

New End-of-Life Benefits Models in Blue Cross & Blue Shield Plans

Interviews and Descriptions: Susan Butler
Editor: Jeanne Sheils Twohig, MPA

September 2001

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Washington, DC 20006
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Supported by The Robert Wood Johnson Foundation, Princeton, NJ

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*Editor: Jeanne Sheils Twohig, MPA, Deputy Director
Promoting Excellence in End-of-Life Care*

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ACKNOWLEDGMENTS

With appreciation to the Promoting Excellence in End-of-Life Care National Program Office for organizing the conference where these projects were presented, June 2001.

To Chuck Butler, Vice President, Government & Public Relations, Blue Cross Blue Shield of Montana, for his guidance in planning the meeting and chairing its sessions.

To Dan Tobin, MD, Co-Director, Section of Palliative Care, VA Healthcare Network, Upstate New York at Albany, and Ira Byock, MD, Director, Promoting Excellence in End-of-Life Care, for separately having the idea for such a conclave that, when they combined forces, came together in such a productive way.

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August 2001

Wonderful things can and do happen when people get together to work and solve problems. This is just what is happening all across the country with Blue Cross and Blue Shield Plans involved in many activities and programs to improve the health and lives of not only our members, but in many cases the general population.

Thanks to The Robert Wood Johnson Foundation®, on June 25 and 26, a Forum on End-of-Life Benefits was held in Washington, DC. I had the pleasure and honor of being asked to bring this group together. Representatives of many Blue Cross and Blue Shield Plans and the Blue Cross Blue Shield Association gathered to share programs they sponsor to improve care for people with chronic or terminal illness, and to learn from each other how to improve the dying process, both for these patients and their families. Blue Cross and Blue Shield programs in Montana, Washington, and New York made presentations, and Blue Cross and Blue Shield programs in Hawaii, New Hampshire, North Dakota, and South Carolina shared written reports.

The document that is enclosed includes descriptions of these 'models' of end-of-life programs currently being participated in, or sponsored by Blue Cross and Blue Shield Plans. We know there must be other programs available, and we would like to hear from you, so we can share your work with others.

Sincerely,

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PROGRAM

Advanced Care for Advanced Disease

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“Before this program was in effect, patients bounced back and forth between the hospital and home, and care became fragmented. Now, families feel more confident in their role as care-givers in the home because of the amount of support they receive.”

— Joyce Keslo, RN, BSN, CCM

**Program Goals and Objectives**

To improve the quality of end-of-life care by:

- Working with stakeholders in the community to provide services;
- Having the Clinical Quality department develop standards of practice;
- Instituting a level of care component to home hospice care.

Program Description

Advanced Care for Advanced Disease provides for hospice care in the home. Care is delivered by nurses from the Visiting Nurse Association & Hospice Division. The internal structure of the program allows for three levels of care, defined and monitored for quality of care by case managers, who work closely with the hospice nurses.

The levels of care include:

Basic:

Physical therapy, occupational therapy, speech therapy, social worker, skilled nursing, HHA medication, equipment, and support and education for the patient and his or her family.

Intermediate:

Advanced pain management, feeding tubes, and an increase in the amount of home aide or nursing services in the home.

Extensive or Continuous Care:

Five days of intense nursing to support patient and family during a crisis period.

Patients might be moved in and out of different levels of care, depending on their needs. This internal design is meant to put flexibility in the plan. Services that are provided are not strictly defined, so that an unmet need (for instance, a blood transfusion), could easily be worked into the plan of care.

Advanced Care for Advanced Disease is an enhancement of Anthem Blue Cross and Blue Shield (Anthem) of New Hampshire's Case Management function. This program was added to allow members access to hospice care without having to restructure the benefits. The Case Management program allows the case managers autonomy and flexibility in their delivery of service and decision-making options.

All commercial members of Anthem BCBSNH are eligible for this program. New cases have been incorporated into the pre-existing caseloads of the case managers. To date, no new staff has been required, although an additional case manager joined the team in July 2001, which will allow an existing case manager to devote more time to program management.

Historical Perspective

To the company's credit, this program began as a response to member dissatisfaction. Anthem had received complaints regarding the quality of care being delivered by particular hospice providers. Reports showed consumer dissatisfaction with the hospice staff's knowledge of pain management. When Anthem received comments that service was unsatisfactory, they initiated a quality improvement process. The decision was made to develop a hospice program that would include end-of-life and palliative care.

The initial team consisted of an interdepartmental group whose membership included contracting agents, network managers, provider representatives, a medical director, case managers, a social worker, clinical quality and disease management. All of these participants brought passion to their mission. A partnership with the Visiting Nurse Association and Hospice providers was developed and enthusiastically received. The Clinical Quality Department, in collaboration with Visiting Nurse Association & Home Health and Hospice, created standards of clinical practice for care. Annually, a Hospice Advisory Board reviews the program and makes recommendations to improve and enhance it. Joyce Keslo, RN, BSN, CCM notes that one of the benefits to having the visiting nurses provide care is that this encourages a smooth transition from home care to hospice at the point when that service becomes necessary. She says patients become familiar with the caregivers and with the hospice philosophy while receiving care for their advanced disease. By the time they need hospice, they are more comfortable with the idea.

One obstacle with the program that Anthem is trying to address, however, is that of physician buy-in. The medical community at large, as well as the general public, requires more education about the benefits of Advanced Care for Advanced Disease (ACAD). Keslo noted that internally at the Plan, many people don't know what hospice is, or what it involves. The education of the community would advance the principal of ACAD. Currently the team is working with various stakeholders in the community to achieve this goal.

Research

Historically, case managers haven't had the ability to show what is called "Hard Savings." They will now be comparing the per diem rate for home care with the per diem rate for acute care, to determine if the program is cost effective. There is always the concern of "adverse selection" in this kind of care, so the data is being analyzed. Measuring quality impact of the program is equally as important—the fact being, that this program is the right thing to do for both customers and the community. Medicare data shows that 58 percent of health care costs are incurred in the last six months of life. Jean Montana, RN, BSN is confident that the program will show its worth in every way.

Education

It would be ideal if the medical community were aware of end-of-life issues and options available for provision of services. More education and acceptance is needed for the entire population, but due to the nature of discussions of death and dying, this is often not a priority. At this time, there is no formal community or provider education component to this program. There is however the potential of partnering with the EPEC trainers to educate New Hampshire providers.

Partnerships

- The Visiting Nurse Association
- Hospice Associations
- The Foundation for Healthy Communities (a pro-active group)
- New Hampshire Hospital Association (in the near future, Anthem anticipates partnerships with palliative care programs in the local hospitals)

Marketing

Publicity efforts have been modest. There has been some effort to publicize the program within the network. A mailing to providers that announced the PBS® series with Bill Moyers was sent (in conjunction with the hospice program information) prior to televising the program. Employees associated with ACAD discussed with providers and local community groups the benefits and availability of the program. As new certificates of coverage are written, information about the ACAD program will be added.

Funding

Since this service has been placed in the Case Management Division of Anthem, it has not required additional staffing.

Vision

The company has agreed to the expansion of the program as part of their corporate initiative to improve the health of members. Quality end-of-life care is beneficial to everyone involved. They are moving forward to the next stages of delivery of service. A Palliative Care Model, which will add a fourth level of care to the program, is in development. Plans are being considered to extend service beyond the six months hospice benefit that is now offered. The company is also working with physicians to develop an extended list of diseases to consider for inclusion in the program. They are looking at the feasibility of adding a per diem rate with the Visiting Nurse Association if a member has to go to a skilled nursing facility, hospital, or inpatient hospice. Providing coverage is seen as the right thing to do, and it looks as though the quality and cost-benefit outcomes are positive, then these become compelling reasons to continue with the program. Montana states it is an extension of the caring that Anthem has always shown in recognizing and supporting community endeavors. It also supports the Anthem Mission to improve the health of its members.

Key Elements of Success

- Commitment by the organization to support this effort
- Hospice providers who wanted to partner with Anthem
- Everyone involved wanted a win-win situation; all wanted to find a way to make this program happen and be successful.

Measures of Program Success

The data that has been collected has been satisfaction data. Questionnaires have been given to the primary caregivers, which ask, among other things, if providers of care are knowledgeable, and if pain management has been satisfactory. Feedback received from customers, although informal, has shown tremendous satisfaction with the program.

Information on provider satisfaction, although mainly anecdotal, shows that physicians are pleased with the program. The feedback received by the Clinical Quality Improvement Committee has shown an excellent response from providers, and the Hospice Association reports great interest in the program.

Measures of success include:

- The amount of support from within the company and provider community;
- Enthusiastic consumer feedback;
- Increased member participation in the program;
- Increased length of stay in hospice with earlier referral into the program.

Necessary Steps

Jean Montana notes that caseloads must be monitored to ensure that the case managers are coordinating care. She is looking forward to the addition of the fourth level of care, as the need for it has been consistently demonstrated.

As for other issues that need to be addressed, the ever-present discomfort that people demonstrate around end-of-life issues and issues of death and dying, hinders this program from being even more effective. Education of providers, patients and the public will help transform the culture of fear surrounding these issues.

What I Wish I'd Known . . .

If Montana had it to do over again, she would include a Program Manager in the design from the beginning. She feels that if the company had initially been able to devote more specific resources to development of the program, they would already have the Palliative Program in place, and would be able to track outcome data more confidently.

This descriptive summary is based on an interview conducted by Susan Butler with Jean Montana and Joyce Keslo, June 14, 2001.

INSTITUTION

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PROGRAM

Pediatric Palliative Care Project

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"It's a matter of getting all the stakeholders to understand the issues and objectives and play a flexible role in making that happen. If you get people on the same page, you can get an awful lot done with existing resources."

— Peter West, MD, MPH

**Program Mission/Objectives**

At Premera, the mission of joining the Pediatric Palliative Care Project (PPCP) was to improve service to members of the health plan. Specific objectives were:

- To identify opportunities to improve care for children with terminal illness;
- To encourage collaboration between hospice, insurers, and providers;
- To find better ways to assess the patient's needs;
- To address the need for timely palliative care.

Program Description

The purpose of Premera's participation in PPCP is to help give families of critically ill children an early entrance to hospice care before they would normally access those services. Seventeen Premera policyholders have enrolled in the Project. Premera has helped these families by creatively using the home health benefits provided by the company, and by promoting active case management.

To provide services, Premera uses a comprehensive Decision Making Tool (DMT). The DMT helps providers, the family, the patient, and Blue Cross coordinate the patient's care and support services. It provides a format to create discussion about all aspects of a

patient's care, including medical indications and options for treatment, family preferences for care provision, and treatment course elected with end-of-life considerations. Quality of life is considered, including activities and relationships that are important for the patient and family to maintain, and contextual background, including family history, home environment, cultural and spiritual issues, and financial and insurance facts. The tool gives equal weight in discussion to each of these four main areas of the plan. Those present at the update, including the physician, then sign the plan, and it is forwarded to all members of the health care team.

Premera acts as a facilitator in that endeavor, addressing such things as how to adjust appropriate goals, how to extend hospice benefits over a longer period of time, and how to deal with issues creatively as they appear. Case management is the key to coordination and to the flexibility that is needed to concentrate services on the issues at hand. The focus of a case manager helps make the most appropriate use of all available benefits.

Any child with life threatening illness who is covered by Premera is eligible for this program, as all plans have hospice benefits. The program covers medical services, home health care, durable medical equipment, rehabilitation, hospice, and pharmacy. Service is limited only by the patient's policy and the medical circumstances.

For delivery of services, hospice-trained nurses are involved in home health visits, so that families receive some of the hospice philosophy before they are even enrolled. "The trick," says Peter West, MD, MPH, Medical Director of Premera, "is getting ahead or in advance of the need for care." Jane Stewart, RN, MSN, CM adds: "We are helping parents to see the need for hospice sooner rather than later. This program gives both parent and child a voice."

Premera has tried to build in what they call "reasoned flexibility" as they assess the medical management of a case. "We can provide that," Kim Boggess, RN, CCM explained. "When a child comes into our scope of range, we work with the physician and the home health nurse to develop the best course for the patient. Together, we have the perspective on what will work." Boggess tries to put the payment mechanism together with the needs of the patient. "We've had aggressive leadership on this, trying to provide the best member service."

Premera's case management capacity serves many populations. They have a low volume of patients who are enrolled in the project. They say they have worked hard to demonstrate to their actuaries and accountants that this would be a cost effective way to provide service.

Historical Perspective

"In hospice services and in care for the dying there are a number of great people," noted Boggess. The project began under the leadership of two physicians at Children's Hospital and Regional Medical Center, J. Russell Geyer, MD, and Ross Hays, MD.

Peter West, MD, MPH believes those two physicians also provided the inspiration and motivation for the program. The physicians at the Center for Children with Special Needs at Children's Hospital were supportive of PPCP from its initiation. At Premera, West has been the champion. Gerri Haynes, RN, the co-manager of the project, has worked in hospice for over a decade. Boggess, currently the Premera liaison for PPCP, has in the past served as Premera's on-site utilization review nurse for Children's Hospital and the Premera primary Pediatric Case Manager. The accumulated expertise is impressive.

Each has brought something different to the program. Haynes has strong community background in hospice care. Boggess thinks Haynes has an affinity for knowing how people need help when they're dying, and an innate ability to listen. West notes that with PPCP, "This was an area where, appropriately, Children's Hospital could do good and do well at the same time. Because of Kim's good work at the hospital, it helped move Premera forward to pick up this work. There was already a relationship there which helped move us forward."

At Premera, they have faced the internal challenge of working a process while they're operating outside of the routine flow of business. Challenges exist in the community as well. Some families are still resistant to having the insurer be in a decision-making role. The solution to that problem has been aided by the fact that this is a collaborative project. Consumers understand that decisions aren't arbitrary. West notes that here the insurer is functioning as a member of the team, rather than the leader of the team.

Research

The Pediatric Palliative Care Project has its own measurement tools to gather information about patient satisfaction with care from all levels, including baseline and follow-up measures.

Premera is tracking issues of quality (member satisfaction per their case management policies), and cost (assessing cost analysis). Member satisfaction includes surveying case-managed members at set periods about their regard for Premera case management services. Cost analysis includes monthly and decision specific cost comparisons to possible/probable course of treatment without intervention.

Partnerships

- Regence BlueShield
- Hospice
- Center for Children with Special Needs at Children's Hospital
- Health care providers
- Home health services

Marketing

Premera hasn't really marketed their participation in the Project, but has tried to keep marketing in the forefront of their medical staff's agenda. They viewed PPCP as a pilot program for a good way to treat their policyholders. They are trying to provide a better quality of care.

Funding

Funding for the PPCP came from a Robert Wood Johnson Foundation grant through the Promoting Excellence in End-of-Life Care program.

Vision

Premera is gaining experience with this program, but as Kim Boggess notes, "At some point, this kind of service ought to be built into a physician's expectations." Premera wants to learn expertise in providing these services.

Key Elements of Success

- Collaboration
- Communication

Measures of Program Success

Kim Boggess recounts "One of my parents, whose child has a chronic disease with severe acute exacerbations, said that before they became involved with the Project, they didn't know that someone was available at their health plan to assist them in pursuing appropriate care for their child. They'd been trying to get certain services in the provider community, unrelated to whether Premera would pay or not, and they felt they just could not get in the right door to get the support they needed. Their initial conversations with Premera were overwhelmingly intense. But as care for their child increased, our discussions became less of an 'event' and more of a collaborative effort about the next course of action. Even the parent could tell that their negative tone and approach had changed. They indicated they would never have come to that place without the Project."

Necessary Steps

For the program to continue, it is necessary to put this mode of cooperation and care out there in front of consumers and providers. "The health plan itself has to seek this kind of engagement," Boggess said.

Beyond that, this is a new role for Premera. Getting operations to be able to respond to creative policy applications has taken work. As an organization, Premera has taken on roles

to facilitate communication, to help families understand what might be useful to them, and to facilitate the decision-making process in a timely manner. There's a capacity external to the insurer to aid that process, but Premera is about to cross that barrier, because staff involved in the Project have been offering those services to both providers and families.

Case finding has been a challenge. "It is not as easy as it should be. We have tried to broaden other resources to find the cases. We've beaten the bushes with the doctors, and it has become easier as the physicians have become more familiar with the program," says West. Still, educating the provider community about the project will result in offering this program to more children in need of services.

What I Wish I'd Known . . .

"Our major competitor is Regence, and we've been participating collaboratively. Each plan uses its own business systems. We're doing it on behalf of the most needy group, and we've been able to do it so smoothly," says West.

This descriptive summary is based on an interview conducted by Susan Butler with Kim Boggess, RN, CCM; Jane Ramenofsky Stewart, RN, MSN, CM, and Peter West, MD, MPH, June 14, 2001.

INSTITUTION

Excellus
Rochester, New York

PROGRAM

1. End-of-Life Palliative Care Quality Initiative
2. The EPEC Project
3. Palliative Care Consultants

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"I think that one of the important things is a recognition of the need to collaborate. We need to reach across the silos to get balance, to be able to partner across lines and move the initiative forward. . . . We need to revolutionize things, ways of caring for people at the end of their lives. We need to accept that death is a natural process and be able to support people there."

— Patricia Bomba, MD



Excellus is involved in many initiatives and projects to promote excellence of care for people at the end of their life. This descriptive summary will report on the development of one project, the End of Life Palliative Care Quality Initiative, which is a community initiative.

Program Mission/Objectives

One of the three operating principles for Excellus is “to improve the quality of life and health status of members of the community, and to reach out to all segments of the community.” As such, objectives of the initiative include:

- Changing the culture in which end-of-life care operates;
- Educating public and professionals;
- Improving education infrastructures;

- Promoting excellence in palliative and end-of-life care;
- Working collaboratively and in partnership with the community and community health organizations.

Program Description

The Rochester Health Care Forum, under the direction of the Rochester Health Commission, is a community-wide effort to enhance the health of the greater Rochester area. The Commission works to increase access to and improve the quality of health care, and reduce the overall cost of care for everyone. In 1999, the BlueCross BlueShield of the Rochester Area (BCBSRA) and its physician partner, the Rochester Individual Practice Association (RIPA), two members of the forum, independently identified the delivery of quality end-of-life care as one of the most pressing health care issues facing the community. The two partnered to conduct a community-wide survey of health care delivery systems in 2000. The results of the survey, released in January 2001, were published in a document called the Rochester Community End-of-Life Survey Report. Results show that in terms of advance care planning, too few people, especially those with chronic illness, have advance directives.

- In terms of pain management, not enough is effectively being done, and
- In terms of hospice referral, in most cases it occurs too late for patients to fully benefit from the program.

The report provided the Forum with a starting point upon which to structure a broad-based community effort to enhance end-of-life care. Members of the Forum suggested that an initiative that built upon community end-of-life/palliative care efforts could have a profound effect on how end-of-life care is delivered, and could also serve as a state and national model. The Initiative is keeping issues of end-of-life care in the forefront of health care discussions in Rochester and beyond, and it is urged to be a priority for providers of care.

Historical Perspective

In 1999, Don Berwick, MD, President and CEO of the Institute for Healthcare Improvement, spoke to internists at the American College of Physicians meeting. Berwick presented a challenge to the internists. He raised end-of-life/palliative care as an initiative, and challenged the internists to make it a priority. BlueCross BlueShield picked up on the challenge and worked with hospice and practicing physicians to make it a reality. BCBS, along with its physician partner organization, RIPA, basically led this initiative under the leadership of Howard Beckman, MD, Medical Director of RIPA.

The RIPA/Blue Cross End-of-Life/Palliative Care Professional Advisory Committee was created. This group conducted a survey of hospitals, nursing homes, hospice, home care agencies and disease management programs to better understand the state of end-of-life

care that was being delivered. The RIPA/BCBSRA Survey provided the Forum with a set of recommendations focused on improving the community's end-of-life and palliative care.

Patricia Bomba, MD presented the survey initially to the Rochester Health Commission and subsequently to the Rochester Health Care Forum Leadership Group. Both the Rochester Health Commission and the Rochester Health Care Forum Leadership Group quickly approved adoption of the Promotion of Excellence in End-of-Life/Palliative Care as an eleventh initiative to the other 10 initiatives that the forum was already actively working on in the community. In the process, an advisory group was developed.

Four work groups have been formed to work toward:

- Exploring and communicating treatment wishes;
- Ensuring patient wishes are identified and honored at all sites of care;
- Relieving physical, psychological and spiritual symptoms and providing patient/family support;
- Facilitating communication and education, both community and professional.

The Rochester Health Commission, under the guidance of Bomba and Mary Jane Milano, Director, Rochester Health Commission, has spearheaded this initiative. The senior management at Excellus, particularly Howard Berman, the CEO, and David Klein, the Chief Operating Officer, and Kevin Hill, President of BCBSRA have supported the work in the community.

"Internally," Bomba says, "there is a recognition that you need to reach out to the community and get everyone on the same page. It is only with the support by the senior management of the organization that one can move a project forward."

Research

The Rochester Community End-of-Life Survey Report was published in January 2001. It makes many far-reaching recommendations. Among them:

- Establish a mechanism of reimbursement for palliative care specialists to provide consultations;
- Promote earlier hospice referrals for terminally ill patients;
- Establish comprehensive pain assessment and treatment standards;
- Encourage health care institutions to set performance goals and track basic statistics regarding end-of-life care;
- Promote universal acceptance of an Advance Directive Form that would be honored at all community facilities.

Partnerships

- Hospice
- Visiting Nurse Association
- RIPA/Blue Cross End-of-Life/Palliative Care Professional Advisory Committee
- Rochester Health Commission
- Rochester Health Care Forum
- Rochester Individual Practice Association

Vision

The vision of the End-of-Life Palliative Care Quality Initiative is to make every delivery component of end-of-life services aware and responsive to the many issues that affect quality of life. The initiative states, “It is critical for individuals to be provided with the highest quality of end-of-life care, and that care at the end of life is provided in a manner that best meets the individual and their family’s preferences and needs.”

“It will take a strong, ongoing community-wide effort to ensure that this occurs. Decisions about end-of-life care are best made before a life-threatening event occurs, with the input of physicians and family. Yet these decisions, if made prior to an individual’s death, are often postponed until a catastrophic event with a family member motivates an individual to take the time to ponder and perhaps articulate his/her own health care wishes for end-of-life care. The recommendations included in the Rochester Community End-of-Life Survey Report should form the basis for action on the initiative which will build upon and strengthen, rather than add to or duplicate, the current community efforts to improve end-of-life and palliative care.”

Key Elements of Success

- Collaboration
- Communication
- Motivation
- Overcome obstacles by trying to maintain awareness of the process

Measures of Program Success

- Buy-in of providers
- Amount of community support
- Acceptance of initiative on many levels

Necessary Steps

“Collaboration and partnership. Education and awareness. To be able to work as teams.” Bomba suggests that these are all elements of the Initiative development process. “There is high visibility leadership involved in the community advisory group, but we also want to involve all segments of our community in the workgroups, being sensitive to cultural diversity.” When that happens, the Initiative will have taken hold.

“We at Blue Cross recognize that this initiative has the potential to improve the quality of life for the community,” Bomba says. “If you look at our mission and core values, and go back to the original mission of Blue Cross being a not-for-profit organization, you will see that this initiative fits the not-for-profit mission of reaching out to the community.”

“Our CEO recognizes the need to improve the quality of life and the health status of the community. Traditionally health care was delivered solely for acute care; however, managed care introduced the concern for promoting wellness. We must do better. The future lies in adding improved management of chronic disease, and improved palliative care and end-of-life care. We, as a community, are just beginning to recognize this need.”

What I Wish I'd Known . . .

“It takes a lot of work and time. In the country right now, there's such a disconnect between what people want and what we're providing in good end-of-life care. And there is really a desire for this to happen. People are interested in collaboration. They need leadership and they need to have a part in doing this.”

“If we don't move now to improve quality of end-of-life care, we will be the recipients of what we do or don't do.”

This descriptive summary is based on an interview conducted by Susan Butler with Patricia Bomba, MD, June 14, 2001.

INSTITUTION

Blue Cross Blue Shield of Montana
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PROGRAM

Advanced Illness Coordinated Care Program

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“No one should have to die in pain. If someone is dying in pain, we should be ashamed of ourselves as a culture.”

— Jennifer Elison, RN, EdD

**Program Mission/Objectives**

The mission of Advanced Illness Coordinated Care (AICC) is:

- To assist patients and their families with end-of-life care, and to be able to advance the concept of peaceful dying;
- To connect patients with hospice early and appropriately;
- To increase communication between families and physicians;
- To enhance the decision-making process;
- To offer a range of psychosocial services to patients and their caregivers.

Program Description

The program is designed to promote hospice and offer services to Montana patients under the age of 65 who have advanced disease. The target patients are eighteen to twenty-four months away from death, they don't meet hospice criteria, and they do need psychosocial support as they make decisions about living and dying. “If you remember that the main focus is to help someone die peacefully, you are working with the living as well as the dying. You provide support to the whole family, and it means so much,” said Jennifer Elison, RN, EdD.

The program, sponsored by Blue Cross Blue Shield of Montana, is unique because a person doesn't have to be a Blue Cross Blue Shield policyholder to participate. In fact, the client doesn't even have to have insurance coverage. Blue Cross Blue Shield pays for the care.

The main component of AICC is psychosocial support for a client and his or her family. Following the model based on the work of Dan Tobin, MD, the program consists of six to nine visits or home visits, with many phone calls in between. The caregiver, or case manager, follows a well-prescribed outline. Each meeting has an agenda, but the person with the illness makes the decisions.

The first visit is an attempt to learn who the person is, or was, before the illness. How did the client fit into the world? Pain assessment, a medical history, a record of medications, a social and spiritual history, the patient's decision-making abilities, and a Lichert scale to obtain a sense of their understanding of their illness, are all parts of a first visit. The case managers explore the patient's ability to confront and express their fears. They assess where the patient is in regards to "CUP" - Do they believe they're in a curative stage, are they uncertain, or are they accepting of palliative care? Have advance directives been discussed?

The second visit gives support to the primary person. The third and fourth visits cover legal, social, and practical issues such as disability benefits. There is an assessment of the well being of the caregiver, a family meeting, and advanced care planning. After each meeting the physician receives a summary of findings and the discussion.

The fifth meeting puts the palliative plan in place. It is thought of as the turning point visit, with anticipatory mourning. If the patient wants one, the DNR directive is signed.

The sixth visit is for finding peace, and the subsequent visits repeat what has been offered before. Elison says, "We go from active caring, to just sitting with someone quietly when they need it."

Continuity of care is a major element of AICC. The case managers work autonomously, but staff at Blue Cross Blue Shield of Montana support and promote the program. The only new hires for BCBSMT have been the twelve case managers who operate out of four of the largest communities in Montana (Helena, Billings, Great Falls, and Missoula).

Historical Perspective

In the spring of 2000, Blue Cross Blue Shield of Montana adopted a theme of "Higher Purpose" as part of their community service, dedicated to helping people with the greatest need. AICC was the first project undertaken as part of that initiative.

Then Executive Vice President, now CEO and President, Peter Babin heard Tobin speak at a Milliman and Robertson meeting in the spring of 2000. Babin was enthusiastic about what he heard and asked Chuck Butler, Vice President of Government & Public Relations, to get in touch with Tobin to explore the idea of adopting the AICC program for their “Higher Purpose.”

Tobin spoke to the Board of Directors of the company at their annual meeting in August 2000. Soon afterward, the Board voted to provide the expenditure for the program. Training for case managers took place in November 2000, led by Tobin and participants from Missoula Demonstration Project. The program was launched in February 2001, with the support of some state physician groups and hospitals.

Case managers are responsible for the program, but they work closely with Blue Cross. Elison noted that every person she’s talked to at Blue Cross has been extraordinarily supportive, not only to the program, but to the agenda. “They’re walking the walk. There’s a group of volunteers there who get very personally involved. It’s nice to see this idea move from somewhere up in a boardroom, to an individual bringing lasagna to a patient. Caring is what it’s about.”

Several champions at Blue Cross made the program go. Because of Babin’s interest in AICC, because of Butler’s personal understanding of the issues surrounding a painful death due to the death of his mother, because of Tracy Koder’s compassion and skills in organizing, the program had an initial boost and ongoing backing. Elison says, “They’ve responded from the heart. When you do that, great things can happen.”

Research

The program is too new for any data to have been gathered. Blue Cross Blue Shield has assured money to fund 120 people in the program. To date, Helena has enrolled nine, Billings is serving nine, Great Falls has enrolled seven, and Missoula is working with two.

Tobin is conducting his own measurements of the program. He is tracking the number of visits given to each patient, diagnoses, hospitalizations at the end of life, number of patients who move into hospice programs, medical services patients receive in addition to counseling, and satisfaction levels of the family and patient.

Education

A major part of this program is patient education about the peripheral issues of death and dying. The case managers provide information to families, patients, the provider community, as well as the greater community in Montana.

Partnerships

- Blue Cross Blue Shield of Montana
- Hospice
- Life Transition Network
- The Cancer Center at St. Peter's Hospital

Marketing

Formally, AICC is being introduced through presentations at social workers groups, nursing facilities, and to physicians. Word of mouth about the availability of this program seems to be most effective. One doctor said, "I work for the patient, so he can have anything the hell he wants. Besides, this is such a great program for him." Physician buy-in is a positive form of spreading the word.

Funding

Funding is being provided entirely by Blue Cross Blue Shield of Montana. Case manager services are contracted back through The Life Institute. The Board has put aside \$150,000 to pay for six to nine visits for up to 120 patients.

Vision

Jennifer Elison would love to see this program offered to people over the age of 65 and see it expand to areas of the state where illness is not so easily treated.

Key Elements of Success

- Collaboration
- Respect for the decisions of patients
- Respect for cultural differences

Measures of Program Success

- Value to families
- Value to Blue Cross Blue Shield employees
- Financial value

Necessary Steps

"Culturally, we don't even like to talk about death," observes Elison. "Kubler-Ross did us a tremendous favor by broaching the subject. A lot of groundwork needs to be done to yet encourage us to communicate about issues surrounding death and dying. We need communication on all fronts."

“Our needs are so great. We need to be aware of caregiver needs, bereavement needs, a family’s reaction to sudden loss. We need to learn respect for people who opt not to go this route.”

“We need continued funding, support from the community, competent people to work. We have that across the state of Montana. We have good, kind, competent people, but there’s a lot of community education work to do.”

In an Ideal World . . .

“In an ideal world this program would be second nature. Peaceful dying—you have to prepare for it. We prepare for births—we need to prepare for death . . .”

This descriptive summary is based on an interview conducted by Susan Butler with Jennifer Elison, RN, EdD, and Chuck Butler, June 14, 2001.

INSTITUTION

Blue Cross Blue Shield of North Dakota
Fargo, North Dakota

PROGRAM

Blue Cross Blue Shield Hospice
Matters of Life and Death Coalition (MOLD), A State End-of-Life Coalition

DIRECTORS

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“Death is a touchy subject, especially in this culture. We try to step delicately. In North Dakota it’s a societal issue, and it’s hard to address. This is Lake Woebegone Country.”

— Dan Ulmer

**Program Mission/Objectives**

The mission and objectives of hospice are well known, which is why Blue Cross Blue Shield of North Dakota is pleased to be a part of the Matters Of Life and Death Coalition (MOLD). Mike Hamerlik said, “It is not our primary mission to ‘save money’ through the activities of MOLD, but more thoughtful and better use of resources is a goal.”

Program Description & Historical Perspective

The hospice benefit of Blue Cross Blue Shield of North Dakota goes back more than eleven years. It began, Hamerlik said, in a reactive way, as an offshoot of Medicare. The hospice benefit parallels the Medicare qualifications. Any person diagnosed with terminal illness, with a life expectancy of six months or less, who is a member of any plan, or is self-insured may use the benefit. The hospice benefit covers all services related to terminal diagnosis. Blue Cross pays a per diem to the hospice unit for home care, hospice, or respite care. There are no maximums in the program and no dollar limits; however, families are responsible for whatever their policy requires. Jon Rice, MD notes that usually people who get into the hospice program have consumed their deductibles. The hospice benefit is included in all policies, and all levels of care are available within that benefit.

Authorization for a patient to enter a hospice program is required through the case management division. A case manager, a nurse, is assigned to work with the family, hospice, Blue Cross and physicians to make sure patient needs are being met.

Blue Cross Blue Shield of North Dakota joined the MOLD coalition, a group of over fifty organizations in North Dakota “committed to improving care given to the dying and their families.” The collaborative project is working to develop professional and community educational opportunities, and to identify a continuum of end-of-life care for the people of North Dakota.

The Matters of Life and Death Project began in 1998, when representatives from a broad spectrum of health and social service agencies joined with other interested organizations and individuals to seek ways to improve the quality of life for North Dakota residents.

The coalition is working to find ways to address four key areas of end-of-life care: professional education; continuum of services, access, and finance; public education; and advance care planning. Expertise is drawn from throughout the community to look creatively at ways of addressing these issues.

Education

The MOLD coalition is working to enhance curricula and provide educational materials for both professionals and students entering fields of health care delivery. In this way they hope to more effectively address end-of-life issues, and increase community awareness of existing resources. Their effort extends to public education through forums, panels, and discussions. One hope is that with education, physicians will be encouraged to enroll patients in hospice earlier, so that they will have a better quality to their end of life.

Partnerships

The MOLD coalition is a broad partnership of representatives of organizations, both public and private, including:

- Health care organizations;
- Human service organizations;
- Academic institutions;
- Religious organizations;
- Public officials and agencies;
- Consumer organizations;
- Concerned individuals.

Dan Ulmer, Assistant Vice President of Government Relations, and Jon Rice, Managed Care Medical Director represent Blue Cross Blue Shield in the coalition. Because of their history of delivery of care in hospice, Blue Cross Blue Shield of North Dakota is enthusiastic about joining in the work of the MOLD coalition.

Funding

The MOLD coalition is funded through grants from The Robert Wood Johnson Foundation, and the Dakota Medical Association.

Vision

The hope for the Matters of Life and Death coalition is that it will ignite and maintain an interest in finding ways to address issues of quality of end-of-life care in North Dakota. As Hamerlik said, “the hope is that champions for these issues will come out of the MOLD coalition.” Progress may be incremental, but it’s still progress. Ulmer noted that the legislature did not pass a living will law, but they were able to pass a durable power of attorney law. If working on end-of-life care issues is approached on many fronts, educationally, legally, and through delivery of appropriate services, the whole community will benefit.

Key Elements of Success

- Flexibility
- Willingness to identify problems and define solutions
- Collaboration

Measures of Program Success

- Initiatives turned into courses of action
- Collaborative efforts at problem solving

This descriptive summary is based on an interview conducted by Susan Butler with Mike Hamerlik; Jon Rice, MD; and Dan Ulmer, June 14, 2001.

INSTITUTION

HealthNow, New York
Buffalo, New York

PROGRAM

Support Blue

DIRECTOR

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“These are patients who have life-limiting illness. The program helps move them along the continuum so they get all the help they need. One of the unanticipated benefits of the program was that we had patients who got better. Through education, delivery of services, family care . . . the patient was bombarded with in-home services. They gained an understanding of how to keep their disease under control, and when their health improved, we discharged them from the program.”

— Cheryl Howe

**Program Mission/Objectives**

The program’s mission is to be responsive to the needs of the patients who have chronic life-limiting illness. The objectives are:

- To decrease the number of hospital admissions for patients with a life threatening illness, resulting in cost-effective end-of-life care;
- To provide comprehensive, coordinated end-of-life care of the highest quality, including continuity of care throughout a life-threatening illness, by maintaining the same team of caregivers (nurse, home health aide and social worker);
- To maximize access to and admit patients to hospice care at the most appropriate time;
- To enhance patient and family satisfaction levels;
- To enhance physician education and awareness of critical end-of-life issues.

Program Description

Chronically ill patients frequently receive treatment at home, and a family member is usually the primary caregiver. Blue Cross Blue Shield of Western New York wanted to be responsive to the needs of these patients, wanted to provide the best services possible, while at the same time wanted to keep these patients out of the hospital whenever possible.

Support Blue is a unique program that packages together services for both a chronically ill patient and their primary caregiver. The program's plan of attack is to educate customers to learn to control their disease in order to have a good quality of life, even with chronic illness.

Support Blue begins with a patient assessment. Once the needs of the patient have been defined, providers deliver services to both the patient and the caregiver. A case manager coordinates services and acts as facilitator for communication among the involved parties. These services include medical, psychosocial, and spiritual help, as they are needed.

Medical services offered in this program include:

- Continuity of care throughout the patient's episode of illness;
- Home visits by an assigned primary registered nurse;
- Home care consultation by a physician, when or if requested by a doctor;
- Rehabilitative services by physical, occupational and speech therapists;
- Intravenous therapy including chemotherapy, antibiotics, hydration and tube feedings.

Other provided services include:

- Education about the illness, such as what to expect during therapy or as the disease progresses, and how to cope with limitations;
- Education for family members or friends in caring for the patient at home;
- Coordination of community services needed for home support;
- Personal care by an assigned home health aide;
- Counseling for individual and family, including referrals for bereavement;
- Support groups;
- Volunteers to give respite time for caregivers;
- Social workers for psychosocial assistance;
- Pastoral care.

The program, designed to be intermittent care, is not limited to adults. It is available to all managed care members, inclusive of Medicaid and Medicare risk. The hospice benefit is consistent across the lines of business with the six-month/210-day standard benefit. Hospice determines which setting the patient requires, whereas case management is available for situations that require extension of benefits.

Support Blue is designed to serve the patient population that is not yet ready for hospice. For example, if the patient and physician agree on continuing aggressive treatment for the illness, if the patient is younger than 65, and significant psychosocial issues exist, Support Blue is available. One goal of the program is to transition patients to hospice as their illness progresses. When that happens, Medicare or Medicaid benefits are initiated.

Historical Perspective

As is so often the case, Cheryl Howe's interest in this issue was engaged when her mother went through the painful difficulties of providing care for her father's chronic illness. She said, "Mother struggled with caring for my father, who had congestive heart failure. It brought these issues to me first hand." Initially, the idea was to identify gaps in care for patients with life-limiting illness, including diagnosis and treatment options.

The collaborative discussion began with the Center for Hospice and Palliative Care. Blue Cross Blue Shield of Western New York partnered with Hospice because that organization is the final care provider to chronically ill patients.

An early champion of the program, along with Howe, was Don Schumaker, the CEO of Hospice. These two high profile people, with help from many others, implemented the program.

Among the obstacles they face in extending Support Blue to more patients is the fact that physicians are not always easily accessible or always receptive to education about other modes of care. Understandably, physicians need to be convinced that this effort does not result in more work for them. Another consideration is that the average age of this managed care population is 46 years old. For this age group, neither patient nor physician is willing to concede to palliative care. Generally, the physician continues aggressive treatment for longer than they would with a patient of the elderly population. Hence, end-of-life costs are much higher.

Historically, Howe says, the physicians' comfort level is with patients dying in a hospital setting, if they are comfortable with death at all. The staff of Support Blue is concentrating on educating physicians, including offering and encouraging CME programs. Staff education to home health nurses, who are extremely supportive of the program, and liaison with the largest cancer center where they work with oncology staff, are two initiatives being undertaken by Support Blue.

One of the original objectives was to help place patients in hospice earlier. Most often, Howe reports, physicians do not put patients into hospice until a week or two before their death, thereby depriving them of the opportunity for a good quality of end of life. The people responsible for this program hope after Support Blue care, patients will have an easy transition to hospice. Although they are trying to reduce the number of inpatient admissions, they also want to create patient satisfaction. This program differs by the provision of support for the caretaker as well as the patient.

Patients are transitioned out of the program when they enter Hospice, expire or change insurance coverage. Since the program's inception, 45 percent of the total enrollment in Support Blue has been transitioned to hospice, vs. 17 percent of the general non-participating population.

Research

Support Blue is gathering facts and looking at statistics for the effectiveness of their program. Patient and family satisfaction is 100 percent as measured by satisfaction surveys.

Education

Although there is no formal education component to the program, education of physicians, staff, and community are priorities that need to be addressed. One of the program objectives is to enhance physician education and awareness of critical end-of-life issues. This ongoing endeavor includes offering and encouraging CME programs.

Partnerships

- Multiple home care agencies
- Hospice/palliative center(s)
- Counseling services from outlier county hospices
- Dan Tobin, MD/Albany VA Medicare Center
- Comprehensive community health service

Marketing

The marketing effort for Support Blue has included a brochure, both member and provider newsletters, newspaper articles, and the intranet for employees. Internet information is in the design stages.

An effort at community education was served through the media with support for Bill Moyers' series "On Our Own Terms: Moyers On Dying." The company is working on an individual physician marketing plan.

A full-time case manager devoted solely to the program works in each market with the purpose of selling and promoting Support Blue. Publicity also comes from participation in a national study.

Funding

Early intervention equates to cost effective end-of-life care by reducing ER visits and hospital admissions; therefore, the company sees the program as financially positive.

Vision

The people involved with Support Blue hope to be able to expand the program to include Skilled Nursing Facility palliative care—care for patients unable to stay at home. Next year they hope to be able to expand to an indemnity. They want to continue to expand the numbers of people who receive this benefit at the chronic illness stage of disease before they reach the need for hospice care. Howe allows that they are trying to move patients along the continuum of care so they will receive all the help they need. “Anything we can do to forward that process is a success for us, and a benefit for them.”

She thinks it is a selfish distinction to think Support Blue is the only program in the nation that is working to this extent, but she would like to see this care supported across the nation. The formal extension of services to caregivers is unique.

Key Elements of Success

- Educating both the caretaker and patient
- Focusing on and offering services to the caretaker, who can be anyone from a family member to a friend or neighbor

Measures of Program Success

- Patient utility
- ER utility
- Patient satisfaction

Necessary Steps

Within the next year, Support Blue will measure cost-effectiveness by using Dan Tobin’s Faircare Study methodology.

What I Wish I’d Known . . .

“At the HMO they have a mental health carve out benefit. One of the key components of Support Blue was the mental health benefit.”

This descriptive summary is based on an interview by Susan Butler with Cheryl Howe, June 15, 2001.

INSTITUTION

Blue Cross Blue Shield of South Carolina

PROGRAM

Complex Case Management Program

DIRECTOR(S)

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“We are rapidly moving away from pre-certification, which I call Mother-May-I Managed Care, toward a case management/disease management model. We’ve identified a population with specific needs, and we’ve developed a program to meet their needs efficiently. I think that’s the model for the way insurance benefits will be structured in the future.”

— Ashby Jordan, MD



Program Mission/Objectives

The mission of Complex Case Management (CCM) is to provide patients with the services they need and want. There is an attempt by the insurance industry to manage down costs. The result from CCM’s work is “we do tend to save money by avoiding hospitalization and emergency room costs. That, however, is a secondary goal.”

Program Description

Franklin Health is a Complex Case Management provider that contracts with Blue Cross Blue Shield of South Carolina (BCBSSC) to provide treatment to the most critically ill of Blue Cross’s clientele. Daily, Franklin Health takes a download of patients from BCBSSC’s pre-certification process patients, to cull the list to see which clients are catastrophically ill. From this list of patients, if the patient and family are interested, a representative from Franklin Health meets with the client to offer their services. Basically they offer to deliver patient information and options, such as advance directives, and goals for symptom management. Franklin Health has a cadre of nurses trained to work with the

sickest patients. If the family agrees to be served by a nurse from Franklin Health, in cooperation with one of the case managers from BCBSSC, Blue Cross contracts that case for service with Franklin Health.

Out of that program at Franklin Health, Mount Sinai Hospital in New York wanted to use the nursing service as a test, taking a cadre of nurses and giving them extra training in end-of-life care to see if that would improve patient care.

Any client of Blue Cross is available for this program, from the youngest neonates to the elderly. The program tries to move people out of the hospital, as long as everyone agrees that that course of action will not be to the detriment of the patient. Almost every service is covered. The company will consider anything to keep patients at home. Any expenditure, from medical equipment to an air-conditioner, may be found appropriate if it can be shown that it will be more cost-effective than a hospital stay. For example, Ashby Jordan, MD says, "if a patient is dying of cancer, if we can keep them comfortable at home, we will." The only dollar limits are those dictated by the patient's policy limit, or the plan's limits. The options for types of coverage are unlimited. The program can be made to fit into various models.

A nurse, on location with the patient and family, manages care of the patient. Under typical circumstances a patient's access to pharmacy or services is often limited. The Franklin Health nurses take control of their cases to see that their patient receives whatever services he or she needs.

At Blue Cross, one nurse and one nurse case manager is dedicated full time to Franklin Health. Jordan works on cases, as the need arises. The rest of the employees who staff this program are Franklin Health employees. Blue Cross has added no new staff.

Historical Perspective

Blue Cross went to Franklin Health to request information about their services. Franklin Health made several presentations, and they were selected to serve BCBSSC's clients.

Those who work in the Managed Care Division at BCBS were the program's champions. They recognized that Blue Cross's case management function was incomplete. The typical case manager didn't address the critically ill population, which was a very high-cost population. The managed care division was effective because its people had the freedom to be innovative. Jordan believes that's what it takes.

The system in South Carolina is seen as innovative and flexible, so there is an environment there in which people are allowed to try different things to see what works.

Altogether, BCBSSC provides benefits to 1.3 million people. Most of those are administrative services only. But one-third, or about 400,000, are fully insured by BC. The company overlays managed care activities—an extension of case management.

The company attempts to assist people by managing their illnesses. In order to initiate this program, no plan or benefit changes were made. Complex Case Management uses the plan of benefits a client already has. If the client exceeds the allowance for hospice or home health care, they are placed in alternative treatment plans, provided the patient chooses to stay at home, which is more cost effective. The company tries to “manage costs down” while providing what the patient needs.

Two palliative care doctors from Mount Sinai hospital in New York, Diane Meier, MD and R. Sean Morrison, MD, were awarded a grant from The Robert Wood Johnson Foundation to contract with Franklin Health and track the efficiency of the nurses trained in palliative care against the non-palliative care trained nurses treating patients with catastrophic illness in the Complex Case Management program. They questioned whether this model could make a difference in how people perceive the end of their life, and how people die.

Initially, BCBS needed a third party to administer the program for them. Dr. Jordan understands that perception is very important. “We don’t want to be perceived as withholding care. Health plans can get into considerable conflict of interest when they’re both the provider of care and the insurer. This is one of the greatest sensitivities we face. Also, we must be sensitive to families and patients in providing options for care. We want to be perceived as offering people options and not being directive. If we become directive, we will miss what the patient wants. This is not for every patient. You can’t make choices for people, but we want people to make informed choices.”

Overall, Franklin Health Plan reports to BCBS. In the first year, their data was that they had saved \$1.2 million of catastrophic case management, “but that’s a fuzzy figure,” Jordan said. “It’s avoided cost, and that is impossible to determine. Intuitively everyone believes it’s working. The senior executives all say that even if it’s cost-neutral, rather than cost-saving, it’s worth doing because it’s the right thing to do.”

Research

Diane Meier and Sean Morrison are looking at outcome measures of:

- Pain and other symptoms;
- Patient and family satisfaction;
- Communication about treatment wishes;
- Utilization measures;
- Acceptability/feasibility to nursing/medical staff/ and industry.

Their utilization measures are

- Hospitalization rate
- Emergency room use
- Doctor visits
- Site of death

- Hospice referral rate
- Home care services used (Social Worker, pastoral, psychiatric, rehabilitation)
- Case management personnel costs
- Analgesic/anxiolytic/antidepressant Rx

Education

Several Franklin Health case management nurses have been formally trained in palliative care through this project. A training curriculum has been designed for the nurses and referenced information sheets on palliative care approaches to specific symptoms have been developed for physicians. Part of the nursing care service involves training patient, family and other providers of care.

Partnerships

- Franklin Health
- Mount Sinai Hospital

Marketing

Selling this voluntary program has been a challenge, according to Dr. Ashby. He says the hard sell has been to members. Initially BCSSC presented the plan to patients by phone or letter. About 70 percent of those contacted agreed to entering the program. However, one nurse had a 95 percent acceptance rate, and now she is doing all the initial patient contact. The overall acceptance rate has risen to close to 90 percent.

Franklin Health markets through its own parameters.

Vision

Ashby Jordan feels that this program might evolve. There may be refinement about the patients Franklin Health chooses for intervention. “There is hope for improvement in the whole culture of end-of-life care in South Carolina, as we come to understand a patient’s needs at end of life.”

The program has the potential to change hospice agencies. “It’s the hospice nurses who really know what needs to be done in a case. The influence of this might expand hospice care beyond the allotted six months of care toward chronic management,” says Jordan.

“I see the next wave as more employer groups and people being involved in these programs. We’re starting to look at other diseases, like diabetes. In South Carolina where there is a large rural poor population, many people can’t get to treatment centers so medical staff can manage their chronic illness. We could provide transportation, and that might be cost effective. There is a whole spectrum of services to be provided. Medicare and Medicaid have never approached this kind of method.”

Key Elements of Success

- Well-trained case management nurses who know the patients and their potential options
- The fact that the program is voluntary
- Flexibility

Measures of Program Success

- Member satisfaction information
- Cost saving information
- Provider satisfaction

Necessary Steps

Ashby Jordan thinks we need more time and data for this program “to fully understand what we can.”

What I Wish I'd Known . . .

“One of the lessons learned is that we must be careful about who presents the program to the family. And the other thing it's taught us is that case management should be more patient centered, not physician centered, and certainly not institutionally centered.”

This descriptive summary is based on an interview conducted by Susan Butler with Ashby Jordan, MD, June 13, 2001.

INSTITUTION

Hawaiian Medical Services Association (HMSA)
Honolulu, Hawaii

PROGRAM

The HMSA Foundation, sponsor of Kokua Mau
A collaborative effort

DIRECTOR

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“Providers all want more money. HMSA is more inclined to address that issue since hospice is a cost-saving program. The fact that it saves us money gives us a greater opportunity to look at increases in the program.”

— Jim Walsh

“An aspect that fosters hospice support in Hawaii is the native concept of extended family. The Hawaiian word is Ohana.”

— Marv Hanson, Provider Service
Sr. Contracting Officer for Hospice

**Program Mission/Objectives**

The mission of Kokua Mau is to improve end-of-life care in Hawaii through:

- Community collaboration;
- Education regarding the value and availability of hospice services;
- Broadening the reach of patients in need of hospice services;
- Improvement of policy related to end-of-life issues.

Program Description

Kokua Mau, an ongoing partnership of individuals, community organizations, and public and private leaders of health care and government, seeks to improve end-of-life care in

the state of Hawaii. Hawaii Medical Service Association (HMSA) has taken a leading role in Kokua Mau, working alongside the Executive Office on Aging, Hospice Hawaii, St. Francis Hospital, and the University of Hawaii Center on Aging.

Kokua Mau has worked on many initiatives. The HMSA Foundation has funded grants for three of these initiatives. Most recently, while discussing potential entry points to hospice service, Kokua Mau identified the clergy and churches as a population closely in touch with people in need. Realizing that they might not be aware of services available, HMSA sponsored a grant to train clergy around the state to minister to and facilitate program entry of persons in need of hospice care. The next initiative that has been funded by HMSA will be to train providers of long-term care. Kokua Mau provides the trainers who make the presentations.

Historical Perspective

Teachers and social workers began HMSA, so it comes naturally to its commitment to community work. The Board of Directors established the HMSA Foundation in 1996 as a way to repay the community for their support of the company, the dominant health plan in Hawaii.

In 1996, the hospice community approached HMSA to collaborate through a research project to assist families of hospice. Fifteen patients were in the original study, and fourteen of those transitioned to hospice. The patient outcomes showed that all fourteen had increased quality of life. Cost savings were substantial as well.

In 1997, the Governor appointed a blue ribbon panel, asking them to look at issues of death and dying toward improving the quality of care being offered. As a result of that panel, the recommendation was made that hospice care be made more available and offered more expediently to the dying. Because of the nature of the Islands, the high level of collegiality and collaboration is not a new thing to the state. Kokua Mau was born out of the interest of HMSA and other entities that worked on the blue ribbon panel. Initially Kokua Mau was funded by a grant from The Robert Wood Johnson Foundation through Community-State Partnerships to Improve End-of-Life Care. It has since been able to secure other grants to continue its activities. Jim Walsh says the budget and leadership of the partnership is truly shared, so if one of the major partners were to disappear, one of the others would “pick up the ball and go with it.” The “volunteers” of Kokua Mau come from the participating agencies, and work collaboratively in a partnership to accomplish the objectives, making this management model somewhat unique.

HMSA has worked with the various partners of Kokua Mau on different initiatives over the years. They participate in community forums, they've funded some of their grant proposals, and as unusual as it might seem, they testified with them in favor of the 1999 Hospice Reimbursement Act. HMSA normally opposes mandated benefits, but in this

instance they felt an exception should be made. HMSA plans to remain involved in the initiative. Along with their other activities, they print brochures, share some of their advertising spots, and they are creating a Web site for advance directives, with registration for members and access for providers.

Jim Walsh believes that the real champions of these efforts in Hawaii were Mitsuo Aoki, D.D., a professor of religion at the University of Hawaii, and Sister Maureen Kelleher. Aoki had an early interest in issues of death and dying, and along with Kelleher, he pioneered hospice in the state. The two of them were, and are, held in high regard. "They have touched a lot of people in their professional and everyday lives. They weren't publicity seekers; they were the opposite of self-aggrandizing. People listened when they talked and they were able to pull groups together. They wound up forming a collaboration of the unions, the clergy, providers, social workers, almost everyone with an interest in hospice care. Also, Dr. Aoki is a native Hawaiian, and if Sister Maureen wasn't native to the Islands, she had lived and worked there for a long time. They had the credibility of long-timers."

The legislature in 1999 passed a law requiring all health plans to pay at least the Medicare level of per diems. These legislative edicts helped to make the public aware of hospice and the programs that HMSA already had in place. All hospice programs participate with HMSA with all lines of business.

The hospice benefit provided by HMSA has two unique components. HMSA will pay for residential services and for one referral visit to a potential hospice patient. They will reimburse the nurse or caregiver to meet with a family or patient. Walsh said that in a sense it is a sales visit. This makes it worthwhile for hospice providers to talk to families, "which they would do anyway, but it validates their services." This benefit introduces people earlier to the potential of hospice care.

Research

The initial hospice study showed that clinical outcomes were:

- Reduced length of hospital stay;
- Improved pain control for patients;
- Positive provider response in terms of case management.

Although HMSA is in the process of gathering data, they have enough now to know that they want to continue developing and promoting hospice. Both customer and provider responses are positive for the program, and the program has proven to be cost saving rather than cost neutral.

One thing they are looking at is whether hospice participation differs by ethnic group. Because Hawaii is culturally such a complex society, this is a perfect venue to explore this

issue. They are currently surveying the community to identify end-of-life issues, and they're sharing the surveys from their Senior Living Program participants.

Education

Education is one of the main focuses of Kokua Mau. They believe that hospice care is in everyone's best interest, and part of their mission is to make everyone aware of the program.

Partnerships

- The Governor's Executive Office on Aging
- Hospice Hawaii
- St. Francis Healthcare System of Hawaii, a hospice provider
- University of Hawaii Center on Aging

Marketing

Hospice Hawaii presents community service ads on both radio and television. The hospital has sponsored both for hospice.

Funding

Kokua Mau, as described earlier, is upheld by grants.

Vision

For HMSA, providing education to the community regarding matters of death and dying is a collaborative effort with all community stakeholders involved. Walsh believes that resources for end-of-life care will not be expanding, so "we need to do more with what we have. Well run and caring hospice programs provide an answer." He reflects, "You need the champions, the key public well-respected figures to be out in the community, promoting the program."

Key Elements of Success

- Education of all factions of the community—providers of care, patients and their families, payers, clergy, counselors, all the stakeholders
- Trying to hit all the entry points of patients to the program
- Community collaboration
- Champions for the programs

Measures of Program Success

- Analysis of member satisfaction
- Financial analysis
- Analysis of physician/provider satisfaction

Necessary Steps

Jim Walsh summed it up in one word: Commitment. “I think everybody has the resources to provide quality care. I think everyone has the opportunity to do this. I think they just have to believe in it, and that goes back to the issue of education about it.”

“Of course,” he continued, “there are obstacles to acceptance of the program. Many physicians struggle with their training, which taught them to keep people alive. That often makes it difficult for them to refer their patients early enough to a hospice program. It’s necessary to be sensitive to their desire to want to save their patients. And families have problems with letting people die. That is cross-cultural.” Kokua Mau is working to overcome these obstacles.

What I Wish I’d Known . . .

Jim Walsh, a former clinic administrator, has been at HMSA for three and a half years. “I came along after the hospice benefit was already going. I’m probably now the in-house champion of it. Getting involved on the Board as a hospice provider brought me along. The one thing that all the plans don’t do, we don’t go out and involve providers to get their input as much as we should. We need input from providers.”

This descriptive summary is based on an interview conducted by Susan Butler with Jim Walsh and Marv Hanson, June 15, 2001.

INSTITUTION

Regence BlueShield
Seattle, Washington

PROGRAM

Pediatric Palliative Care Project

DIRECTOR

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“What has surprised me was the number of hard-core business people who wanted to do this program because it was the right thing to do. Because they wanted to help.”

— Pat Emerick, MSW

**Program Mission/Objectives**

The mission of the Pediatric Palliative Care Program is to increase access to an improved quality of comprehensive pediatric palliative care and end-of-life services for children and their families. The project is designed to meet the following objectives:

- Enhance insurance benefit administration;
- Create coordinated home services for dying children and their families through collaboration with the two largest health insurance carriers in Washington State;
- To modify existing benefit packages to support the range of services needed by dying children and their families;
- To create flexibility in and coordination of home health care, hospice and infusion services;
- To establish a standard of excellence in pediatric palliative care;
- To evaluate the impact of the changes on dying children, their families, the insurers and providers.

Regence BlueShield joined this project in hopes of finding a better way to address the needs of the dying child and his or her family. They were aware that hospice was a rarely used, but much needed benefit for children.

Program Description

This three-year demonstration project was designed to address access and care barriers through fundamental changes in benefit administration. The Project is designed to serve children under the age of 21 who have potentially life-limiting conditions for which palliative care is the most appropriate form of treatment. Any patient is eligible if his or her plan includes a benefits management clause, as most contracts do. A benefits management clause allows Regence, under certain circumstances, to use an existing benefit to pay for services that would not be covered under the member's contract.

Joint case management between hospice nurses and case managers at the insurance company is key to this program. The hospice nurse acts as the eyes and ears, learning the family's needs, and the case manager knows how to use existing benefits to maximize services.

Regence has provided flexibility in providing care to these patients. With a benefits management clause, the usual home health requirements, such as being homebound, can be ignored. For example, under existing home health standards, if a parent can take a child to the doctor, the child is not eligible for home health services, because services can be rendered in the doctor's office. This program rejects that idea. Pat Emerick, MSW says, "it puts less emphasis on service limitations and more emphasis on an effort to maximize existing benefits to honor patient preferences, and to reduce the need for hospitalization."

The case nurse can accompany the family to the doctor's office, which focuses the conversation between physician and parents around what the treatment goals are and how to go about achieving them. Through this program, patients can receive physical or occupational therapy as well as intermittent nursing visits, whatever the care managers agree might help to increase quality of life, reduce pain and suffering, and enable patients to live as fully as possible until they die.

The Decision Making Tool (DMT) tracks goals and plans of care to focus thinking on what the patient truly needs. It was based on an ethical model developed at the University of Washington by Albert Jonsen, PhD, Mark Siegler, MD, and William Winslaide, PhD, JD, leaders in the field of medical ethics. It takes a look beyond the medical side of decision making, and includes patient preferences, quality of life and socio-economic factors. There have been some adaptations to fit pediatric needs in a plan for decision making. The family, doctors, hospice nurse, and program all receive a copy of the plan. This keeps everyone focused on the same goals. Parents like this tool because it reduces ambiguities and they feel their wishes are being heard.

Nurses and social workers in the medical management departments of Regence BlueShield and Premera Blue Cross are involved with the project. For out of contract requests they may seek the opinion of a medical director, a physician licensed in the State of Washington. No special staff has been hired by Regence to manage the project. “The great message here,” says Emerick, “is that this is a version of business as usual. This is not a big scary new initiative that is outside the projected budget.”

Historical Perspective

Each year in Washington State approximately 1,100 children and adolescents die. Of these, about one-third die of conditions known to be life limiting. Yet the rapid growth of adult hospice care has no equivalent in pediatric practice. Few children access hospice or receive comprehensive, coordinated, resource-efficient care at the end of life.

The Pediatric Palliative Care Project was funded through a grant from The Robert Wood Johnson Foundation issued to Regence BlueShield, Premera Blue Cross, and The Center for Children with Special Needs Program, a department of Children’s Hospital. The Center has primary responsibility for the program.

The woman who first held the position of project administrator, Rhonda Jack, MSW, MPH was interested in children with special needs. She was working with Regence to expand Healthy Options, the Medicaid program in Washington for disabled children. When she was approached by The Children’s Center to be a part of the grant, she immediately saw the potential and necessity for the program.

Many people, including Jack, have acted as champions for the program. Physicians have been enthusiastic. “These people are effective at promoting the program,” says Emerick, because they are “an intelligent, persuasive, moral, and ethical group of people whose knowledge of medicine and insurance speaks to the full scope of issues.”

The program has not been without challenges. One has been getting people to think outside the box, including the case managers and hospice workers. Defining the “co” of co-management was another challenge. Initially, some of the participating hospice agencies thought there were no constraints on patient services. It was the adversarial concept of “battling the insurance company” except this time the insurance company could not say “no.” The concept of shared decision making was difficult to grasp.

Regence has tried to overcome obstacles that have arisen by keeping all lines of communication open. It is also worth noting that when it came down to “this child needs this

program,” Regence did not turn down any child. They have enrolled twenty-four children so far. Although the original goal was fifty children for the life of the project, this number was harder to reach than project designers thought it would be.

Research

The Center for Children with Special Needs at Children’s Hospital is tracking several things, but only preliminary data is available. Evaluation components will include quality of care, quality of life, and cost. Early examination of this data shows that peoples’ attitudes toward the insurance company are positive, and that Regence is perceived as an advocate. Initial reports show customer satisfaction has risen substantially.

Partnerships

- Children’s Hospital’s Center for Children with Special Needs
- Premera Blue Cross
- Hospice
- The Department of Social and Health Services
- Medicaid, which was granted a waiver to participate

Marketing

Regence has publicized The Pediatric Palliative Care Program in the provider newsletter. They’ve sent letters to physicians that explained the Project, asking if the option would be beneficial for a particular child. Doctors’ responses have been enthusiastic.

Funding

Funding for this project came from a grant from The Robert Wood Johnson Foundation through Promoting Excellence in End-of-Life Care.

Vision

“Our vision for this program goes in so many directions. So few children ever receive the benefit of hospice, because of the difficulty of facing the fact that a child is dying. To get services to people who are suffering is such a positive thing,” Emerick said. “Many good things could come from this project.”

Under a standard benefit structure, patients usually have access to home health and hospice benefits, although not all plans feature both. The Regence Medical Management department is creating a palliative care policy “add-on.” As an add-on, the insurance components of the PPCP will be available to members who need palliative, rather than curative, care. Within a couple of years Regence will consider formalizing the add-on into the benefits package. The palliative care policy will be available to people of all ages, since

it is illegal to discriminate based on age. As a result, Regence will have progressed from participation in a study grant for the benefit of dying children to an opportunity to provide palliative care to all ages, whether death is imminent or not.

This program has the potential to change the current structure and orientation of hospice agencies. Hospice nurses have experience providing the kind of care such illness requires. It is possible that hospice agencies will want to expand hospice-style care beyond the six months now allotted to care for the dying.

Key Elements of Success

- Flexibility
- Creativity
- Willingness to move out of the adversarial box
- Communication
- Collaboration

Pat Emerick quotes one of the nurses at the Center for Children who is fond of saying, “When people of good will decide to do something, there’s nothing they can’t do.”

Measures of Program Success

- Patient and family satisfaction
- Physician satisfaction
- Financial feasibility

Necessary Steps

The realm of communication and sensitivity to issues is primary. There must be sensitivity to the fact that people’s feelings are not clearly defined about signing a document that says “I understand that this child has six months or less to live” in order to qualify for hospice services. This program offers a better option in this regard. On a national basis, Emerick believes we need to continue working to change people’s attitudes about the end of life. “We need to get death out of the failure category. We need to have a paradigm shift in people’s minds,” she says.

Denying experimental care that people requested for their children was difficult. Regence has implemented an experimental, investigational component to their case management options. In some circumstances, Regence will pay for a child’s participation in a clinical trial. If the trial meets criteria for rigorousness of research study, they will give it real consideration.

What I Wish I'd Known . . .

"I wish I'd known more about the medical policy allowing clinical trials earlier. That might have helped one family on the project get a curative treatment they wanted to try.

I wish I had been more thorough about documenting, and kept a more careful journal from the beginning. I wish we had more organized, and defined feedback about insurance from families. We only asked three questions, because we did not want to make participation in the project burdensome with long questionnaires." — Pat Emerick, MSW

This descriptive summary is based on an interview conducted by Susan Butler with Pat Emerick, MSW, June 13, 2001.

