



Task Force on Serious Illness Care

**North Carolina Institute of Medicine
630 Davis Drive, Suite 100
Morrisville, NC 27560**

**April 12, 2019
10:00am-3:00pm**

Meeting Summary

Co-chairs in attendance: Jonathan Fischer, Joyce Massey-Smith

Members in attendance: Tom Akins, Mary Bethel, Victoria Boviall, Christine Brown, Ken Burgess, Christie Burris, Melanie Bush, David Cook, Wendee Cutler, Linda Darden, M. Bradley Drummond, Bridget Earle, Stacey Ellis-Antisdell, Anne Elmore, Debby Futrell, Elizabeth Golding, Charles Hardy, Michell Heflin, Sheila Helms, Sue Kirkman, Donna Lake, Deborah Love, Kristen Lakis, Sarajane Melton, Adrienne Mims, Debi Nelson, Susan Nestor, Carla Obiol, Laura Patel, John Perry, Melanie Phelps, Janna Pogers, Timothy Rogers, David Sevier, John Smith, Lynn Spragens, Apollo Stevens, Keith Sitrewait, Pam Strader, Charlotte Sweeny, Don Taylor, Lynn Templeton, Betsy Vetter, Stan Walters, Ellie Ward, Christine Weason, Polly Welsh, Senator Mike Woodard

Steering committee members in attendance: Steve Freedman, Cathy Sevier

Guests in attendance: Ryan Lavailey, Corey Remly, Brittany Schwartz, Brian Wood

NCIOM staff in attendance: James Coleman, Michelle Ries, Adam Zolotor

Welcome and Introductions

Joyce Massey-Smith, MPA

Director

Division of Aging and Adult Services

NC Department of Health and Human Services

Jonathan Fischer, MD

Physician

Duke Palliative Care

Assistant Professor

Duke University Department of Community
and Family Medicine



Task Force co-chairs Joyce Massey-Smith and Jonathan Fischer brought the meeting to order and provided a brief introduction to the Task Force. Mrs. Joyce Massey-Smith facilitated member introductions, with each Task Force member introducing him/herself by sharing their name, title, and organization.

Introduction to the NCIOM Task Force Charge and Principles of Engagement

Adam Zolotor, MD, DrPH

President and CEO

North Carolina Institute of Medicine

Dr. Zolotor outlined the NCIOM Task Force process, the focus, and expected product of the Task Force. He also gave an overview of the work of the NCIOM, recent Task Force work and publications, and the intended trajectory of the work of the Task Force on Serious Illness Care.

The Task Force charge will include, but not be limited to examining the following:

1. Delivery of person-centered, family-oriented care, including palliative, hospice, and other types of care –including assessment of gaps in hospital-based palliative care teams; opportunities to extend palliative care services in community settings including ambulatory settings, home health, and long-term care.
2. Communication and advance care planning -consideration of technical and legal issues around completion and utilization of advanced care planning documents including Medical Orders for Scope of Treatment, do-not-resuscitate orders, Power of Attorney, and living wills.
3. Professional education and development -examine training issues for physicians, nurses, gerontologists, and chaplains.
4. Policies and payment systems -examine models in other states to develop recommendations around best practices for financing; impact of costs of care on individuals, families, health systems, and the state.
5. Public education and engagement-assess opportunities to engage in health care provider and community dialogs about cultural norms around caring for individuals with serious illness, palliative care, long-term supports and services, and other caregiver issues.



Perspectives on Serious Illness Care: Workforce

Mitchell Heflin, MD, MHS

Associate Professor of Medicine
Duke University School of Medicine

Dr. Heflin gave an overview of issues pertaining to serious illness care workforce, training, and educating health systems. He discussed the workforce need for an aging population in NC, workforce shortages across rural NC, work force drivers and demands, and the changing/expanding definitions for a health care workforce. He also discussed workforce models (interprofessional teams, scope of practice, licensing and supervision, burnout, and the evolving roles of health professionals (incl. “boundary spanning roles”).

Questions/Comments (select):

- Workforce shortage in home health industry. The huge demand for nurses in home health and hospice, but most nurses end up working in a hospital (made by Tim Rogers).
 - More work needs to be done to recruit newly graduated nurses to home health and hospice care field.
- Healthcare workforce development needs to start in high schools to ensure students have necessary science backgrounds to be able to go into health sciences (made by Pam Strader).
- Emphasize collaborations between community colleges, hospitals, high schools (made by John Perry).

Personal Perspective on Serious Illness/End of Life Care

Facilitator:

Deborah Love, MA, JD, MBA

Sr. Director, Bioethics and Spiritual Care
Novant Health

Speakers:

Janna Pogers, PT, MPT, NCS, CSRS

Senior Physical Therapist level II - Clinical Specialist
Duke Rehabilitation Institute at Duke Regional Hospital

Stan Walters

Patient Advisor
Duke Patient and Family Advisory Council

Ms. Love introduced the speakers for this session and asked them to share their personal experiences as caregivers of loved ones with a serious illness. Ms. Pogers shared her story of being a caregiver for her infant son who had leukemia, her grieving process after her son passed away, and her motivations for joining the pediatric patient council. Mr. Walters talked about the many years he cared for his mother, her medical difficulties, and her end of life experience.



After Ms. Pogers and Mr. Walters shared their stories, Ms. Love asked all the meeting attendees to break off into pairs and discuss their own personal end of life experiences. Towards the end of the session, Ms. Love ask for input from the task force on what they would keep from the current system and what they would change. The topic of “keeps’ and “changes “was continued during the discussion held at the end of the meeting. **The final list of “keeps” and “changes” can be found at the end of this summary.**

Demographics in North Carolina

Mark Hensley

NC Associate State Director of Community Outreach and Advocacy
AARP NC

Catherine Sevier, DrPH, RN

President
AARP NC

Dr. Sevier and Mr. Hensley gave an overview of aging demographics in NC and the potential implications for serious illness care. They discussed aging number projections in NC at the county and statewide level, and about how chronic disease is the leading cause of death and driver of the nation’s health care costs (especially among the elderly). Another major point raised was that as the 45-65 population increases the number of caregivers in the state is projected to decrease. They emphasized that in the future, the projected low caregiver-to-elderly ratio will be a maybe concern. Dr. Sevier and Mr. Hensley also provided a handout of aging demographics in NC to task force members.

Questions/Comments (select)

- Are there data on the number of older adults living alone with no close family members to care for them?
 - There is anecdotal data: You can look at Adult Protective Services data.
- There really is no “system” of care/resources. People have to start the journey themselves and know the questions to ask and know how to start.
 - How can we begin to fix the issues of care coordination, so it is not a new journey for every person?

System of Serious Illness Care—Provider Perspective

Adrienne Mims, MD, MPH, FAAP, AGFS

Vice President & Chief Medical Officer
Alliant Health Solutions

Laura Patel, MD

Chief Medical Officer
Transitions LifeCare



Apollo Stevens, DNP, RN, CHPCA

Director

UNC Hospice

During 3 mini sessions, Dr. Patel, Dr. Mims, and Dr. Stevens focused on definitions of palliative and hospice care, quality of care, and access to care in hospice and palliative care settings. Dr. Patel presented first, giving an overview of hospice and palliative care. She discussed what hospice care is, what services are provided, the four levels of hospice care, hospice utilization, and barriers to hospice. She also talked about what is palliative care, where is palliative care provided, palliative care payment models, barriers to palliative care, and the similarities and differences between palliative and hospice care. Following Dr. Patel, Dr. Mims discussed the quality of care and quality of care issues. During her presentation, Dr. Mims focused on the high rates of hospital readmission for those with several chronic disease, problems with patient's handoff between care teams, and the decision process around whether patients in long term care facilities should be transferred to hospitals. Dr. Stevens wrapped up this session by talking about the patient and family experience and issues of access to services in hospice care. Dr. Stevens discussed stigma that many people have toward hospice care, and minorities usage and views of hospice.

Questions/ Comments (select):

- From a community perspective, outreach and education on advance directives is difficult
- Transfer and handling of advance directives in medical settings is not practical
- Semantics issues with hospice and palliative care
 - No one wants to accept hospice, because it signifies to them "death"
 - Potential solution is more promotion of palliative care

System of Serious Illness Care—Policy and Systems Perspective

Kenneth Burgess, JD

Partner

Poyner Spruill LLP

Don Taylor, PhD, MPA

Professor of Public Policy

Sanford School of Public Policy

Duke University

In this session, Dr. Taylor provided an overview of models of serious illness care, and Mr. Burgess discussed the basics of advance care planning from a legal perspective. Dr. Taylor started off the session by discussing care improvement for patients with serious illness. Main points raised include: the best thing that can be done on the policy and payment side to improve care is to change the "default", by pausing and considering other options before making care decisions. For example, considering hospice or palliative care instead of frequently sending patient to the hospital. Changing the default can keep seriously ill patients from receiving care they do not need. Following Dr. Taylor, Mr. Burgess provided an overview of



what advance directives are, and the barriers to the effective use of them. Some barriers mentioned by Mr. Burgess included consistency of healthcare provider training, legal/ethical issues, confusion around understanding what forms mean and authorized surrogates, and 2-witnesses and notary presence during signing of advance directives.

Questions/Comments

- How much is the default option influenced by cultural norms? Is it all embedded in the American notion to “fix me”?
- Medical teams need to know and understand what advance care documents say and when they should be used
- Using an electronic MOST form is standard in many states and maybe North Carolina should consider doing the same
 - Needs to be an online statewide portal to access advance directive forms

Discussion

Facilitators:

Adam Zolotor, MD, DrPH

President & CEO

North Carolina Institute of Medicine

Michelle Ries, MPH

Project Director

North Carolina Institute of Medicine

During the final session of the meeting Dr. Zolotor and Ms. Ries opened the floor for general discussion about what topics should be examined throughout the duration of the task force and, what should be added to the task force charge. During this discussion session numerous ideas, topics, and additions to the task force charge were raised(select):

- Suggestions for what need to be added to the Task Force charge
 - Add inclusive term home care to the point 1 of the task force charge
 - Include social determinants of health
 - Include family caregiver support
 - Mention vulnerable populations
 - include clinical social workers, community health workers and pharmacists in point 3 of charge
 - Include pediatrics to add a distinction from geriatrics
 - Add continuum of care
 - Mention the prevention of the downward spiral of health status that leads to frequent hospitalization
 - Include psychiatric advance directives
 - Add patient navigation to point 3 of charge



‘Keeps’ and ‘Changes’ of current system

Keep/Promote	Change
Connection between patient/family and trusted member of medical care team	Hands off communication
Including of families in bedside rounds	Lack of acknowledgement of comatose patients
Understanding that end of life is a human experience	Affordability of healthcare (including drug prices)
Home visits from insurance companies to assess and make recommendations family caregivers	Lack of education of family members about what to expect after loved one passes away
Support for caregiver burnout	Lack of communication across healthcare team
Staff in hospitals doing small acts of kindness	Lack of focus on patient needs
Patient navigation	Need of expansion of para medicine
Whole person integrative Care	Healthcare revolving around doctors instead of patients
Bereavement care	Case management and care management needs