

SUMMARY

2021 End of Life Stakeholder Survey and Listening Sessions

March 2021

To ensure resources are invested as effectively as possible, Hospice Giving Foundation routinely examines the strengths and limitations of end-of-life care in our community. In early 2021, we engaged with stakeholders in the local system of care for the seriously ill, whose input and dedication we greatly value. We did this while recognizing the serious disparities that exist in access to health care and how that greatly affects our communities.

The primary goal was to deepen our understanding of what is affecting end-of-life care in our community. We used a survey and four, two hour listening sessions to prioritize the issues to be addressed, identify obstacles for meeting the needs, determine how the changing environment will influence our work over the long term, and be sure we aren't overlooking an important need or issue in our community.

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PART I - SURVEY

The five-question survey was hosted online at <https://www.surveymonkey.com/r/EOLstakeholder>.

Questions:

1. Over the past 3-5 years:
 - a. Do you feel people are more open to talking about death and dying? Y/N
 - b. Do you think people are more willing to prepare for end-of-life? Y/N
2. If yes, what do you think has made it acceptable to talk about death? If no, what could our community do to make it easier to talk and plan? [Open text box]
3. It is understood that money makes a lot of things work better. However, there are always other factors that affect how programs work and your level of pride in your services. List the top three issues that you feel present challenges to your work. [single line text boxes]
4. While we have identified needs that **we** feel are pressing, we cannot make strategic decisions without your input. Please rank order the following from 1= most important to 8= least important. If you feel an issue is not relevant for our community, please assign a rank of 0.

Rank	Issue
	Expansion of professional education at the local level/ EOL workforce development programs
	Programs that address healthcare disparities for end-of-life, hospice care, and palliative care
	Support services for in-home and/or family caregivers to support dying at home and the costs and emotional burdens of caring for a seriously ill loved one.
	In-home hospice care for (a)under-insured, (b)lower economic individuals, (c) culturally/traditionally/faith-based reticent families
	Palliative care services to non-English speaking families and those in rural communities
	Patient navigator programs to facilitate better access to services
	Facility-based hospice for (a)under-insured, (b)lower economic individuals, (c) people who are alone, limited resources and/or no family
	Hospice services for homeless individuals
	Other

5. Agency Input: [open text box]

SURVEY RESULTS

2021 End of Life Stakeholder Survey and Listening Sessions



END-OF-LIFE STAKEHOLDERS SURVEY

2021

PRESENTED BY



PURPOSE -TO HEAR FROM STAKEHOLDERS AND DEEPEN OUR UNDERSTANDING OF WHAT AFFECTS YOUR WORK AND WHAT YOU SEE AS THE NEEDS IN OUR COMMUNITY



authenticate the perceived needs and prioritize the issues to be addressed



identify the obstacles for meeting the perceived needs



determine how to make a more significant and lasting impact with the resources we have



determine how the changing environment will influence our work over the long term



be sure we aren't overlooking an important need in our community

WHO TOOK THE SURVEY

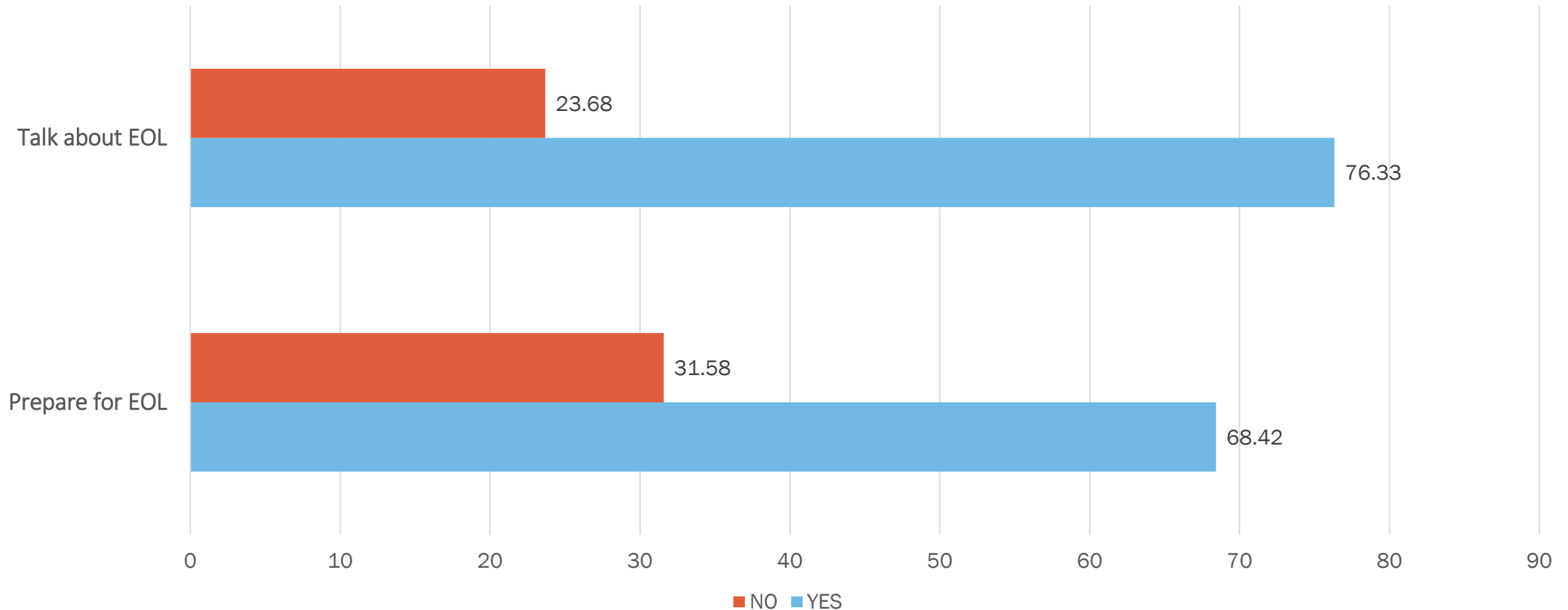
38 people responded including:

- Social workers
- RNs; Nurse Practitioners
- Physicians
- Clergy
- CEOs / Executive Directors
- Hospice leadership
- County Social Services
- Development officers/grant writers
- Outreach Coordinators



Thank you!

Q1 + Q2 - OVER THE PAST 3-5 YEARS, DO YOU FEEL PEOPLE ARE MORE OPEN TO TALKING ABOUT DEATH AND DYING? MORE WILLING TO PREPARE FOR END OF LIFE?



WHAT HAS MADE IT EASIER TO TALK ABOUT END OF LIFE?

- 11 out of 28 comments said COVID has forced people to talk about end of life
- The reality of an aging population, boomers, more published research on the topic of aging, and the work of nonprofits that deal with older constituents
- More publicity and education about Advance Care Planning
- Community events like *Juntos con Esperanza*
- In-patient and out-patient palliative programs, direct physician education
- More open media attention, more awareness of palliative and hospice programs
- People talking in the community

WHAT CAN OUR COMMUNITY DO TO MAKE IT EASIER TO TALK AND PLAN?

Engage **churches +
community** groups

Share **outcomes** from
surviving family members +
impacts when EOL plans are
not made

Outreach + communications
to the **medical community** as
well as the general public

Find the **trusted person**
Talk with **doctors**

Identify **advocates** +
consider 'not obvious'
partners

Public education **Interactive
events** like San Francisco's
Reimagine + workshops

Talk about options,
resources, reading lists
information + guidance in
Spanish and English

Use **media** - bulletin boards,
tv commercials + talk radio

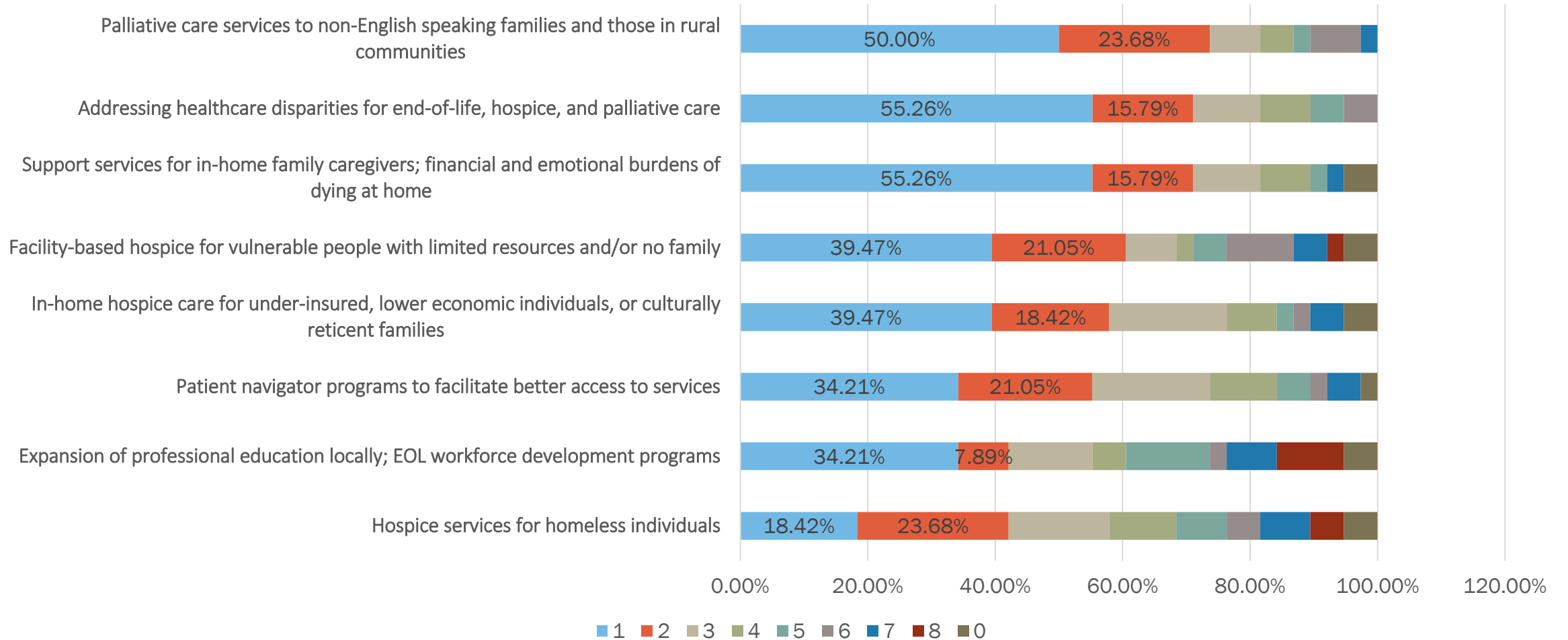
Normalize through
personal stories

TOP ISSUES THAT PRESENT CHALLENGES TO YOUR WORK.

- **Resistance to the Topic** - Cultural dynamics, family norms, family conflicts
- **System of Care** – Lacking resources and time, not enough continuity of care or coordinated communication and difficulties with regulatory issues and reimbursements
- **COVID** - Decreased accessibility of patient visits; phone vs in-person, “it's just brutally hard all around” – fears / anxieties, additional workloads, etc.
- **Lack of Knowledge/Education** – How to educate community partners and disseminate information to the public
- **Misperceptions about EOL work** - Health care providers unwilling to address the subject openly and proactively with their patients; Inconsistent messaging/verbiage
- **Staffing** – not enough clinical and Latinx staff
- **Technology Barriers** - people without access to or lack of comfort with technology

LOCAL PRESSING ISSUES

Most important to least important



WHAT DO YOU FEEL IS MISSING IN END-OF-LIFE CARE IN OUR COMMUNITY?

Coordination: Need **coordinated efforts** to improve end of life in respective care settings across the continuum; including **community outreach/patient navigators**.

Equitable Access: Need **access to health care information for all** members of the community, regardless of financial/cultural circumstances. Coordination of referrals between agencies. **Culturally relevant** educational strategies. People of color serving in the end-of-life space.

EOL Knowledge + Preparedness + Outreach: knowledge sharing to help people understanding scope of EOL services/care. Recommended standard tools, like **a roadmap or flow-chart, to guide decisions**. Need physicians to talk more with patients and families about EOL care.

Funding: Insufficient support for low-income families. Need **resources to help patients** find placement for when there is no financial or family support. More public benefits.

NEEDS SPECIFIC TO HOSPICE + PALLIATIVE CARE

- A lack of understanding of the goals and value of Hospice, **referrals too late**
- Inpatient hospice; **a place to die**
- Robust **in-patient** palliative medicine services in hospitals -robust **outpatient** palliative medicine services throughout community + **coordination of the two**
- Utilization so that patients can **access PC and move to hospice care in a timelier** way
- Solid **provider-led Palliative Care** programs and more individuals to provide the services
- Education and **teaching** methods to continue **the journey of grieving and growth**, such as mindfulness trainings
- Additional **expressive therapies**, especially for adults

PART II – LISTENING SESSIONS

We hosted four facilitated discussions aimed at collecting information based on stakeholder experience and expertise. We requested broad representation at these sessions with people who can represent the services, client/patient/family needs, provider needs, and the organization. Four sessions were offered to make it convenient to participate, and attendees responded for a specific session upon completion of the survey.

While listening sessions did not cover every aspect of the issues, the emphasis was to identify how the issues affect stakeholder's ability, as a provider or an organization, to effectively deliver services. Discussion then focused on what would strengthen the services in this community and identifying what resources and partnerships are needed.

Thursday, Jan 28th, 8:30 – 10:30 AM

Tuesday, Feb 2nd, 4:00 – 6:00 PM

Wednesday, Feb 3rd, 6:30 – 8:30 PM

Friday, February 5th, 12:00 – 2:00 PM

Session Agenda:

- First 30 minutes, HG Foundation report back to group on survey responses
- 1 Hour, group discussion on top issues based on the priorities identified in the survey
- Final 30 minutes, open group discussion to summarize themes, identify next steps, and further explore health care disparities in our communities

To help attendees prepare for the upcoming listening sessions, HG Foundation provided prompting questions and references. On the survey, eight issues were listed, and respondents were asked to rate them on a scale of 1-8: 1 being most important. While all issues received some 'most important' ratings, three issues stood out as consistently receiving either a rating of 1 or 2 on the scale:

1. 73.68% - Palliative care services to non-English speaking families and those in rural communities
2. 71.05% - Addressing healthcare disparities for end-of-life, hospice, and palliative care
3. 71.05% - Support services for in-home family caregivers; financial and emotional burdens of dying at home

Information, prompting questions and references provided to attendees in advance of the session for these top three priorities are included on the following pages. *As of March 4, 2021, we are still summarizing notes from these four sessions based on recorded transcripts. Those will be added to this summary when complete.*

ISSUE # 1: PALLIATIVE CARE SERVICES TO NON-ENGLISH SPEAKING FAMILIES AND THOSE IN RURAL COMMUNITIES

50.00% of respondents ranked this issue as the highest priority in our community; the combined # of 1st and 2nd position rankings = 73.68%

Discussion Opener:

Given the social, economic, and physical conditions in each county, what tools will best allow us to expand access to Palliative Care in rural communities?

Other questions to consider:

- What is the role of community clinics in providing Palliative Care?
- How has telemedicine changed the provision of Palliative Care?
- What is the role of trusted community organizations, like churches, schools, or community centers, in helping improve access to care when someone has a serious illness?

1. *Palliative care services to non-English speaking families and those in rural communities*: 50.00% of respondents ranked the following issue as the highest priority in our community; the combined # of 1st and 2nd position rankings = 73.68%

Background Access to Palliative Care

From our brief search, we found very limited journal articles about Palliative Care in rural communities. One article discussed the issue in Australia, another focused on a small area in Alabama. An article that seemed most relevant is by Ronit Elk entitled, [A Community–Developed, Culturally–Based Palliative Care Program for African American and White Rural Elders with a Life–Limiting Illness: A Program By The Community for the Community,¹](#). This describes a program in rural South Carolina that began its work with community focus groups and then developed a community based palliative care consult program. Other articles that came up during my search were about tele-health and how that has increased access.

According to the U.S. Census Bureau, Monterey County has a total area of 3,771 square miles. By contrast, Santa Cruz County is 441 square miles, and San Benito County is 1,388 square miles. Both Monterey and San Benito are largely rural with major variations in economic wealth and resources. On the Opportunity Index, which includes various factors that influence people’s opportunities including health, Monterey County ranks C+, and both San Benito County and Santa Cruz County score B-.

Discussion Opener:

1. Given the social, economic, and physical conditions in each County, what tools will best allow us to expand access to Palliative Care in rural communities?

Other questions to consider:

2. What is the role of community clinics in providing Palliative Care?
3. How has telemedicine changed the provision of Palliative Care?
4. What is the role of trusted community organizations, such as churches, schools, or community centers, in helping improve access to care when someone has a serious illness?

¹ A Community–Developed, Culturally–Based Palliative Care Program for African American and White Rural Elders with a Life–Limiting Illness: A Program By The Community for the Community, Ronit Elk, Nov. 2017. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5696783/>

ISSUE # 2 - ADDRESSING HEALTHCARE DISPARITIES FOR END-OF-LIFE, HOSPICE, AND PALLIATIVE CARE

55.26% of respondents ranked the following issue as the highest priority in our community; the combined # of 1st and 2nd position rankings = 71.05%

Discussion Opener:

How do healthcare disparities manifest in your organization? What happens to people that you are trying to serve?

Other questions to consider:

- How do you talk to Latino families about hospice and/or palliative care? How do they react to the conversation?
- Starting close to home what is NOT working, what can we do in our communities to make end-of-life care more equitable?
- What resources are needed? What can your organization contribute?

2. **Addressing healthcare disparities for end-of-life, hospice, and palliative care:** 55.26% of respondents ranked the following issue as the highest priority in our community; the combined # of 1st and 2nd position rankings = 71.05%:

Background Healthcare Disparities:

Researchers from the John Hopkins University School of Nursing in Baltimore examined March 2020 data from three national health care databases that outlined disparities in hospice and palliative care. Of the studies the researchers assessed across the PubMed, Embase and CINAHL EBSCO databases, 70% described differences in access outcomes to hospice and palliative care by ethnicity, race or socioeconomic status.

Studies have shown that demographic disparities can limit the [scale](#)² of hospice. Roughly 82% of Medicare decedents in 2018 were Caucasian, according to the National Hospice & Palliative Care Organization (NHPCO). Comparatively, slightly more than 8% were African-American; 6.7% were Hispanic, and 1.8% were Asian. That year, only 0.4% of Medicare decedents were Native American.³

“People from minority groups are often diagnosed with diseases at late stages and have worse outcomes, leading not only to higher mortality rates, but also less engagement in planning activities in end of life [and] under-utilization of hospice care,” said Ritchell Dignam, M.D., chief medical officer for VNSNY Provider Services and hospice medical director for VNSNY Hospice and Palliative Care. “Important factors in disparities for accessing health care, advanced care planning and hospice utilization among minorities of color compared to whites include those based on influences of cultural and religious beliefs, lack of knowledge of hospice services or belief that hospice provides an inferior level of care. Socio-economic status can also affect access to health care providers, for example, lack of insurance with fear of cost when accessing health care.”

About 82% of hospice patients in 2018 were White, compared to 8.2% for African Americans and 6.7% for Hispanics, according to the National Hospice & Palliative Care Organization. The total for all other racial or ethnic demographics totaled 3.1%⁴

Discussion Opener:

1. How do healthcare disparities manifest in your organization? What happens to people that you are trying to serve?

Other questions to consider:

2. How do you talk to Latino families about hospice and/or palliative care? How do they react to the conversation?
3. Starting close to home what is NOT working, what can we do in our communities to make end-of-life care more equitable?
4. What resources are needed? What can your organization contribute?

² **Demographic Disparities Impact Patients, Limit Hospice Scale;** Jim Parker, May 21, 2019, <https://hospicenews.com/2019/05/21/demographic-disparities-impact-patients-limit-hospice-scale/>

³ **Race, Socioeconomics Are Largest Barriers to Hospice and Palliative Care;** Holly Vossel, January 19, 2021 <https://hospicenews.com/2021/01/19/sociodemographic-barriers-to-hospice-and-palliative-care/>

⁴ **Hospices Seek to Bridge Racial Divides in Access to Care;** Holly Vossel, September 20, 2020 <https://hospicenews.com/2020/09/20/hospices-seek-to-bridge-racial-divides-in-access-to-care%ef%bb%bf/>

ISSUE # 3 - SUPPORT SERVICES FOR IN-HOME FAMILY CAREGIVERS; FINANCIAL AND EMOTIONAL BURDENS OF DYING AT HOME

55.26% of respondents ranked the following issue as the highest priority in our community; the combined # of 1st and 2nd position rankings =71.05%

Discussion Opener:

Of the support that is currently offered for in-home caregivers: respite care, hospice visits, volunteer visitors, organically arranged friends/ family / local network visits, paid caregivers, where have you seen the greatest gaps and what has the potential to be augmented in a meaningful way?

Other questions to consider:

- When someone tells you (as a clinician) that they want to die at home, what do you say? What actions do you take to help the patient and family prepare? What is offered throughout the experience?
- If a non-hospice or PC colleague (clinician/physician) told you their patient wants to die at home, what would you recommend?
- If you could develop one program to assist in-home caregivers, what would that be? What would it take? With whom would your organization need to partner to make a significant impact?

3. ***Support services for in-home family caregivers; financial and emotional burdens of dying at home:***
55.26% of respondents ranked the following issue as the highest priority in our community; the combined # of 1st and 2nd position rankings =71.05%

Background Caregiving

The majority of people in the country say they would prefer to die at home. Yet, with that comes burdens and suffering. Below are statistics from Stanford University Palliative Care Program.

- Studies have shown that approximately 80% of Americans would prefer to die at home, if possible.
- Despite this, 60% of Americans die in acute care hospitals, 20% in nursing homes and only 20% at home.
- A minority of dying patients use hospice care and even those patients are often referred to hospice only in the last 3-4 weeks of life.
- However, not every patient will want to die at home. Dying at home is not favored in certain cultures (due to cultural taboos) and some patients may wish not to die at home, out of concern that they might be a burden on the family.

The following excerpt is from Jessica Zitter, MD, in context of her film: [Caregiver: A Love Story](#).

2017 was the first time in over a hundred years that more people died at home than in a hospital⁵. But in bringing the dying home, 53 million family caregivers, who, provide an estimated 37 billion hours of care per year, are now working double-time, and for free, without enough training or support. And while an increasing number of families are benefiting from the important work of hospice, they remain unprepared for the volume of work, some of it requiring significant medical and nursing skill, for which they receive little to no training. Most do not have extra funds to hire outside help-- 32% of caregivers use up their savings doing this work.

Discussion Opener:

1. Of the support that is currently offered for in-home caregivers: respite care, hospice visits, volunteer visitors, organically arranged friends/ family / local network visits, paid caregivers, where have you seen the greatest gaps and what has the potential to be augmented in a meaningful way?

Other questions to consider:

2. When someone tells you (as a clinician) that they want to die at home, what do you say? What actions do you take to help the patient and family prepare? What is offered throughout the experience?
3. If a non-hospice or PC colleague (clinician/physician) told you their patient wants to die at home, what would you recommend?
4. If you could develop one program to assist in-home caregivers, what would that be? What would it take? With whom would your organization need to partner to make a significant impact?

⁵ <https://www.nejm.org/doi/full/10.1056/NEJMc1911892>

INDEX: 2021 End of Life Stakeholder Survey and Listening Sessions Participants

Laurie Bend, Outreach Director, Meals on Wheels
Vicky Canepa Berg, Attorney, Legal Services for Seniors
Elizabeth Birruete, Outreach Coordinator, CCVNA
Karen Blank, Attorney, Legal Services for Seniors
Lori Butterworth, Executive Director, Jacob's Heart Childrens' Cancer Services
Kevin Causey, Vice President, Chief Development Officer, Montage Health Foundation
Cathy Conway, CEO Hospice of Santa Cruz County
Leah Dahlfred, MD, Family Practice Medicine, Mee Memorial Hospital
Rev. Filemón Díaz, Pastor, St. Mark's Church, King City
Alyssa Erikson, RN, PhD, Associate Professor and Chair, Department of Nursing, CSUMB
Andrea Fernandez, RN, Director Westland House and Hospice of the Central Coast
Vivian Garcia, MD, Family Medicine Resident, Natividad Medical Center
John Hausdorff, MD, Palliative Medicine, Oncologist, Montage Health, Chair Monterey County Palliative Care Collaborative
Deacon Warren Hoy, Director of Family Life and Social Justice Ministries, Catholic Diocese of Monterey
Shirley Kiatta, RN, CMC, Elder Care Consultant
Creighton Mendivil, Executive Director Legal Services for Seniors
John O'Brien, CEO Central Coast Senior Services
Kristina Olfson, DNP, RN, FNP-BC
Erika Olivarez, M.A., LMFT, Alliance on Aging
Nora Peyton, Regional Director, Alzheimer's Association
Jennifer Ramirez, Executive Director, Partnership for Children
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Silka Saavedra, Creative Services Director - King City Communications
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