

PALIATIA

journal of palliative care



Volume 4, Number 3, July 2011



www.paliatia.eu

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EDITORIAL

Time for new actions in palliative care in Europe

Prof. dr. Wim J.A. van den Heuvel, Chairman of the International Editorial Board of PALIAȚIA

The interest for palliative care is growing worldwide. The EAPC congress in Lisbon showed a growing interest for investments in palliative care in Africa. At the same time, it must be noted that palliative care services in Eastern European countries are not developing well. Not only the number of participants from Eastern Europe at the EAPC congress was disappointing low, the EAPC inventory of palliative services – recently ‘updated’ – does not indicate new developments. Indeed, as is indicated in this issue of PALIAȚIA national policy in palliative care is still lacking in Romania and Croatia and palliative care services are difficult to get financed by the national health insurances. This probably applies to most Eastern European countries. The EAPC might develop a strategy and action plan to improve this situation in Europe. Overall it is meant to be an *European* association.

Even the question should be raised how representative the EAPC these days is for palliative care in Europe and how effective its ‘declarations’ and ‘task forces’ are to really develop palliative care in Europe. Maybe, the association has to analyze again what the needs in palliative care are, especially in Eastern Europe. Two examples are given in this issue of PALIAȚIA which show the possibilities for a new approach. The one is the development of palliative care in nursing homes in Austria. The Austrian Palliative Care movement indeed has recognized the needs for palliative care in nursing home patients. Additionally, it has developed guidelines to assure palliative care in nursing homes of good quality. The other is, a recent Australian publication on Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients. Indeed such guidelines may be very helpful to ensure quality of palliative care in Eastern Europe. Just two examples of what is needed to stimulate palliative care services of which citizens of Eastern European countries could profit.

This issue of PALIAȚIA also indicates another, hopeful development. In various Eastern European countries motivated and experienced health care professionals are delivering palliative care at home to terminally ill patients. They do what they can despite the lack of resources and skilled personnel. Family members, neighbours and volunteers help to deliver care to the dying patient and are supportive in the grieving process. The mentioned Australian guidelines might be very useful to learn what and how to do so. We believe new initiatives and actions will be needed to stimulate palliative care in Eastern European countries. In 2011 thousands of terminally ill citizens in Eastern Europe do not receive basic care; they do not die in dignity and suffer unnecessarily.

ORIGINAL PAPERS

Palliative care for children with severe disabilities - retrospective analytical study of a sample of children with severe disabilities living in institutions

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Abstract

Palliative care for terminal ill patients (cancers, organ failures, neurologic diseases, AIDS, etc.) has two main purposes: controlling the symptoms and maintaining quality of life. In 2008, Romania had 67 palliative care facilities with 2700 patients taken care for.

Objectives:

- Description of risk factors pre-, peri- and postnatal in children presenting various handicaps;
- Assessment of incidence of signs and symptoms associated with physical disability, mental, sensory and motor;
- Identification and assessment of disease / deficit;
- Description of multidisciplinary medical team interventions for these children (involvement of family and staff).

Material and methods:

The study includes 61 institutionalized children (11 of which died, 15 were transferred to other institutions or were taken home by their parents and 35 still being cared for) as part of an NGO in Bucharest and the Ilfov District Social Centre, starting in the year 2000.

Results:

Most of the children included in the study have parents. The main diagnoses were infant cerebral palsy, hydrocephalus (various forms) and epilepsy, associated with sensory disabilities. Of the studied signs and symptoms, those of greatest impact were: pain, seizures, constipation and vomiting.

Concerning the parents, 95% do not accept the fact that they have a sick child and need psychological counselling and support from the medical team as the disease progresses and following the patient's death.

Certain problems related to attachment may lead to neglect or even mistreating/abandoning a child with special needs (abandonment by the family and, then, by the adoptive family were noted in the case study).

The care for the children (and their families) is a difficult and stressful task for the multidisciplinary team. Especially their motivation and continue involvement are at stake.

Conclusions:

Medical personnel involved in the care of severely handicapped children needs to be supported and motivated, in order to carry out their activity in optimal conditions and avoid detachment to the point of insensitivity but also to avoid excessive attachment.

As part of the recovery program, efforts must be made to rehabilitate and integrate the child as far as possible in agreement with his/her family and social environment. Obviously, this can only happen if the necessary financial resources are available and if a sufficient number of specialists are trained in this field.

Key words: *palliative care, severe handicap, institutionalized child*

(Full text in Romanian)

CLINICAL LESSONS

Patients with fistulas - a palliative approach

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Abstract

In cancer patients the ones at the highest risk to develop a fistula are those with advanced malignancy, with gastrointestinal cancer and the patients receiving irradiation to pelvic organs. These risk factors at the same time decrease the chances of closure of the fistula.

In these cases, a holistic care approach is needed starting with a comprehensive assessment and interdisciplinary care management focusing on quality of life. This care is challenging and has to be based on actual protocols of care.

The purpose of this article is to highlight the importance of holistic approach and to offer practical guidelines for interdisciplinary care for patients with fistula and limited prognosis.

Key words: *fistula, palliative care, holistic, protocols, nursing*

Introduction

In my experience working at Hospice Casa Sperantei with cancer patients I have been particularly impressed by the difficulty and complex cases of patients which present not just cancer with all the symptoms that may occur, but also one or multiple fistulas. This is because a fistula in these cases has a strong negative effect on patient's quality of life and self esteem, and a bad prognosis of closure, raising a serious management problem and above that, the specific resources are limited.

Statistics

In terms of mortality the statistics vary between 6.5- 65% (1, 2, 3). Although closure occurs in at least 50% of all enteric or small- bowel fistulas and in 90% of these cases, the time required achieving closure is 4 to 7 weeks (4). For the patients whose fistula is not spontaneously closed with adequate medical treatment within 7 weeks, the goals of care may change to palliation, particularly if chances of closure are limited by other factors.

Factors contributing to fistula development

In cancer patients the ones at the highest risk are the patients with gastrointestinal cancer and the patients having received irradiation to pelvic organs (4). Other important factors are:

Advanced malignancy
Inflammatory bowel disease
Additional disease in anastomotic sites
Inadequate blood supply

Most fistulas in advanced cancer develop as a result of postoperative infection and/ or radiotherapy. A few are caused solely by tumor progression and necrosis (5).

To be able to tailor the right intervention, a careful assessment is needed:

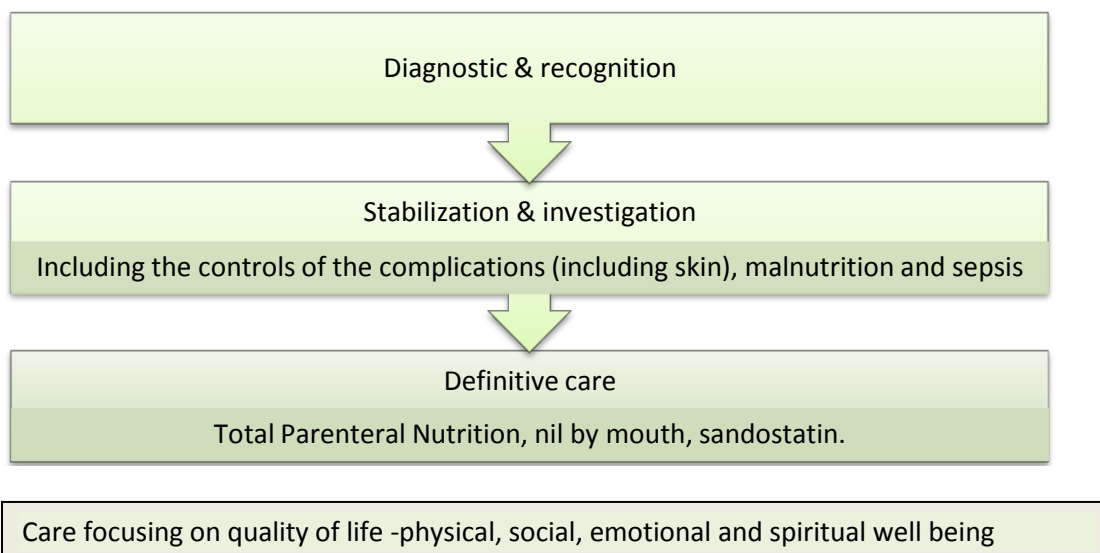
The following aspects have to be assessed:	
The source of the fistula(s)	Diagnostic tests (radiography, fistulography)
Surrounding skin	Erythema, ulceration, maceration, denudation from fistula output- the more caustic the fistula output, the more impaired the surrounding skin integrity, other wounds close to fistula, catheter, folds, incontinence problems
Output	Odor: high odor- likely to be from colon or malignant lesion
	Color: clear or white output is typical of esophageal fistulas, green output- usually from the gastric area, light brown or tan may indicate small bowel sources
	Consistency: thin and watery to thick and pasty consistency- usually from small bowel, pasty to a soft consistency- for colonic fistulas
	pH: proximal fistulas from the gastric, biliary, pancreatic or small bowel consist of activated juices. Colonic fistulas are less of a problem as they have a less aggressive effluent and low excoriation rate (6)
	Quantity: typically high from 500- 3000 ml/ 24 h) for small bowel fistulas; esophageal fistulas- to 1000 ml/ 24 h
Fluid and electrolyte status	The patient with a small bowel fistula is at high risk of fluid balance deficit and or dehydration and metabolic acidosis due to the loss of large volumes of alkaline small- bowel contents; also significant losses of sodium and potassium are common in small bowel fistulas

Other issues to be assess: anatomical orifice location, proximity of the orifice to bony prominences, number of fistula openings (multiple fistula tracts may impede containment efforts), the level of at which the fistula orifice exits onto the skin. Oral fistulas occur between the mouth and the face or neck. In addition to the inevitable psychological distress associated with a visible deformity, oral fistulas cause problems with leakage of saliva or ingested fluids. Absorbent gauze, changed often, sometimes is enough when the orifice is small. Other options may be neonatal stoma appliances or with larger fistulas the use of silicone foam casting should be consider. Silicone foam castings have also been used in the management of enterocutaneous fistulas (7).

Fistula Management

There are several models/ protocols of care:

The following plan is suggests with 3 **management phases** which might be added by a fourth one, especially when closing the fistula(s) is not an option any longer (4):



Houben and van den Bulck (8) listed the following **management objectives**:

Maintain skin integrity

Avoid leakage

Selecting of appropriate dressing or pouching

Odour control

Quality of life

In fistula care an ostomy pouching technique should be used if possible. That can be use in any type of external fistulas, from low to high output and all types of fluids. The advantages are (8):

Optimal skin protection

Drainable system

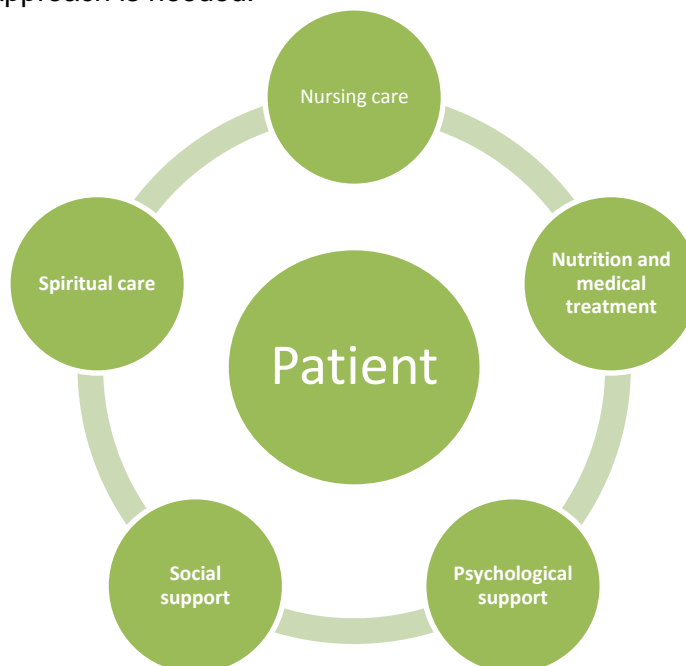
Odour control

The possibility to monitor the loss of fluids through fistula (s)

Usually that is a less expensive technique in comparison with dressing or suction

Holistic care

Holistic care means to consider all aspects important for the patient. Therefore, an interdisciplinary approach is needed.



Nursing care, efficient pouching technique and education provided to the family

The following disciplinary approaches have to be considered:

- Prepare the patient before starting the procedure;
- Allow sufficient time to carry out the procedure, get a person to help, careful prepare all the material need;
- The use of aseptic technique is not usually necessary when caring for a simply fistula; however if the fistula is complicated- situated in a wound, an aseptic technique is indicated;
- Gentle cleaning the skin with warm water; using paste, strips or washers to built the even surface for applying the pouch;



- Choosing the appropriate type of pouch base on output and region to be apply; sometimes pediatric pouches are smaller and more flexible and maybe useful in areas difficult to pouch (neck);



- For abdominal fistulas sometimes a pouch with a bigger flange can be a good choice; the use of pouches allows for odor control, containment of output and protection of the surrounding skin from chemical damage;



- For low output fistulas, where the pouches can not be use, a dressing may help. A charcoal dressing is useful when the output is malodorous. Also, for this types of fistulas a stoma cap can be useful;
- We need to pay attention to the relation between quantity and quality of the output and the drainable site of the pouch: spigot/ tube for liquid output or more wider opening for thick content;
- Patient and family education involves adequate assessment of the ability to self care or caregivers abilities to care for the patient; the teaching issues should include: pouching technique, how to empty the pouch (educate the nursing staff/ patient/ family to empty the bag when is one third- one half full), odor control methods, strategies for increasing fluid or nutritional intake if that is a realistic goal;
- Another method of managing fistulas is by a closed suction wound drainage system (9).

Odor control

- If odor continues to be hard to control with a well fitted pouch, internal body deodorants may be use: charcoal compositions or peppermint oil (10);
- Live yoghurt sometimes may help;
- Changing the bag in a well ventilated room and breath on your mouth can be helpful at the changing time;
- Also, adding absorbent accessories in the bag – pills, gels, suppositories, granules – which absorb the smell and thicken the output it may help;
- If odor is suppose to be produce by anaerobic bacteria, 400 mg metronidazol, orally, three times a day may be helpful (9, 11).

Other simple things can help the situation:

- Address problems of leakage promptly;
 - Facilitate home visits, including staying over night if the pouch is leakage free;
 - Try to control the smell at the patient, in the room (sometimes a tray of cat sand litter or charcoal placed under the bed may help). If the patient is not feeling isolated in a single room, he/ she should use.
 - Help the patient to get the appliance and accessories need accordingly to their rights.
- Romania is one of the countries in which the ostomy bags are reimbursed for the patients who are having a stoma but not for the patients at home who are having fistula(s).

Nutrition and medical treatment accordingly to the common objective

- Fluid and nutritional requirements may be greatly increased with fistulas, especially when that involves gastrointestinal tract;
- The gastrointestinal tract should be used whenever possible for nutritional support; if possible bypassing the fistula site result can be a better absorption and tolerance, but that is not always an option;
- Some of these patients may need intravenous nutrition during early stage of the fistula management but the complications are more severe than with enteral feeding (12). Intravenous hyperalimentation will be consider in patients with prognosis of more than 2-3 months (13);
- The specific goals of fluid and electrolyte and nutritional support for fistula management **needs to be discussed** with the patient and family in view of the palliative nature of the overall care plan (4);
- The dietitian has an important role to play in the assessment of the patients' nutritional needs and ongoing assessment is required to ensure that the patients meet their nutritional requirements (11);
- To help optimize gut absorption when oral food is taken, anti diarrhea medication may be given 30- 60 minutes before a meal (13). Loperamide up to 30 mg/ 24h is useful in low ileal fistulas because it allows more ileal absorption (13);
- Octreotide 250-500 mcg/ 24h may be use for slow the speed of intestinal transit, suppresses secretions and help to increase water and electrolyte absorption (12, 13) Hyoscine butylbromide 60-120 mg/ 24h by SC infusion reduces gastrointestinal secretions (13);
- Antibiotics should be use in treating the septic complications (12) or to control odor (metronidazol).

Psychological support

In palliative care, the patients with fistula have several issues to face: a disease with limited prognostic, associated symptoms and body image problems;

There are few factors that can contribute to a better quality of care in these patients:

- Good communication is critical in all health care situations but is of special significance at the end of life. Palliative care requires skills in verbal and non verbal communication, listening and presence;
- Continuity of care and allowing patients to have some control over the management of their illness (11).

The body image can be terrible disturbed as some of the patients with enterocutaneous fistula may have gut showing through a dehisced wound and the patient can see their own bowel protruding from their body (14). In addition of that, the smell if that can be perceived

around patient is another burden for him/ her and the family. It may raise a barrier between the patient and all the other, contributing at patient's isolation

The change of the body image can be a source of suffering which can lead to process of readjust the individual values' system, regaining the faith or losing it, searching for new meanings of suffering or maintaining hope (15):

- We need to learn to look at the patients and help them to look to themselves, to admit there are specific needs and to encourage them to express the fears and feelings;
- Address all the family's worries relating with contaminating/infectiousness, visiting with children and any other issues which can be a barrier in visiting the patient.

Care of the dying extends far beyond pain and symptom management- important though these are. It includes supporting the patient as he/ she adjust to his decreasing physical ability and as he grieves in anticipation the loss of family, friends and all that is familiar and supporting the family as they adjust to the fact that one of them is dying.

Spiritual care

The **spiritual** needs of the people who are terminally ill and their beloved ones have to be recognized and taken care for. As death is approaching, the patient whole life is reordered. Much of what has been important in the past may either grow significantly or diminish in importance. Dying persons return to a state of absolute vulnerability, requiring assistance with all of their basic needs, letting go of all that keeps them connected to the outer world and to life itself (16).

When a person is faced with impending death or multiple losses, many questions about purpose and meaning may arise, like: why me, why that happened to me, is that a punishment, what is the sense of all this suffering. Some of the patients may associate their fistula with the disease which the Bible describe that Ioram had it as a result of his sinner life in which is said "the flow of inside".

Another area of deeply spiritual work done by the dying person is in the realm of relationships. Byock describes five tasks of the dying and their loved ones: the need for and asking for forgiveness, forgiving, expressing love, saying thank you and saying good bye (17).

Social support

- Families provide the primary support for many sick people. Resources in term of care, transportation, activities of daily living, and social interaction generally start with the family. But not all the families are prepared to provide this support (18). The role of the professionals is to help the families by providing appropriate information, education and support for themselves;
- It is important to avoid the social/ family isolation in the context there are a number of barriers to be overcome;
- Get the financial support for appropriate nutritional intake if the patient or family cannot provide;
- It is important to help the family after the patient's death.

Conclusions

There are many issues surrounding holistic care for patients with fistulas. Starting from a good assessment the care should be tailored for specific needs as the protocols suggested, considering realistic objectives.

The patients usually have needs in each of the four dimensions: physical, social, emotional and spiritual. Above all the good care, the patients self image can be something which he/she lose and never or hardly regain.

Spiritual and practical issues are particularly challenging for the care givers, including family. In Romania, supplies of equipment are often limited and this can mean that the interdisciplinary team has to find creative innovative solutions for the patient.

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Conflicts of interest: none

Received: 2 May 2011

Accepted: 15 June 2011

Pain evaluation in palliative care: a review

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Abstract

Objective:

To investigate methods of chronic pain assessment at neoplasia patients in palliative services.

Methods:

A meta analysis of clinical studies performed to assess and evaluate chronic pain at neoplasia patients. Literature search was executed in Medline and DARE.

Results:

The study indentified 855 titles in Medline and 359 titles in DARE, about chronic pain in cancer patients. Finally, 16 studies about pain scales evaluation studies have been selected.

Recent developments show several pain questionnaires validated to assess chronic pain as well as the emotional and social impact. These instruments may contribute to better therapeutical care and adequate pain control. The scales are easily to apply and appropriate to multiple patient categories regardless their culture or language.

Conclusion:

Chronic pain evaluation is a major challenge in neoplasia patients. There are various scales and questionnaires to assess pain intensity in clinical studies. In clinical practice these instruments are not systematically used. Therefore, it is necessary to implement standards for pain evaluation in practice guidelines.

Key words: pain scales, pain assessment, chronic pain in cancer

(Full text in Romanian)

A patient with pulmonary tuberculosis and chronic obstructive pulmonary disease

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Abstract

Chronic obstructive pulmonary disease (COPD) is currently the fifth leading cause of mortality worldwide and is expected to reach the third cause of death in 2020. COPD is a complex pathological disease, with well-defined pulmonary symptoms, extra pulmonary manifestations and significant multiple co morbidities. Besides, COPD decreases exercise tolerance, functional capacity, and quality of life.

In this case, the consequences of inadequate treatment of this disease are discussed. It concerns a patient of 66 years, smoking, with multiple co morbidities and who has neglected his treatment. His disease developed steadily progressive and irreversible, while his condition deteriorated. This patient would have, under conditions of adequate medical services and palliative care, fewer exacerbations and less respiratory function depreciation. If so, the costs of care (human resources and finance) would have been significant smaller and the patient will have experienced a much better quality of life.

Key words: severe pulmonary disease, quality of life, palliative care, doctor-patient relationship

(Full text in Romanian)

MANAGEMENT

Hospice and palliative care in Austrian nursing homes: development and guidelines

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Abstract

Nursing homes are less often associated with palliative care. HOSPICE AUSTRIA, an association of palliative care providers, has put special attention to palliative care in nursing homes during the last five years. Many of the residents of nursing homes are patients in need for palliative care. In Austria there are about 800 nursing homes. In 2010 around 55.319 professionals cared for about 66.000 residents.

Based on the principles of palliative care and given the relevant number of patients in Austrian nursing homes a different 'culture' in care in nursing homes, a culture of hospice and palliative care, is introduced. Since 2005 HOSPICE AUSTRIA, the umbrella organisation of about 250 hospice and palliative care organisations in Austria, is implementing such a cultural change. A workgroup including all relevant partners in the field has developed guidelines for quality of palliative care in nursing homes. The aim of Hospice and Palliative Care in Austrian Nursing Homes is to enhance quality of life until the end and enabling dying in dignity.

A quantitative and qualitative evaluation was made in the first 12 model homes. Experiences in implementing the guidelines have made clear that any successful implementation in homes needs an organisational development process as well as training of the staff. Results show that all groups involved in the process are more satisfied: residents, close ones and families, all carers and the management of the nursing home.

Based on the experiences in Austria we conclude that the developed guidelines contribute to improve quality of care and the 'culture' in nursing homes. Implementation of such guidelines needs a systematic approach by explaining the background of the guidelines, by combining the training of staff and managers with an organisational development and by certification through a national authority.

The guidelines were approved by the board of „Hospice and Palliative Care in Austrian Nursing Homes“.

Key words: *nursing homes, guidelines, palliative care*

Introduction

Words like „hospice“, „palliative care“ are often associated with dying, death and bereavement. Also palliative care units, mobile palliative care teams, the support by volunteer teams come to mind.

Nursing homes are less often associated with hospice and palliative care. Connecting nursing homes with palliative care is quite new in Austria. HOSPICE AUSTRIA, an association of palliative care providers, was until recently mainly focussing on cancer patients. As in other countries, the focus of palliative care has widened to other terminal patients. HOSPICE AUSTRIA has put special attention to nursing homes during the last five years. The overall awareness has increased that many of the residents of nursing homes are in fact palliative care patients. Many residents of nursing homes suffer from multiple terminal illnesses with phases of progressive deterioration, many suffer from dementia. As a result an expertise in palliative care is highly required on all levels when nursing the elderly, starting with people's admittance to a nursing home until their death and beyond. Nearly all patients in nursing homes need palliative care; starting with day one curative and palliative care are combined.

In Austria there are about 800 nursing homes. In 2010 around 55.319 professionals (80% women, 20% men) cared for about 66.000 residents (80% women, 20% men) with 130.000 family members and close ones (65% women, 35% men). Outpatient services are not included in the number of professionals mentioned before.

Guidelines for Hospice and Palliative Care in Austrian Nursing Homes

Based on the principles of palliative care and given the relevant number of patients in Austrian nursing homes we intended to introduce a different 'culture' in care in nursing homes. A culture of hospice and palliative care includes attention to and control of total pain and its symptoms, increased cross functional and interdisciplinary cooperation, increased communication on all levels, better integration of families and loved ones and examination of ethical dilemma. A culture of hospice and palliative care in nursing homes leads to increased awareness and confidence of all carers by increasing their skills and professional expertise.

Since 2005 HOSPICE AUSTRIA, the umbrella organisation of about 250 hospice and palliative care organisations in Austria, is implementing such a cultural change. HOSPICE AUSTRIA initiated a workgroup including all relevant partners in the field to develop and define guidelines for quality of palliative care in nursing homes.

As a pioneer in the field the hospice movement in Vorarlberg, the smallest of Austria's 9 federal states, started the implementation in some model homes in 2004. In Vienna Caritas Socialis had started introducing hospice and palliative care in their care centres with the help of the palliative care department of the university of Klagenfurt, IFF. Based on the experiences gained in Vorarlberg and Vienna, HOSPICE AUSTRIA published in 2008 guidelines for hospice and palliative care in nursing homes for all of Austria. These guidelines are the foundation of any implementation.

What is special with these guidelines is that they describe the goals and the dimensions to look after for all relevant target groups (residents, close ones and families, managers, nurses, doctors, spiritual carers, social workers, psychotherapists and volunteers).

The aim of Hospice and Palliative Care in Austrian Nursing Homes is to enhance quality of life until the end and enabling dying in dignity.

Implementation

Experiences in implementing the guidelines have made clear that any successful implementation in homes needs an organisational development process as well as training of the staff.

Critically relevant to all issues are gender and cross cultural competence. Sensibility in both areas enhances the quality of care. Women and men (never all, but many) have different interests, wishes and needs due to their gender biased upbringing and/or different situations and settings in their lives up to now. Culture plays an important role as well. Migration as a key element of today's societies has a deep effect on care.

Another remarkable feature of these Austrian guidelines is the high number of persons and organisations included in the process of their development. This is important to create a 'critical mass' for support.

Finally, these guidelines were approved by the board of „Hospice and Palliative Care in Austrian Nursing Homes“. This board is chaired by HOSPICE AUSTRIA and consists of the umbrella organisation of Austrian Nursing homes, the Austrian Doctors' Association, the Ministry of Health, the Ministry of Work and Social Issues, the association of nurse managers, the coordination office of the federal states, the Austrian association of General Practitioners, and the Institute of Health.

Implementation of the guidelines for hospice and palliative care is completed in 12 model homes and in 14 nursing homes the implementation is still going on.

The guidelines underlie also the national certificate of quality with additional auditing of Palliative Care (NQZ+). Nursing homes can apply to go through the certification process. The guidelines may be downloaded in German and English at www.hospiz.at .

Evaluation of implementation

A quantitative and qualitative evaluation was made in the first 12 model homes (2005/2006 and 2006/2007). The quantitative evaluation was a questionnaire with 26 questions to be answered by the director of the home and the nursing director, 20 questions to be answered by the palliative team and 4 (open) questions to be answered in a joint effort by the palliative care representative, director of the home and nursing director. The response rate was 100%. The qualitative evaluation comprised three workshops with the palliative care team and the palliative care representative of the respective homes.

The 8 model homes in Lower Austria currently in the roll out are being evaluated by the NPO Institute (Competence Centre for Non-profit Organisations allocated at the Vienna University of Economics and Business Administration). The evaluation focuses on the outcome of the project, what needs to change with regards to ensure its sustainability and reflects on the project design. Results are due by the end of 2012.

Results of completed implementations indicate that all groups involved in the process are more satisfied: residents, close ones and families, all carers and the management of the nursing home.

A successful implementation requires a combination of organisational development and ongoing training. Organisational development comprises everyone in the nursing home, all carers (inpatient and outpatient) and the management.

The training methods of the curriculum make it easy to meet the diverse needs of people with different educational backgrounds and encourage and request the learners' activity. The training evolves around an imaginary female resident (80% of the residents in nursing homes are women!), who has been created by the participants, and her last period of life, starting with her admittance to the home until her death. Around this character all relevant topics are covered.

The participants' experiences, their knowledge, values and attitudes are part of the learning process. Another learning principle is acknowledging the participants as experts in their daily environment. They are encouraged to contribute their perception, observations, ideas, opinions and experiences. 80% of all staff - from the kitchen to the management— and the outpatient carers like GP's, spiritual carers, therapists take part in it.

A successful integration improves the daily communication both internal and outbound, creates the carers' awareness, confidence and courage, strengthens the multidisciplinary team, supports in dealing with difficult ethical issues and improves the quality of life of the residents and their families and loved ones.

A condition to achieve the objectives, i.e. contributing to quality of life of patients and their families through quality of palliative care, is the availability and presence of sufficiently qualified staff.

Conclusions

Based on the experiences in Austria we may formulate the following conclusions. It is important to develop guidelines to improve quality of care. These guidelines may improve the 'culture' in nursing homes.

An implementation of such guidelines needs a systematic approach by explaining the background of the guidelines, by combining the training of staff and managers with an organisational development and by certification through a national authority. The results indicate that the implementation of such guidelines makes a difference! A living culture of hospice and palliative care in nursing homes enhances the quality of life for all.

Death needs not to be hidden, dying can occur in dignity. It is the task of all societies not only to add years to life but also to care for the quality of these years.

Conflict of interest: This project was made possible due to a generous funding by Fund for Healthy Austria (FGÖ).

Received: 7 February 2011

Accepted: 23 May 2011

Acknowledgements:

{We thank Anna H. Pissarek for translating our paper from German into English.}

Palliative care in the public health department of Primorsko-Goranska county, Croatia: a descriptive analysis

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Abstract

The legal framework for organising palliative care in the Republic of Croatia is established in 2003. However, palliative care is till yet not included in the system of compulsory health insurance, neither does a national health policy for palliative care exist. Nevertheless, in some regions palliative care is developing.

This paper presents the results of the first and the half year of the project on Palliative of the Public Health department of Primorsko Goranska County. The care is given by two teams and delivered in the patients' home.

The data show that care is especially directed at older people, mostly diagnosed with cancer. Patients enroll in the service rather late in the disease process (terminal phase).

We conclude that the need for palliative care at home is large for two reasons: patients prefer to be taken care for at home and alternative services are lacking. This situation is comparable with other Central-Eastern countries

Key words: home teams, enrollment of patients

Introduction

The Republic of Croatia, a country expecting to enter the European Union soon, has given great attention to Recommendation REC (2003) 24 Committee on Ministers of the Council of Europe to member states on the organisation of palliative care, adopted by the Committee of Ministers on 12th November 2003.

The legal framework for organising palliative care in the Republic of Croatia is established in July 2003, when the new Health Care Law became legitimate. In this document, palliative care was listed as one of the health care measures (Article 8) and included in the primary level of health care (Article 25) and in the activities of public health departments (Article 69). At present, almost eight years after the law became legitimate, palliative care has still not been included in the system of compulsory health insurance, no standards or guidelines have been established, and most importantly, there is no national health policy for palliative care. Palliative care is however highly needed in Croatia because of the high cancer mortality which keeps increasing, especially among old people (see Table 1).

Table 1 - Dead caused by cancer in Primorsko-Goranska county (PGC)

<i>Year</i>	<i>Number of deaths by cancer in PGC</i>	<i>Per 100.000 citizens</i>	<i>Number of cancer deaths >65 year old</i>
2004	4897	1603	2365
2005	4697	1537	2384
2006	4739	1551	2425
2007	5321	1742	2803

Although a national policy is failing, in some regions palliative care is developing and growing. We present the results of the first and the half year of the project on Palliative of the Public Health department of Primorsko Goranska County. The Project includes two teams, which provide palliative care at patients home. There is no hospice available in the region, in which over 250000 citizens live. Each team has a physician, a nurse and a administrator to provide palliative care at patients home, in cooperation with physiotherapist, psychologist and other professionals, depending from the needs of the patient.

Methods

The Centre of palliative care in Primorsko-Goranska county is the first, one and only example of development and implementation of palliative care in Croatian Health care system. Therefore, no national registration system exists yet. We administrate basic data, which present an overview of the type of patients enrolling in the palliative care at home service. Frequencies of patients data are presented.

Results

In the first 18 month 312 patients enrolled in the palliative care at home service, 137 women and 175 men. The majority (69%) of the patients were older than 65 years (see Table 2). Only one patient younger than 20 years enrolled in the service.

Table 2- Age distribution of enrolled patients in 18 months, in absolute numbers

<i>Age</i>	<i>Number</i>
< 20 years	1
20-40 years	6
41-65 years	89
>65 years	216
Total	312

Over three quarter (78%) of the patients was diagnosed with cancer. For men the most frequent cancer diagnoses were lung, colorectal, prostate and gastric; for women breast, ovarium, colorectal and lung. Half of the patients stayed 4 weeks or less in the service (see Table 3). More than one quarter stayed over 3 months in service.

Discussion

Palliative care at home is a relative new service in Croatia. The need for palliative care at home is large for two reasons: patients prefer to be taken care for at home and alternative services (like hospices) are lacking. This situation is comparable with other Central-Eastern countries (1). Our service is comparable with the palliative care at home service as was studied in Romania. Also in that study the majority was over 65 years and diagnosed as

cancer patients. Lung cancer, colorectal cancer and breast cancer were the most frequent diagnoses.

Table 3 - Duration (in weeks) patients were in palliative care at home service, in percentages

<i>Time in palliative care at home service</i>	<i>%</i>
< 1 week	30
1-4 weeks	22
4-12 weeks	21
12-24 weeks	12
>24 weeks	15
Total	100

In our study almost one third (30%) of the patients was under palliative care at home service for a very short period of time (< 7 days), which is a much higher percentage than the study in Romania (it was 13%). This may indicate that patients are enrolling in the palliative care service to late, i.e. when patients are in the process of dying. Many patients will have suffered unnecessarily before they enrolled. There is a need to educate, inform and promote palliative care in the general population as well as through health care practitioners.

The basics of the new trends in the hospice movement are reflected in three principles: the approach to the issue, patients' rights, and medical ethics as indispensable parts of care for the ill. Many examples in Europe and worldwide have proved that the organized system of palliative care and the implementation of hospice services in the health care system of a country contributes a lot to improve a human care for terminally ill patients (2). The basics of this human care include primarily treating the pain and other symptoms of the terminal stages of the illness, relieving families from the burden of providing exhausting care, and, also in reducing the financial costs for the therapy of such patients.

Unfortunately, the application of the values of these trends in the Croatian health system is limited due to some important methodological deficiencies, including the non-existence of standards (directives) and protocols for the work of interdisciplinary palliative care teams or hospice palliative care teams in hospices, and the lack of relevant studies on control groups that would reveal reliable data regarding palliative medicine/care. The Croatian health care system needs to develop an observatory at the national and regional level in order to collect, process and widen relevant information about the development of quality palliative care (3).

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Conflicts of interest: none

Received: 11 March 2011

Accepted: 20 May 2011

NEW PUBLICATIONS

Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients

Hudson P, Remedios C, Zordan R, Thomas K, Clifton D, Crewdson M, Hall C, Trauer T, Bolleter A, Clarke D
Centre for Palliative Care, St Vincent's Hospital Melbourne: Melbourne, Australia 2010.
ISBN: 978-1-875271-39-9

This publication of 2010 is important for all professionals and volunteers involved in palliative care. Support for family caregivers is a core function of palliative care. Although most family caregivers will adequately respond to and cope with the care for their beloved one, not all family caregivers will do so. They may experience poor psychological, social, financial, spiritual and physical well-being and some will also suffer from prolonged grief.

So far, there exists a shortage of evidence-based strategies to guide health professionals to provide optimal support for the (family) caregivers when providing care and after the patient's death.

The Australian team of the Centre for Palliative Care of St Vincent's Hospital developed Clinical Practice Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. Of course such guidelines have to be developed multidisciplinary.

The guidelines were developed in four stages: 1. Systematic review of the relevant literature. 2. Focus groups and structured interviews with key stakeholders. 3. National and international expert opinion to further develop and refine the guidelines using a Delphi survey technique. 4. Endorsement of the guidelines.

Fourteen principles were formulated resulting in 20 guidelines. The guidelines are clearly formulated and logically ordered. Communication with patients and family, respecting the needs of patients and their central caregiver and recognizing symptoms and anticipating on (potential) problems are the central issues.

The authors express the hope that these guidelines may also prove valuable for the international palliative care community and for generalist health care providers who may occasionally care for palliative care patients. Indeed, they are. Therefore, it is a significant gesture, that a copy of the complete version of the guidelines may be downloaded.

Please go to: www.centreforpallcare.org

NEWS

The 12th Congress of the European Association for Palliative Care (EAPC) was held in Lisbon, Portugal, from 18–21 May 2011.

The number of participants is increasing each time. That does not apply to participants of Central and Eastern European countries. In Lisbon the total number of these countries was 222. In Vienna 2009 the number of participants was 238 and in Budapest 2007 329. The largest number among Central Eastern European participants in 2011 came from Poland (55), followed by participants from Czech Republic (42). Romania was third with 28 participants, followed by Albania (12), Hungary (11) and Slovakia (11). The next EAPC will be held in Prague 30 May – 2 June 2013. Hopefully more participants of Central Eastern Europe may be able to attend.

The good news is: the book of abstracts may be downloaded on the EAPC website: <http://eapc-2011.org/uploads/File/EAPC-Abstracts-Book-2011.pdf> . This is a worthwhile service of EAPC for those who were unable to attend, but would like to be informed about the most recent developments.