

MIND/BODY/SPIRIT SERVICES FOR WELLNESS IN THE HIV/AIDS COMMUNITY

SILOAM

1133 Spring Garden Street

Philadelphia, PA 19123

215-765-6633 ♦ www.siloamwellness.org



Presentation Objectives

- ◆ To describe Siloam's mind/body/spirit programs for the HIV/AIDS community.
- ◆ To explore the role of spirituality for individuals affected by HIV/AIDS
- ◆ To discuss the impact of participation on clients' quality of life

Workshop Participants

- ◆ Joseph Lukach, M.Div., MSW, MBA - Executive Director
- ◆ Bernadette Kinniry, RSM – Co-founder & Pastoral Counselor
- ◆ Lori Curtis, MSW, LSW - Program Director
- ◆ Cathy Maguire, RSM – Assoc. Exec. Director & Pastoral Counselor
- ◆ Mary Lou Galantino, PT, MS, PhD – Professor of Physical Therapy, Richard Stockton College of NJ
- ◆ Kevin H.– Siloam client
- ◆ Dan M. – Siloam client

Mission Statement

Siloam seeks to enrich the well-being of people impacted by HIV/AIDS by providing a broad range of integrative mind/body/spirit services that empowers them to develop skills and personal strengths leading to more meaningful lives.



Factors Leading to the Founding of Siloam

- ◆ Response of traditional religious institutions to those with HIV/AIDS: people with HIV/AIDS were stigmatized amid fears of transmission.
- ◆ The state of medical care for HIV/AIDS in the 1990's – many people dying.
- ◆ People infected with HIV/AIDS were generally members of marginalized populations, such as gay men and IV drug users, who acquired the virus because of their lifestyle.
- ◆ The stress felt by people infected and affected by HIV/AIDS as well as providers (doctors, nurses, social workers, case managers, etc.) because of the epidemic.
- ◆ Agency name comes from the story of Jesus healing the blind man from the Gospel of John (9:1-41)
- ◆ Important points:
 - ◆ People with illness were regarded as outcasts
 - ◆ Siloam as a place of healing
 - ◆ Siloam is NOT a faith-based organization.



Siloam's Understanding of Mind/Body/Spirit Wellness

- ◆ A holistic perspective of human beings cannot separate our physical, psychological, mental and spiritual dimensions.
- ◆ Siloam's programs reflect the belief that wellness is not possible without addressing all these dimensions.

Spirituality

- ◆ Spirituality can be broadly defined as that which gives people meaning and purpose in life. It is expressed in an individual's search for ultimate meaning through participation in a religion, but it can be much broader, such as a belief in the family, humanism and the arts.
- ◆ Spirituality is what helps people find meaning in the face of suffering, feel life's purpose, experience gratitude for life and provides hope.
- ◆ By spirituality Siloam means the connectedness that a person feels to him/herself, to other people, to a power greater than self (however one understands this) and to the natural world.

What is the Difference between Religion & Spirituality?

- ◆ Religion entails an organized body of thought, beliefs and practices associated with traditions associated with a belief in a god or gods.
- ◆ Spirituality is associated with a personal sense of meaning/values, often connected to religious traditions but not limited to these experiences or theism.
- ◆ While people who practice their religious beliefs are pursuing the spiritual well-being, spirituality is not synonymous with religion.
- ◆ Spirituality cuts across all belief systems and speaks to our common humanity irrespective of one's cultural or religious background, or whether one believes in a higher power.

Services Available at Siloam

- ◆ Support & Discussion Groups
- ◆ Individual Counseling - Pastoral & Supportive Counseling & Spiritual Direction
- ◆ Educational Programs
- ◆ Complementary Therapies
- ◆ One and Three-Day Retreats
- ◆ Special Programs & Activities
- ◆ Support for HIV/AIDS Professionals



Examples of Services Provided

Educational Programs

- ◆ Lunch & Learn Educational Programs
- ◆ Nutrition Matters – monthly lectures and cooking classes
- ◆ Special Workshops, such as Working & HIV/AIDS.

Support Services

- ◆ Support Groups
- ◆ Pastoral Counseling, Spiritual Direction & Supportive Counseling
- ◆ Wellness Retreats (One and Three-Day)
- ◆ Programs for Family & Friends

Special Events & Activities

- ◆ Trips to Longwood Gardens (“Beauty Beholds Beauty”)
- ◆ Halloween Party for children
- ◆ Thanksgiving Dinner Program
- ◆ World AIDS Day Celebration

Professional Support

- ◆ Agency retreats
- ◆ Retreats for professional caregivers
- ◆ Monthly Networking Group for professional caregivers



Complementary Therapies Offered at Siloam

- ◆ Yoga: an ancient Indian practice that combines physical postures, breathing techniques, and meditation
- ◆ Tai Chi: a slow, flowing Chinese practice that improves balance.
- ◆ Meditation: A conscious mental process using certain techniques such as focusing attention or maintaining a specific posture to suspend the stream of thoughts and relax the body and mind.
- ◆ Massage: the manipulation of tissue to relax clumps of knotted muscle fiber, increase circulation and release chronic tension.
- ◆ Reiki: moving a practitioner's hands over energy fields of client's body to increase flow and restore balance.
- ◆ Shiatsu: finger pressure applied to points along the meridians, to balance and increase flow of energy.
- ◆ Reflexology: pressure applied to points on the feet and sometimes the hands to promote relaxation and healing in other parts of the body.

Philosophies Underlying Services

- ◆ Clients decide what services best meet their needs.
- ◆ No cost for services, so clients can “try” yoga, a support group or body work without “losing” anything or making a commitment.
- ◆ Being with others facing similar stresses decreases isolation and unwanted aloneness.
- ◆ With information, clients are better able to make decisions and be proactive.
- ◆ Feeling better about oneself creates a more positive, hopeful attitude that can lead to better adherence to medical regimens as well as an improved quality of life.

Mind/Body/Spirit Wellness = Enhanced Quality of Life

Benefits include a reduction of cognitive and emotional stressors associated with having HIV/AIDS, including:

- ◆ Feeling more in control
- ◆ Feeling more hopeful
- ◆ Having a positive sense of self
- ◆ Having more meaningful social interactions and feeling less isolated

Enhanced Quality of Life, Continued

- ◆ Being more active in one's medical care
- ◆ Being able to better manage symptoms, such as fatigue
- ◆ Enhancing immune system functioning
- ◆ Reducing stress
- ◆ Enhancing coping abilities
- ◆ Developing and strengthening satisfying leisure experiences.

Medical Concerns Individuals with HIV May Have

- ◆ Suppressed immune system
- ◆ Opportunistic infections
- ◆ Side effects of medications and/or the HIV virus, including stomach problems, constipation, diarrhea, sleepiness, dizziness, fatigue, neuropathy, impaired vision, pain, headaches and shortness of breath
- ◆ Lipodystrophy
- ◆ High cholesterol
- ◆ High blood sugar and diabetes
- ◆ Other medical problems (cancer, strokes, hepatitis, heart disease) not necessarily related to the HIV virus.

Psychosocial Concerns People with HIV May Have

- ◆ Low self-esteem
- ◆ Unwanted aloneness / isolation
- ◆ Depression
- ◆ Financial concerns
- ◆ Substance abuse / addictions
- ◆ Mental health problems
- ◆ Relationship issues
- ◆ Fear & anxiety
- ◆ Poor body image

Spiritual Concerns People with HIV May Have

- ◆ HIV as punishment
- ◆ Stigma
- ◆ Guilt
- ◆ Existential distress
- ◆ Fear of death
- ◆ Shame
- ◆ Maintaining hope
- ◆ Defining one's purpose in life
- ◆ Compatibility with religious beliefs

Potential for Transcendence, Rather Than Victimization For People who are HIV+

- ◆ Process of introspection about themselves, their pasts, and current ways of coping.
- ◆ Process of life affirmation that can serve as a strong motivational base for coping
- ◆ Reconceptualizing time with the recognition of possible impending death and the intention to live in the present.
- ◆ Renewed sense of unity with others and the world as a whole.

“Psychological and Spiritual Growth in Women Living with HIV”. Heather T. Dunbar, Charles W. Mueller, Cynthia Medina, Tamra Wolf. *Social Work*, Vol. 43, 1998



Benefits of Addressing Spirituality

- ◆ Evokes comforting emotions and feelings
- ◆ Offers strength, empowerment and comfort
- ◆ Eases emotional burden
- ◆ Offers social support and a sense of belonging
- ◆ Offers spiritual support through a relationship with God [or a Higher Power]
- ◆ Facilitates meaning and acceptance of diagnosis
- ◆ Helps preserve health
- ◆ Relieves fear and uncertainty of death
- ◆ Facilitates self-acceptance and reduces self-blame

“The Perceived Benefits of Religious and Spiritual Coping among Older Adults Living with HIV/AIDS”.
Karolynn Siegel and Eric W. Schrimshaw. *J for the Scientific Study of Religion* (41:1) 2002. pgs 91-102

Addressing Spirituality Recognizes the Personal Strengths In & Empowers People who are HIV+

“It is the great error of our day in the treatment of the human being that physicians separate the soul from the body.”

- Plato

Measuring Outcomes

In the Spring 2009, students from Richard Stockton College of NJ developed and implemented a study to determine the impact of participation in Siloam's programs on their quality of life, under the direction of Mary Lou Galantino, PT, MS, PhD, Professor of Physical Therapy.



Study Sample

- ◆ Sample of convenience
- ◆ 56 participants with HIV disease initially completed demographic and QOL surveys prior to the implementation of a 3 month program.
- ◆ 26 completed the survey after the intervention.



Measurement Tools Used for the Study

- ◆ **HAT-QoL**
 - ◆ **Assesses concerns of people living with HIV/AIDS**
 - ◆ **Covers overall functional dimensions**
 - ◆ **42 items**
(Robinson, 2004)

- ◆ **Facit-Sp**
 - ◆ **Assesses chronic illness therapy & spiritual well-being**
(Peterman, et. al., 2002)

- ◆ **Self-Efficacy**
 - ◆ **Measures individuals' belief that they can manage their chronic condition**
 - ◆ **6 items**

- ◆ **Qualitative Questions**

Qualitative Questions

- ◆ How have Siloam's programs help you live differently?
- ◆ How has your physical, emotional and/or spiritual well-being improved over the last 3 months?
- ◆ What small changes have you been able to make that you feel you will be able to continue?
- ◆ What part of the program have you enjoyed most?
- ◆ What part of the program did you like the least or would like to see changes or improvements?
- ◆ Would you recommend this program to someone in your situation?

Data Analysis and Results

- ◆ SPSS 17.0 was used to analyze the data.
- ◆ 56 participants, comprised of mostly minority populations on disability or unemployed completed the surveys at baseline.
- ◆ Means on all measures of spirituality improved, however there were no significant changes noted through a paired t-test in any of the 3 surveys.
- ◆ Trends in the HAT-QOL subscales demonstrated improvement in various domains of QOL.

Qualitative Question	Most Common Answers
How has Siloam's programs help you live differently?	Peace, acceptance, greater awareness of one's life, and spirituality
How has your physical, emotional and/or spiritual well-being improved over the last 3 months?	Increase in physical, emotional, and spiritual well-being
What small changes have you been able to make that you feel you will be able to continue?	Making more time for oneself and acceptance
What part of the program have you enjoyed most?	Support groups and the instructor/ counselor
What part of the program did you like the least or would like to see changes or improvements?	The majority said they would not change anything about the program
Would you recommend this program to someone in your situation?	Yes

Research Findings

- ◆ Of the 26 completed surveys, all responded to open-ended questions.
- ◆ Increased frequency of peace, "acceptance" and greater awareness of one's life physically, emotionally and spiritually, were primary perceived benefits of the programs at Siloam.
- ◆ The changes that participants felt could be maintained included making more time for oneself and acceptance.
- ◆ The most helpful aspect of Siloam's programs included support groups and the instructor/counselor.

Research Conclusions

- ◆ Spiritual based programs offered in a community based outreach program for people living with HIV disease appear to be a promising intervention.
- ◆ Results show improvement in various aspects of QOL as well as domains of health, spirituality and well-being in an HIV population.
- ◆ These observations may help guide further clinical application of community based integrative therapy programs and future research on the appropriate dose-response relationship throughout one's lifespan with HIV disease.
- ◆ Further research is necessary to determine true effect of integrative therapies.

Research Study Limitations

- ◆ Sample of convenience with no comparator group
- ◆ Clients at various stages of the disease
- ◆ Unable to control for physical activity of participants outside Siloam.
- ◆ Instructors are volunteers that administer the interventions. Standardization of protocols may not be attained if there are different instructors.
- ◆ Gender/age and severity of disease may affect the participation/adherence level of participants.
- ◆ Socioeconomic status may play a role in participation of the HIV/AIDS individuals in the Siloam interventions.

Hopes for Further Research

- ◆ To study the impact that participation in wellness programs has on HIV + clients' physical condition, such as CD4 count and viral load, blood pressure, cortisol levels and other physiological measures.
- ◆ To study the impact that participation in wellness programs has on:
 - adherence to medications,
 - medical appointments, and to
 - the number and duration of hospitalizations.

Complementary Therapies & Funding

Siloam is the only place in Pennsylvania where individuals with HIV/AIDS can get free comprehensive complementary services, however:

- ◆ No federal funds (Ryan White monies) are available for complementary care services.
- ◆ There are no fees for our services and no guaranteed stream of revenue.
- ◆ Siloam receives monies from grants, corporate support, donations and special events.
- ◆ Funding our programs is a chronic concern.

