Health literacy and healthcare engagement as predictors of shared decision making among adult information seekers in the United States: a secondary data analysis of the Health Information National Trends Survey

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Abstract

OBJECTIVE—To examine the relationship between health literacy, healthcare engagement, and shared decision making (SDM).

METHODS—We analyzed Health Information National Trends Survey 4 (Cycle 3) data for 1,604 information seekers who had one or more non-emergency room healthcare visits in the previous year.

RESULTS—SDM was more than two times higher among adults who "always" versus "usually/sometimes/never" take health information to doctor visits (OR=2.54; 95% CI: 1.19–5.43). There was a twofold increase in SDM among adults who were "completely/very confident" versus "somewhat/a little/not confident" about finding health information (OR=2.03; 95% CI: 1.37–3.02). Differences in SDM between adults who understood health information and those who had difficulty understanding health information were not statistically significant (OR=1.39; 95% CI: 0.93–2.07).

CONCLUSION—A Healthy People 2020 goal is to increase SDM. Previous research has suggested that SDM may improve health outcomes across the continuum of care. Only about half of adults report always being involved in healthcare decisions. Even more alarming is the fact that SDM has not increased from 2003–2013. Our findings suggest that increasing health literacy has the potential to increase healthcare engagement and subsequently increase SDM.

PRACTICE IMPLICATIONS—Effective intervention strategies are needed to improve health literacy and promote healthcare engagement.

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Keywords

1. Introduction

Shared decision making (SDM) has been reported to improve long term health outcomes (e.g., treatment adherence) and therefore should be a goal for patient-provider healthcare encounters involving the management and treatment of chronic disease [1–2]. Key characteristics of SDM have been described as the following: (1) at a minimum involves patients and providers, (2) requires good patient-provider communication, such as, patients being able to ask health-related questions and providers making sure that patients understand the health information shared with them, (3) involves patients and providers in making decisions about the patient's healthcare, and (4) agreement between patients (and caregivers if applicable) and providers about treatment plans [3]. Despite the potential benefits of SDM, patients with lower health literacy may be less engaged in their healthcare overall [4–5]. Other vulnerability characteristics (e.g., older age, racial/ethnic minority, lower SES, healthcare access barriers, poor health status) may further exacerbate efforts to improve patient-centered healthcare outcomes [6].

Although SDM is a Healthy People 2020 objective [7], adults who reported that their health care provider(s) (HCP) always involved them in SDM decreased from 61.1% in 2003 to 51.4% in 2013 [8]. The Health Information National Trends Survey (HINTS) data has been used to examine this Healthy People 2020 objective. For example, studies have examined the relationship between cancer survivors' receipt of treatment summaries and patient-centered communication outcomes including SDM [9] and the extent to which HCP provided men with information needed to make an informed decision about PSA testing [10]. Chronic disease prevention is the focus of both of these studies, and therefore these findings may not be generalizable to the context of a general healthcare practice setting [11]. Also, HCPs use a more paternalistic approach to provide patients with health information and may not best represent SDM from an autonomy perspective as some researchers have suggested [12–15].

In fact, little is known about how patients are using the health information that they have found during subsequent patient-provider healthcare encounters, how patients' information seeking relates to healthcare engagement, or how bringing health information to a doctor visit impacts SDM. To this end, the third cycle of the 4th iteration of the HINTS (HINTS 4, Cycle 3) included questions about both patient-centered communication (e.g., SDM) and healthcare engagement (e.g., taking health information to doctor visits). The current study examines patients' health information seeking experiences (i.e., their ability to find health information and understand the health information that they found), and healthcare engagement (i.e., taking health information to doctor visits) as predictors of SDM, which is operationalized by Healthy People 2020 as patients feeling like their HCP always involved them in decisions about their healthcare. To identify SDM predictors that will help the U.S.

reach the target goal of 56.8% of adults reporting that their HCP always involved them in SDM, we will investigate the following research questions:

> RQ1: Are adults who always take health information to doctor visits always involved in SDM?

> RQ2: Are adults who are more confident about their ability to find health information more involved in SDM?

> RQ3: Are adults who are able to understand health information always involved in SDM?

We will also explore whether or not health literacy mediates the relationship between patient-centered provider communication and healthcare engagement. To this end, we will investigate the following additional research questions:

> RQ4: Does healthcare engagement mediate the relationship between health literacy and SDM?

2. Methods

This was a cross-sectional study. Data from the third cycle of the 4th iteration of the Health Information National Trends Survey (HINTS 4, Cycle 3) were analyzed. The self-administered survey was mailed to 12,010 United States (U.S.) household addresses between September-December 2013 [8] and a total of 3,185 adults between the ages of 18–105 years old completed it (26.5% response rate) [8]. Additional details are available on the HINTS 4, Cycle 3 (2013) Methodology Report [8].

This secondary data analysis included 1,604 health information seekers who had one or more non-emergency room healthcare visits in the previous year. We excluded 585 participants who reported that they have never looked for health information, and 425 participants who reported that they did not have any non-emergency room healthcare visits in the previous year. An additional 571 observations with missing data for one or more variables were also excluded.

SDM was the primary outcome of interest. Healthcare engagement was the exposure (i.e., main independent variable). Health literacy was examined as a potential confounder (i.e., mediator or moderator) of the relationship between SDM and healthcare engagement. Sociodemographic, socioeconomic status (SES), health insurance, and health status variables were included as covariates.

A Health Communication and Health Information Technology (HC/HIT) objective (HC/HIT-3) of Healthy People 2020 is to increase the proportion of persons who report that their HCP *always* involved them in decisions about their health care [7]. A single HINTS item was used to assess SDM at baseline. This item was the data source used to establish baseline data in the Healthy People 2020 national goals and objectives [7] and this same HINTS question was used to assess SDM for this study. Specifically, participants were asked, "In the past 12 months, how often did your health professional: Involve you in decisions about your health care as much as you wanted?" A 4-point Likert scale was used (always/usually/

sometimes/never). For the purposes of this study, this variable was dichotomized as "always" versus "usually/sometimes/never" to be consistent with the Healthy People 2020 objective (HC/HIT-3) [7].

A single item was used to assess patients' engagement with their HCP. Participants were asked, "How often do you take health information that you find to your doctor visits?" A 4-point Likert scale was used (always/usually/sometimes/never). This variable was dichotomized as "always" versus "usually/sometimes/never" to be consistent with the Healthy People 2020 assessment of SDM [7].

Although health literacy is still a relatively new construct and the definition continues to evolve [16–17], the following definition of health literacy has been widely used: "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions [18–19]. Two HINTS questions were used to operationalize health literacy goals of being able obtain and understand health information.

Specifically, the ability to obtain health information was assessed by asking participants how confident they were about being able to find health information if they needed it. A 5-point Likert scale was used (completely/very/somewhat/a little/not at all). Information seeking self-efficacy was dichotomized as "completely/very confident" versus "somewhat/a little/not at all confident." This recoding is consistent with how previous studies have examined this HINTS question [20–21].

Participants were also asked if the health information they found was hard to understand. A 4-point Likert scale was used (strongly agree/somewhat agree/somewhat disagree/strongly disagree). Health information was dichotomized as "easy to understand" for participants who disagreed with this statement, and "hard to understand" for participants who agreed with this statement. This recoding is consistent with how other researchers have examined this HINTS question [21].

Sociodemographics included age (<50 or 50 years old), gender (male, female), race/ethnicity (non-Hispanic White, non-Hispanic Black, non-Hispanic other, Hispanic), and marital status (married, unmarried). SES included education (high school, post-secondary training/education), income (<$50,000, $50,000), and employment (employed, unemployed, other). Health status (insured, uninsured) and general health status (excellent/very good/good, fair/poor) were also included as covariates.

HINTS 4, Cycle 3 data have been weighted using a jackknife variance estimation to produce a sample that is representative of the U.S. population [8]. All analyses were performed on weighted data using Stata/IC 13.1 statistical software package (College Station, Texas, USA). Bivariate analyses included Chi-square tests and Spearman's rank correlation analyses. Sample characteristics were assessed by SDM using Chi-square tests. Unweighted frequencies, weighted percentages, and p-values are reported in Table 1 to describe our sample. Spearman's correlation analyses were performed to assess multicollinearity between the key measures (i.e., SDM, healthcare engagement, health literacy). Correlation coefficients and p-values of these relationships are reported in Table 1.

Multivariate logistic regression analyses were also performed. We modeled SDM=always. First, the crude association between our primary outcome (i.e., SDM) and main independent variable (i.e., healthcare engagement) was assessed. Crude associations between SDM and potential confounders and covariates were also assessed. Next, we added each covariate (i.e., sociodemographics, SES, health insurance, general health status) and potential confounders (i.e., health literacy) to the model one-by-one in a forward-stepwise fashion. Any variable that increased or decreased the crude odds ratio for the main independent variable (i.e., healthcare engagement) by more than 10% was considered a potential confounder and kept in the full model. Age, gender, and race/ethnicity were forced into the full model regardless of potential confounding.

For this study, complete data were only available for 50.4% (n=1,604/3,185) of HINTS 4, Cycle 3 participants. Although non-seekers (n=585) and patients who did have any non-emergency room healthcare visits in the previous year (n=425) were not applicable for our study, these participants alone accounted for almost two-thirds (63.9%) of the missing observations (n=1,010/1,581). This still left 571/3,185 (17.9%) observations with missing data unaccounted for across the variables used in this study.

Missing data were most prevalent for race (n=294), ethnicity (n=373), and income (n=446) variables. HINTS used PROC HOTDECK from the SUDAAN statistical software to impute missing data for the following variables: age, gender, educational attainment, marital status, race, ethnicity, health insurance coverage, and cancer diagnosis. We used the HINTS derived race/ethnicity and income variables with imputed values. This reduced the amount of data missing for income from n=466 to n=158. However, missing data for race/ethnicity was only reduced to n=460. Our sample size for our logistic regression analyses was also increased from 1,604 to 1,704 by creating a second analytic sample that only included the main independent variable, potential confounders, and control variables that were used in the full model.

3. Results

Most of the participants were married NH white females <50 years old whose annual household income was/exceeded $50,000. Many of the participants used the Internet, were insured, had received post-secondary training or education, and were in good or better health. These data are reported in Table 2.

RQ1 asked whether adults who always take health information to doctor visits are always involved in SDM. Only 10.5% (n=168) of participants reported that they always take health information they find to doctor visits (Table 2). The chi-square tests approached statistical significance (p=0.06) (Table 2). Both the crude (OR=2.15; 95% CI: 1.07, 4.34) and adjusted (OR=2.54; 95% CI: 1.19, 5.43) odds ratios were statistically significant (Table 3). This suggests that patients' healthcare engagement is a positive predictor of SDM.

RQ2 asked whether adults who are more confident about their ability to find health information are more involved in SDM. Most of the participants (62.1%, n=996) reported that they were completely/very confident about being able to find health information if they

needed it (Table 2). The chi-square tests (p=0.0001) (Table 2), as well as the crude (OR=2.22; 95%CI: 1.50, 3.28) and adjusted (OR=2.03; 95% CI: 1.37, 3.02) odds ratios were statistically significant (Table 3). This suggests that patients' health information seeking self-efficacy is a positive predictor of SDM.

RQ3 asked whether adults who are able to understand health information are always involved in SDM. A majority of participants (76.4%, n=1,225) (Table 2) were able to understand the health information that they found. Although the chi-square tests (p=0.0023) (Table 2) and crude odds ratio (OR=1.80; 95% CI: 1.20, 2.69) (Table 3) were both statistically significant, the adjusted odds ratio (OR=1.39; 95% CI: 0.93, 2.07) (Table 3) was not statistically significant. This suggests that although patients' health literacy may be important, the relationship between health literacy and SDM may be less significant after controlling for other factors.

RQ4 asked whether healthcare engagement mediate the relationship between health literacy and SDM. There were statistically significant crude associations between being able to understand health information and the following: taking health information to doctor visits (OR=0.55; 95% CI: 0.32, 0.96), and always being involved in SDM (OR=1.80; 95% CI: 1.20, 2.69). As reported in Table 3, the crude association between taking health information to doctor visits and always being involved in SDM were also statistically significant (OR=2.15; 95% CI: 1.07, −4.34). The main effect of health literacy (i.e., ability to understand health information) on always being involved in SDM not only remained statistically significant, but was slightly increased (OR=1.90; 95% CI: 1.29, 2.79) in a subsequent logistic regression model that included healthcare engagement and control variables (i.e., age, gender, race/ethnicity). Because the crude association between being able to find health information and taking health information to doctor visits was not statistically significant (OR=0.83; 95% CI: 0.47, 1.48), no further tests for mediation were needed.

4. Discussion and Conclusion

4.1. Discussion

This study's findings suggest that adult information seekers who take the health information that they find to their doctor visits are more likely to report being highly involved in SDM with their HCP. These findings are interesting given the surprisingly low prevalence (10.5%) of "always" being involved in SDM in our study, especially in contrast to the Healthy People 2020 baseline data (51.6%) [7]. The findings from this study also suggest that adults information seekers who are more confident about their ability to find health information may also be more likely to be highly involved in SDM. Healthcare engagement mediated the relationship between health information seeking self-efficacy and SDM. This suggests that SDM intervention strategies should stress on improving patients' ability to find, understand, and use health information at doctor's visits, in addition to focusing on improving providers' SDM skills [1].

Although we anticipated that patients' ability to understand the health information that they found would predict being highly involved in SDM with HCP, this did not turn out to be the case in this study. It is important to note that information seekers often feel overloaded by

the volume and complexity of the health information that they find [22]. Thus, patient-centered communication strategies should seek to reduce this negative impact of information seeking. For example, it might be helpful for providers to refer patients to trusted online sources of health information that offer evidence-based resources that have been written in plain language. The Agency for Healthcare Research and Quality, American Cancer Society, and National Cancer Institute's Cancer Information Service websites are some examples of these resources that patients and their family members can access. Then, providers could add a follow-up note to the patient's chart as a reminder to ask if they had any questions about the information that they found.

Further, these findings make sense in the context of utilizing the patient-provider healthcare encounter as an opportunity to better communicate health information to facilitate patient understanding [3]. In fact, HINTS data suggests that although patients are more likely to look for health information on the Internet, they are more likely to trust HCPs as a source of information about cancer [23]. This underscores the importance of both health information seeking self-efficacy and patient-centered communication during healthcare encounters, especially for patients who, regardless of their health literacy level, may feel overwhelmed by the complexity of the health information. This may particularly be the case for patients with long-term chronic health issues such as cancer [22].

There are several limitations to the study that should be noted. First, we assessed patients' perceptions of SDM, and not actual provider behaviors. This is in addition to the inherent study limitations that are associated with using a cross-sectional study design and a single item to assess SDM [24]. On a basic level, these included self-report and recall bias. Another drawback to using survey data is the fact that we are only able to look at associations and therefore are not able to assess causality. Finally, while the HINTS 4, Cycle 3 survey data was representative of the national population, it is important to note that our sample was largely non-Hispanic white and had a higher SES than those who may have more limited health literacy [4–5]. These factors limit the generalizability of study findings, especially among vulnerable populations (e.g., low socioeconomic status) [5] who would likely benefit the most from SDM. Despite these limitations, this study adds to the growing body of literature focused on patient-centered communication outcomes by underscoring the importance of healthcare engagement to achieving our nation's goal of increasing the number of adults who are highly involved in SDM with their HCP.

4.2. Conclusion

Although some adults with low health literacy are less engaged in patient-provider communication and SDM [5], this may also be the case among high health literate adults who feel overwhelmed by the complex nature of the information that they have found or are given by their HCP [22]. While it is highly likely that improving health literacy will have a positive impact on patient-provider communication and SDM, it is equally important that the healthcare encounter be used to improve patient-centered communication for those who are less health literate and/or feel overloaded by the health information that they have either found on their own or given by their HCP. Either way, health information seeking self-efficacy will play a vital role in moving towards SDM as opposed to a more paternalistic

approach where patients have little involvement and even less autonomy in the decisions that are being made about their health [13–15].

4.3. Practice implications

While being able to understand health information is important, it is imperative that patients are able to talk to their HCP about any unanswered questions or concerns that they may have. As study findings suggest, both improving health information seeking self-efficacy and health literacy have the potential to positively impact healthcare engagement and SDM. This underscores the importance of patient engagement in SDM [25], instead of solely focusing on provider-based education as a strategy for increasing SDM. Not only do these findings contribute to a better understanding of the relationship between information seeking, health literacy, and patient-centered communication (i.e., SDM), but also emphasizes the importance of developing effective SDM interventions that are aimed at improving patients' health information seeking self-efficacy and health literacy as well as HCP communication practices. Thus, multilevel interventions are needed. An example of an intervention strategy that might be explored at the patient level would be an educational program that would teach patients how to access reliable sources of health information. At the provider level, educational strategies include highlighting the importance of using plain language when communicating with patients and using the healthcare encounter as an opportunity to facilitate patient understanding.

Acknowledgments

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Table 1

Spearman correlation matrix (n=1,604)

	SDM	Take Health Info	Obtain Health Info	Understand Health Info
SDM	1.0000			
Take Health Info	0.0916 ***	1.0000		
Obtain Health Info	−0.1629 ***	0.0320	1.0000	
Understand Health Info	0.2221 ***	0.0256	−0.4835 ***	1.0000

*
p<0.05;

**
p<0.01;

***
p<0.001

Table 2

SDM among 1,604 information seekers who had 1 non-emergency room health visits in the past year

Characteristic	Total n[1] (%)[2]	Always %[2]	Usually/Sometimes/Never %[2]	p-value[3]
Healthcare Engagement:				
Take information to doctor visits				0.0628
Always	168 (10.5)	13.2	7.5	
Usually/Sometimes/Never	1,436 (89.5)	86.8	92.5	
Health Literacy:				
Ability to obtain health information				0.0001 ***
Completely/very confident	996 (62.1)	71.0	52.6	
Somewhat/a little/not at all confident	608 (37.9)	29.0	47.4	
Ability to understand health information				0.0023 **
Hard to understand	378 (23.6)	17.8	29.8	
Not hard to understand	1,225 (76.4)	82.2	70.2	
Internet Use:				0.6712
Online	1,448 (90.3)	90.6	89.8	
Offline	156 (9.7)	9.4	10.2	
Sociodemographics & SES				
Age (years)				0.0159 *
<50	942 (58.7)	53.7	64.1	
50	662 (41.3)	46.3	35.9	
Gender				0.0075 **
Female	913 (56.9)	52.5	61.5	
Male	691 (43.1)	47.5	38.5	
Race/ethnicity				0.3870
NH White	1,147 (71.5)	72.9	69.9	
NH Black	159 (9.9)	10.7	9.0	
NH Other	112 (7.0)	5.8	8.2	
Hispanic	186 (11.6)	10.5	12.8	
Marital status				0.3942
Married	1,022 (63.7)	65.3	61.9	
Unmarried	585 (36.3)	34.7	38.1	
Education				0.9211
HS	350 (21.8)	21.6	51.8	
Post-HS training	1,254 (78.2)	78.4	48.2	
Income				0.2449
<$50,000	650 (40.5)	38.2	43.0	
$50,000	954 (59.5)	61.8	57.0	
Employment				0.9964
Employed	1,028 (64.1)	64.3	63.9	
Unemployed	77 (4.8)	4.7	4.8	

Characteristic	Total n[1] (%)[2]	Always %[2]	Usually/Sometimes/Never %[2]	p-value[3]
Other[4]	499 (31.1)	31.0	31.3	
Health Insurance:				0.2096
Insured	1,432 (89.3)	91.1	87.3	
Uninsured	172 (10.7)	8.9	12.7	
General Health Status:				0.0941
Excellent/very good/good	1,410 (87.9)	90.0	85.6	
Fair/poor	194 (12.1)	10.0	14.4	

[1] unweighted;

[2] weighted;

[3] Unadjusted Wald (Pearson) chi-square tests;

[4] Other employment status incudes homemaker, student, retired, disabled; high school (HS); non-Hispanic (NH); socioeconomic status (SES)

[*] p<0.05;

[**] p<0.01;

[***] p<0.001

Table 3

Logistic regression analyses (n=1,704)[1]

Model: SDM=Always	Crude OR (95%CI)	Adjusted OR (95%CI)
Healthcare Engagement:		
Always takes health information to doctor visits (REF=Usually/sometimes/never)	2.15 (1.07, 4.34)[*]	2.54 (1.19, 5.43)[*]
Health Literacy:		
Completely/very confident about ability to obtain health information (REF=Somewhat/a little/not confident at all)	2.22 (1.50, 3.28)[***]	2.03 (1.37, 3.02)[**]
Ability to understand health information (REF=Health information was hard to understand)	1.80 (1.20, 2.69)[**]	1.39 (0.93, 2.07)
Sociodemographics:		
Age <50 years (REF= 50 years)	0.64 (0.46, 0.90)[*]	0.65 (0.45, 0.92)[*]
Gender=Females (REF=Male)	0.76 (0.59, 1.00)[*]	0.73 (0.55, 0.96)[*]
Race/ethnicity (REF=NH White)		
NH Black	1.03 (0.62, 1.72)	1.04 (0.59, 1.83)
NH Other	0.73 (0.37, 1.48)	0.76 (0.35, 1.65)
Hispanic	0.84 (0.50, 1.41)	0.85 (0.49, 1.49)

[1]A second analytic sample that only included the main independent variable, potential confounders, and control variables odds ratio was used; (OR); non-Hispanic (NH) |

[*]p<0.05;

[**]p<0.01;

[***]p<0.001