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### Infertility Help Seeking and Social Support: Do Conventional Theories Explain Internet Behaviors and Outcomes

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INFERTILITY HELP SEEKING AND SOCIAL SUPPORT: DO CONVENTIONAL  
THEORIES EXPLAIN INTERNET BEHAVIORS AND OUTCOMES?

By

Kathleen Slauson-Blevins

A DISSERTATION

Presented to the Faculty of  
The Graduate College at the University of Nebraska  
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INFERTILITY HELP SEEKING AND SOCIAL SUPPORT: DO CONVENTIONAL  
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Kathleen Slauson-Blevins, PhD

University of Nebraska, 2011

Advisor: Julia McQuillan

This dissertation uses data from the National Survey of Fertility Barriers (NSFB), a nationally representative sample, to assess factors associated with face-to-face and internet help seeking and perceived social support. I first examine whether the General Help Seeking Model, a theory that has been used to explain in-person help seeking, generalizes to internet help seeking. I assess four types of help seeking: (1) no help seeking, (2) only internet help seeking, (3) only medical help seeking, and (4) both online and medical help seeking. Results suggest that online help seeking is differentiated from in person help seeking by attitudes towards medical science, infertility stigma, age, income, and educational attainment. Next, I explore whether the type of help seeking that individuals engage in and the types of activities that people do online are associated with perceived social support. Perceived social support does not differ by type of help seeking, nor are the types of online activities associated with perceptions of social support. Finally, I provide descriptive information on patterns of infertility help seeking on the internet – information that is important as the use of the internet for health related activities continues to grow. I show that use of the internet varies by several individual and social characteristics.



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## Chapter 1: Introduction

Growth in the use of the Internet has exploded over the last decade (Fox 2008; Sillence, et al. 2007). As people have increased their computer use exponentially, sociologists have been faced with an interesting question: Is the Internet fundamentally changing the way that people are experiencing social life, or is it just another venue through which people can conduct a variety of social activities that they have done in the past?

Recently, scholars have been focusing on how individuals use the Internet for health related activities. What is emerging is a picture of an engaged e-patient who is taking a more active role in their health (Fox 2008).

As of 2007 approximately 80 percent of Internet users, or some 93 million Americans, have searched for health information online (Fox 2008). This is up from just 55 percent of Internet users in 2000 (Fox and Rainie 2000). Moreover, research suggests that over half (54 percent) of Internet users have at least visited a website that offers social support (Fox and Fallows 2003). The majority of internet health information seekers are searching for information regarding a specific condition or disease (Fox and Fallows 2003; Sillence, et al. 2007).

Infertility is one of many conditions that people report having sought information and social support online for. Individuals experiencing infertility often report that it is extremely stressful (Oddens, den Tonkelaar, and Nieuwenhuysse 1999; Schneider and Forthofer 2005). Women frequently mention that their preoccupation with their fertility difficulties is all consuming, and this seems particularly to be the case for women who are currently undergoing treatments (Daniluk 2001; Parry and Shinew 2004; Redshaw, Hockley, and Davidson 2007).

One mechanism that individuals utilize to deal with the turmoil of experiencing reprod

uctive difficulties is drawing upon their social network for support (Gibson and Myers 2002; Oddens, den Tonkelaar, and Nieuwenhuyse 1999). Research in this area is somewhat contradictory, however, with some studies finding that the infertile seek social support, while others suggest that infertility is too difficult to discuss and is kept a secret (Exley and Letherby 2001; Johansson and Berg 2005; Letherby 1999; Remennick 2000). Women rely on social support as a coping mechanism for infertility to a greater extent than do men (Beutel, et al. 1998; Hjelmstedt, et al. 1999; Jordan and Revenson 1999). Even so, infertility is thought to be a stigmatized and isolating experience for both women and men (Inhorn 2002; Miall 1986; Wirtberg, et al. 2007). Even if people experiencing infertility draw upon their social networks for support, it is unlikely that they will have someone within their network that has experienced similar fertility difficulties or who has expert knowledge of infertility. It is possible, however, to connect with other infertile individuals with similar diagnoses or treatment experiences through the Internet, and many are exercising this option (Wingert, et al. 2005).

People also try to minimize the uncertainty of infertility through seeking more information. Studies report that the informational needs of those in treatment may be particularly high because of increased anxiety associated with medical interventions (Chiba, et al. 1997; Oddens, den Tonkelaar, and Nieuwenhuyse 1999). Individuals in treatment discuss feeling like their physicians were insensitive, dismissive, and did not have enough time to spend with them (Daniluk 2001), all of which can increase informational needs. Moreover, Redshaw, et al. (2007) found that infertility patients

reported a need to learn medical jargon because this is how doctors communicated with them. Furthermore, the authors found that respondents felt that once treatment began they had little control over their care. The Internet offers the potential for those experiencing infertility to regain a sense of control over their health by seeking information online.

There are a growing number of studies that are looking specifically at how individuals who recognize a fertility problem are utilizing the Internet. Statistics on just how widespread the use of the Internet is among the infertile appears to depend on the study sample. For example, Kahlor and Mackert (2008) found that 99 percent of respondents had used the Internet for infertility information and/or support, however, the study was conducted online so this high rate of Internet use is unsurprising. In contrast, Haagen, et al. (2003) surveyed couples attending a fertility clinic and found that 66 percent of couples with Internet access were using the Internet for infertility related activities. The majority (72 percent) of people going online sought information, while 41 percent reported seeking social support (Haagen, et al. 2003).

To date, the majority of the research that investigates infertility draws on samples of those who are already seeking treatment. This is a problem because research suggests that almost half of women do not seek treatment despite meeting the medical definition of infertility (White, et al. 2006). The focus on those already in treatment means that we know little about barriers that keep people from treatment. White, et al. (2006) are an exception; they find that self-identifying as infertile is a primary predictor of whether or not people sought help for fertility problems. The Internet may help people recognize that 12 months of unprotected intercourse with no conception is a symptom of infertility.

The studies examining the Internet health and support seeking behaviors of people experiencing infertility suffer a number of methodological limitations.

Research on the use of the Internet by the infertile suffers from similar limitations. Samples are exclusively drawn from either (a) people who are already seeking treatment, (b) people who are already online, or (c) both seeking treatment and are already online. Studies that rely on collecting data from Internet infertility websites have selection problems because they are asking people to report on a behavior that they are already engaged in. Additionally, data collected this way makes it impossible to compare those use the Internet for infertility related purposes to those who do not.

The present study seeks to overcome the limitations with the existing body of research by using data from the National Survey of Fertility Barriers. This data set is a random, nationally representative sample of women ages 25-45. Women who met the medical definition of infertility, and households in high minority census tracts were oversampled. Using a subsample of infertile women from this dataset I compare four groups: (a) women who have not done any help seeking for infertility, (b) women who have only gone online to seek information and support, (c) women who have only sought in person help from a medical doctor, and (d) women who have both gone online and seen a doctor.

My first goal is to develop a profile of Internet information seekers among the infertile. In addition, among those who go online, I explore what types of activities they are engaging in and how this information impacted their thinking about infertility.

Next, I will draw upon the General Help Seeking Model (White, et al. 2006) to investigate the factors that are associated with facilitating or impeding in-person and

internet help seeking. These help seeking models were developed with the intent to predict seeking help in a face-to-face encounter. It is unclear whether the key elements of need, enabling, and predisposing factors in help seeking models (Anderson, 1968; White, et al. 2006) will similarly predict Internet use among women meeting the criteria for infertility. Factors that predict in-person help could be different from factors that predict on-line help for those with infertility because the internet provides privacy for those embarrassed by an often stigmatized condition.

Finally, I will investigate the association between help seeking activities (none, internet only, medical only, both) and social support. It has been suggested that Internet support groups can offer necessary support in times of a health crisis (Wright and Bell 2003), however, it is unclear whether this support is substituting for other supportive relationships that would occur in a face-to-face context, or if those who already have high general support are also the ones that are more likely to seek additional support online.

## **Chapter Two: Literature Review**

### Advantages of Seeking Infertility Related Information and Social Support Online

We live in a world rife with time constraints. Because of the intense time pressure people are under, they seek to spend their time as efficiently as possible. Pandey, Hart, and Tiwary (2003) have suggested that it can ‘cost’ a lot to obtain health information from traditional sources, both in terms of time and money. The Internet is an efficient way to find health information and social support for chronic or stigmatizing conditions, though there is some concern over the quality of information available (Epstein and Rosenberg 2005; Huang, et al. 2005; Jain and Barbieri 2005).

The sheer number of health related activities that an individual can undertake online is astounding: people can seek information about a specific condition, investigate a prescription drug and research possible interactions, review different treatment options available, give and receive social support, and keep family members apprised of ongoing health conditions (Fox & Fallows 2003). The convenience of conducting health related activities on line is at the core of its popularity. For those who can read and have internet access at home, health information is available online at any time, day or night (Fox 2008). Individuals can search for information on their own, or seek out more interactive methods of obtaining information and support such as chat rooms, list serves, and discussion boards.

Scholars have suggested that the increased access to health information on the Internet holds the potential to be particularly beneficial for those with stigmatizing conditions (Berger, Wagner, and Baker 2005; Kahlor and Mackert 2008; Powell, Darvell, and Gray 2003). People often make an effort to hide a stigmatized condition from others,

and these attempts at concealment may result in delays in seeking care (Berger, Wagner, and Baker 2005). The Internet limits the amount of personal information revealed and personal interaction necessary to get information about a specific health topic.

Social support has been conceptualized as a ‘social fund’ from which individuals can draw when they are experiencing a crisis (Thoits 1995). For those who are suffering from a stigmatized or chronic condition, the Internet allows people to interact with and garner social support for themselves. Not only can the Internet bring together people who are geographically separated (Im and Chee 2008; Pandey, Hart, and Tiwary 2003), which may be particularly useful for those residing in rural areas (Shaw, et al. 2000), it also allows for easier location of others suffering the same condition and/or going through the same types of treatment that they themselves are experiencing (Kalichman, et al. 2003; Kirschning and von Kardorff 2008; Powell, Darvell, and Gray 2003). Porter and Bhattacharya (2008) have referred to this as having access to “experienced based” information that people may not otherwise have available. Using the example of infertility, Kahlor and Mackert (2008) have argued that having specialized support available online benefits those experiencing infertility. Additionally, online sources of support allow support groups to be more specific. For example, women suffering from primary (no children) and secondary infertility (those who have had at least one child) can get information that fits their specific situation.

The Internet is characterized by both synchronous and asynchronous communication (Im and Chee 2008). Synchronous communication refers to real time chatting that takes place online. In contrast, with asynchronous communication people do not necessarily have to be online at the same time to exchange information and



support. Asynchronous communication allows for those who have different schedules to interact and support one another. In their study of breast cancer patients, Shaw, et al. (2000) found that women felt that asynchronous communication provided an advantage because it facilitated more thoughtful interactions because people could think about what they are writing prior to posting it for all to see.

The Internet is better than face-to-face meetings for people with debilitating conditions that prevent them from leaving their homes. Studies of cancer patients have highlighted how therapies often drain energy reserves, thus making it difficult to attend face-to-face support meetings (Shaw, et al. 2000). In addition, in the case of breast cancer, women have reported being hindered by worry over their appearance (Shaw, et al. 2000).

Greater accessibility also adds to the potential advantage of internet sources of social support. This resource is available in the middle of the night, a time in which other sources of social support may not be readily accessible (Shaw, et al. 2000). In their analysis of the Comprehensive Health Enhancement Support System (CHESS), an interactive computer system that provides support for breast cancer patients, Gustafson, et al. (1993) found that 40 percent of participation occurs between the hours of 9 p.m. and 7 a.m. Similarly, in their analysis of CHESS, Shaw, et al. (2000) discovered women appreciated being able to receive support in the middle of the night.

Finally, the Internet has the potential for more diverse groups of people to interact with one another because social cues of difference are minimized compared to face-to-face interactions (Kahlor and Mackert 2008). Computer-mediated communication (CMC) lacks the “elements in the physical and social environment that define the nature

of the social situation as well as cues such as education, dress, or profession that may influence individual status perceptions within a social setting” (Shaw, et al. 2000: p. 40). The removal of social cues of difference means that people interact with one another on the basis of what is said and not preconceived notions based on how people appear. In this way, the Internet holds the possibility of equalizing participation (Gooden and Winefield 2007; Powell, Darvell, and Gray 2003). A digital divide still exists, however, because internet health information and support is not equally accessible for socially disadvantaged and advantaged groups (Kalichman, et al. 2003).

### Infertility as a Stigmatized Condition

The concept of stigma has been defined in a variety of ways depending on the discipline and topic under investigation (Link and Phelan 2001). Crocker, et al. (1998, p. 505) argue that, “stigmatized individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is developed in a particular social context.” Building on Goffman’s (1963) original work on stigma, Link and Phelan (2001) have expanded the discussion of stigma to include five components – labeling, stereotyping, separation, status loss, and discrimination. Briefly, Link and Phelan (2001) note that labeling occurs when there is a recognition of difference on a socially salient characteristic. Labels are then linked to (typically negative) stereotypes. Feelings of separation are a result of the labeled individual feeling as though they are not part of the dominant group. When an individual is unable to participate in social and/or economic life, this indicates that status loss and discrimination have occurred (Green, et al. 2005).

The above conceptualizations of stigma are useful for examining the experience of infertility in the United States. Crocker et al. (1998) also describe the importance of

social context for understanding stigma. The United States is a generally pronatalist social context (Ulrich and Weatherall 2000). The prevalence of pronatalist ideology contributes to women reporting feeling pressure to have children (Dyer, et al. 2004; Franco Jr. et al. 2002; Remennick 2000) and describing infertility as an unanticipated life course disruption (Ulrich and Weatherall 2000). In a series of in-depth interviews, Parry (2005) found that infertile women felt that pronatalism was manifested through insensitive comments that people made and unsolicited advice on how to get pregnant. The expectation revealed in these interviews is that pregnancy and motherhood are desirable, easy, and natural to achieve for women (Parry 2005; Remennick 2000).

Attention to the historical context in which infertility is occurring is important as well. Letherby (2002b) argues that as new technologies were developed cultural perceptions of infertility shifted. It is now thought that physicians can “cure” infertility. As a result, decisions not to pursue treatment (Remennick 2000), or ambivalent attitudes towards motherhood may be stigmatized (Letherby 2002b).

It is common for individuals experiencing infertility who are seeking treatment to report feeling incomplete because they cannot have a child (Letherby 2002a; Redshaw, Hockley, and Davidson 2007). Trying to have a child often becomes an all consuming quest, at least for a particular time in their lives (Johansson and Berg 2005; Parry and Shinew 2004). Those who are having difficulty conceiving often report a high degree of secrecy from others (Letherby 1999; Miall 1986). This secrecy stems not only from the fact that it is difficult to talk about one’s infertility with others (Exely and Letherby 2001), but also for fear of being negatively stereotyped or stigmatized (Greil 1991).

Childless women report experiencing various negative characterizations, for example, others treat them as if they were desperate to have a baby (Letherby 2002a) or pitied them for not having children (Letherby 1999). They also reported that others assume that because they are childless, they are unable to interact with, or have no knowledge of, children (Letherby 2002b). Fears of being stereotyped contribute to infertile women using information management strategies (Exley and Letherby 2001; Miall, 1986; Remennick, 2000), or in some cases cover stories (DeOllos and Kapinus 2002). This secrecy can have negative consequences. Letherby's (1999) participants felt that keeping infertility a secret contributed to further negative opinions, such as the presumption that the infertile woman/couple was simply too selfish to have children (see Bulcroft and Teachman 2003; Gillespie 2003 for similar results).

Consistent with Link and Phelan's (2001) model of stigma, there is evidence that infertility has implications for status as a woman and as a worker. Miall (1986) found that women perceived their infertility as a failure to "work normally" and felt that this meant that they had a discreditable attribute. Remennick (2000) found that the women working in the caring professions (i.e. teaching, nursing) worried that their infertility would hurt their professional status. People feel the need to put their infertility in a "legitimate" context in order to avoid discrimination and negative perceptions (Remennick 2000).

Women experiencing infertility have reported feeling like "outsiders" because of their difficulties reproducing (Exley and Letherby 2001). Moreover, some individuals report engaging in "strategic avoidance" and try to stay away from situations in which their fertility would be discussed (Remennick 2000). As a result of trying to avoid

situations in which one's fertility will be question and/or they would come into contact with children, women experiencing infertility report feeling socially isolated (Parry and Shiness 2004; Remennick 2000).

Taken together, the research on infertility in general and stigma in particular strongly suggests that people who are experiencing infertility feel as though it is a stigmatized condition, and that it hurts their social relationships. Because the internet has been useful for individuals experiencing stigmatizing conditions (Berger, Wagner, and Baker 2005), I expect that the internet will also be an important source of social support for women who experience infertility as a stigmatizing condition.

#### Portrait of Online Activities Related to Infertility

The Internet holds huge potential for the dissemination of health information and social support for patients. Scholars have turned their attention to how women and couples experiencing fertility difficulties utilize this resource. A number of studies have sought to establish prevalence rates for people using the Internet for infertility related purposes; however, these rates are greatly influenced by the samples used. It is not surprising that participant recruitment from Internet websites yields extremely high rates of using the Internet for infertility information (Kahlor and Mackert 2008). Kahlor and Mackert (2008) posted their survey on the RESOLVE: The National Fertility Organization website and found that 99 percent of respondents had used the Internet to seek fertility information. Samples drawn from infertility clinics yield more modest results ranging from 42 to 54 percent of patient populations using the Internet for infertility related purposes (Haagen, et al. 2003; Huang, Al-Fozan, and Tulandi 2003; Weissman, et al. 2000). Samples that examine only those individuals who have access to

the Internet find a higher prevalence of online activities; between 56 and 66 percent of patients who have Internet access use the Internet for infertility related activities (Haagen, et al. 2003; Weissman, et al. 2000).

There are mixed reports of how involved people with infertility become with online activities. In qualitative interviews with infertility patients, Porter and Bhattacharya (2008) found that couples reported spending “hours” online seeking infertility information. In contrast, Haagen, et al. (2003) find that Internet use for infertility was quite sporadic, with 67 percent of couples seeking treatment going online less than once a month for infertility. Some of the discrepant results reported may have to do with the use of patient populations and stage in the treatment process. There is evidence that seeking online information is most common in the period after being referred for treatment at an infertility clinic (Haagen, et al. 2003; Rawal and Haddad 2006).

Compared to men, women are more likely to seek infertility information online. Weissman, et al. (2000) found that in 76 percent of couples, women were the primary seekers of online infertility information. In 14% of couples both partners sought information, and in just 10 percent of couples, men were the main gatherers of information (for similar results see also Haagen, et al. 2003). Because women are often the primary focus of infertility treatment, it is understandable that they are the principal seekers of information. There is, however, some evidence that the infertility related activities that men and women engage in online are different. Huang, et al. (2003) found that women were more likely to seek information on particular medical conditions

whereas men were more likely than women to utilize the Internet as a mechanism to gain a second opinion.

Much of the information that individuals and couples seek is available in a variety of formats, but Kahlor and Mackert (2008) found that the infertile in their study ranked websites as the most helpful source of information available. Most people begin searching for information (91 percent) by using a search engine to identify sites to visit (Huang, et al. 2003).

The internet can be used for multiple types of information. By far the most common activity reported was seeking information about a specific diagnosis or treatment (Huang, et al. 2003; Weissman, et al. 2000). Other activities that are frequently reported include searching for information on the causes of infertility (Haagen, et al. 2003), information to evaluate clinics (Weissman, et al. 2000), or alternative treatments that could be pursued (Porter and Bhattacharya 2008).

Recent studies have documented how common internet use is and what people with infertility use the internet for. Less is known about the behavioral implications of finding information on the internet. The consequences of internet searches need to be better understood. Kahlor and Mackert (2008) found that as a result of their information seeking activities respondents felt better informed and reported that the knowledge gained assisted them in talking to their physicians and partners (for comparable results see Epstein, et al. 2002). Weissman, et al. (2000) found the Internet to be similarly influential on medical and partner communication. In their study the information found online facilitated treatment seeking in 17 percent of couples and influenced the treatment decision making in another 20 percent of respondents. The Internet had an even greater

influence on the participants in Haagen, et al. (2003) study with 64 percent citing improved knowledge and 39 percent of participants reporting that information helped in their decision-making processes.

Physicians have expressed concern over individuals seeking health information online (Silberg, Lundberg, and Musacchio 1997). At the same time the literature suggests that individuals and couples currently undergoing treatment for fertility difficulties feel that they are not given enough information about their fertility problem and treatments. Perceptions of information deficits facilitate the use of the Internet for infertility information seeking (Huang, et al. 2003). After their first visit at a fertility clinic, couples report disappointment with the amount of information they received; in general they feel that the information provided by specialists was no better than that which they could find themselves (Porter and Bhattacharya 2008). Haagen, et al. (2003) found that the motivating factor for seeking information online was dissatisfaction with the information received from their fertility specialist. Particularly troubling is that only 17 percent of the couples in their study actually discussed what they found online with their physicians (Haagen, et al. 2003). In some cases, it is the language used by specialists that spurs couples to seek more knowledge. The Internet provides a venue in which people can get information at a non-technical, comprehensible level after visiting their physicians (Rawal and Haddad 2006). A minority of couples report that they are encouraged to seek information online by their fertility specialists (Haagen, et al. 2003) and having doctors support use of the Internet for information is associated with perceiving this information source as being more useful (Kahlor and Mackert 2008).



Research to date provides insights regarding the types of infertile individuals who are more likely to use the internet and what they use the internet for. What we know is limited, however, by the types of samples that currently dominate research in this area. All existing studies of infertility and the internet have relied on either women/couples who are already seeking treatment or are Internet samples. Therefore little is known about those who are not seeking medical treatment for infertility, nor about those who are not part of infertility web based support groups. My goal is to help fill these gaps in knowledge about the use of the internet for a stigmatized health condition, infertility. The research to date cannot be generalized to the population of infertile women as a whole, and moreover, this body of literature can only speak to specific groups of infertile women – those who are seeking treatment and those who are using the Internet. Additional information is needed on those women who only go online, as well as those women who neither go online, nor seek treatment despite fitting the medical definition of infertility.

### **Models of Help Seeking Behavior**

The decision to seek treatment for a medical condition is a complex process that has interested social scientists for decades. Anderson's (1968) Behavioral Model of Health Services Utilization was one of the first theories to attempt to explain how people made the decision to seek medical care. According to Anderson (1968), there were three components that went into decisions to seek help: the need for help, predisposing and enabling factors. Predisposing factors (health beliefs, gender) refer to attributes that reside within the individual that encourage help seeking while enabling factors (availability of care, income) are those things that facilitate or prevent people from

accessing the care that they wish for. More recently Pescosolido (1992) has proposed a framework that extends earlier help seeking models by emphasizing the role psychosocial variables such as network support and coping play in decisions to seek help. Andersen (1995) revisited his own model and acknowledges the limitations raised by Pescosolido (1992) and argues that social network variables would fit nicely into his Behavioral Model of Health Services Utilization as enabling conditions. Based on these earlier models, White, et al. (2006) developed the General Help Seeking Model that specifically examines infertility help seeking.

General theories on help seeking and White, et al. Generalized Help Seeking Model have been developed to predict the likelihood of a person to seek help in a face-to-face context. It is unclear whether or not help seeking frameworks will be useful for classifying those who are going online to find health information and support. A graph of my theoretical model is in Appendix A.

Research to date suggests that treatment seeking for infertility may be lower than what is expected given the high distress associated with involuntary childlessness (Greil 1991; McQuillan, et al. 2003). In a study of women in the United States, White, et al. (2006) found that just 40 percent of infertile women sought help. To date few studies have examined why women seek help and what barriers keep them from the treatment they desire (see Bunting and Boivin 2007; McQuillan and Greil 2004; White, et al. 2006 for exceptions). More importantly, to my knowledge, no studies have used the four categories of infertile women that I will be using to predict both medical and Internet help seeking.

**Need: Recognition of a Problem and Severity of Symptoms**

Central to theories of help seeking is the idea that people must first recognize that they have some type of medical problem (Shaw 2001). Realizing there is a problem with one's fertility may be more difficult than symptom recognition for other chronic conditions because the first 'symptom' is actually continuing to have a normal menstrual cycle (White, McQuillan, and Greil 2006). People experiencing fertility problems can attribute failure to conceive to a number of factors including mistiming intercourse, stress, and aging (White, McQuillan, and Greil 2006).

Research on help seeking for infertility supports this notion that realizing one has a problem is a crucial component to the help seeking process. White, et al. (2006) found infertile women that sought help were more likely to perceive themselves as having a fertility problem. Another issue that is relevant to problem recognition is whether or not one intends to have a baby. Couples may have unprotected sex for over a year without getting pregnant, but if they are not trying to get pregnant they might not perceive a fertility problem despite meeting medical definitions. Greil and McQuillan (2004) found that women who reported trying to conceive were more likely to seek treatment than those who were not actively pursuing a pregnancy.

Literature examining other health conditions suggests that symptom severity or how much impact a disease is having on an individual's quality of life also play a role in the decision to seek treatment. For example, in interviews with people suffering from urinary incontinence, Shaw, et al. (2001) found that participants sought help when symptoms started to interfere with their quality of life. Sheppard, et al. (2008) found similar results for individuals diagnosed with rheumatoid arthritis. Facione and Dodd

(1995) conducted qualitative interviews with women suffering from breast cancer and found that the women who sought help immediately were those who had definite symptoms (i.e. a lump) or perceived their symptoms posed a malignant threat. In contrast, women who had more benign symptoms tended to monitor their condition until a definitive symptom such as a lump were found.

What is important about these studies of other chronic conditions is that they highlight the necessity of examining the significance or interpretations that people attach to their symptoms. In the context of infertility, it is likely that there are factors that will be associated with women viewing their fertility as more problematic and therefore make them likely to seek help. I expect that those who are currently trying or intend to have more children or have a spouse who wants another baby will perceive the inability to conceive as a problem will be more likely to see help. Similarly, I anticipate that women with a high importance of motherhood will be more likely to seek help. Finally, women who experience social pressure to have children will be more likely to seek help than those who do not experience pressure from their partner and parents to have children.

### **Enabling Factors**

Enabling factors are those features that help facilitate or impede seeking help. There are three categories of enabling circumstances that are relevant for help seeking among the infertile: life course cues (age, marital status, and parity), network communication, and socioeconomic conditions (education, income, health insurance, and the digital divide). The relevant literature related to each of these enabling factors will be discussed.

### *Life Course Cues*

The context in which health decisions are made can be important (Pescosolido 1992), and this is highlighted when you consider the impact that life course cues can have on seeking treatment for infertility. If a young, unmarried woman were to have unprotected intercourse and not conceive she may view not getting pregnant as a positive thing as opposed to a fertility problem (White, McQuillan, and Greil 2006).

Age will be included with the expectation that older women will be more likely to seek medical help for infertility than those who are younger. Similarly, marriage often acts as a normative cue to start a family (George 1993; Marini 1984; White, et al. 2006). Therefore, I anticipate that married women will be more likely to seek help than will those who are unmarried. The final life course cue to be included is parity. Previous research suggests that those who are experiencing primary infertility are more likely to seek help than are those who already have at least one child (Schmidt, Munster, and Helm 1995). White, et al. (2006) found that each additional child that a woman had decreased perceptions of a fertility problem by approximately one-half.

### *Network Communication*

People within an individual's social network can play an important role in urging a person experiencing symptoms to seek help (Vogel, et al. 2007; Zola 1973). For example, Bish, et al. (2005) found that women with breast cancer symptoms were less likely to delay seeking help if they discussed their symptoms within the first week with someone close to them. Friends and family give advice about coping with symptoms and/or encourage medical help seeking (Sheppard, et al. 2008). Sheppard, et al. (2008) found that spouses were a main confidant for those who had rheumatoid arthritis. For

some respondents in this study, particularly males, it was only after the spouses constant urging that someone sought help for their symptoms. In their study of women trying to get pregnant, Bunting and Boivin (2007) found that those who did not seek help were less likely to perceive that their close family and friends wanted them to seek help than did their counterparts who had seen a medical doctor regarding their fertility. I expect those people who have talked about their infertility with others, who have had a family member undergo infertility treatment, and those who have a spouse and family members who encouraged them to see a doctor will be more likely to have sought medical treatment.

*Socioeconomic Factors: Education, Income, Health Insurance, and the Digital Divide*

Link and Phelan (1995) claimed that socioeconomic inequalities were a fundamental cause of disease. Socioeconomic factors such as education, income, and health insurance are critical to understanding health disparities because these factors can help people avoid exposure to conditions or, once one has a condition, can be used to help manage or minimize the effects of a disease (Link and Phelan 1995). They are important factors to investigate when one considers why someone seeks help for chronic conditions like infertility (Facione, et al 1997; White, et al. 2006).

These same socioeconomic factors (education, income, and health insurance) have been linked to using the Internet for health information (Ayers and Kronenfeld 2007; Cotton and Gupta 2004; Kalichman, et al. 2003). Access to the Internet is not equal; this disparity in Internet access is referred to as the digital divide (Powell, Darvell, and Gray 2003). While previous research has found that those that have health insurance are also more likely to seek online health information, this may not be as straightforward for the context of infertility. Many insurance companies do not cover infertility services,

or if coverage is offered, there are often a number of restrictions applied to the use of services (Angard 2000). Therefore, if health insurance is unavailable or infertility treatments are not covered but the Internet is accessible, this may be an option for medical information seeking.

### *Race/Ethnicity*

To my knowledge no previous study has examined racial/ethnic differences in the likelihood of using the Internet for infertility information. There is evidence of a digital divide in both access to the internet (Brodie, et al. 2000; Fox 2011; Wilson, Wallin and Rieser, 2003) and using the internet to seek health information (Fox 2010). Racial disparities in health have been well documented (Fiscella, Franks, and Gold 2000; Weinick, Zuvekas, and Cohen 2000; Williams and Collins 1995). Differences in the chances of experiencing infertility have been found even after controlling for sociodemographic variables such as income, education, and marital status (Stephen and Chandra, 2006; Wellons, et al. 2008).

Previous research finds evidence of racial/ethnic disparities in seeking help for infertility (Stephen and Chandra 2000). Jain (2006) suggests that African Americans and Hispanics are disadvantaged relative to whites because of the high cost of treatment in the United States. Even in states with mandated infertility coverage Blacks and Hispanics are under represented among those who use infertility treatments, while Asian Americans are over represented (Jain and Hornstein 2005). In addition, Jain (2005) found that African American women waited longer to seek treatment than their white counterparts. Chandra and Stephen (2010) find that racial/ethnic differences in help seeking disappear

once income and health insurance status are controlled for. This suggests that resources might be an important factor in racial/ethnic disparities for seeking help.

### **Predisposing Factors**

Predisposing factors are individual aspects that either facilitate or hinder treatment seeking. Four such factors are important to take into account when investigating help seeking for fertility problems. These include: medical locus of control, religiosity, prior experiences of and attitudes towards treatment, and the perceived stigma of infertility. Each of these predisposing factors will be reviewed.

#### *Medical Locus of Control*

Medical locus of control refers to the tendency of individuals to either perceive their health as either being controlled by their own influence (internal locus of control) or by external forces (external locus of control) such as physicians (Kiviruusu, Huurre, and Aro 2007; Mirowsky and Ross 1990). Those who feel more in control of their own health should be less likely to seek professional medical help. For example, Halter (2004) found that those people who felt that depression was under individual control were less receptive to the idea of seeking medical help. Greil and McQuillan (2004) found that women who had high internal medical locus of control were less likely to seek help for infertility. White, et al. (2006) also found that conceptualizing medical problems as outside of one's control was associated with being less likely to seek treatment, but only for those women who perceived that they had a fertility problem. These studies suggest that an internal locus of control will deter seeking medical help; however, the ability to gain health information online should appeal to those who feel that they control their health rather than seeing their health as under their doctor's control. It is expected



that high internal medical locus of control will be associated with only using the Internet for infertility instead of also seeking in-person medical help.

### *Religiosity*

Religiosity is associated with better well being (Thune-Boyle, et al. 2006; Yi, et al. 2006). In part, the benefits of religion are a function of the access to social networks that it provides (Levkoff, Levy, and Weitzman 1999). Church members can offer support and advice in times of a health crisis (Mayers, et al. 2007). Help seeking among religious individuals may be less likely because they feel as though their faith is the most efficacious way of coping with an illness (Abe-Kim, Gong, and Takeuchi 2004). Loewenthal, et al. (2001) have suggested that religious coping (i.e. prayer) may be less stigmatizing than seeking professional help. In their qualitative study of seeking help from a mental health professional, Mayers, et al. (2007) found that the religious respondents felt that seeking secular help could be viewed as a rejection of the belief in God's healing ability. Based on these studies I expect that those who are more religious will be less likely to seek medical help and more likely to use the Internet for infertility than those who are less religious.

### *Prior Experiences and Attitudes towards Treatment*

The help seeking literature suggests that an important step in seeking treatments is an awareness that treatments for a given condition exist (Shaw, et al. 2001; Sheppard, et al. 2008). In their study of people with urinary incontinence, Shaw, et al. (2008) found that when people were unaware treatments were available they were less likely to consult a physician about their symptoms. The Internet can help people identify both symptoms of and potential treatments for chronic conditions.

Prior interactions with physicians also may play a role in help seeking. Many people will avoid going to a doctor until the symptoms become unbearable and/or impact quality of life, but those that have prior experiences with medical professions are more likely to seek help than those who do not (Shaw, et al. 2008; Sheppard, et al. 2008). Moreover, Shaw, et al. (2001) indicate that how a doctor approaches someone revealing symptoms can either encourage or discourage patients from discussing sensitive or stigmatized conditions. Shaw, et al. (2008) expanded on this finding and discovered that previous aversive experiences with physicians were associated with later reluctance to seek medical help.

Research indicates that one barrier to seeking help is fear of medical examinations and treatments (Shaw, et al. 2001). Van Balen and Verduremn (1999) found that the women who opted out of infertility treatments scored higher on a general medical anxiety scale than their counterparts who underwent treatments. In contrast, Frank (1990) found that when making decisions about pursuing a treatment, women paid little attention to the potential side effects of treatments. Instead, weighing heavily into women's decision-making was whether or not the treatment was likely to be effective.

These studies of medical help seeking suggest that women who have positive attitudes towards medical science will be more likely to seek treatment than their counterparts with more negative attitudes. In addition, these findings highlight the role that physicians can play in influencing whether or not someone discusses their symptoms and undergo treatment. Women who have regular physicians and who feel as if their physicians care about them will be less likely to seek out information and support from other sources such as the Internet.

### *Stigma of Infertility*

The literature on help seeking for stigmatized conditions generally posits that fears of stigma will deter people from acknowledging there is a problem, seeking help, and adhering to recommended treatments (Barney, et al. 2006; Golberstein, Eisenberg, and Gollust 2008; Komiti, Judd, and Jackson 2006). Research has found that people are less likely to discuss stigmatized conditions with their health care providers (Shaw, et al. 2008). Shaw, et al. (2008) make the important observation that embarrassment needs to be viewed as a ‘cost’ of treatment; people will not seek help unless the discomfort of the symptoms outweigh the perceived costs of seeking help.

It is important to remember that stigmatized conditions may not be discussed as readily with friends and family. Shaw, et al. (2001) found that urinary incontinence was rarely discussed with other people. Failure to discuss health conditions with network members can have important implications because people often draw information and create causal attributions about symptoms from discussing them with others (Shaw, et al. 2008; Sheppard, et al. 2008). In situations where people are uncomfortable discussing a symptom or condition, the Internet may be a particularly useful informational tool.

There is evidence that people will delay seeking treatment if they fear being given a stigmatizing label. Bunting and Boivin (2007) found that there is a sub-sample of infertile women who do not seek treatment despite meeting the medical definition for infertility. The authors coined the term ‘delayers’ to refer to this group. Delayers appear to avoid treatment because they are significantly less likely to want to know if they have a fertility problem, and moreover, fear getting the label of ‘infertile.’ Based on these

findings it is expected that high perceived infertility stigma will be associated with going online for infertility information only, as opposed to seeing a doctor in person.

### **Social Support and Infertility**

The association between social support and health and chronic conditions has been widely studied for decades (Berkman 1984; House, Umberson, and Landis 1988; Thoits 1995). Research has examined social support both as a coping resource (Meijer, et al. 2002; Thoits 1995) and as a protective buffer when stressful situations arise (Gorman and Sivaganesan 2007; Henrich and Shahar 2008; Mulvaney-Day, Alegria, and Sribrey 2007; Turagabeci, et al. 2007). Thoits (1995) has defined social support as “a social “fund” from which people may draw from when handling stressors” (p. 64). Support from network members can come in the form of instrumental, emotional, and informational support, and financial aid (Berkman 1984; Thoits 1995). Social support has been associated with numerous positive health outcomes including, but not limited to, reductions in morbidity (Berkman 1984) and mortality risks (Birditt and Antonucci 2008), pregnancy outcomes (Hoffman and Hatch 1996; Oakley, Rajan, and Grant 1990), hypertension (Strogatz, et al. 1997; Uchino 1996), and self-rated health (Walen and Lachman 2000).

Supportive relationships provide a number of things that mitigate illness effects, including intimacy, a sense of belonging, and reassurance of one’s self worth, instrumental assistance, and guidance and advice (Berkman 1984). Previous literature suggests that people may be less inclined to seek social support if they have a stigmatized condition (Link, et al. 1989; Perlick, et al. 2001). Most qualitative studies, as discussed

above, find that women and couples who recognize that they are infertile experience infertility as a stigmatized condition.

Slade, et al. (2007) have proposed a model linking perceptions of infertility stigma to high emotional distress due to lower social support. Briefly, their model suggested that perceptions of stigma would result in the infertile being less likely to disclose their fertility problems. Those who do not disclose their infertility may be subject to joking remarks and insensitive comments that potentially result in reduced feelings of support (Slade, et al. 2007). Deficits in perceived support can result in higher emotional distress. Using a sample of new fertility patients, Slade, et al. (2007) found that stigma was not related to likelihood of disclosure of a fertility problem for women. In contrast, men in the study behaved as their model predicted; infertility stigma was associated with lower disclosure of fertility problems to others. For both men and women, stigma was associated with lower rates of social support. Importantly, in this study social support was associated with lower anxiety, depression, and infertility related distress (Slade, et al. 2007).

#### *Infertility and Support within Marital Relationships*

In her review of the literature on social support, Thoits (1995) argues that the most basic and powerful measure of social support is whether or not an individual has a close relationship with someone in whom they can confide. This intimate confidant is typically a partner or spouse, though close friends and other family are thought to have similar, though less powerful protective functions on physical and mental health in times of stress (Thoits 1995).

In the case of infertility, an intimate partner may be a critical source of support, particularly for those individuals who do not wish to divulge their reproductive difficulties to others in their network (Slade, et al. 2007). The research to date has found inconsistent results with regards to the impact of infertility on the marital relationship. Some research studies find that the stresses of infertility and treatment have a negative impact on marriage (Folkvord, Odegaard, and Sundby 2005); whereas other studies find that participants feel that their shared problem of infertility has brought them closer together (Daniluk 2001; Leiblum, Kemmann, and Lane 1987; Webb and Daniluk 1999). Even more common are studies which report inconsistent results within the same sample, with some respondents feeling as though infertility has strengthened their relationship while others feel as if it has caused conflict, or has not changed their relationship at all (Greil 1991; Hjelmstedt, et al. 1999; Imeson and McMurray 1996; Oddens, den Tonkelaar, and Nieuwenhuysen 1999).

Couples that indicate that infertility changed their relationships for the better report that their emotional intimacy and communication have increased and they feel closer to their partner (Hjelmstedt, et al. 1999; Imeson and McMurray 1996). The vast majority of couples do not appear to have a problem discussing fertility difficulties with their partners (Holter, et al. 2006), though Oddens, et al. (1999) did find that relative to fertile couples, infertile couples in treatment did find it harder to communicate with their partners about their difficulty realizing their wish for a child. A spouse or partner is an important source of support when making the decision to seek treatment, and a significant minority of women (32 percent) discuss treatments only with their husbands and physicians (Onnen-Isemann 2000). Johnson and Johnson (2009) found that couple

agreement about the importance of parenthood increased the odds of seeking treatment compared to only talking to a doctor about infertility.

Couples report a number of strategies used to support one another including taking turns providing support, using positive thinking in regards to their fertility problem, creating plans of action, and indulging themselves between treatments (Imeson and McMurray 1996). Because the site of infertility treatments is typically the woman, men have to find ways to be involved and supportive. Throsby and Gill (2004) found that men showed their wives support by giving them hormone injections and keeping track of when the next dose needed to occur, making tea, and providing moral support. Interestingly, the men in this study conformed to traditional gendered scripts to conceptualize support; they felt they needed to be an emotional rock for their partners (Throsby and Gill 2004).

The impact of infertility on the couple relationship may be influenced by the coping strategies used by spouses. Using a sample of couples receiving IVF treatment, Peterson, et al. (2006) found that wives levels of infertility stress and depression were higher when their husbands used a distancing coping strategy. In contrast, support seeking as a coping mechanism appears to help marital satisfaction remain the same or increase among those seeking treatment (Peterson, et al. 2006). McEwan, Costello, and Taylor (1987) found that distress was lower for those couples who shared the problem of infertility within their relationship compared to those who sought support from other network members.

The stresses associated with infertility can potentially cause conflict for couples. Holter, et al. (2006) found that, compared to women, men were more likely to feel that their inability to have a child had caused problems in their marriage. Similarly, Imeson

and McMurray (1996) found that the number of arguments increased for some infertile couples. In situations in which the cause of the infertility is known, some couples report feelings of blame towards the infertile partner (Berger 1980; Imeson and McMurray 1996). These negative feelings partners have for one another may translate into lack of support. Twenty percent of couples undergoing their first IVF treatment reported that either they did not feel like their spouse provided emotional support or understood their feelings, or conversely, felt that they did not provide the support that their partner needed while going through treatment (Holter, et al. 2006).

Taken together, the research suggests that there is a great deal of variety in terms of how couples can respond to a fertility crisis. In some cases couples appear to come together and support one another, whereas in others, infertility is a stressor that damages the relationship. To some degree, the impact that fertility problems have may be associated with how stable the relationship was prior to encountering the challenge of having a child. Infertility may only have positive, supportive side effects when the marital relationship was positive to begin with (Connolly, et al. 1992). I include a measure of whether or not the partner encouraged seeking treatment as a factor that enables help seeking, though not all women included in the sample have partners.

#### *Infertility and Support from Family and Friends*

The evidence to date is mixed on what role family and friends have in supporting people experiencing fertility difficulties. As discussed above, a common theme in the infertility literature is one of secrecy. Infertility is often viewed as a private problem that is hidden from friends and family (Johansson and Berg 2005; Miall 1986; Remennick 2000). Not only do the infertile have to deal with their own emotional reactions to their



fertility problems, additional distress may be experienced if they have to deal with other people's disappointment in their failed attempts to have a child (Imeson and McMurray 1999).

Some individuals do decide to share their infertility with others. When asked to identify sources of support, Gibson and Myers (2002) found that 92 percent of women mentioned female peers. Hjelmstedt, et al. (1999) found that friends were the most common source of social support for both genders. Onnen-Isemann (2000) found that friends were often asked for advice when people were considering seeking treatment for their fertility problem.

The support women gain from their social network can have important implications for psychological well-being. The more support that infertile women can mobilize, the less distress they experience (Stanton, et al. 1992). Similarly, Gibson and Myers (2002) found that partner and family support contributed to predicting infertility stress. Woods, Olshansky, and Draye (1991) found that perceptions of support from social networks increased infertile women's self-esteem and mastery.

Social network members do not always respond to disclosure of a fertility problem in a positive way. Mindes, et al. (2003) found infertility specific unsupportive interactions were positively associated with depressive symptoms and overall distress. Infertile women report that their network members simply do not understand what they are going through (Imeson and McMurray 1999). These feelings are enhanced when the women are the recipients of insensitive comments such as "you are not doing it right," "just relax," "you are trying too hard," and "you are not trying hard enough" (Imeson and McMurray 1999; Ulrich and Weatherall 2000). In their interviews with infertile men,

Throsby and Gill (2004) found that respondents perceived female disclosures as receiving more sympathy. In contrast, when men disclosed fertility problems they experienced jokes about their potency and/or virility regardless of whether the infertility problem resided with them. Because of the social ridicule these men experienced, they either implicitly or explicitly blamed their partners for the infertility (Throsby and Gill 2004).

Finally, social network members may intentionally or unintentionally exclude the infertile, particularly women. Oddens, et al. (1999) found that over half (53.4 percent) of infertile women in their sample had experienced network members reluctance to discuss children in their presence. Similarly, women report that friends and family are hesitant to discuss pregnancy around them (Imeson and McMurray 1999). The unwillingness of others to discuss pregnancy and children around results in infertile women feeling isolated and excluded.

#### *Infertility and Support from Health Care Professionals*

Health care professionals interact with infertile couples that seek treatment and hold the potential to be a source of support for men and women experiencing problems with their fertility. The literature to date suggests, however, that providers are not offering support to couples coming in for treatment. Women are often dissatisfied with the relationship they have with their fertility specialist (Malin, et al. 2001). Studies find that women feel rushed during their appointments (Draye, Woods, and Mitchell 1988) and that the care that they receive is impersonal and lacking sympathy and compassion (Imeson and McMurray 1996; Redshaw, et al. 2007; Yebei 2000). Another often mentioned criticism is that the infertile do not receive as much informational support as they would like during their appointment times (Imeson and McMurray 1996; Porter and

Bhattacharya 2008). Interestingly, dissatisfaction with care is common even when fertility treatments are successful. Using a sample of women who successfully gave birth, Reshaw, et al. (2007) found that half of women were critical of their providers. Those women who do report positive experiences with their infertility care are the ones who had supportive and individualized treatment encounters (Malin, et al. 2001)

Brucker and McKenry (2004) examined gender differences in perceptions of support from health care providers and their associations with psychological outcomes. While no significant differences in perceptions of support were found for men and women, perceived support predicted stress and anxiety for the men in the sample. No such associations were found for women.

### **Online Support Groups**

The research reviewed above indicates that seeking social support is an important coping mechanism among people seeking help for infertility. Difficulties in accessing social support due to the isolating nature of infertility can potentially be overcome by online support groups. Scholars from diverse fields have examined support group use for a variety of conditions including, but not limited to, infertility (Epstein, et al. 2002; Kahlor and Mackert 2008; Malik and Coulson 2010; Malik and Coulson 2008), breast cancer (Shaw, et al. 2000), prostate cancer (Broom 2005), HIV/AIDS (Kalichman, et al. 2003), endometriosis (Whitney 1998), and fibromyalgia (van Uden-Kraan, et al. 2008a). It is striking that this body of literature on online support groups reveal similar advantages and disadvantages to support groups regardless of the type of chronic condition being studied. Because of this consensus, I will be discussing the online support group literature as a whole, unless otherwise specified.

As described, there are a number of conveniences available online that may make the information and support available on the Internet more advantageous than face-to-face help. The convenience aspect of online support groups is a consistent theme in these studies. Briefly, online support allows for connections with similar others any time of the day or night, from the privacy of their own home, to receive access the specific type of support (informational, emotional, or both) that they need (Hinton, Kurinczuk, and Ziebland 2010; Malik and Coulson 2008). Support can be received quickly, and information garnered from similar others that is comprehensible and situation specific (van Uden-Kraan, et al. 2008b). The ability to reach out to a large, diverse set of people is particularly beneficial for those who are isolated due to stigmatized conditions.

Perhaps one of the most important and consistent findings to date is that the Internet social support groups facilitate a sense of empowerment for their users (van Uden-Kraan, et al. 2008b; Malik and Coulson 2008; Shaw, et al. 2000). The only study to date to examine empowerment specifically is by van Uden-Kraan, et al. (2008b). They found a number of outcomes from online support group participation that they think contribute to empowerment. Empowered patients are those individuals that are “considered to be successful in managing their condition, collaborating with their healthcare providers, maintaining their health functioning, and accessing appropriate and high quality care” (van Uden-Kraan, et al. 2008b: p. 406). As a result of the exchange of information, users of Internet support groups feel like they are better informed about their condition and that this information results in more confidence when interacting with physicians. Moreover, being able to gain information from experienced others about treatments and medications helps Internet support group users, including infertile women,

make more informed decisions about treatments and medications (Malik and Coulson 2008; van Uden-Kraan, et al. 2008b). The exchanges online appear to help facilitate greater acceptance of chronic conditions, and additionally, are likely to facilitate being able to disclose information of a disease to others in one's network (van Uden-Kraan, et al. 2008b). Support groups allow people to not only receive support, but also to give support and advice to others who are distressed. Giving similar others advice about their health problem has been found to be rewarding in and of itself (Whitney 1998).

Reports of social comparisons occurring as a result of using online social support groups are common (Dibb and Yardley 2006; Malik and Coulson 2008; Shaw, et al. 2000; van Uden-Kraan, et al. 2008b). Support groups contain similar others and/or others with similar conditions which make comparisons likely. The comparisons that people make can be downward or upward. Downward comparisons, or comparisons with others who are worse off than you are, in online self-help groups have been found to be associated with better functional quality of life (Dibb and Yardley 2006). Bane, Haymaker, and Zinehuk (2005) have argued that online support groups allow people to bias the information that they take in to avoid comparisons that would be distressing.

In a unique study of infertile women using an infertility website, Epstein, et al. (2002) compared those who only used the Internet to talk about infertility (only outlet) and those who used the Internet in addition to alternative sources to discuss infertility (alternative outlet). Those who only used the Internet to talk about infertility had lower educational attainments and incomes, and were less likely to have insurance coverage. In addition, these individuals spent more hours per day online engaged in infertility related activities compared to those women who also had alternative outlets to discuss the

stresses of infertility. Those who only used the Internet also appeared to be disadvantaged in terms of psychological outcomes. Internet only participants were found to be more depressed, perceive less social support, and used less effective coping strategies for dealing with infertility. The authors found that those who only went online felt like they received validation from other site members to withdraw from real-world interactions that could be potentially distressing (Epstein, et al. 2002). Although the internet has the potential to connect people with infertility to each other, this study suggests that the internet also can contribute to reduced face-to-face interactions, and the in person interactions are important to reduce feelings of isolation.

Participants of online support groups have voiced concerns over the quality of information provided online and the possibility of receiving bad advice (Hinton, Kurinczuk, and Ziebland 2010; van Uden-Kraan, et al. 2008b). The potential exists for the amount of information and exchanges to overwhelm users of online support. In discussing conditions with others, Internet support group users may be confronted with the very worst aspects of a condition (van Uden-Kraan, et al. 2008b). Specifically in the case of the infertile, news of others reaching their goal of having a child could be distressing (Hinton, Kurinczuk, and Ziebland 2010). Malik and Coulson (2008) noted that, “over time for certain individuals, particularly those couples who had been through repeated treatment attempts, messages reporting positive treatment outcomes appeared to compound the psychological distress they were experiencing and in some instances resulted in individuals withdrawing active participation in the community” (p. 110). Finally, users of infertility boards have mentioned becoming ‘obsessed’ with reading

online discussions at the expense of real world activities (Hinton, Kurinczuk, and Ziebland 2010; Malik & Coulson, 2008).

### **The Present Study**

In this dissertation I will contribute to sociological understanding of the potential of the Internet to assist individuals with a stigmatized health condition, infertility, by obtaining information and social support. Much of the existing research on the infertile is based on samples drawn from those who are already seeking fertility treatment. This is a problem because prior research suggests that about half of the women who meet the medical definition of infertility yet do not seek treatment (Bunting and Boivin 2007; Greil and McQuillan 2004). Data that include only those who have sought help means that we know little about those who opt out of seeking in-person medical help, and in particular, the barriers that keep them from medical assistance for their infertility.

Similar data limitations are evident in the studies that specifically examine the use of the Internet by the infertile. Research to date is based on samples exclusively drawn from those who are already online or those who are currently accessing in-person medical help for their fertility problem. This is an important limitation, particularly in the case of the samples drawn from Internet sites on infertility, because those predisposed to the internet self-select into the sample. Online surveys of internet users are likely to present distorted portraits of the importance of the internet to those with infertility. Moreover, this means that the existing body of literature has few comparisons between those who do and do not engage in infertility related activities on the Internet. The few studies that do make these comparisons consist entirely of people who are already in treatment. Those

neither seeking treatment nor using the internet are not represented in research on infertility help seeking.

The data set for the present investigations overcomes these limitations. I will be using a sub-sample of women from the National Survey of Fertility Barriers (NSFB), a random, nationally representative sample of women aged 25-45 with an oversample of women meeting the medical criteria for subfecundity to help better understand women who do and do not use the Internet for information and support. I will make comparisons between four groups of women: (1) those who do not engage in any help seeking activities (2) those who only go online for infertility related purposes (3) those who only seek in person help from a medical professional and (4) those who both go online and see a medical doctor.

My first goal is to assess if people who use the Internet for infertility help and information are different from those who do not. In order to gain a better understanding of this, I will first characterize the four groups based on responses to items measuring need, enabling and predisposing factors. Among those using the internet for infertility help, I will describe the frequencies of activities that people engage in online (i.e. found information about a doctor or fertility clinic, found information about a specific treatment, used an Internet support group) and how the information found online impacted thinking about infertility.

Next, I will examine factors that facilitate and impede in-person and Internet help seeking among infertile women. Theories of help seeking examine variables that are associated with seeking help in a face-to-face encounter (Anderson 1968; White, et al. 2006). It remains unclear whether the same factors that have been associated with



seeking professional medical help will also be associated with looking for information and support online. This is a question this study will address. Following the basic structure of White, et al. (2006) General Help Seeking Model I will use variables measuring need, enabling, and predisposing conditions to predict the odds of being in one of the four categories of help/information seeking.

The research reviewed above suggests that using the Internet for infertility related purposes has the potential to be distinctive for three reasons. First is the issue of stigma. The Internet offers those with stigmatized conditions a means of accessing information and support that they otherwise might not access due to the desire to keep a health condition hidden. It is expected that those who only use the Internet for help seeking will have higher infertility stigma than those who seek medical help, those who seek medical and use the Internet, and those who do neither of these things.

Second, to my knowledge no one has examined if medical locus of control is associated with use of the Internet for health information. This study offers an opportunity to examine this question. People with a high internal locus of control feel as though they, not a doctor, are in charge of their own health (Wallston, Wallson, and DeVellis 1978). The Internet offers an exceptional opportunity for those people who have high internal medical locus of control to take an active role in maintaining or improving their health. I expect that those who have a low internal medical locus of control to be in one of the two treatment seeking groups. Further, of the two groups who did not seek treatment, I expect that individuals with a high internal medical locus of control will be more likely to have used the Internet only than done nothing.

The third reason the Internet may be distinctive for help seeking is related to the resources that an individual has available to them. As discussed above, there is still evidence of a digital divide; those who are more socioeconomically disadvantaged are less likely to have Internet access than those who have better economic circumstances (Powell, Darvell, and Gray 2003). At the same time, the United States has no national health insurance coverage and the majority of insurance plans fail to cover infertility treatments (Angard 2000). The high cost of treatments acts as a barrier to the infertile that experience economic hardship. I expect that people with higher incomes will be more likely to seek formal help from a doctor.

Additionally, the literature reviewed above suggests that often women are dissatisfied with the treatment they receive (Imeson and McMurray 1996; Redshaw, et al. 2007; Yebei 2000). Those that are satisfied with medical encounters are the women who perceived their care to be individualized and supportive (Malin, et al. 2001). Literature examining motivations of infertility patients for using the Internet suggest that dissatisfaction with the information received during the treatment encounter may facilitate seeking additional knowledge online (Huang, et al. 2003). Therefore, those that feel less cared for by their doctor should be more likely to go online.

Finally I will test the association between help seeking activities (none, internet only, medical only, and both) and social support. There is evidence that the internet can be a mechanism through which people gain social support in times of a health crisis (Shaw, et al. 2000). Literature examining online support seeking for a variety of medical conditions suggests that this activity should have positive benefits for individuals (Hinton, Kurinczuk, and Ziebland 2010; Malik and Coulson 2008; Shaw, et al. 2000; van

Uden-Kraan, et al. 2008b). When looking at literature that specifically focuses on infertility, however, existing research also points out that only going online compared to going online and discussing infertility in another outlet as well is associated with lower perceived social support (Epstein, et al. 2002). It is unclear how type of help seeking (none, internet only, medical only, both) will be associated with social support. I expect that those who engage in multiple types of help seeking (both seeking in person help and going online) will report more social support than any of my other groups of infertile women. Further, I expect that those who only seek in person help and those who only go online will perceive more social support than those who do none of these things.

Studies suggest that online social support may be particularly helpful for those who are suffering from stigmatized conditions (Berger, Wagner, and Baker 2005). I expect that those who have high infertility stigma will perceive less social support from their networks. If the Internet facilitates perceptions of support among those who have stigmatized conditions, I expect that the negative relationship between stigma and social support will either be reduced or disappear once online support seeking is entered into the model. In this chapter I have provided a brief overview of my current study. Next, in chapter three I will describe my sample and the analysis strategy in more depth.

### Chapter 3: Methods

#### Data Source

Data for this study were drawn from the National Survey of Fertility Barriers, a national probability sample of women ages 25 to 45. Interviews were conducted with 4,712 women and some of their partners. The response rate for this data set was 53%, and while low, this response rate is consistent with declines in telephone survey participation (Curtin, Presser, and Singer 2005). This data set oversampled women from census tracts in which over 40 percent of residents were African American or Hispanic and offered a Spanish language interview. The weighted sample is representative of reproductive aged women living in the 48 contiguous states in households with a telephone.

The sampling frame of potential participants was generated using random digit dialing. Interviews were conducted with the help of computer-assisted telephone interviews (CATI). This is a software program that allows for the development of skip patterns; as participants respond to questions the program determines the direction of the skip patterns, or which questions will be asked next (McQuillan and Greil 2004). The telephone interviews were conducted by the Bureau of Sociological Research at the University of Nebraska-Lincoln and at the Survey Research Center at Penn State University.

The sample design attempted to match telephone numbers with addresses to send out a pre-notification letter and a one or two dollar incentive for participation. Upon contacting a household, interviewers conducted a short screening interview to determine whether there were any women in the household eligible for participation. If there were

not, the interview was concluded. If there were, the woman became the study respondent. Women were selected randomly in households that had more than one eligible female for inclusion in the study. Full interviews were conducted with women who reported a fertility barrier and approximately 10 percent of women who had children, had no desire for future children, and had no fertility barrier. Interviews were ended with remaining eligible respondents after approximately 10 minutes of baseline questions. A “planned missing” design was utilized as a mechanism to minimize respondent burden while still incorporating all measures that were theoretically relevant.

### Analytic Sample

The current study is based on a subsample of only those women who meet the medical definition of infertility and were asked questions about their Internet information seeking behaviors. This subsample includes women who are actively trying to conceive (infertile with intent), infertile but are not attempting to have a baby (infertile without intent) and who were okay either way about pregnancy but were not doing anything explicit about getting pregnant.

There were 2,363 women who met the medical definition for infertility in the NSFB. Unfortunately, the subsample used in the analyses presented here is somewhat smaller due to complex skip patterns designed to minimize respondent burden and distress. All of the women were asked whether or not they had ever gone to a doctor or clinic to discuss ways to have a baby. Two women skipped out of this question because they refused to answer. Subfecund women who reported that they had not gone to a doctor or clinic to discuss ways of getting pregnant were skipped to a subsequent question, “When you did not get pregnant right away despite having sex without birth

control, did you ever wonder about a medical problem?" Women who answered 'no' to this question were skipped out of being asked any questions about seeking infertility information online (n=987). This reduced the sample size to 1,374 cases.

Fourteen cases were removed due to missing data on the imputed scales. As discussed above, a planned missing design was used to minimize respondent burden. Imputation was used to estimate responses that were not available due to the planned missing design. Further exploration of these participants revealed that they were part of a small group of cases that were added to the data set late. Eight lesbian women were removed from the sample; unfortunately there were too few women to analyze this group independently. The final sample size includes 1,352 women.

At present this data set is only cross sectional. The data allow for examination of experiences with infertility, internet use, help seeking, and social support measured at one point in time, but includes both retrospective and current reports. Because of this, I cannot establish the causal ordering of internet use and seeking medical help actions, or to assess perceived social support before and after using the internet.

### The Current Investigation

As discussed above, decisions to seek medical help for health problems involve a complex decision making process. Help seeking theories have been used to examine factors associated with seeking help from a medical professional in a face-to-face context. In this first study, I seek to test the General Help Seeking theory (White, et al. 2006) to see if factors that are typically associated with seeking in person help will also predict whether a person goes online to seek information about infertility.

In order to explore the differences between the four groups of women, I perform chi-square tests for categorical variables and ANOVAs for continuous variables. As describe above, I compare infertile women who (1) do not do any type of help seeking (2) only go online for infertility related activities (3) only see a doctor in person, and (4) both go online and seek medical help for infertility. In addition to the overall F test produced by the ANOVA, to assess specific mean differences between groups I use the Tukey's Honestly Significant Differences (HSD) test to adjust for multiple comparisons.

Next, I will use a multinomial logistic regression to predict the odds of category membership (i.e. no help seeking, internet only, medical only, and both) based on their need, enabling conditions and predisposing factors. Logistic regression is an appropriate method of analysis when you have a dependent variable that is categorical (DeMaris 1995). A multinomial logistic regression is necessary because the dependent variable, type of help seeking, has four categories that are not ordered. This method of analysis will allow me to compare the coefficients across the groups to see whether they vary by types of help seeking activities.

I enter the variables for the multinomial logistic regression in stages, starting first with variables measuring predisposing characteristics. Next variables that measure need will be added, followed by enabling conditions. Based on the literature reviewed, there are a few key associations that I will be paying particular attention to. First, prior research suggests that people with stigmatized health conditions may be more likely to seek information about their condition online rather than in person (Berger, Wagner, and Baker 2005). Based on this, I expect that as infertility stigma increases, women will be more likely to go online for infertility information than only seek medical help.

Second, existing studies indicate that people who feel that they are in control of their own health, or in other words have a high internal medical locus of control, will be less likely to seek help (Greil and McQuillan 2004; Halter 2004). Moreover, the ability to gain personal access to health information should appeal to those who feel as though they are in control of their health. I believe that higher internal medical locus of control will be associated with being more likely to go online for infertility information rather than going to a health care provider.

The second part of the project focuses on social support. Social support can help people cope with infertility (Gibson and Myers 2002; Stanton, et al. 1992; Woods, Olshansky, and Draye 1991). Research on internet support groups suggests that interacting with others online can offer positive benefits including support during a health crisis (Hinton, Kurinczuk, and Ziebland 2010; Malik and Coulson 2008; van Uden-Kraan, et al. 2008). What is unclear is whether the support received online substitutes for other supportive relationships that would occur in a face-to-face context, or whether those who have high social support in general are also those who would be most likely to seek additional support online.

I use ordinary least squares regression to investigate the relationship between social support and the four types of help seeking. I expect that those that do the most help seeking (both go online and see a doctor) will have the most social support, followed by those who only go online or only seek in-person help. Those who do nothing are expected to have the lowest social support. Alternatively, those who already have high levels of social support may not need to pursue other avenues. Therefore, past research



and the help seeking theoretical model do not provide explicit guidance for predicting social support.

Variables for the regression will be entered in stages, starting first with those items that measure predisposing factors<sup>1</sup>. Next variables that measure need will be added, followed by enabling conditions. I will then include dummy variables for the type of help sought. By entering these dummies last, I will be able to determine whether the type of help seeking mediates the relationships between predisposing, need, and enabling conditions and social support. In addition, I will be able to assess which of these four groups has the highest levels of social support.

I expect two relationships in particular to be mediated by type of help seeking – having a friend or family member who has experienced infertility and having talked to someone who has experienced a similar situation<sup>2</sup>. Finally, because I expect that stigma will be negatively associated with social support for those who do not use the internet, but that stigma will have no association with social support for those who use the internet, I include interaction terms of type of help seeking and the stigma scale. If there is a stronger negative association between perceived stigma and perceived social support for those who get help on line, then this suggests that those who have high infertility stigma are compensating for the social support that they are not getting from their face-to-face networks with support online.

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<sup>1</sup> I continue to include predisposing, need, and enabling indicators in my models of social support. I am not testing a theory of social support, but instead, am interested in continuing to learn more about what differentiates the different types of help seeking.

<sup>2</sup> This variable *talked to someone who experienced a similar situation* does not specify where the communications occurred. The interactions with someone who experienced a similar situation could have occurred in person or online.

It is unclear whether the activities that people engage in online will be associated with their perceived social support. Due to the skip patterns the data set, few women were actually asked about the activities that they engaged in online (n=291). Only women who had gone online for infertility information and reported that the internet information seeking occurred in the previous three years were asked about what types of activities they did with regards to their infertility information seeking. The strength of this sample is that recall should be more accurate than if women who had had their episode further in the past were included, and access to the internet should be relatively similar for this group. Additionally, although fairly small, that this is a group selected through a random digit dialing approach, it is a random sample. I will run an additional ordinary least squares regression that includes a series of dummies for online activities to see if the things people actually do online are related to social support. I expect that the activities that are related to interactions with people (i.e. used email or a website to communicate with a doctor or other health care professional about infertility; participated in an online support group) will be associated with higher perceived social support.

### *Measures*

Throughout the description of my measures I will describe the percentages and means for each of the variables in the study. Table 1 in Appendix B provides the descriptive statistics for the dependent variables and variables associated with predisposing, need, and enabling conditions. Table 2 provides an overview of the variables related to online activities.

## **Dependent Variable – Predicting Help Seeking**

### *Type of Help Seeking for Infertility*

The dependent variable *type of help seeking for infertility* is a constructed help seeking classification for infertile women. Women were classified as having sought medical help if they reported consulting a doctor about getting pregnant. Not all women who consulted a doctor about their fertility problem went on to undergo tests and treatments.

As described above, in order to assess Internet use, participants were asked if they had ever looked for information about getting pregnant on the Internet (1 = yes, 0 = no). Answers to the previous two questions were used to construct a variable categorizing all women by the *type of help seeking for infertility that they engaged in*. Infertile women were placed into one of the following four categories using the variables mentioned: (1) those that did not seek help, (2) only used the internet for infertility activities, (3) only saw a medical doctor, (4) both went online and saw a doctor. Approximately 34% of women did not do any type of help seeking, just over 9% went online only, 32% only saw a medical doctor, and 25% saw a doctor and went online.

## **Dependent Variable – Social Support**

### *Social Support*

Social support was measured by a 4 item scale created to measure medically relevant support<sup>3</sup>. This scale was part of a larger 20 item scale developed by the Canadian Community Health Survey (Sherbourne and Stewart 1991). Respondents were

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<sup>3</sup>Social support could conceptually be related to type of help seeking, however, I do not include it in my multinomial logistic models for analytical clarity. Instead, I include several other indicators of social support (i.e. talked to others about fertility problems; talked to others who had experienced a similar situation; know someone who has had treatment; partner, family and friends encouraged treatment).

asked how often the following kinds of support were available if they needed it: “someone to give you advice about a crisis”, “someone to give you information to help you understand a situation”, “someone whose advice you really want”, and “someone to share your most private fears with”. The scale was created by estimating the mean score for available responses to these 4 items. All of the items use the following response categories: (1) = often, (2) = occasionally, (3) = seldom, and (4) = never. Items were coded so that higher numbers represent more social support. The mean score was 3.54<sup>4</sup>.

### **Independent Variables**

#### *Activities Engaged in Online*

Respondents who had used the Internet to look for information about infertility were asked a number of follow up questions about the activities they had engaged in online. Five activities were included: “Looked for medical articles on getting pregnant”, “Looked for information about treatments”, “Used email or a website to communicate with a doctor or other health care professional about fertility treatments”, “Used online information to select or evaluate the qualifications of a reproductive doctor or clinic”, and “Participated in an online support group for women or couples who are experiencing delays in getting pregnant.” Response categories included (1) often, (2) seldom, (3) occasionally, and (4) never.

The majority of women who were asked about their activities online had used the internet to look for information about a treatment at some point often (19%), occasionally (24%), seldom (16%) or never (41%). For the multivariate analyses, I created a series of indicator variables to compare those who reported going online for information about a treatment occasionally, seldom, or never compared to those who did so often.

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<sup>4</sup> This and all other continuous variables were mean centered for the multivariate analyses.

A large proportion of women who have gone online report that they have looked for medical articles often (25%) or at least occasionally (41%). A substantial minority looked “seldom” (25%) and only 9% never looked for medical articles on infertility. I created dummy indicator variables for the responses to *online articles* and compared women who indicated that they did this occasionally, seldom, or never to those who reported going online for medical articles often. One woman answered “don’t know” to this question, and this response was included with those who said “never”.

The remaining three online activities, “Used email or a website to communicate with a doctor or other health care professional about fertility treatments”, “Used online information to select or evaluate the qualifications of a reproductive doctor or clinic”, and “Participated in an online support group for women or couples who are experiencing delays in getting pregnant” were much less common. For each of these variables I collapsed those who reported having often, occasionally, or seldom done that activity compared to those who responded “never” due to having at least one cell that had fewer than five respondents. One participant responded “don’t know” to the question regarding having ever used an internet support group. This response was included with those who said “never”.

Twenty percent of women indicate that they had emailed or contacted a website to communicate with a doctor or other health professional about infertility. Thirty-four percent of women report going online to evaluate a doctor or a clinic. Finally, 21 percent of women mention utilizing an online support group for people with reproductive difficulties.

### *How Internet Information Affected Thinking*

Participants were asked to respond to a series of statements regarding how the Internet had affected their thinking about their fertility problem. The statements included: “The information I got online encouraged me to see a doctor about help or advice getting pregnant,” “The information I got online led me to ask a doctor new questions about getting pregnant,” “The information I got online provided me with a better understanding of health issues that affect ability to get pregnant,” “The information I got online made it easier to work with my doctor regarding treatments to get pregnant,” and “The information I got online discouraged me from seeking treatment.” Respondents could (1) strongly agree, (2) agree, (3) disagree, or (4) strongly disagree.

Sixteen percent of women strongly agreed that the information they received online encouraged them to see a doctor, 48% agreed, 32% disagreed, and 4% strongly disagreed. Online information encourages asking a doctor new questions: 20% strongly agreed, 48% agreed, 28% disagreed, and just 4% strongly disagreed. The internet users overwhelmingly indicate that the internet helped them better understand the health issues that impact pregnancy: 25% strongly agreed, 65% agreed, 9% disagreed, and just 1% strongly disagreed. In response to the following statement, “The information I got online made it easier to work with my doctor regarding treatments”, 12% strongly agreed, 51% agreed, 33% disagreed, and 4% strongly disagreed. Finally, the information received online does not appear to discourage treatment seeking: 1% strongly agreed, 7% agreed, 71% disagreed, and 21% strongly disagreed.

### *Non-Internet Self Education*

Women in the sample were also asked about their self-education activities that they engaged in. Almost half of the women (46%) reported that they had “Read articles on getting pregnant in technical or scientific journals”. Forty-one percent of participants reported that they had “Read a book about getting pregnant.” Far fewer women indicated that they had contacted a support group (11%). These questions were asked of all women included in my sample. The interview did not specify whether these activities were things that were done online or offline. These were all (1) yes or (0) no responses.

### *Most Helpful Source of Information*

Respondents who went online were asked the following question, “You have used several sources for information. Overall, what was the most helpful source of information?” There were nine possible response categories: (1) articles in popular magazines, (2) articles in tech (paper) journals, (3) books, (4) face-to-face support groups, (5) Internet, (6) Internet support groups, (7) professionals on the Internet, (8) information from family and friends, (9) professional (in person), and (10) other or don’t know. Over half of the women (52.5 percent) indicated that the internet was the most helpful source of information. Please see Table 3 for a full list of the percentages of most helpful source of information.

### *Variables Measuring Need*

#### *Perception of a Fertility Problem*

Respondents were asked the following two questions: “Do you think of yourself as someone who has, has had, or might have trouble getting pregnant?” and “Do you think of yourself as someone who has, or has had, a fertility problem?” Responding ‘yes’

to either of these questions resulted in the classification of perceiving oneself as having a fertility problem (1= yes, 0 = no). Sixty-nine percent of women perceived that they had a fertility problem.

### *Fertility Intentions*

Intent to have a baby was assessed by the following item, “Do you intend to have a baby?” Participants could respond “yes” or “no.” Based on this response a follow up question was asked, “Of course sometimes things do not work out exactly as we intend them to or something makes us change our minds. In your case, how sure are you that you will have (or not have) a child?” Response categories are (2) very sure intend, (1) probably intend, (0) don’t know, not sure, and let god decide, (-1) probably no intent (-2) very sure, no intent. The mean response to fertility intentions was -.60 (SD = 1.29).

### *Desire for a Baby*

Respondents were asked to report on their desire for a baby (or another child) by answer the following question, “Would you yourself, like to have a(nother) baby? Would you say definitely yes, probably yes, probably no, or definitely no?” A series of indicator variables for each of these response categories (definitely yes, probably yes, probably no, definitely no) were created with women who report that they would definitely like to have a(nother) baby as the reference category<sup>5</sup>.

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<sup>5</sup> There are three strategies that I could have pursued to deal with these Likert scale variables. I could have dummied them into smaller categories, but clear cut points were missing for some variables (i.e. often, occasionally, seldom, and never). Another alternative that I could have used would be to treat the variables as ordinal continuous; however, some variables did not have a neutral category. I could not safely assume that the jump from “strongly agree” to “agree” was the same as going from “agree” to “disagree”. Therefore, I determined that the best strategy would be to create indicators for the categories which also allowed me to learn more about the differences between the response categories, and I do find many significant associations.



Twenty-five women in the sample responded “don’t know” to this question. It did not seem appropriate to put people who said that they “don’t know” in with those respondents who gave a firm definitely do not want a(nother) child response. I explored this variable with a crosstab and the overall response patterns suggest that those who responded with “don’t know” are most similar to those who said that they probably did not wish to have a(nother) child. The “don’t know” responses were collapsed with women who reported that they probably did not wish to have a(nother) baby. One-third of women (33%) indicated that they would definitely like to have a(nother) baby, 19% said probably yes, 16% said probably no, and 32% definitely did not want to have a(nother) child.

#### *Partner Wants a Baby*

Respondents were asked to share what they perceived their partners feelings were towards having a(nother) baby by answering the following question, “How about your husband/partner? Would he like to have a(nother) baby? Would you say definitely yes, probably yes, probably no, or definitely no?” Dummy variables for probably yes (17%), probably no (11%), definitely no (24%), and not asked compared to women who reported that their partners would definitely like a(nother) baby (25%). The “not asked” category (23%) includes women who the computer skipped out of this question because the respondent had no partner. Fifteen women reported that they did not know whether their partner would like to have a(nother) baby. The small number of cases made it impossible to analyze this group independently. I included these 15 cases in the “not asked” category in order to avoid making assumptions about what a “don’t know” response means.

*Subfecund With and Without Intent, Other Fertility Barriers*

Construction of the subfecund variable is complex. First, all women were asked the following questions, “Currently, are you pregnant, trying to get pregnant, trying not to get pregnant, or are you okay either way?” “Was there ever a time when you were trying to get pregnant but did not conceive within 12 months?” and “Was there ever a time when you regularly had sex without using birth control for a year or more without getting pregnant?” In addition, women who had been pregnant were asked a series of questions about each pregnancy including, “When you got pregnant this time were you trying to get pregnant, trying not to get pregnant, or you were okay either way?” and “How long did you have sex without using birth control before you got pregnant?” Finally, women who experienced two or more pregnancies were asked whether they were breastfeeding at all during the time that they were trying to conceive.

The subfecund with intent variable includes women who are experiencing both primary (no prior pregnancies) and secondary (prior pregnancy) infertility. Women who reported having tried to get pregnant but did not conceive within 12 months and/or reported that there was a time that they had regularly had sex without using birth control for a year or more without getting pregnant, or those who had tried a long time (12 months or more) to get pregnant were classified as subfecund. Next, variables related to whether or not a woman had been trying to get pregnant at the time the subfecundity occurred were examined to further classify respondents as either being “subfecund with intent” or “subfecund without intent”. If the woman reported that she was trying to get pregnant, she was classified as “subfecund with intent” (64%). Those that reported that they were not trying to get pregnant or that they were okay either way were classified as

“subfecund without intent” (20%). Breastfeeding can delay conception. Women who were subfecund without intent and who had no other indication of subfecundity were excluded if they were breastfeeding at the time of their long interval without conception. The remaining 17 % of the subfecund women met the criteria for the category of “other fertility barrier”. Women in this category have reported a history of medical problems, complications, or surgeries that would make it difficult or impossible to get pregnant and they did not meet the criteria for infertility with or without intent.

#### *Importance of Motherhood*

The importance of motherhood was assessed using a 4 item scale that taps the value of being a parent. Participants were asked to respond to the following five questions: “Having children is important to my feeling complete as a woman,” “I always thought I would be a parent,” “I think my life will be or is more fulfilling with children,” and “It is important to me to have children.” Respondents could (1) strongly agree, (2) agree, (3) disagree, or (4) strongly disagree with the first four statements. Answers were recoded so that higher values indicated higher importance of motherhood. On average the mean was above the midpoint of the scale ( $M = 3.35$ ,  $SD = .51$ ).

#### *Important to Partner to Have Children, Important to Parents to Have Children*

Participants in the study were asked a series of statements about children and families and were asked to indicate whether they strongly agreed, agreed, disagreed, or strongly disagreed with them. Included were two statements regarding the importance of children to an individual’s partner and their parents (or in other words, the grandparents to any children that the respondent might have). The statements were, “It is important to

my partner that we have children” and “It is important to my parents that I have children.”

I created a series of indicator variables for *important to partner to have children* that included those who agreed, disagreed and strongly disagreed, and those who were not asked. The reference category is those who strongly agreed that it was important to their partner that they have children. I collapsed the categories disagree and strongly disagree into one group due to the small number of women who strongly disagreed that it was important to their partner to have children (n=24). I was unable to leave the “strongly disagree” women separate because this would have resulted in extremely small cell sizes. For example, just two women who strongly disagreed that it was important to their partner to have children went online only. Women who fall into the “not asked” category (23%) are those women who do not have a partner as well as the 10 women who indicated that they did not know whether their partner felt that it was important that the couple have children. Overall, respondents seemed to think it was important to their partner to have children: 35% strongly agreed, 31% agreed, and just 11% disagreed with this statement.

The same strategy was used to dummy answers to the statement assessing parents’ feelings about the respondent having children. I compare women who reported that they agree, disagree or strongly disagree, have deceased parents or don’t know their parents opinion to those who strongly agreed with the statement, “It is important to my parents that I have children”. I collapsed categories in order to address the problem of extremely small cell sizes. The majority of women strongly agreed (28%) or agreed (42%) that it was important to their parents that they have children. Twenty-two percent of women

disagreed with this statement and the remaining 9% of women either had deceased parents or indicated that they did not know how their parents felt about this issue.

### *Enabling Factors*

#### *Age*

Participants were asked to report their age as of their last birthday. Recall that the sample only includes women between the ages of 25-45. The variable is continuous, and the average age of women included in the analyses was 36 years ( $SD = 5.91$ ).

#### *In a Relationship*

Marital status was measured by the following question: “What is your current marital status? Are you currently married, divorced, widowed, separated, or never married?” Seven response categories were available (1) married, (2) divorced, (3) widowed, (4) separated, (5) never married, (6) lesbian partnership, and (7) cohabiting. A follow up question asked whether participants were living with a partner. Those that reported being married or cohabiting (70%) were dummied as being in a relationship (1 = in relationship, 0 = no relationship).

#### *Parity*

The interviewers collected detailed information about each woman’s pregnancy histories. I use a constructed continuous variable of the number of live births to measure parity. The women had an average of 1.63 live births ( $SD = 1.31$ ).

#### *Talked to Others about Infertility*

Talked to others about infertility was measured with the following question, “Did you talk about your concern with family or friends? Would you say never, seldom, occasionally, or often?” The ‘concern’ this question refers to is a difficulty getting

pregnant. A series of dummy variables were constructed. I compare women who said never (29%), seldom (17%), and occasionally (31%) to the reference category of women who report that they often (23%) talked to their friends and family about their difficulties getting pregnant. There were 26 women who responded that this question “did not apply” to them. These women were included in the “never” category because if this does not apply to them it seems unlikely that they discussed this issue with others. Two women responded that they did not know if they had talked to others about their fertility problems and two women refused to answer. These respondents were also included with the women who never discussed their infertility with friends and family.

#### *Similar Others*

The variable *Similar others* was assessed by the following question, “Did you discuss getting pregnant with others who had experienced a similar situation? Would you say never, seldom, occasionally, or often?” I created indicator variables for each of these responses and compared all categories to the reference category of “often”. In my subsample, 18 women responded that this question did not apply to them. These women were collapsed into with the “never” responses. Following the same logic used above, I do not expect participants who report “does not apply” to be discussing getting pregnant with someone else who has had fertility problems. Two women refused and 3 women reported that they did not know if they had discussed getting pregnant with someone who had gone through a similar situation. These cases were also added to those that said that they “never” discussed getting pregnant with other women who had gone through a similar situation. Women report that they talked to someone who had experienced a similar problem often (15%), occasionally (30%), seldom (21%), and never (34%).

### *Know Someone Who Had Treatment*

The variable *know someone who had treatment* was assessed through the following yes/no question. “Do you have family or friends who have pursued medical help in order to help them get pregnant?” A dummy variable was created (1 = yes, 0 = no). Just over half of the women (52%) had a family member or friend who had pursued infertility treatments.

### *Partner/Family and Friends Encourage Treatment*

During the interviews, participants were asked whether their social networks supported treatment seeking. The exact questions were, “Did your spouse/partner strongly encourage, encourage, discourage, strongly discourage seeking medical help or was it mixed” and “Did your family or friends strongly encourage, encourage, discourage, strongly discourage seeking medical help or was it mixed?”

For the first variable, *partner encouraged treatment*, I created the indicator variables discouraged (6%), it was mixed (23%), don’t know (11%), and not asked (23%) which will be compared to the reference category of encouraged (37%). Women who indicated that their partners strongly encouraged or encouraged seeking medical help were collapsed into a single category. Many women (N = 198) selected “strongly agree” but only four had only sought help online. Similarly, because of small cell sizes I collapsed those who disagreed and strongly disagreed into a single category. The “not asked” category includes women who were not asked this question because they did not have a partner and 10 additional women who refused to answer this question.

I constructed dummies out of *family/friends encouraged treatment* and compared women who were encouraged (23%), discouraged (5%), or said that it was mixed (24%),

and those who were not asked (36%) to women who were strongly encouraged (12%) to seek medical help. I collapsed the response categories “discouraged” and “strongly discouraged” into a single category to manage the small number of cases. The “not asked” category contains women who were not asked this question because they responded “never” to the previous question in the interview, “Did you talk about your concern with family or friends.” Also included in this category were women who reported that the question did not apply and those who said that they did not know whether their family and friends encouraged medical help seeking.

### *Education*

Education was measured by the following question, “How many years of schooling have you completed?” The variable is ordinal and potential responses ranged from (0) no schooling to (22) sixth year of graduate school. The mean level of education for the sample was 13.60 years ( $SD = 2.89$ ).

### *Income*

Participants were asked to report their annual household income. This is an ordinal variable ranging from (1) under \$5,000 to (12) \$100,000 or more. I use dollar equivalents of the midpoint of each category to make the coefficients easier to interpret for the descriptives table and the original values (1-12) to make the multivariate coefficients easier to interpret. The average household income of women in the analytic sample is approximately \$54,000 ( $SD = 32.22$ ).

### *Health Insurance*

Participants were asked about their current health insurance. Health insurance status was measured by the following question, “Are you covered by private health



insurance, by public health insurance such as Medicaid, or some other kind of health care plan or by no health insurance?" Responses were dummy coded into the variable *private insurance* (1= private insurance, 0 = all else). Public health insurance is appropriately coded as no insurance because Medicaid does not cover infertility treatments (Bittler and Schmidt 2006). The majority of women (66%) were covered by private health insurance.

#### *Have a Regular Doctor and Doctor Cares*

Respondents were asked the following question, "Do you have a regular doctor, that is a specific doctor that you consult for most of your health care needs?" I created a dummy indicator variable *have regular doctor* (1 = yes, 0 = no). The vast majority of women report that they have a regular doctor (85%).

Women who indicated that they had a regular doctor were asked a follow up question: "Overall, does your doctor seem to care about how you're really doing? Would you say cares a lot, cares a little, does not care very much" Using dummy variables I compare women who feel that their doctor cares a lot about them (67%) to those who feel that their doctors care a little (20%), do not care very much (5%), and those who were not asked this question (6%). The "not asked" category contains women that the computer skipped out of the question because they indicated that they did not have a regular doctor. Eighteen women in my subsample of infertile women responded that they did not know if their physician really cared how they were doing. I collapsed these "don't know" responses with those women who indicated that they felt their doctor did not care very much because both categories had some extremely small cells. I thought collapsing these categories together was appropriate because if people do not know whether their doctor cares about how they are doing, I do not believe they are

likely to fall into the other categories that indicate higher levels of feeling cared for. Because this question asks generally about feeling cared for by a doctor it will be a loose approximation of feeling cared for by infertility specialists.

### *Race/Ethnicity*

Respondents were asked the following two questions drawn from the Census: “What race or races do you consider yourself to be?” and “Do you consider yourself to be either Hispanic or Latino or neither one?” In the descriptive analyses and bivariate analyses I use a single variable that has separate categories for the five race/ethnicity categories in the study. In the multiple regression analyses I use indicator variables and “white, non-Hispanic” is the omitted reference category. Sixty two percent of women are white, 15% African American, 16% Hispanic, 7% Asian, and less than one percent are some “other” race. The small percentage of women in the Asian and “other” racial/ethnic categories makes race/ethnicity specific analyses challenging. Because for this study race/ethnicity is a control variable, I collapse categories and compare white women to non-white women. This approach allows me to focus on the primary questions of this dissertation. In the future I will examine specific groups because I anticipate that there are race/ethnicity specific differences that will be important for understanding behavioral responses to infertility.

### *Predisposing Variables*

#### *Internal Medical Locus of Control*

Respondents were asked a series of six questions to assess internal medical locus of control, “If I get sick, it is my own behavior which determines how soon I get well again,” “I am in control of my health,” “When I get sick I am to blame,” “If I take care

of myself I can avoid illness,” “If I take the right actions I can stay healthy”, and “The main thing which affects my health is what I myself do.” People could respond to each statement with (1) strongly agree, (2) agree, (3) disagree, or (4) strongly disagree. Items were reverse coded so that higher values are associated with higher levels of internal medical locus of control. The mean of the internal medical locus of control scale was 2.97 (SD = .50).

### *Religiosity*

Religiosity was measured by a four item scale with the following questions: “How often do you attend religious services? Would you say never, less than once a year, about once or twice a year, about once a month, nearly every week, every week, or several times a week?” “About how often do you pray? Several times a day, once a day, several times a week, once a week, or less than once a week?” “How close do you feel to god most of the time? Extremely close, somewhat close, not very close, or not at all close?” and “In general, how much would you say your religious beliefs influence your daily life? Would you say very much, quite a bit, some, a little, none?” I use the mean of the four standardized items as a measure of religiosity. This is coded so that higher values indicate greater religiosity. The mean standardize value for the analytic sample is .05 (SD = .66).

### *Attitudes towards Medical Science*

Attitudes towards medical science were measured by a three item scale that tapped women’s attitudes towards infertility treatments. The following questions were included: “Medical science can be a big help to women who are having trouble getting pregnant,” “Women who have trouble getting pregnant would benefit from consulting a

doctor,” and “With the medical advances available today, women can wait to have a baby until their late 30s and still have a good chance of having a baby.” Response categories ranged from (1) strongly agree to (4) strongly disagree. Items were reverse coded so that higher values indicate a more positive attitude toward medical science. On average, women in this sample have a positive attitude towards medical science; the mean of responses of participants in the analytic sample is 3.36 (SD = .41).

### *Stigma of Infertility*

Participants were asked about the public’s opinion of women experiencing fertility problems. The response categories ranged from (1) strongly agree to (4) strongly disagree. The following questions were included in this stigma scale: “People who have difficulty getting pregnant find it embarrassing,” “People who can’t get pregnant without medical help often feel inadequate,” and “People who experience infertility often feel that their family and friends look down on them.” Items are reverse coded so that higher values equal higher stigma of infertility. The average score on this scale for the analytic sample is 2.73 (SD = .52).

### Multicollinearity Diagnostics and Normality

I regressed the respondent’s identification number on the independent variable to test for multicollinearity as suggested by Tabachnick and Fidell (2001). These analyses suggest that the variables related to partner attitudes are highly correlated (i.e. *partner wants a(nother) baby, important to partner to have children, partner encouraged treatment*). Despite the fact that these variables are highly correlated, I still find significant associations. The analyses do not suggest that the inclusion of the variable *in a relationship* is a cause for concern even though I have included dummy indicators of

“not asked” which are equivalent to not having a partner. To further ensure that this was not a cause for concern, I ran my analyses excluding *in a partner* and find no differences in the patterns of significant associations.

I identified several independent variables that had problems with normality (*fertility intentions, importance of motherhood, parity, income, and age*). My dependent variable in Chapter Six, *social support* had a negative skew. Tabachnick and Fidell (2001) note that issues of skewness and kurtosis decrease as sample sizes increase. My sample of 1,352 is large. I performed transformations on all of these variables to correct for skew. I ran all analyses with the transformed versions of the variables and found that the transformed variables made no difference in the overall patterns of results and significant associations. Because I found no significant differences, I used the original variables in the analysis.

## **Chapter Four: Differences Between Infertile Women by Type of Help Seeking – The Bivariate Relationships**

Appendix B contains all tables for the dissertation. As mentioned previously, Table 1 provides the descriptive statistics for the variables associated with traditional help seeking models. Table 2 contains descriptive information for variables measuring self-education and internet activities, as well as how the internet impacted women's thinking about their fertility problems. Table 3 gives the reader the distribution of participant's reports of the most helpful source of information about infertility that they used.

### Table 4 – Descriptive Statistics by Help Seeking Category for Infertile Women

Table 4 presents the descriptive statistics by the type of help seeking that infertile women engaged in. I performed chi-square tests and ANOVAs to determine whether there are any significant differences between infertile women who do (1) nothing, (2) only go online, (3) only seek medical help, and (4) both go online and seek medical help. For ANOVA's, Tukey's Honestly Significant Differences (HSD) test for specific mean differences while adjusting for the multiple comparisons.

I find no significant differences by type of help seeking at the bivariate level for the following variables: importance of motherhood, children important to parents, social support, internal medical locus of control, and stigma. All other relationships discussed below are statistically significant.

Table 4 suggests that there are clear differences between women who both go online and seek in person help and those who do no help seeking. Perception of a fertility problem increases as involvement in type of help seeking increases. Though infertility episodes were in the past and desire for a child is measured at the time of data collection,

I find an association between type of help seeking and wanting to have a baby. Women who engaged in both types of help seeking were the most likely to report wanting a baby and the proportion was lowest for women who did no help seeking. There is a similar pattern for fertility intentions. Women who are more involved with help seeking (medical only, both) are more likely to be infertile with intent than no intent. A partner's desire for a child is greatest for women who do both types of help seeking and lowest for those who do none. The pattern is similar for women who talk to others about their fertility concerns and have friends or family who pursue treatment. Women in the "both" group had the highest family incomes, educational attainments, had the most positive attitudes towards medical science and were most likely to have private insurance and a regular doctor. Women who did not do any help seeking were the lowest on all of these variables. Non-Hispanic white women were most involved in the help seeking process.

The encouragement to seek help from a partner was associated with medical help seeking. A little over half of the women in the medical only and both medical and internet group were encouraged to seek help. Interestingly, women who were in the internet only group received the least encouragement from partners to see a doctor. The medical only group had the largest proportion of women who were encouraged by family and friends to seek medical help. Those in the no help seeking group received the least encouragement. Feeling cared for by a doctor was associated with type of help seeking. I find that those who only sought medical help have the highest proportion of women and those who do no help seeking have the lowest percentage of women who feel as though their doctor cares. I was surprised that the women in the medical only group had the highest mean religiosity scores and women who both went online and saw a doctor had

the lowest religiosity scores. Consistent with the age restrictions on fertility and cohort familiarity with the internet, average age was highest in the medical only group and lowest in the internet only group.

Engaging in any type of help seeking was related to being in a relationship. Previous research suggests that those who experience primary infertility are more likely to engage in medical help seeking than those who already have one or more children (Schmidt, Munster, and Helm 1995). I find that women in the no help seeking group have the highest average number of live births and women who both sought help from a medical doctor and went online had the lowest average parity.

Internet only women had the largest proportion of women who said that having children was important to their partners and women who did not do any help seeking had the lowest. Women who both went online and saw a doctor were the most likely to talk to others who had experienced a similar situation. Women in the medical only group were the least likely to have talked to similar others. It is possible that women who only see a doctor and do not talk to others are those that experience infertility as a private situation only appropriate for discussions with a physician.

Taken together, Table 4 suggests that there are clear differences between women who do nothing with regards to their fertility difficulties and women who are highly engaged in the help seeking process (both going online and seeking help in person). What is less certain is how women who only go online and women who only see a doctor vary. No clear pattern emerges in the bivariate associations to distinguish these two groups except age.



### Table 5 – Self Education Activities by Help Seeking Category for Infertile Women

Table 5 provides information on self-education activities by type of help seeking. Recall that these questions were asked of all women in the sample and did not specify whether these activities were specific to online or offline behaviors. In all cases, women who reported both going online and seeking a doctor had the highest proportions of women indicating that they had engaged in each behavior. Women who did no help seeking were also least likely to do other types of information seeking. Also interesting, however, is how similar the women who did both types of help seeking and the women who only went online were in the likelihood of having read scientific articles and read a book. In general, few women reported contacting a support group specific to reproductive difficulties, but women who engaged in both types of help seeking were much more likely to seek a support group.

### Table 6 – Type of Online Activities by Type of Internet Help Seeking

Table 6 provides descriptive statistics of the activities that people engage in online by type of internet help seeking (internet only or both). I find no significant differences between women who go online only and women who both go online and seek medical help for the following variables: looked for medical articles, used email or a website to communicate with a doctor, and participated in an online support group. There was a statistically significant difference between the groups for having looked for information about treatment online and using the internet to evaluate a doctor or clinic. As I would expect, women who sought treatment and went online were more likely to report engaging in both of these internet behaviors.

Table 7 – How Online Information Affected Thinking by Type of Internet Help Seeking

Table 7 provides information on how the activities engaged in online actually impacted internet users thinking about their infertility. I find that there are no significant differences between the groups in terms of how helpful the internet was to helping participants better understand health issues that impact pregnancy. Women who both went online and sought in person help were significantly more likely to report that the information they received encouraged them to see a doctor, to ask a doctor new questions about getting pregnant, and that it made it easier to work with a doctor regarding treatments. This group of women who engaged in both types of help seeking was also more likely to strongly disagree that the information they received online discouraged them from seeking treatment.

Table 8 – Most Helpful Source of Information by Type of Internet Help Seeking

Table 8 provides the distribution of responses of participant reports of the most helpful source of information. There is no statistically significant difference between my two groups of internet users. Among women who both went online and saw a doctor and those who only went online, over half (52%) indicated that the internet was the most helpful source of information.

## **Chapter Five: Multinomial Logistic Regression – The Four Help Seeking Categories**

In this chapter, I employ a series of multinomial logistic regression models to determine whether predisposing, need, and enabling factors included in The General Help Seeking Model that have been associated with seeking face-to-face medical care are also associated with seeking information or help only online, only in-person, both online and in person, or neither of these help seeking activities.

In model one, I enter in predisposing conditions. As discussed above, there are two predisposing conditions, infertility stigma and medical locus of control, that might be particularly relevant for differentiating between women who go online compared to women who see a doctor in person or do nothing. Model two adds the need variables controlling for the predisposing conditions. I am interested to see how these variables measuring the perception of need for medical help mediate the predisposing factors. Finally, in model three I include the variables that measure enabling factors and control for measures of both predisposing factors and need.

I report the standard errors, significance levels, and odds ratios. The odds ratios are interpreted as a one unit change in a predictor on the odds of being in the dependent variable category being analyzed (Long and Freese 2006). Odds ratios over one represent increased odds of being in the dependent category under consideration as compared to the dependent reference category, whereas odds ratios under one indicated decreased odds.

For each model I will test model fit in three ways: I include chi-square values and degrees of freedom for each model in its respective table. Using these chi-square values, I calculate tests of model refinement to assess improvement of fit between models. Finally, I include Cragg and Uhler's pseudo  $R^2$  to assess the proportion of variance

explained. I include this information in the table for each model. Cragg and Uhler's pseudo  $R^2$  approximates an  $R^2$  of an ordinary least squares regression while adjusting to ensure the values range from 0 to 1 (Long 1997; Long and Freese 2006). Caution must be used in interpreting pseudo  $R^2$  because different measures can result in varying values. The pseudo  $R^2$  is useful for interpreting the changes between nested models (Long and Freese 2006).

### Model One

In model one (Table 9) I predict the odds of category membership based on predisposing conditions. The variables included in this group are those that reside within an individual and would predispose a person to use a particular method of help seeking for infertility. I am particularly interested in how internal medical locus of control and stigma are related to help seeking because to my knowledge no one has examined how this may influence going online for health information. Prior research using The General Help Seeking Model (White, et al. 2006) suggests that those with high internal medical locus of control are less likely to seek help in-person. Theoretically, it is possible that people who have high internal medical locus of control might find the ability to gain health information online appealing.

I find no significant associations between internal medical locus of control and the help seeking comparison categories. The overall R-square for this model is low; therefore, there is little association between medical locus of control and medical help seeking. Higher attitudes towards medical science are associated with higher odds of going on line compared to doing nothing (OR=1.722). Similarly, more positive attitudes towards medical science are associated with increased odds of having done both types of

help seeking compared to doing nothing (OR=1.903) and compared to only seeking face-to-face medical help (OR=1.598).

I expected that as religiosity increased the odds of seeking in person medical help would decrease and this is what I find. Each one unit increase in religiosity is associated with 37% lower odds of only seeking medical help compared to only going online.

Women with higher infertility stigma have lower odds of both seeing a doctor and going online compared to those who did not do any help seeking (OR= .582) and of doing both types of help seeking compared to only go online (OR=.636). Unexpectedly, higher infertility stigma is associated with decreased odds of doing both compared to only seeking medical help (OR = .644).

### Model Two

Model two includes the variables associated with a perception of need for medical help while controlling for predisposing factors. As discussed above, I am particularly interested in how two predisposing variables, infertility stigma and internal medical locus of control, are related to type of help seeking. I am reporting the associations only for predisposing variables in this model, although the associations for all variables included are available in Table 10. I will discuss the associations between help seeking category and variables assessing need in the full theoretical model (model three).

The overall model fit is significant (chi-square = 477.01, df = 66,  $p < .001$ ). The improvement of fit between the models was also significant (chi-square = 425.19, df = 54,  $p < .001$ ). The pseudo  $R^2$  in model two increased substantially and suggests that I am explaining approximately 32 percent of the variance.

Similar to model one, I continue to find no association between internal medical locus of control and type of help seeking. Attitudes towards medical science are associated with type of help seeking, and the addition of need variables increases the strength of these associations in model two. For each unit increase in religiosity, women have higher odds of going online versus doing nothing (OR= 2.113), of both going online and seeing a doctor than doing nothing (OR=2.652), and of doing both compared to only seeking medical help (OR=1.923).

After including need variables into the model, several new associations between religiosity and type of help seeking emerge. I find that higher religiosity scores decrease the odds of women doing both types of help seeking compared to doing none (OR=.613), internet only (OR=.647), and only seeing a doctor (OR=.646). The association between religiosity and only seeing a doctor compared to no help seeking is no longer significant in model two.

All of the initial associations between infertility stigma and type of help seeking (both versus none, both versus internet only, and both versus medical only) are no longer statistically significant in model two. Two new significant relationships emerge with the inclusion of need variables. I find that for each unit increase in infertility stigma women are 26% lower odds of only seeing a doctor versus not doing any help seeking and have 44% lower odds of only seeing a doctor compared to only going online. This indicates that the associations were suppressed until the need variables were included in the model.

### Model Three

Model three contains measures for the full theoretical model (Table 11). A primary goal of this chapter was to test whether variables associated with The General

Help Seeking Model (White, et al. 2006) that is used to predict in person help seeking for infertility are also useful for predicting whether infertile women go online for infertility help, and in fact, these variables do matter for type of help seeking.

The goodness of fit test (chi-square= 922.35, df= 144, p, .001) and model refinement tests (chi-square= 515.33, df=78, p< .001) were both significant. The pseudo R<sup>2</sup> also increased between model 2 and model 3. After including enabling factors, I now explain approximately 56% of the variance. Due to the complexity of all of the comparisons in Table 11, I will explain each set of comparison groups individually, working down the model.

#### *Internet, Medical, and Both Versus None*

As attitudes towards medical science become more positive women have two times greater odds (OR= 2.229) of going online versus doing no help seeking and almost two times greater odds (OR= 1.818) of both going online and seeing a doctor compared to doing nothing. Women are 28% less likely to engage in both types of help seeking compared to do doing nothing for each increase in religiosity score.

Perception of a fertility problem is associated with the type of help seeking. As expected, women who perceive a fertility problem are more likely to see a doctor (OR= 2.361) and to do both (OR= 3.383) compared to not engaging in any help seeking.

Fertility intentions are associated with type of help seeking for each comparison. As expected, higher intentions to have a baby are associated with greater odds of going online (OR=1.577), seeing a doctor (OR=1.327), and both going online and seeking in person help (OR=1.578) versus doing nothing. Women who indicate that they probably would like to have a(nother) baby have lower odds of going to a doctor (OR=.533) and

doing both types of help seeking (OR=.434) versus doing nothing compared to women the reference category of women who would definitely like to have a(nother) baby.

Relative to women who are subfecund with intent, women who have no intent and women who have some other fertility barrier are significantly lower odds of seeing a doctor or both going online and seeing a doctor compared to women who do none of these things. Interestingly, I find that women who feel that their partners would probably not like to have a(nother) baby are more likely to both go online and see a doctor versus doing nothing when compared to the reference category of women who said that their partner definitely wanted a(nother) baby (OR= 2.504)<sup>6</sup>.

Unexpectedly I find that each unit increase in the importance of motherhood decreases the odds of going online only (OR=.524) and only seeking medical help (OR=.574) compared to engaging in no help seeking. For each additional year in age, women are 9% less likely to go online and 4% less likely to do both types of help seeking compared to doing nothing.

Women in a relationship have greater odds of seeking medical help versus doing nothing (OR= 2.238). I expected that people would be less likely to see help as parity increased, this was only true for women who both went online and sought in person help compared to women who did nothing (OR= .776).

Relative to women who talk to their friends and family about their fertility difficulties often, women who report that they do this occasionally have significantly lower odds of seeking in person help (OR= .556) or both going online and seeking help

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<sup>6</sup> This finding was unexpected; therefore I performed some supplementary analyses. Cross tabulations reveal that approximately 30% of women who would definitely or probably like to have a(nother) child have partners that probably do not want to have a(nother) baby. Potentially, these women who think they might like to have children or desire more children are seeking help to gather information to present to a reluctant partner.



(OR= .418) versus not engaging in any help seeking behaviors. Women who seldom talk to others compared to the omitted category of often also have lower odds of seeing a doctor compared to doing nothing (OR= .449).

Interestingly, talking to individuals who have experienced a similar situation occasionally (OR= 1.868) and never (OR=2.686) have greater odds of seeking in-person help versus doing nothing compared to the omitted category of women who talk to people who have experience a similar situation often. In contrast, women who had seldom talked about their fertility problems with others who had experienced a similar situation had significantly lower odds of going online only as opposed to doing nothing (OR=.439).

Compared to women who were encouraged by their partners to seek medical help, women who were discouraged, mixed, don't know, and women who were not asked had significantly lower odds of seeking medical help or doing both versus not engaging in help seeking. Participants who did not know if their partners encouraged medical help seeking had three and a half times greater odds (OR= 3.538) of going online versus doing nothing compared women who had partners that encouraged them to seek medical help. Women who were not asked about whether a partner encouraged treatment had lower odds of only going online opposed to doing nothing relative to the reference category encouraged.

Women who were not asked about their family and friends encouragement of medical help seeking had lower odds of going online (OR= .164), going to a doctor (OR=.174), or doing both (OR=.230) versus doing nothing relative to women who were in the omitted category of people who were strongly encouraged to seek medical help by

family and friends. Participants who indicated that they were encouraged (OR= .405) or mixed (OR= .319) were less likely to see a doctor versus no help seeking compared to women who were strongly encouraged by family and friends.

I expected women who had higher incomes and educational attainment would be more likely to see help. This is true for women who only go online and both go online and seek medical help compared to those who do nothing. Women who were not asked if their doctor cares (in other words, women who had no doctor) for them had lower odds of going online, seeing a doctor, or doing both versus doing no help seeking compared to the omitted category of doctor really cares for me.

*Medical Only and Both Versus Internet Only*

Each unit increase in religiosity is associated with lower odds of women only seeking medical help compared to only going online (OR= .489). Previous literature suggests that the internet might be a particularly appealing source of health information for people with stigmatized conditions. As I expected, I find that for each increase in infertility stigma women are 38% less likely to only see a doctor and 34% less likely to both see a doctor and go online compared to women who only use the internet.

Perception of a fertility problem predicts help seeking. Women who perceive that there is a problem with their ability to get pregnant are significantly more likely to seek in person help (OR= 1.856) and both go online and see a doctor (OR= 2.659) compared to women who do nothing. Compared to women who report that their partner would definitely like to have a(nother) baby, women who say that their partners probably want a(nother) child (OR= .475) and definitely do not want a baby (OR= .382) are less likely to both go online and seek medical help versus women who only go online.

Women who are subfecund without intent have lower odds of only going to a doctor (OR= .345) and of doing both types of help seeking (OR= .225) versus only going online compared to the omitted category of subfecund with intent. Similarly, relative to subfecund women with intent, women with other fertility barriers are less likely to only see a doctor (OR= .439) versus only go online.

As women age they have higher odds (OR= 1.125) of seeking medical help than only going online. Compared to women who say they often talked to others about their fertility difficulties, women who occasionally did this were less likely to see a doctor (OR= .373) and less likely to both see a doctor and go online (OR= .279) versus only go online. Interestingly, women who reported talking to others who had experienced similar situations occasionally (OR= 4.561), seldom (OR= 3.575), and never (OR= 2.676) had significantly greater odds of seeing a doctor in person versus only going online compared to those who said they talked to people who had similar problems often. This finding is counterintuitive. It is possible that talking to similar others often increases treatment anxiety and makes people more hesitant to seek in person help.

A partner's encouragement of medical help seeking predicted the type of help women sought. Compared to women who said their partners encouraged them to seek help, women who were discouraged, or said it was mixed, or do not know about their partner's encouragement all had lower odds of seeking medical help or both seeking medical help or going online than only using the internet. Similarly, relative to women who were strongly encouraged to seek medical help by friends and family, women who indicate that it was mixed are 62% less likely to go to a doctor versus going online.

Some interesting associations for variables measuring resources emerged as well. Contrary to what I expected, as income and educational attainment increase, the odds of going to seek medical help compared to only going online decrease. Private health insurance is associated with differentiating between seeking some type of medical help (in person only or both) compared to only going online. Women with private health insurance have higher odds of seeing a doctor (OR= 2.339) and doing both types of help seeking (OR= 2.558) compared to women who only go online. Infertile women who have a regular doctor have higher odds of doing both types of help seeking than only going online (OR= 2.461).

*Both Online and Medical Help Seeking Versus Face-to-Face Medical Help Seeking Only*

In the final comparison in Table 11 I explore the differences between the two groups that sought in-person help. Each unit increase in attitudes towards medical science increases the odds of both going online and seeking medical help compared to only seeing a doctor (OR= 1.668). Religiosity is associated with lower odds of doing both types of help seeking versus only seeking medical help (OR= .765). I expected women who have greater infertility stigma to be more likely to go online than to seek face-to-face medical care. This comparison of women who only saw a doctor in person and who both went online and saw a doctor is particularly interesting because both groups of women have sought medical help at some point. I still find an association with the internet; as infertility stigma increases women have higher odds of having both gone online and sought medical help compared to only seeing a doctor.

I find no association between perception of a fertility problem or fertility intentions and type of help seeking, though respondents desire for a baby is associated

with type of help seeking. Compared to women who definitely would like to have a(nother) baby, women who probably do not want a(nother) child (OR= .499) and definitely do not wish to have a baby (OR= .434) have lower odds of doing both types of help seeking versus only going to a doctor. I was surprised to find that women who say that their partners probably do not want a(nother) baby are more likely than women whose partners want a child to both go online and seek medical help versus only seeing a doctor.

For each additional year older a woman is, she is 7% less likely to both go online and see a doctor compared to only seeking medical help. This finding is interesting because on one hand, I would expect that the older women get, the more activities that they would engage in to seek help for infertility because fertility is limited by time. On the other hand, research on the internet demonstrates that internet use for medical information is related to age, and younger people are more likely to do this than those who are older (Fox 2010). This finding suggests that when considering online help seeking, age might be an important factor that differentiates the type of help sought.

Women who are in a relationship are 60% less likely to do both types of help seeking versus only seeing a doctor. I was surprised to find that each additional child a woman has decreases the odds of women both going online and seeking medical help compared to only seeing a doctor (OR= .801). I expected that having more children would lower the odds of help seeking generally. Compared to women who say that they talk to others who have gone through similar situations often, women who indicated that they did this seldom (OR= .496) or never (OR= .457) have significantly lower odds of engaging in both types of help seeking compared to only going to a doctor.

Relative to women with family and friends that strongly encouraged them to see medical help, women who were encouraged (OR= 1.823) and indicated that it was mixed (OR= 2.589) were more likely to both go online and seek in person help versus only go to a doctor. Each unit increase in income (OR= 1.136) and educational attainment (OR= 1.237) was associated with greater odds of going online and seeing a doctor compared to only seeking in person help.

In summary, I find that predisposing, need, and enabling conditions that have been used in the General Help Seeking Model to predict whether people seek in-person help for infertility are useful for determining whether people do nothing, only go online, only see a doctor, and both go online and seek in-person help. Contrary to my expectations, I find no association between internal medical locus of control and type of help seeking. I do however, find that infertility stigma is associated with infertility help seeking as I expected. The results of this analysis suggest that as infertility stigma increases, the odds of doing some type of medical help seeking (medical only or both going online and seeing a doctor) compared to only going online decrease. Particularly interesting is the finding that each unit increase in infertility stigma increases the odds of doing both types of help seeking compared to only going online.

I expected that my variables that measure resources (income, education, health insurance) would differentiate those who did some type of medical help seeking (medical only or both) from those who either did no help seeking or only went online. The analyses suggest a different story. The results presented in this chapter seem to imply that income and education differentiate people who do some type of online help seeking

(online only or both online and medical) from people who do nothing, or only see a doctor. In contrast, health insurance is associated with doing medical help seeking.

In the next chapter, I explore whether perceived social support is associated with these four types of help seeking. In addition, I test whether the types of activities that people do online impact their perceived support.

## Chapter Six: Social Support and Type of Help Sought

Previous research suggests that going online for health information and support should be helpful for coping with illness (Hinton, Kurinczuk, and Ziebland 2010; Malik and Coulson 2008; van Uden-Kraan, et al. 2008), and perhaps particularly useful for those who have a stigmatized condition (Berger, Wagner, and Baker 2005). Epstein, et al. (2002), however, find that women who only go online to talk about infertility compared to women who both go online and discuss infertility in person perceive less social support and report more psychological distress. Therefore it is unclear if using the internet in response to infertility should increase or decrease perceived social support. It is also not clear if only using the internet and not seeking in-person medical help is different from using the internet in addition to seeking medical care. Therefore I explore if the type of help seeking (internet or in-person) is associated with perceived social support. In model one I regress social support on predisposing, need, and enabling variables. In model two I add the indicators of type of help seeking to explore whether or not type of help seeking mediates the relationship between infertility stigma, talking to someone who has gone through a similar experience, and knowing someone who has had treatment and social support. Because I was particularly interested in the possible benefits of the internet for people who perceive infertility as stigmatizing, I include a set of interaction terms for infertility stigma and type of help seeking.

Next, I run a separate OLS regression to investigate whether or not particular types of online activities (i.e. looking for articles about fertility, evaluating a doctor or clinic, or using an online support group) are differentially associated with perceived social support. The questions about the types of activities that people engage in online



were only asked of women who indicated that they had gone online for infertility within the last three years. Therefore the sample decreases to 291 women. I also include an indicator of also seeking medical help in person in addition to going online. In addition, this model controls for predisposing, need, and enabling variables from The General Help Seeking Model.

Table 12 presents the results of the association between type of help seeking in response to infertility and social support. Model one of Table 12 includes the predisposing, need, and enabling variables from The General Help Seeking Model. Before assessing the focal question about type of help seeking and social support, I first investigate how the theoretically implied variables are associated with social support. These variables are important in this model because, as the descriptive table showed, women in the four help seeking type categories differ on many variables, but they do not differ on average social support. Therefore if type of help seeking is associated with social support in this multiple regression analysis it will be because the association was suppressed until the additional variables are included in the analysis.

Several variables in The General Help Seeking Model are associated with social support. Internal medical locus of control ( $B = .068$ ) and religiosity ( $B = .070$ ) are both significantly, positively related to social support. Therefore higher internal medical locus of control and higher religiosity are associated with higher perceived social support. Women who perceived that they had a fertility problem had lower perceived social support than women who did not perceive a problem ( $B = -.073$ ). Compared to women who strongly agreed that it was important to their partner that they have children, women

who just agreed that this was important to their partner reported lower levels of social support ( $B = -.068$ ).

I was surprised that higher parity is associated with lower social support ( $B = -.084$ ). Because this finding was unexpected, I further explored the association to assess non-linearity. The association, however, is linear and negative. Women who indicate that they occasionally talk to others about their fertility problems also perceive more social support than women who say they do this often ( $B = .066$ ). Women who seldom ( $B = -.119$ ) and never ( $B = -.136$ ) talk to someone who has gone through a similar situation report less social support than women who indicate that they often talk to similar others. As expected, women who say that their friends and family discouraged treatment seeking have lower social support than women whose friends and family strongly encouraged medical help seeking ( $B = -.071$ ).

Higher income and education are both associated with higher social support. Doctors can be an important source of support for women experiencing infertility. Prior research suggests that women who are most satisfied with their treatments had supportive and individualized experiences (Malin, et al. 2001). My results are consistent with this. I find that women who indicate that their doctor cares a little ( $B = -.065$ ) or that their doctor does not seem to care very much ( $B = -.096$ ) both have lower social support compared to women who say that their doctor cares a lot about how they are doing. Racial and ethnic minority women report lower levels of social support than white women ( $B = -.132$ ). Contrary to my expectations, infertility stigma is not associated with lower perceived social support for women who meet the medical criteria for infertility.

Additionally, knowing someone who has pursued treatment for infertility is not associated with social support.

In model two I add the focal variable indicators, type of help seeking. In addition to assessing the association between type of help seeking and social support adjusted for the variables in The General Help Seeking Model, adding the indicators for type of help seeking after the measures of the concepts in the general help seeking model provides a way to assess mediation. If the coefficients of the predisposing, need, and enabling indicators included in the General Help Seeking Model decrease after adding the types of help seeking, this suggests that type of help seeking mediates associations these associations.

I do not find that type of help seeking is associated with social support. The indicator variables have small and non-significant associations with social support, and the change in R-square is non-significant<sup>7</sup>. The main effects were not significant. Therefore, I did not run my proposed interactions of infertility stigma by type of help seeking.

In Table 13 I show the results of the relationships between social support and the actual activities for women who went online in the last three years. Recall, my sample size decreases because this analysis only includes women who have gone online in the prior three years. I find no association between the types of things that people do online and their perceived social support<sup>8</sup>.

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<sup>7</sup> In additional analyses that are not show I changed the omitted category for the type of help seeking to test all potential comparisons. I did not find any significant associations with social support.

<sup>8</sup> The sample is small, and I include many variables in the model. I ran supplementary analyses with just type of help seeking and online activities as independent variables and found no significant association with social support.

Overall, my analyses suggest that social support does not vary by type of help seeking. Furthermore, I find no associations between the types of activities that people do and their perceived social support. In the next and final chapter I discuss the results in relation to The General Help Seeking Model for in person medical help seeking, and situate these findings relative to other research on the relevance of the interment for medical help seeking for chronic health conditions in which medical treatment is optional.

## Chapter Seven: Discussion and Conclusions

Individuals in the U.S. and across the globe are increasingly going online to find out more information about conditions that impact their health. Infertility is one of these conditions that people have utilized the Internet to learn more and seek support for themselves. Existing research on using the internet for infertility related purposes has relied on sampling strategies that draw participants from clinic populations, those already online, or individuals who are doing both of these things. This limits our understandings of women who meet medical definitions of infertility but have not sought help, and who may not self-identify as infertile.

The current investigation overcomes many of these limitations. Using the NSFB, a random, nationally representative sample of women between 25 and 45 years of age I am able to compare four groups of infertile women: (1) Women who have not done any help seeking activities, (2) women who have only gone online, (3) women who have only sought in-person help, and (4) women who both went online and saw a doctor.

In the first part of this study I focus on exploring whether indicators that have been associated with in-person medical help seeking are also related to using the internet for seeking help. I find support for many of the concepts in the general help seeking model for medical only, internet only, and medical plus internet help seeking.

Tests of The General Help Seeking Model (White, et al. 2006) find that women who have high internal medical locus of control are less likely to seek in-person help. To my knowledge, no research studies to date have investigated the relationship between internal medical locus of control and internet help seeking. Internal medical locus of control measures an individual's perception of control of their own health (Kiviruusu,

Huurre, and Aro 2007; Mirowsky and Ross 1990). The greater autonomy of internet help seeking should be more appealing to those with high internal locus of control. Contrary to this expectation, I do not find an association between internal medical locus of control and type of help seeking at the bivariate or the multivariate level. The first wave of NSFB data utilized was collected between 2004 and 2007. Internet access and the number of people going online for health information has increased substantially over this time period (Fox 2010), therefore, this potential association warrants further investigation.

A common theme in the infertility research is that the inability to have a child results in a stigmatized identity (Inhorn 2002; Wirtberg, et al. 2007). Scholars studying online health behaviors find that people with stigmatized health conditions prefer the anonymity of the internet for gaining information (Berger, Wagner, and Baker 2005; Kahlor and Mackert 2008; Powell, Darvell, and Gray 2003). I expected to find that women with higher infertility stigma would be more likely to go online for information than to meet with a medical professional face to face. The results support this expectation. Relative to women who only go on line, each unit increase in infertility stigma is associated with a 38 percent lower probability of going online and 34 percent lower probability of seeking in person help. Each increase in the perception of infertility stigma increases the odds of both going online and seeing a doctor relative to only seeing a doctor by about 1.5 times. I am unable to determine causal ordering with these cross sectional data. It is possible, however, that women with high stigma who do both types of help seeking started by going online first and then later sought help because the information they found increased the perception of the need for help enough to overcome

their infertility stigma. Prior research finds that when symptoms start interfering with daily life, or are perceived as severe, people are more likely to seek help (Facione and Dodd 1995; Shaw, et al. 2001).

I expected that more positive attitudes towards medical science would be associated with higher likelihood of seeking medical help. Instead, I find that each unit increase in attitudes towards medical science increases the odds of doing some type of internet help seeking. For each increase in attitudes toward medical science women are more likely to go online and to have both gone online and sought medical help relative to those who did no help seeking. Similarly, more positive attitudes towards medical science are associated with over 1.5 times greater odds of doing both types of help seeking compared to doing medical help seeking only. Furthermore, for each unit increase in attitudes towards medical science women are half as likely to only seek a doctor relative to only going online. These results seem to suggest that women who have more positive attitudes towards medical science may actually have a more positive attitude towards or are more comfortable with technology use in general. Alternatively, my inability to determine causal ordering does not allow me to rule out that it is actually going online and learning more about infertility and potential treatments that increases positive attitudes towards medical science. This is something to explore in future research with the wave two data.

Consistent with the General Help Seeking Model, perceiving a fertility problem appears to encourage people to seek medical help. The results suggest that women who perceive a fertility problem are more likely to do both types of medical help seeking than do nothing or to only go online. I find no associations between perception of a fertility

problem and the likelihood of going online only versus doing nothing. This is interesting because theoretically information about pregnancy and infertility could help women self-identify as having a fertility problem. Instead, these results suggest that it is people who have already identified as having a problem who seek help. I cannot definitively draw this conclusion with this cross sectional data.

Each unit increase in strength of fertility intentions is associated with higher odds of doing some type of help seeking (internet only, medical only, both) compared to no help seeking. The General Help Seeking Model works as expected in terms of predicting who does any help seeking versus no help seeking.

Consistent with the General Help Seeking Model, relative to women who are subfecund with intent, women who are subfecund with no intent and women with fertility barriers have lower odds of seeking medical help or both going online and seeking medical help than doing nothing. Similarly, the results suggest that women who are subfecund without intent have lower odds of only seeking medical help or engaging in both types of help seeking relative to women who only go online compared to the omitted category of women who are subfecund with intent.

An unexpected finding was that compared to women who indicate that their partner would definitely like to have a(nother) baby, women who indicate that their partners would probably not like to have a(nother) child have 2.5 times greater odds to do both types of help seeking than do nothing and have almost 2.5 times greater odds of doing both versus medical only help seeking. It is possible that women who report that their partners probably do not want to have a child or more children may utilize multiple resources to help change their partners' minds about having children. Infertility is



something that is not just experienced as an individual, but also (typically) as a couple (Greil, Leitko, and Porter 1988; Johnson and Johnson 2009). Further research on the types of infertility help seeking when couples fertility intentions are incongruent is warranted. It would also be beneficial to have qualitative data on couples that meet the medical definition for infertility but do not seek medical help. Griel and McQuillan (2010) find that these might be the couples who are “okay either way”, so they may have lower or neutral fertility intentions.

I expected that higher importance of motherhood would result in women being more involved in help seeking. Contrary to this expectation, I find that each unit increase in importance of motherhood decreases the odds that women will only go online or only seek medical help relative to women who do nothing. Bunting and Boivin (2007) discuss a group of “delayers” or women who delay or avoid treatment for fear of being labeled infertile. Similar processes could be at work here if those women who have a high importance of motherhood avoid engaging in help seeking activities that might confirm that they have a fertility problem.

Previous research has found that age can be an important life course cue for seeking medical help (White, et al. 2006). As women age their fertility declines which may impress a sense of urgency that would encourage medical help seeking. I find for each additional year women are more likely to seek medical help than do nothing. In contrast, I find that each year lowers the odds of only going online or both going online and seeking in person help relative to women who do nothing. I also find that for each additional year, women are about 7% less likely to do both types of help seeking compared to only seeing a doctor. These findings that seem somewhat contradictory are

likely explained by comfort levels in using the internet. Fox and Jones (2009) find that using the internet for health information is most common people who are between the ages of 18 and 29 and the likelihood of going online decreases as individuals' age.

Women in a relationship are more likely to seek medical help than do nothing. In contrast, women with partners have lower odds of both going online and seeking medical help relative to women who only see a doctor. These findings highlight the need to study infertility at the level of the couple (Greil, Leitko, and Porter 1988; Johnson and Johnson, 2009). It is possible that women with partners are less likely to go online (a solitary help seeking activity) in addition to seeing a doctor because they view infertility activities as something that should be done as a couple. Or, it is possible that these are women who have partners that go online to gather information for the couple. Research does suggest that men do go online for infertility information, though their use of the internet does not appear to be as extensive as women's information seeking (Weissman, et al. 2001). An alternative possibility is that women in relationships are likely to take their partners with them to appointments. Research suggests that the information needs of women seeking medical help may be particularly high (Chiba, et al. 1997; Oddens, den Tonkelaar, and Nieuwenhuyse 1999). To the extent that this is another person to ask questions and record information, women in couples may have lower information needs than their counterparts who are single.

For each additional live birth, women are less likely to both go online and seek in person help relative to doing nothing and compared to only seeing a doctor. It is possible that the people who are doing both help seeking activities are those who are really

worried about having a child (or more children). As parity increases, you may be less concerned over your fertility difficulties.

When looking at whether or not a partner encouraged treatment a general pattern emerges in which women who were not encouraged (discouraged, mixed, don't know partner's feelings) had lower odds of seeking medical help or doing both types of help seeking relative to doing nothing. It makes sense that women who are not receiving positive messages about going to a doctor would be less likely to actually seek medical help. A similar, though less distinctive pattern emerges for women who occasionally or seldom talked to others about their fertility problems compared to those who did this often.

As I expected, women who have private insurance are more likely to see a doctor or both see a doctor and go online compared to women who just go online. Private health insurance along with educational attainment and income are all measures of resources, and I expected them all to work in a similar manner. Contrary to this expectation, I found that for each increase in income and educational attainment women have greater odds of going online or both going to a doctor and going online than doing nothing. Similarly, increases in these two variables are associated with greater odds of doing both types of help seeking relative to those who only seek medical help. Finally, each increase in education and income levels is associated with decreased odds of only going to a doctor compared to only going online. That women are actually more likely to do some type of internet help seeking as income and education increases may be indicative of mastery of technology use and using one's education to understand the health information that is available online.

Overall, the results presented in this dissertation suggest that the General Help Seeking Model might need some added dimensions to understand seeking help online. In particular, attitudes towards medical science, stigma, age, income, and education seem to differentiate those who go online from those that seek medical help. These differences are consistent with findings on going online for health information generally. National surveys of American's use of the internet for health information indicate that women, younger individuals, and those who have higher incomes and educational attainments are more likely to go online for health information (Fox and Jones 2009). As I mentioned above, I believe that the associations between attitudes towards medical science need further investigation with longitudinal data. At the present time it is unclear whether this association is a result of more positive attitudes towards technology generally or if it is that going online and finding more information about treatments results in more positive attitudes towards medical science.

Models examining factors associated with online help seeking would also benefit from an inclusion of access variables. A limitation of the current investigation is that I have no measure of where people have access to the internet (i.e. home, office, public library, etc) and what type of connection that they have. Prior research suggests that an important factor in who goes online for health information is where people have access, and what type of connections they have (Fox and Jones 2009).

In the present investigation, age is entered into the models as a continuous variable. Age was a key factor in differentiating women who went online from those who did not use the internet. Because age is associated with going online, it might be useful to examine this association in more depth by creating categories of age groups so

that differences between type of help sought and age *category* could be explored. These measures could also capture different cohorts of women who have more or less exposure to and experience with the internet. The challenge with this strategy will be determining what the specific cohorts should be.

In this study, I do not differentiate between women who just talk to a doctor about infertility and women who actually go on to seek treatment. In the future, research should further specify the types of help seeking. As mentioned above, studies of women seeking treatment find that their information needs are quite high (Chiba, et al. 1997; Oddens, den Tonkelaar, and Nieuwenhuys 1999). It could be that the women who are engaging in both types of help seeking are really the women who sought *treatment* and went online.

An important direction for future research will be to examine how women move through the types of help seeking and what factors differentiate the different paths women can take (i.e. what factors are associated with women moving from doing nothing to internet only, medical only, or both; what predisposing, need, and enabling indicators are associated with moving from only going online to doing both online and medical help seeking). This is something that I plan to explore with the second wave of the NSFB.

In the second part of this study I turn my attention to the relationship between social support and types of help seeking. In my first set of models, I explored the relationship between type of help sought and social support. I expected infertile women who know someone who has sought treatment and who spoke to other people who had gone through similar experiences to have higher social support. Previous research suggests that the appeal of online information and support is that people can find

“experienced based” information (Porter and Bhattacharya 2008) or information from “someone like me” (Fox and Jones 2009). Conversely, infertility is viewed as a stigmatized condition, and because of this, women may avoid talking about this with network members resulting in less social support. With this in mind, I explored whether the type of help seeking acts as a mediator between social support and these three variables (talking to similar others, know someone who has had treatment, and infertility stigma).

I find no evidence that type of help seeking mediates the relationship between social support and any of my predisposing, need, and enabling indicators. Even after testing for mediation I do find a direct relationship between having talked to someone who experienced a similar situation and social support. Women who say that they seldom or never talk to similar others have lower social support than women in the reference category of individuals who report that they talk to similar others often.

I find a positive relationship between internal medical locus of control and social support; women with higher internal medical locus of control have more social support. This was an unexpected finding. It is possible that this internal locus of control helps women seek out social support to help cope with stressful health situations such as infertility. Another unexpected finding was that as parity increased, social support decreased. It is possible that as the number of children increases, women have less time to spend interacting with their social network members which reduces their perceptions of social support.

As I expected, I find significant, positive associations between religiosity, educational attainment, and income and social support. Racial and ethnic minority

women report less social support than white women. As income and educational attainment increase, perceived social support also increases.

Doctors and other health care professionals hold the potential to be important sources of support for women experiencing infertility. Previous research suggests that the women who are most satisfied with treatments are those that had supportive and individualized experiences (Malin, et al. 2001). In my study, I find that women who reported that their doctor cares a little or does not care very much had significantly lower levels of social support than women who indicate that they feel as though their physician really cares about how they are doing. Though the ‘doctor’ that women are asked about may not be a fertility specialist, these results do suggest that it is important to explore the doctor-patient interactions of infertile women. It is possible that negative treatment experiences may reduce perceptions of social support.

In my second set of models related to social support I explore if the types of activities that people engage in online are related to social support levels. This model focuses on just those women who have gone online for health information and did this online help seeking in the previous three years. The overall patterns of associations are similar to the social support models described above. I find no association between the type of internet activity and social support.

The findings presented here suggest that neither the type of help seeking that people engage in (none, internet only, medical only, or both) nor the types of activities that people actually do online (information about a specific treatment, articles about getting pregnant, email communication with doctor or health professional, evaluating a doctor or clinic, and using an online social support group) have any association with

perceptions of social support. The sample for the models examining relationships between type of internet activities and social support is unique because it represents a random sample of the population, but it is also fairly small. One advantage of this sample is the recent time frame (the last three years) for reporting online activities.

This relationship between internet help seeking and information gathering requires further exploration. The lack of a statistically significant association in the present study may be a result of data limitations. Data for the NSFB was collected over a three year period from 2004 to 2007. The internet usage questions were asked of women who had gone online in the past three years, which potentially could have women reporting about internet usage that was occurring as early as 2001. Growth in internet access in the U.S. changed quite dramatically during this time frame. For example, while just 46% of Americans had internet access in the year 2000, by 2008, 74% of people had access (Fox and Jones 2009). Moreover, research suggests that during this time going online for health information became more likely. In 2000, just one-quarter of Americans had gone online for health information. By 2008, this proportion of the U.S. population using the internet for health information had increased to 61% (Fox and Jones 2009).

The type of internet access one has matters as well. Over this same period the use of broadband internet access, which is associated with being more likely to go online for health information also increased (Smith 2010). Taken together, recent research on using the internet for health information suggests that internet access has increased, people are becoming more likely to seek health information online, and faster access, which facilitates going online for health information, has become more widespread. The fast



pace of change in internet access suggests that more rapid data collection (not three years for wave 1) may be necessary to more accurately assess relationships between social support and types of help seeking presented here.

I also have concerns about the measures of internet activities. First, most of the activities are related to information seeking rather than support seeking. The wording of the question about online support groups is different from the wording of other items because respondents were asked if they had ever *participated* in an online support group not if they *sought* an online group. It is common for Americans with online access to go online for health information; additionally, 41% of those who go on line have read someone else's commentary about a health experience on websites or blogs (Fox and Jones 2009). Just 6% of internet users have actually created their own health information and shared it online (Fox and Jones 2009). If participants do not include viewing content of personal accounts of infertility as "participating" in a support group, and interpret "participating" instead as the actual act of posting to a support group website, the data may be underestimating the number of people who are actually going online and engaging in activities that might be related to perceptions of social support.

There are a few additional limitations that are noteworthy. The data for the current investigation are cross-sectional and therefore I cannot make definitive conclusions about temporal ordering. This is a particular issue for my analyses involving social support. Ideally, I would have a measure of social support before women engaged in any type of help seeking, and then a follow up measure so that I could measure how type of help seeking is actually influencing social support. The second wave of the NSFBS will be available soon and will make exploring this question more feasible.

Some of the key concepts included in my analyses were measured at the time of interview while others asked women to reflect back to the time of infertility episode. Therefore some items, for example no desire for a child, appear odd in an analysis of women who qualify for infertility. For the analysis I collapsed the race/ethnicity variable into a dummy of white versus non-white respondents. I did this to accommodate small numbers of cases in particular cells, I am limited in my ability to fully explore how types of help seeking and social support differ by racial and ethnic groups.

The data set does not contain measures of where respondents have internet access, the type of connection speed, and whether or not they have mobile access to the internet. As I mentioned above, the internet and how we utilize internet technology is rapidly changing, and these changes are likely to influence how involved people are with the internet. For example, people who have home computers, broadband connections, and mobile internet access are all more likely to seek health information (Fox and Jones 2009; Fox 2010).

The current investigations raise some directions for future research. First, as I mentioned previously, I plan to revisit the questions in this dissertation with the second wave of data from the NSFB. I will be able to disentangle some of the causal ordering that was not clear in the current investigation. For example, access to the second wave of data will give me a baseline level of social support for women who did not do any help seeking. I can then investigate how this perceived social support changes with the type of help seeking that women do.

Second, the findings related to social support suggest that infertile women's perceptions of health care providers are associated with social support. Future research

should investigate this issue to determine how doctors (through behaviors, characteristics, and types of information) help women feel supported during the stressful experience of seeking medical help for infertility.

Third, recent research on the use of internet for health information finds that it is fairly common to go online to research a health condition for someone else. For example, Fox and Jones (2009) find that just over half of all health inquiries online are done on someone else's behalf. Therefore it would be useful to learn more about men's online activities related to infertility. Weissman, et al. (2000) found that in 14% of couples, both members went online for infertility, and in another 10% of couples, only the male partners went online. It is possible that some of the women in my study are not going online themselves, but may have partners that do. Importantly, if partners share what they found online, then their partners are likely to benefit without actually engaging in the help seeking behavior.

Fourth, future research should investigate what social support really means to infertile women. The scale included in these analyses asks general questions about social support such as do you have someone available to give you advice in a crisis. In the context of infertility, a condition which is stigmatized and often kept a secret (Inhorn 2002, Miall 1986, Wirtberg, et al. 2007), these measures of social support might not be accurately capturing women's true experiences. Qualitative research could be used to determine the types of interactions that make women feel understood, accepted, comforted, and emotionally supported. This type of research would also likely highlight the interactions that are perceived to be unsupportive and distressing.

Using the internet for infertility information and support will continue to be an important area of research. At the present time, 17% of cell phone owners have used a cellular telephone to look up health information, and moreover, 9% have used applications to track and/or manage health (Fox 2010). As access continues to become more widespread the prevalence of people engaging in online behaviors is likely to continue to increase. Yet there still may be those who do not have access – and it is likely to be those who have the greatest need (e.g. women who are minority or low SES)

Finally, the explosion in the use of social networking sites is an exciting new potential area in which to study how people are using the internet for health information. A search for “infertility” on facebook reveals an astounding variety of ways to interact with people who are experiencing infertility from formal organization pages (i.e. RESOLVE: The National Infertility Association), support groups, blogs, and common interest groups. In light of the increasing popularity of internet health searches and the vast array of sources and types of information available, it is critical that we understand what causes people to go online and how this information is actually affecting the individuals reading it.

As growth in internet access and using the internet for health information continues to increase it is critical for social scientists to explore the implications of these help seeking behaviors. This dissertation extends our understanding of help seeking for infertility, a chronic health condition that is optional to treat. Using data from the NSFB I examined the utility of the General Help Seeking Model for explaining two new types of infertility help seeking, only going online for infertility information and both going online and seeking medical help. The results suggest that five variables in particular

differentiate those who go online from those who do not: attitudes towards medical science, infertility stigma, age, income, and education. In addition, I find no associations between the type of help sought and infertile women's perceived social support. Future research must continue to explore how infertile women are utilizing the internet in relation to fertility problems, and what implications these activities have on personal identities, help seeking, and doctor patient interactions.

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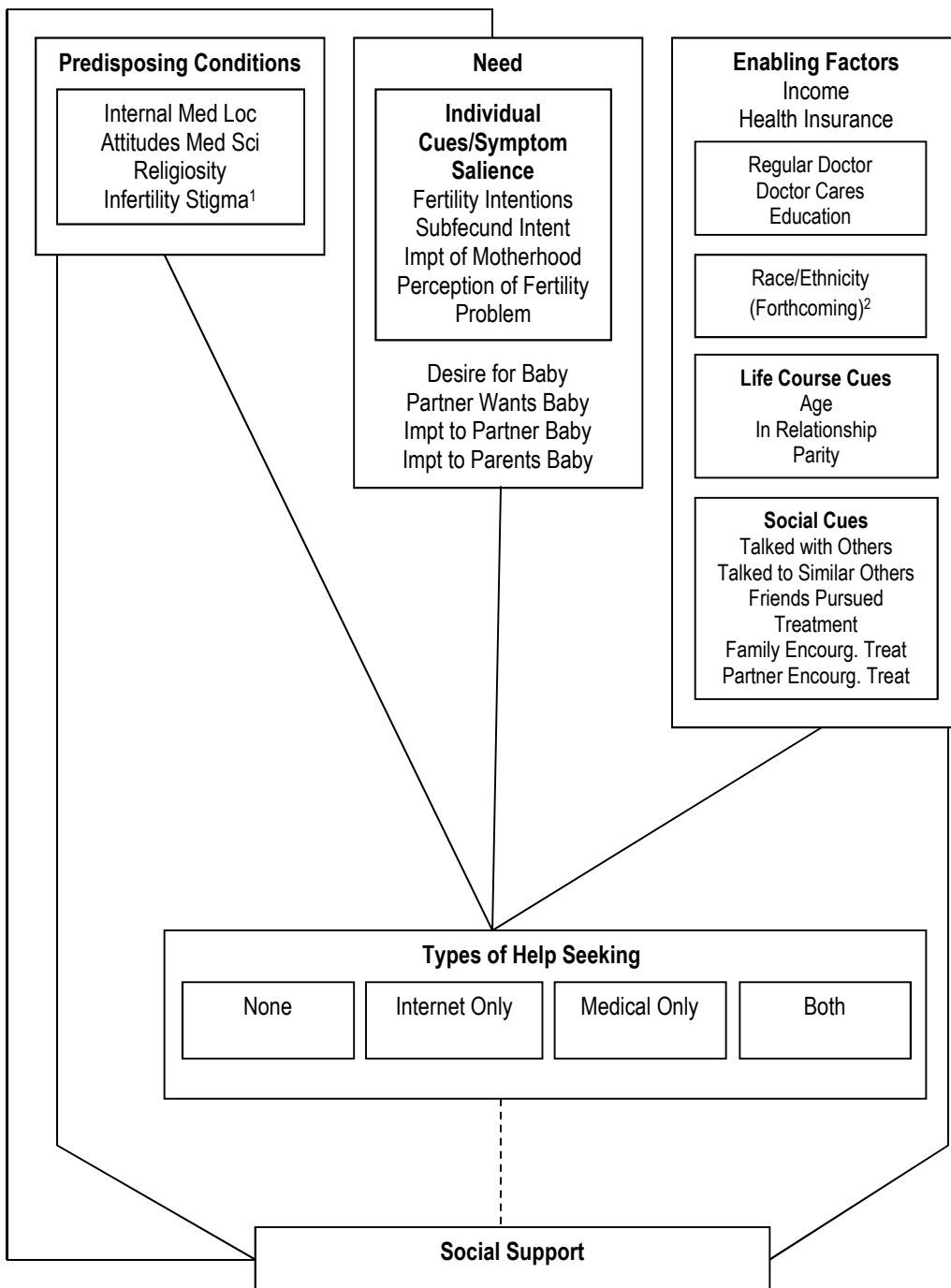


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### Appendix A – Theoretical Model



<sup>1</sup> Unless otherwise specified, predisposing, need, and enabling conditions in boxes are drawn from White, et al. (2006a), White, et al. (2006b).

<sup>2</sup> Greil, et al. (forthcoming)

## Appendix B – Tables

**Table 1. Descriptive statistics of type of help seeking and independent variables**

	% or M	SD
<b>Type of Help Seeking</b>		
No Seeking	33.93	
Internet Only	9.31	
Medical Only	32.12	
Both Internet and Medical	24.65	
<b>Need Variables</b>		
Perception of fertility problem	69.00	
Fertility Intentions	-0.60	1.29
Desire for a Baby		
Definitely yes	33.32	
Probably yes	19.30	
Probably no	15.61	
Definitely no	31.77	
Subfecund		
Subfecund, intent	63.54	
Subfecund, no intent	19.82	
Other fertility barrier	16.64	
Partner like a(nother) baby		
Definitely yes	24.60	
Probably yes	17.40	
Probably no	10.99	
Definitely no	23.78	
Not asked	23.24	
Importance of motherhood	3.35	0.51
Children imppt to partner		
Strongly agree	34.85	
Agree	31.46	
Disagree, strongly disagree	10.83	
Not asked	22.85	
Children imppt to parents		
Strongly agree	27.68	
Agree	41.74	
Disagree, strongly disagree	21.90	
Parents deceased, don't know	8.68	
<b>Enabling Conditions</b>		
Age (25-45)	36.06	5.91
In a relationship	70.24	
Parity	1.63	1.31

Talked to others		
Often	22.81	
Occasionally	30.75	
Seldom	17.10	
Never	29.35	
Talked to similar others		
Often	15.00	
Occasionally	29.67	
Seldom	21.33	
Never	33.99	
Social support	3.54	0.65
Friends pursued treatment	51.55	
Partner encouraged treat		
Encouraged	37.24	
Discouraged	6.31	
It was mixed	22.49	
Don't know	11.09	
Not asked	22.87	
Family/friends encouraged treat		
Strongly encouraged	12.15	
Encouraged	22.96	
Discouraged	4.60	
It was mixed	24.41	
Not asked, does not apply, dk	35.88	
Fam income (1k units)	53.50	32.22
Education (years)	13.60	2.89
Private health insurance	66.44	
Has a regular doctor	84.66	
Doctor Cares		
Cares a lot	67.45	
Cares a little	19.73	
Does not seem to care	5.29	
Not asked	7.53	
Race/Ethnicity		
White	61.60	
African American	14.80	
Hispanic	15.50	
Asian	7.20	
Other	0.90	

***Predisposing Conditions***

Internal med loc of control	2.97	0.50
Attitude towards med sci	3.36	0.41
Religiosity	0.05	0.66
Infertility stigma	2.73	0.52

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Note: N=1,352 Subsample of women ages 25-45 from the National Survey of Fertility Barriers

**Table 2. Descriptive statistics of self-education and internet activities**

	%	N
<b>Self Education Activities</b>		1352
Read a scientific article	46.08	
Read a book	40.99	
Contacted a support group	10.76	
<b>Activities Engaged in Online</b>		291
Looked for information about treatment		
Often	18.62	
Occasionally	23.52	
Seldom	16.13	
Never	41.73	
Looked for medical articles		
Often	25.32	
Occasionally	40.66	
Seldom	24.57	
Never	9.44	
Email communication with doctor (ever)	19.56	
Evaluate a doctor or clinic (ever)	34.37	
Participated in an online support group (ever)	21.07	
<b>How Internet Affected Thinking</b>		
Info encouraged to see doctor		286
Strongly agree	16.24	
Agree	47.70	
Disagree	32.08	
Strongly disagree	3.98	
Ask new questions about getting pregnant		286
Strongly agree	19.58	
Agree	48.11	
Disagree	28.42	
Strongly disagree	3.89	
Understand health issues that impact pregnancy		287
Strongly agree	25.35	
Agree	65.12	
Disagree	9.02	
Strongly disagree	0.51	



Easier to work with doctor regarding treatments		273
Strongly agree	12.49	
Agree	50.80	
Disagree	33.01	
Strongly disagree	3.70	
Info discouraged seeking treatment		285
Strongly agree	1.00	
Agree	6.70	
Disagree	70.99	
Strongly disagree	21.31	

---

Note: Subsample of women ages 25-45 from the National Survey of Fertility Barriers.

N's change because of skip patterns in the data set.

**Table 3. Descriptive statistics in response to the question about the most helpful source of information about getting pregnant**

	%
<b>Sources of Information</b>	
Articles in pop magazines	3.00
Articles in tech journals	2.85
Books	6.26
Support groups (not online)	1.75
Internet	52.54
Internet support groups	2.59
Professionals on the internet	1.06
Info from family and friends	5.00
Professionals (not internet)	8.66
Other/don't know	16.30

---

Note: N = 291 Subsample of women ages 25-45 from the National Survey of Fertility Barriers

**Table 4. Descriptive statistics by helpseeking category for women who meet the medical criteria for Infertility.**

<i>Independent Variables</i>	<b>None (N=460)</b>		<b>Internet Only (N=127)</b>		<b>Med Only (N=436)</b>		<b>Both (N=337)</b>		<b>p</b>				
	<b>% or M</b>	<b>SD</b>	<b>% or M</b>	<b>SD</b>	<b>% or M</b>	<b>SD</b>	<b>% or M</b>	<b>SD</b>					
<b>Need Variables</b>													
Perception of fertility problem	49.89		59.52		79.03		85.89		***				
Fertility Intentions	-0.86	1.14	a	-0.18	1.38	ab	-0.83	1.234	bc	-0.09	1.34	ac	***
<b>Desire for a Baby</b>													
Definitely yes	25.11		37.30		28.05		49.85						
Probably yes	22.49		26.19		13.65		19.82						
Probably no	18.34		8.73		16.09		13.21						
Definitely no	34.06		27.78		42.30		17.12						
<b>Subfecund</b>													
Subfecund, intent	46.41		50.79		76.27		75.68		***				
Subfecund, no intent	32.90		28.00		12.21		8.71						
Other fertility barrier	20.70		21.43		11.49		15.62						
<b>Partner like a(nother) baby</b>													
Definitely yes	16.78		33.33		22.81		34.53						
Probably yes	17.21		19.84		14.98		19.82						
Probably no	10.02		11.11		9.68		13.81						
Definitely no	24.18		19.84		31.11		15.02						
Not asked	31.81		15.87		21.43		16.82						
Importance of motherhood	3.34	0.50	3.30	0.55	3.33	0.52	3.39	0.50					
<b>Children imp't to partner</b>													
Strongly agree	29.04		42.40		35.25		39.64		***				
Agree	27.95		31.20		34.33		32.73						
Disagree, strongly disagree	12.01		12.80		8.29		11.71						
Not asked	31.00		13.60		22.12		15.92						
<b>Children imp't to parents</b>													
Strongly agree	25.27		30.95		26.67		31.23						
Agree	40.74		39.68		44.60		40.24						
Disagree, strongly disagree	23.53		23.02		20.46		21.02						
Parents deceased, don't know	10.46		6.35		8.28		7.51						
<b>Enabling Conditions</b>													
Age (25-45)	36.13	6.30	a	33.41	5.51	ab	37.46	5.46	abc	35.15	5.57	bc	***
In a relationship	60.13			75.40			75.35			75.68			***
Parity	1.99	1.32	a	1.41	1.16	ab	1.74	1.30	abc	1.07	1.14	abc	***
<b>Talked to others</b>													
Often	12.64		17.60		27.36		32.73						
Occasionally	22.88		38.40		36.90		31.83						
Seldom	9.39		16.00		16.32		15.32						
Never	45.10		28.00		20.23		20.12						
<b>Talked to similar others</b>													
Often	12.17		20.80		11.75		20.96						
Occasionally	23.26		28.80		32.49		35.33						
Seldom	24.35		19.20		20.28		19.46						
Never	40.22		31.20		35.48		24.25						
Social support	3.52	0.66	3.59	0.56	3.51	0.70	3.61	0.60	ns				
Friends pursued treatment	42.05		57.14		52.30		61.26		***				
<b>Partner encouraged treat</b>													
Encouraged	18.74		17.46		51.61		51.50						
Discouraged	7.84		12.70		3.44		5.39						
It was mixed	23.31		27.78		19.50		23.35						
Don't know	17.43		29.37		4.36		4.49						
Not asked	32.68		12.70		21.10		15.27						

<b>Family/friends encouraged treat</b>											***		
Strongly encouraged	4.36		7.87		20.23		13.77						
Encouraged	14.16		18.90		27.59		30.54						
Discouraged	4.58		5.51		5.06		3.89						
It was mixed	20.92		34.65		21.61		28.83						
Not asked, does not apply, dk	55.99		33.07		25.52		22.82						
Fam income (1k units)	43.00	28.77	a	57.51	30.17	ab	52.93	32.74	ac	67.11	31.51	abc	***
Education (years)	12.81	2.65	a	14.19	2.88	ab	13.10	2.78	bc	15.11	2.73	abc	***
Private health insurance	55.12			65.87			66.90			81.68			***
Has a regular doctor	78.21			82.54			87.36			90.69			***
<b>Doctor Cares</b>											***		
Cares a lot	61.87			62.70			73.10			69.16			
Cares a little	18.52			26.19			16.78			22.75			
Does not seem to care	6.10			5.56			5.75			3.89			
Not asked	13.57			5.56			4.37			4.19			
<b>Race/Ethnicity</b>											***		
White	56.43			61.90			61.61			67.96			
African American	18.95			18.25			11.03			12.57			
Hispanic	18.74			11.90			19.54			7.49			
Asian	4.79			6.35			6.90			11.38			
Other	1.09			1.59			0.92			0.60			
<b>Predisposing Conditions</b>													
Internal med loc of control	3.00	0.51		2.97	0.45		2.95	0.50		2.96	0.50		
Attitude towards med sci	3.32	0.40	a	3.41	0.36		3.34	0.43	b	3.42	0.43	ab	**
Religiosity	0.10	0.59	a	0.08	0.66	b	0.13	0.66	c	-0.04	0.68	abc	**
Infertility stigma	2.74	0.48		2.81	0.51		2.68	0.52		2.73	0.56		

Note: N = 1,352 Subsample of women from the National Survey of Fertility Barriers

Chi-square tests performed for categorical variables. ANOVA with Tukey post-hocs for continuous variables.

% provided for categorical variables; M and SD provided for continuous variables.

For Tukey post hocs, groups which share a letter are significantly different from each other.

\*p<.05; \*\*p<.01; \*\*\*p<.001.

**Table 5. Descriptive statistics self education activities**

	None	Internet Only	Medical Only	Both	
<b><i>Offline Self Education Activities</i></b>	%	%	%	%	<b>P</b>
Read Scientific Articles	27.89	67.20	42.03	68.47	***
Read a Book	18.78	60.80	36.64	69.67	***
Contacted a Support Group	3.05	7.94	8.97	24.92	***

Note: N = 1,352 Subsample of women from the National Survey of Fertility Barriers. Table displays percent that responded "yes" to each activity.

Chi-square tests performed for categorical variables.

% provided for categorical variables.

\*p<.05; \*\*p<.01; \*\*\*p<.001.

**Table 6. Descriptive Statistics of Activities Engaged in Online by Help Seeking**

	<b>Internet Only (N=92)</b>	<b>Both (N=199)</b>	<b>p</b>
<b><i>Independent Variables</i></b>	<b>%</b>	<b>%</b>	
Looked info about treatment			***
Often	5.49	24.62	
Occasionally	12.09	28.64	
Seldom	17.58	15.58	
Never	64.84	31.16	
Looked for medical articles			ns
Often	23.03	26.50	
Occasionally	50.55	36.00	
Seldom	17.58	27.50	
Never	8.79	10.00	
Email communication with doctor (ever)	17.39	20.60	ns
Evaluate a Doctor or Clinic (ever)	20.88	40.20	**
Participated in Online Support Group (ever)	19.57	22.00	ns

Note: N = 291 Subsample of women who went online in previous three years from the National Survey of Fertility Barriers

Chi-square tests performed for categorical variables.

% provided for categorical variables.

\*p<.05; \*\*p<.01; \*\*\*p<.001.

\*p<.05; \*\*p<.01; \*\*\*p<.001.

**Table 7. How online information affected thinking**

	<b>Internet Only</b>	<b>Both</b>	<b>P</b>	<b>N</b>
<b><i>Online Information Affected Thinking</i></b>	<b>%</b>	<b>%</b>		
Info encouraged to see doctor			**	286
Strongly agree	9.78	18.97		
Agree	39.13	51.79		
Disagree	44.57	26.15		
Strongly disagree	6.52	3.08		
Ask new questions about getting pregnant			**	286
Strongly agree	12.09	23.82		
Agree	42.86	50.52		
Disagree	40.66	22.68		
Strongly disagree	4.40	3.61		
Understanding health issues that impact pregnancy			ns	286
Strongly agree	20.65	27.69		
Agree	66.30	64.62		
Disagree	13.04	7.18		
Strongly disagree	0.00	0.51		
Easier to work with doctor regarding treatments			**	273
Strongly agree	4.55	16.22		
Agree	44.32	54.05		
Disagree	45.45	27.03		
Strongly disagree	5.68	2.70		
Info discouraged from seeking treatment			**	285
Strongly agree	1.08	1.04		
Agree	11.83	4.15		
Disagree	76.34	68.39		
Strongly disagree	10.75	26.42		

Note: Subsample of women from the National Survey of Fertility Barriers.

Chi-square tests performed for categorical variables.

% provided for categorical variables.

\*p<.05; \*\*p<.01; \*\*\*p<.001.

**Table 8. Most helpful source of information about getting pregnant**

	<b>Internet Only (N=92)</b>	<b>Both (N=199)</b>
<b>Sources of Information</b>		
Articles in pop magazines	4.40	2.51
Articles in tech journals	3.30	2.51
Books	4.40	7.54
Support groups (not online)	0.00	5.00
Internet	51.65	52.76
Internet support groups	0.00	4.02
Professionals on the internet	1.10	1.01
Info from family and friends	7.69	3.52
Professionals (not internet)	10.99	7.54
Other/don't know	16.48	16.08

---

Note: N = 291 Subsample of women who went online in the previous 3 years from the National Survey of Fertility Barriers



Table 9. Odds Ratios for Type of Help Seeking by Predisposing Indicators

Type of Help Seeking	Internet			None (Reference)			Medical			Internet Only (Reference)			Medical Only (Reference)					
	Only			Medical			Only			Both			Both					
	OR	SE	P	OR	SE	P	OR	SE	P	OR	SE	P	OR	SE	P			
<b>Predisposing</b>																		
Internal med loc of control	.854	.20		.830	.14		.857	.15		.972	.20		1.003	.21		1.032	.15	
Attitudes towards med sci	1.722	.25	*	1.191	.16		1.903	.18	***	.692	.25		1.105	.26		1.598	.18	**
Religiosity	.915	.16		.809	.13		.971	.14		.627	.20	*	.753	.20		1.281	.14	
Stigma	1.291	.20		.904	.11		.582	.11	***	.988	.16		.636	.16	**	.644	.11	***
$\chi^2$	51.82	12(df)	***															

Note: N = 1,352 Subsample of women from the National Survey of Fertility Barriers

Pseudo  $r^2$  (Cragg and Uhler's) .041

\* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .





Table 11. Odds Ratios for Type of Help Seeking by Predisposing, Need, and Enabling Indicators

Variable	None (Reference)						Internet Only (Reference)						Medical Only (Reference)						
	Internet Only			Medical Only			Both			Internet Only			Medical Only			Both			
	OR	SE	P	OR	SE	P	OR	SE	P	OR	SE	P	OR	SE	P	OR	SE	P	
<b>Predisposing</b>																			
Internal med loc control	.964	.25		.867	.17		1.162	.19		.900	.25		1.205	.25		1.339	.18		
Attitudes toward med sci	2.229	.31	**	1.090	.20		1.818	.24	*	.489	.31	*	.816	.32		1.668	.22	*	
Religiosity	1.092	.20		.941	.14		.720	.15	*	.862	.20		.895	.24		.765	.13	*	
Stigma	1.418	.23		.925	.17		1.326	.19		.624	.24	*	.659	.20	*	1.434	.17	*	
<b>Need</b>																			
Perception of fertility problem	1.272	.28		2.361	.20	***	3.383	.25	***	1.856	.29	*	2.659	.31	**	1.433	.25		
Fertility Intentions	1.577	.13	***	1.327	.10	**	1.578	.11	***	.842	.13		1.001	.13		1.189	.10		
Desire for a Baby																			
Definitely yes (Omitted)																			
Probably yes	.913	.34		.533	.28	*	.434	.29	**	.584	.36		.475	.36	*	.814	.28		
Probably no	.472	.50		1.130	.32		.564	.37		2.396	.52		1.196	.53		.499	.34	*	
Definitely no	1.537	.44		1.350	.30		.586	.36		.879	.46		.382	.48	*	.434	.33	*	
<b>Subfecund</b>																			
Subfecund, intent (Omitted)																			
Subfecund, no intent	.914	.30		.324	.23	***	.206	.29	***	.354	.33	**	.225	.35	***	.634	.29		
Other fertility barrier	.979	.34		.430	.25	**	.545	.27	*	.439	.35	*	.557	.35		1.269	.27		
Partner like a(nother) baby																			
Definitely yes (Omitted)																			
Probably yes	.981	.39		.989	.31		1.408	.33		1.007	.40		1.435	.40		1.424	.30		
Probably no	1.391	.48		1.095	.37		2.504	.40	*	.787	.50		1.799	.50		2.287	.36	*	
Definitely no	.713	.44		1.181	.31		1.191	.37		1.655	.45		1.671	.47		1.009	.34		
Not asked	5.918	.92		1.344	.84		4.060	.88		.227	1.00		.686	.97		3.020	.85		
Importance of motherhood	.524	.29	*	.574	.20	**	.760	.23		1.095	.29		1.450	.30		1.325	.21		





**Table 12. Social Support by Predisposing, Need, Enabling, and Type of Help Seeking Indicators**

Variable	Model One			Model Two		
	B	SE	P	B	SE	P
<b>Predisposing</b>						
Internal med loc control	.068	.034	**	.069	.034	**
Attitudes toward med sci	.004	.041		.009	.041	
Religiosity	.070	.026	**	.068	.026	*
Stigma	-.009	.033		-.006	.033	
<b>Need</b>						
Perception of fertility problem	-.073	.041	*	-.064	.041	*
Fertility Intentions	.010	.018		.021	.018	
Desire for a Baby						
Definitely yes (Omitted)						
Probably yes	.041	.052		.036	.053	
Probably no	.023	.063		.019	.064	
Definitely no	.048	.060		.047	.061	
Subfecund						
Subfecund, intent (Omitted)						
Subfecund, no intent	.047	.046		.039	.047	
Other fertility barrier	.031	.049		.028	.049	
Partner like a(nother) baby						
Definitely yes (Omitted)						
Probably yes	-.049	.059		-.047	.059	
Probably no	-.039	.070		-.035	.070	
Definitely no	-.046	.063		-.045	.063	
Not asked	.119	.143		.131	.143	
Importance of motherhood	.003	.040		-.003	.040	
Children impt to partner						
Strongly agree (Omitted)						
Agree	-.068	.046	*	-.065	.046	*
Disagree, strongly disagree	-.037	.070		-.038	.070	
Not asked	.050	.149		.056	.149	
Children impt to parents						
Strongly agree (Omitted)						
Agree	.027	.043		.027	.043	
Disagree, strongly disagree	-.024	.053		-.021	.053	
Parents deceased, don't know	-.041	.067		-.040	.067	
<b>Enabling</b>						
Age (25-45)	.034	.003		.028	.003	
In a relationship	-.005	.068		-.004	.069	
Parity	-.084	.015	**	-.088	.016	**

Talked to others					
Often (Omitted)					
Occasionally	.066	.047	*	.064	.048
Seldom	.049	.057		.046	.057
Never	-.057	.081		-.054	.081
Talked to similar others					
Often (Omitted)					
Occasionally	-.068	.054		-.067	.054
Seldom	-.119	.057	**	-.122	.057
Never	-.136	.055	**	-.135	.056
Friends pursued treatment	.025	.036		.028	.036
Partner encouraged treat					
Encouraged (Omitted)					
Discouraged	.048	.074		.045	.075
It was mixed	.011	.047		.006	.047
Don't know	.043	.061		.040	.063
Not asked	-.208	.145		-.232	.146
Family/friends encouraged treat					
Strongly encouraged (Omitted)					
Encouraged	-.055	.060		-.057	.060
Discouraged	-.071	.095	*	-.070	.095
It was mixed	-.023	.063		-.024	.063
Not asked, does not apply, dk	-.002	.084		-.018	.085
Fam income	.078	.008	*	.085	.008
Education (years)	.144	.007	***	.153	.007
Private health insurance	.035	.046		.036	.046
Has a regular doctor	.011	.062		.010	.062
Doctor Cares					
Cares a lot (Omitted)					
Cares a little	-.065	.043	*	-.065	.043
Does not seem to care	-.096	.075	**	-.097	.075
Not asked	-.040	.085		-.048	.086
Race					
White (Omitted)					
Non-white	-.132	.038	***	-.135	.038
<b>Type of Help Seeking</b>					
None (omitted)					
Internet only				-.052	.064
Medical Only				-.049	.046
Both				.067	.053
<b>Intercept</b>	.201	.129	*	.348	.132
<b>Adjusted R-square</b>	.181			.182	

Note: N = 1,352 Subsample of Women from the National Survey of Fertility Barriers

\*p<.05; \*\*p<.01; \*\*\*p<.001.



**Table 13. Social Support by Type of Help Seeking, Predisposing, Need, Enabling, and Internet Activities Indicators**

<b>Variable</b>	<b>B</b>	<b>SE</b>	<b>P</b>
<b>Type of Help Seeking</b>			
Internet Only (Omitted)			
Both	-.040	.092	
<b>Predisposing</b>			
Internal med loc control	.080	.077	
Attitudes toward med sci	-.039	.092	
Religiosity	.054	.049	
Stigma	-.108	.068	
<b>Need</b>			
Perception of fertility problem	.014	.098	
<b>Fertility Intentions</b>	<b>.233</b>	<b>.039</b>	<b>**</b>
Desire for a Baby			
Definitely yes (Omitted)			
Probably yes	.146	.105	
Probably no	.047	.176	
Definitely no	.127	.176	
Subfecund			
Subfecund, intent (Omitted)			
Subfecund, no intent	.011	.108	
Other fertility barrier	.012	.098	
Partner like a(nother) baby			
Definitely yes (Omitted)			
Probably yes	.087	.115	
Probably no	.130	.155	
Definitely no	.134	.169	
<b>Not asked</b>	<b>.588</b>	<b>.305</b>	<b>**</b>
Importance of motherhood	-.056	.081	
Children impt to partner			
Strongly agree (Omitted)			
Agree	-.075	.091	
<b>Disagree, strongly disagree</b>	<b>-.239</b>	<b>.147</b>	<b>**</b>
Not asked	.426	.433	
Children impt to parents			
Strongly agree (Omitted)			
Agree	.039	.085	
Disagree, strongly disagree	-.008	.114	
Parents deceased, don't know	.023	.145	
<b>Enabling</b>			
Age (25-45)	.137	.007	
In a relationship	-.012	.141	

Parity	-.161	.036	*
Talked to others			
Often (Omitted)			
Occasionally	-.026	.098	
Seldom	-.055	.123	
Never	.158	.206	
Talked to similar others			
Often (Omitted)			
Occasionally	-.005	.103	
Seldom	.072	.116	
Never	.125	.113	
Friends pursued treatment	.107	.074	
Partner encouraged treat			
Encouraged (Omitted)			
Discouraged	.127	.142	
It was mixed	-.030	.091	
Don't know	.065	.148	
Not asked	-1.166	.523	***
Family/friends encouraged treat			
Strongly encouraged (Omitted)			
Encouraged	.026	.112	
Discouraged	-.120	.223	
It was mixed	-.094	.120	
Not asked, does not apply, dk	-.393	.202	*
Fam income	-.048	.018	
Education (years)	.078	.013	
Private health insurance	.043	.108	
Has a regular doctor	-.058	.132	
Doctor Cares			
Cares a lot (Omitted)			
Cares a little	-.404	.084	
Does not seem to care	-.227	.171	***
Not asked	-.090	.229	
Race			
White (Omitted)			
Non-white	-.004	.075	
<b>Activities Online</b>			
Info about a specific treatment			
Often (Omitted)			
Occasionally	-.016	.111	
Seldom	-.040	.121	
Never	-.044	.112	

Articles about getting pregnant		
Often (Omitted)		
Occasionally	-.023	.094
Seldom	.116	.103
Never	.060	.129
Email communicate with doctor (ever)	.035	.103
Evaluate doctor/clinic (ever)	-.118	.078
Internet support group (ever)	.070	.096
<b>Intercept</b>	.042	.274
<b>Adjusted R-Square</b>	.209	

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Note: N = 291 Subsample of National Survey of Fertility Barriers, Women Who Went Online in Previous Three Years

\*p<.05; \*\*p<.01; \*\*\*p<.001.