

Summer 8-9-2019

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“May I Be Kind to Myself”: A Study on Self-Compassion and Shame on a HIV Nightline

By

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A Capstone Project submitted in partial fulfillment of the requirement for the degree of
Master of Science in Behavioral Health

University of San Francisco

San Francisco, CA

August 2019

A STUDY ON SELF-COMPASSION AND SHAME

Abstract

Purpose: The purpose of this study was to strengthen San Francisco Suicide Prevention's HIV Nightline (NL) communication with worried well callers. As a result, this study focused on identifying any covert emotions this population experienced, such as shame, guilt, and judgement. In addition, precursors to worried well behavior were explored, such as the influence of sex act and sexual partner. A needs assessment was conducted with hotline staff and volunteers, with a brief self-compassion intervention piloted over a two-week period.

Methods: Data collection included 1.) a focus group with hotline staff and volunteers 2.) a volunteer survey to learn about worried well behaviors and 3.) a caller questionnaire, adapted from a Self-Compassion Scale. Finally, self-compassion exercises were piloted by three overnight staff, and one volunteer.

Results: The focus group and volunteer survey provided insight in to the background of the worried well. On the caller questionnaire, callers identified having shame, low self-compassion, guilt, and judgement. However, many volunteers did not ask the questions from the caller questionnaire. Male callers who reported infidelity were receptive of the self-compassion exercises. The exercises were disseminated to a small sample of 16 callers. Out of the 16 callers, nine callers agreed to do one of the exercises. Four out of the sixteen declined, and the other seven callers participated in breathing exercises.

Discussion: As a result of some of the questions on the caller questionnaire not being asked to callers, findings suggested volunteers may not have been comfortable asking questions around shame and self-compassion. Self-compassion therapy is not recommended for "obsessive" worried well callers. They may have a psychiatric component co-existing. However, self-

A STUDY ON SELF-COMPASSION AND SHAME

compassion therapy is recommended for regular worried well callers who are struggling with guilt and shame.

Keywords: worried well, shame, guilt, HIV, compassion, judgment, anxiety

A STUDY ON SELF-COMPASSION AND SHAME

Literature Review

Introduction

In the early 1980s when Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) were identified, many individuals feared they had HIV (Scragg, 1995). HIV/AIDS became a social stigma. HIV telephone hotlines became the space where callers would voice their concerns. Some of these callers eventually accepted they did not have HIV, while others continued to fear they had the virus despite numerous negative HIV tests (Scragg, 1995). Despite hotline telephone counseling, HIV transmission education, and physician reassurance, their conviction they had HIV do not waver. Labels and psychiatric diagnoses have been applied to these individuals, such as “worried well,” AIDS phobia, AIDS panic, and pseudo AIDS (Scragg, 1995). These labels have been defined in the literature as having an underlying fear component, yet the emotional undercurrents behind these fears have yet to be assessed.

The Worried Well

“Worried wells” are a group of individuals who live in a constant state of worry that they have an illness or disease. A “worried well” related to HIV/AIDS has an overwhelming fear they have been exposed to the HIV virus, despite having been at little to no risk of having it (Lombardo, 2004). Despite repetitive negative serological testing and clinical review, “worried wells” continue to call HIV/ AIDS hotlines (Lombardo, 2004). The Nightline at San Francisco Suicide Prevention (SFSP) serves as a line for emotional content to be discussed. However, the agency is continuing to receive calls from worried wells who superficially want nothing more than reassurance they do not have HIV. Giving temporary reassurance to a worried well only increases their call volume. In addition, this distracts volunteers at SFSP from tending to other callers who may be in crisis.

A STUDY ON SELF-COMPASSION AND SHAME

Characteristics of the worried well. Worried wells typically have low risk sexual encounters, and secret and guilt-provoking sexual activity. The rise of HIV/AIDS worried wells came from misunderstandings of HIV transmission, diagnosed hypochondriasis, feelings of guilt, underlying psychiatric disorders, difficulties with sexual adjustment, covert sexual activity, history of STDs, psychological problems, and dependence on romantic relationships (Lombardo, 2004). Bor, Miller, & Goldman (1993) noted that in some cases, worried wells have a misunderstanding of how HIV is transmitted. For example, they may lack knowledge on safe sexual behaviors because they did not receive formal sex education. Also, worried wells may have misperceptions from the public media's limited relayed information (Bor, Miller, & Goldman, 1993).

Worried Well Stages

In a study by Lombardo (2004), 25 individual "worried well" narratives posted to the "Messages of the Worried well" forum page of The Body Web site from July 1998- January 2003 were analyzed. Through the anonymity of posting online, informants were able to be more honest. Out of the 14 postings, 11 were men and 3 were women. Three "worried well" stages were constructed from the researcher's examination of similar emergent themes in each "worried well" experience. The three stages a worried well goes through (not always linear) include, (1) the HIV Concern Stage, (2) the Self-Diagnosis Stage, and (3) the Post-Testing Stage.

HIV Concern Stage. It was an "HIV Concern" event that led the informants to become concerned they contracted HIV after looking back on specific sexual acts that may have put them at risk for HIV (Lombardo, 2004). They convinced themselves they were actually HIV+. Six informants attested they participated in unprotected sexual acts, and 7 mentioned they had protected sexual intercourse. Twelve of the informants did not discuss the type of sexual act.

A STUDY ON SELF-COMPASSION AND SHAME

The Self-Diagnosis Stage. The worried well began to seek out a need for testing, and an HIV diagnosis. They became obsessed with finding information about HIV/AIDS from the medical establishment, internet, and HIV/AIDS hotlines. It was during this stage, they phoned HIV hotlines, sometimes even disguising their voice to avoid being identified (Lombardo, 2004). One informant noted he “harassed” both hotlines and health care workers as a result of his fixation on HIV. Also, informants cited they became so fixated on HIV that they lost enjoyment in everyday activities. Their quality of life was impacted. For example, simply turning on a television show that mentioned HIV lead to obsessive thinking.

Post-Testing Stage. This stage marked either acceptance of the negative test result or having found trust in HIV hotlines, and the medical system. Participants believed their symptoms were caused by something else and some cited the whole process as a learning experience. For example, admitting they should have worn a condom and not been under the influence. (Lombardo, 2004).

Causes of Worried Well Behavior

Worried well behavior has many causes. It may be secondary to psychiatric conditions, such as hypochondriasis and Obsessive Compulsive Disorder (OCD). As a result, worried wells may suffer from OCD itself, or OCD that results from guilt. In addition, worried well behavior stemmed from males who struggled with sexual expression (identity), and males who reported developing a fear of HIV after committing infidelity and/or after having relations with a sex worker.

Illness Phobia/Illness Conviction. When the root problem is fear of HIV, individuals are diagnosed with illness phobia, a configuration of hypochondriasis. Hypochondriasis has two parts: 1.) an individual believes they actually have a disease (illness conviction), and 2.) they

A STUDY ON SELF-COMPASSION AND SHAME

have a hyperbolic fear they will contract a disease (illness phobia) (Scragg, 1995). Those who have an amplified fear of HIV align with the symptoms of obsessive compulsive disorder (OCD). These individuals experience recurring thoughts and impulses which result in anxiety and other emotions (Scragg, 1995). In addition, their fears regarding HIV manifest as coexisting “symptoms.” However, these symptoms may also stem from other areas in their life, such as in relationships and sex (Bor, Miller & Goldman, 1993).

OCD Related to Guilt. In a study from Miller, Acton, & Hedge (1988), 19 patients labeled as “worried well” appeared with self-perceived symptoms of HIV. These symptoms represented anxiety. Patients were compulsively checking their bodies for signs of HIV, thinking back on past sexual encounters which they perceived as high-risk, mentally seeing images of HIV and death, and struggling with fears they infected past partners and their own families. The need for reassurance to confirm they did not have HIV was also present. Six heterosexual males and two females experienced guilt related to marital infidelity, while homosexual and bisexual patients struggled with acceptance over their sexual orientation.

Studies Showing OCD Related to Guilt. Some patients with obsessive thoughts and fear of HIV experienced thoughts and rituals that had nothing to do with HIV. Guilt was present in many patient studies related to fear of HIV (Scragg, 1995). According to Rachman (1993), guilt may arise within an individual because of a self-inflated sense of responsibility. Their own views toward personal, “bad” actions and thoughts resulted in guilt because they felt they did not live up to their responsibilities. (Rachman, 1993).

Van Oppan and Artanz (1994) used Aaron Beck’s cognitive behavioral therapy (CBT) framework to better understand how OCD patients living with a continuous fear of HIV exhibited anxiety and depressive symptoms (Scragg, 1995). Similarly, to Rachman, Van Oppan

A STUDY ON SELF-COMPASSION AND SHAME

and Artzn (1994) found that low self-esteem, depression, and guilt resulted from the individual's perception of having a high responsibility for an event that took place in the past, and one which they saw as negative. As a result, it was noted the obsessions and rituals of OCD performed around HIV helped the individual alleviate and avoid feelings of unworthiness, feelings of failure, and guilt correlated to a negative act. Fear of HIV is an example of this (Scragg, 1995). For example, worried wells felt if had not been in a bar with prostitutes, then HIV would not be a risk factor.

Beliefs Toward The Self. Owens and Ashcroft (1982) proposed that individuals with specific background factors, or who had internal precursors were more vulnerable to developing a fear over HIV(Scragg, 1995). In another study by Wells and Hackman (1993), guided imagery was used to bring out core beliefs in 10 patients (three had fears over HIV). Results showed these patients had negative views of the self, with feelings of inadequacy, and felt they were being punished. Moreover, negative views of the self-arose when worried wells felt they put themselves in a risky situation or "triggering event." This disrupted their core beliefs which lead them to have guilt and worry about HIV (Scragg, 1995; Wells and Hackman, 1993).

Identity Conflicts. As Miller, Acton, & Hedge's (1988) study showed earlier, worried wells face internal conflicts with expression of their sexuality. In addition, the presentation of worried well behavior was seen in individuals who struggled to express their sexuality as a result of either religious or family influence. As a result, they would have covert sexual experiences, and guilt would follow. Miller, Acton & Hedge's (1988) study with 19 patients concluded homosexual and bisexual patients felt they could not be vulnerable about their sexuality.

Worried Well similarity in Montana Study of MSM. Findings from a focus group the researcher conducted (See Results) had an alarmingly similar comparison to literature found

A STUDY ON SELF-COMPASSION AND SHAME

from a study conducted in Montana. A participant in the focus group gave an example of a worried well caller on the San Francisco HIV Nightline who had to leave his southern, conservative hometown in order to have sex with other men. He shared the caller did not feel accepted or safe in his hometown.

Similarly, “An Assessment of the HIV Prevention Needs of Men Who Have Sex With Men (Schwitters, Sondag, & Hart, 2011) highlighted MSM between the ages of 18-69 in rural Montana who left the state in order to have sex with other men for the purpose of keeping their sexual identities concealed. Stigma was the number one reason men chose to remain in the closet. In addition, other reasons were shame, unacceptance, family, religion (Catholic/Christian), social norms, decreased opportunity, masculinity, homophobia, labels, and others. Also, MSM who were married used the internet to seek out partners. These men asked for a picture beforehand to ensure their wives would not find out. They too were afraid they would lose their children.

Infidelity and/or Sex Worker Relations. Another origin of worried well behavior stems from individuals who cheated and/or committed infidelity while in a monogamous relationship. Specific examples of infidelity were with sex workers. In Lombardo’s (2004) study of 25 personal narratives, sexual transgressions drove many to be concerned they had HIV. One account noted it was a sexual encounter outside his regular relationship that prompted him to worry about HIV. He attested that he had made a mistake. Another stated that he had a low risk encounter with a sex worker, and the sinus infection he had weeks later led him to match those same symptoms with HIV. In addition, the type of sexual partner played a role in informants thinking they had HIV. For example, unprotected high risk sexual encounters with sex workers (Lombardo, 2004).

A STUDY ON SELF-COMPASSION AND SHAME

In the Post Testing Stage, some worried wells came to the realization that their symptoms were caused by something else, such as anxiety, which stemmed from another event. Yet, other informants attested their symptoms went away after opening up. One individual noted that once he was able to discuss his sexual transgressions with his doctor he believed his negative test results. Similarly, another reported that confessing to a HIV hotline counselor he cheated on his girlfriend allowed him to accept his test results because the counselor told him, “he should forgive himself” rather than “torture himself any longer” (Lombardo, 2004).

Moreover, worried well fears over HIV symbolized guilt surrounding their sexual acts. Miller, Acton & Hedge’s (1988) study showed worried wells’ struggles with sexual guilt, anxiety, and vulnerability resulted from the general public’s perception toward HIV/AIDS. Within the study 31.0 % of heterosexual men reported sex-related guilt. 15.0% of the males were married. Sex-related guilt was reported in 63.0% of homosexual patients. However, this study was conducted more than thirty years ago and cultural norms around sexuality have changed.

Shame’s Effects on Individual Health

Unlike guilt, there has not been any research conducted on shame within the worried well population. However, sexual identity has been the victim of shameful stigma (Dolezal and Lyons, 2017). Shame has been cited as an active determinant of health because of its implications on individual health and health-related behaviors (Dolezal and Lyons, 2017). Chronic shame has a lasting effect. It leads to depression, stress, anxiety, substance use, and cardiovascular implications (Dolezal and Lyons, 2017). Individuals may not even be aware they are experiencing it. As a result, shame manifests as other emotional distresses, and

A STUDY ON SELF-COMPASSION AND SHAME

psychopathological symptoms. Shame is often misinterpreted as something else (Dolezal and Lyons, 2017).

The Definition of Shame and its Research. Shame researcher, Dr. Brene Brown defined shame as “the intensely painful experience of believing we are flawed and therefore unworthy of love and belonging” (Brown, 2006). Shame is cited as “harm” to the self and the belief “the self” is bad. In contrast, guilt is the individual’s fear of having caused harm to other people. (Gilbert, 2010). For example, “I did something bad,” versus shame, “I am bad” (Brown, 2006).

Dr. Brown conducted a study with more than 700 men and women to learn about their definitions of shame. After interviewing both men and women, she found they had the same views of shame. For example, both groups cited shame as provoking “feelings of fear, blame, disconnection, and unworthiness” (Brown, Hernandez, & Villarreal, 2009, pp. 355-360). However, it was why men and women experience shame that differed, such as masculine and feminine norms. Men stated they felt trapped by the norms of “do not be weak” (Brown, Hernandez, & Villarreal, 2011). From these interviews, Brown constructed the shame resilience theory. In order to be shame resilient, individuals have to lower their fear, blame, and judgement to then increase their vulnerability and empathy (Brown, 2006).

Worried Well Account of Shame. In “Cheating Almost Killed Me:” Collaborative Care for A Man Who Believed He had AIDS (Edwards and Turnage, 2003), a 42 year old male attested that his HIV symptoms began two weeks after he had an extramarital affair. He continued to believe he had HIV, despite numerous negative test results. In the previous affair, his “symptoms” disappeared when he told his wife. However, his wife threatened to leave him if it happened again. As a result, he withheld his most recent affair. His symptoms did not go away, and he became fixated on the belief he had AIDS. His psychologist used a form of narrative

A STUDY ON SELF-COMPASSION AND SHAME

therapy to identify the problem that was actually operating his life; separate from him as a person. The man identified he felt shame over the choices he made in his earlier life; most recently his extramarital affair. His shame led him to keep a distance from his wife and son out of fear he would infect them.

Current Research on Shame and Self-Compassion

Compassion-focused therapy was created for individuals who experience high levels of shame, judgement, and self-criticism. It was based on the premise that compassion is the most effective antidote to shame (Gilbert & Choden, 2014, pp. 53-58). Individuals with low self-compassion are more susceptible to having shame (Gilbert & Proctor, 2006).

Self-Compassion Therapy (SCT) is compassion focused inward (Germer & Neff, 2013) SCT's purpose is to serve those dealing with personal failure, mistakes, and feelings of inadequacy; as well as painful circumstances (Germer & Neff, 2013). SCT consists of three components: loving kindness, common humanity, and mindfulness. Kindness is centered on understanding the self when failure and suffering arise and treating the self as one would treat a friend. Common humanity recognizes that all humans experience suffering, and mindfulness involves seeing situations exactly as they are (Neff, 2003).

A study by Reily, Rochlen, & Awad (2014) with 145 heterosexual men from the general community and a Southwest institution concluded that masculine norms were negatively correlated with self-compassion. Prior studies had showed masculine norms decreased male vulnerability. Results showed that men who were compassionate and emotionally balanced had more self-confidence, and were able to forgive their faults (Reily, Rochlen, & Awad, 2014).

Compassionate Mind Training. A form of SCT is compassionate mind training (CMT). CMT was developed for individuals struggling with shame and self-critical beliefs. The

A STUDY ON SELF-COMPASSION AND SHAME

purpose of CMT is to train the brain to have compassion. In a study by Johnson and O'Brien (2013), shame-prone university students (less than 40 years old) in Canada reflected on a shameful event. Thereafter, they were assigned randomly to 1.) write about the shaming experience with self-compassion 2.) use writing (without self-compassion) to express their feelings 3.) assigned to neither. After two weeks, individuals in the self-compassion group showed a decline in shame and depressive symptoms.

Project Focus Identified From Literature Gap

Although shame has been used in the psychotherapy setting, it has seldom been the focus of intervention research (Dearing and Tangney, 2011). There has been research done on the use of self-compassion with shame-prone individuals. However, there have not been any interventions geared toward addressing shame and other covert emotions on crisis and HIV hotlines, specifically with worried wells. However, emphasis from HIV counselors has been placed on reassurance of the worried well caller's anxiety. The problem is callers' anxiety has not been relieved despite negative test results. A test result does not address the feelings surrounding the risk taking event. When HIV counselors listen for other cues from the caller, such as feelings of shame, guilt, regret, and judgement affiliated with their anxiety, the behaviors of the worried well can be addressed (Calla, Chan, Gaylord, & Lin, 2009).

A STUDY ON SELF-COMPASSION AND SHAME

Agency Profile: San Francisco Suicide Prevention

Background

The agency where the researcher is conducting fieldwork is San Francisco Suicide Prevention. They are a non-profit organization that runs a crisis hotline. In addition, the agency offers a variety of services. San Francisco Suicide Prevention offers 24/7, confidential support to callers, who are feeling suicidal and seeking emotional support. The organization is centered around Carl Rogers' "Client- Centered Approach." This approach prioritizes the caller's feelings, emotions, and feedback. As a result, the mission of San Francisco Suicide Prevention "is to provide emotional support, education, assistance, and intervention as necessary to all persons in crisis and those impacted by them, with the goal of reducing suicides and self-destructive behaviors (San Francisco Suicide Prevention Manual, 2019)."

History

San Francisco Suicide Prevention was the first crisis center formed in the United States. In 1962, Bernard Mayes, an Episcopal priest started to look at San Francisco's elevated suicide rate after being offered an assignment by the British Broadcasting Company (BBC). His findings made a huge impact on him, and as a result Mayes launched a volunteer-staffed suicide hotline (SFSP Manual, 2019). Due to the severity surrounding the topic of suicide, he faced skepticism because the volunteers were not licensed clinicians. As a result, he established a model for a telephone service staffed by carefully selected and highly trained volunteers (SFSP Manual, 2019). What first started in the basement of a building in the Tenderloin, with twelve volunteers, today oversees 200 volunteers.

A STUDY ON SELF-COMPASSION AND SHAME

Overview of San Francisco Suicide Prevention

Services Provided. San Francisco Suicide Prevention offers services which include: The Crisis Hotline, the HIV Nightline, Drug and Relapse Line, the Youth Risk Reduction Program, the Grief and Survivors Program, and training and community outreach. Also, the agency takes calls from external lines (answered for other suicide agencies). These include the National Suicide Prevention Lifeline (NSPL), and Suicide Prevention of the Central Coast (24- hour hotline in Santa Cruz). The Lifeline directs callers to their local or closest crisis line. SFSP answers this 24/7. (SFSP Manual, 2019).

Crisis Hotline. The local San Francisco Crisis Hotline takes calls 24-hours a day, seven days a week. Generally, callers who call from out of California are past Bay Area Residents who moved, but still rely on the hotline for support. Both volunteers and hotline staff answer calls. Based off SFSP's operation under a crisis intervention model, the hotline provides immediate emotional support. A misconception of the hotline is that callers are diagnosed and "treated" on the phone. However, volunteer counselors do not diagnose or provide clinical support. The agency's philosophy is to "meet callers where they're at."

The HIV Nightline. The Nightline (NL) is the second highest operated line. The Nightline provides emotional support for HIV+ individuals, their caregivers, those worried about being at-risk for HIV, and individuals living with AIDS. A majority of the callers are known as "worried wells." The term was penned because individuals would call in repeatedly asking about testing information related to HIV. They have severe anxiety over contracting HIV. The current project focuses on convert emotions, such as shame, guilt, judgment, etc. that are causes of "worried well" behaviors.

A STUDY ON SELF-COMPASSION AND SHAME

Other Services. The HIV Text line, and Drug and Relapse lines are supportive lines answered by both. The Drug and Relapse Lines receive calls from individuals who may have relapsed, regular callers who are addicted to drugs, and third party callers looking to seek help for a family member or friend. Outside of the hotline, the Youth Reduction Program (YRP) gives suicide prevention presentations to roughly 5,000 middle and high schools in the San Francisco Unified School District (SFSP Manual, 2019). The agency's Outreach Department consists of education and training (i.e. YRP) and community outreach in the Bay Area. Finally, SFSP runs a grief group called "The Survivors of Suicide Program." The group is held for eight weeks, five times a year (SFSP Manual, 2019).

Staffing

In July 2019, SFSP announced their merger with Felton Institute, a mental health and social services agency that has provided care for adults, children, seniors, and families. The merger allowed for a broader suicide prevention continuum of care to be provided.

At the core of SFSP are the crisis hotline volunteers, who are overseen by the hotline manager. Currently, the permanent staff to volunteer ratio is 5:150 volunteers. The crisis line staff includes: the crisis hotline manager and youth outreach coordinator. In addition, SFSP has a Program Director who oversees the hotline and grief services, a Director of Development, and a Program Coordinator of Outreach and Communications (SFSP Manual, 2019).

Partnerships

San Francisco Suicide Prevention is affiliated with two accrediting agencies; the American Association of Suicidology (AAS), and the National Lifeline. Some of the agency's community partnerships include: the San Francisco Police Department, La Casa De Las Madres

A STUDY ON SELF-COMPASSION AND SHAME

(intimate partner violence support for women and children), Woman Inc., Project Homeless Connect, the Shanti Project, and the San Francisco Unified School District.

Funding

San Francisco Suicide Prevention is a non-profit organization funded through donations from grants, corporations, small businesses, fundraisers, special events, and family foundations. SFSP receives a large portion of its funding from the San Francisco Public Health Department. As a result of SFSP's partnership with Suicide Prevention of the Central Coast, the agency receives funding for answering overflow calls. According to the agency's 2017-2018 Annual Report, funding came from government grants (56%) and private giving (23%) (SFSP Manual, 2019).

Methods

Research Question(s), Purpose, Aims

The needs assessment methods were designed to identify the precursors and correlates (i.e. emotions, sex acts, type of sexual partner) to worried well behavior, and to see if brief self-compassion exercises reduced the number of worried well calls. Also, to assist San Francisco Suicide Prevention by addressing covert emotions that lie at the root of worried well behaviors. These research questions were answered by:

1. Working with hotline staff and volunteers, and analyzing their individual interactions with worried well callers.
2. Introducing a caller questionnaire for volunteers to use as a guide to improve worried well caller emotional communication.

A STUDY ON SELF-COMPASSION AND SHAME

3. Assessing if worried well callers had self-compassion; specifically with those who said they cheated while in a committed relationship, male callers who had sex with men (MSM), and callers who participated in sexual activities with a sex worker.

Participants

Participants in this research project were callers on the HIV Nightline, hotline volunteers, and hotline staff. Each group of participants played a role in data collection methods. Both hotline volunteers and overnight staff used the questionnaire with worried well callers. In addition, volunteers were introduced to Self-Compassion Therapy.

Sample

Purposive sampling was used when collecting data for the caller self-compassion questionnaire. Women were excluded from this study because there are so few of them that call on a regular basis. Worried well callers were distinguished from non-worried well callers by looking at caller history in the SFSP call database. Non-worried well callers generally call the NL once with a specific question about HIV transmission.

Data Measures

Researcher's Nightline Call Monitoring Observations. Prior to choosing an area of focus, the researcher monitored all calls on the hotline, including the crisis and HIV Nightline. The goal was to gain an understanding of some of the barriers callers faced. The researcher listened to over 50 calls, and recorded topics that came up on calls on a spreadsheet.

Focus Group (Qualitative). After choosing to do research on worried well callers, a formal focus group took place with three hotline staff members and one volunteer at San

A STUDY ON SELF-COMPASSION AND SHAME

San Francisco Suicide Prevention. Flyers were made, and placed in the call room prior to encourage participation from all volunteers. Each participant received a copy of the informed consent form to sign (See Appendix A). They were aware of the two hour discussion, and that anything said would be kept confidential. Sixteen questions served as discussion points (See Appendix B for focus group guide). In order to learn about worried well callers, the goal was to discuss any underlying emotions worried well callers experience. At the end, questions the researcher adapted from a Self-Compassion Scale (Neff, 2003) were discussed. These were going to be used in a questionnaire asked by hotline volunteers to worried well callers. Goals were to obtain feedback from staff and volunteers beforehand.

Volunteer Survey (Qualitative). A survey (See Appendix C) was created via Qualtrics for hotline volunteers who were unable to attend the focus group. The same 16 questions used in the focus group were addressed in the survey. In addition, this qualitative method allowed for volunteers to share their experiences talking to worried wells that they might not otherwise be comfortable discussing in a formal setting.

Caller Self- Compassion Questionnaire (Qualitative). A total of 239 callers received the questionnaire on self-compassion (See Appendix D). Each item on the questionnaire was revised multiple times after receiving feedback from the hotline manager, volunteer coordinator, and volunteers. The questions on the survey were written for the purpose of a ten to fifteen minute phone call, and adapted from a Self-Compassion Scale (Neff, 2003). All phone calls applicable to the questionnaire had corresponding caller notes from the hotline volunteers and staff. Caller notes were collected by San Francisco HIV Nightline volunteers and staff from April to June 2019. As the literature stated, individuals who have low self-compassion experience shame. The researcher was assessing if the caller was prone to shame. Questions

A STUDY ON SELF-COMPASSION AND SHAME

were centered on asking callers if they felt embarrassed, self-conscious when looking up the signs/symptoms of HIV online, judgmental, and compassionate towards themselves when feeling guilty.

Procedure for Pilot of Self-Compassion Exercises. Three self-compassion exercises were adopted from Drs. Kristin Neff and Christopher Germer's workbook on Self-Compassion which consisted of a Self-Compassion Break, Self- Compassion and Shame, and Self-Compassion and Forgiveness (Germer & Neff, 2018). These three were chosen to be used within the 10-15 time frame of a call. The purpose of the Self -Compassion Break exercise was to teach callers about the three components of self-compassion. Six individuals were chosen (3 hotline overnight staff, 3 volunteers) to pilot the exercises with Nightline callers over a two week period. The hotline manager recommended overnight staff pilot half the exercises because staff were working on the hotline two to three nights a week compared to volunteers who commit to one four-hour shift a week. The goal was to expose as many callers to the exercises in the short two week period. The overnight staff and volunteers chosen received detailed instructions in person and via Google Documents about the self-compassion exercises. In addition, throughout the two weeks, the researcher communicated with them through e-mail.

Based on the caller's answers to the questionnaire, staff and volunteers chose one of the three exercises if the caller was willing to participate. They were asked to document in the call database two outcomes 1.) did the caller agree to do the exercise 2.) what was the caller's response to doing the exercise selected?

A STUDY ON SELF-COMPASSION AND SHAME

Results

The goal of this research study was to determine what covert emotions were at the core of worried well behaviors. However, upon the researcher's analysis of the data it appeared the type of sexual act and sexual partner played a role on those emotions. The methods used included a needs assessment done by conducting a focus group with hotline staff and volunteers to gain insight in to worried wells. A Qualtrics survey was sent out to volunteers who could not attend the focus group. Based on volunteer feedback from the self-compassion questions in the survey, a caller questionnaire was implemented with worried well callers. Finally, brief self-compassion exercises were piloted over two weeks. The purpose was to see if the exercises decreased the number of worried well calls, and provide volunteers with a guide to open up emotional communication with worried wells. Result findings were divided according to their order in the process of data collection: 1.) a focus group, 2.) volunteer survey, 3.) caller questionnaire, and 4.) self-compassion exercise(s) feedback. A **conceptual model** (see **Appendix E**) was constructed depicting the sequence of the worried well emotional journey on the Nightline.

Overview of Results

The caller questionnaire showed callers struggled the most with the covert emotion, judgement (84.0%). Only 26% of callers felt they had self-compassion, and as a result, 57% had shame. New findings emerged that were not expected. For example, it was not just concealed emotions callers were struggling with, but the influence of the type of sexual act and sexual partner. These increased certain emotions. Male callers who reported sleeping with other men identified being judgmental toward themselves (23%). Callers who participated in anal sex had high levels of shame (20.3%) compared to oral sex (13.6%). In addition, it is important to note

A STUDY ON SELF-COMPASSION AND SHAME

that many volunteers did not ask the questions from the caller questionnaire. Detailed findings from this are discussed further on.

Focus Group

Due to time constraints of the agency, the focus group was only able to be held on a weekday morning. As a result, three staff and only one volunteer participated. From the conversation, 11 themes were present (See Table 1). The 11 themes were: worried wells, HIV, health anxiety, questioning, obsessive behaviors, emotions, identity, types of sexual relationships, cheating and/or infidelity, stigma, shame, and guilt. Highlights that helped the researcher understand who the worried well were included an overview of the two types of worried well callers and their surrounding circumstances. “Obsessive” worried wells have an underlying psychiatric component, such as illness phobia where they believe HIV is transmitted through non-probable ways. They have searched the internet for every possible symptom of HIV believing they have HIV. “Obsessive” worried well callers have no desire to discuss emotional content with volunteers. However, regular worried wells generally only call once. They will discuss emotional content. When “regular” worried wells call, circumstances related to infidelity, and/or having relations with a sex worker usually come up. If willing, emotions such as guilt, shame, etc. are not brought up by the caller until the end.

Almost all calls on the Nightline are from men. It is very rare for a woman to call in. In general, some first time callers who utilize the Nightline or the HIV Text line have a misconception that the lines are staffed by medical professionals. Hotline counselors are volunteers and hotline staff. Each call begins with the phrase, “I have a question.” Specifically, worried wells focus on informational content and rarely ever discuss emotional content when asked. However, the purpose of the Nightline is to provide emotional support, instead of simply

A STUDY ON SELF-COMPASSION AND SHAME

testing information. The overall goal of a successful worried well phone call is they do not call back. In addition, there is a lack of sex education with callers as to how HIV is transmitted. For example, some callers think they contracted HIV because they touched a bench that was sweaty.

Table 1: Focus Group Themes

Emergent Themes in Focus Group	Participant Quotes
Worried Well	<p><i>“The goal with a worried well call is to reach them to a point where they don't call back.”</i></p> <p><i>“. . . so for your typical worried well, they're questioning if they're safe. There's the, they have this inkling, this feeling that they're in danger. But there's conflict. When I talk with a caller who has had no exposure or has tested negative, but is 100% convinced they have HIV; the problem that they're facing is no one believes them that they have HIV, and the doctors won't treat them. They believe they need to get on the antivirals. Their husband's threatening to leave them . . .”</i></p>
HIV	<p><i>“. . . and then those are the callers that are like, okay, this isn't about HIV. This is about this really intense emotional experience that I'm having, having. And that's the beginning of the process.”</i></p>
Health Anxiety	<p><i>“. . . so I think one of the things that's really interesting is this health anxiety, especially around sexually transmitted diseases, it does have a longer history that it doesn't begin in, uh, in the late seventies with the emergence of HIV.”</i></p>
Questioning	<p><i>“It's like almost every call starts with, I have a question, but sometimes they won't even give their name.”</i></p>
Obsessive Behaviors	<p><i>“So obsessive worried wells worry about it multiple times, and it's like almost like they are reading from a script.”</i></p>

A STUDY ON SELF-COMPASSION AND SHAME

Emotions	<p><i>“You can tell when someone I would say. . . it's a hint, someone's not going to be as frequent as a worried well caller when they <u>immediately work with you on those emotions.</u>”</i></p>
Identity and Types of Sexual Relationships	<p><i>“ It was the first time they did something and it doesn't seem to mesh with who they feel that they are and a big part of it is saying you are allowed to make mistakes and that the first step is to forgive yourself. “</i></p>
Cheating/Infidelity	<p><i>“They don't and they can be secret, and they live with this kind of split life that is also really challenging. And I think that's a <u>space where we see a lot of guilt</u> because it's not that they don't care about their families necessarily. <u>One of my interpretations . . . there's a lot of these callers who have affairs, it's usually with prostitutes, or men sleeping with men, who's the, you know, when we see affairs on calls, I think those are probably the most, uh, the two most common scenarios.</u> Um, a lot of the fear and anxiety that I hear from them, it's about them being afraid of impacting people they care about. <u>And so they're, infidelity isn't an absence of care. It is problematic.</u>”</i></p>
Stigma	<p><i>“ . . . it's a really scary disease and it makes sense that people's fears would latch on to it, but it's not just that it's a racialized disease, and it's a sexuality disease where people look at it within <u>specific biased lenses.</u> And so there's a lot of <u>societal baggage that comes with HIV that might not come with other STDs.</u>”</i></p>
Shame	<p><i>“I think the immediate superficial, not superficial, what the surface emotion that you're dealing with is the anxiety. Yeah. Where you're like, that's the first piece of it, so you can't get to the other stuff without working with the anxiety first. But once you get below that, <u>I think it's almost always shame and stigma and where that shame and stigma comes from.</u>”</i></p>
Guilt	<p><i>“But what I also find interesting is you don't hear about this <u>infidelity or shame or guilt at the beginning or even in the middle of a call.</u> It's not till I <u>have noticed that you start asking about their support system,</u> that they'll say like, oh, well I have a wife, but this is a problem. Like I can't talk to her about it because, and then like, okay, I'll (P2) go into like what happened with the sex worker or with someone</i></p>

A STUDY ON SELF-COMPASSION AND SHAME

in their lives they (caller) didn't know they were interested in."

Volunteer Survey Findings. The volunteer survey (See Appendix C) recorded 24 responses; however, only 15 responses were complete. Participants may not have had the time to complete text responses for all 16 questions. Structural themes were pulled from each question and then emergent themes were generated based on similarity between topics and answers. Some emergent themes included: symptoms, testing accuracy, questioning, exposure, casual sex, sex workers, guilt related to infidelity and cheating, shame related to infidelity cheating; MSM; sexual orientation, risk, and obsessive behaviors.

When asked to provide feedback on the first draft of self-compassion questions for callers, volunteer responses were mixed. For example, the question, "Are you judgmental and hard on yourself when it comes to the people you have sex with?" was favored among the majority. One volunteer noted that this particular question (#4), #3 and #6 were "really great. They touch upon the shame, anger with self, and isolation they may feel." Another volunteer said, "I like #4 because that scenario comes up so often!" Question 5, "Do you feel you have been showing yourself self-respect throughout this process," was also favorable. Other feedback provided suggestions on rewording the questions. There was only one volunteer who said, "I would not ask any of these questions." All feedback was taken into consideration and the questions were modified. The final version appeared on the Nightline Database for volunteers to ask callers.

Caller Questionnaire. After thoroughly analyzing the caller questionnaire and call notes, demographics were noted. Many of the demographics were unknown. The sample of

A STUDY ON SELF-COMPASSION AND SHAME

demographics included 127 males. This was because either the volunteer did not mark the box on the database or the NL caller never shared their race or age with a counselor. Some worried well callers have an established rapport with the NL because they call so often and these demographic variables were collected over months and years. Yet, the same applied to callers with no identifying information. As a result, the largest percentage of worried wells race/ethnicity and age range was unknown. Unknown race/ethnicity was 66.0%, and unknown age range was 53.0% (See Table 2). In the unknown category, callers within the 13-19 range called the most. Caucasian/White males, ages 20-29 (18.0%) were the second.

Table 2. Caller Demographic Variables

Race/ Ethnicity	n=Total	Caucasian/White n= 23	African American/Black n= 8	Hispanic/Latino n=5	Asian n=4	Unknown n=87
Age Range	13-19	6	1	1		6
	20-29	11	2	1	4	5
	30-39			1		2
	40-49					6
	50-59					1
	60+					
	Unknown	6	5	2		67
Gender	Male Caller	23	8	5	4	87
						Total Male Callers= 127

A STUDY ON SELF-COMPASSION AND SHAME

Caller Questionnaire Themes. After the questionnaire and call notes were thoroughly analyzed, structural and emergent themes were found. Some of the emergent themes depicted below (See Figure 1 below) included: 1.) identity, 2.) emotions, 3.) mistake, 4.) cheating, 5.) shame, and 6.) guilt. The hands were used to depict the theme of relationships on the HIV Nightline.

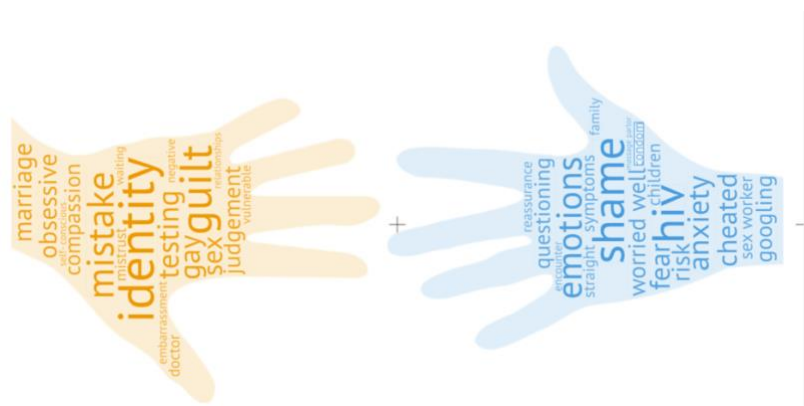


Figure 1. Word Cloud Depiction of Worried Well Emergent Themes

Out of the 239 worried well Nightline calls, only 127 were applicable to this study's research. The 127 calls reviewed consisted of caller testimonials of infidelity/cheating, relations with a sex worker, or MSM. The other 112 calls did not fit this inclusion criteria. The other calls were comprised of "obsessive" worried wells. Example of these calls were individuals who believed they could get HIV from nurses who drew their blood or from being in the same room as someone who was HIV +. Call notes showed they were not open to discussing any emotional content. The table below shows which emotions callers identified with, when asked by the volunteer. Looking at simply covert emotions (see Table 3), callers struggled the most with being judgmental toward themselves (84.0%), followed by identifying with being overly self-conscious when looking up the signs of HIV (58.0%), then embarrassment (57.0%), shame (42.0%), the

A STUDY ON SELF-COMPASSION AND SHAME

ability to be vulnerable with friends or family (39.0%), showing themselves self-respect (33.0%), self-compassion (26.0%), and guilt (23.0%).

Table 3. Percentage of Emotions Callers Identified With

Emotion	Anxiety	Judgmental	Self-conscious	Embarrassment	Shame	Vulnerability	Self-respect	Self-Compassion	Guilt
Percentage (%)	87.0%	84.0%	58.0%	57.0%	42.0%	39.0%	33.0%	26.0%	23.0%

Anxiety was an expected emotion with worried well calls. As the literature stated, worried wells have health anxiety and other forms, such as OCD (Scragg,1995.) However, these findings also suggest that most of the volunteers continued to communicate with worried wells solely based on their superficial anxiety, rather than exploring many of the emotions within the questionnaire. Other reasons may have been because the call content was not relevant to the question(s). Question 3, “Are you compassionate to yourself when you are feeling guilty about the sex you engaged in?” was the question not asked the most. As a result, 74% (See Table 4) of callers were not asked if they had guilt. This had an effect on the researcher determining if the caller had shame because question 3 was assessing if the caller had self-compassion.

A STUDY ON SELF-COMPASSION AND SHAME

Table 4. Percentage of Emotions Callers Were Not Asked or Not Applicable

Emotion not asked	Guilt	Shame	Self-respect	Self-Compassion	Self-Conscious	Vulnerability	Judgement	Embarrassment	Anxiety
Percentage (%)	74.0%	42.0%	38.0%	32.0%	28.0%	22.0%	20.0%	19.0	9.0%

Unexpected Findings. Also, results showed that there was a correlation between the type of sexual act and the particular emotion (See Table 5). For example, callers who participated in anal sex had high levels of shame (20.3%) compared to oral sex (13.6%). In addition, because these callers exhibited shame, they had a low percentage of self-compassion (6.8%). Callers had high levels of judgement (32.2%) and embarrassment (27.1%) when they admitted they participated in anal sex.

There were only 11 calls where a caller noted they had relations with a sex worker. As a result, the total number was not a large sample. Each individual emotion category had a smaller outcome or percentage. For example, 6.0% had guilt from sleeping with a sex worker (See Table 4). Shame was the most prevalent emotion (8.0%) with a sex worker. Also, the type of sexual partner played a role. For example, male callers with male sexual partners reported feeling embarrassed and judgmental the most (23.0%). There were no same sex female relationships reported.

Table 5. Percentage of Emotions Callers Identified With Corresponding to Known Specific Sex Act, Sex Worker, Caller Gender: Sexual Partner, and Current Relationship

A STUDY ON SELF-COMPASSION AND SHAME

Emotion		Shame	Guilt	Self - Compassion	Self-Respect	Embarrassment	Vulnerability	Judgement	Self-Conscious
Sex Act	Anal	20.3%	5.0%	6.8%	15.3%	27.1 %	13.6 %	32.2%	22.0%
	Oral	13.6%	8.4%	11.9%	10.1 %	23.8%	15.3 %	23.9 %	29.0 %
	Group	1.7%	0.0%	1.7%	1.7%	0.0%	1.7 %	0.0%	0.0 %
	Other	13.6%	6.8%	6.8%	8.5 %	10.1 %	8.5 %	18.7%	13.6 %
Sex worker	Yes	8.0%	6.0%	3.0%	3.0 %	6.1 %	3.0%	11.0%	7.0%
	No	3.0%	0.0%	8.0 %	5.0%	3.7 %	7.0%	0.0%	2.0%
Gender: Partner (FM, MF, MM, FF)	FM	4.0 %	2.0%	4.0%	3.0%	8.0 %	4.0%	9.0%	6.0 %
	MF	16.0 %	12.0 %	7.0%	11.0 %	18.0 %	10.0 %	24.0 %	19.0%
	MM	13.0%	6.0 %	11.0 %	12.0%	16.0 %	13.0%	23.0%	23.0%
	FF (no callers).	0.0 %	0.0 %	0.0%	0.0%	0.0 %	0.0%	0.0%	0.0 %
Caller relationship	Hetero	11.0 %	10.0%	6.0%	4.0%	17.0%	12.0%	16.0%	14.0%
	Homo	2.0%	2.0 %	3.0%	4.0%	3.0%	3.0%	5.0 %	5.0%

Survey questions that were not asked or not applicable (N/A). After the researcher analyzed the whole survey and caller note section, two outcomes occurred 1.) certain questions were only asked from the survey, or 2.) the questions were not asked at all. However, questions that were given a response of “N/A” had caller note content that fit the types of callers these questions were designed for (Refer back to Table 3). Many calls where specific sexual

A STUDY ON SELF-COMPASSION AND SHAME

encounters, sexual partner, and current relationship were known did not have the emotions asked (See Table 6). For example, male callers who reported sleeping with a man (MSM) were not assessed for feelings of guilt (24.0%). Any known guilt would have allowed the volunteer to further assess if possible guilt stemmed from identity conflicts or the caller's belief they should not be sleeping with men.

Table 6. Percentage of Emotions Callers Were Not Asked or Were Not Applicable Corresponding to Known Specific Sex Act, Sex Worker, Caller Gender: Sexual Partner, and Current Relationship

Emotion		Shame	Guilt	Self - Comp.	Self-Respect	Embarrassment	Vulnerability	Judgement	Self-Conscious
Sex Act	Anal	33.3%	40.0%	33.3 %	42.9 %	18.1%	33.3 %	25.0%	8.5%
	Oral	46.7 %	37.8 %	46.7%	28.6 %	27.2 %	50.0 %	62.5 %	5.0%
	Group	0%	2.2 %	0%	4.8 %	0%	0%	0%	0%
	Other	20.0%	20.0%	20.0 %	23.8 %	54.6%	16.7 %	12.5 %	6.8%
Sex worker	Yes	2.0%	7.0%	2.0%	5.0%	6.1%	3.0%	2.0%	7.0%
	No	30.0%	67.0%	30.0%	33.0%	64.2 %	19.0%	18.0%	51.0%
Gender: Partner (FM, MF, MM, FF)	FM	2.0%	8.0%	4.0%	5.0%	2.0%	2.0%	2.0%	4.0%
	MF	11.0%	21.0%	11.0%	12.0%	11.0%	9.0%	6.0%	10.0%
	MM	5.0%	24.0%	6.0%	9.0%	5.0%	2.0%	2.0%	3.0%
	FF (no callers)	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Current Relationship	Hetero	9.0%	15.0%	9.0%	11.0%	6.0%	4.0%	8.0%	8.0%
	Homo	2.0%	5.0%	2.0%	1.0%	1.0%	1.0%	2.0%	1.0%

A STUDY ON SELF-COMPASSION AND SHAME

Results of Piloted Self-Compassion Exercises

The self-compassion exercises were piloted over a two-week period in June. The goal was to compare the number of callers who were not exposed to the self-compassion exercises (in May) to those who were. After the two-week period ended, each individual caller profile was assessed to see if their call volume decreased. However, there was not enough sufficient call data to examine this. Initially, the number of participants piloting the exercises were three overnight staff, and three volunteers (not including the researcher). However, the number who actually participated were three overnight staff, and one volunteer. Only 16 callers were asked if they wanted to try the self-compassion exercises. Out of the 16 callers, only 9 callers agreed to do one of the exercises. Four out of the 16 declined, and the other 7 callers participated in breathing exercises. Breathing exercises were not part of the self-compassion exercises. However, some volunteers use breathing exercises to calm callers who are having high anxiety.

One overnight staff member had a total of 91 NL calls over the two week period, but only tried the exercise with two callers. However, those two were receptive. One male caller agreed to do the “Shame and Self-Compassion” exercise (the longest exercise). After the researcher interviewed her, it appeared that a majority of NL callers had not been asked. However, she said the exercises were too long, callers were not receptive, and there were minimal NL calls. When asked which calls the exercises were the most successful on, she said the exercises did not work with obsessive worried wells. Rather, they worked when callers admitted to having guilt. She gave an example of a male caller who was married, and was feeling guilty for having unprotected sex with a lot of women. The “Self-Compassion Break” exercise was asked the most.

A STUDY ON SELF-COMPASSION AND SHAME

Another overnight staff had success with the “Self-Compassion and Forgiveness” exercise with a gay caller who felt they had been violated for having to perform a sexual act. In addition, he stated that because he was the only staff member on an eight-hour shift, going “in depth” with callers was challenging with other calls coming in. However, he stated, “Overall, definitely based on caller feedback, when asked about where the anxiety or fear is coming from, it is shame that someone will find out they are HIV positive.”

The only volunteer did the SCE once on the NL. This NL caller had relations with a transwoman, and said they were “thankful” after doing the “Shame and Self-Compassion exercise.” Outside of the one NL caller, the volunteer incorporated them on the suicidal crisis line. He stated, “when the caller is talking fast or having obsessive thoughts, I would introduce it (the SCE) sooner.”

“Self- Compassion Break” Findings. The first self-compassion exercise, “Self-Compassion Break” was the most successful. Also, it was the shortest exercise to do on the phone with a caller. It worked best on calls where the caller stated, “I made a mistake,” or “I made a lot of bad choices.” Callers said that after saying the phrase “May I be kind to myself. . . may I show myself forgiveness” out loud on the phone, they felt better afterwards. Of the callers who participated in the SCE, only one female caller (not representative of this study’s inclusion criteria) continued to do them with overnight staff. Yet, her call volume went up from 66 in May to 91 in June. This particular caller appeared to be an “obsessive” worried well. The other callers had no identifying information. They either had never called the NL before or were calling from a different number, so their history with the NL was not recorded. The third overnight staff member attested that the “May I forgive myself” statement was the most helpful, and she even had some callers say, “You’re only human.”

A STUDY ON SELF-COMPASSION AND SHAME

Discussion

Overall, the basis of this study was to create a space within the 10-15 min call frame where callers could begin expressing their vulnerabilities. One way of doing this was to identify the concealed emotions worried wells were experiencing; specifically as they relate to callers who admit to infidelity and MSM. In addition, the study was designed to open the doorway for better emotional communication with worried wells. Prior, the NL was heavily focused on asking about the caller's anxiety, but not any other emotions or feelings underlying the anxiety. Without addressing those emotions, it made it difficult to relieve the caller's anxiety because the caller was not able to be honest about their sexual encounter and the emotions that came with it. As a result, worried wells kept calling.

This goals for this study were approached by using the following methods: 1.) a formal focus group with hotline staff and volunteer(s) 2.) a survey sent to volunteers to learn about worried well behaviors, and 3.) a questionnaire designed for NL volunteers to use as a tool with callers to facilitate conversations around difficult, painful emotions. Thereafter, a brief self-compassion intervention was piloted for two weeks.

Results highlighted callers were experiencing emotions that went deeper than their presenting superficial anxiety. The implementation of the caller questionnaire on self-compassion served as a guide for callers to be asked difficult questions. The questionnaire was most effective for callers who felt they were irresponsible and hurt someone they loved. For example, male callers expressing remorse over letting their wife or partner down because they had relations with a sex worker or went to a massage parlor. This is similar to Van Oppan and Artanz (1994) conclusion that guilt magnifies the fear of HIV when an individual recognizes they violated their personal responsibility by participating in a negative act. However, Van Oppan

A STUDY ON SELF-COMPASSION AND SHAME

and Artanz (1994) studied OCD patients, and there is no way of knowing if the male callers on the NL had OCD. The irrational fears of the caller may have simply stemmed from their sexual transgressions. As a result, their “obsession” started when they cheated on their partner, and the way they took back their perceived irresponsibility was to call the NL for reassurance their “symptoms” were not HIV.

Wells and Hackman (1993) used imagery to show that a “triggering event” (risk) ignited a cycle of negative core beliefs within worried wells, such as “I am bad.” Although guided imagery was not used on the hotline, some callers were able to voice their negative core beliefs that were a result of their risk-taking scenario. For example, many callers gave negative evaluations of themselves. One caller stated, “I am a dirtbag” after confessing he let his wife and children “down” for going to a massage parlor. Wells and Hackman (1993) did not explore any shame and self-compassion results in their study. However, on the NL callers had shame and low-self compassion from their sexual encounter or “triggering event.”

Emotions, such as shame, guilt, embarrassment, and judgement increased for MSM, and when they performed a specific sexual act. Judgement is a product of shame, and this aligns with Brown’s (2006) theory that shame causes individuals to feel fear, hide, and have judgement. Worried wells exhibited immense anxiety, which represented the underlying judgement they had toward themselves.

The males in Miller, Acton, & Hedge’s (1988) study struggled with expression of their sexuality due to religion and family influence. As a result, they participated in covert sexual activities. Many of the men on the NL revealed they were in heterosexual relationships, and were having sex with other men. However, on the NL, the role of religion was not brought up as frequently expected. As stated prior, this study was done more than thirty years ago and cultural

A STUDY ON SELF-COMPASSION AND SHAME

norms around sexuality have changed. Yet, it is important to note they may not have changed completely. Also, male callers were not all admitting they had sex with men in secret. Instead, it was their first sexual experience with a male. However, it is important to note that volunteers only understand the caller from the caller's version of the story. In addition, the caller may have not been ready to share.

What stood out from the result findings were that there was a large percentage of callers who did not have the survey questions asked to them. If they did, volunteers chose to ask the ones that were relevant to the call or not at all. Caller notes showed that the subject matter of the calls were applicable to the survey, but "N/A" was marked for the question response. After careful analysis, it appeared a majority of the volunteers were not comfortable asking these questions or they did not understand how to facilitate the questions with the caller. The literature stated that callers can trigger certain emotions within HIV counselors. For example, low/no risk HIV based calls that consist of abuse, cheating, other forms of deception, aggressive, and agitated behavior may offend the HIV counselor (Calla, Chan, Gaylord, & Lin, 2009). Also, they mentioned calls where the caller voiced they were discriminated against because of their sexual orientation. These examples can trigger the counselor and have an influence on how the call is further approached. As the results showed, volunteers were the most comfortable assessing the anxiety of the caller.

The NL caller questionnaire was composed of questions on embarrassment, guilt, self-compassion, self-consciousness, self-respect, and vulnerability. These difficult questions were designed to guide the worried well caller to an emotional place they were ashamed and scared to go to. It appeared that some volunteers struggled to go to that place with callers because the questions were uncomfortable for them to ask. No one wants to talk about shame (Yaz, 2013).

A STUDY ON SELF-COMPASSION AND SHAME

Shame researcher Dr. Brene Brown cited every individual has felt shame in their life. Shame is universal. Brown says individuals fear disconnection if their flaws or mistakes are revealed (Yaz, 2013). As a result, the questions themselves in relation to specific call content may have triggered the volunteer to reflect on some of these emotions they have felt. After doing a thematic analysis of the call notes, results showed volunteers were the most comfortable discussing the caller's anxiety (as before). Anxiety was the most discussed with callers (87%). However, anxiety was not a part of the researcher's questionnaire. In addition, the researcher introduced a new, required questionnaire within the NL database that was not a part of prior protocol. As a result, volunteers may have felt it took longer to document caller notes.

Time constraints showed to be one of the reasons the brief self-compassion exercises were only piloted with nine callers. There is a need for these exercises, as the ones that were done were successful. They worked best on calls where men admitted guilt and remorse. The "Self-Compassion Break" exercise was the most helpful for married males who went to massage parlors. Ultimately, what came out after doing these short exercises was the ability to start being vulnerable, which they had not been able to do living with a secret. There was no way to tell if worried well calls increased or decreased because these specific callers were documented under a generic profile (they called under an anonymous or different number). One female caller did a SCE, but when she called again the volunteer chose breathing exercises (not SCE) to alleviate her anxiety. Also, male callers were chosen for this study's sample.

After reviewing the calls that had deep breathing exercises done, the self-compassion exercises could have been used on those calls as well. It is unclear if the volunteer actually asked the caller if they wanted to do a self-compassion exercise to calm their anxiety, or if the volunteer simply chose to do deep breathing. The researcher noted that when she took calls from

A STUDY ON SELF-COMPASSION AND SHAME

anxious callers admitting they researched HIV symptoms online frequently, the “Self-Compassion Break” exercise was effective to use with them (Germer & Neff, 2018). As a result, they were encouraged to repeat the phrases from the exercise when they were tempted to go online. In her book, *Daring Greatly*, Dr. Brown (2012) notes, “Shame derives its power by being unspeakable.” Therefore, the researcher concluded if callers were not able to “speak” to their shame, then their fears surrounding HIV were going to remain. It is a process that begins with the caller having trust in the hotline volunteer.

Limitations

There were several limitations within this study. First, as noted before, most of the caller questionnaire was not asked. The call note section showed the call content was relevant, yet question #3, “are you compassionate toward yourself when you’re feeling guilty” and #5, “do you show yourself self-respect” were not asked the most. Without an answer to question 3, there was no way for the researcher to know if the caller had guilt, compassion, or shame. As previously stated, individuals with low self-compassion have shame. The outcome of the results were affected. In addition, the sample size for the self-compassion exercises was small. There was no way of tracking the caller’s call progress for two reasons: 1.) the caller was marked under a “generic” profile and there was no way of knowing if the caller called back, and 2.) only one female caller did the exercise again on two separate calls. However, females were not a representative of the sample for this study’s research.

In addition, other independent variables were involved. For example, the organization was merging with another mental health and social services organization, having challenges recruiting volunteers, undergoing staff changes, and there appeared to be a lack of a level of commitment on volunteer shifts. During the time the researcher was during fieldwork, many

A STUDY ON SELF-COMPASSION AND SHAME

volunteers were not committed to keeping their weekly required 4-hr shift, which resulted in absences.

Finally, there are no licensed clinicians on the hotline. However, there is one Marriage and Family Therapist (MFT) who does not engage on a regular basis with callers. As a result, the volunteers on the hotline needed more training in self-compassion therapy. The first barrier lied in explaining that Self-Compassion Therapy was not therapy to all volunteers and staff. This appeared to create confusion. It is designed to ground the individual by helping them initiate kindness to themselves by using mindfulness approaches and saying verbal exercises out loud to the self.

Implications for Practice

The self-compassion exercises show promise on the HIV Nightline with proper training of the volunteers. Mindful Self-Compassion (MSC) trainings are available to individuals who are looking to become more self-compassionate and mindful within a formal setting. These 8-week trainings are for anyone. Some students who graduate from this course go on to become MSC teachers (Center for Mindful Self-Compassion, 2017). However, the researcher is recommending that volunteers at San Francisco Suicide Prevention receive trainings within the organization on self-compassion therapy. An introduction into SCT's background, benefits, indications, and success in anxious, self-critical, and shame prone individuals is highly encouraged. As this research showed, worried wells had anxiety, but were overly self-critical, and admitted to having shame.

Afterward, it is strongly encouraged the three self-compassion exercises piloted be adapted. They can be shortened to fit the 10-15 time frame of call. However, it is recommended that volunteers are trained by SFSP to know when and how to use them on calls. The approach of

A STUDY ON SELF-COMPASSION AND SHAME

the facilitator (i.e. volunteer) doing the exercises with the caller is vital. The three exercises 1.) “Self-Compassion Break,” 2.) “Self-Compassion and Shame,” and 3.) “Self-Compassion and Forgiveness” touch upon the same core emotions from this research’s caller questionnaire (Germer & Neff, 2018). Also, it is recommended trainings are focused on assisting the volunteer with becoming more comfortable in asking callers about painful emotions, such as shame and guilt.

Finally, it is important to note the self-compassion exercises did not work on obsessive worried well callers. As the researcher learned in the focus group, obsessive callers hardly have any desire to discuss about the emotions surrounding their fears over HIV. In addition, despite counselor education on HIV transmission, these callers believe HIV can be contracted from non-probable ways of transmission. Their irrational fears are secondary to a psychiatric illness, such as hypochondriasis. Also, it is not beneficial to the organization or the caller to utilize an exercise that shows no possible progress. It is more vital these callers are seen by a psychotherapist.

Future Research

Self-Compassion Therapy (SCT) shows much potential if utilized on the Crisis Line at San Francisco Suicide Prevention. Many callers on this line are lacking compassion because of depression and anxiety. SCT has shown to improve depressive episodes (Neff, 2003). However, SCT is designed for anyone, and most callers are simply seeking validation they are doing their best “where they are.” This aligns with SFSP philosophy of meeting the caller where they are. In addition, SCT does not aim to replace negative thoughts with positive ones. Instead, it allows the individual to embrace their suffering. Volunteers are trained to be with callers in their moments of suffering, rather than try to treat it.

A STUDY ON SELF-COMPASSION AND SHAME

References

- Brown, B. (2006). Shame resilience theory: A grounded theory study on women and shame. *Families in Society*, 87(1), 43-52. doi:10.1606/1044-3894.3483
- Brown, B. (2012). *Daring greatly: how the courage to be vulnerable transforms the way we live, love, parent, and lead*. New York: Gotham Books.
- Brown, B., Hernandez, V. R., & Villarreal, Y. (2009). Connections: a 12-session psychoeducational shame resilience curriculum. Dearing, R. L., & Tangney, J. P. (Eds.), *Shame in the therapy hour*. (pp.355-360). Washington, DC, US: American Psychological Association.
- Calla, D., Chan, K. B., Gaylord, J., & Lin, A. C. (2009). Counselling guidelines for clients with high HIV anxiety and no/low risk. Retrieved from <https://www.catie.ca/en/resources/counselling-guidelines-clients-high-hiv-anxiety-and-nolow-risk>
- Center for Mindful Self-Compassion. (2017). Practice. Retrieved from <https://centerformsc.org/practice-msc/>
- Dolezal, L., & Lyons, B. (2017). Health-related shame: an affective determinant of health?. *Medical humanities*, 43(4), 257–263. doi:10.1136/medhum-2017-011186
- Edwards, T and Turnage, J. (2003). Cheating almost killed me: collaborative care for a man who believed he had AIDS. *Families Systems & Health* 21(2):233-239 DOI:10.1037/1091-7527.21.2.233
- Gilbert, P., & Choden. (2014). Evolved mind and motivations. *Mindful compassion: how the*

A STUDY ON SELF-COMPASSION AND SHAME

science of compassion can help you understand your emotions, live in the present, and connect deeply with others (pp. 53-58). Oakland, CA, US: New Harbinger Publications.

Gilbert, P., & Procter, S. (2006). Compassionate mind training for people with high shame and self-criticism: overview and pilot study of a group of therapy approach. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=edsbas&AN=edsbas.AAB14C5&site=eds-live&scope=site&custid=s3818721>

Germer, C. K. & Neff, K. D. (2013). Self-compassion in clinical practice. *Journal of Clinical Psychology*, 69(8): 856-867. doi:10.1002/jclp.22021

Lombardo, A. P. (2004). Anatomy of fear: mead's theory of the past and the experience of the HIV/AIDS “worried well.” *Symbolic Interaction*, (4), 531. doi:10.1525/si.2004.27.4.531

Miller, D., Acton, T. M., & Hedge, B. (1988). The worried well: their identification and management. *Journal of the Royal College of Physicians of London*, 22(3), 158–165.

Neff, K., & Germer, C. K. (2018). *The mindful self-compassion workbook: A proven way to accept yourself, build inner strength, and thrive*. New York, NY: Guilford Press.

Neff, K. D. (2003). Self-compassion: an alternative conceptualization of a healthy attitude toward oneself. *Self and Identity*, 2(2), 85-101. <http://dx.doi.org/10.1080/15298860309032>

Neff, K. D. (2003). Development and validation of a scale to measure self-compassion. *Self and Identity*, 2, 223-250.

Rachman, S. (1993). Obsessions, responsibility and guilt. *Behaviour Research and Therapy*,

A STUDY ON SELF-COMPASSION AND SHAME

31(2), 149-154. [http://dx.doi.org/10.1016/0005-7967\(93\)90066-4](http://dx.doi.org/10.1016/0005-7967(93)90066-4)

Raz, G. (Writer). (2013). Can we gain strength from shame [transcript, radio broadcast]. In TED Radio Hour. NPR.

Reilly, E. D., Rochlen, A. B., & Awad, G. H. (2014). Men's self-compassion and self-esteem: the moderating roles of shame and masculine norm adherence. *Psychology of Men & Masculinity, 15*(1), 22-28. <http://dx.doi.org/10.1037/a0031028>

San Francisco Suicide Prevention. (2019). San francisco suicide prevention training and operations manual, *pp.1,17,110-143*. San Francisco, CA.

Scragg, P. (1995). A critical analysis of morbid fear of HIV/AIDS. *Clinical Psychology & Psychotherapy, 2*(4), 278–284. <https://doi-org.ezproxy.sfpl.org/10.1002/cpp.5640020410>

Sondag, A., Hart, K., & Schwitters, A. (2011). A report prepared for the montana state department of public health and human services: an assessment of the HIV prevention needs of men who have sex with men.

Wells, A., & Hackmann, A. (1993). Imagery and core beliefs in health anxiety: Contents and origins. *Behavioural and Cognitive Psychotherapy, 21*(3), 265-273.
<http://dx.doi.org/10.1017/S1352465800010511>

A STUDY ON SELF-COMPASSION AND SHAME

Appendix A: Focus Group Informed Consent



School of Nursing and
Health Professions

Focus Group: Informed Consent Form

Introduction: Thank you so much for coming today. My name is Lauren Swansick and I am here working as the facilitator/moderator of our discussion today. I am a University of San Francisco Behavioral Health Graduate Student, working on a project related to the HIV Nightline. I recently graduated with my Bachelors of Science in Nursing, and want to pursue a career in psychiatric nursing. Joel is my preceptor, and has been assisting me with potential topics to explore here at the agency. The one area that stood out to me surrounded HIV Nightline calls that involve shame as an underlying component.

Purpose: The overall goal of this focus group today is to hear your thoughts about the research project I am working on related to the underling emotions that surround ‘worried well’ behaviors. In particular, I am interested in your views of HIV Nightline callers’ **shame, stigma, guilt, and loneliness that they may experience.** The long-term goal of my quality improvement study is to incorporate an evidence-based intervention, Compassion-Based Therapy. Research has shown that individuals who struggle with shame lack compassion toward themselves. As a result, this could be beneficial to ‘worried well’ Nightline calls.

Participation: I am asking you all here today because you are on the frontlines. You have talked to HIV Nightline callers on a regular basis. You are the experts. This is strictly **voluntary.** Any time you feel uncomfortable, please feel free to leave. I will be taking notes, and with your consent recording our discussion on my iPhone, so I do not miss anything important when I go back and revisit this conversation.

Confidentiality: My project and research paper will be published. As a result, I may use statements/quotes participants state from this focus group. However, I will not be using any participant names. Instead, each participant will be assigned a number (when referred to in the paper). The session is confidential because we are talking about various Nightline caller stories. Also, I ask that you please do not discuss other volunteers’ personal experiences/opinions outside of this discussion.

Length:

The total length of time of the focus group meeting is expected to be about **two hours.**

Benefits and Risks: There are no risks by participating in this study. Benefits include improving SFSP Nightline callers’ quality of life by helping address many of their hidden, painful emotions. Also, you will receive complimentary compassion-based therapy trainings from me 😊

A STUDY ON SELF-COMPASSION AND SHAME

Further questions: If at any time you have questions during this study, please feel free to contact me at Lswan606@gmail.com

I, as the volunteer/hotline staff participant agree to the information above. I have been explained what this study entails and been given the opportunity to ask questions.

Participant Name:

Participant Signature/ Date:

Researcher Name:

Researcher Signature/Date:

A STUDY ON SELF-COMPASSION AND SHAME

Appendix B: Focus Group Guide

Focus Group Guide #1 3/28/19

Introduction: Hello, thank you so much for coming today. My name is Lauren Swansick and I am here working as the facilitator/moderator of our discussion today. I am a University of San Francisco Behavioral Health Graduate Student, working on a project related to the HIV Nightline. My role is to help get a conversation going and to make sure we cover a range of Nightline topics that I would like your input on.

Group Participant Introductions:

Purpose: The overall goal of this focus group today is to hear your thoughts about the research project I am working on related to the underlying emotions that surround ‘worried well’ behaviors.

In particular, I am interested in your views about any HIV Nightline caller **shame, stigma, guilt, and loneliness that they experience.** I am asking you because you all are on the frontlines. You have talked to HIV Nightline callers on a regular basis. You are the experts.

This is strictly voluntary. I will be taking notes, and with your consent recording our discussion on my iPhone, so I do not miss anything important when I go back and revisit this discussion.

Length:

- The total length of time of the focus group meeting is expected to be about **two hours.**

Format/Rules:

- To stay within our time limit, I would like to keep the questions I ask on topic. In addition, I would like to hear every participant’s viewpoint. My intention is for this group to be a safe place where each individual can be heard. There is no right or wrong answer. I want to hear your opinions and experiences from taking calls on the HIV Nightline.
- The session is confidential because we are talking about various Nightline caller stories. Also, I ask that you please do not discuss other volunteers’ personal experiences/opinions outside of this discussion.

Please let me know if you have any questions so far.

Again your participation here today is totally voluntary. So if you are okay with moving forward, I would like to get your consent.

-I have a consent form for you to sign.

- **For me: Research Question:** How do shame and stigma play in to the HIV Nightline callers’ obsessive, “worried well” behaviors?

A STUDY ON SELF-COMPASSION AND SHAME

-How can the SFSP hotline address the shame that may lie at the root of their “worried well” behaviors?

Questions to Ask for Focus Group:

Prompt #1: Information about Nightline (in general):

1. What is a typical Nightline call consist of? What circumstances prompted the caller to phone in?
2. Out of all the calls you have taken, what group of calls do you receive the most about HIV? For example, callers asking about testing information, guilt r/t to infidelity, transmission (improbable ways HIV can be transmitted), and callers who talk about what symptoms (see rash, flu-like, chills, etc.) they have?
3. What are some of the NL calls that affected you the most? For example, you finished a shift and it took some time before the caller’s story left your mind?
4. What is your perception of why most of the callers that phone in are only asking about HIV, and not any other STD’s?
5. What romantic and/or sexual relationships are callers typically involved in? For example, gay, heterosexual, MSM (men who may not identify as gay yet)?

Prompt #2: Focus on ‘Worried Well’ Callers:

6. In your own words, what is a ‘worried well’?
7. What are your experiences talking to ‘worried wells’?
8. **What is your perception of where ‘worried well’ behavior comes from**, when they have taken numerous HIV tests that come back HIV (-)?
9. As hotline volunteers/staff, what are the steps taken when a ‘worried well’ caller asks about testing information? Do you explore the deeper, hidden emotions that they may not want to bring up?
10. Do you think there are underlying emotions going on beside the caller displaying severe anxious behaviors? Please name them.
11. What have callers revealed about how **their work/professional life and personal relationships** have been affected from their fear of contracting HIV (as a result of constantly

A STUDY ON SELF-COMPASSION AND SHAME

looking up HIV related symptoms on Google)? Does it sound like they want to get it because of the guilt they are feeling from sexual practices?

12. What role does loneliness and isolation play in their lives? Do callers have people they can talk to about all the feelings coming up?

-Not in actual question (purpose: for me as moderator/note taker)- to understand how family relationships have been affected? Are callers afraid to speak about it because they may be gay and their family will not accept them or are afraid of the stigma that is associated with having HIV?

13. What are the most frustrating calls you receive on the Nightline? The reason I ask is because I want to know more about the callers who seem to not benefit from the conversations (responses) they have with hotline counselors.

Prompt #3: Leading in to project topic r/t to shame:

What emotions do you think come up for callers if they heard/have heard the words, ‘embarrassment and humiliation?’

-Not in actual question (purpose: for me as moderator/note take-)my goal is to see if staff and volunteers say the word, ‘shame’ from their own observations of NL callers.

-See if they name ‘internalized homophobia.’

- *Tied in to the next several questions: Based on the emotions they name- “do you think ‘blank’ (i.e. r/t to shame) are the emotions and feelings NL callers are experiencing?”*

What do you think is the relationship between guilt and fear for Nightline callers?

Goal-looking for their observations on the calls they have taken w/ those who speak about infidelity.

Prompt #4: Tailored toward Compassionate-Based Mind Training, Dr. Kristin Neff

For the work here on the hotline, what do you think ‘worried wells’ are really seeking, besides “constant reassurance?” How can we help them?

Do you think Nightline callers have a lack of compassion toward themselves?

-Their identities,

-The sexual act committed

-Infidelity if applicable to the call, etc.

Introduce the Self- Compassion Scale, and how I adapted it to fit the calls of the Nightline. Pilot questions. Goal to see how self-compassionate callers are to themselves.

Self-compassion is the antidote to shame.

A STUDY ON SELF-COMPASSION AND SHAME

Explain Part 1: put these survey questions in the SFSP Database for volunteers/staff to ask callers. Also, talk about their perspective and thoughts about training on how to use this scale.

- **Adapted from her Self- Compassion Scale: How I Typically Act Towards Myself In Difficult Times.**
 - **Binary (Yes/No) Answers**
 - **Volunteers can pick the top 3 applicable to the call content, and then explain why they chose those 3 questions. Change to do you questions?**
1. When I am looking up the signs/symptoms of HIV it makes me feel embarrassed.
 2. When I hear the word, 'HIV,' I feel self-conscious.
 3. I try to be kind towards myself when I'm feeling guilt about the sexual act I participated in.
 4. I am able to forgive myself when I have done something I know others will probably criticize me for.
 5. I'm judgmental and hard on myself when it comes to my sexuality.
 6. As I have gone through this very hard time of thinking I may have HIV, I give myself the caring and self-respect I need.
 7. I can be vulnerable and honest with friends and/or family about my identity.
 8. Complete this sentence. I would like to be. . . .

We have come to the end of our questions. Does anyone have any additional questions for me? Thank you for your honesty and openness today. You have provided me with a lot of information to implement part 1 of the project. Further details will be announced soon.

A STUDY ON SELF-COMPASSION AND SHAME

Appendix C: Volunteer Survey

SFSP Volunteer Questionnaire: HIV Nightline Graduate Project

Hello Volunteers!

Thank you for taking the time to complete this questionnaire. The overall goal of this questionnaire is to hear your thoughts about the research project I am working on related to the underlying emotions that surround ‘worried well’ behaviors. In particular, I am interested in your views on HIV Nightline callers’ **shame, stigma, guilt, and loneliness that they may experience.** The long-term goal of my quality improvement study is to incorporate an evidence-based intervention, Compassion-Based Therapy. Research has shown that individuals who struggle with shame lack compassion toward themselves. As a result, this could be beneficial to ‘worried well’ Nightline calls. Please be assured that your responses will be kept confidential

The questionnaire should take you about 30 minutes to complete. Your participation in this research is voluntary. You have the right to withdraw at any point during the study, for any reason, and without any prejudice. If you would like to contact me to discuss this research, please e-mail Lauren Swansick at Lswan606@gmail.com

By clicking the button below, you acknowledge that your participation in the study is voluntary, and that you are aware that you may choose to terminate your participation in the study at any time and for any reason.

Please note that this survey will be best displayed on a laptop or desktop computer. Some features may be less compatible for use on a mobile device.

- I consent, begin the study (1)
- I do not consent, I do not wish to participate (2)

Q1 What is a typical Nightline call consist of? What circumstances prompted them to call?

Q2 Out of all the calls you have taken, what group of calls do you frequently receive the most related to HIV? For example, callers asking about testing information, guilt r/t to infidelity, transmission (improbable ways HIV can be transmitted), and callers who talk about what symptoms (see rash, flu-like, chills, etc.) they have?

A STUDY ON SELF-COMPASSION AND SHAME

Q3 What are some of the NL calls that affected you the most? For example, you finished a shift and it took some time before the caller's story left your mind?

Q4 What is your perception of why most of the callers that phone in are only asking about HIV, and not any other STD's?

Q5 What romantic and/or sexual relationships are callers typically involved in? For example, gay, heterosexual, MSM (men who may not identify as gay yet)?

Q6 In your own words, what is a 'worried well'?

Q7 What are your experiences talking to 'worried wells'?

Q8 What is your perception of where 'worried well' behavior comes from, when they have taken numerous HIV tests that come back HIV (-)?

Q9 As hotline volunteers/staff, what are the steps taken when a 'worried well' caller asks about testing information?

Q10 Do you think there are underlying emotions going on, besides the caller displaying severe anxious behaviors? Please name them.

Q11 What have callers revealed about how their work/professional and personal relationships have been affected from their fear of contracting HIV (as a result of constantly looking up HIV related symptoms on Google)?

A STUDY ON SELF-COMPASSION AND SHAME

Q12 What role does loneliness and isolation play in their lives? Do callers have people they can talk to about their feelings coming up?

Q13 What are the most frustrating calls you receive on the Nightline? The reason I ask is because I want to know more about the callers who seem to not benefit from the conversations (responses) they have with hotline counselors.

Q14 What emotions come up for callers do you think if they heard/have heard the words, ‘embarrassment and humiliation?’

Q15 What do you think is the relationship between guilt and fear for Nightline callers?

Q16 Please share you opinion/feedback on the questions/statements I have made based off a Self-Compassionate Scale:

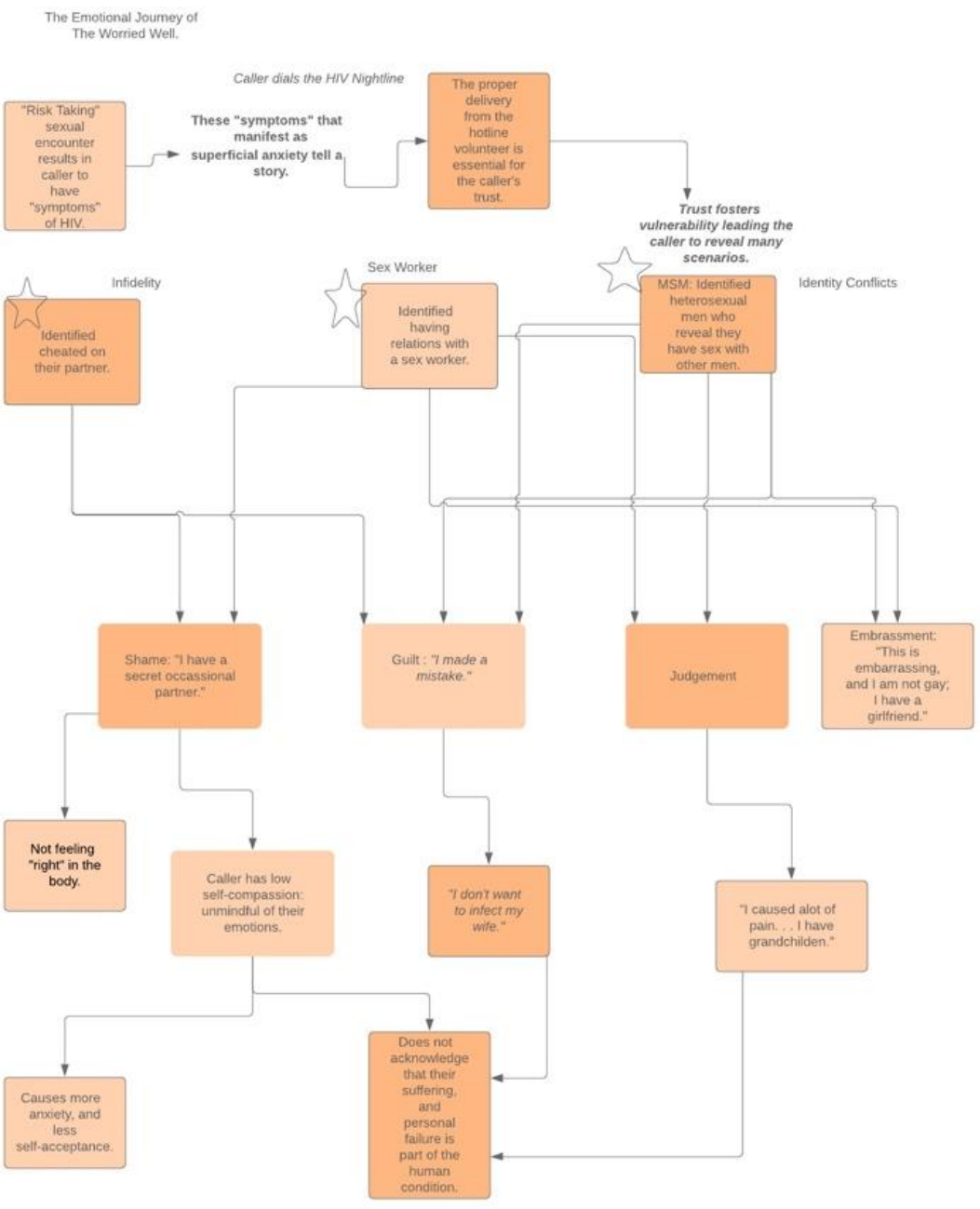
These would be used by you, as volunteers on the Nightline (when the call is applicable): Rather than having the caller rate on a scale of 1-5, you would be asking these questions to the caller for a “yes” or “no” response. The last question is based on whatever the caller chooses to say. The goal is to have volunteers pick the 3 they would like to ask the caller (if it is applicable). Afterward, you would type in a short explanation of you chose them for that call.

1. Do you feel embarrassed when looking up the signs/symptoms of HIV?
2. Do you feel self-conscious when you hear the word ‘HIV?’
3. Are you kind to yourself when you are feeling guilty about the sexual act you participated in?
4. Are you judgmental and hard on yourself when it comes to the people you have sex with?
5. Do you feel you have been showing yourself self-respect throughout this process?
6. Do you feel you can be vulnerable and honest with friends and family about your identity?
7. Complete this sentence. I would like to be. . . .

End of Block: Default Question Block

A STUDY ON SELF-COMPASSION AND SHAME

Appendix D: Conceptual Model



A STUDY ON SELF-COMPASSION AND SHAME

Appendix E: Final Caller Questionnaire

Please pick 3 questions to ask the caller (if relevant to the call), and then explain why you chose those 3 questions.

Yes, No, N/A

- 1.) Do you feel embarrassed when looking up the signs/symptoms of HIV?
- 2.) Do you feel self-conscious when you see the word 'HIV'?
- 3.) Are you compassionate to yourself when you are feeling guilty?
- 4.) Are you judgmental toward yourself?
- 5.) Do you show yourself self-respect?
6. Do you feel you can be vulnerable and honest with friends and family?