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IMPROVING THE HEALTH LITERACY OF RURAL HEALTH CARE CONSUMERS

This article summarizes the health literacy program of a community health education center in a rural, health profession shortage area. The center is an education, research, and community health partnership between the University of South Carolina School of Medicine and Kershaw Family Medicine Associates. Patients were included in the development of health education and promotion materials as well as health care instructions in order to improve the likelihood that they would be able to understand and act on the information.

The program used focus groups, recruited from patients at the family medicine practice, to produce health and health access information products that matched the patients' health literacy levels. The influence of the focus group process on the participants' functional health literacy and self perceptions of their quality of life were also measured with standard survey instruments. Videos and written brochures were produced on the following topics: steps in the prescription application procedure (PAP) for free medications, how to take medications correctly, hypertension, nutrition, diabetes, and physician communication with their patients.

Keywords: health literacy, focus groups, community health, medications assistance, hypertension, nutrition, diabetes, patient communication, quality of life.

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The University of South Carolina-Kershaw Rural Primary Care Education Project (Kershaw Project) was established in 1998 to provide health profession staff and students opportunities for education, research, and community health activities in rural health care delivery. The project is a partnership between the USC School of Medicine (USC SOM) and the Kershaw Family Medicine Associates, LLC (KFMA). The staff of the Kershaw Project consists of a program manager and medical students from the USC SOM, social work graduate students from the USC College of Social Work, an education director and Social Worker who are supported with Kershaw Project funds and are employees of KFMA, and the physicians at KFMA. As many as twenty, third year medical students per year spend four weeks training in community family medicine at KFMA. To further their understanding of environmental influences on their patients' health, the students help develop health information for the Kershaw Project's health literacy program one day per week. Social work graduate assistants who intern at the Kershaw Project help facilitate focus groups, record the perspectives voiced by participants, and help translate these records into health information that consumers can understand and use for constructive action that benefits their health.

The objectives of the health literacy program were three-fold.

1. Develop health information that matches the health literacy of the health care consumers in the KFMA service area.
2. Develop a procedure that enables a group of patients to access a critical health care service by matching the procedure with the patients' health literacy.
3. Provide the health care consumer with the opportunity to have an active role in the development of selected health care and health access information.

These objectives address three salient shortcomings in the health literacy levels of materials that are prepared for the typical health care consumer. First, as much as 80% of health information is written at the twelfth grade level whereas nearly 50% of Americans read at an eighth grade level or lower (Kirsch et al. 1993). Secondly, patients must navigate through a variety of documents and procedures that are often written above their health literacy levels, making their access to health care more difficult. These include consent forms, insurance forms, prescription application procedures (PAPs) for free medications, and instructions for taking medicines and preparing for or recovering from medical procedures. Thirdly,

health information is generally culturally irrelevant and does not match the language of the intended audience because the consumer is usually not involved in its development. This increases the consumers' lack of ownership and further decreases the possibility that the information will be used by the intended audience.

We also expected that involvement of our health care and health education staff in the program would improve their skills in communicating at their patients' health literacy levels. We also expected that the patients who participated in our focus groups would improve their functional health literacy, their self perception of their health, and their self management skills.

KFMA provides services for about 25% of the 18,000 people in the four surrounding census tracts. The area is a Health Profession Shortage Area. Fourteen percent of the population is over 65 years of age, greater than the State average of 12%. Nineteen percent of KFMA patients are Medicaid enrollees, 18% are Medicare enrollees, and 25% are uninsured and self paying. The percent of persons with less than a ninth grade education (10.4%) is greater than the State average (8.3%) and the US average (7.5%).

The forty patients who participated in the four focus groups of the health literacy program completed a Slosson oral reading survey, the verbal or short portion of the Test of Functional Health Literacy for Adults (STOFHLA; Nurss et al. 1995), and a survey assessing self perceptions of physical and mental health (SF-12v2; Ware et al. 2002). The average age of participants was 61.3 years, 42% of participants were African American, and 58% were Caucasian. Females made up 79% of participants and males 21%. Three-fourths of participants read at an eighth grade or lower level. The verbal functional health literacy was inadequate for nearly 39% of focus group participants but 56.4% scored at an adequate level.

1. Design

To produce health and health access information products, the staff was first trained in written and oral communication methods that met the needs of the service population. The staff then recruited patients to participate in focus groups, and patients and staff together produced information products that met the patients' needs and matched patients' health literacy.

1.1. Staff training

The staff was trained to assess the readability of written material with techniques like S.M.O.G. (National Literacy and Health Program 1998) and improve the readability of material. They were taught to limit the content of health materials to two to three “need to know” points and to make materials user friendly with headers, lists, ample white space, and abundant color. They also learned to incorporate Plain Language (National Literacy and Health Program 1998) principles into written and oral materials. Common words of one to two syllables were used, medical jargon was limited, and the tone of material was conversational and used active voice. These skills enabled them to conduct telephone recruitment and one-on-one enrollment meetings, to facilitate focus group meetings in which patient perspectives were collected and health information products were field tested, and to develop written and script materials for brochures and videos. The staff was also trained to administer a USC Institutional Review Board-approved informed consent form as well as survey instruments for reading level, functional health literacy, and patient quality of life.

1.2. Recruitment and retention

Patients from KFMA were recruited into a number of topical focus groups where they became engaged as learners as well as empowered as creators of health information. A script edited for Plain Language was developed for telephone recruitment.

Focus group members were recruited from pools of patients at KFMA with some of the most prevalent health and health access problems. Users of a complicated medications assistance program and those with the complex chronic illnesses of hypertension (30% of patients) and diabetes (10% of patients) were recruited and segregated into topical focus groups.

The focus group discussions enabled the staff to discover the difficulties and weaknesses in the participants’ understanding of medications assistance procedures, their hypertension, and their diabetes that could adversely effect their long term health. Most noteworthy, even patients with higher reading levels had difficulty completing the nonstandard and complicated drug company applications for free medications. The Kershaw Project helps nearly 130 indigent patients complete an average of four to five different applications each quarter for drugs critical to their health. In addition, many patients with hypertension did not

understand the nature of the disease, its causes, and the range of blood pressure readings that was considered "good." Diabetics had trouble understanding how they could practice healthy nutrition in order to maintain healthy glucose levels.

Patients in the medications assistance focus group were selected from those using the assistance program who had been diagnosed with hypertension in order to establish a common feature among focus group members. Of 48 patients contacted over the telephone, 23 participated in the program, and 70% of these participated in all focus group meetings. The participants were further divided into a low and a high reading level group in an effort to promote greater discussion in each group.

To fill the focus group on hypertension, six hundred KFMA patients with hypertension were identified and every tenth person was invited to participate in the focus group until twelve agreed to participate. Eight of these regularly attended weekly focus groups over a two month period.

Patients for the diabetes focus group were recruited from an existing diabetes support group that the medical students had established. Twelve agreed to participate in the focus group and nine attended on a regular basis.

A fourth focus group was recruited from participants in existing hypertension and diabetes support groups to create an educational video that would help health care providers better understand and practice communication styles that patients felt would enhance the quality of an office visit. Twenty were recruited into two focus groups. Many also agreed to express their expectations of doctor-patient communication in the video.

Several reasons can explain the good retention of focus group participants in discussions that extended over a minimum of five sessions. Lunch was always provided and an opportunity for socialization with one's peers was also an incentive. Most important, though, was the fact that group members had worked with the staff in the past and had developed a trusting relationship. In addition, participants expressed an obligation to "give something back" in return for the services they had received.

Conduct of focus groups. A minimum of five focus group meetings at weekly intervals were conducted to develop each health information product. The production of health information products followed a standard set of steps in each focus group. At the first two group meetings, participants were encouraged to discuss their understanding of a health topic. Staff also used this time to develop their own understanding of the language used by participants to describe the topic. At the same time, effort was made to create a non-threatening environment so participants would

openly discuss a topic with minimal inhibition and from their own cultural perspective. This approach made it more likely that the health information would be culturally familiar and thus more likely used. For example, when placemats were being created to show healthy meal planning, the focus group made it clear that foods considered high in empty calories and fat such as grits, sausage, and biscuits, needed to be included in the examples of breakfast meals since in their lives these were standard foods. As a result, these foods were included to increase acceptance of the placemats. However, their quantities were also shown in the recommended serving sizes to teach the importance of proper portion sizes.

At the third meeting, written brochures or video scripts drafted by the staff were presented to the focus groups for their review. The content and language in these first drafts were heavily influenced by the views patients expressed during the first two focus group meetings. Focus group feedback was then used to further revise the presentation of the material. This second draft was then discussed in at least one more focus group meeting before a final draft was produced.

To assure the conformance of content with established guidelines, reviews from health practitioners were obtained and accepted references were consulted. The staff, of course, were the experts on pharmaceutical company PAPs as they routinely helped low income patients receive free medications from five or more companies. For nutrition information, the county's diabetes education center and extension agency were consulted. They advised that the simple concept of one protein and three carbohydrate (four for men and active persons) servings per meal be used as a basis for meal planning. They had found this approach easily understood by their clients and adaptable to the non-diabetic population. Information on hypertension was adapted from patient education material available on a medical website available through the USC SOM library. Development of the video on how a provider could best communicate with patients used information from the American Medical Association Foundation's health literacy program (Weiss 2003).

Implementation. The following health and health access materials were produced for public consumption.

2.1. Medications assistance

Two generic PAPs were developed, one in video and one in written format. The title of both was "Ten Steps to Get your Free Medications."

The video was produced with a local acting group and the media center at a local technical college. The instructions were written in Plain Language and included graphics, lots of white space and color. They were also accompanied by a set of tips for patients to verify the delivery of the correct medications, to keep track of dates when medications should be reordered, and to remember to ask their doctor about the intended effects and side effects of their medications.

2.2. Taking medicines correctly

An additional handout was developed that listed ways to avoid some common mistakes when taking medications.

2.3. Nutrition information – placemats

Diabetes focus group members stated that they knew what foods were healthy but they did not know how to combine these foods into a balanced meal. As a solution, laminated placemats were developed that illustrated balanced meals for breakfast, lunch, dinner, and snacks. Seven sample meals were assembled for each placemat using the one protein and three carbohydrate guideline. The meals were photographed on a contrasting background and then electronically pasted onto the front of that meal's placemat. Subtitles below each sample meal identified foods as a protein or a carbohydrate serving.

Additional nutrition information was printed on the back side of each of the four placemats. The one protein and three carbohydrate concept was linked to the food pyramid model for a balanced meal on the breakfast placemat. Simple methods for conveniently measuring and visualizing a food's serving size were placed on the lunch placemat. The dinner placemat contained a short lesson on how food labels relate grams of carbohydrates to serving sizes. The snack placemat contained helpful hints for limiting portion sizes, such as using a smaller plate, and thereby controlling caloric and fat intake.

2.4. Nutrition information – animated videos

To further illustrate nutrition concepts in a more visually captivating manner, videos were produced using animated characters. A video production company was contracted to create five, one-minute nutrition

videos from scripts provided by the health literacy program staff. The topics of the videos were balanced meals, the definition of a protein, the definition of a carbohydrate, portion sizes, and reading food labels.

2.5. Hypertension

A patient education PowerPoint presentation on hypertension was developed based on the perspectives expressed by the hypertension focus group participants. Participants needed clarifications on the meaning of high blood pressure, how high blood pressure can be managed, and how to prevent a stroke.

Regardless of how many blood pressure measurements a patient has had, a recurring question was whether the reading was “good.” To help patients understand “good” blood pressure, a wallet-size card was developed that pictured a standard bulb thermometer that was shaded from red to yellow to green from its top to the bottom bulb. Pairs of blood pressure numbers (systolic over diastolic) were aligned along the thermometer in descending value much like a scale. The normal pairs of numbers were situated just below the yellow-green junction on the thermometer.

2.6. Diabetes

A wallet size card similar to the blood pressure card was developed to provide patients with a ready reference for blood glucose levels. A horizontal band of colors with green in the center, yellow on either side, and red on the ends was labeled with a scale of glucose levels that increased from left to right. Normal levels were located on the green center of the band.

2.7. Talking to your patients

Medical students developed a seven minute video for health care students and providers on how best to communicate with patients when delivering care. The medical students and focus group participants wrote the script and provided actors for the video. The technical college media center filmed and produced the video.

3. Impact

Staff and students involved in this program have improved their written and oral communication skills when presenting health information.

They have learned to match the content and presentation of material with the health care consumers' health literacy. In the past year, the Kershaw Project staff have used these skills to deliver health education and promotion programs to over one thousand persons in support and education groups, in school settings, at community health fairs, and at senior activity and nutrition centers. All of these presentations have been tempered with the health literacy lessons the staff have learned from involvement in this program.

In addition, the staff are evaluating the health literacy level of materials before they are used for health education and promotion programs. Patient input is sought when new health information is being developed for general distribution.

The program's written brochures and videos on medications assistance, nutrition, hypertension, and diabetes have been distributed to fifteen different county social and health service agencies for their clients use. These agencies have also received presentations on the important influence that the level of their clients' health literacy has on the ability of their services to improve their clients' health care and health outcomes.

The program's PAP guidelines and video are now a standard part of the patient orientation and refresher training in the Kershaw Project's medications assistance program. More patients in this program now understand the process better, are maintaining their prescriptions current, and are completing applications themselves. In addition, some participants in three of the four focus groups have been motivated to continue to meet monthly to learn more about the behavior changes they can make to improve their health.

Over the past three years, nearly fifty medical students and nine social work graduate students have participated in production of the program's health literacy products. During this time, medical students have also made bimonthly presentations on their health literacy projects to about 180 of their fellow students in the community family medicine clerkship at the USC SOM. When students begin their clerkship at the Kershaw Project their orientation includes a viewing of the videos produced by their peers in prior clerkships and by the AMA Foundation on the style of provider-patient communication that encourages the patient to take an active role in the decision-making process during their doctors' visit. Students often comment that until they participated in this health literacy program they were unaware of the health literacy gap that existed between patients and their doctor.

We started with the premise that if the match between patients' health literacy and the health care and health access information they receive were improved, patients' ability to take a more active role in their health care would be enhanced. We felt this would be especially true in our focus group participants because of the active role they played in the creation of health and health access information. We have observed patients gain an increased sense of control of their health as a result of their focus group participation. Many have begun to take a more assertive role in their doctor-patient dialogue and are more comfortable asking questions.

We expected that this confidence would translate into improved self management skills and improved self perceptions of their quality of life. We have not measured self management skill levels in our focus group participants or the patients who have been exposed to our health literacy products. However, we have obtained quality of life surveys for fifteen patients in the medications assistance focus group at the start of their focus group experience and two years later. The before and after results of these quality of life surveys are shown in Table I. The table shows a small improvement in the average member's perception of their mental health and a small decline in their mean perception of physical health. The changes in mean health perception are not significant. However, twelve of fifteen felt that their mental health had improved. This may indicate an increased self confidence in their ability to manage their health despite their aging condition. On the other hand, eleven of the fifteen indicated a decline in their physical health that may be expected since their average age increased from 61 to 63 between surveys.

Table I: Mean Pre and Post SF-12 Scores for Physical and Mental Health for Medications Assistance Focus Group Participants (n=15)

Self Perceptions of:	Pre-focus Group Mean Score (+/- SD)	Post-Focus Group Mean Score (+/- SD)
Physical Health	36.1 (9.9)	31.1 (7.6)
Mental Health	46.2 (14.9)	51.1 (13.2)

Health care consumers' health literacy is their ability to read, understand, and then act on oral and written health information that they receive from their providers and health educators. In the future we would like to expand our measurements of patients' quality of life following exposure to our health information products. In addition, as a measure of the

action part of the definition of health literacy, we would like to quantify changes in patient self management skills when the communications to them from the health care system are changed to more closely match their health literacy levels. We would also like to measure the effect of our health literacy training program on our students' ability to communicate with their patients in a manner that is sensitive to their health literacy.

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