

Palliative Care in a Long-term Care Setting: a 25-year French Experience

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INTRODUCTION

All demographic forecasts indicate that the number of elderly is going to increase. In 2020, there will be six million (of 75.2 million) people over 85 years of age in France, and 21,000 over the age of 100 years (1). Today in France (2), almost 81% of deaths involve patients over 65 years, 59% over 75 years, and 35% of patients over 85 years. Even if dying at home is considered preferable, 70% of patients 75 years or older now die in a hospital, clinic, nursing home, or long-term care environment (3). Approximately 10% to 20% of all French elderly persons will spend time in a long-term care facility before they die, and many who require palliative care will be there during the final weeks and months of their lives. Although research on the influence of palliative care on the families and caregivers of dying elderly has indicated that their health and well-being benefited greatly from these services, there are still too few doctors specialized in this domain, even though the age of death is constantly rising in developed countries. As in Canada (4), palliative care for the elderly still remains neglected in the French healthcare system. The goal of this paper is to present our 25-year experience in developing a program and a culture of palliative care in a geriatric setting. We think this example could help other medical teams who work with elderly patients.

PALLIATIVE CARE IN FRANCE

From 1977 to 1985, there were no specific recommendations for palliative care in our country. Due to a movement in France for euthanasia (essentially by the Association for the Right to Die with Dignity), in August 1986, a document from the minister recommended that tertiary palliative care units be created to train health professionals in palliative methods and to encourage them to spread the knowledge throughout the healthcare

system. The first unit opened in Paris in 1987. At present, there are 291 mobile palliative care teams in France, 91 palliative care units, and about 10 units for specific gerontological palliative care. The French Society of Palliative Care (Société Française d'Accompagnement et de Soins Palliatifs, SFAP) was created in 1989, at the same time the first physicians were trained in palliative care (diplômes universitaires de soins palliatifs). At present there are 27 possible degrees in palliative care in France. The Medical Board required nurses to take an introduction to palliative care as of 1993, and third-year medical students as of 1995. The Law of June 1999 guarantees access to palliative care to everyone. In December 2002, a National Guide to Palliative Care in adults was published in France (www.anaes.fr).

Our Geriatric Department

The University Hospital of Paul Brousse, Villejuif, France, is a 800-bed tertiary-care hospital with about 500 geriatric beds in three departments. Our geriatrics department includes 131 beds in four units, including one specializing in Alzheimer's disease and other types of dementia, one for acute care and rehabilitation, and two for long-term care. Our activities have gradually diversified. In 1977, our department had 200 long-term and nursing home beds, today there are 66 long-term care beds, 50 rehabilitation care beds, nine acute care beds, six gerontological tertiary palliative care beds, an outpatient department, and an Alzheimer's outpatient centre. The palliative care beds are part of a long-term care unit. This is a good solution for providing education on palliative care in the long-term care setting as a part of a continuum of care (5).

Elderly Patients, End-of-Life Care, and Geriatric Institutions

In 1977, death was not discussed in French hospitals and professionals tended to avoid patients once they knew there was no hope. At the same

time, doctors sensed that an ethical attitude should include being present with the patients, listening to their physical, as well as their psychological, social, and spiritual needs, and providing medical care that did not pointlessly extend life by medical means, or even euthanasia, deliberately ending life. During this period, there was no structure and no reference in France to palliative care and the end of life.

In this report, end-of-life care refers to an active, compassionate approach that treats, comforts, and supports older adults who live with, or are dying from progressive or chronic life threatening conditions. Our sources are indisputably Anglo-Saxon, mainly the works of Elisabeth Kübler-Ross (6) and Dame Cicely Saunders (7). However, their ideas have been adapted because their work concerned relatively young cancer patients, while we are dealing with much older patients at the end of their lives who do not necessarily have cancer. There is evidence that many dying seniors have physical and psychosocial needs that are different from those of people who die at a younger age. The elderly have a heightened awareness of the imminence of death and are more concerned with the quality than with the quantity of life. Elderly patients are more likely to die from multiple chronic diseases and disabilities, including cardiovascular disease, cancer, respiratory disease, and dementia disorders. In France, as in other countries, approximately 60% of those who reside in long-term care settings have dementia illnesses. The trajectory of their illness is likely to be slower and less predictable.

Based on our experience and the literature, we gradually identified the clinical, relational and therapeutic specificities of palliative care in the frail elderly (8-17):

- palliative practices must be extended to cover diseases other than cancer, in particular, dementia, neurological diseases, and the multiple pathologies of old age;
- pain and its assessment are particular in the elderly;
- the psychorelational climate is often modified by age and there are common communication problems;
- the social and family context is different (11);
- therapeutics—notably opioids—must be adapted to the pharmacokinetic and pharmacodynamic modifications related to age (12,13).

In 1985, we set out our objectives (10):

1. avoid moving or isolating the terminal patient;
2. treat physical suffering with analgesics, particularly morphine, every time it occurs;

3. feed and hydrate the patient as naturally as possible; avoid any useless tubes;
4. comfort the patient with nursing (eyes, mouth, skin...);
5. favour the presence of family as much as possible, day and night;
6. communicate with the elderly patient as long as possible, including non-verbal communication (handholding...).

In 2001, we published a new version of these recommendations based on a simple mnemonic acrostic (F.I.N.D.E.V.I.E.) (18), similar to that used by Paul Rousseau for American residents (19).

Identifying the dying elderly patient, however, is not easy. When is end-of-life care appropriate? To assist medical strategy and decision making, we developed a questionnaire which could be discussed during multidisciplinary staff meetings (Table 1) (20). It was clear, as shown in a recent study (21), that the initial step in successful palliative and end-of-life care to patients in long-term care is to determine when active treatment is no longer useful.

Palliative Care Organization in our Department

Initially, our project was not to group all dying elderly patients into a specific area, but to provide the dying patient with suitable care in the room and bed where he or she already was, and had sometimes been for a very long time. The aim was to completely integrate the clinical practice of accompanying the dying with palliative care in the department.

Finally, in 1995, six tertiary gerontological palliative care beds were opened. These beds were divided as follows: four were placed together in one long-term care unit, they are open to the public and admit only elderly patients over 75 years of age, most, but not all, with cancer. Two "flying" beds in other units in the department are for patients who are already in the hospital, whose illness has progressed, and who

Table 1 / QUESTIONNAIRE TO ASSIST DECISION OF PALLIATIVE CARE FOR AN ELDERLY PATIENT (1991)

1. What is the main diagnosis of the patient?
2. What is the course of the disease?
3. Is there any acute disease?
4. Is the acute disease curable?
5. Have there been any recent and/or repeated acute events, or association of multiple diseases?
6. What does the patient say (if he/she is able)?
7. What does the patient express though her/his attitude and cooperation to treatment?
8. Is the patient comfortable?
9. What does the patient's family think?
10. What does the nursing staff think?

now require palliative care. This palliative activity has had a positive effect throughout the institution, by increasing awareness and in the treatment of pain, on the reflection about the ethics of care, the respect of patients, and openness towards families and volunteers (20).

Between 1977 and 1995, before we had palliative care beds, the monthly average number of deaths was five out of a population of 200 elderly patients (1,080 deaths in 18 years). From 1996 to 2002, after the creation of palliative care beds, there were 661 deaths with a mean of nine deaths per month. During this period, 339 patients (51%) were specifically hospitalized in palliative care beds. Nevertheless, except for sudden deaths, all dying patients receive the same quality of care in our department.

We also play an important role in teaching and research. In the department there are four residents every six months who train in geriatrics and palliative care. We regularly receive medical and nursing students for one or two weeks. We contribute to medical information on palliative care in the elderly through our French publications.

We developed a scale of behavioural pain assessment, known as DOLOPLUS (www.doloplus.com), with a group of French geriatricians—a very useful tool for use with elderly patients who can no longer communicate (22).

In 1996, with the same group, including seven geriatric hospitals, we studied the characteristics of 337 patients who had died over a 12-month period (data not published). The mean age of the patients was 86 years, 72% were women. Two hundred and forty-seven patients (73%) received palliative care for a mean of 85 days. The mean hospital stay before palliative care was 20 months. The principal medical diagnoses were: terminal cancer (26%), advanced dementia (26%), multiple pathologies (14%), advanced Parkinson's disease or stroke (12.5%), terminal organ failure (10.5%), and miscellaneous (11%).

Psychoanalysis

When working in a geriatric unit, questions are numerous. What can be done when faced with very old patients who are dying? Keep treating them at all costs? Deny their approaching death and experience, and continue treatments that are pointless, disproportionate, and aggressive? Leave them to finish their lives alone and in pain, or hasten the arrival of death deliberately?

As early as 1977, we began to develop a method of working as an interdisciplinary team—physicians, nurses, physiologists, social workers, psychologists—by organizing regular meetings,

including the caregivers from each unit, based on a psychiatric model. This method still exists today and the meetings are a tool for communicating, sharing information, consultation, and interdisciplinary coordination. They are the cornerstone and structure our work in maintaining clear objectives and a group culture, despite the difficulties of staff shortages, the high turnover rate, stress, and team discouragement.

In 1979, we agreed to have a psychoanalyst come on a regular basis to allow us to talk about our difficulty in dealing with the death of our patients (23) in a discussion and reflection group. This allows caregivers to identify what they do and to understand why they do it, on a monthly basis in the presence of a psychiatrist or psychoanalyst. This discussion and reflection group played a truly innovative and founding role, and it is still going on 25 years later.

Psychoanalysts have indisputably allowed caregivers to speak more freely and integrate new caretaking behaviours into institutional practice. They have gradually trained caregivers to listen and think, and to develop a culture of care, taking in their relations with patients and their families, in the systematic approach to the patient and his/her close relations, and in their management of the triangular relationship between patients, families, and caregivers in the department. In an attempt to work with the patient-family as a single unit (12), we arrange meetings with staff and families to better understand, as the natural process of dying, the symbolic, ambivalent language of dying patients, and the family's suffering and aggressiveness before and after the death. Indeed, allowing and recognizing the events and psychoaffective phenomena (24,25) that influence the moment of death, including the final exchanges between the patient and his or her family, is the best way of allowing a patient to die in his or her own time, without succumbing to the temptation of euthanasia.

The active participation of psychoanalysts in palliative care is not unique in France. Two other cancer teams have had similar experiences during the same period, but it is still one of the originalities of the French palliative care movement.

Ritualization

It is impossible to invest emotional energy in patients and to accompany them on their last journey without paying a certain emotional price when they pass on. There is the mourning to be lived through with the family, other elderly people, and everyone who knew and accompanied the patient. There is a ritual that these survivors must perform in the institution:

- a few words are said to evoke the passing on of the person, whose name is repeated, in the team meeting;
- caregivers often go to the funeral and accompany the family in their mourning;
- other elderly people can also come along for a final farewell, if they wish;
- the bed of the deceased is left empty for several days before receiving a new patient.

A ritual of mourning is necessary to be able to live through successive deaths and to be able to invest in other patients afterwards.

This ritualization is performed to "tame" death and to channel the anxiety of a group that must face repeated death. This was confirmed by the French anthropologist Louis-Vincent Thomas in his book *Rites de mort* (Death Rites) (26), in 1985. In it, the author classifies the accompaniment of the dying and palliative care as amongst the oblation rituals marked with solicitude and consideration towards those who are going to die. "The eradication of pain and discomfort is not an end in itself," he writes. "It only makes it possible to set up collectively experienced acts that can be considered to be the modern version of a death ritual." It is clear that the increase in institutionalization at the end of life has led to its medicalization. While palliative care and accompaniment represent the best and most ethical form of this medicalization, they also provide a process of social ritualization that is necessary for the dying patient and for those who survive, including family, caregivers, and volunteers (27). This ethical and anthropological necessity is the basis of all our experience, and it is undoubtedly the best argument to defend the clinical practice of palliative care.

LESSONS LEARNED

From our Geriatric Department

At present, palliative care and the accompaniment of the dying have become widespread and, in some ways, "routine", in the good sense of the word (28). Although circumstances are not ideal, because of a chronic lack of funds, we have been able to humanize the conditions of the end of our patient's lives, as well as for their families and caregivers. As a result, requests for euthanasia from patients and their families, and its practice are rare. When such requests do occur, we are able to listen to and to interpret them as a need for help. As for requests from caregivers, they have, quite simply, disappeared.

We intend to continue our cooperative research with the group of French geriatricians open to palliative care, and one of our team (RSL) works on different ministerial commis-

sions on palliative care and elderly care. In the future, we would like to create a mobile team for the other two gerontology departments, and for the geriatric oncology unit that is being planned in our hospital, as well as for the nursing homes in our area.

More Generally

Within the current and future demographic context, geriatric palliative care is becoming a public health priority. Today, every geriatric hospital or medicosocial institution must integrate the palliative dimension of care in order to provide appropriate, *in situ* care of patients, whatever their end-of-life disease.

Is it necessary to increase the number of palliative care units or beds? In our opinion, it is possible to offer quality primary palliative care (28) without necessarily having specialized beds. Nevertheless, five conditions are essential:

1. The institution must have a real desire to implement the project.
2. The working method must include communication and interdisciplinary cooperation.
3. The team must have received specific training in palliative care.
4. End-of-life care of elderly patients requires as much time as that of younger patients, as we have already proven with a group of French geriatricians (29).
5. The caregivers must have psychological support and meaningful work, whether for religious, philosophical, psychoanalytical, or anthropological reasons.

These conditions are still far from being fulfilled in France, despite the early involvement of numerous geriatricians in these matters. But in our opinion, this is the only way to allow the largest possible number of elderly men and women to have a peaceful and comfortable end of life.

However, specialized units are indispensable to take care of more difficult patients, to teach palliative care, and to do research. At present, there are still not enough in France.

Geriatric medicine and palliative care are global medicines that are a perpetual challenge, requiring continual reassessment of their clinical, educational, and research dimensions to provide the best care of older persons.

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