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Electronic Resources in Patient Education: Issues and Solutions

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Abstract. *Management of electronic resources has become a critical function for successful patient education. The aim of our project is to promote relevant life style changes in the city of Lviv and the nearby region by direct provision of health care consumer educational services that focus on education of patient and caregiving families in the proper ways of modifying life style to improve cardiovascular health conditions. By accessing the most current sources of health information through access to the Internet; development and dissemination of current information for health care providers and educational materials for the general public on cardiovascular disease and lifestyle modification, improvements in both primary and secondary prevention of cardiovascular disease could be achieved..*

Keywords. Public health, health care, literacy, electronic health information, Internet, patient education, computer network, consumer health information.

1. Introduction

Health literacy is a public health goal for the 21st century. More than ever, the public health employs information technology to promote health and aid in health care – or what can be called eHealth. Health information is obtained from different contexts including electronic resources such as the World Wide Web and other technologies that now play an increasing role in consumer health. To benefit from electronic health resources, people should be able to use them to their optimal level that requires eHealth literacy which combines "basic reading and writing skills, working knowledge of computers, a basic understanding of science, and an appreciation of the social context that mediates how online health information is produced, transmitted, and received…" [1].

Until 2004, no formal programs in Ukraine existed to provide healthcare education to sick/disabled people and their caregivers to assist in coping with cardiovascular disease and needed lifestyle changes related to this health problem. To overcome the long-term consequences of the lack of such a program, the project "Educating Health Care Consumers to Prevent Heart Disease" was conjointly developed and implemented to introduce formal patient and family cardiovascular health education, disseminate printed instructional/reference materials regarding cardiovascular disease, and take advantage of group learning opportunities and patient-to-patient peer support. The project focuses on integrating information literacy into patient education, accessing the most current sources of health information through access to the Internet and explaining how to interpret

numerical consumer health information. This healthcare project was made possible by a grant from the Bureau of Educational and Cultural Affairs of the United States Department of State (ECA) through a program administered by International Research & Exchanges Board (IREX).

2. Access barriers to consumer health information

Health care in recent years puts greater emphasis on the active and informed consumer that has led to understanding that both access to and adequate comprehension of health information is still a problem. A report from the US Institute of Medicine entitled "Health Literacy: A Prescription to End Confusion" considered the relationship between health and literacy and showed that those with limited literacy skills have less knowledge of disease management and health promoting behaviors, report poorer health status, and are less likely to use preventive services than those with average or above average literacy skills [2].

2.1. eHealth Literacy Model

According to C. Norman and H. Skinner [3] eHealth literacy is comprised of six core skills, or literacies:

- traditional literacy,
- health literacy,
- information literacy,
- scientific literacy,
- media literacy, and
- computer literacy.

The authors use the metaphor of a lily to describe that the petals (literacies) feed the pistil (eHealth literacy), and the pistil overlaps the petals, tying them together. Within the lily model, the six literacies are organized into two central types: analytic (traditional, media, information) and context-specific (computer, scientific, health) [3].

The eHealth Literacy Scale (eHEALS) has been developed to provide a general estimate of consumer eHealth literacy skills for a wide range of populations and contexts. The eHEALS is a self-report tool that can be used by a health professional. It is "an 8-item measure of eHealth literacy developed to measure consumers' combined knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems" [3].

2.2. Professional and consumer language

Apparently, consumers and healthcare professional speak and think about health-related concepts differently. This vocabulary gap is becoming a more important problem as consumers increasingly explore eHealth resources for their own. Thus, professional language is a barrier to eHealth literacy. Consumers are prefer using a combination of "everyday language", technical terms (no matter if they understand or don't understand those terms) and various explanatory models, all influenced by many contributing factors.

What could be a bridge or crosswalk between consumer expressions and professional terms to aid information communication and retrieval? To address this problem, a concept of a consumer health vocabulary (CHV) was introduced, and "CHV is refers to a collection of expressions, concepts, attitudes, and beliefs observed to be used by most members of a consumer discourse group to communicate about health-related issues…" [4]. Although developing an open-access draft "first-generation" CHV has been reported [4], we had to solve our specific local problem related to the Ukrainian speaking audience and to develop a Ukrainian CHV to be used by consumers in a variety of situations:

- Face-to face communication between patients and physicians,
- Comprehension of information on diagnoses, lab results, personal risk factors, prescribed drugs,
- Submission personal health data in-person and through electronic media,
- Formulation of information retrieval queries to biomedical databases and other information systems that is also a problem to professionals [5, 6].

There are several types of professional terms that are difficult for lay comprehension:

- Difficult general language words which have the same meanings in the professional language (for example, intermittent),

- Medical terms requiring the subject knowledge to understand (for example, diastolic or angina),
- General language words which have different meanings in the professional language (for example, negative (not good) means "absence of a disease condition").

2.3. Why studies are contradictory

Consumers look for simple certain data to help them being healthy. The problem is that single studies rarely provide such certainty. Instead, contradictory studies appear in the media almost weekly. The general public is becoming increasingly skeptical about advice on health and asks why researchers can't get it right the first time.

The IFIC Review explains the nature of the scientific process which is "a road of discovery", but "not necessarily a straight line". It is "characterized by cycles of revisions, conjectures, assertions, and contradictions... In addition, although such cycles often frustrate nonscientists and can contribute to increasing public skepticism about advice on food and health, it is important to understand that science is evolutionary, not revolutionary… Because scientific research explores the unknown, uncertainty is an unavoidable part of current investigations. Only through repeated research and analyses do certainties emerge" [7].

Everybody will agree that consumers read health-related literature to get answers. However the results section of a study provides "data" instead, and these data should be properly interpreted to become answers.

2.4. Understanding numerical data in consumer health materials

Much consumer health information regarding disease or treatment risks and benefits is essentially quantitative in nature that makes it difficult to understand to consumers because the interpretation of this type of information requires significant quantitative skill.

Consumers choosing between health care alternatives need to understand the likelihood of both the negative outcomes (risks) and the positive outcomes (benefits) associated with the available options to make informed choices between them. For example: a women making decisions about hormone replacement therapy to treat menopausal symptoms must understand and weigh the reduced risk of osteoporosis, cardiovascular disease, colorectal cancer, and Alzheimer's disease against the increased risk of breast cancer, myocardial infarction, cerebrovascular disease, and thromboembolic disease [8]. Even fractions and proportions used to present risks and benefits are challenging for the average person. Furthermore, even highly educated people have difficulty performing the quantitative operations that are commonly required in the interpretation of likelihood (for example, converting from percentages to proportions and vice versa). This shows that "the understanding of information regarding risks and benefits proves challenging for many, if not all, people" [8].

However there is an evidence that "the format in which likelihood is presented—verbal, numeric, or visual—influences understanding" [8]. Below is a brief summary of recommended formats.

- ***Verbal format***. Verbal labels be used only to describe probabilities that are unknown or vague. The meaning of a verbal label changes with the outcome being described, particularly if the outcomes range from very low-probability events to higher-probability events. As a result, verbal labels should not be used to describe multiple likelihoods in a single communication. For example, for low-probability risks a 1% chance is labeled high, but when verbal labels are used in a more general context (for example, to describe the likelihood of a false positive test result), a 10% chance is considered a small possibility. The interpretation of these two labels in a single communication presents difficulty for the information consumer that, increases the level of misunderstanding.

- ***Numerical format***. Numerical format of probability are better when likelihood can be precisely specified (for example, the likelihood of medication side effects can be precisely specified on the basis of clinical trial results). For numerical representations, frequency format (for example, 5 times out of 100) is most preferred, followed by percent (e.g., 5%). Probability format (like 0.05) is not

recommended as being most difficult for consumers to understand. When frequency format is used to present multiple risks, the size of the comparison group should be held constant (for example, 1 in 100, 5 in 100, and 20 in 100, but not 1 in 100, 1 in 20, and 2 in 10).

- ***Visual format***. Pictographs showing frequency representations of likelihood tend to be the easiest format to understand. The only disadvantage is that they take up a large amount of space, particularly in comparison to numerical representations and, thus, may be inappropriate when there are many likelihoods to be communicated or when presenting very low probability events.

3. Educating health care consumers in Ukraine to prevent heart disease

Cardiovascular disease is recognized to be one of the most prevalent world health problems and is of considerable concern in Ukraine. According to the data from the Regional Medical Information & Analytical Center in the city of Lviv, cardiovascular disease is known as the primary cause of death for 62 % of those who died in Ukraine during the year 2007. At present, 10.3 persons from every 1000 of the Ukrainian population die from cardiovascular disease. Overall, cardiovascular morbidity in Ukraine has increased by 9.36 % in comparison with the year 2003. Morbidity of cardiovascular origin not only causes a deterioration of health status and shortened life expectancy but also has increased the rates of related disability, which has negatively affected the quality of life for people in Ukraine.

3.1. Patient education project

Although patients in Ukraine get adequate medical treatment they remain at high risk of continued cardiovascular sequalae because the medical treatment provided is not adequately reinforced by relevant modifications of patient life style in such areas as diet, exercise, smoking cessation, and reduction of alcohol consumption, for example. Most cardiovascular patients have poor knowledge of how to change their behavior using disease specific lifestyle modification in the outpatient rehabilitation period, and moreover, they seldom are educated to understand that lifestyle modification is a life long commitment toward maintaining or improving their own health.

The aim of our project was to promote relevant life style changes in the city of Lviv, Ukraine and the nearby region by direct provision of health care consumer educational services that focused on educating patient and caregiving families in the proper ways of modifying life style to improve cardiovascular health conditions. By accessing the most current sources of health information through access to the Internet; development and dissemination of current information for health care providers and educational materials for the general public on cardiovascular disease and lifestyle modification, improvements in both primary and secondary prevention of cardiovascular disease were achieved. Additionally, health professionals, social workers and caregivers were trained to provide outreach educational programs about cardiovascular disease prevention in the community at large.

3.2. Patient education program and educational materials

Classes for patients and other health consumers on modification of life style, disease management and social rehabilitation were conducted once a week. Educational presentations to healthcare/socialwork professionals on the design and provision of educational programs about heart disease prevention were conducted once a month. Workshops for socialwork/healthcare professionals and interested community groups in the general public about heart disease and related issues were conducted once a month in Lviv Regional Cardiology Center.

A series of consumer pamphlets titled "Learning Ways to Protect Your Cardiovascular Health" was published and distributed to a selected target audience and mailed to regional health and academic libraries, hospitals and cardiology centers in Ukraine. Additionally, patient handouts are available from the http://www.ukrcardio.org website. Initially this series was planned to include 5 pamphlets. However, physicians from Lviv Railway Hospital and specialists from the Ukrainian-American Birth Defects Program provided so much additional material on vital related topics

that this information was formatted as three more pamphlets and included in the printed educational series. As a result, the final printed educational series now consists of 8 pamphlets on the following topics:

- Blood Pressure Notebook
- Ischemic Disease
- Eye Conditions in Hypertension Patients
- Birth Heart Defects. Hypertension in Pregnancy.
- Diabetes in Hypertension Patients.
- Hypertension
- Complementary and Alternative Therapy: Diet and Exercises
- Complementary and Alternative Therapy: Herbal Therapy and Hirudotherapy.

Pamphlets and patient handouts were discussed at patient meetings and at Ternopil Medical Library in particular. The educational program, based on a 5-step strategy was developed and improved according to opinions expressed by physicians from Lviv Regional Cardiology Center and Lviv Railway Hospital:

1 - what is a disease and risk factors;
2 - what warning signs are;
3 - what diagnostics techniques are used;
4 - what drugs are administered and why;
5 - lifestyle to follow.

3.3. Project evaluation

Questionnaires and evaluation forms were completed by health care professionals and consumers so that the researchers could learn of beliefs and attitudes towards the patient education system and materials developed during the project.

Our analysis of questionnaires and evaluation forms (completed by 162 patients, 43 physicians and nurses, 36 librarians and information specialists, and 23 administrators) shows that overall participant attitude has been positive regarding the educational program on cardiovascular health.

All respondents considered attending patient classes to have been a very useful adjunct to the drug therapy.

All participating physicians reported that they recommended the pamphlets and handouts to their patients.

Several physicians and information specialists (12 people) joined the project team to present patient classes and develop the pamphlets.

A focus group of patients (20 people) demonstrated an improved level of cholesterol, weight and exercise activity and better understanding of risk factors related to lifestyle (diet and smoking).

3.4. Patients' attitude

A brief review of the project evaluation questionnaires indicates that:

(1) all patients know a normal blood pressure level, but only 20 % patients know a normal cholesterol level;
(2) respondents highly rated the utility of the educational pamphlets (4.9 score out of a 5 point scale), but they are slightly less positive about the comprehensibility of the pamphlets that were developed (4.1 score out of a 5 point scale);
(3) healthcare professionals indicated that a formal patient education system makes their work less time-consuming and more effective provided that patient learning groups are kept small in size, otherwise patients indicated that they prefer speaking to a doctor individually during a healthcare visit.

4. Conclusions

Implementing improvements will be the aim of our continued effort after initial project completion to include the development of additional more focused educational materials and improvements to the delivery of the educational program itself based on the questionnaire recommendations noted above. We think that the educational project could be improved if in future:

(1) a cholesterol-related class would be added to the program;
(2) pamphlets would be peer-reviewed for readability and comprehension;
(3) training in understanding and interpreting health-related numerical information would be added to the program;
(4) patient groups should be limited to 5-7 persons instead of the typical 12-15 members attending each class during the initial project.

Attending the patient classes has become very popular among the patients in Lviv Regional Cardiology Center but it remains important to keep each class size small for improved communication.

Both Ukrainian health care professionals and consumers have responded positively to the idea of continuing these patient education services. The increasing number of participants in this project is further evidence that the initial conjoint cardiovascular project we have described has dealt with important topical and meaningful health issues and concerns of both the healthcare provider and the consumer populations in Ukraine.

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