

# BMJ Open Patients' and oncologists' perceptions towards the discussion on high-cost innovative cancer therapies: findings from a qualitative study

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## ABSTRACT

**Objectives** In the last decades, innovative technologies for cancer treatment were developed rapidly. In most cases, their price is high, with no funding offered by public health systems. The present study examined the perceptions of oncologists, patients and family members regarding the challenges in discussing innovative cancer treatments.

**Design** Qualitative study, using in-depth semistructured interviews. Interviews examined public versus private financing, therapist–patient–family discourse, modes of decision making and implications on health policy and inequalities.

**Participants** Sixteen cancer patients, six family members of cancer patients and 16 oncologists participated in the study.

**Results** Four themes emerged from data analysis: the economic consideration in the decision on cancer treatment, the options of funding high-cost private treatments, psychosocial aspects of the discussion on treatment costs and health policy in oncology and its social aspects.

**Conclusions** Findings emphasise the importance of considering costs when recommending expensive care and addressing the emotional element of innovative treatment, as most patients expect. The findings present various psychosocial aspects taking part in the complicated decision to use unfunded cancer treatment and its broad implications, which may use as a basis for developing a guided framework for oncologist–patient discourse.

## INTRODUCTION

The rising burden of cancer, as a leading cause of death in the western world, has accelerated new developments of cancer treatments, such as personalised medicine, immunotherapy and more.<sup>1–3</sup> High-cost therapies used to treat cancer are a challenge to national budgets, even in wealthy countries.<sup>4</sup> Therefore, public health systems do not fund most of these treatments, the price of which can be very high and continues to increase.<sup>5–7</sup> In 2011, the USA approved innovative treatments for various cancers that cost more than US\$100 000 per

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Data from the current study include in-depth interviews with qualitative tools; therefore, findings cannot be validated by calculating effect size or quantitative statistical analyses.
- ⇒ As common in qualitative studies, relatively small groups of participants were interviewed in the current study, therefore having less statistical power than quantitative studies.
- ⇒ A qualitative method enables in-depth insights into behaviour and perceptions often missed in quantitative epidemiological studies.
- ⇒ The qualitative framework used in the current study enabled flexibility in capturing meaningful data painted a richer, more holistic portrait of the participants' perceptions of the complexity of innovative cancer treatments.

patient for a 1-year treatment, although only a few of these treatments prolonged patients' lives.<sup>5</sup> Gordon *et al*<sup>6</sup> found that around half of 31 generic drugs had significantly increased in price, while the cost of about a quarter of these drugs increased by approximately 200% between 2006 and 2016. Between 2011 and 2017, just three drug indications achieved the level defined for the survival rate of patients obtaining standard care of the drugs approved by the US Food and Drug Administration.<sup>7</sup> In Canada, medical oncologists struggle to give the best possible care to their patients due to differences in access to preferred treatments. In face of these challenges, physicians use clinical trials and private infusion clinics and, at times, may avoid considering drugs with limited access. Many of them are frustrated with the existing funding and approval processes and encourage private payment for unfunded drugs.<sup>8</sup> In a qualitative study conducted in the UK, 31 patients and 21 healthcare professionals were interviewed about their experiences of implicit and explicit drug rationing. The researchers

found that almost all patients wanted to be informed about rationing decisions and regarded implicit rationing as paternalistic. Healthcare professionals revealed that, though they were committed to being open with patients, in practice, due to feeling discomfort at discussing the effect of financial limitations on care, they frequently rationed implicitly.<sup>9</sup>

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 prioritises which new technologies should be added to the basket. According to the Israeli Patient Rights Law, physicians must disclose all information that the patient would need to make a rational decision regarding a proposed medical treatment.<sup>10</sup>

Medical advances in cancer treatment 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, preventing mortality, prolonging life and improving patients' quality of life. The main complexity of the basket committee's discussions is those relating to innovative treatments, as many drugs meet all the criteria relevant to the patient and the health system, but their cost is exceptionally high<sup>11</sup> and their social aspects are often neglected. In addition to public insurance provided to Israeli citizens by the national health plans, citizens are offered supplementary coverage (mainly do not include life-prolonging treatments). Furthermore, commercial insurance companies offer various insurance options and health services tailored to individuals, including pharmaceuticals. The voluntary health insurance market share in Israel covers 84% of the population.<sup>12</sup>

In the present study, we examined the perceptions of oncologists and the perceptions of patients and family members when it comes to 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 behaviour and perceptions often missed in epidemiological research.

### Participants and procedure

In-depth semistructured interviews were conducted with 16 patients with cancer and six family members of patients with cancer between February and June 2020 and with 16 oncologists between January and April 2021. Written 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. In intentional sampling methods,

the researchers select a group of individuals for a sample with the purpose of meeting specific prescribed criteria. The interviewees were selected to obtain optimal variety and serve as potential rich information sources to serve the study objectives. The criteria among the patients were: patients with cancer, men and women, from different regions of Israel, without private health insurance. Among family members, it was important that the patient be close and cared for by the interviewee. Among the physicians, we targeted oncology specialists, men and women, working in hospitals in different regions. The doctors were asked if they had any recommendations for additional interviewees. Physicians recommended six of their colleagues, who also agreed to be interviewed. We received recommendations from patients about four more patients who agreed to be interviewed. All interviews were conducted over the telephone (due to COVID-19 restrictions) by a research assistant, a graduate student in clinical psychology, and lasted between 40 min and 1 hour. It was emphasised to all interviewees that their details would remain confidential, that they did not have to answer all the questions and that they could stop the interview at any time. In addition, all interviewees approved the recording and transcript of their interview.

### Patient and public involvement

Participants were not involved in setting the research question or the outcome measures, but they were central to obtaining the data as interviewees who shared their valuable perceptions.

### Research tool

Two interview guides were formulated based on the literature<sup>6 7 11 12</sup> and input from clinical cancer experts. 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 online supplemental material).

### Data analyses

The interviews were transcribed and analysed using a thematic analysis method with ATLAS.ti V.9 software. The analysis included deductive themes arising from the research topic and literature review, describing health policy and social aspects in oncology, including inequality, the 'health basket' considerations, the need for policy changes and inductive themes that emerged from the data,<sup>13</sup> describing the economic considerations in decisions on cancer treatment, the options for funding expensive treatments and the psychosocial aspects of the discussion on treatment costs. In the first stage, a comprehensive picture of the data was gained through a literal reading of all the interviews by the researchers. In the second stage, initial codes were identified by an external coder, an expert in psychosocial oncology. Subsequently,

the initial codes were categorised 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. In the last stage of the analysis, we compared the perceptions of the two groups of participants: cancer patients and family members (merged into one group of interviewees) and oncologists.

## 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 centre of Israel and one of them worked in a hospital in the country's north. The interviewees worked in various oncology specialties. Six were

current or former members of the 'Basket Committee', which assesses the public funding of new treatments in Israel.

#### Patients with cancer and family members of patients with cancer

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 24–72 years among family members. The interviewees came from a wide geographical area, from all districts of Israel. The patients were suffering from different types of cancer and were at various stages of the treatment procedure.

Four main themes emerged from the literature review and data analysis: (1) the economic consideration in the decision on cancer treatment, (2) the options of funding high-cost treatments, (3) psychosocial aspects of the discussion on treatment costs and (4) health policy in oncology and its social aspects.

**Table 1** The economic consideration in the decision on cancer treatment

Theme (number of quotes)	Subthemes	Illustrative quotes	
		Patients (n=16) and family members (n=6)	Oncologists (n=16)
1. Economic considerations in decisions on cancer treatment (243)	Offering all treatment alternatives, including those that are not in the health basket.	<p>'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).</p> <p>'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).</p> <p>'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).</p>	<p>'I present the costs and benefits and leave it up to the patients to decide if they want to invest. Every patient has the right to know what their options are' (oncologist 7).</p> <p>'I don't discuss treatment alternatives that are not in the basket with patients who don't have private insurance' (oncologist 4).</p> <p>'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 exist' (oncologist 10).</p> <p>'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?' (oncologist 1).</p>
	Clinical versus cost considerations	<p>'The doctor needs to choose the most effective option. The option that causes minor damage to the other systems in the body. That's the consideration that needs to take precedence' (relative of interviewee 5).</p> <p>'The only consideration is the health consideration. Money shouldn't be a consideration at any stage. Patients should be given the most innovative medications, especially when their situation is irreversible' (patient 14).</p>	<p>'I'm not supposed to be concerned with costs. I describe 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 economical price. It's a consideration, but it's not the only consideration' (oncologist 14).</p> <p>'The financial consideration is not our business. We are not pharma people, we don't deal with the money. Our considerations need to be purely data-based' (oncologist 3).</p>

**Table 2** The options of funding high-cost treatments

Theme (number of quotes)	Subthemes	Illustrative quotes	
		Patients (n=16) and family members (n=6)	Oncologists (n=16)
2. Options for funding expensive treatments (242)	Private health insurance	‘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).	‘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 personal insurance’ (oncologist 3).
	Compassionate care	‘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).	‘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).

Table 1 presents the first theme, ‘The economic consideration in the decision on cancer treatment’ and subthemes that emerged from the data with the number of codes included and illustrative quotes.

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 to avoid this ethical dilemma, but doctors still experience this dilemma during medical encounters. Oncologists 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 think that clinical efficacy is the most crucial factor, but expensive treatment should be offered after exhausting all other options in the basket.

Table 2 presents the second theme, ‘The options of funding high-cost treatments’, and subthemes that emerged from the data with the number of codes included and illustrative quotes.

Both physicians and patients criticised 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 for whom treatment costs are out of their reach. This may include admitting patients to research studies, contacting Health Maintenance Organization (HMOs) themselves to ask for funding, referring patients to charities or

contacting pharmaceutical companies to request compassionate care.

Table 3 presents the third theme, ‘Psychosocial aspects of the discussion on treatment costs’, and subthemes that emerged from the data with the number of codes included and illustrative quotes.

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 aspects of the disease. Few oncologists mentioned the emotional side but noted it as the social worker’s role. 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 challenging 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 superficially or incomprehensibly 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 towards their sick relative, so they did not have a guilty conscience if something happened.

Table 4 presents the fourth theme, ‘Health policy in oncology and its social aspects’, and subthemes that emerged from the data with the number of codes included and illustrative quotes.

**Table 3** Psychosocial aspects of the discussion on treatment costs

Theme (number of quotes)	Subthemes	Illustrative quotes	
		Patients (n=16) and family members (n=6)	Oncologists (n=16)
3. Treatment cost discussion (317)	Emotional aspect	‘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). ‘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).	‘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 supportive care and the proper attention from all around and the mental, emotional, and physical support from the family. A strong support network is essential’ (oncologist 13).
	Treatment decision	‘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 know many details about the illness, the doctor should decide. 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 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). ‘On the 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). ‘According to the Patients’ Rights Law, the patient should get all the information from the doctor and make a decision. That’s a challenging 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).

Patients, as well as oncologists, emphasised the influence of the costs of innovative cancer treatments and examinations on inequalities. The results presented in this theme are in line with previous data showing that residents in the country’s peripheries are sicker, have less access to services and have fewer oncologists relative to the population.<sup>14</sup> These poorer populations often lack private insurance, which causes those who need the most assistance to receive insufficient help. Both patients and oncologists pointed to the need to reconsider the current policy related to cancer in its wider aspects, including prevention, early detection, tests, treatment and support, with emphasis on low socioeconomic populations.

## DISCUSSION AND CONCLUSIONS

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. Lomnický *et al*<sup>15</sup> compared drug expenditure trends for 10 major drug classes over 16 years at Maccabi Healthcare Services, the second largest healthcare organisation in Israel. They found that expenditures for cardiovascular drugs, for instance, decreased

during 1998–2014, while the annual increase in net drug costs per HMO member during 1998–2014 was largest for cancer drugs. In addition, they noted that the overall distribution of drug expenditure among drug classes differed significantly between 1998 and 2014 ( $p < 0.001$ ), mainly due to the increase in expenditure for cancer drugs, from 6.8% of total drug cost to 30.3%. With the increase in the number of patients with cancer and the rapid developments in treatments and technologies, the need to rethink the financing policy and the management of the dialogue between oncologists and patients 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.<sup>16 17</sup>

Similarly, Meisenberg *et al*<sup>18</sup> 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<sup>19</sup> (ie, indirect costs of lost opportunities to achieve greater social benefits from

**Table 4** Health policy in oncology and its social aspects

Theme (number of quotes)	Subthemes	Illustrative quotes	
		Patients (n=16) and family members (n=6)	Oncologists (n=16)
4. Health policy and social aspects in oncology (343)	Inequality	<p>‘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).</p> <p>‘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).</p>	<p>‘There’s inequality not only in regard to innovative treatments but regarding all aspects of the surrounding systems: supportive care, nursing assistance, complementary care, and more’ (oncologist 11).</p> <p>‘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 country’s periphery and those living in the center’ (oncologist 13).</p>
	Health basket considerations	<p>‘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).</p>	<p>‘For most 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).</p> <p>‘In the State of Israel, the problem is not the basket. But as a society we are the country who invests the lowest percent of its national budget in healthcare’ (oncologist 14).</p>
	The need for policy changes	<p>‘I think the state should finance all the treatments. That’s why we have national health insurance’ (relative 7).</p> <p>‘There’s a lot of bureaucracy in the healthcare system. It’s not efficient. You need to make a huge fuss to get approvals, which 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 our rights’ (relative of interviewee 5).</p>	<p>‘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).</p> <p>‘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’ (oncologist 13).</p>

the public health basket) 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. In the current study, patients and family members were divided. Some of them argued that the treatments in the health basket should be offered first, and only after these have failed should they attempt to continue with privately funded treatments. In contrast, the others thought that all existing treatments should be offered, regardless of the health basket.

In a study that examined oncologists’ perceptions of the discussion of treatment costs,<sup>20</sup> 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 prioritisation. 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.<sup>21</sup>

Most oncologists who were interviewed in this study said they offered patients all treatment options and were aware of the costs of innovative technologies. It seems that 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. Oncologists 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 are consistent with those of studies conducted in recent years that show the impact of increasing cancer treatment costs on patients’ economic and mental well-being, access to health services and inequality in healthcare.<sup>22</sup> In a qualitative study conducted among 12 Norwegian oncologists, they expressed worries about inequity between patients that can afford private treatment and those who cannot.<sup>23</sup> 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 the accessibility and availability of health services and the medical workforce also exist between the centre of the country and the southern and northern peripheries, with services being poorer in the periphery and health indicators being worse.<sup>14</sup> The health basket in Israel, updated each year, is considered relatively good for oncology compared with other fields of medicine in Israel. However, many innovative technologies are awaiting addition to the basket. Approving new technologies and adding them to the basket often takes a long time and forces patients who cannot pay for them to seek funding opportunities. 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. The fact that some patients with private insurance, those who are wealthier or those who live in the centre of the country (these three parameters are often correlated) can privately fund innovative therapies contributes to inequality beyond the inherent inequality in resource allocation and care infrastructure existed among low socioeconomic groups. Both physicians and patients have raised these issues, which require a change by decision makers regarding resource allocation and affirmative action in favour of low socioeconomic residents in the country’s peripheries. 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 for decision making, in addition to cost–benefit analysis models for innovative technologies, tests and treatments for cancer.<sup>11 24 25</sup>

This study sheds light on the complexity of innovative cancer treatments and raises questions about the ethics of offering patients all treatment options, even if it is clear they will not be able to fund them, especially in peripheral areas of the country. The qualitative examination through in-depth interviews was valuable for presenting a comprehensive and in-depth picture of patients’ and oncologists’ perceptions of the important and complicated discussion on high-cost innovative cancer treatments and provided insight into concerns and thoughts often missed in epidemiological research.

This study had some limitations to be considered. Interviews were conducted only in Israel, which has a public healthcare system. In countries with different types of healthcare systems, perceptions may differ. Therefore, the findings may not be generalised to other countries with their distinct health delivery systems. Second, 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. Third, interviews were conducted over the phone and not face to face, which may affect the nature of the interview and limited the ability to share perceptions and feelings of some of the interviewees. Lastly, patients with cancer and family members were considered as one group of participants, although we acknowledge that the perceptions of patients with cancer and family members may differ as their interests are not necessarily identical. Family members’ concerns about the financial burden should be examined as a unique area of future study.

## CONCLUSIONS

The findings show the need for careful consideration of various psychosocial and ethical aspects taking part in the complicated decision to use unfunded cancer treatment and emphasise the patients’ and family members’ needs.

The current study findings can use as a basis for an open discussion of the issues that were raised, in focus groups that include physicians, patients and counselling specialists. This open discussion becomes even more pronounced when it is apparent that most oncologists do recommend unfunded treatments to their patients. Therefore, it is necessary to help and support oncologists conducting comprehensive and in-depth discussions with patients regarding all aspects of cancer treatment and making a joint decision with patients regarding the optimal treatment. Finally, it is crucial to develop an evidence-based framework for oncologist–patient discourse, which will focus on the psychosocial aspect of the physician–patient relationship, communication styles, inclusivity and empathy between the parties.

Some questions still remain unsolved: why do some patients and family members do not accept the social contract that underlies the use of the health basket? Do physicians think the law requiring full disclosure of all treatments is unfeasible in the reality of the clinic?

Further research can try to answer these important questions related to the issues discussed.

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## REFERENCES

- 1 Fitzmaurice C, Akinyemiju TF, et al. Global Burden of Disease Cancer Collaboration. Global, regional, and National cancer incidence, mortality, years of life lost, years lived with disability, and disability-adjusted life-years for 29 cancer groups, 1990 to 2016: a systematic analysis for the global burden of disease study. *JAMA Oncol* 2018;4:1553–8.
- 2 Sung H, Ferlay J, Siegel RL, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA A Cancer J Clin* 2021;71:209–49.
- 3 Bashkin O, Dopelt K, Asna N, et al. Recommending Unfunded innovative cancer therapies: ethical vs. clinical perspectives among oncologists on a public healthcare System-A mixed-methods study. *Curr Oncol* 2021;28:2902–13.
- 4 Vogler S, Vitry A, Babar Z-U-D. Cancer drugs in 16 European countries, Australia, and New Zealand: a cross-country price comparison study. *Lancet Oncol* 2016;17:39–47.
- 5 Dolgin E. Bringing down the cost of cancer treatment. *Nature* 2018;555:S26–9.
- 6 Gordon N, Ben-Aharon O, Stemmer SM, et al. Price trajectories assessment for Medicare Part B generic anti-cancer drugs. *JCO* 2017;35:6624.
- 7 Ben-Aharon O, Magnezi R, Leshno M, et al. Association of immunotherapy with durable survival as defined by value frameworks for cancer care. *JAMA Oncol* 2018;4:326–32.
- 8 Chan KK, Wong B, Siu LL, et al. Less than ideal: how oncologists practice with limited drug access. *J Oncol Pract* 2012;8:190–5.
- 9 Owen-Smith A, Coast J, Donovan J. The desirability of being open about health care rationing decisions: findings from a qualitative study of patients and clinical professionals. *J Health Serv Res Policy* 2010;15:14–20.
- 10 Weil Z. Informed consent to medical treatment—the Israeli experience. *Med Law* 1998;17:243–61.
- 11 Hammerman A, Greenberg-Dotan S, Feldhamer I, et al. The ESMO-Magnitude of clinical benefit scale for novel oncology drugs: correspondence with three years of reimbursement decisions in Israel. *Expert Rev Pharmacoecon Outcomes Res* 2018;18:119–22.
- 12 Greenberg SB, Dotan E, Arazi R. The insurability of innovative pharmaceutical cancer technologies. *Isr J Health Policy Res* 2020;9:69.
- 13 Charmaz K. *Constructing grounded theory: a practical guide through qualitative analysis*. Thousand Oaks, CA: Sage, 2006.
- 14 Shadmi E. Healthcare disparities amongst vulnerable populations of Arabs and Jews in Israel. *Isr J Health Policy Res* 2018;7:26.
- 15 Lomnický Y, Kurnik D, Loebstein R, et al. Trends in annual drug expenditure – a 16 year perspective of a public healthcare maintenance organization. *Isr J Health Policy Res* 2016;5:37.
- 16 Irwin B, Kimmick G, Altomare I, et al. Patient experience and attitudes toward addressing the cost of breast cancer care. *Oncologist* 2014;19:1135–40.
- 17 Kaser E, Shaw J, Marven M, et al. Communication about high-cost drugs in oncology—the patient view. *Ann Oncol* 2010;21:1910–4.
- 18 Meisenberg BR, Varner A, Ellis E, et al. Patient attitudes regarding the cost of illness in cancer care. *Oncologist* 2015;20:1199–204.
- 19 Holecki T, Węgrzyn M, Frączkiewicz-Wronka A, et al. Oncological diseases and social costs considerations on undertaken health policy interventions. *Int J Environ Res Public Health* 2020;17:2837.
- 20 Altomare I, Irwin B, Zafar SY, et al. Recap: physician experience and attitudes toward addressing the cost of cancer care. *J Oncol Pract* 2016;12:247–8.
- 21 Neumann PJ, Palmer JA, Nadler E, et al. Cancer therapy costs influence treatment: a national survey of oncologists. *Health Aff* 2010;29:196–202.
- 22 Pfister DG. The just price of cancer drugs and the growing cost of cancer care: oncologists need to be part of the solution. *J Clin Oncol* 2013;31:3487–9.
- 23 Feiring E, Wang H. Rationing cancer treatment: a qualitative study of perceptions of legitimate limit-setting. *BMC Health Serv Res* 2018;18:342.
- 24 Smith TJ, Hillner BE. Bending the cost curve in cancer care. *N Engl J Med Overseas Ed* 2011;364:2060–5.
- 25 Mason A, Drummond M, Ramsey S, et al. Comparison of anticancer drug coverage decisions in the United States and United Kingdom: does the evidence support the rhetoric? *J Clin Oncol* 2010;28:3234–8.