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## Physicians' Perspectives on Ethical Issues Regarding Expensive Anti-Cancer Treatments: A Qualitative Study

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### ABSTRACT

**Background:** When anti-cancer treatments have been given market authorization, but are not (yet) reimbursed within a healthcare system, physicians are confronted with ethical dilemmas. Arranging access through other channels, e.g., hospital budgets or out-of-pocket payments by patients, may benefit patients, but leads to unequal access. Until now, little is known about the perspectives of physicians on access to non-reimbursed treatments. This interview study maps the experiences and moral views of Dutch oncologists and hematologists.

**Methods:** A diverse sample of oncologists and hematologists (n=22) were interviewed. Interviews were analyzed thematically using Nvivo 12 qualitative data software.

**Results:** This study reveals stark differences between physicians' experiences and moral views on access to anti-cancer treatments that are not (yet) reimbursed: some physicians try to arrange other ways of access and some physicians do not. Some physicians inform patients about anti-cancer treatments that are not yet reimbursed, while others wait for reimbursement. Some physicians have principled moral objections to out-of-pocket payment, while others do not.

**Conclusion:** Oncologists and hematologists in the Netherlands differ greatly in their perspectives on access to expensive anti-cancer treatments that are not (yet) reimbursed. As a result, they may act differently when confronted with dilemmas in the consultation room. Physicians working in different healthcare systems may face similar dilemmas.

### KEYWORDS


Medical ethics;  
anti-cancer treatments;  
funding and reimbursement;  
access; interview study

### Background

In the past decade, many new anti-cancer treatments have entered the market (Savage and Mahmoud 2015). While these treatments can offer great benefits to patients, they often enter the market at high costs (Siddiqui and Rajkumar 2012; Chen et al. 2019). The costs of the immunotherapeutic agent nivolumab, for example, which was introduced on the market for the treatment of lung cancer in 2015, were estimated at the time at 134.000 euro per life year gained (Zorginstituut Nederland 2015). In the last decade, the budget impact of anti-cancer treatments on health care costs is swiftly increasing and will continue to do so in the near future with the arrival of novel compounds, expansion of indications, and longer treatment duration due to the improved outcome of patients (Dutch National Institute for Public Health and the Environment 2018). Because of rising health care costs, organizing reimbursement for new

expensive anti-cancer treatments is challenging, especially for countries with a universal healthcare system, such as most European countries. In practice, when anti-cancer treatments have received market approval by the European Medicines Agency (EMA), these drugs are not immediately reimbursed in many countries. This results in sometimes long waiting times in many European countries, between the time treatments receive EMA approval and the moment that patients have actual access to these treatments, pending reimbursement decision-making (Uyl-de Groot et al. 2020). This potentially leads to ethical dilemmas for physicians, such as whether to inform patients about treatments that are not (yet) reimbursed, or whether to allow out-of-pocket payments for newly approved treatments that are not (yet) reimbursed.

These ethical issues arise not only in countries with a universal healthcare system, but also in other countries, in which out-of-pocket payments are more

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common. In the United States, for example, physicians find themselves in a similar balancing act in the case of the newly FDA-approved Alzheimer treatment Aduhelm, which is currently not covered by some insurance companies, including Medicare (Sachs and Bagley 2021). It should be noted that this situation is different, as, in the medical community, there is intense debate about its effectiveness and safety. However, this example shows that also in the United States, not all approved treatments are reimbursed by health insurers. This raises questions about moral duties of physicians, including whether they are expected to inform patients about newly approved non-reimbursed treatments. In this interview study we explore the perspectives of Dutch physicians on these dilemmas.

The Netherlands is a country with a universal healthcare system, in which all medically necessary treatments that are standard of care are reimbursed using public funds. All citizens have equal access to healthcare through mandatory basic health insurance. Traditionally, health insurance has covered all approved medical treatments provided in hospitals. However, since 2015, a policy measure is in place requiring that all treatments which are newly approved by the EMA or by the Medicines Evaluation Board in the Netherlands (CBG) which have a national budget impact of 40 million euro per year for all indications or of 10 million euro with a cost of 50.000 euro per patient, are put on hold in a so-called 'lock' during which they are assessed by the National Health Care Institute and the government conducts negotiations with pharmaceutical companies about the price (Zorginstituut 2020). Since the start in 2015, 44 treatments have been placed in this 'lock' (Zorginstituut Nederland 2021). The average waiting time for treatments placed in this 'lock' is 380 days (Vereniging Innovatieve Geneesmiddelen 2020). Sometimes, the Ministry of Health decides not to provide reimbursement of the treatment through basic national health insurance yet. As a result, patients no longer automatically have access to newly approved treatments.

When anti-cancer treatments have been approved by the EMA, but are not (yet) reimbursed within health insurance, physicians are therefore confronted with an impasse. Patients could possibly benefit from these treatments, but do not have access (yet) based on health insurance. Physicians might try to arrange access to these treatments using other channels, such as compassionate use programs, inclusion of patients in clinical trials, asking health insurers for leniency arrangements, or pleading with hospital managers to

have institutions pay the bills. On the one hand physicians might want to try to arrange access to these treatments for their patient because of possible (health) benefits, but on the other hand physicians might wish to wait until the treatment is reimbursed for pragmatic reasons or to respect the ethical norm of equal access for all patients. Until now, little is known about the current practices and choices of doctors in the Netherlands when they are confronted with these dilemmas.

Very little empirical research has been conducted on the choices Dutch physicians make when patients want to pay for a treatment using private funds, and which moral perspectives Dutch physicians have on out-of-pocket payments. Research by Calcoen et. al. suggests that out-of-pocket payments for health technologies are not very common in the Netherlands (Calcoen, Boer, and van de Ven 2017). Although it seems legally possible to prescribe a treatment for a patient who wants to pay for it out of pocket there is very little empirical research available regarding this possibility in practice.

It is important to gain more insight into the practices of physicians and their choices (not) to pursue access to non-reimbursed treatments. If practices amongst physicians differ, variability and thus inequality of access to expensive anti-cancer treatments for patients might ensue. Undesirable variability might give rise to new justice concerns; in the Netherlands, solidarity and equal access to health care are deemed very important values and are spearheads of the mission statement of the Dutch National Health Care Institute (Zorginstituut Nederland, n.d.).

The aim of this study is to map the experiences and moral views of oncologists and hematologists in the Netherlands regarding access to and funding of (new) expensive anti-cancer treatments. We have conducted an interview study in which we have explored physicians' perspectives on their role as doctors with regard to pursuing access to non-reimbursed treatments and on out-of-pocket payments, and their reasons to inform or not to inform patients about new treatments. It is important to take into account the perspectives of physicians regarding these dilemmas in discussions, for instance, on the scope of a legal or moral duty to inform patients about non-reimbursed treatments and on the moral acceptability of out-of-pocket payments. As the number of treatments for which reimbursement is not granted or pending is likely to increase over the next few years in countries with and without universal healthcare systems, new policies will have to be developed to guide practitioners in addressing these dilemmas.

## Methods

### Study design

In order to gain an in-depth understanding of the variety of views and experiences of physicians regarding access to and funding of (new) expensive anti-cancer treatments in different hospital settings, a qualitative research approach was chosen. To be able to collect a diverse sample of the (approximately) 400 oncologists and 300 hematologists working in the Netherlands, oncologists and hematologists were selected from academic and general hospitals, and from different subfields, age cohorts and geographical areas in the Netherlands. In the Netherlands, standard care can be obtained in both general and academic hospitals, but academic hospitals provide more 'complex' care ('tertiary care') and conduct more clinical trials. As hospital type might shape interviewees' experiences regarding the prescription of newly approved anti-cancer treatments, the distinction between academic and general hospitals was made so that the perspectives of physicians working in both hospital types could be included. The distinction in age cohorts, subfields and geographical areas was made to obtain a sample as diverse as possible. To avoid selection bias, oncologists and hematologists were recruited in multiple ways: 20 physicians were approached through the professional networks of the researchers via purposive sampling, and 3 participants were approached through other participants via snowball sampling. When approaching data saturation, 4 physicians were invited at random based on their locations to verify whether data saturation was achieved. Physicians were personally invited for the interview study by e-mail, in which they received information about the study and the contact details of the researchers. Physicians who would like to participate could indicate their willingness to participate by contacting the research team by phone or e-mail. In total, 27 physicians were invited to participate in the interview study. For the design and evaluation of the study the consolidated criteria for reporting qualitative research (COREQ) checklist was used (Tong, Sainsbury, and Craig 2007).

### Interviews

Before the start of the interviews, an interview guide was developed consisting of multiple themes, including physicians' experiences regarding new expensive anti-cancer treatments, their reasons to pursue or not pursue access to non-reimbursed treatments, a duty

to inform, and their perspectives on private funding. The interview guide can be found as an appendix (Appendix A). The interview guide was reviewed beforehand by a multidisciplinary research team (three ethicists, two medical students, one PhD-student and one oncologist) and tested during two pilot interviews with oncologists. After the first few interviews, minor adjustments were made. During the interviews, mainly open questions were asked and participants were encouraged to elaborate on their experiences. The interviews were carried out by one or two researchers (CB and EB) in Dutch from January till March 2021. Both researchers were trained in qualitative interviewing. The interviews lasted approximately 45 minutes. The interviews were carried out at the participants' workplaces, online via Zoom or via the phone, depending on the participant's preference and on the Dutch COVID measures that applied at the time. The interviews were audio-taped and transcribed literally. Participants were not asked feedback on the transcripts.

### Data analysis

All interviews were analyzed independently by two researchers (CB and EB). Transcripts were analyzed thematically (Braun and Clarke 2006). Codes were derived inductively based on the data of the transcripts and refined during multiple readings of the transcripts. When necessary, new codes were added. Discrepancies in coding between the two researchers were solved during discussion, and a codebook was agreed upon. A few of the coded transcripts were discussed in a broader research group with another postdoctoral researcher and Master student. After 18 interviews no new codes were added.

### Ethical approval and informed consent

The research proposal was submitted for review by the research ethics review committee of the Erasmus Medical Center and a waiver was granted (MEC-2020-0828), as the study does not fall within the scope of the WMO (the Dutch Medical Research Involving Human Subject Act).

## Results

### Study participants

In total, 22 physicians chose to participate in the study. An overview of these participants is displayed in Table 1. Three physicians chose not to participate,

**Table 1.** Study participant characteristics.

Participant characteristics		Number (N=22)	Percentage
Gender	Female	8	36%
	Male	14	64%
Age	<45 years	7	32%
	45-55 years	9	41%
	>55 years	6	27%
Medical Specialty	Oncology	15	68%
	Hematology	5	23%
	Oncology-Hematology	2	9%
Hospital	General hospital	13	59%
	Academic hospital	9	41%

due to too little time or illness. Two physicians did not respond to our invitation. Data saturation was reached after 18 interviews, after which 4 more interviews were carried out to confirm this.

### Main themes

In this section we present the main themes which were discussed in the interviews. Each subsection starts with an overview of physicians' experiences, followed by physicians' perspectives and moral views. An overview of the main themes can be found in Table 2 at the end of the Result section.

### Physicians' experiences with reimbursement of new anti-cancer treatments

While it was physicians' general experience that they were able to give their patients the right treatment, most respondents had experienced situations in which they wanted to prescribe a new treatment for which a reimbursement decision was still pending. Some physicians therefore had not been able to prescribe the preferred treatment for their patient:

*"It happens sometimes that I think: this patient should actually get this [treatment], but it is not available yet, so I will give him something else."* Respondent 5

*"...there is a delay between approval and reimbursement. That is why we cannot treat people as optimally as we would want to."* Respondent 7

When asked about their perspectives, some physicians expressed concerns regarding the long waiting times between approval and reimbursement. Other physicians however simply accepted these waiting times as a fact inherent to the process chosen in the Netherlands. Physicians sometimes emphasized the importance of seeing the health benefits associated with new treatments in perspective; often, they felt, those benefits were small or marginal, or good alternative treatments were available. Some physicians mentioned that while the reimbursement decision was pending, they were always able to arrange access for their patient via other ways. However, not all physicians experienced this. Some physicians had multiple patients waiting for reimbursement decisions for various treatments, and considered this to be problematic:

*"On the other hand, I do understand the hospital for saying that you have to wait. I mean, I understand it from the hospital's perspective. But from the patient's perspective it is of course not always the best."* Respondent 21

Almost all respondents mentioned that they believed drug prices and healthcare costs should ideally play no role in the consultation room. As a physician, they wanted to do the maximum possible for their individual patients, regardless of the costs. A few physicians also mentioned that they already felt that reimbursement issues were having a negative impact on the physician-patient relationship and discussions in the consultation room. Respondents had different perspectives on the desired role of the medical profession in societal discussions or policy-making on reimbursement of medical treatments. While some felt that doctors should be actively involved in those discussions, others felt that it should be up to society and politicians to make reimbursement decisions.

**Table 2.** Main themes.

Main themes	Experiences and perspectives
Physicians' experiences with reimbursement of new anti-cancer treatments	<ul style="list-style-type: none"> <li>Most physicians experience waiting time between approval and reimbursement of newly approved treatments.</li> </ul>
Pursuing access to non-reimbursed treatments	<ul style="list-style-type: none"> <li>Some physicians actively pursue access to non-reimbursed treatments via alternative pathways.</li> <li>'Pathways' which are followed by physicians to pursue access are: including the patient in a clinical trial, contacting the insurer or manufacturer, asking the hospital board for reimbursement, or referring the patient abroad.</li> </ul>
Perspectives on out-of-pocket payments	<ul style="list-style-type: none"> <li>Physicians have opposing (moral) views on out-of-pocket payments.</li> <li>Some physicians are in favor, appealing to the moral values of beneficence and liberty.</li> <li>Some physicians are opposed, appealing to the moral values of equality and solidarity.</li> </ul>
Information provision about non-reimbursed treatments	<ul style="list-style-type: none"> <li>Some physicians inform their patients about non-reimbursed treatments if they believe it might become a relevant option in the future.</li> <li>Other physicians do not inform patients about non-reimbursed treatments, not wanting to give their patients 'false hope.'</li> </ul>

*“And that is our role. We are here [...] to decide [about treatment] together with the patient, to take care of the patients as well as possible. But outside the consultation room, we are of course also here to ensure that we have cost-effective health care, and that in ten years from now, we will still be able to afford drugs.”* Respondent 6

*“It muddles the conversation, I believe. Because I want to make [treatment] decisions purely based on medical considerations. And [...] already I very often encounter that an 80-year-old says: [...] expensive treatments, I will not get those, because they must be too costly? Or I am probably too old? And I really do not want to end up in those kinds of conversations, and no, I have not become a doctor to do this, to start counting, to start calculating what I can still do or what is left of my budget. No, I simply want to be able to do the best we have available for that patient.”* Respondent 15

### **Pursuing access to non-reimbursed treatments**

When asked if physicians undertook actions when new treatments had entered the market but were not (yet) reimbursed, some physicians said they tried to pursue access to these treatments for their patients via various ways. The majority of the physicians tried to include their patients in clinical trials (e.g., phase IV trials or trials of off-label uses), if these were available. A few physicians also checked whether there were clinical trials available abroad. If a treatment was not available in the hospital in which the physician worked, but was available elsewhere, the majority of the respondents referred their patients to those other hospitals. This applied especially to physicians working in general hospitals, who often referred their patients to academic hospitals. Physicians mentioned that it may be easier to prescribe newly approved treatments in academic hospitals, because of prior experiences with these treatments during clinical trials or existing agreements with insurers or manufacturers. Furthermore, some physicians tried to arrange access for their patients via compassionate use programs run by manufacturers, and a few physicians sometimes contacted manufacturers personally to try and obtain the treatment – at no cost – for individual patients. Some physicians also occasionally contacted health insurers to ask for leniency arrangements. Multiple physicians had on occasion asked the hospital board to fund treatments. A few physicians also had referred patients to clinics abroad if they knew medical treatments were available there.

Pursuing access to non-reimbursed treatments – outside the context of clinical trials or third-party payers – is not possible in all hospitals. Some hospitals have regulations or standard procedures that preclude

the prescription of non-reimbursed drugs. By contrast, other hospitals have special budgets to pay for non-reimbursed anti-cancer treatments in exceptional situations.

The reason which was mentioned most frequently by physicians to pursue access to non-reimbursed treatments for their patients, was the ‘duty of care’ they felt they had toward their patients and the responsibility they felt to do as much as possible to give their patients the best possible treatments.

*“The patient must be able to rely on it, that if he comes into my consultation room, I do the maximum possible to see what options there are available.”* Respondent 16

*“...considering that if, as a doctor, you feel that this really is a very important treatment option, which is possible now, and which cannot be postponed, then, in my opinion, it is your fiduciary duty to do the utmost to use all possibilities.”* Respondent 19

Physicians sometimes also mentioned the difference between oncology and other fields of medicine; in oncology, patients do not always have the time to wait for a reimbursement decision.

Some physicians felt that it was the duty of all doctors to try and pursue access to non-reimbursed treatments for their patients. One respondent mentioned that while he understands it when colleagues decide not to seek ways of getting access to potentially beneficial non-reimbursed treatments, he could not accept not doing so for himself. He considers being free to seek nonstandard treatment options essential to being a (good) doctor:

*“I think that perhaps some doctors think: well, [I am not going to do it]. And that is the physician’s right, because they stay within the guidelines and they stay within the general agreements. But I think, if I would become that way, I would quit my job.”* Respondent 1

One respondent had even negotiated with the hospital about the possibility to prescribe non-reimbursed treatments as a condition for taking the job.

*“When I went to [hospital], I said, I would like to come, but I do not want any nonsense about those expensive treatments. If there is an indication, I want to be able to prescribe it, otherwise I won’t be coming [to take this job].”* Respondent 16

Multiple physicians had never pursued access to non-reimbursed treatments for their patients, except inviting patients to take part in ongoing trials, for

which they mentioned multiple reasons. Some were practical in nature, such as the expectation that they would not succeed in arranging the required funding, the amount of administrative work it would take, and time constraints. Other reasons mentioned were expecting minimal benefits of the treatment or expecting too many side-effects. Lastly, a few physicians mentioned they wanted to wait for the actual reimbursement based on a more principled viewpoint that it is best to wait for the actual reimbursement for all patients.

*“... time pressure [is the most important reason], I think. It is just... It is not just one phone call. It involves paperwork, it involves waiting, and then trying to find the right person who is in a position to make the decisions. And [there is] a big change that [the request] gets declined. And if you do it for the one patient, then actually you should also do it for the other patients, and you know, that is where it ends [because you cannot]. And I think that everyone has quite a lot of work to do. You just don't have the time, I must say.”* Respondent 15

When asked about situations in which physicians pursued other ways of access to non-reimbursed treatments, they mentioned several conditions (Table 3). First of all, they had to know about the treatment, for instance via conferences or via other physicians in their network. Also, respondents were more willing to pursue access when patients were young, when the expected effectiveness of the drug was high as compared to the alternatives, or when they experienced a sense of urgency. Physicians said they were less likely to pursue access to non-reimbursed treatments if there were satisfactory alternative therapies available, if the benefits of the treatment seemed marginal, if they did not feel experienced enough to prescribe the treatment, if the patient did not seem fit enough, or if the evidence supporting the benefits of the treatment was ambiguous. One respondent considers:

**Table 3.** reasons to pursue or not to pursue access to non-reimbursed treatments.

Facilitating factors for pursuing access to non-reimbursed treatments	Inhibiting factors for pursuing access to non-reimbursed treatments
Expected effectiveness of the drug as compared to reimbursed alternatives	Availability of satisfactory reimbursed alternatives
Youthfulness of the patient	Seemingly marginal benefits of the treatment
Sense of urgency	Evidence for the benefits of the treatment is ambiguous Not enough experience with prescribing the treatment The patient not being fit enough

*“...the drug and the benefit that it brings. The treatment that adds only 2 months may be better than the previous treatment, but that benefit is only relative. And it is a median, so it is also possible that the one patient will experience no benefits at all, or unpleasant side-effects. So then you wait, then I lean towards, just waiting until it is actually accessible.”* Respondent 15

Some physicians also felt it was important to know when to stop prescribing new treatments and to focus on maintaining quality of life, especially at the end of life. Sometimes patients had better spent any remaining time with family rather than start new therapies with minimal effect:

*“If people are expected to die within two months, I do not think it's ethically right to start new treatments. At a certain moment, people have the right to know that they are dying, and as long as you are still receiving therapy, you are disturbing the dying process.”* Respondent 6

### Perspectives on out-of-pocket payments

Respondents did not have any experience with out-of-pocket payments in the Netherlands, except for one. This respondent had initially allowed a patient to pay for a medical treatment out of pocket, after which the hospital decided to reimburse the treatment after all. When physicians were asked about their hospital's policy regarding out-of-pocket payments, not all physicians were aware whether policy in their hospital existed, or what this policy was. Among physicians who did know their hospital's policy, we observed variation: in some hospitals, out-of-pocket payment was allowed, whereas in others, it was not. This variability in hospital policies was flagged by some respondents as problematic.

In other countries, out-of-pocket payments are more common. A few respondents had experience with patients who went abroad and had paid for treatments out-of-pocket or via crowdfunding. One physician referred patients to colleagues in other countries now and then, if he knew patients could afford to purchase treatments that were not available through the healthcare system in the Netherlands:

*“I know exactly what my patients earn. They know about my income, too, by the way. But I am not starting this conversation with someone who lives on a state pension and lives in a state-subsidized rental place. That would not be fair. But if a bank director barges in on his high horse, saying that it is all taking too long in the waiting room, I do tell him that at a small additional cost, he can go to another country.”* Respondent 18

During the interviews, physicians were asked whether they would consider letting a patient pay for a treatment out-of-pocket in the hypothetical scenario that the National Health Care Institute decides not to include an effective treatment in the health insurance package at all, based on the costs. The (moral) perspectives of physicians on out-of-pocket payments varied greatly. Some physicians would allow patients to pay for treatments using private funds. Other physicians said that they would never let patients pay for treatments themselves, for which they put forward multiple reasons. The reason that was mentioned most frequently was that they felt that, as a doctor, they had a responsibility toward all patients, regardless of their financial situations. Physicians often brought up the values of equality and equity, and underlined the importance of equal access to healthcare for all patients. They felt responsible for providing the same treatments to all their patients. Some physicians felt that if it is not possible to provide a treatment to all patients, then no patient should have access.

*“It just does not fit with my professional ethics, to... and also not with my personal ethics... to give better health care to people who can pay more.”* Respondent 17

*“I am not in favour [of allowing patients to use private funds to obtain health care]. I believe that everyone should have the same opportunities, independent from how much money or connections they have.”* Respondent 8

A second reason not to prescribe treatments based on out-of-pocket payment was the concept of solidarity. Physicians felt that if a treatment was not universally reimbursed, patients should not pay for it using private funds, based on solidarity with other patients who could not afford it. A few respondents said they felt anger when confronted with the sheer idea of allowing differences in access to occur between individual patients along the lines of socioeconomic status. Some physicians brought up alternatives to fund non-reimbursed treatments, which they preferred, such as drawing lots or setting up a national donation pot from which the treatments would be reimbursed. Physicians also sometimes felt a responsibility to protect patients against financial distress if they were not sure about the effectiveness of a treatment. One respondent narrates previous experiences with pursuing access to non-reimbursed treatments:

*“[which] eventually have led me to decide that I would not do it anymore, help get people abroad [for treatment]. Because then I was very much facilitating inequality in society. But it is also very difficult, because – because now I am actually saying to people:*

*sorry, I cannot help you, based on solidarity with someone else.”* Respondent 9

Furthermore, some physicians also had practical reasons to resist out-of-pocket payment, for instance, they felt they could not guarantee the safety of the patient, if the patients would pay for the treatment directly to the pharmaceutical company and the drugs would not arrive in time, or worried that the hospital could not arrange the other practical necessities, such as scans, which also would lead to ancillary costs.

*“This is just not how it works, is it? The pharmacist cannot buy [a drug] if there is no reimbursement in place. And the pharmacist cannot, as far I know, send a bill to an individual patient.”* Respondent 18

By contrast, other physicians did not see such practical barriers, as they pointed out that patients without health-insurance (for instance, international patients) also pay for in-hospital treatments themselves, for scans, drugs, hospitalization, etc.

When asked about the hypothetical scenario in which an effective treatment was not reimbursed, there were physicians who would consider out-of-pocket payments. Reasons mentioned by physicians to consider this, were the duty they felt to give their patients the best possible treatment, and the responsibility they felt toward their patients to give them access to a treatment which could improve their health.

*“If the situation arose, though I have not experienced it in the past 15 years, that I really believed there was a good indication for treatment, but that the insurer and the pharmaceutical company and the hospital did not want to pay, and the patient could afford it, then I would cooperate. But I have never experienced such a situation.”* Respondent 4

Another reason mentioned by physicians to allow their patients to pay for a treatment out of pocket, was the concept of liberty. Physicians felt that patients should have the freedom to spend their money as they deem fit, and the purchasing of approved treatments that could potentially improve their health is a legitimate expenditure. Physicians emphasized that if they would contribute to a treatment which would be financed by a patient, it would have to be an evidence-based treatment with proven effectiveness. For this respondent, the reason for allowing patients to access medical treatment using private funds was:

*“Liberty. If we together, all of us, build a system based on solidarity, of which I am a strong supporter, but that system based on solidarity has its limits, in what*



*we do not pay together in solidarity, then I do not believe you can withhold someone from doing something they can afford themselves. There is absolutely no reason that if we do not get paid for a vacation by state funds, that you would prohibit me to go on vacation. And health care is not different from buying quality of life years”* Respondent 18

Lastly, there was also a group of physicians who remained conflicted and did not know whether they would allow patients to pay for treatments out of pocket. These physicians often mentioned the two sides of the dilemma: on the one hand the duty they felt toward facilitating equal access to health care for all patients, and on the other hand the responsibility they felt toward the provision of optimal treatment of their individual patient. However, they did not know which aspect of the dilemma they would give priority to, and some respondents expressed concern, saying, for instance, that being confronted with this dilemma would lead to sleepless nights.

When asked about the dilemma of out-of-pocket payments, multiple physicians started with naming alternatives which would prevent the dilemma from occurring. A few physicians considered a lottery for treatments to be a more just alternative than out-of-pocket payments, as all patients would have equal chances regardless of their financial capabilities. Furthermore, physicians often named ways for cost-reduction in health care, which would prevent treatments not being reimbursed and therefore prevent the dilemma of out-of-pocket payments. Ways of cost-reduction which physicians mentioned were, amongst others, saving costs in the final stages of life by stopping treatments in time, or sharpening the criteria for certain treatments based on age or effectiveness.

### **Information provision about non-reimbursed treatments**

Physicians were asked when in the process of drug development, marketing approval or reimbursement decision-making, they started to inform patients about a new treatment. They named different moments in time. Most physicians informed patients about new treatments which they believed were relevant and accessible options for their patients. However, the perspectives of physicians on accessibility varied. Some physicians never informed patients about treatments of which the reimbursement-decision was negative or pending, but might inform them if the treatment was accessible in other ways, such as compassionate use programs. Reasons not to inform patients about treatments without reimbursement through national

health insurance were not wanting to give patients false hope, or not wanting to let them worry about treatments which they probably would not be able to gain access to.

*“In my opinion, it means you might be giving hope and if then eventually it turns out that you cannot give that treatment, then it is a disappointment for the patient.”* Respondent 21

However, other physicians sometimes informed patients about treatments that were not yet reimbursed, but that might be reimbursed in the future. Their reason for doing so was wanting to give them some perspective on the possible treatment options in the future.

*“I also say that sometimes to instill some courage.”* Respondent 16

*“There are some treatments that over the course of this year will become available. And there are [patients] who are nicely stable on a certain treatment and then you can tell them already, there are a few things that will come their way. The shelf is not completely empty.”* Respondent 5

While a few physicians also informed patients about treatments abroad, most physicians only informed patients about treatments which were available in the Netherlands.

When asked when, according to them, physicians should inform patients about new treatments, all respondents felt that patients should be informed about accessible and realistic options, for which there was a treatment indication. However, there was a wide range in interpretations between physicians about what constitutes an accessible and realistic option. For some physicians, this included treatments that are not (yet) reimbursed, for instance, or treatments that are available only across the border, but for some physicians, it did not.

*“You should not promise something you cannot fulfil. So, nonsense such as flying to the United States once every three weeks or so, that is not realistic. You should temper that. But again, going to Germany, for example, is realistic, I think. That is a realistic option for our patients, and if [German doctors] can offer something that I cannot and that is potentially useful, then I do inform people about it.”* Respondent 20

Physicians also emphasized the importance of adjusting the amount of information to the values, wishes and capabilities of the individual patient.

*“It also depends whether patients ask [about new treatments]. And some people do want to know and others*

*do not. And if you have treated many patients, you know that there are many preferences.”* Respondent 16

All physicians mentioned that if patients had questions about non-reimbursed treatments, they would answer these questions and give the patient more information. However, many questions from patients concerned irrelevant treatments. Physicians mentioned that sometimes these conversations were difficult, but that patients often understood it if a treatment was not yet accessible or reimbursed.

*“Actually, it is not so bad. In practice, it is not so bad. It happens that people say “I want to have this or that”, but in general, it is possible to explain very well why something is available or not. And, so, in general that is all right. And people realize more and more that there are limits to what is possible.”* Respondent 3

*“And then you have to explain to people that it is not reimbursed yet and that you have to go with the second best, if they ask questions about it. Yes. Then you have to explain it, and sometimes that is quite difficult.”* Respondent 7

A few physicians thought that empowered patients who ask many questions might get more access to new expensive anti-cancer treatments than patients who do not ask those questions. However, they believed this might not always be to the advantage of the empowered patients because of the risks of overtreatment and side effects. Physicians emphasized wanting to give their patients the best possible treatment, and felt that new treatments were not always the best option. Also, some respondents said that patients who asked more questions did not receive different treatment. They felt a responsibility to avoid such differentiated treatment.

*“I believe that the principle of equality should definitely be taken into account. It should not be possible, that I treat one patient who is very outspoken, differently than another, more humble patient. If I did that, I would no longer consider myself credible. So I watch out for that.”* Respondent 1

*“I would do the same for every patient. With me, a patient does not have to start to mention it. I believe it should be up to the doctor and not the patient, to aim for the maximum possible.”* Respondent 10

## Discussion

This study shows that the practices and perspectives of Dutch oncologists and hematologists regarding expensive new anti-cancer treatments that are not (yet) reimbursed, differ greatly.

While some physicians pursue access to non-reimbursed treatments for their patients, and actively look for other routes to gain access, some physicians prefer to wait for reimbursement. These practices seem linked to physicians' conceptions of the role and moral duty of the physician: whereas some emphasize the importance of maximizing health outcomes for individual patients, which may require pursuing nonstandard treatment options, others wish to adhere to standards and ensure the best possible health care for all patients. The latter group may consider it wrong to make exceptions and pursue access to non-reimbursed treatments for individual patients, referring to values such as justice, solidarity, and equal access. In practice, this means that some patients may be able to access newly approved treatments, while others may not, depending on the (moral) perspectives of their physicians. This may give rise to inequalities in access to new anti-cancer treatments. While this study focusses on physicians' perspectives regarding post-approval access to treatments, the findings show similarities with earlier findings regarding physicians' perspectives regarding pre-approval (so-called 'expanded') access to investigational treatments. For instance, a qualitative study found that estimated effectiveness and lack of approved alternatives (“back against the wall” situations) were important reasons for Dutch physicians to pursue access (Bunnik and Aarts 2021). Some of physicians' objections against expanded access are also quite similar, such as the argument of ‘false hope’. However, one important difference lies in physicians' perspectives on the safety of the treatment, which was mentioned less frequently as a concern in the context of post-approval access to non-reimbursed treatments than in that of expanded access to unapproved treatments.

Secondly, this study also suggests that while some physicians inform their patients about treatments that are not (yet) reimbursed, most do not, and inform their patients only about treatments that are already reimbursed. These findings align with an interview study held among Australian oncologists: while 72-94% of the physicians would discuss a new drug with a patient if it was subsidized (based on different scenario's), only 28-41% of the physicians would discuss the same drug with their patient if it was not (yet) subsidized (Jefford et al. 2005). Thus, physicians may be less likely to inform patients about relevant treatments if they are not reimbursed. A recent study in Israel showed that while most oncologists believed that patients should be offered all relevant treatment options regardless of their

reimbursement status, physicians did experience difficulties when deciding whether to inform patients with financial difficulties about non-reimbursed treatments (Bashkin et al. 2021). A study amongst the Australian general public showed that 91% of the respondents did want to be informed about (hypothetical) new expensive drugs which were not (fully) subsidized and required out-of-pocket payment, even if only 51% indicated to be willing to pay for it (Mileshkin et al. 2009). This suggests that there may be a discrepancy between the type of information patients wish to receive about available treatment options, which, for the majority of Australian respondents, should include information about non-reimbursed options, and the type of information which is generally given to patients by physicians. Further research on patient perspectives in other countries should corroborate and elucidate these findings. In the interim, it may be important for patients – in the Netherlands and elsewhere – to know that physicians might not inform them about newly approved treatment options that are not (yet) reimbursed through health care insurers. For the medical profession, it is important to be aware of potential discrepancies between physicians' perspectives on the appropriate scope of information provision about non-reimbursed treatments, and to develop guidance on appropriate practices of information provision about non-reimbursed treatments. In contemporary medicine and medical ethics, shared decision-making is deemed important, which implies that the physician and the patient should together decide upon a treatment plan, taking into account the patient's preferences and strengthening their autonomy (Beers, Nilsen, and Johnson 2017). Being well-informed about possible treatment options is one of the three conditions – besides competency and voluntariness – for autonomous decision-making and informed consent (Beauchamp and Childress 2019). As to some patients, information about non-reimbursed treatments might be relevant, this should perhaps be included in the informed consent process, to ensure that patients are able to make autonomous decisions about their treatment plans.

Thirdly, the perspectives of Dutch oncologists and hematologists on out-of-pocket payment vary greatly. It is striking that these perspectives seem to be based on stark and opposed moral views. While some doctors emphasize the values of autonomy and liberty, and would allow their patients to pay for treatments using private funds, other doctors attach more moral importance to the values of equality and solidarity, and would not prescribe treatments which are not

reimbursed within national health insurance. Equality seems a prominent reason for Dutch doctors not to support out-of-pocket payments. Physicians use a leveling down argument; if it is not possible to reimburse a medical treatment universally for every eligible patient, then no patient should have access. Leveling down arguments are often criticized – also known as 'the leveling down objection' –, as they lead to a lowering of outcomes or opportunities for everyone (Parfit 1991). Therefore, it is noteworthy that many of our respondents seemed to rely on this argument. Besides their worries about equal access for patients to anti-cancer treatments, physicians are also concerned about the potential financial distress that out-of-pocket payments might cause for patients. This is in line with another interview study conducted among Australian oncologists, that showed that the majority of respondents had prescribed unsubsidized anti-cancer drugs in the previous months, and that the respondents were mostly worried about 'the potential financial hardship' for patients (Karikios et al. 2017). Also in the United States, more attention is being paid to 'cost discussions' in the consultation room, and the role cost considerations should (or should not) have in patient and physician decision-making about treatments plans (Carrera, Kantarjian, and Blinder 2018). Furthermore, it was notable that during the interviews physicians tried to steer clear from out-of-pocket payments and wanted to prevent this moral dilemma from occurring. Therefore, physicians often named several other ways for cost-reduction in health-care. With these cost-reductions, they hoped it would still be possible to reimburse all relevant treatments for patients in the future and the moral dilemma of out-of-pocket payments would not have to occur. However, when treatments are not reimbursed and out-of-pocket payments are not allowed, patients and physicians might pursue treatments abroad (as some of our respondents had done). This could lead to an increase in medical tourism, giving rise to other ethical issues, including individual risks for patients and issues of distributive justice. Concerns have been raised in the ethical literature that the international hospital may not always have access to patients' medical dossiers, which may adversely impact the quality of care. Also, the existence of linguistic barriers might interfere with the decision-making process. Lastly, conflicts of interests could arise as international hospitals have financial interests in accepting patients from abroad - who might not (sufficiently) benefit (Benedetti, Golshan, and Kesselheim 2018).

Fourthly, physicians depend on existing third-party policies and in-hospital guidelines when trying to

pursue access to non-reimbursed treatments. It is noteworthy that policies amongst hospitals seem to differ. For instance, while some hospitals seem to never fund non-reimbursed treatments and have explicit regulation against out-of-pocket payments, in other hospitals there is funding for non-reimbursed treatments and no existing regulation against out-of-pocket payments. As physicians are acting in the context of society and current policies when deciding to pursue access to non-reimbursed treatments, further research is needed to gain more insight into current hospital policies and moral perspectives of policy makers, hospital managers and patients on the ethical dilemmas regarding access to new anti-cancer treatments.

This study has several strengths and limitations. Due to the applicable COVID measures at the time, most of the interviews had to be carried out via ZOOM. While these online interviews had a less natural setting, it still proved possible to conduct in-depth interviews online and to generate extensive and refined data. Furthermore, we have aimed to recruit a diverse sample of respondents by purposively selecting physicians from different backgrounds. However, as this was an interview study amongst Dutch oncologists and hematologists, and the results are largely dependent on their personal moral perspectives, the results must be interpreted against the social-cultural background of the Netherlands and the physicians' professional fields. However, certain ethical dilemmas which arose during these interviews, such as when to inform patients about non-reimbursed treatments taking into account the potential harms of false hope or financial consequences, are also very relevant in other countries.

This study is the first to investigate the experiences and perspectives of Dutch oncologists and hematologists regarding anti-cancer treatments that are not (yet) reimbursed. Our results give a fine-grained insight into physician's experiences and moral views. As the number of participants which can be included in a qualitative interview study is limited, it is difficult to establish the frequency of occurrence of these dilemmas amongst physicians, the distribution of their moral perspectives and to map or monitor variability in practices of information provision. Therefore, it is recommended to conduct additional quantitative research. Furthermore, future research on patients' perspectives could provide valuable input for the development of guidance for the use of non-reimbursed treatments in line with patients' expectations and preferences. In the meantime, hospital boards and organizations should be aware of the current discrepancies

in practices amongst physicians in the Netherlands. In the absence of clear guidance, dilemmas regarding access to non-reimbursed treatments are currently arising in the consultation room of the individual physician. This is undesirable, as it places moral burdens on physicians and is not conducive to transparency about treatment options for patients. It is important for the medical profession and for policy makers to articulate whether and under what conditions physicians are expected to pursue access to non-reimbursed treatments, and whether physicians should inform patients about such treatments. Here lies a task ahead for researchers, policy makers and the medical profession to design suitable guidelines, educate physicians, and increase transparency for patients.

## Conclusion

There are stark differences between oncologists' and hematologists' experiences and perspectives regarding non-reimbursed anti-cancer treatments in the Netherlands. Firstly, some physicians are willing to pursue access to non-reimbursed treatments via alternative routes while other physicians are not. Secondly, some but not all physicians inform their patients about non-reimbursed treatments. Thirdly, while some physicians would allow patients to pay for a treatment using private funds, citing moral values such as liberty and beneficence, others are expressly against doing so, based on moral values such as equality and solidarity. It is striking that Dutch doctors have diametrically opposed and strongly felt opinions on what they ought to do when medical treatments are (not) yet reimbursed. For patients, these differences in practices and moral perspectives can lead to variability in opportunities to obtain access to new anti-cancer treatments that are not (yet) reimbursed. Health professionals, physicians and policy makers have to address these differences and explicate what is expected from physicians to minimize existing moral uncertainties for physicians as well as patients.

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The authors report no conflict of interest.

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