Relays, Fartleks and Marathons: Changing the Pace of Care While a Disease Runs Its Course

Rev. Alice Tremaine, M.Div, BCC
Chaplain Manager
Baptist Health Corbin
alice.tremaine@bhsi.com

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Objectives

1. Identifying and addressing spiritual needs throughout the course of chronic and life threatening illnesses.
2. Collaborating with physicians and other team members to address spiritual needs.

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Relays

Fartleks

Marathons

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Dying in America

- Median age of death is 77
  - Among survivors to age 65, median age at death is 84 for women and 80 for men
- Leading Causes of Death
  - Heart Disease (28.5%)
  - Malignant Neoplasm (22.8%)
  - Cerebrovascular Disease (6.7%)
  - COPD (5.1%)
  - Accidents (4.4%)
  - Diabetes (3%)
  - Pneumonia (2.7%)

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Dying in America

- Site of Death
  - Hospitals (49.4%)
  - Nursing Homes (23.2%)
    - 38% of deaths of the elderly
  - Home (23.4%)
  - Other (4%)

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Illness Trajectories

- Sudden death
- Progressive decline with accelerated end
- Progressive decline punctuated with exacerbations
- Long gradual decline

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Functional Trajectories

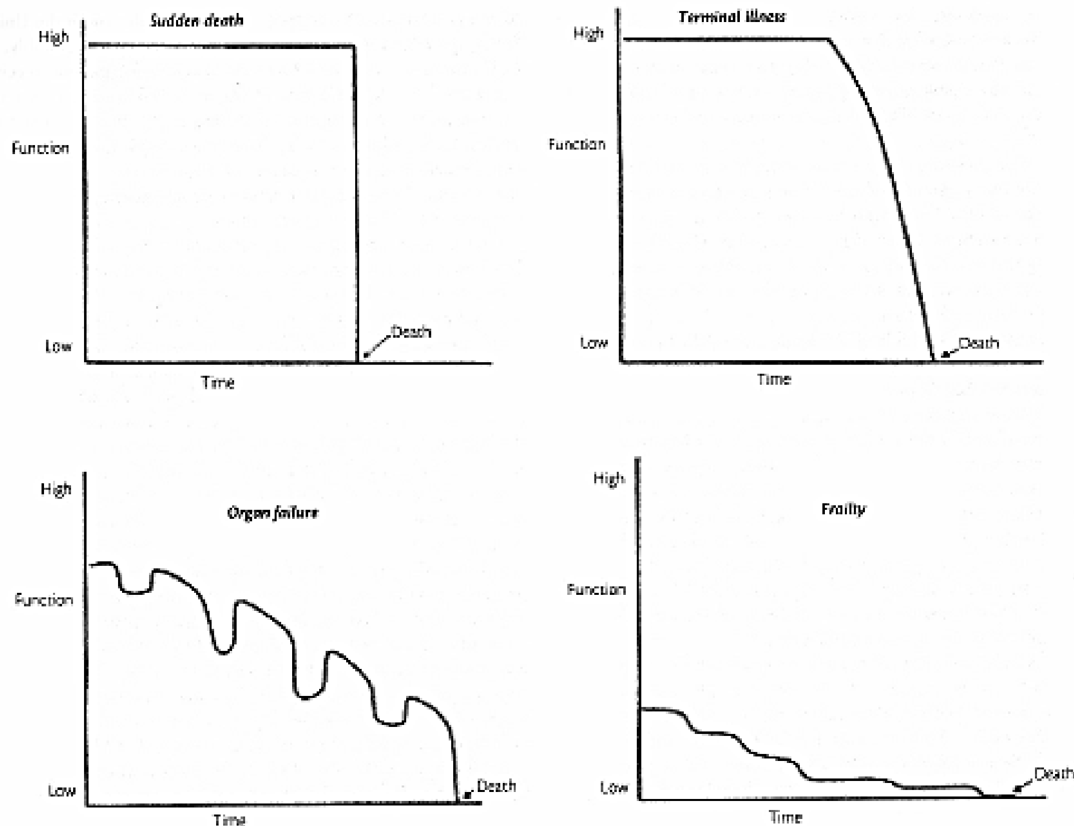

Figure 3.2.5 Functional trajectories at the end of life.
Source reproduced from Lunney, J.R., Lynn, J., Hogan, C. (2002). Profiles of Older Medicare Decedents. *Journal of the American Geriatric Society*, **50**(6), 1108–12, with permission from Wiley-Blackwell Publishing.

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Terminal Illness

- Advanced cancer
  - Easiest to prognosticate / most predictable trajectory
  - Cancer patients most frequently well functioning early in final year and more functionally disabled 3 months prior to death.

Terminal Illness

- Some cancer patients may have illness experience more similar to chronic organ failure, while others may decline faster.
- Cancer patients more likely to die at home due to predictable trajectory.

Palliative Performance Scale

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Level of Conscious
100	Full	Normal activity, no evidence of disease	Full	Normal	Full
90	Full	Normal activity, some evidence of disease	Full	Normal	Full
80	Full	Normal activity with effort, some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable to do normal work, some evidence of disease	Full	Normal or reduced	Full
60	Reduced	Unable to do hobby or some housework, significant disease	Occasional assist necessary	Normal or reduced	Full or confusion
50	Mainly sit/lie	Unable to do any work, extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
40	Mainly in bed	Unable to do any work, extensive disease	Mainly assistance	Normal or reduced	Full, drowsy, or confusion
30	Totally bed bound	Unable to do any work, extensive disease	Total care	Reduced	Full, drowsy, or confusion
20	Totally bed bound	Unable to do any work, extensive disease	Total care	Minimal sips	Full, drowsy, or confusion
10	Totally bed bound	Unable to do any work, extensive disease	Total care	Mouth care only	Drowsy or coma
0	Death	—	—	—	—

Palliative Performance Scale (PPS)

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Symptoms at End of Life: Cancer vs. Other Causes of Death

	Cancer	Other
Pain	84%	67%
Trouble breathing	47%	49%
Nausea and vomiting	51%	27%
Sleeplessness	51%	36%
Confusion	33%	38%
Depression	38%	36%
Loss of appetite	71%	38%
Constipation	47%	32%
Pressure ulcers	28%	14%
Incontinence	37%	33%

Seale and Cartwright, 1994

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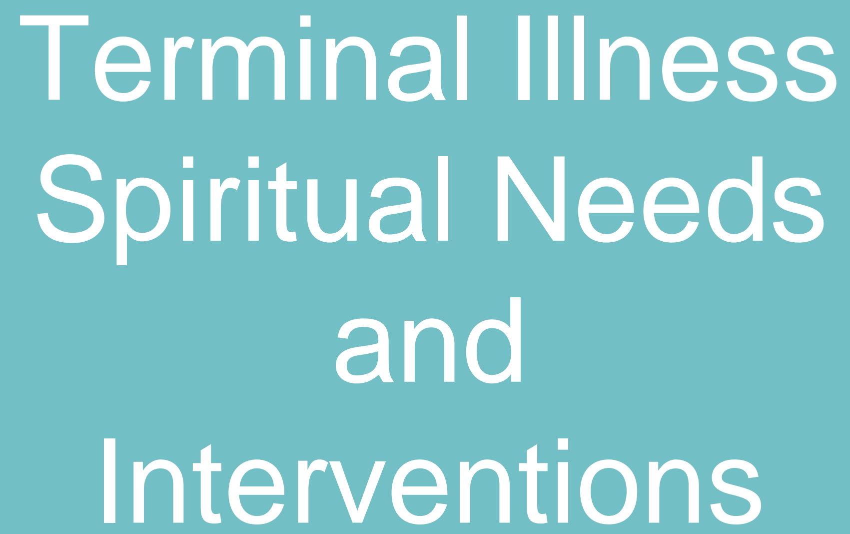
Terminal Illness

- Hospice eligibility guidelines for non-cancer patients:
  – Life-limiting illness
  – Palliative rather than disease modifying plan of care
  – Documented evidence of progressive disease which may include recent functional decline, or
  – Documented decline in nutritional status in previous 6 months.

Terminal Illness Spiritual Needs and Interventions



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Terminal Illness: Spiritual Needs

- Shock of diagnosis; loss of anticipated plans and dreams

- Demoralization

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Demoralization

“ If only I could express myself! I could give lectures, I could do lots of things, but I just sit here. Being unnecessary. Well, then it is easy to develop a desire for death. ”

“ I went out with Anita, watching birds, and uh, I said, ‘Oh, I need to pee,’ so I walked out of the bird hide, stood there and then I peed. But then, I’ll just say it, I suddenly pooped too. Then I deeply, deeply cried, standing there outside in nature. I became intensely sad… I do not know, I burst into tears, I felt so sad about this happening to me… I had no control at all, it just happened without my involvement. ”

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Demoralization

- Study: majority of terminal cancer patients indicated varying degrees of burden-related distress, with 23% scoring within the highest quartile of distress.
  - Aside from fatigue and appearance, other physical issues were neither significantly associated with sense of burden to others, nor was the actual degree of physical dependency.
  - Satisfaction from social support did not correlate significantly with patient ratings of sense of burden to others.
  - The most significant correlations were seen between sense of burden and hopelessness, depression and outlook. (Chochinov et al, 2007)

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Demoralization

- Patients were most concerned about burden related to provision of physical care, witnessing their death, and substitute decision making.
- Demoralization vs. depression:

(Robinson et al, 2015)

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Demoralization and Desire to Hasten Death

- Cancer pain severity
- Pain interference with function
- Depression
- Perceived absence of social support
- Lower levels of physical functioning

- Improvement in depression was independently predictive of a decrease in patients’ desire for hastened death. (O’Mahony et al, 2005)

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Terminal Illness: Spiritual Needs

- Difficulty making decisions regarding treatments
  - "Four commonly invoked reasons for inappropriate treatment at end of life"
    - Hope for a miracle
    - Refusal to give up on God of faith
    - Conviction that every moment of life is worth preserving at any cost
    - Belief that suffering can have redemptive value

(AS Brett, MD and P Jersild, ThD)

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“ Don’t lie down, get up and fight it, ‘cause it can be beat, and you’re the only person that can beat it. ”

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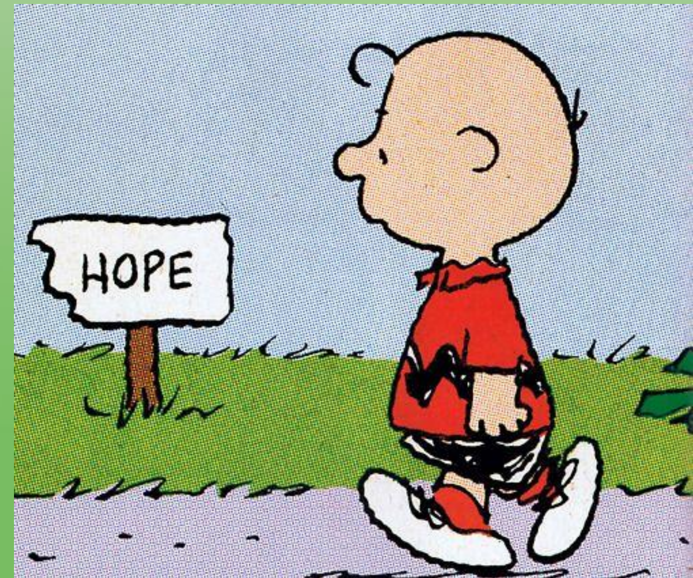
Interventions

- Meaning-making
- Decreased isolation
- Advance Care Planning
- Reframing imagery and story telling



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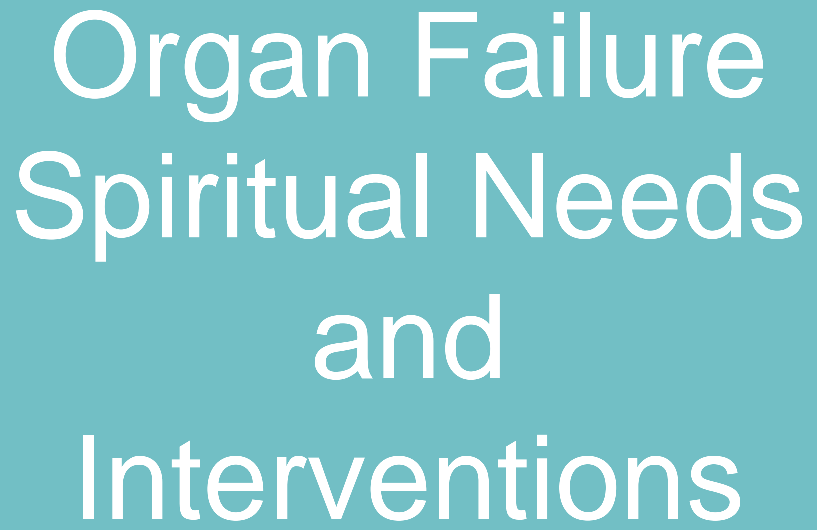
Organ Failure

- Fluctuating pattern of functional decline with poorer functioning last 3 months prior to death.
- Acute admissions

Organ Failure

- Social withdrawal identified as an independent marker of the imminence of death in literature review. (Kennedy et al, 2014).
- Hospital chaplaincy services underutilized but greatly appreciated if used. (Murray et al, 2004)



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Organ Failure: Spiritual Needs

- Hopelessness, isolation and altered self-image associated with chronic illness and disability. (Murray, 2004)
- Difficulty preparing for death
- Specific needs related to specific diseases:
  - Heart Disease related to depression and fatigue
  - COPD related to anxiety

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“ [Fatigue] gives me a pain that can be compared with carrying a very heavy bag of cement on my shoulders, you know, a bag of Portland weighing 50 kilos, all day anywhere and anytime. I wake up with it, I go to sleep with it. But I have learned to downplay it to a certain extent… It is a deadly fatigue. A painful feeling of being dead tired. Very heavy fatigue. It is pain… It’s so extremely heavy. ”

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Interventions

- Advance Care Planning
- Introduction of Legacy Making
    - Guided Imagery, music, and other integrative therapies
    - Social/church support
    - Chaplain initiated visits

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Frailty

- Relatively more functionally disabled throughout final year
- Fewer prognostic markers
- Those impaired for at least 12 months before death more likely to die in nursing home

Frailty

- Early signs of impending death reported by staff, family and residents in study:
  - Declining participation in social activities
  - Less zest for life
  - Disinterest in or reduced intake of food and/or fluids
  - Increased time spent in bed/ decreased mobility
  - Speaking or dreaming of predecessors
- Reported signs that death is near:
  - Changes in breathing patterns
  - Decreased level of consciousness
    - Abnormal body temperature
    - Mottling of the extremeties. (Cable-Williams, 2014)

Frailty

- Physical indicators of death in frail elderly:
  - Anorexia
  - Increased pain
  - Greater frailty or weakness
  - Weight loss
  - Altered breathing patterns
  - Mottled skin
  - Distinctive odor.
- Behavioral indicators of death in frail elderly:
  - Personality and mood changes

    - New tendency to decline social interaction

    - Increased restlessness, anxiety or agitation

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Frailty:
Spiritual Needs

“ I feel like a sawed-off tree. Completely sawed-off. But a sawed-off tree still has roots. I have no roots anymore, no strong bonds anymore, and no close connection to life anymore. (…) Of course, I value those bonds, but hey, you fall in love, you get married, you have a ‘Living Apart Together’ relationship. Well, that's it, that's as far as it goes. It's a gilded edge, a nice dessert. But it's not something to keep you alive. ”

Loneliness

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Frailty: Spiritual Needs

- Memory Loss, difficulty connecting with others, loss of roles/self.
- Uncertainty about appropriate balance of curative, restorative and palliative goals of care.
- Undermedicated for pain, agitation.

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Interventions

- Story telling
- Music
- Reconnection with religious rituals and sacred texts

- Early advance care planning
- Ongoing reassessment of goals of care

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Collaborating with physicians and other team members

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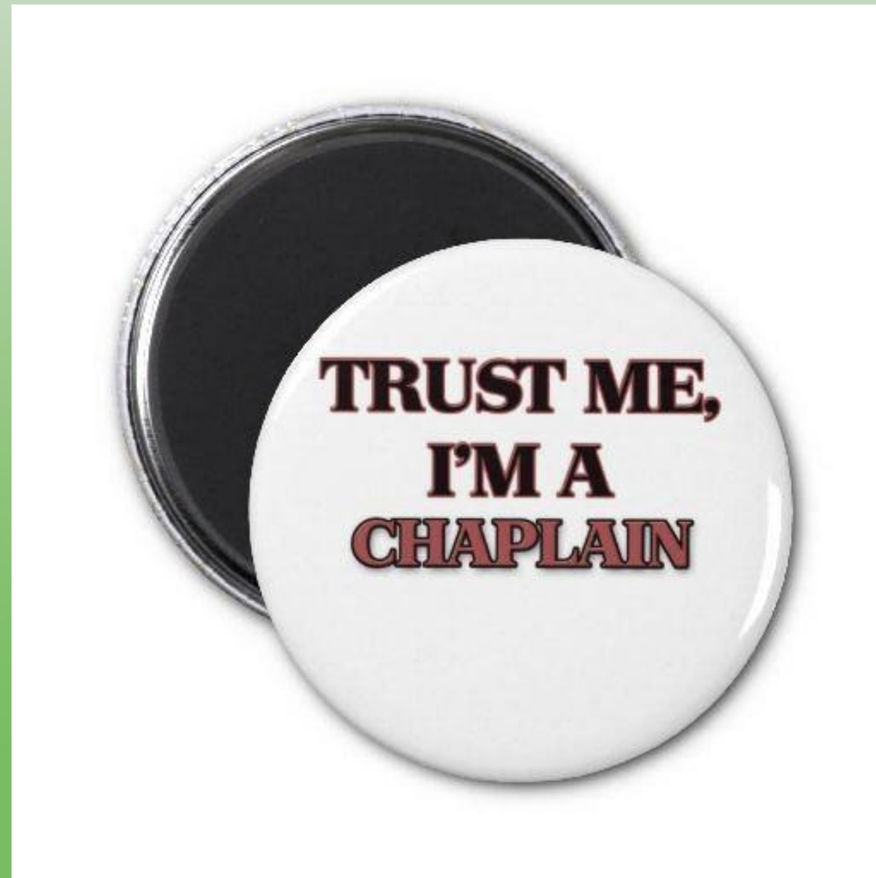
Chaplain as a strategic partner



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Chaplain as a strategic partner

- Subversive role?
- Acting as interpreter for healthcare team
- Clinical documentation
- Committee service
- Educating team members in spiritual care

- Meyer Spiritual Suffering Risk Scale
- Team development and initiatives

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"It's the closure fairy."

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