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LOMA LINDA UNIVERSITY
School of Behavioral Health
in conjunction with the
Department of Counseling and Family Sciences

Pathways for Healing:
An Online Therapeutic Support Group Program

by

Lisa Yvette Salazar

A Project submitted in partial satisfaction of
the requirements for the degree
Doctor of Marital and Family Therapy

June 2022

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Marital and Family Therapy.

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Thank you, God, for loving, healing, and saving me. Thank you for giving me a calling to help other women, like myself.

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To all mesh survivors, this is for you.

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ABBREVIATIONS

ACA	Affordable Care Act
BDI-II	Beck Depression Inventory-II
BPS	Bio-Psycho-Social
BPS-S	Bio-Psycho-Social-Spiritual
CD	Chronic Disease
CHESS	Comprehensive Health Enhancement Support System
CI	Chronic Illness
CICO	Check-In, Check-Out Oral Report
DSM-V	Diagnostic and Statistical Manual of Mental Disorders-5 th edition
FACIT-F	Functional Assessment of Chronic Illness Therapy Measurement System
FACIT-SP	Functional Assessment of Chronic Illness Therapy Management System-Spirituality
GAD	Generalized Anxiety Disorder
GST	General Systems Theory
HRQOL	Health-Related Quality of Life
LMFT	Licensed Marriage and Family Therapist
LMFT-A	Licensed Marriage and Family Therapist Associate
MDD	Major Depressive Disorder
NT	Narrative Therapy
OTSG	Online Therapeutic Support Group

PFD	Pelvic Floor Dysfunction
PFDI-20	Pelvic Floor Distress Inventory-Short Form 20
PFPT	Pelvic Floor Physical Therapist
PFIQ	Pelvic Floor Impact Questionnaire-Short Form 7
PHC	Primary Health Care
SBI	Spiritual Beliefs Inventory
SES	Socio-Economic Status
SF-36	RAND 36-Item Health Survey
SPT	Physical Therapist Student
UTI	Urinary Tract Infection

ABSTRACT OF THE DOCTORAL PROJECT

Pathways for Healing:
An Online Therapeutic Support Group Program

by

Lisa Yvette Salazar

Doctor of Marriage and Family Therapy,
Department of Counseling and Family Sciences
Loma Linda University, June 2022
Dr. Nichola Seaton-Ribadu, Chairperson

Pathways for Healing: An Online Therapeutic Support Group Program (OTSG) is for women, ages 18 to 65 years old, diagnosed with chronic pelvic floor dysfunction (PFD). The program focuses on women living in Texas rural communities with limited access to mental health providers. The aim for this study is to determine if an OTSG program, utilizing narrative therapy (NT) within a biopsychosocial-spiritual lens (BPS-S) will improve overall health-related quality of life (HRQOL). Support groups are provided in English and Spanish, over the course of 12 weeks, facilitated by a licensed marriage and family therapist (LMFT) and licensed pelvic floor physical therapist (PFPT). Administering pre and post-tests (before 1st session, after the 6th and 12th session, and 3- and 6-months post group participation), data is collected utilizing: 1) The Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-SP), 2) Pelvic Floor Impact Questionnaire-Short Form 7 (PFIQ), 3) Pelvic Floor Distress Inventory-Short Form 20 (PFDI-20), 4) Beck Depression Inventory-II (BDI-II), 5) RAND 36-Item Health Survey (SF-36), 6) Check-In, Check-Out Oral Report (CICO), and 7) Survey for

Participants. Data will determine if the OTSG program decreases anxiety and depression, improves overall HRQOL, and decreases chronic PFD symptoms.

Keywords: pelvic floor dysfunction, online therapeutic support group, health-related quality of life, medical family therapy, Texas rural communities and therapy, integrative therapy, biopsychosocial-spiritual, narrative therapy.

CHAPTER ONE

PROJECT PURPOSE

As Americans live longer, the likelihood of developing a chronic illness (CI) increase, with 80% of the population diagnosed in their lifetime (Restorick-Roberts, et al., 2017). According to the National Council of Public Health, chronic illness (CI) and chronic disease (CD) are used interchangeably. CI is defined as a disease that has lasted three months or longer, is an ongoing, life-long condition, incurable, cannot be prevented by medication or vaccines, will not resolve on its own, persistent, symptoms gradual progress, and can contribute to other chronic conditions (National Health Council, 2014). According to the World Health Organization, CI kills up to 38 million people around the world each year (Olivares, et al., 2017).

CI is a biomedical disease that remains for the duration of a person's life, with identifiable risk factors, such as: age, obesity, lack of physical activity, alcohol intake, smoking, not eating enough fruits and vegetables, non-Caucasian, lower socio-economic status (SES), which limits daily activities and physical ability (Martin, 2007, Olivares, et al., 2017). While heart disease, diabetes, depression, and asthma are commonly identified as CI, there are other lesser-known conditions that have the same risk factors and challenges, such as pelvic floor dysfunction (PFD) (Bernell & Howard, 2016). PFD is a broad term that refers to the biological components related to the bladder, uterus and vagina, prostate, and rectum, related to four areas in the body: 1) urological (cystocele, urethrocele, urinary incontinence), 2) gynecological (dyspareunia, uterine prolapse, vaginal prolapse, enterocele, rectocele), 3) colorectal (constipation, fecal incontinence,

rectal prolapse), and 4) biological (pelvic pain, levator spasm, proctalgia fugax, perineal descent) (Grimes & Statton, 2020, Cleveland Clinic, 2020). Chronic PFD is the result of genetics, trauma, nerve damage, prolapse, inflammation, gastrointestinal disorders, vaginal delivery, sexual/physical abuse, or physical damage to the body (Manley & Odom, 2006).

While PFD occurs in men and women, this project focuses solely on biological females, because of the increasing rise of PFD in women each year. Every year, over 600,000 hysterectomies are performed in the United States, which increases the likelihood of developing CI, and over 300,000 women are diagnosed with PFD (Parsons, 2019, Blandon, et al., 2009). Based on the National Health and Nutritional Examination Survey, over 25% of women in the United States are diagnosed with chronic PFD, as a result of vaginal childbirth, hysterectomy, physical injury, and disability (Wu, et al., 2014). Unfortunately, improper assessments, delayed medical intervention and mental health services, impacts women physically, psychologically, and affects relationships within the family system (Smith & Witherow, 2000).

Depression is a common comorbid diagnosis with chronic PFD and negatively impacts women's ability to engage in daily living activities, increases social isolation from family and friends, amplifies feelings of hopelessness surrounding the diagnosis, and creates financial stressors (Restorick-Roberts, et al., 2017). Women also report feeling anxious about the prognosis, are concerned and worried about treatment outcomes, and experience a decrease in overall health-related quality of life (HRQOL) (Skoczylas, et al., 2015). Because 7-10 minutes is typically spent on each patient, medical providers are unable to address the psychological impact chronic PFD has on HRQOL,

limiting the ability to adequately address the psychological and social impact of living with PFD (Huljev & Pandak, 2016). As a result, women report not having sufficient psychoeducation and lack mental health services to cope with PFD and manage the physical symptoms (Wagner, et al., 2001, Callebaut, et al., 2017). Unfortunately, 21% of American women report finding information on the internet, with inadequate information about living with chronic PFD that contributes to the delay of medical and mental health services (Griffiths, et al., 2012). Healthcare costs, lack of access to service providers in rural areas, and limited counseling sessions determined by insurance companies are additional added stressors, delaying the treatment of appropriate medical and mental healthcare.

The purpose of creating an OTSG program is to address the impact chronic PFD has on women's overall HRQOL, while also providing services in rural communities to address the lack of mental health services available. Therapy and consistent medical care provide the support needed for women living with chronic PFD (Weihs, 2002).

Therapeutic support increases effective communication, encourages modifications of daily activities, promotes resilience, incorporates coping skills, introduces stress management, promotes self-care, and active health management. Self-care and health management requires familiarity of chronic PFD and its symptoms, medication management and potential surgical options that are safe, collaboration with the medical team, and support from others, which the OTSG program will also introduce (Martire & Helgeson, 2017).

Pathways for Healing is an OTSG program that offers mental health services for women diagnosed with PFD, which provides opportunities to increase communication

and becoming an advocate for personal health, increases emotional and spiritual support, and utilizes community resources to better cope with chronic PFD (Grassi, et al., 2017). Without therapeutic support, women with chronic PFD manage their daily life, however, feel isolated, unsupported, discouraged, report feeling lack of connection with family and friends, and experience marginalization within their communities (Mejias, et al., 2014). Learning to manage daily activities, balancing home responsibilities, maintaining relationships with family and friends, and relying on spirituality and faith, are goals for women in the OTSG program (Van Houtum, 2015). Women connecting with others, who also are living with PFD, offer support, understanding, and learn healthier ways to manage stressors.

Developing an OTSG program within a biopsychosocial-spiritual (BPS-S) framework addresses the whole person, to better manage living with chronic PFD. Incorporating a BPS-S model addresses overall HRQOL by focusing on the biopsychosocial-spiritual (BPS-S) factors that impact women living with chronic PFD, such as: 1) the biological (genetics, physical history, diet), 2) psychological (mental diagnosis, coping skills, stressors identified), 3) sociological (cultural framework, support system, community support/services) and 4) spiritual (beliefs, spirituality, prayer) factors for treating the whole person (Holthouse, 2016). Offering support groups for women diagnosed with chronic PFD includes identification of BPS-S factors most impactful to each participant, identifies ways to modify daily living activities, incorporates psychoeducation, and promotes self-advocacy and awareness campaigns through the Sisterhood Ambassador Program.

Living with chronic PFD is managed with proper tools, support, and therapeutic interventions, to improve overall HRQOL. Trained licensed marriage and family therapists (LMFT's) and marriage and family therapy associates (LMFT-A's) identify strengths and challenges for women in the program and encourages active engagement with one another. Through storytelling and personal reflections, women become self-advocates for healthcare and daily living needs, learn new coping skills, improve the management of daily living activities, and advocate for the care of others (Gucciadri, et al., 2016). The OTSG program helps women living in rural communities, who do not have access to mental health services, and are seeking medical treatment and mental health services. Because women can feel overwhelmed with the lack of information about living with chronic PFD, the program provides a safe space for women to connect with others, manage physical symptoms, and improves overall HRQOL.

CHAPTER TWO

LITERATURE REVIEW

According to the National Council of Public Health, chronic illness (CI) is defined as a disease that is ongoing, long term, incurable, can be treated symptomatically, and has occurred for a minimum of three months (Hopman, et al., 2016). The likelihood of being diagnosed with a form of CI increases with age, as Americans are living longer than in the 19th and 20th century (Olivares, et al., 2017). CI is increasingly difficult to diagnose and often takes time and different tests to accurately determine the root cause of the symptoms (Nes, et al., 2017). Women with CI report an increase in symptoms, such as: pain, fatigue, insomnia, foggy brain, worrying and rumination over physical issues, anxiety, depression, stress, and gastrointestinal issues, which are not visibly identifiable to others (LaFountain, 2010, Nes, et al., 2017). Often times, women will mask depression by isolating from others, staying in bed, and limiting social contact in person and online. Unmanaged stress can exasperate symptoms of anxiety, fatigue, and pain, creating physical barriers between women and family members, perpetuating the cycle of isolation and depression (Egeli & MacMillan, 2008).

One form of CI is chronic pelvic floor dysfunction (PFD), impacting relationships, physical and mental abilities, and the management of daily activities (Weihs, 2002). CI creates a strain on finances, as women determine treatment based on cost, which can increase stress on the family's finances (Kanfl, 2002). In the United States, over 600,000 hysterectomies are performed on women, each year, increasing the likelihood of developing PFD symptoms that can become chronic (Parsons, 2019). Every

year, over 300,000 American women are diagnosed with PFD, and are offered surgery as a first option, without mental health services (Blandon, et al., 2009). While one does not cause the other, women who have had a hysterectomy have a higher propensity to develop a form of PFD in their lifetime, leading to chronic PFD.

Problem Statement

Women in the United States are living an average of 34 years longer today, in comparison to the 19th and 20th century, due to improved education, nutrition, advanced medical treatment options, and community support (Smith & Witherow, 2000). As a result of living longer, there is an 80% chance that women will be diagnosed with CI within a lifetime (Restorick-Roberts, et al., 2017). Women are diagnosed more often than men, due to visiting doctors more frequently and are more apt to seek medical treatment to alleviate presenting symptoms (Bussing, et al., 2010). While CI is typically identified as heart disease, diabetes, and HIV, chronic PFD is also a form of CI with similar risk factors that include: 1) age, 2) obesity, 3) lack of physical activity, 4) alcohol consumption, 5) smoking, 6) not consuming enough fruits and vegetables, 7) lack of higher education, and 8) belonging to a non-white ethnic group (Smith & Witherow, 2000, Olivares, et al., 2017). There are two types of PFD: acute and chronic, however the OTSG (online therapeutic support group) program focuses on women diagnosed with long-term PFD. Chronic PFD fits the criteria for CI, which lasts longer than three months, is incurable, cannot be eradicated from medication or a vaccine, limits daily living activities based on physical abilities, is persistent with long term effects, is not contagious or terminal, progressively worsens over time, contributes to other illnesses,

and requires ongoing medical care (Bernell & Howard, 2016).

Based on the National Health and Nutritional Examination Survey, at least one form of chronic PFD impacts 25% of women in the United States, which is likely to occur as a result of vaginal childbirth, hysterectomy, physical injury, genetics, and/or disability (Wu, et al., 2014). PFD is diagnosed when one or more of the following conditions are identified by a urogynecologist, urologist, and/or gynecologist: 1) obstructed defecation, 2) rectocele, 3) pelvic floor prolapse, 4) paradoxical puborectalis contraction, 5) levator syndrome, 6) coccygodynia, 7) proctalgia fugax, and 8) pudendal neuralgia, contributing to ongoing bladder infections, kidney infections, peripheral neuropathy, incontinence, bladder spasms, chronic pain, and difficulty walking (The American Society of Colon and Rectal Surgeons, 2020, Weihs, 2002). For women who choose surgical options, there is an increased likelihood of experiencing complications or severe foreign body response to mesh/transvaginal tape/urethral sling, which can cause bladder and/or pelvic pain, vaginal discharge, neuropathy, fistulas, urethral perforation, leakage, kidney and bladder infections, antibiotic resistance from chronic infections, erosion, disability, and even death (Ordorica, et al., 2008). Complications related to surgery impact women's inability to maintain physical intimacy, due to severe pain and the increased likelihood of developing chronic urinary tract infections (UTI) and bladder infections.

In addition to the physical complications, women living chronic PFD experience, also experience psychological challenges that impact self-esteem, relationships, and self-care. Depression is a common comorbid diagnosis, which is compounded by an increase of social isolation from family/friends, feelings of hopelessness, financial stressors

related to cost for treatment, and reduced overall health-related quality of life (HRQOL) (Restorick-Roberts, et al., 2017). Unmanaged stress is exasperated by symptoms of fatigue, anxiety, and pain, impacting relationships with others, and decreases the overall HRQOL on a biopsychosocial-spiritual (BPS-S) level (Egeli & MacMillan, 2008). Depression and psychological distress can result from having a low support system, lack of medication management, strained relationships with family and friends, and a decrease in overall HRQOL (Wagner, et al., 2001). The lack of support from family/friends and experience of marginalization within the community is compounded, due to the lack of familiarity with chronic PFD and its impact on women and the family system (Mejias, et al., 2014). Oftentimes, women mask depression through isolation, lack of social connection with family and friends, and minimal medical and mental health care services.

Women living in rural communities are likely to experience a decline in mental health, due to the lack of medical and mental health service providers within their community (Callebaut, et. al., 2017, Clark, et al., 2017). Women required to travel outside of their community are less apt to receive medical and mental therapies, due to cost, distance, and physical abilities. Healthcare costs and lack of access of to service providers in rural areas create challenges for women to access therapeutic services within their local community, which delays a proper diagnosis and treatment (Clark, et al. 2017). There are ten factors that contribute to a decline in physical and mental health: (1) ethnicity, (2) education, (3) socioeconomic status (SES), (4) community support, (5) lack of health insurance, (6) cultural belief systems, (7) family support, (8) financial resources, (9) access to mental health and medical providers, and (10) social and spiritual support (Weihs, et al., 2002, Sandberg, et al., 2018).

One third of those living with CI report lower levels of HRQOL, which impacts: 1) basic living (finances, employment, housing, medical and mental health care) and 2) social issues (relationship with spouse, lack of participation in children's activities, inability to participate in social gatherings) (Van Houtum, et al., 2016). The Patient Protection and Affordable Care Act (ACA) helps women receive affordable care, despite having a pre-existing condition. However, there are not many service providers located in rural areas qualified to treat chronic PFD, thereby requiring women to travel outside their areas for treatment (Clark, et al. 2017). Due to the financial cost for treatment and lack of service providers in the area, women may not receive the necessary treatment needed to improve overall HRQOL. Delay in medical care can be related to: 1) misdiagnosis, 2) financial cost, and 3) inadequate access to medical specialists, negatively impacts the woman's psychological and social well-being (Smith, 2000). As a result, women self-diagnose and treat symptoms, while continuing to balance the responsibilities of being a wife, mother, and employee (Van Houtum, et al., 2016).

Systemic Analysis of the Problem

Chronic PFD affects both genders and all ages, however it is more prominent amongst biological women over the age of 18 years old. The likelihood of developing chronic PFD increases with age, which crosses over ethnic and socioeconomic factors (Curry, et al., 2010). Women with a poor prognosis tend to have lower education, lower SES, belong to a non-Caucasian ethnic group, and lack a spiritual connection (Weihs, et al., 2002). Women with poor prognosis are more likely to receive minimal to no medical treatment and may not receive mental health services, resulting in low quality HRQOL (Brown, et al., 2018). One third of women living with CI, such as chronic PFD, have

limited coping skills and are unable to adapt to the changes and limitations (Van Houtum, 2015). Women with chronic PFD experience difficulty managing daily activities, which means the responsibilities may shift to family/friends and co-workers, thereby increasing self-shame because of the inability to complete tasks independently. The challenges of balancing home responsibilities, financial obligations, maintaining employment, remaining connected with friends, prioritizing important relationships with close and children, and prioritizing daily living responsibilities are difficult to manage with CI (Van Houtum, 2015). The financial cost for medical and therapeutic interventions are added stressors, which burden the family's finances and directly impact the woman's roles within her home and work environment. As a result, it is common for women to streamline treatments, thereby limiting therapeutic interventions that are needed to improve HRQOL, by focusing only on the presenting symptoms, which may change or worsen over time. Stroh (2015) stresses the importance of addressing these problems, rather than simply focusing on the symptoms, as a long-term goal. Because medical providers are trained to treat symptoms, rather than the root problem, treatment may not fully address chronic PFD, which can be costly over the woman's lifetime.

Minority women living in lower SES communities with limited education, tend to receive inconsistent and minimal care and are isolated from a strong support system (Brown et al., 2018). Without proper care and resources, women are unable to access medical and mental health services needed to manage chronic PFD. Within the Latino community, CI is viewed as a form of weakness that only occurs in the mind and spirit of the woman diagnosed (Corvin, et al., 2017). This can cause women to suffer in silence, while attempting to overcompensate with responsibilities in the home, even when sick or

in pain. Latina women will seek curanderos (healer), who offer herbs, teas, prayer, physical treatments, spiritual consultation, and ritual suggestions to ward away the evil spirit for spiritual, physical, and mental healing (Reyes-Ortiz, et al, 2009). Latina women may also not seek medical treatment and mental health services, due to the cultural expectations to self-diagnose for holistic treatment and religious rituals. There is also great shame surrounding urinary incontinence and other symptoms related to chronic PFD that may be considered too personal to discuss with medical providers, especially if the provider is male, not Latina, and not familiar with the community.

Medical providers who do not view chronic PFD as a form of CI are typically unfamiliar with the physical, psychological, and social impact it has on women. Because symptoms are not always consistent and evolve slowly over time, it is difficult to receive the correct diagnosis at the onset of the disease. Women not properly assessed and given an accurate diagnosis will not receive the medical care needed, which can exasperate the symptoms and increase the decline in mental health. Due to the lack of time spent with patients, rapport is not built to establish trust, which prevents women from disclosing the psychological impact of their symptoms and are not referred to mental health providers to collaborate with the overall healthcare treatment plan.

Women diagnosed with chronic PFD report a decrease in overall HRQOL, which impacts self-care, relationship with self and others, their social and spiritual connections, and their physical and psychological health. HRQOL is identified as life conditions, such as financial factors, physical and mental health, community and environmental conditions, and the socio-psychological quality of life that impacts those living with forms of CI (Sosnowski, et al., 2017). Identifying the overall HRQOL components in

women is based on their individual perceptions and social position, as well as cultural, social, and spiritual values that influence standard of care and expectations (Sosnowski, et al., 2017). As a result, women may not disclose their psychological challenges related to their physical symptoms with their medical provider, and instead believe it is unrelated or have cultural expectations to self-treat or may view treatment as a sign of personal weakness. Medical specialists aware of HRQOL and the connection it has to overall pelvic health identify four dimensions with women, to provide a more comprehensive assessment and treatment plan. These four domains are: 1) physical (identifying biological and motor skills related to chronic PFD), 2) mental state (identifying negative and positive emotional levels, psychological adjustment to chronic illness), 3) economic conditions (financial stressors and ability to pay for treatment), and 4) somatic perceptions (personal view of physical symptoms related to diagnosis) (Sosnowski, et al., 2017). The importance of addressing these domains will offer a broader scope of how CI has impacted women by identifying each component utilizing a biopsychosocial-spiritual lens.

Needs Assessment Analysis

Risk factors are defined as characteristic traits that increases the likelihood of negative outcomes, which impact biological, psychological, family, community, and sociocultural levels (Olivares, et al., 2017, SAMSHA, 2019). Some risk factors cannot be changed, such as genetics or hereditary factors, and can increase the likelihood of developing more than one CI over the course of a lifetime. Chronic PFD has similar risk factors to heart disease and diabetes, such as: 1) obesity, 2) lack of physical activity, 3) alcohol, 4) smoking, 5) mental illness, 6) chronic physical symptoms, 7) age, 8) lower

levels of education, 9) race/ethnicity, 10) lower socioeconomic status (SES), 11) not eating enough fruits and vegetables, 12) lower education level, 13) non-Caucasian, and 14) lacking spiritual connection (Keyes, 2005, Olivares, et al., 2017, Smith & Witherow, 2000, Weihs, et al., 2002).

In addition to physiological symptoms, women with chronic PFD experience psychological symptoms, which can result from: 1) low support system, 2) lack of medication management, 3) relationship challenges, 4) mental health disorders prior to diagnosis, such depression/anxiety, 5) isolation, 6) financial difficulties, and a 7) decrease health quality of life (HRQOL)) (Wagner, et al., 2001). The impact of the psychological and physiological stressors affects daily living activities, the roles and rules within family and work systems, and the connection with supporters and their community. Women living with chronic PFD report experiencing: (1) limited physical activities and abilities, (2) inability to perform efficiently at work, (3) an increase of missed days at the place of employment, (4) social isolation from family/friends, (5) stresses about the finances impacted by the medical diagnosis, and (6) negatively impacts psychological functioning (Keyes, 2005, Restorick-Roberts, et al., 2017).

Unfortunately, the lack of mental health services in the community delays improved overall HRQOL with management of stressors and improved therapeutic skills to adapt to a CI diagnosis. The high costs of medications and mental health services delays proper treatment, which delays treating the physical and psychological symptoms. While the cost for treatment may be difficult to pay, women also experience the stress of feeling unable to adequately pay for these services when the impact of chronic PFD can cause reduction in work hours or termination of a job. Because friends and family may

not understand the seriousness of the disease, phone calls and visits decrease, help with meals and childcare become less, and emotional support diminishes. There is also a high risk for separation and divorce because of the financial, emotional, and physical strain chronic PFD causes.

When diagnosed with chronic PFD, the family is impacted, as well. The burden of living with a long-term illness contributes to the feelings of hopelessness, physical limitations, lack of social engagement with others, increased fear of becoming a burden on loved ones, and mental health issues such as: depression and anxiety (Restorick-Roberts, et al., 2017). As a result, women may be less apt to disclose PFD symptoms to family, friends, and co-workers. This can inadvertently perpetuate the cycle of isolation and depression, while also creating tension within the family system. When the family does not receive proper psychoeducation regarding living with chronic PFD, a breakdown in communication occurs amongst family members and supports, further increasing conflict and social isolation. Feeling alone and misunderstood, women may be told the symptoms are imagined, not as severe, and be expected to maintain the responsibilities and roles within the family that existed prior to the development of issues and diagnosis of chronic PFD. Reports of not feeling well, leaving work early to attend doctor's appointments, difficulty driving, and managing work responsibilities increasing the propensity for termination of employment, placing a financial burden on women and the expenses medical and mental health treatment can accrue.

Healthcare costs and lack of access to service providers, in rural areas, compound the challenges women living with chronic PFD experience (Clark, et al., 2017). For those insured, medical and therapeutic interventions are limited by insurance company's

treatment approval, designating the number of sessions provided, regardless of the need for more sessions for those living with chronic PFD. This means that women have to determine which services to seek, which treatment services need to be paid of out of pocket, and which services/medications to limit or eliminate. Women living in rural communities are likely to experience a decline in mental health, due to the lack of services offered, financial cost, and physical disabilities that prevent traveling to other communities (Callebaut, et al., 2017). Services offered outside of the community prevent women from continuing medical and therapeutic care because of transportation issues, cost, and time. The cost and out-of-pocket fees for therapeutic services increase the likelihood that mental services will not be part of the woman's healthcare plan, which decreases HRQOL (Clark, et al., 2017).

Because chronic PFD looks differently for women, it can be difficult for medical providers to identify chronic PFD, properly assess and treat, and offer mental health referrals. Chronic PFD encompasses a wide range of symptoms, which can slowly progress over time and may not present at the onset of diagnosis. Different symptoms may also be more pronounced than others, which can delay an accurate diagnosis and medical treatment needed (Clark, et al., 2017). Another challenge for medical providers is the lack of time to meet with each patient, which can delay the woman providing information regarding the psychological challenges and stressors at home/work, resulting in lack of mental health referrals and psychoeducation. These challenges, while interrelated within a biopsychosocial-spiritual (BPS-S) framework, are treated independently or not addressed at all, leading to a delay in accurate diagnosis, effective medication, and therapy treatment, because of the lack of identifying the BPS-S dynamics

influencing overall HRQOL.

The average medical visit is between seven and ten minutes, which is not sufficient for women to share their concerns fully and for medical doctors to understand how chronic PFD has impacted psychosocial issues within the family system (Huljev & Pandak, 2016). Medical providers utilize a traditional, medical model to treat disease and CI, while not addressing the whole person, utilizing a BPS-S framework (Yaghmaian & Smedema, 2019). Medical providers, who are not connected to a larger agency and work in isolation, may be unaware of the treatments utilized, resulting in inconsistent medical care and lack of mental health services (Kaslow, 2007). Unfortunately, mental health services may not be sought because of the lack of referrals provided, the cost, and lack of mental health providers in their community. Psychological distresses and mental disorders can be directly linked to chronic illness, disability, and depression because of the sense of hopelessness, inability to cope with a condition that worsens with time and age, and an inability to participate in daily living activities (Turner & Kelly, 2000). The likelihood of developing mental illness increases with CI, which is often overlooked, because the symptoms of depression and CI overlap (Turner & Kelly, 2000).

Comorbidity is typically common for those living with CI, with diagnoses of major depression disorder (MDD) and generalized anxiety disorder (GAD) present in women diagnosed with chronic PFD (Olivares, et al., 2017). Therefore, medical specialists collaborating with mental health providers is important to the improvement of overall HRQOL and physical symptoms presented.

Protective factors increase the overall HRQOL and determine the ability to overcome the daily challenges of living with chronic PFD. Positive factors decrease the

likelihood of negative outcomes and are improved through: 1) strong support relationships with family and friends, 2) community services designed to support women's physical and psychological health, 3) faith-based services that promote faith, hope, and healing, 4) appropriate medical treatment that includes mental health services, and 5) community policies protecting women's health issues (SAMSHA, 2019). These positive factors promote resilience, which motivate women to overcome the challenges of living with chronic PFD (Keyes, 2005).

Other protective factors include an integrative treatment plan with a medical team that includes mental health services. Additionally, supporters (family, friends, and church members) are helpful with the balance of daily living activities, such as assisting with childcare, home responsibilities, and transportation to medical and mental health visits, which decreases stress for women and promotes community support. Spiritual wellness is an essential component to increasing resilience and improving HRQOL, which also helps reduce stress and decrease depression, anxiety, and other symptoms related to living with chronic PFD, by encouraging hope and promoting strength (Bredle, 2011). Achieving spiritual wellness also means incorporating prayer, meditation/mindfulness, and attending church services/Bible studies to better manage living with chronic PFD (Glover-Graf, 2007). Expressing gratitude, having compassion for others, and developing a prayer life are ways women incorporate spirituality into daily living, which are essential components to increasing protective factors that will overall improve HRQOL.

Currently, there are not OTSG programs providing holistic care for women living with chronic PFD. However, there are programs that meet face to face, utilizing a BPS-S approach for different issues, however chronic PFD is not the primary focus. For

example, there is a healing centered approach designed to work with teens, impacted by childhood trauma. The program incorporates spirituality, government/community activism, cultural identification, and healing, (Ginwright, 2018). Rather than focusing on the “problem”, teens focus on ways to live beyond the trauma, and become self-advocates to create positive change within their community.

A study conducted in Argentina that reports an eHealth program proved successful, as it provides support and interventions to communities by health professionals, who are able to work directly with clients needing services to reduce unhealthy behaviors that increase risk factors contributing to CI (Olivares, et al., 2017). Another study conducted, through River Plate Adventist University School of Medicine, collaborates with the local primary health care system (PHC). The study aims to determine if an online program reduces the percentage of deaths related to chronic disease (CD) (Olivares, et a., 2017). The study focuses on a socioeconomically disadvantaged community, in the city of Diamante, from 2014 to 2015. A total of 1044 persons, including 679 women, enrolled in the study to measure lifestyle and health related issues (Olivares, et al., 2017). The online program consists of a website client’s access to learn information regarding risk factors, identify ways to improve health, and increases health awareness.

An Australian study closely resembles the OTSG program, which is an online support group for adults diagnosed with depression. Adults participate in a study to determine the efficacy of an internet-based support group. A randomized trial conducted with 311 adults, between the ages of 18 and 65 years old, indicates depressive symptoms decreased after 3 months, 6 months, and 12 months follow-up (Griffiths, et. al., 2012).

This study report's implications are: 1) long-term (OTSG) programs are effective for women with chronic PFD, 2) psychoeducation and peer support decreases depressive symptoms over time, and 3) therapy utilizing a BPS-S approach can decrease depressive symptoms. Three groups are identified in the study: 1) control group, 2) psychoeducation only group, and 3) psychoeducation and therapeutic intervention. The control group reports no change in depressive symptoms, and the group limited to only psychoeducation indicates depressive symptoms decrease temporarily. The group with therapeutic intervention shows a decrease in depressive symptoms, that continues to show an improvement in overall emotional well-being after a 12-month follow-up (Griffiths, et al., 2012).

While chronic PFD is not curable, early intervention and a treatment plan focused on a BPS-S improves overall HRQOL (Olivares, et al., 2017). A BPS-S online therapeutic support group for women living with PFD identifies goals designed to improve overall HRQOL, such as: 1) psychoeducation, 2) emotional support, 3) increased communication, 4) collaboration between health providers for overall healthcare, 5) spiritual and emotional support, 6) utilization of community resources to better assist daily living activities, and 7) advocacy and self-care (Grassi, et al., 2017). Each of these studies emphasize the importance of collaboration between providers and patients, so that women can receive consistent and holistic healthcare treatment. Because this is not always possible, the OTSG program offers therapeutic services within the comfort of the woman's home, while also addressing areas of support still needed. The OTSG program addresses unrealistic expectations to better manage family/home responsibilities and work, introduces healthier ways to live with chronic PFD, identifies psychological and

sociocultural stressors, and incorporates spirituality as an essential component for the woman's overall well-being (Hatchett, 1997).

The maintenance of the problem is focusing on short term goals, while hoping for long term benefits (Stroh, 2015). However, treating the presenting symptoms only will overlook the long-term benefits of treatment that is ongoing and consistent to the needs of overall health. Women living with chronic PFD may feel pressure to not modify daily living activities, as a result of low support systems and lack of family understanding the impact chronic PFD has on woman's overall HRQOL, thereby intensifying symptoms and accelerating the progression of CI. When this happens, the initial symptoms increase and intensify, creating an amplified deviation process (Maruyama, 1963). The temporary resolution to the presenting issue, ignoring symptoms, fear of letting someone down, and the internal need to fulfill obligations for daily living activities and responsibilities worsen the symptoms long term, intensifying the progression of PFD, and decreasing overall HRQOL.

Managing the presenting issues and symptoms, women decrease medications and stop therapeutic interventions to avoid financial stressors, by treating symptoms sporadically to avoid the overall cost of medical and mental health treatment. Homeostasis occurs when the treatments become less consistent, appointments begin to be cancelled or occur less often, and the responsibilities at home and work increase, to make up for time lost. The positive feedback loop pattern is when women attempt to pull away from the management of symptoms, however the symptoms become amplified and make the symptoms worsen over time. While using the same behavior and rules that existed prior to the diagnosis of chronic PFD, first order change attempts to find solutions

that address presenting issues and symptoms temporarily.

Second order change occurs when women living with chronic PFD are informed inconsistent medical and therapeutic interventions can amplify symptoms over a long-term period, which then compels necessary modifications made, resulting in improvement of overall HRQOL and better management of PFD. When openly discussing family and work concerns to modify family and work expectations, the support system stabilizes and adjusts towards balanced and healthier solutions, with women compromising and delegating responsibilities and tasks (Hall, 2011). Second-order change recognizes women living with chronic PFD contribute to the problem and maintain it by overworking, not establishing healthier boundaries, and increasing negative self-perceptions (Hall, 2011).

Managing living with chronic PFD can be improved with therapy, appropriate medication management, participating in therapeutic support groups, building a support system, and relying on spiritual faith. Through second order change, recognizing and identifying how PFD impacts daily living activities, while also making necessary adjustments will promote self-care and help slow the progression of PFD (Restorick-Roberts, et al., 2017). Third order change identifies BPS-S factors, addresses the root problem to better manage chronic PFD, which leads to improved relationships, promotion of self-care, and advocacy within the community and existing systems within and outside the family unit (Weihs, 2002). Providing therapeutic support to the individual and family increases communication, encourages modification of daily activities, increases resilience, and incorporates coping skills and stress management. Incorporating a collaborative treatment plan with consistent treatment increases utilization of services,

through online support counseling services, (Restorick-Roberts, 2017). Living with chronic PFD can be managed with the proper tools and support, which will improve overall HRQOL.

Chronic PFD impacts relationships, physical and mental abilities, and the management of daily activities, which can improve through mental health services and consistent medical healthcare (Weihs, 2002). Women with chronic PFD, who have difficulty accessing support services outside of their home (due to physical limitations), can benefit from a therapeutic OTSG program. Providing an OTSG program increases communication, encourages modification of daily activities, promotes resilience, incorporates coping skills, and introduces stress management, (Oravec, 2000). An OTSG program provides an opportunity to receive mental health services for women unable to access services outside their community to increase resilience, adaptability to stressors, modification of daily activities, offers a safe place to connect with others, and promotes advocacy and self-empowerment, in the comfort of her own home (Oravec, 2000, Restorick-Roberts, 2017).

CHAPTER THREE

CONCEPTUAL FRAMEWORK

Will an online therapeutic support group (OTSG) program, utilizing narrative therapy (NT) within a biopsychosocial-spiritual lens (BPS-S), improve overall health-related quality of life (HRQOL) for women living with PFD? Integrating a BPS-S theoretical framework, while utilizing the tenets of narrative therapy (NT), utilizing general systems theory (GST) assumptions are the premise for the OTSG program. Currently, there are not any OTSG programs for women living with chronic PFD, however; there are other online programs that integrate general systems theory (GST), the BPS-S model, and the NT theoretical framework.

Every year, 31.5% of the American population report living with a form of CI, accounting for 86% of healthcare spending in the United States (Rebhan, 2017). Traditionally, the medical model is used to treat those living with CI, identifying illness and disease through a reductionist lens. Rather than exploring how CI impacts the whole person and the interrelated relationships within the family system, it treats the condition through a narrow scope, which entails providing medical treatment solely on the biological issues and symptoms present, without identifying the psychological and social impact chronic PFD has on women and their family system (Ahn, et al., 2006). Untreated chronic PFD impacts women's responsibilities, such as family roles, work obligations, and social relationships, making it difficult to manage the chronic condition on a long-term basis (Walker & Peterson, 2017). Unfortunately, the medical approach does not consider external factors, such as educational level, lifestyle, sociocultural factors, family systems, and income, which means interventions and treatments are addressed to improve

the psychosocial and spiritual factors that impact chronic PFD (DeHaven, 2017).

Utilizing the BPS-S framework with tenets of narrative therapy (NT) are used to provide the foundation for an OTSG program focused on helping women manage daily living activities by offering tools to maintain healthy relationships, increasing positive communication, develop self-advocacy to collaborate with medical providers, increasing resilience, and learning to better manage the challenges living with chronic PFD.

Therapeutic Lens

General systems theory (GST), founded by Ludwig von Bertalanffy, observed sea urchins, and recognized living organisms respond differently from inanimate objects (Von Bertalanffy, 1972). Based on this observation, GST identifies three major assumptions, which contribute to developing an OTSG program. The first assumption is the discovery of systems are universal and happen to all kinds of groupings, meaning that organized systems build on concepts and are interrelated. A second assumption is GST views behaviors and interactions as circular causality, which impacts relationships and contributes to the maintenance of the problem (Walonick, 1993). A third assumption is GST identifies the system as a whole, recognizing one part of the whole cannot be treated or examined in isolation (Whitchurch & Constantine, 2009). These assumptions serve as the foundation for an OTSG program because it highlights the importance of recognizing that chronic PFD impacts not only women's health, but also their family relationships, social networks, work responsibilities, and community connections.

One program that incorporates the assumptions and tenets of GST is the Harbin Medical School in Heilongjiang Province, China, which developed a program aimed at

reducing the increasing prevalence of chronic disorders within their communities. The program reduces the incidence of CI within the community, which alleviates the burden on healthcare systems, recognizes multimorbidity, and offers interventions exploring biobehavioral and socio-environmental contributing factors impacting the progression of the disease on the individual (DeHaven, 2017). The program aims at understanding CI by treating the whole person and offers interventions that extend beyond the disease, which is impacted by lifestyle, education, environment, and income level (DeHave, 2017).

George Engel's development of a conceptual framework challenges the traditional biomedical model. The biomedical model solely focuses on the treatment of presenting symptoms, whereas the BPS-S model focuses on the whole individual, the condition of the mind, family relationships and interactions, and spiritual connections as factors that can exasperate symptoms without proper support and therapeutic interventions (Taukeni, 2019). The BPS model, while not a theory, is equally important to the development of an OTSG program. The BPS model recognizes treating the symptoms for CI is limiting, when the psychological and social factors are not considered as part of the overall treatment for women living with PFD (Farre & Rapley, 2017).

Engel's view of GST incorporates a systemic approach that integrates four domains for the overall treatment of the client: biological, psychological, social, and spiritual (Farre & Rapley, 2017). Three BPS-S assumptions, which shape the development of the OTSG program are: 1) chronic conditions can be identified earlier based on risk factors present within social systems (family and economics), psychological (mental illness and conditions), and biologically (genetic risk factors and onset of recurring illnesses), 2) the biological system cannot exist in isolation and cannot be

treated without consideration of other systems (psychological, social, and spiritual domains), and 3) when one domain is not supported, illness exists, because the systems are interrelated and dependent on one another as a protective factor (Bolton, 2019, Quinter, et al., 2008).

Over the last 40 years, the BPS-S model has evolved to include spirituality, which decreases symptoms of depression and anxiety, increases coping skills, and provides comfort through prayer, meditation, Bible readings, and spiritual connection with God or higher being (Pivarunas, 2006). The World Health Organization and the Joint Commission on Accreditation of Healthcare Organizations identify spirituality as a component to healthcare and an extension to George Engels's original model that did not include spirituality. Today, the model includes spirituality and recognizes health as a state of well-being that includes physical, psychological, social, and spiritual factors within the person (Saad, et al., 2017, Anandarajah, 2008).

While spirituality and religion are used interchangeably, its definitions are clearly distinct. Religion is viewed as ascribing to a particular group or institution that has the same values and beliefs, whereas spirituality is a connection to a higher being or concept that is sacred and personal, which offers hope, solace, and comfort based on a personal relationship with a Higher Power (Elkonin, et al., 2014). Although spirituality is individualistic and can apply to religious and non-religious persons, it is ultimately one's search for meaning, purpose, and understanding in relation to one or more of the following: self, others, nature, and community, which is expressed by one's beliefs, values, and practices (Saad, et al., 2017). With continued emphasis on the importance of

including spirituality in treatment protocols, healthcare programs recognize the benefit and improvement for overall HRQOL (Anandarajah, 2008).

One program incorporating the BPS-S model is an integrative center at MD Anderson Cancer Center, located in Houston, Texas. The integrative center provides different therapeutic services at one localized facility. Focusing on a BPS-S wellness model, the center offers acupuncture, physical therapy, nutritional counseling, psychotherapy, therapeutic massage, and pastoral care for cancer patients (MD Anderson, 2019). Offering a holistic approach, patients receive collaborative care from a team of medical doctors, therapists, and chaplains, as an integrative approach to improving symptoms and overall HRQOL. The benefits of utilizing the BPS-S framework are that it includes a whole person approach that is individualized to meet the needs of each client, while incorporating the biological, psychological, social, and spiritual aspects to formulate a treatment plan.

Michael White and David Epston developed narrative therapy (NT), a post-modern constructionist framework that can be utilized working with women diagnosed with chronic PFD (Williams-Reade, 2014). NT is one of the first psychotherapy models used in a hospital and medical setting that identifies the person as a client (not a patient) and is their own expert in finding workable solutions to promote overall HRQOL (Williams-Reade, 2014). The assumptions that support the development of an OTSG program are from a strengths-based perspective, with a primary focus on solutions, rather than the problem itself. One assumption is viewing the problem external to the person, with realities constructed through personal experience, which are socially, culturally, and environmentally influenced (Signs, 2015). Another assumption is viewing the client as

the expert, who has the solutions to resolve the presenting problem (Williams-Reade, 2014). Utilizing NT means providing solutions to create meaningful change, which impacts the family and transcends to larger systems, such as the community (Crocket, 2014).

NT has four primary concepts. The first concept is Deconstruction, which is breaking apart labels and language considered problematic for the client, and asking how societal messages have shaped those views, (Williams-Reade, et. al., 2014). Women with PFD break down the diagnosis and labels that accompany it: disabled, chronic illness, sick, a burden on others, etc. The second concept is Externalization, which means the diagnosis is separate from who the woman, while examining behaviors, attitudes, relational issues, and sociocultural pressures and expectations from others and self that contribute to the problem (Williams-Reade, et.al., 2014). The therapist helps dissect these issues through open ended questions and active listening skills. The third concept is Mapping the Effects, which identifies how PFD impacts and contributes to the problem-saturated story, while evaluating how these views shape personal opinions and self-perceptions (Williams-Reade, et.al., 2014). The fourth concept is Re-Authoring, which creates a new storyline that includes support from community and family/friends. Re-authoring identifies new outcomes, as the client begins to view the diagnosis and physical limitations separate from personal identity (Williams-Reade, et.al., 2014).

One program utilizing NT tenets is the Comprehensive Health Enhancement Support System (CHESS), which provides an online therapeutic support for breast cancer patients. CHESS follows the tenets of NT, based within a social constructionism framework, and focusing on self-perceptions and recognizing its impact within social

interactions and environmental factors experienced (Shapiro, 2002). A program in Australia offers an online support group for those diagnosed with depression. A randomized trial conducted with 311 adults, between the ages of 18 and 65 years old, shows the depressive symptoms decreased after 3 months, 6 months, and 12 months follow-up (Griffiths, et. al., 2012). This study provides implications that long-term OTSG programs are effective for women diagnosed with chronic PFD, through psychoeducation, peer support, mental health therapy that focuses on BPS-S and NT tenets.

Utilizing NT offers women new possibilities and choices that strengthen family relationships and improves social support (Crocket, 2014). With NT, language and perspectives change in a meaningful way that offers hope and possibilities. In first order change, women experience a problem saturated world and are unable to look beyond the diagnosis of PFD. Through second order change, a new narrative is created, challenging old thoughts, and developing new language and perspectives to improve overall HRQOL. Third order change occurs when family and community become part of the positive change by adopting new language and perspectives to identify new ways to improve living with chronic PFD.

With access to the internet, women receive online support through individual therapy and peer support groups to improve (Parsons, 2019). The OTSG program provides an opportunity to receive mental health services for those unable to access services outside her home, offering support and increasing social support systems, to improve overall HRQOL (Oravec, 2000). The OTSG program provides emotional support to increase self-resilience, adaptability to stressors, encourages modification of

daily activities, provides a safe space to connect with others, and promotes advocacy and self-empowerment, in the comfort and privacy of her own home (Restorick-Roberts, 2017).

A BPS-S model integrated into an OTSG program offers the foundational framework for utilization of NT in an integrative program focused on working with women living with chronic PFD. The OTSG program aims to provide mental health services to women living with chronic PFD, with objective goals to increase psychoeducation, improve emotional support for women, develop social support, increase communication, and utilizes community resources to improve overall HRQOL (Grassi, et al., 2017). Integrating NT within a BPS-S framework is the foundation for the OTSG program. Pathways for Healing (OTSG program) provides support groups to connect others experiencing similar challenges, addresses expectations and modifications to better manage family/home/work responsibilities, addresses psychological and sociocultural stressors, and incorporates spirituality as an essential component for overall HRQOL (Hatchett, 1997). Identifying BPS-S factors is utilized to improve ongoing support and increase services for the whole person, as the root problems are identified to better manage living with chronic PFD (Restorick-Roberts, 2017). The OTSG program aims to assist participants to better manage therapeutic services, medication management, and psychological support, which improves overall HRQOL. The OTSG program identifies support systems, strengthens family communication, incorporates spiritual support and connection, provides encouragement, and identifies ways to live beyond a diagnosis.

CHAPTER FOUR

METHODOLOGY

The purpose of this chapter is to determine if an online therapeutic support group (OTSG) program, utilizing narrative therapy (NT) within a biopsychosocial-spiritual (BPS-S) therapeutic lens, improves the overall health-related quality of life (HRQOL) for women living with PFD. Factors that can prevent women from seeking treatment or not receiving the proper medical and mental treatment needed are: 1) lack of time, 2) limited access to health providers, and 3) social and cultural location. One challenge is the length of medical visits. Because medical visits last for an average of seven to ten minutes, providers do not have enough time to gather information regarding HRQOL and the impact chronic pelvic floor dysfunction (PFD) has on daily living activities, family relationships, and work responsibilities (Huljev & Pandak, 2016). As a result, women do not receive a treatment plan that addresses the physical and psychological challenges, including mental health referrals.

Delaying mental health and medical treatment, 21% of American women may choose to self-diagnose and treat by seeking help online through websites and non-therapeutic social media groups and pages (Griffiths, et al., 2012). The second challenge is lack of access to service providers in rural communities, which prevent women from seeking treatment from providers not known, distance to providers, and the time spent traveling to doctor appointments. In addition, the cost for travel is an added stressor, which can limit the types of treatment women receive to better cope with chronic PFD (Clark, et al., 2017). The third challenge is social and cultural location, which is based on ethnicity, education, socioeconomic status (SES), community services, and sociocultural

factors impacting belief systems (Weihs, et al., 2002). The social and cultural location determines how women seek treatment, how much self-disclosure is expressed at visits, language barriers, and socio-cultural beliefs that can determine which treatments are sought and the approach for treatment, as well.

Pathways for Healing offers mental health services, without the challenges of living nearby for mental health services and medical treatment support. With access to the internet and teletherapy becoming more readily available, mental health services are more accessible for online peer support groups and individual therapy, while also learning how to manage living with chronic PFD (Parsons, 2019). Offering an alternative to in-person support groups, online groups increase accessibility and participation. In the United States, 86% of the American population has internet services, with 2.5% reporting limited or no access for online services, regardless of economic and sociocultural factors (Lally, et al., 2018). Pathways for Healing aims to provide OTSG program services, regardless of SES and inaccessibility to technological assistance, through the use of partnerships and grants, which can provide electronic tablets for personal use.

Pathways for Healing incorporates a BPS-S model, while utilizing narrative therapy (NT) tenets within a general systems theory (GST) framework offers a well-rounded program for women living with chronic PFD. Pathways for Healing focuses on providing mental health services, which includes psychoeducation, psychotherapy, and peer support (Grassi, et al., 2017). The OTSG program connects women experiencing similar challenges, identifies expectations and challenges, provides tools to modify and improve better management of home and work responsibilities, teaches healthier ways to manage living with PFD, explore psychological and sociocultural stressors, and

incorporates spirituality to improve stress management and coping skills (Hatchett, 1997). The OTSG program's goals are: 1) increase communication, 2) encourage modification of daily living activities, 3) improve and strengthen relationships, 4) promote resilience through psychoeducation and support, 5) incorporate coping skills and 6) improve stress management (Oravec, 2000). The program offers a safe space to connect with others in the comfort and privacy of women's homes, removing financial challenges, language barriers, and increasing accessibility for mental health services regardless of physical location. Utilizing a BPS-S model for an OTSG program can help women improve overall HRQOL, while learning to better manage a life-long diagnosis, such as chronic PFD. Overall, the OTSG program identifies and strengthens existing support systems, improves family communication, incorporates spirituality, and relies on its benefits, while addressing the challenges that impact overall HRQOL.

Providing therapeutic support increases communication, encourages modification of daily activities, promotes resilience, incorporates coping skills, and introduces stress management. Chronic PFD, a form of CI, contributes to ongoing bladder infections, kidney infections, neuropathy, severe foreign body response to mesh, and incontinence, which is helped through therapy and consistent medical care (Weihs, 2002). Living with chronic PFD can be managed with the therapeutic services, medication management, and psychological support, which will improve her quality of life, which improves overall HRQOL. Identifying support systems, strengthening family communication, incorporating faith, and collaborating with health providers gives women hope and encouragement that there is life beyond diagnosis.

The OTSG program offers homebound women access to mental health services unavailable to them, due to challenges with travel, finances, and lack of access to mental health providers in their communities. Pathways for Healing provides emotional support, increases self-resilience, assists with adaptability to diagnosis, encourages modification of daily activities, provides a safe place to connect with others, and promotes advocacy and self-empowerment, without leaving their home to access services (Restorick-Roberts, 2017). With access to the internet, women receive online support and individual therapy, participate in peer support groups, and receive information specific to their health and diagnosis, (Parsons, 2019). For those who do not have access to internet services or devices, the OTSG program offers electronic tablets needed for women to actively participate in the weekly support groups.

The OTSG program facilitates group meetings, once a week for 12 weeks, scheduled at various times and days throughout the week. This allows women to determine which group time, language preference (English or Spanish), and day of the week works best for their schedule. Each group is co-facilitated by female therapists: 1) licensed marriage and family therapist (LMFT) and 2) pelvic floor physical therapist (PFPT). However, under the supervision of their appropriate licensed, licensed marriage and family therapy associates (LMFT-A's) and physical therapy students (SPT's) can also facilitate support groups. The purpose for female identifying therapists is to build rapport, connection, trust, and offer a safe space for group participants who may have challenges working with a male therapist, due to sociocultural factors (Yaghmaian & Smedema, 2019).

Each group has 15 participants per group, with multiple groups meeting at different times to help women find a group time that is best for her. Pathways for Healing focuses on working with women, diagnosed with chronic PFD, by addressing several needs: 1) psychoeducation, 2) emotional support and group counseling from a LMFT (or LMFT-A), 3) peer support, 4) increasing communication and collaboration with health providers, 5) utilization of community resources to better assist daily living, 6) psychoeducation and support from a PFPT (or SPT), 7) and advocacy and community awareness through the Sisterhood Ambassador Program (Grassi, et al., 2017). Pathways for Healing connects others experiencing similar challenges, identifies ways to live with chronic illness, addresses expectations and modification to managing family, home, and work, teaches healthier ways to live a productive life with pelvic floor dysfunction, addresses psychological and sociocultural stressors, and incorporates spirituality as an essential component for well-being (Hatchett, 1997).

Utilizing an integrative and therapeutic model helps women receive comprehensive care, by addressing the root problem and the impact chronic PFD has on daily living and relationships (Restorick-Roberts, 2017). The OTSG program addresses several needs through psychoeducation, emotional support, increasing communication and collaboration between health providers, and utilizing community resources (Grassi, et al., 2017). The support groups identify unrealistic expectations regarding managing family/home responsibilities and work, incorporating healthier ways to live a productive life with chronic PFD, working through psychological and sociocultural stressors, and incorporating spirituality as an essential component for well-being (Hatchett, 1997).

Women, with chronic PFD live with symptoms that impact daily living. The OTSG program identifies support systems, aims to strengthen family communication, incorporates spirituality, and collaborates with medical health providers, which offers women hope and encouragement regarding their diagnosis. The spirituality component to the BPS-S model incorporates spirituality to decrease symptoms of depression and anxiety, increases coping skills, builds relationships, and provides comfort to women and their caregiver (Pivarunas, 2016). Providing group therapy on topics of spirituality and wellness are integrated into sessions. Prayer, meditation, Bible readings, and spiritual support provide comfort and hope, which is also integrated in the group sessions (Pivarunas, 2016).

Phases of the Online Therapeutic Support Group Program

The objective for the OTSG program is to provide online support for women, who are diagnosed with chronic PFD. The goals are measured through assessments compared to the pre-test, after the 6th week group session, after the 12th week session, 3-months post-group completion, and 6-months post-program completion. The program provides specialized training for therapists, including the necessary steps for the OTSG program, and the curriculum used for health members and caregivers. There are three phases with the OTSG program. The purpose of the first phase is to recruit, select, and inform women about Pathways for Healing. The first phase includes working with urologists, urogynecologists, gynecologists, and pelvic floor therapists, who work with women diagnosed with chronic PFD.

Women are informed of the study by their medical specialist doctor, and provided information about the study, should they decide to participate. Pathways for Healing is provided at no cost to participants and is voluntary. Women can decline to participate at any time and may discontinue during the program. While women will be referred by their medical specialist doctors, the OTSG program is independent and not affiliated with any particular hospital and women do not need to be affiliated with any particular medical system. Women sign the consent form document and take pre-pre-tests to determine eligibility: Pelvic Floor Impact Questionnaire-Short Form 7 (PFIQ), Pelvic Floor Distress Inventory-Short Form 20 (PFDI-20). After initial evaluation and group placement, participants will take pre-tests, which are: 1) The Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-SP), 2) Beck Depression Inventory-II (BDI-II), and 3) RAND 36-Item Health Survey (SF-36), to identify women's emotional, spiritual, and physical needs, and overall HRQOL, 4) Survey for Participants (once at the end of the 12th group session, and 5) Check-In Check-Out Oral Report (CICO) at the end of each group session.

The Clinical Liaison meets with health care providers, medical facilities, homeopathic centers, hospitals, spiritual leaders, and holistic providers, to establish a partnership and increase opportunities for collaboration (Fields, 2019). This allows for healthcare providers to understanding the importance of working together, for women to receive integrative care and increase consistency of care, while also helping women self-advocate to medical specialists. The Clinical Liaison is also responsible for providing community awareness campaigns, to help with third order change, by educating the community and creating awareness about the impact chronic PFD has on women and

their family system. Research assistants help set up accounts for members, address technical challenges, and assist with internet access. Women unable to access electronic devices will be issued one that is provided through the grants and community partnerships.

Groups are ongoing, with new groups beginning each month. This allows group facilitators to discuss initial rules and group expectations, address confidentiality and safety precautions, and discuss group formats at the beginning of each group, in a closed-format to build trust and connection amongst group members (Chang, et al., 2003). During the first phase, women are also placed in the appropriate group, based on time and day preference, language (English or Spanish), and ability to meet consistently for 12 weeks.

The second phase occurs during the 12 weeks of support groups. The purpose of this phase is for members to meet once a week, for twelve weeks, designed to provide support and inform about ways to better manage living with chronic PFD. The first meeting is intended to discuss group format, express expectations for the group, discuss logistics, discuss rules and goals for the group, and for both facilitators an LMFT (or LMFT-A), and a PFPT (or PTS), who will introduce themselves and their role within the group. Group members introduce themselves, share group expectations, discuss reasons for joining the group and what they hope to gain from group participation, and are assured of the process to self-disclose (Chang, et al., 2003).

Each week, group members explore different topics, such as: 1) living with PFD, 2) stress management, 3) modifying daily living activities, 4) nutrition and natural supplements, 5) integrative medicines and therapies, 6) family roles, responsibilities, and

expectations, 7) social supports and community resources, 8) self-advocacy with the medical team, 9) adjusting and modifying work, family, and other responsibilities, 10) mindfulness and meditation training, 11) goal setting for health and daily living, and 12) incorporating spirituality to improve overall HRQOL (Lally, et al., 2018). Each monthly topic is guided through a BPS-S lens, while incorporating NT tenets. This mode of therapy identifies the challenges women are faced with, and utilizes externalization, mapping, and reauthoring, which empowers, creates a new narrative, and offers hope and empowerment to women living with PFD (Williams-Reade, et al., 2014).

Within the second phase, there are two sections: 1) the first six sessions and 2) sessions seven through twelve. The first session, which pertains to the first six sessions, facilitators identify concerns women have and offers an opportunity to meet other women who understand the challenges of daily living with PFD. Utilizing a BPS-S theoretical lens, while incorporating NT tenets encourages women to discuss health challenges, share concerns regarding wellness and life, and identify their strengths and coping skills (Heggdal, 2015). The OTSG program encourages women to apply self-care with tools to manage chronic illness, to improve health and healing (Heggdal, 2015). The curriculum provides psychoeducation about chronic PFD, disease management, coping with identified stressors, and improving mental health, (Shapiro, 2002). Women learn new stress management strategies and identify ways to manage daily activities. In the beginning of each group session, facilitators record self-reports from each participant through a check-in and check-out format, which is used to measure the efficacy of each group topic and determine if the group sessions need to be modified for future group sessions.

During the second section, in sessions seven through twelve, group facilitators continue to utilize the self-reporting format with check-in and check-out to determine the efficacy of the group and measure the data at the end of program completion. Group facilitators address ways to better manage PFD, identify individual strengths, spirituality beliefs, emotional and physical symptoms, barriers based on socioeconomic and cultural factors, and offers psychoeducation to become a self-advocate for healthcare (Koithan, et al., 2007). Discussing relationship challenges is also addressed, with women identifying concerns and strengths within the relationship, incorporating ways to improve communication, and encouraging application of healthy lifestyle choices for improved HRQOL (Shields, 2012). The group facilitators encourage active engagement with one another and provide opportunities to share fears and concerns in a safe and confidential space. Through storytelling and person reflection, women identify strengths and become more knowledgeable about disease management, are a stronger self-advocate for healthcare and personal/work responsibilities, improve communication and redefine roles within their relationships, rely on their spiritual connections, utilize community resources, and continue on the path to improving overall HRQOL (Gucciadri et. al, 2016).

The third phase occurs after the 12th session is completed. Women, who have completed the 12 weeks of the OTSG program, are invited to join the Sisterhood Ambassador Program. Women can choose to participate in the Sisterhood Ambassador Program, as they transition to an unstructured monthly support group. Psychoeducation and continued support are facilitated by LMFT-A's, with guest speakers presenting on ways to continue support, build network, promote self-advocacy, and engage support for

women living with chronic PFD. Women are invited to assist with community presentations with the community, medical groups, and other local meetings. By sharing personal experiences, women in the Sister Ambassador Program educate others of the psychological and physical impact of PFD and ways to manage living with CI.

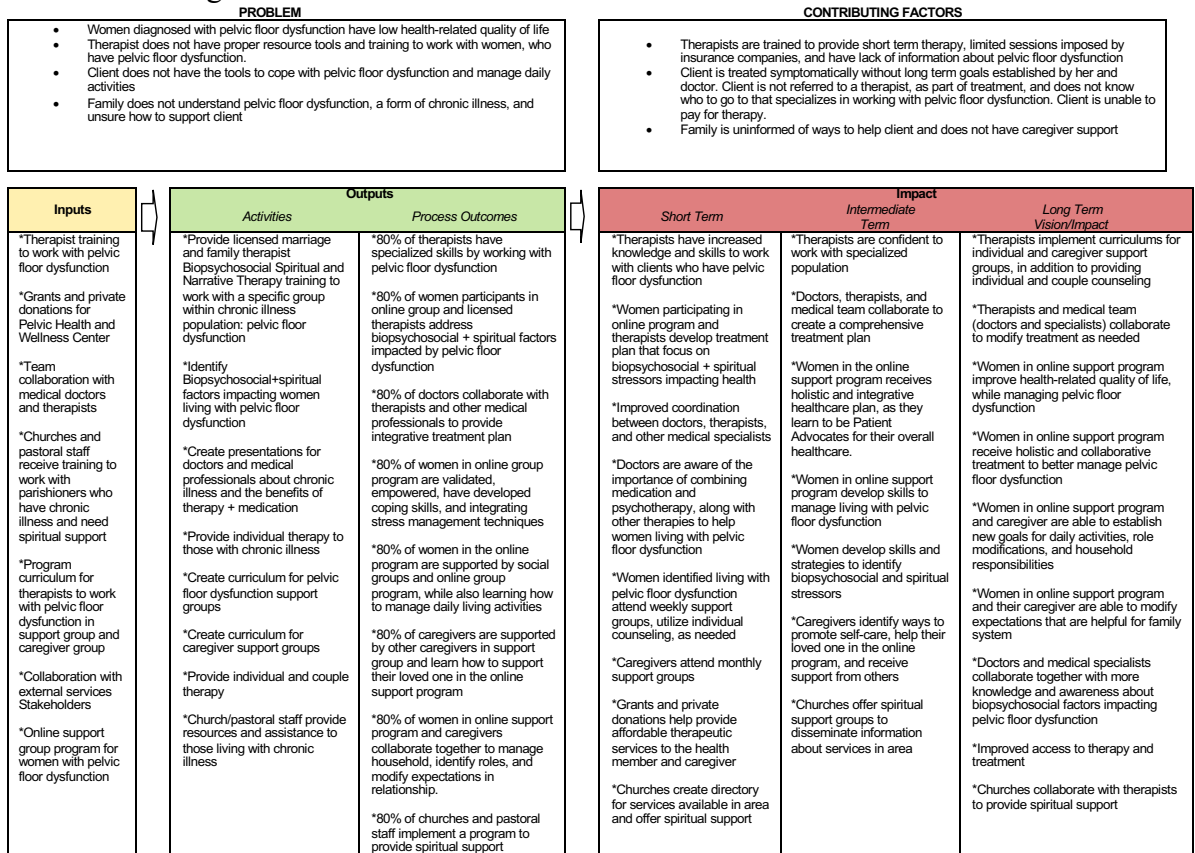
Pathways for Healing aims to decrease physical symptoms, as well as depression and anxiety symptoms alleviated with coping skills, while applying spirituality, mindfulness, and stress management skills (Arnouk, et al., 2017). As a result, providing a platform for advocacy and continued support is important to the improvement of overall HRQOL. The Sisterhood Ambassador program also introduces opportunities for women to reach out to others also impacted by chronic PFD, engage in social media campaigns and community awareness opportunities to educate the community on the impact of chronic PFD and resources available to improve HRQOL.

Logic Model

The logic model (see Table 1) recognizes there is insufficient training for therapists, working with women living with chronic PFD and there is a lack of resources and services for women through an online platform, who are living in rural communities. Process and outcome objective are also included, to identify ways to integrate care through a biopsychosocial-spiritual lens, while also recognizing ways to support and achieve third order change. One challenge is that therapists are not adequately trained in integrative care and do not have training in pelvic floor dysfunction and chronic illness. A second challenge is recognizing women are unable to physically leave their home, which makes it difficult to access therapeutic services, because of physical limitations.

As a result, women cannot access healthcare services and are unable to receive therapeutic support to manage living with chronic pelvic floor dysfunction. A third challenge is women do not have an online platform with psychoeducation, mental health services, integrative healthcare, and a support group program designed to improve overall HRQOL.

Table 1. The Logic Model.



Note: This chart is based on online therapeutic support and centralized care, identifies chronic pelvic floor dysfunction as a form of chronic illness. The problem, contributing factors, and goals (short-term, intermediate, and long-term) are based on the process and objective goals identified.

Process Objectives

The measure of success is identified by comparing pre- and post-tests collected after the sixth session, twelfth session, three months post-group completion, and six months post-group completion of the program. The OTSG program's success is based on two factors: 1) training, 2) participants completing program, and 3) participants reporting a decrease in depression and an improvement in overall HRQOL. One measurement of success is 80% of LMFT's and PFPT's are trained properly and receive specialized therapeutic skills for chronic PFD. This accounts for 20% of therapists who are unable to complete training, unwilling to learn integrative care and chronic PFD challenges, or drop out of training prematurely. These trainings occur monthly, with monthly supervision to provide continued support and resources for group facilitators. At the end of 12 weeks, group facilitators will complete Survey for Group Facilitators, which will provide information on ways to improve

The second factor is the successful completion of the 12-week program and transitioning into the Sisterhood Ambassador Program. Women attend 80% of weekly support groups, develop coping skills and stress management techniques, decrease depressive symptoms, increase overall HRQOL, and report a decrease in PFD symptoms. A 20% adjustment is considered for participants unable to complete the OTSG program, discontinue medical care with their referring provider, move to another state, have other health issues that complicate attending group meetings, and/or have difficulty accessing internet and wi-fi capabilities.

The third factor bases the success of the program by 80% of participants reporting an increase in coping skills and stress management techniques, a decrease depressive

symptoms, an increase in overall HRQOL, and report a decrease in overall chronic PFD symptoms. The 20% adjustment is considered for participants who do not complete the program, do not continue to meet with their medical provider regularly, and do not follow their treatment protocol established by their medical provider, the PFPT, and the LMFT overseeing their care.

Outcome Objectives

The first outcome objective for Pathways for Healing is to train and educate group facilitators about chronic PFD and the OTSG program's purpose and goals. The second outcome objective is for group participants to identify their specific BPS-S stressors and improve HRQOL, each week. The third outcome objective is for women to complete the OTSG program and transition to the Sisterhood Ambassador Program, with a decrease in depressive symptoms and anxiety, decrease in chronic PFD symptoms, and an increase in overall HRQOL, as skills are applied, and new coping strategies are applied. Both assessments (CICO and Survey for Participants) will determine the efficacy of the OTSG program and determine if the outcome objectives have been met.

Because women in minority populations tend to prefer female physicians, this study will utilize therapists identifying as female to establish trust and build rapport. It is also important for therapists (group facilitators) to be cultural and ethnically diverse and patient-centered in their approach, when working with clients who might experience racial issues arising in group, while being socioculturally sensitive to all participants in the program (Meyer, O.L. & Zane, N., 2013). While the study is solely focused on adult biological women participants working with therapists identifying as female (LMFT and PFPT), participants choose their primary healthcare provider regardless of gender, as this

does not impact the data for this study.

Pathways for Healing is available to women who live in the state of Texas, regardless of religious affiliation, ethnicity, race, and SES backgrounds. The program is for women between the ages of 18 years old and 65 years old. Women, who are biological females and diagnosed with chronic PFD, women referred by a medical specialist are also eligible to participate in the OTSG program. Due to state laws, the OTSG program is limited to women living in Texas, with primary consideration for women living in rural communities. Women who speak English and/or Spanish will qualify for the program and placed in the group specific to their primary language. Because the program is online, women are required to have access to internet services and have a mobile device to log on for support group attendance. However, if women are unable to access an electronic device, Healings for Pathways will provide one to be used for the OTSG program.

Women, under the age of 18 and over the age of 65, are not eligible for the OTSG program. Women not diagnosed with chronic PFD are also ineligible for the program. Men and non-biological females are ineligible, as the program is specific to biological females and provides support aimed for their specific biological and psychological needs. While women are able to determine their medical treatment, eligibility for the OTSG program requires collaboration with a medical provider to integrate health and mental care. As a result, women not working with a medical provider, are ineligible. Because the program is spiritually focused, those uncomfortable or not wanting to participate in a spiritually focused program are ineligible, as the program utilizes BPS-S components.

Women, who do not have access to internet services or are unable to drive to a local library or community center for internet access, are ineligible for the OTSG program. Women with severe depressive issues and suicidal/homicidal ideations, are ineligible for the program, but are referred to mental health professionals in their area. Women unable to commit to the program, for the duration of the support groups, are also ineligible. Lastly, those who move out of Texas are not eligible for the OTSG program because LMFT's and LPFT's are licensed only within the State of Texas.

Typically, therapeutic services are limited by a set number of sessions, determined by insurance companies. Insured women face the same challenges as those who are uninsured because of the financial burden living with CI creates. Living in rural communities' limit accessibility for mental health services, regardless of health insurance. Women, who have to travel outside of their community for mental health services are less apt to seek services, because of financial limitations and transportation challenges. Due to the cost and lack of access to service providers in rural communities, women are not receiving the mental health services needed for those living with PFD (Clark, et al., 2017). The benefits of the OTSG program addresses these challenges through: 1) no cost for participation in groups, 2) access to mental health providers online, 3) providing an electronic device if women do not have one, 4) offering support groups in women's primary language (English or Spanish), 5) collaboration with medical providers to integrate care, and 6) providing an aftercare program: Sisterhood Ambassador Program, for women completing the OTSG program.

Group Format

Pathways for Healing's OTSG program offers closed groups, which means members are screened for eligibility, offered a link with password access to the group site, and new participants are placed in other support groups that are beginning at a later time (Chang, et al., 2003). The OTSG program offers synchronous participation, offering a platform for group members to interact simultaneously with an LMFT and PFPT, and engaging with other women also diagnosed with chronic PFD. By providing closed groups, women build trust with one another and participate in the program on a weekly basis for twelve weeks, before transitioning to the Sisterhood Ambassador Program. The closed group format encourages communication, offers safety and familiarity with the same group members, and provides consistency with the same group facilitators overseeing the weekly groups each week.

Because multiple groups begin each week, there are concurrent multiple groups at different times and days, to allow for flexibility and offer more women to participate. New participants meet with the Clinical Liaison, who shares information about the program, oversees the consent forms, provides pre-screening to determine eligibility of the OTSG program, and assists with group placement. Once in a group, participants are provided pre-tests, which will be provided at the end of the sixth session, 10th session, three-months post-group completion, and six-months post-group completion. These tests are provided by the group facilitators, which Research Assistants will collect the data and analyze it to determine the effectiveness of the OTSG program.

The OTSG program utilizes an open recruitment and engagement process to place women in the group that works best according to their preference of day, time, and

language. Reviewing the inclusion and exclusion criteria, it is expected that 60% of participants who are referred to the OTSG program qualify. Upon agreement of participation in the OTSG program, women sign the consent form document and take the pre-tests (PFDI-20 and PFIQ).

Pre-Group Placement

Before group placement, women answer a questionnaire to determine if the potential participant has chronic PFD. The assessments also identify social support systems, reports cognitive functioning, recognizes depression and anxiety symptoms, identifies physical limitations and health issues related to chronic PFD, recognizes family issues, and identifies daily activities that are now limited. This information determines severity of issues and concerns, and which group the participant will benefit most from. Women also identify their primary language preferred: English or Spanish, as the groups are available in both languages. The group meetings include psychoeducation, addresses medical challenges, and offers support for its participants.

Prior to completing the pre-tests, a consent form (see Appendix A) is provided to the potential participant, with the form being read and questions about the consent form answered by the Clinical Liaison. The consent form is strictly confidential, as medical staff and therapists administer the tests will adhere to HIPAA regulations. Typically, the PFDI-20 & PFIQ are administered prior to bladder surgery, 3 months, and 6 months post-surgery, however this form will be administered once before being admission into the program, determining eligibility for the OTSG program (Barber, et. al., 2005). The instruments are administered by paper and pen, and reviewed for consideration of admittance into the program, along with the consent form. Both assessments will also be

utilized as part of the assessments used to collect data for the efficacy of the OTSG program.

Assessments

Data collected will consist of questionnaires, surveys, and results from assessment tools (see Table 2). The first step of the program is determining eligibility. Two assessment instruments are used and administered by the referring medical specialist. The Pelvic Floor Distress Inventory (PFDI-20) and the Pelvic Floor Impact Questionnaire (PFIQ) contain 20 questions and 3 scales: urinary distress inventory, pelvic organ prolapse inventory, and colorectal anal distress inventory, which is measurable tool to determine how PFD has impacted the health member's quality of life, (Barber, et. al., 2005).

Both the PFDI-20 and PFIQ provide data to determine eligibility for participation in the program. the baseline for each participant in the OTSG program. The pre-test will be compared to the post-tests, which are provided after the sixth session, twelfth session, post three months, and post six months. For a reduction in attrition rates, the post-test format consists of updating phone numbers, emails, and contact information, to follow-up with the participants. The researchers and therapists continue to maintain close contact with the medical specialists and will reach out to the women for holidays, birthdays, and special occasions (to encourage close contact and improve relationships with the participants). Access to the patient's medical file will also be utilized to improve and update information as needed for each participant.

The clinical liaison provides the initial pre-pre-test to determine program eligibility. After group placement, assessments are administered by group co-facilitators,

which will be analyzed by research assistants. The assessments provided are: 1) The Pelvic Floor Distress Inventory (PFDI-20), 2) the Pelvic Floor Impact Questionnaire (PFIQ), 3) The Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-SP), 4) Beck Depression Inventory-II (BDI-II), 5) RAND 36-Item Health Survey (SF-36), and 6) the Check-In, Check-Out Oral Report (CICO) (see Table 10). These assessments will identify if there has been improvement in women's emotional, spiritual, and physical needs, and overall HRQOL. It will also show areas for improvement, areas that are continuing to negatively impact overall HRQOL, and areas of growth. At the end of the 12th session, participants will complete the Survey for Participants (see Table 9) which includes qualitative data with open-ended questions included.

The measures utilized determine if the OTSG program improves overall HRQOL for women with chronic PFD. Depression is a common comorbid diagnosis with PFD, because it impacts the ability to engage in daily living activities without restrictions, increases social isolation from family and friends, feel hopeless about the diagnosis, and creates financial stressors (Restorick-Roberts, et al., 2017). Comparing pre and post-tests will determine if there is a significant decrease in depressive symptoms and increase in overall HRQOL. Information from 60% of participants, with 80% of the responses completed, provides enough data for a robust sample.

Table 2. Assessment Tools.

Assessment Name	Measures	Objective/Process Goals	Scoring
Pelvic Floor Impact Questionnaire-Short Form 7 (PFIQ)	Health-related quality of life	Establishes baseline to determine if eligible for the program Goal: evaluate potential participants for program. Those not eligible are referred to mental health providers and offered resources.	0-300: Lower scores determine less impact chronic pelvic floor dysfunction has on overall health-related quality of life (HRQOL).
Pelvic Floor Distress Inventory Short Form 20 (PFDI)	How chronic PFD impacts overall HRQOL	Establish baseline and then show a decrease in chronic PFD impacting overall HRQOL.	0-300: Lower score determines chronic PFD has less impact on overall HRQOL.
The Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-SP)	Health-related quality of life: physical status, emotional well-being, functional well-being, family/social issues, sexual/intimacy, work status, and work goals.	Identify biopsychosocial-spiritual factors and ways it has impacted overall health-related quality of life. Goal: Increase in score to determine overall health related quality of life has improved.	0-16, with a higher score indicating improved overall health-related quality of life and a deep spiritual connection.
RAND 36-Item Health Survey (SF-36)	Measures 1) physical functioning, 2) role-physical, 3) bodily pain, 4) general health, 5) mental health, 6) social functioning, 7) role-emotional, and 8) mental health	Identify specific areas impacted by chronic PFD and how it has improved with the program. Goal: increase in improvement of functioning that correlates to health-related quality of life.	0-100, with higher score determining level of functioning.
Beck Depressive Inventory-II (BDI-II)	Measures range of depression (mild to severe)	Identify level of depression. Goal: decrease depression	0-63, with lower score indicating lower depressive symptoms
Check-in, Check-Out Oral Report (CICO)	Measures overall experience each week in support group	To improve experience and application of skills learned Goal: improved experience and application of skills	Qualitative; subjective
Survey for Group Participants	Determines overall personal experience of support group	To show support group is helpful to increasing HRQOL Goal: identify areas support group is helpful	Qualitative; subjective

Note: Evaluative measures are used to determine the efficacy of the online therapeutic support group program.

PFDI-20 and PFIQ

The Pelvic Floor Impact Questionnaire (PFIQ-7) was developed in 2004 to measure HRQOL for women diagnosed with chronic PFD (Barber, M., et al., 2011). The questionnaire can be completed on paper with pencil and is easy to understand. This assessment offers responses from a scale of 0 (not at all) to 3 (quite a bit). With a total score of 300, the higher the score, the more chronic PFD has on HRQOL. The lower the score, the less impact PFD has on HRQOL. The correlation score ranges from -1.0 to +1.0, with the r value close to +1.0 showing values increase linearly (Barber, M., et al., 2011). The test-retest reliability is $=.77$, construct validity demonstrates significant association with symptom severity with chronic PFD and HRQOL (Barber, M., et al., 2011).

The Pelvic Distress Inventory Questionnaire-20 (PFDI-20) is designed for women over the age of 18 years old, with a form of chronic PFD. This assessment consists of 20 questions, with a response of “yes” or “no”. If the response is “yes”, it has a follow-up question that is answered using a range of 0 (not at all) to 4 (quite a bit). The sum provides a total up to 300. The higher the score represents lower HRQOL related to PFD symptoms, with a lower score representing chronic PFD symptoms not impacting HRQOL. The assessment has three scales: 1) pelvic organ prolapse distress inventory, 2) Colorectal-Anal Distress Inventory, and 3) Urinary Distress Inventory. The correlation is represented by r value ranging from -1.0 to +1.0, with 0.0 meaning there is no correlation. The value r closest to -1.0 indicates values decrease linearly and r value closest to +1.0 means both values increase linearly, suggesting correlation with chronic PFD symptoms

and HRQOL (Barber, et al., 2011). The test-retest reliability reflects a value of $r=.93$, with construct validity showing a significant association with symptoms related to HRQOL.

Typically, both the PFDI-20 (see Table 3) and PFIQ-7 (see Table 4) are instruments used together and are for women experiencing chronic PFD, who have symptoms impacting overall HRQOL. Both will measure the relationship chronic PFD symptoms have to overall HRQOL and if the potential participant has been negatively impacted and will benefit from the OTSG program. For participants not eligible because she has not been officially diagnosed with chronic PFD by a medical specialist or exhibits severe mental health issues, an appropriate referral will be made for individual therapy more appropriate. These assessments will be provided as a pre-pre-test assessment and compared after the sixth and 12th session, and three-months and six-months post group completion.

Table 3. Pelvic Floor Disability Index (PFDI-20).

Pelvic Floor Disability Index (PFDI-20)

Instructions: Please answer all of the questions in the following survey. These questions will ask you if you have certain bowel, bladder, or pelvic symptoms and, if you do, **how much they bother you**. Answer these by circling the appropriate number. While answering these questions, please consider your symptoms over the last 3 months. The PFDI-20 has 20 items and 3 scales of your symptoms. All items use the following format with a response scale from 0 to 4.

Symptom scale:
0 = not present
1= not at all
2 = somewhat
3 = moderately
4 = quite a bit

Pelvic Organ prolapse Distress Inventory 6 (POPDI-6)

Do You...	NO	YES
1. Usually experience pressure in the lower abdomen?	0	1 2 3 4
2. Usually experience heaviness or dullness in the pelvic area?	0	1 2 3 4
3. Usually have a bulge or something falling out that you can see or feel in your vaginal area?	0	1 2 3 4
4. Ever have to push on the vagina or around the rectum to have or complete a bowel movement?	0	1 2 3 4
5. Usually experience a feeling of incomplete bladder emptying?	0	1 2 3 4
6. Ever have to push up on a bulge in the vaginal area with your fingers to start or complete urination?	0	1 2 3 4

Colorectal-Anal distress Inventory 8 (CRAD-8)

Do You...	NO	YES
7. Feel you need to strain too hard to have a bowel movement?	0	1 2 3 4
8. Feel you have not completely emptied your bowels at the end of a bowel movement?	0	1 2 3 4
9. Usually lose stool beyond your control if your stool is well formed?	0	1 2 3 4
10. Usually lose stool beyond your control if your stool is loose?	0	1 2 3 4
11. Usually lose gas from the rectum beyond your control?	0	1 2 3 4
12. Usually have pain when you pass your stool?	0	1 2 3 4
13. Experience a strong sense of urgency and have to rush to the bathroom to have a bowel movement?	0	1 2 3 4
14. Does part of your bowel ever pass through the rectum and bulge outside during or after a bowel movement?	0	1 2 3 4

Urinary distress Inventory 6 (UDI-6)

Do You...	NO	YES
15. Usually experience frequent urination?	0	1 2 3 4
16. Usually experience urine leakage associated with a feeling of urgency, that is, a strong sensation of needing to go to the bathroom?	0	1 2 3 4
17. Usually experience urine leakage related to coughing, sneezing or laughing?	0	1 2 3 4
18. Usually experience small amounts of urine leakage (that is, drops)?	0	1 2 3 4
19. Usually experience difficulty emptying your bladder?	0	1 2 3 4
20. Usually experience pain or discomfort in the lower abdomen or genital region?	0	1 2 3 4

Scoring the PFDI-20

Scale Scores: Obtain the mean value of all of the answered items within the corresponding scale (possible value 0 to 4) and then multiply by 25 to obtain the scale score (range 0 to 100). Missing items are dealt with by using the mean from answered items only.

PFDI-20 Summary Score: Add the scores from the 3 scales together to obtain the summary score (range 0 to 300).

Table 4. Pelvic Floor Impact Questionnaire-Short Form 7 (PFIQ).

Pelvic Floor Impact Questionnaire - Short Form 7 (PFIQ-7)

Name _____ Date of Birth _____ Today's Date _____

Height _____ ft. _____ in. Weight _____ lbs.

Instructions: Some women find that bladder, bowel, or vaginal symptoms affect their activities, relationships, and feelings. For each question, check the response that best describes how much your activities, relationships, or feelings have been affected by your bladder, bowel and vaginal / pelvic symptoms or conditions **over the last 3 months**. Please be sure to mark an answer in **all 3 columns** for each question.

How do symptoms or conditions in the following usually affect your	<i>Bladder or Urine</i>	<i>Bowel or Rectum</i>	<i>Vagina or Pelvis</i>
1. Ability to do household chores (cooking, laundry housecleaning)?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
2. Ability to do physical activities such as walking, swimming, or other exercise?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
3. Entertainment activities such as going to a movie or concert?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
4. Ability to travel by car or bus for a distance greater than 30 minutes away from home?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
5. Participating in social activities outside your home?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
6. Emotional health (nervousness, depression, etc.)?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
7. Feeling frustrated?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
Summary Score: _____ 0	UIQ-7: _____ 0	CRAIQ-7: _____ 0	POPIQ-7: _____ 0

Functional Assessment of Chronic Illness Therapy Measurement System

The Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-F) is a questionnaire that measures health related quality of life (HRQOL) for those with chronic illness (Webster, et. al., 2003). The FACIT-SP is an added component inquiring about spirituality and its impact on HRQOL. The measurement tools, developed by patients with cancer and healthcare specialists can be applied to a variety of diseases, chronic illness conditions, and non-threatening diseases. The assessment tools provide data on the woman's physical status, emotional well-being, functional well-being, family/social issues, sexual/intimacy, work status, and future goals, (Webster, et. al., 2003). The FACIT-SP is a common tool used to measure spiritual well-being among those with chronic illnesses, cancers, and other medical conditions, such as PFD, (Munoz, A., et.al., 2015).

The FACIT-SP (see Table 5) provides valuable information to determine if spiritual well-being helps women living with PFD decrease psychological distress, by measuring level of faith, strength, and comfort (Munoz, et. al., 2015). The measurement tools are administered in over 45 languages, offers an added spiritual component, can be completed in 5-10 minute, is written at a 4th grade reading level for easy understanding, and can be self-administered or completed by interview, (Webster, et. al., 2003). While the FACIT-SP is a newer assessment that has limited cross-sectional studies, it is one of the few assessments that utilizes spirituality as an important component to consider utilizing a biopsychosocial-spiritual model of health, which impacts overall HRQOL. As a result, the spiritual domain will be solely utilized, rather than the whole assessment to determine if spirituality improves HRQOL, which is part of the online support program.

Utilizing a 5-point Likert scale, the whole assessment contains 39 questions and measures 1) physical well-being, 2) social/family well-being, 3), emotional well-being, 4) functional well-bring, and 5) spiritual well-being, which can be completed in 10-15 minutes by participants aged 18 and up (Bredle, et al., 2011). However, for the purpose of this study, 12 questions will be asked that focus on faith, peace, and meaning. Internal reliability and validity have been established in older populations and ethnically diverse populations, without a specific adherence to a faith or religion.

The measurement tool has been administered in over 45 languages, is written in a 4th grade reading level, and can be administered over the phone, pen/paper, or computer (Webster, et al., 2003). Ranging in scores from 0-16, a high score indicates strong spiritual connections that improve overall HRQOL. The scale has been validated and undergone four phases: item-generation, item-reduction, scale construction, and psychometric evaluation (Webster, et al., 2003). FACIT-SP's internal validity and external reliability for spiritual well-being is associated with improved overall HRQOL ($r=.48$) (Bredle, et al., 2011). Compared to the Spiritual Beliefs Inventory (SBI), the FACIT-SP is brief, reliable, valid, and is particularly useful in assessing the role of both religious and non-religious spiritual well-being and its impact on HRQOL (Bredle, et al., 2011). Internal consistency is high ($\alpha = 0.95$) and the three subscales for the spiritual domain indicate the importance of including this measurement for the purpose of this study: (meaning/peace, $\alpha = 0.90$; faith, $\alpha = 0.93$; relational, $\alpha = 0.83$), with social support, and self-esteem, (ranging from 0.41 to 0.49; $p < 0.01$) (Bredle, et al., 2011).

Table 5. The Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-SP-version 4)

FACIT-Sp (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

<u>PHYSICAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4
<u>SOCIAL/FAMILY WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i>					
GS7	I am satisfied with my sex life	0	1	2	3	4

Table 5. The Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-SP-version 4)(continued).

FACIT-Sp (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the **past 7 days**.

<u>EMOTIONAL WELL-BEING</u>		Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

<u>FUNCTIONAL WELL-BEING</u>		Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling.....	0	1	2	3	4
GF3	I am able to enjoy life.....	0	1	2	3	4
GF4	I have accepted my illness.....	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now.....	0	1	2	3	4

Table 5. The Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-SP-version 4)(continued).

FACIT-Sp (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<u>ADDITIONAL CONCERNS</u>		Not at all	A little bit	Some-what	Quite a bit	Very much
Sp1	I feel peaceful.....	0	1	2	3	4
Sp2	I have a reason for living.....	0	1	2	3	4
Sp3	My life has been productive.....	0	1	2	3	4
Sp4	I have trouble feeling peace of mind.....	0	1	2	3	4
Sp5	I feel a sense of purpose in my life	0	1	2	3	4
Sp6	I am able to reach down deep into myself for comfort	0	1	2	3	4
Sp7	I feel a sense of harmony within myself	0	1	2	3	4
Sp8	My life lacks meaning and purpose.....	0	1	2	3	4
Sp9	I find comfort in my faith or spiritual beliefs.....	0	1	2	3	4
Sp10	I find strength in my faith or spiritual beliefs	0	1	2	3	4
Sp11	My illness has strengthened my faith or spiritual beliefs....	0	1	2	3	4
Sp12	I know that whatever happens with my illness, things will be okay	0	1	2	3	4

Note: This chart consists of physical well-being, social/family well-being, emotional, functional, and additional concerns that pertain to a spiritual component, to address the biopsychosocial-spiritual factors impacting overall health-related quality of life.

RAND 36-Item Health Survey

The RAND-36-Item Health Survey (SF-36) determines how PFD can impact daily living, social activities with others, and overall HRQOL (see Table 6). Women with significant depressive symptoms tend to score worse on the RAND 26 Item Health Survey (SF-36) and have lower HRQOL, than those with mild to no depressive symptoms (Hays, 1993). The Medical Outcomes Study began as a longitudinal, cross-sectional study, that has evolved to become SF-36, which is available in over 170 languages and is incorporated in over 13,000 publications. The self-report measure utilizes a 5-point Likert scale, focused in two domains: physical and mental health with eight concepts: 1) physical functioning, 2) role-physical, 3) bodily pain, 4) general health, 5) mental health, 6) social functioning, 7) role-emotional, and 8) mental health (Hays, et al., 1993).

The SF-36 (see Table 7) has internal validity (88%-95%) and reliability across 24 different ethnic and sociocultural diverse groups, who have a form of CI with different levels of severity (McHorney, et al., 1994). The SF-36 has internal consistency of 97%, item-discriminant validity of 92%, with reliability coefficients ranging from .65 to .94 (McHorney, et al., 1994). SF-36 has achieved 80%-90% empirical validity, compared to other tests that focus on physical and mental health studies, with an 80%-85% reliable variance (Ware, 2000). With a correlation of .99, the SF-6 is compared to the Medical Outcomes Study, with internal reliability and validity consistent (Hays, 1993).

Table 6. RAND 36-Item Health Survey (SF-36).



RAND > RAND Health > Surveys > RAND Medical Outcomes Study > 36-Item Short Form Survey (SF-36) >

36-Item Short Form Survey Instrument (SF-36)

RAND 36-Item Health Survey 1.0 Questionnaire Items

Choose one option for each questionnaire item.

1. In general, would you say your health is:

- 1 - Excellent
- 2 - Very good
- 3 - Good
- 4 - Fair
- 5 - Poor

2. **Compared to one year ago**, how would you rate your health in general **now**?

- 1 - Much better now than one year ago
 - 2 - Somewhat better now than one year ago
 - 3 - About the same
 - 4 - Somewhat worse now than one year ago
 - 5 - Much worse now than one year ago
-

Table 6. RAND 36-Item Health Survey (SF-36)(continued)

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
3. Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
4. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
5. Lifting or carrying groceries	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
6. Climbing several flights of stairs	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
7. Climbing one flight of stairs	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
8. Bending, kneeling, or stooping	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
9. Walking more than a mile	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
10. Walking several blocks	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
11. Walking one block	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
12. Bathing or dressing yourself	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

	Yes	No
13. Cut down the amount of time you spent on work or other activities	<input type="radio"/> 1	<input type="radio"/> 2
14. Accomplished less than you would like	<input type="radio"/> 1	<input type="radio"/> 2
15. Were limited in the kind of work or other activities	<input type="radio"/> 1	<input type="radio"/> 2
16. Had difficulty performing the work or other activities (for example, it took extra effort)	<input type="radio"/> 1	<input type="radio"/> 2

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	Yes	No
17. Cut down the amount of time you spent on work or other activities	<input type="radio"/> 1	<input type="radio"/> 2
18. Accomplished less than you would like	<input type="radio"/> 1	<input type="radio"/> 2
19. Didn't do work or other activities as carefully as usual	<input type="radio"/> 1	<input type="radio"/> 2

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- 1 - Not at all
- 2 - Slightly
- 3 - Moderately
- 4 - Quite a bit
- 5 - Extremely

Note: This survey measures data, utilizing a 5-point Likert scale, focused on: 1) physical functioning, 2) role-physical, 3) bodily pain, 4) general health, 5) mental health, 6) social functioning, 7) role-emotional, and 8) mental health.

Table 7. Summary of SF 36 Physical and Mental Scales and Summary Measures.

Scales	Correlations		Number of				Reliability		Definition (% observed)	
	PCS	MCS	Items	Levels	Mean§	SD		CI*	Lowest Possible Score (Floor)‡	Highest Possible Score (Ceiling)‡
Physical Functioning (PF)	.85	.12	10	21	84.2	23.3	.93	12.3	Very limited in performing all physical activities, including bathing or dressing (0.8%)	Performs all types of physical activities including the most vigorous without limitations due to health (38.8%)
Role-Physical (RP)	.81	.27	4	5	80.9	34.0	.89	22.6	Problems with work or other daily activities as a result of physical health (10.3%)	No problems with work or other daily activities (70.9%)
Bodily Pain (BP)	.76	.28	2	11	75.2	23.7	.90	15.0	Very severe and extremely limiting pain (0.6%)	No pain or limitations due to pain (31.9%)
General Health (GH)	.69	.37	5	21	71.9	20.3	.81	17.6	Evaluates personal health as poor and believes it is likely to get worse (0.0%)	Evaluates personal health as excellent (7.4%)
Vitality (VT)	.47	.65	4	21	60.9	20.9	.86	15.6	Feels tired and worn out all of the time (0.5%)	Feels full of pep and energy all of the time (1.5%)
Social Functioning (SF)	.42	.67	2	9	83.3	22.7	.68	25.7	Extreme and frequent interference with normal social activities due to physical and emotional problems (0.6%)	Performs normal social activities without interference due to physical or emotional problems (52.3%)
Role-Emotional (RE)	.16	.78	3	4	81.3	33.0	.82	28.0	Problems with work or other daily activities as a result of emotional problems (9.6%)	No problems with work or other daily activities (71.0%)
Mental Health (MH)	.17	.87	5	26	74.7	18.1	.84	14.0	Feelings of nervousness and depression all of the time (0.0%)	Feels peaceful, happy, and calm all of the time (0.2%)
Physical Component Summary (PCS)			35	567 [†]	50.0	10.0	.92	5.7	Limitations in self-care, physical, social, and role activities, severe bodily pain, frequent tiredness, health rated "poor" (0.0%)	No physical limitations, disabilities, or decrements in well-being, high energy level, health rated "excellent" (0.0%)
Mental Component Summary (MCS)			35	493 [†]	50.0	10.0	.88	6.3	Frequent psychological distress, social and role disability due to emotional problems, health rated "poor" (0.0%)	Frequent positive affect, absence of psychological distress and limitations in usual social/role activities due to emotional problems, health rated "excellent" (0.0%)

Note: From Ware, Kosinski, and Keller.⁶⁸
* CI = 95% confidence interval.
[†] Number of levels observed at baseline; scores rounded to the first decimal place (n = 2474).
[‡] Percentage observed comes from general U.S. population sample.
§ Scores for eight scales are the percentage of the total possible score achieved for each of these scales. Scores for PCS and MCS are T-scores.
PCS = physical component summary; MCS = mental component summary.

Note: This table contains statistical information, according to each scale domain. Focused on construct validity, t-scores are used to interpret the scores, which includes the M, r, CI, and SD for each domain.

Beck Depression Inventory-II

Because depression is a common co-morbidity diagnosis for women with PFD, the BDI-II (see Table 8) is a self-assessment tool that will determine range of depression (mild to severe) and has proven content and structural validity (Wang & Gorenstein, 2013). The BDI-II is a 21-item self-reporting questionnaire, developed by Aaron Beck and colleagues in 1961, focuses on negative cognitive distortions contributing to depression (Gordon, 2016). Using a 4-point Likert scale, scores 0-63 indicate level of depression: 0=symptoms absent, 1-13=minimal depression, 14-19= mild depression, 20-28=moderate depression, and 29-63-severe depression (Gordon, 2016). Revised to reflect Major Depressive Disorder in the Diagnostic and Statistical Manual of Mental Disorders-5th edition (DSM-V), BDI-II has been used in over 7,000 studies, is available in 73 languages, is designed for self-administration for 13–80-year old's, has internal consistency of .9, and re-test reliability (.73 to .96) (Wang & Gorenstein, 2013). Re-test reliability has a correlation ($r=.93$), with internal reliability based on Cronbach's coefficient (.85), internal reliability (.91) (Wang & Gorenstein, 2013). The BDI-II positively correlates to the Hamilton Depression Rating Scale ($r=.71$), has high content, improved concurrent content with structural validity, and construct validity in comparison the Minnesota Multiphasic Personality Inventory with a correlation rating of .77 (Beck, et al., 1996).

The assessments are completed over the phone, pen/paper, or on computer. A high score indicates a good HRQOL, with low score meaning low HRQOL. Missing data from participants can still be accepted, so long as 4 of the 6 items are answered, with an overall response rate of 80%, meaning 22 of 27 items are answered, (Webster et. al.,

2003). The timeline for administration is before the first session (at intake), after 6 group sessions, 12 sessions, 3 months, and 6 months post-study. This will determine if the program is helping increase HRQOL and continue to identify areas needing additional support.

Table 8. Beck Depression Inventory-II (BDI-II).

Beck's Depression Inventory

This depression inventory can be self-scored. The scoring scale is at the end of the questionnaire.

1.	0	I do not feel sad.
	1	I feel sad
	2	I am sad all the time and I can't snap out of it.
	3	I am so sad and unhappy that I can't stand it.
2.	0	I am not particularly discouraged about the future.
	1	I feel discouraged about the future.
	2	I feel I have nothing to look forward to.
	3	I feel the future is hopeless and that things cannot improve.
3.	0	I do not feel like a failure.
	1	I feel I have failed more than the average person.
	2	As I look back on my life, all I can see is a lot of failures.
	3	I feel I am a complete failure as a person.
4.	0	I get as much satisfaction out of things as I used to.
	1	I don't enjoy things the way I used to.
	2	I don't get real satisfaction out of anything anymore.
	3	I am dissatisfied or bored with everything.
5.	0	I don't feel particularly guilty
	1	I feel guilty a good part of the time.
	2	I feel quite guilty most of the time.
	3	I feel guilty all of the time.
6.	0	I don't feel I am being punished.
	1	I feel I may be punished.
	2	I expect to be punished.
	3	I feel I am being punished.
7.	0	I don't feel disappointed in myself.
	1	I am disappointed in myself.
	2	I am disgusted with myself.
	3	I hate myself.
8.	0	I don't feel I am any worse than anybody else.
	1	I am critical of myself for my weaknesses or mistakes.
	2	I blame myself all the time for my faults.
	3	I blame myself for everything bad that happens.
9.	0	I don't have any thoughts of killing myself.
	1	I have thoughts of killing myself, but I would not carry them out.
	2	I would like to kill myself.
	3	I would kill myself if I had the chance.
10.	0	I don't cry any more than usual.
	1	I cry more now than I used to.
	2	I cry all the time now.
	3	I used to be able to cry, but now I can't cry even though I want to.

Table 8. Beck Depression Inventory-II (BDI-II)(continued).

11.	0	I am no more irritated by things than I ever was.
	1	I am slightly more irritated now than usual.
	2	I am quite annoyed or irritated a good deal of the time.
	3	I feel irritated all the time.
12.	0	I have not lost interest in other people.
	1	I am less interested in other people than I used to be.
	2	I have lost most of my interest in other people.
	3	I have lost all of my interest in other people.
13.	0	I make decisions about as well as I ever could.
	1	I put off making decisions more than I used to.
	2	I have greater difficulty in making decisions more than I used to.
	3	I can't make decisions at all anymore.
14.	0	I don't feel that I look any worse than I used to.
	1	I am worried that I am looking old or unattractive.
	2	I feel there are permanent changes in my appearance that make me look unattractive
	3	I believe that I look ugly.
15.	0	I can work about as well as before.
	1	It takes an extra effort to get started at doing something.
	2	I have to push myself very hard to do anything.
	3	I can't do any work at all.
16.	0	I can sleep as well as usual.
	1	I don't sleep as well as I used to.
	2	I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
	3	I wake up several hours earlier than I used to and cannot get back to sleep.
17.	0	I don't get more tired than usual.
	1	I get tired more easily than I used to.
	2	I get tired from doing almost anything.
	3	I am too tired to do anything.
18.	0	My appetite is no worse than usual.
	1	My appetite is not as good as it used to be.
	2	My appetite is much worse now.
	3	I have no appetite at all anymore.
19.	0	I haven't lost much weight, if any, lately.
	1	I have lost more than five pounds.
	2	I have lost more than ten pounds.
	3	I have lost more than fifteen pounds.

Table 8. Beck Depression Inventory-II (BDI-II)(continued).

- 20.
- 0 I am no more worried about my health than usual.
 - 1 I am worried about physical problems like aches, pains, upset stomach, or constipation.
 - 2 I am very worried about physical problems and it's hard to think of much else.
 - 3 I am so worried about my physical problems that I cannot think of anything else.
- 21.
- 0 I have not noticed any recent change in my interest in sex.
 - 1 I am less interested in sex than I used to be.
 - 2 I have almost no interest in sex.
 - 3 I have lost interest in sex completely.

INTERPRETING THE BECK DEPRESSION INVENTORY

Now that you have completed the questionnaire, add up the score for each of the twenty-one questions by counting the number to the right of each question you marked. The highest possible total for the whole test would be sixty-three. This would mean you circled number three on all twenty-one questions. Since the lowest possible score for each question is zero, the lowest possible score for the test would be zero. This would mean you circles zero on each question. You can evaluate your depression according to the Table below.

Total Score	Levels of Depression
1-10	These ups and downs are considered normal
11-16	Mild mood disturbance
17-20	Borderline clinical depression
21-30	Moderate depression
31-40	Severe depression
over 40	Extreme depression

http://www.med.navy.mil/sites/NMCP2/PatientServices/SleepClinicLab/Documents/Beck_Depression_Inventory.pdf

Note: This table contains 20 questions with scoring instructions for identification of normal to extreme levels of depression, based on a value of 1-30.

Table 9. Survey for Participants.

Survey for Participants: Based on a scale of 1 to 5, please circle the number that best represents your answer.

1. **My overall experience of the online support group with other women.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
2. **The content of the group discussions.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
3. **The online platform used for support groups.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
4. **The information and resources provided in online support groups.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
5. **The frequency of the group meetings: once a week.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
6. **The length of the group meetings: 90 minutes, for 12 weeks.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
7. **The group facilitators leading the discussions.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
8. **The group exercises and hand-outs provided in online support groups.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
9. **Meeting others with similar condition and sharing with one another.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
10. **Gained practice advice and increased my knowledge of the condition.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
11. **In what ways can the online program be improved?**

12. **In what ways did this program help you?**

13. **Can you identify 4 ways in which you can improve your overall mental and social health?**

14. **How can the group facilitators be more helpful to you?**

Note: This survey is provided after week 12, to determine the effectiveness of the online therapeutic support group program. The data will help determine ways to improve the program.

Table 10. Check-in, Check-Out Oral Report (CICO).
Support Group Check-In and Check-Outs

Week 1

Check -In

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.
- ⇒ Inform participants the group is voluntary, and each have the choice to provide as little or as much information about themselves and their condition throughout the entire group process. Being respectful of participants, who choose to not participate with an activity or an answer, and modeling setting boundaries as part of the learning process.

Check-Out

- ⇒ Ask what surprised them most about their first meeting.
- ⇒ Provide participants with 24-hour crisis hotline, crisis text line, and have space for each participant to fill in the numbers and contact information of their medical team.

Week 2

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Ask each participant what they hope to incorporate as part of self-care for the following week.
- ⇒ Invite participants to make final comments and summarize what was helpful and not helpful.
- ⇒ Provide list of resources in their community that can contribute to self-care.

Week 3

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to evaluate current self-care activities related to daily living and identify where changes and modifications can be made.
- ⇒ Each participant lists 1-2 ways modifications will be made and how it will help.

Week 4

Check-In:

- ⇒ Review group rules
- ⇒ Ask each participant will say: “My name is _____ and I hope to achieve today _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to evaluate the chart and add one way they will practice self-care through nutrition.

Table 10. Check-in, Check-Out Oral Report (CICO) (continued).

Week 5

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Identify one way in which the session was helpful or not helpful. Evaluate the chart and add one way they will practice self-care through nutrition.

Week 6

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Before closing the group, discuss what was helpful and wasn’t helpful this week. After closing, the participants will be administered a post-test to determine how the support group is being helpful and not helpful

Week 7

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to evaluate their needs and determine how each plan to inquire about services available.

Week 8

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to share how self-advocacy will be achieved for the following week.

Table 10. Check-in, Check-Out Oral Report (CICO) (continued).

Week 9

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to share how they will practice self-care for this week.
- ⇒ Meditation exercise handout

Week 10

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Provide all the exercise handouts to try at home
- ⇒ Discuss what was most helpful and what wasn’t in session. Identify one exercise that will be tried for the following week.

Week 11

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Each participant discloses what was helpful and not helpful in this session. Each participant will also discuss which goals will be implemented for the following week and how it can improve overall healthy daily living.

Table 10. Check-in, Check-Out Oral Report (CICO) (continued).

Week 12

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Have each participant describe what was most helpful and not helpful overall each week. Describe ways in which the program can help and not help others and ways to improve it.
- ⇒ Post-Test: The tests will be administered after the completion of group online, which will then be submitted for data collection by Research Assistants.
- ⇒ Afterward and Advocacy: Sisterhood Ambassador Program-Inform participants ways to help other women living with chronic pelvic floor dysfunction and inform community about resources available.
- ⇒ Post-Test at three months and six months after the completion of group. These tests will be completed by participants, who have completed the program, which will occur online and submitted for data entry by Research Assistants

Note: This assessment is provided at the end of each group session, by the group facilitator, to determine effectiveness of each group session.

CHAPTER FIVE

PROJECT OUTCOME

According to the World Health Organization, chronic illness kills up to 38 million people around the world each year (Olivares, et al., 2017). One form of chronic illness (CI), while not commonly understood, is chronic pelvic floor dysfunction (PFD). Acute PFD can be resolved with mediations, therapies, and other treatment options, differing from chronic PFD because the condition is ongoing, does not resolve within three months, and aligns itself with the criteria for chronic illness (National Health Council, 2014, Restorick-Roberts, et., al, 2017, & Wu, et. al., 2014). Chronic PFD is broad term that refers to the biological components related to the bladder, uterus and vagina, prostate, and rectum (Cleveland Clinic, 2020). Chronic PFD is the result of genetics, trauma, nerve damage, prolapse, inflammation, gastrointestinal disorders, vaginal delivery, sexual/physical abuse, or physical damage to the body (Manley & Odom, 2006). The term PFD refers to four groups: urological (cystocele, urethrocele, urinary incontinence), gynecological (dyspareunia, uterine prolapse, vaginal prolapse, enterocele, rectocele), colorectal (constipation, fecal incontinence, rectal prolapse), and biological (pelvic pain, levator spasm, proctalgia fugax, perineal descent) (Grimes & Statton, 2020).

Based on the National Health and Nutritional Examination Survey, at least one form of chronic PFD impacts 25% of women in the United States, which can be exasperated after vaginal childbirth, hysterectomy, physical injury, and disability (Wu, et. al., 2014). However, women are not assessed or diagnosed properly, which either delays

the treatment received or causes further complications, impacting psychological and social well-being (Smith & Witherow, 2000).

Depression is a common comorbidity diagnosis with PFD, because it can impact the ability to engage in daily living activities without restrictions, increases social isolation from family and friends, feel hopeless about the diagnosis, and creates financial stressors (Restorick-Roberts, et al., 2017). Women also report feeling anxious about the prognosis, are concerned and worry if the treatment(s) will improve HRQOL (health-related quality of life), feel isolated from others, and are overcome with feelings of loneliness, brokenness, and shame about chronic PFD (Skoczylas, et al., 2015).

Unfortunately, doctors are unable to address the psychological impact chronic PFD has on overall HRQOL, and are unable to address concerns regarding the diagnosis, because 7-10 minutes is typically spent on each patient and limits the ability to address these concerns (Huljev & Pandak, 2016). As a result, women also report not having enough education on proper medication management and lack of mental health services (Wagner, et al., 2001).

Women can experience a decline in mental health, due to the lack of services offered in rural communities and physical limitations (Callebaut, et al., 2017). Because 21% of those in the United States report finding their information on the internet, misinformation about mental health and PFD is found online, which can delay the services needed (Griffiths, et al., 2012). Healthcare costs, lack of access to service providers in rural areas, and limited counseling sessions determined by insurance companies are added stressors, which increases the difficulty of receiving appropriate healthcare. The financial cost of managing PFD is an added stressor, which impacts the

family system, as well. Those who have to travel outside of their local community's healthcare services are less apt to seek treatment, because of financial limitations and transportation challenges (Clark, et al., 2017).

The purpose of creating an online therapeutic support group program (OTSG) is to address chronic PFD, which includes addressing gaps of services in rural communities. Therapy and consistent medical care provide the support needed for women living with chronic PFD (Weihs, 2002). Therapeutic support increases communication, encourages modifications of daily activities, promotes resilience, incorporates coping skills, and introduces stress management. Self-care and health management requires familiarity of PFD and its symptoms, medication management and potential surgical options that are safe, collaboration with the medical team, and support from others (Martire & Helgeson, 2017).

An OTSG program providing mental health services for women diagnosed with PFD, by providing opportunities to focus on increasing communication and becoming an advocate for personal health, increasing emotional and spiritual support, and utilizing community resources to better cope with chronic PFD (Grassi, et al., 2017). Women with chronic PFD manage their daily life, in spite of physical limitations. However, women often feel isolated, unsupported, discouraged, report feeling lack of connection with family and friends, and report feeling marginalized within their communities (Mejias, et al., 2014). Learning to manage daily activities, balancing home responsibilities, maintaining relationships with family and friends, and relying on spirituality and faith, are goals for women in the OTSG program (Van Houtum, 2015). Women connecting

with others, who also are living with PFD will offer support and understanding, while also learning healthier ways to manage stressors.

Developing an OTSG program within a biopsychosocial-spiritual (BPS-S) framework addresses the whole person, to better manage living with PFD. Incorporating a BPS-S model will address the biological (genetics, physical history, diet), psychological (mental diagnosis, coping skills, stressors identified), sociological (cultural framework, support system, community support/services) and spiritual (beliefs, spirituality, prayer) factors for treating the whole person (Holthouse, 2016). The goals are to identify BPS-S factors, offer group counseling, identify ways to modify daily living activities, incorporate psychoeducation, and promote awareness to the community about the impact PFD, and educating the community about treatment options for PFD and discuss the therapeutic benefits for the OTSG program.

Living with chronic PFD is managed with proper tools, support, and therapeutic interventions, improving overall HRQOL. Trained LMFT's identify strengths and challenges for women in the program and encourages active engagement with one another. Through storytelling and personal reflections, women are strong advocates for their own healthcare, learn new coping skills, improve the management of daily living activities, and advocate for the care of others (Gucciadri, et al., 2016). The OTSG program helps women living in rural communities, who do not have access to mental health services, and are seeking medical treatment. Because women can feel overwhelmed with the lack of information about chronic PFD and are wanting to learn how to better manage living with the diagnosis, the program creates a bridge of support for women to connect with others and receive therapeutic support.

The Patient Protection and Affordable Care Act (ACA) helps women receive affordable care, despite having a pre-existing condition. However, there are not many service providers located in rural areas and lower income communities, requiring women to travel outside their areas for treatment (Clark, et al. 2017). Due to cost and lack of access to local service providers in the area, it is difficult for women to receive therapeutic services, such as: physical therapy, medication management, chiropractic services, counseling, acupuncture, and nutrition. Other factors contributing to lack of services and treatment are related to ethnicity, education, SES, the community, and belief systems (Weihs, et al., 2002).

Because 21% of Americans find information on the internet, misinformation about mental health and other health related issues found online can delay therapeutic interventions needed to improve HRQOL (Griffiths, et. al., 2012). Self-management is promoted as a cornerstone to healthcare in the United States, which means that women are required to monitor health symptoms, communicate with healthcare providers and advocate for treatment, oversee medication management, and manage household responsibilities and family responsibilities (Van Houtum, et al., 2015). These responsibilities, creates more stress because of the expectations women experience managing everyday living activities, while living with chronic PFD with inadequate support and lack of proper treatments. Research shows that women have difficulty recognizing and treating chronic PFD because of the physical energy it requires, the challenge of finding healthcare providers familiar with the diagnosis and management of symptoms and complications of living with PFD (Van Houtum, et al., 2015).

Currently, there are not any OTSG programs providing holistic care for women living PFD. However, there are in person programs, which utilize the BPS-S approach. For example, there is a healing centered approach designed to work with teens, who have been impacted by trauma. This approach incorporates spirituality, government and community activism, cultural identification, and healing (Ginwright, 2018). Rather than focusing on the “problem”, teens focus on ways to live beyond their trauma, becoming self-advocates and creating change within their communities. While not a BPS-S program, psychiatrists and Chinese medicine doctors also incorporate aspects of the BPS model. Psychiatrists utilize chiropractic services, and Chinese medicine doctors observe physiological and psychological factors, to better determine the root cause of the disease (Gordon, 1990).

A study in Argentina reports that an eHealth program provided successful, as it provided support and interventions to communities by health professionals, who are able to work directly with clients needing services to reduce unhealthy behaviors that increases risk factors contributing to CI (Olivares, et al., 2017). The study, conducted through River Plate Adventist University School of Medicine and in collaboration with the local primary health care system (PHC), to determine if an online program can help reduce the percentage of deaths related to chronic disease, which at the time of the study was 81% (Olivares, et a., 2017). The study began in a lower socioeconomically disadvantaged community, in the city of Diamante, from 2014 to 2015. A total of 1044 persons, including 679 women, enrolled in the study to measure lifestyle and health related issues (Olivares, et al., 2017). The online program consists of a website that clients can access to learn information regarding risk factors, ways to improve health, and

health awareness, to provide knowledge and practical tools to improve over health. However, the clients did not have access to a health provider.

In Australia, an online support group for those diagnosed with depression, participated in a study to determine the efficacy of an internet-based support group. A randomized trial conducted with 311 adults, between the ages of 18 and 65 years old, indicates depressive symptoms decreased after 3 months, 6 months, and 12 months follow-up (Griffiths, et. al., 2012). This study reports implications that a long-term online therapeutic support group are effective for women with PFD experiencing depression and anxiety, with psychoeducation, peer support, along with therapy utilized through a BPS-S lens and narrative therapy (NT). The control group records no change in depressive symptoms, and the group limited to only psychoeducation indicates depressive symptoms decrease temporarily. The group with therapeutic intervention shows a decrease in depressive symptoms, that continues to show a decrease through a 12-month follow-up (Griffiths, et. al., 2012).

At MD Anderson Cancer Center, in Houston, Texas, there is an integrative center that provides acupuncture, physical therapy, nutrition, therapeutic massage, and other services designed to help the overall health of the patient living with cancer (MD Anderson, 2019). Because health providers work collaboratively, the patient receives consistent medical and therapeutic treatment. It also removes the barrier of time and distance, as she does not need to travel to multiple locations to receive the various therapies in a holistic and cohesive environment, which helps improve overall HRQOL.

Women living with chronic PFD, who receive early intervention and a treatment plan, can improve overall HRQOL with the appropriate tools and support (Olivares, et

al., 2017). However, medical providers may not correctly diagnose mental illness, because the symptoms of CI, such as chronic PFD, are similar in symptoms, such as lack of energy, fatigue, impaired sleep and appetite, physical pain, foggy brain, and a decrease in energy (Turner & Kelly, 2000). Living with chronic PFD is a continuous balance of the physical and psychological challenges that occur, while managing everyday living activities (Van Houtum, et al., 2015). One third of those living with chronic PFD describe problems consisting of basic living issues such as an increase in unemployment, financial strains to pay medical bills, housing, and lack of social connections reducing coping skills and social support interventions (Van Houtum, et al., 2015).

Project Purpose

A biopsychosocial-spiritual (BPS-S) online therapeutic support group (OTSG) for women living with chronic pelvic floor dysfunction (PFD), addresses several needs for women, such as psychoeducation, emotional support, increased communication, and collaboration between health providers for overall healthcare, spiritual and emotional support, and utilization of community resources to better assist daily living activities (Grassi, et al., 2017). Understanding the importance of collaboration and not working in isolation, women can receive consistent and holistic healthcare treatment. Because this is not always possible, an OTSG program will offer therapeutic services within the comfort of the woman's home, while also addressing areas of support still needed. These groups can address expectations on managing family/home responsibilities and work, introduce healthy ways to live with PFD, address psychological and sociocultural stressors, and

incorporate spirituality as an essential component for the woman's overall well-being (Hatchett, 1997).

Identifying BPS-S factors provides support for the whole person and addresses the root problem: managing pelvic floor dysfunction and modifying daily activities to improve quality of life. Chronic PFD impacts relationships and the management of her disease, which is helped through therapy and consistent medical care (Weihs, 2002). Providing therapeutic support to the individual and family increases communication, encourages modification of daily activities, increases resilience, and incorporates coping skills and stress management. Incorporating a collaborative treatment plan with consistent treatment increases utilization of services, through online support counseling services, (Restorick-Roberts, 2017). Living with chronic PFD can be managed with the proper tools and support, which will improve her quality of life.

Chronic PFD impacts relationships, physical and mental abilities, and the management of daily activities, helped through therapy and a consistent medical care team (Weihs, 2002). Women with chronic PFD, who have difficulty accessing support services outside of their home (due to physical limitations), can benefit from a therapeutic OTSG program. Women often feel isolated, unsupported, discouraged from their lack of connection with family, and marginalized within their community (Mejias, et al., 2014). However, it can be managed with appropriate therapeutic services, medication management, and psychological support, which can improve overall HRQOL (Restorick-Roberts, et. al., 2017).

With access to the internet, mental health services are readily accessible for online support and individual therapy (Parsons, 2019). Providing an OTSG program increases

communication, encourages modification of daily activities, promotes resilience, incorporates coping skills, and introduces stress management, (Oravec, 2000). An OTSG program provides an opportunity to receive mental health services for women unable to access services outside her home, offers support and increases her support system, and improves communication with family, (Oravec, 2000). The OTSG program provides emotional support, which increases self-resilience, adaptability to stressors, modification of daily activities, offers a safe place to connect with others, and promotes advocacy and self-empowerment, in the comfort of her own home (Restorick-Roberts, 2017). Developing an online program allows women to receive mental health services, without having to worry about transportation, or physical limitations.

Because medical providers are trained to treat symptoms, rather than the root problem, the OTSG program may be helpful to address the whole person, within a BPS-S framework. The OTSG program connects others experiencing similar challenges, identifies ways to better manage living with chronic illness, addresses expectations and modifications for managing family/home/work responsibilities work, teaches healthier ways to live a productive life with chronic illness, addresses psychological and sociocultural stressors, and incorporates spirituality as an essential component for well-being (Hatchett, 1997). Identifying BPS-S factors provides support for the whole person and addresses the root problem: managing PFD and modifying daily activities to improve HRQOL, through an online platform (Restorick-Roberts, 2017).

Having a connection with God and receiving spiritual support is also an important tenet within the OTSG program. Incorporating spirituality components to a therapeutic program helps decrease symptoms of depression and anxiety, increases coping skills,

builds relationships, and provides comfort to women and their family support system (Pivarunas, 2016). Providing group therapy on topics of spirituality and wellness, are integrated into sessions. Prayer, meditation, Bible readings, and spiritual support provide comfort and hope, as she copes with pelvic floor dysfunction (Pivarunas, 2016). Providing therapeutic support increases communication, encourages modification of daily activities, promotes resilience, incorporates coping skills, and introduces stress management. An OTSG program helps identify support systems, strengthen family communication, incorporates faith, and increases spiritual support and connection, offers peer support and encouragement, while identifying ways to live beyond a diagnosis. In addition to financial cost and physical challenges, women living in rural communities have additional stressors, such as lack of access to service providers and therapeutic support services (Clark, et al., 2017, Weihs, 2002). Feeling unsupported, discouraged from lack of connection with family and friends, physical challenges limiting participation in church and community events, and experiencing marginalization within the community contribute to the psychological well-being of women living with chronic PFD, which can exasperate the physical symptoms of the condition (Mejias, et al., 2014).

Women living with PFD in rural communities can benefit from an online therapeutic support group program, due to limited access to medical providers and therapeutic services, physical limitations, transportation challenges, and financial difficulties. In addition to medication management, an OTSG program can improve overall HRQOL by offering psychological support, psychoeducation, and connection with other women also living with PFD (Restorick-Roberts, et al., 2017). Utilizing the BPS-S framework, tenets of NT are used to provide the foundation for an OTSG program

focused on helping women better manage daily living activities, offering the tools to maintain healthy relationships, increasing communication and self-advocacy to collaborate with medical providers, promoting resilience, and learning to manage the challenges living with PFD.

Vision and Mission Statement

Pathways for Healing's OTSG program's vision is empowered women creating change in their personal lives and communities. Our mission is to provide online therapeutic support group services and integrative healthcare to educate, empower, and support women living with chronic PFD. This program allows homebound women access to services unavailable to them, due to travel, finances, and inability to leave home. The OTSG program provides emotional support increases self-resilience, adaptability to stressors, encourages modification of daily activities, provides a safe place to connect with others, and promotes advocacy and self-empowerment, in the comfort of the participant's own home (Restorick-Roberts, 2017).

The program objectives are to provide therapeutic support to increase communication, encourage modification of daily activities, promote self-resilience, incorporate coping skills, and introduce stress management. Additional objectives are to identify support systems, strengthen family connections, improve communication, and collaborating with health providers offers women hope and encouragement that there is life beyond diagnosis. The goals for the OTSG program are to identify biopsychosocial factors, provide group counseling, identify ways to modify daily activities, incorporate psychoeducation, and promote an advocate awareness initiative about chronic PFD and

its impact on women and families. The OTSG program connects others experiencing similar challenges, identifies ways to better manage living with chronic PFD, and addresses expectations and modifications to managing family, home, and work responsibilities. The program, Pathways for Healing, teaches healthier ways to modify daily living activities, identify and offer support based on psychological and sociocultural stressors, and incorporate spirituality as an essential component for overall HRQOL (Hatchett, 1997). With access to the internet, participants receive online support groups and support from a mental health therapist: 1) licensed marriage and family therapist (LMFT) or licensed marriage and family therapist associate (LMFT-A) and a pelvic floor physical therapist (PFPT) or a physical therapist student (SPT).

The OTSG program will have meetings once a week, for 12 weeks, scheduled at various times and days throughout the week, for women living with chronic PFD. Pathways for Healing addresses several needs: psychoeducation, emotional support for her and her family, peer support, increasing communication and collaboration with health providers, and utilizing community resources to better assist her daily living (Grassi, et al., 2017). The program connects others experiencing similar challenges, identifies ways to live with chronic illness, addresses expectations and modification to managing family, home, and work, teaches healthier ways to live a productive life with chronic PFD, addresses psychological and sociocultural stressors, and incorporates spirituality as an essential component for well-being (Hatchett, 1997).

Utilizing an integrative and therapeutic model helps women receive comprehensive care, by addressing the root problem and the impact chronic PFD has on women, which can identify ways to adopt modification of daily activities can be

implemented to improve quality of life through services provided online (Restorick-Roberts, 2017). Pathways for Healing addresses several needs through psychoeducation, emotional support, increasing communication and collaboration between health providers, and utilizing community resources (Grassi, et al., 2017). The support groups address expectations on managing family/home responsibilities and work, healthy ways to live a productive life with chronic PFD, working through psychological and sociocultural stressors, and incorporating spirituality as an essential component for well-being, are all important tenets of the program (Hatchett, 1997).

The objective is to provide online support to women, who have chronic PFD. The goals are measured through assessments prior to women beginning the program (pre-pre-test and pre-test), at the 6th week and 12th session, and 3-months and 6-months after program completion. The program will provide specialized training for therapists, including the necessary steps for the OTSG program, and the curriculum used for health members and caregivers. The specific activities outlined describe the program's four key interventions and specific activities for online support, which includes advocacy and awareness.

There are three phases to the OTSG program, designed to improve overall HRQOL. The first phase includes working with urologists, urogynecologists, gynecologists, and pelvic floor therapists, who work with women living with chronic PFD. Women are informed of the study by their medical specialist, and given more information about the study, should they decide to participate. Because it is completely voluntary, and women can decline to participate at any time and may discontinue during the program. While women will be referred by their medical specialist doctors, the OTSG

program is independent and not affiliated with any particular hospital and women do not need to be affiliated with any particular medical system.

Women sign the consent form document and take pre-tests: The Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-SP), Pelvic Floor Impact Questionnaire-Short Form 7 (PFIQ), Pelvic Floor Distress Inventory-Short Form 20 (PFDI-20), Beck Depression Inventory-II (BDI-II), and RAND 36-Item Health Survey (SF-36), to identify women's emotional, spiritual, and physical needs, and overall HRQOL. The Clinical Liaison meets with health care providers, medical facilities, homeopathic centers, hospitals, spiritual leaders, and holistic providers, to establish a partnership and increase opportunities for collaboration, (Fields, 2019). This allows for healthcare providers to understanding the importance of working together, for women to receive integrative care and increase consistency of care, while also helping women self-advocate to medical specialists.

Phase two consists of women being placed into a group, that is limited to 10 participants per group session. During the first six sessions, the OTSG program identifies concerns women have and offers an opportunity to meet other women who understand the challenges of daily living with PFD. Utilizing a BPS-S theoretical lens, while incorporating NT tenets encourages women to discuss health challenges, share concerns regarding wellness and life, and identify and build strengths and coping skills, (Heggdal, 2015). The OTSG program encourages women to apply self-care with tools to manage chronic illness, to improve health and healing, (Heggdal, 2015). The OTSG program offers a curriculum that provides education about living with chronic PFD, disease management, coping with identified stressors, and improving mental health (Shapiro,

2002). Women will also learn new stress management strategies and identify ways to manage daily activities. At the end of session six, participants take post-tests: The Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-SP), Pelvic Floor Impact Questionnaire-Short Form 7 (PFIQ), Pelvic Floor Distress Inventory-Short Form 20 (PFDI-20), Beck Depression Inventory-II (BDI-II), and RAND 36-Item Health Survey (SF-36), to identify if there has been improvement in women's emotional, spiritual, and physical needs, and overall HRQOL.

The second section in phase two consists of sessions 7 through 12, which will address ways to better manage PFD, improve overall HRQOL. This is achieved through identifying individual strengths, spirituality beliefs, emotional and physical symptoms, barriers based on socioeconomic and cultural factors, and offers psychoeducation to be a self-advocate for healthcare, (Koithan, et al., 2007). Receiving emotional support and psychoeducation regarding chronic PFD will learn how to manage daily living activities to improve overall HRQOL. Discussing relationship challenges is also addressed, with women identifying concerns and strengths within the relationship, incorporating ways to improve communication, and encouraging application of healthy lifestyle choices for improved health, (Shields, 2012). The group members will encourage active engagement with one another and provide opportunities to share their fears and concerns. Through storytelling and person reflection, women identify strengths and become more knowledgeable about disease management, are a stronger self-advocate for healthcare and personal/work responsibilities and improve communication with relationships (Gucciadri et. al, 2016). At the end of week 12, participants will take post-tests, and follow-up with post-tests at 3 months and 6 months to determine if there is an

improvement in overall HRQOL: The Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-SP), Pelvic Floor Impact Questionnaire-Short Form 7 (PFIQ), Pelvic Floor Distress Inventory-Short Form 20 (PFDI-20), Beck Depression Inventory-II (BDI-II), and RAND 36-Item Health Survey (SF-36), the Check-In, Check-Out Oral Report (CICO), and the Survey for Participants.

The third phase consists of the aftercare program, after the twelfth session, where women participate in the Sisterhood Ambassadors Program, offering support, awareness, and opportunities for advocacy in their community. Through social media campaigns, print and radio advertisements, television ads, and educational forums, awareness of pelvic floor dysfunction awareness. Women are identified as Sister Ambassadors, building an advocacy group to educate others about living with PFD, and sharing testimonies through active involvement within their communities and social awareness campaigns and local events, (Pumar et.al, 2017).

Group Values

Facilitators utilize best practices that are ethically sound according to their licensing standards, which serve as key principles and values that form the foundation of the support groups: (1) Respectful: Providing a safe and secure space that is dignified and non-judgmental, (2) Education: Promotes psychoeducation, awareness about chronic PFD and the impact it has on women, families, and the community, and self-advocacy, (3) Confidentiality: Maintaining ethical standards, to encourage participation, and promote empowerment, (4) Equal Accessibility: Fair access to services provided, regardless of sexual identity, gender identity, race, ethnicity, religious affiliation, socio-economic

status, and insured/uninsured, (5) Accountability: Providing supervision and monitoring support groups to ensure zero tolerance of bullying, social isolation, hostility towards group participants, and promoting positive support and advocacy, and (6) Research-Evidence: Governance and accountability through assessment forms, screening, and data collection.

There are five key functions to manage the online support groups, managed by facilitators are: 1) organization, 2) support, 3) safety, 4) sociocultural awareness, and 5) ethics and confidentiality. The first function is organization of the support groups, which are the responsibilities for the facilitators to oversee each week. This includes set-up and technological assistance for online participations, preparation of materials utilized in group and online availability for dissemination, and ensures participants have access to mobile devices. Organization also includes explaining the necessary group rules, managing the group format, and providing structure to stay within the scope of the group goals and providing a safe space for full disclosure from participants. The second function is providing support by encouraging participation, validation, and respecting personal experiences, recognizing the needs and experiences of group members, staying up to date on resources and services to further assist participants outside the scope of group, and addressing misconceptions and stereotypes of women living with chronic pelvic floor dysfunction. The third function is safety, which ensures the group participants are able to process their experiences in an environment that is safe and respectful. While the groups are held online, facilitators are still required to offer a safe and secure environment, utilizing a HIPAA compliant software, and offering groups in a

location that is private and quiet. Therefore, facilitators are not able to host the support groups in libraries, coffee shops, or areas where there is a lot of noise and foot traffic.

Facilitators are also mindful of risk assessments to ensure suicidality is determined at each session, with referrals and crisis intervention offered by a therapist and services in their area. The fourth function is providing sociocultural awareness and diversity, which ensures all participants are offered access to participation and equal participation, regardless of sexual and gender identify, race, ethnicity, religious identify, and level of severity with chronic pelvic floor dysfunction. Providing support groups that are respectful and considerate to women living with chronic pelvic floor dysfunction includes providing fair access and diversity, that is anti-discriminatory and welcoming without prejudice and barriers. The fifth function of the support group is ensuring confidentiality is upheld and maintained at all times with participants. The facilitators are responsible for ensuring electronic and hard copy files and information are properly stored, confidentiality agreements are stored, and that participants are reminded of the confidentiality agreement before each session begins. It is also important for facilitators to remind participants of the limits of confidentiality, which are found within their consent forms.

The OTSG program is available to women who live in the state of Texas, regardless of religious affiliation, ethnicity, race, and SES backgrounds. Women, who are biological females and diagnosed with chronic PFD, are referred by their urologist, gynecologist, urogynecologist, pelvic floor therapist, and primary care doctors, will be eligible to participate in the OTSG program. Women aged 18 and up and either speak English or Spanish will qualify to participate in the program. Women diagnosed with

chronic PFD, who may experience bladder pain, neuropathy, bladder leakage, kidney and/or bladder infections, antibiotic resistance, sling erosion, surgical complications from sling placement, and disability (Ordorica, et al., 2008). Because of medical illness and physical disability, it can be difficult for women to leave their home for support groups that are not nearby, due to living in rural communities. Online support groups are easier to access, regardless of physical challenge or financial readiness. Women are referred by their medical provider, who is typically their urologist, gynecologist, urogynecologist, pelvic floor therapist, and primary care doctors. Due to state laws, the OTSG program will be limited to women living in Texas, with primary consideration for women living in rural communities. Women, ages 18 through 65 years old, are eligible for the program and those who speak English and/or Spanish will qualify for the program. Because the program is online, women will be required to have access to internet services and have a mobile device to log on for support group attendance.

Women, under the age of 18, are not eligible for the OTSG program. Women not diagnosed with chronic PFD are ineligible. Men and non-biological females are ineligible for the program. Women not working with a medical provider, are ineligible. Because the program is spiritually focused, those uncomfortable or not wanting to participate will also be ineligible. Women, who do not have access to internet services or have a mobile device, will be ineligible at this time. Women, who have severe depressive issues and suicidal/homicidal ideations, will be ineligible for the program, and will be referred to mental health professionals in their area. Women unable to commit to the program, for the duration of the support groups will be ineligible. Women, who move out of state or are unable to access internet services, will also be ineligible.

While there are many formats for support groups, the OTSG program offers closed groups, which means members will be screened for eligibility, offered a link with password access to the group site, and new participants may not join an existing group once it begins (Chang, et al., 2003). The OTSG program will offer synchronous participation, allowing group members to interact simultaneously with a licensed marriage and family therapist and pelvic floor therapist. Women know who the other participants are, as the same group meets each week. This will encourage communication, offer safety and familiarity with same group members, and consistency. Because there will be many meetings that begin each week, new participants will have adequate time for pre-screening, pre-test, and receiving information about the program.

The OTSG program uses an open recruitment and engagement process that will add women to the study every week, for the duration of the program. Based on the current program census demographics, based on the inclusion and exclusion criteria, there is an expected 60% of participants who will qualify. Women will sign the consent form document and take the pre-test. A reduction in attrition rates is achieved through the post-test format, which consists of updating phone numbers, emails, and contact information, to follow-up with the participants. The researchers and therapists continue to maintain close contact with the medical specialists and reach out to the women for holidays, birthdays, and special occasions to encourage close contact and improve relationships with the participants. The Clinical Liaison and Research Assistant access the patient's medical file, which is utilized to improve and update information, as needed for each participant.

Prior to being assigned to a group, women answer a questionnaire to determine if PFD has been determined and identify social support systems, cognitive functioning, depression and anxiety symptoms, physical limitations, health issues related to PFD, family issues, and limited daily activities. This information will determine severity of issues and concerns, and which group the participant will benefit most from. The participant will also identify language preferred: English or Spanish, as the groups will be available in both languages. The group meetings will include psychoeducation, address medical challenges, and offer support for its participants.

Prior to completing the pre-test, a consent form (Appendix B) will be provided to the potential participant, with the form being read and questions about the consent form answered by the Clinical Liaison. The consent form is strictly confidential, as medical staff and therapists administer the tests will adhere to HIPAA regulations. Typically, the PFDI-20 & PFIQ are administered prior to bladder surgery, 3 months, and 6 months post-surgery, however it will be used to determine program eligibility for the OTSG program (Barber, et. al., 2005). The instruments are administered by paper and pen, and reviewed for consideration of admittance into the program, along with the consent form.

Data collected will consist of questionnaires, surveys, and results from assessment tools. The first step of the program is determining eligibility. Two assessment instruments are used and administered by the referring doctor. The Pelvic Floor Distress Inventory (PFDI-20) and the Pelvic Floor Impact Questionnaire (PFIQ) contain 20 questions and 3 scales: urinary distress inventory, pelvic organ prolapse inventory, and colorectal anal distress inventory, which is measurable tool to determine how PFD has impacted the health member's quality of life, (Barber, et. al., 2005).

The measures utilized will determine if the OTSG program improves overall (HRQOL) for women with pelvic floor dysfunction (PFD), a form of chronic illness (CI). Depression is a common comorbid diagnosis with PFD, because it impacts the ability to engage in daily living activities without restrictions, increases social isolation from family and friends, feel hopeless about the diagnosis, and creates financial stressors (Restorick-Roberts, et al., 2017). Comparing pre and post-tests utilizing the RAND 36-Item Health Survey (SF-36), Beck Depression Inventory-II (BDI-II), and FACIT-SP will show if there is a significant decrease in depressive symptoms and increase in overall HRQOL. In addition to the assessments, CICO (provided after each group session) and a Survey for Participants (provided after the 12th group session) will be administered. Information from 60% of participants, with 80% of the responses completed, will provide enough data for a robust sample. Participants will have the opportunity to talk to the Lead Therapist by phone or a HIPPA regulated video platform, such as Doxy.me, paper/pen answer, or answer via computer.

Group Rules

Rules are used to provide group interaction that is safe and respectful, offers stability within the group, supports group goals, and establishes communication that is mutual, respectful, and ethical. This process involves group participants in the development of group goals is important, as it helps everyone feel valued and engaged in the beginning process. It also motivates participants to follow the group rules and is the first group activity that everyone can engage in. Some questions to ask are: 1) What will help you fully participate in group? 2) What would make it possible for you to share

about personal experiences? 3) What would prevent you from expressing yourself? 4) What do you think will help you feel safe in our group?

As each participant helps create the rules, the facilitator writes the rules down on the chat box, which are then forwarded to each member to agree and sign. The rules are to remain present each week, for reminders and to help keep participants accountable to the group process. While the group will develop their own rules, it is important for the facilitator to consider these as part of the rules:

- (1) Give everyone an opportunity to speak. Each person should avoid dominating the discussion, including the facilitator.
- (2) Active listening is important, which includes not muting oneself, not hiding profile, avoiding communication with family members and others not in group, and not answering calls or texting.
- (3) Be respectful of others, and not interrupt when others share or minimize other's experiences.
- (4) Be honest without sharing names of doctors and medical facilities that may not have been helpful.
- (5) Confidentiality is crucial, and any personal information share in group should not leave group, without express consent.
- (6) Consistent attendance is important, staying for the full meeting and not leaving early, being disruptive by answering calls or texts, and by being respectful of others sharing.

Most of the time, participants will adhere to the agreed rules, and will be supportive and cooperative towards each other. Unfortunately, there are exceptions when, intentionally or not, a participant may break the established group rules. If this happens, the facilitators should clearly indicate as soon as the violation is noticed and use effective

techniques to resolve it. Repeated violation of group rules is best solved with one-to-one sessions to discuss the meaning behind the behavior and try to come to an agreement on how this can be worked through. To maintain the integrity of the support group, sometimes participants may be better suited in another group or be better suited in individual therapy.

Process and Outcome Objectives

The measure of success is comparing pre-tests to post-tests after the 6th session, 12th session, 3 months, and 6 months post completion of the program. The OTSG program's success is based on multiple factors. One factor is that 80% of therapists are trained properly and receive specialized therapeutic skills for chronic PFD, with 20% of therapists unable to complete training, unwilling to learn integrative care and chronic PFD challenges, or those who drop out of training prematurely. Another factor for the successful completion of online therapy support is group participation. Women attend 80% of weekly support groups, develop coping skills and stress management techniques, decrease depressive symptoms, increase overall HRQOL, and decrease in PFD symptoms. A 20% adjustment is considered for participants unable to complete the OTSG program, discontinue medical care with the referring provider, move to another state, have other health issues that complicate attending group meetings, and/or have difficulty accessing internet and wi-fi capabilities.

The outcome objectives for the OTSG program are for therapists to have increased knowledge and skills to work with women living with chronic PFD. Together, the therapist and group participant develop a healthcare plan that identifies the

biopsychosocial and spiritual stressors impacting overall HRQOL. Women receive psychosocial support online with other women living with chronic PFD, attending weekly support group meetings facilitated by a licensed marriage and family therapist (LMFT) or licensed marriage and family therapist associate (LMFTA-A), and a pelvic floor physical therapist (PFPT) or a physical therapist student (SPT). At the conclusion of the support groups, women can transition to an aftercare support group, becoming Sister Ambassadors and participating in advocacy and awareness initiatives. Through grants and private donations, the OTSG program is free and/or low cost, so that women can focus on healthcare without limitations of traveling and financial costs.

Online support groups for the woman and caregiver, teletherapy services, and advocacy awareness provide the support needed, promotes education about chronic PFD and advocates for women's health in the communities' women represent. Bringing awareness to these challenges and presenting options, women are able to make decisions about their health with more information. Those who do experience chronic pain, illness, and depression, can receive services tailored to better manage her health and lifestyle through a referral program. Providing hope and support will help her know she is not alone and give her the tools needed to manage daily activities and remain connected with loved ones.

The group format encourages and promotes beliefs that recognize individual strengths, encourages independence and self-advocacy, offers respect and dignity, and empowers each group participant. In order to create an empowering atmosphere within the support group, the facilitator is non-judgmental, empathetic, and supportive while promoting skills learned in group. The primary facilitators are LMFT's and PFPT's. The

support facilitators are licensed pelvic floor therapists, offering support services and are co-facilitators for group sessions. Therapists have the necessary qualifications in the state of Texas, to facilitate support groups, receive a 30-hour training by the primary creator of the support group program, and are able to continue to receive monthly training and support for the program. Group facilitators receive education and training in: 1) systemic thinking, 2) chronic illness, 3) chronic pelvic floor dysfunction, 4) diversity and social location, 5) group facilitator skills, 6) group therapy basics, 7) counseling skills, 8) physical therapy, 8) integrative therapy and medicines, and 9) familiarity with co-morbidities, such as depression and anxiety.

A licensed marriage and family therapist and pelvic floor therapist will co-facilitate the support groups. The role of the facilitators is to be actively engaged, provide the format for open dialogue, offer support, instill hope, and teach new coping strategies to better manage living with chronic PFD (Chelvanavagam, et al., 2007). Both facilitators are well-informed about acute and chronic PFD and are familiar with therapies to manage related symptoms. Another role is to help group members connect online, assist with basic technical challenges, offer psychoeducation based on each topic, answer questions as needed, navigate the group process, and address any issues between members (Chang, et al., 2003).

Facilitators have knowledge in the following areas to oversee support groups for women living with pelvic floor dysfunction:

- Physiological understanding of pelvic floor dysfunction.
- Psychological, spiritual, and social understanding of the impact pelvic floor dysfunction has on women and their families.

- Treatment protocols, including mediations, natural supplements, therapies, and management of pelvic floor dysfunction.
- Implementation of skills for support group: listening skills, promotion of self-advocacy and awareness, confidential communication, personal and professional boundaries, crisis intervention skills, medical treatment planning and collaboration with medical team, appropriate documentation, and preparation for support group meetings.
- Develop and implementation safety plans, referral options, and identification of potential crisis situations, suicidality, and suicide assessments for referrals.
- Identify the negative effects pelvic floor dysfunction has on women and ways to lessen the impact it has, while also promoting self-advocacy for medical and treatment care.
- Understand the influence and perspectives women have based on culture, ethnicity, race, religion, gender identity, and sexual identity.
- Understand the challenges women having living in rural communities, including the limitations and ease of access to health care services and knowledge of community demographics to offer additional support services as identified.
- Adherence to AAMFT Code of Ethics and CITI Human Subjects Training Certifications in Biomedical/Social-Behavioral Research Investigator and Good Clinical Practice and ICH at <https://about.citiprogram.org>.
- Promotion of self-care and self-advocacy, while also advocating for other

women living with pelvic floor dysfunction.

Facilitators possess group management skills, communication skills that are able to express effectively verbally, written, and provide body language that is reflective of what is being said. Utilizing active listening skills, facilitators respond empathetically and are able to handle challenges that may arise in group sessions. The facilitators uphold ethical and legal obligations pertaining to their licenses and AAMFT Code of Ethics. This includes providing professional boundaries and not getting personally involved with the women's lives, offering off-site counseling, and medical advice. Evaluating the effectiveness of the program and reporting the outcomes will impact the way the groups are structured and facilitated. Facilitators have experience working in a group setting, are able to plan and facilitate group work, have basic understanding of the internet and word processing, and can assist participants with simple technological issues that may prevent active participation.

Each support group will consist of one pelvic floor therapist and one licensed marriage and family therapist. The co-facilitators of pelvic floor dysfunction support groups have a primary role to ensure sessions are safe, supportive, and inclusive. Co-facilitators are trained within their respective field of pelvic floor therapy and licensed marriage and family therapists. Facilitators utilize their skills, experience and knowledge about pelvic floor health, families, and systems, as well as understanding group dynamics, and assisting participants to maintain group cohesion, respect, and stability. Because the support groups are tailored for biological women, the facilitators are women, who can provide support and understanding, while also helping the participants be comfortable in the group setting. This helps to avoid the unconscious or conscious

repetition of the male/female power imbalance that can be evident in relationships based on sociocultural expectations and roles. Female led support groups empower women through the example of female leadership and, in this case, female co-group facilitators.

Both facilitators focus on the strengths and capabilities of women and in their abilities to change, adapt and discover better solutions to their problems. Facilitators encourage participants to share about their experiences regarding living with pelvic floor dysfunction, create discussions that improve self-esteem, build support, and trust, and validate the experiences of each participant. Participants will be helped to better understand chronic pelvic floor dysfunction, while also learning about support services available in their communities. Through the use of assessment tools, facilitators will determine efficacy of the program and provide useful information to improve support groups.

Weekly Manual: Support Group Themes and Activities

Meetings are held once a week, for 12 weeks. Each meeting consists of 90 minutes to allot for adequate time for check-ins, assessments, joining, and engagement. Below are the weekly meetings with activities and group format.

Overview of Session Outlines: Schedule for 90 minutes:

- I: 1-15 minutes: **Goals for Session:** Goals designed to align with each weekly topic, which support the group participants living with chronic pelvic floor dysfunction.
- II: 16-20 minutes: **Check-In:** Group facilitators ask each participant to give brief update on how their week went, and any challenges and issues that can disrupt the flow of the session. Group rules are established by participants with guidance from facilitators.
- III: 21-45 minutes: **Learning and Topic Discussion:** Facilitator's share psychoeducational support and encourage discussion to help participants attach meaning and connection to their own personal experiences. It also allows for group support as participants learn from each other's experiences and integrate their own stories with new information about chronic pelvic floor dysfunction.
- IV: 46-70 minutes: **Activities:** Activities can be discussion related to the weekly topic, working on a hand-out, or exercise that encourages learning, self-discovery, and life application.

These activities also help participants practice self-care and learn new coping strategies.

V: 71-90 minutes: **Check-Out:** This is a time for participants to wrap-up, bring closure to the meeting, and transition back to their everyday living activities. This gives an opportunity for participants to offer a brief comment after group discussion and each take turns stating one way self-care will be implemented that week. Resources are also provided that can be useful to group participants and also to provide a bridge to support group and community services.

***During weeks for assessments, after the 90-minute session, assessments will be administered.**

Weekly Curriculum

Week 1: Theme: Living with Chronic Pelvic Floor Dysfunction

Pre-Test: Administer pre-tests prior to beginning of group. This can be done before group begins, up to the day of group, before the first session.

- ⇒ Facilitators explain group will be asked to complete a pre and post-test throughout the duration of the support group and couple of times afterwards (3 months and 6 months post-test).

Goals for Session:

- ⇒ To begin development of a safe group environment for women living with chronic pelvic floor dysfunction can become empowered and learn to live with a form of chronic illness.

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: "My name is _____ and what I hope to achieve in this group today is _____".
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.
- ⇒ Inform participants the group is voluntary, and each have the choice to provide as little or as much information about themselves and their condition throughout the entire group process. Being respectful of participants, who choose to not participate with an activity or an answer, and modeling setting boundaries as part of the learning process.

Learning and Topic Discussion:

- ⇒ Describe difference between acute and chronic pelvic floor dysfunction
- ⇒ Identify ways to treat pelvic floor dysfunction and how each week, some coping skills

will be addressed

- ⇒ While discussing this, address how difficult emotions and past experiences may be triggered in the weekly groups and brainstorm ways the group can handle these reactions during and between group sessions. Remind participants to not offer advice on what the other participant should do, but to use “I” statements on what has been helpful.

Activities:

- ⇒ Ice Breaker: Participants introduce name, where they live, identify a favorite dessert, and a cultural tidbit about their family.

Check-Out:

- ⇒ Ask what surprised them most about their first meeting.
- ⇒ Provide participants with 24-hour crisis hotline, crisis text line, and have space for each participant to fill in the numbers and contact information of their medical team.

Week 2: Theme: Stress Management

Goals for Session:

- ⇒ To incorporate ways to decrease stress and maintain a healthy emotional, physical, and spiritual life.

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: "My name is _____ and what I hope to achieve in this group today is _____".
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Learning and Topic Discussion:

- ⇒ Emotional regulation-when participants have an emotional response, it is important to identify it, recognize it, and address it. Accepting emotional responses to situations help to decrease intensity, rather than rejecting it and replacing it with fear.
- ⇒ Emotional regulation is one way to practice self-care, which helps manage stress.
- ⇒ Identify ways to reduce stress management: 1) proper exercise, 2) balance nutrition, 3) sufficient quality and quantity of sleep, 4) preventative and ongoing medical care, 5) resting when not feeling well and modifying daily living activities, 6) learn a new activity/hobby or make time for an existing one, 7) utilize strong network of support that consists church attendance and Bible studies, and 8) utilizing resources for support and stress management, 9) being mindful of community services and unity, and 10) understanding personal beliefs and values that guide decision making and roles in relationships.

Activities:

- ⇒ Self-Care Wheel (see Figure 1): Break into smaller groups to discuss ways participants are currently practicing self-care and what can be incorporated. Return to large group to have overall discussion.



Figure 1. Self-Care Wheel. This figure is based on the physical, psychological, emotional, spiritual, professional, and personal ways to balance life. Retrieved from www.OlgaPhoenix.com.

Check-Out:

- ⇒ Ask each participant what they hope to incorporate as part of self-care for the following week. Invite participants to make final comments and summarize what was helpful and not helpful.
- ⇒ Provide list of resources in their community that can contribute to self-care.

Week 3: Theme: Modifying Daily Living Activities

Goals for Session:

- ⇒ Identify and explore adaptations for daily living activities (see Table 11).

Check-In:

- ⇒ Review group rules. Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Learning and Topic Discussion:

- ⇒ Physical health can impact emotional and spiritual health when living with chronic pelvic floor dysfunction.
- ⇒ Discuss how daily living activities have been impacted with chronic pelvic floor dysfunction and what challenges and accomplishments have been made.
- ⇒ Discuss ways family and community supports these modifications and ways it can improve.
- ⇒ Identify how cultural beliefs and traditions can limit and support modifications of daily living activities.
- ⇒ Learn about resources that are available and how to ask for help from family, friends, church, and community services.

Activities:

- ⇒ Identify each section in the worksheet to recognize which activities can be accomplished independently and which ones need assistance/modification.
- ⇒ Break into groups to discuss ways to modify and encourage family support. Return to large group to discuss 1-2 sections that changes can be focused on before next session.

Table 11. Checklist of Activities of Daily Living.

FUNCTION	INDEPENDENT	NEEDS HELP	DEPENDENT	DOES NOT DO
Bathing				
Dressing				
Grooming				
Oral Care				
Toileting				
Transferring				
Walking				
Climbing Stairs				
Eating				
Shopping				
Cooking				
Managing Medications				
Using the Phone				
Housework				
Doing Laundry				
Driving				
Managing Finances				

Note: This table determines daily living activities and ability level. Retrieved from: [pbs.org/caringforyourparents](https://www.pbs.org/caringforyourparents)

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to evaluate current self-care activities related to daily living and identify where changes and modifications can be made.
- ⇒ Each participant lists 1-2 ways modifications will be made and how it will help.

Week 4: Theme: Nutrition and Natural Supplements

Goals for Session:

- ⇒ Understand factors that support integrating nutrition, natural supplements to compliment traditional medical treatment (see Figure 2).

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Learning and Topic Discussion:

- ⇒ Identify different types of therapies (homeopathy, Ayurveda, naturopathy, traditional Chinese medicine, juicing, massage, chiropractic care, and nutrition).
- ⇒ Discuss ways that the mind, body, and spirit need balance and how it looks differently for everyone.

Activities:

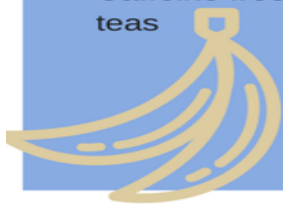
- ⇒ Break into small groups and have participants discuss supplements and natural remedies that have been helpful.
- ⇒ Discuss ways each would like to incorporate some new therapies discussed, including nutrition and ways to minimize discomfort and issues through nutrition.
- ⇒ Bring back into large group to give general discussion of ways each plan to incorporate or address one need for the following week.

Do's & Don'ts

What to eat for a healthy pelvic floor:

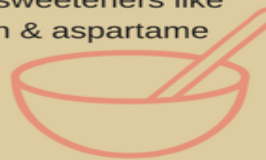
Pelvic Floor Dream Team:

- Pure water
- Low-acidic fruits like apricots, bananas & melons
- Omega-3 fatty acids
- Caffeine free herbal teas



Pelvic Floor Foes:

- Caffeinated beverages
- Carbonated beverages
- Acidic fruits like tomatoes, cranberries & oranges
- Spicy foods
- Artificial sweeteners like saccharin & aspartame
- Alcohol



An effective pelvic floor friendly diet comes with moderation of the good and bad.

For more information visit: <https://urogyn.coloradowomenshealth.com/blog/pelvic-floor-diet>

Figure 2. Do's and Don'ts: What to Eat for a Healthy Pelvic Floor.

Retrieved from: <https://www.urogyn.coloradowomenshealth.co/blog/pelvic-floor-diet/>

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to evaluate the chart and add one way they will practice self-care through nutrition.

Week 5: Theme: Integrative Medicines and Therapies

Goals for Session:

- ⇒ Learn new therapies that complement traditional medical care.

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Learning and Topic Discussion:

- ⇒ Break into small groups and have participants review ways they can incorporate self-care looking at physical, spiritual, lifestyle, mental/emotional, and support from family, friends, and community (see Figure 3).
- ⇒ Discuss ways each would like to incorporate some new therapies discussed, including nutrition and pelvic floor therapy.



Figure 3. The Goals to Feeling Vital, Balanced, and Free from Depression and Anxiety. Retrieved from: <https://slidetodoc.com/trauma-informed-practices-working-with-children-and-adolescents/>

Check-Out:

- ⇒ Identify one way in which the session was helpful or not helpful. Evaluate the chart and add one way they will practice self-care through nutrition.

Week 6: Theme: Family Roles, Responsibilities, and Rules

Goals for Session:

- ⇒ Explore ways to offer support to one another, adapting family responsibilities and expectations, while adjusting responsibilities to be more helpful to women living with chronic pelvic floor dysfunction.

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Learning and Topic Discussion:

- ⇒ Culture impacts family roles, responsibilities, and rules in the home regarding home/work/and community.
- ⇒ Supportive family, friends, and community can help with modification or daily living activities, responsibilities, and roles.
- ⇒ Setting time aside to discuss concerns with family and support system to discuss ways to improve balance, not isolating and doing responsibilities alone, as well as making time for self-care (see Figure 4).

Activities:

⇒ While the article below pertains to chronic fatigue syndrome, many women living with pelvic floor dysfunction can relate to some of the comments below. In smaller groups, participants will reflect on which ones most apply to their family roles and rules and how cultural identity applies to some of those beliefs. Afterwards, in a larger group, discuss what was most impactful and ways to apply something new to their family system the following week.

25 THINGS
 You want your friends and family to know

1. UNDERSTAND THAT IT IS THE PAIN THAT LIMITS ME FROM BEING ABLE TO BE ALL MY CHILDREN NEED AS A PARENT! DIRECT YOUR ANGER AT THE CRPS INSTEAD OF ME.

2. WE ARE NOT EXAGGERATING THE PAIN.

3. COPING WITH CHRONIC PAIN LEAVES ME DRAINED MENTALLY, EMOTIONALLY AND PHYSICALLY EVERY DAY.

4. I NEED YOUR HELP AND SUPPORT TO GET THROUGH THIS.

5. I TRY AND SHIELD YOU FROM HOW BAD THE PAIN REALLY IS.

6. I HATE BEING A BURDEN TO MY FAMILY.

7. THAT WHEN YOU HAVE TO SAY THE SAME THING TO ME TEN TIMES A DAY, IT'S NOT BECAUSE I WASN'T LISTENING BUT BECAUSE CRPS REALLY AFFECTS MY MEMORY.

8. CRPS IS REAL!

9. I REALLY APPRECIATE THE FACT THAT YOU HAVE STOOD BY ME AND NEVER DOUBTED MY FEELINGS FOR A SECOND; EVEN WHEN THE DOCTORS TOLD ME IT WAS IN MY HEAD.

10. MY FAMILY IS VERY SUPPORTIVE, BUT I WANT YOU TO KNOW IF I SOMETIMES GET IRRITABLE AND SNAP AT YOU, IT'S THE CRPS PAIN TALKING AND NOT ME. I LOVE YOU.

11. HELP ME TO UNDERSTAND THAT WHILE I CANNOT DO WHAT I DID BEFORE, THERE ARE MANY THINGS I CAN DO NOW.

12. THAT IT IS NOT ALL IN MY HEAD!

13. I WANT YOU TO FEEL YOU CAN TALK TO ME ABOUT IT AND ASK QUESTIONS, ESPECIALLY MY CHILDREN.

14. DON'T HIDE BAD NEWS OR YOUR OWN PAIN FROM ME BECAUSE "I ALREADY HAVE ENOUGH TO HANDLE".

15. I REGRET NOT BEING ABLE TO WORK AND FINANCIALLY PROVIDE FOR MY FAMILY

16. PLEASE LEARN WHAT CRPS IS ALL ABOUT.

17. THAT IT'S OKAY TO COME TO ME AND ASK TO BE HELD BECAUSE YOU HAD A BAD DAY.

18. THAT EVEN ON DAYS WHEN "I LOOK GOOD", I AM STILL IN A LOT OF PAIN. IT DOES NOT GO AWAY.

19. IT OVERWHELMS ME AND I FEEL LIKE FAILURE AS A PARENT.

20. THIS DOES NOT CHANGE THE WAY I FEEL ABOUT YOU.

21. DON'T BE AFRAID TO HUG AND HOLD ME, JUST ASK FIRST IF TODAY IS A "HUGGING DAY".

22. I AM THE SAME PERSON UNDER THE PAIN, THAT I USED TO BE AND THAT I NEED THEM

23. THAT I AM THE STILL THE SAME HUMAN BEING, JUST NOT THAT SAME HUMAN DOING.

24. THIS DOES NOT CHANGE THE WAY I FEEL ABOUT YOU

25. THAT IT IS NOT MY FAULT THAT I GOT CRPS.

WWW.SURVIVINGCHRONICPAIN.COM WRITTEN BY KRISTEN HENSLEY

Figure 4. 25 Things You Want Your Family and Friends to Know. Retrieved from: www.survivingchronicpain.com

Check-Out:

- ⇒ Before closing the group, discuss what was helpful and wasn't helpful this week. After closing, the participants will be administered a post-test to determine how the support group is being helpful and not helpful.
- ⇒ Post-Test: The tests will be administered after group ends. It will be completed online and submitted to the Research Assistants for data entry.

Week 7: Theme: Social Supports and Community Resources

Goals for Session:

- ⇒ Physical, emotional, social, and spiritual support allow for women living with chronic pelvic floor dysfunction to be encouraged, decrease stressors, and improve overall quality health of life.

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Learning and Topic Discussion:

- ⇒ Social support is an important factor to decreasing depression, anxiety, and improving overall health quality of life.
- ⇒ Making a plan to find out what support services are in your area is essential to knowing what is available and what is still needed.
- ⇒ Seek more support from those in your circle because not everyone knows what is needed and how to help.
- ⇒ Be patient and write down needs, possibilities of assistance and who can help, and how to achieve more assistance.
- ⇒ Building friendships and networks with new people in groups can also be helpful, while navigating through life with chronic pelvic floor dysfunction and learn from each other.

Activities:

- ⇒ Pelvic floor therapist will discuss about support, services in area, and information pertaining to more services.
- ⇒ Identify benefits of social support system and community resources, which apply most:
1) ability to cope with medical challenges and stressful situations, 2) alleviate emotional stress, 3) healthy mental well-being, 4) improve self-esteem, 5) improve medical issues such as pain, 4) promote cohesiveness and relationships as more gather to help.
- ⇒ Once it is identified, determine ways to gather resources: 1) visit local library, 2) meet with social worker, 3) ask family therapist for list of resources, 4) inquire with church about programs and support groups, 5) community services and programs
- ⇒ Each participant will write what is needed, how to achieve it, and a time frame for which to inquire and pursue more information.

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to evaluate their needs and determine how each plan to inquire about services available.

Week 8: Theme: Self-Advocacy and The Medical Team

Goals for Session:

- ⇒ Self-advocacy is a way to promote self-esteem and help tailor medical treatment that is most helpful to the specific woman living with chronic pelvic floor dysfunction.

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Learning and Topic Discussion:

- ⇒ Self-advocacy is self-care, and it is important to keep track of what is working, what isn't, and writing down questions to ask of the medical team.
- ⇒ Know your personal health rights and ability to ask questions and get second and third opinions.
- ⇒ It is okay to start conservatively before surgical options.
- ⇒ Listen to others and ask questions.
- ⇒ Self-advocacy is important because it allows others to know your needs, gives an opportunity to speak on concerning matters, and increases confidence with decreased anxiety, becoming part of the treatment plan.

Activities:

- ⇒ Have each participant answer: “Self-advocacy means to me: _____”.
- ⇒ Self-advocacy means collaborating with your medical team. Who are others you would want to self-advocate with: 1) social worker, 2) therapist, 3) employees/staff, 4) friends, 5) family, church community, 5) community service programs? What does that look like and what can you share with each person/group?
- ⇒ Have each participant write down 5 goals to promote self-advocacy and what that looks like.

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to share how self-advocacy will be achieved for the following week.

Week 9: Theme: Work, Family, and Self Care

Goals for Session:

- ⇒ Recognizing cultural barriers and strengths within the family, faith, and community networks that can increase resilience, while also advocating and promoting self-care.

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Learning and Topic Discussion:

- ⇒ Identify logistical barriers such as financial burdens, challenges for work obligations, limited resources, childcare challenges, and relationship concerns

Activities:

- ⇒ Art, drawing, and mapping activity
- ⇒ Break into small group to talk about activity, then bring back into large group to share

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful. Encourage each participant to share how they will practice self-care for this week.
- ⇒ Meditation exercise handout

Week 10: Theme: Mindfulness and Meditation Training

Goals for Session:

- ⇒ Learning ways to incorporate mindfulness and meditation can be useful when having difficult moments, at the doctor's office, and other stressful moments.

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: "My name is _____ and what I hope to achieve in this group today is _____".
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Learning and Topic Discussion:

- ⇒ Identify positive and negative stressors
- ⇒ Share coping strategies that include mindfulness and meditation, such as 1) recognizing stressors and how it impacts the body and pelvic health, 2) practice deep breathing when overwhelmed, 3) take time to reflect, stretch, and share with others, 4) nutrition and sleep, and 5) goal setting.

Activities:

- ⇒ Somatic exercise, Muscle Stretching, Mindfulness and Meditation exercises
- ⇒ Small groups try a specific exercise and discuss in larger group their experience.

Check-Out:

- ⇒ Provide all the exercise handouts to try at home
- ⇒ Discuss what was most helpful and what wasn't in session. Identify one exercise that will be tried for the following week.

Week 11: Theme: Goal Setting for Health and Daily Living

Goals for Session:

- ⇒ Maintaining a healthy emotional, physical, and spiritual life will help with overall self-care and wellness.

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of chronic pelvic floor dysfunction.

Learning and Topic Discussion:

- ⇒ Goal setting looks different for everyone. We can't assume everyone is the same or has the same needs.
- ⇒ Healthy living encompasses 8 dimensions (see Table 12): physical, financial, spiritual, intellectual, occupational, family, social, and psychological/emotional wellbeing. Describing each dimension allows for each participant to understand which are most important and ways to incorporate each dimension for healthier daily living and overall health.

Table 12. Healthy Coping Strategies and Goal Setting.

Healthy Coping Strategies and Goal Setting		
Cognitive	Emotional	Behavioral
<p>Write things down</p> <p>Make small, daily decisions</p> <p>See the decisions you are already making Give yourself permission to ask for help Plan for the future</p> <p>Get the most information you can to help make decisions</p> <p>Anticipate needs</p> <p>Remember you have options</p> <p>Review previous successes</p> <p>Problem solve</p> <p>Have a Plan "B"</p> <p>Break large tasks into smaller ones Engage your intelligence in a new area, (e.g. go to an art museum, history exhibit, sports event, auction, theatre performance) Read literature that is unrelated to work Say no to extra responsibilities sometimes</p>	<p>Allow yourself to experience what you feel Label what you are experiencing</p> <p>Give yourself permission to ask for help Be assertive when necessary</p> <p>Keep communication open with others</p> <p>Remember you have options</p> <p>Use your sense of humor</p> <p>Spend time with others whose company you enjoy</p> <p>Stay in contact with important people in your life</p> <p>Give yourself affirmations, praise yourself Love yourself</p> <p>Reread favorite books, review favorite movies</p> <p>Identify comforting activities, objects, people, relationships, places and seek them out</p> <p>Use "positive" words and language</p>	<p>Spend time by yourself</p> <p>Spend time with others</p> <p>Limit demands on time and energy</p> <p>Help others with tasks</p> <p>Give yourself permission to ask for help Do activities that you previously enjoyed Remember you have options</p> <p>Find new activities that are enjoyable and (mildly) challenging</p> <p>Set goals, have a plan</p> <p>Take time to chat with co-workers.</p> <p>Make quiet time to complete tasks</p> <p>Set limits with clients and colleagues</p> <p>Arrange your workspace so it is comfortable and comforting</p> <p>Get regular supervision or consultation</p> <p>Have a peer support group</p> <p>Develop a non-trauma area of professional interest</p>
Spiritual	Interpersonal	Physical
<p>Discuss changed beliefs with spiritual leader</p> <p>Meditation</p> <p>Give yourself permission to ask for help Practice rituals of your faith/belief's Spiritual retreats/workshops</p> <p>Prayer</p> <p>Remember you have options Mindfulness</p> <p>Find spiritual support</p> <p>Read Spiritual literature</p> <p>Make time for reflection</p> <p>Spend time with nature</p> <p>Cherish your optimism and hope</p> <p>Be aware of nonmaterial aspects of life Try at times not to be in charge or the expert</p> <p>Be opened to not knowing</p>	<p>Give yourself permission to ask for help Take time to enjoy time with trust friend/partner</p> <p>Hugs</p> <p>Healthy boundaries</p> <p>Remember to use "I" statements</p> <p>Use humor to diffuse tense conversations Play together</p> <p>Talk with trusted partner/ friend</p> <p>Apologize when stress causes irritable behavior or outbursts</p> <p>State needs and wants as clearly as possible</p>	<p>Aerobic exercise</p> <p>See doctor and dentist</p> <p>Routine sleep patterns</p> <p>Minimize caffeine, alcohol, and sugar</p> <p>Give yourself permission to ask for help Eat well-balanced, regular meals</p> <p>Drink water</p> <p>Wear comfortable clothes</p> <p>Engage in physical luxuries: spa, massage, bath, exercise trainer</p> <p>Remember to breathe – deeply</p> <p>Take mini-breaks</p> <p>Get medical care when needed</p> <p>Dance, swim, walk, run, play sports, sing, or do some other physical activity that is fun</p> <p>Make time away from telephones</p>

Note: Retrieved from: <https://opentextbc.ca/introductiontopsychology/chapter/15-2-stress-and-coping>

Activities:

- ⇒ Break into groups to discussing healthy coping strategies and which ones can be identified as goals. Discuss how to implement the identified as goals and what that will look like for each one. Return to the large group and discuss how it will be implemented.

Check-Out:

- ⇒ Each participant discloses what was helpful and not helpful in this session. Each participant will also discuss which goals will be implemented for the following week and how it can improve overall healthy daily living.

Week 12: Theme: Incorporating Spirituality to Improve Overall Health

Goals for Session:

- ⇒ Identifying ways to include spirituality in a way that is helpful and promotes hope.

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Learning and Topic Discussion:

- ⇒ Spirituality offers meaning and purpose that can improve overall health, providing hope and encouraging motivation to continue forward. For those who do not identify in a Higher Power, may find spirituality in nature, music, art, or other ways that bring comfort.
- ⇒ Each person may express it differently, as it offers a positive world view and sense of self, offers comfort and hope, provides a community of others like minded, encourages connection with a Higher Power, and encourages thankfulness for small goals and steps towards overall spiritual well-being.

Activities:

- ⇒ Guided Reflection on spirituality: 1) think of a moment that was a powerful experience connected to a Higher Power, 2) Close your eyes and describe the setting, how body and mind felt, using 5 senses, and 3) describe how spirituality has helped through living with chronic pelvic floor dysfunction and connections made.

Check-Out:

- ⇒ Have each participant describe what was most helpful and not helpful overall each week. Describe ways in which the program can help and not help others and ways to improve it.
- ⇒ Post-Test: The tests will be administered after the completion of group online, which will then be submitted for data collection by Research Assistants.
- ⇒ Afterward and Advocacy: Sisterhood Ambassador Program-Inform participants ways to help other women living with chronic pelvic floor dysfunction and inform community about resources available.
- ⇒ Post-Test at three months and six months after the completion of group. These tests will be completed by participants, who have completed the program, which will occur online and submitted for data entry by Research Assistants.

CHAPTER SIX

PROJECT SUMMARY AND APPLICATIONS

Pathways for Healing is an online therapeutic support group (OTSG) program, designed to provide support to women diagnosed with chronic pelvic floor dysfunction (PFD), who live in Texas rural communities. There are two primary forms of chronic PFD: 1) acute (resolves with medication, surgery, and therapy) and 2) chronic (cannot resolve regardless of treatment option used). Chronic PFD is a form of chronic illness (CI), as it meets the criteria, such as: 1) lasts longer than 3 months, 2) cannot be cured, and 3) progressively worsens over time (Bernell & Howard, 2016). Unfortunately, comorbidity diagnoses are common, such as depression, anxiety, and high levels of stress, which can intensify with lack of support system, limited medical intervention and management, and emotional support. Women with a limited psychosocial and spiritual support primarily identify as non-Caucasian, have lower completed levels of education, low socioeconomic status, are uninsured, and living in communities with minimal to no medical and mental health services (Weihs, et al., 2002).

The average doctor visit is seven to ten minutes, which does not provide adequate time to build trust with the medical specialist and explore the issues for a proper diagnosis (Huljev & Pandak 2016). Additionally, women tend to not share symptoms to medical doctors because of shame and guilt surrounding female's anatomy, cultural expectations to resolve the issues on one's own, spiritual beliefs that reflect praying more and ritual healings, lack of awareness what symptoms are, and financial stressors that add up with medical visits (Restorick-Roberts, et al. 2017, Taukeni, 2019). With the financial

stressors of paying for multiple medical visits, living in a rural community often means having to travel to main cities for specialist and therapy. With the limitations of medical providers in their community and mental health therapists, women may choose to self-diagnose and treat, suffering in silence and shame, because of the lack of the information and awareness regarding PFD and the impact it has psychologically, socially, and physically.

Interpretations

Pathways for Healing is an OTSG program that works closely with medical providers, such as urologists, gynecologists, and urogynecologists, who refer their patients to the program for mental health services. Collaborating with licensed pelvic floor therapists and licensed marriage and family therapists, research assistants explore the data to determine if an OTSG program utilizing narrative therapy (NT) within a biopsychosocial-spiritual lens (BPS-S) improves overall health-related quality of life (HRQOL) for women diagnosed with chronic PFD, living in rural communities. The hypothesis is that women diagnosed with chronic PFD receiving consistent medical care coupled with participation in 12-weekly online therapeutic support group programs facilitated by licensed marriage and family therapists and pelvic floor therapists will improve overall HRQOL, which will provide long lasting support to women six months post group participation. Due to the geographical location of rural communities in Texas, offering support groups in English and Spanish prove beneficial and allow for more participation of Texas patients.

Each week, participations meet with a licensed marriage and family therapist and licensed pelvic floor therapist, along with a maximum of nine other participants (a total of 10 per support group), discussing topics related to living with chronic PFD. The incorporation of the BPS-S model addresses several areas that comprise the whole person, offering psychoeducation, emotional and social support, improved communication, spiritual connection and increased hope, access to community resources, and collaboration with the medical and therapy team (Grassis, et al., 2017). The topics consist of addressing the biological and physical challenges, psychological and mental health issues, sociological and cultural implications, and spirituality factors, all of which are utilized to share how women can modify daily living activities, promote self-care and advocacy, improve relationships, increase social support systems, and rely on faith and hope to improve overall HRQOL. The inclusion of narrative therapy, (NT) allows for women to share their own story and journey without expectation or judgement, is a strengths-based theory that helps women solve challenges rather than focusing on the problems and offering opportunities to create meaningful solutions that help promote self-care and advocacy for self and others (Crocket, 2014).

Prior to admittance into the program, Pelvic Floor Impact Questionnaire-Short Form 7 (PFIQ) and the Pelvic Floor Distress Inventory Short Form 20 (PFDI-20) are administered by the medical providers to determine eligibility in the Pathways to Healing OTSG program. The pre and post-tests administered are: 1) The Functional Assessment of Chronic Illness Therapy Measurement System (FACIT-SP), 2) Beck Depression Inventory-II (BDI-II), 3) RAND 36-Item Health Survey (SF-3), 4) Pelvic Floor Impact Questionnaire-Short Form 7 (PFIQ), 5) Pelvic Floor Distress Inventory Short Form 20

(PFIQ-20), 6) Check-In, Check-Out Oral Report (CICO), and 7) Survey for Participants. Research assistants administer the pre-tests and post-tests after the sixth session, 12th session, three months, 6 months post completion of the program. In addition to the tests, after each session, participants participate in a brief CICO assessment, stating what was most helpful and what wasn't helpful, to gather data on the effectiveness and helpfulness of each group session.

After each post-test, scores will be measured against the pre-tests and post-test scores from the previous measurements, showing a decrease in depressive and anxiety symptoms and improvement in overall HRQOL. Because the measurement tools also identify physical status, emotional and functional well-being, family and social concerns, relationship and sexual intimacy, work efficiency, spiritual connectedness, and long-term goals, the improved scores determine the OTSG program addresses these issues and improves overall quality of life (Webster, et al., 2003). While some women may not complete the program, due to moving to another state, physical illness, lack of medical treatment continuation, or lack of interest, 80% of women complete the program and post-tests. The results determine there is an increase in social skills and support, improvement in stress management and emotional well-being, better management of PFD symptoms as a self-advocate, better collaboration with medical specialists, and an improvement in HRQOL.

Implications

Women living with chronic PFD report decreased overall HRQOL, due to the physical, emotional, social, and spiritual issues experienced daily (LaFountain, 2010,

Nes, et al., 2017). In addition, living in rural communities limits the access to medical and mental health providers and can impact the care received, which primarily affects non-Caucasian females, lower levels of education, lower socioeconomic status, uninsured, and limited to no spiritual and social support (Clark, et al., 2017, Weihs, et al., 2002, Sandberg, et al., 2018). Protective factors that improve overall HRQOL are: 1) support of family and friends, 2) access to mental health services and therapy, 3) collaboration with medical and mental health providers, 4) incorporation of spirituality, and 5) community resources (SAMSHA, 2019). This demonstrates the effectiveness of utilizing a BPS-S model for an OTSG program that addresses chronic illness and disease such as PFD. The OTSG program's success is based on evaluating and comparing the pre-tests and post-tests after the sixth session, 12th session, three months post-group, and six months post-group completion of the program. The results support the importance of mental health services provided to women living with chronic PFD. Women working with their medical provider, coupled with online support groups, help provide resources and tools to better manage the challenges of chronic PFD. These findings reveal the importance of providing women with proper medical care, psychological support, resources, and assistance to self-manage and advocate for others living with PFD.

Pathways for Healing's OTSG program promotes psychoeducation about chronic PFD, self-care and management of the symptoms, increased manageability of daily living activities, improved family awareness and social support, spiritual health and increased hope, medication management, and advocacy for others through the Sisterhood Ambassador Program. The inclusion of an LMFT (or LMFT-A) and a PFPT (or SPT) strengthens the program, as women are able to ask more about their physical symptoms

and ways to address it through pelvic exercises and proper management between doctor visits. This also models collaboration with different specialists, as both professionals integrate their work together and invest in the overall well-being of each participant in the OTSG program.

The OTSG program also enforces the importance of providing an online platform for women with physical challenges, financial stressors, and transportation challenges. The ease and flexibility of using the online platform demonstrates that women are more apt to attend weekly support group sessions, meeting other women living with chronic PFD to build support and learn more about their long-term health condition. The 12-week support group also proves useful, as opposed to a shorter group program, because it allows for women to learn more about the Sisterhood Ambassador Program, where graduates of the program can participate in community awareness campaigns and be a support for women beginning the program. By doing this, women are able to continue their participation in the program in a leadership role that allows for continued support and helping other women, whose experiences may be similar. As a result, the positive correlations the test results and the OTSG program provide indicate mental health is equally important as medical treatment and that an online platform increases participation, which results in overall improvement for HRQOL.

Limitations

Pathways for Healing OTSG program does lack data, as the groups are limited to rural communities in Texas for women and does not include a city group to compare the data findings. In addition to this, women actively involved in the weekly support groups

are also under the medical care of a specialist provider, ensuring physical and medical treatment is established for each participant. Therefore, the data does not compare the results to women only receiving medical treatment versus women receiving medical treatment and support group engagement, which impacts reliability of the data. Because the study focuses on the women diagnosed with chronic PFD, it does not measure the efficacy of the facilitators, who are leading the support groups each week. Co-facilitators are provided weekly training, offered support, support group materials and tools, assessments are not provided to measure the efficacy and outcome of each group in comparison to one another. Because it is beyond the scope of this study, the facilitator's performance is not measured or used to determine if one group is more effective in improving the overall HRQOL.

Recommendations

Further research is needed to determine the efficacy of OTSG programs for women living with chronic pelvic floor dysfunction in rural communities, in comparison to women in the city and suburbs with access to mental health providers in their community. While there is an overall improvement in HRQOL, due to the OTSG program and Sisterhood Ambassador Program, it will be helpful to provide caregiver support groups concurrently. Another recommendation is offering in-person support group programs at local hospitals and clinics to decrease the amount of travel. This will also be a great opportunity for caregivers to interact with one another and gain support, awareness, and collaborate with others to better support their loved one diagnosed with chronic PFD. Funding through grants, community partnerships, and collaborations with

hospitals can provide funding for Pathways for Healing, as well as providing electronic tablets for group participants. This will also ensure the program is free to minimal cost for women in the program. The data collected from Pathways for Healing will determine the efficacy and equity so that the OTSG program can continue for women living with chronic PFD, regardless of geographic location, financial status, insurance, ethnicity, religious affiliation, and language. While women living with chronic PFD may experience physical, emotional, social, and spiritual challenges, the support received from OTSG programs will help improve overall HRQOL.

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APPENDIX A
CONSENT FORM

Informed Consent

*Informed Consent for to Participate in a Needs Assessment for an
Online Therapeutic Support Group Program for Women with Pelvic Floor
Dysfunction*

Loma Linda University

Department of Counseling and Family Sciences, 11065 Campus St., Loma Linda, CA,
92350

Name of Principal Investigator: Lisa Salazar, MA, LMFT, LPC

Phone Number of Principal Investigator: 281-940-4050

A. PURPOSE AND BACKGROUND

Lisa Salazar, MA, LMFT-S, LPC-S, a doctoral student from Loma Linda University is conducting research on the potential therapeutic benefits of an online therapeutic support group program for women with pelvic floor dysfunction. The purpose of your participation in this research is to help the researcher identify gaps in mental health services and components needed for an online therapeutic support group program for women with pelvic floor dysfunction. You were selected as a possible participant in this study because you were referred by a medical provider, have pelvic floor dysfunction, and live in the State of Texas.

B. PROCEDURES

If you agree to participate in this research study, the following will occur: You will answer a brief questionnaire provided by your medical provider. If you are diagnosed with pelvic floor dysfunction and are interested in participating in an online therapeutic support group program, Lisa Salazar will contact you and facilitate 2 assessment tools by phone and/or computer. The amount of time for these tests is less than 30 minutes and are available in English and Spanish. The questionnaires will ask how pelvic floor dysfunction has impacted your overall quality of life and how spirituality has or has not helped you. The assessments will be provided initially, after 3 months, 6 months, and then yearly, so long as you are in the online therapeutic program. This helps tailor the program to better fit your needs and help address areas of concerns that pelvic floor dysfunction impacts.

C. RISKS

Some of the risks include being uncomfortable answering questions about urinary frequency, pelvic issues, embarrassed by some of the questions, and inconvenienced with your time.

D. CONFIDENTIALITY

The records from this study will be kept as confidential as possible. No individual identities will be used in any reports or publications resulting from the study. All questionnaires, data from assessments, transcripts, recordings, and summaries are confidential and will be given codes and stored separately from any names or other direct identification of participants. Research information will be kept in locked files at all

times. Only research personnel will have access to the files and data collected, and only those with an essential need to see names or other identifying information will have access to that particular file. After the study is completed and 5 years past the last assessment completed, all data will be destroyed.

E. BENEFITS OF PARTICIPATION

There will be no direct benefit to you from participating in this research study. The anticipated benefit of your participation in this study is to determine if there are therapeutic benefits for an online therapeutic support group program.

F. VOLUNTARY PARTICIPATION

Your decision whether or not to participate in this study is voluntary and will not affect your relationship with Loma Linda University or your medical provider. If you choose to participate in this study, you can withdraw your consent and discontinue participation at any time without prejudice.

G. QUESTIONS

If you have any questions about the study, please contact Lisa Salazar at 281-940-4050 with any questions about the rights of research participants or research related concerns.

CONSENT

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN A RESEARCH STUDY. YOUR SIGNATURE BELOW INDICATES THAT YOU HAVE DECIDED TO PARTICIPATE IN THE STUDY AFTER READING ALL OF THE INFORMATION ABOVE AND YOU UNDERSTAND THE INFORMATION IN THIS FORM, HAVE HAD ANY QUESTIONS ANSWERED AND HAVE RECEIVED A COPY OF THIS FORM FOR YOU TO KEEP.

Signature _____ Date _____ Research

Participant

Signature _____ Date _____ Interviewer

APPENDIX B.

EVALUATION MEASURES

Assessment: Pelvic Floor Impact Questionnaire-Short Form-7 (PFIQ)

Pelvic Floor Impact Questionnaire–short form 7

Instructions: Some women find that bladder, bowel, or vaginal symptoms affect their activities, relationships, and feelings. For each question place an **X** in the response that best describes how much your activities, relationships, or feelings have been affected by your bladder, bowel, or vaginal symptoms or conditions **over the last 3 months**. Please make sure you mark an answer in **all 3 columns** for each question.

How do symptoms or conditions relate to the following usually affect your ↓ →→→→	<i>Bladder or urine</i>	<i>Bowel or rectum</i>	<i>Vagina or pelvis</i>
1. Ability to do household chores (cooking, housecleaning, laundry)?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
2. Ability to do physical activities such as walking, swimming, or other exercise?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
3. Entertainment activities such as going to a movie or concert?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
4. Ability to travel by car or bus for a distance greater than 30 minutes away from home?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
5. Participating in social activities outside your home?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
6. Emotional health (nervousness, depression, etc)?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit
7. Feeling frustrated?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit

Scoring the PFIQ – 7:

All of the items use the following response scale:
 0, Not at all; 1, somewhat; 2, moderately; 3, quite a bit

Scales:

Urinary Impact Questionnaire (UIQ-7): 7 items under column heading “Bladder or urine.”

Colorectal-Anal Impact Questionnaire (CRAIQ-7): 7 items under column heading “Bowel or rectum.”

Pelvic Organ Prolapse Impact Questionnaire (POPIQ-7): 7 items under column heading “Pelvis or vagina.”

Scale scores: Obtain the mean value for all of the answered items within the corresponding scale (possible value 0 to 3) and then multiply by (100/3) to obtain the scale score (range 0 to 100). Missing items are dealt with by using the mean from answered items only.

PFIQ-7 Summary Score: Add the scores from the 3 scales together to obtain the summary score (range 0 to 300).

Note: Retrieved from:

<http://www.palmerphysicaltherapy.com/sites/default/files/Pelvic%20Floor%20Impact%20Questionnaire%20%28PFIQ-7%29.pdf>

Assessment: Pelvic Floor Distress Inventory (PFDI)

Pelvic Floor Distress Inventory—short form 20

Instructions: Please answer all of the questions in the following survey. These questions will ask you if you have certain bowel, bladder, or pelvic symptoms and, if you do, how much they bother you. Answer these by putting an **X** in the appropriate box or boxes. While answering these questions, please consider your symptoms over the **last 3 months**.

The PFDI-20 has 20 items and 3 scales.

All items use the following format with a response scale from 0 to 4.

<p>Do you _____?</p> <p><input type="checkbox"/> No; <input type="checkbox"/> Yes</p> <p>0</p> <p>If yes, how much does it bother you?</p> <p><input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4</p> <p>Not at all Somewhat Moderately Quite a bit</p>

Scales

Pelvic Organ Prolapse Distress Inventory 6 (POPDI-6):

1. Usually experience *pressure* in the lower abdomen?
2. Usually experience *heaviness or dullness* in the pelvic area?
3. Usually have a bulge or something falling out that you can see or feel in your vaginal area?
4. Ever have to push on the vagina or around the rectum to have or complete a bowel movement?
5. Usually experience a feeling of incomplete bladder emptying?
6. Ever have to push up on a bulge in the vaginal area with your fingers to start or complete urination?

Colorectal-Anal Distress Inventory 8 (CRADI-8):

7. Feel you need to strain too hard to have a bowel movement?
8. Feel you have not completely emptied your bowels at the end of a bowel movement?
9. Usually lose stool beyond your control if your stool is well formed?
10. Usually lose stool beyond your control if your stool is loose?
11. Usually lose gas from the rectum beyond your control?
12. Usually have pain when you pass your stool?
13. Experience a strong sense of urgency and have to rush to the bathroom to have a bowel movement?
14. Does part of your bowel ever pass through the rectum and bulge outside during or after a bowel movement?

Urinary Distress Inventory 6 (UDI-6):

15. Usually experience frequent urination?
16. Usually experience urine leakage associated with a feeling of urgency, that is, a strong sensation of needing to go to the bathroom?
17. Usually experience urine leakage related to coughing, sneezing, or laughing?
18. Usually experience small amounts of urine leakage (that is, drops)?
19. Usually experience difficulty emptying your bladder?
20. Usually experience *pain or discomfort* in the lower abdomen or genital region?

Scale scores: Obtain the mean value of all of the answered items within the corresponding scale (possible value 0 to 4) and then multiply by 25 to obtain the scale score (range 0 to 100). Missing items are dealt with by using the mean from answered items only.

PFDI –20 Summary Score: Add the scores from the 3 scales together to obtain the summary score (range 0 to 300).

Note: Retrieved from: <https://www.sralab.org/rehabilitation-measures/pelvic-floor-distress-inventory-20>

Assessment: Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-SP)

FACIT-SP (Version 4)

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

PHYSICAL WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very much
Q11	I have a lack of energy	0	1	2	3	4
Q12	I have nausea	0	1	2	3	4
Q13	Because of my physical condition, I have trouble meeting the needs of my family.....	0	1	2	3	4
Q14	I have pain	0	1	2	3	4
Q15	I am bothered by side effects of treatment.....	0	1	2	3	4
Q16	I feel ill	0	1	2	3	4
Q17	I am forced to spend time in bed.....	0	1	2	3	4
SOCIAL/FAMILY WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very much
Q18	I feel close to my friends.....	0	1	2	3	4
Q19	I get emotional support from my family.....	0	1	2	3	4
Q20	I get support from my friends.....	0	1	2	3	4
Q21	My family has accepted my illness.....	0	1	2	3	4
Q22	I am satisfied with family communication about my illness.....	0	1	2	3	4
Q23	I feel close to my partner (or the person who is my main support).....	0	1	2	3	4
Q24	Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.					
Q25	I am satisfied with my sex life	0	1	2	3	4

FACIT-SP (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

EMOTIONAL WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very much
Q26	I feel sad.....	0	1	2	3	4
Q27	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
Q28	I am losing hope in the fight against my illness.....	0	1	2	3	4
Q29	I feel nervous.....	0	1	2	3	4
Q30	I worry about dying.....	0	1	2	3	4
Q31	I worry that my condition will get worse.....	0	1	2	3	4
FUNCTIONAL WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very much
Q32	I am able to work (include work at home).....	0	1	2	3	4
Q33	My work (include work at home) is fulfilling.....	0	1	2	3	4
Q34	I am able to enjoy life.....	0	1	2	3	4
Q35	I have accepted my illness.....	0	1	2	3	4
Q36	I am sleeping well	0	1	2	3	4
Q37	I am enjoying the things I usually do for fun.....	0	1	2	3	4
Q38	I am content with the quality of my life right now.....	0	1	2	3	4

FACIT-SP (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

ADDITIONAL CONCERNS		Not at all	A little bit	Some-what	Quite a bit	Very much
Sp1	I feel peaceful.....	0	1	2	3	4
Sp2	I have a reason for living.....	0	1	2	3	4
Sp3	My life has been productive.....	0	1	2	3	4
Sp4	I have trouble feeling peace of mind.....	0	1	2	3	4
Sp5	I feel a sense of purpose in my life.....	0	1	2	3	4
Sp6	I am able to reach down deep into myself for comfort.....	0	1	2	3	4
Sp7	I feel a sense of harmony within myself.....	0	1	2	3	4
Sp8	My life lacks meaning and purpose.....	0	1	2	3	4
Sp9	I find comfort in my faith or spiritual beliefs.....	0	1	2	3	4
Sp10	I find strength in my faith or spiritual beliefs.....	0	1	2	3	4
Sp11	My illness has strengthened my faith or spiritual beliefs.....	0	1	2	3	4
Sp12	I know that whatever happens with my illness, things will be okay.....	0	1	2	3	4

FACIT-SP12 or FACIT-SP Non-Illness 2-Factor Scoring Guidelines (Version 4)

Instructions: *1. Record answers in "Item response" column. If missing, mark with an X

2. Perform reversals as indicated and sum individual items to obtain a score.

3. Multiply the sum of the item scores by the number of items in the subscale, then divide by the number of items answered. This produces the subscale score.

4. The higher the score, the better the QOL/Spiritual well-being.

Subscale	Item Code	Reverse Item?	Item response	Item Score		
Meaning/Peace	Sp1		0	+	_____	=_____
	Sp2		0	+	_____	=_____
	Sp3	0	-	_____	=_____	=_____
	Sp4		4	-	_____	=_____
	Sp5		0	+	_____	=_____
	Sp6		0	+	_____	=_____
	Sp7		0	+	_____	=_____
	Sp8		4	-	_____	=_____
Sum individual item scores: _____				Multiply by 8: _____		
Divide by number of items answered: _____				=Meaning/Peace subscale score		
Subscale	Item Code	Reverse Item?	Item response	Item Score		
Faith	Sp9		0	+	_____	=_____
	Sp10		0	+	_____	=_____
	Sp11*		0	+	_____	=_____
	Sp12*		0	+	_____	=_____
Score range: 0-16						

Scoring for FACIT-SP

FACIT-Sp 3-Factor Scoring Guidelines (Version 4) – Page 1

Instructions:*
 1. Record answers in "item response" column. If missing, mark with an X.
 2. Perform reversals as indicated, and sum individual items to obtain a score.
 3. Multiply the sum of the item scores by the number of items in the subscale, then divide by the number of items answered. This produces the subscale score.
 4. Add subscale scores to derive total scores (FACT-G & FACIT-Sp).
 5. The higher the score, the better the QOL/spiritual well-being.

Subscale	Item Code	Reverse item?	Item response	Item Score
PHYSICAL WELL-BEING (PWB) Score range: 0-28	GP1	4 -		
	GP2	4 -		
	GP3	4 -		
	GP4	4 -		
	GP5	4 -		
	GP6	4 -		
	GP7	4 -		
Sum individual item scores: _____ Multiply by 7: _____ Divide by number of items answered: _____ = PWB subscale score				
SOCIAL/FAMILY WELL-BEING (SWB) Score range: 0-28	GS1	0 +		
	GS2	0 +		
	GS3	0 +		
	GS4	0 +		
	GS5	0 +		
	GS6	0 +		
	GS7	0 +		
Sum individual item scores: _____ Multiply by 7: _____ Divide by number of items answered: _____ = SWB subscale score				
EMOTIONAL WELL-BEING (EWB) Score range: 0-24	GE1	4 -		
	GE2	0 +		
	GE3	4 -		
	GE4	4 -		
	GE5	4 -		
	GE6	4 -		
Sum individual item scores: _____ Multiply by 6: _____ Divide by number of items answered: _____ = EWB subscale score				
FUNCTIONAL WELL-BEING (FWB) Score range: 0-28	GF1	0 +		
	GF2	0 +		
	GF3	0 +		
	GF4	0 +		
	GF5	0 +		
	GF6	0 +		
	GF7	0 +		
Sum individual item scores: _____ Multiply by 7: _____ Divide by number of items answered: _____ = FWB subscale score				

FACIT-Sp 3 Factor scoring template 22APR2020

FACIT-Sp 3 Factor Scoring Guidelines (Version 4) – Page 2

Subscale	Item Code	Reverse item?	Item response	Item Score
Meaning Score range: 0-16	Sp2	0 +		
	Sp3	0 +		
	Sp5	0 +		
	Sp8	4 -		
Sum individual item scores: _____ Multiply by 4: _____ Divide by number of items answered: _____ = Meaning subscale score				
Peace Score range: 0-16	Sp1	0 +		
	Sp4	4 -		
	Sp6	0 +		
	Sp7	0 +		
Sum individual item scores: _____ Multiply by 4: _____ Divide by number of items answered: _____ = Peace subscale score				
Faith Score range: 0-16	Sp9	0 +		
	Sp10	0 +		
	Sp11	0 +		
	Sp12	0 +		
Sum individual item scores: _____ Multiply by 4: _____ Divide by number of items answered: _____ = Faith subscale score				

To Derive a FACIT-Sp12 total score:
Score range: 0-48

(Meaning score) + (Peace score) + (Faith score) = _____ = **FACIT-Sp12 total score**

To Derive a FACT-G total score:
Score range: 0-108

(PWB score) + (SWB score) + (EWB score) + (FWB score) = _____ = **FACT-G total score**

To Derive a FACIT-Sp total score:
Score range: 0-156

(PWB score) + (SWB score) + (EWB score) + (FWB score) + (Sp12 score) = _____ = **FACIT-Sp total score**

*For guidelines on handling missing data and scoring options, please refer to the Administration and Scoring Guidelines in the manual or on-line at www.facit.org.

FACIT-Sp 3 Factor scoring template 22APR2020

Note: Retrieved from: <https://www.facit.org/measure-english-downloads/facit-sp-12-english-downloads>

Assessment: Beck Depression Inventory-II (BDI-II)

Beck's Depression Inventory
This depression inventory can be self-scored. The scoring scale is at the end of the questionnaire.

1.
 - 0 I do not feel sad.
 - 1 I feel sad.
 - 2 I am sad all the time and I can't snap out of it.
 - 3 I am so sad and unhappy that I can't stand it.
2.
 - 0 I am not particularly discouraged about the future.
 - 1 I feel discouraged about the future.
 - 2 I feel I have nothing to look forward to.
 - 3 I feel the future is hopeless and that things cannot improve.
3.
 - 0 I do not feel like a failure.
 - 1 I feel I have failed more than the average person.
 - 2 As I look back on my life, all I can see is a lot of failures.
 - 3 I feel I am a complete failure as a person.
4.
 - 0 I get as much satisfaction out of things as I used to.
 - 1 I don't enjoy things the way I used to.
 - 2 I don't get real satisfaction out of anything anymore.
 - 3 I am dissatisfied or bored with everything.
5.
 - 0 I don't feel particularly guilty.
 - 1 I feel guilty a good part of the time.
 - 2 I feel quite guilty most of the time.
 - 3 I feel guilty all of the time.
6.
 - 0 I don't feel I am being punished.
 - 1 I feel I may be punished.
 - 2 I expect to be punished.
 - 3 I feel I am being punished.
7.
 - 0 I don't feel disappointed in myself.
 - 1 I am disappointed in myself.
 - 2 I am disgusted with myself.
 - 3 I hate myself.
8.
 - 0 I don't feel I am any worse than anybody else.
 - 1 I am critical of myself for my weaknesses or mistakes.
 - 2 I blame myself all the time for my faults.
 - 3 I blame myself for everything bad that happens.
9.
 - 0 I don't have any thoughts of killing myself.
 - 1 I have thoughts of killing myself, but I would not carry them out.
 - 2 I would like to kill myself.
 - 3 I would kill myself if I had the chance.
10.
 - 0 I don't cry any more than usual.
 - 1 I cry more now than I used to.
 - 2 I cry all the time now.
 - 3 I used to be able to cry, but now I can't cry even though I want to.
11.
 - 0 I am no more irritated by things than I ever was.
 - 1 I am slightly more irritated now than usual.
 - 2 I am quite annoyed or irritated a good deal of the time.
 - 3 I feel irritated all the time.
12.
 - 0 I have not lost interest in other people.
 - 1 I am less interested in other people than I used to be.
 - 2 I have lost most of my interest in other people.
 - 3 I have lost all of my interest in other people.
13.
 - 0 I make decisions about as well as I ever could.
 - 1 I put off making decisions more than I used to.
 - 2 I have greater difficulty in making decisions more than I used to.
 - 3 I can't make decisions at all anymore.
14.
 - 0 I don't feel that I look any worse than I used to.
 - 1 I am worried that I am looking old or unattractive.
 - 2 I feel there are permanent changes in my appearance that make me look unattractive.
 - 3 I believe that I look ugly.
15.
 - 0 I can work about as well as before.
 - 1 It takes an extra effort to get started at doing something.
 - 2 I have to push myself very hard to do anything.
 - 3 I can't do any work at all.
16.
 - 0 I can sleep as well as usual.
 - 1 I don't sleep as well as I used to.
 - 2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
 - 3 I wake up several hours earlier than I used to and cannot get back to sleep.
17.
 - 0 I don't get more tired than usual.
 - 1 I get tired more easily than I used to.
 - 2 I get tired from doing almost anything.
 - 3 I am too tired to do anything.
18.
 - 0 My appetite is no worse than usual.
 - 1 My appetite is not as good as it used to be.
 - 2 My appetite is much worse now.
 - 3 I have no appetite at all anymore.
19.
 - 0 I haven't lost much weight, if any, lately.
 - 1 I have lost more than five pounds.
 - 2 I have lost more than ten pounds.
 - 3 I have lost more than fifteen pounds.

Assesment: BDI-II (continued).

- 20.
- 0 I am no more worried about my health than usual.
 - 1 I am worried about physical problems like aches, pains, upset stomach, or constipation.
 - 2 I am very worried about physical problems and it's hard to think of much else.
 - 3 I am so worried about my physical problems that I cannot think of anything else.
- 21.
- 0 I have not noticed any recent change in my interest in sex.
 - 1 I am less interested in sex than I used to be.
 - 2 I have almost no interest in sex.
 - 3 I have lost interest in sex completely.

INTERPRETING THE BECK DEPRESSION INVENTORY

Now that you have completed the questionnaire, add up the score for each of the twenty-one questions by counting the number to the right of each question you marked. The highest possible total for the whole test would be sixty-three. This would mean you circled number three on all twenty-one questions. Since the lowest possible score for each question is zero, the lowest possible score for the test would be zero. This would mean you circles zero on each question. You can evaluate your depression according to the Table below.

Total Score	Levels of Depression
1-10	These ups and downs are considered normal
11-16	Mild mood disturbance
17-20	Borderline clinical depression
21-30	Moderate depression
31-40	Severe depression
over 40	Extreme depression

http://www.med.navy.mil/sites/NMCP2/PatientServices/SleepClinicLab/Documents/Beck_Depression_Inventory.pdf

Assessment: RAND 36-Item Health Survey (SF-36)



RAND > RAND Health > Surveys > RAND Medical Outcomes Study > 36-Item Short Form Survey (SF-36) >

36-Item Short Form Survey Instrument (SF-36)

RAND 36-Item Health Survey 1.0 Questionnaire Items

Choose one option for each questionnaire item.

1. In general, would you say your health is:

- 1 - Excellent
- 2 - Very good
- 3 - Good
- 4 - Fair
- 5 - Poor

2. Compared to one year ago, how would you rate your health in general now?

- 1 - Much better now than one year ago
- 2 - Somewhat better now than one year ago
- 3 - About the same
- 4 - Somewhat worse now than one year ago
- 5 - Much worse now than one year ago

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
5. Lifting or carrying groceries	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
6. Climbing several flights of stairs	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
7. Climbing one flight of stairs	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
8. Bending, kneeling, or stooping	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
9. Walking more than a mile	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
10. Walking several blocks	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
11. Walking one block	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
12. Bathing or dressing yourself	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
13. Cut down the amount of time you spent on work or other activities	<input type="radio"/> 1	<input type="radio"/> 2
14. Accomplished less than you would like	<input type="radio"/> 1	<input type="radio"/> 2
15. Were limited in the kind of work or other activities	<input type="radio"/> 1	<input type="radio"/> 2
16. Had difficulty performing the work or other activities (for example, it took extra effort)	<input type="radio"/> 1	<input type="radio"/> 2

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
17. Cut down the amount of time you spent on work or other activities	<input type="radio"/> 1	<input type="radio"/> 2
18. Accomplished less than you would like	<input type="radio"/> 1	<input type="radio"/> 2
19. Didn't do work or other activities as carefully as usual	<input type="radio"/> 1	<input type="radio"/> 2

20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- 1 - Not at all
- 2 - Slightly
- 3 - Moderately
- 4 - Quite a bit
- 5 - Extremely

Assessment: RAND SF-36 (continued).

21. How much **bodily** pain have you had during the **past 4 weeks**?

- 1 - None
- 2 - Very mild
- 3 - Mild
- 4 - Moderate
- 5 - Severe
- 6 - Very severe

22. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

- 1 - Not at all
- 2 - A little bit
- 3 - Moderately
- 4 - Quite a bit
- 5 - Extremely

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

- | | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time |
|---|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|
| 23. Did you feel full of pep? | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | <input type="radio"/> 5 | <input type="radio"/> 6 |
| 24. Have you been a very nervous person? | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | <input type="radio"/> 5 | <input type="radio"/> 6 |
| 25. Have you felt so down in the dumps that nothing could cheer you up? | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | <input type="radio"/> 5 | <input type="radio"/> 6 |
| 26. Have you felt calm and peaceful? | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | <input type="radio"/> 5 | <input type="radio"/> 6 |
| 27. Did you have a lot of energy? | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | <input type="radio"/> 5 | <input type="radio"/> 6 |
| 28. Have you felt downhearted and blue? | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | <input type="radio"/> 5 | <input type="radio"/> 6 |
| 29. Did you feel worn out? | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | <input type="radio"/> 5 | <input type="radio"/> 6 |
| 30. Have you been a happy person? | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | <input type="radio"/> 5 | <input type="radio"/> 6 |
| 31. Did you feel tired? | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | <input type="radio"/> 5 | <input type="radio"/> 6 |

32. During the **past 4 weeks**, how much of the time has **your physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

- 1 - All of the time
- 2 - Most of the time
- 3 - Some of the time
- 4 - A little of the time
- 5 - None of the time

APPENDIX C.

SUPPORT GROUP MANUAL MEASURES

Assessment: Survey for Participants:

Based on a scale of 1 to 5, please circle the number that best represents your answer.

1. **My overall experience of the online support group.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
2. **The content of the group discussions.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
3. **The online platform used for support groups.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
4. **The information and resources provided in online support groups.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
5. **The frequency of the group meetings: once a week.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
6. **The length of the group meetings: 90 minutes, for 12 weeks.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
7. **The group facilitators leading the discussions.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
8. **The group exercises and hand-outs provided in online support groups.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
9. **Meeting others with similar condition and sharing with one another.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
10. **Gained practice advice and increased my knowledge of the condition.**
1=very negative 2=slightly negative 3=neutral 4=slightly positive 5=very positive
11. **In what ways can the online program be improved?**

12. **In what ways did this program help you?**

13. **Can you identify 4 ways in which you can improve your overall mental and social health?**

14. **How can the group facilitators be more helpful to you?**

SUPPORT GROUP MANUAL MEASURES

Support Group Check-In and Check-Outs

Week 1

Check -In

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: "My name is _____ and what I hope to achieve in this group today is _____".
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.
- ⇒ Inform participants the group is voluntary, and each have the choice to provide as little or as much information about themselves and their condition throughout the entire group process. Being respectful of participants, who choose to not participate with an activity or an answer, and modeling setting boundaries as part of the learning process.

Check-Out

- ⇒ Ask what surprised them most about their first meeting.
- ⇒ Provide participants with 24-hour crisis hotline, crisis text line, and have space for each participant to fill in the numbers and contact information of their medical team.

Week 2

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: "My name is _____ and what I hope to achieve in this group today is _____".
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Ask each participant what they hope to incorporate as part of self-care for the following week.
- ⇒ Invite participants to make final comments and summarize what was helpful and not helpful.
- ⇒ Provide list of resources in their community that can contribute to self-care.

Week 3

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: "My name is _____ and what I hope to achieve in this group today is _____".
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to evaluate current self-care activities related to daily living and identify where changes and modifications can be made.
- ⇒ Each participant lists 1-2 ways modifications will be made and how it will help.

Week 4

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: "My name is _____ and what I hope to achieve in this group today is _____".
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to evaluate the chart and add one way they will practice self-care through nutrition.

Week 5

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: "My name is _____ and what I hope to achieve in this group today is _____".
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Identify one way in which the session was helpful or not helpful. Evaluate the chart and add one way they will practice self-care through nutrition.

Week 6

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: "My name is _____ and what I hope to achieve in this group today is _____".
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Before closing the group, discuss what was helpful and wasn't helpful this week. After closing, the participants will be administered a post-test to determine how the support group is being helpful and not helpful

Week 7

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: "My name is _____ and what I hope to achieve in this group today is _____".
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to evaluate their needs and determine how each plan to inquire about services available.

Week 8

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: "My name is _____ and what I hope to achieve in this group today is _____".
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.

- ⇒ Encourage each participant to share how self-advocacy will be achieved for the following week.

Week 9

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Have each participant identify one way in which the session was helpful or not helpful.
- ⇒ Encourage each participant to share how they will practice self-care for this week.
- ⇒ Meditation exercise handout

Week 10

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Provide all the exercise handouts to try at home
- ⇒ Discuss what was most helpful and what wasn’t in session. Identify one exercise that will be tried for the following week.

Week 11

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Each participant discloses what was helpful and not helpful in this session. Each participant will also discuss which goals will be implemented for the following week and how it can improve overall healthy daily living.

Week 12

Check-In:

- ⇒ Review group rules
- ⇒ Go around the group and each participant will say: “My name is _____ and what I hope to achieve in this group today is _____”.
- ⇒ Acknowledge each person and give opportunity to address issues that are concerning and part of their chronic pelvic floor dysfunction.

Check-Out:

- ⇒ Have each participant describe what was most helpful and not helpful overall each week. Describe ways in which the program can help and not help others and ways to improve it.
- ⇒ Post-Test: The tests will be administered after the completion of group online, which will then be submitted for data collection by Research Assistants.
- ⇒ Afterward and Advocacy: Sisterhood Ambassador Program-Inform participants ways to help other women living with chronic pelvic floor dysfunction and inform community about resources available.
- ⇒ Post-Test at three months and six months after the completion of group. These tests will be completed by participants, who have completed the program, which will occur online and submitted for data entry by Research Assistants.