The ENABLE Telemedicine Intervention

Highlights from December 5, 2013, CHCF Palliative Care Action Community meeting, *presented by Marie Bakitas, DNSc, NP-C, FAAN, University of Alabama at Birmingham*

PURPOSE. To understand how a telemedicine intervention can be applied in palliative care settings.

The ENABLE (Educate, Nurture, Advise Before Life Ends) Telemedicine Intervention began in 1999 as a collaboration between a hospice and a cancer center to provide concurrent palliative and oncology care led by advance practice nurses (APNs). Over the past 15 years, this telemedicine model has been tested and implemented in settings across the US, demonstrating a successful approach to providing palliative care where access to face-to-face services can be a challenge, such as in rural areas.

The goal of ENABLE is to improve the quality of life for people with advanced cancer and for their caregivers. The intervention provides palliative care soon after a cancer diagnosis, concurrent with oncologic treatment. Using a coaching model, patients and caregivers are empowered to prevent crises by learning how to anticipate and plan for progressive illness and the challenging situations that may arise as the end of life approaches.

Key components of ENABLE:

- **In-person standardized assessments** are conducted on each patient by a board-certified palliative care provider (nurse practitioner or physician).
- **Nurse coaches** conduct four to six structured weekly phone-based sessions (averaging 30 to 60 minutes each) focused on problem-solving, communication, symptom management, and advance care planning. Ongoing monthly phone follow-up and care coordination continues after the initial structured sessions. The nurse coach is supportive and can consistently work with patients and their family members as they navigate the medical system. Coaches present options for care and work with patients and families so they can get care that matches their needs and values.
- **Charting Your Course curriculum** is a self-paced educational program for patients that is reviewed with the nurse coach during weekly phone sessions.

Results of a randomized controlled trial showed that, compared with participants receiving usual care (regular oncology clinician appointments and access to palliative consult team and supportive care services), those participating in the ENABLE intervention had better scores for quality of life, mood, symptom intensity, and improved survival (the latter two were clinically, but not statistically, significant improvements). Days in the hospital and ICU, and emergency department visits, were lower than national averages in both the intervention and usual care groups.[1]

1. Marie Bakitas et al., "Effects of a Palliative Care Intervention on Clinical Outcomes in Patients with Advanced Cancer," *JAMA* 302, no. 7 (2009): 741–749.

Challenges and Lessons Learned

- Nurse coach training is intensive (24 to 36 hours), and given this investment in training, turnover can be challenging for program sites.
- Some patients do not like phone interventions, so telemedicine care is not for everyone.
- Just as with in-person visits, patient no-shows can be a problem.
- Caregivers need individualized attention — not just patients.
- Because patients were being trained to communicate directly with their clinicians, nurse coaches did not need to do much communication with the care team directly.
- Initial concerns about establishing rapport and doing assessments via phone turned out to be unfounded.
- Some patients worried about being perceived as disloyal to their oncologist by working with the nurse coach.
- Some patients felt having this intervention soon after their diagnosis was too early, as they did not want to spend so much time and energy in the patient role at that stage.
- A broader economic analysis is still needed.
- The research team wants to define the essential elements of the intervention to support replication and sustainability.

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Layperson Health Advisory Model: Patient Care Connect

Highlights from December 5, 2013, CHCF Palliative Care Action Community meeting, *presented by Elizabeth Kvale, MD, University of Alabama at Birmingham*

PURPOSE. To understand how a layperson community health advisor model can be applied in palliative care settings.

The Patient Care Connect program, a collaboration among members of the Deep South Cancer Care Network of cancer treatment centers, links layperson community health advisors with cancer patients across the illness continuum (www.patientcareconnect.org). At each Cancer Care Network site, trained lay person health advisors (also known as navigators) work under a nurse program manager and other support staff to extend the reach of palliative care into the community.

The overall aim of the model is to provide the highest quality of life for people with cancer, with the additional goals of reducing the use of ineffective therapies and maximizing the appropriate use of health care resources, including reducing emergency department visits and unnecessary hospital and ICU days, reducing use of chemotherapy in the last two weeks of life, and encouraging earlier adoption of hospice care. The intervention is targeted at Medicare patients 65 years or older who have a cancer diagnosis, with a specific focus on patients with high-risk disease, psychosocial complexity, or both.

Community health advisors focus on:

- **Empowering patients to take an active role in their care.** Advisors help patients identify resources in the community, recognize clinical symptoms, understand their disease and treatment options, and engage in end-of-life discussions with their providers.
- **Eliminating barriers.** Advisors connect patients to providers, coordinate care between multiple providers, and link patients with community transportation resources.
- **Ensuring timely delivery of care.** Advisors help patients navigate the health care system and assist with access to and transitions in care.

In this initiative, participating sites recruited community health advisors who were already established members of their community and were seen as natural helpers — people who would likely have helpful guidance for people with health issues. Many advisors come from helping professions, such as retired schoolteachers or people with some medical exposure, such as staff in a physician's office. Others are cancer survivors themselves. The community health advisors go through five days of face-to-face training and team-building, with a focus on communication and motivational interviewing; general cancer education, including information on symptoms; advance care planning; and responsibilities and boundaries of the community health advisor role.

Challenges

- Time-consuming process to build strong relationships with sites implementing the program
- Turnover among community health advisors
- Training a lay population with wide variation in experience and knowledge
- Technical and software challenges requiring ongoing system modifications
- Monitoring and evaluating processes and tools used by community health advisors
- Obtaining comparison data to assess impact

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The Patient Support Corps

Highlights from January 15, 2014, CHCF Palliative Care Action Community webinar, *presented by Jeff Belkora, PhD, University of California, San Francisco (UCSF)*

PURPOSE. To discuss the development of a support program for people with cancer that leverages existing community resources, and how similar strategies could be implemented or adapted in different settings.

Patients with serious illnesses often struggle with information and communication needs, including experiences at different points along the treatment continuum:

- **At diagnosis.** "Too much, too little, conflicting information."
- **During visit.** "I forgot to ask questions that were keeping me awake at night."
- **After the visit.** "I can't recall — it all went in one ear and out the other."

Research has demonstrated the effectiveness of several strategies to address these challenges:

- Decision aids (educational materials that present the spectrum of care options during a particular crossroad) increase patient knowledge.[1]
- Listing questions in advance of a provider visit increases the likelihood that questions are asked.[2]
- Summaries and recordings of provider visits increase patients' information recall.[3]
- Informed and involved patients have better outcomes.[4]

Despite this evidence, these strategies are not widely implemented in clinical practices, and patients and family members typically do not effectively self-administer decision aids or reliably bring a skilled note-taker to clinical appointments.

To address these barriers and to support patients facing care decisions, UCSF's Breast Cancer Center developed the Patient Support Corps program (www.patientsupportcorps.org). With limited resources, the program began by training existing paid interns in the Breast Cancer Center — recent college graduates with plans to enter a health care profession — to also serve as Patient Support Corps interns. These interns typically spend 80% of their time on research and quality improvement projects and 20% on patient support activities, partnering with patients for a specific visit or a defined set of visits around a particular issue.

Intern's Role

BEFORE THE VISIT. The intern calls the patient and offers Patient Support Corps services. If the patient accepts the services, the intern and patient discuss which decision aids would be most useful, and a time is set to discuss the decision aid and to develop a question list. The intern sends the decision aid and question list form to the patient by mail or email, then has a 30- to 60-minute phone discussion with the patient to walk through the question list template. The intern writes up the question list, sends it to the patient for review, and then sends the final version to the physician before the appointment.

DURING THE VISIT. The intern attends the clinic visit with the patient, asks the patient to review the question list again, and makes any final adjustments. The intern takes notes during the visit and makes an audio recording.

AFTER THE VISIT. The intern provides the patient with a copy of the recording of the visit before leaving the appointment. Within 24 hours, the intern edits the notes, sends them to the physician for review, and then sends the notes to the patient.

The interns use the SCOPED framework to help patients develop their question list, and as a framework for note-taking during the visit:

- **Situation.** Clarifying known facts about patient's condition
- **Choices.** Clarifying which options are available
- **Objectives.** Clarifying patient's goals and priorities
- **People.** Clarifying roles and responsibilities
- **Evaluation.** Clarifying how patient choices affect their objectives
- **Decisions.** Clarifying which choice is best and next steps

Interns have observed that physicians' approaches to using the question list varies from physician to physician and even from patient to patient. Approaches include using the list to structure the visit and going through each question one by one; reviewing the list in advance, conducting the visit, and then reviewing the list afterward to make sure the physician has addressed all of the listed issues; and reviewing the list but not using it explicitly in the visit.

Program Growth and Modifications

To expand the model at an affordable cost, the program also uses undergraduates in pre-med or other health-related majors to serve as Patient Support Corps interns for academic credit.

Now formalized as a national initiative, the Patient Support Corps program is being implemented in other parts of UCSF and at Dartmouth Medical Center, and some elements of the program have been replicated in Cancer Support Community affiliates. The program also provides technical assistance to other organizations that want to collaborate with students to support patients.

While the program has focused on patients with a new diagnosis or who are new to the clinic (either early or late stage), program leaders are in the early stages of considering how the program could be used to support existing patients if their condition worsens and they face new decision points.

Key Considerations

Organizations interested in implementing a model like the Patient Support Corps should consider:

- Ability to make a three-year commitment for pilot and implementation.
- Access to resources for a staff coordinator who will lead recruitment of physicians to the program, collaborate with schedulers, and take on other administrative roles.
- Access to a liaison in an academic institution who will recruit students. It is helpful to require that students make a one-year, renewable commitment.
- Degree of motivation among clinicians whose patients the program aims to serve. Clinicians must buy into the model for it to succeed in addressing patients' needs.

Additional Resources

Resource centers, www.cancersupportcommunity.org

Decision aids, www.ohri.ca/decisionaid

Question prompts, www.sydney.edu.au

Dictated notes, www.myopennotes.org

Audio recordings and communication tips, www.carecoach.com

Professional patient advocates, www.healthadvocate.com

Second opinions, www.grandroundshealth.com, www.bestdoctors.com

Endnotes

1. Annette O'Connor et al., "Decision Aids for People Facing Health Treatment or Screening Decisions," *Cochrane Database Systematic Reviews* 2 (2003).
2. Paul Kinnersley et al., "Interventions Before Consultations for Helping Patients Address Their Information Needs," *Cochrane Database Systematic Reviews* 3 (2007).
3. Marie Pitkethly et al., "Recordings or Summaries of Consultations for People with Cancer," *Cochrane Database Systematic Reviews* 3 (2008).
4. Simon Griffin et al., "Effect on Health-Related Outcomes of Interventions to Alter the Interaction Between Patients and Practitioners: A Systematic Review of Trials," *Annals of Family Medicine* 2, no. 6 (2004): 595–608.

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Use of Technology in Community-Based Palliative Care

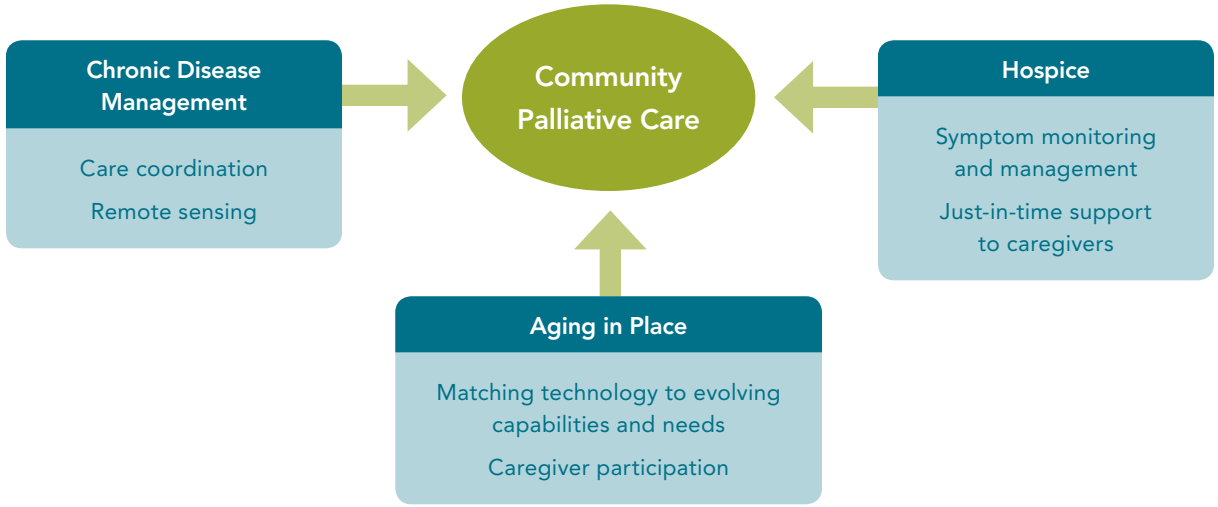
Highlights from November 13, 2013, CHCF Palliative Care Action Community webinar, *presented by David Lindeman, PhD, Center for Technology and Aging and Jill Joseph, MD, PhD, UC Davis Betty Irene Moore School of Nursing*

PURPOSE. To learn about technologies that could extend the reach or effectiveness of community-based palliative care services.

In considering opportunities to use technology in community palliative care settings, we can draw on experiences from other health care programs, as shown in Figure 1.

Based on the experiences of hospice and other programs, there are four areas in which technology can be used to improve CBPC:

Figure 1. Shared Opportunities for Leveraging Technology



- **Access.** Improving the ability of patients, caregivers, and palliative care providers to communicate about symptoms, plan of care, and other care needs outside of a traditional clinic or home visit
- **Training and support of informal and professional caregivers.** Enabling family and friend caregivers, as well as professional caregivers, to improve their skills in managing patients' care needs and to get support and guidance from peers
- **Decision support.** Providing real-time or asynchronous guidance to providers to ensure high-quality care
- **Documentation and billing.** Supporting providers in capturing essential information about care provided, both to communicate with other providers and to ensure maximum appropriate reimbursement for the services provided

For each of these areas, there are various technology solutions to meet organizations' needs (see Table 1 on the following page).

Table 1. Opportunities for Integrating Technology in Community-Based Palliative Care (CBPC)

	KEY FEATURES	TYPES OF TECHNOLOGIES	BENEFITS	BARRIERS	EXAMPLES
Access	➤ Builds on routine telephonic experience ➤ Videoconferencing available through multiple vendors ➤ Supports access to distant family ➤ Can use special-purpose or general-purpose hardware (e.g., cell phone) ➤ Evaluations show good acceptance of these uses of technology among patients and families, but mixed for staff	➤ Telehealth ➤ Remote patient monitoring (e.g., blood pressure, weight) ➤ Videoconferencing (between team members or with patient/family) ➤ Web-based tools (e.g., care management protocols that patient and provider can access) ➤ mHealth — mobile technologies (e.g., referral application available on smartphone)	➤ Enhances uptake of CBPC/hospice services ➤ Improves access geographically and functionally (e.g., reduces transportation burdens) ➤ Reduces costs (unnecessary visits) ➤ Improves patient/caregiver quality of life ➤ More efficient use of resources (e.g., time and effort of family members) ➤ Enhances communication ➤ Improves workforce efficiency	➤ Technical interoperability and regulatory compliance (e.g., HIPAA compliance) ➤ Reimbursement (need to establish a fee schedule for teleconsults) ➤ Lack of organizational readiness for technology adoption ➤ Technical quality challenges (e.g., dropped calls, dead zones)	➤ At **Saint Luke's Home Care and Hospice** clinicians carry devices to monitor patients' clinical status (e.g., oxygen saturation) and patients use remote monitoring technologies such as Health Buddy and Philips Lifeline www.saintlukeshealthsystem.org www.bosch-telehealth.com www.lifelinesys.com ➤ **Telehospice Project** is a national telehealth research project for caregivers of hospice patients www.telehospice-project.org ➤ **Hospice by the Bay** has a mobile application that streamlines referrals and consultations and provides information on having conversations with patients about hospice www.hospicebythebay.org
Training and support of informal and professional caregivers	➤ Builds on generic distance learning ➤ Recent emphasis on program evaluation ➤ Multiple tools for including patient/family in clinical team meetings ➤ A few gaming applications: primarily adolescent/young adult audience	➤ Telehealth ➤ Remote patient monitoring ➤ Videoconferencing ➤ Web-based tools ➤ Patient portals ➤ Electronic Health Records (EHRs) ➤ Sensors ➤ Gaming	➤ Improves communication and team functioning ➤ Improves knowledge and access to information ➤ Improves social connectedness (family engaged in care of patient) ➤ Increases patient and family participation in care planning ➤ Reduces costs ➤ Reduces health effects of caregiver stress	➤ Digital divide — variation in reliable access to computers, smartphones, and Internet ➤ Privacy concerns ➤ Lack of organizational readiness for technology adoption ➤ Stress of adopting new technologies ➤ Unclear evidence of benefits ➤ Loss of human interaction	➤ **University of Missouri ACTIVE Intervention** (Assessing Caregivers for Team Intervention via Video Encounters) evaluates impact of caregiver/patient participation in hospice team meetings via videoconference on improving family ability to address pain management www.fcm.missouri.edu ➤ 2013 **Virtual Learning Collaborative** through ASCO and AAHPM helps providers learn palliative care skills www.asco.org

Decision support	➤ Often builds off home health or chronic disease management models ➤ Wide-ranging capabilities and sophistication of these tools	➤ Telehealth ➤ Remote patient monitoring ➤ Videoconferencing ➤ Web-based tools ➤ EHRs ➤ Sensors ➤ mHealth — mobile technologies	➤ Enables remote and passive monitoring of patients ➤ Data trends can be used to predict and anticipate escalating health or safety concerns ➤ Mobile health can improve communication around pain management ➤ Improves care provider confidence	➤ EHR adoption barriers ➤ Technology cost ➤ Organizational readiness for technology adoption	➤ **Quality Data Collection Tool (QDACT)** includes basic decision support to help improve care, such as indicators if a problem was present on last assessment www.vimeo.com/51688989
Documentation and billing	➤ Clinical applications: electronically stored advance directives, POLST ➤ Internal or system-linked EHR, e-notes ➤ Can link metrics and billing	➤ EHR ➤ Management and evaluation tools ➤ Web-based tools ➤ Database technologies	Targeted outcomes include improvement in: ➤ Workforce productivity — improved efficiency, engagement ➤ Patient, caregiver, provider communication ➤ Patient safety ➤ Health care utilization — reducing avoidable medical utilization	➤ Cost of technology ➤ Implementation and integration into EHR systems ➤ Training staff on new technologies	➤ **University of Michigan Palliative Care Metrics and Billing Database** allows providers to track patient demographics, referral activity, consult activity, services provided, associated billing, care providers, and patient disposition www.inventions.umich.edu ➤ Electronically stored advance directives, such as the **US Living Will Registry** www.uslwr.com

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Volunteers Supporting Patients: Zen Hospice Project

Highlights from February 11, 2014, CHCF Palliative Care Action Community webinar, *presented by B. J. Miller, MD, executive director and Roy Remer, director of volunteer services, Zen Hospice Project*

PURPOSE. Examine one organization's experiences with running a successful volunteer program to support people with advanced illness, and discuss how this could be applied in other settings.

Zen Hospice Project's (ZHP) volunteers are an integral part of care delivered to residents of the ZHP Guest House, a residential hospice. They also serve residents at Laguna Honda Hospital and Rehabilitation Facility, a nursing facility and rehabilitation center owned and operated by the San Francisco Department of Public Health.

The organization considers volunteers to be a critical part of their care staff, and aims to integrate the work of volunteers and professional caregivers so that patient care is seamless and coordinated from the patient and family perspective (www.zenhospice.org).

Volunteers serve two roles:

- **Caregiver volunteers** work directly at the bedside with patients and families.
- **Special skills volunteers** serve as kitchen assistants, general office support, musicians, shoppers, or massage therapists for patients and families. This role requires less training than caregiver volunteers.

Volunteers are typically recruited by word of mouth. A detailed application is required in which potential volunteers describe their personal experiences with loss. Volunteer applicants go through an interview process, which can last two to three hours. Caregiver volunteers receive about 43 hours of initial training (two evenings and two weekends), plus four additional sessions in the first four months after the initial training. The training focuses on psycho-spiritual and practical issues, such as the role of and appropriate boundaries for volunteers, self-care, rules and regulations, intentions for service, and community-building among volunteers. A volunteer director oversees the program, and a volunteer coordinator at each site manages the administration and scheduling of 50 to 80 volunteers per site, serves as a liaison with other staff, and provides general support for volunteers.

Volunteers make a one-year commitment (though many stay much longer) to work weekly five-hour shifts. Each site has three shifts per day, and the volunteer coordinator facilitates shift change meetings during the overlapping hour between shifts to ensure smooth transitions. These meetings provide volunteers with a chance to process their experience and to voice concerns.

Other venues for communication among volunteers and between volunteers and staff include email; patient charts (volunteers are considered employees under the ZHP's license and have access to charts); interdisciplinary team meetings; monthly volunteer community meetings, which often include educational presentations; and quarterly meetings with organizational leadership.

Important Considerations for Volunteer Programs

- How will volunteers spend their time? What kind of support do patients and families need? It is important to match patients with the appropriate volunteers who have the characteristics, skills, and preferences that help fill identified needs.
- What is the volunteer trying to accomplish through their service? Volunteers should be clear about their intention for service, so that the organization can help support them as stressful or emotional situations arise or their interest wanes.
- How will the volunteer program be integrated with existing services? Staff should be prepared for the program, and the organization should be prepared to provide logistical support to volunteers (e.g., parking, lockers, meeting space).
- Who will take on the volunteer coordinator role? It is important for this person to have considerable volunteer management experience, be able to manage and navigate between diverse personalities and cultures (staff, volunteers, residents), be nimble and proactive in intervening and advocating for residents and volunteers, and have strong organizational capacity to manage many moving pieces.

Potential Pitfalls

- Volunteers are not free labor. A healthy volunteer program needs support and nurturing, and requires an organizational investment and commitment.
- The organization needs to strike a balance between acknowledging its dependence on volunteers without exerting pressure on them.
- Each volunteer has different expectations about the time and attention they want from staff.

Translating the Volunteer Model to Other Settings: Community-Based Palliative Care

While volunteers could support patients further upstream in the disease course, the logistics of running a volunteer program in an outpatient palliative care setting would be more complex than in ZHP's institutional and residential settings. Would clinic volunteers do shifts, working with whoever comes in that day (likely missing out on longitudinal relationships with patients), or be assigned to a specific patient and family (requiring scheduling flexibility)? If volunteers work in outpatient programs that see patients in a number of physical settings, it would be important to provide these volunteers with opportunities to meet with each other and with a coordinator for support.

One way a community-based palliative care provider might consider "testing the waters" with volunteers could be to partner with a local hospice agency that has a strong volunteer program to use their volunteers for a specific time period or role.

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