

XIV General Assembly...

« Close by the incurable sick person and the dying:

Scientific and Ethical aspects”

Accompanying the dying person: a responsibility to share

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Many papers or announcements about palliative care say that death is a normal part of life and that a dying patient is still a living person and a member of the human community. This is meaningful and we will come back to it later. But, at first, it leads us to remember those times when assisting to the death of somebody was a common familial and social experience. Dying was not a medical event. Then, the presence of neighbours and friends around the bed of the dying decreased when, in the occidental countries, death occurred more and more often inside hospitals and when the rural society with its traditions was progressively replaced by the urban society who had no longer any traditional behaviour toward dying persons and their families. This led to an experience of loneliness that many patients and their next of kin reported, an experience which was increased by the strangeness and high tech environment of the hospital and thus, by a feeling of becoming an object instead of a human subject. Hospices and Palliative Care were created somewhat in reaction to this modern process. This is probably why pioneers in Palliative Care have developed home care simultaneously with Hospice care. In some countries, due to the high cost of hospital terminal care, home care is seen as a priority. For instance, in the USA “the most prevalent hospices are home-based programs¹.”

¹ Anonymous :Hospice Care, (accessed dec.5, 2007 at <http://www.alsnetwork.com/hospice-care.htm>)

Hospice care was launched in the United Kingdom by Dame Cicely Saunders when she opened St. Christopher's Hospice in London in 1967. She was the first to associate professional carers and volunteers in the common project of Palliative Care. She has told the story of the beginnings of Palliative Care on many occasions and she always referred to David Tasma, a patient she met in 1947 when she was a medical social worker. She regarded him as *"the true founder of St. Christopher's Hospice"*.² As this man, a Jewish patient rescued from the Warsaw ghetto, had lost faith, she spontaneously tried to share her personal Christian faith with him. Let us cite Dame Cicely Saunders about this patient: *"Discussions about a setting that could have helped him find not only symptom relief but also time and space to make his own terms with an apparently unfulfilled and meaningless life, led not only to an initial inspiration but also to his own quiet place. Two key phrases from those long conversations were founding insights for the hospice movement. When he said of a small legacy "I'll be a window in your home", he gave a commitment to openness. Seen first as openness to end from the world, it grew later to a challenge to be open not only to patients and families but also among ourselves. In another, more personal exchange, he said: "I only want what is in your mind and in your heart". Again, later thought led to a commitment to all that could be brought together of continually developing skill, understanding and research together with a readiness for personal concern. When he died, having made a quiet and personal peace with the God of his forefather, he left me with the assurance that he had found his answers and that all our caring must give total freedom to others to make their own way into meaning"*.

In France, and in continental Europe as well, modern medicine was so respected and supported in the opinion that it took some time before patients began to share their experience of loneliness and to be listened to. Only in the 70'ies in my country, some authors began to plead in favour of a respect of the dying persons and of their death as a personal

² SAUNDERS C., *Some challenges that face us*, Palliat. Med. 1993, 7(suppl.):77-83

and natural process³. The word, “to accompany” in relation with palliative care was employed in the late 70’s, first by a priest, father P.Deschamps⁴, then in the vocabulary of nurses at a time when Palliative Care were still unknown. The term meant both to relieve pain and suffering and to stop aggressive therapies. It meant to accept the death of a patient as a natural process and to take into account his/her own desires as the priorities of care. It meant to listen to the words of the dying person as an expression of his/her subjectivity. Thus, “accompaniment” of a dying patient, - as we say in French, - is a common aim and responsibility of professional carers, which is shared with families and volunteers. It is the simplest way to respect the four principles of autonomy, beneficence, non maleficence and justice toward the dying and their families. Before discussing the ethical aspects of this shared responsibility, we need to look at what “to accompany” means 1) for professional carers on the one hand and 2) for volunteers on the other.

1 – Accompaniment as the aim of palliative professional care:

It is not necessary again to recall the basic ideas and principles of Dame Cicely Saunders, the founder of Palliative Care. Total pain will be described in another part of this meeting and the consequences in terms of total care as well. Nevertheless, not all terminal patients are admitted in Palliative Care units or settings and a majority, even in developed countries, still die in non specialized hospital wards or in nursing homes. In France and in other European countries, pain relief and other symptom treatment have been in progress even though they still need to improve. But the relational component of “accompaniment”, mainly emotional support and listening of patients and families, remains, as far as I know, a part of professional responsibility that is felt optional and, too often, left to the good will of professional carers,

³ VIANSSON-PONTE P. ET SCHWARTZENBERG L. - *Changer la Mort*, Paris, Albin Michel, 1977

⁴ DESCHAMPS P., *La mort à l'hôpital, Projet*, 1975, n°98, 924-933

according to their own skills and feelings⁵. Even though humane relationships with patients are the professional ideal of many nurses and doctors, this aim is often unconsciously repressed for many reasons among which they usually quote the lack of time and the prevalence of technique as an imposed priority of care. Less often they acknowledge that taking time to listen to a patient or having with him/her a more personal relation is not always approved by other team members. Last, some carers would find “accompaniment” as an intrusion in the intimacy of the patients, mainly if spiritual needs are concerned. Yet, patients do expect such a personal relationship with their carers, including the doctors. It took me some time to understand what some of my patients meant when they told that they wanted their doctor to be “humane” with them. I finally understood that they did not expect compassion or any favour in the way they were treated ; nor did they mean to be correctly informed and associated to the process of decision making ; they meant that in some way the doctor would admit and share with them that s/he is a human being like them. What does that practically mean in the daily practice of care? It means to be able to recognize patient’s emotions and to legitimate them. Thus it means to learn how to listen to, and, last, to respect the entire subjectivity of the dying person.

Listening is more than answering properly or to enable somebody to give an informed consent. Listening consists in an alert and careful analysis of feelings and emotions that are expressed through the words and attitudes of a person; then in making clear that s/he has been understood and that all s/he has told is legitimate. Listening consists in encouraging such a person to go on in the expression of her/his feelings and even of her/his spiritual query. Too often indeed do the doctors or nurses interrupt a patient before the end of his/her sentence, just because they guess what will be said and think they have already the good answer! A point which is not always understood by professional carers is that a patient may need to be listened to by any one of them if s/he feels it is the right person at this moment.

⁵ FLETCHER W.S., “*Doctor, Am I terminal?*” Am.J.Surg., 1992, 163 : 460-462

So, any one in a team, - including doctors, - may be the right person to give a time of listening and emotional support to a patient. The only useful tool at that moment is a chair. Indeed, to take a chair and to sit beside a patient means that the caregiver will take the time and that s/he is ready to listen not as a technician but as a fellow human being, even though the patient will never forget the professional status of the listener.

2 – Volunteers: an organized accompaniment.

At the origin of the Hospice Movement, volunteers may have been recruited because palliative care needed to be as less expensive as possible and because some tasks were common daily tasks that everybody is able to achieve: making and helping tea or other drinks, manning the telephone, cooking meals, transportation of patients or relatives by car from or back to their homes...etc. Still now, in many hospices, in the USA or in the UK, volunteer roles comprise such tasks, including to provide respite to the family of a patient, light housekeeping, making errands, helping for eating or drinking,...etc. Many years ago, I asked Dr. Therese Vanier, from St. Christopher's Hospice, what precisely the role of volunteers was; she answered me in French: "Volunteers are here to give time to the professionals of the Hospice for the "accompaniment" they are trained for." Obviously, things have evolved since that time and, in many hospices, the role of volunteers⁶, as it appears in the literature, is in a wider range, including listening, providing emotional support to patients and families and bereavement support^{7,8}. In continental Europe, particularly in France, volunteers are not involved in hands on care or in material tasks and remain assigned to relational support of patients and families. Indeed, in these countries, for many reasons,

⁶ We will not discuss here about volunteers who are involved in "non patient areas" or in areas affected to the running of charities which support Hospice or Palliative Care units.

⁷ Anonymous, *Help your Hospice, volunteers' stories*, (Accessed December 8, 2007 at : http://www.hospicevolunteering.info/volunteers_stories.asp)

⁸ Palliative.org, Regional Palliative Care Program in Edmonton Alberta, *Information of the general public, Volunteer education and recruitment* . (Accessed December 8, 2007 at : <http://www.palliative.org/PC/GeneralPublic/EduRecruitment/VolEduRecldx.html>)

including legal ones, volunteers would not be allowed to participate in professional tasks nor in common home tasks.

The difference between a volunteer palliative care accompaniment and the spontaneous accompaniment which anybody is able to give to a friend or to a neighbour relies in its organization. This means that volunteers are members of a team and accept the modalities of their recruitment, selection, training, and support ; they agree with its discipline and ethical principles. Most hospice Internet sites mention that being a volunteer means to be the member of a team which includes the patient and family, professional carers, doctors and chaplaincy. *“...Volunteers are important members of an interdisciplinary team working to “de-institutionalize” the dying experience and provide a more humane system of care for the dying and their families.”*⁹

Volunteer training depends of the hospice they apply to and the task they will be assigned. In a majority of hospices, volunteers receive a theoretical training that lasts an average of 20 hours (range: 12-34) in USA and in Canada. As far as I know, the theoretical training is shorter in the UK. In many countries, selection and training of volunteers is the responsibility of a “volunteer service manager”, usually a salaried member of the professional care team¹⁰.

In the French movement JALMALV¹¹, we usually propose to new volunteers a one year theoretical training composed of four week-end sessions and of a participation in the regular meetings of their local association; the aim of such a delay is to enable each new candidate to go deeply in his/her project and to discover his/her own difficulties to listen to somebody ; in a sense, we train people as counsellors rather than spontaneous volunteers. Training is

⁹ HOSPICE FOUNDATION OF AMERICA – *Be a Hospice Volunteer*, (Accessed December 7, 2007 at :<http://www.Hospicefoundation.org/hospiceInfo/volunteer.asp>)

¹⁰ DOYLE D. – *Volunteers in hospice and palliative care : a handbook for volunteer service manager*. Oxford University Press, 2002

¹¹ JALMALV, is the acronym of « Jusqu'à la mort accompagner la vie » (“Until death, to accompany life “). Federation JALMAV is a national movement composed of circa 80 local associations. (For more information look at : <http://www.jalmalv.org>).

preceded and followed by an interview with a psychologist in order to deter kindly people who are not qualified for accompaniment. Then, trained volunteers who persist in their project are admitted in one team, under the leadership of a coordinator, a volunteer by her/himself, who will organize their agenda. Our volunteers do not participate in hands on care and restrict themselves to listening and to emotional support of patients and families. Except in a few palliative care centres, volunteers do not commonly participate in the meetings of the professional carers. Once a month or every six weeks, they have to attend a support meeting under the supervision of a psychologist. Once a year, they have a personal interview as to evaluate their situation. What is important and specific in France about volunteer accompaniment of dying patients is its organization in the framework of an association which is accountable toward the institution. It warrants the quality of volunteers toward the professional carers and families; it watches over the respect of patients and of carers and over the well being of the volunteers as to spare them the experience of burn out. In France, the framework of such an organization is the purpose of a law¹². Written conventions are to be signed between hospitals and associations. Unfortunately, until now, a difficulty that has been met by our associations is to share regular and opened relations with professional carers and their teams.

A national survey conducted in 2003 showed that in France 5000 people belonging to more than 200 associations were active accompanying volunteers. As told before, they do not intervene mainly in palliative care units but more widely in oncology wards, internal medicine, geriatrics institutions or nursing homes, and at home. The assessed number of volunteers in the UK is 100 000, including those who are not involved in the care of the patients¹³. In the USA “more than 400,000 active volunteers represent the faces of caring in communities across the

¹² LOI 99-477 09/06/1999 « *Visant à garantir le droit à l'accès aux soins palliatifs.* » Journal Officiel de la République Française n° 132 du 10 juin 1999 page 8487

¹³ Help the Hospices : a common Internet site for the national organization « Help the hospices » and St. Christopher's Hospice. (Accessed December 5, 2007 at http://www.hospicevolunteering.info/why_volunteer.asp)

nation providing support to an estimated 1.2 million patients – and their families – in more than 4,100 hospice programs annually”¹⁴. Obvious discrepancies between those numbers reflect not only differences between the extent of palliative care institutions in those different countries but also the fact that, in the USA and in the UK palliative care relies more upon volunteers than in continental Europe where volunteer activity is generally restricted to emotional support and listening.

3 – A shared responsibility: ethical aspects of accompaniment of the dying

Accompaniment, as defined previously, aims at the well being of a dying person and his/her family as well as the fulfilment of the professional project of carers. Thus beneficence and autonomy are central principles in palliative care and this under many aspects. As told briefly before, the principle of autonomy needs to be defined more widely than in the common situations of care and, as far as terminal care is concerned I should propose instead to refer to the principle of “subjectivity”. Autonomy views a person as an individual and at a given time, - mainly when a decision must be made¹⁵, - whereas subjectivity takes into account a wider aspect of his/her personal life. Subjectivity in that context means that the patient or any member of the next of kin is considered as a unique subject including his/her personal history, his/her conscious and unconscious psychological life, his/her personal philosophical or religious beliefs, his/her familial and social links and traditions. In the same way, D.Roy and Ch-H.Rapin, use the term “Humanity principle”¹⁶. Nevertheless many authors would agree that all these items are included in the principle of autonomy so it will not be my purpose to discuss it further. I will focus now on ethical issues that are involved in this part of palliative

¹⁴ NHPCO, *National Volunteer Week, Sample Letter to the Editor, April 15 - 21, 2007* (Accessed December 6, 2007 at : <http://www.nhpc.org/files/public/communications/volunteer-letter-editor.doc>)

¹⁵ GILLON R. *Medical ethics: four principles plus attention to scope* - BMJ. 1994 ;309(6948):184-188

¹⁶ ROY D., RAPIN CH.-H. - *A propos de l'euthanasie* - Eur.J.Pall.Care, 1994, 1, 57-59.

care that we call “accompaniment” in French and which is referred to in English by the terms of emotional support and listening. But again I must say that emotional support and listening are tightly linked with body care and cannot be separated from them.

- 1) To share with the dying person.

To come in the bedroom or into the home of a patient and his/her family means to enter a private and intimate domain. Even though the intent is to benefit the person, such an intrusion needs to be accepted and to remain respectful of privacy, intimacy, and modesty. This may be easier to respect in principle than in the daily practice, for instance when we become more intimate with a patient we have already visited regularly for some time. As far as relational accompaniment is concerned, the respect of privacy and intimacy means to knock at the door, to present oneself and to ask the permission to enter and to sit. It means to come out the bedroom if a doctor or a nurse comes in. It means that priority would be given to members of the family at the time they come. It also means that any tactless question or remark would be avoided. As D.Doyle writes: “*volunteers should never enquire about private matters that are not relevant of the patient’s care and that the patient does not wish to discuss*”¹⁷

What about “telling the truth”? The underlying ethical question is how to respect the subjectivity of the patient without telling her/him what s/he does not need or want to know. Although it is widely accepted now in western countries that, for sound ethical reasons, a patient should be informed when s/he is in a terminal state, some authors admit that the desire of a patient of being not told must be respected. For instance, in the CHPCA (Canada) “model to guide patient and family care”¹⁸ confidentiality is understood as the right of a

¹⁷ DOYLE D. – *Volunteers in hospice and palliative care : a handbook for volunteer service manager*. Oxford University Press, 2002

¹⁸ Canadian Hospice Palliative Care Association, *CHPCA Model to guide patient and family care*, March 2002.(Accessed December 5, 2007 at : <http://64.85.16.230/sdh/educat/content/resources/chpcanorms.html>)

patient to receive only the information s/he wants to receive. So professional carers and volunteers have the duty to inform each other what a patient has asked to be told about his/her disease and status, then to restrict what they may tell the patient when caring for her/him. The conviction that it would be better for a patient to know about her/his prognosis does not allow a carer or a volunteer to give any information that s/he has not asked to receive. In some cultures¹⁹, like, for instance among migrants from North Africa in France, disclosing the truth about an impending death would not be accepted by the family and usually is not asked for by the patient who is culturally ready to be entirely supported by her/his family. Indeed, letting the patient to know, - in a timely manner - that death is coming in a near future is accepted as an ethical duty in occidental countries. I find it more respectful of the patient's subjectivity to let him/her speak freely about his/her death, without being contradicted²⁰. Indeed, patients at the end of their lives do speak spontaneously of their death but they do it discreetly, through allusions, so that the listener may or may not take advantage of the hint. For instance, a patient will speak of his/her life as a thing of the past. If the listening person is able at that time to grab the allusion and to show s/he understands, then the patient will tell about his/her fears and expectations about his/her impending death. My experience is that patients who speak spontaneously of their death with their doctor are able to be extremely realistic about it but that in all cases their ability to hope is preserved.

Listening as defined before is the cornerstone of accompaniment because none of us may assume what a patient needs to share at the moment we meet together. As we know, listening is not a common social attitude and we more commonly use to cut short a conversation which makes us uncomfortable. So we must learn how to listen to a suffering person and get trained in that field. Listening means also that confidentiality will be

¹⁹ BRUERA E., NEUMANN CM, MAZZOCATTO C, STIEFEL F ANS SALA R., *Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients*, Palliative Medicine, 2000 : 14 : 287-298

²⁰ SCHAEERER R. - *Parler de sa mort avec un malade*, - in : Humanisme médical - Pour la pérennité d'une médecine à visage humain, ed by Michel Mignon et Claude Sureau - Paris, John Libbey Eurotext, 2003 : 171-177.

warranted. The patient, or family members, must be certain that secrets that they will share will be kept confidential by the listening person. What is difficult is that listeners often need afterwards to share with someone else matters that they feel unbearable. Of course, in a given team, such a sharing is possible only within the limits of what will be useful to the care of the patient; with greater reasons, would any sharing of confidences outside the team be unacceptable on an ethical basis.

As quoted before from C. Saunders, accompaniment consists in “*openness*” toward patients at the end of their lives. Active listening helps patients to find the right words to express their feelings. It gives them the possibility to share freely their most intimate feelings, emotions, fears, desires and hopes without being judged or contradicted. Sometimes listening makes it possible to share a secret that has never been told. So accompaniment breaks down the feeling of loneliness and legitimates the expression of things that may be difficult to share with family members. It takes into account and contributes to the relief of the psychological component of “total pain”²¹. Beyond this sharing of emotional distress, accompaniment offers a witness to the free expression of the spiritual query of patients. To tell it with Cicely Saunders’s own words : “*all our caring must give total freedom to others to make their own way into meaning*”²². Some authors use to speak about “spiritual needs” or “spiritual pain”. I would prefer the terms of “spiritual query” or “spiritual work” to describe the mental process by which all along our life we try to affirm our values and our identity and to find the meaning of our life. Each of us has a spiritual life, whether is it expressed inside a religious tradition or in a secular way. Experience shows that facing death renders this spiritual work somewhat urgent, but not necessarily painful and that a listening person is required so that the dying person might hand on a unique message which represents the outstanding achievement of

²¹ SAUNDERS C., and BAINES M, Living with Dying: A Guide to Palliative Care, Oxford Medical Publications, 1983, 64 p.

²² SAUNDERS C., Some challenges that face us, Ibid.p.79

all his/her life. So, pastoral and spiritual care are not to be confused as it occurs sometimes in the literature. In secular institutions, spiritual needs are to be taken into account by professional carers and by volunteers. When they are expressed in the language of a religious tradition which is not shared by the carer or the volunteer, the patient should be offered to be introduced with a member of a pastoral care team or of the convenient religious community. Yet, in that case, it should be wrong to think that the previous accompaniment by carers or volunteers comes to an end: the patient may need to go on his/her spiritual query with the same witness s/he has undertaken.

A last question must be raised about sharing with a patient. Even though this is an uncommon situation it deserves to be mentioned. Some volunteers may be the witnesses or the confidants of malpractice from family or professional carers. When this occurs in France, volunteers wonder how to behave, particularly when patients do not want them to denounce what they share with them in this field. D.Doyle suggests that *“volunteers should be aware of the channels of communication and the possibility of approaching top management if they have an issue that they believe should be dealt with at that level”*¹⁰

2) To share inside the volunteer team:

Listening to the suffering of somebody is demanding. That's why it is so necessary to professional carers and to volunteers to have the possibility to attend regularly a support group. In such meetings, volunteers discover that they may experience similar feelings, emotions or fears than others in the same team. When the supervisor of the group names those feelings by a common term, then they appear legitimate and become more bearable. In French, we call those groups *“Groupes de parole”*²³. They are supervised by a professional, usually a psychologist. Again, what is shared in these groups remains strictly confidential.

²³ RUSZNIEWSKI M. – *Le groupe de parole à l'Hôpital* – Paris, Dunod éditeur, 1999. 176 p.

As told before, confidentiality is a duty even inside a team which supports the same patients. In France, volunteers often have a note book through which they communicate about patients of families. This note book is left at the disposal of professional carers on the ward and is appreciated as a way of ameliorate their knowledge about patients. What is to be shared in this note book is a question that was raised in some volunteer teams²⁴. Indeed, confidences that patients would not have accepted to be shared might appear in that note book so some volunteers decided to avoid reporting any personal confidence inside; in some other teams, volunteers decided to reserve the note book for their mutual information. This exemplifies how confidentiality may appear difficult to respect in practice.

Sometimes in a volunteer team it appears that a member of the team is involved in a deeper relationship with a patient or family member. We call this a “privileged relation”. Provided this relation remains within the frame work of emotional support, we think it can be recognized and accepted by the team, at the condition the volunteer who is involved would accept to tell about it in the team and to accept any further decision of the coordinator. This example raises the wider ethical issue of the “relational boundaries” (D. Doyle)²⁵ of volunteers toward patients and professional carers. Limits that are to be respected are to be set during training and selection process.

Volunteers as team members have reciprocal duties. They respect the discipline of their agenda and attend their team meetings with regularity. It must be stressed also that volunteers have a personal spiritual life which needs to be nourished, supported and encouraged. In countries like France where secularity is the common rule, volunteers insist on their duty to respect the religious faith or the atheism of their colleagues. But “to share” means more than keeping silent on those topics. It means to make all the members of a team

²⁴ AUDHUY B. et al., “*Ecrits et confidentialité dans l’accompagnement*” – Revue JALMALV, n°75, décembre 2003,

²⁵ DOYLE D. – *Volunteers in hospice and palliative care : a handbook for volunteer service manager*. Oxford University Press, 2002

free to express their convictions or questions without being judged or blamed or despised and to be helped to find their own responses. This openness to the spiritual life of each member of a team, whatever the convictions it relies on, is a key in accompaniment.

3) To share with the family members:

Beside and around a dying person, a natural accompaniment is provided by family members and next of kin when they exist and when familial links have not been disrupted. Their role in supporting their beloved one is to be fostered. Sometimes, they need to acquaint themselves to care for their patient and to receive a kind of training. Their common history must be taken into account without any judgment or appreciation. Their traditional behaviour with a dying must be respected. Practically this means that they will be met *“only in settings where privacy can be ensured”*²⁶ and that information will be given to them *“in a language and manner understandable and acceptable”*. When associated to a decision making, family members will need to be assisted not only to select the best priorities but also to express their anxiety and guilt if any at that time.

A frequently met problem is the existence of a discrepancy between the feelings or wishes of family members. This leads to the need of individual opportunities to be supported mainly when sharing is no longer possible inside the family group. Volunteers are in the front line in these circumstances. Again, listening is the right attitude to accompany those people and to help them to share unbearable things they cannot share inside their family.

Last, as this has been developed from the origin of the Hospice movement, bereavement support is a part of palliative care. Yet, social grieving habits have completely changed in less than one century in Europe and bereaved people often experience loneliness. Family members may need to be accompanied in their grief by trained volunteers or counsellors.

²⁶ Canadian Hospice Palliative Care Association, *CHPCA Model to guide patient and family care, March 2002.* (Accessed December 8, 2007 at : <http://www.chpca.net>)

Listening has the same importance in bereavement support than in the accompaniment of terminal patients: grieving persons need to recall freely, over and over again, their beloved one and the circumstances of his/her death; they need to express feelings that they cannot share with people around them as sadness, fears, guilt or irrational beliefs. Accompaniment may be offered individually or in groups. But it must be said to professional carers and to volunteers that grieving families often need to meet also with those people who have cared for their beloved one and who can tell about his/her last moments or last words, or who can state that the very end was not painful.

4) To share inside the Palliative Care team:

A majority of Hospices in England, USA, Canada, Australia or New Zealand define the volunteers as fully members of the palliative care team. As members of the team they are associated to the care of patients and participate in regular meetings of the professional carers. This is far less common in my country where Palliative Care centres or units are seldom and where a majority of terminal patients are cared for in active specialized wards or in nursing homes. Volunteers who get involved in those institutions usually do not participate in the meetings of the care teams. This makes tough any sharing of information and it is no longer honest to tell about team approach in palliative care. But how can a palliative care project be accomplished without an organized collaboration between professional carers – including doctors, - and volunteers? Such an organization needs a common plan and regular meetings where all the aspects of the patients care are addressed and in which all the carers get involved. Volunteers should be invited at these meetings or at least represented by their coordinator. The aim is not to participate in diagnoses or treatment discussions but to share about the patients' needs, desires, expectations, emotions, feelings and spiritual query.

But, on the other hand, when volunteers are tightly associated to the care team, another risk may arise. It has been underlined in France by R.W.Higgins²⁷. According to this author, the risk would be, if we arrange everything for terminal patients so they can die peacefully in specialized structures, cared for by specialized carers and volunteers, that dying people might become “*a new category of citizens: the dying*”, assigned precisely to “*articulate death*”, to put it in words, “*to personify the absolute otherness*”, thus sparing society “*the confrontation with the enigma of death*”. Higgins and others stress that the experience of human death is vital for the society to construct itself and maintain solidarity between all its members. So we would suggest that volunteers keep in their mind that they are a link between the care setting and the society.

5) To share with the society

Indeed, a common tendency to modern societies is to deny death and to exclude people at the end of their lives. So, it appears as a moral duty to share, with the societies we live in, our experiences with persons at the end of their lives. It does not mean at all that confidentiality will not be respected. It means that as well as volunteers represent the society beside its dying members, in the same way they witness that death does exist. They will also be witnesses of the frailty of mankind and that nevertheless, even at the end of their lives, a man - or a woman - remain living persons. Indeed, an ultimate aim of volunteering in palliative care is to stimulate a new behaviour among the society toward people at the end of their lives and toward their families so that they would no longer suffer loneliness and exclusion.

²⁷ HIGGINS R.W - *L'invention du mourant. Violence de la mort pacifiée*. Revue ESPRIT, 2003, January, 139-169