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Health Literacy Levels Among Adult Support Group Members and the General Adult Public : A Focus Group Approach

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ABSTRACT

Health literacy has been identified as lacking in 47% of Americans (The National Academies, 2004). While health literacy reports of studies conducted in the southern section of the United States are available (DeWalt et al., 2004; Kennen et al. 2005), this research team found limited research that provides health literacy levels of the southeast, rural Georgia population. The purpose of this exploratory study was to examine and compare health literacy of health-related support group members and non group members in southeast Georgia utilizing a focus group methodology developed by Kreuger (1994). After Institutional Review Board approval at a local university, the research team utilized 5-10 established Health-related Support Groups of 6-10 individuals in the southeastern part of the United States. An additional four focus groups composed of persons not associated with a health-related support group were also used for comparative purposes. Participants were recruited with the assistance of local health care providers. The initial open-ended questions consisted of items such as: "Describe your experience reading health resources." "What makes a health resource difficult to read, as well as easy to read?" The moderator utilized additional probing questions and reframing comments as necessary (Kreuger, 1994). The data were analyzed by the qualitative content analysis method described by Berg (1989). The themes that emerged across groups reflected confusion about medication directions, health terms, and communication from health care providers and doubt about the integrity of and inability to read the small print of health information. Prevention and faith in God were identified as important to self-care. Rationales for themes and future research ideas are discussed.

INTRODUCTION

The success of educational programs is dependent on the students' ability to understand that which is read, discussed, and/or experienced in a variety of ways. The same principle holds true for the public at large. While the inability to understand general terms interferes with everyday life, limited health literacy interferes with one's health status (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Kennen et al., 2005; Kolasa, Peery, Harris, & Shovelin, 2001; Paasche-Arrow, Parker, Gazmararian, Nielsen-Bohman, & Rudd, 2005). Without the ability to understand health-related terms and instructions, the citizens of America, including the rural population of southeast Georgia, might consider health promotion and disease prevention as only words that are tossed about by health professionals rather than the means to a better way of life, a healthy life.

Health literacy has been identified as lacking in 47% of Americans (The National Academies, 2004). While health literacy reports of studies conducted in southern states such as in North Carolina (DeWalt et al., 2004) and Louisiana (Kennen et al. 2005) are available, this research team found no studies that provide health literacy levels of the southeast, rural Georgia population. The purpose of this exploratory study was to examine and compare health literacy of health-related support group members and non group members in southeast Georgia utilizing a focus group methodology developed by Kreuger (1994). By comparing the participants of support groups (persons who are regularly exposed to educational programs) with the general public, health literacy levels of both groups can be identified and methods for addressing the deficits can thereafter be developed. For the purposes of this study, health literacy was defined 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" (Healthy People 2010, nd).

METHODS

Participants

The research team utilized four established Health-related Support Groups of 6-10 individuals who reside in rural Southeast Georgia. These support groups centered around four specific ailments (Alzheimer's disease, Parkinson's disease, chronic lung disease, and fibromyalgia). In addition, four non health-related support groups were utilized. Members of the non-support groups were associated with local churches. An informed consent letter explaining the purpose of the study and the focus group method was sent to all potential participants. During the focus group meeting, the informed consent was signed by the participants.

Procedures

A series of semi-structured "interview guide" questions was developed by the research team. The initial questions consisted of:

- "Describe your experience reading health resources."
- "What makes a health resource difficult to read, as well as easy to read?"
- "Describe your experience with the media in understanding health resources."
- "Describe your experience with basic self care."
- "If you were to describe the best way a health professional can communicate with you about health resources, how would you describe it?"

These questions were followed by more specific questions derived from the discussion. Because group discussions can be free flowing, the moderator utilized additional probing questions and reframing comments as necessary (Kreuger, 1994).

DATA ANALYSIS

Qualitative content analysis (Berg, 1989) was used for this project. A preliminary reading of the transcripts by a qualitative research team provided potential themes. In addition, all responses to the respective questions were grouped together for analysis using the NVIVO software. Patterns and trends were focused within each key question. Those quotes showing similar themes were grouped together until the dominant themes of importance emerged from the data.

RESULTS

Using the methodology described above, the interviews of support and non support group participants were transcribed and placed into themes, so that the experience of health literacy could be determined. This section contains quotes from the participants to illustrate their thoughts on health literacy.

Health Resources

The first question elicited the participants' experiences with reading health resources.

THEME: CONFUSION ABOUT TAKING MEDICINE

Both support and non-support group members immediately disclosed confusion of the when, what and how regarding medicines. This "confusion" was the major theme throughout the interviews. More specifically, both support and non support group members described the difficult words and hard to follow directions that many of the prescriptions entailed. Members of Support Groups 1 and 2 stated:

"It needs to be written down where the patient can understand. But usually when we get medication that has got a pamphlet on it and sometimes you don't understand the meaning of the word on the pamphlet. Then if you don't, you need to ask your doctor about it and they can break it down for you. But medical terms....words are kind of hard and complicated and if you don't understand them, they need to be broken down. Some people that take it...don't even know the meaning of the words. And it needs to be broken down so a little girl can understand it." (Support Group 1)

"For me, it is so difficult to understand the words on the directions. I get confused on when I should take this, do that and for how long. I wish they could spell it out in an easier manner. Like on a calendar or something like that." (Non Support Group 2)

Non support group members described the difficulty of many of the prescriptions which use abbreviations.

"A lot of them are using abbreviations. I don't understand why they break it down to abbreviations because when it's shortened, it is very confusing." (Non Support Group 1)

THEME: INTEGRITY OF HEALTH INFORMATION

After discussing the confusion associated with taking medicine, many of the groups went directly to the integrity of the health resources. Members from non support group numbers 3 and 4 stated:

"I find that with internet information, you have to be real careful about which sites you choose to get information from and you really should look at those that are from recognized health groups like, you know, if it's from the Mayo Clinic or it's from a recognized institution of health, like Tuft's or that type thing." (Non Support Group 3)

"Magazine advertisements, they have all kind of information, but really it's slanted so that it makes it sound like it's a perfect cure for anything. I am not sure how much research was involved with the mentioning of that information." (Non Support Group 4)

Moreover, support group members described the health resource advertisements' reading level.

"You get a lot of ad stuff and just people's opinions and some of them are kind of far fetched as well. What I find is that the level of reading is more middle class and upper class...above middle class people who tend to try to access the most information and have the resources to access the information and very oftentimes the literature that's there for them even in print that's given out to them by their physician or what's on the internet or in a magazine or whatever, is above the grade level that they're able to read at." (Support Group 2)

Reading Health Resources

The second question was "What makes a health resource difficult to read, as well as easy to read?"

THEME: PRINT SIZE OF HEALTH RESOURCES

Support group members immediately stated the print size of most resources is so small that it is difficult to read.

"The words so small I can't read them without my magnifying glass. They need to make those pamphlets large worded. Even my friends cannot read them." (Support Group 3)

"They are just so hard to read. The best prescriptions or resources are ones that have large words with dark colors that can be read easily. So many of these health pamphlets are so small that I can't see them." (Support Group 3)

THEME: DIFFICULTY OF HEALTH TERMS

Non support group members predominately stated the length and difficulty of understanding the essence of the words were problematic for them as they read health resources.

"More details. Like big words, medical terms need to be broken down, especially to our age group because there's a lot of stuff we don't understand." (Non support group 4)

Influence of Media on Understanding Health Resources

The third question asked the participants to describe their experience with the media in the understanding of health resources.

THEME: DISTRUST OF THE MEDIA

The major themes derived from this question consisted of the money making marketing machine most companies use to put their product in a positive light. Confusion occurred to the participants on what to believe is the ultimate truth. This theme of distrust of the media and marketing seems to cut across both support and non support groups.

“The advertising is very confusing. Their job is to make money. The media is selling to you. Everything is about selling, selling, selling and they do the same with physicians and at the hospital. I’ve seen it. You always know the drug reps because they have nice suits on, starched white shirts and they’re dragging around suitcases going from floor to floor to unit to unit and my doctors many times have said, oh let me go see if we have a trial going on or something. And they go in their, you know, we get their five free doses and here try this. If you like it, then you get...”here’s a prescription.” And, you know, it works that way. Everything you see it’s being thrown at you to make money.” (Non-Support Group 3)

“They’re promoting all the new medicines. They don’t sell some of the older medicines that treat the same condition that are just as good and probably cheaper. But people will jump and say I’ve got to have this new medicine. It’s fantastic. But it may not be.” (Support Group 1)

“I don’t believe and don’t pay attention to the media. I say they are just trying to advertise their products. Some will come on and say one thing about something. Another one will come on and say don’t take that. And I say, well who you going to believe.” (Support Group 3)

Self-Care

In addition, the participants elaborated on the statement “Describe your experience with basic self care.”

THEME: SELF-CARE – PREVENTION

The major self care theme that surfaced from the transcripts was the importance of prevention. They did not delve into specific ailments or what they would utilize to relieve pain, but rather they mentioned the importance of prevention by exercising, eating healthy and maintaining good hygiene. Again, both support groups and non support groups disclosed the same theme of prevention. For example:

“Eat right most of the time. Exercise. Get rest.” (Non Support Group 1)

“Good hygiene.” (Non Support Group 3)

“I go to the community center and she’s got us exercising.” (Support Group 4)

“Well one thing to do is to take care of yourself! Like I was telling my husband this morning, we should not want to sit and don’t move. Move your hands, move your legs. You can’t only take the medicine. You’ve got to be active. Exercise more. Do all that stuff like that.” (Support Group 2) “I go on my walk every day for three miles until it gets cold. Then I like...oh keep my hair shampooed, showers every day, keep a positive outlook on life. Enjoy life. I enjoy life and I love helping others.” (Support Group 1)

THEME: SELF-CARE - IMPORTANCE OF FAITH IN GOD

Another interesting sub-theme that came out of self care was the importance of faith on health for both support and non support group members.

“When I wake up every morning I just give God praise and then I say the 23rd psalm.” (Non Support Group 3)

“We have to pray and say Lord give me something that I can do for myself, you know.” (Non Support Group 4)

“We could sit here and talk all day. But everything is in God’s hands.” (Support Group 4)
“We can’t depend on the doctor. We got to pray and Lord give me something that I can do for myself, you know.” (Support Group 2)

THEME: SELF-CARE - SELF RESEARCH

Support group members were more likely to go on their own and research a specific topic or ailment through the internet or library.

“I know I go on the internet and I’ll look up stuff and I know my husband, they put him on B12. Well he’s broke out with a rash and the doctor just gave him something for it, but I went on the internet the other day and what that B12...B12 is causing him to have a reaction. So I took him off of that.” (Support Group 3)

“My husband is in renal failure and some of the medications they give do not seem correct. I get on the internet just like you do and it says not prescribed for people with, you know, kidney failure. It’s very hard for me to understand why this drug is being given when it’s contraindicated.” (Support Group 1)

“Then you get on the internet and I find out a lot of information on it.” (Support Group 2)

Health Professionals’ Communication

The last question the participants discussed was “If you were to describe the best way a health professional can communicate with you about health resources, how would you describe it?”

THEME: TIME SPENT WITH HEALTH PROFESSIONAL

The themes of time with the health professional to ask questions and written literature about topic at hand seem to be overriding for both support and non support group members.

“They need to speak in laymen’s terms and written also.” (Non Support Group 1)

“The people who can answer your questions competently often are nonexistent.” (Non Support Group 3)

“They are so busy and they’ll take time to, you know, talk to you.” (Support Group 1)

“They don’t seem to take the time to even explain anything unless you ask and they don’t have enough time, so why don’t they do handouts.” (Support Group 1)

“I realize they don’t have time, but you know, if they could have somebody that was capable of doing some handouts for them or maybe there’s a program about specific sicknesses or injuries.” (Support Group 2)

THEME: LACK OF INFORMATION BY HEALTH PROFESSIONAL

An interesting theme from the non support groups was the notion of the lack of information health professionals tell. For example:

“Well they should explain that you got two different kinds of medicine to take and they’re not against each other. It won’t bother the body. But see they don’t tell you that. They just say well okay, you take this and you take that and come back. So you don’t know whether you’re alright or not. And I think that’s what causes a lot of people to die.” (Non Support Group 2)

“So that’s why you must be careful. Make sure you got the right understanding from the doctor when he orders you something. Make sure he tells you enough information about the medicine or injury. They never tell you enough unless you ask questions. They are always in a hurry.” (Non Support Group 1)

DISCUSSION AND CONCLUSIONS

Many of the participants enjoyed the opportunity to sit and talk about health literacy amongst themselves, as well as describe it to the researchers. Several of the participants enjoyed using that time to reflect on the past and realized how important understanding health resources can be for an optimal life. One participant even expressed how his life is healthier now that he is accountable for understanding health information. “I feel like that my life is on a better track now that I take control of the information that is presented to me. If I don’t know something, I will research it and find out about it. This action has made me a healthier person.” (Support Group 1)

We concluded that the participants in both the support and non-support groups sought to improve their health literacy. Obstacles to reaching health literacy included the small print and high reading level of healthcare information/directions, limited time and attention to language level by healthcare providers/physicians for diagnosis and treatment explanations, abundance of confusing medication advertisements, and too little attention by physicians and others to the prevention of untoward interactions of multiple medications. While this qualitative study’s findings cannot lead to a conclusion that the support and non-support group members differed in levels of health literacy, we did conclude that the support group members provided more examples of self-care knowledge and activities than the non-support group members.

Recommendations

This study of support group and non-support group members resulted in themes that are consistent with previous health literacy literature. For example, Williams (2002) noted the lack of understanding relative to written directions for taking medication. Suggestions for improvement included “slowing down” and “using living room language instead of medical terminology” (p.

417). The suggestions for improvement are also consistent with the suggestions made by this study's participants. However, the qualitative method used in this study did not address differences in health literacy between those who attend and those who do not attend support groups. Therefore, to determine if a difference in health literacy exists between persons who attend and do not attend support groups exist, we recommend a quantitative, comparative study with a larger sample. Support groups exist to educate as well as provide support for those who attend; therefore, to direct the recommended quantitative study, we propose that persons who attend support groups have higher levels of health literacy than persons who do not attend support groups.

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