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Expectations and Experiences of Seeking Infertility Information via the Internet and the Telephone Directory



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Anigbogu, J. & Rice, R. E. (2001).
Expectations and experiences of seeking infertility information
via the Internet and telephone directory.
In R. E. Rice & J. E. Katz (Eds.),
The Internet and health communication:
Expectations and experiences
(pp. 121-143). Thousand Oaks, CA: Sage

This chapter provides two perspectives on how a person new to the Internet might experience the accessibility and usability of health information. The first part follows a woman as she tries to understand what appears to be a problem of infertility in her marriage. With our help, she turned to the Internet to find resources outside of her regular doctor and her family. As she was a complete novice at computing and Internet usage, this case study provides interesting insights into how "ordinary" people might actually first experience this new environment, rather than as utopian advertisements portray, and how this experience might change people's perceptions of their problems, their health providers, and even their own relationships. The second part considers a related dimension of this case: To what extent do traditional information resources, here the local telephone directory and hospital referrals, and new information resources, here specialized Internet lists and search engines, reflect a common physi-

cal health environment? Is it accurate to say that the Internet is "just" a faster and easier way to find the same information? Finally, both of these cases show that the process of using the Internet for health information is far more complex, and involves many more tacit assumptions and prior knowledge, than is typically portrayed in the media or conveyed in training materials.

PART I: RESEARCHING INFERTILITY ON THE NET: A CASE STUDY

Mr. and Ms. Doe wish to remain anonymous. June met Ms. Doe through another friend, and considers her an acquaintance. Their initial phone conversation was held on May 27, 1999.

Situation: A couple married for 7 years, in their early and late forties, residing in Union, New Jersey, have been trying to have children for 4 years. The wife confides that she has been to an OB-GYN and undergone a number of female-oriented tests that proved that she would not have any difficulties in the area of reproduction. She then confided that it was her husband who eventually was examined and found to have a low to nonexistent male reproductive count. "Male infertility is a new frontier that had not been dealt with until recent times" (<http://maleinfertility.com/contact.html>, Center for Male Reproductive Medicine and Microsurgery).

The following pages are the dialogue between Ms. Doe and the first author, from the beginning computer sessions to her personal investigation of the doctor's inquiries and her consideration of possible treatments for herself and her husband.

GETTING ONLINE: ISSUES OF PHYSICAL, EXPERIENTIAL, AND COGNITIVE ACCESS

Phone Conversation on
June 9, 1999, with Ms. Doe

I called Ms. Doe on June 9 to verify whether she was still interested in being shown how to get online. She said she definitely was still interested in the session, so we decided to meet on Friday, June 11, at 3 p.m. at my place in New Brunswick. I asked her if it would be okay if I taped her. She

said, "Definitely not, are you trying to Linda-Tripp-me-up?" I said, "No, I would never do that to anyone. Could I take notes?" Ms. Doe agreed.

First Meeting, June 11 at My House

Our first meeting was an eye-opener for me. My definition of computer illiteracy was definitely inaccurate. I always thought that to be computer illiterate, one had to know how to design computer programs and use other computer program designs, as well as have the ability to set computers up on a network. So I always said that I was computer illiterate. After being involved in a training session with Ms. Doe, I realized that I am computer illiterate according to some standards.

When we sat down, I kept in mind that she wanted to learn how to get on and off the Internet to investigate fertility issues and available clinics. I thought it would be a quick and easy process of clicking on an icon and waiting for the connection to take place over the phone line. I thought that the majority of individuals in the United States had some knowledge of computers. As Ms. Doe got adjusted in front of the monitor, she said anxiously, "OK, what do I do?" I spoke in a casual, matter-of-fact voice, so as not to talk down to her or underestimate any computer skills I thought she might have.

I responded, while pulling out the keyboard: "Click your mouse on the [browser] icon, and just wait a few minutes and you're online."

Ms. Doe looked at the keyboard tray, which included the mouse, and then at me and said, "What mouse? Where is the mouse?"

At that point I knew this would take some time! I picked up the mouse, which was on the left side of the keyboard, and placed it on the right side, since she was right-handed, at the same time telling her, "This is your mouse." I said this with a straight face and trying not to show my feelings of surprise and disbelief.

Ms. Doe: It does look like a mouse, its tail goes to the computer. (we laughed)

I repeated the same instructions, apologizing for the unseen keyboard, thinking that maybe she was nervous about the fact that this friend of a friend (me) had knowledge of her private problem.

June: OK, now click your mouse on the Internet icon.

Ms. Doe: What or where is the icon?

I casually explained the convenience of an icon, and then I explained how she could also go to the start button, and then to any computer program. I thought, how can she not know this? My curiosity got the best of me, so I asked, "Do you have a computer at home?"

Ms. Doe: Yes, but my husband only uses it on special occasions, and I am not allowed to touch it at all until I learn how to use it. Sounds crazy, huh? I ain't computer literate . . . never was interested in computers until now. This is a special occasion, looking for a clinic or hospital online for my husband. I got the idea from my girlfriend.

June: What Microsoft program do you have at home, '95 or '97?

Ms. Doe: I think my husband said Microsoft Word 4.6 or 7. I really am not sure. What did I do, the computer stopped!

I was taking notes and had not noticed what took place to make the computer freeze.

June: What exactly did you do?

Ms. Doe: I pushed both buttons on the mouse at the same time, I think.

June: Push Alt, Control, and Delete. This is a way of rebooting or restarting the computer. (I pushed the buttons in one smooth move for her, and the computer came back up.) Now push the left button on the mouse.

I watched as she clicked the button and found that she held it down too long. The computer froze again. This happened three times; after the third time the computer came back up. I took her hand along with the mouse so she could feel how my finger bounced or doubled clicked the mouse.

Ms. Doe: Oh, I get it!

When we finally were dialing onto the Internet, Ms. Doe asked what were the little whirling sounds going on. I explained that we were being hooked up online through the telephone wire to my Internet service provider.

Ms. Doe: I don't know what my husband's server is, do you have to have it to get online?

June: Yes. (we connected) Now we are hooked up to the outside world.

I showed her the two little green computers at the bottom of the screen that also told us we were online.

Ms. Doe: Whoa! Isn't that something! So, I can contact anything or anyone online?

I tried to explain the difference between e-mail, being person to person, and the Internet, which was one person communicating with the world; that was hard, as I considered myself a novice.

June: Now, let's do our research. Once you're online you use different search engines to look up anything you're interested in. In your case, you want a health issue, infertility. So, let's go to a Web page that has many search engines to choose from, my professor, Dr. Rice's . . .

Ms. Doe: (interrupting) Wait! You're going too fast, what is a Web page, and I think I understand a search engine, it sounds self-explanatory. A computer engine that searches things out, like researches for you . . . right, like a car engine drives you around?

June: Yeah, something like that.

As long as it made sense to her! Dr. Rice's Web page came up.

Ms. Doe: Look, that is so neat, is that his name moving? June, what does www stand for? I hear it all the time on TV. I know the com stands for computer, right?

I printed Dr. Rice's Web page and explained what a Web page was, and she began to read what the computer abbreviations stood for.

Ms. Doe: Oh wow, stupid me, com stands for commercial, www is World Wide Web, here are all the meanings, like a computer dictionary, neat-o. I wondered what that http meant, it says here that it stands for hypertext transfer protocol. I bet my

husband don't know this. Oh yes, wait 'til I show him. I'll be on that computer in no time. Thank you so much for this.

June: You're welcome, no problem. Now, let's do some research on the health issue.

I instructed her to click on the meta-search engine and investigate fertility for men.

Ms. Doe: Is that like Yahoo? Can we go to the Yahoo on line . . . I want just to check out a music group . . . uhum . . . the Spice Girls.

She clicked Yahoo! slowly, like a little baby that just had learned how to walk, being cautious with each new step, which hung the computer up again. I showed her how to push Refresh and continue and not to be afraid to push/click the mouse fast. I showed her where to click on music, and then type "spice girl" as the group she wished to search.

Ms. Doe: That little finger pointing, what does that mean?

June: You can go into that site, just double click.

She double clicked after she was in the Spice Girl site, on a song. It began to play.

Ms. Doe: My god . . . this is like TV or computer radio with pictures. I think that she is avoiding the health issue, or maybe she is really into the excitement of the new computer experience. She also wanted to know if she could transfer information from online to her computer. I showed her how to hold the mouse button down and highlight the info, then press Control-letter C, then bring up the computer word processing program, and then push Control-letter V. I did it the first time so she could see how it was done. Then she tried on her own.

Ms. Doe: It worked . . . I did it, I can't believe it, I can copy from the online world! I wonder if my husband can do that?!

I think there are other issues she is dealing with in her home with hubby besides the infertility one, because she keeps referring to her husband like they are in competition or she knows something that he might not know.

June: (trying again) Now let's check health issues online.

Ms. Doe: Wait, look, I want to click on shopping.

She clicks on shopping, then types in J. Crew. J. Crew's colorful site pops up.

Ms. Doe: WOW! This is great! I can't believe this, it is really space age, that's modern technology for ya. Have you ever shopped on the World Wide Web?

June: No.

I went on to explain that shopping online is fine but, once your info is out there a lot of companies can contact you, and I did not want that. It made sense to her, and she agreed.

Ms. Doe: It's getting late—I have a ways to go to get home. I really appreciate meeting with you, and your help. I think this is enough to get me going with health research.

June: When next week do you wish to meet again?

Ms. Doe: Maybe Monday.

She called on Monday, but could not make it because of sickness. I told her I got info for her via mail regarding a clinic, and I gave her a number to call.

A NEW WORLD OF INFORMATION: CHANGES IN PERSONAL, FAMILY, AND PHYSICIAN RELATIONS

Phone Conversation on July 9

I called Ms. Doe regarding her progress on the Internet. We had not met because of illnesses. She informed me that she had been searching the Net at home using the search engines from Dr. Rice's Web site that I had printed out for her.

June: Well, how's the research on the Internet going?

Ms. Doe: I am doing OK, I move slow and sometimes I freeze the mouse when I don't click fast enough, so . . . I do that little Alt-Control-Delete trick. But now I'm becoming more familiar with the computer and the Internet thing. I feel I understand how it works, I just can't get off the computer, I mean I really can't stop . . . it's like I'm going into other

worlds inside my home. June, you know what I mean . . . I am going some place, without actually going some place. It's mind baffling! Now my husband has to cook his own dinner, because I'm on the Internet and I haven't cooked. I think he's happy for me. I think I have talked my husband into getting the latest computer package or program put on the computer. I told him that we have to move into the new millennium.

June: I know exactly what you mean, the world of computers is enlightening, right? I'm glad that you're getting better on the computer, and you're getting it upgraded. So, how about the health information, how much progress have you made regarding your fertility research?

Ms. Doe: You know, I found out anything that I type into those little long squares and push the search button, after waiting forever the information that I requested comes up, usually more than I ask for or want. There are so many things about fertility for women, and I saw some of the tests that they did on me . . . in the hospital to make sure I could have kids. It's a hysterosalpingogram. All the doctor said was everything looks OK, but he never went into detail about what he saw, or what he actually did. All I know is that I hurt like everything. But in that fertility site for women I saw in color the procedure that was done to me, and why they did it. It was to see if I had any fibroids. Now I'm going to call my gynecologist to see if my uterus was a normal shape and . . . I have so many questions to ask my doctor about myself.

I explained to Ms. Doe that that is the process, and having options is good. Also, it is up to her to narrow her search, or choose the Web site that is of interest to her or appropriate for her. She agreed, replying, "Uhuhuhum."

June: Well, that's good. What about your husband?

Ms. Doe: There's not much information about male infertility on the Internet. But that urologist, we have made an appointment for July 14. We know that his male count is low, but . . . we'll just see what happens.

June: There is a lot of info on male infertility. Go into <http://www.medicine.uiowa.edu/urology> or just input "male infertility" in any search engine, or long-search squares [which is how Ms. Doe identifies the input boxes] and a number of Web sites will be shown so you can research them the next time you come over.

Ms. Doe: OK. You know we can talk on the phone if you don't mind.

June: That's fine with me, that is quite funny because I was going to ask you if the conversations on the phone were more convenient for you. Can I call you Friday, July 16, just to touch base with you on the research?

Ms. Doe: I guess so . . . I thought I gave you enough information, June, but since you have really helped me with this infertility research and learning the computer and the Internet, I will call you next Friday on the 16th, OK? In the meantime, I will check out the male infertility info on the Net. Now, my husband is private so whatever the outcome, please keep it private.

Phone Conversation July 16, After Mr. Doe's Appointment With the Urologist

I called Ms. Doe around 6 p.m., knowing that she promised to call me back, and after not hearing from her that afternoon. I hoped that I was not intruding. Mr. Doe answered.

June: Hi, Mr. Doe, I am June Anigbogu, an acquaintance of your wife. How are you?

Mr. Doe: Hello, yes uhuhum I'm fine and you? Uhuhum, hold the line a minute . . . Hon!! Come to the phone! [he tries in vain to cover the phone] It's that one research lady. . . . June with the last name. [He whispers, and I hear it] Honey, you don't gotta stay long with her . . . OK?"

Ms. Doe came to the phone. I felt that this conversation was not going to be an easy undertaking. From the sound of her husband, she might not be able to talk freely. Maybe that was why she didn't call me back as she had promised . . . my speculation.

Ms. Doe: Hello June, I'm really busy right now, but . . . I can give you a few minutes.

June: Ahh . . . OK. [she was curt but I understood why] I know that you and your husband have just returned from the urologist, I hope the appointment was favorable. I do not wish to disturb the both of you, but was just wondering if you were able to talk to your GYN regarding the information that you found on the Internet?

Ms. Doe: Well . . . I did. I'll get back to you on that, because it's like I said, I am busy. Maybe I'll call you tomorrow. OK? 'Bye now.

June: OK, I understand. 'Bye.

Her husband was there, so she could not talk freely. I'll call her back if need be before next class, to reach closure for the case study.

Phone Conversation on August 2

Ms. Doe did not call me back (maybe she was going to, but I was too impatient) so I called her at midday on Monday, hoping that it was a better time for her to speak freely.

June: Hi. How are you? I called because you might have missed me. I have been out and in, so I thought I would touch bases with you. To see if you called. Is this a good time to talk?

I felt like I was harassing her, like in the movie *Cable Guy*.

Ms. Doe: Hi June. . . . I hadn't called, but I guess this is as good a time as any. You have been awfully helpful to me so. . . . [She immediately jumped into what she wished to discuss with me.] I did call my GYN and asked him the details of my hysterosalpingogram. I tell you, I think he was shocked that I asked, because he asked me who have I been talking with, and did I get a second opinion with another GYN. I said no, I just went to the Internet and I found what a normal uterus looks like and the minor or major complication that can be found during a hysterosalpingogram.

June: I hate to interrupt, but could you spell that for me?

Ms. Doe: Sure, I got this spelling from the Internet . . . H-y-s-t-e-r-o-s-a-l-p-i-n-g-o-g-r-a-m. Anyway, I couldn't believe what he told me. He said that the hysterosalpingogram showed that there was a cyst on one of my fallopian tubes. And according to the pelvic sonogram I have a small fibroid. He said my uterus was not enlarged but it did show a slightly bulky contour. I asked him why didn't he tell me before now? He said "because you can still have children, so does it matter?" I was upset because it's my body, and I let him know it. My silly GYN said are you going to let me take care of your body or a computer? I told him "you, but you have to tell me everything about me!" Well, anyway, June, I guess I am still upset and I am venting. I am glad you called, I will call you this Friday without fail regarding what the urologist said regarding my husband, whether it's good as well as bad, after that I think I was helped by you and used by you enough. Don't you think?

June: Well, I hope things turn out well, and please don't think I was using you. I hope that we have helped each other.

Ms. Doe: Yes, well . . . maybe so. . . . Sometimes it's good to not know so much . . . about things. Oh what am I saying?! June, it was good talking with you, I've gotta go. I'll call you Friday, OK?

June: OK. Have a good one.

THE INTERNET AS EMPOWERMENT

Phone Conversation on August 6

Ms. Doe finally called me on her own—I was shocked!

Ms. Doe: Hello, June? I bet you're surprised that I called, huh? I thought the least I could do is initiate the last call, right?

She was letting me know in a nice way that this would be her last call.

June: Yes, this is a surprise.

After exchanging 2 minutes of pleasantries, we finally began the conversation about her situation.

Ms. Doe: Well, first I would like to thank you for the referral to the urologist, it proved to be quite positive. I think that I had told you that my husband had a low male reproduction count. We took his lab results with us so the doctor could analyze the report. In a nutshell . . . the doctor said that yes the count is low which makes for the abnormal analyses. But the report also shows good sperm morphology and good swimming velocity, this is the good news. He said the best way for us to have children is IVF, that is in-vitro fertilization, where the sperm and egg are retrieved and fertilized, and then placed into the uterus for potential pregnancy. I had already read about this procedure from the Web site that you gave me—www.incid.org. There is so much positive information in that program about infertility.

I corrected her and told her it is a Web site and not a program.

Ms. Doe: I can't believe I am talking so free and unrestricted about this. I found out that everyone talks freely on the computer about everything, you know? June, life is not as restrained as we make it. Although it will cost a lot of money for the procedure, my husband is really depressed about it. I guess it's a man thing. He doesn't want me to say anything to our friends about the procedure. We'll start this right away as soon as we see what our insurance covers. We'll hopefully have children. I guess I won't be talking to you any more, my husband has signed me up with a computer class at a junior college. June, my husband is a very private person, and I am sorry for any inconveniences that might have occurred. But, if you need any more help please feel free to call me. One thing I found out about that Internet: It's the information key that unlocks any door to the outside world, and I have become a part of that world. It's more informative than TV, I just keep comparing it to TV.

She finally pauses.

June: Well, I am glad everything worked out for you and your husband. I believe you have a point about the Internet because

the urologist and some of the other information that you received was from the Internet.

Ms. Doe: You know, although I needed the fertility info, I mainly needed to get out of the house. The computer got me out of the house, I got help with our fertility problem, and I made my own GYN know not to take me or my body for granted. At first I was going to change my GYN after I found out he was holding back information about my body. But now that he knows that I have my own personal resource—the computer—to check things out, I know he'll be honest. So, I don't feel like breaking in another GYN. I feel so changed, so much in control. I have the edge on just about everything, you know what I mean?

June: Not really. Edge? What is your edge?

I had an idea what she meant, but I wanted her to clarify her "edge" in detail, because this might be the last time we talk.

Ms. Doe: My edge is the computer, June. Don't you see it? I don't care what it is concerning my health, my house, or my husband, I can find it on the Internet. Speaking of which, that is my next step, I am sure there are resources on the Internet about husbands who are control freaks. He thinks that I don't know what he is doing. My edge is the computer. I have a way out, while I am inside my home. June, I think I hear the hubby, he was not supposed to be home this early. I guess I better go, thank you again for everything.

June: OK, I thank you for your time, and once again I am glad everything turned out fine for you. Take care! Bye.

Ms. Doe: Bye, now.

What might have grown into a good friendship remained only a business agreement and case study. Maybe because I knew too much about her personal life, or maybe because her husband did not want her to get too close to anyone who knew too much about their fertility condition. It would be very wrong for me to perceive her husband as a domineering person on a power trip since I do not know him or have any background about his experiences and situation.

through these two media. Two questions served as the primary motivations for this study: How well do the two sources reflect a shared physical reality of health resource providers? And what kind of processes and search activities might be required to become aware of this health resources environment? Using the prior case on infertility information as a backdrop, we attempted to document all the efforts and results associated with this experience. As with the case study, we hope this analysis emphasizes the many difficulties, circuitous paths, implicit knowledge, and inconsistent information involved in finding appropriate health resources. Vendors, implementors, health service providers, Web site designers, researchers, educators, and novice and expert users should become more realistic about just what is involved in such activities. This is also written from June's perspective.

Results From the Telephone Directory

I live in New Brunswick, New Jersey, which is located in Middlesex County. I knew that it would be feasible to begin my research at home with my phone book, which I thought would be part of the New Brunswick and Edison areas of Middlesex. I went directly to the yellow pages and wrote down all the hospitals and clinics that I thought would cover these geographic areas. I knew this portion of my research might be a little difficult given that I am from Des Moines, Iowa, and have been a resident of New Brunswick for only 3 years; I am still familiarizing myself with the city and county regions. In view of that, I would need to make sure that the hospitals and clinics for Union, Middlesex, and Somerset counties that I had written down were correct. To check this I went to the Alexander library on the Rutgers University campus to check other phone books for these specific counties to make sure I did not omit any of the hospitals or clinics in the chosen areas. I thought there would be specific or separate phone books for the Union, Middlesex, and Somerset counties.

Once inside Alexander library I spoke with the librarian at the reference desk, asking her where the phone books were. First she laughed, and then said that the library does not carry phone books anymore, and for me to use the yellow pages on the computers. She began to tell me that she was actually one of the librarians on Busch Campus and was waiting behind the desk to go to lunch with a fellow librarian. The Busch Campus librarian began to clarify how they had gotten rid of their phone books because they were taking up space, replacing them with specialized science directories.

Phone Conversation on August 9

I called Ms. Doe to see if she would be interested in reading what I had written, and adding anything to the case study.

Ms. Doe: No, I feel that I have given enough of myself and time as a guinea pig, I don't mean any harm. In addition, just like you have received something, so have I. If it weren't for our meeting, I would not have inquired with a computer about my health. Through the Internet experience I got nerve or courage to confront my doctor. My doctor was someone that I always trusted and never questioned, I almost revered him, it was a Southern thing. Because my Mom felt the same way about her doctor. I now know he is a man who can make mistakes or hold back information. I will continue interacting within the computer world. I am a part of it and it has become a part of me now. It was great meeting you, and maybe I'll see you around. 'Bye.

As I told her 'bye, I thought about the impact the computer and the Internet had on Ms. Doe. I wondered what would eventually happen to her. I gave Ms. Doe the www.rba-online.com/male.html site, which I felt would be very informative for her husband regarding infertility. She thanked me and we said our goodbyes. It seemed Ms. Doe had other issues with her husband that she was dealing with besides infertility. Or maybe it was the infertility issue that was predominant in the home and that made other conflicts or issues occur. Nevertheless, her experience with the Internet opened a number of possibilities and raised a number of issues for her and her husband.

PART II: HOSPITAL AND CLINIC REFERRALS FROM THE TELEPHONE DIRECTORY COMPARED TO THOSE LISTED ON THE INTERNET, IN THE NEW JERSEY COUNTIES OF MIDDLESEX, SOMERSET, AND UNION

This section analyzes fertility-related hospitals and clinics in three counties in New Jersey (Middlesex, Somerset, and Union) identified from the telephone directories and subsequent referrals, and from the Internet, in an attempt to compare the "health resources environment" represented

She explained that, in place of the phone books, they provide total use of the Internet, the Iris online catalog, and the online yellow pages. I thanked her and explained that my research still needed a hard-copy phone book. The Busch Campus librarian referred me to the New Brunswick Public Library. I later found out that the Alexander Library did in fact have phone books!

That day I went to the New Brunswick Public Library reference department. The librarian was a recent graduate of the Rutgers Master of Library Science (MLS) program. After I explained my research need, she directed me to the phone books, and she made copies of postal zip codes so I could verify the county areas where the hospitals and clinics are located. The New Brunswick librarian also gave me the Web site for the New Jersey Hospital Association, <http://www.njha.com>. This Web site provides a listing of New Jersey hospitals alphabetically or by county, and was useful when I began the research for hospitals and clinics on the Internet.

After accumulating all the required information, I went back to the Alexander library to double-check my phone book findings, to make sure I didn't exclude any institutions. The librarian explained that each phone book has a map in the front, showing the county areas that are covered inside. I made a copy of the map and then grouped the health institutions by county areas.

I was happy to find out, after looking in a number of different phone books, that all the hospitals and clinics would be contained in one phone book. The librarian informed me that I should have this exact phone book at home. From the looks of the front cover, I indeed had a copy at home! I had not realized that Middlesex, Somerset, and Union counties were all contained in my home phone book, because I am new to the state.

The results of the phone book research showed Middlesex with a listing of seven hospitals, Somerset with two hospitals, and Union with four hospitals. The phone book also had a listing for 16 clinics in the tri-county area: 7 were abortion clinics, while the other 9 clinics were a mixture of diagnosis care and mental health care facilities. Out of the 16 clinics, I researched only the 5 that corresponded with the infertility issue.

I attempted to contact each health institution by telephone and requested to be referred to a fertility clinic. I thought the phone investigation would be a 1-day event, but instead it ended up being a 3-day ordeal because I had to wait for the callbacks. I took on the role of a desperate older woman who needed a fertility referral. The operator at the first hospital responded immediately in a very empathic voice, "We don't have a fertility clinic, but I believe XXX Medical Center does; here is the address and

phone number." I used this speech for the remaining health institutions. Either the operator gave me a clinic name and address, or she referred me to the hospital social worker who, after asking a host of questions, gave me a referral to a fertility clinic. The majority of the operators or social workers were very sympathetic. There were two hospital operators that I considered rude. One talked to another operator while talking to me and then got upset with me because she did not understand what I was saying, so I had to repeat my problem twice to her. The other operator started out asking about my problem; as I related my story to her she was repeating it to her co-workers and joking about it. I could only imagine the anguish that would be felt by a person really in need who was treated in such a way. However, other than these incidents, the overall phone contacts with the operators, social workers, and physicians' referral services were positive, with rewarding responses. I even received a follow-up letter from one of the hospitals regarding the referral they had given to me.

One of the hospitals was closing, and I just happened to call them on their last day. They were sending all their patients and inquiries to two other hospitals. In this particular instance an Internet listing could be updated immediately, while the phone book would not reflect those changes until the next issue came out, so a phone book would be inaccurate for a while.

Results From the Internet

My research experience with the Internet while searching for hospitals and fertility clinics was just the opposite of my experience with the phone books at the libraries. With the Internet, the investigation for hospitals and fertility clinics was less confusing and involved no stress or inconvenience. Everything was at my fingertips via the keyboard and Web links through search engines.

I started my Internet research by using search engines. The first was the bigbook.com yellow pages. After getting online, I input gts.superpages.com into the computer. The search phrase that I used was "hospitals in New Jersey," which resulted in 266 hospitals in New Jersey. By continuing to use different search engines, I received a broader scope of what was available on the Internet. For example, through the Switchboard search engine I found a relevant health service. This site had a few hospitals that are located in New Jersey that the health service uses as hospital referrals

for New Jersey residents. I called the health service, asked for a urologist, and was referred to one.

I then went to <http://www.incid.org> (The InterNational Council on Infertility Information Dissemination), which was a start in narrowing my geographical search. This Web site was very rewarding. It has a geographic directory of physicians treating infertility. I was able to zero in and obtain the names of physicians and a few clinics in the tri-county area of New Jersey: Middlesex, Union, and Somerset. This particular Web site would be beneficial to any couple doing an in-depth investigation on their fertility problem and wanting immediate answers. The [inciid.org](http://www.incid.org) site index includes roundtable chat transcripts on various fertility topics, and chat rooms. The site also has Fertility Industry News, which includes infertility treatment and technology news reports, and fact sheets, which are repositories of essays, articles, commentaries, and facts. There is also a glossary of infertility terms and acronyms, another method this site uses to educate infertile couples. Inciid's Web site is dedicated to the enlightenment of the infertile couple, even down to a humor page to make them laugh.

The next search engine I used was Yahoo! I entered "infertility" as the search word, although I was to search hospitals and fertility clinics first. I thought I would also acquire a few interesting sites for my case study on Ms. Doe at the same time. The search resulted in 460 sites. I pulled a few down for Ms. Doe that pertained to male infertility. Next, one of the Web links that appeared was <http://www.hospitallink.com>; this site contained some of the major hospitals in the wider New Jersey area.

Using a meta-search engine allowed me to try out other search engines. These search engines included MetaCrawler, where I found IVF of North Jersey: <http://www.ivfnorthjersey.com>. Also, Infoseek gave me <http://members.aol.com/fertilmd>; this site was very useful. It was called Dr. XXX's Infertility Home Page/Infertility Info Center, and contained causes of infertility and information on reproductive surgery, although not as many Web pages and links as [inciid.org](http://www.incid.org).

On the Lycos search engine, the homepage stated, "Ask Jeeves any question." Jeeves was a smiling male cartoon figure. I did not ask Jeeves anything, although I thought the computer suggestion was cute. I went straight to the search box and input "New Jersey infertility clinics." I did not receive a list of clinics per se, but instead a host of Web pages that could connect with clinics: for example, <http://www.infertilityto/clinics.html>. Also, the site included Web pages that gave information on the "Partial Birth Abortion Ban act of 1997" (<http://www.senate.gov/~rpc/release/>

1997/PARBLN.704.htm), and stories behind the story (e.g., the story, "Who are the egg donors," <http://www.wnet.org/archive/innovation/show1/html/3sb-egg.html>, about women who were selling their eggs). I changed my search to "health clinics in New Jersey" and received more Web pages—some of them were on New Jersey Health Initiative 1998 (<http://www.rwjf.org/library/njhl-98.html>), which is a grant-giving foundation. Using the Lycos search engine resulted in 17 articles, with 9 of them having Web sites. The majority of the articles were related to the issue of infertility. Some articles were unrelated, however, such as an article on doctors standing up to HMOs, "AIDS Care October 1998," and "Intelhealth—Home to Johns Hopkins Health Information: Mental Health." One relevant site was South Jersey Online—Women's Health (http://www.southjersey.com/promos/women/health/pregnancy/cfmsout_hjersey.com.html). Lycos also had many IVF counseling centers listed in New Jersey.

I chose the (Cornell) Center for Reproductive Medicine and Infertility (<http://www.ivf.org/ptcood/direct/nj.htm>), though it was not in New Jersey, to examine next in the Lycos search engine. I wanted to investigate what the Center's Web page offered couples. It was a nice Web page; the school seal added to the credibility of the page. The organization specialized in male reproductive medicine and microsurgery.

As stated before, the Lycos search engine had a number of helpful links, mainly Web page articles from the news media and Web sites. But I also noticed at the end of page 2 that there was a Web page for an IC Yellow Page Web that was unrelated to fertility clinics. This site was a business clearinghouse, stating that individuals and businesses could find financial solutions. It seemed that the Lycos search engine allowed unrelated Web site topics to appear in a specified search.

I briefly visited the AltaVista search engine, entering "New Jersey/infertility clinics": 2,495,115 web pages were available! Like Lycos, AltaVista had a mixture of other topics that were not related to my search.

The homepage for the Galaxy search engine was very impressive. The title was, "Galaxy, The Professional's Guide to a World of Information." This statement might put a thought in the Web user's head, such as, "This information must be the best if professionals use this search engine." As a novice, I believed that some professionals must use this search engine because Galaxy was well set up. I liked its sophisticated Web site layout, with the Web sites in numerical order and each one followed by an outline. I entered "male infertility" in the Galaxy search engine, and 53 documents came up, 1 of which was <http://www.fertiltext.org>. The resulting Web

pages were all focused on my topic of male fertility, unlike on Lycos and AltaVista, where unrelated topics appeared.

Discussion: Hospital Referral Research Versus Computer Research

Table 6.1 summarizes the results for each of the three counties for entities listed both in the telephone directory and on the Internet, the telephone directory only, and the Internet only.

The research on the Internet and the verbal research on the phone with the hospitals were two contrasting experiences. The Internet research was personal; I could enter into a search box anything I wanted that pertained to anyone or to myself. In other words, I could personalize my search to suit my own needs and research goals. With the Internet's research I can go beyond the boundaries of my own environment and in a short time investigate other realms of social and cultural society. I can research ad infinitum without sharing my personal needs or problems with anyone else. I felt more in control with the Internet research. It was so wonderfully overwhelming, I had almost to pull myself away. It was easy to look up and find I had been on the computer almost 5 hours a day with no breaks. Some of my time was spent reading the available material, other time going from Web site to link to Web site and from one search engine to another. Sometimes I just wanted to see how far I could go on the Internet.

The research with the hospitals via word of mouth referrals as well as the library research was personable because I received live, not necessarily face-to-face, but real-time verbal telephone contact. However, responses from this part of the investigation were not all rewarding or positive. Because of human nature, a response was occasionally inaccurate (such as the original advice from the library, leading to unnecessary trips elsewhere) or became unpleasant (as in several of the telephone calls). On the phone, people could treat me any way they desired, either rudely or courteously; they had the upper hand as information providers. So, what actually made the call easy or hard was determined by the response from the personal contact I had with the operators. For instance, if the hospital operator was positive or sympathetic, the call went smoothly. Even if the operator was impersonal, I considered it a positive call if I got the information that I wanted without a host of negative responses.

The overlap between the telephone directory referrals and the Internet resources showed that many of the hospitals that are on the Web are also in

Table 6.1 Summary of Comparative Results of Search for Infertility Resources in Three New Jersey Counties via the Telephone Directory and Hospital Referrals, and the Internet

MIDDLESEX COUNTY

Both telephone directory and Internet:

One hospital, listed on both njha.com (included "university" in name) and gte.superpages.com (listed it as a medical center). The operator said they didn't have a fertility referral but gave the phone number of the next entity (university hospital).

One university, listed on both njha.com (different phone number) and gte.superpages.com. The operator transferred the researcher to the hospital social worker, who provided a fertility clinic and was very polite.

One medical center, listed on both gte.superpages.com (with a slightly different name) and njha.com. The operator transferred the researcher to a resources specialist who was polite and very kind, and who found a convenient doctor in the area.

One medical center, listed on njha.com only (with a slightly different name). The operator was rude and asked about the researcher's problem, and at the same time joked about the call with co-workers during the phone conversation, and said simply to "call your local hospital."

One medical center, listed on njha.com only (with a different phone number). The center was actually closing permanently, and asked to have their number removed from the researcher's personal phone directory.

One center, listed only on gte.superpages.com (with the same phone but a different address). The operator was too busy to handle the call, but took the researcher's number and called back with a fertility specialist; was very professional.

And one health service, listed only on njha.com (with a slightly different name).

Telephone directory only:

Three centers and 1 "choice." The latter operator asked the reason for the call, as they were a therapy clinic. The operator explained that they were not listed that way in the telephone directory. She said they had no fertility listings, to call a gynecologist for a referral, and seemed very annoyed with the call.

Internet only:

Ten listings, 4 on inciitd.org/new-jersey, 6 on gte.superpages.com, and 1 on njha.com. There were 5 centers: 1 doctor, 1 outpatient clinic, 1 dentist (!), 1 hospital, and 1 surgical.

UNION COUNTY

Both telephone directory and Internet:

One hospital, listed on both gte.superpages.com and njha.com. The operator wondered why the researcher called, the researcher explained that they were listed as a hospital; they referred her to another hospital.

One specialized hospital, listed only on njha.com. The operator was very kind and transferred the researcher to their physicians' referral service, which provided a referral and followed up with a letter!

One medical center, listed on both gte.superpages.com and njha.com. The operator was very sympathetic and referred the researcher to a fertility clinic.

(continued)

The research over the phone was different—I was in need of information that was at others' disposal. They were in the position to say what they wished to me, and I felt I had minimal power. Although I felt the computer investigation was the least complicated and the phone book and phone referral investigation full of anxiety and confrontation, another individual might feel differently.

CONCLUSION

Several results are quite clear from this experience and analysis. First, the health resources in one's physical environment can appear radically different between the traditional telephone directory and the specialized Internet listings for the same locale. There were many more Internet listings than telephone directory listings. Further, there was considerable divergence, even among the specialized Web pages and search engines. Also, sometimes specific information (entity name, phone number, address) varied between (and sometimes within!) the different sources. It is simply not the case that the Internet reflects the same health environment (at least with respect to infertility) that the traditional telephone directory and referral process does; the Internet seems considerably more expansive. Relying solely on the Internet would not omit many providers or referrals in the local area.

As seen from the summary above (and in Table 6.1), telephone interaction is usually quite personally supportive and courteous, a kind of interaction missing from the Internet search attempts. Note, however, that several of the telephone interactions were themselves quite unsatisfying, discourteous, and unprofessional. So we must avoid overromanticizing the "personal" nature of the telephone (and, by implication, direct face-to-face interaction, such as the initial library advice, even ignoring the vastly greater time and effort required for such contacts). Some interactions with personal representatives of health entities may be less satisfying and less emotionally supporting than using the Internet.

Finally, as with the case study of the woman seeking infertility information, the experience of searching the Internet can be daunting, requiring considerable experience and persistence, and accumulated tacit knowledge. Yet it can also be personally rewarding, opening up new vistas of awareness and providing access to a wide, never fully knowable, range of health resources.

Continued

One hospital, listed on both gte.superpages.com and njha.com. The operator wanted details about the fertility condition and gave a referral while talking with other operators in the background.

Telephone directory only:

One medical group; no phone contact made.

Internet only:

Twelve entities: 4 hospitals, 3 medical centers, 1 specialized hospital, 1 health system, 1 development center, 1 institution for rehabilitation, and 1 dialysis center (†).

Two hospitals were listed on both gte.superpages.com and njha.com, and one of these had different phone numbers and no street number on the two sites.

One specialized hospital was listed twice on gte.superpages.com, with different street spellings.

SOMERSET COUNTY

Both telephone directory and Internet:

One medical center, listed only on njha.com. The operator referred the researcher to a hospital social worker who asked a host of questions and then provided a referral.

Telephone directory only:

No entities.

Internet only:

Six entities: 1 center was listed on two sites (ihr.com/infertility and ivfni.com). Four (2 medical centers, foundation, hospital) were listed only on njha.com. One fertility clinic was listed only on incitd.org/new-jersey.

the phone book, though the Internet had more hospital and clinic options available to an individual than did the phone book. The overlap in the resulting "health environments" varied widely, even across the three counties. How current or reliable that information was also was an important issue to consider.

When I tried to assess both research situations (the telephone and the Internet), I saw myself retaining a certain amount of personal and cognitive power on the computer. Although I consider myself a novice, I saw myself confidently driving around the information superhighway and aggressively investigating new sites and search engines. I felt powerful with what little I knew, and unthreatened: No one was there but me and my friend the computer to interact with as I progressed online. I felt more comfortable giving out personal information via computer than having impersonal contact over the phone.