Primary Palliative Care and Women's Health

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Palliative Care

SPOILER ALERT
EVERYONE DIES
Why do we need palliative care?
How Americans died in the past . . .

- 1900
  - average life expectancy: 47.3
  - childhood mortality high
  - adults lived into their 60s
. . . How Americans died in the past

- Prior to antibiotics, people died quickly
  - infectious disease
  - Accidents

- Medicine focused on caring, comfort

- Sick were mostly cared for at home
Medicine’s shift in focus . . .

- Science and technology

- Marked shift in values and focus
  - “death denying”
  - value productivity, youth, independence

- ER, Chicago Hope, and Rescue 911 in 1994 and 1995
  - 75% immediate survival, 67% survive to D/C
  - Real life 0-30% survival depending on location (in or out of hospital) and age

  Diem et al. NEJM 1996 334:1578-1582
Population by Age and Sex: 1960

Age
85 and over
80 to 84
75 to 79
70 to 74
65 to 69
60 to 64
55 to 59
50 to 54
45 to 49
40 to 44
35 to 39
30 to 34
25 to 29
20 to 24
15 to 19
10 to 14
5 to 9
0 to 4

Millions

US Census Bureau, 2005
Population by Age and Sex: 1980

- Age
  - 85 and over
  - 80 to 84
  - 75 to 79
  - 70 to 74
  - 65 to 69
  - 60 to 64
  - 55 to 59
  - 50 to 54
  - 45 to 49
  - 40 to 44
  - 35 to 39
  - 30 to 34
  - 25 to 29
  - 20 to 24
  - 15 to 19
  - 10 to 14
  - 5 to 9
  - 0 to 4

- Male
- Female

Baby Boom

Millions

US Census Bureau, 2005
Population by Age and Sex: 2000

Age
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Millions

15
10
5
0
5
10
15

Male
Female

Baby Boom

US Census Bureau, 2005
The “Silver Tsunami”

◊ The population over age 65:
   ◊ 35 million in 2000
   ◊ 87 million in 2050

◊ Ratio working age/non-working age:
   ◊ 4.8 in 2000
   ◊ 2.6 in 2050

US Census Bureau, 2004
Patient Preferences: ≥ age 60, limited life expectancy due to cancer, CHF, COPD

<table>
<thead>
<tr>
<th>Situation</th>
<th>% would choose treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low burden, restored health</td>
<td>98.7</td>
</tr>
<tr>
<td>Survival with severe functional impairment</td>
<td>26.6</td>
</tr>
<tr>
<td>Survival with severe cognitive impairment</td>
<td>11.2</td>
</tr>
</tbody>
</table>

Fried TR, NEJM, 2002, 346(14):1061
Where do People WANT to die?

- Home – >90%
- Hospital – Rare
- Nursing Home - Never

Where DO People Die?

- Hospital – 50%
- Nursing Home – 30%
- Home – 20%
Type of Death

< 10%

Lunney, JAMA. 2003
Ideally, palliative care would not exist
Patients Want to talk about this stuff

- Of 105 patients with severe COPD
  - 94% had opinions about intubation
  - 99% wanted to discuss advance directives with their physician

- 19% had discussed with their physician
- 14% thought their physician understood their wishes

Heffner, Am J Resp Crit Care, 1996;154:1735
“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
Palliative Care

- Specialized medical care for people with serious illnesses
- Focused on providing patients with relief from the symptoms, pain, and stress of a serious illness

- **Goal:** to improve quality of life for both the patient and the family

- Appropriate at any age or stage in a serious illness

- Can be provided together with curative treatment.
Palliative Care aims to improve care in 3 domains:

1. Relieve physical and emotional suffering
2. Improve patient-physician communication and decision-making
3. Coordinate continuity of care across settings
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Is this any different than primary care?
This is mostly YOUR job!
Suffering

- Physical
  - Pain
  - Nausea
  - Diarrhea
  - Constipation
  - Agitation
  - SOB
  - itching

- Psychological

- Social

- Spiritual

Hospice vs. Palliative Care

**Hospice**
- focus is on pain and symptom management
- patient has a terminal diagnosis with life expectancy of less than six months
- not seeking curative treatment

**Palliative Care**
- focus is on pain and symptom management
- patient does not have to be terminal
- may still be seeking aggressive treatment
- is not linked to reimbursement
Palliative Care: Not an “Either-Or”

Traditional Care Model

Integrated Care Models

“Curative” Care

“Palliative” Care
The Medicare Hospice Benefit

- Hospice is defined by the Medicare hospice benefit
- Eligibility:
  - 6 month prognosis (as determined by two physicians)
  - Goals of care must align with hospice

- 343 doctors provided survival estimates for 468 terminally ill patients at the time of hospice referral.
- Physicians overestimated prognosis by a factor of 5.3
  - Christakis, BMJ 2000;320:469–73
The Medicare Hospice Benefit

- The hospice team – RNs, SW, chaplain, supervision of a hospice physician, nurses Aids up to 1-2hrs daily, volunteers (usually 3 hrs a wk), and bereavement support for up to 13 months after
- Medications/therapies for the sole purpose of palliation of symptoms related to the primary diagnosis
- Medical equipment for safety/symptom relief
- Dressings/other care needs related to the diagnosis
- 24 hr coverage
Common Hospice Misconceptions

1. The patient must be bedridden in order to be eligible for hospice care.
   - Hospice promotes QOL and function!

2. The patient must have cancer.

3. Being on hospice means giving up hope.
   - Help patients and families re-frame their hope.
Common Hospice Misconceptions (cont)

4. I need to be “DNR” to sign-up for hospice.

5. I lose control/access to medical care if I sign-up for hospice.

6. I cannot dis-enroll from hospice if I change my mind or get better. (Hospice survivor)

7. It’s “too early” for me to sign-up for hospice.

-If patient is medically appropriate for hospice, focus on the extra support they will receive at home, and improved quality of life because of symptom control.
Primary palliative care can be provided by the interdisciplinary team.

Palliative and hospice care can ease caregiver burden.

Solicitation of EOL preferences early in disease process.

Caregivers more satisfied if patient died in preferred location.
Caregiving – a women’s health issue

“And do you take Goldie, to be your lawfully wedded primary caregiver?”
Caregiver Burden is REAL

- Advanced age
- Higher caregiver hours
- Caregiver health problems
- More patient comorbidities
- Caring for more than one family member
Caregiver Burden is REAL

I’ve never felt caregiving was my gift...I tend to feel like I’m being imposed upon at times...that I am being called upon.
The caregiving perspective in heart failure: a population based study

Patricia M Davidson¹,², Amy P Abernethy³, Phillip J Newton¹, Katherine Clark³ and David C Currow⁴

Abstract

Background: Heart failure (HF) is a frequent condition in the elderly and mortality is high. This study sought to describe the profile of those providing care in the community and their needs.

Methods: The South Australian Health Omnibus is an annual, random, face-to-face, cross sectional survey conducted within the state. Having standardized data to the whole population, the study describes the subset of the population who identify that they actively cared for someone at the end of life with HF in the five years before survey administration.

Results: Three hundred and seventy three respondents (20% of the whole population; 4.9% of caregivers) reported being a caregiver of someone with HF. There were 84 active caregivers (day-to-day or intermittent hands on caregivers) for people with HF. Mean age for caregivers for those with HF was much higher than other caregivers (55.7 vs 49.4; p < 0.001) with care lasting for an average of 48.9 months (SD 66.2). People caring for those with HF were far less likely to access specialist palliative care services (38.1% vs 60.9%; p < 0.0001) despite having much greater levels of unmet needs for physical care 28.3% vs 14.1%; p = 0.008).

Conclusion: Study findings suggest that there is a significant burden placed on caregivers for people with HF over extended periods in the community. There are differences in access to services for these caregivers compared to those dying from other conditions, particularly cancer.

Keywords: Heart failure, Caregivers, Australia
Caregivers in Dementia

- 172 Caregivers of people with dementia
- 132 Women, 40 men
  - 48% Daughters
  - 41% Spouses
  - 6% Sons
  - 5% Other
- 68% “highly burdened”
- 65% Depressed

Papastavrou E et al. 2007
Summary

- Recognize the role of primary care providers in providing primary palliative care

- Focus on caregivers and include them in as many discussions as possible, including decision making