

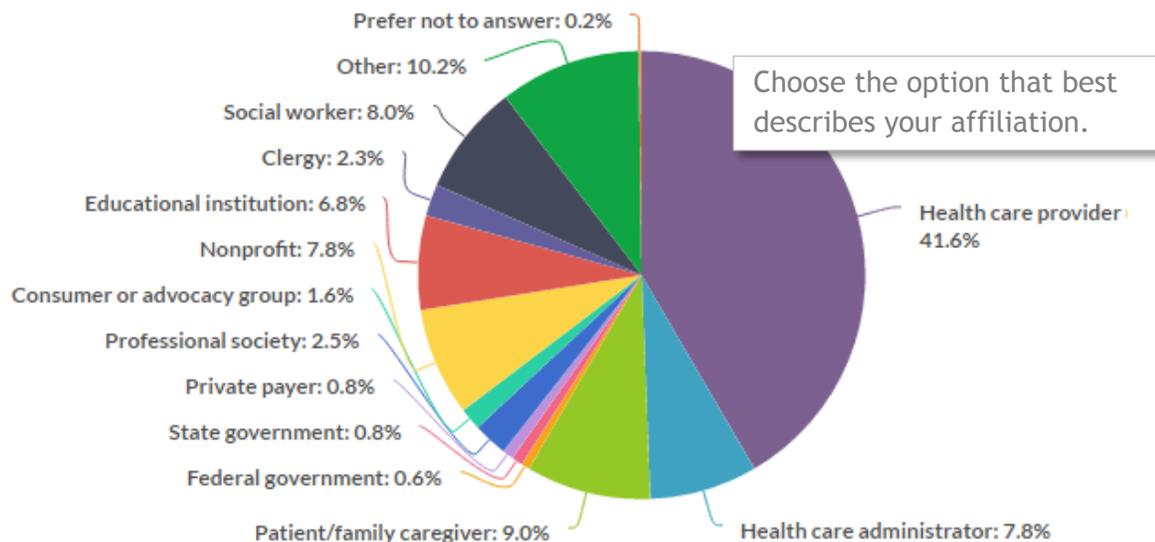
Questionnaire: Progress, Barriers, & Needs in End-of-Life & Serious Illness Care

Summary Results

Background: Between March 17 and May 16, 2016, the National Academy of Medicine collected responses to a questionnaire to assess progress since the release of the *Dying in America* report and to inform the work of a new Roundtable on Quality Care for People with Serious Illness at the National Academies of Sciences, Engineering, and Medicine.

Total responses: 496

The vast majority of respondents were health care providers. Of the providers who specified their profession, there was strong representation from nurses, nurse practitioners, physicians, and palliative specialists of all kinds.

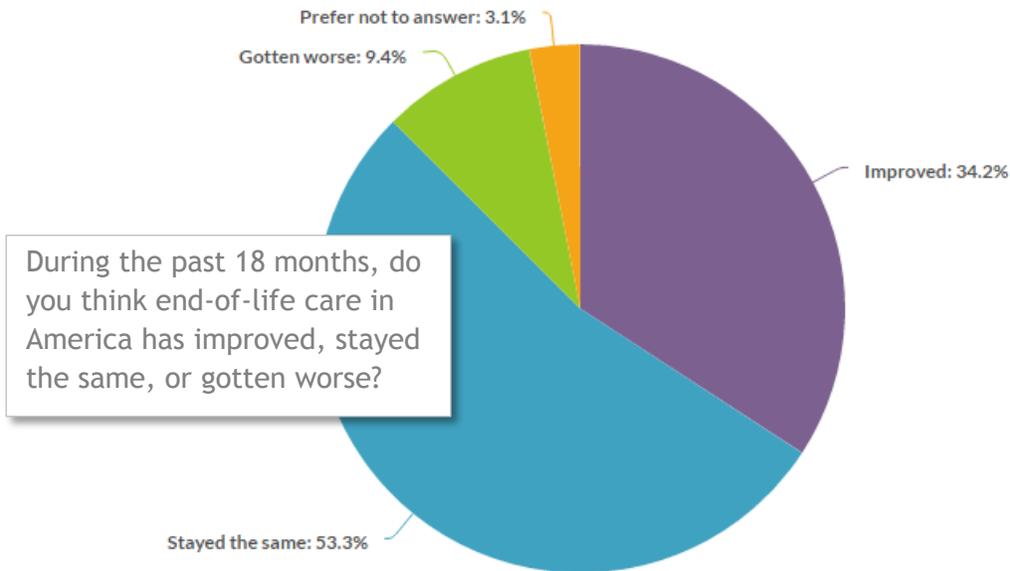


Almost 87 percent of respondents were familiar with findings and recommendations from the *Dying in America* report, and about 56 percent said other members of their professional peer group were either somewhat or very familiar with the report.

About 54 percent of respondents said the *Dying in America* report had affected their professional or personal lives. Themes emerging from the open-text responses indicated that the report has

- validated or reinforced work already being done; provided credibility and an evidence base to justify investments
- raised visibility and increased public awareness
- served as a tool for organizations to evaluate programs and identify gaps
- served as a useful teaching resource
- contributed to the development and funding of new positions and programs

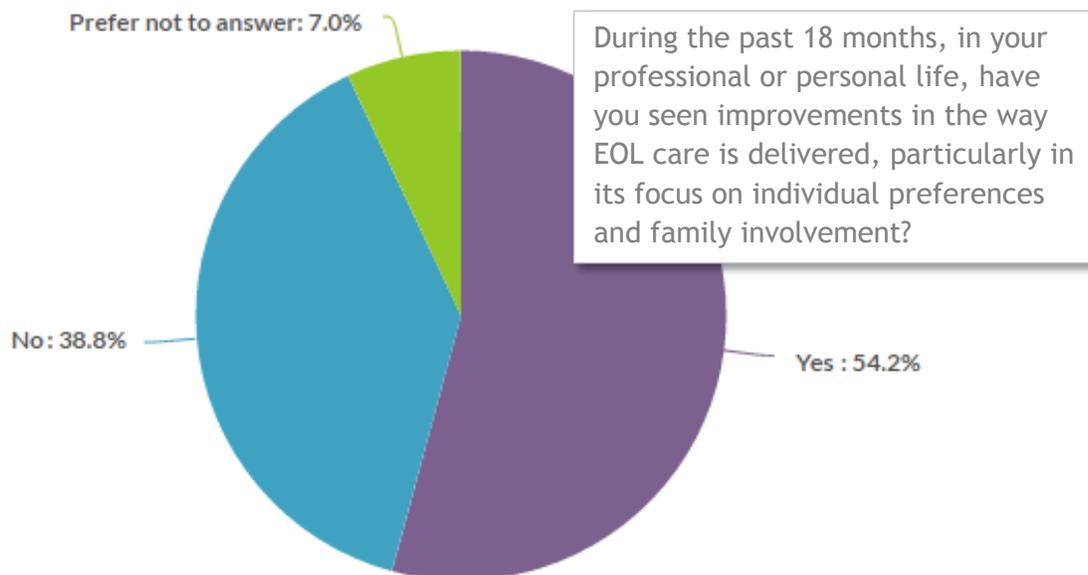




More than [one-third](#) of respondents said end-of-life care had improved in the past 18 months. More than half said it had stayed the same, and about 9 percent said it had gotten worse.

Care Delivery

When asked to specify whether they had seen improvements in the way end-of-life care is delivered, particularly in terms of a focus on individual preferences and family involvement, about [54 percent](#) said yes, while about 39 percent said no.



Examples given by those who saw improvements in care delivery:

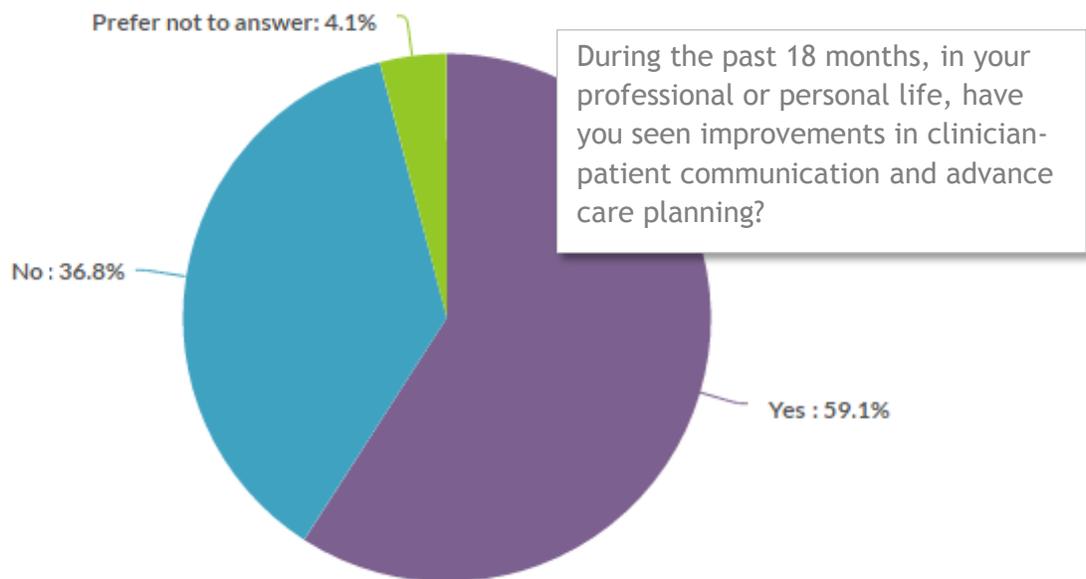
- Faster referrals to palliative care and hospice; more frequent consults with palliative care teams
- Greater awareness of the importance of communication and advance care planning (ACP) among health care providers
- Greater knowledge of care options among patients and families

Examples given by those who did not see improvements in care delivery:

- Hospice funding and eligibility challenges; late referrals and shorter lengths of stay in hospice
- ACP counseling still occurring too late
- Ongoing reluctance among patients, families, and providers to acknowledge that death may be near
- Too few options for palliative care in the community

Communication and Planning

When asked to specify whether they had seen improvements in clinician-patient communication and advance care planning (ACP), about **59 percent** said yes, while about 37 percent said no.



Examples given by those who saw improvements in communication and ACP:

- More ACP counseling thanks to Medicare reimbursement
- Media focus on ACP leading to greater awareness and support among health system leadership, providers, and families

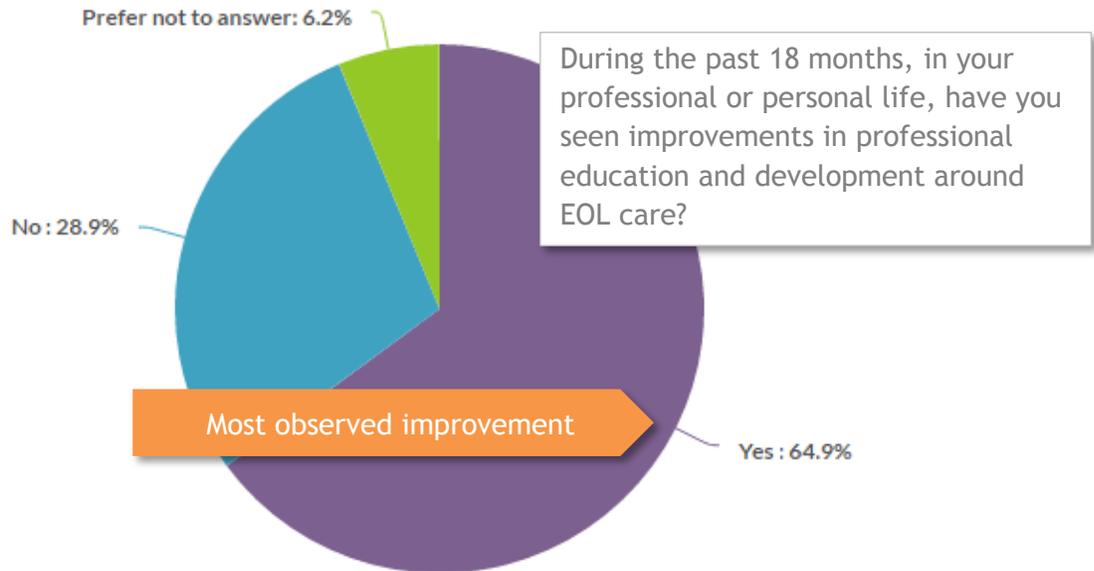
Examples given by those who did not see improvements in communication and ACP:

- Gaps in primary care, pediatrics, and for minority populations

- Although importance of ACP is acknowledged, implementation resources are lacking
- Physicians are still reluctant to bring up the subject; lack training
- Providers do not have enough time with patients for meaningful conversations

Professional Education and Development

When asked to specify whether they had seen improvements in professional education and development around end-of-life care, almost **65 percent** of respondents said yes, while about 29 percent said no.



Examples given by those who saw improvements in professional education and development:

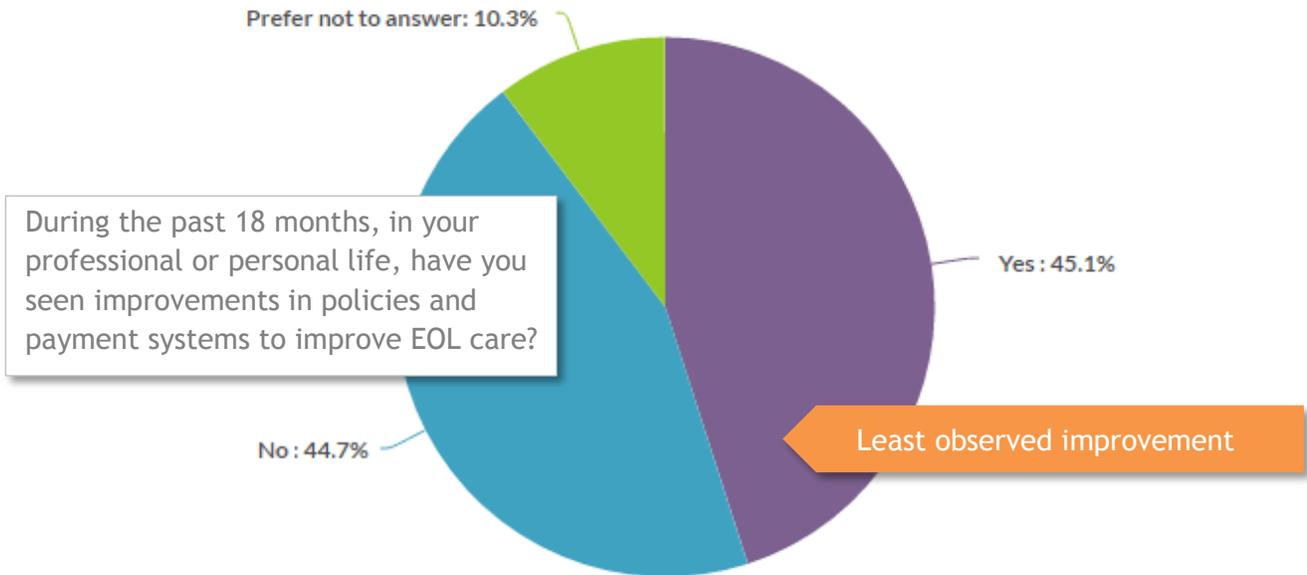
- Proliferation of training opportunities and informational resources, including CAPC, ELNEC, C.A.R.E.S., Vital Talk, Respecting Choices
- More dedicated courses and CME options
- Frequent focus of conferences and symposia

Examples given by those who did not see improvements in professional education and development:

- Lack of resources; budgetary obstacles
- Lack of interest in available opportunities

Policies and Payment Systems

When asked to specify whether they had seen improvements in policies and payment systems to improve end-of-life care, about **45 percent** of respondents said yes, while almost 45 percent said no.



Examples given by those who saw improvements in policies and payment systems:

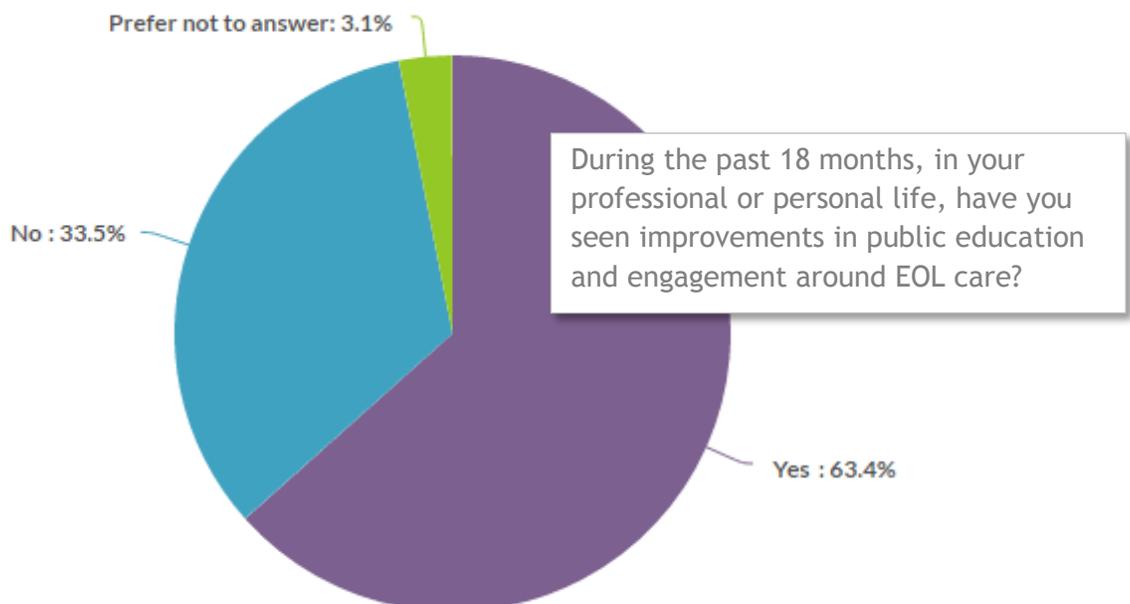
- Medicare reimbursement for ACP counseling
- New laws in California and Massachusetts

Examples given by those who did not see improvements in policies and payment systems:

- Financial incentives for acute interventions
- Restrictive hospice admission criteria and funding challenges

Public Education and Engagement

When asked to specify whether they had seen improvements in public education and engagement around end-of-life care, about 63 percent of respondents said yes, while about 34 percent said no.



Examples given by those who saw improvements in public education and engagement:

- High-profile media attention, including bestselling books (e.g., *Being Mortal*), television specials (e.g., PBS *Frontline*), newspaper and magazine articles
- Proliferation of tools and resources for the public, including the Conversation Project, National Healthcare Decisions Day, and Death Cafes
- Use of social media to advance the conversation

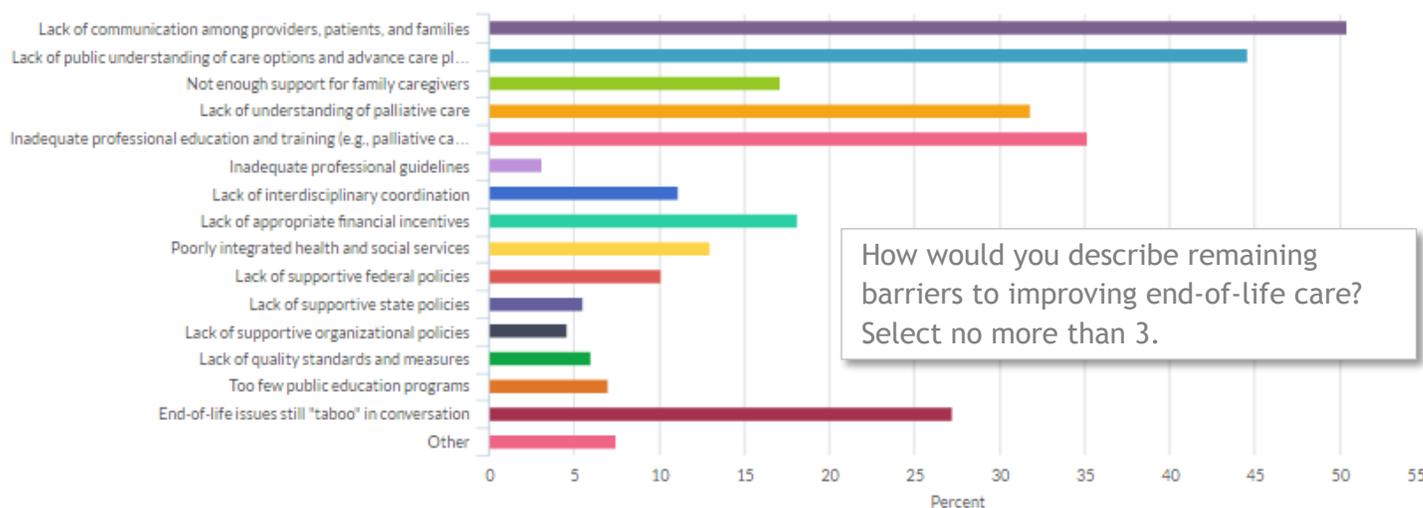
Examples given by those who did not see improvements in public education and engagement:

- Media attention is not translating to differences at the community level
- Myths, misconceptions, and taboos persist

Remaining Barriers and Priority Focus Areas

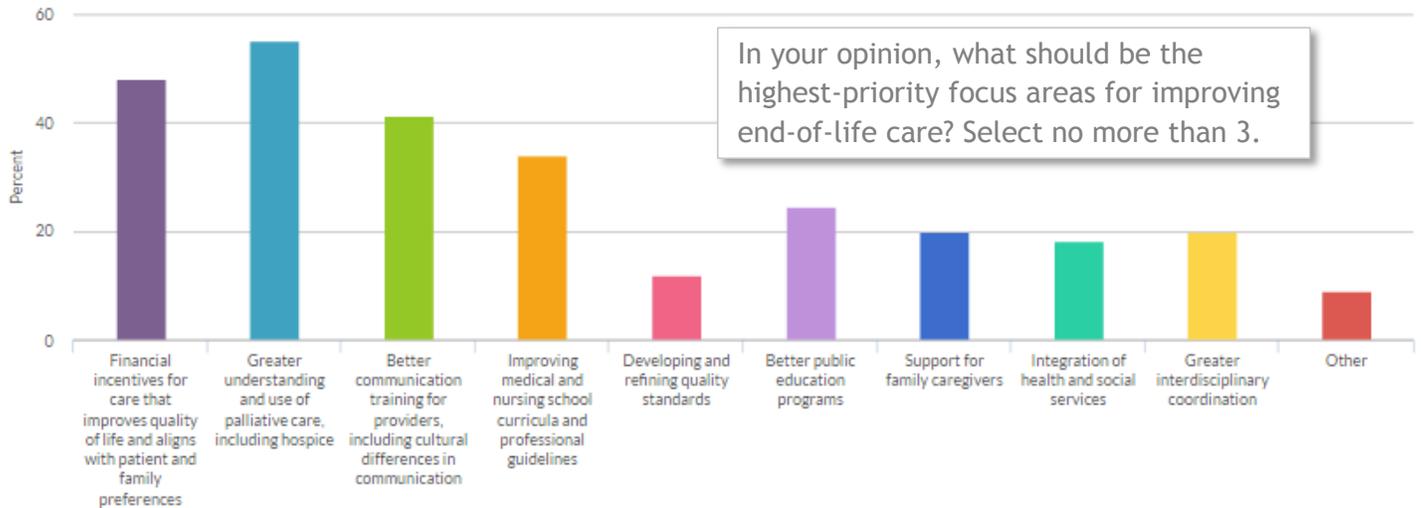
Respondents ranked the top 5 remaining barriers to improving end-of-life care as follows:

- 1 Lack of communication among providers, patients, and families
- 2 Lack of public understanding of care options and ACP
- 3 Inadequate professional education and training
- 4 Lack of understanding of palliative care
- 5 End-of-life issues still “taboo” in conversation



Respondents ranked the top 5 highest-priority focus areas for improving end-of-life care as follows:

- 1 Greater understanding of palliative care, including hospice
- 2 Financial incentives for care that improves quality of life and aligns with patient and family preferences
- 3 Better communication training for providers, including cultural differences in communication
- 4 Improving medical and nursing school curricula and professional guidelines
- 5 Support for family caregivers/greater interdisciplinary coordination



Gaps in the Questionnaire

Top responses when asked what the questionnaire failed to cover:

- Challenges for rural areas and minority populations
- Funding and support for non-physician care providers
- Opportunities for technology to play a role (e.g., electronic health records)

Disclaimer: This questionnaire is intended to help inform and stimulate discussion. Results do not necessarily reflect the views of the National Academy of Medicine (NAM). This document has not been subjected to the review procedures of, nor is it a report of, the NAM or the National Academies of Sciences, Engineering, and Medicine.