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Health Literacy, Information Seeking, and Trust in Information in Haitians

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Abstract

Objectives—To assess health literacy, health information seeking, and trust in health-related information among Haitian immigrants seen in primary care.

Methods—Health literacy was measured by the Brief Health Literacy Screen (BHLS); items on health information use were from the 2007 Health Information National Trends Survey.

Results—BHLS scores differed according to age, education, and survey language. Participants with lower levels of health literacy tended to be more likely to place “a lot” or “some” trust in family and friends and religious organizations and leaders as sources of information about health or medical topics.

Conclusions—Constructing a culturally-tailored and appropriate intervention regarding health promotion requires understanding how the population accesses and conveys health information.

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Conflict of Interest Statement: This manuscript has not been previously published and is not under consideration in the same or substantially similar form in any other peer-reviewed media. All authors have contributed sufficiently to the project to be included as authors and all authors have approved the manuscript being submitted. To the best of our knowledge, no conflict of interest, financial or other, exists.

Keywords

health literacy; health communication; primary care; minority groups

To access health-related information successfully, and, ultimately, make good decisions regarding health, patients must have adequate health literacy. According to the National Library of Medicine, health literacy is “the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.”¹ Lower levels of health literacy have been associated with increased utilization of healthcare services and worsened health outcomes, including greater emergency room use, increased hospitalizations, and a higher risk of mortality.^{2,3} Additionally, persons with lower perceived health literacy have been shown to have greater difficulty making an informed choice with respect to health promotion activities.⁴

Although accessing and understanding health information is necessary to make informed health decisions, it is not sufficient. The next step relates to the preferred method of acquiring and delivering health-related information. The Patient Protection and Affordable Care Act of 2010 has highlighted the need for greater use of evidence-based medicine, shared decision making, comparative effectiveness research, and transparency of cost and quality information.⁵ To promote these methods and aspirations, organizations have tended to rely on disseminating written materials.⁶ Differences in culture, language, and health literacy may create barriers, and, ultimately, widen disparities, with regard to the ability to access written language.

Haitian immigrants comprise a growing subgroup of Blacks with a unique culture, belief system, and health habits that dictate the need for a targeted approach to health promotion.^{7,8} In the United States, Haitians represent one of the fastest growing Caribbean immigrant populations and the population of persons of Haitian ancestry has more than tripled since 1990.⁹ To date, no published articles have assessed health literacy in Haitians. Compared with native-born Americans, Haitian immigrants may have lower levels of health literacy, given their migration to the US, and on average, lower formal educational attainment.¹⁰⁻¹³ Because Haitian Creole is largely a spoken language, immigrants may be dependent on the oral tradition to obtain health-related information.¹⁴ Adding to this complexity, evaluating health literacy tends to be done through written documents as opposed to measuring oral and listening skills or numeracy. For languages with direct phoneme-grapheme correspondence, such as Haitian Creole, written health literacy may be difficult to ascertain, given that many commonly used instruments are based upon word pronunciation tests.¹⁵

Health literacy may differ according to race/ethnicity or even within a single group, and health literacy-related disparities in accessing and using technology are widespread.^{16,17} Disadvantaged immigrant groups are more impacted by low health literacy due to differences in language and culture.¹⁸ For Haitians, compared with persons with lower levels of written health literacy, persons with higher levels of written health literacy might be more likely to report seeking health-related information, especially through the Internet. They also may be less likely to obtain health information through oral communication.

Engaging in information-seeking behavior through the Internet would facilitate access to best practices derived from comparative effectiveness research, thereby promoting shared-decision making.¹⁹ In terms of trusting health information, Haitians with higher levels of health literacy might be more likely to trust written sources of information whereas Haitians with lower levels of health literacy may trust oral communication such as radio and family and friends.

The following study aimed to examine these issues in a convenience sample of Haitian Creole-speaking patients seen at an ambulatory care practice at Queens Hospital Center. This location was chosen because Queens County, New York City is home to one of the 5 largest Haitian populations among all US counties.¹³ We used a measure of health literacy that was based on an individual's self-reported difficulty with understanding information or performing reading tasks that might be encountered in a healthcare setting.^{20,21} In addition, we asked about how participants preferred to hear information and how much they trusted this information from various sources.

Specifically, we had the following hypotheses based on a review of the literature:^{10,22,23}

- Older age, lower educational attainment, completing the questionnaire in Haitian Creole, and shorter length of residence in the United States would be expected to be associated with lower levels of health literacy;
- Haitians who report looking for health and medical topics and cancer information from any source as well as accessing the Internet would have higher scores of health literacy;
- Health literacy scores for Haitians who report looking for information from oral forms of communication (family and friends/coworker, radio) would be lower compared to health literacy scores for Haitians who report looking for written sources of information such as books, brochures, pamphlets, and the Internet; and,
- Health literacy scores for Haitians who report a lot/some trust in oral forms of communication such as family and friends, the radio, and religious organizations and leaders would be lower than for Haitians who place less trust in these sources.

Methods

Sample

This cross-sectional study surveyed people who were aged 18 and older who attended Queens Hospital Center Ambulatory Center during July and August of 2013. Queens Hospital Center is a member of the New York City Health and Hospitals Corporation and a major healthcare provider in the borough of Queens. The foremost mission of QHC is to provide quality, comprehensive care to all New Yorkers, regardless of their ability to pay or immigration status.

Measures

Health literacy was measured by the Brief Health Literacy Screen (BHLS).^{20,21,24} The BHLS is comprised of 3 questions—"How confident are you filling out forms by yourself?"

(“Confident with forms”), “How often do you have someone help you read hospital materials?” (“Help Read”), and “How often do you have problems learning about your medical condition because of difficulty reading hospital materials” (“Problems reading”)? These items had been used by Chew et al²⁰ to screen for inadequate or marginal health literacy in a large VA population and have been validated for use in routine clinical care.²¹ The measure takes approximately one minute to complete. Scores range between 3 and 15 with higher scores indicating higher subjective health literacy; Cronbach's alpha was found to be 0.71 when the BHLS was administered by a research assistant to a clinic sample.²¹ We modified these questions by inserting “in English” in each of the 3 questions so that participants who completed these items in English and participants who completed these items in Haitian Creole were answering the items with the same reference point.

The 5 items on health information use were derived from the 2007 Health Information National Trends Survey (HINTS), a national survey designed to collect nationally representative data on the country's need for, access to, and use of cancer-related information.²⁵ HINTS was developed in the Division of Cancer Control and Population Sciences of the National Cancer Institute and is publicly available in English and Spanish. The items chosen asked about looking for information about health and medical topics from any source, looking for cancer information from any source, where a person went first the most recent time he/she looked for information about health or medical topics, how much a person would trust information about health or medical topics from specified sources, and what a person would do to address his/her health concern.

The final section of the questionnaire contained a number of socio-demographic characteristics, including age, sex, education, race and ethnicity, years living in the United States, country of birth, employment, and marital status.

Translation and Administration of Questionnaires

The English-language source questionnaires were translated into Haitian Creole and back translated into English by an approved translation vendor that also provided Certificates of Authenticity. The target translations then underwent rigorous review and adjudication by the native speaker teams.²⁶ A bilingual (English/Haitian Creole) research study assistant (RSA) approached patients in the waiting room prior to a healthcare visit. Potential participants were informed that the study was voluntary and that the interview would be anonymous and confidential. Participants were given the choice of having the study administered by the RSA in English or Haitian Creole, based on the language with which they had the most subjective comfort and familiarity. Participants received a transportation card (\$15) in thanks for their valued time and effort in completing the study.

Data Analysis

Patient characteristics were summarized using the frequency and percent for categorical factors and the median and range for continuous factors both in the overall patient population and stratified by survey language (English vs Haitian Creole). Differences in patient characteristics by survey language were examined using Fisher's exact test when categorical and the Kruskal-Wallis test when continuous. Next, we used Cronbach's alpha to

assess the internal consistency of the 3 Brief Health Literacy Screen (BHLS) questions both overall and separately by survey language. A scale was formed by summing responses to the 3 questions so that higher scores represent higher levels of health literacy. Finally, we examined associations between patient demographics and health information use with health literacy score using the Kruskal-Wallis test. Multivariable analysis was not plausible due to sample size constraints. Statistical significance was defined by a p -value $< .05$. Data were analyzed using SAS software, Version 9.2 of the SAS System for Windows (SAS Institute Inc., Cary, NC, USA, 2009).

Results

Eighty-five out of 94 Haitian participants who were approached were recruited at Queens Hospital Ambulatory Care Center (90.4% response rate). The median age of participants was 52.0 (range = 23.0-80.0) and 74% were women. More than 90% ($N = 80$) were born in Haiti and 81% ($N = 69$) completed the questionnaire in Haitian Creole. The majority of participants had less than a high school level of education or the equivalent of high school (Table 1). Compared with participants completing the questionnaire in English, participants preferring Haitian Creole were older (median age 55.0 vs 37.5 years, $p < .001$), more likely to have been born in Haiti (97.1% vs 81.3%, $p = .006$), and more likely to report a lower educational attainment ($p < .001$) (Table 1).

The Cronbach's alpha for the Brief Health Literacy Screen (BHLS) was 0.779 for the entire sample and 0.776 for the 69 Haitian Creole speakers. Because the internal consistency was high for the full sample, associations with BHLS scores were not stratified by survey language. BHLS scores for the entire sample differed according to age, education, and survey language but not according to sex, years living in the US or marital status. Specifically, median scores tended to be lower for those aged 50 and above, persons with a lower educational attainment, and those who completed the survey in Haitian Creole ($p < .001$ for all) (Table 2).

With regard to accessing information, participants who reported ever going online to access the Internet or World Wide Web had higher health literacy than participants who did not ($p = .001$). Participants who reported seeking health information from any source had higher health literacy scores than participants who did not ($p = .012$), as did participants who reported having ever looked for cancer information from any source ($p = .009$) (Table 3). Scores of health literacy tended to be highest for participants reporting first looking for information about health or medical topics through the Internet, and lowest for participants reporting initially going to radio or family, friend/coworker but these differences were not statistically significant ($p = .111$). Participants with lower levels of health literacy tended to be more likely to place "a lot" or "some" trust in family and friends and religious organizations and leaders as sources of information about health or health or medical topics as opposed to participants with higher health literacy who were more likely to report less trust (a little/ not at all) in these sources ($p = .029$ and $p = .027$, respectively). Additionally, although not statistically significant, mean BHLS scores tended to be lower for persons who placed "a lot" or "some" trust in radio as a source of information about health or health or medical topics as compared with persons who reported less trust (a little/not at all) ($p = .$

066). No difference in health literacy was observed between participants' level of trust in doctors as a source of health information.

Discussion

Our study is the First to attempt to examine health literacy in Haitian Creole speakers using a validated health literacy measure, the Brief Health Literacy Screen. We viewed health literacy as one prerequisite for the ability to make appropriate health-related decisions and we used a screener that was more culturally and linguistically salient for our population. Because of the sparse information available on these topics among the Haitian population, we formulated a number of hypotheses based on the literature from the general US population and other ethnic/racial minority populations.¹⁰

Compared to a US-born majority sample, lower health literacy would be predicted to be more of concern in our sample, given the lower levels of educational attainment of New York City Haitian immigrants¹³ compared with the general population and with other Haitians living in the United States. Specifically, whereas 9% of native-born Americans and 22% of Haitian immigrants living in the United States have not graduated from high school,²⁷ 42.3% of our sample had not graduated from high school (data not shown). Additionally, nearly our entire sample was born in Haiti; immigration to the US, rather than language spoken at home, has been reported to predict lower health literacy.¹⁰

Our Cronbach alpha of 0.779 for the total sample and 0.776 for Haitian Creole speakers was comparable to the values obtained by Wallston et al²¹ when the original (English) version of the screener was administered to a clinic sample by a research assistant. In our sample, health literacy scores varied according to age, education, and language. These results are consistent with the body of literature regarding the general population.² Of note, health literacy did not differ between duration of residence in the United States (< 10 years vs > 10 years).

Our study showed that persons with lower mean BHLS scores were less likely to access the Internet, a finding that also has been noted by other investigators.^{28,29} Although verbal communication is important, studies indicate that combining verbal and written information is more important than verbal information alone with regard to improving patients' knowledge and recall of medical facts.³⁰ Consistent with the literature, Haitians who reported seeking information on health or medical topics, including cancer from any source, had higher mean BHLS scores than Haitians who did not. Data from the 2007 Health Information National Trends Survey (HINTS) indicate that respondents with lower educational attainment who completed the 2007 HINTS were less likely to seek health information and had decreased confidence in their ability to obtain health information.³¹

With regard to sources of trust, participants with lower health literacy placed greater trust in family and friends and religious organizations and leaders. Other investigators have noted that race, ethnicity, language, and social class are associated with trust in cancer information. Investigators examining the 2003 HINTS reported an inverse relationship between income and reporting a lot of trust in cancer information from family and friends.³²

The inability to speak English also may require that Haitian Creole-speaking persons rely more exclusively on friends and family and religious leaders. Because Haitian Creole is mainly a verbal form of communication, the immigrant Haitian community may be dependent on the oral tradition to obtain and disseminate information.³³ Other investigators conducting focus groups of minority women have highlighted the importance of family, friends, and community in understanding and disseminating health-related information as well as the desire for a local community context in health communication.³⁴ Our finding that health literacy did not differ between persons with more or less trust in the information provided by their doctor was not surprising. Gutierrez et al³⁵ showed that level of health literacy did not impact patient's reliance on their healthcare providers to obtain health information in the primary care setting.

Improving how health information is acquired and delivered may serve as a means to lessen health disparities between minority and nonminority groups as well as within a given group.³¹ The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care's principal standard centers on providing care that is responsive to diverse cultural health beliefs and practices, preferred languages, and health literacy.³⁶ Similarly, the National Action to Improve Health Literacy emphasizes the need to support and expand local efforts to provide adult education, English language instruction, and culturally and linguistically appropriate health information services in the community. Culturally-tailored education programs have been developed with increasing frequency and shown to improve health-related knowledge and knowledge of the English language among disadvantaged populations.³⁷ Ultimately, these gains in knowledge and language could translate into improvements in health literacy.^{38,39} On a practical note, organizations have been increasingly translating materials into Haitian Creole that focus on salient health conditions.^{40,41} Such materials are intended for low literacy audiences and would be well-suited for distribution in the primary care setting.

Our study has a number of limitations. Our sample was drawn from patients seen at a single ambulatory care practice in New York City, thereby limiting the generalizability of these findings to the general population of Haitian Creole speakers. Because those sampled have access to healthcare and a primary care provider, these patients would be expected to have a greater trust and comfort with their providers and the medical setting. Our sample size also was small, limiting the number and type of comparisons that were able to be made. In particular, we were unable to do multi-variable adjustments for health-information seeking behavior and degree of trust about health or medical topics from various sources. Additionally, we used a measure of health literacy that was validated in the clinical setting, but it presently is unknown if higher or lower mean and median scores translate into clinically meaningful outcomes.²¹ Finally, we only assessed written health literacy and, as such, did not account for other forms of health literacy, such as oral (speaking), aural (listening), and numeracy. Patients with lower levels of health literacy in one area may not necessarily have lower levels of literacy in other areas and, therefore, may be able to receive health-related information effectively through other modalities.⁴² To date, however, there has been an over-reliance upon written communication,⁶ a finding that may become more prominent with the introduction of Web-based portals where patients can access health information in addition to their electronic health records.

This is the first study to examine health literacy in Haitian immigrants in the primary care setting using a 3-item measure. The measure distinguished groups according to age, educational attainment, and language of survey. Health literacy also was associated with seeking health information and degree to which participants would trust various sources of information regarding health. Constructing culturally-tailored and other appropriate interventions regarding health promotion and disease prevention requires better understanding of how the population accesses health information and how—or by whom—this information should be conveyed, thereby requiring the integration of linguistic and cultural factors into health communication efforts. Our sample had a number of characteristics—language, immigration, educational attainment—that should be considered when designing culturally-tailored interventions that can engage and activate patients and, ultimately, improve health. These interventions should be based on health-related topics that have salience for the Haitian community and might be derived through a community-based participatory approach.

Human Subjects Statement

The researchers submitted the project as a prospective exempt research application to the Memorial Sloan Kettering Cancer Center (MSKCC), City College of New York (CCNY), and QHC Institutional Review Boards following the Office of Human Research Protections decision charts for determination of exempt research. The MSKCC, CCNY, and QHC Institutional Review Boards deemed the research involving human subjects eligible for exemption under 45 CFR 46.101.b (2).⁴³ The request to waive Health Insurance Portability and Accountability Act authorization and informed consent was also granted as per 45 CFR 164.512(i)(2)(ii) and 45 CFR 46.116(d).⁴³ As per MSKCC Institutional Review Board guidelines, any substantial change to the exempt protocol was reviewed by the institutional review board to ensure that the project continued to meet the exempt status definition. Although the research was deemed exempt and the waiver of informed consent was determined, per Good Clinical Practice⁴⁴, prior to conducting the anonymous survey, we verbally outlined the risk and benefits of the research, the voluntary nature of the study and how refusal would not affect care at QHC. Verbal agreement to participate was obtained prior to survey administration.

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The study was reviewed and approved as exempt research by the Institutional Review Boards at The City College of New York (CCNY), Memorial Sloan-Kettering Cancer Center (MSKCC), and Queens Hospital Center. We have included acknowledgements, conflict of interest, and funding sources after the discussion.

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Table 1
Characteristics of 85 Survey Participants

	Survey language			p-value ^a
	Overall (N = 85)	English (N = 16; 19%)	Creole (N = 69; 81%)	
Age (years), Median (range)	52.0 (23.0, 80.0)	37.5 (23.0, 66.0)	55.0 (32.0, 80.0)	<.001
Age (years), N (%)				<.001
<50	35 (41.2)	13 (81.3)	22 (31.9)	
50	48 (56.5)	3 (18.8)	45 (65.2)	
Sex, N (%)				.546
Male	22 (25.9)	3 (18.8)	19 (27.5)	
Female	63 (74.1)	13 (81.3)	50 (72.5)	
Where born, N (%)				.006
US	3 (3.5)	3 (18.8)	0 (0.0)	
Haiti	80 (94.1)	13 (81.3)	67 (97.1)	
Other	1 (1.2)	0 (0.0)	1 (1.4)	
Years living in US, N (%)				.156
10	29 (34.1)	3 (18.8)	26 (37.7)	
>10	54 (63.5)	13 (81.3)	41 (59.4)	
Marital status, N (%)				.213
Married/living with partner	44 (51.8)	8 (50.0)	36 (52.2)	
Single	22 (25.9)	7 (43.8)	15 (21.7)	
Divorced/separated/widowed	17 (20.0)	1 (6.3)	16 (23.2)	
Salary, N (%)				.049
<\$10,000	17 (20.0)	2 (12.5)	15 (21.7)	
\$10,000-\$29,999	32 (37.6)	5 (31.3)	27 (39.1)	
\$30,000	19 (22.4)	8 (50.0)	11 (15.9)	
Education, N (%)				<.001
Less than high school/GED	49 (57.6)	1 (6.3)	48 (69.6)	
2-year college/trade school	20 (23.5)	8 (50.0)	12 (17.4)	
4-year college or more	13 (15.3)	6 (37.5)	7 (10.1)	

Note.

^a = p-value from Fisher's exact test when categorical and Wilcoxon test when continuous; missing observations excluded from calculation of p-value

Table 2
Characteristics of Participants by Brief Health Literacy Screen (BHLS) Score

	Brief Health Literacy Screen Score		p-value ^a
	Mean (SD)	Median (Range)	
Age (years)			<.001
<50	13.4 (2.4)	15.0 (7.0, 15.0)	
50	10.4 (3.9)	11.0 (3.0, 15.0)	
Sex			.539
Male	12.0 (3.8)	13.0 (3.0, 15.0)	
Female	11.7 (3.6)	13.0 (3.0, 15.0)	
Education			<.001
Less than high school/GED	10.5 (3.9)	11.0 (3.0, 15.0)	
2-year college/trade school	14.0 (2.2)	15.0 (7.0, 15.0)	
4-year college or more	12.8 (2.6)	14.0 (8.0, 15.0)	
Marital status			.909
Married/living with partner	11.6 (3.7)	12.5 (3.0, 15.0)	
Single	12.1 (3.7)	14.0 (3.0, 15.0)	
Divorced/separated/widowed	11.4 (3.5)	12.0 (5.0, 15.0)	
Years living in US			.334
10	11.2 (3.9)	12.0 (3.0, 15.0)	
>10	12.0 (3.5)	13.5 (3.0, 15.0)	
Language			<.001
English	14.1 (1.8)	15.0 (9.0, 15.0)	
Haitian Creole	11.2 (3.7)	12.0 (3.0, 15.0)	

Note.

^a = p-value from Kruskal-Wallis test; missing observations excluded from calculation of p-value

Table 3
Sources of Health-Information and Level of Trust

	Brief Health Literacy Screen Scores		
	Mean (SD)	Median (Range)	p-value ^a
Have you ever looked for information about health or medical topics from any source?			.012
Yes	12.4 (3.4)	15.0 (3.0 - 15.0)	
No	10.8 (3.7)	11.0 (3.0 - 15.0)	
Have you ever looked for cancer information from any source?			.009
Yes	13.0 (2.7)	14.5 (7.0 - 15.0)	
No	10.8 (3.9)	11.0 (3.0 - 15.0)	
The most recent time you looked for information about health or medical topics where did you go first?			.111
Books, brochures, pamphlets, etc.	12.0 (2.6)	12.0 (9.0 - 15.0)	
Family, Friend/coworker	9.5 (1.7)	9.5 (8.0 - 11.0)	
Doctor or health care provider	11.3 (4.0)	13.0 (3.0 - 15.0)	
Complementary, alternative or unconventional practitioner	15.0 (.)	15.0 (15.0 - 15.0)	
Radio	9.0 (2.8)	9.0 (7.0 - 11.0)	
Internet	13.4 (2.3)	15.0 (8.0 - 15.0)	
Religious leader	11.0 (5.7)	11.0 (7.0 - 15.0)	
In general, how much would your trust information about health or health or medical topics from each of the following?			
A doctor			.129
A lot/Some	11.9 (3.5)	13.0 (3.0 - 15.0)	
A little/Not at all	9.4 (4.7)	8.0 (3.0 - 14.0)	
Family or Friends			.029
A lot/Some	11.3 (3.7)	12.0 (3.0 - 15.0)	
A little/Not at all	13.1 (3.0)	15.0 (7.0 - 15.0)	
Newspapers or Magazines			.408
A lot/Some	12.2 (3.0)	13.0 (3.0 - 15.0)	
A little/Not at all	11.4 (3.9)	13.0 (3.0 - 15.0)	
Radio			.066
A lot/Some	10.9 (3.8)	11.0 (3.0 - 15.0)	
A little/Not at all	12.4 (3.4)	14.0 (3.0 - 15.0)	
Internet			.978
A lot/Some	11.9 (3.1)	13.0 (3.0 - 15.0)	
A little/Not at all	11.6 (3.9)	13.0 (3.0 - 15.0)	
Television			.714
A lot/Some	12.0 (3.2)	13.0 (3.0 - 15.0)	
A little/Not at all	11.5 (4.0)	13.0 (3.0 - 15.0)	
Government Health Agencies			.575
A lot/Some	11.5 (3.6)	12.5 (3.0 - 15.0)	
A little/Not at all	12.0 (3.7)	13.0 (3.0 - 15.0)	

	Brief Health Literacy Screen Scores		
	Mean (SD)	Median (Range)	p-value ^a
Charitable Organizations			.232
A lot/Some	12.1 (3.4)	13.0 (3.0 - 15.0)	
A little/Not at all	11.3 (3.8)	12.5 (3.0 - 15.0)	
Religious Organizations and Leaders			.027
A lot/Some	11.0 (3.7)	11.0 (3.0 - 15.0)	
A little/Not at all	12.6 (3.3)	14.5 (3.0 - 15.0)	
Spiritual healer			.386
A lot/Some	11.3 (3.8)	12.0 (3.0 - 15.0)	
A little/Not at all	12.2 (3.4)	14.0 (3.0 - 15.0)	
Do you ever go on-line to access the Internet or World Wide Web?			.001
Yes	12.9 (2.6)	14.0 (7.0 - 15.0)	
No	10.1 (4.2)	11.0 (3.0 - 15.0)	

Note.

^a = p-value from Kruskal-Wallis test