

Gratitude and Palliative Care

Gratitude and Palliative Care:

*A Dialogue between Philosophers
and Clinicians*

Edited by

María Arantzamendi and Mariano Crespo

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Edited by María Arantzamendi and Mariano Crespo

Translated by Herman Cloete

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ATLANTES
GLOBAL OBSERVATORY OF
PALLIATIVE CARE

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PROLOGUE

Nowadays it is not uncommon to associate palliative care with a negative perspective, with situations "where there is nothing more to be done". It seems that palliative care is a last resort for hopeless patients. However, nothing could be further from the truth. Today, more than ever, it is necessary to promote a positive mentality when it comes to the care of patients with advanced and irreversible diseases. With this in mind, the *ATLANTES Global Observatory of Palliative Care* group of the Culture and Society Institute of the University of Navarre aims to promote a positive mentality in society and in medicine when it comes to providing palliative care for a patient. Among the objectives of this group is to explore the anthropological, historical and ethical aspects of palliative care by examining values such as gratitude, compassion, and dignity, among others. Through its research and dissemination work, it seeks to engage the various social agents with a vision based on the dignity of the person and promoting professional care, accompaniment and respect for the natural course of the illness and the integral care of the person, including the emotional and spiritual dimension.

This book brings together a series of papers arising from the research project entitled, "The phenomenon of gratitude in the field of palliative care. Analysis of its ethical and anthropological relevance", as funded by the Institute for Culture and Society (ICS2020/01) and developed in the academic years 2020-2021 and 2021-2022. Most of these contributions were presented at the International Symposium "Gratitude and palliative care: a dialogue between philosophers and clinicians", which took place on the 12th of May, 2022 at the University of Navarra in Pamplona.

From the outset, one of the main aims of the project from which this volume arises was to bring philosophers and clinicians into dialogue around a phenomenon of particular relevance in the field of palliative care, namely gratitude. Despite the fact that this type of care is given in a situation of irreversibility and, therefore, of non-recovery of health, it is very common for health professionals to receive various types of responses of gratitude from patients and/or their relatives. This raises several questions, one of the most important of which concerns the object of gratitude in an end-of-life situation. However, this is not the only question, as the various contributions to this volume will show.

The book begins with a section entitled "Palliative Care and Gratitude" which aims to establish the existence and relevance of gratitude in this field. Thus, in his article, Carlos Centeno refers to his itinerary in the field of palliative care, focusing especially on the experience of receiving letters of gratitude from patients and on the account of exchanges with other medical colleagues, both Spanish and foreign, who had collected this type of letters. Centeno emphasises that the gratitude of patients and their relatives is proof of the quality of the care offered. María Arantzamendi insists that palliative care improves the quality of life of patients (adults and children) and their families when they face physical, psychological, social or spiritual problems inherent to a life-threatening illness. At the same time, they provide a support system to help patients live as actively as possible until death. Arantzamendi highlights how patients' relatives value, and therefore appreciate, the "humanity", the professional care, the emotional support and the creation of a special atmosphere that provides holistic care for the sick person. From the experience of having practised palliative medicine in very different cultures, José Pereira analyses various cultural ways of expressing gratitude across different cultures. Despite what might appear as differences at first glance, these expressions have much in common.

The second section of the book is devoted to the conceptualisation of gratitude. This section opens with an illuminating contribution by Alicia Hernando on the etymology of the term gratitude. She points out how gratitude is conceived as a gift that arises as the fruit of love. Besides, gratitude generates a positive effect, as the recipient experiences an impulse to reciprocate. One of the most striking results of Hernando's etymological analysis is that she finds evidence of gratitude being innate to humans. For her part, Mariana Riojas continues the reflection on the type of experience that gratitude consists of by emphasising that it is a response which does not arise from complete spontaneity alone but is rather a free act that arises from among many other possibilities. Riojas draws on Peter Goldie's analysis of the paradigmatic connections between *recognising* features that invoke emotions and *responding* with emotional experiences. He concludes that to be grateful is to permit that something emerges from ourselves, to discover that we resonate with something much larger than what we imagine ourselves to be.

The third section of the book is devoted to the object of gratitude and opens with a contribution by Mariano Crespo who asks what, "*in the proper sense*", is there to be thankful for in the field of palliative care. Certainly, for obvious reasons, it is not about health, unless we have a broader concept of health than the one that is usually used in terms of the absence of illness. The palliative care patient, as well as his or her relatives, rather than aspiring

to regain health, are aiming for the suffering associated with the patient's illness to be mitigated and alleviated. But is it only the alleviation of suffering that palliative care patients and their families are grateful for, or is it something or someone else? Anthony Steinbock reframes the question of gratitude in an interpersonal setting of gift and humility and suggests that a gift is only a gift in the context of personal love and that, similarly, gratitude is possible in an interpersonal space of caring. By examining the positions of Derrida and Maimonides he concludes that giving the gift and giving thanks serve the interpersonal connection, they do not establish it. The gift and gratitude emerge from the connection without being the object of it. Hence the point is not to detach *the gift from the* terms of the encounter. What it means is that participation with another, expressed through gifting and gratitude, is other-oriented. The section closes with a paper by Enric Benito in which he reflects on his experience as an oncologist and a palliative care specialist. In the face of a culture of denial of a reality that we do not want to confront, such as death and suffering, Benito insists that in these extreme situations' authenticity emerges, as well as the need to find closure.

The fourth section of the book is devoted to the subject of gratitude. The opening chapter is by Sergio Sánchez-Migallón. In his work, dedicated to psychological factors that favour or inhibit gratitude, he deals with the internal attitude of gratitude by looking at the internal conditions of the patient receiving palliative care. In doing so, he focuses on the psychological factors that positively or negatively influence the internal response of gratitude. His fundamental thesis is that gratitude requires, as a necessary condition, an adequate grasp of the good or benefit received. This same line of analysis is undertaken by Paulina Taboada, who, from a joint clinical and philosophical perspective, refers to three obstacles and three enablers of gratitude. Among the obstacles she includes the rejection of suffering and death, the refusal to depend on or need others, and indifference or blindness to values; while among the enablers, there is the possibility of finding meaning in suffering, the acceptance of dependence and help from others and, finally, the willingness to perceive and respond to certain values. The section concludes with the contribution of Julio Gómez who, through the consideration of profound personal experiences, illustrates the differences and connections between gratitude received and gratitude offered. Particularly relevant is his analysis of the gratitude received by health professionals and how it can renew the meaning of their professional practice.

The fifth and final section of the book is dedicated to the impact of gratitude. María Aparicio takes a close look at the impact of being grateful

or practising gratitude. She focuses on the review of the scientific literature on expressions of gratitude from patients and their families towards health professionals. These expressions are found to be a source of motivation and devotion to continue working in this field. At the same time, they have several positive effects that include serving as a shelter from emotional fatigue, and to inspire health workers to become a better version of themselves, among others. Luca Valera, for his part, reflects on four complementary levels: on the level of the philosophy of medicine, he reflects on the difference between caring and curing, with particular attention to palliative care; on the anthropological level, he outlines some ideas starting from the concept of human vulnerability, which emerges in the context of the impossibility of cure and of human limit (both of the patient and of the physician); at the cultural level, it highlights the culture of gratitude that emerges from the two previous aspects, as opposed to a "throwaway culture" that emphasizes the dignity of the human being solely on the basis of his or her functionality; and at the etymological level, it refers to some ideas on the said culture of gratitude. The book closes with Mathieu Bernard's contribution on why gratitude is of interest in palliative care for patients and their families. He focuses on the linkages between gratitude and positive psychological changes, psychological distress and well-being.

As we mentioned at the beginning, this book is the result of a sincere dialogue between philosophers and clinicians on a phenomenon as important as gratitude, especially in the field of palliative care. The diverse backgrounds of the authors have, in our opinion, contributed to the richness of this dialogue. However, despite the differences between the philosophical and clinical approaches, both coincide in a genuine interest in giving an account of the things themselves, dispensing with any hasty attempt at systematisation.

A book on gratitude cannot conclude without giving thanks. First of all, we would like to thank the Institute for Culture and Society of the University of Navarra for funding the research project that gave rise to this book. Without their help, this book would not have been possible. Special thanks also go to Alicia Hernando for her valuable help in editing the manuscript of this book and to Estefanía Berjón, who superbly managed the research project.

We hope that reading this book will help a wide circle of readers to think about the value of care received in vulnerable situations and the gratitude that patients and families experience in these situations.

María Arantzamendi
Mariano Crespo
Pamplona, May 2024

SECTION 1:

PALLIATIVE CARE AND GRATITUDE

CHAPTER I

GRATITUDE IN PALLIATIVE CARE

CARLOS CENTENO

Gratitude at the end of life: unusual and worthy of study

When I started working in Palliative Care in Los Montalvos, Salamanca, I was surprised by the heartfelt letters of thanks we often received. These letters were passed from hand to hand, left on display and discussed among everyone. Sometimes, instead of finding their way directly to us, families would send them to the "Letters to the Editor" section of the local newspaper, and we would read them there. Whenever this happened, the surprise and joy was even greater. This provoked comments in the hospital and at home, congratulations from the director, calls from the Management Board or from the Regional Ministry... And we, who had just started to work in that unit as a new project, felt happy.

On 10 January 2001, a letter published in *La Gaceta de Salamanca* fascinated us¹. It explained palliative care perfectly, as if it were a master class! There was something special about it. It was written by a simple

¹ *La Gaceta Regional de Salamanca*, Letters to the editor, "La Unidad de Cuidados Paliativos de los Montalvos". 10th January 2001. The text is as follows:

When we all talk about the dehumanisation of healthcare, life has given us a surprise. In a difficult and sad situation we have found a place where persons are persons; they are not numbers or merchandise, at a time when sadness invades you and pain overwhelms you, we have found a place where they listen to you, they share your emotional state "for real", they are concerned as much for the health of the patient and of those accompanying them, not only for the physical but also for the mental and spiritual health of all, resentful when you see a loved one going through the difficult moments to which a terminal illness has subjected them. When life puts you through such an ordeal, the treatment given by each and every one of the people with whom we have had contact in the Palliative Care Unit has been a balm for us, has eased our pain, calmed our anxiety and allowed us to cope with the situation in a much less traumatic way. (...). Thank you all.

family and they dedicated very beautiful sentences to us, seeking to reciprocate what they had received from us. They wanted to make known what they had discovered. At the International Palliative Care Congress in the Netherlands, we presented a first analysis of letters in a scientific communication: it was a surprising way of explaining palliative care².

Years later, I moved to another city. I was about to move to the University of Navarra, and my colleagues from those intense years of work in Salamanca organised a farewell dinner. I felt that a stage was coming to an end, for me and for all of us. And I wanted to compile the letters we had received as a way of closing that cycle, of carrying it in my memory and also of passing the baton on to others. I did so and, at the dinner, I gave each of my companions a bound copy of the photocopies I had made, which I named "Los Montalvos, 2000-2005". Even now, that small volume accompanies me and inspires me.

When I arrived at the University of Navarra, I met many interesting people. One day, María Arantzamendi, a doctor in Nursing, told me about the benefits of qualitative research methods. She told me that it was a different way of exploring reality and that it was very suitable for analysing the hidden values in Palliative Care. I explained how we had analysed some letters and presented them at a conference. She immediately challenged me to be more rigorous and to do an analysis of all the letters in the bound volume. We set about examining them together. When we sent the result of our analysis to the *Journal of Palliative Care* for publication, we had a hard time getting the reviewers to understand the study. We were fortunate that the article was eventually sent to Professor Phil Larkin, who gave a complimentary review and comments, to which the editor himself enthusiastically added his own. And so, the first research article on gratitude in palliative care was approved and saw the light of day³.

At that time, he taught a research course every year at the University of Lisbon in the first Masters in Palliative Care in Portugal. He told the story of Los Montalvos and presented the work of the letters as an example of qualitative research. Listening to him, a nurse doing her Master's degree named María Aparicio, thought that she could analyse her own letters as a Master's research project since she received similar letters at the palliative

² Centeno, C., García, I., Sánchez, L., Rodríguez, B., Vara, F., *Do we really apply palliative care principles in our work? A study of acknowledgement letters from the relatives*. Communication at 8th Congress of the European Association for Palliative Care. The Hague (The Netherlands), April 2003.

³ Centeno, C., Arantzamendi, M., Rodríguez, B. and Tavares, M., Letters from relatives: a source of information, team support and a deep insight into the experience of the family in palliative care, *Journal of Palliative Care* 2010, 26 (3): 167-175.

home care team in Odivelas (near the centre of Lisbon) where she worked. Maria is Spanish and had been working in Portugal for several years. She assured me that the Portuguese expressed their gratitude in different ways and that it would be interesting to compare the similarities between what we received, in a hospital unit, and what they received, working at home. Maria pursued her goal with perseverance, defending her Master's thesis with the highest grade possible⁴. We were then able to compare our respective studies. This second time, in addition to finding nuances between cultures and differences due to the location of the palliative care activity, we came to the conclusion that thank you letters are a users' quality audit of the service they receive⁵.

María Aparicio wanted to continue her research in the field and, when she moved to London, she decided to spend some time exploring the topic of gratitude in Palliative Care. Maria and I accepted the challenge of supervising a doctoral project remotely⁶. The thesis began with an in-depth review of the literature on gratitude in the healthcare relationship and a national study on perceived gratitude in Spanish Palliative Care Services⁷. It continued with a study of the phenomenon through semi-structured interviews with a group of professionals in the sector. The results showed us that we were analysing something peculiar, characteristic of, and a consequence of the holistic and multidimensional approach to palliative care; and also allowed us to confirm the deep meaning for those caregivers who receive this gratitude^{8,9}.

⁴ Aparicio, M., *A satisfação dos familiares de doentes em cuidados paliativos*. Master Dissertation, Universidade de Lisboa, Lisboa 2009.

⁵ Aparicio, M., Centeno, C., Carrasco, J.M., Barbosa, A., Arantzamendi, M., What are families most grateful for after receiving palliative care? Content analysis of written documents received: a chance to improve the quality of care. *BMC Palliative Care* 2017, 16 (1): 47.

⁶ Centeno, C., Aparicio, M., Centeno, C., & Arantzamendi, M., The significance of gratitude for palliative care professionals: a mixed method protocol. *BMC Palliative Care* 2019, 18 (1): 28.

⁷ Aparicio, M., Centeno, C., Juliá, G. and Arantzamendi, M., Gratitude from patients and relatives in palliative care-characteristics and impact: a national survey. *BMJ Supportive & Palliative Care* 2019, Aug 30, pii: bmjpspcare-2019-001858.

⁸ Aparicio, M., *La experiencia de gratitud al cuidar y su significado para el profesional de cuidados paliativos*. Doctoral thesis, University of Navarra, Pamplona 2019. (Online). Available at: <https://dadun.unav.edu/handle/10171/59847> {02.05.2022}.

⁹ Aparicio, M., Centeno, C., Robinson, C., Arantzamendi, M., Palliative Professionals' Experiences of Receiving Gratitude: A Transformative and Protective Resource. *Qualitative Health Research*, 2022, 32 (7): 1126-1138.

Other chapters of this book present some of the results obtained by a working group of philosophers, researchers and clinicians as a result of the interdisciplinary project conceived by María Arantzamendi and Mariano Crespo. For me, as a doctor, it has become clear how much we can learn and deepen our understanding if we were to listen to and converse with thinkers. The title of one of the papers we have published sums up well one of the main findings: "Reflection on the essence of gratitude in Palliative Care: healing in serious illness and professional affirmation through accompanying patients to the end".

Compilations of Letters in Palliative Care Services

With the idea of doing a cross-cultural study, I had the opportunity to visit Ottawa in Canada where I met with the oncologist and palliative care professional Martin Chasen. He too, had a collection of thank you letters, which he kept and read carefully, especially when found he was running low on strength. In Stockholm, at Stockholms Sjukhem, one of Sweden's pioneering centres, Carl Johan Fürst showed me an album-book that they kept in a prominent place. In this book, they wrote down the names of those who died in the unit. Something meaningful was also written about the person, as a way of keeping their memory alive and honouring the work they had done. They would also paste the cards and postcards they received there. In Porto, in the Palliative Unit of the IPO, they published a book with letters from the families to the collaborators. At Grey Nuns Hospital in Edmonton, the latest cards received are displayed on a wall. And in Dumfries, Scotland, the Unit's doctor explained to me that, when submitting the annual evaluation, she enclosed cards as testimony of the quality of care.

At the Palliative Medicine Service of the *Clínica Universidad de Navarra* (the Clinic), we keep these letters and testimonies in a filing cabinet. Very often, they are sent to us spontaneously; while on other occasions, we cut them out of newspapers. I must confess that I also use them as a reminder of the quality of care we provide. Almost every time we receive a letter, I make a photocopy and send it to the director of the clinic. It can certainly be a joy to receive a letter from a grateful family despite the fact that their loved one was not "cured" and I found that it encourages the health professionals to continue to take care of their patients.

Many letters that the Clinic receives are in response to a personalised letter that we send to families weeks after the death of their loved one, which has now resulted in a substantial collection of letters after years of work. But the record in Spain surely belongs to El Sabinal Hospital in Las Palmas. These pioneers in palliative care have kept their letters since the first one

arrived. Marcos Gómez, the director, even refers to them in the annual report.

In palliative care it is typical that letters are addressed to the whole team, which affirms the overall team spirit of caregiving. In these letters addressed to everyone, at times someone is mentioned who was perhaps more involved in caring for a particular patient, but still these personal letters are an exception. There might be other reasons why the next of kin writes or singles out one member of a team: it could be an indication that the relationship was particular to that person and that there was less involvement with the team as such, which would then serve as some food for thought.

Other ways of expressing gratitude

But palliative care is not the only health service which receives testimonies of gratitude, but I believe that their testimonies are quite different from others. Doctors, especially surgeons, often receive personal and luxurious gifts as a sign of gratitude. An oncologist friend of mine from Madrid, had a wall in his living room covered with bottles of *whisky* given to him by his patients (which he did not drink, by the way). It is common sight in hospital wards to see packets and boxes of sweets that were gifted by patients and their families. A colleague of mine, when he was on duty, joked about which floor always had chocolates, and a nurse assured me that there were always snacks from families at the nursing checkpoint.

Some ways of expressing gratitude may be more peculiar to some services. In Salamanca, for example, there was a certain tradition of using the "Letters to the Editor" section of the newspaper. In Pamplona, it is common to see in the obituaries of the press a few words of thanks to the health service that attended to the deceased. In Canada and, in most English-speaking countries, there is more of a tradition of using postcards with printed phrases.

In Las Palmas de Gran Canaria, offices and halls are full of plaques engraved in every imaginable way. It's curious that the Canarians need to materialise their gratitude in this way. Why might it be that they need an indelible medium to ensure that gratitude does not fade away as our memories do?

When the palliative team uses instant messaging applications on their phones to communicate with patients' families (*WhatsApp*, for example), the same system can facilitate expressions of gratitude when the patient dies. We know that the team at Hospice La Cima, in the city of San Salvador, found that almost all of the families they cared for conveyed their gratitude

with short *WhatsApp* messages¹⁰. In these short, condensed messages, they are still able to fit in their thankfulness for the affection, the good disposition and the accompaniment and comfort of the Palliative Care professionals.

In our culture, gratitude is less often expressed in the form of donations. In contrast, it is well known that in the UK, hospices are partly funded by family support. In several UK hospices, in the entrance hall, I have seen murals of a tree with leaf-shaped plaques, engraved with the names of families in various sizes and forms.

Intangible ways of expressing gratitude

Yet, the gratitude that is most appreciated is not the gratitude that we often see in the form of letters or gifts. Priceless gratitude can be seen in the day-to-day work of palliative care, done well. The nature of the work we do, played out over an unhurried rhythm, fosters a climate of slow, pensive conversations and exchanges. A moment of gratitude emerges at its own accord, in the spaces between the coming and going. Sometimes it springs upon you as a conversation comes to a close or it sidles up on you when saying goodbye. The family senses that something is missing and adds: "Thank you for...". And, on a day-to-day basis, it is not expressed in material support and often it manifests without words, or just a few ones at times. Gratitude is perceived, but in an intangible way. It is born in silence and is carried on a mere look or a smile directed at the professional. And the sensitive professional is able to appreciate it when they permit themselves a quiet moment to reflect.

I remember a young woman, finally pain-free after a few days in hospital. We were having a conversation about what to do if things went wrong. She expressed her frustration with the disease: "It's too soon," she would say. Tears escaped her and several times, in the absence of a handkerchief, I had to wipe her tears with the cushion. After listening for a long time, I commented on the fact that she is now pain-free. She interrupted me by saying: "No. The good thing is not only that. What you have given us here, we have not received anywhere else". At that moment, she turned and gave me a broad smile. I remember many other sick people's looks that say THANK YOU in capital letters. The gratitude is perceived with such

¹⁰ Rodríguez, M., Feng, A.T., Menjívar, C., López Saca, M., Centeno, C., Arantzamendi, M., WhatsApp as a Facilitator of Expressions of Gratitude for Palliative Care Professionals. *International Journal of Medical Informatics*, 2022, 166: 104857.

intensity that, many times, the health professional feels blessed and feels that the work we do has something sublime about it¹¹.

Although gratitude is expressed every day in silence, with a look and a smile, it often also relies on physical contact between the professional and the patient. Sometimes, one can sense that the patient subtly responds to an appropriate contact (a light caress of the hand or arm, for example), with a complicit movement, or by squeezing the hand or prolonging the contact. Sometimes, when the consultation is over, it is the intensity of a handshake when saying goodbye or that a final greeting spontaneously turns into a grateful embrace.

Gratitude may also be present at the moment of dying, with the intense grief of separation felt alongside the gratitude for the care received. The precise moment when the patient dies is possibly the most intense for their loved ones. At that moment, although we do not seek to be present, in order to respect privacy, sometimes family members let us know just before. And then we are there at the moment or we appear moments after the death. It is up to us to confirm the death and to offer condolences and our support to the family, while remaining in the background. Grief at such moments is expressed in a thousand ways and often with great intensity. When, in the midst of it all, the family member forgets their grief for a moment and thanks you, it is a sign that the family has integrated the team into their heart (it is an intimate moment) and is also making a very positive assessment of how their family member has been cared for until the end. In the midst of the worst, the family is able to keep in mind what they have received from the team and to be grateful for it. "I will never forget; I will never forget what you have done," I heard recently.

In a few lines, I have summarised a research itinerary that began twenty years ago with the unusual letter from a grateful family. Although gratitude is present in many ways in the healthcare relationship, in palliative care it is embodied in heartfelt written testimonies that professionals' treasure, because of the significance they hold. They are grateful for the way we work, but above all families are grateful for the relief of the profound suffering the end of life brings. This gratitude expressed in words and on paper is only a part of the gratitude that is received when working in palliative care. The intense contact with the patient, the tenor of palliative care itself, means that every day we receive more from the patient and family than we have been able to give them. And we receive these gifts in the silence of a look or a grateful smile.

¹¹ Rodriguez-Prat, A., Experiencing the Sublime in a Palliative Care Unit. *Journal of Pain and Symptom Management*, 2021, 62 (1): 202-204.

CHAPTER II

NUANCES OF GRATITUDE IN PALLIATIVE CARE

MARÍA ARANTZAMENDI

Gratitude in the care relationship

Gratitude is present in life and constitutes a quality of being human. It has been the subject of both philosophical and theological reflection and has recently begun to be studied, in the field of health, within the framework of positive psychology¹. Gratitude has been considered as a virtue, an emotion or even a personality trait².

A first approach to the phenomenon shows that gratitude has as its object something that has been experienced as positive and that has its origin in the benevolent action of another person. It is, therefore, an interpersonal experience that aspires to be expressed to its recipient. Gratitude arises when one person perceives that he or she has received something good from another. This also occurs in the context of health³. People are grateful to health professionals who cared for them and helped them, when they gave birth or when they are cured of an illness⁴. Such gratitude in the context of

¹ Cunha, L.F., Pellanda, L.C., Reppold, C.T., Positive Psychology and Gratitude Interventions: A Randomized Clinical Trial. *Frontiers in Psychology* 2019, 10, p. 584.

² Roberts, R., *The Blessings of Gratitude: a conceptual analysis*. In: Emmons, R.A., & McCullough, M.E., (ed). *The psychology of the gratitude*, Oxford University Press, Oxford 2004, pp. 58-78.

³ Day, G., Robert, G., Rafferty, A.M., Gratitude in Health Care: A Meta-narrative Review. *Qualitative Health Research*. 2020, 30 (14): 2303-2315.

⁴ Aparicio, M., Centeno, C., Robinson, C., Arantzamendi, M., Gratitude between patients and their families and health professionals: a scoping review. *Journal of Nursing Management* 2019, 27 (2): 286-300.

the care relationship is also present in palliative care,⁵ which is what we will elaborate on here.

A professional recalls the experience of a mother's gratitude:

"I have been remembering some phrases that parents have said to me, which I personally will never forget in my life (...) There is one, for example, that I remember very well, that of a mother of a child who died at the age of 7 (...) She told me that they usually tell you that the happiest moment in a person's life is the birth (...). However, when a child dies, it is the most terrible moment. Then she said to me: "Look, I don't remember the face or the name of the midwife who assisted me, but I will never forget your face and your name. Thank you. That is a phrase that I have engraved in my heart, (...) These things are unforgettable. They are unforgettable"⁶.

Gratitude in palliative care is an international reality

Such an experience may seem unusual. It may come as a surprise considering that it is a situation of grief and loss of a loved one. At the beginning of life there is certainly gratitude, but also at the end.

Palliative care provides care for people who have an advanced, irreversible illness and a limited prognosis for life. Palliative care improves the quality of life of patients (adults and children) and their families when faced with the physical, psychological, social or spiritual problems inherent in a life-threatening illness. It provides a support system to help patients live as actively as possible until death, yet it is not recognised as a human right⁷.

However, in society debates about palliative care have tended towards a negative discourse characterised by a sad perspective on life. It is still associated with death and ideological social debates and, to a lesser extent with the provision of a health service^{8,9}.

How is it possible that in a context of loss and the end of life, there is gratitude? The person experiences the progression of the disease and its

⁵ Cf. Carlos Centeno's contribution to this volume.

⁶ Aparicio, M., *La experiencia de recibir gratitud al cuidar y su significado para el profesional de cuidados paliativos*. Doctoral thesis... op. cit.

⁷ World Health Organization (WHO). *Palliative Care*.

<https://www.who.int/es/news-room/fact-sheets/detail/palliative-care> {20.08.2020}

⁸ Carrasco, J.M., Gómez-Baccaredo, B., Navas, A., et al., Social representation of palliative care in the Spanish printed media: A qualitative analysis. *PLoS ONE* 2019, 14 (1): e0211106.

⁹ Shalev, A., Phongtankuel, V., Kolov, E., et al., Awareness and Misperceptions of Hospice and Palliative Care: A Population-Based Survey Study. *American Journal of Hospice and Palliative Medicine*. 2018, 35 (3): 431-439.

consequences, such as the manifestation of multiple symptoms and their deterioration, the emotional impact thereof, the loss of autonomy, among other factors. Little else can make one more aware of how vulnerable we are during this time¹⁰. The context of palliative care is very specific, since knowing that a loved person has died (or will die), brings suffering. But what happens then for gratitude to emerge in such a situation? Can gratitude emerge in such a situation? The answer is a resounding yes. The thank-you press releases published by relatives are a natural example of this, and yet they only scratch the surface. There are an infinite number of expressions of gratitude in palliative care, as found in the gestures of gifting chocolates, writing letters and words, and expressing congratulations. A variety of ways of expressing, each in their own way, their gratitude towards the health professional and the work carried out. But these expressions also occur unsurprisingly in other care contexts where patients are recovering and getting better.

A survey carried out in Spain in palliative care services shows that 80% of healthcare professionals receive explicit thanks after providing palliative care¹¹. This signifies an overwhelming affirmation of the positive appreciation of the care received during a process that is difficult for everyone. We may think that this tendency to express emotions and show gratitude is very specific to the cultural context, but the evidence suggests that culture influences the way gratitude is shown and not whether it is demonstrated or not. For example, in the United States, a family who lost their son to a serious haematological condition set up the DAISY foundation as a sign of gratitude for the care they and their son received. This initiative was to make visible the exquisite and compassionate care they received. In this case, they highlighted the work of the nurses. Out of a need to convey their gratitude and honour all the care they received, they created a foundation to enable other patients and families to express their gratitude to the nurses who provide extraordinary compassionate care¹².

We know that palliative care professionals from all over the world receive expressions of gratitude. Our list includes the United Kingdom, Aachen (Germany), Cape Town (South Africa); Stockholm (Sweden); Las Palmas de Gran Canaria (Spain), Italy, Canada, the United States, affirming

¹⁰ Broyard, A., *Ebrio de enfermedad*. 2013, Ed. La Uña Rota, Segovia, pp. 23-24.

¹¹ Aparicio, M., Centeno, C., Juliá, G., and Arantzamendi, M., *Gratitude from patients and relatives in palliative care-characteristics and impact: ... op. cit.*

¹² The Daisy Foundation. Honoring nurses internationally in memory of J. Patrick Barnes. <https://www.daisyfoundation.org/about>

that gratitude in palliative care is present internationally¹³. Here are some examples of testimonies that convey a deep, intense and lasting gratitude.

"Thank you, thank you, thank you. I will never tire of saying it... Again, I say thank you. You have been my rainbow in a tunnel" (This is part of the story of a daughter who has lost her mother to esclerosis)¹⁴

"It is said, sometimes too often, that one cannot find the words to say thank you for a particular act. I have searched for a way to describe how they behaved in this unit with my father in the months he was with them, how they cared for him, as if he were one of their family, their pampering even in the smallest details, their great affection in those very difficult moments, their concern for him and my mother, their support for each of us and, in short, how they transformed a sad place, a few bitter days into something warm and peaceful. I have searched for ways to thank them, but I don't think I can ever thank them enough. I send you all my love"¹⁵.

Who gives thanks? And how?

The presence of gratitude in palliative care is well established, but who gives thanks? Patients and relatives convey their gratitude throughout the entire illness process, but especially in the final phase. Relatives express gratitude, especially in the final moments, just after death and more than 50% are shown during bereavement¹⁶.

Patients themselves also pass on their gratitude during their illness and some even plan and instruct their family members to express their gratitude to professionals when they are not there. One might ask, how can one think of expressing gratitude when they are dying or grieving the loss of a loved one?

The patient or relative makes an effort, musters up the energy and courage to approach the professional who cares for them or has cared for them and conveys that they value their work very much and are grateful for

¹³ Cf. Aparicio, M., Centeno, C., Carrasco, J.M., Barbosa, A., Arantzamendi, M., *What are families most grateful for after receiving palliative care?...* op. cit. p. 47.

¹⁴ *El correo de Alava* (Cancho, R.). "Han sido mi arco iris en un túnel". 13 October 2018.

<http://osaraba.eus/wp-content/uploads/2018/10/Rreportaje-Unidad-de-Medicina-Paliativa-de-la-OSI-Araba.pdf>

¹⁵ *La Gaceta Regional de Salamanca*. Letters to the editor, "La unidad de Cuidados Paliativos de Los Montalvos", op. cit.

¹⁶ Cf. Aparicio, M., Centeno, C., Juliá, G. and Arantzamendi, A., *Gratitude from patients and relatives in palliative ...* op. cit. p. 3.

it. In this interaction, is there a patient-health professional relationship, or a relative-health professional relationship? What is the nature of the interaction that captures such appreciation? Well, examples of terms that are often heard include *friends, how they took care of you, as if you were family, and they indulged us even in the smallest of details*. But who is really doing the thanking if the one who writes is the relative or the patient, but uses words like these? The relationship is a professional one between the patient and their family and the health professionals, but the narratives convey a different inter-relational experience, which warrants further reflection.

"Thank you from the bottom of my heart, friends, for your presence and for every grain of sand that each of you contributed to the process".

"The reason for this letter is none other than to thank you for the treatment given, both to my mother, Laura, and to all the family And friends, once again, there you were, silent, being there but not being there, far away but close, her absence and your presence, both silent, and between them, the pain, a dry pain, like a "sledgehammer", but mitigated by the company of a handful of professionals who have made a family broken by pain, a pain that lasted six years, look at death head on, a pain that lasted six years, to look death in the face, without fear, without resentment, and above all, thanks to you, that "I don't know what" that death produces, the loss of a loved one, becomes the closest thing to something "natural".

The example shown is part of a letter, but professionals report that they receive expressions of gratitude in a variety of forms: words, gifts of food, thank you letters and to a lesser extent personal gifts or donations. Each person conveys it in his or her own way, as he or she wishes, and shows greater or lesser personalisation of gratitude, bearing in mind the recipient. Thus, one professional interviewed said:

"She had said to me in her last days: "I am preparing something that I hope you will like". After the funerals and everything, one day her husband came and gave us the recording... It was a real gift, because it's a gift that I make a lot of use of. It struck me, it hit the nail on the head. That woman, watching us, maybe she realised how we enjoy teaching those who come, how we enjoy teaching at the university, how we try to show what palliative care is, and she was like: "I'm going to help him by giving him a tool so he can use it for what he likes", and he got it, of course he did!"¹⁷.

¹⁷ Aparicio, M., *La experiencia de recibir gratitud al cuidar...* op. cit., p. 168.

The focus of gratitude

The expressions of gratitude are very diverse; but what generates this desire or need to convey gratitude? What is it that patients and families are grateful for?

Analysis of thank you letters from several palliative care services in Portugal and Spain shows that relatives highly value the humanity, professional care, emotional support and the creation of a special atmosphere that provides holistic care¹⁸.

"In a difficult, sad situation, we found a place where patients are people, not numbers or commodities..."

"Our gratitude is to those people with vocation, zeal, kindness, tenderness and professional consistency who are far above anything that can be expected or imagined".

"I will always be grateful to you, and I thank God for being so privileged and for having seen the beautiful face of death which, thanks to you, I now know exists".

"I am especially grateful for the speed with which he has responded to our phone calls or personal requests for help when we have needed it".

Likewise, a later study of letters from relatives who cared for their loved one at home with the help of the palliative care service, highlights the care received, especially valuing the kindness, listening skills, empathy, closeness and the therapeutic relationship established; the relief of suffering, the improvement in well-being and quality of life, the possibility of dying at home with support and the feeling of serenity during bereavement¹⁹. The aspects mentioned are diverse and relate not only to the care of the patients, but also to the relatives.

"Thank you for helping the sick and not only the sick, but also the relatives who are depressed and don't know how to deal with a patient".

"With your ability and sense of solidarity, you made us feel less alone in the most painful moments we went through and I am sure that you helped to reduce my father's suffering."

¹⁸ Cf. Centeno, C., Arantzamendi, M., Rodríguez, B. and Tavares; M., *Letters from relatives...* op. cit., p167.

¹⁹ Cf. Aparicio, M., Centeno, C., Carrasco, J.M., Barbosa, A., Arantzamendi, M., *What are families most grateful for after receiving palliative care?... op.cit. p. 6.*

"I am aware that I have done everything possible to ensure that he suffered as little as possible during the period of illness, and then in death. But this situation was achieved to a large extent only because of your extraordinary support....".

Patients and families tend to highlight the aspects from this interaction with palliative care professionals that touched them the most. They convey many emotions, adjectives and use words such as: unconditional, lifelong...

"During the six months that he remained in the room of this unit, the stations, medical and nursing care provided were those necessary for the physical well-being of our father, as we could not fight his illness with other weapons. But we do not only want to highlight these facts; the performance and the know-how of the staff of this unit went beyond what we could all expect. Our mother, as a companion, and our father were cared for in all their needs as people, appreciated and loved, and their stay during the six months was the closest thing to our home..... They all know that our thanks can never be sufficiently recounted in these lines".

Reading these expressions of gratitude, it seems as if words fall short, as some explicitly put it; gratitude is not limited to an intellectual acknowledgement. But what is it that is common to all these expressions, what is it that, deep down, in their essence, they are grateful for and that makes them, in spite of suffering or pain, go out of their way and turn to the professional to convey gratitude? "Giving thanks means looking up for a moment and recognising the other as a person, as someone more than a means to the pursuit of my ends"²⁰. It does not seem that this thanksgiving is reduced to a fleeting courtesy, but is full of gratitude. Gratitude for...?

"Two months have passed,... I, her eldest daughter, who was always her secretary in these matters of thanking doctors and nurses, have felt incapable every time I have tried to write these lines. I am beginning to come out of my disbelief and begin to accept the reality, with all the pain in my heart, that we will never take her home again... I send you our affectionate remembrance and the feeling of gratitude, without ceilings, from the four children for the attention full of delicacy and kindness that we all received... by some great professionals... Forgive us for not knowing how to express it to the extent that they deserved. For our mother, everything is too little, and I suffer for not knowing how to do it as she would have done it. She always did it well. With our fondest memories, the expression of our most sincere gratitude and the wish for the best in your lives, we send you our most affectionate greetings".

²⁰ Schwarz, B., *Del agradecimiento*, op. cit., p. 28.

"The only reason I am writing to you is to thank you for all that you did for my sister... I would like to tell you that every day that passes I realise how much more you have done for my sister, which goes far beyond the obligation to treat a sick person. You were patient, agreeable, loving and kind not only with her, but also with me who was having a hard time... I reiterate my thanks and I encourage you to continue helping as you did with my sister. A hug to all of you with my deepest thanks".

What is the object of gratitude understood as the authentic and genuine thing to be grateful for? What underlies it?

"Nowadays, when everything is reduced to numbers, it is significant, striking and to be appreciated that, in the face of such a painful situation, personal treatment takes precedence over the medical aspect, which is of the highest level... I sincerely believe that we don't know what we have until we need it. I can only tell you one thing: Thank you. "Everyone sees what you look like, but few feel what you are" (Machiavelli)²¹.

Appreciation goes beyond the expression of thanks, encouraging and commending professionals to continue so that other patients and families, like themselves, can benefit from the care received.

"...you have contributed over the years to my dear mother's wellbeing".

"...I wish you strength and courage and my sincere congratulations that you manage to continue on this path, until the end [of people's lives]".

"Thank you very much and we look forward to your continued good work.

"I would like to thank you on behalf of all my family and myself for the treatment and attention you received, and I would like to congratulate the management of the Centre, doctors, nurses, religious services... and all the other people who provide their services there, who treat the sick with such sympathy, simplicity and humanity. Without further ado, congratulations and onward".

"We would also like to encourage them to continue their work, which was so beneficial to us during the painful illness of our husband and father".

²¹ *Tribuna de Salamanca (Vaquero-Veroz), Carta de agradecimiento al Departamento de Oncología-Hematología. 1 December 2001.*

The impact of gratitude

The experience and expression of gratitude is important for the development and maintenance of healthy relationships²² or even to protect health professionals from *burn out* syndrome²³. Authentic expressions of gratitude shown suggest that they have received more than expected, a gift that cannot be asked for, an involvement, affection or gift of the human being that is the professional and that they have become a giver of something that patients and family deeply value. This leads some relatives to offer to collaborate and contribute.

"(...)I know I can help your team in some way. As a nurse? It's a bit late for that. As a volunteer supporting the families, who knows! (...) I repeat that I am at your disposal for whatever you need, even if that means just driving".

Recent studies suggest that when patients express gratitude, their own perceptions of quality of life improve²⁴. On the other hand, palliative care professionals attribute to the expressions of gratitude they receive immense value and a possible impact on job satisfaction, a source of support in difficult situations and encouragement to continue. All these potential impacts are not related to the 'amount' of gratitude received, suggesting that it is not the 'amount' that is key but the gratitude itself²⁵.

These snippets of experiences of gratitude in the clinical context of palliative care show that gratitude is also common in situations of serious advanced illness. It is an acknowledgement of a good provided that is recognised in the care received but goes beyond that and generates a deep and authentic feeling of gratitude that transcends what might appear to be a strictly professional relationship.

²² Lambert, N. M., Fincham, F. D. Expressing gratitude to a partner leads to more relationship maintenance behaviour. *Emotion* 2011, 11 (1): 52-60.

²³ Converso, D., Loera, B., Viotti, S., and Martini, M., Do positive relations with patients play a protective role for healthcare employees? Effects of patients' gratitude and support on nurses' burnout. *Front Psychology*. 2015, 21 (6): 470.

²⁴ Althaus, B., Borasio, G.D., and Bernard, M., Gratitude at the end of life: A promising lead for palliative care. *Journal of Palliative Medicine* 2018, 21 (11): 1566-1572.

²⁵ Cf. Aparicio, M., Centeno, C., Juliá, G. and Arantzamendi, A., *Gratitude from patients and relatives in palliative ...* op. cit. p. 6.

