

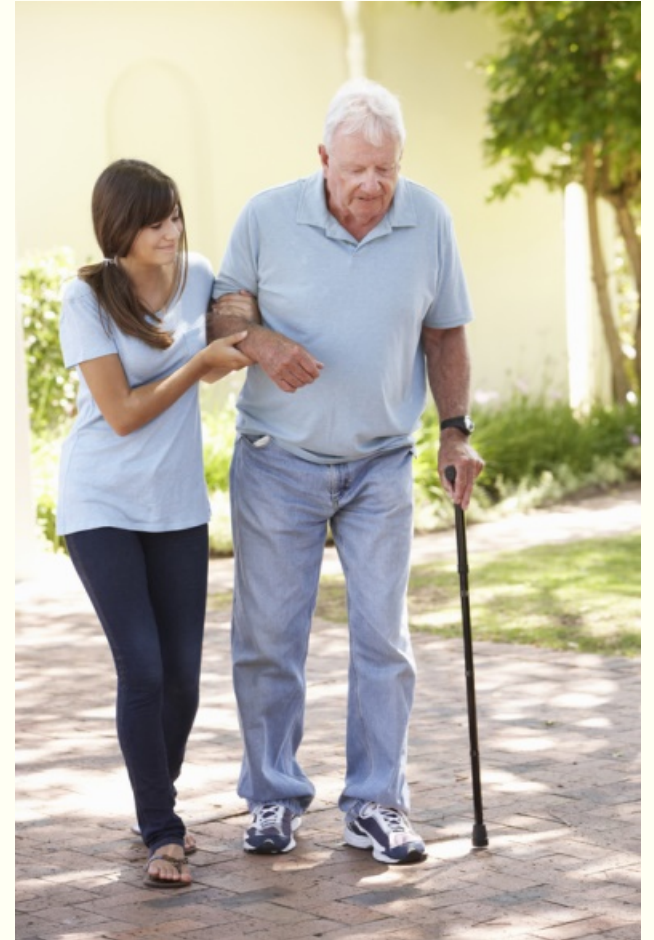
LIGHT IN A DARK TUNNEL: SUPPORTING YOUNG CAREGIVERS IN END-OF-LIFE CARE

Sharon B. Hamill, PhD
Faculty Director, CSU Institute for Palliative Care at CSUSM
November 17, 2017



Overview

- Need for focus on young caregivers
- The help young caregivers provide to family members
- Impact on young caregivers
- Key issues in end of life care



Need for Focus on Young Caregivers



1.3-1.4 million caregivers
(National Alliance for Caregiving and
United Hospital Fund, 2005).



7 million children live in
grandparent headed-
households (US Census
Bureau, 2012; 2014)

10,000 baby boomers
retire each year (Cohn
& Taylor, 2010)

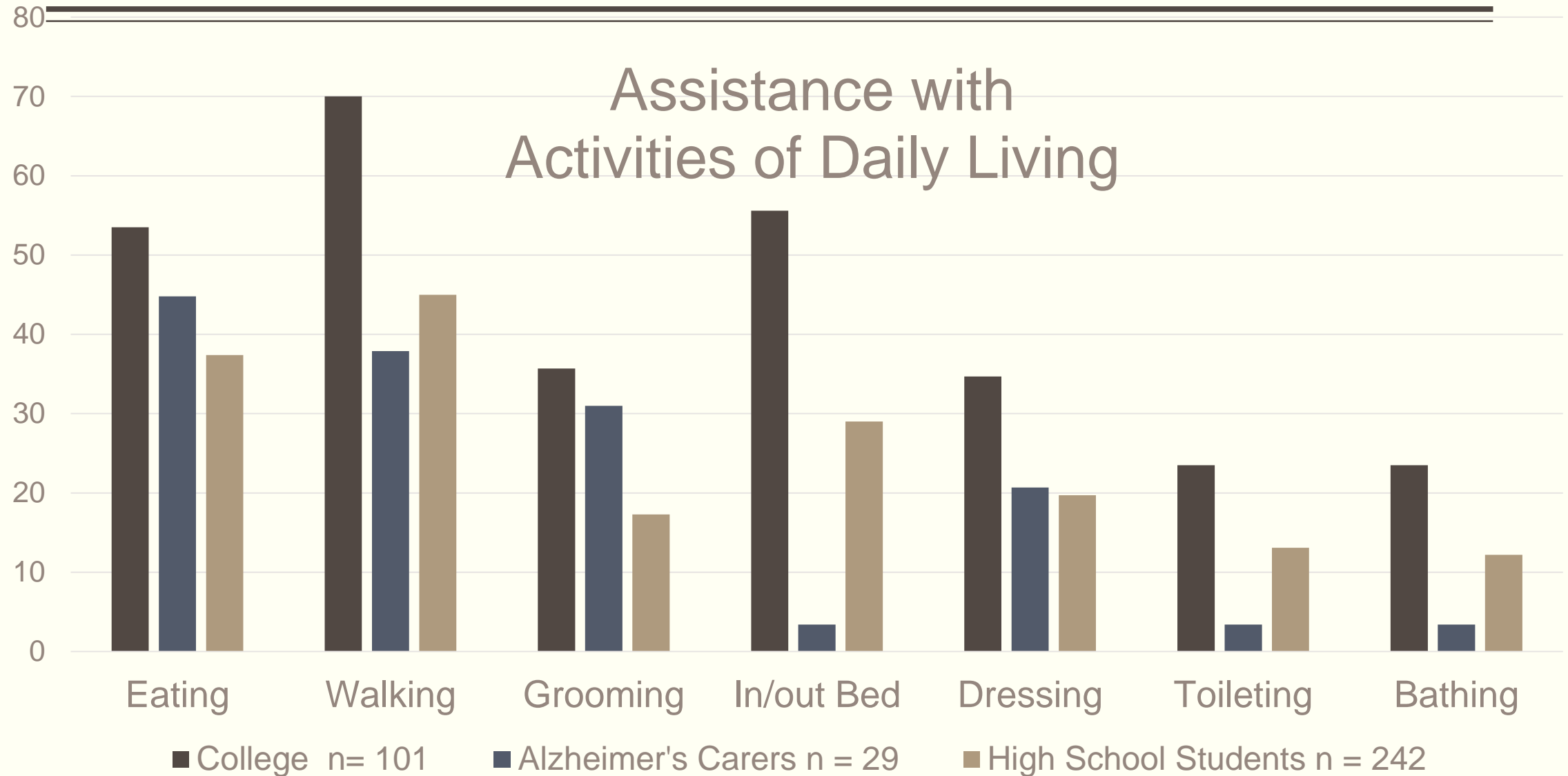


©Andi Berger ID 3716271

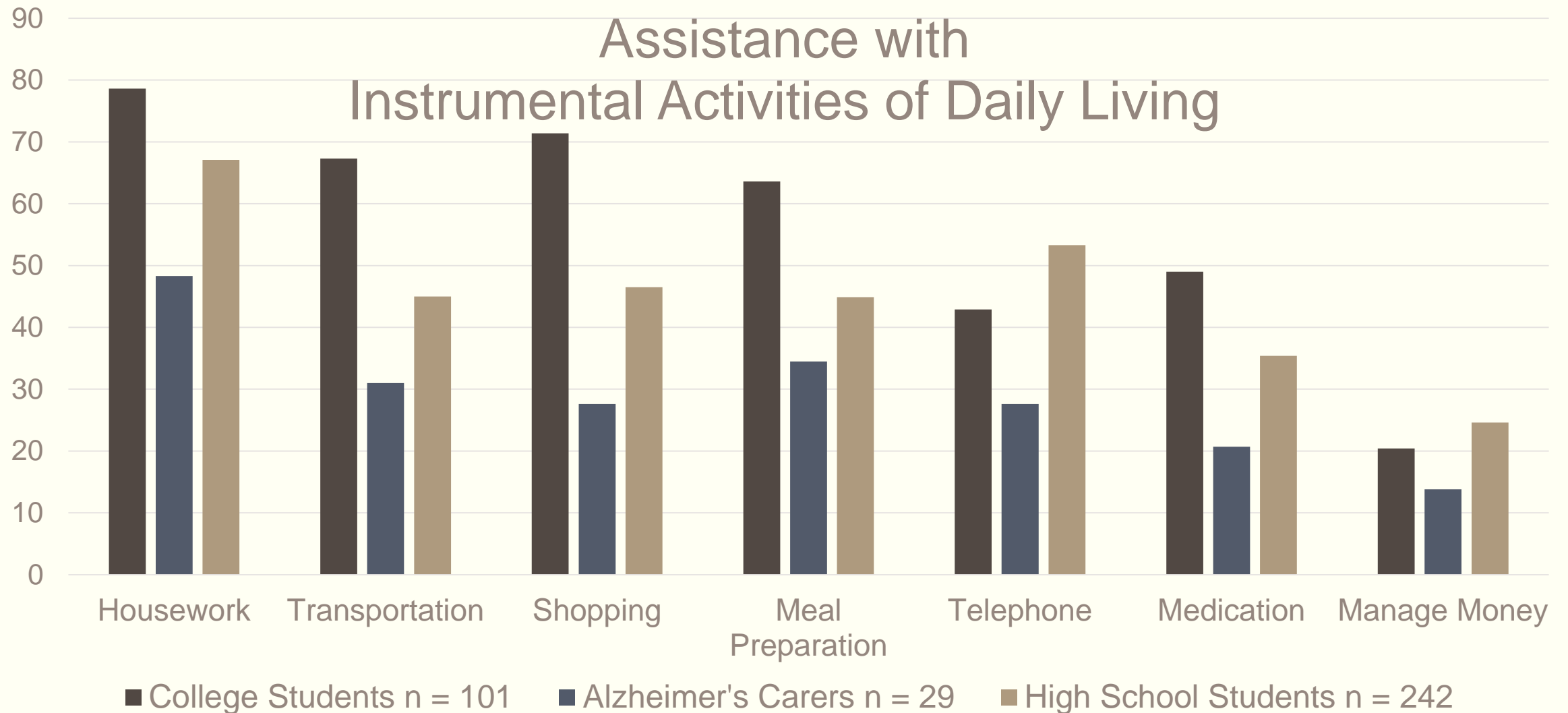
Need for Focus on Young Caregivers

- “Young Carers are children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult” (Becker, 2000).

The Help Young Caregivers Provide



The Help Young Caregivers Provide



Impacts on Young Caregivers



Mental and Physical Health

- Anxiety and depression, bullying (NAC & UHF, 2005)
- Somatic complaints, drug/alcohol use (Hamill et al., 2016; Pakenham et al., 2006)



Academics

- Missing school (Diaz, et al., 2007)
- Failure to complete assignments (Siskowski, 2006)



Psychosocial Development

- Lower levels of psychosocial maturity (Hamill et al., 2016).
- Feeling older than they are (Johnson & Mollborn, 2009)

Positive Outcomes

- Empathy
- Mother-adolescent bonding
- Learned something positive
- Will care for others in the future

(Beach, 1997; Celdran, Triado & Vellar 2009; Hamill & Shapiro, 2014)



End of Life Issues

National Study:

17% help the care recipient communicate with doctors or nurses

15% over age 12 make arrangements for health care services. (NAC & UHF, 2005)

Hamill Lab:

27.4% of high school student caregivers took their grandparents to doctor's visits



End of Life Issues: Palliative Care



Improves the quality of life by preventing and relieving suffering through:

- identification,
- assessment, and
- treatment of pain (physical, emotional, psycho-social and spiritual)

End of Life Issues: Palliative Care

Appropriate at any age and at any stage in a serious illness

Decreases hospital admissions, increased longevity, improved quality of life (Lukas, Foltz, & Paxton, 2013; May, Normand & Morrison, 2014; Rabow et al., 2016)

But if young caregivers/families don't know about it, they can't ask for it.



End of Life Issues: Palliative Care

Only 1.9% of high school students were able to identify palliative care

Young caregivers (29% of the sample) were more likely to correctly identify non-caregiving peers.... But only 3% could do so.



End of Life Issues: End of Life Option Act



The End of Life Option Act (ABx2 15)

End of Life Issues: End of Life Option Act

- 18 years or older
- Able to make and communicate health care decisions
- California resident
- Have a terminal illness likely to end in death \leq 6 months
- No one can ask for it on another person's behalf

End of Life Issues: End of Life Options Act

- What impact will this legislation have on this population of young caregivers who are largely ignored?



End of Life Issues: End of Life Option Act



- Physican-assisted death is not suicide.
 - But will young people be able to make the distinction?
- Suicide contagion research suggests we need to address this proactively (Blasco-Fontecilla, 2012; Smith, 2017).
- Need to prepare educators and others who work with young people -- need for vigilance.

End of Life Issues: Young Caregiver Support

- There are **350** Carer Centers in the United Kingdom.
- There is **one** center for young caregivers in the United States [American Association of Caregiving Youth]





We need to be the light.