The palliative care in dementia context: health professionals point of view about advantages and resistances

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Abstract. Background and aim: The 38/2010 law has expanded the provision of palliative care to patients with chronic-degenerative diseases. The ISTAT data show that 60% of the dying population is suffering from these diseases and could, according to the literature review, benefit particularly from such treatments. This study investigates the point of view of healthcare professionals, working in the context of dementia, regarding the knowledge and application of palliative care in the field of dementia. The focus is on the analysis of the resistance that may prevent the spread of palliative care, slowing the application of such care in different settings of terminality. Methods: The method is a qualitative phenomenological approach. A grid of semi-structured interviews was created and was proposed to 33 health workers (18 women) who work in Health Centres or in the Alzheimer Nucleus of Northern Italy. Results: Most operators think they understand palliative care, they believe it to be useful and necessary, but often only connect it with terminal illness. Others have a broader vision based on a more abstract and theoretical level than on real practical knowledge. A majority of respondents think that the spread of palliative care is slow and difficult because of the prevalence of the biomedical model that holistically and prejudicially hinders the introduction of new models. Conclusion: Appropriate training is the fundamental key to overcoming resistance. The professionals interviewed showed that they were aware of their lack of knowledge and declared that they had little competence in managing the complexity of long-term pathologies.

Key words: palliative care, dementia, chronic diseases, application resistances, health care operators

Background

The first important definition of palliative care was given by the World Health Organization (WHO) in 1990 (1). The most important points of this authoritative document concern the centrality of the patient, the consideration of the multifaceted nature of the human condition and the identification of quality of the life as a final goal (2, 3). It considers the patient as a whole, consisting of an interconnected plurality of dimensions (e.g., biological, physiological, psychological, socio-cultural, spiritual) (4, 5).

Palliative care has been created to provide active and total assistance to patients affected by a disease that no longer responds to specific treatment and whose direct evolution is the end of life. In 1999, the WHO (6) defined this condition as terminality, a state no longer reversible through treatment, characterised...
by a progressive loss of autonomy, and by the manifestation of physical and psychic symptoms that involve the family unit and social relationships. At this stage of the disease, the medical system interrupts all attempts at healing, limiting itself to treating the symptoms and alleviating suffering (7), through a remodelling of the assistance interventions in progress in relation to the new goals of treatment (8).

A big step forward was the introduction of the 38/2010 law that clearly and precisely defines the basic elements that constitute palliative care in our national context and sets out to address such care even for the patient suffering from a chronic illness with an evolutionary trend pathology, thus opening the horizons to a new vision of a person having the right of access to such care. Chronic conditions are defined as medical conditions associated with symptoms or disabilities that require long-term management (9) and the persistence of a morbid state to which the possibility of a resolution is not seen (10). Although some chronic disease conditions only cause minor disadvantages, others can cause important symptoms and limitations of activities (11). The management of these conditions can be difficult for patients, as it must include learning strategies for living with symptoms and disabilities, and addressing identity problems that may result from the same chronic condition (9). In many types of chronic disease the symptomatology is similar to that of cancer diseases; the only aspect that differentiates them is the prognosis. The chronic patient can live for years with their pathology that goes through different phases, characterised by episodes of exacerbation. The trajectory, not always predictable, often ends in a gradual or rapid decline that leads to death (12).

By 2050, there will be a demographic and epidemiological transition that will lead to an 8-fold increase in the number of people aged over 80 and to an incidence of chronic conditions of 20% (9). According to the WHO, the need for palliative care services will continue to increase, due to the increase in chronic diseases and the aging of the population around the world (13). National health systems must therefore include palliative care in the continuum of care, for people with chronic conditions, through prevention strategies, early diagnosis and planned treatments (14).

The analysis of epidemiological data highlights how dementia can be considered to be among the most serious of chronic diseases, due to the numerous disabilities of the people affected, the significant social and health impact, and the growing increase in the world population. Therefore, dementia represents a global public health priority in relation to the alarming data associated with it, as defined in the WHO Report.

The symptoms of the dementia patient are complex: restlessness, wandering, incontinence, delusions, hallucinations, reduced motility and eating disorders (15). In the international context, about 46.8 million people suffer from dementia. Of these, 60-70% suffer from Alzheimer’s, and this figure will tend to double every 20 years, up to 74.7 million in 2030 and 131.5 million in 2050, with 7.7 million new cases each year (1 every 4 seconds) and an average survival of 4-8 years after the diagnosis (16).

The significant impact in economic, social and ethical terms, and the complexity of the phenomenon, require an extraordinary capacity for governance capable of integrating very different skills and knowledge. In Italy, the Ministry of Health established a National Chronicity Plan, in which it emerged that the “integrated management model” is now considered the most appropriate approach to improve care for people with chronic illnesses. In fact, such patients need, not only effective and modulated treatments at different levels of severity, but also continuity of assistance, information and support (17). Dementia, not curable but treatable, can last longer than ten years, so the treatment of dementia poses at least two orders of problem: (a) the identification of the needs of the person and of those who take care of them in the various phases of the disease and in the different contexts of life; (b) the integration of responses to different and changing needs (18).

It is therefore essential to analyse this pathology in the field of palliation. However, in the medical and nursing literature, palliative care applied to dementia is still an under developed issue today. Therefore, this study launches a new challenge: to move towards a cultural change that arises from the recognition, by professionals, of a medicine centred on “caring” rather than on “curing”.
Aim of the work

The aim of the study is to investigate the point of view of health professionals working within the field of dementia, dealing with pathologies considered interesting for their chronicity characteristics but especially for the critical issues related to daily care practice. The analysis focuses specifically on the knowledge and availability of the application of palliative care in these areas, with particular attention to the analysis of the resistances that could prevent the spread of, or slow down the application of, such treatments within contexts different from terminal illness.

Methods

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.

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 discover the subjective and personal meanings that participants give to their reality (19, 20).

Instrument

The data were collected through a semi-structured interview built ad hoc. The interview is characterised by flexible questions that represent a perimeter within which the interviewee and the interviewer have freedom of movement, while maintaining the rigor that allows the latter to deal with all the topics necessary for the cognitive objectives (20, 21). The interview grid was tested through a pilot survey administered to a coordinator of the medical team of a hospice in northern Italy. His availability and decades of experience in this field, has allowed the researcher to modulate the questions effectively, as well as to confirm the elements to be explored. Following the pilot phase, and based on the research objectives, 13 questions were composed to explore the following areas of investigation: (a) Opinion and knowledge of palliative care (interview questions example: “Do you know what palliative care is? Do you know them?”; (b) Opinion on the application of palliative care in a chronic context (e.g., “What specific advantages could the application of palliative care bring to your working context?); (c) Use of palliative care in the context of work (e.g., “Would you be willing to introduce new methods of care and assistance to the patients in your daily practice?”; (d) Resistances to the application of palliative care (e.g., “In your opinion, how could the resistances be overcome?”). With the prior written consent of the participants, the interviews were audio-recorded. Their duration ranged from 30 to 40 minutes. They were conducted in the period between October and December 2016 and were then fully transcribed in order to be analysed.

Participants

The selected participants are health professionals, who work as health care professionals with dementia patients. More specifically, the inclusion criteria of selection for the study were: voluntarily consenting to participation, operating in a care setting in the area of dementia, personally assisting patients with moderate to severe dementia, participating in a team of health professionals in the management of clinical cases of dementia.

The participants were recruited from the Health Care Residences, or the services of protected residencies, or the Alzheimer Nucleus of Northern Italy, in the provinces of Pesaro, Modena, Reggio Emilia, Verona, Mantova and Monza, through the use of a convenience sample.

A total of 33 professionals took part in the research (18 female), of which 15 were physicians (8 male), 12 were nurses (9 female), 3 were psychologists, 1 was an occupational therapist (male) and 2 were social health professionals (both female).
Data analysis

The texts of the interviews were transcribed, giving each operator a name of convenience (only the name of the profession was made recognisable).

The transcriptions were submitted to an analysis of the content, according to some well-defined steps (22): (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 operators’ 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.

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 sub areas that highlight the prevalent contents (meanings) specified by the participants (Table 1).

1. Opinion and knowledge of palliative care
   a. Knowledge of palliative care
      The majority of the professionals declare that they know about palliative care and describe it from two different points of view: connected exclusively to terminality (17 out of 33), and to be used at the end of life (P2: “Palliative care is a set of different treatments, that are provided basically to people nearing death and to people who have incurable diseases, therefore to cancer patients rather than to patients with serious infectious diseases”) or as a holistic approach to the care (15 out of 33) in a broader and more complex view of the patient (M4: “What we face daily comes into palliative care. We aim at a global well-being aimed at the person at 360 degrees.”).
      Only a small percentage of professionals (3 out of 33) say they do not know about it, or say they vaguely remember references to it (I2: “I have heard about it, but now if I had to say exactly what it is, I don’t remember.”).
   b. Opinion on the usefulness of palliative care
      The professionals, questioned about the usefulness of palliative care, in almost all cases report an extremely positive opinion, considering it indispensable in the practice of care (20 out of 33) (M12: “It is also fundamental in non-oncological and terminal diseases. Its usefulness is inescapable”), others (9 out of 33) define it - despite a minor emphasis as - useful, considering it a great opportunity to be undertaken in the care pathways (I11: “I think it’s a great opportunity for the person and for the family.”).
      Only one operator considers palliative care as unnecessary, defining it as risky and unreliable (I6: “I prefer normal treatments, because in my opinion it is always a risk, I wouldn’t trust a lot.”).

2. Opinion on the application of palliative care in a chronic context
   a. Usefulness of palliative care in chronic diseases
      The point of view of the professionals has been specifically investigated regarding the usefulness of palliative care in chronic illness, such as for Alzheimer patients.
      Although palliative care is an area considered by some to be still unexplored and little known, the majority of respondents (23 out of 33) testify that palliative care is absolutely essential not only in oncological contexts, but should begin to be a presence in all health areas (recognised utility) (M10: “It is the future, I believe in it and it must be applied to chronic-degenerative diseases and I’m fighting for it, I hope it can become a tool in the central health care sector in the near future.”).
      There are some professionals (4 out of 33) who, not fully aware of what palliative care involves; they did not express such a definite judgment (doubtful utility due to lack of knowledge). Some think it depends on the degree of the disease and on the patient’s clinical situation, others on the wishes of the family and on the patient him/herself (doubtful utility due to lack of knowledge) (A1: “I don’t know exactly what it might
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"...bring, or if it is really valid, for example, for dementia, also because I have never had the opportunity to try it out."

Others (3 out of 33) believe palliative care is an innovative topic, that has not yet taken hold in Italy and which needs to be extended to all realities, with the help of palliativist doctors and, above all, through a cultural change that allows it to establish itself. It is highlighted that there is still little knowledge of palliative care in contexts of chronicity, as it is an extremely new topic (M7: “Then we say that we are still at the be-

Table 1. The results

<table>
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<tr>
<th>Macro area</th>
<th>Sub area</th>
<th>Meanings</th>
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<tr>
<td>1. OPINION AND KNOWLEDGE OF PALLIATIVE CARE (PC)</td>
<td>a. Knowledge of palliative care</td>
<td>- terminality - holistic approach - no knowledge</td>
</tr>
<tr>
<td>b. Opinion on the usefulness of palliative care</td>
<td>- indispensable - useful - unnecessary</td>
<td></td>
</tr>
<tr>
<td>2. OPINION ON THE APPLICATION OF PC IN CHRONICITY</td>
<td>a. Usefulness of palliative care in chronic diseases</td>
<td>- recognised utility - doubtful utility due to lack of knowledge - innovative topic - unrecognised utility</td>
</tr>
<tr>
<td>b. Benefits of palliative care in chronicity</td>
<td>- control and management of symptoms - global management - improvement in team work</td>
<td></td>
</tr>
<tr>
<td>3. USE OF PALLIATIVE CARE IN PRACTICE</td>
<td>a. Use of palliative care</td>
<td>- daily use - pain therapy and terminal phases - sporadic - not used - no answer</td>
</tr>
<tr>
<td>b. Usefulness of palliative care in resolving critical issues</td>
<td>- useful - doubts as to usefulness</td>
<td></td>
</tr>
<tr>
<td>c. Availability to open up to new ways of treatment</td>
<td>- availability</td>
<td></td>
</tr>
<tr>
<td>d. Availability of the working context to open up</td>
<td>- favourable - lack of knowledge - lack of dialogue / comparison - opposed</td>
<td></td>
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<tr>
<td>e. Urgency in the application of palliative care</td>
<td>- immediate urgency - urgency only in the terminal phases - no urgency</td>
<td></td>
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<tr>
<td>4. RESISTANCE TO THE APPLICATION OF PC</td>
<td>a. Slow and difficult diffusion</td>
<td>- biomedical model - pharmaceutical and political interests - lack of training - Catholic Church culture - lack of laws and well-defined guidelines</td>
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<tr>
<td>b. Resistance to the application</td>
<td>- cultural resistance / prejudice - lack of training - lack of personal motivation - resistance to the use of morphine</td>
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<td>c. Overcoming resistance</td>
<td>- training - communication</td>
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ginning and we need a lot of knowledge of this new culture, which, however, must be more specific to our field.”).

Among all the interviewees, we distinguish only one operator who believes palliative care associated with chronic diseases is absolutely useless (unrecognised utility), as it cannot be standardised in the way that has already happened for cancer patients (M5: “It is useful with cancer patients because it started many years ago and is standardisable in some aspects, but if we refer to the emotional and psychological field of patients, both chronic and demented, we are lacking in knowledge.”).

b. Benefits of palliative care in chronicity

The professionals have highlighted how the introduction of palliative care in chronic conditions could lead to an improvement in the control and management of symptoms, such as pain, respiratory crises and dysphasia. It can also lead to better management of complications caused by chronic disease (M13: “In diseases such as Alzheimer’s, being a highly complex disease and with a slow course, I would apply palliative care, always and especially in the terminal phase to alleviate the complications of the disease.”).

The professionals underlined how the use of palliative care can allow a global management of the patient and the family members, guaranteeing a holistic vision by all health professionals. The advantages are found in: - improvement of quality of life; - reduction of suffering; - accompanying the patient (I4: “It is precisely a day-to-day caring for the patient and their family, which is what we do, and what’s more, it also means listening to what they have to say and then finding the right path to help them and accompany them on their journey.”).

According to other operators, the introduction of palliative care in chronic contexts could lead to an improvement in team work and the possibility of building an integrated territorial network among the various professionals. Team work, according to this vision, can provide more adequate interventions according to the patient and the stage of illness (M11: “Certainly introduce interventions that should be coordinated with other professionals. It would be useful to have a team that evaluates, together with the general practitioner and the patient’s family, the most appropriate interventions depending on the stage of the disease.”).

3. Use of palliative care in the context of work

a. Use of palliative care

Some of the professionals (16 out of 33) tell us that they use palliative care every day. Specifically they refer to using it daily, since it is inherent in their role (M10: “I apply it daily during the course of my profession and I have also had experience in a personal context.”).

Other professionals (3 out of 33) claim that the use of palliative care within their structure is as a protocol exclusively used as pain therapy and in the terminal phases (I12: “The diagnostic therapeutic treatment path we have worked on involves the phase of palliation for patients with dementia even if only in the terminal phase. The course would have to be recalculated as palliative care is applied too late.”).

Others (4 out of 33) tell instead of having used it in the past, of having experienced it only a few times or that, within their structure, it is not used in a systematic way but only for sporadic use (for example on the basis of the presence or not of a palliativist doctor) (M7: “In the structure, not in a systematic way because we have to do a training course for all staff, to provide everyone with basic knowledge of the palliative culture and later, more specifically, in the department that we are going to organise in those terms.”).

Many interviewees (7 out of 33) claim to have never had anything to do with it, that in their structure they have not used it, or, in any case, they are not even familiar with it. Some even claim that there is no dedicated team, that there are no guidelines and describe their department as not suitable for treatment of this type (I6: “No, in the ward where I work, it is neither known nor applied”; M11: “We don’t have a dedicated team or even guidelines.”).

Other professionals (5 out of 33) say they do not know how to answer this question because they are having trouble understanding what is really meant by using palliative care, not knowing what it really is and what it consists of (M5: “No, is there palliative care?”; I1: “I can’t give you an answer, because I don’t know what it does.”).

b. Usefulness of palliative care in resolving critical issues

The majority of professionals (25 out of 33) believe that the application of palliative care is useful in resolving various critical issues present in everyday
work: - fewer worries about the emotional management of patient and family suffering; - fewer doubts about the interventions and the management of some symptoms such as pain and the use of analgesics; - a shared management necessary to work in an integrated manner to safeguard the patient; - avoid unnecessary hospitalisations and too much technicality (I10: “Yes, absolutely yes, help the patient at that time, but also help the awareness and the accompaniment of family members, so it becomes a type of shared management in the phase of terminality and suffering. It is absolutely primary for us, precisely to work in a complete manner and to safeguard the patient.”).

A minority of professionals (5 out of 33) have strong doubts about the fact that palliative care can resolve daily critical issues (T1: “But I do not think it works with the big problems to be faced every day that have to be solved”; M6: “No, I do not think it can solve problems.”).

c. Availability to open up to new ways of treatment

Despite the different points of view, most of the operators (24 out of 33) declare that an attitude of readiness to innovate is necessary, with a view to the usefulness of learning, and of being able to work better in a team. For example, some professionals propose the introduction of a psychologist into their structure or the possibility of using palliative care not only in the terminal phase of illness but also in the early phase (I1: “Of course, our work is also based on this: we need to be able to accept new things and above all put them into practice.”).

d. Availability of the working context to open up

However, most professionals (20 out of 33) think that their colleagues would support the introduction of palliation, as the idea that it is useful is shared and there is a lot of sensitivity on the subject. It is very noticeable availability especially by nurses.

Some professionals think it is a way to confront problems, but the need for skills and training also emerges (I12: “I notice enlarged sensitivity with respect to these treatments; some people don’t know them but they understand their necessity.”).

Many professionals, however, point out that for some colleagues a lack of knowledge prevails, since one does not invest in a specific formation and in the course of studies one does not speak about it; others have distorted knowledge, as they link palliative care only in relation to cancer patients; others consider it a real taboo (M12: “Some people do not really know it, in particular the general practitioners who should be the most interested.”).

Only two operators point out how, in the structure in which they work, there is a lack of comprehension on this issue and that they do not talk to colleagues about this topic (I7: “I do not know, we never talked about it”; P3: “I do not think there is, we do not talk about this topic.”).

Only one operator declares that his colleagues would be opposed to the use of palliative care in the structure in which he works (I9: “All my colleagues are against it!”).

e. Urgency in the application of palliative care

Many professionals (10 out of 33) believe that palliative care should be urgently applied and are driven by important motivations: - feeling powerless next to patients who suffer; - wanting to give patients a better quality of life and end of life; - being able to respect the wishes and needs of patients and their family members (M4: “I would say that it is very urgent: the goal of quality of life is fundamental.”).

Some professionals (4 out of 33) consider it necessary, but refer only to the application of palliative care in the terminal phase of disease, and, even then, according to the classic application (I12: “It is urgent, but certainly not immediately when the person is still in good condition.”).

A small number of respondents (8 out of 33) agreed that the real urgency is not in having to apply, or not having to apply palliative care, but in other priority issues (no urgency). This is linked to the fact that, on the one hand, there is little time available to be able to insert palliative care into everyday work practices, on the other hand, there is a belief that something like this is already being done as part of patient care, and that this is sufficient (I6: “It would be a good idea, but it is not really urgent”; T1: “In my opinion there is no high urgency.”).

4. Resistance to the application of Palliative Care

a. Slow and difficult diffusion of palliative care

All respondents think that the diffusion of palliative care is difficult and slow because:
- a biomedical model predominates, in which there is no wish to surrender to the disease and the triumph of death over life (M3: “There is no mentality, in the sense that one does not speak of death. So if you do not talk about death you can’t even talk about palliative care.”); - the company is characterised by an interest in pharmaceutical companies and politics; - in healthcare facilities, assistance is hasty; there is a lack of time and of staff expertise in this matter; there is still a lot of confusion on the subject because - as mentioned - there is no training and there is little interest from health professionals in this developing area of medicine that (T1: “In my mind, there is a lack of adequate training. I think there is a reduction in staff and an increase in the user base that causes us to run in all directions without being able to devote time to important things, such as, for example, the introduction of palliative care.”). On the other hand, the Catholic culture is deeply rooted in the value assigned to life, in which the idea that man must bear earthly suffering predominates (M4: “Because of the Catholic Church. The diffusion of palliative care is culturally hampered by the fact that it is confused with the definition of port to death, the last days of life. In Italy, a country so rooted in Catholic culture, there is a perception of pain as being the way to salvation”). Palliative care is also linked exclusively to the end of life, it is lacking laws and well-defined guidelines to allow professionals to work in the best way (P1: “I often see that nurses are more concerned with administering therapy or writing up deliveries and do not evaluate everything that is around the patient, because, unfortunately, they don’t have the time.”).

b. Resistance to the application of palliative care

Some professionals (7 out of 33) argue that the resistance is mainly cultural: the idea is that it is caused by the prejudices present in our society, also influenced by the Catholic Church and the fear of communicating to the patient and family members the diagnosis of an incurable disease. In a society where commitments are deemed to be burdensome and highly empowering, selfishness and rejection of disease seem to be predominant (I12: “We live in a society influenced by the Catholic religion that causes poor integration with palliative care. Also, there is an extreme individualism devoted to power, beauty and non-acceptance of disease and death.”).

Other professionals (7 out of 33) think that the resistance is a consequence of the lack of training, which could be overcome on several levels: for example by informing people more, by training in the concepts and through master classes, conferences and congresses dedicated to palliative care. (M4: “Training at 360°, with masters, conferences, seminars.”).

Some professionals (2 out of 33) attribute the resistance, not so much to the lack of training, but more to the personal motivation of the operators, as their ability to get involved (M7: “Training is not enough to find the inner motivation and get involved with your first patient, because palliative care brings us close to death, a fundamental existential aspect of life; we need to find opportunities and tools that encourage motivation.”).

Some respondents (2 out of 33) think that the resistance is related to the use of morphine as it is considered as a drug that causes the death of the person and it is administered as the last resort, at the last moment, when it is often too late (M8: “There is fear, yet someone sees morphine as killing ... we proceed to spot leopard, some know its use well, others not.”).

c. Overcoming of resistance

Almost all professionals (27 out of 33) think that training in palliative care would be essential and fundamental: it would help to overcome resistance and could change the cultural model. Training is therefore seen as a cornerstone to ensure dignified care and professional growth in step with the times, not based on prejudice and the classic “ways of doing things” that are now obsolete and outdated (I10: “Training and information at the various levels of the profession are urgent ... Training must be understood by all the actors involved, because each actor has a precise and important role in the implementation of palliative care.”).

To overcome the resistance, some professional operators (6 out of 33) think that the key can also be found in communication with family members and professionals, in an exchange of ideas, in a social network, which is open to the sharing of choices and experiences (M8: “We need to involve family members in the choices ... every day there should be an exchange of information that can make a common understanding grow.”).
Conclusion and Discussion

From the literature, a theme emerges that palliative care, in the current context, is mainly addressed to cancer patients in the terminal phase of their life (23). However, epidemiological data show how the demographic transition expected in the coming years will lead to a significant increase in the number of people with chronic diseases (9). Da questi dati, si evince quindi come il problema sia ancora sottostimato.

The analysis of the scientific literature shows, on the one hand, a lack of studies in this area, but at the same time, the intent of palliative care experts to extend such care even to people suffering from chronic-degenerative diseases (24, 25), providing an integrated approach with pharmacological therapies from the initial stages of diagnosis (26-28).

Based on these premises, the data emerging from this research show a wealth of information and specific aspects that make the results particularly interesting when compared to the initial objectives.

Most professionals, regardless of their professional role, think they know palliative care, but some only connect it with the terminally ill. Others have a wider vision, but it is based more on an abstract and theoretical level than on real practical knowledge. Knowledge of this subject seems to be, in summary, confusing and superficial. The answers of the professionals, regarding if and how palliative care is used within their own working reality, are most heterogeneous. A lack of homogeneity is noticed both between professionals working in the same structures and between those who carry out the same profession. This is due to a lack of knowledge of the subject and a lack of awareness of the application of palliative care in practice. There is a discrepancy between the individual availability of the professional and that of the work context, because, according to the perception of many interviewees, the context in which they work is still not very mature for the introduction of innovative ways of treatment. From this, it emerges that the availability of the individual is not lacking, but rather the tools and knowledge provided by the work context.

An important fact to underline is that, despite the confusion and the lack of knowledge, almost all the interviewees have a positive vision of palliative care, considering it useful and necessary even in chronic patients. The issue of chronicity has brought out different opinions of the operators regarding the usefulness and urgency of the application of palliative care in this area. For some professionals, it is useful and urgent because its use could improve the management of symptoms, the overall care of the patient and their family and contribute to the development of a multidisciplinary team. For some professionals, palliative care is considered an innovative topic but not of primary importance. In contrast to these professionals, a much lower percentage does not consider it useful for chronic patients.

With respect to enforcement resistance, palliative care is still considered as to be a weak discipline. It is almost always associated with the concept of the end of life. The most common types of resistance, emerging from the analysis of the interviews, are those related to cultural factors, where medical biology predominates, and those related to the training deficit in this area. There is resistance linked to prejudice due to lack of knowledge, such as the fear of the use of morphine/opioids. This is because these drugs are usually associated with terminality and there is motivational resistance, linked to the personal sensitivity of each professional and his ability to engage in the discussion. It is interesting to underline that, from the point of view of professionals, resistance can be overcome by communication at various levels, highlighting how little work is done in the team and how little one considers the opinion of the patient and his family about his care.

Training is the basic key to the possible overcoming of resistance and to allowing palliative care to spread to different fields, such as chronicity. To substantiate this, there is the emergence of a strong will among the majority of professionals working with dementia, towards a change of model, in the awareness of being poorly prepared and with a sense of inadequacy in the management of critical issues.

In conclusion, the questions that arise spontaneously from this exploratory study are: “What kind of professionals have we become and in what direction are we going?”, “As professionals and human beings, are we preparing to face and manage such a heavy burden of responsibility?” The results show that there is a long way to go towards an awareness of the needs that chronic
degenerative diseases cause in patients and their families, and of their human and professional role in their fulfilment.

References


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