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The Barriers: Psychosocial and Economic Resistance Men Face in Seeking Fertility Evaluations

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ABSTRACT

There has been a minimal amount of research conducted regarding barriers presenting to male patients presenting for fertility evaluations. Research that focuses on the male gender's reactions to infertility has been just as limited. The purpose of this research, which was preformed through a literature review and custom survey, was to find some foundational insight on the barriers encountered by men seeking a fertility evaluation. These barriers include psychosocial and economical barriers. The medical field can use the outcomes of this research to as a basis to direct further studies, and to better understand barriers affecting men from seeking infertility evaluations. All of this may help improve health care providers' abilities to customize the needs of their patients. This research may also serve the opportunity for family practice providers to educate their patients in male fertility evaluations and normalize the stigma attached and break down psychosocial barriers.

TABLE OF CONTENTS

LIST OF APPENDICES

CHAPTER 1

Introduction

This chapter introduces the background of the problem, the variety of ways infertility affects males, and the minimal emphasis that is placed on male-factor infertility. Furthermore, this chapter presents the problem statement, the purpose of the study including its significance, and the limitations encountered during the study.

Background to the problem

In most cultures, women are stereotypically viewed as more sensitive and emotional than men. When it comes to infertility, women have a large network of support in the medical practice, but unfortunately men do not. The results of a study published in 2007 show that infertile men have decreased social support than that of women (Peronace, 2007). Not only does this study show that men feel they have deceased social support, but that men feel male infertility is less socially acceptable than that of women (Peronace, 2007). Therefore, with growing infertility diagnoses pertaining to men, a need exists for more support for males going through the process of diagnosis and treatment. In fact, "Male factor infertility is involved in up to 50% of all cases of infertility, but there is a limited amount of research that examines the effect of a male factor diagnosis on a man's physical and psychological wellbeing" (Peronace, 2007). Despite stereotypes, when faced with the diagnosis of being infertile, males may need just as much support as females because "[f]or many men, fatherhood represents adulthood, sexual adequacy, and normalcy" (Sherrod, 2006).

The emotional effects on men were found to be profound in Sherrod's study and the results indicate the impact infertility has on a male's quality of life, concluding there

is an exclusion of men in the research on the psychosocial consequences of infertility (Sherrod, 2006). Though there is a limited amount of research available on men and the psychosocial consequences of infertility, but with the minimal results available, Sherrod's study found the emotional effects to be profound.

"To date, investigations of the experiences of infertility have focused disproportionately on women, and the short- and longer term psychosocial consequences of male factor infertility for men have been less thoroughly examined" (Fisher, 2009 p. 574).

Mikkelsen (2013) conducted a descriptive study of male patients undergoing intracytoplasmic sperm injection treatments for fertility. The goal was to explore physiological needs of an infertile man. The conclusion states that the men within the study wished to be regarded as equal participants by healthcare professionals on the same terms as their female partner (Mikkelsen, 2013). Therefore, one-third of the men who took part found that infertility affects their masculinity negatively.

Fisher (2009) explored infertility-specific anxiety and found it to be elevated in men at the initial investigation, diagnosis, and treatment. However, according to Fisher (2009), depression and anxiety in these men was no greater than the general population, and it's suspected that depression and anxiety is due to an avoidant coping style. A Swedish source study found that males find support in the following: friends (38%), their own mothers (27%), fathers (23%); but a large proportion (47.3%) had not confided in anyone other than their spouse. In an American source conducted on 36 volunteer couples, it was found that men with male factor infertility had more negative experiences such as lack of support and resources.

A qualitative study by Jafarzadeh-Kenarsari in 2015 had the main purpose of exploring the needs of infertile couples. Some of the factors taken into account were: different causes of infertility, different types of infertility (primary and secondary), different stages and durations of infertility treatment. The findings concluded that there is a great need for social, emotional, financial and educational support for infertile men (Jararzadeh-Kenarsi, 2015). Overall patients need to have more education and information on infertility so that there is a more positive outlook for psychosocial effects of infertility (Jararzadeh-Kenarsi, 2015).

Problem Statement

Male patients may not be receiving the emotional support that they need when it comes to an infertility diagnosis. Pronounced emphasis on male fertility support is not as strong relative to women's fertility support, and problematically, proper support is crucial for proper treatment (O'Brein, 2015). Psychological, economic, and physical barriers are being overlooked and minimized, possibly due to gender stereotypes (O'Brein, 2015). The problem is defining and recognizing those barriers (psychosocial and economic) and the support for quality of life that need to be addressed to aid in proper support for patients.

Purpose

The purpose of this research is to compile and create a clear view of barriers that affect males before and after an infertility diagnosis. This research is filling an important research gap, which will help shape treatment for males experiencing infertility. This research defines emotional, social, and economical hindrances for men. This study will allow practitioners to create new ways and adapt old ways to serve male patients, whom

are beginning their fertility work-up or continuing their treatment. Through extensive literature review and compilation of the differing thoughts and research on male infertility, the aim of this study is to better understand the barriers and quality of life regarding male infertility.

Significance of Problem

As our population continues to grow, both males and females have a significant need for infertility treatment. However, though research on those barriers is limited, what is available demonstrates males have more psychosocial barriers than women according to research conducted and data collected (Fisher, 2012; Sherrod, 2006). The reasons behind male psychological barriers are important to dissect if we want to understand male fertility patients and their needs more clearly. To fill this void in understanding, this study clearly assesses the psychological impact of infertility on males.

Research Questions:

The following research questions are addressed in this study:

1. Do barriers exist to men seeking a fertility evaluation?
2. If there are barriers, what types of barriers (psychosocial, economical, or other) are present?

Definition

Infertility is "a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse" (Zegers-Hochschild, F., Adamson, G., Mouzon, J. D., Ishihara, O., Mansour, R., Nygren, K., Vanderpoel, S, 2009). A misconception is that female factor infertility counts for a majority of the cases. However, male factor contributes to near fifty percent

of infertility cases. (Thonneau P, Marchand S, Tallec A, Ferial ML, Ducot B, Lansac J, Lopes P, Tabaste JM, Spira A, 2009).

Conclusion

Unfortunately, the support during infertility diagnosis and treatment is not being addressed, and this lack of support may be deterring males from seeking evaluation. Men with infertility face many psychological, social, and economic barriers. In this chapter, the background of the problem was introduced; the variety of ways infertility affects males and the minimal emphasis that is placed on male-factor infertility. The problem statement, the purpose, and limitations were all also discussed.

In the next chapter, we explore the research that has already been conducted and what has been concluded from those studies.

Chapter 2: Literature Review

Introduction

This chapter compiles literature reviews focusing on barriers to male fertility evaluations. The literature review demonstrates that the research community has neglected male infertility. This chapter gives a view of the research that is currently available on men and infertility, as well as shedding light on how much is left to be studied. "One might anticipate that certain conditions, such as male infertility, would be perceived as posing a particular threat to conventional views of masculinity. There is some support for this, although there is little research into the social construction of male infertility" (Gannon, Glover, and Abel, 2004, p. 1169).

The literature collected on barriers to male fertility evaluations is categorized by the type of barrier. A better way to understand the overall barriers is to look at the picture as a whole and how each barrier may be affecting the choice to seek an evaluation. The literature in this chapter assists in explaining the background of each different type of barrier and what roles they play in men's decisions to seek fertility evaluations. The following categories of barriers are outlined below: (1) the gender gap (differences between men and women's infertility in the healthcare and social communities); (2) psychosocial (what men deal with psychologically and socially from a standpoint of infertile/fertile); and (3) economic (how cost may affect the number of men that are able or willing to seek evaluation). Categorization of these barriers allows for a more in depth assessment and understanding of the custom survey that is associated with this research project.

The Gender Gap

When it comes to an infertility diagnosis, there is an overall perception that women have a higher sensitivity or increased psychological reaction than men. There is a perceived socialization process that creates different sex role expectations to fertility. For women, childbearing is central to a women's identity whereas for men it is associated with virility (Edelmann and Connolly, 2000). Emotional expressionism between men and women differ as well.

Edelmann and Connolly (2000) focused on the emotional responses of infertility amongst men and women. This longitudinal study compared scores from different psychological and personality measurements, including: Eysenck Personality Questionnaire, General Health Questionnaire, Beck Depression Inventory, State-Trait Anxiety Inventory, and the Dyadic Adjustment Scale. The study compares men and women undergoing fertility evaluations and treatments. Each couple was asked to complete the questionnaires at the first visit to either clinic and again after 6-7 months of infertility visits. At the infertility clinic, more women than men (116 vs 107) completed the questionnaire, this data was not reported for the IVF clinic participants (Edelmann & Connolly, 2000). The results of Edelmann and Connolly's study found no difference in the distress scores between men and women undergoing infertility evaluations and IVF treatments, initially and over a year's time (Edelmann & Connolly, 2000). The study's conclusions are contrary to the societal beliefs that women undergo more emotional distress than men during infertility evaluations and treatments (Edelmann & Connolly, 2000).

Another component that presented a gender limitation was that men may be more prone to denying their emotional state (Edelmann & Connolly, 2000). Edelmann & Connolly's study (2000) concluded that previous studies have shown women have larger reactions to infertility than men, which may be due to the collection methods, such as direct interviewing. Specifically, they stated, "[d]ifferences of this kind may be primarily a function of the methodology adopted, the findings reflecting simply a tendency for women to express their feelings more readily to a stranger than are their partners" (Edelmann & Connolly, 2000, pg. 372). The perception that men feel less emotionally compromised when it comes to infertility could be due to the fact that it is harder to get men to discuss their emotional feelings regarding infertility. This suggests if everyone was equally as comfortable sharing emotions' on the topic, there may be less of a gap between the genders and their responses.

Related to this point, other literature has supported the conclusion that the differences in men and women's emotional expressionism may hinder the evaluation of the emotional impact of infertility. *Overcoming male infertility: Understanding its causes and treatments*, by Schover & Thomas (1999) was written to explain psychological and physical states of male infertility. Dr. Anthony Thomas is a male urology specialist, and Dr. Leslie Schover's expertise is psychology of infertile couples. Together, these specialists determined that men are more likely to mask their feelings and learn coping mechanisms in exchange for perceived toughness (Schover & Thomas, 1999). This finding indicates that social examinations of men's emotions toward infertility may not be dependable. "It is to be concluded that men may experience just as much distress as men when dealing with an infertility diagnosis" (Schover & Thomas, 1999).

On top of these findings that men and woman share similar levels of distress, there is a clear imbalance in the support system available for men and women. There is much more support for women, as if they do experience greater distress, (but as literature shows, this is a misconception). These supports stem from society, friends, family, and health care providers. The infertility support system may be lacking at large for men undergoing fertility evaluations. This can present a large barrier to men than currently available when deciding whether to seek an evaluation. More support for men is essential; however, the amount of support is just as important as the type of support.

There are differences between the specific support needed for women and men due to the differences in how they might perceive their diagnosis, as well as the overall differences in emotional presentation and biological makeup. For example, men have a stigma of masculinity attached to fertility. In certain African cultures literature has shown that that infertility is solely female factor, and anything other than that explanation is taboo, or avoided, even by healthcare providers in order to protect a male's masculinity (Petok, 2006). Although this is an example of a subset of cultures, it may be applicable throughout other cultures as well. The limited acceptance or understanding of male factor infertility may lead to a barrier of men seeking evaluations.

To militate this barrier, society needs to be aware of the prevalence of male-factor infertility, and the myths need to be addressed. Men prefer a sense of control when it comes to their health and bodies, and infertility is no different. Men would prefer to find a solution to a problem on their own, rather than seek help, especially for sensitive issues such as infertility. On the other hand, women are more likely to reach out to other women or healthcare providers if they are not conceiving. This difference plays a large role

seeking healthcare for infertility concerns. Women's infertility has been more broadcasted in society, where they can feel more comfortable sharing their hardships and health concerns, whereas men may still feel that it is a private battle and slightly more taboo to talk about.

This significant focus on women's infertility has made it generalized as a female cause due to the minimized amount of light shed on male infertility factors. Socially it is assumed that if a couple is infertile, it is the female's inability to get pregnant. This assumption is proven wrong by the large portion of infertility that is male factor. According to Petok, "The net impact of this invisibility makes working with men who experience infertility an ongoing challenge" (Petok, 2015. Pg 261). The challenge also exists for men themselves, in their reluctance to respond openly and emotionally about their infertility (Petok, 2015). The less publicized male infertility is, the larger chance that men will feel as if they are alone in the diagnosis and that it is rare among other men (Petok, 2015).

Psychosocial Barriers

As healthcare providers, the initial, and most important step, is to understand our patient's concerns and how they are coping. Conforming to society's expectations of masculinity. There is significant pressure on males to be fertile, with social cues such as "carrying on the family name," "producing an heir," or "fulfilling the woman's desire to have a child." The loss of masculinity may be a large barrier in seeking a fertility evaluation since it has been shown that men who are evaluated and diagnosed as infertile tend to have low sexual self-esteem. Smith et al. presented their results from a cross-sectional analysis in 2009, of 357 men who were in an infertile relationship. The analysis

used written surveys, as well as interpersonal interviews to identify the psychosocial impacts (social, personal, marital, and sexual), of male factor infertility. The overall conclusion the authors formed in the study, was that sexual, social, and personal strains affect men negatively and at a clinically significant level (Smith et al., 2009).

Another major, and common psychosocial barrier for men, is anxiety. To shed light on anxiety felt by men in the midst of fertility evaluations, Terzioglu designed a descriptive study in 2007. This study assessed those undergoing genetic testing for assisted reproductive treatment. Terzioglu's study focused on helping both healthcare providers in the planning, training, and counseling services for men with infertility. The study concluded that 24.5% of participants, after informed that the test results were normal, would have liked more support during the infertility process. Counseling after the test was demanded by 38.3% and of those 65.32% asked for psychological counseling and more information (Terzigolu, 2007). The results confirm the need for more support for males undergoing infertility evaluations and treatments (Terzigolu, 2007). The study concludes that there is a need for further research on the appropriate supporting methods for men that are undergoing fertility evaluations. It also demonstrates the impact that these evaluations may have on men and in turn presenting a barrier to those seeking evaluations.

In 2015, Petok completed a literature review that complied literature supporting the lack of attention given to men in regards to infertility counseling and the overall experiences of infertility for men. Petok points out the public awareness limitations, as well as the lack of coverage in literature and media. As the research continues to grow, it is more apparent that men who are infertile have negative emotional experiences and a

lack of resources, or willingness to use resources (Petok, 2015). “Several factors contribute to underutilization, including narrow awareness, lack of high-visibility individuals willing to speak about the problem, and male avoidance of mental health services” (Petok, 2015, pg. 260).

Aside from the lack of support for men, Petok touches on the obvious misconceptions of male infertility. Infertility may be seen solely as sexual dysfunction problem for men. Pregnancy is known in society as being woman’s matter and that it all occurs in the female body. Whereas there are truths to that physiologically, experts know that the lack of a pregnancy may have nothing to do with the woman’s health. Male fertility has been termed as a social “blind spot.” The feelings of being sexually inadequate may be heightened by a diagnosis of infertility, contributing to a male’s avoidance of confronting infertility. It may be possible that men would rather ignore the chance of infertility being male-factor, than to have it confirmed. The unknown may be easier to handle than the possible diagnosis. Petok references the book *Overcoming male infertility: Understanding its causes and treatments*, by Schover & Thomas. From this, Petok states that, “Some use denial to such an extent that they fail to seek medical treatment. Conflating a low sperm count with erectile failure is common. No man wants to be known as ‘shooting blanks”(Petok, 2015, pg. 261).

The diagnosis of infertility itself is accompanied by an intrusive examination. The overall population of men may not be comfortable undergoing these examinations of genitalia, as well as intimate questioning. Men are much more reserved about their health issues, as has been described. A fertility evaluation may be an uncomfortable situation for many men and avoidance of this discomfort is desired. This avoidance presents a large

barrier to evaluations. If providers can ease the minds of men to be more comfortable in these situations, the barrier may be diminished.

Along with a possibly uncomfortable examination, the fertility evaluation requires a semen analysis. The masturbation required to collect the semen may be more uncomfortable for men than just the physical exam. Pottinger, Carroll & Mason (2015), researched the problems and views that men have on masturbation to provide a semen analysis for fertility evaluations. The research was conducted in Kingston, Jamaica at the only fertility clinic available. There were 83 final participants (out of 94, there were 11 that declined due to the sensitivity of the questions, or personal timing conflicts). A survey was distributed and collected between February and August 2014. The survey included demographics, medical history, and sexual health history (Pottinger et al. 2015).

The survey also included eight questions to determine the participant's social views on masturbation. This included questions about comfort, need for external stimuli, emotional views on masturbation, and origin of emotional/social views (Pottinger et al. 2015). The results confirmed that there is an underlying anxiety component to the ability and willingness to masturbate to provide semen for analysis or IVF/IUI. In the results, 34% of participants were not comfortable with masturbation and 42% being only somewhat comfortable. Although there were approximately half of the men that associated masturbation with pleasurable thoughts, there were negative views as well. The survey results showed that 23% of the participants associated masturbating with negative feelings without any co-positive emotion (Pottinger et al. 2015). Three negative feelings that were most commonly reported were: feeling like "less of a man," masturbation is dirty, and that it will do harm in the long run (Pottinger et al. 2015). It

was found that 77% of the men had masturbated before, and the other 23% either had not masturbated before or did not respond. There were 18% of participants who admitted to having a problem being able to masturbate, and 46% admitted to needing an external stimulation to masturbate. Of those that reported a problem with the ability to masturbate, 20% mentioned problems with sexual dysfunction (Pottinger et al. 2015). Another important statistical result that the research found was the origin of masturbating views, which included: Peers' opinions, personal opinion, religion, Jamaican culture, and parents' attitude/teaching (Pottinger et al. 2015). The most common selected origin of views were peers' opinions, personal opinions, and religion (Pottinger et al. 2015). "Thus, the stress of masturbating adding to anxiety levels in men pursuing infertility investigations must be considered" (Pottinger et al. 2015, pg. 4). "Infertility specialists need to pay more attention to the male psychology of the subfertile or infertile male" (Pottinger et al. 2015, pg. 4). Masturbation is a crucial part to a fertility evaluation, and an evaluation usually requires more than one semen analysis. If men are unable to masturbate for an analysis, it can incur more expensive and invasive options for sperm retrieval (Pottinger et al. 2015).

Economic Barriers

Not only are examinations intrusive, and potentially unsuccessful, but the medical interventions required for fertility evaluation are also often costly. The costs of treatments range widely for infertility with a single cycle of IVF costing $15,000 at the higher end. There is no guarantee of insurance coverage for infertility testing or treatment. If there is coverage, it may be minimal, or may cover testing, but not treatment. There is also a large barrier if men have no insurance at all. The cost of the doctor's visit alone can range from

$150 to $300, and that is not including lab testing. Only 15 states require that insurance companies provide coverage for infertility treatments (Resolve, 2017).

An article published in the Asian Journal of Andrology in 2016, reviewed cost questionnaires completed by 111 men that had infertility-related expenses. “64% of the men had out-of-pocket expenses of more than $15,000 wheras 16% reported expense of >$50,000” (Dupree, 2016). These costs accounted for 16%-20% of the annual income of the survey respondents. “…47% experienced financial strain due to infertility treatments and 46% had treatment options limited by cost” (Dupree, 2016).

For easier ailments, there may be a quick fix, such as an inexpensive treatment. However, for the case of infertility, there is more than just a quick doctor’s visit for most cases. Generally, it requires serial visits, along with testing, and treatment procedures. With all of that combined, there is still no guarantee that these methods will work, and the outcome is uncertain. This may present as a barrier to men, and they may be less determined to seek evaluation.

Mehta et al., complied literature and data to explain access to care for infertile men, and corresponding limitations and barriers. According to Mehta et al., 2016, economic barriers exist at many different levels and include: (1) high out-of-pocket costs faced directly by patients; and (2) limitations in research and public health funding faced by scientists and healthcare providers. The estimated cost for one cycle of IVF represents 44% of annual disposable US income. One cycle can cost on average $12,000 (Mehta et al., 2016). The average cost per delivery using IVF is estimated to be more than $56,000. (Mehta et al., 2016). Intracytoplasmic sperm injection is usually $3,000 to $5,000 higher. Combined with limited insurance coverage, these costs come out-of-pocket and are

substantial to those seeking infertility treatment (Mehta et al., 2016). Out-of-pocket expenses are an important factor in the ability of couples to undergo evaluation and treatment for male factor infertility. For men seeking infertility care, 64% spent more than $15,000 in out-of-pocket infertility related expenses, which represented 16%–20% of their annual income (Mehta et al., 2016). When analyzing the cost journals of 332 couples, the median out-of-pocket cost ranged from $912-$19,234 (Mehta et al., 2016). Men undergoing non-obstructive azoospermia, outpatient testicular or epididymal biopsies alone, cost more than $500, with microsurgical epididymal or testicular sperm extraction costing a mounting $5,000. For those with obstructive azoospermia, vasal reconstructive surgery or vasectomy reversal, cost is up to $10,000 (Mehta et al., 2016).

Insurance coverage is one of the biggest barriers for males seeking infertility evaluations and treatment. There is a perception that infertility care is an elective option instead of a medical necessity. Infertility was recognized as a disease by the ASRM in 2008; however, federal and third-party insurers have failed to include infertility in the covered diseases (Mehta et al., 2016). There are fifteen states with laws mandating insurance coverage for infertility and seven states with laws that mandate insurance coverage for female infertility but do not address care for males with infertility (Mehta et al., 2016). “Besides the financial cost of undergoing fertility treatment, there may be intangible physical, psychological, and emotional costs that are harder to define” (Mehta et al., 2016, pg. 7).

Chapter 3: Methodology

Introduction

This study analyzes the barriers that present to males with infertility, seeking fertility treatment, undergoing fertility treatment, and post fertility treatment with the goal of recognizing fundamentals that will help healthcare providers to approach and treat these patients more effectively. This chapter discusses the design of the study, instruments that used for data collection, selection of participants, and the reliability and validity of the study. This chapter also outlines the statistical methods used to analyze the data and how the data will be stored.

The following research questions were addressed in this study:

1. Do barriers exist to men seeking a fertility evaluation?
2. If there are barriers, what types of barriers (psychosocial, economical, or other) are present?

Design of the study

This study is a quantitative and qualitative study.

Selection of participants

Participants were selected from Metropolitan Urology in Woodbury, MN and all participants were solely patients of this practice and/or patients of Dr. Aaron Milbank. Consent to obtain information (age, marital status, occupation, and income) and to survey these participants through Metropolitan Urology was given through written consent. This documentation can be found in Appendix A. All patients were given the opportunity to participate in the survey within a one-month time frame if they met the following criteria

to participate: 18 and older; able to give informed consent; are seeking fertility evaluation, follow-up, or treatments.

Data collection instruments

Researchers created a novel survey that includes questions about participant demographics: age, marital status, income, occupation, as well as questions to evaluate barriers (psychosocial and economic.) that inhibited patient from seeking initial evaluation.

To look more closely at the barriers, survey questions were designed to obtain information such as determining why the patient decided to come in for their evaluation, and how long it took to take action to make an appointment. Then questions focused on what reasons the action to make an appointment may have been postponed, such as economical or insurance reasons, emotional or physiological reasons, reasons regarding lack of knowledge, or other explanations that are not yet identified.

The survey then followed up on details to participants' responses and looked in depth to psychosocial, economical, knowledge, and other reasons, that the participants had for delaying their initial appointment. There were multiple choice questions, based on literature review on the subject, as well as short-answer alternatives if participants' experiences do not meet any of the provided choices. Once any initial barriers for the participants were recognized, there were then questions directed to getting a diagnosis and beginning treatments. Being able to pinpoint where patients were in their treatment or evaluation courses, and basic demographic information, allowed for a broad, as well as specific assessment and unique cross-reference to each individual case.

Relevant Variables

Economic and psychosocial were the independent variables as they were independent from infertility evaluation. However, infertility evaluation was the dependent variable because it "depends" on economic, psychological, and social factors. Whether infertility evaluation is sought is influenced by those factors.

Statistical methods and data storage

Excel software was utilized. Data was stored while being analyzed on a password protected computer. After the analysis was completed, data was secured in a locked area of Bethel University's Physician Assistant Program for a minimum of 5 years.

Reliability and validity

Researchers drafted the survey with the intent that it be understandable to all participants in the same context. We strived to create a study that can be repeated at another time or place and gain similar results. The survey created was taken and analyzed by a group of practicing providers to ensure its reliability.

Limitations

Some of the limitations to this study included the response rate to the survey. The response rate may be impacted by inconvenience due to lack of time to complete the survey. Other response rate limitations include the sensitive nature of the questions, and relatedly, participants not wanting to disclose such personal information. To avoid this, participants were instructed that they did not need to complete questions that they feel were too personal, which was communicated to them in the informed consent. However, even though the questions are personal, they will benefit others that are going through

similar medical situations. Limitations also included sample size and race and economic class variation, of participants due to the patient population at Metro Urology.

Conclusion

In this chapter the design of the study, instrument that were used for data collection, selection of participants, and the reliability and validity of the study were outlined and clarified. An outline of what methods were used to analyze data and how the data was stored was also presented and elucidated. In the next chapter the results of our data collection will be presented.

Chapter 4: Data Analysis & Results

Introduction

In this chapter, the analysis process of the collected data is explained. The results are also presented as numeric values and visual aids. In the following chapter, you will find the explanation of these results in context with the research questions.

Data collection was completed on November 31st, 2017. There were a total of thirty-three completed surveys (n=33) that were collected and used in the data analysis. The expected number of men to have an opportunity to complete the survey was 90 (n=90). This expected number and actual collected number gives this project a 36.67% response rate. The expected response rate was based on the average clinic work days by the physician within that two-month collection period, as well as the number of fertility appointments on average per day.

Statistical analysis was completed by using descriptive statistics. The data was compiled into Excel by the researchers. Excel was used to compute the statistics and overall analysis of the results. The data was entered in numerical form, with each number pertaining to a specific answer on the survey (i.e. A=1, B=2, C=3, etc.). This allowed for the Excel program to compute the values and for the researchers to easily find the corresponding values to each of the survey's questions. There were two sections in the survey that have corresponding sections in this chapter:

- Section one contained demographic information including age, salary, marital status, status of conceiving.

- Section two contained the 9 questions addressing the possible barriers that men may experience in seeking fertility evaluation. These barriers, as discussed throughout this research, are psychosocial and economical barriers.
    - Within the second section, question number ten was an optional comment section for respondents regarding their subjective experiences. These comments will be discussed later as they pertain to certain barriers in the research questions.

There were six surveys that did not have any demographic information completed. These six surveys were otherwise complete, and still considered valid for the remainder of the research analysis. They were used in the calculation of data regarding fertility barriers; they were however excluded from demographic calculations. The reasoning for this was that although the demographics are important to help generalize findings in specific populations, this research is focused solely on the barriers to seeking fertility evaluations. The demographics were an addition to the survey to see if there were any patterns or correlations between demographics and specific barriers, but is not the aim of this research. The correlations made between demographics and barriers to seeking fertility treatment would be useful for a follow up study, and in that case those six surveys would be excluded.

Demographics Analysis

The demographic results calculated here are with a total of twenty-seven surveys. As stated before, the six surveys in which participants did not complete the demographic

information, have been omitted from the calculations, and represented in the graphs as "no answer".

The mode age group of participants was thirty-one to forty years old, this accounted for 70.37% of the respondents. There were 14.81% that were between the ages of twenty-five and thirty. There were 14.81% that were greater than forty years old. No respondents marked the ages of eighteen to twenty-four years old. With six surveys missing demographic information we cannot assume that there was no one in this age group taking the survey. However, we can still assume the true mode age of participants was thirty-one to forty years old.

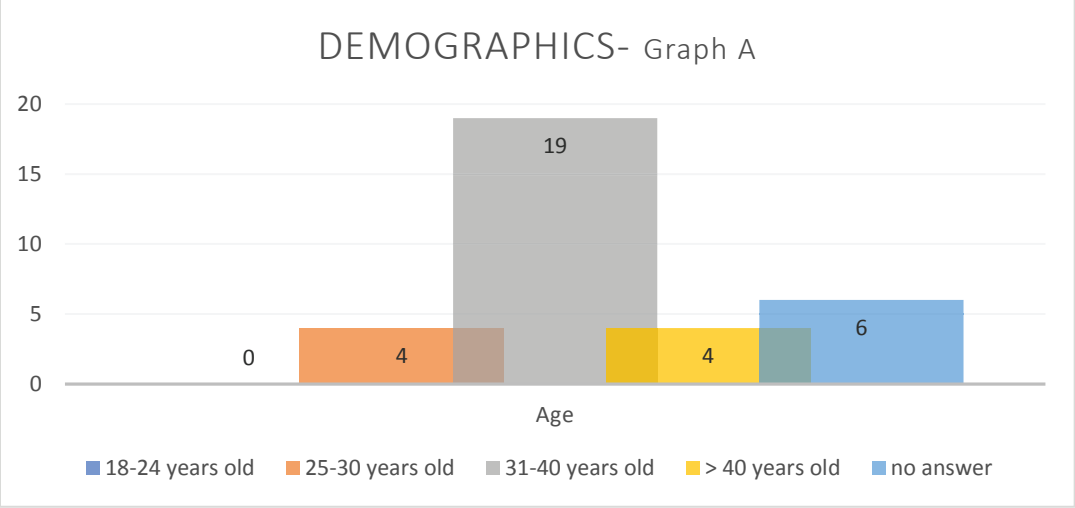
The mode salary made by those taking the survey was $40,000 - $60,000 annually. 37.04% of the respondents fell within this income category. 29.63% of the participants reported to having an income greater than $100,000 annually. According to the 2014-2015 report by the United States Census Bureau, the average calculated income for men (full-time, year-round employment) was $51,212/annually (Proctor, Semega, Koller, 2016) This is consistent with the respondents' answers.

Most common relationship status of those who participated the survey is married, accounting for 96.30%. Those not married but currently with a partner was 3.70%. This again being calculated from twenty-seven surveys total, omitting five without demographic information.

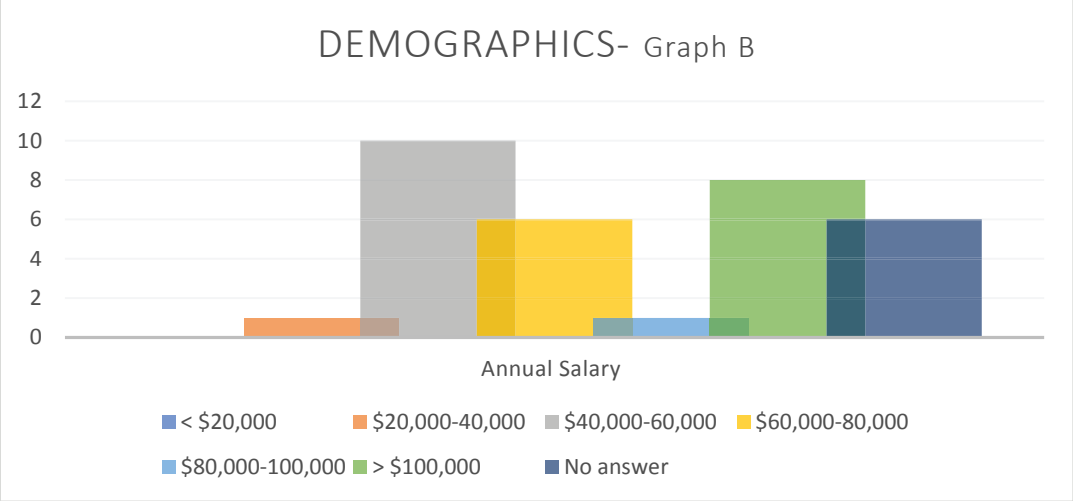
Most common status of conceiving among the survey participants is that they were actively trying to conceive; 96.00% of respondents fell into this category. The other 4.00% who answered this question were not actively trying to conceive at the time the survey was taken. This leaves open some questions as to whether or not they were

planning on actively trying in the near future or if they had been actively trying in the recent past. This is something in general to consider, although does not change the course of this study.

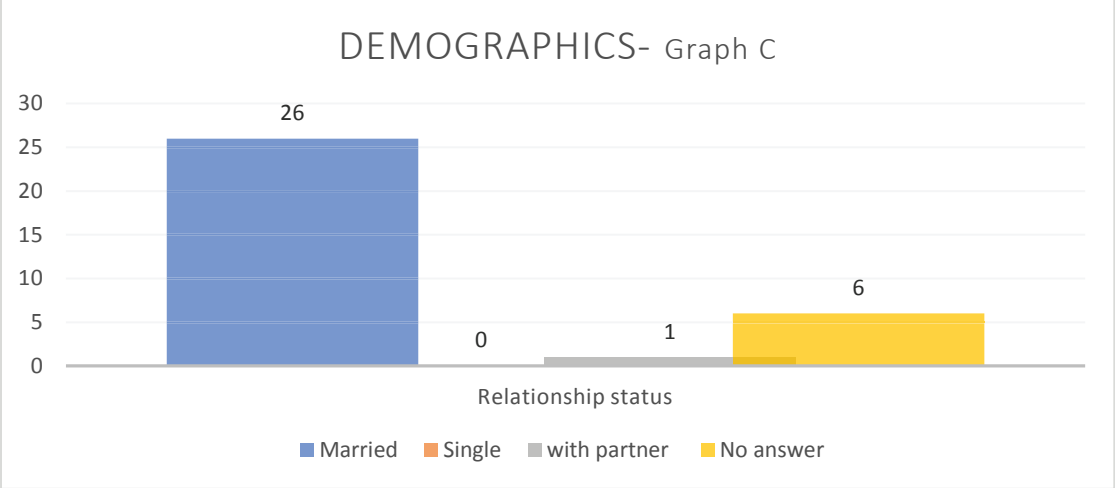
The majority, 62.96%, of the participants had been trying to conceive for 1-3 years. Participants trying for less than one year were the next highest occurrence, at 22.22%. There were 7.41% of participants who reported trying for greater than five years, and 3.70% who stated they had been trying to conceive between three and five years.



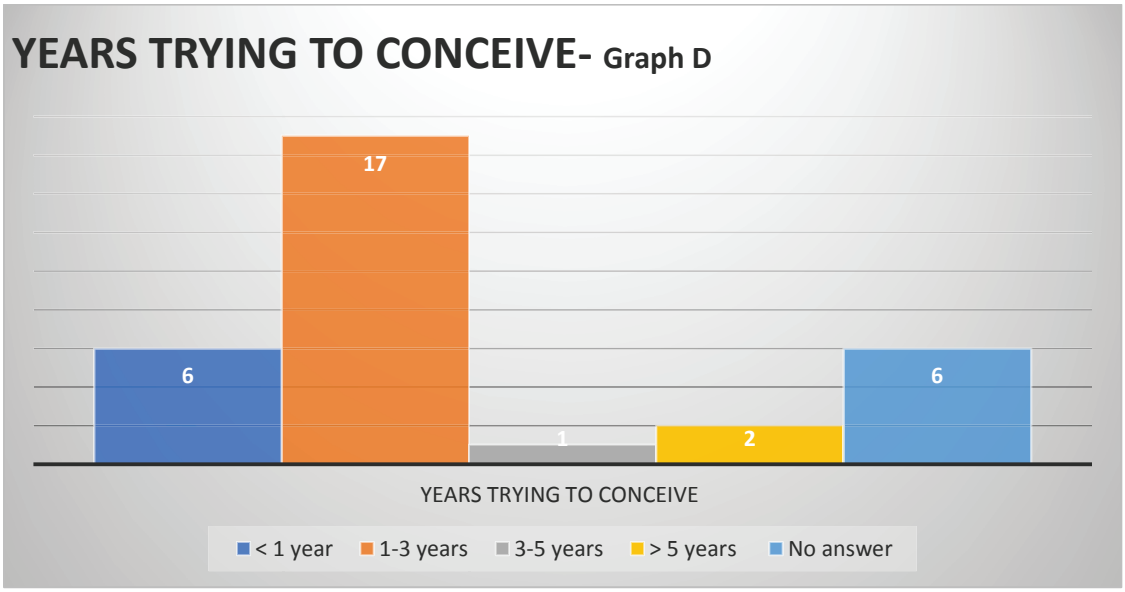
Graph A. [Representing the survey answers relating to age.]



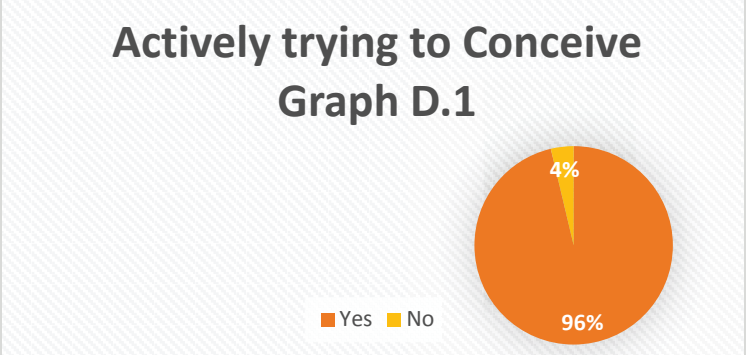
GRAPH B. [Representing the survey answers relating to annual salary.]



GRAPH C. [Representing the survey answers relating to relationship status.]



Graph D. [Representing the survey answers relating to years the respondent has been trying to conceive. Smaller graph represents the status of trying to conceive.]

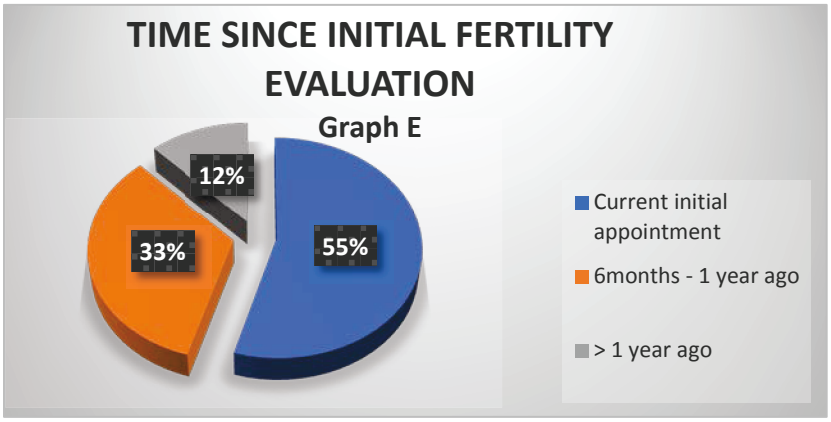


Graph D.1 [Representing the number of participants who were seeking a fertility evaluation during the time in their life they were actively trying to conceive children.]

Fertility Barriers Analysis

Participants were asked a total of nine questions that pertained to specific barriers to be identified. Two questions were focused solely on economic barriers, including cost of evaluation, insurance coverage, cost of treatments. Three questions were made to address multiple barriers at once. Participants could answer multiple choices in relation to their personal experience. The answers were created to include choices of both economic barriers, as well as psychosocial barriers.

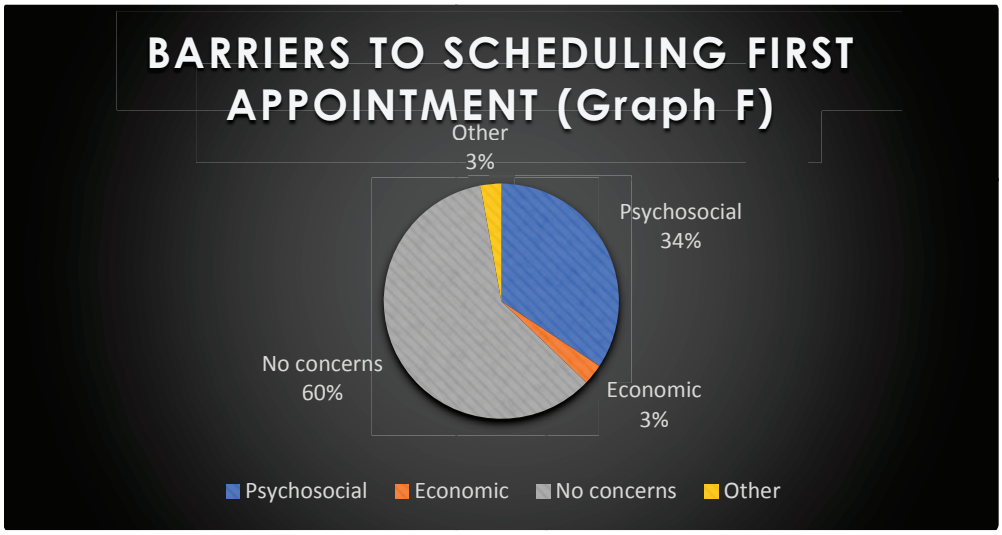
The majority (55%) of the participants were attending their initial visit the date their survey was taken. There were 33% who had had their initial fertility appointment between six months and one year ago. Finally, 12% of participants had their initial evaluation greater than one year ago. The breakdown is illustrated in the graph below



(Graph E).

Graph E [Represents the time since initial fertility appointments in comparison to the day of their participation.]

When scheduling the first fertility appointment, 60% of participants stated that they had no hesitation in making their first appointment. The remaining 40% presented with some type of barrier in making their first appointment. Psychosocial reasons (being worried about the evaluation results, and being worried/nervous about spouse reaction to results), accounted for 34% of responses. Economic reasons, (insurance coverage and costs of tests and appointment), accounted for 3%. This breakdown is represented in

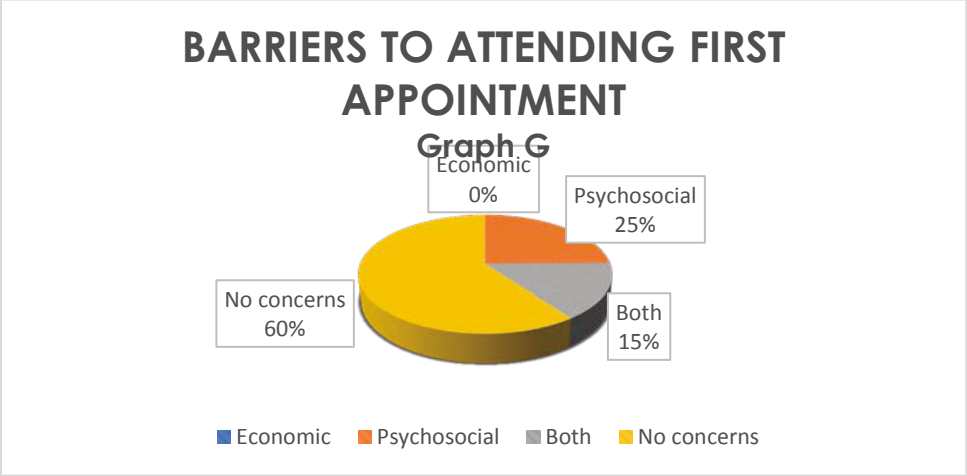


Graph F.

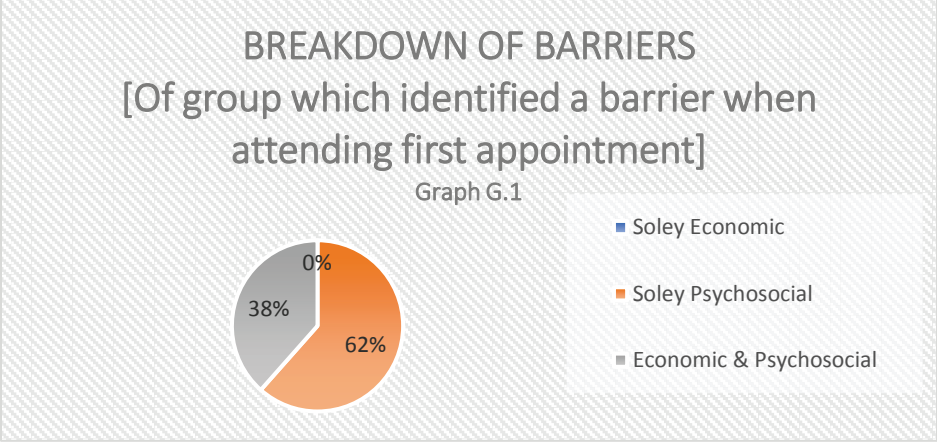
Graph F [Represents the barriers faced to scheduling an initial fertility appointment.]

Participants were also asked to state if they were nervous/worried about attending their first appointment. The majority (60.61%) stated they were not worried or nervous. The other 39.39% answered that they were worried/nervous about attending their first appointment. Out of those 39.39% of participants, they answered the subsequent question pertaining to “why” they were worried/nervous. The answer choices were categorized by the researchers into ‘Economic’ and ‘Psychosocial’ answers and grouped accordingly. Participants could select multiple answers if necessary. Therefore, the data was analyzed

into groups of ‘Economic Only’, ‘Psychosocial Only’, and ‘Economic and Psychosocial’. The most common response (62%) was an answer pertaining to a psychosocial denotation. This included a choice of A, B, D, and/or E on question number five in the survey (Appendix B). If a respondent chose any of the above options along with option C, they were included in the 38% those with ‘Economic and Psychosocial’ barriers.



Graph G [Represents the breakdown of barriers to attending the first appointment]



Graph G.1 [Represents the barriers presented to those who stated they were worried/nervous about attending their first appointment.]

Conclusion of Data

This chapter outlined the findings and relating statistics to this research project. Included in this chapter is graphical representation of the data has a thorough explanation of the data collected. Represented in graphical form were the demographic findings of age, income, and relationship status. The barriers to fertility evaluation that have been addressed were also presented in graphical form. These were categorized into the following: psychosocial barriers, economic barriers, no barriers, and barriers that fell into categories other than psychosocial and economic. Barriers that fell into a category other than economical and psychosocial will be briefly explained in the next chapter.

Chapter 5: Conclusion

Introduction

In the conclusion of this project, the data is presented as it relates to the research questions. The purpose of this study was to determine the barriers (psychosocial and economic) that men face when seeking fertility evaluations. To accomplish this, it was essential to explore the infertility evaluation in its entirety. This included barriers that may present when making the initial appointment, and barriers that may present when

attending the initial appointment. The novel survey (Appendix B) was distributed to patients seeking a fertility evaluation. Results were analyzed (refer to Chapter 4 for details regarding data analysis), and pertinence was correlated to this project's research questions:

1.) Do barriers exist to men seeking a fertility evaluation?
2.) If there are barriers, what types of barriers (psychosocial, economical, or other) are present?

This chapter divulges the conclusions and recommendations that resulted from this study.

Presence of Barriers

The first question is to identify if there are any barriers that men face when seeking a fertility evaluation. The majority (60% respectively) of participants stated that they were not worried or nervous about scheduling or attending their first appointment. However, this still leaves 40% (respectively) of respondents that were worried or nervous about scheduling or attending their first appointment. Although it was not the majority, it still represents that at least one third of the sampled population identify some type of barrier to seeking their fertility evaluation.

Type of Barriers

The second research question is to identify the type of barriers (psychosocial, economical, or other) that men confront when seeking fertility evaluations. The following percentages were then calculated from the 40% of participants that identified a barrier being present. The data gathered showed a relative degree of patients who had a psychosocial barrier to attending their first appointment, accounting for 34% of

participants who identified a barrier. The survey had multiple answers and questions that were categorized as psychosocial. The 34% of participants that identified the presence of a barrier, identified one of the following as their psychosocial barrier: being worried about the evaluation results, and being worried/nervous about spouse reaction to results, worried/nervous about the examination expectations, worried/nervous about having to tell others about an infertility diagnosis, worried/nervous about the negative stigma associated with male infertility.

In finding that 34% of the participants who identified a barrier, felt some sort of psychosocial barrier, was consistent with the literature review that was available. As outlined in the second chapter (Literature Review), the conclusion was that men are negatively affected by psychosocial strains attached to infertility. One of the biggest presentations of psychosocial stresses found in the literature, was the stigma that male factor infertility is directly related to sexual dysfunction. Those that participated in the survey and stated they were nervous/worried about the negative stigma are most likely referring to this common stigma. This would be an opportunity for a follow up exploration to categorically define what other stigmas are attached to male factor infertility. Keeping people educated on the causes of male infertility and breaking the stigma that it is simply a sexual dysfunction may help decrease this barrier for men seeking evaluations.

With healthcare costs and plans constantly changing, and variability in the coverage for fertility medicine, it was surprising that 97% of participants did not identify any economic barriers to scheduling their first appointment. Found throughout literature review, infertility comes with high out-of-pocket costs, as well as expensive treatments

and interventions. The large gaps in insurance coverage for infertility were thought to be a large barrier to seeking evaluations. However, 0% of the participants identified solely an economic barrier for attending their first appointment. Although 38% did have economic concerns along with their psychosocial concerns. These barriers included: cost of lab work, office visit, treatments if needed. Other economic barriers to be identified were: uncertainty about insurance coverage or knowing insurance does not cover the evaluation. Participants did identify these economic barriers as co-existing with their psychosocial barriers. In the open comment section an unidentifiable participant stated, "It was challenging to deal with the ambiguity of the results and unknown costs." This perfectly represents the co-existing barrier between psychosocial and economic.

However, it was interesting that none of them presented with a solely economic concern when attending their first appointment. This helps conclude that although there are many gaps in healthcare coverage and many uncertainties in fertility coverage through healthcare, it does not seem to be the main barrier that men face when seeking their evaluation.

If participants did not think an answer to a question was appropriate to their situation, they were given the opportunity to fill in any other concerns that they may have had when seeking their evaluation. This gave the research an opportunity to reveal any other barriers that may allow for further follow up and research. Although only 12.12% of participants provided any supplemental concerns, 75% of those presented with the barrier of time and limited resources for them. This included the ability to find fertility specialists, as well as the wait time to get in for appointments. It was also mentioned that limitation of specialists required travel that may have been difficult for the patient.

Moreover, guiding the steps for advancement in the care by providers who are aware of these barriers for these patients is an important step in moving forward in healthcare. This holds true to what Fischer stated in 2009, "To date, investigations of the experiences of infertility have focused disproportionately on women, and the short- and longer term psychosocial consequences of male factor infertility for men have been less thoroughly examined." (Fisher, 2009 p. 574). In doing this research, an important foundation has been initiated and the missing gap in male infertility is beginning to be filled. Although it is imperative to continue these studies and look further into the barriers more specifically, this will hopefully induct more sensitivity for males experiencing fertility evaluations.

Limitations

In reflecting on the data brought forth, it is apparent that the response rate was an indeed limitation. The reasons that the response rate may have been smaller than desired is multifactorial. The sensitivity of the subject may have been a deterrent for participants. Most of the survey participants did not identify as being nervous/worried about their appointment. This could possibly help conclude the fact that those who were nervous/worried may have not given priority to the survey at that time.

Another factor in the limitations of the sample size, was the surveys were distributed to the patients of one provider (Dr. Aaron Milbank) at one clinic (Metropolitan Urology). This put dependency on the provider's schedule and patient load. The provider is available for appointments other than male fertility evaluation, therefor the number of fertility appointments during the period of survey distribution could have varied quite a bit.

The last and possibly most minimal factor is staffing resources. The surveys were distributed to patients at the beginning of their appointments. The survey purpose, confidentiality, and directions were briefly discussed. Specific staff working with the provider were responsible for distribution and explanation to the participants. Due to busy clinic schedules and limited resources, it may be possible that not all patients received a survey due to time constraints or other restrictions.

Recommendations for Future Research

The following recommendations are offered for related research in the barriers faced by males seeking evaluation for infertility:

1. Distribution of the survey can be changed in multiple manners to allow a greater response rate. The following are options for this adjustment:
    a. Survey distribution at multiple clinics, with multiple providers
    b. Survey distribution to mass participants through an online resource
    c. Survey collection length could be extended
2. Comparison of demographics and barriers that are faced by those men. This would be able to analyze and find any connections between specific barriers and age groups and income.
3. Addition of race or religious demographics to the survey to create a basis for comparison of race/culture/religion to barriers that are confronted. This may be helpful in divulging if there is a link between specific barriers and cultural views on infertility.

4. Further investigation into what the public education is on male infertility. Divulging if it is a historical or present idea of a stigma, and if public education in the subject is where it should be. This may help in steering education of male infertility to the public, and possibly decrease the stigma barrier for men to seek their evaluations.

Conclusion

The following two research questions guided this project:

1) Do barriers exist to men seeking a fertility evaluation?
2) If there are barriers, what types of barriers (psychosocial, economical, or other) are present?

Without doubt, men do identify barriers to seeking their fertility evaluations. The most present barrier is that of psychosocial nature. Although much more can be done to consider the specifics of these barriers, this research project was created to identify their presence. The literature review that was done for this project was in line with the findings of the survey. Psychosocial barriers, including negative social stigma, fear of testing results, fear of reveling testing results to spouse, family or friends, were found in literature and were also a finding throughout the survey from participants.

Although economical barriers were represented to be much more minimal then expected from this project's literature review, they were still present, in most as co-existing factors with the psychosocial barriers. It is known from this survey that economical obstacles were not the main concern for men seeking fertility evaluations, despite the limited coverage and healthcare breaches for fertility care.

This research was able to achieve its purpose and shed a light on the presence of barriers that men may face when seeking a fertility evaluation. The project was able to compile information from the thirty-three participants and identify that the 40% (respectively) of participants admitted to experiencing a barrier when seeking their evaluations. The most common concern was those of psychosocial meaning. Woven in with psychosocial barriers, many identified an economical component with this. Overall, the presence of barriers is very real, and the focus on psychosocial majority, gives further research opportunities to examine psychosocial events that plague men in regard to fertility.

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APPENDIX A
INFORMED CONSTENT

Fertility Barrier Research Informed Consent

Dear Patient/Participant,

We are two physician assistant students from Bethel University, conducting research in partial fulfillment of the requirements for a Master's Degree in Physician Assistant Studies. By performing our study, we hope to learn more about the factors that hinder patients from seeking a fertility evaluation. Minimal research has been performed in this area. It would be of great value to the medical community to understand barriers to care as a first step towards addressing them.

The questions that you answer will be anonymous (your name will not be attached or recorded anywhere on the form) and will only be used for research purposes. It is understood that the topic of fertility is a personal topic, but you are encouraged to answer all the questions. This will allow us to gain more information from the study. We really appreciate your input and help with this project.

Attached is a survey with questions about how you came to this point in your fertility evaluation. The survey should take approximately 10-15 minutes to complete. By completing this survey, you are indicating informed consent to participate in this study. Reports and subsequent data will not discuss individual responses and will include only grouped data.

We understand that your time is valuable and may be limited. Please realize that your participation is vital to the success of this research. The information that you provide is essential to the validity of this study. Thank you in advance for your prompt response to this study. Please complete the survey by 11/XX/2016.

If you have any questions, please contact Cynthia Konrath (cyh49465@bethel.edu) or Ashton Makwana (asm53872@bethel.edu), or the Faculty Chair Christy Hanson (XXXXXXXXX).

Thank you again for your help.

Sincerely,

Cynthia Konrath & Ashton Makwana

By continuing with this voluntary survey, you are acknowledging that you understand your answers are anonymous and you are giving your informed consent for us to use your responses in this study. You are also acknowledging that you are 18 years of age or older.

APPENDIX B
SURVEY

Fertility Evaluation Barriers Survey

Background Information:

Age: (circle one)

18-24 years old

25-30 years old

31-40 years old

>40 years old

Annual salary/income: (Circle one)

Less than $20,000

$20,000-$40,000

$40,000-$60,000

$60,000-$80,000

$80,000- $100,000

Greater than $100,000

Relationship Status: (Circle one)

Single

Married

With partner

Are you actively trying to conceive?

Yes or No

If yes, how many years trying to conceive? (Circle one)

Less than 1 year

1-3 years

3-5 years

Greater than 5 years

Fertility Evaluation Progress

Please answer the following questions with the best answer that fits your experiences. If more than one answer applies please circle all. If none of the answers apply, please use the "other" space provided to briefly explain/state an answer.

1. **When was your *initial* fertility evaluation?**
    a. Today's appointment is my initial fertility evaluation.
    b. Greater than 6 months ago, but less than 1 year ago
    c. Greater than 1 year ago

2. **What was the main reason you decided to come in for your *initial* evaluation?**
    a. I have family history of **male** fertility complications.
    b. I have a known diagnosis of infertility.
    c. My spouse/partner encouraged me to get a fertility evaluation.
    d. I made the personal decision to have a fertility evaluation.
    e. I have had an abnormal semen analysis in the past.
    f. We have attempted to conceive without success for ____ years, and evaluation is the next step for us.
    g. Other: (post-vasectomy, history of mumps, testicular cancer, radiation, chemotherapy, or injury, etc.)

3. **Were there any reasons that you were worried/nervous about scheduling your *first* appointment?**
    a. I was worried about the results of an evaluation.
    b. I was worried about how my spouse would react to results of my evaluation.
    c. I was hesitant to schedule my appointment due to economic reasons/insurance coverage for fertility appointments/tests.
    d. I was not hesitant to make my first appointment.
    e. Other

4. **Were you worried/nervous about attending your *first* appointment?**
    a. Yes
    b. No

5. If yes, why?

a. I was worried/nervous about knowing the results of testing/medical findings.

b. I was worried/nervous about the examination.

c. I was worried/nervous about the cost of the fertility evaluation.

d. I was worried/nervous because I didn't know what to expect from the exam/testing.

e. I was worried/nervous about not being able to communicate effectively with the provider (due to language barriers or hearing difficultly/speech or other disability).

f. Other:_____

6. If you were worried/nervous about the <u>cost</u> of the fertility evaluation, what statement best applies?

a. I know my insurance doesn't cover the fertility exam.

b. I do not have insurance.

c. My insurance covers only a small part of the exam, and my portion is still expensive.

d. I do not know what my insurance does/does not cover.

e. Other: _____

7. Before going to your *<u>initial</u>*** appointment, what would you say your education level was on the process of the fertility evaluation?**

a. No education at all.

b. Some education from family/friends that have had a fertility evaluation in the past.

c. Some education from online/other sources that I looked at prior to my appointment.

d. Higher education on the subject (through work experiences, schooling or other)

e. Other:_____

8. When making your <u>initial</u> appointment what economical component were you most concerned about?

a. Cost of lab work.

b. Cost of office visit.

c. Cost of any treatments if they were needed.

d. I was not concerned about costs.

e. Other:_____

9. Which of the following situations did apply to you when <u>scheduling</u> your *initial* appointment? (Please circle <u>ALL</u> that apply.)

a. I was worried/nervous about cost of services and/or treatments.

b. I was worried/nervous about having to tell my partner/family/friends about an infertility diagnosis.

c. I had neither positive nor negative feelings pertaining to the initial appointment.

d. I was unsure of transportation to/from my appointment.

e. I was concerned about effective communication with the provider, due to language barriers, hearing/speech difficultly or other disability.

f. I was worried/nervous about the negative stigma associated with male infertility.

g. Other:
_____

10. Please provide any comments that you are willing to share about anything you found difficult when seeking your *<u>initial</u>* fertility evaluation.

_____
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