# Keeping PACE with the Pandemic:
## Experiences from and Impacts of COVID-19 on Care Provision Among North Carolina's Programs of All-Inclusive Care for the Elderly, a Qualitative Study

By
Neha Aggarwal

Senior Honors Thesis
Department of Health Policy and Management
Gillings School of Global Public Health
University of North Carolina at Chapel Hill

Spring 2021

*Approved:*

_____

**Sheryl Zimmerman, PhD, MSW; First Reader**
University Kenan Distinguished Professor
Co-Director of Program on Aging, Disability, and Long-Term Care at UNC Cecil G. Sheps Center for Health Services Research
Director of Aging Research at UNC School of Social Work

_____

**Karl Umble, PhD, MPH; Second Reader**
Associate Professor of Health Policy and Management
UNC Gillings School of Global Public Health

**Abbreviations**

ACA – Affordable Care Act

ADL – activity of daily living

AL – assisted living

CARES – Coronavirus Aid, Relief, and Economic Security

CDC – Centers for Disease Control and Prevention

CMS – Centers for Medicare & Medicaid Services

COVID-19 – coronavirus disease 2019

ED – emergency department

HHS – U.S. Department of Health and Human Services

IADL – instrumental activity of daily living

ICS – incident command system/team

IPC – infection prevention and control

IRB – Institutional Review Board

KFF – Kaiser Family Foundation

LTC – long-term care

NCDHHS – North Carolina Department of Health and Human Services

NH – nursing home

OBRA – Omnibus Budget Reconciliation Act

PACE – Program of All-Inclusive Care for the Elderly

PPE – personal protective equipment

SARS-CoV-2 – severe acute respiratory syndrome coronavirus 2

WHO – World Health Organization

## ABSTRACT

**Background:** The novel coronavirus disease 2019 (COVID-19) pandemic has deeply affected long-term care (LTC) for older adults, particularly in Programs of All-Inclusive Care for the Elderly (PACE). Older adults are more susceptible to serious illness and/or death from COVID-19, so studying care for this population is important. The pandemic arose in the midst of a larger LTC crisis in the United States centered on an aging population, unsustainability of current financing methods, and provider and staff shortages, among other challenges. COVID-19 is an opportunity to reform LTC, and this study may help shape the future of LTC by examining the resilience of the PACE model against the health system pressures of COVID-19.

**Objective:** This study investigates the immediate and long-term effects of COVID-19 on care provision in North Carolina's PACE (NC PACE) programs. Since PACE is organized by state, the research team chose to investigate sites in North Carolina.

**Methods:** NC PACE administrators were recruited and interviewed through online audio conferencing with a structured interview designed by the research team. The totality of NC PACE (N=12) was represented in the study. The interviews were transcribed, coded, and qualitatively analyzed using thematic analysis.

**Results:** Five themes emerged from thematic analysis, each with 2-3 subthemes: insufficient access to and integration with LTC providers and medical and mental healthcare specialists, reevaluation of the core PACE model with the transition to home-based care, that the provision of high-touch care promoted participants' psychosocial wellbeing, reorientation to pivot toward family-oriented care delivery, and that a culture of caring enabled a successful COVID-19 response.

**Conclusion:** PACE was overall successful in mounting a COVID-19 response that upheld safety of its participants, promoted the physical and mental wellbeing of its participants, and responded to the needs of informal/family caregivers. Administrators project that PACE's service model has permanently changed after the pandemic toward increased home-based care. Results from this study also have implications for the provision of mental health care in the PACE service population and for the federal government's financial relationship with PACE. PACE's success during a period in which it was difficult to uphold care quality presents a learning opportunity for LTC in the future.

## INTRODUCTION

The novel coronavirus disease 2019 (COVID-19), declared a pandemic by the World Health Organization on March 11, 2020, raises the question of how to protect citizens across the United States and the world. The fraught COVID-19 response in the U.S. has revealed systemic issues in health care, such as insufficient stockpiles of personal protective equipment (PPE), weak supply chains of vital medications and testing kits, poor infection prevention and control (IPC) protocols in several health care facilities, workforce shortages, insufficient interoperability for information sharing, and poorly developed palliative care for aging adults at the end of life.[1–4] It has also revealed a slow and uncoordinated government response with regard to physical distancing, testing, and dissemination of consistent guidance.[5] Such problems manifest in the data: as of October 7, 2020, the U.S. constituted 4.2% of the world population but 21% of its COVID-19 cases and 20% of COVID-19-related deaths.[6] Simply stated, the pandemic has been a test of the nation's policies, principles, and priorities.

Older adults are particularly susceptible to both COVID-19 and the chronic health conditions that exacerbate it, such as diabetes, heart disease, and chronic lung disease.[7–10] The risks for becoming severely ill (i.e. requiring hospitalization, intensive care, or a ventilator to aid breathing) and for dying from COVID-19 increase with age; the Centers for Disease Control and Prevention (CDC) reports that 8 out of 10 deaths related to COVID-19 nationally have occurred in adults aged 65 or older.[7] This issue is especially salient in North Carolina, where in 2018, 84% of older adults had at least one chronic disease, and 55% had multiple chronic diseases, placing them in the highest risk category.[11]

Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus that causes the coronavirus disease, is spread primarily via respiratory droplets and contact routes, but it can

also spread through airborne transmission within indoor spaces and through fomites that have been in close proximity to an infected individual.[12,13] Therefore long-term care (LTC) settings such as nursing homes (NHs) or assisted living (AL) communities, and community-based group programs such as the Program of All-Inclusive Care to the Elderly (PACE) are particularly susceptible to experiencing outbreaks of COVID-19 due to their congregate arrangement and focus on care for older adults. Furthermore, these and related settings provide care to persons with dementia, who may be unable to remember safety measures and/or have health issues that mask indications of COVID-19 infection.[14–16] Consequently, in May 2020, residents of LTC facilities in North Carolina comprised 62% of COVID-19-related deaths.[17] Around the same time, Americans living in NHs and AL communities comprised 0.6% of the U.S. population but accounted for an estimated 35-42% of deaths in the U.S. associated with COVID-19.[18]

Despite older adults' status as the most susceptible group to shoulder serious health consequences from COVID-19, and the noted challenges of LTC to meet their needs, national and international LTC experts have condemned COVID-19 responses that undermine the dignity and autonomy of older adults and harbor ageist attitudes.[19–21] Scholars have conveyed the disheartening truth about COVID-19 by characterizing it as a "disease of aging," and they have characterized the prospect of COVID-19 in LTC's congregate living facilities as the "perfect storm."[9,22] While deaths from COVID-19 have occurred across all age groups,[23] this first characterization refers to the disease preferentially targeting the most aging population. The latter characterization portends a harmful and unsustainable situation in LTC management both amid the COVID-19 pandemic and other future outbreaks. Together these claims arise in the midst of a broader LTC crisis in the U.S.[24,25]

Even before the onset of the COVID-19 pandemic, scholars advocated for improved and updated models of LTC, and the pandemic may well be a catalyst on this front.[26,27] To facilitate such change, LTC will need supportive policies and perhaps new organizational structures to face growing demand in the context of an aging U.S. population.[26,28] For example, policy improvements may be made in the following areas: government and accrediting agencies setting and enforcing standards, quality incentive improvements through Medicare, Medicaid, and other payers, consumer information and choice, and organizational and cultural commitment to quality improvement.[29] Scholars suggest the following additional factors that may guide LTC improvement: personal choice to stay at home as one ages, medical treatments for dementia, participation of caregivers in design of individualized care plans, relationship-centered care, and biopsychosocial patient wellness checks.[4,26] One such care model founded upon these principles is PACE, which focuses on patient-centered, holistic care for the older adult population in the U.S. This study will explore the COVID-19 experiences of PACE in particular to understand its resilience against the health system pressures imposed by the pandemic. Since PACE programs are organized by state, this study will look at all PACE sites in North Carolina (NC PACE).

According to the Kaiser Family Foundation (KFF), the number of people in the U.S. over the age of 85, a demographic with the highest need for LTC services and supports, is expected to increase by close to 70% over the next two decades.[30] This datum reflects even more strongly in the population of North Carolina: the North Carolina Department of Health and Human Services (NCDHHS) projects a 107% increase in the population over 85 years old between 2016 and 2036.[11] As PACE organizations reconsider their operations to more comprehensively serve this increasing portion of the state and national population, a rigorous reexamination of their policies,

procedures, and practices amid the health system pressures imposed by the COVID-19 pandemic is crucial for developing safe, sustainable models of care.

Given the expanding number of seniors, an existing focus on new models of LTC, and the heightened susceptibility of older adults to adverse health consequences from COVID-19, it is critical to understand the particular ways in which PACE administrators adapted to the demands of COVID-19 and which of these changes are sustainable. No research has been done on the effect of a pandemic of COVID-19's length and scope among PACE. By examining NC PACE's responses to COVID-19, this study can inform quality improvement activities and contribute to the evidence for necessary increased capacity in several domains. Findings will be useful to PACE providers as they consider modifying their models of medical, mental, and/or psychosocial care based on lessons learned from the pandemic. They may also be of interest to state and federal policymakers as they consider the effectiveness of financial disbursement policies for PACE in the context of LTC; and to government agencies like CDC and NCDHHS as they reflect on the effectiveness of their IPC guidance for LTC sites and PACE during the pandemic. These efforts hold promise to improve the quality of life and care provided to older adults in the U.S. both during normal practice and during future epidemics, pandemics, or other infection outbreaks.

## Research Questions

In this study, researchers interviewed PACE administrators about how they adapted their care model, care practices, and service provision to maintain their participants' medical, mental, and psychosocial wellbeing during the COVID-19 pandemic. The study population is all PACE sites in North Carolina (N=12). Results indicate the effectiveness of these adaptations and assess

the implications for future care provision both during business-as-usual and during future public health emergencies. Furthermore, conversations with PACE administrators reveal facilitators and barriers to these changes. Beyond producing implications for resources and resulting care during pandemics, the results of this study may help shape the future of LTC. The following research questions summarize the focus of this investigation.

1. How has the COVID-19 pandemic affected care provision in North Carolina's Programs of All-Inclusive Care for the Elderly (NC PACE)?
2. What are the lasting impacts of the pandemic on NC PACE?

## LITERATURE REVIEW

### Overview of Long-Term Care, Residential Settings, and PACE Organizations

LTC provides services designed to meet a person's health and/or personal care needs during a short or long period, supporting these individuals in living as independently and safely as possible.[31] Primary LTC users are elderly who are disabled (aged 65+), nonelderly who are disabled (aged less than 65), those with intellectual disability, and those who are mentally ill.[32] This support may include help with activities of daily living (ADLs) such as eating, moving around, bathing, dressing, and toileting, or instrumental activities of daily living (IADLs) such as housekeeping, shopping and running errands, preparing food, doing laundry, and doing chores.[32] While formal LTC is provided through organizations such as the types that will be discussed in this section, most LTC is unpaid and provided at home by informal caregivers (e.g. family and/or friends). The American Medical Association estimates that daughters who are primary caregivers of older parents spend 266 hours each month assisting them with basic personal care and tasks –

more than most people spend at full-time jobs.[33] It is important to recognize the efforts of informal caregivers before turning the focus to formal, paid care.

Traditionally, formal LTC has been provided in congregate living structures, most notably NHs. For many older adults, NHs are used for long-term residence, providing 24-hour supervision and ongoing nursing care to maintain their residents' quality of life given their physical and/or mental limitations. However, residents of NHs may also receive short-term care, such as for rehabilitative stabilization after hospital discharge. NHs provide a wide range of health and personal care services, focusing on nursing and medical care. Services include nursing care, three meals per day, assistance with ADLs, and rehabilitation services (e.g. physical, occupational, and speech therapy).[34] NH care is primarily covered by Medicaid, which contributes a significant portion of NHs' funding.[8,30,35] In 2015-2016, 61.8% of NH residents used Medicaid as a payment source,[36] and payment for NH care constituted 31.7% of total Medicaid expenditures.[37]

Over the last few decades, AL communities have mushroomed as an alternative form of residential LTC for people who require ongoing supportive care but not the nursing services provided in a NH. AL is state-regulated and developed to provide residents with a home-like environment designed to fulfill personal and social needs. AL programs also provide 24-hour supervision, like NHs, but are not required to provide nursing care.[38] They also provide medication monitoring, 1-3 meals per day, housekeeping, social and recreational activities, and limited health monitoring.[39] Most do not accept Medicaid and none accept Medicare, so private pay funds AL costs.[40] As an AL resident needs increasing amount of assistance, they may need to be moved to a NH. NHs provide significantly more health services than AL facilities and have more lenient admission policies, but they offer less privacy to residents.[41] The history behind

these LTC options and the motivations for their enactment will be further discussed in the next section.

PACE organizations, on the other hand, provide an option for older adults who are NH-eligible based on functional and/or cognitive impairments to live within their own homes rather than a congregate living setting.[42] PACE is a provider-based health plan that offers the full continuum of care along with long-term services and supports, so participants disenroll from other health plans before joining PACE. Comprehensive care is made possible by an interdisciplinary team of health professionals and a PACE day center at which participants receive medical care and partake in recreational activities. PACE covers all services offered by Medicare (Parts A, B, and D) and Medicaid services along with additional services that the interdisciplinary team of health professionals deems medically necessary, including health care provider visits (primary care and specialty), home care, hospital visits, and NH stays.[43] The interdisciplinary team may include a physician, nurse, occupational therapist, physician therapist, social worker, speech therapist, dietician, and personal care aide.[43] Additional services covered include adult day primary care, dentistry, emergency services, laboratory/x-ray services, meals, nutritional counseling, occupational therapy, physical therapy, prescription drugs, preventive care, social services (e.g. caregiver training, support groups, respite care), social work counseling, and transportation to the PACE center for activities or medical appointments.[43] **Figure 1** summarizes the PACE model of care and the relationships among the components described. Thus, PACE provides for many types of medical and lifestyle assisting services and covers participants' means of accessing these services.

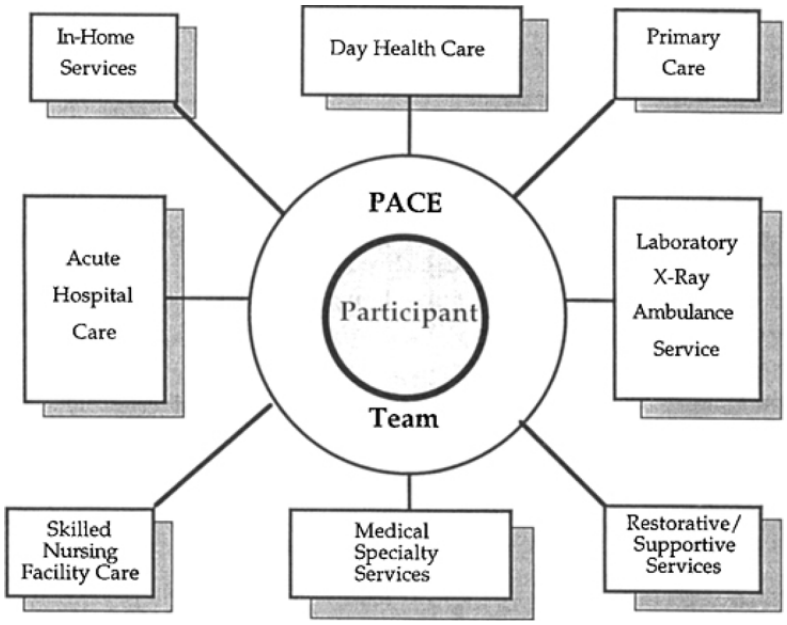



Figure 1. Interdisciplinary PACE model centered on participants, reproduced from Eng, et al.[44]

PACE is financed on a capitated model, so the organizations receive fixed monthly payments from Medicare, Medicaid, and private payers to provide care necessary for the continued wellbeing of their participants.[45] Consequently, PACE sites are responsible for participants' NH stays, hospital stays, and medical specialist visits. Private payers are involved for participants who are not dual-eligible for Medicare and Medicaid, a population that constitutes approximately 10% of national PACE participants; thus, Medicare and Medicaid are the primary funding sources for PACE.[46] Since PACE is both a health provider and a health plan, capitation incentivizes PACE organizations to provide preventive care to avoid future emergency health expenses (e.g. emergency department [ED] visits, NH stays) and to avoid duplicative care.[46] Prevention of ED visits is important because between 2005 and 2015, those aged 65+ had the most hospital admissions from ED visits out of all age groups, ranging 34-42% admissions.[47] PACE facilitates prevention of health problems by not only providing medical services, but also providing meals, recreation, socialization, and personal care at the PACE centers. In the

participants' homes, PACE provides skilled care, personal care supportive services, and physical supports to promote participants' safe and autonomous living such as with the use of grab bars and ramps.[46] The payment structure additionally encourages PACE to individualize care plans to best serve the specific needs of each participant.[48] PACE organizations are approved, regulated, and monitored by CMS and state Medicaid agencies.[49]

To qualify for PACE, an individual must be 55 years of age or older, live in the service area of a PACE organization, need a NH-level of care as determined by the state of residence, and be able to live safely in the community with help from PACE.[43] As of 2020, PACE serves over 51,000 participants in 31 states[46]; North Carolina has 12 PACE sites. The National PACE Association reports that the average age of participants is 77 years old, and many have multiple and complex medical conditions, cognitive or functional impairments, and/or significant long-term care needs.[48] The average participant has eight medical conditions.[48,50] The most common chronic medical conditions include diabetes, dementia, coronary artery disease, and cerebrovascular disease; common behavioral conditions include major depressive, bipolar, and paranoid disorders.[50] Approximately half of participants have some form of dementia.[51] Thus, eligible participants are expected to be a costly group for health coverage, but through its care model PACE strives to keep costs controlled.[50]

This program is a response to the preference among older adults in the United States to live in their communities whenever possible.[26] Upon enrollment, a prospective participant undergoes a medical evaluation and home assessment to inform the interdisciplinary care team of the participant's situation.[48,50] Initial assessment is just one strategy out of many to promote both quality care and cost-effectiveness. Some other strategies, according to the National PACE Association, include caregiver engagement in participants' health care decision-making,

communication among all people who provide care for a participant, and addressing all health concerns and long-term care needs within the care plan.[48,52] As of 2018, more than 90% of PACE participants live in their homes, while 7% live in skilled nursing facilities.[50] In PACE, participants' physical and mental health improves, they receive high quality of care, and their care is cost-controlled, as reported by the National PACE Association and CMS.[50,53–55] PACE programs have managed to keep ED visits and hospitalizations low, including for persons with dementia, enabling a safer living environment in the homes.[50,56,57] They also promote psychosocial wellbeing of participants by maintaining regular day center attendance; on average, PACE participants attend the day center three days per week to access health clinics, therapy, and social and recreational activities.[45] The history of PACE and how it improves on previous LTC models of care will be discussed in the next section.

**Evolution of Programs of All-Inclusive Care for the Elderly**

PACE originated as a model of care in 1971 in a Chinese community of San Francisco, California.[42] It was originally called On Lok Senior Services, which is Cantonese for "peaceful happy abode."[50] On Lok was developed as an alternative to NH care for the community's older adults, which was regarded as a culturally undesirable option.[42,45] The intention and design of On Lok was to provide older adults with the means to live independently and happily in their own homes through the end of life. The first On Lok program had adult day care with a comprehensive package of medical services, rehabilitation services, respite, and social services.[42] Since the model was able to serve older adults with different health concerns, the program was successful and was nationally recognized and funded: in 1979, On Lok began receiving Medicaid reimbursement for adult day health care, and it received a U.S. Department of Health and Human

Services grant to expand its care to include meals and housing assistance.[42] A few years later, On Lok demonstrated 15% lower cost of care for its participants than in the fee-for-service payment model for the same age group. On Lok was approved to test out a capitated payment model, and despite the financial risk that typically accompanies this transition, the program remained financially stable. The program has expanded since then; the 1986 Omnibus Budget Reconciliation Act (OBRA) allowed for 10 On Lok sites across the country, the 1990 OBRA allowed for 16 sites, and in 1997 PACE became a permanent Medicare program under the Balanced Budget Act with a plan for expansion in future years.[51] As of March 2021, 272 PACE centers exist across 31 states with 138 sponsoring organizations.[58] PACE enrollment has steadily increased; between 2012 and 2020, it nearly doubled.[58] The capitated model continues to work as well; on average, states pay PACE programs 13% less than they pay Medicaid for the care of a comparable population, including NH stays.[58]

Despite the robust research supporting PACE's success, it is not without its drawbacks. One major challenge is the recruitment of primary care physicians, particularly geriatricians who are rare among medical providers in the U.S.[42,44] Most PACE physicians are internists (83%) or family practice physicians (17%), and few completed geriatrics fellowships.[44,59] Furthermore, PACE programs must compete with academic medical centers and managed care health systems for the limited pool of geriatricians.[44] Another challenge exists in PACE that is common across all health settings in the U.S.: finding qualified staff and leadership in the hiring process to ensure that care can be optimally coordinated, and shouldering the costs associated with hiring leaders who can effectively facilitate this mission.[42] Since PACE is both a provider and a health plan, administrative tasks such as claims processing and coordination with CMS for reimbursement and reporting requirements have weighed on PACE providers.[42] Importantly,

PACE faces a significant challenge expanding its service population to those who do not qualify for Medicaid.[42,51] Medicaid pays for two-thirds of PACE's costs, so those who are Medicaid-ineligible would need to pay this price out-of-pocket, an unattractive and often financially infeasible option for PACE candidates.[51] Thus, with its current financing structure, PACE is limited in the population it can realistically serve.[51] Scholars praise the integrated care model of PACE but warn that it has been possible only with the support of federal government funds. Future improvement may only be possible with additional federal support through developmental funding, federal loan programs, individual tax incentives, and public/private partnerships through Medicaid.[51] PACE expansion and improvement must also be considered within the market of LTC in which it is situated, as well as the local needs and preferences of its eligible population across service areas.

Returning now to the original reason that PACE programs began, a relevant question is, "Why were NHs seen as so undesirable by the community in San Francisco and for many others around the nation?" The question of why this perception persists is particularly concerning given that NHs have been the primary source of institutional care for older adults since the enactment of Medicare and Medicaid.[41] In short, institutionalized LTC has historically evoked feelings of hopelessness and despair, reduced autonomy, and the desire for the facilitation of more meaning in end-of-life care, among other limitations. An article in the *Journal of the American Medical Association Internal Medicine* described NHs as "arguably the most criticized sector of the U.S. health care system," characterized by "cycles of public clamor for improvement and ineffective governmental responses."[60] At its core, NHs were not designed for the people they intended to serve. The precursor to NHs was Great Depression-era poorhouses; people accepted that they had very low quality and considered them a last resort.[60] The poorhouses eventually became

public old age homes, which were again viewed as undesirable.[60] Thus, the historical precedent of a poorhouse was a conduit to shuttle out a portion of the population into institutionalized living, where they could be monitored, controlled, and excluded from society. NHs had poor regulation and building inspection until the 1950s, when the Hill-Burton Act stimulated NH construction with the standards of acute care hospitals.[60] This action established NHs as medical institutions and arguably contributed to the medicalization of aging in U.S. society. The next action addressing NH quality came with the 1965 programs Medicare and Medicaid, which established care standards upon which federal funding was contingent.[61] While these programs drastically increased the number of NHs around the country, they also inadvertently led to the industry becoming dominated by for-profit owners and failed to establish a precedent of safety and quality requirements that were enforced and taken seriously, in part and on occasion resulting in widespread fraud, neglect, and abuse of residents.[60] This cycle, in which NHs are the focus of updated legislation but receive the regulatory short stick, continues to this day. Many NHs are privately owned by for-profit companies yet publicly funded, which can lead to financial instability exemplified by massive bankruptcy claims.[62] On top of unsustainability, NHs continue to be criticized for poor quality of care and endangerment of their residents.[60]

AL communities were created to address some of these challenges. While still congregate living settings, AL sought to be more home-like, with independence, autonomy, and privacy for their residents, including what was referred to as an "invisible support system" in a residential setting.[41,63,64] They are not licensed as NHs but provide personal care for ADLs and provide round-the clock staff to respond to residents' unanticipated needs.[63] As NHs became more like hospitals, AL communities flourished and became a popular option among older adults with moderately high income levels, while those of moderate or low income levels typically cannot

afford this service.[63,64] To illustrate, from 1990 to 2002, the number of AL beds grew 97% to almost 1.2 million beds in 40,000 settings, while NH beds grew by 7% to 1.7 million.[65] However, AL communities have challenges of their own, including that the term is adopted by sites that do not abide by these goals, and therefore AL communities cannot definitively distinguish themselves from NHs.[41,64] As congregate living settings with the challenges of governmental regulation, AL communities are at risk for inheriting some of the same problems as NHs. This concern is especially important because AL communities are responsible for residents with increasingly complex medical conditions, are understaffed, and have maintain minimal staffing requirements.[66] Additionally, AL communities serve a diverse demographic, thus making it difficult to assess overall quality.[66]

In contrast, PACE demonstrates successful participant outcomes and is well-regarded among its users. In one study, PACE participants had a 24% lower hospitalization rate than other dually-eligible Medicare and Medicaid beneficiaries.[67] Part of the reason behind this outcome is that preventive care is prioritized in PACE, especially with regard to vaccines (i.e. influenza, pneumococcal) and hearing and vision problems.[54,55] An important measure of PACE's success is participant and family satisfaction: in 2018, 96% of family members were satisfied with PACE support, and 98% of caregivers would recommend others to join PACE.[68] Furthermore, PACE staffs a broad spectrum of providers and specialists, giving participants access to resources they need to fulfill specific health and wellness concerns.[44] Despite well-documented racial disparities in health in the U.S., a 2003 longitudinal cohort study among 12 PACE sites concluded that black PACE participants are more likely to survive than white participants a year after enrollment.[69] While a concern within PACE is participants who live alone, a 2006 study among 11 PACE sites showed that participants without informal caregivers are not at higher risk for

nursing home admission.[70] In summary, PACE programs were designed specifically for the population that they intend to serve, which allows them to focus on the specific overlapping problems faced by older adults and work on preventive care to support participants and their families.[68] Furthermore, PACE's payment structures theoretically align incentives between the providers and the participants: higher quality care for lower cost. The next section will situate these developments in LTC within the broader context of aging in the U.S. and consequent healthcare financing problems in the next few decades.

**The United States Long-Term Care Crisis Intersecting with the COVID-19 Pandemic**

The proportion of older adults to working-age people is rapidly rising in the United States, which raises concerns about the sustainability of LTC financing mechanisms, as will be shown. Specifically, the population of older adults is estimated to increase from 35 million in 2000 to 69.4 million in 2030.[71] Furthermore, the health needs of this age group are significant; in 2016, people aged 65+ years constituted 13.5% of the U.S. population but 45.2% of the top 10% of healthcare users.[72] Older adults constitute the only age group for whom health insurance is an entitlement, but the financing mechanisms are imperfect.[32] In 2016, about 13 million Americans required some form of LTC.[73] In the same year, LTC costs were estimated at $366 billion, while the cost of unpaid family care provided by more than 41 million Americans was estimated to be as much as $470 billion.[73] Provision for LTC financing in the United States is highly fragmented, with no public or private LTC insurance program except for individuals who spend down their assets for an income below the federal poverty level ($12,760 or less in 2020) to become eligible for Medicaid benefits.[73]

In 1965, the healthcare financing programs Medicare and Medicaid were introduced as amendments to the Social Security Act, thereby vastly increasing the federal government's hand in paying for healthcare services. Medicare is a federal program designed to support the acute care needs of those who are elderly and disabled, so while it covers skilled nursing care and home health benefits, it does not cover LTC.[32,74] The joint federal-and-state program Medicaid does cover LTC, primarily through NH funding, but when it was first passed it did not cover care in the home, thus creating a bias in favor of institutional LTC. After a series of LTC reform since then, the government became the largest payer for LTC, and NH utilization skyrocketed.[74] In 2010, the Affordable Care Act (ACA) provided new incentives for states to improve LTC infrastructure and expand home- and community-based services.[74] LTC was covered not by a singular insurance scheme but rather by a patchwork of Medicaid and (often financially burdensome) out-of-pocket expenditure.

The ACA created the first national voluntary long-term services and supports insurance program through the Community Living Assistance Services and Supports Act, which was later repealed in 2013 through the American Taxpayer Relief Act of 2012 because the program could not meet its three objectives: self-sustainability, financial soundness for 75 years, and affordability to consumers.[74,75] Historically, the high premiums of LTC have inhibited buy-in for a national insurance program, and federal and state dollars have been insufficient to buoy even Medicare. As the number of Americans aged 85 and older quadruples between 2000 and 2050,[76] the ratio of working Americans contributing to the Social Security fund to Americans receiving Social Security benefits will decrease; according to the 2019 Medicare Trustees report, Medicare Hospital Insurance Part A fund will be depleted in 2026.[77] This is a significant problem because in 2018, Medicare spending totaled $605 billion, which accounted for 15% of the federal budget;

in 2017, Medicare accounted for 20% of national healthcare spending, 30% of spending on retail prescription drugs, and 25% of spending on hospital care.[77] Even more financial strain will befall Medicaid, which pays for 45% of LTC expenses and also shoulders the healthcare costs of the nation's poorest citizens.[35]

Chronic underfunding of LTC on the federal and state levels has resulted in tangible consequences at the NH level, culminating in a LTC crisis. Underfunding occurs in part because the private market for LTC insurance contains several problems and disincentives, such as Medicaid as a safety net, the uncertainty involved in paying for care that may not be used for another 30+ years, inadequate benefits to cover the expenses, adverse selection which drives up premiums, and high administrative costs.[33] The consequences include, but are not limited to, staffing shortages, inability to meet federal quality standards, disparities in NH quality based on racial characteristics, differences in non-profit and for-profit NH care quality, insufficient mechanisms for reporting abuse and neglect, and insufficient information on home- and community-based care.[78] These problems are exacerbated by COVID-19, and the parent study under which this investigation sits sought to understand these problems in NHs and AL communities further. However, the pandemic also presents an opportunity for LTC providers to envision new, sustainable models of care supplemented by federal and state policy.

PACE could potentially become a part of this sustainable model of care. The COVID-19 pandemic focused the nation on the quality and financing of LTC given that the disease disproportionately affected these older adults.[9,20] It is possible that PACE's past success in avoiding hospitalizations, providing preventive care, maintaining quality of care, and upholding participants' quality of life may be resilient during the pandemic. PACE uses a combined payment of Medicare, Medicaid, and limited private pay, which prevents cost shifting, a

consequence of multiple payers and profit incentives.[50] July 2020 data showed that PACE was resilient against many of the key indicators of decline across LTC settings during COVID-19; specifically, skilled nursing facilities and AL communities experienced significant declines in census, but PACE sites remained relatively stable.[79] This study investigated the scope and causes/facilitators for resilience among PACE, which may be leveraged for future LTC planning.

**Government Assistance for PACE and Residential LTC during the COVID-19 Pandemic**

To contextualize PACE programs' changes to practices of care during COVID-19, this section will summarize guidance and support provided by federal and state governments to LTC sites and PACE specifically during the pandemic.

First, with regard to guidance, the state of North Carolina provided in-depth guidelines, checklists, and resources to help LTC providers adjust their practices to the constraints introduced by COVID-19 via the NCDHHS website, which are supplemented by guidance and webinars from the CDC. Specifically, NCDHHS created and disseminated a COVID-19 Outbreak Toolkit for Long-Term Care Settings, an IPC assessment tool, IPC education resources, strategies to optimize PPE, and advice about staffing.[80] Additionally, in March 2020 NCDHHS formed a Long-Term Care COVID-19 Response Team, which works with LTC settings, local health departments, industry associations, advocacy groups, hospitals, and others on strategies for prevention, capacity, testing, managing outbreaks, and oversight.[81] Outside of this information, if LTC settings had questions pertaining to the implementation of the recommendations, they could contact their local county health department for specific, tailored guidance.[82] In May 2020, NCDHHS expanded measures to prevent and contain COVID-19 in LTC settings. It provided LTC settings with 14-day PPE supplies for more than 3,000 state-licensed LTC settings (including AL, NHs, and intermediate care facilities for individuals with

intellectual disabilities) and a limited Medicaid rate increase to support IPC measures as previously described.[83] Questions in the structured interview used in this study queried LTC providers about the effectiveness and reach of this standardized assistance in their COVID-19 containment and/or prevention.

A primary source of funding was the Coronavirus Aid, Relief, and Economic Security (CARES) Act, which was passed in March 27, 2020, to financially support individuals and businesses during the COVID-19 pandemic. Within LTC, CARES Act funding prioritized NHs, then AL communities, and finally PACE. The CARES Act-authorized NH Provider Relief Fund distributed $5 billion to protect NH residents from the impact of COVID-19.[84] The aid was organized as an initial $2.5 billion disbursement in August 2020 for increased testing, staffing, and PPE needs, followed by additional performance-based distributions throughout the fall.[84] As of August 7, 2020, CARES Act funding for NHs was provided automatically through a calculation that offered a fixed payment and an additional amount per certified bed.[85]

As noted earlier, Medicaid is the primary payer for NH services. During a pandemic when LTC sites have needed more funding to address IPC-related and other emerging challenges, North Carolina's Division of Health Benefits within NCDHHS granted a 5% Medicaid rate increase for skilled nursing facilities, hospice facilities, local health departments, private duty nursing, home health, fee-for-service personal care services, and others, indefinitely beginning in March 2020.[86] This measure responded to a need for financial assistance for personal care assistance and home health services to help older adults stay at home, where there is less risk of COVID-19 exposure.[81]

AL administrators became eligible to apply for CARES Act funding via the Phase 2 – General Distribution between September 1-21, 2020.[87,88] The North Carolina Assisted Living

Association additionally received $16 million in relief funds.[89] PACE programs, on the other hand, were excluded from the Phase 2 – General Distribution, but could be eligible if they fulfilled certain criteria, including having billed their state Medicaid program or Medicaid managed care program in the past year.[90,91] The interview used in this study asked about the accessibility of these funds to PACE and how beneficial they were toward successful COVID-19 response. However, initial literature scoping indicates scholars' observations that the portion of CARES Act stimulus funding the LTC sector is less than for hospitals and other health providers, which may indicate that national priorities lie outside of LTC.[73] Results from this study and the parent study will better inform such tentative conclusions.

## METHODS

As explained above, the context for this study includes the disproportionate harm of COVID-19 on older adults, an escalating LTC crisis, and an aging U.S. population. These overlapping problems create urgency for research to assess the resilience of LTC care models during COVID-19. Since PACE is a promising care model, it was chosen for study. Thus, this study sought the experiences of NC PACE administrators during COVID-19 to understand the short-term and long-term effects of COVID-19 on care provision in NC PACE.

### *Overview*

This study was funded by the National Institutes of Health, through the North Carolina Translational and Clinical Sciences Institute housed at UNC School of Medicine. The investigators comprise an interdisciplinary team of national experts on LTC, health services, geriatrics, gerontology, and IPC who are affiliated with the UNC-Chapel Hill Cecil G. Sheps

Center for Health Services Research and the Schools of Medicine, Social Work, and Public Health. This project was informed by the team's related efforts to compile and compare IPC practices across different settings of care.

### *Sample and Recruitment*

This study was conducted under a parent study that looked at three types of LTC settings across North Carolina: NHs, AL communities, and PACE sites. To learn about the COVID-19-related practices across North Carolina's PACE programs, the investigative team contacted administrators from each PACE site in the state. The study size is N=12, the totality of all PACE sites in North Carolina. Appendix A contains the regions served by PACE sites and ongoing COVID-19 outbreaks in nearby congregate living settings in October 2020.

We recruited participants by mailing a brief letter describing the project and indicating our intention to call within the week to conduct an interview. The letter packet contained a telephone number that they could call if they did not wish to participate in the study. If data collectors received no objection, they contacted the individual to discuss the project in greater detail and solicit verbal informed consent for participation. If the administrator was not available, an alternate suitable representative from the organization was invited to participate in the interview. All procedures and materials were approved by the UNC-CH Institutional Review Board (IRB).

### *Interview Development and Data Collection Process*

We used a structured interview that required approximately 1 hour to complete, and all participants received a modest compensation of $50 for their time. The interview items were based on a review of the grey and peer-reviewed literature and consultation from key leaders in

PACE, NH, and AL administration. Related to this project, we asked PACE administrators questions about successes, challenges, recommendations for the future, barriers, and facilitators pertaining to medical, mental, and psychosocial care during the COVID-19 pandemic. Certain close-ended questions were based on domains from the CMS Toolkit on State Actions to Mitigate COVID-19 Prevalence in Nursing Homes,[92] which were modified to include items of additional relevance to PACE and AL. Domains included visitation, socialization and isolation, personal protective equipment, screening, testing, infection control practices, transfers and admissions, and workforce and staffing; new domains included external health care providers and advance care planning. Additional close-ended questions were included in the interview to characterize the study population (e.g., PACE administrator characteristics, PACE participant characteristics, PACE enrollment numbers). This study was conducted within a more comprehensive investigation of several aspects of LTC sites during the pandemic, the domains of which are described in greater detail below.

The interview began by summarizing the intent of the study to gather experiences, facilitators, and challenges of the LTC providers in order to improve their ability to respond to similar public health emergencies in the future. First, we provided an opportunity for the participants to provide their one most important comment related to the COVID-19 pandemic; we began with this item so as not to influence their response by the questions that followed. We then asked close-ended questions about PACE site characteristics (e.g. enrollment changes due to COVID-19, number of participants attending the day center, number of participants in other LTC settings), information about PACE participants (e.g. demographic characteristics, Medicaid status), infection prevention (e.g. dedicated staff for IPC management), infection prevention (e.g. personnel in charge of coordinating response), COVID-19 testing and cases (e.g. number of

regular tests conducted, transfers/hospitalizations/deaths due to COVID-19), and external providers (e.g. availability of telemedicine and mental health services). Next, an open-ended section contained standardized prompts related to providers' successes, challenges, and recommendations for the future in the following domains: organizational leadership, staffing, resident/participant care (medical and psychosocial), and family relationship support. The participants were then asked about other barriers and facilitators related to COVID-19, impacts of COVID-19 on the organizations' financial health, and any innovative processes or programs they implemented. Lastly, a quantitative, close-ended section inquired about the need for remedies in the aforementioned domains. Appendix B contains the full interview guide.

Interviews were conducted via Zoom audio software and were recorded upon obtaining permission of the participants. We obtained verbal consent for participation in accordance with approved IRB procedures at the start of the interview. The Zoom transcript feature was used to obtain the interview transcripts and for data entry into a qualitative data analysis program (ATLAS.ti). The Zoom interviews were conducted over a secure link initiated by UNC research staff.

### *Qualitative Data Analysis*

After the interviews were conducted, the research team downloaded transcripts from Zoom and reviewed them for accuracy. All five members of the team separately coded the transcripts. In the coding process, the team members first independently coded certain transcripts then met regularly to compare codes and reconcile differences in code interpretation/use. During these discussions, the number of codes, the categories used to define them, and selection of illustrative quotes were continuously in flux until consensus was achieved after rigorous

discussion.[93] We used the qualitative data analysis software ATLAS.ti to store, manage, and code the data collected from interviews. We used the final codebook (Appendix C) to analyze our qualitative data through thematic analysis.[94,95] For each query domain, we inductively determined themes that could lead to conclusions from the data.

### *Ethical Considerations*

The questions contained in this study could be perceived as challenging to LTC administrators if they were thought to uncover the shortcomings of their COVID-19 practices, which was not at all the intention. Therefore, the introduction of the interview stressed the intent of the project being to inform the future of LTC, and the questions themselves asked what worked well, along with what did not work well, and suggestions for the future. In addition, participants were allowed to refuse to answer any questions and to end the interview at any point. To protect our participants' privacy, we stored identifiable data on a secure server at the Cecil G. Sheps Center, access to which was restricted to members of the research team. The interviews were conducted in a private room at times convenient to the participants.

## RESULTS

Interviews were conducted with the PACE administrators between December 3, 2020 and January 28, 2021, with the midpoint date being December 31, 2020. **Table 1** describes the characteristics of NC PACE administrators who participated in the interviews (N=12) and of the PACE participants (clients) who received PACE services at the time of data collection. Most administrators were female (58%) and white (67%), and had a graduate degree (83%). On average, they worked as administrators for 13.4 years (standard deviation [SD] 7.7) and at their PACE site for 8.7 years (SD 4.2). PACE participants (clients) are mostly between the ages of 65 and 84 years (70.2%), majority white (54.7%), and 97.3% receive state financial assistance.

**Table 1. PACE Administrator Characteristics (N=12)**

| | **N (%) or Mean (SD)** |
|---|---|
| **Administrator Characteristics** | |
| Female | 7 (58) |
| Race | |
| White | 8 (67) |
| Black or African American | 2 (17) |
| Other | 2 (17) |
| Hispanic | 1 (8) |
| Education | |
| Bachelor's degree | 2 (17) |
| Graduate degree | 10 (83) |
| Job title | |
| Executive Director / Administrator | 11 (92) |
| Associate Director | 1 (8) |
| Licenses/certifications | |
| Certified nursing assistant | 0 (0) |
| Medication technician | 0 (0) |
| Registered nurse | 1 (8) |
| Administrator license | 3 (25) |
| Other | 4 (33) |
| Length in position (years) | 6.3 (3.8) |
| Length of time worked at organization (years) | 8.7 (4.2) |
| Length of time as administrator, any organization (years) | 13.4 (7.7) |
| **PACE Participants (Clients) Characteristics** | |

| | |
|---|---|
| Age (mean percent) | |
| <65 years old | 12.3 (5.4) |
| 65-74 years old | 38.8 (9.1) |
| 75-84 years old | 31.4 (9.8) |
| 85-94 years old | 13.8 (7.1) |
| 95 and older | 3.8 (3.5) |
| Male | 33.1 (9.2) |
| Race | |
| White | 54.7 (22.7) |
| Black or African American | 43.6 (21.7) |
| Other | 1.8 (1.8) |
| Hispanic | 5.4 (2.8) |
| Uses wheelchair as primary mode of locomotion | 51.5 (17.8) |
| Has Alzheimer's disease or a related dementia | 51.3 (14.5) |
| Receives state financial assistance or Medicaid | 97.3 (3.8) |

**Table 2** describes PACE enrollment and changes since COVID-19 began in March 2020. During the time of data collection, the average PACE enrollment was 165.9 (SD 49.8). Compared to March 2020 (pre-pandemic), enrollment decreased for 11 of the 12 PACE sites, on average by 16.4 participants. The number of participants attending the day center decreased from an average of 95.2 in March 2020 (pre-pandemic) to 17.1 in December 2020-January 2021.

**Table 2. PACE Enrollment, and Changes Related to COVID-19 (N=12)**

| | **N (%) or Mean (SD)** |
|---|---|
| **Overall participants** | |
| Enrollment/number of PACE participants (December 31, 2020)[1] | 165.9 (49.8) |
| Enrollment change since March 2020 | |
| Same | 1 (8) |
| Decreased | 11 (92) |
| Decrease in enrollment (number of participants) | 16.4 (10.8) |
| **Day center participants** | |
| Number of participants attending day center prior to March 2020 | 95.2 (14.3) |
| Number of participants attending day center (December 31, 2020)[1] | 17.1 (11.2) |
| **Nursing home residents** | |
| Number of participants in nursing home (December 31, 2020)[1] | 12.3 (6.9) |
| Change in participants in nursing home since March 2020 | |
| Same | 3 (25) |
| Increased | 4 (33) |
| Decreased | 5 (42) |

| | |
|---|---|
| Decrease in number of participants in nursing home | 4.8 (3.1) |
| **Assisted living residents** | |
| Number of participants in assisted living (December 31, 2020)[1] | 1.5 (1.9) |
| Change in participants in assisted living since March 2020 | |
| Same | 4 (67) |
| Decreased | 2 (33) |
| Decrease in number of participants in assisted living | 2.0 (1.4) |

[1] Data were collected from December 3, 2020-January 28, 2021. December 31, 2020 is the midpoint of the range.

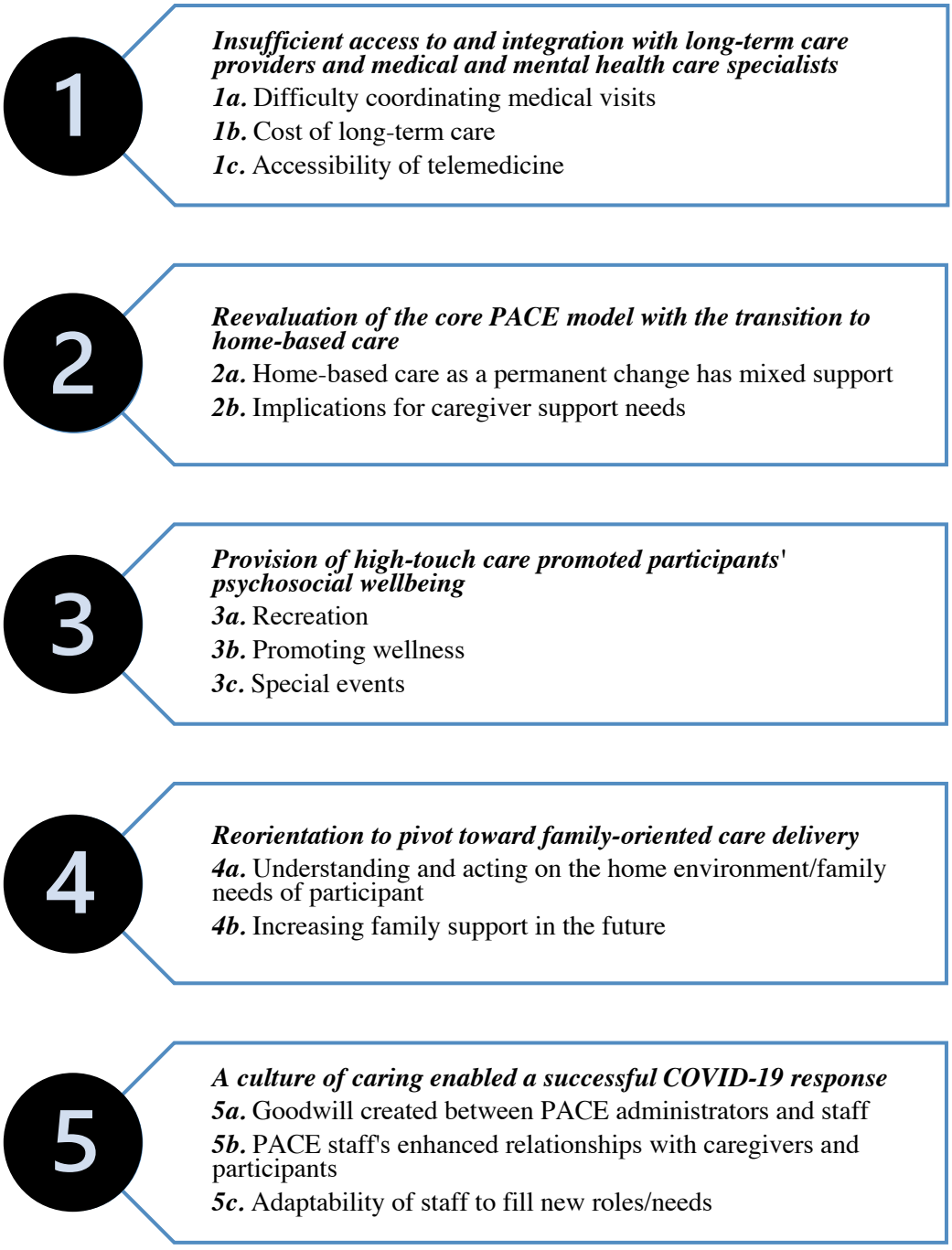
**Table 3** compiles basic statistics about COVID-19 positivity and outcomes among PACE participants and staff. Up until the time of data collection at midpoint December 31, 2020, NC PACE had on average 12.3 COVID-19 cases per 100 participants (SD 2.9). Of those positive cases, an average of 4.6 participants per 100 were hospitalized due to COVID-19 (SD 1.6), and an average of 1.9 participants per 100 died due to COVID-19 (SD 1.4). On average, NC PACE had 3.9 positive staff cases per 100 participants served (SD 2.2).

**Table 3. COVID-19 Cases in NC PACE (N=12)**

| | **Mean (SD)** |
|---|---|
| Positive participant cases (per 100 participants) | 12.3 (2.9) |
| Participants hospitalized due to COVID (per 100 participants) | 4.6 (1.6) |
| Participants that died due to COVID (per 100 participants) | 1.9 (1.4) |
| Positive staff cases (per 100 participants) | 3.9 (2.2) |

Analyses identified five themes, each including 2-3 subthemes. **Figure 2** lists the themes and sub-themes; the material that follows describes each theme in turn. **Table 4** further elaborates on the themes and sub-themes and provides illustrative quotes to explicate their meanings, and it is provided at the end of this section. **Figure 4** illustrates an emerging model of PACE that results suggest may persist after the COVID-19 pandemic subsides and is provided before "Emerging Themes."

**Figure 2. Main Themes and Sub-themes**



**THEME 1. Insufficient Access to and Integration with Long-term Care Providers and Medical and Mental Health Care Specialists**

PACE programs rely on services from residential long-term care (NH and AL) and medical specialists to improve and/or maintain the health of their participants. During COVID-19, PACE programs had difficulty accessing and using these services, particularly in relation to mental health. Sub-themes include coordinating medical visits, cost of long-term care, and accessibility of telemedicine. This section describes each sub-theme and how it fits into the overall theme.

***1a. Coordinating medical visits.*** Due to the capitated service model of PACE, the site with which a participant is affiliated shoulders the cost of medical provider visits and is responsible for the logistics of that care provision. During the COVID-19 pandemic, PACE administrators reported difficulty in coordinating medical visits. Particularly in the 2-3 early months of the pandemic (i.e. April-May 2020), medical facilities were slow to adapt their sites to increased demand from the pandemic, and some closed down altogether. This created a delay for specialist providers to see PACE participants. While this situation became resolved later on as medical facilities adapted to demands, PACE sites experienced challenges during the early period of transition. Out of 12 administrators interviewed, 7 reported experiencing challenges having medical providers visit participants face-to-face, while 9 experienced challenges having mental health care providers visit patients face-to-face. Additionally, PACE sites encountered hurdles with LTC facilities such as nursing homes. One administrator described their collaboration with nursing home facilities as "our biggest struggle." The administrator recalled a story illuminating the tense relationship between the two parties:

> *"I have a lady here that needed a lot of therapy. We wanted to get her out of the facility and back home. And so how we needed to do that was let our therapists work with her at least one day a week for maybe a month and then get her back to her home. And so long story short, the facility wouldn't let her come out and come to our location for our type of therapy. And so I finally just had my people call the Ombudsman and get involved at the state level and then they allowed her to come out and come to therapy."*

The need to involve state authorities in resolving the case of a participant requiring nursing home-level care indicates deeper systemic issues regarding the infrastructure for coordination between PACE sites and LTC facilities.

***1b. Cost of long-term care.*** Along with transporting participants to and from nursing homes, PACE sites are also responsible for paying for these services. PACE participants could be in nursing homes long-term or for acute reasons. After leaving a nursing home, a participant usually either needs "skilled nursing facility automatically or quarantine for 14 days." This responsibility proved to be a significant challenge for PACE sites because nursing home rates increased drastically during the pandemic by 300% (from $200/day to $800/day). In some cases, introducing a COVID-positive patient into a nursing home increased the nursing home rate from $200/day to $900/day. The PACE care model does not allow the site to make rate adjustments based on COVID positivity, so the sites mostly had to shoulder the increased costs. Furthermore, all 12 PACE sites received a 5% Medicaid increase, but as many administrators said, "that does not nearly pay for the nursing home rates," and another expressed "we're having to pay those higher rates and we're not getting any kind of financial funding from the state for that." Administrators further commented on the feeling of being left behind in state funding: "We're definitely not in the category of nursing homes or anything, so [we received] very minimal

relief." Indeed, CARES Act funding was not automatically apportioned for PACE sites as they were for nursing homes and assisted living communities, so PACE sites had to absorb the insufficiencies of funding for the LTC facilities while buoyed primarily but insufficiently by the 5% Medicaid reimbursement increase.

***1c. Accessibility of telemedicine.*** The physical distancing standard introduced by the pandemic inspired a new relevance for telemedicine across all disciplines, and PACE was no exception. All 12 PACE administrators described a transition at least in part to offering their participants medical and mental health care appointments through telemedicine. However, PACE administrators cited a major concern that telemedicine is inaccessible to many participants they serve. As one administrator put it,

> *"A lot of our participants don't have families, don't have Internet connection. Or if they do have an Internet connection, they don't really have a cell phone. Or they have cell phones by-and-large, but not one that they could really use for telehealth. So it was a pretty large percentage of our participants [who] aren't set up … at the time [to] use telehealth."*

Specifically, administrators cited issues with participants' access to technologies that enable telemedicine visits, a stable Internet connection, and capacity to utilize such technologies effectively. Administrators reported that in the past month, on average, 22.3% of medical visits were by telemedicine, and 44.2% of mental healthcare visits were by telemedicine. Their satisfaction with these services on a scale of 1-4 was 2.8 and 2.4, respectively. This indicates that mental health services were particularly hard hit during the pandemic. However, PACE sites pursued other ways to support the mental health of their participants, which will be elaborated upon in the later section, "Goal-driven Culture Enabled a Successful COVID-19 Response."

Despite these technological challenges, administrators were hopeful when seeing the capabilities of grand pads, which are technological devices similar to tablets that are designed specifically for the older adult population but are also cost-prohibitive at the time. An administrator commented that during the pandemic, they were wishing for telehealth equipment that "directly reports to our EMR with alerts" and allowed for clear visualization of physical medical problems in order to "keep our finger on the pulse" of their participants.

Administrators had additional recommendations about expanding and modifying the use of telehealth tablets in the homes so that providers could see the participants' home environments and their physical appearances. An administrator commented, "You know, a lot can be told by hearing [participants'] voices, but also to be able to look at their faces." In particular, telehealth can be a tool to support participants' mental health while they are in the homes. Accompanying the administrators' comments on telehealth moving forward was a discussion about shifting the PACE care model from more day center-based care to home-based care. Administrators commented that while they decrease the amount of time participants spend in the day center, their care can continue in the homes with telemedicine. The specifics and implications of the administrators' perceived transition to home-based care will be discussed in the next section.

**THEME 2. Reevaluation of the Core PACE Model with the Transition to Home-based Care**

While most PACE sites were required to transition to home-based care during the pandemic, reactions about what this change means for the future are mixed, with the majority of opinions favoring the shift to more home-based care. This change prompts reflection on the core tenets of PACE and whether it can operate without the PACE center. This section will first

describe the change to a home-based model within PACE, then it will elaborate upon the following sub-themes: home-based care as a permanent change has mixed support and implications for caregiver support needs.

Given the physical distancing requirements released by CDC to prevent the spread of COVID-19, PACE sites had to adjust their model of care. Participants could not consequently come to the day center as frequently as before, so PACE shifted from a day center-based organization to a home-based care organization. To accommodate this need, PACE administration rapidly applied to the state governor for a homecare license to be able to provide care in the homes. One administrator summarized the experience as follows:

> *"Our state does not allow us to go see our participants in the home and do any type of care, physical therapy, or any of that unless we have a homecare license. So, in the midst of a pandemic, I had to apply for a homecare license, which was a two-month process. And I had to … redo policies that were completely separate from our day-to-day policies for PACE, and they had to be home care policies. So that was quite a challenge. But now that we have that I do think that will help us in the future whenever we're faced with anything like this."*

Another administrator described this process of acquiring a homecare license as "incredibly burdensome," while many were grateful for the state's willingness to grant a homecare license in a time that required rapid changes to the model of care. However, this license is not permanent. To illuminate the extent of this change, one administrator said,

> *"Most PACE programs are very what they call center-centric, which means that probably 85% of all services are provided in the adult day health center of the PACE*

*center. With COVID, that has completely switched to 75%, I would say, are being provided in the home with 25% in the day center."*

Furthermore, the majority of administrators regard PACE's shift to a more home-based model of care as a fairly permanent change resulting from the pandemic. As one administrator phrased it,

*"From where I'm sitting, I'm feeling like from now on, a PACE program is going to have to have basically two community-based care scenarios. One will be what we're used to, as an adult day center to some level. Then after that, we're going to have to continue to pursue developing a home-based PACE program where we can do most of our work for the participants in the home environment."*

While many others echoed this sentiment, they added that the model may continue as a hybrid model that simply shifts the balance between day center and home. In total, 11 out of 12 administrators believed that they changed their business model due to COVID-19, and 11 out of 12 administrators believe that the pandemic has permanently changed how they will deliver care.

***2a. Home-based care as a permanent change has mixed support.*** The majority of administrators responded favorably to the shift toward home-based care, describing it as innovative, necessary, an improved model than the previous model, and a permanent change moving forward. One administrator commented that a home-based model will improve the sustainability of PACE, and they used a hub-and-spoke model metaphor to explain this change: before the pandemic, the day center was a hub with no spokes, but now it is a hub of activities with spokes extending to participants' homes. **Figure 3** illustrates this analogy. Another administrator commented that the model shift will improve quality outcomes with the following description of changes in clinical care processes:

> *"So the things that have changed that we will continue to do, [the pandemic] has changed the way that we deliver therapy services and the way that we operate our day center. I anticipate that we'll continue to operate them almost as if they're strictly outpatient. We'll rely less on the attendance to the day center as a means to schedule therapy and our clinic visits. We have even redefined some of our standards of care for the frequency that we need to see people, increasing the frequency that we need to see people on an outpatient basis, even if they're not in the day center. And I think that's going to improve quality outcomes going forward."*

By converting the day center into a *de facto* outpatient clinic, PACE sites can limit interactions of participants in the day center to the essential medical visits alongside the high-touch social activities that are a hallmark of PACE. By differentiating participants' reasons for visiting the day center, it becomes a dynamic site of multiple kinds of activity. When PACE supplements its capacity to check on the medical and mental wellbeing of its participants in the homes, it removes the necessity of participants to come to PACE; rather, PACE comes to the participants. Finally, the shift has been successful because PACE has had time throughout the duration of the pandemic to minimize day center staffing while keeping the facility operational. One administrator said, "I don't think we'll go back to the frequency that people would attend today's center. It has a huge place in terms of building the community for a program, but people maybe don't need to come three days a week, maybe they need to come less frequently." Thus, the pandemic has inspired new consideration among PACE administration about the optimal levels of participant engagement in the day center versus the homes.

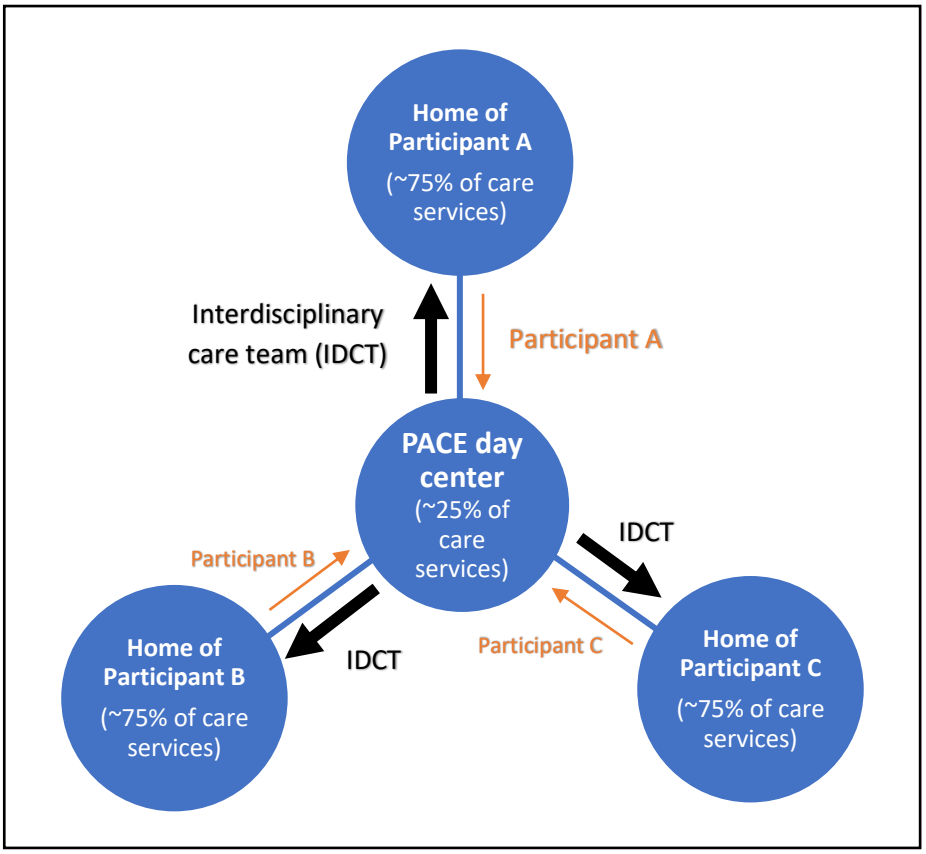



Figure 3. A hub-and-spoke model of PACE used by administrators during COVID-19, in which orange arrows represent participants traveling to the day center, and black arrows represent the interdisciplinary care team traveling to participants' homes.

A few administrators expressed reservations about the shift of PACE to a home-based model. When asked if the pandemic will permanently change the way their PACE site will deliver care, one administrator said:

> *"I certainly hope not… the reason that we have PACE facilities is to support caregivers and to provide respite and to keep our participants at home for longer periods of time versus them being in a nursing home setting. And, you know, if this is permanent for us then it's going to be difficult for us to do that because they'll all be at home. And it just*

*sort of defeats the purpose of trying to prevent nursing home placement, so that's why I say I hope not."*

Thus, the shift to a home-based care organization challenges the core of what PACE seeks to do and how it fulfills this goal. The above comment also indicates that PACE administrators may disagree on the primary goals of PACE or have different visions about how to achieve those goals. Additionally, administrators noted the challenge with differentiating PACE from other types of health care services: "We could expand [our home health] but then we'd be no different from the next home health agency, and … our participants were just happier and healthier when the center was open." The same administrator expressed concerns about PACE's ability to continue avoiding hospitalizations and providing successful preventive care with the new model. A few administrators also commented on the decreased social interaction among participants with the shift to a home-based model and that this reduces a crucial social aspect of the program:

*"The PACE model prior to COVID that really centered on the day center, where participants would come in and socialize with one another. And as I mentioned earlier, we would have 98 participants, and they would all be in these rooms together. They're very close tables of six elbow to elbow and having a blast. I just don't see that ever happening again in terms of having that many people in the day center."*

The above comment represents the opinion of an administrator who did not explicitly oppose the shift to home-based care but did anticipate losses.

***2b. Implications for caregiver support needs.*** Lastly, the shift to a home-based care model has implications for PACE's consideration of caregiver support needs. When the pandemic hit families around the nation, those who are caretakers of PACE participants had

increased responsibility while the PACE day centers were closed. As one administrator summarized families' challenges,

> *"I felt bad for [the families]. We were challenged to adequately support them because they were left you know, with somebody with dementia, who … sometimes challenging behaviors. It's not a favorable way to position it, but it can be really tiring on a caregiver and lots of burnout and frustrations on their part, understandably. They weren't able to get back to work when their loved one 24/7 needs coverage, and you know our doors were closed effectively. So that was really hard."*

However, NC PACE sites modified their care processes to adjust for the increased family needs. They described this process as "keeping their service model balanced," in which the degree to which participants were in their homes and in the day center fluctuated to fill in the needs of the time. One PACE administrator described undergoing physical modifications to the day center to increase capacity for 5-6 more participants in the day center for families who need respite. However, this change was in addition to the shift to home-based care rather than in replacement. According to their metrics, PACE sites' modifications according to families' needs were successful. As an administrator stated:

> *"I was apprehensive about it you know because things have changed significantly this year. We had the highest customer satisfaction score that we've ever had. Our families felt the reassurance and the support of a full interdisciplinary team, medical team, and healthcare professionals that were still engaged in managing their loved ones' care and wellbeing, and services were still being provided in the home and/or a hybrid in the medical clinic, therapies, physical therapy, occupational therapy, personal care*

*assistance help, medical care. So, I think it just proved that support system had significant value."*

Thus, PACE sites encountered new challenges with incorporating families' needs into their care plans, but they responded to these challenges with intention and success.

**THEME 3. Provision of High-touch Care Promoted Participants' Psychosocial Wellbeing**

A central feature of PACE is its holistic understanding of participant wellbeing. This recognition has engendered specific ways of responding to participants' psychological and social needs during the otherwise socially isolating pandemic to sustain the high-touch social environment created by PACE. This section will describe how PACE sites adapted to COVID-19 to maintain participants' psychosocial wellbeing and will discuss the following sub-themes: recreation, promoting wellness, and special events.

The PACE experience is the cumulative effect of many small social interactions that welcome participants into a community of caretakers and friends. This "high-touch" experience has been difficult to replicate during the COVID-19 pandemic, but NC PACE sites have approximated such an environment through several gestures that one administrator notably termed "just tiny little things." Augmenting their medical care with such gestures was crucial due to the social isolation felt by many participants early in the pandemic. The following quote from an administrator describes the complexity of participants' emotional challenges during the pandemic:

*"Initially, it was the isolation that they were feeling and the fear that they were feeling. Then as we moved into the summer and we opened our center up to a small group of*

*participants, it was the challenge of those that could come in versus those that either couldn't come in, or did not want to come in." (302)*

The pervasiveness of social isolation challenged PACE sites to prioritize participants' psychosocial wellbeing while abiding by the physical restrictions characteristic of the pandemic. They were able to do so with specific strategies that will be discussed below.

***3a. Recreation*** PACE sites' activity departments pivoted their day center activities to "cognitively appropriate activities in the home." Several administrators praised their activity departments for their creations of effective activity packets and virtual YouTube channels. These avenues for engagement took advantage of technology to facilitate social interaction among participants and retain connection. One administrator described a PACE points system in which participants could receive points for turning in activity packets. At a town hall meeting during the pandemic, one of their participants expressed sadness that they could not redeem their PACE points for items at the PACE center, which they hoped to use for Christmas gifts. "So they get a virtual pay store, and then the drivers delivered the items that they selected from the store virtually, so it worked out in the long run. So the activities department has really been fantastic at finding ways to help people still be connected," the administrator concluded. Additionally, the online video channels used included chaplain channel, activity channel, town hall meeting channel, and PACE of the Triad channel. Thus, PACE worked to keep their participants mentally active and socially connected during the pandemic.

***3b. Promoting wellness.*** Participants received regular wellness calls from the PACE staff in order to check up on their health and provide them support. While some of these interactions occurred over video-based chat, it was mostly telephone calls. As one administrator described:

*"We organized a weekly COVID call screening … staff were calling a selected group of participants every single week checking in on them, making sure they were doing okay and identifying needs that they might have as well as screening them for COVID."*

Thus, some PACE sites had a dual purpose to regularly call with regard to checking possible COVID status of their participants while also providing connection with the PACE site. To systematize this approach, some PACE sites used a template to conduct these weekly calls and to standardize the information about wellbeing sought from participants. The templates, as one administrator described, "touch base on all the particular issues or needs of that patient, everything from medical, functional, psychosocial issues (that could be caregiver supports), and I think in that way we're helping to identify psychosocial needs as they are presenting." To augment these calls, PACE sites used technology by organizing grief support groups over Zoom, chaplain support groups over Zoom, and Gospel songs by phone. Thus, regular check-ins from staff served to mimic or replace the friendly welcomes of PACE staff upon participants' typical entries into the day center.

***3c. Special events.*** PACE sites additionally maintained a sense of community among their participants by organizing gestures during holidays. One administrator notably called these gestures, such as "cards with pictures and our signatures saying 'we miss you, from your nurse or your social worker'," "just tiny little things," but when considered in aggregate, they accumulated to provide the high-touch interactions that create cultures of inclusion within PACE. Some more specific examples are listed by the same administrator:

*"We dropped by Mother's Day bouquets. We did window visits with posters at our nursing home participants' windows who were locked down, we couldn't visit, wave to them. We sang, we went caroling at Christmas time. We delivered, you know, candies on*

*Father's Day and little bow ties and so you know there are little things … helium balloons arrived by your driver delivering your medication just one random day, you know there's just little tiny things."*

Such gestures did not need to be preceded by a specific holiday either. Many acts were motivated by the desire to reduce boredom and social isolation of participants. To curb the monotony created by the pandemic, some PACE sites "did tours where three cars went to about 20 different homes a day just to stand outside and wave and say hello [to participants]. And so some had parades at a building; we took our parade on the road and went to their homes." These actions by PACE sites created a sense that even an ordinary day was worth celebrating.

**THEME 4. Reorientation to Pivot Toward Family-oriented Care Delivery**

The COVID-19 pandemic required PACE sites to structure care not only around their participants' needs, but also by the degree to which their families would need assistance in their homes. Since COVID-19 shifted the balance of care into participants' homes, families were challenged to care for their relatives alongside their work and other responsibilities. PACE's practice of continued revision of participants' care plans facilitated its adaptation in this area. This section will explain the theme and the following sub-themes: understanding and acting on the home environment/family needs of participants, and increasing family support in the future.

As previously discussed, a transition to home-based care was accompanied by newfound challenges with regard to participants' families' needs for respite. As PACE sites have shifted more to the homes, they have been made more aware of the roles of families in the care process. The recognition of families' needs to balance their lives outside of caretaking with their responsibilities to PACE participants has inspired PACE administrators to think not only about

how to tailor care to the participants, but also how to tailor it to the specific home environment and caregiver needs. As one administrator phrased it, "[The COVID-19 pandemic has] really opened our eyes to how strong our families are in the home setting and what we're able to do with our participants [when it's not] so center-centric like we had before. I think it's really helped us to think outside the box as far as services that we provide as well." This section will explore the specific ways in which PACE sites thought outside the box to cater to families' needs.

***4a. Understanding and acting on the home environment/family needs of participants.*** During the pandemic, PACE sites increased their commitment to understanding and acting on the home environment and family needs of their participants. While PACE is known to continually revise its care plans for individual participants, they recognized that extending this revision to family needs was crucial when time spent in the homes increased. It was important to administrators to stay on top of family needs to "make sure that they didn't experience the burnout." As one administrator said,

> *"We risk-stratified our patients early on and as we were able, we allocated resources accordingly. So if there was a high risk of caregiver burnout, that was a participant who we were going to try and bring in more frequently … or figure out homecare [to] allocate resources … the feedback was really, really very quite good."*

To grasp an understanding of the resource reallocation needs, PACE sites did weekly COVID calls with "extensive scripts" that PACE staff use to ask participants, family members, and caregivers standardized questions that cover a broad spectrum of topics, including "how they're doing," "any symptoms related to COVID," "areas that we can care plan for," "mental health," "physical health and functional status," "nutrition," and "family situation," as administrators described. PACE sites broadly reported that they were successful when revising care plans

according to this information. They responded by adding in-home aide hours with routine follow-ups to help with the physical needs of participants. PACE sites educated and empowered caregivers by providing live virtual caregiver skills trainings, as well as uploading videos to YouTube to which caregivers could refer when caring for their loved ones. The videos were compiled by physical and occupational therapy departments within PACE and consisted of information about "proper body mechanics and transferring and assisting with transfers of their loved ones." Additionally, PACE sites did town hall meetings for participants and their families to maintain a sense of connection and voice within PACE when not being able to physically visit the sites as frequently. However, one of the most concrete and direct relief to caregivers was provided by a PACE site whose administrator commented:

> *"Traditionally,… we would reach out to a skilled facility and arrange for respite. We weren't able to do that, but one of the things that we were able to do on several occasions was to provide overnight care with our home care aides in the home to allow caregivers that break. In addition, we would send an aide into the home so that they could go the grocery store or get their hair done, or just check out for three or four hours."*

Thus, PACE encouraged its medical providers to increase their availability and flexibility to provide respite to participants' caregivers. The shift to home-based care had to accommodate for families' increased needs in this way.

***4b. Increasing family support in the future.*** Accordingly, PACE administrators had reflections and recommendations for how their organizations can increase family support in the future. Administrators expressed a common sentiment in this regard:

> *"I just wish that I could provide them more support systems. Particularly for those caregivers who are at it alone and don't get an opportunity for much of a break, except*

*with PACE. And I think that home care programs have helped so that when we come the caregiver can leave the home and go, you know, go to the grocery store, whatever it is they need to do, and get out of the house, or go to a doctor's appointment."*

PACE administration regarded the shift to home-based care delivery as a way to relieve caregivers of their duties. One administrator described the tension in the language of "caregiver," since the term implies a sense of distance and obligation that family members or friends do not typically feel toward their loved ones who are participants of PACE. Thus, "it's hard for them to really acknowledge that they need support." This situation encourages PACE to play a more active role in relieving caregivers' duties, since being proactive can reduce burnout down the line. Their recommendations include some of the actions taken during the pandemic as well as others. They recommended offering virtual or in-person caregiver support groups, providing overnight care at the day center for participants, and education for caregivers about the proper care of their loved ones who are participants of PACE. One administrator described these actions as encouraging families "to allow us to be a part of a solution for them, rather than them, for lack of a better word, isolating themselves." This recognition indicates that PACE sites perceive their roles not only as medical providers for their participants, but as an interdisciplinary team that looks out for the wellbeing of its participants' families.

It should be noted that not all participants have been able to live with their families in their homes during the pandemic. Only one administrator referenced participants without families as part of a discussion about their inability to access and use telemedicine technologies. Thus, the shift to a home-based care model must also be considered from the vantage of these participants in future studies to ensure that the changes to models of care can be adapted to participants' specific needs.

**THEME 5. A Culture of Caring Enabled a Successful COVID-19 Response**

While the COVID-19 pandemic was a stressful time for many, the PACE model's relationship strengthening capacity extended beyond participant-to-participant interactions. The resulting circumstances fostered new or improved relationships involving PACE participants, caregivers, staff, and/or administration. This section will explore the following related sub-themes: opportunity for stronger relationships between PACE leaders and staff, enhanced relationships with caregivers and participants, and adaptability of staff to fill new roles/needs.

***5a. Goodwill created between PACE administrators and staff.*** Within workers of NC PACE, COVID-19 as a common challenge with regard to prevention, containment, and the psychosocial ramifications was seen as an opportunity for collaboration and resilience. Initially, however, PACE employees experienced fear and anxiety:

> "*We had a lot of anxiety on our staff about COVID. I mean everybody's fearful a lot, a lot of people are fearful nationally and that doesn't go away in a workplace. And so, [we were] wanting to talk situations through [to help staff] understand why the organization's stance or practice is what it is…, or how they're protecting their staff while fulfilling their mission, or meeting whatever metrics we have to meet to keep the doors open.*"

From these initial fears, however, arose enhanced models for collaboration among the interdisciplinary provider teams of PACE such as the incident command team, which will be further discussed in the Emerging Themes section, "Interdisciplinary leadership." Part of what made this effective was PACE's positive workplace culture. Initially, one PACE site paid its workers whether or not they came to work for the first three months of the pandemic. This action

demonstrated to workers that PACE administration cared about their workers' wellbeing and respected their choices with regard to coming to work during a pandemic. As the administrator put it, it created goodwill that then "brought team members together; we focused on our mission and our values and our care for the participants." The administrator described the broader 2-year-old "organizational journey" of the PACE site which served as the context upon which COVID-19 entered the picture as "redefining our mission, focusing our values for the past two years, and really trying to focus our care in our values, so that when tough decisions had to be made, we could look at our values." To further explicate this statement, the administrator described a specific value of mutual respect and how that influenced their staff relations.

> *"To give you an example, one of our values is mutual respect for both our participants and our team members. …During [the pandemic], we have a really dedicated staff, and they really do love what they do and love taking care of this frail population, and so that helped. In addition to that, some rotation so that our team members who were delivering care in the home rotated on an on-off basis, maybe three days a week one week and then two days a week the next week. …What that did in fact was give them some work time paid and some non-work time paid, so some goodwill was generated there. Over time, we did have some folks resign, there were a few, not too many, because that model, just they tried it and that model of care just wasn't going to work for them."*

Thus, PACE administration took care of their staff so that staff could then take care of participants and families. In this way, PACE has been consistently successful with its COVID-19 response up until at least December 2020, the time of interview data collection.

***5b. Enhanced relationships with caregivers and participants.*** As PACE administration supported staff camaraderie, this action of goodwill flowed to enhanced relationships of PACE

staff with participants and caregivers. PACE administration acknowledged broadly that with the unique set of challenges posed by COVID-19, they could not continue bread-and-butter practice but had to adapt by shifting their care to the homes rather than solely at the day center. They believe that this shift resulted in better relationships between team members and with participants and caregivers. As one administrator said, "The fact that we were willing to come into the homes [to] deliver care, check on folks, sit and hold hands, give baths, … I think that's a game changer." Indeed, the high-touch interactions between PACE workers and participants in the homes created stronger and new relationships that will likely persist beyond the fading out of COVID-19. As another administrator phrased it:

> *"[Participants] appreciated the face-to-face interaction, that worked well. ... Shifting or increasing our workforce in the home has helped to have friendship. We also implemented daily calls there in the beginning to check in and make sure they were adapting okay to not coming into the center. And those calls have continued to be twice a week. So we have what we call friendship calls to just, you know, chit-chat and socialize and that's really helped with the mental and social wellbeing of our patients."*

Characterizing these relationships as friendships implies social support that extends beyond the traditional provider-patient paradigm, in a time when this support was much needed.

***5c. Adaptability of staff to fill new roles/needs.*** Another way in which staff acted on organizational values was the adaptability they demonstrated to fill new roles as needs related to COVID-19 emerged. This was characterized as "the biggest challenge" by one administrator:

> *"Team members from the beginning of COVID were asked to perform tasks that they weren't hired for. For instance, there were aides that were working in the center and when we transitioned all of our care to the home, those aides, as well as nurses,*

*providers, therapists, social workers were asked to do home visits and or deliver care in the home. That was probably the number one challenge that we had was that change management. It had to happen fast and we weren't prepared for that."*

The transition was not easy, but the high caregiver satisfaction scores from these changes demonstrate that PACE sites were able to adapt to this challenge effectively. In particular, licensed social workers and chaplains were able to fill the gaps of inadequate mental health care. Administrators described their service as "very instrumental" to the continued wellbeing of both participants and their caregivers. They were "very in-tune with the participants, and they know which of them needed additional calls and check-ins." One administrator described the impact of social workers (licensed clinical social workers and masters of social work) on the care and wellbeing of their participants in the following way:

*"They've I think just created new ways of interacting with participants … They've done face-to-face telehealth. They've [brought] higher-risk participants … to the centers again for these urgent care needs visit, but in this case it's just scheduled visits with a social worker who then wears a mask and a face shield and physical distances in a private room."*

In addition to social workers' efforts, chaplains provided spiritual support by calling participants and caregivers, and facilitating prayers, scripture readings, and support groups. All of these efforts point to the willingness and adaptability of PACE workers to pivot toward fulfilling participants' needs rather than strictly containing their efforts to their official job descriptions.

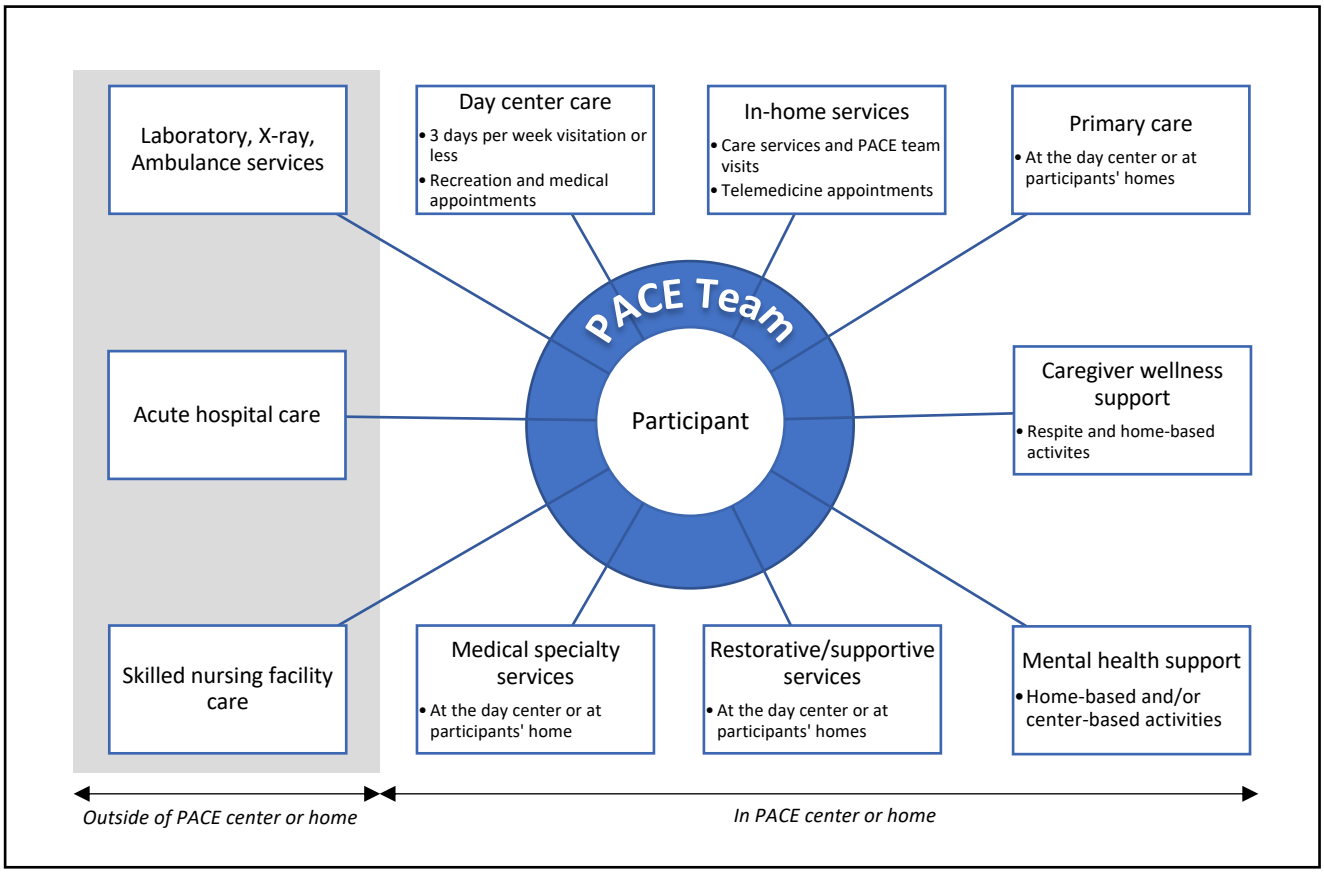



Figure 4. The emerging post-COVID-19 NC PACE model, modified from Eng, et al.[44]

## EMERGING THEMES

Certain topics were uncovered in this study as potential emerging themes: proactivity vs. reactivity to public health emergencies and interdisciplinary leadership. To assess their pervasiveness in and impact on PACE, they would benefit from separate studies with instruments designed to scrutinize their relationships and connections with points discussed in this paper.

***Proactivity vs. reactivity to public health emergencies.*** As one PACE administrator said, "our job is to keep people in the community and provide proactive health care, and so the COVID environment created more reactive responses by clinicians." COVID-19 challenged PACE by introducing a situation for which prior preparation was difficult, although PACE considers preventive care a key component of its care model. PACE administrators concluded

that their organizations' continued practice in infection prevention and control strategies for COVID-19 has resulted in a keen awareness of hygiene and disease prevention for the future. One administrator said, "I see in my entire community where people are so much more aware of the importance of such a simple thing like washing hands." Other proposed measures were regularly disinfecting the PACE building, using PPE more frequently especially during flu seasons, and having pathogen-detecting tests available on-site. Some other IPC-related suggestions related to IPC management rather than particular resources, as exemplified below:

> *"I think we've learned a lot about communication … in different ways. And though I think we were definitely practicing infection control for COVID, you know according to standards, it's just highlighted it so much, it's increased the importance of it so much. But I think it's helped us … to understand even for just the seasonal flu and common colds and, you know, other sorts of infections or contagious diseases that we need to make sure that there are even more things in place to prevent it, the spread of it. So I think in terms of infection control, I think in terms of how we communicate and in some ways how we're providing care and services, [we] will definitely do things differently."*

Administrators also commented that they will now use their IPC protocols developed during COVID-19 in the future, and they will use the learning opportunity posed by the pandemic to update their policies, procedures, and emergency preparedness plans.

The administrators also mentioned that it was difficult to be respond quickly to the emergent situation of COVID-19 because PACE is not recognized as a category in the national framework of LTC. The following quote demonstrates this concern:

> *"I think the barrier is that PACE is often not listed in COVID communications. You have the traditional long-term care kind of statement and then you have your hospitals. But*

*there are a myriad of service providers that take care of the elder chronically ill patient who typically doesn't do as well with COVID-19. And I think that's been a bit of a barrier is having to explain [what PACE does] to get the resources needed. … [we] need to be in a category so to speak, as to how it will be handled. And that would be not only the barrier, but my number one recommendation."*

The above administrator referred to the following items as resources which were difficult to access: PPE equipment, testing equipment, and vaccines. However, PPE shortage was not a global concern among NC PACE. This situation, that state and federal governments did not recognize PACE as service providers for the older adult population in a discrete category assigned relief and resources, may be a reason that PACE sites must be more proactive than reactive to future infectious disease outbreaks. One administrator conveyed that their PACE site is now striving "to keep at least two months of personal protective equipment in storage at all times." Another administrator mentioned that all of their drivers who transport participants to the PACE center, medical appointments, etc. stored full PPE in their vans during transit, although the administrator did not comment on whether this would be a permanent change.

***Interdisciplinary leadership*.** Some PACE sites achieved successful COVID-19 responses due to their involvement of medical providers in key leadership roles, who then provided an informed direction to their response. Administrators from three sites lauded their incident command teams, which was alluded to previously in the section, "A Culture of Caring Enabled a Successful COVID-19 Response." The incident command teams are interdisciplinary teams of leaders and decision-makers representing relevant aspects of the pandemic response, including a medical director, director of nursing, executive director, providers, administrative staff, other nursing staff, and quality control specialists. The teams met regularly to "troubleshoot

together and to develop protocol." The team meetings also facilitated communication flow with staff, participants, family members, and stakeholders about these decisions. One administrator described the team in the following way:

> *"We immediately implemented what we call the incident command team, and we met once a day for 30 minutes since the beginning of the pandemic. When we moved into Phase 3, we moved it down to twice a week, I think it was. And then we ramped that back up to once a day come late November when the numbers were starting to spike up again, and we've been there since. That's worked really well for us. It's kept communication on pretty tight and that PACE incident command team is our leadership group effectively, including: medical, nursing, infection control, you know operations, [and] administration. … We happen to really care about each other as well as a team and so it was [a] nice group to work with, and I think it was effective."*

In particular, having workers trained in infection control was important to PACE administrators because they bring important insights into management that prioritize safety over other organizational interests. In addition, their insights facilitate the dissemination of accurate and actionable information. One administrator phrased it as such:

> *"We didn't have an epidemiologist on staff, but we do have clinical staff who understand infection control very well and know what to do with that information, so I think that's vital. Communicating with all staff on an ongoing basis as to the status of what's going on in the organization, what's going on [in] the community, and what we need to do in terms of our own behavior and our understanding of how we are to provide care and services … has been something that's been extremely important."*

Specifically, the PACE incident command team was an offshoot of the pre-COVID emergency response procedure. During the pandemic, they met at least once every weekday and sometimes on weekends. At the time of interviewing one administrator, they expressed the following:

> *"Just an hour ago, we were discussing where we are in terms of the vaccine for our participants and staff and who's providing that [in] the different counties, and we're starting to sort of fill in the blank for the next … six months. Again, a lot we don't know now, but we want to make sure we're on board."*

They cited the following benefits of the incident command team: centralizing information, engaging stakeholders, involving those who conduct day-to-day operations with those conducting contact tracing, creating new tools of communication such as the PACE COVID toolkit containing changes in IPC or other protocol, and providing training about the toolkit. Thus, the broader structure of the incident command team allowed for smaller changes to occur in an informed way.

**Table 4. Themes, Sub-themes, and Illustrative Quotes**

| *Theme* | *Description of Theme* | *Sub-theme* | *Illustrative Quote(s)*[1] |
|---|---|---|---|
| *Insufficient access to and integration with long-term care providers and medical and mental health care specialists* | PACE programs rely on services from residential long-term care (nursing homes and assisted living) and medical specialists to improve and/or maintain the health of their participants. During COVID-19, PACE programs had difficulty accessing and using these services, particularly in relation to mental health. | Coordinating medical visits | "Our biggest struggle is with the nursing facilities and allowing us to go in and out." (307) |
| | | Cost of long-term care | "If we have a COVID patient in a nursing home that cost went from like $200 a day to $900 a day, and we're having to pay those higher rates and we're not getting any kind of financial funding from the state for that." (306) |
| | | Accessibility of telemedicine | "A lot of our folks did not have the capacity nor the technology and perhaps even the Internet … connectivity to manage a Zoom [meeting]." (304) |
| *Reevaluation of the core PACE model with the transition to home-based care* | While most PACE sites were required to transition to home-based care during the pandemic, reactions about what this change means for the future are mixed, with the majority of opinions favoring the shift to more home-based care. This change prompts reflection on the core tenets of PACE and whether it can operate without the PACE center. | Home-based care as a permanent change has mixed support | *Positive opinions:*<br>"Our program, I think, is fairly permanently changed, and I think it's for the good. And we still have work to make sure we can do better in the homes … there's been a lot of loss in not having, you know, those participants able to come to the center as much and often as we want. So we're not there yet, but I think it is ultimately going to be a good thing for us that it's permanently for our program changed our model." (304)<br><br>"The pendulum has swung from being a PACE Center-centric model to a home-centric model with some limitations … it's probably indefinitely changed and for the good [of] the sustainability of the PACE model." (303)<br><br>*Negative opinions:*<br>"The reason that we have PACE facilities is to support caregivers and to provide respite … it just sort of defeats the purpose of trying to prevent nursing home placement." (300)<br><br>"We could expand [our home health] but then we'd be no different from the next home health agency and within that you know, we'd have more competition and our … participants were just happier and healthier when the center was open." (300) |

| | | | |
|---|---|---|---|
| | | Implications for caregiver support needs | "We were challenged to adequately support [the families] … They weren't able to get back to work when their loved one 24/7 needs coverage, and you know our doors were closed effectively. So that was really hard."(304)<br><br>"I was apprehensive about it, you know, because things have changed significantly this year. We had the highest customer satisfaction score that we've ever had. Our families felt the reassurance and the support of a full interdisciplinary team." (311) |
| *Provision of high-touch care promoted participants' psychosocial wellbeing* | A central feature of PACE is its holistic understanding of participant wellbeing. This recognition has engendered specific ways of responding to participants' psychological and social needs during the otherwise socially isolating pandemic to sustain the high-touch social environment created by PACE. | Recreation | "Our activities department [refocused] their efforts from activities in the day center to focusing into cognitively appropriate activities in the home." (309) |
| | | Promoting wellness | "We organized a weekly COVID call screening … staff were calling a selected group of participants every single week checking in on them, making sure they were doing okay and identifying needs that they might have as well as screening them for COVID." (300)<br><br>"We have a weekly phone call with a standard … template that we [use to] touch base on all the particular issues or needs of that patient … everything from you know, medical, functional, psychosocial issues, that could be caregiver supports, and I think in that way we're helping to identify needs, psychosocial needs as they are presenting." (304) |
| | | Special events | "We dropped by Mother's Day bouquets. We did window visits with posters at our nursing home participants' windows who were locked down, we couldn't visit, wave to them. We sang, we went caroling at Christmas time. We delivered, you know, candies on Father's Day and little bow ties and so you know there are little things … helium balloons arrived by your driver delivering your medication just one random day, you know there's just little tiny things." (304) |

| | | | |
|---|---|---|---|
| *Reorientation to pivot toward family-oriented care delivery* | The COVID-19 pandemic required PACE sites to structure care not only around their participants' needs, but also by the degree to which their families would need assistance in their homes. Since COVID-19 shifted the balance of care into participants' homes, families were challenged to care for their relatives alongside their work and other responsibilities. PACE's practice of continued revision of participants' care plans facilitated its adaptation in this area. | Understanding and acting on the home environment/family needs of participants | "We risk-stratified our patients early on and as we were able we allocated resources accordingly. So if there was a high risk of caregiver burnout that was a participant who we were going to try and bring in more frequently … or figure out homecare [to] allocate resources … the feedback was really, really very quite good." (304)<br><br>"We were able to really talk to the family or the caregiver about specifically what their needs [were], readjust how the home care was being deployed, and in most cases meet the need." (309)<br><br>"We added in-home aide hours for some of those, and with the routine follow ups, we were able to identify [family burnout], but that has to be about the biggest challenge for them. It's because they were also either working from home or laid off and then they were a 24/7 caregiver again. So trying to really stay on top of that and make sure that they didn't experience the burnout." (301) |
| | | Increasing family support in the future | "We still got families that won't let us in the house and so all contact is by phone … Somehow we've got to come up with a better way of educating our families to allow us to be part of a solution for them, rather than them for lack of a better word isolating themselves." (307)<br><br>"Look into providing overnight care at the center. You know, that is one area that we would like to pursue do for caregiver stress." (302)<br><br>"For the future you know, I, I'm going to say caregiver support groups, virtual support groups … they don't feel like their caregivers, they just feel like they are family members, taking care of their loved one. So it's hard for them to really acknowledge that they need support, and that support group would be helpful for them." (305) |

| | | | |
|---|---|---|---|
| *A culture of caring enabled a successful COVID-19 response* | While the COVID-19 pandemic was a stressful time for many, the PACE model's relationship strengthening capacity extended beyond participant-to-participant interactions. The resulting circumstances fostered new or improved relationships involving PACE participants, caregivers, staff, and/or administration. | Goodwill created between PACE administrators and staff | "So we've essentially for three months paid everyone for whether they came to work or not. So, there's a lot of team members that didn't have to provide any care at all. And so we were able to sustain that level, so there was goodwill that was generated. And then from that point on, essentially, we brought team members together, we focused on our mission and our values and our care for the participants." (302) |
| | | Enhanced relationships with caregivers and participants | "The fact that we were willing to come into the homes [to] deliver care, check on folks, sit and hold hands, give baths and that kind of thing. You know, I think that's a game changer." (302)<br><br>"Shifting or increasing our workforce in the home has helped to have friendship." (311)<br><br>"I think it just proved that support system had significant value." (302)<br><br>"A lot of touches [worked well]. A lot of informal or formal touches. Home visits and also encourage … people to rely more on their natural support, such as neighbors, friends, family members, and such." (308) |
| | | Adaptability of staff to fill new roles/needs | "But we do have some licensed clinical social workers as well. And they've I think just created new ways of interacting with participants." (303)<br><br>"We have a chaplain on our team and we also have a recreational therapist as well as social work. And they were very instrumental, particularly the chaplain. He would call out and call and do scriptures and prayers and things of that nature with our participants and even the caregivers." (300) |

[1]Interviews with PACE administrators were labeled 300-311 to correspond to respondents; the number in parentheses following each quote reflects this respondent ID.

## DISCUSSION

COVID-19 tested the resilience of PACE to health system pressures pertaining to care and finances. Maintaining PACE participants' medical, mental, and psychosocial care can be difficult during a pandemic because the contagious nature of the virus rendered them often conflicting goals; for example, psychosocial care is aided by elderly participants' social interactions with PACE staff and other PACE participants, but such activity poses risks of virus spread. Additionally, routine medical care is difficult within social distancing and PPE guidelines when PPE supplies are limited.[96] Not only PACE participants, but also their caregivers and/or family members living with them were deeply affected by the pandemic. On a global scale but particularly for LTC, COVID-19 was a focusing event that tested the resilience of LTC models and provided an opportunity to understand the system's pressure points.

Specifically, the pandemic challenged PACE programs to rapidly pivot their model of care to adjust to the specific IPC demands of COVID-19, such as social distancing and mask wearing. It additionally challenged them to address the mental health consequences of social isolation experienced by their PACE participants and informal caregivers. As learned in this study, perhaps the most significant development of NC PACE programs in response to the pandemic was their transition to shifting the epicenter of care from the PACE day center to participants' homes. What began as a logical closure of the PACE day center for regular participant socialization and recreation turned into an opportunity for care that is even more person-centered. At the same time, PACE accommodated for the participants' reduced opportunities for social engagement through effective home strategies such as activity packets, online channels, and kind gestures/home visits administered by PACE staff. When PACE was gaining traction early in its history, one of its significant developments occurred when it

supplemented care to in-home meals and housing assistance.[42] Broadly, the significance arose from *meeting participants where they are*. PACE is no stranger to the person-centered medical home model, which places patient wellness – not administrative ease, financial expediency, or other auxiliary goals – at the center of care.[97] PACE's documented success in this area has allowed it to successfully manage the care of older adults with complex, intersecting medical conditions.[44,98] While administrators' opinions about the change in the care model were somewhat mixed, 10 out of 12 administrators expressed enthusiasm that the new model will last. It remains to be seen whether the home-based model was a short-term *adjustment* to the pandemic or a long-term *epiphany* about an improved PACE model of care. The state-granted homecare license that PACE administrators received during the pandemic is temporary, and the concern still stands about how PACE will differentiate itself from a home health agency with this change if it were to extend into the future.

This study additionally shows that NC PACE had an increased focus on family caregivers' wellness during the pandemic. For the older adult population served by PACE, families and other informal caregivers are key components of care because they spend the most time with the PACE participants and witness their daily health needs. Prior to the pandemic, family caregivers were primarily involved in PACE care by helping to inform their relative's care plan upon initial assessment and at the time of enrollment.[48,50] The interdisciplinary team then periodically checked in on the participants and adjusted their care plans.[48] COVID-19 placed stress on working-class Americans due to job insecurity, prolonged social isolation, and health concerns, among many others.[99] The CDC Foundation reported that concerns about fear and anxiety among caregivers of older adults are not new, but were heightened by the pandemic.[100] According to the study, caregivers' highest needs were more respite services and

balancing their own physical and mental health needs along with those of the elders in their care.[100] This study shows that while operating under the principle of patient-centeredness, NC PACE added caregivers as a variable to the calculation of their participants' care plans during COVID-19. NC PACE administrators shared that they incorporated caregiver burnout into their participants' risk assessments and used them to modify participants' care plans. The implementation of caregiver support groups, overnight care at the day center, respite for caregivers through interdisciplinary team home visits, and caregiver educational opportunities demonstrate how PACE dug deeper into the roots of their participants' wellbeing by acknowledging that caregiver wellbeing is closely intertwined. This recognition contributed to PACE's efforts to maintain the psychosocial wellbeing of its participants, and it demonstrates an advantage of PACE over congregate living settings that imposed strict visitor policies during the pandemic to prevent potential viral spread.[101,102]

However, some PACE administrators were met with resistance from families due to the complex emotions behind caregiving, including protectiveness, resistance to mask wearing, and general resistance to outside help. Furthermore, the divisive nature of the pandemic facilitated by partisan political discourse about the nature and ubiquity of the virus[103–105] could have contributed to the tension involved in PACE's home visits. Rapid spread of information and misinformation during pandemics demonstrates the importance of strong communication among the entire care team, including participants, their caregivers, their interdisciplinary team, and PACE administrators. During a time replete with noise from many media sources and the spread of misinformation, communication among these stakeholders was vital.

With regard to medical care provision, it is unsurprising that PACE sites experienced challenges maintaining the frequency of medical visits during the early months of the pandemic

(i.e. April-May 2020), although it does indicate points of weakness in the health system. COVID-19 systematically impacted the U.S. healthcare system across many provider and healthcare setting types.[1] Thus, for this care to have been initially delayed but then to have rebounded in frequency within a few months may indicate healthcare strength, at least in NC. It is not known whether PACE providers in other states were able to resume medical services as quickly as in NC.

Mental health care provision was also strained during the pandemic; in any given week, an average of 44% of this care was moved to a telemedicine format. On a four-point scale, PACE administrators' levels of satisfaction with mental and medical health care services were 2.4 and 2.8, respectively. Some PACE administrators noted that current telemedicine technologies may be inappropriate for the older adult population and instead suggested the use of grand pads, which are tablets designed for older adults that allow them to stay in touch with their family and friends, contact their PACE providers, and access activities released by their PACE program. PACE administrators describe these technologies as desirable but expensive and not immediately achievable with their current financial situation.

This study also has implications about the federal government's financial relationship with PACE and how well PACE's capitation model handled economic pressure from the pandemic. The pandemic financially harmed businesses in many industries, to different extents but often simultaneously. The CARES Act was the federal government's major stimulus package for businesses across the country. Much like the concept of medical triage during emergency situations, the timeliness, order, and degree of support allocated to different industry and business types indicates their level of priority. As mentioned in the literature review, PACE was not explicitly or automatically provided funding as were NHs and AL communities. However, all

NC PACE sites were given a 5% Medicaid reimbursement increase, which many administrators noted was insufficient to compensate for 300% increases in NH daily rates. PACE assumes full financial risk of their participants, including unanticipated increases in medical providers' rates. The pandemic pressured the PACE capitation model, but PACE administrators did not express serious financial losses. As stated earlier, improvement in PACE will likely be funded by the federal government[51], so it remains to be seen whether the federal government will act on the demonstrated success of PACE. The degree of the federal government's financial involvement in PACE may depend on how the LTC industry as a whole is affected by COVID-19 in the short- and long-term, including which types of LTC are perceived to need more federal monies to stay afloat after the pandemic has subsided. Again, PACE must be considered in the context of its LTC market, whose eventual landscape in a post-COVID-19 world is uncertain.

Overall, PACE demonstrated resilience during COVID-19 and may be well-positioned to respond to future health emergencies with the responsibility of the care of older adults. Based on the data in North Carolina, PACE sites' financial model stayed afloat despite some setbacks, and some programs reportedly received high participant/caregiver satisfaction scores. With modifications and greater federal government support, the pandemic may have permanently changed PACE for the better. While certain problems expressed by PACE administrators existed before COVID-19, including LTC financing and provider access, the pandemic has shone new light on these issues. The renewed attention is partially because COVID-19 disproportionately affected older adults, thereby pointing to the need for safety and efficacy when caring for them; the severe economic impact on the healthcare industry, thereby emphasizing the need to use healthcare dollars efficiently; and the heightened focus on public health awareness and prevention, including PACE and other care models that work toward preventive, holistic care.

PACE seems to have demonstrated resilience not only by sustaining its normal operations during COVID-19 (e.g. through a shift toward home-based care), but also successfully tackling the additive challenges of the pandemic (e.g. social isolation, logistical challenges) due to its focus on high-touch, cost-efficient, person-centered care and a staff/leadership culture aligned with its goals. The elements of PACE's strength and adaptability uncovered from this study may be used by LTC providers and state policymakers to leverage NC PACE's improvement and expansion in the future. The administrators' insights and projections for the future may be revisited in the future to assess real long-term impacts of COVID-19 on PACE's care model and service provision.

**Limitations**

This study gathered the perspectives of administrators about the COVID-19 pandemic from all 12 PACE sites in North Carolina between December 3, 2020 and January 28, 2021. Data collection occurred before the pandemic fully subsided, and administrators' perspectives may have been influenced by the particular severity and scope of the pandemic preceding and at the time of data collection. **Figure 5** below indicates the daily case counts in North Carolina as reported by NCDHHS from March 2020 to March 2021. The dates of data collection are highlighted, and the midpoint of data collection at December 31, 2020 is circled; on the start date, midpoint date, and end date, North Carolina had 5,637, 6,487, and 6,490 cases, respectively.[106] During this period, most of the case increases occurred in the population between ages 25 and 64, which marginally includes a PACE-eligible population.[107] Despite the concentration of case demographics in younger people at this time, the high case counts for the entire NC population undoubtedly weighed on PACE administrators during data collection.

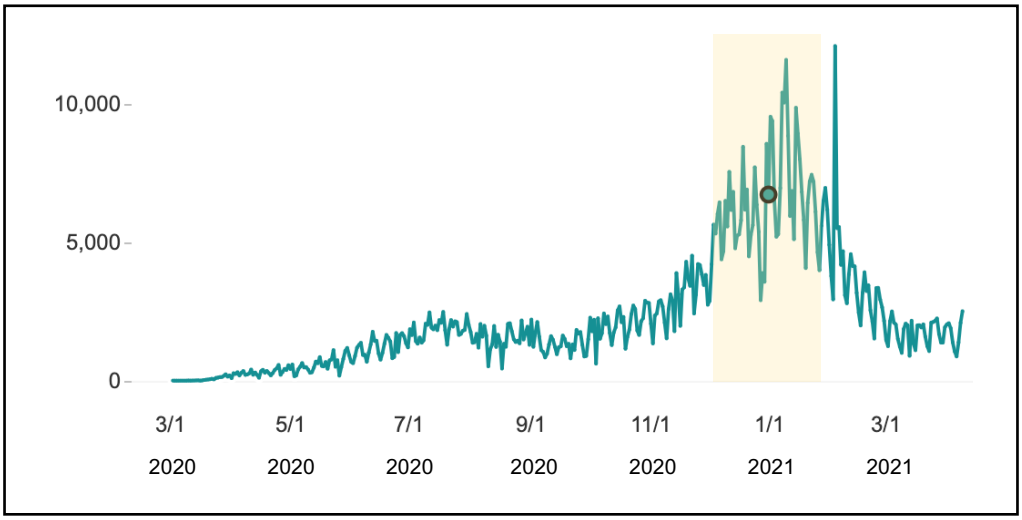



Figure 5. Daily COVID-19 cases in North Carolina between March 1, 2020 and March 1, 2021, as reported by NCDHHS.[106]

Additionally, this study does not capture administrators' perspectives after January 2021, while the pandemic continued. The interviews were conducted at the cusp of Group 1 vaccine distribution in the United States; the first person in the U.S. to receive a vaccine was inoculated one day into the onset of data collection for this study on December 14, 2020.[108] While the vaccine was an imminent opportunity for the pandemic to subside, the news was coupled with uncertainty about the pace and efficiency of vaccine distribution in the country. Thus, the start of vaccine rollout may also have influenced administrators' perspectives about the lasting effects of the pandemic.

Furthermore, the quality of the data collected in this study relied on the expertise, experience, and recall ability of the LTC administrators being interviewed, along with their willingness to share their perspectives. Information in response to the interview questions were only asked of one administrator per site. This must be considered as well when reading quotations from specific administrators, as they each represent just one perspective about the COVID-19 experience at the relevant PACE site. However, the results represent points of

agreement among PACE administration. Furthermore, the information gathered was limited by the specific language and questions contained within the research instrument. While the same research team member conducted all PACE interviews, the administrators may have differed in the extent to which they elaborated on their answers to the prompts contained in the instrument. For example, some quotes analyzed for this study revealed information that was not explicitly asked of administrators. While the study included the totality of the NC PACE population, the instrument queried the administrators in several areas in 1-hour interviews; more definitive conclusions may be possible with further studies. Additionally, data about PACE participant demographics and enrollment provided in Tables 1 and 2 represent administrators' estimates rather than precise numbers, although many administrators referenced documents during the interviews to verify the numbers they provided.

Lastly, this study only queried PACE in North Carolina; because different states have had different experiences with and reactions to COVID-19, the results may not reflect those of LTC providers in other states. Consequently, data from this study may be considered alongside multi-state studies on LTC practices during COVID-19 for a more comprehensive overview of relevant changes and challenges.

**Future Research Directions**

Regarding the earlier themes discussed, it would be beneficial to conduct further studies 5 and 10 years after the COVID-19 pandemic has subsided to understand which changes have persisted past immediate outbreak concerns. In addition to the themes of this paper, the emerging themes presented in the Results section are topics that may be further explored in future studies: proactivity vs. reactivity to public health emergencies and interdisciplinary leadership.

The first emerging theme relates to proactivity vs. reactivity to public health emergencies, particularly relating to infectious diseases. It remains to be seen whether PACE will act on its demonstrated heightened awareness of infection prevention and control practices long-term after the pandemic subsides. More specifically, which infection prevention and control measures will PACE continue to employ after the world has reached herd immunity from COVID-19? Which elements of COVID-19-related IPC measures will it deem pertinent for future public health emergencies? How long will NC PACE remain serious about abiding by and enforcing these measures? More generally, will PACE sites carry through on their administrators' intentions to proactively respond to the next public health crisis or disease outbreak? In addition, it may not be feasible to proactively respond to the next public health emergency, given that its nature is uncertain and that COVID-19 showed lack of adequate government recognition of PACE as a service provider. Future studies may investigate these ideas by asking targeted questions about the specific policies and procedures being considered toward this aim of proactivity.

The second emerging theme relates to the effectiveness of interdisciplinary leadership during the spread of emergent COVID-19 and the potential for this leadership model during future public health emergencies. During the pandemic, many hospitals and health systems used incident command systems or teams (ICS) to coordinate their COVID-19 responses, gather stakeholder perspectives, enforce IPC measures, and maintain communication among actors.[109–111] In the future, this topic may be researched further because only a handful of PACE sites explicitly discussed their ICS. Specifically, the structure and effectiveness of the ICS may be assessed for its ability to adapt to rapid changes emerging from a public health crisis. Additionally, the flexibility of the PACE ICS to respond to different types of public health crises could be investigated, rather than only a respiratory viral disease as was the case with COVID-

19. PACE's precedent for interdisciplinary collaboration on the care side may situate it well for successful ICS, in which many professional perspectives come together to solve problems.

## ACKNOLWEDGEMENTS

Completing this honors thesis was an effort supported and facilitated by many people, who are named below in gratitude.

**Sheryl Zimmerman, PhD, MSW,** is a University Kenan Distinguished Professor who serves as the Co-Director of the Program on Aging, Disability, and Long-Term Care at the UNC Cecil G. Sheps Center for Health Services Research and as the Director of Aging Research at the UNC School of Social Work. She was my first reader on this thesis project and generously provided her expertise to help me refine my ideas for this paper. Dr. Zimmerman was even more than a thesis advisor to me; she was also a mentor who invested in my learning and cultivated my research skills. I am very grateful to her for allowing me to join her team on the energizing work of LTC research.

**Karl Umble, PhD, MPH** teaches our Health Policy and Management thesis courses, and he was my second reader on this thesis project. Dr. Umble led our class with untiring enthusiasm and encouragement in two semesters of entirely online instruction during the COVID-19 pandemic. He cultivated our thesis class into a community of shared learning, growth, and support. My classmates and I appreciated his efforts deeply.

**Philip Sloane, MD, MPH** is a family physician and geriatrician at UNC School of Medicine who serves as the Co-Director of the Program on Aging, Disability, and Long-Term Care at the UNC Cecil G. Sheps Center for Health Services Research. His experience as a health care practitioner was crucial during my interpretation of results from the interviews. I am also grateful to him for his investment in me as a student and aspiring physician.

**Kimberly Ward, MPH** serves as the Associate Director of the Collaborative Studies of Long-Term Care, and she was the project manager for our research team. Kimberly also

conducted the interviews of PACE administrators for this study. I am grateful to Kimberly for welcoming me to the team and carefully guiding me through processes such as conducting interviews.

**Christina Horsford, MSW** is a PhD candidate who was on our research team. I thank Christina for her warm, uplifting personality throughout the project and for guiding me through the process of coding transcripts for qualitative data analysis.

The **12 NC PACE administrators** shared their experiences and insights with our team and allowed us to share their stories with the health care community. I was delighted to hear about their experiences, and I am humbled by their dedicated efforts to serve people in their communities amid the pandemic.

**Funding Source**

This project was funded by the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health (grant UL1TR002489).

## REFERENCES


1. Slavitt A. The COVID-19 Pandemic Underscores the Need to Address Structural Challenges of the US Health Care System. *JAMA Health Forum*. 2020;1(7):e200839. doi:10.1001/jamahealthforum.2020.0839
2. Grimm CA. Hospital Experiences Responding to the COVID-19 Pandemic: Results of a National Pulse Survey March 23–27, 2020. U.S. Department of Health and Human Services. https://www.oig.hhs.gov/oei/reports/oei-06-20-00300.pdf. Published April 2020. Accessed October 7, 2020.
3. Blumenthal D, Fowler EJ, Abrams M, Collins SR. Covid-19 - Implications for the Health Care System. *N Engl J Med*. 2020;383(15):1483-1488. doi:10.1056/NEJMsb2021088
4. Inzitari M, Risco E, Cesari M, et al. Nursing Homes and Long Term Care After COVID-19: A New ERA? *J Nutr Health Aging*. July 2020. doi:10.1007/s12603-020-1447-8
5. Schneider EC. Failing the Test - The Tragic Data Gap Undermining the U.S. Pandemic Response. *N Engl J Med*. 2020;383(4):299-302. doi:10.1056/NEJMp2014836
6. COVID-19 Map - Johns Hopkins Coronavirus Resource Center. https://coronavirus.jhu.edu/map.html. Accessed October 8, 2020.
7. Centers for Disease Control and Prevention. Older Adults and COVID-19. https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/older-adults.html. Published April 16, 2021. Accessed October 3, 2020.
8. Musumeci M. COVID-19 Issues and Medicaid Policy Options for People Who Need Long-Term Services and Supports. Kaiser Family Foundation. https://www.kff.org/coronavirus-covid-19/issue-brief/covid-19-issues-and-medicaid-policy-options-for-people-who-need-long-term-services-and-supports/. Published April 16, 2020. Accessed September 18, 2020.
9. Santesmasses D, Castro JP, Zenin AA, et al. COVID-19 is an emergent disease of aging. *Aging Cell*. 2020;19(10):e13230. doi:10.1111/acel.13230
10. Shi S, Qin M, Shen B, et al. Association of Cardiac Injury With Mortality in Hospitalized Patients With COVID-19 in Wuhan, China. *JAMA Cardiol*. 2020;5(7):802-810. doi:10.1001/jamacardio.2020.0950
11. Reddy S. North Carolina is Aging! North Carolina Department of Health and Human Services. https://files.nc.gov/ncdhhs/documents/files/NC%20State%20Aging%20Profile%202016.pdf. Published December 2017. Accessed October 7, 2020.
12. Modes of transmission of virus causing COVID-19: implications for IPC precaution recommendations. https://www.who.int/news-room/commentaries/detail/modes-of-transmission-of-virus-causing-covid-19-implications-for-ipc-precaution-recommendations. Accessed October 6, 2020.
13. Centers for Disease Control and Prevention. Scientific Brief: SARS-CoV-2 and Potential Airborne Transmission. Coronavirus Disease 2019 (COVID-19). https://www.cdc.gov/coronavirus/2019-ncov/science/science-briefs/scientific-brief-sars-cov-2.html. Published October 5, 2020. Accessed October 25, 2020.
14. Alzheimer's Impact Movement. North Carolina Alzheimer's Statistics. Alzheimer's Association. https://www.alz.org/media/documents/northcarolina-alzheimers-facts-figures-2018.pdf. Published 2018. Accessed October 7, 2020.

15. D'Adamo H, Yoshikawa T, Ouslander JG. Coronavirus Disease 2019 in Geriatrics and Long-Term Care: The ABCDs of COVID-19. *J Am Geriatr Soc*. 2020;68(5):912-917. doi:10.1111/jgs.16445
16. Wang H, Li T, Barbarino P, et al. Dementia care during COVID-19. *Lancet*. 2020;395(10231):1190-1191. doi:10.1016/S0140-6736(20)30755-8
17. Brosseau C. Coronavirus deaths keep rising at Triangle nursing homes, assisted living facilities. *The News & Observer*. May 30, 2020.
18. Israelsen-Hartley S. COVID-19: Why nursing homes are taking the brunt of the impact - Deseret News. DeseretNews. https://www.deseret.com/indepth/2020/6/7/21258676/coronavirus-utah-nursing-homes-long-term-care-pandemic-covid-19-assisted-living-death-cna-nurses. Published June 7, 2020. Accessed October 27, 2020.
19. Colenda CC, Reynolds CF, Applegate WB, et al. COVID-19 Pandemic and Ageism: A Call for Humanitarian Care. *Am J Geriatr Psychiatry*. 2020;28(8):805-807. doi:10.1016/j.jagp.2020.04.005
20. Fraser S, Lagacé M, Bongué B, et al. Ageism and COVID-19: what does our society's response say about us? *Age Ageing*. 2020;49(5):692-695. doi:10.1093/ageing/afaa097
21. Cesari M, Proietti M. COVID-19 in Italy: Ageism and Decision Making in a Pandemic. *J Am Med Dir Assoc*. 2020;21(5):576-577. doi:10.1016/j.jamda.2020.03.025
22. Ouslander JG, Grabowski DC. COVID-19 in Nursing Homes: Calming the Perfect Storm. *J Am Geriatr Soc*. 2020;68(10):2153-2162. doi:10.1111/jgs.16784
23. National Center for Health Statistics. COVID-19 Provisional Counts - Weekly Updates by Select Demographic and Geographic Characteristics. Centers for Disease Control and Prevention. https://www.cdc.gov/nchs/nvss/vsrr/covid_weekly/index.htm. Published December 30, 2020. Accessed January 4, 2021.
24. Werner RM, Hoffman AK, Coe NB. Long-Term Care Policy after Covid-19 - Solving the Nursing Home Crisis. *N Engl J Med*. 2020;383(10):903-905. doi:10.1056/NEJMp2014811
25. Hussain A, Rivers PA. Confronting the challenges of long-term health care crisis in the United States. *J Health Care Finance*. 2009;36(2):71-82.
26. Sloane PD, Zimmerman S, D'Souza MF. What will long-term care be like in 2040? *N C Med J*. 2014;75(5):326-330. doi:10.18043/ncm.75.5.326
27. Grabowski DC. Strengthening Nursing Home Policy for the Postpandemic World: How Can We Improve Residents' Health Outcomes and Experiences? *Commonwealth Fund*. 2020. doi:10.26099/b19s-cb53
28. The Graying of America: More Older Adults Than Kids by 2035. https://www.census.gov/library/stories/2018/03/graying-america.html. Accessed October 8, 2020.
29. Institute of Medicine (US) Committee on Improving Quality in Long-Term Care. Executive Summary. In: Wunderlich GS, Koehler PO, eds. *Improving the Quality of Long-Term Care*. Washington, DC: National Academies Press; 2001.
30. Kaiser Family Foundation. Medicaid's Role in Meeting Seniors' Long-Term Services and Supports Needs. Kaiser Family Foundation. https://www.kff.org/medicaid/fact-sheet/medicaids-role-in-meeting-seniors-long-term-services-and-supports-needs/. Published August 2, 2016. Accessed October 7, 2020.
31. U.S. Department of Health and Human Services. What Is Long-Term Care? National

Institute on Aging. https://www.nia.nih.gov/health/what-long-term-care. Published January 5, 2017. Accessed November 18, 2020.
32. Doty P, Liu K, Wiener J. An overview of long-term care. *Health Care Financ Rev*. 1985;6(3):69-78.
33. Johnson RW. The strains and drains of long-term care. *Virtual Mentor*. 2008;10(6):397-400. doi:10.1001/virtualmentor.2008.10.6.pfor1-0806
34. National Institute on Aging. Residential Facilities, Assisted Living, and Nursing Homes. U.S. Department of Health and Human Services. https://www.nia.nih.gov/health/residential-facilities-assisted-living-and-nursing-homes. Published May 1, 2017. Accessed November 19, 2020.
35. Cohen MA, Kumar N, Wallack SS. Long-term care insurance and Medicaid. *Health Aff (Millwood)*. 1994;13(4):127-139. doi:10.1377/hlthaff.13.4.127
36. Harris-Kojetin L, Sengupta M, Lendon JP, Rome V, Valverde R, Caffrey C. *Long-Term Care Providers and Users in the United States, 2015-2016*. National Center for Health Statistics (U.S.); 2019.
37. Truffer C, Wolfe C, Rennie K. *2016 Actuarial Report on the Financial Outlook for Medicaid*. Centers for Medicare & Medicaid Services; 2016.
38. Stone RI, Reinhard SC. The place of assisted living in long-term care and related service systems. *Gerontologist*. 2007;47 Spec No 3:23-32. doi:10.1093/geront/47.supplement_1.23
39. Simon J. The Different Types of Long Term Care Facilities - SmartAsset. Smart Asset. https://smartasset.com/retirement/types-of-long-term-care-facilities. Published January 8, 2020. Accessed November 20, 2020.
40. Phillips CD, Holan S, Sherman M, Spector W, Hawes C. Medicare expenditures for residents in assisted living: data from a national study. *Health Serv Res*. 2005;40(2):373-388. doi:10.1111/j.1475-6773.2005.00362.x
41. Zimmerman S, Gruber-Baldini AL, Sloane PD, et al. Assisted living and nursing homes: apples and oranges? *Gerontologist*. 2003;43 Spec No 2:107-117. doi:10.1093/geront/43.suppl_2.107
42. Hirth V, Baskins J, Dever-Bumba M. Program of all-inclusive care (PACE): past, present, and future. *J Am Med Dir Assoc*. 2009;10(3):155-160. doi:10.1016/j.jamda.2008.12.002
43. Centers for Medicare & Medicaid Services. PACE. Medicare.gov. https://www.medicare.gov/your-medicare-costs/get-help-paying-costs/pace. Published 2020. Accessed November 18, 2020.
44. Eng C, Pedulla J, Eleazer GP, McCann R, Fox N. Program of All-inclusive Care for the Elderly (PACE): an innovative model of integrated geriatric care and financing. *J Am Geriatr Soc*. 1997;45(2):223-232. doi:10.1111/j.1532-5415.1997.tb04513.x
45. National PACE Association. *Understanding PACE*. Alexandria, VA: National PACE Association; 2021.
46. National PACE Association. PACE: Frequently Asked Questions. National PACE Association. https://www.npaonline.org/sites/default/files/PACE%20FAQs%20Oct%202019.pdf. Published 2021. Accessed April 7, 2021.
47. Sun R, Karaca Z, Wong HS. Trends in hospital emergency department visits by age and payer, 2006–2015: statistical brief #238. In: *Healthcare Cost and Utilization Project (HCUP) Statistical Briefs*. Rockville (MD): Agency for Healthcare Research and Quality

(US); 2006.
48. National PACE Association. PACE Fact Sheet. National PACE Association. https://www.npaonline.org/start-pace-program/enrollment-operations/fact-sheet. Published 2021. Accessed April 6, 2021.
49. North Carolina Department of Health and Human Services. NC Medicaid: Program of All-Inclusive Care for the Elderly (PACE). NC Medicaid Division of Health Benefits. https://medicaid.ncdhhs.gov/providers/programs-services/long-term-care/program-of-all-inclusive-care-for-the-elderly. Published 2021. Accessed April 7, 2021.
50. Kwiatkowski J. Program of All-Inclusive Care for the Elderly (PACE): Integrating Health and Social Care Since 1973. *Rhode Island Medical Journal*. 2019;102(5):30-32.
51. Gross DL, Temkin-Greener H, Kunitz S, Mukamel DB. The growing pains of integrated health care for the elderly: lessons from the expansion of PACE. *Milbank Q*. 2004;82(2):257-282. doi:10.1111/j.0887-378X.2004.00310.x
52. American Health Care Association, National Center for Assisted Living. Facts & Figures. American Health Care Association. https://www.ahcancal.org/Assisted-Living/Facts-and-Figures/Pages/default.aspx. Published 2020. Accessed October 27, 2020.
53. Center for Medicare and Medicaid Services. Chapter 1 – Introduction to PACE. In: *PACE Model Manual*. Center for Medicare and Medicaid Services; 2011.
54. *Program of All-Inclusive Care for the Elderly (PACE) Key Research Findings: Quality Care, Improved Health, Cost-Effective*. Alexandria, VA: National PACE Association; 2012. https://www.aha.org/system/files/content/11/111212postacutecall-npabrief.pdf. Accessed April 8, 2021.
55. Beauchamp J. *The Effect of the Program of All-Inclusive Care for the Elderly (PACE) on Quality*. Princeton, NJ: Centers for Medicare and Medicaid Services; 2008.
56. Chen L-Y, Hsu T-J, Ke L-J, et al. Care for older adults with dementia: PACE day care or residential dementia care units? *Arch Gerontol Geriatr*. 2021;93:104310. doi:10.1016/j.archger.2020.104310
57. Larson L. A better way to grow old: the PACE model. *Trustee*. 2002;55(7):10-14, 19, 1.
58. National PACE Association. PACE by the Numbers. National PACE Association. https://www.npaonline.org/sites/default/files/4068_pace_infographic_update_mar2021%20%281%29.pdf. Published March 2021. Accessed April 8, 2021.
59. Cassells JS, Harris-Wehling J, Ball MJ, et al. Strengthening training in geriatrics for physicians. *J Am Geriatr Soc*. 1994;42(5):559-565. doi:10.1111/j.1532-5415.1994.tb04980.x
60. Winzelberg GS. The quest for nursing home quality: learning history's lessons. *Arch Intern Med*. 2003;163(21):2552-2556. doi:10.1001/archinte.163.21.2552
61. Institute of Medicine (US) Committee on Nursing Home Regulation. Appendix A: History of Federal Nursing Home Regulation. In: *Improving the Quality of Care in Nursing Homes*. Washington, DC: National Academies Press (US); 1986.
62. Kitchener M, O'neill C, Harrington C. Chain reaction: an exploratory study of nursing home bankruptcy in California. *J Aging Soc Policy*. 2005;17(4):19-35. doi:10.1300/j031v17n04_02
63. Wilson KB. Historical evolution of assisted living in the United States, 1979 to the present. *Gerontologist*. 2007;47 Spec No 3:8-22. doi:10.1093/geront/47.supplement_1.8
64. Hawes C, Phillips CD, Rose M, Holan S, Sherman M. A national survey of assisted living facilities. *Gerontologist*. 2003;43(6):875-882. doi:10.1093/geront/43.6.875

65. Harrington C, Chapman S, Miller E, Miller N, Newcomer R. Trends in the Supply of Long-Term-Care Facilities and Beds in the United States. *J Appl Gerontol*. 2005;24(4):265-282. doi:10.1177/0733464805275366
66. Zimmerman S, Sloane PD, Eckert JK, et al. How good is assisted living? Findings and implications from an outcomes study. *J Gerontol B, Psychol Sci Soc Sci*. 2005;60(4):S195-204. doi:10.1093/geronb/60.4.s195
67. Segelman M, Szydlowski J, Kinosian B, et al. Hospitalizations in the Program of All-Inclusive Care for the Elderly. *J Am Geriatr Soc*. 2014;62(2):320-324. doi:10.1111/jgs.12637
68. National PACE Association. PACE Reduces Burden of Family Caregivers. National PACE Association. https://www.npaonline.org/about-npa/press-releases/pace-reduces-burden-family-caregivers. Published August 30, 2018. Accessed April 8, 2021.
69. Tan EJ, Lui L-Y, Eng C, Jha AK, Covinsky KE. Differences in mortality of black and white patients enrolled in the program of all-inclusive care for the elderly. *J Am Geriatr Soc*. 2003;51(2):246-251. doi:10.1046/j.1532-5415.2003.51065.x
70. Friedman SM, Steinwachs DM, Temkin-Greener H, Mukamel DB. Informal caregivers and the risk of nursing home admission among individuals enrolled in the program of all-inclusive care for the elderly. *Gerontologist*. 2006;46(4):456-463. doi:10.1093/geront/46.4.456
71. United States Census Bureau. Fueled by Aging Baby Boomers, Nation's Older Population to Nearly Double in the Next 20 Years, Census Bureau Reports. United States Census Bureau. https://www.census.gov/newsroom/press-releases/2014/cb14-84.html. Published May 16, 2014. Accessed April 9, 2021.
72. Zayas CE, He Z, Yuan J, et al. Examining Healthcare Utilization Patterns of Elderly Middle-Aged Adults in the United States. *Proc Int Fla AI Res Soc Conf*. 2016;2016:361-366.
73. Van Houtven CH, Boucher NA, Dawson WD. *Impact of the COVID-19 Outbreak on Long-Term Care in the United States*. Portland State University Institute on Aging; 2020.
74. Kaiser Family Foundation. Long-Term Care in the United States: A Timeline. Kaiser Family Foundation. https://www.kff.org/medicaid/timeline/long-term-care-in-the-united-states-a-timeline/. Published August 31, 2015. Accessed November 22, 2020.
75. Appleby J. CLASS Dismissed: Obama Administration Pulls Plug On Long-Term Care Program. Kaiser Health News. https://khn.org/news/class-act-implementation-halted-by-obama-administration/. Published October 14, 2011. Accessed November 22, 2020.
76. Spencer G. *Population Projections of the United States by Age, Sex, Race, and Hispanic Origin: 1995 to 2050*. Bureau of the Census; 1996.
77. Cubanski J, Neuman T, Freed M. The Facts on Medicare Spending and Financing | KFF. Kaiser Family Foundation. https://www.kff.org/medicare/issue-brief/the-facts-on-medicare-spending-and-financing/. Published August 20, 2019. Accessed November 22, 2020.
78. Harrington C, Wiener J, Ross L, Musumeci M. Key Issues in Long-Term Services and Supports Quality. Kaiser Family Foundation. https://www.kff.org/medicaid/issue-brief/key-issues-in-long-term-services-and-supports-quality/. Published October 27, 2017. Accessed November 23, 2020.
79. Higgins C. *Expected Impact of COVID-19 on PACE Programs*. Health Dimensions Group; 2020.

80. North Carolina Department of Health and Human Services. NC DHHS COVID-19: Guidance. NCDHHS COVID-19 Response. https://covid19.ncdhhs.gov/guidance#long-term-care-facilities. Published 2020. Accessed November 23, 2020.
81. North Carolina Department of Health and Human Services. Supporting Our Long-Term Care Facilities During COVID-19. NCDHHS. https://files.nc.gov/covid/documents/info-for/health-care/Supporting-Our-Long-Term-Care-Facilities.pdf. Published 2020. Accessed November 23, 2020.
82. North Carolina Department of Health and Human Services. COVID-19 Outbreak Toolkit for Long-Term Care Settings. NCDHHS. https://files.nc.gov/covid/documents/guidance/healthcare/Long-Term-Care-Outbreak-Toolkit-Instructions.pdf. Published September 2020. Accessed November 23, 2020.
83. North Carolina Department of Health and Human Services. NCDHHS: NCDHHS Expands Measures to Prevent and Respond to COVID-19 in Long-term Care Facilities. NCDHHS. https://www.ncdhhs.gov/news/press-releases/ncdhhs-expands-measures-prevent-and-respond-covid-19-long-term-care-facilities. Published May 18, 2020. Accessed September 18, 2020.
84. Department of Health and Human Services Press Office. HHS Announces Allocations of CARES Act Provider Relief Fund for Nursing Homes. Department of Health and Human Services. https://www.hhs.gov/about/news/2020/08/07/hhs-announces-allocations-of-cares-act-provider-relief-fund-for-nursing-homes.html. Published August 7, 2020. Accessed November 23, 2020.
85. Assistant Secretary for Public Affairs. CARES Act Provider Relief Fund: General Information. Department of Health and Human Services. https://www.hhs.gov/coronavirus/cares-act-provider-relief-fund/general-information/index.html. Published May 4, 2021. Accessed November 22, 2020.
86. NC Medicaid. NC Medicaid: SPECIAL BULLETIN COVID-19 #32: Rate Increase and Claims Reprocessing. NC Medicaid Division of Health Benefits. https://medicaid.ncdhhs.gov/blog/2020/04/03/special-bulletin-covid-19-32-rate-increase-and-claims-reprocessing#:~:text=Effective%20March%2010%2C%202020%2C%20the,date%20of%20the%20rate%20increase. Published April 3, 2020. Accessed November 22, 2020.
87. Department of Health and Human Services Press Office. Trump Administration Announces Provider Relief Fund Application for Assisted Living Facilities. Department of Health and Human Services. https://www.hhs.gov/about/news/2020/09/01/trump-administration-announces-provider-relief-fund-application-for-assisted-living-facilities.html. Published September 1, 2020. Accessed November 15, 2020.
88. Bowers L. Feds announce Provider Relief Fund application for private-pay assisted living. McKnight's Senior Living News. https://www.mcknightsseniorliving.com/home/news/feds-announce-provider-relief-fund-application-for-assisted-living/. Published January 9, 2020. Accessed November 22, 2020.
89. North Carolina Assisted Living Association. Become a Member of NCALA. North Carolina Assisted Living Association. https://www.ncala.org/membership.html. Published January 5, 2021. Accessed November 23, 2020.
90. Health Dimensions Group. Federal COVID-19 Funding for Senior Care —Navigating the Uncertainty. Health Dimensions Group. https://healthdimensionsgroup.com/covid-funding/. Published June 11, 2020. Accessed November 23, 2020.

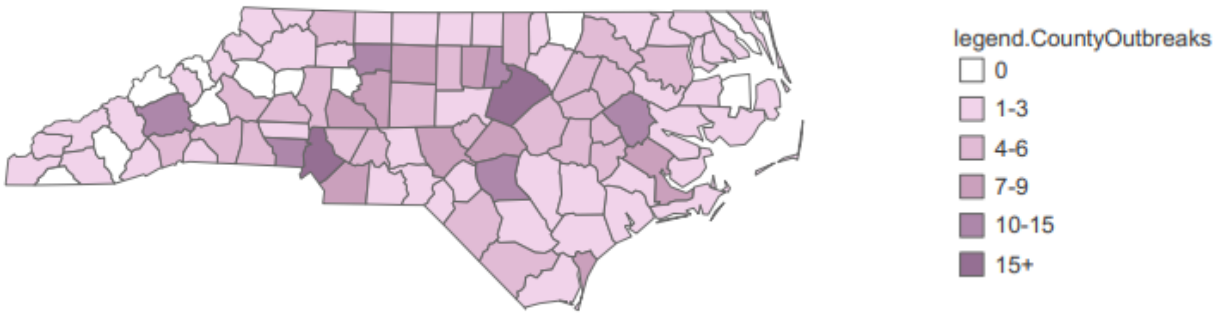
91. Assistant Secretary for Public Affairs. General Distribution FAQs. Department of Health and Human Services: Coronavirus. https://www.hhs.gov/coronavirus/cares-act-provider-relief-fund/faqs/general-distribution/index.html. Published March 31, 2021. Accessed March 31, 2021.
92. Centers for Medicare & Medicaid Services. *Toolkit on State Actions to Mitigate COVID-19 Prevalence in Nursing Homes* . 1st ed. Centers for Medicare & Medicaid Services; 2020.
93. Zimmerman S, Dobbs D, Roth EG, Goldman S, Peeples AD, Wallace B. Promoting and protecting against stigma in assisted living and nursing homes. *Gerontologist*. 2016;56(3):535-547. doi:10.1093/geront/gnu058
94. Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *Int J Qual Methods*. 2017;16(1):1-13. doi:10.1177/1609406917733847
95. Green J, Thorogood N. *Qualitative Methods for Health Research*. 3rd ed. London: SAGE Publications Ltd; 2014.
96. McGarry BE, Grabowski DC, Barnett ML. Severe Staffing And Personal Protective Equipment Shortages Faced By Nursing Homes During The COVID-19 Pandemic. *Health Aff (Millwood)*. 2020;39(10):1812-1821. doi:10.1377/hlthaff.2020.01269
97. National PACE Association. Quality Health Care, PACE and The Medical Home Mode. 2021.
98. Cacchione PZ, Eible L, Gill LL, Huege SF. Person-Centered Care for Older Adults With Serious Mental Illness and Substance Misuse Within a Program of All-Inclusive Care for the Elderly. *J Gerontol Nurs*. 2016;42(5):11-17. doi:10.3928/00989134-20160413-04
99. Giorgi G, Lecca LI, Alessio F, et al. COVID-19-Related Mental Health Effects in the Workplace: A Narrative Review. *Int J Environ Res Public Health*. 2020;17(21). doi:10.3390/ijerph17217857
100. NORC at the University of Chicaco. *Needs Assessment and Environmental Scan Report: Maintaining Physical and Mental Well-Being of Older Adults and Their Caregivers During Public Health Emergencies*. CDC Foundation; 2021.
101. Markowitz A, Paulin E. AARP Answers: Nursing Homes and the Coronavirus. American Association of Retired Persons. https://www.aarp.org/caregiving/health/info-2020/nursing-homes-coronavirus-faqs.html. Published March 11, 2021. Accessed April 9, 2021.
102. Centers for Medicare & Medicaid Services. COVID-19 Long-Term Care Facility Guidance. April 2020.
103. Halpern LW. The Politicization of COVID-19. *Am J Nurs*. 2020;120(11):19-20. doi:10.1097/01.NAJ.0000721912.74581.d7
104. Gollust SE, Nagler RH, Fowler EF. The Emergence of COVID-19 in the US: A Public Health and Political Communication Crisis. *J Health Polit Policy Law*. 2020;45(6):967-981. doi:10.1215/03616878-8641506
105. Hart PS, Chinn S, Soroka S. Politicization and Polarization in COVID-19 News Coverage. *Sci Commun*. August 2020:107554702095073. doi:10.1177/1075547020950735
106. North Carolina Department of Health and Human Services. Cases. NC DHHS COVID-19 Response. https://covid19.ncdhhs.gov/dashboard/cases. Published April 11, 2021. Accessed April 10, 2021.

107. Cases Demographics, Cases by Age for North Carolina. NCDHHS COVID-19 Response. https://covid19.ncdhhs.gov/dashboard/cases-demographics. Published April 12, 2021. Accessed April 15, 2021.
108. The New York Times. U.S. Starts Vaccine Rollout as High-Risk Health Care Workers Go First. *The New York Times*. January 4, 2021.
109. Farcas A, Ko J, Chan J, Malik S, Nono L, Chiampas G. Use of Incident Command System for Disaster Preparedness: A Model for an Emergency Department COVID-19 Response. *Disaster Med Public Health Prep*. June 2020:1-6. doi:10.1017/dmp.2020.210
110. Cook J. Incident Command in the Time of COVID-19. *Lab Med*. 2020;51(6):e78-e82. doi:10.1093/labmed/lmaa073
111. Stifter J, Terry A, Phillips J, Heitschmidt M. A short report on an interprofessional mobilizer team: innovation and impact during the COVID-19 pandemic. *J Interprof Care*. 2020;34(5):716-718. doi:10.1080/13561820.2020.1813696

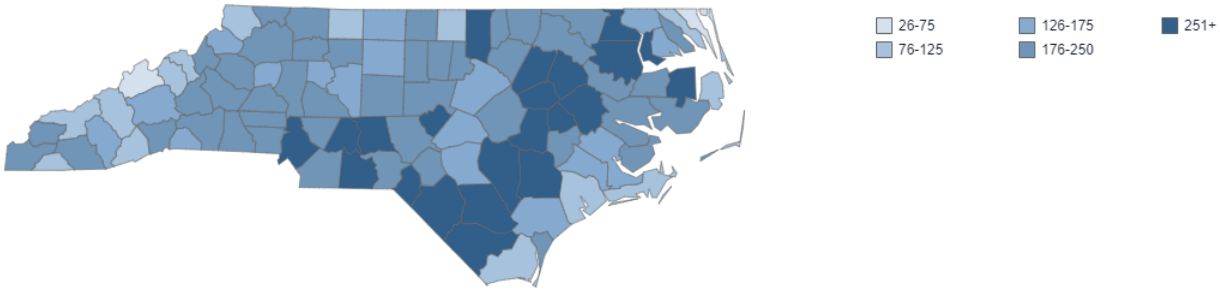
## Appendix A: Determination of PACE-served Regions for Sampling

### Map of Geographical Areas Served by PACE


### Ongoing Outbreaks in Congregate Living Settings (downloaded from NCDHHS 10/2/2020)




### County Map by Cases per 10,000 Residents (Molecular (PCR) and Antigen) – downloaded from NCDHHS 10/2/2020



**Appendix B: Interview**

# North Carolina COVID-19 Project (NC TraCS)

# PACE/Nursing Home/Assisted Living Interview

**Site ID:** | | | |

**Interviewer ID:** | | |

**Date:** | | | | | | | | |

M M D D Y Y Y Y

The experiences you've had throughout the COVID pandemic have implications for the future of infection prevention. The topics we're going to discuss are intended to inform the future, so that (*PACE organizations, assisted living communities, nursing homes*) are better able to prevent and respond to future health crises – regardless what those crises might be.

**I. Participant Information**

| | | | |
|---|---|---|---|
| So that we can describe our participants, let's begin with a few basic questions about you. | | | |
| 1. | What's your gender? | ☐1 | Male |
| | | ☐$_2$ | Female |
| | | ☐$_3$ | Other: _____ |
| 2. | How do you describe your racial background? *(May select more than one)* | ☐1 | White |
| | | ☐$_2$ | Black/African American |
| | | ☐$_3$ | American Indian or Alaska Native |
| | | ☐$_4$ | Asian |
| | | ☐$_5$ | Native Hawaiian or Pacific Islander |
| | | ☐$_6$ | Other: _____ |
| 3. | Are you Hispanic or Latino(a)? | ☐0 | No |
| | | ☐1 | Yes |
| 4. | What's the highest schooling that you completed? | ☐1 | Completed high school (or GED) |
| | | ☐$_2$ | Technical or Trade School |
| | | ☐$_3$ | Some college/Associate's degree |
| | | ☐$_4$ | Bachelor's degree |
| | | ☐$_5$ | Graduate degree |
| 5. | What's your job title at (*name*)? | _____ | |
| 6. | Which of the following licenses or certifications do you have? Are you licensed or certified as a … | No<br>Yes<br>☐0<br>☐1 | a. CNA (certified nursing assistant) |
| | | ☐0<br>☐1 | b. Medication technician |
| | | ☐0<br>☐1 | c. LPN/LVN (Licensed practical/vocational nurse) |
| | | ☐0<br>☐1 | d. RN (Registered nurse) |
| | | ☐0<br>☐1 | e. Administrator license, NH or AL |
| | | ☐0<br>☐1 | f. Other: _____ |
| 7. | How long have you been in your position here? | __ __ years OR __ __ months (if < 1 year) | |
| 8. | How long have you worked here, in total? | __ __ years OR __ __ months (if < 1 year) | |
| 9. | How long have you worked as an administrator in total, including elsewhere? | __ __ years OR __ __ months (if < 1 year) | |

## II. Organizational Information

And now I have a few basic descriptive questions about (*name*). (*Ask EITHER A or B depending on type of organization*.)

| | | | |
|---|---|---|---|
| **A. NH or AL Characteristics** | | | |
| 1. | Is your organization's ownership for profit, non-profit, or government? | ☐1 | Profit |
| | | ☐2 | Non-profit |
| | | ☐3 | Government |
| 2. | How many beds does *(name)* have overall, and how many are occupied today? | **(1) Total** | **(2) Occupied** |
| | | ___ ___ ___ | ___ ___ ___ |
| 3. | Are any of your beds specified for persons with dementia? | ☐0 | No (Skip to Q 4) |
| | | ☐1 | Yes |
| | *If yes*: a. How many beds are specified for persons with dementia, and how many are occupied today? | **(1) Total** | **(2) Occupied** |
| | | ___ ___ ___ | ___ ___ ___ |
| 4. | Has your census stayed the same, or increased or decreased, since March 2020? | ☐0 | Same (Skip to C) |
| | | ☐1 | Increased |
| | | ☐2 | Decreased |
| | *If change:* a. By how much has your census (*increased/decreased*) since March 2020? | _____ residents | |
| 5. | *AL and NH only: Are you a COVID referral site?* | ☐0 | No |
| | | ☐1 | Yes |
| | *If yes:* a. How did this come about and how does it work? | | |
| **B. PACE Characteristics** | | | |
| 1. | As of today, what is your total enrollment? | _____ participants | |
| 2. | Has your enrollment stayed the same, or increased or decreased, since March 2020? | ☐0 | Same (Skip to Q 3) |
| | | ☐1 | Increased |
| | | ☐2 | Decreased |
| | *If change:* a. By how much has your enrollment (*increased/decreased*) since March 2020? | _____ participants | |
| 3. | Prior to COVID, on average how many participants attended the day center per day? | _____ participants | |
| 4. | As of today, on average how many participants attend the day center per day? | _____ participants | |
| 5. | As of today, how many participants are in a nursing home? | _____ participants | |
| 6. | Have the number of participants in a nursing home stayed the same, or increased or decreased, since March 2020? | ☐0 | Same (Skip to Q 7) |
| | | ☐1 | Increased |
| | | ☐2 | Decreased |

| | | |
|---|---|---|
| | *If change*: a. By how much has the number (*increased/decreased*) since March 2020? | _____ participants |
| 7. | As of today, how many participants are in assisted living? | _____ participants |
| 8. | Have the number of participants in assisted living stayed the same, or increased or decreased, since March 2020? | ☐0 Same (Skip to C)<br>☐1 Increased<br>☐2 Decreased |
| | *If change*: a. By how much has the number (*increased/decreased*) since March 2020? | _____ participants |

**C. Resident/Participant Information**

The next few questions ask for numbers of (*residents/participants*) in certain categories. Please provide your best estimate; it's not necessary for you to review records for this information.

| What percent of your current (*residents/participants*) are… | | | |
|---|---|---|---|
| 1. | Age *(total should equal 100%)* | 1. <65 years old | ___ ___ ___ % |
| | | 2. 65-74 years old | ___ ___ ___ % |
| | | 3. 75-84 years old | ___ ___ ___ % |
| | | 4. 85-94 years old | ___ ___ ___ % |
| | | 5. 95 years old and over | ___ ___ ___ % |
| 2. | Gender | Male | ___ ___ ___ % |
| 3. | Race *(total should equal 100%)* | 1. Black | ___ ___ ___ % |
| | | 2. White | ___ ___ ___ % |
| | | 3. Other | ___ ___ ___ % |
| 4. | Ethnicity | Of Hispanic Origin | ___ ___ ___ % |
| 5. | Use a wheelchair as their primary mode of locomotion? | | ___ ___ ___ % |
| 6. | Have a diagnosis of Alzheimer's disease or a different type of dementia? | | ___ ___ ___ % |
| 7. | Are currently receiving state financial assistance or Medicaid? | | ___ ___ ___ % |
| 8. | NH only: Are currently receiving post-acute rehabilitation under Medicare Part A or from another payor? | | ___ ___ ___ % |

## III. Primary Thought Regarding COVID

Thanks for providing those numbers. Now, we're ready to launch into questions relate to COVID.

1. Before I start asking specific questions, I'd like to hear what's most on your mind related to the entire COVID experience. So, please finish this sentence: The most important thing I'd like to say about COVID in the context of (*name*) is … *(Prompt as needed to be sure the reply is complete.)*

_____

_____

_____

_____

_____

## IV. COVID Testing and Cases

I have a few questions about COVID testing and cases, some of which ask for numbers. If you'd prefer to not to provide numbers, that's fine, but please keep in mind that everything you tell me will be confidential, and we'll never provide information that can be identified with you or (*name*).

| | | | |
|---|---|---|---|
| 1. | At the present time, are you routinely testing (*residents/participants*) for COVID? | ☐0 | No (Skip to Q 2) |
| | | ☐1 | Yes |
| | *If yes*: a. How often are you routinely testing? | _____ | |
| | b. What percent of (*residents/participants*) do you test? | ___ ___ ___ % | |
| 2. | At the present time, are you routinely testing staff for COVID? | ☐0 | No (Skip to Q 3) |
| | | ☐1 | Yes |
| | *If yes*: a. How often are you routinely testing? | _____ | |
| | b. What percent of staff do you test? | ___ ___ ___ % | |
| 3. | Do you use a molecular RNA/PCR test, or a rapid antigen test? | ☐1 | Molecular RNA/PCR |
| | | ☐2 | Rapid antigen test |
| | | ☐$_3$ | Both tests are used |
| | *If RNA/PCR is used:* a. On average, how long does it take to get a result back? | _____ days | |
| | *If rapid antigen is used:* b. Is the test done on-site? | ☐0 | No |
| | | ☐1 | Yes |
| 4. | How many positive (*resident/participant*) cases have you had? | _____ people | |
| | *If any:* a. How many were hospitalized due to COVID? | _____ people | |
| | b. How many died due to COVID? | _____ people | |
| 5. | How many positive staff cases have you had? | _____ staff | |

## V. Recommendations and Support

1. COVID has placed many demands on long-term care providers. I'm going to name 12 different areas, and for each one I'd like to know to what extent you need additional assistance to effectively manage that issue. The answers can be no additional assistance, some assistance, a moderate amount of assistance, and a great deal of assistance.

| *Note: Items adapted from CMS Toolkit on State Actions; omitted "communication" due* | No additional assistance | Some assistance | A moderate | A great deal of assistance |
|---|---|---|---|---|

| | | | | |
|---|---|---|---|---|
| *to numerous stakeholder groups with whom communication occurs.* | | | amount of assistance | |
| (1) Obtaining and using personal protective equipment/PPE | 1 | 2 | 3 | 4 |
| (2) Conducting screening for COVID | 1 | 2 | 3 | 4 |
| (3) Conducting testing for COVID | 1 | 2 | 3 | 4 |
| (4) Reporting suspected or known cases of COVID | 1 | 2 | 3 | 4 |
| (5) Implementing other infection control practices, such as disinfecting and sanitization | 1 | 2 | 3 | 4 |
| (6) Training staff on infection control practices | 1 | 2 | 3 | 4 |
| (7) Addressing socialization and isolation | 1 | 2 | 3 | 4 |
| (8) Responding to requests for new admissions or readmissions | 1 | 2 | 3 | 4 |
| (9) Handling staffing problems | 1 | 2 | 3 | 4 |
| (10) Working with healthcare providers | 1 | 2 | 3 | 4 |
| (11) Conducting advance care planning because of COVID | 1 | 2 | 3 | 4 |
| (12) *NH/AL only*: Addressing visitation of families or close others | 1 | 2 | 3 | 4 |

| | | | |
|---|---|---|---|
| 2. | What three resources – either documents or organizations (*if needed clarify they can be government, non-government, public, and private*) -- best helped (*name*) respond to COVID-19, and in what way? | | |
| | a. Document/organization: | | |
| | a1. In what way: | | |
| | b. Document/organization: | | |
| | b1. In what way: | | |
| | c. Document/organization: | | |
| | c1. In what way: | | |
| 3. | To what extent did you receive support from your local health department during COVID? | ☐$_1$ | Not at all/a little |
| | | ☐$_2$ | Somewhat |
| | | ☐$_3$ | Moderately |
| | | ☐$_4$ | Very much |

| | | | |
|---|---|---|---|
| | a. What could have improved the support you received? | | |
| 4. | To what extent did federal financial relief help you during COVID? | ☐1 | Not at all/a little |
| | | ☐2 | Somewhat |
| | | ☐3 | Moderately |
| | | ☐4 | Very much |
| | a. What could have made the relief more helpful? | | |
| | b. *If not already addressed*: Has your Medicaid reimbursement rate increased since COVID began? | ☐0 | No |
| | | ☐1 | Yes |
| | | ☐2 | NA (don't accept Medicaid) |

**VI. Medical and Mental Health Care Providers**

| | | | |
|---|---|---|---|
| 1. | During COVID, did you experience challenges having medical providers visit patients face-to-face? | ☐0 | No (Skip to Q 2) |
| | | ☐1 | Yes |
| | *If yes*: a. What were the challenges? | | |
| | | | |
| | b. How were the challenges addressed or solved? | | |
| | | | |
| 2. | During COVID, did you experience challenges having mental health care providers visit patients face-to-face? | ☐0 | No (Skip to Q 3) |
| | | ☐1 | Yes |
| | *If yes*: a. What were the challenges? | | |
| | | | |
| | b. How were the challenges addressed or solved? | | |
| | | | |
| 3. | What percent of medical visits in the past month were by telemedicine, meaning video conferencing? | | ___ ___ ___ % |
| | *If > 0%:* a. How satisfied are you with this service? | ☐1 | Not at all/a little |
| | | ☐2 | Somewhat |
| | | ☐3 | Moderately |
| | | ☐4 | Very |
| 4. | What percent of mental health care visits in the past month were by telemedicine, meaning video conferencing? | | ___ ___ ___ % |
| | *If > 0%:* a. How satisfied are you with this service? | ☐1 | Not at all/a little |
| | | ☐2 | Somewhat |
| | | ☐3 | Moderately |
| | | ☐4 | Very |

## VII. Experiences in Select Areas

Now I'll ask about your thoughts in four different areas, organization leadership, staffing, resident psychological and social well-being, and family relations. For each area, I'll ask what needs or challenges you had, how (*name*) responded to the need or challenge, what worked well, and what you recommend for the future.

| |
|---|
| **1. I'll begin with the topic of organizational leadership. Regarding your organization's leadership in relation to COVID …** |
| a. What needs or challenges did you have? |
| |
| |
| |
| |
| b. How did your organization respond to those needs and challenges? |
| |
| |
| |
| |
| c. In general, what worked well related to your organization's leadership? |
| |
| |
| |
| |
| d. Related to your organization's leadership, what do you recommend for the future, so (*name*) is better able to prevent and respond to future health crises? |
| |
| |
| |
| |
| **2. Regarding the staff you employ, and your experiences related to COVID…** |
| a. What needs or challenges did you have? |
| |
| |
| |
| |
| b. How did your organization respond to those needs and challenges? |
| |
| |
| |
| |
| c. In general, what worked well related to staffing? |
| |
| |

d. Related to staffing, what do you recommend for the future, so (*name*) is better able to prevent and respond to future health crises?

**3. Regarding providing care for your (*residents'/participants'*) psychological and social well-being in relation to COVID …**

a. What needs or challenges did you have?

b. How did your organization respond to those needs and challenges?

c. In general, what worked well related to psychological and social well-being?

d. Related to psychological and social well-being, what do you recommend for the future, so (*name*) is better able to prevent and respond to future health crises?

**4. Regarding the family of your (*residents'/participants'*), in relation to COVID …**

a. What needs or challenges did you have?

b. How did your organization respond to those needs and challenges?

c. In general, what worked well in relation to families?

| |
|---|
| |
| d. Related to families, what do you recommend for the future, so (***name***) is better able to prevent and respond to future health crises? |
| |
| |
| |
| |
| **5. Has the financial health of (*name*) been affected by COVID?** ☐0 No (Skip to Q 6) ☐1 Yes |
| *If yes:* a. How has it been affected? |
| **6. Have you had to change your business model due to COVID?** *By this I mean have you changed….types of people served; staffing and services provided; charges, payment, reimbursement;* or other things ☐0 No (Skip to Q 7) ☐1 Yes |
| *If yes:* a. How has it been affected? |
| **7. Other than the topics we discussed, did anything else create a barrier in relation to (*name*) preventing or managing COVID?** |
| |
| |
| |
| |
| **8. Other than the topics we discussed, did anything else facilitate your effort to prevent or manage COVID?** |
| |
| |
| |
| **9. Other than what you've mentioned previously, did (*name*) do anything especially innovative to prevent or manage COVID?** |
| |
| |
| |

## VIII. Relative Importance

We've talked about potential needs and challenges in many different areas. I'll name each area, and ask to what extent it's necessary to address that challenge and put remedies in place before the next crisis occurs – regardless what that next crisis might be.

| *Note: The original eight areas were changed to seven, because external providers overlapped with medical and mental health care.* | **Not at all necessary** | **Somewhat necessary** | **Moderately necessary** | **Very necessary** |
|---|---|---|---|---|
| 1. Regarding <u>organizational leadership</u> … to what extent is it necessary to put remedies in place before the next crisis occurs – regardless of what that particular crisis might be? Would you say it's…. | **1** | **2** | **3** | **4** |
| 2. Regarding <u>staffing issues</u> … to what extent is it necessary to put remedies in place before the next crisis occurs – regardless of what that particular crisis might be? Would you say it's…. | **1** | **2** | **3** | **4** |
| 3. Regarding (*residents'/participants'*) <u>psychological and social well-being</u> … to what extent is it necessary to put remedies in place before the next crisis occurs – regardless of what that particular crisis might be? Would you say it's…. | **1** | **2** | **3** | **4** |
| 4. Regarding (*residents'/participants'*) <u>family relations</u> … to what extent is it necessary to put remedies in place before the next crisis occurs – regardless of what that particular crisis might be? Would you say it's…. | **1** | **2** | **3** | **4** |
| 5. Regarding <u>regulations and recommendations</u> … to what extent is it necessary to put remedies in place before the next crisis occurs – regardless of what that particular crisis might be? Would you say it's…. | **1** | **2** | **3** | **4** |
| 6. Regarding (*resident/participant*) <u>medical and mental health care</u> … to what extent is it necessary to put remedies in place before the next crisis occurs – regardless of what that particular crisis might be? Would you say it's…. | **1** | **2** | **3** | **4** |
| 7. Regarding <u>monetary issues</u> … to what extent is it necessary to put remedies in place before the next crisis occurs – regardless of what that particular crisis might be? Would you say it's…. | **1** | **2** | **3** | **4** |

## IX. Impact on Future Care Delivery

We're almost finished. I have one last question to ask related to COVD.

| | | | |
|---|---|---|---|
| 1. | Do you think the pandemic has permanently changed how (*name*) will deliver care in the future? | ☐0 | No (end interview) |
| | | ☐1 | Yes |
| | *If yes*: a. How do you think it will change? | | |

## Appendix C: Codebook (Domain Codes and Topic Codes)

| *DOMAIN CODES* | |
|---|---|
| **ABBREVIATION** | **DESCRIPTION** |
| **CHALL** | Challenges, needs, struggles, barriers |
| **COMM** | Communication (group [not 1:1], written, electronic, social media; not telehealth); do not co-code with GUIDE |
| **DEI** | Diversity, equity, and inclusion; includes reference to race/racism/disparities; often co-coded with PEOPLE codes |
| **FUTURE** | Future impact on / change in care delivery expected for own organization or other long-term care setting(s) |
| **GUIDE** | Guidelines/regulations/restrictions/requirements; expressly references something told to do;<br>may be co-coded with source, such as federal, state, provider organizations |
| **INITIAL** | Initial impression ("what's most on your mind" question beginning of interview) |
| **QUOTE** | Quote (especially descriptive / impactful; can include emotional reactions/feelings) |
| **RECOM** | Respondent's recommendations/suggestions (whether or not in practice; need not use word "recommend") |
| **SUCCESS** | Comments about success around response to pandemic |
| *TOPIC CODES* | |
| **ABBREVIATION** | **DESCRIPTION** |
| **CHANGE** | |
| DECISION | Decision-making (explicit comment about decision-making/weighing options, pro's and con's); includes regarding making a choice; another key word may be voluntary |
| FAC | **Enacted** facilitator, support (makes it easier to do/achieve something; precursor to success); often co-coded |
| FLEX | Flexibility (e.g., **specific comments** about being flexible, nimble, able to adapt; not simply creativity or change) |
| **EXTERNAL ENTITY** | *Note: during analysis, be mindful that DHHS may not assuredly be state* |
| FED | Federal (e.g., CDC, CMS) |
| HOSP | Hospitals / health systems |
| LOCAL | Local / County (includes health departments) |
| LTC | Long-term care settings (other PACE, NH, AL) – can include any reference to another LTC setting |
| PROVIDE | Provider organizations (excluding of own personal setting) |
| STATE | State (NCDHHS, DHHS, NC SPICE); includes reference to state regulators |
| VEND | Vendors – can include temporary workers |
| **INFECTION** | |
| COVID | COVID cases/outbreaks in the setting/organization |
| EDUCATE | Education/training related to COVID |
| INF PRACT | Infection prevention/control practices (includes social distancing, isolation) |

| | |
|---|---|
| INF RES | Resources to prevent infection, or lack thereof (e.g., PPE); resources can be physical or personnel |
| SCR/TEST | Screening, testing |
| TRACE | Contact tracing |
| **MEDICAL and MENTAL HEALTH** | |
| MED | Medical care or medical care providers |
| MED STATE | Medical and functional status (health, function) |
| MENT CARE | Mental health care (includes recreation, social engagement) |
| MENT PRO | Mental health providers |
| MENT STATE | Mental health (includes psychological well-being) |
| **OPERATIONS** | |
| CARE | Overall care or business model (e.g., differentiating self from other care settings) |
| CENSUS | Census/occupancy (includes narrative about family taking care recipient out of the setting) |
| FINAN | Finances/funding (includes staff salaries, insurance) |
| PHYSIC | Physical/built environment and outdoors (can refer to building, rooms, offices, use of physical space) |
| TECH | Technology; includes telehealth |
| VISIT | Family visits; non-staff visits |
| **PEOPLE** (use only if direct, substantive reference made) *Note: during analysis, look for "resident/participant" deductively* | |
| FAM | Families; often co-coded |
| LEADER | Leadership (clearly refers to or expressly refers to leadership); often co-coded |