

Health literacy and patient activation: potential targets for improving health-related quality of life among patients with COPD

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Background

Patient engagement in self-management behaviors is an essential component of the chronic care model for providing optimal care of patients with chronic diseases (Coleman et al. 2009). A number of social and psychological factors may affect the level of patient engagement including attitudes, knowledge, motivation, and skills. Because the determinants of patient engagement are so complex the challenge for researchers and clinicians is how to detect and enhance the level of patient engagement to improve health outcomes? While there is no single instrument for measuring and predicting patient engagement, selected components have been studied including health literacy (HL) and patient activation (PA).

HL is the degree to which individuals have the capacity to obtain, process, and understand health-related information and low levels of HL are associated with poorer health status and outcomes (US DHHS 2010, Berkman et al. 2011, Koh et al. 2012, Omachi et al. 2012). Moreover, low health literacy is common in the US, but often goes unrecognized and untreated partly because of the limited evidence on effective systems for detecting and addressing gaps in patients' health literacy. Most measures of health literacy reported in the literature are research instruments that are not feasible for use in a busy health care setting.

PA describes patient characteristics that enable active participation in their health care (Hibbard et al. 2005). Limited evidence in the Medicare population using administrative data suggests that PA is associated with better health care experiences and greater rates of immunizations (Heller et al. 2009). However, scant evidence is available on the potential usefulness of measuring PA in the clinical setting.

Objectives

To determine the potential usefulness of two simple measures of HL and PA among patients with chronic diseases by describing the relationships between HL and PA, and health-related quality of life (HRQOL) among a representative sample of patients with COPD.

Methods

This is a cross-sectional analysis of baseline data from patients with COPD eligible for pulmonary rehabilitation enrolled in a self-management clinical trial. HL was measured using three questions: confidence in filling out forms (HL1), frequency of help to read hospital materials (HL2), or problems learning about medical condition (HL3) (Chew et al. 2008). PA was measured using two questions: confidence on when to seek medical care (ACT1) and frequency of taking a list of medications to doctor visits (ACT2) (Heller et al. 2009). HRQOL was measured using generic (SF-12) and disease-specific (Chronic Respiratory Questionnaire [CRQ]) instruments. Associations between HL and PA were examined using stratified and multivariate analyses adjusting for age, gender, race, marital status, income, and education.

Results

Of 325 patients the mean age (SD) was 76.7 (10.7) years with 49.5% male and 91.7% white. The severity of spirometric impairment included 43.7% moderate, 42.2% severe and 14.1% very severe. For HL, the majority of patients reported high levels of confidence completing forms (HL1-extremely/quite a bit=73.2%), and a minority reported needing help reading hospital materials (HL2-most of the time/all of the time=11.4%) or having difficulty reading and learning about their condition (HL3-most of the time/all of the time=9.7%) (Table). Of the components of HL the only significant association in the unadjusted analysis was between HL2 and SF-12 mental composite score ($p=0.02$). When the highest tertile of the composite HL scores was compared to the lowest tertile there was a clinically and statistically significant association only with the SF-12 mental composite score both in the unadjusted (-3.5 , $p=0.002$) and the adjusted (-6.3 , $p=0.009$) analyses.

For PA, the majority of patients reported being confident/very confident when to get medical care (ACT1=82.5%) and taking a list of medicines (ACT2=63.4%) (Table). In the unadjusted analysis ACT1 was directly and significantly associated with SF-12 physical ($p=0.04$) and mental ($p=0.004$) composite scores, and CRQ-fatigue ($p=0.006$) and CRQ-emotional ($p=0.004$). However, the only significant association in the adjusted analysis was between ACT1 and SF-12 mental composite score (2.97 , $p=0.0001$). There were no significant associations between ACT2 and any of the components of SF-12 or CRQ in either the unadjusted or adjusted analyses.

Conclusion

In this sample of patients with COPD representative of the spectrum of severity seen in primary and specialty care, a high proportion of patients report high levels of HL and PA, both of which are significantly associated with improved mental health-related quality of life. The composite HL score comparing the highest and lowest tertiles, and the self-efficacy component of PA (i.e., ACT1) were significantly associated with the mental health composite score of the SF-12.

While a high proportion of patients reported high levels of HL, these reports were limited to reading and comprehension skills, which may overestimate disease-specific HL skills. In a separate qualitative analysis of interviews conducted with 47 patients from the same study sample (Wortz et al. 2012) one of the major themes was need for better information and understanding about their disease. They expressed general lack of understanding about their condition including how to care for themselves, fear associated with uncertainty about their prognosis, and frustration knowing how to get informational and medical needs met.

Overall, our findings suggest that simple measures of patients' HL and self-efficacy may be useful for detection of patients at risk for low levels of engagement for self-management and poorer HRQOL, and highlights the need for interventions to enhance HL and self-efficacy with the goal of improving patients' HRQOL.

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Table
Distributions of Responses to Questions on Patient Activation and Health Literacy

MEASURE	%
Patient Activation (n=325)	
How confident are you that you can identify when it is necessary for you to get medical care?	
Very confident	55.1
Confident	27.4
Somewhat confident	15.4
Not at all confident	2.1
How often do you take a list of all of your prescribed medicines to your doctor visit?	
Always	52.6
Usually	10.8
Sometimes	15.4
Never	21.2
Health Literacy (n=175)	
How confident are you filling out forms by yourself?	
Extremely	42.2
Quite a bit	30.9
Somewhat	21.2
A little bit	2.3
Not at all	3.4
How often do you have someone help you read hospital materials?	
None of the time	60.0
A little bit of the time	11.4
Some of the time	17.1
Most of the time	5.7
All of the time	5.7
How often do you have problems learning about your medical condition because of difficulty reading hospital materials?	
None of the time	50.9
A little bit of the time	19.4
Some of the time	20.0
Most of the time	6.3
All of the time	3.4