Aims and reasons: ethical questions about palliative systemic anticancer therapy

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CHAPTER 6

PROBABLY INEFFECTIVE PALLIATIVE SYSTEMIC TREATMENT: CAN IT BE JUSTIFIED?

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Abstract
Physicians have strong objections to treating patients with metastatic cancer if this treatment is toxic and if it is most unlikely to be effective. Despite objections that treatment should not be too harmful and should be effective, physicians sometimes still prescribe ‘probably ineffective palliative systemic therapy’ (PIPST). In the casuistry discussed in this paper, it even appeared to be a form of good care. The central question is ‘Can giving PIPST be justified in specific situations, and if so, how can this be done?’ In practice it seems that there are reasons other than effectiveness that make patients want to undergo PIPST. For example, they want to ‘have tried everything’. The physician may be able to justify prescribing PIPST if this form of treatment fits into a coherent life story.
6.1 Introduction

Where end-of-life treatments are concerned, doctors are in complete agreement with Schneiderman’s powerful words on ethical obligation:

“One should redirect efforts from life-saving treatments towards the aggressive pursuit of treatments that maximize comfort and dignity for the patient and grieving family.” If palliative systemic therapy for metastatic cancer is, or is likely to be, ineffective then this type of treatment should be avoided. However, in oncology practice what we will call ‘probably ineffective palliative systemic therapy’ (PIPST), is regularly given. A number of studies have shown that over the past few years PIPST has been increasingly prescribed. These studies present the percentage of patients who underwent chemotherapy during the final weeks and months of life. The closer to the end of life treatment is given, the smaller the chance that it will be effective.

Broadly, in the treatment of metastatic cancer two situations in which the palliative systemic therapy is ‘probably ineffective’ can be distinguished. One situation is if a tumour is relatively insensitive to therapy and there is almost no effective treatment available. The other situation is when a number of courses of treatment have been given for tumours that are, in principle, sensitive to therapy, but where sequential treatment of these tumours is progressively more ineffective. The problem is when a treatment should be stopped if it is hardly or no longer effective. In some cases, such as the ones we will mention below, PIPST would even appear a form of good care. This is the situation despite the objections that physicians have to this treatment. The questions that spring from this are: 1) What are the objections that physicians have to PIPST? and 2) Can the use of PIPST be justified in specific situations, and if it can, how can this be done?

6.2 Casuistry

The casuistry on the use of PIPST that we used in our analysis comes from two interviews with medical oncologists that formed part of a larger study. Here we present a summary of the case study.

A medical oncologist (from now on referred to as Doctor Verloop) was telling the interviewer about a patient with metastatic gastric cancer (Mister Adriaanse). This patient wanted treatment very much indeed and, even though the doctor was hesitant to do so, he prescribed a course of capecitabine/epirubicine/cisplatin. After the first course of...
treatment, the patient’s condition deteriorated and treatment was changed to capecitabine alone, which can be given orally. In the interview, Doctor Verloop said that the aim of the treatment was ‘in the psychological area’. He also told about his experiences during the illness of his own mother (Mrs Huizinga). His mother was presented as an example of someone who very much wanted treatment but for whom there was very little likelihood of it being effective. He still thought that treatment was a good thing because now she and her loved ones really felt that they had tried everything. Doctor Verloop also spoke of a number of conditions for the implementation of this sort of treatment, as the immediate evaluation of a course of treatment and the use of well-known therapies.

Another medical oncologist (Doctor Friesema) spoke of a patient (Mrs Aboula) who also very much wanted to be treated with chemotherapy while the physician herself could see no benefit in it. Three days after the second course of treatment this patient died. Doctor Friesema talked of how in a discussion with the family following the patient’s death, she had expressed her sorrow that despite her doubts, the treatment had been started. However, the family indicated that the patient would not have wanted it any other way. They were grateful for the treatment, even if it had not lead to any improvement, because now at least everything was tried.

6.3 Doctor in trouble

‘And then he began the course of treatment that I had doubts about (...) if it had been up to me I think I would rather have stopped.’ (Doctor Verloop)

‘I am sorry that I prescribed that treatment, actually I’ve always felt bad about it (...)’ (Doctor Friesema)

Why is it that when physicians speak of administering PIPST, they often do so in terms of hesitation and regret? What exactly are their objections to prescribing PIPST? Three major objections can be distinguished in the casuistry. First, if patients receive complete and honest information about the range of treatments available and their outcomes (in terms of benefits, adverse effects and alternatives), then patients would decline further treatment. Second, according to their professional standards, doctors may only prescribe treatment that has proven to be effec-
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tive, therefore not treatment that will probably be ineffective. Finally, treatment should do as less harm as possible to the patient; for example, no toxic chemotherapy or targeted therapy should be given if it will do more harm than good.

It is very clear that these three objections are serious. How is it then that physicians still prescribe PIPST, and how do they justify this? The three objections mentioned above do not always prove to be as strong as they appear. The objections themselves contain escape routes and short cuts that allow for prescribing PIPST anyway.

6.4 Escape routes

Before we start to look for possible justifications of PIPST, we will examine these escape routes one by one in relation to each objection. Where possible we use the casuistry for illustration.

6.4.1 Well informed

According to the first objection, a reasonably well-informed patient would not want to undergo probably ineffective treatment that would be very likely to cause damage anyway. Of course, information is important but is it missing in the casuistry? In fact, the patients appear to be well informed. These cases are of course recounted from the perspective of the physician, but it is implicit that Mr Adriaanse, for example, was fully informed of the situation, knew what he wanted, and, together with his doctor, was involved at every stage in deciding what the next step should be. The mother of Doctor Verloop (Mrs Huizinga) also appeared to be fully informed about her situation. This can be concluded from the fact that Doctor Verloop said that Mrs Huizinga would have wanted the treatment ‘even against her better judgement’. These cases give the impression that the doctor provided the patient with adequate information and even that ‘continued or negotiated informed consent’ was given. This means that treatment was continually being evaluated and that information gained from this evaluation was dealt with and used as a basis for further decision-making. So, let us assume that the provision of information process is complete. It is difficult to dismiss PIPST if the patient is well informed and yet evidently still wants to have this treatment. But this alone is not enough to justify PIPST.

Professional guidelines state that treatment should not be given if it will be ineffective and harmful. How does this affect the situation?
6.4.2 You never know

The treatment these patients wanted is diametrically opposed to professional guidelines. Evidence-based medicine (EBM) requires that treatment must have been proven to be effective.\textsuperscript{10,11} This means that its effect is measured using established outcome measures.\textsuperscript{12} Frequently these are so-called ‘hard’ measures such as overall survival (OS) and time to tumour progression (TTP) instead of, for example, patient satisfaction.\textsuperscript{13,14} PIPST may turn out to be effective when measured on the patient satisfaction outcome scale. According to the usual hard outcomes, the treatments in the casuistry are probably ineffective treatments. Doctor Verloop also realised that it would be a probably ineffective form of treatment for Mr Adriaanse and Mrs Huizinga. At least, according to the hard outcomes. However, there are other outcomes. When the interviewer asked him about the aim of treatment, he answered that the treatment could be effective on other outcomes: ‘Not so much medical, but probably more in the psychological domain.’

If the treatment is indeed working in the psychological domain and in terms of evidence based medicine ineffective: How then can Doctor Verloop reconcile the professional norms with the wishes of the patient to have PIPST? This appears to be an impossible task. An important reason for patients to want to undergo chemotherapy in particular (and not anything else) is that this type of treatment allows them to hope for a miracle. Physicians too do not completely exclude the chance of a miracle. This has everything to do with ambivalence within EBM itself. EBM requires that treatment must be effective, but the effectiveness of treatment is evaluated in terms of chances and expectations. EBM generates knowledge of a probabilistic character. One end of the statistical normal distribution curve shows the most fortunate group - they, for instance, live a year longer than the average of 6 weeks. Theoretically speaking, this knowledge leaves space for the success of probably ineffective treatment (it’s all in the name of PIPST...). It is never certain if chemotherapy will or will not work in any indicated case, and this gives room to hope for an improbability. Because oncology treatment is often given within a research setting (to obtain proof at population level), this too contributes to the uncertain character of outcomes. Again the physician cannot rule out an improbability.\textsuperscript{15}

So the professional norm that requires effectiveness, does theoretically leave some room for PIPST. However, this still does not mean that prescribing PIPST is justified. Certainly not if an other professional norm, i.e. that a doctor should do no harm, is also considered.
6.4.3 Wished for despite harm

Informing the patient, better and the professional standard of effectiveness leave escape routes for prescribing PIPST. Here we discuss the third objection - primum non nocere - first do no harm. How do the doctors in the casuistry deal with the idea of harm? In retrospect, Doctor Friesema questions with regard to Mrs Aboula whether the treatment she finally prescribed was the good choice because of the harm it did.

'I remember a patient who died, not caused by the chemotherapy, but, well, you can never know for sure. I've always had the idea that if we'd done nothing she would have lived a month longer.' (Doctor Friesema)

This physician was referring to the most serious form of toxicity caused by palliative systemic therapy: premature death. Prior to treatment, this physician was also much aware of the potential harm and burden it could cause. The burden of the weekly hospital appointments involved in this treatment also weighed heavily in her considerations on the matter. The doctor does not want to give harmful treatment, and if he or she does prescribe this treatment anyway (as both doctors from the casuistry did) then he or she would do everything in their power to limit its harmful effects. Doctor Verloop said that only those types of chemotherapy may be given of which there is some experience and that: 'They are accepted treatments. That it is not unusual for it to be given.' Also, there should be no risk of unforeseeable toxicity: 'There are certain types of medical treatment that are simply irresponsible, so if the treatment concerned is mild then I think it is alright to try it.' Furthermore, Doctor Verloop is of the opinion that courses must be extra carefully evaluated after every single course.

So the physicians do not want to prescribe harmful treatment and try to limit the damage it does. The treatment concerned is a very damaging one, which may even cause premature death. This is important to physicians. However, the patient was told about the toxicity beforehand, and in the full knowledge of this still wanted to go ahead. During the interim evaluations the patients in these cases made it very clear that, although they were experiencing toxicity during the courses of treatment, they still wished to carry on with the treatment. Also after completion of treatment, when the doctor was discussing her doubts, the family of Mrs Aboula maintained that she wanted treatment and would have been unhappy if she had not had it. There is a clear, strong and well-considered wish although the treatment may be harmful. May a
doctor harm someone if it is that person’s wish? Yes, if the ‘to do no harm’ objection that doctors have to PIPST can perhaps be partially overcome if the harm is minimised as much as possible and if the patient accepts this harm and still wants the treatment. However, this might be an escape route but still is no justification for prescribing PIPST.

6.5 Narrative coherence

When considering the question how a well-informed patient may still want to undergo harmful and probably ineffective treatment, it seems that the possible effects of treatment are not the only reason for wanting to undergo treatment. Apparently there are other reasons for wanting this treatment.

> ‘My mother too, underwent treatment against better judgement. To me it seemed that it was the right thing to do for her. And also the rest of the family thought: Well, she tried’. (Doctor Verloop about his own mother Mrs Huizinga)

> ‘Well (…) if you hadn’t done it then none of us could have coped. Now we can accept what has happened because everything that could be done, was done.’ (Doctor Friesema recalling the point of view of the husband of Mrs Aboula)

These quotations show that the patients in these cases wanted to have treatment and not only for its possible effect, but because they wanted ‘to have tried everything’. It seems that it is not so much the results achieved, but more the idea that the patient had gone to their limit and even further than the last ‘possibility’, and did not give up.

Is this a good reason for a doctor to prescribe PIPST, overruling professional objections? We suggest to look for possible justification for PIPST in the ‘suitability’ of the treatment, inspired by ideas about eudaemonia (=good life). Eudaemonia is not a goal in the sense of an end, a point to be reached where movement stops. It is a goal that accompanies process: the process of a human life. It is constituted by activities. We propose the idea of the treatment of metastatic cancer as a continuous process in which every activity carries moral weight and should fit in with the patient’s life story. A treatment is suitable if it can be fitted into the patient’s life story and also into the end of this story.

In order to flesh out the idea of suitability, we introduce the concept of ‘narrative coherence’, a term which we devised ourselves. The structure and content of a narrative about the patients’ lives give the professional
information about who the person he/she is treating is, and the patients whose life stories these are get to know themselves better as well. The life story helps to provide insight into what is important for that person. New decisions about treatment can be seen in this light, namely as forming part of the narrative.\textsuperscript{18}

Within this concept of narrative coherence an important assumption is that the rounding off of someone’s life is an essential part of the life story as a whole. Aristotle talked of this idea in the so-called Solon saying.\textsuperscript{19} He dealt with the question of if someone can truly judge if they are happy during their lifetime, or if like Solon, they must wait until they ‘see the end’. For Solon, life in all its aspects had only been successful if was concluded successfully. Of course, we should not take this saying too literally because then we would not be able to say anything about the value of someone’s life because we would have to wait until they actually drew their last breath. The Solon saying actually emphasises that the last phase of life is a very important part of life as a whole.

In order to get an impression of the suitability of treatment, the physician may consider how the treatment fits into the life of the patient and the ending of this life. How would this work in real terms? Because we do not know the life stories of the patients from the casuistry, we will hypothesize life stories to demonstrate how the concept of narrative coherence can work for the physician. These examples also highlight a number of possible objections to the concept of narrative coherence.

Let us assume that Mrs Aboula played sports all her life and took up every physical challenge she was offered. In the same way, she tried to overcome her cancer by physical means. To her, PIPST represented a final challenge to once again go to her limits and win her life back. The physician can judge treatment to be suitable if the wish for treatment is consistent with in the patient’s life story and the end of this story. However, he or she may also have problems with the idea that life may be able to be ‘won back’. We will return to this later.

Narrative coherence can be expressed in many ways and may include a wish for treatment that breaches a previous pattern of behaviour. For example, a patient never took life for granted before he/she became ill, instead she always went to her limits. But now she no longer wants to fight her disease although that is what she always did. This is narratively coherent and in this case PIPST is clearly unsuitable. Doctor and patient agree and the doctor has no problem. The prospect of death can be such a huge existential experience that it may lead to a change in values. ‘Narrative coherence’ must therefore not be confused with ‘narrative con-
sistency'. In the interests of coherence, the changed values should be recognizable, understandable or able to be explained by linking them to the values which are being left behind.

Patients may also tell/show a story that does not justify PIPST. For example, Mr Adriaanse explains his wish for treatment in the context as his life as a scholar. Equally, he interprets the end of his life as a scholarly puzzle. From the mishmash of all possible treatments, he has to search out the treatment that will mean that his children will not remember him as a bedridden father but rather as an active scholar who also was able to play football with them even when he was ill. This explanation appears to be less narratively coherent. After all, at the end of life there do not appear to be any immediately available ‘scientific solutions’ to cancer. Rather than giving PIPST, it is the duty of the doctor here to help bringing about narrative coherence. PIPST may turn out to not be suitable, then the patient could well be satisfied with it. The subject of suitability of treatment (or no treatment) must be continually raised by doctor and patient.

Judging suitability by using the concept of narrative coherence becomes difficult when personal values of doctor and patient differ a lot. The life of Mrs Huizinga may have always been devoted to the service of others. She saw PIPST as a treatment that fitted into her life because she didn’t want to give up and let her family down. She felt that all the people around her supported her in this. The casuistry shows that families often play a big role. The considerations of the patient in relation to treatment never really stand alone but the patient is part of a social network.

In addition, the form that the end of life takes, plays an important part in the way that a person is remembered by family and friends. This is not only because it is the most recent memory but also the end of life is an important part of the way in which someone has lived their life. And it is exactly this thought that may influence a terminally ill patient in the way in which he or she experiences and conducts the last phase of their life. An idea of ‘fighting until the end’ might dominate this process.

In this example, in which much importance is attributed to the wishes of the family, a problem with narrative coherence emerges. The life story of this patient appears to be narratively coherent but the doctor may think that a life in the service of others is bad for the patient. The personal values of the patient -or is it better to say family values?- may clash with the personal values of the doctor. Here the doctor has the duty to find out together with the patient whether family values are also really the patient’s values. In that way is carefully looked for the most suitable end of life.
In the case of Mrs Aboula who wanted ‘to win her life back’, the treatment seems to fit with the patient’s life story. For narrative coherence it obviously does not have to fit with the physician’s values.

6.6 Justification

The concept of narrative coherence should help the doctor to form a better picture of the patient’s wishes related to treatment and the suitability of the treatment within the patient’s life. This concept gives the physician tools to look for the possible situations where prescribing PIPST may be justified. In the process of questioning the suitability of this treatment, the physician sees if the story is recognizable and understandable, and coherent with the life story. The physician might not interpret the wishes of the patient as being definitive but help the patient by means of deliberation and reflection on his or her values, wishes and considerations.

6.7 Tragic

Explaining patient’s wishes regarding PIPST treatment by using the concept of narrative coherence makes it possible to take these wishes seriously by interpreting them as something that is suitable to the end of someone’s life or not. In this way patient’s wishes are not discarded as being irrational, poorly-founded or incompatible with the patient’s interests but are actively dealt with.

In this way the concept of narrative coherence may help when considering if PIPST can be justified. Naturally, the documented objections that doctors have to PIPST continue to be relevant: a patient must be well informed, treatments must be probably effective rather than ineffective and do as little harm as possible. We want to state clearly that we believe that in principle PIPST should be avoided, unless some specific situations that we studied in detail appear to be present. Narrative coherence at the end of life is something to continuously work on by thinking about and weighing treatment options by patient and physician. The casuistry gave insight in some conditions that might guarantee a good use of PIPST.

Continued informed consent, immediate evaluation of a course of treatment, and the use of well-known therapies are examples of this.

Prescribing PIPST remains problematic and may also be tragic for the doctor: the duty of the doctor to relieve suffering may conflict with the treatment that the patient wishes. The tragedy becomes very clear
in the case of Doctor Friesema who supported her patient Mrs Aboula in her very strong wish for treatment, contrary to her own wishes. Even in retrospect, even after having been reassured by the family, this doctor continued to feel sorrow and regret about prescribing PIPST. Giving PIPST is often tragic, but it sometimes seems the best a doctor can do.
Reference List


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