

Palliative care transfer announcements: Qualitative analysis of the perspective of physicians and their patients with cancer

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Abstract

Purpose: An incurable cancer patient, already facing a large amount of bad news due to his/her disease, may be offered to be transferred to a palliative care unit when his/her status worsens. This prognostic disclosure has not been specifically investigated, while palliative care physicians and nurses ignore the exact level of information provided to the patient.

This study aimed to analyze palliative care transfer disclosure modalities by the physician and how they are perceived by the incurable cancer patient in order to gain a better understanding of the consequences, impacts and meaning of such a disclosure for both stakeholders.

Methods: This qualitative study consisted of semi-structured interviews conducted with incurable cancer patients admitted within less than 72 hours to the Palliative Care Unit in a University Hospital and physicians, who disclosed a transfer to palliative care within less than 7 days.

Results: A transfer to palliative care unit disclosure is a disruptive milestone in patient management as it triggers the full awareness of a patient's incurability and imminent death and the end of the therapeutic alliance that underscored the physician-patient relationship. The complexity of this phase leads to communication difficulties and eventual misunderstandings, complicated by patients (n=6) and physicians' (n=4) negative representation of palliative care.

Conclusions: Early palliative care could provide better incurable patient identification needs, improved information and decision processes, and reduced suffering for end-of-life patients.

Introduction

The treatment process for cancer patients is punctuated by a series of announcements such as the initial diagnosis and additional ones as the disease progresses. If the prognosis is negative, the patient may receive a variety of news that are difficult to handle: relapse, cancer spreading, decision to end targeted treatment, and the beginning of the palliative phase. All of the above may be classified as "bad news", defined as "information that radically and negatively changes how the patient sees his/her future" [1].

In France, a cancer diagnosis system has been in place since 2003 so that patients can receive information in the best possible circumstances [2].

As this system's primary focus is the delivery of the treatment program, it does not fully meet the expectations of doctors and patients faced with a worsening prognosis. For almost 50% of oncologists, the most difficult part of their job is informing patients that curative treatment will cease and only palliative care will continue. Despite

medical communication being seen, as one of the most important needs by most patients with advanced cancer, it is often deemed unsatisfactory [3-5]. In palliative and terminal cases, high-quality doctor-patient communication can improve quality of life. It involves a preference for care that enhances patient comfort rather than extends their life, and a more frequent use of palliative care in end-of-life cases [6,7]. The Wright study revealed that 37% of the 332 patients studied

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with terminal cancer had talked about their final days with their doctor; this did not, however, produce a greater risk of depression. They preferred medical treatment that focused on symptoms as opposed to aggressive treatments and were hospitalized in palliative care units (PCUs) more than other patients [8].

In palliative situations, announcements are generally about the prognosis, such as the incurable stage of the disease, the level of metastasis, the termination of targeted treatments, or the transfer to a Palliative Care Unit (PCU) [9]. Regarding the transfer to a PCU, this seemed to occur earlier when the doctor had been able to discuss end-of-life treatments with the patient [8].

The Tiby-Levy survey of PCU patients and their families revealed that the way traditional hospital departments delivered the news of a transfer to a PCU was unsatisfactory due to incomplete information and a poor bedside manner [10].

These studies raise the question of how much the patients that are treated know about their medical situation. Considering the context of a terminal illness, associated with a lot of losses and renouncements, how well are these patients able to absorb the information given when the transfer announcement is made? More specifically, how do doctors deliver the news of admission to a PCU? Beyond a change of department, what is involved in this announcement?

To the best of our knowledge, there has never been a study that specifically addressed how a doctor announces the transfer to a PCU to a patient with incurable cancer.

In a systematic review by Bousquet et al. examining the delivery of bad news in oncology, of the 40 qualitative studies chosen, 17 touched on the discussion of the prognosis and end of life, while 9 touched on the change in treatment objectives [11]. When delivering news of transfer to a PCU, one or more of these themes may be discussed by the doctor with their patient.

The purpose of this study is to analyze how the news of a transfer to a PCU is delivered and how a doctor and a patient with incurable cancer perceive the announcement. The aim is first to use this analysis to better understand the challenges posed by this announcement in terms of communication and doctor-patient relationship and then to assess its impact and meaning for both parties.

Method

We carried out a qualitative, empirical pilot study based on recordings of semi-structured interviews with six patients with incurable cancer (solid cancer or hematological malignancy in the palliative phase), who had been admitted to a PCU in a French University Hospital within 72 hours, and four senior doctors who had delivered the news of the transfer within the past seven days. Exclusion criteria solely applied to patients: clinical status rendering a recorded interview impossible or inability to secure informed consent (fatigue, confusion, uncontrolled distress, etc.), patients with difficulty communicating or unable to speak French, and patients under legal protection. Interviews were carried out by the unit's two doctors (one of whom was a researcher in the study), using a specific interview guide compiled by interdisciplinary authors, tested and approved by the study's steering committee and focused on communication methods, and how the news of transfer to a PCU was experienced and under what conditions (appendix). With patients' agreement, interviews were recorded and then transcribed verbatim by the researcher. The content of the transcription was analyzed using conceptual categories as part of

a comprehensive approach [12-14]. The analysis of four transcriptions was triangulated by the steering committee researchers. The study's protocol was approved by the ethics committee of Strasbourg's Faculties of Medicine and Odontology, approval number was FC/2016-43.

Results

Inclusion criteria and population characteristics

For the duration of the study, which ran from April to July 2016, six patients (P1-P6) were included, as well as four doctors (D1-D4). Of the 57 patients admitted to the department during this time, 29 patients (51%) presented a medical state precluding them from the interview (confusion, drowsiness, distressing symptoms, fatigue). Time elapsed between announcement and admission, admission and interview, as well as the length of stay in the unit and patient's manner of departure are noted in table 1. The time-frames set in the protocol were met. Average length of stay was 25 days.

Patients' demographic and medical data are summarized in table 2. Average age of patients was 67.3 years old. Two patients (P3 and P5) were still receiving oral chemotherapy that continued during their stay in the PCU. For the four other patients, targeted treatment was ended between four days and seven months prior to their admission to palliative care. The Karnofsky Performance Scale (KPS) had an average of 46.6% upon admission. None of the patients were followed by a Mobile Palliative Care Team (MPCT).

The demographic and professional data for the doctors are summarized in table 3. All the doctors were female, with an average age of 37.2 years.

Interview analysis

Analysis of the interview content was made by exploring three themes in three dimensions. The themes were communication methods (content of news, verbal and non-verbal aspects), how the news was received (emotions felt) and the conditions under which it was delivered (any prior knowledge, time, place, and people present). The three aspects were the referential aspect (what the patient/doctor said regarding the news), the modal aspect (what the patient/doctor was thinking about the news) and the illocutionary aspect (what the patient/doctor did with the news).

Analysis of the 10 interviews revealed certain themes shared by both doctor and patient:

- The news of the transfer to a PCU is an event and a radical separation
- It reveals the complexity of communication and disrupts the doctor-patient relationship.
- It raises existential questions and ideas regarding palliative care

An event and a radical separation. The time of the announcement seems to be an event for the patients and the doctors insofar as their narratives describe the conditions of the announcement, the feelings of each subject, as well as the roles of the family and other caregivers. Apart from hematology, the news was always delivered in a private room. None of the patients clearly remembered the name of the doctor that delivered the news, but they could all precisely recall the time between the announcement and admission to the PCU. "It was very short, it was this morning..." (Patient 4). Patient 1 saw the news as an order: "You have to go into palliative care". Several patients felt that the doctors were pressed for time when making the announcement: "They

Table 1. Length of stay in the unit and patient’s manner of departure

	Time between Announcement of transfer/Admission In days	Time between Admission/Interview In days	Length of stay In days	Manner of departure
P1	1	3	16	Transferred to another PCU
M1		2		
P2	1	3	17	Death
M2		6		
P3	1 (time before announcement: 4)	1	20	Death
M3		1		
P4	0	0	13	Discharged
M4		5		
P5	2	1	48	Death
P6	0	2	36	Death

Table 2. Patients’ demographic and medical data

	Gender	Age	Type of cancer Stage of cancer	Date targeted treatment stopped	Date admitted to PCU	Karnofsky Performance Scale Index (%)	Treated by MPCU
P1	M	64	AML Treatment stopped working	04/29/2016	05/07/2016	50	No
P2	M	62	Renal cell carcinoma Metastatic	06/20/2016	06/24/2016	50	No
P3	M	66	Pulmonary adenocarcinoma Metastatic	NA	07/12/2016	60	No
P4	M	78	Multifocal hepatocellular carcinoma Treatment stopped working	December 2015	07/20/2016	50	No
P5	F	71	RAEB, possible AML Treatment stopped working	NA	06/30/2016	40	No
P6	F	63	Squamous cell carcinoma of lower oesophagus Metastatic	06/30/2016	07/04/2016	30	No

Table 3. The demographic and professional data for the doctors

	Gen der	Age	Medical specialism	Hospital grade	Senior experience	Time in post
M1	F	42	Haematologis t	Hospital practitioner	14 years	14 years
M2	F	31	Oncologist	Contracted hospital practitioner	1.5 years	1.5 years
M3	F	29	Pulmonologis t	Deputy Head of Clinic	1 year	1 year
M4	F	47	ER Doctor	Hospital practitioner	16 years	11 years

were totally swamped”, “So busy”. The doctors revealed how hard it is to deliver the news: “It isn’t easy (...), it’s a weight on your shoulders (...), you take the full force of all of the patient’s worries” (Doctor 1) and showed that they perceive their patients’ emotions, such as fear: “It made him grind his teeth a bit” (Doctor 3), sadness, anger, suspicion, and despair. Although family plays an important role for patients, a rift appears when the news is delivered, with patients appearing torn between their need for support and their desire to protect their families. All doctors spoke to the families to explain the treatment’s objectives: “Family members are often easier to persuade” (Doctor 1). Doctors mentioned the role of caregivers in sharing the decision-making with regards to the patients and in the “rewording” of bad news. This team spirit was deemed necessary to offer patients the best support.

In the interviews, the idea of radical change occurred on different levels: progression of the disease, treatment plan, and doctor-patient relationship.

Patients are initially on a path to cure their disease, and then this line of treatment is broken: “The doctor told me: there’s nothing more we can do (...), there’ll be no more transplants, we’ve got you a room at

the palliative thing” (Patient 1). Patients find this change in direction incomprehensible, and it simultaneously ends their relationship with the doctor. Patients also become aware that their life has changed direction: “I saw myself having a peaceful retirement, but things turned out differently”. (Patient 5).

Doctor-patient relationship & communication. In four situations, the term “palliative” was used when announcing the transfer, and there is a correlation between the words of patients and those of doctors. However, beyond the news of the transfer to a PCU itself, the interviews revealed other prognostic discussions, such as news concerning disease progression or end of treatment. It is often difficult to give this bad news, and discords appeared between the words of patients and those of doctors: “He kind of understood what he wanted to understand... Palliative care had already been mentioned, but that didn’t stop him from asking why we were going to stop his treatment every day” (Doctor 2). Doctors needed to call on their communication skills to deliver this complex news and did not always feel sufficiently well-trained. Patients mentioned how harsh the news was: “It was brutal”, “I found that moment very difficult”. The trauma was further intensified by the fact that, in our study, the news was never delivered by the doctor

that usually treated the patient. Most of the time, the announcement of the transfer to a PCU meant a break in the doctor-patient relationship.

Existential questions and ideas regarding palliative care. News of the transfer gave rise to existential questions, in relation to time and death, e.g., “I know I’m going to die... very soon”, hope and uncertainty: “If we can stop the disease... that’s the only hope”, and regarding palliative care, sometimes contradictory: “For me, the word palliative means death” (Patient 3), “It wasn’t really frightening... I was hoping they’d take me there...” (Patient 6).

Discussion

Limitations

While carrying out this exploratory research, some ideas and questions were brought to light. Regarding the choice of the interview method, there is the issue of suggesting a predominant and socially acceptable point of view, mainly on the part of the healthcare professionals: this risk is greater in our modern society, where the nature of the news given to patients carries great significance [15]. Furthermore, the retrospective nature of the study may produce a memory bias. In this study, we examined individual experience, subjective reality in relation to the announcement and the interactions between patients and doctors. Lastly, in this pilot study, we interviewed 10 subjects. We should continue with a larger sample in order to make this unprecedented work more robust.

Challenges and changes of direction with the news

The announcement of a transfer to a PCU is a turning point in the trajectory of the disease. The phase of the end of life tends to upset the existence of the patient and his/her marks [16]. The consequences stemming from these modifications are underlain by the level of knowledge that the patient has of it; the results of our study show that the patient did not have time or was not able to integrate the prognostic information allowing him, at least partially, to face it. Literature shows that very few patients with metastatic cancer possess accurate knowledge regarding their prognosis, even though there still is a need for information, including in the advanced stage [17,18]. The obstacles we identified are as follows:

- Doctors’ tendency to overestimate the survival of their terminal cancer patients [19].
- Doctors’ reluctance to discuss end of life (due to lack of training in how to communicate during the palliative phase, due to fear of causing the patient to lose all hope, and out of defiance against death) [20-22].
- Families’ refusal to accept palliative care or their desire to withhold information from the patient [23].

In the palliative phase, prognostic announcements raise the question of the information transmitted to the patient. The question of his/her autonomy arises as the patient participates in the decision-making process, or not. In discussions regarding treatment cessation, patients may find themselves in a situation where there is no choice to make, all the more if these discussions occur in the last days of life [24]. In our study, in six out of the ten interviews, the term “palliative” was not used, which is revealing in terms of what is left unsaid between patients and doctors: even in the newly extended conversations, there was no shared decision-making. In this context, the announcement of the transfer to a PCU was experienced as a traumatic event by patients for whom the end of treatment was the reason for the transfer decision. On the other hand, the patients who were more conscious

of a death threat at the time of the announcement (due to a better understanding of their prognosis), are paradoxically the ones who lived their admission in the PCU the best, by reintroducing uncertainty in a future and a temporality reorganized by their clinical reality. However, for all patients, admission to the PCU represented a turning-point in the course of their disease, their treatment journey, their relationship to health care professionals and eventually, their lives.

Perspectives

Interview analysis in this study revealed the complexity of the announcement of the transfer to a PCU. Delivering the news cannot be reduced to a “skill” that can be learned or a “technique” that can be used again. It must be adapted to the conditions in which it is taking place and the unique nature of each patient: there is no standardized way to deliver the information. Given that current communication in the palliative phase has been found to be lacking, it is possible that having identified the obstacles, we could propose actions to be taken and investigated, in order to improve communication.

A transfer to palliative care may attenuate the shock of the news for patients with advanced or terminal cancer. It seems to be possible as long as relevant palliative prognostic factors are established, doctors’ and nurses’ interpersonal and communication skills are improved, and a quality doctor-patient relationship is maintained throughout treatment. It entails cooperation between frontline teams and those skilled in handling complex situations when a cure is no longer possible. Lastly, the integrated approach of palliative care also requires that palliative care professionals are called in early and on a case-by-case basis to work with patients and other healthcare professionals. More specifically, mobile palliative care teams have the skills required to implement this transition, particularly by supporting healthcare staff in the delivery of difficult news, at every stage of treatment.

In this system, PCUs would form an additional layer of assistance in particularly complex cases and would be presented to patients as a place for treatment, as well as somewhere where their needs, worries, and wishes will be heard.

Conclusion

This analysis of semi-structured interviews with six terminal cancer patients recently admitted to a PCU and four doctors who delivered news of the transfer to the unit gave a voice to the people involved in this unique announcement and collected their points of view. Difficult both to say and to hear, news of the transfer is a significant event and often a traumatic one for patients insofar as it changes the course of their disease, treatment, and lives. The news is particularly difficult when it comes suddenly, as it does when the way has not been paved by earlier discussions of the prognosis or, on the contrary, if other prognostic news, such as cessation of treatment, have been delivered immediately beforehand. It always occurs in a difficult physical (progression of disease, appearance of distressing symptoms) and psychological (awareness of incurability, fear of death) context. It is also often delivered under inappropriate conditions, e.g. delivered by a doctor that had not been treating the patient. For doctors, the news forms part of a complex decision-making process in which kindness is more important than the patient’s independence. Faced with their own impotence and limitations, the transfer to a PCU is the last act of care that a doctor can offer their patient, as well as the last news they can provide.

To reduce the tension inherent to this phase, a palliative approach that is integrated earlier into treatment may prevent crisis situations.

The key is a better sharing of the disease progression with the patient, sharing medical decisions, and considering their consent, even for the end of life. These treatment models will only be possible when doctors and nurses will be better trained in delivering bad news and with the gradual improvement of the negative image of palliative care, which still acts as an obstacle to the early treatment of fragile patients with incurable cancer.

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