Online Data Collection in Women's Health Research: A Study of Perimenopausal Women with Migraines

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Abstract

An estimated 17 to 18 percent of all women, and six percent of men, experience migraines. Hormonal shifts may cause migraines to recur, worsen, or even begin during the perimenopause and are a significant cause of discomfort and disability. However, very little research has explored the experience of migraines in this population. The purpose of this study was to describe the experiences of perimenopausal women with migraines, via online questionnaires and discussion boards, and to evaluate the feasibility of collecting women's health data via the Internet. In an earlier study, we found that midlife women had difficulty attending focus groups due to other time commitments. This study was designed to increase accessibility to the research via the Internet. Of the 43 women recruited into the study, 21 were also interviewed in "real-time" qualitative interviews; all received passwords to complete online questionnaires and participate in three- to four-week discussion boards on the study Web site. Quantitative data were imported into SPSS; narrative qualitative data from discussion boards were transferred to a software package for analysis. Online questionnaires and discussion boards were found to be feasible methods for data collection for this population. Qualitative data analysis revealed themes related to women's efforts to predict and control their headaches, the relationship of headaches to women's menses and menopausal symptoms, and the effects of migraines on their lives. In this paper we describe the process of using the Internet, feminist issues related to this innovative methodology, and also discuss the results of a major study theme, the experience of headaches in relationship to the menstrual cycle.

Keywords

migraine headaches; qualitative research; women's health

Background

According to epidemiological studies (Lipton et al. 2001; Stewart, Shechter, and Rasmussen 1994), the prevalence of migraine headaches is approximately six percent among men and 18 percent among women. However, it is estimated that less than half of all migraines are correctly diagnosed, either because headache sufferers do not seek care for their headaches, or because their headaches are not diagnosed as migraines by health care providers (Lipton et al. 1992; Dowson and Jagger 1999; Stang, Osterhaus, and Celentano 1994). The higher incidence of migraines in women is thought to be due in part to the influence of hormonal fluctuations that occur with menarche, menstruation, and menopause. Although clinicians have noted that migraines occur in relationship to the perimenopause and menopause, a thorough examination of this phenomenon has not been undertaken (Raskin 1998). This phenomenon was the focus of the study described in this paper, as well as that of a previous pilot study, in which we found that midlife women had decreased access to traditional focus groups because of their multiple family and job commitments.

Because of this problem, we had difficulty recruiting perimenopausal women into focus groups, although they were eager to participate on a one-to-one basis in qualitative interviews in their homes or offices. Therefore, one of the objectives of the current study was to evaluate the feasibility of using the Internet to conduct virtual focus groups with this population. The concept of using an Internet-based focus group has become attractive to researchers, as use of the Internet has grown, and as people's lives have become more complicated. Because recruitment problems for traditional focus groups will probably grow, given the increasingly common problem of scheduling group meetings with busy people, the use of online research "focus groups" has the potential to be an important tool used to combat this problem (Morgan 2000). In addition, because of the number of computer applications that now allow group chatting and message boards, researchers (Lakeman 1997; Klemm and Nolan 1998; Smith and Leigh 1997) are concluding that creating a "virtual" focus group is a feasible undertaking.

Study Purposes

The purposes of this study were to examine the experiences of perimenopausal women with migraine headaches, and to explore the feasibility and effectiveness of collecting this data via the Internet. The study used a quantitative health history tool (HHQ), a migraine-specific quality of life instrument (MSQOL) (Wagner et al. 1996), and an MOS 36-Item Short-Form Health Survey (SF-36) (McHorney, Ware, and Raczek 1993; Ware, Kosinski, and Keller 1994), all of which were completed online; and online discussion boards that functioned qualitatively as "virtual focus groups." In addition, actual qualitative interviews were conducted with a subset of the sample, to ensure that adequate data were obtained to meet the primary study purpose. The primary purpose of this paper is to describe our experiences with using the Internet as a data collection method, describing the study design and process, and reflecting on logistical, technical, and feminist issues related to this innovative method. Use of the Internet for data collection has the potential to increase the opportunities for participation by less accessible women, thereby giving 'voice' to women who have until now not been heard in research studies.

To provide an example of the data collected using this innovative method, we also describe a major qualitative theme of the study, women's reflections about their headaches in relationship to changing menstrual cycles and perimenopausal symptoms. Other findings with respect to perimenopausal women's experience of migraines are in preparation for later publication.

Sample

Forty-three women met criteria for migraine headaches and perimenopause, and were willing to participate in the study using the Internet. Recruitment was accomplished through local flyers, word-of-mouth, and response to Internet inquiries. To facilitate Internet recruitment, links were placed from the study Web site to university search engines, and later to an Internet menopause Web site. Most participants volunteered for the study by e-mail or phone; several volunteered by downloading a sample consent form from the study Web site, completing it, and mailing it to the principal investigator (PI).

Of the 43 participants, 37 were Caucasian, five were African American, and one identified herself as English Indian. All participants were between the ages of 40 and 55. Twenty-seven participants were from the Atlanta area; 16 were from other Georgia locations or from one of 11 other states. Educational levels ranged from completion of high school through graduate school.

Study Design

The study used mixed methodology, which included the three quantitative questionnaires that were completed online, and online discussion boards that collected narrative qualitative data. In addition, 21 actual qualitative interviews were conducted, in person or by phone, before the participants began the online data collection process.

A mixture of technologies was used. The discussion boards were built using an application called WWWBoard, a fairly common software package. This software was chosen because it is used by the Information Services (IS) department for all of its online discussion boards; the IS consultants, therefore, had experience administering and configuring the application. WWWBoard is also "freeware," meaning it is distributed on the Internet free of charge for anyone who would like to use it, and "open source," meaning the product can be modified by a programmer without penalty.

The online questionnaires were written using Cold Fusion, a software package that allows creation of Web-based front-end to back-end databases. The data that are entered via the Web are automatically stored in a database, which in this case was a Microsoft SQL database. This is extremely important for later data analysis because having the data in a standard, structured database format makes it very easy to run reports and extract data for analysis in statistical programs.

The qualitative interviews, when conducted with individual participants, followed screening and completion of informed consent. Participants were then given individualized passwords and login names to access the online questionnaire portion of the study. At this time they were also given an orientation packet that included detailed instructions about accessing and completing the questionnaires, accessing the Internet, and suggestions about "netiquette," which increased participants' repertoire of communication nuances for discussion boards. When four to eight participants had completed the questionnaires, a new discussion board was created and placed on the Web site. New login names and passwords unique to that group were then given to those participants. Each participant was also asked to choose a pseudonym for the discussion board and was given instructions to access and use the board.

The discussion boards were accessible at any time during the life of the board, and participants were asked to access the board at least once a week. Several open-ended threads were initially placed on the board by the PI, who functioned as the moderator, to start the discussion, and included such postings as "Please begin by telling us something about yourself, your history of headaches, the things you have tried for your headaches, and anything else you think is important." The PI posted other new threads over time, depending on the discussion. Sometimes a comment in a posting was drawn out and used as the beginning of a new thread, and sometimes a new thread was begun on a topic that hadn't been addressed by the group but was part of the PI's agenda. For example, one participant mentioned her husband's reactions to her headaches. The PI picked up this comment and began a new thread by asking about other participants' relationships. Also, participants frequently posted their own threaded questions to the group. It was initially planned that each board would be left up for three weeks; however, several of the boards were continued for up to five weeks because of slow participation and/ or interference by major holidays. A total of eight discussion boards were conducted, over a 15-month period.

At the end of each discussion group, individual short open-ended follow-up interviews were conducted to evaluate the experience of being in the study (including questions regarding study access problems, identification of group interaction issues, and any other feedback important to the participant). These evaluations were completed by phone or e-mail. Participants were then paid a small incentive fee.

Data Analysis

Quantitative questionnaire data were imported into SPSS for analysis. Data from the HHQ were analyzed using frequency distributions (and measures of central tendency such as means). Likert-scale data from the SF-36, and from the MSQOL data, were analyzed using the scoring techniques appropriate to each instrument, to create a quality of life score for each participant.

Narrative data from open-ended qualitative questions on the HHQ, from the qualitative interviews, and from the online discussion boards were transferred into a text management software package for qualitative analysis, Atlas.ti (Muhr 1997). An interpretive approach was used to analyze the qualitative data, looking first at each overall transcript, and then examining the data line by line for emerging themes and larger patterns.

In addition, the research team analyzed the ways in which the quantitative and the qualitative data confirmed and clarified each other. The use of mixed methodology in this study, quantitative instruments with qualitative interviews, provides a detailed picture of the experience of migraine headaches in this population that will provide a foundation for the development of interventions to prevent or alleviate migraines.

Results

Feasibility of Using the Internet for Data Collection

Evaluation of the feasibility of using the Internet as a data collection tool, as an innovative method that would extend access to women whose busy lives precluded focus group participation, was accomplished in several different ways. We evaluated the timeliness and completeness of the online questionnaires; evaluated the process of the online discussion groups both in terms of participants' feedback and our own perceptions of the experience; and evaluated the quality of the data obtained. In this section, we will discuss the questionnaire completion and the use of the online discussion boards. As an example of the data actually collected using this method, we then provide qualitative data about women's migraines and menstrual cycles from the individual interviews and the discussion boards.

Completion of the Online Questionnaires—Participants completed the three online questionnaires described above. The HHQ, a relatively straightforward questionnaire that included history of other illnesses and medication use, contained a series of questions with forced choices, open-ended questions, and some questions that required making lists. This descriptive questionnaire was used without difficulty in a previous study as a paper-and-pencil version (Moloney and Melby 2001). All the questionnaires underwent Internet testing before the actual data collection began. Undergraduate students piloted the Web site, which included completion of the questionnaires. The students then provided feedback about their experiences completing the questionnaires over the Internet. The practice sessions revealed that the format developed for entering medications over the Internet was somewhat confusing, and this was revised. The SF-36 and MSQOL both consisted of simple Likert-type scales, and because the IS consultants formatted them in a way that resembled the paper-and-pencil versions, they were relatively easy to complete.

While most participants completed the questionnaires without difficulty, some required assistance. A problem that arose in actual data collection was that participants who had older Web browsers were sometimes unable to advance through the questionnaire from page to page. The format was then revised to accommodate this problem, and a note was placed on the questionnaire site that recommended the use of newer browsers. Although some participants experienced difficulties in completing the questionnaires (several participants required multiple phone calls from the researchers to identify and resolve problems), everyone

eventually succeeded in completing the questionnaires. Even the participants who had difficulties were quite patient; several commented in their evaluations that they understood that this was a new, untried research process, and that they were providing valuable input. Participants frequently expressed satisfaction at being in the study, indicating that they had found it interesting and educational to learn about how other women managed their headaches. One participant noted that it was "like talking to kindred spirits—comforting, though it's a sickness support group."

Online Discussion Boards—The discussion board format used in this study consisted of an ongoing site where participants could log on at any time, read others' postings, and post their own thoughts. New "threads" were posted by the PI as starting points for conversation; participants responded to these when and if they wished and were also free to start their own discussion threads. The narrative that accumulated was saved on the actual board until the board was dismantled, so that participants could scroll up and down to see what had been written over the life of the board. This format is different from another type of Internet discussion modality, chat rooms. The term "chat room" usually refers to a discussion site functioning in real time, where the site is available at a specific time and several participants may be chatting back and forth together; Internet Relay Chat (IRC, or "instant messenger") is a type of chat room. Chat room data are not usually saved over time, although they can be archived using special software. Most of the discussion boards in our study were made up of women from diverse geographical locations, who were then able to participate at different times of the day and night. In their evaluations, the women noted that they appreciated the ability to enter the board at convenient times—some read and posted entries during work hours, some worked at night at home, and several reported staying late at work to work on the board.

Most of the participants were already computer-savvy, although some had never completed online questionnaires, and most had not participated in an online discussion group. For the most part, these individuals had very little difficulty completing data entry, even though they often needed to be reminded to do so. Several needed more assistance and phone or e-mail support, and one participant did not have personal computer access to the Internet. An undergraduate nursing student working on the study was assigned to work with this participant, meeting her at the public library and assisting her to complete the questionnaires and the discussion board entries.

Although it was convenient to use a discussion board that was available at all times, it also presented some problems. For the PI, it was essential to check the board for new entries at least once a day, in order to respond immediately to new postings, especially if participation from other group members was slow. This was time-intensive and required distant access on some occasions. In addition, many participants had hectic schedules and tended to forget to post their comments to the discussion board, requiring regular reminders from the researchers.

Issues related to lack of face-to-face communication somewhat offset the convenience of flexible participation. Participants sometimes carried on individual conversations, not responding to questions or probes from the PI. Some individuals enjoyed reading the other postings but posted few comments themselves. It was more difficult for the PI to involve these individuals than it would have been in an actual face-to-face focus group setting.

Another issue affecting participation was related to Internet access. Several times there were computer or Internet problems on the participant's end, or the university's end, or somewhere in the network between the two, and the board could not be accessed. One participant was unable to access her discussion board for over a week when the power was out in her area with an ice storm and her computer was damaged. At another time, a "scripting error" in the application caused the discussion board data to disappear.

A final advantage (or disadvantage, depending on the participant's viewpoint) was that participants used pseudonyms on the board, allowing them to voice their thoughts anonymously. The online interface permitted women who might be more reserved in a live group to be more forthcoming, and some participants appreciated this anonymity. As one woman posted, "It felt funny at first discussing these 'private matters' with strangers—but after being in the group for a while I have felt a comradery [*sic*]." Others, however, stated that they missed having the personal contact with other women in what they often reported felt much like a support group.

Migraines and Menstrual Cycles in the Perimenopause—Participants met specific criteria for migraines, which were based on the Criteria for Migraine Headaches With or Without Aura (Headache Classification Committee of the International Headache Society 1988). To be eligible, participants must have experienced at least one migraine within the past month; however, most participants experienced at least two or three headaches per month, and some had headaches much more frequently. In addition, participants met criteria for perimenopause. The term "perimenopause," which generally refers to the time around the end of the reproductive years and the onset of menopause, has not been consistently defined in research. In this study, "perimenopause" was defined by age and by menstrual cycle changes. The criteria for being perimenopausal included: (1) Between the ages of 40 and 55; (2) Occurrence of a menstrual period within the preceding three months; and (3) History of at least one of the following: hot flashes, night sweats, or irregular menses. Women whose headaches did not meet the migraine criteria were excluded, as were women who had not had a menstrual period in at least three months, women who had had hysterectomies, and women who were not fluent in English. Although most prospective participants were aware that their headaches were migraines, several were uncertain about their diagnosis and seemed relieved to receive a definite diagnosis when entering the study.

The women all reflected upon their changing status as perimenopausal women, describing the ways in which their headaches had changed over the years and months, and sharing their thoughts about aging and their body changes. Most of the women monitored their headaches and menses carefully, and readily described the various headache patterns that they noticed. Several different lifetime headache patterns emerged from the stories: women who had had migraines in their adolescent years (for a few beginning earlier) which improved during their 20s and/or 30s, and then recurred or worsened as they approached the perimenopause (usually the early 40s); women who had headaches consistently all their lives but had noticed that their headaches increased in severity and/or frequency (or at least did not improve) during the perimenopause; and women whose first remarkable headache occurred during the perimenopause. They also noticed their periods changing and often related a changing pattern of headaches to this shifting menstrual pattern. One woman, who had begun having migraines when she was 10 years old, posted this description of her migraines:

> As I grew older I remember having headaches on a monthly basis... sometimes pre-menstrually and sometimes at the end of my period. The pre-menstrual headaches seemed related to retention of water. I felt as if I was swollen all over... including my brain. To this day I get headaches before and after my period. As I grow older the headaches that occur after my period are the ones that are most intense and migrainous. About three years ago I started have [*sic*] visual changes with my headaches which had not happened before. (Participant, discussion board 7)

Another noted in an interview that "closer to menopause I think the severity and the lasting of the headache is much... much longer... for the first time on my last period I had a five-day headache... I've never had that before" (Interview 010219). This woman went on to note that prior to a year ago, she could not usually predict headache onset, but now she almost always has headaches with her menses. In addition to noting that their headaches seemed to be

increasing in frequency and severity, a number of women mentioned that these menstrual headaches seemed to be more difficult to treat effectively.

The women were asked specifically about whether they experienced other perimenopausal symptoms, such as hot flashes. A few described marked hot flashes, insomnia and irritability. However, there seemed to be a consensus that the migraines were a bigger problem than the other symptoms, and most of the participants, when questioned, had not noticed a relationship between their headaches and the occurrence of hot flashes, only between their headaches and changing menses. Several participants also noted that they were experiencing more life stress than previously, and that this seemed to be another factor in their headaches. As one participant put it: "Certainly all three elements: menstrual cycles, stress levels, and migraine length and intensity have all changed around the same time of my late 30s" (Participant, discussion board 3). Another woman posted:

> As far as the perimenopausal thing—I can't say that it's made a difference in my migraines. Over the years, I've gone from a 5- to 8-day menses to a 2- to 3-day menses. In addition, I used to spot a few days before and after. Now, it's wham, bam, we're done. My first day may be heavier than in the past. I can still depend upon (98% of the time) a migraine somewhere within the 5 days before to the first day of, and although it's more severe than it used to be, all of my other migraines are, too, but I can blame that on stress. (Participant, discussion board 1)

This woman's story also serves to illustrate the careful attention that women paid to their headache and menstrual patterns, and their efforts to discern the causes of their headaches. The question of estrogen use, whether in menopause "replacement" form, or as an oral contraceptive, arose spontaneously throughout the discussions, related in part to the fact that the controversial 2002 report of the Women's Health Initiative (Rossouw et al. 2002) was published while the first discussion board was underway. One participant posted a new discussion thread, entitled "HRT! Is it worth it?" which generated a long discussion about the pros and cons of using estrogen. Several women noted that their headaches seemed to be much better since they started taking estrogen, and one participant said, "It's so obvious to me now that when I'm not taking supplemental estrogen, my headaches are very, very severe... and that's frightening to think about having to go off them because how often now would I have headaches if I weren't taking the estrogen... if they are so related to my estrogen" (Interview 010210). A number of the women were using oral contraceptives (OCs), both for contraception and to help control their headaches; several had begun OCs for contraception and then noticed that their headaches were better. One woman began OCs so that she would not menstruate while on a cruise, and two months later noticed that her headaches were improved. And another participant posted: "The birth control pill has helped my headaches and my perimenopausal symptoms—but I do get estrogen withdrawal migraine" (Participant, discussion board 2).

Finally, the women reflected on the aging process and about being menopausal. Some remembered that their mothers were better after menopause, or had been told that their headaches would probably improve then. One woman said that "somebody told me when I turned 40 they were going to get better, but I don't see any difference" (Interview 010208), and another woman remarked:

> As I mentioned, my mom said she used to get them when she was my age and then after she got through menopause they quit, but I wish they would find the remedy... you know, sometimes the pills work, sometimes they don't... more often than not they don't. (Interview 010211)

Several women described their fears about aging; two participants expressed their regrets at not having had children. One of these women, who had begun to have night sweats, was at first considering whether she might have tuberculosis, and said, "I thought... maybe... no, I can't

be in menopause... because it's... like an assault on my womanhood... what do you mean I'm in menopause?"(Interview 010210). This participant, who was 42 at the time of the interview, went on to say, laughing, "I'm just a child... this isn't happening to me... I'm still a child... I'm just growing up." Others, however, described their feelings about the perimenopausal experience quite differently. One woman, in describing her increasingly heavy menses, noted that she had "always loved menstruating" and felt more "womanly" with her heavier periods (Interview 010202). Finally, in response to a researcher-initiated question about menopause and hormone therapy, this woman posted the following affirmation of her menopausal transition:

> Menopause symptoms that I have, and I understand the list of related symptoms reaching over 100, are typical. I have hot flashes, headaches, changes in appetite, bloating, dysphoria, irregular heart rhythm, temperament changes, taste changes, less enthusiasm, and insomnia. I have a sense of pride in knowing that these symptoms exist and pushing forward with maintaining exercise regimen, plenty of water, less sugar, more fiber, relaxation. I am hopeful that the emerging generation of female scientists study this issue and advance the treatment regimens. I have witnessed and heard of too many hit and miss type treatments for desperate women. So, my thoughts re: hormone therapy are reserved. How this affects my headaches is that I feel I have reduced the severity of my headaches by following the basic pyramid of good food, good friends, exercise, sleep, etc. (Participant, discussion board 6)

Discussion and Implications

Use of the Internet proved to be a feasible approach for data collection in this sample of perimenopausal women, and data collected were rich and appropriate. Although the learning curve for the research team was steep, the team now has a foundation for future work. For the most part, the participants expressed the view that the study had been very worthwhile, both in terms of their often-expressed goal of contributing to knowledge that would help others, and in gaining knowledge for themselves. Indeed, following the completion of the various discussion boards, a number of participants expressed a sense of loss for the ending of the group interaction in which they had participated. In discussing the study outcomes, we have considered the project in terms of use of the Internet as a data collection method, and in terms of the actual data collected. In the next section, we first discuss selected issues regarding Internet use, and then present a short discussion of the women's menstrual/migraine experience.

Using the Internet to Collect Data

Advantages of using the Internet: A number of advantages accrued from this approach, both for the research team and for the participants. For the researchers, a primary advantage was that questionnaires and forms could be set up on the Internet so that data could be downloaded directly into data management programs. The model described earlier, with a Web front-end to a database back-end, was the best way to achieve this goal. For development of the data collection protocol, we found it essential that we have an IS specialist who had experience with setting up Web sites for data collection that could be easily entered, downloaded, and kept secure and confidential. Because the nurse researchers were not experienced in computer information services, an interdisciplinary team was necessary. Although the development of this working relationship involved the "growing pains" of researchers and computer consultants working together across disciplines and across schools, the joint venture has proven advantageous to both groups. The time saved in data entry, the access to a national (and conceivably international) study population, and the flexibility of doing discussion group postings at odd hours were definite advantages. In addition to the time- and cost-saving ability to move data directly into data management programs, it should be noted that the qualitative

discussion board data were also moved directly, avoiding the time and expense of hiring a transcriptionist. At the completion of each discussion board, data were entered into a word-processing package for analysis, and thus became immediately available for review and analysis.

For the participants, an advantage of Internet data collection was that they could return to the Web site and complete questionnaires at their leisure when they became fatigued. For this, a mechanism to remind participants to return to the Web site to complete questionnaires was required so that the amount of missing data would not increase. In addition, as noted above, participants could access the discussion board whenever they had free time, thus avoiding the time and expense of scheduling meetings.

Feminist issues: A number of feminist issues arose in the course of doing Internet research, and we will address a few in this section, some of which are analogous to those encountered in conventional research. The first concerns the relationship between the researcher and the research participant. For the feminist qualitative researcher, engagement is crucial to collecting rich data and is a significant part of the feminist commitment (Oakley 1990). The Internet, which puts distance between the researcher and the researched, diminishes likelihood of engagement. Indeed, a number of the participants in our study remarked that they would have liked to be more closely engaged with the researcher as well as with the other participants. We noted that sometimes when we posted new threads that apparently were uninteresting, participants didn't respond at all to them; in a real focus group, eye contact and direct engagement with the participants would enhance the likelihood of collecting these data. On the other hand, we established relationships with participants when we did the screenings, and stayed in contact with our participants by phone or e-mail at intervals throughout the study. Because many of the participants were interested not only in providing research data, but also in learning more about their headaches, they often asked the researchers and the other participants numerous questions throughout the process. Our response to this was to commit to answering questions at the study's conclusion, and to provide educational information at that time when appropriate.

A second feminist issue is access. Use of the Internet is rapidly increasing across all sectors of the population, and in the most recent study conducted by the Georgia Institute of Technology there were an estimated 36-million Americans on the Internet (Graphic, Visualization, and Usability Center 1998). Although 38.4 percent of these Internet users were women, the majority were younger women; the fastest growing group of female Internet users was college-aged women. Race and age also influence Internet usage: in this study, 87 percent of users were white, while African American users accounted for only 1.9 percent, Hispanics for 1.3 percent, and Asian Americans for 2.9 percent; with regard to age, the vast majority of Internet users were between 21 and 45 years of age, with the numbers dropping sharply with age. Although Internet usage is increasing quickly, age, race, and gender are still barriers to access. However, in spite of the barriers to having access to the Internet, which are usually thought of as being primarily socioeconomic, this innovative technology also improves access for some women.

In our study, most of the participants were white. Several African American participants were recruited individually by the researchers, and several responded to flyers. Still, these participants were computer-literate and worked in environments where they had computer access. Originally, we planned to recruit workers in housekeeping and cafeteria management environments but were unable to entice participants from these groups; we hypothesize that this was at least partly related to the need for computer access. As noted above, one African American participant volunteered after seeing a flyer in a clinic setting; although she did not have ready computer access, she had some experience with computer usage in the past and was able to use a public library to participate in the study. Use of the public library system is largely

untapped for research purposes and could represent a viable way to increase access to research studies. Such innovative approaches are essential to provide access to research studies for those women who lack race and class privilege. Additionally, researchers working with female populations should consider using a variety of approaches to collect data (e.g., Internet instruments and discussion boards, actual focus groups, paper-and-pencil instruments, and individual real-time interviews) so as to maximize data collection with diverse populations.

Another feminist question related to using the Internet addresses the concept of voice. In our study, it seemed that some women were reluctant to assert themselves by posting to the Internet. It may be more intimidating to express one's thoughts in writing on an Internet board than it would be in an actual group (which is reminiscent of other women's groups, and thus more comfortable). As noted earlier, in this study, there were a number of women who liked to read postings but were reluctant to post their own responses. These women might have participated more readily in a real setting, although it is possible that for some other participants, the anonymity may be liberating (Im and Chee 2001). Also, the women were asked to tell a story about their migraine experience. Even on an Internet board the telling of stories may help some women find a voice, as researchers have noted about other qualitative research (Moloney 1995; Olesen 1994).

Technical issues: A number of technical issues surfaced during the completion of the discussion boards. Some problems were episodic and easily remedied, such as problems with data transfer, and the discussion board's level of "user-friendliness," while other larger issues remained concerns throughout the study.

The discussion board, as it was originally created, was based on a technology already available in the IS department. There are many advantages to using pre-packaged software like the one used in this study. Most notably, the software does not need to be written from scratch, saving time and development costs. However, as with any noncustomized product, the researcher is then dependent upon the features that are built into the product. This can limit the options available for users. The board was functional, but somewhat difficult to follow, requiring the user to move about the screen to complete a posting; the placement of postings, names, and dates was also somewhat confusing for a novice user. Before the first discussion board was loaded onto the Web site, a demonstration board was created and piloted with a small group of undergraduate nursing students. The students, who were experienced with using various Internet discussion boards and chat rooms, provided feedback that enabled revisions making the board easier to use. That is why it is also important to use a product that is open source so changes can be made if necessary. However, too many customizations can be time consuming. So, the researchers needed to balance the desire for customizations with the risk of negating the benefits of pre-packaged software.

A minor source of confusion was related to login names and passwords. Each participant had an individual login name and password to access the questionnaires. However, for each discussion board, the participants for that group were given a new login name and password to enable them to log in only to that particular discussion board. The double set of login names and passwords created confusion, with some participants trying to use their questionnaire login names and passwords and having to call for help.

Another logistical issue related to the use of multiple modes of communication. Although the research was Internet-based, getting into the study required a pencil and paper. The consent form, while online, had to be downloaded, printed, and mailed, or else the researchers mailed a consent form to the prospective participant for completion and mailing. The screening was done by phone, as was the post-study evaluation, and the tape-recorded qualitative interviews were done either in person or by phone. This meant that instead of being able to complete the

entire project online, several different modes of communication were needed. This was cumbersome, increased the time spent completing study paperwork, and was clearly a different level of technology from the on-line work.

Validity and reliability: Several important issues regarding reliability and validity should be considered. First, not all instruments are appropriate for Internet use. When selecting instruments for Internet data collection, it is best to start by selecting those that have prior evidence that they have metric properties of high quality. A concern that the investigator must consider is whether the Internet is a good forum for collecting the data for each measure and if this approach is likely to influence the quality of the data obtained. A reality of measurement that should not be forgotten is that instruments that have been reliable and valid in one situation may not function well under other circumstances. In most cases, questionnaires that have been shown to be reliable and valid for self-report using paper and pencil methods are also likely to be reliable and valid for completion over the Internet. However, one should not assume this is the case. Ideally, the reliability and validity of questionnaires administered over the Internet should be assessed prior to using them in a major Internet study. At the very least, the reliability of questionnaires with formats amenable to internal consistency reliability assessment needs to be calculated once data have been collected. Lack of internal consistency would be an indication that the data are either not reliable or lack insufficient variability. Questionnaires that are not reliable are also not valid.

Questionnaires and forms that have complicated or confusing formats may present special problems for the Webmaster to place on an Internet site and are also more likely to be difficult for participants to complete accurately. Reliable and valid quantitative data collection over the Internet requires that participants have the ability to navigate the Internet to the extent that they can access the Web site. In addition, they need to have the ability to read and enter data at a level appropriate for the reading and comprehension levels of questionnaires placed on the Web site.

Other issues that may affect the validity of Internet data are data fraud, data generalizability, and self-selection bias (Smith and Leigh 1997). It is possible that in some studies, individuals who complete questionnaires over the Internet could complete them multiple times. To deal with this situation, software can be set up to identify the domain address so that multiple sets of responses from the same Web address can be identified. For this study, each questionnaire, when completed, could not be repeated by that participant because identifying information was entered by the researchers that informed them when the data collection was completed, and participants were then prohibited from duplicate completions. No one was admitted into the questionnaire site on the Internet without receiving her individualized login name and password.

Other issues, regarding data generalizability and selection bias, are related. It is likely that those who participate in an Internet-based study are different from the general population because those who cannot afford a computer are less likely to participate. The extent to which members of the target population for a study have computer access could result in selection bias by making the sample more affluent than the population of interest. In this study, many of those recruited had found the study on the Internet, meaning that they already had computer expertise. Other participants were recruited from flyers and word of mouth in the local community. Several of these participants had little computer experience but with support were able to access the Web site and complete the instruments. As noted above, one participant had very little computer expertise and did not have direct access to a computer. An undergraduate assistant met with this participant in a local public library, helped her create a free e-mail account, and assisted her in logging on to the Internet to complete the questionnaires and the discussion board. Therefore, public libraries with Internet access are a viable option for including

participants who cannot afford a computer in an Internet-based study, thereby reducing selection bias. However, it should be noted that this process required a major commitment of time and energy by both the participant and the researchers.

Several other issues, related to reliability and validity, are also important to consider when collecting qualitative data over the Internet. First, it is imperative that the process adheres to the philosophy of the approach used. Prior to selecting the Internet as a means for data collection, the researcher should consider whether Internet data collection allows the research process to remain true to the philosophy of the qualitative approach desired. It is possible with some approaches that all the data required for the study could be collected over the Internet. This may be the case with many phenomenological studies, which focus on the meaning of one's lived experience (Morse and Field 1995); interviews with some individual participants who are able to articulate their thoughts in writing may be appropriate in some studies. Qualitative focus groups may also be appropriate. Other approaches may only be amenable to having part of the required data collected over the Internet. For example, part of the data collected for a grounded theory approach could be obtained via the Internet because this approach focuses on theory development, often using a combination of techniques such as interview, observation, and record review. On the other hand, the ethnographic approach may not be highly amenable to use of the Internet for data collection because it focuses on studying behaviors from within the culture.

In addition, in qualitative data collection the researcher plays a crucial role, and the successful use of the Internet for data collection will depend on how well the researcher can use interview skills within the context of Internet facilities available. In qualitative data collection the researcher is the instrument (Burns and Grove 2001), so the researcher's expertise is important. It takes a highly adept researcher to collect qualitative data of high quality because it is necessary to ask the right questions, clarify responses given, probe when responses need further exploration, and observe the participant's behaviors within the context of the data collection session. The Internet may place certain restrictions on these necessary skills, particularly if computer facilities do not allow their full application.

The qualitative researcher who prepares for data collection over the Internet will not only need to know what information will be sought, but will need to understand the special opportunities and limitations afforded by Internet data collection. Therefore, the researcher is required to have adequate knowledge of the computer technology that is available for the study and will need to determine which approach to Internet data collection will be best. As discussed earlier, real time data collection with simultaneous written responses by the participant ("instant messenger") can be used, or a set of interview questions can be placed on an Internet site that will be responded to at a later time by participants (discussion board). No matter which strategy is chosen, the researcher's skill in developing questions for data collection that are salient to the study's focus and data needs are of utmost importance. Therefore, preparation of clear and understandable questions that are central to the topic is a crucial step in Internet data collection as it is in any qualitative data collection process. However, when the researcher develops questions for participants to respond to at their convenience, this point is particularly important.

In today's highly technological society, it is possible to collect qualitative data over the Internet in real time, or synchronous communication, with the participant providing responses verbally and in writing. On the other hand, the investigator may prefer to prepare open-ended questions to which the participant would provide answers over the Internet in written form at a later convenient time or through asynchronous communication. Each of these approaches has advantages and limitations.

When data are collected over the Internet in real time, open-ended questions can be submitted to the Web site in advance or at the time that the computer interaction occurs. In either case the interviewer and participant will need to schedule a time for the participant to respond in real time so that both the researcher and the participant are available simultaneously. As the participant types in the responses to the questions, the responses appear on the interviewer's screen instantly. The advantage of this approach is that the interviewer can clarify confusing written comments or probe comments that require further explication at the time the participant supplies them. This can increase the quality of data, and the interviewer has more control over the data collected, such as keeping the participant engaged and on the topic, thus enhancing the possibility that answers are provided to probes or clarifying questions.

When Internet data collection is not conducted in real time, the researcher must review the participant's comments after they have been entered at the Web site. The researcher will be required to check the Web site frequently so that clarifying questions and additional probes can be provided in response to the participant's answers to the original set of open-ended questions. Hence, probes and clarifying questions are submitted at a later time. In this circumstance, it is easy for the participant not to respond at all or to provide partial answers to the information requested; both of these situations occurred in the course of this study's discussion boards. It is also easier for participants to wander off the topic rather than providing information relevant to the study. Therefore, the researcher has less control over the data collection process.

Internet data collection of qualitative data has an advantage over telephone interviews in that it costs less to connect to the Internet than making contact via telephone, particularly when participants are from other states or geographic regions. Clearly, an advantage of Internet data collection is that it can afford an investigator access to participants who would not have been available for recruitment locally since participants can be recruited nationally or internationally, if appropriate, with little additional costs. However, when participants are recruited over the Internet, demographic and screening data must be carefully obtained to ensure that participants are part of the desired target population. In addition, the investigator needs to consider whether geographic location and culture could be important factors in the nature of the experience communicated by the participant. If so, the geographic region for recruitment would need to be restricted or the investigator should be careful that interpretations of the data reflect regional or cultural concerns and issues.

Security: Security is an important consideration for any researcher using the Internet, as it is with other Web users. There are two important facets to this security: keeping out those who don't belong in the study, and keeping individual participants' identities and personal data confidential. As noted above, personal contact with participants probably helps to decrease the likelihood of someone attempting to access the study when they do not qualify for it. Specific potential security issues include the possibility of participants using public computers (such as in a library) and leaving their browser windows open when they are finished, thus leaving the discussion board open to others who follow; the possibility of participants sharing their passwords with others not admitted to the study; and the possibility of participants printing out or saving the discussion board postings. Using a separate login name and password for each discussion board probably helped prevent some problems, and having small groups (four to eight participants) meant that the researcher knew who each participant was. Highlighted reminders on the discussion board encouraged users to close the board when finished with that session. While not foolproof, these measures diminish the likelihood of acquiring falsified data, or of other sabotage occurring. Encryption of e-mail is also a measure that would enhance security and confidentiality, along with server firewalls and other security.

Specific recommendations for those who are interested in creating an online discussion board include:

- Providing encouragement and monitoring of participant involvement in the discussion boards to enhance continued involvement in the discussion process over the time of the board; this continued involvement with participants was found to be crucial to data collection.

- Contracting with participants for number of postings (we informally asked participants to post at least once a week), and providing incentives for completion of discussion board process.

- Simplifying format and procedures for accessing the Web site and discussion board, so that participants who are less experienced will not be discouraged from participating.

- Piloting Web site and tools for user-friendliness; consider piloting with a variety of computers/browsers.

- Considering an "electronic signature" for the consent form, which can be returned by e-mail.

Migraines and the Perimenopause—For many women, the migraine experience is difficult; migraines are often not readily apparent to others, and non-sufferers may not understand the diminished quality of life that is often encountered. In addition, migraine headaches are often considered a "women's disease" (Warshaw, Lipton, and Silberstein 1998). Although to some extent this has changed, women are still sometimes perceived as malingering, and a number of women in the study alluded to the stigma that still surrounds the diagnosis of migraine headaches.

For women in the perimenopause, symptoms such as hot flashes, insomnia, and irritability are compounded by new or worsening headaches. Although women are often assured that headaches will disappear when menopause finally occurs, which happens for about two-thirds of all women with migraines (Fettes 1999; Neri et al. 1993), the perimenopause may last for years. For some women in this study, the worsening or onset of headaches began in their 30s and could be anticipated to last until the actual menopause (one year after the final menstrual period). The women's need to monitor their menstrual cycles, often heightened as menses became irregular and sometimes unpredictable, was increased by the need to monitor headaches also, in an effort to predict and prevent their occurrence. As the women noted, their headaches were often worse than their other menopausal symptoms; we would speculate as to whether menopausal symptoms, such as hot flashes, were milder for this sample of women, or whether the severity of their headaches took precedence over other forms of discomfort.

Most of the women were very committed to participating in the study, and in fact were quite patient with glitches in the software that necessitated multiple phone calls and extra postings. It was clear that the discussion boards provided a form of support group; in fact, a number of participants remarked in their evaluations that they would like to participate in an ongoing discussion board for educational and support purposes.

The fact that many migraine sufferers do not seek appropriate headache treatment is compounded by the fact that clinicians (and women themselves) often do not identify perimenopausal headaches as being migraines (particularly when the migraines are not accompanied by aura, as most are not). For many women, the perimenopausal years are often a time of multiple family commitments, career intensity, and lifestyle changes; this time may be significantly, and perhaps unnecessarily, worsened by their headaches.

Finally, it should be pointed out that most of the women in this study retained a sense of humor, describing their experiences in a sometimes-rueful manner, anticipating the day that their headaches might abate. Until that day, increased awareness of the debilitating nature of migraines in the perimenopause, by health care providers and by women themselves, may increase understanding of this very common symptom of menopause. This study demonstrates the value of using an Internet-based approach toward accomplishing a goal.

Summary

Our experience indicates that using Internet discussion boards is a feasible way to collect focus group data, and can be a cost-effective and timesaving way to conduct research. The Internet is an exciting communication medium with new possibilities and uses evolving daily. For many prospective research participants, access to the Internet is convenient and efficient and makes it possible for them to participate in a study that is otherwise inaccessible. Although barriers to Internet use remain, this technology also improves access for some women; it is likely that this access will increase over time. In many ways, the advantages as well as the potential pitfalls of using the Internet are similar to the more traditional ways of collecting data to which they are related. In a study such as this study of perimenopausal women, use of the Internet as a data collection tool creates access for women who would not have otherwise been able to participate in the study, providing invaluable data regarding women's experiences with migraines.

Acknowledgments

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