

# Palliative care and its own identity, through an autoethnography: do you recognize these patterns?

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Palliative Care & Social Practice

2022, Vol. 16: 1–12

DOI: 10.1177/  
26323524221122346

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## Abstract

**Introduction:** After more than 25 years working in palliative care (PC) observing thousands of patients and family behaviors, I use my long experience and notes as a source of data for a qualitative research study. The aim is to identify frequent families' behavior patterns in PC and better describe the culture in PC.

**Methods:** This article is part of a larger project, using autoethnography as methodology, with the aim of helping doctors and interested health professionals better understand the culture and reality of PC. The focus is not *the author* but patients and families' patterns of social behavior – *the social* context – within the end-of-life period and how to deal with these professionally. Confidentiality and privacy of patients' data were guaranteed.

**Results:** The vast number of treated cases, the regular observation and recording, and the continuous reflection and analysis over many years have led to these results. Due to editorial restrictions, in this article I only describe four of at least eight typical scenarios I have identified. Each is given a short title and I explore some of their inside-issues, integrating previous knowledge, research, and explanations, with practical suggestions on how to deal with them.

**Significance:** As far as we know, these scenarios/patterns have never been described in this way. This work expands knowledge, innovates, and contributes to better describing PC culture. The final goal is to create a set of scripts that can be used to help clinicians quickly identify the clinical situation and how to deal with it in clinical practice. Reflecting on how patients and families frequently behave in PC can be very useful and then teach other professionals to better deal with these challenges.

**Keywords:** autoethnography, palliative care, patterns in end-of-life care

Received: 27 December 2021; revised manuscript accepted: 28 July 2022.

## Introduction

After more than 25 years working as a doctor in palliative care (PC) and reflecting on the teachings and richness of my professional experience, I have identified frequent and consistent behavioral patterns in families. These contribute to define the identity and the culture of PC but are less commonly studied.

Some patterns are already well described in PC: patterns of functional decline,<sup>1</sup> clusters of symptoms,<sup>2</sup> clusters of psychological adaptation to

illness,<sup>3</sup> or patterns of messages that, as a PC team, we transmit to our patients and families.<sup>4</sup>

With this article, we aim to enlarge the knowledge regarding PC and share accumulated practical knowledge with other professionals, mainly young doctors. We also aim to help students and doctors to develop clinical reasoning and decision making,<sup>5,6</sup> going far beyond strict symptom management, opening their horizons to the whole nature of intervention in suffering.

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The aim of this study is to better describe PC culture, identifying frequent families' behavior patterns and how to deal with them in clinical practice.

**Methods**

This report was inspired by my personal experience with more than 7000 patients (oncological and non-oncological) and families in PC, first in the community and in the last 15 years in a tertiary patient unit.

In line with the goal of the study, I adopted a qualitative approach, autoethnography (AE), less frequently used in medical sciences. Methodologically, AE goes beyond a simple personal narrative, opinion, or autobiography;<sup>7-9</sup> it uses personal experience as a window to capture, question, and describe that culture,<sup>7,9-14</sup> turning it into scientific evidence. A researcher uses tenets of autobiography and ethnography to perform and write AE, with the purpose of extending cultural and sociological understanding. Thus, as a method, AE is both a process and a product.<sup>7-9,12,13</sup>

In PC, researchers can uncover cultural nuances that evidence different realities and investigate practices in which it is often challenging to contemplate the multiple dimensions of human beings. The complexities and intangible values of PC are many, and here the AE method can be useful, mainly when applied at a 'micro' level of the care relationship.<sup>4,9,12,14</sup>

There are several forms of this methodology, including the evocative or emotional form, and the analytical form.<sup>12,14</sup> I opted for the latter,

advocated by Chang.<sup>9,12</sup> I wrote about my clinical experience focusing on others and on their patterns of behavior during the end-of-life (EOL) period – the *social*, with a more theoretical and interpretative angle. This involved less emotion, controversy and subjectivity,<sup>9,12,13</sup> and adherence to Chang's five AE standards<sup>9</sup> (Table 1).

Ethical standards (anonymity warranty, confidentiality, and privacy) normally applied to this type of clinical research<sup>7,15-18</sup> were followed, and no personal details were disclosed.

I used my vast experience as a source of data to describe in detail some of the scenarios that I consistently observed in my journey, choosing those that were more frequent (seen every week). For this purpose, I called upon my memory, records and reflections, constructing a field diary; all these notes were gradually assembled into a coherent narrative.

In qualitative research, data analysis starts with data collection and with the beginning of writing.<sup>7,9,14,18,19</sup> After group conversations with six colleagues who confirmed that my interpretations resonated with their clinical experience, ensuring the transferability of data and their validity, I proceeded with personal reflection, and the narrative, in which the patterns emerged, was rewritten.<sup>19-21</sup> In AE data come in words, not in numbers, and the validity and credibility of my data can be verified by what specialists in the field call 'narrative truth'<sup>13</sup> – by which our work seeks verisimilitude, evoking a feeling in reader that the experience described is lifelike, believable, and possible.

**Table 1.** Five Standards for the desirable AE (adapted from Chang<sup>9</sup>).

Standard	Description
Authentic and trustworthy data	The AE uses authentic data, with different data collection techniques (self-observation, self-reflection, self-analysis, interviews . . .)
Accountable research process	Describe and reflects on the research process
Ethics toward others and self	Follows ethical standards in protecting others and the autoethnographer self; considers the impact of data exposure
Sociocultural analysis and interpretation	Answering about the sociocultural meanings of human experience
Scholarly contribution	Meaningfully engaging the extant literature for wider scholarly contribution
AE, autoethnography.	

Chang<sup>9</sup> also stresses the importance of connecting the experience of the researcher to the literature and to the broader research community; but this must not be confused with a narrative literature review. To identify useful and relevant literature in which to frame and deepen my reflection on the topics identified, I searched PubMed/Medline, EBSCO/CINAHL, and Cochrane Library databases for literature relating to the topics for literature relating to the topics PC, EOL, medical humanities, medical education, qualitative research, AE, methodology, family support, artificial nutrition, communication, hope, and patient-centered care, selecting the relevant information (around 80 titles) by the title and abstract.

Finally, based on that evidence and my own experience, I describe practical interventions to deal with each scenario.

### Results: selected behavior patterns

#### *'Please, don't take his/her hope away'*

Too many people do not want their loved ones to be referred to PC because they think that will destroy their 'hope' and it will not help them recover. The concept that one should not honestly speak about clinical progression and expectations is still very frequent in our practice. I do not mean mere collusion; I am referring to giving up hope. This behavior is influenced by the pre-conception that, faced with the truth, patients will lose hope about the positive clinical evolution.

In the past years, withholding information to protect patients, based on the belief that this would not diminish hope, was common practice.<sup>22</sup> Many physicians mistakenly equated PC and discussing bad news with giving up hope.<sup>23</sup> However, patients with serious illness usually want to hear the truth from their physicians and benefit from knowing the facts,<sup>24–26</sup> and the physician can play a valuable role in helping each patient define his hopes.<sup>27</sup> Many doctors confuse the decision to administer therapy in instances of little likely benefit – futile therapy – with the act of providing or preserving hope.<sup>28</sup>

What 'hope' is this? Is it the hope that the illness is always curable, the 'hope' that their loved ones will not die? The hope that if they do not discuss the possibility of death, then it will not happen. It is the hope that if you believe it, you will be cured.

With the belief that this behavior is the best thing to protect their loved ones, this attitude hides the reality and, in doing so, condemns the patients to frustration, isolation, and anger.<sup>26,27</sup> Relatives try to protect themselves because they do not have the tools to deal with this painful truth or strong emotions, and sometimes doctors or nurses do not explore this fear with them or do not offer to help. To some physicians, death inevitability feels like failure.<sup>22</sup>

It seems there is only one 'hope': the hope the illness will be cured. That is false and illogical. Hope is a multidimensional complex concept and must be reframed. As Brody<sup>29</sup> wrote, *'Hope means different things to different people, and different things to the same person as he/she moves through stages of illness'*. Hope is the positive expectation of achieving a goal, whatever it is, and it plays a role in the successful coping with illness and in improving the quality of a person's life. For patients and families struggling with life threatening illness, hope is not an unwavering state of mind.<sup>30</sup> Rather, it tends to evolve through phases as the disease advances and death approaches. Hoping is a process that endures despite the loss of prospects for cure or recovery.

Hope and terminal illness are not mutually exclusive.<sup>31</sup> When the cure is not realistic, we must shift the goal of care from cure to care, to comfort and promotion of quality of life. This does not mean 'giving up', doing nothing or abandonment; it means doing the right thing, treating the incurable patient's needs, and promoting symptom control and active intervention in total suffering.<sup>32</sup> Despite progressive physical illness, it is important that the patients know you will be with them and will not let them down, whatever the evolution will be: commitment to non-abandonment is a central value in PC.<sup>27,33</sup>

There is unrealistic and realistic hope. With the progression of disease, the former will result in disbelief in health professionals and carers and in feelings of frustration and even anger. The latter, realistic hope, must be actively promoted in PC, exploring concerns and expectations with patients, helping them to refocus on what they are able to do, and defining personal goals (from family reunions to meeting an idol or someone they admire, receiving a visit from a pet or going home).<sup>30–32,34,35</sup> This is done by positive reappraisal, wherein patients abandon unrealistic hopes and adopt new ones. What is important is

**Table 2.** Interventions that foster hope (adapted from Rosseau<sup>31</sup>).

- Impeccable symptom control
- Fostering and developing interpersonal relationships
- Assistance in attaining practical goals
- Supporting and identifying personal attributes, such as determination, courage and serenity
- Encouraging lightheartedness when appropriate
- Affirming worth by treating the patient as a valued individual
- Recalling uplifting memories with life review
- Exploring spiritual and religious beliefs

to have concrete short-term goals and finding the means to put them into practice. This demands a great creativity from PC professionals.

When hope for the indefinite prolongation of life no longer exists, the focus can be shifted to an expectation for preserving what is meaningful in life's experiences. This is the result of a temporal shift in the dimension of hope, bringing it closer to the moment of experience. Hope can then be about the positive experience of the present moment.<sup>32,34</sup>

Common ways to foster hope are summarized in Table 2, with strong emphasis on good symptom control and short-term goals.<sup>31</sup> This is done through an empathic process, through transcendence and spiritual support, whereby patients find meaning and purpose by reaching both outward to others, including their clinicians, and inward to find a personal core of awareness and strength. Impeccable symptom management removes a formidable barrier to the development of intrinsic hope. Another way of promoting hope is by helping the patient leave their legacy, either by means of a transmission of values to those that stay<sup>36</sup> or through a life review process using different strategies (memory box, a film, a book, a family album).<sup>37</sup>

Factors that often decrease hope include feeling devalued, abandoned, or isolated ('there is nothing more that can be done'), lacking a plan or goals and unrelieved symptoms.<sup>38,39</sup>

We know that people in EOL have different levels of hope, and these can fluctuate. The Herth Scale<sup>40</sup> is a good tool to measure hope levels and explore patients' concerns and hopes.

Although it may seem contradictory, hoping for the best while *at the same time* preparing for the worst – the so-called 'fingers crossed strategy' – is a useful strategy for patients with potentially life-limiting illness. It is important to encourage this

approach but not to impose it. By acknowledging all the possible outcomes, patients and their physicians can expand their medical focus to include different trajectories and disease-modifying and symptomatic treatments and attend to underlying psychological and existential issues. The palliative approach of hoping for the best while preparing for the worst in several 'what if' scenarios is very useful.<sup>41</sup> This approach requires a dual role from the physician, providing two types of coaching: optimism (*Let's hope*) and realism (*Let's prepare*).

The difficulty for physicians is to acknowledge and support patient hopes while recognizing the severity of their disease, thus offering an opportunity to discuss EOL concerns. Both patients and physicians want to hope for the best. At the same time, some patients want to discuss their concerns about dying and others should prepare because they are likely to die sooner rather than later.

The '*hope topic*' must be recognized by PC teams and actively included in management care plans for their patients.

*'He was fantastic in the past weeks! Why is he dying?!' (or 'denial, the broken record and the glass of water that overflows')*

Only too often do we come across family members that, following explanations regarding the poor prognosis, incurable nature and progression of a disease, the proximity of death of their loved one, come back – sometimes again and again – with the same questions. They seem not to understand the decline of their loved one, referring to facts such as 'He was so well, walking, eating, out of bed . . . we were not expecting this'.

Acting as if nothing has been said before. This is a real challenge for team members and requires good communication among them and with the families.

**Table 3.** Strategies for managing denial (adapted from Rabinowitz and Peirson<sup>42</sup>).

- Maintain a neutral, non-confrontational stance; show respect; avoid power struggles and threats
- Do not take denial personally; do not project your own feelings of disempowerment, distress, or fear
- Assure communication is optimized; employ active and empathic listening
- Make sure adequate information has been given
- Support your patient; offer to meet with family and others important to the patient
- Assure your patient you will be available to them even if they do not want to follow your advice now
- Avoid confrontation; this may be especially difficult if you are anxious, distressed, or frustrated by your patient's refusal to follow your recommendations; know yourself
- Regularly assess the effects of your interventions; Is denial getting better or worse? If it is getting worse, consider changing your strategy or seeking consultation

It is difficult to listen to the same questions asked by someone that speaks with you as if it were the first time. Being aware of the diagnosis of an advanced disease and its natural history, we feel surprised by these words. Why does this happen?

One assertive communication technique is what is known as 'the broken record': a verbal response that is firm, clear, and conveys a message that you mean what you say. It tends to work well in situations where people do not want to listen and are non-compliant with treatment, forgetful, or disorganized. The aim is not to upset or offend but rather to prevent further conflict, manage care more effectively, or clarify information. One speaks as if one were a record that is cracked and so repeats itself again and again. This requires persistence, sticking to the point and repeating it, ignoring all side issues, and using a calm voice. Provided that the manner is not aggressive, people tend to get the message without feeling threatened. It is very important to always let colleagues know what has been said so that they do not inadvertently sabotage your plans. It is very important to record this message in the medical files so that the whole team is aware of the communication issues.

We are challenged by the fact that some people do not want to listen or deny what is so difficult for them to accept. This denial is different from lack of knowledge and is much more an emotional and protection mechanism rather than a rational one.<sup>42</sup> So, we must bear this in mind and reflect some emotional issues when addressing the carers: 'I can imagine how difficult it must be for you to see your loved one become weaker . . . but is important to recognize this and see how to best help both of you'; 'we are here to support you and to treat your relative'.

Repeating what has already been said and adopting a strict rational attitude do not help. Denial

may be a valid coping mechanism for those who are unable or not yet ready to adapt to the reality of a terminal illness.<sup>42,43</sup> This mechanism is usually ambivalent, and its level may change over the progression of the illness. It is important to monitor changing perceptions and to explore inconsistencies among patients and family members. Sometimes only the patient is in denial and sometimes the reverse is true; not all cases of denial are psychologically harmful. From a clinical perspective, denial should be separated into two major categories: adaptive and maladaptive,<sup>42,43</sup> based on its real or expected effects on treatment seeking, adherence to recommendations, and medical decision making. We must worry with persistent maladaptive denial, which may present an extra burden to family members.<sup>44</sup>

Help comes from adequately confronting the patient or caregiver with facts, with disease progression, and always with reassurance and non-abandonment<sup>42</sup> (Table 3). Not speaking about the facts will not prevent the illness to take his course. Preparing for something difficult that will inevitably happen can help everyone to deal better with reality.

The first step is to check whether families are aware of the irreversibility of the clinical situation. If it is someone that you have treated previously, you may have to remind of previous conversations, when you explained the clinical progression and the inevitability of death. On better analysis, the patient was not as well as the families may have perceived and in fact was already dying. If the patient had been followed elsewhere, it is important to verify the facts but in general it emerges that the patient was already very ill.

Usually, we assess the suffering of family members, validate it, offer support, and stress that their loved one is weak and frail but comfortable

and free from suffering. We also use metaphors<sup>45</sup> to help them better understand what has been happening: one example is that of a glass which has been filling slowly and unnoticed for a long time and only when it spills over do we see it, or of a scrunchie that has been stretched far too many times and now breaks.

It is apparent that there is a certain level of denial and fear of death in family members.<sup>42,43,46</sup> This happens for many reasons – cultural, fear, and anxiety.<sup>47</sup> Even understanding, at a rational level, that a relative is dying is emotionally hard to accept.<sup>45,46</sup> Here lies an opportunity for PC professionals to introduce the topic, and help clarify and normalize the conversation about EOL.

Communication during EOL can be fraught with challenges, as many societies possess an attitude of avoidance regarding death and dying, which are seen as taboo.<sup>24,43,48</sup> Some families think talking about death and dying is morbid and fear these intense moments because they do not know how to behave and what to say.<sup>46</sup>

Medical services in general continue to regard death as something to be resisted, postponed, or avoided. For some physicians, accepting death inevitability feels like a failure.<sup>47</sup>

*'I promised my father he would die at home; I do not want him to die in the hospital'*

I hear to this phrase very frequently; families feel guilty if they fail to care of their loved ones at home in the last phases of life. They feel that they made promises in the past that now they cannot break, especially regarding parents. When confronted with the lack of home support, with the burden of care that the whole situation imposes to the family or that their loved one is not well cared for at home, they suffer and feel stuck, not knowing what to do.<sup>45,49,50</sup> The family caregiver often accepts their carer role as natural, presumably imposed by society or by the wish of honoring his/her values. The role of family caregiver is stressful<sup>51,52</sup> and is still poorly supported by society, health care teams, and family systems.

Good PC implies considering families as part of the care unit and supporting them during the bereavement period.<sup>51,52</sup> PC teams should remember the need for 24-h coverage, for social support but, most of all, for adequate clinical support at home. A Cochrane systematic review shows good PC

support in the community increases the chances of dying at home and reduces symptom burden.<sup>52</sup> But many patients do not have access to these specialized teams and not all illnesses or clinical conditions are easy to control at home. Sometimes, dying at home is not practicable and the most complex cases must be dealt with in an in-patient setting (hospital, PC unit, nursing home).<sup>52–54</sup>

Many relevant issues are raised by when caring for very ill and frail patients at home: falls, bathing and feeding, changing diapers, administering medication, and 24-h assistance. These are complex needs which are very demanding, and most family carers cannot stop working to have the time required to carry out these functions.<sup>50,51,53,54</sup>

Paying a domiciliary team to do everything correctly might cost too much. There is an increase in private PC carers: they are expensive and do not always provide the adequate clinical support needed by frail or terminal patients. Despite some good experiences with some domiciliary PC teams, support in the community is scarce and our national health system still fails most Portuguese who are dying at home and need clinical and social support.<sup>55,56</sup>

Many studies indicate that people prefer dying at home. According to a large European study, that accounts for 51% of the Portuguese population.<sup>57</sup> I usually call it a 'romantic delirium' because people are not fully aware of what it really means to 'suffer from a terminal illness and being cared at home'. In our country, more than 65% of people die in hospital.<sup>56</sup> Once confronted with reality, the preference for the place of death may change and 'end of romance'. I agree we should put our efforts to guarantee that people die where they prefer, but much must be done to allow that to happen.<sup>56</sup>

As health professionals in PC, we support families and help find the best option, relieving them from guilt and from this additional suffering. We must explain that, when they promised a family member they could die at home, they were not aware of the clinical complexity involved, of the costs involved or of the lack of resources in the community. When confronted with this burden, they are forced to reframe the options and decide what is available and guarantees the best comfort for their loved one.<sup>54</sup> Sometimes it is better to break the promise and give priority to proper care, in a nursing home, in a PC unit, or in a hospital.<sup>51–53</sup> Staying at home without clinical support could

have a negative impact on the patient and on family wellbeing.<sup>54</sup> If that is the case, we must free the family from past promises, help finding quality resources and assess the best option for all, and stress that this does not mean that they failed at caring for their dear dependent patients.<sup>51,53</sup>

Some of these terminal cases may be treated at home, but health professionals must be aware of the pros and cons on choosing one place over another, with knowledge of the community and family resources, prioritizing the wishes and wellbeing of the patient but never forgetting the impact of this decision on family dynamics and the potential disruption to daily life.<sup>48,50,51,58</sup>

The burden of care,<sup>50</sup> which is a caregiver's multidimensional biopsychosocial reaction resulting from an imbalance between the demands of care and the caregiver's personal time, social roles, physical and emotional states, financial resources, and formal care resources, may be very costly and painful for some carers.<sup>48–50,58</sup> The majority of carers are women, and they tend to the patient's daily needs (bathing and personal needs) and also perform complex tasks, such as giving special medication or feeding through a nasogastric tube. The family caregiver is often considered to be an 'overall task performer' by health care teams.

Although 66% of family caregivers are reported to experience severe burden from this activity, only 25% indicated that this burden had a negative impact on their daily lives.<sup>50</sup> Caregiving can be a highly rewarding task, but caregivers must receive support, supervision, and have the guarantee they can rest for some periods, with the possibility of admission of their dependent relative for respite care. Caregivers should be informed of any personal benefits that may provide relief; they cannot become invisible to health care system. If not, longer term caring will have a negative impact on the health of family carers. Beyond normal fatigue, symptoms of exhaustion and burnout may happen, and these situations must be identified and professional support offered.<sup>50,51,53,58</sup> A review by Alam *et al.*<sup>50</sup> recommends the Cares Framework (Table 4) as a guide to care for caregivers.

*'He is not eating! My father is dying of thirst and hunger!'*

In last days of life, because of the disease progression, a great number of patients lose their capacity to eat and drink.<sup>59</sup> PC teams are frequently

questioned regarding their loved one dying of hunger and thirst.<sup>59,60</sup> This is a very emotional topic that may create many tensions within the family and between the patient and the team.<sup>60</sup> Speaking proactively about nutrition and hydration is crucial in this phase, explaining that the patient is not dying of starvation.<sup>59,61,62</sup> The decline is caused by disease progression, not by lack of food or drink.<sup>61</sup> Cachexia results from biochemical mediators in the context of systemic inflammatory responses and global catabolism of the organism and is not corrected by forcing nutrition.<sup>63</sup>

Offering food and drink is part of an emotional reaction through which relatives feel they are 'doing something to push death away'. It is very important to stress that the goal of care is to promote comfort and that these actions do not prolong or shorten life; to insist on feeding and hydrating artificially may increase the symptomatic burden of the patient.<sup>59–62</sup> An open and calm conversation – or multiple conversations – considering the different aspects of this topic (Table 5) is mandatory.<sup>59</sup>

This also might be a sign that family does not accept that death is near. To help remove the stigma that surrounds death and dying, one must focus on family communication during the EOL period, despite it being uncomfortable. 'Protecting' a loved one from the truth about their condition may initially seem like a good idea but withholding information can lead to resentment and disappointment.<sup>46,51</sup> Discussing death adequately is crucial as it may help reduce anxiety, misunderstandings, and fears; explore wishes regarding the process of dying; and initiate the grieving process.<sup>46</sup> The conversation about death and dying should begin earlier rather than later. But doctors must be trained and prepared to do it in a non-confrontational way, respecting patient and family timings.<sup>46,59</sup> The family does not substitute the professionals on speaking with the dying person and they must be reassured, and not feel pressured or helpless in having this discussion, that may seem so difficult or awkward. Professionals must give direction and offer support.<sup>64,65</sup> The fears and feelings that surface now are better aired than ignored. Families need support not only on emotional issues but also for practical details such as feeding, decision making, place of death, and funeral arrangements.<sup>48–50,56–58</sup> When families of terminally ill patients have an opportunity – as in a family meeting – to speak at

**Table 4.** The CARES framework for family caregivers (adapted from Alam *et al.*<sup>50</sup>).

Domain	Description
Consider caregivers as part of the unit of care	Consider caregivers as part of the unit of care as well as part of the care team
	Acknowledge the importance of the caregiving role
	Respect the patient's wishes regarding the nature and degree of caregiver participation in decision making
Assess the caregiver's situation, perceptions, and needs	Document the caregiver's relationship to the patient, their living situation, employment, and whether care is being provided for other dependents (e.g., children)
	Assess the caregiver's capacity and willingness to provide care
	Inquire about the caregiver's physical and mental health
	Assess the impact of caregiving, including social isolation and financial strain Inquire about the caregiver's perception of the patient's status and ability for self-care
Refer to appropriate services and resources	Refer the caregiver to locally available resources: palliative care teams; home care services, respite care Social work, psychology, spiritual care Community resources, support groups, online resources
Educate about practical aspects of caregiving	Ensure the caregiver and patient have a joint understanding of the patient's cancer, its treatment, its typical course, and signs of advancing disease
	Check understanding of symptom control (e.g., dosing, adverse effects, addiction potential)
	Ensure education for practical skills (e.g., dressing changes, injections, lifting/transferring) Highlight the importance of personal health and self-care and the availability of benefits and services for caregivers
Support caregivers through bereavement	Clarify when it is important to call and who should be called Be available by phone or in person to discuss caregiver concerns
	Offer referral to local bereavement support services
	Call or send a card to the caregiver after bereavement

length with members of the staff about their fears and concerns, they may be better able to cope with their loved one's death.<sup>64-66</sup>

It is essential to explain what clinical evolution is expected in these last weeks/days of life, explaining the symptoms that are observed and stressing that weakness must not be confused with suffering.<sup>59,60</sup>

### Discussion/conclusion

The purpose of academic research and its publication is to contribute to expand knowledge.<sup>12-15</sup>

By describing these family/PC professional behavioral patterns using AE as a privileged spectator, reflecting, analyzing, and deepening their contents are both innovative and useful to the scientific and lay community.<sup>5,9,15-19</sup> This article adds knowledge in a complementary way to other patterns well described in PC,<sup>1-4</sup> knowledge rooted in the care of thousands of patients and in research.

To the best of our knowledge, there are no other published studies reporting patterns like those we describe here, which limits the discussion.



**Table 5.** Main topics about nutrition and hydration in last days and hours of life (adapted from Hui *et al.*<sup>59</sup>).

- Clinicians should have honest discussions with patients and families about prognosis and goals of care.
- In the last days of life, patients often have symptoms that prevent them to eat/drink properly (e.g., dysphagia) and do not desire eating. Patients should not feel guilty about not being able to eat/drink or be force fed.
- If desired, patients may try eating and/or drinking small amounts orally as tolerated, with the goal of maximizing comfort while balancing the risk of complications (e.g., aspiration).
- Active measures may be undertaken to treat any potential nutritional impact symptoms and/or complications, providing that they are consistent with the patients' goals of care. For example, pain control should be optimized and oral care should be provided regularly.
- The inability to eat/drink and body image issues can be associated with significant emotional distress among patients and caregivers. It is important to normalize their reaction and provide longitudinal education and counseling.
- For patients in the last days of life, artificial nutrition is not recommended because it has no benefit and may cause harm. There is no ethical distinction between withholding and withdrawing artificial nutrition.
- Although there is also no definitive evidence to support that artificial hydration offer any benefits in this patient population, the adverse effects associated with hydration are generally limited. Thus, artificial hydration may be considered in selected patients after careful discussion of the risk, benefits, and goals of care.

Family needs and support are major topics in PC and have previously been presented and discussed.<sup>48,50,58</sup> However, it is not always easy in daily practice<sup>67</sup> to identify those issues and apply more abstract recommendations. The description of these behavioral patterns, seen repeatedly in our PC practice, identified by synthetic verbal expressions (*in italic*), can be useful to enable PC professionals to provide optimal care to patients and their families.

In summary, these results and explanations contribute to a better systematization of the evolved topics and show that PC doctors must deepen their family support skills in areas like fostering hope, dealing with issues concerning decisions about place of death, about rapid status decline denial, and about artificial nutrition and hydration in the last days of life.

### Strengths, limitations of this study, and further research

AE is gaining acceptance as a legitimate research method in health science,<sup>9</sup> and is indicated and practiced by experts in PC research.<sup>4,8,10,11,21,67</sup> I have tried to overcome the frequent criticisms regarding low objectivity and the fact the author is researcher and participant in AE methodology by focusing more on culture (*ethno*) and research (*graphy*), than on the self (*auto*).<sup>7,9,16,18</sup>

As a qualitative in-depth, intensive, and non-extensive analysis study, absolute or relative frequencies of observations assume less importance.

However, the experiences here described are sufficiently frequent to permit pattern recognition, reflecting realities transferable into other palliative contexts (transferability).

At the center of the research was the possibility to describe the totality of the scenarios in depth, as patterns within a cultural context.

As a clinician and teacher, greatly valuing the transmission of the intangible values of PC,<sup>68-70</sup> I found this report meaningful and hope others do as well. By describing these scenarios, I intend draw attention to PC, not to myself, and hope to contribute to a better understanding of PC, both to outsiders and to insiders of our clinical area. Most of all, I want to honor and evidence the vast experience of suffering during EOL and the richness of the caring human relationships in those difficult times.

These four patterns described here are very frequent in the Portuguese culture, and their description is part of a larger research project investigating PC culture and reality. A limitation of the study is the fact that it is based on Portuguese EOL culture and may not generalize to other cultures and health systems.

However, these data cannot be generalized and this points to the need for greater dialogue and research. In future work, I plan to complete this research project with the identification and

description of further patterns and the reports of international PC expert interviews,<sup>65,66</sup> across countries and cultures.

### Declarations

*Ethics approval and consent to participate*  
Not applicable.

*Consent for publication*  
Not applicable.

### Author contribution

**Isabel Galriça Neto:** Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Visualization; Writing – original draft; Writing – review & editing.

### Acknowledgements

The author would like to thank the encouragement and support in this manuscript from Paula Sapeta, PhD, and Maria Arantzamendi, PhD, and the final translation revision by António Almeida, PhD.

### Funding

The author received no financial support for the research, authorship, and/or publication of this article.

### Competing interests

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Availability of data and materials

Not applicable.

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