Rochester Community End-Of-Life Survey Report

October – November 2000

RIPA / Blue Cross
End-Of-Life / Palliative Care
Professional Advisory Committee

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End-Of-Life Survey Report

INTRODUCTION:

In our Speaking Out commentary in the March 20, 2000 *Democrat & Chronicle*, the RIPA/Blue Cross End-of-Life/Palliative Care Professional Advisory Committee promised to "collect data about our current practices and make the result of our work public." We viewed collecting data as the most effective way to identify the most pressing issues in delivering quality end-of-life care. Based on these results, we are committed to encourage a community-wide initiative to improve: 1) patients' awareness of the options available near life's end, 2) the management of pain and other symptoms, and 3) the health system's honoring of patients' preferences in managing their terminal care. This report is a summary of our work over the past year. The members of the Professional Advisory Committee are listed in Appendix I.

Our survey was directed to area hospitals, home care agencies, disease management programs, hospices, and skilled nursing facilities. The greater than 50% response rate exceeded our expectations, suggesting that as a community, the leaders of Rochester health care institutions are concerned about end-of-life issues. They are willing to share their experiences, both positive and negative, in order to create a better system. The response rate for the 16 area hospitals was 56%; for the 13 certified home care agencies, 69%; for the four insurance company disease management programs, 50%; for the 35 skilled nursing facilities, 57%; and for the 4 hospice programs, 100%. A list of respondents is included as Appendix II.

In addition, copies of policies, procedures, patient care pathways, and advance directive tools were requested so we could identify best practices that might be shared throughout the community. We also provided space for comments, which were analyzed and are presented in the results.

SUMMARY OF ANSWERS TO SURVEY QUESTIONS:

The eight questions surveyed and their answers are as follows:

1. **Are Advance Directives solicited on admission to your facility? If so, what percentage of patients had advance directives in their records?**

   One hundred percent of responding facilities said they solicit Advance Directives on admission. One of the two disease management programs routinely inquires about Advance Directives. Skilled nursing facilities reported that 72% of residents have Advance Directives in place. Most other facilities do not track the percent of patients who have completed Advance Directives. One large home care agency reported 40% of its clients have Advance Directives. Hospitals reported that 38% of patients have Advance Directives in their record. This is based on a small sample of twenty-five chart audits at each of the three hospitals. Hospice programs do not specifically track these statistics, because upon enrollment into hospice all patients are involved in detailed planning about Advance Directives.

2. **What percent of residents/clients/patients have living wills, durable power of attorney, DNR orders, or health care proxy?**

   Residents in skilled nursing facilities had the largest percent of Advance Directives. The majority of other facilities do not track these statistics. In skilled nursing facilities, 53% of 2674 residents had a health care proxy, 10% had a living will, while 10% had both a health care proxy and a living will. In one home care agency, 29% of 2956 clients had health care proxies, 11% had living wills, and 6% had DNR orders. Several nursing homes have created additional advance planning options including comfort care, resuscitation measures, no hospitalization, and no feeding tubes. Where offered, 14% of residents or their families chose comfort care, 24% chose no hospitalization, 50% chose no feeding tube, 72% chose a Do Not Resuscitate (DNR) order, and 15% chose Cardiopulmonary Resuscitation (CPR) orders. For hospitals, there was insufficient data to comment. Hospices and disease management programs do not track the types of patient advance directives.

3. **What percentage of patients with cancer, heart failure, chronic obstructive pulmonary disease (COPD)/emphysema or dementia have an Advance Directive or a Do Not Resuscitate (DNR) order in place? (Home Care and Hospice only)**
   Note: Heart disease, cancer, COPD/emphysema, and dementia are among the leading causes of death for patients older than 65 years of age.

   Home care agencies reported that advance directives are in place for only 23% of patients with COPD/emphysema, 9% of cancer patients, 8% of patients with heart failure, and 6% of dementia patients. For these same groups, the percent of home care clients with active DNR orders were 3%, 2%, 1%, and 3% respectively. Hospices reported that they do not track this information.

4. **Do your disease management pathways for cancer, heart failure, COPD/ emphysema, and dementia include a discussion of advance care planning**?

   Overall, advance directives are solicited as part of the admission process, rather than within disease pathways. With regard to Advance Directives, our committee judged Lakeside Hospital to have best practice pathways for heart failure and COPD, reviewing advance directives on admission and again prior to discharge. Likewise, Health Care Resources (HCR), a home care agency, was judged to have a best practice pathway for heart failure, which prompted discussion of advance directives mid-way through the pathway.

5. **Is pain recorded as a vital sign by nurses/aides in your institution?**

   Generally, pain is not recorded as a vital sign. Effective January 1, 2001, the Joint Commission on the Accreditation of Health Organizations (JCAHO) requires that hospitals record pain as a vital sign. All area hospitals reported they plan to comply. One hundred percent of hospices reported comprehensive pain assessments on their patients. Sixty-six percent of home care agencies and 56% of hospitals reported routine pain measurement, either as a vital sign or an assessment. Skilled nursing facilities reported similar assessments only 10% of the time. Our group judged the pain-as-a-vital-sign policy at ViaHealth (Rochester General Hospital, The Genesee Hospital, and Home Care) as a best practice because of its depth and quality of detail.

6. **What percent of hospice patients die within 7 days of referral to the program?**

   In 1998, 39% of 1,990 patients died within 7 days of referral to hospice. In 1999, 40% of 2,100 patients died within 7 days of referral. The hospice benefit is available for those with a prognosis of less than six months. Referrals within 7 days of death was chosen as an important measure because during the first few days, physical measures can be addressed, but the social, spiritual, and psychological aspects of dying often go underaddressed.

7. **What is the average length of stay for hospice patients referred from hospitals, home care, doctor's offices, and skilled nursing facilities?**

   Based on one hospice's data, the average length of stay for patients referred from various referrals sites for 512 patients in 1998 and 541 patients in 1999 was as follows:

Site of Referral	1998 Length of Stay	1999 Length of Stay
Home Care	36 days	41 days
MD Office	21 days	32 days
Hospital	18 days	28 days
Skilled Nursing Facility	34 days	49 days

8. **What percent of opioid prescriptions are for long-acting preparations?**
   Yet to be collected.

CONTENT ANALYSIS

Review of comments mostly from nursing homes revealed the following themes:

1) Communication between staff and residents/families is time-consuming and difficult.

2) Many residents and families do not understand Advance Directives.

3) Many residents and families deny the need to make end-of-life decisions.

4) The lack of discussion between a resident and his/her proxy resulted in conflicts for care providers regarding the resident's expressed wishes and those of the designated proxy.

5) Clarity between resident, family, proxy, and staff results in following resident's wishes, which increases staff's professional satisfaction.

SUMMARY OF RESULTS

Given the results of the survey, it is apparent that the following four dimensions of end-of-life care are most in need of attention:

1) Assuring that a greater percentage of patients, especially patients with chronic debilitating illnesses, understand, complete, and use Advance Directives. Once completed, health care institutions must ensure their availability and commit to honoring them.

2) Promoting earlier hospice referrals for terminally ill patients so that the social, spiritual, and psychological components of suffering can be addressed.

3) Establishing comprehensive pain assessment and treatment standards at all facilities.

4) Encouraging health care institutions to set performance goals and track basic statistics regarding end-of-life care.

RECOMMENDATIONS

Advance Directives

1. Offer multiple professional and lay presentations on Advance Directives.

2. Promote universal acceptance of an Advance Directive form, which, once completed, would be honored at all community facilities.

3. Establish community standards and basic measures that should be tracked at all health care institutions.

4. Share resource materials that assist with the discussion of Advance Directives.

5. Recommend Advance Care Directives prompts on all Rochester Health Commission guidelines and site-specific chronic disease pathways.

6. Clarify, then educate primary care physicians about reimbursement options for discussing Advance Directives with patients.

Hospice Referrals

1. Educate professionals and case managers regarding symptom indicators in chronic illness that predict a six-month or less prognosis.

2. Recommend inclusion of hospice referral prompts as appropriate in disease management pathways.

3. Encourage earlier referrals to hospice, thereby decreasing the percentage of patients dying within seven days of admission to hospice.

4. Provide feedback to facilities regarding hospice referral patterns on a quarterly basis (hospitals, home care agencies, skilled nursing facilities, and physician organizations).

Evaluation and Management of Pain & Other Symptoms

1. Recommend standards for routine pain assessment and management for all facilities. Distribute examples of "best practice" policies.

2. Establish a mechanism of reimbursement for certified palliative care specialists to provide consultations at all area hospitals, hospice programs, home care agencies, and skilled nursing facilities by 12/31/01.

3. Report opioid usage patterns per disease for the Rochester Community.

CONCLUSION:

From our work to-date, the next steps in providing humane high quality care at the end of life are clear. To succeed, there must be more effective collaboration between professional groups, health care agencies, insurers, patients, their families, and proxies. We must find ways to talk more openly about the dying process and turn those conversations into action that benefit patients and families. We need more effective ways to educate both professionals and the public about available options and programs. We need an accepted community wide Advance Directive form. The professional community is accountable for honoring each patient's request.

We must do better in managing pain and distress at the end of life. Patients and their families should expect relief of pain. Together they should work with health care and other professionals to relieve suffering. Toward that end, we must refer patients for hospice care earlier in the course of their disease so that physical, spiritual, and psychological needs can be addressed.

The agenda is robust, but large portions of it are within our reach!

APPENDIX I

Members of the RIPA/BCBSRA Professional Advisory Committee

Howard Beckman, M.D., Medical Director, RIPA, Committee Chair

Judith Gedney Baggs, Ph.D., R.N., Associate Professor University of Rochester School of Nursing and School of Medicine and Dentistry

Edgar Black, M.D., Chief Medical Officer, BCBSRA

Patricia Bomba, M.D., Excellus Medical Director, Geriatrics,

Patricia Heffernan, C.S.W., VP, Genesee Region Home Care

Robert McCann, M.D., Chief, Department of Medicine, Highland Hospital

Kathy McGrail, M.D., Medical Director, VNS Hospice

Timothy Quill, M.D., Director of Program for Bio-Pyschosocial Studies at the University of Rochester

Bernard Shore, M.D., Medical Director, Jewish Home of Rochester

Julia Smith, M.D., Oncologist and Director, Palliative Care Unit, Genesee Hospital

Rocco Vivenzio, M.D., Geriatrician and Board member, RIPA.

APPENDIX II

Institutional Respondents to the RIPA/BCBSRA Survey

Hospitals: Clifton Springs, Highland, The Genesee Hospital, Geneva General, Lakeside Health System, Park Ridge, Rochester General Hospital, St. Mary's, Strong Memorial Hospital

Home Care Agencies: Finger Lakes VNS, Genesee Region Home Care (GRHC), Health Care Resources (HCR), Livingston County CHA, Seneca County CHA, ViaHealth CHA, Visiting Nurse Service of Rochester & Monroe County, Wyoming County CHA, Yates County CHA

Hospices: Genesee Region Home Care Hospice, Livingston County Hospice, Ontario-Yates Hospice, Visiting Nurse Service Hospice

Disease Management Programs: BCBSRA, Monroe Plan

Skilled Nursing Facilities: Blossom Nursing Home, Brae Loch, Brightonian, Edna Tina Wilson Living Center, Episcopal Church Home, Highland Living Center, Hill Haven, The Hurlbut, Jennifer Matthew, Jewish Home of Rochester, Latta Road, Latta Road A, Maplewood, Monroe Community Hospital, Nor Loch Manor, Park Ridge Nursing Home, St. Ann's, St. John's, Wedgwood Nursing Home, Woodside Manor

APPENDIX III

End-of-Life Performance Improvement Measures for 2001

Recommendations for Hospitals, Home Care, and Disease Management:

Please consider including the following measures in your facility's annual performance improvement plan. An annual sample of 5 - 10% of admissions per year is suggested.

1. The number of patients with Advance Directives (Health /Care Proxy, Living Will, other) in their record at discharge _____.
   The number of charts reviewed _____/ _____ total number eligible.

   Please include the type of Advance Directive **for patients identified above.**
   a. Health Care Proxy _____
   b. Living Will _____
   c. Both HCP and LW _____
   d. Other (DO NOT include time-limited or hospital only DNR) _____

2. For patients with the following diagnoses, the number with Advance Directives on admission compared with the number with Advance Directives at discharge.

		Admission	Discharge
a.	Cancer	_____	_____
b.	CHF	_____	_____
c.	COPD	_____	_____
d.	Dementia	_____	_____

3. Total number of terminal patients assessed to have moderate pain (>5, scale 0-10) in which there is evidence of intervention for the pain in the record. _____
   Total # of terminal patients assessed to have moderate pain. _____

Recommendations for Hospice:

Please consider including the following measures in your facility's annual performance improvement plan. An annual sample of 5 - 10% of admissions per year is suggested.

1. The number of hospice patients with Advance Directives (Health /Care Proxy, Living Will, other) in their record _____.
   The number of charts reviewed _____/ _____ total number eligible (admitted).

   Please include the type of Advance Directive **for patients identified above.**
   a. Health Care Proxy _____
   b. Living Will _____
   c. Both HCP and LW _____
   d. Other (DO NOT include time-limited or hospital only DNR) _____

2. The number of patients admitted to hospice with the following diagnoses:
   a. Cancer _____
   b. CHF _____
   c. COPD _____
   d. Dementia _____
   e. Other _____

3. The number of terminal patients assessed to have moderate pain (>5, scale 0-10) in which there is evidence of intervention for the pain in the record. _____
   Total # of terminal patients assessed to have moderate pain. _____

4. The number of patients referred to hospice who died within 7 days of admission into the program _____.
   The number of patients admitted to hospice for the year. _____

5. For the patients who died within 7 days, please indicate the number of patients referred from each site.
   a. Home Care _____
   b. Physician's office _____
   c. Hospitals _____
   d. Skilled Nursing Homes _____

6. What was the average length of stay for patients admitted to hospice who were referred from:
   a. Home care _____
   b. Physician's office _____
   c. Hospitals _____
   d. Skilled Nursing Homes _____

Recommendations for Skilled Nursing Facilities:

Please consider including the following measures in your facility's annual performance improvement plan. An annual sample of 5 – 10% of admissions per year is suggested.

1. The number of patients with Advance Directives (Health /Care Proxy, Living Will, other) in their record _____.
   The number of charts reviewed _____/ _____ total number eligible.

   Please include the type of Advance Directive **for patients identified above.**
   a. Health Care Proxy _____
   b. Living Will _____
   c. Both HCP and LW _____
   d. Other (DO NOT include time-limited or hospital only DNR) _____

2. Total number of terminal patients assessed to have moderate pain (>5, scale 0-10) in which there is evidence of intervention for the pain in the record. _____
   Total # of terminal patients assessed to have moderate pain. _____