Welcome to Quality Matters Conference

December 14-15, 2023

QMC Quality Matters Conference
December 14-15, 2023

PCQC

Who is the Palliative Care Quality Collaborative?

The only unified national registry of specialty palliative care quality data

Houses both program- and patient-level data as well as a powerful quality collaborative of members and thought leaders

A 501(c)3 non-profit organization incorporated in 2019

Supports over 2,000 palliative care programs nationally

Started data collection in early 2021

PCQC by the Numbers

2,200+
Basic Members

253
Advanced Members

93
Premium Members

1,500
Active Users

89,000
Unique Patients

338,000
Patient Encounters

13,500,000
Data Points

THANK YOU TO OUR SPONSORS!

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CAMBIA™ health foundation

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HO | CHIANG
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Center to Advance Palliative Care
capc

Today's Agenda

Now – 1:10pm	***Quality: What is it Good For?***
1:10pm – 2:10pm	***Perspectives of Health Equity***
2:10pm - 2:50pm	***Break***
2:25pm - 3:15pm	***Palliative Care for Parkinson's Disease: Building Evidence and Changing Culture to Foster A Higher Standard of Care***
3:20pm - 4:10pm	***The State of Our Field***
4:10pm - 5:00pm	***Palliative Care Outcomes Collaborative***

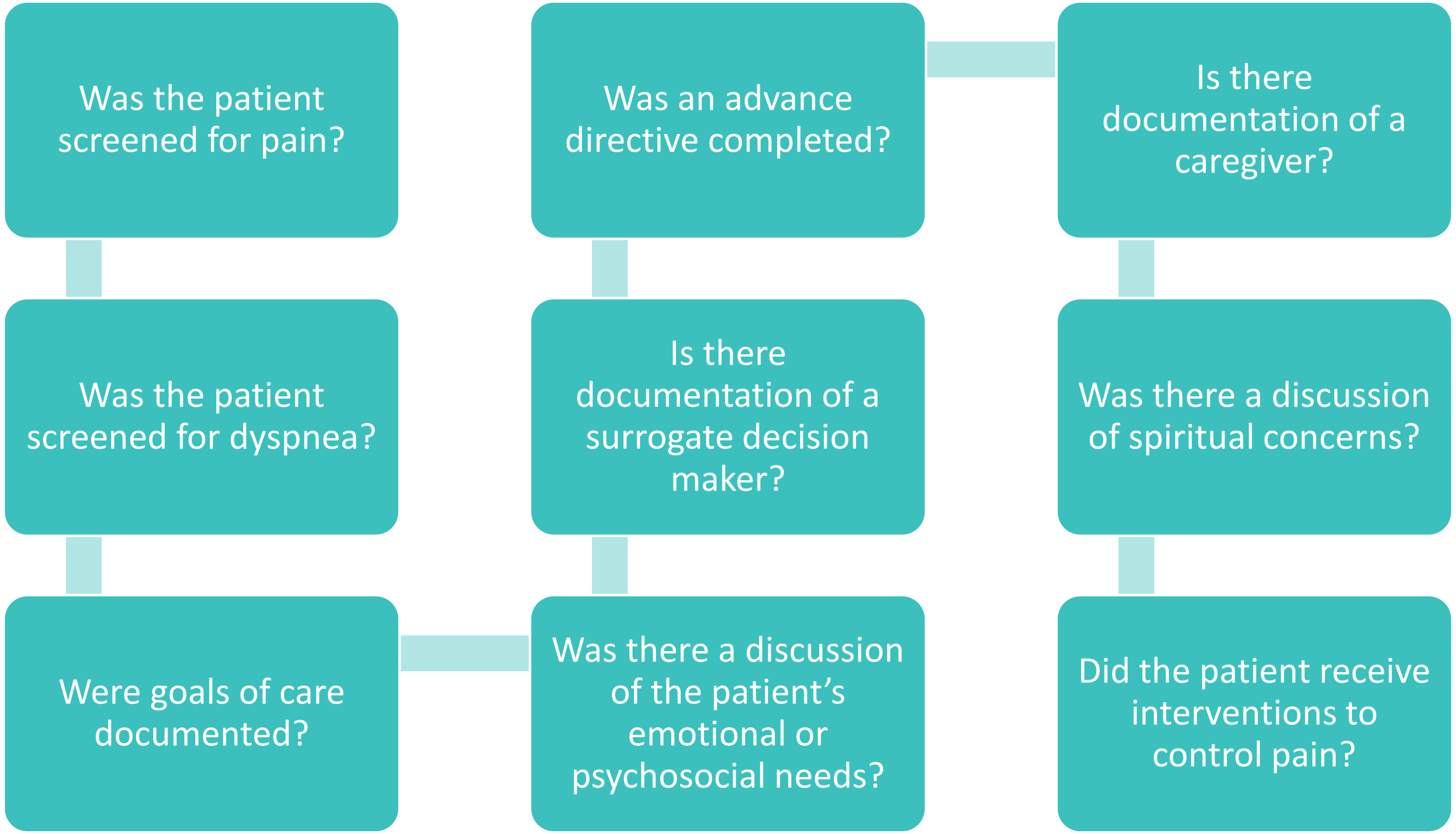
What is Quality?

The standard of something as measured against other things of a similar kind; the degree of excellence of something

But What Does This Mean?

- Outcomes?
- Clinical experience?
- Cost of care?
- Timeliness?
- Support for loved ones?
- Cultural competency?

Established Quality Measures



Was the patient screened for pain?

Was the patient screened for dyspnea?

Were goals of care documented?

Was there a discussion of the patient’s emotional or psychosocial needs?

Is there documentation of a surrogate decision maker?

Was an advance directive completed?

Is there documentation of a caregiver?

Was there a discussion of spiritual concerns?

Did the patient receive interventions to control pain?

IOM: Six Domains of Quality

Quality

Safe

Effective

Patient-Centered

Timely

Efficient

Equitable

Diane E. Meier

MD, FACP, FAAHPM

Director Emeritus and Strategic Advisor,
Center to Advance Palliative Care
Professor, Department of Geriatrics and
Palliative Medicine
Icahn School of Medicine at Mount Sinai

Quality: What is it Good For?

Quality: What is it Good For?

Diane E Meier MD FACP FAAHPM
Center to Advance Palliative Care
Professor, Department of Geriatrics and Palliative Medicine
Icahn School of Medicine at Mount Sinai
diane.meier@mssm.edu
www.capc.org
www.getpalliativecare.org

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Disclosures

- I have no conflicts of interest to report.

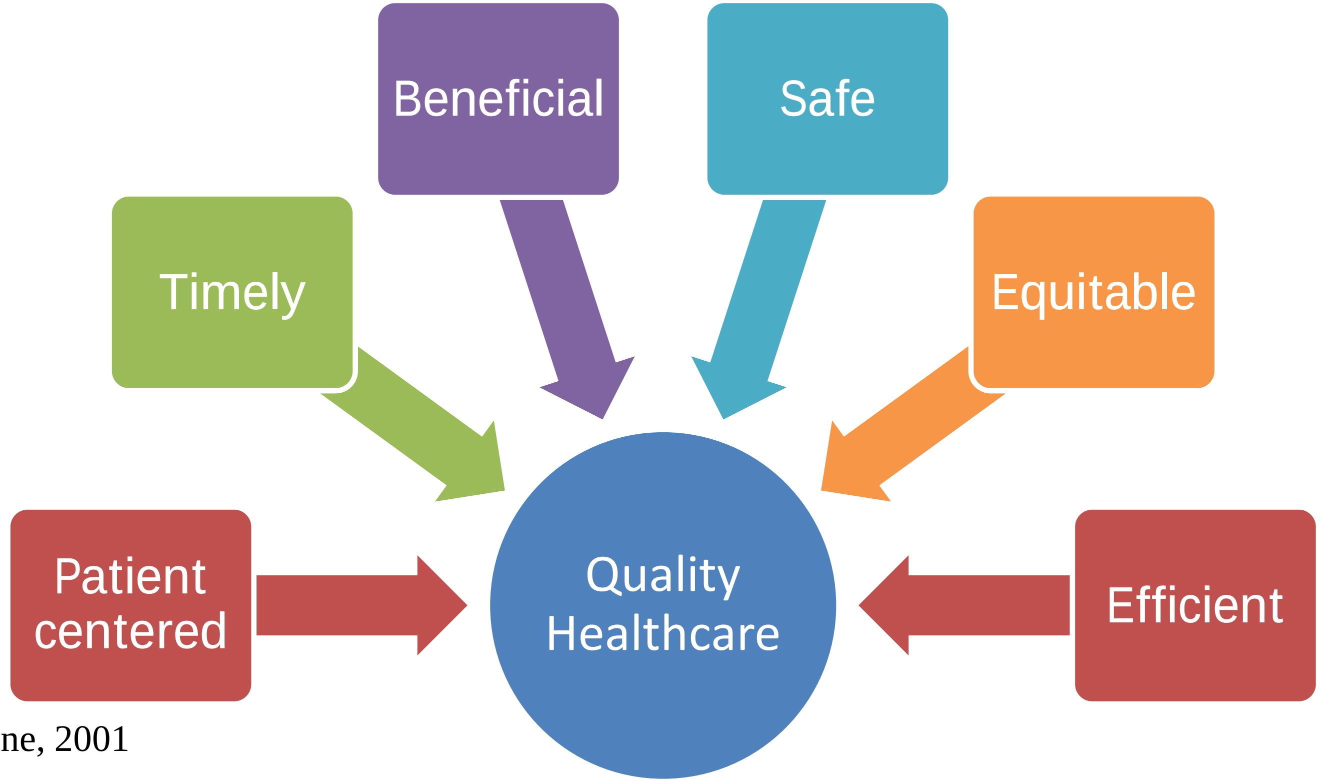
Objectives

Learners will:

- Identify the 6 key components of quality in health care
- Understand how quality measurement will improve not only the level of care we provide to our patients but also how we get paid
- Implications of payment policies for palliative care clinicians

What is Quality?

Degree to which health services increase the likelihood of desired health outcomes and are consistent with current professional knowledge



Beneficial

Safe

Timely

Equitable

Patient centered

Quality Healthcare

Efficient

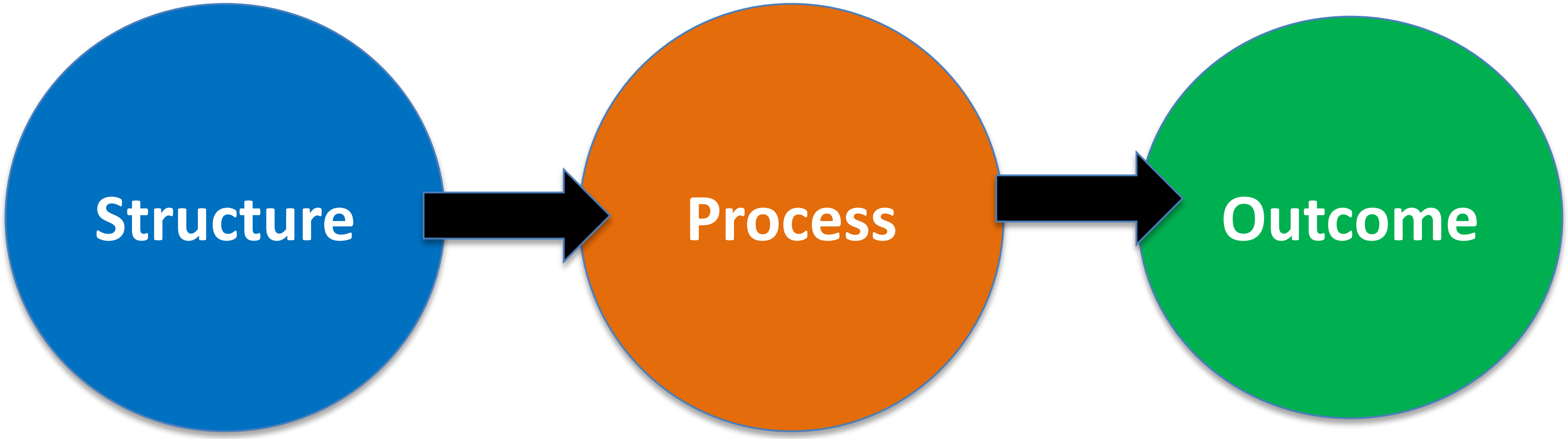
Institute of Medicine, 2001

Why is quality measurement worth doing?

1. Patient-Centeredness
2. Outcome Improvement
3. Safety
4. Resources
5. Accreditation and Regulatory Compliance
6. Continuous Improvement
7. Data-Informed Decisions
8. Public Accountability and Transparency

How is it measured?

- 3 essential elements



Structure

Process

Outcome

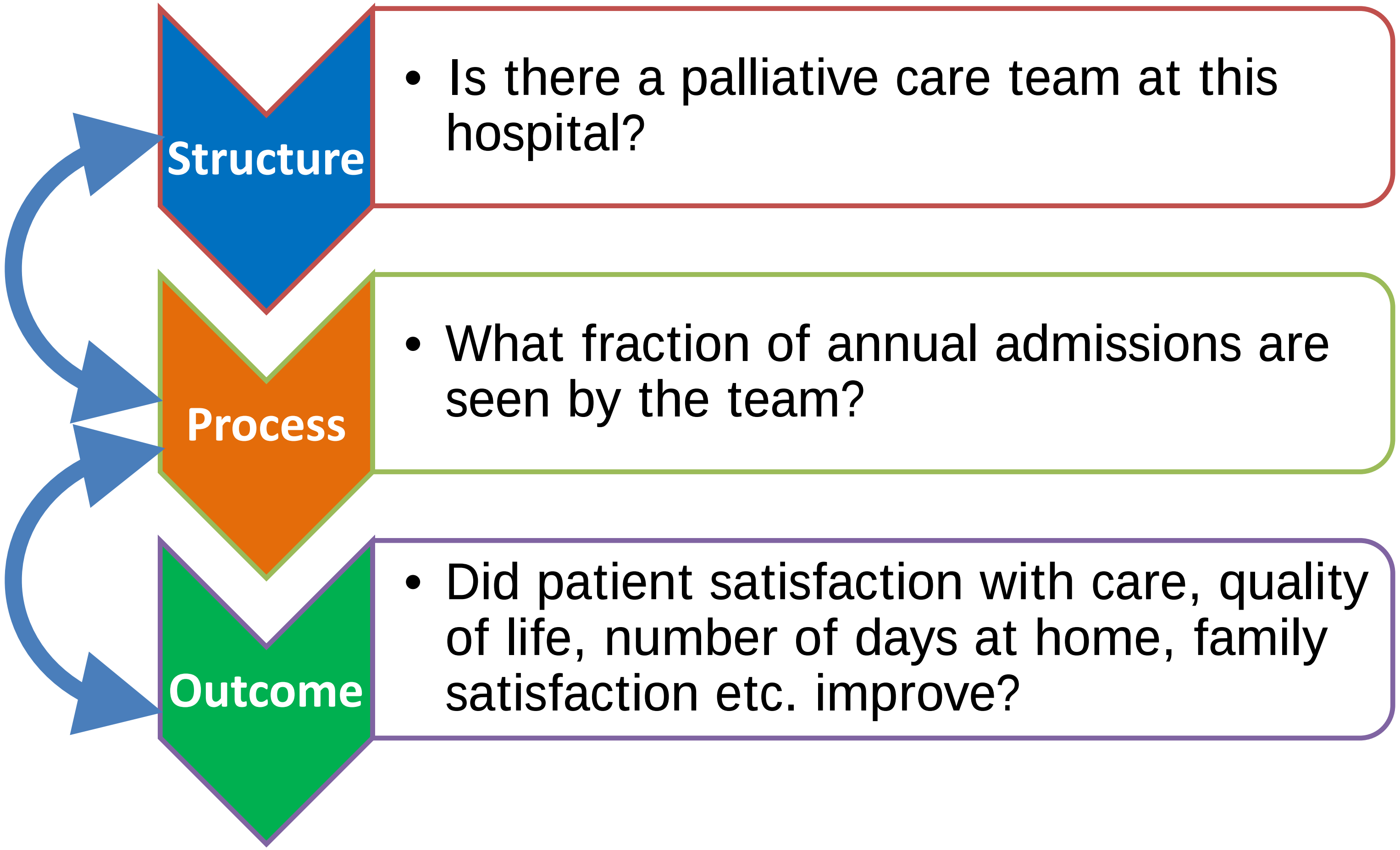
- All are necessary, in sequence, to improve quality

Meaning for Clinicians

The “HOW” of quality improvement:

- Structures/processes should be directly and closely linked to outcomes
- Outcomes should link reliably to the preceding structures and processes
- Otherwise, clinicians cannot be held accountable for improving outcomes

3 Types of Quality Measures



Structure

- Is there a palliative care team at this hospital?

Process

- What fraction of annual admissions are seen by the team?

Outcome

- Did patient satisfaction with care, quality of life, number of days at home, family satisfaction etc. improve?

Avedis Donnabedian

“How can you tell if you have good quality health care?”

- Born in Beirut of Armenian ancestry
- Parents fled persecution in Turkey, grew up in an Arab village near Jerusalem
- Studied medicine at American University in Beirut
- Harvard SPH in 1953→ U Michigan in 1961
- Father of the modern field of quality measurement

Avedis Donnabedian: Framework

- Assesses quality through the lens of health care structures, processes, and outcomes
- But, omits factors also important to health outcomes:
  - Patient factors like genetics, sociodemographics, health habits, beliefs, attitudes, and preferences
  - Environmental factors like cultural, social, economic, political, personal, and neighborhood characteristics
  - Factors related to the health profession itself like implicit bias, stress, time pressures.

https://en.wikipedia.org/wiki/Donabedian_model

So, what makes for a good measure?

Measures only drive improvement If they are. . .

1. **Important/relevant**
    - o Relevant to a large population—public health impact *
    - o Impact on patients/caregivers (key stakeholders)
2. **Scientifically acceptable**
    - o Evidence linking structure/process to outcome
    - o Strong operational definition (reproducible, valid) *
3. **Feasible**
    - o Measure can be captured in clinical care, preferably via claims or EHR *
    - o Acceptable burden/cost
4. **Usable and actionable**
    - o Measure currently in use *
    - o Able to be acted upon in response to gaps in care
5. **Responsive**
    - o Measure improves with feasible changes in structure and process

Hazards of Quality Measurement

"For every problem there is a solution which is simple, clean,…"

Example of a well-intended quality measure

- Malnutrition and weight loss associated with increased morbidity and mortality in the elderly
- Nursing home residents are at high risk for malnutrition, weight loss and dehydration
- Weight loss selected as an external quality indicator for the minimum data set (MDS) in nursing homes

…and wrong" – H. L. Mencken

The unintended consequence

- Seriously ill and dying patients lose weight
- Broad application of weight loss as a quality indicator led to:
  - Increased use of feeding tubes, restraints, aspiration
  - Increase in transfers to acute care facilities because of weight loss
- Poorly selected measure resulted in inappropriate care

Purposes of Quality Measurement for Palliative Care

Internal: Quality Improvement

External: Accountability

Internal Quality Measures

- Undertaken by entities providing care for purposes of quality improvement, *not* external accountability
- Voluntary, limited audiences, usually undertaken within a single organization
- As detailed and comprehensive as desired
- **This is how we know whether or not we are delivering the quality of care we hope we are**

External Quality (Accountability) Measures

- Required by purchasers/payers, government, regulatory bodies
- Designed for broad audiences, undertaken across multiple organizations
  - Measures must be simple, consistent, inexpensive
- High standard of reliability/validity essential with respect to the relationship between structures/processes and outcomes
  - Because real consequences for public reporting, provider choice, certification, reimbursement

Role of Registries in Supporting Quality Improvement

- Standardizes measures for the field
- Enables benchmarking (comparison to peer institutions/programs)
- Enables collaborative quality improvement
- Identifies and disseminates best practices
- Monitors service operations
- ***Proves your value to your C-Suite and your payers***

Why bother? The so-what question for quality measurement

Can use your own data

- Monitor service operations
- Demonstrate value locally
- Support standardized assessment
- Improve care

Need standardized data

- Conduct collaborative QI
- Identify best practices
- Advance the field
- Justify payment

So where does the *Palliative Care Quality Collaborative* come in?

Palliative Care Quality Collaborative Metrics, Measures, and Reports

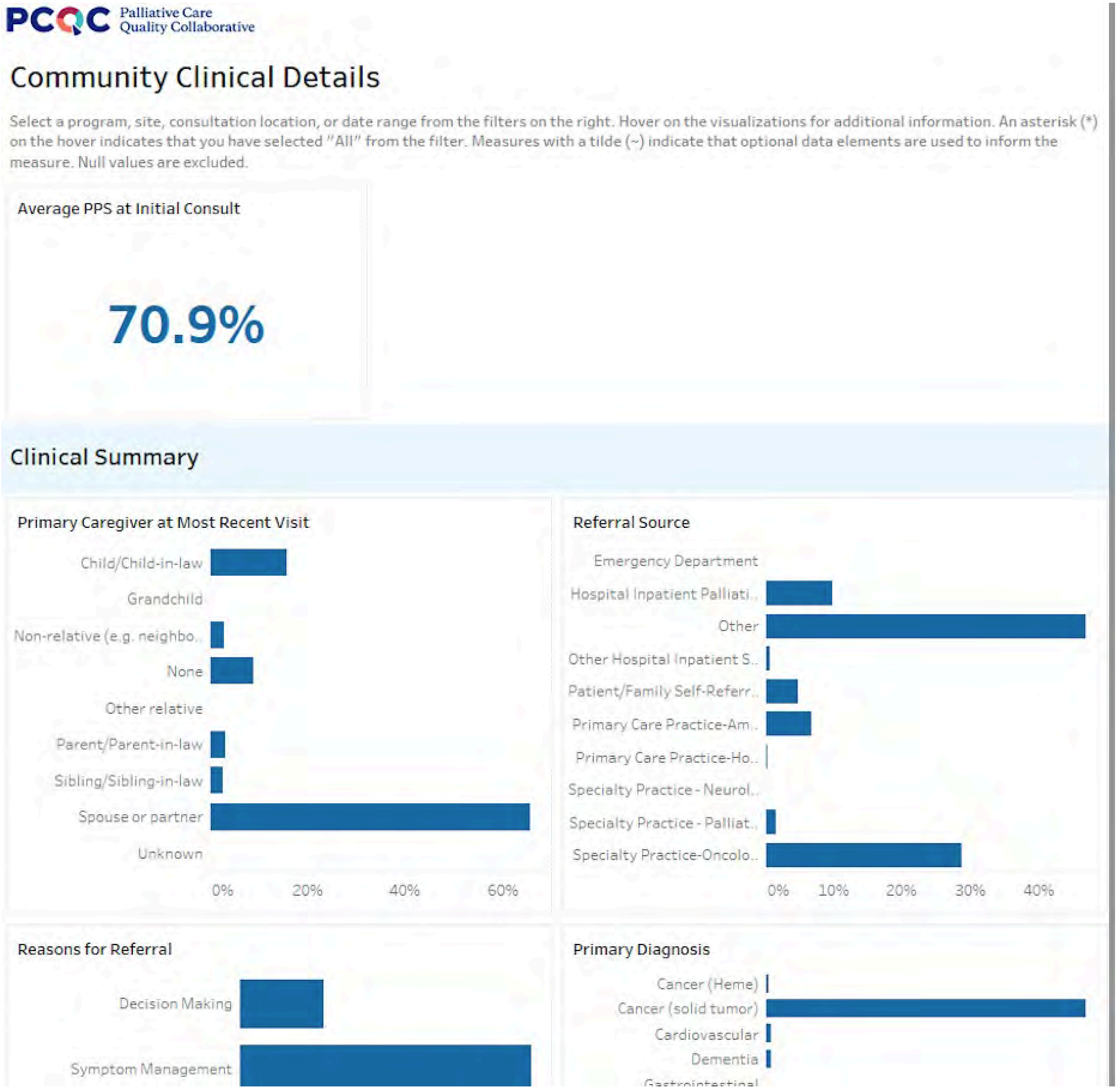
PCQC
Palliative Care
Quality Collaborative

PCQC Measures

Enter data via EHR integration or manually

- All settings
- Demographics, insurance, social determinants
- Staffing and workload/FTE
- Symptom + spiritual assessment
- Impact of assessment on symptom burden
- Goals of care documentation
- # patients, episodes, LOS

https://palliativequality.org/registry-access/registry-resources



PCQC Palliative Care Quality Collaborative

Community Clinical Details

Select a program, site, consultation location, or date range from the filters on the right. Hover on the visualizations for additional information. An asterisk (*) on the hover indicates that you have selected "All" from the filter. Measures with a tilde (~) indicate that optional data elements are used to inform the measure. Null values are excluded.

Average PPS at Initial Consult

70.9%

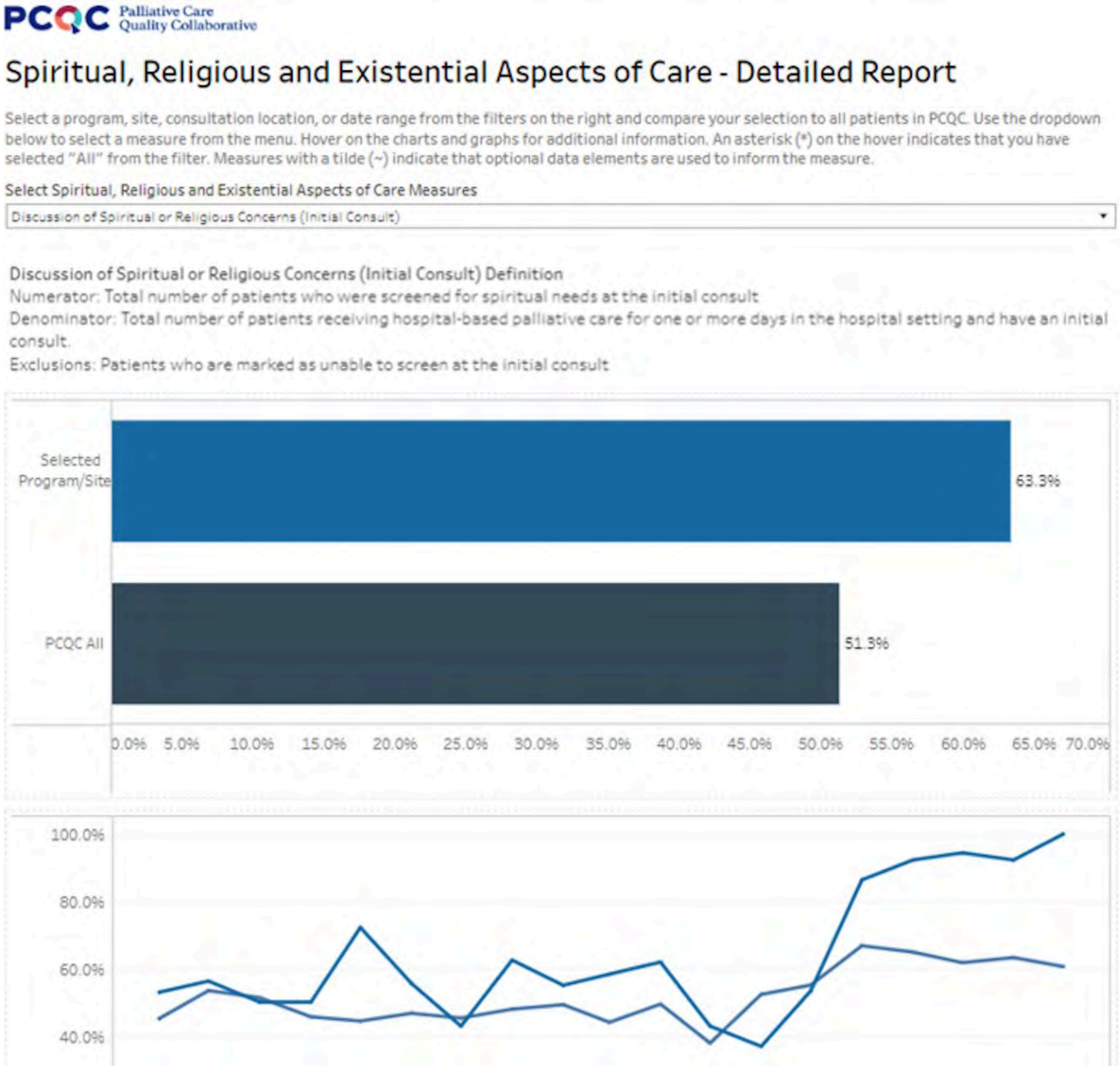
Clinical Summary

Primary Caregiver at Most Recent Visit

Referral Source

Reasons for Referral

Primary Diagnosis



PCQC Palliative Care Quality Collaborative

Spiritual, Religious and Existential Aspects of Care - Detailed Report

Select a program, site, consultation location, or date range from the filters on the right and compare your selection to all patients in PCQC. Use the dropdown below to select a measure from the menu. Hover on the charts and graphs for additional information. An asterisk (*) on the hover indicates that you have selected "All" from the filter. Measures with a tilde (~) indicate that optional data elements are used to inform the measure.

Select Spiritual, Religious and Existential Aspects of Care Measures

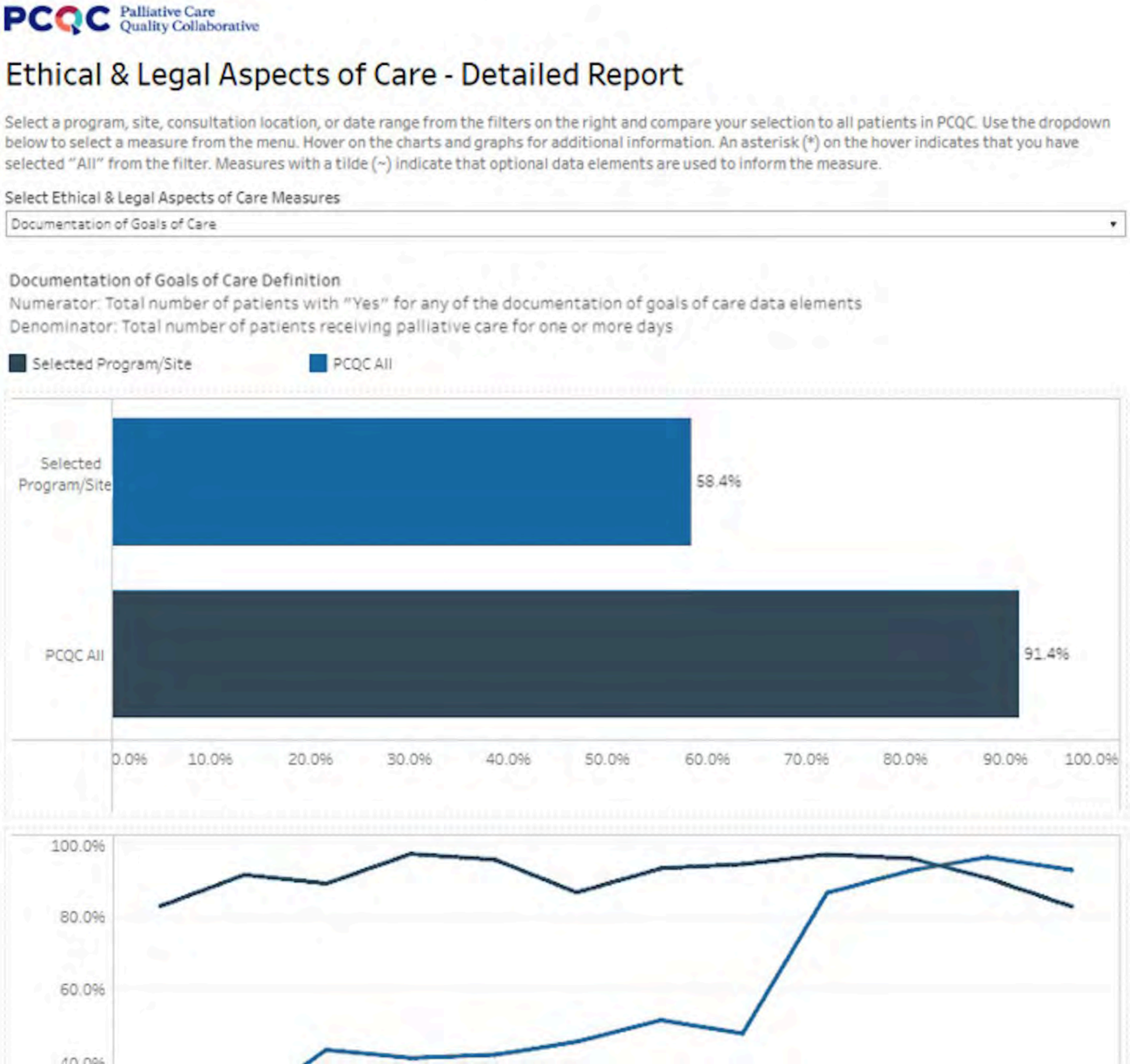
Discussion of Spiritual or Religious Concerns (Initial Consult) ▾

Discussion of Spiritual or Religious Concerns (Initial Consult) Definition

Numerator: Total number of patients who were screened for spiritual needs at the initial consult

Denominator: Total number of patients receiving hospital-based palliative care for one or more days in the hospital setting and have an initial consult.

Exclusions: Patients who are marked as unable to screen at the initial consult



PCQC Palliative Care Quality Collaborative

Ethical & Legal Aspects of Care - Detailed Report

Select a program, site, consultation location, or date range from the filters on the right and compare your selection to all patients in PCQC. Use the dropdown below to select a measure from the menu. Hover on the charts and graphs for additional information. An asterisk (*) on the hover indicates that you have selected "All" from the filter. Measures with a tilde (~) indicate that optional data elements are used to inform the measure.

Select Ethical & Legal Aspects of Care Measures: Documentation of Goals of Care

Documentation of Goals of Care Definition

Numerator: Total number of patients with "Yes" for any of the documentation of goals of care data elements

Denominator: Total number of patients receiving palliative care for one or more days

PCQC Palliative Care Quality Collaborative

Hospital Physical Aspects of Care Scorecard

Select a program, site, consultation location, or date range from the filters on the right. Hover on the visua
on the hover indicates that you have selected "All" from the filter. Measures with a tilde (~) indicate that
measure.

Pain

Patient Screened for Pain

75.6%

Patient Screened for Pain (During Initial Encounter)

63.2%

Pain Treatment (During Initial Consult)~

36.9%

Pain Improvement from First to Last Assessment

54.4%

Dyspnea

Patient Screened for Dyspnea

70.4%

Patient Screened for Dyspnea (During Initial Encounter)

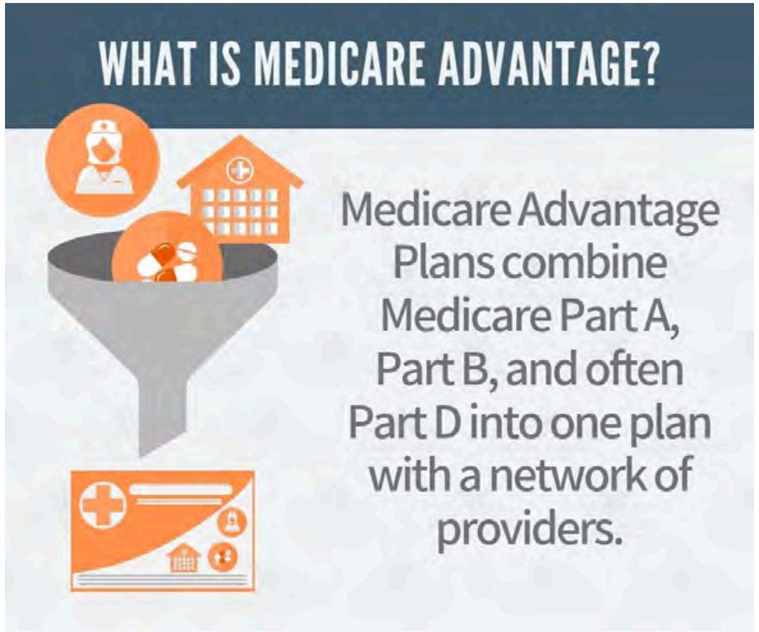
57.8%

Does anyone but us care about delivery of quality palliative care?

Tectonic Plate Shifts in US Health Care:

1. Shift to managed care
2. *Privatization* of Medicare and Medicaid managed care
3. What are their incentives?

Medicare beneficiaries have the option of leaving Traditional Medicare and enrolling in a private health plan for coverage



WHAT IS MEDICARE ADVANTAGE?

Medicare Advantage Plans combine Medicare Part A, Part B, and often Part D into one plan with a network of providers.

No coverage outside the plan's network.

Pre-authorization and
other utilization management.

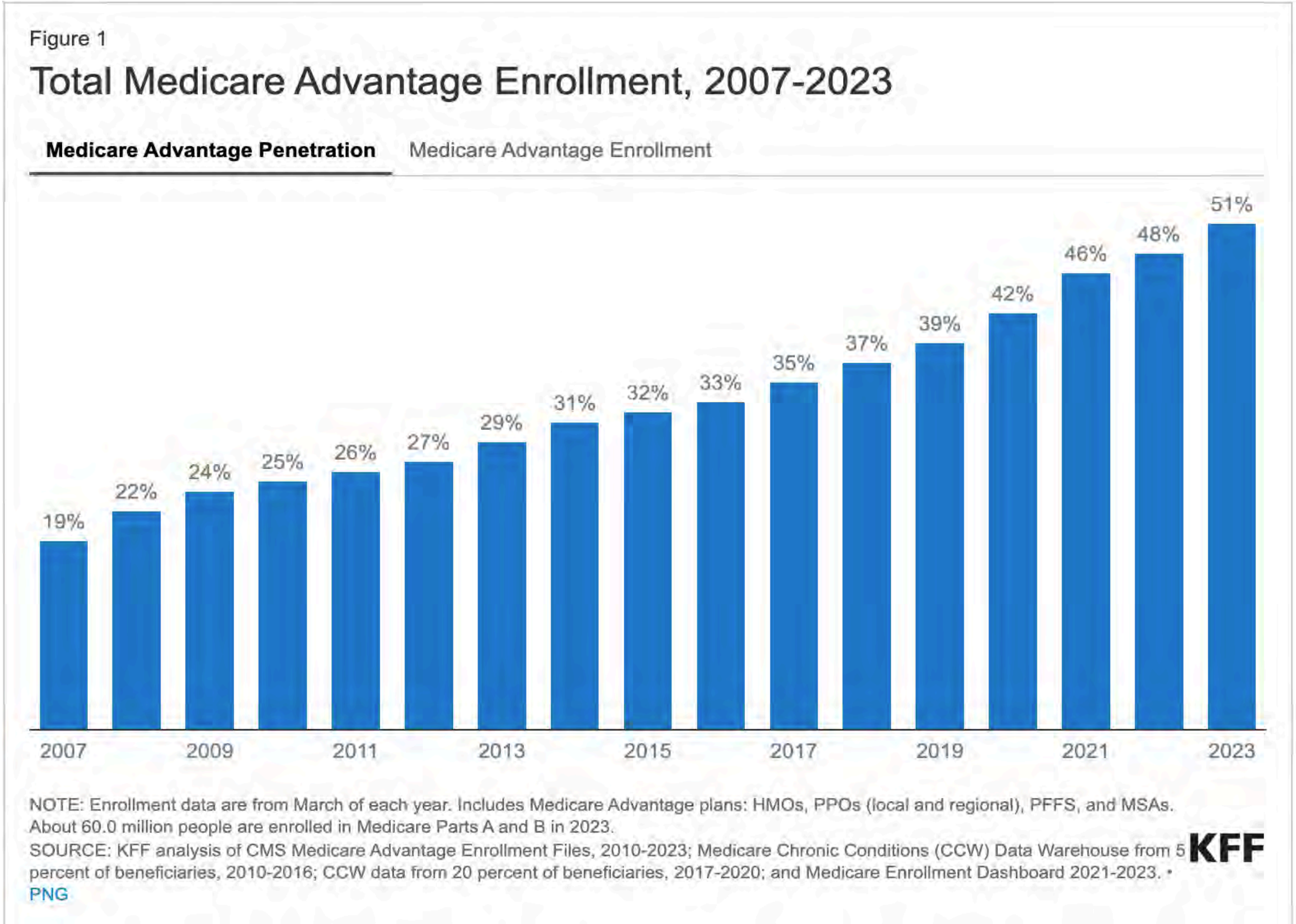


Figure 1

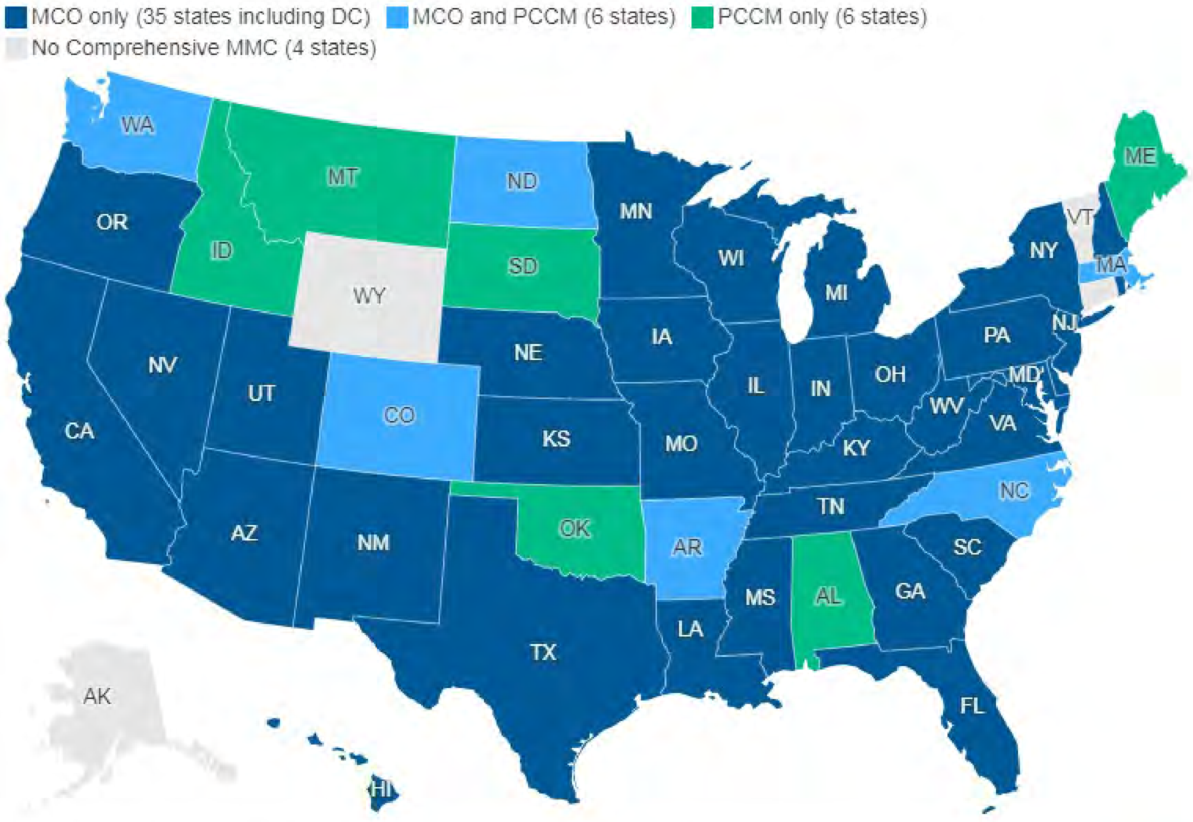
Total Medicare Advantage Enrollment, 2007-2023

NOTE: Enrollment data are from March of each year. Includes Medicare Advantage plans: HMOs, PPOs (local and regional), PFFS, and MSAs. About 60.0 million people are enrolled in Medicare Parts A and B in 2023.

SOURCE: KFF analysis of CMS Medicare Advantage Enrollment Files, 2010-2023; Medicare Chronic Conditions (CCW) Data Warehouse from 5 percent of beneficiaries, 2010-2016; CCW data from 20 percent of beneficiaries, 2017-2020; and Medicare Enrollment Dashboard 2021-2023. •

https://www.kff.org/medicare/issue-brief/medicare-advantage-in-2023-enrollment-update-and-key-trends/#:~:text=More%20than%20half%20of%20eligible,enrolled%20in%20Medicare%20Advantage%20plans.

Medicaid beneficiaries in 41 states are being covered by private insurers running Medicaid Managed Care Organizations



NOTE: ID's Medicaid-Medicare Coordinated Plan has been recategorized by CMS as an MCO but is not counted here as such since it is secondary to Medicare. AZ, CT, and SC use PCCMs but are not counted here as such. DC is included in count of states with MCO only. Publicly available data used to verify status of four states that did not respond to the 2021 survey (DE, MN, NM, and RI).

SOURCE: KFF survey of Medicaid officials in 50 states and DC conducted by HMA, October 2021. • PNG

KFF

Insurer Plan Quality → Payment

- How is quality assessed for managed care plans?
  - Medicare Advantage
  - Medicaid Managed Care
- **Healthcare Effectiveness Data and Information Set (HEDIS)-**
- **MA Star ratings including Consumer Assessment of Healthcare Providers and Systems (CAHPS)-**
- HEDIS Ratings vs Star Ratings
  HEDIS is managed and defined by the NCQA and applies to essentially everyone in the healthcare space. Star ratings are managed by CMS, and apply to Medicare Advantage plans.
- **LINKED TO PAYMENT: Payers care a lot about these ratings**

Why do managed care plans care about star ratings?

- Their payments and enrollment depend on it
- Star ratings based on
  - screenings
  - tests and vaccines
  - chronic condition management
  - **member experience (CAHPS)**
  - member complaints
  - customer service

What’s in HEDIS?

- Colorectal Cancer Screening
- Car
- Use COPD
- Pha
- Cor
- Per
- Ost
- Ant
- Foll
- Pot
- Use
- Transitions of Care
- Plan All-Cause Readmissions

Nothing related to quality of care during serious illness

What’s in CAHPS?

- Complaints
- Members choosing to leave
- Timeliness of appeals
- Interpreter access
- Getting needed care
- Timely appointments
- Customer service
- Likelihood to recommend
- Care coordination
- Medication reconciliation
- Pain assessment

How well do these measures reflect quality of care for people living with serious illness?

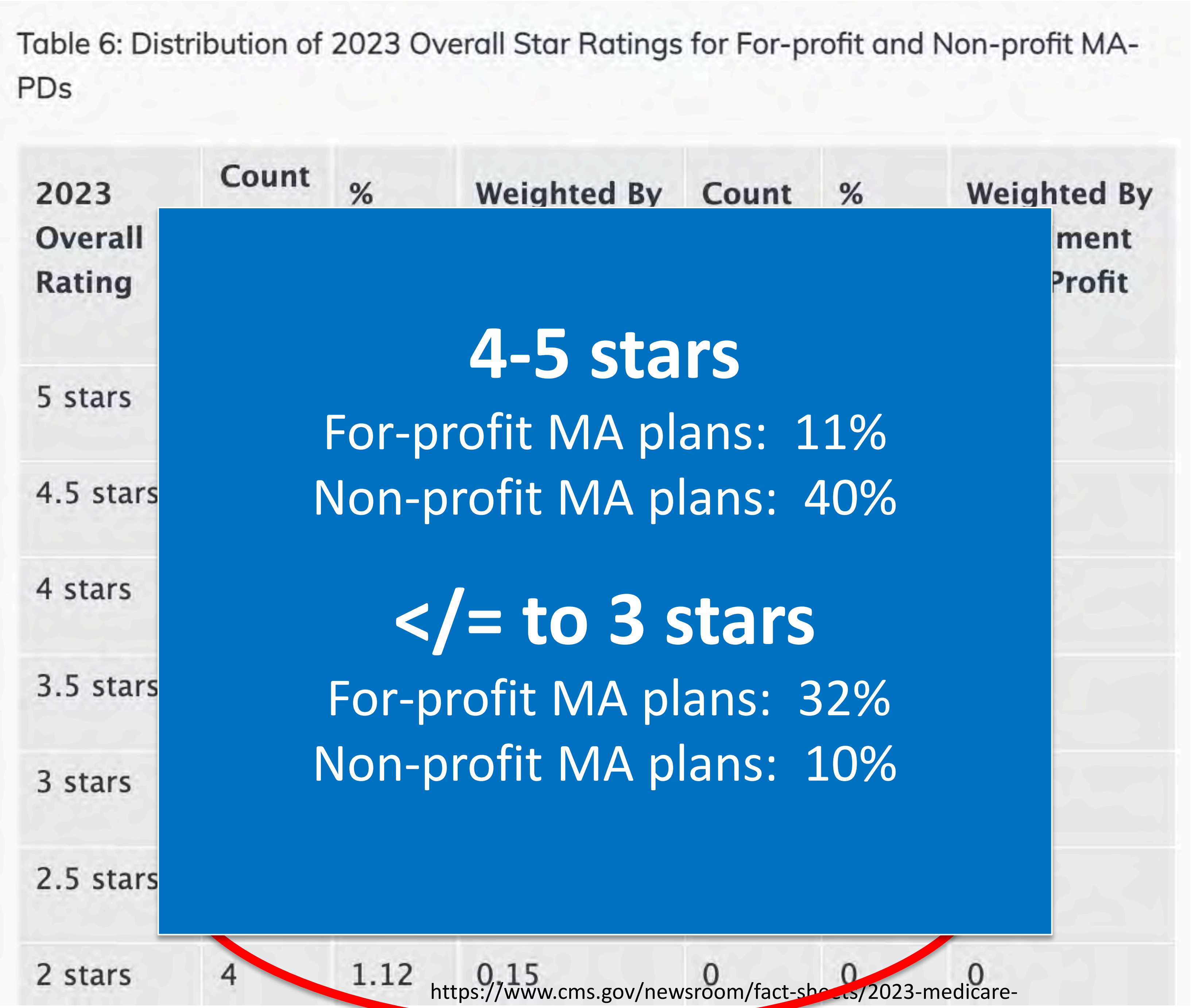


Table 6: Distribution of 2023 Overall Star Ratings for For-profit and Non-profit MA-PDs

2023 Overall Rating	Count	%	Weighted By	Count	%	Weighted By ment Profit
5 stars						
4.5 stars						
4 stars						
3.5 stars						
3 stars						
2.5 stars						
2 stars	4	1.12	0.15	0	0	0

4-5 stars

For-profit MA plans: 11%

Non-profit MA plans: 40%

</= to 3 stars

For-profit MA plans: 32%

Non-profit MA plans: 10%

https://www.cms.gov/newsroom/fact-sheets/2023-medicare-advantage-and-part-d-star-ratings#_ftn1

How Registries Support Payment

California example:

- SB1004 required MediCal Managed Care providers to offer simultaneous palliative care and curative intent care.
- Partnership Health Plan in CA decided that contracting for palliative care services required knowing what services were being provided+of what quality.
- Plan paid providers a PMPM both for the PC service and for joining and participating in PCQN, now PCQC, in return for reporting and meeting process metrics (visits per month) and quality metrics (POLST completion).
- Other Managed MediCal providers across the state adopted the same approach.
- *"It's really a great example of policy change driving PC services and quality."* Steve Pantilat

How did SB1004 come to pass?

Email on 12/02/23 from Judy Thomas, former CEO of the **California Coalition for Compassionate Care**: ‘

“The idea for the bill was inspired by CA’s pediatric concurrent care benefit. A legislative staffer, with familiarity with PC who worked for Senate Health Cmte, saw the potential of PC to benefit older adults (specifically her own aunt) to stay out of SNFs. She convinced the Cmte chair, who was a physician, to author the legislation. Since the pediatric concurrent care benefit was already in place & was cost neutral, the bill moved along pretty smoothly. The Catholic health community supported the bill, which kept the right to life community neutral.

As introduced, the bill would have required the state to pursue a federal waiver for adult PC (just like peds). Late in the legislative process, the State of CA weighed in and the bill was restructured so that the implementation would occur thru Medicaid Managed Care, rather than a slow-moving federal waiver process.

As soon as the bill was signed, the State reached out to CCCC and CHCF to talk about implementation. That was the beginning of efforts to keep the State and managed care plans on track with implementation, which involved years of strategic efforts and private sector philanthropy. ”

Drivers leading to passage of SB 1004

- Personal experience of a Health Committee staffer
- Success of an earlier pediatric palliative concurrent care waiver in terms of cost neutrality → business case
- Organizing and advocacy via the **California Coalition for Compassionate Care**
- Convening and implementation support ($) from the **California Health Care Foundation**

Legacy of SB 1004: 15 more States!

- Hawaii
- Washington
- Oregon
- Maine
- Maryland
- New Jersey
- + nine other states in process

- https://www.capc.org/toolkits/palliative-care-state-policy/
- https://nashp.org/policy/aging-and-disabilities/palliative-care/
- GOCCNJ 2023 Impact Report (goalsofcare.org)

Implications of States requiring access to palliative care under Medicaid Managed Care Plans

Medicaid managed care plans will need to standardize access and quality – as is happening now in CA, this requirement can be met through participation in PCQC. Hopefully this trend will lead to similar requirements for MA plans.

- https://www.capc.org/toolkits/palliative-care-state-policy/
- https://nashp.org/policy/aging-and-disabilities/palliative-care/

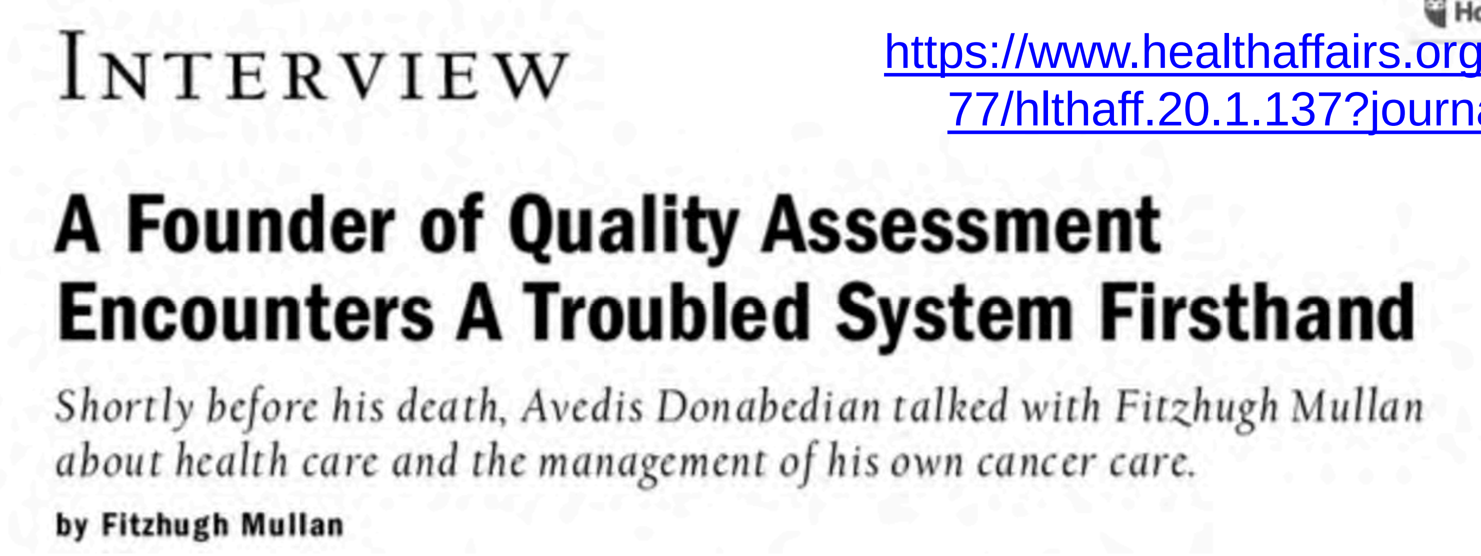
Impact of CA SB1004

- https://www.chcf.org/resource/sb-1004/sb-1004-basics/
- https://www.dhcs.ca.gov/provgovpart/Pages/Palliative-Care-and-SB-1004.aspx
- https://www.chcf.org/resource-center/californias-palliative-care-evolution/

Wayne Gretzky, “The Greatest” (b.1961)

- “You miss 100% of the shots you don’t take.”
- “Skate to where the puck is going, not where it has been.”

https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.20.1.137?journalCode=hlthaff



INTERVIEW

A Founder of Quality Assessment Encounters A Troubled System Firsthand

Shortly before his death, Avedis Donabedian talked with Fitzhugh Mullan about health care and the management of his own cancer care.

by Fitzhugh Mullan

> *"Ultimately, the secret of quality is love. You have to love your patient, you have to love your profession, you have to love your God. If you have love, you can then work backward to monitor and improve the system."*

Avedis Donabedian

Perspectives of Health Equity

Panelists

Khaliah Johnson
MD
Division Chief, Pediatric Palliative Care
Associate Professor, Department of Pediatrics,
Emory University School of Medicine
Attending Physician, Grady Ponce de Leon Center

Carey Candrian
PhD
Associate Professor, Division of General Internal Medicine,
University of Colorado

Karen Bullock
PhD, LICSW, FGSA, APHSW-C
Louise McMahon Ahearn Endowed Professor in the Boston College School of Social Work and in Global Public Health

Health Equity Research in Pediatric Palliative Care

December 14, 2023

Khaliah A. Johnson, MD

Quality Matters Conference
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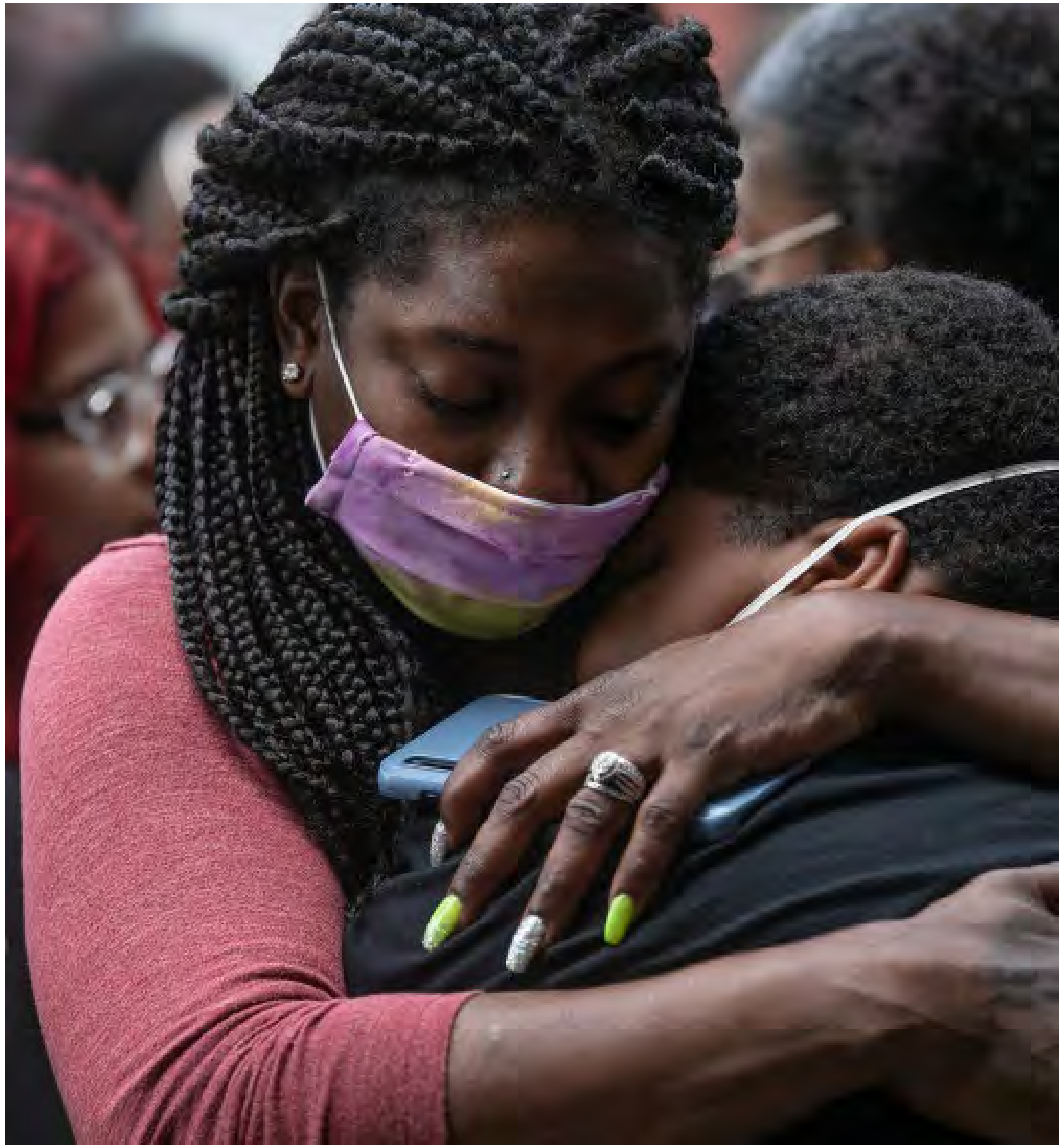
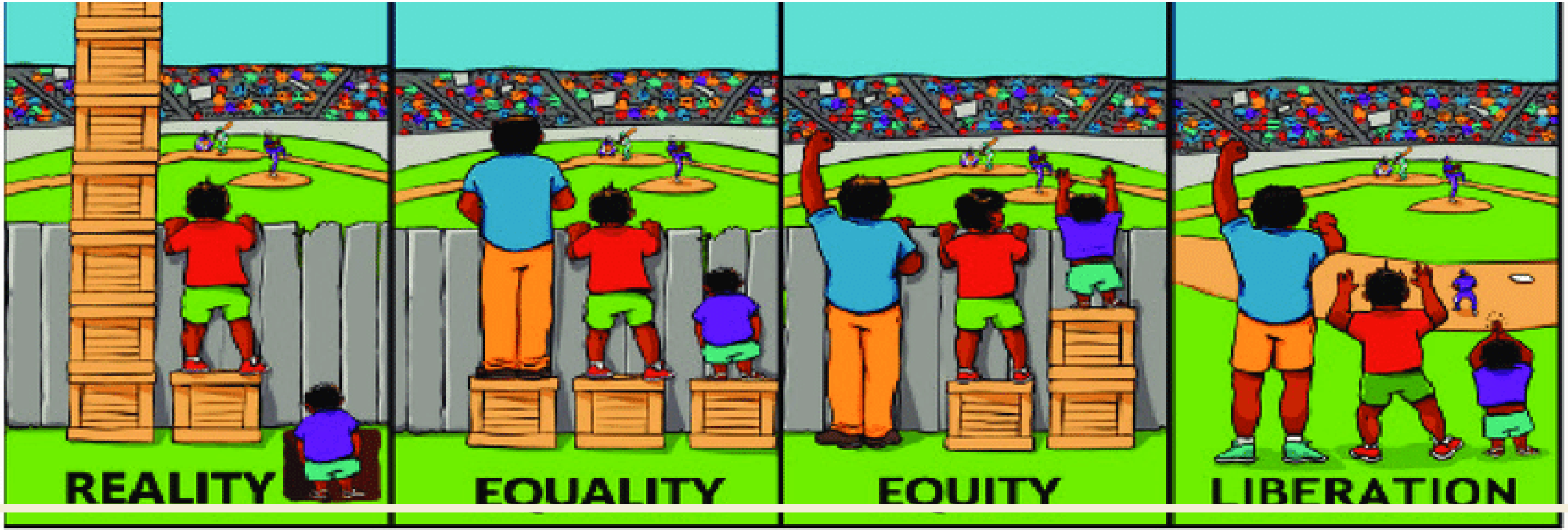
Disclosure

Declare any relevant financial relationship(s) with ineligible companies:

I have no relevant financial relationships to disclose.

Framing the challenge at hand





Defining health equity

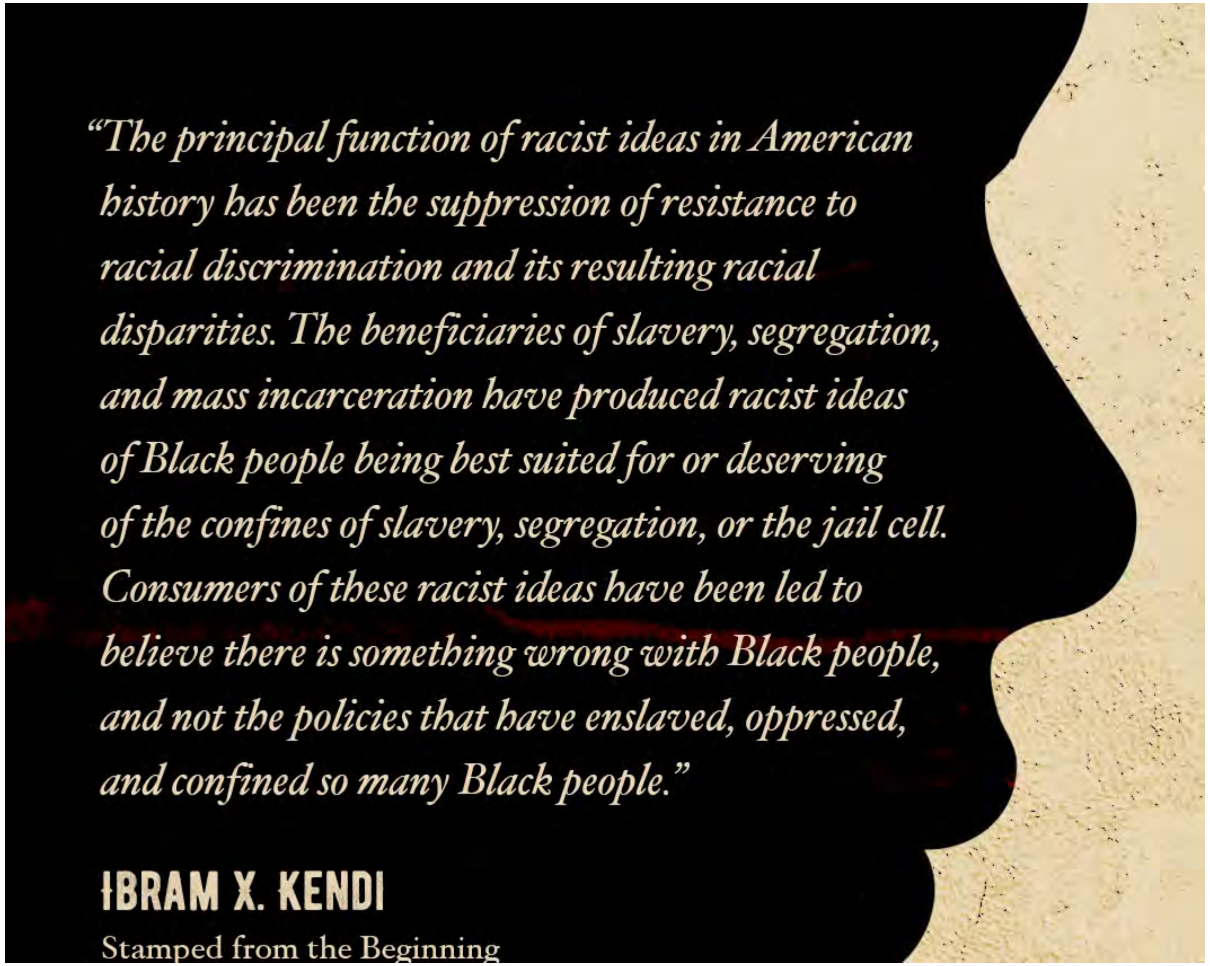
→ "The state in which everyone has a fair and just opportunity to attain their highest level of health."

Disparities in pediatric serious illness: what do we know?

Social determinants of health in pediatric serious illness

- Poverty
- Financial toxicity
- Housing
- Health literacy
- Healthcare access and quality
- Community

The issue of racism and why it uniquely matters

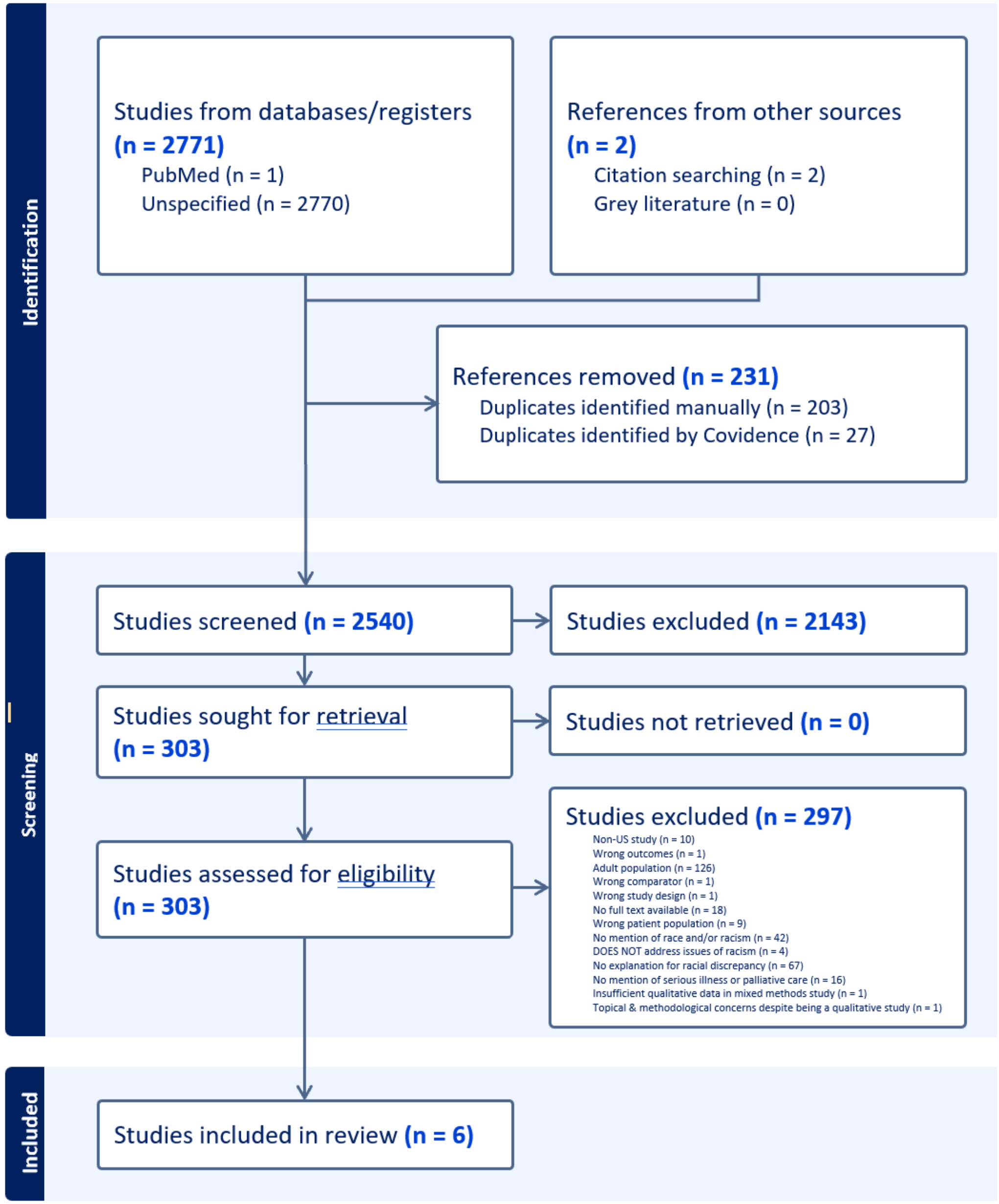


"The principal function of racist ideas in American history has been the suppression of resistance to racial discrimination and its resulting racial disparities. The beneficiaries of slavery, segregation, and mass incarceration have produced racist ideas of Black people being best suited for or deserving of the confines of slavery, segregation, or the jail cell. Consumers of these racist ideas have been led to believe there is something wrong with Black people, and not the policies that have enslaved, oppressed, and confined so many Black people."

IBRAM X. KENDI

Stamped from the Beginning

What are the gaps in our knowledge?



Identification

Studies from databases/registers **(n = 2771)**
PubMed (n = 1)
Unspecified (n = 2770)

References from other sources **(n = 2)**
Citation searching (n = 2)
Grey literature (n = 0)

References removed **(n = 231)**
Duplicates identified manually (n = 203)
Duplicates identified by Covidence (n = 27)

Screening

Studies screened **(n = 2540)**

Studies excluded **(n = 2143)**

Studies sought for retrieval **(n = 303)**

Studies not retrieved **(n = 0)**

Studies assessed for eligibility **(n = 303)**

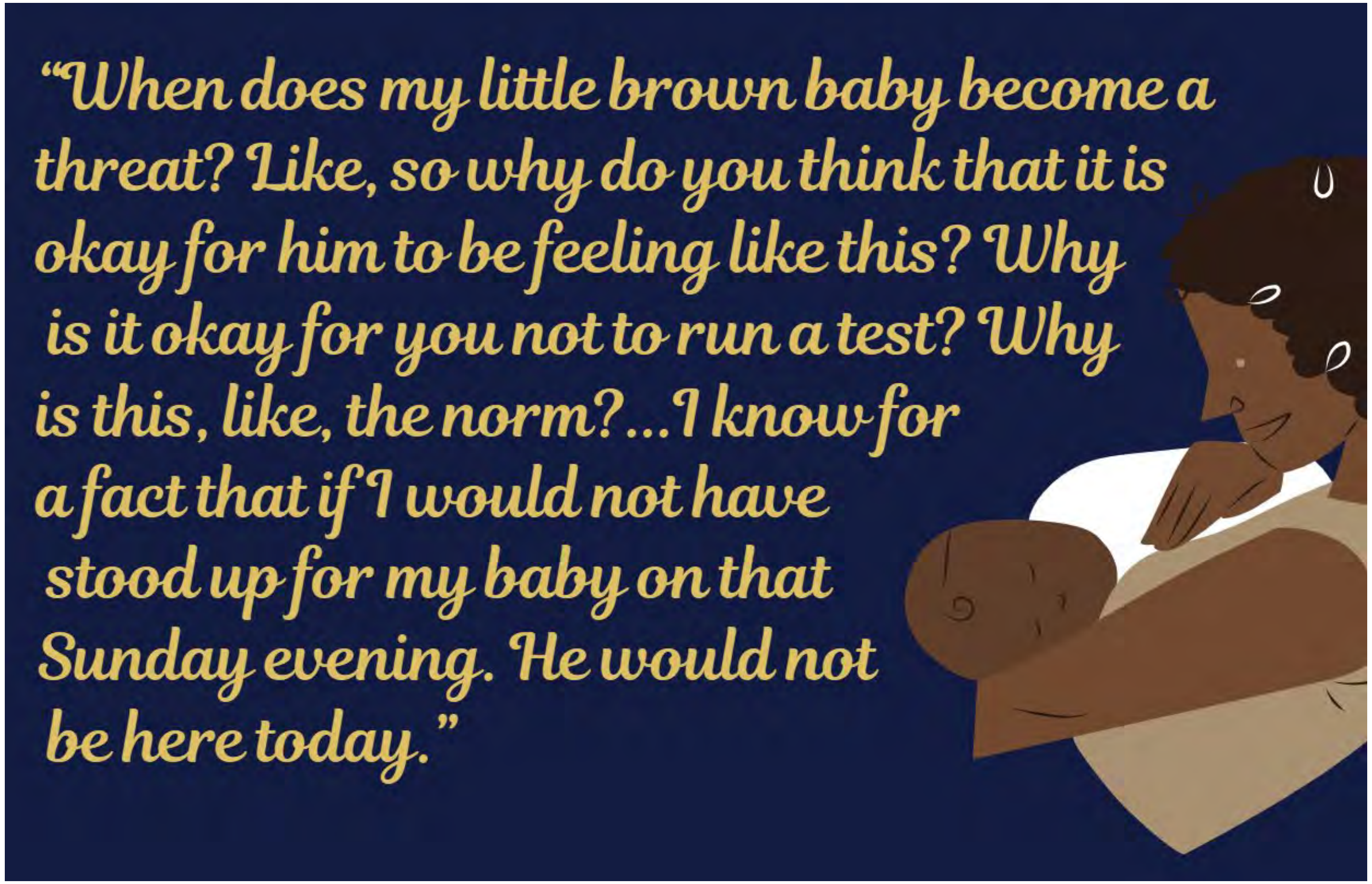
Studies excluded **(n = 297)**
Non-US study (n = 10)
Wrong outcomes (n = 1)
Adult population (n = 126)
Wrong comparator (n = 1)
Wrong study design (n = 1)
No full text available (n = 18)
Wrong patient population (n = 9)
No mention of race and/or racism (n = 42)
DOES NOT address issues of racism (n = 4)
No explanation for racial discrepancy (n = 67)
No mention of serious illness or palliative care (n = 16)
Insufficient qualitative data in mixed methods study (n = 1)
Topical & methodological concerns despite being a qualitative study (n = 1)

Included

Studies included in review **(n = 6)**

Centering in the margins: the importance of qualitative research

The power of perspective



"When does my little brown baby become a threat? Like, so why do you think that it is okay for him to be feeling like this? Why is it okay for you not to run a test? Why is this, like, the norm?...I know for a fact that if I would not have stood up for my baby on that Sunday evening. He would not be here today."

What voices need to be amplified?

- → Indigenous patients and families
- → Individuals experiencing intersectionality
- → Fathers (and other non-participating caregivers)
- → Siblings
- → Interdisciplinary providers- social workers, chaplains, community organizations

A call to action

- → Invest in **qualitative research** in pediatric palliative care that centers the experience of historically marginalized patients
- → Support research aimed at addressing **systemic challenges** that impact health and well being in pediatric serious illness
- → Consider the impact of research that incorporates **interdisciplinary perspectives** on addressing health inequities
- → Encourage studies that interrogate the concept of **total pain** and how social determinants (including racism) impact pain and suffering
- → Fund the work of **historically underrepresented scholars** working to address inequities in pediatric serious illness (as well as their allies)

References

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Thank You!

- Presenter(s) contact information:
  - Khaliah A. Johnson, MD
  - Children’s Healthcare of Atlanta
  - Email: khaliah.johnson@choa.org; kjohn31@emory.edu

- Gratitude:
  - Dio Kavalieratos, PhD
  - Tammie Quest, MD
  - Blyth Lord
  - Camille Murray

Perspectives on Health Equity: The case of LGBTQ adults

Carey Candrian, PhD (she/her)

PCQC: Palliative Care Quality Collaborative

December 14, 2023

Quality Matters Conference
December 14-15, 2023

Division of General Internal Medicine
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UNIVERSITY OF COLORADO **ANSCHUTZ MEDICAL CAMPUS**

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Health disadvantages

→ Financial

→ Social Support

→ Stigma and discrimination

Stigma: effects on health

-12 years

Source: *Harvard Medical Magazine*, 2020

Stigma: The health burden

→Anxiety, depression

→Substance abuse

→Cardiovascular disease

→Cancer burden (lung, breast)

→Suicide

Sources: National LGBT Cancer Network & Healthy People 2020

Do not come out to medical provider:

48%

Source: AARP, 2018

Discrimination in healthcare

- →**56%** report experiencing discrimination.
- →**70%** of trans or gender diverse experience discrimination.

Source: American Heart Association, 2021

Breaking the script

→Who's the biggest support in your life?

→Do you live with anyone?

→Who needs to be in the room when we talk about your care?

→Who's going to need support, so they can support you?

→Who are your people?

Data:
Sexual Orientation and Gender Identity (SOGI)

For Gender Identity:

- **What sex were you assigned at birth?**
- **What is your current gender?**
- Response categories:
  - Male
  - Female
  - Transgender
  - Nonbinary
  - This person uses a different term (w/ space to write in a response)

Source: Federal Register/ Vol. 99, No. 180 September 19, 2023
These questions are in alignment with current recommendations from NASEM and OMB

For Sexual Orientation:

→ **Which of the following BEST represents how you think of yourself?**

→ Response categories:

- Gay or lesbian
- Straight – that is, NOT gay or lesbian
- Bisexual
- This person uses a different term (w/ space to write in a response)

Source: Federal Register/ Vol. 99, No. 180 September 19, 2023
These questions are in alignment with current recommendations from NASEM and OMB

Summary of Research Recommendations

→ **Break the script: “Are you married?”**

- Who’s the biggest support in your life?
- Do you live with anyone?

→ **Break the script: “Family meeting”**

- Who needs to be in the room when we talk about your care?
- Who’s gonna need support, so they can support YOU?
- Who are your people?

→ **Consistently ask questions about Sexual Orientation & Gender Identity (SOGI) & include SOGI data in research.**

Equity in Quality Care Begins with Knowing and Understanding the Strength of an Interdisciplinary Team

Karen Bullock, PhD, LICSW, FGSA, APHSW-C
Ahearn Endowed Professor
Boston College
School of Social Work & Global Public Health

Quality Matters Conference
December 14-15, 2023

PCQC

Disclosure

There are no other financial relationships with any commercial interest.

Learning Outcomes

- Highlight gaps in the serious illness care literature on advancing equitable care.
- Understand guiding principle seeking and including the perspectives of patients and caregivers to address inequities.
- Describe ways that clinicians and other research team members can leverage the collective strengths of a diverse team to promoted patient-centered goal concordant care.

Social Work Perspective on Quality Care

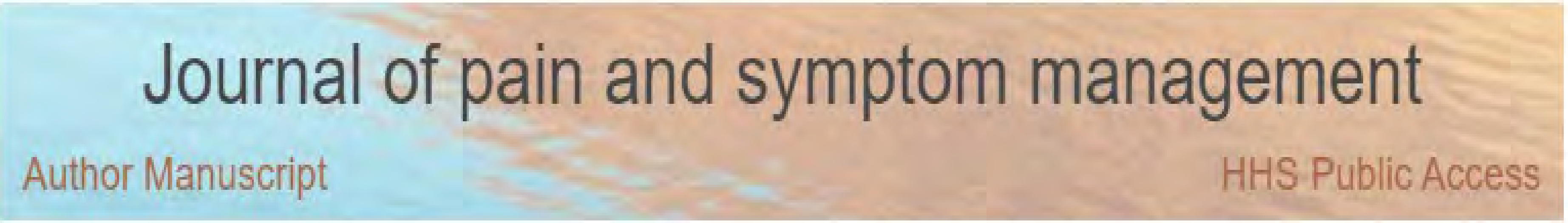
- Describe the social workers’ roles, responsibilities and competencies as facilitators of health equity engagement and actions.
- Discuss the importance of equity and inclusion in the delivery of serious illness care.
- Identify strategies for improving quality data gathering for addressing inequities in serious illness care.

Health Equity in Serious Illness Care

→Serious illness care often reproduces inequities.

→Numerous studies that have revealed inequitable outcomes for Black patients compared with White patients.

→Quality care should aim to reduce disparities and increase equitable outcome.



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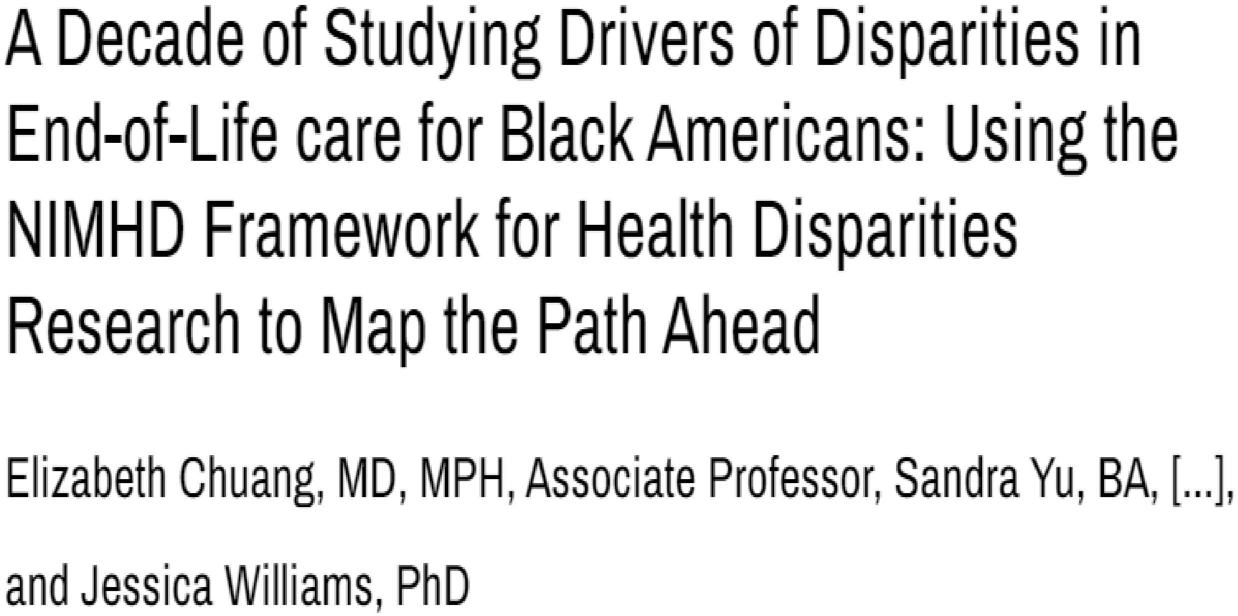

A Decade of Studying Drivers of Disparities in End-of-Life care for Black Americans: Using the NIMHD Framework for Health Disparities Research to Map the Path Ahead

Elizabeth Chuang, MD, MPH, Associate Professor, Sandra Yu, BA, [...], and Jessica Williams, PhD

→ The sociocultural environment, physical/structural environment, behavioral and biological domains remain understudied areas of potential causal mechanisms for racial disparities in care.

→ Studies focusing on individual factors should be better screened to ensure that they are of high quality and avoid stigmatizing Black communities.

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Journal of Pain and Symptom Management

Volume 64, Issue 5, November 2022, Pages e289-e299

Special Article

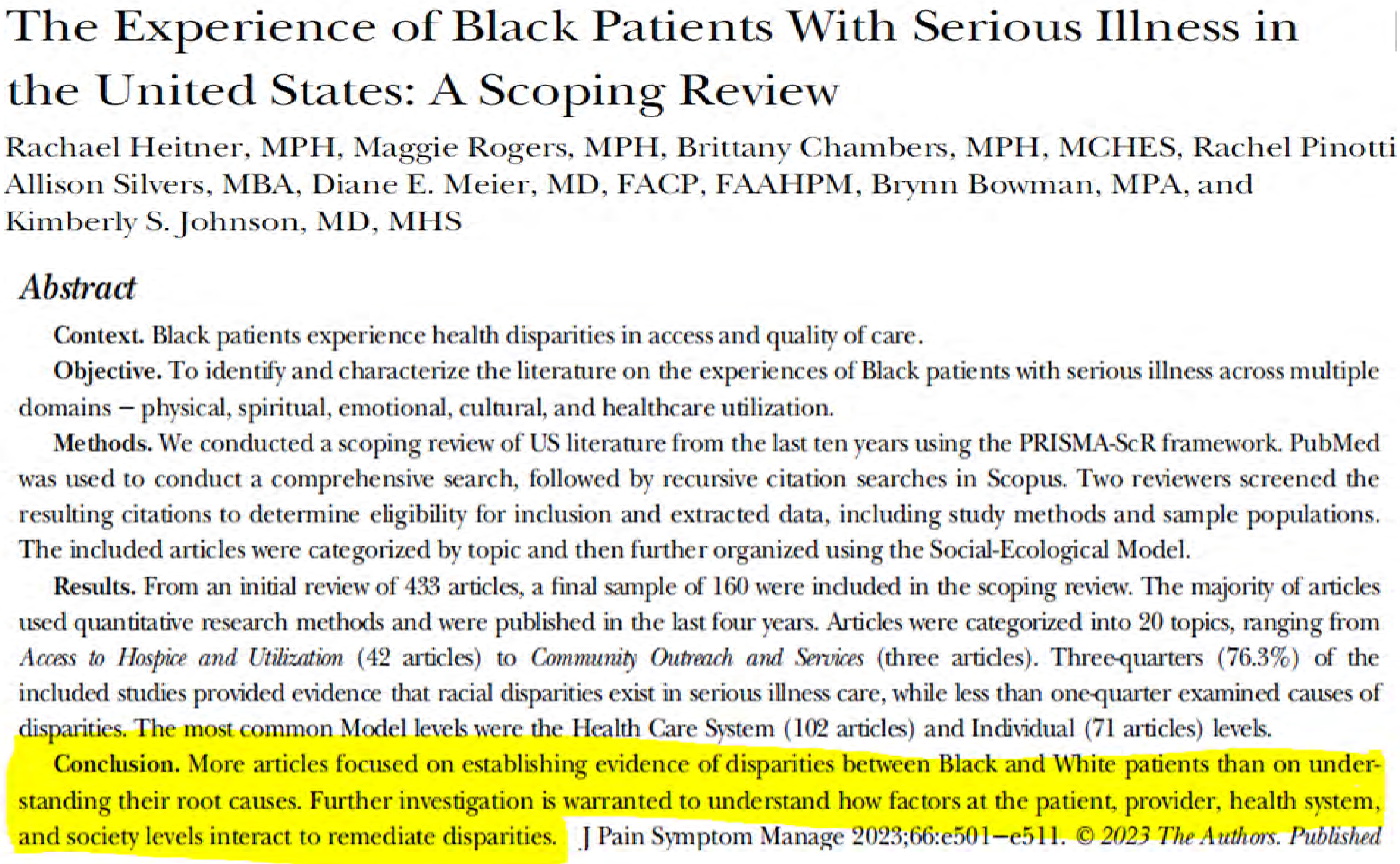
A Review of Race and Ethnicity in Hospice and Palliative Medicine Research: Representation Matters

Ramona L. Rhodes MD, MPH, MSCS[1,2,3], Nadine J. Barrett PhD, MA, MS[4], Deborah B. Ejem PhD[5], Danetta H. Sloan PhD, MSW, MA[6], Karen Bullock PhD, LCSW[7], Kenisha Bethea MPH[8], Raegan W. Durant MD, MPH[9], Gloria T. Anderson PhD, LMSW[7], Marisette Hasan BSN, RN[10], Gracyn Travitz BS[11], Anastatia Thompson BS[12], Kimberly S. Johnson MD, MHS[13,14]

→ To evaluate the race and ethnic diversity of study participants and the reporting of race and ethnicity data in HPM research.

→ 1253 studies screened, 218 were eligible and reviewed. There were 78 unique race and ethnic group labels. Over 85% of studies included ≥ one non-standard label based on Office of Management and Budget designations.

→ One-quarter of studies lacked an explanation of how race and ethnicity data were collected, and 83% lacked a rationale. Over half did not include race and/or ethnicity in the analysis



The Experience of Black Patients With Serious Illness in the United States: A Scoping Review

Rachael Heitner, MPH, Maggie Rogers, MPH, Brittany Chambers, MPH, MCHES, Rachel Pinotti
Allison Silvers, MBA, Diane E. Meier, MD, FACP, FAAHPM, Brynn Bowman, MPA, and
Kimberly S. Johnson, MD, MHS

Abstract

Context. Black patients experience health disparities in access and quality of care.

Objective. To identify and characterize the literature on the experiences of Black patients with serious illness across multiple domains – physical, spiritual, emotional, cultural, and healthcare utilization.

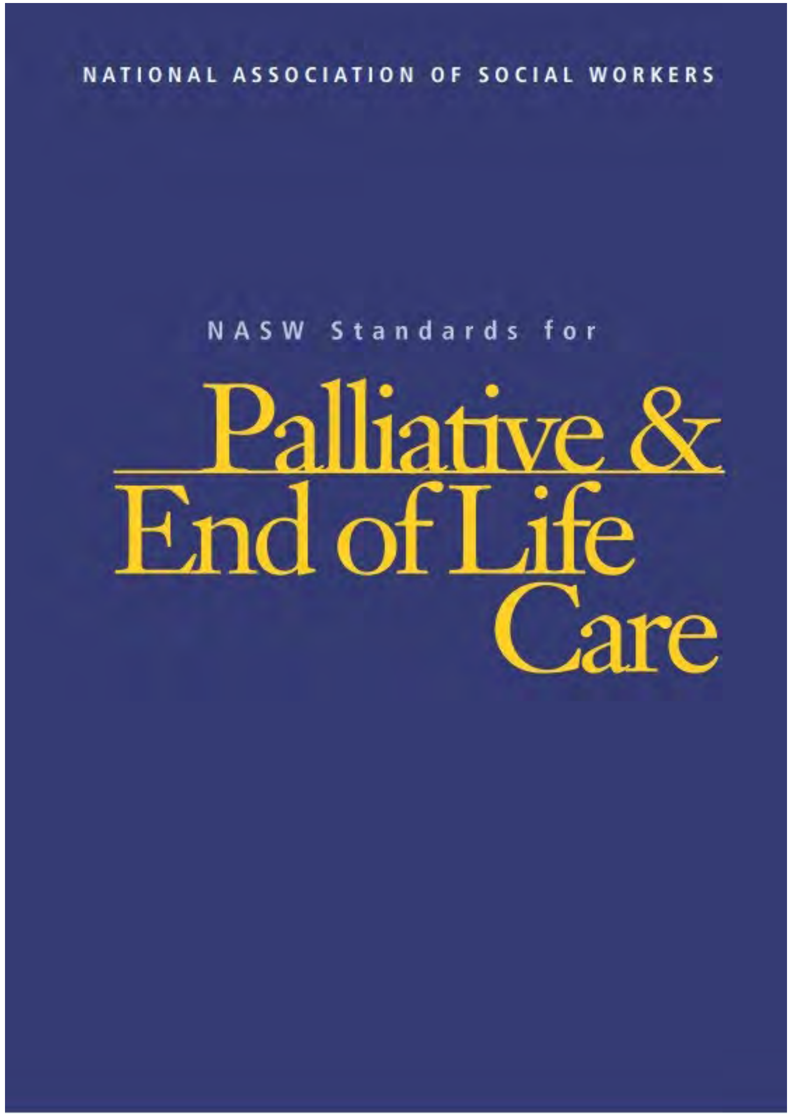
Methods. We conducted a scoping review of US literature from the last ten years using the PRISMA-ScR framework. PubMed was used to conduct a comprehensive search, followed by recursive citation searches in Scopus. Two reviewers screened the resulting citations to determine eligibility for inclusion and extracted data, including study methods and sample populations. The included articles were categorized by topic and then further organized using the Social-Ecological Model.

Results. From an initial review of 433 articles, a final sample of 160 were included in the scoping review. The majority of articles used quantitative research methods and were published in the last four years. Articles were categorized into 20 topics, ranging from *Access to Hospice and Utilization* (42 articles) to *Community Outreach and Services* (three articles). Three-quarters (76.3%) of the included studies provided evidence that racial disparities exist in serious illness care, while less than one-quarter examined causes of disparities. The most common Model levels were the Health Care System (102 articles) and Individual (71 articles) levels.

Conclusion. More articles focused on establishing evidence of disparities between Black and White patients than on understanding their root causes. Further investigation is warranted to understand how factors at the patient, provider, health system, and society levels interact to remediate disparities. J Pain Symptom Manage 2023;66:e501–e511.

Interdisciplinary Research and Engagement

- → Social workers play an important role as clinicians in the delivery of equitable serious illness care and we can do so in research.
- → Awareness, Skills and Knowledge to advance health equity, is rooted in our NASW Code of Ethics, which promotes “diversity, equity, inclusion” and “anti-racist” practices….
- → Prepared to advance health equity in interdisciplinary serious illness care research and engagement.



NATIONAL ASSOCIATION OF SOCIAL WORKERS

NASW Standards for

Palliative & End of Life Care

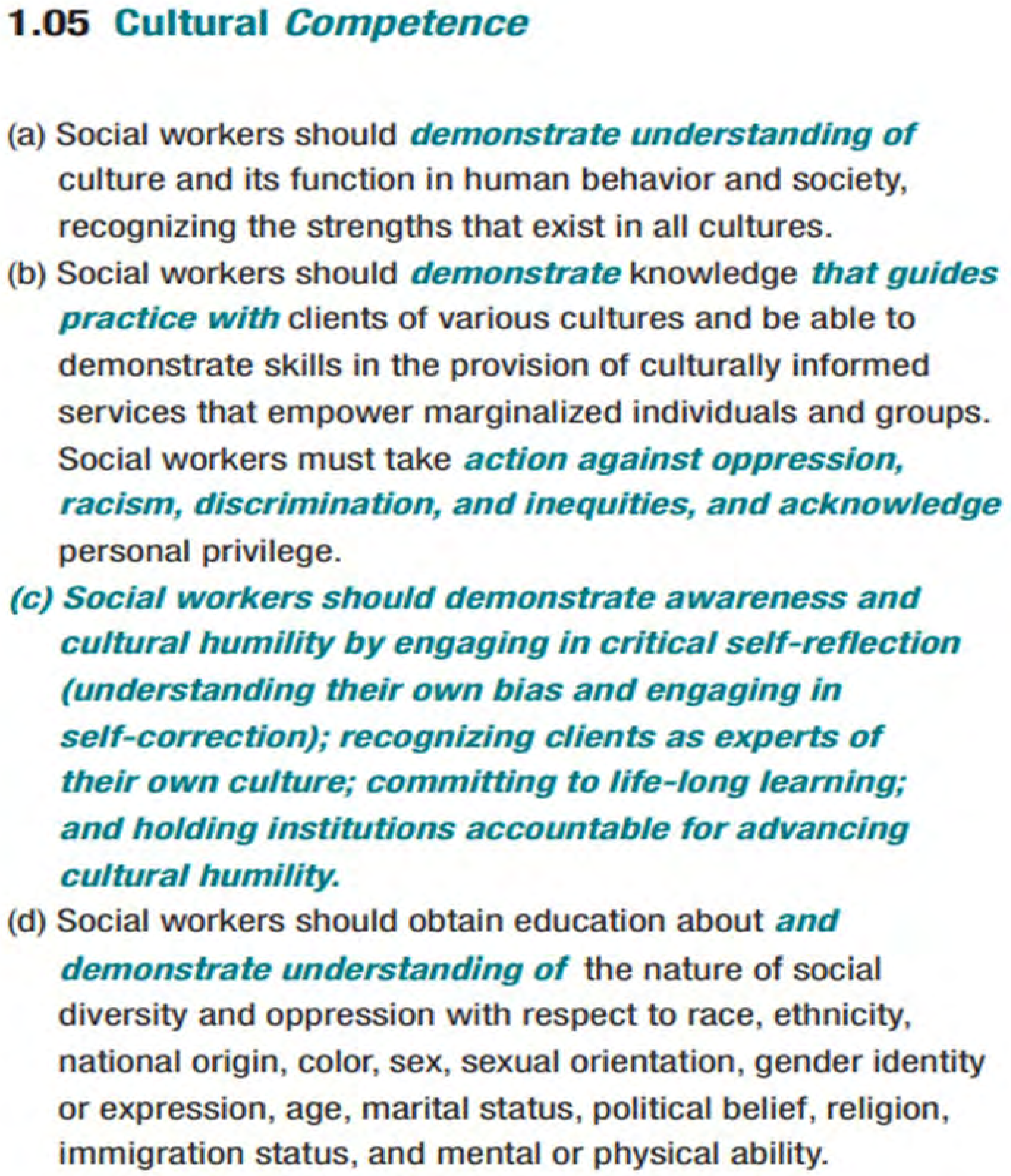
Social Work Practice Standards

NASW
National Association of Social Workers

1. **Ethics and Values**
2. Knowledge
3. Assessment
4. Intervention/Treatment Planning
5. **Attitude/Awareness**
6. **Empowerment and Advocacy**
7. Documentation
8. **Interdisciplinary Teamwork**
9. **Cultural Competence**
10. **Continuing Education**
11. Supervision, Leadership, and Training

https://www.socialworkers.org/Practice/NASW-Practice-Standards-Guidelines/Standards-for-Palliative-and-End-of-Life-Care

Social Work Practice Standards



1.05 Cultural *Competence*

(a) Social workers should ***demonstrate understanding of*** culture and its function in human behavior and society, recognizing the strengths that exist in all cultures.

(b) Social workers should ***demonstrate*** knowledge ***that guides practice with*** clients of various cultures and be able to demonstrate skills in the provision of culturally informed services that empower marginalized individuals and groups. Social workers must take ***action against oppression, racism, discrimination, and inequities, and acknowledge*** personal privilege.

(c) Social workers should demonstrate awareness and cultural humility by engaging in critical self-reflection (understanding their own bias and engaging in self-correction); recognizing clients as experts of their own culture; committing to life-long learning; and holding institutions accountable for advancing cultural humility.

(d) Social workers should obtain education about ***and demonstrate understanding of*** the nature of social diversity and oppression with respect to race, ethnicity, national origin, color, sex, sexual orientation, gender identity or expression, age, marital status, political belief, religion, immigration status, and mental or physical ability.

Social Work, Health Equity, Patient, Family and Community Engagement

- → Social work has roots in structural change efforts and patient advocacy.
- → Social workers are trained and educated to foster relationship between individuals and broader systems of care; and communities at large.
- → Moreover, social workers recognize “racism” as a social determinant of health and aim to eliminate structural and systemic barriers to equitable serious illness care.

> J Pain Symptom Manage. 2023 Jan;65(1):1-5. doi: 10.1016/j.jpainsymman.2022.09.009. Epub 2022 Oct 2.

Racism in Palliative Care Research: We Still have a Ways to Go

Stacy Fischer [1], Mary Isaacson [2], Rashmi K Sharma [3], Kimberly S Johnson [4]

Affiliations + expand

PMID: 36198336 DOI: 10.1016/j.jpainsymman.2022.09.009

> JAMA Netw Open. 2023 Jul 3;6(7):e2321746. doi: 10.1001/jamanetworkopen.2023.21746.

Perspectives About Racism and Patient-Clinician Communication Among Black Adults With Serious Illness

Crystal E Brown [1 2 3], Arisa R Marshall [2], Cyndy R Snyder [4], Kristine L Cueva [5], Christina C Pytel [6], Sandra Y Jackson [7], Sherita H Golden [8], Georgina D Campelia [3], David J Horne [2], Kemi M Doll [9], J Randall Curtis [1 2], Bessie A Young [10 11]

Advancing Health Equity in Serious Illness Care

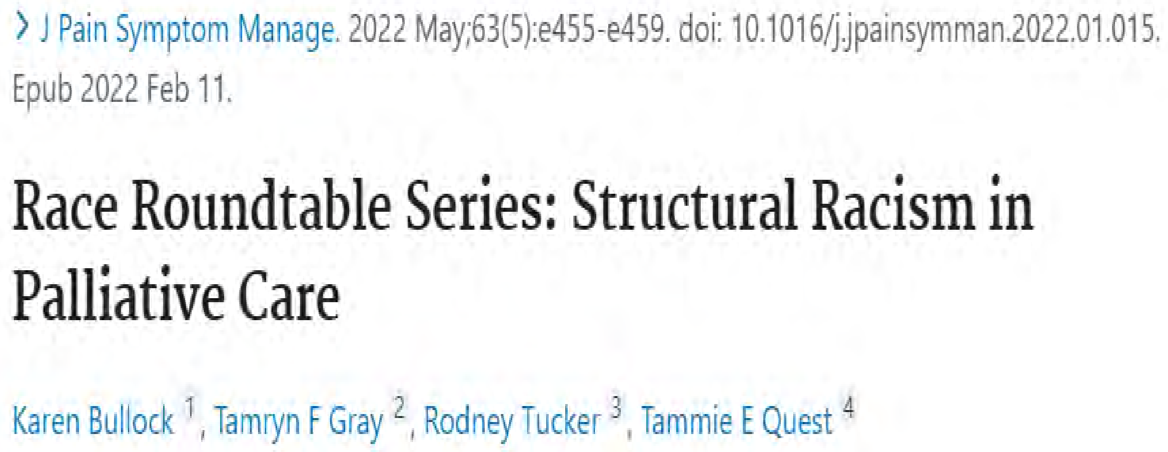
→ Health inequity is focused on addressing observable disparities in health between groups that are avoidable, unfair and unjust [7].

→ Unequal access to and utilization of palliative care/symptom relief is one of the greatest disparities in serious illness care [8].

→ Equity is about improved access to existing care and/or modifying existing care to meet the needs of diverse patient populations, especially those that have been historically and legally denied access to care in U.S. healthcare systems.

→ Addressing structural and systemic barriers to equitable palliative care is an ethical responsibility of health systems [9] and care providers.

Social Workers Center Social Justice and Lead the Charge of Dismantling Structural and Systemic Racism


› J Pain Symptom Manage. 2022 May;63(5):e455-e459. doi: 10.1016/j.jpainsymman.2022.01.015. Epub 2022 Feb 11.

Race Roundtable Series: Structural Racism in Palliative Care

Karen Bullock [1], Tamryn F Gray [2], Rodney Tucker [3], Tammie E Quest [4]


Unmet Needs in Health Disparities Research-It's Not Just About Patients

Nadine J Barrett [1], Karen Bullock [2], Kimberly S Johnson [3 4]

Affiliations + expand

PMID: 35816348 DOI: 10.1001/jamainternmed.2022.2877

> "What is most exciting about REACH Equity is its goal to move from describing racial and ethnic disparities in health to developing actionable ways for health care providers and health systems to improve patient care and reduce these disparities."
> - Dr. Kimberly S. Johnson, Director of REACH Equity


Drivers of racial/ethnic differences in perceived end of-life care quality: More questions than answers

Karen Bullock [1], Lena K Makaroun [2 3]

Affiliations + expand

PMID: 35226353 PMCID: PMC10152395 DOI: 10.1111/jgs.17663

Involve Social Workers At All Stages of Data Analysis and Reporting

DEVELOP DIVERSE TEAMS

Demonstrate Respect and Cultural Responsiveness

Ensure Transparency

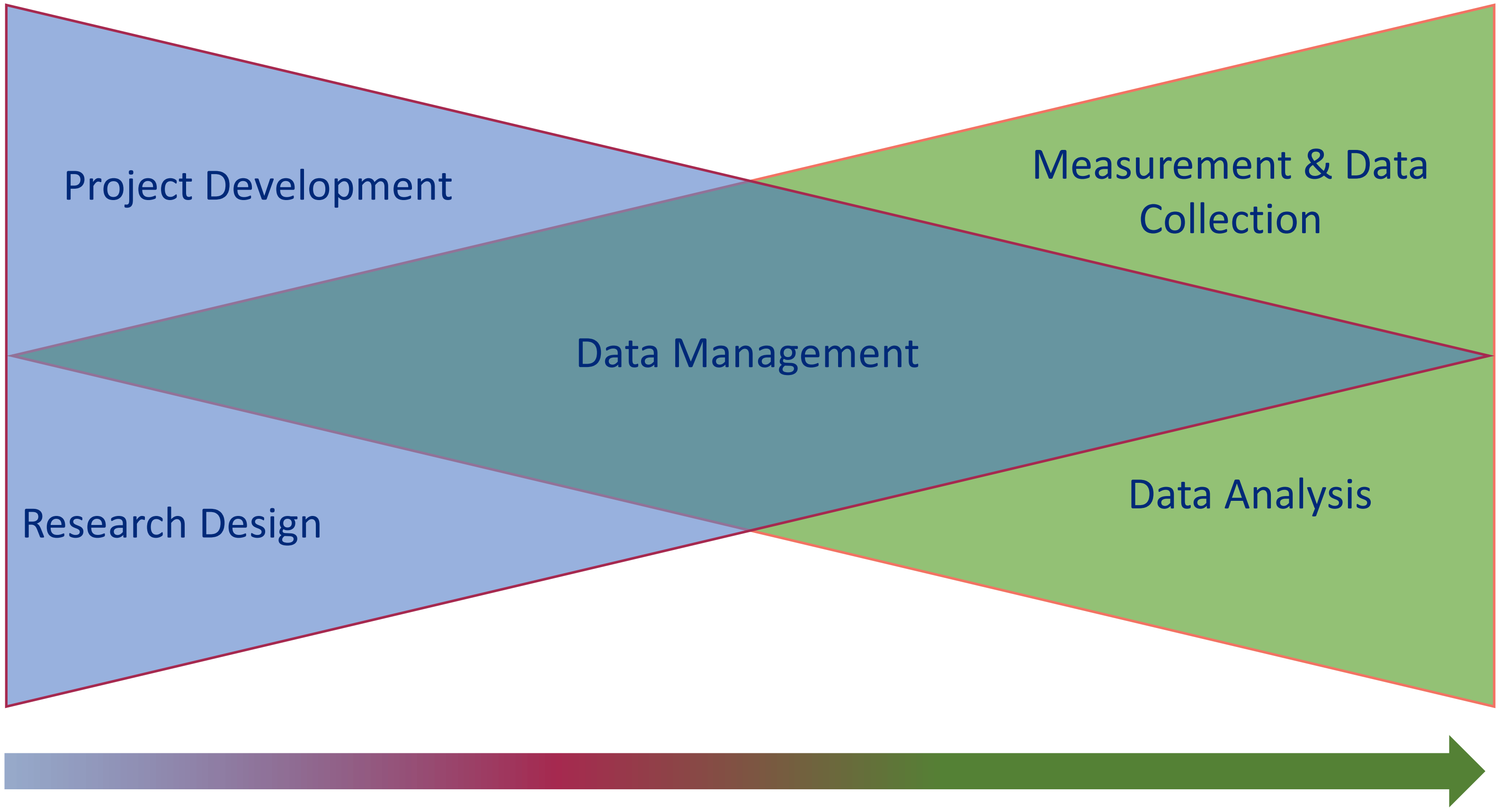
Involve the Community

Acknowledge and Address Bias

Address Historical Exclusion

Center Equity

Social Workers are Social Science Researcher



Project Development

Measurement & Data Collection

Cultural Responsive Care

Data Management

Research Design

Data Analysis

Resource Equity

Psychosocial Interventions & Supportive Care Care

Reporting & Dissemination

Adaptation of Hawley, P,H. (2014). The Bow Tie Model of 21st Century Palliative Care. *Journal of Pain and Symptom Management*. Retrieved from http://dx.doi.org/10.1016/j.jpainsymman.2013.10.009

Take Away Points:

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Journal of Pain and Symptom Management
Volume 63, Issue 6, June 2022, Page 1140

Association and Causation Without Adequate Representation: An Evaluation of the Reporting of Race and Ethnicity of Study Participants in Hospice and Palliative Medicine Research (GP751)

Ramona Rhodes MD, Deborah Ejem PhD, Nadine Barrett PhD MS MA, A'mie Preston PsyD, Cardinale Smith MD PhD, Karen Bullock PhD LCSW, Kenisha Bethea MPH, Marisette Hasan BSN RN, Kimberly Johnson MD MHS

Social workers are an underutilized resource and may have the capacity to increase diversity, equity, and inclusion in interdisciplinary palliative care research.

Thank you!

Thank You!

- Presenter contact information:
  - Karen Bullock, PhD, LICSW, FGSA, APHSW-C
  - Boston College, School of Social Work
  - K.Bullock@bc.edu
  - Phone (617) 552-0324
  - Website: https://www.bc.edu/bc-web/schools/ssw/faculty/faculty-directory/karen-bullock.html

Benzi Kluger
MD, MS
Julius, Helen and Robert Fine
Distinguished Professor of Neurology
Director, Palliative Care Research Center
University of Rochester

Palliative Care for Parkinson's Disease

In this session we will review the evidence that people living with Parkinson's and their families have significant palliative care needs that are often not met under current standards of care. We will review evidence supporting palliative approaches to improve patient and family-centered outcomes and areas where additional collaborations with neurology or neuro-specific approaches may help palliative care teams. Lastly, we will discuss efforts to challenge systems and change culture to improve care.

Palliative Care for Parkinson’s Disease: Building Evidence and Changing Culture to Foster A Higher Standard of Care

Benzi Kluger, MD, MS
Julius, Helen and Robert Fine Distinguished Professor of Neurology
Director, Palliative Care Research Center
University of Rochester

QMC Quality Matters Conference
December 14-15, 2023

Disclosure

I have received support for Palliative Care Research from:

- The University of Colorado Hospital Clinical Effectiveness and Patient Safety Grants Program
- The Veterans Affairs Medical Center Clinical Research to Improve Care Coordination Grants Program
- National Institute on Aging (K07AG030337; K02AG062745; R01AG07753)
- Parkinson Disease Foundation Conference Grants
- Patient Centered Outcomes Research Institute (IHS-1408-20134; DI-2019C2-17499)
- National Institute on Nursing Research/National Institutes of Aging (R01NR016037)
- National Institute of Neurologic Disease and Stroke (RF1NS132673)

Learning Outcomes

Upon Completing this session, participants will be able to:

1. Recognize the multidimensional palliative care needs of persons living with Parkinson's and those who care for them.
2. Review the evidence supporting palliative care approaches to improving patient and family-centered outcomes.
3. Understand the challenges and opportunities in changing culture and challenging systems to integrate palliative care as a new standard of care for Parkinson's.

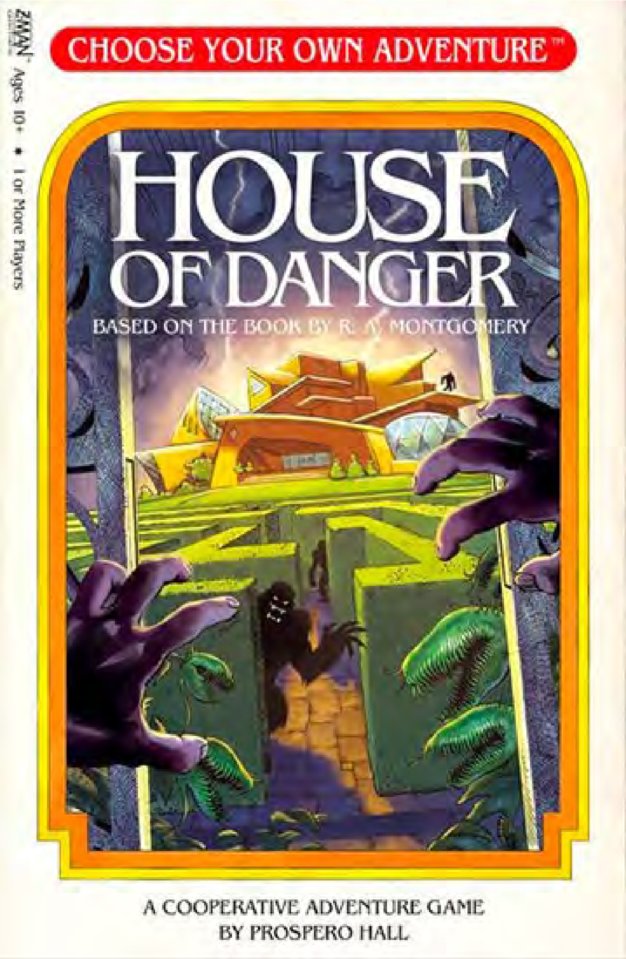
Six Domains of Healthcare Quality

- **Safe**: Avoiding harm to patients from the care that is intended to help them.
- **Effective**: Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).
- **Patient-centered**: Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.
- **Timely**: Reducing waits and sometimes harmful delays for both those who receive and those who give care.
- **Efficient**: Avoiding waste, including waste of equipment, supplies, ideas, and energy.
- **Equitable**: Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

Parkinson's: A Prototype for Neuropalliative Care

- Common
- Motor symptoms
- Nonmotor symptoms
- Dementia
- Multiple causes of disability
- Variable prognosis
- Progressive
- Terminal

Parkinson's: Choose your adventure



A. (slightly better than) Usual Care

- 65 yo man presents with right-sided rest tremor, stiffness and shuffling. Dx with Parkinson's. Started on Sinemet. Follow up in 6 months.
- 7 years into illness is on a complex regimen of medications every 3 hours, an antidepressant, and bowel regimen.
- 10 years into illness dementia is diagnosed and donepezil is started.
- 12 years into illness after two hospitalizations (for UTI and PNA) and prolonged SNF gets palliative care consult while in hospital after failing a swallow evaluation
- Dies in hospital on comfort unit two days later

B. Integrated palliative approach

Mr. Jones is a musician who notes difficulties in keeping up as a jazz drummer and had a fall while jogging:

- Attends newly diagnosed group clinic with his wife within one month of diagnosis to get oriented to new, serious illness
- Because care is coordinated, pain from neuropathy and shoulder is addressed and he receives supportive counseling for grief
- Advance care plans are reviewed annually and goals for independence and comfort are clarified.
- Wife receives individual attention to reinforce self-care and get help at home to prevent burn-out.
- Hospice is started following first hospitalization and Mr. Jones dies at home 6 months later

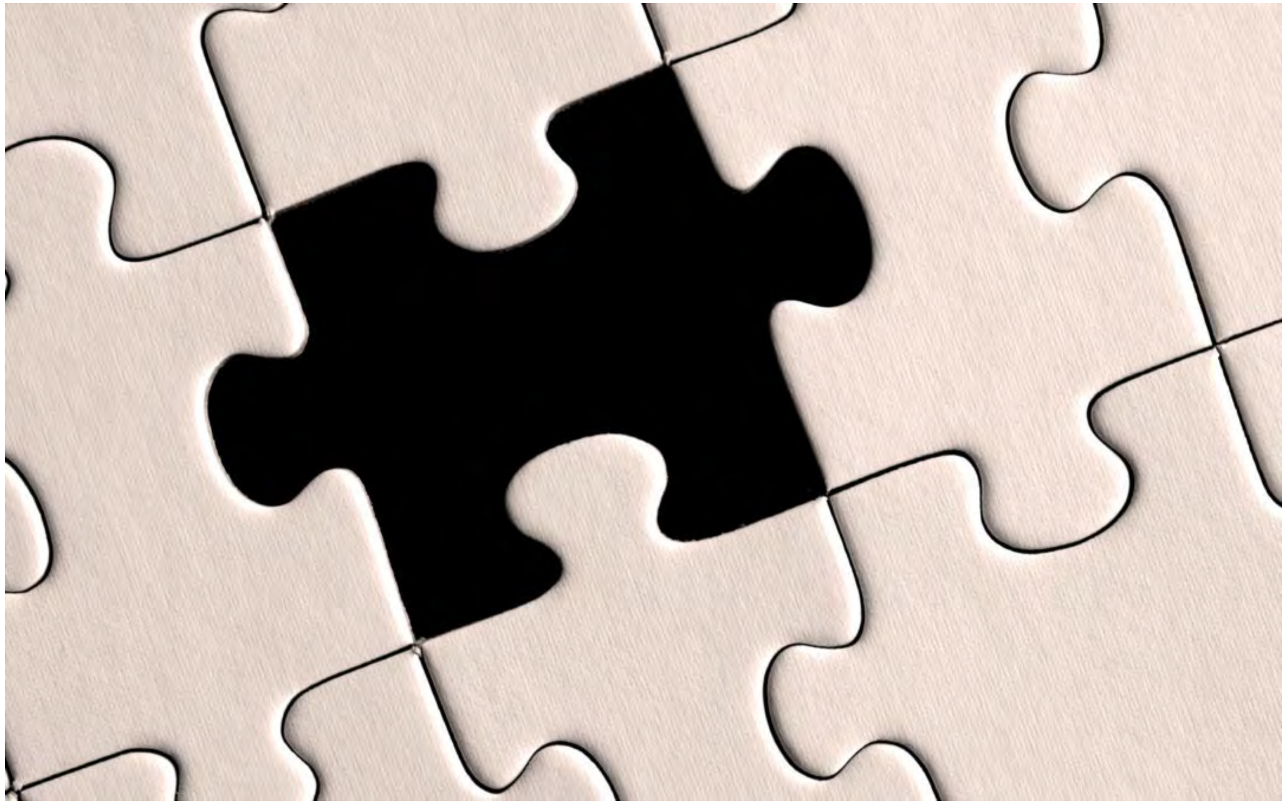
C. Choose Your Own Adventure

- You wake up tomorrow morning with an intermittent rest tremor in your dominant hand.
- You note increasing difficulties keeping up with cognitive demands of work.

QUESTIONS:

- Is this good or bad news?
- What’s most important to you in the care your receive and the systems that provide it?
- What’s becomes most important in your life?
- How do you move forward?

I. Evidence of Unmet Palliative Care Needs



People living with PD have palliative needs.

Movement Disorders

RESEARCH ARTICLE

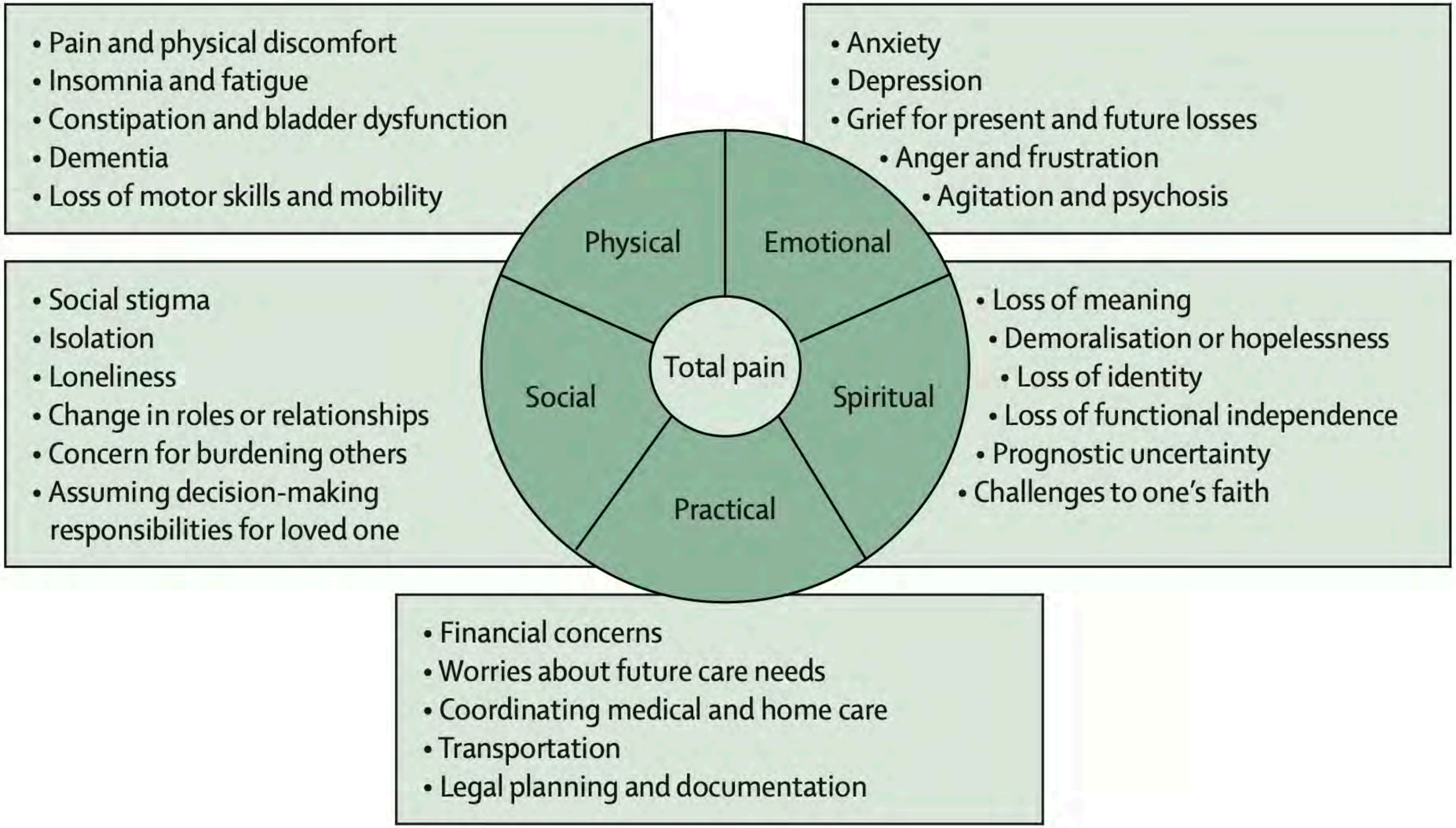
CLINICAL PRACTICE

Defining Palliative Care Needs in Parkinson's Disease

Benzi M. Kluger, MD, MS,[1,] Jo Shattuck, MA,[2] Julie Berk, MS, PA-C,[1] Kelly Sebring,[1] Wallace Jones,[1] Fabian Brunetti,[1] Isabel Fairmont, MS,[1] Daniel W. Bowles, MD,[3] Stefan Sillau, PhD,[1] David B. Bekelman, MD, MPH[4]*

ABSTRACT: Objectives: Palliative care addresses the suffering of patients and families affected by progressive illness through the management of medical symptoms, psychosocial issues, and spiritual concerns. Although there is an emerging interest in applying palliative care to Parkinson's disease (PD), potential palliative care needs have not been systematically investigated in PD patients. Our primary objective was to determine the prevalence of clinically significant symptomatic, psychosocial, and spiritual issues in PD and understand their

Neurological diseases cause multidimensional suffering for patients and families



- Pain and physical discomfort
- Insomnia and fatigue
- Constipation and bladder dysfunction
- Dementia
- Loss of motor skills and mobility

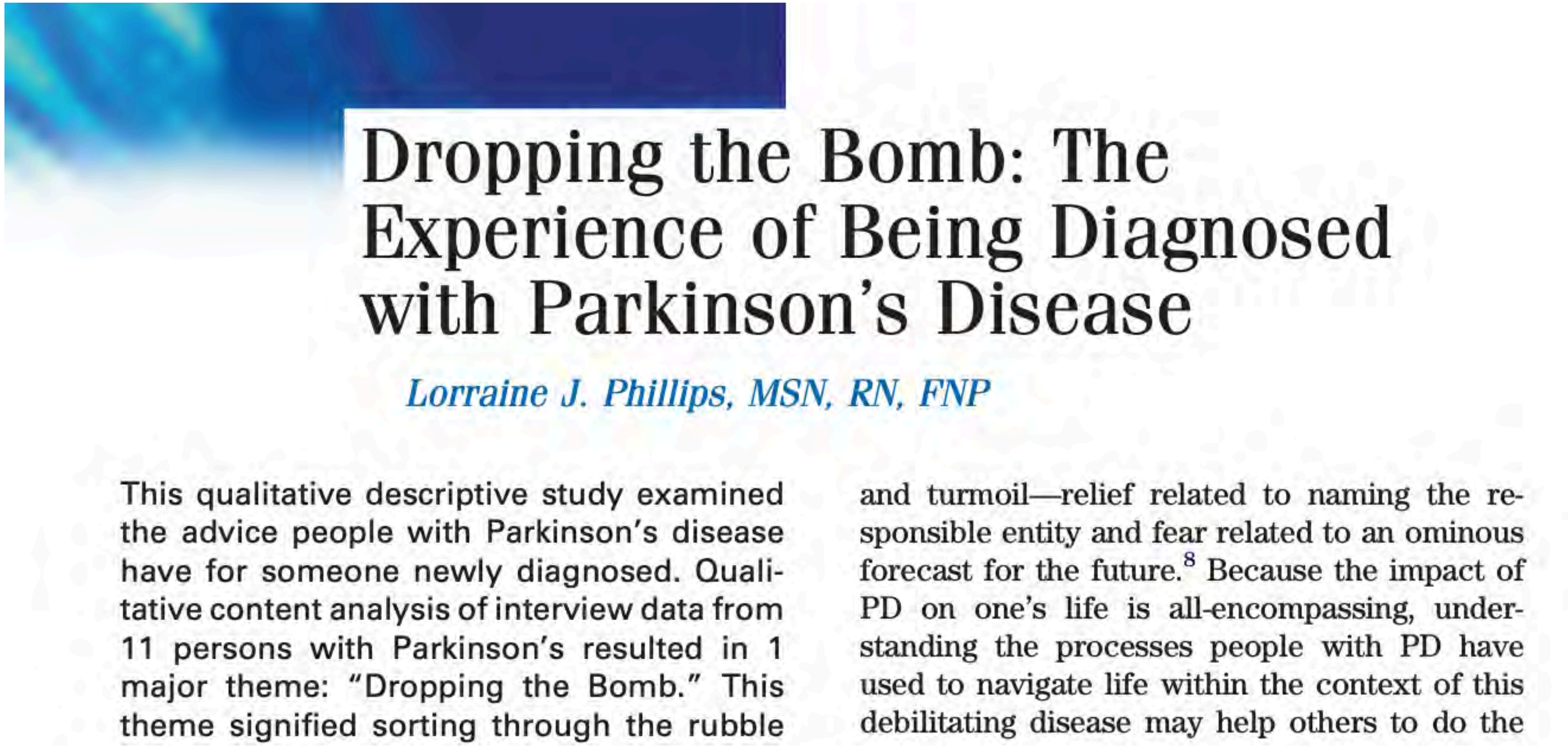
- Anxiety
- Depression
- Grief for present and future losses
- Anger and frustration
- Agitation and psychosis

- Social stigma
- Isolation
- Loneliness
- Change in roles or relationships
- Concern for burdening others
- Assuming decision-making responsibilities for loved one

- Loss of meaning
- Demoralisation or hopelessness
- Loss of identity
- Loss of functional independence
- Prognostic uncertainty
- Challenges to one’s faith

- Financial concerns
- Worries about future care needs
- Coordinating medical and home care
- Transportation
- Legal planning and documentation

Palliative needs begin with diagnosis….



Dropping the Bomb: The Experience of Being Diagnosed with Parkinson's Disease

Lorraine J. Phillips, MSN, RN, FNP

This qualitative descriptive study examined the advice people with Parkinson's disease have for someone newly diagnosed. Qualitative content analysis of interview data from 11 persons with Parkinson's resulted in 1 major theme: "Dropping the Bomb." This theme signified sorting through the rubble and turmoil—relief related to naming the responsible entity and fear related to an ominous forecast for the future.[8] Because the impact of PD on one's life is all-encompassing, understanding the processes people with PD have used to navigate life within the context of this debilitating disease may help others to do the

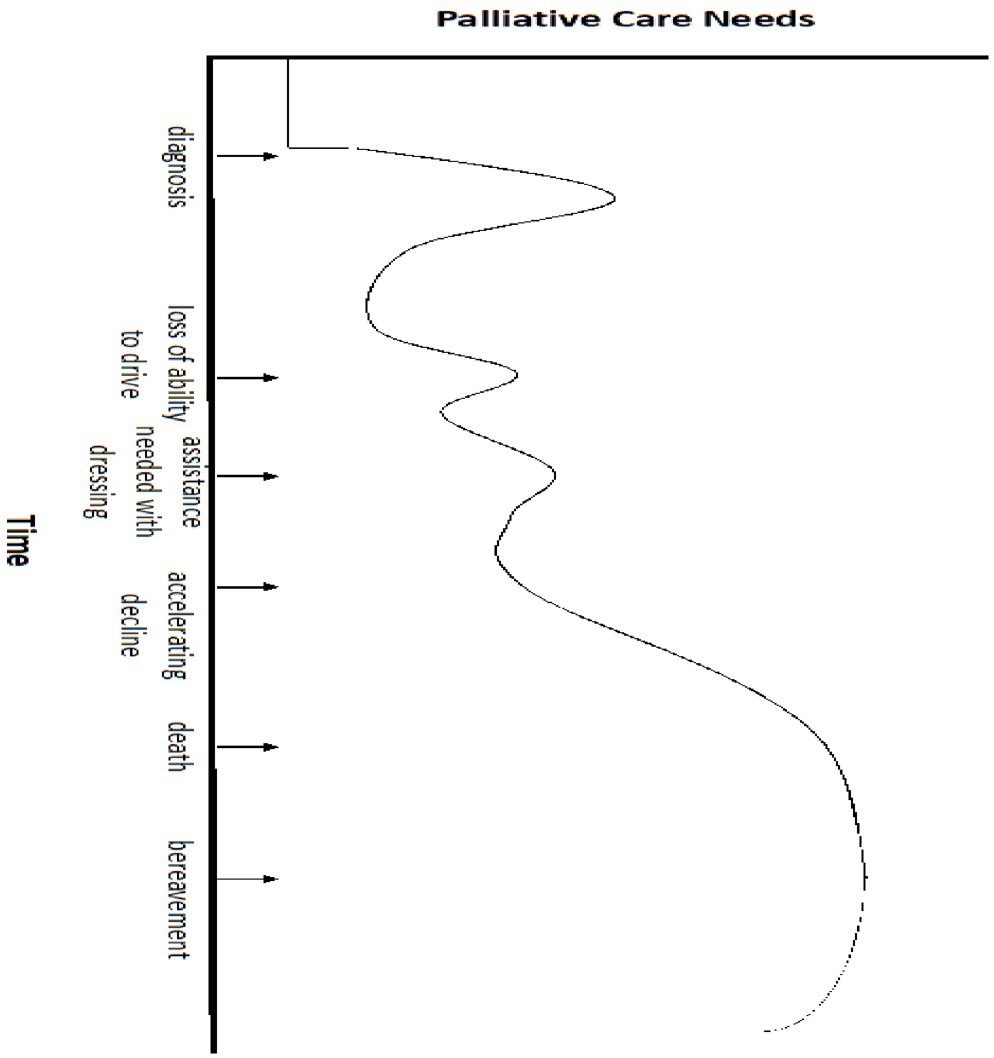
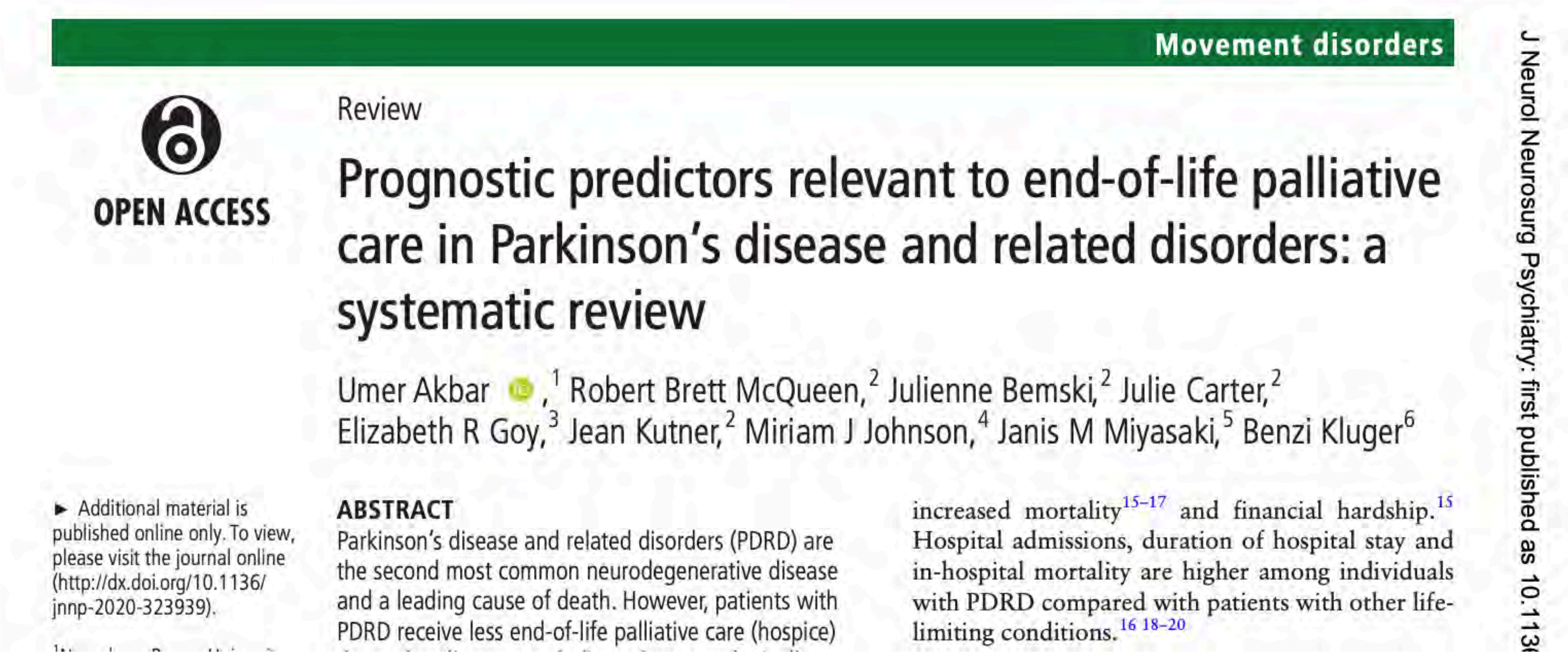


Figure 1: Continuum of Palliative Care

…and must include death and bereavement.



Movement disorders

OPEN ACCESS

Review

Prognostic predictors relevant to end-of-life palliative care in Parkinson's disease and related disorders: a systematic review

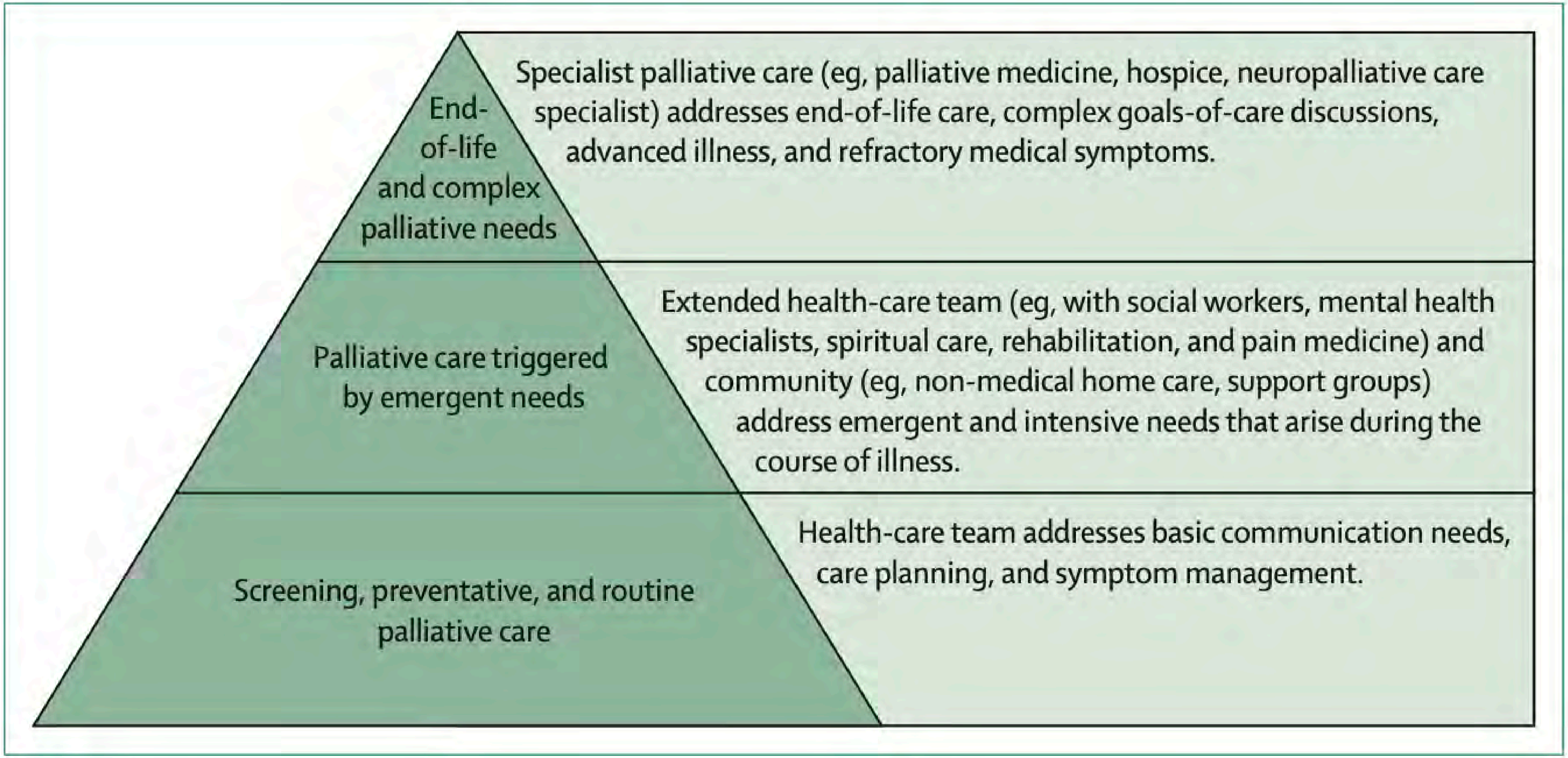
Umer Akbar ,[1] Robert Brett McQueen,[2] Julienne Bemski,[2] Julie Carter,[2] Elizabeth R Goy,[3] Jean Kutner,[2] Miriam J Johnson,[4] Janis M Miyasaki,[5] Benzi Kluger[6]

► Additional material is published online only. To view, please visit the journal online (http://dx.doi.org/10.1136/jnnp-2020-323939).

ABSTRACT
Parkinson's disease and related disorders (PDRD) are the second most common neurodegenerative disease and a leading cause of death. However, patients with PDRD receive less end-of-life palliative care (hospice)

increased mortality[15–17] and financial hardship.[15] Hospital admissions, duration of hospital stay and in-hospital mortality are higher among individuals with PDRD compared with patients with other life-limiting conditions.[16 18–20]

Specialists, generalists and extended teams are needed to optimally prevent and reduce suffering.



End-of-life and complex palliative needs

Specialist palliative care (eg, palliative medicine, hospice, neuropalliative care specialist) addresses end-of-life care, complex goals-of-care discussions, advanced illness, and refractory medical symptoms.

Palliative care triggered by emergent needs

Extended health-care team (eg, with social workers, mental health specialists, spiritual care, rehabilitation, and pain medicine) and community (eg, non-medical home care, support groups) address emergent and intensive needs that arise during the course of illness.

Screening, preventative, and routine palliative care

Health-care team addresses basic communication needs, care planning, and symptom management.

Current models of care frequently miss palliative needs.

RESEARCH ARTICLE

Reach of Palliative Care for Parkinson Disease

Results From a Large National Survey of Patients and Care Partners

Sandhya Seshadri, PhD, MA, MS, Megan Dini, MA, Zachary Macchi, MD, Peggy Auinger, MS, Sally A. Norton, PhD, RN, Jodi S. Holtrop, PhD, MCHES, and Benzi M. Kluger, MD, MS

Neurology: Clinical Practice 2023;13:e200214. doi:10.1212/CPJ.0000000000200214

Correspondence
Dr. Seshadri
sandhya_seshadri@
urmc.rochester.edu

To meet end stage needs well you must start early.

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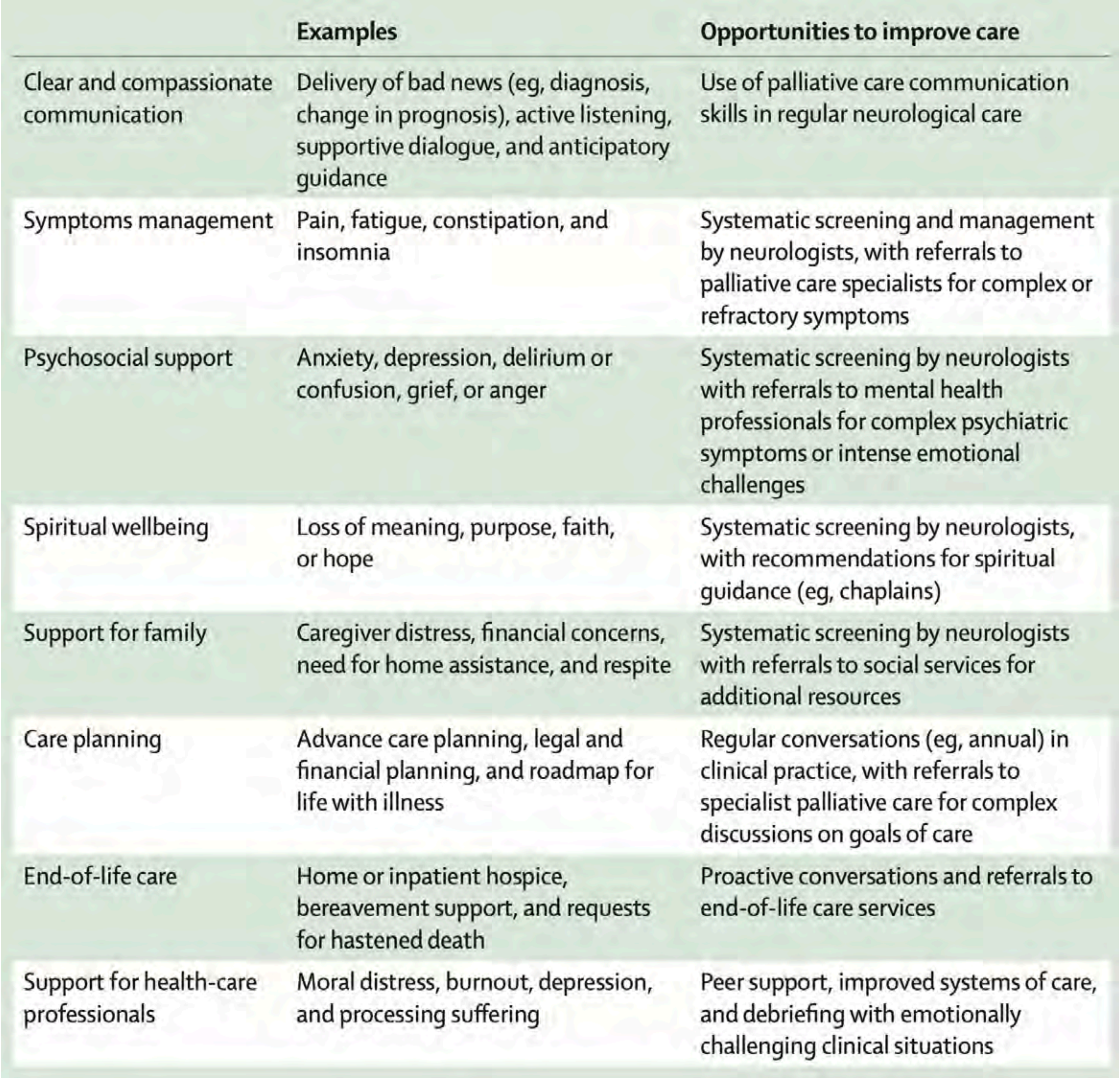
Originally published on 1992-05-21.

Palliative care needs represent opportunities to prevent and address suffering



	Examples	Opportunities to improve care
Clear and compassionate communication	Delivery of bad news (eg, diagnosis, change in prognosis), active listening, supportive dialogue, and anticipatory guidance	Use of palliative care communication skills in regular neurological care
Symptoms management	Pain, fatigue, constipation, and insomnia	Systematic screening and management by neurologists, with referrals to palliative care specialists for complex or refractory symptoms
Psychosocial support	Anxiety, depression, delirium or confusion, grief, or anger	Systematic screening by neurologists with referrals to mental health professionals for complex psychiatric symptoms or intense emotional challenges
Spiritual wellbeing	Loss of meaning, purpose, faith, or hope	Systematic screening by neurologists, with recommendations for spiritual guidance (eg, chaplains)
Support for family	Caregiver distress, financial concerns, need for home assistance, and respite	Systematic screening by neurologists with referrals to social services for additional resources
Care planning	Advance care planning, legal and financial planning, and roadmap for life with illness	Regular conversations (eg, annual) in clinical practice, with referrals to specialist palliative care for complex discussions on goals of care
End-of-life care	Home or inpatient hospice, bereavement support, and requests for hastened death	Proactive conversations and referrals to end-of-life care services
Support for health-care professionals	Moral distress, burnout, depression, and processing suffering	Peer support, improved systems of care, and debriefing with emotionally challenging clinical situations

People living with parkinsonism don’t need a crystal ball, they need a good road map.


Original Article

Optimizing future planning in Parkinson disease: suggestions for a comprehensive roadmap from patients and care partners

Sarah R. Jordan[1], Benzi Kluger[2], Roman Ayele[3,4], Adreanne Brungardt[1], Anne Hall[5], Jacqueline Jones[4], Maya Katz[6], Janis M. Miyasaki[7], Hillary D. Lum[1,8]

- ☐ Where are we?
- ☐ Where are we headed?
- ☐ What should we be looking for?
- ☐ What’s the best, worst and most likely road ahead?

Prozac is not always the answer.

"Could we up the dosage? I still have feelings."

People living with Parkinson's priorities align with a palliative care approach.

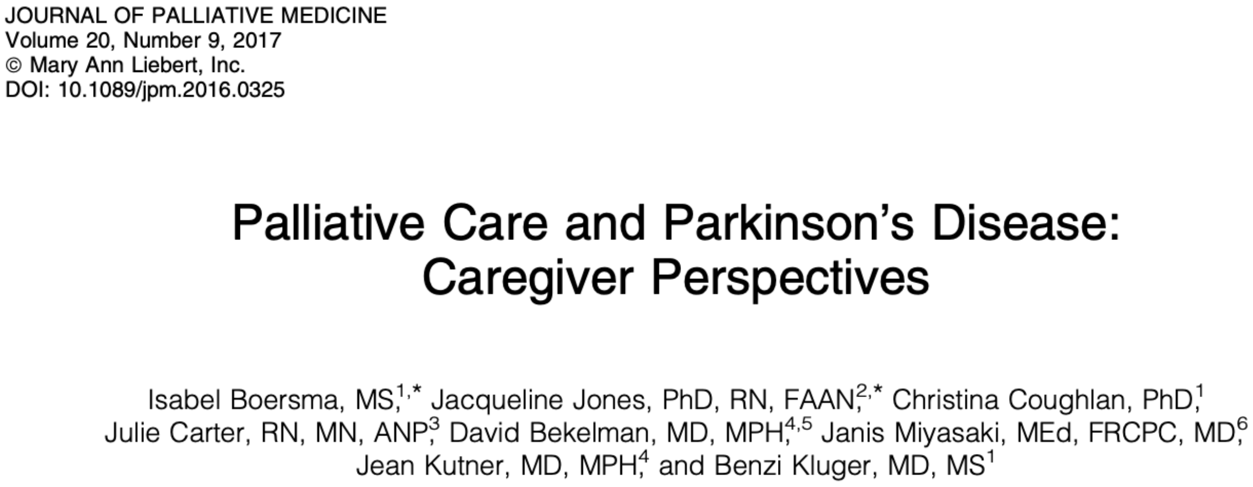
Neurology® Clinical Practice

Research

Parkinson disease patients' perspectives on palliative care needs

What are they telling us?

Isabel Boersma, MS; Jacqueline Jones, PhD, RN; Julie Carter, RN, MS, ANP; David Bekelman, MD, MPH; Janis Miyasaki, MEd, FRCPC, MD; Jean Kutner, MD, MSPH; Benzi Kluger, MD, MS



JOURNAL OF PALLIATIVE MEDICINE
Volume 20, Number 9, 2017
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2016.0325

Palliative Care and Parkinson's Disease: Caregiver Perspectives

Isabel Boersma, MS,[1,*] Jacqueline Jones, PhD, RN, FAAN,[2,*] Christina Coughlan, PhD,[1] Julie Carter, RN, MN, ANP,[3] David Bekelman, MD, MPH,[4,5] Janis Miyasaki, MEd, FRCPC, MD,[6] Jean Kutner, MD, MPH,[4] and Benzi Kluger, MD, MS[1]

II. The Evidence that Palliative Care Improves Outcomes

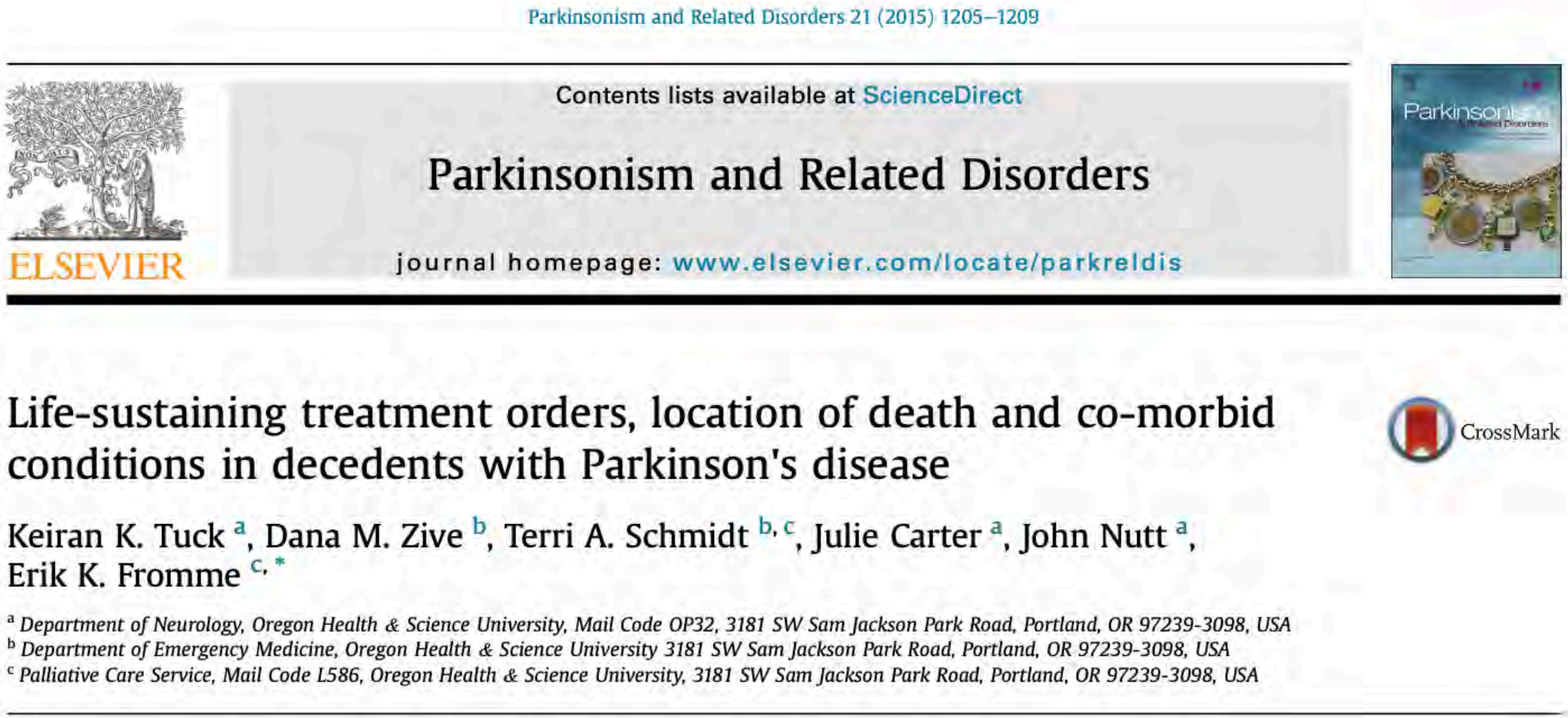
Individual Clinical Expertise

Patient's Values and Expectations

Improved Patient Outcomes

Best Available Clinical Evidence

Advance directives reduce hospital deaths.



Parkinsonism and Related Disorders 21 (2015) 1205–1209

Contents lists available at ScienceDirect

Parkinsonism and Related Disorders

journal homepage: www.elsevier.com/locate/parkreldis

ELSEVIER

Life-sustaining treatment orders, location of death and co-morbid conditions in decedents with Parkinson's disease

Keiran K. Tuck [a], Dana M. Zive [b], Terri A. Schmidt [b, c], Julie Carter [a], John Nutt [a], Erik K. Fromme [c, *]

[a] Department of Neurology, Oregon Health & Science University, Mail Code OP32, 3181 SW Sam Jackson Park Road, Portland, OR 97239-3098, USA
[b] Department of Emergency Medicine, Oregon Health & Science University 3181 SW Sam Jackson Park Road, Portland, OR 97239-3098, USA
[c] Palliative Care Service, Mail Code L586, Oregon Health & Science University, 3181 SW Sam Jackson Park Road, Portland, OR 97239-3098, USA

Interdisciplinary outpatient palliative care improves symptom control.

Parkinsonism and Related Disorders 18 (2012) S6–S9

Contents lists available at SciVerse ScienceDirect

Parkinsonism and Related Disorders

journal homepage: www.elsevier.com/locate/parkreldis

Palliative care for advanced Parkinson disease: An interdisciplinary clinic and new scale, the ESAS-PD

Janis M. Miyasaki*, J. Long, D. Mancini, E. Moro, S.H. Fox, A.E. Lang, C. Marras, R. Chen, A. Strafella, R. Arshinoff, R. Ghoche, J. Hui

The Palliative Program for Parkinson Disease and Related Disorders, The Morton and Gloria Shulman Movement Disorders Centre, Toronto Western Hospital, University of Toronto, Canada

A B S T R A C T

Home-based palliative care team can improve outcomes in advanced disease.

Research

Specialist palliative care improves the quality of life in advanced neurodegenerative disorders: NE-PAL, a pilot randomised controlled study

Simone Veronese,[1] G Gallo,[1] A Valle,[1] C Cugno,[1] A Chiò,[2] A Calvo,[2] P Cavalla,[2] M Zibetti,[2] C Rivoiro,[3] D J Oliver[4]

Original Article

Check for updates

Interdisciplinary palliative care for people with advanced Parkinson's disease: a view from the home

Jori E. Fleisher[1], Ellen C. Klostermann[1], Serena P. Hess[1], Jeanette Lee[1], Erica Myrick[1], Joshua Chodosh[2,3]

Addressing palliative care through nurse-led care managers.

ARTICLE CLASS OF EVIDENCE

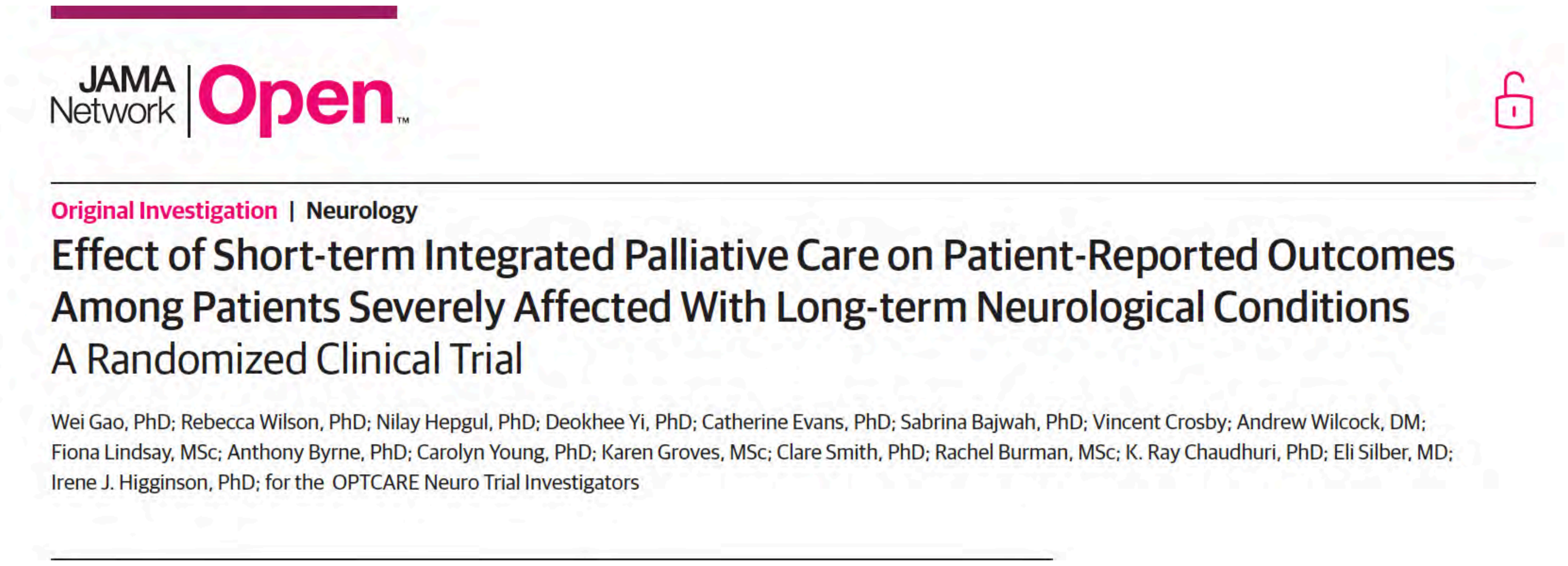
Randomized trial of care management to improve Parkinson disease care quality

Karen I. Connor, PhD, RN, MBA, Eric M. Cheng, MD, MS, Frances Barry, MA, Hilary C. Siebens, MD, Martin L. Lee, PhD, David A. Ganz, MD, PhD, Brian S. Mittman, PhD, Megan K. Connor, RN, MSN, MPH, Lisa K. Edwards, BA, Michael G. McGowan, MA, and Barbara G. Vickrey, MD, MPH

Correspondence
Dr. Connor
kiconnor@ucla.edu

Neurology® 2019;92:e1831-e1842. doi:10.1212/WNL.0000000000007324

There may be limitations to a consultative short-term integrated model.



JAMA Network Open

Original Investigation | Neurology

Effect of Short-term Integrated Palliative Care on Patient-Reported Outcomes Among Patients Severely Affected With Long-term Neurological Conditions

A Randomized Clinical Trial

Wei Gao, PhD; Rebecca Wilson, PhD; Nilay Hepgul, PhD; Deokhee Yi, PhD; Catherine Evans, PhD; Sabrina Bajwah, PhD; Vincent Crosby; Andrew Wilcock, DM; Fiona Lindsay, MSc; Anthony Byrne, PhD; Carolyn Young, PhD; Karen Groves, MSc; Clare Smith, PhD; Rachel Burman, MSc; K. Ray Chaudhuri, PhD; Eli Silber, MD; Irene J. Higginson, PhD; for the OPTCARE Neuro Trial Investigators

Integrated & embedded outpatient palliative care improves outcomes in persons with high needs.

Research

JAMA Neurology | **Original Investigation**

Comparison of Integrated Outpatient Palliative Care With Standard Care in Patients With Parkinson Disease and Related Disorders

A Randomized Clinical Trial

Benzi M. Kluger, MD; Janis Miyasaki, MD; Maya Katz, MD; Nicholas Galifianakis, MD; Kirk Hall, MBA; Steven Pantilat, MD; Ryan Khan, MDiv; Cari Friedman, LCSW; Wendy Cernik, BSN; Yuika Goto, MD; Judith Long, MS; Diane Fairclough, DrPH; Stefan Sillau, PhD; Jean S. Kutner, MD

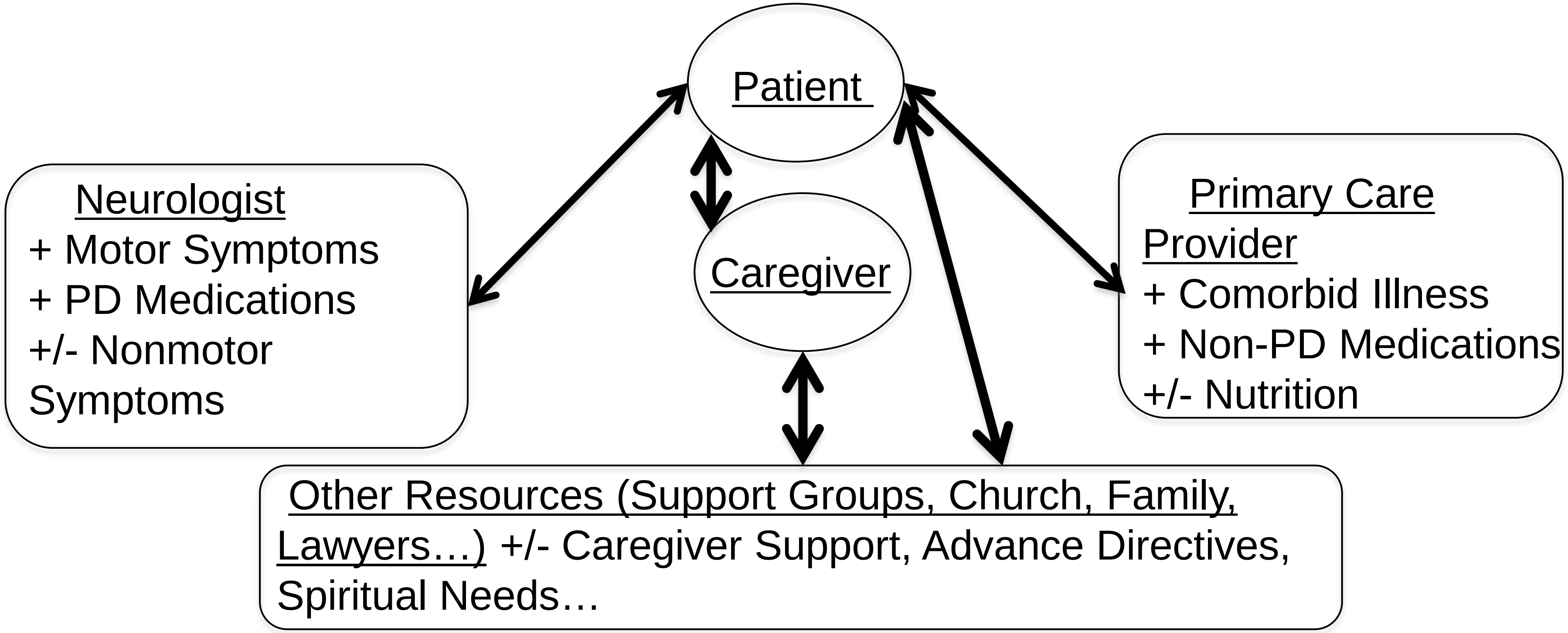
IMPORTANCE Parkinson disease and related disorders (PDRD) have consequences for quality of life (QoL) and are the 14th leading cause of death in the United States. Despite growing interest in palliative care (PC) for persons with PDRD, few studies are available supporting its effectiveness.

OBJECTIVE To determine if outpatient PC is associated with improvements in patient-centered outcomes compared with standard care among patients with PDRD and their caregivers.

+ Editorial

+ Supplemental content

Current Chronic Care Model for Parkinson's Disease



Patient

Neurologist
+ Motor Symptoms
+ PD Medications
+/- Nonmotor Symptoms

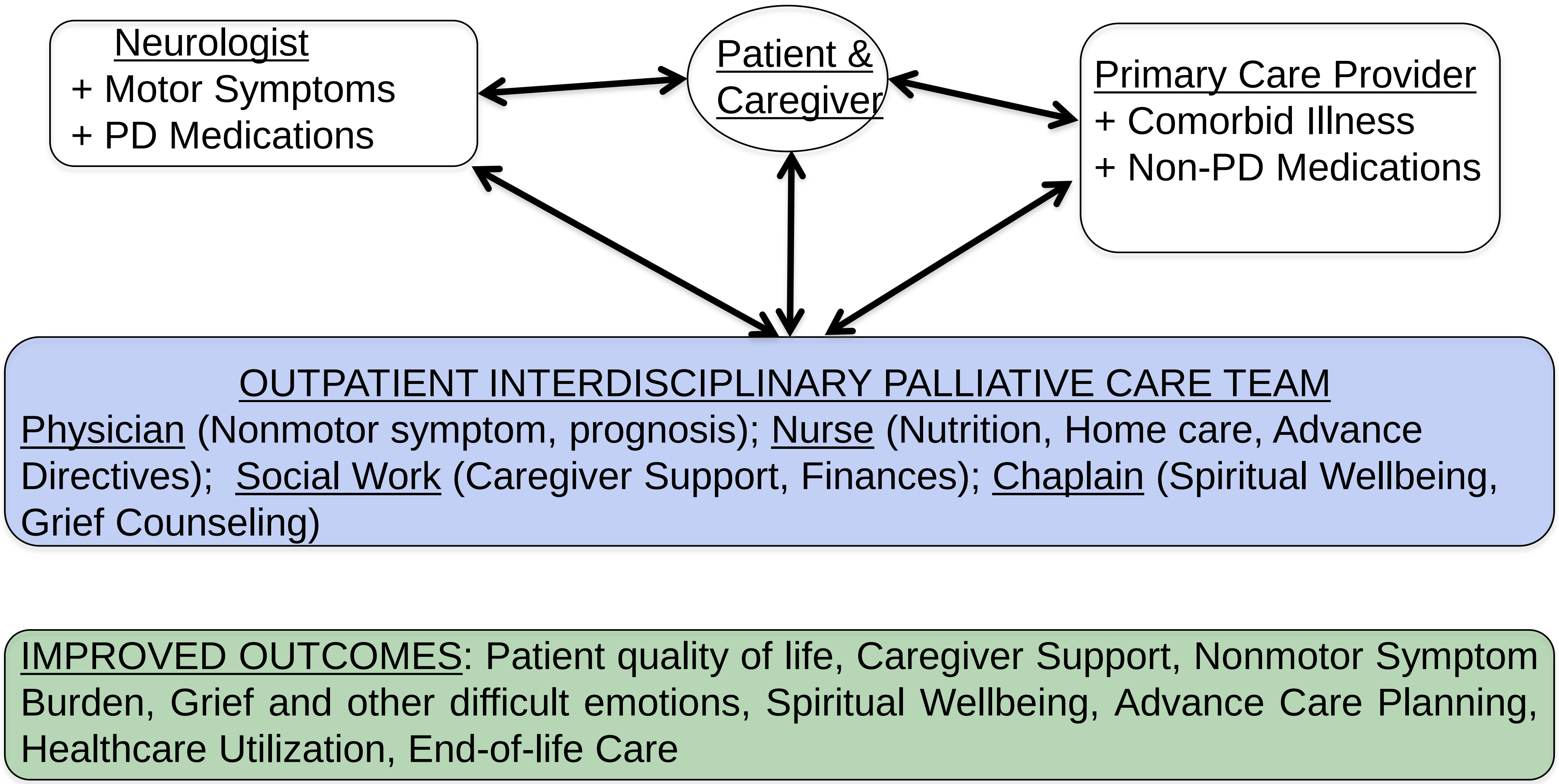
Caregiver

Primary Care Provider
+ Comorbid Illness
+ Non-PD Medications
+/- Nutrition

Other Resources (Support Groups, Church, Family, Lawyers…) +/- Caregiver Support, Advance Directives, Spiritual Needs…

TYPICAL OUTCOMES: GOOD: Motor Symptom Control;
FAIR: Nonmotor Symptom Treatment
POOR: Advance Care Planning, EOL Care, Caregiver Support, Psychosocial & Spiritual Needs

Outpatient Team-based Palliative Care Model for Parkinson's Disease



Neurologist
+ Motor Symptoms
+ PD Medications

Patient & Caregiver

Primary Care Provider
+ Comorbid Illness
+ Non-PD Medications

OUTPATIENT INTERDISCIPLINARY PALLIATIVE CARE TEAM
Physician (Nonmotor symptom, prognosis); Nurse (Nutrition, Home care, Advance Directives); Social Work (Caregiver Support, Finances); Chaplain (Spiritual Wellbeing, Grief Counseling)

IMPROVED OUTCOMES: Patient quality of life, Caregiver Support, Nonmotor Symptom Burden, Grief and other difficult emotions, Spiritual Wellbeing, Advance Care Planning, Healthcare Utilization, End-of-life Care

Comparative Effectiveness Study Results

- Improved patient quality of life
  - Improved symptom control, grief, advance care planning and motor symptoms
- Improved caregiver burden
  - Improved anxiety and spiritual wellbeing
- Qualitative Results:
  - Improved sense of guidance, support and clarity
  - Difficult conversations led to improved engagement with life and hope

Augmented primary palliative care may improve some outcomes in community settings.

JAMA Neurology | Original Investigation

Patient and Family Outcomes of Community Neurologist Palliative Education and Telehealth Support in Parkinson Disease

Benzi M. Kluger, MD; Maya Katz, MD; Nicholas B. Galifianakis, MD; Steven Z. Pantilat, MD; Joshua M. Hauser, MD; Ryan Khan, MDiv; Cari Friedman, LCSW; Christina L. Vaughan, MD; Yuika Goto, MD; S. Judith Long, MS; Christine S. Martin, BS; Megan Dini, MA; R. Brett McQueen, PhD; Laura Palmer, BS; Diane Fairclough, DrPH; Lauren C. Seeberger, MD; Stefan H. Sillau, PhD; Jean S. Kutner, MD, MSPH

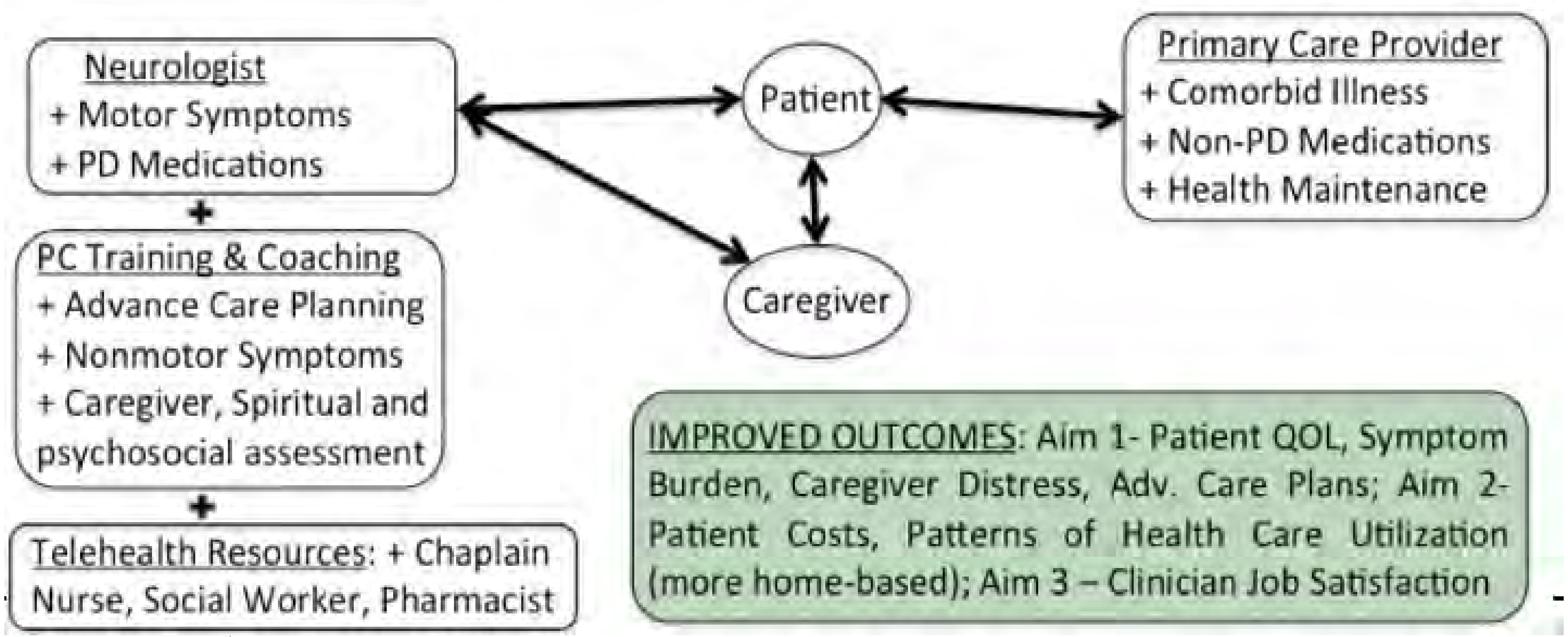
Supplemental content

IMPORTANCE Parkinson disease and related disorders (PDRD) are the fastest growing neurodegenerative illness in terms of prevalence and mortality. As evidence builds to support palliative care (PC) for PDRD, studies are needed to guide implementation.

OBJECTIVE To determine whether PC training for neurologists and remote access to a PC team improves outcomes in patients with PDRD in community settings.

Implementation:
Community-Based Palliative Care

Usual Care *plus* Community Primary Palliative Neurology
***augmented* by a Multidisciplinary Palliative Care Clinic (INTERVENTION)**



Neurologist
+ Motor Symptoms
+ PD Medications

+

PC Training & Coaching
+ Advance Care Planning
+ Nonmotor Symptoms
+ Caregiver, Spiritual and psychosocial assessment

+

Telehealth Resources: + Chaplain Nurse, Social Worker, Pharmacist

Primary Care Provider
+ Comorbid Illness
+ Non-PD Medications
+ Health Maintenance

IMPROVED OUTCOMES: Aim 1- Patient QOL, Symptom Burden, Caregiver Distress, Adv. Care Plans; Aim 2- Patient Costs, Patterns of Health Care Utilization (more home-based); Aim 3 – Clinician Job Satisfaction

Pragmatic Trial Study Results

- Improved patient quality of life and advance care planning
- No impact on caregiver burden or other outcomes
- Opportunities for improvement:
  - Ongoing coaching
  - More intensive remote team-based support

III. Changing Culture and Challenging Systems to Care for People and Families

VIEWPOINT

Palliative Care and Parkinson's Disease: Time to Move Beyond Cancer

Benzi M. Kluger, MD, MS,[1*] Rachel Dolhun, MD,[2] Malenna Sumrall, PhD,[3] Kirk Hall, MBA,[3] and Michael S. Okun, MD[4,5]

Dissemination: Centers of Excellence

Parkinson's Foundation Launches Palliative Care Program Across U.S. Centers of Excellence

Funds awarded by the Patient-Centered Outcomes Research Institute

MIAMI & NEW YORK – August 11, 2020 – The Parkinson's Foundation is partnering with the University of Rochester Medical Center, a Parkinson's Foundation Center of

Operational Definition of Palliative Care

THE FIVE PILLARS

1. Systematic assessment and management of nonmotor symptoms
2. Systematic assessment and management of spiritual and psychosocial issues (demoralization, grief)
3. Systematic assessment and support for care partners
4. Annual advance care planning conversations
5. Timely referral to hospice or specialist palliative care

Core Principles

→ All people living with PD deserve a palliative care approach.

→ Some people living with PD need specialist palliative care.

→ The palliative approach must be supported by specialists, generalists and community organizations.

→ We cannot be proactive if we are not systemat

→ We must make the lives of clinicians better if th work will be sustainable.

PCORI Implementation Grant Aims (EPIS)

0. Understand how COVID and telemedicine has impacted PD patients, care partners, and clinicians.
1. **Explore** resources/context and **Prepare** implementation plans for COE
2. **Implement** palliative care and adapt to local COE context
3. **Sustainment** plans for palliative care within COE and Parkinson's Foundation

Aim1: Healthcare Provider Interviews

OPPORTUNITIES

- Improve comprehensive care
- Network with other COE to share best practices
- Enhance provider effectiveness and satisfaction

BARRIERS/CONCERNS

- Time
- Workflow
- Availability of key services

Aim 1: Patient & Caregiver Perspectives

- Patients and families desired more comprehensive supportive services AND had confusion about the role of palliative care
- Patients at COEs reported higher rates of nonmotor symptom management, care partner support and quality of communication
- There were no differences between COE and non-COE patients in advance care planning, spiritual care, or PC referrals
- Rates of several critical PC outcomes were low (<40%) including pain management, emotional support, carepartner support, and anticipatory guidance

Aim 2: The Implementation Intervention

- Select and train a COE palliative care champion
- Train all relevant members of COE in primary palliative care
- Provide ongoing coaching for palliative care champion to lead QI projects
- Develop working groups within Parkinson’s Foundation to support palliative care and palliative champions at COEs
- Create palliative care resources at Parkinson’s Foundation for patients and clinicians
- Develop infrastructure (data collection, research grants) within Parkinson’s Foundation to support palliative care

Aim 2: Current Status of Implementation

- 33 of 34 US COEs have launched palliative care programs
- Over 500 healthcare providers and staff have begun training and several COE have completed training
- Over 100 coaching calls hosted to date
- Many COEs have made visible progress on structure (e.g., new chaplain), process (e.g., use of templates or scales) and outcomes (e.g., increased hospice referrals)
- We have developed tools to support COE in the work of palliative care implementation

Emerging Keys to Success

1: Behavior change rarely happens after a lecture.

- PC Educational initiatives must address not only knowledge, but skills, comfort and attitudes.
- Physicians do not want to be told what to do AND do not want to reinvent the wheel.
- Be prepared to follow up with education after/as healthcare providers are getting into implementation.
- Education can be facilitated by engaging local champion(s).

2: There is an art & science to program building.

- Structures that support PC (and other care initiatives) are not always supported by institutions.
- Successful COEs have found ways to work within their department and institution to grow and sustain team-based care.
- This typically includes relationships with administrators, creating business plans, and philanthropy.
- This can include partnerships outside of one's department (e.g., palliative medicine, chaplains, community resources).

3: Teamwork, leadership and culture matter.

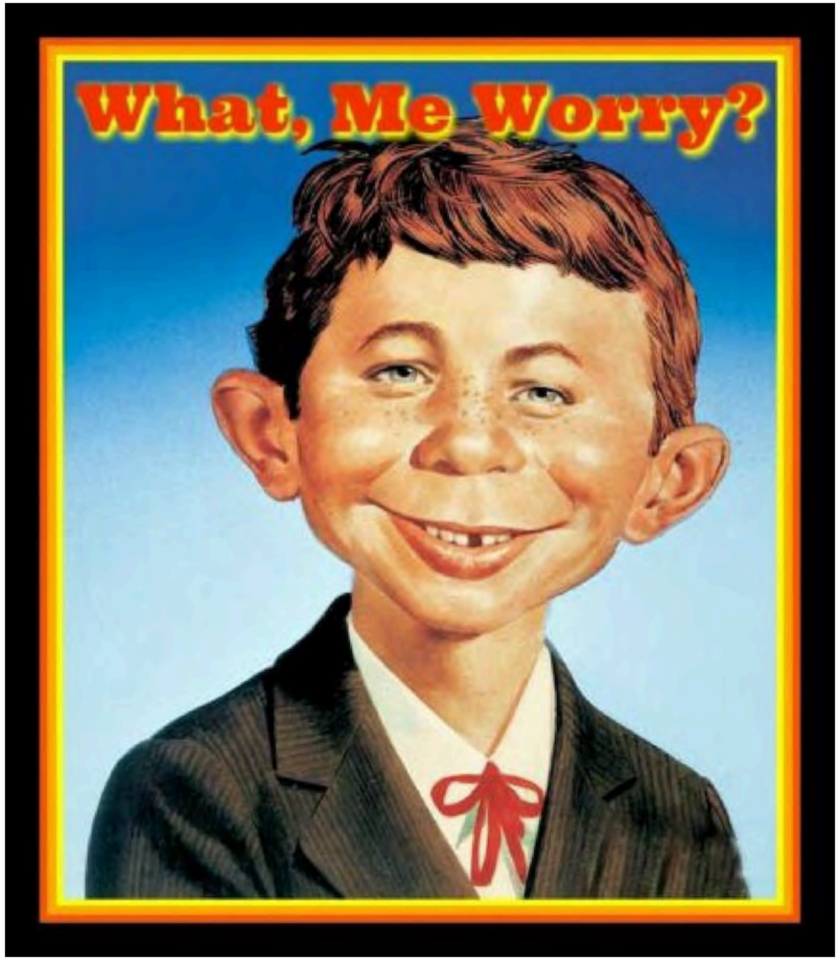
- Processes that support PC depend on excellent teamwork, leadership and culture.
- Successful Centers find motivation around shared mission and vision for outstanding care across providers.
- Outstanding teamwork can enhance problem solving, consensus building, and distribute work across providers.
- Team culture can also mitigate (or contribute to) burnout.

4: It takes a village to provide person and family-centered care.

- Important outcomes of palliative care fall outside of the traditional biomedical model.
- Social, emotional, and spiritual support for people living with PD and their families can be integrated into care delivery.
- Successful COEs have found creative ways to meet these needs and support the providers (and volunteers) with expertise in these domains.

IV. Lessons from Growing Two Neuropalliative Care Programs

“The problem with learning from **experience** is that you get the test before the lesson.”
- Alfred E. Neumann



Lesson 1: Listen to the real experts in serious illness.

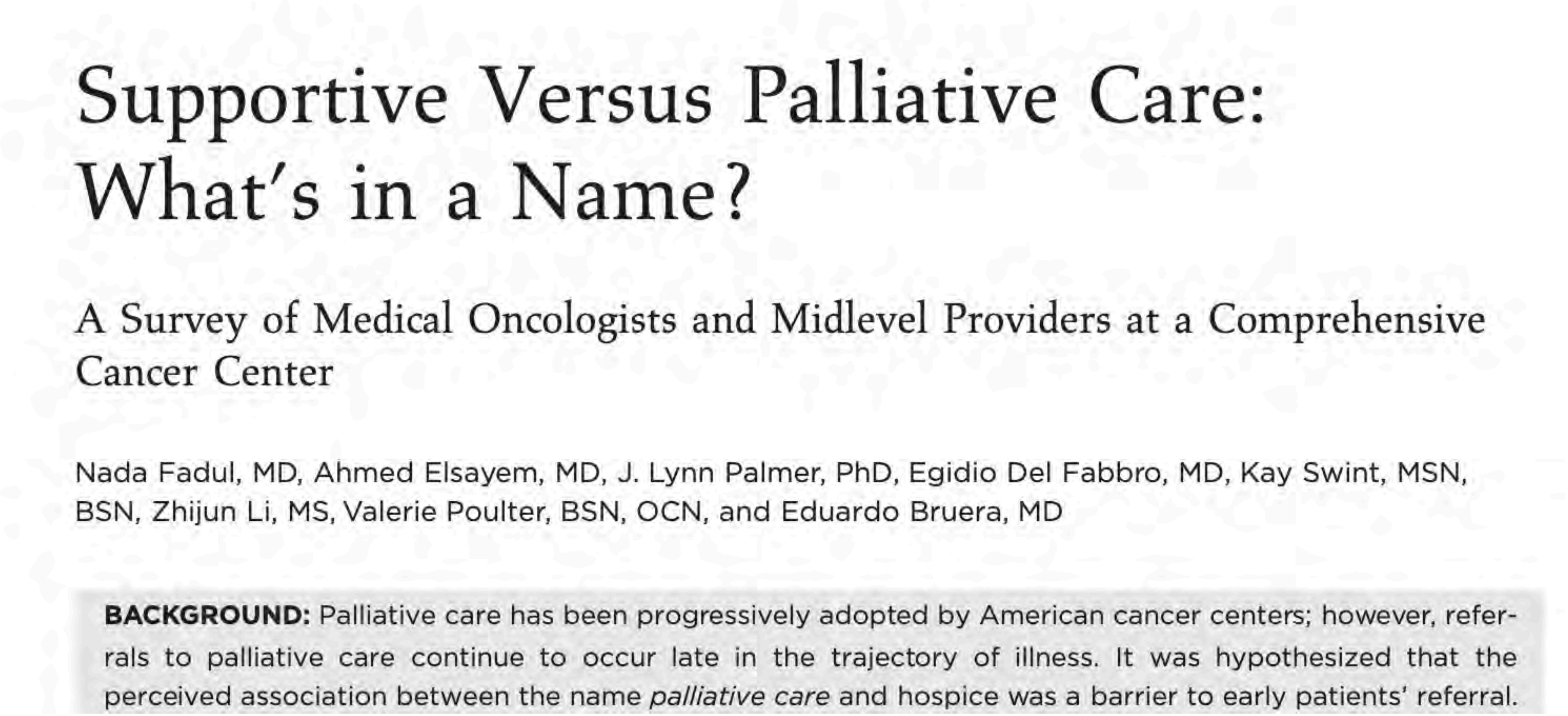
Lesson 2: We all must face sickness, old age and death.

Lesson 3: Find your people.

Lesson 4: Just do it.

ASK FOR
FORGIVENESS
NOT
PERMISSION

Lesson 5: Words Matter



Supportive Versus Palliative Care: What's in a Name?

A Survey of Medical Oncologists and Midlevel Providers at a Comprehensive Cancer Center

Nada Fadul, MD, Ahmed Elsayem, MD, J. Lynn Palmer, PhD, Egidio Del Fabbro, MD, Kay Swint, MSN, BSN, Zhijun Li, MS, Valerie Poulter, BSN, OCN, and Eduardo Bruera, MD

BACKGROUND: Palliative care has been progressively adopted by American cancer centers; however, referrals to palliative care continue to occur late in the trajectory of illness. It was hypothesized that the perceived association between the name *palliative care* and hospice was a barrier to early patients' referral.

Lesson 6: It takes time and effort to create a high-functioning team.

Original Article

Implementation issues relevant to outpatient neurology palliative care

Benzi M. Kluger[1], Michael J. Persenaire[2], Samantha K. Holden[1], Laura T. Palmer[1], Hannah M. Redwine[1], Julie Berk[1], C. Alan Anderson[1,3], Christopher M. Filley[1,3], Jean Kutner[4], Janis Miyasaki[5], Julie Carter[6]

Lesson 7: Be Systematic

ARTICLE IN PRESS

Vol. 00 No. 00 xxx 2022 Journal of Pain and Symptom Managemen

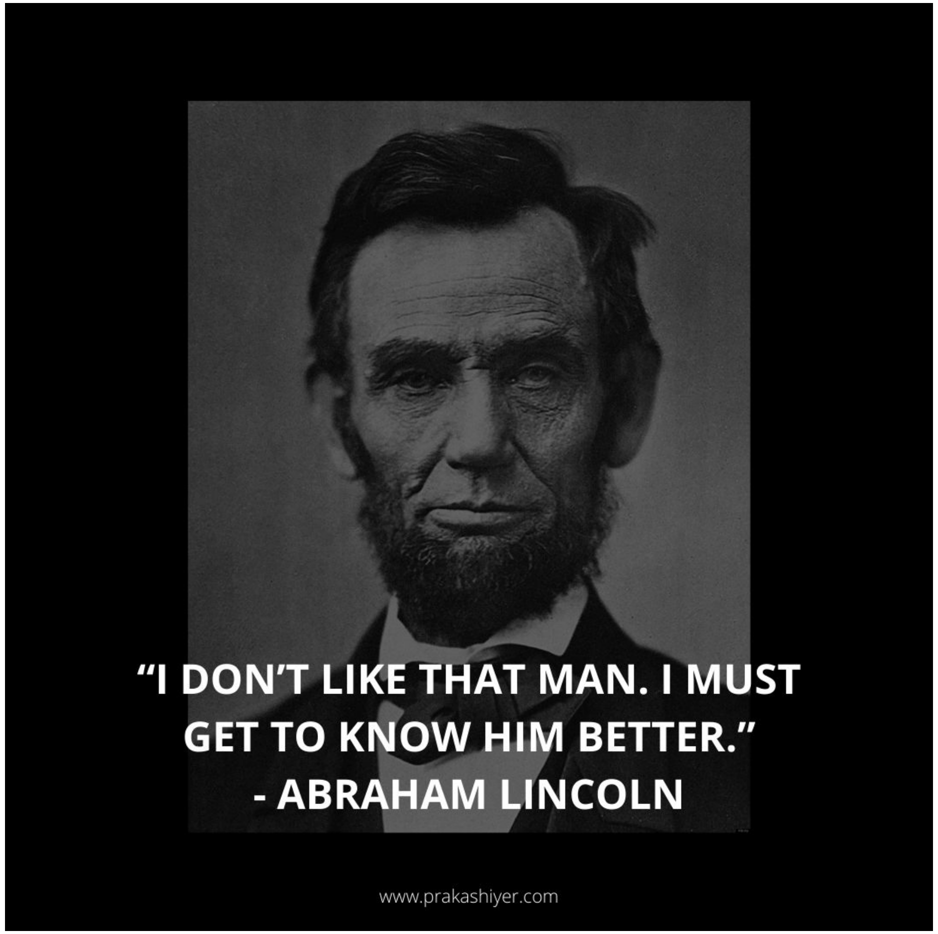
Original Article

What's in the Sauce? The Specific Benefits of Palliative Care for Parkinson's Disease

Meredith Bock, Maya Katz, Stefan Sillau, Kwame Adjepong, Kristine Yaffe, Roman Ayele, Zachary A. Macchi, Steven Pantilat, Janis M. Miyasaki, and Benzi Kluger

Department of Neurology, University of California, San Francisco, California, USA; Department of Neurology, Stanford University, Califor USA; Department of Neurology, University of Colorado Anschutz Medical Campus, Colorado, USA; Department of Psychiatry, University of California, San Francisco, California, USA; Department of Epidemiology, University of California, San Francisco, California, USA; San Francisco Veterans Affairs Medical Center, San Francisco, California, USA; Department of Health Systems, Management and Policy, Unive of Colorado Anschutz Medical Campus, Aurora, Colorado; Department of Medicine, Division of Palliative Medicine at University of Califor San Francisco California, USA; Department of Medicine, Division of Neurology, University of Alberta, Edmonton, Canada; Departments of Neurology and Medicine, Division of Palliative Care, University of Rochester, Rochester, New Year, USA

Lesson 8: Practice palliative care on your colleagues & administrators.



"I DON'T LIKE THAT MAN. I MUST GET TO KNOW HIM BETTER."
- ABRAHAM LINCOLN

www.prakashiyer.com

Lesson 9: Develop services not divisions.

Lesson 10: Models of palliative care are complementary, not competing.

npj | Parkinson's Disease

www.nature.com/npjparkd

COMMENT OPEN

Palliative care for Parkinson's disease: suggestions from a council of patient and carepartners

Kirk Hall[1], Malenna Sumrall[2], Gil Thelen[3] and Benzi M. Kluger[4] on behalf of the 2015 Parkinson's Disease Foundation sponsored "Palliative Care and Parkinson's Disease" Patient Advisory Council

Review Article

Palliative care and Parkinson's disease: outpatient needs and models of care over the disease trajectory

Christopher G. Tarolli[1,2], Robert G. Holloway[1]

Three Challenges for the Field

"What if we don't change at all ...
and something magical just happens?"

Equity

Comment & Response

September 8, 2020

Palliative Care in Parkinson Disease—Is It Beneficial for All?—Reply

Benzi M. Kluger, MD, MS[1]; Steven Pantilat, MD[2]; Janis Miyasaki, MD, MEd[3]

» Author Affiliations | Article Information

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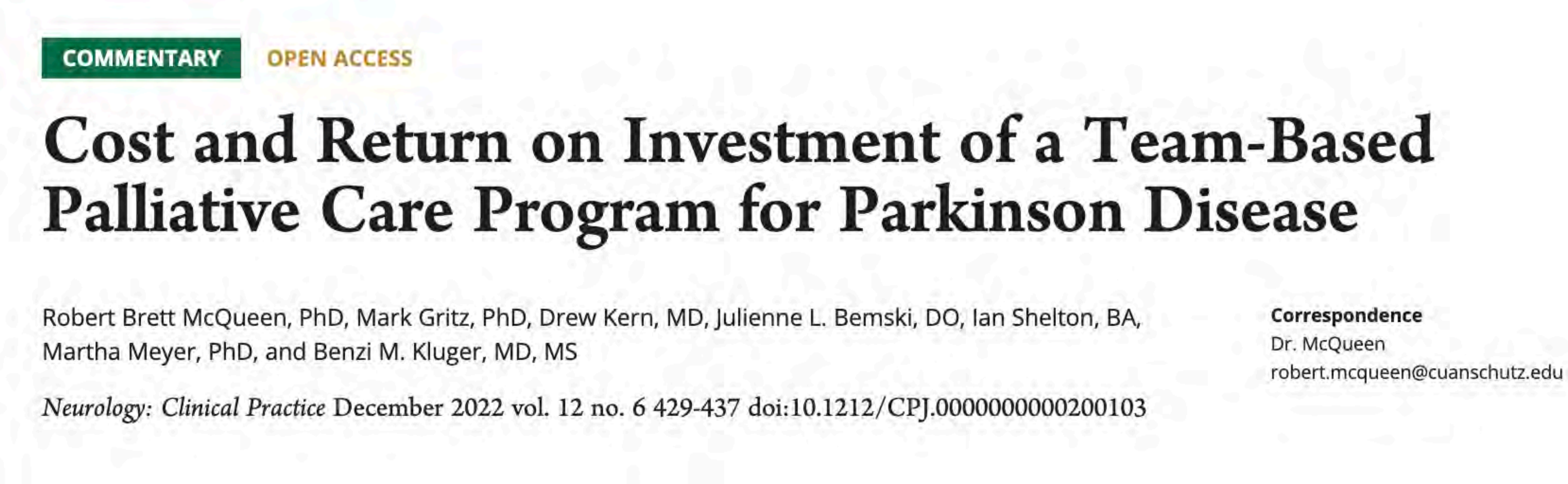
Business Models



COMMENTARY OPEN ACCESS

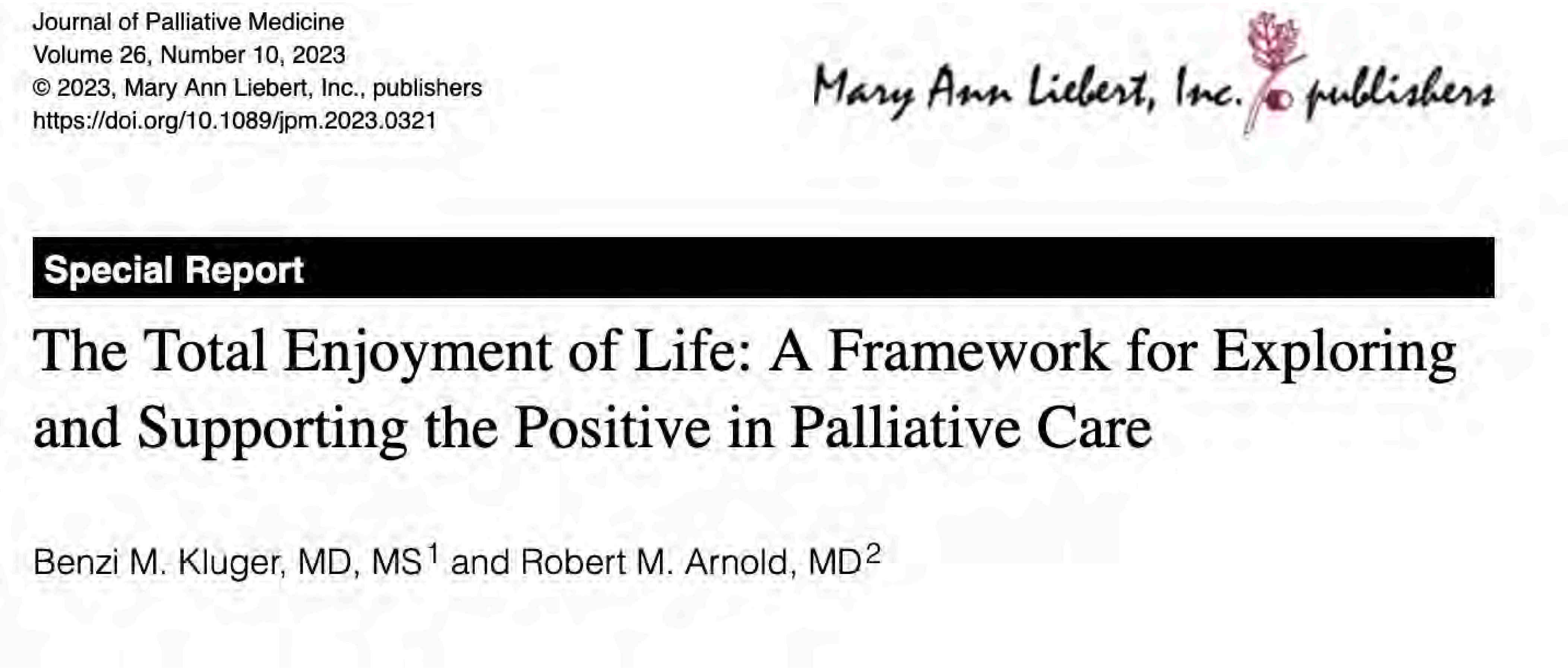
Cost and Return on Investment of a Team-Based Palliative Care Program for Parkinson Disease

Robert Brett McQueen, PhD, Mark Gritz, PhD, Drew Kern, MD, Julienne L. Bemski, DO, Ian Shelton, BA, Martha Meyer, PhD, and Benzi M. Kluger, MD, MS

Neurology: Clinical Practice December 2022 vol. 12 no. 6 429-437 doi:10.1212/CPJ.0000000000200103

Correspondence
Dr. McQueen
robert.mcqueen@cuanschutz.edu

Capturing (and sharing) Positive Outcomes



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Special Report

The Total Enjoyment of Life: A Framework for Exploring and Supporting the Positive in Palliative Care

Benzi M. Kluger, MD, MS[1] and Robert M. Arnold, MD[2]

If you are moved, join the movement.

International Neuropalliative Care Society

4th Annual Meeting: *Fall 2024*

International Neuropalliative Care Society (INPCS)

Our Mission: To raise standards of care for all people affected by neurologic illness.

Our Vision: A world where high quality, person-centered supportive care for persons affected by neurologic illness is the rule rather than the exception.

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Steve Pantilat
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Christine Ritchie
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Judy Long

Jean Kutner
David Bekelman
Janis Miyasaki
Julie Carter
Jacquelyn Jones
Steve Ringel
Brett Mcqueen
Laura Palmer
Holly Prigerson
Maya Katz
Stan Dempsey

Sue Ouellette
Nick Galifianakis
Wendy Cernik
MK Christian
Cynthia McRae
Ryan Khan
Cari Friedman
Candace Ellman
Brennan Summers
Patients and families from our palliative care clinics

References

Patient and Family Outcomes of Community Neurologist Palliative Education and Telehealth Support in Parkinson Disease. Kluger BM, Katz M, Galifianakis NB, Pantilat SZ, Hauser JM, Khan R, Friedman C, Vaughan CL, Goto Y, Long SJ, Martin CS, Dini M, McQueen RB, Palmer L, Fairclough D, Seeberger LC, Sillau SH, Kutner JS. JAMA Neurol. 2023 Nov 13:e234260. doi: 10.1001/jamaneurol.2023.4260.

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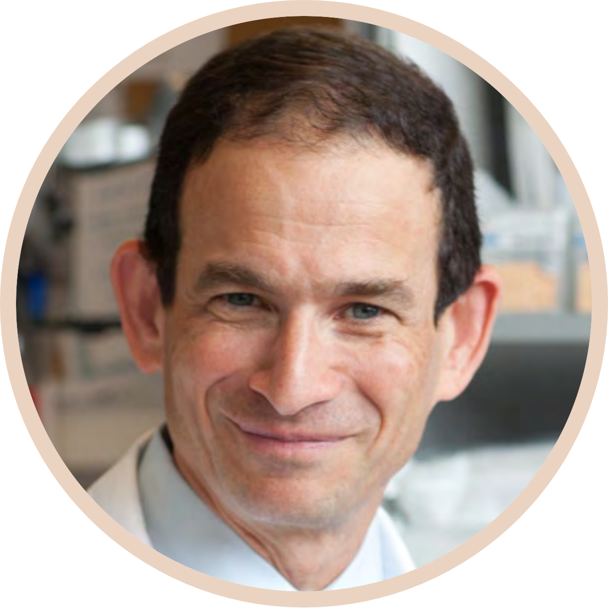
Thank You!

- Presenter(s) contact information:
  - Benzi Kluger, MD, MS
  - University of Rochester
  - benzi_kluger@urmc.rochester.edu
  - www.benzikluger.com

The State of Our Field

Fred Friedman

Registry Manager
Palliative Care Quality Collaborative



Steve Pantilat
MD, MHM, FACP, FAAHPM
Kates-Burnard and Hellman Distinguished Professor in Palliative Care and the Chief of the Division of Palliative Medicine, University of California San Francisco

In this overview of the structural and operational data of palliative care programs collected during the 2022 PCQC Annual Program Survey, we will review how palliative care programs operate across the country. We will also review staffing models of palliative care teams and identify how the PCQC Registry can be utilized to identify areas of growth and opportunity for the field.

The State of Our Field

An overview of 2022 PCQC structural, operational, and clinical data of palliative care programs identifying areas of growth and opportunity for our field.

Fred Friedman, Registry Manager, Palliative Care Quality Collaborative
Steve Pantilat, MD, MHM, FACP, FAAHPM, Kates-Burnard and Hellman Distinguished Professor in Palliative Care and the Chief of the Division of Palliative Medicine, University of California San Francisco

QMC Quality Matters Conference
December 14-15, 2023

Disclosure

Neither Steve Pantilat nor Fred Friedman have financial relationships to disclose.

Learning Outcomes

Upon completing this session, participants will be able to:

1. Characterize palliative care program operations across setting types
2. Describe staffing of palliative care teams
3. Describe how the PCQC Registry can identify areas of growth and opportunity for our field

Palliative Care is Good for Patients & Families

Could it be better?

Could it be more effective?

Could it be more efficient?

Could it be more equitable?

Temel et al. *NEJM* 2010;363:733-42
Kavalieratos et al. *JAMA* 2016;316:2104-14
Kluger et al. *JAMA Neurol* 2020;77:551-60

Pantilat *Arch Int Med* 2012;172:1172-3
El-Jawahri et al. *JAMA* 2016;316:2094-2103
Rogers et al. *JACC* 2017;70:331-41

PCQC Data

- All settings of care
- Program level data PROGRAM
  - Any (every!) PC team can submit
  - Summary of annual structure and process data from the previous calendar year
  - In 2023, data from 2022 was collected
- Patient level data PATIENT
  - Collected in real time by PCQC Premium members
  - Patient level outcomes and process of care

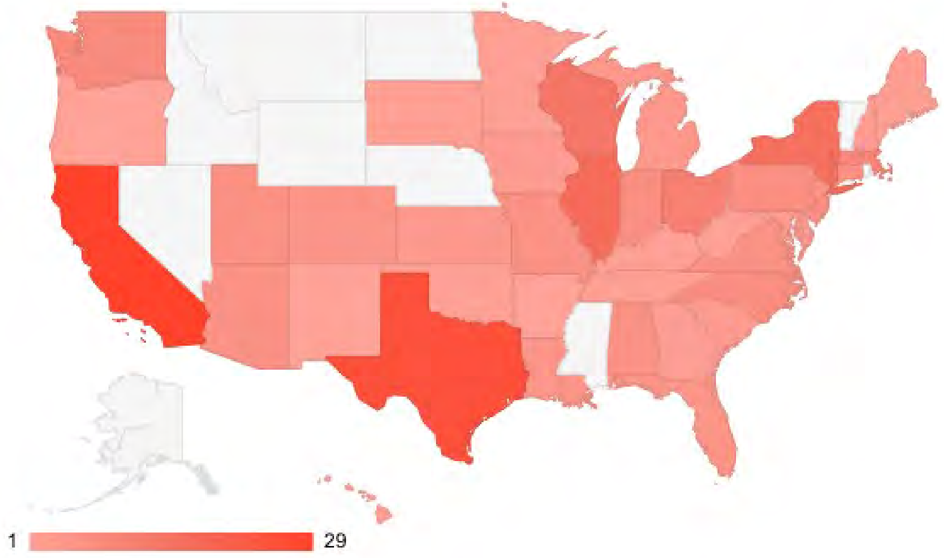
Where does PCQC data come from?

Us

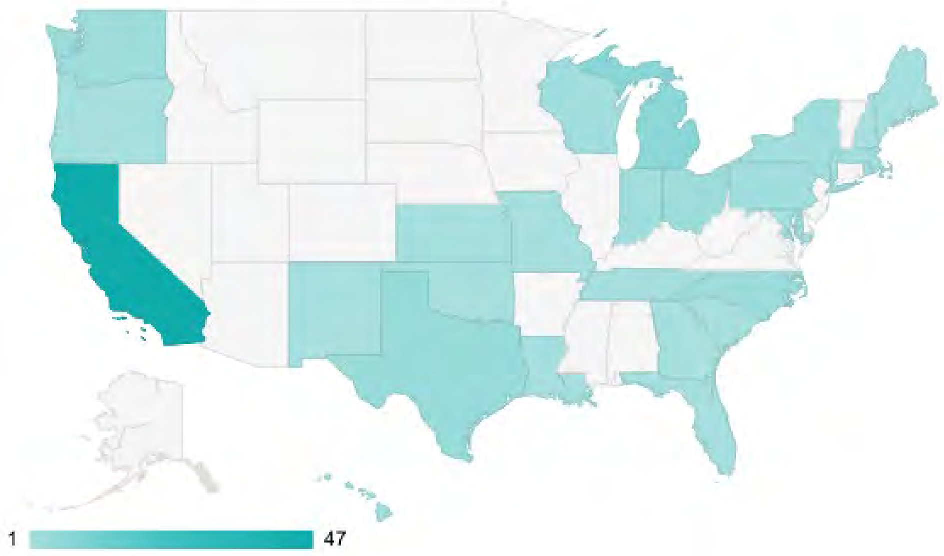
2022 PCQC Annual Program Survey
253 unique programs

Premium PCQC Registry
93 unique programs

PROGRAM



PATIENT



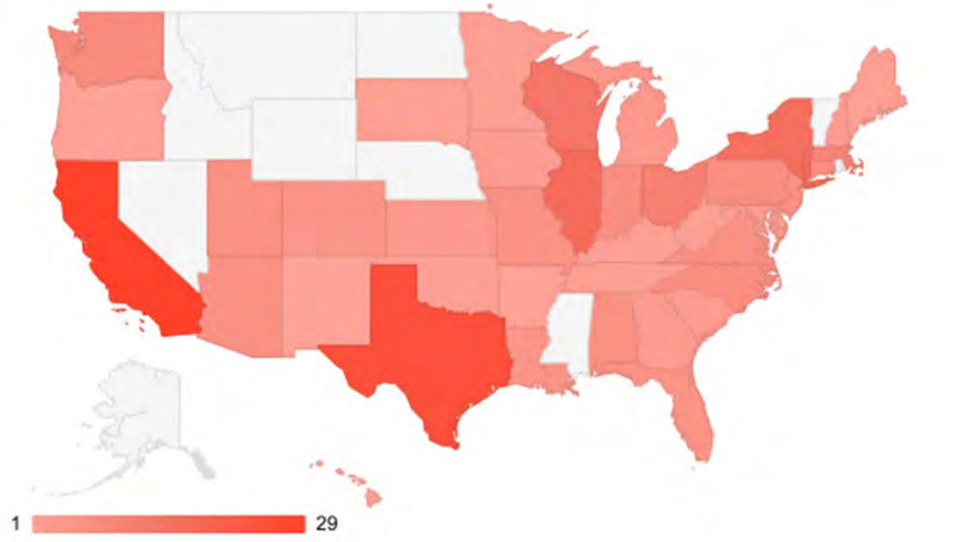
PCQC Annual Program Survey:
253 Unique Programs

PROGRAM

- Hospital setting: 222 programs
  - 275 hospital sites
  - 31 Pediatric programs

- Community setting: 99 programs
  - 55 Clinic/Office sites
  - 40 Home sites
  - 12 Long Term Care sites
  - 7 Pediatric programs

- Hospital *and* Community: 53 programs

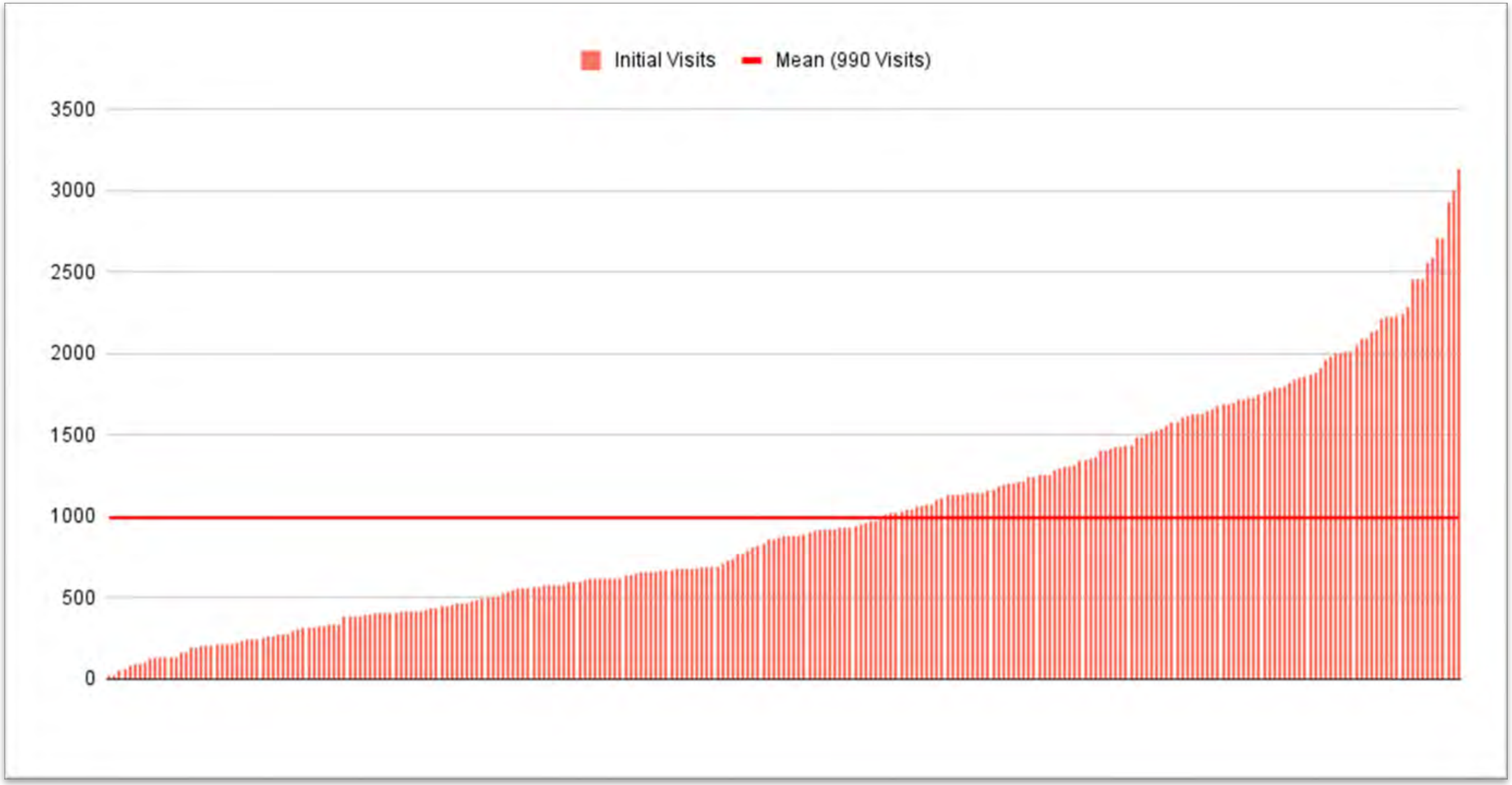


Hospital Setting

Annual Visits: Hospital

PROGRAM

N = 265 Programs

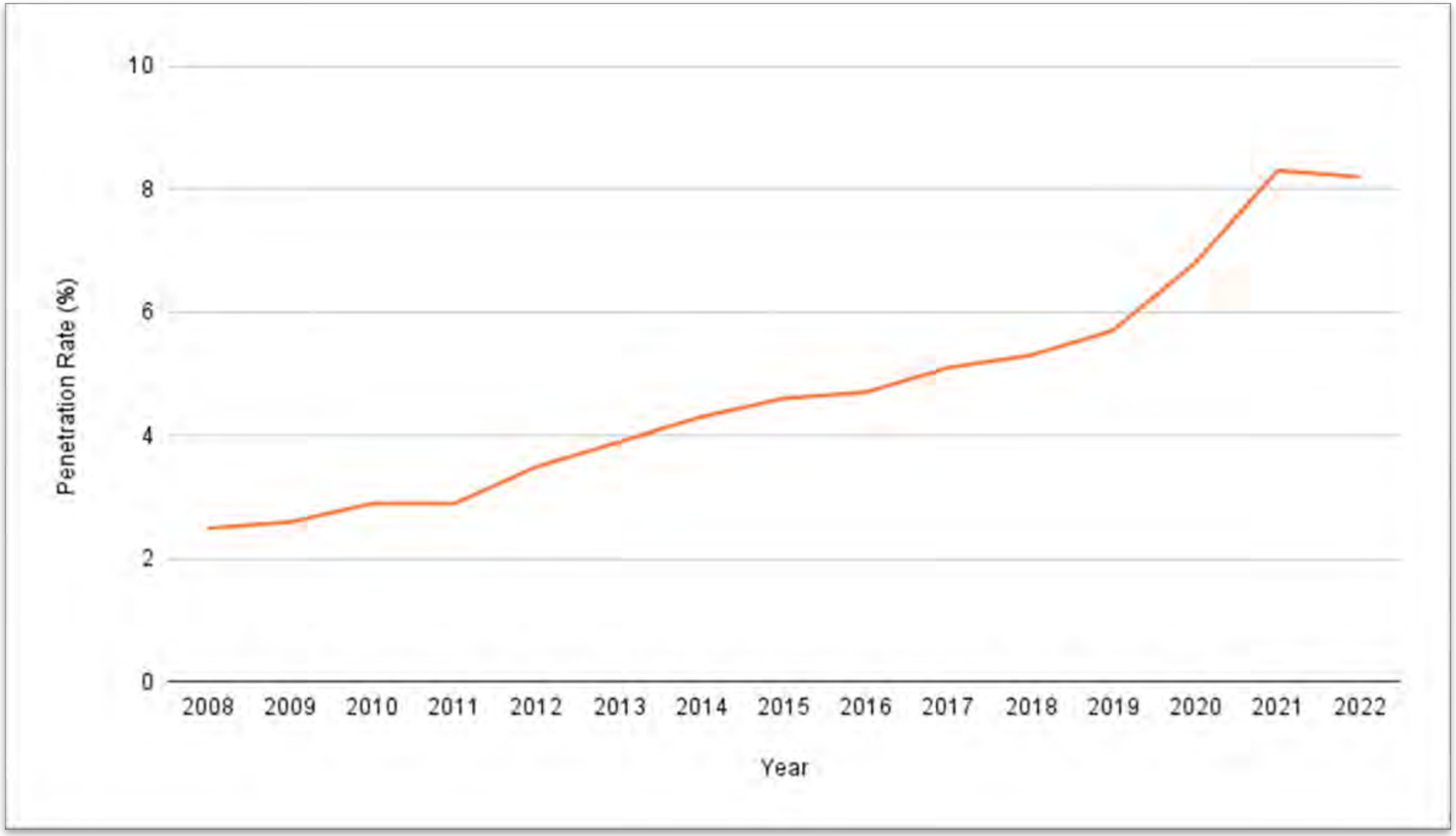


Subsequent Visits per Patient (N = 190 Programs)	
Median	2.1
Mean	2.5
Range	<1 - 18

Penetration Rate: Hospital

PROGRAM

N = 1,216 Sites



Staffing – Hospital

PROGRAM

Discipline	% with Discipline	Median FTE	Mean FTE	% of Programs w/ Certified Staff
Advanced Practice Registered Nurse (NP, CNS, CRNA, CNM)	83%	1.6	1.8	46%
Registered Nurse	43%	0	0.6	21%
Social Worker	65%	1	0.9	21%
Chaplain/Spiritual Care	46%	0	0.4	8%
Physician	87%	1	1.6	71%
Physician Assistant	12%	0	0.2	N/A
Pharmacist	11%	0	0.1	N/A
Psychologist	5%	0	<0.1	N/A
Administrator/Program Manager	64%	0.1	0.3	N/A
Admin Support or Data Analyst	42%	0	0.3	N/A

N = 263 Programs

Workload: Hospital

PROGRAM

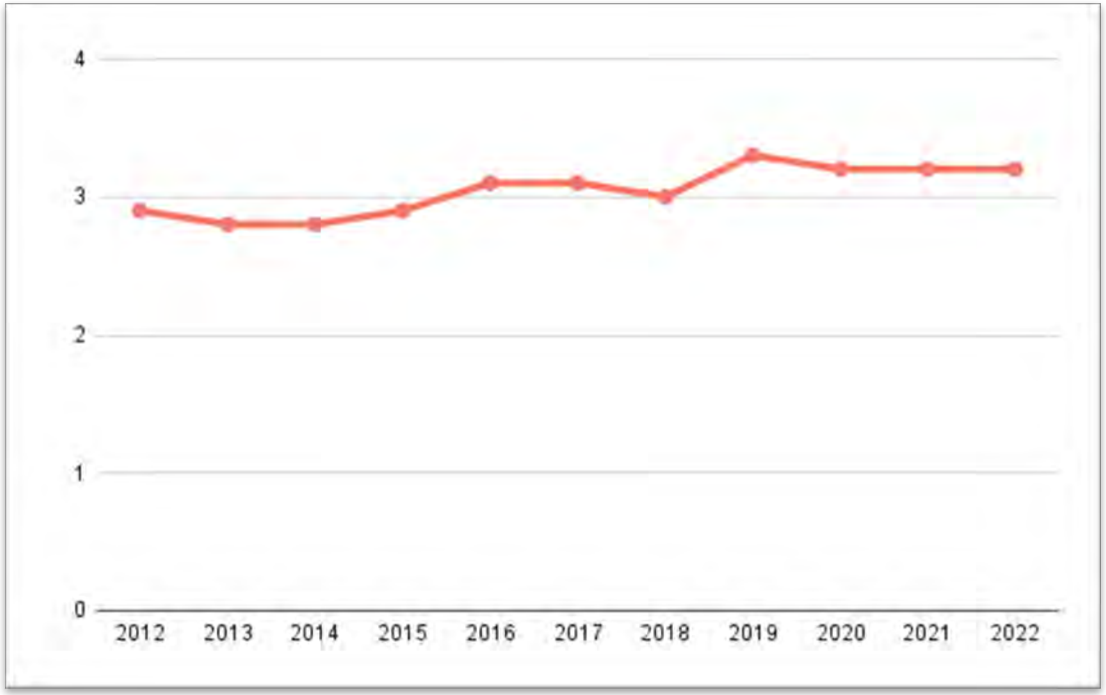
Initial Visits/Total FTE (by hospital size)		
1-100 Beds N = 24	Median	103
	Mean	122
	Range	16 – 376
101-300 Beds N = 108	Median	169
	Mean	212
	Range	29 – 836
301+ Beds N = 119	Median	161
	Mean	188
	Range	8 – 836

Initial Visits/Billing Provider FTE (by hospital size)		
1-100 Beds N = 24	Median	235
	Mean	238
	Range	32 – 619
101-300 Beds N = 103	Median	330
	Mean	373
	Range	60 – 1843
301+ Beds N = 118	Median	296
	Mean	342
	Range	20 – 2113

Average Visits per Patient: Hospital

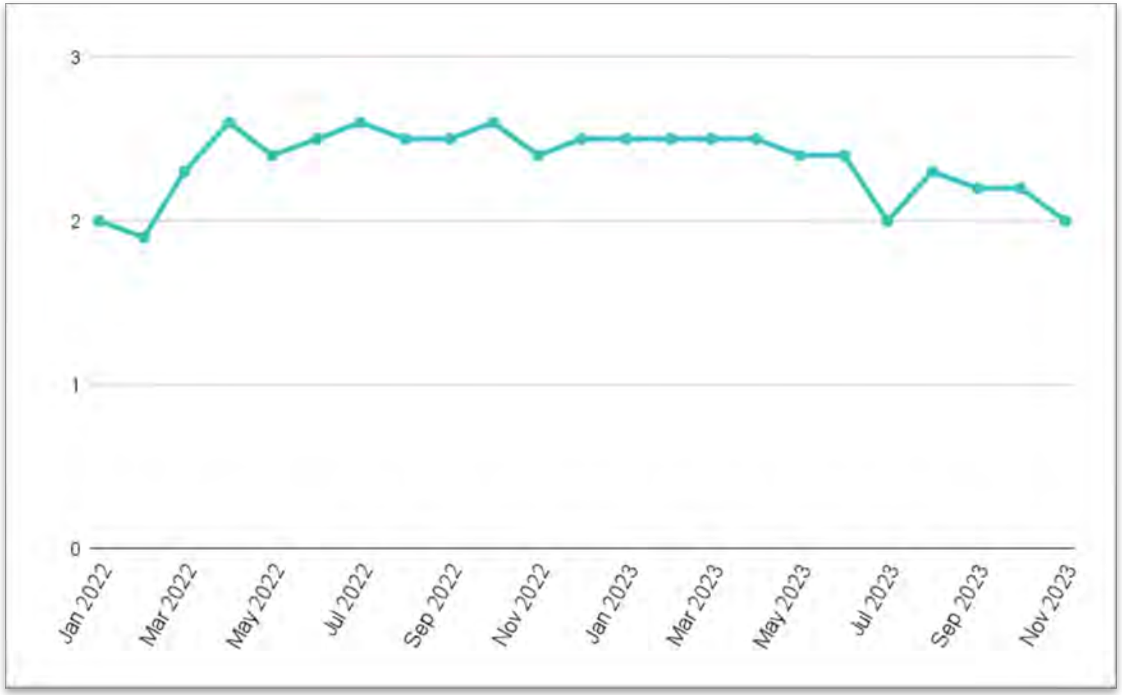
PROGRAM

N = 1,031 Programs



PATIENT

N = 37,212 Patients



Length of Stay: Hospital

[1/1/2022 through 11/30/2023]

PATIENT

	Admit to Initial Consult N = 40,317 Admissions	Initial Consult to PC D/C N = 31,452 Admissions
Mean (days)	5	6
Median (days)	3	3
Range (days)	0 – 380	0 – 517

Most Common Referring Sources: Hospital

N = 198 Programs

PROGRAM

Referral Source	Percentage
Hospital Medicine	44%
General Medicine	15%
Critical Care	14%
Oncology	7%
Surgical Specialties	4%
Cardiology	4%
Pulmonary	3%
Emergency Medicine	3%
Neurology	1%

PATIENT

Reasons for Referral: Hospital

N = 40,857 Patients; 1/1/2022-11/30/2023

Reason for Referral	
Decision Making	77%
Providing Support to Patient/Family	43%
Symptom Management	30%

Most Common Diagnoses – Hospital

N = 156 Programs

PROGRAM

Diagnosis	Percentage
Cancer	22%
Cardiovascular	14%
Pulmonary	10%
Infectious	10%
Neurology	8%
Gastrointestinal	4%
Renal	3%
Dementia	3%
Trauma	3%
Hepatology	3%
Vascular	1%
Metabolic/Endocrine	1%
Hematology	1%
Genetic/Chromosomal	1%

Most Common Discharge Dispositions: Hospital

N = 192 Programs

PROGRAM

Discharge Disposition	
Home Without Hospice	28%
Died	21%
Other Health Care Facility	19%
Home With Hospice	14%
Hospice Health Care Facility	10%
Acute Care Facility	4%

PROGRAM

Care Processes

	Hospital	Community
Does program utilize triggers?	50%	22%
If yes, is it embedded in the EHR?	48%	--
Available to patients and families 24/7 in-person or via telehealth?	33%	Clinic: 33% Home: 43%

Outcomes: Hospital Pain Improved From First To Last Visit

PATIENT

N = 37,212 Patients

Discharge Outcomes: Hospital

PATIENT

Discharge Disposition
N = 34,326 Discharges

Patient Status	Percentage
Alive	80%
Dead	20%

Services Referred to at Discharge
N = 18,576 Discharges

Service	Percentage
None	29%
Hospice	13%
Home Health	13%
Palliative Care	8%
Other	34%
Unknown	3%

1/1/2022 – 11/30/2023

PPS at Initial Consult

[1/1/2022-11/30/2023]

PATIENT

PPS	Hospital N = 34,883 Consults	Community N = 7,860 Consults
0%	0.2%	0.1%
10%	14.9%	0.2%
20%	9.6%	0.6%
30%	18.5%	4.8%
40%	18.4%	10.1%
50%	15.6%	23.2%
60%	9.4%	19.4%
70%	5.5%	18.7%
80%	2.3%	9.3%
90%	0.8%	4.8%
100%	0.3%	0.9%
Unknown	4.6%	7.9%

33.0%

5.6%

8.9%

33.7%

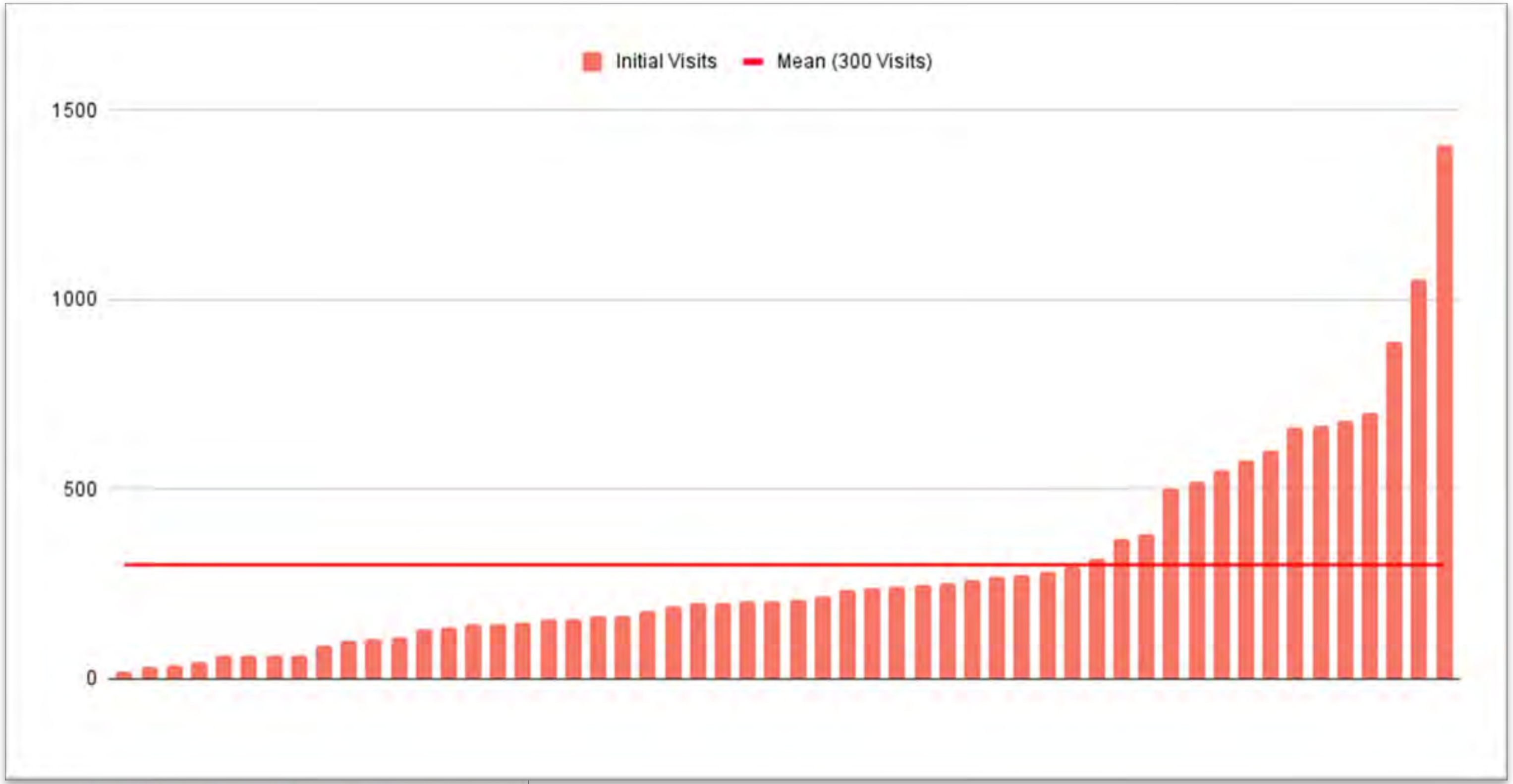
Community Setting

Clinic & Home

PROGRAM

Annual Visits: Clinic

Initial Visits
N = 54 Programs



Subsequent Visits per Patient N = 50 Programs	
Median	3.5
Mean	4.1
Range	<1 - 18

Staffing: Clinic

PROGRAM

N = 50 Programs

Discipline	% of Programs with Discipline	Median FTE	Mean FTE	% of Programs with Certified Staff
Advanced Practice Registered Nurse (NP, CNS, CRNA, or CNM)	70%	0.5	0.9	36%
Registered Nurse	62%	1.0	1.0	20%
Social Worker	54%	0.1	1.3	18%
Chaplain/Spiritual Care	24%	0	0.2	6%
Physician	88%	1.0	1.2	74%
Physician Assistant	12%	0	0.1	N/A
Pharmacist	6%	0	<0.1	N/A
Psychologist	8%	0	0.1	N/A
Administrator/Program Manager	68%	0.2	0.4	N/A
Admin Support or Data Analyst	62%	0.3	0.6	N/A

PROGRAM

Workload: Clinic

Total Initial Visits/ Total FTE N = 50 Programs	
Median	55
Mean	64
Range	10 - 360

Total Initial Visits/ Billing Provider FTE N = 49 Programs	
Median	141
Mean	177
Range	14 - 714

PATIENT

Reasons for Referral: Community

N = 6,600 Patients; 1/1/2022-11/30/2023

Reason for Referral	Community	Hospital
Symptom Management	86%	30%
Decision Making	60%	77%
Providing Support to Patient/Family	53%	43%

N = 40,857 Patients

Most Common Referring Sources: Clinic

N = 21 Programs

PROGRAM

Referral Source	Percentage	Range
Oncology/Cancer Center	51%	0 – 90%
Primary Care Practice	10%	0 – 56%
Palliative Care	9%	0 – 65%
→ Hospital Inpatient Service (Non-Palliative Care)	8%	0 – 28%
→ Hospital Inpatient Palliative Care Service	3%	0 – 24%
Neurology	3%	0 – 35%
Cardiology/Heart Failure Clinic	3%	0 – 95%
Patient/Family Self-Referral	1%	0 – 21%
Emergency Department	<1%	0 – 4%
Hospice	<1%	0 – 2%
Nephrology/Dialysis Center	<1%	0 – 6%
Nursing Home/Long-Term Care	<1%	0 – 5%
Geriatrician	<1%	0 – 2%

Most Common Diagnoses: Clinic

PROGRAM

Diagnosis	Clinic
Cancer	80%
Neurology	6%
Cardiovascular	3%
Pulmonary	2%
Dementia	1%
Renal	1%
Hepatology	1%
Genetic/Chromosomal	1%

N = 24 Programs

Hospital
22%
8%
14%
10%
3%
3%
3%
1%

N = 156 Programs

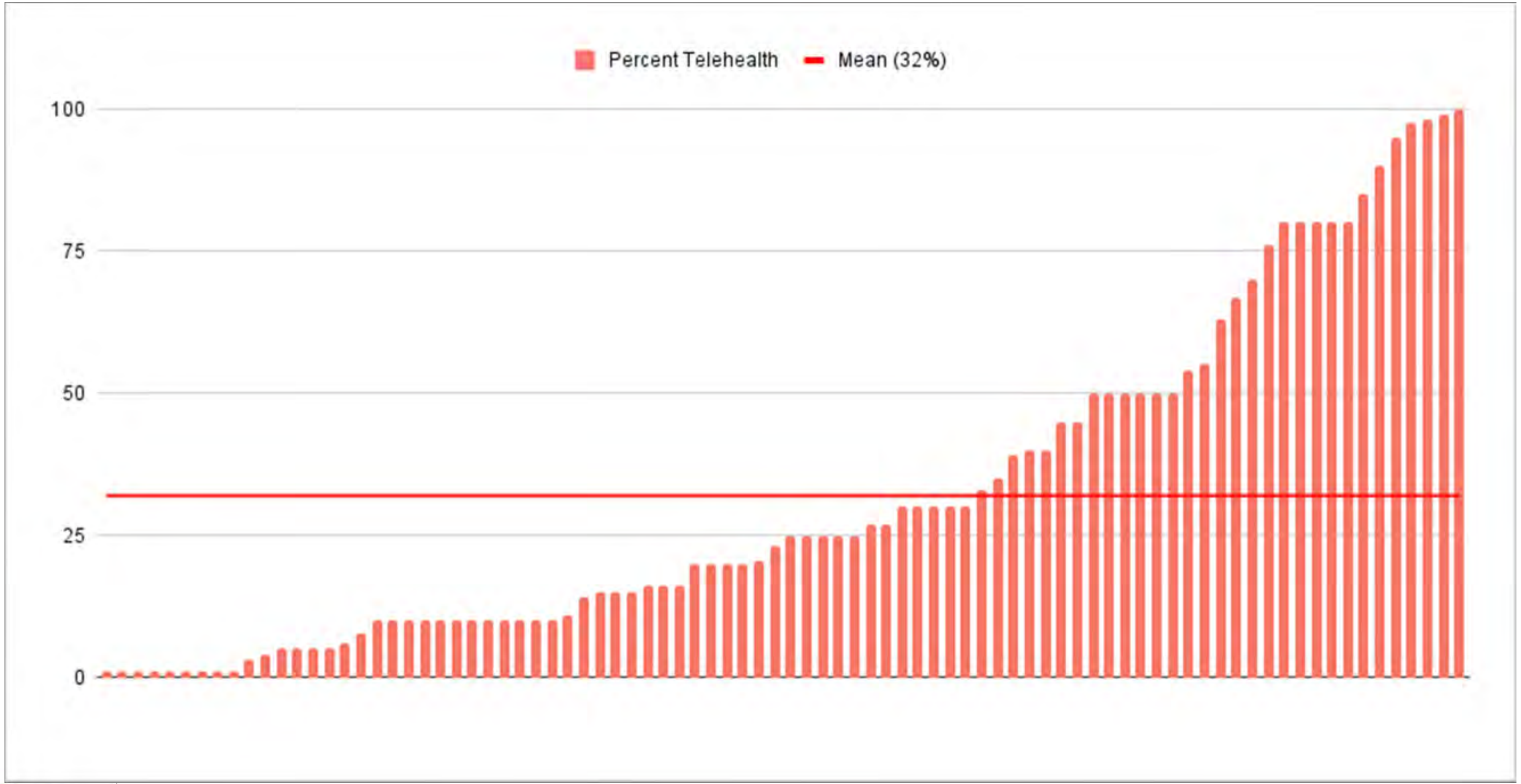
Telehealth: Community

N=99

PROGRAM

95% offer Telehealth

Percent of patients seen by telehealth (N = 86)



32%

Most Common Discharge Dispositions: Clinic

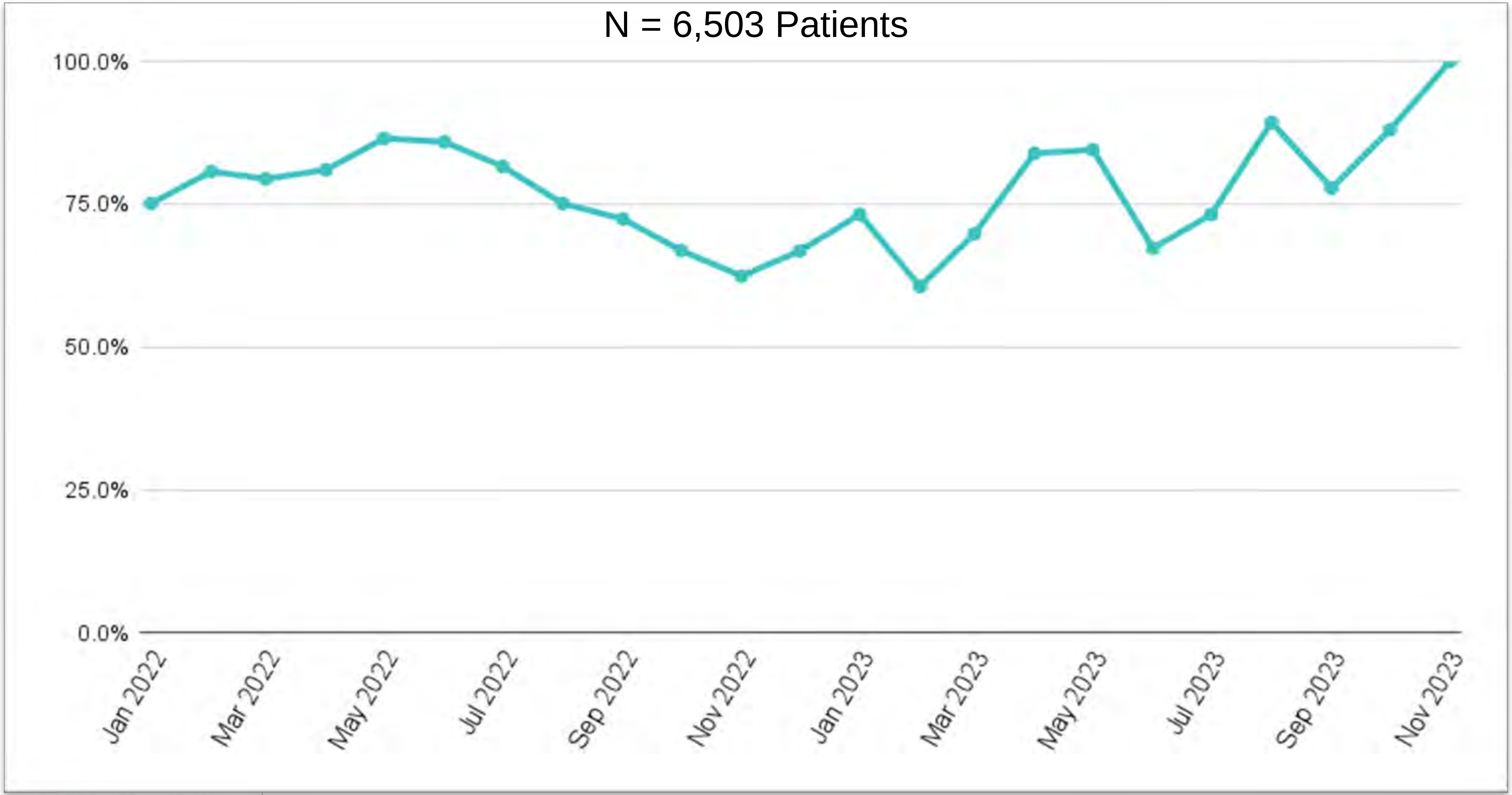
N = 11 Programs

PROGRAM

Discharge Disposition	
Remained on Office Practice or Clinic	38%
Died	35%
Transferred to Hospice Service Line	15%
Disenrolled from Palliative Care Service	8%
Transferred to Home Palliative Care Services	<1%

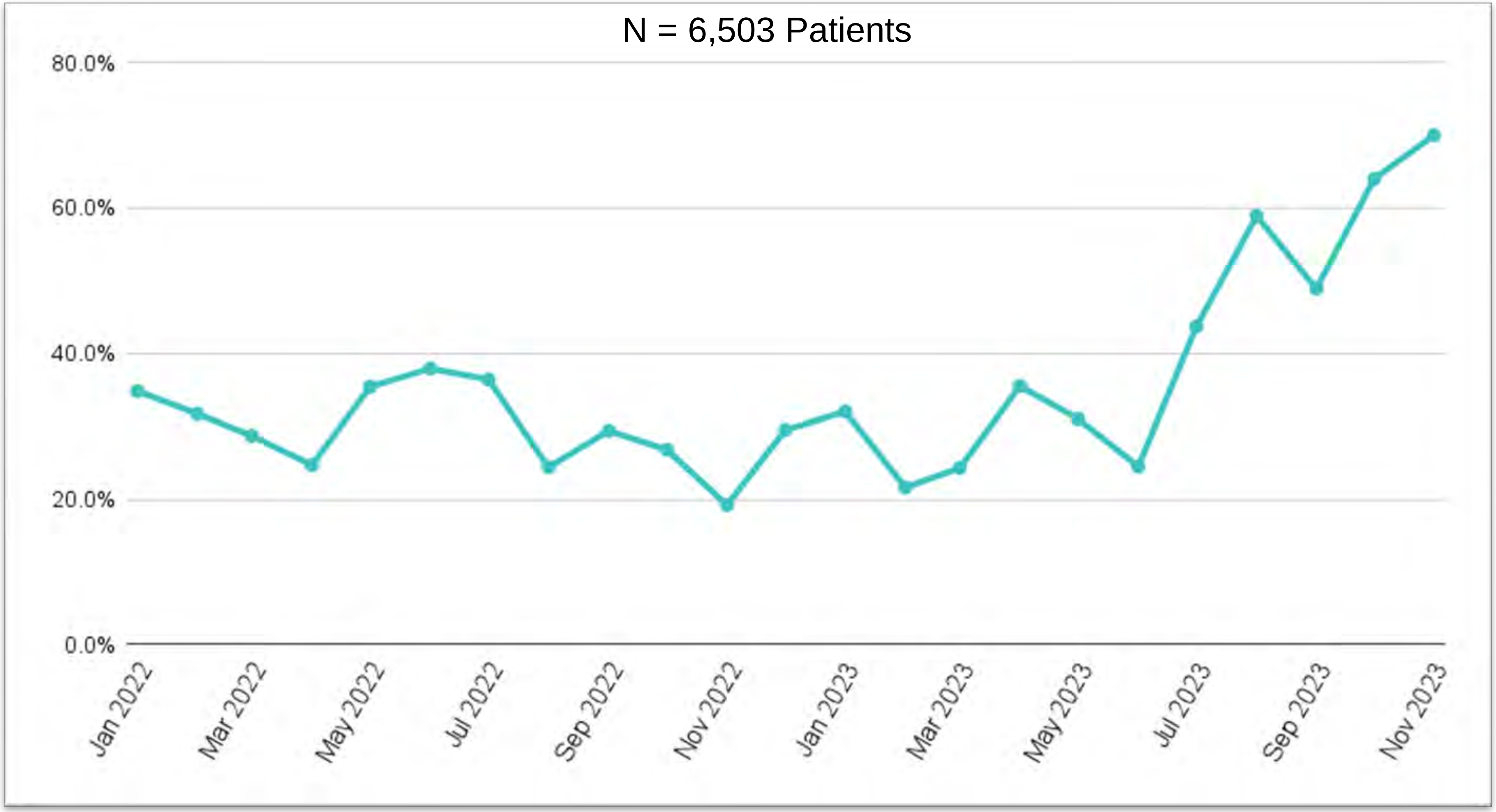
Documentation of Goals of Care: Community

PATIENT



Discussion of Spiritual/Religious Concerns at Initial Visit: Community

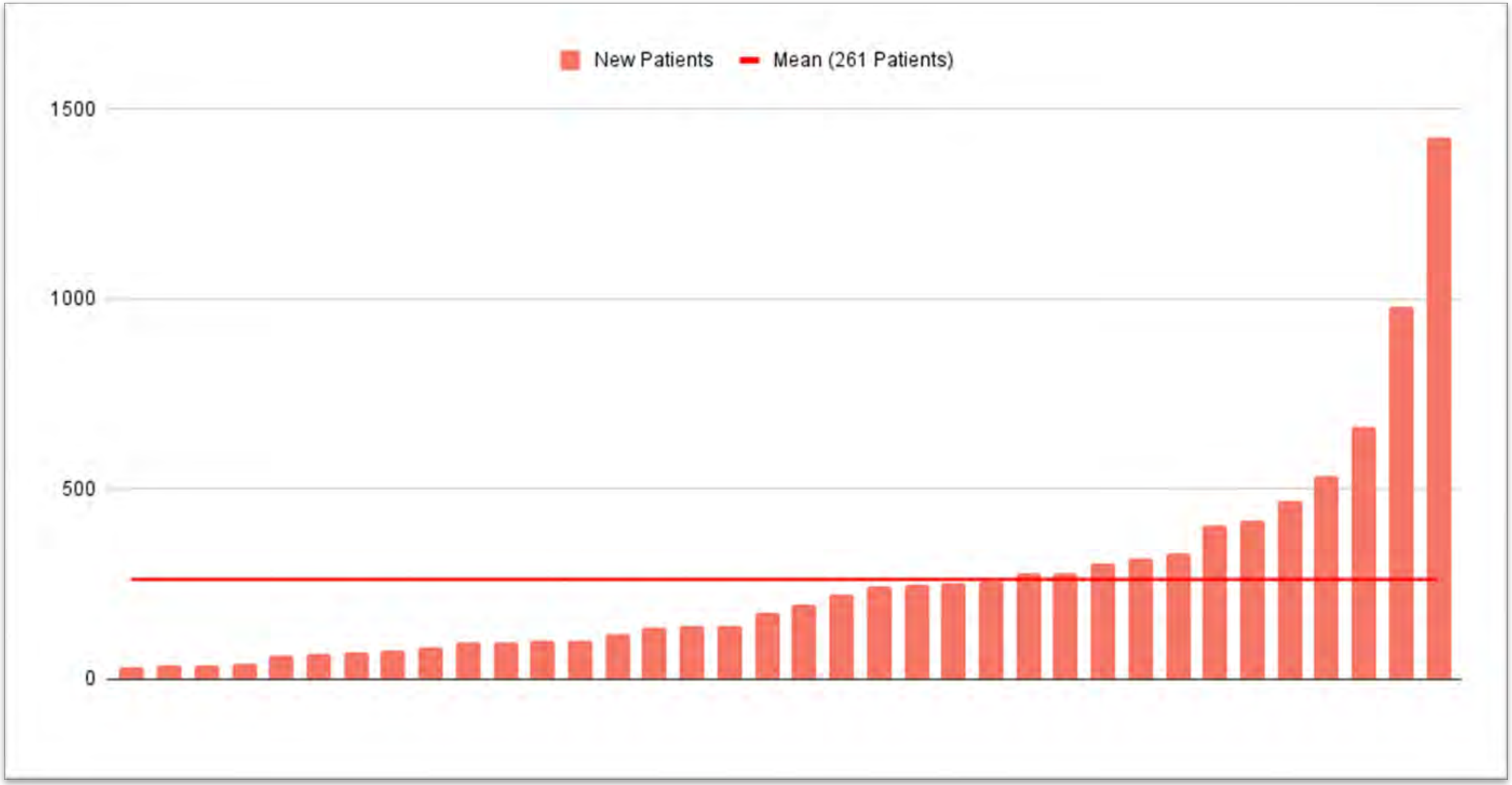
PATIENT



Annual Visits: Home

PROGRAM

New Patients
N = 36 Programs



Staffing: Home

N = 35 Programs

PROGRAM

Discipline	% of Programs with Discipline	Median FTE	Mean FTE	% of Programs with Certified Staff
Advanced Practice Registered Nurse (NP, CNS, CRNA, or CNM)	86%	1.2	2.3	43%
Registered Nurse	69%	1	2.2	34%
Social Worker	86%	1	1.5	23%
Chaplain/Spiritual Care	49%	0	0.4	9%
Physician	80%	0.5	0.7	54%
Physician Assistant	17%	0	0.2	N/A
Pharmacist	11%	0	0.1	N/A
Psychologist	0%	0	0.0	N/A
Administrator/Program Manager	89%	0.5	0.7	N/A
Admin Support or Data Analyst	89%	1	1.0	N/A

PROGRAM

Workload: Home

New Patients per Total FTE N = 34 Programs	
Median	36
Mean	44
Range	2 – 280

New Patients per Billing Provider FTE N = 34 Programs	
Median	102
Mean	143
Range	21 - 894

Most Common Referring Sources – Home

PROGRAM

N = 21 Programs

Referral Source	
Primary Care Practice	32%
Home Health Agency	13%
Oncology/Cancer Center	12%
Geriatrician	9%
Hospital Inpatient Palliative Care Service	8%
Palliative Care Clinic	7%
Hospital Inpatient Service (Non PC)	5%
Patient/Family Self-Referral	3%
Nursing Home/Long-Term Care	2%
Hospice	2%
Cardiology/Heart Failure Clinic	2%
Neurology	1%
Emergency Department	<1%
Nephrology/Dialysis Center	<1%

PROGRAM

Most Common Diagnoses: Home

Diagnosis	Home	Hospital	Clinic
Cancer	33%	22%	80%
Cardiovascular	17%	14%	3%
Pulmonary	14%	10%	2%
Dementia	10%	3%	1%
Neurology	9%	8%	6%
Renal	6%	3%	1%
Hepatology	2%	3%	1%
	N = 18	N = 156	N = 24

PROGRAM

Most Common Discharge Dispositions: Home

N = 20 Programs

Discharge Disposition	
Remained on Home Palliative Care Service	43%
Transferred to Hospice	35%
Disenrolled from Home Palliative Care Service	11%
Died	10%

State of our Field

- PC teams are busy in all settings
- Patient populations differ across settings with opportunities for more equitable access by disease
- Program and Patient-level data complement each other
- Palliative Care programs provide comprehensive care
- Many opportunities for improvement exist and variations in practice identify and model best practices
- More data allows for more granular comparisons

References

- Data obtained from Palliative Care Quality Collaborative Annual Program Surveys: https://palliativequality.org/registry-access/registry-resources
- Temel et al. *NEJM* 2010;363:733-42
- Pantilat *Arch Int Med* 2012;172:1172-3
- Kavalieratos et al. *JAMA* 2016;316:2104-14
- El-Jawahri et al. *JAMA* 2016;316:2094-2103 Kluger et al. *JAMA Neurol* 2020;77:551-60
- Rogers et al. *JACC* 2017;70:331-41

Thank You!

Presenters' contact information:

Steve Pantilat

- Division of Palliative Medicine, UCSF
- Palliative Care Quality Collaborative, Board of Directors
- Email: Steve.Pantilat@ucsf.edu

Fred Friedman

- Palliative Care Quality Collaborative, Registry Manager
- Email: ffriedman@palliativequality.org

Barbara Daveson

PhD

Associate Professor, Palliative Care
Outcomes Collaboration (PCOC),
Faculty of Science, Medicine and Health,
University of Wollongong, Australia

Palliative Care Outcomes Collaborative

The Palliative Care Outcomes Collaborative (PCOC) is a national voluntary program that is improving the quality and outcomes of palliative care in Australia. During this session, PCQC welcomes PCOC to share best practices of high-quality palliative care learned within their Australian-based collaborative. Participants will learn about the PCOC suite of measures and reports to inform quality improvement benchmarking as well as be able to describe how the PCOC model can help improve equity in palliative care outcomes.

The Palliative Care Outcomes Collaboration (PCOC): How and why it matters with respect to quality improvements

Associate Professor Barbara Daveson
PCOC National Director
PCOC Lead Chief Investigator
Faculty of Science, Medicine and Health | University of Wollongong

Quality Matters Conference
December 14-15, 2023

PCOC

No disclosures to declare

Learning outcomes

Upon completing this session, participants will be able to:

1. Describe the PCOC model that drives improvements in palliative care outcomes both at an individual patient level and health service level

2. Describe the PCOC suite of measures and PCOC service reports inform quality improvement benchmarking initiatives to ensure national improvements, and monitoring and surveillance of palliative care outcomes

3. How the PCOC model can help improve equity in palliative care outcomes

Outline of presentation

1. Australia – An overview

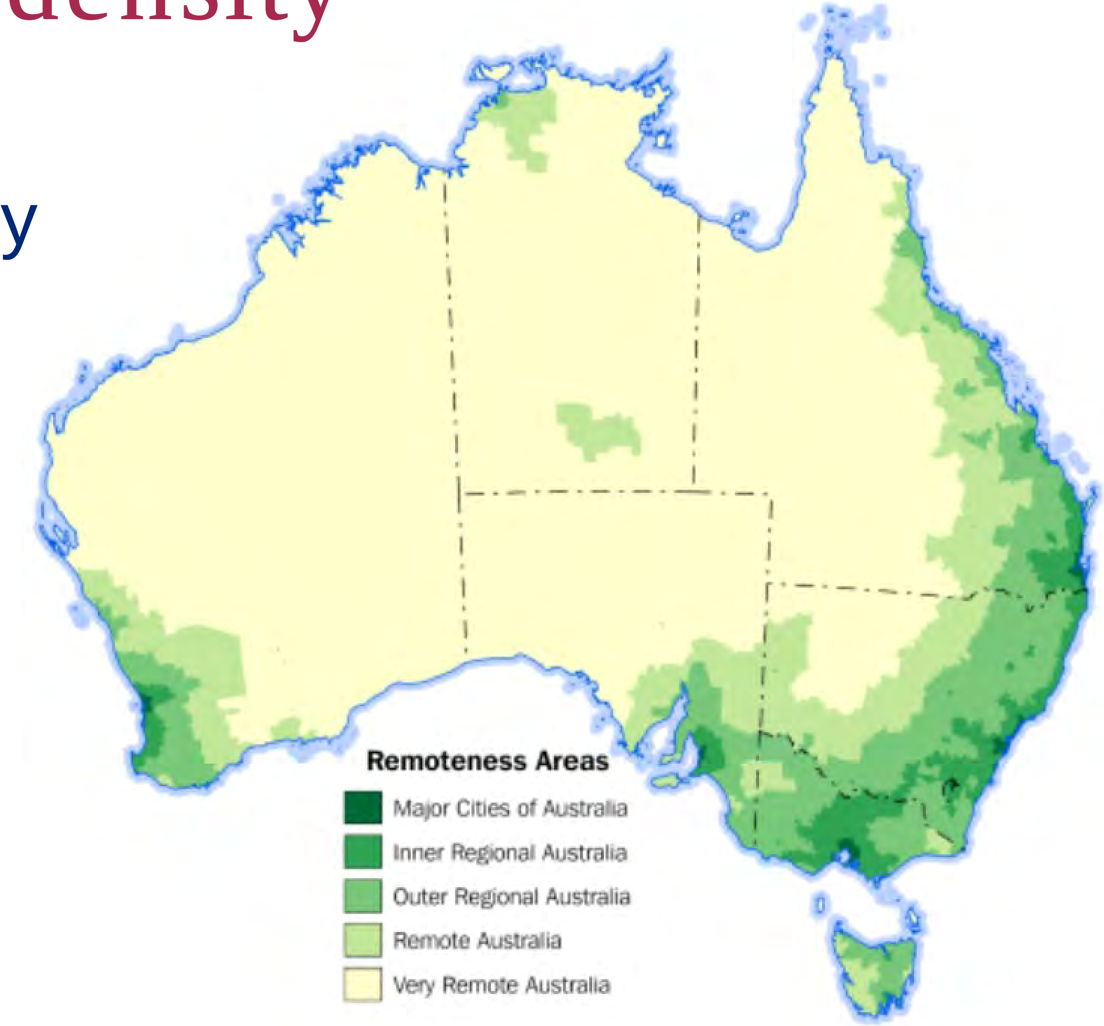
2. Development of palliative care in Australia

3. The PCOC program

Australia: An overview of the population and health system

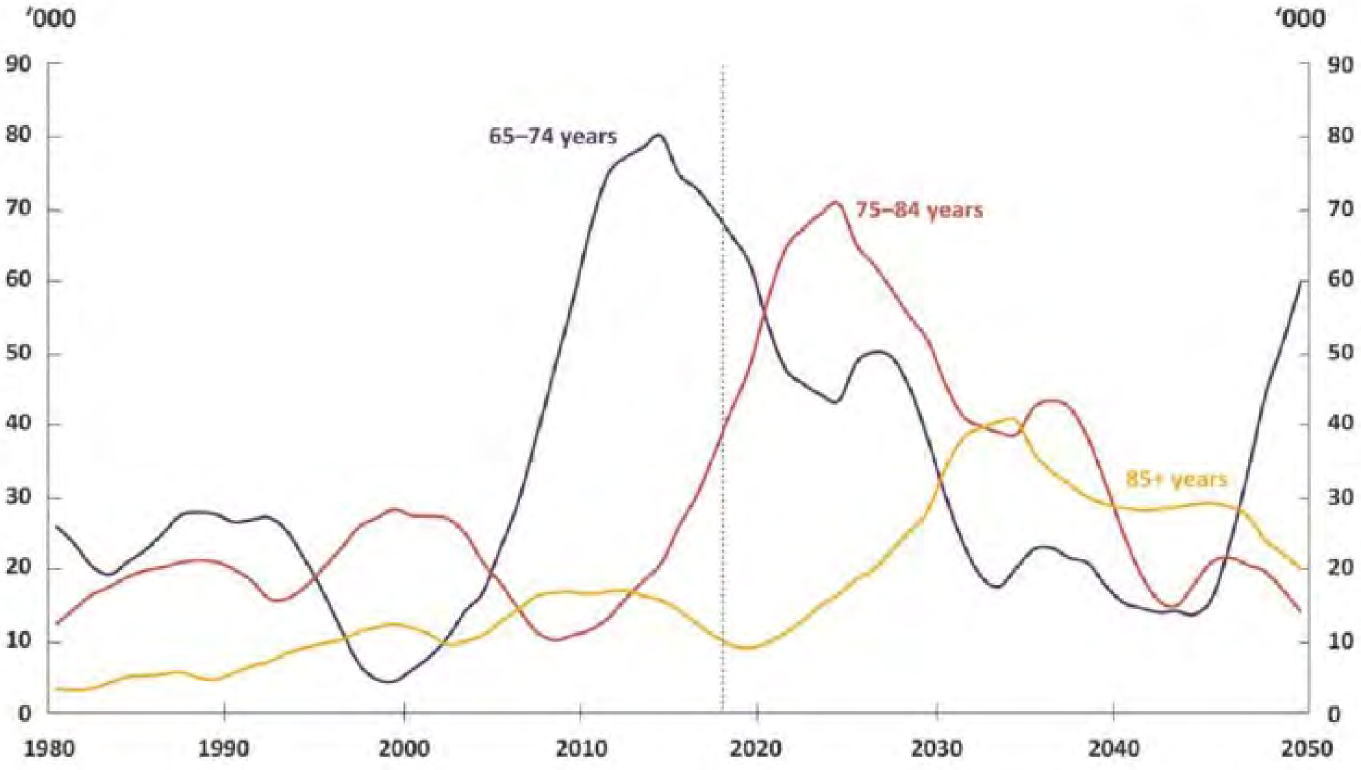
Vast country, dispersed population with vast differences in population density

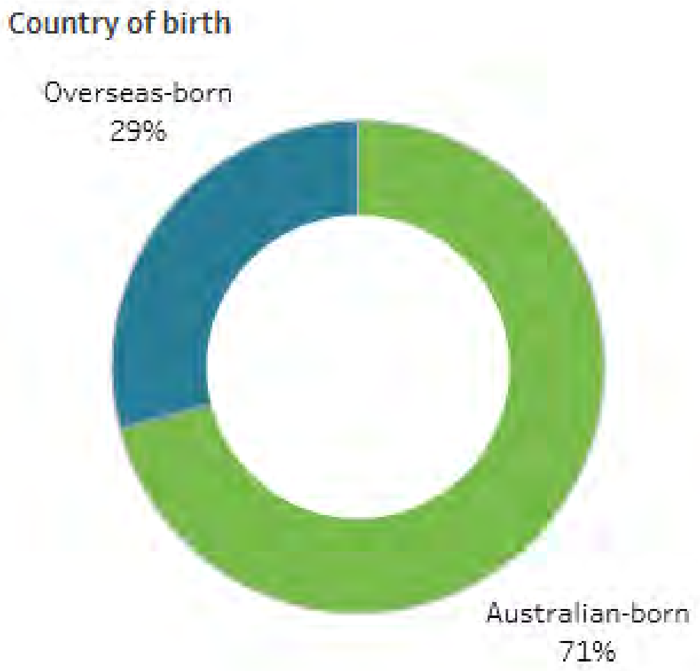
- Population: 26.MM
- Vast differences in population density
- Aboriginal and or Torres Strait Islander people 3.8%



(Australian Institute of Health & Welfare (AIHW), 2023; Australian Bureau of Statistics (ABS), 2023)

Population is diverse and aging





(AIHW, 2023; Australian Bureau of Statistics (ABS), 2023)

Universal health coverage but out-of-pocket costs vary, and costs can be substantial

Out-of-pocket costs vary by cancer type
(Breast and lymphoedema 907AUD vs prostate cancer 11,077 AUD)

At risk of out-of-pocket cost, financial burden or both:

- Younger aged patients (≤65 years)
- Aboriginal and Torres Strait Islander people
- People in rural and/or remote areas
- Households with low income
- The unemployed
- People with private health insurance were at increased risk


Home › Individuals › Medicare

medicare

We deliver Medicare and related programs, providing Australians with access to some health services at low or no cost.

History of development of palliative care in Australia

In 1970s - Began with geographically and limited hospice services

Foundation Sisters outside of the first dedicated hospice and palliative care service for the Little Company of Mary (in Kogarah, New South Wales, Australia) 1966

Greenwich Home of Peace Hospital - Deaconess Society, (1963)

Caritas Christi was opened in 1938 by the Sisters of Charity (Kew, Victoria, Australia)

National palliative care strategy and investments

National Palliative Care Strategy 2018

Australian Government
Department of Health

Implementation Plan
for the
National Palliative Care Strategy 2018

Australian Government
Department of Health

Standards for Providing Quality Palliative Care for all Australians

Palliative Care Australia

Major investments by the Australian Government to improve the quality of palliative care

PCOC
palliative care
outcomes collaboration

Palliative Care Clinical Studies
Collaborative (PPCSC)

CARESEARCH®
palliative care knowledge network

PCC4U
PALLIATIVE CARE
CURRICULUM FOR
UNDERGRADUATES

The Palliative Care Outcomes Collaboration

History of development of PCOC

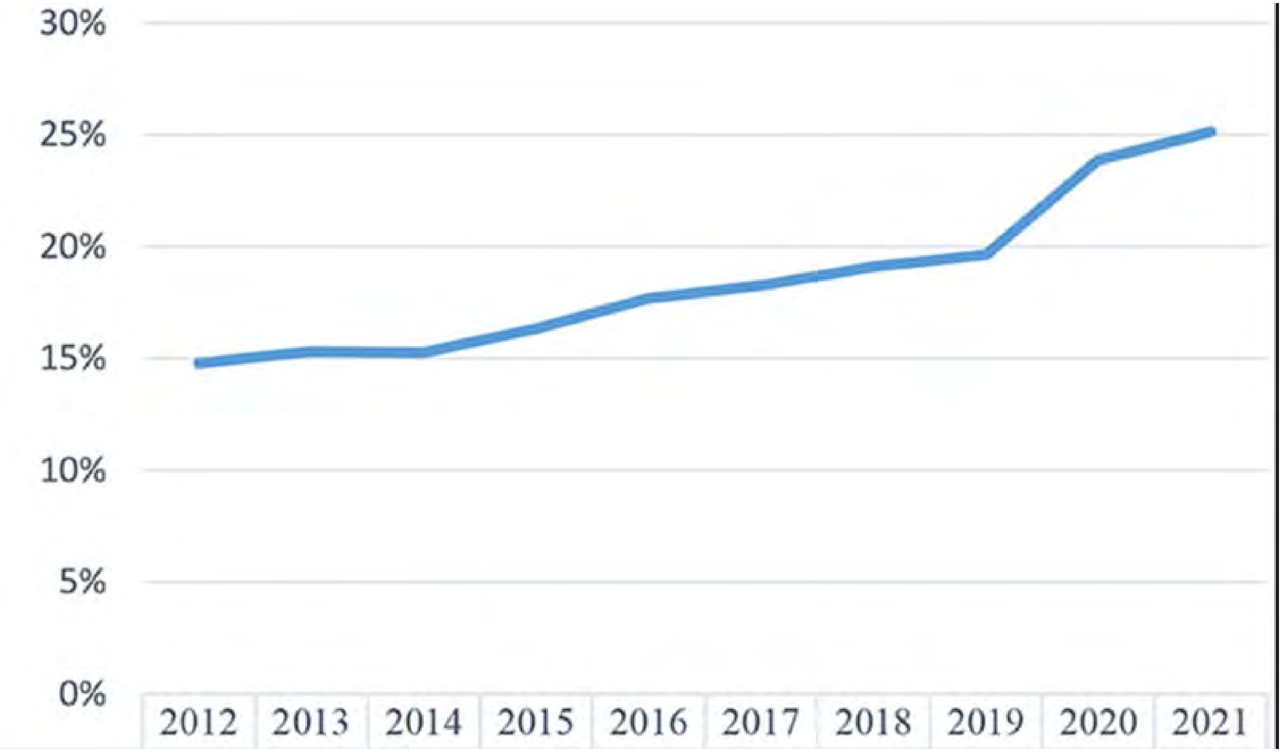
- Collaborative between four universities with founding chief investigators
- National palliative care outcome measures adopted in 2005
- National palliative care outcome benchmarks progressively from 2009 through sector consultation
- Benchmarks revised periodically based on outcome trends
- Recognised as core pillar palliative care program
- Most specialist palliative care programs are registered

Founding CIs: Prof Eagar, Prof Currow, Prof Kristjanson, Distinguished Prof Yates

Year-on-year growth in those that may benefit from specialist palliative care

60,000 patients annually and 3% annual growth

25% of the population that may benefit from specialist palliative care



(Daveson et al., *Front. Public Health*, 2023)

A unit of counting makes it work

- Patients have one or more episodes of palliative care (defined by setting) – hospital or home
- Episodes of care consist of one or more Palliative Care Phases
- The ‘outcome’ is the change from beginning to end of each phase measured against the outcomes of comparable scores from patients

Vital signs

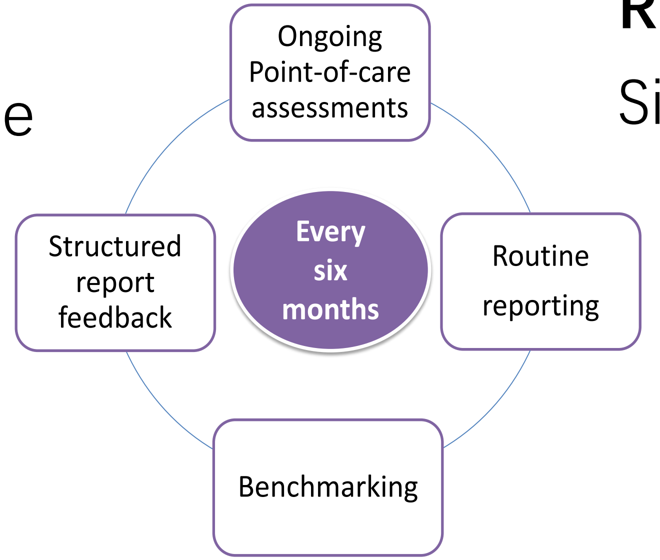
Palliative Care Phase (phase)	Acuity and urgency of patient and carer need
Symptom Assessment Scale (SAS)	Symptom distress
Palliative Care Problem Severity Scale (PCPSS)	Symptom severity
Australia-modified Karnofsky Performance Scale (AKPS)	Performance status
Resource Utilisation Group–Activities of Daily Living (RUG-ADL)	Functional dependence

(Abernethy et al., 2005; Aoun et al., 2004; de-Wolf Linder et al, 2019; Eagar et al., 2004a, 2004b; Fries et al., 1994; Masso et al., 2015)

Quality education and report cycle

QEP

- Essentials course
- Workshops for clinical leaders
- National benchmarking workshops for services



Ongoing Point-of-care assessments

Routine reporting

Benchmarking

Structured report feedback

Every six months

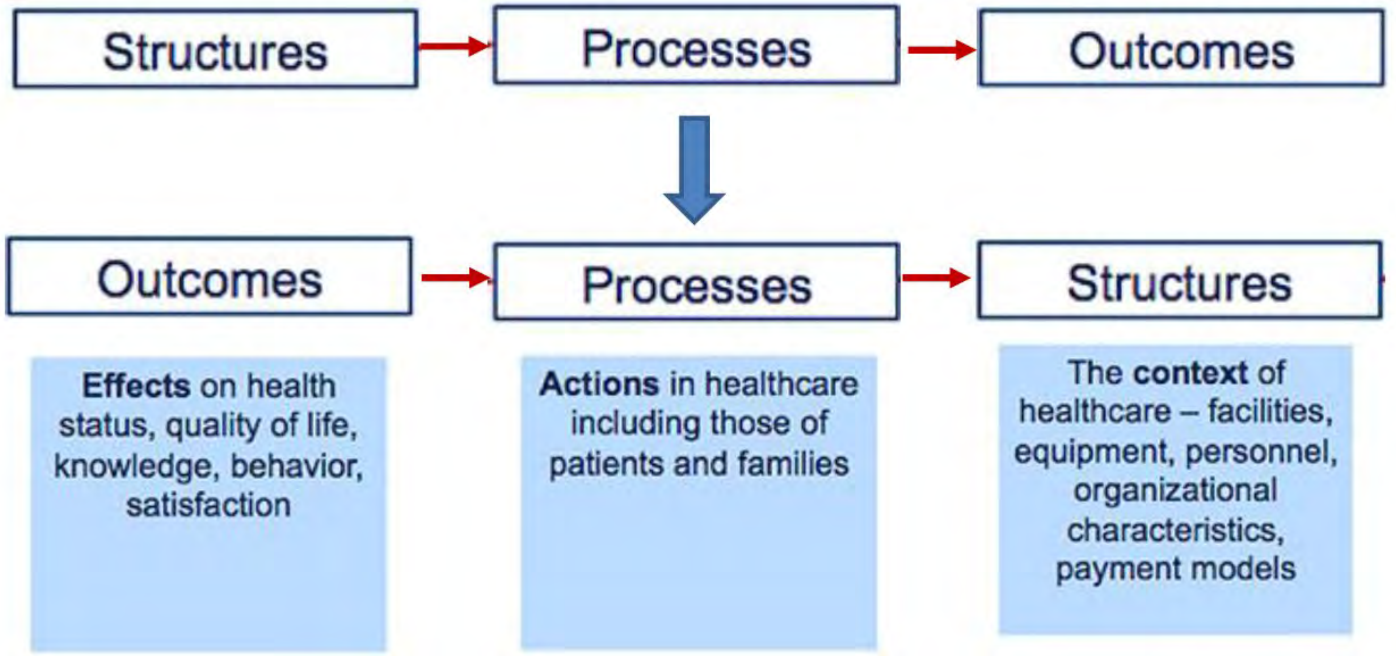
Report cycle

Six-monthly reports for:

- Services
- States and territories
- Nation

(Clapham et al., 2020 *PCOC Assessment & Response Protocol,* AHSRI, UOW;
Clapham et al., *2020 Implementing PCOC: A guide for services, AHSRI, UOW*)

PCOC's change logic: Donabedian outcome model reverse-engineered



Structures → Processes → Outcomes

Outcomes → Processes → Structures

Effects on health status, quality of life, knowledge, behavior, satisfaction

Actions in healthcare including those of patients and families

The **context** of healthcare – facilities, equipment, personnel, organizational characteristics, payment models

(Donabedian, *Milbank Mem Fund Q*, 1966 (reprint *Mem Bank Q* 2005; Donabedian et al., *Med Care,* 1982)

National benchmarks

- Domain is clinically important
- Evidence of variation between services and patients
- Evidence demonstrating that the domain is amenable to intervention
- The benchmark threshold reflects good rather than average practice (20% percentile)
- The benchmark is the same regardless of sector (public/private), location or role
- Through the eyes of the patient is key

Focus is on individual patient outcomes regardless of care setting

There are 20 benchmarks:

1 benchmark on **timeliness of care**

1 benchmark on **responsiveness to urgent needs**

6 benchmarks on **pain management***

9 benchmarks on **symptom management***

3 benchmarks on **family/carer problems***

Outcome data standardised for mix of patients in each service. Controls for the impact of **phase** of illness and initial **level of symptom/problem** on patient outcomes

Collaborative not competitive benchmarking

Benchmarking is a systematic approach to identifying the benchmark, comparing yourself to the benchmark, and identifying and adopting practices that enable you to improve

4 key components

- Identification of focus through data
- Sharing with and learning from others
- Adopting new behaviours
- Sustained effort and continuous process

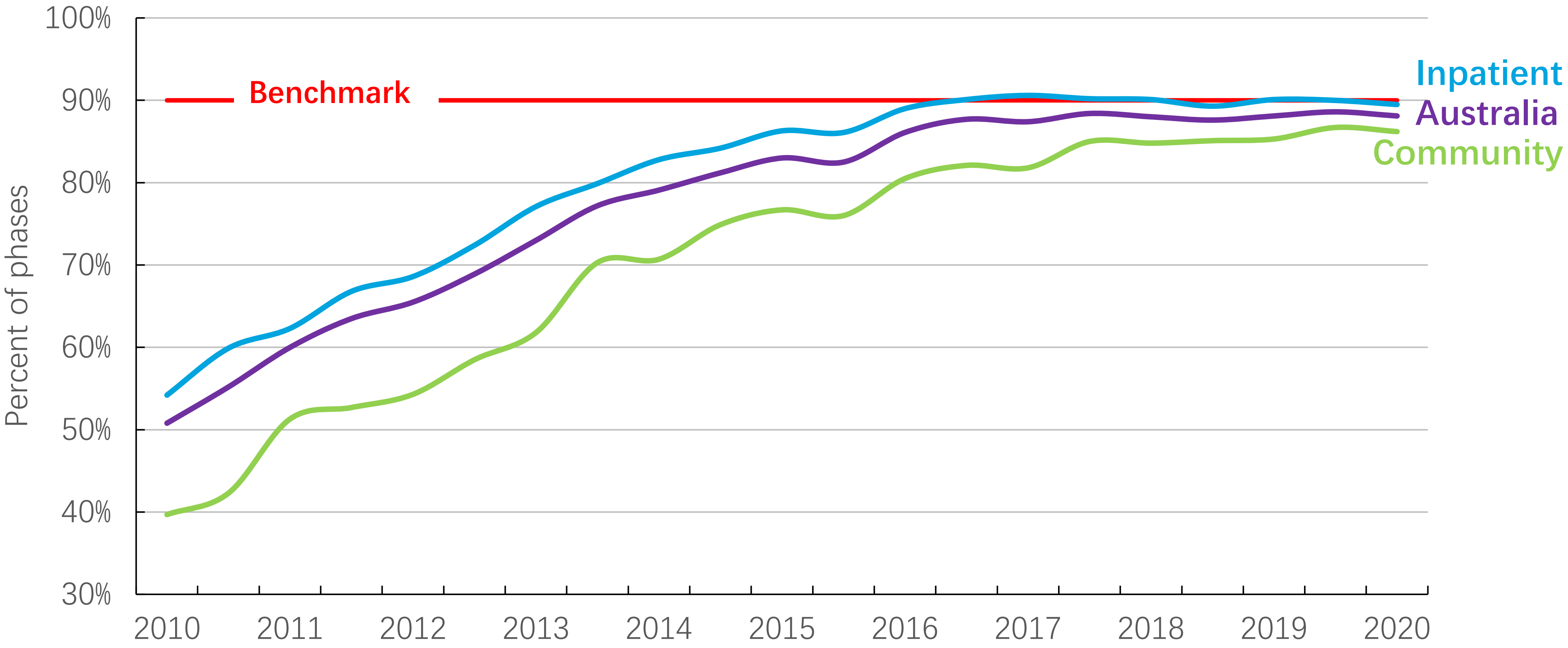
(Balm 1992; Camp 1989; EFQM 2009; Ettorchi-Tardy 2012; Kay 2007; Fitz-enz 1993; Vlaseanu et al. 2007)

Communities of practice

- Common concern, problems or a passion
- Develop knowledge / expertise through ongoing interaction
- Find value in their interactions
- May create resources
- Develop a unique perspective, body of common knowledge, practices, approaches, ways of interacting and personal relationships
- Common sense of identity

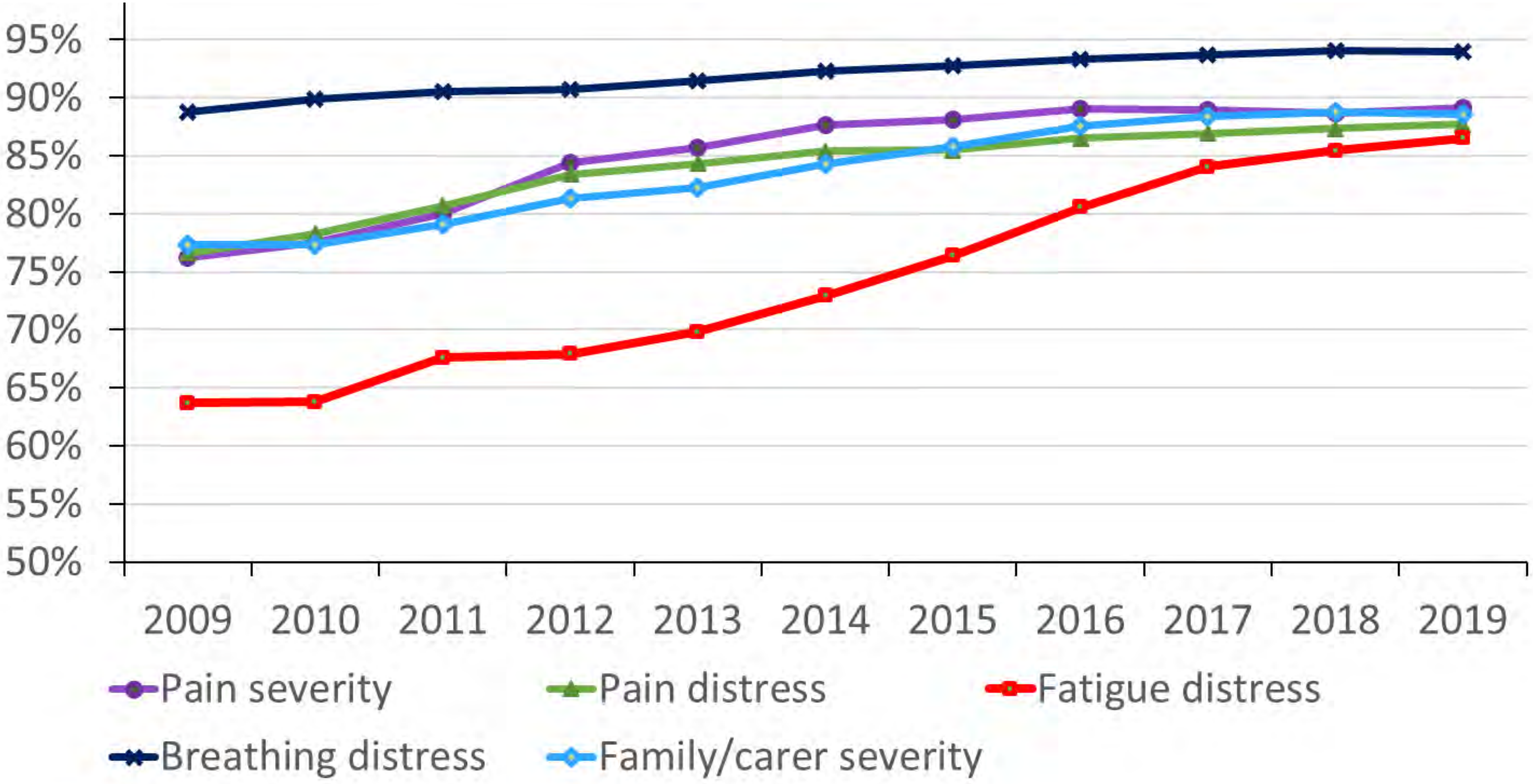
(Ranmuthugala et al., BMC Health Services Research, 2011; Weng al., *Cultivating Communities of Practice* 2002)

National benchmark: % patients* in an unstable phase for 3 days or less



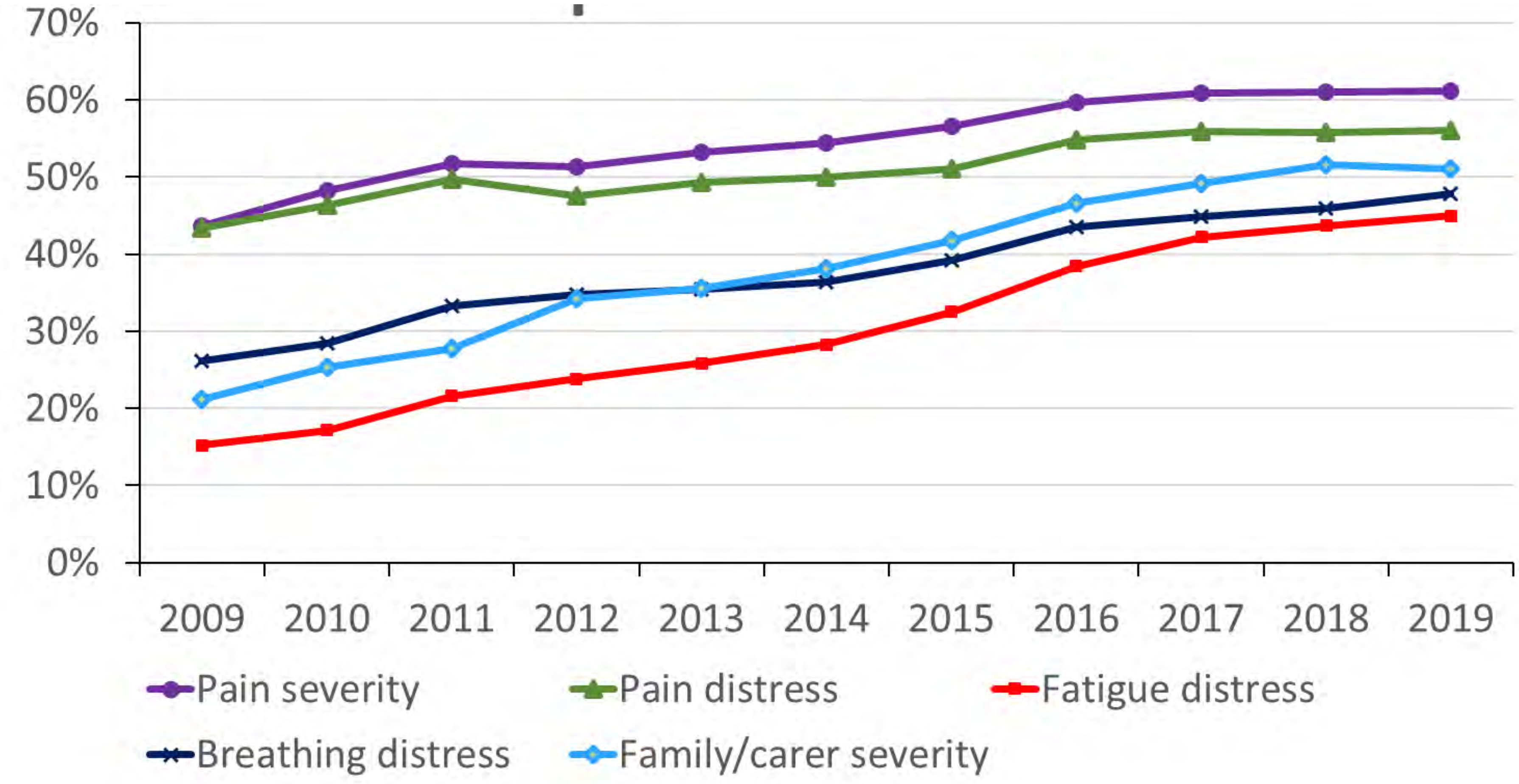
* Palliative care phases are presented

Anticipatory care benchmarks

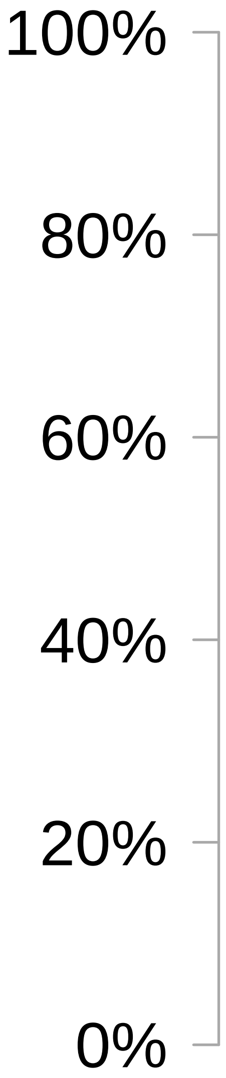


Care that anticipates the needs of the patient and their family (or carers) and that prevents severe problems developing; Percentage of palliative care phases with absent or mild symptoms who stay that way

Responsive care benchmarks



Care provided to patients with moderate or severe symptoms or distress;
Percentage that start with moderate or severe symptoms who have absent or mild symptoms at phase end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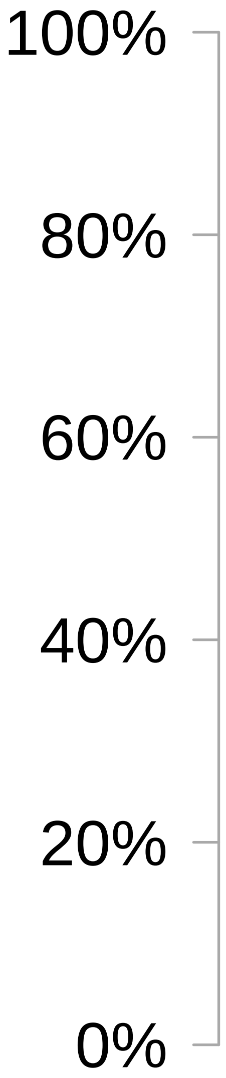
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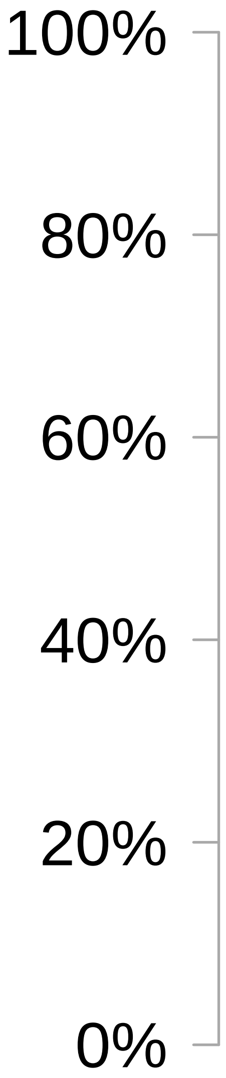
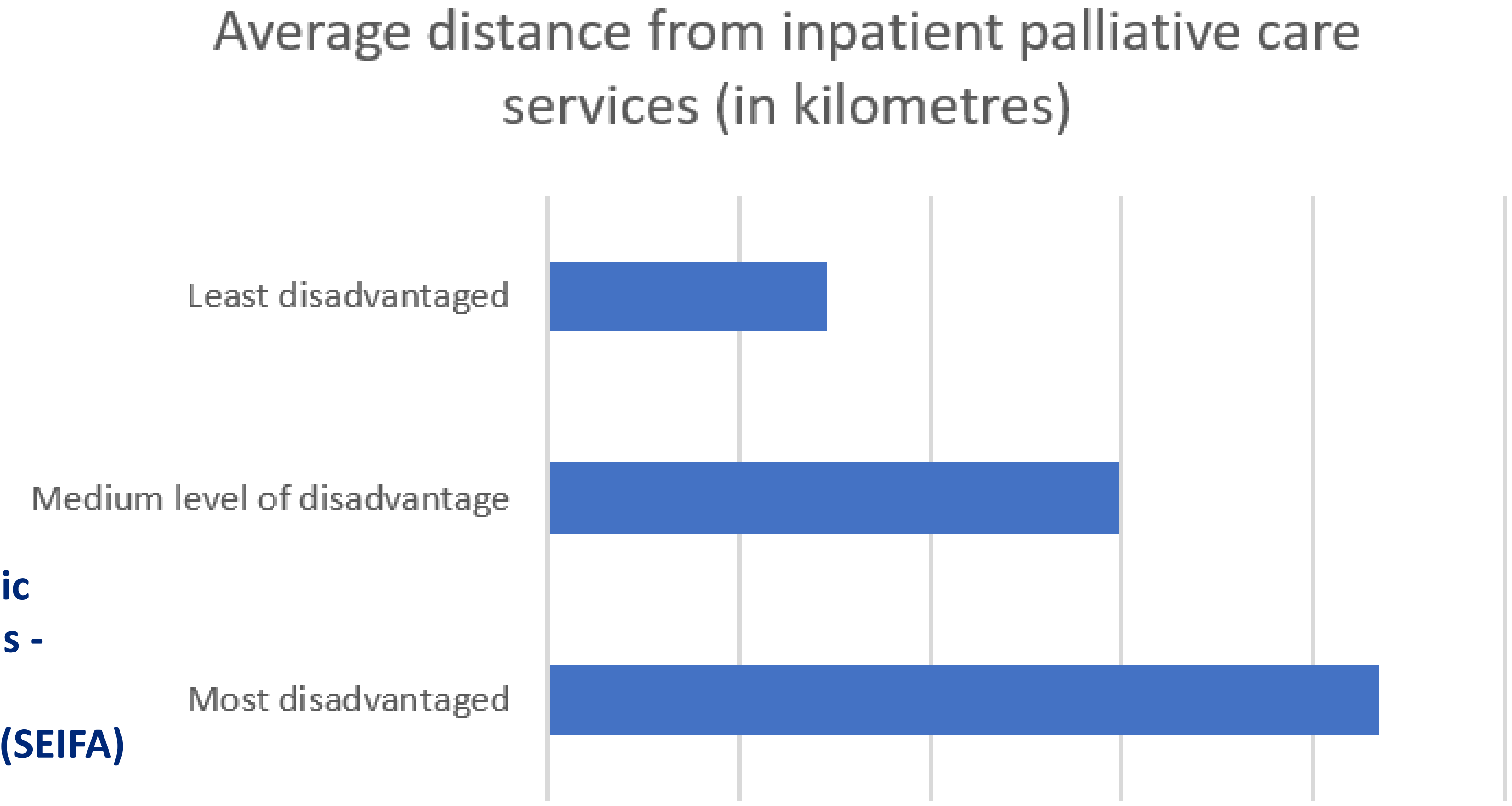


PCOC
palliative care
outcomes collaboration

Example 1: Socio-economic disadvantage and geographical access to palliative care

Distribution of palliative care services

Those that were disadvantaged had to travel three times the difference to receive inpatient palliative care, as compared to those least disadvantaged

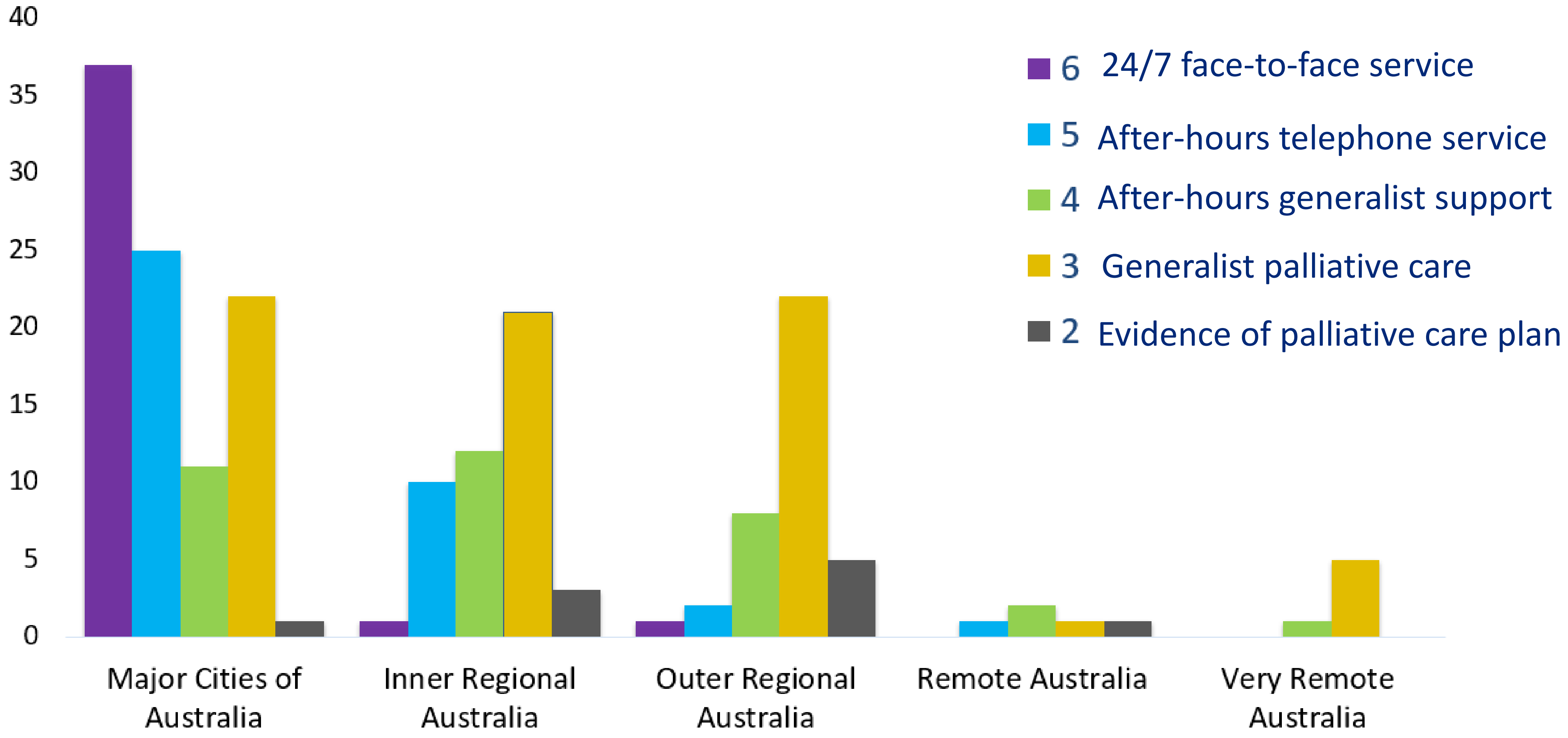


Socio-Economic Index for Areas - Index of Disadvantage (SEIFA)

Kilometres

(Currow et al., BMC Health Service Research, 2012)

Distribution of services in Australia



(Clapham, *PCOC conference 2019,* 2019)

Example 2: Culturally and linguistically diverse peoples

Culturally and linguistically diverse patients

- Older adult (≥65 years) diaspora communities are becoming increasingly diverse
- Substantial health disparities between native-born and immigrant populations but the evidence is mixed
- The “healthy immigrant effect” upon arrival but this deteriorates
- Cumulative exposure to individual-level, social-level and organisational stressors
- Intersectionality a consideration (e.g., women and children 48% of all international migrants, traditionally as spousal dependents to a male partner)

(Elshahat et al., *J Immigr Minor Health,* 2022; Rezaho et al., *Aust health Rev*, 2016)

Entry to palliative care

- Most that access palliative care are native-born (62%), followed by those born in North-Western Europe (14%) and South-Eastern Europe (14%)
- A substantial proportion that access palliative care prefer to speak a language other than English (30%) (MENA 58%)
- Across all CALD groups the rank order of diagnostic clusters are similar and similar to native-born residents
  (cancer, other non-cancers, end-stage organ failure, neuro-degenerative disease, Alzheimer's disease and other dementias)

(Daveson et al, under review, 2023)

Healthcare utilisation and distress by preferred language

- Evaluate symptom distress and severity between those that prefer to speak English and those that don’t
- Analysed all palliative care patients with a cancer diagnosis who died between 2016-2019 (n=53,964; 104,064 assessments)
- Logistic regression with sensitivity analysis to account for age, care setting, palliative care phase

(Roydhouse et al, *BMJ Open*, 2023)

Preferred language: Access, symptoms and problems (n=53,964 patients; n=104,064 assessments)

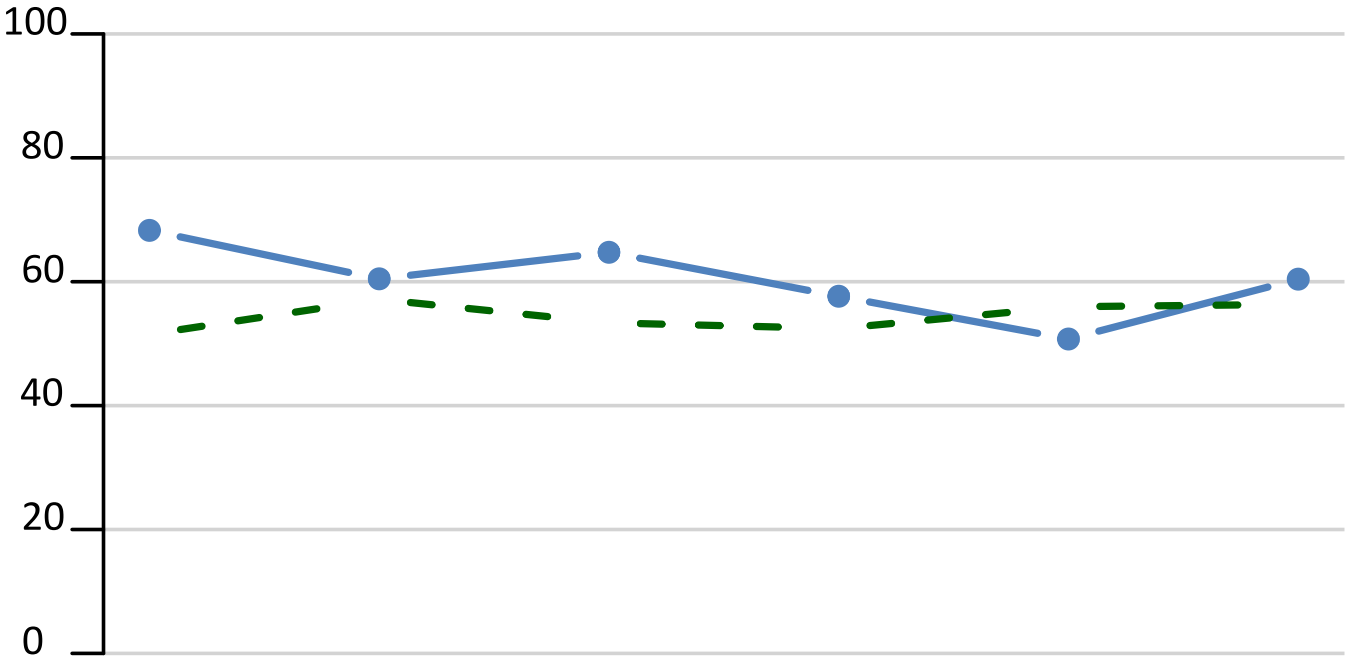
Patients who prefer to speak a language other than English:

- More likely to socio-economically disadvantaged
- More likely to receive care within an inpatient setting
- Less likely to report symptom distress or symptom/problem severity

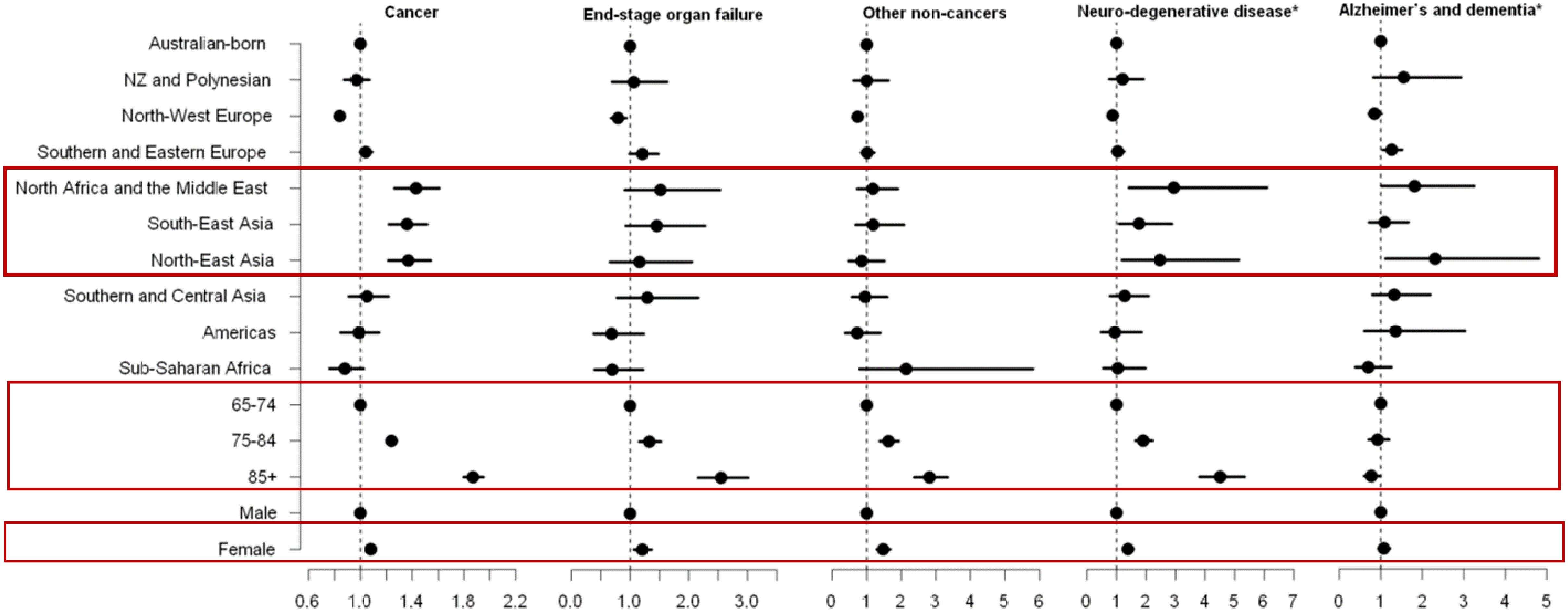
Symptom / problem	All palliative care phases	Terminal phases only
Distress related to the symptom		
Pain	0·89 (0·84–0·94)	0·89 (0·83–0·95)
Breathing	0·84 (0·79–0·89)	0·97 (0·89–1·04)
Severity of the symptom		
Psychological	0·84 (0·80–0·89)	0·95 (0·88–1·01)
Family / carer	1·24 (1·12–1·31)	1·24 (1·15–1·33)

(Roydhouse et al, *BMJ Open*, 2023, Analysed all palliative care patients with a cancer diagnosis who died between 2016-2019)

Family / carer problems during COVID impacted CALD patients in the state with a prolonged lockdown



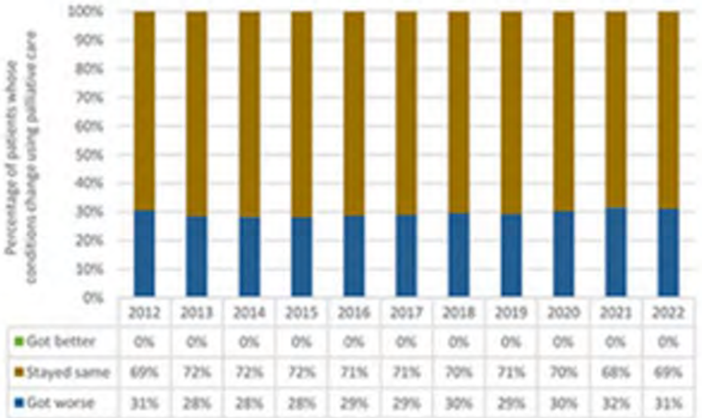
Country of birth: Ability to perform common tasks as indicated by AKPS (n=150,561)



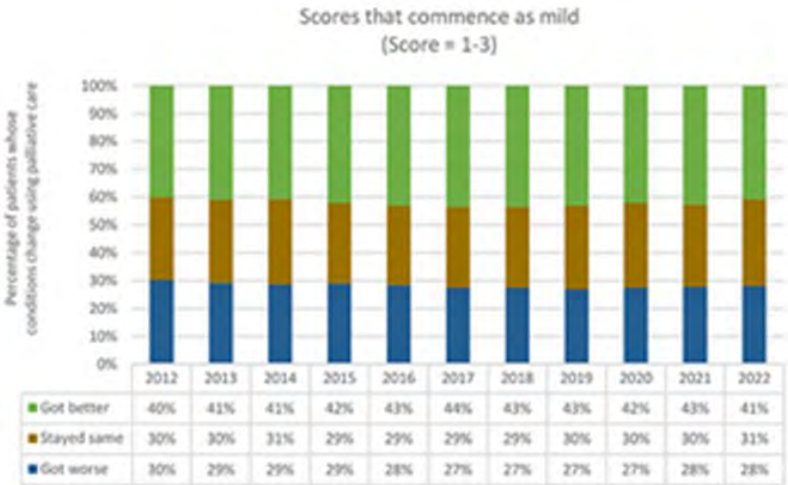
(Daveson et al, under review)

There is still more for us to do…

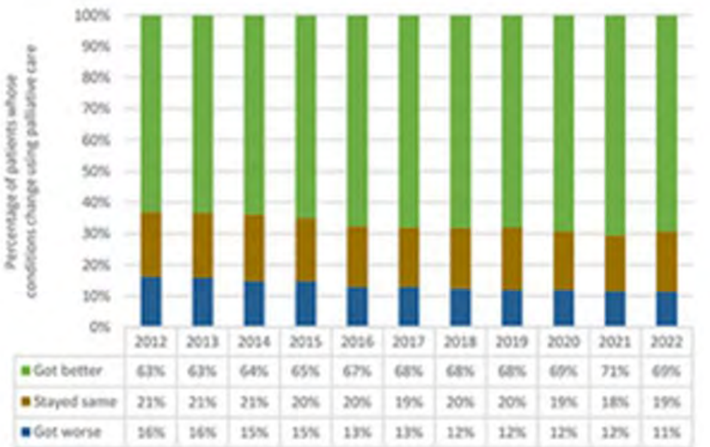
- **To improve access**: More comprehensive understanding of referral pathways
- **To improve symptom management models:** Capture chronic symptoms that substantially predate life-limiting illnesses, including anxiety, depression, pain


Scores that commence as absent (Score=0)

	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
🟩 Got better	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
🟫 Stayed same	69%	72%	72%	72%	71%	71%	70%	71%	70%	68%	69%
🟦 Got worse	31%	28%	28%	28%	29%	29%	30%	29%	30%	32%	31%


Scores that commence as mild
(Score = 1-3)

	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
🟩 Got better	40%	41%	41%	42%	43%	44%	43%	43%	42%	43%	41%
🟫 Stayed same	30%	30%	31%	29%	29%	29%	29%	30%	30%	30%	31%
🟦 Got worse	30%	29%	29%	29%	28%	27%	27%	27%	27%	28%	28%


Scores that commence as moderate
(Score = 4-7)

	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
🟩 Got better	63%	63%	64%	65%	67%	68%	68%	68%	69%	71%	69%
🟫 Stayed same	21%	21%	21%	20%	20%	19%	20%	20%	19%	18%	19%
🟦 Got worse	16%	16%	15%	15%	13%	13%	12%	12%	12%	12%	11%


Scores that commence as severe
(Score = 8-10)

	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
🟩 Got better	80%	77%	77%	76%	78%	77%	77%	76%	79%	79%	81%
🟫 Stayed same	17%	19%	20%	21%	19%	20%	21%	22%	18%	18%	17%
🟦 Got worse	3%	4%	3%	3%	3%	3%	2%	2%	2%	2%	2%

(Daveson et al., *Front. Public Health*, 2023)

…and still more to do…

Enhancing holistic care and recognising complexity:

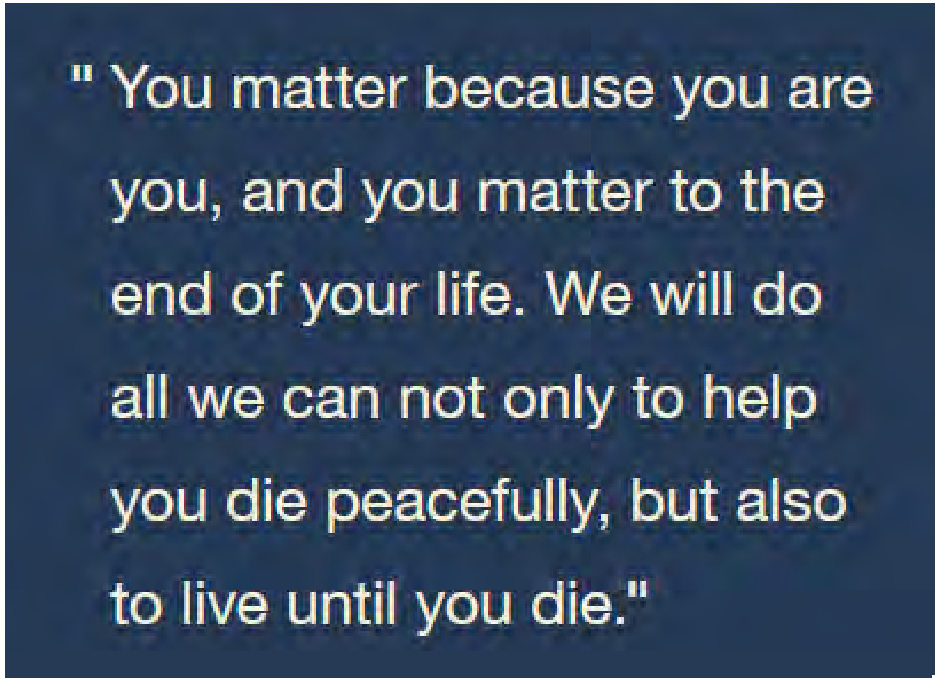
- Social determinants of health (economic, environment, relationships)

Family centred care:

- Caregiver items (proximity, availability)

Enabling sustainable models:

- Distinguishing between primary (generalist) and specialist palliative care
- Establishing national referral and discharge criteria



> " You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

- Dame Cicely Saunders

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Acknowledgments

Email: bdaveson@uow.edu.au
PCOC website:
https://www.uow.edu.au/ahsri/pcoc/

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Palliative care services registered with PCOC

Founding chief investigators of PCOC: Professors Eagar, Yates, Kristjanson, Currow

Current chief investigators: A/Prof Daveson, A/Prof Auret, Distinguished Professor Yates, and the PCOC team