Internet Supported Standardized Patient Information for Selfcare

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Abstract

Background. An informed patient is a better partner for the physician than an uninformed one. Such a patient will be more likely to practice effective selfcare, appropriately utilize the health care system, and be prepared to seek and obtain health care services that meet his needs.

Objectives. To develop a system of presenting standardized medical information for the general population based on guidelines developed for general practitioners (GPs).

Methods. Guidelines are instruments to be used by GPs to assure comprehensive and consistent enhancement of the quality of care. At the same time, guidelines describe the actions which could be expected by patients in various clinical situations. These materials establish a good basis for the patient's understanding of health care procedures and when and how to utilize health services. These materials will have to be adapted in form, content, and nomenclature in order to be understandable with the background knowledge of the average "citizen". This information for patients is currently being developed in various forms of presentations and applications. The use of web-oriented tools is a priority, because web content offers the patient a very simple and easy way of browsing and searching for the latest relevant information on both basic and advanced/detailed levels, including supporting pictures and animations. Materials are also being developed in other formats such as printed leaflets, audio presentations and videoclips.

Results. Web content and printed materials based on clinical guidelines have been created. Focus groups of health professionals and non-professionals were used for evaluation of the materials. General practitioners have tested written materials in practices.

Conclusions. The development and preparation of information and materials for patients has become an integral part of the GP practical guideline development cycle.

Introduction

Standardization of health care is a response to increasing demands of patients and professionals towards quality [1]. The requirements for public education designed to change the public's attitudes to "own health" are an important element of health care policy of EU member states. Modern medicine can be quite complicated and hard to understand for non-professionals. Misunderstanding medicine can result in inappropriate health care consumption, resorting to questionable alternative methods or irrelevant use of over the counter (OTC) products.

The informed patient is a better partner for the physician in prevention, treatment and clinical decision making. Such a patient will be more likely to practice effective selfcare, rationally utilize the health care system, and be prepared to seek and obtain health care services that meet his needs.

Informed selfcare means positive attitude to life, to own body and soul. It includes prevention and health promotion, awareness of alarming signs and symptoms and an active involvement in diagnostics, treatment and rehabilitation. Information for selfcare should be without myths and prejudices, rational and evidence-based, compatible with clinical guidelines and widely available.

The quality of information sources is often discussed in connection with the question of how harmful poor-quality information can be to the health of specific groups of patients. Recent studies indicate that 36% to 55% of internet users use the web to find treatment information which most probably influences their choice of treatment [2–5]. Many cancer patients intensively search for knowledge regarding their health troubles and so they may be particularly vulnerable to inaccurate or misleading information [6].

Clinical guidelines are an example of a systematic tool supporting standardization and quality development in practice. Their impact on clinical medicine and behaviour of physicians depends on various conditions [7]. In the Czech Republic, as in many other European countries, guidelines are evidence or consensus based recommendations, which provide essential and well-balanced information on the benefits and limitations of various diagnostic and therapeutic interventions. In some countries, guidelines have legal consequences (and not following them accordingly can raise problems for the physician). Guidelines support clinicians in exercising clinical judgment in individual cases [8, 9]. From the physician's and the patient's points of view, guidelines represent the current state of art in the respective clinical situation. Given the increasing public interest in information on health care, health promotion and increasing responsibility for own health; guidelines serve as an important basis for information on selfcare and appropriate health care utilization.

The aim of the project was to develop an integrated methodology for standardizing patient information and materials, based on existing guidelines developed by Czech Society of General Practice. Information should be understandable to patients and families, linked to existing guidelines which would support patient participation in health care, rationalize the consumption of care, enhance the process of standardization and assist physician when informing patients.

Although there are many publications about selfcare such as "The Home Doctor" or "Family Health" available on the market, there has been no systematic support within the process of clinical guidelines development for standardized health education and information aimed at patients. The bridge between guidelines and patient's information was missing.

The authors of the project have identified key guidelines where information for patients should be developed as a priority. Based on those key guidelines, comprehensive information and materials on selfcare have been created both for web distribution and for printed materials for use in practices and pharmacies.

Material and Methods

The project team consisted of general practitioners, a psychologist, informaticians, a publisher, a lawyer and health care journalists. As a part of the project, research and analysis of the current situation, trends and legislative norms in the field of selfcare in the Czech Republic and Europe were performed. Cooperation between the project team and The Centre for Guideline Development of the Czech Society of General Practice [10] was established. Clinical guidelines which have been developed over the last three years were translated by academic general practitioners into patient information (expanded guideline). A review of each expanded guideline was performed by three non-academic general practitioners for each item. The following criteria were used for assessment:

- accuracy
- consistency with clinical guidelines
- consistency with the verbal information given in the consultation
- readibility
- use of language appropriate to non health professional population.

Only materials which complied with these criteria were processed further for web information.

The use of web-oriented tools is a priority, because web content offers the patient a very simple and easy way of browsing and searching for the latest relevant information (on both basic and advanced/detailed levels), including supporting pictures and animation.

From the very start, the web application has been prepared according to widely accepted quality criteria for health information sources. The web page www.sebepece.cz was designed in compliance with the principles of the HON code [11]. The criteria for the RANKMED automated system for the quality assessment of health information sources [12] were taken into account during the processing of the pages. On the basis of the HON code criteria, RANKMED provides assessment of concrete indicators of the technical and publication quality of health-related websites. The database structure of the web application is ready for the implementation of code lists of diagnoses according to ICD-10 which are in place in the Czech Republic, medicines and medical materials. Texts describe individual examinations, medicines and illnesses. Texts are interlinked to the code lists in the database and make it possible to retrieve the required information from the pages. The structure of the texts, with a description of illnesses, medicines and diagnostics (Table 1) is identical for each of the main groups of information. The structure of the texts was defined with regard to guidelines for general practitioners. The texts contain frequently asked questions from patients regarding individual topics.

Symptoms represent the fourth main type of information. The texts in this section describe particular symptoms and provide links to a list of illnesses with which such symptoms may be associated. The description of the symptoms always starts with information on the most common causes of the relevant problem.

The web application and leaflets were discussed in two focus groups (health care professionals and non-professionals) and tested in general practice settings.

For an assessment of functionality of the web selfcare application, we used focus groups method [13, 14, 15, 16, 17]. We examined the opinion of future typical consumers of the web selfcare application – well educated lay persons (9 persons) and general practitioners (8 persons). Both groups were informed about the reason for the focus group meeting and an evaluation sheet was sent to both of them in advance. Two hour sessions were organized subsequently. The groups were again informed about the reason for the self-care support system elaboration and related web application was presented thoroughly. Probands scored the web application, being assisted by the moderator. The set of web application related evaluation criteria in English translation follows:

- How do you evaluate the implementation of the web application concerning health, disease and selfcare generally?
- How do you evaluate the implementation of the web application concerning health, disease and selfcare with respect to its easiness to grasp?
- How do you evaluate the implementation of the web application concerning health, disease and selfcare with respect to graphics and user friendliness?

Table 1 – The structure of the text with a description of illnesses, pharmacotherapy and diagnostic methods

Illnesses	Pharmacotherapy	Diagnostic methods
Name	Drug name	Name
Introduction / basic description	Introduction / basic description	Introduction / basic description
Definition	How does it work? / mechanism of effect	Why is it irreplaceable?
Symptoms	Warning / notice	How is it done?
Causes	Dosage	How does it work? / function
Diagnostics	What is it used for? / Indications	What is it used for?
Treatment	Who can use it? / contraindications	Risks
Complications	Side effects, undesirable effects	Complications
Prevention	Frequently asked questions	Frequently asked questions
Frequently asked questions	Visual documentation or link to sources	Visual documentation or link to sources
Visual documentation or link to sources	References	References
References	Selected links	Selected links
Selected links		
Audio / video clips		

The other forms of patient information were printed leaflets for practices and pharmacies, audio presentations and videoclips. Printed materials were distributed to nine general practices participating in a collaborative network attached to the Department of General Practice of Charles University in Prague. General practitioners were asked to use them in clinically appropriate conditions.

Results

The scheme of preparing expanded guidelines for patients derived from information from within the complex process of practical guideline development was created (Figure 1). Information in various forms of presentations and applications were elaborated with emphasis placed on the appropriateness of language for non health professional population. The process of patient information development has been harmonized with the process of guideline development. Patient surveys on the appropriateness, dissemination and availability of materials have been included in the development cycle. The first six patient versions of guidelines have been produced. The first elaborated topics were: High Blood Pressure, Asthma bronchiale, Dyspeptic complaints, Depression, Prostatic illnesses and Prevention of Colorectal Cancer.

The website appearance is illustrated in Figure 2. The focus areas of our approach (diseases, drugs, diagnostic measures, etc.) form a semantic net, and are linked together on the web site through the use of hyperlinks between content focus areas.

In the focus groups, probands were asked to use five point scales to score the application (the best 1, the worst 5). For all evaluation criteria the average value was better than 2. That is why we can make a preliminary conclusion that the pilot version of web selfcare application was accepted very well.

The same graphic design used in the web application was used for information in paper leaflets. Printed materials were distributed in general practices and used in daily practice as a tool for healthcare professionals when discussing management

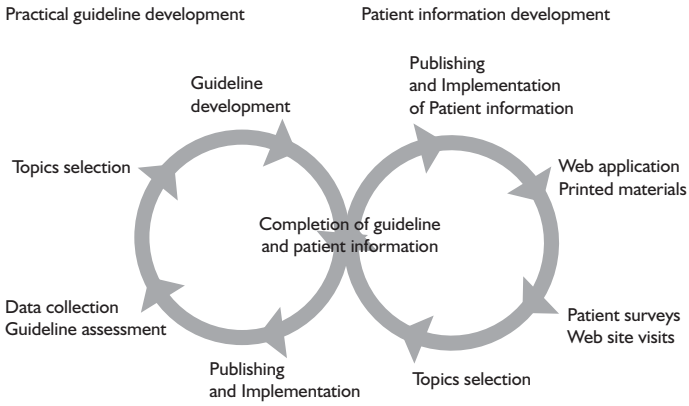

Figure 1 – Expanded guideline development. Development of patient information as a substantial part of guideline development.

and treatment options with patients and their families. The feedback from nine general practices, that used printed materials and received comments from patients, has been positive. General practitioners valued the role of printed materials in assisting them to explain the condition to patients and to increase the compliance with lifestyle modification advice, secondary prevention procedures (such as colorectal cancer screening with faecal occult blood testing), treatment and follow up.

Discussion and Conclusion

The particular intention of this project was to link the evidence based medicine with the general public information.

Clinical guidelines based on evidence and interdisciplinary consensus have been developed in multi-professional teams using scientific and sophisticated methodology for guideline development. Guidelines have been disseminated and implemented within the framework of the continuous medical education (CME) program for primary care physicians. Maintenance of the clinical guidelines has been ensured by performance auditing and focused implementation.

Within the process of guideline development and implementation, primary care physicians transform guidelines into patient information. The rationale behind choosing general practitioners for that task was their expertise and experience as front line physicians, nearest to patients, in explaining conditions and procedures in

Figure 2 – Appearance of the website (in Czech) contents navigation to groups of illnesses with the basic introduction to different clinical conditions.

every day practice. In addition, these texts have been edited by professional journalists. The Czech Society of General Practice has become one of the first guideline developers to produce this type of information. Similarly this process has been started since 2007 in Scottish Intercollegiate Guidelines Network (www.sign.ac.uk).

Focus groups were used because of the preliminary and pilot character of the project. The research team intended to become acquainted with the general reaction of small sets of the main consumer groups' representatives. Based on these results, we continued in the further phases of the project.

The observance of standards for the quality monitoring of online health information sources provides clear guidance about how to set up a quality information source during the preparation of the web site; however, the observance of standards cannot guarantee that the lay public will perceive the information presented favourably. Individual visitors to web pages perceive a number of subjectively very different criteria and assess their quality according to them. The visitor's assessment typically starts with the graphic layout and style of descriptive texts and ends with the degree of satisfaction with the search results. However, a recommendation by a general practitioner can influence this process in a significant manner, giving credibility to the web site and increasing the potential for the patient's effective use of the site. Therefore, it will be necessary to continue to expand the information database of the web application and actively promote its use among general practitioners. Methods for encouraging contributions and feedback from individual lay persons or patient organizations in the patient information development process have also been discussed.

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References

1. RIORDAN M., SEUNTJENS L., GROL R.: Improving patient care in primary care in Europe, EQuiP 2004, ISBN 90-5793-175-3
2. LEBO H.: The UCLA Internet report: surveying the digital future. Year three. Los Angeles, CA: UCLA Center for Communication Policy, 2003.
3. FOX S, RAINEE L.: The online health care revolution: how the Web helps Americans take better care of themselves. Washington, DC: The Pew Internet & American Life project, 2006.
4. METZ J. M, DEVINE P., DENITTIS A., JONES H., HAMPSHIRE M., GOLDWEIN J., WHITTINGTON R.: A multi-institutional study of internet utilization by radiation oncology patients. *Int. J. Rad. Oncol. Biol. Phys.*, Vol 56, Issue 4, 1201–1205, 2003.
5. BIRKMANN C., DUMITRU R. C., PROKOSCH H. U.: Evaluation of Health-related Internet Use in Germany. Methods of Information in Medicine 2006; 45: 367–376.

6. SCHMIDT K., ERNST E.: Assessing websites on complementary and alternative medicine for cancer. *Ann. Oncol.* 15(5): 733-42, 2004.
7. KUMAR A., SMITH B., PISANELLI D. M., GANGEMI A., STEFALENELLI C.: Clinical guidelines as Plans – An ontological Theory. Methods of Information in Medicine 2006; 45: 204–210.
8. GROL R.: Beliefs and evidence in changing clinical practice. *Br. Med .J.* 315: 418–342, 1997.
9. GROL R., DALHUISEN J., THOMAS S., VELD C., RUTTEN G., MAKKINK H.: Attributes of clinical guidelines that influence use of guidelines in clinical practice; obervational study. *Br. Med. J.* 317: 858–861, 1998.
10. WWW.SVL.CZ, website of Czech Society of General Practice
11. HON Code of Conduct (HONcode) for medical and health Web sites [online]. Hon Foundation, 2001 [cit. 2006-09-16] http://129.195.254.33/Project/HONcode.html
12. ADLA T., KASAL P., JANDA A., HLADÍKOVÁ M., NAIDR J. P., FEBEROVÁ J.: Weights of criteria for evaluation of health resources on the web. Congress Mednet 2003. Technology and Health Care 2003; 11(5): 378–379.
13. STRAUSS A.: Qualitative analysis for social scientists, Cambridge University Press, 1988.
14. STRAUSS A., CORBINOVÁ J.: Základy kvalitativního výzkumu (in Czech), Albert, Boskovice, 1999.
15. MAYS N., POPE C.: Qualitative Research in Health Care, BMJ Publishing Group, London, 1997.
16. MILES M. B., HUBERMAN A. M.: Qualitative Data Analysis, SAGE, London, 1994.
17. MORGAN, D. L.: Ohniskové skupiny jako metoda kvalitativního výzkumu (in Czech), Albert, Boskovice, 2001.