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Information Needs in Palliative Care: Patient and Family Perspectives

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1. Introduction

The development of palliative care in France is relatively recent compared to English-speaking countries. The first French Palliative Care Unit opened its doors in Paris in 1987 (following “the Laroque circular” of August 26, 1986 that defined palliative care and support), but it was only twelve years later that a specific law was passed, the law of June 9, 1999. This law is important because it aims at “guaranteeing the right of access to palliative care for all citizens who are in need of it” (article 1). Consequently, palliative care became a national health priority and the object of ministerial programmes¹ for development at the level of the home as well as at the institutional level.

- First, in the home, two types of structures were set up to ensure that people wishing to remain at home could do so: on the one hand, Home Hospitalisation services (that depend on a hospital), and on the other hand, palliative care networks, which coordinate a range of private practitioners providing home care to patients while maintaining links with hospitals, should rehospitalisation becomes necessary.
- In France, the Anglo-American notion of “hospice” does not exist. From the beginning, the clearly stated policy choice was for palliative care to be integrated into hospitals (rather than existing outside them). Three types of hospital structures facilitating the provision of graduated care were thus created: Palliative Care Units (PCUs), Identified Palliative Care Beds (IPCBs), and Mobile Palliative Care Teams (MPCTs). While PCUs are small units with a dozen beds reserved for the most complex cases, the IPCBs are beds located directly inside acute care services. The latter are of recent creation (2004) and permit patients to stay hospitalised in their regular department, thus reducing risks related to the separation to which they have already been exposed by entering into palliative care. In contrast to the PCUs and IPCBs, the MPCTs have no beds. These are teams that intervene across the hospital at the request of acute care services to give support in caring for their patients at the end of life. On December 31, 2010, there were estimated to be in France 107 PCUs (1.176 beds), 353 mobile teams and 4.826 IPCBs (spread over 784 care institutions) (Aubry, 2011). At the same time, all hospital caregivers confronted with death are requested to “progressively integrate palliative care into their practice”, whether or not they practice as a palliative care team (circular

¹ 1999-2002, 2002-2005, 2008-2012

dated February 19, 2002). In order to do this, "a guide to best practice in the palliative approach" was written up and the diffusion of "the palliative culture" in all departments is strongly encouraged (circular dated June 9, 2004).

2. Major issues involved in the provision of information in Palliative Care

2.1 Information/communication: a fundamental need at the end of life

Faced with a crisis in medical care (worsening working conditions for nurses, loss of trust in caregivers, the disclosure of judicial cases, etc.) and searching for legitimacy, patients in the 21st century have become authentic consumers of the health care system. Armed with rights they intend to have respected, concerned with transparency and able to make informed decisions, they now appear to be fully participating actors in their own care. In this context, they are increasingly inclined to develop their own standards for what constitutes quality of care (Falls, 2008). While this quality encompasses several dimensions (physical comfort, psychological care, configuration of the care facilities etc.), one topic - that of information and, more broadly, communication with the care team - is found to recur frequently in the literature, as it constitutes a potentially important source of conflict with caregivers. It is this dimension, not specific to the end of life but rather exacerbated in this context, that we have chosen to address in this article.

Many studies underline the extent to which information transmission and communication between patients, families and caregivers represent major issues in care given to persons at the end of life. While some authors describe as "extremely important" the quality of communication in the special context of palliative care (de Haes & Teunissen, 2005), others insist on "the decisive importance" that information, communication and attitudes of professionals have on these patients' families (Andershed, 2006). It is also argued that providing information (together with the possibility to make choices) is one of three principal needs in palliative care, the other two being social and psychological support on the one hand and attention to financial concerns on the other (McIlpatrick et al., 2007).

However, while communication is thus important, it is particularly difficult in the context of the end of life. Indeed, not only must one know how to announce bad news, but also be able to sensitively discuss treatments, establish good relationships with the families and be ready to listen to patients and those close to them (Buckman, 2000). Despite of the importance of the need for information, it is clear that defects in communication are frequent at the end of life (Mangan et al., 2003; Rainbird et al., 2009). This lack of communication is especially common in situations of treatment cessation, the unmet communication needs being due both to a lack of listening and of information (its timeliness, honesty and clarity) (Norton et al., 2003). In this context, it seems particularly important that physicians are aware of these conflicts (even if they are infrequent) and that they investigate them. This would enable them to reduce both the frequency of conflicts that may occur as well as the stress they cause (Norton et al., 2003). While the lack of communication among caregivers, patients and families is often mentioned, a second problem (equally important) is also emphasized: the lack of communication within medical teams themselves (Fassier, 2005; Faulkner, 1998). Thus, the development of palliative care and multidisciplinary care is described as an "urgent need" (especially in Europe) and as an effective way of promoting end of life care in

intensive care units (Fassier, 2005). In this context, because of their enhanced communication skills, the potential impact of palliative care teams on hospitals is stressed (Jack et al., 2004).

2.2 Information as the founding principle of Palliative Care

Generally speaking, and aside from any context of palliative care, information for patients and their families has become both a right and a duty in several countries, including France (National Assembly, 2002; National Agency for Accreditation and Evaluation in Health, 2000; National Council of the Order of Physicians, 1995), where the content as well as the form of this information are the subject of recommendations. As concerns the content, it is stipulated that the duty to inform should include information on the state of patients' health (diagnosis, prognosis), their treatment (its nature, effectiveness, urgency and risks) as well as the potential consequences of refusing treatment (National Assembly, 2002). As concerns the form taken by information to be communicated, caregivers are asked that it be provided to patients "honestly, clearly and appropriately" (the doctor should "take account of the patient's personality in his explanations and ensure they are understood" (National Council of the Order of Physicians, 1995), that it be conveyed in a "progressive and adapted" way (National Agency for Accreditation and Evaluation in Health, 2002) and that "the wish of someone to be kept in ignorance of a diagnosis or prognosis" be respected (except if there is a risk of transmission to others) (National Assembly, 2002). A difficult question, and one widely discussed in official texts and the literature, faces those persons responsible for communicating the information. This concerns the disclosure of the truth, which may be defined as the act of giving truthful information to family members of a patient or to the patient him or herself, even when it is liable to be psychologically painful or unpleasant. Should the truth always be stated, in its entirety, and to whom, when and in what manner?

For French palliative care professionals, informing patients and their families, and more generally "communication", constitutes one of eight fundamental principles of care, on the same level as respecting patients' comfort, evaluating their overall pain, or preparation for bereavement (National Agency for Accreditation and Evaluation in Health, 2002). If properly done, effective communication may enable not only "the evaluation of the psychological and social suffering" of the patient and his or her family, but also an understanding of their needs and expectations concerning the care team, in order to better respond to them (National Agency for Accreditation and Evaluation in Health, 2002). In this end of life context, it is often suggested that to tell the truth is not only necessary, but also desirable for patients themselves as well as for their families, the premise being that the latter need this information, especially for saying their goodbyes. But whereas giving information is considered a basic principle, for some authors, the act of informing can become a source of uneasiness for caregivers, especially if they have not been well prepared for it. "The bad news, regardless of all the definitions one might have, is the narrative of an impending death announcement and the 'don't say anything' finds a place, or at least the 'don't say anything about the future', since it is so difficult to express but also because it is often associated with a 'fear of speaking ill'" (Julian-Reynier, 2007).

This trend, aimed at establishing recommendations for communicating information to persons at the end of their life and to their families, is part of a much larger context than the one described above. Thus, professional guidelines on best practice in palliative care are regularly put in place at an international level, each country defining its own standards (National

Hospice and Palliative Care Organization, 2008). In this context, the Council of Europe has defined the main principles concerning communication of caregivers with patients and families. In particular, it is recommended that: 1) care be delivered in an atmosphere encouraging clarity of information delivered to patients and their families, which implies an appropriate attitude on the part of care personnel; 2) professionals communicate openly with patients desiring to be informed about their situation, with particular attention to cultural differences; 3) doctors adapt their imparting of information to the emotional or cognitive barriers often associated with a progressive and incurable illness (Council of Europe, 2003).

2.3 Study objectives

Within this context of disseminating best practice, it is important to define “best” palliative care, not from a professional point of view, but from that (less well-known) of patients and their families. Going beyond the general rules established over time and their resulting recommendations, the objective of this article is to answer a central question: how is this flow of information perceived by those receiving it (patients benefiting from palliative care and families)? Within a policy framework promoting palliative care, two further questions arise: 1) what aspects of information are most appreciated by patients and their families? 2) what are the main sources of their dissatisfaction in this respect, or of tensions with caregivers? Attempting to answer these questions will draw attention to techniques and improvements that should be encouraged.

3. Methodology

Data used here are part of a larger research project on needs and expectations of individuals and their families at the end of life (Tibi-Levy, 2007; Tibi-Lévy & de Pouvourville, 2007, 2009). Although the delivery of information is only one dimension of patient and family satisfaction regarding care given, our work shows the central place it occupies in the perceived quality of care. Indeed, not only is the question of information brought up repeatedly, but it constitutes an important potential source of friction with caregivers as well.

This study was carried out exclusively in Palliative Care Units (PCUs). All together, 5 PCUs participated (3 in the Paris region and 2 in cities outside this region). They were located in public hospitals and had from 8 to 15 beds. They were chosen on the basis of size, level of staff supervision, and location. We had no prior information or assumptions concerning the reputations of these units. In each PCU, five patients and five families were selected to participate in the study, for a total of 50 persons. The patients studied were recruited according to their clinical status (those patients too tired, confused, disoriented or having difficulty communicating were excluded) and the time between their admission and the interview (recent admissions were excluded). Average age was 63 years (35-88 years) and two-thirds were women (64%). All had cancer and had been hospitalised for an average of two weeks (standard deviation = 14 days) and their average Karnofsky score was close to 40% (“disabled patient, requires special care and assistance, relatively autonomous with limited ability to move about”). In most cases (and to the extent possible) families in the study were those of the patients studied (18 patient-family duos). Out of the 25 families studied, the spouse was the person met with in half the cases (48%), the children in a third of cases (32%) and the parents and brothers/sisters in close to 10% of cases. In seven out of ten cases, these were women (68%).

This qualitative study is based on individual semi-directed interviews with 25 patients and 25 families. These persons were interviewed by a sociologist from outside the hospital, using an interview guide specifically focused on the way the care team took into consideration their needs and expectations generally speaking (cf. Interview guide below) (Tibi-Levy & de Pouvourville, 2007, 2009). The same guide was used for patients and families, with certain variations being occasionally introduced. Interviews lasted 40 minutes on average. Out of the 50 interviews, 42 were recorded (with the agreement of the interviewees) and completely transcribed, representing more than 500 single-spaced pages of discourse. Handwritten notes taken for the eight others (4 "patients" and 4 "families") were also transcribed. After having extracted them from the main body of discourse, we carried out a content analysis on those passages relating to information and communication with the care team. Narratives were submitted to a vertical and horizontal thematic analysis, with the screening tool used identifying two topic areas: 1) those aspects of the information they received that the interviewees found satisfying and that they emphasized; 2) those aspects causing dissatisfaction or even tension with the care team.

INTERVIEW GUIDE

I - Relationship of the patient with the unit

Can you tell me about your first contact with this unit?

What happened? **What information were you given at that time?***

What questions did they ask you at that time?* Did some things capture your attention more than others?

How did you feel about this first contact?

What happened when you arrived here? (admission)

What information were you given at that time?* **What questions did they ask you at that time?*** Did some things capture your attention more than others?

How did you feel about this contact?

How is your hospitalisation here going overall?

How are your relationships with the doctors? And with the rest of the team? **What kind of questions do they ask you?*** **Do they give you enough information?*** (example)

Do you **feel you are being listened to enough*** in this unit. By whom? (example)

What do you think about the environment in the unit (your room and the common rooms)?

II - Attention to the needs and expectations of the patient by the care team

What aspects of care do you think are especially important today? (important aspects)

Do the team doctors pay sufficient attention to these aspects? And does the rest of the team? (example)

OR What do you think is especially important today in the way this unit takes care of you?

Do the doctors pay sufficient attention to this? And does the rest of the team?

What would you like the staff in this unit to do for you?

What aspects of your care would you like to see improved? (example)
OR What improvements would you like to see in the way this unit takes care of you? (example)

III. - Former situation

Could you tell me a little about your situation before you arrived in this unit? Where were you? How did that go? Were you satisfied with service where you were? (medical care and relationships with caregivers)

Did you personally choose to come to this unit? Why?

IF NOT: Who directed you to this unit? **What reasons were you given at that time?***

* **Underlined questions: questions related to information provided**

4. Results

Table 1 displays the main findings described below, identifying those aspects appreciated by patients and families on the one hand (to promote and disseminate) and potential sources of dissatisfaction on the other hand (to be resolved).

4.1 Factors related to satisfaction with the information received

4.1.1 Aspects of satisfaction

Eighty percent of patients and families interviewed said they were completely satisfied with the quality of information given by caregivers, because of a combination of five of its aspects:

- its accessibility: "If there is a lack of information, I can ask a question. Anyone, depending on their competence." (n°22, male, 62 years old, PCU5); "When we ask questions, we get all the answers we want." (n°34, patient's sister, PCU2).
- its completeness: "Every time I ask a question, I have a complete answer." (n°22, male, 62 years old, PCU5), "They explain everything. They don't do anything without telling the patient and us (n°45, spouse of a patient, PCU4).
- the frankness with which the explanations are given (no "taboos", "evasiveness", "lies", or "little secrets"). "Here, the doctors don't hide behind their white coats to avoid giving an answer. And that is very important." (n°22, male, 62 years old, PCU5); "They favour openness. They don't beat around the bush, you see. Whereas where we were before, the doctors kept passing the buck to each other. In the end, I didn't know any more than before. But here, everything's perfectly clear." (n°47, spouse of a patient, PCU5).
- its appropriateness : «When my mother asks you a question, answer her question. But, it's not your role to get ahead of things [by telling her everything] because the patient doesn't need to know everything» (n°38, daughter of a patient, PCU3).
- its comprehensibility (clearness): "Some doctors are still difficult to understand. Then I understood what they anticipated for me. And for me, that was tremendous. I started to come out of the fog I was in." (n°21, female, 71 years old, PCU5).

Table 1. Providing information in Palliative Care

Those things most appreciated by patients and families (to disseminate)		Things causing concern (to resolve)
Factors giving satisfaction according to the kind of information given		From "too much" to... "not enough" information
<ul style="list-style-type: none"> - Accessibility - Completeness - Frankness - Appropriateness - Comprehensibility (clearness) 		<p>Too much information</p> <p>Too "blunt":</p> <ul style="list-style-type: none"> - People who say they "know what to expect" and therefore prefer not to ask questions - Idea that one must not "provoke misfortune"
<p>Interpersonal skills of caregivers:</p> <ul style="list-style-type: none"> - "Availability, openness" - "Get on people's level" - "Real understanding, real dialogue, real interest" 		+ Situations resulting from the way persons experience (lack of information, elusive attitudes from caregivers)
Techniques identified for delivering information		Desires to filter information for families
Patients	Families	
<ul style="list-style-type: none"> - Availability of caregivers - The consultations-conversations - Attention given to the non-verbal - Fact that caregivers regularly ask questions 	<ul style="list-style-type: none"> - To be "taken aside" - The fact that caregivers ask them questions (especially, how they are experiencing things) - To be told if there is a problem - The booklets "with all the telephone numbers" 	<ul style="list-style-type: none"> - Worries about "protecting" their ill family member from information - As a result: 1/ apprehension in these families; 2/ the desire to withhold information for their family culture - A desire to withhold information generally well respected as a duty to inform (sharp reminders to families that they have a duty to inform) - Families that revised upwards their judgement concerning the need for information
The positive impact of using these techniques		
Patients	Families	
<ul style="list-style-type: none"> - Establishes confidence - Helps to progress 	<ul style="list-style-type: none"> - Reduces drama - Helps in coping - Helps give support to their ill family member 	
Calming words and attitudes		Upsetting words and attitudes
<ul style="list-style-type: none"> - Enables patients to cope with the shock of the announcement - "Beneficial" hospitalisations 		<ul style="list-style-type: none"> - Repeated calls to take courage...that are discouraging - Overly sympathetic behaviours
... knowing that there are situations where the patients and families will never be satisfied, regardless of caregiver communication skills (especially when patients are waiting for an "effective treatment")		

The quality of information goes hand in hand with the interpersonal skills of the caregivers. Many people emphasized these skills (“availability, openness, real understanding, real dialogue, real interest”), and interpret them as a sign of attention and of “professionalism”, that lead them to believe the caregivers are “truly” interested in them, as these two excerpts demonstrate: 1) “I have the impression the doctors really want to communicate with me, to discover any progress, to discuss what I do or do not want to do, to inform themselves clearly on what’s happening to me, to the extent I ask for it, with no holding back of information, and not at all with a desire to use doctor talk, but a good explanation of things. That’s striking.” (n°6, female, 48 years old, PCU2); 2) “The doctor made a good impression on me from the beginning because he seemed to be a professional who knew what he was talking about. I think a current passed between us and that he is going to try and do what he can.” (n°4, male, 80 years old, PCU1). In this context, the ability of caregivers to “put themselves at the level” of the patients is highly appreciated, as this patient describes: “Here, the caregivers feel like they are on the same level as we are; a doctor and a worker, it’s like that [they’re the same].” (n°17, male, 58 years old, PCU4).

4.1.2 Techniques for delivering information

Techniques and attitudes used by caregivers for informing patients and families are pointed out by some and they often compare their present hospitalisation in a PCU with what they observed in other types of facilities throughout the course of their stay.

Patients highlight four positions adopted by caregivers, reproduced here in the context of the diffusion of palliative culture:

- the availability of caregivers and their ability to “take their time”: “The doctor really took her time to explain to me the sequence of events from A to Z. It wasn’t just an interview: your last name, first name, motivations. It was the time that she devoted to me. Somehow, that made me feel better, especially since in the hospital where it’s usually a factory, where there’s no tendency to devote time to you. Therefore, when you have this illness, sometimes you have a tendency of wanting to be listened to.” (n°8, male, 35 years old, PCU2).
- the fact that medical visits “are like conversations”: “The doctor sits on the table or a chair. You’re on the bed or sitting there. And then, the visit is carried on like a conversation, which is most probably focused by the practitioner on particular topics that you don’t always notice in the conversation, but that are certainly aimed at particular questions.” (n°25, male, 82 years old, PCU5).
- the fact that caregivers show an interest in what is non-verbal as well (facial expressions and body language), an interest that suggests to them the team “is concerned about them”: “From the nurse’s aid to the nurse, they don’t hesitate to talk a couple of minutes, to say: ‘oh, you’re looking sad today, what’s the matter, do you have some bad news, what’s wrong?’ They see it in your expression.” (n°19, female, 63 years old, PCU4).
- the fact that caregivers regularly ask them questions about their needs and expectations: “We get information practically daily when we are in the unit. They ask you questions: ‘are you alright madam, do you have any questions, you can ask questions, do you need anything, would you like something?’ They ask me if I slept badly for example or if I have some bad news, is there a reason why I’m in this state.” (n°19, female, 63 years old, PCU4).

For their part, families evoke four techniques used by caregivers in their role to inform:

- to be “taken aside” by caregivers at admission to evaluate what the patient knows: “When we got here, the doctor took me aside and asked me if mama realised what type of service she had ‘landed in’.” (n°32, daughter of a patient, PCU2).
- to be questioned by caregivers on the health status of their ill family member, as well as on how they personally experience the events, as a family: “What struck me was the professionalism because they asked questions on her status, on how we felt about things.” (n°32, daughter of a patient, PCU2).
- to be informed by the care team as soon as there are problems: “In some hospitals, they tell you: yes, everything’s fine, everything’s fine. And then when you arrive, things aren’t fine at all. Whereas here, they telephone you and tell you: things aren’t going well today. There. They let you know.” (n°34, sister of a patient, PCU2).
- the giving family members “booklets with all the telephone numbers of the team”, and insisting on the fact they can call them at any time: “Above all, which is pretty rare, they say: you can call us whenever you wish, day or night, there’s no need to take an appointment.” (n°32, daughter of a patient, PCU2).

4.1.3 Reasons for satisfaction

These ways of giving out information, based on communication techniques, have the effect, on the one hand, of “gaining the patient’s trust” (“All this makes you trust them.” (n°8, male, 35 years old, PCU2)) and on the other hand, helps them to move forward (“It was important that I understand what was in store for me, what I could expect. He was very explicit. For me he’s a doctor who knew how to use the words that helped me.” (n°21, female, 71 years old, PCU5)). In addition, some families emphasized this process of gaining trust with relief (“They were able to get my mother to trust them. That means they have considerable powers of persuasion, but through human warmth, through gentleness I think. And I find that brilliant because a lady like my mother, the fact she was able to find calm here...that’s wonderful!” (n°33, daughter of a patient, PCU2)). These families say they also feel comfortable reaching out to caregivers and stress how important it is for them “to be able to talk to them without fear of being rebuffed or told lies” (n°34, sister of a patient, PCU2).

The question concerning the truth is evoked more by the families than by the patients. Some of them explain that, in their case, knowing the truth is preferable for two reasons. On the one hand, they can avoid “over dramatising the situation” (“We make a lot of assumptions that are generally wrong. We always think its worse, worse than it is.” (n°47, spouse of a patient, PCU5)). On the other hand, it helps them cope and give support to those close to them (“When we are faced with the facts, we can react differently, both me and my husband. He can react differently, given the state of his illness, since he is very much of a fighter as well, and say to himself: well no, I’m not going to let myself sink, I’m going to give it a go. And from our side, we can carry on and encourage him to fight.” (n°47, spouse of a patient, PCU5)).

4.2 Friction with the Palliative Care teams about information provided

Discourse analysis brings out three potential sources of dissatisfaction: inappropriateness in the amount of information given by caregivers, fear within some families that the patient will “learn the truth”, and disturbing attitudes or words.

4.2.1 From “too much” to ...“not enough” information

While three people feel there is too much information given, four others think that, on the contrary, there isn't enough. These feelings of over-abundance or insufficiency are sometimes found in the same care unit and are essentially related to the announcement, or not, of the approaching end of life; should it be announced or not, and to whom?

As concerns the perception of too much information, the arguments used by patients and families are similar. It is felt the caregivers are “too blunt”, as explained by a patient and her daughter, interviewed separately: “They were less considerate with me than where I was hospitalised before. It doesn't bother them to talk to you about your illness.” (n°13, female, 48 years old, PCU3); “Its not for the doctors to take the initiative. I don't see the point of going into a room and telling someone: ‘you know, you have tumours in the stomach, ok, if you have a blockage, you could have one, if you have one, we wouldn't be able to operate on you.’” (n°38, daughter of a patient, PCU3). The information can also appear redundant: “Ok, I know it now, let's not talk about it anymore. It's no use going on and on about it.” (n°23, female, 48 years old, PCU5). In this context, some people prefer not to ask questions, either “to not know the answers” (n°13, female, 60 years old PCU3), or in order “not to bring on bad luck” (n°22, male, 62 years old, PCU5):

- *The interviewer:* When you arrived here, the team may have talked to you about this term “palliative care”; may have said something to you?
- *The patient:* Oh no, no, no. Nobody talks about that here.
- *The interviewer:* And didn't you ask any questions?
- *The patient:* No. There are taboo questions that I really avoid asking. No, I'm not going to go looking, I'm not going to bring on bad luck.

As for observations concerning a lack of information, these are often accompanied by a felt difficulty in obtaining answers to questions, to the extent these questions can even be formulated. These patients are disappointed that the doctors don't visit their rooms enough on the one hand (“You don't see the doctors every day. They could stop by to ask if your better, for example” (n°24, female, 56 years old, PCU5)) and that some of their questions are not answered on the other hand (“The doctors are not especially talkative. Sometimes, when you want an answer, you have to pester them several times with the question.” (n°24, female, 56 years old)). Taken to the extreme, this feeling of lack of information can give the impression of being abandoned, as noted by this gentleman waiting for a “cure”: “Uh, they [the doctors] don't come very often, they hardly ever come. Here I haven't got anything [any cure]! They just put me there like a guard dog...” (n°16, male, 64 years old, PCU4), or this bewildered sister: “The patients don't know why they are here, beginning with my sister. What I think is that they are at the end of life and there are people that die. And they know this, they even see them go by their room. So when a patient asks questions, like my sister's question: ‘is this a place to die?’ Yes, I think it's the last place you go and you leave from. It's not really completely clear. As for me, the doctor doesn't contact me. I don't have any report on anything. No explanation whatsoever. I come every day, I just don't know. Ok, I can guess why she's here. But no one told me anything at all, at all.” (n°40, sister of a patient, PCU3). But from this woman's point of view, normally, it's not for the families to go towards the doctors... but the opposite: “They should be the ones to make contact, for the simple reason that every time they come to see my sister, I'm always in the room. And I

can't talk in front of her, ask the questions I want answers to. So I wait. But apparently, it's when there's nothing more that can be done that they contact you." (n°40, sister of a patient, PCU3).

These perceptions of having too much or too little information are felt to be even more negative by these patients and their families because the announcements of a transfer to a PCU by the traditional hospital departments were considered unsatisfactory, for at least one of the following three reasons, mentioned by the daughter of a patient (n°32, daughter of a patient, PCU2) and reiterated less strongly by six other people (three patients and three families): 1) an unsatisfied need for supplemental information ("I wanted to know a little more. And then I told myself: ok, I'll get more information at the place."); 2) attitudes of avoidance on the part of referring physicians ("It wasn't her doctor who told her: 'you're going into palliative care'. And that was someone who had followed her for nine years and who didn't have the courage to tell her to her face! It was the young departmental intern where she was who told her. And I find that absurd."); 3) a feeling of a lack of tact in the announcement of the transfer ("One evening, I call my mother and she says to me: 'they just told me that I'm being transferred to palliative care'. Then, I really got mad. I called the nurse and said: 'give me a doctor'. Impossible to talk to a doctor. And the head nurse tells me: 'oh yeah, we're transferring her to hospital Y'. And I told her: 'you have no tact at all, my mother is in tears now, you just announce it to her like that'. And she answers: 'yes, but you know, we explained to her that it would be good for her and in any case, I'm telling you, she's not going to die right away'."

4.2.2 A desire by the families to filter information

The issue of imparting unpleasant information directly to patients was brought up by two families in particular, who desired that the information should go through them first, or at least, that it be communicated to their loved ones less bluntly. Their reason is a desire to protect them: 1) "My husband doesn't know he has cancer. I never wanted him to know. He would have rapidly let himself die. Whereas now, he's eating again, he's walking. If he knew he had cancer, he wouldn't do all that anymore, he'd really let himself go." (n°50, spouse of a patient, PCU5); 2) "If they tell you everything, they douse whatever little spark of life force you have left." (n°38, daughter of a patient, PCU3).

These people regret the present tendency of wanting to tell everything to patients out of principle, and are afraid their loved ones will end up being informed of their critical state ("I'm always worried, because I'm afraid they'll tell things to my husband too directly. Nowadays, it's true they say things to patients a little too directly" (n°46, spouse of a patient, PCU5)). Aside from these concerns, these families perceive the failure of caregivers to comply with their wishes as a lack of consideration for their family culture, as clearly expressed by the daughter of a patient: "What I didn't like was that they didn't take the family into consideration enough, the family structure, the reasons why you hide things from your family. Why? Because you know your family better than anyone. We're really close to one another, very, very close, really close. Now, when you have doctors who tell you after five minutes that they understand your family structure, your family, and that they understand it better than you do..." (n°38, daughter of a patient, PCU3).

However, in spite of this dissatisfaction, the study shows that the desire to withhold information is generally well respected by the caregivers. Thus, some patients don't know

what kind of unit they are hospitalised in (two think they are in a rest home², one thinks he's in a pain unit³ and two others say they don't know where they are⁴) and others talk about getting better, like this woman who died a month later: "Most people see palliative care as the end of life. But these services also have the objective of compensating for problems, so you can get back on your feet. Palliative care is also a place where you can recover." (n°6, female, 48 years old, PCU2). In addition, attitudes are not fixed and the teams adjust their behaviour during a hospitalisation, as this woman emphasises: "Here, they hide nothing, they tell the truth. I told them: 'I'm not asking you to lie to her, I'm just asking you not to tell her anything'. Now, things are a lot better. But in the beginning, I really felt bad." (n°38, daughter of a patient, PCU3).

4.2.3 Words and attitudes of caregivers in their role to inform

The study underlines the importance of caregivers' attitudes and words in the way the information delivered is perceived by patients and their families. They are alternately described as destructive or as an important source of comfort.

In the first instance, some people express dismay in regard to some caregivers, because of their words or their behaviours. Two factors are felt to be responsible:

- repeated calls to "take courage" that are... discouraging ("I noticed that each person told me to take courage, things like that. And that weakened me more than anything else because I don't need that plus the rest. I felt like they were driving the point home even more, telling me: 'you're almost there'. I come here to be with my husband, to have some good moments with him and not to be crying all the time. He doesn't need to see me like that either, because that makes it worse for him. I told the doctor, I made him understand that I should be talked to in a normal way, that I had to hold up for my husband and I absolutely shouldn't break down, because of my husband. Since then, it's a lot better." (n°29, spouse of a patient, PCU1).
- exaggeratedly sympathetic behaviours (compassionate looks and smiles, excessive niceness and gentleness, decorations that are not typical for a traditional hospital department) ("I noticed that sometimes, when my mother was going to say something, they would look at her with a smile, give her a little caress. She said to me: 'did you see, they look at me that way, I really feel like it's the end, that I'm finished'." (n°38, daughter of a patient, PCU3); "It's nice here. I mean there are flowers. It's like the friendliness, it's nice... but then right after you say to yourself it's because..." (n°37, daughter of a patient, PCU3)).

Similar attitudes can, on the contrary, prove soothing (and that is the second instance), such as for this patient: "It's true that, in the beginning, palliative care was horrible. I was really

² "I wasn't strong enough to stand that new operation. That's why they put me in a convalescent home, two or three weeks, to be able to rest in a calm place, to eat well, to pay attention to what I eat." (N°15, female, 45 years old, USP3)

³ "My doctor decided to hospitalise me here, in a pain unit, in a department specialising in pain." (n°25, male, 82 years old, USP5)

⁴ "My lung specialist told me they are well-known here, so she preferred to send me directly here. She said: 'it's very, very good'. That's all. Because it has a good reputation." (n°10, female, 47 years old, USP2)

afraid. I imagined that someone was dying in every room. Now, it's better. I see that you can live and continue your life. I feel good in my room. I mean, I feel just as good as if I were at home. Here, I am reassured by the team. It changed the way I see this kind of place." (n°7, female, 52 years old, PCU2). Another patient explains how beneficial the hospitalisation has been for her because of the attitude the team has taken concerning her: "I like simplicity. And I have been lucky for that as well. These are people that are flexible, who love life and give it to you. They share this with you. Its funny, but I would never have thought that one day I would stay so long in hospitals and that it would bring me so much." (n°23, female, 48 years old, PCU2). Some patients nevertheless have other expectations, not always possible to meet: "I'm looking for efficiency; I'm looking for a cure, not words. I think it's normal for a hospital to look for a cure!" (n°16, male, 64 years old, PCU4)).

5. Discussion

These results highlight two topics for discussion, central to the way patients and families perceive the information activities of caregivers: 1) the team's communication and interpersonal skills; 2) the ability of the caregivers to manage unique situations by adapting the information they deliver according to the needs and expectations of each person. The discussion is based in particular on a review of literature covering the past ten years (2001-2011) via Medline (key words: "palliative care", "information", and "communication").

5.1 Providing information: knowing how to communicate

5.1.1 Communication skills: contours and visibility

Discourse recorded among patients and families confirms the substantial overlapping of the activities of informing and communicating in the context of palliative care and approaching death (Faulkner, 1998; Kirk et al., 2004). To inform is to know above all how to communicate. This means making the information accessible, providing complete answers, being frank and expressing oneself in a comprehensible way (cf. Table I). These four elements are associated with a fifth, more overarching one: the availability of caregivers, which is a special skill for opening up to those they care for, putting themselves in their place and making time available to them. Kirk et al. underlined the special attention to be given to these aspects and stressed in particular three of them: fairness on the part of caregivers, the clarity of their discourse and their ability to take time with patients (Kirk et al., 2004). It's what one of the interviewed patients in our study called "a good explanation of things, and not just doctor talk" (n°6, female, 48 years old, PCU2). But communicating is more than delivering information; it's a two-way relationship that gives patients and their families the impression that caregivers are "really" at their side ("real listening", "real dialogue", "real understanding", "real interest", "real desire to communicate", etc.). It appears then that "what the patient wants is a truthful relationship rather than just a medical truth" (Ruszniewski, 2004). The issue is not whether one should tell the truth, to whom, how and about what, but rather whether the relationship caregivers have with patients and families is "real", that is, whether caregivers are able put themselves in a position to listen.

In this context, one of the contributions of our work is to have shown that the efforts expended on communication in a PCU are highly visible to patients and families:

- First, it shows that techniques used by caregivers to inform are seen not only for what they are (consultations-conversations, frequent and regular questions, booklets with all the telephone numbers, etc.), but also in contrast to their experience in acute care facilities (e.g., a feeling of being listened to, the possibility of talking to caregivers without fear of bothering them, a perception that doctors have time for them and that they communicate on the patient's level, etc.). This contrast, mentioned spontaneously⁵, is confirmed when we compare these results with those of studies carried out in acute care facilities. The latter scenario has the doctors on one side who "don't say anything" and on the other side, the patients who "don't dare to ask questions" and who feel they've "lost possession of their bodies", or are even "not involved in the consultation" (Fainzang, 2006). In particular, our work highlights two things to be given priority in traditional hospitalisations: on the one hand, increased use of protocols in announcing the transfer to a PCU (timing and place of the announcement, the caregiver who should do it, the words to be used, the attitude to adopt) and on the other hand, the integration into these departments of relationship techniques used in PCUs.
- Secondly, some patients and families underline the strong impression the caregivers' communication skills have on them: confidence building, not overdramatising the situation, helping to fight, etc. Some family members emphasise in particular the positive effect the attitude of the caregivers has on their sick relative ("calming") and explain that this pleasant attitude encourages them to approach the caregivers more easily than they would have spontaneously (absence of "fear of being rebuffed or told lies" (n°34, sister of a patient, PCU2)). Efforts by team members to adapt their actions to be more in line with actual needs and expectations of patients and families are also reported by some. The perception of these efforts is actually reflected in the positive changes in the way they see their hospitalisation (e.g. "I explained [such and such] to the caregivers. Now, things are a lot better").

5.1.2 Interpersonal skills: associating patients and families with the information process

Communication skills are related to a larger concept, that of caregivers' interpersonal skills. Two sensitive points are mentioned in the interviews, underlining the desire of many people to be truly associated with the informational process that concerns them most: the announcement of diagnoses and prognoses on the one hand, and the importance of maintaining hope on the other.

- On the first point, recent work has found that a significant proportion of patients in palliative care do not know their diagnosis and/or their prognosis. This information was not given to them by the physicians in their department, in spite of all the professional recommendations published on the topic. In this respect, silence is judged by caregivers to be more effective than an intrusive announcement in aiding patients to face death with dignity (Giardini et al., 2011), while some families complain about the lack of information they are given on prognosis (Yoshida et al., 2011) and many patients leave the hospital with false hopes (Gott et al., 2011). This censoring of information by physicians is based on what may appear to be a legitimate concern, that of protecting

⁵ That is, without a precise question about this being asked during the interview.

the patient from potentially upsetting, depressing or bad news (Fallowfield et al., 2002). Sometimes, it's the families themselves⁶ who withhold information. Indeed, it is not rare that they explicitly request the caregivers (sometimes in an insistent manner) to not tell the truth to their ill family member (Fainzang, 2006; Faulkner, 1998), whether this person is in palliative care or not. In fact, many patients and some families are kept in ignorance and uncertainty about their condition, as our study has shown. While this may suit some of them (in spite of their right to information and transparency), others explain on the contrary that being left in the dark is worse for them than knowing the truth, even if it is serious. Knowing would in fact allow them not to overdramatise the situation, while giving them more strength to "fight" and "give support" to each other. More than silence or the blunt truth (two extreme attitudes commonly observed in hospitals in the end of life context), some authors affirm that a third position, deceit, is even more damaging because it prevents patients and families from reorganising their lives accordingly and from doing what can be done at that moment in time (Fallowfield et al., 2002). In this respect, our study clearly shows that, contrary to what has often been noted in traditional hospital departments (Fainzang, 2006), caregivers in PCUs do not attempt to avoid their responsibility of transmitting information, on the pretext that the family doesn't want the patient to know the truth. Starting from the premise that patients should be informed about their critical condition, they regularly attempt to increase the families' awareness of patients' need for information, at the risk of being in disagreement with them. (e.g., "I told the doctors: 'listen, it's not necessary to tell my mother everything'. And they told me: 'yes, but you understand, it's necessary to tell them the truth'." (n°38, daughter of a patient, PCU3)). Because of this, the desire on the part of families to withhold information probably constitutes a greater source of friction in a PCU than in other types of units, where caregivers more frequently renounce giving information.

- Maintaining hope clearly emerges as a fundamental component in patient and especially family satisfaction concerning information, a result also found in the literature (Innes & Payne, 2009; de Haes & Teunissen, 2005). Even when all appears lost, many people still want to believe in a "miracle" (Kirk et al., 2004). Although physicians have the duty and responsibility to inform patients and families about the past, the present and the coming situation (Hippocratic Oath), they must do it while respecting the need for ambiguity about the future, among patients who desire this (Innes & Payne, 2009). While telling the "blunt truth" is sometimes called "criminal" (Serryn, 2008, as cited in Roy, 1988), giving false hope is equally open to criticism (Gott et al., 2011; Ngo-Metzger et al., 2008). In this respect, the "truth step by step" model seems to be a good alternative to either a "headlong rush" (consisting of "telling everything", under the pretence of honesty and frankness) and a "paternalistic attitude" (in which the physician "says nothing") (Ruszniewski, 2004). This model consists in disclosing information in a gradual way and to "qualify one's statements", which implies that caregivers let themselves be guided by the patients and families, and that leaves a place in the practice for "an absence of rules" on the matter. Sometimes, what patients and families want is not to be told things, but to be listened to, as explained by a young patient in our study: "When you have this illness, sometimes you have a tendency of

⁶ When they have been informed.

wanting to be listened to.” (n°8, male, 35 years old, PCU2). The debate about the truth moves from the question of announcements (announce what, when and how?) to that of listening (how does one listen?). More generally, the confidence patients and families have in caregivers is a major factor in building a solid caring relationship (de Haes & Teunissen, 2005), as is the degree of empathy found in that relationship (Schaefer & Block, 2009). Other factors should also be encouraged here, such as talking to patients fairly early about palliative care (when the illness is not too far advanced and they still feel well) or the prioritising of key points to discuss with them (Ngo-Metzger et al., 2008).

If it's necessary to inform “without giving the blunt truth” (Roy, 1988) and to be honest while “maintaining hope” (Innes & Payne, 2009), “there aren't any [miraculous] recipes” for doing that (Ruszniewski, 2004). On the other hand, caregivers' interpersonal skills can be noticeably improved by gaining a minimum of knowledge in this area. To this end, recommendations for best practice in palliative care have been developed in several countries (National Hospice and Palliative Care Organization, 2008; National Agency for Accreditation and Evaluation in Health, 2002) and disseminated in health facilities. In particular, the announcement of bad news, the notification of transfer to palliative care, as well as the disclosure of medical errors should be given special attention (Hatem et al., 2008). In addition, programmes of study on special topics exist almost everywhere, within the context of initial training of caregivers (medical schools, nursing schools) as well as in continuing education programmes. Their goal is to teach health professionals to be more vigilant concerning the content of what they are going to say, the way they say it and the circumstances surrounding the delivery of information. The people we interviewed spontaneously cited some of the important points, such as the fact that caregivers make themselves available, sit down next to them and regularly ask them questions about their health. There is a rich literature concerning this training (Hatem et al., 2008; Miyashita et al., 2008; Ferrell et al., 2007; Alexander et al., 2006; McFarland & Rhoades, 2006; Clayton et al., 2005), which is aimed at increasing the communication skills of caregivers, or at least making them aware of these issues. It is none the less necessary that their aspirations and actual conditions of work on a daily basis make possible the desired improvements.

5.2 Giving more attention to the needs and expectations of each person

5.2.1 Recognising a two-fold heterogeneity

This study shows the extent of subjectivity in the perception of good informational activity by each patient or family member, due to a two-fold heterogeneity that must be taken into account:

- While the place and role of families is largely recognised and developed in palliative care, their needs and expectations regarding care teams are not necessarily similar to those of the patients themselves. For example, our study shows that the patients don't always ask for diagnostic and prognostic details, contrary to families, who expressed no reservations on this point and would sometimes like to know even more (especially on the time left to live). These results confirm those of Kirk et al. in particular, showing that informational needs of patients and families diverge as the illness progresses, with patients not wanting to have details, especially concerning their prognosis, while

families wish to have that information (Kirk et al., 2004). Because of this, many families take up a position of defending the interests and well-being of their loved one, evoking the importance, from their perspective, that caregivers “don’t say anything” so that the patient doesn’t lose hope (e.g.: “If my husband knew he had cancer, he’d have let himself die in a short time” (n°50, spouse of a patient, PCU5)). Therefore, and for each hospitalisation, caregivers should bear in mind and evaluate these two levels of needs (patients, families), that are sometimes opposed to each other.

- The second type of heterogeneity is more complex since it is conditioned by the uniqueness of the needs and expectations of each person concerning care and information. This infinitely variable uniqueness depends not only on clinical characteristics of patients (pathology⁷, symptoms, disparities linked to age⁸, etc.), but also to specificities in the broader sense of each individual (nationality⁹, culture¹⁰, personality, experience, family circle, social status, etc.). In addition, all these components can fluctuate over time because of the extreme variability of this population. Thus, aside from the heterogeneity of the illness and of the people affected, the question for each caregiver of what information to deliver (quantity, content) depends on the person it is intended for. And the perception of each patient or family concerning the information received varies according to his or her own expectations (this is especially obvious in situations of over and under information described above). What suits some does not necessarily suit others, as expressed a patient’s wife concerning the repeated statements to “take courage” addressed to her by several members of the team: “That’s the way I am. Maybe it would be okay for other people, but not for me.” (n°29, spouse of a patient, PCU1). In spite of their desire to “do the right thing”, caregivers can then find themselves in an awkward situation, even in latent or open conflict with some patients and/or families. Even in PCUs, where the interpersonal skills of caretakers are well developed, increased attention should be given to deciphering the real needs and expectations of those under care, which requires even more attention to the personality of each one, to their personal experiences, and, as underlined by the daughter of a patient, to their “family culture” (n°38, daughter of a patient, PCU3).

5.2.2 Manage uniqueness by better adapting information to be communicated

The diversity of patient situations found in care facilities highlights a fundamental aspect of satisfaction for patients and their families: the importance (as suggested in the interview results) of caregivers further adapting the way they disclose information. This means individualising it to the extent possible, according to the unique needs and expectations of each person. Personalisation implies adapting norms of professional conduct and attitudes on a case by case basis. This requires a special skill, that of managing the uniqueness of

⁷ Cancer (Rainbird, 2009; Parker et al., 2009; Nanton et al., 2009; Mills, 2009), cardio-respiratory illnesses (Exley et al., 2005), renal diseases (Kurella Tamura & Cohen, 2010), intellectual disabilities (Tuffrey-Wijne & McEnhill, 2008), etc.

⁸ Paediatrics (Hsiao, 2007; Meyer, 2006), the elderly (Just et al., 2010)

⁹ Differences according to country (Cartwright et al., 2007)

¹⁰ Aborigines (Decourtney et al., 2010), African-Americans (Jenkins, 2005), etc.

situations as they occur daily. In order to meet the need for further adaptation of the information process (Kirk et al., 2004), discussions should be held (in PCUs as well as in acute care facilities) on methods and techniques to be put in place for evaluating what patients and families know, what they would like to know (or not) and what they find satisfying (or not) in terms of the quantity and quality of the information received.

The first type of strategy is based on the establishment of an open and direct dialogue with patients and families. In this respect, several authors emphasize the benefit of family conferences in PCUs (Yennurajalingam et al., 2008), as well as in intensive care units (Curtis, 2005 et al.; Lautrette et al., 2006). This involves formal and structured meetings between caregivers and families. These are the occasion for taking the opportunity to create a space for dialogue, for listening to families, answering their questions and sharing their feelings, while respecting key principles of medical ethics and palliative care (consideration of patient preferences, explanation prior to taking decisions, reassurance of non-abandonment) (Curtis et al., 2005). To do this, such conferences should consider the needs of families (to reassure them, for example, of the proper management of their relative's symptoms), be the place to deliver clear explanations concerning decision-making, and give continuous and compassionate attention to the needs of the patient, until his or her death (Lautrette et al., 2006). Therefore, these conferences are considered by some authors as an opportunity to considerably improve the quality of care for palliative care patients (Hudson et al., 2008), even the "keystone" around which care at the end of life should be built (Lautrette et al., 2006). From this perspective, recommendations on the preparation, conduct and evaluation of these meetings with families have been made (Hudson et al., 2008). More generally, the international literature highlights the importance of testing structured approaches to disseminating information, to determine the most appropriate attitude to adopt for each unique situation (Hudson et al., Aranda & Kristjanson, 2004). In addition, some authors underline the importance of promoting advanced directives in order to facilitate communication between caregivers and patients concerning the end of life (Pautex et al., 2008). This concerns written instructions given in advance by competent adults, in the event they are no longer able to express their wishes when a decision to stop treatment is envisaged. While this scheme is relatively new in France (law of 22 April 2005 on patients' rights and end of life), it would significantly reduce the degree of anxiety and depression of those involved, thus improving their overall satisfaction with regard to the care they receive (Pautex et al., 2008).

The second type of strategy appears even more structured. This entails several tools which caregivers can use either for evaluating the needs and expectations of each person in the initial stages (often not disclosed by the latter), or for evaluating *a posteriori* the quality of care from the patients' and families' points of view. In this respect, information and communication constitute one dimension among others of the quality of care given, and evaluations are generally done using a scale (Casarett et al., 2008) or questionnaires (Mystakidou et al., 2002). The results of our study can contribute to initiating such an approach by identifying attributes of "good" information transfer from the patients' and families' viewpoint (on five basic dimensions: the accessibility of information, its appropriateness, its frankness, its completeness and its comprehensibility). In addition and along with these tools that have become traditional in the area of care, others are beginning to appear. New technologies¹¹ have the potential of markedly improving

¹¹ for example, electronic patient reported outcome collection, web-based tools, cyber infrastructure, etc.

communication in palliative care, not only between patients and caregivers, but between caregivers themselves (Dy et al., 2011; Madhavan et al., 2011; Kallen et al., 2011). As an example, we can cite schemes put in place in the context of hospice programmes (to achieve proactive patient management) and including e-mail alert systems, based on answers by patients to various aspects of care (for example, their uncontrolled symptoms or their medication needs) (Dy et al., 2011). But whereas all these standardised tools (scales, questionnaires, new technologies) appear especially interesting for significantly improving patient and family satisfaction concerning the provision of information, they should not replace caregivers' interpersonal skills, nor their communication skills. In other words, communication aids should not be a substitute for communication.

6. Conclusion

One of the contributions of this study, carried out in 5 PCUs among 50 patients and families, was to underline what they like and what they regret about the communication of information, in terms of its form as well as its content. While identified factors leading to satisfaction should be encouraged and broadened with a goal of disseminating best practice in palliative care, factors leading to dissatisfaction can be considered as levers for improvement. Indeed, further adjustment efforts should target these aspects. Three elements in particular have been emphasised: 1) the broad overlapping in palliative care of information skills, communication skills and interpersonal skills; 2) the high visibility, to those interviewed, of communication efforts made by the team, which suggests the presence of a special *savoir-faire* in PCUs (this point is supported by numerous comparisons made spontaneously by interviewees between their present hospitalisation and what they observed in acute care facilities); 3) the difficulties inherent in the coexistence of opposing viewpoints, which express the considerable heterogeneity of the needs and expectations of each person in terms of information, and thus the need to further adapt this information to particular personalities and family cultures.

Within a national and international context of promoting palliative care, these reflections on what information should be provided constitute an important issue, especially if we highlight the positive impact that techniques and attitudes of caregivers have had on many of the patients and families interviewed in this study. Beyond simply knowing the degree of patient and family satisfaction with respect to information communicated, the development and use of specific evaluation tools may help to effectively implement the necessary corrective actions (in Palliative Care Units as well as in acute care facilities) and to meet as nearly as possible the unique needs and expectations of each person. However, while these new modes of communication are promising, they must be envisaged as a way of better understanding and meeting the needs and expectations of patients and their families, and not as a substitute for the interpersonal skills of caregivers.

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This book is designed to provide a comprehensive insight into the key and most prevalent contemporary issues associated with palliation. The reader will find viewpoints that are challenging and sometimes discerning, but at the same time motivating and thought-provoking in the care of persons requiring palliation. This book is divided into three sections. Section 1 examines contemporary practice; Section 2 looks at the challenges in practice; Section 3 discusses models of care. This book is an excellent resource for students, practising clinicians and academics. By reading the book, reflecting on the issues, challenges and opportunities ahead, we hope it will create within the reader a passion to take on, explore and further develop their palliative care practice.

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