"NO-CRISIS" CARE:
Toward Lifetime Health and Wellbeing in Dementia

NAPA Advisory Council, April 29-30, 2024

SOO BORSON MD
PROFESSOR OF CLINICAL FAMILY MEDICINE, USC KECK SCHOOL OF MEDICINE
CO-LEAD, BOLD CENTER OF EXCELLENCE ON EARLY DETECTION OF DEMENTIA
PROFESSOR EMERITA OF PSYCHIATRY AND BEHAVIORAL SCIENCES, UNIVERSITY OF WASHINGTON

Disclosures:

- Journal of the American Geriatrics Society, Medscape/WebMD
- Roche Genentech, Biogen, Eisai, NovoNordisk, Abbvie, Lilly, and Linus Health

The ideas and materials discussed in this presentation are those of the author and do not necessarily represent the official views of, nor an endorsement by CDC, HHS or the U.S. Government.

1

Roots of dementia care

Social and Community Services

Dyadic Engagement, Coaching, and Support

Medical and Health Care Activities

2

14 Components	Sample Resources	Estimated Uptake
Detect cognitive impairment	AWV codes	~30% (2023)
Diagnose the problem	Recommended dx steps (checklist)	Unknown
Track (assess and reassess)	Cognitive Assessment and Care Planning	<3% (CMS data)
Plan care	Cognitive Assessment and Care Planning	<3% (CMS data)
Medical management	Routine clinical visits	(Few dementia-specific standards)
Inform, educate, and support	Informal, and Cognitive Assessment and Care Planning	Unknown
Engage/support person with dementia	Informal; support groups	Unknown; patient/family complaints persist
Support everyday function	Family, social/community care	Unknown
Engage, support, assist care partners	Research-validated interventions; Cognitive Assessment and Care Planning	Data from specific intervention studies + CMS
Prevent/mitigate BPSD	Validated caregiver interventions	Not generally available
Assure safety for person with dementia	Safety Checklists	Unknown
Foster therapeutic environment	(not developed for ambulatory care)	(limited to residential care)
Manage care transitions	**C**aregiver **A**dvise **R**ecord **E**nable Act (many states); Transitional Care codes	<10%
Refer and coordinate care/services	CACP/CCM codes	Very low (2024: new GUIDE option)

***HHS-ASPE/RTI1 Dementia Care Framework – 2016* Systems - Ecological Perspective**

3

Consolidating Dementia Capable Care Systems: Core Principles, Meaningful Outcomes

- Detect early – *before a crisis*
- Center continuity – *the foundation of effective chronic care*
- Embrace complexity – *it's here to stay*
- Manage risks – *make "No Crisis" a goal of care*

Borson S, Chodosh J. Clin Geriatr Med 30 (2014) 395–420

4

Detect early? Nearly half of patients are diagnosed during an unplanned hospital stay.

Age at first dementia diagnosis ~ 80.

	Clinic-Diagnosed by Clinician Discipline				
	Primary Care (n = 4756)	Geriatrics (n = 5322)	Neuro/Psych (n = 3399)	All Clinic[a] (n = 13962)	Hospital-Diagnosed[a] (n = 11,316)
Cognitive status and history					
ADRD Diagnosis Subtype					
Unspecified dementia	4124 (87%)	3153 (59%)	2222 (65%)	9869 (71%)	9405 (83%)
Alzheimer's dementia	359 (8%)	1732 (33%)	733 (22%)	2881 (21%)	634 (6%)
Other, non-AD dementia	273 (6%)	437 (8%)	444 (13%)	1212 (9%)	1277 (11%)
Any memory loss, MCI, or delirium code in prior 24 mo	1620 (34%)	1348 (25%)	1186 (35%)	4342 (31%)	4119 (36%)
Any cognitive assessment with dx (MOCA, SLUMS, MMSE)	681 (14%)	3319 (62%)	1138 (33%)	5160 (37%)	230 (2%)
MOCA	151 (3%)	1353 (25%)	371 (11%)	1882 (13%)	43 (0%)
	15.0 (5.71)	16.1 (5.16)	15.3 (6.12)	15.8 (5.44)	12.1 (8.42)
SLUMS	5 (0%)	314 (6%)	62 (2%)	384 (3%)	2 (0%)
	14.0 (4.06)	13.5 (5.20)	14.6 (4.90)	13.7 (5.15)	8.0 (1.41)
MMSE	526 (11%)	1930 (36%)	782 (23%)	3250 (23%)	190 (2%)
	19.4 (5.88)	20.5 (5.58)	20.4 (5.61)	20.3 (5.65)	18.5 (8.01)
Elixhauser Comorbidity Index	6.8 (3.42)	7.0 (3.41)	7.1 (3.38)	7.0 (3.43)	8.7 (3.78)

Nguyen, Borson, Khang et al. Alzheimer's Dement 2022; 8:e12279

5

Once diagnosed: High continuity of medical care reduces crises.

	Amjad et al JAMA IM 2016	Godard-Sebillotte et al JAGS 2021
Setting	Medicare FFS	Quebec CA
N	1,416,369	22,060
Age (mean)	81	81
Baseline ambulatory care utilization	4+ visits (2015)	2+ visits(2014-15)
Continuity of care	High/Med/Low tertiles	High (66%) vs Low (34%)
Hospitalizations	**High < Low**	**High < Low (RR .90)**
ACSC admissions	**No difference**	**High < Low (RR .87)**
ED visits	**High < low**	**High < Low (RR .92)**
Cost of care	$22,004 vs $24,371	N/A
Number needed to prevent 1 episode	N/A	**118 for ACSC hospitalization, 97 for all-cause hospitalization, 29 for ED visit**

6

Primary care clinicians talk about what they do, what they value, and how relationship matters in dementia care.

Interviews with 39 CA primary care clinicians and 20 US family medicine physicians

PCPs play multiple roles in dementia care

- Maintain continuity of care - personalized long-term, trusting relationships with patients and families
- Participate in detection and diagnosis
- Educate, guide, and support patients and families – now and future
- Coordinate care
- Manage complexity, monitor safety, prevent complications
- Respect patient and family wishes, tailor care to support their goals
- Minimize test and treatment burden

Health systems undervalue PCP contributions

- Low investment in dementia detection, care pathways, and support for key roles
- Little consensus around primary vs specialty roles
- Payment models not working for PCPs

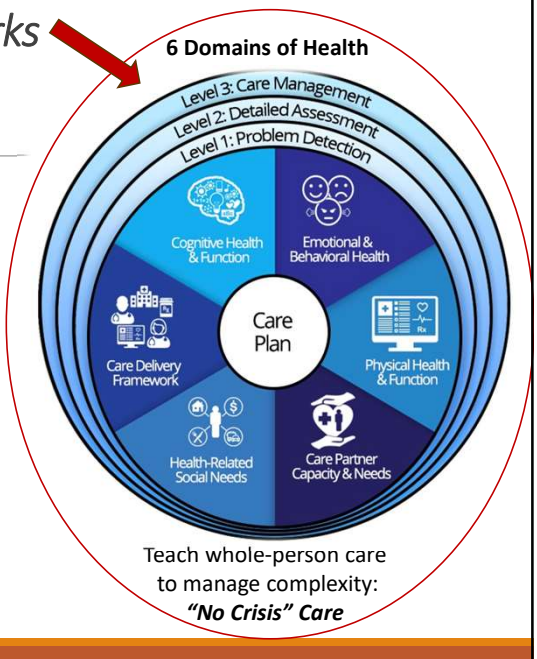
Sideman et al, JAMA Network Open 2023; Sideman, Wood, and Borson in preparation

7

Three teachable health care frameworks

4 Ms
Design age-friendly health systems

5 Ms
Differentiate geriatricians: multi-complexity specialists

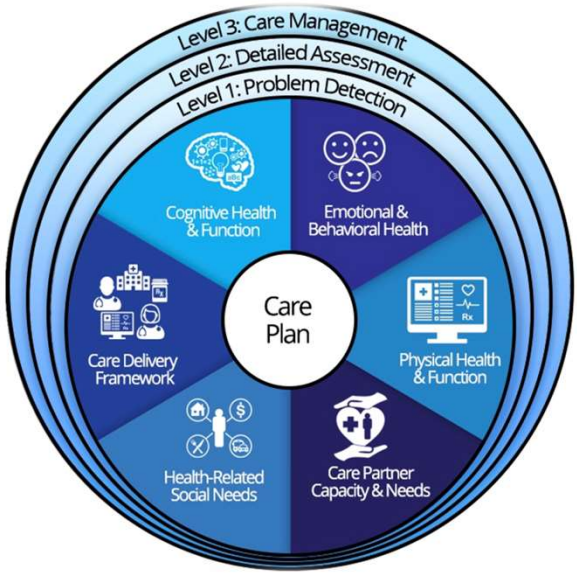


Teach whole-person care to manage complexity:
"No Crisis" Care

8

SIX DOMAINS OF HEALTH

A Teachable Framework for Whole Person Care



Why these six? Each one can cause a crisis in dementia.

9

Six Domains of Health: Three Focus on the Patient

Domain 1. Cognitive Health and Function.
Encompasses overall cognitive status and treatments. Cognition includes remembering, learning, thinking, making decisions, being aware of and responding appropriately to social cues, planning ahead, and completing everyday activities needed to live independently. Changes may be acute or chronic, stable, or progressive. When progressive, dementia becomes an organizing principle of care: clinical decisions about all aspects of health must consider the impact of cognitive impairment on treatment choices.

Domain 2. Emotional, Behavioral, and Spiritual Health.
Addresses mental health symptoms (e.g., loss of motivation, anxiety, depression, hallucinations, delusions), altered behavior (e.g., sleep, emotional reactivity, disinhibition, aggressive outbursts), and their treatment and management. It also focuses on identifying and meeting the overall emotional and spiritual needs of a person living with dementia.

Domain 3. Physical Health and Function.
Includes general medical conditions and treatments, physical functioning, and vulnerabilities, and includes frailty, mobility and fall risk, nutritional status, and sensory impairments (hearing, vision).

Sadak, T., Borson S. (in press, 2024) Palliative Approaches to Dementia Care. Oxford Textbook of Palliative Nursing. 6th edition. Eds: Albrecht, T., Coats, H., Brody, A., Battista V.

10

APPLYING THE SIX DOMAINS

TO DESCRIBE PATIENTS


ORIGINAL RESEARCH article

Front. Dement., 22 June 2023
Sec. Dementia Care
Volume 2 - 2023 | https://doi.org/10.3389/frdem.2023.1188955

This article is part of the Research Topic
Editors' Showcase: Dementia Care
View all 8 Articles >

Six domains of health: a practical approach to identifying priorities in dementia care

Tatiana Sadak[1*] and Soo Borson[2,3]

88 people living with dementia discharged home after an acute medical admission

Cognitive health and function
- 2/3 moderate to severe dementia, average 7 of 8 IADLs impaired
- 1/2 dementia NOS
- 1/4 on cognitive-enhancing medication; 1/3 care partners failed to report it or didn't know what it was for

Behavioral and emotional health and function
- >1/3 altered mental status/delirium on admission
- After discharge, average of 3 challenging behaviors
- 2/5 'depression' diagnosis in the EMR.
- 2/5 taking psychotropic medication; >1/3 of CPs failed to report it or didn't know what it was for

Physical health and function
- Average 2 of 7 basic ADLs impaired
- Mean Charlson Comorbidity Index =9; 8 chronic conditions, 7 post-discharge medications, and 4 prior-year acute care episodes
- >50% prescribed at least one high-risk medication
- Care partners missed important diagnoses, not just medications – heart disease, diabetes…

Sadak, T., Borson S. (in press, 2024) Palliative Approaches to Dementia Care. Oxford Textbook of Palliative Nursing. 6th edition. Eds: Albrecht, T., Coats, H., Brody, A., Battista V.

11

Six Domains of Health: Three Focus on Care

Domain 4. Care Partner Capacity & Needs.
Focuses on building partnerships with care partners and how they can best integrate care demands into their everyday lives (e.g. manage stress, care for themselves, learn what they need to know about being a care partner, and activating additional supports as needed).

Domain 5. Health-Related Social Needs.
Evaluates and intervenes to improve life conditions that affect well-being, health, social connection, and access to supportive care and services.

Domain 6. Care Delivery Framework.
This domain specifies the attributes of dementia-capable healthcare systems and aspirational goals for universal, equitable access to high quality care.

Sadak, T., Borson S. (in press, 2024) Palliative Approaches to Dementia Care. Oxford Textbook of Palliative Nursing. 6th edition. Eds: Albrecht, T., Coats, H., Brody, A., Battista V.

12

APPLYING THE SIX DOMAINS

TO DESCRIBE CARE


ORIGINAL RESEARCH article

Front. Dement., 22 June 2023
Sec. Dementia Care
Volume 2 - 2023 | https://doi.org/10.3389/frdem.2023.1188953

This article is part of the Research Topic
Editors' Showcase: Dementia Care
View all 6 Articles >

Six domains of health: a practical approach to identifying priorities in dementia care

Tatiana Sadak[1*] and Soo Borson[2,3]

Care partner capacity and needs
- Nearly 40% - moderate to severe stress
- 30% screened positive for depression and/or anxiety
- 20% rated their overall health as fair or poor
- 20% screened positive for cognitive impairment

Health-related social needs
- 17% of people living with dementia were dually enrolled in Medicare and Medicaid
- 41% of care partners reported difficulty paying for basic care needs

Care delivery framework
- No formal dementia care pathway in the system
- Few referrals to care coordination/transitions, specialty geriatric, palliative, and cognitive disorder services
- Gaps in discharge planning: > 80% of records had no dementia-related recommendations or care partner coaching
- Gaps in pre-hospital outpatient care: rare mention of dementia-related care plan or CP needs
- Gaps in care partner-clinician communication
  - 30% CPs reported never being told by a healthcare provider about the care recipient's dementia diagnosis
  - Most couldn't recall any conversation about how to prepare for the future
  - 40% couldn't recall ever being asked about care preferences

13

APPLYING THE SIX DOMAINS

TO ORGANIZE CARE


ORIGINAL RESEARCH article

Front. Dement., 22 June 2023
Sec. Dementia Care
Volume 2 - 2023 | https://doi.org/10.3389/frdem.2023.1188953

This article is part of the Research Topic
Editors' Showcase: Dementia Care
View all 6 Articles >

Six domains of health: a practical approach to identifying priorities in dementia care

Tatiana Sadak[1*] and Soo Borson[2,3]

Sorts complex information into manageable components.

- Creates a "dyadic snapshot" to identify priorities without losing sight of overall complexity.
- Identifies essential structural components.
  - Human infrastructure – differentiated team roles
  - Health information infrastructure – simple assessments in searchable EMR fields
- Helps make comprehensive dementia care feasible, actionable, and measurable.

14

Thanks

University of Washington School of Nursing team: Tatiana Sadak PMHNP, PhD (now Yale); Christina Coulter ARNP; Sarah McKiddy BSN; Emily Ishado MSW; Laurel Barchet BS, ADN; Melinda Schultz MS.

Kaiser Permanente Southern California, Division of Health Services Research & Implementation, Department of Research & Evaluation: Huong Nguyen PhD, RN, Interim Director.

Many friends and colleagues who helped with this work and refined my thinking over the years.

15