Oncologic Patients' Misconceptions May Impede Enrollment Into Clinical Trials

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Abstract

Background Clinical trials are an essential source for advances in oncologic care, yet the enrollment rate is only 2-4%. Patients' reluctance to participate is an important barrier. This study evaluates patients' level of understanding and attitudes towards clinical trials.

Methods Two-hundred patients receiving active anti-neoplastic therapy at a large tertiary hospital completed an anonymous questionnaire comprised of demographic information, past experience in clinical research and basic knowledge on clinical trials.

Results The majority of respondents did not meet the minimum knowledge level criteria. The concerns of those who replied that they would decline to participate in a clinical trial were related to assignment to the placebo arm, provision of informed consent and trust issues with their oncologist. Those with adequate knowledge were significantly more interested in participating in. Patients with past experience in clinical trials had a higher level of academic education, were less religious, had a better understanding of medical research and were inclined to participate in future research.

Conclusions Misperceptions of clinical trials may contribute substantially to the unwillingness to participate in them.

Trial registration The study was approved by the Tel Aviv Sourasky Medical Center ethics committee (0565-14-TLV January 7th, 2015) and it was conducted in full accordance with the guidelines for Good Clinical Practice and the Declaration of Helsinki. Agreement to respond to the questionnaire was taken as formal consent to participate in this study.

Background

Clinical trials are the cornerstone of advances in clinical oncology and essential for the evaluation of novel therapies and treatment strategies. The success of clinical trials depends upon adequate patient recruitment, but it has been reported as being as low as 2-4% of all oncologic patients [1]. Unger and colleagues analyzed data from 1,262 patients and found that only 12%-17% of eligible patients eventually participated in clinical studies [2]. It is estimated that about 60% of the currently >10,000 recruiting oncologic clinical trials would enroll less than 5 participants at each site, and more than 20% would enroll none. As a result, only one in 5 recruiting clinical trials would eventually be achievable [3].

This extremely low rate of willingness to participate may be attributed to several factors. The major reasons are the limited availability of appropriate trials and the highly specific eligibility requirements [4], together accounting for the preclusion of up to 75% of the oncologic population from participation [5]. Other barriers are attributable to the reservations of the treating oncologist, such as ethical dilemmas, insecurity regarding patient recruitment for early phase research, ageism and others [6-8]. Finally, as many as 15% of the oncologic population refuses outright to participate [5].

Patient refusal may be due to practical considerations, such as time commitment or transportation requirements. Certain socioeconomic and demographic characteristics are also linked with the likelihood of consent [9-11]. Specifically, patients with lower income, low education level, as well as the senior population (over 75 years) are less likely to agree to participate in a clinical trial [12,13]. Cultural differences are also reported as an important barrier to participation, mainly due to distrust of the medical community [13]. Other significant barriers are patient misconceptions and poor understanding of the rationale behind clinical trials [14]. Key areas of conflict involve concerns regarding the informed consent process [15–17], the unease with the randomization process and the fear of being assigned to the placebo arm [4], the sense of losing control and of being "a guinea pig" [18], concerns regarding potential adverse events and their possible impact on quality of life [12], and interestingly, trust issues with the treating oncologist [19].

The limited understanding of the clinical trial process itself, however, is the most definitive reason for noncompliance and it is mainly due to lack of knowledge and sparse information given by the caring physician, according to Center for Information and Study on Clinical Research Participation (CISCRP) [20]. Many studies suggested that the lack of available information that is presented in a clear manner to the potential participants as well as to their treating physicians poses a significant barrier to the success of a recruitment process [21–24].

Educational patient- and physician-centered programs were demonstrated to improve the knowledgeability of the primary caregivers and their readiness to share the information with their patients as well as the patients' willingness to participate in clinical trials. However, the relative importance of the specific issues addressed in the educational programs and their impact on the final decision to participate in a clinical trial have not been studied in depth.

The aim of our study, therefore, was to identify the key issues which significantly contribute to the refusal to participate in clinical trials. We evaluated the level of knowledge about clinical trials and the attitudes towards them on the part of the oncologic population at the Tel Aviv Sourasky Medical Center (TASMC), Israel, a tertiary center with over 4,000 new oncologic patients yearly and with a clinical research unit, which runs phase I to phase IV clinical trials. We sought to answer the question of whether selected misconceptions of clinical trials among active cancer patients more significantly pose barriers to clinical trial recruitment.

Methods

We conducted a survey among patients diagnosed with cancer who were actively undergoing treatment in the oncology department or day care unit at the TASMC oncology division. From January 2015 to September 2016, patients were invited to voluntarily complete a hospital-approved anonymous questionnaire for evaluating their attitudes toward clinical trials, and the level of their understanding of relevant key concepts. Eligible patients were Hebrew-speaking, 18 years of age and older and willing to sign a written consent form. The questionnaire's structure was based on others in the literature [14,25,26]

and adapted for the Israeli population (Appendix A). It was comprised of 2 parts: the first evaluated demographic information and past experience in clinical research, and the second was composed of a 21-item true/false test on basic knowledge regarding clinical trials, including methods, goals and expectations. In the third section, the patients were asked whether they would agree or decline to participate in a clinical trial were they offered to do so. Entering free text about their main concerns about participating in a clinical trial was optional. The questionnaires' simplicity and clarity were evaluated by 15 members of the medical staff. Internal validation was performed by utilizing the α-Cronbach test on a pilot cohort of 50 oncologic patients, and further confirmed on a final cohort of 200 participants, with an excellent score set at 0.909 on the α-Cronbach test. The study was approved by the hospital's ethics committee and it was conducted in full accordance with the guidelines for Good Clinical Practice and the Declaration of Helsinki. Agreement to respond to the questionnaire was taken as formal consent to participate in this study.

Statistical analysis

Descriptive statistics were used to define patient characteristics. A score of 60% correct answers on the knowledge test was considered a "high level of knowledge" and a score lower than 60% was considered "low level of knowledge". Answers with extremely high or low percentages were described separately. Differences among binary categorical variables were evaluated with Fisher's exact test, and differences among continuous variables were evaluated with a non-parametric Mann-Whitney test. Statistical significance was defined at the $\alpha = 0.05$ level, and all tests were 2-sided. Internal validation was performed by the α-Cronbach test, as above.

Results

A total of 200 patients completed the questionnaires out of 235 patients that were invited to participate, representing an 85% response rate. The main reason given for refusal was lack of time. The mean ± standard deviation age of the participants was 58.3±12.8 years, and 45.9% (N = 90) were males. The most common cancer sites were breast (21.9%), colorectal (17.2%) and lung (10.4%). Almost one-half of the population (49.2%, N = 93) was born in Israel, defined themselves as being non-religious (62.3%, N = 124) and had some level of academic education (43.7%, N = 86). The questionnaire included the official Israeli government-issued statistic on average monthly income in New Israeli Shekels and 100 participants (50%) reported that their income level ranged from average to high. Most participants reported living with a partner (70.9%, N = 141, Table 1).

Nearly one-half of the surveyed population (47.7%, N = 92) agreed or very much agreed that they have a high level of understanding of how clinical trials work. The majority of them (63.8%, N = 120) would agree to participate in a clinical trial were they offered to, and 35.6% (N = 67) would decline.

Analysis of past experience in clinical trials

Forty-six (23.4%) of the respondents had participated in a clinical trial in the past. Most of them had an academic education compared with those who had no experience in clinical trials (67.4%, N = 31 vs. 36.9%, N = 55, respectively, $p < 0.0001$), the majority of them defined themselves as secular (non-religious Jews; 76.1%, N = 35 vs. 58.3% religious Jews, N = 88; $p = 0.037$) and were more likely to live alone rather than with a partner or caregiver (28.3%, N = 13 vs. 14.6%, N = 22, respectively, $p = 0.046$). As expected, patients with clinical trial experience were significantly more likely to define themselves as having a good understanding of how medical research works, compared to those without experience (84.4%, N = 38 vs. 36.5%, N = 54, $p < 0.0001$). They were also more inclined to participate in a future study, compared to those with no experience (73%, N = 33 vs. 44.9%, N = 66, $p = 0.01$). The participants' demographic characteristics and analysis of their responses according to past experience in clinical trials are presented in Table 1.

Analysis according to level of knowledge

The vast majority of the participants (164 out of 200, 82%) did not meet the minimum knowledge level on the knowledge test, with similar proportions of high- vs. low-level knowledge among Israeli-born and non-Israeli-born respondents. There were notable differences between the high- and low-level knowledge groups. Those with high-level knowledge were more likely to have an academic education compared with those with low-level knowledge (66.7%, N =24 vs. 38.5%, N = 62, respectively, $p = 0.003$). The proportion of patients with a "much higher than average" level of income was higher for the high–level knowledge group (11.5%, N = 4 vs. 2.5%, N = 2, $p = 0.039$).

As expected, the high-level knowledge group contained a significantly larger proportion of patients with past experience in clinical trials compared with the low-level knowledge group (47.2%, N = 17 vs. 18%, N = 29, $p < 0.0001$). Also as expected, those with high-level knowledge were significantly more interested in participating in a future clinical trial than those with low-level knowledge (94.3%, N = 33 vs 57.5%, N = 88, $p < 0.0001$; Figure 1. Interestingly, patients with high-level knowledge who had no past experience in clinical research were more inclined to participate in a clinical trial compared to those with low-level knowledge (94.4%, N = 17 vs 50.8% N = 64, $p < 0.0001$) (Table 2).

The patients who would decline to participate in clinical trials were asked to rate the importance of selected parameters that would affect their decision. The difference between the 2 knowledge groups regarding the fear of receiving a placebo drug and not the experimental drug reached a level of near significance: most of those with high-level knowledge considered the argument as "not important" while most of those with low-level knowledge considered the argument as "important" ($p = 0.055$ Mann-Whitney U Test).

Major misconceptions and common knowledge

We analyzed our questions according to the rate of correct answers for each question. Questions that had 80% correct answers represented “common knowledge”, and questions that had a maximum of 40% correct answers represented the most frequent misconceptions. According to our questionnaire, common

knowledge in the study's population consisted of: 1. The aims of a clinical trial were to evaluate the safety and the efficacy of an experimental drug, and 2. A new drug must be studied in a preclinical setting prior to the administration to a human patient. Common misconceptions that were revealed from this analysis were: 1. Receiving a placebo precludes receiving the standard of care; 2. Signing an informed consent abolishes the possibility of a future refusal; 3. The choice of the experimental drug depends entirely upon the oncologist's preferences; 4. The recruiting physician personally benefits from the patient's enrollment into clinical trials.

Discussion

The results of this study outline the attitude towards clinical trial participation of oncologic patients from a large tertiary referral hospital in Israel with an active clinical trial unit. Fewer than 40% of this study population predicted that they would decline to be enrolled in a clinical trial should they be offered an opportunity to participate. Our results are in line with those of Klabunde et al. who evaluated factors influencing accrual in a large National Cancer Institute cohort and found that approximately 40% of the clinically eligible patients refused to be enrolled into a study [27]. Although many respondents in several large trials made by the CISCRP perceived clinical trials as highly important, their actual understating of the trials was very limited.

In accordance with other studies [9–11], we found a strong correlation between patients' willingness to participate in a study and specific socioeconomic characteristics: the typical consenting patient was more likely to have an academic level of education and to have an average or above-average income. Neither sex nor place of birth had any significant effect. Interestingly, we found that patients who live alone were more likely to consent to participate. Our hypothesis is that persons without a significant other to closely care for them and monitor their health may be more inclined to evaluate the setting of a clinical trial in a more positive light. Interestingly, the level of religious observance also seemed to be related with attitude towards participation in clinical trials: secular Jews were more open to doing so than orthodox Jews. This may be related to possible reluctance to take risks that could potentially shorten life [28].

Importantly, we found a discrepancy between the self-reported level of familiarity with how clinical research works and the actual knowledge as demonstrated in the knowledge test. More than one-half of the population in the study was convinced that they had a high level of understanding, yet the majority of them performed poorly on the knowledge test. Other studies showed similar results when using different questionnaires and scoring systems [14,29,30]. As hypothesized, we found that patients with higher levels of knowledge were more likely to be willing to participate in clinical trials, and the difference was statistically significant (Fisher exact test, $p < 0.0001$).

Wide information gaps and misconceptions that were crucial for the decision-making process were identified among the patients who had poor results on the knowledge test. Specifically, the concepts of "placebo" and "standard of care" were poorly understood, and the informed consent procedure was perceived as being obligatory and non-rescindable. An especially worrisome result was the erroneous

belief that the treating physician personally benefits from patient enrollment. Such disturbing perceptions of the levels of ethical adherence on the part of physicians might partially explain the hesitant attitudes that patients demonstrate toward clinical trials.

When considering participation in a clinical trial, patients have to face more than a few uncertainties, most of which are based on their knowledge and perceptions that ultimately dictate their decision. The findings of our study are in line with earlier reports on the advantages of providing accessible clinical trial-related information to potential participants [21–24]. The findings of the current survey suggest that such interventions should focus on developing patient education strategies that could minimize specific gaps in knowledge. They support previous observations on the important role of the physicians in communicating the correct essential information on clinical trials [21–24].

Strengths And Imitations Of This Study

Our study adds to the accumulating evidence of patient participation in oncologic clinical trials, and provides data to explain why so many patients are reluctant to do so. Our study was limited by the fact that participants were recruited in a single center who may not adequately represent the entire patient population nationwide. Furthermore, our study participants were Hebrew-speaking, whereupon certain subgroups of the Israeli society may not have been well-represented.

Conclusion

In conclusion, the findings of this study suggest that patient reluctance to participate in clinical studies can be attributed in part to lack of knowledge regarding the clinical research system and, specifically, the rights of study participant and the ethical obligations of the physician. This insight can form the basis of a paradigm of patient as well as physician education, starting from an early course of the disease that may enhance the rates of enrolment into oncologic clinical trials.

Practice implications

Our results suggest that the best practice for recruiting oncologic clinical trial participants involves educating patients about clinical research, explaining the lack of vested interest on the part of the treating oncologist, assuring the patient's ability to withdraw consent at any time and for any reason and explaining the implications of assignment to the non-active treatment arm of a study.

Abbreviations

CISCRP
Center for Information and Study on Clinical Research Participation
TASMC
Tel Aviv Sourasky Medical Center

Declarations

Ethics approval and consent to participate

The study was approved by the Tel Aviv Sourasky Medical Center ethics committee and it was conducted in full accordance with the guidelines for Good Clinical Practice and the Declaration of Helsinki. Agreement to respond to the questionnaire was taken as formal consent to participate in this study.

Consent for publication Consent to answer the questionnaire was taken as formal consent to participate in this study

Availability of data and material: The datasets used and analyzed during the current study available from the corresponding author on reasonable request.

Competing interests:

Nethanel Asher: no conflict of interest. Ari Raphael: no conflict of interest. Ido Wolf: Honoraria: BMS; Lectures/Research grant: Novartis, BMS, Roche; Consulting and Advisory: Roche. Sharon Pelles: no conflict of interest. Ravit Geva: Options: BOL Pharma; Honoraria: MSD, Novartis, BMS, Roche, Janssen, Medison, Lilly, Bayer, Pfizer; Consulting and Advisory: BOL Pharma, MSD, Bayer, Novartis, Boehringer Ingelheim; Travel, Accommodations, Expenses: Bayer, Merck, Medison, BMS.

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Author Contributions:

Dr. Nethanel Asher – Design, questionnaire formulation and validation, data collection, statistics, writing of manuscript, editing

* Work was performed while in residency at Tel-Aviv Sourasky Medical Center

Dr. Ari Raphael – writing, editing, review of manuscript

Prof. Ido Wolf – data validation, supervision

Dr. Sharon Pelles – review of manuscript

Dr. Ravit Geva – Study conception and design, data validation, review of manuscript, supervision

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References

1. Lara PN, Higdon R, Lim N, Kwan K, Tanaka M, Lau DH, et al. Prospective Evaluation of Cancer Clinical Trial Accrual Patterns: Identifying Potential Barriers to Enrollment. Journal of Clinical

Oncology. 2001;19(6):1728–33.
2. Unger JM, Gralow JR, Albain KS, Ramsey SD, Hershman DL. Patient Income Level and Cancer Clinical Trial Participation. JAMA Oncology. 2016;2(1):137.
3. Curt GA, Chabner BA. One in Five Cancer Clinical Trials Is Published: A Terrible Symptom—What's the Diagnosis? The Oncologist. 2008;13(9):923–4.
4. Denicoff AM, Mccaskill-Stevens W, Grubbs SS, Bruinooge SS, Comis RL, Devine P, et al. The National Cancer Institute–American Society of Clinical Oncology Cancer Trial Accrual Symposium: Summary and Recommendations. Journal of Oncology Practice. 2013;9(6):267–76.
5. Go RS, Frisby KA, Lee JA, Mathiason MA, Meyer CM, Ostern JL, et al. Clinical trial accrual among new cancer patients at a community-based cancer center. Cancer. 2006;106(2):426–33.
6. Gray SW, Hlubocky FJ, Ratain MJ, Daugherty CK. Attitudes Toward Research Participation and Investigator Conflicts of Interest Among Advanced Cancer Patients Participating in Early Phase Clinical Trials. Journal of Clinical Oncology. 2007;25(23):3488–94.
7. Meropol NJ, Wong Y-N, Albrecht T, Manne S, Miller SM, Flamm AL, et al. Randomized Trial of a Web-Based Intervention to Address Barriers to Clinical Trials. Journal of Clinical Oncology. 2016;34(5):469–78.
8. Ross S, Grant A, Counsell C, Gillespie W, Russell I, Prescott R. Barriers to Participation in Randomised Controlled Trials. Journal of Clinical Epidemiology. 1999;52(12):1143–56.
9. Virani S, Burke L, Remick SC, Abraham J. Barriers to Recruitment of Rural Patients in Cancer Clinical Trials. Journal of Oncology Practice. 2011;7(3):172–7.
10. Unger JM, Hershman DL, Albain KS, Moinpour CM, Petersen JA, Burg K, et al. Patient Income Level and Cancer Clinical Trial Participation. Journal of Clinical Oncology. 2013;31(5):536–42.
11. Gross CP, Filardo G, Mayne ST, Krumholz HM. The impact of socioeconomic status and race on trial participation for older women with breast cancer. Cancer. 2005;103(3):483–91.
12. Avis NE, Smith KW, Link CL, Hortobagyi GN, Rivera E. Factors Associated With Participation in Breast Cancer Treatment Clinical Trials. Journal of Clinical Oncology. 2006;24(12):1860–7.
13. Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes and beliefs of african americans toward participation in medical research. Journal of General Internal Medicine. 1999;14(9):537–46.
14. Cameron P, Pond G, Xu R, Ellis P, Goffin J. A comparison of patient knowledge of clinical trials and trialist priorities. Current Oncology. 2013;20(3):193.
15. Gotay CC. Accrual to cancer clinical trials: Directions from the research literature. Social Science & Medicine. 1991;33(5):569–77.
16. Wray RJ, Stryker JE, Winer E, Demetri G, Emmons KM. Do cancer patients fully understand clinical trial participation? A pilot study to assess informed consent and patient expectations. Journal of Cancer Education. 2007;22(1):21–4.
17. Joffe S, Cook EF, Cleary PD, Clark JW, Weeks JC. Quality of Informed Consent: a New Measure of Understanding Among Research Subjects. JNCI Journal of the National Cancer Institute.

2001;93(2):139–47.
18. Quinn GP, Bell BA, Bell MY, Caraway VD, Conforte D, Graci LB, et al. The Guinea Pig Syndrome: Improving Clinical Trial Participation among Thoracic Patients. Journal of Thoracic Oncology. 2007;2(3):191–6.
19. Comis RL, Miller JD, Colaizzi DD, Kimmel LG. Physician-Related Factors Involved in Patient Decisions to Enroll Onto Cancer Clinical Trials. Journal of Oncology Practice. 2009;5(2):50–6.
20. Anderson A, Borfitz D, Getz K. Global Public Attitudes About Clinical Research and Patient Experiences With Clinical Trials. JAMA Network Open. 2018;1(6).
21. Arnaout A, Kuchuk I, Bouganim N, Pond G, Verma S, Segal R, et al. Can the referring surgeon enhance accrual of breast cancer patients to medical and radiation oncology trials? The ENHANCE study. Current Oncology. 2016;23(3):276.
22. Unger JM, Cook E, Tai E, Bleyer A. The Role of Clinical Trial Participation in Cancer Research: Barriers, Evidence, and Strategies. American Society of Clinical Oncology Educational Book. 2016;36:185–98.
23. Madsen LT, Kuban DA, Choi S, Davis JW, Kim J, Lee AK, et al. Impact of a Clinical Trial Initiative on Clinical Trial Enrollment in a Multidisciplinary Prostate Cancer Clinic. Journal of the National Comprehensive Cancer Network. 2014;12(7):993–8.
24. Haugen M, Kelly KP, Leonard M, Mills D, Sung L, Mowbray C, et al. Nurse-Led Programs to Facilitate Enrollment to Children's Oncology Group Cancer Control Trials. Journal of Pediatric Oncology Nursing. 2016;33(5):387–91.
25. Al-Tannir MA, El-Bakri N, Shaheen AKA-. Knowledge, Attitudes and Perceptions of Saudis towards Participating in Clinical Trials. Plos One. 2016;11(2).
26. Lux MP, Hildebrandt T, Knetzger S-M, Schrauder MG, Jud SM, Hein A, et al. Knowledge and attitudes regarding medical research studies among patients with breast cancer and gynecological diseases. BMC Cancer. 2015;15(1).
27. Klabunde CN, Bethesda, Springer BC, Butler B, Winston-Salem, White MS, et al. Factors Influencing Enrollment in Clinical Trials for Cancer Treatment. Southern Medical Journal. 1999;92(12):1189–93.
28. Bayes JB. What are the attitudes of strictly-orthodox Jews to clinical trials: are they influenced by Jewish teachings? Journal of Medical Ethics. 2012;39(10):643–6.
29. Hutchison C, Cowan C, Mcmahon T, Paul J. A randomised controlled study of an audiovisual patient information intervention on informed consent and recruitment to cancer clinical trials. British Journal of Cancer. 2007;97(6):705–11.
30. Curbow B, Fogarty LA, Mcdonnell K, Chill J, Scott LB. Can a brief video intervention improve breast cancer clinical trial knowledge and beliefs? Social Science & Medicine. 2004;58(1):193–205.

Tables

Table 1 Participant characteristics according to past experience in clinical trials

Characteristic		All participants		Past clinical research experience		
				No/not sure, n	Yes, n	p value*
Total		200	100%	151 (76.6%)	46 (23.4%)	
Mean age (years)		58.3 ± 12.8				
Sex	Male	90	45.90%	65 (43.3%)	24 (54.5%)	0.189
	Female	106	54.10%	85 (56.6%)	20 (45.4%)	
Birthplace	Israel	93	49.2%	61 (41.5%)	31 (68.9%)	0.744
	Russia†	18	9.5%	86 (58.5%)	14 (31.1%)	
	Europe	56	29.6%			
	Africa	11	5.80%			
	Asia	5	2.6%			
	America	6	3.1%			
Education	Elementary/Junior high,	15	7.60%	94 (63.1%)	15 (32.6%)	< 0.0001
	Professional school /agricultural	23	11.70%			
	High school	22	11.20%			
	Yeshiva (religious college)	5	2.50%			
	Non-academic training	46	23.40%			
	Academic	86	43.70%	55 (36.9%)	31 (67.4%)	
Religion	Secular (non-religious Jewish)	124	62.30%	88 (58.3%)	35 (76.1%)	0.037
	Observant	50	25.10%	63 (41.7%)	11 (23.9%)	
	Religious	15	7.50%			
	Orthodox	4	2.00%			
	Other	6	3.00%			

Characteristic		All participants		Past clinical research experience		
				No/not sure, n	Yes, n	p value*
Residential Status	Alone	35	17.60%	22 (14.6%)	13 (28.3%)	0.046
	With family/partner	141	70.90%	129 (85.4%)	33 (71.7%)	
	With caregiver	10	5.00%			
	Other (nursing home, etc.)	13	6.50%			
Income	Much more than average	8	4.10%	36 (24.2%)	19 (42.2%)	0.194
	More than average	47	24.00%			
	Average	45	23.00%	80 (53.7%)	17 (37.8%)	
	Less than average	31	15.80%			
	Much less than average	23	11.70%			
Perception of understanding how clinical trials work	Agree/strongly agree	92	47.70%	54 (36.5%)	38 (84.4%)	< 0.0001
	Neutral/disagree/strongly disagree	101	52.30%	94 (63.5%)	7 (15.6%)	
Agree to participate	Yes	120	63.80%	66 (44.9%)	33 (73.3%)	0.01
	No	67	35.60%	81 (55.1%)	12 (26.7%)	
Cancer site	Breast	42	21.90%			
	Colorectal	33	17.20%			
	Lung	20	10.40%			
	Prostate	10	5.20%			
	Other	87	45.30%			

*Compared between the groups with and without experience in clinical trials.

†Provided separately because of the large proportion of Russian-born participants

Table 2

Expressed willingness to participate in clinical trials according to past experience in a trial and score on the knowledge test (n = 186)

Past Score on knowledge test experience		Willingness to participate		
		Yes	No	p value
No past research	Low-level knowledge	64 (50.8%)	62 (49.2%)	p < 0.0001
	High-level knowledge	17 (94.4%)	1 (5.6%)	
Past research	Low-level knowledge	24 (96%)	1 (4%)	p > 0.05
	High-level knowledge	16 (94.1%)	1 (5.9%)	

Bold indicates significance.

Figures

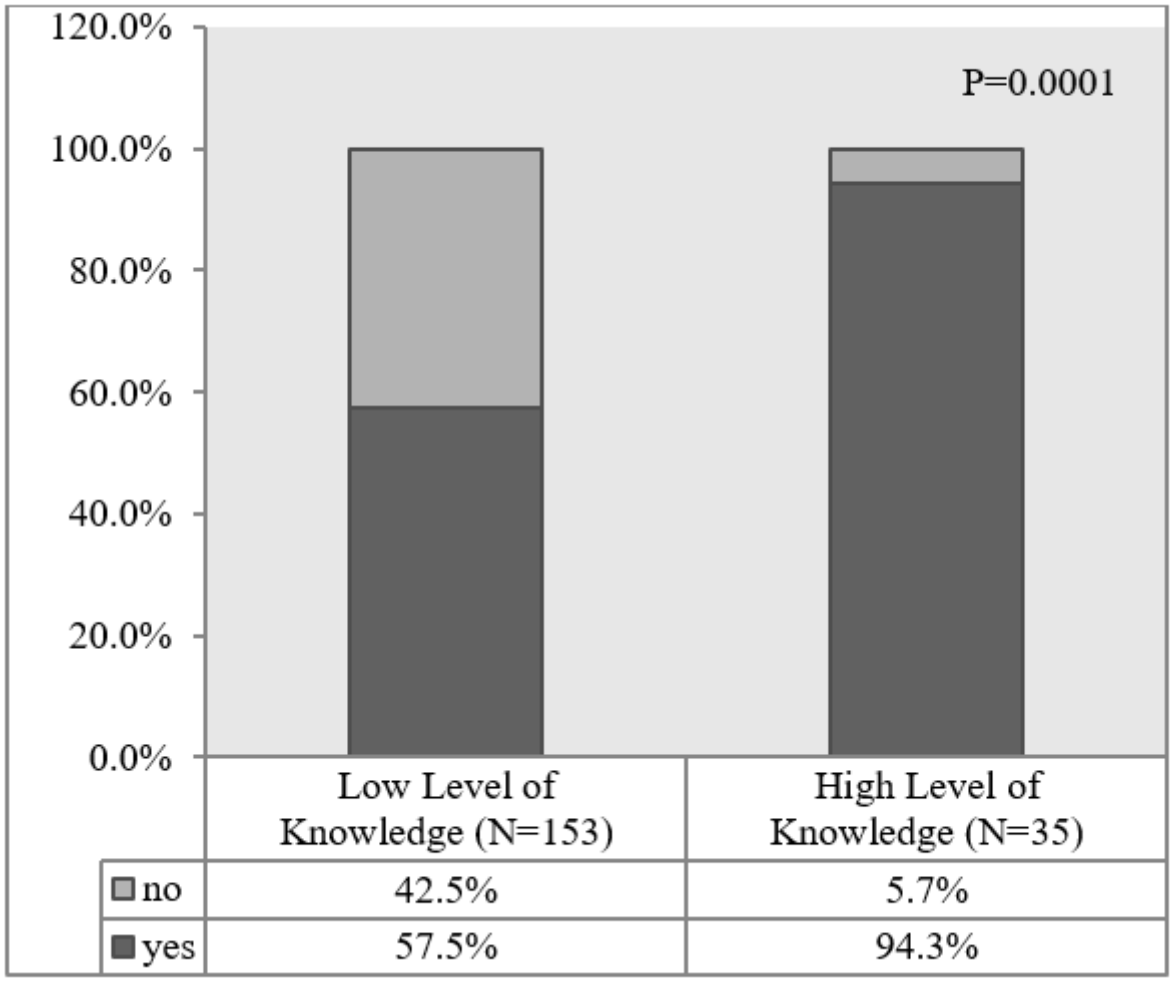

Figure 1

willingness to participate in future clinical research according to knowledge test score; a score of 60% correct answers was considered as a passing mark.