Preparing for the Future of Caregiving in Minnesota

A Review of Wilder Research Studies on Caregiving and A Description of Wilder’s Caregiver Services

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By Greg Owen
Minnesota is officially in a period of rapid demographic change.
Between 2010 and 2030 Minnesota’s older adult population will more than double!
What do we know about caregiving today

- Caregivers are managing complex conditions
- Being a caregiver can be isolating and stressful
- Stressors often greater for those with little support
- Caregivers often lack knowledge of services
- 90%+ of care recipients want to remain at home
- Increased longevity results in greater number of care recipients with some form of dementia
- Recent MBA study shows one-half of MN caregivers care for someone with dementia
A few caregiving statistics

- 585,000 caregivers provided unpaid care to an adult in Minnesota (AARP, 2015)
- Estimated annual value of caregiving in MN is $7.86 billion
- Family caregivers often struggle with health, employment, or both
- Funding for federally funded services for caregivers has remained flat while the number of caregivers served has increased every year
What factors will shape the future of caregiving and caregiver services in MN?

- Dramatic increase in the number and diversity of older adults with long-term care needs including dementia
- Projected decline in available caregivers
- Uncertain status of Affordable Care Act (ACA) legislation that emphasizes a Community First Choice Option and encourages a rebalance of Long-Term Care (LTC) with greater emphasis on supporting care at home
What factors will shape the future of caregiving and caregiver services in MN?

- 2008 Health Care Home legislation that incent hospitals and clinics to create strong partnerships with families and community resources
- Widely used central referral mechanism (SLL) that makes caregiver supports more accessible
- State of Minnesota public awareness campaign to reach more caregivers
How will more recent state actions impact the future of caregiving services?

- 2012 law requires those wishing to enter assisted living programs to contact Senior LinkAge Line® (SLL) and receive offer of Long-Term Care Consultation (LTCC) services
- 2013 law further modified the work of the SLL and role in care transitions requiring hospitals and health care homes to refer older adults at risk of nursing home placement to the SLL
- Minnesota’s Return to Community Initiative
Recent research shows many challenges for caregivers

- The majority of caregivers receive little informal support, have poor knowledge of available services.
- Caregivers have difficulty planning ahead for the relative’s future care needs.
- Caregivers themselves report a lack of preparedness to provide care.
- Those caring for family members with dementia often feel trapped because of the constant and substantial needs of their care recipient.
Understanding Caregivers’ Networks of Support

The Caregiving in Context Study
Key Study Questions

- Who are the caregivers and how did they assume their role?
- Where do caregivers look for help or guidance?
- How are caregivers supported and what do their networks of informal support look like?
- What do caregivers say would help them the most?
Who we talked to...

- In-depth interviews with 212 caregivers in St. Paul

- **141 Primary caregivers**
  (mainly responsible for care of older adult)

- **71 Secondary caregivers**
  (assist an older adult)
Who we talked to...

Average age

- Caregivers: 57
- Older adults: 80

Caregivers are diverse:

- Men (31%) and women (69%)
- 25% people of color
- 29% at or below 200% poverty
- 54% employed full-time
- Spouses, adult children, friends, and neighbors
Who they are...

Primary (N=141)

- Spouses, 23%
- Daughters, 37%
- Sons, 21%
- Other relatives, 12%
- Non-relatives, 7%

Secondary (N=71)

- Spouses, 1%
- Daughters, 28%
- Sons, 14%
- Other relatives, 17%
- Non-relatives, 39%
Pathways to caregiving

One in five (21%) said they planned to be a caregiver.

“My sister and I provide the support to my mother jointly. We met as a family and talked about how we were going to deal with the challenges.”

62% said their expectation of becoming a caregiver simply fell to them.

“My father remarried after my mom died, and his second wife died in March 2010. At that point, my father decided that he wanted me to become his primary caregiver.”
Caregiving: A snapshot

- 86% spent at least 1 year in role of caregiver; 30% spent 10 years or more

- Average time spent providing care:
  - Primary caregivers: 37 hours per week
  - Secondary caregivers: 9 hours per week

- One in four (40%) share their home with the older adult they care for

  *(mostly primary caregivers who are relatives of the older adult)*
Caregiving: A snapshot

Caregivers assist with a wide variety of tasks.

- 69% of caregivers help with 5 or more of these daily tasks.
- 19% of caregivers help with all 10 daily tasks listed here.
Focus on support

What is the most important resource that supports you as a caregiver? (N=141)

- Support from family, friends, and/or neighbors: 62%
- Health care resources: 48%
- Home-based services: 15%
- Community-based resources: 8%
- Faith community: 6%
- Personal resources: 6%
- Professional service: 4%
Measuring informal support networks

8 items in our scale:

- Help with caregiving tasks
  1. # of family members assisting the caregiver
  2. # of others outside family assisting caregiver
  3. # of tasks the caregiver received help with in the past month
  4. Support in caregiver’s absence (1 month or longer)
Measuring informal support networks

Reaching out for support

5. # of people the caregiver reached out to for help, who then began to help

6. # of community activities used for support

7. # of different information sources used
8. Weekly contact including:
   - personal visits;
   - phone; or
   - email contact
     with a close friend or family member about their caregiving role
Informal support networks

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<th></th>
<th>31%</th>
<th>44%</th>
<th>25%</th>
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<tr>
<td><strong>Lower score</strong></td>
<td>Lower score (0 to 4)</td>
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<tr>
<td>Caregiver has less informal support overall.</td>
<td>Caregiver has a range of informal supports in place</td>
<td>Caregiver is well-supported by family members or friends.</td>
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Caregivers with lower scores

Who they are

• More men than women; lower income households; not working; living with the older adults

• Spouses, sons, other relatives

Caregiving role

• Felt role of caregiver was expected of them

• Intense level of commitment (hrs per week, tasks) with fewer using home-based services

• 51% using home-based services
Caregivers with higher scores:

**Who they are**

- Women; somewhat younger, employed; not living with older adults; caring for others
- Daughters, some wives, and few sons

**Caregiving role**

- Fewer hours per week and tasks
- More years in caregiving role
- 60% using formal services
Informal support matters

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<th>Caregivers with lower network score</th>
<th>Caregivers with higher network score</th>
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<td>43% feel other family members could be helping but are not</td>
<td>21% feel other family members could be helping but are not</td>
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<td>More likely to describe health as “fair” or “poor”</td>
<td>More likely to describe health as “excellent” or “very good”</td>
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<td>19% described caregiving as “very stressful”</td>
<td>4% described caregiving as “very stressful”</td>
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What caregivers say would help them

- Information about services and financial assistance.
- Advice and support related to caregiving tasks.
- Help identifying quality services.
- Finding other caregivers to talk with and places to connect for support and education.
- Help with basic needs like transportation, financial support, and care.
- Respite care.
Other recent Wilder studies of caregiving

- MAAA focus group study
- BC/BS Worksite support of caregivers
- Entira/Wilder caregiver study
- Review of Social Security Title III-E service
Wilder’s Community Center for Aging
Wilder’s Caregiver Services
Caregiver Coaching and Consultation

- Phone, email, or in-person services & support
- A wide range of supports including:
  - consultation
  - coaching
  - comprehensive assessments
  - in-home visits
  - service information
Family Meeting Facilitation

- Support in resolving family issues
- Facilitation of family meetings to:
  - Promote effective group communication
  - Set goals and make decisions
  - Plan for the future
  - Assist long-distance caregivers
Other Caregiver services available from Wilder

- **P.S. I Understand** – a peer-to-peer support program involving experienced caregivers

- **Caregiver support groups** – provide a community of support and understanding

- **Caregiver education** – educational opportunities to learn more about an illness, strategies for communication, ways to manage emotions

- **Respite care** – help in arranging time away from your caregiving responsibilities
Caregivers who receive caregiver services report …

- Improvements in their caregiving skills: 89%
- More confidence handling their caregiving responsibilities: 89%
- Greater ability to meet the needs of the person they care for: 85%
- A reduction of strain they feel in their caregiving role: 80%
- Being more hopeful or optimistic about their ability to continue their caregiving role in the future: 78%
Caregivers who receive caregiver services report they are …

- Better able to take care of their own health: 70%
- Better able to balance their caregiving with other responsibilities: 68%
- More able to engage in social activities or favorite pastimes: 50%

Source: Follow-up of Wilder Caregiver Services clients, 2014
To learn more about our research
www.wilderresearch.org

To learn more about Caregiver Services
visit our center at 650 Marshall in St. Paul
contact (651) 280-CARE (2273)
or email us at caregiving@wilder.org