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Internet Use Leads Cancer Patients to Be Active Health Care Consumers

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Abstract

Objective—This study examines whether cancer patients' Internet use leads them to prefer a more active role in medical decision making and whether the effects of Internet use on active participation preferences vary according to patients' education levels.

Methods—Randomly drawn sample ($N = 2,013$) from Pennsylvania Cancer Registry, comprised of breast, prostate, and colon cancer patients, completed mail surveys in the fall of 2006 (overall response rate = 64%). Of 2,013 baseline respondents, 85% agreed to participate in follow-up survey ($N = 1,703$). Of those who agreed, 76% ($N = 1,293$) completed follow-up surveys in the fall of 2007.

Results—Cancer patients' Internet use for health information at wave one led them to want to be more active participants in medical decision making at wave two ($\beta = .06, p < .05$). This applied to all cancer patients regardless of their education levels.

Conclusion—Higher levels of Internet use among cancer patients may lead patients to want to be more actively involved in medical decision making.

Practical Implications—Considering the beneficial effects of patients' active participation in medical decision making, it will be worthwhile for health educators to recommend Internet use to cancer patients.

Keywords

the Internet; Active Participation; Patient Education; eHealth; Medical Decision Making

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1. Introduction

Recently, the traditional, paternalistic, paradigm of health care delivery has been rapidly transformed into one that places a greater emphasis on shared medical decision making or consumer-based care [1–3]. Physicians and hospitals have become increasingly sensitive to patients' values, needs, and preference. In this process, patients assume a more active role in their own health and health care [4–6]. Many scholars have argued that new information and communication technologies (ICTs), especially the Internet, may act as a catalyst or facilitator of this rapid change [7, 8]. Because the Internet provides health care consumers with ample opportunities to actively search health and medical information, it may help to empower and educate patients [9–11]. This study aims to empirically test this argument.

It has been reported that patients' active participation in medical decision making may lead to more positive physician-patient relationships [4, 5] and improve health outcomes [2]. Patients who actively participate in medical decision making are found to be more satisfied with health care service, are more compliant with recommended treatment regimens, and are more likely to follow-up with future appointments [5, 6]. Research focusing on the population of cancer patients also supports these results. Arora [1], for example, showed that women with early stage of breast cancer reported higher levels of quality of life if they felt in control of treatment decisions. These women were less anxious about their illness and experienced depression less often than patients who took a less active stance. Also, Mallinger, Griggs, and Shields [12] demonstrated that breast cancer patients who reported feeling that their opinions were highly valued during the treatment decision making process showed higher levels of satisfaction with information that they were provided.

Despite these benefits, however, not all patients express a desire to actively engage in shared medical decision making [13–16]. Prior research has shown that, younger patients, highly educated patients, and females are more likely to take a more active role in medical decision making [17, 2, 18]. Moreover, recent studies have found that patients' preferences in shared decision making are influenced by such factors as self-efficacy and health locus of control [1, 6], and that factors influencing preferences (such as self-efficacy) are often shaped by patients' access to information and their knowledge about their disease and treatment options [7, 8]. In recent years, the Internet has become a source of health and medical information for cancer patients [19, 9]. Many studies have reported that a substantial number of cancer patients rely upon computer-mediated support programs delivered by health professionals, as well as informal, loosely structured self-help groups [20, 21]. Also, many patients were reported to frequently visit major health organizations' websites [20]. By accessing these types of online health information, patients may realize that there are multiple treatment options for a given condition. They may also realize that, in some instances, no single option is clearly superior to other options, that many medical decisions are often made under conditions of uncertainty, and that cancer treatment decisions can be guided by individual patient or physician preferences [2, 6]. In addition, health consumers may use the Internet to learn about emerging tests, treatment options, and cutting-edge medical research [9, 22]. Finally, they can also interact with other patients who have similar medical conditions [23], potentially empowering themselves to become more active health service consumers.

Little empirical research has been conducted to examine the role of the Internet on patients' preferences for medical decision making [13]. A majority of previous studies have used small convenience samples and are cross-sectional (which precludes any evaluation of causality) [19, 14]. Others studies have mainly focused on the general population, not cancer patients [10, 24]. To address these limitations, we analyzed data from a large, population-based, longitudinal survey of breast, colon, and prostate cancer patients, and examined the relationships between cancer patients' Internet use and their preferences for active participation in medical decision making over time. Knowledge regarding the effect of Internet use on active participation preferences has important research and practice implications for the education of cancer patients.

We first propose the following hypothesis based on the assumption that cancer patients' Internet use increases cancer-related knowledge, leads them to have higher levels of confidence during medical encounters, produces greater cancer-related self-efficacy and therefore empowers them to be active health care consumers [25, 9, 26]:

Hypothesis 1: Internet use for health information will lead cancer patients to prefer a more active role in medical decision making.

Our second hypothesis explores whether there are variations in the effects of Internet use on preferences for medical decision making according to cancer patients' education levels. The knowledge-gap hypothesis posits that the information available through the media does not equally benefit high- and low-socioeconomic status (SES) people and that this inequality may restrict the effectiveness of new communication technologies such as the Internet [27, 22, 28]. It was argued that knowledge gaps occur partly because people with high SES (primarily measured by education) are more likely to comprehend information obtained through the media than people with low SES [28]. We argue that the underlying mechanism of the knowledge-gap hypothesis can be applied to the effect of Internet use on active participation preferences. Specifically, Internet use may lead to greater preferences for active participation in medical decision making only if cancer patients can adequately understand online health information. Because education levels can be a proxy measure for cancer patients' online health information literacy [29], we evaluated education as a possible moderator of our relationships.

Hypothesis 2: The effect of Internet use for health information on preferences for active participation in medical decision making will be greater for those with high levels of education.

2. Methods

2.1. Participants and recruitment

Our sample includes patients diagnosed with breast cancer, colorectal cancer, and prostate cancer. These are three of the most prevalent cancer types affecting the US population today [30]. Patients were stratified by cancer and randomly sampled from a list of patients diagnosed in 2005 in Pennsylvania provided by the Pennsylvania Cancer Registry (PCR). Cancer cases are legally reportable to the PCR within six months of diagnosis. The sampling

frame, drawn in the fall of 2006, included approximately 95% of all cases that would eventually be reported to the PCR.

The response rates for the primary sample were 68%, 64%, and 61% for the breast, prostate, and colorectal cancer patients, respectively (overall response rate = 64%) [31]. Of 2,972 people originally sampled across the three types of cancer, 1,638 returned usable questionnaires, 64 responded but claimed to not have cancer, and 347 were estimated to have passed away. Mortality estimates were based on Surveillance Epidemiology and End Result (SEER) cancer mortality information and Centers for Disease Control (CDC) Pennsylvania overall mortality information, taking into account age and time since diagnosis at the date questionnaires were distributed. There was subsequent oversampling for colorectal cancer, Stage 4, and African American respondents to increase sample sizes for analyses of those subgroups (adding 372 cases to the sample). Because the inclusion of the African American oversample might bias our results, we controlled for race/ethnicity in our regression models. In other words, because the main effects of the oversampling of African Americans were taken into account, our results in this study are unbiased to race/ethnicity.

At baseline, participants were asked if we could contact them in one year to hear about their subsequent experiences with cancer. Of 2,013 baseline respondents, 85% ($N = 1,703$) agreed to be re-contacted; of those who agreed to be re-contacted, 76% ($N = 1,293$) completed the follow-up survey in the fall of 2007 (breast: 79%, prostate: 77%, colon: 75%) – a raw follow-up response rate of 65% across cancers. The detailed information about the sample characteristics, study design, and mailing procedure of our questionnaires was reported elsewhere [32–34].

For the sample characteristics, see Table 1.

2.2. Measures

Our dependent variable, i.e., medical decision making preferences, was adapted from Llewellyn-Thomas, McGreal, Thiel, Fine, & Erlichman [35]. We used the following statements: “After patients have all of the information they need about their illness and possible treatment, some prefer to leave decisions about their treatment up to their doctor, while others prefer to participate in these decisions. Of the following statements, please choose the one that best describes what you prefer to happen. (1) The doctor should make the final decision without considering my opinion; (2) The doctor should make the final decision after seriously considering my opinion; (3) The doctor and I should share responsibility for the final decision; (4) I should make the final decision after seriously considering my doctor’s opinion; (5) I should make the final decision on the basis of the facts that I learn from my doctor and elsewhere, without considering my doctor’s opinion.” It should be noted that many respondents chose more than one category. We recorded these respondents’ scores as the middle point among the options they chose. For example, if a respondent marked 1 and 2, we recorded their response as 1.5. In this way, we recoded our dependent variable as a 9-category ordinal measure (i.e., 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, and 5).

Our independent variable is cancer patients’ *Internet use for health information acquisition*. In order to examine the independent effects of Internet use, we controlled for other media

usage and interpersonal health communication. Thus, we asked respondents the following question: “People find out about health and medical issues from a variety of sources. Please indicate how often you have done each of the following in the past 30 days?” The sources are as follows: Read about health issues in newspapers or general magazines; Read special health or medical magazines or newsletters; Watched special health segments of television newscasts; Watched television programs (other than news) which addresses health issues or focus on doctors or hospitals; Read health information on the Internet; Talked with family or friends about health issues. For each source, respondents were asked to answer on a four-point scale (i.e., 1 = “not at all,” 2 = “less than once per week,” 3 = “once per week,” 4 = “two or more times per week”).

We controlled for cancer patients’ cognitions that are highly related to active participation in the medical decision making process. An average index of *perceived awareness of cancer treatment and consequences* was created by asking respondents whether they agree, on a five-point scale (1 = “strongly disagree,” 2 = “disagree,” 3 = “neither disagree nor agree,” 4 = “agree,” 5 = “strongly agree”), with the following statements: “I know about possible future treatments for my cancer”; “I know about the long-term risk of my cancer coming back”; “I know about future health problems I might face because of my cancer.” *Cancer management self-efficacy* was measured by asking respondents to rate their agreement, on the same five-point scale, with the following statements: “I am confident in my ability to (1) actively participate in decisions related to my cancer (2) get help if I don’t understand something about my cancer (3) ask my doctors or nurses questions about my cancer (4) manage any unexpected problems related to my cancer and (5) manage any unexpected problems related to my cancer.”

We also controlled for self-reported sociodemographic variables (i.e., age, gender, education, race/ethnicity, marital status), cancer type, and cancer stage. In addition, frequency of doctor visit was measured by asking respondents “How many times have you seen a doctor for your cancer in the last 12 months?”

2.3. Analysis Procedure

To examine our hypotheses, we first conducted the cross-sectional association of reported Internet use with their preferences for active participation in medical decision making. Also, by entering a product term consisting of Internet use and education, we examined whether there was an interaction between these two variables. Moreover, to test our model in a multivariate manner and to establish evidence for causal order, our analyses took explicit account of a range of measured confounders outlined above, and examined the lagged association of Internet use at W1 with active participation preferences at W2, while controlling for active participation preferences at W1. The central analyses used ordinary least squares (OLS) regression.

Multiple imputation was used to address missing data following procedures recommended by Allison [36] using STATA 10 and the ICE program [37]. That procedure created 5 datasets with imputed values for each of the cross-sectional and lagged analyses. The MIM program was then used to generate parameter estimates by averaging across the five datasets. These results are unweighted. The use of weighting procedures inflates standard

errors, and thus decreases sensitivity to effects. Since we focused on tests of theory rather than on making claims about the population, this tradeoff – more statistical power for reduced confidence in representativeness – was preferred. It is worth noting, however, that when population weights were applied, there was no material change in the crucial coefficients.

3. Results

About 39% of the respondents were found to use the Internet to attain health information in the past 30 days in 2006. Likewise, in 2007, 37.1% of the respondents reported that they acquired health information on the Internet.

The cross-sectional tests of our hypotheses are presented in Table 2. Even after controlling for other sources (i.e., TV, newspaper, special magazine, general magazine, interpersonal channels) as well as for other confounders, Internet use was positively associated with preferences for active participation in medical decision making, which supports Hypothesis 1 ($\beta = .05, p < .05$). However, we did not find an interactive effect between Internet and education on preferences for active participation, which does not support Hypothesis 2 ($p > .05$, not presented in table).

Table 3 provides parallel analyses to Table 2, but the outcome variable is W2 active participation preferences, and W1 active participation preferences were included among the predictors. The results showed that Internet use for health information increases preferences for active participation in medical decision making among cancer patients, which supports our Hypothesis 1 (see Table 3). That is, the greater the Internet use at W1, the higher the preference for active participation in medical decision making at W2 ($\beta = .06, p < .05$), even after controlling for the strongest predictor, active participation preference at W1. However, there was no interactive effect of W1 Internet use and education on W2 active participation preference, which does not support Hypothesis 2 ($p > .05$, not presented in table). In sum, both cross-sectional and panel analyses support the positive relationship between Internet use and active participation preference.

The two-wave data allows the examination of the additional possibility that the cross-sectional association between Internet use and active participation preference, as reported in Table 2, were partly the results of the effects of active participation preference on Internet use. Internet use at W2 was regressed on active participation preference at W1, after controlling for Internet use at W1 (see Table 4). We found that active participation preference at W1 did not affect Internet use at W2, when Internet use at W1 was controlled. These results demonstrate that Internet use affects preferences for active participation rather than the reverse.

4. Discussion and Conclusion

4.1. Discussion

We found that that higher levels of Internet use among breast, colon, and prostate cancer patients may increase patient preferences for active participation in medical decision

making. Our findings suggest that Internet use may empower patients to want to be more actively involved in their medical care and that the impact of Internet use on patient preferences may be distinct from the affect that is seen from patient health information seeking from other interpersonal or media sources. Our findings are in line with previous, cross-sectional studies that have shown an association between patient Internet use and greater patient involvement in medical encounters, greater patient confidence to talk to physicians about their concerns, greater medical decision-making ability, and greater perceived cancer-related self-efficacy [19, 9, 10, 24].

There are many possible reasons why Internet use may lead cancer patients to want to be more actively involved in the medical decision making process. One explanation is that the Internet provides cancer patients with greater access to information about their disease, possible treatment options, and prognosis, and that more informed patients are more likely to engage in their health care. Studies have shown that cancer patients are highly satisfied with the Internet as an information source and that the Internet remains an important source of information for cancer patients well past their initial diagnosis and into the survivorship period [9].

In addition to disease and treatment specific information, the Internet may also provide cancer patients with information related to health care delivery options or direct access to medical care. We know that cancer patients seek out information related to the experience or qualifications of physicians and medical staff, the quality of medical equipment and supplies, options related to health care systems, and available research [26]. While patients can turn to many sources for information related to the medical system and access to care, there is evidence that the use of the Internet for this purpose is on the rise [10]. Additionally, patients are increasingly turning to the Internet for products and services, such as medicine and complementary or alternative medical treatments [38–41]. Internet access to information about options within the medical system, care quality, and direct access to care may help to enhance patient autonomy, improve access to high quality care, and enhance informed medical decision making.

Another possible explanation for the association between Internet use and an increased preference for active participation in the medical decision making process relates to the fact that the Internet may enhance patients' cancer-related communications and expand cancer-related social networks [42, 23, 9]. For instance, Eysenbach has noted that the Internet is being increasingly used as a tool for enhanced communication and community building by cancer patients [9]. The use of e-mail and involvement in online cancer-related support groups or social networking sites may provide patients with valuable information and social support which may provide them with the tools or confidence to be more actively engaged in their health care.

It should be noted that our data did not support our second hypothesis; education did not moderate the effects of Internet use on preferences for active participation in medical decision making. One possible explanation for this result is that the relationship between Internet use and active participation preferences is not accounted for by Internet-related increased health knowledge, as we initially expected. Preferences for active participation in

medical decision making may be influenced by factors other than knowledge acquisition. For example, it is possible that Internet use may alter patients' notions of descriptive social norms [43]. If cancer patients encounter online stories exemplifying other cancer patients' active engagement with doctors, they may realize that many cancer patients actively participate in their medical decision making. Our data are not equipped to test this alternative explanation. This represents a promising area for future research.

In addition, we did not detect an effect of active participation preferences on one-year changes in health-related Internet use. One must, however, exercise caution before interpreting these results as definitive evidence for rejecting the reverse causal order. The fact that active participation preferences did not predict Internet use one year later does not necessarily mean that Internet use is not influenced by the extent to which cancer patients prefer an active role in medical decision making. Scholars have noted that one of the methodological challenges involved in designing panel surveys is to adopt time lags which can adequately capture both media effects and media selectivity [44, 45]. If a longitudinal survey design does not match the expected time lag between a hypothesized cause and effect, researchers may come to an erroneous conclusion about causal effects. The appropriate lag between preference for active participation in medical decision making and increased Internet use may be greater or less than one year. Future studies should consider alternate time lags between these variables to provide a stronger, more definitive test of this hypothesis.

Our study has a number of limitations that should be noted. First, because we conducted a survey study, we elicited preferences for medical decision making but we were unable to measure actual medical decision making. Additionally, we used self-reported information on Internet use and did not have direct measures of actual Internet use. Second, while we have found a statistically significant effect of Internet use on preferences for more active participation in medical decision making, our effect sizes are small and more work is needed to determine how much influence the Internet has on cancer patient clinical decision making and clinical encounters. Third, we have surveyed three of the leading types of cancer but we acknowledge that we cannot generalize our findings to other types of cancer patients.

Despite these limitations, our study has a number of strengths that are worth mentioning. We have surveyed a large, population-based sample of cancer patients thus helping to advance the field with a more representative patient population than in many prior, small studies. In addition, we have adjusted for many potential confounders in our models and we have also used panel analysis helps to evaluate causal relationships in a way that is not possible with cross-sectional data alone.

4.2. Conclusion

Over the last few decades patients have become increasingly involved in their medical care and medical decision-making. While the cause of this paradigm shift is likely multi-factorial, increased patient access to cancer-related information, particularly through the Internet, has been postulated as an important component of this change. Our study provides evidence that higher levels of Internet use among cancer patients may lead patients to want to be more actively involved in the medical decision making process.

4.3. Practice Implications

We have seen that Internet use for health information acquisition may directly impact the clinical encounter by altering cancer patients' preferences for active participation in medical decision making. Internet-associated changes in active participation preferences may be of particular importance for cancer patients from lower education levels because prior work has shown that patients with low levels of education are often less likely to play an active role in medical decision making [17, 2, 18]. While these findings are promising, it is important to note that there are persistent disparities in computer ownership and Internet access in the US [46]. These disparities pose a significant threat to the realization of health-related benefits of Internet use. More educational, policy, and philanthropic efforts are needed to close the digital divide. Moreover, it was reported that many online health resources do not contain information that cancer patients and their significant others want [47]. Thus, health program developers should conduct more careful assessment of cancer patients' information needs. In addition, while there may be health-related benefits of patient Internet use and patients' active participation in medical decision making, both patients and providers need to be cognizant of the fact that there may be downsides to patient Internet use. Direct access to medical care over the Internet may be detrimental to health if companies, in the absence of strict regulation related to information provision, mislead patients about the costs, benefits, and limitations of their products, and if patients may make bad medical decisions based on Internet information. Therefore, it is essential that health care providers take the time to counsel their patients about the potential benefits and risks of Internet use, guide them to high-quality websites, and advocate for greater access to the Internet for all patients.

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Table 1

Descriptive statistics of the sample

	Wave 1			Wave 2		
	N	M	SD	N	M	SD
Age	2,012	66.16	12.38	1,293	65.47	11.92
Gender	2,010	50.9% female		1,293	51.4% female	
Education in years	1,979	13.14	2.57	1,290	13.43	2.57
White race	2,013	85.6% white		1,293	88.2% white	
Marital status	1,979	67.1% married		1,287	70.0% married	
Cancer stage	1,967			1,260		
	1,224	60.8%		812	64.4%	
In situ or local						
Regional spread	431	21.4%		285	22.6%	
Metastasis	312	15.5%		163	12.9%	
Doctor visits in past year (times)	1,958	4.56	2.22	1,242	3.18	2.10
Type of cancer	2,013	Colon: 34.0%, Breast: 33.7%, Prostate: 32.3%		1,293	Colon: 31.9%, Breast: 34.8%, Prostate: 33.3%	
Cancer management self-efficacy (1–5)	1,919	4.24	.59	1,226	4.24	.59
Perceived awareness of cancer treatment and consequences (1–5)	1,894	3.69	.83	1,214	2.35	.80
Newspaper/Special magazine use for health information (1–4)	1,973	2.62	1.06	1,281	2.67	1.03
General magazine use for health information (1–4)	1,923	2.01	.94	1,258	2.03	.92
TV use for health information (1–4)	1,935	2.28	.89	1,260	2.24	.86
Interpersonal health communication with family and friends (1–4)	1,930	2.74	.97	1,259	2.69	.96
Internet use for health information (1–4)	1,876	1.63	.93	1,236	1.60	.92
Preferences for active participation in medical decision making (1–5)	1,917	3.21	.84	1,251	3.26	.78

Note: This table provides the descriptive statistics of the unimputed sample.

Table 2

Ordinary least squares regression analysis predicting preferences for active participation in medical decision making: Cross-sectional analysis

Variable	Zero-order correlation coefficient	Final standardized regression coefficient β
Age	-.01 ***	-.02 ***
Education	.04 ***	.05 *
White race (white=1, others=0)	.00	.02
Marital status (currently married=1, others=0)	.09 *	-.01
Colon cancer female (colon cancer female=1, others=0)	-.09	-.08 **
Colon cancer male (colon cancer male=1, others=0)	-.18 ***	-.11 ***
Breast cancer (breast cancer=1, others=0)	.02	-.11 ***
Cancer stage	-.07 ***	-.09 **
Frequency of doctor visit	-.02 *	-.06 *
Cancer management self-efficacy	.13 ***	.05 *
Awareness of cancer treatment and consequences	.01	-.01
Newspaper/Special magazine use for health	.02	-.02
General magazine use for health	.02	.01
TV use for health	.03	.02
Interpersonal health communication with family and friends	.04 *	.02
Internet use for health	.11 ***	.05 *
R^2 adj (%)		6.3 ***

Notes: $N=1,917$.

* $p < .05$;

** $p < .01$;

*** $p < .001$.

The analysis is based on the imputed sample.

Table 3

Ordinary least squares regression analysis predicting preferences for active participation in medical decision making: Two-wave panel design

Variable	Zero-order correlation coefficient	Final standardized regression coefficient β
Age	-.01 ***	-.08 *
Education	.02 **	.00
White race (white=1, others=0)	.15 *	.04
Marital status (currently married=1, others=0)	.13 **	.03
Colon cancer female (colon cancer female=1, others=0)	-.05	-.02
Colon cancer male (colon cancer male=1, others=0)	-.09	-.03
Breast cancer (breast cancer=1, others=0)	-.01	.07 *
Cancer stage	-.08 ***	-.12 ***
Frequency of doctor visit	-.01	.02
Cancer management self-efficacy	.05	.00
Awareness of cancer treatment and consequences	-.03	-.03
Preferences for active participation in medical decision making (W1)	.36 ***	.35 ***
Newspaper/Special magazine use for health	-.02	-.04
General magazine use for health	-.02	.02
TV use for health	-.06 *	-.06
Interpersonal health communication with family and friends	.00	.00
Internet use for health information	.08 **	.06 *
R^2 adj (%)		1.6 ***

Notes: $N = 1,251$.

* $p < .05$;

** $p < .01$;

*** $p < .001$.

The analysis is based on the imputed sample.

Table 4

Panel analysis of predictors of Internet use for health information in W2

Variable	Zero-order correlation coefficient	Final standardized regression coefficient β
Age	-.02***	-.01***
Education	.09***	.00*
White race (white=1, others=0)	.04	.04
Marital status (currently married=1, others=0)	.11*	.02
Colon cancer female (colon cancer female=1, others=0)	.08	-.02
Colon cancer male (colon cancer male=1, others=0)	-.13	-.03
Breast cancer (breast cancer=1, others=0)	.12*	.06
Cancer stage	.03	-.01
Frequency of doctor visit	.07***	.01
Cancer management self-efficacy	.14**	.00
Awareness of cancer treatment and consequences	.08**	-.03
Newspaper/Special magazine use for health	.17***	-.03
General magazine use for health	.17***	.01
TV use for health	.15***	-.05
Interpersonal health communication with family and friends	.19***	.00
Internet use for health (W1)	.64***	.58***
Preferences for active participation in medical decision making (W1)	.12***	.30
R^{2adj} (%)		4.5%

Notes: $N = 1,236$.* $p < .05$;** $p < .01$;*** $p < .001$.

The analysis is based on the imputed sample.