Emotional experiences in palliative care and professional quality of life: a qualitative approach

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Abstract

Objective: To explore the experiences that significantly impact the professional quality of life of people providing palliative care (PC) in Ecuador.

Design: Observational cross-sectional qualitative research.

Methods: In September 2022, 10 focus groups were carried out in four cities in Ecuador; each group lasted from 1 to 2 h, was audio recorded, and transcribed verbatim. Recruitment was conducted through convenience sampling, and a total of 71 individuals (15 students, 50 professionals, and 6 volunteers) linked to PC participated. Content analysis with a phenomenological and inductive approach was used to analyze the data.

Results: People recognized their experiences in PC as having positive and negative impacts on their professional quality of life. Experiences were mapped as affecting them at individual, relational, and contextual levels. These experiences included personal growth, opportunity to provide care, teamwork, death-related issues, inability to deal with work-related stress, social acceptance of PC, and dealing with inefficient health systems, among others.

Conclusion: Despite the positive emotions that arise with caring for others, individuals working and volunteering in PC experience situations that influence their professional quality of life. Addressing these factors to increase satisfaction and ease the burden of PC work is essential. Undergraduate education, continuous professional training, and PC teams should incorporate actions to address these factors at all levels, such as teaching coping skills, fostering social support, and increasing awareness of PC.

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Plain language summary

How experiences shape professional quality of life in palliative care

This study explored how working in palliative care impacts the professional quality of life of people providing palliative care in Ecuador. The research team conducted 10 focus groups in four cities in Ecuador with 71 participants. The results show that people's experiences impact their professional quality of life in positive and negative ways. These experiences also affect people at individual, relational, and contextual levels. This study has identified common experiences that should be addressed to increase satisfaction and ease the burden of working in palliative care. These should be considered in undergraduate education, continuous professional training, and within palliative care teams.

Introduction

Palliative care (PC) aims to alleviate the severe suffering caused by serious health conditions by providing comprehensive support through an interdisciplinary team that addresses the patient's and family's multidimensional needs.[1] The scope of PC extends beyond the patient's passing, encompassing assistance during the entire bereavement process and supporting the family's recovery.[2] A complete PC team includes professionals able to ensure that the patient's and the family's needs are met, it must be holistic.[3]

Caring for others is usually accompanied by positive feelings of gratification for contributing toward helping others.[4] This state of joy or pleasure experienced by the professional is known as compassion satisfaction and is related to increased commitment, effort, and security in their interaction with the patient and the family, accompanied by greater satisfaction with their performance.[5]

Continuous exposure to suffering can lead to what is known as compassion fatigue, a state of mental and physical weariness that could have negative effects on family dynamics,[6] physical, emotional, and organizational well-being, impacting productivity.[7] Some signs and symptoms of compassion fatigue are exhaustion, anger, irritability, negative coping behaviors, alcohol and drug use, decreased job satisfaction, absenteeism, difficulty in decision-making in caring for others (it could be negligent),[8] alterations in professional's ability to empathize, dissociative behaviors, and constant psychological distress,[5] and avoidance behaviors.[9] Furthermore, compassion fatigue can contribute to an increase in medical mistakes, hinder effective communication within the healthcare team,[7] and act as a barrier to providing proper PC.[10]

Empathy, resilience, and hope are personal protective factors against compassion fatigue.[5] Providers who empathize with patients and develop strong relationships perceive their work as more meaningful.[8] Moreover, certain sociodemographic factors such as advanced age, education level, and experience are considered protective factors against compassion fatigue.[5] External factors that mitigate compassion fatigue are manageable working hours, support management, and reasonable cases for a day (workload).[5] Adequate economic remuneration, positive relationships with the healthcare team, and access to resources and support can decrease compassion fatigue.[11] On the other hand, rurality and its related barriers may also increase it.[11]

PC teams are affected by the above signs and symptoms of compassion fatigue and health services should develop support mechanisms appropriate for their communities. By getting a deeper understanding of the experiences and perspectives of people directly involved in PC provision, we can better the interventions and support to effectively address the challenges they encounter, especially in a country like Ecuador where PC is not well established and is still unknown to many.[12] Thus, the research question guiding this qualitative study was: What experiences have impacted professionals, volunteers, and students in Ecuador in themselves related to the reality of PC?

Methods

This observational qualitative study had the Ethical approval of the Research Ethics Committee of Universitat de les Illes Balears, UIB [274CER22]. The reporting of this study conforms to the consolidated criteria for reporting qualitative research (COREQ)[13] (Supplemental Material).

Sampling and recruitment

Recruitment was conducted through a non-probabilistic convenience sampling, including individuals from a Hospice and the Ecuadorian Association of Palliative Care (ASECUP, for its name in Spanish). Letters were distributed through institutional emails and social media messages, and interested individuals were invited to contact the project's principal investigator in Ecuador for more information. Professionals, volunteers, and students linked to PC care in four cities in Ecuador (Quito, Guayaquil, Cuenca, and Loja) participated. Inclusion criteria were as follows: (a) professionals currently in the direct care of PC patients, volunteers accompanying PC patients, or students in a university degree program who had completed an internship in a PC care unit during the current academic year; (b) people over 18 years of age; and (c) people who consent to participate. There were no excluded participants.

Data collection

Ten focus groups (FG) were conducted in September 2022 ($n=3$ FG with students; $n=7$

FG with professionals and volunteers). Each group lasted from 1 to 2 hours and was conducted by AJCL, (female) and SV (male), both PhDs in Education, researchers at UIB, and experts in group dynamics. Only the participants and the two researchers were present during the development of the FG. This data collection technique was selected because FG allow to shed understanding and meaning on the object of study, both for the participants and the researchers.[14] Data were collected in different settings to accommodate participants: in Quito, the FG were carried out at a university and a local Hospice; in Guayaquil, they were carried out at a hospital (workplace); in Cuenca, they took place at a local PC organization; and in Loja, at a university. The interview guide was not directly shared with participants and there were no field notes taken during the FG. Data collection stopped at 10 groups when the research team determined saturation had been reached.

Participants signed an informed consent form, and two members of the research team explained and answered any questions regarding the project before starting the FG. No relationship was established prior to the commencement of the study and only general information about the researchers was shared with participants (e.g. country of residence, classes taught at UIB, and previous experiences facilitating groups and researching in PC). With participants' consent, all groups were digitally recorded in audio. Group topics included an exploration of the individuals' critical experiences related to fatigue, burnout, satisfaction, self-care practices, and strategies to stay in contact and transition positively with illness and death. This manuscript delves into experiences related to fatigue, burnout, and satisfaction.

Data analysis

This study used a qualitative content analysis with a phenomenological and inductive approach to understand the meanings the participants assign to their experiences. The authors used an interpretative phenomenological analysis with an integrative hermeneutic phenomenology.[15,16] Data analysis began immediately after FG were completed. FG recordings were transcribed verbatim and the transcripts were not returned to participants. An initial framework for the coding of group transcriptions was developed. An investigator (PHA) coded transcripts independently, meeting with other authors (AJCL and SV) to discuss coding after each transcript, using the constant comparative technique.[17] Data analytic strategies were implemented, sorting through the data to identify similar and important features to decide on categories that hold true for the data, and looking for differences and commonalities for further consideration and analysis. Regular meetings were held with research team members to address trustworthiness.[18] Using Atlas.ti v23, coding reports were run, reviewed, and discussed by research members allowing for re-reading, reviewing, and refining of the findings.

Results

A total of 71 individuals (13 men and 58 women) met the inclusion criteria and participated in the FG; there were no dropouts. There were 15 students, 50 professionals, and 6 volunteers in PC. The participating professional and student profiles were physicians (adult and pediatric), social workers, psychologists, nurses, nutritionists, physiotherapists, and occupational therapists. The mean age of the sample was 20.8 for students and 40.2 for professionals and volunteers, and the average time working in PC was 10 years. Details from the participants have not been included, as the focus was on analyzing the results with the PC team as a whole in mind.

As in previous research,[19] our results were mapped on different levels; however, we combined their 'organizational' and 'policy' levels in one named 'contextual/structural'. Thus, the themes identified were mapped on the individual, relational, and contextual/structural levels. The participants' experiences were characterized by positive and negative factors that are perceived as both a cause and a consequence of signs and symptoms of compassion satisfaction, burnout, and compassion fatigue (see Table 1).

The following section deepens the findings by level and exemplifies the themes with verbatim participants' quotes. The themes are shown in bold.

Individual level

This level comprises individual experiences that are lived and perceived independently rather than as part of a group, community, or system. Positive outcomes of working in PC included accounts of **personal growth**, understood as maturing or transforming oneself positively due to the

Table 1. Themes surrounding the experiences of working in PC (frequencies shown in square brackets).

	Individual level	Relational level	Contextual/structural level
Factors with positive impacts	• Personal growth [28] • Value life more [21] • Personal experiences as tools [6]	• Opportunity to provide care [64] • Teamwork [15] • Post-death gratitude [5]	• Holistic care [7]
Factors with negative impacts	• Death-related issues [61] • Demanding job [21] • Inability to cope with stress from work [21]	• Over-involvement [27] • Consequences on patients' family members [21] • Communication-related issues [20] • Social acceptance of PC [5]	• Inefficient health system [18] • Lack of knowledge • Socioeconomic contexts [15] • Late referral to PC [9]
PC, palliative care.			

experiences at work. For example, a participant mentioned that he had grown because 'I see life go by in the blink of an eye' (student, FG 1).

Another positive factor at the individual level was being able to **value life more**, which involves learning to further appreciate life and its nuances. According to a participant, in PC 'you learn to value life. It teaches you to be more human (. . .)' (professional, FG 4). Finally, another common experience was the **ability to use personal experiences as tools** or instruments for working in PC and better empathize with patients and families. For example, a participant commented 'Seeing your father and mother die. . . helps you. You have an experience of pain that can also turn into a tool to help others' (professional, FG 2).

Regarding the factors negatively affecting participants at an individual level, **death-related issues** were recurring. Although these could also be perceived as a relational factor, participants' comments frequently referred to how the experience affected them individually, so it was placed at this level. Participants' comments varied when talking about death. There seem to be different perceptions about death and its consequences when it refers to pediatric and young adults; patient's death; acknowledgment of the fact that life is finite; and fear of your death or that of someone you care about. However, participants mentioned that in general, '[PC] takes you, number one, on a personal level to experience that suffering when you realize the reality, the finiteness of life, both yours and the people you love' (volunteer, FG 2).

PC as a demanding job was another theme that negatively affected participants at an individual level. The challenging nature of working in PC involves emotional, physical, and cognitive demands. One of our participants mentioned that certain situations are particularly harder than others, for example 'when there are people who question things from the afterlife, the spiritual part, and sometimes we are not prepared, nor do we have the knowledge to be able to answer consistent with what we have been asked' (volunteer, FG 9).

Finally, the **inability to cope with stress from work** was another negative consequence of working on a PC. In this category, we excluded the consequences of overinvolvement with patients. A participant clearly describes the difficulty of not taking home the anxieties or worries from work:

> Emotionally, I did leave tired; apart from the fact that I was already physically tired, there was physical and emotional exhaustion. And it happened to me, for example, that I would go to sleep, but I kept thinking about what happened to me or about the story that impacted me that day. Or it may not be from that day, it may have been a month, and I keep thinking about what happened to that patient. (professional, FG 3)

Relational level
The factors that are part of this level are those that affect an individual's life through the relationships that arise from working in PC. When viewed through the lens of systems theory, this level includes the micro, meso, and exosystem.[20]

The most frequently mentioned positive factor at this level was having the opportunity to care for someone else. This involved the gratification of assisting others or having the comfort of helping others, witnessing a patient's improvement or symptom management, supporting individuals through the process of dying or accepting an illness, being accepted by the patient, or receiving positive feedback from a patient. A participant explains it as follows: 'What is really satisfying is to see that, through your guidance and support, the families of the patients manage to carry out this process, perhaps more lightly, despite how difficult it is' (professional, FG 2).

Another important factor was **teamwork.** Collaborating with the rest of the PC team and/or receiving help from the team members when needed eased the burdens of work and contributed to the main goal of helping others. One participant described that 'the most enriching thing (. . .) is knowing that we also have each other on the team (. . .) to be able to support each other and make decisions for the well-being of that patient' (volunteer, FG 2).

The last commonly mentioned factor was **post-death gratitude** or receiving recognition or appreciation from a deceased patient's family. Being appreciated as people and as workers meant a lot to the participants; one mentioned: 'The families return. . . I think that gratitude is really legitimate (. . .), it's like heartfelt; they are really very grateful for a job that we do' (professional, FG 2).

Regarding the negative factors at the relational level, **over-involvement** being affected by a patient's situation or over-identifying with him/her was a recurring strain. Also, witnessing the **consequences on the patient's family members** was another factor that negatively affected people involved in PC. This included over-empathizing with the emotional impact of relatives of people in PC. As a participant puts it,

> It is difficult to find that balance and set a threshold for how far I will get. And many times, it is very easy to make friends and cross that threshold with the family or the patient. And once you get past that, it's harder to handle. (professional, FG 4).

Another main factor involved all the **communication-related issues** that PC workers experience. These included a lack of positive teamwork with other colleagues due to different points of view or diminishing someone's expertise, as well as invalid efforts to make relatives or patients understand their situation or PC-related concepts and suggestions. A participant of the expert group describes these communication issues as a 'resistance':

> There is resistance. . . on many occasions so marked, that it is exhausting because you deplete all the alternatives, all the means of communication, but obviously, you have to respect their decision in the end. And sometimes it is very hard to have to see a person suffer, have pain, and who does not accept being helped. (professional, FG 2)

The **social acceptance of PC** also influenced participants' experiences. This referred to the lack of approval from society (i.e. relatives, and friends) for working in PC. For example, when knowing they are involved in PC, they get comments such as 'What are you doing?! It seems to me that this is negative, you should no longer have negative things in your life' (professional, FG 2).

Contextual or structural level

This level encompasses elements of the culture and institutions that individuals cannot directly modify. It can be compared to the macrosystem within Bronfenbrenner's ecological systems theory.[20] In this level, only one positive factor was identified, **holistic care**. It emphasizes the multidisciplinary and diverse nature of PC, allowing individuals to take full advantage of its approach.

> In PC we have learned to approach the person from the human side (. . .). We have learned to connect not only with the physical part, but with the spiritual part, and the social part, and you see that all is integrated. (volunteer, FG 8)

Regarding the factors that negatively affected participants, the **inefficient health system** was addressed frequently. Participants mentioned their wrath due to all the problems rooted in the health system such as lack of medication, resources, or training that affected their patients. Some participants explained how Ecuador has a national strategy to apply proper PC, 'but there is no health team. In other words, there is lack of resources, lack of personnel, and lack of all' (professional, FG 10).

Another commonly mentioned negative structural factor was **the lack of knowledge**. This refers to illiteracy or ignorance about PC issues that affect patients' treatments and care. This theme does not include communication issues with colleagues and lack of instruction due to an inefficient health system. One participant mentioned the experience of working with other colleagues during the pandemic and how 'it was possible to feel the ignorance about PC; it was visible. There was a lot of limitations regarding the management of these patients. Patients who came in at the end of life. . . care and quality of life were not offered' (student, FG 6).

The **socioeconomic context** of patients and their families was another factor that negatively affected participants. They mentioned feeling overwhelmed due to the difficult social and economic realities of patients. A story by one of the experts shows the reality some people experience and how it affects others who are not able to modify it:

> It is also very painful when we arrive at a house and see that, although the issue is working quite well, the family is going through sacrifices and very, very, very complex relationship logistics. So, one would like to go further but, of course, it is not always possible. [For example,] you see that there are girls and adolescents out there and they have to give up the room to their grandfather and they have to sleep on the living room floor. . . So, it's complex. They are hard things. (volunteer, FG 8)

Last, **the late referral to PC** is another issue negatively affecting people working in PC. They argue that some patients are still being referred to PC services too late (e.g. only at the end of life); thus, they are not able to properly care for him/her and provide a better quality of life. When cases like this happened, a participant mentioned that 'you are left with all that feeling of everything that could have been done or we would have done as an institution for that family' (volunteer, FG 2).

Discussion

People working in PC experience a wide range of emotions that tend to fluctuate during their work, putting them at risk of developing compassion fatigue and burnout.[21] This manuscript presents an exploration of personal narratives concerning the experiences that have impacted people involved in PC in Ecuador. To the best of our knowledge, this is the first research that examines the individual and collective experiences of workers, students, and volunteers who are part of PC teams in Ecuador. As in previous qualitative research,[19] participants' experiences were mapped into different levels: individual, relational, and contextual or structural. Participants identified those experiences as impacting them positively and negatively in and outside work. These could be perceived as both a cause and a consequence of signs and symptoms of compassion fatigue.

The shared experiences do not differ much from PC professionals in other countries.[3,5,21–23] This could be because human suffering is universal, and health systems might face similar problems delivering proper PC, especially to vulnerable populations. In addition, given that PC development is relatively new in Ecuador,[24] healthcare providers might still be adapting international models and expectations to the reality of a country where death is still taboo and PC provision does not reach all who need it.[12] Our current results also indicate that there has not been much development in addressing the barriers to PC in the last years, given that the experiences described relate to those already identified by caregivers in Ecuador in previous research.[25]

Compassion satisfaction has been portrayed as the positive side of caring for others[5] and few studies delve into it. In this study, positive experiences at the individual level included personal growth, valuing life by having a different perspective of what is important and using personal experiences as tools to help others. Personal growth has also been reported in previous literature with nurses in PC.[23] At the relational level, the opportunity to provide quality care, proper teamwork, and gratitude from the families was also perceived as positive. This is supported by previous research that shows that having social support and cohesion among the team is a protective factor to prevent compassion fatigue and ease the burdens of working in PC.[23] Moreover, sharing experiences within the team contributes to improve competence and reduce feelings of failure.[22] Feeling helpful or producing benefits for patients also promotes satisfaction and fulfillment.[19] At the structural level, only the holistic concept of how PC should be provided was perceived as positive.

On the other hand, negative factors might challenge a person's confidence and cause them to

question their work and vocation. Students or junior staff might be at higher risk or more vulnerable to these challenges 'as they have limited exposure to challenging clinical experiences and often have not yet developed appropriate coping strategies'.[21] The experiences perceived as negatively affecting participants at the individual level were dealing with death-related issues, how demanding working in PC is, and the inability to cope with stress from work. They were especially affected by working with pediatric patients. Research shows that working with dying children and adolescents favors the appearance of strong emotional reactions, stress, and emotional overload.[21,23] Previous findings have also acknowledged how PC work sometimes left care providers feeling irritable outside of work.[21]

At the relational level, over-involvement with patients' situations and suffering, noticing the consequences of the illness on patients and family members, communication, and the social acceptance of PC were common experiences that participants felt affected them negatively. Patients and families who oppose medical recommendations and disagreements with medical staff as a source of strong emotional reactions in PC professionals.[21] However, research shows that providers who empathize with patients and develop strong relationships get more meaning from their work, which could be a protective factor for the development of compassion fatigue.[8]

Contextual-level experiences that were perceived as having a negative impact included the perception of an inefficient health system, a generalized lack of knowledge about PC, patients' challenging socioeconomic contexts, and late referrals to PC. Previous research in the Ecuadorian context shows limited knowledge about PC[26] and a lack of knowledge and access to opioids.[27,28] In addition, participants in this study felt overwhelmed due to the difficult social and economic realities of patients, which has also been reported as eliciting strong emotional reactions in PC professionals in a different cultural context, such as Australia.[21] Achieving timely referrals to PC could improve end-of-life care and promote comfortable deaths which supports positive emotions in health providers.[21]

The shared experiences in this study offer new perspectives for other landscapes where crisis, death, and bereavement are implicit. Given that continuous exposure to traumatic situations precedes compassion fatigue,[23] individuals involved in PC work should be mindful of their emotional states and engage in reflective practices.[21] Therefore, regarding future actions, researchers should explore the feasibility of conducting training sessions to recognize and address these emotionally enhancing and exhausting experiences and promote self-care practices to improve the professional quality of life. In addition, support groups could be established among colleagues to facilitate the sharing and release of emotions, and there could be continuous coping skills training and awareness of PC at different educational levels.

While research examining professional quality of life is not uncommon, this study contributes by identifying specific experiences and challenges relevant to PC professionals in Ecuador, who might share similar experiences to other professionals in the region. By mapping out these experiences by levels, the study provides a comprehensive view of their influences on professional quality of life. Taking back these results into daily PC work could influence clinical practice. For example, understanding the positive experiences and challenges faced could increase personal awareness of factors influencing individual and organizational well-being and inform the development of support programs. When providers are aware, supported, and satisfied in their roles, they can provide better care. Moreover, healthcare organizations could potentially retain a satisfied workforce, which could make the field more attractive to future generations and fulfill the growing demand for PCs.

Regarding research, this study could be a milestone to delve into other practical aspects of professional quality of life. It has the potential to stimulate research at various levels. For example, future research could help implement organizational changes to improve working conditions and support systems, evaluate the interventions developed to address the factors found in this study, or assist in the incorporation of content on professional quality of life, stress management, and self-care into training programs to better prepare students for the realities of working in PC.

Despite the in-depth understanding of people involved in PC in Ecuador and the possible implications of our results, it is important to mention the limitations of this study. As with any other qualitative research, there might be limited

generalizability and subjective interpretation of the data. However, by providing rich qualitative descriptions, readers will be equipped with adequate evidence to facilitate informed decisions regarding aspects of the study that are transferable to their contexts. Although the recruitment process involved people from different fields and stages of their careers and were from different parts of the country, those who were more vulnerable might have chosen to not be part of the expert groups. Also, it was difficult to identify professionals and volunteers working in PC without help from ASECUP, as not all regions have specialized centers or specific PC units. There is a need to promote proposals that highlight the need for recognizing a specialization in PC. This recognition would help in advocating for quality PCs.

In conclusion, the factors identified in our results could be further explored as protective factors to navigate the emotional landscapes of being involved in PC because, according to previous studies, high levels of compassion satisfaction generate continuity of the person with the same organization. While many of the experiences and themes could overlap on more than one level and fall on a positive-negative spectrum, this classification can assist individuals and policymakers in developing tailored strategies and interventions to enhance and sustain formal caregivers' professional quality of life and to motivate and retain them in the PC landscape.

Declarations

Ethics approval and consent to participate
Ethical approval was granted by the Research Ethics Committee of Universitat de les Illes Balears [274CER22]. Participants signed an informed consent form, and two members of the research team explained and answered any questions regarding the project before starting the focus groups.

Consent for publication
This manuscript does not contain any identifiable data from participants; however, informed consent for publication was provided by the participants.

Author contributions
Ana Josefa Cañas-Lerma: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Writing – original draft; Writing – review & editing.

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Competing interests
The authors declare that there is no conflict of interest.

Availability of data and materials
The data that support the findings of this study are available from the corresponding author, PHA, upon reasonable request.

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Supplemental material
Supplemental material for this article is available online.

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