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Review

# Serious Illness Management: A Fuller Approach to Integrative Palliative Care

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Across the nation, hospitals have established comprehensive palliative care programs to help patients navigate the complexities of serious illness by utilizing interdisciplinary teams of specialized physicians, nurses, social workers and chaplains within the acute setting. The annual report card from the Center to Advance Palliative Care [1] shows an uptick in hospitals that have these programs, but there are clear disparities in access to care and new opportunity for palliative care to continue evolving to include integrative therapies and better serve its mission to help people live longer with the best possible quality of life.

The question programs like the Steward Center for Palliative Care in Savannah, Georgia must answer is: how best do we meet the needs of our seriously ill neighbors outside the inpatient setting and provide a truly integrative palliative service? The Steward Center established an outpatient clinic four years ago to offer support to patients after they leave the hospital and while this has been a successful addition, there have been key learnings that have inspired a new approach to the care we provide. Firstly, we serve a patient population that is amongst the most underserved in the country. Georgia reports that at least 16% of its population, or approximately 1.38 million people,

lack insurance coverage, increasing incidence of chronic illness, and low socioeconomic status just to name a few risk factors [2]. It's rural populations tend to have greater overall health disparities when compared to urban populations leading to higher rates of COPD, cardiovascular disease and cancer among residents [3]. This makes attending a clinic appointment very difficult for people, especially for those who are experiencing symptom exacerbation. Secondly, we know that many physicians and patients still do not understand the difference between palliative care and hospice, leading to stigma that often prohibits early access to palliative treatment [4]. Above all else, we know that true integrative palliative care is more than a one-shot conversation in the hospital or clinic and it includes more than medical management. Thus, in order to truly understand how our team can add value and honestly establish trust with our patients, our care must follow them home and integrate their environment and unique needs into the care plan. However, with the burden of low reimbursement rates for palliative services coupled with state regulations that prohibit cost-effective means of staffing home-based programs, this is not an easy task.

Over the last nine months, the Steward Center has implemented a model of care that utilizes palliative social workers and nurse practitioners called Serious Illness Management (SIM). The SIM model expands on current approaches by bringing palliative care to the emergency room, nursing homes, assisted living facilities and into the homes of especially complex patients as a means of early and continuous intervention. The social work component functions on trigger criteria rather than physician referral, effectively eliminating the connection to palliative care being dependent on the training of hospital physicians. If a patient meets criterion, the "Serious Illness Specialist" (SIS) connects with the patient in the emergency room to provide a social assessment focused on palliative needs, goals of care and barriers to effective symptom management, advocates for a consult to palliative care when appropriate, and facilitates earlier intervention for other supportive services. This not only provides focus to the patients care plan by helping physicians and nursing staff identify goals of care and limitations to traditional symptom management before an admission, it aims to provide cost savings to the hospital and health plan by avoiding expenditure that is not in line with a patient's wishes. The program identified 1491 patients that screened positive for intervention from a SIS and successfully navigated 552 of those patients in the first six months, focusing limited human resource on patients who had repeat visits to the emergency department and a diagnosis of congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD). Utilizing a workflow that touches on as many variables of the patient's lived experience as possible, the SIM team realized great success at discovering where exactly things were going wrong in the care plan and helped the patient find a way to overcome barriers to success.

For patients discharging to nursing homes and assisted living facilities served by the Steward Center, our nurse practitioners and social workers go to them. This has been the most eye-opening aspect of our program. Of the patients we are able to follow to their home setting, 79% have not had a readmission or repeat emergency room visit. There have been clear improvements to crisis management, ongoing advance care planning and earlier transition into hospice. Patients and families have direct access to palliative care all the time to ensure that they have the opportunity to stay ahead of a crisis through after hours' tele-services, on-call providers and holistic resources for managing symptom burden without medication.

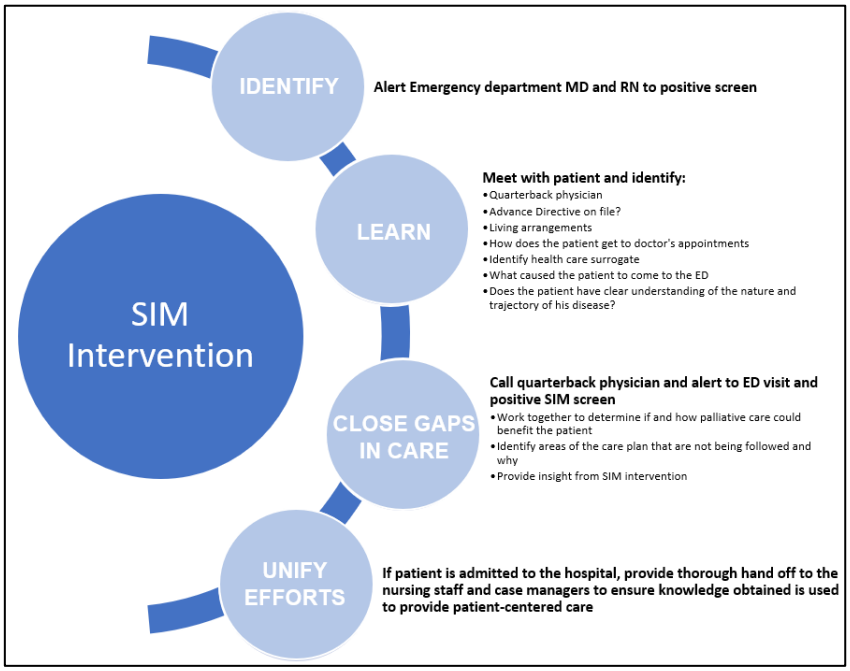


**Figure 1** The Serious Illness Management Intervention figure above shows the process utilized to identify patient care plan issues and intervention strategy aimed at closing any gaps in care and removing barriers to accessing palliative care

Although palliative care focuses on improving quality of life for seriously ill patients, many programs often have an emphasis on traditional medical intervention, giving less weight to the potential impact of integrative therapies. For many of the patients identified through the SIM model, restrictions on controlled substances, unique physical traits of the patient, past traumas or a desire to avoid opioids posed a barrier to providing lasting pain relief. By introducing integrative therapies like massage, music therapy and our most popular, virtual reality, the SIM models offers a fuller approach to palliative care that can be tailored to a patient's lived experience.

Mr. Hall, an 87-year-old man suffering with worsening COPD with a history of frequenting the emergency room for symptom relief is a valuable case study for the success of the SIM model.

Mr. Hall arrived at the emergency room on a Sunday evening for the seventh time in the last six months. The doctors and nurses knew his face well and were sad to see him there again struggling to breathe, overwhelmed with anxiety. He had previously experienced a respiratory event resulting in a month long hospital stay where he required ventilator support. The fear of experiencing that again was palpable. Given his progressive illness and frequent visits to the emergency room, the Serious Illness Specialist (SIS) was alerted and quickly went to the patient to learn more about his and his family's concerns and determine what services and resources could help. "I get so nervous when I get short of breath. I just panic! And every time, I end up back here." the patient shared.

During their interaction, the SIS was able to learn that the patient relied on the help of his older wife, a very tired caregiver who was running out of ideas on how to help her husband. The patient shared that he was living at a nursing home and that all of the staff were not equally prepared to help him with breathing treatments when he went into distress. As more light was shed on the dynamics of his care and his hopes for the future it also became clear that Mr. Hall had not had the opportunity to fill out an Advance Directive or POLST form to make clear what his wishes were. From there, the SIS called Mr. Hall's pulmonologist, the quarterback of his care team, to let him know his

patient was in the emergency room again and initiate a discussion about palliative care. Within an hour, the physician placed an order for Mr. Hall to be seen by the Palliative Care team and the SIS had arranged for his wife to be present for the consultation while he was in the observation unit. By the next morning, a plan was in place for the patient to return to a different nursing home that offered the additional palliative support. The SIS mediated a thorough discussion about advanced care planning and the patient was able to convey his treatment preferences to his wife and make sure his children were also informed about his goals for future intervention. Once Mr. Hall was discharged and set up in his new facility, virtual reality was introduced as a way for him to cope with the anxiety that comes with managing difficulty breathing. It has now been five months since Mr. Hall was last seen in the emergency department, but he does report that he takes occasional virtual trips to the mountains to help calm his nerves and avoid the panic he had previously been accustomed to when he experiences periods of exacerbated symptoms. This, for us, illustrates that the trajectory of a patient's care can be transformed when we prioritize the need to meet patients where they are and incorporate strategies for coping that address their unique experience alongside the disease process.

Although our results are limited given the SIM program is in its infancy, they draw attention to the change that is needed to have lasting impact. We have to take charge of the full continuum of care to fully support patients, families and other specialty providers. When our teams become an integral part of the entire disease management process, patients live longer with better quality of life outside of the hospital. There is much for legislators, health systems and payors to change in order for this type of care to be provided efficiently and effectively for the broader population. Georgia has some of the most restrictive laws that govern the practice of nurse practitioners making it very costly to provide home-based care. Given our area's rural geography, the organizational cost of physicians making house calls is a sizeable burden. In states like Washington and Oregon where mid-level providers can be utilized to the full extent of their ability, models similar to Serious Illness Management are flourishing [5]. This suggests a need for further research and outcomes reporting to show the impact of integrative palliative care beyond its traditional, acute care functions.

## Author Contributions

K.B. conceived the idea for the Serious Illness Management program and supervised the project. M.G. developed the programming and performed the data collection. E.A. verified the research methods. All authors discussed the results and contributed to the final manuscript. M.G. carried out the qualitative work that informed the findings of this article. M.G. wrote this article with support from E.A. and K.B.

## Competing Interests

The authors have declared that no competing interests exist.

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