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EXPRESSIONS OF CONCERN AND SOCIAL SUPPORT ABOUT REPRODUCTIVE
CARE FOR YOUNG WOMEN ON AN ONLINE MESSAGE BOARD

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Communication and Information
at the University of Kentucky

By

Sarah Elizabeth Riley

Lexington, Kentucky

Co-Directors: Dr. Timothy L. Sellnow, Professor of Communication
and Dr. Chike Anyaegbunam, Professor of Journalism &
Telecommunications

Lexington, Kentucky

2013

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ABSTRACT OF DISSERTATION

EXPRESSIONS OF CONCERN AND SOCIAL SUPPORT ABOUT REPRODUCTIVE CARE FOR YOUNG WOMEN ON AN ONLINE MESSAGE BOARD

The experience of a pelvic exam or Pap smear is something that, while necessary to maintain reproductive health, can be fraught with difficulty for women. Ouj, Igberase, Exe, and Ejikeme (2011) note that “[m]ost women feel a level of discomfort or pain and for some it is embarrassing, dehumanizing, degrading and associated with fear, anxiety and apprehension” (p. 637). However, little recent research has focused on the specific communication surrounding reproductive care for young women. The Internet is a common place for young people to seek health information, understand their own health risks, and seek social support from others. The current study utilizes information gleaned from the archives of an internet message board and sexual education website to examine the way that young women communicate about reproductive health care, risk, and social support with experts and peers in the online community. Results indicate that young women request, seek, and receive several different types of social support in the online community. Further, themes illuminate the complex nature of women’s concerns about potential risk and reproductive care.

Keywords: Online Communication, Reproductive Care, Social Support, Online Message Boards, Health Communication

Sarah Elizabeth Riley

December 18, 2013

EXPRESSIONS OF CONCERN AND SOCIAL SUPPORT ABOUT REPRODUCTIVE
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This work is dedicated to my children, Colin and Anna.
Whether big or small,
never be afraid to ask questions.

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Chapter 1: Introduction

Due to the prevalence of sexually transmitted infections, it is crucial that all sexually active individuals seek regular reproductive care. Because most of those infections occur in young adults, care should not be delayed or avoided. In spite of being at significant risk for serious health consequences, young women often do not get this care. This problem arises from missing or incorrect information and anxiety about reproductive care, yet little research has focused on the messages young women receive or how it influences the way they perceive their own risks. The Internet provides an opportunity to examine interactions as women ask questions about reproductive care. The current study attempts to understand and evaluate the messages women receive about reproductive care while providing a framework for understanding social support for anxiety reduction on an online message board.

Rationale

In 1998, Gold and Gladstein noted that approximately 25% of the 15 million reported new STD infections occurred in teenagers. According to a CDC study published in 2004, in the year 2000 almost 19 million new cases of STD were reported, nearly half of which occurred in individuals between ages 15-24 (Weinstock, Berman, & Cates, 2004). This indicates that as the number of newly reported STD cases increases, the number of those occurring in younger people steadily increases as well. In fact, an estimated two-thirds of all sexually transmitted infections (STI) occur in individuals younger than age 25 (NIH, 2003). Based upon these statistics individuals aged 15-24 are clearly a high-risk group.

As STD infection rates continue to rise and young women find themselves at even greater risk for serious consequences due to these diseases, care providers need to focus on getting young women the reproductive care that they desperately need. The days when the prevailing ideology dictated that a gynecological examination was only necessary when a woman turned 21 or got married (unless the woman in question had a complaint prior to that time) are quickly disappearing. New guidelines place emphasis on beginning Pap smears and STD testing as soon as sexual activity begins (U.S. Department of Health and Human Services, 2003). In its advice for pediatricians prescribing contraceptives, the American Academy of Pediatrics also suggests that screenings for sexually transmitted infections should not be put off, even if a first pelvic exam is delayed (Committee on Adolescence, 2007).

While reproductive care is clearly necessary for young women, many are not receiving the care they need. Pelvic exams have long been reported as cause for anxiety among women. This anxiety may be the result of fear of pain, discomfort, embarrassment, or a variety of other factors (Tiefer, 1979; Willie, 1982; Kowalski & Brown, 1994; Larsen, Oldeide, & Malterud, 1997; Oju, Igberase, Exe, & Ejikeme, 2011). Various surveys have found between 16-31% of female respondents had never received gynecological exams (Meyer, 1992; Moss, n.d.; Tountas, Creatas, Kimitrakaki, Antoniou, & Boulamatsis, 2004). Further troubling is the finding of Tountas et al. (2004) that only 4% of respondents saw their gynecologists for preventative care. In another study, Jay (2004) noted that only 22% of young women surveyed would seek STI testing absent symptoms. These results point to a concerning lack of care and especially a dearth of preventative care.

More recent research indicates a troubling lack of knowledge among young women about sexually transmitted infections and reproductive care. For example, Friedman and Bloodgood (2010) interviewed 125 women aged 15-25. Less than one-fifth of respondents were able to provide basic information about Chlamydia beyond knowing it was a curable STI (Friedman & Bloodgood, 2010, p. 1825). Twenty percent of participants believed that one test (usually the Pap test) screened for all STDs and the majority were not aware of the recommendation for annual Chlamydia screening (Friedman & Bloodgood, 2010, p. 1825). Participants reported receiving information about sexually transmitted diseases from pamphlets they received, during health visits, from high school classes, family and friends, and media. Of those reporting they received STD information from the media, “magazines (33%), TV (58%), and the Internet (45%) were the most commonly cited” information sources (Friedman & Bloodgood, 2010, p. 1826).

In a study of college students from the United States, Buhi, Daley, Fuhrmann, Smith (2009) found that the Internet was a leading source of sexual health information for students. In another study of college students in Taiwan, Lu (2009) concluded that the Internet has surpassed both traditional mass media and interpersonal channels for accessing information about STDs and HIV/AIDS. In spite of finding that participants rated the credibility of online information as lower than that of traditional media, the benefits provided by online information are attractive to students (Lu, 2009). Information is easily accessible, private and personalized, cost-effective, interactive, and not impacted by time constraints (Lu, 2009). Further, online health information and websites provide a

site for interaction with both experts and peers for young women seeking information about reproductive health care.

Young people are a group at high risk for sexually transmitted infection. As a group, young women are at particular risk and research indicates they may lack knowledge about those risks. It is crucial for them to seek both information and care, yet many do not. Individuals are increasingly using the Internet to access health information because of the benefits it offers.

The current study involves data collected from the website Scarleteen. Founded in 1998, Scarleteen.com is one of the best known and respected websites on the Internet today. The site bills itself as “inclusive, comprehensive and smart sexuality information and help for teens and 20s” (“Scarleteen,” n.d.). The website offers both static content (articles, expert advice, etc.) and interactive message boards. Scarleteen logs around three-quarters of a million visitors each month with the majority being aged 15 to 25 (“About Scarleteen,” n.d.). As a website that is the highest ranked sex education and sexuality advice site online and is targeted specifically at young people, Scarleteen represents a key location for young women’s conversations about reproductive health care.

Purpose of Current Study

The current study’s objective is to better understand how young women are using online message boards about health information. The study seeks to provide a formative understanding of the interaction between young women looking for information about reproductive care and the information and interaction they experience on a popular online sex education website. By better understanding the interactions between the young

women using these boards, their peers, and experts, this study may also give the producers and moderators of these types of online communities important information about the concerns and needs of their users.

Organization of Dissertation

To achieve the goals set forth in the study, this dissertation has been organized into six chapters.

Chapter One provides an introduction to the problem and the location of the study. A brief overview of the Scarleteen.com website is provided and the purpose of the study is discussed.

Chapter Two includes an overview of relevant literature. It begins with a discussion of the relationship between reproductive care and anxiety for women, followed by a discussion of the way risk perception influences communication about topics like reproductive care. Next, a review of online information seeking literature is provided. Finally, literature about social support is included. The chapter closes with the study's research questions.

Chapter Three presents a discussion of the study's methodology. First, an extensive discussion of the Scarleteen website is provided. This includes information about its background and values, content, past use in research, and message board registration process. Next, the specific data set is explained. The data collection process and ethical considerations are discussed. An overview of the method, thematic analysis, is also provided. Finally, the chapter closes by revisiting the research questions and listing the study's step-by-step procedures.

In Chapter Four, study results begin to emerge in the consideration of messages posted by young women seeking information and social support at Scarleteen. The chapter first includes a discussion of the categories of social support sought, including both action-facilitating and nurturing support. Next, the themes present in the young women's questions and expressions of concern are discussed. These themes include concerns about privacy and parental knowledge, anxieties expressed, the influence of past experiences, timing of care sought, whether the need for care is posed as a question or a statement, and pre- and post-care concerns.

The discussion of results continues in Chapter Five, where the analysis includes the replies given by experts and peers. The chapter again begins by considering the categories of social support provided, both action-facilitating and nurturing. In the latter half of the chapter, themes in the peer and expert replies are explored. These themes include privacy and parental knowledge reassurances, addressing anxieties, descriptions of care, suggestions about whether or not to seek care, and requests for further information.

Chapter Six presents a brief synthesis of the results discussed in the previous two chapters. The chapter then includes a discussion of the implications of the research for providing social support to young women seeking information about reproductive care online. Finally, a consideration of limitations and future directions is provided.

Chapter 2: Review of Literature

The experience of a pelvic exam or Pap smear is something that, while necessary to maintain reproductive health, can be fraught with difficulty for women. The current review of literature will explore the link between reproductive care and anxiety, online information seeking, risk perception, both face-to-face and online social support, and finally propose the research questions for this study.

Reproductive Care and Anxiety

Ouj et al. (2011) note that “[f]or most gynaecologists, this procedure appears both routine and necessary. For patients though, this might be an experience worth varied interpretation. Most women feel a level of discomfort or pain and for some it is embarrassing, dehumanizing, degrading and associated with fear, anxiety and apprehension” (p. 637). In order to understand this experience of reproductive care for women, we must explore the history and current guidelines, avoidance of and barriers to care, and suggested methods for anxiety reduction during reproductive care.

History and current guidelines. As Hein (1984) asserts, in America the passage into full womanhood is marked by the first pelvic exam. In earlier times, this rite took place only when a woman was of age or when she took the next step in her reproductive life by entering into marriage. Beginning in the 1950s and continuing for nearly two decades, the first pelvic exam was a ritual for brides-to-be where the primary focus was on introducing the woman to vaginal penetration in order to reduce any trauma she might experience during first intercourse (Lewis, 2005). During that period, the focus was on sexual adjustment, rather than on detecting infections or other problems.

As young women continue to become sexually active outside of traditional marriage, ignoring this rite or delaying gynecological exams until a woman is 21 or married may have consequences. Putting off the first exam can lead to further spread of disease and place a woman's fertility and life in danger. More recent recommendations indicate that women should begin regular pelvic exams, which include cervical cancer screenings, once they have been sexually active for at least 3 years or have reached age 21 (Nicoletti, 2005). However, they also note that other tests and examinations for sexually transmitted infections (such as urine tests) should be conducted as soon as sexual initiation has occurred (Nicoletti, 2005). Not all sources agree with this assertion, however. You et al. (2005) found that the majority of cancers diagnosed in women under age 25 were in the 21- to 25-year-old age group. Further, the cervix and ovaries were the most common site for gynecological cancers in patients under age 25. This led the authors to conclude that for women in this age group, it was important to continue to get pelvic exams and PAP tests (You et al., 2005). In spite of a clear need for care, many women avoid these important exams.

Avoidance of care. Given the current infection rates and guidelines for beginning care, the obvious answer is to encourage young women to seek regular exams, especially if they are sexually active. However, the issue is not that simple. One study of female college students (age 18-25) found that 25% reported that they had never received a pelvic exam (Meyer, 1992). A similar study of thirty college women aged 20-22 years found that 16.7% of respondents reported never having a gynecological exam (Moss, n.d.).

Tountas et al. (2004) surveyed 1500 individuals age 16-45 in Greece regarding information sources and knowledge about contraception. While most women over age 25 had visited a gynecologist at least once in their lifetime, 25% of women age 19-24 and 30.6% of women age 16-18 had never been seen by a gynecologist. Women aged 25-34 and 35-45 reported the gynecologist as their main source of information about contraception, followed by media sources and friends. Young women under age 24 mainly received information through media and friends with only 43% receiving information from their gynecologist (Tountas et al., 2004, p. 3). Of women aged 16-18, the authors found that only 22.8% of women received information about contraception from their gynecologists. Additionally troubling is the finding that only 4% of women, when asked about their reason for visiting the gynecologist, were being seen for preventative care (Tountas et al., 2004, p. 5). When examining knowledge about contraception, a majority of respondents' felt at least fairly informed about contraceptive issues. After testing the respondents knowledge of the use and effectiveness of various contraceptive methods, only 30.6% of women were able to answer 50% or more of the questions correctly, indicating that actual knowledge about methods is very low (Tountas et al., 2004, p. 7). Further analysis indicated that women who had visited their gynecologist before had a 40% greater likelihood of providing more correct answers (Tountas et al., 2004, p. 7). These findings point to serious concerns about the sources of information as well as the information itself that women have about reproductive issues.

Jay (2005) reported on the results of a study of 89 adolescent females (age range 13-20 years) and found that pelvic examinations are "a substantive barrier to both partners in the physician-patient dyad" (p. 873). When presented with a variety of STI

screening methods, only 12% preferred a pelvic exam. Others indicated they would rather have home or clinic based urine testing or a self-collected vaginal swab. However, even more alarming is the fact that only 22% indicated they would seek any kind of STI testing if they were not experiencing symptoms. Jay (2005) notes that while it seems there is promise in home-based STI testing for adolescents, the “indifference toward testing when asymptomatic is a cause for concern” (p. 873) and that we do not know how these individuals would interpret positive results of these at-home tests and whether treatment would even be sought. So while it seems that taking the clinical setting out of the equation is preferable to many adolescents, we do not yet know what the result of such a move would be for overall health concerns. Looking beyond the clinical setting, there are also other barriers to reproductive care for women.

Barriers to reproductive care. To more fully understand the information women receive about pelvic examinations, researchers need to consider the sources of those messages. Millstein, Adler, and Irwin (1984) found that the most frequent source of information regarding pelvic exams reported by the adolescent females in their study was peers. Participants also indicated that the most common message they received from these peers was that the examination was painful. Others may let their fear of the exam keep them from even calling to make an appointment for a gynecological exam. Little research beyond this has been done examining the origin of the information women receive regarding gynecological examinations.

Similarly, few researchers have investigated the reasons for delaying pelvic exams. Tiefer (1979) suggests fear of examination, no perceived need for examination, concern about personal hygiene, embarrassment about undressing, fear of pain, and worry

about finding a problem can give a woman reason to delay. This was later supported by the findings of Willie (1982), which indicated fear of pain, embarrassment, fear of the unknown, lack of need, and fear of finding a problem as reasons for delaying pelvic exams. In a study of 82 Caucasian women, social anxiety and physique anxiety influenced intention to get an exam as well as actual reception of the exam (Kowalski & Brown, 1994). These findings point toward the role of anxiety in putting off these important exams.

Whether it is linked to pain, embarrassment, or even the fear of finding a problem, it is clear that this type of emotional upset is a part of the process of anxiety. Larsen et al. (1997) found that all but one of the 13 Danish women they interviewed expressed anxiety in advance of pelvic examination appointments. Again, the participants pointed toward concerns about pain as being an important part of their anxiety. The women in this study also highlighted other issues as playing a role in their experience of the procedure, such as the doctor's gender, their physical positioning, nakedness, and informed communication. To help reduce these barriers, several anxiety reduction methods have been proposed.

Anxiety reduction methods. This anxiety surrounding gynecological exams has led researchers and practitioners to make several suggestions concerning methods that can reduce exam anxiety. One method that has gained popularity recently involves allowing patients to postpone first pelvic exams for up to six months, but still receive oral contraceptives (Donovan, 1992). This approach attempts to put the patient in control by allowing them to choose when they were ready for the pelvic exam and to encourage them to utilize contraceptives by removing the perceived barrier of the pelvic exam. One

evaluation of delayed exams found that of the 627 teens enrolled in a program where exams could be put off, there was no significant difference between the STD infection rates of individuals who postponed the pelvic exam and those who had the exam (Donovan, 1992). Around one-quarter of participants opted to delay the pelvic exam and approximately 40% delayed blood tests (Donovan, 1992). The author also noted that participants who delayed the exam waited longer after the initiation of intercourse to use birth control. Donovan (1992) notes that those who delayed "...had also waited significantly longer after becoming sexually active to make a family planning visit. Almost 60% had waited more than six months, compared with fewer than 50% of those who did not delay. Half of the teenagers who postponed the pelvic exam had believed that it would be embarrassing, compared with 38% of those who did not delay" (para. 12).

Another widely accepted method of reducing anxiety surrounding first pelvic exams involves informing physicians about the needs and concerns of patients and training them to be sensitive during gynecological exams. Millstein et al. (1984) found in their study that provider messages often have a lesser effect on patient anxiety than do the messages they receive from their peers. Similarly, a study conducted in Denmark found that there was a significant need for practitioners to focus on emotional contact and communication with patients prior to gynecological examinations (Hilden et al., 2003).

While the need for training in dealing with patients during this type of exam is clearly indicated in both research publications and training materials for practitioners, it is easy to question the utility of focusing on provider training alone. Davis (2003), for example, provides practitioners with suggestions for performing gynecological exams on

pediatric patients. Similarly, Pelorme and Jamieson (2004) provide some suggestions for health care providers performing first gynecological exams. These include ideas such as working slowly and gently, describing the exam to the patient, and being cognizant of the patient's fears and anxieties. Hennigen, Kollar, and Rosenthal (2000) suggest that care providers working with adolescent patients can help patients reduce anxiety by assessing a young woman's coping style, offer the woman a sense of control by being flexible and spending adequate time explaining the procedures, and encouraging the use of stress reduction techniques like deep rhythmic breathing, progressive muscle relaxation, or the guided imagery technique.

But information during the stressful examination period may not be enough for women as they cope with issues of anxiety surrounding gynecologic exams. As Millstein et al. (1984) highlighted, the primary messages about the exams came from peers, and the impact of the physician's messages were much smaller. While it is never a bad thing to be aware of the feelings and needs of patients, it is conceivable that this approach just does not go far enough.

A third approach, conducting patient training seminars to reducing the anxiety surrounding first gynecological exams by educating patients ahead of time shows promise. The idea of incorporating patient seminars about the topic is not new. Indeed, Frye and Weisbert (1994) suggest that "In addition to providing training when there are fewer stressors, methods for reducing anxiety may be employed proximate to exams...may be useful in decreasing anxiety associated with pelvic examinations" (p. 33). The suggestion of patient interventions is also found in other articles discussing the things that physicians can do to reduce patient stress. Palerme and Jamieson (2004), for

example, suggest that an outline of the exam may benefit some patients. So the idea of incorporating an intervention is not revolutionary, but it does seem to have been overlooked.

Sawyer, Pincaro, and Anderson-Sawyer (1998) conducted a study that examined the potential benefits of an intervention for reducing anxiety surrounding first gynecological exams. In this study, the authors sampled 132 university women. They prepared a survey instrument to collect demographic data as well as to measure the anxiety that the women felt about having a pelvic exam. Additionally, the researchers prepared a videotape that followed “Tina” through her first pelvic exam. The participants were assigned to one of three groups for the study. The first group received a presentation that included discussion about what happened during a pelvic exam, a discussion of contraceptive methods, and a viewing of the “Tina” videotape. The second group received only the videotape (the remainder of the presentation was given to this group following their post test) and the third group received the presentation without the videotape. Peer educators conducted the discussion groups. All groups were tested prior to their participation in the intervention. Posttests were administered after they completed their interventions. Eighty-seven percent of the women surveyed indicated that they had not previously received a gynecological exam (Sawyer et al., 1998). A comparison of the results of the survey responses revealed that all of the women surveyed reported anxiety prior to the treatment. The examination of the posttest scores revealed that all three of the treatments resulted in a decrease in the level of anxiety reported. The educational program with the video produced the largest change, while the educational program without the video produced the smallest change in anxiety. When the authors asked the

students what they most liked about the intervention, they reported that they appreciated the peer educators and the comfortable environment. This would seem to support Frye and Weisbert (1994) in their assertion that a lower stressor environment is a beneficial site for discussing examinations. Further, the women's feelings of anxiety relating to the test being painful decreased from 45% to 16% (Sawyer et al., 1998).

This would lead us to believe that there is at least some hope for the user of interventions to reduce patient anxiety. As these interventions can be conducted for patients in groups rather than in the patient-provider dyad, there is evidence as well that a good intervention would not only reduce anxiety levels, but also be very cost effective (Sawyer et al., 1998). Furthermore, it is possible that, taking into account the influence of peers on anxiety levels (as highlighted by Millstein et al. (1984)), providing a more positive image about pelvic exams could be created through the discussion group, thus combating the effect of the horror stories told by some mothers and friends. However, the problem inherent in the current approach to these types of interventions is the lack of a clear understanding of women's messages about these exams.

Allowing patients to actively participate in the exam itself is a fourth suggested anxiety reduction method. After creating and testing an instrument to assess patient satisfaction with speculum self-insertion, Wright, Fenwick, Stephenson, and Monterosso (2005) conducted an experiment in which 198 women were asked to insert the speculum on their own during a routine gynecological exam. Participants completed a demographic survey and the STAI (State Trait Anxiety Inventory). The 133 women who agreed to participate in the self-insertion then received instructions from the clinician about how to insert the speculum. The clinician stepped away from the table to offer the woman greater

privacy (Wright et al., 2005). After the exam was completed, participants completed the STAI again and also the Speculum Self-Insertion Satisfaction Questionnaire. Results indicate a statistically significant decrease in anxiety for women who participated in the speculum self-insertion (Wright et al., 2005, p. 1106). The authors found that “[n]early 91% of women (n=118) either agreed or strongly agreed that they were satisfied with the experience of self-insertion with 93.8% (n=122) women agreeing or strongly agreeing that they would choose to self-insert the speculum again” (Wright et al., 2005, p. 1106). Participants responding to open-ended questions indicated that while some may have felt unsure to begin with, they later experienced feelings of greater understanding due to the care providers’ instructions and more control. They reported the experience as being more positive (Wright et al., 2005). Clinicians reported that the technique did not increase appointment times or create significant issues of placement or specimen quality (Wright et al., 2005).

Allowing patients to take an active role in their own care allows for greater feelings of control and a reduction of anxiety without apparent drawbacks in terms of treatment time. While Wright et al. (2005) results are promising for women who are already in the office; the study does not indicate how this technique might be useful for reducing anxiety to get women into the office for the appointment initially. Further research should be conducted to see if this technique is useful for those who have not yet interacted with the care provider and are deciding whether or not to seek care.

Kocabas and Khorshid (2012) suggest changes to the clinical setting as another method of anxiety reduction. The authors conducted an experiment in which a special gynecological garment and music were introduced. Ninety Turkish women (aged 15-49)

were randomized into one of three experimental groups. Women in the control group were given the traditional gynecological exam drape, women in the first experimental group received the special gynecological exam garment, and women in the second experimental group received the special garment plus soothing music playing during their exam. The researchers found “a statistically significant difference between the mean state anxiety scores of the three groups after gynaecological examination” (Kocabas & Khorshid, 2012, p. 796). Women in the control group reported higher state anxiety scores afterward than those in either experimental group.

These study results indicate that changes to the clinical setting may provide further assistance to reduce anxiety. However, as with the use of speculum self-insertion, special garments or music focus only on women who are already in the care provider’s office. Patient training require a woman to set aside time and actively engage in the seminar prior to an appointment. The current research does not provide evidence of whether these interventions would have an impact on women who have not yet entered the clinical setting. Before ever making an appointment, a woman will have information about reproductive care gleaned from family, peers, institutions (schools, churches, etc.), and media. Therefore, it is necessary to gain a better understanding of the interactions that occur when women are seeking information about whether or not they should get reproductive care.

Further, a woman’s perceptions about her health may influence her anxiety (or lack thereof) about seeking care. Tiefer (1979) and Willie (1982) highlighted the fact that women identify the fear of discovering a health problem as a factor in increasing anxiety.

This indicates the need to consider how a woman's own assessment of her risk may influence her anxiety and the conversation about reproductive care.

Risk Perception

The motivation to seek reproductive care may, at least in part, be related to the perception of risk by the individual in question. If a woman perceives she is at risk for pregnancy or an STI, this may change her behavior with regard to seeking out information about gynecological care and also to seeking out the care itself. As previously noted, Jay (2005) found that only 22% of respondents would seek out preventative STI screening. Beyond simply looking for information, an individual's reaction to the information they receive may also influence their behavior and future communication about that risk. Further, a woman's perception of risk associated with her reproductive health may influence the way she expresses concerns when interacting with others.

Risk perception has been studied with regard to a variety of health topics. In a study of 629 Korean adults participating in a cholesterol and blood pressure screening, Panzer and Renner (2008) wanted to understand how individuals react spontaneously to feedback about their risk. The researchers found that 55% generated a single reaction and 45% generated multiple reactions (Panzer & Renner, 2008, p. 621). In examining the type of reactions generated, emotional reactions were the predominant type of spontaneous reaction (generated by 47% of participants), followed by descriptions of the risk feedback valance (37%), expectedness (24%), and future lifestyle change (20%). The categories of causal attribution, implication for future health, need for information and acceptance were also noted, though they were generated by less than 15% of respondents (Panzer &

Renner, 2008, p. 621-622). The authors also note that “similar types of spontaneous reactions were generated by individuals receiving low, borderline-high, or high risk feedback and upon receiving blood pressure and cholesterol risk feedback” (Panzer & Renner, 2008, p. 624). Further, they note that the prevalence of emotional reactions as the most frequent response to risk feedback were fascinating because “most studies assessing the psychological impact of individualized risk feedback focused on cognitive reactions” (Panzer & Renner, 2008, p. 624). These emotional reactions occurred not only with bad (borderline or high risk) news, but with similar frequency regarding good news. While this finding has implications for all health screening behavior, it may be of particular interest when examining issues like reproductive care, which may already be highly emotionally charged. The results also highlight the role of expectancies in the response to feedback. Lifestyle related reactions did show a difference based on the threat level posted by the risk feedback, indicating that negative feedback may provide more pressure to change (Panzer & Renner, 2008).

When respondents in Friedman and Bloodgood’s (2010) study about Chlamydia and STD testing were asked who needed to be tested the authors note that “two responses emerged most frequently, with over half of respondents reporting that either everyone who is sexually active or people with multiple partners (“who are promiscuous”) should be tested. Other common responses included people who do not use protection and people in their teens to early 20s” (p. 1825). The majority of young women in the sample were not aware that Chlamydia could be asymptomatic in nature, might cause infertility and did not realize how common it was. Further, they did not believe that others like

them knew much about Chlamydia either (Friedman & Bloodgood, 2010). The authors note that their analysis indicated that

Young women's discussions suggested they have low levels of perceived susceptibility to STDs. Participants commonly stated that STD testing is for people with multiple partners or who are promiscuous. Although most participants guessed that people should be screened for Chlamydia at least annually, they did not seem to perceive this recommendation as relevant to themselves. Only about half mentioned ever being tested for STDs or knowing a friend who had. (p. 1828)

While young women reported an apparent low susceptibility to STDs, the authors note that Chlamydia is the most commonly reported notifiable disease in the U.S. and that the majority of infections are among females aged 15-24 years (Friedman & Bloodgood, 2010). The finding points to a disconnect between young women's level of risk and their perception of their risk.

Interpretive research about risk perception. Horlick-Jones and Prades (2009) note that the “mismatch between lay risk perceptions and official scientific risk assessments, and their associated behaviors, has characterized a great many areas of public controversy” during the last decade (p. 410). Further, the authors note that “[i]n methodological terms, it has become increasingly clear that questionnaire-based research alone did not capture the complexity of risk perception in specific hazard locations, suggesting that methods more sensitive to context were needed” (Horlick-Jones & Prades, 2009, p. 411). They argue that interpretive research provides information about practical reasoning about risk issues by providing a recognition of people's need to present themselves as reasonable in socially difficult situations related to blame and responsibility, recognizing that risk reasoning happens in situations where individuals have imperfect knowledge and reasoning that may change as levels of understanding

change, and that technology is important in understanding individual risk reasoning (Horlick-Jones & Prades, 2009, p. 415-416).

Qualitative examinations of risk behavior are important in helping to truly understand the myriad of individual motives and influences. In a systematic review of published qualitative research about conceptualizations of cancer risk, Lipworth, Davey, Carter, Hooker, and Hu (2010) note that a wide variety of different emotional processes, individual factors, and beliefs influence people's understanding of cancer risk. The authors reviewed 87 articles that utilized qualitative research methods to understand how people construct cancer risk. They identified eight overriding categories in the current research: "(i) perceptions of risk factors; (ii) process of risk perception; (iii) seeking control and taking responsibility (motivational factors); (iv) experiencing cancer directly; (v) constructing risk temporally; (vi) embodying risk; (vii) identifying with risk; and (viii) constructing risk in a social context" (Lipworth et al., 2010, p. 117). They note that these findings point to the place of qualitative risk research in confirming and elaborating upon what has been found in quantitative examinations. Perhaps more importantly, they argue for the use of this kind of qualitative research to provide a deeper, more elaborate understanding of the experience of individuals, who are at risk and the way they manage that risk in their complex social lives (Lipworth et al., 2010).

Risk perception in social systems. Communication about risk for individuals does not exist in a vacuum. Rather we know it happens inside complex social systems, where there are multiple information sources and individuals may make comparisons with others. In a study of risk perception and social comparison, Schmieg, Klein, and Bryan (2010) conducted two experiments utilizing flossing behavior. The authors note

that they chose flossing as a health risk behavior because it is a private activity about which one would be unlikely to know the behavior of others. The authors note that “the results demonstrated the importance of social comparison information, even when objective or expert standards were also readily available...evidence across both studies that receiving social comparison information predicted several outcomes, including attitudes, intentions, and behavior” (Schmieg et al., 2010, p. 755). In one of the experiments, they also found support for the effect of social comparison on risk perception and perceived worry. Those effects were dependent upon whether or not expert recommendations were also available (Schmieg et al., 2010, p. 756). Further, when later behavior was included, a strong main effect was found for social comparison on behavior. The authors also noted a lack of sensitivity to suggestions from experts in spite of participant ratings of expert recommendations being of greater value and believability (Schmieg et al., 2010). This may point to the idea that social comparisons have greater impact because they come from referents closer to the individual and thus more compelling than those from a removed, abstract authority. The authors note that further research is needed to understand the mechanisms underlying the impact of information from social comparison (Schmieg et al., 2010, p. 756).

As individuals assess and understand their risk, they communicate about it within these complex social systems. Thus it is crucial to understand the way these discussions about risk influence an individual’s risk perception.

Communication about risk. Verbal discussions of risk are important because the way that risk is addressed has been shown to influence individuals’ behaviors. Young and Oppenheimer (2009) conducted three studies examining the relationship between

description and risk perception. The first study presented 59 San Francisco residents with semantic descriptions of low-likelihood events and asked them how they quantitatively perceived the risk. A second study gave 29 undergraduates semantic versus numerical information about medication side effects and examined their perceived risk and intentions to adhere to treatment. The third study involved 125 San Francisco Bay area residents who were given semantic versus numerical information about disease risk and asked about their perceived risk and intentions to adhere (Young & Oppenheimer, 2009). The authors found that “[t]he results of three studies suggest that people overestimate low risk events when they are presented with verbal descriptors, and people’s behavioral intentions reflect this lack of calibration. The studies suggest that people overestimate the degree of risk that the verbal descriptors were intended to convey (Study 1a) and that this bias can discourage (Study 1b) or encourage (Study 1c) intentions to adhere to a prescribed behavior, depending on whether the risks pertain to engaging or failing to engage in the stipulated behavior” (Young & Oppenheimer, 2009, p. 437). In spite of the relatively small sample sizes and hypothetical nature of the method (as opposed to a natural or clinical setting), the implications of these findings are of interest. The language used to describe a risk can be either a benefit or a drawback, depending upon how the individual perceives that risk and how it relates to the behavior in question. While the authors indicate that their findings do not provide a strong indication for the benefit of one type of descriptor over the other, they do note that they “demonstrate that verbally presented information produces a systematic bias in decision-making” (Young & Oppenheimer, 2009, p. 439). In other words, the way risk is discussed matters. This provides an impetus for researchers to examine specifically the language that is being

used by individuals talking about risk and the way this may influence their perceptions and behaviors.

Risk perception is situated within the context of others. To better understand the messages about risk, it is also crucial to examine the supportive messages being provided by others in key relationships. Internet provides easy access to information and a potentially supportive community of experts and peers.

Online Information Seeking

Research in the area of online information seeking paint a complicated picture of when and how individuals are using the Internet for health care information and support. In a 2008 survey by the Pew Internet and American Life Project, researchers found that “about 80% of Internet users, or 61% of U.S. adults, have used the Internet to search for health-related information, and many of them believed that the Internet had a great influence on how they cared for their health (Fox & Jones, 2009)” (as cited in Hou & Shim, 2010, p. 187).

Rosen and Knauper (2009) conducted a study using linguistic manipulation to examine interactions between situational uncertainty, intolerance of uncertainty, worry, and information seeking. In a sample of 153 college students, the researchers found that individuals in situations where there was high situational uncertainty and they were induced to have a high intolerance of uncertainty reported being most worried and sought the most information. Those who sought the least information and were the least worried were those who had low situational uncertainty and low intolerance of uncertainty (Rosen & Knauper, 2009). The researchers note that this is the first study to “demonstrate the effect of an interaction between individual differences in IU and SU on information

seeking and worry due to uncertainty” (Rosen & Knauper, 2009, p. 235). The existence of this interaction points to a connection between health information seeking and the anxiety and uncertainty experienced by individuals.

In a study of 4,551 adults who were identified as Internet users, Hou and Shim (2010) found that the way patients perceived interactions with their health care providers influenced their use of the Internet for health information. Patients who perceived lower patient centeredness during face-to-face interactions with health care providers were more likely to use the Internet for health information (Hou & Shim, 2010). The authors note that “[i]ndividuals’ media use was goal directed and motivated, and they had enough awareness to seek information by using different media to satisfy emotional and informational needs, and to address medical uncertainty. The majority of the sample in this study not only sought health information on the Internet, but they also actively used websites to manage their lifestyles, searched health care providers online, and used other types of media for health information. Their diverse media consumption indicates that in this new media era, interpersonal and mediated communication channels complement each other in a health-related context” (Hou & Shim, 2010, p. 195). These findings indicate that those seeking online health information do so in a deliberate fashion. Users feel that they are not receiving adequate information and support from other sources and seek to fulfill those needs online.

Similarly, in a study of online information seeking by cancer survivors, Dolce (2011) noted that participants “were highly engaged with the Internet and found online communities to be particularly valuable” (p. 358). The study participants did not feel that the information they received from care providers was sufficient and therefore turned to

the Internet to look for information, support, and a feeling of empowerment (Dolce, 2011).

While Internet users may purposefully seek out online health information, this does not automatically indicate the ability to utilize that information in making health care decisions. Kim and Kwon (2010) examined cancer e-patients (patients who are Internet-savvy) use of different health information sources. The authors found that these patients commonly used the Internet as their primary source of health information even though they preferred information from their doctors (Kim & Kwon, 2010). However, the study did not find that e-patients with cancer were any more competent online health information seekers than online information seekers without cancer or traditional (offline) cancer patients (Kim & Kwon, 2010, p. 729). Further, e-patients with cancer reported higher levels of trust in online health information than did their offline counterparts. The authors note though that it is unclear whether this trust is a result of e-patients greater knowledge and use of credible Internet resources or if it demonstrates that e-patients lack the skills to critically assess the information they encounter (Kim & Kwon, 2010). Results also indicate a preference by e-patients for cancer organizations as their third most preferred source of information, which points to the patients' preference for credible sources. In contrast with previous research about the importance of the Internet for support, Kim and Kwon (2010) noted that only a small portion of their sample of e-patients participated in online support groups and suggest that further research in the area is necessary to reveal why e-patients are not utilizing online cancer support groups (p. 729).

Not all studies found support for Internet use for health-information seeking. Baxter, Egbert, and Ho (2008) found that “[d]espite the growing computer expertise of the current college-student generation, computer-based mass media events on health topics were relatively infrequent. When our participants did record listservs, chatrooms, or Web pages, they tended to report doing so in an effort to find health-related information or advice” (p. 432). However, the authors also note that their study is limited by focusing on self-report data (engaging only the participants self-reports and their perceptions of behavior). The authors did not look at whether the information sought was preventative or treatment-oriented, which could also impact the information-seeking behaviors (Baxter, Egbert, & Ho, 2008).

Eastin and Guinsler (2006) posit that health anxiety is one of a variety of reasons for people seeking health information online. The authors define health anxiety as a “concern about health in the absence of pathology, or excessive concern when there is some degree of pathology” (Eastin & Guinsler, 2006, p. 494). In an online survey of 240 individuals, Eastin & Guinsler (2006) found that individuals with moderate or higher levels of anxiety seek higher amounts of online health information. Those who frequently seek information online tended to make more appointments with their health care providers. However, Eastin & Guinsler (2006) also found “a negative relationship between searching for health information online and visiting a doctor based on that information for individuals at the lower end of the health-anxiety spectrum” (p. 497). For those who have lower health anxiety, searching for information online may discourage them from seeking expert care. While some of the results were not significant, findings

do indicate a complex relationship between anxiety, online information seeking, and health care.

Percheski and Hargittai (2011) note that most studies of online health information-seeking focus on age, education and gender as important variables. However, they also note that little work in the area of online health information-seeking has examined differences in cognitive ability, web skills, social support or other factors (Percheski & Hargittai, 2011, p. 379). In their own study of 1,060 first year college students, the authors found that female college students were more likely to use the Internet for health information than were their male counterparts (Percheski & Hargittai, 2011). Additionally, while they found no correlation between parental education and use of the Internet for health information, Percheski and Hargittai (2011) found that those with greater Web skills were more likely to use the Internet to locate health information. Social support was strongly positively associated with contact with medical professionals and family and friends, but not with traditional media or the Internet. Students with higher ACT scores had lower odds of consulting health care providers and using traditional media as sources of health information (Percheski & Hargittai, 2011). Further, those with more Internet access had greater odds of consulting with medical professionals (Percheski & Hargittai, 2011).

The Internet and sexual health information. The Internet offers a place for individuals to access and engage with sexual health information. In a study of two online teen message boards, Suzuki and Calzo (2004) found that teens used the boards focusing on sexuality and teen issues to voice “personal opinions, actionable suggestions, concrete information, and emotional *support* and allowed teens to candidly discuss sensitive

topics, such as sexuality and interpersonal relations” (p. 685). So teens are using these boards actively to seek information as well as emotional support.

Another example of young women seeking support online for health and sexuality related issues can be found in Dunham, et al. (1998). The authors examined a group of young mothers given access to a computer mediated social support network. They found that the majority of replies to messages on the site’s message boards provided emotional support, followed by informational support and tangible support. The presence of this site allowed the young mothers not only to find information and tangible assistance, but also they found a safe place to find emotional support. In fact, 98% of the replies to posts were some form of positive social support (Dunham, et al., 1998).

The Internet is providing a valuable resource for those searching for information about health and sexuality. A 2001 study found that 18% of online youth were searching for sexual health information (Lenhard, Rainie, & Lewis, 2001). Guttmacher (2012) notes that 55% of 7th through 12th graders report having searched for health information online when researching an issue impacting themselves or someone they know. It is certainly worthwhile to examine this source of information for young women, especially in light of the importance of the information they are seeking (health information) and the ever-increasing reach of the Internet. Further, the Internet provides not only a space for seeking information, but also for the creation of communities where users can obtain social support about a variety of health issues.

Social Support

Social support is defined by Burleson and MacGeorge (2002) as “verbal and nonverbal behavior produced with the intention of providing assistance to others

perceived as needing that aid” (p. 374). Albrecht and Adelman (1987) conceptualized supportive communication as, “interaction that reduces one’s perceptions of uncertainty and helps the individual develop a sense of control over stressful circumstances” (as cited in Apker & Ray, 2003, p. 358). This type of communication can be crucial in understanding the way that young women interact as they seek information reproductive care.

Support acts as a structure to help individuals manage their uncertainty about a situation (Apker & Ray, 2003). By managing the uncertainty, individuals gain a measure of control over the situation, which allows them to feel more comfortable because “people cope best when they feel well informed and actively involved” (du Pré, 2005, p. 174). Many different individuals provide social support. Further, this support addresses a variety of health topics.

Social support and women’s health issues. A significant gap in the literature exists with regard to the social support women do or do not receive from their family and peers in regard to gynecological exams. However, some prior research has examined the interactions between social support and women’s experiences with breast exams. Because both gynecological exams and mammograms are situations that are unique to female patients, it may be possible to use the knowledge of one circumstance to inform the other.

Social support from friends and family. Social support has been found to influence women’s care seeking behavior. Taylor et al. (1998) examined 348 inner-city women’s experiences. The authors looked for predisposing, enabling, and reinforcing factors for seeking breast cancer screenings. One of the main reinforcing factors for screening behaviors was whether the woman’s doctor, family, or friends had encouraged

her to seek breast cancer screening. Mickey, Durski, Worden, and Danigelis (1995) further support these findings. In their study of 653 women, one of the reinforcing factors for breast cancer screenings was family and friend support.

Similarly, Katapodi, Facione, Miaskowski, Dodd, and Waters (2002) sampled 833 Latina, Caucasian, and African American women in the San Francisco Bay Area. The authors measured social support and the women's adherence to breast cancer screening guidelines. Findings indicated "a significant relationship existed between social support and adherence to breast cancer screening guidelines that validates the assumption that women with more social support are more likely to adhere to recommended breast cancer screening guidelines" (Katapodi et al., 2002, p. 850). Clearly, the encouragement of a woman's peer group influences whether or not she seeks care.

Health care providers and social support. In addition to family and friends, members of the medical community provide social support to individuals seeking care. Physicians can actively participate in providing social support as well, aspects of which can be positively correlated with variables like patient satisfaction. For example, Greene et al. (1994) found that for older patients in initial medical encounters, patient satisfaction was positively correlated with issues like supportiveness about topics raised by the patient and laughter. Cahill and Sias (1997) assert that, "social support is fundamentally a communication phenomenon" (p. 232), making it clear that the issue must be addressed in both understanding how patients communicate with physicians, but also in how they interact with others around them which may then impact interactions in the medical setting.

Not all social support is the same, however. Regardless of the source, several different types of support can be offered to individuals.

Types of social support. Cutrona and Suhr (1994) categorize social support into two categories: action-facilitating support and nurturing support. Action-facilitating support involves favors, tasks, and providing information (du Pré, 2005). Physicians primarily participate in the information-providing facet of action-facilitating support. In Larsen, Oldeide, and Malterud (1997), participants indicated that they appreciated the doctor's willingness and ability to explain what is being done during the pelvic exam. These explanations contributed to feelings of trust and helped patients feel in control of their situation. Fridfinnsdottir (1997) found that physicians were the most valuable source for informational support for women in the process of being diagnosed with breast cancer.

Nurturing support generally involves esteem support, emotional support and social network support. Physicians will more often provide esteem support and emotional support in their dealings with patients. "Esteem support involves efforts to make a distressed individual feel valued and competent" (du Pré, 2005, p. 177). The reassurance suggested by Palerme and Jamieson (2004) while performing pelvic exams on high school age women would be an example of esteem support. The authors suggest that allowing the patient to express concerns before beginning the process and then reassuring them that the care provider can stop the exam at any time helps the patient feel in control. This would also seem to allow the patient to feel like a competent part of the exam process. They are the experts about their own body and the practitioner values their input in the process. The simple act of listening to the patient's concerns is also an act of

esteem support, as it is not uncommon for individuals to just want someone to listen to them (Lehman, Ellard, & Wortman, 1986).

The second aspect of nurturing support often displayed by physicians in their dealings with patients is emotional support. Fridfinnsdottir (1997) indicated that in addition to being an important source of informational support, physicians provided a valuable source for emotional support for their breast cancer patients. Emotional support involves showing empathy for others by acknowledging what they are feeling and trying to understand where they are coming from (du Pré, 2005). As pelvic exams can be traumatic events for some women (Domar, 1985), it seems increasingly important that physicians strive for this empathy with patients in the gynecological setting.

Usually, social support is provided by an individual's social network. This network is typically made up of family, friends, co-workers, doctors, and others from whom the individual derives support. The support provided can be either action-facilitating or nurturing support (Cutrona and Suhr, 1994). Action-facilitating support involves favors, tasks, and providing information. Nurturing support generally involves esteem support, emotional support and social network support (du Pré, 2005).

As many female participants expressed in Larsen et al. (1997), the physical situation surrounding a pelvic exam places a woman in a defenseless and potentially embarrassing situation. Patients expressed that they felt "small and naked" (Larsen et al., 1997, p. 150) and that it was not enjoyable to place oneself in that position. In a situation where a woman is in a blatantly vulnerable position, social support would appear to be a crucial aspect to address both in terms of what is offered by a woman's social circle and her health care provider.

The Internet and social support. Social support is not limited to face-to-face scenarios. The online environment also provides opportunities for social support. Individuals seek support online anytime of the day or night and can do so from the comfort of their own homes or anywhere else they can access the Internet. Online message boards are of particular interest regarding social support because individuals can interact in this private space yet receive specific feedback about their messages. Further, message boards also provide individuals with a space to discuss difficult or stigmatized topics, like sexual health.

Benefits of message boards for social support. One of the most positive aspects of Internet message boards is their multi-functionality for their users. They allow readers to participate by providing commentary, seeking social support, helping others, or simply observing (Gleason, 1995). Internet boards provide a forum for those who have no other forum they feel comfortable in. As Gleason (1995) found when examining college students utilizing a bulletin board to discuss eating disorders, the boards can serve the function of self-help groups without the face-to-face contact that may put off some people who need assistance.

There is indication that the peer-to-peer aspects of the electronic bulletin board are also beneficial. We know that youth listen better to peers than to authority figures (JACH, 1993). For example, Millstein, Adler, and Irwin (1984) found that the most frequent source of information regarding pelvic exams reported by the adolescent females in their study was peers. So in terms of reaching teens, utilizing the peer-to-peer aspects available through bulletin boards might be helpful. While peer-to-peer advising provides the opportunity for added assistance, there are also risks associated with it as well. In

regards to the information that the adolescent females were receiving from their peers, the most common information that they were receiving was that gynecological examinations were painful (Millstein, Adler, & Irwin, 1984). This information is not helpful in getting the women to visit the doctor, even if they have need. So it would seem to be very important to carefully monitor the information being provided on these types of peer-to-peer forums.

Electronic bulletin boards also provide a forum for social support. Albrecht and Adelman (1987) conceptualized supportive communication as, “interaction that reduces one’s perceptions of uncertainty and helps the individual develop a sense of control over stressful circumstances” (as cited in Apker & Ray, 2003, p. 358). Social support provided through Internet bulletin boards has also provided effective social support forums for groups, such as the parents of mentally ill children, which are also cost effective (Scharer, 2005).

Research Questions

The objective of this study is to identify patterns of expression of concern and information seeking by young women about gynecological care and the related social support provided by peers and experts on an Internet message board. To meet this objective, the study will answer the following research questions:

RQ1: What types of social support are sought by young women seeking information and support on an online message board?

RQ2: What types of social support are offered in expert and peer replies to young women seeking information and support on an online message board?

RQ3: What themes are present in posts made by young women seeking information and social support on a message board?

RQ4: What themes are present in expert and peer replies to young women's message board questions about seeking gynecological care?

The current study aims to provide an understanding of the way young women use online social support for anxiety reduction surrounding reproductive examinations. This study will also attempt to understand the link between risk perception and social support for women with regard to gynecological care. The data collected will help evaluate the messages women currently receive.

Chapter 3: Methods

Introduction

The current study used theme analysis to examine message board postings at Scarleteen.com. This chapter will discuss the data source, set, collection, ethical considerations, method, and procedures.

Data Source

Scarleteen.com was founded in 1998 and is one of the best known and respected sexuality education websites on the Internet today. The site's front page notes that it is "inclusive, comprehensive and smart sexuality information and help for teens and 20s" ("Scarleteen," n.d.). Since its inception, Scarleteen has focused on serving the needs of young people. According to "About Scarleteen" (n.d.):

Scarleteen was created out of an expressed need: young people had written Scarleteen's founder letters asking for sexuality information and support through a website she maintained about adult women's sexuality, and she had nowhere online she could refer them that provided direct service for young people. Scarleteen was created and built based on what young people asked for, through existing experience in alternative education, writing, social justice activism, health and sexuality Heather and a few volunteer writers shared, with an understanding of human sexuality as a positive and beneficial part of life. We sourced sound sexuality, relationship and health data and perspectives from reliable, reputable resources online and in print and got feedback, support and help from progressive thinkers working in the field of sexuality. To date, that remains our central approach, but we now benefit from a larger network of sexuality resources and individuals working in sexuality who generously provide feedback and advice, from increased cultural conversation about and support for sex education, and from a larger and more diverse group of young people who share what they want and need with us each day. (para. 8 & 9)

The site is visited by around three-quarters of a million people each month, with the majority of visitors being aged 15 to 25 ("About Scarleteen," n.d.). It is the highest-ranked sex education and sexuality advice website online. The site notes that:

Since 2006 alone, our site has had over one billion hits and nearly 70 million page loads. We have an above-average rate of page reads and amount of time spent at our site: young people spend almost twice as long here as users of Facebook and nine times as long as users on YouTube or MySpace (Nielsen, 2009). We engage in around 5,000 direct conversations with users online per year via our message boards alone. (“About Scarleteen,” n.d., para. 2)

The site provides a variety of different modes of engagement. They have online static content (created by both teenage and adult contributors) such as articles, guides, factsheets, expert answers, and a collective blog (“About Scarleteen,” n.d.). The site also offers interactive services such as an online message board and text/SMS service. Finally, they provide referrals to other sexuality and reproductive care services, mentoring and leadership opportunities, and other outreach (“About Scarleteen,” n.d.).

The site aims to provide sexuality education that is guided by a set of core values including “equality, respect, dignity, fairness, consent, liberty, freedom of thought and expression and other core human rights” (“About Scarleteen,” n.d., para. 14). The site further notes that it:

aims to serve all sexes, genders, economic and social classes, sexual orientations and relationship models, types of embodiment and more, including information on contraception, safer sex and sexual health, reproductive choice, masturbation, anatomy, sexual orientation and other aspects of sexual identity, gender identity and equity, pleasure and human sexual response, body image, sexual and romantic relationship formation, communication and negotiation, sexual and other interpersonal abuse, self-esteem and care and compassion in sexual enactment that is not intentionally exclusive to any one group, save privileging those in their teens and twenties. (“About Scarleteen,” n.d., para. 16)

Further core values include:

Respectful messaging encouraging critical thought, self-care and care for others, rather than shame or fear, which suggests and supports non-participation in sexual activities until such a time or a situation in which an individual wants to participate in those activities for themselves; until an individual feels prepared to manage and handle them well, including care for physical and mental health, adequate assertiveness and esteem and the ability to recognize and enact the import of mutual consent and benefit. (“About Scarleteen,” n.d., para. 17)

...Clear acknowledgment that human sexuality poses both potential benefits as well as potential detriments, and education and communication about sexuality that communicates and recognizes both, providing information that makes risks of unwanted or negative outcomes clear and educates learners on how to reduce their risks as well as how to sustain sexual well-being. (“About Scarleteen,” n.d., para. 21)

It attempts to provide content and interaction that is developmentally and culturally appropriate, based on medical and scientific knowledge, and encourages education and ethical decision making. Conversations and content are moderated by a trained volunteer staff to provide an inclusive, supportive context (“About Scarleteen,” n.d.).

Scarleteen has been referenced as a part of past studies about online sex education websites. Bey-Cheng (2001) included Scarleteen as one of fifty two sexuality education websites on which the author examined values and norms transmitted to adolescent audiences. Similarly, Noar, Clark, Cole, & Lustria (2006) examined 21 websites (including Scarleteen) as part of a study about targeting, safer sex messages, theoretical strategies, and interactivity on safer sex websites. Whiteley, Mellow, Hunt, and Brown (2012) coded twenty nine sexual health websites targeting teens for range and depth of sexual health information, usability, authority, and credibility. The authors noted that Scarleteen had the second highest cumulative score (Whiteley et al., 2012).

The website provided an ideal location for the current study for several reasons. First, the Scarleteen website and community are extremely active. New static content is added weekly and the message board service has a high level of daily activity. Also, because of its wide reach, Scarleteen provides data from a significant range of users of a variety of different ages, backgrounds, and cultures. The site’s stated focus is on providing sexuality information to teens and young adults. Further, because the website is moderated it provides a safe space for interaction about reproductive health and sexuality.

Finally, the interactive nature of the website allows for the inclusion of both expert and peer voices.

In order to participate in Scarleteen’s message boards, a user must first go through a registration process. First, a new message board user must verify their age by submitting a date of birth. The site’s guidelines note that, “Due to United States COPPA law, registration at the boards is not available for users under the age of 13. If you are under 13 and want an account, we will need a parent or guardian to email us permission for you” (“Rules, Policies, and Disclaimers,” n.d., para. 6).

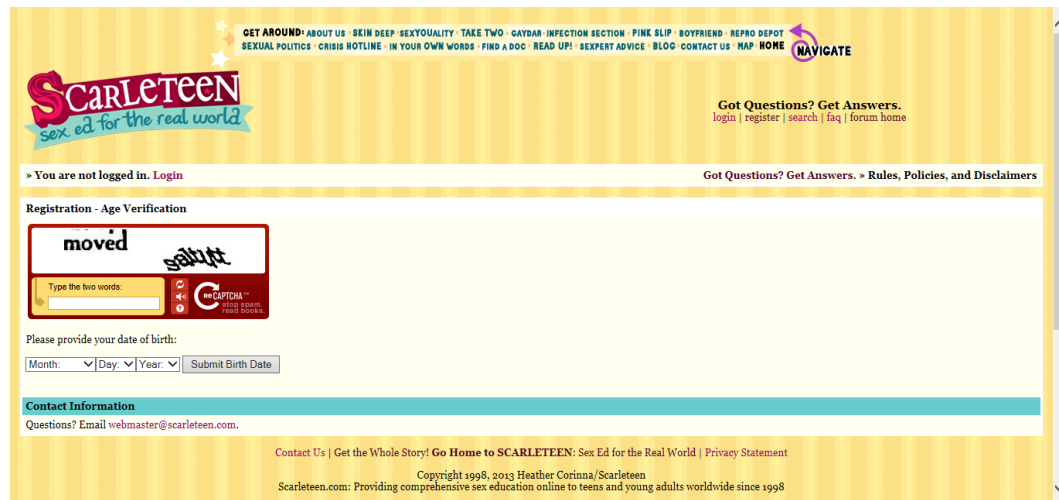


Figure 1. Screenshot of age verification screen.

As a part of this process, the individual then agrees to the site’s terms of service which set forth the rules for behavior within the community. Potential new users are reminded that posts are not private and are publically viewable. The site notes that,

To best protect your privacy and to comply with our guidelines, when choosing a username do NOT use your real or full name, a name you use anywhere else online or in offline life, or a handle which you think those who know you would recognize. Do NOT post anything you do not want viewed publicly and

permanently. Protecting your anonymity here is primarily your responsibility...Given the personal nature of posts here and the fact that the Internet is a public medium, protecting your anonymity is important. Safeguarding your identity at Scarleteen is your responsibility. For your safety, you may not post personally-identifying information, such as full names, phone numbers, personal photos, links to social networking sites, and/or e-mail or postal addresses. (“Rules, Policies, and Disclaimers, n.d., para. 2-3, 9).

As evidenced by their guidelines, Scarleteen takes user privacy very seriously.

Administrators may edit any profiles or posts that contain personal information that is prohibited by the user guidelines.

The site’s guidelines further set forth the requirements for behavior in the community. They address copyrighted materials, general behavior (the use of proper grammar and spelling, forbidding bigotry or hate speech, posting guidelines, etc.), and remind users that the website will not answer questions about sexual technique. The guidelines also introduce Scarleteen’s overarching values, such as being sex-positive, inclusive, and pro-choice. Users are instructed about the behaviors that will result in their posts being edited or removed or their registration being revoked. The guidelines remind users that the information “is provided for informational purposes and is NOT meant to and cannot substitute for the advice provided by an in-person medical professional” (“Rules, Policies, and Disclaimers,” n.d., para. 7).



Figure 2. Screenshot of Rules, Policies, and Disclaimers

The main Scarleteen website also lists these guidelines and a more extensive discussion of the privacy policy (“User Guidelines and Privacy Policy,” n.d.).

After accepting the privacy policy, the new user then chooses a unique user name and submits some basic information such as an email address (which is not shared or available to the public).



Figure 3. Screenshot of registration form.

On this screen, users are also able to include other information in their profile such as general location, interests, sexual identity/orientation, and first language, though this information is not required. No specific identification information is requested or allowed to be posted. The user is also able to create a personal “signature” that will appear at the bottom of each of their posts on the message boards. Except for the executive staff of the website, users are not allowed to post photographs of themselves. They are also warned about posting identification information on the boards or sharing it with others. The message board system does track IP addresses of posts, but the information is only available to site administrators. The guidelines note that this information could be made available to authorities in case of harassment or legal action arising from a user’s participation (“Review User Agreement,” n.d.). The site also does not allow private messaging between posters or sharing of email addresses.

Data Set

The current study utilized messages posted on the Scarleteen.com message boards. The site includes 18 active forums that are accessible to regular users and staff (there are three additional areas that are only available for staff to edit or post in and one password protected area for users at high risk and staff only). Additionally, articles and expert answers from the website were examined since message board users were often referred to these pieces of content.

The data set from the main Scarleteen.com website was made up of 7 articles (average length 1,613 words) and 23 expert advice questions (average length 113 words) and answers (average length 740 words). The data set from the message boards is made up of 105 threads from 7 different sections. Eighty-three threads contained conversations

with staff only, 3 threads contained responses from other users only, and 19 threads included responses from both staff and other users.

Data Collection

Data was obtained by utilizing the message board's search function to look for "gynecologist," "OBGYN," and "pelvic exam" in the sections of the board that are available for both regular users and staff. These terms were selected because they are likely to feature prominently in both questions and answers regarding the seeking of gynecological care. Only posts that concerned the medical visits for women's reproductive care were included in the final data set. Posts dealing with health care provider visits for check-ups, mental health issues, diet, or other health concerns were excluded. Further, posts related to men's reproductive health care were not included in the data set. While general health topics are important, the current study sought to focus only on women seeking reproductive care. Search results were limited to the time period of January 2010 through December 2012.

Both the original questions and the associated replies were included in the data. Posts were examined individually and grouped into their associated threads. The data set included both the initial post and the replies so that the conversation between the inquirer and the experts and peers who respond were considered.

The main website tag function was used to identify articles and expert answers that relate to sexual health care for young women. Each piece of content has been tagged by staff when submitted for the website. These tags allow related content to be categorized and searched together. This is an example of what Spinello (2002) refers to as a "keyword metatag" which is "a list of key words or terms which can be used to

describe a particular web site or web page within that site” (p. 24). The following tags were examined: “gynecologist,” “healthcare,” “medical,” “reproductive health,” “sexual health,” and “sexual healthcare.”

Ethical Considerations

Garcia, Standlee, Bechkoff, and Cui (2009) posit that “[a]s Ruhleder (2002) and Taylor (1999) note, the use of archived materials enables ethnographic research on cultural artifacts (e.g., Web pages and listservs), and interactions (e.g., online discussion boards) which are examined after the fact...” (p. 74). Walther (2002) suggests that “[i]t is important to recognize that any person who uses publicly-available communication systems on the Internet must be aware that these systems are...mechanisms for the storage, transmission, and retrieval of comments” (p. 207). The information recorded on Scarleteen’s website and message boards are a part of the Internet’s public record. The postings are available and accessible to anyone on the Internet.

Scarleteen’s guidelines stress that users should consider that “...the Internet is a public medium...you may not post personally-identifying information, such as full names, phone numbers, personal photos, links to social networking sites, and/or e-mail or postal addresses” (“Rules, Policies, and Disclaimers, n.d., para. 2-3, 9). The guideline’s statement supports the assertion by Hookway (2008) that “...there are researchers who argue that archived material on the Internet is publicly available and therefore participant consent is not necessary...[t]his position rests on the analogy between online forums and public space...” (p. 105). Walther (2002) argues that

The analysis of Internet archives is not human subjects research if a researcher does not record the identity of the message poster, and if the researcher can legally and easily access such archives...[I]t seems fairly clear that the analysis of publically-available Internet-stored conversations does not constitute human

subjects research, and may therefore be exempted by IRBs from human subjects regulation. Researchers must make their own individual ethical decisions with regard to activities such as quoting or reflecting names or pseudonyms in their ultimate publications. (p. 207)

As data was collected, user names were removed and pseudonyms were assigned. Although user names were already not associated with information that could identify individuals, pseudonym assignment was conducted to provide an extra level of anonymity. Because participants in this study came from a variety of different cultures, simple letters have been assigned as pseudonyms.

As a researcher becomes immersed in the situation however, further ethical implications may be brought to light. Kendall (2009) notes that the relational boundary, the “relationships between researchers and the people they study,” may be of concern (p. 22). I first registered on the message boards at Scarleteen in 2000 and have been a member of the volunteer staff for more than 10 years. Due to my involvement, my immersion in the site is relevant to the current project.

Steinmetz (2012) argues that “[b]ecause of the nature of message boards, the line between ethnography and content analysis/archival research is blurred” (p. 27). The current study is not fully ethnographic in that the message board interactions were not observed as they were happening. Instead, conversations were subjected to content analysis after they had taken place. However, Hine (2009) notes that in ethnography “...the researcher should become immersed in the social situation being studied and should use that experience to learn how life is lived there...” (p. 6). As a long-time member of the community, I am immersed in the site in a unique manner. As Steinmetz (2012) notes, “[t]he one feature which distinguishes virtual ethnography of online message boards as ethnography is the immediacy, the emotions, and the connection to

other users the researcher can feel and experience in the field site—the social links often missing in content analysis and archival research” (p. 27). My immersion in the community allows me to better understand these social links. While the current study is primarily a content analysis, since it involved observations of the Scarleteen community (via the message boards and expert answer submissions) it can still be considered a somewhat ethnographic undertaking.

Further, Hine (2009) suggests that “[t]he internet also provides some intriguing possibilities for ethnographers to exploit based on the many traces of social activities that it preserves, in the form of web sites, message boards, hyperlinks, etc.” (p. 11) and that “[t]he results are studies that illuminate the social dynamics at the heart of the technologies concerned” (p. 12). My placement in reference to the data is beneficial in that I was familiar with the community, its rules, and its norms at the beginning of the project. The language and flow of interaction within the community is easily recognizable for me. In this type of research, Steinmetz (2012) notes that “...there is an obvious blurring of boundaries between primary ethnographic experience and secondary content analysis...[f]or those who embrace the complex, the blurring of methodologies may be welcomed” (p. 27).

However, as noted above, the preexisting relationship is not without concern. Participation in the community makes the examination, in part, autoethnographic (Hine, 2009). As a volunteer specifically, my own participation had the potential to be included in the data set. To moderate this impact on the analysis of the message boards, the time period chosen was one in which I was not active on the message boards. However, my voice as a staff member may appear in some of the static content (articles or expert

answers) data from the website. The inclusion of my own voice is important since I am a member of the community. boyd (2009) notes that when looking for patterns a researcher must "...try to look at what you're observing from a new angle. Try to make sense of practices in terms of the practitioner and the observer. Be reflexive of your own biases, and question any and all biases that you have" (p. 29). It is my responsibility then to situate myself within this data and be aware of any bias that may exist due to my participation.

Method

Lindlof and Taylor (2002) note that "...qualitative researchers seek to preserve and analyze the situate form, content, and experience of social action, rather than subjecting it to mathematical or other formal transformations" (p. 18). Since this study attempts to better understand the experience of message board participants, a qualitative approach is appropriate. As Butler-Kisber (2010) indicates,

Qualitative inquiry questions focus on what, how, and why, using participant voices and experiences to explain (or in other words to present a small 't' theory) about phenomenon or what is happening in a certain context. Maxwell (2006) suggests that the strengths of a qualitative study are that it focuses on the situations and/or experience of people, it is inductive or emerges from these situations or experiences, and it emphasizes the use of words instead of numbers. (p. 26)

This study uses the voices of study participants to better understand the requests for and provision of social support on an online message board and then to inductively explore their conversations about reproductive care.

The current study utilized thematic analysis, a form of qualitative research. Butler-Kisber (2010) notes that "[t]hematic inquiry uses categorization as an approach (Maxwell & Miller, 2008) for interpretation that produces a series of themes that emerge

in the process of research that account for experiences across groups or situations” (p. 8). In other words, “[t]hematic analysis focuses on identifiable themes and patterns of living and/or behavior” (Aronson, 1994, para. 3). Thematic analysis has been used to examine social support in online communication about a variety of topics. For example, Tichon and Shapiro (2003) examined themes present in an online self-help group for siblings of children with special needs. Christian (2005) identified two primary themes in the postings of step mothers in an online stepfamily forum. Coulson (2005) conducted a thematic analysis of postings in online support group for individuals with irritable bowel syndrome. In a study of emotional expression, Lieberman and Goldstein (2006) identified themes expressed by women in an online breast cancer support forum. Thematic analysis has also examined other online cancer support contexts including online cancer conversations between retired persons (Donelle, Hoffman, & Goetz, 2009), patient attitudes in online cancer support groups (Im et al., 2007), cancer support groups for patients and families (Schultz, Stava, Beck, & Vassilopoulou-Sellin, 2003), and the experiences of facilitators of online cancer support groups (Owens, Bantum, & Golant, 2009). Beyond cancer, online message boards have provided a site of study for other chronic diseases such as unmoderated online diabetes forums for retired persons (Hoffman-Goetz, Donelle, & Thomson, 2009), communities focusing on disordered eating (McCabe, 2009), online lupus support groups (Miles, 2009), and depression support (Siriaraaya, Tang, Ang, Pfeil, & Zaphiris, 2011). Online message boards for women’s health issues are also a popular topic for studies using thematic analysis. Research includes women’s experiences with menopause (Cousineau, Rancourt, & Green, 2006; Im, Liu, Dormire, & Chee, 2008), discussion of pregnancy and family life

(Kouri, Turunen, Tossavainen, & Saarikoski, 2006), and fertility (Van Selm, Tuil, Verhaak, Woldringh, & Kremer, 2008). Thematic analysis of online message boards has been used to examine a variety of other health topics including medications (Macias, Lewis, & Smith, 2005; Pestello & Davis-Berman, 2008) and message boards about general health issues (Wikgren, 2003).

The use of thematic analysis was appropriate for the current study because it focused on the relationship between the data and the categories that emerged during coding (Lindlof & Taylor, 2002). The objective of the current study is to understand how individuals are using online message boards about health information and what their reactions are to that information. The coding used for this data provided an organic understanding of the interactions on this message board by allowing the data to gather into appropriate categories.

Each post and thread was read multiple times in order to identify the themes present. Articles and expert answers were also be examined for themes. After the initial readings, thematic analytic techniques (Lindlof & Taylor, 2002) were used to categorize the responses into broad semantic patterns (Meyer & O'Hara, 2004). A theme was considered to be present when it appeared three or more times within the data. Once themes were identified, a constant-comparative method was used where examples of the themes were compared to one another to confirm their presence and importance. Themes were then collapsed into categories. Excerpts are provided to give additional support for the themes and categories identified.

Research Questions

The study will answer the following research questions:

RQ1: What types of social support are sought by young women seeking information and support on an online message board?

RQ2: What types of social support are offered in expert and peer replies to young women seeking information and support on an online message board?

RQ3: What themes are present in posts made by young women seeking information and social support on a message board?

RQ4: What themes are present in expert and peer replies to young women's message board questions about seeking gynecological care?

Procedures

Step 1: The message board search function was utilized to locate threads dealing specifically with young women's reproductive health care. The following search terms were used: "gynecologist," "obgyn," and "pelvic exam." The search was limited to the January 2010 through December 2012 time period. Posts were copied and saved for further analysis. User names were removed from the dataset and pseudonyms assigned. Any posts that were not specifically about women's reproductive care were eliminated. This included questions about check-ups, mental health exams, diet, and other general health topics.

Step 2: The website tag function was utilized to locate articles and expert answers dealing specifically with young women's reproductive health care. The following tags were examined: "gynecologist," "healthcare," "medical," "reproductive health," "sexual health," and "sexual healthcare." Any content that was not specifically related to women's reproductive health care was eliminated.

Step 3: Individual message board posts were examined to identify themes present in concerns expressed by young women seeking information and social support on a message board. (RQ1) Questions submitted in expert answers were also be examined for themes.

Step 4: Conversations were examined to identify themes present in expert and peer replies to concerns expressed. (RQ2) Responses were coded openly and also utilized Cutrona and Suhr's (1994) categories of social support by examining action-facilitating support (favors, tasks, and providing information) and nurturing support (esteem support, emotional support, and social network support). Responses to ask the expert questions and website articles were examined to provide further information about expert replies to concerns expressed.

Step 5: Individual posts were examined to identify themes present in questions asked by young women seeking support. (RQ3) Questions submitted in expert answers were be examined for themes.

Step 6: Conversations were examined to identify themes present in expert and peer replies to young women's message board questions about seeking gynecological care. (RQ4) Responses were coded openly and also utilized Cutrona and Suhr's (1994) categories of social support by examining action-facilitating support (favors, tasks, and providing information) and nurturing support (esteem support, emotional support, and social network support). Responses to ask the expert questions and website articles were examined to provide further information about expert replies to concerns expressed.

Step 7: Once themes had been identified, examples were compared to verify their presence and importance. And then the themes were collapsed into categories. The

resulting themes identified provided evidence to answer the research questions. Broad categories from both individual posts and conversation in threads displayed the communication of social support during conversations about gynecological care on an Internet message board and provided insight for understanding the supportive communication that occurs on this message board.

Chapter 4: Results (Posts by Information Seekers)

Reviewing the posts made by young women seeking information and support on an online message board point to the complicated nature of women's feelings about seeking reproductive care. Posts commonly included multiple themes as women expressed their concerns about care and the physical, mental, emotional, and social consequences of receiving that care. The posters sought both action facilitating and emotional social support from others on the boards. Further, they expressed fears about privacy, anxieties about pain, embarrassment, normality, body image, the reactions of others, and concerns about potential health problems. Some posters discussed their past experiences as survivors of sexual assault or worried about the impact of past interactions with health care providers. The timing of the care sought, whether it was preventative or for an emergent issue, like an STI or possible pregnancy, also appeared as salient issues for these young women. Some information seekers stated their need for care, while many others requested advice about whether they should seek care or not. Finally, it should be noted that some of the posters were seeking advice prior to seeking reproductive care while others came to the message boards to try to make sense of what had already occurred during an appointment.

Quotations provided in this analysis have been left unaltered. Spellings, abbreviations, and uses of grammar have been presented exactly as submitted by the post's author. In order to help situate each participant, information about age, location, and number of posts on the message board are included (when available). When location information has been provided, it is listed as the user submitted it.

Categories of Social Support Sought

The first research question asked, what types of social support were sought by young women seeking information and support on an online message board? For posters on Scarleteen's message boards about seeking reproductive care, the quest for social support is clearly a primary goal. Cutrona and Suhr (1994) offered two categories for social support: action-facilitating support and nurturing support. Every message included a request for some type of support, with the vast majority including appeals for multiple support types.

Action-facilitating support. Action-facilitating support was apparent in many of the posts made at Scarleteen. Action-facilitating support involves requests for favors, tasks, and providing information (du Pré, 2005). The vast majority of requests in this category were for information.

Some users posted on the boards asking for specific information about finding care. S (age unknown, Virginia, 90 posts) asks "I would really like to get an IUD, but I have no idea where/how to find an OBGYN that can insert one for me. How do I find a doctor?" She indicates that she would like care, but does not know where to find the care she needs. Like many other users, she asks for information about how to find a care provider. I (age unknown, "probably somewhere," 5 posts) expresses concerns about talking to her mother about getting reproductive care. She then notes "Is there any way I can tell her I'd like to get checked out without her getting suspicious? Or, is there any way I can see a free doctor without being 18?" Similarly, T (age unknown, England, 122 posts) notes:

I'm a little confused. The way that I've gathered that any specialist sort of doctor in the nhs is: You go to your gp, and explain your problem, and they refer you to a

specialist. This referral will then result in an appointment... in about a month and a half's time... If I need a gynecologist for pap smears/sti testing/to get birth control etc. does it still happen through this very lengthy process? Or will the gyn also be a gp and I can just make an initial appointment with them?

In the above post, it is clear that T is seeking information about navigating the process of getting an appointment with a care provider through the NHS in England.

Other users ask for information about what happens once they have made the examination. They have already made appointments with providers, and in some cases have already been to see their care provider.

I went to the OB/GYN today for the first time. When the doctor was doing my pelvic exam, I noticed that I felt a bit of tenderness on one side of my abdomen when she pressed down on it. I figured that would have been normal to feel since she is pressing down. Is it normal to feel some pressure though when they are doing the exam? (V, age unknown, United States, 71 posts)

As is clear in the above question, V is requesting specific information about what is normal during a pelvic exam. She indicates that this was her first examination of this type. Another poster, D (age unknown, USA, 9 posts) notes “My question is, what can I expect and what kinds of things do they generally test for? How do they conduct the test?” She wants to know about specific tests and how they are conducted. N (19 years old, Raleigh, 43 posts) notes “My boyfriend and I are going to get an exam and screening done tomorrow after school. This will be the first time we've done this, and we aren't sure what to expect. Any information would be much appreciated.” She and her partner are being tested together, but do not know what to expect. Like many users, N thanks responders in advance for any informational support they may be able to provide. R (age unknown, Mexico, 23 posts) states “I just need some guide to make the most of my visit to the doctor!”

Another poster, EE (age unknown, Chicago, 32 posts) notes that she is also approaching her first exam and asks “On Friday I'll be having my first STD test ever. The doctor's office wasn't really able to give me very much information over the phone... Can anyone tell me what to expect?” Of particular interest in EE's question is her statement that her care provider's office was not able to give her information about what to expect in the examination. After being unable to get acceptable answers from her doctor's office, she sought support online.

Y (age unknown, United States, 61 posts), came to the message boards with questions about bleeding after a recent Pap smear. After exchanging posts with a staff member, she asked, “Also, if for some reason the test does come back abnormal, what could be some reasons?” In this case, the poster is looking for more information about what could cause Pap tests to return an abnormal result. Y's post also illustrates that users are asking for informational options. Another user, W (age unknown, Nebraskaland, 10 posts) says “Don't get me wrong, I don't expect you to diagnose and treat me through a computer, but if you could maybe give me some perspective as to some options I have, I'd really appreciate it.” Like many other posters, she notes that she is looking for perspective, opinions, or options with the realization that this will not replace information from her doctor.

Many users also sought information about the process of a pelvic exam. L (age unknown, USA, 115 posts) asks,

But I guess my question is, when I go in do I ask about BC before the exam? What should I expect? Do they check for std's? Hepitatitis? I know that I don't have any vaginal discomforts. I'm just freaking myself out for no reason..

Like many posters on Scarleteen's message boards, L wants to know what to expect from a visit with a gynecologist. O (14 years old, Panama City, 11 posts) asks, "This is my first visit, so what should I expect?" The post continues as she asks about what specific type of questions she should expect and how the exam will likely progress.

Some posters have already received some kind of care and want information about future examinations. P (20 years old, location unknown, 25 posts) explains that she has already seen a care provider in order to obtain birth control. The care provider opted to delay the pelvic exam, but gave her a 6 month prescription for birth control. PP comes to Scarleteen to ask "At this next doctor's appointment, do you think she is likely to give me a pelvic/vaginal exam? I'm 20 years old (although I'll be 21 at the time of the appointment). If she is planning on doing so, will she tell me prior to the appointment?" She seeks information about what her care provider may do during subsequent appointments.

Other users who have already interacted with care providers want information about how they can influence the process of future exams. For example, T (age unknown, location unknown, 13 posts) noted:

Is there anything I can do to make sure the next time I see a gynecologist it doesn't hurt so much? I didn't really know what to do. Telling her to stop didn't feel like an option because if she couldn't find my cervix, how could I get a pap smear? And how do I stop freaking out about the whole thing and take care of my poor beleaguered vagina?

T's previous exam was painful. Her description of her vagina as "poor beleaguered" indicates she feels very strongly about using the information gained to better care for her body during future examinations.

Another category of action-facilitating support is that of a request for help with tasks. While there were fewer requests for task help, users still occasionally asked others for practical assistance. Almost all posts in this category involved users asking for help in finding resources. For example, A (19 years old, Pennsylvania, 94 posts) asks:

I live in Philadelphia, PA. Can somebody help me find the free clinics in my city? Condoms are expensive and google isn't much of a help in finding any clinics or planned parenthood places. any websites or something that would be helpful would be great. I just don't have any money to buy condoms and I don't have the pill, so it's important...

A indicates that she has sought assistance herself, but has not been able to locate any free clinics in her city. She posts on Scarleteen in the hopes that someone might have access to resources that she does not.

Nurturing support. Nurturing support generally involves things like emotional support, esteem support, or social network support (du Pré, 2005). Posts on Scarleteen clearly identify reproductive care as a highly emotional issue for young women. JJJ (age unknown, Australia, 23 posts) described her experience seeing her doctor to discuss contraception. Her primary care doctor provided information about many different contraceptive options and gave her a referral to a gynecologist. JJJ notes:

So here I am at home, and I'd like to share my experience with entering into the seemingly vast world of contraception and gynecology as well as get some feedback/discussion on my situation. My head, quite frankly, is reeling from all of this right now :o

JJJ's characterization of her head "reeling" is similar to the expressions of other young women in the dataset. They report feeling similarly overwhelmed or exhausted and unsure about how to deal with those feelings.

Y (age unknown, USA, 14 posts) notes that "Overall the whole situation has been making me think a lot lately and causing me quite a bit of stress!" The word stress is one

used many times by posters in this dataset. Like Y, they request help dealing with the stress of upcoming appointments, concerns about making an appointment, or managing the aftermath.

Other posters request help dealing with fear that they are experiencing. B (age unknown, Puerto Rico, 76 posts) describes her symptoms and then notes:

I have an appointment with my gynecologist on Monday but I needed someone to talk to because I'm so scared. I'm too afraid to even have sex with my boyfriend this weekend because it could make it worse. I just need to get all these feelings of my chest...

B has symptoms and has made an appointment with her care provider, but describes a very high level of fear about her situation. Her post makes no mention of needing advice, but rather a need to share her anxieties with someone who will listen. B's fear of having sex with her boyfriend would also suggest that she may not be getting the needed emotional support from those she interacts with face-to-face.

K (age unknown, London, 2 posts) ends a post requesting information about seeing a gynecologist for pre-conception care by stating "Im feeling very depressed, please help to answer..." Highly emotional words like "depressed" were common in posts by young women seeking support. Another poster, Z (age unknown, location unknown, 26 posts) posted about a recent diagnosis of HPV by her gynecologist after a routine exam. She notes that "It was horrid, not because of any pain but because my mind was racing, 'How the heck did this happen?' most of the entire time." Z describes her feelings about the HPV diagnosis by saying, "I'm just absolutely confused and unhappy. It almost makes me feel so dirty that I don't want to have sex anymore." When her doctor's office called back to schedule another procedure, Z notes that "I've been too pissed off about having HPV that I just sounded "Bleh" over the phone while my doctor

talked about the procedure.” Several times, Z refers to her posts in this conversation with a Scarleteen expert as “venting” or “whining” and in her last post, she notes that “Even though I might sound pissy, I really appreciate it!” It is clear by Z’s tone and word choice that emotional support is a clear priority. She described her mind as racing as she experiences negative emotions like confusion, unhappiness, and anger. Further, she thanks the expert for the emotional support they have provided for her.

Fewer young women in the sample made posts requesting esteem support. However, the instances of esteem support always involved posters seeking verification of information they had already sought out. For example, W (22 years old, Eurpoe, 236 posts) is concerned about the appearance of her external genitalia and wonders whether she should see a doctor about it. She notes that she has examined her own body using a mirror and writes:

I tried looking at a ton of pictures of how a vagina generally looks like but none of them didn't really look like what I have. Only a few with hymens had a resemblance, but didn't quite look the same. (ie they were red or covered the opening, while mine is light and doesn't cover much... could be just a variant though?)

In this post, W appears to be seeking reassurance of her own competence. She has inspected her body, compared it with examples she found online, and now wonders if she needs to see a doctor. Similarly, V (age unknown, Canada, 1 post) notes “Okay soo, I've been looking at diagrams of vaginas because I think somethings wrong with mine, and it doesnt match with the diagram.” Like W, she later asks if she should see a doctor to find out if her research and assessment are reasonable.

Body image issues are not the only ones where posters requested assurance about whether their research was correct. X (18 years old, Louisville, 6 posts) reports that she

has been having painful sex and has been putting off going to a gynecologist to explore the problem further. She notes “I know there's a number of problems that could cause such pain, but I don't think I have most of the things I've found while researching.” Rather than seeking face-to-face advice from a care provider, she wants reassurance that that her self-diagnosis is correct and that it is not any of the problems found in the research.

Similarly, many posters note that they have read Scarleteen's materials about reproductive care. They mention specifically that they have interacted with the article “Your First Gynecologist Visit,” other materials about STI testing, or have searched the site and boards for information. In mentioning these materials specifically, the young women seeking support want reassurances that they have prepared and researched completely.

A final type of nurturing support sought by young women coming to Scarleteen is social network support. The most striking aspect of poster's requests for social network support is their statements that they lack support in their existing social networks. TT (19 years old, Nova Scotia, 9 posts) posts for advice about getting gynecological care and how to discuss it with her parents. She notes:

Perhaps a few outside views will make my head a bit less murky... the irony in all this is that I am totally sexually free and communicative, and game for anything... Perhaps I'm letting my mom get the better of me, or perhaps she's totally justified? I understand that my parents are not sexually progressive people and I won't receive any guidance or support from them on that matter, but was it selfish of me to assume my mom would have reacted better?

TT then requests that other posters share their experiences with her. The post indicates that she lacks network support from her parents. TT's request for input from others is a clear example of a user seeking to form a new online support network.

Another user, FF (age unknown, location unknown, 150 posts) discloses about a conversation with her father on the way home from a recent visit to her care provider.

She notes:

On the car ride back, my dad basically dismissed everything she said. He's a doctor himself, and he said my mom goes through the same irregular periods and he doesn't want them to prescribe or do tests that "aren't necessary"... I'm actually in tears right now.

FF's experience indicates a perceived lack of support from her familial social network with regard to her reproductive health. Other users noted a lack of network support from their friends. XX (age unknown, Germany, 42 posts) states "...and I wouldn't want to trouble my best friend with this, who was also raped. I guess I just need some help as to what to do next..." While she would like support from her best friend, XX feels the friend will be unable to provide her with that support due to her own prior experiences. Because of their lack of network support, these posters have turned to Scarleteen to form a new social network that they perceive as being more supportive.

Themes Present in Questions & Expressions of Concern

The third research question examined themes present in posts made by young women seeking information and social support on an online message board. As young women expressed their concerns about reproductive care, constant comparison revealed several important themes. Many young women expressed concerns about privacy and parental knowledge of their health care. They also expressed a variety of different anxieties. Many information seekers were concerned about how past experiences would impact their reproductive care. Preventative and emergent issues (such as STIs or pregnancy) were clearly delineated in posts. A division also occurred among those asking

if they should seek care versus those stating they knew that they needed care. And finally, pre-care and post-care concerns were expressed.

Privacy & parental knowledge. W (age unknown, Nebraskaland, 10 posts) sums up her experience with discussing reproductive care with her parents as follows: “I’ve never been to a gynecologist and I don’t enjoy discussing sexual health issues with my parents.” Another poster, EE (age unknown, NYC, 3 posts) simply notes, “I don’t want parents involved.” Many of the young women posting at Scarleteen were concerned about their privacy and parental knowledge when seeking reproductive care. LL (16 years old, Oklahoma, 3 posts) asks, “So how confidential is a gyno required to be? Can they tell their patients' parents about sexual partners?” This statement exemplifies the concern expressed by many young women posting on Scarleteen’s message boards. For many posters like LL, the concern about privacy or parental notification appeared as an important factor. After one of the website volunteers provided an answer to her question, LL even followed-up by asking, “So for a routine check up, most clinics won't reveal anything to parents?” This clearly indicates that privacy is a very salient concern for LL, so much so that she needs reassurance that her understanding of the expert’s answer is correct.

AA (age unknown, Arizona, 3 posts) worries about disclosing identifying information and insurance and how that might result in her parent being notified.

I've read about how to get birth control on the Scarleteen website ([link](#)) and it says that the doctor would ask for my name, address, phone number, and social security number. Is there any way my mother would be able to find out that I was trying to get birth control through any of these? Would I need to have insurance, and would my mom be able to find out through that? Is there any way I can not tell them any of these things, especially address and/or social security number?

This concern about disclosing personal information is repeated over and over again in the data. Many posters' concerns surrounded parental notification due to insurance use and billing for reproductive care visits. P (19 years old, usa, 20 posts) notes "I will be 20 in a few months. The thing is, my mom doesn't know that I am sexually active, and she would know if I asked to go or went on my own because I am still on her insurance." Some posters, like P, state that they assume their parents will be notified if they use insurance. Young women who expressed this theme did not comment on the source of their belief about parental notification when using insurance. This is particularly interesting for posters from the United States. HIPPA and other patient privacy regulations control the level and amount of information provided about patients. Concerns about insurance and parental notification are not limited to the posts of young women from the United States. MM (age unknown, canada, 12 posts) asks "When I am asked tomorrow if I am sexually active...do I say yes? I don't want to because I know they will do STD test and show up on my mother's insurance. She is unaware of this experience." For MM, concerns about parental notification of STD testing are very real. VV (age unknown, USA, 8 posts) asks, "Should I try to go to a clinic or talk to a doctor, I don't want to go to my normal doctor, because it's on my mother's insurance and they might have to tell her or something."

Young women discussed their concerns about parental knowledge of their need for reproductive health care in extremely descriptive terms. VV (age unknown, USA, 8 posts) notes that "I'm so scared, I can't tell my parents either...They would be so disappointed..." Like others, VV's concern about her parents disappointment points to a desire by young women to carefully manage the perceptions of their parents. Poster FF (age unknown, location unknown, 150 posts) states that her father sees her as a "perfect

angel daughter” and is concerned about how being sexually active or seeking out care could change that view. These young women are clearly concerned about how disclosure to parents will influence their perceptions.

Another poster O (14 years old, Panama City, 11 posts) notes that “I feel like this is some sort of way my karma is punishing me for enjoying sex. My mom is the type of person to get angry with everything, even if you try and reason or talk to her...” Like O, many other posters express fear of their parent’s anger if they find out, or concerns that their parents will prevent them from seeing their romantic partners.

Some posters in the sample expressed uncertainty about their parent’s reaction to the young woman’s desire to seek reproductive health care. YY (17 years old, USA, 29 posts) states “My only issue is that I am 17, and have no idea how to talk about this with my mom. I have no idea what her reaction will be.” She also notes that she wants to be “responsible and healthy.” Another user, C (age unknown, location unknown, 3 posts) requests that responders “Please keep in mind that I’m still living with my parents and may have trouble asking to see a gynecologist.” For these young women, tentative language highlights the uncertainty surrounding conversations with parents about their reproductive care. Words like “may,” “might,” “uncertain,” and “unsure” frequently appear in posts.

A few young women specifically asked for help in talking with their parents about their reproductive health care. TT (19 years old, Nova Scotia, 9 posts) asked other users to share their experiences communicating with parents about reproductive care and birth control. After relaying her story about a visit with her gynecologist and telling her parents about the cost of an IUD, she reports that her father responded somewhat supportively

and her mother responded negatively by “growling” at her and judging her sexual choices. TT then asks, “I would love to hear from some people about their experiences' going to their parents about birth control; preferably people who have older parents who are "living in the dark ages" as I say...” TT’s characterization of her parents as “living in the dark ages” points to a perception of disconnection that was common in posts by other young women asking about how to talk with their parents. Another user, I (age unknown, “probably somewhere,” 5 posts) expresses that her mom “doesn't understand my relationship very well,” causing I to wish to keep her from finding out about her reproductive care visit. Expressions of disconnection leading to an enhanced need for privacy were almost exclusively connected to young women feeling that their parents didn’t understand their romantic relationships or their sexual activity.

A few posters in the sample reported having supportive parents, or at least parents who are not actively unsupportive. J (17 years old, New York, 3 posts) notes “My parents know all of this, and my mom says I need to see a gynecologist, because apparently that's just what you do when you're having sex.” Her mother is encouraging her to seek out reproductive care and is aware of her sexual activity. Some other users reported similar encouragements from parental figures, but the majority of young women in the sample who mentioned parents noted that their parents were unsupportive or that they wished to hide their need or desire for reproductive care from them.

User BB (18 years old, “my house,” 48 posts) expresses a less common privacy concern. BB asks, “Can a doctor share my personal information with other doctors?” A few young women in the sample posed similar questions. They state concerns about care providers sharing information with one another. This is of particular interest given that it

does not seem logical on the surface. In order to have continuity of care, it is desirable to have an individual's health care providers communicate with one another. However, for young women stating this privacy concern, it appears that the desire to control their own health information and the need to manage identity are more important. For these posters, the sharing of information between care providers is not viewed positively.

Anxieties. C (age unknown, location unknown, 3 posts) notes that "I'm not trying to flip out, but I'm really, really worried." C's concerns about being "really worried" mirror many of those expressed by other young women at Scarleteen. Others characterize themselves as being "freaked out" or experiencing "anxiety." This is not surprising given previous research indicating that women specifically report experiencing anxiety about gynecological examinations (Tiefer, 1979; Ouj et al., 2011). As user DD (21 years old, location unknown, 12 posts) notes, "...I know I need to see a gynecologist at my age but I'm absolutely terrified; I can't do it. Just thinking about it makes me want to cry, so I can't imagine what a scene I'd make if I actually tried it." DD goes on to state "I feel like the biggest baby in the world right now, but I have no idea who to talk to or where to start to figure out how to deal with this." Clearly, this anxiety is not a minor issue for many young women. In their own words, posters at Scarleteen provide a clearer picture of common issues that cause them anxiety when they consider seeking reproductive care.

Pain. Many young women expressed anxiety about feeling pain during a reproductive examination. Surprisingly, the vast majority of posters expressing concerns about pain had already visited care providers in the past. Poster T (age unknown, location unknown, 13 posts) noted "I went to a new gynecologist today for my annual exam, and

the whole exam really hurt, which made me tense, which probably made it hurt more.” She then asks how she can prevent pain during future examinations.

T’s assertion that she had experienced pain during an exam was not unusual. Another Scarleteen poster, M (24 years old, location unknown, 64 posts) states that her care provider “...was going to do the pelvic exam and pap smear but was unable to because I wasn't able to tolerate it. too painful, he said its because Im a virgin and that its not my fault.” T’s experience also overlaps that of other users concerned about pain due to virginity. It is important to note that most users expressing worries about pain and “virginity” do not provide a definition for this term. It is most often unclear whether these young women have been completely sexually abstinent or whether they mean that they have not engaged in intercourse, but may have been otherwise sexually active.

Embarrassment. “Also, please understand that I'm very scared and embarrassed to discuss this. This is why I came to an online forum - where I can remain anonymous” states RR (21 years old, New York, 3 posts). The word “embarrassment” features prominently in young women’s posts at Scarleteen. Feelings of embarrassment surrounding reproductive exams are clearly salient for these posters. “So I hope I get through this embarrassing appointment tomorrow somehow, anything I should know and what to expect?” asks U (21 years old, Michigan, 108 posts). Many young women posing questions about a first exam report that they already perceive the examination to be embarrassing.

While some young women don’t use the term “embarrassment,” the feeling is still apparent in their posts. For example GG (19 years old, USA, 46 posts) notes:

i REALLY dont feel comfortable with a stranger all up in my business. really not comfortable with that. my bf is one thing. he loves me and i know him and im

comfortable around him. a gyno = i dont know them they dont love me and i would feel completely uncomfortable. especially if its a guy. there is no way im gonna lay on a table with my legs in the air for some guy to be touching and lookin at my vajayjay. can somebody please help me?!? i want to feel comfortable about it when the time does come but i cant even get myself convinced that there will be a necessary time. ugh god the thought of going.....help!

GG is comfortable with her boyfriend having contact with her genitals, but uncomfortable with the idea of a gynecologist, especially a male one, examining the area. Her characterization of an exam as laying on a table with her legs in the air while “some guy” is looking at her reproductive organs paints a clear picture of how powerless GG feels about the situation.

Embarrassment is not limited to young women approaching a first exam, however. As M (24 years old, location unknown, 64 posts) notes she is “still embarassed” after an attempted pelvic exam. M’s statement exemplifies the feelings suggested by other users that their embarrassment develops or persists after appointments with care providers. This suggests that feelings of embarrassment may not always be alleviated by “getting it over with” when it comes to reproductive care for young women.

Body image. Concerns about body image featured as a prominent cause of anxiety for young women at Scarleteen. User II (age unknown, California, 2 posts) asks, “will this exam change the size/shape of my vagina? I'm really worried about that because I'm a very petite person and I have low self esteem regarding my lady parts..” In II’s case, her concerns about body image are directly related to her perception of her genitals.

Other posters have other specific concerns about body image with health care providers. F (age unknown, Ohio, 42 posts) notes:

I went there last year but she didn't do an examination because, at the time, I was still a virgin. Now that I'm not, she's going to have to do one if I want a refill on

birth control pill prescription. I'm a little scared. Should I shave or trim before going? What is she going to do to me? Please help! Thanks.

F's question about whether she should "shave or trim" relates to concerns about the state of her pubic hair. Beyond typical grooming, she is clearly thinking about the care provider's perception of her body hair. A smaller number of responses in this category also dealt with posters' concerns about other people's perceptions of their bodies. For example, OO (age unknown, California, 3 posts) wants to make an appointment to have a care provider look at a mole on her vulva. She notes that "Even though it doesn't bother me that much, I want it removed asap because I am scared guys will be disgusted or grossed out if I decide to get intimate with them." Like some other posters in the sample, she notes that she is not uncomfortable with her body on its own, but that she fears what others might think of it.

Often, however, body image discomfort related by young women in the sample is noted much more generally. NN (age unknown, boston, 11 posts) says "I kinda scared to ask my doctor , he's a guy & it makes me feel awkward talking abt any sex or body parts to him." She reports being afraid to talk with her doctor about her body. In this care, NN connects the discomfort to the gender of her care provider.

Others indicate that they are private with their bodies and therefore are uncomfortable with a care provider examining them. YY (22 years old, location unknown) notes in an expert question posted to Scarleteen's main site that "I'm also a very private and am not comfortable being around others if I'm not fully clothed, even changing my shirt with my roommate in the room - another problem I have with prospect of the exam." Some posters expressing this theme note that they are not sure why they feel concerned by the prospect of baring their bodies to a care provider. Others feel that

they can trace the discomfort back to messages from family or other sources about the need to keep their bodies covered in all instances.

Is this normal?

I am 23 years old and I am extremely self conscious about vaginal odor. I don't like my boyfriend to perform oral sex because I am so worried that I smell bad. I scrub and scrub my genitals in the shower but an hour later the smell is back. When I asked my OB/GYN about it he said that he would check me for STD's but never explained anything to me. I haven't had an STD ever and I have had this since I was 13, what is it? How do I know if its normal? Please help! (Anonymous user, 23 years old, location unknown)

As this anonymous user asked in the expert advice area of Scarleteen's main site, many of the young women in the sample were concerned about whether their situations or experiences were normal.

Some posters were concerned about whether their bodies were normal. W (22 years old, Europe, 236 posts) has concerns about the appearance of her vulva. She has looked online at pictures of other vulvas in an attempt to see how hers compares. W notes "Only a few with hymens had a resemblance, but didn't quite look the same. (ie they were red or covered the opening, while mine is light and doesn't cover much... could be just a variant though?)." In a follow-up post she notes "...I guess I'll see a gyn. Now I'm just worried I have some weird mutant vagina." W's characterization of her perception of her body as having a "weird mutant vagina" is extremely descriptive. She clearly fears that her body is not normal, even though her earlier question about whether what she sees "could be just a variant" would seem to indicate she feels normality is a possibility. However, this possibility is stated very tentatively, while the idea that it might be abnormal uses much stronger, more descriptive language.

A few users were concerned about whether things that happened during a reproductive exam were normal. For example, V (age unknown, United States, 71 posts) asks “Is it normal to feel some pressure though when they are doing the exam?” Another poster, HH (age unknown, USA, 97 posts) writes about a traumatic experience having a pelvic exam. She notes that she is a survivor of abuse and that she had a panic attack during her exam. HH’s care provider did not respond in what she felt was an appropriately supportive manner. She notes that:

It felt like she was saying that what happened to me was normal, and that the way I reacted was what was alarming. I'm usually very hard on myself, but I honestly think I've done alright considering everything. So my question is, was she out of line in saying those things to me, and should I find a new doctor?

In this case, HH feels that her reaction was not abnormal, but her provider acted as if it was. She is considering seeking other care because of the way the provider treated her.

Fear of diagnosis. A final key anxiety expressed is that of a fear of a diagnosis. L (18 years old, USA, 115 posts) notes, “I've always been told to go in before now, but I've always been afraid. Like what if my vulva isn't right? What if there is something wrong? I've just always been afraid, and I don't really have any reason to be.” Although L feels that there is no reason for her to be afraid, she still expresses anxiety that there is something wrong. This anxiety has caused her to avoid seeking care.

The fear of diagnosis is not exclusive to young women who are deciding whether or not to seek care for the first time. Even posters who have already received care express anxiety about what might be wrong after an examination. Y (age unknown, United States, 61 posts) is concerned about spotting during and after a recent Pap test. She states “And I'm nervous! I bled a little during my pap smear and had some minimal spotting after. I googled this and it said that my cervix is probably inflamed and I might have an

infection. I'm scared and I don't know what to do.” Like many other posters, she expresses significant anxiety that there is something wrong.

XX (20 years old, Connecticut, 6 posts) notes that, while she has been receiving reproductive care, she has not been honest with her care providers due to anxiety about her mother finding out. She reports being extremely nervous about an upcoming exam because she is going to “come clean” to her OBGYN about being sexually active for the past several years.

I guess the reason I'm writing this is because I'm VERY afraid that I have HPV or Cervical Dysplasia since I have been sexually active for so long without getting a pap smear. I did not finish the Gardasil vaccinations because I reacted badly to the first one. I am absolutely terrified that I will end up with HPV or Cervical cancer. I have gotten pelvic exams before, and I have been tested for STDS at Planned Parenthood and the results were negative....but I am nervous because I have recurring BV and Yeast Infections. Could the underlying cause be HPV? I always have a very thick, lotion-like white discharge which I have had for years. I am certain I will find out exactly what is wrong on Friday....but I am wondering how high is my risk for HPV/Cervical Dysplasia? What if I have either of these?

XX already has several recurring diagnoses and is afraid that she is at risk for other, more serious health conditions. She is unsure about what will happen if her diagnosis is more serious. Another user, CCC (age unknown, USA, 7 posts) asks a similar question but more simply states that she is “having an HPV panic attack” about an upcoming appointment.

Concerns about HPV diagnoses specifically appeared frequently within the dataset. For example, user SS (age unknown, “:),” 295 posts) states:

Last week I went to the gynecologist for a yearly exam. This morning I got a phone call from my doctor's office and they told me I had "mild dispasia" (and that they were precancerous cells on my cervix) I'm so afraid. What can this be caused by? The woman on the phone told me that it normally goes away and wasn't a big deal. She said sometimes its caused by HPV. That's scares me so bad. My mom had cervical cancer, Is it just hereditary? Do you think maybe the last time I was at the doctor the cells just didn't show up? What else causes these "pre-

cancerous" changes? If I by any chance did have hpv how am i supposed to tel my boyfriend.. I feel like no man will ever want me if I told them, and its their right to know..PLease help me, I'm so afraid

Even though SS's care provider reported that her test results were not "a big deal" and that it would likely resolve on its own, clearly the potential for an HPV diagnosis is scary for SS. She mentions specifically three times within this brief paragraph that she is frightened by the situation. Further, like other posters with similar concerns, the diagnosis of a mother or other relative are specifically mentioned with anxiety about a poster's own diagnosis. SS's mother has a history of cervical cancer, but other users mentioned similar worries about issues like endometriosis, cervical cancer, and irregular periods.

Poster B (age unknown, Puerto Rico, 76 posts) notes that "I've now been referred to my gynecologist and I'm terrified. I've been reading online about how it may be ovarian cancer and it scares me so much." Like XX, B reports anxiety about being diagnosed with a serious health issue. Another user, WW (age unknown, USA, 172 posts) states:

I had a long discussion here earlier about STI testing as my current obsession is about having an STD (specifically HIV) for as long as 8 years and not knowing about it. I do not have any real reason to think this other than the fact that I have never been tested... I have a gynecologist appointment Monday and I was going to ask for the testing but now I am wondering if I should or not. I know that logically I should but I am terrified of what might come up.

While WW notes that she is diagnosed with OCD (Obsessive Compulsive Disorder) and that she believes her current obsession with HIV is a manifestation of her OCD, several other posters in the sample report similar fears about HIV even without the OCD diagnosis.

Past experiences. As a part of questions posed about reproductive care, many young women in the dataset were concerned about the way their past experiences would

impact their reproductive care. These worries appeared almost exclusively about two separate issues.

First, many young women reported being survivors of sexual assault or abuse and noted that this influenced the way they felt about reproductive care. QQ (age unknown, location unknown, 363 posts) began a thread about her fears that she has an STI. She states:

I was recently raped. He took my virginity away. He did not break my hymen that I know of since I did not bleed. He also did not go "all" the way in. At least I don't think so. I went and had a kit done and there was semen and saliva present. I was on meds to prevent any STDs. I am also on the pill. I know I am not pregnant. I want to know if I can still have an STD and if a doctor can tell if you had sex once. I have to go back and have a pelvic exam and am scared it happened 3 months ago and I have a doc apt. in a week and there is only a male doctor available I am scared is it ok to be scared? I kind of wish he got me pregnant so I'd have something to look forward to. Is that normal? It's hard for me to be next to a male or have anyone touch me in any way even if it's an arm graze by accident.

Her recent rape has resulted in her having a difficult time being near any male figures or being touched by anyone. The only doctor available is male, which increases her fears about having a pelvic exam.

ZZ (20 years old, USA, 34 posts) reports similar concerns about abuse further in her past. She writes:

My issue and fear is putting myself out there physically to someone I don't know. I have big trust issues with people when it comes to touching my body and trust issues in general. My grandfather sexually assaulted me when I was 10, along with being around domestic violence when I was younger. My real father abused my mother, a lot of yelling went on. I watched my uncle abuse his kids (my cousins) when I stayed over at my aunt's house (which was a lot when my mother worked and didn't have enough money to get me into daycare). Past boyfriends have only wanted one thing from me and that was sex or my body... never wanted to just be loved by me only from me. So, now... I'm afraid of men (physically, sexually and emotionally)... Laying on the table even with my mom present scared the living daylights out of me.

ZZ's past sexual assault and history of domestic violence has resulted in her fearing reproductive care. She goes on to ask for advice in dealing with the emotional after effects of these experiences so that she can seek care without fear. Unfortunately, ZZ's statements are not unusual within this sample. Other posters who have been victims of abuse are also describe being afraid or even terrified about receiving potentially necessary gynecological care.

The second set of concerns expressed by young women about their past experiences deal with interactions they have already had with health care providers. M (24 years old, location unknown, 64 posts) states that her doctor "was going to do the pelvic exam and pap smear but was unable to because I wasn't able to tolerate it. too painful." She is now concerned about how she will deal with future exams.

Poster BB (18 years old, "my house," 48 posts) expresses similar concerns after an experience with a gynecologist. She notes:

I saw a gynecologist a while back and he gave me some antibiotic and it didnt work so I called to ask for a refill. He told me that he told all the gynecoligists in the practice not to see me unless I got a psychological evaluation because I was nervous during my visit and I asked him if he could look at my clitoris only and I didnt want him to touch my vagina. I had clitoral pain so since the pain was on the outside I just asked that he didnt touch me.

In a follow-up post in the same thread, BB notes "So in the end I called the doctor back and he denied everything and banned me from ever coming back to his clinic" and then asks if this will influence her ability to receive care at other clinics. BB states her intention to seek future care from a different care provider with whom she is already comfortable instead of trying to return to see this gynecologist. Several months later, BB returns to the board to post about the way the experience is still impacting her. She writes:

Hi a while back I had a really horrible experience with a gynecologist that is really affecting me sexually and emotionally. Basically this doctor told all the doctors in his clinic about what happened when i went to see him and during my visit he laughed at me and treated me horribly. Now I feel uncomfortable being intimate with my partner because i cant stop remembering it. The gynecologist was the first person in my whole life to see my privates and I trusted that it would be safe for me. But it hurts being naked and exposed in front of someone mocked me and who turns around and shares your private information with other people. It made me feel really embarrassed and ashamed of my body and so now I feel really uncomfortable sharing it with someone I actually care about. I dont feel as comfortable with my sexuality as before I saw that doctor. Can a therapist help me get back to normal? Also should I tell my partner about what happend ?

BB's experience was traumatic enough that it influences not only her future care, but also her ability to be sexual with her partner and her feelings about her own body. She wonders if she should seek therapy to try to deal with the aftermath. While most posters did not describe their experiences as being as traumatic as BB's, several did report that the reproductive exam process caused them to feel afraid about future exams.

Timing of care sought.

Young women in the dataset reported seeking care both preventatively and due to emergent issues in almost equal numbers. A few posters expressed that they were considering seeking care even though they were not sexually active nor were they expecting to become active in the near future. JJ (16 years old, Ontario, Canada, 837 posts) states "I currently do not see a gynecologist, and I was wondering what age it is recommended that I do so. I am currently 16 and I began my period 3 years ago. I had heard that you should go within one year of your first period, but I have also heard that you should go when you turn 18." Other users expressing a desire to seek care when they were not planning to become sexually active in the near future had similar questions. For these posters, the need for care was often significantly age related.

Other users report that they may become active in the near future and they want to seek care in order to be prepared. For example, L (18 years old, USA, 115 posts) notes:

Well I'm 18, I've never had sex and I'm going for my first pap soon. I've always been told to go in before now, but I've always been afraid... I'm going to ask about BC because I do have a boyfriend, and although were not having intercourse, I think it's a smart choice to get on it, because anything can happen in the heat of the moment and I want to be safe...

Even though she is not sexually active, she feels that it may happen. Another user, I (age unknown, "probably somewhere," 5 posts) states "I'm 17, and I feel ready to have sex with my boyfriend. I've read several times on this site that I should get checked out by a gynecologist or OBGYN before I'm sexually active." She feels ready to be sexually active and wants to seek care prior to that occurrence. Other users express similar concerns about seeking birth control or STI testing before becoming sexually active with a partner for the first time or with a new partner.

The other significant portion of reports in the sample were seeking care for emergent issues. In these cases, the young women perceived they had some kind of risk or health issue and moved to seek care because of it. Sometimes posters reported concerns about potential STI infections. VV (age unknown, Albuquerque, 23 posts) reports "I've been having sharp vaginal pain and i was wondering what it could be?" She has been tested for chlamydia and gonorrhea, but still does not have answers about her pain and wants to continue seeking care.

Other posters were concerned about possible pregnancy. For example, UU (20 years old, USA, 47 posts) notes "...I sort of really always want to call my OBGYN nurse, but I am too afraid/ashamed to call. Like "Hey! I'm getting these symptoms, and I'm religious with my BCP, but I am paranoid that I'm pregnant. Can you talk through this

with me?" Or "WHY THE HECK ARE MY BOOBS SO SORE 7 MONTHS IN? Am I pregnant?" ...” UU is clearly concerned about pregnancy, but is afraid to call her care provider to seek help.

A few posters sought care for emergent issues that they did not believe to be pregnancy or STI related. In these cases, they often reported not being sexually active, but noted that they had concerning symptoms that might need care.

Do I need care?

Is this really necessary? This seemed to be a salient question for many young women on Scarleteen’s message boards. Posters report their experiences or symptoms, and then ask for the perspectives of those on the message boards about seeking that care. For example, M (24 years old, location unknown, 64 posts) says “Anyway, with all of this information I offered, does it sound like I need to see a gynecologist? (I know may sound silly) but I wanted an experts advice.” She seeks an analysis of her situation and wants to know if care is really necessary.

Another user, HHH (age unknown, British Columbia, 1 post) writes:

i'm 18 years old i'm currently sexually active with my boyfriend .i'm worried because my friends keep saying i should get tested but i don't know where to go to get tested and i'm shy at that fact. i've only been with two guys my boyfriend and my ex boyfriend.will i get some sort of disease if i dont go ?? should i go visit my family dr??

Her friends have suggested that she seek care, but she wants advice from others about whether that is necessary, what the consequences might be, and who she should see for care. Other young women making similar posts reported that parents (generally mothers) had suggested that they see a health care provider.

A few posters in this category even asked if seeking care should be necessary or advisable at all. They ask experts for clarification about current guidelines for when care is needed. Or, in a few cases, note that the standard of care timing is different in their culture than it is in American culture. For example, one user reference guidelines for receiving care referenced in another thread and asked for a citation for the information. She noted that in her culture, pelvic exams were only for sexually active women. Some young women in the sample stated explicitly that they knew they needed care, but the majority questioned whether care was appropriate in their situations.

Pre- vs. post-care concerns.

Young women in this sample expressed concerns and posted questions both before and after they sought reproductive care. As noted previously, many asked about whether or not they should seek care. Others indicated that they already planned to seek care and had questions or concerns about the upcoming care. However, not all posters posed questions prior to an appointment. Many posted questions after receiving care. Some had follow-up questions that they had not asked while meeting with a care provider. Others sought clarification of things their care provider said or tried to make sense of what happened during an appointment. A final set of messages appeared to question whether further care was warranted.

MM (age unknown, canada, 12 posts) writes:

...if they do they STD test, how long will it take for me to get results? I've already waited months for this appointment. I've worried and worried about tomorrow... Do you think it is likely for me to have an STD? and if so, would the gynecologist be able to tell without me waiting a week for results? Will my mother know?

MM has scheduled an appointment and is seeking care. However, she is concerned about the testing to be performed, whether she might have an STD, and what might be

disclosed to her mother about the appointment. Other posters ask specifically about what will occur during an exam or describe symptoms and pose questions about what might be wrong.

Other young women in the sample already received care and still had questions or concerns. H (age unknown, Central America, 4 posts) writes:

I decided to use oral contraceptives as method of birth control combined with condoms. I went to my gynecologist for a checkup and asked what type of pill she recommended. She prescribed a pill called Mia and gave me instructions on how to use it. She told me that I had to take the first pill(since they are all numbered) on the first day on my next period and to go on for 28 days until I finish that pack and THEN to wait for seven days without taking any pills and to start with the new set of pills. I'm having some doubts. I do intend to call her and ask her this same question, but I thought that the seven day break was for oral contraceptives that only include 21 active pills. This particular brand has 28 pills and in the piece of paper that comes with the indications on how to use them it says that it has 21 active pills and 7 placebo pills and it doesn't say anything about a seven day break between the end of the old set of pills and the start of the new set. So basically, to sum up, is what my doctor told me correct or am I just misunderstanding how do the pills work?

According to H's post, she visited her gynecologist for an examination and received a prescription and instructions for taking oral contraceptives. However, she walked out of the exam unsure of the information provided by her care provider. Although she expresses the intent to contact her care provider again to verify the instructions, like other young women expressing this theme, she still came to Scarleteen to seek clarification.

Other young women posted about their dissatisfaction with the care they received and sought advice about how to move forward with their care provider. CC (22 years old, New Jersey, 17 posts) researched intrauterine devices (IUD) as a method of contraception and then went to see her care provider. She discusses her thoughts about why the IUD would be an ideal method of birth control for her and states she asked her gynecologist about it. CC then notes:

...my doctor was very dismissive towards me, and refused to discuss it with me. She says she does not typically insert IUDs in women that have never had children before. This bothered me, because I have done my research and have read countless articles about the safety of copper IUDs for all women. I am aware of the risks and am confident in my ability to make informed decisions about my health and my body, but after speaking with my doctor I felt very trapped and upset...All I want to do is prevent pregnancy in the healthiest way possible for myself. Why should it have to be so hard?? I really need you to help show me how convince my doctor to give me the IUD, in the most intelligent and mature way I possibly can. Or, do you recommend that I just find a different doctor?

CC notes that she is not pleased with the care she received. Her doctor was dismissive, leading her to feel “trapped and upset,” as if the situation was more difficult than necessary. CC researched and felt confident in her knowledge, but did not receive the confirmation she sought from her doctor. Like others in the dataset expressing this theme, CC wants advice about how to proceed to either convince her doctor to provide the care she seeks or to seek care elsewhere.

When examining the themes expressed by posters in this category, a clear variation appeared in the way young women positioned their questions. Most posters who had not yet sought care posed direct, succinct questions. With the exception of those describing symptoms that concerned them, posts were primarily a few lines to a short paragraph. Conversely, women with post-care concerns tended to situate their experience by providing extensive descriptions. These posts were often several paragraphs in length and described what occurred in the appointment and their feelings. Further, many offered their own analysis before asking for advice about how to proceed.

After examining questions posed by young women seeking information and social support at Scarleteen, the true complexity of discussing reproductive healthcare becomes clear. Posters sought both action facilitating and nurturing support in their posts. Further, they expressed concerns about privacy and parental knowledge and a variety of anxieties.

Past experiences clearly played into the way they felt about future care. Some considered seeking care preventatively while others worried about emergent issues. Some users wrote about the need for care as a question while others made it a statement. Finally, all of the young women in the sample situated their question as either prior to care or involved post-care concerns.

Chapter 5 Results: (Replies by Experts & Peers)

Experts and peers replying to questions posted by young women seeking information and support at Scarleteen show the complex nature of discussions about reproductive care for young women. These themes appeared not only in the message board replies, but also in articles and expert responses posted on Scarleteen's main website. Replies commonly included multiple themes as responders addressed the complicated messages posted by information seekers. Both experts and peers provided action facilitating and nurturing support in their messages. Other themes appearing in replies included reassurances about privacy and parental knowledge and the addressing of expressed anxieties. Responders also provided descriptions of care or referred information seekers to other resources. Some of these care descriptions included general information while others disclosed about personal experiences receiving reproductive care. Experts and peers also offered insight on whether a young woman should seek care or not, often expressing that the best thing to do was call the woman's own care provider and ask. Many messages also contained themes of empowerment or encouragement for the poster. Finally, some replies requested more information from the original poster.

In this analysis, the term expert refers to individuals on staff at Scarleteen. Staff members come from a variety of different backgrounds and most are volunteers. Members of Scarleteen's volunteer staff have their identification verified by the site's director. Further, staff members participate in online training and regular training updates conducted by the director. The site notes:

Founder Heather Corinna continues to direct and manage Scarleteen with the help of assistant director CJ Turett and several international volunteers, most of whom are or were recently young people themselves. We also benefit from the

generously donated skills and talents of guest writers, educators and consultants. (“About Scarleteen,” n.d., para. 10)

Some volunteers may be close in age to the young women coming to the site to seek information and support. On the main website, each volunteer has a brief posted biography on a page that specifically identifies them as staff. On the message boards, volunteers and staff are identified with titles such as “Executive Director & Founder,” “Volunteer Assistant Director,” or “Scarleteen Volunteer.”

As in the previous chapter, quotations provided in this analysis have been left unaltered. Spellings, abbreviations, and uses of grammar have been presented exactly as submitted by the post’s author. In order to help situate each participant, information about age, location, and number of posts on the message board are included (when available). When location information has been provided, it is listed as the user submitted it.

Categories of Social Support Provided

The second research question asked, what types of social support are offered in expert and peer replies to young women seeking information and support on an online message board? As noted previously, Cutrona and Suhr (1994) offered two categories for social support: action-facilitating support and nurturing support. Replies in this analysis often offered both types of support.

Expert replies. Of the 105 total threads posted on Scarleteen’s message boards within the time period of this study, 102 of them received a reply from at least one site expert. The 23 expert advice questions submitted to the main website also represent responses by staff members, as do the 7 main website articles included in this analysis. This results in a total of 132 instances of Scarleteen staff members providing information

and support to website users. Responses from experts include both action facilitating and nurturing support.

Action facilitating support. Favors, help with tasks, and providing information are typical forms of action facilitating support (du Pré, 2005). Experts responding to questions at Scarleteen provided all three types of action facilitating support.

Many young women in the dataset asked for information about specific services or reproductive care in general. For example, SSS (volunteer, 24 years old, Pennsylvania, 3395 posts) “If you want to check, go to their website and put your zip code into the finder, it'll tell you where they are closest to you. Then you can call and see what they can do to help with payment too.” SSS’s response came after a poster asked for information about Planned Parenthood. In this case, the expert is offering specific information about how to access outside resources.

Another specific request for information made by young women at Scarleteen referenced specific guidelines for reproductive care. Several posters in the sample asked about the current guidelines for when someone should begin to receive reproductive care. EEE (director, 40, “An island near Seattle,” 64730 posts) responds to one of these questions by noting:

Paps are currently recommended to begin no later than when someone has been sexually active (not just intercourse) for three years, and/or when someone is 21, whichever comes first. But some practices have starting paps and pelvic exams (which is separate from a pap in terms of what it's for) on a different schedule in terms of their own guidelines.

Experts also commonly provided action facilitating support in the form of information about reproductive care or related health topics. Young women often posted questions about what to expect during a gynecological exam. AAA (volunteer, 27 years

old, Canada, 5435 posts) provides the following response as part of an extended exchange with a poster about expectations:

When it comes to the actual exam, generally the doctor will sit down with you first and ask if you have any particular concerns about your health, tell you what the exam will entail, and then they'll leave the room so that you can get undressed. If they don't go through the details of the exam with you at that point, it's always okay to ask them to walk you through it first. You won't just have to sit there naked from the waist down though - you'll get a sort of blanket-type thing to put over your lap (sometimes it's fabric, sometimes paper) so no one will be able to see anything.

The expert provides a brief description of what to expect during the early part of an exam in response to the poster's questions and expressed anxieties. Other experts responding to similar questions provided links to materials from the main Scarleteen website, such as the "Your First Gynecologist Visit," "Testing, Testing..." or other articles about specific sexual health topics. Within this sample, it was very common for experts to provide links to the website's article about "Your First Gynecologist Visit" when posters asked very general questions about what would happen during a reproductive care exam. This article provides specific information about what happens during women's reproductive care examinations.

Some expert responses provided information about health topics when users indicated particular concerns. For example, a poster came to Scarleteen having an "HPV freakout." She posed specific questions about HPV, inquired about how long it would take to get the results of a Pap smear she had scheduled for the next day, and about whether her parents would be notified. EEE (Director, 40, "An island near Seattle," 64730 posts) responded:

HPV, like other STIs can be transmitted through oral sex as well as intercourse. HPV can also be transmitted through skin to skin contact, so your #3 question does pose a risk.

Now, do keep in mind that most forms of HPV are harmless in most people, you can get vaccinated for four of the most serious strains, and most women under 30 clear HPV from their systems eventually.

Typically the results of a pap smear come back in a week or two. Your parents insurance will say that you went to the doctor and perhaps had a pap smear done, but it will not say anything else. Your doctor is required to keep what you tell her confidential.

This response from EEE offered information about a specific health topic, HPV in this case. The expert's response also included informational support by noting how long it would take for the results of a Pap smear to be available and briefly explained care provider's confidentiality. This type of response was not uncommon, as posters often described a health concern and then inquired specifically about a visit for reproductive care. Experts often provided information about health topics like pregnancy, birth control, or STIs. The staff members often include links to articles from the website about the topic in question as well.

Young women also came to Scarleteen requesting help finding or accessing reproductive care. In response to a poster asking about whether she can access free care without needing her parent's permission, EEE (Director?, 40 years old, "An island near Seattle," 64730 posts) writes, "Some areas have free clinics, others have sliding-scale fee clinics, others have low-cost clinics. If you want help finding out what's in your area, we can help with that with a zip code." After briefly offering general information about clinics, the expert offers to help the poster locate a clinic in her area if she provides her zip code.

In response to a similar question, AAA (volunteer, 27 years old, Canada, 5435 posts) suggests "If you are not comfortable seeing your regular doctor, we can help you find a clinic, if you'd like. Or, you can see if anyone's entered any listings for your area in

our Find-a-Doc database on the main site.” In this case, the expert offers to help the young woman find a clinic, but also suggests the use of a main website function to find a resource in the poster’s area.

SSS (volunteer, 24 years old, Pennsylvania, 3395 posts) writes: “I did a quick search for you on Planned Parenthood's site, and found this list of clinics in your area: <http://www.plannedparenthood.org/health-center/findCenter.asp?s=PA&o=1&p=12&c=P&l=0>.” A young woman asked for help finding free clinics in her city. SSS offered help in the form of a favor by searching for a list of clinics in her area. Another expert, CCC (volunteer, age unknown, location unknown, 3318 posts) answered a similar request from a poster for help locating a health care provider in her area by stating, “I may be able to get the name of a healthcare provider in Charlottesville but that may or may not be close enough for you. (Before I ask around, is it?)” In this case, CCC offers to seek out the specific information for the young woman who is searching for a care provider.

Some experts also offer action facilitating support when in the form of favors. At Scarleteen, most favors involved an expert locating information for a poster. Favors differ from help with tasks in that they occur when a poster has not specifically requested assistance, but a staff member provides it unsolicited. For example, a young woman posted that she was experiencing problems with bleeding. One expert replied, asking the poster if she could see a gynecologist to have it checked out. The young woman answered that she had not seen a care provider due to lack of insurance. At this point another expert, EEE (director, 40, “An island near Seattle,” 64730 posts) replies, “What about a public health clinic? Here are a list for you locally:

http://www.cchn.org/health_centers.php Those clinics see patients regardless of ability to pay.” The young woman did not post asking for help finding resources in her area, but EEE provided the assistance anyway.

Experts at Scarleteen provided action facilitating support for posters by offering information, assistance with tasks, and favors. In offering these types of supportive communication, experts presumably help the young woman feel more secure in her knowledge and provide the information necessary to interact in the health care setting.

Nurturing support. Nurturing support generally involves emotional support, esteem support, or social network support (du Pré, 2005). Each of these was evident in the expert replies posted at Scarleteen.

A young woman posting in an expert reply only area of the boards indicated that she had been sexually active for several years and also was experiencing some pain. The poster indicated that she knew she needed to seek reproductive care and had done research about potential causes for her pain, but that she was very nervous about receiving a pelvic examination. In response, AAA (volunteer, 27 years old, Canada, 5435 posts) notes, “You’re definitely not alone in being nervous about seeing a gynecologist for the first time. It is important though, and there are a few things that can help with that nervousness.” AAA offers emotional support to the young woman by reassuring her that she is not alone in her anxiety. The same expert offers similar advice to another poster expressing anxiety about reproductive care. AAA notes:

Per your worries about the exam itself, they’re all very valid concerns and you’re definitely not alone in having them. Many people feel uncomfortable at the thought of a gyn exam, and it can be an experience that makes people feel especially vulnerable. Good doctors understand that, and if you mention that you’re uncomfortable with the idea of an exam, they will generally do their very best to help you with that.

Again we see an expression of solidarity with the poster. AAA reassures the young woman that she is not alone and others feel uncomfortable as well. Further, she provides reassurance that even health care providers understand the anxiety and will try to provide help as well.

Emotional support was a very common style of nurturing support in response to situations where posters disclosed a history of sexual assault or abuse. In response to a user disclosing a sexual assault and asking for help figuring out what to do and how to get care PPP (volunteer, age unknown, Cologne, Germany, 8593 posts) notes, “(Also, if there's ever anything you can better express in German, that's fine, too: that's actually my mother tongue, so I'd be able to understand you just fine).” The expert offers emotional support by suggesting that the poster can use her native tongue (German) to express herself. PPP offers support in helping the young woman be more comfortable.

The most obvious way experts expressed esteem support at Scarleteen was through responding to posters' questions. As noted earlier, 102 of the 105 threads included in this analysis had at least one response from an expert. Most responses were also delivered reasonably quickly, with almost all receiving at least one expert response within 24 hours of the original post. Experts also commonly engaged posters in conversation. By providing responses and encouraging further conversation, experts make young women at Scarleteen feel valued and important, thus providing esteem support.

A second form of esteem support provided by experts were reassurances of competence. For example, a young woman posted with concerns about STIs and seeking testing. She indicated that she knew that several STIs could be transmitted via manual

sex. RRR (volunteer assistant director, 31, “Washington DC suburbs,” 5431 posts) notes in her reply, “You're right that there are some STIs you can get from manual sex.”

Similar to RRR’s response, most expert replies in this category were brief and straightforward, confirming the correct information offered by the poster. PPP (volunteer, age unknown, Cologne, Germany, 8593 posts) offered a similar reassurance to a poster relating her experience having a conversation with her parents about reproductive health care. PPP offers, “As far as telling your parents, I think you did a pretty good job.” The expert provides reassurance that the young woman was competent in her handling of the situation.

Experts at Scarleteen also provided social network support to posters seeking information and social support. Expressions of social network support tended to be briefer and most often appeared as acknowledgements of the young woman as part of the community or simple invitations to continue to engage in the conversation.

In response to a young woman posting about needing care after a sexual assault, RRR (volunteer assistant director, 31 years old, “Washington DC suburbs,” 5431 posts) writes:

Hello <poster’s name> and welcome to Scarleteen.
I am sorry you feel so scared and alone. WE talk to a lot of people who have survived rape...
What kind of support do you have from friends and family? Do they know what happened? Are they helpful and supportive to you?...
How else can we support you through this?

The convention RRR displays in welcoming the poster to the community by name was a common social network support displayed by experts in this sample. Staff members often (although not always) began posts by acknowledging the poster specifically. By welcoming the young woman to the community, experts invite the poster to feel like a

part of the community and to engage with it. RRR further provides network support by reassuring the poster that there are others in the online community with similar experiences. Finally, RRR asks the poster how the community can offer her support as she moves forward. This last request invites the young woman to continue on as a part of the social network.

Responses to young women coming to Scarleteen seeking information and support garnered both action facilitating and nurturing support from experts. Messages typically included multiple types of social support. The most commonly displayed form of support involved providing information. Experts typically provided posters with more information about examinations or other health topics referenced in the original post.

Peer replies. Of the 105 total threads posted on Scarleteen's message boards, 22 involved a peer reply. Clearly, there are fewer responses from peers in the dataset when compared to expert replies. However, peer replies still offered social support to young women seeking information and support at Scarleteen.

Action facilitating support. Peers at Scarleteen offered action facilitating support primarily in terms of information and offering favors. Unlike experts, peers did not seem to reply as often to young women's requests for help in completing tasks, like finding resources. However, in a few cases, peers offered favors by providing resources without being asked.

Some peers in the dataset offered information to others asking questions. For example, MMM (age unknown, location unknown, 1324 posts) responded to a post by a young woman concerned that she might have vaginismus or some other health condition

causing painful penetration. The poster was worried that something might be wrong and also that an examination might be painful. MMM writes:

When women do start getting smears it's important to tell the smear-taker about any pain they have or any worries about smears. They usually can still take the smear, but they will use special precautions. For example, using a smaller speculum, having a support person for you, taking pain relief or a mild sedative beforehand.

MMM's response offers the poster information about what might happen during an exam for a woman who expresses pain associated with a Pap smear test. She offers concrete examples of steps that can be taken by the care provider to reduce the chance of pain.

Some peer responses also provided more general information. In response to a poster asking why one would seek reproductive care when one does not have symptoms, MMM (age unknown, location unknown, 1324 posts) notes, "Let me give you some reasons why you might see a GYN when you're not "super sick"..." MMM continues to list services provided by gynecologists for women who are well, such as discussing contraception, testing for STIs that can be asymptomatic, and providing the HPV vaccine. Other peers providing responses in this category offered information about what occurred during gynecological examinations, or provided information about specific conditions.

Although peers did not provide as many links to other information as experts did, the providing of links to other materials, like the "Your First Gynecologist Exam" article, did appear in peer responses. Throughout multiple posts responding to a young woman's concerns that her vagina is "too tight" and overall sexual readiness, OOO (age unknown, USA, 97 posts) provides links to three separate articles at Scarleteen dealing with topics referenced by the original poster.

A few posts by peers also offered favors to posters. For example, DDD (20 years old, London, UK, 1269 posts) offered: “I can look into some trans-friendly gynecologists for you, if you'd like me to - are you willing to share your zip code? If you have insurance, do you know what it will cover? If you don't, what's your price range?” The original poster had noted that their gender identity was “ftm” (female to male), indicating that they were physically female-bodied, but identified as male. The poster noted that they were sexually active, but wondered whether it was still necessary to get reproductive care. In order to help, DDD offered to try to locate a gynecologist who might be welcoming to transgendered individuals. This is considered an example of a favor because the poster did not ask for help finding resources, but the peer responding offered assistance.

Nurturing support. Peer responses also offered nurturing support, primarily in the form of emotional support. Replies by peers often recounted their own experiences with the topic referenced by the original poster. For example, many a common expression is that “the same thing happened to me.” TTT (age unknown, Canada, 126 posts) replied to a young woman asking a question about having two Pap smear tests conducted where not enough cells were collected to complete the test. TTT noted that “the same thing happened to me... twice in a row.” Similarly, BBB (age unknown, Ohio, 34 posts) replied to a young woman concerned about having a mole on her vulva examined. BBB states,

If it makes you feel any better, I have a large mole on my labia also. It's probably the size of a dilated pupil, though not too raised or anything. I'll be honest, once I hit puberty and got hair down there, I'd completely forgotten I had it. Then a few years ago I decided to go "bald" and was unpleasantly surprised at the "new" discovery. But, it doesn't really bother me anymore...

BBB offers her experience specifically for the purpose of making the user feel better. As GGG (22 years old, “canyon,” 13 posts) succinctly states, “Hey, i totally understand where you are coming from!”

Peers in the dataset offered fewer statements of esteem support than did experts. Like experts, peers did offer some esteem support in the form of replies to young women’s posts. Of the 105 total threads, 35 were posted in areas of the board where both peers and experts were asked to reply. Of those 35 threads, 21 received at least one reply from a peer. One thread posted in an “expert replies only” area also garnered a response from a peer. By responding to posts, peers can also be seen communicating the message that the original poster is valuable.

Peers also provided a few responses including reassurance of competence. For example, OOO (age unknown, USA, 97 posts) gives a user “props to you for taking care of your health by seeing a gynecologist!” In another thread, MMM (age unknown, location unknown, 1324 posts) writes “Good on you for going to get tested...” Rather than offering reassurances about specific information the way experts did, peers tended to offer more general reassurances of competence.

Few responses from peers in the dataset offered specific examples of social network support. Like experts, a few peers addressed the original poster by name or welcomed them to the community. As OOO (age unknown, USA, 97 posts) simply states “Hi <poster’s name>. Welcome to Scarleteen.” Use of names and specific welcomes were far less typical in peer responses than in expert replies.

Themes in Expert and Peer Replies

The fourth research question asked: what themes are present in expert and peer replies to young women's message board questions about seeking gynecological care? Experts and peers at Scarleteen reassured posters about privacy and parental knowledge surrounding reproductive care. Responses also addressed anxieties posed by posters. Both general descriptions of care and personal experiences are provided. Peers and experts also provide advice about reproductive care and offer messages of encouragement and empowerment. Finally, messages often include requests for further information.

Privacy and parental knowledge reassurances. As many young women's posts at Scarleteen expressed concerns about privacy when receiving reproductive care and parental knowledge about such care, replies from experts and peers often addressed these concerns. In response to a poster asking whether her doctor will ask if she is sexually active when she seeks vaccination for HPV, NNN (age unknown, Canada, 13 posts) reassures the young woman that "...you can tell your doctor anything.. they have to keep it confidential.. it's the laww." NNN offers a very general reassurance to a peer that her health information will be kept private. Another young woman asked about going to a Planned Parenthood clinic in her area to seek care without insurance and parental notification or consent and EEE (director, 40, "An island near Seattle," 64730 posts) replies that, "With Title X clinics in the states -- and PP clinics are -- you can get all of those things, and contraception, confidentially and without parental consent or notification." Here we see that both peers and experts at Scarleteen offer users brief, general reassurances about privacy when receiving reproductive health care.

Not all privacy reassurances were brief in nature, however. Many messages about privacy were extended in nature. In response to a poster asking whether reproductive care providers would tell patient's parents about their sexual partners, EEE (director, 40, "An island near Seattle," 64730 posts) offers:

It depends, but for the most part, very confidential.

One thing to know, is that in the United States, if you go to a Title X clinic for your sexual/reproductive healthcare, you can be 100% sure your information will all be kept confidential.

With private GYNs, you can expect similar due to HIPAA laws and other policies.

The big exceptions in either case are if any laws have been broken or if your health of life appears to be in danger like, for instance, if someone is diagnosed HIV positive and is not taking their medications.

The expert offers a more extensive explanation, addressing both Title X clinics and private practices. The message also notes the caveats about privacy, such as when a patient's life is in danger. The majority of extended reassurances about privacy appeared in expert responses.

Replies also reassured posters about how their visit to a care provider might be represented on a statement if they used their parent's insurance. AAA (volunteer, 27 years old, Canada, 5435 posts) reassured a young woman that her doctor would not disclose health information to her parents but notes that "However, if you were to use your mother's insurance for the visit, whatever tests were performed would likely show up on her statement from the insurance company." Some responses to similar questions offered more clarification about what might appear on a parent's insurance statement. PPP (volunteer, age unknown, Cologne, Germany, 8593 posts) writes, "If you are on your mother's insurance, then she may be able to see an STI test on her statements. However, it's unlikely to explicitly refer to STI testing, it's more likely to refer to general lab work."

PPP's response offers reassurance that testing would appear on a statement from the insurance, but that it would not state specifically what tests were conducted.

When responding to messages where posters specifically expressed concern about telling their parents or mentioned that they wished to hide their need for care, messages often contained a suggestion to disclose to parents. For example, PPP (volunteer, age unknown, Cologne, Germany, 8593 posts) writes:

Telling your mother also doesn't need to be a big deal: it is usually recommended that women start their reproductive health care once they start menstruating, regardless of whether or not they are sexually active. So you can talk to her about seeing a gyn without mentioning your boyfriend. (Though it also may not be a bad idea to use this opportunity to come clean and tell your mother about the boyfriend. These things tend to come out sooner or later, anyways, and it always looks better if you were honest up-front.

The message that honesty with parents about sexual activity or the need for care is preferable was consistent throughout the dataset. In virtually all instances where a poster indicated the desire to hide, experts suggested being honest rather than hiding.

Messages that encourage young women to be open with their parents about their sexual activity or need for care still leave the choice about whether or not to do so in the poster's hands. HHH (director, 40 years old, "An island near Seattle, 64730 posts) writes:

Well, you have a couple of options.
OB/GYN care isn't just for people who are sexually active. It's for people who have a uterus and/or a vulva. part of that care is about sexual healthcare, but not all of it. It's also about things like periods or other reproductive health concerns and issues.
So, while I'd suggest you consider being honest with your mother -- especially since sneaking around if you become sexually active is something that often gets discovered anyway, and this is a way better way to build trust -- you can also ask to go for other reasons.
But if she knows you two have been having some kinds of sex, it seems she already knows you need this care -- it's not just intercourse that facilitates a need for sexual healthcare. So, again, is being honest an option at all? If it is, it can be a good one.

You also can get care for yourself without being 18 or having a parent's permission in most areas. That's not always free, but it can be. Some areas have free clinics, others have sliding-scale fee clinics, others have low-cost clinics. If you want help finding out what's in your area, we can help with that with a zip code.

The expert suggests that honesty with the young woman's mother is preferable. However, she also offers another way to frame the message by stating that gynecological care is necessary not just for those who are sexually active, but for anyone with a vagina. Further, she offers to help locate resources if the poster still feels that she needs to access care without involving her parent.

In each case of a young woman bringing up privacy concerns, experts and peers offered reassurances about privacy. In very few cases, however, were privacy regulations explained thoroughly. Most messages noted that information would be kept private or that care would be confidential. A few specifically mentioned HIPAA laws or Title X clinics with regard to patient confidentiality. Only a couple of replies offered more detailed explanations of these regulations. In some cases, responses noted that they were unsure about privacy or patient confidentiality regulations in the original poster's country.

Addressing anxieties. Young women coming to Scarleteen to seek information and support about receiving reproductive care expressed many different anxieties. In response to these posts, replies from experts and peers addressed a variety of different anxieties.

Fear of pain. Some posters expressed concerns about pain or discomfort during a gynecological exam. In an expert answer on Scarleteen's main website, EEE (director, 40, "An island near Seattle") notes that "...if you're worried about pain or discomfort,

most women -- myself included -- will generally agree that a trip to the dentist is usually more uncomfortable than a trip to the gynecologist.” EEE does not state that the exam will be pain free or completely comfortable, but suggests that by comparison a visit to the dentist is likely worse.

In another main site expert reply, ZZZ (volunteer, age unknown, location unknown) writes:

Do Pap smears hurt? Not really. I mean, it's not as delightful as getting a foot massage. But it's not like the UN will ban it for being like torture. ... This can be uncomfortable for girls who are nervous and tense. So, if you can relax, it's not bad at all. The swab itself is not painful and often doesn't feel more than a gentle poke or swipe. However, because the doctor's sweeping some stuff off your cervix, it can result in a day or three of light spotting.

ZZZ's response again offers a comparison for evaluating the discomfort of a Pap smear.

It is not as enjoyable as getting a foot massage, but not so bad that it is likely to be banned as a form of torture. She notes that discomfort might occur if one is tense and that the swab itself is typically not painful.

Another volunteer, CCC (volunteer, age unknown, location unknown, 3318 posts) notes in a message board reply that, “Testing can be pretty painless or even painful to some, a lot depends on a person's pain tolerance, comfort level, and how conscientious the tester is being. It shouldn't be horrible but most people would prefer something fun over a GYN exam.” Like other responses dealing with anxieties, CCC offers support while still leaving room for the individual nature of discomfort a woman may experience. Like ZZZ's assertion that if an individual is tense or nervous, they may have pain, CCC suggests that individual variables like pain tolerance and comfort level matter.

While experts offered most of the replies to concerns about pain, a few messages about pain were also provided by peers. YYY (unknown age, Australia, 172 posts)

suggests “You may experience discomfort or pain (and i really advise you to speak up if you do), but your body will not be altered” in response to a young women who stated she was concerned that her vagina was small and therefore she might have pain during an examination. Similar to expert responses, the peer notes that pain or discomfort might occur, but that it should be brought to the attention of the care provider. A later expert reply in the same thread reinforced this message and added that thoughtful care providers would be aware of a woman’s experience and try to make her as comfortable as possible.

Messages addressing anxiety about pain are particularly thoughtful in that they do not disregard the concerns posed by the posters. Rather than indicating that pain will not occur at all, responses indicate that some discomfort may occur and suggest ways to manage it. Further, pain is discussed in context and tangible comparisons are sometimes proposed to help the poster better understand what to expect.

Embarrassment. AAA (volunteer, 27 years old, Canada, 5435 posts) tells a Scarleteen poster that “It can be uncomfortable bringing up the topic of sexual health with doctors, but sometimes it helps to realise that body parts are body parts to medical professionals, and there is really no reason to be embarrassed.” The suggestion that care providers look at body parts as body parts is a common theme in this dataset. Health care providers are referred to as professionals who have experience conducting reproductive care examinations. In response to a young woman’s expression of anxiety that her health care provider might perceive her vaginal lubrication as sexual arousal during an examination, RRR (volunteer assistant director, 31, “Washington DC suburbs,” 5431 posts) writes:

I highly doubt that a doctor would see your vaginal lubrication and assume you were aroused. They see all sorts of things, and would know, I should hope, that

vaginas secrete varying amounts of lubrication depending on the time in the menstrual cycle, various environmental factors, and a woman's unique body.

RRR's offering again focuses on the care provider as a competent professional who has experience with women's bodies and knowledge of the way they function.

When a poster expressed anxiety at being in a vulnerable position during an exam with a stranger examining her body, MMM (age unknown, location unknown, 1324 posts) suggests "I would try hard not to think of a GYN as a stranger up in your business or some guy who doesn't love you. They're a doctor doing a job, providing healthcare, helping you to help yourself." Again, the message focuses on the gynecologist as a professional who is providing a service.

Some other responses to posts mentioning or implying embarrassment attempted to address the anxiety by providing personal accounts of the respondents' own experiences and feelings. For example LLL (19 years old, Upperstate NY, 112 posts) recounts her experience having a pelvic exam and notes "I was seriously freaked out about the OB/GYN exam too. REALLY freaked out. I was so shy and nervous and embarrassed. But it really wasn't so bad. They're very professional and understand how uncomfortable you are." LLL notes that she was embarrassed as well, but that the experience was not as bad as she expected. This was an admission by a peer that she also found the examination to be embarrassing at first, but later felt as if it was not as bad. The identification may help the poster to feel less alone in her embarrassment.

Body image. Young women's concerns about body image in posts at Scarleteen often received replies offering reassurance similar to the way concerns about embarrassment were handled. For example, a poster who noted she was worried about her doctor's reaction to her body hair was told by AAA (volunteer, 27 years old, Canada,

5435 posts) that “Just because it's an everyday experience for them, and they see all sorts of bodies and genitals and amounts of hair, they know that it's not an everyday experience for you, and there are lots of ways to make it a bit less intimidating.” The expert reassures the user that her care provider has seen many bodies and that the provider will try to help her through the experience.

Other reassurances about body image tended to suggest that the poster’s body was likely within the normal range of variations. One young woman posted concerns that her breast development was not correct because they did not look like others she had seen. She noted that she felt like “less of a girl” because of this and wondered if she needed to see a doctor. QQQ (volunteer, age unknown, Ontario, Canada, 1168 posts) responds that:

Everyone goes through puberty at different rates and experiences it in different ways, so it's possible that this is normal for you and that your breasts will develop in time. Don't feel that it makes you any less of a girl; you are so much more than just some body part(s). Also, you can totally ask your doctor about it anyway, as they are there to help you and answer any questions you have!”

After the poster provided further description of her body concerns, experts suggested that it sounded like she had inverted nipples. In response to a question by the original poster about how to fix the problem, EEE (director, 40, “An island near Seattle,” 64730 posts) replies that “Inverted nipples don't need to be fixed, they're a common variation.” In these replies, experts suggest that the one body part does not define the individual and also reassure the young woman that her body is within the range of normal. The initial response that the poster can ask her care provider about her body is another common response to body image concerns. Replies to these anxieties often suggest that the young woman consult with her care provider about the area of the body in question.

Normal or not. Questions and concerns about the normality of a young woman's feelings and experiences were fairly common at Scarleteen. When the initial poster expressed concerns about a health issue, often responses did not specifically provide a yes or no answer to this question. For example, when a user described symptoms and wondered about their normality, suggestions about possible issues this could indicate were provided. The provision of information served as a response to the normality concern, requiring the poster to determine whether their symptoms were within the normal range or not.

However, when women expressed extreme menstrual symptoms, the replies often indicated that those should not be automatically dismissed as normal. In a discussion of a young woman's pain during menstrual periods, EEE (director, 40 years, "An island near Seattle," 64730 posts) responds that "Extreme menstrual pain is NOT normal, and when it's like this, something often is wrong that needs addressing. As well, at 24, if you haven't started getting annual exams and pap smears, you're also late to the game. So, by all means, I'd make a GYN appointment and start there." The expert's reply suggests that the pain is not normal and needs further consideration. Later in the conversation, EEE further states:

It's unfortunate that all too often, older women who have had painful periods -- especially those who never had that pain evaluated and treated -- will suggest to younger women that it;s normal for periods to be really painful. But based on everything we know in reproductive health, there is almost always a cause, even if sometimes it's difficult to identify that cause or it can't be identified.

The response points to the cultural assumption that menstrual pain is normal, even though reproductive care providers know that significant pain has a cause. EEE's reply is similar

to other replies to concerns about body pain or discomfort. The sense that pain is not a normal experience is clearly displayed throughout responses.

Responses also addressed concerns about whether experiences while receiving reproductive care were normal. For example, when a young woman wrote about having bleeding after a Pap smear, she was reassured that some spotting after the test was normal. In some cases, replies also addressed concerns about test results. Experts explained what normal were and how a care provider might proceed after abnormal test results.

For those describing unpleasant or traumatic experiences during reproductive exams, responses provided feedback about the encounter being abnormal. When a poster with a history of PTSD due to abuse asked whether her gynecologist's reaction to her disassociation during a pelvic exam was normal, EEE (director, 40, "An island near Seattle," 64730 posts) writes "...I feel what she said to you was COMPLETELY out of line, profoundly insensitive, and really crap practice." Later in the conversation, EEE notes "Given she knew about your history, that really makes everything that went down and how she handled it even worse."

Another user brought up similar concerns about a traumatic experience during a breast ultrasound. PPP (volunteer, age unknown, Cologne, Germany, 8593 posts) responded that

It definitely sounds like that doctor was very careless and unprofessional. Ultrasounds can be pretty uncomfortable, since doctors sometimes have to press down the wand pretty hard to see what they need to see, and a good doctor will check in with you, tell you what they're doing, and make sure you're okay. So, what happened to you is NOT how a typical experience with this should be, and it was not okay.

In both EEE and PPP's replies the young woman is given reassurances that the care provider's conduct was not typical or acceptable. In these cases, the poster is reassured that their experience was not normal.

Descriptions of care. Many responses to questions about receiving reproductive care included a description of what was involved in gynecological examinations for young women. As many posters at Scarleteen expressed that they were unsure about what a reproductive care exam entailed, this information was commonly included. Some descriptions of care were general in nature, while others provided more personal explanations.

General descriptions. Scarleteen provides young women seeking information with general information about reproductive care examinations. "Your First Gynecologist Visit," an article posted on Scarleteen's main website asserts "If you're getting an exam, here's how the whole thing goes." The article then provides a clear explanation of what happens during a gynecological examination. It describes the process by which a doctor will ask questions about a woman's medical history, conduct a basic physical and abdominal examination, possibly take blood samples and provide a gown and drape for the patient to change into for a pelvic exam. The article notes that if a patient is under 21 or not experiencing symptoms, the examination may be complete at this point. The process for a bimanual exam and Pap smear test are also detailed. Another main website article entitled "Testing, Testing..." provides a similar overview of the process for STI testing.

In response to message board posts asking about what happens during a gynecological examination, young women are often referred to one or both of these main

website articles. For example, when a poster described her symptoms, stated that she had an upcoming appointment with a gynecologist, and asked what to expect during an examination, PPP (volunteer, age unknown, Cologne, Germany, 8593 posts) writes, "I'm glad to hear that you're getting health care, and I wish you good luck! This article should help you prepare for what's in store..." and provides a direct link to the "Your First Gynecologist Visit" article. Most expert replies to similar questions included a simple suggestion to look at the article for information about the exams. Only a few provided a more thorough general description in the reply.

Personal experiences. Some more specific responses about experiences with reproductive care were also provided at Scarleteen. On the main website, a series of articles entitled "The Testing Diaries" offer individual staff member's experiences with reproductive care exams and STI testing. These stories provide a personal narrative of the experience of reproductive care. In response to a young woman's concerns about a first pelvic exam, JJJ (volunteer, age unknown, "in transition," 2262 posts) asserts:

Personally I just have a preference that the provider describe everything that she's doing while she's doing it (as a survivor myself, I think it would be extremely difficult for me to handle a male doctor performing a pelvic exam, and thus far I've always been able to get care from women who do this description in general). For me it also does help to be going back and forth with some sort of conversation, even if it's Her: "So, I'm about to do the pap." Me: "Okay. Isn't the weather today terrible?..."

JJJ reassures a poster with a history of abuse by recounting her experiences and preferences during reproductive care.

Some replies also provided accounts of specific procedures. For example, when a young woman asked for advice from others about how they had spoken with a parent about birth control (specifically an IUD), the conversation later turned to experiences

with IUD insertion and use. Both experts and peers provided narrative accounts of their conversations with parents about birth control and their experiences with IUDs.

Not all descriptions provided painted a positive picture of interactions with care providers. For example, in the Scarleteen article “Yo, Doctors: Pelvic Exams Shouldn’t Be Quickies,” the author recounts a series of unpleasant examinations and tests she underwent while seeking a diagnosis for a gynecological problem. In message board responses, experts and peers also sometimes recounted their own unpleasant experiences as well.

Advice. As young women often posted at Scarleteen seeking advice, it should not be surprising that both experts and peers offered suggestions regarding seeking care and also about specific health concerns. For example, when a poster described her health concern, her reluctance to seek care and uncertainty about doing so, and asked for advice, VVV (volunteer, age unknown, Ohio, 842 posts) responded, “I would have to say that the best place for you to start is to go and see your regular Dr. and/or ask their office for a referral to a gynecologist, since this has been going on for a while and you are at an age where it is not a bad idea to establish a good relationship with a gyn.” The expert suggests that the best place to start with the health concern is by seeking care from a professional. In reply to another young woman experiencing pain, FFF (volunteer, age unknown, Seattle, 833 posts) simply states, “Since you are in so much pain I really recommend seeing a doctor as soon as you can.” Again, the response clearly provides a recommendation to seek care, in this case quickly.

Empowerment and encouragement. In response to a young woman posting about her health concerns and noting that she had scheduled an appointment with a care

provider, PPP (volunteer, 27 years old, Cologne, Germany, 8593 posts) states, “First of all, kudos to you for taking charge of your reproductive health care!” Many replies from experts and peers expressed similarly positive messages about young women’s behavior when they stated that they had scheduled an appointment, researched a health issue, or spoken with a parent or partner about concerns.

Another common theme of empowerment displayed particularly in expert responses was that of asking young women specifically how the expert could help them feel in better prepared to deal with their situation. For example, EEE (director, 40, “An island near Seattle,” 64730 posts) asks a poster “Do you feel like you need any help with these talks about communication, and then communicating together? Happy to talk you through some of it and to also give you some links that might help.” Rather than offering advice automatically, the expert asks the young woman specifically what she needs from Scarleteen to help her communicate.

Referrals to other resources. Many of the replies from experts and peers in this dataset referred young women to other resources. In some cases, links were provided to other resources at Scarleteen. For example, PPP (volunteer, age unknown, Cologne, Germany, 8593 posts) writes, “This article should give you a good overview, and we’re happy to help if you have further questions: Your First Gynecologist Visit.” Links to other site resources were also provided when young women had specific questions about birth control or STIs.

Replies also provided referrals to resources outside scarleteen. When a young woman posted about an assault, PPP (volunteer, age unknown, Cologne, Germany, 8593 posts) responded with the following links:

If talking to someone you know isn't an option right now, there is also always the option of going to a crisis counseling center. There are several such places in Munich: <http://www.frauennotrufmuenchen.de/>
<http://www.frauenhilfe-muenchen.de/>
<http://www.imma.de/>

When another user expressed concerns about privacy and noted that she was from Ireland, AAA (volunteer, 27 years old, Canada, 5435 posts) provided links to information about patient privacy in Ireland.

Requests for more information. A final theme present in replies from peers and experts involved asking young women for more information or clarification about their questions or concerns. When a poster expressed very generally that she was experiencing anxiety when thinking about having a reproductive exam, PPP (volunteer, age unknown, Cologne, Germany 8593 posts) asks, “What part has you freaked out? Can you explain what it is about it that freaks you out?” The expert requests more information from the young woman about what it is about the exam that causes her to be concerned. Other experts and peers posed similar questions to the authors of threads.

Requests for more information appeared to serve a dual purpose. First, they invited posters to engage further with the individual replying. In other words, the respondents were interested in beginning a conversation rather than providing an answer without encouraging a reply. A second purpose seemed to be a request for more information so that specific or tailored responses could be offered. Often young women asking very brief or general questions may not have provided much background or context that would allow for specific replies. In these cases, respondents asked for more information so that specific advice could be generated.

Chapter 6: Conclusion and Implications

The current study's objective was to better understand how young women are using online message boards about health information. The study sought to provide a formative understanding of the interaction between young women looking for information about reproductive care and the information and interaction they experience on a popular online sex education website. In order to accomplish this goal, message board posts and website content from Scarleteen.com, a well-respected sexual education and information website were examined.

Research Questions Answered

In order to better understand the communication surrounding reproductive care for young women on an online message board, several research questions were posed. Data was analyzed using thematic analysis to answer these questions.

RQ 1: Social support requested. The first research question asked: what types of social support are sought by young women seeking information and support on an online message board? Analysis showed that women sought both action facilitating and nurturing support. Most of the action facilitating support sought was in the form of information about reproductive care or other health topics. As reproductive care is clearly a highly charged issue, it is not surprising that women also sought nurturing support, especially in the form of emotional support.

It should be noted that within the sample, few posts by information seekers at Scarleteen contained requests for just one kind of social support. Most messages appealed for multiple types of support. When posts sought a single type of support, they typically were short, direct, and most often sought action facilitating support. The majority seemed

to request multiple types of support, often both action facilitating and nurturing in nature. This points to the complicated, entwined nature of young women's need for social support regarding reproductive care.

Expert support wanted. Of the 105 total threads about seeking reproductive care posted on Scarleteen's message boards January 2010 through December 2012, 70 of the threads were posted in "expert reply only" areas. Given the fact that posters choose where to place their threads when they start them, the prevalence of posts in expert areas indicates that many young women come to Scarleteen specifically seeking advice from experts.

Young women's preference for expert reply areas about this topic is somewhat surprising. Some research indicates that youth listen better to peers than authority figures (JACH, 1993). The preference for expert advice is also interesting given previous research about pelvic exams. Millstein, Adler, and Irwin (1984) found that the most frequent source of information regarding pelvic exams reported by the adolescent females in their study was peers and that the main message they received was that the examination was painful. However, in this sample at Scarleteen, posters expressed a preference for expert advice by specifically posting in those areas. None of the young women in the sample offered a clear reason for this preference. Based on their posts, it is apparent that at least some had received messages from other sources like family or friends. This may indicate that they felt they needed more information than their family or peers had provided or that they were not happy with the information they received from those sources. Another possible explanation is that at Scarleteen, the line between

peer and expert is somewhat blurred. Fukkink (2011) examined the use of peer counseling in an online chat service. The author notes that:

Young people appear to be able to support other young people with psycho-emotional problems in an online chat environment, filling in a counselor-type role... This evaluation of this online peer-support project demonstrates that online support can also be provided when relatively young volunteers have an active and leading role in real-time online support and are responsible for the progress of every incoming chat conversation. However, it must be emphasized that the young people were trained prior to the start and were also supervised during the project. (Fukkink, 2011, p. 250)

While the volunteer experts at Scarleteen receive training, they are not physicians.

Further, many of the volunteers are similar in age to those asking questions. This may lead to synergy of expert and peer identity in one spot, seeming to offer those seeking information the best of both worlds.

Action facilitating support. Young women at Scarleteen clearly appealed to those on the website and message boards for action facilitating support. The most common type of action facilitating support sought was displayed through requests for information. Prior research found that women appreciated a doctor's ability and willingness to explain what happened during a pelvic exam (Larsen, Oldeide, & Malterud, 1997). Women at Scarleteen posed questions in this vein. Many young women sought information about what happens during a reproductive care exam. It was not always clear what information the posters had prior to asking their questions, but clearly reliable information about exactly what to expect during a pelvic exam or Pap smear was not available or was not easy to understand for these young women. The unknown nature of the reproductive care exam obviously prompted feelings of anxiety for posters in the sample. Young women in the sample also requested information about how to find care.

This is particularly interesting in light of the mass media attention given to other types of reproductive screening behaviors in order to help reduce the mystery surrounding them. For example, after an on-air mammogram, “Good Morning America” correspondent Amy Robach was diagnosed with breast cancer (Associated Press, 2013). “The Today Show” recently featured hosts Matt Lauer and Al Roker undergoing prostate exams live on the air (Stump, 2013). In 2010, CBS news anchor Harry Smith had a colonoscopy on-air, a test that Katie Couric and others have also had live (CBSNews, 2010). Screenings for breast cancer, prostate and testicular cancer, and colon cancer are a fixture of October and November news programming. However, pelvic exams and Pap smears receive little of the same attention. Comedian Kathy Griffin had a public Pap smear for her show “My Life on the D-List” in 2010, but this appears to be the only example of this test receiving celebrity media attention (Huffington Post, 2010).

A lack of reliable information available from a young woman’s family and peer group and in the mass media may explain why so many young women came to Scarleteen to seek information about reproductive examinations. Because most posters did not explain specifically why they chose to seek information at Scarleteen, the current study is unable to pinpoint a specific explanation for the young women’s lack of information about what takes place during a reproductive care examination.

Regardless, it is crucial that information about these examinations be made available and accessible to young women. Previous research and the current study have shown that pelvic exams are an anxiety inducing experience for many young women. Providing information and helping young women to feel more knowledgeable about and in control of their reproductive care may be a step in the right direction.

A second form of action facilitating support that was sometimes requested was that of help with tasks. Primarily these requests involved asking for help locating resources, such as care providers within the young woman's geographic area. The website already offers a "Find a Doc" page to help users locate providers in their area. Requests for assistance in this area may indicate that posters are not aware of the service or that they are not able to find providers in their area in the database.

Nurturing support. Young women posting at Scarleteen also clearly sought nurturing forms of support. The highly emotive language chosen by posters displayed this need. Individuals often talked about their feelings, emotional experiences, stress, anxiety, and fear regarding reproductive care. In order to prompt others to respond with empathy and acknowledgement of the poster's experience (du Pre, 2005), expressed their own emotional state and requested others respond to their experiences. In some cases, posters came to Scarleteen to "vent" emotionally about their experience. This venting is a part of the process of expressing the emotions the poster was undergoing. Rodham, McCabe, and Blake (2009) noted a similar use of venting in their study of support on a message board for people with Complex Regional Pain Syndrome. The authors note that, "[a]n overriding issue to emerge from this theme was that the message board users needed to feel like they were understood" (Rodham et al., 2009, p. 626). Young women at Scarleteen used emotional expression in a very similar manner. In expressing their emotions and frustrations with their experiences, posters asked others to express understanding of what they experienced.

Requests for esteem support were also evident in young women's posts at Scarleteen. Some wanted reassurances about their own competence. This was typically

expressed through requests for verification of information the poster had already sought out. Though this type of support request was not as evident as the search for emotional support, it was still present. Of interest is the finding that requests for esteem support were not limited to requests for verification about materials already accessed (such as posters noting that they had already read information available at Scarleteen), but extended to issues like body image as well.

Results also indicated that many of the young women in this study who came to Scarleteen in search of social support felt that they lacked social network support in their existing FTF networks. Posters often expressed that their parents did not support their romantic relationships or their need for reproductive care. They came to Scarleteen, in part, to find a network that was supportive. Rodham et al. (2009) notes that

While face-to-face support groups provide members with the opportunity to help each other cope...online message boards provide similar opportunities...but also open up the possibility for the discussion of taboo topics and forms of self-expression that are often unavailable in the everyday offline life of users...(p. 620-621).

Young women in the current study appeared to lack a supportive social network to discuss reproductive care, and may therefore have turned to the online community to fulfill their need.

RQ2: Social support offered. The second research question asked: types of social support are offered in expert and peer replies to young women seeking information and support on an online message board? Both experts and peers at Scarleteen provided action facilitating and nurturing support. An interesting finding regarding social support in this study is that both action facilitating and nurturing support messages were prominent. Most messages (both initial questions and replies) contained multiple types of

social support. Few were limited in their scope to just one type of support. This points to the complex and intertwined nature of social support.

Expert and peer replies. As many young women came to Scarleteen seeming to seek expert advice, staff members were ready to reply. Experts replied in 102 of the 105 message board threads analyzed. Further, staff members created static content for the main website in the form of articles and responses to expert queries posted there. This indicates that the expert staff members were invested in providing support to the posters coming to the website seeking help. Peers also provided both action facilitating and nurturing support to young women seeking help and support at Scarleteen. However, when compared with expert replies over the same period, fewer peers responded although they used similar supportive behaviors in many cases.

Action facilitating support. As expected, Scarleteen's expert staff supplied a significant amount of action facilitating support. Experts offered this in the form of informational support by telling users about specific services, guidelines for reproductive care, and information about reproductive care or other health topics. The expert focus on providing information is consistent with Hennigen et al.'s (2000) suggestion that care providers work to reduce anxiety in part by carefully explaining procedures. While Scarleteen's staff is not comprised of care providers, they fill an expert role, potentially allowing them to provide similar benefits in terms anxiety reduction via of the provision of information. As Suzuki and Calzo (2004) point out, teens are not only using internet message boards for emotional support and opinions, but also for to seek "concrete information" (p. 685).

Peers also provided action facilitating support in the form of information similar to that provided by experts. Peers posting replies offered both specific and general information. They offered information about pelvic exams or other health topics. When compared with expert replies, peers offered fewer links to outside resources. It is not surprising that peers would also provide information support. Ho and Coulson (2008) noted that posters in an online HIV/AIDS support group often provided informational support to one another.

Another way that experts offered action facilitating support was with regard to tasks and favors. When asked for help, experts offered to assist women in searching for a clinic or other care provider that would help them, a form of task support. In other cases, a poster might not have asked for help, but the expert offered or provided it anyway, support in the form of an unsolicited favor. This finding was similar to what Coulson and Greenwood (2011) identified as task and willingness support in online support groups for families impacted by childhood cancer. The authors note that posters on the message board sometimes offered to do tasks related to the other person's situation, or simply indicated willingness to help (Coulson & Greenwood, 2011).

Compared with experts, peers offered no help with tasks and far fewer examples of favors. Based on the data, it is unclear why this discrepancy occurs. Because experts at Scarleteen replied so promptly within this sample, it is possible that peers did not feel they had the opportunity or need to provide help with tasks or favors. Another possible explanation is that peers simply may not have knowledge of the resources necessary to provide favors or task help the way experts did.

Nurturing support. Experts at Scarleteen also offered nurturing support.

Emotional support was evident as experts reassured posters that they were not alone in their experiences. In some cases, these messages dealt with health issues, feelings about reproductive care, or responses to disclosures about sexual assault or abuse.

Frindfinnsdottir (1997) posited that it was crucial that physicians provide not only information support, but also emotional support for their patients. Similarly, it appears that experts at Scarleteen feel it is important to provide emotional support for the young women that come there seeking help.

Peers also offered nurturing support to posters at Scarleteen. This was primarily in the form of emotional support. Peers often recounted their own experiences or shared similar emotions to those expressed by the original poster. Similarly Coulson and Greenwood (2011) found that emotional support was commonly offered by members of the message board they studied. The messages from peers at Scarleteen were similar to the sympathy and empathy they identified in their sample (Coulson & Greenwood, 2011).

Experts also provided esteem support to young women at Scarleteen. First, they provide esteem support by responding to poster's questions. Most threads in this dataset received at least one expert reply, many included multiple expert replies. By replying to posters, experts seek to make the individual feel valuable and worthy of time and effort. Lehman et al. (1986) highlighted the role of listening to patients concerns as a part of esteem support for health care providers. In the same way, experts at Scarleteen show that they are listening to the needs of young women by replying to them. Volunteers also provided esteem support by reassuring posters of their competence. They offer support of the way they handled situations or assure them that the knowledge they already have is

correct. Coulson and Greenwood (2011) identified similar types of esteem support in their study, noting that replies from other members offered compliments to support seekers. These positive reassurances should help information seekers feel more confident in their knowledge.

Peers offered fewer esteem support statements than did experts. Similar to experts, peers offered esteem support first by simply replying to posts. Twenty-one threads received at least one peer reply. They convey that the poster is valuable by replying. Peers also provided messages that reassured the poster of their competence. Unlike expert messages which often included reassurances about specific information, peer esteem support more often involved offering general compliments. This is similar to the idea of compliments as esteem support that Mo and Coulson (2008) and Coulson and Greenwood (2011) identified in their examinations of social support on online message boards.

A final type of nurturing support provided by experts was that of social network support. Love et al. (2012) note that “[o]ne community-building function of the online support group involves talk that signifies who is and is not a member of the community” (p. 557) Experts offered this support by acknowledging young women as a part of the community at Scarleteen. This support was stated more briefly than the other types of nurturing support. It could be as simple as an acknowledgement of the poster as a part of the community or an invitation to continue in the conversation. The convention of welcoming a poster by name was very common in expert replies in this sample.

Fewer peer responses offered specific examples of social network support. Similar to experts, peers sometimes addressed a poster by name or welcomed them to the

community. Ho and Coulson (2008) note network support messages “appeared to broaden the recipient’s social network by establishing access to new members” (p. 373). They invite the new person in or remind the poster that they are part of a community, thus establishing the person’s place in the social network.

RQ3: Themes in questions. The third research question asked: what themes are present in posts made by young women seeking information and social support on an online message board? Posters expressed concerns about privacy and parental knowledge, a variety of different anxieties, the influence of past experiences, the timing of care sought, questions about whether care was needed, and pre- and post-care concerns.

As they wrote about reproductive care, it was clear that for many women this was an embarrassing, anxiety laden experience. Posters expressed fear of the reactions of their parents or in some cases their partners. Similarly, Friedman and Bloodgood (2010) that their findings “...indicate that stigma and misunderstandings about STD testing continue to prevail...[p]revious findings also suggest that screening is not perceived as a routine health practice and may carry moral connotations” (p. 1828). This thought is supported by the findings of the current study. Experts at Scarleteen routinely reminded posters that reproductive care was normal and necessary for “anyone with a vagina.” In spite of this, young women’s perception of reproductive care clearly was not that it was a part of normal, preventative care for female bodied individuals. Although some posters reported receiving supportive messages from parents about getting care, many expressed concerns about how seeking care would change their parent’s views of them, reinforcing the idea that reproductive care remains a stigmatized issue.

Privacy is a big deal. As Spear and English (2007) note, “ On one hand, several studies have documented that a majority of adolescents using family planning clinics do so with their parents’ knowledge, or even at their explicit suggestion. On the other hand, many adolescents say they would not use the clinic or would avoid certain services if their parents had to be notified” (p. 74). Privacy and confidentiality are issues of concern for all patients, and specifically for adolescents. Friedman and Bloodgood (2010) noted that participants in their study reported mothers being present and fear that the provider would tell her parents as barriers to talking with care providers about STDs. Prior research would note that this concern is not entirely unfounded. Deneryer et al. (2011) note that “[a] body of research conducted over the past decades found that privacy is of significant concern for adolescents and that privacy issues influence their interactions with the healthcare system” (p. 1159). Further, the authors assert that “[t]he perceived absence of confidentiality is a major barrier for an adolescent to seek medical help” (Deneryer et al., 2011, p. 1162).

Concerns about privacy and parental knowledge were clearly an issue for young women on Scarleteen’s message boards. Many posters questioned the level of privacy they would have if they sought help from a care provider. They expressed concern about whether a doctor or insurance company would inform their parents. This finding is of particular interest because privacy concerns are not cited in the research specifically surrounding pelvic exams for women. Tiefer (1979) found that fear of examination, no perceived need for care, concerns about hygiene, embarrassment about undressing, fear of pain, and worry about diagnosis were reasons given for delaying exams. Willie (1982) and Larsen et al. (1997) reported similar findings. Miller, Adler, and Irwin (1984)

reported that the most common message their study participants received from their peers about pelvic examinations was that it was painful. While these studies highlighted other concerns, they do not reference patient privacy as an issue. However, the current study found confidentiality and privacy to be a significant topic of discussion.

Further, examination of the posts of young women shows a lack of clarity about confidentiality laws surrounding health care. Regardless of country of origin, many of the young women in the study appeared to be unsure about how their doctor or insurance company was supposed to handle their private information. This points to a need for further clarification by both care providers and insurance companies about confidentiality.

Another issue of note regarding conversations of confidentiality and privacy is that the concern was not limited to adolescents. Among posters who disclosed their ages, the theme was expressed by those both under and over age 18. This highlights the idea that privacy is not just crucial for adolescents. Even older women who may still be highly connected to parents or utilize their insurance may be concerned about keeping their reproductive and sexual health care needs private.

Anxieties. Young women at Scarleteen expressed anxieties about pain, embarrassment, body image, normality, and fear of diagnosis. The anxieties expressed were similar to those highlighted in past research about pelvic exams (Tiefer, 1979; Willie, 1982; Millerstein et al., 1984; Kowalski & Brown, 1994; Larsen et al., 1997). The current study, however, is interesting in that posters at Scarleteen expressed anxieties surrounding pain less commonly than other anxieties. Fears of pain played a role in their messages, but not as significantly as other anxieties did. Based on this sample, it is not

clear why concerns about pain were not more prevalent, as would be expected based on past research.

Regardless, anxieties surrounding pelvic exams were very real for young women at Scarleteen. They discussed their fears using highly emotional, descriptive language. They often engaged in conversation, going back and forth with experts and peers about the topic as they tried to make sense of their experiences and address the anxieties.

Past experiences. The role played by past experiences in young women's experiences with pelvic examinations is another topic of discussion that is completely absent in the previous research about the issue. Like privacy concerns, none of the seminal studies in the area reported the impact of sexual assault or of previous experiences with health care providers as an issue. The current study expands this literature by pointing to this as a key issue of concern for young women that requires further exploration. Posts about past experiences by young women in this sample tended to be rich in detail and heavy in anxiety messages. Clearly these issues are an important aspect of women's experiences.

McMahon, Goodwin, and Stringer (2000) note that the "body of published literature on the potential associations between sexual violence and reproductive health is relatively small and recent" (p. 121). The authors go on to argue that most current studies in the area focus on health care in the immediate aftermath of rape, but that future research also needs to address "the ongoing reproductive health care needs of women with a history of sexual violence..."(McMahon et al., 2000, p. 122). The current study would support this assertion. Many of the posters at Scarleteen articulated a history of

sexual assault and specifically expressed fears about how they would feel about a reproductive care exam.

Young women in the sample at Scarleteen also spoke about previous experience with health care and their concerns about the impact on future reproductive care. Like the influence of sexual assault, these past experiences are totally absent from the current research. However, the current study indicates this as an issue of serious discussion. While a few young women in the sample referenced past care positively, many expressed that they were unhappy with the care they received or that they were unsure about what occurred during previous appointments. Prior research about pelvic exams has provided a plethora of suggestions for care providers about reducing women's anxieties about pelvic examinations (Donovan, 1992; Hennigen, Kollar, & Rosenthal, 2000; Davis, 2003; Hilden et al., 2003; Pelerme & Jamieson, 2004). The continued expression of concerns about past experiences point to a need for a more complete consideration of these past experiences.

Timing of care. Young women at Scarleteen expressed different perceptions about their risk factors. Those who sought advice before becoming sexually active and were not experiencing symptoms at the time typically addressed their questions and concerns relatively calmly. On the other hand, young women who were sexually active and/or were experiencing symptoms were more likely to phrase their concerns in more descriptive, frantic terms. Further, some young women in the sample who were active or experiencing symptoms expressed very strong desires not to seek care at all. In spite of having risk factors, some posters clearly wanted to perceive themselves as being at low risk and therefore not needing care. Eastin and Guinsler (2006) found “that individuals

with even moderate levels of anxiety seek higher amounts of online health information” (p. 497). Clearly these young women experienced concern and sought information online, as would be expected.

Pre- and post-care concerns. Young women expressed concerns both before and after getting reproductive care. The post-care concerns highlighted in this study indicate that more consideration of provider communication during reproductive care examinations with young women is needed. A number of posters in the sample sought further information at Scarleteen because they were unsure about information they received during a reproductive care exam. This would seem to indicate a breakdown in the patient-physician dyad for these young women. As Hou & Shim (2010) note, patients with providers who did not do patient-centered communication often relied on the Internet as another source of health information.

RQ4: Themes in replies. The fourth research question asked: what themes are present in expert and peer replies to young women’s message board questions about seeking gynecological care? Analysis revealed reassurances about privacy, addressing anxieties, descriptions of care, advice, messages of empowerment and encouragement, referrals to other resources, and requests for more information.

Privacy reassurances. Past research highlights the fact that patient privacy concerns for adolescents are not entirely unfounded. In a study of pediatricians in Belgium, Deneryer et al. (2011) found that only 35% of doctors offered adolescents the option of having a private conversation and nearly 80% gave all information about the medical consultation to parents as a rule with less than 3% giving no information at all to parents. They calculate that pediatricians only use about 13% of confidentiality

procedures for minors (Deneryer et al., 2011). The authors argue that this points to a need for better understanding of the privacy and confidentiality needs of adolescents and the employment of already mandated privacy procedures. In the United States, for example, federal HIPAA privacy rules provide privacy protection for minors specifically in terms Title X and Medicaid. HIPAA also defers to other federal and state regulations governing privacy for minors which often provide them with the ability to consent to treatment in certain situations and protects their privacy there (McGuire & Bruce, 2008).

Most privacy reassurances posted at Scarleteen, however, were relatively general in nature. This was true of both brief and extended discussions of privacy. For example, a responder might reference “Title X clinics” or “HIPAA,” but these regulations were not explained. Given the prevalence of confusion about patient confidentiality expressed by young women in the sample, it seems that a more thorough discussion of privacy regulations would be appropriate.

Addressing anxieties. Experts and peers addressed the anxieties expressed by young women in their replies. They responded to messages about fear of pain, not by invalidating the worry, but rather by providing comparison to other common experiences or reassuring the poster that discomfort will not be serious and that they should let their health care provider know about their worries. This is particularly interesting in that respondents do not disregard the poster’s concern by telling them “it will all be okay” or that it doesn’t hurt. Instead, they validate the poster’s feeling and offer frames for understanding the experience. These messages were aligned with the provision of types of nurturing social support.

Respondents also responded to poster's concerns about embarrassment. This theme often related to the idea of a care provider as a professional who is doing a job. Rather than undermining the physician-patient dyad, experts and peers offer a frame for the provider that should reduce the poster's embarrassment. Further, care providers are a part of an individual's social network. It is possible that offering this perspective on the provider's role seeks to reassure the poster about the provider's place in that network. Responses to embarrassment also involved respondents relaying their personal experiences and feelings as a way to create identification and show empathy for the poster.

Another type of anxiety addressed by both experts and peers at Scarleteen dealt with body image concerns. Responses offered reassurances that care providers had seen bodies before, that the poster's body was likely within the normal range of variations, and that the young woman should consult her doctor if she is concerned. Body exposure is a necessary part of reproductive care, so it is not surprising that responders addressed body image issues. Tiefer (1979), Kowalski and Brown (1994), and Larsen et al. (1997) found that body concerns were a common worries for women about receiving reproductive care. Body image therefore is an issue that needs to be addressed.

A final anxiety addressed peers and experts was that of normality. Young women commonly expressed anxiety about whether or not their feelings and experiences were normal. Often information was provided to offer possible suggestions about experiences or symptoms. However, it is of note that when extreme symptoms were mentioned, posters were often assured that the experience was not normal and should not be dismissed without further exploration by a care provider. Similarly, when posters

expressed concerns about traumatic reproductive care visits, they were assured that the experience was not normal. Rodham et al. (2009) notes that members of an online message board for those with CRPS often respond with messages focusing on the positive and moving away from negative experiences. The current study's findings seem somewhat contrary to this previous finding. Not all messages about normality were positive. Rather than trying to recast the poster's negative experience in a positive light, respondents offered validation of the experience as negative. However, these responses often then offered a positive perspective for the future. While a past experience might have been negative, they offered hope and reassurance about better future experiences.

Descriptions of care. Both general and personal descriptions of reproductive care were provided at Scarleteen. Like privacy concerns, the many responses describing care indicate the need to provide information about what happens during reproductive care. Some responses given were general in nature, providing links to website information describing care or general overviews. Other responses were more personal in nature, involving the sharing of an individual's experience with reproductive care. These may be responses to what Willie (1982) identified as women's fear of the unknown with regard to reproductive care. By providing concrete information about what happens responders seek to reduce the poster's uncertainty about the situation.

Most accounts were framed in a positive or neutral fashion, though a few descriptions did recount negative experiences as well. Malik and Coulson (2010) note that women in an online support group for women experiencing infertility report that reading about the negative experiences of others actually increased their worry and anxiety by giving them new things to worry about and negatively impacting their moods.

Responses in the current study do not speak to whether posters felt that these descriptions impacted them negatively. Further, the negative descriptions in the current data set were much less common than positive or neutral descriptions.

Advice. Experts and peers at Scarleteen commonly provided advice in response to poster's questions. Respondents offer suggestions about courses of action or next steps for the questioning individual. Coulson and Greenwood (2011) identified advice as a primary form of support provided on message boards for families impacted by childhood cancer. Ho and Coulson (2009) also noted the prevalence of advice on a message board about HIV/AIDS. Advice messages in the current study are often associated with the provision of informational support.

Empowerment and encouragement. Messages of encouragement and empowerment were also provided by responders at Scarleteen. Leung (2008) suggests that the Internet provides users with a means to become empowered participants in their own health care. Oh and Lee (2012) found that diabetes patients who perceived informational, emotional, and esteem support from respondents in their online communities reported feeling more empowered. The authors also found that an elevated sense of empowerment was strongly related to reports of intention to speak with a care provider. They note that their study "provides a significant instance of patient-driven empowerment...a strong sense of empowerment was not given by health care professionals or organizations, but instead developed by patient initiatives in online communities" (Oh & Lee, 2012, p. 38). Through interaction at Scarleteen, posters and responders create a situation where empowerment can be created. Experts and peers respond to concerns and questions with positive messages about behavior. Responders

also specifically ask what a young woman needs to enable her to feel that she can interact with others. In some cases, young women came replied with their empowerment needs or suggested that they were able to make appointments or communicate with a care provider or adult about their health care. Unfortunately, few followed up with their actual behavior, making it difficult to ascertain whether most posters felt empowered by these exchanges or not.

Referrals. Many replies from both experts and peers included referrals to other resources. In some cases, these resources were already available on Scarleteen's website. Other referrals suggested outside resources. Often resources were offered that related directly to the young woman's country of origin. The provision of resources allowed responders to tailor the information to an individual woman's needs. Further, references to outside materials may also provide additional credibility to the website's information. Kim et al. (2011) noted that providing references was one aspect used by online information seekers to evaluate website credibility. So by providing other materials, experts and peers not only give supportive information, but also reinforce the credibility of the community.

Requests for more information. Peers and experts also commonly asked posters for more information or clarification of their messages. These requests for specific information from posters appear designed to obtain more information so that replies can be more complete and also to engage the individual in conversation within the community. By opening up lines of communication, responders involve the individual in process and gain better assessments of risk and risk perception.

Implications

The current study has several implications for online communities for young women seeking information and social support about reproductive care. First, this study highlights the multifaceted nature of social support (summarized in Table 1). The vast majority of messages posted by young women in this study did not appeal for only one kind of social support. Instead, they seemed to seek a variety of different styles of support. Therefore, it is crucial that experts providing support online or trying to create a community where support can be offered create a context in which these needs are met. Providing information alone is not sufficient; providing emotional support alone is not sufficient. The support provided needs to be a good match for the support requested.

Table 1

<i>Types of Social Support Requested and Received</i>		
<u>Support type</u>	<u>Support requested</u>	<u>Support provided</u>
Action facilitating		
Information	How to find care	Information about specific services
	What happens during an examination?	General information about reproductive care
	Information about health issues	Information about health topics
Tasks	Help finding resources	Help finding resources
Favors		Offers to help find resources
Nurturing		
Emotional	Emotional language	You are not alone
	Expressions of fear or anxiety	Solidarity with experience
Esteem	Verify information they have	Providing responses
	Assurance the individual is correct	Reassurance of competence
		Encouragement
Social network	Perceived lack of support outside	Acknowledge as a part of the community
		Invitation to participate

The results of the current study indicated a high level of attunement by responders to the needs of the initial poster. Posters requested multiple types of support and, in most cases, received multiple types of support in return. Further, themes present in responses often directly aligned with the themes expressed by initial posters. In terms of reproductive care, providing a safe space for discussion is fraught with peril, given the stigmatized nature of the topic. This indicates an even greater impetus for modeling and encouraging social support that is truly responsive to the needs of the original poster.

Second, the current study highlights the need to address privacy concerns as a part of reproductive care. Confidentiality and privacy were major concerns for young women in this study. Information provided in these online communities about reproductive care needs to clearly address privacy concerns. Further, confidentiality issues need be dealt with in a manner that is easy to understand for the target audience. Many young women in the sample had no prior experience with reproductive care upon which to draw. They did not understand patient privacy regulations or how those regulations related to them. Further, some expressed confusion about how insurance use and privacy were related. Some had prior experiences that made them distrustful of institutions. Support providers must not assume that community members understand or buy into patient privacy. It should be addressed directly and completely in these communities.

Past experience also matters in conversations about reproductive care. A number of young women in the current sample referenced their past experiences with reproductive care or a history of sexual assault. These are clearly important issues that information and support seekers are wrestling with; therefore they need to be taken into account in the community as well. Similarly, the current study makes it clear that anxiety

surrounding reproductive care is a very real and very complicated experience for young women. Expressions of anxiety or fear are related to a variety of different issues. This highlights the importance of looking at the messages at the root of the anxiety and addressing those as a part of the dialogue. In short, responders need to think in terms of providing support, but also asking questions to allow that support to be tailored to the specific needs of the original poster.

A final important implication of the current study is in the role of community. Young women in this study make it clear that something is lacking in their current communities. Therefore, they seek networks support online. They search for a place to engage in dialogue. While there were some threads in this dataset that contained only the initial post and one reply, many included multiple community replies and conversations between the original poster and those responding. Rodham et al. (2009) notes:

...it is becoming more common for patients to use online message boards (instead of joining face-to-face support groups), as a means of making contact with other people in similar health situations. Through this medium, patients can talk freely in a non-time limited manner about issues linked to their condition that are bothering them. (p. 620)

The building of community, as message board users connect with others similar to them, is therefore a very important part of this dialogue.

Limitations

The current study provides a deeper understanding of young women's conversations about reproductive care on online message boards. However, this examination is not without limitations. As is often the case with research in online communities, identity cannot be verified for those within the sample. In some cases, information about age or location is not available. As Steinmetz (2012) notes, "[t]o dwell

on the idea that the researcher can never really know who is on the other side of the screen unless they are met in the physical world is to ‘risk paralysis in the research process’ (Markham, 2005, p. 800)” (p. 31). In the current study, the individual’s identities are accepted as presented. Whether the online identity presented matches up with the user’s physical age, gender, or other information, or whether it is a misrepresentation, this research chooses to accept the presented identity as one that is authentic to the user in this community.

Limitations also exist based on the chosen sample. This study sampled content and message boards on only one website. Further, it utilized specific search terms to locate data within a limited time period. Additionally, the sample of peer responses to young women’s questions in this study was relatively small when compared to the number of expert replies. A final potential limitation related to the chosen sample is that the highly moderated format of Scarleteen’s message boards cannot be seen as representative of all online communities that allow discussions of reproductive care. As previously noted, the community requires registration for participation and includes a strict set of behavioral guidelines that are enforced by moderators. Other communities with a looser structure may see differences in the presentation of questions and especially in peer responses.

A final limitation of note relates to the information provided by young women in their posts. Because the analysis involves only information that is posted by the young women during the time period sampled, there was not an opportunity to ask posters for clarification about their thoughts or feelings. Further, this analysis does not show how the information and support received at Scarleteen fits into the framework of other

information young women are receiving. Little follow-up information was available detailing whether the poster sought care or what the outcome of that care might have been. Therefore, it is impossible to assess the impact of Scarleteen on the behavior of its users.

Future Directions

As the current study has shown, more research is needed to assess the communication surrounding reproductive care for young women. First, the addition of issues such as privacy concerns and past experiences on young women's reproductive care requires further exploration. Previous research asking women how they felt about pelvic exams did not identify those issues, but given their prevalence in the current study, they clearly are on women's minds. Future research needs to explore these topics, but also to attempt to more clearly understand how women feel about reproductive care.

Secondly, future research is needed to understand the complex origins of messages about reproductive care. As earlier noted, previous research highlights the role that peers, family, and reproductive care providers give women about gynecological care. Some work has even highlighted the role of mass media and online information seeking. However, the current picture is still vague and shadowed when it comes to what specific information comes from each source and how those messages interact with one another.

Finally, it would be helpful to understand the link between information gleaned from online sources about reproductive care and actual care obtained. While the current study was not able to follow posters to see if they sought care after posting questions and most did not follow up to report whether or not they had received care, knowing the

impact on actual behavior would provide a more robust understanding of the influence of online communities.

Conclusion

The current study has explored the experiences of young women seeking social support and information about reproductive care on an online message board. Results showed that posters sought both informational and nurturing support and that both types of support were provided by experts and peers within the community. Themes about privacy and parental knowledge; anxieties about pain embarrassment, normality, body image, and concern about potential health problems; the influence of past experiences; timing of care; the need for care; and pre- and post- care concerns were apparent in questions posted by young women seeking information and support. Expert and peer replies provided reassurances about privacy, addressed expressed anxieties, provided descriptions of care, offered advice, contained messages of empowerment and encouragement, and requested more information from the original poster.

The results of this study help illuminate the complex nature of conversations surrounding reproductive care examinations for young women. The discussion of these topics in offline and online communities provide (or in some cases do not provide) women with information and support. It is a delicate topic that remains stigmatized and provokes anxiety. Young women are not even clear about the exact nature of reproductive care examinations, pointing to a need for better understanding of women's experiences and more information to be provided to them as they navigate the health care system.

In research funded by a biosciences company that produces a self-screening kit for cervical cancer and other vaginal and cervical infections, Westhoff, Jones, and Guiahi (2011) argue that pelvic exams are anxiety laden, embarrassing, and inconvenient for women. The authors argue that in order to maximize appointment time to provide “other proven preventative services...[i]t is time to get asymptomatic women off the table; we need to preform speculum examinations less frequently and completely do away with bimanual examinations in asymptomatic women...” (Westhoff et al., 2011, p. 8). The authors further argue that the overuse of both speculum and bimanual examinations do not improve clinical outcomes. While self-sampling technology may provide another excellent tool for women’s health, it does not seem reasonable to throw out examinations primarily on the basis that they cause anxiety without first understanding the source of that anxiety and attempting to reduce that anxiety. Even if a reduction in certain examination methods is warranted based on health outcomes, women still will need to see care providers and interact about reproductive health topics. Examinations will continue to be a crucial part of protecting a woman’s sexual health. Therefore, the impetus is on researchers and health care providers to understand the communication surrounding these topics and find ways to better inform and empower young women as they take control of their own reproductive health care.

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