

Application of palliative care in demented patients: the caregivers' point of view

Sabina Zapponi¹, Aline Ferreira², Paolo Galvagni³, Camilla Roccatagliata⁴, Simone Rodolfi⁵, Miriana Spina⁶, Chiara Foà⁷, Leopoldo Sarli⁷, Giovanna Artioli⁸

¹University Teaching Hospital, Parma, Italy; ²Dementia Unit, Nursing Home Villa Minozzo Reggio Emilia, Italy; ³Hospice San Giuseppe Gorlago, Bergamo, Italy; ⁴Hospice Maria Chighine, San Martino Hospital, Genova, Italy; ⁵Nursing Home Villa Paola, Castelnovo ne Monti Reggio Emilia, Italy; ⁶Orthopedics, Franciacorta Chiari Hospital Garrison, Brescia, Italy; ⁷Department of Medicine and Surgery, University of Parma, Parma, Italy; ⁸Azienda USL - IRCCS, Reggio Emilia, Italy

Abstract. *Background:* The 38/2010 law has widened the supply of palliative care for patients with chronic and degenerative illness. Dementia is a chronic and debilitating illness and it requires specific, complex and constant assistance, involving the health professionals' community and family, and should also benefit from palliative care. But what do the caregivers of these patients think about it? *Aim:* To explore the point of view of caregivers accompanying dementia patients regarding palliative care and the accompaniment of the medical team. *Method:* A qualitative method with phenomenological approach: 29 semi-structured interviews have been submitted to caregivers of patients suffering from dementia. The interviews were submitted to analysis of thematic content. *Result:* In the majority of cases the caregiver is a member of the family and holds this position because of the affective relationship he/she shares with the patient. They too live the illness of the relative as if it were theirs. The caregiver doesn't know about palliative care or has only heard of it, but is resistant to the application of this care, especially when its correct meaning and use are explained. At the same time, the health professionals' role is important when it comes to taking decisions: caregivers rely completely on the team's competence and on their judgement. *Conclusion:* A correct sharing of knowledge is fundamental. The healthcare professionals must be trained in palliative care in order to correctly inform caregivers and to avoid false beliefs about or resistance to the application of these useful pathways.

Key words: caregiver, palliative care, dementia, health care professional, interview

1. Background

The first important definition of palliative care, given by the World Health Organization (WHO), highlights the patient's central position, the observation of the multifaceted nature of the human condition and the identification of the quality of life as a final goal. Palliative care indeed promotes a complex and holistic approach, identifying and satisfying the complexity of the patients and of their physical, psychological, socio-relational and spiritual needs. Palliative care was created precisely to provide global assistance

to patients affected by a disease that does not respond to specific treatment. WHO (1) defines this condition as terminal, a non-reversible state, even with the use of therapies, and which is characterized by a gradual decline of autonomy, by the manifestation of physical and psychological symptoms, which involve both family and social relationships. In this stage of the illness, the medical team suspends all recovery attempts, restricts the therapies to taking care of the symptoms and soothing the patient's suffering, through the remodulation of helpful ongoing interventions (2), by new objectives of cure and care (3). The introduction of

the 38/2010 law also clearly defines the basic elements that establish palliative care in Italian background, and also settle this care to people who are affected by chronic and degenerative disease (4, 5). Chronic conditions require long-term management and the presence of a morbid state without the possibility of a resolution (6). Although some chronic illness conditions cause only minor problems, others may cause serious symptoms and limitations of activities. The management of such conditions can be difficult for the patients, since it must include the learning of abilities that allow the coexistence with symptoms and disabilities, and facing up to identity problems that may result from the very own chronic condition (4). In various types of chronic diseases, the symptomatology is similar to that of oncological diseases; the only aspect that diversifies them is the prognosis. The chronic patient can coexist for years with his or her illness which passes through different phases and is characterized by episodes of flare. The trajectory is not always predictable, but it often ends in a gradual or fast decline, which leads to death (7).

Epidemiological data are also alarming. By 2050, a demographic and epidemiologic transition is expected that will bring an 8-fold increase in the number of people older than 80 years old, and a 20% increase in the incidence of chronic conditions (4). It follows that, according to WHO, the necessity of palliative care services will continue to grow because of the increase of chronic diseases and the world's ageing population (8). An analysis of the epidemiological data also highlights how dementia can be considered one of the most interesting diseases, both because of the many people with disabilities who are affected by it, and because of its significant social health impact (9).

Thus, among the different chronic diseases that represent an important public health problem – threatening both the patient's and their family's quality of life – dementia is not only increasing worldwide, but it has been described by the WHO as a global public health priority related to the alarming data associated with it. As with the majority of chronic and debilitating diseases, the patient with dementia requires specific, constant and complex care, which involves not only the medical and social health community, but also and above all the family (10). When a person is

affected by a chronic and debilitating disease, one of the main consequences is the loss of ability to conduct everyday activities. As the disease gradually progresses, the patient becomes increasingly less autonomous and begins to depend on the caregiver's help in every activity. The caregiver is a helpful figure whose numbers are growing in Western countries. The caregiver is becoming more common mainly due to the increase in the elderly population, the lengthening of life expectancy, and because of the decrease in mortality due to the improvement in the preventive diagnostics and to the quality of care provided (11). Besides their helpful role, the caregiver must face the gradual deterioration of their relationship and communication with the patient with dementia. There are two main factors standing in the way: the decay of the cognitive function and the relentless progression of the disease (12). The therapeutic team should therefore “support the supporters” throughout the progression of the disease.

2. Aim of the work

The aim of the work is to investigate the point of view of caregivers of dementia patients receiving palliative care, in order to assess whether a common path shared with health personnel – from the early stages of the treatment process – may be a predisposing factor to the introduction of new therapeutic approaches.

3. Method

Qualitative research methods are increasingly important in the development of nursing knowledge and improving the quality of care. Qualitative research responds appropriately to the need to describe, explore and explain increasingly complex phenomena, with an approach centred on the subject and not on the variables (13, 14). Specifically, this study made use of a phenomenological approach to research. The goal of the phenomenological approach applied to qualitative research is purely descriptive and is limited to outlining the experiences of participants as they have been lived. The goal is not to create theories or models of the phenomenon under consideration but to try to dis-

cover the subjective and personal meanings that participants give to their experienced (15, 16).

3.1. Participants

The participants are recruited according to the following criteria: to be a caregiver caregiver of patients with senile dementia and assisted in hospital; a willingness and approval to participate in the research. They have been selected by samples of convenience; 29 caregivers of patients with dementia joined the study (of which 26 were women). They were staying in two facilities: Nursing Home Villa Paola of Castelnovo Ne Monti, a province of Reggio Emilia (15 participants, all women), and Hospice Vaglietti – Corsini Onlus of Cologno Al Serio (a province of Bergamo). Participants are aged between 51 and 70 years old.

3.2. Instrument

The data are collected through a semi-structured interview built ad hoc. The interview is characterized by flexible questions in which the interviewee and the interviewer have freedom of movement, while maintaining the rigour that allows the latter to address all the necessary topics to the research objectives (17, 18). Some guiding questions are expressed aimed at exploring three macro-areas: a. The caregiver and their history (interview question example: *What changes have occurred in your life since you've been taking care of him/her?*); b. The application of palliative care (interview question example: *How do you evaluate the possibility of applying palliative care to your relative?*); c. The collaboration with the health-care professionals (interview question example: *How much do you feel included in the decision-making by the medical staff?*). The interviews are conducted between October and December 2017, in a private room. They last from 30 to 50 minutes.

3.3. Data analysis

The texts of the interviews have all been entirely transcribed, conferring to every participant a name¹. The transcripts are exposed to the analysis of the thematic subject, according to some well-defined transi-

tions (19): a) detection of the issues emerging from the transcripts, in which the members of the research group reach agreement on the definition of the salient contents that emerge from the caregivers' narratives; b) passage from the final themes to a report capable of underlining the meanings connected to the participants' experiences. The analysis and the connections between the meanings that emerged lead to a reconstruction of a representative sense of the experiences of each interlocutor and at the same time allow us to outline recurring modalities of attribution of meaning to the experiences that accompany them.

4. Results

From the analysis of the interviews, a series of macro-areas emerge that correspond to the issues investigated with the interview grid. Each macro-area is composed of subareas that highlight the prevalent contents (meanings) specified by the participants (Table 1).

4.1. The caregivers and their history

4.1.1. Because I am the caregiver

Thirty-nine participants describing the reason that leads them to be the main reference of care, speak of the **deep bond** that unites them to their relative: they describe being in the 'front line' in terms of affection, need for closeness and sense of responsibility towards those you love.

C2D: *my father is very close to me and consequently if he does not see me every day he goes into total panic.*

C4D: *It's me and my brother who has always been in charge of the care [...] I've always lived with her.*

Similarly, an equal number of participants argue that the reason that leads them to be the reference person is logistical / organizational (**family organization**): for example, because they live nearby, because

¹The operators are identified with the initial C corresponding to 'Caregiver' followed by a progressive number and gender (D=woman; U=man).

Table 1.

Macro area	Subarea	Meanings
1. The caregivers and their history	a. Because I am the caregiver	- Deep Bond - Family Organization - Gratitude - Gender
	b. Time dedicated to the relative	- Long Time - Average Time - Short Time
	c. Patient problems	- Cognitive Problems - Physical Problems - Emotional Problems
	d. Caregivers' problems	- Activities of daily living - Acceptance - Hard Work - Lack of Assistance - Inexperience
2. Application of palliative care	e. Expectations of the disease	- Cognitive and physical decline - Caregivers cannot imagine - Inevitable death
	f. Therapeutic Obstinacy	- No therapeutic obstinacy - Therapeutic obstinacy
	g. Knowledge of palliative care	- No information - Partial Idea - Good Information
	h. Receivers of palliative care	- End of life/Oncology - Everyone - No able to define
	i. Application of palliative care in the care project	- Favour - Chosen by the medical team - Not Agree
	j. Resistance to change	- No Resistance - Moral Doubt
3. Collaboration with health-care professionals	k. Relationship with the health-care professionals	- Good relationship - Fluctuating Relationship - Difficult Relationship
	l. Inclusion in the decisional trial	- Fully Included - Enough Included - Little Included
	m. Sanitary team as accompaniment to palliative care	- Delegation of Decision - Specific Explanations - Psychological Support

they are the only child, or because they were the only one to offer availability.

C19D: *Because I am the one who lives at home with her.*

C13D: *My brothers work, but I have stopped working and I have the possibility of staying at home.*

Sixteen caregivers describe the need to give back to their parents what they have received before, with a view to mutual exchange and **gratitude** towards parents, retracing the generational life cycle.

C17U: *Parents are definitely older, so we decided to help them and assist them in order to give them a bet-*

ter quality of life. After all they did for us it seemed more natural.

C3D: *She was alone; she kept my son when she was younger. Now I have a big house and I made an extra room for her with her bathroom and I took her into my house.*

Four caregivers claim that they are in charge of the elderly because they are women (**gender**). This evokes a gender bias, which sees the idea that women have a greater predisposition and responsibility toward care activities.

C16D: *It's because he had a female daughter in my opinion.*

C29D: *The other, my brother, as a man has other things to do.*

4.1.2. Time dedicated to the relative

Twelve participants despite having their relatives in a health facility tend to spend most of their time in caring (**long time**).

C19D: *Look at me, apart from my work, I dedicate all the time to her.*

C18U: *All the time I can steal from my work.*

Nine caregivers tend to give constant but not continuous assistance, trying to stay with their relative several times during the week, even if not every day (**average time**).

C10D: *I come one day yes and one day no, [...] Let's say three days a week I come to visit my mother.*

C21D: *I come four times a week, usually I stop two hours -two and a half hours.*

Six caregivers report not providing continuous and present assistance, mainly due to time and distance problems from the place of hospitalization (**short time**).

C17U: *I'm away all week and so weekends have always been available to my parents. One day is dedicated to me visiting them*

C23D: *Eh, not so much, I come once a week.*

4.1.3. Patient problems

In the eyes of 22 of the caregivers, describing the

pathology of their relatives, **cognitive problems** appear primarily.

C17U: *He could not drive as much; he began to always repeat the same things, to show us at home the same things, which were his clothes, his paintings.*

C6D: *There were moments when my mother did not recognize my father. She called me and told me there is a man here at home and I do not know him, come, send him away, not only during the day, even at night.*

Three caregivers see the pathology of their relative as a **physical problem**, suggesting the progressive decay of the organism as peculiar to the pathological condition of the patient.

C8U: *Something that is incurable, that goes down the person who has it.*

C12D: *He started to walk less and less, to have more and more difficulties, he wanted to go on and on but he did not understand where and making him understand that he could not get up on his own again was very difficult.*

Finally, four caregivers define the problems related to the **psychological / emotional sphere** as characteristics of the pathology of their relatives, drawing attention to aspects such as depression, aggression and emotional crises.

C23D: *She suffered a lot and was in crisis; it is not that she has a strong character*

C8D: *...was very angry, there were scenes after scenes, until the bomb exploded and it went crazy and she even hit me that day.*

4.1.4 Caregivers' problems

Fifteen caregivers say that the main difficulties in the home concern the daily management (**activities of daily living**), activities of daily life such as dressing, eating, washing

C7D: *It took four women, but she did not want to know. Whoever washed it, who put it in place, put it at home, who put it in the tub.*

C17U: *Dad went from morning at nine up to six o'clock during the days of the week to a day centre and in the evening the caregiver came to prepare him for bed and everything.*

Ten caregivers report that the main difficulty in the home management of their relative concerns the emotional plan of **acceptance** of the situation and of the suffering observed.

C15D: *I see the unhappiness of my father, who never understood the situation.*

C21D: *I always thought about my mother even though there was this lady at home. More than once I asked the work to be able to get away from work so I lived badly and I saw that my mother always regressed.*

Eight caregivers say instead that the role they play has a heavy impact (**hard work**), changing lifestyle and habits.

C25U: *So many things change [...] now that I have to devote myself to him for half a day [...] I always lose three hours, three hours and a half. So I've had to give up so many things.*

C11D: *A lot, the hours that take you away are many and also it engages you morally in the sense that if you decide to go on vacation for even 2 days you have to know that there has to be someone to replace you. The last 2 years was much too hard, not being able to have even a free weekend.*

Six caregivers state that the main difficulty of home-based management was the presence of a higher welfare burden than the resources possessed (**lack of assistance**).

C23D: *I had put a woman close, but when I came home from work she always called me constantly for some trivial things and I was always under pressure.*

C5D: *They could not do too much; there were so many tips, I learned many things, but the service on Saturday and Sunday of the medical team was not there.*

Four participants state that they deal with a reality of which they knew nothing, with which they had never dealt with, making it necessary in a short time to understand everything. The problem referred to is therefore **inexperience**, finding themselves managing an unknown pathology with new tools.

C17U: *It was very difficult because I was not prepared.*

C16D: *I saw a reality different from the one I knew I have never looked after a person.*

4.2. Application of palliative care

4.2.1 Expectations of the disease

Caregivers view the course of their relative's illness according to three different aspects.

The **cognitive and physical decline** is considered the main reason for twelve caregivers for the relative's deterioration: the lack of memory, the inability to recognize relatives and friends, loss of appetite and difficulty in walking are the main symptoms described.

C1D: *He cannot move anymore, he does not understand, he does not know who he is, he does not know anyone. The only thing that can happen to him on a physical level will be when he will not eat again. I can hardly see a single person anymore. Honestly, I am of the idea that if he does not eat, he will meet his fate.*

C4D: *As they have told me it will only get worse. I don't know how it will end, it scares me. Looking at these five years, the more we go on, the more we will decline. She has no great expectations and the disease goes on, until the brain will no longer function and those stimuli like opening the mouth and swallowing – even those will disappear.*

Nine **caregivers cannot imagine** the course of the disease, some because they are not aware of what kind of worsening can lead to dementia, others do not want to think about it because the thought of losing their relative causes too much suffering

C23D: *here we have never discussed in depth my mother's illness, we were in denial, we see that sometimes she will have those moments where she does not remember your name, does not know who you are but we have not gone beyond that.*

C17U: *Little, to tell you the truth, a little. I do not know. Dad is very old. Those are things that are hard work, but I was a bit scared. And I do not know, I do not know how it might be, I've never imagined it.*

Other participants speak of **inevitable death**, but with the hope that this will happen without suffering for their relatives

C3D: *I only hope that you fall asleep and do not wake up anymore, I don't want her to suffer. None of us can know when it's time, I accept what it is, the important thing is that she does not suffer.*

C21D: *I hope that if something happens, because more than that I do not think it gets worse. The only variation can be death; I hope it happens in your sleep.*

4.2.2 Therapeutic obstinacy

Twenty-six participants consider that the ideal would be an accompaniment to the end of life **without therapeutic obstinacy**, paying attention to the quality of life itself to the detriment of its duration.

C5D: *No, quality of life. I do not conceive the obstinacy, I think when it comes to the situation that there is nothing more to do, in my opinion is a torture, I see it that way. If one day I was in the same situation and if I had the reason to understand these things, I would pray that those around me did not make me undergo remedies.*

C28D: *I think that the obstinacy is violent. The obstinacy is for the family to get away from guilt and to stand the non-processing, I think the obstinacy is really an insult to the dignity and stories of people.*

Only two respondents say they were in favour (**therapeutic obstinacy**), exposing their difficulty in accepting the disease and death itself.

C16D: *If she lived 100 years I am happy because she is a cheerful, sunny person. I see her smiling a lot; she cries a little now, in fact I would miss her if she were not there anymore.*

C18U: *I would say for myself to stretch as much as possible because I want to die before my wife. I told my children that if she dies I die.*

4.2.3 Knowledge of palliative care

Eleven caregivers have declared that they have no knowledge of palliative care or have only heard of it, but are not informed or have not understood what they are actually dealing with (**no information**).

C20D: *Palliative care –I have heard about it, but I have not understood what it is.*

C10D: *Yes, I've heard about it, but I do not have a specific idea of what it is. I know what they say, but not that much. I have never studied the subject.*

Eleven caregivers show a **partial idea** on the topic, giving correct, but unclear and incomplete definitions.

Most of them think that palliative care deals only with removing physical pain, while others define it as an accompaniment to death without knowing how this happens.

C15D: *Yes, I know very little about it. I know it is used in the case of strong pain. For me one should suffer as little as possible during the course of a disease.*

C8D: *Honestly, I've heard about it, but I'm not very informed. I do not know if I'm wrong, I do not know if it's those treatments that make you feel better but do not cure the disease.*

Seven instead show to have **good information** on palliative care, using clearer and more precise explanations, with terms such as 'quality of life' and statements on the psycho-physical aspect

C4D: *Yes, I've heard about it, these new treatments are welcome. If they are a help to those who suffer, that you take away a bit of suffering, well good. It always improves giving a little dignity to these people, removing the suffering and not only the physical suffering.*

4.2.4 Receivers of palliative care

Relating to the patients receiving palliative care, twelve caregivers answered that it is dedicated to the **end of life and to oncologic** patients, confirming the classic vision of their application

C25U: *Palliative care to terminal patients, to patients who fight against suffering everyday and patients who have no hope; according to me it's a slow walking towards death in a dignified condition. Without making people suffer.*

C9D: *I believe in people who are cancer patients, I've quickly read a couple of things on the Internet.*

On the contrary, twelve other caregivers think they are meant for all the patients (**everyone**) because they are treatments necessary for pain control: whoever has physical pain should be eligible for palliative care. Every suffering patient should have it, especially where traditional treatments have no more effectiveness, regardless of age and illness.

C28D: *So palliative care was, till some time ago, the care for the end of life. Recently, thanks to God, the field has grown and it has become, they wanted like to become, they should become the cure of chronicity.*

C8D: *I think it is applied in the case of suffering. When a person hurts, no matter how old he or she is or which illness they have, it's fair not to make them suffer, it's a nonsense.*

Only four caregivers are **not able to define** the type of patients eligible for palliative care, because of the limited knowledge about them.

C10D: *No, sincerely I don't about this; I'm not able to answer you.*

4.2.5 Application of palliative care in the care project

The majority of the interviewees (fifteen) are in **favour** of introducing a palliative care approach to the assistance in order to reduce both physical suffering and emotional one.

C4D: *If I were sure that my mother had no pain I would be the happiest person of the world. In fact, I only ask that she isn't suffering, that she is brought to the end peacefully.*

C28D: *I hope my mother will have only palliative cures. I don't want any other treatments, I don't want her to go to hospital, and I want her end to be simple and natural.*

Five caregivers claim they agree with the application of palliative care but only if it's **chosen by the medical team**, with the assumption of responsibility, and if they don't feel at ease with the importance of this choice and its outcomes.

C27D: *So, it's hard for me to answer, but I would ask the experts in palliative care. I trust them; that is, if it is a person who is specialized in this field, I may expect that they provide me information about what I can do; I think people who have studied are able to help me to manage this situation.*

C8D: *I don't know when ... I wouldn't know when the moment comes. I think health-care professionals should decide when and how. They can see and understand better than me what she needs, when they think it's necessary.*

A great part of the caregivers, ten, declare that they do **not agree** with the application of palliative care for their relative, matching to this choice the hope

that the patient could live as long as possible as possible

C16D: *I don't know them but I want her to live as long as possible because she is a smiling happy person. If she lived 100 years, I would be happy.*

C18U: *But I don't believe in palliative care, I've never believed in it.*

4.2.6 Resistance to change

Twelve among the interviewees declare not to have any particular resistance to possible palliative approach; as a matter of fact, they wished this could be an active part of the supporting project (**no resistance**).

C4D: *For my mother I would also like to see it offered at this time. I don't want my mother's life to be extended.*

C21D: *Maybe, when you think about morphine. We thought about morphine as something hard, dangerous, and even in my ignorance, that it reduced life. Actually it only helps and so anything which can ward off pain is welcome.*

Two caregivers show, on the contrary, some decision-making uncertainties (**moral doubts**) because they don't know their dears will; but they also show a positive opinion towards palliative care; they underline the fact that, as they don't know the patient's thoughts, they have a moral duty.

C22D: *I could make a mistake, would I make a good decision in using palliative care? Is it good for a patient or not? I do a right thing for him or he wants to live despite everything. It's a moral matter.*

C15D: *The only thing which could stop me is not knowing what my mother wanted for herself. As far as I know she was against euthanasia. But if you told me my mother is suffering then I wouldn't think twice about it, beyond her will. When you arrive at the end of your life, as my mother who is 85 years, it's a nonsense to suffer. By now the bow of life is accomplished, it's not an option to make her live one more year with pain.*

4.3. Collaboration with health-care professionals

4.3.1 Relationship with the health-care professionals

Twenty-four caregivers declare that they have a

good relationship with the medical staff; particularly in respect to their presence, their availability and the possibility to have an open dialogue with them.

C21D: *Very good, always available. I am also perhaps, sometimes, I am always afraid of the sense of guilt and I always resort to you to be reassured and to know that what you are doing for my mother is the correct thing and also necessary.*

C13D: *I rate it as excellent, yes excellent. If I need to ask anything or they need to ask me something, I ask and I get an immediate answer to everything, both from the physicians and the nurses, from the volunteers and everyone .*

Four interviewees have talked of the relationship with the health professionals as a **fluctuating relationship**, which depends on the present operator in the context, and how much each builds a different collaboration.

C8D: *It's very subjective from person to person, in the sense that you don't succeed in having a collaboration with everyone. I find if I ask, however if I am not me to do before and to hardly ask they come me to say as the person you/he/she is going or if there are some problems.*

A **difficult relationship** has finally been rendered explicit by one single caregiver, because of the scarce availability of the health professionals to talk about his/her relative.

C19D: *No, I have not had of it, unless has not asked anything.*

4.3.2 Inclusion in the decisional trial

Fifteen relatives have expressed that they had been informed and involved in every change of treatment (**fully included**).

C2D: *In the health structures you/they have always asked me what I thought of things. When they have had to stop some of the therapies that were normally given, they have always asked me for my opinion and they have always told me the reasons for doing what they are doing.*

C28D: *I was able to express my opinion and I was heard. I did not want any therapeutic fury and no fury was done.*

Seven respond that they have not always been involved in the decisional trials or that they have not had

the occasion (or for the past small time in structure or for lack of necessity) (**enough included**) of it

C5D: *At times him, at times no. any decision is picked me up I have the right to know it as daughter*

C13D: *I think that if they decide for a different care they inform me as principal referent, I think really that is their owe to inform me if they change the care. I think of him, to be included in these decisions.*

Finally, in equal measure, six participants say they have little collaboration with the team, specifying a lack of information with respect to changes of therapy and physicians of reference (**little included**).

C1D: *... little, because you only find out things when they have already happened.*

C8D: *... I don't feel very included because of this lack of collaboration and I know it is also probably a fault on my behalf as well. I miss out on these things and I would sincerely prefer to have a more in-depth relationship, to be more involved .*

4.3.3 Sanitary team as accompaniment to palliative care

Six caregivers have commented on the remarkable importance of the health professionals, attributing them with a fundamental role at the decisional (**delegation of the decision**) level in comparison to the application of the caregivers. The caregivers entrust themselves completely in the competences of the physicians and their evaluations.

C8D: *if theirs propose me this thing I trust me of the physician and of the nurses that are here there and if they made me this proposal it wants to say that they have appraised her and I would approve because surely it has been serious.*

C11D: *I am not competent in the matter, I could document myself, but I trust them, and I hope they are always working for the quality of life.*

In an equivalent way, six of those interviewed attribute an essential importance to the level of **specific explanations** given by the team. The caregivers expose the necessity to be well informed before taking a decision.

C4D: *The physician will be important to stuffed to understand the worsening situation of my mother, but then the decision will be up to me and my brother.*

C15D: *Personally I am not able to understand how much my mother can now cope with her suffering, and I would like the team to help me to understand it.*

One caregiver believes that the relationship with the health professionals can guarantee a suitable **psychological support**, in such a delicate moment from a mental and emotional point of view.

C5D: *I already have clear ideas, I know that I won't fight with obstinacy and therefore the health team will serve as a support for me with a moral support, so that I will know I have made the correct choice.*

5. Conclusion

The results show how caregivers, in most cases, belong to the patient's family and play this role on the basis of the emotional bond and the sense of responsibility towards those who require their care. The data also show a strong prejudice for type: the care of relatives seems to belong – again – mainly to the female gender. This is made explicit in the narratives and is also witnessed by the type of participants: men make up 10% of the participants.

In every case, independently from the type, the caregivers appear people with some characteristics of 'fragility', in how much they are forced to change in major ways their style of life (in terms of leisure time, habits, in demand competences) in order to be able to assist their relatives. Difficulties also emerge from the emotional-psychological point of view: social isolation, depression and problems with the actual family nucleus. From the point of view of the health professional it is therefore useful to foresee the lived of these people, who are called to undertake a very complex task, with an emphatic attitude that takes into account both the needs and skills of each. A particularly interesting fact is that the greatest part of the caregivers do not know about palliative care, or they have only heard about it. In addition, those who are more informed, possess in every case confused and superficial knowledge: some exclusively associate palliative care with terminal illness or to the care of physical pain, while others have a broader vision, but based more on an abstract and theoretical level than on a real practical knowledge.

It is, however, worth noting that almost all of those interviewed possesses a positive vision of palliative care, considering it useful and necessary in chronically ill patients, leading to less suffering both on an emotional and physical level. And it emerged that although people knew little about palliative care, when better informed they show an open attitude and they are favourable to its use with their relatives. The emerged data noticed a fundamental role of the provider at a decisional level: caregivers rely completely on the expertise of the medical staff and their assessments. The caregivers also declare that they have a good relationship with the health professionals, to have moments of comparison and feel they have been included in the therapeutic plan.

The practitioners are also identified by the caregiver as ideal to inform on palliative care and also to point out the correct moment for its introduction, with respect to the person. It is therefore fundamental that the providers from the medical point of view, but above all free from their own prejudices and resistances in such circumstances (9), sustaining the self-determination of the person.

Acknowledgement

This research has been conducted as part of the Master "Palliative care and pain therapy for health professions", University of Parma, 2018.

References

1. NHO National Hospice Organization. Standards and Accreditation Committee. Medical Guidelines Task Force 1999.
2. Società Italiana Cure Palliative. Cure Palliative Precoci e Simultanee. Simultanee [Early and Simultaneous Palliative Care]. SICP 2015.
3. Bruera E, Hui D. Palliative care models: international prospective. *J Palliat Med* 2002; 5: 319-327.
4. Smeltzer CS, Bare BG, Hinkle JL, Cheever KH. *Infermieristica medico-chirurgica. chirurgica* [Medical-surgical nursing]. Casa Editrice Ambrosiana, 2010.
5. Digiglio G. *Vade retro del pregiudizio. Piccolo dizionario di salute mentale. mentale* [Vade retro of the injury. Small mental health dictionary]. Armando Editore, 2005.
6. Thoonsen B, Engels Y, Groot M, Verhagen S, Vissers K, Van

- Well C, Van Rijswijk E. Early identification of palliative care patients in general practice: development of RADboud indicators for palliative care needs (RADPAC). *Br J Gen Pract* 2012; 625-631.
7. Corbin JM. The Corbin and Strauss chronic illness trajectory model: an update. *Sch Inq Nurs Pract* 1998; 12(1): 33-41.
 8. WHO. Cancer pain relief and palliative care: report of a WHO expert committee (Technical Report Series 804). Geneva: World Health Organization 1990.
 9. Zapponi S, Ascari MC, Feracaku E, Masin S, Paglia P, Petroccione R, Pinzaru A, Foà C, Artioli G, Sarli L. The palliative care in dementia context: health professionals point of view about advantages and resistances. *Acta BioMed* 2018; 89 (4): 45-55.
 10. Artioli G, Foà C, Cosentino C, Sulla F, Sollami A, Taffurelli C. "Could I return to my life?" Integrated Narrative Nursing Model in Education (INNE). *Acta BioMed* 2018; 89 (4): 5-17.
 11. Moroni L, Sguazzin C, Filipponi L. "Caregiver Need Assessment: uno strumento di analisi dei bisogni del caregiver". *G Ital Med Lav Erg* 2008; 30 (Suppl B): B84-90.
 12. Vigorelli P. "Communicating with patients suffering from dementia: from ineffective communication to happy conversation". *G Gerontol* 2005; 53:483-487.
 13. Artioli G, Foà C, Taffurelli C. An integrated narrative nursing model: towards a new healthcare paradigm. *Acta BioMed* 2016; 87 (4):13-22.
 14. Artioli G, Foà C, Cosentino C, Sollami A, Taffurelli C. Integrated narrative assessment exemplification: a leukaemia case history. *Acta BioMed* 2017; 88 (3):13-21.
 15. Calamandrei C. Le forme di conoscenza infermieristica [The forms of nursing knowledge]. *Nursing Oggi* 2002; 4.
 16. Coggi C, Ricchiardi P. Progettare la ricerca empirica in educazione [Designing empirical research in education]. Carocci Editore, 2005.
 17. Cosentino C, Fama M, Foà C, Bromuri G, Giannini S, Saraceno M, Spagnoletta A, Tenkue M, Trevisi E, Sarli L. Unplanned Extubations in Intensive Care Unit: evidences for risk factors. A literature review. *Acta BioMed* 2017; 88 (5): 55-65.
 18. Bichi R. La conduzione delle interviste nella ricerca sociale [Conduction of interviews in social research]. Carocci, 2007.
 19. Smith JA, Flowers P, Larkin M. *Interpretative Phenomenological Analysis: Theory, Method, Research*. London: Sage, 2009.
-
- Correspondence:
Sabina Zapponi, PHD
University of Parma, Italy
Tel. +39 3470561827
E-mail: sabina.zapponi@unipr.it