PALLIATIVE CARE CONSIDERATIONS IN DIVERSE POPULATIONS

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Project Echo-Dementia

OBJECTIVES

- Outline the demographics of older adults with dementia in the United States
- Describe the specialty and concept of palliative care
- Define the differences between palliative care and hospice
- Explain the intersection of dementia and palliative care
- Identify special considerations for diverse older adults

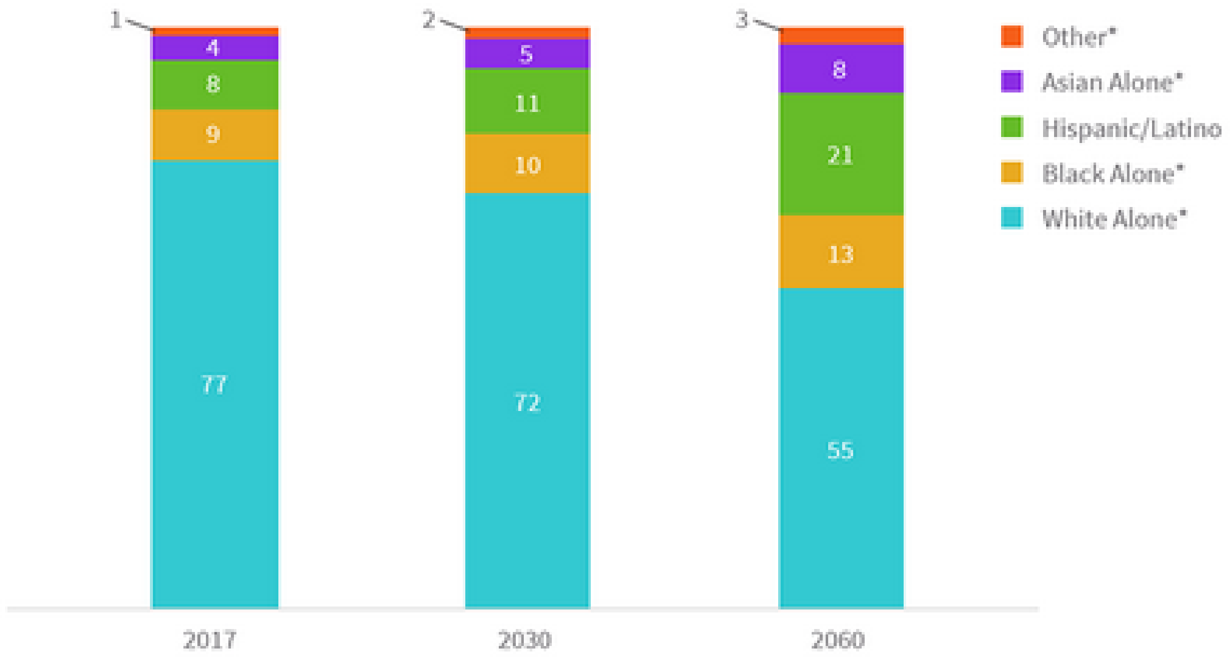
DEMENTIA IN THE UNITED STATES

- More than 6.5 million older adults (≥65 years of age) are living with dementia in the US (projected growth to 12.7 million by 2050)
- Foreign-born older adults in the US:
  - Associated with higher prevalence of dementia
  - Higher prevalence of undiagnosed dementia
  - More advanced disease at time of diagnosis

FIGURE 2

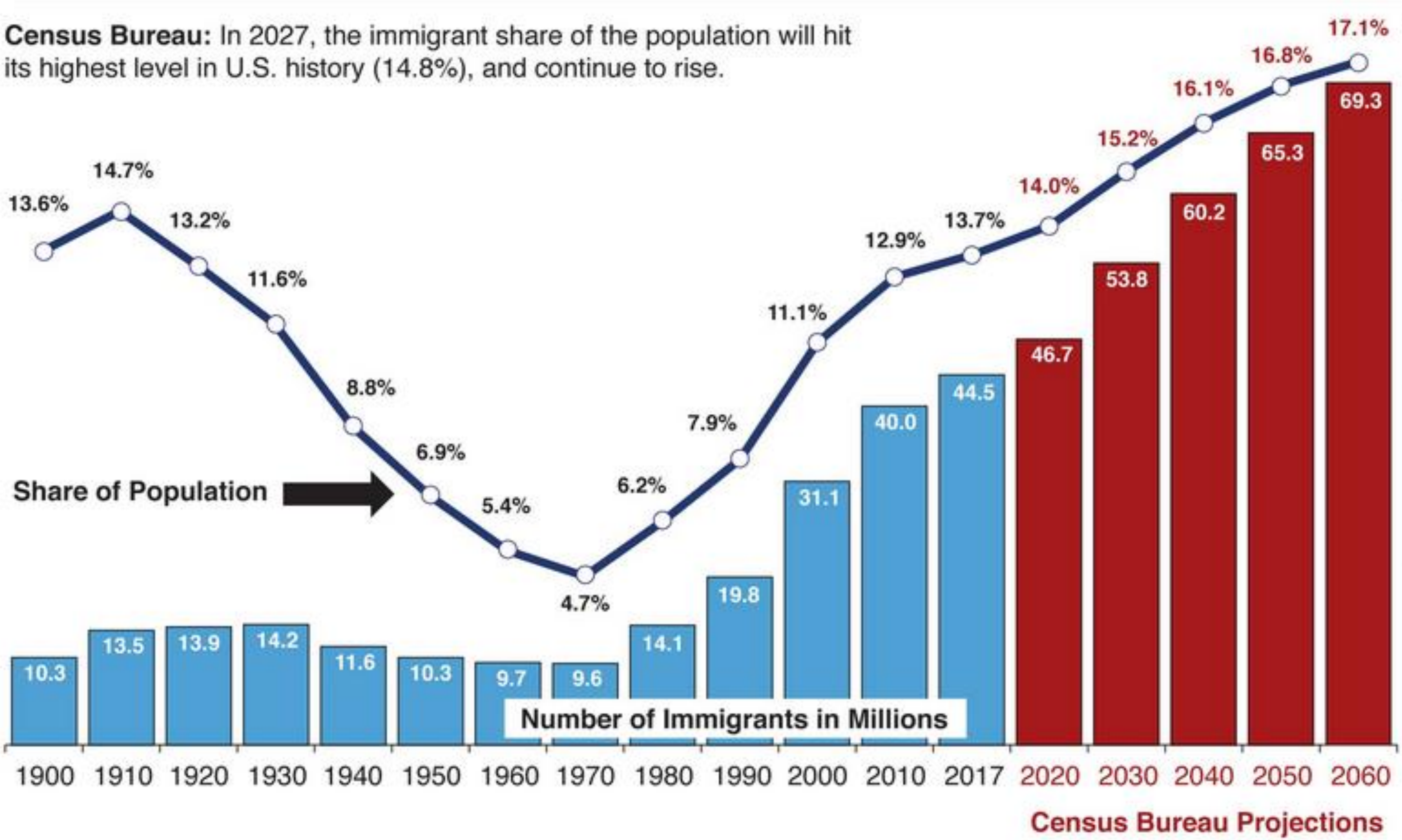
Racial and Ethnic Minorities Will Make Up an Increasing Share of the U.S. Older Population

Percent Distribution of the U.S. Population Ages 65 and Older by Race and Ethnicity, 2017, 2030, and 2060



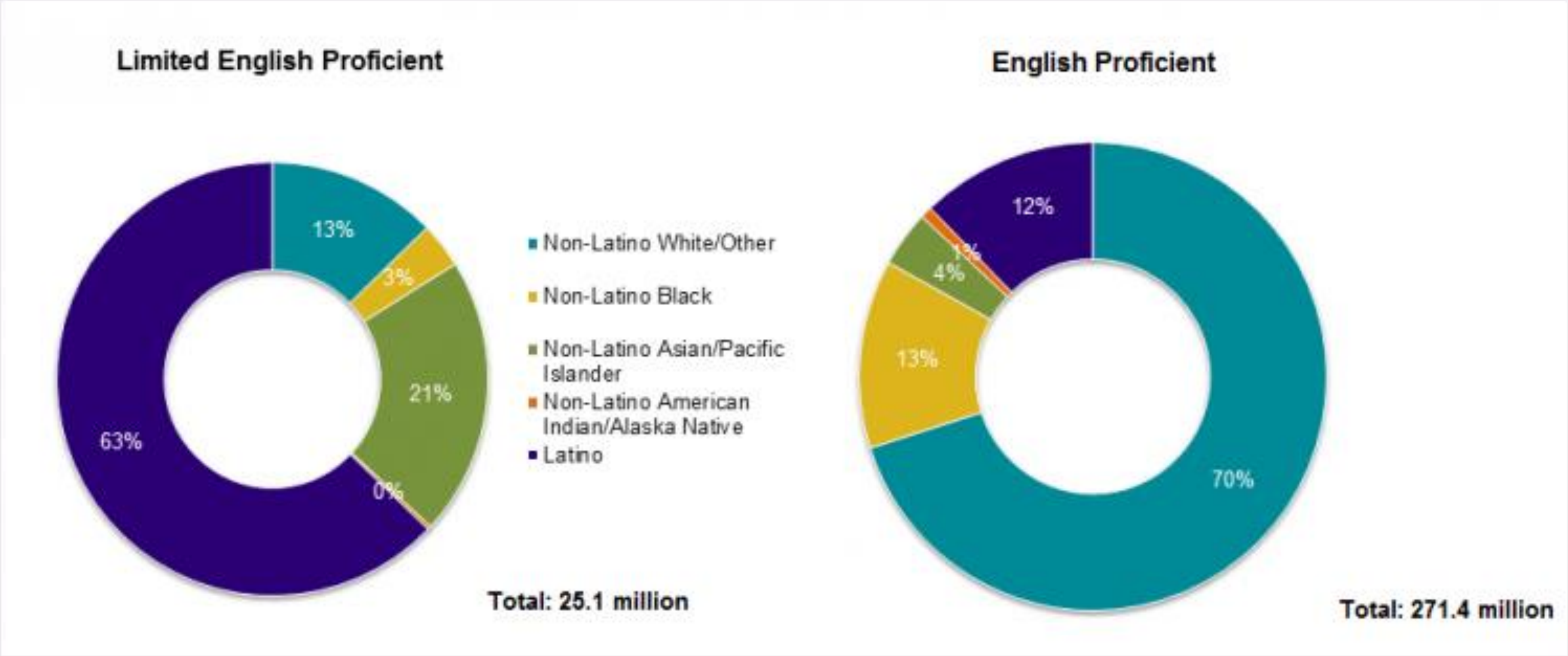
Note: An asterisk denotes non-Hispanic.

Source: U.S. Census Bureau, 2017 Population Projections.



Census Bureau: In 2027, the immigrant share of the population will hit its highest level in U.S. history (14.8%), and continue to rise.

Figure 4. Race and Ethnicity of LEP and English-Proficient Populations, 2013



Source: MPI tabulation of data from the U.S. Census Bureau 2013 ACS.

CONTRIBUTING FACTORS AND OUTCOMES

- **Language barrier** is the largest contributor of higher prevalence of dementia and rate of undiagnosed dementia
- Contributing factors to worse cognition in foreign-born older adults
  - Socioeconomic
  - Health literacy
  - Cultural
  - Psychosocial factors
- Older foreign-born adults are more likely to:
  - Have lower ACP engagement and completion of AD’s
  - Receive aggressive care at EOL
  - Die in a hospital
  - Have poor symptom management
  - Receive goal-discordant care
  - Less likely to utilize supportive services like palliative and hospice care

WHAT IS PALLIATIVE CARE?

TO PALLIATE

“make (a disease or its symptoms) less severe or unpleasant without removing the cause”

Dictionary Definition

PALLIATIVE CARE

“Palliative care is an approach focusing on the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual.”

World Health Organization

Palliative Care is specialized care for people with serious illness

PHYSICAL
Understanding Disease
Symptoms
Function
Medications

EMOTIONAL
Mood
Coping Mechanisms
Support
Hope

FUTURE PLANNING
Advance Directives
Decisions

SOCIAL
Relationships
Work – Hobbies
Resources
Finances

SPIRITUAL
Source of Strength
Source of Meaning
Religion – Faith Community
Legacy

What is the impact of serious illness on all parts of your life?

Source from SSM Health 2019: [Palliative Care: Caring for the whole person | SSM Health]

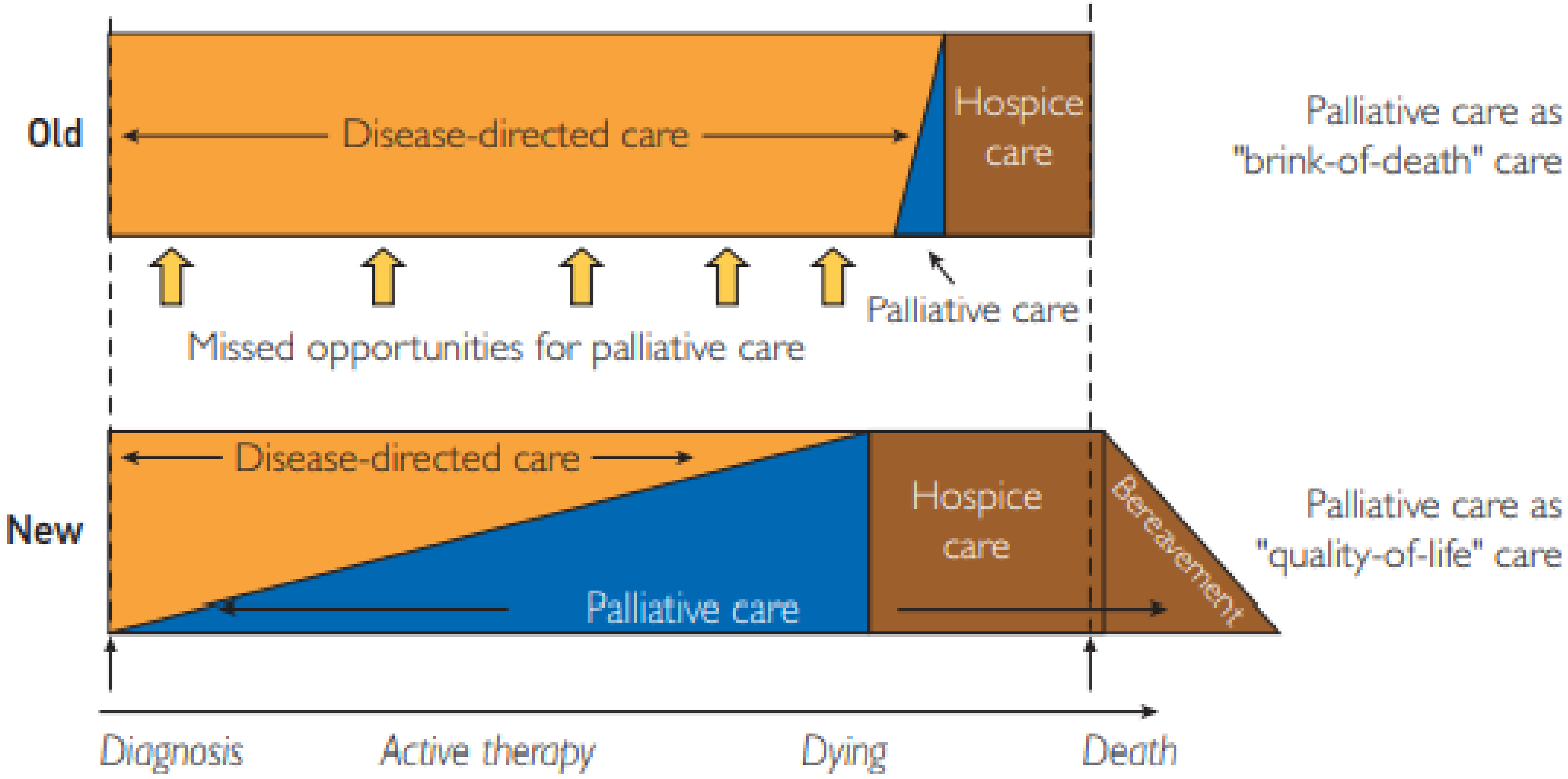


FIGURE. Palliative care—models of integration. Adapted from *J Palliat Med.*[21]

Buss M (2017)

WHO CAN BENEFIT FROM PALLIATIVE CARE?

- Anyone living with a serious illness regardless of age, prognosis, disease stage, or treatment choice
- Ideally provided early and throughout the illness in conjunction with curative or life-prolonging treatments

DEMENTIA CONSIDERATIONS

- Disease progression differs with dementia and does not often follow a “normal” disease trajectory
- Often a slow and steadily progressive illness considered as “chronically progressive”
- Unique challenges later in illness
  - Communication challenges
  - Increasing support for caregiver
  - Difficulty defining “terminal” phase of illness
  - Balancing the decision of medical interventions

NEXT STEPS

- Start conversations now and keep the conversations open, especially important when individual is able to make their own decisions
  - What matters most to you?
  - Who matters most to you?
  - What is an acceptable quality of life?
- Establish with palliative care earlier on

PALLIATIVE CARE VS HOSPICE?

"It's important to understand that while all hospice is palliative care, not all palliative care is hospice"

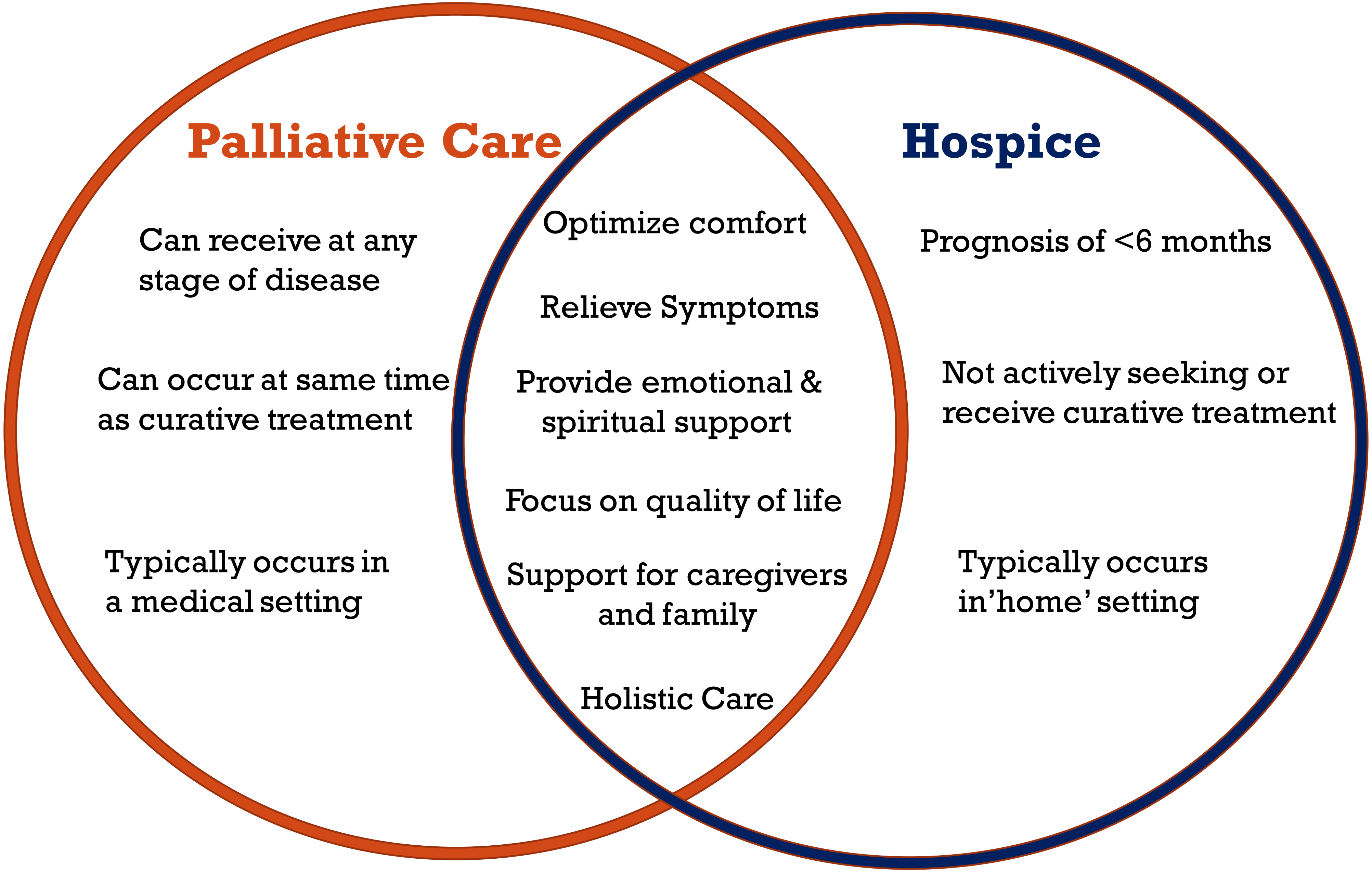
"We are not here to help patients give up, but rather to affirm their life during serious illness."

DR. SAGGAR

SSM Health Palliative Medicine Division Chief for Wisconsin region

HOSPICE

- Hospice is not a place, but a philosophy of care
- Prognosis of <6 months if disease follows its natural course
- Utilizes comprehensive interdisciplinary team-based approach



Palliative Care

Can receive at any stage of disease

Can occur at same time as curative treatment

Typically occurs in a medical setting

Hospice

Prognosis of <6 months

Not actively seeking or receive curative treatment

Typically occurs in’home’ setting

Optimize comfort

Relieve Symptoms

Provide emotional & spiritual support

Focus on quality of life

Support for caregivers and family

Holistic Care

FUTURE PLANNING

ADVANCE CARE PLANNING

- Process that includes discussions about care preferences and what matters most
- Improves receipt of medical care that is aligned with preferences, values and goals
- As illness trajectory changes, so can goals of care → Should continue with open conversations

CHALLENGES

- Population is older and more diverse than ever
- Foreign-born or immigrant older adults are different and have unique needs
- Navigating EOL care for older immigrants is challenging
- Older immigrants are more likely to:
  - Have lower ACP engagement and completion of AD’s
  - Receive goal-discordant care

PROVIDER EXPERIENCES

- 86% or providers reported conducting EOL care decision-making was challenging
- LEP patients had worse quality of GOC discussions w/o interpreters
- Difficult to conduct EOL conversations with **ALL** patients → Especially with different ethnicity
  - Language and medical interpretation issues
  - Religious and spiritual beliefs about death and dying
  - Ignorance of cultural beliefs, values and practices
  - Cultural differences in truth handling and decision making
  - Limited health literacy
  - Mistrust of doctors and the health care system

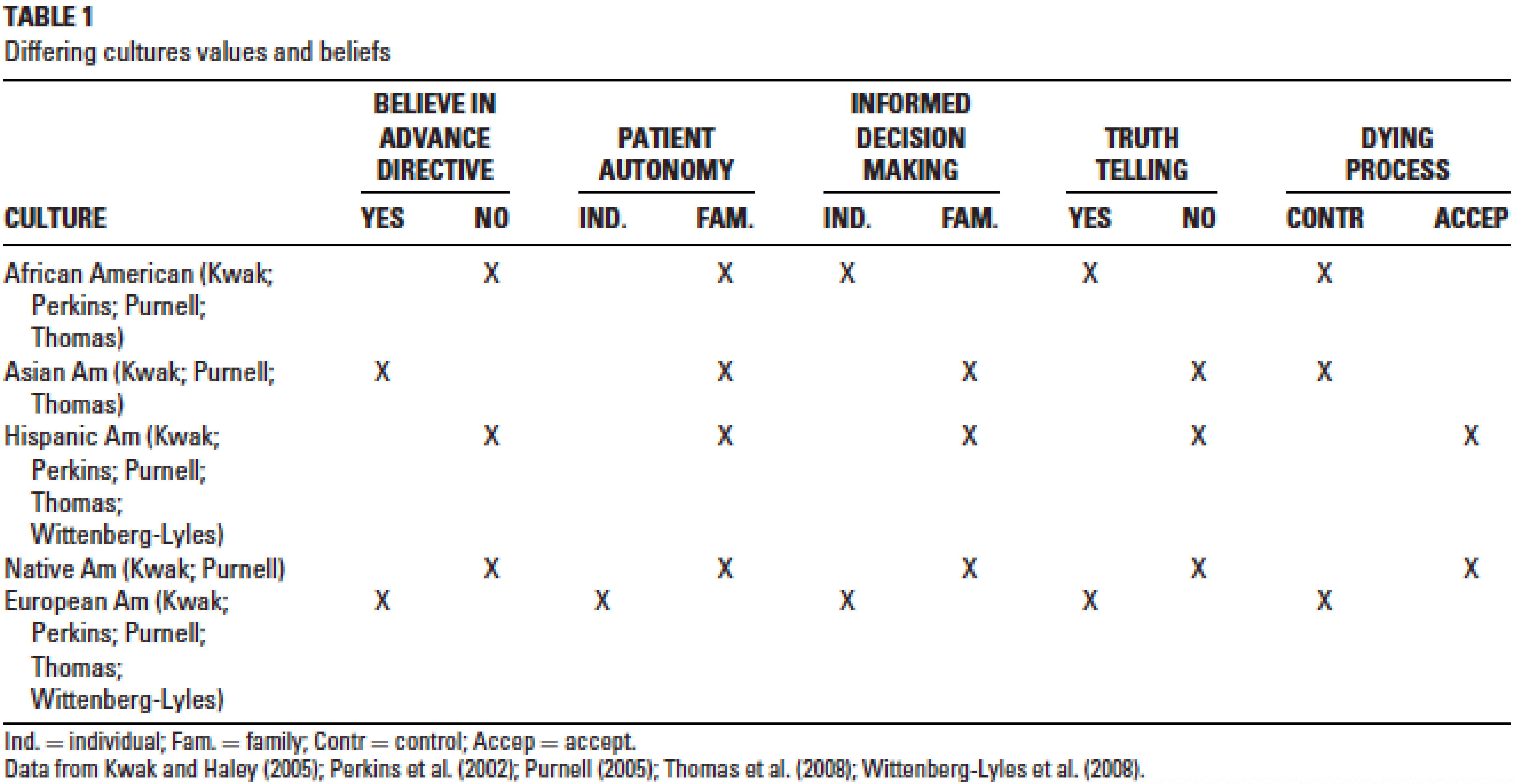


TABLE 1

Differing cultures values and beliefs

	BELIEVE IN ADVANCE DIRECTIVE		PATIENT AUTONOMY		INFORMED DECISION MAKING		TRUTH TELLING		DYING PROCESS	
CULTURE	YES	NO	IND.	FAM.	IND.	FAM.	YES	NO	CONTR	ACCEP
African American (Kwak; Perkins; Purnell; Thomas)		X		X	X		X		X	
Asian Am (Kwak; Purnell; Thomas)	X			X		X		X	X	
Hispanic Am (Kwak; Perkins; Purnell; Thomas; Wittenberg-Lyles)		X		X		X		X		X
Native Am (Kwak; Purnell)		X		X		X		X		X
European Am (Kwak; Perkins; Purnell; Thomas; Wittenberg-Lyles)	X		X		X		X		X	

Ind. = individual; Fam. = family; Contr = control; Accep = accept.

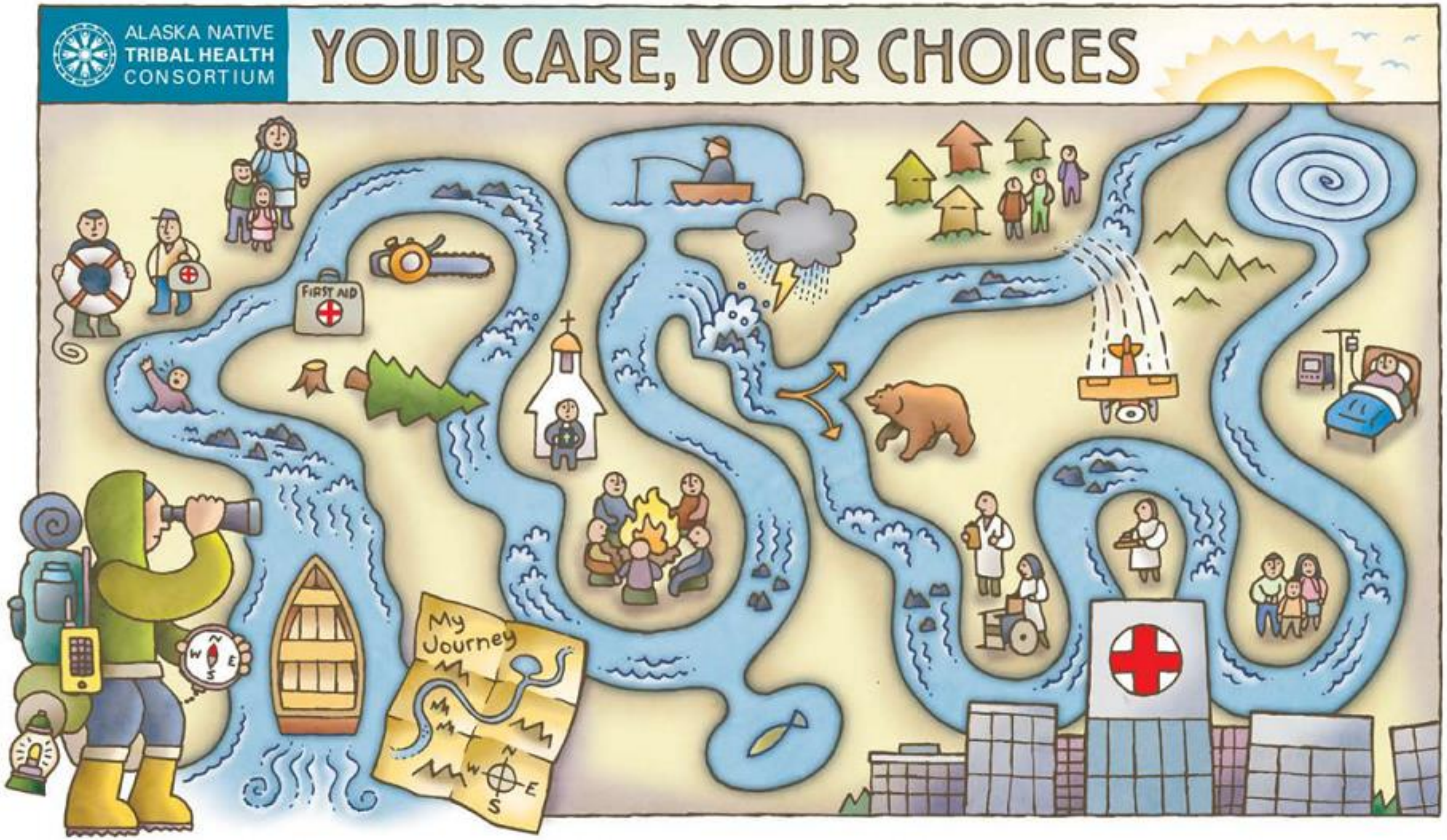
Data from Kwak and Haley (2005); Perkins et al. (2002); Purnell (2005); Thomas et al. (2008); Wittenberg-Lyles et al. (2008).

Zager BS and Yancy M. A call to improve practice concerning cultural sensitivity in advance directives: a review of the literature. *Worldviews on Evidence-Based Nursing*. 4th quarter. 2011.

CONVERSATION CONSIDERATIONS

- Patient and Family Perspective on:
  - Dementia terminology
  - Hospice and palliative care services (and definition)
  - Communication (such as the need for interpreter services or that only certain words are acceptable when discussing illness and dying)
  - Death and dying
  - Role of the family, including who is considered part of the family
  - Role in problem-solving and process of decision-making
  - Health and suffering
  - Western health care practices and their use of alternative traditional practices
  - Role of spiritual and religious beliefs and practice

Cultural Relevance in End-of-Life Care - EthnoMed



ANTHC's Wellness Map which is used to guide advance care planning (ACP) conversations

"By giving space and listening to the life experience of an individual, culture is no longer a barrier."
--Rona Johnson, MSN, A-GNP, NP-C, RN, OCN, CHPN
(Palliative Care Nurse Practitioner Alaska Native Tribal Health Consortium)

THANK YOU!

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