The Emperor of All Maladies Meets a New Model in CPE Training: Creating an Outpatient Cancer Center Year-Long Unit

Naima Barbour, Terry Culbertson,[1]
Eric Malcom, Perry Mouncey, and Linda Mulrooney

INTRODUCTION

We recently developed a new CPE model for State University of New York Upstate Medical University's outpatient cancer center. Exciting, unexpected findings made this new CPE model worth the time and energy it took to design and create. This CPE program tailored to outpatient oncology contributed to patient satisfaction scores above the national benchmark; laid the groundwork for a more integrated spiritual care service; built strong provider relationships, especially with palliative care staff; and taught the three students involved leadership skills and pastoral authority while giving them the opportunity to be part of a new and innovative program. In this article, we describe how this was done and encourage others to consider trying out a similar model in specialized clinical settings.

CLINICAL CONTEXT

The Department of Spiritual Care was invited by the administration of State University of New York (SUNY) Upstate Medical Center's Cancer Center to apply for a one-year foundation grant to expand the existing limited spiritual care that was currently being provided. The Upstate Cancer Center opened August 2014 as a 110,000-square-foot facility dedicated to outpatient cancer services for both adults and children. It is the region's most comprehensive resource for cancer care, offering advanced outpatient treatment, clinical research studies, and support services in one location. Upstate sees more than 2,000 new cancer patients per year, resulting in 45,000 visits to the downtown

[1] Rev. Terry Ruth Culbertson is Manager of the Department of Spiritual Care, State University of New York Upstate Medical University in Syracuse, New York. Email: culbertt@upstate.edu. Naima Barbour, Rev. Perry Mouncey, and Linda Mulrooney were chaplain residents in the CPE unit described in this article. Fr. Eric Malcom is Palliative Care Chaplain at State University of New York Upstate Medical University. Email: malcome@upstate.edu.

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campus and additional visits to satellite locations. Services and resources to help patients and families throughout treatment include social work, nutritional counseling, patient navigators, financial counseling, a survivorship program, outpatient palliative care, a healing garden, a meditation room, and integrative therapies such as reiki.[i]

Our department had no designated outpatient chaplain position; we only responded to referrals due to limited staffing. One CPE student had been assigned to the Cancer Center as a clinical assignment in 2014, and for several years a spiritual care volunteer provided some on-site rounding. Since 2018 our part-time reiki team coordinator has provided reiki in the Integrative Therapy Room or in infusion. The pediatric chaplain visits on request with pediatric outpatients receiving infusion chemotherapy.

RESEARCH AND REVELATIONS

A search on the ACPE website for other CPE programs designed for outpatient cancer centers yielded no results. A research review led us to the conclusion that no CPE center had previously implemented training in this specialized context. We conducted a brief REDCap survey of our Cancer Center staff to assess awareness of spiritual care availability and their understanding of what spiritual care could provide.[ii] Of the thirty-three respondents in the survey, 93.9 percent indicated awareness of availability of spiritual care for patients and 51.5 percent of its availability for staff. The main reasons for referral were bereavement/grief (92.9 percent), religious rituals such as sacraments and prayer (85.7 percent), and patient/family distress and end-of-life issues (82.1 percent). However, the literature showed that one of the biggest barriers chaplains face in outpatient settings is the lack of understanding among many providers of the services chaplains can actually provide.[iii] Our hypothesis was that, despite the level of awareness indicated by our survey, a full understanding of the role and benefits of spiritual care might be lacking, limiting referrals and possibly receptivity. Our experience on this unit bore out our hypothesis, as we discuss in the section titled Lessons Learned.

We also learned from the literature that although the vast majority of patients do not take issue with discussing spirituality with their providers, many have spiritual needs that are addressed minimally or not at all. Research has also showed that more creative methods of engaging patients, such as tele chaplaincy, are extremely helpful.[iv] Addressing spiritual needs has been shown to result in "improved quality-of-life, improved perceptions of quality-of-care, shorter intensive care unit stays, and lower end-of-life costs."[v]

CREATING A NEW CPE MODEL FOR THIS CONTEXT

The concept of a yearlong CPE unit of 400+ hours at Upstate was created in 2014 for four advanced learners in the role of chaplain residents who were unable to commit to a shorter training period due to work or other commitments. Each covered a different

specialty service. The exit interview from that unit included comments noting that the longer unit allowed more time to integrate learning and that peer relationships benefitted from this slower process. The potential of creating a CPE unit focused on one identified, shared, unique clinical setting held promise of a more cohesive curricular focus.

Our grant proposal request provided for a small monthly stipend and covered the cost of tuition for the students. It stressed that the unique spiritual/religious needs of our outpatients at the Cancer Center were not being assessed or addressed, thus limiting the ability of the Center to provide wholistic care in a service designed to be comprehensive. It is important to note that both the National Consensus Project (2018)[vi] and the National Cancer Coalition Network Distress Management Guidelines (2019) emphasize that spirituality must be addressed in and across every setting rather than simply considered as an afterthought.[vii] We pitched the idea that having on-site regular chaplain residents working closely with providers, building trusted relationships, receiving education about oncology and treatments, and utilizing their learning to better serve not only cancer patients but also reaching out to their loved ones while providing supportive care to the center's staff would be a unique project that could benefit all involved. We saw the stress of coping with a cancer diagnosis and treatment along with COVID-19 isolation as potential sources of exacerbated spiritual distress and reduced patient well-being. The grant was approved with the target of holding the CPE unit May 2021–April 2022.

The concept that emerged for this specialty unit was to recruit four learners who would each provide coverage on-site at the Cancer Center for one eight-hour day per week for one year. A retired chaplain with four CPE units expressed interest in participating in the role of course assistant, which included one day a week for on-site visits. Class would be held twice a month for a total of 10 hours and would include devotions, a didactic, two verbatims, and open agenda group (OAG/IPR). Individual supervision was monthly and as needed. Each student was either already trained as a reiki practitioner or was offered the opportunity to take this training. This spiritual intervention provided an additional way of engaging with patients and families, particularly for one of the residents.

A significant factor at the time of this grant was that COVID-19 restrictions did not allow a family member to accompany any patient. Linda[viii] had been serving on our remote spiritual care team for a year, regularly calling non-vented patients. She reflected: This experience later served as fertile ground for calling families while [I was] a resident in the Outpatient Cancer Center. Not even realizing it at that time, I believe the anxiety of returning to the outpatient setting helped me to connect well with patients as they were facing the same fear, of the pandemic, along with the fear of cancer. Like them, I too was able to put my trust in something deeper, God.

UNEXPECTED VALUE OF THIS MODEL WHEN RECRUITING STUDENTS

The decision was made to accept only mature learners with at least one prior CPE unit from Upstate who had already demonstrated the ability to function independently. There were several previous CPE students either working, in school, or retired who were interested in a more extended residency that would take place over the course of a year and would allow them the time to complete one CPE unit. Naima was a forty-nine-year-old Muslim African American woman in her second Level 1 unit. Perry was a seventy-three-year-old white ordained Episcopal priest in her second Level I unit. Linda was a sixty-year-old white Roman Catholic woman in her third CPE unit and first Level 2 unit, as was Cynthia, a sixty-six-year-old white woman ordained by Missio Global Ministries. Being part of a new and innovative program that required flexibility was viewed as an incentive, as well as the opportunity to develop specific knowledge and skills in the field of oncology. As Perry stated, "I felt it fit my lifestyle." Naima reflected:

I readily accepted the offer to join the 12-month residency program at the Cancer Center for several reasons. It satisfied my desire to continue the CPE experience. Instead of a fast=paced summer unit, I found it easier to commit to a longer experience that was less demanding per week. There was no financial obligation. The grant awarded to the residency program took care of the tuition, parking, meals, materials, etc. The Cancer Center experience seemed like the opportunity I needed to finally process my own feelings around my personal cancer journey. I felt it was time to work through long-held beliefs and fears with the hope of being able to journey with patients and families struggling with cancer diagnosis, treatment, and/or death. The residency was entirely new. I was genuinely excited about being on the ground level of something totally new to Upstate, knowing that I would be part of the creative process of the residency as it progressed. Upon accepting the offer to join, I envisioned myself as one of the first graduates of the program.

Cancer Center administration requested that the newly recruited students wear a jacket that clearly identified their role. The month prior to their beginning CPE, the group was given the task of designing the jackets as their first group assignment to begin building peer relationships. It provided a good onboarding context for experiencing conflict and working toward conflict resolution. Linda agreed to organize this conversation. She commented:

> Offering to organize this was advantageous for me. It gave our group a chance to get to know each other in an atmosphere that I found fun as well as intimate. Revealing and laughing at oneself over color and style can be a great groundbreaker. Who would have thought this task would be so involved!

EXPECTING THE UNEXPECTED

A retired chaplain and former LPN had agreed to work with the certified educator in developing and implementing this CPE unit. She spent two months becoming

acquainted with Cancer Center staff and operations and was instrumental in providing hands-on clinical orientation so the certified educator could focus on orienting the summer CPE unit students. Residents found this uniformly positive. One commented that "Kelly's familiarity with the Center and the ease with which she moved within it put me mostly at ease." Kelly was unable to continue after our first month due to personal issues, however, and her departure was experienced as unexpected and abrupt. This became grist for the mill in our open agenda group as we contained and explored feelings around her loss.

Another loss was student Cynthia, who had to leave due to ill health at the end of the third month of training, reducing the number of chaplain residents to three. The group was working hard to establish a visitation routine and gain access to ambulatory electronic medical records for charting while working through issues with staff resistant to their presence. There was a sense of group bonding, of the students offering each other moral and emotional support. The group created an email 'handoff' process that kept them all in touch with what had happened during clinical days. Cynthia in particular was experienced as a peer with "positive energy" who was "attentive, reflective, and supportive." At the final open agenda group with Cynthia, the remaining students expressed feelings of discouragement and the sense of a void about where the group was going. Linda reflected, "I felt our small team was coming apart at the seams."

Mid unit was a turning point for the group, especially during our off-site all-day retreat where 'verbatims with God' were shared, goals reviewed, and bread broken. The opportunity to have our department's new palliative care chaplain join the group was presented. Eric had completed his fourth CPE unit that summer and had been hired to fill this vacant position. He achieved provisional board chaplaincy certification that fall. He was responsible for continuing to integrate spiritual care into ambulatory and outpatient palliative care teams. This was a significant positive development in the group process for the existing residents. One resident commented that Eric's arrival in the latter half of the residency seemed to be the balm our group sorely needed. He offered fresh perspectives, his organizational and research skill, wit, and humor. . . . As the palliative care chaplain, he added a strong, new knowledge base, a guy in our midst, and a great sense of humor.

CURRICULAR DEVELOPMENT

A significant challenge was to design a unique curricular focus that progressively built up the foundation of knowledge necessary to function competently as a chaplain in both the outpatient setting and within this specialized field. What was also needed was a creative training framework related to CPE learning outcomes that would deeply engage the learners in their formation, reflection, and competency. Following our opening retreat day where we engaged with our personal narratives related to families of origin, spiritual journeys, and experiences with cancer, our first month was spent

laying a relational foundation for the year by having the residents meet with the Cancer Center administrator, the director of nursing, social workers, a psycho-oncologist, the medical director, and nurse navigators and tour the on-site lab. Two weeks were devoted to a one-on-one clinical orientation by the course assistant. We studied relevant articles and book chapters on outpatient chaplaincy[ix] and reviewed group process theory to prepare for open agenda group.[x]

By our second month, we had launched into a year-long text study over lunch of *The Emperor of All Maladies: A Biography of Cancer* by Siddhartha Mukherjee[xi] that required rotating the book study facilitation of the group discussions. It took time for each student to develop skill in serving as group leader for these discussions, learning to define questions for discussion rather than reviewing extensive content. Linda reflected that "the feedback from the group helped me to continually hone in and explore appropriate thoughts/questions for the group." This text became a significant source of knowledge about the historical timeline of cancer, cancer as a class of illnesses, and the political, economic, and social impacts of cancer research and treatment. Perry commented,

> As we took turns presenting the reading for each class, this encouraged creativity in the presentation. I feel that I now have a much better understanding of how Upstate got to its current forms of cancer treatment as well. I'm also struck by the dedication of so many people worldwide who committed their lives to this research.

A brief devotion followed each noon book study, serving as an opportunity to theologically reflect, center, and segue to contextual learning. This was seen as an essential part of the development of group relationships and foundational for chaplaincy, as evident in the following student comments:

> Devotions allowed me to offer reflections on some of the things happening within the group and/or the community at large (e.g., loss, hope, gratitude, holidays).
>
> They [the devotions] were an opportunity for creativity and reflection together.
>
> The themes chosen were appropriate for the season or for specific issues. I found our devotion times a chance to "shift gears" and to be inward focused.
>
> Involving personal heritage and spirituality was particularly of interest to me. It helped me to understand my colleagues on a deeper level.

Didactic topics included guest speakers on genetics and cancer, research practices in chaplaincy, the importance of contributing to the patient experience, an assessment of conflict dynamics, trends in integrative medicine and palliative care, internal family systems, spiritual pain, social determinants of health, nutrition, radiation, and infusion nursing. Chaplain residents were encouraged to suggest topics and recruit speakers. Naima commented that "the content was varied, well planned and thought provoking. Each topic was very useful and helped me learn about the Cancer Center or cancer-related issues and a variety of psychosocial topics."

Each resident was responsible for a monthly clinical presentation of a verbatim or case. Two members of our CPE Professional Advisory Council, a former hospice medical

director and a retired palliative care nurse practitioner, joined us several times as 'wisdom seat' members to share in seminars and join in verbatim role plays. We ended each training afternoon with open agenda group, using a systems-centered orientation approach that these students had experienced during their previous training. Naima reflected that

OAG was a real challenge for me as I was initially fine with remaining silent or deflecting attention from myself. What I found was that the Cancer Center experience was too large for me to keep my latent emotions from coming to the surface. As time went on, sharing in the group became easier. It encouraged reflection and sharing with the group in relation to certain events and my own self and feelings.

Other curricular additions included the creation of a standardized patient visit (a simulated patient visit) with a couple grieving the death of their son and raising his daughter while struggling with the wife's new stage 4 cancer diagnosis.[xii] Residents had the opportunity to extend their learning through tailored learning experiences, such as visiting our traveling mammogram van and the Gamma Knife Center. The group was invited to participate in offering the invocation when our other hospital campus opened an on-site cancer center. The unit ended with a group presentation on what had been learned from the year of training to a room full of supporters, family, clinicians, providers, and chaplains, followed by a catered reception.

CHALLENGES ENCOUNTERED

Despite support from administration, staff resistance to our presence was obvious in the early months on the floors. There was push-back about being able to round through infusion. Instead, nursing was instructed to indicate on a sign in each infusion station if a visit with a chaplain was desired. However, this requirement never was actualized. Naima reflected that "much of it, I believe, had much to do with certain staff not understanding our role within the sphere of patient care." It took time and persistence before the chaplain residents began to feel accepted and welcomed by the staff.

The charting format in the Cancer Center was different than in the hospital. It took several months before this challenge was sorted out by Information Management Technology and the group was finally able to chart. As Linda commented, "This was annoying for us and for Rev. Terry, who had to do all our charting." Perry stated, "I still feel like I haven't completely grasped the nuances of the Cancer Center EPIC [the electronic medical record system used in the Cancer Center] nor used its full functionality."

Linda identified another challenge, which was "finding my voice/way in multi-disciplinary rounds. I never felt on par with the team. It's important to acknowledge no one made me feel this way. The medical team was looking for ways to save lives. I questioned the value of my presence, other than that I was there."

And there was one pragmatic challenge. When the Cancer Center was built, the Meditation Room included a small 'closet office' with the hope that someday a staff chaplain would be on site. This became the shared home of the chaplain residents. However, as Perry pointed out, "This meant that on occasion I would interrupt someone using the room for prayer when I needed to go into or out of our office."

LESSONS LEARNED

The chaplain residents reported that the patients and families they visited were generally very receptive and appreciative of their visits. One unexpected lesson was the opportunity to accompany patients over an extended period and develop significant spiritually supportive relationships. The opportunities to move from Infusion to the Emergency Department in the hospital following a rapid response team code, which occurred with some frequency during infusion, gave patients and their family members a continuity of support they appreciated. Time with patients was not scheduled or promised, whether in person or through regular follow-up tele chaplaincy calls. Linda reflected that outpatient work showed me that I had to make the most of each patient encounter, no matter where (in -person or phone) or how brief. There's a chance you may never see or hear from the patient again once they go home or hang up.

The chaplain residents identified a key lesson they learned from their time in the Cancer Center: patients need a place to share difficult feelings. Every provider had specific roles. The chaplain residents grew in their skill of listening and being present in a different way from other those in other disciplines. Naima commented:

> Willingness to listen is the key skill. Listening opens the door to even the most difficult questions. Sometime through open-ended questions the patient and family were able to look at their illness from a different perspective. The extended one-year period allowed me the time to follow patients over months. I found this dynamic beneficial for both me and the patients. Establishing a good rapport with the patients, what I did not expect was to see it mirroring my personal struggle with cancer.

As the residents became more comfortable with the Cancer Center setting and staff, they experienced the development of relationships with staff. A repeat of our original REDCap survey in March 2022 had sixty respondents, almost twice the original number. Although the percentage of those who were aware that spiritual care was available for Cancer Center patients (93.3 percent) remained about the same, now 65.6 percent of staff were aware that spiritual care was also available to support them. The key reasons for referral had shifted to an increased focus on patient/family distress as well as end-of-life issues (81.4 percent) and reasons related to poor prognosis and bereavement/grief (76.3 percent). Perry observed that although the lack of welcome I felt from the staff early on made it uncomfortable sometimes to visit patients, our persistence

paid off. Once staff became more welcoming of our presence, it was a joy for me to feel comfortable during my visits.

I believe the sense of welcome came about because we were open and friendly with the staff and our presence with the patients could sometimes make life easier for the staff.

Peer relationships appeared to develop on a deeper level due to the slower pace of training and the depth of focus in the clinical materials and group process. The students established a hand-off process that kept them connected despite less direct contact. They identified opportunities to communicate with patients through ongoing tele chaplaincy and creating a specially designed spiritual care card they used for sending notes to patients, letting them know of their ongoing concern and care.

Because of the slower pace of this stretched-out method of education, the students had time to engage deeply with the materials and apply their learning to visible growth through the action-reflection-action model with their clinical ministry and with themselves. Linda reported that she found the model of action-reflection prevalent in most of her encounters, both with patients and staff. "In this particular unit (likely because it was the third), I was able to access much more quickly that I was experiencing countertransference, triggers/feelings that might get in the way of the conversation." A similar process was experienced in clinical encounters, writing reflections, identifying new insights, utilizing supervision, and working with a therapist. As Naima commented, The reflective segments of the course, in my opinion, were the most necessary parts of the content. I had not anticipated that so much could happen within our group and my personal life in just 12 months.

SIGNIFICANT OUTCOMES TO CONSIDER

We had advocated for an additional question to be added to the existing outpatient Oncology Press Ganey survey (which focuses on an overall assessment of the Cancer Center) that would provide a quantitative measure of this CPE initiative and demonstrate a return on investment to administration. The question "Degree to which chaplains respected your family's cultural and spiritual needs" was added to the concluding section four of the Press Ganey questionnaire. The average score from January 2021 through May 2022 on this question for all outpatient oncology facilities nationwide was 94.58 out of 100; the Upstate Cancer Center average score was 97.22 (see figure 1). This higher score was proof that our presence made a difference to the patients and to the overall system as well.

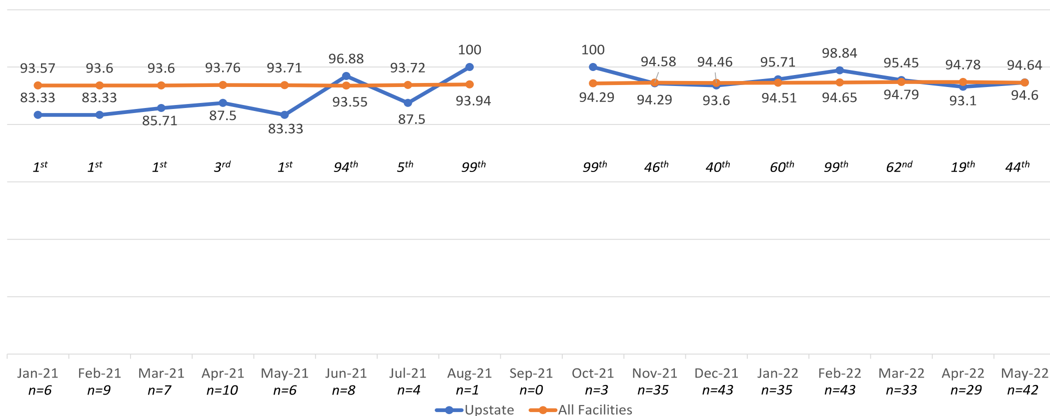

Figure 1. Responses to one question on the outpatient oncology Press Ganey questionnaire January 2021 through May 2022 for Upstate Medical University facilities compared to outpatient oncology facilities nationwide.

RECOMMENDATIONS AND FUTURE CONSIDERATIONS

The value of this model and of the focused clinical context is evident for both the learners and those they served. Accepting only learners who had taken at least one CPE unit at Upstate was important for onboarding and orientation as well as for their understanding of the clinical method of learning and having the ability to function independently. The pace, requirements, and ability to be creative and develop something new was time-consuming yet energizing. Because the certified educator also taught a summer and extended unit during this time, overextension in that role was a reality. Future considerations are to build on our first-time efforts and tailor our year-long unit to incorporate what we learned. It is worth the time and effort to connect deeply with persons with cancer, their loved ones, and the staff that care for t

NOTES

[i] Christine Benton (Update Medical University Social Media and Events Coordinator), personal communication with Terry Culbertson, March 10, 2022.

[ii] REDCap is a web application that Upstate uses to conduct surveys in a variety of settings. We conducted the survey on May 5, 2021.

[iii] George Handzo et al., "Chaplaincy in the Outpatient Setting—Getting from Here to There," *Journal of Health Care Chaplaincy* 28, no. 2 (September 2020): 199, https://doi.org/10.1080/08854726.2020.1818359.

[iv] Allison Kestenbaum et al. "Top Ten Tips Palliative Care Clinicians Should Know about Spirituality in Serious Illness," *Journal of Palliative Medicine* 25, no. 2 (December 2021): 313, https://doi.org/10.1089/jpm.2021.0522; Alison Snow et al., "Integrating Spiritual Care in the Outpatient Oncology Setting," *Oncology Issues* 37, no. 1 (2022): 52, https://doi.org/10.1080/10463356.2021.2006017; Petra J. Sprik et al., "Chaplains and Telechaplaincy: Best Practices, Strengths, Weaknesses—A National Study," *Journal of Health Care Chaplaincy* (January 2022): 1–23, https://doi.org/10.1080/08854726.2022.2026103.
[v] Petra J. Sprik et al., "Using Patient-Reported Religious/Spiritual Concerns to Identify Patients Who Accept Chaplain Interventions in an Outpatient Oncology Setting," *Supportive Care in Cancer* 27, no. 5 (2018): 1861, https://doi.org/10.1007/s00520–018–4447-z.
[vi] Clinical Practice Guidelines for Quality Palliative Care," 4th ed., in *Palliative Care Guidelines*, National Coalition for Hospice and Palliative Care (NCP), 2018, https://www.nationalcoalitionhpc.org/ncp/.
[vii] "Distress management guidelines," National Comprehensive Cancer Network, 2019, https://nccn.org/.
[viii] In this article, co-authors who were participants in the program have their real names given. One person who left the program and patients have been given pseudonyms.
[ix] The articles we reviewed are as follows: Susan Sontag , *Later Essays* (New York: Library of America, 2017); Denise M. Giacomozzi May, "The Harvest Is Plenty: A Guide for Visiting Outpatient Units," *Journal of Pastoral Care* 52, no. 1 (1998): 62–68. https://doi.org/10.1177/002234099805200108; Handzo et al., "Chaplaincy in the Outpatient Setting; Richard M. O'Neill et al., "Systems-Centered® Training's Functional Subgrouping: A Path to *Koinonia* in Pastoral Care," *Chaplaincy Today* 28, no. 1 (2012): 2–13, https://doi.org/10.1080/10999183.2012.10767443; Herbert Anderson et al., *Ministry to Outpatients: A New Challenge in Pastoral Care* (Minneapolis: Augsburg, 1991).
[x] Open agenda group is the same as interpersonal relationships group using a systems centered theory orientation. See O'Neill et al., "Systems-Centered® Training's Functional Subgrouping."
[xi] Siddhartha Mukherjee, *The Emperor of All Maladies: A Biography of Cancer* (London: Fourth Estate, 2009).

[xii] The Standardized Patient Program has been utilized by our CPE program since 2004. For more information, see the website for the Association of Standardized Patient Educators: https://www.healthysimulation.com/medical-simulation/organizations/aspe-association-of-standardized-patient-educators/.