

The Hidden Costs of Caregiving

DEBBIE WARD

JULLIE GRAY

I will use two lenses:

- A macro economic lens
- A feminist lens



And my interest is based in the start to my nursing career as a home health aide

- My first home health experience

Why am I talking first?

What are the benefits of caregiving?

- What do you think?



What about the costs?

- I'm talking about costs today though we know there are benefits.

Care has benefits and costs


Gender in Caregiving

60 % of family caregivers are women.


Men provide much care, but women provide more and spend 50% more time doing so.

Men and women do different kinds of caregiving.

The average duration of elder caregiving is **4 years**, but 15% of elder caregivers provide care for more than 10 years.



Elder caregivers spend an average of **24 hours a week**, but a quarter of them spend 41 or more hours per week providing care.



Caregivers for demented family members report an average of **9 hours per day** providing help.

Time in caregiving

Money in Caregiving

If we measure using money, what are the effects of caregiving on caregivers?

- Out of pocket expenses
 - Lost time in paid work
 - Reduced job advancement
 - Quicker retirement
 - Others?
-
- And Opportunity Costs

The \$ value of Caregiving

The estimated value of services provided by informal caregivers in 2013 was **470 billion dollars**.

- That exceeds the value of Medicaid spending and paid home care combined.

What's the value of caregiving to the nation?

01

A subsidy to the national good

02

The cost of care to frail elderly is greater than the cost of child rearing

03

Yet child-rearing has greater financial and policy support than elder caregiving.

Why is this?

What the feminist Economists think...

Family = free

Informal = casual, sporadic

Housework = not real work

Money taints otherwise virtuous acts.

How might women caregivers think?

What is the effect on our perceptions of caregiving by applying money to it?

And why should this matter more for women?

Womens' work

- Paid
- Unpaid
- Who benefits?
- Who pays?

Rosalynn
Carter,
Institute for
Human
Development

“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who need caregiving.”

Personal Costs of Caregiving

Career suffers

Social support declines

Self-care takes a back seat

Stress, depression & anxiety increase

Illness strikes

Financial security crumbles

Men

- Reduced work hours
 - - \$127 K wages
 - - \$38 K Social Security lifetime benefits
- Completely stopped work
 - - \$284 K in wages, pension & SS

Women

- Reduced work hours
 - - \$121 K wages
 - - \$64 K Social Security lifetime benefits
- Completely stopped work
 - - \$324 K in wages, pension & SS

Source: MetLife 2011

Strain on Family Dynamics

Complex lives of families...

Role changes

Unresolved feelings

Family secrets

Family history of dealing with hardship

Current life and issues are brought to the table on top of all of the above

Relate with mom/dad as s/he was, not as s/he is

Strain on Sibling Dynamics

Each sibling....

Has a distinctive relationship with his/her parent

Has a individual viewpoint/experience of family history

Comes to the situation from a unique position/different place in life/different life experience

Has different strengths

Has old wounds

Mythic parent, what mom/dad never did or was. Own needs may be unmet and may never be able to be met.

Experiences loss and grief in their own way

Cultural Differences in the Caregiving Experience

Sources:

- American Psychological Association. Cultural Diversity and Caregiving. www.apa.org
- Pinquart, M. & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, 45, 90-106.
- SAGE www.sageusa.org

Asian-American caregivers make less use of professional support services than White caregivers.

Hispanic and Asian-American caregivers experience more depression than White caregivers.

African-American caregivers experience lower levels of caregiver burden and depression than White caregivers.

All ethnic minority caregiving groups report worse physical health than the White caregivers.

LGBT caregivers have limited access to LGBT-affirming support services in their communities.

For many rural caregivers, poverty combines with lack of health services, fewer resources and living in an underserved area to negatively impact caregiving.

What can
be done to
help
caregivers?

Listen!!

Validate, provide hope,
empower, re-frame

Encourage limit and
boundary setting

Develop a caregiving plan

Formal caregiver agreement

What can be done to help caregivers?

Education – including a focus on managing difficult behaviors

Ensure adequate respite is in place

Monitor for burnout

Encourage self-care

Caregiver counseling & support groups

Assess/re-assess needs and connect with appropriate supports/services

What can
be done to
help
caregivers?

What else?

Discussion & Questions



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