**Psychosocial and ethical challenges of patient–oncologist discussions around high-cost innovative cancer therapies**

**Abstract**

Increases in cancer incidence have led to the accelerated development of innovative technologies for cancer treatment. However, some of these treatments are not funded by public health systems, and their cost can be very high. The present study examined the perceptions of oncologists, patients, and family members regarding private funding for innovative treatments for cancer: public versus private financing, therapist–patient–family discourse, modes of decision making, and implications for health inequalities and policy. In-depth semi-structured interviews were conducted with 16 cancer patients, 6 family members of patients with cancer, and 16 oncologists. Four themes emerged from our data analysis: economic considerations in the treatment decision, funding options for expensive private treatments, psychosocial aspects of the discussion around treatment costs, and health policy relating to oncology and its social aspects. Our study sheds light on the complexity of recommending and using expensive innovative technologies, as reflected in the personal experiences of oncologists, patients with cancer, and the family members of cancer patients. The study raises questions about the necessity to offer all patients all treatment options, regardless of their financial burden; how to consider the social cost when recommending expensive care; and whether to address the emotional aspect of treatment, as most patients expect to focus on the clinical aspect alone. There is a need for careful consideration of the various psychosocial aspects that play a role in the complicated decision to choose unfunded cancer treatment and to be more sensitive toward cancer patients’ and their family members’ needs.

**Background**

Cancer has become the leading cause of death in the Western world [Fitzmaurice et al., 2017]. By 2020, approximately 19.3 million new cancers were diagnosed worldwide, and there were 10 million cancer-related deaths [Sung et al., 2021]. The increase in cancer incidence has accelerated the development of innovative technologies for cancer treatment, such as personalized medicine, immunotherapy, genetic testing, and more [Bashkin et al., 2021; Di Giacomo et al., 2021]. However, public health systems do not fund some of these innovative treatments, the price of which can be very high and continues to increase. In 2011, the United States approved innovative treatments for various cancers that cost more than $100,000 USD per patient for a one-year treatment, although only a few of these treatments prolonged patients’ lives [Dolgin, 2018]. Gordon et al. (2017) found that out of 31 generic drugs, around half of them had significantly increased in price, while the cost of about a quarter of these drugs increased by approximately 200% between 2006 and 2016. Just 3 drug indications (of the 23) achieved the level defined for the survival rate of patients obtaining standard care (minimum 20%) of the drugs approved by the U.S. Food and Drug Administration (FDA) between 2011 and 2017 [Ben-Aharon et al., 2018].

Under the National Health Insurance Law, Israel has a public healthcare system in which the state funds a designated set of medical treatments (basket of services) for every citizen. Each year, the national health basket committee prioritizes which new technologies should be added to the basket (Angel, Niv-Yagoda & Gamzu, 2021). According to the Patient Rights Law (1996) in Israel, physicians are required to disclose all information that a reasonable person in the patient’s position would need in order to make a rational decision regarding a proposed medical treatment (Weil, 1998).

Medical advances in cancer treatment, in terms of diagnosis, surgery, and medication, have resulted in oncology becoming a key area in the Israeli health basket. The considerations guiding the basket committee are treatment efficiency, efficiency in prevention, saving lives and preventing mortality, prolonging life, and improving patients’ quality of life. All of these considerations must take into account alternatives, experiences in Israel and around the world, costs, and short- and long-term benefits. The main complexity of the basket committee’s discussions are those relating to modern oncology, as there are many drugs that meet all of the criteria relevant to the patient and the health system, but their cost is extremely high. The basket committee is forced to respond to this by narrowing the criteria, and drugs that may have been included in the basket several years ago are not included today. While this situation is inevitable given the proliferation of drugs, increased costs, and an increase in the number of patients, the social and ethical dimensions of this situation are often neglected. Their “value”, which is not measured in cost indices per se, adds complexity to the decision-making process [Hammerman et al., 2018].

In the present study, we examined the perceptions of oncologists on the one hand and the perceptions of patients and their family members on the other when it comes to private funding for innovative cancer treatments. Aspects we explored included public versus private financing, therapist–patient–family discourse, modes of decision making, and how they are reflected in health policy and inequalities.

**Methods**

We used a qualitative method to gain in-depth insights into aspects of behavior and perceptions often missed in epidemiological research (Teti et al., 2020). The study was approved by the Ashkelon Academic College Ethics Committee (Approval # 4-2019).

Participants and procedure

In-depth semi-structured interviews were conducted with 16 cancer patients and 6 family members between February and June 2020 and with 16 oncologists between January and April 2021. Informed consent was obtained from all interviewees. The sampling method used was intentional sampling combined with snowball sampling, maintaining variability in participant characteristics and stages of the treatment procedure. All interviews were conducted by a research assistant who was a graduate student in clinical psychology, and lasted between forty minutes and one hour. It was emphasized to all interviewees that their personal details would remain confidential, that they did not have to answer all of the questions, and that they could stop the interview at any time. In addition, all interviewees approved the recording and transcript of their interview.

Research tool

Two interview guides were formulated based on the literature and input from clinical cancer experts. The oncologist interview guide was formulated based on preliminary analyses of the patient interviews. The interview guides comprised similar non-directive and open-ended questions about perceptions, concerns, emotions, and experiences with unfunded high-cost cancer therapies. The wording and order of the questions changed according to the interview dynamics, to maintain continuity and flow and encourage openness among the interviewees (see Supplementary Materials).

Data analyses

The interviews were transcribed and analyzed using a thematic analysis method with ATLAS.ti v.9 software. The analysis included both deductive themes, arising from the research topic and literature review, and inductive themes that emerged from the data (Charmaz, 2006). Patient/family members’ and oncologists’ interview transcripts were coded and analyzed separately. The content of the interviews was analyzed in several stages, according to Shkedi’s method (2003). In the first stage, a comprehensive picture of the data was gained through a literal reading of all the interviews. In the second stage, initial codes were identified by an external coder who was an expert in psychosocial oncology. The initial codes were subsequently categorized into potential subthemes and then into higher-order themes. The third stage involved an iterative analysis process, with codes, themes, and subthemes refined and discussed by the coder and the authors, to ensure the relevance and distinctiveness of the resulting themes.

**Results**

Population

Oncologists - Eight interviewees were male, and eight were female. Eight worked in two hospitals in southern Israel, seven worked in two hospitals in the center of Israel, and one worked in a hospital in the north of the country. Six were interns near the end of their internship, and ten were specialist physicians. Six were current or former members of the “Basket Committee”, which assesses the public funding of new treatments in Israel. The interviewees worked in various oncology specialties, including urinary tract, genital, breast, digestive system, skin, and lung cancers. The interviews were conducted face-to-face in the hospitals, except for two interviews that were conducted over the telephone due to COVID-19 restrictions.

Cancer patients and family members - Thirteen interviewees were female (eight patients and five family members), and nine were male (eight patients and one family member). Ages ranged from 37 to 73 years among patients and from 24 to 72 years among family members. Of the interviewees, only one patient and one relative were single. The interviewees came from a wide geographical area, from all districts of Israel. The patient were suffering with different types of cancer and were at various stages of the treatment procedure. Ten interviews were conducted face-to-face in a private area chosen by the interviewees, and twelve were conducted over the telephone due to COVID-19 restrictions.

Themes

**Table1.** Themes, subthemes, and illustrative quotes

|  |  |  |  |
| --- | --- | --- | --- |
| **Illustrative quotes** | |  |  |
| **Oncologists (n=16)** | **Patients (n=16) and Family members (n=6)** | **Subthemes** | **Themes (number of quotes)** |
| *I present the costs and the benefit and leave it up to the patients to decide if it’s something they want to invest in. Every patient has the right to know what their options are (Oncologist 7).*  *I don’t get into a discussion about treatment alternatives that are not in the basket with patients who don’t have private insurance (Oncologist 4).*  *A doctor doesn’t need to present all the alternatives, he needs to see who the patient in front of him is and understand their situation. It’s important not to give patients hope when it doesn’t really exist (Oncologist 10).*  *Once I had a patient who was a pensioner farmer living on stipends from National Insurance. [Now if] I know that there’s a very slight possibility that a certain medication that’s not in the basket could help him and I know he can’t afford it, why do I need to tell him about it? Isn’t it enough that he got this punishment from God? Do I need to punish him again [by telling him that] if he had the money to pay for the treatment maybe it could help him? (Oncologist 1).* | *All the alternatives need to be offered, because some people will be able to make the payments or raise the funds. At the end of the day we’re talking about human lives (Patient 4).*  *On one hand, the doctor gives you the hope of treatment, but on the other hand he says it’s only for people who can afford it. I think expensive, unsubsidized treatment should only be offered after all the other alternatives have failed (Relative of Interviewee 8).*  *Doctors need to consider the patient’s financial situation when they suggest a treatment. Some people don’t have the means or don’t have private insurance and have no way of financing the costs (Patient 10).* | Offering all treatment alternatives, including those that are not in the health basket | 1. The economic consideration in the decision on cancer treatment (243) |
| *The financial consideration is not our business. We are not pharma people, we don’t deal with the money. Our considerations needs to be purely data-based (Oncologist 3).*  *I’m not supposed to be concerned with costs. I don’t represent the Ministry of Finance. I represent the medical considerations. I know there are expensive drugs, and there are some drugs that don’t justify the price. But I can’t look at the economic price. It’s a consideration but it’s not the only consideration (Oncologist 14).* | *The doctor needs to choose the most effective option. The option that causes the least damage to the other systems in the body. That’s the consideration that needs to take precedence (Relative of Interviewee 5).*  *The only consideration is the health consideration. Money shouldn’t be a consideration at any stage. The patient should be given the most innovative medications, especially when their situation is irreversible (Patient 14).* | Clinical vs. cost considerations |  |
| *We can’t ignore the crazy costs. Patients can’t withstand these kinds of expenses. We need to raise awareness regarding the importance of taking out private insurance. When a patient has private insurance it’s convenient. We’re in the periphery of the country, not in the center. Very few of the patients here take out private insurance (Oncologist 3).*  *I don’t decide that a drug that costs fifty thousand shekels is too expensive. I say that the drug can provide such and such benefit according to the literature, and the patient needs to decide if that justifies the cost. Of course, when a patient says that they have private insurance it’s a lot easier. It’s easier to make the decision (Oncologist 16).* | *The doctor asked me first if I had private insurance, and only after she had made sure that I did, she said we would send the sample overseas (Patient 9).*  *Even when you have health insurance, you still need to pay for a lot of things privately. There’s medical equipment that I need to finance myself. There are things that aren’t in the public system and anyone who doesn’t have private insurance needs to pay [for these things] (Relative of Interviewee 7).* | Private health insurance | 2. The options of funding high-cost private treatments (242) |
| *There are some organizations we refer patients to. They get a few free treatments, which don’t cure them but extend their life at a good quality of life (Oncologist 2).*  *Some compassionate care programs are good. Because our patients don’t have private insurance we try to help them. They can get a new medication that’s not in the basket for free (Oncologist 6).* | *More compassionate care treatments should be made available, to give several free treatments to people who are terminal. I know these companies are for profit, it’s a shame they lose their humanity along the way (Patient 13).* | Compassionate care |  |
| *Treating cancer patients involves much more than the doctor or the medication, and I think this is under-budgeted and there’s not enough awareness [regarding this issue]. It’s so much more about the supporting care and the right attention from all around and the mental, emotional, and physical support from the family. Beyond the sixty thousand shekels or dollars a month for the medication, the strong network of support is extremely important. The fact that they cancelled the medical clown that used to come here because it was a financial burden on the hospital is ridiculous. It’s just as important (Oncologist 13).* | *These aren’t the type of people who sit with you and talk with you about feelings. They don’t have time for it, they don’t have the headspace for it. They specialize in the illness itself and not its external ramifications (Patient 16).*  *They need to pay attention to the emotional and mental needs. They don’t place any emphasis on this at all. They only talk about the technical details, if it’s the doctors, the nurses, anyone that’s around. Outpatient care, inpatient care, the attitude is purely technical (Patient 2).*  *A doctor, first and foremost, needs to be a psychologist. He needs to see who’s sitting in front of him. He needs to be sensitive. He can’t be cold and dry (Interviewee 20).* | The emotional aspect | 3. Treatment costs discussion (317) |
| *The right things to do is to discuss the medication with the patient and describe the clinical and financial implications. But I think that as part of our professional integrity, the right thing to do at the end of the discussion, is to give a recommendation—should they or shouldn’t they do it (Oncologist 10).*  *According to the Patients’ Rights Law, the patient should get all the information from the doctor and make a decision. That’s a tough position for the patient to be in. I can barely make the decision so how can he make it? It doesn’t benefit the patient to put them in that situation (Oncologist 12).*  *On one hand, I try to present all the options. On the other hand, I try to steer them towards the decision that would benefit them more. I feel obligated to give them a clear recommendation (Oncologist 14).* | *If the treatment is very expensive, there might not be a choice and the decision will have to be made together. The patient needs to decide if they can withstand the costs or not. But generally, the decision about the treatment needs to be made by the doctor (Patient 14).*  *In the beginning, when the patient doesn’t really know a lot of details about the illness, the doctor should make the decision. But in the more advanced stages, when the patient has a better understanding of things, he can participate in the decision-making, especially when he is made aware of the side-effects and the odds (Patient 4).*  *I learned to put things on the table, and I learned that the doctor is not God. I hear the doctor’s answers and if they don’t sit right with me I ask more questions, and if that doesn’t sit right with me I go to others and consult with them, too (Patient 20).* | The treatment decision |  |
| *There’s inequality not only in regards to innovative treatments, but regarding all aspects of the surrounding systems: supportive care, nursing assistance, complementary care and more (Oncologist 11).*  *People who have the means get to a doctor sooner. They’ll get their imaging done faster, as well as the results of their more advanced molecular screening. There’s inequality in residential areas and the availability of medical services between those living in the periphery of the country and those living in the center (Oncologist 13).* | *Some patients raise funds. How can it be that the state just ignores this? Patients will do anything to save their lives, but why do they need to ask the public to pay for their medication? (Patient 16).*  *The financial issue is very important. People lose their jobs and a lot of financial resources. Financial support is very important in dealing with the disease. What’s called for is an integrative view that takes the financial, emotional, and spiritual aspects into account (Interviewee 17).* | Inequality | 4. Health policy and social aspects in Oncology (343) |
| *For the vast majority of my patients, who live in areas of lower socio-economic status compared to the center of the country, I prefer to use the drugs that are already in the basket, and I don’t offer what’s not in it, especially to those who have no way of financing the treatment (Oncologist 4).*  *In the State of Israel, the problem is not the basket. Our basket is actually relatively good. But as a society we are the country who invests the lowest percent of its national budget in healthcare (Oncologist 14).* | *More medications need to be added to the basket. Every drug that’s been proven to be effective, that helps patients, that extends life or saves lives, needs to be in the basket. I, as a patient, shouldn’t have to carry the burden of proof myself (Patient 16).* | Health basket considerations |  |
| *We need to invest in the entire healthcare system. You can’t just deal with cancer treatment. These patients need hospitalizations, medical teams, advanced equipment. The basket can be expanded, but we need good infrastructures (Oncologist 4).*  *The state doesn’t invest enough in cancer treatment, early detection, and follow-up in the community. If there were more budgets for doctors and imaging tests, the entire treatment of cancer patients would be better. There would be more availability, both in the center and the periphery of the country. When we have to discharge patients to continue follow-up with their GPs, who aren’t skilled enough in the field, only because we don’t have enough doctors—to me that’s a bad distribution [of resources] (Oncologist 13).* | *I think the state should finance all the treatments. That’s why we have national health insurance (Relative 7).*  *There’re a lot of bureaucracy in the healthcare system. It’s not efficient. You need to make a huge fuss to get approvals, and this makes things difficult for the patient and their family. I understand that it costs them money, but we are citizens with rights, and we don’t always know what our rights are (Relative of Interviewee 5).* | The need for policy changes |  |

1. Economic considerations in decisions around cancer treatment

All patients thought that doctors should offer all treatment alternatives. Among the oncologists, there was no consensus on this issue, despite the obligation imposed on them by the Patient Rights Law. The law was established in an attempt to avoid this ethical dilemma, but doctors still experience this dilemma during medical encounters. Physicians have a moral obligation to patients, so most have argued that it is not their role to consider financial costs but to only act according to clinical considerations. However, most of them noted the discomfort they feel when presenting expensive treatments to patients who have no financial ability to pay for them. In practice, doctors gently learn a patient’s financial status and whether they have private insurance and then consider the financial cost when recommending treatment. Similarly, family members tended to consider that clinical efficacy is the most important factor, but expensive treatment should be offered after all other options in the basket have been exhausted.

1. Options for funding expensive private treatments

The existence of private health insurance makes it easier for doctors to discuss all treatment alternatives with a patient, although private health insurance can result in unnecessary testing. Both physicians and patients criticized the way public funding was managed. Patients are often required to navigate cumbersome bureaucracy and are not fully aware of their rights. Most doctors are involved in helping patients who are out of reach. This may include admitting patients to research studies, contacting HMOs themselves to ask for funding, referring patients to charities, or contacting pharmaceutical companies to request compassionate care.

1. Treatment cost discussions

The medical encounters usually include the patient–oncologist–family member triangle. While patients and family members seek compassion and responses to emotional aspects, physicians focus on the technical\clinical aspect of the disease. Few oncologists mentioned the emotional side, but as the role of the social worker. Physicians stressed the importance of providing accurate medical information to patients regarding the efficacy of the drugs and their side effects. Regarding decision making, physicians noted that their patients often find it difficult to make their own decision and that the physician’s role is to help the patient make the best decision possible. Patients and family members stressed the need to obtain information about the treatment offered and its implications. However, they also noted that they were often provided with information in a superficial or incomprehensible manner and had experienced difficulty in searching for information online. Some family members said they took an active part in the decision-making process, especially regarding the self-financing of expensive treatments. Others said they preferred to be passive in the decision-making process and acted supportively toward their sick relative so they did not have a guilty conscience if something happened.

1. Health policy and social aspects of oncology

In Israel, as in many countries, there are inequalities in health among population subgroups in terms of health measures, morbidity, mortality, and life expectancy. Differences in these indicators and in the accessibility and availability of health services, as well as in the medical workforce, also exist between the center of the country and the southern and northern peripheries, with services being poorer in the periphery and health indicators being worse (Shadmi, 2018). The same is true for cancer. Residents in the peripheries of the country are sicker, have less access to services, and fewer oncologists relative to the population. These are poorer populations that often lack private insurance; in fact, those who need the most assistance receive least help. The health basket in Israel, which is updated each year, is considered relatively good for the field of oncology, compared with other Western countries. Still, before the innovative technologies reach the basket, the gap between approving new technologies and adding them to the basket often takes a long time and forces patients who are unable to pay for it to seek funding.

**Discussion**

This study has shed light on the clinical, economic, social, and ethical complexity of funding innovative cancer treatments in a public healthcare system, such as the healthcare system in Israel. The expenditure on cancer drugs out of total spending on drugs in Israel has increased by 24% in the last decade, due to an increase in the granting of approvals for biological and other innovative drugs [Lomnicky et al., 2016]. With the increase in the number of patients and the rapid developments in treatments and technologies, the need to rethink the financing policy and the management of the dialogue between oncologist and patient regarding the use of innovative technologies is evident. The first step in this process is to understand the perceptions of oncologists and patients, based on their own experiences. Patients express a strong desire for information and discussion regarding medical care costs, but studies show that, in practice, less than 20% of patients talk to their oncologist about this [Kaser et al., 2010; Irwin et al., 2014]. Similarly, Meisenberg et al. [2015] noted that 71% of patients with cancer rarely consult with oncologists about treatment costs. At the same time, most of them do not want the individual or social costs of treatment to influence the treatment decision. Moreover, when patients were told to assume that high-cost and low-cost treatments had similar clinical efficacies, only 28% responded that they would prefer lower-cost treatment. They argued that the treatments in the health basket should be exhausted first (regardless of their cost to the health system) and only after these have failed should attempts continue with privately funded treatments.

In a study that examined oncologists’ perceptions of the discussion of treatment costs [Altomare et al., 2014], more than 90% of oncologists indicated that they always offer patients all treatment options regardless of charge, and about half claimed they had never made a cost-based prioritization. In addition, most oncologists agree that it is their responsibility to consider the individual and social costs of innovative cancer treatments when deciding on the appropriate treatment. However, more than 70% of oncologists indicated that they do not have the proper resources, knowledge, or skills to discuss care costs with their patients. Many physicians do not know how to interpret and make correct use of research data and cost-benefit analyses of innovative drugs. Therefore, they do not feel ready to discuss these matters with their patients [Neumann et al., 2010].

Most oncologists interviewed in this study said they offered patients all treatment options and were aware of the costs of innovative technologies. They noted that while clinical considerations were the guiding principle in their treatment decisions, they certainly “pushed” patients to use the drugs that are in the basket, especially when they do not have private insurance.

The findings of our study reveal the perceptions of oncologists, patients, and family members regarding the use of innovative technologies for cancer treatment and are consistent with those of studies conducted in recent years that show the impact of increasing cancer treatment rates on patients’ economic and mental well-being, access to health services, and inequality in health care [Zafar et al., 2013; Pfister, 2013]. Cancer is often a terminal illness, and patients and family members will frequently agree to pay exorbitant costs for innovative treatments even if their clinical efficacy is not always apparent. Social and ethical challenges arise when patients with private insurance, those who are wealthier, or those who live in the center of the country (these three parameters are often correlated) can privately fund innovative therapies, beyond the inherent inequality in resource allocation and care infrastructure in the periphery. Both physicians and patients have raised these issues, which require a perceptual change by decision-makers regarding resource allocation and affirmative action in favor of residents in the peripheries of the country. The application of methodologies for comparing drugs in terms of their efficacy and side effects, as well as in terms of their psychosocial impacts and costs to the patient and the health system, may be helpful in decision-making on this subject, in addition to cost–benefit analysis models for innovative technologies, tests, and treatments for cancer [Smith & Hillner, 2011; Mason et al., 2010; Brammli-Greenberg et al., 2020].

Limitations

This study had some limitations. Interviews were conducted only in Israel, which has a public healthcare system. In countries with a different type of healthcare system, perceptions may differ. In addition, the sample was relatively small. However, we did manage to maintain a mix of interviewees of different ages and from various geographical areas within Israel.

**Conclusions**

This study sheds light on the complexity of recommending and using innovative privately funded cancer technologies in Israel, as reflected in the personal experiences of oncologists, cancer patients, and family members. The study raises questions about the ethics of offering patients all treatment options, even if it is clear that they will not be able to fund them, especially in peripheral areas of the country. These questions include: 1) Is it the oncologist’s role to discuss treatment costs or to consider only the clinical efficacy of medications?; 2) Should the oncologist consider the social price when recommending expensive care (even if it is in the basket)?; and 3) Should the oncologist address the emotional aspect of treatment, as most patients expect them to focus only on the clinical aspect? This study is not critical of oncologists, who perform their job in good faith and try their best to help their patients. There is, however, a need to change policy and allocate additional resources to oncology for research, development, and prevention. The field of oncology should be declared a field of distress, and plans should be made to encourage medical students to specialize in oncology, with an emphasis on the geographical peripheries of the country and ways to reduce health disparities.