

# Perspectives of State Association Leaders During the COVID-19 Pandemic

Debra Parker Oliver, MSW, PhD<sup>1,\*</sup> ,  
Karla T. Washington, MSW, PhD<sup>2</sup> , Jacquelyn Benson, PhD<sup>2</sup>,  
Patrick White, MD<sup>3</sup>, Keisha White, MD<sup>4</sup> , Aja Jones, BA<sup>5</sup>,  
Lindsey R. Debosik, BS<sup>6</sup>, and George Demiris, PhD<sup>7</sup>

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## Background

Hospice care in the United States began as a community movement; however, with the introduction of the Hospice Medicare Conditions of Participation in 1982, it became a formal part of the healthcare system. The original hospice background in volunteerism and not for profit service is an important backdrop in understanding the hospice landscape during COVID-19.

The first hospice in the United States was in New Haven, Connecticut, and began in 1973.<sup>1</sup> Early hospices were community supported and often managed and care provided with volunteers as there was no payment for services. Five years later, the National Hospice Organization was organized largely to advocate for hospice reimbursement and regulation. In 1982, the Hospice Medicare Benefit was enacted as part of the Tax Equity and Fiscal Responsibility Act, providing financial footing for the previously volunteer movement. Shortly thereafter, state associations began forming to organize hospices within a state in an effort to encourage statewide access and manage local hospice regulation and policy issues.<sup>1</sup> For years there was not only a lack of competition in hospice but also a lack of access to this care in many parts of the country. With payment for services, regulations, and standardization of care as well as state licensing, community volunteer service for the dying transformed into a medical specialty recognized in 2008 with Board Certification in Hospice and Palliative Medicine.<sup>2</sup> With the rapid transformation also came important educational, political, and regulatory needs for hospice agencies and their staff.

State hospice and home care associations represent nearly 15,000 hospice agencies coast to coast.<sup>3</sup> The National Hospice and Palliative Care Organization (NHPCO) has within its structure The Council of States, a forum of state leaders that promote and enhance quality end of life care throughout most of the states. There are 48 associations listed on the website directory covering the majority of the United States.<sup>4</sup> Some

states have more than one association as a member in the Council of States and some state associations represent more than one state.

The hospice industry, like all of healthcare, has been hit hard by COVID-19.<sup>5</sup> As a provider focusing largely on care delivered in the home, the challenges of delivering care to dying patients, all fragile, and some with COVID-19 is well documented. Additionally, hospice provides care to those dying in long term care facilities. In the early part of the pandemic, hospice agencies were unable to visit their patients in nursing facilities as were families of those in nursing home residents. At the same time, the demand for hospice rose dramatically as more people wanted to die at home and wanted to avoid the hospital or nursing home settings.<sup>6</sup>

<sup>1</sup>Ira Kodner Professor of Research in Supportive Care, Division of Palliative Medicine, Department of Medicine, Washington University in St Louis, St. Louis, MO, USA

<sup>2</sup>Division of Palliative Medicine, Department of Medicine, Washington University in St Louis, St. Louis, MO, USA

<sup>3</sup>Stokes Family Endowed Chair and Chief, Division of Palliative Medicine, Department of Medicine, Washington University in St Louis, St. Louis, MO, USA

<sup>4</sup>Department of Pediatrics, Washington University in St Louis, St. Louis, MO, USA

<sup>5</sup>Department of Psychological & Brain Sciences, Washington University in St Louis, St. Louis, MO, USA

<sup>6</sup>Graduate Student, George Washington University, Milken Institute School of Public Health, Washington, DC, USA

<sup>7</sup>Department of Biobehavioral and Health Sciences, School of Nursing, Epidemiology and Informatics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA, USA

## Corresponding Author:

\*Debra Parker Oliver, MSW, PhD, Ira Kodner Professor of Research in Supportive Care, Division of Palliative Medicine, Department of Medicine, Washington University in St Louis, St. Louis, MO, USA.  
Email: [oliverd@wustl.edu](mailto:oliverd@wustl.edu)

## A Conceptual Model For Understanding Change: Associations and Civil Society

There are many challenges for community based charitable services as they transform into a healthcare business. The community roots in hospice meant the local service was rooted in civil society. This historical context lead hospice agencies to collectively create various non-for-profit associations based upon their common needs. French sociologist and political scientist Alexis de Tocqueville saw associations as having two roles: a means for solving collective problems and a means of having individuals focus on something larger than their individual circumstances to work together for a greater good. He believed that associations were critical to the civil society and the success of democracy. Consistent with this historical perspective, associations of all types appear throughout the United States, each with a mission to serve its members and promote the collective good.<sup>7</sup>

It is similar with healthcare associations, including those in hospice and palliative care. A voluntary collection of individuals and organizations with the same collective interests come together for the common good of the members to create change and foster collaborative success. The nature of the mission of associations requires them to understand the issues and concerns facing their members. There are international, national, state and regional hospice, and palliative care associations. These organizations have formed with the mission to organize, advocate, and educate their members. They hold a wealth of information and insight on the current state of hospice care given their exposure to numerous programs.

This study sought to better understand the challenges facing hospices during the COVID-19 pandemic by sampling their association leaders to answer three research questions. First, in light of the many changes in hospice care what are the current challenges facing state hospice associations following the COVID-19 pandemic? Second, what challenges are individual hospice agencies facing that impact state associations? Finally, how are state hospice associations adapting to these challenges?

## Methods

This study was approved by the University Institutional Review Board. Using the NHPCO Council of States Directory we interviewed state hospice association leaders to learn about their organization, their members and the challenges they face following the COVID-19 pandemic. Association leaders were contacted by email using the online directory and asked for consent to be contacted to schedule an interview. Interviews were conducted by graduate students (AJ and LD) who were trained using role play prior to making calls. Interviews were audio recorded and lasted approximately 60 minutes. Participants were offered \$50 for their time. The interviews were transcribed and coded using a Framework Analysis method which codes data with a pre-established theoretically based

and operationally defined coding framework.<sup>8</sup> The interview questions asked about the history and organization of the association, the association challenges and challenges facing their member hospices (see [Table 1](#)). Using the pre-established coding framework, a two-step coding process was implemented based on the Framework analysis qualitative coding technique.<sup>8</sup> Two coders independently coded two interviews each and discussed their codes. The remaining interviews were then coded independently and compared. A handful of differences were discussed and consensus was reached. The first step in coding was to read and code narratives into the pre-established framework parent codes based on the interview questions. A second step involved analyzing each of the parent codes and further defining themes or child codes that provided more specificity to the parent code. Trustworthiness was built into the process by co-coding and member checking of the findings (one participant and both interviewers reviewed findings).<sup>9</sup>

## Results

### Participants

The sample represented nearly 50% of all state associations in the Council of States. The sample represented nearly 50% of all state associations in the Council of States Directory. [Table 2](#) shows there were 21 states served by 19 state associations and represented by 21 association leaders who agreed to be interviewed (Some associations serve more than one state). The gender of participants was equal. The gender of participants was equal. [Table 3](#) summarizes participant characteristics. Participants were largely Executive Directors (41%) but also there were Board Chairs (18%), CEO/Presidents (18%), Hospice Directors (10%), and Board Members (10%). Slightly more than half of the participants had graduate education (55%) while the remaining had undergraduate college degrees. There was a significant number of interviewees (41%) who had more than 10 years of experience with their association.

### Themes

Themes emerged in two overall categories. The first were themes related to the association itself. These themes involved the history and administrative structure of the association and the challenges the association is currently facing. The second category involved the association member hospice agencies and their challenges.

### State Hospice Associations

**Structure.** State associations are organized in a variety of ways but all reported having a Board of Directors which consists of volunteer leaders, often elected, from the membership. Most hospice associations have very small paid staff to implement the day to day running of the organization. In most cases the Board of Directors

**Table 1.** Interview Questions for State Hospice Association Leaders.<sup>1</sup>

First, I'd like to ask some basic demographic questions

- What is your current age?
- What is your gender?
- What is your position with your Hospice Association?
- How many years have you worked with your Association?
- What is your highest educational degree?

Now that we have an understanding about you I'd like to ask you about your Association.

1. I'd like to start by asking you about your Hospice Association?
  - a. What criteria do you have for membership?
  - b. How many hospice agencies are members?
  - c. What states/regions do you represent?
2. Can you share a brief history of your Association?
  - a. When did it start?
  - b. What was its founding purpose?
  - c. How has it changed?
3. What is the organizational structure of the Association?
  - a. Do you have a Board of Directors?
  - b. Do you have a President of that Board? Might they be interested in talking with me as well and can you share their contact information?
  - c. How involved is your Board in the day to day operations?
  - d. Do you have a Medical Officer?
4. How involved are you with the NHPCO Council of States?
  - a. How is this organization helpful?
  - b. Do you regularly attend their meetings?
5. What benefits does your association provide to its member agencies?
6. What are the top three challenges your Association faces at this time?
  - a. Do you have a strategic plan on how to manage these?
7. What are the challenges your members face at this time?

**Table 2.** Summary of Association Leaders Participating. N = 21 leaders of 19 Associations representing 21 states.

Association	States
Home Care and Hospice Association of New Jersey	New Jersey
Home Care and Hospice Association of Utah	Utah
Ohio Council for Home Care and Hospice	Ohio
Home Care, Hospice and Palliative Care Alliance of New Hampshire	New Hampshire
Washington State Hospice and Palliative Care Organization	Washington
The Carolinas Center for Hospice and End of Life Care	North Carolina South Carolina
Hospice Council of West Virginia	West Virginia
Idaho Health Care Association	Idaho
Kansas Hospice & Palliative Care Organization	Kansas
Connecticut Association for Healthcare at Home	Connecticut
Hospice & Palliative Care Association of Arkansas	Arkansas
Louisiana Mississippi Hospice and Palliative Care Organization	Louisiana Mississippi
Michigan Homecare & Hospice Association	Michigan
Home Care & Hospice Association of Colorado	Colorado
Maine Hospice Council & Center for End of Life Care	Maine
Illinois Hospice & Palliative Care Organization	Illinois
Hospice & Palliative Care Network of Maryland	Maryland
Alabama Hospice & Palliative Care Organization	Alabama
Florida Hospice & Palliative Care Association	Florida

**Table 3.** Interview Participant Table n = 21.

	N (%)
Gender	
Male	10 (48%)
Female	11 (52%)
Position	
Board Chair	4 (19%)
Executive Director	9 (42%)
CEO/President	4 (19%)
Hospice Director	2 (10%)
Board Members	2 (10%)
Education	
Bachelors degree	9 (42%)
Masters Degree	10 (52%)
Doctoral Degree	2 (10%)
Years in position	
0–5	6 (29%)
6–10	5 (24%)
More than 10	9 (42%)
unknown	1 (5%)
States represented	21

do not handle the day to day issues but oversee the strategic direction of the organization. As one association leader noted:

The board is not involved in the day-to-day operations very much at all. Their role is primarily in a strategic capacity. Now, I do reach out to my board members quite regularly to get direction and insight, and input on different things happening at the association.  
Participant 103

### *Evolving Mission*

There was agreement among all the association leaders that the mission of state associations has changed since their initial formation. In the early days these civic organizations were formed to help build hospices across the state and assure everyone in the state had access to hospice care. Later, they became the educational hub for hospice continuing education and state advocacy issues. Today's association is searching for an identity as once again, the industry is changing. Many hospice associations have merged with home care, nursing home, or other associations as a fiscal means of survival. Hospice agency mergers have resulted in large national corporate hospice organizations with many branch officers. These national hospice corporations are managing their own education and are not as invested in the regulatory issues within a specific state. Instead national hospice corporations tend to focus more on national policy concerns. One leader explained:

... traditionally, 20 years ago, it used to be more just education. It was providing ... hospice education to providers. The founding, really, mission of [state hospice association], over the years, we've really

expanded, and we say we have a three-fold purpose.... our mission itself is to protect people's rights and access to care by supporting and promoting [name of state] home-based health, hospice, and personal care industries. Our three-fold mission is really education, advocacy, and community outreach. We've done a lot more for advocacy and working with the community over the years. Participant 102

Another leader shared a specific example:

... membership has changed significantly over the years, and that's due to a trend—it's going on across the country, but a trend for agencies to merge and be acquired by other agencies for economies of scale and costs. Just as an example, I told you there's 24 hospices in [state]. There were 32 just 2 ½ years ago. Participant 203

### *Association Challenges*

There was consensus among leaders that the top challenge for the state association is sustainability. Having depended on membership fees and income from annual conferences, state associations are discovering they need new revenue streams to make ends meet. Memberships are falling and the needs of members are changing, causing associations to rethink their mission and redesign how they stay sustainable. Having been built largely on revenue from memberships and educational events, those options are becoming limited as hospice agencies merge and education is available from corporate affiliations. One association leader lamented, "*The majority are not dues paying members anymore*". (participant 208). Another leader described the challenge:

I will be quite honest with you. Because it's not mandatory for a provider to be a member of an association, so it's voluntary, and so you have to prove value every single day. I try to keep abreast of what their needs might be. ... when we started years ago, hospices were just getting into the hospice arena, and so, when you think about 40 years ago, when hospice was just getting started in the [state], hospices didn't have access to everything that they have now. When you see programs growing, when they're able to have more staff, when they are members of the national organization and they have a staff that can actually can be nimble and do the things that they need done, they may not always feel like they need the association. Participant 107

When we inquired with leaders about innovative services now being offered or strategies for sustainability. The most common response was a more toward webinars as a less expensive more accessible method of providing education. This method was reported to meet with mixed success. There were three leaders who were focusing on grant writing to help supplement their work. Finally, two leaders spoke about innovative programs they were trying. One state association leader has hired a Director of Community Relations to expand community engagement in their member hospices as a new service focus. Another state association reported developing a free membership category for community citizens. Their goal was to get the community

engaged in advocacy and policy change. These were the only new strategies expressed by any program.

### Association Members

The criteria for membership in the state association are fairly consistent across associations. Members pay the dues and provide hospice care and they can belong. There were three associations that also required acceptance of a code of ethical conduct. When asked what the top three problems for their member hospice were all but one association ranked staffing as the first or second challenge for their members. Hospice staffing has hit critical levels and in some cases patients have had to be turned away or placed on a waiting list. Payment for hospice has remained fairly stable for several years. This stable reimbursement has meant that wages have not increased at the same pace that wages in the private sector has and there is agreement they need to rise in all positions. The home health aide position was identified as especially problematic because the employment opportunities outside of healthcare, including fast food, starting wages are now paid higher than the current nurse aide job in hospice. One participant explained:

I know that staffing is by far the biggest challenge everybody has. They can't hire enough people to serve the need, and then we're starting to see burnout where the people that are there are being overworked because they're just as anyone else. Staffing is by far the number one thing. I think if you were to call agencies, they would say that's number one. Participant 103

The second most concern mentioned for members is the mergers and acquisitions. The merging and realigning of hospice agencies have impacted both the state association, by reducing the number of hospices that can join, but also the member agencies who have to adapt to agency policy and leadership changes. The merger and acquisitions were said to be stressful as they are outside the control of the association and the individual hospice staff member, yet they have tremendous impact on their lives. A hospice leader explained:

Mergers and Acquisitions are a constant challenge for us, and one that we continue to keep up on. For instance, many of these mergers take a few years to fully implement. We may have a connection with the leadership who is a part of the organization acquired, but they're somewhat powerless with essentially the new powers that they gave to the new multistate organization that they have turned their organization over to. Participant 206

### Discussion

The most recent hospice statistics published by NHPCO in 2020 report that in 2018 there were 4639 Medicare hospices providing care with an average daily census of 67 patients and a median census of 31.8. Of those Medicare certified programs nearly 70% were for profit, a nearly 25% increase over the

previous report. Given these responses by state association it is expected those numbers will change dramatically with the next report. Given the challenges identified by the association leaders, it might be expected that fewer hospices will be documented and most likely the ones remaining will have larger average patient census. These statistics are pushing state associations to redefine their role and rethink their strategic plans. Individual hospices are having to justify their membership to national headquarters and this is becoming more and more challenging.

Given the fiscal problems reported by associations and individual hospices, association leaders state they are challenged to meet the needs of their members; meanwhile, local hospices are faced with having to advocate and justify membership with their corporate executives. To survive, state associations are rethinking their purpose and mission. Historically, association missions focused on working with state members to solve common problems, given the new corporate leadership of hospice agencies, associations may need to refocus now on working together with their hospices to collaborate for the common good. Given the staffing problem was reported as the most identified issue for member hospices, associations may benefit from a focus on hospice staffing.

While representing the views of nearly half the state hospice associations, generalization of these data should be done with caution. There were differences in states that have several small rural hospice agencies and those with more large urban agencies. The common theme of staffing however ran throughout all states. A state association that can find a way to help their members with staffing issues may be have the best justification for hospices to belong. There is also a need for innovative programming, again doing things that benefit all hospice members more effectively than they can do themselves. This aligns with Tocqueville's suggestion that associations collaborate for the common good.<sup>7</sup> Finally, it is worth noting that it is not only hospice associations that face these challenges, it is all health care associations. Healthcare, like hospice, is in transition and the same mergers and acquisitions facing hospice can be found in other associations, creating the same issues. One response has been to merge associations, hospices and health care in general has done this by merging nursing home associations with hospice and home care associations. If Tocqueville is correct and these associations are critical to the civil society, we all have a vested interest in their redefinition and continued realignment with society change.

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### ORCID iDs

Debra Parker Oliver  <https://orcid.org/0000-0002-8354-0859>

Karla T. Washington  <https://orcid.org/0000-0002-1100-9524>

Keisha White  <https://orcid.org/0000-0003-2643-1303>

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