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“Do you think I should be worried?” Building a Call Structure for HIV(-) Callers to the Nightline

Ivy Epstein
hellothisisivy@gmail.com

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“Do you think I should be worried?”

Building a Call Structure for HIV(-) Callers to the Nightline

Ivy Epstein

University of San Francisco

Author Note

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

Abstract

San Francisco Suicide Prevention's HIV Nightline provides emotional support to those living with human immunodeficiency virus (HIV) as well as support and basic medical information around relative risk and testing for who may have been exposed to HIV. Nightline counselors use a harm-reduction model, active listening, reflection of emotions, and encouragement to promote health maintenance and mental health self-care behaviors. Until now, there has been no process to assess whether callers had disproportionate anxiety about HIV given their actual risk level. Consequently, HIV(-) anxious callers could receive inconsistent information. The goal of this improvement study was to develop a call structure that could be used to take a sexual health history and assess whether callers were suffering from symptoms consistent with health anxiety or simply searching for health information. **Methods.** Over two Plan-Do-Study-Act cycles (34 calls), counselors tested an adapted version of the Centers for Disease Control and Prevention's sexual health assessment and asked callers questions from two scales designed to assess illness anxiety. Counselors provided feedback on the assessments, individual anxiety assessment questions, their comfort level using the assessments, and their perception of the caller's response to each question. **Results.** Counselors felt questions helped maintain or improve rapport with callers, accurately assess callers' needs, and guide provision of appropriate information. The new sexual health and illness anxiety questions will become incorporated in the regular call structure and counselor training. **Implications.** The assessment questions may help other counselors more accurately assess the needs of those concerned about HIV exposure.

Keywords: HIV, AIDS, hotline, health anxiety, phone assessment, AIDS phobia, worried well

Executive Summary

Introduction and Background

San Francisco Suicide Prevention's HIV Nightline provides emotional support to those living with HIV as well as emotional support and basic medical information around relative risk and testing for those who experienced a potential HIV exposure. SFSP's trained volunteer counselors focus on harm reduction and emotional support via active listening, reflection, and encouragement to engage in basic health maintenance and self-care on both the crisis lines and on the Nightline. In the absence of a risk assessment and call structure on the Nightline, determining callers' needs, emotional state, and risk level is at the discretion of the counselors.

Need and Goals

As time has passed since the acute crisis of the initial HIV outbreak, the Nightline has increasingly supported callers whose exposure puts them at minimal risk of HIV transmission. Callers may be pragmatic, in pursuit of basic information about HIV, with little reported anxiety. Other callers report anxiety disproportionate to their risk and may call the Nightline repeatedly for days, weeks, or months for reassurance that they are HIV(-), unconvinced by information from medical clinicians, HIV tests, and other hotlines. Callers reaching out to the Nightline may initially request facts about risk levels or testing timelines, without disclosing anxiety, past calls, test-taking, or other factors that would help counselors provide more meaningful care. This project aimed to build a constructive framework of terminology within which to discuss callers. This project further aimed to introduce a call structure to proactively determine the actual risk level and relative health-related anxiety level of callers so that counselors might provide tailored care to the caller, focusing on the caller's mental health care needs and self-care .

Methods

After a review of the literature on assessing AIDS phobia in the early years of the epidemic, the worried well as a treatment population, and current standards in identifying and managing health anxiety, a call structure was designed. The pilot call structure included a three-question adaptation of the sexual health assessment used by the Centers for Disease Control (US Department of Health and Human Services, 2011) for callers referencing to sexual transmission, as well as questions adapted or adopted from two scales: the Illness Attitudes Scale (Kellner, Abbott, Winslow, & Pathak, 1987) and the Multicomponent AIDS Phobia Scale (Harrell & Wright, 1998). This structure was assessed for acceptability to counselors and callers and helpfulness to counselors in two Plan-Do-Study-Act cycles consisting of 21 calls (PDSA 1) and 13 calls (PDSA 2).

Results

Counselors were positive about the addition of the sexual health assessment, some asserting that it improved their comfort level in asking personal questions and others observing how open callers were to answering these questions. Additionally, counselors reviewed the inclusion of the sexual health assessment as helpful (3.5/5 on a 5-point Likert scale), comfortable to administer (5/5), and apparently acceptable to callers (4.5/5). Counselors also rated the inclusion of the health anxiety assessment questions as helpful (4.6/5 on a 5-point Likert scale), comfortable to administer (4.75/5), and acceptable to callers (4.5/5). No strenuous objections were presented to the inclusion of the sexual health assessment or to the anxiety assessment questions. However, many counselors abbreviated the assessment structure by skipping questions from one or both of the assessments. This behavior may be addressed by

additional training, better contextualization of anxious callers' needs in the spectrum of services SFSP provides, and expanded explanation of the benefit of these questions to callers.

Discussion

Counselor response to the call structure was positive. The call structure was not reported to be disadvantageous in any way for counselors or for callers, even for callers who responded in ways indicating they were not suffering from health anxiety. Overall, counselors rated the individual components of this call structure as helpful and comfortable, and callers were rated by their counselors as comfortable responding to each component.

Recommendations

Based on the success of this project, we recommend that the HIV Nightline adopt this call structure for its HIV Nightline calls with HIV(-) callers. As this was a quality improvement study with inherent limitations on rigor, further research is warranted into long-term implications of this structure for callers and for the Nightline, including whether it reduces the duration or frequency of calls from repeat HIV(-) callers.

San Francisco Suicide Prevention's HIV Nightline provides emotional support for persons living with HIV as well as information to parties concerned about HIV transmission. The Hotline Director at SFSP estimates: "It'd be safe to say we receive at least a dozen 'worried well' calls per day" (C. Brown, personal communication, April 19, 2017). Per organizational lore, these callers typically ask the odds they have contracted HIV from a past sexual encounter, often ones low risk for HIV transmission but highly stigmatized (e.g. extramarital but protected sexual acts). These callers seek validation that they will not test positive for HIV and may reference several prior negative tests. As the same team answers all calls, these callers are in direct competition for counselor time with callers in crisis, so efficiency in identifying and responding appropriately to them is critical. SFSP is concerned these callers may use the service to soothe their feelings of anxiety and as a result not develop techniques to manage this anxiety unassisted.

Counselors answering Nightline calls are encouraged to focus on the emotional content underlying the caller's explicit reason for calling. For example, counselors may validate feeling anxious after a one-night stand if the caller has reached out to the Nightline to find out risk of transmission from that one-night stand. SFSP is concerned about the efficacy of providing care to these callers, who may re-call the Nightline shortly after hanging up with a counselor or conceal their identity and critical details about their situation on calls. This practice improvement project aimed to superimpose a call structure onto Nightline calls. This structure will help counselors treat callers more effectively and avoid counselor behavior that might perpetuate a caller's cycle of anxiety, instead refocusing the caller on management of their anxious state. This new approach to screening and supporting worried well callers may in turn produce better

outcomes for callers and more effective use of counselors' time, which can be spent with callers who are in crisis.

Literature Review

Unfounded fears of AIDS transmission have been documented since the early days of the AIDS epidemic but are not well understood (Wright, Bonita, & Mullick, 2011). For some, HIV testing is tied to anxiety or guilt: “[I]t is not surprising that after having engaged in what has been perceived to be risky sexual conduct many gay men feel anxious and even guilty. The HIV antibody test offers a release from this concern as... it provides an effective assessment of HIV infection” (Flowers, Duncan, & Knussen, 2003, p. 188). This feeling may be reasonable for individuals who engage in high-risk behaviors, but Worthington and Myers (2003) describe similar experiences among people at low risk for HIV:

I've always been fairly assured that I would be negative. So it's not as though I've engaged in what would be widely recognized as unsafe practices that would then prompt me to test, right? But it's been a sort of need for confirmation. Just to have a sense of ease... almost as if there's a cycle of anxiety that happens...I get so I just have to get tested (p. 641-642).

Thus some individuals repeatedly testing for HIV are driven to do so less by risky behavior and more by anxiety. In fact, worried well patients focused on HIV “are either at very low risk of infection, or have tested negative for HIV,” and are usually clinically diagnosable with a mental health disorder such as depression or anxiety (Sowadsky, 2010a, para. 1). Individuals retesting for HIV may pursue other short-term reassurance, including hotlines like the HIV Nightline. This literature review examines prior work with persons anxious about HIV, including assessments and treatments, and characteristics of the worried well and those with health anxiety.

The following diagram explains the connection between a physical symptom or feeling and all the various disorders featuring health-focused anxiety:

S. Rachman / Behaviour Research and Therapy 50 (2012) 502–512

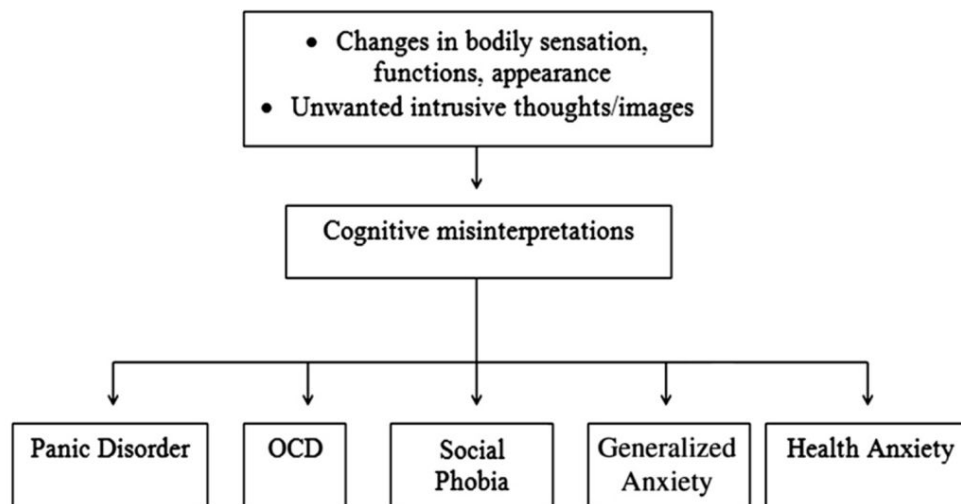


Fig. 1. The relation of health anxiety disorders to other types of anxiety disorder.

Figure 1. “The relation of health anxiety disorders to other types of anxiety disorder.”

This image clarifies anxious behaviors and diagnostic terms (Rachman, 2012, p. 503).

One typical behavior of health anxiety is pursuit of reassurance from “sympathetic, patient, authoritative” persons who will convey health-related information that the sufferer in fact already knows--e.g. that the symptom they are experiencing is not a sign of HIV--but relief from this reassurance does not last, and actually perpetuates maladaptive behavior (Rachman, 2012, 507). Health anxiety is treated with cognitive behavioral therapy (CBT) to reduce

reassurance-seeking and conviction that patients have a disease (Rachman, 2012).

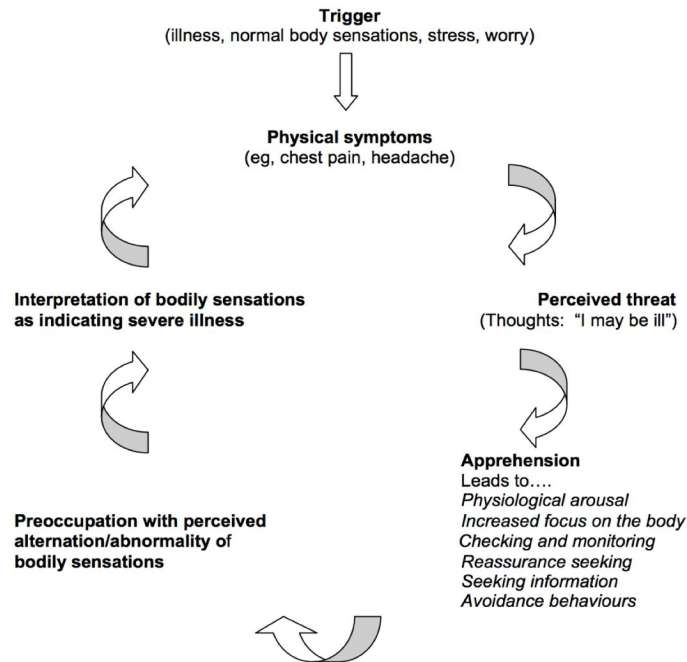


Figure 2. This image depicts the health anxious behavioral cycle (Hogan, 2010, p. 6).

This suggests that sufferers from health anxiety, including those suffering from a fear of HIV, need psychological support other than the reassurance they pursue.

So-called worried wells and persons with health anxiety appear in historic literature on sexually transmitted diseases (STDs) predating the HIV epidemic. Macalpine (1957) described syphilophobia: patients confident they had syphilis despite evidence to the contrary, implicitly as punishment for sexual misbehavior such as sex outside marriage. Macalpine concluded that syphilophobia had no relationship to actual risk of syphilis, but that patients had often sought diagnosis from many clinicians, which they concealed from other clinicians; and the prognosis for patients after treatment for anxiety was excellent (Macalpine, 1957). Efficient management of patients with comparable concerns across services may confer benefits extending beyond HIV-focused anxiety to anxiety about other STDs.

Symptoms of the worried well might include those of anxiety or depression as well as those that mimic symptoms of AIDS (Miller, 1986, as cited by Cochran & Mays, 1989). In 1988, two doctors in the United Kingdom described patients who could not be convinced of their HIV(-) status by negative test results (Riccio & Thompson, 1988). The doctors connected this occurrence to a recent awareness campaign around HIV, noted that the “AIDS-phobic” patients they saw met clinical diagnostic criteria for hypochondriasis, and further noted patients suffering from this fear were also called worried-well or AIDS-phobic among other terms (Riccio & Thompson, 1988). In 1998, Harrell and Wright validated a scale assessing “AIDS phobia,” a fear of HIV in the HIV(-) that aligns with contemporary definitions of the worried well. The authors cite research by Bruce and Stevens (1992) and Jager-Collet (1988) demonstrating that such anxious patients test repeatedly for diseases as a means of anxiety reduction, as well as research by Hualla and Jager (1988) that these patients often reported a specific sexual encounter about which they felt guilty. As the fundamental basis for their scale aligns with research into supporting worried well persons, their scale questions may adapted to identify such persons. For purposes of this project, anxious HIV(-) callers to the Nightline preoccupied with HIV transmission and testing will be described as worried well or as health-anxious.

Impact and Long-Term Concerns: Patient relationship with hotlines

There are personal and systemic ramifications of failing to treat HIV-focused anxiety. Researchers in a 1986 study of irrationally AIDS-fearful patients in Finland found that of eight convinced that they were HIV positive, three took their own lives; all were men, married, HIV negative, and terrified of spreading the illness to loved ones (Vuorio, Aarela, & Lehtinan, 1990, as cited in Kausch, 2004). This anxiety has serious, potentially life-threatening implications for

those affected. It is critical to understand how to identify this anxiety so that afflicted individuals can be supported appropriately. The best treatment may be education on mental health self-care, not medical care (Diamond, 2003). This issue also has expensive societal implications: as Sowadsky notes, “[E]ven if you pay for tests yourself, it ultimately DOES increase healthcare costs. This is because when tests are done unnecessarily, it costs extra money for the lab to hire and train additional staff to do those tests” (2010b, para. 7). The full economic impact and the rate of occurrence of this behavior have not been studied.

Worried well callers focused on HIV may call hotlines in pursuit of reassurance they do not have HIV, which may perpetuate a cycle of reassurance seeking and hotline re-calling, absorbing disproportionate counselor resources. An Australian study found that 3% of crisis line callers made 60% of calls, and these repeat callers are more likely than non-regular callers to suffer from mental illness including suicidality (Spittal et al., 2015). A study of the Dutch AIDS helpline found that 44% of their 13,000 callers per year specifically want to discuss their relative risk for contracting HIV, while another 30% have broader about HIV transmission (Bos, Visser, Tempert, & Schaalma, 2003, p. 203). Approximately half of callers in a subsequent study had overestimated their risk, subsequently receiving emotional support from their counselor in the form of reassurance that they were low risk (Mevissen et al., 2012). Here lies the feedback loop: the caller contacts a hotline for short-term reassurance, the caller doubts the reassurance, and the caller reaches back out to the hotline for more reassurance.

Assessments

Identification of a worried well patient is critical to providing on-target care. Sowadsky (2010a) offers a self-assessment for individuals with health-related anxiety around their health.

The self-assessment is focused on whether the patient self-identifies as obsessed with HIV, is willing to believe a negative test result, calls phone lines focused on HIV to ask the same question repeatedly, and attributes physical symptoms to HIV (Sowadsky, 2010a). This parallels the Multicomponent AIDS Phobia Scale (MAPS) (Harrell & Wright, 1998). Another tool that may be adapted to identify the health-anxious is the 29-item Illness Attitudes scale (IAS), which “has nine subscales: (I) worry about illness, (II) concerns about pain, (III), health habits, (IV) hypochondriacal beliefs, (V) thanatophobia (fear of death), (VI) disease phobia, (VII) bodily preoccupations, (VIII) treatment experience, and (IX) effects of symptoms” (Hedman, et al., 2015, p. 4) and which has been independently validated. This scale was designed for clinical use and is considered reliable for assessing health-related anxiety (Hedman et al., 2015). To adapt such a scale to HIV-centered anxiety, allusions in the scale to general illness may be replaced with references to HIV or AIDS. The Health Anxiety Inventory and the Whiteley Index also have excellent reliability and may be similarly reviewed for applicability to HIV in particular (Hedman et al., 2015). Given the constraints of a phone call, any scale adaptation for use at the HIV Nightline would also need to be clear and brief to allow for enough counselor-patient interaction around callers’ emotional content within a 10-15 minute timeframe. Adapting any of these scales for hotline use therefore needs practical validation. The MAPS and IAS were selected for use in this project based on their alignment with each other and with observed anxious Nightline caller themes.

Care Recommendations

Providing reassurance to worried well or health-anxious patients is not an effective care strategy. Those working with worried well patients should instead validate their symptoms

experience; determine the source of the patient's illness fears; provide explanations for symptoms that are not based in the illness they fear; and recommend mental health counseling (Childress, 2004). A guide for sufferers of health anxiety recommends other techniques for those suffering from this anxiety, including: list coping mechanisms for their anxiety and how well those techniques worked in the past; avoid asking for reassurance; avoid monitoring symptoms and attributing them to disease; and distract the mind from such thoughts (Hogan, 2010).

Conclusion

The body of research on the worried well population indicates that individuals may use services such as the Nightline as one source of the reassurance that perpetuates their anxiety. To minimize such a feedback loop at the Nightline, identification of callers as worried well prior to provision of reassuring health-related information is essential. Several scales, including the Multicomponent AIDS Phobia scale or the Illness Attitudes Scale, may be adapted to identify worried well persons in pursuit of such health-focused reassurance, though they have not been validated for use on hotlines. Anxious callers should be facilitated in self-care and anxiety management strategies (Diamond, 2003), while non-anxious callers may continue to be served by Nightline counselors' expertise in HIV transmission and testing.

Agency Background

San Francisco Suicide Prevention is a community-based 24-hour hotline agency originally established by Bernard Mayes in 1962 (San Francisco Suicide Prevention, 2017b). After receiving funding from San Francisco in 1972, SFSP became responsible for several other lines, including the AIDS/HIV Nightline in 1989 (San Francisco Suicide Prevention, 2017c). SFSP's mission 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, 2017a). SFSP’s target audience is there anyone who perceives themselves or someone in their lives to be in crisis, regardless of gender, age, origin, mental or physical health, or any other demographic criteria.

The primary service offered by San Francisco Suicide Prevention is the supportive listening provided by volunteers on each of its 24-hour hotlines--a format that allows clients to determine when to seek help and allows them to maintain some anonymity. Volunteers are extensively trained in methods of active listening and emotional validation and reflection. These techniques are used across all lines answered at San Francisco Suicide Prevention, and volunteers typically answer calls on all lines as needed (with the services of a third-party translator if the caller does not speak English). SFSP never diagnoses callers. Paid staff oversee and train volunteers and provide guidance on calls as needed, but most staff are not licensed clinicians. SFSP offers a life-saving service at no cost to callers. The service it provides represents a genuine human connection--a timeless, universal need for individuals in crisis.

Project Goals

This quality improvement project aimed to produce a call structure that would help volunteer counselors distinguish anxious callers seeking short-term reassurance from pragmatic callers pursuing information. A successful call structure would be consistently rated as helpful and comfortable by counselors and consistently rated as implicitly comfortable for their callers.

Needs Assessment

Needs Assessment Methods

Prior to drafting a call structure, a preliminary needs assessment was conducted with

seven SFSP volunteer counselors. Interviews took place at SFSP's headquarters, outside of the room where volunteer counselors stay on-shift (to preserve the privacy of the counselors' responses). One interview was conducted over the phone. Participants represented men and women across multiple shifts. Counselors' experience at SFSP ranged from under six months to nearly eight years. Counselors were asked to sign an informed consent form (Appendix B), though such a practice is not required for internal projects of this nature. All counselors were asked questions about their personal practices and perspective, including: "How do you typically handle someone who calls in who almost definitely doesn't have HIV (from the exposure they're talking about)?" "How do you think we can help them?" (Appendix A). Counselors described their own categories of HIV(-) Nightline callers to analyze if and how counselors assessed Nightline callers for anxiety, obsessive calling of the Nightline, and/or HIV retesting. Interviewees also provided feedback on the acceptability of all questions from each of the two scales being considered for incorporation into the Nightline call structure.

Needs Assessment Results

Of seven counselors, five reported feeling comfortable answering Nightline calls generally, while two reported working to increase their comfort level. No two counselors categorized HIV Nightline callers the same way, suggesting minimal consensus in identifying and tailoring treatment to this caller group. While many counselors reported communicating with anxious Nightline callers in a way consistent with Nightline policy (reassuring the caller they were not at risk), only one volunteer communicated with such callers in a way consistent with the most recent literatures' recommendations.

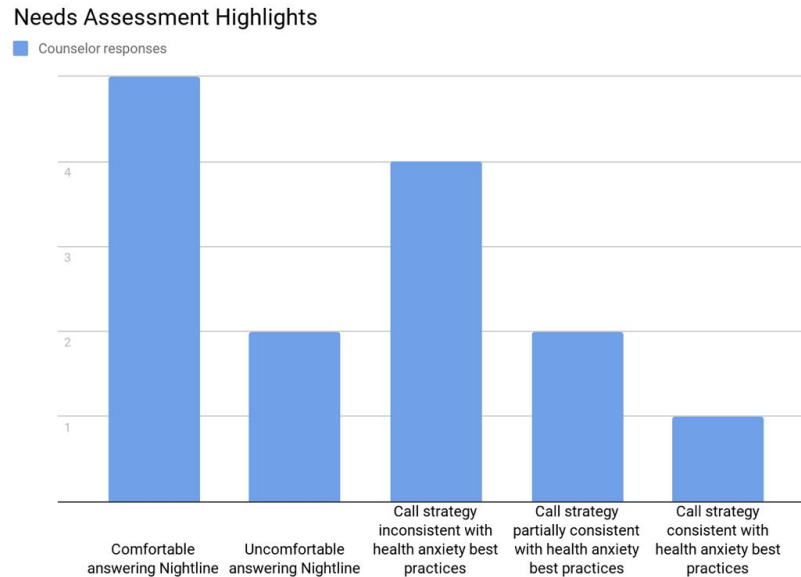


Figure 3. This image depicts counselor responses during the needs assessment.

“Health anxiety” and associated terminology are not in common use at SFSP, and volunteer counselors may not have access to the information that they need to provide care to these callers that is consistent with current strategies for patients with anxiety focused on their health.

Counselor feedback across proposed questions represented a wide range of opinions and little consensus. Based on the needs assessment, most questions from Multicomponent AIDS Phobia Scale’s section on Avoidance were excluded from the tested call structure: counselors felt they were too focused (“sounds weird and nitpicky”) and not sufficiently relevant to Nightline callers. Additionally, some counselors were concerned that asking unprompted questions about avoidant behavior would suggest to the caller that they should begin to engage in such avoidance.

Counselors also expressed concerns about introduction of a single assessment flow for all callers. One remarked, “For the Nightline there’s such a wide variety of callers I could see them being less receptive to a generic list of questions before you enter the conversation because they

may not apply to them at all. And they don't know if the line is for people with HIV, or for testing... Maybe start with "why are you calling" and then asking the questions or not, or asking a different version of the questions, depending on what they say." This feedback was incorporated into the final drafted call structure.

The results of the needs assessment highlighted the need for SFSP to introduce assessment tools and improve consistency of self-care recommendations for callers anxious about HIV. As counselors had diverse strategies for grouping callers by behavior and for helping callers identify self-care strategies, it is likely that already anxious re-callers are receiving inconsistent or ambiguous information across calls. To address these proposed areas of care improvement, a call structure incorporating a formalized sexual health assessment and several questions meant to gauge health anxiety severity into HIV Nightline calls was drafted for testing.

METHODS

Background, Development, and Monitoring

Background. Volunteer counselors and staff at San Francisco Suicide Prevention are trained in appropriate call content, when to end a call, when to probe for more detail, and when to assess a caller for suicide. Within this general call structure, counselors have significant freedom in what they say and ask, what tone of voice they adopt, and what topics they cover with the caller. It is expected that repeat callers will at times have more productive calls than others depending on their frame of mind and their unique relationship with counselors. Callers are gently discouraged from asking for specific counselors or for a very specific kind of call (i.e. "I only want medical information and that's it.") although caller preferences are accommodated within reason. This practice improvement initiative was designed to improve the Nightline call

structure by testing caller assessment questions and incorporating updated self-care suggestions on Nightline calls over two Plan-Two-Study-Act cycles. The methods described below were reviewed by the University of San Francisco Institutional Review Board. The project was given “exempt status.”

Development of screening questions. Questions for the modified call structure were incorporated from three key sources: a sexual health history assessment adapted from the Centers for Disease Control (US Department of Health and Human Services, 2011), and two sets of questions to assess HIV or health-related anxiety from the Illness Attitudes Scale (Kellner, Abbott, Winslow, & Pathak, 1987) and Multicomponent AIDS Phobia Scale (MAPS) (Harrell & Wright, 1998). Current Nightline policy permits counselors to ask almost any question of a caller as the situation requires. All of the proposed additions to the call structure represent questions that could reasonably be asked on a typical Nightline call.

While all HIV Nightline counselors are trained in determining relative risk of potential sexual exposures to HIV, how this assessment is performed, when, and how the risk assessment is connected to the emotional content of the call is all also at the discretion of the counselor. By standardizing the questions asked as a sexual health assessment and by moving these questions to the start of the call immediately after the caller has loosely described their exposure scenario, consistency and clarity of information provided to callers may be improved. Incorporation of the caller’s sexual health history into this call structure was first recommended by Stefan Rowniak, PhD, MSN, a published author in STD education and a nurse practitioner at San Francisco City Clinic (S. Rowniak, personal communication, April 8, 2017) . Health anxiety disorders are known to be aggravated by “inconsistencies and ambiguities in medical care and by the lack of

an acceptable explanation” (Mayou, R., 2002, p. 742, reviewing book by Asmundson, G. J. G, Taylor, S., & Cox, B. J.). Given the under-15 minute duration of a Nightline call, brevity was key in adapting any existing assessment. Furthermore, since taking a sexual health history would not make sense to callers asking for information about a non-sexual exposure, we limited use of a sexual health assessment to callers concerned about sexual exposure to HIV. We adapted three questions from the Centers for Disease Controls Guide to Sexual History for use in PDSA 1: How many sexual partners have you had in the last few months? Have you had experience with STDs before? What kinds of sex have you had lately? (US Department of Health and Human Services, 2011). Based on counselor feedback in the pilot of PDSA 1, we adapted a fourth question to test in PDSA 2: Was the sex protected or unprotected? Relative risk for HIV transmission is an essential factor as counselors determine a caller’s needs. As this standardized sexual health assessment should allow all counselors who interface with a caller about an exposure work with the same information about that caller, explanations of a caller’s relative risk may be made more accurate and less ambiguous.

The MAPS (Harrell & Wright, 1998) is one of the few scales focused on HIV-centered anxiety. As written, it aligns with several themes brought up by anxious Nightline callers, as expressed by counselors in the Needs Assessment. The following questions were adapted from the MAPS (Harrell & Wright, 1998):

- When you feel aches or pains, do you usually think it could be HIV?
- Do you worry about giving AIDS to others?
- Do you frequently check your body for signs of AIDS?
- Have you been unable to stop yourself from worrying about HIV?

- Are you worried that you will die from AIDS?
- Do you consider yourself high risk for HIV?
- Do you think that HIV test results can't be trusted?
- If your partner had AIDS, would you still touch them? What about have sex with them?

The IAS (Kellner, Abbott, Winslow, & Pathak, 1987) has been extensively validated (Stewart & Watt, 2000) as an assessment tool for the illness-focused anxiety previously described clinically as hypochondria. When phrased to focus on HIV, questions from the IAS mirrored themes on Nightline calls observed both prior to and during this project. The following questions were adapted (except as noted) from the IAS (Kellner, Abbott, Winslow, & Pathak, 1987):

- Are you afraid you may have any other serious illnesses, other than HIV?
- How often do you talk to a clinician about HIV testing or transmission? (Any frequency higher than "once every six months may indicate an obsessive tendency)
- Do you believe that you have HIV but the doctors haven't diagnosed you correctly?
- When your doctor tells you that you do not have HIV, do you refuse to believe them?
- When you read about or hear about HIV, do you get symptoms similar to what you've heard or read about?
- When you notice a sensation in your body, do you find it difficult to think of something else? (Adopted as written.)
- Do your bodily symptoms stop you from working/enjoying yourself/concentrating on what you're doing?

Counselors were asked to use at least three of the questions above per call to help identify whether a caller was likely to be an anxious caller. The nature of a hotline call prevents counselors from directly using Likert scales as this would be incongruous with the tone of the call. However, counselors benefit from significant additional context from the caller's explicit response (what they say in reacting to questions) and implicit cues (tone of voice, speed of response, change in affect in response to questions, and so on). Therefore these questions were asked as yes/no questions, and the caller's response was coded by the counselor and the graduate student monitor as 1) never; 2) sometimes; or 3) often. Any answer coded other than "never" was taken as a potential indicator of health anxiety and a proxy for potential repeat calling.

Counselors were encouraged to guide callers towards the following care at their discretion:

- Callers who have tested negative or who are concerned about low-risk transmissions should not be encouraged to take unnecessary HIV tests (Sowadsky, 2010b)
- Callers who indicate anxious tendencies around HIV ((answering at least one health anxiety assessment question with a 2 or 3) may:
 - Take steps to manage their anxiety, ideally with treatment from a mental health provider (Diamond, 2003);
 - Call back on the crisis line to discuss their anxiety, rather than on the Nightline to discuss their risk of HIV transmission (to distinguish between anxious symptoms and physical illness);
 - Articulate for themselves that they are low-risk, or the facts around their HIV risk or testing procedures (rather than having counselors provide this as reassurance) (Hogan, 2010).

The project altered typical Nightline calls in a few key places (see flowchart below).

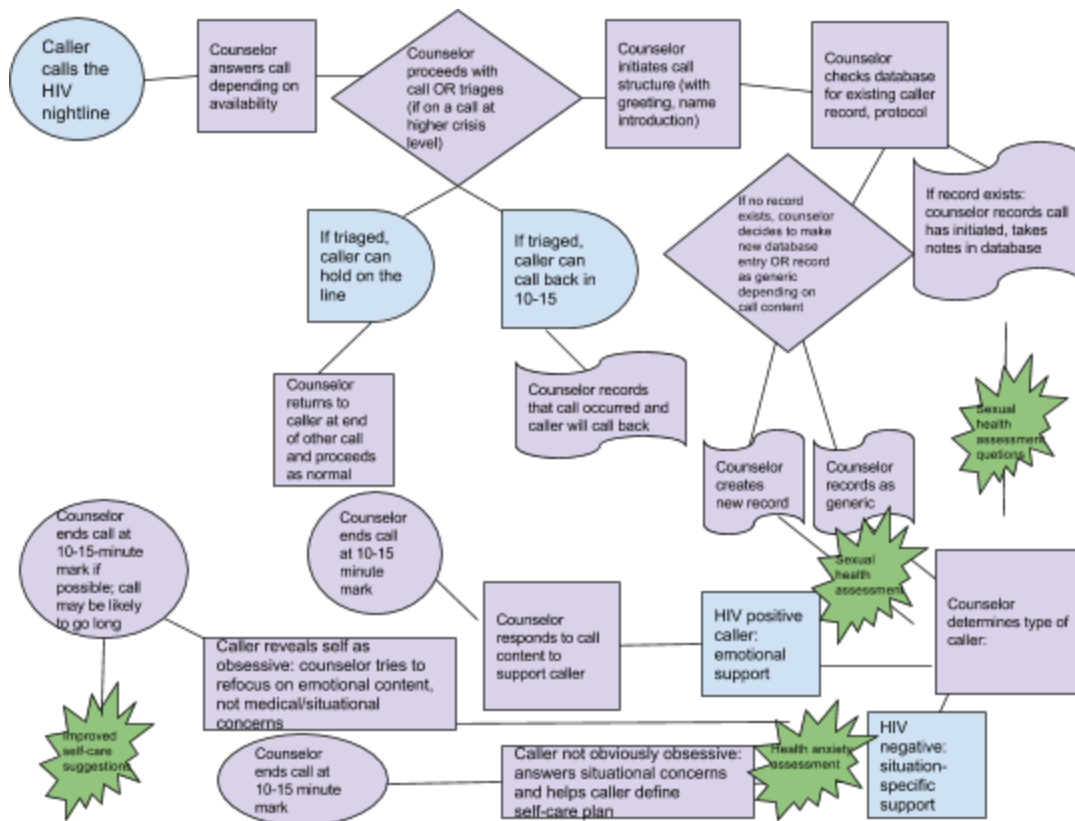


Figure 4. Flowchart of current Nightline calls, with proposed project changes in green.

Call monitoring. The intern monitored qualifying calls in the call room using a listen-only feature built into each phone, as is standard at SFSP for counselors-in-training and at the discretion of counselors who may want feedback from shift mates on a call. Callers were not told they were being monitored, but upon calling SFSP, all callers hear a message cautioning that calls may be monitored for “quality and training.” Because this study aimed only to evaluate efficacy of the proposed call structure for anxious Nightline call, monitoring the call did not represent an infringement of the caller’s rights or a greater-than-usual invasion of privacy.

Testing Cycles

Pilot. In a pilot prior to the first full cycle, one counselor was verbally briefed on the project and trained on the two new types of assessments. This counselor then tested the sexual health assessment with one caller on one call and provided extensive feedback, including a recommendation to ask callers whether they had used protection during sex. The caller in the pilot reported a high-risk potential exposure to HIV, so the counselor and intern determined to address his concerns without incorporating the anxiety assessment. As pilot data was promising, no changes were made prior to initiating PDSA 1, and data from the pilot was analyzed with PDSA 1 data. On subsequent calls, level of anxiety was assessed even for callers who reported high-risk encounters to validate the assessment tool on such calls.

PDSA 1. Each participating counselor received a verbal explanation of the project and handouts detailing the sexual health assessment, health anxiety assessment, and self-care strategies. Health anxiety assessment questions were randomized and counselors' assigned questions were provided to them before or during their call. Counselors were asked to get through as many of their three assigned questions as they felt comfortable on the call. Counselors tested both the sexual health assessments and the health anxiety assessment questions on callers until each question had been asked three times (or had been removed from the list). In PDSA 1, once the counselor determined that the caller was eligible to participate in this quality improvement project (i.e. not in crisis, and not HIV(+)), they were given up to three randomly selected questions (using Excel's random number generator) from the list above to ask the caller. At times, counselors abstained from asking a question because they felt uncomfortable, it was a poor thematic fit with all content, or because the intern was not able to provide them with the

question fast enough on the call. If a question was received negatively by multiple counselors, it was removed from the list of questions for subsequent testing. This cycle incorporated 21 calls.

PDSA 2. In PDSA 2, the abbreviated list of questions was made available to counselors and counselors chose which health anxiety assessment questions to use. Questions were again reviewed based on caller response and counselor feedback. The drafted call structure, including the sexual health assessment and health anxiety assessment questions, continued to be tested by a mix of new counselors who had not yet answered a call as part of the project (though they may have been trained for participation in PDSA 1) and those who had taken calls as part of the project. All were provided with instructional printed slides outlining the changes to the call structure (see below). For ease of counselor reference, questions from the MAPS and IAS were presented divided by theme. PDSA 2 incorporated 13 calls.

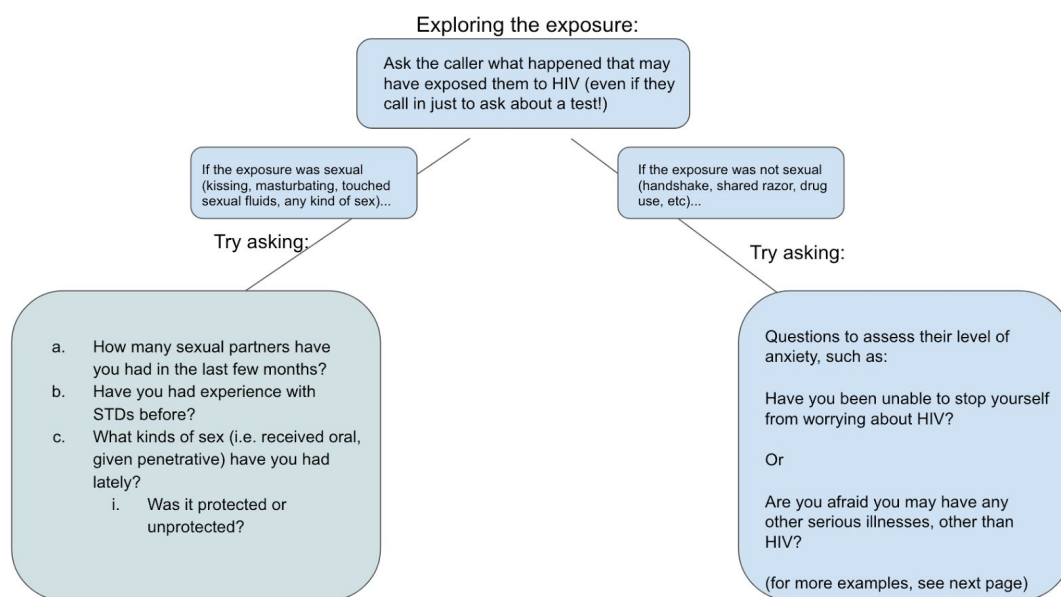


Figure 5. Flowchart provided to counselors to use on calls. Shows call start through sexual health assessment. Includes content from the CDC (US Department of Health and Human

Services, 2011), MAPS (Harrell & Wright, 1998) and IAS (Kellner, Abbott, Winslow, & Pathak, 1987).

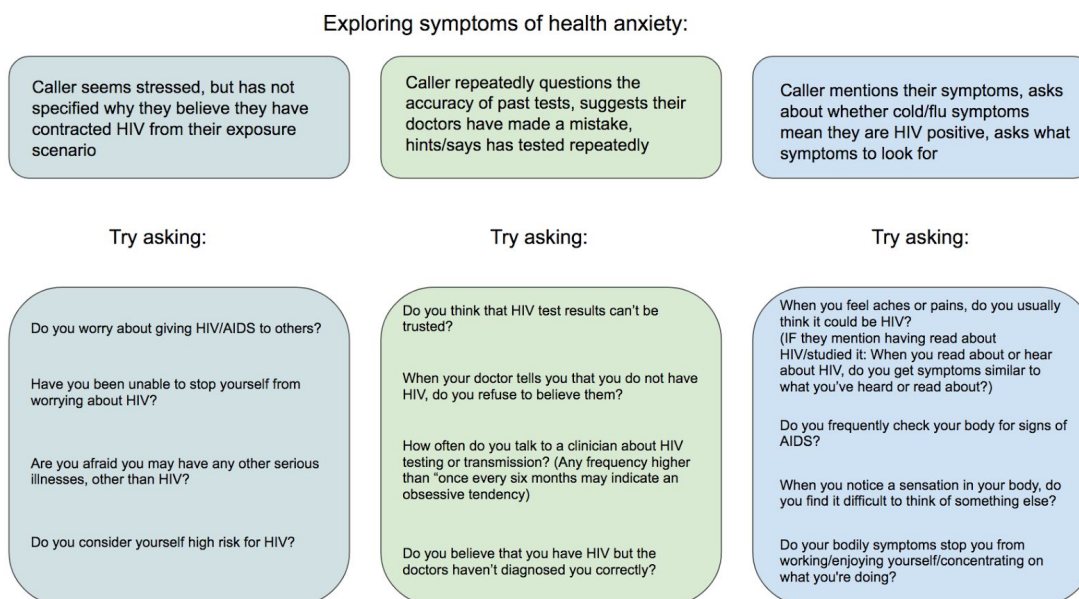


Figure 6. Chart provided to counselors with loose thematic groups of questions from the MAPS (Harrell & Wright, 1998) and IAS (Kellner, Abbott, Winslow, & Pathak, 1987) for use on calls.

Participants. The project included a convenience sample of callers to the HIV Nightline. Because the HIV Nightline is a passive source of participants, the decision to utilize the new call structure with callers depended on the following criteria:

1. If the caller asked questions about HIV transmission, in which case they may be included
2. If the caller is a known obsessive caller (i.e. with a profile, or recognized by a counselor), in which case they may be included
3. If the caller presented as suicidal, in which case addressing the crisis took precedence

Participants and Data Collection

Risks and benefits to participants. Any Nightline caller who utilized SFSP services while the graduate intern was monitoring calls and who was not in immediate crisis was

considered eligible to participate. (One Spanish HIV caller and one Crisis line caller with HIV-focused content also participated.) No data pertaining to age was asked or recorded as part of this study, and callers of any age were eligible to participate. There was no advertisement for recruitment. There were no direct benefits for participants in this study. The primary risk to participants in this study was that their sense of care provided by the Nightline may have been temporarily disrupted when counselors asked for details about their history or perspective. Given the discretion provided to counselors around what to say to callers, it is unlikely that a question asked as part of the modified call structure represented a disruption of care or was seen as a substantial change in practice. As on any HIV Nightline call, there was a chance the caller might respond negatively to a counselor's question. All counselors had been trained to reflect emotions and change approaches as needed to mitigate any such response. The nature of the Nightline permits callers to end a call at any time with no negative consequences. Therefore, this study posed minimal risk to participants. Participants were not compensated.

Data collection and analysis. The following data was recorded for qualifying calls:

1. Anonymized participating caller number (P01, P02, P03...)
2. Anonymized volunteer counselor number (V01, V02, V03...) in PDSA 1; in PDSA 2, counselor's first name and basic demographics (male, female, approximate age and race);
3. Caller responses to the sexual health assessment, at a sufficiently high level that they could not be used to identify the caller in any way;
4. Caller outcome post sexual health assessment (i.e. better, same, worse; rapport better, same, worse); and qualitative notes;

5. Which health anxiety assessment questions the caller answered, and how (1, never; 2, rarely; 3, often), as well as qualitative notes on caller responses at the thematic level
6. Counselor feedback on relative success of questions, 1-10, where 1 is not successful and 10 is extremely successful;
7. In PDSA 2 only, counselor feedback on a Likert scale (1-5): helpfulness of sexual health assessment; counselor comfort administering sexual health assessment; counselor rating of caller comfort responding to sexual health assessment; helpfulness of the health anxiety assessment; counselor comfort administering health anxiety assessment; counselor rating of caller comfort in responding to health anxiety assessment; helpfulness of each health anxiety assessment used and qualitative notes on specific questions.

Collection and storage of data. Caller data in notes were anonymized (i.e P01, P02) and no caller demographic data were collected. Thematic notes were recorded such that no caller would be identifiable. Collected data were stored in a Google Drive spreadsheet and not linked to SFSP's records. While SFSP records some caller information, this information was not linked with the project. No audio, video, photos, or specimens were collected.

Results

PDSA 1. PDSA 1 aimed to utilize three counselors on three shifts in asking the proposed assessment questions of their callers until each question had been asked five times, while the student intern monitored live call audio and provided prompts and suggestions to the volunteer counselor. However, call volume on the Nightline can be wildly unpredictable, with hours sometimes passing between individual calls or multiple partially-overlapping calls occurring in quick succession. Additionally, not all counselors asked all three health anxiety questions

assigned to them on each call. If the questions did not make sense within the themes of the call, or if the counselor did not feel comfortable asking a question, the counselor would sometimes skip some of the questions they were assigned. For example, one counselor skipped the question "Are you afraid you may have any other serious illnesses, other than HIV" because the caller's content was already focused on a recent diagnosis with a different illness. Per the counselor, the caller "already had [another illness] AND [fear of] HIV, I didn't want to start her brain thinking about anything else right now because that would take her down another spiral." Additionally, if the student intern judged that a question would be destructive to the rapport of the call (e.g. the question requested redundant information and might indicate to the caller that their counselor was not listening) the student intern sometimes indicated that the counselor was not required to ask the redundant question. Because of constraints on call volume and on testing of questions, 13 counselors across several evening and weekend shifts asked each question three times across 21 calls total, and more counselors were briefed on the call structure but did not engage a qualifying participant. After each question had been asked once, the questions were edited based on counselor feedback including: counselor resistance to asking a question; observed counselor skipping of asking a question; observed redundancy of content. At the conclusion of PDSA 1, the initial list of 15 health anxiety questions was edited down to 12 questions to be tested in PDSA 2.

PDSA 2. In PDSA 2's six calls, part or all of the sexual health assessment was employed. In the two cases in which only part of the sexual health assessment was employed, counselors collected information on types of sex the caller has had and whether the sex was protected but not on how many partners they had had recently or past experience with STDs.

Counselors were asked to rate sexual health assessment questions they used on their call on a Likert scale of 1-5, where a score of one indicated a negative experience and a score of five indicated an extremely positive experience. The sexual health assessment was reviewed well by counselors. Its mean scores indicate that it is acceptable to both counselors and to callers. While helpfulness was not ranked as highly as other measures, the value of the sexual health assessment questions would be significantly enhanced if the assessment were used consistently across callers as it would effectively contextualize caller experiences on a spectrum of health behaviors. These ratings are reviewed below.

Table 1

Sexual Health Assessment Ratings by Counselors

Attribute	Mean score (Likert 1-5)	Number of Calls (n=)
Helpfulness	3.5	6
Counselor comfort in employing	5	6
Caller comfort in responding	4.5	6

PDSA 2 included of 13 calls in which at least one health anxiety assessment question was used. In six calls, the target of asking three health anxiety assessment questions was met, and in two additional calls two health anxiety assessment questions were used. The most common health anxiety questions chosen by counselors were “Have you been unable to stop yourself from worrying about HIV?” (n=7), “Do you think that HIV test results can’t be trusted?” (n=4), “When your doctor tells you that you do not have HIV, do you refuse to believe them?” (n=3), and “Do you consider yourself high risk for HIV?” (n=3). Counselors often paraphrased

questions to make them suitable to their conversant style. Not all questions included in PDSA 2 were employed in this cycle; however, testing every question was not essential to this cycle.

Table 2

Health Anxiety Assessment Ratings by Counselors

Attribute	Mean score (Likert 1-5)	Number of Calls (n=)
Helpfulness	4.6	11
Counselor comfort in employing	4.75	12
Caller comfort in responding	4.5	12

Counselors were also invited to rate the individual questions they 1-5 for helpfulness and to explain why they selected the questions they did. The scores indicate positive experiences using the proposed health anxiety assessment and high rates of acceptability among callers. Counselor ratings and explanations included:

- One counselor paraphrased “Have you been unable to stop yourself from worrying about HIV?” to a caller by suggesting “It sounds like you’ve been worrying about this a lot.” She rated this question’s helpfulness a 4: “[The question] helped get to the emotional content quicker.”
- One counselor who asked “Do you consider yourself to be high risk for HIV?” rated the question a 5 for helpfulness and said it was a great way to lead into a call because it helped him to “[t]ry to determine what their knowledge of HIV risk is.”
- One counselor who asked “Do you feel you can’t trust what your provider is telling you?” to combine two questions, “Do you think that HIV test results can’t be trusted?” and “When your doctor tells you that you do not have HIV, do you

refuse to believe them?" explained: "I just wanted to know what he thought his risk was personally. And it sounds like in his mind, he knows--he didn't really insist that he must have HIV despite these results. It's a good way of just kind of identify[ing] where the emotions are coming from and asking: is it because you don't trust the results or is there something else that's happening? And in this case it seemed like other things, stressed out by the environment and the guilt." This counselor rated the health anxiety assessment a 4 for helpfulness.

On one PDSA 2 call, the caller terminated the call prematurely, a potential indicator of dissatisfaction or discomfort with the call structure. However, this caller terminated the call just as the counselor was initiating the call structure: the counselor asked the caller if his concerns about HIV were preventing him from performing other activities, and the caller responded in the affirmative before terminating the call. As the call was so brief, it is not possible to assess for certain whether this caller rejected the call structure, terminated the call intentionally for another reason, or terminated the call unintentionally. Hang-ups and negative caller feedback on the new call structure should be tracked as the call structure is implemented to maintain caller satisfaction and avoid disrupting standard care on the Nightline.

Discussion

Counselor feedback on the call structure was positive: counselors felt the sexual health assessment and health anxiety assessment questions were helpful, sufficiently easy to ask, and acceptable to their callers. Based on this positive review of the assessment structures, SFSP plans to introduce these structures into their next round of volunteer trainings.

Counselors were encouraged to take the health anxiety questions as written as thematic guidelines and to fit the questions into their own voice and call context. This is in line with SFSP's current policy on assessing for suicidality in callers, in which certain information must be collected from the caller--whether they are having suicidal thoughts, a plan, the means to enact that plan, and so on--but the phrasing of questions is flexible. One example of such paraphrasing is a counselor asking "Do you feel you can't trust what your provider is telling you [about your HIV status]?" instead of the question as written, "When your doctor tells you that you do not have HIV, do you refuse to believe them?" This paraphrasing would most likely elicit identical content to the question as written. Future research may evaluate whether phrasing of questions has impact on the validity of the information collected. For purposes of this quality improvement project, aligning the call structure with current practices at SFSP was prioritized over more rigorous analysis of the implications of phrasing and wording changes.

Despite the enthusiasm with which counselors accepted the sexual health assessment in PDSA 1, three counselors (six calls) did not use the sexual health assessment as suggested in PDSA 2. Justifications for skipping all or part of the sexual health assessment varied: one said "If [the caller doesn't] go into [the exposure], I don't bring them into it, so we can talk about the anxiety," a second forgot to make use of the health assessment questions, and a third admitted "I didn't prioritize it." Encouraging counselors to make consistent use of the sexual health assessment may prove challenging as it may be perceived as optional, of marginal benefit to a particular caller, or may be skipped unintentionally. Mitigations may include presenting the sexual health assessment as imperative to maintaining, rather than potentially worsening, the mental health of anxious Nightline callers, as well as implementing prompts in the Nightline

database mandating collection of the information targeted by the sexual health assessment (C. Brown, personal communication, August 8, 2017). Similarly, while the health anxiety assessment questions were enthusiastically received by counselors, four counselors (across four calls) asked one or fewer health anxiety assessment questions on a potentially qualifying call. In one case, the counselor asked a health anxiety assessment question as part of her standard practice and not because she intended to as part of the review of the assessment questions. Furthermore, on one qualifying call, a counselor did not engage a caller with either the sexual health assessment or the health anxiety assessment because, while the caller had questions about HIV symptoms, the counselor perceived these questions as pragmatic and felt it more appropriate to encourage the caller to direct the questions to a medical health professional. Additional training and education on the value of these assessment tools and their place in the cycle of anxiety focused around health may help mitigate counselors' temptation to respond directly to callers' questions without gathering the context provided by the assessment tools.

The target of three health anxiety assessment questions was set as a benchmark practice: brief enough not to interrupt the call, but more likely to identify a caller concealing their anxiety than one question alone. As thematic content is so broad on the Nightline (i.e. a caller who tests for HIV every week may not be fixated on symptoms,) giving the caller multiple opportunities to respond to scale items is valuable. Whether three questions is a mandatory minimum to identify health anxiety or whether two or fewer questions may be used equally effectively in this context should be reviewed in the future. Helping counselors understand the broader context of how the Nightline might unintentionally perpetuate anxiety in callers as a means of contextualizing the value of these questions may be critical to integrating the assessments into standard Nightline

practice. Mitigations could also include supplementary training to current counselors focused on the benefits of asking the sexual health assessment questions. Introducing the questions as a mandatory part of the call structure for calls with sexual content may also minimize pushback from counselors concerned with sounding intrusive or about distracting from the caller's emotional content. Future new counselor trainings at the Nightline will incorporate instruction on distinguishing between pragmatic and anxious callers, as described in this project. The training will include role plays to facilitate use of the assessments developed as in this project.

While the call structure was not meant to be tested on callers in crisis, two cases arose that indicate it may not be harmful for such callers. In PDSA 1, a caller reached out on the Crisis line with qualifying content for participating in this project, as determined by the counselor answering the call. The structure was used on this Crisis line call without incident. In the second instance, a Nightline caller participating in the project gradually indicated distress such that the intern suggested the counselor assess the caller for suicidal thoughts. The caller did report recent suicidal ideation and was from that point treated per SFSP policy for callers in crisis. When debriefing at the end of the call, the counselor reported that while some anxiety assessment questions may have triggered the caller's anxiety, he also felt the call had been cathartic for the caller, and rated the helpfulness of, counselor comfort in asking, and caller comfort in answering the health anxiety assessment questions a 5, the highest possible score. Effects of these structures on callers in crisis should continue to be assessed as the Nightline implements these strategies. Two methods of evaluation may include call themes after administration of health anxiety assessment questions and tracking caller suicidality at the end of Nightline calls (whether suicidality increased or decreased from the start of the call).

Limitations

This project was conceived of as a quality improvement project. This allowed for flexibility in the study design, recruitment of counselors for participation, and administration and phrasing of questions. This flexibility, including ad hoc question changes and phrasing updates, facilitated designing a call structure proposal that meets acceptability criteria for the organization and its counselors. However, this limits the rigor of the research, including the consistency of methods and results.. Future research projects not focused on quality improvement may provide more structured and rigorous insight into the clinical and/or long-term implications of this call structure. Additionally, recruitment for this project was constrained to a convenience sample. Caller demographics were not collected in this project to protect caller privacy. Future research may include more rigorous sampling methods and control groups.

Future Research

As this call structure is implemented at the Nightline, it should continue to be evaluated for helpfulness and acceptability by counselors and callers. Training of new and current volunteers should be evaluated. Future projects may address the limitations of quality improvement study design.

Originally, project goals included reducing the duration and frequency of anxious HIV(-) Nightline calls. However, tracking timing and frequency data was not feasible on this project as identifying caller data was not recorded. Therefore, participating calls could not be compared to prior or subsequent caller behavior. The long-term implications of this new call structure for the Nightline and its callers are as yet unknown and should be assessed. This proposed call structure could also be adapted and piloted for in-person settings offering HIV testing.

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Appendix A: Needs Assessment Interview Guide for San Francisco Suicide Prevention
Volunteer Counselors

1. How long have you been volunteering with SFSP?
2. Do you have other clinical psych experience or goals?
3. How do you feel about answering HIV Nightline calls generally?
4. If you were going to break down Nightline callers into a few different types of callers, what would that look like?
5. How do you typically handle someone who calls in who almost definitely doesn't have HIV (from the exposure they're talking about)?
6. How do you typically handle someone who calls in who almost definitely doesn't have HIV, but has a caller profile/you know calls in a lot?
7. Do you have any tricks for figuring out who these HIV-negative repeat callers are?
8. Have you ever thought someone MIGHT be an obsessive caller and then find that you're wrong? What happened?
9. Do you have any you're thinking about trying?
10. Why do you think these callers call us so frequently?
11. How do you think we can help them?
12. What kind of self-care do you usually land on with these callers?
 - a. What kinds of things do you suggest?
 - b. What kinds of things do they think they might do/try/suggest themselves?
13. There are a few questions we're considering suggesting SFSP counselors use when talking to callers to see if they help us identify this kind of caller faster and more successfully. What do you think of:

MAPS -- Fear of Infection section (adapted)

- a. When you feel aches or pains, do you usually think it could be HIV?
- b. Do you worry about giving AIDS to others?
- c. Do you frequently check your body for signs of AIDS?
- d. Have you been able to stop yourself from worrying about HIV?
- e. Are you worried that you will die from AIDS?
- f. Do you consider yourself high risk for HIV?
- g. Do you think that HIV test results should be trusted?

MAPS -- Fear of others/avoidance

- h. Would you not share a glass with a friend because of AIDS?
- i. Would you feel comfortable being in the same room with a friend who has AIDS?
- j. Do you avoid watching TV programs that have a storyline about HIV or AIDS?
- k. Would you prefer to wear gloves because surfaces might be contaminated by HIV?
- l. If your partner had AIDS, would you still touch them? What about have sex with them?

Illness attitudes scales

- m. Are you afraid you may have any other serious illnesses, other than HIV?
- n. How often do you see a doctor?

- o. How many different doctors or clinics have you visited in the past year?
 - p. Do you believe that you have HIV but the doctors haven't diagnosed you correctly?
 - q. When your doctor tells you that you do not have HIV, do you refuse to believe them?
 - r. When you read about or hear about HIV, do you get symptoms similar to what you've heard or read about?
 - s. When you notice a sensation in your body, do you find it difficult to think of something else?
 - t. Do your bodily symptoms stop you from working/enjoying yourself/concentrating on what you're doing?
14. The questions I mentioned are from two different scales--one is meant to measure "AIDS Phobia" and the other is meant to measure a patient's attitudes towards illness. Did the questions I showed you raise any other questions for you? Is there anything else you think we should consider as we move forward?

Appendix B: Informed Consent Form -- Needs Assessment

Ivy Epstein

San Francisco Suicide Prevention + University of San Francisco

Capstone Project on HIV- Nightline Callers

Part I: Information Sheet**Introduction**

I'm working on my capstone project for the Masters of Behavioral Health program at the University of San Francisco. For our projects we all partner with a nonprofit and develop some kind of project including a final paper in conjunction with the agency. I had already volunteered at SFSP for several months before starting school, so I wanted to do my project with this agency. My personal favorite calls are Nightline calls, and Courtney had a project in mind for me to do in association with the Nightline specifically, and focused on HIV-negative Nightline callers. You can talk to anyone you would like to about this project within the normal bounds of SFSP confidentiality policies. You can take as much time as you need to decide if you want to participate, and if you have questions at any point, just let me know any time.

Purpose of the research

The Nightline regularly gets calls from HIV negative callers who seem convinced they may have HIV. We think these callers have different emotional needs from other callers and would like to treat them in a more effective way. We also know these callers sometimes conceal their goals from SFSP counselors, intentionally or not, so we'd like to find a way to identify what kind of caller they are faster. The goal is that counselors will treat these callers better and faster, leading to better outcomes for the callers and letting counselors spend more time with other callers.

Type of Research Intervention & Procedures

This will be about a 20-30 minute interview. I'm going to ask you some questions about your own style of addressing Nightline callers, what your strategies are when dealing with this type of caller, and so on. I'll also show you some questions we're thinking about adding to our call structure and ask for your feedback on what works and what doesn't. These questions might be things like "How long have you volunteered here" and "how long does it typically take you to identify callers on the Nightline" or things like that. If you feel like you can't or don't want to answer any question at any point, just let me know! We'll go in a conference room so that we can talk without being interrupted and your answers won't be shared with your shift-mates. I'm going to label the interview forms with a number, not your name, so your name won't be linked with your responses at all.

Participant Selection

Anyone at SFSP who answers calls can participate in this project. You've been chosen because you're interested in helping out!

- Do you feel like you understand what this study is about at this point?

Voluntary Participation

Participation in this interview is completely voluntary. You can stop participating anytime. Whether

or not you participate and what you say in the interview won't have any bearing on your ability to volunteer here or anything like that.

- Do you understand that you do not have to participate in the study and can stop at any time? Any questions or concerns?

Duration

The interview will last about 15-20 minutes. Right now we're not planning on doing any follow-up interviews. Since I'm trying to collect unbiased feedback from volunteers, please don't let anyone know the specific questions I'm asking you for the next week—then feel free to discuss with your shift-mates!

Risks

There are no known risks to this research study. If you at any point feel physically or emotionally uncomfortable, let me know and we will stop immediately to resolve the situation.

Benefits and Reimbursements

Ultimately the study should benefit you in that you will be able to use the interview questions and practices coming out of the study on your own calls. They probably won't be ready for you for another few months, though. There's no other compensation.

Confidentiality

I may use quotes or context from your interview in writing my final paper for USF and/or for the contents of a presentation or paper to be published in a journal. Again, your name won't be recorded anywhere in these materials and your responses won't be attributed to you in any way. I may record the audio of these interviews to check my notes; that audio will be linked to your participant number, not your name, and will not be shared with anyone.

It's possible, depending on what you say and who you share your responses with on your own time, that someone you know might recognize a quote from you if it is published. SFSP and its volunteers will get access to my final project before it's shared with the outside world. Your name and identifying information will definitely not be shared or associated with anything you share with me. I will ask Courtney to share the results of my project with all volunteers when the project is done!

Right to Refuse or Withdraw

Remember that you can always stop participating in this project at any time. Just let me know you'd like to stop or simply leave the room.

Who to Contact

If you have any questions at any point, just let Courtney or me know! You can email me at icepstein@dons.usfca.edu and you can reach Courtney at courtneyb@sfsuicide.org. This part of the project has not undergone IRB consideration because it's internal research.

Part II: Certificate of Consent

I have been invited to participate in research HIV Nightline counseling practices.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

Day/month/year

Appendix C: Anxiety Assessment Questions Asked of Callers in PDSA 1

- Do you think that HIV test results can't be trusted?
- How often do you talk to a clinician about HIV testing or transmission? (Any frequency higher than "once every six months may indicate an obsessive tendency)
- Are you worried that you will die from AIDS?
- Do you believe that you have HIV but the doctors haven't diagnosed you correctly?
- Have you been unable to stop yourself from worrying about HIV?
- Are you afraid you may have any other serious illnesses, other than HIV?
- When you read about or hear about HIV, do you get symptoms similar to what you've heard or read about?
- When you feel aches or pains, do you usually think it could be HIV?
- When your doctor tells you that you do not have HIV, do you refuse to believe them?
- When you notice a sensation in your body, do you find it difficult to think of something else?
- Do you worry about giving AIDS to others?
- Do you consider yourself high risk for HIV?
- Do you frequently check your body for signs of AIDS?
- If your partner had AIDS, would you still touch them? What about have sex with them?
- Do your bodily symptoms stop you from working/enjoying yourself/concentrating on what you're doing?

Note: After all questions had been asked once, the following merges were performed based on counselor feedback before the questions were asked a second time.

- When you feel aches or pains, do you usually think it could be HIV? (IF they mention having read about HIV/studied it: When you read about or hear about HIV, do you get symptoms similar to what you've heard or read about?)
- Do you worry about giving AIDS to others? IF NO: are you worried that you will die from AIDS?