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HEALTH LITERACY AND HEALTH-RELATED QUALITY OF LIFE AMONG A POPULATION-BASED SAMPLE OF CANCER PATIENTS

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Abstract

Health-related quality of life (HRQOL) is an important outcome in cancer care. Few studies indicate that health literacy (HL) influences cancer patients' HRQOL, but additional investigation is needed. We examined the relation between HL and HRQOL among cancer patients. A cross-sectional survey was conducted with cancer patients in Wisconsin during 2006–2007. Data on sociodemographics, clinical characteristics, HRQOL, and HL were obtained from the state's cancer registry and a mailed questionnaire. Regression analyses were used to characterize the association between HRQOL and HL. The study sample included 1,841 adults, newly diagnosed with lung, breast, colorectal, or prostate cancer in 2004 (response rate=68%). HRQOL was measured with the Functional Assessment of Cancer Therapy-General (FACT-G). Adjusting for confounders, higher HL was associated with greater HRQOL ($P < .0001$). Controlling for covariates, we found significant differences between those in the highest and lowest health literacy categories ($P < .0001$) and in the physical ($P < .0001$), functional ($P < .0001$), emotional ($P < .0001$), and social ($P = .0007$) well-being subscales. These associations exceeded the minimally important difference threshold for overall HRQOL and functional well-being. HL is positively and independently associated with HRQOL among cancer patients. These findings support adoption of HL best practices by cancer care systems.

Background

Health-related quality of life (HRQOL) has been shown to be an important outcome for evaluating breast, colorectal, lung, and prostate cancer treatment, cancer survival, and longer-term survivorship (Cella, Hahn, & Dineen, 2002; Montazeri, 2009; Jansen, Koch, Brenner & Arndt, 2010; Trask Hsu, McQuellon, 2009; Quinten, Coens, Mauer, Comte et al., 2009). Health-related quality of life is also an important component in treatment decisions

among providers and patients (Montazeri, 2009; Pusic, Cemal, Albornoz et al., 2013; Wachai, Armer, Stewart, 2011).

Among cancer patients, HRQOL is affected by sociodemographic factors (e.g. age, income and education), social networks, comorbidities, and physical and psychological symptoms (Jansen, Koch, Brenner, & Arndt, 2010; Sun, Borneman, Koczywas, et al., 2012; Gupta, Lis, Granick, et al, 2006; Peters & Sellick, 2006). Increasingly, health literacy and effective patient-provider communication are also recognized as influencing care across the cancer continuum (e.g., cancer screening; symptom management; communication about end of life care) and subsequently may be a determinant of HRQOL among cancer patients (Aziz, Miller, & Randall, 2012; Berkman et al., 2011; Davis, Williams, Marine, Parker, & Glass, 2002; Song, Mishel, Bensen, Chen, Knafl, Blackard, et al, 2012).

Approximately 12% of U.S. adults are proficient in health literacy (Kutner, Greenberg, Jin, & Paulsen, 2003). Health literacy is a dynamic concept that comprises an individual's ability to obtain, understand, and act upon health information amid a complex healthcare environment (Nielsen-Bohlman, Panzer, & Kindig, 2004). Health literacy can be viewed as the interplay between individual health literacy skills and the demands and complexity of health care organizations. Individual skills are not limited to the patients' health literacy ability. Providers' ability to be responsive to patients' preferences, communicate health information appropriately, engage in reciprocal communication, and ensure patients' understanding are also important health literacy skills (Brach et al., 2012; Institute of Medicine, 2001; McCormack, Treiman, Rupert, Williams-Piehot, Nadler, et al., 2011). An individual's ability to function in a healthcare environment may fluctuate based upon their actual and perceived health, provider communication skills, and the degree to which the design of the healthcare system is patient-centered (Nielsen-Bohlman, Panzer, & Kindig, 2004; Brach, Dreyer, Schyve, Hernandez, Baur, Lemerise, & Parker, 2012); DeWalt, Callahan, Hawk, et al., 2010). The Institute of Medicine (IOM) calls for promoting health literate organizations, defined as organizations that enables individuals to navigate, understand, and utilize health information and services (Brach et al., 2012). The IOM has also recommended healthcare organizations to pursue patient-centered care, a concept rooted in health literacy best practices, at the interpersonal and system levels (Brach et al., 2012; Nielsen-Bohlman, Panzer, & Kindig, 2004; DeWalt, Callahan, Hawk, et al., 2010; Institute of Medicine, 2001). Increasingly, understanding of health literacy is shifting the emphasis from individuals to a larger public health approach that includes healthcare organizations and public health departments (Institute of Medicine, 2014).

Despite increased interest in organization-level health literacy level, most research has focused on the impact of limited health literacy at the patient level. Low levels of health literacy in patients are related to inadequate utilization of health care services, higher mortality, worse self-rated health, poorer physical functioning over time among older adults, and poorer skills in interpreting health information, managing medications, and understanding medication-related instructions (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Smith, O'Connor, Curtis, Deary, Paasche-Orlow, & Wolf, 2015). Health literacy is a particularly important issue for cancer patients who must navigate a complex and fragmented health care system while in receipt of life changing diagnoses and

treatments (Koay, Schofield, & Jefford, 2012). Limited health literacy may hinder a patient's ability to understand the risks and benefits of cancer treatment and potentially impact their HRQOL (Davis, Williams, Marine, Parker, & Glass, 2002). Inadequate understanding or misconceptions about cancer treatment and misinformation provided by physicians are related to non-adherence to cancer treatment regimens (Puts, Tu, Tourangeau, Howell, Fitch, Springall, & Alibhani, 2014).

An evidenced-based review of pathways between patient-level health literacy and health outcomes has identified three plausible causative relationships (Paasche-Orlow & Wolf, 2007). Health literacy may affect patient access and utilization of health care (e.g. navigation skills, self-efficacy), patient-provider relationship (e.g. participation in decision making, provider communication skills.), and self-care (e.g. knowledge/skills, problem-solving) (Paasche-Orlow & Wolf, 2007). Consequently, decreases in HRQOL domains, such as symptom distress, could be mitigated by improving patients' understanding and self-management of physical and psychological distress or symptoms (Peters & Sellick, 2006; Herman & Looney; 2011; Hsiao, Moore, Insel, & Merkle; 2013; Yeom & Heidrich, 2013).

Few studies have examined the association between patient-level health literacy levels and HRQOL among cancer patients and the results have been mixed (Song, Mishel, Bensen, Chen, Knafl, Blackard, et al, 2012; Hahn, Garcia, Du, & Cella, 2010). One study found that literacy was not an independent risk factor for poorer HRQOL after controlling for measurement bias and other covariates (Hahn, Cella, Dobrez, Weiss, Du, Lai et al., 2007). However, another found that education, an important determinant of health literacy, predicted HRQOL among men with prostate cancer (Knight, Latini, Hart, Sadetsky, Kane, DuChane, & Carroll, 2007). Song et al., (2012) found that health literacy was positively related with mental well-being among prostate cancer patients. There is a paucity of research assessing the relationship between health literacy and HRQOL among cancer patients. Therefore, this study examined the association of HRQOL and health literacy among a registry-based statewide sample of breast, lung, prostate, and colorectal cancer patients in Wisconsin.

Methods

Setting and Study Participants

We conducted an analysis of data from the Assessment of Cancer Care and Satisfaction (ACCESS) study (Walsh, Trentham-Dietz, & Schroepfe, 2010). ACCESS was a cross-sectional survey conducted from 2006–2007 that gathered data on cancer care, patient satisfaction, co-morbid conditions, and HRQOL among a population-based sample of Wisconsin cancer patients. Eligible participants were Wisconsin residents aged 18–79 years old, newly diagnosed with lung, prostate, breast, or colorectal cancer in 2004 and reported to the Wisconsin Cancer Reporting System (WCRS), with valid addresses and alive at first contact per the Social Security Death Index or study telephone call. Eligibility for lung cancer cases also required a publicly available telephone number. In 2006, a random sample (N=2,582) of non-Hispanic white breast, colorectal, and prostate cancer cases was drawn from the WCRS. In addition, all non-white and/or Hispanic cases (N=269) were selected for participation. In all, the total initial sample was 3,265 patients. Of these, 2,431 subjects

meeting the eligibility criteria, who were living, and had valid addresses, were mailed a packet including a self-administered survey, cover letter, a study information sheet, return envelope, and a book of US postage stamps that served as an incentive (value: \$7.80). One week following the initial mailing, a postcard reminder was sent to all subjects. At three weeks, a cover letter, a second (identical) questionnaire, and study information sheet were sent to non-respondents and, at five weeks, telephone calls were made to the remaining potential study participants. Trained interviewers offered non-responders the opportunity to complete the survey over the phone.

Due to poor prognosis, lung cancer patients were approached with modified methods. An introductory letter was mailed to lung cancer patients without the survey. After one week, lung cancer patients were called by a trained interviewer to verify that the letter was received. Once verified that the patient was living, the survey and other study materials were mailed to the patient as previously described, but patients were also called 1 week after the initial mailing and offered the opportunity to complete the survey by phone. Of the 390 living lung cancer patients, 309 were eligible for the study (had valid phone number and mailing address).

A total of 1,841 cancer cases completed the survey (1,686 by mail and 155 by phone). Additional details about the recruitment and study methods have been published previously (Halverson et al., 2013; Walsh, Trentham-Dietz, & Schroepfe, 2010). The ACCESS study was approved by the Health Sciences Institutional Review Board at the University of Wisconsin-Madison.

Outcome Variable

Health-related quality of life was measured using the Functional Assessment of Cancer Therapy-General (FACT-G) (Cella, Tulsky, Gray Sarafian, Linn, Bonomi, et al., 1993). The FACT-G is an instrument specific to cancer patients included in the Function Assessment of Chronic Illness Therapy (FACIT) measurement system. The FACT-G and FACIT have been under development since 1987 and validated in over 50 languages and multiple populations, including older adults and rural residents (Cella et al. 1993; Winstead-Fry & Schultz, 1997; Overcash, Extermann, Parr, Perry, & Balducci, 2001; Cella, Zagari, Vondra, Gagnon, Hurtz, & Nortier, 2002; The FACT-G is one of the most reliable and widely used HRQOL measures in oncology research (Pearman, Yanez, Peipert, Wortman, Beaumont, & Cella, 2014.). The instrument comprises 27 self-reported items organized in four subscales that measure emotional, social, physical, and functional well-being. Responses are on a 5-point Likert scale. Higher FACT-G scores indicate better HRQOL. A minimally important difference (MID) in the FACT-G scale is 5 points for the total score and 2 points for the subscales (Bruckner, Yose, Cashy, Webster, & Cella, 2005). The FACT-G is written at approximately a 7th grade level (per the Fleish-Kincaid readability grade level) and previous research indicates no systematic literacy bias in reporting HRQOL (Hahn et al., 2007).

Main Effect Variable

Health literacy was assessed using four questions rated by self-report on a 5-point Likert scale. Three of the questions have been validated in previous studies using the Short Test of

Functional Health Literacy (STOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM) (Chew, Griffin, Partin, et al., 2004; Chew, Griffin, Partin et al., 2008). Questions included “How often do you have someone help you read hospital materials?; How often can you fill out medical forms by yourself?; How often do you have trouble taking your medications properly by yourself?; How often do you have problems learning about your medical condition because of difficulty understanding written information?” (Chew, Griffin, Partin, et al., 2004; Chew, Griffin, Partin et al., 2008). A composite health literacy score (Cronbach’s $\alpha = 0.63$) was created by summing the scores of the 4 questions (reverse coding the question “How often can you fill out medical forms by yourself?”). Scores could range from 4–20 and higher scores reflected higher levels of health literacy. This composite health literacy scale has been used in previous research with cancer patients (Halverson et al., 2013). In addition, we constructed a categorical measure using the quartiles as the cut points to divide patients in three groups: low (scores ≤ 16 , 1st quartile), medium (scores > 16 and ≤ 19 , 2nd quartile), and high health literacy (scores > 19 , 3rd and 4th quartiles). Individuals with one or more missing responses to the health literacy questions (6.8%, $N=126$) were excluded from the analyses.

Covariates

Data on sex, age, cancer site, county of residence, and extent of disease at time of diagnosis were obtained from the WCRS. We used the National Center for Health Statistics’ (NCHS) 6-level Urban-Rural classification for county of residence (Ingram & Franco, 2013). Milwaukee County is the only county in Wisconsin classified as Large Central Metro and was designated as “urban”. Milwaukee County is unique due to its high levels of health disparities and a high prevalence of poor health indicators and outcomes (University of Wisconsin, Population Health Institute, 2013). For the purposes of this study, Large Fringe Metro, Medium Metro, and Small Metro were combined and designated as the “mixed urban-rural” group. Micropolitan and Noncore counties were designated as “rural” (Halverson, et al, 2013). A categorical variable was created for extent of disease at first diagnosis, with four categories: localized/in situ, regional, distant/systemic, and unknown.

Race, ethnicity, and levels of income and education were based on responses to the survey. An indicator variable was created for race and ethnicity categorizing White, Non-Hispanic into one group and all other races and ethnicities into another. Education levels were classified according to the highest degree or year of school completed: Grades 1–11 or lower (less than high school), grade 12 (high school diploma, GED, or equivalent), 1–3 years of college (junior college), 4 years of college (college degree), or advanced degree (M.A., Ph.D., M.D., J.D., etc.). Income levels were categorized by total annual household income: $< \$15,000$, $\$15,000$ – $\$29,999$, $\$30,000$ – $\$49,999$, $\$50,000$ – $\$99,999$, and $> \$100,000$. Respondents missing information on income ($n=229$) or education ($n=40$) were included in the analysis with indicator variables representing missing education and income data.

Statistical Analyses

Descriptive statistics were computed for all variables and by health literacy level, and differences between levels tested by overall chi-square and F-tests. Unadjusted and multivariable linear regression models were fit to characterize the association between the

HRQOL and health literacy. The four HRQOL subscales were used as secondary outcome variables in separate regression models. Health-related quality of life was regressed on each covariate separately and then in a joint model (Table 2). We conducted our analyses using both the continuous and categorical health literacy measures to analyze the association between the variables and to emphasize the clinical interpretation of the findings. A quadratic term (not shown) was included to check for model fit of the continuous health literacy predictor. With health literacy as a categorical variable, high literacy was used as the reference category.

Respondents with missing data on HRQOL (n=136), health literacy (n=126), race (n=4), and ethnicity (n=26) were excluded from the fully adjusted model resulting in a sample size of N=1,632. All analyses were conducted in SAS, Version 9.1 (SAS Institute, Inc., Cary, North Carolina).

Results

A total of 1,841 cancer cases completed the survey (1,686 by mail and 155 by phone), yielding a response rate of 68%. Table 1 shows the sociodemographic, clinical, and HRQOL characteristics for the study sample overall and by health literacy level. About 50.8% of the survey respondents were women and had an average age of 63.2 (Standard Deviation [SD]=10.7). The racial and ethnic composition was mostly White, non-Hispanic (93%). Approximately 4.3% of the sample was African-American, 1.7 was American Indian/Alaskan Native, and 1% reported “other” as their race. Those of Hispanic or Latino ethnicity comprised 1.8% of the sample. Mixed urban-rural residents comprised the largest residential group (55.2%), followed by rural (29.3%), and urban (15.5%). Breast cancer patients comprised the largest (33.9%) and lung cancer (8.3%) the smallest cancer types. The extent of disease at first diagnosis was local/in situ (65.7%), followed by regional (27.1%), distant/systemic (5.5%), and unknown (1.7%). The mean HRQOL total score was 88.6 (SD=15.3). Mean scores for the physical, functional, social, and emotional well-being subscales were 23.9 (SD=4.7), 21.9 (SD=5.9), 22.9 (SD=5.0), and 19.9 (SD=3.9), respectively (Table 1). Participation in the survey varied across cancer type, however, response rates across cancer type were >60%. No significant differences in age (<60 years, 60–69 years, 70 years of age), race/ethnicity, and extent of disease at first diagnosis were detected between those who returned the survey and non-responders.

The average health literacy score was 18.8 (SD=2.8). By health literacy group, mean health literacy scores were 13.8(SD=2.5) for low, 18.2(SD=0.79) for medium, and 20(SD=0) for high. The lowest levels of health literacy were associated with male gender ($P < .0001$), non-White Hispanic race or ethnicity ($P < 0.02$), less than a high school education ($P < .001$), incomes lower than \$15,000 per year ($P < .0001$), rural residence ($P = 0.01$), lung cancer ($P < .0001$), and unknown extent of disease ($P = 0.005$) (Table 1). In general, average HRQOL scores, overall and for each subscale, were significantly greater among groups with higher level of health literacy ($P < .001$; Table 1 and Figure 1).

Unadjusted regression models indicated that health literacy was positively and significantly related to HRQOL scores ($b=1.4$, $P < .0001$) (Table 2). In addition, age ($b=0.1$, $P = .001$) and

being Non-Hispanic white ($b=3.6$, $P=0.01$) was associated with greater HRQOL scores. Compared to their referent groups, HRQOL scores were significantly lower among cancer patients with 1–3 years of college ($b=-5$, $P=0.0003$), a high school degree or equivalent ($b=-4.9$, $P=0.0001$), less than 12 years of schooling ($b=-6.2$, $P<0.0001$), annual incomes of \$15,000–29,000 ($b=-7.3$, $P<0.0001$) or less than \$15,000 ($b=-9.5$, $P<0.0001$), living in urban ($b=-3.7$, $P=0.0004$) and rural ($b=-2.1$; $P=0.01$) counties, colorectal ($b=-2.5$, $P=0.007$) and lung ($b=-10.2$, $P<0.0001$) cancer patients, and cancer patients with distant/systemic cancer at diagnosis ($b=-10.7$, $P<0.0001$).

Health literacy remained associated with HRQOL scores ($P<0.0001$) after inclusion of the covariates into the model (Table 2, adjusted analyses). Age at diagnosis ($P<0.0001$), annual incomes of \$15,000–29,000 ($P<0.0001$) or less than \$15,000 ($P<0.0001$), urban residency ($P=0.03$), lung cancer ($P<0.0001$), and regional ($P=0.02$) and distant/systemic ($P<0.0001$) extent of disease at first diagnosis also remained significantly associated with overall HRQOL scores. Minimally important differences in HRQOL were detected for those with income levels of <\$15,000 and between \$15,000–29,999 per year, with lung cancer, and distant/systemic extent of disease in adjusted models (Table 2). However, rural residence, sex, race/ethnicity, breast cancer, colorectal cancer, and education were not significantly associated with HRQOL scores after adjusting for health literacy and other study covariates (Table 2).

Health literacy was also positively and significantly ($P<0.0001$) related to each HRQOL scale, with regression coefficients ranging from 0.18 (SE=0.04) for the social-well-being subscale, 0.30 (SE=0.04) for the physical well-being, 0.31 (SE=0.03) for the emotional well-being, to 0.43 (SE=0.05) for the functional well-being scale (Table 3).

In the analysis using health literacy as a categorical variable, we found that health literacy remained significantly associated with total HRQOL scores and each of the subscales. Individuals in the medium and low health literacy categories had significantly lower HRQOL scores compared to those in the high health literacy category. Furthermore, coefficients estimated for the group with lowest health literacy level were consistently stronger than those estimated for the medium health literacy level. For cancer patients in the lowest health literacy quartile, the results indicated MIDs in the unadjusted HRQOL total score ($b=-7.5$, $P<0.0001$) and in the physical ($b=-1.9$; $P<0.0001$) and functional ($b=-3.1$; $P<0.0001$) well-being subscales compared to those in the highest health literacy level (Table 1). Minimally important differences persisted for the overall FACT-G score ($b=1.2$, $P<0.0001$) and functional well-being subscale ($b=-2.0$; $P<0.0001$) after adjusting for covariates (Table 3).

Discussion

This study indicates that health literacy at the patient level is positively associated with HRQOL among cancer patients. The association became weaker but remained significant after adjusting for sociodemographic and clinical covariates. The findings suggest that cancer patients with lower levels of health literacy have worse HRQOL scores overall and in each HRQOL domain.

The association between health literacy and HRQOL was consistent regardless of how health literacy was operationalized (continuous or categorical). When using health literacy as a continuous predictor of HRQOL, health literacy was found to have a small but significant association with the overall HRQOL score and across each subgroup. When using it as an categorical health literacy measure, the magnitude of associations with the overall FACT-G score and functional well-being subscale were above the MID threshold, suggesting that differences in HRQOL for patients with lower levels of health literacy are of clinical importance. These findings expand upon the limited amount of research that has investigated the relationship between health literacy and HRQOL among cancer patients. Song et al. (2012) examined health literacy and HRQOL among prostate cancer patients. A significant relationship between only mental well-being and health literacy in models fully adjusted for covariates was found (Song et al., 2012). Song et al., (2012) used different instruments to assess HRQOL and health literacy and, by definition, their sample was restricted to males. Participants in the Song et al., (2012) sample were generally older than cancer patients in our study. This may account for the differences between the two studies with respect to physical well-being. We examined the relationship between health literacy and HRQOL among a subsample of prostate cancer patients. We found significant differences in physical well-being between those in the highest and lowest health literacy categories in the unadjusted model ($b=-0.93$, $P=0.02$) but these differences did not achieve statistical significance in the adjusted model. Further analyses among our prostate cancer subsample found those with lower health literacy reported worse HRQOL. In the fully adjusted categorical models, significant differences were found for functional well-being ($b=-3.15$, $P<.0001$) emotional well-being ($b=-1.5$; $P<.0002$), and overall HRQOL ($b=-5.6$; $P=0.0007$) comparing the highest and lowest health literacy levels. Similar to the entire sample, minimally important differences in functional well-being and overall HRQOL were detected between prostate cancer patients with low and high levels of health literacy.

In general, our study with cancer patients adds to the larger body of literature showing a significant association between health literacy and HRQOL among patients with other complex diseases, such as chronic obstructive pulmonary disease, epilepsy, heart failure, and asthma. (Omachi, Sarkar, Yelon et al., 2012; Bautista, Tannahill, Shetty, & Wludyka, 2009; Macabasco-O'Connell, DeWalt, Broucksou, Hawk et al., 2011; Gandhi, Kenzik, Thompson, DeWalt, et al., 2013). Building on these findings, future research must investigate the mechanisms through which health literacy may affect HRQOL among cancer patients and focus on identifying interventions that may effectively improve HRQOL among cancer patients with low health literacy. Paasche-Orlow & Wolf (2007) have proposed a model describing system and individual-level characteristics that could explain the relationship between health literacy and HRQOL. For example, patients with low health literacy or risk factors associated with low health literacy may not be able to adequately navigate a complex and fragmented health care system. Those with lower levels of health literacy may not have knowledge of signs or symptoms of concern, may delay needed or preventive care, resulting in overutilization of emergency services and underutilization of preventive care. This could result in suboptimal management of disease and could negatively impact HRQOL. Patients with low health literacy may have difficulties obtaining and/or understanding health information, be slower to adopt positive health behaviors, and be less likely to participate in

medical decision-making. These individual-level factors coupled with the variation in providers' ability to communicate health information effectively could result in poorer HRQOL.

The extent to which these pathways apply to the association between health literacy and HRQOL in cancer patients needs to be investigated. Cancer patients must navigate a complex healthcare system and meet multiple health literacy demands (Davis et al., 2002; Aziz, Miller, & Randall, 2012; Koay, Schofield, & Jefford, 2012). For example, cancer patients with low health literacy may have difficulty navigating the health system, understanding the rules and regulations related to insurance coverage, and may have difficulty managing their treatment plan. These factors, alone or in combination, could lead to a delay in care for cancer treatment-related side effects, suboptimal symptom management, resulting in exacerbated treatment-related symptoms, worse quality of life, and overutilization of emergency or urgent care. Kim et al., (2001) posited that low health literacy and knowledge of disease among a sample of prostate cancer patients may have hindered patient involvement in shared decision-making with a physician. Poor patient-provider interaction is another pathway through which low health literacy could be associated with worse clinical outcomes. Cancer patients may have difficulty understanding information given by provider and/or do not feel empowered to ask questions about their cancer care. Smith et al., (2015), found that inadequate health literacy was associated with worse physical functioning among older adults over time. Insufficient understanding, misconceptions of treatment, and physicians improperly communicating treatment are associated with non-adherence to cancer treatment regimens (Puts et al., 2014). Confusion about diagnoses, care plan, and disease management could ultimately result in worse clinical outcomes, HRQOL included, for cancer patients. Additionally, research indicates that appropriate information provision is associated with better mental and global HRQOL among cancer survivors (Husson, Mols, & van de Poll-Franse, 2011).

Effective strategies to prevent disparities in HRQOL among cancer patients with low levels of health literacy need to be identified. Our findings support previous research that underscores the importance of patient-provider communication about cancer, treatment, and management of side effects (Davis et al., 2002; Koay, Schofield, & Jefford, 2012; Martinez-Donate, Halverson, Simon, Schaaf Strickland, Trentham-Dietz, Smith, Linskens, & Wang, 2013). Improving patient understanding is a potential pathway for improving patient outcomes and satisfaction (Paasche-Orlowe & Wolf, 2007; Husson et al., 2011; Martinez-Donate et al., 2013). Health literacy can fluctuate due to an individual's well-being as well as the emotional toll of a cancer diagnosis and treatment (Davis et al., 2002; Koay, Schofield, & Jefford, 2012). Therefore, regardless of an individual's education or ability to understand health information, applying best health literacy practices in all patient interactions may be of benefit. Interventions targeting the health literacy environment of healthcare institutions would be a positive step in improving the delivery of quality cancer care. Considering greater concentrations of low health literacy in certain populations, these interventions seem to be critical for organizations serving racial/ethnic minorities, patients with lower incomes or education, and rural cancer patients (Kutner et al., 2006; Halverson et al., 2013; Dumenci, Matsuyama, Riddle, Cartwright, Perera, Chung, et al., 2014; Smith,

Kobayashi, Wolf, Raine, Wardle, & von Wagner, C., 2014; Busch, Martin, DeWalt, & Sandler, 2015; Bennet, Chen, Soroui, & White, 2009).

Research to identify effective interventions to reduce health literacy barriers at the patient, provider, and system level is still in its infancy. Interventions aimed at promoting shared decision-making, effective provider communication, and written information adhering to health literacy principles could enhance the quality of cancer care for all patients. Patient navigation embodies these principles and intervenes at the individual and health care system levels. The American College of Surgeons' Commission on Cancer (CoC) has added patient navigation as one of their Cancer Program Standards necessary to receive CoC accreditation (American College of Surgeons, 2012). These interventions would help to meet the IOM's call for improving the health literacy level of healthcare organizations and advancing patient-centered cancer care (Brach et al., 2012; Levit, Balogh, Nass, & Ganz, 2013). Utilizing recommended programs or techniques, such as patient navigation, "teach-back" to check for patient understanding, and plain language to explain diagnoses, treatment, and management of side effects, could mitigate health literacy barriers and improve patients' HRQOL (DeWalt et al., 2010; Martinez-Donate et al., 2013). Future studies will need to test the impact of these strategies on cancer care delivery and patient outcomes.

Limitations

This study has a number of limitations. The data are cross-sectional, therefore a causal association between health literacy and HRQOL cannot be inferred. The results may also be subject to survival bias. Responses to questions of health literacy, HRQOL, and socioeconomic factors are based on self-report and could be subject to social desirability, non-response, and other sources of bias. The quality of life instrument used for this study was designed to require relatively low literacy levels (i.e. it was written at approximately 7th grade level) and previous research has indicated scores are not subject to systematic literacy bias (Hahn et al., 2007). However, Hahn et al., (2007) tested literacy bias among participants (high vs. low literacy) completing the FACT-G using a Talking Touchscreen. Still, the health literacy variable may affect responses to the HRQOL among those with very low levels of literacy. Our findings should therefore be replicated in the future with other quality of life instruments that require even lower literacy levels. The mailing materials (cover letter, information sheet) and written survey may exclude those with low literacy or those otherwise unable to physically complete the survey, including those with lowest levels of HRQOL. However, the recruitment efforts made to contact non-responders and offer the option of completing the survey over the phone potentially mitigated the literacy burden. Additionally, the 68% response rate for the survey and lack of differences in age, race/ethnicity, and extent of disease at first diagnosis, suggests that those with lower levels of literacy would have been included in the study sample. Approximately 43% of the sample reported the highest health literacy score which may reflect a ceiling effect of the health literacy measure.

Conclusion and Implications

Low health literacy at the patient level may be a determinant of poor HRQOL among breast, lung, prostate, and colorectal cancer patients. Given that patient understanding is affected by

individual health literacy skill and the health literacy demands of the healthcare system, these findings highlight the need for system level adoption of health literacy best practices (Levit et al., 2013). These interventions could improve patients' ability to effectively communicate with their medical team or understand information critical to their treatment, choices, and recovery. Ultimately, these interventions may improve patient-reported outcomes and system-level performance indicators.

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Figure 1.

Unadjusted health-related quality of life score, overall (0–108) and by subscale (0–28 for physical, functional, and social well-being; 0–24 for emotional well-being), according to level health literacy (low, medium, high) among cancer patients in Wisconsin (N=1,646).

Table 1

Characteristics of cancer patients as a group and stratified by health literacy level.

Characteristics	Health Literacy Level ^{a,d}				P value ^b
	All	Low	Medium	High	
	N=1,841^d	N=446	N=521	N=748	
Age, N, mean, (SD) ^c	1,841	446	521	748	<.0001
	63.2(10.7)	65.9(10.1)	62.2(10.5)	61.5(10.7)	
Sex, N, (%)					
Male	843 (49.2)	260 (30.8)	251 (29.8)	332 (39.4)	<.0001
Female	872(50.8)	186 (21.3)	270 (31.0)	416 (47.7)	
Race/Ethnicity, N, (%)					
Race Other	119 (7.0)	43 (36.1)	28 (23.5)	48 (40.3)	0.02
White Non-Hispanic	1580 (93.0)	396 (25.1)	489 (30.9)	695 (44.0)	
Place of residence					
Mixed Urban-Rural, N, (%)	946 (55.2)	219 (23.2)	293 (30.9)	434 (45.9)	0.01
Rural	502 (29.3)	154 (30.7)	155 (30.8)	193 (38.5)	
Urban	267 (15.5)	73 (27.3)	73 (27.4)	121 (45.3)	
Education, N, (%)					
Advanced degree	170(9.9)	14(8.2)	48(28.3)	108(63.5)	<.0001
Completed college	229 (13.4)	24 (10.5)	67(29.2)	138(60.3)	
1–3 years of college	386 (22.5)	77(20.0)	114(29.5)	195 (50.5)	
Completed HS or equivalent	715 (41.7)	216 (30.2)	237 (33.2)	262 (36.6)	
< High School	194 (11.3)	108(55.7)	47(24.2)	39(20.1)	
Missing	21 (1.2)	7 (33.3)	8 (38.1)	6 (28.6)	
Income, N, (%)					
>\$100,000	166(9.7)	15(9.0)	48(28.9)	103(62.1)	<.0001
\$50–99,999	410(23.9)	61(14.9)	119(29.0)	230(56.1)	
\$30–49,999	403(23.5)	86 (21.3)	137(34.0)	180(44.7)	
\$15–29,999	363(21.2)	130 (35.8)	115 (31.7)	118(32.5)	
<\$15,000	189(11.0)	96 (50.8)	40 (21.2)	53(28.0)	
Missing	184 (10.7)	58 (31.5)	62(33.7)	64(34.8)	

Characteristics	Health Literacy Level ^{a,d}				P value ^b
	All	Low	Medium	High	
	N=1,841 ^d	N=446	N=521	N=748	
Cancer Site, N, (%)					
Prostate	515 (30)	130 (25.2)	163 (31.7)	222 (43.1)	<.0001
Breast	581 (33.9)	110 (18.9)	187 (32.2)	284 (48.9)	
Colorectal	476 (27.8)	154 (32.4)	130 (27.3)	192 (40.3)	
Lung	143 (8.3)	52 (36.4)	41 (28.7)	50 (34.9)	
Extent of disease, N, (%)					
Local/in situ	1127 (65.7)	271 (24.1)	344 (30.5)	512 (45.4)	0.005
Regional	465 (27.1)	129 (27.7)	147 (31.6)	189 (40.7)	
Distant/Systemic	94 (5.5)	33 (35.1)	28 (29.8)	33 (35.1)	
Unknown	29 (1.7)	13 (44.8)	2 (6.9)	14 (48.3)	
Health Related Quality of Life (FACT-G), ^{c,d}					
Total Score, N, mean, (SD)	1705	424	502	720	<.0001
	88.6 (15.3)	83.6 (17.6)	88.9 (14.3)	91.1 (13.7)	
Physical well-being, N, mean, (SD)	1751	434	512	739	<.0001
	23.9 (4.7)	22.6 (5.4)	23.8 (4.3)	24.5 (4.2)	
Functional well-being, N, mean, (SD)	1765	436	516	741	<.0001
	21.9 (5.9)	19.8 (6.7)	22.0 (5.5)	22.9 (5.2)	
Social well-being, N, mean, (SD)	1738	429	510	733	0.0009
	22.9 (5.0)	22.1 (5.6)	23.2 (4.6)	23.1 (4.7)	
Emotional well-being, N, mean, (SD)	1742	431	511	735	<.0001
	19.9 (3.9)	18.9 (4.5)	19.7 (3.7)	20.5 (3.6)	

Abbreviations: SD, standard deviation; FACT-G, Functional Assessment of Cancer Therapy-General.

^a Percentages by health literacy level equal 100% within each row.

^b P values are based on chi square tests unless otherwise indicated

^c Means and standard deviations are based on univariate analyses. P values are based on F-tests.

^d N across health literacy levels do not equal N in All or total FACT-G columns due to missing data in self-reported variables.

Table 2

Association between patient characteristics and health related quality of life (HRQOL) scores among cancer patients in Wisconsin.

Independent Variable(s)	Unadjusted Models		Fully Adjusted Model ^c (N=1,632)	
	b (SE)	P Value ^a	b (SE)	P Value ^b
Age at diagnosis (centered at 63)	0.1 (0.03)	0.001	0.25 (0.03)	<.0001
Sex				
Male	Ref.		Ref.	
Female	−0.9 (0.7)	0.19	−0.5 (1.2)	0.65
Race/Ethnicity				
Race Other	Ref.		Ref.	
White, Non-Hispanic	3.6 (1.4)	0.01	−0.6 (1.4)	0.68
Residence				
Mixed Urban-Rural	Ref.		Ref.	
Rural	−2.1 (0.8)	0.01	−0.3 (0.8)	0.73
Urban	−3.7 (1.1)	0.0004	−1.3 (1.0)	0.03
Education				
Advanced degree	Ref.		Ref.	
Completed college	−1.3 (1.5)	0.41	−0.4 (1.5)	0.74
1–3 years of college	−5.0 (1.4)	0.0003	−2.1 (1.4)	0.12
Completed HS or equivalent	−4.9 (1.3)	0.0001	−0.5 (1.3)	0.70
< High School	−6.2 (1.6)	<.0001	0.7 (1.7)	0.65
Missing	−3.8 (3.4)	0.26	2.8 (3.7)	0.45
Income				
>\$100,000	Ref.		Ref.	
\$50–99,999	−0.9 (1.4)	0.47	−1.1 (1.4)	0.42
\$30–49,999	−1.8 (1.4)	0.19	−2.0 (1.4)	0.16
\$15–29,999	−7.3 (1.4)	<.0001	−7.2 (1.5)	<.0001
<\$15,000	−9.5 (1.6)	<.0001	−9.2 (1.8)	<.0001
Missing	−2.6 (1.6)	0.11	−2.5 (1.7)	0.14
Cancer Site				
Prostate	Ref.		Ref.	
Breast	−1.4 (0.9)	0.12	0.5 (1.5)	0.74
Colorectal	−2.5 (0.9)	0.007	0.2 (1.1)	0.82
Lung	−10.2 (1.4)	<.0001	−6.4 (1.6)	<.0001
Extent of disease				
Local/in situ	Ref.		Ref.	
Regional	−3.5 (0.8)	<.0001	−1.9 (0.8)	0.02
Distant/Systemic	−10.7 (1.6)	<.0001	−6.8 (1.6)	<.0001
Unknown	−1.9 (2.7)	0.47	−2.3 (2.7)	0.39
Health literacy (4–20)	1.4 (0.1)	<.0001	1.2 (0.1)	<.0001

Abbreviations: Ref., Reference category; SE, standard error.

^a All coefficients were produced from separate regression models and correspond to a change in FACT-G scores for unit of change of each covariate.

^b P values were derived from a multiple linear regression model using FACT-G scores as the dependent variable, health literacy as the main predictor, and all other study variables included as covariates.

^c N=1,632 for the fully adjusted model.

Table 3

Association between health literacy (continuous and categorical) and health-related quality of life (total and subscale HRQOL scores) among cancer patients in Wisconsin.¹

	HRQOL Total Score			HRQOL Subscales					
	FACT-G (N=1,632)	Physical well-being (N=1685)	Functional well-being (N=1693)	Social well-being (N=1972)	Emotional well-being (N=1677)				
	b(se)	P Value	b(se)	P Value	b(se)	P Value	b(se)	P Value	P Value
Health Literacy Score	1.2 (0.14)	<.0001	0.30 (.04)	<.0001	0.43 (0.05)	<.0001	0.18 (0.04)	0.0002	0.31 (0.03)
Health Literacy Level ²									
High	Ref.		Ref.		Ref.		Ref.		
Medium	-1.8 (0.85)	0.03	-0.5 (0.26)	0.04	-0.65 (0.32)	0.04	0.13 (0.28)	0.64	-0.79 (0.22)
Low	-5.9 (0.96)	<.0001	-1.4 (.29)	<.0001	-2.0 (0.36)	<.0001	-0.88 (0.32)	0.007	-1.7 (0.25)

Abbreviations: SD, standard deviation; FACT-G, Functional Assessment of Cancer Therapy-General; Ref.: Reference category.

¹ Based on multiple linear regression models with HRQOL scores as dependent variables, health literacy as the main predictor, and gender, age at diagnosis, race/ethnicity, education, income, place of residence, cancer site, and cancer stage as covariates.

² Using first and second quartiles as cut off points.