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ORIGINAL ARTICLE

Variation in coordination of care reported by breast cancer patients according to health literacy

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Abstract

Background Health literacy is the ability to perform basic reading and numerical tasks to function in the healthcare environment. The purpose of this study is to describe how health literacy is related to perceived coordination of care reported by breast cancer patients.

Methods Data were retrieved from the Patient-Centered Outcomes Research Institute-sponsored "Share Thoughts on Breast Cancer" Study including demographic factors, perceived care coordination and responsiveness of care, and self-reported health literacy obtained from a mailed survey completed by 62% of eligible breast cancer survivors ($N = 1221$). Multivariable analysis of variance was used to characterize the association between presence of a single healthcare professional that coordinated care ("care coordinator") and perceived care coordination, stratified by health literacy level.

Results Health literacy was classified as low in 24% of patients, medium in 34%, and high in 42%. Women with high health literacy scores were more likely to report non-Hispanic white race/ethnicity, private insurance, higher education and income, and fewer comorbidities (all $p < 0.001$). The presence of a care coordinator was associated with 17.1% higher perceived care coordination scores among women with low health literacy when compared to those without a care coordinator, whereas a coordinator modestly improved perceived care coordination among breast cancer survivors with medium (6.9%) and high (6.2%) health literacy.

Conclusion The use of a single designated care coordinator may have a strong influence on care coordination in patients with lower levels of health literacy.

Keywords Continuity of patient care · Quality of health care · Patient-centered care · Health literacy · Breast neoplasms · Patient navigation

Introduction

Health literacy is defined as the capacity of individuals to obtain, process, and understand basic health information and services needed to make appropriate health decisions [1]. Measurement of health literacy varies across studies, and no single threshold for low health literacy has been defined. However, scientists generally agree that low health literacy is an extensive problem in the USA, where about one third of adults have limited health literacy [2, 3].

Research indicates that those with low health literacy may have difficulty understanding, obtaining, and retaining health

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information [4], resulting in under-utilization of preventive healthcare services [5, 6], increased use of emergency services [7] and hospitalizations [6, 8], worse physical functioning and mental health [5, 6], and increased mortality [9]. Among breast cancer patients, health literacy may contribute to racial disparities in health outcomes after diagnosis.

The Agency for Healthcare Research and Quality defines care coordination as "the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care" [10]. Care coordination has also been identified by the Institute of Medicine as a key strategy to improve the efficiency of the healthcare system, and research suggests that it can be used to address deficiencies in care that result from low health literacy [11].

Deficits in health literacy have been associated with increased healthcare utilization [6–8]; however, there is limited evidence on the direct effects of limited health literacy on care coordination and if the inclusion of coordinators or navigators in the treatment process can mitigate the effects of limited health literacy on health outcomes. Even though having a single person coordinating care can be costly, such an intervention may be justified for patients with low health literacy since they are the most vulnerable during the care process. The primary objective of this study was to describe the associations between perceptions of care coordination and health literacy among cancer patients while considering the presence of a single healthcare professional that coordinated care. We analyzed questionnaire and linked tumor registry data from the *Share Thoughts on Breast Cancer Study*, a project conducted within the Greater Plains Collaborative (GPC) Clinical Data Research Network (CDRN) [12]. The GPC is one of 13 CDRNs in PCORNet, the National Patient-Centered Clinical Research Network sponsored by the Patient-Centered Outcomes Research Institute.

Methods

The protocol for this cross-sectional survey study was approved by the University of Iowa Institutional Review Board (IRB). The IRBs for the following collaborating medical centers ceded IRB review to the University of Iowa IRB pursuant to the GPC reliance agreement: University of Texas Southwestern Medical Center, University of Kansas Medical Center (KUMC), University of Wisconsin Carbone Cancer Center, University of Nebraska Medical Center, University of Minnesota, Medical College of Wisconsin, and Marshfield Clinic Research Institute.

Study population

Each participating medical center extracted, transformed, and loaded North American Association of Central Cancer Registries (NAACCR)-formatted data from their institution's tumor registry into its i2b2 (Informatics for Integrating Biology and the Bedside) research warehouse. The GPC i2b2 research warehouse is fully de-identified with re-identification possible when accompanied by an approved IRB protocol [12]. From this research warehouse, each medical center selected a cohort of all patients age 18 years or older diagnosed with breast cancer between January 2013 and May 2014. De-identified data files were submitted to the GPC Honest Broker who applied eligibility criteria and selected a random sample of 250 eligible patients from each center's file. Eligible patients were women with microscopically confirmed ductal carcinoma in situ or invasive (but not metastatic) breast cancer diagnosed during the study period. Women who had previously been diagnosed with cancer per tumor registry records were excluded as were women known to be deceased at the time the sample was selected. The sample of patients plus a list of up to ten replacement patients was provided to each center for re-identification and recruitment. The replacement list was used if a mailed survey was returned unopened or a patient was deceased. Two sites had fewer than 250 patients diagnosed during the study period.

Data collection and management

All study materials were mailed in a single packet containing a cover letter from the participating medical center, a 21-page questionnaire, medical record consent, and $10 incentive. Questionnaires were mailed over a 6-week period beginning June 19, 2015, and one re-mailing to non-respondents was conducted 4 weeks after the initial mailing. A total of 1235 women (out of 1986; 62.2%) returned a completed questionnaire. Signed consent to obtain information from medical records was obtained from 852 (69%) women.

Study data were managed using Research Electronic Data Capture (REDCap) hosted at the University of Kansas Medical Center [13].

Measurements

Independent variable: health literacy

Table 1 shows the survey items that were used to assess health literacy, perceived care coordination, and quality of care.

Table 1 Survey items related to patient's health literacy and perceived care coordination, Share Thoughts on Breast Cancer Study

Health literacy[a]
1. How often do you have someone help you read hospital materials?
2. How often can you fill out medical forms by yourself? (Reverse Coded)
3. How often do you have problems learning about your medical condition because of difficulty understanding written information?
4. How often do you have problems understanding medical statistics?
5. How often do you have trouble taking your medications properly by yourself?
Perceived care coordination[b]
1. How often did you think that your health problems related to your cancer or its treatments were handled quickly enough?
2. How often were you able to see the specialists such as cancer doctors you wanted to see for your cancer?
3. How often did the doctors, nurses, and other medical staff providing your care seem to work well together as a team?
4. How often did your doctors seem to be aware of treatments for your cancer that other doctors recommended?
5. How often did you know who to ask when you had any questions related to your cancer or its treatments?
6. How often did you feel that your doctors, nurses, and other medical staff did everything they could to treat your health problems related to your cancer or its treatments?
Quality of care[c]
1. Overall, how would you rate the quality of your health care since you found out you had breast cancer?

[a] Answer options included a 5-point Likert scale (Always, Often, Sometimes, Occasionally, and Never)

[b] Answer options included a 4-point Likert scale (Never, Sometimes, Usually, Always)

[c] Answer options included a 5-point Likert scale (Excellent, Very good, Good, Fair, Poor)

Health literacy was assessed using five questions rated by self-report on a 5-point Likert scale (Always, Often, Sometimes, Occasionally, and Never). The first three 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) [14, 15]. The question "How often do you have problems taking your medications properly by yourself" has been used in previous research studies with cancer patients [16, 17].

A composite health literacy score (Cronbach's alpha = 0.71) was created by summing the scores of the five questions (The question "How often can you fill out medical forms by yourself?" was reversed coded). Scores could range from 5 to 25 and higher scores reflected higher levels of health literacy. This composite health literacy score has been used in previous research with cancer patients [16, 17]. By using five questions rather than three, as previously validated, we improved classification of patients, as demonstrated by the increased Cronbach's alpha (0.71 vs 0.58) while retaining 80% agreement between the two scoring methods (weighted kappa value 0.78, 95% CI 0.75–0.81). In addition, results of the composite health literacy score were displayed in a categorical variable based on quartiles as the cut-points to divide patients into three groups: low (scores ≤ 20, 1st quartile), medium (scores 21–23, 2nd quartile), and high health literacy (scores ≥ 24, 3rd and 4th quartiles).

Primary outcome: perceived care coordination

Perceived care coordination was assessed using six questions rated by self-report on a 4-point Likert scale (Never, Sometimes, Usually, Always), using the same methodology described by Ayanian et al. [18]. A composite score was created by summing the scores of the five questions (Cronbach's alpha = 0.85). Scores could range 6–24, and higher scores reflected increased perceived care coordination. The scores were converted to a 100-point scale, with 100 representing optimal care.

Covariate of interest: a single care coordinator

Another item assessed the presence of an overall care coordinator by asking "Was there one health professional who coordinated your care?" and will be referred to as having a care coordinator. This covariate was evaluated as a potential confounder of the association between health literacy and perceive care coordination and as an effect modifier.

Statistical analysis

Descriptive statistics were computed according to level of health literacy, with differences between levels tested by chi-square tests. A two-sided p value of 0.05 was considered statistically significant.

Unadjusted and multivariable linear regression models were fit to characterize the associations between the covariates, health literacy, and perceived care coordination scores. Least squares means for the perceived care coordination score and *p* values from *F* tests were calculated using multivariable analysis of variance including covariates for age, income, education, having a coordinator, health literacy, random effects for recruitment site, and adjusted from time since diagnosis. Interaction between health literacy scores and the presence of a care coordinator was tested by adding a cross-product term to the model. A second analysis was performed stratifying patients according to the presence of a care coordinator.

Women with missing date of birth ($N = 13$) or date of diagnosis ($N = 29$) were assigned the median known dates of birth and September 15, 2013, respectively. Individuals with no responses to the health literacy questions were excluded ($N = 14$), leaving data for 1221 women in the statistical analysis. An additional 44 women did not answer all the items related to perceived care coordination, so these analyses were restricted to 1177 participants. Respondents who did not provide information on race, income, or education were included in the analysis using indicator variables representing missing data. Analyses were conducted using SAS 9.4 (SAS Institute, Inc., Cary, NC).

Results

Health literacy level was considered low in 24% of patients, medium in 34%, and high in 42% (Table 2). Women reporting younger age, non-Hispanic white race/ethnicity, private insurance, higher education and income, and fewer comorbidities had higher literacy.

Mean perceived care coordination score was 90.0 (SD 12.3). Higher perceived coordination scores were observed for women older than 65 years, women with higher income, those who rated their quality of care as very good or excellent, and those with greater health literacy (Table 3). The relationship between health literacy scores and perceived coordination was modified by the reported presence of a single health professional that coordinated care (test for interaction $p = 0.003$; Fig. 1). Overall, 62.5% ($n = 755$) of the patients reported having a care coordinator, 25.5% ($n = 308$ patients) reported not having a care coordinator, and 12.0% ($n = 145$ patients) did not know if they had a care coordinator. Among women reporting both low health literacy and no single healthcare professional that coordinated care ($N = 47$), perceived care coordination scores were 17.1% lower (mean 76.7, 95% CI 72.7–80.8) than among low health literacy women reporting a care coordinator ($N = 187$, mean 89.8, 95% CI 88.3–91.2). Among women with medium or high health literacy, the presence of a care coordinator was associated with more modest increases in perceived care coordination scores (6.9 and 6.2%, respectively).

Most (88.6%) women reported having family members involved during treatment visits, and this proportion varied according to health literacy category: 85.6% of women with high health literacy had family attend visits, compared to 88.5% in the medium health literacy group, and 93.9% among those with low health literacy ($p = 0.002$). In multivariable analysis, adjustment for family involvement in visits did not alter the relation between health literacy and care coordination scores (data not shown).

Discussion

Our study shows that health literacy is related with perceived care coordination among breast cancer survivors, and the presence of a single healthcare professional that coordinated care was significantly associated with higher perceived coordination scores especially among those with low health literacy. Although other studies have described the association between health literacy and perceived care coordination [19, 20], our results highlight the benefits that a care coordinator offer among breast cancer patients with low health literacy.

One third of US adults have health literacy deficiencies, and limited health literacy is more prevalent among minority and underserved communities [21]. Low health literacy was associated with lower educational attainment levels and annual household income below $35,000; similar associations have been described in previous studies [16, 17]. Studies have also shown that breast cancer patients tend to have higher literacy scores than patients with other types of cancer [17].

Lower health literacy has been associated with worse healthcare outcomes among individuals with a wide array of diseases, including cancer [2, 6, 9, 22]. In this regard, a study by Halverson et al. showed that, among cancer patients, low health literacy was correlated with lower health-related quality of life, even after adjusting for sociodemographic characteristics [17]. Additionally, lower health literacy has been associated with increased costs, increased healthcare utilization, and less use of preventive care [5, 23–25]. These patients may experience difficulties with multiple aspects of the healthcare experience: understanding insurance coverage, navigating a complex healthcare system, following instructions from providers and managing chronic conditions; these factors often result in more advanced or severe conditions that require emergency department evaluation or frequent inpatient stays [23, 24].

Low health literacy has also been associated with lower satisfaction with healthcare, difficulty understanding the information provided, dissatisfaction with treatment decision process, and worse perceived coordination of care [19, 20, 24, 26, 27]. We observed that the presence of a care coordinator was

Table 2 Descriptive characteristics of surveyed patients according to health literacy level, Share Thoughts on Breast Cancer Study

		Health literacy level			
	Total (%) *N* = 1221	Low (%) *N* = 294	Medium (%) *N* = 410	High (%) *N* = 517	*p* value[a]
Age at diagnosis (years)					
21–44	160 (13.1)	37 (12.6)	51 (12.4)	72 (13.9)	< 0.001
45–54	305 (25.0)	46 (15.7)	109 (26.6)	150 (29.0)	
55–64	360 (29.5)	80 (27.2)	121 (29.5)	159 (30.8)	
65–74	261 (21.4)	69 (23.5)	90 (22.0)	102 (19.7)	
75–93	135 (11.7)	62 (21.1)	39 (9.5)	34 (6.6)	
Race/ethnicity					
White non-Hispanic	1121 (92.8)	251 (87.5)	384 (94.1)	486 (94.7)	< 0.001
African-American non-Hispanic	49 (4.1)	18 (6.3)	18 (4.4)	13 (2.5)	
Other	38 (3.2)	18 (6.3)	6 (4.4)	14 (2.7)	
Insurance					
Uninsured	19 (1.9)	10 (4.1)	5 (1.6)	4 (1.0)	< 0.001
Medicaid	52 (5.3)	20 (8.1)	15 (4.7)	17 (4.1)	
Medicare	203 (20.6)	83 (33.6)	50 (15.6)	70 (16.7)	
Private (employer/self)	609 (61.8)	115 (46.6)	203 (63.4)	291 (69.5)	
Other	103 (10.5)	19 (7.7)	47 (14.7)	37 (8.8)	
Highest degree obtained					
Less than high school	40 (3.3)	27 (9.4)	10 (2.5)	3 (0.6)	< 0.001
High school degree	275 (22.8)	101 (35.3)	102 (25.1)	72 (14.0)	
1–3 years of college	339 (28.1)	81 (28.3)	109 (26.9)	149 (29.0)	
Completed college	552 (45.8)	77 (26.9)	185 (45.6)	290 (56.4)	
Annual household income					
< $35,000	255 (24.8)	96 (41.6)	73 (21.4)	86 (18.9)	< 0.001
$30,001–$75,000	332 (32.3)	79 (34.2)	115 (33.6)	138 (30.3)	
> $75,000	441 (42.9)	56 (24.2)	154 (45.0)	231 (50.8)	
Number of chronic conditions					
0	469 (38.5)	83 (28.3)	168 (41.1)	218 (42.3)	< 0.001
1	295 (24.2)	80 (27.3)	91 (22.3)	124 (24.0)	
≥ 2	454 (37.3)	130 (44.4)	150 (36.7)	174 (33.7)	
Quality of care					
Excellent	588 (48.5)	97 (33.3)	200 (49.0)	291 (56.73)	< 0.001
Very good	408 (33.7)	113 (38.8)	140 (34.3)	155 (30.2)	
Good	168 (13.9)	60 (20.6)	56 (13.7)	52 (10.1)	
Fair	42 (3.5)	18 (6.2)	11 (2.7)	13 (2.5)	
Poor	6 (0.5)	3 (1.0)	1 (0.3)	2 (0.4)	

Column percentages are shown

[a] Based on chi-square tests

associated with an improvement of the perceived coordination score, which suggests that care coordinators can facilitate navigation of the healthcare system, and this may be especially helpful to patients with lower health literacy during and after treatment.

Care coordination has been described as a measure of quality of care, which correlates with the findings in our study: those patients that rated their quality of care as very good or excellent had significantly higher perceived care coordination scores. Hawley et al. showed that perceived low care coordination was associated with younger age, lower educational attainment, and the presence of more than two comorbidities [19]. However, Balbale et al. showed that higher educational attainment was significantly associated with lower perceived care coordination scores, possibly as a result of expectations of care [28]. In our study of primarily highly educated breast

Table 3 Perceived care coordination score according to patient characteristic, Share Thoughts on Breast Cancer Study ($N = 1177$)

		Perceived care coordination score			
	N	Age-adjusted mean[a]	Multivariable-adjusted mean[b]	95%CI[b]	p value
Age at diagnosis (years)					
21–44	156	89.4	88.9	87.1–90.8	< 0.001
45–54	302	88.8	87.8	86.4–89.2	
55–64	349	89.8	89.3	88.0–90.6	
65–74	253	92.7	92.1	90.6–93.6	
75–93	117	92.6	92.7	90.6–94.9	
Race/ethnicity					
White non-Hispanic	1084	90.5	89.9	88.9–90.8	0.97
African-American non-Hispanic	48	89.5	89.0	85.7–92.3	
Hispanic/other	34	90.1	89.9	86.0–93.8	
Insurance					
Uninsured	19	92.1	92.6	87.5–97.7	0.29
Medicaid	49	91.6	91.2	87.8–94.6	
Medicare	188	90.8	90.6	88.7–92.4	
Private (employer/self)	594	90.3	89.6	88.5–90.7	
Other	97	88.7	87.7	85.3–90.1	
Highest degree obtained					
Less than high school	36	91.9	93.2	89.4–96.9	0.09
High school diploma	262	90.2	90.3	88.8–91.8	
1–3 years of college	326	90.8	90.5	89.2–91.9	
Completed college	540	90.2	89.0	87.9–90.2	
Annual household income					
< $35,000	241	90.3	89.9	88.3–91.5	0.002
$35,001–$75,000	321	88.7	87.8	86.5–92.1	
> $75,001	434	91.4	90.8	89.5–92.5	
Number chronic conditions					
0	457	90.7	90.1	88.9–91.4	0.78
1	284	90.2	89.8	88.4–91.2	
≥ 2	434	90.1	89.5	88.2–90.8	
Quality of care					
Excellent	573	95.1	94.6	93.7–95.6	< 0.001
Very good	394	88.2	88.1	87.0–89.1	
Good	157	82.9	82.8	81.2–84.4	
Fair	41	74.8	74.4	71.4–77.4	
Poor	5	72.9	72.9	64.3–81.4	
Having a coordinator					
No	308	86.6	85.7	84.3–87.1	< 0.001
Yes	755	92.3	91.9	90.9–92.9	
Do not know	145	87.7	87.7	85.8–89.6	
Health literacy					
Low	294	87.1	86.8	85.4–88.3	< 0.001
Medium	410	90.5	91.0	89.7–92.2	
High	517	92.0	92.7	91.5–93.9	

[a] Least squares means, *F* tests, and *p* values are from an analysis of variance model adjusted for age

[b] Least squares means, *F* tests, and *p* values are from an analysis of variance models adjusted for age, income, education, having a coordinator, health literacy, and random effects for recruitment site

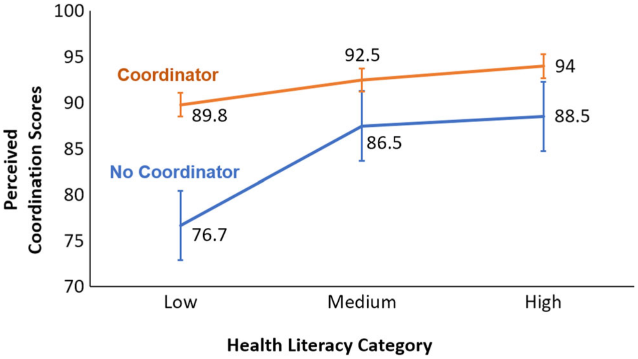

Fig. 1 Association between health literacy and care coordination scores, stratified by presence of a care coordinator, Share Thoughts on Breast Cancer Study. Health literacy defined as a categorical measure using quartiles as the cut-points to divide patients into three groups: low (scores ≤ 20, 1st quartile), medium (scores 21–23, 2nd quartile), and high health literacy (scores ≥ 24, 3rd and 4th quartiles). Mean scores, 95% confidence intervals, and p values are from analysis of variance models adjusted for age, income, education, and random effects for site. Test for interaction between health literacy scores and presence of a care coordinator, p value = 0.003

cancer survivors, there was a modest ($p = 0.09$) correlation between lower educational attainment and greater coordination scores.

Care coordination has been associated with a decrease in healthcare costs by reducing duplication of services and the use of inappropriate resources [29], and because of this, the Agency for Healthcare Research and Quality (AHRQ) provides several measures of care coordination [30] that can be used for research or quality improvement purposes. However, in current clinical practice, there is a lack of uniformity regarding titles and functions that are involved with care coordination, to the point that care coordinators can also be referred to as case managers or patient navigators, but their functions can differ across settings [31]. Patient navigators work with patients in helping them to "navigate the system" or overcome barriers of care [10], while care coordinators oversee multidisciplinary teams, provide information to multiple providers, and participate in the monitoring and evaluation of the care delivered [32]. Having a "key person to coordinate care" or care coordinator has been associated with better healthcare utilization and better health outcomes [33, 34].To our knowledge, our study is the first one to quantify the benefits of a coordinator on groups with low health literacy, but our study did not evaluate the title of the person that "coordinated care" or the specific activities that they performed as part of their work, which limits the generalization of our results.

Another limitation of our study is that health literacy scores and perceived coordination scores among our patients are right-skewed towards higher values, and participants were generally highly educated, white, and held private insurance. Studies recruiting more diverse samples are critically needed since cancer patients with lower health literacy are more vulnerable to the effects of inadequate, redundant, or disorganized care. Our cross-sectional study was not designed to identify causality between the variables, and our results highlight only the relations between self-reported health literacy and perceived care coordination scores, which are both subjective measures. Additional research will be required to evaluate objective measures of quality and care coordination and to identify the elements of care coordination that are more likely to mitigate lower health literacy. Furthermore, our results may be affected by survival bias or selection bias, even though we adjusted our analysis for time since diagnosis; in these types of bias, patients with shorter survival and those that did not participate in the study might have reported a different relation between health literacy and care coordination than what we identified. While our results account for treatment and system variations across the participating institutions, more data are needed to assess perceived care coordination at non-academic institutions.

Conclusion

The presence of a care coordinator significantly modified the relationship between health literacy and perceived care coordination. Among women reporting low health literacy, the presence of a coordinator was associated with a 17.1% improvement in care coordination score whereas among women with medium or high health literacy, the presence of a coordinator was associated with a 6–7% difference compared with no coordinator. The implication is that a coordinator might make the greatest difference among patients with low health literacy; however, more research is required to assess the elements of care coordination that most effectively mitigate low literacy effects. In the meantime, our results highlight the need for patients to receive information using approaches that follow universal health literacy recommendations.

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Compliance with ethical standards

The protocol for this cross-sectional survey study was approved by the University of Iowa Institutional Review Board (IRB).

Conflict of interest The authors declare that they have no conflict of interest.

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