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INFORMED CONSENT IN THE (MIS)INFORMATION AGE

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Abstract: Recent studies suggest that large numbers of healthcare consumers are turning to the Internet as a source of health information. This article considers the potential impact of on-line health information on women's health-care decisions, and the role of physicians relating to their patients' use of the Internet as an information source. In particular, the article examines the effect of on-line health information on the informed consent process. Physicians' disclosure obligations (their legal duty to provide information to patients) and the law of informed consent are briefly described. The article then considers the Internet as a source of health information, and instances and types of misinformation. Finally, the article suggests steps physicians may take to help their patients benefit from Internet health information and to become critical consumers who do not fall victim to inaccurate or misleading information. The article concludes by suggesting that physicians make a practice of asking their patients about alternate sources of information they may have accessed, in order to help ensure that patients' health-care decisions are based on current, accurate, and complete information.

Résumé: Des études récentes indiquent qu'une grande partie de la population a recours à l'Internet comme source d'information sur la santé. Le présent article examine l'effet que pourrait avoir les renseignements sur la santé obtenus en ligne sur les décisions que prennent les femmes en matière de santé, ainsi que le rôle des médecins relativement à cette utilisation de l'Internet comme source d'information par leurs patientes. Il examine aussi tout particulièrement l'effet de ces renseignements sur le processus d'obtention d'un consentement éclairé. Nous y décrivons brièvement les obligations du médecin en matière de divulgation (son devoir légal de transmettre l'information à ses patients) et la loi sur le consentement éclairé. Ensuite, nous examinons les types de renseignements sur la santé disponibles sur Internet, de même que des exemples et des catégories de transmission de renseignements erronés. Nous envisageons alors les mesures que peuvent prendre les médecins pour aider leurs patients à profiter des renseignements disponibles sur Internet, ainsi qu'à exercer leur jugement critique, afin de ne pas être victimes d'une information

Key Words

Informed consent, disclosure, Internet, physician-patient relations, prenatal care

Competing interests: None declared.

Received on May 6, 2003 Revised and accepted on June 16, 2003 inexacte ou trompeuse. Enfin, cet article suggère aux médecins de prendre l'habitude de demander à leurs patients s'ils ont obtenu de l'information auprès d'autres sources, de manière à pouvoir s'assurer que les décisions de ces derniers, en matière de santé personnelle, sont fondées sur des renseignements actuels, exacts et complets.

Obstet Gynaecol Can 2004;26(1):43-8.

INTRODUCTION

The law of informed consent has traditionally assumed that patients are informed about matters of testing, diagnosis, and treatment by their physicians. Disclosure requirements, or the physician's legal duty to provide information, are premised on both patient autonomy and physician knowledge. In other words, patients need information about their health and their health-care options in order to make autonomous decisions, and physicians are the source of that needed information. Information has generally been transmitted vertically from physician to patient. Increasingly, however, the notion of the physician as the only, or even primary, source of information is eroding.

In today's "information age," the general public is being constantly bombarded with information on a seemingly endless array of topics. It is difficult enough to process the volume of information encountered on a daily basis, let alone to evaluate its reliability and utility. A number of studies have recently been conducted to determine whether and how individuals are using the Internet to obtain medical information, and to evaluate the reliability and integrity of medical information available online.²⁻⁴ Misinformation on the Internet can take a variety of forms: information may be incomplete or inaccurate, and therefore misleading, or be deliberately misleading in the pursuit of politicized or marketing objectives. Physicians' responses to instances of misinformation must be sensitive to the cause of the patient's misunderstanding. Other factors that influence the manner in which physicians respond to misapprehensions that arise from on-line information include the timing of the patient's use of the Internet in the informed consent process, and the manner in which concerns are raised by the patient.

The objective of this article is to discuss the use of Internet information in medical decision-making, in the context of how

women use information obtained outside the bounds of the physician-patient relationship, and how this use might affect the physician's disclosure obligations. The law of informed consent is described, followed by consideration of the use of Internet-derived health information and its potential effects on traditional notions of informed consent. The potential impact of Internet information on the informed consent process, and the policy implications that may arise for physicians in this context, will be explored.

INFORMED CONSENT AND INTERNET INFORMATION

Since the Supreme Court of Canada's decision in the case of Reibl v Hughes⁵ in 1980, it has been clear that physicians are required to disclose material information to patients when seeking their consent to a proposed treatment, diagnostic test, or other medical intervention. This case involved a claim of lack of informed consent by a patient who underwent a carotid endarterectomy and suffered a stroke as a result of the surgery. Mr. Reibl had not been informed prior to the surgery that a stroke was a potential risk of the procedure. In Reibl v Hughes, the court articulated the physician's duty in terms of the information needs of the patient: what would the reasonable person in the position of this patient want to know before making a decision about the proposed procedure? The fact that the question is framed from the patient's perspective underlines the importance of patient autonomy as a foundation for the physician's duty of disclosure. As the Supreme Court of Canada stated in Reibl v Hughes, "[w]hat is under consideration here is the patient's right to know what risks are involved in undergoing or foregoing [medical treatment]."5

At the very least, *Reibl v Hughes* mandates disclosure of the material risks of the proposed treatment; the provision of information regarding alternative treatments, including their material risks; responses to patient questions; and the likely outcome if treatment is declined. In the more than 20 years since the decision in *Reibl v Hughes*, the courts have continued to add to the physician's duty of disclosure, which now requires a much broader range of information than had been envisioned in that case. As Bernard Dickens has explained, the respect accorded to individual autonomy by "modern health law makes it likely that courts will continue to broaden the scope of required disclosure." Given that materiality of information is a matter to be determined in each case, the scope of material information must be capable of continued expansion.

In addition to these basic disclosure requirements, physicians must disclose information about other matters, including conflicts of interest and cost containment measures that render certain alternatives unavailable.⁸⁻¹⁰ Dickens suggests that where cost containment strategies limit options available to patients, "...[i]f patients have means to obtain indicated care in another hospital, town, province or country, physicians may

be obliged to inform them [about options that appear unavailable to them], because the option may be material to patients' choice between accepting the lesser care at hand or seeking superior care elsewhere." Dickens further asserts that if physicians are not aware of whether their patients have such means, physicians should ask.

Physicians' disclosure obligations also extend to making efforts to ensure that the patient has understood the information provided. As one commentator notes, "Simply telling the patient about the risks without making any attempt to see that the patient has understood the information can be negligent...The risks must be dealt with in terms that register with the plaintiff, and where it is quite apparent to the doctor that the patient has not understood he [sic] may have to make further efforts."

Clearly, physicians' obligations with respect to informed consent are demanding, obliging physicians to provide information that might, at first mention, appear to be unrelated to patients' need for information with regard to a particular treatment or diagnostic intervention. On reflection, however, it is apparent that the information provided by these "additional" disclosure requirements is extremely relevant to patients' decision-making. Given the emphasis on individual autonomy in contemporary discussions of informed consent, the breadth of the duty of disclosure should come as no surprise.

As will be discussed in detail below, interesting issues have been raised that delineate both increasing Internet usage by those seeking health-care information and the questions that have been raised about the accuracy and comprehensiveness of the information available on the Internet.

INTERNET USAGE AND HEALTH-CARE DECISION-MAKING

Even if it can be safely assumed that the majority of patients are obtaining most information about their health and health care from their physicians in the conventional way, the lure of the Internet cannot be ignored. A recent report indicated that 62% of U.S. Internet users (73 000 000/118 000 000 people) "relied on the Internet to make critical health decisions."12 The report also indicated that "health seekers," i.e., those who go on-line to access health information, are reassured by statements that are repeated on more than one Web site, and that 72% of these individuals (84 960 000/118 000 000) say "you can believe all or most of the health information online."12 The lure of the Internet as a source of information is not specific to those seeking information on health care, as a recent Australian survey indicated that 53% of those surveyed (531/1001) said that the Internet was where they would most likely seek information about biotechnology. 13 Most of those who seek health information on the Internet find the information they discover to be helpful in health-care decision-making. As reported by Fox et al., 12 "Overall, when we asked these health seekers about their most recent search for information, 68% said it had some impact on their decisions related to their own health care or a loved one's care." 12

Studies specific to *patient* usage of on-line health-care resources have also been conducted, and have arrived at similar conclusions: a significant number of individuals turn to the Internet as a source of health information, and most are of the view that information obtained on-line is accurate and reliable.^{2,3} This perception is particularly interesting in light of a 2001 study of on-line health information, which concluded that "consumers using the Internet may have a difficult time finding complete and accurate information on a health problem. If people are relying on the Internet to make treatment decisions, including whether to seek care, deficiencies in information could negatively influence consumer decisions."⁴

Similarly, Taylor *et al.*,² in their study of Internet use to obtain genetics-related information, noted that further consideration must be given to the extent to which "patients actually do understand the information encountered and [to] whether the information is accurate." Other concerns include the reading comprehension level of on-line health information,^{2,4} the unregulated nature of the Internet,³ and the fact that much of the medical information available on-line is provided by entities unrelated to medical professionals.³

The Internet has the potential to be a valuable resource for patients and physicians alike, in that it may permit patients to become more knowledgeable about health issues. If health information on the Internet were to become more reliable, physicians would be able to refer their patients to the Internet for information that could be reviewed and discussed at the next patient visit. Patients would have access to more information than physicians could provide during a visit and additional time to better comprehend what they have read. Currently, however, the quality of on-line health information is variable, ²⁻⁴ and as the Berland study delarifies, there are often significant gaps in the information. The Internet has the capacity to inform patients as never before, but it also has the capacity to misinform.

INTERNET USAGE AND INCOMPLETE OR INACCURATE INFORMATION

One source of "misinformation" on the Internet is incomplete or partially incorrect information. For example, some Web sites relating to prenatal screening and diagnostic procedures either partially explain or incorrectly explain the purpose of maternal serum screening and the distinction between such screening and diagnostic testing. ^{14,15} Consider the following comment, found on a university biology department's Web site, regarding Down syndrome:

There are two different screening tests performed to determine if a fetus has Down Syndrome. The first is Amnio-

centesis, which is a sample of the amniotic fluid that surrounds the fetus. It is a routine procedure around 14–16 weeks after conception. Amniocentesis is 99.8% accurate for chromosome disorders. However, there is a risk of miscarriage after the procedure. The second test is maternal serum alpha feto-protein (MSAFP). MSAFP is a test of the mother's blood...¹⁴

Much of the information in this statement is accurate (if incomplete), apart from the obviously incorrect statement that amniocentesis is a "screening test" and that it is "routine." Amniocentesis is offered only if specific risk factors, the most significant of which is maternal age, are present. While these errors might seem insignificant, in light of the difficulty individuals have in understanding genetic testing 16 and the nature of a screening test as opposed to a diagnostic test (particularly in the context of prenatal testing), the errors have the potential to create misunderstanding. It is easy to see how the decision of a woman who had seen this or similar information prior to, or even in conjunction with, discussing prenatal testing with her physician might be "negatively influenced." She might decide to go ahead with the MSAFP but not amniocentesis, regardless of the results of the MSAFP testing, because of her understanding that both tests provide essentially the same information and that amniocentesis carries more significant risks to her fetus. Furthermore, a woman might misunderstand exactly what the MSAFP test is able to tell her and, therefore, make a decision about testing that she would not have otherwise made.

A similar example of misinformation was found on a Web site that explains the alpha fetoprotein (AFP) test and then states that "AFP is of dubious reliability. The test is affected by things such as multiple pregnancy, and due date miscalculation, and does yield many false positives. An initially positive test will invariably lead to further tests because of this." Information on the maternal serum screen (MSS) is given on the same Web site: "MSS is another test which measures levels of AFP. Again, it involves screening a blood sample from the mother. It is not wholly reliable, and is usually followed up by amniocentesis." 15

The problem is not so much that the information is entirely inaccurate, rather that it is accurate enough to sound close to what a physician may well have said, but is either missing key facts or contains some fundamental misconceptions. Apart from AFP measurement, the MSS also measures levels of other substances, depending on whether the double, triple, or quadruple screening test is used. ^{17,18} A pregnant woman who reads this on-line description of the screening tests might decide to forego both MSAFP and MSS testing because she perceives that she will definitely have an amniocentesis, whatever the results, and is concerned about the risks posed by that test. Likewise, a woman might forego MSS and proceed directly to amniocentesis, thus taking a risk she is not keen on taking, and might not have needed to take, depending on the results

of MSAFP and MSS screening tests. At the very least, a woman reading such information might not understand that the decision to undergo initial or follow-up testing is ultimately hers to make, and that it is therefore not inevitable that MSS testing will be followed by amniocentesis.

Another consideration is the possibility that a woman will perceive a conflict between information given by her physician and information she has found on the Internet. One pregnant woman posted the following to an on-line bulletin board: "My doctor called and I've screened positive for Downs [syndrome]...I am so conflicted with what to do next, because my doctor tells me one thing and the Web tells me another. Can anyone please advise me!!" 19

The woman goes on to explain that her physician had informed her that there is a 1 in 200 chance of miscarriage as a result of amniocentesis, and that amniocentesis is only 62% to 65% accurate. By contrast, the Internet information she found indicates that there is a 1% to 2% chance of miscarriage with amniocentesis and that amniocentesis is more than 99% accurate in detecting Down syndrome. The most likely explanation for this woman's confusion is not that her physician gave her incorrect information, but that she misunderstood her doctor's advice - the 62% to 65% accuracy referred to is probably in reference to the results of the serum screening. Whatever this might say about the timing and effectiveness of counselling during pregnancy, it does show that women may be willing to trust information found on the Internet, even if that information seems to conflict with advice provided by their physician. 20,21 As noted in a report on Internet usage by "health seekers," one woman who participated in an on-line focus group explained that "[b]ased on what [she] read on-line about the risks and trade-offs of prenatal testing, [she] decided not to go through with amniocentesis to find out if the baby had Down syndrome."12 The potential influence of health information obtained from the Internet on patient decisionmaking should not be underestimated.

INTERNET USAGE AND POLITICIZED MISINFORMATION

Much of the information on the Internet is potentially misleading because it is either politicized or commercial information.³ This is particularly the case when biased information is presented as being based on scientific or otherwise verifiable sources. One example of such information, outside of the prenatal diagnostic context but still very relevant to women's health, arises from a number of Internet sites that claim that abortion is causally related to breast cancer. One such site, http://www.abortionbreastcancer.com, claims: "16 of 17 statistically significant studies report increased risk of breast cancer among women choosing an abortion. 7 studies report a more than twofold increased risk." The Web site is run by the Coalition on Abortion/Breast Cancer, self-

described as an international women's organization committed to protecting women's health and saving women's lives by educating women about abortion as a risk factor in breast cancer. Based on consumer-oriented guidelines intended to assist individuals in assessing the reliability of Internet health information, this site appears to contain reliable information. 23,24 For example, it is clear who operates the site, what the purpose of the site is, and authority is provided for assertions made on the site. Very few in the medical field, however, agree with the Coalition and its experts as to their interpretation of the findings of studies.²⁵⁻²⁹ The Coalition accuses such organizations as Planned Parenthood, the American Cancer Society, and the National Cancer Institute of concealing evidence or providing misleading information. The position of the American Cancer Society on the issue of abortion and breast cancer is as follows:

The topic of abortion and breast cancer highlights many of the most challenging aspects of epidemiologic studies of human populations and how those studies do or do not translate into public health guidelines. The issue of abortion generates passionate personal and political viewpoints, regardless of any possible disease connection. Breast cancer is the second most common cancer in women, and it can be a life-threatening disease that most women fear. Still, the public is not well-served by false alarms...At the present time, the scientific evidence does not support a causal association between induced abortion and breast cancer.³⁰

A recent review article notes that the results of studies have been inconsistent, but that "[a]t present, level II-2 evidence (cohort and case-control studies) supports a class B recommendation (fair evidence) that induced abortion does not increase a woman's risk of breast cancer later in life."31

There are obvious political overtones in the Coalition on Abortion/Breast Cancer position (following some of the links provided on the Web site make this abundantly clear), yet this is painstakingly disguised and is not readily apparent from the content of the Web site. Again, it is easy to see how such information could negatively influence the health-care decisions of those who rely on it.

MITIGATING THE IMPACT OF MISINFORMATION

What can physicians do to help ensure that patient decision-making is not negatively influenced by misinformation found on the Internet? Physicians can begin by educating patients about being critical consumers of on-line health information, ^{23,24} particularly by explaining that the information provided on-line is not regulated,³ and is often not supported by medical organizations.³ Physicians can inform patients that the health information they find on-line is potentially out of date,

due to the rapidly evolving nature of health-care technology, and suggest that patients check the date the site was last updated.²³ Physicians can also provide guidance about sites they feel contain accurate, current, and helpful content, as well as offering literature to supplement the information they provide. The Society of Obstetricians and Gynaecologists of Canada, for example, posts its Clinical Practice Guidelines on-line, including a guideline on prenatal testing,³² and the Alberta Medical Association provides an on-line pamphlet containing information on prenatal ultrasound.33

CONCLUSIONS

In light of the potential for incomplete and misleading information to influence health-care decisions and the pervasiveness of health information on the Internet, the physician's legal duty of disclosure may one day include assisting patients to understand information obtained from other sources.

Caulfield and Feasby³⁴ have argued that physicians would be prudent to ask patients about their usage of complementary and alternative therapies as part of the informed consent process, given the considerable proportion of the public who use such therapies (and given that most do not inform their physicians of this usage). Likewise, it is suggested that physicians give some thought to the fact that large numbers of their patients use the Internet as a source of health information. It is clear from the case law that physicians are required to make efforts to ensure that patients understand the information that is provided to them. 35,36 It follows that where patients may have difficulty understanding a proposed treatment or its risks because of information they have obtained on the Internet, physicians would be wise to make efforts to ensure that the information they have provided has been understood. These steps are sound practice, whether or not there is any legal obligation resting on physicians to discuss alternate information sources with their patients.

As one study¹² noted, only approximately one-third of "health seekers" spoke to their physician or other health-care providers about the information they located on the Internet. It is therefore sensible for physicians to make a practice of questioning their patients as to the types and sources of information they have read or heard about regarding their condition, a proposed treatment, or a diagnostic intervention. In this way, physicians can ensure that patients' decisions are based on current, accurate, and complete information.

ACKNOWLEDGEMENTS

The author would like to thank Dr Jonathan Davidow and Professor Timothy Caulfield for their helpful comments on earlier drafts of this article. The author would also like to thank the anonymous peer reviewers for their helpful comments.

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