Infertility and the Internet

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With more information being made available on-line, and support groups helping to increase awareness of infertility, patients have a seemingly limitless amount of information now available to them. One direct result of the ongoing information revolution is that patients today are becoming more knowledgeable and empowered than ever before. Infertility patients are particularly benefiting, as technology changes in this field even faster than many textbooks and books for lay people can be updated. Fortunately, this trend toward better-informed patients coincides with a growing trend toward physicians being more responsive to patients’ questions and needs. Hopefully, the days are long gone when a patient is afraid to ask her doctor a question about her diagnosis, treatment, or therapeutic options. With an estimated 40 million users of the Internet in the United States, and with infertility patients constituting approximately 20% of the reproductive age population, it is apparent that a large number of infertility patients are now logging on and learning first hand about their disease. A search of the word “infertility” on a search engine yields over 20,000 “hits” or pages. The amount of “endometriosis” (7,000 hits) and “IVF” (4,000 hits) also attests to the magnitude of the electronic information available. By researching a topic, a patient can be well armed for her next conversation with her physicians. Though it is clearly not ideal for a patient to learn medicine and self-diagnose and self-treat from the Internet, it is important that a physician be open to a patient’s suggestions and queries regarding her treatment. A patient who has some background information may be less afraid to ask her doctor a question about her diagnosis, treatment or therapeutic options.

Some Internet sites are incredibly well researched and well written. However, others may contain information that may be neither factual nor up-to-date. In fact, when a patient purchases a book at a book store, he or she usually researches the credentials of the author, and may even look at the publisher, assuming that a major company would have most likely done careful screening and fact checking.

With the Internet however, anyone can post a home-made remedy or anecdotal tale of how she conceived, and within days, thousands of infertile couples may read that “information”, take it as gospel, and even pass such misinformation on to others. As always, it is important to consider the source of the information in helping to decipher its credibility and accuracy. Professional organizations have become important disseminators of information on the Internet. One of the most comprehensive sites is INCID (http://www.inciid.org) This site has a good glossary, some basic and advanced articles about specific topics, and excellent bulletin boards. http://www.fertilitext.org, http://www.ihr.com/infertility, and of course, and our local AIA home page, http://www.americaninfertility.org, all have much well researched information.

Though patients have used the Internet to purchase discount fertility drugs from overseas (http://www.fertilethoughts.net/faq/drugs.html) patients should be aware of the FDA’s position, which can be found at http://www.ceri.com/import.htm. Support groups geared toward couples who are experiencing infertility, have grown and flourished on the Internet as well. The knowledge that there are many other couples facing the same frustrations and challenges of infertility, may help a patient who feels alone. AIA, as a national organization for infertility patients, has provided excellent support for couples undergoing the trials and tribulations of infertility.

There are other support groups for patients grieving a miscarriage, a stillbirth, an ectopic pregnancy and other heartbreaking experiences. A particularly noteworthy site is maintained by one of my
former teachers at Yale-New Haven Hospital - Dr. Michael Berman at http://www.hygeia.org. Dr. Berman has written moving poetry for his patients who have experienced losses, and visitors are invited to share their experiences with others. Newsgroups are discussion forums that use postings for sharing information. Some computers or on-line servers require special programs to post and read messages. Examples of such newsgroups are “alt.infertility”, where a variety of aspects of infertility are discussed, and “misc.health.infertility”, where specific medical aspects of infertility are explored. Bulletin boards (also called ), are similar to newsgroups but are easier to access and to read. The site at http://www.inciid.org has numerous bulletin boards on a variety of topics and even has the ability to search through thousands of postings for information about specific diseases, clinics, or even individual physicians.

Other noteworthy web sites include http://www.IVF/com, the site maintained by the Atlanta Reproductive Health Center, and http://www.asrm.com, which is the home page for the American Society for Reproductive Medicine, where available resources include “frequently asked questions”, fact sheets and patient information booklets. An important Resource for patients undergoing in vitro fertilization is http://www.cdc.gov/nccdphp/drh/arts/. This site provides the success rates for all clinics that have registered with the Society for Assisted Reproductive Technology. Unfortunately, the information published by the CDC is nearly three years old and may not always be relevant or representative of the current status of a specific IVF Program.

It is important to remember that information obtained on-line is by no means a substitute for medical care by a physician. While general answers to common problems may be often helpful as guidelines, specific answers, accurate diagnoses and appropriate treatment plans can only be obtained by dialogue with the patient, review of all appropriate past records and a thorough physical examination. In addition to losing the ever-important doctor-patient contact by e-mailing questions and answers, state laws actually prohibit the practice of tele-medicine without licensure in each state.

Clearly, it is important for patients to differentiate accurate information from misinformation. Statements found on infertility web sites will never be a substitute for good medical care delivered by a qualified physician. I do believe however, that the educated patient is an empowered patient. The Internet is a valuable tool in patient care. In a field as rapidly evolving as infertility, it will continue to help patients retrieve the most up-to-date information and help doctors and patients communicate efficiently and effectively.

**References:**
Dr. Copperman can be found at the Mount Sinai Medical Center Assisted Reproductive Technologies Program web site at http://www.mssm.edu/ivf

**Source URL:** http://www.obgyn.net/infertility/infertility-and-internet

**Links:**