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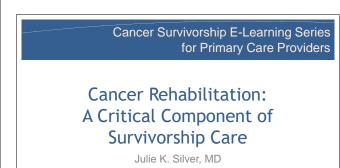
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Disclosures

Founder, Oncology Rehab Partners which has developed the STAR Program® (Survivorship Training and Rehabilitation) certifications for hospitals and cancer centers in the United States that provide a comprehensive model for cancer prehabilitation and rehabilitation.

Author/editor of several books on cancer rehabilitation & recovery.





Learning Objectives

At the end of this presentation, you will be able to:

- Describe the role and importance of rehabilitation post-treatment
- Identify interventions to assist in the physical and psychological recovery of cancer survivors

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Gap in Care

- 163 community dwelling patients with metastatic breast cancer
- 92% had at least one physical impairment
- 530 impairments identified
- 92% of the impairments required physiatry but only 30% received this care
- 88% required physical therapy (PT) and/or occupational therapy (OT), but only 21% received this care

Conclusion: More than 90% of patients needed cancer rehab but fewer than 30% received this care. In the ambulatory setting, less than 2% of patients received care.

Authors' comments: "This seems particularly unfortunate in view of the efficacy of standard rehabilitation interventions in treating many of these impairments in patients with cancer..."

Source: Cheville AL, et al. J Clin Onc. 2008.
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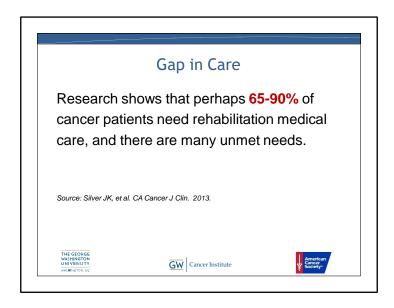
Cancer

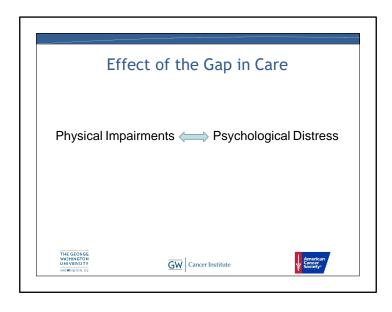
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Health Related Quality of Life (HRQOL) of Cancer Survivors vs. Others

Survivors (n=1,822) Others (n=24,804)

Poor physical Poor physical HRQOL=24.5% HRQOL=10.2%

Poor mental HRQOL=10.1% Poor mental HRQOL=5.9%

This represents 3.3 million U.S. cancer survivors with poor physical HRQOL & 1.4 million with poor mental HRQOL.

Source: Weaver KE, et al. Cancer Epidemiology Biomarkers & Prevention. 2012.

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Addressing Physical and Psychological Effects

- 1. If there are more cancer survivors who have reduced QOL due to physical problems (vs. psychological ones), and
- 2. A leading cause of psychological distress is physical disability, then
- 3. Treating physical impairments will significantly impact 3 important things: physical disability, psychological distress and QOL.

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Recognition of the Gap in Care

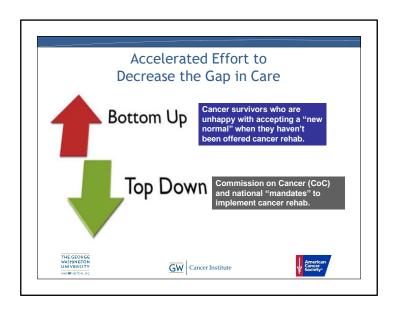
Many people now recognize the opportunity to significantly improve physical, psychological and QOL outcomes in oncology patients and are actively focusing on strategies to decrease the gap in cancer rehabilitation care.

This is creating a major shift in oncology care towards incorporating cancer rehab into the cancer care continuum.

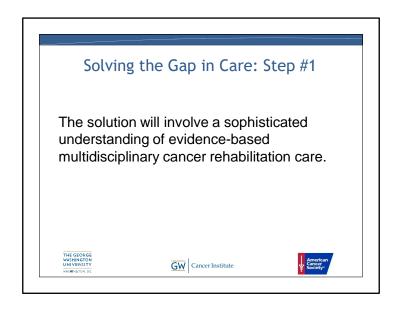
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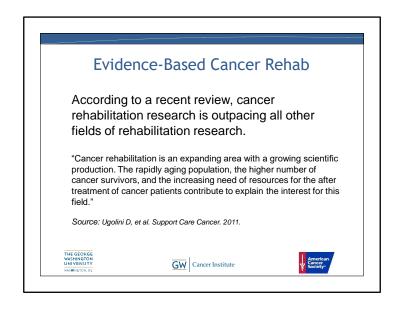


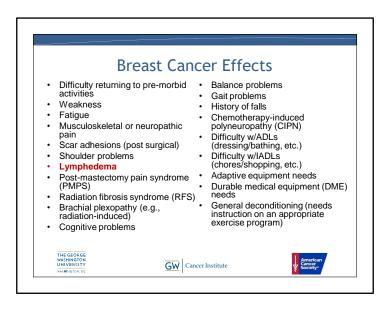


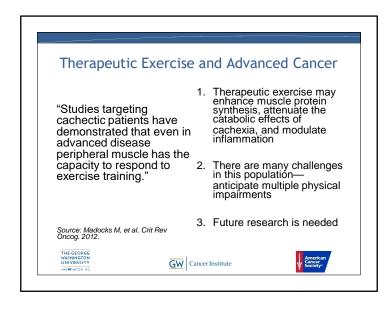


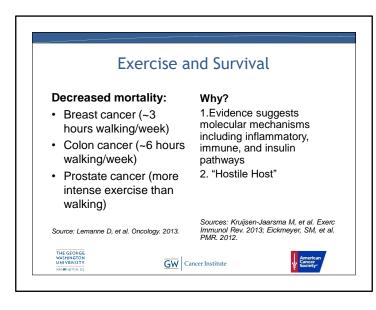


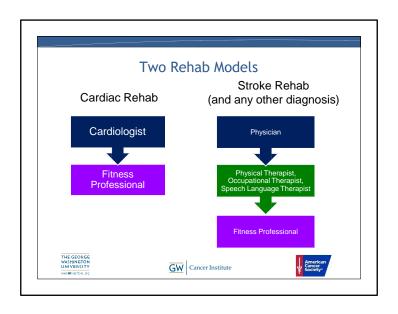




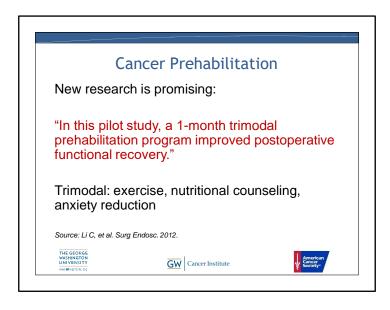












Esophagectomy: Fast Track vs. Conventional

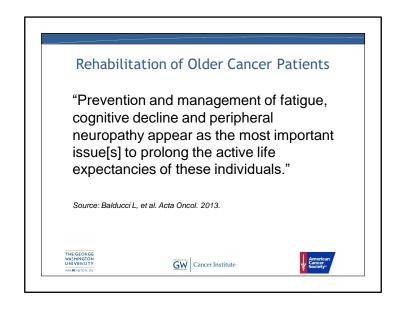
- Hospital stay (7.7 vs 14.8 days)
- Complications [30d] (29.1 vs 47.4%)
- Patient satisfaction [very good/pain] (87.3 vs 57.4%)

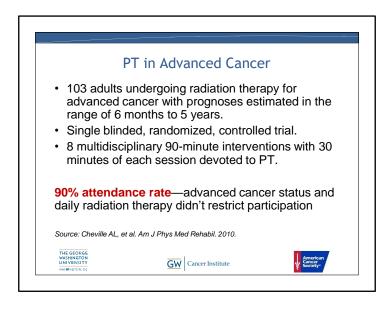
"The fast-track rehabilitation program results in fewer complications, less postoperative pain, a reduction in hospital length of stay, and quicker return to work and normal activities after esophagectomy."

Source: Cao S, et al. Support Cancer Care. 2013.









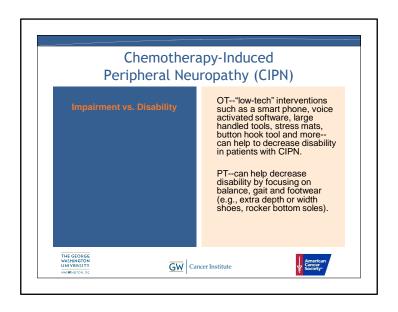
Chemotherapy-Induced Peripheral Neuropathy (CIPN)

Chemotherapy induced peripheral neuropathy (CIPN), a possible side-effect of some chemotherapy drugs that can injure nerves, is the most prevalent neurologic complication of cancer treatment.

Source: Kannarkat G, et al. Curr Opin Neurol. 2007.







Cancer-Related Fatigue (CRF)

- For cancer survivors who have impairments, it is important to refer them for rehabilitation therapy consultations rather than group exercise classes.
- This is similar to how stroke survivors and other patients with impairments are rehabilitated.







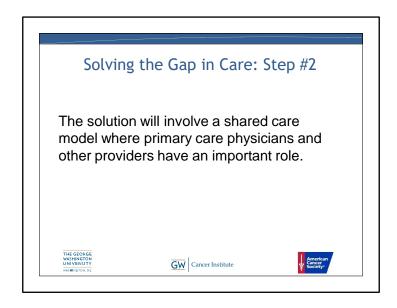
"Chemo Brain"

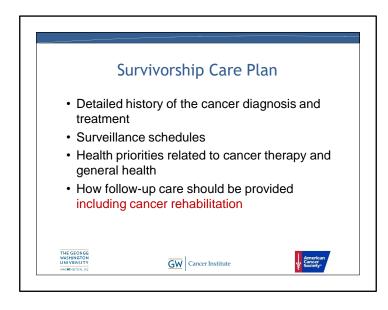
- Mild cognitive impairment in cancer survivors has often not been adequately addressed. However it's likely that the same types of strategies used for other conditions would work well in this population, too.
- Neurocognitive rehabilitation interventions (e.g., post-concussive syndrome) have been well studied and use strategies to assist with focus, concentration, attention, memory and organizational skills.

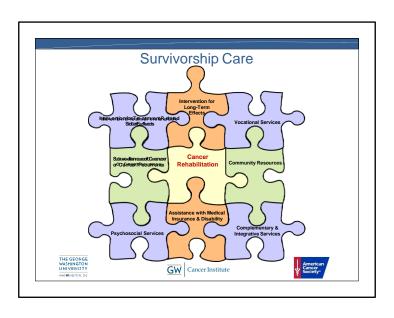
Source: Langenbahn DM, et al. Arch Phys Med Rehabil. 2013.

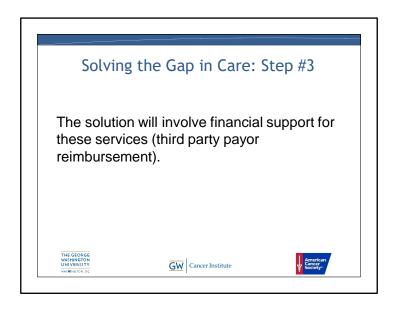


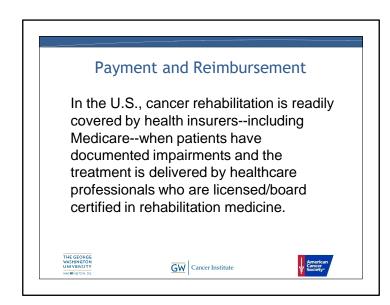


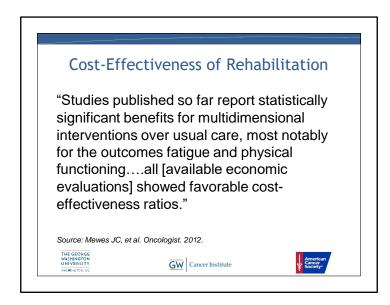


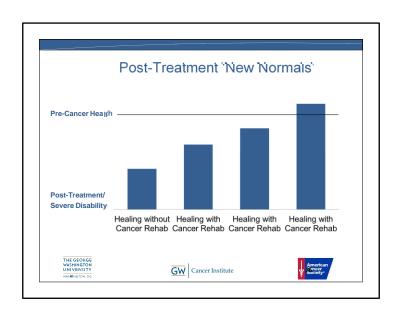


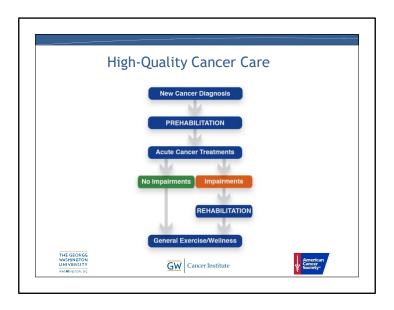












Strategies that Work

- 1. Start at diagnosis: prehabilitation
- 2. Implement evidence-based multimodal fast track rehabilitation care
- 3. Identify impairments all along the continuum
- 4. Refer patients with impairments to licensed/board certified rehabilitation healthcare professionals

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Next on the Horizon

- 1. More and better studies on cancer rehab
- 2. More sophisticated understanding by healthcare professionals of the difference between general exercise vs therapeutic exercise to treat impairments
- 3. Huge increase in survivors demanding cancer rehab
- 4. Huge increase in providers wanting rehab care of their patients (high-quality cancer care)

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Cancer Survivorship

The Role of Spirituality in Cancer Care

Christina Puchalski, MD, MS
Executive Director, The George Washington
Institute for Spirituality and Health
Professor of Medicine & Health Science
The George Washington University School of
Medicine







Disclosures

Christina Puchalski, MD, MS, is the exec director of the George Washington University Institute for Spirituality and Health (GWISH) and an editor of the Oxford Textbook of Spirituality in Health Care. The Archstone Foundation sponsored the 2009 "Improving the Quality of Spiritual Care: A Consensus Conference" referenced in this presentation. The meeting was co-led by GWISH and City of Hope.

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Learning Objectives

At the end of this presentation, you will be able to:
Describe the role and importance of spirituality
during recovery post-treatment
Identify interventions to assist in the physical and
psychological recovery of cancer survivors

THE GEORGE WASHINGTON UNIVERSITY WASHINGTON, DO Spirituality:
An Essential Part of A Person's
Humanity and a Critical Factor
in Health and Well-Being of
Patients

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World Health Organization (WHO): Definition of Health

"Dynamic state of complete physical, mental, spiritual and social well-being and not merely the absence of disease or infirmity"

Source: 101st Session of the WHO Executive Board, Geneva, January 1998, Resolution FR101 R2

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Spiritual Distress

73% of cancer patients expressed at least one spiritual need

40% of newly diagnosed cancer patients have significant levels of spiritual distress
Cancer patients with low level of spiritual well-being more likely to show significant levels of spiritual distress, including hopelessness and a desire for hastened death

Sources: Astrow AB, et al. J Clin Onc. 2007; Holland JC, et al. J NCCN. 2010; Chochinov WB and Breitbart HM. Handbook of Psychiatry in Pall Med. 2009.

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Secondary Spiritual Distress Diagnoses (a primary must be present to be considered spiritual)

Behavior/mood alterations as evidenced by anger, crying, withdrawal, etc. Pain Feeling out of control Gallows humor Anger
Nightmares/sleep disturbances
Abandonment
Trust



Definition of Spirituality

This definition is based on two conferences....building on two major consensus conferences. People were able to achieve consensus on a broad definition of spirituality.

A global consensus derived definition of spirituality is:

"Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices."

(Puchalski, et.al., 2014)

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Healthcare Outcomes

Research shows the spirituality and/or religion results in:

- >Improved quality of life, >Decreased depression/anxiety >Increased will to live

- > Better physical Well-being,
 > Improved coping,
 > Increased adherence to treatment,
 > Improved social functioning and maintaining social relationships

(Balboni, et.al., 2017; Barlow, et.al., 2013; Holt, et.al., 2009; Jafari, et.al., 2013; Salsman, et.al., 2015

From all of these association studies the most frequent outcomes cited include

- In of these association studies the most frequent outcomes cited in Improved quality of life,
 Decreased depression/anxiety
 Better physical Well-being,
 Improved coping,
 Increased adherence to treatment,
 Improved social functioning and maintaining social relationships

Spirituality helps patients:

Adjust to and cope with the cancer experience Find meaning and purpose Find a sense of health in the midst of disease

Source: McClain CS, et al. Lancet. 2003.



Spiritual well-being in cancer patients:

Lower levels of depression
Decreased despair near end of life
Decreased desire for a hastened death
Lower levels of distress and greater quality of
life across life expectancy prognosis

Sources: Breitbart W. Support Care Cancer. 2002; Greenstein M and Breitbart W. AM J Psychother. 2000; Laubmeier KK, et al. International Journal of Behavioral Medicine. 2004.

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Cancer Diagnosis: Why Me?

Spirituality may help people find answers, find hope, meaning

Cancer patients report their spirituality helped them find hope, gratitude and positivity in their cancer experience Spirituality can help with reframing

My illness is a blessing

What an opportunity to see life in a different way

Sources: Taylor E. Cancer Nursing. 2003; Gail TL and Cornblat BA. Psycho-Onc. 2002; Ferrell B, et al. Onc Nursing Forum. 1998.

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Spiritual Care Interventions:

Interdisciplinary Palliative Care Intervention for Patients

In a study of <u>491 patients</u> with lung cancer, investigators assessed the effectiveness of an Interdisciplinary Palliative Care Intervention. The intervention consisted of three main components

First, a nurse completed a comprehensive baseline assessment, including Quality of Life (QOL), symptoms, and psychological distress.

Second, patients participated at weekly Interdisciplinary team (IDT) meetings, and case presentations with nurses, palliative medicine physicians, thoracic surgeons, medical oncologists, geriatric oncologist, pulmonologist, social worker, dietitian, physical therapist, and chaplain.

Third, patients receive four educational sessions, led by nurses, where content was organized around the physical, psychological, social, and spiritual domains of quality of life.

Patients Outcomes of the Group which Received the Spiritual Education Session:

Less depression and less anxiety outcomes of an Interdisciplinary Palliative Care Intervention

Improved spiritual wellbeing Improved patient experience

(Ferrell, et.al., 2015)

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Improving the Quality of Spiritual Care as a Dimension of Palliative Care: A Consensus Conference

Convened February 2009
Betty Ferrell, PhD, MA, FAAN, FPCN, RN
Christina Puchalski, MD, MS, FACP

Supported by the Archstone Foundation, Long Beach, CA, as a part of their End-of-Life Initiative.





National Consensus Practice Guidelines Address 8 Domains of Care

Structure and processes

Physical aspects

Psychological and psychiatric aspects

Social aspects

Spiritual, religious, and existential aspects

Cultural aspects

Imminent death

Ethical and legal aspects









These seven key areas were developed from the original five focus groups from the Consensus Conference.

Interprofessional Spiritual Care: An Integrated Model

Recommendations:

- · Integral to any patient-centered healthcare system
- · Based on honoring dignity, attending to suffering
- Spiritual distress treated the same as any other medical problem
- Spirituality should be considered a "vital sign"
- Generalist-specialist model of care (Board certified chaplains are the experts in spiritual care; clinicians are the generalist spiritual care providers). All patients get a spiritual history or screening
- Integrated into a whole person treatment plan

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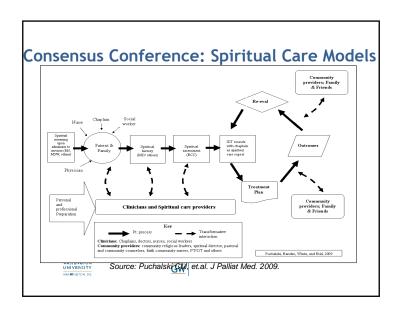
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Source: Puchalski CM, et.al. J Palliat Med. 2009.

Interprofessional Spiritual Care

It is the responsibility of everyone on the team and in the community to:
Listen to patient's spiritual issues
Identify spiritual distress
Support spiritual resources of strength





Terms: Spiritual Distress

Impaired ability to experience and integrate meaning and purpose in life through connectedness with self, others, art, music, literature, nature, and/or a power greater than oneself.

Source: North American Nursing Diagnosis Association International, 2005.

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Spiritual Diagnosis

| Diagnoses (Primary) | Key feature from history | Example Statements |
|-----------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------|
| Existential | Lack of meaning / questions meaning about one's own existence / Concern about afterlife / Questions the meaning of suffering / Seeks spiritual assistance | "My life is meaningless" "I feel useless" |
| Abandonment of God or others | Lack of love, loneliness / Not being remembered / No Sense of Relatedness | "God has abandoned me" "No one comes by anymore" |
| Anger at God or others | Displaces anger toward religious representatives / Inability to forgive | "Why would God take my child its not fair" |
| Concerns about relationship with deity | Closeness to God, deepening relationship | "I want to have a deeper relationship with God" |
| Conflicted or challenged belief systems | Verbalizes inner conflicts or questions about beliefs or faith / Conflicts between religious beliefs and recommended treatments / Questions moral or ethical implications of therapeutic regimen / Express concern with life/death and/or belief system | "I am not sure if God is with me anymore" |

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Spiritual Diagnosis (Con't)

| Diagnoses (Primary) | Key feature from history | Example Statements |
|---------------------------------|----------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|
| Despair/ Hopelessness | Hopelessness about future health, life / Despair as absolute hopelessness, no hope for value in life | "Life is being cut short" "There is nothing left for me to live for" |
| Grief/loss | Grief is the feeling and process associated with a loss of person, health, etc. | "I miss my loved one so much" "I wish I could run again" |
| Guilt/shame | Guilt is feeling that the person has done something wrong or evil; shame is a feeling that the person is bad or evil | "I do not deserve to die pain- free" |
| Reconciliation | Need for forgiveness and/or reconciliation of self or others | "I need to be forgiven for what I did" "I would like my wife to forgive me" |
| Isolation | From religious community or other | "Since moving to the assisted living I am not able to go to my church anymore" |
| Religious specific | Ritual needs / Unable to practice in usual religious practices | "I just can't pray anymore" |
| Religious/Spiritual Struggle | Loss of faith and/or meaning / Religious or spiritual beliefs and/or community not helping with coping | "What if all that I believe is not true" |

Diagnosis Discernment in Clinical Care (Diagnosis Pathway)

Is the patient in distress? If so, is it physical, emotional, social, spiritual or a combination of these?

Who needs to be involved on the team to address the different sources of distress? (mental health, chaplain, clergy, etc.)

What can the clinician identifying the distress do on his/her own? (simple v complex)





Formulation of a Biopsychosocialspiritual **Assessment and Treatment Plan**

Recommendations:

Screen, History and Assess

All health care professionals should do spiritual screening

Clinicians who refer should do spiritual histories and develop appropriate treatment plans working with

Board Certified Chaplain, if possible

Identify spiritual distress (diagnostic labels and codes)

Treatment plans that include psychosocial and spiritual support

Support/encourage in expression of needs and beliefs



- Screen and assess every patient's spiritual symptoms, values, and beliefs and integrate them into the plan of care.
- All trained healthcare professionals should do spiritual screening and history-taking. These caregivers should also identify any spiritual diagnoses and develop a plan of care. Detailed assessment and complex diagnosis and treatment are the purview of the board-certified chaplains working with the interprofessional team as the spiritual care experts.
- Currently available diagnostic labels (e.g., National Comprehensive Cancer Network [NCCN] Distress Management/Pastoral Services guidelines, Diagnostic and Statistical Manual [DSM] code V62.89, and NANDA nursing diagnoses) can be used, but further work is needed to develop more comprehensive diagnostic codes for spiritual
- 4. Treatment plans should include but not be limited to
 - Referral to chaplains, spiritual directors, pastoral counselors, and other spiritual care
 - providers including clergy or faith- community healers for spiritual counseling Development of spiritual goals

 - Meaning-oriented therapy d. Mind-body interventions
 - Rituals, spiritual practices

should be honored.

- Contemplative interventions
- Patients should be encouraged and supported in the expression of their spiritual needs and beliefs as they desire and this should be integrated into the treatment or care plan and reassessed periodically. Written material regarding spiritual care, including a description of the role of chaplains should be made available to patients and families. Family and patient requests specifically related to desired rituals at any point in their care and particularly at the time of death
- Board-certified chaplains should function as spiritual care coordinators and help facilitate appropriate referrals to other spiritual care providers or spiritual therapies (e.g., meditation training) as needed.
- Spiritual support resources from the patient's own spiritual/religious community should be noted in the chart.
- Follow-up evaluations should be done regularly, especially when there is a change in status or level of care, or when a new diagnosis or prognosis is determined.
- Treatment algorithms can be useful adjuncts to determine appropriate interventions.
- 10. The discharge plan of care should include all dimensions of care, including spiritual needs.

Interventions Clinicians Can Do

Compassionate presence and follow up
Reflective listening/query about important life
events—spirituality as connection
Support patient sources of spiritual strength
and note in chart
Connect patient to community resources
Referral to chaplain or other spiritual care
professional



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Spiritual Screening

Do you have any spiritual beliefs or practices that might affect your care?
How important is spirituality in your coping?
How well are those spiritual resources working for you at this time?

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F – Faith and Belief

"Do you consider yourself spiritual or religious?" or "Is spirituality something important to you" or "Do you have spiritual beliefs that help you cope with stress/difficult times?" (Contextualize to reason for visit if it is not the routine history). "What gives your life meaning?"

I – Importance

"What importance does your spirituality have in your life? Has your spirituality "What importance does your spirituality have in your nie? Has your spirituality influence how you take care of yourself, your health? Does your spirituality influence you in your healthcare decision making?" (e.g. advance directives, treatment etc.)

F - Faith, Belief, Meaning I - Importance and Influence C - Community A - Address/Action in Care

"Are you part of a spiritual community? Communities such as churches, temples, and mosques, or a group of like-minded friends, family, or yoga, can serve as strong support systems for some patients. Can explore further: Is this of support to you and how? Is there a group of people you really love or who are important to you?"

A – Address in Care

"How would you like me, your healthcare provider, to address these issues in your healthcare?" (With the newer models including diagnosis of spiritual distress; A also refers to the "Assessment and Plan" of patient spiritual distress or issues within a treatment or care plan.)



FICA: Spiritual Assessment*
The acronym FICA can help structure questions in taking a spiritual history:

For more information on patient spirituality and the role of spirituality in healthcare, contact The George Washington Institute for Spirituality and Health: www.gwish.org

*Adapted with permission from Pachalski CM, Romer AL. Taking a spirinal history allows clinicians to undernand patients more fully. J of Pall Med 2003;128–37. © Copyright, Christina M. Pachalski, MD, 1996

Validation of FICA Tool

Inter-item correlation between FICA quantitative and COH spirituality domain of QOL instrument:

Religion Spiritual Activities Change in spirituality Positive life change Purpose Hopefulness

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> > (Borneman, et.al., 2010)

The FICA tool was validated in a study with 76 patients with solid tumors at City of Hope. Patients were predominantly female (77.6%), had a mean age of 58.7, and 50% were ethnic minorities. Most patients self-identified with a religious preference, with Catholic as most predominant. Breast cancer was the most common diagnosis.

To understand the potential relationships between aspects of spirituality, the inter-item correlations of the Spiritual Well-Being subscale of the **quality of life tool** (spiritual activities, change in spirituality, uncertainty, positive life change, purpose, and hopefulness) and the FICA quantitative item (How would you rate the importance of faith/belief in your life?) have been calculated. These five variables from the other subscales were selected from the quality of life tools as aspects of quality of life recognized as potentially contributing to spiritual distress.

Quantitative data did show that the FICA tool was able to assess several dimensions of spirituality based on correlation with the spirituality indicators in the City of Hope- quality of life tool, specifically religion, spiritual activities, change in spirituality, positive life change, purpose, and hopefulness.

Doris

58 year old female with strong family history of breast cancer

At age 52 a mammogram showed a suspicious lesion, on biopsy it was found to be positive.

Had bilateral mastectomy. The decision caused considerable stress and concern.

Underwent surgery, had a good outcome and doing well since the surgery.

She comes in with new back pain and is worried that this could be a metastasis. She has no other symptoms. She has had chronic back aches in the past.

Exam is consistent with musculoskeletal lumbar tightness. Neuro exam is negative. The rest of the exam is normal.

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Doris is a 58 year old female with a strong family history of breast cancer. She had been vigilant with her yearly follow-ups a the breast center. At age 52 an mammogram showed a suspicious lession, on biopsy it was found to be positive. She decided to have bilateral mastectomy so that she would not "need to worry about breast cancer again". The decision was hard and caused considerable stress and concern. She had times of envisioning a "terrible" outcome as she has seen in family members. She became depressed and struggled with her decision. She had decided to spend time in her family's cabin in the woods before making her decision. She underwent surgery, had a good outcomes and has been doing well since the surgery. She comes in with new back pain and is worried that this could be a metastasis. She has no other symptoms. She has had chronic back aches in the past. Exam is consistent with musculoskeletal lumbar tightness. Neuro exam is negative. The rest of the exam is normal.

Spiritual History

F: Spiritual, non religious; finds meaning in relationships, work, nature and art.

I: Feels her ability to deal with the uncertainty at the time of diagnosis was due to her inner peace which she gets from daily meditation; she uses time in nature and solitude to help her "ground herself." Is having trouble using those spiritual resources now even though she realizes the worry about the back ache may be excessive.

C: Strong family support.

A: Appreciates talking about her inner beliefs and values. Would like help with meditation and is also willing to talk with an art therapist and/or chaplain.

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Narrative example: Biopsychosocial-Spiritual Model Assessment and Plan

| Doris is a 58 year old who had bilateral mastectomy and has done well since her surgery 6 years ago, now with | | |
|---------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------|--|
| Physical | Physical therapy, nonsteroidal anti-inflammatory drugs (NSAIDs) for one week. | |
| Emotional | Support expression about fear of cancer recurrence at this time, reassurance that this is normal. | |
| Social | Continued family support. | |
| Spiritual THE GEORGE | Explore underlying fear of return of the cancer, referral to chaplain, art therapist, provide resources for meditation teachers in the area. | |
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Conclusions

Spirituality is integral to person-centered care

It impacts health care decisions, treatment, outcomes

It's the basis of dignity and patient—centered care

Models are created to make spirituality an equal
domain of care

For more information about a full online course on Interprofessional Spiritual Care, please see https://reliasacademy.com/rls/ispec/

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Interprofessional Train-the-Trainer Spiritual Care Education Curriculum (ISPEC)

ISPEC is a global training program whose mission is to improve spiritual care for patients with serious and chronic illness. ISPEC's goal is to train clinicians, spiritual care professionals and others in health settings to be able to recognize, address, and attend to the suffering of patients with serious and chronic illness and that of their families.

The ISPEC Online Course is a great opportunity to learn about the evidence, best practices, models, and ways to develop whole person assessment and treatment plans, how to work with spiritual care professionals, and enhance your ability to be an advocate for spiritual care.

The Online ISPEC Course is available here:

https://reliasacademy.com/rls/ispec/

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GWish, www.gwish.org

Education resources (SOERCE, National Competencies)
ISPEC: Interprofessional Spiritual Care Education Program
Retreats for health care professionals (Assisi, U.S.)
Time for Listening and Caring: Oxford University Press
Oxford Textbook of Spirituality in Health Care, Oxford
University Press
Making Healthcare Whole, Templeton Press
FICA Assessment Tool—online DVD
GTRR: Interprofessional Reflection Rounds
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