



# End-Of-Life Care

## END-OF-LIFE CARE Meeting Summary of the Expert Panel May 29, 2001

### **Panel Members:**

Joan Armbruster, Dr. John Brehm, Charlene Farrell, John Grey, Parker Haddix, Cathy Chadwell, Linda Sovine, Sallie Hunt, Dr. Sue Warren, Debbie Ruppert, Mary Emmett, Jeff Carrier, Tamara King

### **Meeting Agenda:**

- Review and revise the pain management indicators for nursing homes, home health, hospice and palliative care
- Review intent of the Death Certificate Study
- Review recommendations from the study on “Medicaid and End-of-Life Care” study by Jane Tilly and Joshua Wiener
- Review composition of palliative care network
- QUAG meeting, June 26
- Next steps

### **Pain Management: Nursing Homes:**

The data elements collected on the Minimum Data Set (MDS) for all nursing home residents within 14 days after admission and routinely each quarter thereafter unless changes in resident status indicate a need to complete an assessment prior to the quarterly schedule. Data on the minimum data set are as follows:

- Pain Symptoms – Frequency
  - 0 – No Pain
  - 1 – Pain less than daily
  - 2 – Pain daily
- Pain Intensity
  - 1 – Mild Pain
  - 2 – Moderate Pain
  - 3 – Times when pain horrible or excruciating
- Pain Site (circle all sites from which resident experiences pain) Back pain 2. Bone pain 3. Chest pain while doing unusual activities 4. Headache 5. Hip pain 6. Incisional pain 7. Joint pain (other than hip) 8. Soft tissue pain (e.g. lesion, muscle) 9. Stomach pain 10. Other

The panel reviewed and critiqued the data elements from the MDS. The intent is to understand the extent of persistent pain among residents in the home. The panel concluded the following as important when measuring and reporting pain assessment and pain management in nursing

homes:

- Pain level (intensity)
- Site of the pain and or cause of pain
- Cognitive status of the resident
- Intervention – medication data

For reporting purposes the following suggestion was made:

- Remove from the data all residents with cognitive impairment\*\*
- Assess level/intensity of chronic pain
- The first quarter assessment would be the definable point in time to produce the first report

\*\*Pain assessment on cognitively impaired individuals is extremely difficult since the people cannot speak for themselves and the methods of assessment are not well defined.

Joan Armbruster noted that Pain is not, currently, a resident assessment protocol (RAP) for the nursing home residents. A draft of the RAP is currently being reviewed nationally.

Next steps: obtain a user agreement and begin data analysis.

#### **Pain Management: Home Health, OASIS:**

The following data are collected on home health clients:

- Frequency of Pain – Interfering with patient’s activity or movement:
  - Patient has no pain or pain does not interfere with activity or movement
  - Less often than daily
  - Daily, but not constantly
  - All of the time

Next Steps: review data for presentation to the panel.

#### **Pain Management: Hospice, NHPCO:**

The data elements proposed by the National Hospice and Palliative Care Organization are as follows:

- “Was your pain brought to a comfortable level within 48 hours of your admission to the hospice program?”
- Follow-up after 48 hours (includes only patients who reported being uncomfortable because of pain on admission) – “Was your pain brought to a comfortable level within 48 hours of admission to hospice?”

Next Steps: Larry Robertson is to present these data elements to the Hospice Council for their discussion. Charlene Farrell will inquire as to whether or not the data once collected are available to the State.

### **Pain Management: Palliative Care:**

A suggestion was made to use the same data elements for palliative care as used for nursing homes. The panel discussed this idea and proposed that palliative care network consider using the following:

- Upon admission to palliative care, if the person has pain, use a scale of 0 to 10 and report their pain score.
- After 48 hours, using a scale of 0 to 10, reassess the person's pain and report their score.

Next Steps: Dr. Sue Warren will take this suggestion to the Palliative Care Network in July. Mary Emmett will analyze the data collected from the first 208 individuals on whom a pain score was obtained, using the criteria above, and report that analysis to Dr. Warren. This data could serve as a baseline.

### **Other quality indicators reported in the MDS:**

- Advanced Directives
- Living Will
- Do not resuscitate
- Do not hospitalize
- Organ donation
- Autopsy request
- Feeding restrictions
- Medication restrictions
- Other treatment restrictions
- None of the above
- Special treatments, procedures and Programs
- Hospice care

### **Other quality indicators reported in OASIS:**

- Life Expectancy
- Life expectancy is greater than 6 months
- Life expectancy is 6 months or fewer

### **Death Certificate: Study:**

- Hanson, Danis and Garrett, 1997, published, "What is Wrong with End-of-Life Care?" The results indicate a need to improve communication with families and provide better pain control.
- The study using death certificate data would be an opportunity to explore from the families perspective ways to improve communication, pain management, and bereavement.
- Panel suggested that the study be conducted at a future date.

### **Number of Sites With Palliative Care Teams:**

- Eight hospitals (8)
- Eight nursing homes (8)
- Two Rehabilitation Centers (2)
- Six Community (home) (6)
- Locations include: Wheeling, Charleston, Morgantown, Beckley, Martinsburg, Huntington, Preston County

**Study by Tilly and Wiener, 2001, “Medicaid and End-of-Life Care:**

The results of this study confirm the observations of the panel:

- Require better data descriptive of the Medicaid population
- Gain health systems attention regarding the importance of end-of-life care
- More funding for palliative care
- Improve pain management in nursing homes and home care
- Restructure the Medicaid hospice benefit

**QUAG Meeting – June 26:**

Members of the panel would be willing to facilitate a discussion of the quality indicators during the meeting. Mary Emmett to prepare information for the facilitators.

**Next Step:**

- Prepare for QUAG meeting
- Develop data presentations
- Develop data sharing arrangement for analysis of nursing home and home health data
- Assess the value of the pain management data collected from the palliative care assessments