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ACO Serious Illness Care: Survey And Case Studies Depict Current Challenges And Future Opportunities

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ABSTRACT Care for people living with serious illness is suboptimal for many reasons, including underpayment for key services (such as care coordination and social supports) in fee-for-service reimbursement. Accountable care organizations (ACOs) have potential to improve serious illness care because of their widespread dissemination, strong financial incentives for care coordination in downside-risk models, and flexibility in shared savings spending. Through a national survey we found that 94 percent of ACOs at least partially identify their seriously ill beneficiaries, yet only 8–21 percent have widely implemented serious illness initiatives such as advance care planning or home-based palliative care. We selected six diverse ACOs with successful programs for case studies and interviewed fifty-three leaders and front-line personnel. Cross-cutting themes include the need for up-front investment beyond shared savings to build serious illness infrastructure and workforce; supporting the business case for organizational buy-in; how ACO contract specifications affect savings for serious illness populations; and using data and health information technology to manage populations. We discuss the implications of the recent Medicare ACO regulatory overhaul and other policies related to serious illness quality measures, risk adjustment, attribution methods, supporting rural ACOs, and enhancing timely data access.

Caring for people living with serious illness remains a key challenge for US health care reform. People with serious illness receive care of varying quality, and the care often is fragmented,^{1,2} does not reflect patients' goals,^{3,4} and does not adequately address patients' pain and symptoms.¹

People living with serious illness are those with a condition with high risk of mortality or multiple comorbid complex conditions, high health care utilization, and limited function.³ They require medical and social services delivered across multiple settings.⁴ The fact that in-

sufficient numbers of providers are trained in palliative care, hospice, or general geriatrics further complicates care delivery.⁵ Notably, fee-for-service reimbursement does not incentivize needed infrastructure and services, such as 24/7 access outside of emergency departments (EDs), patient and caregiver education, care coordination, and shared decision making.⁶

Accountable care organizations (ACOs) offer the potential to improve serious illness care nationwide, given that 1,011 ACOs cover almost thirty-three million people.⁷ ACOs—especially those participating in models with downside financial risk, which encourage movement away

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from fee-for-service reimbursement⁸—have strong incentives to coordinate care, avoid unnecessary hospitalizations and ED visits, and develop meaningful data and analytics. Beginning July 1, 2019, all Medicare ACOs entering new contracts will be required to participate in downside risk earlier,⁹ increasing the impetus for care redesign efforts that pay off. Organizations debating whether to invest in a palliative care workforce may consider the ACO model a potential venue to do so, given its financial flexibility that allows investment in new infrastructure. Limited extant case studies show this potential: Integra Community Care Network, Mayo Clinic, Moffitt Cancer Center, OSF HealthCare, ProHEALTH, and Sharp HealthCare ACOs have implemented promising pilots in home-based palliative care and integrating palliative care into primary care.^{10–15}

Despite promising steps, these ACOs are among the very few to innovate and succeed in serious illness care: The field shows slow progress.^{16,17} This is because few ACOs are moving toward more advanced models involving the downside risk necessary to encourage substantial care redesign⁷ and because early evidence shows that ACO savings are coming from broad interventions rather than ones focused on high-risk patients.¹⁸

The untapped potential of ACOs to improve serious illness care underscores the need for a better understanding of organizations that do this well under models with more significant shifts away from fee-for-service payment. In this study we took a multimethod approach to identify best practices and lessons learned, understand workforce capabilities and solutions, and outline the business case and strategies to scale initiatives.

Study Data And Methods

SURVEY DATA We first present results from the 2018 Annual ACO Survey conducted by Leavitt Partners and the National Association of ACOs, fielded in April–July 2018, with a response rate of 20 percent ($N = 203$). This survey included structured questions that assessed the breadth of implementation of serious illness care initiatives and free-response questions to provide context for themes later identified in the cross-case study methodology described below. The conditional response rate to these questions was 84–93 percent ($n = 171–188$). Online appendix exhibit 1 contains questions and additional details on survey methods and response.¹⁹

CASE STUDIES Simultaneously, we identified twenty-nine ACOs with serious illness initiatives by reviewing literature, analyzing public ACO

data and online information about ACO programs, and soliciting expert recommendations (including through convening forty stakeholders). We selected six ACOs for case studies that had advanced programs for serious illness care; had sustained success in performance metrics (savings, quality, and so on); had not been studied previously for their serious illness programs; and were diverse in terms of geographic region, urbanicity, size, leadership structure, and payers.

We worked with each case-study ACO to select interviewees with knowledge on one or more of the following topics: historical context and organizational change; financing, operations, and the business case; “on the ground” care delivery and challenges; data and health information technology (IT); and quality measurement, quality improvement, and regulatory compliance. Interviewees included ACO leaders (CEOs and other senior officers) and front-line serious illness care providers and coordinators. We used a semistructured interview guide developed from the literature review, and we conducted thirty-six interviews with fifty-three people, mostly during on-site visits. Collectively, the interviews took thirty-five hours, and we interviewed six to thirteen people per ACO. The interviews were recorded and transcribed. The six individual, in-depth case-study reports are available online.²⁰ We synthesized emerging themes from interview transcripts using team-based consensual qualitative research methods²¹ (drafting high-level theme memos for each ACO, having a team of people from diverse backgrounds independently interpret and confirm findings, using debriefing to discuss findings and address discrepancies, and further reducing and synthesizing findings across the memos into cross-cutting themes). In the results, “many” refers to points echoed by roughly half or more ACOs, and “some” refers to points discussed by fewer than half of ACOs, but those ACOs felt strongly about the particular issue.

LIMITATIONS Our study had two key limitations. First, the survey response rate was low (20 percent). Responders were less likely to be commercial ACOs and hospital-led compared to the known population of 1,011 ACOs in the Leavitt Partners ACO Database but were similar to the known population of ACOs by size (number of covered lives) and geographic region. Second, the case-study ACOs were not intended to represent all ACOs but were selected to be diverse. The themes we derived from the case studies provide rich contextualization to illustrate how these ACOs built successful serious illness programs.

Study Results

NATIONAL LANDSCAPE OF ACCOUNTABLE SERIOUS ILLNESS CARE Ninety-four percent of the survey respondents reported “partially” or “widely” implementing strategies to routinely identify their serious illness population (exhibit 1). Implementation of serious illness care programs was substantially lower in prevalence, with 8–21 percent widely implementing any particular one. The least widely implemented initiative was community-based palliative care, followed by advance care planning, hospital-based palliative care, and 24/7 clinical response efforts. Fifty-eight percent of the respondents reported partially implementing advance care planning services, but only 30–38 percent partially implemented one of the other interventions.

The survey results highlight a research question for our qualitative component: Why are many ACOs working on routinely identifying their seriously ill patients, yet few widely implement serious illness care programs? From the six case studies, we sought to learn how these ACOs functioned, what they were doing successfully, and what major challenges they had encountered, so that more of the 1,011 existing ACOs could develop such programs and improve the serious illness workforce.

QUALITATIVE ANALYSIS OF SERIOUS ILLNESS CARE BY ACCOUNTABLE CARE ORGANIZATIONS

Some of the six case-study organizations identified themselves as ACOs, while others had a mixture of ACO and at-risk contracts and identified themselves as broadly delivering accountable care (exhibit 2). Half of the serious illness programs included care in the home (one had such care as its entire ACO program). The other half used a higher-touch adaptation of complex care management not in the home. Programs generally involved high frequency of patient contact (in-home or via telemedicine or phone calls) that tapered off as patients’ needs and utilization stabilized. All programs worked to connect patients to community resources that addressed social determinants of health (such as legal assistance, food insecurity, housing, and transportation), often hiring social workers or community health workers.

The following sections summarize five key themes that emerged from case-study interviews (exhibit 3).

► **UP-FRONT INVESTMENT NEEDED TO BUILD INFRASTRUCTURE AND WORKFORCE:** ACOs emphasized that general ACO infrastructure can cost a million dollars or more, and infrastructure for serious illness care requires additional capital.

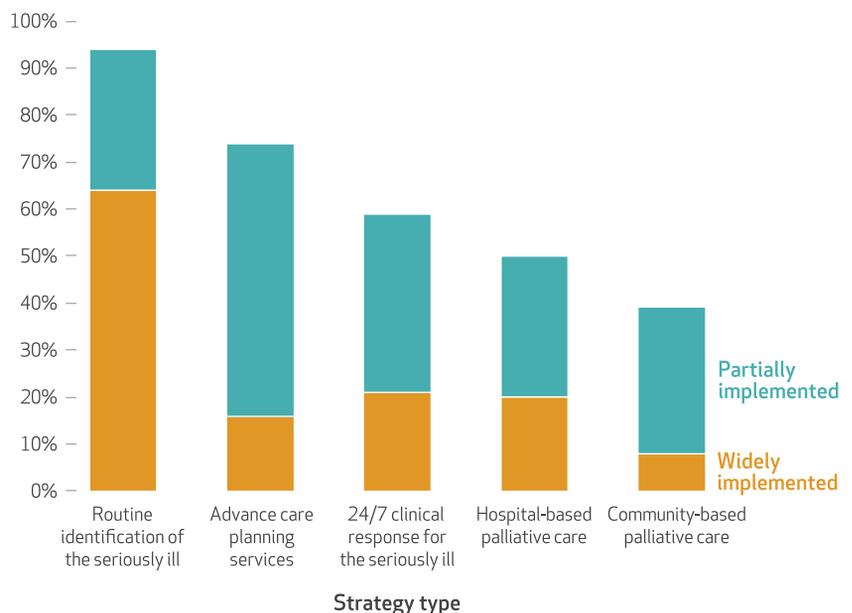
First, most interviewees identified funding data infrastructure as a key challenge because

it requires up-front capital, whereas an ACO’s shared savings are in the future and not guaranteed. Safety-net and rural ACOs often sought grants for pilot programs, while ACOs from larger systems leveraged funding from their parent organizations. Others received capital from management organizations that aggregate small practices into ACOs. All ACOs tried to identify existing infrastructure that could be leveraged (such as from existing patient-centered medical homes). Several started with pilots that focused on common conditions (such as congestive heart failure or chronic obstructive pulmonary disease) and then gradually expanded.

Second, there was a consistent need to build a workforce with expertise beyond standard care management, adding care coordinators, social workers, and so on—who may be poorly reimbursed under fee-for-service. ACOs varied in whether they used in-house palliative or hospice clinicians or partnered with external organizations. In-house services allowed ACOs to reap efficiencies, yet they required up-front capital and start-up time and thus involved risk. As a result, several ACOs worked with external palliative care or serious illness organizations under contract arrangements. One member of an ACO’s palliative care group noted: “Less than a year prior, our organization...received signifi-

EXHIBIT 1

Percent of ACOs that implemented serious illness identification or care strategies, by strategy type and breadth of implementation, 2018



SOURCE Authors’ analysis of data for 2018 from the Annual ACO Survey, conducted by Leavitt Partners and the National Association of ACOs. **NOTES** Survey respondents were allowed to interpret the definition of what constituted “widely” and “partially” implemented strategies. Additional information on the survey methods and responses is in the online appendix (see note 19 in text).

EXHIBIT 2

Overview of the case-study accountable care organizations (ACOs), their serious illness programs, and key results and outcomes

Case-study ACO	Summary of ACO	Description of serious illness work	Key results and outcomes
US Medical Management	Physician group-led ACO with an MSSP contract; headquartered in Troy, MI, and operating in 12 states.	Home-based primary care focused on patients limited to their home or a facility.	Achieved shared savings every year in the MSSP; \$46 million in net savings in 2017.
Presbyterian Healthcare Services	Statewide integrated delivery system and medical group in NM; has multiple ACO contracts and general accountable care approach.	Complete Care program serves high-need patients with primary, urgent, palliative, and Hospital at Home care in the home or clinic; provides RN case management, social work support, advance care planning, and 24/7 support.	Decreased cost by 38% per member per month, compared to predicted cost for similar populations; 16% of Complete Care patients received an urgent home visit each month to avoid ED visit or hospitalization.
NYC Health + Hospitals, HHC ACO Inc.	Hospital-led ACO; part of the largest public hospital system in the US, whose patient population has a large fraction of people who are on Medicaid or uninsured; has MSSP contract.	Identifies complex and seriously ill populations through a data dashboard that synthesizes claims, clinical, and administrative data; addresses social needs, including housing, legal assistance, food insecurity, and transportation.	Generated shared savings every year in 2013–17; reduced ED visits per 1,000 person-years by 10% since 2013; achieved an average composite quality score of about 90% in 2015–17 and was in the top 5% of ACOs for measures such as screening for clinical depression and use of statin therapy.
Facey Medical Group	Physician-led ACO based in the Los Angeles, CA, region; has multiple full-risk contracts (including commercial ACOs) that cover about 70% of its patients.	Community-based palliative care program for seriously ill patients, including a 24/7 call center; palliative care team includes a physician trained in palliative care, a nurse practitioner, care managers, social workers, and providers of spiritual support.	Achieved savings in almost all of the 6 years it has existed; key palliative care results include high patient satisfaction, 68% fewer hospitalizations, and 55% fewer ED visits.
MaineHealth	ACO with hospital and physician participants and Medicare and commercial ACO contracts; covers lives across ME and northern NH, including urban and rural areas.	Complex care team consists of nurse care managers, social workers, and health guides; the team educates and engages patients and helps with care management and medication adherence; the MaineHealth ACO has multiple protocols and guidelines for different common conditions, including heart failure and COPD.	MSSP expenditure per beneficiary is 6% lower than national fee-for-service Medicare expenditure; quality scores above 90% every year in the program; preliminary results of their SNF heart failure protocol show a readmission rate of 10% for patients on the protocol versus a baseline rate of 20.1% prior to protocol implementation.
Vidant Health, Coastal Plains Network	Physician-led ACO in eastern NC; has MSSP contract; patient population is largely rural and underserved, with many social needs.	Provides telehome monitoring to reduce utilization for rural patients with complex chronic conditions; aligns all care interventions that provide services to high-risk patients; has outreach programs to faith communities to help address social risk factors.	Generated shared savings in 2 of 3 MSSP years of 3.6–4.5% (had net savings all 3 years); reduced readmission rates from 10.0–20.0% or more to 1.5–5.0% after beginning serious illness work.

SOURCE Authors' analysis of key-informant interviews from the case-study organizations listed in the table and of publicly available information on the ACOs and their performance. Full case-study documents for each ACO in the table are available from Duke-Margolis Center for Health Policy. Serious illness and accountable care organizations (see note 20 in text). **NOTES** MSSP is Medicare Shared Savings Program. RN is registered nurse. ED is emergency department. COPD is chronic obstructive pulmonary disease.

cant grant funding from a local philanthropic organization [for] launching community-based palliative care...so when [the ACO] approached us, we were...already about eight months into programming. And we were able to say, "Yes." In external contracting, ACOs could directly fund salaries of the serious illness team (bearing all risk but accruing all shared savings) or could provide a per member per month rate (with less risk but with savings passed on to the care team).

► **BUSINESS CASE FOR ACCOUNTABLE SERIOUS ILLNESS CARE:** The survey results suggest that almost all ACOs are considering targeting seriously ill populations, yet few have dedicated care programs—which suggests that the business case is underdeveloped. According to the case-study ACOs, the business case often centered on three things. First, seriously ill patients account for a substantial amount of the total cost of care, yet much of their utilization is consid-

EXHIBIT 3

Cross-cutting themes for accountable care organizations (ACOs) in providing serious illness care and associated challenges

Theme	Challenges
Making a business case: showing short-term return on investment using financial flexibility from ACO shared savings; building on existing infrastructure and projects.	Return on investment is difficult to estimate; hospital-led ACOs have lower revenue if they reduce hospitalizations.
Obtaining organizational buy-in: emphasizing culture, history, and mission; “the right thing to do.”	Hard to get buy-in and change culture without organizational champions; while providers respond to professional and ethical incentives, leaders may need financial incentives.
Structuring an ACO contract: contracts use different methods to calculate shared savings and to determine which high-expenditure patients to include; benchmarks and risk adjustment differ and are evolving; choice of attribution methods (prospective or retrospective) affects the business case.	Current risk adjustment often underestimates expenditures for seriously ill patients; high patient mortality can reduce the attribution of seriously ill patients to the ACO; current quality measures do not capture concepts that are important to seriously ill patients.
Data and health IT: contracts often allow access to claims data; ACOs are building data tools and dashboards to identify the actionable population and facilitate care coordination; there is a need for near-real-time data for care management, such as from HIEs.	Expensive up-front investment; serious illness identification is work in progress, and available data have limited sensitivity; HIEs are not available in many states; interoperability between EHRs remains an issue for communication between the palliative care team and other clinicians.
Building viable infrastructure and sufficient workforce: multiple (often new) workforces, health IT, and other infrastructure are required to start a serious illness program; various workforce models are used for serious illness teams and with in-house and partner organizations.	Start-up costs for an ideal infrastructure for ACO serious illness care can be high; it can be hard to pay for infrastructure without grants or capital from parent organizations.

SOURCE Authors’ analysis of key-informant interviews from case-study organizations, supplemented with context from other published case studies (see notes 10–15 in text); free-response questions in the 2018 Annual ACO Survey, conducted by Leavitt Partners and the National Association of ACOs; and expert recommendations. **NOTES** HIE is health information exchange. IT is information technology. EHR is electronic health record.

ered unnecessary and harmful. Second, the ACO model provides new tools: Necessary serious illness services have limited fee-for-service reimbursement, and shared savings in the ACO model provides flexibility to invest in them and the necessary workforce regardless of the fee schedule. Third, while other ACOs have focused on reducing low-value care across all patients, some ACOs interviewed were already functioning efficiently across their general population, and focusing on their seriously ill patients was the path to improving value. One interviewee summarized the case made to leaders: “A lot of it is rooted in...[the] top 5 percent responsible for 45 percent of the expenditures.... That’s why we need to do things differently for this 5 percent.” Hospital-led ACOs faced additional challenges if interventions reduced “heads in beds,” though some interviewees emphasized that this may be financially overcome by reducing (or eliminating) readmissions penalties or by greater patient loyalty to their health system.

To counteract challenges in calculating a return on investment, many ACOs tracked utilization surrogates such as hospitalizations, readmissions, and ED visits. Those concepts resonated with ACO leaders and were within organizations’ existing capabilities to generate. Such measures were also seen as quality proxies. While many ACOs cited a positive return on investment from their serious illness efforts,

others felt that their return on investment was lower than expected even when positive. One reason was that ACOs had challenges in identifying an accurate control group, and these programs were young. Finally, it was difficult to value indirect savings (for example, provider efficiency) or noneconomic impacts (such as improved patient satisfaction).

► **ORGANIZATIONAL BUY-IN FOR SERIOUS ILLNESS CARE:** Many ACOs drew on an existing organizational culture of caring for the seriously ill to implement their programs. They noted that they provided serious illness care because it is “the right thing to do,” and they identified how serious illness care fits into their mission. Leaders used different historical arguments to bolster their serious illness culture. One leveraged an organization’s history as a tuberculosis ward a century ago.

These ACOs noted that at the provider level, clinicians are mission driven and respond to ethical and professional incentives, so this argument resonated strongly. One ACO leader said that “we’re just doing it because it’s the right thing to do. Period. For the patient,” and that the business case would improve as more and better data are accumulated.

► **STRUCTURING THE ACCOUNTABLE CARE ORGANIZATION CONTRACT FOR SERIOUS ILLNESS CARE:** Contracts between payers differ in the technical details, and ACOs noted that these var-

iations had a significant impact on how they approached serious illness care. First, multiple methods exist for excluding outlier high-expenditure patients from the shared savings calculation. Second, financial benchmarks can be risk-adjusted differently for the overall health of an ACO's population. The most popular is the Hierarchical Condition Categories model, which some ACOs believed underestimated costs for their highest-risk patients. Third, the ACOs disagreed on whether historical or regional benchmarks were more appropriate based on risk-adjustment challenges. Fourth, whether beneficiaries were attributed to the ACO retrospectively or prospectively, and whether patients treated in skilled nursing facilities were counted toward attribution, affected the number of seriously ill patients attributed in the same population. Finally, quality measures to evaluate ACO performance in many models were designed for general population health and might not be applicable to the seriously ill population.

► **DATA AND HEALTH INFORMATION TECHNOLOGY—IMPORTANT FOR SUCCESS BUT COSTLY:** ACOs viewed access to actionable data as necessary for identifying and tracking their serious illness populations, measuring results, and prioritizing efforts. Some ACOs entered the Medicare Shared Savings Program (MSSP) to access claims data (though quarterly lags in Medicare data can limit their utility). Health information exchanges, established in many states, provided ACOs with significant value, delivering near-real-time “actionable” data that allow providers to coordinate patients’ hospital and ED care and prevent unnecessary readmissions. One interviewee summarized, “[In] any state that has unified hospitalization exchange...we know who went in the hospital, we can go visit them in the hospital, make sure they get discharged back to home.”

As demonstrated by the survey results, almost all ACOs undertake efforts to identify people with serious illness. Case study and survey responses indicated substantial diversity in identification algorithms. Many ACOs developed homegrown algorithms to identify patients with high utilization and severe (or multiple) chronic conditions, with some ACOs also using proxies to assess functional limitation (for example, medical equipment use) and social risk (for example, ZIP code changes as an estimate of housing instability) because direct measures were not available. Others used multiple algorithms (home-grown and external) to stratify populations for potential clinical intervention, such as home-based palliative care, intensive care management, and social supports and services.

Several ACOs were challenged in identifying

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which patients could have their care trajectories changed. Some high-cost patients may always require high expenditures regardless of interventions, whereas others may regress to the mean without intervention—which limits the ability to identify the most appropriate interventions. Multiple interviewees noted that even their most sophisticated efforts remained a work in progress, and clinicians’ identification of patients still helped.

Given care coordination challenges with the serious illness population, ACOs have invested in data dashboards, population health management software, and other data systems that aggregate claims, clinical, financial, and utilization data to allow front-line physicians and care managers to understand where patients are receiving care. Despite these efforts, limited interoperability between electronic health record systems remains a challenge. One ACO found that effective partnering with an external palliative care group depended on the ability of the palliative care clinicians to document directly in the clinical group’s electronic health record; a prior attempt at a similar program with the same palliative care staff did not succeed because their medical documentation could not be seen by the clinical group. Data tools can add burden to providers and meet resistance from them, which some ACOs overcame by engaging providers in tool development.

► **CONTEXT MATTERS:** Lastly, we summarize the contextual factors that ACOs mentioned as having challenged and facilitated dissemination of their serious illness care programs (exhibit 4).

While we cannot generalize findings from these six organizations to all ACOs, they showed contexts where serious illness care can differ. ACOs in rural or urban safety-net settings had greater difficulty investing in new initiatives because of resource constraints. Rural areas also meant scant palliative care and hospice providers spread across large distances. One inter-

EXHIBIT 4**Contextual factors affecting the success of accountable care organizations' (ACOs') serious illness care programs and the opportunity to disseminate those programs**

Contextual factor	Description of issues from ACO case studies on serious illness care
Local market and population context	Challenges building infrastructure in resource-constrained markets (especially rural or safety-net markets); different patient beliefs, needs, and interests depending on culture, health, caregiver access, and engagement.
Institutional context	ACOs and their large organizations vary in their history of delivering serious illness care; large, centralized organizations often have more access to capital, while smaller, decentralized ACOs often have more flexibility.
Regulatory context	ACO contracts vary by payer in benchmarking, stop-loss, risk adjustment, and quality measures; access to data (such as through health information exchanges) varies; serious illness workforce is limited by regulations related to scope of practice and clinical training programs.

SOURCE Authors' analysis of key-informant interviews from case-study organizations, supplemented as explained in the source information for exhibit 3.

viewee said that remote locations even make telehealth hard, as “there are certain areas [where] we can't get internet.” Organizations without long histories of serious illness care had to educate their workforce about the value of such care. ACOs owned by a parent organization felt that they benefited from access to broader infrastructure and a full spectrum of services, whereas ACOs with a more decentralized structure valued their ability to design, adapt, and innovate their programs. Lastly, the case-study ACOs mentioned that regulatory trade-offs—such as payer mix; the availability of health information exchanges; and variation in state laws related to opioid regulation, scope of practice, and clinical training programs—affected the ACO workforce, structure, choice of contracts, and reporting requirements.

Discussion

Our study presents novel survey data on the breadth of serious illness programs in ACOs nationally. The results align with the limited prior research. Sangeeta Ahluwalia and coauthors found that only 20 percent of ACOs had advanced care processes and 60 percent had basic processes,²² which is consistent with our result that 16 percent of ACOs had widely implemented advance care planning (58 percent had partially implemented it). Similarly, Julia Driessen and Turner West found that approximately 25 percent of ACOs in the Medicare Shared Savings Program had contracted with hospice or palliative care physicians,¹⁷ which reinforces our finding that only 20 percent of ACOs widely offered hospital-based palliative care and 8 percent offered community-based palliative care. We found that 94 percent of ACOs reported having at least partially implemented efforts to identify their serious illness population, yet much smaller numbers were widely providing related initiatives. The qualitative portion of our study

showed the various workforce models that ACOs have implemented, including developing competencies in house, contracting with outside organizations, or leveraging other services offered by the organization. Notably, the prevalence of ACOs that provided community-based palliative care in the survey was particularly low, yet half of the case-study ACOs did this and achieved successful performance results. This suggests that investing in a workforce for home-based serious illness care in risk-based models could pay dividends for patients and payers, but more research is needed. The central tension for the ACO is figuring out how fast they can become comfortable with going from modest steps such as identifying patients to more substantial palliative care and support interventions with confidence that they will help avoid other costs.

A first step in implementing serious illness care is making the business case and generating organizational buy-in. Several ACOs were familiar with the general case for palliative and serious illness care,^{23,24} although the survey highlighted competing priorities for infrastructure, capital, and workforce needed for care improvements. The case-study ACOs employed organizational buy-in strategies, many of which are consistent with prior research on achieving change in payment and delivery reform models.²⁵

Beyond organizational change, shared savings provided some financial flexibility to invest in services that are poorly reimbursed by fee-for-service payment. Interviewed ACOs noted that contractual details (MSSP versus commercial contracts, benchmarking, quality measures, and so on) affected the resources and infrastructure available for care improvements. A major contractual consideration for serious illness was the stop-loss provision, which aimed to separate insurance risk (for a sick population) from provider performance risk and reduce the “cherry-picking” of healthy populations. The MSSP stop-loss excludes patients in the top 1 percent

nationally, whereas commercial contracts often exclude patients in the top decile of expenditures or above a negotiated threshold (for example, \$200,000), which affects who to focus on—namely, the highest-risk patients or the “rising-risk” seriously ill populations. One ACO had limited ability to control pharmacy use and no ability to control rapidly rising drug prices for its seriously ill patients, and it considered bringing pharmacy in as a risk partner—a contracting consideration for the field to explore.

ACOs consistently identified infrastructure (data, social supports, or workforce) as a major challenge in providing serious illness care, especially finding up-front capital. Many successful ACOs leveraged resources from a larger parent organization or had a dominant market position, which highlights the challenge for smaller, independent organizations in developing infrastructure. This raises a larger point across themes: While shared savings can provide financial flexibility for serious illness care transformation, shared savings are modest and received in the future (not guaranteed). Work on accountable care reforms both domestically and internationally echoes this theme that up-front investments are needed²⁶ to achieve substantial change and scale up innovation in serious illness care redesign, data, analytics, and workforce.

Our case studies showed that many ACOs built their serious illness programs starting with care management programs, which is consistent with recent findings that almost all ACOs report some care management efforts. Two-thirds reported comprehensive chronic care management,²⁷ which provides a starting point for ACOs to develop serious illness programs that are more high-touch, comprehensive, and specialized.

Policy Implications

Our study has multiple policy implications, especially given the recently published 2018 Medicare Shared Savings Program final rule.⁹ The concern that ACO quality measures are appropriate for seriously ill patients (or potentially harmful, in the case of mammography and colonoscopy, as some ACOs mentioned) is further complicated by the limited current quality measures for this population.^{28,29} Some ACOs thus strategically focused their efforts on a smaller number of required measures. ACOs worked to implement or develop new quality measures in areas such as meeting patients’ goals, the appropriate use of home-based primary or palliative care, or functional assessments, which suggests that innovation is occurring. One ACO partnered with the American Academy of Home Care Medicine to submit pilot serious illness quality mea-

asures to the Centers for Medicare and Medicaid Services (CMS).

Another technical issue is whether common risk-adjustment methodology (Hierarchical Condition Categories scores) underestimates the cost of caring for seriously ill patients,³⁰ causing those ACOs to have lower benchmarks than they should and making ACOs with more seriously ill patients look less efficient than others, as measured by their regional benchmark. CMS’s final rule incorporates regional spending adjustments in the first period,⁹ whereas historical benchmarks largely avoid this issue. This is an emerging issue to watch. One ACO stated, “Now it’s gonna be based on regional [benchmarks].... Because our patients will be under-scored terribly, we will not save money.” CMS’s Programs of All-Inclusive Care for the Elderly (PACE) applies a frailty factor to Hierarchical Condition Categories scores to help address unexplained cost differences in functionally impaired patients,³¹ which could address this issue if applied to ACOs.

ACOs also flagged challenges with attribution methods, such as whether prospective or retrospective attribution differentially captures patients who die, and how recent skilled nursing facility attribution changes affected care management approaches.³² Under the final rule,⁹ ACOs gain an annual choice of prospective or retrospective assignment, which is another emerging topic to watch. Given the longer time frames needed to stabilize seriously ill patients, CMS could also consider multiyear attribution.

Another policy implication concerns rural ACOs. Many ACOs are aggregated across large rural regions or across smaller physician groups to share greater economies of scale, infrastructure, and lessons learned.³³ Rural ACOs can struggle to find capital for serious illness infrastructure, often relying on grant programs—which reinforces the value of continuing programs such as CMS’s ACO Investment Model.³⁴ Rural ACOs with distance challenges may benefit from the new MSSP final rule that allows the greater use of telehealth for ACOs in two-sided risk.⁹

Finally, ACOs flagged the challenge of accessing data. Many relied on state or regional health information exchanges for data, especially through admission, discharge, and transfer (ADT) feeds about hospitalizations and ED care. State governments have played a critical role in creating policies for health information exchanges (such as opt-in versus opt-out consent). Acting on its statutory authority under the 21st Century Cures Act of 2016, the Office of the National Coordinator for Health IT has drafted the Trusted Exchange Framework and Common Agreement³⁵ to create networks that allow

broader health data exchange—which could help ACOs accept risk for serious illness populations.

Conclusion

CMS's recent overhaul of the Medicare ACO program includes faster transitions to higher levels of risk and further movement away from fee-for-service,⁹ which suggests that greater care redesign will be necessary for success. Few ACOs are currently committed to the widespread implementation of serious illness care, despite the potential success of the ACO model. Our study presents novel survey data on the national state of ACOs and aggregates themes from case studies and experts in the field. We show current implementation challenges, including those related to

the workforce, contractual structures, and data infrastructure, along with successful strategies for organizational buy-in and the business case. Changes such as these will become more important as ACOs are required to take more risk, and serious illness programs offer new potential so far untapped by most.

We also show how these programs can be successful in different market, organizational, and regulatory contexts, to illustrate the variety of unique and innovative options that ACOs have to deliver care for seriously ill patients. Such innovation remains critical for accelerating the transition to value-based care that will lower costs while improving outcomes and quality of life for these high-need populations. ■

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