

Understanding provision of chemotherapy to patients with end stage cancer: qualitative interview study

Hilde M Buiting, researcher,¹ Mette L Rurup, researcher,¹ Henri Wijsbek, ethicist,¹ Lia van Zuylen, medical oncologist,² Govert den Hartogh, professor in ethics¹

¹University of Amsterdam, Department of Philosophy, Oude Turfmarkt 141-147, 1012 GC Amsterdam, the Netherlands

²Erasmus MC, University Medical Center, Department of Medical Oncology, PO Box 2040, 3000 CA Rotterdam, the Netherlands

Correspondence to: H M Buiting
h.m.buiting@uva.nl

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ABSTRACT

Objective To examine health professionals' experiences of and attitudes towards the provision of chemotherapy to patients with end stage cancer.

Design Purposive, qualitative design based on in-depth interviews.

Setting Oncology departments at university hospitals and general hospitals in the Netherlands.

Participants 14 physicians and 13 nurses who cared for patients with metastatic cancer.

Results Physicians and nurses reported trying to inform patients fully about their poor prognosis and treatment options. They would carefully consider the (side) effects of chemotherapy and sometimes doubted whether further treatment would contribute to patients' quality of life. Both groups considered the patients' wellbeing to be important, and physicians seemed inclined to try to preserve this by offering further chemotherapy, often followed by the patient. Nurses were more often inclined to express their doubts about further treatment, preferring to allow patients to make the best use of the time that is left. When confronted with a treatment dilemma and a patient's wish for treatment, physicians preferred to make compromises, such as by "trying out one dose."

Discussing death or dying with patients while at the same time administering chemotherapy was considered contradictory as this could diminish the patients' hope.

Conclusions The trend to greater use of chemotherapy at the end of life could be explained by patients' and physicians' mutually reinforcing attitudes of "not giving up" and by physicians' broad interpretation of patients' quality of life, in which taking away patients' hope by withholding treatment is considered harmful. To rebalance the ratio of quantity of life to quality of life, input from other health professionals, notably nurses, may be necessary.

INTRODUCTION

The progress in the treatment of many cancers is substantial.^{1,2} With new, more effective treatment options, deciding about treatment at the end of life has become a delicate process. In general, when a curative goal has become unfeasible, the goal of treatment is to delay and relieve tumour related symptoms. In the case of chemotherapy (the most commonly used treatment option), however, these goals are often at the price of

serious side effects such as nausea and fatigue. With end stage cancer, another possible consequence of further treatment is that patients are prevented from preparing themselves for death.³ Putting too much emphasis on the prolonging of life could therefore have a negative outcome, and possible overuse of treatment is now widely debated in the medical arena.⁴⁻⁷

The trend towards increasing use of chemotherapy at the end of life has been described as "a trend towards the aggressiveness in cancer care."^{5,8,9} It is frequently investigated in relation to the quality of care provided to patients with metastatic cancer because overly aggressive treatment has been identified as an indicator of poor quality of care.⁵ However, severely ill patients sometimes wish for chemotherapy even when such treatment is probably ineffective.¹⁰ It is a physician's professional duty only to provide treatment that is in the patient's interest.¹¹ However, in a pluralistic society in which patient autonomy is a key value, it is not a priori clear what "the patient's interest" involves.¹² It could be argued that, by respecting patients' informed preferences concerning end of life treatment, any disagreement between patient and doctor may be resolved. However, Mack et al recently showed that carers reported better ratings for quality of life in cancer patients who initially preferred life prolonging care (including chemotherapy) but eventually did not receive such care in the last week of life than in patients who did receive such care.¹³ Because of their professional skills and experience, doctors may be better at judging patients' wellbeing than they are themselves.

Health professionals' thoughts about the benefits and burdens of chemotherapy in end stage cancer are largely unknown. We therefore investigated health professionals' experiences of and attitudes towards the use of chemotherapy at the end of life, and tried to relate these findings to the depicted trend towards increasing use of chemotherapy. We interviewed physicians and nurses, having different responsibilities towards the patients, who had cared for patients with metastatic cancer.

METHODS

Design and setting

This study is the qualitative part of a larger research project to investigate the role of medical professionals

in the context of (the limits of) patient autonomy. In the present study we interviewed physicians and nurses who cared for patients diagnosed with metastatic cancer. Qualitative interviews are particularly useful for exploring doctors' and nurses' own ideas, as they give respondents the opportunity to address themes that the researchers may not have anticipated.¹⁴ We recruited physicians and nurses from university hospitals and general hospitals.

Recruitment and sampling

Physicians

Participants were purposely¹⁴ sampled to represent a wide range in medical specialties, age, and sex to reflect the possible diversity of opinions. In four hospitals (two academic hospitals and two general hospitals) a contact person at the oncology department provided us with names of physicians who were willing or likely to participate in the study. Furthermore, three physicians were recruited through a "snowball technique"; one of those physicians had recently worked in a university hospital but was presently working in a hospice, another physician combined hospice work with his work in a general hospital.

Nurses

A similar procedure was followed to recruit the nurses. In the same four hospitals, a contact person provided us with names of nurses who were willing or likely to participate in the study. We recruited nurses working at the inpatient unit (where patients can stay for a while), nurses working at the outpatient unit (where patients come only to receive chemotherapy), and research nurses (responsible for experimental treatment with chemotherapy). Again, we sought maximum variety with respect to age and sex.

Interviews

Data for this study were collected from June to October 2010 through face to face, semi-structured interviews that lasted an average of 40 minutes (standard deviation 10 minutes) for the physicians and 35 (10) minutes for the nurses. All interviews took place in each physician's or nurse's practice. We approached the participants by telephone or email, and the primary researcher (HMB) explained the study aims and methods. Each participant also received an information sheet. Interviews were held until data saturation was reached.¹⁵ HMB conducted a total of 14 interviews with physicians and 13 interviews with nurses. According to Dutch policy, the study did not require a review by an ethics committee because the data collection was anonymous with regard to the participants and the content of the interviews was not considered to be possibly incriminating.

We used semi-structured topic lists for the interviews that were based on a topic list of earlier work. That list began with general questions about the health professional's background; then open ended questions about the health professional's general experiences with care and treatment decisions; and finally questions about

two patients whom the respondent had personally looked after and who had already died.¹⁶ In the present study, it concerned one patient with whom the communication about treatment had been rather straightforward and one with whom dilemmas had arisen as to whether (additional) treatment should be given. In the present study, we tried to address similar topics for the physicians and nurses as far as possible.

Several issues were explored—the decision making process, the distinction between curative and palliative care, the way treatment alternatives and the option of "doing nothing" came up during consultations, the perceived role of nurses in treatment decisions, the way nurses were informed about physicians' treatment policies, discussions about death and dying and their ideas about futile practice in oncology. We did not use any specific definition when we spoke about "treatment" but evaluated what the respondent actually meant during the interview. (In the Results section of this paper, however, the term "treatment" means palliative chemotherapy unless stated otherwise.) We studied physicians' and nurses' experiences of all types of cancer patients, but always took into account the type of cancer of the patients concerned, as the cancer trajectories, such as the time until death, may vary. The most common cancer types discussed were cancers of the colon, pancreas, breast, lung, and prostate.

All respondents consented to the interview being audiotaped. The interviews were transcribed verbatim.

Analysis

The first available data (two interviews within each of the physician and nurse respondent groups) were discussed by a multidisciplinary project group with expertise in health sciences, sociology, medical anthropology, and ethics (HMB, MLR, GdH, HW, K Davis, and M Stapel). These discussions led to rephrasing and a different ordering of some of the questions on the topic list. In addition, questions were added that triggered physicians and nurses to give their personal opinions about patients who wanted to continue with treatment until the very end, and patients who refused all treatment even though it would be beneficial.

Data analysis was informed by qualitative methodology, based on a constant comparison approach.^{15,17} After having interviewed sufficient respondents, we (HMB and MLR) independently read through five interviews in each respondent group to identify general themes, and then to identify specific categories within the themes to check for interpreter consensus concerning the assignment of text fragments to major themes. Together, we discussed these themes until we reached consensus. We then rephrased some of the questions and put different emphasis on some of the items in the topic list: although we asked respondents about all treatment decisions that had been made, we focused more on the decision when further treatment was withheld. HMB subsequently coded the remaining interviews. We later discussed our findings with different members of the project group, and worked towards

consensus about the interpretation of key themes. HMB checked these interpretations with the existing data. LvZ finally evaluated whether the quotes were used in the right medical context. All data were analysed with qualitative research software (Atlas.ti 6.1.12). A professional translator translated the quotes that we eventually chose to illustrate our results.

RESULTS

Respondent characteristics

We tried to contact 22 physicians for an interview. Six declined and two could not be contacted, leaving 14 physicians to be interviewed (see table). These physicians had an average age of 41 years, and eight were women. Work experience within oncology varied, with seven having less than five years' experience.

We approached 13 nurses for an interview, all of whom agreed to participate (table). Their average age was 40 years, 11 were women, and seven had had special education in oncology.

Qualitative findings

We identified four domains that provided insight into the use of chemotherapy for patients with metastatic

cancer: rational arguments to prescribe chemotherapy, the phenomenon of cooperative patients and cooperative physicians, ambivalence, and ways to interrupt patients' and physicians' mutually reinforcing attitudes of "not giving up."

Rational arguments to prescribe chemotherapy

Physicians and nurses clearly differentiated a curative approach from a palliative approach. They reported that, with a palliative approach, it is more important to look critically whether the (side) effects make it worth going ahead with treatment. They agreed that patients need to be informed about the approach.

"Yes, I think the distinction [between a palliative and curative approach] is always extremely important. I think it is important for the patient to know that, but it also has a tremendous impact on the way you administer the course of treatment.... In the case of palliative treatment, a holiday awkwardly planned in the middle of that treatment suddenly becomes nevertheless very important so that you have to adapt the treatment schedule accordingly."—Physician 9 (general hospital)

Not surprisingly, physicians and nurses reported that they would initially focus on disease modifying treatments (mostly chemotherapy) to diminish patients' symptoms and prolong life. They accepted that it was sometimes necessary for patients to experience severe side effects of treatment for a relatively short period to live a longer life. Actively treating patients with recently diagnosed metastatic cancer was thus an obvious thing to do.

"And 'palliative' can sometimes, of course, take quite a long time; we're talking at least about a few years, definitely in the case of breast cancer or other cancers for that matter, so people can really be quite fit."—Physician 6 (university hospital)

However, when cancer had progressed despite chemotherapy, physicians' approaches to choosing when and whether to prescribe further treatment varied. Some physicians said they waited for patients' symptoms to develop before prescribing chemotherapy, whereas others reported prescribing chemotherapy in the absence of symptoms. They all highly valued patients' quality of life, but the moment they chose to prescribe further chemotherapy seemed to depend more on the importance they attached to prolonging a patient's life.

"Because if you say, 'We'd be better off waiting until there are symptoms,' people find that quite strange, because, after all, 'I've come at an early stage and I want treatment now.'... And then I think, as a physician, you tend to be fairly quickly inclined, after all, to start chemotherapy earlier than perhaps would be strictly indicated clinically speaking.... I do think that people really must have symptoms which I think 'can be combated with chemotherapy,' yes."—Physician 8 (general hospital)

Table 1 | Characteristics of health professionals interviewed about the use of chemotherapy for cancer patients at the end of life

	Physicians (n=14)	Nurses (n=13)
Mean (SD) age (years)	41 (8)	40 (8)
Sex (men:women)	6:8	2:11
Setting:		
University hospital	6	7
General hospital	8	6
Specialty of physician:		
Internal medicine, oncology, or haematology*	12	—
Oncology with special education in palliative care†	2	—
Specialty of nurse:		
General	—	3
Oncology	—	7
Research	—	3
Work experience within oncology (years):		
0–5	7	2
5–10	3	4
>10	4	7
Physicians' most difficult situation during treatment‡:		
Patients insisting on having treatment despite low chance of response	8	—
Patients refusing all treatment options despite high chance of response	3	—
Both situations are difficult, if in the extreme	3	—

*All had followed courses on palliative care.

†Both physicians worked in a university hospital and were appointed to take care of cancer patients in the last stage of life. They were thus primarily responsible for pain and symptom management. One physician was also an oncologist; the other was primarily responsible for palliative care.

‡Physicians were asked, in an open ended question, about their most difficult situations during treatment. Two situations could be distinguished:

(1) Patients who persisted in wanting treatment. "I personally have greater difficulty with patients who want to continue treatment come what may. I sometimes think, 'Call it a day. For goodness' sake, try to enjoy the time you have left.'"—Physician 7 (university hospital)

(2) Patients who refused all possible treatment options. "No, if they don't want to. If I think that someone could really benefit from it [treatment] without too many problems, and they really don't want to.... It is much more difficult if they don't want to go on."—Physician 14 (general hospital)

“Yes, it was directed at prolonging a patient’s life, but for me the most important thing is quality of life. And in his case it was good, so you provide treatment in the hope that you can postpone the symptoms and misery as long as possible. Because he had no symptoms which we had to do something about. And, yes, in his case prolongation of life was certainly a goal.”—Physician 7 (university hospital)

Second or third line chemotherapy often had lower response probability and more severe side effects, which complicated the treatment decision making in the late stages of the disease. Arguments often used to justify continuing with treatment (if in accordance with the patient’s wish) were the difficulty of predicting treatment outcomes for individual patients and positive experiences with chemotherapy in situations that were initially unpromising. It thus seems that rational arguments are not over-riding in deciding whether treatment is not in a patient’s interests.

Cooperative patients, cooperative physicians

The way physician and patient interact seems to drive the provision of chemotherapy in the final stages of disease because the patients’ and physicians’ attitudes of “not giving up” seem to be mutually reinforcing.

The fact that patients have become better informed about treatment options through media and internet was highly appreciated by physicians and nurses, as this made it possible to achieve greater equality in making treatment decisions and understanding about possible treatment courses. Nevertheless, physicians and nurses regarded patients as a cooperative group; patients still usually followed their physicians’ advice about treatment. One physician said that patients actually get scared when they really have to decide for themselves.

Interviewer: “And how do patients react to that, that they themselves can choose?”

Respondent: “Frightening. Yes, it always scares them: ‘How can you make a choice like that?’ Yes. Well, sometimes there simply isn’t any best option, and then the patient can certainly decide for himself. Often I have an opinion and I will say what I think, and usually that is the choice that is made. But sometimes there is simply no best option, and to my mind you can just as well do either. And then they can choose for themselves.”—Physician 14 (general hospital)

With patients being better informed, both physicians and nurses reported that clear communication about treatment options—with the prognosis and the advantages and disadvantages of treatments carefully explained—was of the utmost importance. They were aware of the fact that the way they motivated their reasons for providing further treatment could determine whether a patient agrees to continuation of treatment. “Yes, as long as you have good reasons ... and what I just said, if an oncologist says, ‘We’ll just give you a short course of chemotherapy,’ that already sounds a lot different from saying. ‘We’re going to

use chemotherapy, and this is what it entails, these are the side effects,’ and a person sees that quite differently.”—Nurse 13 (general hospital)

Apart from being open and honest with their patients, physicians did not want to disappoint their patients by not helping them or by taking away their hope by giving them “nothing.” Patients’ wellbeing was considered extremely important. Some physicians adapted the manner in which they offered treatment to match their patients’ preferences. Thus, patients were regarded as cooperative with health professionals, but physicians themselves seemed to be cooperative with patients.

“Yes, you know, you don’t come out with ‘It’s going badly,’ you just don’t... You certainly don’t do that with patients, and especially not with such a young girl who is also extremely anxious and scared of suffocating. And that is a real prospect. The tumour is there, and it is a really enormous tumour and presses on everything. And after all, every time I came with some bad news, but even so a little bit of good news.”—Physician 11 (university hospital)

“I understand it from the physician’s point of view because you are so keen to offer something, people want to hear something, but sometimes it goes too far for me, yes.”—Nurse 11 (general hospital)

Physicians’ inclination to be cooperative could explain why speaking about death or dying rarely came up during consultations, and nearly always only in the final stage of the disease. A substantial proportion of the physicians stated that giving chemotherapy and simultaneously speaking about the dying process was too much of a contradiction, and that such discussions would negatively affect the patient’s wellbeing. Some of the nurses, however, said that they considered speaking about death and dying confrontational and therefore difficult to initiate.

“We know from experience that if you talk about it [death, dying] in a very early stage that people find that very hard to take. So yes ... I bring it up later in the process, if I think, ‘Now it could be relevant in the relatively near future.’”—Physician 3 (university hospital)

Interviewer: “Yes, but is it exceptional, that you have conversations of that kind [about death, dying]?”

Respondent: “Well, that depends on the patient. You more often ... I think that it also depends an awful lot on your own nerve. You have to have the nerve to start talking about it, as it were, and just put it into words.”—Nurse 4 (general hospital)

According to the physicians and nurses, options for further treatment seemed to be interpreted by patients as signs of hope. Just as physicians tried to anticipate what patients wanted, so patients seemed to anticipate what they thought physicians wanted. Thus, according to physicians but particularly to the nurses, patients were often more optimistic about their medical condition towards their physician, hoping for further treatment options.

“But he keeps, he keeps holding on ... though not anymore, but he always wanted to keep the option of chemotherapy open. It gave him hope.”—Physician 4 (university hospital)

“That is our [nurses’] idea rather. If they say to the physician, ‘Dear me, I really don’t feel well and I don’t know whether I can cope with this whole process,’ then it seems that if they say the same thing to me they are much less non-committal than when they say that to a physician, or it’s easier to say it to me because I’m not going to stop the course of treatment... But with the physician, it would appear that they think that he can say, ‘Oh, then we’ll just stop’ or something.”—Nurse 2 (university hospital)

Ambivalence

Physicians and nurses were eager to grant patients’ wishes for treatment, to preserve hope and to prolong life as much as possible, but they also sometimes doubted whether further treatment would contribute to the patients’ quality of life. Similarly, they did not want to take away patients’ hope by discussing death and dying while giving chemotherapy, but they realised that delaying such discussions reduced their patients’ time to accept death and to say farewell.

“And we certainly don’t start [discussions about death, dying] at that point because you are indeed administering a course of chemotherapy. Yes. But that means therefore that if you keep going on in that way, ultimately someone will have a very short period of time to really say farewell.”—Physician 8 (general hospital)

Physicians and nurses seemed to find greatest difficulty with the “grey area” in which a patient’s medical condition would theoretically permit another line of chemotherapy, and the patient explicitly wants the treatment, but they would, balancing the treatment benefits and burdens, advise against it.

“Yes, it’s difficult when you do it and when you don’t [prescribe another course of chemotherapy]... When it’s down to the last wire and someone wishes for treatment, I simply think, ‘Let’s get on with this.’ ... There have also been patients that make you think, “If I don’t act now, they could be gone within days.”—Physician 6 (university hospital)

All physicians and nurses sometimes had these ambivalent feelings but most often in situations where patients wanted to continue fighting and would accept any kind of treatment as a last straw to prolong life. They reported that, despite repeated conversations with physicians and nurses, these patients did not want to talk or think about death and dying at all. The physicians and nurses were caught between providing a treatment that could be considered invasive and too burdensome for patients at this stage of the disease and refusing to give it, which could cause unbearable suffering for these patients.

“So he seemed to think, ‘If I stop now then it’s finished for me. I can’t go home and sit and wait

until I die.’ That’s how they explain it.”—Physician 10 (general hospital)

However, patients also sometimes seemed to be ambivalent about their treatment preferences: towards physicians and nurses, but also towards themselves. Physicians and nurses reported that patients sometimes would speak freely with nurses about how they felt and what they feared, but would simultaneously ask their physicians for further treatment. Furthermore, they sometimes behaved towards physicians and nurses as if they were ignorant of their poor prognosis and life expectancy, but the physicians and nurses questioned whether this was truly ignorance or “not wanting to know.”

“I suppose so ... but I think it’s sometimes really hard to tell whether people really don’t know or don’t want to know.... I tend to think, rather, that more often they repress it than that they don’t hear. That it’s a coping mechanism that the people themselves adopt.”—Nurse 7 (general hospital)

Nurses more often seemed to be ambivalent about further treatment than physicians. Whenever physicians had ambivalent feelings, they rarely chose to refuse treatment explicitly but tried to reach a shared decision, which could also be a compromise. They preferred to suggest a mild alternative, to “try out one dose,” or to advise a patient to consult another physician in another hospital rather than explicitly refuse treatment. Having the possibility of “just try and see how it goes” was regarded as a great advantage of chemotherapy (every line consists of several doses).

“You could say ‘Let’s try one course of treatment and then see how it goes, how many side effects there are.’... There’s no question of that in the case of resuscitation; a resuscitation is black and white, you do it or you don’t. And in the case of chemotherapy you say, ‘Well, perhaps we could try it.’”—Physician 9 (general hospital)

Ways to interrupt patients’ and physicians’ mutually reinforcing attitudes of “not giving up”

Physicians generally reported little difficulty in withholding treatment when a patient’s medical condition was clearly insufficient to start another line of chemotherapy. The same held for situations in which patients and physicians together came to the conclusion that further treatment would no longer be beneficial. This was not the case in “grey area” situations, however. Although a substantial proportion of the physicians admitted being inclined to prescribe further treatment in such situations, they seemed unsure whether and when they should switch towards purely symptom-directed care.

To preserve a patient’s quality of life, physicians and nurses however had made up their minds how to withhold further treatment in grey area situations. Only a few, mainly younger physicians, said that, in being responsible for a patient’s quality of life, it is the physician’s task to explicitly refuse the patient’s wishes for further treatment in grey area situations. Conversely,

only a few, mainly older physicians, said that good communication and sufficient information about what patients could expect from future treatment could abate patients' wishes for treatment in grey area situations.

"If you say at a certain point in the case of an illness for which there are different courses of treatment available, 'You're making progress, I can still treat you, but the number of options is now diminishing. I have two more possibilities but then that's it,' then you are actually announcing a year or six months in advance that that point in time is approaching.

While if you deliberately choose not to discuss it at that moment ... either because of the time aspect or because you think you have a different opinion and will thus impose a burden on the patient, then the blow comes much harder at the point when you have to say it."—Physician 13 (general hospital)

Furthermore, some physicians explicitly mentioned that they provided the option of "doing nothing" together with treatment options during bad news consultations. Physicians and, in particular, nurses stressed the importance of carefully explaining the meaning of "nothing." Physicians' use of technical jargon could sometimes be misinterpreted by patients, and then could result in an even stronger wish for "something." "For me it is always a very clear option [not starting chemotherapy], and not everyone thinks the same way about this.... And if people are really in a poor state, or if they are older and they have a metastatic disease, then I think that 'doing nothing' is often a good option, because then you substantially retain the quality of life."—Physician 14 (general hospital)

Despite these ideas about how to prevent the prescription of burdensome treatment, one physician reported seeing in colleagues how an attending physician and patient often slowly grew together during the course of the disease. This emotional bond understandably made it difficult for the attending physician to disengage from the physician's and patient's shared intention "not to give up." During the course of treatment, patients as well as physicians hoped for the best. "And that you're in a situation ... where the patient together with the oncologist is so dug in, that together they are hanging on to life for all they are worth. And then you have little opening to get something moving."—Physician 1 (university hospital)

Such observations were also made by some of the nurses. Nurses, however, sometimes presumed that physicians would not seriously listen to them if they voiced their concerns. Physicians, in contrast, reported greatly appreciating nurses' contributions—for example, in providing information about a patient's psychosocial situation. Nurses saw their role as someone who reassures and supports patients, who further explains the information given by the physician, and who informs physicians when patients are deteriorating. Some of the nurses also felt they had an important role in protecting patients from further treatment with

burdensome side effects, for instance by assisting patients in preparing questions they could address to their physician.

Interviewer: "And did they [physicians] listen to this [nurses' concerns about continuation of treatment]?"
Respondent: "Yes ... they did ... but they wanted to continue with this very last option. So, they listened to our concerns, but they nevertheless continued."—Nurse 11 (general hospital)

"Well, yes, in that sense, as a nurse, you are sometimes rather in the middle, and that's not a bad thing. As a nurse, you have more contact with the patient than a physician, so in that sense you can assess the non-clinical aspects better than a physician. And you can talk about that with a physician, if the patient can't. Or be supportive to the patient in this respect."—Nurse 4 (general hospital)

DISCUSSION

Out of fear of negatively affecting the wellbeing of a patient with end stage cancer, physicians seem to be inclined to offer further treatment and to strive for prolonging the patient's life. Nurses, however, seemed to be inclined to express their doubts concerning further treatment to allow patients to make the best use of the time that is left. Physicians' emphasis on treatment can be explained by patients' and physicians' mutually reinforcing attitudes of "not giving up," and by their broad interpretation of a patient's quality of life, in which taking away the patient's hope by withholding treatment is considered harmful. Physicians emphasis on treatment and their feeling that discussing death or dying at the same time as administering chemotherapy was considered contradictory make withholding treatment in an earlier stage in the course of the disease difficult.

Strengths and weaknesses of study

A feature that increases the validity of this study is the purposive sampling across settings (university and general hospitals in the Netherlands) and across disciplines (physicians and nurses with various backgrounds). Taking the perspectives of both physicians and nurses into account offers further insight into the reasons behind treatment decisions.

Our study also has limitations. Part of our study describes the way physicians and nurses interacted with their patients. The most appropriate study design for this would have been a combination of observational study and interviews, including interviews with patients. However, observing consultations in situations in which the patient is near the end of life is ethically problematic.

Another limitation of our study is that we focused on "difficult" and "straightforward" cases rather than on the type of cancer; our study may therefore not be representative for the whole cancer population. However, physicians' underlying reasons to withhold chemotherapy is best illustrated with atypical patient

cases.³ By asking physicians and nurses about straightforward cases also, we were able to find out how they themselves distinguished between straightforward and difficult situations. Situations in which health professionals and patients had contrasting ideas about treatment (mostly when patients persisted in wanting treatment) were often considered difficult and the most unsatisfactory in hindsight; the differences were not dependent on the type of cancer.

Finally, the fact that the primary researcher had conducted all of the interviews and had coded the majority of them could be considered as a limitation of the study.

The provision of chemotherapy at the end of life: medicine on demand?

Various studies have depicted a trend towards increasing use of chemotherapy for patients with end stage cancer,^{5,8,9} and doubts about the benefits of such use are rising. This raises the question of why this trend exists and whether it is the result of greater demand from patients—that is, respect for this demand from physicians. In the past decade, the patient's role and patient autonomy in end of life decisions have been extensively discussed.^{18,19} Our study findings suggest that greater attention towards patient autonomy is not the key explanatory factor of increasing use of chemotherapy at the end of life. Instead, this trend could first of all be explained by patients' and physicians' mutually reinforcing attitudes of “not giving up.”

It seems that physicians are inclined to offer further treatment to strive to prolong a patient's life, and they do not want to disappoint patients who explicitly wish for treatment by taking away their hope. Patients, in turn, eagerly follow their physicians' well meant offers of treatment, which they seem to interpret as a sign of hope. Patients and physicians thus seem to mutually reinforce the continuation of treatment. This shared intention not to “give up” seems to be strengthened by the intense physician-patient relationship that develops and by the nature of chemotherapy itself—deciding about chemotherapy is not a clear-cut decision and includes many options.²⁰ Physicians (consciously or unconsciously) seemed to be hesitant to force a break from cancer treatment (and thus a switch to comfort care). This may partly be explained by physicians' reluctance to initiate discussions about death or dying while administering treatment. It also seemed that breaking from cancer treatment was not possible at all with patients who did not accept their own mortality.

What is in the patient's best interests?

Physicians took account of various aspects of a patient's situation in their decision making, as has been reported by Van Leeuwen et al.²¹ In “grey area” situations, a substantial proportion of the physicians admitted they preferred to continue treatment rather than explicitly withholding it despite sometimes doubting whether the treatment benefits would outweigh the burdens. Yet, physicians only sometimes

referred to chemotherapy as treatment that was not in a patient's interest, although professional medical standards describe that treatment should do as little harm as possible.²²

We found that the nurses more frequently seemed to question whether further treatment would be in a patient's best interest. In “grey area” situations, they also admitted to sometimes doubt the benefits of further treatment. However, on balance, instead of continuation of treatment, they seemed to prefer that patients be allowed to make the best use of the time they had left. This difference in attitude is not particularly surprising²³ since nurses often heard a different patient story from that told to physicians—a story in which patients' doubts about further treatment were more pronounced. Moreover, nurses are differently schooled and have different responsibilities towards patients than physicians. In general, nurses are more inclined to focus on the consequences of cancer and cancer treatment for patients' and relatives' lives in the broadest sense, whereas physicians are more inclined to focus on the patient's present physical and mental condition and on the consequences of treatment.

However, there is no generally accepted definition of what is in a patient's best interests nor a practical guideline for determining it.²⁴ Physicians seemed to use a broader interpretation of a patient's quality of life, in which taking away the patient's hope by withholding treatment was considered harmful. The physicians' broad notion of patients' quality of life, and their occasional positive experiences with chemotherapy when they were initially unsure about its effectiveness, may explain why they rarely referred to chemotherapy as treatment that is not in a patient's interest. Our data suggest that nurses' idea about the usefulness of chemotherapy was sometimes more accurate than that of physicians, since physicians held that doing “something” and never give up hope, especially in the final stages of the disease, was sometimes more important than the expected treatment outcome. Nevertheless, our data also showed that in rare cases providing probably ineffective treatment may be beneficial for the patient.

Research and implications for clinicians and policy makers
Our findings have direct relevance for discussions about the increasing use of chemotherapy in end stage cancer. They are also applicable to other medical settings, since overuse of treatment—from diagnostic tests to new forms of screening—receive wide attention.²⁵ To initiate a behavioural change in physicians' emphasis on treatment, three aspects demand further attention.

(1) Physicians' inclination to preserve a patient's hope by offering further treatment is understandable. Retaining hope allows patients to continue to focus their minds on aspects that give meaning to their lives.²⁶ Our findings suggest that, although physicians try to inform patients accurately about the severity of their disease, they do not want to take away their hope,

WHAT IS ALREADY KNOWN ON THIS TOPIC

Deciding whether to administer chemotherapy in end stage cancer is not a clear cut decision but includes many options

Studies have reported a trend toward increasing use of chemotherapy at the end of life

WHAT THIS STUDY ADDS

Physicians' and nurses' attitudes towards patients with end stage cancer seem to be expressed differently: physicians are more inclined to offer further treatment to strive to prolong patients' lives, whereas nurses are more doubtful about further treatment, preferring that patients be allowed to make the best use of the time that is left

Patients and physicians seem to mutually reinforce each other's attitudes of "not giving up," which leads to an emphasis on continuation of treatment

Discussion about a patient's approaching death while administering treatment is considered contradictory as this could diminish the patient's hope, which makes withholding treatment at an earlier stage of the disease even more difficult

and they seem to try to maintain this by offering treatment options or by evading end of life discussions. Physicians sometimes give partial information to ensure that patients stay optimistic about recovery, and patients retain their unrealistic hope by a biased listening to their physicians.^{17,27} A moral evaluation is needed to explore whether it is always desirable to preserve patients' hope if that is based on unrealistic expectations.

(2) The physicians in our study considered a discussion about a patient's approaching death while administering treatment to be contradictory, which makes withholding treatment at an earlier stage of the cancer disease trajectory even more difficult. Our findings suggest that there may be a role for other healthcare professionals to interrupt patients' and physicians' shared intention of "not giving up," perhaps by timely initiation of end of life discussions. An earlier switch from active (disease directed) treatment to comfort (symptom directed) treatment would shorten the course of chemotherapy. Future research should focus on how such interruption of patients' and physicians' mutually reinforcing attitudes should be accomplished. Simultaneously, a moral evaluation is needed to explore whether such interruption is always the most beneficial approach for patients, especially for patients who want to go on till the very end.

(3) Physicians seem to have a less restrictive attitude towards continuation of treatment than nurses, which could partly be explained by nurses having a better understanding of their patients' feelings. Our findings suggest that improving communication between physicians and nurses could result in a more realistic mutual understanding of a patient's medical condition. In addition, media communication about the negative outcomes of cancer treatment as well as adequate information about end of life care would probably widen patients' and physicians' ideas about treatment. A recent US study, however, showed that news reports about cancer often discussed aggressive treatment and the chances of response but rarely discussed treatment failure, adverse events, and end of life care or

death.²⁸ This too merits attention from a health policy perspective.

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