SPECIAL ISSUE: **PALLIATIVE CARE**
FEATURING CONFERENCE COVERAGE: **ACCC**

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THE AMERICAN JOURNAL OF MANAGED CARE®
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RESEARCH & LEADERSHIP

Evidence-Based ONCOLOGY™

APRIL 2020
VOL. 26 • NO. 4

ALSO IN THIS ISSUE

DYING WITHOUT FEAR. Kashyap Patel, MD, oncologist with Carolina Blood and Cancer Care Associates and associate editor of Evidence-Based Oncology,™ has published an account of his efforts to engage patients on the topic that was never covered in medical school: facing death. A review, SPXXX.

CARE CONNECTIONS. A session of the Institute for Value-Based Medicine in Tampa, Florida, with Florida Cancer Specialists covered how payers, oncologists, and leaders in primary care can cooperate for the benefit of patients, SPXXX.

ACCC MEETS. One of the last conferences to take place before in-person medical meetings were canceled, the Association of Community Cancer Centers gathered March 4 to 6, 2020, in Washington, DC. For full coverage, see SPXXX-SPXXX.

TO COME. *AJMC*® catches up with leading physicians and advocates to discuss palliative care and the transition to the Oncology Care First model, SPXXX-SPXXX.

DIGITAL TECHNOLOGY

The Need for a Serious Illness Digital Ecosystem (SIDE) to Improve Outcomes for Patients Receiving Palliative and Hospice Care

Jonathan Nicolla, MBA; Hayden B. Bosworth, PhD; Sharron L. Docherty, PhD, PNP-BC; Kathryn I. Pollak, PhD; Jeremy Powell, MEd; Nichole Sellers, BA; Bryce B. Reeve, PhD; Greg Samsa, PhD; Linda Sutton, MD; and Arif Kamal, MD, MBA, MHS

Introduction

Palliative and hospice care services produce well-known benefits for patients living with serious illness and for their families. Benefits include improved quality of life and reduced symptom burden, spiritual and emotional distress, and caregiver distress.[1] Additionally, when integrated into usual care, palliative and hospice services result in savings to patients, caregivers, payers, and health systems, particularly from reducing avoidable hospital admissions and emergency department visits.[1]

Pillars of Model

CONTINUED ON SP61 »

FRONTIERS IN CARE

Why Palliative Care Is the Answer to the Serious Illness Question in Payment Reform

Maggie R Salinger MD, MPP; Nathan A Boucher, DrPH, PA, MS, MPA; Thomas LeBlanc, MD, MA; Kevin Oeffinger, MD; Kathryn Pollak, PhD; Jesse D Troy, PhD; and Arif H Kamal MD, MBA, MHS

FOLLOWING ENACTMENT OF the Patient Protection and Affordable Care Act, the Center for Medicare & Medicaid Innovation (CMMI) was established to design and analyze payment models that would replace a fee-for-service reimbursement structure. To that end, CMMI launched reimbursement programs that use risk-adjusted budgets alongside quality-driven rewards to promote value and innovation at the care delivery level. These came to be known as alternative payment models (APMs).

CONTINUED ON SP61 »

REIMBURSEMENT

Lack of Clarity on Medicare Advantage Palliative, Other Cancer Care Benefits Limits Consumer Uptake

Ted Knutson and Mary Caffrey

STARTING IN 2019, Medicare Advantage (MA) plans were allowed to change with the times and offer new social benefits to support patients with serious illness or chronic conditions, such as home-based palliative care.[1]

But the lack of clarity about these benefits has limited uptake by consumers, experts say. In December, CMS proposed funding the hospice benefit differently, which would allow MA plans to "carve in" to this benefit. Although some say this could help seniors in the long run, in the near term it has created uncertainty about how the government will fund care for the seriously ill.[2]

CONTINUED ON SP61 »

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The Need for a Serious Illness Digital Ecosystem (SIDE) to Improve Outcomes for Patients Receiving Palliative and Hospice Care

Jonathan Nicolla, MBA; Hayden B. Bosworth, PhD; Sharron L. Docherty, PhD, PNP-BC; Kathryn I. Pollak, PhD; Jeremy Powell, MEd; Nichole Sellers, BA; Bryce B. Reeve, PhD; Greg Samsa, PhD; Linda Sutton, MD; and Arif Kamal, MD, MBA, MHS

CONTINUED FROM COVER

Due to the national shift toward value-based payment models, health systems and payers share a heightened motivation to incorporate palliative and hospice services into their service mix for seriously ill patient populations. For instance, health systems currently leverage palliative care specialists to complement other specialists (eg, pulmonologists, oncologists) as an extension of the care team to "provide an extra layer of support." Palliative care specialists also provide oversight and accountability for patients' issues ancillary to disease-directed treatments.[2] In addition, health systems have integrated community hospice staff into serious illness delivery settings to socialize hospice care benefits with patients early in their disease progressions.[3] However, despite an increased emphasis on these services, many patients who could benefit from palliative and hospice care do not access the care.[4-6]

During the last decade, a tremendous amount of capital has been invested to better integrate information technology into healthcare.[7] These investments include development of technologies to promote utilization or completion of palliative care services and activities. But the entrance of specialized solutions into the marketplace has created a fragmented mobile health landscape, as many solutions have been designed to solve narrow problems.[8,9] For instance, health systems have invested in technologies that specialize in identifying patients with serious illness that, because of increased risk of poor outcomes (eg, hospitalization, death), may benefit from care by specialty palliative care services. Similarly, health systems have invested in technologies that guide patients through completing advance care planning documentation. Although these solutions may solve discrete problems, no coordinated and comprehensive strategy exists to link such efforts together to create a cohesive approach that seamlessly transitions from identification of patients through receipt of palliative and hospice care services.

The Serious Illness Digital Ecosystem

The Serious Illness Digital Ecosystem (SIDE) is the intentional aggregation of disparate digital and mobile health technologies into a single system that connects all of the actors involved in serious illness patient care. A SIDE leverages deployed health technologies across disease continuums and geographic locations of care to facilitate the flow of information among patients, providers, health systems, and payers. A SIDE represents a holistic approach to serious illness patient and population management that eliminates barriers created by niche solutions, establishing a heightened level of connectivity between the patient and all other key stakeholders.

A SIDE recognizes the need of each component of the ecosystem to thrive, allowing the system to provide better insights into the patients it serves. Cyclical in nature, no single component of the ecosystem is more valuable than the next and cannot be optimized without the last. Five pillars constitute a SIDE and each one is critical to the success of the system. The 5 pillars of a SIDE are: Identification, Education, Engagement, Service Delivery, and Remote Monitoring.

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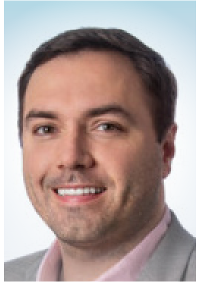
Abstract

Palliative and hospice care services produce immense benefits for patients living with serious illness and for their families. Due to the national shift toward value-based payment models, health systems and payers share a heightened awareness of the need to incorporate palliative and hospice services into their service mix for seriously ill patient populations.

During the last decade, a tremendous amount of capital has been invested to better integrate information technology into healthcare. This includes development of technologies to promote utilization of palliative and hospice services. However, no coordinated strategy exists to link such efforts together to create a cohesive strategy that transitions from identification of patients through receipt of services.

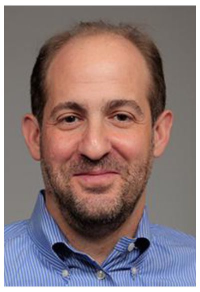
A Serious Illness Digital Ecosystem (SIDE) is the intentional aggregation of disparate digital and mobile health technologies into a single system that connects all of the actors involved in serious illness patient care. A SIDE leverages deployed health technologies across disease continuums and geographic locations of care to facilitate the flow of information among patients, providers, health systems, and payers. Five pillars constitute a SIDE, and each one is critical to the success of the system. The 5 pillars of a SIDE are: Identification, Education, Engagement, Service Delivery, and Remote Monitoring.

As information technology continues to evolve and becomes a part of the care delivery landscape, it is necessary to develop cohesive ecosystems that inform all parts of the serious illness patient experience and identifies patients for the right services, at the right time. ◆



NICOLLA

Jonathan Nicolla, MBA, Duke Cancer Institute



BOSWORTH

Hayden B. Bosworth, PhD, Department of Population Health Sciences, Duke University School of Medicine

DOCHERTY

Sharron L. Docherty, PhD, PNP-BC, Duke School of Nursing

POLLAK

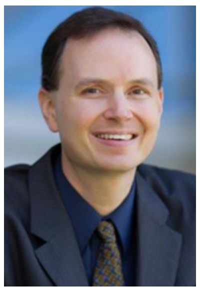
Kathryn I. Pollak, PhD; Professor in Population Health Sciences, Duke University School of Medicine

POWELL

Jeremy Powell, MEd, Acclivity Health Solutions

SELLERS

Nichole Sellers, BA, Acclivity Health Solutions



REEVE

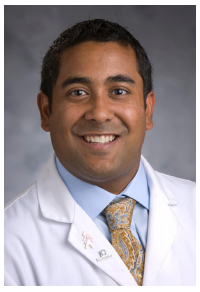
Bryce B. Reeve, PhD, Duke Department of Population Health Management

SAMSA

Greg Samsa, PhD, Department of Population Health Sciences, Duke University School of Medicine

SUTTON

Linda Sutton, MD, Duke Cancer Network



KAMAL

Arif H Kamal MD, MBA, MHS; Associate Professor of Medicine, Business Administration, and Population Health Sciences, Duke Cancer Institute, Duke Fuqua School of Business

Each pillar of a SIDE allows a health system to answer a specific fundamental question about their serious illness patent population. In such a population, the typical entry point for a patient into a SIDE is through the Identification pillar. This is where a health system, payer, or other accountable entity can answer the question, “How do we identify the right patients for palliative and hospice services?”

In the Education pillar, stakeholders can answer the question, “Now that we have identified patients who qualify for these services, how can we educate them on the benefits of these services?” While education is important, research shows that merely educating a patient on these services, if not accompanied by patient engagement, is ineffective in converting a patient into a user of palliative and hospice care services.[10,11]

From the Education pillar, a patient transitions to the Engagement pillar, which answers the question, “Once we have educated the patient on the benefits of these services, how do we empower them to participate in palliative care or share their care preferences with their clinical team?”

As a patient and their caregiver(s) become further engaged in the patient’s care, we transition to the fourth pillar, Service Delivery, which answers the question, “How can we provide usable information to the clinical team to impact delivery of care?” This includes pre-visit assessments of unmet needs, priorities for care, and goals and preferences for the interactions with the palliative care team.

Finally, once an informed treatment plan is in place and a clinical encounter is completed, the patient moves to the fifth pillar, Remote Monitoring, where the SIDE answers the question, “How do we determine the health of a patient away from a clinical visit to ensure their continued well-being?”

As a patient transitions through all 5 pillars of the SIDE, patient, caregiver, and administrative data are being collected. These data are integrated back into the SIDE model to further inform the Identification pillar, allowing the system to continually learn from itself and better manage future seriously ill patients who enter the ecosystem.

Identification

Despite administrative measures to improve usage of hospice and palliative care services, it is often difficult for health systems to determine patient suitability and to time delivery of these services. Daunting challenges presented by prognostication difficulties and rapidly evolving treatment paradigms require that information beyond clinician intuition and estimation be used. Utilizing “big data” is a potentially efficient way to synthesize medical information for a given patient and contrast it against data about similar patients within a population to accurately identify which patients would most benefit from palliative and hospice services.

Health systems that utilize predictive analytics, advanced algorithms, machine learning, and artificial intelligence are able to manage large patient populations. Rather than relying merely on clinical intuition and experiential prognostication, these tools often allow health systems to more quickly and accurately identify patients who are appropriate for these services by combining available data from administrative, billing, and clinical data sets. Coupling this analytic ability with clinical intuition allows health systems to initiate the process of enrolling the right patients into the right services at the right time, leading to improved patient outcomes and cost savings for the health system.

Systems in the marketplace have demonstrated that using a machine learning or artificial intelligence solution can increase efficiency, lower cost, and improve patient experience. Most notably, Stanford University established in 2017 that using a deep neural network and historic electronic health record information to mark patients who would benefit from palliative care could return prognostication at 3, 6, 9, and 12 months on a patient’s likelihood to die. Commercialization of such models provide clinicians with a prepopulated list that can be more than 90% accurate in predicting death in the next 3, 6, 9, or 12 months.[12]

Education

As patients are identified within a health system for palliative or hospice services, the next challenge becomes connecting them to these services. A key driver of the underutilization of palliative and hospice care services is a patient’s knowledge gap: having misconceptions about the benefits of these services, including hospice care and palliative care, and about how these services can be integrated into the usual care experience. In one recent large survey, 71% of patients could not accurately articulate the difference between hospice and palliative care, often confusing the care goals of the 2 services.[13] For this reason, and possibly others, patients eligible for palliative care hesitate to enroll despite its benefits. This knowledge barrier carries similar implications for patients who may be eligible to receive hospice benefits.

> **Some of the most widespread use of digital engagement platforms in the serious illness space has been within advanced care planning. Traditionally, health systems have had difficulty in messaging and operationalizing advance care planning, often leading to inaction and confusion among patients, providers, and family members.**

To close the gap between patients who are identified for hospice and palliative services and the utilization of these resources, the Education pillar of the SIDE model emphasizes the need for patients to access targeted, understandable, just-in-time content. In multiple instances, digital health platforms have been successfully deployed to educate patients on the benefits of hospice and palliative care. For instance, PCforMe, a web-based mobile health platform, uses short videos to educate seriously ill patients on the benefits of palliative care, covering topics such as “What is palliative care?” and “How is palliative care different than hospice care?”[12] Additionally, ACP Decisions has created and tested series of educational videos that prepare patients and family members to have discussions with their medical team about serious illness and planning for the future, and offer ways to incorporate these conversations into their treatment plans.[14]

Engagement

Education is an important first step in activating a patient; next, health systems must engage the patient in care planning with their clinicians. Historically, health systems have faced challenges in promoting active participation by patients and family members in planning their care.[15] Utilizing digital tools in the SIDE model allows a health system to achieve the following with patients: (1) Contextualization: Patients need a space to contextualize the care services they need to their individual preferences; (2) Application: Patients need tools that will allow them to organize their thoughts into an action plan that can be shared with their clinical team; and (3) Empowerment: Patients need a mechanism to help them convey their preferences to their care team and to facilitate conversations that lead to actionable changes, ones that incorporate the patient's preferences for their treatment plan.

To date, some of the most widespread use of digital engagement platforms in the serious illness space has been within advance care planning. Traditionally, health systems have had difficulty in messaging and operationalizing advance care planning, often leading to inaction and confusion among patients, providers, and family members during the most critical moments of patient care.[16] In response, patient engagement websites have been designed that use simple technology and social media to help patients create and share their advance care planning wishes with their clinicians. Further, technology companies have partnered with health systems to establish a simple patient engagement solution that facilitates the advance care planning documentation process for the patient and provides a universal repository system for advance care planning documentation.

Service Delivery

After a health system has identified, educated, and engaged patients and their families, how is this translated into service delivery for the patient? Patients seek a more active role in sharing their preferences and in guiding clinical care that addresses their concerns, priorities, and preferences.[17] The SIDE model recognizes that the information a patient provides is only as effective as the ability of the care team to execute their wishes. Clinicians need to collect information from patients in a way that allows them to easily locate, understand, and apply patient preference into their care plan.

Effective outputs from patient engagement tools must accomplish 3 goals for the clinician:

1. Clinicians must be able to easily access and navigate the preferences of a patient.
2. The information from the patient must be presented in such a way that it can be easily understood by the clinician.
3. The information must facilitate a conversation between the clinician and patient about how to incorporate patient preference into the care plan.

Successful patient engagement tools focus not only on capturing the patient voice, but also the ability to impact service delivery for clinicians.[18] For example, Cake, a web-based end-of-life planning tool developed by the Massachusetts Coalition for Serious Illness Care, first asks a patient to complete a series of questionnaires regarding end-of-life preferences. Then, the tool packages the patient's responses into a PDF packet that can be easily shared with the clinician, allowing the clinician to better understand how to incorporate the patient's preferences into care planning.

Remote Monitoring

Overwhelmingly, the majority of the patient experience with serious illness happens outside a clinical setting. Patient distress, symptom burden, and functional limitations are experienced away from healthcare professionals, often in their own homes alongside loved ones and informal caregivers. However, health systems have very little actionable insight for what is happening to patients while they continue their daily routine. Often, during the weeks or months between clinical appointments, the well-being of patients with serious illness can drastically change. Therefore, at the time of a consultation with the patient, clinicians are obtaining a snapshot of information at that point in time, rather than longitudinal information around the time when the patient experienced the challenges. This can lead to a loss of valuable time for a patient and clinician, causing a lag in care that can impact numerous outcomes for the patient. For this reason, the final vital component of a SIDE is remote patient monitoring, which provides clinical insight into the well-being of patients to the clinical team in real time.

Traditional patient home-based monitoring has been primarily conducted by clinical staff using a telephone to perform checkups on patients or to reconnect with patients who call a triage line with a question or concern. While this technique can be helpful for patients and caregivers to obtain information, it presents limitations regarding how that information can be used to improve patient care. First, by nature, phone calls allow only for the capture of unstructured data, leading to variation in the capture and interpretation of the data. Second, because the data-capture method occurs outside of a technology platform, it is difficult to utilize these data to inform urgency of care or perform a needs assessment across a population. Lastly, as these data are not presented in a structured way into an analytics engine, the ability to learn based off its existing population and improve on its ability to identify patients is greatly limited. By structuring this process in a SIDE, we allow the system to accomplish the following: to (1) improve identification of patients; (2) integrate routine collection of data on distress, symptom burden, and functional impact using validated questionnaires that are shared with the clinical team; (3) allow patients to feel more connected to their clinical team as they are providing constant feedback away from the clinic; and (4) efficiently utilize clinical staffing resources.

Conclusions

As information technology continues to evolve and become a part of the care delivery landscape, it is necessary to develop cohesive medical ecosystems that inform all parts of the patient experience and align patients in the right services, at the right time. This is particularly important for patients suffering from serious illness. Application of a SIDE provides numerous benefits for patients, family caregivers, and health systems by optimizing appropriateness and timeliness of care, leading to an increase in utilization of palliative and hospice care services. ◆

ACKNOWLEDGMENTS

The authors would like to acknowledge Duane Feger for his contributions in framing the Identification section of the manuscript and Anne Perez for her contributions in the design of the accompanying graphic of the manuscript.

DISCLOSURES

JN is an owner and president of Prepped Health, LLC, and chief product officer of Acclivity Health Solutions Inc. JP is founder and chief executive officer of Acclivity Health Solutions Inc. NS is employed by Acclivity Health Solutions Inc. AK is an owner and chief executive officer of Prepped Health, LLC, and chief medical officer of Acclivity Health Solutions Inc.

ADDITIONAL AUTHOR INFORMATION

Duke Cancer Institute (JN), Durham, NC; Department of Population Health Sciences, Duke University School of Medicine (HBB, KIP, GS), Durham, NC; Duke School of Nursing (SLD), Durham, NC; Acclivity Health Solutions (JP and NS); Center for Health Measurement, Duke Department of Population Health Management (BBR), Durham, NC; Duke Cancer Network (LS), Durham, NC; Duke Cancer Institute and Duke University Fuqua School of Business (AK), Durham, NC.

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