Vascular surgery and the Internet: A poor source of patient-oriented information

Laurel C. Soot, MD, Gregory L. Moneta, MD, and **James M. Edwards, MD,**
Portland, Ore

Objective: **Increasing numbers of patients use the Internet to obtain medical information. The Internet is easily accessible, but available information is under no guidelines or regulations. We sought to evaluate the type, quality, and focus of vascular disease information presented on the Internet and the role in patient education with simple search techniques.**

Methods: **The arbitrarily chosen search phrases "abdominal aortic aneurysm (AAA)," "carotid surgery (CEA)," "claudication surgery," and "leg gangrene surgery" were entered into five common Internet search engines. No attempt was made to refine searches. As indicated by the search engines, the 50 most commonly encountered web sites for both AAA and CEA were reviewed. The first 25 claudication sites and the first 25 gangrene sites were combined for a total of 50 leg ischemia (LIS) sites. An information score (IS) was developed as a weighted score ranging from 0 (poor) to 100 (outstanding) and was designed to assess how well the web page educated the patient about the disease, the treatment options, and the medical and surgical complications. Each vascular surgery web site was classified according to the author, the referenced information source, and the therapeutic recommendations. This was followed by an evaluation of each web site with the IS independently scored by two observers.**

Results: **Of the 150 web sites, 146 were accessible. Ninety-six sites (65.8%) had no useful patient-oriented information (IS < 10). The mean IS and the ranges were: AAA, 14.9 (0 to 72.0); CEA, 17.5 (0 to 77.0); and LIS, 12.2 (0 to 44.5; $P = .9$). The mean IS of the 59 sites with scores of more than 10 were: AAA, 39.8 (n = 17); CEA, 44.8 (n = 19); and LIS, 24.8 (n = 23; $P < .01$, as compared with LIS scores). Differences in IS between observers were not significant ($P = .9$). Misleading or unconventional care recommendations were recognized in one AAA site (1 of 47, 2.1%), two CEA sites (2 of 49, 4.1%), and 13 LIS sites (13 of 50, 26.0%). The Joint Vascular Societies web page was identified only as a tertiary link.**

Conclusion: **Patient-oriented vascular surgery information, for common vascular diseases, is difficult to find on the Internet. The overall quality is poor, and information is difficult to obtain in part because of the large number of irrelevant sites. Of the sites that were relevant to patient education (33%), one third presented information that was classified by the authors as misleading or unconventional. This was most apparent in the leg ischemia sites. The Internet is a poor overall source of patient-oriented vascular surgery information and education. Focused and refined searches and improvements in search engines and educational web sites may yield improved information. Public and medical community awareness needs to be improved regarding the severe limitations of the Internet as an information resource. (J Vasc Surg 1999;30:84-91.)**

From the Division of Vascular Surgery, Oregon Health Sciences University, and Portland Department of Veteran's Affairs Hospital.

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Reprint requests: Dr James M. Edwards, Division of Vascular Surgery, OP-11, 3181 SW Sam Jackson Park Rd, Portland OR 97201-3098.

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The use of the Internet is increasing rapidly in the United States. There are an estimated 24 million (11% of the US population) frequent users of the Internet. Of US households, 40% have a personal computer, and 37 million people have access to the Internet via their home or business computer.[1-3] In the last several years, there has been an astronomical increase in the absolute number and range of web site categories presented on the Internet. This has resulted in an informational

database that is remarkably broad and easy for the general public to access.

Medical information presented on the Internet can be obtained from many different sources: e-mail, MEDLINE and other medical databases, on-line journals, discussion groups, and specific web sites.[4] However, web site accessibility has no limitations and web page authors do not have mandated publishing regulations or evaluations regarding the content and accuracy of their presented information. The Internet can be accessed by patients who seek medical information, but the quality of this patient-oriented information, with respect to vascular disease, has not been evaluated or analyzed. The goal of this study was to assess the type, quality, and focus of vascular disease information presented on the Internet and its role in patient education with a simple search strategy.

METHODS

Selection of web sites

The following three common vascular surgery topics were chosen for evaluation: abdominal aortic aneurysm (AAA), carotid disease, and leg ischemia (LIS). Five arbitrarily selected, broad-based, full-text Internet search engines were used to identify each vascular disease web site: Excite, Hotbot, Lycos, Metacrawler, and Yahoo. The specific search phrases used to access the web pages were "abdominal aortic aneurysm (AAA)" and "carotid surgery (CEA)." The LIS web sites were accessed with two search phrases: "leg gangrene surgery" and "claudication surgery." The search phrases were chosen by the authors as terms a patient or family member might search to obtain more information before a proposed surgical procedure. The searches were not further refined or restated regardless of the information returned. Each web site was identified by entering the specific search phrase into the search engine. The search engines ranked each web page from 0% to 100% according to its pertinence to the searched term. The results from the searches, with the five different search engines, were compiled, and the 50 most commonly identified and highest ranked web pages for each vascular subject underwent further in-depth review. The LIS group was composed of the 25 most commonly identified and highest ranked sites for each of the search terms, "claudication surgery" and "leg gangrene surgery," totaling 50 LIS sites.

This simple searching method was chosen and performed without further search phrase refinement in an attempt to analyze the initial search results. The goal was to produce a list of web sites similar to one that would be generated by a person who has a limited medical, internet, or computer knowledge base.

Classification of web site author

Each web site then was classified according to the identity of the web page author. Seven author classifications were identified: academic, biomedical, commercial, news, personal, physician, and unidentified. *Academic authors* were those individuals or departments whose web page was affiliated with a university or private educational research institution. *Biomedical authors* were associated with organizations that were not affiliated with a specific institution (eg, American Heart Association). *Commercial authors* were those who were marketing specific health care products in the field of vascular disease. *News authors* were identified by their use of Internet, newspaper, and television media logos and web page addresses (eg, www.healthreport.com, www.cnn.com). The *personal authors* were nonphysicians who produced a vascular disease web site but did not represent an institution or organization. *Physician authors* were individual physicians or physician practice groups who produced a web page that was not affiliated with an academic institution, biomedical group, commercial company, or news organization. *Unidentified authors* produced web pages that were expired, outdated, and otherwise unidentifiable.

Classification of web site contents

The recommended treatment and diagnostic evaluations, for the three vascular disease processes, were also examined and placed in the following four therapy classifications: conventional, unconventional, misleading, and unrelated. We recognize that the definitions given subsequently are arbitrary and are made on the basis of author opinions, yet we did make an effort not to be overly judgmental. *Conventional therapy* was defined as the standard evaluation and treatment management strategies for abdominal aortic aneurysms, carotid disease, and limb salvage that are outlined in current text books and journals of vascular surgery.[5,6] An additional requirement for conventional therapy was that the device used in the suggested therapy be approved by the US Food and Drug Administration for use in that disease process or artery. *Unconventional recommendations* were defined as those that advocated experimental therapy as the sole mode of treatment and failed to mention any of the more conventional therapeutic options. *Misleading therapeutic recommendations* were those that emphasized experimental therapy and did not give equal time to, or

Table I. Information score: categories and relative weights used to quantitate web sites with respect to patient-oriented vascular disease education

Subheadings	*Raw score (range)* *Maximum 70 points*	*Weight*	*Weighted score (range)* *Maximum 100 points*
Disease summary	0 to 10	3.0	0 to 30
Treatment options	0 to 10	2.0	0 to 20
Disease complications	0 to 10	1.5	0 to 15
Surgical options	0 to 10	1.5	0 to 15
Surgical complications	0 to 10	1.0	0 to 10
Recovery expectations	0 to 10	1.0	0 to 10

Maximum score, 100 (excellent); minimal score, 0 (poor).

Table II. Distribution by vascular disease process and web page author

Author (n = 146)	*AAA (n = 47)*	*CEA (n = 49)*	*LIS (n = 50)*
Academic (n = 75)	29	24	22
Biomedical (n = 24)	7	16	1
Commercial (n = 12)	2	3	7
News (n = 6)	0	0	6
Personal (n = 10)	4	4	2
Physician (n = 8)	2	0	6
Unidentified (n = 11)	3	2	6

AAA, Abdominal aortic aneurysm; *CEA,* carotid surgery; *LIS,* leg ischemia.

downplayed or debased, more conventional therapeutic methods. Information classified as *unrelated* was information that did not enhance patient knowledge or understanding of the vascular disease process (eg, vascular surgery meeting information, departmental members biographies, surgical textbook advertisements).

Classification of web site information source

Each web site also was analyzed with regards to the referenced source of the information presented by the author. The reference source was classified as: conventional, anecdotal, none, or unable to reference. *Conventional references* were those that cited literature that could be examined and validated (eg, journal articles, textbooks). *Anecdotal references* were presented by authors who cited their experiences or beliefs regarding the diagnosis and treatment of the specific vascular topic. *No referenced source of information* were those sites that cited data or results but did not state the source of their information. Web pages were considered *unable to be referenced* if they presented information that is not customarily referenced (eg, meeting information, textbook advertisements, departmental member biographies, and expired web sites).

Web site information score

After the previously described qualitative assessment had been performed, each web site then was quantitatively scored with an information score (IS). The IS is a standardized scoring system developed by the authors. It is designed to assess the ability of the vascular web sites to educate patients about specific disease processes, treatment options, medical and surgical treatment complications, and recovery expectations. The IS ranges from 0 points (poor) to 100 points (outstanding). The score is weighted, placing emphasis on patient education regarding disease causes, prevention, and general treatment options (Table I). Disease complications, surgical treatment options and complications, and recovery expectations also were incorporated into the IS but were not weighted as heavily. Therefore, nonsurgical sites could receive a score of 70 without discussing the details of surgery, its complications, and recovery expectations. A web page was considered unrelated to patient education if the IS score was less than 10.

Each site was scored independently by two observers (L.S., J.E.). Interobserver variability was assessed with the Winer Single Score reliability index for interclass correlation. Statistically significant differences among the different categories and classifications were analyzed with analysis of variance and were defined with a P value of less than .05. Statistical analysis was performed with StatView Macintosh and SAS Windows computer programs (Cary, NC).

RESULTS

Of the 150 web sites identified by the search engines, 146 were accessible. Four (2.6%) were unable to be accessed despite multiple attempts.

Web site author

Of the seven author classifications, the academic (75 of 146, 51.4%) and biomedical (24 of 146, 16.4%) authors were most commonly encountered. In the academic classification, the 75 authors were equally distributed among the three vascular topics (AAA, n = 29, 38.7%; vs CEA, n = 24, 32.0%; vs LIS, n = 22, 29.3%). The 24 biomedical authors were more likely to discuss carotid disease (AAA, n = 7, 29.2%; vs CEA, n = 16, 66.7%; vs LIS, n = 1, 4.2%; Table II). The commercial, physician, and news

authors were more commonly encountered in the LIS group. Eleven of the 146 web sites (7.5%) had an unidentified author.

Web site referenced information source

Most authors referenced conventional sources of information (89 of 146, 60.9%). Thirty-eight sites were unable to be referenced (Table III). These web pages included outdated and expired links, departmental biographies, journal abstracts, and textbook advertisements. Sixteen of the 19 remaining web sites cited a personal source of information, two were anecdotal, and one cited no reference to the information presented.

Further analysis of the web pages was done with a reexamination of the references compared with the authorship of the web page. The academic authors presented sources that were unable to be referenced 20% of the time (15 of 75; Table IV). The remaining academic sites almost exclusively cited conventional sources of information (59 of 75, 78.7%), as did the biomedical sites (17 of 24, 70.8%). The commercial sites placed their emphasis on physician marketing and therefore cited sources of information that were largely unable to be referenced (7 of 12, 58.3%). Seven of the eight physician-produced web sites cited conventional sources of information, and one site was purely an anecdotal reference.

Web site diagnostic evaluation and treatment recommendations

Despite being identified in the first 50 sites of their respective searches, the vast majority of the 146 accessible web pages were unrelated to patient education (96 of 146, 65.8%). Only 50 sites were pertinent in regards to patient education. Thirty-four of the 50 sites recommended conventional therapy, and 14 sites were misleading (Table IV). All except one of the 14 misleading sites were in the LIS group. These sites promoted the use of growth factors, mechanical circulation assist devices, etc. Two sites (CEA) presented unconventional therapeutic recommendations, and both were biomedical sites. In summary, 16 of the 50 educational patient-oriented vascular web pages (32.0%) presented information that was classified as either misleading or unconventional (LIS, n = 13; AAA, n = l; CEA, n = 2) and only 34 of 146 accessible sites (23.3%) presented patient-oriented conventional information of any sort.

Web site information scores

All sites. The 146 identified web pages were independently scored by two observers with the IS.

Table III. Distribution by web page referenced source of information and web page author

Author (n = 146)	*Unable to reference (n = 38)*	*Conventional (n = 89)*	*Anecdotal (n = 18)*	*None (n = 1)*
Academic (n = 75)	15	59	1	0
Biomedical (n = 24)	5	17	2	0
Commercial (n = 12)	7	1	3	1
News (n = 6)	0	5	1	0
Personal (n = 10)	0	0	10	0
Physician (n = 8)	0	7	1	0
Unidentified (n = 11)	11	0	0	0

The average score and range for each vascular disease topic was: AAA, 14.9 (0 to 72.0); CEA, 17.5 (0 to 77); and LIS, 12.2 (0 to 44.5). There were no significant IS differences between the three groups ($P = .9$). Sixty-seven percent of the sites were completely unrelated to patient education (IS < 10). Web site uniform resource locators that scored an IS of more than 50 are shown (Table V).

Patient-oriented sites. All unrelated sites (IS < 10) were dropped, and the descriptive statistics were recalculated. The average scores of the patient-oriented information sites were: AAA, 39.8 (n = 17); CEA, 44.8 (n = 19); and LIS, 24.8 (n = 23). Significant group score differences then were found: AAA versus LIS ($P < .001$) and CEA versus LIS ($P < .001$). There were no significant score differences between the AAA and CEA groups. Interobserver scores revealed no significant differences ($P = .9$). As a base of reference, the Joint Vascular Society web page was scored with the IS. A small portion of this web site is directed toward patient education in their "frequently asked questions" section. Although this site does not specifically present information on abdominal aortic aneurysms, carotid disease, and leg ischemia, it does address questions regarding the causes of strokes, aneurysms, atherosclerosis, and claudication. They received the following IS: AAA, 43.5; CEA, 53.0; and LIS, 30.5.

DISCUSSION

The Advanced Research Projects Agency Network developed the Internet as a networking experiment in 1968. It was designed to improve computer-based communication at remote sites for computer science investigations. In 1986, academic computer networks were developed by the National Science Foundation. Funding by the National Science Foundation ceased in 1995, and regional networks began purchasing their own Internet connections.[7,8] During this peri-

Table IV. Distribution by web site therapy recommendations and web page author

Author (n = 146)	*Unrelated (n = 96)*	*Conventional (n = 34)*	*Misleading (n = 14)*	*Unconventional (n = 2)*
Academic (n = 75)	53	20	2	0
Biomedical (n = 24)	13	9	0	2
Commercial (n = 12)	8	0	4	0
Personal (n = 10)	10	0	0	0
News (n = 6)	0	1	5	0
Physician (n = 8)	1	4	3	0
Unidentified (n = 11)	11	0	0	0

Table V. Web site uniform resource locators with an Information Score of more than 50

Abdominal aortic aneurysm
http://www.best.com/~gek/Aneurys.htm
http://members.aol.com/gvg97/aaainfo.htm
Carotid endarterectomy
http://www.amhrt.org/Heart_and_Stroke_A_Z_ Guide/cendart.html
http://156.40.137.201/healinfo/disorder/stroke/ceguide.htm
http://www.ninds.nih.gov/HEALINFO/disorder/stroke/ceguide.htm
http://www.cma.ca/journals/cmaj/vol-157/issue-6/0653fig1.htm
http://www.grand-rounds.com/2no6CartAsym.html
http://www.sm.ic.ac.uk/surgery/acst/
Leg ischemia
None

od, computer software developers were rapidly improving their user interfaces, resulting in a product that dramatically changed the Internet user identity from academic computer scientists to the general public and personal computer systems.[9] The increased ease of use and the widespread applicability of Internet software led to a heightened interest in the Internet as an informational and commercial distributing tool in the public, scientific, business, and private sectors. As discussed by Schatz and Hardin,[10] in the mid 1990s, there was a distinct and central change in the focused objective of the Internet. It had previously been viewed as a computer network system that facilitated file and database transfer. Currently, it is considered an "information space," allowing ease of communication, access, and improved awareness of vast amounts of knowledge and information.[10] This informational base is remarkably broad, ranging from scientific and business web pages to travel, sports, and other entertainment web sites.[11]

There are two common ways that Internet users search for information.[12] One method is to follow links from a known information page. A second method is to use one of many commonly available search engines. This second strategy is the one that we chose to follow, assuming that most patients and their families would not have previously bookmarked the Joint Vascular Societies web page or a similar site dedicated to vascular disease. There are many problems associated with searching for information with search engines. First, no search engine has indexed more than about one third of web pages available.[13] In addition, searching the web for information of any type is an art. Simple searches, such as the terms we chose, often yield more garbage than useful information, yet trying to figure out which search terms to use next to narrow a search to yield more useful information is not a simple task. Finally, there are such huge numbers of sites on the web that are not directed at or designed to be used for patient information that the few good sites are the proverbial needle in the haystack.

The explosion of information on the Internet resulted in a proportional expansion in number of web sites dedicated to providing medical information.[7] Numerous articles have been written heralding the advantages of the Internet for the medical community. Use of online medical information has been shown to improve physician's clinical decision making and may decrease their overall health care practice expenses.[14] Specific reports exist that target Internet use in both private practice and research settings for a wide variety of specialties including: emergency medicine, pediatrics, general surgery, otolaryngology, dermatology, and neurosurgery.[1,2,4,7,15-38] Systematic evaluation of whether the Internet provides useful patient-oriented information about specific vascular disease processes, their complications, and treatment options is, however, lacking.

We determined that there was a large number of accessible vascular web sites on the topics of abdominal aortic aneurysm, carotid surgery, and leg ischemia surgery. With simple searching techniques, patient-directed vascular disease education was difficult to obtain and the quality and relevance of information was poor. On the basis of our data, the patient searching on the Internet for medical information and education related to vascular disease will encounter sites that are not oriented to patient education and do not enhance their knowledge base 67% of the time. This irrelevant information was most commonly presented in the form of literature abstracts, departmental directories, meeting information, and advertisements. A user who is highly educated in computer or medical literature search techniques may be able to further refine the search criteria and produce a greater number of relevant web sites. We chose not to further refine searches because most patients and their families are not familiar with both medicine and the Internet.

In addition, nearly one third of the 50 web sites with patient-oriented information presented information that was misleading or advocated unconventional therapy. This was particularly true of the leg ischemia sites. The leg ischemia web sites had significantly lower IS scores than did the AAA and CEA sites and had a much higher incidence of advocating experimental and misleading treatments. These sites included reports on recent growth factor trials, interventional radiology, and cardiology sites (which reported transluminal angioplasty as always superior to surgery or medical management). These sites often failed to mention the benefits and options of more conventional therapeutic methods.

Although the Internet has been touted as a wonderful new means of dispersing educational information, there are clearly severe limitations to use of the Internet as a scholastic resource. Information is presented to many different populations (physicians, patients, commercial companies, hospitals) under the general heading of health-related topics. The extensive number of available web pages makes it difficult to identify specific types of information directed at a certain segment of the general population. The Joint Vascular Society's web page was rarely identified even as a tertiary link. It was never directly identified during the search. Most of this web site is directed toward vascular surgeons. A section is aimed at patient education, but it is not clearly labeled.

There are several strategies that could be pursued to improve the ability of patients to obtain useful medical information from the Internet. First, providers, Societies, and other healthcare organizations should be encouraged to put up Internet sites directed at patients, and, in their headers, the sites should be clearly labeled as patient-information sites. This will not necessarily make the sites easier to find among the many noneducationally directed sites, but it may allow patients to quickly recognize the site as potentially useful once they find the sites. These sites should contain links to other known educational sites because this is a common way for users to obtain further information about a subject or a related topic.[12] For this reason, site authors should be encouraged to link to known good medical information sites, even if they are not related to the subject presented. Society web pages, such as the Joint Vascular Society web page, should have a clearly marked patient information page, even if the primary purpose of the site is to service its members. This patient information link does not actually have to provide any unique information, again a list of known good medical links would be sufficient. Finally, it may be possible to modify available search engines to determine whether a searcher is looking for patient-friendly information about a disease process and to direct the patient to educationally directed sites.

There are no regulations or organizational guidelines governing the reliability of health-related information presented on the Internet. Concerns about the accuracy and completeness of the presented medical information also have recently been voiced by the pediatric community. Impicciatore et al[39] evaluated the reliability of Internet-presented health information on pediatric fevers. They discovered that only four of 41 web pages discussed the currently published treatment guidelines for pediatric fevers and gave complete information about the evaluation and treatment of this common, and sometimes life-threatening, childhood malady.[39] A recent study that assessed the quality of medical information provided on a Internet discussion group, regarding painful hand and arm conditions, also discovered that the overall quality of the information was poor when compared with current therapeutic recommendations. Thirty percent of the information was "unconventional," and the authors expressed concern that the Internet had become the media for "purveying snake oil."[40] Unfortunately, because of its ease of use, the Internet has the potential of reaching far more people than did the traveling medicine man of a century ago.

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DISCUSSION

Dr Anthony J. Roon (Everett, Wash). The Internet is undoubtedly a poor source for patient information. I believe the authors are exactly correct in their assertions, if one is an uneducated information gatherer. Most patients fall into this category because they do not possess the information about vascular disease that we all do. I believe that this study provides us with that conclusion. After being asked to discuss this paper, I spent several sessions on the Internet in an attempt to be scandalized by the purveyors of alternative therapies for vascular disorders. I was impressed that this type of information and promotion is as equally scarce as good advice. This study is an honest attempt to show that the information in cyberspace is incomplete and perhaps misleading. I would agree with this conclusion, but I would ask the authors several questions regarding their conclusion.

First, do you think that the print and broadcast media have published a more accurate information base for the general public?

Second, do you think the vascular surgical community has spent enough time or effort in educating the public?

Third, do you consider that the meager space provided to the general public's questions is an adequate resource on the vascular society's web page?

Fourth, what sort of information is given to patients by their primary care providers regarding vascular disorders? Do you think this information is accurate? I certainly have found a distinct lack of knowledge about vascular disease amongst our medical colleagues.

And finally, what proposals would you consider in correcting the current lack of useful information available to the public and the general medical community?

I have enjoyed reading your paper and presume you have some opinions regarding the improvement of the current situation. I hope that the Oregon Health Sciences University has developed its own web site and newsletter. I am certain that the vascular surgeons at this renowned institution are at least providing its medical trainees with an appropriate education in vascular disorders.

It is my hope that we may be able to educate the public in the prevention of vascular disease in the future. One simple fact that could save many lives and limbs would be to teach people that smoking causes a large number of these miseries. This fact alone would be an important one to center on in any educational campaign.

For those of you in vascular surgery who wonder why so much attention is paid to coronary atherosclerosis and so little to peripheral arterial disorders, it is my contention that we, as a group of vascular specialists, have ignored our responsibilities in the education of the public. It is about time we turned this around.

Dr Laurel C. Soot. Thank you for your kind remarks. I agree that vascular disease education for the general public could be greatly improved. Currently, it does not appear that the answer lies with the Internet. I will address your questions in the order received.

First, I believe that the media often publish sensationalized or misleading information regarding new medical information and scientific breakthroughs. I do not believe the problem is as severe as that with the Internet. Although there are not formal guidelines for the media, the public expects at least some self-imposed publishing guidelines.

To answer your second and third questions, the vascular surgical community needs to improve the education of the general public if they want to increase the overall understanding of common vascular conditions. The Internet is one method that could be used. Currently, the Vascular Society's web page has a "frequently asked questions" section that is directed toward public education. This site is very informative, but it is not easily found. It could be greatly improved by developing a separate patient education web page or improving the usability and identification of the current site.

Fourth, I agree that, with the exception of coronary artery disease, there appears to be a general lack of knowledge about vascular disease among our medical colleagues. This is most apparent with peripheral vascular disease. I do not have a good understanding of what their knowledge base is on training completion or what they are responsible for on their board certification. Effort could be placed on improving this portion of their graduate and postgraduate medical training.

Lastly, it is our job as physicians to educate patients and colleagues about vascular disease causes and medical and surgical management strategies. To improve the current level of understanding, a distinct and focused effort must be made by the Vascular Societies. The American Heart Association effort, with respect to coronary artery disease and stroke, serves as a good example.