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Grief, Loss, and Sexually Transmitted Infections

by

Erin E. Blase, LSW

MSW Clinical Research Paper

Presented to Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, MN

Master of Social Work

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Jessica E. Toft, Ph.D., MSW
Benjamin Wolf, MSW, LICSW
Jan Boehlke

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract**Grief, Loss, and Sexually Transmitted Infections**
By Erin Blase, LSW

Research Chair: Jessica Toft, Ph.D., MSW

Committee Members: Benjamin Wolf, MSW, LICSW; Jan Boehlke

Having a sexually transmitted infection (STI) affects people of all ages, races, and cultural backgrounds. Being diagnosed with an STI has implications across the lifespan. The purpose of this study was to examine the effects of grief and loss on having a sexually transmitted infection and how these effects manifest across the lifespan of an individual. Using a mixed-methods design, ten individuals responded to an anonymous Qualtrics survey and answered a series of questions related to grief, loss, and having an STI. Data was analyzed using descriptive and open-coding techniques from the survey responses and then linked to the existing literature. The findings indicated that the majority of respondents experienced some type of loss related to having an STI, as well as stigma from society. Also, the findings indicated that several of the respondents experienced some type of positive growth and change as a result of being diagnosed with an STI. These findings outline the need for further research in this area to develop effective social work intervention strategies on a micro, mezzo, and macro level.

Acknowledgements

I would like to acknowledge and thank my research chair, Jessica Toft, and my committee members, Jan and Ben, for guiding me through the research process. I am also grateful to my family, friends, and colleagues for supporting me during this endeavor.

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Grief, Loss, and Sexually Transmitted Infections

Introduction

Sexually transmitted infections (STI's) are a common phenomenon that affects people on a global scale. STI's have existed for millions of years; epidemics are mentioned in documents as early as the Old Testament (Burg, 2012). While there used to be only a small number of STI's, there are now dozens of types and subtypes. According to the Medical Institute for Sexual Health (2013) there are 27 different types of viral, bacterial, ectoparasitic, and protozoal sexually transmitted infections.

A sexually transmitted infection is generally acquired through sexual contact by organisms that are transferred from person to person through blood, semen, vaginal fluids, or other bodily fluids (Mayo Clinic, 2013). Some infections can also be transmitted non-sexually, such as from mother to child during pregnancy, sharing needles, or through blood transfusions (Mayo Clinic, 2013).

Sexually transmitted infections impact each gender, age group, economic group, and ethnic group. Young people, ages 15-24, represent nearly half of all newly diagnosed STI cases and women often experience greater health issues due to STI's as compared with men (Office on Women's Health, 2009). Having a sexually transmitted infection affects a person both physically and emotionally; grief and loss issues are often associated with an STI diagnosis. People who contract an STI often face stigma from society, shame from peers and family members, and are blamed for the healthcare costs to treat STI's (Earnshaw, Bogart, Dovidio & Williams, 2013).

Over 110 million people in America are living with an STI (Center for Disease Control and Prevention, 2013). According to a study conducted by the Center for Disease Control in

February of 2013, over 20 million new cases of sexually transmitted infections are reported each year (Center for Disease Control and Prevention, 2013). STI's are divided into two categories: curable and non-curable. Bacterial STI's are curable and include chlamydia, gonorrhea, bacterial vaginosis, chancroid, chlamydia, donovanosis, lymphogranuloma venereum, genital mycoplasma, syphilis, treponematosi, endemic, public lice, scabies, candidiasis, vulvovagina, amebiasis, cryptosporidium, giardiasis, and trichomoniasis (Medical Institute for Sexual Health, 2013).

Incurable STI's include cytomegalovirus, Epstein Barr virus, hepatitis A, hepatitis B, hepatitis C, hepatitis D, herpes simplex virus (HSV-1 and HSV-2), human immunodeficiency virus (HIV), human papillomavirus (HPV), human T-cell lymphotropic virus (HTLV-1), and molluscum contagiosum (Medical Institute for Sexual Health, 2013). When first diagnosed with an STI, one's reaction may vary if the infection is curable or non-curable.

The significance of sexually transmitted infections on persons is apparent. Often, STI symptoms are silent and many people are unaware of being infected, thereby increasing the chances of passing along the infection to another person. Citizens who are diagnosed with a sexually transmitted infection, however, have to cope with physical and emotional ramifications.

Common physical symptoms of having an STI involve itching, burning, headaches, weeping sores, and swelling (Center for Disease Control and Prevention, 2013). Having an STI may also inflict emotional burdens. According to McLarnon and Kaloupek (1988), people who have genital herpes experience a sense of social isolation, periodic episodes of depression, fear of rejection, and faulty ideas about themselves. Citizens with an STI may also have difficulty in establishing and maintaining romantic relationships.

Besides experiencing physical and emotional consequences, having an STI often comes with grief and loss issues. Reactions may vary if the STI is treatable or non-treatable. People who are diagnosed with an STI may be faced with the loss of health and fertility, loss of stable romantic relationships, rejection from romantic partners, loss of trust in relationships, and loss of dreams for the future (Boss, 2006).

Societal stigma is also associated with having an STI. Since the early days of the HIV/AIDS epidemic, those suspected of having the infection have been subjected to social ostracism, violence, and discrimination (Herek, Capitanio & Widaman, 2003). Stigma is often an unfortunate factor that accompanies an STI diagnosis. People who are diagnosed with an STI may have to endure ridicule and insensitive comments from peers, judgment from religious organizations, and scrutiny expressed by the media.

Society has progressed in the last several decades to become more accepting of HIV/AIDS. There are foundations to sponsor research, walks, and to raise funds to find a cure for AIDS as the stigma has lessened. However, STI's such as genital herpes and Hepatitis B lack sound support and financial backing to seek a cure. Recently, the Fred Hutchinson Cancer Research Center, together with scientists from the University of Wisconsin, conducted a study which identified immune cells which suppress the herpes virus; this discovery may lead to a vaccination to prevent the spread of genital herpes (Fred Hutchinson Cancer Research Center, 2013).

Having a sexually transmitted infection also carries financial weight. The cost of having a sexually transmitted infection upon the American health system is estimated to be over \$15 billion (American Sexual Health Association, 2013). In the ever-changing sphere of healthcare,

STI's have caused the medical community to take notice. Many community clinics exist for the sole purpose of offering free STI testing. Incurable STI's, such as HIV and HPV last for a lifetime and are the most expensive to treat; The Center for Disease Control states the cost of treating the eight most common curable STI's to be over \$742 million (Center for Disease Control and Prevention, 2013).

Sexually transmitted infections affect every gender, age group, and ethnic group. Having knowledge of sexually transmitted infections is important for social work as STI's do not discriminate; having an STI can affect people who are young, old, gay, straight, or transgendered. Demonstrating awareness of cultural values and differences will aid social workers in serving clients of different ethnic backgrounds diagnosed with an STI. According to the National Association of Social Worker's Code of Ethics, social workers are bound to see the value of each person, understand the importance of human relationships, and display competence in practice; clients who experience an STI will benefit from being served by a social worker who employs these ethical principles (National Association of Social Work, 2008).

The purpose of this study is to explore in what ways people experience grief and loss after being diagnosed and how people live with a sexually transmitted infection. The current study examines the relationship between the diagnosis of a sexually transmitted infection and grief and loss. The wide-arching effects of sexually transmitted infections will be explored using lenses of culture, age, and sexual orientation.

Literature Review

Sexually Transmitted Infections

Current research related to sexually transmitted infections focuses on defining STI's, condom usage, age, and how gender roles influence sexually transmitted infections. The current research also examines how age and culture influence the acquisition of an STI, stigma, intervention and treatment strategies, the influence of chemical use on obtaining an STI, and the disclosure of STI status.

Sexually transmitted infections are divided into two categories: curable and non-curable. STI's are a variety of bacterial and viral infections that are passed from one person to another during vaginal, anal, or oral sexual activity (Boston Women's Health Book Collective, 2011). STI's are spread through several means, such as vaginal fluids, semen, anal secretions, and discharges from sores caused by STI's (Boston Women's Health Book Collective, 2011). Common curable STI's are caused by bacteria and include syphilis, trichomoniasis, chlamydia, and gonorrhea (Barton & Coyne, 2007); incurable STI's are caused by a virus and include genital herpes and human immunodeficiency virus (HIV) (Boston Women's Health Book Collective, 2011).

Syphilis, caused by the spirochete *Treponema pallidum*, is classified as an epidemic in countries with high rates of congenital diseases, such as Africa, South America, and Southeast Asia (Barton & Coyne, 2007). Syphilis is transmitted through direct contact with syphilis sores and occurs most often during unprotected sexual activity (Boston Women's Health Book Collective, 2011). Stillbirths and genital ulcers are associated with syphilis, as well as passing

along the condition in utero; increasing rates of transmission among men who have sexual relations with men (MSM) is often attributed to unprotected oral sex (Barton & Coyne, 2007).

According to a recent study conducted in China among university students, the syphilis rates among MSM in Beijing is over 10%; findings suggest that younger MSM are at greater risk for contracting syphilis than older MSM, as this population is more likely to engage in high-risk sexual behaviors (Zheng, Wu, Poundstone, Pang & Rou, 2012). Over the past five years, 96% of syphilis cases have been reported among males with an average age of 42; 38% self-disclosed to also having HIV and 80% of case patients reported MSM risk behavior (Katz, Cadorna, Lee, Komeya, Kiaha & Ohye, 2009).

Trichomoniasis, caused by the single-celled parasite *trichomonas vaginalis*, is the most common curable STI in young women and manifests as a vaginal discharge; this condition can cause discomfort during intercourse, painful urination, and irritation of the genital area (Boston Women's Health Book Collective, 2011). In men, trichomoniasis symptoms may not be as obvious and can manifest as urethritis, mild discharge, burning after urination, and increases predisposition for HIV infection; this condition can cause low birth weight and preterm birth (Barton & Coyne, 2007).

Genital chlamydia infection is the most common bacterial STI in the developed world; The World Health Organization estimates that 92 million new cases of chlamydia are diagnosed each year (Barton & Coyne, 2007). Chlamydia is caused by the bacterium *Chlamydia trachomatis* and is a leading cause of early infant pneumonia and conjunctivitis (Boston Women's Health Book Collective, 2011). Chlamydia can cause adverse health effects for both men and women. In men, this bacterial STI can cause inflammation of the testes, Reiter's

syndrome, and infertility; in women, it can cause tubal factor infertility, chronic pelvic pain, pelvic inflammatory disease, and ectopic pregnancy (Barton & Coyne, 2007).

Gonorrhea is caused by the bacterium *Neisseria gonorrhoeae* and can grow and multiply easily in warm, moist conditions, such as a woman's reproductive tract (Boston Women's Health Book Collective, 2011). Gonorrhea can cause cervicitis, tubal factor pregnancy, pelvic inflammatory disease, ectopic pregnancy, and first trimester spontaneous abortion in women and can also cause urethritis and inflammation of the testes in men (Barton & Coyne, 2007). Gonorrhea can affect children as well as adults. If children are born with this condition, they may contract ophthalmic disease that may lead to corneal perforation and total blindness; gonococci infection also makes one more susceptible to contracting HIV (Barton & Coyne, 2007).

Generally, Herpes Simplex Virus (HSV) type 2 causes most genital herpes, whereas orolabial herpes occurs as a result of contracting HSV Type 1; this type usually occurs in childhood and manifests as cold sores (Barton & Coyne, 2007). Genital Herpes is spread through genital contact and causes warts and sores (Boston Women's Health Book Collective, 2011). Most people who have herpes do not know it, as the herpes virus can be asymptomatic (Boston Women's Health Book Collective, 2011). According to Mertz (1993), in addition to being asymptomatic, there is a chance the virus can be spread through asymptomatic viral shedding. This involves transmission of the virus when the infected individual is not currently experiencing a herpes breakout (Conley, Jadack & Hyde, 1997).

Herpes can have adverse effects on children as the virus can be passed along in utero; pregnant women who experience an outbreak during the last trimester are encouraged to have a

caesarean for delivery (Boston Women's Health Book Collective, 2011). Genital Herpes also contributes to the sexual transmission of HIV (Barton & Coyne, 2007).

According to the Center for Disease Control and Prevention, Human Papillomavirus (HPV) is the most common sexually transmitted infection in the United States; approximately 99.7% of cervical cancer is caused by HPV (Schiffner & Buki, 2006). Women who have yearly Pap tests that detect abnormalities in cervical cells before they become cancerous have an advantage in staying one step ahead of HPV; as HPV can be asymptomatic, college students are at higher risk if they have multiple sexual partners (Schiffner & Buki, 2006). Two vaccinations have been approved in the United States to protect against the two strains of HPV which cause most cervical cancers: Cervarix and Gardasil (Center for Disease Control and Prevention, 2013).

Human Immunodeficiency Virus (HIV) can lead to acquired immune deficiency syndrome (AIDS); as the virus can be spread from mother to fetus during pregnancy and childbirth, the Center for Disease Control and Prevention discourages HIV-positive women from breastfeeding (Boston Women's Health Book Collective, 2011). HIV is contracted through unprotected sexual contact or sharing needles during chemical use (Boston Women's Health Book Collective, 2011). According to Barton and Coyne (2007), urethritis, trichomonas, genital herpes, and syphilis increase the likelihood of contracting HIV. HIV is frequently associated with the concept of MSM. In a recent study conducted in China, MSM accounted for 14.7% of the 740,000 people thought to be living with HIV/AIDS (Zheng, Wu, Poundstone, Pang & Rou, 2012).

Condom Use

The use of condoms can dramatically reduce the transmission of STI's. While using a condom during sexual activity is not guaranteed to be 100% effective, it can lessen the chances of passing an STI to another person. Condoms are used by both men and women. While the evidence suggests that using a condom can help prevent STI's, there are also barriers to using condoms, including lack of knowledge of how to use them, age, cultural influences, gender bias, and lack of access to condoms. According to Corneille, Tademy, Reid, Belgrave & Nasim (2008), condoms used on a consistent basis is negatively associated with relationship length and trust; partner trust may diminish the thought that a partner has HIV/AIDS. The more one utilizes condoms, the less likely one's partner may suspect the other partner has an STI (Corneille, Tademy, Reid, Belgrave & Nasim, 2008).

According to Purdie, Norris, Davis, Zawacki, Morrison, George and Kiekel (2011), it is important to understand what influences women's ability to negotiate the use of a condom if their male partners are unwilling to employ one, as using a male condom is an effective way to prevent the transmission of HIV and other STI's. Helweg-Larsen and Collins (1994) found that American society has specific scripts for women and men in sexual encounters and as a result, gender roles are likely to be different regarding the casual dynamics of condom usage (Conley, Jadack & Hyde, 1997).

The age of a person can impact whether or not a condom is used during sexual activity. Data procured by Baldwin and Whiteley (1992), Buzi et al. (1998), Jemmott et al. (2002), and Sabogal, Perez-Stable and Hiatt (1995), show that only a small percentage of Latino college students report using condoms during intercourse (Schiffner & Buki, 2006). One reason for not

using a condom cited in this study was lack of knowledge on how to use one, which put the students at greater risk for contracting HPV because the women had to depend on their male partners, who may also be ill-informed about proper usage (Schiffner & Buki, 2006).

According to Hillman (2008), older adults are more likely to practice unprotected sex than younger adults due to a lack of knowledge and experience with condoms, coupled with a decreased fear of pregnancy. In a study performed by Cleary, Barhman, MacCormack and Herold (2002), reasons cited for not using a condom include embarrassment about asking to use one, the belief that using a condom was not necessary because other birth control methods were being used, and a fear of ruining the intimate moment. Many women also assumed their male partner would know how to use a condom and recognize the need for its use; many participants were not aware that condom use does not prevent the failure of condoms or guarantee protection from all STI's (Cleary, Barhman, MacCormack & Herold, 2002).

Prescribed cultural norms can also have an impact on condom usage. According to Gil and Vasquez (1996), in Latin cultures, women are socialized to remain chaste and faithful to their partners (Schiffner & Buki, 2006). Morris, Lusero, Joyce, Hannigan and Tucker (1989) found women are to refrain from openly discussing sexual issues (Schiffner & Buki, 2006). Due to such cultural expectations, it can be difficult for women to negotiate condom usage. Furthermore, college students feared if they were seen picking up condoms at the student health center, their reputation within the Latino/a community would be tarnished (Schiffner & Buki, 2006).

Previous research indicates that if a woman believes a man to be likeable, he must not have an STI; therefore, women do not insist that a man wear a condom (Purdie, Norris, Davis,

Zawacki, Morrison, George & Keikel, 2011). In a study conducted by Purdie, Norris, Davis, Zawacki, Morrison, George and Kiekel (2011) to investigate the consumption of alcohol and partner risk on how women make sexual decisions, researchers concluded that the more women desired sexual intercourse, the stronger she believed in the benefits of not insisting that the man use a condom. Furthermore, if women lack information with which to gauge a man's sexual risk, they may not assign any risk to him, especially when drinking alcohol (Purdie, Norris, Davis, Zawacki, Morrison, George & Kiekel, 2011). Alcohol impairs judgment and may make a woman more likely to engage in risky sexual activity, such as not insisting that a man wear a condom.

In a study performed by Corneille, Tademy, Reid, Belgrave and Nasim (2008), there were several reasons for using condoms, including pregnancy prevention and to avoid contracting an STI during sexual encounters outside of the primary relationship. Other participants in the study cited using condoms due to not trusting women and their sexual histories (Corneille, Tademy, Reid, Belgrave and Nasim, 2008). Protection from STI's, the heat of the moment, increased sexual pleasure, and not being in a monogamous relationship were reasons cited for not using condoms (Corneille, Tademy, Reid & Belgrave, 2008).

Similarly, in a study performed by Cleary, Barhman, MacCormack and Herold (2002), many female participants reported no discussion about sexual health issues prior to sexual activity with a new partner. The participants who did have communication reported it was not substantial and was focused only on using a condom to prevent pregnancy; little attention was paid to discussing STI history, sexual histories, perceived HIV risk, or STI testing (Cleary, Barhman, MacCormack & Herold, 2002).

In a study conducted by Zheng, Wu, Poundstone, Pang and Rou (2012), the belief that it is not necessary to use a condom with a regular sex partner was a substantial predictor of unprotected anal intercourse. In another recent study related to young women and HPV testing, fewer participants reported that their partner would be equally responsible for a positive STI test result (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007). Participants tended to presume their male partner would be the source of the STI but would share the responsibility as they remained with the male partner, despite knowing he was not monogamous and did not insist he use a condom (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007).

Psychological Factors and Chemical Use

While there are numerous physical effects associated with having a sexually transmitted infection, psychological effects also exist. While STI's can cause unpleasant physical reactions, there are also emotional aspects to consider. An STI diagnosis can leave a person feeling isolated, depressed, angry, frustrated, unworthy, and lacking hope for the future. Stress may compound psychological reactions to an STI diagnosis and can be associated with other mental health disorders. Feelings of guilt and regret may also align with having an STI (McLarnon & Kaloupek, 1988).

Goldmeier and Johnson (1982) and Katcher et al. (1973) discovered that people suffering more from generalized anxiety, depression, or obsessions experience higher rates of recurrence of genital herpes outbreaks (McLarnon & Kaloupek, 1988). According to a survey conducted by the American Social Health Association of people with genital herpes, 70% of respondents reported feeling isolated and 84% experienced periodic episodes of depression (McLarnon & Kaloupek, 1988). Two recent studies conducted by Maissi et al. (2004) and McCaffery et al.

(2003) suggest that a positive HPV test in adults may lead to a significant increase in distress, anxiety, and concern about sexual relationships (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007).

Themes of guilt and regret are often attributed to individuals diagnosed with a sexually transmitted infection. The distinction between interpersonal harm and intrapersonal harm is important to note when discussing guilt and regret (Baumeister, Stillwell & Heatherton, 1994). Interpersonal harm is the basis for guilt when the harm is self-inflicted and intrapersonal harm is the basis for feelings of regret, as the harm was assigned to another person (Baumeister, Stillwell & Heatherton, 1994).

Guilt is described according to Baumeister, Stillwell and Heatherton (1994) as an individual's unpleasant emotional state associated with possible objections to his or her actions, inactions, intentions, or circumstances, and as regret over the wrong thing that was done (Zeelenberg & Breugelmans, 2008). A person who contracts an STI may feel guilty about contracting it and passing it along to someone else.

In a recent study related to the meaning of HPV test results in young women, over one half of the participants reported they would direct guilt upon themselves if their pap test was abnormal (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007). Reasons for feeling guilty focused on not taking care of themselves, not monitoring sexual partners, and not practicing safe sexual behaviors (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007). Elements of shame included a sense that the HPV diagnosis was a secret; participants stated they would not tell anyone, including their sexual partners, about their test results (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007).

Additionally, Baumeister, Stillwell and Heatherton (1994) report regret can be described as a more or less painful cognition and emotional state of feeling sorry for losses, limitations, shortcomings, transgressions, or mistakes (Zeelenberg & Breugelmans, 2008). A person who acquires an STI may feel regret about the circumstances surrounding the transmission, especially if it was contracted during an affair that occurred outside of a seemingly monogamous relationship. Another layer of regret may be added if one's partner becomes infected.

According to Dressler, Oths and Gravlee (2005) and Meyers (2009), psychosocial factors are associated with promoting risky sexual behavior, one being racial discrimination (Roberts, Gibbons, Weng, Simons, Simons, Gerrard, Murry & Lorenz, 2012). The negative influence of discrimination extends to risky sexual behavior, which could include exposure to STI's (Roberts, Gibbons, Weng, Simons, Simons, Gerrard, Murry & Lorenz, 2012).

Researchers Clark, Anderson, Clark and Williams (1999), Sanders-Phillips, Seattle-Reaves, Walker and Brownlow (2009) found that early discriminatory experiences are stressful and the emotional, cognitive, and behavioral responses to this stress stimulate maladaptive behaviors, such as risky sexual behavior (Pascow & Richman, 2009; Williams & Mohammed, 2009; Roberts, Gibbons, Weng, Simons, Simons, Gerrard, Murry & Lorenz, 2012). This study found African American youths who experienced more racial discrimination at age 10 were partaking in more sexual risk-taking behaviors eight years later. Stress can also have a profound effect on an individual's reaction to an STI diagnosis. Leserman (2003) found that chronic stress is correlated with faster HIV progression and a shortened rate of survival among people living with HIV (Cleary, Barhman, MacCormack & Herold, 2002).

The use of alcohol and other drugs can influence the acquisition of STI's. When under the influence of chemicals, individuals can make decisions about sexual activity that they would not make under normal circumstances. According to Purdie, Norris, Davis, Zawacki, Morrison, George and Kiekel (2011), the consumption of alcohol has been shown to influence aspects of sexual decision making, including risk perception, unprotected sexual intentions, condom negotiation skills, and appraisal of sexual potential.

Alcohol use affects decisions related to sexual activity by impairing judgment (Purdie, Norris, Davis, Zawacki, Morrison, George and Kiekel, 2011). In contrast with the previous study, researchers Corneille, Tademy, Reid, Belgrave and Nasim (2008), found more participants felt the use of alcohol or marijuana influenced their interactions with women and their decisions to have sex, rather than alcohol use, affected their choice to use condoms.

There are numerous ways to emotionally cope with an STI diagnosis. Initially, individuals may experience shock and be ill-prepared to deal with the news of diagnosis. Some people express their feelings while others avoid addressing their emotions. Rasera, Vieira and Japur (2004) found that initial reactions of shock, surprise, indignation, and sadness were expressed when study participants learned of their HIV diagnosis; many respondents recalled images of depression, death, hopelessness, and suicide. According to McLarnon and Kaloupek (1988), individuals who avoided talking, thinking, or ruminating about their herpes diagnosis fared better related to medical and psychological consequences.

Gender Roles and Cultural Factors for Women

Contracting a sexually transmitted infection manifests itself differently for women, whose unique reproductive systems, physical anatomy, age, and emotional make-up have an

impact on reactions to having an STI. Contrasting gender roles also have an impact on STI status for men and women. According to Scott (1988), gender is a constitutive element of social relationships based on perceived differences between males and females; gender is a means to identify relationships of power and control (Rasera, Vieira & Japur, 2004). Females experience their own set of unique issues related to gender roles, cultural factors, and contracting an STI.

Rates of sexually transmitted infections manifest differently among cultures. Ethnic disparities are evident among diagnoses of STI's with African Americans, Hispanics, and Native Americans who demonstrate higher rates of reported gonorrhea, syphilis and chlamydia than Caucasians, while Asian/Pacific Islanders demonstrating the lowest rates of reported STI's (Katz, Cadorna, Lee, Komeya, Kiaha & Ohye, 2009). Ethnic and racial minorities at risk of and living with HIV/AIDS are often subject to other stigmas, including transgender identity or expression, illicit drug use, prostitution, incarceration, and immigration (Cleary, Barhman, MacCormack & Herold, 2002). The rate of seeking medical treatment also varies among racial groups. According to Cleary, Barhman, MacCormack and Herold (2002), Latinos have the longest wait time between HIV diagnosis and treatment, followed by African Americans, with Caucasians having the shortest delay.

African American men and women are also disproportionately affected by the HIV/AIDS virus; this population accounts for 49% of new diagnosis with African American women and homosexual African American men being most affected (Corneille, Tademy, Reid, Belgrave & Nasmin, 2008). According to Ries et al. (2002), incidence rates of cervical cancer that can be caused by HPV are up to three times higher for Latinas and the rate of death is 50% higher for Latinas when compared to women from other ethnic groups (Schiffner & Buki, 2006).

Women who contract an STI may have limited financial resources, are more likely to be single parents, and may lack access to treatment (Boston Women's Health Book Collective, 2011). Economic status, traditional caregiving responsibilities, transportation issues, and a lack of knowledge about available resources may deter women from seeking treatment for an STI. According to the Center for Disease Control (1999), high levels of poverty, limited or no access to quality health care, a high prevalence of STI's, fear of deportation for undocumented workers and illicit drug use put minority groups at an increased risk for infection (Schiffner & Buki, 2006).

The age that a woman is diagnosed with an STI can have a profound effect on the rest of her life. According to Hillman (2008), the greatest increase in AIDS cases is among older, inner-city minority group women who are less likely to have access to health care, education, and resources for STI testing. As compared to younger women, older women are less likely to have knowledge about birth control measures and are less likely to discuss sexual matters with their physicians (Hillman, 2008).

In cultures that value independence and assertiveness, it may be easier for women to seek treatment services for STI's. However, in some cultures, women are encouraged to be submissive and hold a lower status than men. In such instances, it can be harder for a woman to refuse unwanted sexual activity, which can lead to unwanted STI's (Boston Women's Health Book Collective, 2011).

Families and partners of women who are diagnosed with an STI can react in a myriad of ways. According to Rasera, Vieira and Japur (2004), family members and partners of HIV-positive women viewed the women as striving, fighting victims coping with existence by finding

new arrangements and new relationships. Women diagnosed with an STI face an additional layer of reaction if the infection is passed to a child during pregnancy. Rasera, Vieira and Japur, (2004) found that women who place a high level on the importance of motherhood blamed themselves for passing the HIV infection along to their children; women in the study often felt God was punishing them and they experienced guilt during pregnancy.

For women who are socialized to avoid discussing sexual issues, a lack of knowledge may lead to misinformation. In one study, 70% of college-age participants did not have any knowledge about HPV and 80% did not know cervical cancer could be fatal (Schiffner & Buki, 2006). Furthermore, the participants admitted that the lack of discussions about sexual health, sex, and other feminine issues in their families hindered their ability to gain knowledge about sexual concerns (Schiffner & Buki, 2006).

Seeking STI testing may cause problems for women who are dependent on cultural values or religious backgrounds. In a recent study, Indian and Pakistani women reported such testing might raise suspicions because it is inconsistent with traditional and religious practices and women are presumed to be monogamous and not at risk for contracting STI's (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007). In addition, Caucasian British women reported taboos about sexual activity in traditional Catholic families which may discourage women from seeking HPV testing (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007).

Gender Roles and Cultural Factors for Men

The roles of gender and culture play a part in how men react to contracting a sexually transmitted infection. Ideas about sex and sexual experience are socialized into children from an

early age. According to Gil and Vazquez (1996), in some cultures, men are encouraged to be sexually knowledgeable and seek sexual contact at an early age, as in the Latino culture (Schiffner & Buki, 2006). Having HIV/AIDS can threaten a man's masculinity in Brazilian culture, as the infection means they are vulnerable, fragile, and possess less emotional and physical control over their lives (Rasera, Vieira & Japur, 2004).

Further research is needed to examine men's sexual health beliefs and behaviors related to how these correlate with women acquiring sexually transmitted infections, including HPV (Schiffner & Buki, 2006). Reactions to acquiring an STI can vary among the friends and family members of men. In a recent study examining gender and sexuality on HIV-positive status, men were thought to be in need of care after learning of the diagnosis and were unable to live by themselves (Rasera, Vieira & Japur, 2004).

Corneille, Tademy, Reid, Belgrave & Nasim (2008) found that African American men are more likely than men of other racial groups to become infected with an STI; due to higher rates of infection, every unprotected sexual encounter increases the risk for contracting HIV. Prejean et al.(2002) found that at the intersection of race, sexual orientation, and age, the rate of increase of new HIV infections among young African American men who have sex with men was 48% from 2006-2009, far higher than any other racial/ethnic group (Cleary, Barhman, MacCormack & Herold, 2002).

According to Corneille, Tademy, Reid, Belgrave and Nasim (2008), African American men who display strong affiliations with religious organizations and attend services regularly are less likely to practice risky sexual behaviors. In addition, therapists' open discussions with African American men about what it means to be masculine might provide men with increased

awareness of the correlation between sexual risk behaviors and overcompensating masculinity (Corneille, Tademy, Reid & Belgrave & Nasim, 2008).

According to Hunt, Myers and Dyche (1999), in a study involving male partners of HIV-positive women, a large percentage of the men presumed their risk of HIV infection to be low, even though the majority of respondents reported having regular unprotected sex with their HIV-positive partner. The study also concluded that men in seroconcordant couples (both partners have HIV) have higher risk histories and participate in more high risk sexual behaviors than men in serodiscordant relationships (men are HIV-negative and women are HIV-positive) (Hunt, Myers & Dyche, 1999).

Common misconceptions abound regarding men and sexually transmitted infections. In a study conducted by Rasera, Vieira and Japur (2004), it was thought that only homosexual men, and men who use illegal drugs, become infected with HIV and that virile men will not acquire HIV.

Age

The age at which one acquires an STI has an impact on one's future. Effects will vary if an STI is acquired in utero as compared to later in life. Rosenthal, Cohen, Biro, and DeVellis (1996) conducted a study to explore family reactions regarding STI acquisition among adolescent girls and concluded that girls who came from families that were more involved in their lives had more positive expectations about their parents' reaction to having an STI; these characteristics correlated to reduced-risk taking sexual behaviors. According to Donaldson, Whalen and Anastas (1989), adolescent girls who admit to feeling powerless and shame may

preclude a desire to seek closeness through risk sexual encounters that could result in sexual infection or pregnancy (Azzarto, 1997).

Older adults are not to be excluded from the examination of sexually transmitted infections. DeLamater and Sill (2005) found that older adults, people aged 65 and over, are maintaining moderate or high levels of sexual interest into their 70s (Hillman, 2008). Based on this finding, sexual activity can lead to the acquisition of an STI at an older age, even though the traditional view of sexuality in older adults is presumed to be negative (Hillman, 2008).

Relatively little data is available about the prevalence of STI's among older adults. According to available data, older adults account for 1.3% of all STI's, with genital herpes occurring most often for women and bacterial infection occurring for older men (Hillman, 2008). Growing concern for older adults acquiring HIV/AIDS is based on the fact that older adults are at an increased risk for antiviral medication side effects, HIV- associated dementia that can be misdiagnosed as Alzheimer's disease, and increased mortality (Hillman, 2008).

Stigma

The concept of stigma related to having a sexually transmitted infection appears frequently in the current literature. Stigma involves having negative feelings toward a particular group of people due to a shared characteristic, such as an STI. Stigma can be expressed both directly and indirectly through words, actions, and assigning negative labels to people who have an STI. Stigma can surround both curable and non-curable STI's. Cultural factors also influence the existence of stigma. How one acquired an STI can also have an impact on the type or amount of stigma displayed.

History abounds with examples of both hidden and expressed stigma. Goffman (1963) defines societal stigma as social devaluation and discrediting correlated with a personal mark, attribute, or characteristic, including ethnicity, race, or sexual orientation (Earnshaw, Bogart, Dovidio & Williams, 2013). Stigma can be structural and manifests as segregation, medical mistrust, and historical traumatic assaults. Stigma can also occur at an individual level and involve prejudice, making stereotypes, and discrimination (Cleary, Barhman, MacCormack & Herold, 2002).

According to Herek, Capitanio and Widaman (2003), history is ripe with examples of stigma interfering with constructive collective response to illnesses, such as cholera and syphilis. Moral judgments pertaining to how a person contracted the illness were connected to the societal reaction and affected societal response (Herek, Capitanio & Widaman, 2003). According to Conley, Jadack and Hyde (1997), people who have contracted STI's are often viewed as immoral because of the disease itself or what they did to acquire it. Nack (2000, 2002) suggests that women who have STI's experience stigma due to traits society correlates with STI's, such as uncleanliness and promiscuity; these traits are not compatible with cultural definitions of traditional feminine goodness (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007).

The concept of stigma can involve risk to one's position in society. Burriss (2000) coined the term *social risk*, the danger that a person will be socially or economically penalized should he or she become identified with an expensive, disfavored, or feared medical condition (Herek, Capitanio & Widaman, 2003). Social risk involves both the objective threat of harm and the subjective perceptions of possible risk of harm (Herek, Capitanio & Widaman, 2003). People

who have an STI may fear the societal penalties of being public with their condition and keep it a secret, to avoid shame and ridicule.

Burris (2000) also noted that the more illness-related policies are put in place by perpetrators of stigma, the stronger the potential for members of the stigmatized group to react to such policies (Herek, Capitanio & Widaman, 2003). Internalized stigma, also known as self-stigma, involves discrediting and devaluing one's group, or oneself, based on stigma held by an individual (Cleary, Barhman, MacCormack & Herold, 2002).

Testing for STI's can increase the sense of felt stigma. According to Barton and Coyne (2007), testing for STI's that involve genital swaps are unpopular and people are concerned about protecting confidentiality. The public health professionals realize that fears of stigma and discrimination that follows may deter people from being tested for STI's, especially AIDS (Herek, Capitanio & Widaman, 2003). This finding is of concern because testing is the only way for one to discover an STI diagnosis; not being tested will only serve to spread infection and hinder treatment. Stigma and shame have been revealed to be strong barriers to testing, diagnosis, and treatment of STIs' (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007).

A significant amount of stigma is still attached to being gay in America, despite the success of recent legislative efforts to legalize gay marriage. According to Cleary, Barhman, MacCormack and Herold (2002), self-stigma is correlated with sexual risk among gay men and bisexual men; individuals who feel stigmatized may be at increased risk for engaging in risky sexual behaviors as a short-term escape from depression and shame. Given the solid correlation in the United States between AIDS stigma and negative attitudes toward gay and bisexual men, it

may be of particular importance for the public health community to administer programs to combat discrimination and sexual prejudice against the LGBTQ community (Herek, Capitano & Widaman, 2003).

Stigma surrounding STI's is not limited to the United States. In a study conducted by Zheng, Wu, Poundstone, Pang and Rou (2012) among MSM university students in China, those who admitted to feeling anxious about being gay were more likely to consider themselves at risk for HIV than those who reported not being anxious. A study conducted by Herek, Capitano and Widaman (2003) found in a nationwide telephone survey that most respondents expressed concern about being stigmatized if they themselves were to test positive for HIV and for more than one third of respondents, this would affect their decision to be tested.

How an STI is acquired can impact the appearance of stigma. According to a study conducted by Chin and Kroesen (1999), HIV was found to be stigmatizing but being infected by having sex is separated from blood transfusions as a further source of stigma. One respondent stated, "The A group is the poor unfortunate group, through no fault of their own got blood transfusions or whatever. The rest of us are sluts. The women who got it through sex have that shame about them" (Chin and Kroesen, 1999).

In a study conducted by Kahn, Slap, Bernstein, Tissot, Kollar, Hillard and Rosenthal (2007), participants focused almost entirely on social rejection as a consequence for a positive HPV or abnormal pap test. Participants labeled girls who acquired HPV as, "dirty, nasty, and trifling" (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007).

Interventions and Treatments

Various STI interventions and treatment strategies are suggested in the current literature. Simply visiting a medical doctor to be tested is a fundamental method to be certain about whether one has an STI. Educational campaigns and programs in schools and in the community can also provide knowledge about STI symptoms, treatments, and effective condom usage for people of all ages. For some people, attending counseling is a way to cope with emotions due to an STI diagnosis.

Testing is the only means to successfully diagnose an STI. Once a person is aware of having an STI, steps can be taken to prevent the infection from spreading. However, there can be barriers to STI testing. In a recent study conducted by Schiffner & Buki (2006), college-age women who were uncertain about having a pap smear sought advice from their mothers. They were discouraged from testing, citing that it was inappropriate for young women to have a pap test; a further barrier to screening was a fear that their mothers would discover that they had been sexually active (Schiffner & Buki, 2006). Fear of shame inflicted by family members became a barrier to STI testing.

There is a need for further research to develop and evaluate educational measures to address misinformation about sexually transmitted infections. Additional understanding is also needed about the role of ethnic values in shaping beliefs about sexual health matters that differ according to demographics (Schiffner & Buki, 2006). Giordano and Groat (1989) suggested that isolation, loneliness, and feelings of alienation are key linkages among vulnerability factions in youths at risk for contracting AIDS; these findings support the benefit of researching and addressing the emotional needs of high-risk youths in preventing AIDS (Azzarto, 1997).

Seeking psychological treatment is a way to cope with an STI diagnosis. A study performed by McLarnon and Kaloupek (1988) to investigate the impact of psychological intervention on features of genital herpes found that cognitive restructuring therapy in a group format was associated with reduced frequency of lesion recurrence at follow up. The authors of the study concluded that psychological factors influence health status and psychological intervention may reduce the recurrence rate of infection (McLarnon & Kaloupek, 1988).

According to Longo, Clum and Yaeger (1988), psychosocial intervention reduced the frequency rates, episode severity, and episode duration of genital herpes. Psychosocial intervention also decreased rates of emotional distress and loneliness; the researchers concluded that a problem-solving, skills-based treatment structure is necessary to help people cope with having herpes (Longo, Clum & Yeager, 1988).

In a study conducted by Purdie, Norris, Davis, Zawacki, Morrison, George and Kiekel (2011), prevention and intervention programs would profit from focusing on alcohol in evaluating a potential partner's sexual risk. Women would benefit from education programs which highlight how the effects of alcohol increase sexual risk taking, regardless of a potential partner's sexual risk (Purdie, Norris, Davis, Zawacki, Morrison, George and Kiekel, 2011). In a study conducted by Zheng, Wu, Poundstone, Pang and Rou (2012), HIV testing services and health programs would benefit from stressing the importance of condom use, testing, and disclosing HIV status to potential sexual partners.

Discussing options with healthcare providers can shed light on the diagnosis of sexually transmitted infections for people of all ages. According to Kahn, Slap, Bernstein, Tissot, Kollar, Hillard and Rosenthal (2007), clinicians discussing STI test results with adolescents face

challenges of correcting misconceptions about what the results mean and helping adolescents cope with psychological consequences, such as shame and social stress. Similarly, health care providers are in a unique position to aid young women in rejecting cultural misconceptions and decrease stigmatization by being nonjudgmental (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007).

Furthermore, for those adolescents who have supportive family members, it is important to provide family-centered bio-psychosocial care to treat STI's (Rasera, Vieira & Japur, 2004). Community-centered support groups fostered by health care social workers are well-suited to provide primary prevention information to support the development of healthy adolescents (Azzarto, 1997).

Hillman (2008) argues that mental health providers are in a unique position to aid older adults by providing an open discussion of sexuality, especially during initial patient interviews. According to Cleary, Barhman, MacCormack and Herold (2002), fostering a sense of empowerment, trust, contact, and social support within communities can aid in the process of reducing stigma related to STI's and educate citizens on the importance of testing.

After a person is diagnosed with an STI and has processed the inevitable emotions of fear, disbelief, sadness, anger, or anxiety, another layer of coping sometimes occurs: acceptance. According to Rasera, Vieira and Japur (2004), acceptance means that people living with a diagnosis have a pool of individual resources to cope with the infection. However, the authors argue that little is known about the personal meaning people attribute to their diagnosis (Rasera, Vieira and Japur (2004).

The literature reveals several barriers to seeking treatment and intervention means for sexually transmitted infections. Language barriers for people who do not speak English and mistrust of medical professionals may deter individuals from seeking STI treatment (Cleary, Barhman, MacCormack & Herold, 2002). Also, perceived stigma from providers may also stop people from accessing medical care (Cleary, Barhman, MacCormack & Herold, 2002). Students in school under the age of eighteen may also face barriers to seeking treatment. Many public schools teach an abstinence-only health curriculum that could leave students feeling confused about sexual matters. This lack of knowledge puts young people at a disadvantage; students may not be aware of how to use condoms, the risk factors of engaging in un-protected sexual activity, or where to seek help if STI symptoms arise.

Disclosing STI Status

Discussing sex and sexual health with a new potential partner can be difficult and is made more difficult if the conversation includes an admission of STI status. The decision to disclose the diagnosis of a sexually transmitted infection can be deeply personal and challenging, especially if the STI is incurable. The person who has an STI may fear the reaction of their romantic partner, family, friends, and colleagues. Diagnosed individuals may also fear judgment from their doctor, other medical professionals, and members of their faith community. Disclosing a positive STI status may also have moral and cultural implications.

Understanding the reasoning behind disclosing STI status is important. There is evidence that many people who have STI's are choosing to avoid telling their sexual partner about the infection (Conley, Jadack & Hyde, 1997). Research speaks to the rates of disclosing STI status. Pliskin (1997) noted that in a sample of young adults with genital herpes, 49% revealed never

telling their potential sexual partners, which could lead to passing along the infection to others (Cleary, Barhman, MacCormack & Herold, 2002).

Along with telling potential sexual partners about one's STI status, the identification of sexual and social networks is important to the investigation and control of STI outbreaks (Katz, Cadorna, Lee, Komeya, Kiaha & Ohye, 2009). A study performed by Cleary, Barhman, MacCormack and Herold (2002) found participants were fearful about initiating sexual health related discussions due to concern over losing the relationship, concern about being judged, a wish to not offend their partner, and a fear of discussing sex.

Herek and Glun (1988) noted that people who chose to disclose STI risk may face personal rejection, being ostracized by family members, being shunned during community events, and discrimination (Chin & Kroesen, 1999). Gock (1994) and Yep (1993) found that sharing HIV status has particular significance for Asian/Pacific Islanders due to its association with death, illness, drugs, and homosexuality, which are cultural taboos (Chin & Kroesen, 1999).

Whether a culture is predominately individualistic or collective can also impact the choice to disclose one's STI status. According to Triandis (1995), being HIV-positive in an Asian culture may be seen as negative not only to oneself but also to one's family. Due to the collectivist nature of the culture; the potential for shame and loss of face increase after the announcement of disclosure (Chin & Kroesen, 1999).

A study performed by Simoni et al., (1995) found Spanish-speaking Latina women shared their STI status with fewer people than English-speaking Latinas; furthermore, white men disclosed more than English-speaking Latino men, indicating that the extent of one's cultural orientation and level of acculturation may influence the disclosure process (Chin & Kroesen,

1999). According to Chin and Kroesen (1999), study participants tended to dissociate from friends upon learning about their HIV diagnosis; one participant distanced herself from friends to avoid the problem of having to disclose her illness. Other reasons for choosing not to disclose STI status included concern about disappointing or burdening others, fear of stigma, and concern about discrimination (Chin & Kroesen, 1999).

Fear of disclosure is further realized when sensitive and personal information is not kept confidential. Stigma can be increased when medical staff does not hold to the oath to protect patient data, as was the case in a study conducted by Chin and Kroesen (1999); two medical staff in the community told others about a participant's diagnosis, enhancing the participant's fear of being judged.

Disclosing STI status may have moral implications depending upon one's individual values, cultural values, and social group associations. According to a study conducted by Conley, Jadack and Hyde (1997), people who reported a history of recurrent genital herpes demonstrated a higher level of moral reasoning in response to dilemmas about STI's than those who did not have a STI; the findings indicate reasons for disclosing or not disclosing a diagnosis of genital herpes to a partner were focused on the rights of the partner and the obligations to maintain good relationships. Another finding of the study concluded people who had more negative experiences with herpes may also have lower moral reasoning scores related to STI's; people become self-focused after having a less than positive experience with herpes and base their moral reasoning on increasing rewards towards themselves (Conley, Jadack & Hyde, 1997).

Mandated reporting procedures exist in some parts of the world that require governments to track of the prevalence of STI's. According to Herek, Capitanio and Widaman (2003), many

U.S. states have implemented a named reporting policy to monitor HIV status. However, California, the largest US state, continues to use anonymous identifiers to report new HIV infections (Herek, Capitanio and Widaman, 2003). In order to protect confidentiality and also to keep the public informed, surveillance policies should include strict confidentiality measures and anti-stigma campaigns should be launched at the local, state, and national levels (Herek, Capitanio & Widaman, 2003).

Katz, Cadorna, Lee, Komeya, Kiaha and Ohye (2009) state it is vital to establish trust and rapport with clients while performing STI investigations; field interviews could be used to identify infected persons who may be unable to attend an appointment in a traditional office setting. To date, the United Kingdom is the only country in Europe that has a system of clinics, known as specific genitourinary medicine (GUM) clinics that keep track of attendance and diagnosed cases of STIs; these clinics file mandated annual returns (Barton & Coyne, 2007).

To date, the literature is lacking in exploring the specific grief and loss issues related to sexually transmitted infections. While the literature does outline treatment options for STI's, rates of condom usage, and rates of disclosure, as well as cultural, gender, and moral implications of having an STI, it has not sufficiently canvassed the emotional and grief-related effects of having an STI. Therefore, the research question for this study is: What are the grief and loss issues related to having an STI and how do these issues manifest across one's lifespan?

Conceptual Framework

Multiple frameworks and models exist to examine grief and loss. Greenstreet (2004) describes grief as a person's personal response to loss that includes physical, emotional, spiritual, cognitive, and behavioral dimensions (Buglass, 2010). Mourning is the outward and active

expression of grief and bereavement is the period after loss during which mourning and grief occur (Buglass, 2010). Dunne (2004) noted that people often travel between grieving and attempting to come to terms with a loss (Buglass, 2010). Furthermore, grief is not limited to a kind of perception, feeling, judgment, or mental state that can be captured at any moment in time; rather, grief is both an active and passive process which ebbs and flows and is best understood through a narrative account (Goldie, 2011).

Bereavement Model: Dual Process

According to Strobe and Shut (1999), the Dual Process model of bereavement describes how a person has to cope with the experience of death simultaneously through actions of restoration and grief (Buglass, 2010). In addition to lifestyle alterations caused by death, one has to face both the losses and factors aimed at renewal (Buglass, 2010). Stroebe (1999) lists loss-oriented processes aimed at active grieving which include grief work, intrusion of grief, denial/avoidance of restorative changes, and breaking bonds. Restorative-oriented processes include attending to life changes, distraction from grief, doing new and different things, and establishing new roles, identities, and relationships (Buglass, 2010).

Using such a model, a person diagnosed with an STI is not grieving the loss of a person through death, but rather the loss of a life before having an STI. Individuals are dealing with grief related to diagnosis and uncertainty about the future. At the same time, people are simultaneously attempting to establish new facets of life by renegotiating relationships and making new meaning about their situation. Mourning and constructing a new existence occurs in the same continuum.

Hidden Distress Model

The Hidden-Distress Model, originated by Scrambler (1998), is a valuable theoretical framework for examining grief, loss, and distress around having a diagnosed sexually transmitted infection. This model is based around the experiences of people diagnosed with epilepsy and distinguishes between enacted and felt stigma; enacted stigma involves actual discrimination and felt stigma involves the fear of discrimination (Scrambler, 1998).

There are four parts to this model. First, upon diagnosis, individuals create an acute sense of felt stigma before any actual exposure to enacted stigma occurs (Scrambler, 1998). Second, non-disclosure and concealment of the diagnostic label manifest due to felt stigma (Scrambler, 1998). Third, as few people are aware of one's diagnosis, instances of enacted stigma are less frequent (Scrambler, 1998). Fourth, felt stigma proves to be a more destructive force in people's lives than enacted stigma due to successful concealment and fewer instances of enacted stigma (Scrambler, 1998).

Felt stigma may be worse than enacted stigma due to the fear of experiencing discrimination versus actually experiencing the phenomena. Felt stigma refers to the fear of discrimination whereas enacted stigma denotes actual discrimination (Scrambler, 1998). People who live in fear of discrimination can experience decreased self-esteem, insecurity, and threats to positive life chances (Scrambler, 1998).

The Hidden-Distress Model is applicable when discussing loss related to sexually transmitted infections due to the stigma, both enacted and felt, that can accompany diagnosis. In cases where individuals choose not to reveal an STI diagnosis, the felt stigma can become internalized and have a negative impact on quality of life. A person who is open about an STI

diagnosis may face enacted stigma through discrimination from peers, family members, spiritual communities, or the media.

Loss of Dreams Theory

Loss of Dreams theory coincides with grief and loss due to having a sexually transmitted infection. Mitchell and Anderson (1983) note that there are six major types of losses: material, relationship, functional, role, and systemic (Bowman, 1994). The last type of loss is intrapsychic loss linked to losing an emotionally significant image of oneself, losing the possibilities of what might have been, forsaking of plans for a certain future, and the dying of a dream (Bowman, 1994).

Loss of Dreams theory involves the realization that a loss has occurred, not the loss of a physical person, but the loss of something intangible that was hoped for, planned for, or longed for (Bowman, 1994). For example, after a person who is diagnosed with genital herpes discloses the information to their romantic partner and the non-infected partner ends the relationship, the infected partner experiences a loss of the relationship, a future with the former romantic partner and uncertainty that another romantic partner may be found.

Bowman (1994) outlines a framework for coping with the loss of dreams that is divided into six steps. Step one is to name losses as actual losses of dreams, which is followed by step two: grieving the loss of dreams (Bowman, 1994). Step three is to know what one is giving up with the loss of a dream and step four encourages one to keep dreaming, in spite of the loss that has occurred (Bowman, 1994). Step five outlines the idea that one is not alone in the grieving process and step six involves building or constructing a support system (Bowman, 1994).

Individuals diagnosed with a sexually transmitted infection may face a loss of dreams, depending on the type of STI contracted. Certain types of STI's can lead to infertility and birth defects in children. Having an STI may also limit the number of romantic partners in a lifetime once a diagnosis is revealed. Those living with an STI may have to learn to cope with lost dreams for a future which may never come to pass. It is important to remember that even in the midst of facing the loss of a dream, relying on a solid support system and constructing dreams for a new future can aid a person to move on and develop a positive outlook on life.

Methods

Research Design

This study examined the grief and loss issues associated with having a sexually transmitted infection and how these losses manifest across the life span. A one-time, cross-sectional, mixed-methods approach was used to explore the grief and loss issues related to having a sexually transmitted infection. Specifically, an anonymous web-based survey questionnaire was constructed using the Qualtrics system.

Sample

The researcher used a convenience sample and constructed a flyer to recruit participants who were voluntary in nature. The flyer was posted in the St. Thomas library and on two bulletin boards on the St. Thomas campus. The flyer was also posted at the Minnesota AIDS project, the Annex Teen Clinic, and in two coffee shops. Invitations were also posted to three sponsored online dating forums, one Yahoo group dedicated to lesbians with genital herpes, on Facebook, and one independent social group related to having an STI. An invitation to join the study was

also posted in Vitamin Magazine. The flyer displayed an invitation to take the anonymous online survey and had a link to Qualtrics.

Participants were able to take individual flyers with the Qualtrics site as a reminder to take the survey. The researcher hoped for 30-40 responses and obtained 21 responses, 10 of which were fully completed surveys. The researcher attempted to place flyers in three non-profit clinics that serve people who have STI's. After hearing the researcher's proposal, these clinics declined to participate and display the flyers. The researcher also attempted to post the flyer at two senior community centers. The researcher did not receive a call back from the community centers with permission to post the flyers.

Recruitment

The researcher completed an application through the Institutional Review Board (IRB) through St. Thomas University. Once the application was approved, data collection commenced. Participants were recruited through responding to a flyer asking participants to take an anonymous, online survey through Qualtrics. Participants were able to take the survey online and answered questions about age, race, demographics, and STI diagnosis. Open-ended questions, demographic questions, and true and false questions were used to gauge an individual's experiences about loss, grief, treatment options, stigma, and relationship changes since being diagnosed with an STI.

Voluntary Nature

Participants were asked to read a letter of informed consent before beginning the survey and continuing with the survey indicated voluntary participation in the study. Participants had the option to skip questions and to quit the survey at any time. See Appendix A.

Confidentiality

The online survey through Qualtrics was completely anonymously and participants were not asked to answer question about identifying information. Participants were only asked about their gender and STI diagnosis in the demographics section of the survey. The researcher was not able to determine the identity of the participants as Qualtrics assigned each respondent a random survey number which appeared in the researcher's notifications after a survey had been completed.

Data Collection

The researcher authored a survey to study the grief and loss issues related to having a sexually transmitted infection and how these issues manifest across the lifespan. While reviewing the current literature, the researcher discovered limited information and studies surrounding grief, loss, and sexually transmitted infections. The survey was created to ask direct questions and gain knowledge about grief and loss issues related to having an STI.

The survey consisted of demographic questions, true and false questions, and open-ended questions. The survey was divided into sections to assess demographics, current medical symptoms, and mental health symptoms. Other sections assessed grief and loss as a result of having an STI, including loss of relationships, loss of dreams for a future without an STI, and loss of a healthy body. Questions related to stigma expressed by family, friends, society, and the media, both blatant and subtle, were also addressed.

Additional sections also addressed disclosure techniques, or how one explained having an STI to a potential sexual partner. The last section of the survey asked about current supports in place, such as family, friends, and social groups. Questions also addressed any positive changes

that have occurred since being diagnosed with an STI, such as learning about oneself and adapting to new circumstances. See Appendix B.

Data Analysis

The data from the Qualtrics survey was analyzed in several ways. As the data was both qualitative and quantitative, different methods were employed. Data was analyzed using descriptive, statistical, and content analysis methods. Descriptive analysis was also used to analyze questions involving a yes or no answer to obtain frequency counts. The open-ended questions were analyzed using content analysis. Participant's answers were coded and analyzed for meaningful themes.

Strengths and Limitations

The purpose of this study was to examine the grief and loss issues related to having a sexually transmitted infection and how such losses manifest across the lifespan. Both strengths and limitations existed in this study. Strengths of this study included adding valuable information about grief and loss related to having an STI. This information can be used to develop successful treatment interventions for people living with an STI. One possible limitation of this study was that participants may not have answered every question in the survey, leading to incomplete information. Another limitation is that because the survey was only available online, it may have deterred people who do not have access to a computer from taking the survey. An additional limitation is that people may have taken the survey that did have an STI, leading to false data.

Findings

This research was conducted to examine the grief and loss issues associated with having a sexually transmitted infection and how these losses manifest across the life span. The survey included both qualitative and quantitative questions. The survey was divided into sections that inquired about the participant's demographics, symptoms, past and current STI's, disclosure, grief and loss, and seeking support. The researcher received a total of 21 responses to the anonymous survey, though only 10 surveys were filled out completely; the completion rate of the anonymous survey was 47%.

Demographics

Of the 10 survey participants, seven (or 70%) were female and three (or 30%) were male. None of the participants described themselves as transgendered. Of the 10 participants, three (or 30%) were between the ages of 18-25; four (or 40%) were between the ages of 26-35; two (or 20%) participants was between the ages of 36-50; and one (or 10%) participant was between the ages of 51-60. Please see Figure 1.

Figure 1.

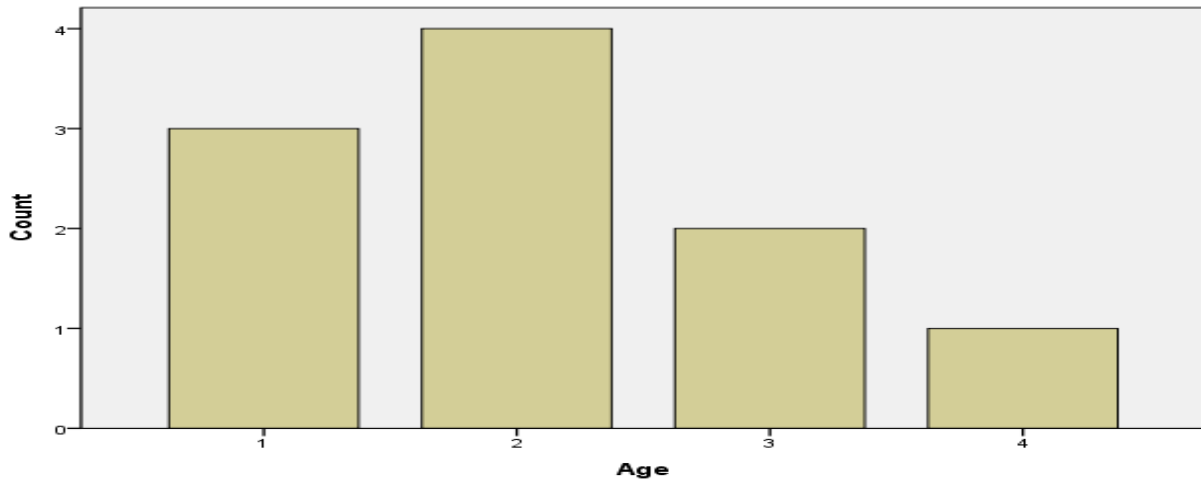


Figure 1. Age
1= 18-25, 2=26-35, 3=36-50, 4=51-65

Nine (or 90%) of the participants identified their race as Caucasian and one (or 10%) participant identified their race as Asian. None of the participant identified themselves as African American, Hispanic/Latino/a, Pacific Islander, or American Indian. When asked about sexual orientation, one participant (or 10%) identified as being gay. Eight of the respondents (or 80%) identified as being straight. One respondent (or 10%) identified as bisexual. The majority of survey participants were female, Caucasian, heterosexual, and aged 35 or younger.

Symptoms

The next sections of the survey inquired about current STI symptoms. Three respondents (30%) responded to this question. One respondent (10%) reported having lower abdominal pain, abnormal menstrual bleeding and fatigue. One participant (10%) reported having vaginal discharge and diarrhea. One participant (10%) reported having only vaginal discharge. Seven participants (70%) did not respond.

Current and Past Sexually Transmitted Infections

Research participants were asked about their current and past STI status. When asked about types of current STI's, one participant (or 10%) reported having Hepatitis B and two participants (or 20%) reported having HSV 1. Two participants (or 20%) also reported having HSV 2. When asked about types of past STI's, three participants (or 30%) reported having chlamydia. One participant (10%) reported having gonorrhea; two participants (or 20%) reported having pubic lice, and one participant (10%) reported having candidiasis/vulvovagina (yeast infection). Two respondents (or 20%) reported that this is their first STI. One participant did not report having a current or past STI. Seventy percent of participants reported having an STI in the past and 30% reported having a current STI. HSV 1 and HSV 2 was the most frequently selected current STI and chlamydia was the most common past STI for participants.

Only 70% of participants responded to the survey question, "How long have you lived with your current STI?" One participant (or 10%) responded less than 31 days and two participants (20%) reported living with their current STI for one to three years. Two participants (or 20%) reported living with their current STI for four to six years. In addition, two participants (or 20%) reported living with their current STI for more than 22 years.

Sixty percent of participants responded to the survey question, "How long did your former STI last?" Two participants (20%) reported their past STI lasted for less than 31 days. One participant reported their past STI lasted for one to three months. One participant (10%) reported their former STI lasted for seven to nine months. Two participants (20%) stated that this was their first STI. Sixty percent of participants responded to the question, "If you currently have an STI, are you receiving medical treatment?" Only two (20%) of participants stated that they are

receiving medical care while the additional four participants (40%) are not receiving medical care for their STI.

The survey question, “Who first knew about a past or current STI?” received a 90% response rate. One participant (10%) told a friend/acquaintance. Two participants (20%) first told a family member. Five respondents (50%) reported a medical doctor first knew about the STI diagnosis. One participant (10%) reported not telling anyone about the diagnosis. None of the survey participants selected their current sexual partner, past sexual partner, mental health therapist, or spiritual advisor to be the first person who knew about the STI diagnosis. Please see Figure 2.

Figure 2

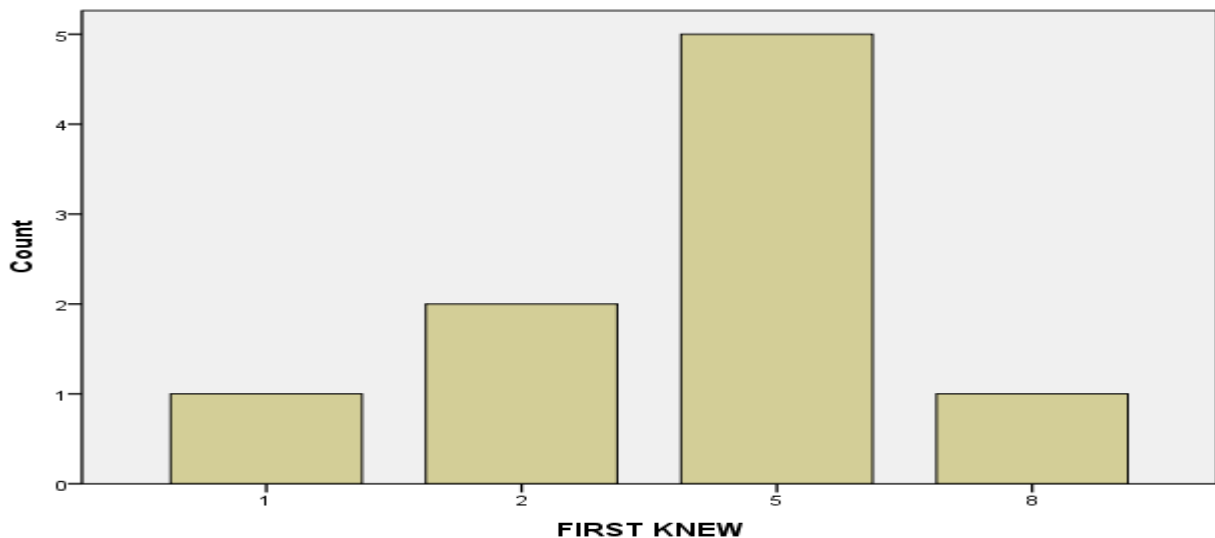


Figure 3. Who First Knew About Past or Current STI
1=Friend of acquaintance, 2= Family member, 5=Medical doctor, 8= Other

Disclosure

In the next section of the survey, participants were asked questions about sexual encounters and reactions from current or potential partners about having an STI. When asked,

“Have you had a sexual encounter in which someone gave you an STI and did not tell you they were infected?” eight participants (80%) responded yes. Two participants (20%) responded no. All eight of the participants that responded yes included a brief description of their reaction to the diagnosis. Two participants described feeling shocked and upset about the diagnosis. Other respondents described feeling:

“Totally freaked out! Then went straight to the doctor!!!”

“I was upset but when I asked my partner he had no clue also I had an abnormal pap (hpv) but got that treated and the doctor said I am fine now.”

“I was extremely hurt and angry. I broke up with him and it was very dramatic and difficult to overcome.”

“I was grateful it wasn't something worse.”

“I was in a daze for several days. Didn't know what to do. Kept asking the doctor how this could have happened because I didn't have any recent partners.”

The participants who chose to share their initial responses displayed themes of surprise, feeling upset and even feeling gratitude about the diagnosis, realizing it could have been worse. Reactions were highly individualized, as were the events following the diagnosis. One participant ended their relationship and two participants sought immediate medical attention. An overall theme of feeling hurt and upset by the diagnosis can be ascribed, given the survey responses.

Seven participants (70%) responded to the question, “How often do you disclose your STI to potential sexual partners?” Three participants (30%) chose not to answer this question. Five participants (50%) of respondents stated that they always disclose STI status. One participant (10%) reported sometimes revealing STI status. One participant (10%) reported never

revealing STI status. Overall, participants who answered this question did reveal STI status to their potential sexual partners.

Nine participants (90%) responded to the question, “How have your potential sexual partners found out about your current or past STI(s)?” Five respondents (50%) informed their partner about the STI in person. One respondent (10%) informed the partner about the STI through a text message/email. One participant chose not to answer this question. Three participants (30%) of participants checked the “other” category and responded:

“Mine has never been technically diagnosed, only suspected, it was not diagnosable until the last couple years and I’m not due for an annual exam till next September... dreading it..”

“I am clean now as is my fiancé. I told him about my past and he understands.”

“I didn’t tell them because I didn’t know them.”

The last open-ended question in this section, “If you are in a relationship, what was your partner’s reaction to your diagnosis?” was answered by five participants (50%). Responses included:

“Supportive.”

“Not currently in a relationship but past relationships since getting this my partner did more research and felt ok about still dating me.”

“Good because no longer have it.”

“Again... It has not been confirmed only most likely I have it because of issues I have had, so I have mentioned it to my long-time boyfriend but never got much of a reaction.”

“Supportive of me going through the treatments to get a normal pap back.”

A strong theme of support runs through the answer to this question. Participants felt

generally accepted and supported by their partner's reaction to the STI diagnosis.

Grief and Loss

The next section of the survey asked questions related to grief, loss, and stigma around having an STI. Participants were asked about which types of losses they have experienced after being diagnosed with a past or current STI, with the option of selecting more than one loss category. Participants were asked to choose from the loss of romantic relationships, loss of opportunities for sexual encounters, loss of friendships, loss of family relationships, loss of faith/spirituality, loss of certainty about the future, loss of the ability to have children, and the loss of job opportunities. Participants could also select the "other" category to type free text responses.

This question received a 90% response rate; one participant did not respond to the question. Five (50%) respondents selected feeling a loss of romantic relationships. Four participants (40%) chose feeling a loss of opportunities for sexual encounters. One participant (10%) chose feeling the loss of friendships. No one selected feeling the loss of a family relationship. Two participants (20%) felt a loss of faith/spirituality. Seven participants (70%) reported feeling a loss of certainty about the future. One participant (10%) reported the loss of the ability to have children. No participants felt the loss of job opportunities. Overall, participants experienced the greatest amount of loss in the categories of certainty about the future and the loss of romantic relationships.

Three participants selected the "other" loss option and stated via free text:

"Loss of confidence and love for myself. I felt disgusted with myself and was

embarrassed to know I got an STI.”

“I have trust issues, not necessarily directly associated with my STI.

“Loss of self-respect.”

The responses to this question suggest a theme of shame and loss of respect for oneself as a result of having an STI. One respondent felt embarrassed due to the diagnosis and another respondent had issues trusting others.

The next open-ended question in the survey asked participants about any changes that have occurred in romantic relationships due to having an STI. Respondents answered via free text:

“Much more cautious, take things slow.”

“I feel it’s harder for potential partners to always accept you once you tell them. Understandable, but it makes dating a lot harder.”

“Don't know if anything has messed up my chances of having children yet.”

“There have been unconfirmed times when I feel like it is ‘active’ and I tend to shy away from my partner for fear it will cause an issue.”

“Nothing.”

“It was a long time ago, but I think it made me feel bad about myself and support the negative feelings I had about myself before I got the STI.”

“There's two things: 1) I'm more selective over who I consider dating. I must feel they are mature enough to have an honest conversation about STI's. 2) It adds uncertainty if they will be comfortable dating someone with an STI. I must [have] conversations I don't want to have, but it's a necessity for a healthy relationship.”

There are several themes in these responses: caution when dating, taking relationships at a slower pace, and a sense of low self-esteem. Another question in the section of the survey

asked about participants' experience with stigma. Participants were asked to select all categories that apply related to stigma since being diagnosed. Participants could choose loss of family relationships, loss of friends, loss of connection to spiritual community, felt judgment from social media sites, felt bullied/belittled by peers, and felt judgment from jokes made about STI's in the media. Participants could also select, "I have no experience with stigma," or "other" to type in free text.

Seven participants (70%) responded to feeling some type of stigma. Two respondents (20%) reported feeling no stigma and one participant (10%) did not answer the question. One participant (10%) selected feeling stigma in the form of loss of friends. One participant (10%) reported feeling stigma in the form of a loss of connection to a spiritual community. Three participants (30%) reported feeling stigma in the form of felt judgment from social media sites. One participant (10%) experienced feeling bullied/belittled by peers. Five participants (50%) felt judgment from jokes made about STI's in the media. No one responded to feeling the loss of a family relationship. Overall, participants felt the most amount of stigma in the form of felt judgment from jokes made about STI's in the media. The one participant that selected "other" stated feeling stigma from a potential partner.

Seeking Support

The last section of the survey asked questions about experiencing mental health symptoms, seeking support, and positive changes since being diagnosed with an STI. Participants were asked if they have struggled with mental health symptoms since being diagnosed with an STI. Nine participants (90%) responded, while one participant (10%) chose not to answer. Three participants (30%) answered yes to experiencing mental health symptoms. Three participants

(30%) answered no to experiencing mental health symptoms. Three participants (30%) answered not being sure if they have experienced mental health symptoms. Responses were equally divided among respondents.

When asked if they have struggled with anxiety, six participants (60%) responded, while four respondents (40%) chose not to answer. Five respondents (50%) answered yes to experiencing anxiety since being diagnosed with a past or current STI. One participant (10%) answered “no” to experiencing anxiety. This suggests that of the participants who chose to answer this question, most experienced anxiety after being diagnosed with an STI.

When asked if they have struggled with depression since being diagnosed with an STI, six respondents (60%) answered, while four chose not to. All six respondents (60%) confirmed experiencing depression since being diagnosed. Nine respondents answered the question, “Have you sought mental health or grief counseling due to having an STI?” One participant chose not to answer. Two participants (20%) answered yes and seven participants (70%) answered no to seeking counseling. This finding suggests that while many participants experienced anxiety or depression after being diagnosed with an STI, most chose not to seek mental health therapy. When asked if this counseling support has been beneficial, the two respondents answered:

“No, it felt like they didn’t know where I was coming from on the subject.”

“I think the STI was a symptom of the mental illness, mild form of depression and anxiety. Anytime that I have gone to therapy it gave my spirit a lift, also anti-depressants.”

These open-text responses do not correlate to a specific theme, as they are contradictory.

One participant felt that therapy was not helpful and another participant experienced relief from attending therapy. When asked about attending a support group to cope with the STI, nine respondents (90%) of the participants answered no, while one participant chose not to answer the question.

The last two questions of the survey were open-text responses. Participants were asked about any positive changes that have occurred since being diagnosed with an STI. Eight participants (80%) answered and two participants (20%) chose not to answer. Open text responses were:

“Found partners to be more accepting than I thought.”

“I think I am more aware of the risks and how to better protect myself in the future.”

“More aware of my health, my choice with sexual partners, my trust with individuals.”

“Since I have not been diagnosed, but I do seem to carry it, I have made sure to promote to young girls to get the current vaccine available that was not available when I became sexually active.”

“I feel I am more aware and smart about my sexual interactions.”

“None associated with it. But overall, since diagnosed in 2010 and then cured, I have grown spiritually.”

“Well it was treated and then life went on. I have seen therapists off and on throughout my life; Every experience with a therapist gave me the help to get over the issues at the time.”

“After being diagnosed with my STI, it gave me the opportunity to reassess my priorities that I would not have had otherwise.”

Overall themes of the survey responses suggest that participants are concerned with health promotion as a result of having an STI. Respondents realize it is important to protect,

educate, and inform themselves, their partners, and the community about sexual issues. Participants also have the chance to take stock of their values in light of having an STI. Respondents have experienced positive changes since being diagnosed with an STI.

The last question of the survey asked participants how they have grown as a result of being diagnosed with an STI. Eight participants (80%) answered the question while two (20%) chose not to answer. Responses were:

“I only seek long term relationships now.”

“I would say yes. I feel I am less judgmental of other people's health history and past mistakes due to mine.”

“More general awareness.”

“I try to feel it does not define who I am and strive to promote sexual awareness whenever I can.”

“I am now smart and take precautions to stay safe when I have sex now.”

“I have grown spiritually, not directly associated with the STI.”

“I reach out for help and because of therapy and meds and my spiritual community I feel better about myself.”

“Yes. See above.” (re-assessing priorities).

The responses to the final survey question suggest that respondents are open to other's health experiences and increasing awareness of sexual issues. Participants have grown spiritually and take care when establishing long-term relationships.

Discussion

This research explored the question, “What are the effects of grief and loss on having a sexually transmitted infection and how do these effects manifest across the lifespan?”

Quantitative and qualitative data survey questions were used to gain a glimpse into the lives of 10 people living with an STI. The findings indicate that participants experienced loss in romantic relationships, stigma from social media sites, and had mixed reactions after disclosing STI status to partners. Similarities and divergences occurred in the findings when compared to the literature.

Demographics

The demographics displayed a sample that was not very heterogeneous, as most of the survey respondents were female and Caucasian. Though 21 people began taking the survey, only 10 chose to finish it completely. Perhaps the questions were too personal and people felt uncomfortable answering, or the participants misunderstood that in order to complete the survey, one had to have either a past or a current STI. The survey may have contained too many questions and participants ended the survey prematurely. Also, it was difficult to find agencies and clinics willing to post the survey link, which made finding participants more difficult.

The average age of survey participants was age 35 or younger. While STI's affect every age group, the literature spoke about the relatively limited amount of data available regarding older adults and STI's. One survey participant was between the ages of 51-65 and was diagnosed with chlamydia, gonorrhea, and candidiasis/vulvovagina. This diagnosis contradicts

the work of Hillman (2008) which stated that the most-often occurring STI among older women is genital herpes. This participant kept the diagnosis a secret from the sexual partner, and experienced a loss of self-respect as a result of procuring an STI.

Reactions from family, friends, and romantic partners can vary when discussing STI's. One male participant in the survey had a supportive reaction and found potential partners to be more accepting than anticipated. This finding differs from a study conducted by Rasesa, Vieira and Japur (2004) in which men were found to be in need of care after learning about an STI diagnosis and were unable to live alone. Two male participants disclosed STI status first to family members. One participant had HSV 1 and the other had Hepatitis B. Initial reactions to an STI can be dependent upon whether the STI is curable or non-curable.

Another portion of the demographic section dealt with race. Only two survey participants reported receiving medical treatment for their STI and these participants were both Caucasian. This finding is similar to that of Cleary, Barhman, MacCormack and Herold (2002), who stated that Caucasians have the shortest amount of delay between diagnosis and treatment of STI's. With regard to STI symptoms, three survey participants reported having chlamydia, which is the most common bacterial STI in the developed world (Barton & Coyne, 2007). This finding supports the literature. One survey participant also had gonorrhea, a common, curable STI (Barton & Coyne, 2007).

One participant stated that having HPV in free text response led to having a loss of confidence and love for herself. This participant also felt disgusted and embarrassed for having an STI; this is consistent with studies conducted by Maissi et al. (2004) and McCaffery et al. (2003) that a positive HPV test may lead to distress, anxiety, guilt, shame, and concern about

sexual relationships (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007).

Yet when the survey participant was asked about the reaction to the STI from a romantic partner, the partner was found to be supportive of the participant going through treatments to get a normal pap test. This is not consistent with the literature as the partner was supportive and the survey participants chose not to keep the diagnosis a secret from the partner (Kahn, Slap, Bernstein, Tissot, Kollar, Hillard & Rosenthal, 2007).

However, the survey participant who wrote about having HPV displayed misinformation about ways to fight HPV, which is consistent with the findings of Schiffner and Buki (2006). This participant talked about having HPV in free text, but did not indicate having HPV when asked about current or past STI status. Perhaps she chose to skip this question at the beginning of the survey, but wanted to talk about it later in the free text portion.

The literature is consistent when discussing the survey results and genital herpes. Two survey participants identified suffering from anxiety and depression since being diagnosed with HSV 1 and HSV 2, which is consistent with findings from Goldmeier and Johnson (1982) and Katcher et al. (1973) that people diagnosed with genital herpes reported feeling isolated and having periodic episodes of depression (McLarnon & Kaloupek, 1988). The initial responses to learning about an STI diagnosis are consistent with the findings of Rasera, Vieira and Japur (2004). Several survey participants talked about feeling shock, dazed, surprised, and sad after learning about their diagnosis.

The responses from the survey participants regarding stigma and social risk are consistent with the literature. Half of the survey participants listed feeling stigma related to jokes made on social media sites, which is consistent with the findings of Herek, Capitanio and Widaman,

(2003). Similarly, survey participants listed feeling stigma on an individual level from friends and members of their spiritual communities, which is consistent with the findings from Cleary, Barhman, MacCormack and Herold (2002).

Also, perceived stigma from providers may also stop people from accessing medical care, according to Cleary, Barhman, MacCormack and Herold (2002). While survey participants were not asked specifically why or why they were not receiving medical treatment after being diagnosed, perceived stigma from the medical community could be a factor.

Of the two participants who answered 'yes' to seeking mental health treatment after being diagnosed, both described the support as not being beneficial. This challenges the research completed by McLarnon and Kaloupek (1988), which reported that using cognitive restructuring in group therapy led to reduced frequency of lesions. Furthermore, the survey findings contradicted the research findings of Longo, Clum and Yeager (1988), which stated that psychosocial intervention decreased rates of emotional distress and loneliness and therefore, a problem-solving, skills-based treatment structure is necessary to help people cope with having herpes. The survey participants may not have had trusting, established relationships with their mental health providers, leading to treatment hindrance. Or perhaps the therapists were not well versed in how to serve clients with STI's, also contributing to treatment hindrance.

The survey participants who reported having HSV 2 reported always disclosing their STI status to potential sexual partners. This finding is not consistent with the research performed by Pliskin (1997), which noted that 49% revealed never telling their potential sexual partners about their STI status, which could lead to passing along the infection to others (Cleary,

Barhman, MacCormack & Herold, 2002).

The one survey participant who identified as Asian reported always disclosing STI status to potential sexual partners. This person also reported telling a family member when first diagnosed with their STI, which is not consistent with the research conducted by Gock (1994) and Yep (1993), who stated that sharing HIV status is taboo in Asian culture. (Chin & Kroesen, 1999). This survey participant also reported not experiencing any stigma, which is also inconsistent with the findings of Chin & Kroesen (1999).

The conceptual frameworks outlined in the literature review both support and diverge from the survey findings. In the Dual Process model, which contains both restorative-oriented and loss-oriented processes, the restorative-oriented process include attending to life changes, distraction from grief, doing new and different things, and establishing new roles, identities, and relationships (Buglass, 2010). Survey participants reported positive changes and growth in free text form as a result of having an STI. The free-text responses are consistent with the restorative-oriented portion of the Dual Process model coined by Buglass (2010).

The conceptual framework of Scrambler's Hidden Distress model supports the survey findings involving enacted stigma, but not felt stigma. Participants reported feeling enacted stigma from friends, their spiritual community, social media sites, peers, and jokes made about STI's in the media. The Loss of Dreams theory (Mitchell & Anderson, 1983) was consistent with the survey findings in that survey participants experienced relationship losses and systemic losses. None of the survey participants reported feeling the loss of a role, materials, or function.

A majority of the participants reported loss of certainty about the future. It is probable the research respondents did not imagine having an STI as part of their future plans. However, due to having an STI, participants now face a new and different future. Having an STI will become part of their life history and how the effects will manifest remains a mystery. An STI diagnosis contributed to feelings of uncertainty for research participants.

Survey participants did report having several intrapsychic losses, including loss of trust in oneself, loss of confidence, loss of certainty about the future, and a loss of self-respect, which is consistent with Loss of Dreams theory (Bowman, 1994). The last three steps involved in Loss of Dreams theory are consistent with the survey findings. Several survey participants reported experiencing positive changes and growth since being diagnosed with an STI (Bowman, 1994).

Implications for Social Work Practice

There are several implications for social work practice, based on the survey results. First, further research needs to be conducted in this topic area to develop further evidenced-based social work interventions to aid this particular population. While scant, some responses indicated that therapists were not well-versed in how to work with STI's.

People diagnosed with STI's face a unique set of circumstances and social workers need to be aware of how best to serve this group of people in individual and group therapy settings. Therapists who work in medical settings would benefit from additional training on STI's and collaborating with doctors and other providers to serve those with STI's in a holistic manner.

Second, the social work community would benefit from recognizing that being diagnosed

with an STI can be accompanied by a number of losses and people may experience stigma. Third, social workers should seek out opportunities to develop community awareness of STI's and programs to further educate the general population about STI's.

Lastly, social workers should organize and develop anti-stigma campaigns to combat stigma and misinformation surrounding STI's. Given the culturally different responses in addressing STI's, these campaigns would be most effective if tailored to specific cultural demographics. Feelings of shame, both hidden and enacted, are associated with having an STI and social workers need to be prepared to work with clients experiencing shame. Exploring the origins of shame and how shame affects those with STI's is a worthy research topic.

Implications for Policy

Numerous implications for policy surround the topic of grief, loss and STI's. First, policy-makers should lobby for schools to include in traditional sex education the potential losses and stigma that may come from contracting an STI. Adolescents need to be aware of the long-lasting effects of STI's and potential effect on future sexual relationships.

Second, policy-makers should advocate for additional funding for health programs for low-income citizens available in diverse languages. Spreading information about STI's is vital for awareness, prevention, and treatment. This information should be made available in all languages and in relevant ways so that diverse community members can be well informed.

Third, policy-makers should research ways to fund programs to combat stigma surrounding STIs. Policy should be set in place for schools and work places to combat the negative effects of stigma. The diagnosis of an STI should also be included as a special class

that should receive consideration when trying to prevent discrimination and bullying.

All citizens should be made aware of the effects of STIs. Knowledge campaigns should be designed to reach people of all socioeconomic statuses. It is not enough to simply have the correct information about STI's; the information needs to be applied and delivered to people in a meaningful manner. Policy makers should also inspect how to work effectively with different cultural and ethnic groups to deliver pertinent information about condoms.

Lastly, policy-makers should examine the current disclosure laws about STI's. More research needs to be done about the impact of disclosure. Policy makers should consider both privacy rights and promoting public health in the matter of STI disclosure policy. The research participants who reported disclosing STI status experienced support instead of shame.

Implications for Future Research

Further research needs to be conducted about the experience of loss and grief due to STIs, as there is not a wealth of information. The ambiguous loss model (Boss, 2006) could be used as a framework to examine grief, loss, and STI's. Future research should examine the effects of grief and loss and also make the distinction between those who have a curable or non-curable STI.

Knowledge campaigns should be launched to determine how to reach people in communities of color. Campaigns should also be launched to examine how to effectively transmit information about STI's to the general public. Differences in loss should be explored from the unique viewpoints of both men and women. Loss should also be researched based upon the differences in age and cultural background. In addition, compassion training should

be part of employee education for providers in medical settings to better serve those with an STI diagnosis.

Research should also be done to explore how one's sense of self, or perspective of one's self, may alter as a result of having an STI. Additional studies should be conducted to examine the clarification of one's individual values and values in relationships after being diagnosed with an STI. More research should also include mental health conditions acquired as a result of being diagnosed with an STI.

For additional studies to be completed, advertisement should be made on relevant internet and social media sites, as the internet is utilized daily by millions of people. People of all ages should be sought out to participate in future studies, as the effects of STI's manifest across the lifespan. Longitudinal studies should be administered to examine positive growth and changes that occur after being diagnosed with an STI. Further research will also add to the current body of literature.

Strengths and Limitations

There were both strengths and limitation to this study. First, one strength is that 10 people chose to respond to this anonymous study. Ten people had the opportunity to have their voices heard about the effects of grief and loss and having an STI. Ten stories will now add to the body of literature on this subject. Furthermore, not many studies have specifically targeted the effects of having an STI on loss and grief. Finally, the mixed method allowed both prevalence and quality of the experience to be considered.

While strengths existed in this study, there were also limitations. One limitation was using

flyers to advertise for participants; this was not an effective recruitment method. The flyers were posted for a number of weeks without generating any responses. Posting the link to the survey on social media, STI support group websites, and advertising in Vita.mn magazine finally added to the response totals.

Conclusion

In conclusion, exploring the effects of grief and loss on having an STI brought about interesting data, both qualitative and quantitative. This study may open the door for more awareness and discussions about the topic. It might also encourage additional research to be done on the subject, with the hope of creating effective clinical interventions to aid clients who are working through the difficult waters of having an STI.

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Appendix A

**CONSENT FORM
UNIVERSITY OF ST. THOMAS****GRIEF, LOSS, AND SEXUALLY TRANSMITTED INFECTIONS**

I am conducting a study about examining the effects of grief and loss related to having a sexually transmitted infection and how these effects manifest across the lifespan. I invite you to participate in this research if you are age 18 or over, currently have a sexually transmitted infection, suspect you may have a sexually transmitted infection, or have had a sexually transmitted infection in the past. Please read this form before agreeing to be in the study.

This study is being conducted by Erin Blase, a graduate student at the School of Social Work, University of St. Thomas/St. Catherine University and supervised by Dr. Jessica Toft.

Background Information:

The purpose of this study is to examine the effects of grief and loss related to having a sexually transmitted infection and how these effects manifest across the lifespan.

Procedures:

If you agree to be in this study, I will ask you to do the following things: complete one 10-20 minute anonymous online survey accessed through the Qualtrics operating system during which you will respond to a list of questions about grief and loss issues related to having a sexually transmitted infection. The only identifying information I will ask for is demographic. The results of this survey will be analyzed and the data will be presented on May 19th, 2014. The survey will remain confidential.

Risks and Benefits of Being in the Study:

The study has some risks. Questions will be asked regarding your sexually transmitted infection and how this has affected your mental health and relationships with others. These questions may invade your privacy and the privacy of your romantic partner(s). These questions may also bring up psychological stressors. These questions may make you slightly uncomfortable due to the personal and sensitive nature of the subject matter. Risk will be minimized as this study is confidential. Resources are listed below if you feel that talking to a mental health professional or a medical health professional will be beneficial after participating in this study.

NorthPoint Health and Wellness Center-STI testing and mental health counseling
1313 Penn Ave. N
Minneapolis, MN 55411
612-543-2500
www.northpointhealth.org

Minnesota Mental Health Clinics-grief and loss counseling/adjustment to a new health condition
(651) 454-0114

Minnesota STD/Family Planning Hotline 1-800-783-2287
www.stdhotline.state.mn.us

Minnesota STD Department (612) 676-5414

Room 111 (Ramsey County Public Health) STI Testing Resources
651-266-1352
555 Cedar Street, St. Paul MN

Red Door Clinic- Free testing for STI's
4th Floor, 525 Portland Ave S, Minneapolis, MN 55415
(612) 543-5555

Planned Parenthood- STI testing and education resources
1200 Lagoon Avenue
Minneapolis, MN 55408
612.823.6300

Face to Face Health and Counseling Service, Inc.- HIV Testing and Counseling for Youth up to age 23
1165 Arcade Street
St. Paul, Minnesota 55106
651.772.5555

Minnesota AIDS Project (MAP)- HIV testing for gay and bisexual males
1400 Park Avenue South
Minneapolis, Minnesota 55404
612-341-2060

Turning Point-support groups, education groups, and and STI testing for African Americans
1500 Golden Valley
Minneapolis, MN 55407
612-520-4004

The study has no direct benefits.

Confidentiality:

The records of this study will be kept confidential. Survey responses will be emailed to my Qualtrics account, which is password protected. The data will be analyzed on my personal computer, which is password protected. The data will also be analyzed in the computer lab at The University of St. Thomas, which is password protected. The link to the survey and all survey responses will be deleted by May 19th, 2014.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the survey at any time. Your decision whether or not to participate will not affect

your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. If you decide to participate in the survey, you are free to withdraw at any time without penalty.

Contacts and Questions

My name is Erin Blase. If you have questions later, you may contact me at blas3799@stthomas.edu. You may also contact my instructor, Jessica Toft at 651- 962-5803. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction.

By clicking Accept you agree to participate in this research study.

-Accept

Appendix B

Interview Questions:

Demographics:

1. What is your age? (check one category: 18-25, 26-35, 36-50, 51-65, 66 plus)
2. What is your race? (drop down menu. Check all that apply...African American, Pacific Islander, Asian, Caucasian, American Indian, Latino/a, bi-racial, other)
3. What is your gender? (choose from male, female, transgendered)
4. What is your sexual orientation? (straight, gay, lesbian, bisexual, transgendered, choose from drop down menu)
5. Do you think you have an un-diagnosed STI? (check yes/no)
6. What symptoms do you have? (open text or drop-down menu)

Painful urination, Lower abdominal pain, Vaginal discharge in women, Discharge from the penis in men, Pain during sexual intercourse in women, Thick, cloudy or bloody discharge from the penis or vagina, Abnormal menstrual bleeding, Painful/swollen testicles, Painful bowel movements, Anal itching, Strong vaginal odor, Vaginal itching or irritation, Itching or irritation inside the penis, Fever, Headache, Sore throat, Swollen lymph glands, Rash, Fatigue, rectal pain, blisters on the mouth, genitals or rectum, Weight loss, Cough and shortness of breath, Persistent, unexplained fatigue, Soaking night sweats, Shaking chills or fever higher than 100.4 F (38 C) for several weeks, Chronic diarrhea

7. What type of STI(s) do you currently have? (Choose from list. Check all that apply)

Chlamydia (the clam, Goopy stuff) , gonorrhea (the clap, dose, trip) bacterial vaginosis, chancroid (ru) , donovanosis, lymphogranuloma venereum (climatic bubo) genital mycoplasma, syphilis (pox, bad blood), treponematosi s, pubic lice, scabies, candidiasis/vulvovagina (yeast infection), amebiasis, cryptosporidium, giardiasis (beaver fever), trichomoniasis (trich), cytomegalovirus, Epstein Barr virus (HHV-4), hepatitis A, hepatitis B, hepatitis C, hepatitis D, herpes simplex virus (HSV-1 and HSV-2), human immunodeficiency virus (HIV, has the package), human papillomavirus (HPV), human T-cell lymphotropic virus (HTLV-1), and molluscum contagiosum (water warts) (or none)

8. What type of STI's have you had in the past?

(Choose from list. Check all that apply) chlamydia (the clam, Goopy stuff) , gonorrhea (the clap, dose, trip) bacterial vaginosis, chancroid (ru) , donovanosis, lymphogranuloma venereum (climatic bubo) genital mycoplasma, syphilis (pox, bad blood), treponematosi s, pulic lice, scabies, candidiasis/vulvovagina (yeast infection), amebiasis, cryptosporidium, giardiasis (beaver fever), trichomoniasis (trich), cytomegalovirus, Epstein Barr virus (HHV-4), hepatitis A, hepatitis B, hepatitis C, hepatitis D, herpes simplex virus (HSV-1 and HSV-2), human immunodeficiency virus (HIV, has the package), human papillomavirus (HPV), human T-cell lymphotropic virus (HTLV-1), and molluscum contagiosum (water warts) (or none)

9. How long have you lived with your STI? (less than 31 days, 1-3 months, 4-6 months, 7-9 months, 10-12 months, 1-3 years, 4-6 years, 7-9 years, 10-12 years, 13-15 years, 16-18 years, 19-21 years, more than 22 years)

10. Are you receiving medical treatment for your STI? (YES/NO)
11. Who first knew about your STI? (friend, family, current partner, past partner, acquaintance, MD, spiritual advisor, other-list)
12. Have you had a sexual encounter in which someone gave you an STI and they did not tell you about it? (yes/no)
13. If yes, how did you react to the news? (open text)
14. How have your potential partners found out about your STI? (partner/s was/were diagnosed, told potential partner/s in person, received the news in a text message or email, (open ended) How did they react? (open ended)
15. How often do you disclose this information to potential sexual partners? (always, sometimes, never)
16. If you are in a relationship, what was your partner's reaction to your diagnosis? (open ended)
17. Often times people experience loss when diagnosed with an STI. Which losses have you experienced (if any) since being diagnosed? (loss of romantic relationships, loss of opportunities for sexual encounters, loss of friendships, loss of family relationships, loss of faith/spirituality, uncertainty about the future, loss of the ability to have children, loss of job opportunities, other-list, check all true statements)
18. What changes (if any) have occurred in your romantic relationships due to your STI? (open ended)

19. Have you struggled with mental illness since learning about your STI diagnosis?
(yes/no/not sure)
20. Have you struggled with anxiety due to having an STI? (yes/no/not sure)
21. Have you struggled with depression due to having an STI? (yes/no/not sure)
22. Have you sought mental health/grief counseling for your STI? (yes/no) [if answered
“yes,” go to next two questions. Otherwise skip to 23] How has this support been beneficial?
(open ended) How has it not been helpful? (open ended)
23. Some people experience unfair or prejudiced treatment after being diagnosed with an STI
from family, friends, or in the media. What has been your experience with stigma since being
diagnosed? (check all that apply. Loss of family relationships, loss of friends, loss of connection
to spiritual community, felt judgment from family/friends/spiritual community, felt judgment
from social media sites, experience with bullying, felt judgment from jokes made about STI’s in
the media; check all that apply, or none, other-free text)
24. Have you attended a support group for your STI? (yes/no) {if yes, proceed to next
question. If no, skip to question 25} In person or online? (Yes/No78)
25. What positive changes have you experienced since being diagnosed with an STI? (open
ended)
26. How have you grown as a result of being diagnosed with an STI? (open ended)

Appendix C

Recruitment Flyer

University of St. Thomas

Volunteers Needed For A Research Study:

Grief, Loss, and Sexually Transmitted Infections (STI's).

Seeking volunteers who currently have an STI, or have had an STI in the past, to participate in an anonymous, online survey. As a participant, you will be asked 30 SHORT questions about grief and loss issues related to having an STI.

If you are interested and age 18 or over, please take a link to the survey below.

This study has been reviewed and approved by the Institutional Review Board

University of St. Thomas

http://stthomassocialwork.qualtrics.com/SE/?SID=SV_4NI2NIcG8TIDqXX