take off the beads from the dress I gave you to dress me in, when I die ..."

Two weeks later she was suddenly moved to a hospital where she was put on intensive care. She couldn't communicate verbally, but she resisted to instruments of intensive care. She was tied up...

Service in charge told me that it is their duty to do everything possible to prolong her life... she died after two days.

Last moments - and what to do the next?

A 68 years old patient with longlasting Parkinson's disease

"Please, come immediately, what is going to happen now, what do I have to do? He's dying... I'm so scared"- spoke his wife on the phone... For the first time during so many years of his illness, she was completely lost... We had so many telephone calls, like true partners who care about the patient. She was taking care of everyone and everything, from her mother to her children, and of making money. And he was depending on her like a small child. She said that the "urgency" car arrived that morning

and a very kind physician accepted not to take him to the hospital; she appreciated it very much. The immobility increased and during the last few days there was no contact, at all, no wish for food or drink. The day before he had vomited content similar to black coffee!

He didn't recognize me; I guess he didn't even see me. Stiffness was less pronounced, eyes were widely open, without blinking. Eyelids, if put down remained so for a few moments... then they would slowly go up. The corneal reflex was gone. On the throat's mucosa there was a trace of the black substance, vomited yesterday. Something like a sucking reflex appeared, while trying to clean the throat by gauze with olive oil. He would hold the gauze firmly with his lips and jaw. He couldn't swallow. Breathing was with long silent pauses after very loud periods. You were unable to count the pulse frequency; the legs were cold and livid. The excretion of dark urine was only 2 decilitres in 18 hours.

His wife had already spent two sleepless nights alongside his bed. She would say " that it was difficult at times... but we have spent so much wonderful time together and that's what I will remember... that will be in my thoughts when everything is over..."

And we would sit by his side... I tried to explain what would happen next. The pauses in breathing will be longer, with a possible groan. "Is he suffering", she asked me. "Probably not, it seems his brain is already dead." She called me in the evening, said that the breathing became calmer. In the morning she called me again to say that, half an hour ago, he had passed away on her arms.

Daughter a bigger problem than the dying mother

A female patient, 87 years old. My collaborators from "Centre" asked me to come because the circumstances had become extremely complicated. The previous day, no one had answered the telephone calls. The day before, her daughter took her to hospital for the transfusion. The doctor criticized her "do you not see that she is dying!" When my team and I came in front of the door, we heard shouting: "go to Stenjevec...". Finally, the mother opened the door. The daughter was on a sofa, facing the wall and not reacting to our arrival.

We started talking to the old lady, who was treating herself for the intensive jaw pain by using the warmth of the electric device and Tinidil. The pain soon disappeared. She told us how every time her condition became worse, when the daughter reacted in an always worse way; and that she needs nothing but peace and someone to clean up the flat ... nothing else. I asked about her diagnosis, she said she had surgery of peptic ulcer... when she wanted to find out more, nobody answered. She started talking at large about her previous apartment, where she couldn't sleep because of electrical units, nearby.

The daughter finally came. She was almost screaming, "she couldn't that tolerate any more". She threw the discharge letter on the table and left. I accompanied now the daughter, again laying on the sofa, and repeating the same complaint. I was sitting by her head on the next sofa, and at the end stroking her hair. She became calmer and started explain, why she hadn't answering the phone: she wanted to kill herself and her mother; but she couldn't do it.

She couldn't imagine her mother dying because she was the only one, she had ever had in this world. Her father left them when she was young and because of financial reasons, she couldn't study what she had wanted. In spite of that she managed to get a good job and travelled a lot. She had sold the small, cold apartment and bought a bigger one with a higher bioenergetics' rate. Nevertheless, that apartment was not as desired and the cousin who had borrowed them money wanted her money back. They had to move out... If she would tell her mother that she has the cancer, she told that she would kill herself...and when she is in pain, mother yells so loudly... and the daughter couldn't imagine her mother dying...

We came repeatedly, the daughter had to be put to psychiatric department the mother refused any kind of transfer... and she finally bled to death.

Generation chain of revenge... has she forgotten?

A 75-year-old female patient with diagnosis of amyotrophic lateral sclerosis. She was a person who managed her life perfectly; a well-off, dominant mother of three children, father was never mentioned. Now she is completely immobile and has impaired speech and swallowing. Still she manages to control everything: medicaments, diet, and liquid intake. Even in that terminal stage, she requests to have discrete make up and doesn't allow others to take off her underwear, for a long time. She doesn't want to listen to texts written for hospice or music specially chosen for hospice, but everyday TV program or CD's with romantic novels. She has a 24-hour private caring nurse.

Her son presents the family problem: the patient was rejected by her own mother, who didn't allow her to come to her death bed. This patient also has a daughter that she is in conflict with. The daughter wanted to reach her mother, but she energetically refuses the visit. The son is afraid of continuation of chain of revenge.

The neurologist in charge of the hospice team decides to start negotiations. After sitting in silence, she starts by saying: "your daughter would like to see you". The patient is very surprised, but proudly refuses by the head movement that option. "But your daughter would really like to see you. I know that she's guilty, but we all carry a certain kind of guilt." The reaction was almost a scream of refusal. The neurologist kept on talking: „I'm telling you this as a physician who is worried for your health. Forgiveness helps to feel better and to relax. "After the pause the neurologist continues: "I would like you to spend this final stage of your life in the best possible way. This is the most important part of life. I know you are not religious, but you have a strong personality and you have managed to overcome many things, so you will be able to do this...". The patient starts crying, in a way gives in, but still doesn't give verbal consent. And again a longer pause... the neurologist continues: "Your daughter is blood of your blood and that stays... and her daughter as well... You are now tired, let's continue in a week..."

After the conversation she was very peaceful and her demand for higher dosage of analgesics seized. The terminal process in the meantime became more advanced so there was no chance of repeating this type of conversation.

The daughter came to the funeral.

Don't change the habits of those whose life is coming to an end. Non-health volunteer

A 69-year-old patient, electrician and chess player, very sociable, heavy drinker and smoker, jealous of his second life partner, a very lovely woman.

The diagnosis of bronchial cancer came by accident; he had surgery, but stopped with chemotherapy and controls.

We found him cachectic, with spasmodic cough and choking attacks, with repetitive vomiting of foamy sticky content. Little dose of morphine treatment eased the cough and pain, expectoration was better. He then started to drink again, which was problematic for his wife.

She asked the hospice team to forbid the brandy. He was now feeling better, gained some weight, started visiting the buffet in the neighborhood. We agreed upon a compromise: we won't increase the morphine dosage and control brandy intake, with his wife providing him with a brandy of desired quality. When his condition became worse, we would control it with injections of Hyoscinebutylbromide or benzodiazepine. His GP was following the development of the situation.

The problem was leaving the husband alone in the apartment, in an improved, but still difficult condition. The wife could no longer leave her work, and a solution had to be found. The patient's neighbour was our very experienced and emphatic non-health volunteer, who would visit the patient in the morning and wait for the wife. If there was some change in his condition, she would call the members of hospice team and, if necessary, notify the wife. The volunteer was present there over a year, in total, more than 120 visits

The changes in his condition were very upsetting for his wife. She wanted him to be hospitalized in case he would die soon. What would it look like? The patient was irritated by her behaviour, so he would threaten to jump from the seventh floor. After more than a year of hospice visits, he fell down in the toilet while he was coughing and hurt his ribs. His wife and hospice nurse took him to hospital in order to have his x-ray taken. The wife insisted on hospitalization, he was persistent on rejecting. At the end, he was hospitalized. In the hospital the drinks were banned... resulting in an abstinence crisis. Thus, he died in hospital in a week.

Insecurity of medical prognosis

A female patient of 75, very determined and capable, and willing to help others with different problems. In 1968 she had a surgery of breast cancer in the current method, with resection of thorax muscles. After the surgery a severe arm lymphedema developed. The life prognosis was 6 months. Soon a primary cancer appeared on the other breast. She refused to have a surgery on it. It continued to grow and... "Flourishing".

In 1994 she started the first round of chemotherapy due to severe metastases on lungs. She was almost dying. The chemotherapy effect was almost miraculous. In the meantime severe polyneuropathy appeared, possibly due to a higher intake of wine also. She healed it with energetic massages – using a scrub brush!

She lived, fighting with the disease in her specific way. She would say: "illness is something one just has to get used to." She only wanted someone to bring to her house the things she needed and... to listen to

her. She could talk for hours about the things she had experienced or read. Her memory and narration were excellent. To repeat chemotherapy or radiation was something she completely ignored. Resection of intestine because of severe polyposis, which caused very prolonged constipations, was an operation she completely rejected. It was supposed to be her 11th surgery.

She was dying slowly, quietly, accompanied by voluntary hospice home visitors and wonderful care of a friend, in the year 2000.

Conclusion

In both private and professional life, it is crucial to differentiate between the important and the less important. That is crucial in the transfer of news from the developed society, which is rich in tradition

and spiritual and material sources to less developed society. The truth, material and spiritual, no matter what it is, should be faced. Real values, instead of private ambitions, should be promoted. Only respect of truth creates trust, which is the basis for developing professions and society. We should concentrate on the important things, such as the transfer of real and high-quality information about the dominant opinions, in the profession we represent.

References

1. Jušić A. Ključne etičke rasprave u hospicijskoj/ palijativnoj skrbi. *Acta Med Croatica*.2008; 62:447-454
2. Dva života Anice Jušić. Razvoj neurologije i hospicijskog pokreta u Hrvatskoj tijekom druge polovine 20 stoljeća. Ur. Marko Pećina i. Stella Fatović-Ferenčić, *Rasprave i građa za povijest znanosti, Knjiga 13, HAZU, Zagreb*.2015