**Improving End-of-Life Care for African Americans**

**Summary of Teaching Points**

**Module 1: Overview of Research Data Management**

* Lack of planning for how to transfer data to and from contracted analyst at other university

**Module 2: Types, Formats, and Storage of Data**

* Audiotapes, Microsoft Word document

**Module 3: Contextual details**

* No naming conventions for tape-recorded data
* Transcribed data reviewed for accuracy

**Module 4: Data Storage, Backup and Security**

* Lack of plan for backup of transcribed data and outcome data

**Module 5: Legal and Ethical Issues**

* Informed consent needed from participants
* De-identification of participants needed

**Module 6: Data Sharing and Re-Use**

* Further de-identification of transcript subsets for re-use in methodology course

**Module 7: Plan for archiving and preservation of data**

* No plan for preservation of source or outcome data at PI’s site other than published manuscript

**Case C: Improving End-of-Life Care for African Americans1**

An MD applied for grant funding to do a qualitative study focusing on how to improve physician communication with African Americans (AA) and their relatives when their patients were receiving end-of-life care.

This qualitative study was conducted to expand knowledge about AA experiences and opinions about end-of-life care. Multiple-meeting focus groups were held to build trust and allow time for full participation. Following a review by a Community Advisory Board (CAB), protocols were approved by the University’s Institutional Review Board. Participants were AA adults who had experienced at least one death of a significant other or family member. Convenience sampling by staff and CAB members was used to recruit participants, and flyers were distributed at neighborhood activities. Participants were screened for eligibility and assigned to one of two focus groups. Focus group 1, which met for four sessions, was comprised of AAs with family members who had died at home. Focus group 2 met for three sessions and included AAs with family members who had died in the hospital. An average of five individuals attended each session. Three participants worked in health care, and their observations reflected experiences with a dying family member, as well as experiences with caring for terminally ill AA patients.

*Data collection* All participants gave informed consent. An open-ended interview script stimulated discussion about (1) positive and negative experiences of participants related to end-of-life care in the hospital or at home, (2) preferences for treatment by health care providers, (3) communication issues, and (4) end-of-life decision making pertaining to living wills and advance directives. An AA member of the project staff moderated the focus groups.

Each session was audio-taped taped. Unlabeled tapes were mailed to a transcriptionist in their plastic cases which were labeled. During the mailing process the package was damaged and the plastic tape cases broke and were no longer associated with the tapes for which the cases had been labeled. The tapes, however, were not damaged. The transcriptionist transcribed the tapes and the transcripts were sent back to the project team for identification of which focus group and which session should be used to identify each transcript. Focus Group Participants’ comments were identified on the transcript by either Miss, Mrs. or Mr. plus the first initial of their first name. The transcripts were also reviewed for accuracy by the project team.

*Data analysis* Transcripts were reviewed for themes through a continuous process of text data segment comparison based on qualitative research techniques. After reading the transcripts several times, a codebook was developed defining themes and subthemes, and a numeric theme code was assigned to each particular category of text responses. Microsoft Word was used to create transcript tables of participant responses which then could be sorted by theme code. Participants’ responses were coded and sorted accordingly into differing categories which were then summarized to capture the richness and range of data within each theme code. The analysis was systematic and involved triangulation of data from the two focus group sources. Within-focus group set analyses were performed, as well as cross-focus group set analyses to develop a set of themes/recommendations for how end-of-life care communications might be conducted to improve the process for all concerned.

*Resulting Data:* In a subsequent publication[[1]](#footnote--1), the results were published as follows: Analysis of the transcripts revealed five major theme groupings. These groupings contained text data related to:

1. Communicating about dying and end-of-life care

2. Choice about dying at home or in the hospital

3. Dying in the hospital

4. Dying at home

5. Other end-of-life care issues

Additionally the implications for clinical care were summarized as follows:

• Be mindful of the diversity of preferences and needs within any population subgroup

• Recognize that many AAs have very strong religious and spiritual beliefs about dying and that their words often reflect that the patient is preparing to leave his or her earthly home

• Empower dying AAs and their family members by speaking respectfully, using lay terminology, and checking for understanding. Encourage the patient to be the primary decision maker and ensure that the dying person is not infantilized.

• Determine whether the dying person and/or caretaker has adequate assistance. Since awareness of home and hospice services is low, facilitate getting necessary support and resources, including connections with social services.

• Encourage patients to decide how the family should be informed about prognosis and provide assistance in telling the family if requested.

• Determine in advance who the primary family contact is and where to contact him or her in the final hours if the patient is hospitalized. If possible, ensure that the family has the opportunity to spend the last hours with the patient. The “gathering of the family” is very important during this phase of life.

• For patients dying in the hospital, treat patients the way you want to be treated with nurturing, compassion, dignity, love, touch, and careful listening. Diligent monitoring of the patient’s medical status, needs, and cleanliness is imperative.

The tapes were eventually destroyed and the transcripts and other files generated during the analysis remained with the analyst who was not part of the project team and was affiliated with another medical school. The analyst was very involved with the drafting of the publication. Excerpts from the transcripts were later re-used as examples for a qualitative analysis class taught by the analyst; however, for the reuse, all participant IDs were changed to P1, P2, etc.

**Module 1 (Overview module) discussion question:**

What issues need to be addressed on this project related to the 7 segments of the data management plan components?

**Discussion Questions for Other Modules:**

1. Types of data
2. What types of data are being collected for this study?
3. How will you ensure all research staff used the same data sources and data definitions?
4. What needs to be in the plan related to the data capture for the various data sets?
5. What analytical methods and mechanisms will be applied to your data either prior to or post integration?
6. What type of outcome data will be generated?
7. File Formats and Contextual details
   1. What file formats and naming conventions will be used for the separate data sources and for the integrated file used for analysis?
   2. What impact would the naming conventions have on later data access?
   3. What other contextual details would you specifically need to document to make your data meaningful to others?
   4. In what form will you capture these details?
8. Data Storage, Backup, Security
9. Where and on what media will the data from each data source be stored?
10. How will you manage data security across research staff and transcriptionist on the study for each data source?
11. How long following the completion of your study will you store the data?
12. Data protection/privacy
13. How are you addressing any ethical or privacy issues?
14. Who will own any copyright or intellectual property rights to the data from each source?
15. How will the data be associated with a study ID?
16. Policies for reuse of data
17. Will you need to create a de-identified copy of the data?
18. Will the data be restricted to be re-used only for certain purposes or by specific researchers?
19. Are there any reasons not to share or re-use data?
20. Policies for access and sharing
21. Will some kind of contribution or fee be charged for subsequent access to this data?
22. What process should be followed to gain future access to your study data?
23. Archiving and preservation
24. What is the long-term strategy for maintaining, curating and archiving the data?
25. What data will be included in an archive?
26. Where and how will it be archived?
27. What other contextual data or other related data will be included in the archive?
28. How long will the data be kept beyond the life of the project?

1. Case loosely modeled after the study described in *End-of-Life Care and African Americans: Voices from the Community*, CAROLYN JENKINS, Dr.P.H., F.A.A.N., NANCY LAPELLE, Ph.D., JANE G. ZAPKA, Sc.D., and JEROME E. KURENT, M.D., M.P.H., JOURNAL OF PALLIATIVE MEDICINE, Volume 8, Number 3, 2005, © Mary Ann Liebert, Inc. [↑](#footnote-ref--1)