

Health Disparities in End-of-Life Care Grant Report

February 2020



Goals of Care Coalition
of New Jersey

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Executive Summary

The remarkable medical advances of the 21st century have helped more people live longer with serious and complex illnesses than ever before. While top-quality disease management is critical, care for patients with serious illnesses must also respect a person's priorities around quality of life and his or her specific wishes for end-of-life care.

There is a limitation to this undeniable progress, and it is particularly evident in the state of New Jersey. Currently, during a person's final months of life, patients in New Jersey will often experience more intensive medical care than those in any other state in the nation. This may result in burdensome or unwanted treatment that reduces the quality of a person's final months of life. There are numerous reasons for this disparity between the care a patient desires, and what he or she may receive but a key one is the lack of effective communication between patients, families and health care providers. This is particularly the case with communication between health care providers and patients from minority populations where the providers and patients often come from quite different cultural, linguistic, and ethnic backgrounds.

There is a critical need to improve the quality of the health care provider-patient dialogue at the end of a person's life. A grant from the Robert Wood Johnson Foundation was utilized to establish highly-targeted local initiatives to help educate health care providers and patients about the need for high quality communication about end-of-life care.

“People with serious illness have priorities besides simply prolonging their lives... their top concerns include avoiding suffering, strengthening relationships with family and friends, being mentally aware, not being a burden on others, and achieving a sense that their life is complete.” —Atul Gawande, *Being Mortal: Illness, Medicine and What Matters in the End*

Background

Making decisions about end-of-life care can often be a tumultuous and difficult time for many families. In addition to the obvious emotional and psychosocial aspects there may be little advance care planning, the complexity of family dynamics/communication styles, and relatively low health literacy. Patients and families often benefit from help with decision-making when facing a life-threatening illness. Despite this widely prevalent issue that will affect most of the population at some point, most Americans nearing death do not have access to palliative services and high quality end-of-life care. This is particularly true for African-American, Hispanic and Asian patients along with other minority or under-served patient populations. In addition to access and health literacy issues, many patients and families in these populations experience various linguistic and cultural barriers to end-of-life care. In fact, African-American, Hispanic and Asian patients nearing the end of life are more likely to be hospitalized and to receive intensive, life-prolonging treatment rather than palliative or hospice care.

New Jersey

These issues around end-of-life care are particularly evident in New Jersey, due in part to the unique demographics of the state. New Jersey has the most ethnically diverse healthcare provider population and the third most diverse patient population in the United States. While these differences contribute to the rich cultural milieu of New Jersey they also increase the risk for misunderstandings between health care providers and patients—the impact of which can dramatically affect the quality of end-of-life conversations.

A lack of clarity in this communication can fundamentally affect the type of health care utilization among patients with serious illness across the state. Studies have found that patients near the end of life in New Jersey are treated with more intensive medical care than any other state in the nation. High-quality disease state management is obviously critical, but it is also necessary to maintain a patient's autonomy in decision making, as much as possible, so he or she receives care which is aligned with their wishes and values.

There are clearly numerous reasons why patients in New Jersey may not receive treatment that reflects their wishes, but with end-of-life care, a key one is a lack of communication between patients, families and health care providers. A recent analysis found that more than 60% of patients in New Jersey had discussed end of life medical care with family and health care providers, but less than half of patients had documented those wishes in writing. Furthermore, Medicare hospice utilization varies widely across racial and ethnic groups. Medicare hospice care is highest among Caucasian patients (49.7%), followed by Hispanic (41.3%), African American (37.5%), and lowest among Asian American patients (33.7%). Of course, not all of these minority patients would choose to receive hospice but it is likely that some would. The exact preferences for hospice care by ethnic background is beyond the scope of this work, but the trend toward less use of hospice care by minority groups could reasonably be regarded as a lack of awareness for a patient's wishes and/or a need for patient education about the options available for end-of-life care. A disproportionate number of New Jersey's minority patients are experiencing more intensive medical care than actually reflects their personal wishes at the end of life.

“Patients near the end of life in New Jersey are treated with more intense medical care than any other state in the US. There are many reasons for this, but one is a lack of quality communication between health care providers and patients.” —David Barile, Founder & Chief Medical Officer, Goals of Care Coalition of NJ

Patients may receive unwanted or burdensome intensive medical care at the end of life for various reasons, but an area that has not been extensively addressed is the unintentional or implicit biases that clinicians may bring to discussions about end-of-life care with patients from minority populations. While this is clearly not deliberate, health care providers may not be aware of or sensitive to the various communication styles or preferences of patients from different ethnic or cultural backgrounds. This may inadvertently create obstacles to advance care planning and good palliative care. To address these issues, we found there was a clear need for programs to assist health care providers in their discussions with minority patients as they approached the end of life. To complement the efforts from the health care provider perspective, we found there was a parallel need for culturally focused and ethnically sensitive educational materials about end-of-life care for patients.

To address these issues, we developed highly-targeted educational initiatives by leveraging the resources of The Goals of Care Coalition of New Jersey (GOCCNJ). The organization is comprised of experts in advance care planning, palliative care, policy, and elder care under the leadership of Founder & Chief Medical Officer, Dr. David Barile, a palliative medicine specialist with formal training on end-of-life conversations.

We focused our efforts on communities where the majority of residents are of African-American, Hispanic or Asian descent. Specifically, we targeted Essex and Union Counties, where 41.9% and 23.7% of the population is African-American; Hudson and Passaic Counties, where 42.9% and 42.3% of the population is Hispanic; and Middlesex and Somerset Counties, where 25.1% and 18.6% of the population is Asian. To help improve end-of-life care within these target areas, we worked to identify racial and ethnic disparities that existed in advance care planning, developed initiatives to communicate the benefits of advance care planning to clinical and patient audiences, and educated patients/families on options for end-of-life care and the importance of advance care planning.

Initiatives

Due to the complex and multifactorial challenges involved, we found that addressing both the providers and recipients of end-of-life care would likely provide the greatest chance for enduring attitudinal and behavioral change necessary to address these issues.

Healthcare Professional Outreach, Education & Training Programs

A guiding principal for each of these initiatives was to encourage clinicians to practice “cultural humility,” that is, to approach each patient as an individual with unique life experiences and values that inform his or her perspectives on end-of-life care. A panel of consultants were employed to ensure that the content developed to support this education would improve health literacy, particularly in ethnic communities, and would be relevant with low literacy elders.*

*We would like to thank the following individuals for their expert review of *Cultural Intelligence: Breaking Barriers in End-Of-Life Care* and the *Let's Talk* educational materials: Fred A. Kobylarz, MD, MPH and Robert C. Like, MD, MS.

Grand Rounds

Program objectives:

- increase knowledge of issues around racial/ethnic disparities in advance care planning
- foster an increased willingness and comfort with guiding end-of-life care conversations
- increase the intention to educate patients about palliative and hospice care and conduct advance care planning services

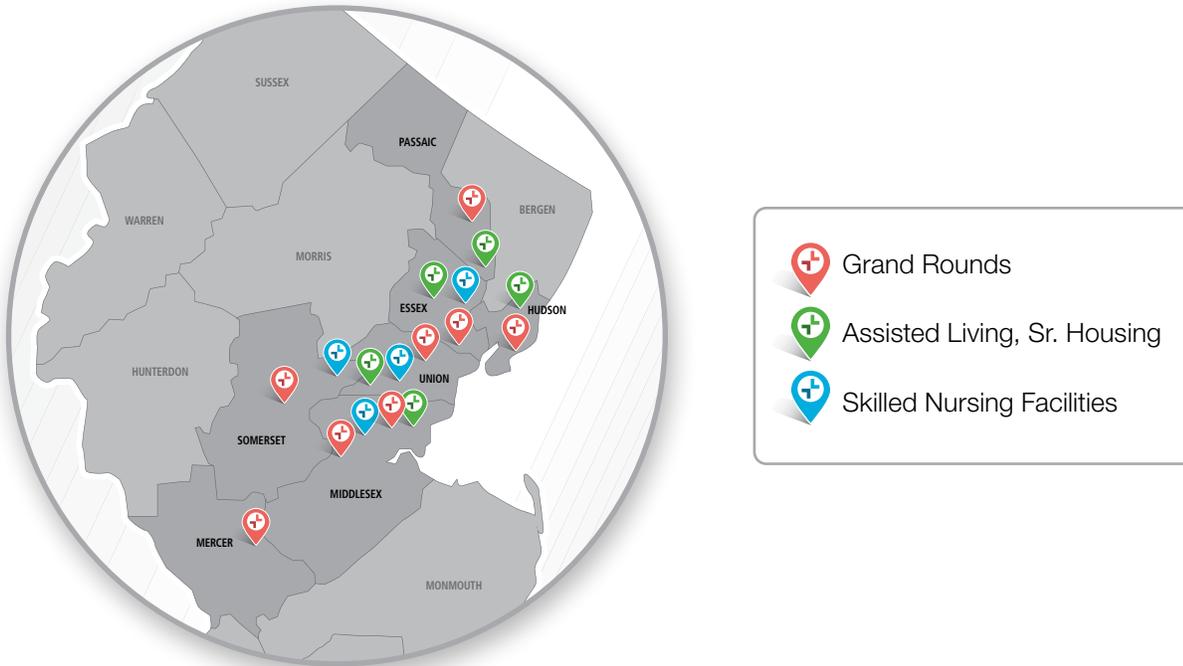
We created, coordinated, and promoted a Medical Grand Rounds at the largest hospital in each target county where the majority of residents are of African-American, Hispanic or Asian descent. To enhance the delivery of information, all content was reviewed for cultural literacy and alignment with the ethnogeriatric competencies from the [Stanford Geriatric Education Center](#).

The counties and facilities of focus included: Essex County at RWJBarnabas Health Newark Beth Israel; Union County at Overlook Medical Center; Hudson County at RWJBarnabas Health Jersey City Medical Center; Passaic County at St. Joseph's; Middlesex County at JFK Medical Center; Somerset County at RWJBarnabas Health New Brunswick. Additional grand rounds were conducted at Mercer County at Penn Princeton Medical Center and Middlesex County at Rutgers Robert Wood Johnson Medical School. In total we addressed more than 900 physicians, nurses, social workers and hospital staff/chaplains in the target communities with a significant population of minority patients over 65 years of age. We used The American Academy of CME, Inc. (Academy), a NJ-based, not-for-profit foundation dedicated to improving health by providing continuing education, for the healthcare team for accreditation. The Academy designated the live grand rounds activity for 1.0 AMA PRA Category 1 Credit(s)TM for physicians and for 1.0 contact hours for nursing professionals. The activity also met criteria to be considered part of the NJ mandate requiring HCPs to receive two hours of continuing education credit in EOL care bi-annually.

Lunch & Learn Training

Program objectives:

- Provide educational materials about end-of-life care to patients and families
- Work with the facilities in each county to identify eligible patients and families



We coordinated, conducted, and promoted Lunch & Learn programs for health care providers in a targeted Skilled Nursing Facility and an Educational Social in an Assisted Living Community in each of the target counties. We addressed more than 100 staff members in targeted Skilled Nursing Facilities including physicians, registered nurses, nursing assistants, social workers, unit managers and chaplains; similarly, we addressed more than 150 residents in Assisted Living Communities and Senior Housing Centers.

For all initiatives, various metrics and likelihood for behavior change was assessed through post-event evaluations. Specific feedback from the American Academy of Continuing Medical Education (AACME) reported overall satisfaction with the faculty, methods, materials, balance, and other aspects of the educational experience was extremely high. Specific survey responses and percentage of participants who agreed with the statement are listed below.

When asked if the content was *useful and relevant to my practice* (100%) and *the activity was fair, balanced, and free of commercial bias* (100.00%) learners reported.

Participants reported affirmatively to the following:

- *I am better able to describe barriers to “Good Medicine” during final phase of life* (83%)
- *I am better able to describe and utilize strategies to improve health literacy across cultures* (83%)
- *I am better able to review how “Cultural Intelligence” may influence decisions* (100%)
- *I am better able to communicate/collaborate with other members of the healthcare team* (83%)

- *I am better able to communicate/collaborate with patients and their families about end-of-life-decisions (100%)*
- *I would recommend this activity to others (100%)*
- *The information learned during this activity will help improve my skills or judgment within the next six months (100%)*
- *Instructional effectiveness and expertise of faculty was excellent (100%)*

Participants were asked to identify what they intended to do differently in practice because of what they learned. Responses were:

- Implement new information or skill in care of my patients
- Create/revise protocols, policies, and/or procedures
- Seek additional information on Good Medicine

When asked about specific practice changes they intended to make, the majority of participants focused on improving communication among the team and improving patient/caregiver discussions. Responses included:

- To further address conversation with the team to work with family on information shared more consistently
- Continue to practice effective communication
- Review material and see how it may alter/benefit Atlantic strategies in this area

Patient & Family Decision Maker Education Materials

A critical component for improving the patient/provider dialogue about end-of-life care was to focus on improving the health literacy of the target patient population. We developed and distributed materials to African-American, Hispanic and Asian patients/families and their health care providers about end-of-life care. These materials were designed for both English-speaking and non-English speaking audiences. Information included an explanation of palliative and hospice care, the importance of advance care planning, and provided an overview of advance care planning documents (5 Wishes, POLST—Physician’s Orders for Life-Sustaining Treatment).



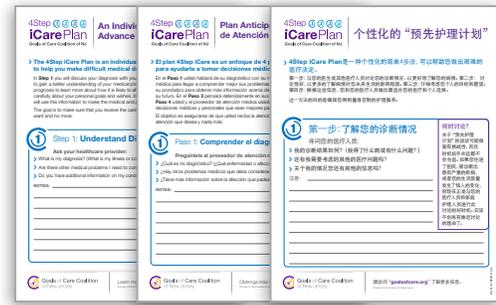
Patient education materials

We developed a culturally sensitive patient education guidebook about end-of-life care tailored to patients and families of various races and ethnic backgrounds. The *Let’s Talk Guidebook* covers the benefits of advance care planning and the importance of documenting a loved one’s wishes for end-of-life care. The guidebook was translated and produced in Spanish and Chinese.



Additional materials

We customized and translated the GOCCNJ patient decision aid, the 4Step iCare PlanSM into Spanish and Chinese. We also re-worked the 4Step iCare PlanSM Healthcare Professional Conversation Assistant to include cultural sensitivities and instruction for the healthcare professional.



The 4Step iCare PlanSM, both for patients and healthcare professionals, and the previously mentioned *Let's Talk Guidebook* were distributed in targeted hospitals, skilled nursing facilities, alternate level care facilities and made available online.

Website

We translated portions of our Patients & Family Caregivers section into both Spanish and Chinese. Now, this information can be easily accessed when visiting the Goals of Care website and when searching the topics on the internet.



In 2019, we experienced a significant increase in visits to our website. We went from 7,700 visits in 2018 to over 33,000 visits in 2019; a 328% increase.



Videos

We created 9 new videos for patient education that addressed the following topics:

- [Let's Talk: The Importance of Advance Care Planning](#)
- [Advance Care Planning: Discuss, Decide, Document](#)
- [Palliative Care and Hospice: Understanding Your Options](#)
- [Hospice Care](#)
- [Documenting Your Decisions](#)
- [Intro to the 4Step iCare PlanSM](#)
- [More on the 4Step iCare PlanSM](#)
- [Intro to the NJ POLST Form](#)
- [Completing the NJ POSLT Form](#)



We developed and translated subtitles into Spanish and Chinese for each of these 9 videos which were also made available online. The reach and effectiveness of each of these tactics was assessed by tracking distribution of patient education materials; measuring downloads of the 4Step iCare PlanSM and tracking website activity.

Challenges

Behavior change can often be difficult and there were some challenges that inevitably emerged as we implemented these initiatives. According to post-event surveys from the American Academy of Continuing Medical Education, the most common barriers to implementing the knowledge gained was: institutional; a patient's lack of knowledge regarding disease/treatment; and challenges in communication/collaboration among members of the care team. All of these issues provided opportunities for enhancements of the initiatives and are being addressed as we continue our work.

Some of the other challenges were inherent to the issues we are trying to address. These “macro” challenges include entrenched individual and institutional treatment approaches and the often slow pace of change on an institutional level. There can also be a reluctance to dedicate resources (time and financial) to additional staff training within facilities. Fundamentally this is an under-represented, under-served patient populace without vocal advocacy. Therefore, the awareness or urgency to address the need for improvements in end-of-life care discussions is relatively low.

Future plans

We have gained valuable insights as we continue our work to improve the quality of end-of-life care for minority patient populations in New Jersey. The twofold approach through clinician training and patient education continues to be the most effective framework for addressing these issues. Recognizing this need, NJ's Gov. Phil Murphy (D) recently signed a law requiring certain medical facilities, including hospitals and skilled nursing facilities, to educate their staff, patients and families about palliative and hospice care. Learnings from this program and the content that was developed to address cultural disparities surrounding EOL care in New Jersey will sufficiently address that mandate. We continue to add associations to Goals of Care Coalition of New Jersey which helps increase awareness, build advocacy, and exert influence on institutions about end-of-life care issues. We are also identifying and engaging with advocates and influencers in the health care professional space to champion the issues. On a very tactical level we are translating and developing additional educational materials specifically tailored for the non-English speaking patient population. We've seen significant progress and received positive feedback on the initiatives up to this point and we look forward to continuing our work to ensure that everyone involved in end-of-life care, from provider to patient to families, has the shared goal of utilizing treatment that reflects a person's individual wishes and goals of care.

Sources

- American Academy of CME (AACME). Outcomes Analysis: Goals of care. Communication to J Juchniewica from P Miniter. 2019
- Belch, M., Willis, L. (2006, July 11). Family decision at the turn of the century: has the changing structure of households impacted the family decision-making process? <https://onlinelibrary.wiley.com/doi/pdf/10.1002/cb.94>
- Chaudhry, C., Herrin, J., Phillips, C., Butler, J., Mukerjee, S., Murillo, J., ... Krumholz, H. (2011, February). Racial disparities in health literacy and access to care among patients with heart failure. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3053061/>
- Chen, P. (2010, August 12). When the doctor doesn't look like you. <https://www.nytimes.com/2010/08/12/health/12chen.html>
- Earley, C. P. & Mosakoski, E. (2004, October). Cultural Intelligence. <https://hbr.org/2004/10/cultural-intelligence>
- Emanuel, L. & Glasser Scandrett, K. (2010, October 8). Decisions at the end of life: have we come of age? <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2964548/>
- Eneanya, N., Winter, M., Cabral, H., Waite, K., Henault, L., Bickmore, T., ... Paasche-Orlow, M. (2017, December 6). Health literacy and education as mediators of racial disparities in patient activation within an elderly patient cohort. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5718153/>
- Herrmann, E., Call, J., Hernandez-Lloreda, M., Hare, B., & Tomasello, M. (2007, September 7). Humans have evolved specialized skills of social cognition: The Cultural Intelligence Hypothesis. <http://science.sciencemag.org/content/317/5843/1360>
- Howard, D., Sentell, T., & Gazmararian, J. (2006, August 21). Impact on health literacy on socioeconomic and racial differences in health in an elderly population. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1831584/>
- <https://www.dartmouthatlas.org/DartmouthAtlasofHealthcarefrom2008-2014>.
- <http://www.goalsofcare.org/nj-polst/nj-polst-form/>
- <http://www.nj.gov/health/advancedirective/ad/forums-faqs/>
- <http://www.njhqcqi.org/wp-content/uploads/2016/04/Rutgers-Eagleton-NJHCQI-EOL-Poll-for-Website.pdf>
- <http://www.njhqcqi.org/initiative/health-matters-poll/new-jerseys-end-of-life-care-planning/>
- https://www.qualityforum.org/Publications/2017/09/Palliative_and_End-of-Life_Care_Off-Cycle_Measure_Review_2017.aspx
- National Quality Forum. Palliative and End-of-Life Off-Cycle Measure Review 2017.
- Johnson, K. (2013, November). Racial and ethnic disparities in palliative care. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3822363/>
- Johnson, T. (2018, January 17). What you need to know about foreign-trained doctors in the U.S. healthcare system. <http://immigrationimpact.com/2018/01/17/foreign-trained-doctors-healthcare-system/>
- Lee, B. (2017, February 4). Study suggests that immigrant doctors provide better care than U.S. medical graduates. <https://www.forbes.com/sites/brucelee/2017/02/04/study-suggests-that-immigrant-doctors-provide-better-care-than-u-s-doctors/>
- Lee, M., Hinderer, K., & Alexander, C. (2018, July 17). What matters most at the end-of-life for Chinese Americans? <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6050625/>
- Livermore, D. (2018, December 13). Why you need to stop teaching cultural differences. <https://culturalq.com/why-you-need-to-stop-teaching-cultural-differences/>
- Mebane, E., Oman, R., Kroonen, L., & Goldstein, M. (2015, April 27). The influence of physician race, age, and gender on physician attitudes toward advance care directives and preferences for end-of-life decision-making. <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1532-5415.1999.tb02573.x>
- Rothchild, E. (1994 (July). Family dynamics in end-of-life treatment decisions. <https://www.sciencedirect.com/science/article/pii/S0163834394900043>
- Smith, A., Sudore, R., & Perez-Stable, E. (2009, November 25). Palliative care for Latino patients and their families: "Whenever we prayed, she wept." <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2782583/>
- Su, C., McMahan, R., Williams, B., Sharma, R., & Sudore, R. (2014, January 2). Family matters: Effect of birth order, culture, and family dynamics on surrogate decision-making. <https://onlinelibrary.wiley.com/doi/abs/10.1111/jgs.12610>
- United States Census Bureau. Quick Facts Essex County, Union County, Hudson County, Passaic County, Middlesex County, Somerset County New Jersey. 2019. <https://www.census.gov/quickfacts/fact/table/>

About Us

The Goals of Care Coalition of New Jersey is a 501(c)(3) nonprofit organization. We are a partnership of leading healthcare providers, government agencies, and community organizations working together to ensure that patients receive the care they need and no less, and the care they want and no more. We believe human interests, values, and dignity must be at the core of medical decision-making. We aspire to create a standard of care for NJ where people explore their wishes for care towards the end of life, express those wishes, and have their wishes honored. Through education and advocacy, our mission is to ensure that healthcare providers, patients, and family caregivers have the information, resources, training, and tools they need to facilitate discussions that result in a care plan that aligns treatment with the patient's goals of care.

Our founding members include the NJ Hospital Association, the Medical Society of NJ, the NJ Association of Health Plans, the Health Care Association of NJ, HQSI, the Home Care & Hospice Association of NJ, LeadingAge NJ & DE, the NJ Health Care Quality Institute, the NJ Palliative Care APN Consortium, the VNA Health Group, Samaritan Healthcare & Hospice, the National Association of Social Workers - NJ Chapter, the NJ Association of Mental Health and Addiction Agencies, College of Pastoral Supervision & Psychotherapy - Princeton Chapter, Jewish Sacred Aging, and the NJ Long-Term Care Leaders Coalition representing the Association of Directors of Nursing Administration/LTC, the New Jersey Medical Directors Association, the New Jersey Geriatrics Society, the New Jersey Chapter - American College of Health Care Administrators, S-COPE Statewide Clinical Outreach Program for the Elderly, and Dietetics in Health Care Communities of New Jersey.

We also have established strategic alliances with the NJ Department of Health (DOH), the Office of Minority & Multicultural Health, the Coalition to Transform Advanced Care (CTAC), and the following academic institutions: Rutgers NJ Medical School, Rutgers Robert Wood Johnson Medical School, Rutgers School of Public Health, Cooper Medical School of Rowen University and Rowan University School of Osteopathic Medicine.



Founding Members



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Academic Collaborative

