Executive Summary

Palliative care in its own discourse: A focused ethnography of **professional messaging in palliative care**

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BACKGROUND

» The original message that Palliative Care (PC) is focused on total care, helping to live until the person dies, is being replaced and linked to feelings of fear, anxiety and death, instead of compassion, support or appropriate care.
» The society is still afraid to speak its name, and specialized units are identified as "places of death" as opposed to "places of life" meant to treat suffering.
» This issue is prohibitive to the implementation and development and integration of PC policies worldwide.
» It is imperative to identify what message PC professionals are conveying to patients and other healthcare specialists.
» We hypothesize that a deep understanding how these professionals transmit PC values to patients and caregivers may aid the development of targeted communication strategies to disseminate a more accurate understanding of PC in the future.

Aim of the study: to understand what message is conveyed by PC professionals, explicitly or implicitly, in their daily clinical practice.

METHODS

» Focused ethnography: 242 hours of participant observation within three PC teams in three different regions of Spain was made.
» Daily continuous observation was performed in each team by the same researcher (CR).
» Field notes and informal conversations with professionals were recorded.
» A reflexive diary was used to reflect on the observation process and track analytic concepts.
» A thematic analysis of field notes and internal documents was conducted based in the following research question: "What is the message about PC that these professionals transmit to patients and caregivers in their daily practice?".
» This study was approved (No. 2018.009) by the Ethics Committee of the University of Navarra (UNAV).

RESULTS

PC professionals convey three central messages during their daily clinical interaction with patients and families:
» i) We are a team: focused on your wellbeing;
» ii) You matter: we want to meet you as a person;
» iii) Family matters: they are also important to us.

Message 1. We are a team: focused on your wellbeing

1.1. We are a multidisciplinary team

» All professionals introduce themselves as a team, working together to meet the patient's needs.
» They explain "what they do" rather than "who they are", transmitting a common objective: help the patient.
» The expression "Palliative care team" was used selectively in their conversation. However, they explicitly use it in their badge and business cards when explaining the patient/family that they were available to address any problem.

(The PC team has a young hospitalized woman) In addition to all anxiety that the patient presents, it does not seem that there is an excellent family relationship. The team decides that its psychologist is going to visit her today. "Hello, how's your day today? Dr A, the doctor of our team told me about you. I am the team psychologist, and I would love to speak with you for a while. Is that alright?" (Kiri, inpatient service)

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1.2. We are experts in symptom control

» PC professionals convey directly that they can help control symptoms during acute situations and prevent possible future symptoms. It was common to ear the expression: "We are here, so you do not have pain".

» It was frequent to assess symptoms using different scales, re-evaluating with patients to prevent symptoms.

» PC professionals highlighted it was crucial for them to reach the patient, to improve the clinical situation and not to cause any more suffering. For this reason, the teams unanimously justified their avoidance of the term "palliative care" as it may make them not welcome by the patient. They shared the idea that the most important thing was to demonstrate their ability to solve problems.

"It has to be something progressive. Our presentation is the gateway, and it can be done through symptoms or not. We have experience of being rejected when we want to get deeper into the speech... We have to go in slowly." (Oak, outpatient consult)

Message 2. You matter: we want to meet you

2.1. We want to know about you as a person

» Professionals facilitated conversations with their patients to listen to their life stories. This helped them better understand their patients promoting a symmetrical person-to-person relationship.

» PC professionals dedicate time to their patients, with no sign of haste, even if later they were often seen walking quickly along the corridors.

» Professionals' behaviours and conversations with patients conveyed availability, unconditional acceptance, welcoming and active listening towards the person.

The team is visiting a patient at home. They know that she has had difficulty sleeping. The doctor gets on his knees by the bed and asks the patient: "How are your flowers?" (the patient was a florist by profession, and she has a garden at home that she is very proud of) - "Ahh!!!!" (sighs, smiles) "Very well!" (responds the patient) - "No, no. I'm not talking about these flowers [points to the garden]. I'm talking about the most beautiful flowers you have, your daughters." They start to talk about her daughters, her family, her needs and the support she may need. (Oak, home care service)

2.2. We want to know about your experience with the disease

» PC professionals showed concerns regarding the trajectory of the disease and the resultant symptoms.

» Professional's behaviour was active in solving clinical problems and dealing with patient concerns. They tackle patients' or families' wishes during the disease process and talk through decisions to be made, on a message of availability.

» PC professionals' attitudes aim to care for the patient throughout the trajectory of the disease, to establish a therapeutic relationship, personal and professional, based on trust and dedicated time.

"It is essential to know the cause of the suffering of this person to know how best to relieve it. I see her as a person who suffers, and I can help clinically. Knowing her, allow me to identify her internal resources. That may help to deal with the disease." (Kiri)

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Message 3. Family matters: they are also important to us

3.1 We are here to relieve the suffering of the family | 3.2 We want to support the caregivers

›› PC professionals proactively try to know more about the patient's family and their situation. They are always alert to signs of suffering.

›› They help families to take care of the patient, how to deal with difficult conversations and facilitating the understanding and acceptance of the disease trajectory.

›› Professionals showed a disposition to help with whatever the family needed. The ultimate intention was to intervene and reduce the suffering of all and to make both physical and emotional pain tolerable.

In a family conference, the caregiver says she will not tell her mother, who is in residence, that her father is dying. The team sits with her to help her in this difficult decision so (as they later discuss) she does not feel bad about the decision when the father dies. "She has the right to know, don't you think?" (PC professional) The daughter cries and says, "I do not know what to do." The team wants to help her decide and demonstrates how she could communicate this news: "If your mother does not ask for your father, do not worry. But if she has conscious moments when she asks about him and asks why he does not visit her, we can try to tell her the truth. For example, tell her that he is not well, that he probably will not come so quickly, and so on progressively. If we speak naturally, the dialogue happens." (Oak, inpatient service)

These three messages are conveyed through an attitude of being present, availability and disposition towards the patient and their family, sometimes implicitly. Perhaps we should consider the message that PC professionals relay as simply:

"I am a health professional willing to care for you (person with severe illness and suffering family) and anything that concerns you. I want to help you to live, treating you as a "whole person" and, gradually, helping you adapt to the situation."

CONCLUSION

PC professionals forgo self-interest to care for the patient throughout the trajectory of their illness, to alleviate suffering and to support the patient's family. These messages are transmitted through availability, disposition and acceptance towards the ill person. The PC health professionals sacrifice being identified more readily by their profession for the sake of what they perceive as their patients' wellbeing. PC professionals forget self-interest to care for the patient in order throughout the trajectory of their illness, to alleviate suffering and to support the patient's family. These messages are transmitted through availability, disposition and acceptance towards the ill person. However, not naming and not explicitly discussing the purpose of Palliative Care and its usefulness to patients and their families can perpetuate the myths, misunderstanding and lack of awareness of PC. The conclusions of this study are potentially transversal to other European countries.

REFERENCE

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Key messages that Palliative Care professionals convey **to patients and families**

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1 We are **a team: focused in your wellbeing**

We are a multidisciplinary team

- Attending the holistic needs
- Explaining "what we do" rather than "who we are"
- Using the word "Palliative Care" selectively

We are experts in symptom control

- Using pain assessment tools to measure, (re)evaluate, and prevent pain and other symptoms
- Softly introducing "palliative care" through their badge and business card
- Starting conversations as: "We are here, so you won't have pain"

2 **You matter:** we want to **meet you as a person**

We want to know about you

- Focused in experiences and life moments
- Symmetrical person-to-person relationship

We want to know about your experience with the disease

- Therapeutic relationship: exploring symptoms and other issues
- Slow-paced work when they see patients
- Active clinical problem-solving/ decision making

3 **Family matters:** they are also important to us

We are here to relieve the suffering of the family

- Be alert to signs of suffering
- Know and listen their experinces

We want to support the caregivers

- To take care of the patient
- To take care of themselves

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