



MPHA Policy Forum Notes
A Community of Caregiving: For Aging Parents
January 10, 2014

Moderator:

- Ellen Benavides, Independent Health Policy Consultant, previously Assistant Commissioner for the Minnesota Department of Health
 - Opening Remarks:
 - We are all caregivers for friends, families, etc. regardless of how we think about it

Panel:

- Mark Reese, counselor for the Families and Long Term Care Research Projects at the University of Minnesota
- Jenny West, Community Educator for FamilyMeans, a non-profit organization providing diverse services to families, children, couples and individuals headquartered in Stillwater
- Michael Aguirre, MSW, Licensed Graduate Social Worker working for the Metropolitan Area Agency on Aging

Opening Commentary by panelists:

Mark Reese

- Got into field because of personal experience. In 1992 brother died, his mother was later diagnosed with dementia and father was diagnosed with brain tumor. This all occurred over a span of 12 years. He shares this story because it is important to build rapport with others.
- Individuals who are caregivers may have metabolic function of someone 10 years older, their immune function may be decreased for 3 years after, and 33% could be diagnosed with depression.
- Some statistics on caregivers:
 - Can expect a \$5,000 - \$6,000 increase in expenses while experiencing 15% less income
 - 47% caregivers use all or most of lifesavings during this time

- Caregiver rated as most important in continuity of care. There is an increase of 4X-10X of hospital visits without caregiver.
- Caregivers often experience problems with HIPAA when trying to get information about those they are caring for, but...
- 25% of cases of medications came in incorrect if more than two transfers
- \$375 billion in caring a year in economy
- The impact of caregiving may lead to a work- lose of \$billions.

Jenny West

- Having to care for someone may either happen really fast (as in a crisis) or over time so someone might not even notice- this is why caregiving is often undefined
- Often the term “caregiving” is not used in other cultures- and it may not even be a term in someone’s language.
- Helping individuals identify as a caregiver may help with emotional stress. This will help them develop a plan and increase their confidence (ex: know where healthcare directive is, had that conversation, etc.). This self-identification may lead to a decrease rollercoaster of emotions a little (the height).
- Caregivers often provide 27 hours per week of care while maintaining a full-time job.
- There is also a need for a support system for the caregiver. The care receiver often has many people (dietician, doctor, etc). Caregivers need to identify their system and the fact that it may look different.
- Formal vs. informal caregiving.

Michael Aguirre

- 90% of individuals who identified as caregivers sought out more information after having self-identified.
- His job is to give an overview of caregiving to people he meets with, including impacts on health (mental emotional, physical, etc) and how important it is to seek out additional services. May be overwhelming for caregiver.
- Many who are caregivers don’t know where to start and/or which questions to be asking.
- He looks at specific situation the caregiver is in, whether they want to keep care receiver at home or move them to a support service.
- Senior Linkage Line: information assistance line about services available in area or general questions about aging.
 - Can’t just let it end at this.
 - Also have to think about how to provide support for caregivers.
- When caregivers seek out supportive services => better outcomes for both caregivers and care receivers.
- Some additional places to look for services:
 - Minnesotahelp.info is a great resource

- A Longterm care choices navigator which includes 17 section Assessment to find additional supportive services and where to start.
- Possibly most important lesson for individuals he works with: Understand importance of planning ahead so where to return to when things change (where to turn to with more questions)
- One problem he has found in caring for his mother from long distance: It is sometimes hard for doctors to understand why it is important for him to keep up with her care
- 83% of those who identified as caregivers believe lead to increased confidence when dealing with physicians

Q1: How have changes in family dynamics impacted caregiving:

Michael: There is a wealth of information about providers. There are many specializations for different care options. It is important to find a resource that is trusted- this is vital in the process. There is such a thing as Longterm Care Counseling to assist people in navigation of services and questions to ask in each situation.

Jenny: The amount of communication needed and who is going to do what (identification) has changed. Multiple people may want to be in charge (and multiple people may not) and it is important to find the balance within family unit. It is important to find out what individuals can they do comfortably and what they cannot do. If someone feels uncomfortable with their responsibility, it may lead to a break in continuity of care. This means someone may need to expand their circle of people to ask to help to fill in any blanks.

Mark: There needs to be more conversation in education across an entire family. Individuals who are not geographical close to family may not know what is actually happening in terms of care. With dementia, individuals may have short moments of clarity and “trick” those who they are just talking to over the phone. There also needs to be more family therapists trying to facilitate education conversations about care.

Q2: What advice would you give about being a caregiver if have a parent who is unwilling to accept help.

Mark: Make sure to get an accurate assessment of if they do need help. A good question to ask relates to driving: would you put your son/daughter in car with them? Start the conversation as a family. Get everyone to do their wills, etc. together and make sure to start with self first- ex: “This is what I want.... What do you want?”

Jenny: Use media and news as a start to story. “Have you heard this...” The care receiver needs to be part of conversation. Ask them what they are willing to do to stay at home-ex: bring caregivers into house will require this much money. Don’t start these conversations during holidays. Set a specific time and place without distractions. Plan ahead and give them time to get ready and even give them articles to read if helpful.

Michael: Use baby steps to get to your point. Become an ally and make sure they understand that you are. Often times individuals are concerned with independence, therefore make sure they feel empowered. Encourage them to seek out information on own or provide information and let them digest it in their own time. Don't come to them with your own fears and make that the leading argument.

Mark: More accurate portrayals of residential care in media. Often how the public views these facilities is 10-15 years older than what it actually is.

Jenny: Present options when they aren't actually need. Tour a new facility when it opens, etc.

Q3: As a group of public health professionals. How can we educate our providers and family members about this?

Jenny: We are lucky to live in Minnesota because there are many great options. On the Minnesota Linkage Line she spoke with a woman who was worried about bringing her husband who had dementia to the barber because of the lights and distractions. Upon looking at Minnesotahelp.info, she was able to find a mobile barber for the woman.

Michael: Help professionals to be engaging caregiver more frequently. Caregivers are often neglecting their own healthcare needs when caring for someone else.

- 72% not going to doctor enough
- 55% not attending own doctor appointments

Mark: Formal education of providers. Working with caregiver is culture competency. Upon looking over programs, only 1 program had 8 hour component, most were 4 hours. Dr. Jim Pacala- a geriatrician at the University of Minnesota put together program (5 yrs ago) which achieved national recognition. Medical students were given a bag with glasses, knee brace, etc. and asked questions. Every few hours these individuals were given new bag with more objects and asked questions. The point of the exercise was to experience a reduction in mobility, tactile sensitivity. This allowed a new healthcare person to feel what it is like to age.

Q4: What are the most important needs for aging in place.

Mark: Nursing block programs. Medical systems have grown larger which has led to a physical removal of communities and healthcare. This changes the hierarchy and difference in power. Care needs to be decentralized and moved back into community.

Michael: Education and planning. Importance of seeking out information and knowing where to turn to. Centers for Medicare/Medicaid has some pilot projects including one in MN called Community CareTransitions Programs which seeks effective models for individuals to transition from hospital setting to community.

Jenny: It is important to remember that dreams and goals never die no matter how old are. What can we do as professionals? Make sure bring services to people so they can maintain their quality of life. Engage the wisdom that is out there.

Mark: Caregiver training programs used to be statewide, but have disappeared. They are now localized in research institutes in rarefied settings. He would like to see increased availability.

Q5: How do we pay for what we want?

Michael: Generally speaking, it is important to look at policies and how plans are written. Look at finances and plan well ahead. Average costs:

- Nursing home annual cost: \$76,000
- Assisted living (low): \$37,000; no set criteria except 24 hour services
- Home care \$52,000

Free county services: long term care consultation. Look at finances available.

Jenny: Ask parents how much money they actually have. Make sure to Plan ahead and have conversations about their long-term goals. It may be helpful to speak with an elder law attorney and have them look at all assets and come up with multiple plans. It may also be helpful to look into community services and non-profits because some can't turn individuals away. There are also places with sliding fee scales. Know that homecare services may range from \$17-35 per hour.

Michael: Often there is an unwillingness of family member to use their money for this because they may want to continue saving it for a later date. Remember that the cost of services are going to increase if put off for crisis- therefore it is better to use earlier for prevention. There may also be limited resources during crisis.

Q6: What can we do from a public health standpoint to support rural communities?

Jenny: These communities do have fewer services. In these situations it is important to look at informal support system. Look on the internet if can. Nurses are visiting farmers during the workday in Wisconsin to build relationships. Because of this more of the farmers are willing to say that will work on exercise. These small communities may not have local senior center, but may have local café where everyone goes-> do something there? It could also be useful to have own system with neighbors- ex: if light is still on, call me; if shade is not up, all me. She knows of a casserole crew which will bring dish over and support you, not just when there is a death in the family.

Mark: At the UMN Mini Med School he gave a presentation where an individual said there were no groups in the area- this person had already checked. He suggested taking out an ad in the paper. 3 months later he heard back and this individual now has 1 full support group and 3 more starting. No one was talking about it until the ad had been placed.

Q7: What is happening to elders with no family involvement?

Mark: Cognitive impairment, depression, anxiety. Failure to thrive, more isolation.

Kelly: May be due to a lack of knowing services that are out there. Often they are brought in when receive a call of someone knowing of an individual who needs help. Their organization often works with caregivers so they don't know of these people.

Michael: His job is reaching out. He does his job hoping that anyone and everyone knows of at least one starting point. Hopefully he'll get it out to enough people's hands.

Q8: What about caregivers who are not ready to accept help?

Jenny: Her job to help people identify as caregivers. Often they will hold events and no one shows up even though 1/6 people in MN are caregivers. Once they see they aren't alone, they will begin to reach out. Alzheimer's Association working with peer mentors. There is a common thread "if you don't have to have to go through what I went through, I want to help". It is important to just bring caregivers together.

Michael: There were recently billboards "I am a Caregiver". Often these people aren't recognizing the value of identifying as a caregiver.

Jenny: Also be aware that caregiving with a chronic illness can be 24/7, but it can also be an elective surgery. Caregiving also happens when an individual is not living right next to them. Caregiving can also be short-term.

Mark: Recognizing goals of caregiving. Sometime the switch point for individuals is that caregiving for self is not a selfish act. How can you provide help if your health is not alright? It can be helpful for caregivers to carve out time for themselves. This time could be something simple as 15 minutes with coffee and trade journal in the morning. The importance of this can be seen when spouses care for each other. When one of them have dementia (and over 65)- the caregiver often dies before the person giving care to. What happens then? Mentoring can help reinvigorate and give life to someone after the experience.

Other helpful resources:

FamilyMeans Support for Families: <https://www.familymeans.org/>

MCSCollaborative: 25 different agencies with caregiving services in metropolitan area

Wilder Foundation Caregiving Resource Center:

<http://www.wilder.org/programs-services/caregiving-resource-center/Pages/default.aspx>

Metropolitan Area Agency on Aging (MAAA): tcaging.org