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RESEARCH AND PRACTICE ARTICLE

Toward the Development of Cancer Literacy Assessment Tools

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ABSTRACT:

Background: This study represented the first that documents the development of breast and cervical cancer literacy assessments that can be administered orally by laypersons.

Methods: Critical indicators of cancer literacy were identified through a review of pertinent literature and interviews with ethnically diverse women. The pilot-test consisted of a 29-question assessment for language appropriateness. A score of 75% was established as the threshold for functional cancer literacy.

Results: The assessment tools demonstrated a high level of internal consistency. Paired t-test analysis of pre- and post-intervention tests showed that the instrument was sensitive to changes in literacy of breast and cervical cancer as well as improvements in functional cancer literacy.

Conclusion: The analysis demonstrated that the instrument is a reliable and valid indicator of breast and cervical cancer literacy. These assessment instruments can provide researchers and educators a tool to measure functional cancer literacy that can enhance their ability to tailor appropriate health interventions and promotions.

INTRODUCTION:

Health literacy has captured broad attention since the 2004 Institute of Medicine (IOM) of The National Academies report *Health Literacy A Prescription to End Confusion* (Nielsen-Bohlman, Panzer & Kinding, 2000). This report was followed by the American Medical Association's book *Understanding Health Literacy Implications for Medicine and Public Health* (ed. Schwartzberg, VanGeest & Wang, 2000). In the IOM publication (Ratzan and Parker, 2000) define health literacy as "The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions." This challenges researchers and health educators to develop educational tools for varying literacy levels and to design instruments that measure health literacy that can be integrated into interventions. The Institute of Medicine has reported there are a limited number



of health literacy instruments and those currently used do not consider oral language skills or may not capture the full scope of the constructs of health literacy (Nielsen-Bohlman, Panzer & Kinding, 2000). In addition, Williams and colleagues noted another limitation with the current structured health literacy assessments, such as the Test of Functional Health Literacy in Adults (TOFHLA) and Rapid Estimate of Adult Literacy in Medicine (REALM), was noted (Williams, Mullan, & Fletcher, 2006). The vocabulary of the current structured health literacy assessments is not representative of a woman's functional literacy for a specific disease, like breast cancer. Being able to read the word "cancer" does not mean a woman has a functional understanding of breast cancer that will allow her to adhere to screening guidelines. Williams and colleagues expanded the definition of health literacy by making it specific to breast and cervical cancer. "Breast and cervical cancer literacy is a woman's functional understanding of her personal and familial risk of the disease, including how to minimize her risk and the risk of her family through preventive early detection screenings and life style changes and understanding how to access the health system and engage providers to minimize her risk and the risk of her family."

As we contemplated assessments for our own intervention, Kin KeeperSM Cancer Prevention, an intervention that focused on African American women who were eligible for public health programs and had varying degrees of literacy (i.e. the ability to read and write), it was clear from the literature (Meade, 2005; Williams, Baker, & Hoing, 1998; Lindau, Tomori, & Lyons, 2002; Baker, Parker, & Williams, 1997) that breast and cervical cancer literacy would have to be fully woven throughout the cancer prevention education intervention. This means that appropriate assessment tools would need to be designed to provide data about the importance of health literacy in engaging women in cancer prevention and screening programs (Lee, Arozullah, & Cho, 2004). To mesh with the proposed intervention, the tools would have to: 1. Be able to be administered orally, 2. Be simple enough that a layperson, like a community health worker, could administer them in non-clinical settings and, 3. Be able to capture a woman's functional understanding of breast and or cervical cancer.

METHODS:

The first task was to develop an assessment that measured a women's functional understanding of her personal and familial risk of breast and cervical cancer. There were three main components to the approach taken toward instrument development. These components included domain definition, the use of critical indicators to develop the assessment's questions, and pilot testing the newly created assessment tool. Each one of these components was rigorously tested to ensure validity at each step.

Domain Definition

The first step was to define the domain of knowledge that would be covered by the instrument. The domain was defined through a review of the literature and through the use of the critical incident technique (Guion, 1998). The critical incident technique was used because the time allotted for responding to the instrument needed to be kept no more than one hour to gain cooperation from the women in the study. This meant that full domain coverage was not possible. Rather, critical indicators of levels of knowledge were identified through interviews of a small sample of women. This second step involved interviewing women who mirrored the



target population, namely women who are Medicaid eligible. After obtaining approval from the University Committee of Research Involving Human Subjects, a total of seven women were recruited from Michigan-based community-based organizations. The women represented diverse ethnic backgrounds; African American (n=2), Latina (n=2), Asian American (n=1) and Native American (n=2). Three were over 40 years of age and were in good health. Selecting women from diverse ethnic backgrounds provided us with a cultural perspective for future research.

The participants were recruited through collaboration with local community organizations. Community leaders referred Medicaid eligible women from diverse ethnic groups. Participants received a stipend for their participation in a 1-hour interview that took place at a local community clinic. The interview protocol included questions such as: “Do you recall how you were first exposed to cancer?”; “If I ask you to tell me your personal risk for getting breast cancer what would you say?”; “At what age and how often should a woman conduct a self-breast examination, clinical breast examination or a mammogram?”; and “What do you know about your family’s risk for getting cervical cancer?” The interviews were transcribed by a professional stenographer and analyzed in terms of emerging patterns, dimensions and critical indicators. Data obtained from this last step, based on interviews, was used to develop the cancer literacy assessment tools. Following the extraction of the critical indicators, the process resulted in the development of 16 questions on breast cancer literacy and 12 questions on cervical cancer literacy. The transcripts of the targeted interviews were carefully analyzed to determine the topics that differentiated the women who seemed to have the most knowledge and those who had a little.

Using Critical Indicators to Create Assessment Tool

The second main component was the development of the questions for the assessment instrument. The steps described above involve the development of the critical indicators. Once these were identified, the first step of this component was to list them as descriptive phrases. In addition, the desired level of knowledge about each topic was specified. Second, questions were identified that should elicit the level of knowledge each woman had about the topic. Third, questions were pilot tested on another small sample of five women to make sure that the language was appropriate for the specific population for the study, and that the responses to the questions would be sufficiently informative to allow reliable judgments of levels of knowledge. Working with a reading specialist to edit the questions to be at the 5th grade reading level, the research team made changes and revisions to the instrument based on feedback obtained from these interviews. These resulted in 4 questions being revised. Finally, after completion of the final version of the breast and cervical cancer literacy assessment tools, several health professionals from the Michigan State Breslin Cancer Center reviewed the instruments. The group was composed of professionals with extensive work experience in areas pertaining to clinical cancer trials and cancer education a total of seven oncology experts reviewed the assessments. These experts proposed a score of 75% of the maximum as the cut score for functional breast and cervical cancer literacy. This cut off score is also supported in the literature on grade-level ability for individual readers in the Institute of Medicine Report (2004).



Pilot- test of Breast and Cervical Cancer Assessment Tools

Pilot testing of the breast and cervical cancer literacy assessment was conducted with the community health workers and their respective supervisors who would impart cancer literacy to African American women participating in already established health promotion programs. Prior to the Kin KeeperSM Cancer Prevention Intervention training none of the participants had been trained in cancer prevention. A total of 16 women (2 supervisors and 14 community health workers) were assembled for training in cancer literacy at Michigan State University. The 16-hour training was modeled on the Kin KeeperSM Cancer Prevention Intervention Curriculum and Workbook© (Williams & Lawshe, 2006). The participants were administered the assessments under field conditions and a facilitator read the questions and answers for the participants.

After the pilot study, a final version of the assessment instrument was prepared for use as part of the intervention. When the study data was collected, the data from the instruments was analyzed to both describe the level of knowledge and skills at each point in the study and to determine the reliability and validity of the instrument. For the former analyses, score distributions and descriptive statistics were produced. The reliability of the instrument was determined by computing coefficient alpha. Construct validation was the conceptual basis for collecting validity evidence. Two approaches were taken. The first is to identify groups that should differ in their level of literacy and determine whether the instruments could detect the expected differences. The second approach is to check whether the literacy scores were correlated with variables that should be related to literacy and not correlated with variables that should not be related. In addition, validity evidence was obtained both through expert judgment of the content coverage of the instrument. The scores from the assessment instruments were also correlated with demographic measures and other indicators to determine if the pattern of correlations was consistent with the hypothetical construct implied by the domain definition. A pre-post design was used to collect the necessary data and the results were analyzed using t-tests to determine if the instruments were sensitive to expected differences in literacy.

In summary, using the critical indicator approach, we designed two (breast and cervical) cancer literacy assessments that could be used together or separately. We pilot tested a 29-question assessment instrument for language appropriateness and established a score of 75% as the threshold for functional cancer literacy. This undoubtedly raises the question of do we need separate health literacy assessment tools to measure different diseases? Although this presents a worthwhile inquiry it is not in the scope of this paper to answer this question. In this section, we presented our process, the steps in developing the assessment tools, piloting the assessments with community health workers and analysis using standard statistical tests.

RESULTS:

Assessment Development

The research team analyzed the data by exploring emerging themes, critical indicators, and dimensions for both breast and cervical cancer. The first emerging theme was breast cancer awareness. Critical indicators of breast cancer awareness included first exposure to breast cancer, knowledge of breast cancer, and understanding of preventative breast cancer care guidelines.



Based on information gathered from the participants of the first pilot test to develop critical indicators, exposure to breast cancer has been experienced through direct influence from family members and/or friends and indirectly through mass media means such as television ads or documentaries. Most of the participants demonstrated lack of knowledge regarding the different types of exams available to detect breast cancer. More specifically, participants seemed highly confused when asked about their knowledge of the terms “breast self-exam, clinical breast exam, and a mammogram.”

The majority of the participants did seem to know basic preventative/control breast cancer care guidelines and mentioned age 40 as the optimal age to begin screening for breast cancer. However, when asked “How often do you or have you conducted a self-breast examination?” most participants responded that they do not do any monthly breast exams. The participants also demonstrated some degree of understanding on how to prevent/control breast cancer. Specifically, they elaborated on their individual risks for getting cancer and understanding of their family risks. However, it is important to note that a lack of knowledge of available community resources was evident. None of the participants were able to mention a single resource available in their communities to assist them if they discovered a lump or had any cancer-related questions/concerns.

Critical indicators of cervical cancer awareness included first exposure to cervical cancer, knowledge of cervical cancer, and understanding how to prevent/control cervical cancer. Overall, responses demonstrated that participants were not able to make a connection with cervical cancer and Pap Smear screening. Participants were first exposed to the concept of cervical cancer directly by family members and also through information provided by their health care providers mainly in the form of the need for a Pap Smear due to pregnancies. Most of the participants lacked knowledge on cervical cancer other than what has been generally explained to them by their health care providers. They did indicate knowledge of some guidelines such as screening, having an exam after becoming sexually active, and following up with a health care provider on any cervical cancer questions/concerns. In regards to understanding how to prevent/control cervical cancer the resonating themes included limiting the amount of sexual partners, regular testing specifically after first becoming sexually active and/or after giving birth.

Participants mentioned the importance of regular testing to be able to detect cervical cancer at an early stage where it could be controlled. Further elaboration was obtained on participants’ individual risks for getting cancer and understanding of their family risks. Participants seemed to be unsure about cervical cancer being hereditary and mentioned a regimen of exercise and a healthy diet as key components to prevention/control of cervical cancer. This study was conducted before the media campaign on cervical cancer and the HPV vaccine.

Pilot

The community health workers and their respective supervisors completed pre and post tests on breast and cervical cancer literacy. From a construct validation perspective, if the instrument is assessing cancer literacy, the post test scores should be higher than the pre-test scores. The results in Table 1 show that this was indeed the case. The mean scores improved and the



proportion above the cut score of 75% of the maximum also increased (see Table 2). Analysis of variance is constrained in this pilot study by the small sample size (n=16). However, improvements in literacy scores resulting from Kin KeeperSM intervention appear to be independent of age, education, income level, and other potentially confounding variables (Table 3).

Internal consistency of the literacy assessment is high. Cronbach's Alpha for the 16 questions in the breast cancer assessment is .85, and for the 12 questions in the cervical cancer assessment it is .87. Combining these assessments into an overall measure of cancer literacy returns a Cronbach's Alpha of .91.

DISCUSSION:

This study represented the first study, according to our literature review, that documents the development of breast and cervical literacy assessments that measure functional literacy combined with instruments administered orally by a layperson. The combined approach makes a unique contribution to the science of health literacy. In addition to showing the design process, we reported the results of piloting the two cancer literacy assessment tools. Increasingly as researchers and health educators design interventions aimed at addressing the cancer disparity gap, they will be forced to design health literacy instruments that specifically measure a cancer site (Williams, Mullan, & Fletcher, 2006). Such instruments will enable them to more accurately tailor their interventions.

It was valuable to work with community health workers who were also representative of the underserved women we aimed to recruit into our intervention. The community health workers served as a check and balance. This methodology was in keeping with community based participatory research (Minkler, 2003) as well as instrument design (Johnson, Willeke, & Steiner, 1998). All of the women regardless of their role in our study provided us with a realistic picture of measuring the functional breast and cervical cancer literacy. Their participation gave us a perspective of women who are eligible for public health services and have varying literacy levels. For example, in the process of developing the critical indicators and domains for the assessments, the structured interviews revealed that the study participants had both cultural and age perspectives of breast and cervical cancer (Meade, 2005; Chavez, McMullin, Mishra, & Hubbell, 2001). We also noticed that across cultures and ages, women had a hard time differentiating between clinical breast examination and a mammogram. In the pilot with community health workers this was also the case where 75% of them were confused about the differences between clinical breast examination and a mammogram.

Functional cancer literacy entails a woman's ability to understand the basics about breast and cervical cancer screening, prevention and control. How women define breast and cervical cancer in their own mind as well as their understanding of preventive and early detection screening is the difference between functional literacy and non-functional literacy, ultimately impacting their screening practices. If a woman thinks mammograms and clinical breast examinations are the same, then it is likely she would think that during the annual check up in the doctor's office she received a mammogram when in fact the provider performed a clinical breast examination. Or, if she thinks they have the same purpose, she may be less likely to adhere to screening guidelines.



From this woman's perspective she believes that she is adhering to mammogram screening guidelines.

If a woman thinks that cervical cancer is hereditary, she might assume that since no one in her family had it, then she does not need a Pap test although she is sexually active. Or, if she only associates the Pap test with prenatal visits and not as a cervical cancer screening, then she is likely to not to get screened once she passes her childbearing years, although she may be sexually active.

Having a pilot sample of community health workers and their supervisors proved to be effective for a couple reasons. When the workshop facilitator administered the assessments orally, she was modeling how the community health workers should administer the instruments once they were in the field. She read questions and answers choices. Participants were able to follow along regardless of their reading level. This is a critical because in the field, we anticipate that women will have various degrees of reading comprehension as well as breast and cervical cancer prevention and control comprehension. The goal is to measure what they know, regardless of their literacy skills. With people who struggle with literacy, their oral skills are often more developed than their written literacy skills (Baker, Parker, & Williams, 1998). This means that a woman could understand the aspects of breast cancer prevention and be compliant to the specified guidelines, yet not be able to complete a survey that reflects her knowledge or behavior. Administering the assessments orally enabled us to gain a more accurate measure of participants' comprehension of functional breast and cervical cancer literacy without inaccuracies that could result from limited reading skills.

Using the matched pair *t*-test, we were able to analyze the measurement of functional breast and cervical cancer literacy with women who were considered health literate in one public health issue, other than cancer. The community health workers were skilled in assisting their clients to navigate the health care system as it related to either material child health or diabetes and were adept in administering health promotion education. However, their cervical cancer literacy pre-test mean score of (56.7) was well below the 75% standard compared to their breast cancer literacy pretest mean score (75). Their post mean scores increased significantly for cervical (81.2) and breast (86.7). It is plausible that exposure to breast cancer awareness through the media has markedly outpaced cervical cancer awareness marketing. At the time of data collection for this study, the cervical cancer awareness television commercials had not made their debut. These findings further confirm that health literacy is more than being able to read and write (Nutbeam, 2000).

The limitations of this study included the lack of a control group to compare pre and post test cancer literacy scores. In addition, although the data analysis was subjected to reviews by a panel of experts in the subject area and inter-rater validation, there is still the danger that researchers' bias and values may have influenced interpretations. Also, given the small sample size from interviews and community health workers add a potential for bias and value influences on the part of the researchers. However, in spite of these limitations the strength of this study lies in its ecological validity in that the instrument development is based on real accounts from community participants and health workers working in a variety of settings. Overall, this study provides scope for more research.



The Institute of Medicine reported health literacy measurements are limited (Neilsen-Bohlman, Panzer, & Kinding, 2000). While researchers are attempting to answer the call to expand health literacy assessment, the fundamental question will be. *What do we want to measure?* Do you want to measure a “macro” comprehension of health literacy or do you want to measure a “micro” comprehension of the health issue at hand? The former contributes to the science globally and the latter contributes to solving the health issue.

The next step for this research is to conduct another pilot test with actual target audience to determine usability of the breast and cervical cancer assessment tools. Further, instruments will be put in the field to determine its’ psychometric properties. The reliability and validity of the cancer literacy assessment tools will need to be determined by measuring the internal consistency of items, item structure and functionality.

*Table 1.
Paired Samples Test on Pre- and Post- Intervention Literacy Scores*

	Pre- Intervention on Mean Scores	Post Intervention on Mean Scores	Mean Difference in Score (Post – Pre)	SE Mean	t ⁴	df	p ⁶
Breast Cancer	12.75	14.88	2.125	0.831	2.57	15	0.022
Cervical Cancer	6.88	9.75	2.87	0.735	3.910	15	0.010
Overall	19.63	24.63	5.000	1.390	3.596	15	0.003

*Table 2.
Paired Samples Test on Pre- and Post- Intervention Functional Literacy Pass Rate*

	Pre- Intervention on Pass Rate	Post- Intervention on Pass Rate	Mean Difference in Pass Rate(Post- Pre)	SE Mean 2	t ⁴	df5	p ⁶
Breast Cancer	0.750	0.938	0.188	0.101	1.861	15	0.083
Cervical Cancer	0.313	0.875	0.563	0.128	4.392	15	0.001
Overall	0.563	0.938	0.375	0.125	3.000	15	0.009



*Table 3.
Improvements in Functional Literacy of Community Health Workers by Demographic Variables*

		Pretest		Post Test	
		Fail Count	Pass Count	Fail Count	Pass Count
Age	27 to 45	1	7	0	8
	46-64	4	2	0	6
Marital Status	Married	0	5	0	5
	Single/Never Married	0	4	0	4
	Divorced	4	0	1	3
	Widowed	2	0	0	2
Education	High School Diploma	1	1	1	0
	Some College	2	3	0	5
	College Degree	3	3	0	6
	Graduate Degree	0	2	0	2
Income	\$0-20,000	4	2	1	5
	\$20-40,000	0	3	0	3
	Over \$40,000	2	4	0	6
Employment status	Regular full- or part-time	3	9	1	11
	Retired or stopped working	3	0	0	3
Health status	Very good	1	2	0	3
	Good	1	5	0	6
	Average	4	1	1	1
	Poor	0	1	0	1

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