CC Hospice Care: and Pain & Palliative Care Service and Spiritual Care Department

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Working Together:
Pain & Palliative Care and Spiritual Care

- The CC hospice unit grew out of our 2 programs' combined missions focused on the physical, spiritual, psychological, and social needs of CC patients at end-of-life
- Hospice is very much NOT an isolated unit but part of BOTH of our bigger programs
- We follow patients from days to years and then, if and when they are ready, they transfer to our hospice.
- Working closely together allows:
  - Our teams to connect closely
  - Depending on patients' needs at any moment, either our pain and palliative care experts or our spiritual care professionals, OR BOTH can respond and offer compassionate care
- This strong collaboration is one of the things that makes our CC unit unique from other hospices

Palliative Care at the NIH CC

- As Dam Cicely Saunders did at St Christopher's Hospice in London, the CC established palliative care; includes these missions:
  - Clinical Care
  - Education
  - Research
- Not limited to end of life care
- Optimized by early initiation and implementation across the disease process
- Not limited to pain management; interventions for any quality of life issue
- Delivered concurrently with research
- Combination of active and compassionate therapies focused in physical, psychological, social, and spiritual dimensions. The goal is to help heal the patient, family, and health care providers.

Palliative Care at the NIH CC "Clinical"

- Built an interdisciplinary team: spiritual care, rec therapy, social work, nutrition
- Inpatient and outpatient services; we see at least 1/4 of inpatients every day
- Half the patients seen are younger than 39 years
- Introduced a Bereavement Program (2005); more than 2000 families served
- Began debriefing program for staff; coordinated by Spiritual Care
- Annual memorial services; coordinated by Spiritual Care
- Integrative modalities: reiki, acupuncture, aromatherapy, mindfulness, biofeedback, pet therapy, art therapy, etc.
- Two in-patient hospice beds

Palliative Care at the NIH CC "Education"

- Fellowship program in hospice and palliative care (since 2004)
- Other trainees: medical and nursing students, residents, fellows, chaplains, social workers, bioethics, others
- Intramural research training award: Research program involves post-bac and post-doc programs
- Rotations for one month include
  - All oncology fellows from NIH and WRNMMC
  - All pain fellows from Walter Reed National Military Medical Center
  - Palliative care fellows from George Washington University

Palliative Care at the NIH CC "Research"

- Palliative care outcomes in surgical oncology malignancies (2002-2011); mixed methods
- Increasing the number of out-patients receiving spiritual assessments (2014-2015)
- An evaluation of a Bereavement Program in a US research hospital (2005– 2015)
- Spirituality in patients with chronic GVHD following bone marrow transplant
- Healing Garden Project at WRNMMC (2009 – present); mixed methods. Funding: Nature Sacred: TKF
- NIH HEALS (Healing Experience of All Life Stressors): development of a psychosocial spiritual assessment tool
- Mindfulness Based Self-Care: to reduce stress and burn out
- Nature adventure ± mindfulness for health care providers working with pts with covid

Hospice Rooms

- Opened July, 2018
- Two beds
- Each bed has an attached family room
  - Chair
  - Sofa bed
  - Microwave/Refrigerator

Hospice Nurses

- Nurses from 3SEN
- Education (CC lectures)
- Observation hours at Montgomery Hospice
- Observation hours with NIH Pain & Palliative Care Team

The tea cart!

Goal of Hospice Care

- Care to focus on quality of living, even as the patient is close to end of life
- Involve the family to the greatest extent possible
- Patient comfort
  - Continuing only those interventions and medications that can add to patient comfort
  - Hospice order set developed to facilitate transfer into the hospice unit
  - MEC policy to guide care

Family Meeting Room for Hospice Beds


AUG 9 2002

Hospital day transferred to hospice

mean: 30.5 ± 46.5

Hospital day	n	%
0 (admit day)	6	11.1
1-10	19	35.2
11-20	10	18.5
21-30	6	11.1
31-40	4	7.4
41-50	1	1.9
51-60	1	1.9
61-70	1	1.9
71-80	0	0
81-90	2	3.7
91-100	1	1.9
> 100 days	2	3.7
> 200 days	1	1.9

Length of time in NIH hospice bed

mean 6.6 ± 10.5

# of days	N	%
< 1	4	7.4
1-5	31	57.4
6-10	14	25.0
11-15	2	3.7
16-20	0	0.0
21-25	1	1.9
35d, 70d	2	3.7

Place of death

- Some patients were transferred to hospice care, either at home, or in a hospice in-patient unit.

Place of death	n	%
Clinical Center	47	87.0
Transferred out	7	13.0

Percent of NIH CC deaths in hospice (8 July 2018 – 30 Sept 2021)

Place of death	m	%
Hospice	48	35.8
ICU	67	50.0
Other	17*	12.7
Peds	2	1.5
Total	134	100%

- *1 hospice pt transferred to covid unit; she died there
- Peds end of life care provided on peds unit with PPCS very involved
- Other patients transferred out to home hospice prior to death

Rapid autopsy

Rapid autopsy	n	%
Yes	8	14.8
No	46	85.2


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driventocure.org
Our Mission
Bringing awareness and funding for the research of rare kidney cancers in children and young adults.
#F CANCR

Hospice Patients

- July 2018 – July 2021
- 54 patients
- Age: 21 – 92 years; X 58.4 ± 14.4
  - Does not include children who received end of life care on the pediatric unit

Patient Characteristics

Gender	n	%
Male	35	64.8
Female	19	35.2

Race	n	%
Asian	4	7.4
Black	16	29.6
White	31	57.4
Unknown	3	5.6

Religion	n	%
Christian	16	29.7
Christian-Catholic	13	24.1
Jewish	4	7.4
Muslim	3	5.6
None	16	29.6
Not Specified	2	3.6
Total	54	

Institute Utilization

Institute	n	%
NHLBI	2	3.7
NCI	45	83.3
NCI urology	1	1.9
NIAID	1	1.9
NINDS	5	9.3

Note: **3 NINDS patients were in the last 2.5 months; one additional in the last 6 months, prompting a new collaboration to introduce palliative care earlier with one group of patients.**

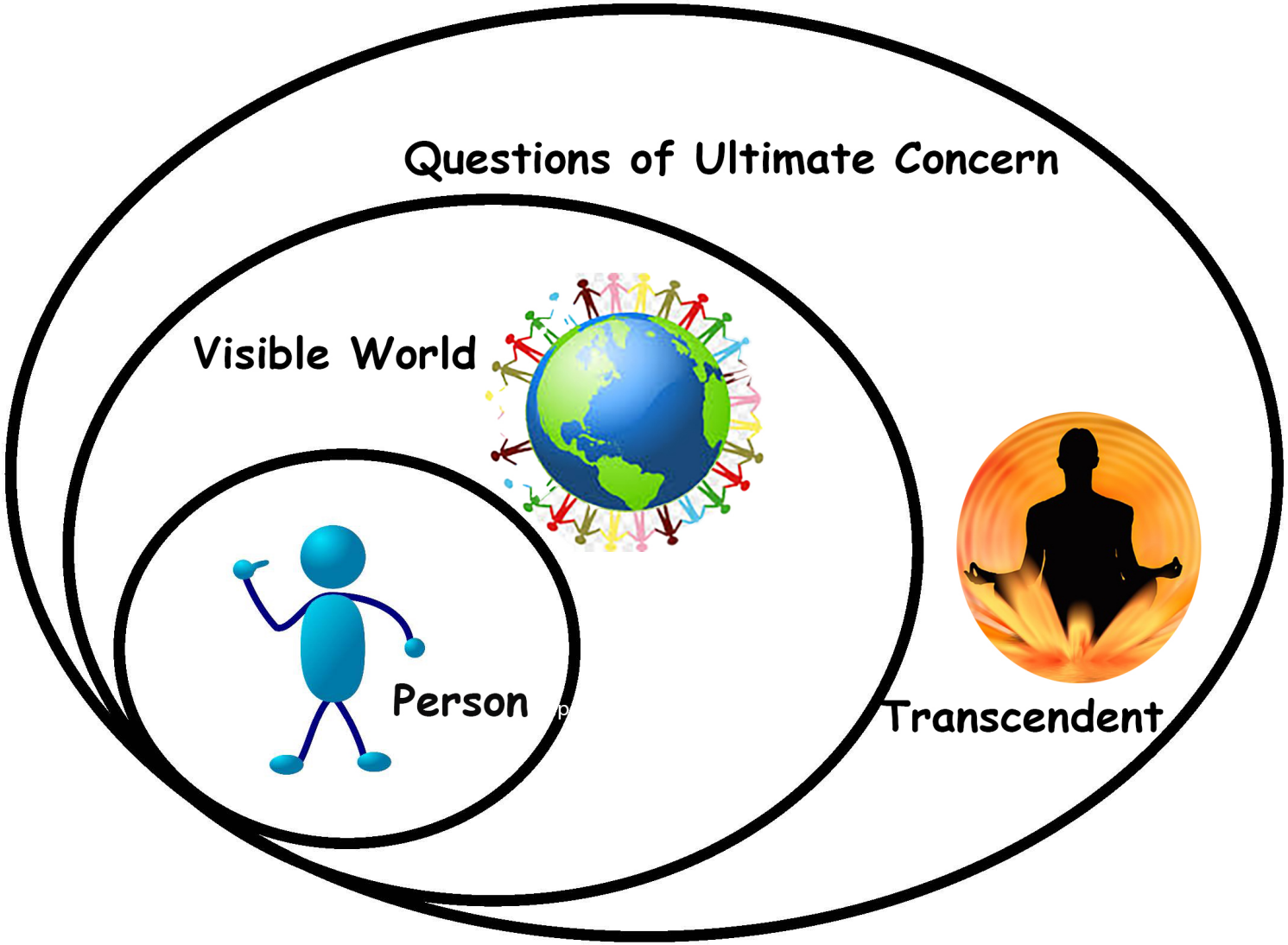
Spirituality is . . .

. . .the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.

Puchalski, et. al. (2009)

…and especially important at the end-of-life

Dimensions of Human Experience



Spiritual Care Core Principles for Hospice Care

- Not everyone has a religion but everyone has a spirit
- Dedicated, individualized care for those whose sources of meaning and purpose range across diverse religious, philosophical, ethical and existential commitments
- Provided within a system of spiritual care
- Professional chaplains and supervised trainees

Provision of Spiritual Care

- **All hospice patients and families will be seen by a chaplain within 24 hours of admission to hospice.**
- **Most will have a preexisting relationship with a chaplain from their in-patient stay or clinic appointments.**
- **Spiritual care includes the patient's social system – one illness but a shared suffering**
- **Spiritual care for CC hospice nurses and other hospice caregivers that includes:**
  - **1:1 spiritual support**
  - **Debriefing groups**
  - **Memorial services**

Shared Goals for the Future

- Train additional hospice nurses
- Expand training for pediatric patients; currently receive End-of-Life Nursing Education Consortium (ELNEC) training, in-services, and other education
  - currently patients remain on peds and receive hospice care
- Continue to collaborate with ICU to determine optimal setting for care at end of life: hospice or ICU.
  - If ICU, how can we optimize?
- Continue strong partnership between Pain & Palliative Care and Spiritual Care teams

Take Back to Practice

Palliative Intervention

- **Early**
- **Available**
- **Integrative**
- **Reassurance**

To our patient-Heroes disguised as ordinary people going on an extraordinary journey !

…and they lived at peace each day they had……