A Community Based Psychosocial Spiritual Model of End-of-Life Care: Reflections on over a decade of service

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The Jewish Healing and Hospice alliance is an initiative of UJA-Federation of NY. Through the vision and funding of this Alliance, three community agencies have developed programs which bring social work services, integrative nursing and spiritual care to individuals and families facing life threatening and life changing illness. We will discuss the formation of the alliance, the mission to serve the Jewish community, development of the three Regional Care Centers serving both urban and suburban areas, hospice, palliative care and community collaborations, a unique model of staff development in response to a rapidly changing health care climate which addresses the issues presented by the Affordable Care Act.

Our community-based paradigm demonstrates the unique way we seamlessly enhance our clients and their families’ level of care and quality of life. Through clinical collaboration where current cases and psychosocial-spiritual issues are discussed among our three community agencies, we are able to share knowledge of current Palliative care advances coupled with clinical practice in order to better serve our clients. Monthly collaboration integrates the services of a professor/facilitator, leader in the field of Palliative and E-O-L Care, expert psychiatrists in field of Trauma and End-of-Life Care, and our RCC staff of social workers and clergy.

We hope to demonstrate how this collaboration has strengthened our knowledge of the field of Palliative Care Social Work utilizing the vast expertise of leaders in the field and the support of our sister agencies, and how it has evolved over the past decade.
The Initiative

UJA – Federation of NY
The Jewish Healing and Hospice Alliance

NYC
JBFCs – The Shira Ruskay Center

Westchester
WJCS – Pathways to Care

Long Island
FEGS (MJHS) Partners in Dignity

Community Partners
Mission

- Integrate both spiritual and religious resources in the delivery of client service
- Enhance community awareness thru the development of community agency collaborations
- Educate Rabbis and Synagogue Communities about EOL issues and resources
- Educate the Jewish Community about EOL issues and resources
- Educating medical professionals

Improve the quality of life for the Jewish Community facing Life Threatening Illness

Educate and refer clients to appropriate medical and community based care

Support and counsel the client and caregiver thru the course of the illness

Provide support, education, and community towards an integration of grief and loss.

Integrate both spiritual and religious resources in the delivery of client service
Objectives

- Provide caring support to the Jewish Community facing E-O-L or Life Limiting Illness
- Ready our system to deliver Culturally Competent Care
- Maintain Three Regional Centers
  - New York City
  - Long Island
  - Westchester
- Develop Community Partnerships
Mobilize the Community

- Hospitals
- Hospices
- Long Term Care Facilities
- Synagogues
- Primary Care Physicians
- JCCs & Human Service Agencies
Community and Agency Collaboration

- Hospitals
- Hospices
- Community Physicians
- Home Care Agencies
- Senior Case Management Agencies
- Faith Based Organizations
- Social Service Agencies
- Collaboration between SISTER programs
- Professional and agency associations
Direct Care Services

- Discuss values & goals
- Present range of care options
- Access supportive services
- Coordinate care between settings
- Link to community Supports
- Connect to benefits and health services
- Arrange for volunteer assistance
- Respond to changing conditions
- Provide ongoing and episodic support
- Meet the client where they are in various settings
- Offer spiritual support
Integrated Program Staffing
Psychosocial and Spiritual Intervention

Social Workers

- Telephone information and referral
- Office visits
- Home visits
- Community education
- Individual, Family, and Group Intervention
- Bereavement Counseling- Individual and Group
- Navigating Healthcare Systems and Linkages to Resources
- Assistance with Advanced Directives
- Care Management
- Advocacy
- Caregiver Support
- Entitlement Counseling and Emergency Assistance
Integrated Program Staffing
Psychosocial and Spiritual Intervention

Rabbis- Chaplains-Spiritual Care Coordinators

- Spiritual counseling and religious guidance
- Office visits
- Home visits
- Community and Professional Education
- Individual, Family, Group Intervention
- Bereavement Counseling- Individual and Group
- Advance Planning for Funerals
Spirituality

- Concepts of Spirituality:
  - Forgiveness, Hopefulness, Acceptance, Gratitude, Complaint
- Providing compassionate, comforting care always incorporates spirituality.
- Spirituality is intricately weaved through each empathetic interaction, and essential to the provision of effective Palliative Care and Bereavement Counseling.
- Spirituality may be expressed by Jews through specifics of Jewish practices, wisdom, theology and interaction with the community.

- Preparing Meaningful Legacy
- Beyond the Jewish Community
Nursing as Care Partner - Vignette

• Caroline is 62 year old woman who has advanced uterine cancer. She is an intelligent woman who has always been in charge of her life and a great support to her 6 children and many grandchildren. She has risen above a painful history of abuse, neglect and abandonment as a child and wife, becoming an advocate for abused women and a teacher of dysfunctional parents. She is an inspiration to many.

• It has been very difficult for Caroline to accept the severity of her illness and her wish to do everything and anything to prolong her life was responded to by her very caring medical team with new recommendations for chemo when one was not working. The Partners in Dignity Social Work Care Manager worked very closely with Caroline for several months. Seeing her through several hospitalizations and helping her assess and analyze recommendations in order to make decisions. The conversation regarding advance directives and goals of care were initiated. As soon as we were able to engaged our nurse practitioner in this process. Caroline was so relieved. She was experiencing very painful symptoms. She was miserable. During his first visit, he was able to establish an excellent rapport and trust. His meeting with her was unrushed and undistracted. He gave her his full attention, listened carefully and made suggestions which ultimately led to relieving her symptoms. During his second visit, he addressed her concerns and biases regarding pain medication. He also elaborated on advance directives and discussed the MOLST, answering her questions. Not only did the involvement of a competent nurse practitioner help our client/patient, his involvement also provided needed support and information to her caregivers, including the PID Care Manager. He introduced the hospice benefit and as a result Caroline is receiving much needed hospice care at home.
Westchester Jewish Community Services
Pathways to Care Program (PTC)
Community Based Collaborations

• Connecting with Others Support Group answers local need for those living with life limiting and chronic illness. Curriculum based sessions allow clients to express themselves through literature, poetry and other creative means.

• Collaboration with the Bereavement Professionals Association of Westchester and Fairfield Counties allows for broader range of services provided to clients, as well as peer support and psycho-education.

• Chosen as a Partner of Excellence with Sharsheret, a national not-for-profit organization supporting Jewish women and their families facing breast, ovarian and other genetic cancers. PTC staff to provide community education through awareness events and individual and family support.

• Designated by the Alzheimer’s Association – Hudson Valley Chapter to provide care consultations for individuals and family members. PTC to provide assessments, care plans, resource referrals, linkages to community resources, as well as education and support.
R – 69 year old male diagnosed with stage 2 a/b pancreatic cancer. R was referred to PTC through his sister’s synagogue. R is a self-described “loner” with few contacts in the community. R is very athletic, loves to cook and write fiction. R discusses with PTC worker his fears over dying and his loss of control during treatment. R often expresses anger during his therapy sessions directed toward the illness, the medical community and others. R rejects the support and advice the PTC worker offers.

Over the course of R’s illness the PTC worker validates R’s strengths urging him to use his love of writing as an avenue to discuss his feelings surrounding the cancer. Through weekly office, home and hospital visits the PTC worker is able to gradually gain R’s trust. Using clinical feedback the PTC worker received during monthly Regional Care Center supervision she was able to work with R on coping skills for his anger, loss of control and attachment issues. PTC’s holistic nurse provided Reiki treatments to R for relaxation and symptom management, and a nurse was brought in from a local Cancer Support agency to assist R with navigating the medical world. PTC supported R from diagnosis to his death 1 year later. He was able to finish in his final days the short story he wrote about his cancer journey. R expressed his gratitude to PTC worker for “sticking with him”. His sister commented to PTC that we helped him leave a lasting legacy. PTC continued to support R’s sister after his death with individual bereavement counseling.
Collaborative
Mount Sinai Medical Center, Ruttenburg Treatment Center
JBFCS/Shira Ruskay Center

- Identified need for psycho-social and treatment for patients following active phase of cancer treatment.
- Following acute treatment, psycho-social-spiritual support through the outpatient palliative care clinic is limited and home visits to ill patients caregivers are not available.
- Partnership has resulted in a meaningful program providing support to 39 patients and families representing a culturally diverse population. Monthly meetings are held with staff of both partners.
- 631 service interventions were offered including 153 home visits.
- Response to need for increased community collaboration following Affordable Care Act.
Vignette: “Helping a Patient to Reconnect with his Community of Support via Spiritual Intervention”

- C, a 40 year old, single man with rectal cancer. Referred to SRC by Hospital partner shortly after discharge from hospital; was often tearful, feeling isolated from friends, and struggling to be hopeful about taking his life off hold. The change in his physical appearance was distressing to him. During meetings with Rabbi he explored his reluctance to allow friends to see him because of the changes in his physical appearance, his unpredictable fatigue and the potentially unpleasant smells, sounds and need to be near a bathroom caused by his specific cancer. Early on he had posted frequently on Facebook and had felt support, but since the second tumor he had not posted anything. Rabbi encouraged him to return to Facebook and the online support that had been helpful in the past.

- At the next meeting, he reported that he had posted and blogged with more details about the specific cancer and the symptoms that made it hard to be social. He was overwhelmed by the support he received from friends and acquaintances around the world. He was also more willing to allow friends in NYC to visit him. During this time, he was able to speak openly with his medical team, to discuss different mood stabilizing medications. C and Rabbi prepared for first anniversary of initial diagnosis; he told her how much it was helping him to follow her recommendation on finding a small, ordinary thing to be grateful for each day, rather than waiting for big things to happen.
Annual Palliative Care Conference

• Molloy College, in collaboration with FEGS Health & Human Services and a network of community partners presents an Annual Palliative Care Conference on LI. The conference focuses on the new developments in this growing and dynamic field. Experts from Medicine, Nursing, Pastoral Care, Child Life and Social Work will present the latest advancements in the fields of symptom management, ethics and communication, staff self-care and bereavement. Clinicians from across the continuum will engage participants in discussions about best practices and barriers to timely excellent palliative care in hospitals, nursing homes, and hospice organizations.
Staff Development

- Regional Care Center Model of Advanced Training and Supervision
- Individual Supervision
- Peer / Team Support and Case Review
- Collaboration and Service Support from Larger Agency
- EOL Issues/Bereavement Issues/Palliative Care Initiatives
- Profession-Specific Conferences and Meetings
Regional Care Center Model of Advanced Training and Supervision

- Monthly Meeting of all Program Staff
- Facilitated by PhD Social Work Professor from NYU School of Social Work
- Co-facilitated by Psychiatrists 4-6 times per year
- Alternating agency written case presentations (2 per meeting)
- Half Day Expert Training Sessions 1-2 times per year with guest lecturers
- Topic Examples:
  - Complicated Grief
  - Cognitive Behavior Techniques
  - Common Psychological and Physical Symptomatology of Cancer, Alzheimer’s Disease, ALS, Parkinson’s Disease.
  - Working with Children
  - Suffering and despair
Service Statistics

- Over a two year period 3 agencies provide:
  - 1,157 New Clients with Individual Services
  - 3,960 Total Clients with Individual Services
  - 833 Total Clients with Bereavement Services
  - 863 Total Clients with Caregiver Support
  - 5,102 Home Visits
  - 194 Community Educational Events

- Client interventions can range from 1 assessment/intervention session, to weekly sessions over a period of 1-2 years. Services are always provided based on our professional assessment of need, and may be continuous or intermittent depending on needs of clients.
Community Education/Professional Education Topics

- Jewish Approaches to Grieving
- Spiritual Issues for Caregivers
- Intimacy, Sexuality and Cancer
- How to Begin the Conversation
- Life Choices: Understanding the Options for Medical Treatment and Care
- Palliative Care on the Frontline: Diagnosis through End of Life
- Training for synagogue volunteer Chesed/Caring Committees
- When someone you love loses someone they love (for 20-45)
- Jewish teachings about Miracles
- Guilt and Forgiveness in Loss
- Untangling the Web of the New Health Care Environment
Community Education/Professional Education Topics (cont’d)

- Life Is a Journey: Helping Caregivers Ensure the Rights of the Developmentally Disabled Individual at the End of Life
- Rabbinic Training Course in End Of Life issues
- P.A.C.T. (Preparing Advanced Care Together): End of Life issues in working with the Developmentally Disabled
- Bereavement in the Very Young: Skills to address the needs of children 0-4 facing loss and bereavement in “at-risk” communities
- Communicating with Clients about End of Life Issues
- Intergenerational Transmission of Grief: Working with Holocaust Survivors and their Families
- Complicated Grief
- In This Moment: Increasing Our Awareness of the Spiritual and Religious Needs of Clients at End of Life
- Jewish teachings about EOL for medical professionals
Bereavement/Grief Services and Programs

- Individual counseling
- Bereavement groups
- Holiday programs for the bereaved
- Psycho-education around grief
- Community consultation in the event of a traumatic death
Groups

- Loss of a Spouse/Partner
- Sibling Loss
- Support for the Divorced and Separated
- Loss of a Parent
- SIDS (Sudden Infant Death Syndrome) group for parents
- Parents who Lost a Child
- Suicide loss groups
  - M’kom Shalom: A Place of Peace
    (for Jewish survivors of a close one’s suicide)
- Caregiver Support Groups
- Chronic Illness Support Group
Reflections on Over a Decade of Service

- Model of service allows us to engage with clients episodically as the initial illness progresses, is in remission, or is cured
- Client reengagement over time
- Cultural change in use of hospice and palliative care
- Clients living with chronic Illness
- Beyond End-of-life services
- Funding beyond initial grant
- Institutional survival
Client reengagement over time: Vignettes

• J received support through her mother’s final illness and then attended a bereavement group for young adult parental loss. She shared that her sister had very advanced MS and she was in contact with SRC staff over a period of years as her sister, who had then abused J as a child, survived a number of life threatening episodes and then decisions had to be made after she did not come out of a coma. J continues to receive individual bereavement support as needed during the year since her sister’s death.

• L came to a bereavement group following the loss of her partner from prostate cancer. During the course of the group, her father, who also had prostate cancer reached a terminal phase. L, a long distance caregiver, child of alcoholics, and living with her own chronic illness, consulted often on care management and spiritual issues. After her father’s death, she came to a parental loss group. Last year, she returned for similar support as her mother was diagnosed with Alzheimer’s and has just been moved to NYC.
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