Policy changes in end-of-life care: Social work & aid-in-dying*

Social Work Hospice and Palliative Care Network General Assembly
February 19-21, 2017
Mary S. Carlsen, MSW, LISW
Professor of Social Work - St. Olaf College

Hopes for our learning today

- Describe the relationship between aid in dying (AID) policies and the NASW Policy Statement on End-of-Life Decision-Making and Care
- Describe some basic findings in literature on social work and AID
- Articulate one’s own knowledge and policy stance on AID legislation

Introductions

- **Me**
- **You** - How many have directly engaged with AID in practice and/or advocacy in your state?

- My hope is that we respond to the policy directive from NASW: to offer “continued study and education, both within and beyond the profession, to enhance understanding of the complex issues associated with PAD” (Social Work Speaks, 103)

Why is this important?

- Increasingly integral to palliative care and EOL discussions as “the boundaries between … curative therapy and … palliative care become more blurred, and the bright line separating acts intended to relieve suffering … from acts primarily intended to hasten death grows dim”. (Linder, 2012)
- Of particular interest/importance to SW
### Why is this important?

- Most professions have policy statements that oppose authorization of aid in dying
- **SW the exception - neutral to supportive**
  - Focused on autonomy & self-determination
  - Oregon NASW maintained neutrality in Death with Dignity process (Miller & Hedlund, 2005, 76)
  - California NASW officially supported, and 77% of Washington social workers supported legalization of assisted suicide prior to the DWDA in 2008 (Ogden & Young, 2003).
  - Minnesota NASW board considering a policy statement

### What’s the issue?

*Healthy, active public debate about EOL care options, including PAS, should be a goal of social work as a manifestation of the profession’s commitment to social justice* (Csikai, 2003)

- Brittany Maynard (1984 - 2014)

### Social work ethical principles

- The NASW Code of Ethics principles that can be applied directly to aid in dying:
  - the primacy of person’s choice
  - individual autonomy
  - patient self-determination
  - social justice
  - respect for the individual client
  - an appreciation of the tension that can exist between individual rights & the common good (Linder, 2012)

### Findings from SW literature

- More experienced SWers were more willing to participate in euthanasia_ASSISTED suicide situations and the less likely to worry about potential for abuse if legalized (Csikai, 1999, 91)
- RNS/MDs similar rates of support, opposition and neutrality toward PAS, tending toward support since 1994; **SWers significantly more supportive of PAS and more strongly supportive;** MD/RN associations generally oppose PAS; SW organizations place greater emphasis on individual autonomy/choice and are neutral on PAS (Miller, et al, 2006)
Findings from SW literature

- 2000 NASW Policy on Client Self-Determination in End-of-Life Decisions: “Social workers need to preserve the ability of seriously and terminally ill elderly to make choices about the end of life, even if this means a choice for physician assisted suicide, if legal in their state” (Csikai & Manetta, 2002, 93)
- Considerable support for PAS among LTC SWers:
  - 48% agreed it should be legalized
  - 85% agreed with right to withhold and withdraw treatment
  - 50% said it is SW role to participate in PAS decisions
  - 60% would want the option for themselves or family members in the face of intractable suffering
  - However, nearly 70% were concerned about the vulnerability of the elderly if legalized (Erlbaum-Zur, 2005)

Findings from SW literature

- More RNs (39%) than SWers (12%) opposed/strongly opposed AID. One RN and no SWers indicated they would actively oppose a request for AID
- 95% of SWers believed hospice should support or remain neutral when a patient requests assisted suicide and that hospice should continue to care for these patients; non-abandonment and starting where the client is
- Hospice SWers work with dying patients’ psychological, relational & existential issues and resource needs, so are likely already involved
- Top 3 factors influencing SW EOL attitudes: respect for self-determination, enhancing client quality of life, personal religious beliefs (Linder 2012)

Findings from SW literature

- 155 CA SWers before law passed in 2015:
  - Social workers generally supported assisted suicide (55.5%) or were neutral (23.2%)
  - No evidence to support an assertion that religious upbringing bears decisively on California hospice SWers’ current attitudes toward assisted suicide, however...
  - Respondents’ current self-identification as Catholic, frequently attending church and being conservative toward social policy each independently predicted increased opposition to PAS
  - Patients, then care givers, were most likely to initiate discussions with SWers about legal and illegal death-hastening options (Linder, 2012)

Findings from SW literature

- 62 EOL SWers from MN, WI, and IA
- More than half support “PAS” legislation and ¼ are neutral or undecided
- The majority felt moderately to very well prepared to have conversations and assist patients in decision-making around PAS
- Very few had accurate awareness of PAS legislation in their of state and few have attended educational or advocacy events

Gaston (2016)
Is this a dilemma??

- Duty to heal/preserve life/do no harm vs. autonomy/self-determination??
- Or maybe “a conflict between competing theories for good, and not a dispute between proponents of autonomy and the sanctity of dignity of life”


NASW policy: EOL decision-making & care (2015-17)

“Deep-seated inequities pose barriers to individuals and families’ options for, and informed decision making regarding, care at the EOL… rectifying such inequities and supporting clients’ end-of-life decision-making constitute key roles for social workers… a variety of opinions exist regarding the legalization of PAD. Mindful of this diversity, NASW has not adopted a national position either in support of, or in opposition to, legalization of PAD. In states where PAD is legal, however, NASW affirms both the right of individuals to choose this option and the responsibility of health care systems and practitioners to honor clients’ choice…

NASW policy: EOL decision-making & care (2015-17)

- ...In states in which PAD is either legal or under consideration, NASW also affirms the social work role in creating and implementing state policies and procedures that reflect the ethical values and principles of social work such as preventing abuse of individuals in vulnerable situations... NASW upholds the social work role in client’s end-of-life decision-making processes and encourages further study, both within and beyond the profession of the many complex issues associated with PAD” (103)

Current legislation

- Oregon Death With Dignity Act (1994)
- Montana (judicial ruling – 2009)
- Vermont Patient Choice & Control at End of Life (2013)
- California End of Life Options Act (2015)
- Colorado End of Life Options Act (2016)
- Congress is reviewing legislation approved by the D.C. Council (2016); 16 states are considering (AK, AZ, CT, HI, IN, KS, ME, MD, MA, MS, MO, NJ, NM, NY, PA & UT).
- https://www.deathwithdignity.org/take-action/
Aid in dying is...

• A component of EOL care – one option
• NOT an alternative to hospice care
• In Oregon, 92% enrolled in hospice & 90% died at home (2014)

Positive Impact

• Oregon hospice use has increased since DWD and is now double the national average
• All 4 states with DWD in 2014 received “A” grade in 2015
• More people die at home than in health care institutions
• “...it is possible that the Oregon DWD Act has resulted in or at least reflects more open conversation and careful evaluation of end-of-life options, more appropriate palliative care training of physicians, and more efforts to reduce barriers to access to hospice care.” (Wang, et al, 2015)

Public opinion

• “Americans have consistently favored the freedom to end one’s life when the perceived quality of life has significantly diminished, either by one’s own hand or with the assistance of a physician” (Allen, et al 2006, 5)
• Of course, many oppose: “no suicide is a good death” (Schneidman, 2007, 245)
• Pew Research (2015) Religion, Race, Age
http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/
• Gallup Poll (2015) – “Nearly seven in 10 Americans (68%) say doctors should be legally allowed to assist terminally ill patients in committing suicide, up 10 percentage points from last year. More broadly, support has risen nearly 20 points in the last two years and stands at the highest level in more than a decade...The percentage of young adults aged 18 to 34 who support doctor-assisted suicide climbed 19 points this year, to 81%.”
http://www.gallup.com/poll/183425/support-doctor-assisted-suicide.aspx

Conclusions

• As care and policy environments change, social workers are called to proactively consider and engage in discussion/changing end-of-life policies and practices
• Consider your own level of comfort with this topic – your personal values, the values of social work, your religious beliefs, your ideas about death and dying. What has been your personal experience? Have you been exposed to a family member or friend who was in palliative or hospice care? Have people you loved had painful death experiences? Self awareness is key
Conclusions

• I hope your knowledge has increased and your position been clarified on the role of social workers in discussions of AID and in the legislative process on End of Life Options Act legislation around the country.

Thank you for listening!

Reference list available carlsen@stolaf.edu