CLINICAL TRIALS ETHICS

Clinical Trials 2011; **8:** 616–623

Altruism among participants in cancer clinical trials

Tony H Truong[a], *Jane C Weeks*[b], *E Francis Cook*[c] *and Steven Joffe*[d,e]

Background Patients' motivations for participation in cancer clinical trials are incompletely understood. Even less is known about the factors that influence participants' motivations for enrolling in trials.

Purpose We studied the reasons why adult patients and parents of pediatric patients agree to participate in cancer trials. We focused on the role of altruism across all phases of trial.

Methods We surveyed adult patients and parents of pediatric patients participating in phase I, II, or III cancer clinical trials. We asked respondents why they agreed to enroll, and examined correlates of altruistic motivation using univariate and multivariate analyses.

Results Among 205 adults and 48 parents of children participating in cancer trials, 47% reported that altruistic motivations were 'very important' to their decisions to enroll. In multivariate analysis with phase III trial participants as the reference group, phase I trial participants least often identified altruism as a 'very important' motivation for enrolling (phase I OR 0.4, 95% CI (confidence interval) 0.2–0.8; phase II OR 0.9, 95% CI 0.5–1.5, overall $P = 0.017$). Thirty-three respondents (13%) reported being motivated primarily by altruism. In multivariate analysis, participants with poor prognoses—defined as an expected 5-year disease-free survival of $\leq$10%—reported altruism as their primary motivation less often than those with better prognoses (OR 0.2, 95% CI 0.1–0.5, $P = 0.001$). Altruistic motivations did not differ between adult patients and parents of pediatric participants.

Limitations The data are derived from related academic medical centers in one city, and the study sample reflects limited sociodemographic diversity, thereby limiting generalizability to other settings.

Conclusions Although cancer trial participants commonly report that altruism contributed to their decision to enroll, it is rarely their primary motivation for study participation. Participants in early phase trials and those with poor prognoses are least often motivated by altruism. *Clinical Trials* 2011; **8**: 616–623. http://ctj.sagepub.com

Introduction

The primary goal of clinical research is to advance our understanding of health, illness and the treatment of disease for the benefit of society. Although trial participation may benefit individual subjects, the primary purpose of trials is to improve outcomes for future patients. Nonetheless, many patients presume that trials are designed primarily to provide them with personal benefit, a belief termed the therapeutic misconception [1,2].

Patients' motivations for participation in trials can be classified into three broad categories: altruistic, self-interested, and others [3–7]. Altruistic motives include helping other patients with the

[a]Division of Haematology/Oncology, Department of Paediatrics, Hospital for Sick Children, University of Toronto, Toronto, Canada, [b]Department of Medical Oncology, Dana-Farber Cancer Institute, Boston, MA, USA, [c]Department of Epidemiology, Harvard School of Public Health, Boston, MA, USA, [d]Department of Pediatric Oncology, Dana-Farber Cancer Institute, Boston, MA, USA, [e]Department of Medicine, Children's Hospital, Boston, MA, USA

Author for correspondence: Steven Joffe, Dana-Farber Cancer Institute, 450 Brookline Ave, Boston, MA 02215, USA
Email: steven_joffe@dfci.harvard.edu

10.1177/1740774511414444

same disease and advancing medical and scientific knowledge. Self-interested motives include direct medical benefits such as access to specific medical treatments or tests, extra care and attention, or receipt of associated personal benefits such as financial incentives. Other factors may include pressure or encouragement from family and friends, trust in clinicians, feeling that one has little choice, or a sense of obligation to the study doctor or the hospital.

The existing literature on patients' motivations for participation in clinical trials paints a mixed and uncertain picture. A number of studies in the setting of early phase oncology trials suggest that self-interested motivations for enrollment predominate over altruistic ones [8–12]. In a systematic review of ethical issues in late phase trials, Edwards et al. similarly found that altruism plays a secondary role [13,14]. The President's Advisory Committee on Human Radiation Experiments, which interviewed almost 1900 medical oncology, radiation oncology, and cardiology patients at academic, Veterans Affairs, and community hospitals in five geographic regions of the United States, concluded that self-interested motivations outweighed altruistic ones among patients who had previously participated in 'therapeutic' research [15]. Yet other studies, including surveys by Jenkins and Fallowfield of adults participating in randomized cancer trials and by Simon et al. of parents of children with leukemia considering phase III trials, highlight the importance of altruism in motivating participation [16,17]. Unfortunately, efforts to understand this variation and to identify the participant, trial, or contextual characteristics that are associated with various motivations for participation are hampered by the methodological heterogeneity of the published literature and by the paucity of studies examining motivations across a range of research contexts.

Understanding why patients and parents choose to enroll themselves or their children in clinical trials is crucial to patient recruitment and retention, fulfillment of participant expectations, and high-quality informed consent. Motivations for cancer trial participation are incompletely understood, however, with most studies to date focusing on participants in early phase trials [8,12,18–21]. In particular, the role of altruism in motivating participation across the spectrum of cancer trials remains unclear. Furthermore, to our knowledge, no study has compared motivations between adult trial participants and parents of pediatric participants. We therefore surveyed adult cancer trial participants and parents of pediatric participants across a wide range of trials to assess their understanding of the trial, their experiences with consent, and their reasons for participation. Outcomes related to the quality of informed consent, our primary objective, have been reported [22]. Our aim in the present analysis was to characterize the motivations reported by patients and parents for their decisions to enroll themselves or their children in cancer trials. We also sought to identify factors associated with altruistic motivations for trial enrollment. We were especially interested to learn whether altruistic motivations differ between adult patients and parents of pediatric patients or among patients participating in phase I, II, and III trials.

Methods

Study population

We conducted a cross-sectional survey of adult cancer patients and parents of pediatric cancer patients participating in phase I, II, or III clinical trials of cancer-directed therapy. The patients and parents approached were those who had signed consent to a qualified cancer trial at Dana-Farber Cancer Institute (DFCI), Brigham and Women's Hospital, Massachusetts General Hospital, or Children's Hospital Boston within the previous 14 days. Participants were excluded whenever consent was obtained by an investigator of the present study or in a language other than English, if the participant's mailing address was outside the USA, or if the participant had been removed from the trial within 14 days of signing consent or had died. Questionnaires were sent to all eligible patients or parents, without requiring permission from the patient's physician. The DFCI Institutional Review Board approved the study protocol and waived the requirement for documentation of informed consent.

Survey administration

Details of survey administration methods have been published [22]. Briefly, surveys were mailed to participants' homes or delivered to their hospital rooms 3 to 14 days after consent to participation in the trial. Whenever a completed survey questionnaire was not returned within 2 weeks, a second questionnaire was sent, together with a card on which the patient or parent could decline participation. Two weeks later, we telephoned non-respondents to ensure receipt of the questionnaire and to answer any questions. When requested, we mailed a third questionnaire. Follow-up questionnaires were not sent to patients who had discontinued participation in their trial. Concurrent with the initial mailing, we sent a brief questionnaire to the

physician who had obtained the participant's consent for the trial. Whenever necessary, a second physician questionnaire was sent 14 days later.

Enrollment of adult patients took place from June 1999 to January 2000; recruitment of parents of pediatric patients continued until May 2001.

Survey instrument

The study questionnaire included nine statements, modeled on surveys by Daugherty et al. [12] and by the Advisory Committee on Human Radiation Experiments [15], addressing the respondent's motivation for joining the trial. Two statements—'I wanted to help future cancer patients' and 'I wanted to help advance medical science'—indicated altruistic motivations. Respondents were asked to rate how important each motivation was to their decision on a 5-point scale, anchored by 'Not important at all' and 'Very important.' After rating the importance of each motivation, respondents were asked to identify their single most important motivation from among the nine statements.

Correlates of altruism

Potential correlates of altruism were obtained from administrative data (age, gender, phase of trial) and from the respondent and physician questionnaires. The respondent questionnaire included information about ethnicity, education, marital status, and first language. The physician questionnaire included disease status at time of trial entry (newly diagnosed, relapsed, or progressive disease) and estimated probability of 5-year disease-free survival (DFS: $<1\%$, 1–10%, 11–50%, 51–90% and $>90\%$). In the present analysis, poor prognosis was defined as an estimated probability of 5-year DFS of $\leq 10\%$.

Study outcomes

The primary outcome of interest for study analyses was altruistic motivation for participation in the trial. We defined altruistic motivation in two ways. According to the first definition, respondents were considered to have altruistic motivations if they rated either 'I wanted to help future cancer patients' or 'I wanted to help advance medical science' as a 'Very important' reason for participation. According to the second, more stringent definition, respondents who chose either of these two items as their *single most important* reason for participation were considered to be motivated *primarily* by altruism.

Statistical analysis

We examined potential covariates of altruism, according to both definitions, using univariate logistic regression. Independent variables that were significant at $p<0.20$ (2-tailed) were entered into multivariate logistic regression models. A manual stepwise backward elimination sequence was used, keeping all variables in the models that achieved significance at $p<0.05$ (2-tailed), to identify the most parsimonious models. Models were built in two stages: variables derived from patient/parent surveys and from administrative data were included in the first stage, and variables derived from provider companion surveys (available for most respondents) were evaluated in the second stage. All analyses were performed using SAS version 9.2 (SAS Institute, Inc, Cary, NC, USA). Although the sample size for the study was determined by the primary objective (quality of participant understanding) [22], a sample of 250 respondents gave 90% power (with 2-sided alpha error = 0.05) to identify 15% differences in altruistic motivation between any two equal-sized groups.

Results

Sample characteristics

Questionnaires were mailed to 287 adult cancer trial participants and 65 parents of pediatric cancer trial participants. Of these, 207 (72%) adult patients and 49 (75%) parents responded. Three respondents (two adults, one parent) denied being enrolled in a trial and were excluded from the analysis, resulting in 253 evaluable respondents. Adult patients were older than parent respondents (mean age 55.0 years vs 38.8 years). Non-central nervous system solid tumors were most common among adult respondents, whereas hematologic malignancies and brain tumors were most common among children. Most adults (50%) participated in phase II studies, whereas most children (61%) participated in phase III studies. Based on provider responses, adult patients more often had relapsed or had progressive cancer and had lower physician-reported estimates of 5-year DFS (Table 1).

Altruistic motivations for trial participation

Figure 1 shows the percentage of respondents who rated each motivation as 'Very important' to their decision to participate, stratified by adult patient vs parent respondent (Figure 1A) and by phase of trial (Figure 1B). Of 253 respondents, 120 (47%) reported

Table 1. Respondent characteristics

Characteristic	Adult (n=205)[a] *N* (%)	Parent of child (n=48)[a] *N* (%)
Respondent age category		
≤ 44 years	44 (22)	38 (79)
45–64 years	115 (56)	10 (21)
≥ 65 years	46 (22)	0
Respondent gender[b]		
Female	113 (55)	35 (74)
Race/ethnicity		
White	183 (91)	45 (94)
Hispanic	6 (3)	2 (4)
African American	6 (3)	1 (2)
Asian and Pacific Islander	4 (2)	0
Others	2 (1)	0
College education	107 (53)	30 (63)
Married/living with partner	155 (76)	41 (85)
Only English used at home	193 (95)	45 (94)
Disease group		
Solid tumor	184 (90)	7 (15)
Hematologic malignancy[c]	16 (8)	29 (60)
Brain tumor	5 (2)	12 (25)
Phase of study		
I	50 (24)	10 (20)
II	102 (50)	9 (18)
III	53 (26)	29 (61)
Relapsed or progressive cancer[d]	91 (53)	10 (24)
Probability of 5 year DFS ≤ 10%[e]	111 (65)	13 (32)

SD, standard deviation; DFS, disease-free survival.[a]Numbers may not sum to 205 (adult participants) or 48 (parents of children) due to missing responses for some items.[b]For pediatric patients, refers to gender of parent respondent.[c]Includes lymphoma.[d]Data obtained from companion physician surveys (n=173 for adult, 41 for parent).[e]Data obtained from companion physician surveys (n=169 for adult, 41 for parent).

at least one altruistic motivation as very important in their decision to participate. There were no statistically significant differences between adult patients and parents in the proportions reporting altruistic motivations for participation (Figure 1A). Respondents in phase III trials more often reported altruistic motivations, whereas phase I trial participants less frequently reported altruistic motivations (p=0.01 for 'I wanted to help advance medical science'; p=0.05 for 'I wanted to help future patients') (Figure 1B).

In univariate analyses, earlier phase of trial (phase I OR 0.4, 95% CI (confidence interval) 0.2–0.8; phase II OR 0.9; 95% CI 0.5–1.5), poor prognosis (OR 0.7, 95% CI 0.4–1.1), and relapsed/progressive disease (OR 0.7, 95% CI 0.4–1.2) tended to be negatively associated with reporting that altruistic motivations were 'Very important' in the decision to join the trial at $p < 0.2$, the threshold for inclusion in the initial multivariate model. In contrast, female gender (OR 1.4, 95% CI 0.8–2.3) tended to be positively associated with altruistic motivations. Ethnicity, marital status, education level, language spoken at home, and time between consent and questionnaire completion were unassociated with altruistic motivations.

In multivariate logistic regression analysis, only phase of trial was significantly associated with altruistic motivations. Participants in phase I trials identified altruism as a very important motivation for enrollment less often compared to those in phase III trials (phase I OR 0.4, 95% CI 0.2–0.8; phase II OR 0.9, 95% CI 0.5–1.5; overall p=0.017).

Altruism as the primary motivation for trial participation

When asked to identify the *single most important* reason for choosing to take part in their trials, the largest group of respondents selected 'To receive medical benefits' (95/226, 42%). Thirty-three respondents (13%) selected 'To help future patients' or 'To help advance medical science' as their most important motivation. These respondents were classified as being motivated primarily by altruism.

There were no statistically significant differences between adult patients and parents of pediatric patients with respect to being motivated primarily by altruism (Figure 2A). In contrast, being motivated primarily by altruism was positively correlated with phase of trial (p=0.0006, Figure 2B).

In univariate analysis, altruism as the *primary* motivation for trial participation tended to be associated with six factors at $p < 0.2$, the threshold for inclusion in the initial multivariate model. These included phase (phase I OR 0.1, 95% CI 0.02–0.47; phase II OR 0.4, 95% CI 0.2–0.8); female respondent (OR 1.8, 95% CI 0.8–3.9); parent of a pediatric patient (OR 1.8, 95% CI 0.7–4.1); respondent age (age ≥ 65 OR 0.7, 95% CI 0.3–1.9; age 45–64 OR 0.3, 95% CI 0.1–0.7); poor prognosis (OR 0.2, 95% CI 0.1–0.5), and relapsed/progressive disease (OR 0.4, 95% CI 0.2–1.0). Ethnicity, marital status, education level, language spoken at home, and time between consent and questionnaire completion were unassociated with being primarily motivated by altruism.

In multivariate analysis, poor prognosis was the only factor significantly associated with altruism as the primary motivation for participation. Respondents with an expected 5-year DFS ≤10% reported altruism as their primary motivation less often than those with better prognoses (OR 0.2, 95% CI 0.1–0.5, p=0.001).

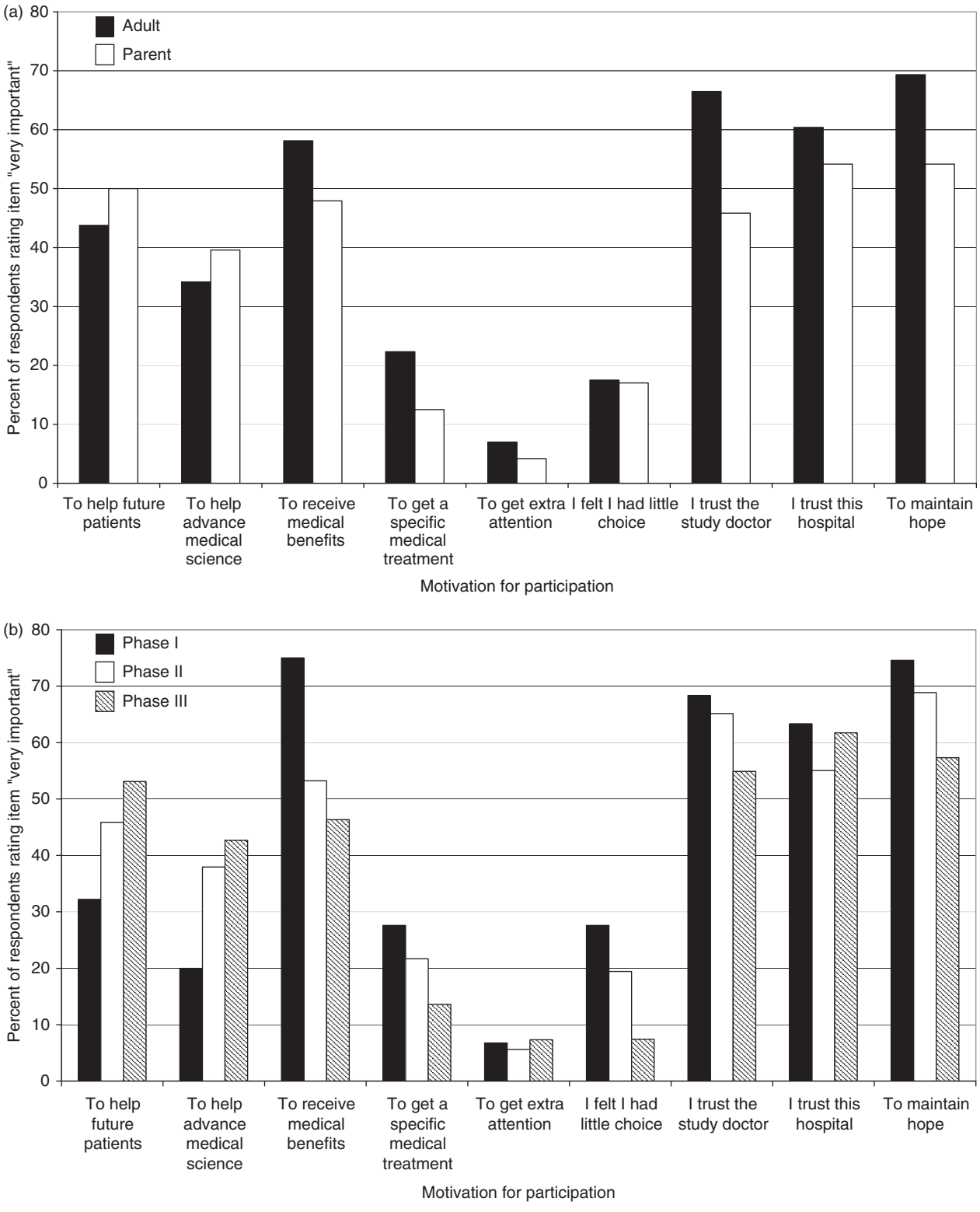

Figure 1 (a) Reasons for participation in a clinical trial, by adult patient versus parent of pediatric patient. (b) Reasons for participation in a clinical trial, by phase.

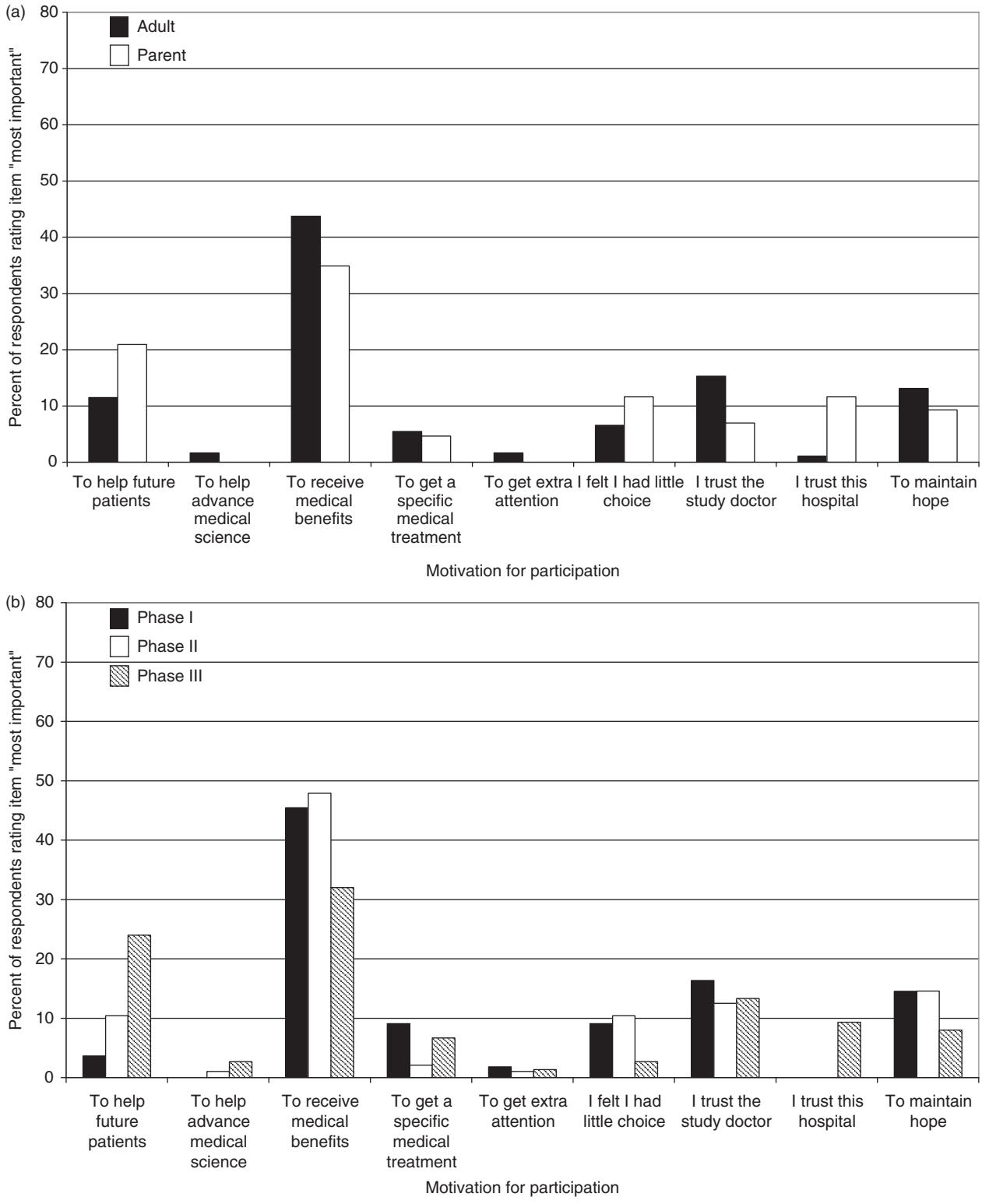

Figure 2 (a) Most important reason for participation in a clinical trial, by adult patient versus parent of pediatric patient. (b) Most important reason for participation in a clinical trial, by phase.

Discussion

We examined motivations for enrolling in cancer clinical trials among adult patients and parents of pediatric patients, with a focus on the role of altruism. Several noteworthy observations emerge from our data. First, although approximately half of respondents identified altruism as a very important motivation, less than 1 in 7 reported that altruism was their primary reason for joining the trial. Second, we observed no differences between adult participants and parent participants in the proportions citing altruistic motivations for study entry. Third, and most striking, patients with poor prognoses and those participating in early phase trials less often reported altruistic motivations for study enrollment.

In view of the low likelihood of sustained clinical benefit associated with phase I trial participation [23,24], it may seem counterintuitive that altruism should play a secondary role in motivating participation in these trials. Our data do not directly explain the mechanism underlying this relationship. However, this observation must be understood in light of the fact that phase I trial candidates typically have advanced or relapsed cancer and poor prognoses. We hypothesize that patients with favorable prognoses, who are often eligible for later phase trials, may view themselves as having several reasonable options, including trial participation, for treating their cancer. For such patients, altruism may tip the scales in favor of enrolling in the trial. In contrast, patients with poor prognoses who are eligible for early phase trials typically lack effective alternatives for anti-cancer treatment. Given their limited options and their life-threatening circumstances, such patients may perceive themselves as lacking the luxury of altruism when making treatment decisions.

Although understandable, the modest role of altruism among phase I participants and those with poor prognoses raises concerns about the adequacy of informed consent. Clinical research, regardless of phase, is designed primarily to create generalizable knowledge and to benefit future patients [25]. Furthermore, an extensive empirical literature documents the limited probability of direct benefit associated with phase I trial enrollment [23,24,26]. Thus, one might expect that if phase I trial participants understood the future-directed purpose of the research and the low probability of direct benefit, altruism might figure more prominently in their decisions to enroll. Invoking altruism during consent discussions may be helpful in reminding prospective participants of the purpose of the research, thereby counteracting tendencies towards therapeutic misconceptions [27]. Potential policy changes based on our findings may include clear and specific descriptions of anticipated benefits of clinical trial participation, encouraging patients to take time to make trial-related decisions in advance of their recruitment, and providing more educational material and resources to such patients to improve the consent process.

Several limitations should be considered in interpreting our findings. First, the data are derived from a single group of geographically and administratively related academic medical centers, and the study sample reflects limited sociodemographic diversity. Over 90% of our study sample was of majority race and ethnicity, thus limiting our ability to detect important differences in motivation that may be associated with these factors. Additional studies in more diverse settings are needed to further clarify the role of altruism and other motivations in decisions about cancer trial enrollment. Second, data collection ended in 2001; modifications to the informed consent process or changes in clinical trials, such as the increased role of molecularly targeted interventions, may have influenced patients' motivations for enrolling since that time. Nevertheless, because the nature of the choices facing cancer patients with both good and poor prognoses is not fundamentally different today than it was when these data were collected, it is highly unlikely that the underlying distribution of motivations has substantially changed. Furthermore, there is no reason to suspect that the associations we observed between phase and prognosis on the one hand and altruistic motivations on the other should have disappeared during the interval since the data were collected. Third, our findings should not be generalized to participants in supportive-care or non-oncology clinical trials. Finally, although we observed no difference between adult trial participants and parents of pediatric participants in reported motivations, it is important to note the conceptual differences between 'altruism-by-proxy' among parents and altruism among adult trial participants [28].

At the same time, this study has notable strengths. First, it is among the largest to date to query cancer patients about their motivations for trial entry. Second, unlike previous studies, it clearly distinguishes between altruism as a contributing factor to trial enrollment and altruism as the primary motivation for joining a trial. Third, it is the first to compare motivations for cancer trial enrollment between adult participants and parents of pediatric participants. Fourth, it is the only study of which we are aware to examine motivations for trial enrollment across the spectrum of cancer trials, and to demonstrate directly the relationship between phase and reasons for joining the trial. Finally, it is the first study to identify the critically

important association between an unfavorable prognosis and lower odds of altruistic motivations for trial entry.

In summary, although altruism commonly contributes to the decisions of cancer patients and pediatric patients' parents to join a trial, it is seldom a primary reason for study enrollment. Altruism is especially uncommon among patients joining early phase trials and those with poor prognoses. We suggest that this relationship derives from the perception that altruism is a luxury that few such patients believe they can afford.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

References

1. **Appelbaum PS, Roth LH, Lidz CW,** *et al*. False hopes and best data: Consent to research and the therapeutic misconception. *Hastings Cent Rep* 1987; **17**: 20–4.
2. **Lidz CW, Appelbaum PS, Grisso T, Renaud M.** Therapeutic misconception and the appreciation of risks in clinical trials. *Soc Sci Med* 2004; **58**: 1689–97.
3. **Mattson ME, Curb JD, McArdle R.** Participation in a clinical trial: The patients' point of view. *Control Clin Trials* 1985; **6**: 156–67.
4. **Catania C, De Pas T, Goldhirsch A,** *et al*. Participation in clinical trials as viewed by the patient: Understanding cultural and emotional aspects which influence choice. *Oncology* 2008; **74**: 177–87.
5. **Langley JM, Halperin SA, Mills EL, Eastwood B.** Parental willingness to enter a child in a controlled vaccine trial. *Clin Invest Med* 1998; **21**: 12–16.
6. **Tait AR, Voepel-Lewis T, Malviya S.** Participation of children in clinical research: Factors that influence a parent's decision to consent. *Anesthesiology* 2003; **99**: 819–25.
7. **Verheggen FW, Nieman F, Jonkers R.** Determinants of patient participation in clinical studies requiring informed consent: Why patients enter a clinical trial. *Patient Educ Couns* 1998; **35**: 111–25.
8. **Daugherty CK, Banik DM, Janish L, Ratain MJ.** Quantitative analysis of ethical issues in phase I trials: A survey interview of 144 advanced cancer patients. *IRB* 2000; **22**: 6–14.
9. **Kass N, Taylor H, Fogarty L,** *et al*. Purpose and benefits of early phase cancer trials: What do oncologists say? What do patients hear?. *J Empir Res Hum Res Ethics* 2008; **3**: 57–68.
10. **Nurgat ZA, Craig W, Campbell NC,** *et al*. Patient motivations surrounding participation in phase I and phase II clinical trials of cancer chemotherapy. *Br J Cancer* 2005; **92**: 1001–5.
11. **Tomamichel M, Jaime H, Degrate A,** *et al*. Proposing phase I studies: Patients', relatives', nurses' and specialists' perceptions. *Ann Oncol* 2000; **11**: 289–94.
12. **Daugherty C, Ratain MJ, Grochowski E,** *et al*. Perceptions of cancer patients and their physicians involved in phase I trials. *J Clin Oncol* 1995; **13**: 1062–72.
13. **Edwards SJ, Lilford RJ, Braunholtz DA,** *et al*. Ethical issues in the design and conduct of randomised controlled trials. *Health Technol Assess* 1998; **2**(i-vi): 1–132.
14. **Edwards SJ, Lilford RJ, Hewison J.** The ethics of randomised controlled trials from the perspectives of patients, the public, and healthcare professionals. *BMJ* 1998; **317**: 1209–12.
15. **Advisory Committee on Human Radiation Experiments**. *The human radiation experiments: Final report*. 1996469Oxford University Press, New York, NY.
16. **Jenkins V, Fallowfield L.** Reasons for accepting or declining to participate in randomized clinical trials for cancer therapy. *Br J Cancer* 2000; **82**: 1783–8.
17. **Simon C, Eder M, Kodish E, Siminoff L.** Altruistic discourse in the informed consent process for childhood cancer clinical trials. *Am J Bioeth* 2006; **6**: 40–7.
18. **Meropol NJ, Weinfurt KP, Burnett CB,** *et al*. Perceptions of patients and physicians regarding phase I cancer clinical trials: Implications for physician-patient communication. *J Clin Oncol* 2003; **21**: 2589–96.
19. **Rodenhuis S, van den Heuvel WJ, Annyas AA,** *et al*. Patient motivation and informed consent in a phase I study of an anticancer agent. *Eur J Cancer Clin Oncol* 1984; **20**: 457–62.
20. **Cox K.** Informed consent and decision-making: Patients' experiences of the process of recruitment to phases I and II anti-cancer drug trials. *Patient Educ Couns* 2002; **46**: 31–8.
21. **Berg SL, Winick N, Ingle AM,** *et al*. Reasons for participation in optional pharmacokinetic studies in children with cancer: A Children's Oncology Group phase 1 consortium study. *Pediatr Blood Cancer* 2010; **55**: 119–22.
22. **Joffe S, Cook EF, Cleary PD,** *et al*. Quality of informed consent in cancer clinical trials: A cross-sectional survey. *Lancet* 2001; **358**: 1772–7.
23. **Roberts TG Jr., Goulart BH, Squitieri L,** *et al*. Trends in the risks and benefits to patients with cancer participating in phase 1 clinical trials. *JAMA* 2004; **292**: 2130–40.
24. **Horstmann E, McCabe MS, Grochow L,** *et al*. Risks and benefits of phase 1 oncology trials, 1991 through 2002. *N Engl J Med* 2005; **352**: 895–904.
25. **National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research**. *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Biomedical and Behavioral Research* (Washington, DC: U.S. Government Printing Office, 1979).
26. **Shah S, Weitman S, Langevin AM,** *et al*. Phase I therapy trials in children with cancer. *J Pediatr Hematol Oncol* 1998; **20**: 431–8.
27. **Joffe S.** Altruistic discourse and therapeutic misconception in research informed consent. *Am J Bioeth* 2006; **6**: 53–4.
28. **Wendler D, Jenkins T.** Children's and their parents' views on facing research risks for the benefit of others. *Arch Pediatr Adolesc Med* 2008; **162**: 9–14.