Engaging Marginalized Populations in Advance Care Planning

WMU Diversity & Inclusion Conference 2019

Hilary Kerr -- Feb 22, 2019
Objectives

1- Identify marginalized underserved populations in our region

2- Review how advance care planning conversations contribute to autonomous healthcare choices

3- Identify influences and barriers

4- Discuss solutions for reaching disadvantaged populations here in SW Michigan

No conflicts of interest to report
• **Ethnic Minorities**
  - African Americans
  - Hispanic Americans
  - American Indian (SW Mi Pokagon bands)
  - SW Michigan: Burmese

• **Under-resourced**
  - Rural
  - Low-income
  - Disabled
  - LGBT
  - SW Michigan: Migrant workers
Social Inequities
Race/ethnicity
immigration status
sexual orientation
gender

Institutional Inequities
Government Agencies
Schools
Corporations/ Businesses
Nonprofit agencies

Social Determinants of Health
80% of health outcomes are associated with social determinants of health
African Americans & Hispanics twice as likely to live in poverty

Lack of trust

- Access to Healthcare
  - Income
  - Transportation
  - Where reside/ location

- Insurance Affordability
  - Jobs that do not provide health insurance
  - Specialists/providers not accept Medicaid

Nearly 1/3 of providers will not accept a new Medicaid patient

{4} {5}
What if I have a sudden accident, injury or health change and am unable to make decisions?

Advance Care Planning

What if I have progressive chronic illness or disease and I am not able make medical decisions?

Planning for future healthcare

- Written plan stating life sustaining goals of care. What are acceptable and unacceptable ways for you to live?
- Who will speak for me if I can’t make my own medical decisions?
- Do my loved ones know my healthcare preferences?

ALL adults should talk to loved ones and document their wishes.
Advance Care Planning Ensures Care Your Way

Advance care planning conversations clarify the person’s goals of care

• Promote autonomy
• Foster shared decision-making & informed choice
• Foundation that guides a person’s medical decision.

Benefits of Advanced Care Planning:

• Increase likelihood person’s wishes are followed

• Less intensive treatments at end of life. Increase use of Hospice, decrease hospitalizations.

• Family/loved ones:
  More satisfied with the care
  Reduced emotional stress with difficult decisions
  Less complicated grief following the death of their loved one
The gift of your choices

Advance Care Planning Process

DECIDE
1- Patient Advocate(s)
2- Life-sustaining wishes / goals-of-care

DOCUMENT on advance directive
* signature witnessed by two individuals
* Patient advocate signatures willing if asked/able

DISCUSS preferences and values with loved ones

DISTRIBUTE advance directive so can be found

UPDATE with life changes

What skills and abilities are so important that you cannot imagine living without them?
Advance Care Planning Conversations

Future Healthcare

Advance Care Planning Education & Documentation
People make basic healthcare decisions of who they want as a patient advocate and how much life support to provide in event of emergency if they ever lose decision-making capacity. The key process is discussing preferences with patient advocates.

With Health Decline/Change

Goal of Care Conversations
Medical providers use patient’s specific diagnosis, prognosis and overall health condition to discuss and document personal healthcare goals.

Medical Care Decisions

Healthcare Medical Decision-Making
This may be the patient, the healthcare agent or guardian who makes person-centered medical decisions based on the situation and the wishes of patient.

Advance Directive

Ongoing ACP Conversations Guide Healthcare Decisions

Provider documentation in EMR
Some cases MI-POST form (Summer 2019)

Treatment Decisions align with wishes
Barriers:
* Lack of awareness
* Cultural differences
* Confusion
* Denial/ death-denying culture

Influences:
- Place/time/ recent situation as underlying influence
- Culture / Spirituality; Religion
- Life experiences of family/friends situations
- Family/loved ones direct or indirect pressure
- Health Literacy; understand and interpret medical information
Cultural differences should not separate us from each other, but rather cultural diversity brings a collective strength that can benefit all of humanity.

Robert Alan

Excellent resource: 2013 Chaplaincy Handbook of Patients’ Spiritual and Cultural Values for Health Care Professionals
Compounding Factors

Practitioners report several common barriers:
- Time
- Personal discomfort with the topic and patient emotions
- Lacking confidence to say the right thing
- Lack of training

Interestingly, a May 2018 survey by University of Massachusetts showed that while 13% of people say they’ve discussed their end-of-life wishes with their doctor, 60% of the time it is the patients or the family who initiate the conversation with the medical practitioner.
Patient's self-identified barriers to advance care planning...

- ACP perceived as irrelevant 84%
- Personal Barriers 53%
  (sad, not want to think about death, too busy)
- Relationship issues 46%
  (*poor relationship w family/friends or no supports*)
- Information needs 36%
- Health encounter time constraints 29%
- Problem with advance directive form 29%

2009 Schickedanz et al. study
Reaching out to underserved populations...

- **Translated resources:** ACP information, advance directives, appropriate reading levels, decisional aids. & use of translators

- **ACP outreach at targeted places:** support groups, organizations, gatherings (Pride events)

- **Collaborate with faith-based organizations/clergy** to help spread the message (could use *conversation sabbath* Oct 26-Nov 4 from The Conversation Project message)

- **Train community individuals in evidence-based Respecting Choices ACP facilitators** social/cultural organizational groups (ie Burma center) so message being spread and shared from within with trusted shared cultural understanding

- **Education and training programs** increase cultural sensitivity increasing knowledge and understanding on how different cultures view dying, communication and decision-making.

- **Train medical staff on communication techniques of delivering difficult diagnosis** and full disclosure of complete health status and options.
I have an advance directive, not because I have a serious illness, but because I have a family.

Do you have an advance directive?

What treatments would want or not want if you could not speak for yourself?

Have you chosen who would carry out those decisions?

Have you taken steps to increase chances your family was alerted if you have sudden medical event?

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Hilary available advance care planning outreach!

• To general audiences (clubs, churches, support groups etc.) Why important, steps of advance care planning and resources)

• Professionals who work with aging populations on more detailed advance care planning processes, forms and legalities

• Informational booth at health expo’s, fairs, events

• Employee meetings
Ain’t the Way to Die

Zdogg MD
Eminem/ Rihanna Remixed

https://www.youtube.com/watch?v=NAInRHicgWs

If time allows
References


Types literacy image on slide 11: https://teenliteracynow.files.wordpress.com/2013/04/rainbow.jpg

Chaplaincy Resource Link:
http://www.healthcarechaplaincy.org/userimages/Cultural%20Sensitivity%20handbook%20from%20HealthCare%20Chaplaincy%20%20(3-12%202013).pdf
References p 2


{11} University of Massachusetts Goals-of-Care Survey (May 2018). Obtaining document from library (but found within http://www.wbur.org/commonhealth/2018/05/15/gawande-end-of-life-conversations


Presenters Reminders….

We all have culture----It guides worldview and decision-making

SW Michigan/ Potawatomi in Michigan
   Pokagon band
   Match-e-he-nash-she-wish (Gun Lake tribe)
   Nottawaseppi Huron band

Powerful, complex forces exist/ influencers (SDoH)
   health and biology, genetics, individual behavior
   available health services -------legislative policy
   socioeconomic status physical environment (water, air)
   discrimination, racism
   literacy levels, (read but+health, technology, financial, data, insurance)