Care of the Complex, High Cost, High Need Patient

Andrew Schamess, M.D, F.A.C.P.

March 11, 2019

My life in the world of complex patients

- 1996-2000: Medical Director, La Clinica del Pueblo in Washington DC / faculty practice, George Washington University Medical Center

- 2000-2001: Head of Primary Care, Prevention and Planning, Washington DC Department of Health

- 2001-2012: Rural primary care practice

- 2012-2016: Started and ran home-based primary care program for patients with chronic illness and disability in the OSUMC Division of General Internal Medicine

- 2016-present: Home-based primary care for patients with sickle cell disease, The James Cancer Hospital (plus half-time primary care practice in GIM).

I. The Health Policy Perspective (the view from 10,000 feet)

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The U.S. spends more of its GDP on health care than other developed countries, and our spending is rising faster than theirs.

Exhibit 1. Health Care Spending as a Percentage of GDP, 1980–2013
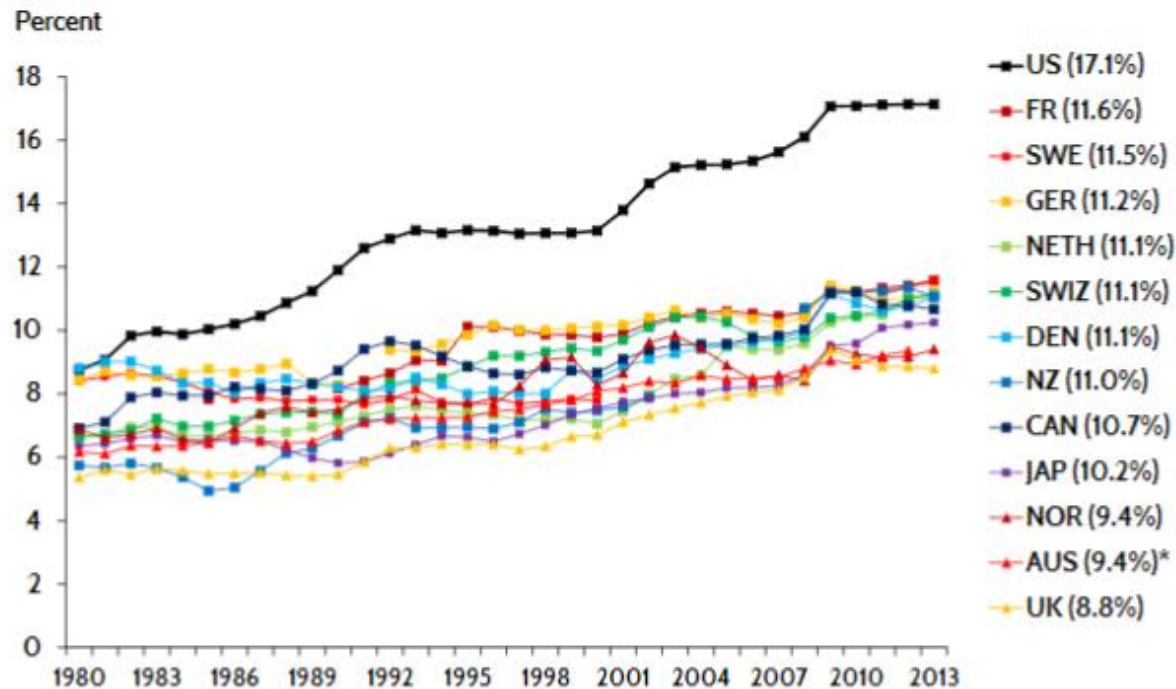
* 2012.
Notes: GDP refers to gross domestic product. Dutch and Swiss data are for current spending only, and exclude spending on capital formation of health care providers.
Source: OECD Health Data 2015.

Squires D, Anderson C. US health care from a global perspective: spending, use of services, prices, and health in 13 countries. The Commonwealth Fund. 2015;15:1-16.

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Where's all that money going? One current paradigm

"The US spends more on healthcare than any other industrialized nation, and much of that spending is concentrated on a small percentage of the population for whom behavioral health and social needs are major contributors to poor health outcomes."
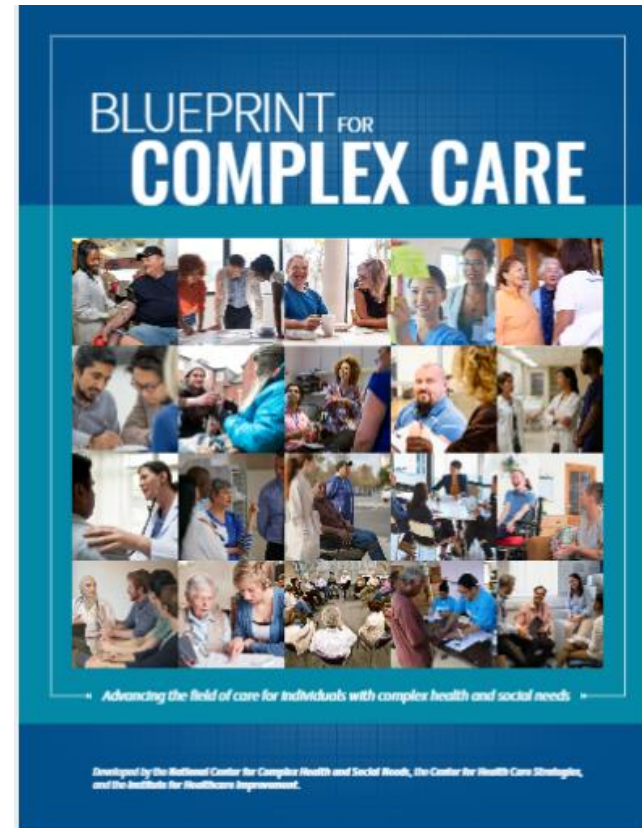
Humowiecki M, Kuruna T, Sax R, et al. Blueprint for Complex Care: A Strategic Plan for Advancing the Field - Center for Health Care Strategies. National Center for Complex Health and Social Needs; 2018.
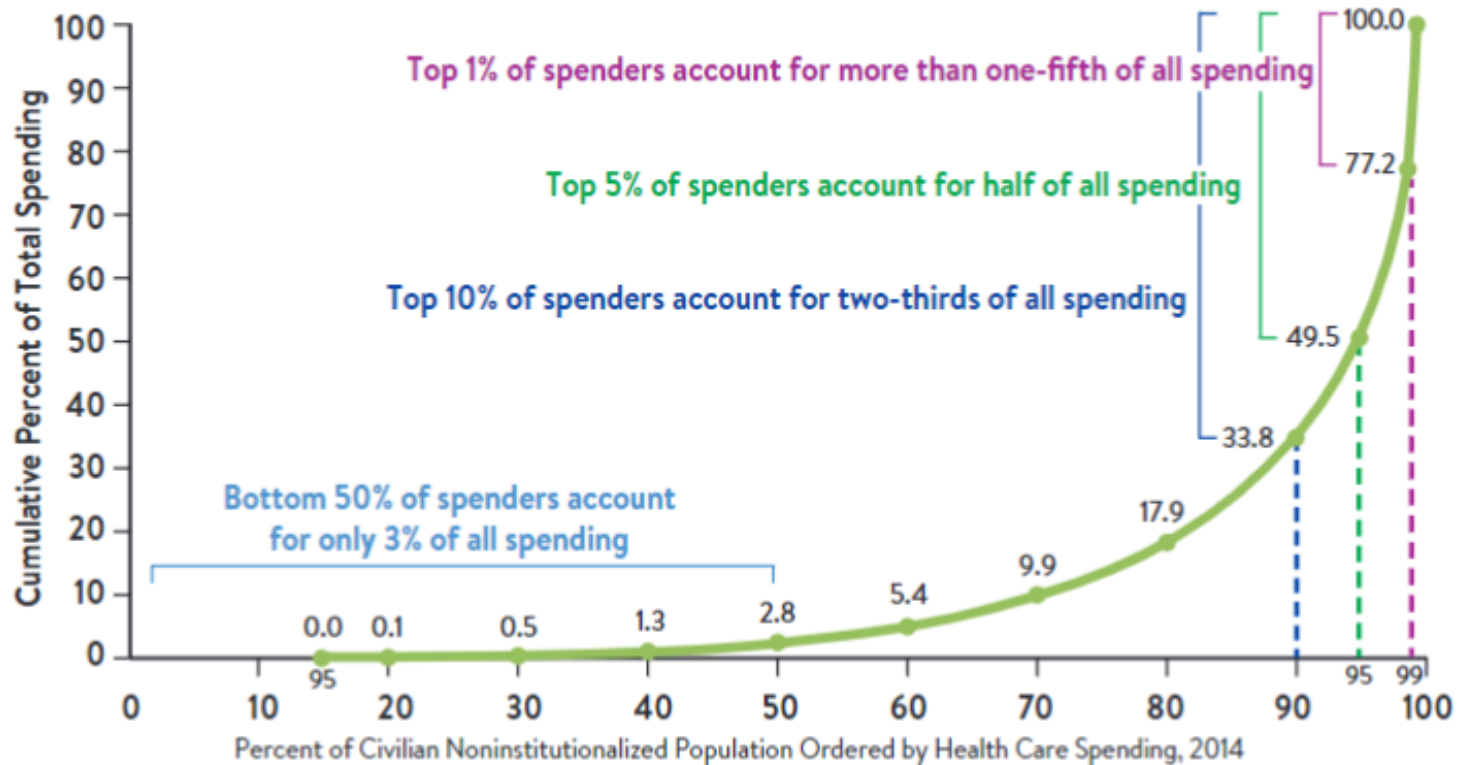
High-cost patients

FIGURE S-1 | Distribution of personal health care spending in the US civilian noninstitutionalized population, 2014.

Dzau VJ, McClellan MB, McGinnis JM, et al. Vital Directions for Health and Health Care: Priorities From a National Academy of Medicine Initiative. JAMA. 2017;317(14):1461-1470.
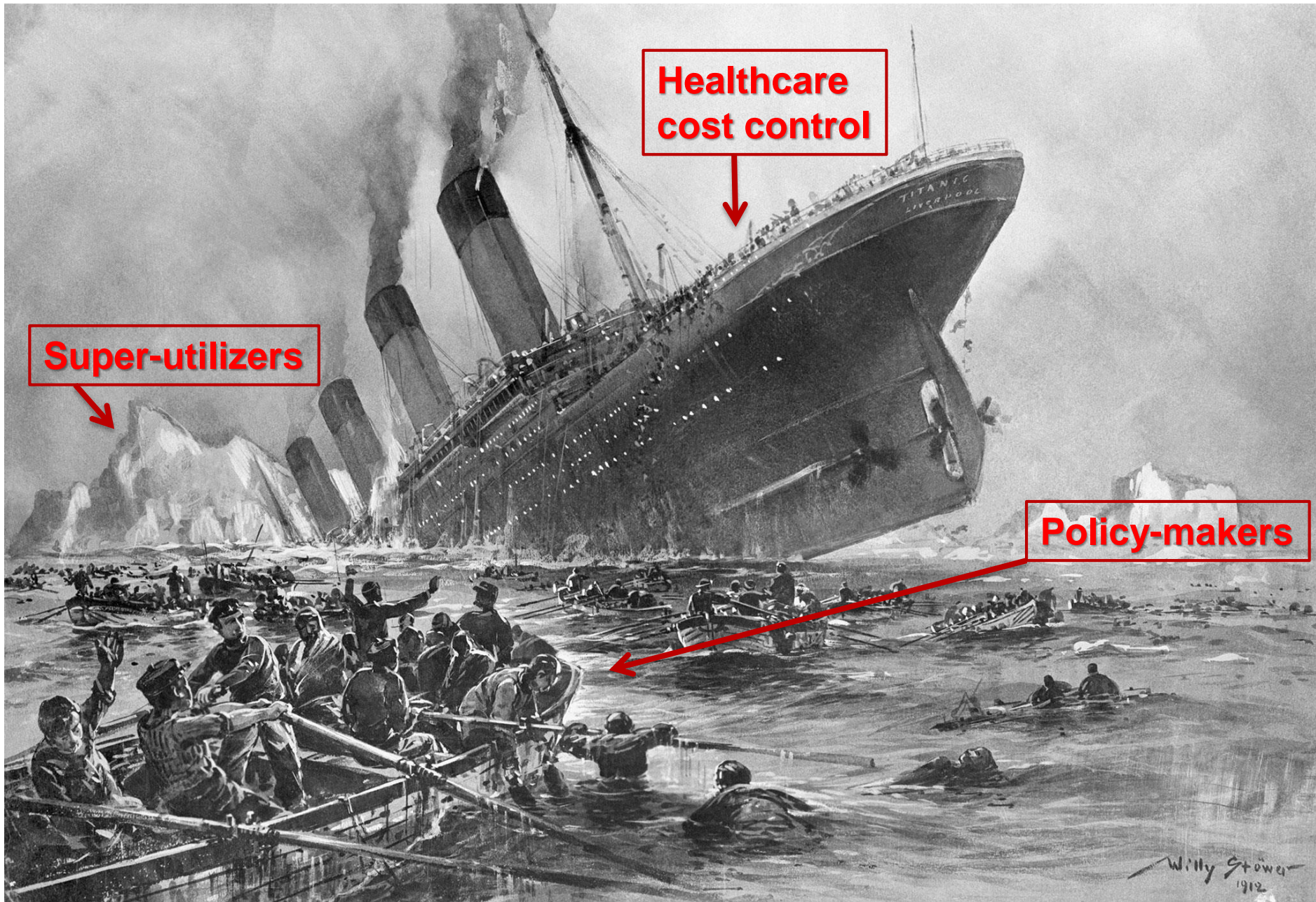
"Super-utilizers"

Selected Utilization and Health Status Information for the Costliest 1% of Patients Whose Care Is Managed by Partners HealthCare, According to Payer Type.*			
Variable	**Medicare**	**Medicaid**	**Commercial**
Average annual spending for high-cost patients ($)	146,584	85,347	101,359
Proportion of overall spending accounted for by high-cost patients (%)	14	17	22
Average no. of co-occurring chronic conditions in high-cost patients	8.1	5.1	4.4
Most prevalent chronic conditions (% of high-cost patients)	Hypertension (88) Chronic kidney disease (67) Ischemic heart disease (64) Congestive heart failure (61) Hyperlipidemia (60)	Depression (24) Anxiety (23) Hypertension (20) Bipolar disorder (15) Asthma or COPD (14)	Hypertension (55) Hyperlipidemia (43) Depression (25) Arthritis (25) Chronic kidney disease (25)

* Populations represent the costliest 1% of patients in each payer category, according to 2014 health care spending. Spending for Medicare and Medicaid patients represent total medical expenses. Spending for commercially insured patients was cost standardized across payers. Chronic conditions were identified using the Center for Medicare and Medicaid Services chronic condition grouper. Data are from an internal analysis of 2014 claims data from Partners HealthCare. COPD denotes chronic obstructive pulmonary disease.

Powers, B. W. and S. K. Chaguturu (2016). "ACOs and High-Cost Patients." New England Journal of Medicine 374(3): 203-205.

Healthcare cost control

Super-utilizers

Policy-makers

Total U.S. Healthcare Spending by Number of Chronic Conditions in 2010

35.0% for persons with more than 5 chronic conditions

14.2% for persons with no chronic conditions

14.8% for persons with 1 chronic condition

13.0% for persons with 2 chronic conditions

11.8% for persons with 3 chronic conditions

11.2% for persons with 4 chronic conditions
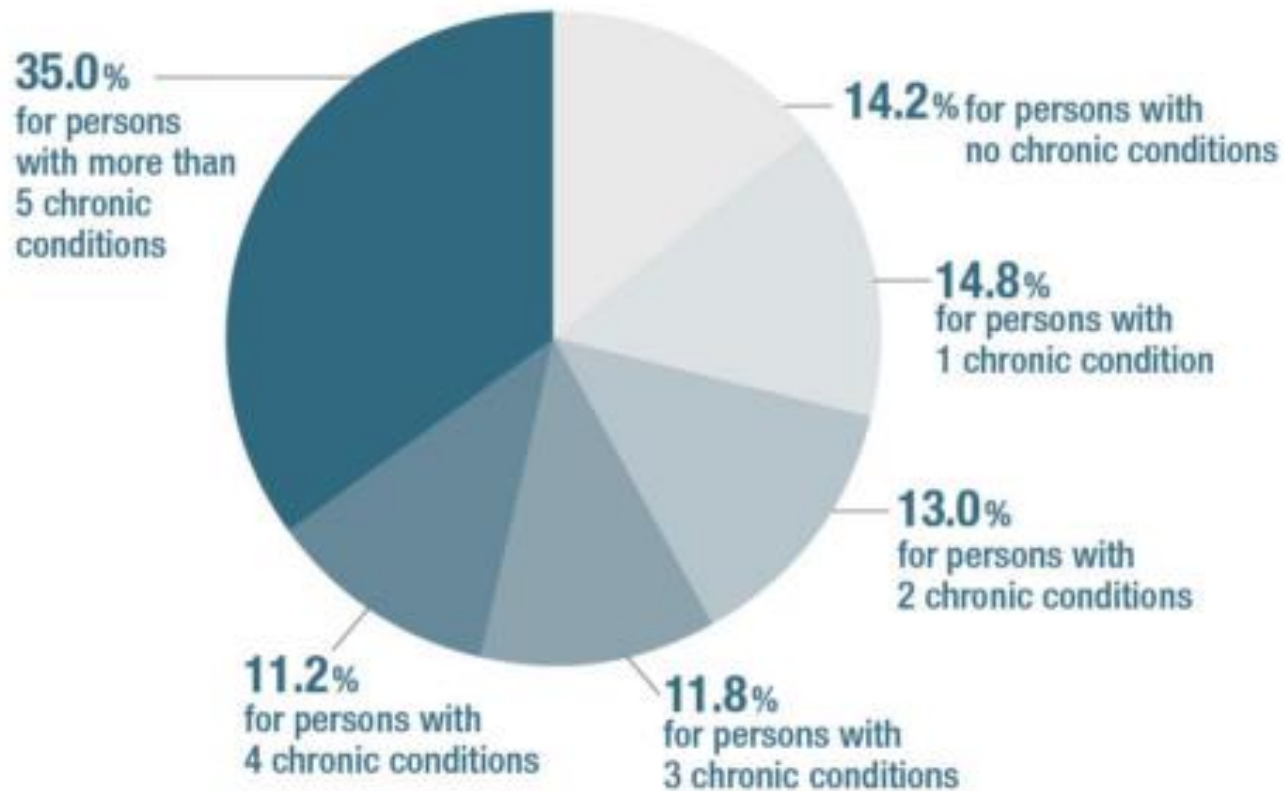
Gerteis, J., et al. (2014). Multiple Chronic Conditions Chartbook. Rockville, MD, Agency for Healthcare Research and Quality.

Overlap of functional limitations and chronic conditions defines an especially high-cost group
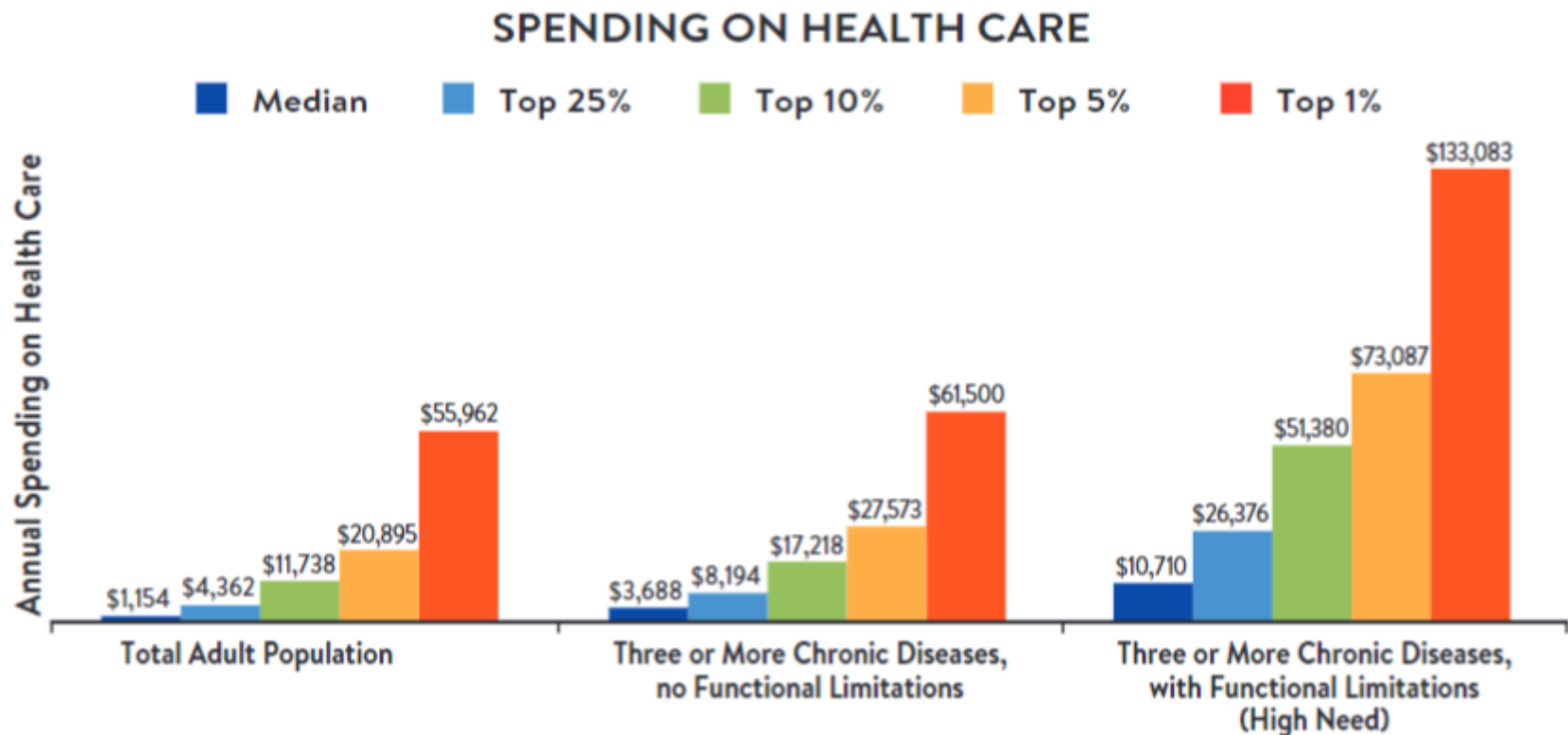
SPENDING ON HEALTH CARE

Legend: ■ Median   ■ Top 25%   ■ Top 10%   ■ Top 5%   ■ Top 1%

Y-axis: Annual Spending on Health Care

Total Adult Population
- $1,154
- $4,362
- $11,738
- $20,895
- $55,962

Three or More Chronic Diseases, no Functional Limitations
- $3,688
- $8,194
- $17,218
- $27,573
- $61,500

Three or More Chronic Diseases, with Functional Limitations (High Need)
- $10,710
- $26,376
- $51,380
- $73,087
- $133,083

Long PV, Abrams M, Milstein A, et al. Effective Care for High-Need Patients: Opportunities for Improving Outcomes, Value, and Health. Washington, DC: National Academy Of Medicine; 2018.

High utilizers: overlap of chronic disease and disability
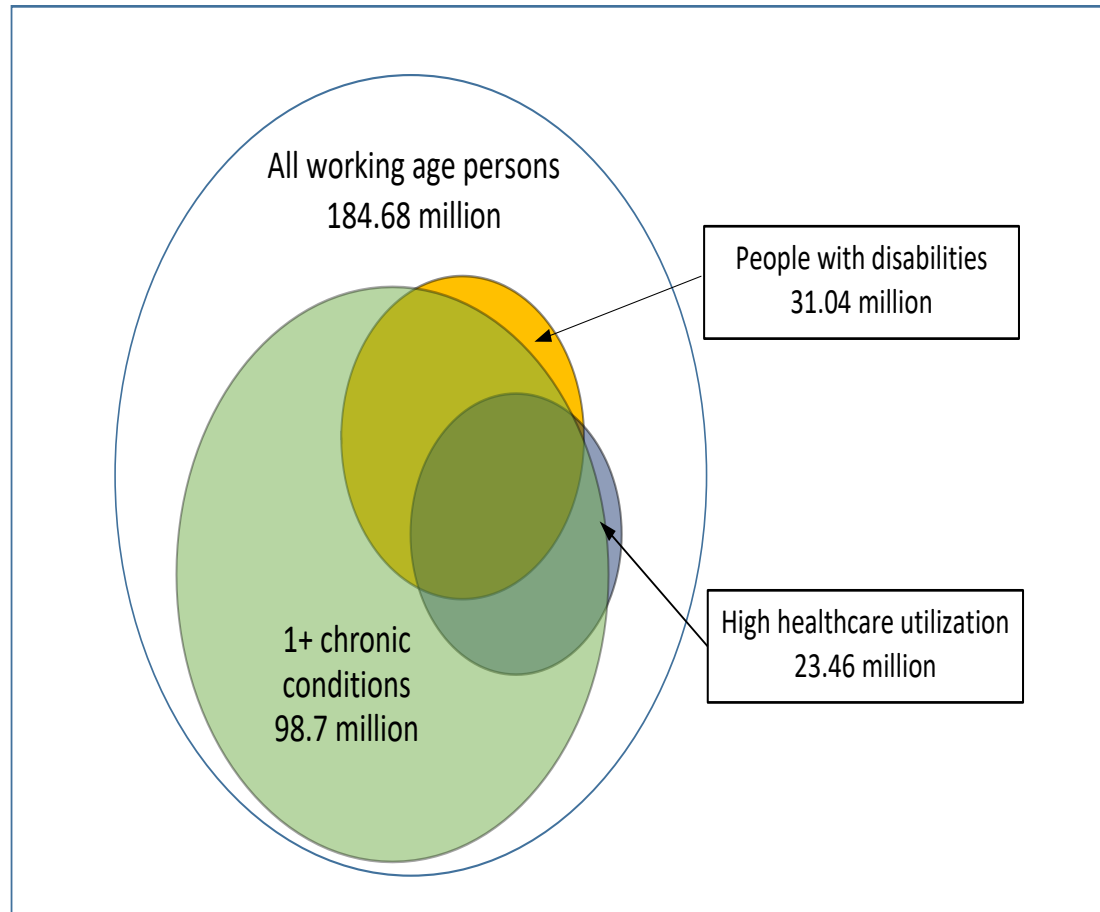
Area proportional Venn diagram, pooled annual estimates, MEPS 2006-8

Slide courtesy Elizabeth Rasch and Steven Gulley, National Institutes of Health

Association Between a Measure of Community Economic Distress and Medicare Patients' Health Care Utilization, Quality, Outcomes, and Costs

- Higher distressed community index score correlates with:
  - Enrollment in Medicaid
  - No annual wellness check
  - Prescribed high-risk medications
  - If diabetic – not up to date with recommended tests
  - More likely to be admitted with ambulatory care sensitive condition
  - Higher 30-day readmission
  - Higher mortality
  - Higher per capita spending on hospital, SNF, home health, hospice, and durable medical equipment

II. Modeling Clinical Complexity in High Utilizers

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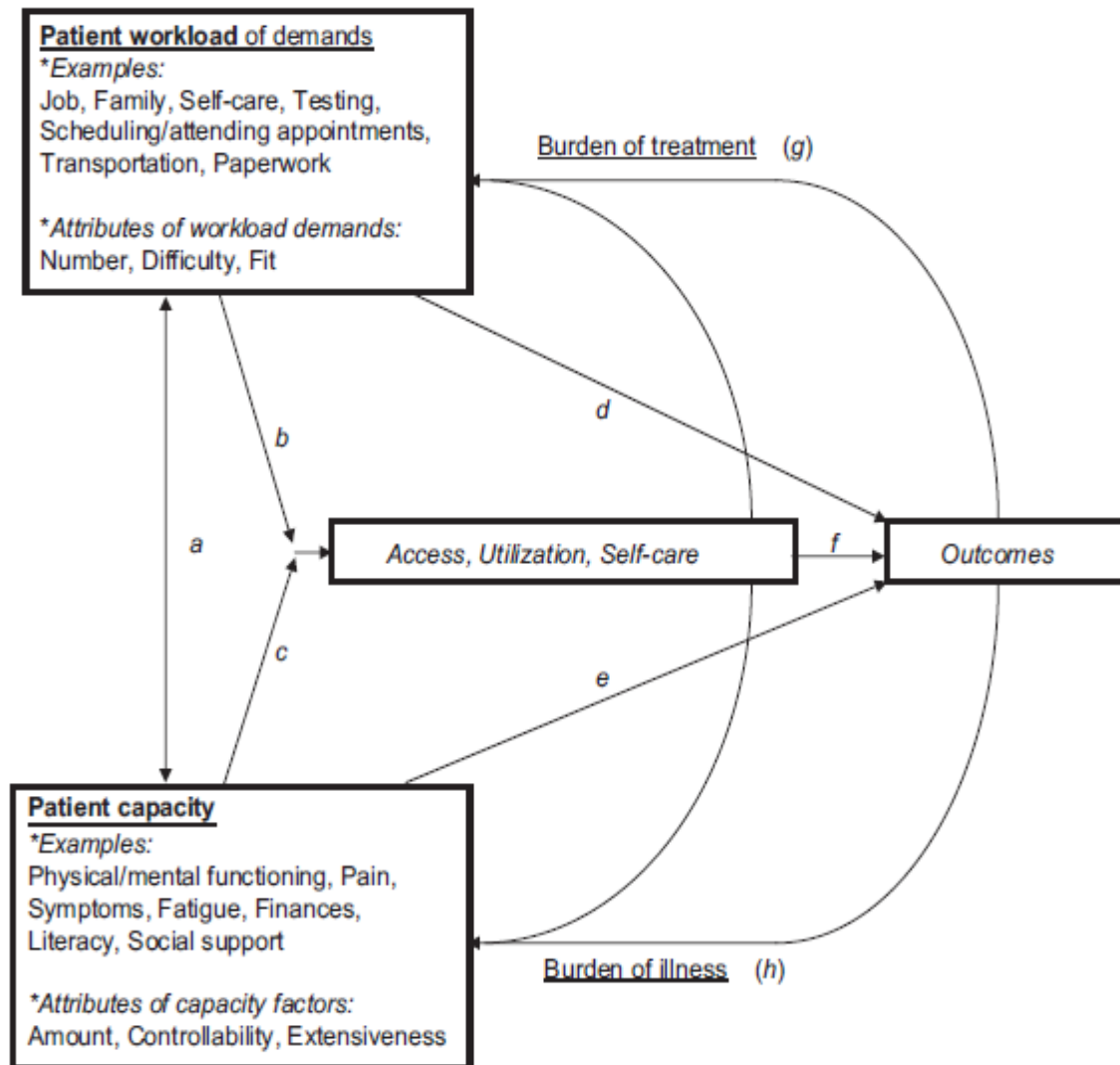
Fig. 2. The cumulative complexity model.

Multiple chronic conditions and utilization

Chronic conditions - progression and complications

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Impairment
- Motor
- Sensory
- Cognitive

Increased burden of treatment
- Office visits
- Diagnostics
- Medications
- Dietary restrictions

Decreased self-management capacity
- "Keeping track of it all"
- Communication
- Travel
- Income and insurance

Disruption and fragmentation of care
- Missed visits
- Unfilled prescriptions
- Reliance on 911 / ED
- Frequent admissions

Multiple determinants model of high need patients
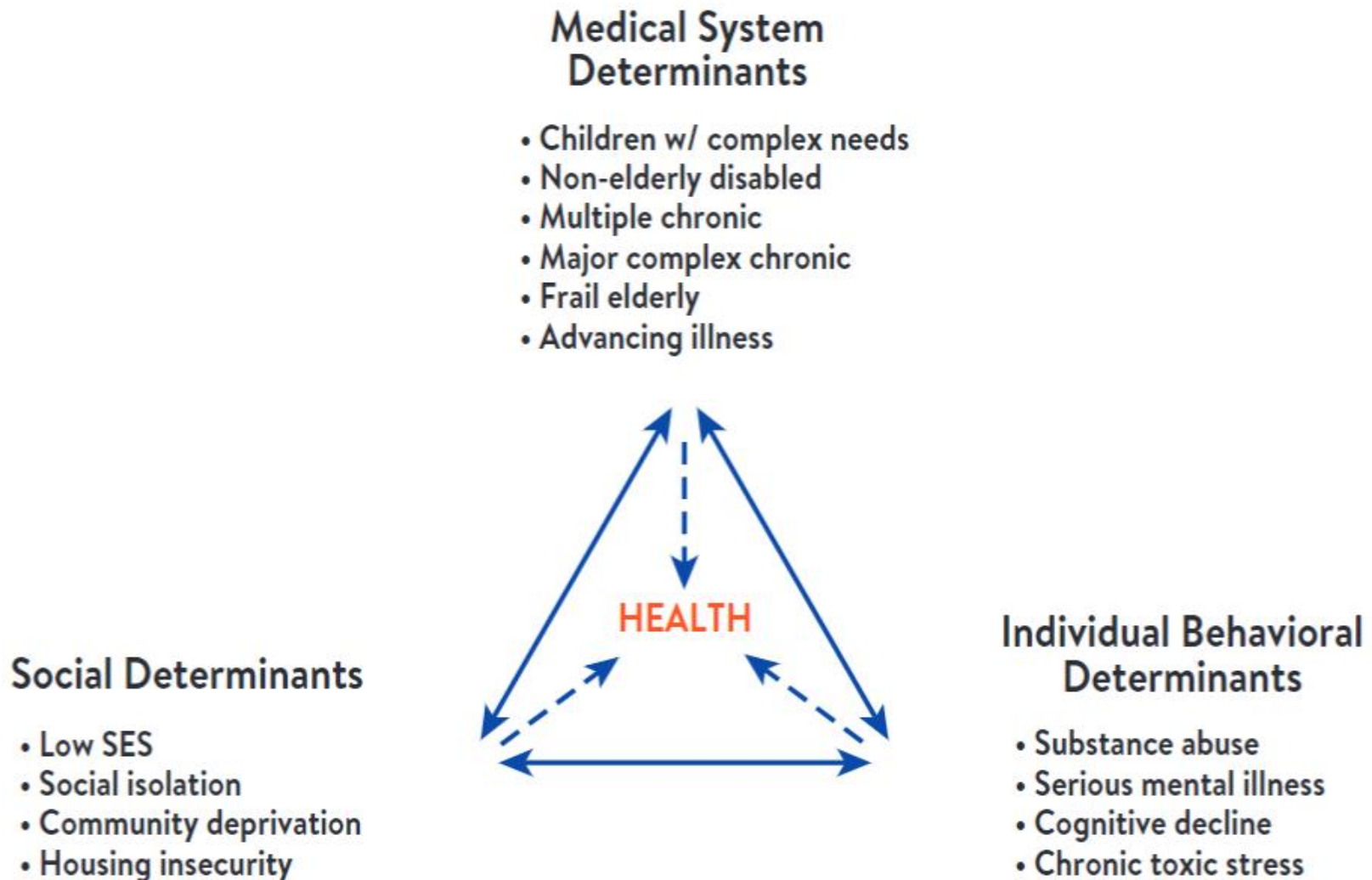
Medical System Determinants

- Children w/ complex needs
- Non-elderly disabled
- Multiple chronic
- Major complex chronic
- Frail elderly
- Advancing illness

HEALTH

Social Determinants

- Low SES
- Social isolation
- Community deprivation
- Housing insecurity

Individual Behavioral Determinants

- Substance abuse
- Serious mental illness
- Cognitive decline
- Chronic toxic stress

Long PV, Abrams M, Milstein A, et al. Effective Care for High-Need Patients: Opportunities for Improving Outcomes, Value, and Health. Washington, DC: National Academy Of Medicine; 2018.

Figure 3. The Complex Care Ecosystem

Humowiecki M, Kuruna T, Sax R, et al. Blueprint for Complex Care: A Strategic Plan for Advancing the Field - Center for Health Care Strategies. National Center for Complex Health and Social Needs; 2018.

# III. Complex patients: the clinical perspective (the view from the ground)

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Two patients, Washington, DC, 1996

John F.

- Lawyer with lobbying firm. Lived in Bethesda with wife and two children.

- Presented to faculty practice with headache, reduced exercise tolerance, easy bruising.

- Exam showed heart rate 96, pallor, scattered ecchymoses.

Jose R.

- Immigrant from El Salvador. Full time custodial work at night and per diem construction. Roomed with 6 other men. Sent income to family at home.

- Presented to free clinic with fatigue, difficulty working.

- Exam showed heart rate 101, pallor, scattered ecchymoses.
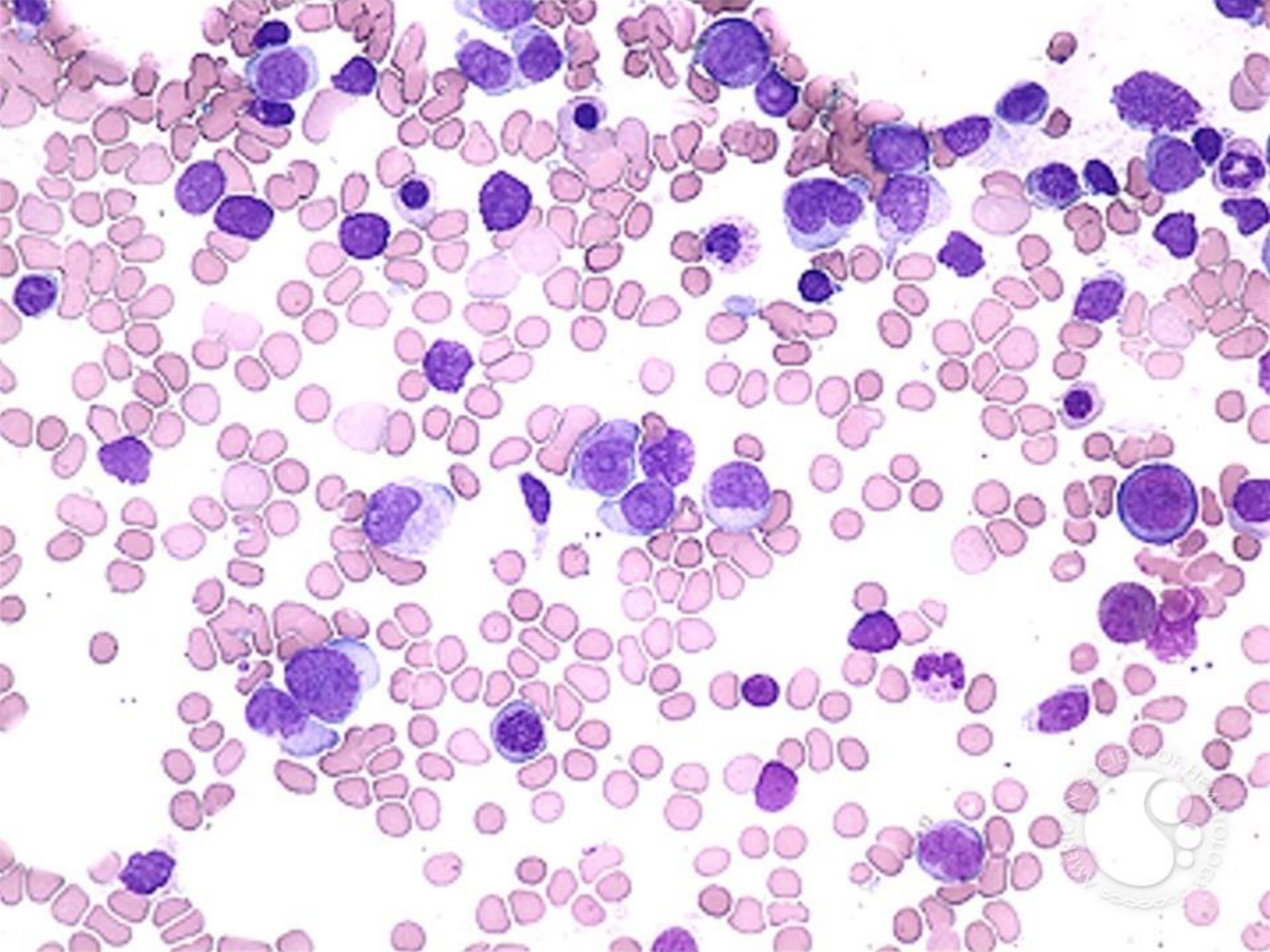
Two patients – follow up

John F.

- Admitted immediately to George Washington University Hospital. Underwent bone marrow transplant.

- A year later, no evidence of cancer, and patient was back to full time work as a lawyer.

Jose R.

- Uninsured and ineligible for Medicaid due to temporary protected status.

- Cancer treatment not available on a charity basis from Washington hospitals.

- Friends took up a collection to allow him to travel back to El Salvador, where he died surrounded by his family.

In order to describe a disease, <u>the symptoms that necessarily accompany it, and that are its own, are to be carefully separated from those that are accidental and fortuitous</u>, such as those that depend on the temperament and age of the sick, and on the curative method that is employed…

Unrelated circumstances have to be omitted. In describing the characteristics of sage [a herb], a Botanist does not advise talking about the bite of caterpillars.

Thomas Sydenham (1624-1689) quoted in The 'Preliminary Discourse' to Methodical Nosology, by François Boissier de Sauvages (1772)

Josh Heston

- Juvenile myoclonic epilepsy age 13.

- Testicular cancer age 21, treated with platinum based chemotherapy regimen after surgery.

- Cauda equina syndrome, age 25: foot drop, neuropathic pain. Spinal stimulator in situ.

- Global gastrointestinal dysmotility syndrome, age 25. Unable to take food by mouth – requires lifelong TPN.

- Multiple episodes of small bowel obstruction requiring decompression. Venting gastrostomy and ileostomy (age 31).

- Central line complications include multiple episodes of sepsis and thrombosis; chronic SVC syndrome.

- Noninsulinoma pancreatogenous hypoglycemia syndrome (age 35).

- Social hx: conservatory-trained tuba player with Ph.D. in music theory and performance.
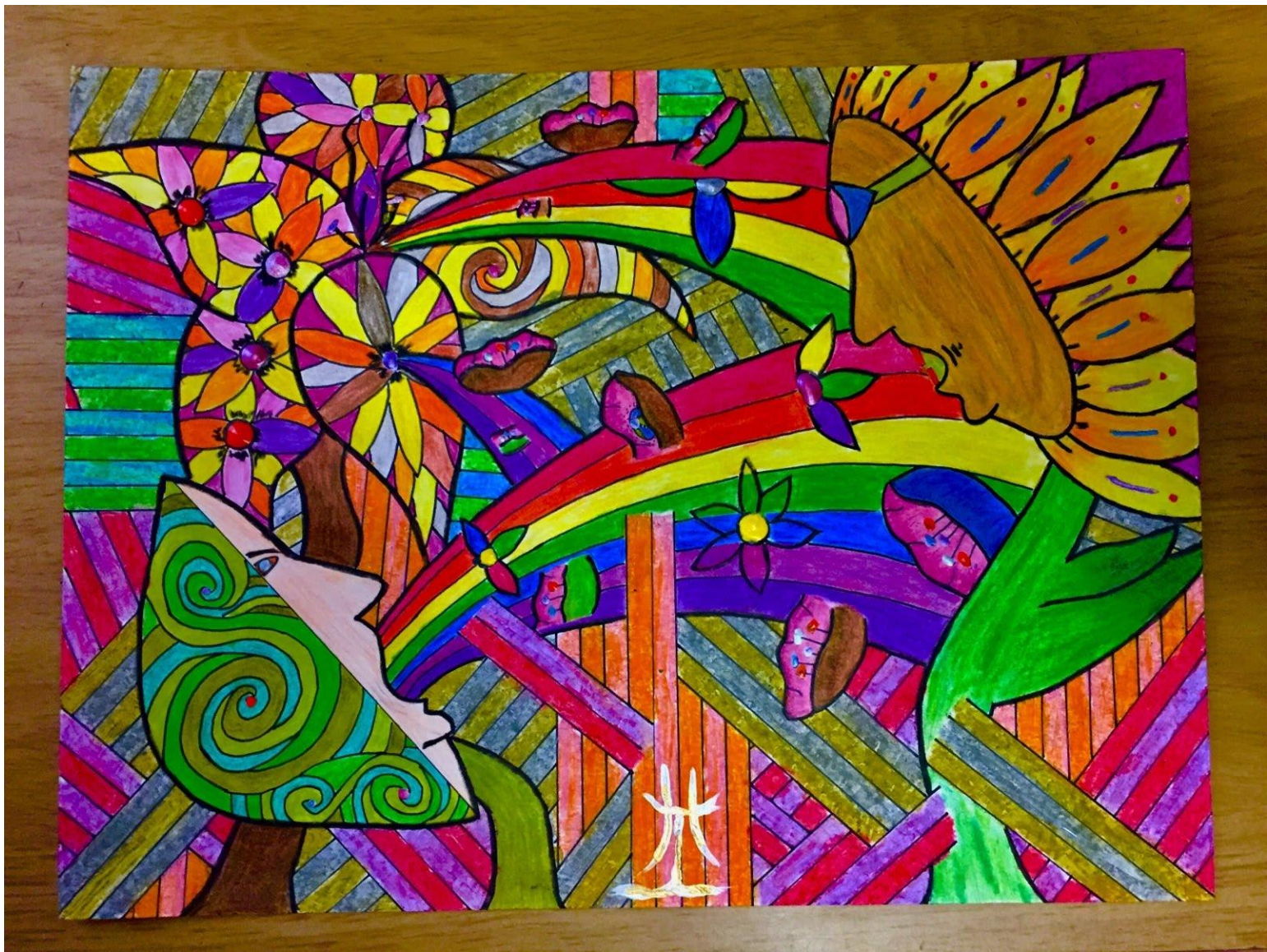
A few thoughts on Josh's narrative…

- We can be too quick to dismiss patients' complaints if we don't recognize the underlying illness (and vice versa: we won't recognize the illness if we dismiss the complaints).

- Trusting our patients = listening, validating their experience, not jumping to a conclusion if it doesn't fit what the patient is saying.

- That can be difficult if the encounter has a high negative emotional content (i.e. patient unhappy, critical, mistrustful or angry).

- For patients with complex conditions, it takes effort and skill to communicate effectively with doctors.

- What happens to patients who don't have those skills?

Two ways to listen to the patient:

Illness narrative

- The story of the illness as related by the patient.

- Based on the patient's experience and understanding.

- Attempts to convey what the patient feels it's important for the listener to understand.

- May address the moral and emotional meaning of illness to patient.

Illness script

- Cognitive device: how doctors retain and recall information about disease.

- Typical form: risk factors, pathophysiology, consequences, treatment.

- The doctor needs to extract an illness script from the patient's narrative to make diagnostic and treatment decisions.

- Competing illness scripts (differential diagnosis).

Example

Illness narrative

- Doc, I've been having trouble breathing for the past week

- I know I smoke and drink too much

- My wife said I had to come in, my friend died recently of cancer

- My feet have been swollen, and I've been sleeping in the recliner

Illness script

- Pathophysiology: heart, lung, blood… subacute onset…

- Risk factors for CAD, COPD, malignancy…

- Blah, blah…

- Consequences: edema, orthopnea – likely heart failure

Why narrative matters

- The diagnosis is often embedded in the narrative.

- Physician authority only goes so far in convincing patients to do what you say. Better treatment decisions derive from a shared understanding of illness and agreement on goals of care.

- This sometimes requires engaging non-dominant narratives: female, LGBTQ, non-white, economically disadvantaged, and the unique experience of any patient.

- The doctor-patient relationship is built on communication and mutual trust.

- Hearing people's stories is part of what makes medical practice interesting.
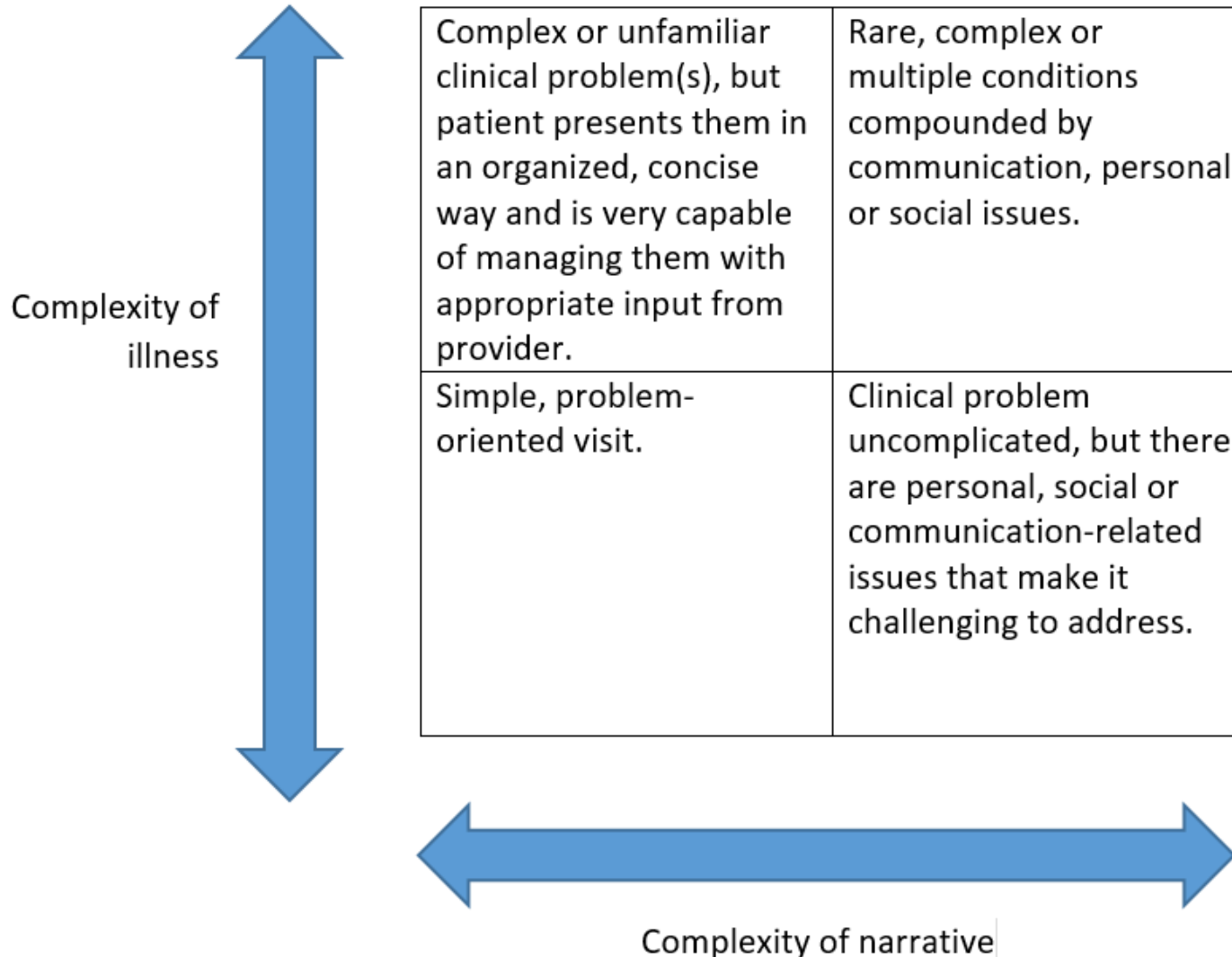
Dual, Yet Dueling Illnesses:
Multiple Chronic Illness Experience at Midlife

Gail L Markle, Brandon K. Attell, and Linda A. Treibe

- **Diagnostic limbo**: contested symptoms, misdiagnoses, erosion of trust in physician authority.

- **Quest for knowledge**: multiple opinions, Internet and social media, dialogue with other affected individuals. Patients may become experts in their own illness.

- "**Identity work**": reconciling former self-image as responsible, working adult with newly assigned illness identity – disabled, dependent, "professional patient."

- **Stigma and social rejection**: risk factors = personal flaws; lack of common experiences with peers; physical isolation = social isolation. Social expectation of positive attitude limits authentic discussion of illness experience.

Complexity in the medical encounter:
A clinician's view

Complexity of illness

Complexity of narrative

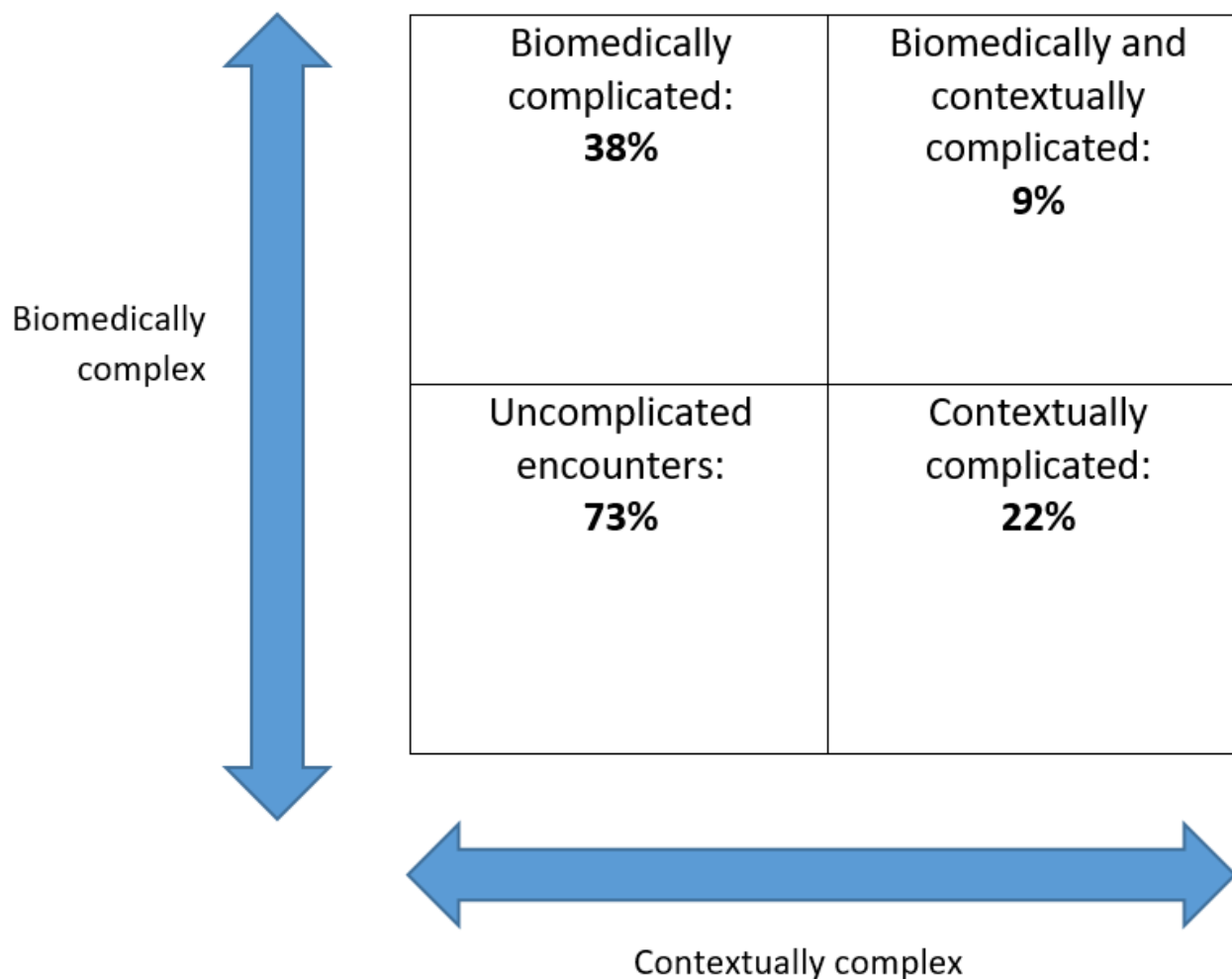|	
Complex or unfamiliar clinical problem(s), but patient presents them in an organized, concise way and is very capable of managing them with appropriate input from provider.	Rare, complex or multiple conditions compounded by communication, personal or social issues.
Simple, problem-oriented visit.	Clinical problem uncomplicated, but there are personal, social or communication-related issues that make it challenging to address.

Contextual errors and failures in individualizing patient care: a multicenter study
Weiner SJ, Schwartz A, Weaver F, et al. Ann Intern Med. 2010;153(2):69-75.

- Decision making error: physician fails to identify clinically important information or incorporate into plan of care.

- Contextual error: when the information not incorporated in the plan of care is related to patient's environment or behavior.

- Participants: 111 physicians agreed to see 4 incognito standardized patients over 1 year. Encounters to be recorded by patients.

- Case scenarios involved standard clinical scenarios +/- "red flags" for biomedical or contextual factors that would require different approach to care.

- Example: worsening asthma.

- Recordings scored by trained coders with validation.

Error-free care by encounter type
Weiner SJ, Schwartz A, Weaver F, et al. Contextual errors and failures in individualizing patient care: a multicenter study. Ann Intern Med. 2010;153(2):69-75.

Biomedically complex ↕	Biomedically complicated: **38%**	Biomedically and contextually complicated: **9%**
	Uncomplicated encounters: **73%**	Contextually complicated: **22%**

Contextually complex ↔

Initial approach to the complex patient

- Identify the challenges
  - What are the patient's high-priority needs?
  - What do you need to get done to care for patient?

- Set achievable, explicit goals for encounter.

- Define role: what you can/can't do for patient.

- Note the emotional content of the encounter

- Within the boundaries you've set, try to align with patient and family.

- After visit: marshal your resources to care for this patient
  - Length and frequency of appointments
  - Involve the team – nursing, schedulers, practice manager, social work, etc.
  - External resources: case manager, home health
  - Communicate with specialists

- Master the problem list

Reasonable expectations

Patient should expect…

- Access to care (scheduled and acute visits, phone)

- Courtesy and respect

- Physician knows and can manage their conditions

- Problems addressed during encounters

- Mutually agreed plan of treatment

- Meet chronic needs (refills, supplies)

Physician should expect…

- Attendance at scheduled appointments

- Respect for doctors' time

- Appropriate use of resources

- Adherence to agreed plan of treatment (or explanation why not)

- Feedback

When you feel like you're missing the mark…

- Communication problem
  - Do you understand the symptoms the patient is describing?
  - Do you understand why they're important to the patient?
  - Do you and the patient have a shared illness model as the basis for further decisions?
- Medical diagnosis / management problem
  - Do you have all the relevant facts?
  - Do you have a hypothesis?
  - Do you have a differential diagnosis?
  - Do you know what to do next?
- Three magic words: "I don't know."

Time management strategies

- The secret superpower of primary care physicians: return visits.

- The patients you dread to see may be the ones you need to see most often.

- Book some patients for extended visits.

- Respectful limit-setting.

- Phone medicine is still medicine.

- Delegate some communication tasks.

- Good handouts.

- Team / structural approach.

- Quick access to medical knowledge resources.

Billing for time spent (a very brief overview)

- Standard office visit codes can be assigned based on time spent, if you document it: i.e. 99213 = 15 minutes, 99214 = 25 minutes. "More than 50% of visit spent on patient education and counseling."

- Prolonged face-to-face time in addition to standard E/M: **99354** (first hour) and **99355** (each additional half hour).

- Prolonged evaluation and management before/after face to face care: **99358** (31-74 minutes) and **99359** (each subsequent 30 minutes).

IV. Some helpful trends in health policy

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Care models with demonstrated efficacy National Academy of Medicine 2018

- **Enhanced primary care**. Programs in the primary care setting defined by the use of supplemental health-related services that enhance traditional primary care and/or employ a team-based approach, with a provider and at least one other person.
  - **Interdisciplinary primary care**. A team comprising a primary care provider and one or more other health care professionals (e.g., nurse, social worker, rehabilitation therapist) who communicate frequently and provide comprehensive primary care *(e.g., Guided Care, GRACE, IMPACT, PACE, or Care Management Plus)*.
  - **Care and case management**. Collaborative models in which a nurse or social worker helps patients with multiple chronic conditions and their families assess problems, communicate with providers, and navigate the health care system *(e.g., Integrated Care Management Program at Massachusetts General Hospital)*.
  - **Chronic disease self-management**. Structured, time-limited interventions designed to provide health information to patients and engage them in actively managing their chronic conditions *(e.g., Chronic Disease Self-Management program at Stanford)*.
- **Transitional care**. Facilitate safe and efficient transitions from the hospital to the next site of care (e.g., alternative health care setting or home). Interventions are usually led by a nurse, known as a "transition coach," who provides patient education about self-care, coaches the patient and caregiver about communicating with providers, performs a home visit, and monitors the patient *(e.g., Naylor Transitional Care Model)*.
- **Integrated care**. Cross-disciplinary models which engage or focus on social risk interventions and behavioral health services in addition to medical care and functional assistance *(e.g., IMPACT or Camden Coalition)*.
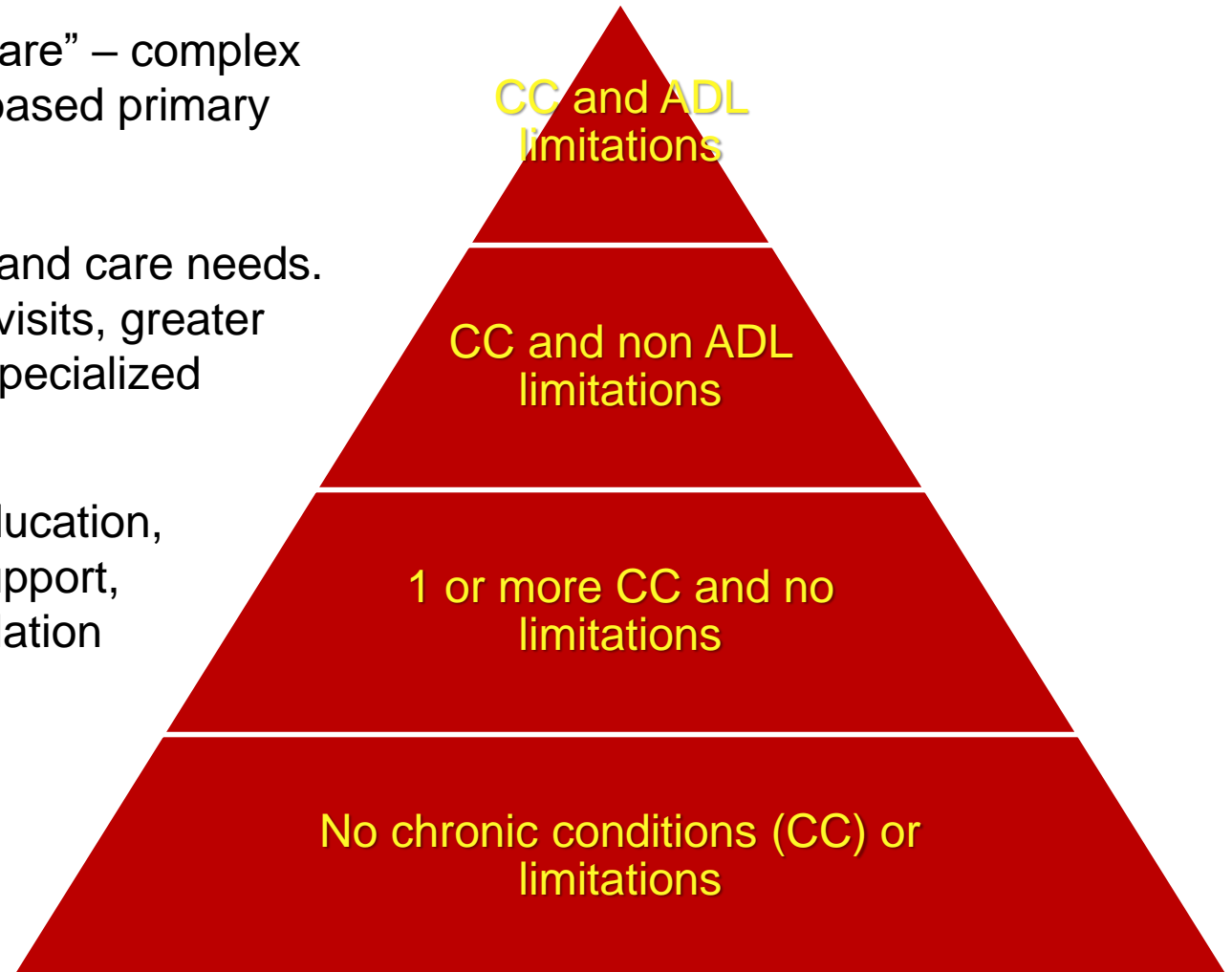
A stratified approach to chronic disease and disability (Super-utilizers are the tip of the iceberg)

"Intensive primary care" – complex care clinics, home-based primary care

Greater complexity and care needs. May require longer visits, greater care coordination, specialized team

Increased patient education, self-management support, registry-based population health monitoring

Routine care

CC and ADL limitations

CC and non ADL limitations

1 or more CC and no limitations

No chronic conditions (CC) or limitations

Care stratification in practice

Panel Management

Tier ≥ 1 Patients
e-Touch Programs
- Diet support
- Flu vaccine reminders
- Well-child visit reminders
- Appointment reminders
Pediatric Recall
Integrated Behavioral Health
Clinical Social Work

Care Management for Chronic Disease

Tier ≥ 2 Patients
Pediatric Asthma Home Visits
Pediatric Asthma Recall
Diabetes/Hypertension Management
Pharmacotherapy Management
Transitions of Care Coordination

Complex Case Management

Tier ≥ 3-4 Patients
Enhanced Care Teams
- Patient navigators
- Nurse care coordinators
- Clinical pharmacists
- Clinical social workers

High-Intensity Treatment Teams

Tier 4 Patients
Intensive Outpatient Clinic
Children with Special Health Care Needs Clinic
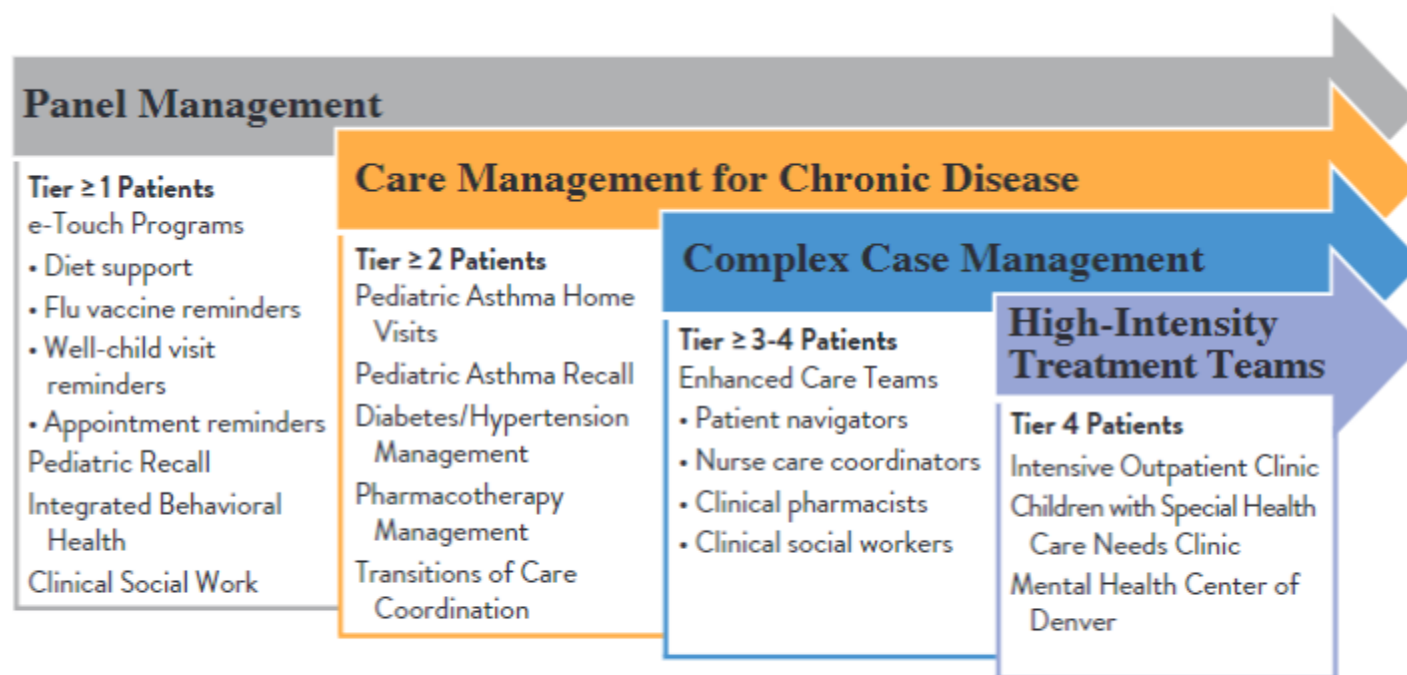Mental Health Center of Denver

FIGURE 4–3 | Denver Health's use of Clinical Risk Groups to assign patients to care programs.

Long PV, Abrams M, Milstein A, et al. Effective Care for High-Need Patients: Opportunities for Improving Outcomes, Value, and Health. Washington, DC: National Academy Of Medicine; 2018.

Payment trends that support successful care models

- Address the lack of reimbursement for care coordination and social services in fee-for service model.

- Capitated and mixed models that pay for care outcomes and encourage new models of care (patient-centered medical home, home-based primary care).

- CMS granting state waivers that free up funds to develop care systems for Medicaid and dual-eligible populations.

- Improve data systems to better measure meaningful patient outcomes.

Long PV, Abrams M, Milstein A, et al. Effective Care for High-Need Patients: Opportunities for Improving Outcomes, Value, and Health. Washington, DC: National Academy Of Medicine; 2018.

The good physician treats the disease. The great physician treats the patient who has the disease.

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William Osler

Thank You