


Patients', family caregivers', and professionals' perspectives on quality of palliative care: A qualitative study

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Abstract

Background: The quality of palliative care is the foremost preoccupation of clinicians, decision-makers, and managers as well as patients and families. Major input from healthcare professionals is required to develop indicators for the quality of palliative care, but the involvement of patients and families is also recognized as essential, even though this is rarely achieved in practice.

Aim: The objectives of this study were to identify (1) convergences and divergences in the points of view of different stakeholders (patients, families, healthcare professionals) relative to key elements of the quality of palliative care and (2) avenues for refining existing indicators of quality of palliative care.

Design: Cross-sectional qualitative study.

Setting/participants: There were six settings: two hospital-based palliative care units, one hospice, and three other medical units where a mobile palliative care team intervenes. Semi-structured interviews were conducted among 61 patients, families, healthcare professionals, and managers.

Results: Four major dimensions of quality of care are deemed critical by patients, their families, and professionals: comprehensive support for the patients themselves, clinical management, involvement of families, and care for the imminently dying person and death. Differences exist between various stakeholders regarding perceptions of some dimensions of quality of care. Avenues for improving current quality of care indicators are identified.

Conclusion: Our study results can be used to refine or develop quality indicators that truly mirror the points of view of patients and their families and of healthcare professionals.

Keywords

Palliative care, quality of healthcare, quality indicators, qualitative research

What is already known about the topic?

- Quality of palliative care is a multidimensional process. Quality is moving from performance measurement and standardization process to a patient focus with attention to concepts of personal dignity, autonomy, and meaning at the end of life.

What this paper adds?

- Four major dimensions of quality of palliative care are common to all the stakeholder groups (patients, families, healthcare professionals, and managers): comprehensive support for the patients themselves, clinical management (including pain control), involvement of families, and the care provided to the imminently dying person.

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- Two examples of differences between professionals, patients, and families are highlighted:
- Both families and healthcare professionals would like to achieve complete pain relief at any price, while patients want to maintain the ability to choose between level of pain control and level of consciousness;
- For healthcare professionals and families, the presence of a psychologist and volunteers is essential, while patients prefer having time with the doctors and nurses.

Implications for practice, theory, or policy

- There is a need for a multidimensional assessment of quality involving patients and families. To develop quality indicators for clinical practice, it is paramount to interview patients, families, and professionals directly and not only to review patient files.

Introduction

The last decade has witnessed enormous growth in hospice and palliative care. It is thus more important than ever to ensure consistent and high-quality care, as shown by some major initiatives such as the US National Consensus Project's (NCP) *Clinical Practice Guidelines for Quality Palliative Care*¹ and the National Quality Framework developed in Australia.² The NCP¹ example furnishes a blueprint for the essential components of palliative care programs. It states that these programs must provide for the assessment and treatment of pain and other symptoms, help with patient-centered communications and decision-making, and coordinate care across the continuum of care settings. The NCP represents a consensus among recognized experts on evidence-based guidelines to ensure the quality and consistency of care. It covers eight domains of palliative care: (1) structure and processes; (2) physical; (3) psychological and psychiatric; (4) social; (5) spiritual, religious, and existential; (6) cultural; (7) care of the imminently dying patient; and (8) ethical and legal.

It is now recognized that "quality is moving away from performance measurement, uniformity of service and standardization of process to providing a patient focus" (p. 593).³ As well, "A new view of dying began to emerge which sought to foster concepts of personal dignity, autonomy, and meaning at the end of life" (p. 2).⁴ It is therefore essential to involve patients and families in the development of the indicators as well as in assessments of the quality of palliative care. Involving patients and families in the development of quality indicators will permit the development of new frameworks that truly meet the needs of all involved. Whether an end-of-life treatment is *dignified* depends partly on the capacity to obtain information, manage pain, respect rituals, and so on. In this sense, quality depends on the individual's capacity to assert his or her needs and expectations, which is often limited by the constraints of institutional management and rules. Improving practices for end-of-life patients requires disseminating practices based on a participatory model of the patient-physician relationship, but also on a renewed conception of the patient's status and scope of action.

Although involving patients and their families is essential in order to construct quality indicators, there is little

evidence of such involvement from the patients' perspective,^{3,5,6} and the families' point of view is even more sparsely represented in the literature.^{5,6} We identified one study that surveyed patients and their families, but it was conducted in an intensive care unit.⁵ In another study, researchers interviewed families, but only after the relative had died.⁷ Only one study has assessed the acceptability of quality indicators among different stakeholder groups—healthcare professionals, patients, and family caregivers—but the end-of-life quality indicators were pre-identified.⁸ To our knowledge, no study has simultaneously involved patients, families, healthcare professionals, and managers in developing indicators of quality of care. There is a need to improve our understanding of how to take into account the points of view of healthcare professionals and managers as well as patients and their families, and also to learn how to integrate these multiple perspectives.⁹

The objectives of this qualitative study conducted among various key stakeholders (patients, families, healthcare professionals, and managers) were to identify (1) convergences and divergences in the points of view of different stakeholders relative to key elements in the quality of palliative care and (2) the avenues that can be pursued to refine existing indicators of quality of palliative care and, more specifically, to explore the NCP's domains.

Methods

This cross-sectional qualitative study was conducted in the Paris metropolitan region in six settings: two hospital-based palliative care units, one hospice, and three other "standard" medical units employing a mobile palliative care team. This study is based on the Grounded Theory^{10,11} approach and presented according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist for qualitative research.¹² The local ethics committee approved this study (CPP XI Ile-de-France #12059).

Participants

We used a maximum variation sampling strategy¹³ to recruit a representative sample of participants among patients and

healthcare professionals. Key professional informants were recruited, that is, professionals with a thorough knowledge of both the care provided to patients in palliative care and the current challenges in their organizations. Patients were recruited to ensure variation in terms of setting, status, gender, age, and type of cancer. They were first approached by their usual healthcare professional. The strategy was to apply an iterative method with an ongoing data collection and data analysis process¹¹ (called constant comparison). We thus recruited participants using a snowball strategy until theoretical saturation (we recruited additional participants as needed until no new categories emerged from gathering further data).¹¹

Data collection

We used different methods to interview the participants, depending on their role and whether or not we could conduct focus groups. Accordingly, individual semi-directive interviews were used with the patients and their families and with professionals not working in palliative care units. Interviews with patients and families lasted 45 min on average. Only one interview was shorter (20 min) since the patient became too tired to continue. Professionals working in palliative care units were met in six focus groups, formed according to their location and background/position, in order to facilitate group dynamics and avoid a desirability bias. Interviews were conducted and focus groups were held at the beginning of 2010.

Participants were interviewed using a semi-directive interview guide and were asked to describe criteria essential for delivering quality care. The interview guide was first developed based on the key concepts identified in the literature review and then was adapted on the basis of a preliminary analysis of the first interviews. We remained open to new dimensions that emerged from the discussions. Following an open question, follow-up questions were asked in order to have participants consider many dimensions, including comfort, privacy and dignity, management of symptoms and functional impairments, information/communication, support, availability of professionals, the role played by families, and the coordination and continuity of care (see Appendix 1). The objective of the research as presented to the patients and their families was to obtain their points of view on the quality of hospital care in general. We did not specify that the study concerned palliative care since the word “palliative” sometimes has overly negative connotations. Some teams and researchers prefer using the term “supportive care” since it allows them to intervene earlier with patients.¹⁴

Data analysis

All the interviews were digitally recorded and transcribed verbatim in their entirety. The verbatim transcripts of the

interviews were read and coded by one researcher (V.G.) and validated by another (I.V.) to ensure that the data analysis would accurately reflect reality. Neither interviewer was involved in clinical practice. The data were analyzed following the standard methods for qualitative thematic analysis.^{15–17} The iterative analytical process was principally inductive and followed the steps of the Grounded Theory^{10,11} approach, which consists in the coding of open, axial, and selective data and allows for the rigorous analysis of qualitative materials based on repeated back and forth movement between the codes produced and the materials. The iterative coding and recoding operations ended only when a point of saturation was reached, that is, when no new category, concept, or dimension emerged in the development of the conceptual framework.¹⁰ NVivo8 was used to support the analysis process.

Results

In order to achieve theoretical saturation, 61 patients, families, healthcare professionals, and managers were recruited and participated in the study:

- In all, 26 healthcare professionals and managers working in palliative care units or a hospice (9 physicians, 6 nurses, 1 nurses' aide, 2 psychologists, 3 middle managers, and 5 directors);
- A total of 15 healthcare professionals and managers working in other medical units with a mobile palliative care team (3 physicians, 4 nurses, 2 psychologists, 2 nurses' aides, and 4 middle managers) (Table 1);
- In total, 20 patients and their families: 14 end-of-life patients and 6 family members. All but two of the patients had cancer. Of the two without cancer, both were over 70 years of age, one had a mild case of Alzheimer disease and was able to be interviewed and the other had a respiratory disease. The patient group comprised 8 women and 6 men: 7 were over 70 years of age, 5 were aged 50–65 years, and 2 were aged 35–40 years. The family caregivers included two husbands, one sister, two wives, and one daughter.

Analysis of the interviews and focus groups shows the essential dimensions of high-quality end-of-life care—both its human and technical/physical aspects—from the points of view of patients, families, and professionals. We begin by detailing the different domains of quality in palliative care and then compare our results with those proposed in the NCP framework.

Patient support

The professionals, the patients, and their families spontaneously expressed, albeit in different terms, the concept of

Table 1. Participants: Healthcare professionals.

Units	Background, position	N
Hospital-based palliative care units and hospice	Physicians	9
	Other healthcare professionals	6 nurses, 1 nurses' aid, 2 psychologists
	Middle managers and directors	8
"Standard" medical units—mobile palliative—supportive care team	Physicians	3
	Other healthcare professionals	4 nurses, 2 psychologists, 2 nurses' aides
	Middle managers and directors	4

humane treatment of patients. Thus, the professionals frequently described the concept of a *global approach* to patient care; its underlying idea is that a technical approach alone would not suffice since the relational dimension is also important. It is important to be able to soothe and relieve patients (both physically and psychologically) throughout their journey, including at the moment of death. A global approach also involves taking the family into account, which is, for many, a clear imperative of palliative care:

I took him to surgery. I found the management fragmentary, there was no comprehensive approach to the person. (Healthcare professional, nurse)

It was my goal to understand the patient better as a human being and to ensure a place for families; it always struck me that, often in curative treatment, there is the patient and that's all, and I think that it's this human side, this understanding of the other, that's why I'm in palliative care, while remaining very much a doctor. Because it's not that ... you don't abandon the technical aspects when you choose palliative care. (Healthcare professional, physician)

Analysis of the interviews and focus groups reveals that both the users (patients and families) and the healthcare professionals identified the relationships between patients and their caregivers and healthcare professionals as an essential dimension of the quality of the end-of-life experience. This patient support can be provided in different ways and by different types of professionals, as described below.

Support provided by medical staff (physicians and nurses) to patients and caregivers. The quality of the relationship with these providers was a fundamental criterion for patients and their families; the professionals' ability to be attentive and available was deemed essential. When patients felt they actually received this attention, they valued it highly and showed gratitude. The expected relationship was judged both in terms of its frequency and duration as well as its quality and depth:

I think that what I like least is when you have the impression that they want to leave almost as soon as they have arrived, because they have other things to do. (Patient)

Patients and caregivers found that the availability of clinicians (e.g. physicians, nurses) paves the way to patient-centered care and individualized care management. Patients who felt dependent on their healthcare providers, especially when they could no longer get out of bed, valued the professionals' abilities to anticipate their needs. Not always having to ask for something is also a question of dignity:

They spend their time saying, "The bed, is it OK? We could place you a little further down or up; we'll do this in a half hour and especially don't hesitate to remind me, the bell is there," [...] and organize the room, organize everything that is the life of a sick person who can no longer do much, what he might need to have around him to ... to be content. (Patient)

The professionals were well aware of the importance to both patients and families of the time they could spend together and of their own availability. Having time for the patient is one of the principal motives mentioned by the doctors specialized in palliative care:

I remember making a bet with a colleague, saying to him, "Listen, here in the ER, we don't really have time to deal with people, we go kind of fast, but I bet you that one day, I'll have time, as much time as I want, to devote to the person in front of me." [...] and the day that happened, I called him up and said, "OK, I did it." (Unit Director)

Other professionals felt distress at not finding time to demonstrate their availability. For example, nurses described the problem they have going from a room where they have to provide curative care, such as monitoring chemotherapy or a graft, to a room where the person is in an end-of-life situation. Such situations require strong mental gymnastics and agility. Nurses sometimes feel overwhelmed, which translates into insufficient psychological availability for end-of-life patients because priority is too often given to patients requiring curative care:

I'm always defenseless in these situations. It's hard to deal with, it takes time, finally; it's not a case of having time, but it's ... Here, it's too varied, in fact; we can have chemotherapy, or gastrointestinal surgery, patients in, in palliative care, that's what happens, and it's what gives us the feeling of not being very effective, in fact. (Healthcare professional, nurse)

Finally, palliative care professionals insisted on the need to continually adapt to each situation, to each patient, their family and friends, and to their expectations. This represents a permanent challenge that is sometimes difficult to handle.

Support provided by psychologists to patients and caregivers. In some units, support is provided through consultations with a psychologist. The professionals found the presence of a psychologist in their department very valuable, viewing it as an essential condition to high-quality management. Families also considered psychological interventions as key; beyond the help that a psychologist could provide them in accepting the impending death of their relative, this professional was sometimes sought to serve as an intermediary in dealing with the end-of-life person. For example, a husband, who did not know whether his wife knew she was dying, said,

I wanted, finally I wanted to try to see if the psychologist might come and talk to her, to see if she, if she was able to accept the intervention of the psychologist and to understand that she was at the end of her life. She talks very little about that, so ... (Family, husband)

Nonetheless, patients barely mentioned the availability of a psychological consultation as critical and preferred having time with the doctors and nurses. They often considered the offer of a psychologist as an indication that physicians, nurses, and nurses' aides were unavailable. They were reluctant to consult with a psychologist and preferred discussing any psychological issue such as anxiety or depressive symptoms with physicians or nurses since they perceive their symptoms as directly linked to their disease.

Support from other professionals. In some departments, the patients also had opportunities to see volunteers, music therapists, hospital beauty therapists, hair-dressers, and so on. Patients were highly divided on this subject; they experienced these additional interventions, like those of the psychologists, as second-best stopgap measures. For their part, the professionals underlined the importance of being able to offer diverse forms of support to enhance patients' quality of life. The families not only found comfort for themselves from the other support staff they met, they also appreciated finding their hospitalized family member with her hair done and wearing make-up; they saw this as a sign of respect and personal dignity. According to the families, such support represented a feature that distinguishes a palliative care unit from other departments or healthcare facilities:

For example, the beauty therapists who came, who made her up, then when her children came, everyone noticed it, and that really pleased her; finally someone noticed, and there was this

make-up, much more luminous, much more ..., that really pleased her ... Yes, I also think that the fact that someone touched her, did her hair, did "stuff," styled her hair, I think that it wasn't like before, when she felt abandoned, when she was letting everything go. (Family, husband)

Physical/technical care: management of pain and other symptoms

According to the patients, their families, and the professionals, management of pain and, to a lesser degree, other symptoms is the other important criterion for quality of palliative care.

Pain management. Patients and professionals had differing points of view about the necessary level of pain relief. Patients judged the quality of pain treatment along two dimensions: (1) the relief of pain (or lack thereof) and (2) the possibility of being able to choose between the level of relief and a desired level of consciousness, even when this implied incomplete pain control:

They told me that if I needed relief, I had to ask for pain killers. I was never neglected in that respect, once it was decided what I needed. Sometimes I said that I was uncomfortable, but I didn't want to take anything because sometimes it put me to sleep, and I didn't want to be too sleepy, and they respected that; they said, "It's your decision, you tell me," and I really appreciated that. (Patient)

For families, the question of pain relief was a constant concern; when they had previously been faced with the patient's pain, this issue became paramount. The idea of seeing their relative suffering became unbearable and was linked to the concept of respect for human dignity:

That was absolutely ... in my whole life, I'd never experienced that. All they had was just one packet of aspirin. That was absolutely, incredibly appalling, just appalling. They had nothing, it was a convalescent home, but with no medical care at all. [...] Given her condition, on two occasions I arrived and found her in a fetal position in bed, shaking, crying, screaming, lying in her urine and feces. (Family, sister)

All the professionals also listed pain management as fundamental to being able to provide good quality of care. Like the families, they consider pain intolerable and a priority for professional intervention. It is difficult for clinicians to see a patient suffering and to be confronted with the limits of their clinical intervention. It is also sometimes difficult for clinicians to accept that a patient could choose to stay conscious and refuse to take pain killers:

Yesterday we had a death that did not go well ..., I didn't deal with it well either, there are several deaths where [...] you see that the patient is suffering, that she is still conscious, despite everything; well actually she was in a coma, it was no longer

possible to talk with her, we could no longer communicate, but based on very specific tests, we knew that she was still aware of what was happening to her, and so, to hear her moan all morning while ... being unable to do anything for her, it was hard. (Healthcare professional, nurse)

Healthcare professionals thus sometimes feel powerless to support their patients. This is a concern on all palliative-supportive care teams. Managers provide the means for healthcare professionals to step back and have respite at times (through team meetings, psychological support, etc.). The objective is for healthcare professionals to avoid burning out and remain mentally available to respond to multiple patients' needs.

Management of other symptoms. Beyond the question of pain, some other technical clinical procedures are required, such as the management of some symptoms associated with gastrointestinal problems or respiratory distress. Patients and their families, even when questioned directly on this subject, said little about this aspect of care management. They seemed to have an a priori confidence in the staff with respect to the technical and factual aspects of their care; they would rather evaluate technical competence in terms of relational competence than with respect to the explanations provided for the procedures performed:

I ask them to ... if I have a problem, to try to take it into account to see how they could improve it, but I have no choice to give them. (Patient)

The nurses were kind [...] to me personally, kind enough to explain what was going on, so I would know what was happening, but it's the approach, if you will, the contact with people, the staff, that is most important for me, I think. (Patient)

The professionals also had relatively little to say about these aspects of care. One physician even recognized that these aspects were generally underestimated by clinicians working in non-palliative units:

There are transit problems, or coughing, things that the [palliative care specialists] do much better than we do, at least in terms of evaluation. It's true that we focus on the big symptoms, somewhere, so it's true that they are much better than we are for that, so we rely on them a lot. (Healthcare professional, physician)

Involvement of families

Hospitalized patients had differing points of view regarding the role that their families should play. Their attitudes were primarily linked to family circumstances and personal history. For example, an Algerian man in his 60s,

who had built his life in France after leaving his family in Algeria, hotly rejected the idea of his family speaking directly with the doctors. In contrast, a woman in her 60s discussed at length the importance she gave to her husband's constant presence. The other patients' attitudes fell somewhere in between these two extremes.

The family as an interlocutor for the professionals. The families described in detail how it was important for them to be able to be frequently at the patient's bedside and to know that the professionals were taking their opinions and decisions into consideration:

The physician keeps me informed, fairly often, of what they're doing, of his condition, of what they envision doing finally and, what I found good, they weren't obligations, that is, at least they give me the impression of taking my opinion, my choices, into account ..., so it is fairly agreeable. It's very good because it gives me a lot of confidence, reassures me. (Family, wife)

The professionals themselves underscored how important it is to support the families. They consider it important that healthcare professionals involve the family in the care process, which includes voicing patients' needs and caring for patients. They highlighted the fact that while the patient's distress or difficulties were sometimes difficult to handle, often the family's anxiety and suffering were even harder to deal with. This sometimes became an intense experience for the professionals who were not well enough prepared for it:

Helping the family and friends, it's an awareness that there are things to do, things to be set up when someone dies. So it's always a brutal situation. In the patient's final days, no one is forewarned, everyone learns about it suddenly, and that's difficult. The patients don't understand, the families don't understand, we are always swept up in the intensity of the emotions. (Healthcare professional, nurse's aide)

The staff's objective is to ensure that patients express themselves freely while the families express their own expectations; these expectations are not always aligned. The staff encourages patients and families to express their expectations, and this can be demanding. Healthcare professionals tend to find it difficult when they have to arbitrate between patient and family expectations. Different units vary widely in their capacity to continually adapt to the expectations of patients and families.

Accommodations available for families. Beyond support, the actual space available for families is constrained by the physical layout of the facility. However, when patients and families discussed this issue, they rarely referred to material conditions because they were already satisfied with being able to be together. Nonetheless, families were

particularly appreciative of having a space to themselves, such as a lounge space and a bathroom.

The professionals also mentioned the importance of having appropriate surroundings in which to meet and talk with families:

I think that we lack space, that is, we don't have rooms to talk to families in private, not in the doctor's office, either, which is overloaded with files. We don't have a specific room to see families in, quietly; otherwise we see them in the room called the "hospitality room," but it's in the middle of the hallway, [and isn't a closed room]. So we see them in the intern's office. It's a doctor's office, so by definition it's a mess, there are patients' files everywhere, it's not what we need ... So we need one more room, but I don't see how we can get it, because we're too full. (Healthcare professional, physician)

Care for the imminently dying person and death

The issue of death was not raised systematically during the interviews with patients and families. For ethical reasons, it was not included in the interview form. This section is thus based solely on the spontaneous discourse of patients and their families.

Presence at the moment of death. Some families talked about the importance of being present at the moment of death:

We always said that one of us is going to go first, but that the other would try to stay there to the end, to hold hands. [...] I know that now he knows he's going to die, he's accepted without [...] a problem, it's like this now, we wait peacefully. So, we don't worry. I'm here all day long, I sleep in his room, so we are together, side by side, and that, I can assure you, that I thank heaven, really, to be able to stay close by like this. (Family, wife)

It was primarily the nurses and nurses' aides who spoke more extensively on this subject, possibly because they are the ones who provide care at the very end. Unlike the nursing staff, the physicians felt that the moment of death does not require their presence:

At one point the physician withdraws a bit and waits for the moment of death. Then he confirms the death, because it's almost a tradition to confirm a death to the family, even if it's obvious that the person is dead. (Healthcare professional, physician)

Managing the rituals of death. Healthcare professionals mentioned how important it is for them to respect the rituals surrounding death. Many learn about this either through their peers or through personal experience. In some units, this activity is included in the formal objectives of the

unit. In such cases, these practices are structured. In other units, these practices are not part of the unit's objectives; however, some healthcare professionals may perform these informal and unrecognized practices on a voluntary basis:

I've learned, I know a little, I read a little. When it's a Jew, they have specific rituals, the Muslims also, and the Christians too, I've read a little bit on the subject. I'm not trained for that, so I respect ... Sometimes people will say that they're Muslims, they're Jews, so it's almost the same, when it's Jews or Muslims; women wash the women, men wash the men, so we try to respect that. [...] Good, I know that my colleague, no one knows it, he's Muslim too, when the deceased is a man, he will do it. It's not that I don't want to, but I respect it, I tell him to do it. When the deceased is a woman, he asks me, "Can you do it for me?" I respect that, everyone is ... A person who says to me, or a Buddhist, the Buddhists too, you cannot touch their dead, you have to leave it to them. (Healthcare professional, nurse's aide)

Avenues for refining current quality of care indicators

After having identified convergences and divergences in the points of view of different stakeholders relative to key elements of the quality of palliative care, we compared the results of our qualitative study to the currently used domains, that is, the domains of the NCP for Quality Palliative Care.¹ This allowed us to propose various avenues for refining the existing domains of palliative care, as presented in Table 2.

Discussion

Palliative care is considered a holistic interdisciplinary approach focused on supporting the quality of the end-of-life experience and is based on a vision of palliative care that is shared by patients and all the caregivers involved.¹⁸ Our study reveals four major critical dimensions of quality of palliative care: comprehensive support for the patients themselves; clinical management and, in particular, pain control; involvement of families; and the care provided to the imminently dying person and following their death. Our study shows that these dimensions are, to a great extent, common to all the stakeholder groups, but that there exist some differences between professionals, patients, and families in their assessments of the dimensions or how they prioritize them.

In line with recent calls to evaluate the points of view not only of professionals but also of patients and families,^{3,5,8,9} our study shows that it is paramount to take into consideration the dimensions of quality of palliative care identified by all stakeholders, including professionals as well as patients and families. Although most studies of quality of care are

Table 2. Synthesis of the results of our study and comparison with currently used domains of quality of care according to the NCP.¹

NCP domain	Some NCP recommendations	Added by our study: patients' points of view	Added by our study: families' points of view	Added by our study: professionals' points of view
Domain 1: structure and process of care	Expressed needs of patient and family Use of volunteers Not specified	Quality of the relationship between patients and healthcare professionals (attention, availability, individualization of care, anticipation of needs so that the patient does not have to ask, promotion of dignity) Preference for support from healthcare professionals rather than volunteers Not mentioned	Importance of volunteers' (or professionals' and music therapists) (beauty and music therapists) Not mentioned	Global approach (physical care and psychological support); time devoted to patients (availability); individualization of care (continuous adaptation to the patient's situation) Support of professionals and training, especially for the nurses caught between palliative and curative care, which are very different
Domain 2: physical aspects of care	Side-effects of pain, and other symptoms and treatments, are managed using best practices	Pain relief is essential; possibility of choosing between level of pain treatment and desired level of consciousness (ability to refuse total pain relief)	Complete pain relief is essential, at any price	Support of professionals and training, especially for the nurses caught between palliative and curative care, which are very different
Domain 3: psychological and psychiatric aspects of care	Treat documents and communicates patient/family to make informed choices Psychological and psychiatric issues are assessed and managed; team employs pharmacologic, non-pharmacologic, and complementary therapies as appropriate Social workers	Be kept informed of and participate in decisions about the management of other symptoms Intervention of psychologist to be reserved for cases of mental illness; patient support preferably should come from the unit team (healthcare staff) Not mentioned	Intervention of psychologist for almost all patients	Have the tools required to meet patients' expectations, regardless of the moment, anticipated prescriptions, liaison sheets with patients' preferences, and so on
Domain 4: social aspects of care		Not mentioned	Not mentioned	Stressed by some professionals, especially for young patients
Domain 5: spiritual, religious, and existential aspects of care	Not specified	Support to facilitate family involvement; respect for the level of confidentiality expected by the patient	Possibility of being with the patient; organization of space for families (e.g. bed, specific room)	Importance of having a plan to support families; being able to assess the patient's point of view, independently from that of their families, to prevent the family from becoming the primary interlocutor of information; professionals' availability to families (e.g. meetings without appointments); organization of space for families (e.g. bed, specific room)
Domain 6: cultural aspects of care	Not specified	Same as above	Not mentioned	Management of death difficult depending on the different rituals of different communities
Domain 7: care of the imminently dying patient	Not specified	Not mentioned	Possibility for the family to be present	Respect for rituals after death
Domain 8: ethical and legal aspects of care	Not specified	Have patients participate in the decision-making; balance the requests of families and patients	Not mentioned	Professionals' difficulty in accepting the patient's choice to remain in pain in order to remain more conscious

NCP: National Consensus Project.

limited to documenting care and reviewing patient files,¹⁹ our results suggest that it is also important to interview patients, families, and professionals directly. The individual's status and physical impairments, their degree of dependence on healthcare professionals, and the framework of the interaction can all limit patients' ability to speak for themselves and can prevent them from acting as decision-makers in the care process. Nonetheless, our data reveal that patients and families are able to express opinions on the quality of their care. While it is well known that patients and family caregivers see a three-fold role for palliative-supportive care teams (physical symptom control, psychological support, and reliable liaison),²⁰ our results suggest that patients and families also emphasize the importance of patients' comfort and dignity. In hospital units, families need information and want to be involved in the care process, much like families that have a relative in palliative care at home.²¹ In addition, families in hospital units have other specific needs, such as appropriate accommodations.

Our study results can be used to refine or develop quality indicators that represent the opinions of healthcare professionals as well as those of patients and their families. Examining these different perspectives simultaneously reveals nuances that are difficult to perceive solely on the basis of the quantitative indicators currently in use. One very interesting result concerns patients' opinions on pain management. While the objective of complete pain relief is shared by healthcare professionals and families, patients need more nuanced options. Patients believe that it is essential to maintain a balance between level of pain control and level of consciousness.

Overall, good quality palliative care is determined subjectively based on input from healthcare professionals, patients, and families. It is pointless to search for a single truth.⁹ Our study shows that stakeholders' points of view remain associated with feelings and subjective evaluations that are inseparable from the human history of each end-of-life situation. For example, the relationships between patients, families, and healthcare professionals—both in terms of quantity and depth-of-quality—are viewed as essential by all stakeholders. It is therefore necessary to use these more subjective dimensions⁹ as important indicators of quality of care.

Our study has some limitations. It was conducted in only one country and may well reflect country-specific cultural issues. We nevertheless believe that the participants' different points of view shed light on important dimensions of the quality of palliative care, dimensions that may well vary in intensity but most likely not in nature if this study was to be conducted in another setting. This study took place in hospital units and one hospice and does not provide information on the specifics of outpatient palliative care.

Despite these limitations, this study has some important strengths. It provides insights into the principal groups of stakeholders, consisting of a variety of

healthcare professionals and managers as well as patients and their families, and it took place in various types of palliative care units. Based on a comparison of our results with the domains proposed by the NCP guidelines, we provide some guidance on how to refine and develop indicators that will take into account multiple perspectives, including identifying themes common to professionals, patients, and caregivers, as well as themes specifically revealed by each group of stakeholders.

Conclusion

Our study examines the key dimensions of quality in palliative care. The results suggest that it is crucial to take into account the points of view of professionals, managers, patients, and families simultaneously. Overall, this investigation provides concrete results that can be used by researchers, managers, and clinicians in future studies assessing the quality of palliative care.

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Appendix I

Interview guide used with patients

Could you tell me about the circumstances that brought you here?

What do you consider important for your hospital care to go well?

More specifically, I am going to mention several things that can help you judge the quality of your hospital care, and I'd like you to share your thoughts with me:

Comfort

- Is this important to you?
- What can be important to patients in terms of comfort?

Respect for your privacy and dignity

- Is this important to you?
- What can be important to patients in terms of their privacy and dignity?

Pain management

- Is this important to you?
- What can be important to patients in terms of pain management?

Management of other symptoms (breathing difficulties, fatigue, constipation, other digestive symptoms, overall health status, sleeping disorders)

- Is this important to you?
- What can be important to patients in terms of how other symptoms are managed?

Management of functional difficulties (difficulties walking, getting dressed, eating, changing position in bed, etc.)

- Is this important to you?
- What can be important to patients in terms of how functional difficulties are managed?

Information/communication

- Is this important to you?
- What can be important to patients in terms of the information received and discussions with professionals?

Taking your care preferences into account (the medications prescribed, interventions by caregivers, etc.)

- Is this important to you?
- What can be important to patients in terms of the respect shown for their preferences?

Support, human presence, availability

- Is this important to you?
- What can be important to patients in terms of support, a human presence, and availability?

Psychological care

- Is this important to you?-
- What can be important to patients in terms of the psychological care they receive?

The place of family and friends

- Do you have any family members or friends taking care of you?
- Is it important for you that family members and friends are allowed to play an important role at the hospital?
- What can be important to patients in terms of the place occupied by family and friends?

Care coordination/continuity of care (that all caregivers work toward the same ends, in an organized manner)

- Is this important to you?
- What can be important to patients in terms of how their care is coordinated?

Are there any dimensions that you see as important but that I haven't mentioned?

- To your mind, what are the three most important things determining the quality of your hospitalization?