Community-Based Palliative Care

A Chance to Design Systems That Improve Equity

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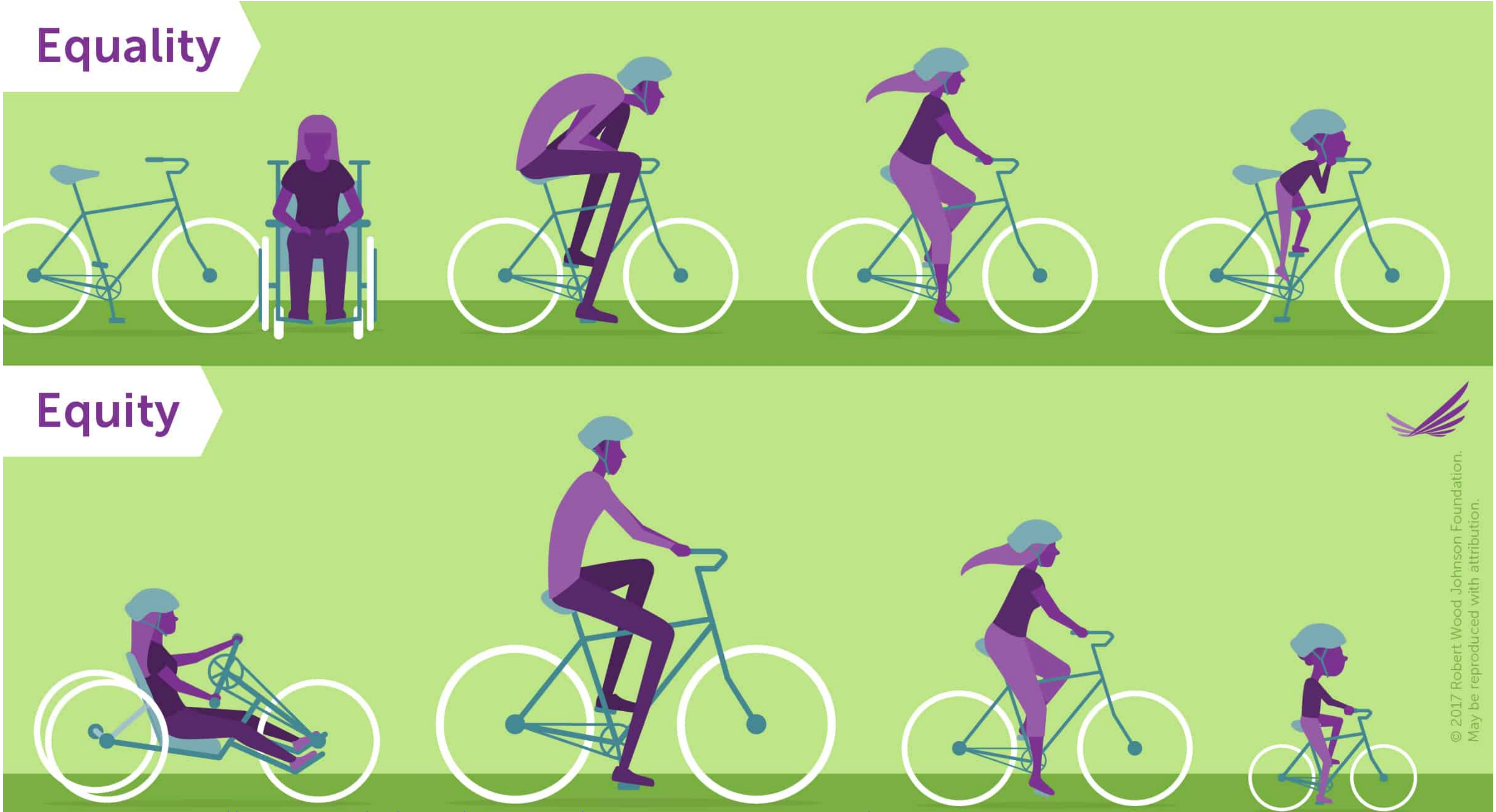
Disclosures

I have no actual or potential conflict of interest in relation to this presentation

Learning Objectives

- Critically think through and identify systemic and structural causes of inequities in access to quality palliative care
- Be able to identify interventions that improve equity across fields and how they may be applied to palliative care care-delivery models
- Apply knowledge to think through the creation of a model of community-based palliative care that prioritizes equity



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https://www.rwjf.org/en/library/infographics/visualizing-health-equity.html#/download

Who Experiences Disparities in Palliative Care/End-of-Life?

- Minority Races
- Hispanic Ethnicity
- Non-English Language Speaker
- Geographic (rural; South)
- Low socioeconomic status
- Disability status
- Presence of severe mental illness
- Low Health Literacy

Determinants of Health Equity

Societal Determinants of Health

Opportunities

Discrimination

Trust

Values

Power

Equity

Safety

Social Cohesion

Social Determinants of Health

Quality Food And Housing

Affordability

Environment

Transportation Access

Education

Jobs

Health Related Social Needs

Transportation

Literacy

Housing

Support

Food

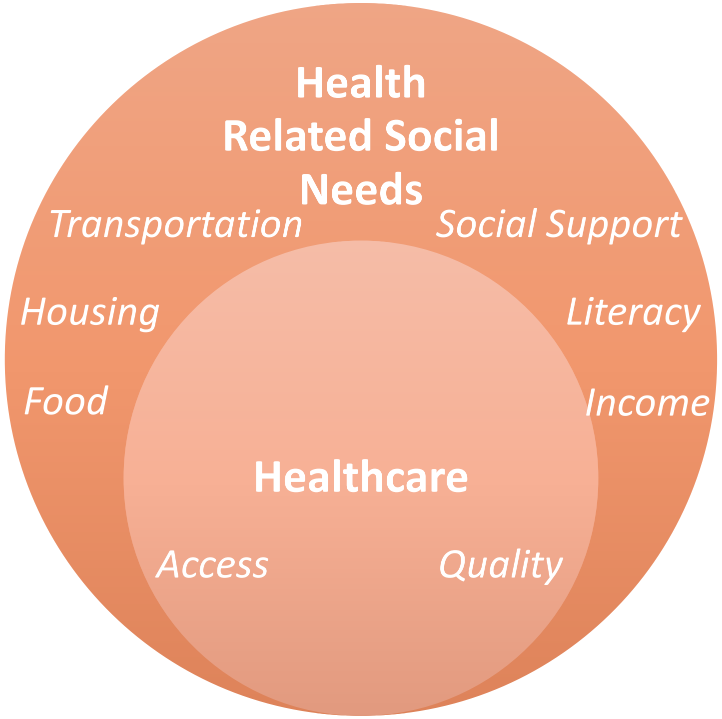
Income

Healthcare

Access

Quality

Where do we start? - Circles of control and influence by healthcare delivery systems



Health Related Social Needs

Transportation

Social Support

Housing

Literacy

Food

Income

Healthcare

Access

Quality

What are the known disparities in end-of-life care?

ACCESS

- Lower use of hospice
- Lower use of palliative care
- Delay in outpatient palliative care consultation
- Lower percent with advanced directives
- Less access to opioids in rural and minority neighborhoods

QUALITY

- Communication ineffectiveness
- Higher transitions at end of life: Home, home hospice, inpt hospice, SNF, hospital
- Higher rates of disenrollment from hospice with fewer re-enrollment
- Less treatment of pain at end of life
- Higher rates of discordant care from documented preferences
- Higher utilization of care at end of life

BARRIER FREE ACCESS

How easy is it for the most disadvantaged patients to access palliative care services?

Does palliative care exist?

Do people know about it?

Can they get it?

Can they afford to it?

Quality

Safe

- Does it cause harm?
  - Worsening mistrust –disenrollment; discordant care from documented preferences

Effective

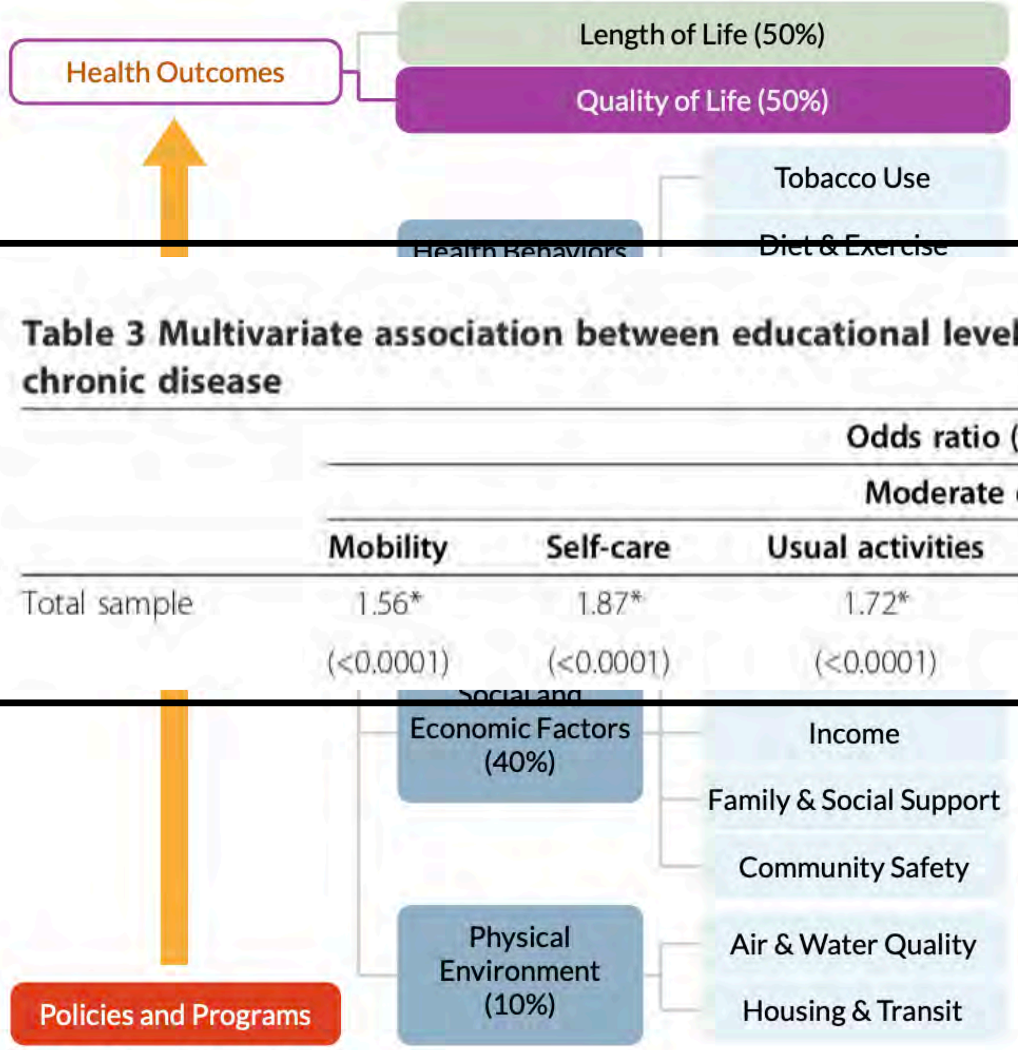
- Evidence-based care provided
  - Less treatment of pain; higher transitions of care locations; higher utilization at end of life

People-Centered

- Responds to individual preferences, needs, and values
  - Communication ineffectiveness; Mistrust;

https://www.who.int/health-topics/quality-of-care#tab=tab_1

Health-Related Social Needs: Quality of Life



County Health Rankings model © 2014 UWPHI

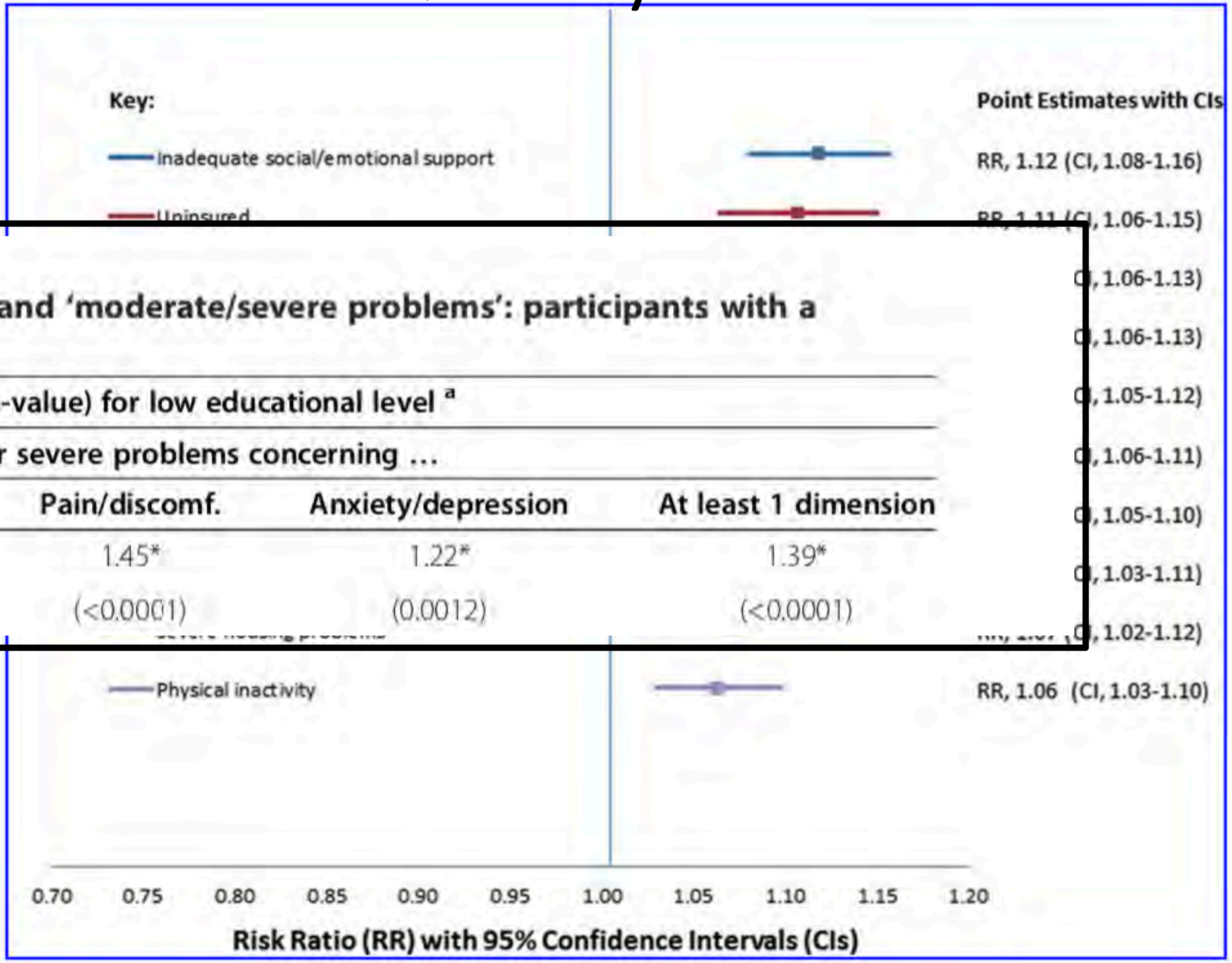


Table 3 Multivariate association between educational level and 'moderate/severe problems': participants with a chronic disease

	Odds ratio (p-value) for low educational level [a]					
	Moderate or severe problems concerning …					
	Mobility	**Self-care**	**Usual activities**	**Pain/discomf.**	**Anxiety/depression**	**At least 1 dimension**
Total sample	1.56*	1.87*	1.72*	1.45*	1.22*	1.39*
	(<0.0001)	(<0.0001)	(<0.0001)	(<0.0001)	(0.0012)	(<0.0001)

https://www.countyhealthrankings.org/explore-health-rankings/measures-data-sources/county-health-rankings-model
Mielck et al. Health and Quality of Life Outcomes 2014, 12:58 http://www.hqlo.com/content/12/1/58
POPULATION HEALTH MANAGEMENT Volume 21, Number 3, 2018 DOI: 10.1089/pop.2017.0142

Framework To Address

Disparity

- Identify the populations facing the disparity

Drivers

- Identify the major drivers of disparity

Mitigation

- Identify changes through engagement with population or ones that have been shown to mitigate disparity

Access

	Disparity	Drivers	Mitigation
Does Palliative Care Exist?	Rural; South; minority hospitals	Not enough trained palliative care providers; pharmacies do not carry medications in rural and minority neighborhoods; financially money-loosing specialty in current fee schedule in FFS payment model	Telehealth; Alternative payment models; Training primary providers; multi-disciplinary nurse-led care teams
Do People Know About It?	Racial; Ethnic	health literacy, misinformation, confusion with hospice	Palliative consults (in hospital) and co-located within specialty clinics (oncology); Community education (churches); Targeted outreach; CHW; video education models
Can They Get It?	Low SES; rural; Disabled	No transportation and no internet; low health literacy prevents navigation of complicated system; hours of availability; language barriers;	home care; telehealth; 24/7 coverage of services; language lines/interpreters; CHWs/navigators; transportation
Can They Afford It?	low SES; insurance coverage	Hospice doesn’t cover caregiving (only wealthy families can afford caregivers to take off work); Co-pays; Medication costs	Philanthropy services; Value-based payment models; Concurrent care models

Creating systems that improve equity

- Lessons learned from other fields (cardiology): Must be a targeted intervention specific to the population, not general quality improvement
- Must track disparities
- Must engage and have interventions designed by the community that you are targeting (CBPR)
- Racial diversity in workforce
- Acknowledge and help to mitigate SDoH as barriers to access/quality through partnerships in community
- Acknowledge and respect the mistrust patients have in health system with patience and humility
- Respect culture and practice cultural humility
- Meet patients where they are: both on their life/care journey and physically (at their home, in their churches, or when they are receiving care elsewhere)

Health-Related Social Needs

jaba
Live better. Longer.

regionten
a better life, a better community

Leading People Home
TJACH
Thomas Jefferson Area
Coalition for the Homeless

Loaves & Fishes
FOOD PANTRY

United Way
Thomas Jefferson Area
United Way

PVCC
PIEDMONT VIRGINIA
COMMUNITY COLLEGE

Charlottesville
Free Clinic

It Takes A Village

NETWORK
2 WORK
@PVCC

PATHWAYS
TO POPULATION HEALTH

partner
FOR
MENTAL
HEALTH

Jaunt

UVAHealth

ON OUR OWN
OF CHARLOTTESVILLE

CVHS
HEALTH SERVICES

Major delivery models of community-based palliative care (CBPC)

Clinic-based palliative care

- Imbedded in specialty clinic (i.e. oncology)
- Separate specialty clinic (referrals)
- Traveling clinic to other clinic sites (infusion center, specialty appointments, etc)

Home-based palliative care

- Comprehensive in-home services: provider, social work, nursing, etc.
- Telehealth
- RN/SW Case management – telephone coordination services

Continuity Palliative Care

- Follow patient in all settings

How to Design Systems with Equity at Center

Lessons from study on designing rural telehealth palliative care consultation in hospital:

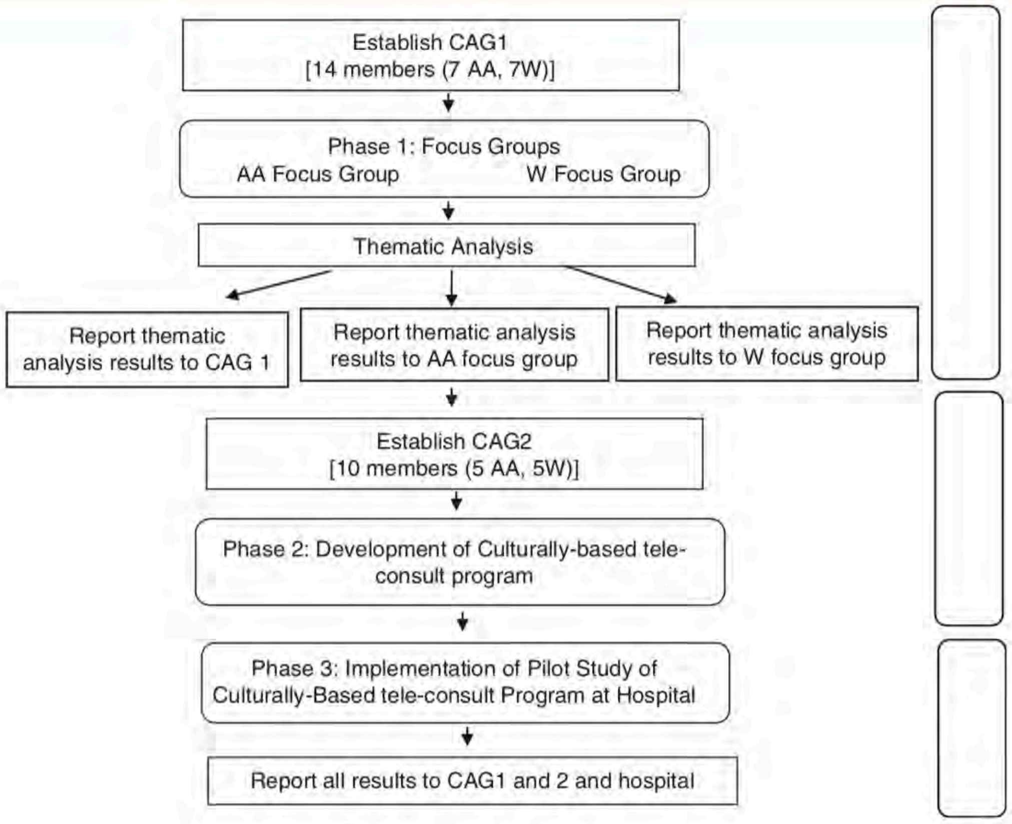


FIG. 1. Study design.

Health Equity Volume 4.1, 2020; DOI: 10.1089/heq.2019.0120

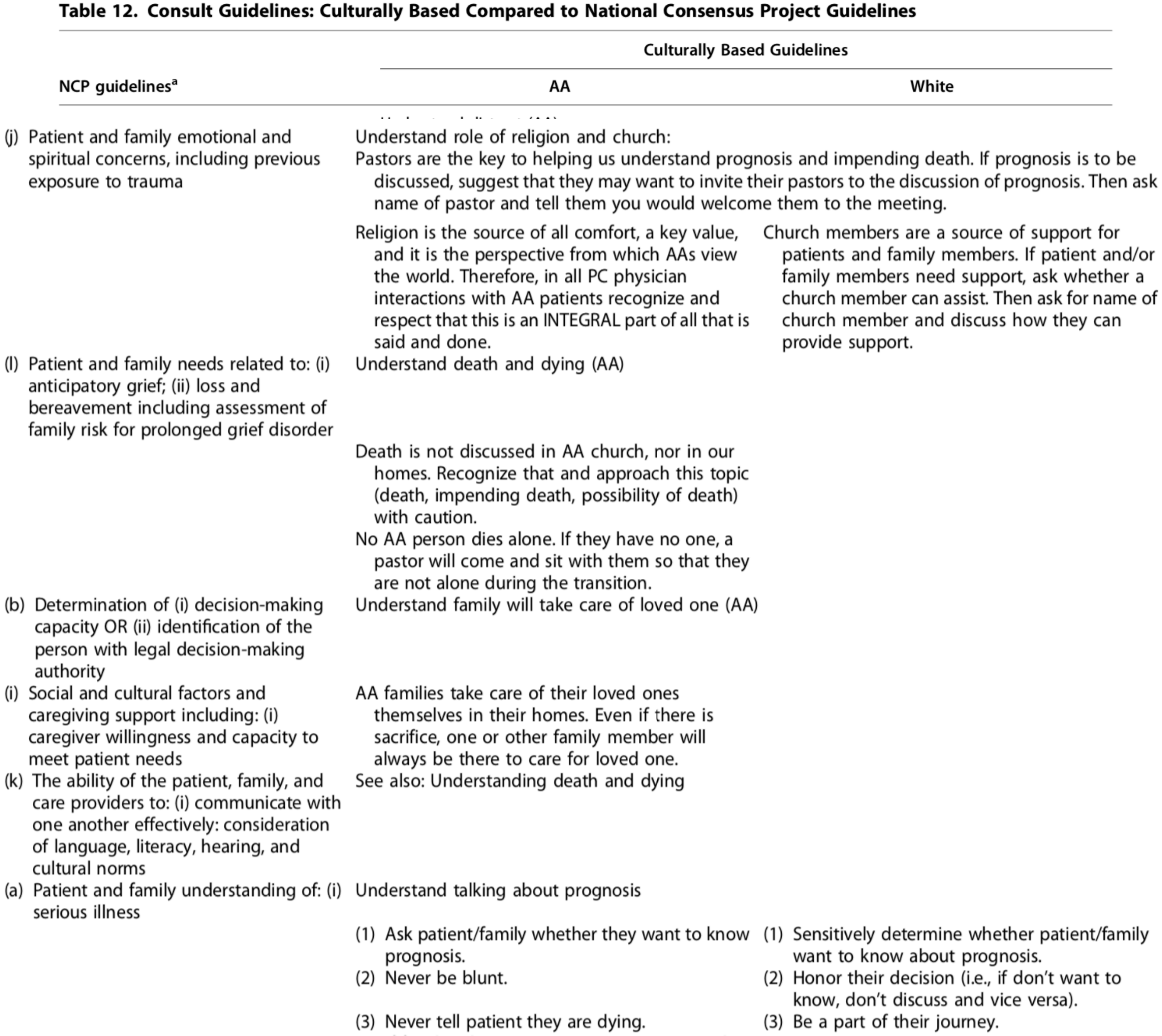


Table 12. Consult Guidelines: Culturally Based Compared to National Consensus Project Guidelines

	Culturally Based Guidelines	
NCP guidelines[a]	AA	White
(j) Patient and family emotional and spiritual concerns, including previous exposure to trauma	Understand role of religion and church: Pastors are the key to helping us understand prognosis and impending death. If prognosis is to be discussed, suggest that they may want to invite their pastors to the discussion of prognosis. Then ask name of pastor and tell them you would welcome them to the meeting.	
	Religion is the source of all comfort, a key value, and it is the perspective from which AAs view the world. Therefore, in all PC physician interactions with AA patients recognize and respect that this is an INTEGRAL part of all that is said and done.	Church members are a source of support for patients and family members. If patient and/or family members need support, ask whether a church member can assist. Then ask for name of church member and discuss how they can provide support.
(l) Patient and family needs related to: (i) anticipatory grief; (ii) loss and bereavement including assessment of family risk for prolonged grief disorder	Understand death and dying (AA)	
	Death is not discussed in AA church, nor in our homes. Recognize that and approach this topic (death, impending death, possibility of death) with caution. No AA person dies alone. If they have no one, a pastor will come and sit with them so that they are not alone during the transition.	
(b) Determination of (i) decision-making capacity OR (ii) identification of the person with legal decision-making authority	Understand family will take care of loved one (AA)	
(i) Social and cultural factors and caregiving support including: (i) caregiver willingness and capacity to meet patient needs	AA families take care of their loved ones themselves in their homes. Even if there is sacrifice, one or other family member will always be there to care for loved one.	
(k) The ability of the patient, family, and care providers to: (i) communicate with one another effectively: consideration of language, literacy, hearing, and cultural norms	See also: Understanding death and dying	
(a) Patient and family understanding of: (i) serious illness	Understand talking about prognosis	
	(1) Ask patient/family whether they want to know prognosis. (2) Never be blunt. (3) Never tell patient they are dying.	(1) Sensitively determine whether patient/family want to know about prognosis. (2) Honor their decision (i.e., if don't want to know, don't discuss and vice versa). (3) Be a part of their journey.

Health Equity Volume 4.1, 2020; DOI: 10.1089/heq.2019.0120

Community-Based Palliative Care: A promising model

Existing positives:

- Ability to help with mistrust from discharges from hospice without re-enrollment
- Address some of the stigma of hospice
- Inequities in access to palliative care for those who want more aggressive curative treatment options (Wang et al.)
- Meets patients where they are (physically and on journey of end-of-life)
- Some targeted outreach/interventions by predictive models

Continued barriers:

- Mistrust
  - Partnerships with churches, employ more staff of color, and hire more community health workers
- Financial: support for family caregivers/payment for outside organization support (time of pastors, food, housing, other health-related social needs)/cost of care coordination
  - Concurrent care models and either increased fee structure or value-based payment models
- Integration/coordination with existing care team
- Health literacy – ensuring care matches goals
  - More video instruction; easier accessibility of information

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What Are Your Ideas for Equity in Palliative Care?