Make Room for Chaplains!

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1. Your position in life and what you do doesn’t matter as much as how you do what you do. Elizabeth Kubler-Ross

Your role on the team doesn’t matter as much as how you fulfill your role on the team. Me

2. “Interdisciplinary spiritual care requires all disciplines to be attentive to the spiritual wellbeing of patients and families. Assessments and interventions by team members other than the spiritual counselor are crucial to overall spiritual care and become particularly critical when a spiritual counselor or community clergy person is not directly involved. All team members can develop assessment skills and contribute to initial and ongoing spiritual assessments, guided and supported by close consultation with the spiritual counselor.” (NHPCO Chaplain Standards and CoPs)

3. Common Obstacles

- Where are chaplains in the “pecking order”?
- Where are your caseload numbers?
- Do you know why?
- Getting stuck by thinking what you already know...is enough.
- Not taking every opportunity to teach the IDT about the critical nature of addressing spiritual suffering and spiritual distress at the end-of-life.
- Not taking a skillful and assertive (not aggressive) leadership role (personal responsibility) for the state of spiritual care in your organization.

4. Medicare

§418.64(d) Standard: Counseling services
Counseling services must be available to the patient and family to assist the patient and family in minimizing the stress and problems that arise from the terminal illness, related conditions, and the dying process.

Counseling services must include, but are not limited to, the following:
(1) - Bereavement counseling
(2) - Dietary counseling
(3) - Spiritual counseling
5. Spiritual Counseling: 418.64 (d)(3)
   The hospice must: Make all reasonable efforts to facilitate visits by local clergy, pastoral counselors, or other individuals who can support the patient’s spiritual needs to the best of its ability.

   There should be evidence in the clinical record that the hospice has offered and/or provided spiritual counseling in accordance with the patient/family’s desires. If a patient and family desires spiritual counseling, then a hospice should facilitate visits by local clergy, pastoral counselors, or others to the best of its ability.

   1. How does the hospice introduce the availability of spiritual counseling?
   2. What mechanisms are in place to meet the patient/family spiritual needs?

6. How are your spiritual assessments conducted?

7. What is the role of a hospice Chaplain?

8. Define: “assertive chaplaincy practice”

9. Is the biggest challenge…getting through the door?

10. The Chaplain as part of an interdisciplinary team AND Chaplains at team meetings.

11. Addressing Spiritual Distress in the Hospice Setting

12. Teach staff/volunteers to recognize warning signs
   Adapted from “Spiritual Distress” by the Institute for Innovation in Palliative Care

   - Asking questions about the meaning of life
   - Questioning belief systems or suddenly losing spiritual or religious beliefs
   - Asking questions about pain and suffering
   - Negative self-talk like asking, “Why are these things happening to me?”
   - Feelings of anger and despair
   - Feelings of being isolated and alone or abandoned by God
   - Others
13. Past Trauma Can Lead to Spiritual Distress

An ongoing response in some individuals who experienced a traumatic event leading to:

- Mild to moderate disruptions in the person’s life
- Acute disruptions - Acute Stress Disorder
- Posttraumatic Stress Disorder
- Phobias, paranoias, intense rage
- Physical health problems

14. Interventions

Most important: Assure all team members are aware of their roles:

- What should they watch out for?
- How to respond when questions are asked?
- When to refer back to you.
- Others?

Do not forget volunteers, CNAs, physicians, on-call, etc.

15. Interventions continued (Depending on time)

- Motivational Interviewing
- Mindfulness work – Prayer
- Meaning work
- Socialization (connect with members of their community if they have been isolated by the illness)
- Grounding
- Cognitive Behavioral Therapy approaches
  - Redirect faulty thinking
  - Behavioral activation
  - Emotion regulation
  - Distress tolerance
  - Interpersonal effectiveness

16. Examples

- Patient/family found out about the terminal prognosis 1 hour before hospice was called and are in extreme distress
- The wife (caregiver) feels her husband is being punished by God for past sins. The husband agrees. Their minister agrees.
- The person who is ill asks you to pray for a miracle. She believes that since you have a direct line to God you can request “the cure” for her.
The person who is ill is in serious pain (a constant 10 on the scale). She says she needs the pain to cleanse her of her sins so that when she dies she can go straight to heaven.

Some family members want dad to return to the church before he dies. They feel he will go to hell if he doesn’t. Others say “leave him alone”. It is causing a lot of family distress.

The person who is ill tells you he is an atheist. He says he is struggling with the meaning of life. He also asks you to pray with him.

The patient/family do not want you to visit.

The patient/family always want you to stay longer. They don’t want you to leave. You feel they need your time. They say you are the only one who understands them.

The person who is ill tells you he has thanatophobia.

The person who is ill tells you she has been diagnosed with PTSD.

You discover the volunteer is reading the Bible to a Jewish family.

In team meeting someone says “The Chaplain needs to get out there and tell the family that cancer is not a punishment from God.”

17. Documentation
   1. Why did you make the visit? (Referral, initial visit, crisis, follow-up)
   2. Issues discussed (Let’s talk about this one)?
   3. What interventions were provided? (Theoretical frameworks utilized)
   4. Patient/family response to the interventions?
   5. What is the future plan?

Notes
Spiritual Acuity Scale – Hospice

The following lists are not all inclusive and reflect a suggested minimum number of visits.

Level 1 (Critical Need/Spiritual Distress – see suffering scale)
3+ Visits Per Week/Chaplain Contact within 24 hours with ongoing team coaching

- Chaplain contact within 24 hours
- Ongoing team guidance with or without pt/fam consent for Chaplain to visit

Situations where Chaplin intervention is appropriate and/or required (Visits are not specifically denied by patient/family. Chaplain serves as coach/guide for visiting team members as well):

- death anticipated within one week of admission and/or:
  - recent notification of terminal prognosis
  - expresses hopelessness and/or despair
  - asking questions such as “Why me?” or “Is this a punishment from God?”
  - making statements such as anger towards God or “God has let me down”
  - refusal to take pain medications stating “I need the pain to cleanse me of my sins” or “This pain is a punishment from God?”
  - feelings of guilt, regret, the need for punishment or deserving of punishment
  - feelings of being bad, not worthy of love, sinful
  - anxious/distressed or preoccupied with thoughts/feeling about afterlife, hell, etc.
  - questions the moral or “religious” correctness of pain medications and other treatments
  - questions religion, dogma, various belief systems, etc. “Which is the ‘correct’ religion?”
  - acute pain/symptom crisis with spiritual/religious undertones
  - method of coping is problematic or potentially problematic to pt/fam
  - suicidal ideation within pt/fam system
  - multiple loss (or other dynamics) leading to acute complicated grief
  - caregiver breakdown with spiritual/religious dynamics
  - other family crisis
  - self-isolation, interpersonal stressors, family discord that interferes with care, etc.
  - immediate need for coaching/guidance/intervention related to dying

also, pt/fam not in crisis but death is likely to occur soon and pt/fam guidance surrounding a “good death experience” is helpful (our role is to assist people to have their best possible end-of-life experience which becomes a critical need when time is very short).
Level 2 (Mid-Level Critical Need/Lower Level Spiritual Distress – see suffering scale)
Chaplain visit within 2 business days/telephone contact within 24 hours/2 + visits/contacts per week/ongoing team coaching when Chaplain intervention is appropriate and/or required

- Telephone contact within 24 hours
- Chaplain visit within three days
- One or more visits per week
- Ongoing team guidance with or without pt/fam consent to visit

- Length of stay estimated to be two weeks or more and/or:
  - Needs same as level one but with less urgency per pt/fam and/or other team members
  - Longer length-of-stay anticipated with concurrent crisis
  - Method of coping with spiritual distress is problematic or potentially problematic to pt/fam
  - Pt/fam not in crisis but pt/fam guidance surrounding “good death experience” is important (moving beyond “problem solving” and exploring opportunities)
  - Actively engaged in existential exploration w/ low level or no distress (example: pt engages in life review to explore questions around meaning and purpose to identify legacy.

Level 3
Chaplain visit within 3 business days/telephone contact within 3 business days/4 + visits/contacts per month/ongoing team coaching

- One or more telephone contacts during weeks without visits
- Ongoing team guidance with or without pt/fam consent to visit
- Length-of-stay estimated to be longer than national median: 3 weeks
- Supportive home and caregiver situation
- Family members cohesive and supportive
- Pt/fam satisfied with their level of coping
- Satisfactory involvement from neighbors, extended family, and/or religious/cultural/community
- No other expressed or identified needs requiring immediate intervention
- Pt/fam not in crisis but death is likely to occur soon and pt/fam guidance surrounding “good death experience” is important
- Pt/fam not in crisis but pt/fam guidance surrounding “good death experience” is important (moving beyond “problem solving” and exploring opportunities)

Note: The absence of “expressed or identified needs” does not mean that the pt/fam will not benefit from guidance/counseling related to terminal illness and/or anticipatory grief. Also, most can benefit from education and/or connection to resources, the development of a time-of-death plan, etc.
Assessing Suffering

Patient:
1. Do you ever wish this were all over?
2. What do you hope for? If person says “a cure”, acknowledge and explore “what else?”
3. Besides the physical symptoms of your illness, what causes you the most distress? (Or use a word/words that are more appropriate for this person such as “discomfort”, “stress”, “worry”, “concern”, “guilt”, etc)
4. On a scale from 0 to 10, (0 is the absence of distress and 10 is intense distress) how would you rate this suffering?
5. Compared to your physical pain and symptoms, which would you consider to be worse for you at this moment?

Family or Members of this Person’s Circle of Support:
1. Do you ever think that life is not worth living now or after your loved one dies?
2. What do you hope for? If person says “a cure” acknowledge and explore “what else”?
3. Besides your loved one’s physical symptoms, what part of all this is most distressing for you now?
4. On a scale from 0 to 10, (0 is the absence of distress and 10 is intense distress) how would you rate your suffering? (or, how would you rate this distress? Again, select a word or words that are most appropriate for this person or family) Which is worse for you right now, your loved one’s illness or the distress you have just described?

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References and Additional Resources

Assessment for Spiritual Distress: Penn Health Management
http://www.uphs.upenn.edu/pastoral/resed/UPHS%20spiritual%20assessment.pdf

Spiritual Distress Assessment Tool: New Hampshire Hospice and Palliative Care Organization
References and Additional Resources

CMS: Medicare Hospice Conditions of Participation

ProfessionalChaplains.org
Standards of Practice for Professional Chaplains in Hospice and Palliative Care

A Therapist’s Guide to Brief Cognitive Behavioral Therapy
http://www.mirecc.va.gov/visn16/docs/therapists_guide_to_brief_cbtman.pdf

Stroebe M¹, Schut H. The dual process model of coping with bereavement: rationale and description. Death Stud. 1999 Apr-May;23(3):197-224

Motivational Interviewing

Video Demonstrations of MI Sessions
Motivational Interviewing - Building Confidence (video)
http://www.youtube.com/watch?v=Cfl4d-qQ-co

The Effective Physician – Motivational Interviewing Demonstration (video)
http://www.youtube.com/watch?v=URiKA7CKTfc

Motivational Interviewing in Primary Care (video)
http://vimeo.com/18577370

Modifying Automatic Thoughts (video)
http://www.youtube.com/watch?v=a0YyC1iS8Rc

Patient-Centered Collaborative Care (video)
http://www.youtube.com/watch?v=h7jHp5ooNec

Books


Building Motivational Interviewing Skills – A Practitioner Workbook by David Rosengren., the Guilford Press, New York, 2009
Motivational Interviewing in Nursing Practice by Michelle Dart, Jones and Bartlett, Sudbury, MA, 2011


Cognitive Behavioral Therapy


Modifying Automatic Thoughts (video)
http://www.youtube.com/watch?v=a0YyC1iS8Rc

A Therapist’s Guide to Brief Cognitive Behavioral Therapy

Books


Mindfulness and Relaxation

Relaxation Therapy
Susan G. Komen
http://ww5.komen.org/BreastCancer/Relaxationtherapy.html

6 Mindfulness Exercises You Can Try Today
Pocket Mindfulness
http://www.pocketmindfulness.com/6-mindfulness-exercises-you-can-try-today/

Mindfulness Exercises
Living Well

BOOKS

MORE

*Chaplains and Chronic Pain*
Chaplains on Hand.org

*The Chaplain’s Role in Pain Management*
Edward K. Stratton
Taylor& Francis Online
Page 129-136 | Published online: 15 Jan 2014

*Standards of Practice for Professional Chaplains in Hospice and Palliative Care Association of Professional Chaplains*

*Pain Management Meditation*
[https://www.youtube.com/watch?v=2kVKx-6uzsE](https://www.youtube.com/watch?v=2kVKx-6uzsE)

3Hr Soothing Headache, Migraine, Pain and Anxiety Relief - Gentle Waterfall
[https://www.youtube.com/watch?v=5jmrIggwCXc](https://www.youtube.com/watch?v=5jmrIggwCXc)

*The McGill Quality of Life Questionnaire:*

*Searching for Meaning in Loss: Are Clinical Assumptions Correct?*
Christopher G. Davis, Camille B. Wortman, Darrin R. Lehman, Roxane Cohen Silver

*Entering the World of Charting and Spiritual Assessments* - by Mary M. Toole