

Primum non nocere: could the health care system contribute to suffering?

In-depth study from the perspective of terminally ill cancer patients

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ABSTRACT

OBJECTIVE To explore terminally ill patients' perceptions of their own suffering in order to describe, from these patients' perspective, some elements of health care providers' response to suffering.

DESIGN Qualitative study using content analysis methods suited to a grounded theory approach.

SETTING Teaching and nonteaching hospital oncology clinics, palliative care services (both ambulatory and in-unit), and family practices.

PARTICIPANTS Twenty-six patients diagnosed with terminal cancer.

METHODS Interviews were audiotaped and transcribed verbatim. Data from each interview were coded and categorized to identify and define themes. Themes were discussed and refined until those rating them agreed on them. Data were collected until saturation of emerging issues was reached.

MAIN FINDINGS In our health care system, patients are caught in a pervasive pattern of suffering avoidance, which in turn contributes to increased suffering. Health care services are perceived as a battlefield where physicians and patients are engaged in a losing struggle to ward off illness and death. Both physicians and patients engage in avoiding skepticism and muffling distress. The unavoidable avowal of powerlessness in the face of terminal disease is perceived as capitulation and therapeutic abandonment. Budgetary restraints and understaffing, along with a pervasive culture that implicitly denies death, produce an environment conducive to the avoidance of suffering. To counter this, health care practices that foster increased overlap and continuity between the spheres of oncology, palliative care, and family medicine seem worth developing.

CONCLUSION The suffering of gravely ill patients might be hard to alleviate in the context of modern health care organizations. In some cases, health care delivery directly contributes to increased suffering. Providing support while also helping patients and their families to face upcoming harsh realities is a delicate balancing act that needs to be further explored.

EDITOR'S KEY POINTS

- This study documents patients' perceptions of their dealings with health care providers. Participants had all been advised by their physicians that they had terminal cancer.
- Results indicated that suffering was a major component of respondents' experience, yet it remains poorly addressed in the current health care system. In some cases, health care delivery directly contributed to increased suffering.

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Suffering is a complex, multi-dimensional, eminently personal phenomenon.^{1,2} Attempts to define the concept of suffering have appeared relatively recently in the medical literature.³⁻⁹ Alleviation of suffering is universally considered to be a primary aim of medicine.^{10,11} Few studies, however, have attempted to investigate on an empirical basis whether suffering is, in fact, alleviated. Since we do not know how suffering is alleviated, the lack of formal training on how to relieve suffering could contribute to physicians' adopting behaviour that increases rather than decreases patients' suffering.^{12,13} There is often a link between requests for euthanasia and the presence of "unbearable and hopeless suffering."¹⁴⁻¹⁸

Studies of patients' communications with their physicians document the effects of specific interactions on patients' experience of terminal cancer.¹⁹⁻²¹ Studies have demonstrated that acknowledging a terminal prognosis earlier rather than later in the course of disease contributes to relief of suffering.²² These studies, however, do not identify the precise mechanisms whereby health care practices modulate patients' distress. Much is lacking in our understanding of the complex combination of influences that shape health care providers' approaches to relief of suffering.

This study was designed to document patients' perceptions of their dealings with health care providers. We selected a population facing the palliative stages of cancer care because we hoped to hear about a variety of highly charged interactions between patients and their caregivers. These interactions would be taking place within the broader context of one of life's most demanding challenges.

METHODS

We designed a qualitative study using content analysis methods suited to a grounded theory approach.²³⁻²⁶ Qualitative methodology was selected in order to access information on patients' experiences that could not be obtained through a quantitative design²⁷ and to explore the reality of patients' lives in context.²⁸ The main selection criterion was that participants had all been advised by their physicians that their cancer was incurable and terminal. Purposeful sampling was used to maximize

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the variability of respondents' experiences. Several sampling sites were tapped: teaching and non-teaching hospital oncology clinics, palliative care services (both ambulatory and in-unit), and family practices. A step-by-step recruiting strategy allowed for constant comparative analysis of data. All respondents approached by their physicians agreed to participate. The final sample consisted of 16 women and 10 men aged 33 to 91. Cancer diagnoses varied, and respondents came from many walks of life (**Table 1**).

Data were collected from 3 sources: semistructured in-depth interviews conducted separately by 4 of the authors (V.L., S.D., S.M., E.H.), notes researchers made after the interviews, and medical files.

Interviewers began by asking respondents to comment on their experience of illness and their contacts with health care services. The interview grid was modified during data gathering according to previous findings. Interviews were audiotaped and transcribed verbatim for content analysis. Data from each interview were coded and categorized to identify and define themes. Themes had to be agreed on by at least 3 of the authors, and interviews continued until consensus and saturation of emerging issues were reached. Empiric and theoretic saturation was reached when the last interviews failed to produce new material or challenge existing categories. Data analysis was conducted with the support of NUD*IST software. Ethical approval was obtained from all participating institutions' local ethics committees.

FINDINGS

Initial emerging categories and themes

Systematic scrutiny of interview content yielded rich descriptions of numerous facets of patients' experience of suffering. Initial categories were grouped into 2 main sections: experience of illness and interactions with services. Data on experience of illness have been presented elsewhere.⁹ The 129 themes relating to patients' dealings with health care services were finally summarized into 5 main categories: initial shock, battle against cancer, paradox of increased suffering, final abandonment, and positive aspects of health care services.

Shock upon learning the diagnosis

"It fell upon me like a bomb! For sure at that point it's a shocker, because you realize... maybe you're going to die," said Martin (all names are fictitious). Most participants recalled having an extreme reaction upon being informed of their diagnoses. Some reactions were perceived as so brutal they felt they were sent reeling as from a physical blow. Some participants attributed their diagnoses to the unavoidable hand of fate, but most reacted as if they were a painful absurdity.

Table 1. Characteristics of participants

PSEUDONYM	SEX	AGE (Y)	CANCER DIAGNOSIS	NO. OF YEARS OF SCHOOLING COMPLETED	OCCUPATION	TIME BETWEEN DIAGNOSIS OF INCURABILITY AND INTERVIEW (MO)
Thérèse	F	70	Breast	11	Clerk	96
Sophie	F	51	Brain	11	Clerk	21
Martin	M	50	Lung	17	Professional	12
Lynne	F	54	Lymphoma	11	Nurse's aide	24
Ernest	M	62	Colon	7	Manual work	6
Berthe	F	72	Rectum	No data	No data	4
Sonia	F	67	Pancreas	12	Sales	3
Solange	F	55	Breast	17	Nurse	3
Ernest	M	65	Esophagus	22	Professional	9
Benoît	M	33	Lymphoma	15	Professional	2
Bill	M	50	Biliary tract	No data	Management	2
Lionel	M	41	Melanoma	16	Sales	14
Florence	F	45	Throat	13	Manual work	6
Céline	F	45	Lymphoma	12	Office clerk	31
Arthur	M	52	Liver	12	Manual work	7
Mylène	F	45	Lung	12	Office clerk	6
Guillaume	M	84	Leukemia	9	Farmer	1
Odette	F	68	Lung	7	Manual work	26
Lucien	M	74	Lung	10	Manual work	8
Françoise	F	42	Ovary	18	Professional	30
Adèle	F	73	Ovary	12	Manual work	9
Anne	F	73	Breast	8	Manual work	0.5
Marthe	F	62	Breast	No data	No data	17
Tancredé	M	62	Lung	5	Manual work	2
Benjamine	F	65	Breast	6	Manual work	2
Éterna	F	91	Liver	7	Manual work	4

Among many losses, one of the most poignant seemed to be the illusion of immortality and the carefree innocence of which patients were abruptly robbed forever.

It was 10:30 in the evening. A physician came up to me. He came right by the stretcher where I was lying. He put his pad down on the railing and he said, "I saw the results of all your tests and it's over! You have cancer, rectal cancer, and it's big like that!" And he said, "The kidney is affected, the liver is affected, the lungs are affected, and it's over!" He's right on top of me and he's saying it's over! Then he gets a hold of my wife in the hallway. She still doesn't know anything, and he grabs her and again he says, "It's over, Mrs T!" She just about fainted right then and there. (Ernest)

Mobilizing for the ultimate battle

Following the initial shock, most participants appeared to mobilize against the terrifying prospect of giving in to despair. All available inner resources were summoned

to try to recover a badly battered sense of invincibility. Solange said, "I told myself I was not going to let it get the better of me. I said I'm going to beat the odds. I said he's not going to get me like that." Lynne stated, "I took it really hard. I freaked out in the doctor's office, and then I told myself, I can fight this, I can overcome it. And I've fought non-stop ever since." Françoise added, "It's now or never because if I don't fight, I won't get better. I need to fight a bit more."

To ward off negative influences, emotions were reined in, a fighting stance was adopted, and several strategies were deployed to bring a measure of order to an existence now perceived as vulnerable to chaos. Daily activities were broken up into manageable bits so patients were less likely to give way to pessimistic thinking. Medical interventions were courted as an essential component of a battle respondents believed could be won.

Quite a few participants, though well aware of the palliative nature of treatments offered, harboured an

irrational hope of survival that found nurture in what they described as their physicians' combative stance. Any form of encouragement or perceived vagueness regarding options available and expected outcomes appear to have been construed by patients as warranting optimism. Françoise said, "Even when things are not so rosy, the doctor always manages to say something like, 'With you, one never knows,' which means everything. It means you've given us a couple of miracles, why not a third?"

From this perspective, with patients referring to cancer as the enemy and medical help as weapons and shields, health care as a system can be likened to a battlefield where illness and death are warded off with sustained illusions of miraculous recovery as a backdrop. The notion of battle, alluded to in those terms in our respondents' discourse, can be conceived as a fundamental dimension of the health care system. "Maybe I can be cured. Miracles happen. I tell myself, since they once rid me of breast cancer, they can beat this too with all the treatments and all the stuff they give us," said Benjamine. Health care providers thus unwittingly raise their patients' hopes and enable them to entertain a wish for immortality, or at the very least, to implicitly deny impending death.

Paradox: health care services increase suffering

Gaining entry into the medical battlefield comes at a price. Just as patients reportedly slice up their existence into bearable fragments, so does the health care system seemingly divide them up into manageable units of pathology, affected organs, and side effects of treatment. Participants related their impressions of being viewed as faulty mechanical components rather than as people dealing with illness.

I'm the same person, except the feeling I get is I'm all parceled up. When I go see my physician, I feel like I'm a labeled something. I'm the oat cell, if one had to put a name on it, that's it, it's an oat cell.... My doctor... I don't think she even knows what I do for a living, if I work even... as a person I'm not there. And that, too, is part of the suffering and the loneliness. (Martin)

They're sandwiched between priorities, the patient on one side and the system on the other. They have no choice but to obey the system's rules. And the patient, if possible he should survive. So they're neglecting the psychological, emotional impacts, all that it destroys in the patient's goodwill. I find the human side is lacking. They're so much under pressure, the nurses short-staffed, working horrendous shifts, their numbers dwindling and their workload increased. Nurses have less and less time to spend with patients. They can't be there to listen. (Lionel)

When asked, "How do you envision what's ahead? Do you sometimes talk about it?" Thérèse answered, "To whom?" The interviewer continued, "To your physician, for instance." She replied, "No, there's not much time, I barely spend 10 minutes with her. And you know, the waiting room's always full."

Fragmentation of ailing patients into objectified bits appears to be a prerequisite for the fight against disease and death. This implicit need, apparently worked into a silent pact between patients and health care providers, adds a measure of distance that further alienates patients from their global experience of suffering.

The system as a whole is perceived as functioning under extreme stress, with overworked health care providers under pressure to conform to more or less explicitly stated rules of productivity. Many patients report having suffered greatly from what they describe as the insidious brutality of this environment. A system perceived as so rigidly set up is seen to impede further the expression and acknowledgment of mixed feelings, contradictions, and fears, which are part and parcel of human existence and its trials. In this context, patients seem to feel they have no choice but to muzzle their own suffering so as to safeguard the structured power of medical interventions.

Failure to cure: unbearable abandonment?

When advised of the cessation of curative treatments, patients are faced with a sudden change of pace. They often feel abandoned and perceive their physicians' decisions mean they are giving up the fight.

I felt so small.... But there, his words were like gospel, what he had just told me was I would die, I would not come out of it alive. The person he left behind when he went out of the room was not the same as when he entered. He destroyed something; he crushed something, which means there had been something left and he had come and set fire to it. He said, "Nothing more to be done!" Twice now I've been counted out, told I'm ripe for palliative care, bye-bye dear! That's their diplomatic way of bringing bad news; they ask you if palliative care has ever crossed your mind. (Françoise)

Thus labeling themselves as failures, patients are overtaken by what they describe as intense suffering, feeling both crushed and helpless in the face of this ultimate desertion. In reality, participants' physicians did not give up on their patients. All of them were clearly seen to follow up with referrals to palliative care. In the absence of prior contact with palliative services, patients perceive these services in a most unfavourable light. When shown the exit from the health care battlefield and its curative aura, participants equated palliative care with therapeutic abandonment and capitulation.

Positive aspects of health care services

Though many participants perceived that health care services were liable to generate suffering and add to their burden of illness, many mentioned feelings of gratitude toward some of the health care providers they encountered. Ernest said, "My family doctor is super kind. He checks everything. And he speaks softly.... The other physician, when I asked him questions, I never got answers. My family doctor always tells me, 'If you have questions, ask me. I'll answer.' He's a gem!"

What's special about this doctor is that he always comes to call on his patients, not through the PA system, but taking the trouble to come and greet them. I found it remarkable because right there he creates a bond with the person. Maybe that person senses his warmth and feels better able to ask questions than he would have otherwise. (Martin)

Florence was asked, "You mentioned that a doctor was 'human.' Can you tell me what that means to you?" She replied, "Well, he spoke to me. He spoke to me just as clearly, but not as bluntly as the other one. He was able to sit with me, as we do now, talking, explaining, telling me that effectively the odds were slim. But he also always conveyed hope."

While some interactions increased suffering, others undeniably alleviated it. Physicians perceived as providing gentle care, as being available to answer queries, and who, through simple gestures, were seen as attending to the person as a whole, did indeed provide solace. When complications arose, the ongoing availability of family physicians seemed especially reassuring, all the more so if they could remain involved in care through communication with specialists. Most important, in any case, was the capacity of health care providers to safeguard hope.

DISCUSSION

Our results indicate that suffering was a major component of our respondents' experience, yet it remains poorly addressed in our current health care system. Unalleviated suffering was reported by all respondents, regardless of their attitude toward the system as a whole. In some cases, health care delivery directly contributed to increased suffering. The quote from Ernest provides an example: communication of bad news was clearly associated with an increase in suffering. Ernest was eloquent on this issue, though his experience was surely not the only sort encountered by cancer patients. Increased suffering related to health care services was reported regardless of time elapsed between diagnosis and interview.

During the "battle phase," many patients reported feeling caught in a pattern of suffering avoidance, which

in turn contributed to increased suffering. Resolving this dilemma appears anything but simple. Many patients expressed the need for an all-out fight against cancer and for maintaining hope, even if it was unrealistic. Our results do not allow us to state whether patients had more to gain or lose from such a stance. For some, engaging in battle allowed them to mute their suffering for several weeks. Held-back expressions of suffering, however, can become so intense in the end as to defy all attempts to soothe the sufferer. How to provide support in this battle while also helping patients to face upcoming harsh realities is a delicate balancing act that needs further exploration.

While it would be pointless to aim to eradicate suffering, many respondents suggested simple ways to alleviate the burden, ways that might work even in the context of major budgetary restraints. They said they would be content with increased individualization of care and with small humanizing touches, such as chatting for a few seconds about hobbies or personal interests unrelated to illness. Other studies have suggested that understanding and empathy can be conveyed even in the context of a busy clinical practice.²⁹

To better address suffering, some avenues are worth investigating. Case nurses, for instance, who are increasingly included on oncology teams, could be ideally suited to respond to some needs. We also need to find out whether earlier contact with palliative care, established when incurability is diagnosed and palliative chemotherapy is ongoing, would foster opportunities to alleviate suffering. The importance of the role of family physicians for patients in the palliative stages of their illness cannot be overestimated; in our study and other studies, many patients emphasize the close ties established over the years with these practitioners who are often seen as more attuned to global needs, as has been found in other studies.^{30,31} During the process of referral to oncology and palliative care, however, family physicians' role can be undermined.

Limitations

Selecting respondents through their physicians might have biased results because patients deemed to have had more negative experiences with the system might have been unconsciously left out. If such was the case, however, expressions of suffering related to health care practices would have been artificially diminished in our results, giving added weight to our conclusions. Could our conclusions be relevant to other health care environments? As regards representativeness, our sample was varied. Constant comparative analysis gave ample support to our conclusions, which could lay claim to theoretical generalization.³² As well, inter-rater agreement, which was always attained through consensus, added to the credibility of our results. Finally, respondents had no other contact

with interviewers, which excluded bias stemming from ongoing therapeutic ties.

Conclusion

The picture we obtained of patients' suffering and health care providers' response to it is far from complete. Still lacking is health care providers' point of view. Exploring the solutions mentioned by patients is crucial. An interesting question is whether our health care system induces suffering because dwindling resources are increasingly invested in high-tech equipment rather than in more humane and supportive interventions. We could ask whether the physical component of suffering is uniformly predominant. Are other components just as relevant? Can we identify expressions of suffering for which no relief is ever attainable? What is the role of hope in the context of terminal disease? These questions deserve further study so that modern medicine can eventually fulfil its function and attain its goals. ❁

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