

Agenda

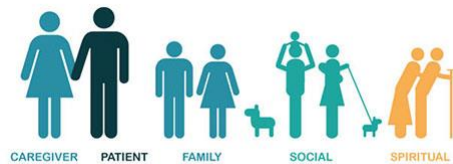
- Describe evolving **context of giving and receiving care**
~ the enduring challenges
- Review current trends inclusive of caregivers, including the ACA ~ the positive opportunities
- Define ***Person and Family Centered Care***
- Cite two examples of Family Centered Programs
- **Discussion: What does this mean for you?**

(Very) Brief History of Caregiving

- **60's** ~Construct of "Caregiver Burden" provided a foundation for research and programs
- **70's**~Family studies (Troll, Cantor, Zarit, etc)~Self-help books emerge for caregivers~ support groups
- **80's**~ First national surveys of informal caregivers ~ Alzheimer's Association and Hospice Care begin
- **90's**~Family and Medical Leave Act~UK passes Carers Act~Intervention evaluations and caregiver stress process (Pearlin)
- **00's**~National Family Caregiver Support Program~Lifespan Respite Care Act~Paid Leave (California)~Caregiver Identity Theory/T-Care

Andrew Scharlach

“The advances gained in understanding have led to family caregiving now being viewed as a complex process that affects and is affected by gender, culture, socioeconomic status, and lifespan developmental process”



Question #1

What percentage of caregivers are taking care of two people?

- 15%
- 25%
- 34%
- 40%



CHALLENGES OF CAREGIVING

Context of Care 2015

Caregiver Identification the perennial issue



Caregiving as a Public Health Concern

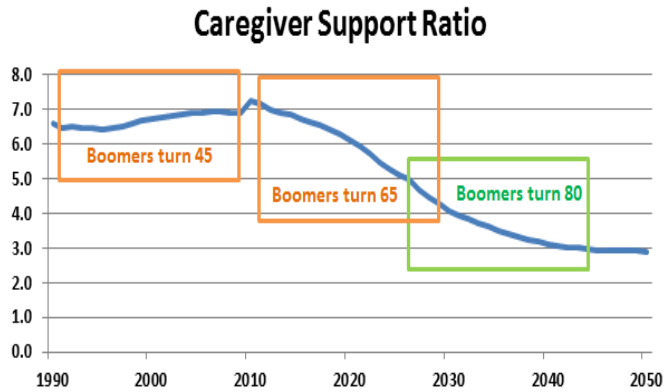
- Demographics!
- Changes in Family Composition
- Geographic Mobility of Families
- Physical, emotional, financial impact of caregiving
- Shorter hospital stays
- Workplace participation for women
- More chronic illnesses related to obesity epidemic
- Dementia Care
- Increasing Diversity among caregivers

Home Alone Acuity of Care 2015



<https://www.uhfnyc.org/publications/880853>

Caregiver Support Ratio



Andrew Scharlach

“Families are on their own to a greater degree than they have been in decades”



Status of Professional Caregivers

- Low wages—one half live in households that rely on public benefits like Medicaid or food stamps
- Missing benefits
- On-the-job injuries
- Limited opportunities for training and career advancement
- High turnover rates
- 57% are 45 years and older



Bottom Line

There will not be enough caregivers (professionals and family) to accommodate the 70% of Baby Boomers that the Department of Aging estimates will need long term care.

Question #2

What percentage of caregivers report that
“caregiving is the most stressful event in
their lives”?

- 4%
- 22%
- 48%
- 68%



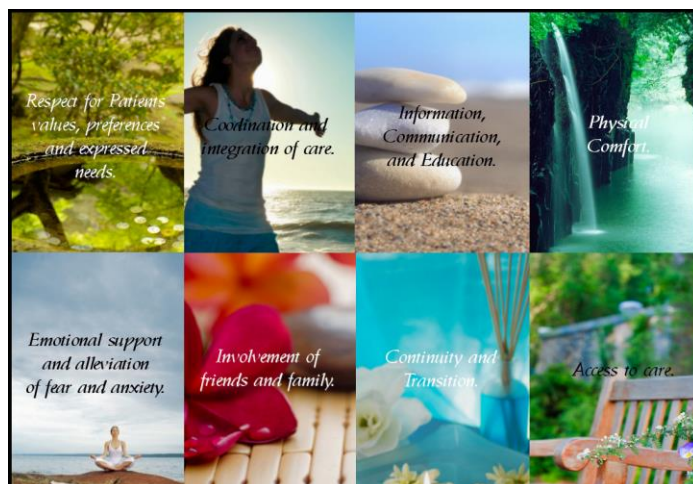
OPPORTUNITIES

The good news

Trends Helpful to Caregivers

- Person and Family-Centered Care perspective
- Affordable Care Act
- *Next Step in Care/Better Together* tools for transitions
- Technological Innovations
- Workplace Flexibility and Support
- Caregiver Assessments

Person and Family Centered Care



Person/Family Centered Care: The Five Elements:

1. Respect and dignity for the older person and his or her family
2. Recognition of the whole person
3. Assessing and addressing both the individual's and family caregivers' information, care, and support needs, as well as their experience of care
4. Promotion of communication, shared decision making and empowerment
5. Emphasis on coordination and collaboration across care settings

Person-Centeredness for Cognitive Impairment



The early and moderate stages of memory loss offer a window of opportunity to express wishes and daily preferences for care with their family caregivers—this will enhance their autonomy and improve quality of life.

<http://www.benrose.org/inc/Research/Values&PreferencesScale.pdf>

Bottom Line

Family Caregivers are no longer viewed as just a “resource” for their loved ones; rather, they are recognized as individuals who may themselves need information, training, and support.

? Question #3 ?

How many times does the ACA explicitly mention the term “caregiver/family caregiver”?

- 12
- 27
- 46
- 57



Affordable Care Act



- Engages individuals and their families in shared decision making and addresses family experience of care
- Recognizes caregivers as part of the care team in new models of care
- Bolsters education and training of the health care workforce including family caregivers
- Improves support for services at home and in the community, and for family caregivers

ACA Innovations Toward Coordination

Accountable Care Organizations (ACO's)

- Patient/Family Centered Care
- Payment Reform
- Focus on prevention and careful care coordination of persons with chronic disease
- Integration of behavioral health services and community linkages
- Build standards/develop programs for evidence-based medicine/best practice

Medical Home Model

- Patient/Family Centered Care
- Philosophy of comprehensive primary care
- Holistic orientation
- Team-based
- Enhanced access to care
- Continual improvement focused on quality and safety

Winston Churchill

“You can always count on Americans to do the right thing—after they’ve tried everything else”



Families as Partners during transitions

Next Step in Care

For Family Caregivers, guides and checklists:

http://www.nextstepincare.org/Caregiver_Home/

For Healthcare Professionals, questions and toolkit:

http://www.nextstepincare.org/Provider_Home/

For Hospital Staff:

http://www.nextstepincare.org/Provider_Home/Project_RED/

HIPPA & Caregivers:

http://www.nextstepincare.org/Provider_Home/Guides_HIPAA/

Institute for Patient-and-Family-Centered Care

Better Together Campaign:

<http://www.ipfcc.org/advance/topics/better-together-partnering.html>

Companion Guides for Staff and Families:

<http://www.ipfcc.org/advance/topics/guides-for-teams.html>

Individual and Family Engagement in the Medicaid Population:

<http://www.ipfcc.org/advance/topics/Individual-Engagement.pdf>

Hospital Visiting

<http://www.ipfcc.org/advance/topics/better-together.html>--

Technological Changes helping caregivers

Catalyzing Technology
to Support Family
Caregivers Report:

http://www1.pwweb.com/prfiles/2014/07/15/12013404/Catalyzing%20Technology%20to%20Support%20Family%20Caregiving_FINAL.pdf



- Internet—information, online caring communities, blogs, training, online care coordination tools
- Caregiver apps/GPS devices
- Remote home monitoring systems/Webcams for 2 way communication ~ “Smart homes”
- Wearables
- Telemedicine
- Electronic health records (EHR)

? Question #4 ?

What percentage of caregivers are employed?

- 38%
- 59%
- 65%
- 70%

Workplace Flexibility and Support

Best Practices in Workplace Eldercare:

- <http://www.caregiving.org/wp-content/uploads/2010/01/BestPracticesEldercareFinal1.pdf>
 - Paid Time off and Flexible Scheduling
 - Geriatric Care Management Services and Consultation
 - Planning for the Workplace Program based on assessment and feedback
 - Offering employee benefits matching consumer benefits (Healthcare programs)
 - Evidence-based programming (i.e. Powerful Tools for Caregivers)
 - Volunteer program/Management Champions

ReACT: Caregiver Experience Snapshot

- http://respectcaregivers.org/?attachment_id=629

Caregiver Assessment

Caregiver Assessment:
Voices and Views From
the Field (2006)

https://caregiver.org/sites/caregiver.org/files/pdfs/v2_consensus.pdf



- Critical to Caregiver Services in the community, they are relatively new tool in health care settings
- Systematic process
- Process recognizes needs and vulnerabilities as well as strengths
- Assessment Triggers
 - Transition points
 - Caregiver profile

Good to Know



Rosalynn Carter Institute for Caregiving

- http://www.rosalyncarter.org/caregiver_intervention_database/
- http://www.rosalyncarter.org/what_makes_caregiver_programs_effective/

Respite Study ~ Dr. Dale Lund

- <http://ahd.sagepub.com/content/79/2/157.full.pdf+html>
- <http://gerontology.uncc.edu/sites/gerontology.uncc.edu/files/media/Respite.pdf>

The CARE Act in Minnesota

National Coalition on Care Coordination (N3C)

- <http://www.nyam.org/social-work-leadership-institute-v2/care-coordination/n3c/>

National Transitions of Care Association

- <http://www.ntocc.org/portals/0/pdf/resources/ntoccissuebriefs.pdf>
- <http://www.ntocc.org/Portals/0/PDF/Resources/PatientBillOfRights.pdf>

Bottom Line...

Kathy Greenlee ~ Assistant Secretary of Aging:

“Families are the core of the system. They always have been. They are the both the center and the soul of the system. We need family caregivers—we need them because there is no replacement. You can’t make this a commodity. But we also need them economically as a nation, because we can’t afford to buy this care from strangers”

PCC EXAMPLE

Caregiver Consultation

Service Definition

CAREGIVER CONSULTATION

- Personalized service that equips family caregivers with knowledge, skills and tools to achieve a balanced lifestyle while caring for another person
- They assist caregivers in identifying needs and values...facilitate goal-setting and development of person-centered plan....provide ongoing coaching and support to assist caregivers in reaching established goals
- People who provide this service in MN are usually referred to as caregiver consultants.

Alzheimer's Association- Care Consultation Program

Meet Gina

Gina's Story



- 45 year old, single, adult daughter caring for parents (Mother-MCI, Father-Alzheimer' s disease).
- She recently moved to MN, sibs live throughout US.
- Overwhelmed ! Caregiver Stress!
- Troubles communicating with parents and siblings.

Person-Centered Plan

- Adjust expectations of her caregiving role
- Meditation/yoga/journaling
- Family Meeting when siblings visit
- Psycho education—role playing. Setting limits/ establishing boundaries
- Community Resource/Referral



ANOTHER EXAMPLE

Caregiver Consultation-Family Centered

Family Memory Care
Meet the Bradford Family....



Details....

- Primary Concerns: Sara recently diagnosed with YO Alzheimer's. Problems at work and home. Jim-working as teacher about 20 miles from their home.
- Frequent arguments about schedule and kids
- 3 kids-17, 15, 13 (active in school)
- Scored high in burden and moderate depression
- Feels "stuck" in his grief

Family Considerations

- Kids—don't understand Alzheimer's. Getting into fights at school. "Using" mom's diagnosis to their advantage.
- Other family: Jim-parents, brother and sister-in law. Sara-parents, 2 sisters (1 married, 1 single).



Family Meetings

- 2 family meetings—Sara attended one meeting, only extended family
- disease education
- legal/financial/work planning (elder attorney, HCD's)
- safety concerns (car, Sara's work?)
- parenting/school plan, planning for meetings with kids
- emotional wellness resources (depression, grief/loss)
- use of informal supports

Family Meetings

- Two family meetings-kids, and extended family.
 - disease education
 - problem-solving how family could support Sara with her memory issues
 - grief/loss—processing diagnosis
 - school/friends



Family Centered Plan

- Legal/financial/health care directives completed
- More support from extended family with child care-transportation, assistance with Sara's appointments, grocery shopping, occasional meals
- Kids-all schools informed, 1-therapist, less troubles in school
- Sara-talked with HR-shared her dx, made modifications to work duties and schedule

DISCUSSION

? Reflective Questions for You ?

How do you work with caregivers in your work?

How would you rate your work in terms of Family-Centeredness?

In what ways could this be expanded?

Summing Up

- ***Put the patient and family in the center of the healthcare team***
- ***Assess the caregiver and provide training for caregivers during care transitions***
- ***Develop better technologies to support patient health at home***
- ***Promote caregiver-friendly work environments***

THANK YOU!

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