

The narratological approach in accompanying people towards the end of life: the experience of “Teatro DiLetto”

Ivano Malcotti¹, Linda Alfano², Rosagemma Ciliberti²

¹Società Genovese di Cremazioni, SO. CREM. Italy; ²Department of Health Sciences, University of Genoa, Genoa, Italy

Abstract. *Background:* The care of patients in the terminal phase of their lives requires a broader approach that encompasses emotional, psychological, relational, and spiritual support for the person. *Methodology:* This paper describes the “TeatroDiLetto”, a project aimed at exploring the possibility, for terminally ill patients, to express their experiences, stories, and emotions through various artistic forms, with the aim of promoting their emotional and psychological wellbeing and a better quality of care. The project involved three Italian associations dealing with healthcare support and a multidisciplinary group composed of: doctors, bioethicists, psychologists, therapists, and theatre actors. Training sessions were organised for the operators involved in the project, and individual interviews were conducted with all participants, before and after the artistic experience. *Results and Discussion:* Preliminary results suggest that the valorisation of patients’ narratives, life stories, memories, and wishes can have a significant impact on their well-being and on the quality of the operators’ professional performance, while fostering that sense of community and sharing among all those involved, which is the basis of any authentic care support process as well. *Conclusions:* Healthcare professionals should be prepared to interact with different humanities professionals, so that they might collaborate in the realisation of a personalised care project that is attentive to: the specific history of each subject, cultivating constant dialogue between knowledges, and drawing on a multiple and interactive panorama of competences.

Keywords: narratological approach, narrative medicine, bioethics, palliative care, end of life, symptom management, end-of-life communication; end-of-life education, theatre-therapy

Introduction

The end of life represents one of the fundamental moments of human existence, one in which emotional support and the quality of time still available to the person become priorities, as do all those palliative treatments which, while not changing the now unstoppable course of the disease, are nevertheless able to support the patient and their affective references in the arduous path of accepting one’s destiny (1, 2).

Therefore, accompanying the person in the terminal phase of their life constitutes a human intervention charged with ethical values and represents one of the most demanding aid relationships for the operators involved in its psychological, anthropological, relational, and affective aspects (3-5).

In fact, approaching a person close to the end of their existence, entails the ability to accompany their human journey towards the uncertain, to contact their concept of the end of life, and to create a basic alliance that enables us to experience together the awareness of our mutual vulnerability. Contact with the dying person touches on meanings and dimensions that meet unprecedented and inescapable intensities, since they also solicit the anguish of one’s own frailty and of a shared destiny. Professionals engaged in this field must, in fact, respond to the person’s global care needs, including the emotional, social, and spiritual ones, that the delicate moment of the end of life calls into question.

For these reasons, it is necessary to transmit those specific listening, proximity, emotions’ management,

and collection of memories skills to the operator in a renewed perspective of attention to the human dimension of the dynamics of reception and forms of support and care. One increasingly recognised today as fundamental, even by the code of medical ethics that enhances the time of communication as 'time of care' (6, 7).

In the context of a process aimed at enhancing the humanisation of care, attention to this phase assumes therefore a fundamental value in relation to the meagreness of the time available to the person, and their caretaker, and the problems that gravitate around them (8, 9).

The importance of this phase is part of that ethical viewpoint that interprets care beyond the narrow dimension of recovery, that wants to accompany patients, rather than abandoning them, the aim of which is to make the last moments meaningful, in an integrated approach that comprises attention, care, sociability, appropriate diet, meditation, and creative stimuli... (10-13).

Literature attributes a particular importance to the use of a narratological approach, for its capacity to act on the patient's inner world and emotional life (14, 15).

This methodology favours the process of re-appropriation of the person's planning possibilities since telling and recounting oneself, being able to explore the past, and reconstructing the different trajectories that have been part of one's biography, allows one to rediscover expectations, questions, interrupted or laid aside abilities and, with them, the possibility of bidding farewell to one's affective references and oneself (16).

Every story is, therefore, a journey of individuation, an operative biography.

In Italy, the narratological approach became part of qualitative research at the end of the 1970s, after having undergone both theoretical and empirical systematisation, especially in the field of psychological disciplines and, subsequently, in sociological ones.

The product of biographical practices is usually a story, i.e. a construction, a tale that one tells together with another, which can take various forms of expression as poetry, theatre, music, and painting.

To be effective narrative practices require collaboration between two parties, maximum freedom of content and tone, and a welcoming, intimate, and

non-judgmental environment. In the specific moment of an illness with an inauspicious prognosis, storytelling allows patients to translate emotions into words, metaphors, symbols, which can also succeed in depicting what can no longer be said, accepted or shared. Stories are, therefore, personal and confidential expressions that can help patients cope with the illness. Sometimes the most significant stories are those that show a hermetic and unfinished facet, where the suffering person may realise, through distancing himself from their own experiences, that they are unable to fully understand themselves, to accept the anxiety of uncertainty, to take the risk of not being able to reach any definitive answer regarding their own identity. But it is precisely in this place, marked by doubts and precariousness, that the person can succeed in giving meaning to the thin border that separates life from death.

Representing stories, turning them into poems, songs, paintings, and plays, offers patients the opportunity to explore and observe their emotions from the outside, in a more concrete and physical way, and to approach their emotional experiences with less anxiety, even when those are bitter and difficult.

The 'Teatro DiLetto' project

With this in mind, the 'Teatro DiLetto' project was developed and implemented in Genoa (Northern Italy) with the aim of experimenting new frontiers of caring for people suffering from serious illnesses with an inauspicious prognosis.

The aim of the project was to strengthen care pathways at the very end of life, promoting constant attention by healthcare personnel on the centrality of the patient, and their affective references, through the enhancement of the narratives of the ill, their life stories, memories, and wishes.

The idea, born from the initiative of the poet and writer Ivano Malcotti, was to bring theatre to the patient's bedside to allow, in a continuous interchange of communications, emotions, and sensations, the construction of an identity memory that, like a casket, would cradle the most significant steps of the patient's biographical paths, representing, at the same time, their possible gift to loved ones.

The proposed activity intends to contribute in alleviating the suffering of the sick person and their family members, by personalising it, to promote a growing appreciation of the memory, and memories, of the person's life, to encourage the construction of a universe of meanings around the approaching experience of death, and delivering a purpose capable of imparting motivation, desire, and life to the time still available to them. The activity also intends to promote moments of confrontation and comfort, to encourage the construction of strategies of well-being and good living, and to enhance a greater ability to react in the face of the unexpected.

The methodological premise refers to the techniques of biographical reconnaissance and is based on the affirmation and enhancement of the person's ability to give themselves a meaning autonomously, to appropriate knowledge and its self-transformative power, to compare the different experiences of their life and all the connections they have formed and experienced with others, objects, and themselves as well. Narrative practices, therefore, aim to place the 'expert' professional and the sick person on the same level, as they are both endowed with their own history, and with the right-and-duty to interpret and make sense of it.

This project involved personally: therapists, bioethicists, doctors, health workers, and caregivers within the framework of three Italian associations dealing with care support: Associazione Gigi Ghirotti, Associazione Onlus Città di Genova, and the Istituto Italiano di Bioetica.

The activities were divided into different phases.

Firstly, the project was shared with the hospice and home care operators of the Gigi Ghirotti Association, the body chosen for an initial trial of the project. A number of meetings were planned and organised to train the operators in charge of running the narrative workshop, medical humanities and, in particular, the practices of storytelling, autobiographical narration, and therapeutic theatre.

Then the facility managers identified possible patient-participants to whom the initiative was explained and whose free, and voluntary, participation was guaranteed. Particular attention was paid to respecting the patient's needs, identifying the most appropriate communication style, and constantly seeking the active participation of the person. This last goal was achieved

thanks to the mediation of operators, who had already established a good relationship of care and trust with the patient.

Patients who chose to participate in the project were encouraged to tell their stories of illness and life, using the artistic form closest to them, and were helped in finding meaning and purpose to their experience in as intimate and supportive an environment as possible.

Below are some narratives expressed in poems, as well as an excerpt from a play (staged with the author's permission after her passing), taken from the DiLetto theatre workshop conducted in a Genoese hospice.

Surviving

By dint of surviving
One even wears out
The sentence of living

The Life Of Others

I live intensely
I live the life of others
Because my own
I know
Too
...little

High Voice

Now to divide us is only
a fracture of silence
because your words
like caresses
speak aloud...
will forever speak
in a loud voice.

Excerpt from the play "Wendy and Catherine"

We are two souls... Wendy and Caterina who, through an oversight of God, ended up in the body of a little girl. Nobody noticed this, not least because souls are invisible...Everything seemed to be running smoothly didn't it Wendy? Until a big problem appeared in our lives and, for the first time, we found ourselves fighting a serious illness...Hands and knees were swollen and pains everywhere...and a terrible diagnosis: rheumatoid deforming arthritis.

I wait for you where houses are reflected in the sea
 where youth
 does not deceive me with ephemeral memories.
 But if you arrive at the hour of sunset
 Let that moment
 turn into an aurora.

I hate hospitals, there is a lack of hygiene, a lack of respect for the sick, I have lost my identity and become number 18.

Giuseppe graduated, started working.

He asked me to marry him, I am in love with him, but I am afraid to face marriage.

He reassures me that the disease doesn't matter in our life, but I have many doubts.

Who decides people's destinies, I don't know...the only certainty is that life is one and you have to live it as best you can, and the only hope is that it doesn't all end with death, but that death will serve to clear up all doubts.

Discussion

Several researches suggest that the use of imagery and art in patient support can have a significant impact on the individuals' well-being and consequently on the emotional condition of their closest relatives (17, 18).

The various art forms can, indeed, enable patients to give voice to their deepest emotions, offering a sense of relief, completion, and legacy (19).

Narrative, be it imaginary or autobiographical, can foster a progressive acceptance of reality. In narratives, in fact, patients tell their own stories and share their experiences through a private, and personal, symbolism that doesn't require any effort from them to be decoded. They talk about illness, death, and suffering using metaphors, symbols, and anecdotes, thus managing to give a face to what they feel and know, even if such process isn't always conscious.

Most of the people who came to the Teatro DiLetto workshop produced stories that could not be completed, that got stuck in difficult passages, that were abruptly discontinued. The narratives, which were precise, com-

plete, and detailed photographs of personal inner stories, were also a way of facing fears without being emotionally overwhelmed. Indeed, transforming the experience of pain and illness into a known, albeit mythological, imaginary, and performative entity means turning it into something more understandable and manageable. It means sharing thoughts and deriving support from another's attention and understanding (20).

Through narratives it is also possible to identify both the factors which, on several particular occasions have triggered a break in the patient's equilibrium, and the internal resources and strategies previously used by the same to cope with crises and to reduce their negative impact on their everyday life. These elements take on a particular relevance if we consider how, in the field of care, the increasing acceleration of scientific and technological development has created a paradoxical situation: on the one hand providing an exponentially increasing availability of knowledge, but on the other hand fostering a lessened ability to manage critical moments.

The stories of the ill, and their representation in the various artistic forms, not only have the capacity to bring forth a new life project, compatible with the (sometimes very short) time of those who are approaching the end of their existence, but also allow it to be shared, and transformed, into a spiritual and affective testament of great intensity, to be donated and shared with others.

The stories of an ill person can also evoke the memories and experiences of their listener and be a welcome attention and of help not only to the narrator, but also to those who urge them to retrace their memories.

From the interviews conducted with the patients and their caregivers, we can see these creative activities appear to have produced positive effects, also with regard to the quality of healthcare received, which was perceived by all as more attentive and responsive to needs. Patients who had grown dull and resigned rediscovered, albeit for brief moments, some joy in participating in the workshop, and attending the reading, and dramatisation, of moments from their past made impossible by the disease.

The workshop helped improving the self-esteem and confidence of many participants, creating a more

empathetic and welcoming environment. It represented a cathartic experience that welcomed the expression of grief and the acceptance of the resulting emotions.

In individual follow-up interviews, patients reported an increased sense of emotional well-being and life satisfaction. Meaningful connections were created between caregivers, actors, patients and family members that enabled the sense of community, of sharing, and of collectivity that underpins any authentic care support journey.

It emerged that almost all the participants developed more constant collaborations in their own care, greater emotional resilience, and a reduced need for drugs for the management of physical and psychic pain, acquiring tools for managing the stress and criticalities associated with their illnesses from the creative expression of their own narratives.

Family members and caregivers, interviewed separately, expressed feelings of gratitude for the comfort given to their loved one, and for sharing their fatigue and pain, as well. Family members reported how participation in the initiative had improved communication between them and their loved one, emphasising how this understanding had reduced the sense of helplessness and anguish resulting from uncertainty and the inability to understand the needs and emotional requirements of the person they were caring for.

The activities also proved to be a powerful tool to encourage critical reflection among healthcare personnel in order not to lose sight of the richness, both in clinical and epistemological terms, of the person's subjective experience (21). In fact, the operators interviewed reported how, through the exploration of patients' stories, they had matured a greater attention and sensitivity towards the experiences, feelings, and challenges faced by the patients, identifying more personalised and effective communication strategies capable of reducing stress and fatigue.

The introduction of narrative techniques in end-of-life accompaniment may also be useful for an evaluation of the current organisation of care, which continues to privilege scientific and medical knowledge over all the other forms of knowledge that, with equal dignity, play an important role in the protection of the sick person and their family. What is certain is that no progress will be achieved unless the illusion of being

able to optimise resources and therapeutic results by eliminating confrontation, discussion, and multidisciplinary (as it often happens in these structures) is overcome. A mistake still made in spite of the humanities' researches on healthcare all emphasising in their findings how these factors listed above represent the conditions that, more than others, guarantee the viability of the therapeutic pathways and their effectiveness in terms of patient's well-being.

In reality, an approach based on the attention to, and valorisation of, all the different aspects of the person does not entail a deviation from the rules aimed at containing health care costs, but imposes an organisational style in which, by placing the individual at the centre of the health care apparatus, one succeeds in favouring the best conditions of well-being and the highest quality of services and structures, since the high technical quality of the service cannot disregard the quality of the human relationship that is established in the treatment.

It is therefore important to ensure that health workers are adequately trained to develop listening, communication, and collaboration skills with the various professional figures, including non-health professionals (22, 23).

Complexity is the main concept of contemporary science, in all fields.

In the field of healthcare, we must retain the awareness that we are moving on a complex terrain, where nothing can be trivialised, where there are no certainties, where we are always facing emergencies, where the pressure of the media distorts as well, creates error and tensions, where scientific knowledge and investigation methodologies are always evolving, in continuous development, and where work is studded with decisions to be taken.

Limiting the reference to a single technical knowledge means debasing professionals by turning them into mere executors of rules and procedures, hindering the formulation of personalised aid and support projects, undermining the personal and professional investment of health workers, exacerbating the conflict between families and services, and growing further away from the possibility of shared support interventions (24). As it has been pointed out, biomedical development has provided physicians with increasingly

powerful and sophisticated tools for dealing with once hopeless diseases, but a reductionist approach is not sufficient, on its own, to deal with the difficulty of the challenges arising, not only from the disease, but also from the complexity of the healthcare structure, and the problems posed by technological and scientific development itself (25).

Here all the contradictions of an ambivalent health system emerge. A system oscillating between a medicine increasingly oriented towards the sciences of the artificial and technology, and a medicine increasingly in need of returning to its origins as a human science, that puts its focus on the person, and the complexity of the networks of interactions in which he, or she, is immersed in. Moreover, even in the past, music, theatre, and the reading of philosophical texts, as well as personal care and cosmetics, played an important role in the individual's quest for mental harmony and health (26-29).

Assigning an ancillary role to humanities, verticalising knowledge into precise and divided sectors, runs the risk of frightening precisely the fragile people whom one would like to help, of alienating them more and more from public services, and of leaving them alone. On the contrary, an awareness of the importance of recovering the deeper meaning of the narration within every therapeutic act, urges the valorisation of every cultural resource capable of stemming the cultural drift towards a merely technological medicine.

In this scenario, the autobiographical workshop can become the instrument to reconnect not only different knowledge and skills, experts and not, but also to build, together, a story capable of erecting a bridge between collective and subjective representations of illness.

As Rita Charon emphasised one can, through reading and writing, train and develop those listening and attention skills necessary not only to a more correct diagnosis, and to build more shared therapies, but also to really take care of those who suffer, in contrast to a health system that seems to put corporate and bureaucratic concerns before people's needs (30).

The awareness of the inescapable subjectivity of each person, even the one who is suffering, not only does not invalidate scientific thinking, but supports it, precisely through the careful collection of their experiences and subjective perceptions.

Conclusions

The workshop experience described represents an innovative approach for the of the whole person.

The possibility of allowing patients, who are reaching the end of their lives, to express their emotions through shared storytelling techniques represents a valuable opportunity to improve their quality of life, to foster their emotional well-being, and to promote greater social connectedness.

Scientific evidence suggests that the use of alternative forms of expression can improve communication and pain tolerance, with important positive effects on families' relationships with care institutions.

Through the use of stories and storytelling, health professionals can gain a greater understanding of their patients, identify more effective channels of relationship, and build a more humane, person-centred clinical practice, capable of addressing the complex challenges of today's health care system.

Health professionals should be prepared to interact with the different professionals of human sciences so that, while respecting their different competences, they may collaborate in the realisation of a personalised care project, that is attentive to the specific history of each person to be assisted, cultivating a constant dialogue between knowledges, and drawing on a multiple and interactive panorama of competences.

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- Corresponding author:**
Rosagemma Ciliberti
Department of Health Sciences, University of Genoa, Genoa, Italy
E-mail: rosellaciliberti@yahoo.it