The Task Force on Serious Illness Care assessed serious illness across the life course and the system and culture changes required to reduce stigma. Community collaboration, culture change, cultural competency, and attention to health equity are requisite for addressing the challenges of serious illness care across the spectrum of care for the person with serious illness and her family and community.

COMMUNITY COLLABORATION TO TAKE US TO A HIGH-QUALITY SYSTEM OF SERIOUS ILLNESS CARE

There is no singular group or governing body that currently exists in North Carolina to serve as a general coordinator to oversee the implementation of the task force's recommendations. Such entities exist in a few states, for example, the Massachusetts Coalition for Serious Illness Care and the Oregon Coalition for Living Well with Serious Illness. The Massachusetts coalition has over 100 member organizations and has a mission to "ensure that health care for everyone in Massachusetts is in accordance with their goals, values, and preferences at all stages of life and in all steps of their care."[1] The coalition fields surveys of state residents about views on serious illness and advance care planning, publishes monthly newsletters, hosts a yearly summit, and has created a toolkit for promoting advance care planning. Inspired directly by the Massachusetts coalition, the Oregon coalition includes 40 individuals and organizations and seeks to "educate, communicate, and connect in order to help people with serious illness and their caregivers live well."[2,3] Membership in both groups includes health care professionals, hospices, hospital and health systems, policymakers, caregivers, and consumers, among others.

In North Carolina, several groups have been working on some of the issues related to the recommendations of this report. The North Carolina Coalition on Aging, for example, "works collaboratively to give voice to issues that affect older North Carolinians" by providing education and hosting events to support issues of interest to member organizations. With several overlapping member organizations, the Partnership for Compassionate Care formed separately to help educate health care providers about end-of-life issues, focusing primarily on educating health care providers about Physician Orders for Life-Sustaining Treatment (POLST) and Physician Orders for Scope of Treatment (POST), and other resources to increase conversations about goals of care.

NORTH CAROLINA SERIOUS ILLNESS COALITION

Over the course of the task force's work, members established a coalition to coordinate and oversee the implementation of the task force recommendations, organize work groups as identified in the recommendations, and serve as a repository for information, resources, and expertise in many aspects. This effort should also build upon the existing work of the many state stakeholders currently working to promote messages around serious illness care and ensure that North Carolinians have the information needed to face the challenges of serious illness.

Therefore, the task force recommends:

RECOMMENDATION 2.1:
Establish coordinated statewide leadership to facilitate implementation of recommendations and ongoing work to achieve quality of living for individuals with serious illness (PRIORITY)

The North Carolina Serious Illness Coalition should provide statewide coordinated leadership to oversee and coordinate the implementation of the recommendations from the Task Force on Serious Illness Care. Under the direction of an executive committee, the Coalition should:

1. Identify and appoint appropriate stakeholders for membership in the Coalition
2. Determine statewide standards for what defines "serious illness" and how it is applied across recommendations
3. Identify and support work groups charged with additional development and implementation of specific recommendations and to serve in an advisory capacity to additional partners. Workgroups may include: awareness/communication, quality metrics/ measurement, advance care planning, workforce (including wages), and policy/regulation
4. Develop work plan for prioritization and implementation of recommendations
5. Report progress on implementation on an annual basis to relevant stakeholders
6. Provide support and leadership for the North Carolina Partnership on Compassionate Care
7. Pursue sustainable funding from philanthropic organizations for ongoing work of the Coalition

The following recommendations involve the Coalition: 3.5, 4.2, 4.8, 4.9, 4.15.

PROMOTING HEALTH EQUITY WHEN ADDRESSING SERIOUS ILLNESS CARE DISPARITIES IN RATES OF DISEASE

Serious illness affects all populations, yet some groups experience higher rates than others due to a range of issues, such as socioeconomic conditions and access to health care. Across the range of conditions contributing to serious illness that were detailed in Chapter One, populations of color often experience greater disease burden and rates of mortality than their white counterparts. **See Table 2.1** on the next page for detailed information across diseases.

TABLE 2.1 Rates of Serious Illness by Race/Ethnicity

	WHITE	BLACK/AFRICAN AMERICAN	ASIAN/PACIFIC ISLANDER	AMERICAN INDIAN	HISPANIC
Alzheimer's Disease[A]	10%	14%	‡	‡	12%
Cancer (incidence/mortality), per 100,000[B]	437.7 / 156.7[C]	430.1 / 178.2[C]	288.0 / 96.7	302.4 / 141.4[C]	336.3 / 110.5
Diabetes[D]	10.7%	14.9%	‡	‡	11.3%
Heart Disease[D]	5.0%	3.8%	‡	‡	‡
Chronic Kidney Disease[E]	14.2%	19.3%	14.5%	14.6%	13.6%
Stroke[D]	3.5%	4.8%	‡	‡	‡

‡ Data not available
A Percentage of adults aged 65 and older with Alzheimer's disease; https://www.cdc.gov/aging/data/pdf/american-alzheimers-racial-ethnic-disparities-infographic-508-h.pdf
*B All cancer sites combined; National Cancer Institute. Surveillance, Epidemiology, and End Results Program. SEER*Explorer. https://seer.cancer.gov/explorer/index.html*
C Includes Hispanic ethnicity
D Centers for Disease Control, Behavioral Risk Factor Surveillance System
E Percentage of Medicare patients age 65+ https://www.usrds.org/2019/view/USRDS_2019_ES_final.pdf

DISPARITIES IN EXPERIENCE OF CARE

Disparities in rates of serious illness across populations are due in part to differing experiences accessing health care services. This is an issue across racial/ethnic groups, and across factors such as geographic location (rural versus urban), health insurance status, and immigrant documentation status. North Carolina has a relatively high population living in rural areas (34%).[4] Forty counties in the state have fewer primary care clinicians (physicians, physician assistants, and nurse practitioners) than recommended for the population.[5] This creates challenges for rural populations seeking access to primary care for chronic health issues like diabetes.

Another basic challenge to accessing health care is lack of health insurance. Nearly 13% of North Carolina residents under the age of 65 are uninsured.[6] Access to comprehensive, quality health care services is critical to achieve and maintain health, prevent and manage disease, and achieve health equity. Health insurance is the most common means used to obtain affordable health care services.[7] For those without health insurance, care may be inaccessible and unaffordable, resulting in poor health outcomes. In North Carolina, rural residents, non-citizens (54%), Hispanic populations (31%), men (14%), and people who earn less than 200% of the Federal Poverty Level (21%) are more likely than their counterparts to be uninsured.[8,5]

Social needs such as transportation, quality housing, and nutritious food are highly influential factors in an individual's experience of serious illness and the care they receive. Individuals who do not have adequate transportation may not be able to access clinical services that they need to monitor, treat, or alleviate pain or other side effects of their condition. Living conditions and nutrition can exacerbate the severity of an illness and prevent individuals from adhering to treatments recommended by the health care professionals caring for them.

DISPARITIES IN END-OF-LIFE CARE

The use of hospice care services varies by population. White populations use hospice services at the highest rates, with 34% of whites who died while on Medicare using hospice services, compared to 28% of Hispanics, 27% of African Americans, and 26% of Asians and American Indians. This disparity has been changing, and non-white groups had larger percentage increases in hospice use between 2014 and 2017 than whites.[9] Also, women (58%) use hospice services more than men (42%).

North Carolina has long been a hub for immigrants and refugees from around the world. As of 2017, 7.8% of North Carolina's population was foreign-born, according to the U.S. Census Bureau. The state ranks 10th in the nation for number of refugees settled; in 2015, more than 3,000 refugees settled here, with 2,200 more following in 2016. Providers and systems strive to meet the medical needs of all our residents, but unique challenges and barriers to care remain. Interpretation services can be difficult to obtain, even where legally required. Farmworkers, in particular, are at higher risk of developing chronic conditions such as high blood pressure, as well as higher rates of related serious illnesses such as heart disease. For immigrants and refugees with serious illness in need of additional clinical care, human services, or financial assistance, these barriers may be exacerbated.

Sources: http://nciom.org/caring-for-north-carolinas-immigrant-and-refugee-populations/ https://www.migrantclinician.org/files/4%20Frank%20et%20al%20Health%20care%20access.pdf

Preference for use of aggressive treatments up to the end of life and a lack of trust in the health care system based on historical inequities may account for the differing use of services across populations by race/ethnicity. Additionally, differences in advance care planning may account for some of the disparity. African Americans are less likely to have completed advance directive documentation, which has been the focus of efforts to encourage people to plan for end-of-life care.[10] The predominant reason why fewer African Americans have completed advance directives is distrust of the health care system. Other racial and ethnic groups may have differing beliefs about death that make them less likely to have advance directives.[11] African Americans who have advance directives may be less likely to have outcomes impacted by stated preferences. One study found that African Americans who had a documented preference for less aggressive end-of-life treatment received the same amount of aggressive treatment as African Americans who did not have preferences documented. This was not the case for whites, who received less aggressive treatments if those wishes were documented.[12]

The treatment that people receive for a serious illness can also be variable. Research has shown that people of color are more likely to have pain underestimated by health care providers, less likely to have pain scores documented in medical records, and less likely to have their pain treated than white patients.[13] Studies of non-white individuals who received palliative care have shown that they are less satisfied with their care, their communication with providers, and their pain management than their white counterparts.[14]

The competency of hospice and palliative care staff to work with culturally diverse individuals at the end of their lives is a challenge to providing equitable opportunities for people of all backgrounds to feel comfortable using these services. A survey of hospice and palliative care organizations in one southeastern state found that staff, who are predominately white, lacked awareness of issues around cultural diversity, were not providing information in a culturally appropriate manner, and lacked access to and contact with diverse communities.[15] While limited, research into the barriers non-white individuals face in receiving palliative and end-of-life care has shown that low levels of race-concordant staff, lack of language interpreters, and limited outreach to diverse communities may contribute to inequitable access to these services.[14]

Throughout the task force process, and in this report, "caregiver" is used to address family members, friends, or other social supports that provide unpaid care for an individual with serious illness. The task force also emphasized that "family" should also be inclusive of family of choice. For example, many LGBTQ individuals form strong "families of choice" in response to familial rejection over sexual orientation or identity. These families of choice provide important emotional and social support. The task force recommendations are inclusive of families of choice when referencing family and caregivers.

Source: https://www.caregiver.org/special-concerns-lgbt-caregivers

HEALTH EQUITY

Health equity is the opportunity for all people to attain the highest level of personal health regardless of demographic characteristics.[16] The task force has placed a high priority on the achievement of equity in the availability and quality of serious illness care. As the research into reasons for disparities suggests, growth in cultural competency and understanding of implicit bias by health care professionals is needed to achieve the goal of equity. Cultural competency in health care is the "ability of systems to provide care to patients with diverse values, beliefs, and behaviors, including tailoring delivery to meet patients' social, cultural, and linguistic needs."[17] Cultural competency in serious illness care could be improved through strategies like hiring more diverse staff, training staff to increase cultural awareness, knowledge, and skills, incorporating culture-specific attitudes and values in printed materials, and including family and community members in the health care decision-making process.[18] Health care providers require training to understand their implicit biases. Implicit bias is a "set of assumptions about a social group that affects judgment and decision-making without conscious awareness of that influence."[19] Implicit bias harms patient-provider communications and trust.

Recommendations through this report reflect the task force's value of developing an equitable system of serious illness care for patients and their caregivers. The reports embed health equity in recommendations about training for health care providers (**Recommendation 2.2**), development of culturally competent workforce models and standards for advance care planning conversations (**Recommendation 4.4**), and studying the disparities in availability of and access to caregiver services (**Recommendation 4.12**).

The greater burden of serious illness that populations of color often face and the growing number of people with serious illness make cultural competency and health equity priorities for providing the best care possible. Therefore, the task force recommends:

RECOMMENDATION 2.2:
Increase research on cultural competency and health equity as it relates to serious illness care

Industry and professional associations, private funders, and other stakeholders should promote policies and processes that support and encourage improved health equity and understanding of cultural competency in serious illness care, to include:

1. Increased funding for research into disparities in the utilization of serious illness care and advance care planning
2. Health policy researchers, health services researchers, schools of medicine, schools of nursing, continuing education providers, and others, should increase research focused on the structural causes of health disparities and cultural understanding that may affect the utilization of serious illness care (including palliative and hospice care) and influence its delivery. Research goals should also include the development of evidence-based methods to reduce disparities in health outcomes and experience of care, as well as to increase cultural competency among providers
3. Incorporation of patient experience data (including disaggregated by race/ethnicity, rural/urban, and other potential areas of disparity) into the development of new models of care, processes, and technologies relevant to serious illness care delivery
4. Promotion of evidence-based training models in health equity and cultural competency for health care providers and members of serious illness care teams

RECOMMENDATION 2.3:

Prioritize health equity and the reduction of disparities as guiding principles throughout implementation of all recommendations of the Task Force on Serious Illness Care (PRIORITY)

The following recommendations are directly related to impacts on underserved populations, and have been included in chapters reflecting the broader principles of health equity and reduction of disparities:

Recommendation 2.2: Increase research on cultural competency and health equity as it relates to serious illness care

Recommendation 2.3: Prioritize health equity and the reduction of disparities as guiding principles throughout implementation of all recommendations of the Task Force on Serious Illness Care

Recommendation 3.1: Deliver goal-concordant, coordinated, team-based care for individuals with serious illness

Recommendation 4.1: Support patient and family engagement through health care organization policies and processes

Recommendation 4.2: Develop statewide initiative for improved awareness of, and support for, completion of advance care planning

Recommendation 4.5: Incentivize advance care planning that that prioritizes the assessment and honoring of individual goals of care

Recommendation 4.11: Expand Home- and Community-based Services to better serve individuals with serious illness and their caregivers

Recommendation 5.5: Expand programs for community paramedicine

Recommendation 5.6: Expand community health worker programs

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