

# Hospice policy advocacy: Understanding structural inequities, changing demographics, and possible policy solutions

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## PROBLEM STATEMENT

Structural assumptions embedded in the Medicare Hospice Benefit limit patient choice and perpetuates inequities<sup>1,2</sup>. The inability to meet these assumptions will become more prevalent in the future due to changing demographics.

## GOAL FOR THIS POSTER

The goal of this project is two-fold. First is to assemble evidence of the scope and causes of the problem. Second is to review potential alternatives for addressing the issues. Current vulnerabilities significantly limit the ability of hospice patients to meet the hospice assumptions and changing demographics will increase these challenges. Three main assumptions are explored, and they combine leading to long term care placement. Policy solutions are offered for each of these issues. A fourth assumption, that of predictive terminal illness trajectory is not covered here, but impacts policy solutions on hospice in the nursing home environment.<sup>3</sup>

## CALL TO ACTION

Advocacy around these limitations are a key social justice issue for hospice patients and thus an area for policy advocacy for hospice and palliative care social workers.

## REFERENCES

Staple references here.

## THE HOSPICE ASSUMPTIONS:

### SAFE AND SECURE HOUSING

#### Safe and Secure Housing

- ~ People experiencing homelessness have higher prevalence of chronic illness.<sup>4</sup>
- ~ The average life expectancy of someone who experiences chronic homelessness is about 50 years old.<sup>5</sup>
- ~ The numbers of elderly that are unhoused is projected to grow in the coming decades.<sup>6</sup>
- ~ In addition to unhoused people, it's important to consider those with insecure housing. Some housing is unstable, such as staying with friends, or inadequate, such as lacking basic utilities and appliances. Not everyone wants to die at home.<sup>7</sup>

**Serving people first requires meeting basic needs before medical intervention or goals of care exploration.<sup>8</sup>**

Figure 12: National Projections of Older Homeless Adults: 2017-2030

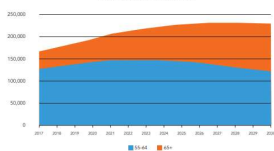


Image source: <https://aisp.upenn.edu/wp-content/uploads/2019/01/Emerging-Crisis-of-Aged-Homelessness.pdf>

#### Policy Solutions:

- Placement in long term care setting<sup>9</sup>
- Dedicated hospice facilities for those experiencing homelessness<sup>9</sup>
- Priority access to residential supports plus expanded caregiving supports

### INFORMAL SUPPORT NETWORK

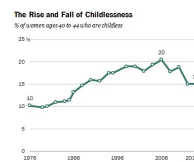
#### Informal Support Network

- ~ People are having fewer children and more people aren't having children.<sup>10,11</sup>
- ~ More older adults are living alone and potentially physically and socially isolated.<sup>11-13</sup>
- ~ The overall aging population in addition to demographic shifts results in fewer caregivers available to provide care for older adults.<sup>14</sup>
- ~ In the absence of personal supports, people either pay for services or if they cannot afford them, they can use home and community-based services. However, this program does not currently cover 24-hour caregivers which are likely needed on hospice.<sup>15</sup>
- ~ Furthermore, caregiving significantly impacts caregivers: decreasing employment, leading to a loss of wages, and worsening SES for caregivers.<sup>16-21</sup> This disproportionately impacts women and creates a feedback loop that will potentially impoverish the next generation when they need care.

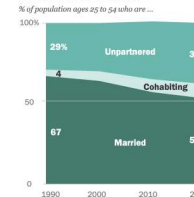
Image sources: from top to bottom: <https://www.pewresearch.org/social-trends/2018/02/07/childlessness/>; <https://www.pewresearch.org/social-trends/2021/10/05/living-alone-of-u-s-adults-are-living-without-a-spouse-or-partner/>; <https://www.fisc.usc.edu/2013/03/05/the-future-supply-of-family-caregivers/>

#### Potential Policy Solutions:

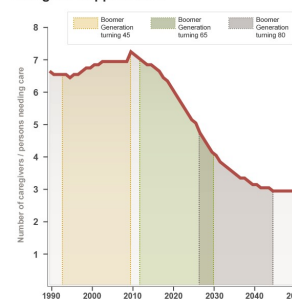
- Increased home and community-based services for hospice patients
- Increased employment supports for caregivers who are also working
- Increased hospice caregiving supports<sup>21</sup>



A rising share of U.S. adults are living without a spouse or partner



#### Caregiver Support Ratio

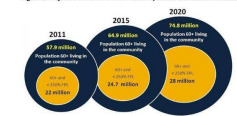


### ADEQUATE FINANCIAL RESOURCES

#### Adequate Financial Resources

- ~ In 2020, NHPCO reported that 84% of patients served were 65+.<sup>22</sup>
- ~ Most beneficiaries rely on social security for their income, and reliance increases with age as we deplete our savings.<sup>23-25</sup>
- ~ Reliance on social security, and therefore financial insecurity, is higher among Black, Hispanic, and Asian elders.<sup>13,26</sup>
- ~ Our population is aging, with an increase in people older than 65 while projections suggest older workers will experience downward mobility in their old age.<sup>27</sup>
- ~ Financial hardship is associated with intensive end of life care, even after adjusting for SES and patient preferences.<sup>28</sup> Lower income has also been found to be associated with substantial care needs.<sup>29</sup>

Figure 1: Projected Increase in Older Adult Population and Economic State



#### Most Elderly Beneficiaries Rely on Social Security for the Majority of Their Income

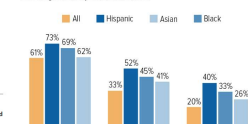


Table 1.

Percentage of the population aged 65 or older for whom Social Security benefits accounted for at least 50 percent and at least 90 percent of family income, by selected characteristics, 2012 and 2014

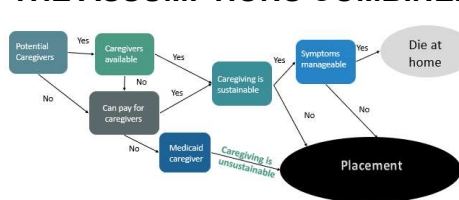
Characteristic	2012 CPS (2012)		2014 CPS (2014)	
	>50%	>90%	>50%	>90%
Total	65.9	26.7	61.8	24.7
Sex				
Women	65.9	29.6	65.2	27.4
Men	65.1	23.6	47.5	21.3
Age				
65 or older	65.9	25.7	61.6	24.7
65-69	61.6	17.9	41.7	16.3
70-74	65.7	25.7	51.1	23.3
75-79	61.8	36.3	67.9	26.8
80 or older	66.2	36.4	61.4	32.7
Sample size	25,162		20,912	

Image Sources, counter-clockwise from top left corner: <https://www.ssa.gov/policy/docs/ssb/0770007701.html>; <https://www.gapings.org/issues/economic-security/>; <https://www.cbp.org/most-elderly-beneficiaries-rely-on-social-security-for-the-majority-of-their-income-1>

#### Potential Policy Solutions: (related to supports for care)

- hospice specific income guidelines for more generous access to Medicaid
- increased services offered through the hospice benefit
- increased services offered through Medicaid for hospice patients

## THE ASSUMPTIONS COMBINED



When someone is unable to live independently and does not have supports to live in the community (either through informal caregiver supports, financial resources to pay for care, or Medicaid home-based supports), US policies favor institutionalization.<sup>30</sup> Care needs increase significantly at end of life, and what might have been sustainable at one time may become untenable.<sup>31-33</sup> Nursing homes have significant quality issues.<sup>34,35</sup> Nursing home deaths have higher rates of unmet needs for pain and are less likely to be treated with respect at the end of life.<sup>31,36</sup>

**Need: Increase acceptable options or acceptability of options for placement**

#### Potential Policy Solutions:

- Support for hospice specific facility placement though access to Medicaid room and board funding and/or Medicare/insurance coverage
- Training and support to increase assisted living comfort and capacity for end-of-life care
- Skilled hospice benefit to cover room and board at nursing homes with significant limits<sup>37</sup>
- Nursing hospice benefit that is not limited to 6-month prognosis due to patient mix<sup>38</sup>

## WHAT WILL YOU BE AN ADVOCATE FOR?