

PATIENT EDUCATION: THE NEED AND AAN PROGRAMS TO FILL THE NEED

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Health Literacy

Any discussion of patient education must begin with a discussion of Health Literacy. Inadequate health literacy is pervasive in all segments of society. Research suggests that health literacy is a stronger predictor of health status than socioeconomic status, age or ethnic background (Lindau et al, 2002, Schillinger et al, 2002, Parker et al 2003)! Since patient education is generally undertaken to improve health literacy, the importance of successful patient education efforts cannot be overstated.

Ratzen and Park (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 definition was used by Healthy People 2010. It involves skills in listening, speaking, mathematics, problem solving and decision making. It is no longer sufficient to simply create written materials at low reading levels. Patient education must involve ensuring that our patients have the tools they need to actually use the information to get their healthcare needs met. The Institute of Medicine formed a Committee on Health Literacy to address the issue of limited health literacy in the U.S. and make recommendations based on this assessment. The committee noted that because the medical and public health literature indicate that health materials are complex and often far above high school level, approximately 90 million adults lack the needed literacy skills to effectively use the U.S. health system. By some estimates this costs the healthcare system more than \$58 billion annually. The committee published a full report, entitled *Health Literacy A Prescription to End Confusion* (Neilsen-Bohlman et al 2004) however what follows is a summary of their observations and recommendations.

A health-literate American would be a society in which:

- Everyone has the opportunity to improve their health literacy
- Everyone has the opportunity to use reliable, understandable information that could make a difference in their overall well-being, including everyday behaviors, such as how they eat, whether they exercise and whether they get health check-ups
- Health and science content would be basic parts of K-12 curricula
- People are able to accurately assess the credibility of health information presented by health advocate, commercial and news medial sources
- There is monitoring and accountability for health literacy policies and practices
- Public health alerts, vital to the health of the nation, are presented in everyday terms so that people can take the needed action
- The cultural contexts of diverse peoples, including those from various cultural groups and non-English speaking peoples, are integrated into all health information
- Health practitioners communicate clearly during all interactions with their patients, using every day vocabulary
- There is ample time for discussions between patients and health care providers
- Patients feel free and comfortable to ask questions as part of the healing relationship
- Rights and responsibilities in relation to health and health care are presented or written in clear, everyday terms so that people can take needed action
- Informed consent documents used in health care are developed so that all people can give or withhold consent based on information they need and understand

The Partnership for Clear Health Communication Working to Provide Practical Solutions to Low Health Literacy Epidemic: Good Questions for Patients' Good Health

The Partnership for Clear Health Communication, the first national coalition of organizations working together to promote awareness and solutions around the issue of low health literacy and its effect on health outcomes, supports the findings in the Institute of Medicine report described above. The Partnership and its members have been working to raise awareness about low health literacy, and developing and researching practical solutions to improve communication between healthcare providers and patients. The group is committed to offering free and low-cost resources and programs that deliver information, medical education and practice management tools to health care providers and organizations that share information with patients.

The Partnership Action Agenda includes:

1. Educating patients and providers about health literacy
2. Developing and applying practical solutions to improve patient-provider communication
3. Conducting nationally coordinated research to further define the health literacy issue and evaluate solutions
4. Increasing support for health literacy policy and funding

Because clear communication is the foundation for patients to be able to understand and act on health information, the Partnership has launched its first solution-based initiative from its action agenda, titled *Ask Me 3*. Asking 3 is a quick, effective tool designed to improve health communication between patients and providers. Through patient and provider education materials developed by leading health literacy experts *Ask Me 3* promotes three simple but essential questions that patients should ask their providers in every health care interaction. Providers should always encourage their patients to understand the answers to:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

Patients can be directed to www.AskMe3.org for information on the program.

Methods to Educate Patients

Numerous studies have shown that patients actually retain less than 50% of the information given to them at a physician's office visit. The reasons for this are many, and include but are not limited to poor communication skills on the part of the physician, anxiety on the part of the patient, illiteracy on the part of the patient. Terry and colleagues studied the physician's role in educating patients visiting a family practice clinic (Terry et al 2000). Patients were divided into three groups: patient received a self-care booklet from the physician during the visit; patient received the booklet through the mail; patient had usual care with no booklet given. Patients who received the booklet directly from their physician reported greater satisfaction with the visit in 11 of 13 variables related to patient-physician communication and quality of care. While this study does not prove that patient understanding of their illness was better in the group receiving the booklet directly from the physician, it clearly shows the positive impact of this intervention.

Millions of dollars are spent each year on the production and distribution of written patient education materials (Williams et al 2004). As mentioned above, these materials in and of themselves are not enough. One study showed that these materials are much more effective when the physician is very familiar with the materials and gives the materials directly to patients at the office visit (McVea et al 2000).

There is a growing literature linking the patient's understanding of their illness and treatment with better outcome. A recent Greek study performed a cross-sectional, observational study of 1,000 consecutively treated hypertensive patients for compliance to antihypertensive treatment (Yiannakopoulou et al, 2005). Compliance was found in only 15% of the patients and was found to be significantly associated with good blood pressure control. Compliance was more common in patients aged <60 years, city dwellers, the better educated, those more adequately counseled by their physician, those followed by a private physician and those taking only one antihypertensive medication per day. Frequent changes in medication was associated with poorer compliance, as was changing physicians. Another study evaluated the relationship between medication adherence and healthcare utilization and costs for four chronic conditions (diabetes, hypertension, hypercholesterolemia and congestive heart failure) in 137,277 patients (Sokol et al. 2005). The study showed that higher medication adherence was associated with lower avoidable healthcare utilization and morbidity across these conditions and emphasizes the need to include medication adherence in the effective management of chronic conditions. Blackburn and colleagues demonstrated an association between increased cardiovascular morbidity (myocardial infarction, unstable angina, PTCA, CABG and death) and nonadherence with statin therapy (Blackburn et al 2005). Among 1,056 patients, those in the adherent group were half as likely to have a myocardial infarction as those in the nonadherent group. A case-control study of the effects of discontinuing aspirin therapy on the risk of ischemic stroke found that aspirin interruption yielded an odds ratio for ischemic stroke/TIA of 3.4 (95% CI, 1.08-10.63, p<0.005) (Maulaz et al, 2005), highlighting the importance of aspirin therapy compliance in stroke prevention. Buelow and Smith found that the perception of medication management by people with epilepsy was far from reality. Although 14 of 25 people studied reported good compliance, 10 of these 14 had an actual compliance score that was lower than 34% (Buelow and Smith 2004). This has great implications on the management of these patients in terms of dosage adjustments and even changing medications.

Patient's beliefs about their medications also profoundly influence whether and how they take them. Patients obtain information from many sources about their illnesses and medications. Several studies have shown that the most common source of information for most patients is family and friends, followed by the mass media, the internet and finally, their physicians (Budtz et al 2002; Stevenson et al 2000) It is extremely important to assess patients' attitudes and beliefs about prescribed medications and to address them in order to increase the

likelihood of compliance. Many patients do not consider medications such as aspirin a “real” medication. Complementary and alternative medications are also frequently not reported to physicians. Asking patients to talk about all medications, supplements, vitamins, etc. is important in both developing a better understanding about patients’ practices and beliefs and also to prevent potential drug interactions that can occur between “alternative” medications and prescribed medications. This can be an important patient safety issue.

Techniques to Improve Patient Communication

Six Steps to Improve Interpersonal Communication With Patients

1. **Slow down.** Communication can be improved by speaking slowly and by spending just a small amount of additional time with each patient. This will help foster a patient-centered approach to the physician-patient interaction.
2. **Use plain, non-medical language.** Explain things to patients as you would if you explain them to a non-medical family member.
3. **Show or draw pictures.** Visual images can improve the patient’s recall of ideas.
4. **Limit the amount of information provided, and repeat it.** Information is best remembered when it is given in small pieces that are pertinent to the tasks at hand. Repetition further enhances recall.
5. **Use the teach-back or show-me technique.** Confirm that patients understand by asking them to recall and restate your instructions. (Scientific evidence has demonstrated that this technique is one of the 11 top patient safety strategies.)
6. **Create a shame-free environment.** Make patients feel comfortable asking questions.

Patient Education and the Internet

Thompson and colleagues performed a descriptive project to determine internet access to determine the feasibility of using the internet for cardiac education (Thomson et al 2005). Subjects over 50 years of age were surveyed. Over 66% had internet access at home, and 51% said they used the internet daily. Participants indicated their willingness to access an internet site for continued educational information after discharge from a secondary prevention cardiac clinic. Tak and colleagues tested the use of the internet for health information by older adults (over 60 years of age) with arthritis (Tak et al 2005). In this sample, 28% said they had internet access in their homes, and 39% of these said they used the internet for information. People with more education were more likely to use the internet. While we generally think that younger people are more comfortable with using the internet, these data suggest that programs targeting older people may be successful, as well.

AAN Patient Education Resources

The AAN has a variety of patient education resources. All of these resources have been carefully developed to provide the most recent information in a format that is engaging and can be easily understood by the lay public. The websites recommended in these materials have been screened and are credible sources of additional information.

Neurology Patient Page

The Patient Page has been an online feature of *Neurology* since July 2002. It provides a critical review of groundbreaking discoveries in neurological research that are written especially for patients and their families. It also contains a section that provides the most up-to-date patient information about many neurological diseases. In addition, it links to other information resources for neurological patients, such as the AAN Foundation website, www.thebrainmatters.com.

The *Neurology Patient Page* was developed in response to the need expressed by AAN members for good patient education material. The Patient Page focuses on important neurologic topics accompanying current articles published in *Neurology*.

Between July 2002 and February 2003, the *Neurology Patient Page* received the most website hits of all features in *Neurology*. Articles are selected for the *Neurology Patient Page* because they have the potential to impact a large number of people or generate particular interest. Topics to date have included articles ranging from stroke as a medical emergency (“brain attack”) to neurologic complications after stem cell transplantation in children. The Patient Page is written specifically for patients and their families to provide clear and accurate, up-to-date information about the diagnosis, management and treatment of neurologic illnesses.

The *Neurology Patient Page* can be viewed online by selecting an article from the public area of the *Neurology* website. All *Neurology Patient Page* articles can be easily downloaded and printed, and may be reproduced to distribute for educational purposes. Copies of the *Neurology Patient Page* are available by going to www.neurology.org.

AEI Book Series

The patient education book series published its' first book on Migraine in January of 2005. Another book on ALS has just been released. These books are paperback, of modest cost, and the number of pages ranges between 250 to 300. Dr. Austin Sumner is the Editor-in Chief and Demos is the publisher of this venture. Dr. Sumner expects to publish four titles per year, with topic selection coordinated with the launch of other products of the same topic (e.g. Patient Version of the AAN Practice Guidelines).

These books can be purchased through the AAN online store:



Amyotrophic Lateral Sclerosis (ALS) Book

Item #201701

"The authors are all experts in the management of ALS, and this book will be much appreciated by patients and professionals alike." -Lewis P. Rowland, MD, Neurological Institute, Columbia University Medical Center

Member Price - \$19.95



Migraine and Other Headaches Book

Item #201700

"Migraine and Other Headaches is an excellent guide for those experiencing headaches who want better care or more information about their condition." -Robert B. Daroff, MD, President, American Headache Society

Member Price - \$16.95

Alzheimer's Disease Book

Item #201702

"This book is an essential tool for all families coping with Alzheimer's disease."

- Austin J. Sumner, M.D., Editor-in-Chief of the patient education book series

Your Price: **16.95**

Stroke Book

Item #201703

From hospital admission to discharge and rehabilitation, to the reutn home with a prevention plan, this book answers essential questions for stroke patients and their families.

Member Price: 16.95

AAN Foundation thebrainmatters.com Website

Thebrainmatters.com website was created by the AAN Foundation to support patient education. The Brain Matters Website at www.thebrainmatters.org carries disease-specific information, patient stories, and links to other useful sites in an engaging and user-friendly format. The AAN Foundation is grateful to Medtronic, the Groff Foundation and members of the AAN Foundation Corporate Roundtable for their investment in this site. It is designed for easy navigation. The topics that are currently available on the website are Alzheimer's disease, brain injury, dystonia, epilepsy, migraine, multiple sclerosis, pain, Parkinson's Disease, sleep disorders and stroke.

Patient Brochures

Patient brochures are published by the AAN Public Education office in conjunction with the AAN Practice Committee. Disease topics are researched and the brochure content written by AAN Education staff and edited by a Practice sub-committee. The patient brochures have always been popular with Neurologists as a means of educating patients on specific disease topics. These brochures have been completely revised with regards to updated content and a fresh visual appearance. They are available in the online store and are available through the AEI catalog.

BROCHURES

- ▶ [What is a Neurologist? \(brochure\)](#)
- ▶ [Understanding Alzheimer's Disease \(brochure\)](#)
- ▶ [Understanding Epilepsy \(brochure\)](#)

- ▶ [Understanding Migraine \(brochure\)](#)
- ▶ [Understanding Multiple Sclerosis \(brochure\)](#)
- ▶ [Understanding Parkinson's Disease \(brochure\)](#)
- ▶ [Understanding Stroke \(brochure\)](#)
- ▶ [Understanding Brain Injury \(brochure\)](#)
- ▶ [Brochure Display](#)

Patient Version of Practice Guidelines

The lead author for the AAN Practice Guidelines develops summaries of these guidelines for clinicians and also for patients. These guidelines are approved by the Quality Standards and Practice Committee and by the AAN Board of Directors. Summaries are posted on the AAN website on the day of publication and sent in all AAN member mailings that month following the publication of the guideline. All other AAN patient education initiatives adhere to these guidelines in the discussion of specific disease topics. Patient versions are available to view, print or download for all of the following by going to the AAN website.

Neurology Now Magazine

Neurology Now, a health and wellness magazine that is published six times a year for neurology patients and their families and friends is a very exciting new collaboration between the AAN and Lippincott, Williams and Wilkins, Inc. to publish (publisher of *Neurology*, *Neurology Today* and *AAN News*).

The publication's mission is to enhance doctor-patient communications; patient-disease awareness and self-management; and public outreach for the AAN. The magazine has compelling artwork and design. It provides accurate and important new information of substance, authority and usefulness about advances in the diagnosis and treatment of neurological diseases. Each issue covers in-depth stories about three neurological disease topics, and many others will be covered in our regular editorial departments. We use positive and inspiring messages about wellness and prevention; basic neuroscience research and clinical trials, and patient stories that stress strategies for coping with neurological disorders.

Neurology Now is available free of charge to the public. 300,000 copies are distributed through neurologists' offices. Over 35,000 readers have subscribed and received the magazine delivered free of charge to their homes. It is being paid for by advertising. We are employing the highest and most rigorous standards to ensure that the ads themselves are accurate and appropriate for a direct to consumer audience and also that editorial content is not in any way influenced by advertising.

Direct to Consumer Advertisement (DTC) as a Means of Patient Education

Spending for prescription drugs was \$79 billion in 1997 and increased to \$150 billion in 2001. Industry spending on promotional activities was \$15 billion in 2000. 85% of this was directed towards physicians and 15% towards consumers. Industry spending on DTC advertising was \$47 million in 1990 and increased to 2.7 billion in 2001. Much of this increased spending was due to a relaxation of FDA guidelines in 1997 that allowed broadcast advertising. DTC advertising was mostly concentrated on a small number of drugs that are used to treat chronic conditions. Interestingly, in 2002 the average price of top-selling drugs promoted through DTC ads was \$102, while the average price of products not promoted through DTC ads was \$127.

The assumption made by the FDA based on surveys they conducted is that DTC ads provide important educational information to the lay public. To be approved by the FDA, ads must include accurate information, including a brief summary relating to side effects, contraindications and effectiveness and a fair representation of benefits and risks. The American Medical Association has a policy on DTC ads which includes the following:

- Ads should be disease-specific and enhance consumer education
- Ads should convey a clear, accurate and responsible health education message
- In all cases, the ads should refer patients to physicians for more information
- The ad should not encourage self-diagnosis or treatment, but should identify a consumer population at risk
- Discussion of the use of the product should exhibit fair balance
- Warnings, precautions and adverse warnings should be clearly explained so as to facilitate a discussion of such between patient and physician
- No comparative claim can be made for the product
- The brief summary should be presented in lay language
- The ad must comply with FDA rules
- The ad should be part of a manufacturer's education program
- The manufacturer should not run concurrent incentive programs for prescription prescribing and pharmacist dispensing

The AAN also has a policy on support accepted by the AAN including revenue obtained from DTC. It must abide by the Principle Governing AAN Relationships with External Sources of Support, approved by the AAN BOD on June 26, 2004, which includes:

- AAN mission and values must drive activity
- External support relationship must preserve or promote trust in AAN and medical profession
- AAN must retain objectivity with respect to health issues regardless of external support
- Externally supported activity must benefit public health, patient care, research or physician practice
- AAN supported activity shall comply with applicable laws, regulations and codes of ethics.
- AAN shall apply the principles of disclosure and transparency for all external support relationships.

There is a debate about the value of DTC advertisement. Arguments for include that it educates consumers about new treatments, promotes patient compliance, increases treatments for under-diagnosed conditions, and helps patients make better-informed health care decisions. Arguments against include that it may interfere with physician-patient relationship, raises health care costs, increases consumption of new, more costly products over older, cheaper and possibly safer alternatives and over-simplifies complex issues, which may confuse consumers who lack medical knowledge.

What do the data show? In a telephone survey of national probability sample of 3,000 adults (response rate 53%), 76% were white, non-Hispanic, 38% college graduate, 88% with health insurance, 54% saw doctor in last 3 months, 86% had seen or heard a DTC ad, 35% were prompted by an ad to have a discussion with a physician about a health concern or advertised drug (Weissman et al. Health Affairs Web Exclusive 2003:83-95). 95% of people with a DTC ad- prompted visit had some action taken:

- Doctor prescribed any drug – 73%
- Doctor prescribed DTC Ad drug – 43%
- Referred to specialist – 33%
- Suggested life-style change – 53%
- Ordered lab test – 57%
- Suggested quit smoking/drinking – 34%

In another study, Effects of DTC were greater (more positive) in people with low socioeconomic status regarding requesting preventative care, screening or blood tests (Murray et al JABFP 2004;17:6-18). In this survey, the respondents had the following feelings about DTC ads:

- Give patients confidence to talk to their doctors about concerns (88%)
- Encourage people to follow treatment instructions or advice from doctors (81%)
- Drive up the cost of prescription drugs (76%)
- Improve people's understanding of medical conditions and treatments (72%)
- Help patients get treatments they wouldn't get otherwise (69%)
- Promote unnecessary fear of side effects (54%)
- Promote unnecessary doctor visits (48%)
- Cause patients to take up more of their doctors' time (38%)
- Interfere with good relationships between doctors and patients (30%)

In a mail survey of 500 Colorado physicians, 261 national physicians and telephone survey of 500 Colorado households, most physicians viewed DTC ads negatively (Robinson et al Arch Intern Med 2004;164:427-432). Physicians felt that ads rarely provide enough information about cost (98.7%), alternatives (94.9%) or side effects (54.8%), they lengthened patient encounters (55.9%), lead to requests for specific medications (80.7%) and changed patients' expectations of physician prescribing practices (67%). Public respondents opinions differed. They felt that DTC is a positive trend in health care (29%), made them better informed about health problems (28.9%), motivated them to seek care (10.5%) and did not particularly motivate them to seek specific medications from their physicians (13.3% said it did motivate them vs 80.7% who felt that way in the physician survey).

In an outcome survey on the effects of DTC ads on adherence to treatment guidelines for depression, 30,621 depressed individuals whose insurance claims were included in MarketScan database between 1997-2000 were studied (Donohue et al Med Care 2004;42:1176-1185). Outcome variables included spending on DTC ads, detailing to physicians and free samples for 6 antidepressant drugs. In individuals diagnosed with depression during periods when spending on class-level antidepressants DTC ads was highest, they had a 32% higher relative odds of initiating antidepressant therapy. Promotion to physicians was not associated with initiation of antidepressant treatment.

Thus, DTC Advertising of prescription drugs has the potential to benefit the public by providing educational materials which can benefit their health by:

- Seeking treatment for an undiagnosed condition

- Increasing motivation to comply with physician's instructions
- Encouraging physician-patient dialog
- Providing particular benefit to people of lower SES, who traditionally are harder to reach with public health campaigns

Advertising policy for *Neurology Now*:

- Maintain a strict firewall between editorial content and advertising
- Editorial calendar is developed without consideration of ad sales
- Require that all ads have FDA approval
- Editor will review all advertising prior to its acceptance in the magazine
- Require that ads be written in lay language, including the "brief summary"
- A statement will be included in each issue stipulating that the AAN does not endorse or support any of the claims that may be made in advertising
- A Disclosure statement will appear at the end of every article that includes an interview with an individual who receives funds from industry if it is relevant to the material discussed in the article.

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