

Featured Innovation: Part 1

Providing Home-based Palliative Care for People with Congestive Heart Failure (CHF) and Chronic Obstructive Pulmonary Disease (COPD):

An Interview with [Betsy Clark, RN, CHPN](#)

Hospice & Palliative CareCenter (HPCC), which was the first hospice in North Carolina when it was started in 1978, provides interdisciplinary, comprehensive, coordinated home care and hospice services, encompassing medical, emotional, spiritual and social support, to almost 2,000 patients in eight counties within a 50-60 mile radius of its headquarters in Winston-Salem, North Carolina. Formerly known as Hospice of Winston-Salem/Forsyth County, the organization recently changed its name and expanded its mission to include palliative care. HPCC provides a wide range of services for patients near the end of life in both home and long-term care settings, facilitated by a highly trained interdisciplinary staff, a large group of volunteers, and collaborative relationships with medical centers, nursing homes, academic institutions, and community organizations. It also offers rotations for medical residents and fellows, free bereavement support to anyone in the community, advance care planning, and programs targeting particular vulnerable populations, such as infants and children. This year, HPCC is one of three recipients of the American Hospital Association's Circle of Life Award for innovative work in end-of-life care. Among several groundbreaking programs that HPCC has undertaken is one designed to provide coordinated, comprehensive disease management and emotional support to patients with congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD). This initiative, entitled FOCUS, is described by one of its founders and coordinators, Betsy Clark, RN, CHPN in the following interview with Innovations Associate Editor Karen S. Heller, Ph.D.

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Please tell us about how the FOCUS project began.

As you know, for the past few years, many hospices have been considering the best ways to serve people who have diagnoses other than cancer, which is the group that hospices traditionally have served. We launched a specific program for patients with congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD) patients in 1999, when our hospice participated in a six-month Breakthrough Series Collaborative on improving care for patients with advanced CHF and COPD. The Collaborative was presented by The Institute for Healthcare Improvement (IHI), the U.S. Department of Veterans Affairs, and The Center to Improve Care of the Dying. In March 1999, we started FOCUS as a coordinated, comprehensive disease management program for CHF/COPD patients in order to reduce the number of exacerbations of symptoms they experienced that required outside interventions, such as emergency room visits or hospitalizations. Until that time, we had served a small number of CHF/COPD patients, but had not yet developed a specific program for them. Since Hospice & Palliative CareCenter in Winston-Salem is licensed for both hospice and home health care, almost anyone with a chronic, debilitating diagnosis of CHF or COPD would be eligible for one of our programs. Patients don't need to have the six-month

prognosis required under the Medicare Hospice Benefit to be eligible for our care.

Prior to joining the Collaborative, we had looked at our hospice census and state health statistics for Forsyth County to see which segments of the patient population in our county we might not be serving well. Four years ago, we were serving about 1 in 7 patients who died from CHF or COPD in our county. At that time, those diagnoses made up less than 5 percent of our average daily census. In 2002, by contrast, we served 1 in 4 people who died from these two diagnoses in our county, and had more than doubled the proportion of patients with these diagnoses among the patients we serve across the whole organization (home health care as well as hospice). Now, close to 50 percent of our patients have diagnoses other than cancer. Of these non-cancer patients, about 25-30 patients with CHF and COPD are enrolled at any given time, which comprises 10-15 percent of our total patients served. Another 35-40 percent of patients have ALS, stroke, dementia, and other non-cancer diagnoses.

Although most of the CHF/COPD patients in FOCUS are living at home, there are now a few patients in the program who are living in skilled nursing facilities or in assisted living settings. Approximately one-third of our average daily census is in extended care facilities and 5 percent of those patients are enrolled in the CHF/COPD program.

Project Goals

What were your goals for the project?

Our aims then, as well as now, were threefold: (1) to help our patients with CHF and COPD and their families reduce the number of exacerbations of symptoms that resulted in an emergency room visit or hospitalization, (2) to provide them with palliative symptom management so that they could be comfortable at home and not have to make those traumatic visits to the hospital, and (3) to help the patients, their families, and our staff feel more in control regarding the disease process and attendant symptoms, and more in control of the plan of care.

In choosing a name for the program, it struck us that what we were doing was emphasizing the focus that we place on palliative, comprehensive, customized care for this patient population, alleviating symptoms, and providing good medical management, all in the home care setting. So, rather than find an acronym that would encompass all of that, we decided to call the program "FOCUS."

Taking a Continuous Quality Improvement Approach

How far along were you in developing FOCUS when you joined the Breakthrough Series Collaborative?

We were still very early in its development when we joined the Collaborative. In fact, we had really only looked at it from the standpoint of how much of our average daily census was impacted by these two diagnoses, how many people with these diagnoses in our county could we be serving, and in what ways could we improve the care that these folks were getting in order to keep them at home. So, immediately after we found out we were going to be in the Collaborative, we did a retrospective chart audit, and looked at the patients we had with these diagnoses for the three months before the Collaborative started. We found that of 54 patients with exacerbations of symptoms, all 54 had been hospitalized or presented to an emergency department. I'm pleased to say that during the first three months *after* we initiated the program in 1999, of 71 patients with exacerbations, only two were

hospitalized. Over the past four years, we have maintained our success, averaging anywhere from 8-20 exacerbations per month and only 0-2 hospitalizations per month. ([Figure 1](#) shows the number of outside interventions compared with the number of symptom exacerbations in 2002).

How did participation in the Collaborative influence the directions that you took and your whole process of developing the FOCUS program?

I would have to say it had a strong influence. The Rapid Cycle continuous quality improvement process promulgated by the Collaborative includes an ongoing cycle of activities—Plan, Do, Study, Act (PDSA)—which we used to plan and implement the FOCUS program here. What we learned from the Collaborative guided how we came up with our aims and formulated the measures that we used to track what we did. Our participation in the IHI Collaborative ended in September 1999. We have continued the FOCUS program ever since.

Implementation of the FOCUS Project

Internal Support

Was your hospice administration supportive of your plans?

They were extremely supportive from the beginning, which is a big part of this program's initial success. We were very lucky that from our CEO on down, the leadership and staff of our hospice were very committed to this program, including making and supporting the changes we needed in our usual processes and policies, and the forms we used. It is a measure of this support that our administration has made the FOCUS program the standard of care for our organization for these two patient populations.

Patient Eligibility

How do you determine which patients are eligible for care under this new program?

The initial criterion is that CHF or COPD is the primary diagnosis for which the patient was referred to us. Referrals come to us through patients' families, clergy, neighbors, nurses, and physicians. If the patient is referred by someone other than the physician, we call the physician to verify the diagnosis and ask the physician if that patient would benefit from the program. Then, when the admission team goes to the patient's home and explains the program, the team evaluates the patient and his or her caregiver to see if they are willing and able to participate. We focus the education and care on both the patient and family. Since we are primarily a hospice, it is habitual for us to speak of the patient and family as one unit, and I will do so here. However, the FOCUS program also serves patients who live alone and we do not require patients to have family members in order to participate.

Upon evaluation by the admitting team, some patients may be deemed unable to benefit from the program because they may not have the capacity to learn the necessary information (for example, they may have an additional diagnosis of dementia) and/or the caregiver may be debilitated or impaired in some way that would make the program more of a burden than a benefit. It is not necessary that the patient or caregiver be able to read in order to participate, because we use various visual tools (drawings, sponges, balloons) to communicate the information they will need. Of course, patients and or families have the right to refuse to participate if they choose.

Initially, during the six months that we were in the IHI Collaborative, we excluded nursing home residents with CHF or COPD from the FOCUS program because it required a little more investment of time to work with nursing home administrators, directors of nursing, and pharmacy consultants to create policies for them to use, and to secure the urgent medication kits, because that's not something that long-term care facilities are used to having around. In addition, because of the large number of caregivers involved, teaching the educational material was a challenge. Not only was it difficult to reach all caregivers, some long-term care staff felt our attempts at education were intrusive. Now, however, we follow the same steps if someone with CHF/COPD living in a nursing home is referred to the program as we do with someone living at home. In addition to calling the patient's physician, we talk with the director of nursing at the facility to make sure that she and her staff, who perform the caregiving functions that family members would perform when patients are at home, are willing to participate in the program as well. We had to adapt our education and policies to facilitate the inclusion of nursing home and assisted living residents in the program.

Key Elements of the Program for Patients Living at Home

Can you outline the key features of the program for patients and families living at home?

The elements include:

- Twice a week home visits during the first month after enrollment to educate and support patients and families
- 24-hour, 7 days a week on-call service
- Intensive patient/caregiver teaching about disease and symptom management, using key tools, including a self-care calendar to be completed daily by the patient or family caregiver and a workbook with disease-specific information about COPD or CHF and its treatments, and tips on self-care for patients and family caregivers
- An urgent medication kit authorized by the patient's doctor is kept in the home for emergency use by FOCUS on-call nursing staff
- Weekend check-in phone call by social worker
- Patient's primary physician manages the care overall; the assigned FOCUS team communicates weekly with this doctor
- Seamless transition to hospice care, when needed

What happens when someone in the home setting is admitted to the FOCUS program?

Once we have verified the patient's diagnosis and whether or not the patient's physician feels that that person would benefit from the program, we schedule an appointment for the admitting team to make a home visit. During that visit, the admitting team explains the program to the patient and family and evaluates them for their ability to participate. If the physician has agreed, at the time he was called, to write a standing order for the [COPD urgent medication kit](#) or the [CHF urgent medication kit](#), that kit would be delivered by our pharmacy the same day. However, if the primary physician does not agree to the urgent medication kit, that decision is clearly documented in the medical record. In addition, the nursing staff would ask our Medical Director, Dr. Richard

Stephenson, to contact that particular physician to discuss his or her concerns peer-to-peer.

If we do not get orders from the primary physician for the urgent medication kit, it can affect our ability to control the patient's symptoms quickly at home. In the event that the patient had an exacerbation of symptoms, our on-call nurse would make the home visit, and then call to report her findings to the primary physician and attempt to obtain orders for medication at that time. Once the nurse obtains orders from the physician, she would then have to contact the pharmacist (who would need to come in to the pharmacy after hours, as well) and the nurse might have to leave the patient to go to the pharmacy and pick up the prescription and then return to the home, by which time the patient could be in great distress. This delay in symptom management is what often compels the patient to go to the emergency room for urgent care. So, having the urgent medication kit at hand in the home is an important factor in what makes this program effective.

How does the program unfold after a patient is admitted?

In the FOCUS program, the patient's care is managed by their primary physician, but each patient is cared for by an assigned team of a nurse and support care person (chaplain or social worker) All our orders come through communications with the primary physician. The patient's assigned team (a nurse and social worker or chaplain) verbally updates the primary physician on a regular basis, initially at least once a week.

The day after the admitting team visits the patient, the assigned nurse makes a first visit (of approximately an hour to an hour and a half), and the following day, the assigned social worker visits the patient and family. During these visits, the nurse and social worker review with the patient and family caregiver what the program includes and begin the process of educating them about the disease and managing its symptoms. This intensive face-to-face educational process unfolds through twice weekly home visits over four to six weeks.

A central tool in this education process is a **workbook** for each diagnosis (CHF and COPD), which is geared to both the patient and family caregiver⁴. Terrie Spease, LPN, and I developed the workbook and the whole educational process ourselves, in consultation with a clinical nurse specialist from cardiology private practice and a physician's assistant from pulmonary private practice.

Tools for teaching and tracking: The workbook and self-care calendar

The workbook includes either a [COPD self-care calendar](#) or a [CHF self-care calendar](#) that our staff teach the patient and/or caregiver to complete on a daily basis. We use the calendar as a way to track what happens to the patient in between visits, so it's important that he or she understands how to complete it. The calendar has little check blocks on it that the person can check if particular symptoms that are specific to the disease are experienced, and then there is a place at the bottom where the patient rates that day overall as "good" or "bad" with respect to symptom management. This calendar is a good way for our staff to track disease progression. For example, each month, staff are responsible for documenting the number of "bad" days a patient has indicated on the calendar; then, staff compare month to month to see whether the "bad" days are increasing. The calendar is also beneficial to patients and families in that if they have had several "good" days, but then have a "bad" day, they can look back and evaluate that day to see whether there may have been precipitating factors to the bad day. For example, the factors might be that they didn't take their meds, or they were exposed to increased allergens or smoking, or there were emotional triggers.

The workbook also includes a list of commonly used medications for the given disease. The staff uses that particular sheet to highlight for an individual patient what medications he or she is on, and explain in easily understood language how each medication works, what it is supposed to do (e.g., to relieve shortness of breath or relieve feelings of nervousness or anxiety) and why it's important that the patient take it. We have found that persons with COPD/CHF are prone to not taking medications appropriately due to the side effects, which can include increased urination, increased nervousness, and so forth. Often, these noncompliant patients do not have a clear understanding of why the medications are important in controlling their disease. We have found that patients become much more compliant in taking these medications when they truly understand their importance in managing their disease.

Teaching about disease process and management

On subsequent visits, the team will begin working with the patient and family caregiver on the disease process and disease management sections of the workbook. We provide staff with different tools, such as drawings in the workbook, and sponges and balloons, to use during the teaching process. The sponge is a great way to show how a healthy heart functions versus a diseased heart, and the balloon is used as a model for the lungs. For example, the nurse can use the sponge to soak up a large quantity of water and squeeze it all out quickly, then soak up more water, this time squeezing it out slowly and incompletely. The balloon is blown up fully with the air quickly expelled, then blown up slightly, the top is pulled tight, and the air is slowly let back out. These additional visual cues really help the patient and family understand how a healthy organ would function and how theirs may be functioning.

Part of the education that the assigned teams provide to patients and their family caregivers concerns what symptoms they can expect to experience, what to do when symptoms worsen, and how to handle each symptom. Staff also review when and how to use a breathing treatment, inhalers, and additional equipment. They also teach what medications are in the urgent medication kit and when and how to use them if the hospice nurse instructs them to do so prior to her arrival. In addition, staff take the opportunity to do some practice drills in which they rehearse the steps that the patient would take if certain exacerbations occurred; in other words, "If this happened, what would you do?" This process is similar to the "Stop, Drop and Roll" drills the fire department uses to teach people about how to respond if caught in a blaze. Because of that education, we all know what to do should we catch fire. Our thought was that our staff could do the same thing for disease symptoms, such as dyspnea, dizziness, and so forth.

Do you formally evaluate people's knowledge and ability to manage their symptoms?

Not formally. There is a log in the back of the workbook that staff are required to complete at each home visit, whether it's a nurse completing a clinical piece of the training or a social worker or a chaplain completing the guided imagery or non-pharmacologic symptom management, or going over advance directives. On this form, staff record the date of their visit and their initials, and under each item that they taught or worked on for that visit, they note what they instructed or re-instructed, and code the log as to whether that learning objective has been achieved or whether it needs further instruction. So, if a PRN person or an after-hours person does go to the home, he or she can flip through that log to see whether there's a specific area that they feel is in need of attention and where the patient is in the training.

How does the team continue to provide care to the patient and family?

For the first month, the team visits patients twice a week, and we have a palliative care social worker assigned every weekend who calls every person in the program to check in with them and/or their caregiver. These weekend follow-up calls are made to patients and/or caregivers throughout their participation in the program. One of our goals in requiring staff to make these calls was that we didn't want our clients or their family members to feel marooned when Friday at 5 o'clock comes. Crises don't tend to stick to the workday schedule. Plus, persons facing these types of illness tend to have increased anxiety, and anxiety tends to increase when they feel alone.

Patients or family caregivers also can call into our 24-hour, 7-days-a-week on-call service. We have on-call service nurses who make emergency home visits. Since 1999, when we began this program, support staff (such as a medical social worker or chaplain) are also on-call and available to make these visits. So, if the triage nurse receives a call from one of the patients in the program or their caregiver concerning symptoms that need to be managed, she would notify an on-call nurse and on-call support staff person to go out to the home. When we started this program, the support person would come to the house the following day, but patients and family members have let us know that they prefer the support person to accompany the nurse to address any emotional issues at the same time as the medical issues, so now both staff go to the home at the same time.

Our organization now serves eight counties, which are within a 50-60 mile radius in any direction from our home office in Winston-Salem. We're located right off Interstate 40, which runs across the county from one side to the other, and gives us good access to anywhere we need to go. During the day, we have approximately 20 nurses working, but after hours, our staff is scaled back significantly. Only 3 nurses work at night and are available only for urgent care. If you have one call coming from a patient in a northern county, one in a far western county, and one in a southern county, and somebody right in the middle of town needs something, any one of these nurses could be 50 miles away at any given time. We still try to reach patients' homes within 30 to 60 minutes.

We teach patients that if they experience certain symptoms, they should call the on-call number, but also do the exercises they have been taught, knowing that by the time the patient has completed these tasks, the on-call team will likely arrive at their home. For example, while waiting for the nurse, the patient can do one of their controlled breathing techniques or a relaxation exercise, or take their Lorazepam or their Alprazolam, or use their breathing treatment. Waiting for the nurse to arrive has not been a problem very often, because we are very fortunate in that our triage staff are very knowledgeable and well-versed in the protocol for CHF and COPD patients. While simultaneously dispatching the support person and the on-call nurse who will perform the assessment and administer any medication that may be needed according to the standing physician orders, the triage staff person can stay on the phone with the patient and/or family caregiver, to provide a calm and reassuring voice to guide them through whatever steps they are undertaking until the nurse arrives.

If the patient needs to be hospitalized, how do you ensure continuity of care?

If the patient does need to go to the hospital, or has a change in provider for some reason, the nurse who last saw the patient while under our care completes a written transfer form regarding his or her condition at the time of transfer, any advance directives that the patient may have in place, what the code status is, and any particular psychosocial issues that need to be addressed, either ongoing or related to this particular incident. The transfer form is taken to the hospital with the patient. Ideally, one of our staff is there with the patient and the reason for hospitalization is that we could not manage their symptoms at home. Our agency also has a hospital coordinator who will locate where that patient is in the hospital and go over the information on the transfer form with the hospital

nurse assigned to that patient. Then that form is placed into the hospital medical record so that hospital staff have a record of what our plan of care is, what the patient's advance directives are, what medications he or she was on at home, if the patient already had oxygen or not, and things like that. When the patient is discharged back home, the hospital completes a form that they send back to us with any changes that were made in the plan of care. This process has worked very well to ensure continuity of care in those rare instances when a patient needs to go to the hospital.

Providing a Seamless Transition to End-of-Life Care

What happens when people are near the end of their life? Does the process change?

When a patient is dying, the assigned teams increase the frequency of their home visits. The education provided to the patient and family then includes what to expect at the time of death, the disease-specific changes that will be seen, along with some of the overall changes that would be expected, and what to do when those occur. If the caregiver is overwhelmed with continuing to manage the patient's care on their own in the home, as a hospice, we have the advantage of being able to provide 24-hour nursing care (crisis care or continuous care) in the home. That level of care is covered by the Medicare and Medicaid Hospice Benefit, some commercial insurance, and other payers.

Are these patients transferred to hospice care at that point?

Yes, if they had not been admitted to the hospice program initially, there would be a family meeting and a consultation with their physician and they would be transferred into the hospice program; however, their assigned care team would remain the same as before. We try not to transition teams. That's why all of our patients, whether enrolled in the FOCUS program or not, are assigned geographically, based on their zip codes, to teams. So, the same team would take care of the patient at whatever level of care they need, for however long they are under our agency's care.

After the patient's death, for how long do you follow up with the family?

We follow up with the family for 13 months after a death. At scheduled intervals, we mail them written information about the grief process, how they might be feeling, situations that might come up, decisions they might need to make. We also mail something to them on anniversaries of special occasions, such as the patient's birthday or what would have been their wedding anniversary. If they need bereavement counseling, we have Masters-level prepared counselors who can do one-on-one counseling, and who regularly conduct support groups for all kinds of grief and loss, continuously throughout the year, for anyone in our community who wants to participate. In addition, our counselors offer 12 free counseling sessions to anybody in our community who may need and request this, regardless of their involvement with our organization.

Engaging Physician and Other Staff Interest

How did you get physician support for the FOCUS program?

After we developed the workbooks for each diagnosis, we needed to obtain buy-in from the physician community. Just getting them to work with us and to agree on what medications should be included in the urgent care kits and how these should be used was a big piece of our initial effort. At the time, I was the hospital coordinator for our agency, so I had an advantage in that I was able to track most of the physicians down face-to-face, one-on-one, on rounds every morning. I was the

hospital coordinator for both major hospitals in our region, the Wake Forest University Baptist Medical Center and Forsyth Medical Center, a division of Novant Health in this region, which is a fairly large hospital.

We started with the pulmonologists and the cardiologists. Terrie Spease and I went to the physicians' offices and one-on-one, educated them regarding the entire FOCUS program, what was in the medication kits, how the kits were used, what the nursing staff was taught, and what the patients and families were being taught. With a list of medications in hand, I asked each physician, "Which medications would you agree to have in the kit?" The opinion of the majority of physicians determined what actually was included in the kit. Once we developed a collaboration with these specialists, and they decided what they wanted in the urgent medication kits for COPD and CHF, respectively, and how they wanted their two patient populations treated, then we approached some of the other physicians, primarily those in internal medicine and general practice.

How many physicians did you reach in that way? It sounds very labor intensive.

It was. We were able to involve several large group practices. We had two pulmonary practices and two cardiology group practices, which together encompassed 20 to 30 physicians in private practice, and then we involved two extremely large group practices at Wake Forest University Baptist Medical Center, which together added another 60 physicians.

We started talking with physicians even before we went to the first Collaborative meeting. The initial work of meeting only with the cardiologists and pulmonologists took us about three months. As the Collaborative progressed, and since then as we have continued the program, we expanded our educational outreach to internal medicine, general practitioners, and other physicians. We go back to the medical center probably every 18-24 months to reach the new health professionals practicing there.

In addition to physicians, we went to the hospital discharge planners and educated them about the program. At the time, we had two fairly large managed care organizations that were a large part of the health care market here. Terrie and I went to see each of their nursing coordinators and their managed care Medicare coordinators as well.

When we started this project, Terrie and I did all the outreach to health care professionals ourselves. Two and one-half years ago, we hired a full-time medical liaison who does all this now. Part of her job is to make routine visits to physicians in the area to educate them about the FOCUS program. We're very fortunate that we have an excellent internal and external education staff. We also now have three hospital coordinators, not just one, and a specific nurse liaison for the extended care facility community. These five people really provide significant educational outreach in our local community of Winston-Salem and Forsyth County, North Carolina.

Staffing for the FOCUS program

Do you have separate designated staff for the FOCUS program, or do all staff rotate through this program?

Our organization has five home health and hospice teams that carry anywhere from 35 to 55 patients. Each team has both home health and hospice patients, and as I mentioned earlier, patients are assigned to teams geographically. Two of the five teams are dedicated solely to nursing homes and can carry as many as 60 patients sometimes. Teams consist of four nurses, two medical social

workers, a chaplain, and two certified nursing assistants. If a patient is seen by after-hours staff, that staff person reports back to the patient's assigned team.

All of our hospice and home care staff are now trained to care for the CHF/COPD patient population. Initially, however, we asked for volunteers from our staff for this program. We had some nurses, in particular, who were interested in the CHF/COPD patient population. We selected a small group consisting of two nurses, one social worker and one chaplain. They were trained and initially they handled any patient who was admitted to our service and enrolled in the program. We also trained our after-hours staff. So, from the beginning, we sought to ensure that anyone who would have contact with the patient and family was well-versed in the program and its different elements.

One of the lessons that we learned, however, was "be careful what you ask for," because this program was very well received and we were just bombarded with referrals. In response, we quickly had to expand our education to the entire clinical staff, so that everyone could begin taking patients that were enrolled, because the small group was overwhelmed and could not handle all the patients that were being enrolled.

Staff Supervision

As leaders of this program, do you supervise the teams that go to patients' homes?

No. I think that was probably a sore spot for Terrie and me at first, because we felt that we were charged with responsibility for doing all of this, yet we have no control over the people who are out there doing it. But we meet regularly with the nurse managers who are the leaders of each team; each month we go over the exacerbations that have occurred and the reasons for any hospitalizations that may have resulted. We discuss with the team leaders whether we could have done anything differently and ask for their feedback about whether the teams have the resources they need and anything in our process of education and care that might need to be tweaked. In addition, at the weekly team meetings held to discuss all our hospice and home care patients, the team leader asks the team specific questions to elicit information about the CHF/COPD patients, which they could then bring to us.

Staff Training

How did you train your staff?

At the same time that we were doing the initial outreach to physicians and health care professionals in the community, we provided education about the new program to our own staff, even the seasoned staff, because we wanted to make sure that everybody understood the expectations of the program uniformly so there would be no unanswered questions. We needed to make sure that our staff, who were well qualified generalists and knowledgeable about the ethics of terminal care, received a little more education and disease-specific training on these two diagnoses. We couldn't expect patient/family teaching to be successful if our own staff were not comfortable handling the symptoms.

Either Terrie or I held in-service education classes internally here at HPCC. We did all the education ourselves, except for a few specific pieces. We taught staff about the workbook and its contents, which included sections on disease process and management for each of the diagnoses. For those sections, we invited specialists from one of our local pulmonary and cardiology offices to come and

provide some disease-specific training for our staff. We also did some role-playing with staff to show them how the notebook would be used in educating the patient and family.

In addition, we also trained our staff on changes we made in how we responded to calls from CHF/COPD patients or their caregivers.

Policy Changes

What changes did you make in your agency's policies and practices as part of implementing this program?

One of the first changes we had to make was training our own staff, as I've just described. Then, we created an identification marker for each CHF/COPD patient participating in the program that went into our 24-hour on-call information, so that anyone who took a call could readily identify the patients participating in FOCUS. When we began this program four years ago, HPCC had a triage nurse who would take calls from patients or caregivers 24 hours a day, and then--on the telephone--talk people through whatever was going on with them. With the new program for CHF/COPD patients, we eliminated the step of talking patients through their symptom management on the telephone and substituted a new policy of immediately dispatching a nurse and support staff person to the patient's home with the goal that they would arrive there within 30 minutes, at most within an hour. This is the process we still follow in training our staff and in responding to calls from these patients, 24 hours a day, 7 days a week.

Eliminating the walking through symptom control on the phone was one of the pieces we had to encourage our nursing staff to do, because that is what they had been used to doing. Immediately making a home visit was a big change for them. Our thought was that if we are teaching the patients and families to control the symptoms, yet they are calling for help, either our teaching is ineffective or incomplete or the symptoms are beyond the patient or family's control. So, in such cases, an immediate nursing visit is required to assess what is going on and if the urgent medication kit is available in the home because physician had agreed to write a standing order for it, the nurse would administer the medications. The nurses carry the supplies with them to administer injectible medications, if the symptoms are not controlled by other means. The only injectible medications are Lasix (Furosemide) in the CHF kit and Solu-Medrol (Methylprednisone) in the COPD kit, which are administered intravenously. Although we found it necessary for the nurses to carry the supplies for administering the medications with them, both federal and accreditation regulations do not permit our staff to carry the medications themselves.

Another change was that prior to initiating this program, our support staff (chaplains and medical social workers) had not been required to visit anyone who called in complaining of symptoms after hours or on weekends. That was always strictly a nursing visit. But because almost 50 percent of the symptom exacerbations in our CHF/COPD patients were either completely or partially related to the anxiety about the worsening of symptoms, we required that support staff visit the patient at the same time as the nurse. They would assist with the patient's anxiety, either through some relaxed breathing or guided imagery, or if it truly was a medical emergency and the nurse needed to provide interventions and medication administration, then the human service or support service staff person was there to assist the family or caregiver while the medical intervention was taking place.

One of the biggest changes was establishing the standing physician orders for the urgent medication kit. At that time, we did not have our own pharmacy. So, we had to meet with our pharmacy

provider and explain to them what we were doing. They were kind enough to come up with a way to dispense and package the urgent medication kit for us, and then work with the physicians who wrote the orders. The first thing we did was to have the physicians decide what they wanted in the kit. We still provide constant education to physicians and physicians' staff about the kits and the orders, and how that process works. We fax the order forms for the kit to the physicians' offices; the physicians' staff have the orders signed and faxed back to us; then, we deliver the kit to the patient's home and the nurse explains to the patient and family how the kit is used. These are probably the main changes we have implemented.

How have the emergency home visits been received?

They have worked very well, and we have received good feedback from patients and family. Staff now appreciate this approach, as well. In fact, we have instituted this process across the board now, regardless of the diagnosis, in response to patient or caregiver calls related to an exacerbation of symptoms. We do very little walking folks through on the phone anymore. This occurred because we saw that the results of this approach have been very good.

Barriers to Successful Implementation of the Program

What have been the major barriers you faced in implementing this program, and how have you surmounted them?

Probably the most significant barrier that we have found is that almost every exacerbation that results in a hospitalization now is due to the fact that the exacerbation cannot be controlled without medication, and, for one reason or another, there is no urgent medication kit in the home. Usually this is because we still have a few physicians who are reluctant to give what they consider a blanket order for the use of the urgent medication kit. Sixty to seventy percent of referring physicians sign the standing orders for the urgent medication kit; however, a few are reluctant to do that. One factor may be that the kit contains 3 cc's of oral, liquid morphine. When we began approaching physicians about this program, some of them had very distorted and inaccurate ideas about the use of morphine to treat these patients' pain, and about appropriate hospice care, in general, which should never be equated with physician-assisted suicide. I had a pulmonary physician say to me after I explained the program to him and went over the medication kit, "Well, I'm just glad you're not going to treat my patients like you do the rest of your patients and give them that Dr. Kevorkian kit." That was their mindset when we began this: if you refer a patient who doesn't have cancer to hospice, the staff would treat him like all their cancer patients and give him all the same drugs. When they realized that we had distinct treatments for patients with CHF/COPD, that we were providing them with different information and education, and that the medications in the kit were almost entirely different from those in the standard kit that goes to patients with other diagnoses, the physicians grew more comfortable in referring patients to us. The standard kit has some of the same medications as in the CHF/COPD kit; e.g., liquid morphine (for pain and shortness of breath) and Ativan (for anxiety), but it also has medications for constipation, fever, nausea and vomiting, control of secretions, and things that would be unrelated to symptom control for CHF and COPD.

Have physicians ever expressed concern about possible interactions between the medications that patients are already on and the medications in the urgent care kit?

That has not been the issue expressed by them. Part of what our pharmacists do, every time we admit a patient, is cross-reference all the medications that the patient is on, even the ones that are

not dispensed through our pharmacy, and the urgent medications that they may need, to make sure that there are no allergies or drug interactions. We're very fortunate that we own and operate our own pharmacy.

Have patients or family members been concerned about having morphine in their home?

No. The medication kit was originally packaged in a small box, which was sealed and labeled by the pharmacy, with instructions to keep it in the refrigerator and that they should not open it unless instructed to do so by the hospice nurse. So, generally patients were not opening and self-administering these medications. We are now in the process of changing the packaging of the kit to a Ziploc bag. The bags are sealed with a gummed label that is placed on it by the pharmacist at the time it is dispensed, with directions that it is only to be opened under the direction of the hospice nurse.

In addition to resistance from some physicians to signing a standard order for the urgent medication kit, have you met resistance from your own staff to any part of this program?

The only other area of resistance was in changing the mindset of nursing and human service staff with regard to making after-hours visits. We had to demonstrate to the nursing staff the need to make the after-hours visit in a timely manner, as opposed to the previous practice of initially advising the patient and/or caregiver by phone if possible before making a home visit. We also had to educate the human service staff as to the importance of these visits.

Sources of Feedback about the Program

How do you invite staff feedback?

Originally, when Terrie and I first developed and implemented the program, we met with the teams every week to receive a progress report and find out what aspects of the program were working or not working, and what needed to be tweaked. In addition, because both Terrie and I are nurses, and pastoral care and social work were not our strong suits, we initially sought a lot of input from our chaplains and social workers regarding those pieces in the patient and family workbook that concern self-care and meditation and things like that. Currently, our hands-on involvement in program implementation is limited, but we meet with the team leaders on a monthly basis. Virtually everybody knows that if an issue comes up, they certainly need to share it with us and that we can work with them to make any needed adjustments.

How do you solicit feedback from patients and family caregivers?

Three months following the patient's death or discharge from the program, a program-specific survey is sent to family caregivers (and/or patient, as appropriate) asking whether they were satisfied with how the program assisted them in controlling their symptoms at home, and other related topics.

If the patient or family caregiver has complaints about the staff or other aspects of the program, how are those handled?

Any complaint goes through our risk management and compliance officer. If it is something specific about the fundamentals of the program or the operation, she brings that to Terrie or me; for example, if there was something attributable to a failure to follow the program procedures, or

something in the program that was offensive to this particular patient, or to determine why something didn't work. If a complaint specifically concerns staff, that would go directly to the team's manager.

Measuring Success

How have you measured your success overall?

We have measured the success of the program primarily through a significant decrease in hospitalizations of these patients. We also measured patients and family satisfaction with the assistance they have received through the program in maintaining themselves and managing their symptoms at home. In our pre-admission survey, one of the questions that we asked patients and family caregivers was "Would you prefer to control your symptoms at home?" I believe almost 100% said "Yes." Yet, we had demonstrated that before we started this intervention, none of the patients were comfortable doing so; all 54 patients with CHF or COPD had gone to the hospital. So, with the FOCUS program, patients and families have been able to feel in control at home, and at the same time know that if they had done everything they were taught and had practiced in their drills with the staff, and their symptoms still were not relieved, a team from our agency would come to see them right away.

During the initial six months of the program, we also measured an increase in the number of patients with these two diagnoses who were enrolled in our program. I believe the number of patients with CHF/COPD who enrolled tripled during the year we were in the Collaborative. That increase measured our effectiveness in recruiting, but also indirectly, the effectiveness of the education we provided to the medical community about the program, their understanding of our goals, and their satisfaction with the program so that they continue to refer.

Sustaining the FOCUS program

How has this project been funded, both at the beginning and now?

Initially, as a hospice, we just did it, without an independent revenue stream to support it.

Our participation in the Collaborative came out of the hospice's administrative budget. The education piece came out of the clinical budget; it was just part of what we did as an organization. Patient care generally was covered under one of the usual reimbursement categories, either for home health or hospice care. If CHF or COPD patients did not fall into a reimbursement category, and the patient and family were in need of the services, and the physician said "Yes, this would benefit them," then our community funding was used to pay for the services. We have a generous community here with regard to hospice. Private donations cover 12-15 percent of our budget every year. We continue to sustain the program through these same sources of revenue.

Distinctive Features of This Program

How is your program distinct from other efforts that also emerged from that IHI Collaborative on CHF/COPD? What is unique about your program?

Our unique features are probably the intensive, ongoing education of the patient and family, and the fact that we treat the exacerbations of symptoms in the home care setting, with an urgent medication kit readily available in the home. Most of the other participants in the Collaborative were looking at

either telephone monitoring or advanced care planning or modifying their medical record in some way. Kaiser Permanente, in California, was already serving CHF/COPD patients in 1999, but their program primarily involved clinical nurse specialists doing telephone management of symptoms; they didn't have in-home medication kits or anything like that. To the best of my recollection, we were the only ones who actually were making home visits to provide the symptom management. Another workbook for patients and family caregivers has come out of the Collaborative². Our workbook probably has some of the same components as that one; however, what may be different is the way that our staff uses it during the 4 -6 week, twice weekly intensive face-to-face educational process with the patient and family.

Why did you choose to do in-home patient and family education and symptom management by an assigned interdisciplinary team instead of doing telephone coaching like some of the other hospices are doing?

We felt that given that we are a hospice and home care is what we do, we would have a better chance of making a significant impact on the patient and family--not just through advocacy and symptom management--but by helping them feel in control and comfortable with their disease process, even though most of them are end-stage, some farther along than others. We wanted them to feel comfortable that if something does happen, they would know what to do, at least until someone can get there to help them.

To your knowledge, are you still unique in that regard among hospices that may address this population?

From the feedback that I have received from the few hospices that have called and asked, I believe that most other groups are just now starting these kinds of programs.

Lessons Learned

Looking back, what would you say are the major lessons you learned from undertaking the FOCUS program?

First, I think your organization's administration has to be on board -- they have to support this effort and the changes that are required. Since we had excellent support from our administrators from the beginning, this was not so much a factor for us as it may be for some other organizations that might seek to replicate our efforts. Then, the next two big challenges are finding buy-in from physicians and from your own staff. Educating our staff and having them work with us on making the changes that were required in our normal processes in order to implement this effort effectively was another important piece. Then -- we learned that you have to be ready, because when people find out they like this, you can get overwhelmed by the increase in referrals. You're creating a demand and you have to be prepared to meet it, because you don't want to do this half-heartedly.

Advice for Others

Are there any other things that you would advise others interested in following this example?

I, personally, truly feel that this would not be successful without the urgent medication kit. It is of major importance in providing management for symptoms in a home care setting, because if somebody is experiencing these kinds of symptoms and needs something done, they need it done

then. You can't tell somebody, "Oh, well, you'll just have to wait for relief." If that little box or bag is not there in the home, with the appropriate medicine for that symptom right then, there is no choice but to send the patient to the emergency room. So, it's extremely important to have the urgent medications readily available and accessible for the nurse to use. The patient and family have not had to wait for longer than an hour for someone to arrive, and they have been very well taught about what to do in the meantime.

Concluding Thoughts

It sounds as though your overall goal with the CHF/COPD patients is a little different from that for your hospice patients – it is more about trying to keep people alive and comfortable, rather than easing their death.

Well, it's funny that you should say that. One of our social workers who listened to all the teaching we provided, and read all the materials, commented, "You know, we're really good at telling people what to do to get ready to die. But we really need to be teaching these people what to do to take care of themselves while they're still living." So, the focus of this effort is on how to have a good quality of life for whatever time period you have, and good control of your symptoms so that you can do what you are able to do.

What is the cutting edge now in this work? Where do you hope it will lead?

Our hope is that this program will be replicated elsewhere so that coordinated, comprehensive care is being provided for patients with CHF/COPD who need it, regardless of whether they have six months to live or not. We also would like to see this model of care extended to other patient populations. Hospice needs to get out of that box of providing and reimbursing for palliative care only to people who are diagnosed as terminal within six months. I know that I may be biased, but I just can't understand why people who look at the results that we've had would not think, "This is a good thing. Why don't we do this for everybody?"

References:

1. See [Resources and Tools](#) page if interested in obtaining a copy of the workbook for CHF or COPD. [\[Return to Featured Innovation\]](#)
2. See the Washington Home Center for Palliative Care Studies entry on the [Resources and Tools](#) page for this workbook. [\[Return to Featured Innovation\]](#)