

Care Coordination in the Home: Trends in Palliative Care, Advanced In-Home Care, and Community Health Care in West Virginia

WV PEL

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WVU SON & SOM

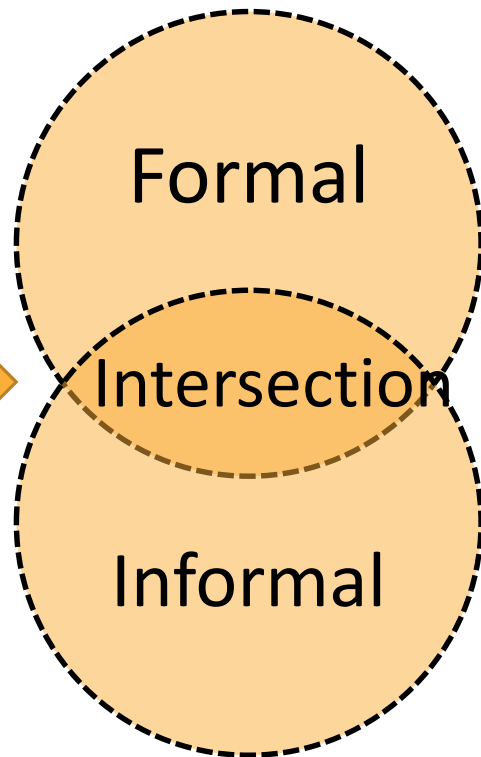
PRINCIPAL INVESTIGATOR: BRIDGES TO HEALTHY TRANSITIONS

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Bridges to Healthy Transitions

<http://www.hsc.wvu.edu/eastern/SON/Bridges>



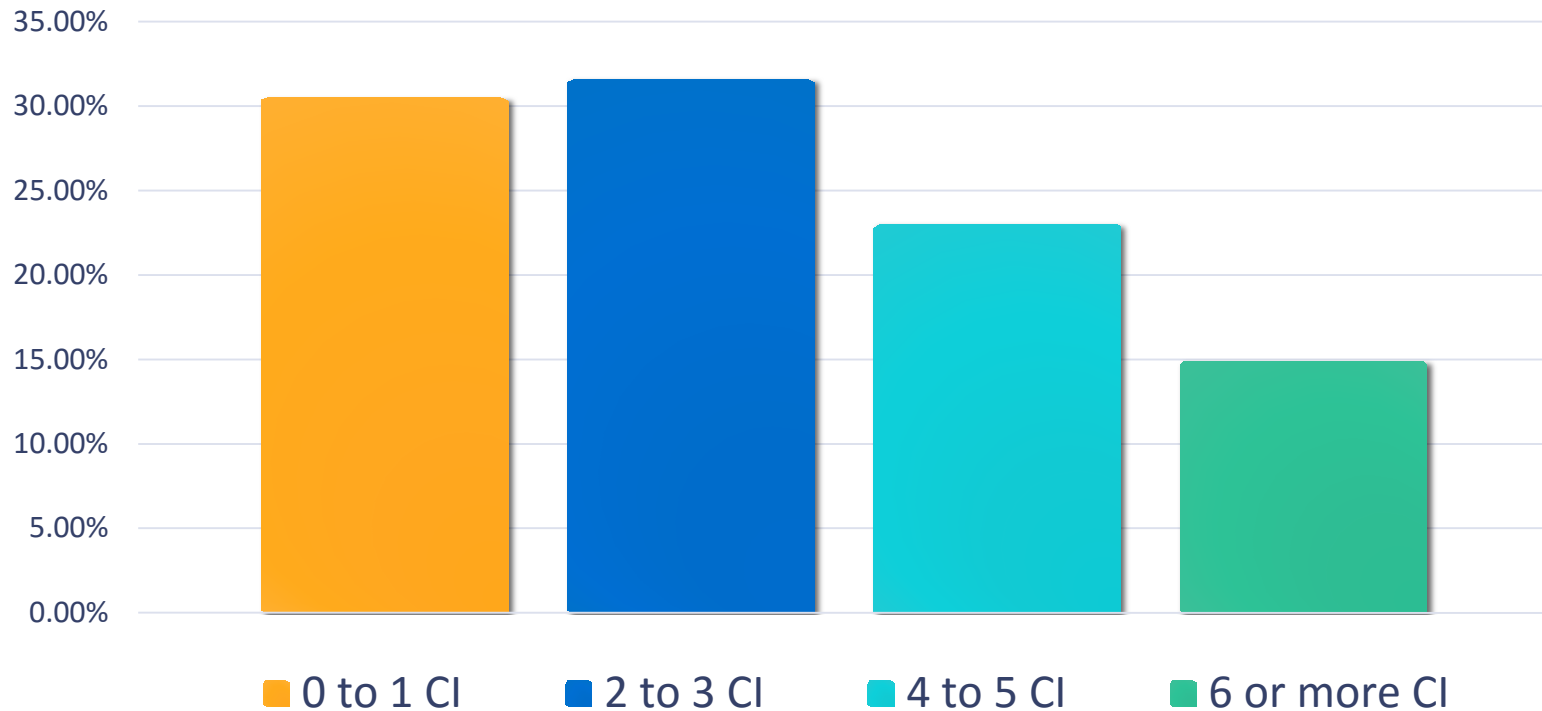
- Building Capacity for Rural Integrated Palliative Care: Bridges to Healthy Transitions *
- Mobilizing for Action through Planning and Partnerships**
- WV Elder Transitions in Chronic and Advanced Illness***
- University Healthcare Community Health Needs Assessment ****
- Building Bridges to Integrated Palliative Care: A Lay/Interprofessional Educational Collaborative**
- Future Generations: Community Health Worker (CHERP) Evaluation*****

Landscape - Costliest 5%

- “Costliest 5%” has remained constant
- In 2010, the costliest 5%
 - accounted for 39% of annual Medicare FFS spending
 - accounted for 82% of FFS spending.
- 2015 Institute of Medicine EOL report...
 - accounted for 50% of Medicare spending.
- **Only 11%** of the “5%” are in their last year of life
 - Primary and secondary prevention

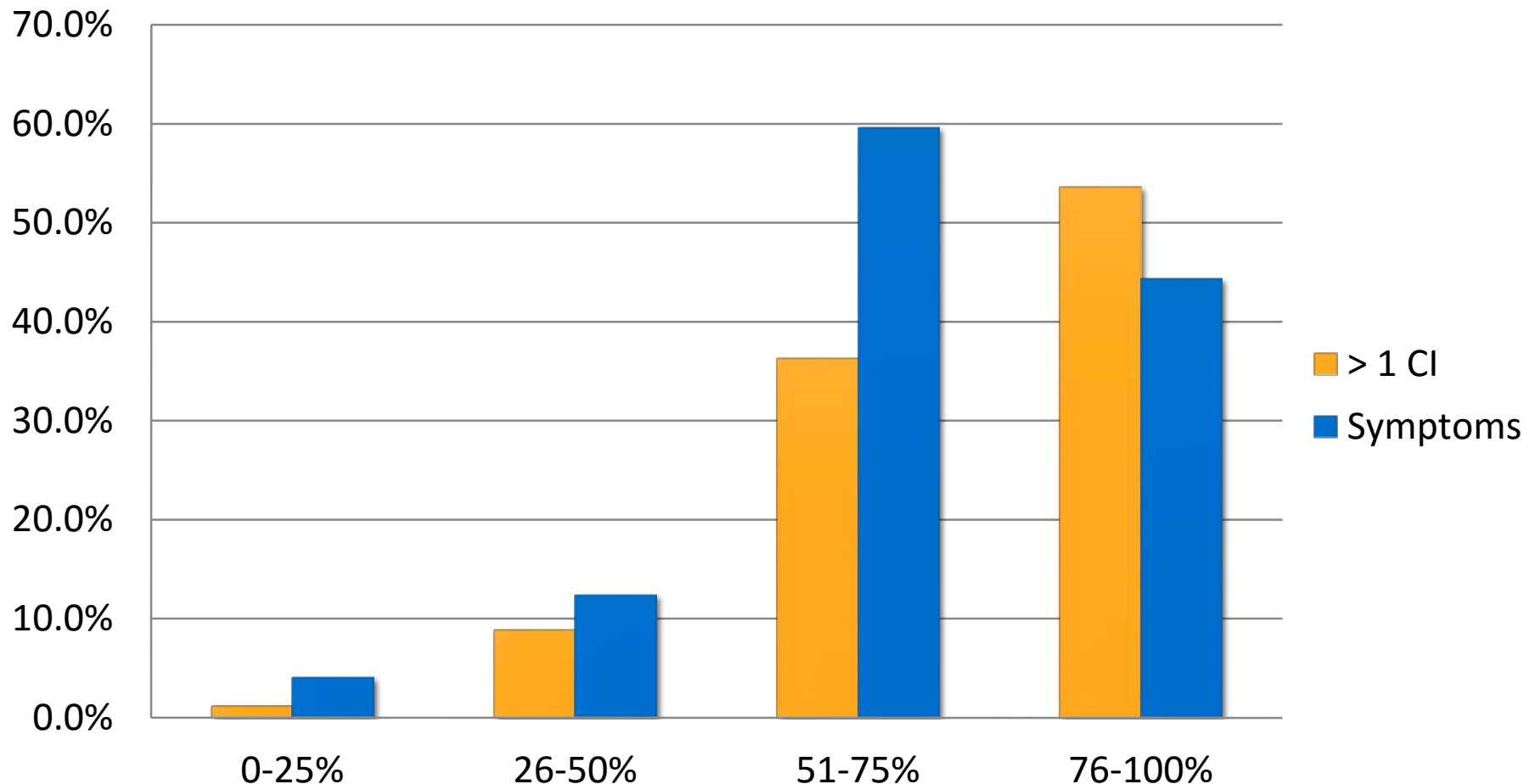
Chronic illness among WV Medicare Beneficiaries

WV Medicare Beneficiaries and Chronic Illness



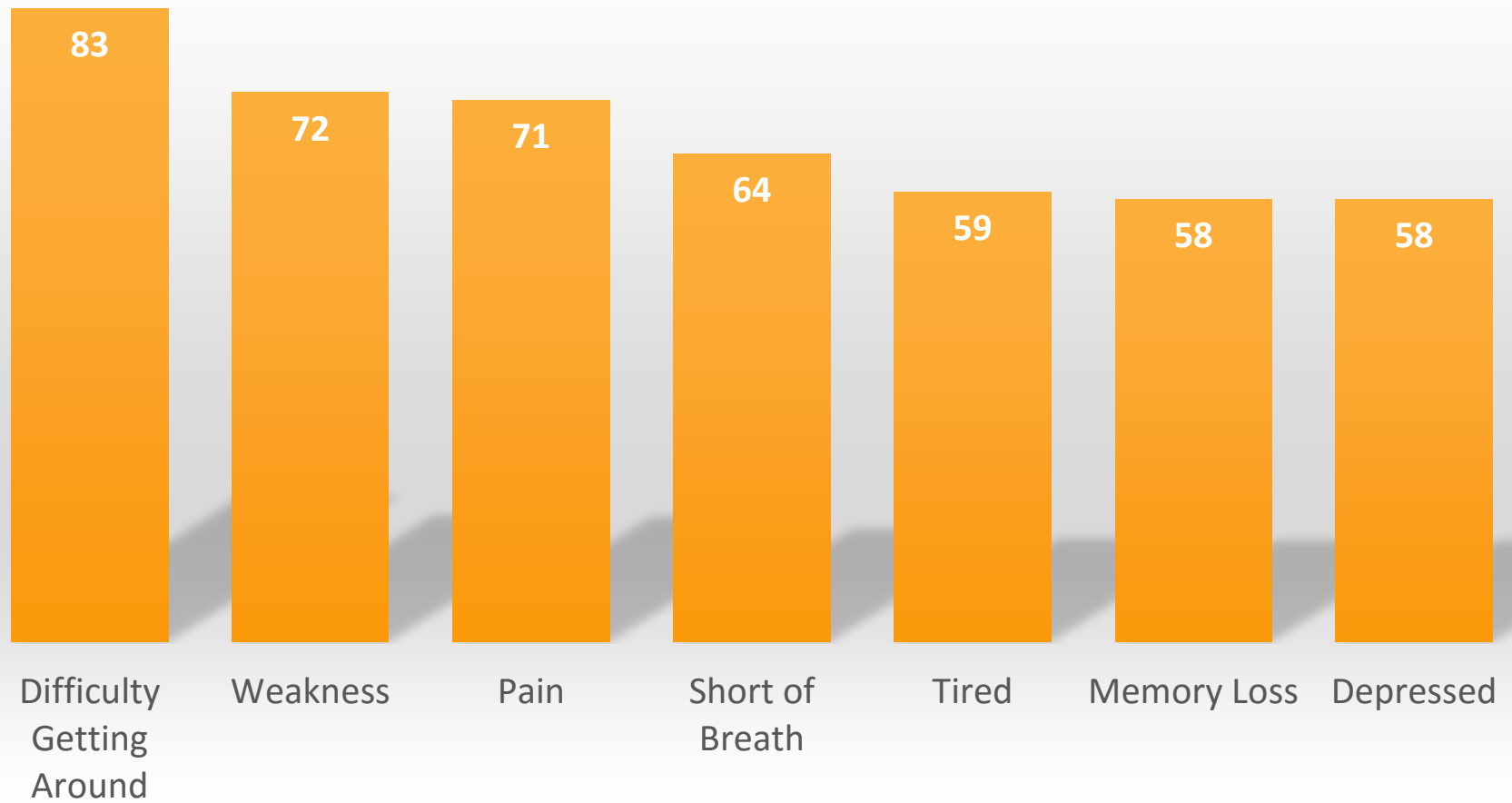
WV PEL Elder Transitions in Chronic and Advanced Illness (n=229)

1. What percentage of your clients have more than one chronic illness?
2. What percentage of your clients have symptoms that negatively impact quality of life?



Elders and Caregivers: Top Symptoms Reported (*n*=221)

Frequency of Report



Case 1

- A 63 y.o. woman post 9 month hospitalization for perforated bowel and sepsis
- Husband works and has insurance but job threatened due to wife's illness
- Moves into daughter's house for care/home health for wound management
 - Woman has extreme anxiety and is a hoarder which causes tension with daughter's husband
- First month: appointments with 9 providers/3 states
 - Closest 40 miles, lab work before appointment
 - 6 providers out of network
 - Co-pay range \$25 - \$50 – 2 require full payment up front
- Three months: oldest brother has stage four colon cancer and is refusing treatment. She is too sick to travel.
- Four months: daughter's husband dies suddenly and husband loses job

Case 2

- 66 y.o. man with poorly controlled IDDM, HTN, heart failure, and COPD
 - On 14 medications , fatigue, SOB, peripheral neuropathy, nausea
- On SS – dually eligible for Medicare/Medicaid
- 14 hospitalizations in 9 months
 - Left BTK amputation, 2 toes amputated right foot
- Discharged from SNF to community after 6 months
 - No family – estranged brother in California
 - Home health for 2 months/nursing/PT/OT
 - Senior Center support
- History of poly substance abuse – currently in recovery
- History of depressive episodes – untreated

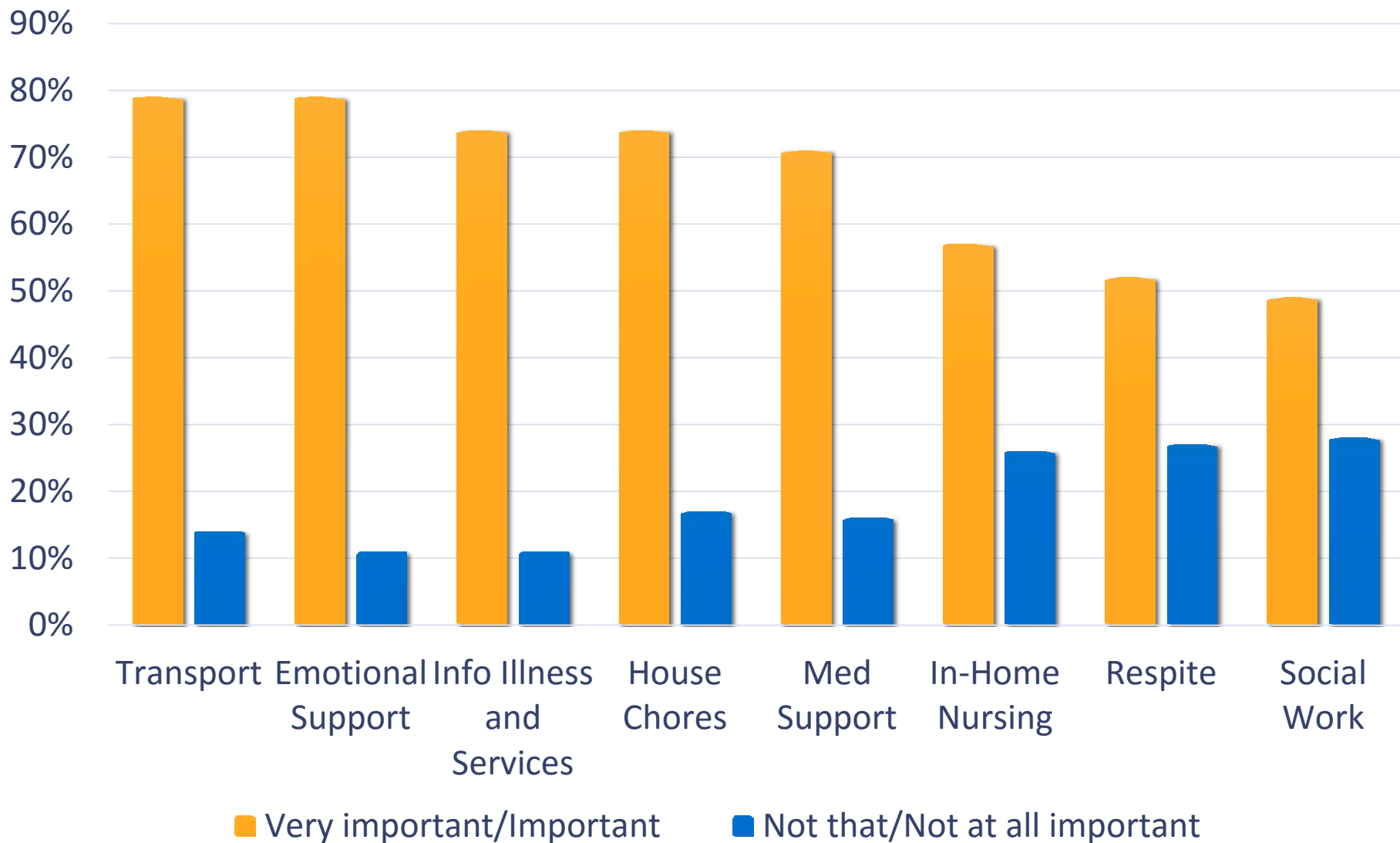
Case 3

- 78 y.o. male with diabetes, HTN, CHF, and undiagnosed progressive neurological condition with with periods of confusion and agitation. 6'8" tall. Neuropathy, toe amputations and non-healing stasis ulcers on right leg.
- Lives in rural area with wife who is primary caregiver who is 5'5" and has HTN and diabetes. 2 adult children with families within 70 miles.
- 7 hospitalizations, 4 specialists, one primary care in two different states. Home health nurse, PT, OT – nearing discharge. Does not qualify for Medicaid waiver and too rural for senior services.
- Durable medical equipment in home – wife unable to operate.
- Transport to medical providers an extreme challenge. Cannot afford ambulance or other transport.

Who's providing care?

- The vast majority of care in communities and homes
- Approximately 1,820,000 family caregivers in West Virginia provided more than 290 million hours of unpaid care in 2009.
- The estimated economic value of West Virginia family caregivers' unpaid contributions in 2009 was approximately \$2.8 billion.¹⁰
- 46% of family caregivers provide complex care for persons
- Direct-care workers provide an estimated **70% to 80%** of the paid hands-on care for older adults or those living with disabilities or other chronic conditions.³
- How well is the current system meeting their needs?

Elders and Caregivers: How important are the following?



Bridges to Integrated Palliative Care Findings

Health care providers

- They didn't listen, they didn't hear, they didn't come
- "Treat me like I am a person"
- They cared about me and my family

Rural Culture

- "I don't like it but It is what it is."
- "Give me something so I can help myself"
- "If Aunt Bessie says it isn't so..."
- Place and kinship

Financial and regulatory barriers

- "\$74 over"
- Advance care planning
- Hospice, palliative care, home care

Shifting costs and burdens

- "It's a co-pay here and a co-pay there"
- Burdens of caregiving
- Burden of being cared for
 - "Do I have to die so my daughter can have a life?"
- Societal and opportunity costs

Advanced Direct Care Workers?

- Advanced Direct Care Worker:
 - Improve Quality and Efficiency of Care for Older Adults
 - Meet unmet need for direct care
 - Observation, documentation, and communication
 - Adaptation for specific communities and settings
 - Alignment with expressed needs of elders and caregivers
 - Intrinsic motivation of current workforce
 - Career ladder
 - Improve health outcomes of ADCW and family?
- Proper support and supervision critical

Training

Advanced Direct Care Workers

- Critical components in training
 - Palliative care concepts
 - Behavioral health (Behavioral Health First Aid)
 - Person-centered/Family-focused care
 - Communication
 - Cultural diversity
 - Disease specific information
 - Early detection and intervention
 - System navigation – resource availability and quality
 - Specific skills for specific settings
 - Continued competence

Palliative Care & Care Coordination

Palliative care can reduce...

- Symptom burden, hospitalizations/readmissions, higher quality of life
- Caregiver burden and distress/increased productivity
- Out of pocket costs and health care utilization (potential)

Care coordination/care or case management:¹⁶

- Reduces hospitalizations and associated costs
- Increases patient and family satisfaction
- Improves communication among PCP and specialists
- Enhances treatment adherence and medication reconciliation
- Can improve patient and caregiver knowledge, skill, and self-efficacy to manage illness and associated treatments.

RCT: Nurse-Led Telephonic Palliative Care

- N= 322 advanced cancer patients in rural NH+VT
- Improved quality of life and less depression ($p=0.02$)
- Trend towards reduced symptom intensity ($p=0.06$)
- No difference in utilization, (but v. low in both groups)
- Median survival: intervention group 14 months, control group 8.5 months, $p = 0.14$

Prolonged Survival: Integrated Palliative and Cancer Care

- 151 patients with NSCLC at Mass General
- Immediate vs. delayed palliative care with standard
- Early pc patients with...
 - Improved QOL
 - Less depression; Less chemo in last 2 weeks
 - Fewer hospitalizations in last month
 - Nearly 3 months longer survival (11.6 mos. vs. 8.9 mos., $p < 0.02$)

Temel, NEJM, 2010

Promising Models

Comprehensive Care Coordination

1. Care Management Plus (CMP)
2. Geriatric Resources for Assessment and Care of Elders (GRACE)
3. Guided Care
4. Home Based Primary Care (HBPC)
5. Improving Mood-Promoting Access to Collaborative Treatment (IMPACT)
6. Program of All-inclusive Care for the Elderly (PACE)

Care Transitions

1. Better Outcomes for Older Adults through Safe Transitions (Project BOOST)
2. The Bridge Model
3. Care Transitions Intervention (CTI)
4. Interventions to Reduce Acute Care Transfers (INTERACT II)
5. Re-engineered Discharge (RED)
6. Transitional Care Model (TCM)

Primary Palliative Care

Provided by all health care professionals

- Management of chronic illness
- Care coordination
- Person-centered/family-focused/holistic
- Basic symptom management
- Communication
- Advanced care planning, goal setting
- Resources/training:
 - **HPNA** (*Hospice and Palliative Nurses Association*) training for RNs, LPN, CNA
 - **ELNEC** (End of Life Nursing Education Consortium)
 - **EPERC** (End of Life/Palliative Education Resource Center)
 - **CAPC** (Center to Advance Palliative Care)
 - **NHPCO** (National Hospice and Palliative Care Organization)

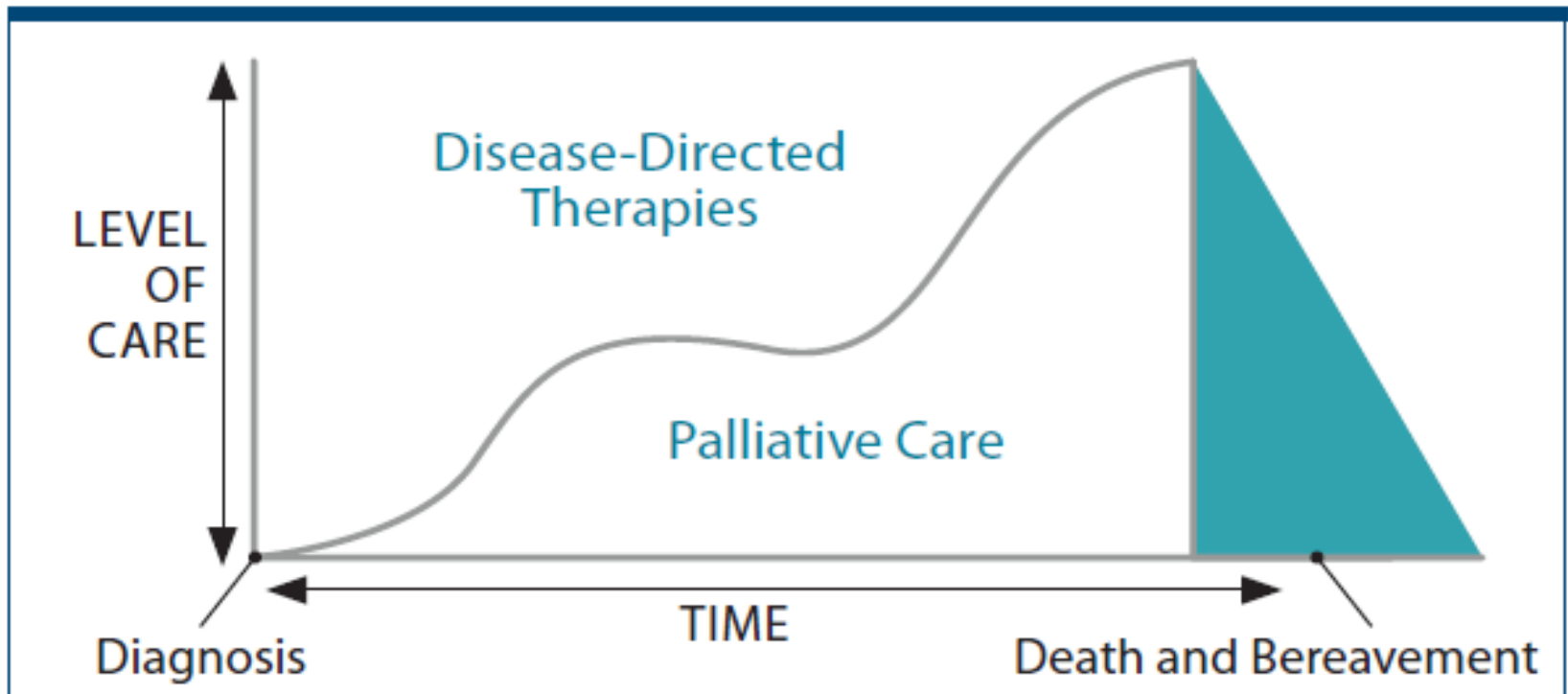
Specialty Palliative Care

Subspecialty in nursing, medicine, social work, and chaplaincy

- Focused on alleviating suffering and promoting quality of life for patients and families with complex needs who are living with a life threatening illness or severe advanced illness.
- Interdisciplinary – professionals with specialty training/certification in palliative care
- Domains inclusive of physical, social, psychological, spiritual/existential, cultural, ethical aspects of care
- Hospice, acute care, community-based

Palliative Care Across the Continuum

Figure 1: Continuum of Palliative Care



Palliative Care - Hospice

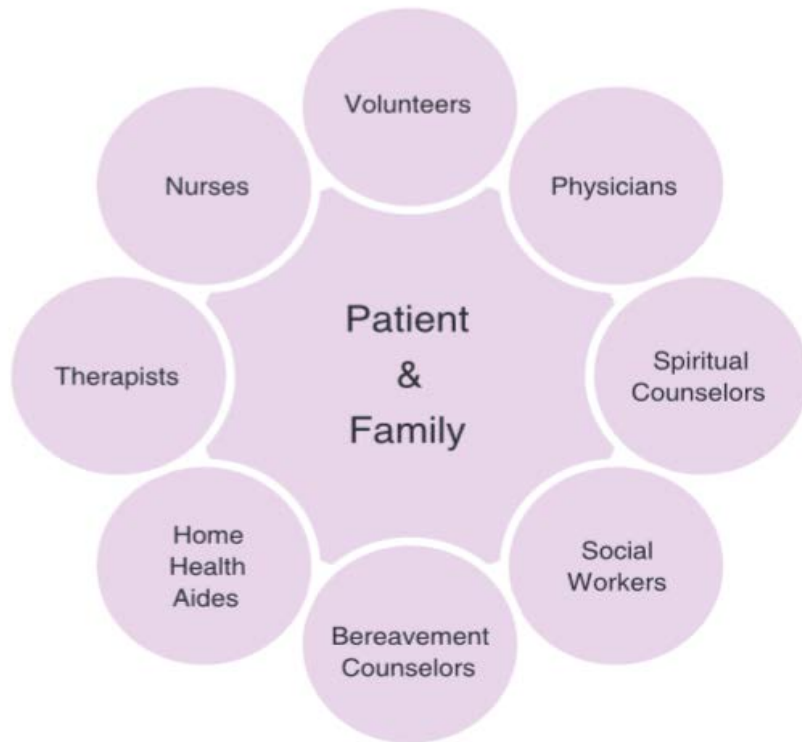
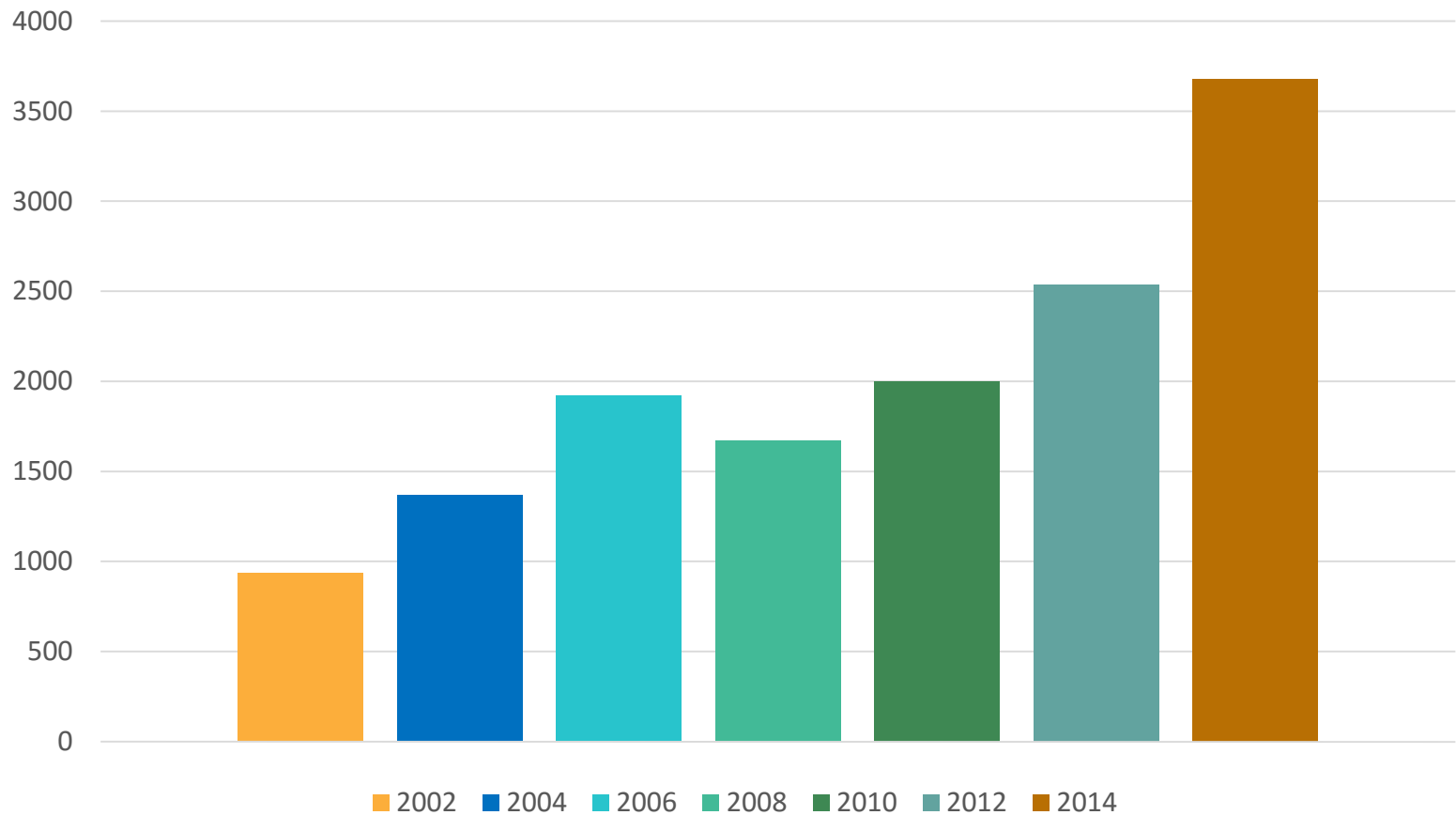


Figure 1. Interdisciplinary team

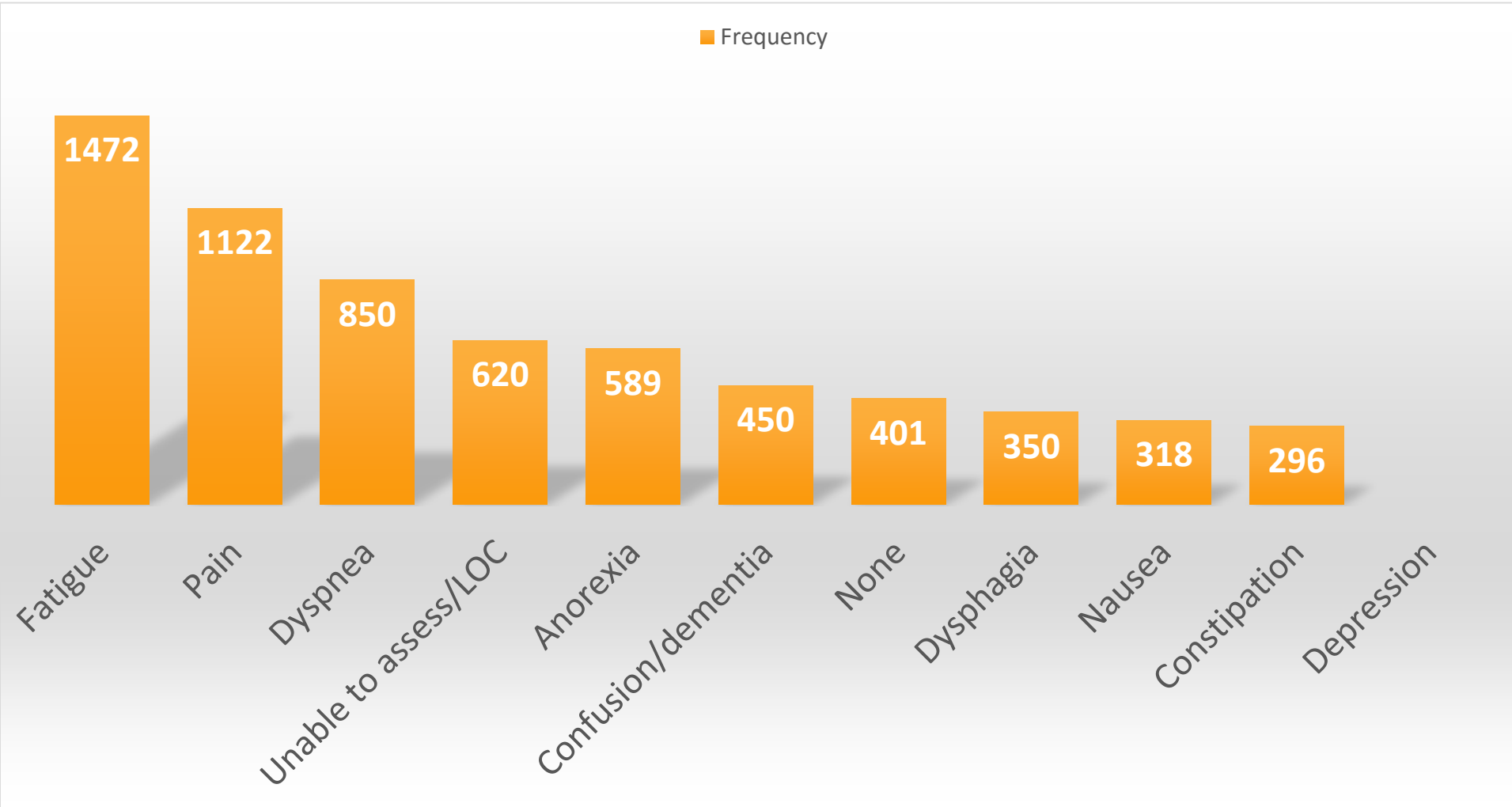
Hospice Care

- Life limiting disease
- Prognosis – 6 – 12 months
 - Specific criteria
- Forego curative treatment
- IDT and services
- Bereavement
- Medicare and Medicaid, private
- 2013 & 2014
 - WV hospices provided services to approximately 10,000-11,000 each year
- CMS Concurrent Care Demonstration
 - Medicare Care Choices Model

WV Palliative Care: Patients Served 2002-2014



2014 WV Palliative Care Report: Symptoms at Initial Assessment (Patients $n=3676$; Symptoms $n=7,383$)



Community-Based Palliative Care

- Range of care delivery models

- Advanced illness management (AIM) programs
- Extensive non-hospice palliative care KY, NC, VA
- Outpatient clinics – emergent trend
- Supportive care programs
 - WVU perinatal and pediatric
- Integrated Delivery Systems: Kaiser and Department of Veterans Affairs
- Aetna, Excellus BlueCross BlueShield, and Highmark, Inc. evaluation

- Medicare Care Choices Model (MCCM)

- Concurrent hospice and curative care
- Wrap around services – including dietary, spiritual, and bereavement counseling

Professional/Lay Educational Intervention

o Community-based care

- o Organizational culture assessment
 - o Discontinuity between goals/reimbursement
- o PC beliefs, attitudes and practice
- o Tailored educational intervention
 - o Person-centered/family-focused communication
 - o Symptom assessment and management
 - o Toolkits

o Outcomes

- o PC self-efficacy (staff/caregiver)
- o CDSM/Symptom/caregiver burden

Education and Training

- Independent Seniors Council, United Way of the Eastern Panhandle, Inc.
- Shepherdstown Area Independent Living, Inc. (SAIL)
- Good Shepherd Caregivers
- Meals on Wheels
- Other community volunteers
 - Home Health
 - Senior Centers
 - Hospice
- Family caregivers
- University Healthcare Physicians (UHP/Eastern Division)
- Home Health (Mental Health First Aid)

CHW Project Evaluation

- Efforts to develop the capacity of community-based organizations in rural, distressed areas are complex and require significant time, flexibility and adaptability.
- Successful implementation of this type of project requires that project staff dedicate sufficient time and energy early on to understanding target communities, selecting appropriate community-based partners, and developing relationships with them.
- Rural, community-based organizations can really benefit from outside expertise and resources. However, outside entities need to meet these organizations where they are and develop trust.
- Improving health outcomes by developing local capacity should be viewed as a **long-term strategy**. Changes in health outcomes among a large number of participants should not be expected in the short-term.
- Improving the capacity of local organizations to engage in health education and promotion has a greater likelihood of sustainability and impacting a growing number of community members over time.

Summary

Health care system design and culture

- Fragmented, poor communication, complicated financing
- Not always aligned with or responsive to needs of persons with complex health and social problems
- Gaps in supply and demand
- Professional and lay interpretations often differ
- Balance voluntary and paid workers
- Primary palliative care is just good care

Burdens of complex chronic/serious illness

- Symptom, caregiver, economic, societal
- Rural health disparities
- Intergenerational impacts

Recommendations

- Focus upstream – palliative care as primary and secondary prevention
 - Person with serious illness and family
 - Societal benefits
- Education/training for all level of providers, workers, and volunteers
- Offer tools so folks can “help themselves”
- Advanced direct care workers can serve as “bridge” with education and supports
- Respecting culture and maximizing cultural strengths
- Be realistic about limitations

WE CANNOT SOLVE OUR PROBLEMS
WITH THE SAME THINKING
WE USED WHEN WE
CREATED THEM

- Albert Einstein

