Pieces of the Whole: Using the Research Process to Integrate Data Management and Information Literacy Skills

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The research process is naturally embraced as part of the academic curriculum in higher education. Graduate students write theses and dissertations based on their original scholarships, undergraduate students produce papers for courses and work in labs or in the field, and both participate in faculty-led research projects. The research process is tackled holistically through coursework, yet when library instructors are invited to teach students about information literacy and research data management topics, these may be presented as tangential to or mistimed with other course content and learning activities. In this chapter, the authors present a comprehensive, student-centered model for teaching research data management and information literacy as components embedded in the research process. The approach presented in this chapter is comprehensive in several ways:

- It merges research data management and information literacy instruction into a single session.
- It positions these library instruction components within the context of the research process.
- It aligns instruction outcomes with course objectives.
The authors describe two courses in which they have adopted this approach—an undergraduate science class and a doctoral level nursing seminar—to highlight how it can be repurposed for different learning environments.

**BACKGROUND AND LESSON PLAN OVERVIEW**

Over the past several years, course instructors in many disciplines at the University of New Hampshire (UNH) have invited subject and data services librarians into their classrooms to teach often separate, one-shot sessions about research skills. While course instructors have typically been interested in making space for librarians to work with their students, these invitations have almost always been made in isolation from one another. As a result, students were exposed to siloed conversations about information literacy and research data management and were not presented a cohesive picture of how information is produced and used.

The research data services librarian and two subject librarians—specifically, the life sciences and agriculture librarian and the health and human services librarian—decided to design a more integrated approach to their work in these classrooms. In this new model, a subject librarian and the research data services librarian worked together to teach collaboratively and to integrate their respective instruction components. Instead of having separate sessions for the data services and subject librarians, this approach combined two sessions for a more cohesive and holistic library instruction session. The lesson plans for the combined sessions focused on situating library instruction within the ongoing work of the course or program and reframed the research skills presented and practiced in the sessions as part of a research process in which the students were active participants. Students were invited to shape their own research process through activities and to apply newly acquired data and information literacy skills in their coursework.

There were three key components to the approach:

1. A visual representation of the research process that emphasized components of research data management and information literacy
2. Active learning activities
3. A case study

The librarians used a visual representation of the research process that depicted a detailed, iterative lifecycle model spanning from ideation to dissemination...
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of information (see figure 1.1). It was intended to be adaptable and applicable across multiple disciplines, and it combined elements of library research, the scientific method, scholarly inquiry, and data management. The visual representation illustrated a non-linear approach to the research process, which underscored the iterative process of research. The purpose of the visual representation was to show the many ways in which literature searching and research data management are key pieces that make up parts of the whole research process. The librarians aligned their discussion of the research process to course or curricular learning objectives. Students were encouraged to identify how their work prior to the session aligned with the model.

Active learning shapes the approach to all library instruction sessions at UNH. There is a growing body of research that suggests active learning has the potential to improve learning outcomes, critical thinking, and information retention. In an active learning approach, the librarians “engage students to

FIGURE 1.1
Visual representation of the research process, a lifecycle model

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be fully involved and to participate in the learning process.” In the approach described here, the librarian pairs used course objectives to design case study discussions, interactive online quizzes, hands-on activities, and small group interactions to “[encourage students] to use their higher-order thinking skills (e.g., analysis, synthesis, reflection, evaluation), while [they] engage in activities that help them think critically and explore their own attitudes and values.” This strategy helped students connect with the content and engage with the session’s learning objectives. Students were also able to immediately and practically apply session concepts to their own research needs.

Case-based learning is one method of active learning in which “problems are embedded in cases to allow students to make real-world connections and apply knowledge in authentic problem situations.” This approach to instruction has a long history, with experience and research suggesting that it can be effective across disciplines for improving student engagement with and understanding of course content. The case studies that were selected for the sessions were tailored to the course. The librarians selected an appropriate narrative and developed discussion questions based on the discipline, the course assignment, and both the course learning objectives and their own session learning objectives. In both examples presented in this chapter, the librarians adapted research cases published by the New England Collaborative Data Management Curriculum. The librarian pairs used the case studies to encourage student discussion and exploration, to examine the assignment that the session supported, and to design the session theme.

COLLABORATION

When scheduling library instruction, librarians are often put in a position of negotiation. Course instructors who request one-shot library instruction sessions may have a limited understanding of the diverse educational opportunities that librarians can bring to their classrooms. To develop effective research skills in their students, course instructors may default to focusing on scholarly information access through the library, either via physical or virtual services points. Yet the contributions that librarians make to student learning extend well beyond using “library resources.” They engage students in actively finding, using, and contributing to scientific information and research. Librarians, as educators, can support student research by encouraging students to
explore and think critically about the information choices they make in each part of the research process.

Collaboration is a critical element to the success of the integrated instruction model presented here. Collaboration between librarian pairs and between librarians and course instructors strengthens the creation and delivery of course content. Engagement with a course instructor can help to integrate library content more seamlessly into course objectives and outcomes and to enhance the impact to student learning by identifying the needs of students within the course. In this case, the librarians were fortunate to have established relationships with highly collaborative and engaged course instructors who saw librarians as teaching partners; however, the authors recognize that it can be difficult to develop these types of collaborations and that “[m]any faculty do not perceive librarians as partners in teaching and learning, especially to the degree of involvement at the assignment design level.” Yet, identifying and building these collaborative relationships is the first step to integrating information literacy and research data management concepts meaningfully into a course.

In the two cases presented here, the subject librarian was the main contact with the course instructor and initially established an understanding of what the instructor needed for their course. The librarian pairs worked together to design the lesson plan, identify and create activities, and set an agenda for the session. Each librarian was then responsible for their area of expertise. The research data services librarian introduced the research process, provided the lecture on data management, and led the case study discussions. The subject librarian was responsible for literature searching, citation management, and subject-specific content. The librarian who was not facilitating or presenting provided support, helping students during literature searches, fielding questions, and posing guiding questions to the class to introduce a concept or to initiate student engagement.

**IMPLEMENTATION**

To implement this approach, the librarians selected courses or programs with the following characteristics: the course or program included a significant research component as part of its requirements, the course instructor was willing to explore a new approach, and the length of the session was substantial
enough to allow the learning outcomes for research data management and information literacy to be integrated. The first case took place in an undergraduate science course and included a topic mapping exercise, keyword development worksheet, and discussions on planning research projects, preparing for data collection, and managing field research data. The second case took place in a doctoral-level nursing seminar and included hands-on literature searching, interactive online quizzes, and discussions on ethics, data management challenges for clinical research, and health disparities in patient populations. In both examples, the model is now established, and the librarian pairs teach the session annually.

Undergraduate Science Course

Each fall, the life sciences and agriculture librarian and research data services librarian teach an instruction session in a research-based, undergraduate wildlife management course with an enrollment of about thirty students. The students in this course are assigned a semester-long group project to design a field research study and write a mock grant proposal to the US Fish & Wildlife Service to fund the study. The librarians teach a five-hour lab session when the student groups are beginning to plan their research projects. The session’s activities use their existing project groups and provide an opportunity for groups to make progress on their research project’s planning. The learning objectives include the following:

Students will:

- recognize key data management concepts (data organization, description, and storage) as applied to their field research projects
- design a research plan for a wildlife field study
- develop a research question that is right-sized and researchable
- select keywords and practice search strategies
- organize and share sources in research groups

The session begins with an overview of the research process, which emphasizes where in the process the learning objectives for the lab are positioned. This content portion also includes a high-level overview of research data management foundational practices and their positions in the research lifecycle. Students are then introduced to the lab’s first activity: a case study
discussion that includes guiding questions that focus on research design and data management planning (see appendix 1.1). Students are asked to do a close reading of the case study while annotating areas of the case where they identify components of the research process or data issues. After reading the case, the research data services librarian leads a discussion. This first exercise is meant to serve as a warm-up for students and to allow them to begin to explore some of the data management topics presented. The case study also provides context for the main lab activity, where groups are asked to develop a research plan and to apply some of the same concepts within a more complex and novel framework.

Next, each group is asked to convene to discuss their initial research topic idea. The life sciences and agriculture librarian provides an introduction to shaping and resizing a research question so that the question will inspire an appropriately scoped review of the literature and then asks groups to work on a topic mapping exercise. As groups create their topic maps, they are asked to brainstorm different lines of inquiry related to their topics, think about what background information and data they will need to seek out, and suggest different ways to refer to the concepts outlined in their maps. After completing the topic mapping exercise, each group shares their refined research question with the instructors and their peers for discussion. Students are asked to consider if the question is too specific or too broad or to identify different ways to frame the question as they begin to think about their study’s design. Research questions tend to transform from topics such as “the movement of gray wolves” to “How do food choice behaviors impact the migratory patterns of the gray wolf in northern New England forests?”

This second exercise sets up a librarian-led discussion about preparing for a literature search, gathering keywords, and developing search strategies. Next, the librarians and students discuss strategies for literature searching and explore the process of building a search strategy using Web of Science. The life sciences and agriculture librarian asks students to help her design a search strategy for an example topic by brainstorming keywords and creating a search structure. Using the terms that the students generate, the librarian demonstrates the search in the Web of Science, discusses the results, and asks students to help revise the search strategy to retrieve a more relevant set of results. Students are encouraged to recognize their own agency in designing search strategies and that the choices they make will shape their research
outcomes. Students, as scholars, make decisions about what is examined and emphasized in the review of the literature. They are also encouraged to learn from the literature that they find and to explore new angles of their research topic, potentially using the process to refine their research questions further.

The main activity of the lab is the research plan worksheet. The groups spend time together discussing their topic map, conducting literature searches, and beginning to outline key questions that need to be addressed in the final project deliverables. The worksheet is modeled after a Kanban board, a popular project management tool, which has been customized to suit the criteria required for the course assignment, such as what research questions are being asked, what areas of the literature need to be explored, what kinds of data will need to be collected, and how will they share the data and reports. Similar boards can be found at Academic Toolkit. The librarians, along with the instructor, facilitate this activity, providing one-on-one support to groups as they work independently through the initial planning phase.

Finally, in the last part of the session, groups return to discuss the outcomes of their research plan with the full class. Groups share their process and expected next steps. The librarians also review the importance of citation management and sharing citations in their groups and briefly demonstrate the citation management software Zotero.

**Doctoral-Level Nursing Seminar**

Each semester, the health and human services librarian and research data services librarian conduct an instruction session in a doctoral-level nursing seminar that takes place during a two-day intensive residency. The residency lays the foundation for students who are beginning their doctoral program, which includes a capstone project related to quality improvement in a clinical practice environment. The librarians provide an hour-and-a-half long orientation session to a class of ten to fifteen students. The session uses a narrative presented in the case study to provide overall context for the learning objectives. Students in the nursing program are intimately familiar with the case study approach to learning within healthcare and often use this approach in other education settings. The librarians leverage this and provide a case study ahead of the session for students to review. Learning objectives include the following:
Students will:

- understand the value of digital information management to the success of a project
- describe an approach for planning data storage, backup, and security for a project
- articulate data management concepts as a component of the responsible conduct of research and scholarly activity
- strategically search for relevant literature to answer clinical questions in biomedical resources
- recognize the importance of feasibility and availability of interventions for specific patient populations
- use Zotero to gather, organize, and cite sources

The session begins with an overview of the research process emphasizing where in the process the learning objectives for the orientation are positioned. The research data services librarian presents two versions of the research process. The first version is a linear, simplified model of the research process that describes key activities including reviewing the literature, refining the research question, data collection, and reporting results as distinct actions. The other version (see figure 1.1) is a lifecycle model that depicts research as an iterative, interconnected process and emphasizes the often-obscured underlying actions of data management and literature analysis. Then, the librarian has students describe their unique approaches to research and compare them with the presented models. This introduction helps students to visually frame data management and information literacy as pieces of the research process.

Following the introduction, the health and human services librarian provides a short lecture on evidence-based practice with an emphasis on health equity and the unique needs of patients using the narrative from the case study. Students share with one another their experiences working with a diverse set of patients and meeting patient needs, particularly patients from marginalized communities. This exercise helps prepare students to critically reflect on their current practices, center the results of research and clinical practice around evidence-based practice and patient outcomes, and critically interrogate patient populations in published research. The exercise underscores the values of the health and human services librarian as an educator and the mission of the nursing program, which embraces reflective practice,
healthcare as a partnership, and evidence-based nursing knowledge.11

Building from the topic in the case study, the health and human services librarian provides a hands-on demonstration of literature searching and building search strategies using PubMed. The demonstration addresses foundational searching strategies, database features, and additional library services including interlibrary loans. Through the search process, the librarian also demonstrates how to utilize Zotero to save, organize, and cite research results. Students are encouraged to follow along on their own devices and ask questions. At this point, an online presentation tool called Mentimeter12 is introduced for a fun, low-stakes quiz that reviews search strategy concepts.

After exposure with building search strategies, the research data services librarian provides a general overview of research data management topics with a focus on file organization, secure storage, and ethical data sharing. The overview is designed to highlight foundational research data management concepts and strategies for adopting these practices into one’s workflow. To help the students engage with the content, the librarians encourage them to share their experiences with file naming conventions, data loss, and storage/backup solutions.

The orientation session concludes with a discussion of the case study using guiding questions that highlight data management challenges, ethical research with human participants, and health disparities in patient populations, pulling the learning objectives together using a story about research (see appendix 1.2). This exercise is meant to serve as a “wrap-up” for students and to allow them to reflect on some of the topics presented in the session.

COVID-19 PANDEMIC

The COVID-19 pandemic introduced new barriers and challenges to the library instruction examples presented in this chapter. To contend with the COVID-19 pandemic, in the fall of 2020, UNH opened its campus for some face-to-face instruction until November 2020 and implemented strict public health guidelines including keeping the on-campus population low by allowing for some online and hybrid courses. The approach and objectives of each course are different, which contributed to how course instructors were able to adapt their courses during this time.

In one case, the undergraduate science course prepares students to design
a field research study and involves labs in the field. With the added challenge of a compressed schedule, the course instructor had to make the difficult decision to cut the research data component of the original lesson plan and focus primarily on the content that met the immediate course objectives. Because the undergraduate science course is a field research course and typically includes regular excursions to research sites around the state, the compressed in-person schedule, due to shorter time on campus for in-person classes, complicated the amount of time available for work in the field. In addition, while the campus aimed to stay open for in-person instruction until the end of November (and in fact was able to do so), whether test-positivity rates would remain stable with minimal and controlled outbreaks among the campus community was an open question that led to much uncertainty in the learning environment. The course instructor had to shift her entire course schedule and prioritize the most essential, in-person fieldwork early in the semester, knowing that a campus closure was always a possibility with little notice. As a result, the library session was reduced from a five-hour lab to two one-hour online sessions that focused on research topic development and literature searching taught by the life sciences and agriculture librarian. While aspects of the data lifecycle were still covered, the integrated model, along with much of the research data content, fell by the wayside during this understandably challenging semester.

In the other case, the doctoral nursing degree is offered as a distance program. While the two-day residency is usually delivered in person, all credit-bearing courses for the degree occur in an online format to meet the needs of students, who often work as full-time healthcare workers. When the spring 2020 cohort was unable to safely travel to UNH to attend the two-day residency as many were grappling with patient care during the COVID-19 pandemic, the head of the nursing doctoral program decided to hold the residency virtually. As a result of that increased flexibility, the head of the program gave the librarians as much time as they requested for their collaborative session, noting that based on previous student feedback, the session had been one of the most informative and helpful of the residency. The lesson plan and class activities consist of several group discussions, making the transition to online teaching relatively seamless. In the new two-hour online format, the librarians relied more heavily on Mentimeter and other digital tools such as the Zoom breakout room feature to engage students in the low-stakes quiz
and small group discussions about the case study. The students in this program are typically a very engaged cohort during in-person sessions. Using small breakout rooms, Zoom’s chat feature, Google slides, and Mentimeter encouraged class participation during the online instruction session. The additional thirty minutes allowed the librarians to explore their topics and spend more time on student discussion without feeling rushed.

LESSONS LEARNED

The librarians are motivated to improve instruction sessions to meet the needs of the students and have implemented a few channels for informal assessment, including feedback from students from the course evaluations, feedback from the instructor appraising how students performed on the activities, and reviewing their in-class work. For assessment, librarians have access to the students’ work from the session through shared Google documents and Mentimeter that provide some evidence of student learning outcomes. Librarians also ask for instructor feedback and record notes after each class about how the session went for future improvement. From these materials, the librarians continuously revise their lessons to fine-tune their approach. For other academic librarians interested in adapting this approach, this section describes some key lessons that were learned.

Articulate your teaching philosophy. Each of the librarians’ teaching philosophies includes a spirit of experimentation and flexibility. They aim to recognize and honor the expertise and knowledge that each student brings to the classroom and empower them to shape and direct their own learning. The librarians hope that the students come to understand information as both a science and an art in each session and that they learn to think more critically about how it is created, disseminated, and used. Students begin to see themselves as scholars as they identify and reflect on their own information-seeking behaviors and the values and ethics that they bring to their own research process. Students were encouraged to make new connections between information sources to shape and reshape their understanding and eventual contributions to the scholarly conversation.

Plan and document. These sessions take a significant amount of time to plan. The librarians create and document their lesson planning and activities so they can be repurposed and continuously improved. They build in time to
check in with the course instructor in advance and to ask for feedback after the sessions. The librarians collect documentation of feedback, student activities, and informal assessments when available. The librarian pairs conduct debriefs or postmortems with each other after each session, documenting post-class librarian reflections to make meaningful adjustments for future classes. In these meetings, the librarians discuss aspects such as the timing, questions asked, and outcomes of the activities and documented areas that need improvements or changes.

**Build buy-in.** Buy-in from course instructors is key to the successful implementation of this model. A large part of this is due to the rapport that has been fostered between the subject librarian and the course instructor. The head of the nursing doctoral program is incredibly supportive of the librarians and open to updates and improvements to the orientation session. She trusts the librarians to shape and deliver the session in a meaningful and effective way. The faculty for the undergraduate science course is more hands-on and willing to devote an entire lab session for library instruction. She has requested meetings before the sessions to provide input on the librarians’ lesson planning so that it is well-timed with the pace of the course and practical for the students’ needs. Though the style of collaboration varies between the two faculty members engaged with the librarians, important common features include strong communication between those involved, trust in one another’s expertise, and the strategic alignment of activities and objectives to student and course needs.

**Less really is more.** In both courses, the librarian pairs find that it is more effective to scale down learning objectives for maximum student impact. Using assessment data, the librarians adapt the implementation, revised activities, re-ordered session components, and reduced overly ambitious lesson plans. For example, in the undergraduate science course, the librarians completely redesigned the project plan worksheet after the first time they ran the lab session. The first iteration was too detailed so the librarians revised the worksheet to more closely align with the criteria required in the final course deliverable and to not use prompts that delved too deeply into the concepts. In the doctoral-level nursing seminar, the librarians removed more advanced information-searching content and activities to allow for more emphasis on foundational skills. By reducing the number of session objectives, the librarians could establish stronger foundational skills for students to build upon
during these sessions.

**Get involved with the student work after the session.** In both cases highlighted here, all students are encouraged to follow up with the librarians via individual or group consultations as they continue to execute their coursework, and many take them up on this offer. In the undergraduate science course, both librarians are also invited to critique the students’ final group research presentations at the end of the semester, further emphasizing the importance of information and data literacies for the course research project. Additionally, the health and human services librarian is the instructor of record for an evidence synthesis course, a required course in the doctoral nursing program in which she sees many of the students in the cohort later in the curriculum and builds on some of the learning objectives from the residency library instruction session.

**Reflect and advocate.** While the course instructor sees the robust library session design described here for the undergraduate science course as impactful and beneficial to the students in achieving their course objectives, designing their wildlife field research study, and completing their research proposal, the time for the librarians was significantly reduced in the fall of 2020 due to the COVID-19 pandemic. The librarian pair used this opportunity to reflect on why the data management pieces were seen as less essential in the classroom, and what that perception means for the strategic advancement of this model post-COVID. Will data skills continue to be viewed as an add-on to literature search skills? Can the longer-term implementation of this model more permanently stabilize the inclusion of data literacy skills into library sessions? It is important to reflect on these questions and continue to advocate for comprehensive integrated approaches.

**Embrace being part of a whole.** The goal of the model and the final lesson plans is to embed research data management and information literacy instruction into the research process in a way that aligns with course or curricular objectives. But being part of the whole extends beyond library instruction being part of the research process. It also means thinking holistically about the content. For example, in the doctoral-level nursing seminar, the librarians revised the guiding questions for the case study to provide a more overarching discussion that tied together most of the learning objectives rather than focusing only on data management. This way, the students were able to reflect on all the different pieces they had learned using a single case narrative.
The approach also raises students’ awareness of research data services and subject-specific data support, normalizing conversations about research data management with students and faculty.

CONCLUSION

This model for library instruction focuses on integrating research data management and information literacy, presenting them as components of the research process and aligned with curricular goals. This framing empowers students as scholars by emphasizing their learning needs for their course work in a way that holistically integrates information concepts and highlights research data management rather than a focus on the library or its resources as stand-alone components. Ultimately, the authors hope that this integrated instruction can improve relationships with course instructors by providing high-value library instruction that is deeply tied to the research process and existing course objectives and that normalizes the inclusion of research data management competencies within information and disciplinary curricula.

Notes


A PhD student in biology is conducting research on grassland bird habitat quality. She would like to create a tool that could be used to assess the suitability of habitat management sites and inform decisions on which sites would benefit most from management. It could also be used to assess when the benefits of management for grassland birds would be relatively minor (since managing a habitat for grassland birds can be the opposite of what other species of concern may need).

RESEARCH TEAM

The student is working with her thesis advisor (in this advisor’s lab), and the lab has four field assistants. The lab is collaborating with two additional researchers and their teams at universities in another state.

DATA COLLECTION AND ANALYSIS

For her research project, the student uses a rectangular sampling tool called a quadrat, which is a grid that separates an area into twenty symmetrical plots. She records data based on the measurements and observations of organisms and habitat within these plots: the types of vegetation in the field, the vegetation height,
and leaf litter depth, among others. She also records data on the flight initiation
distance, which is the distance at which an approaching stimulus (predators,
humans, etc.) will cause grassland birds to move away. The student also collects
data related to “openness”—these are measures of a landscape’s boundaries,
which she contextualizes with observations of the habitat’s relationships within
this larger landscape, and how energy flows in and out, etc. She uses a portable
GPS to record coordinates for location, angles to the horizon, distances to the
habitat’s edges, and compass bearings.

The student has already collected several hundred GBs of data. Early in her
research, she recorded data using hard copy data sheets that she then had to
enter into a computer. One of the field assistants would check over the data
sheets to ensure the accuracy of her data entry. Now the student enters her data
directly on her laptop in the field.

She enters observational and GIS data into MS Excel™ spreadsheets and a pro-
prietary mapping software program, ArcGIS™. Data are examined in MS Excel™
or ArcGIS™ and analyzed using SAS™ software. In addition to the data she collects
from the field, she has downloaded a large amount of existing GIS datasets from
online public access data repositories, processed these files using ArcGIS™ and
Python™ software, and analyzed them using Python™ and SAS™ software.

STORAGE

She stores her hard copy data sheets in binders, with copies of these binders in her
PI’s lab. Electronic files are stored on her lab’s space on the university’s servers,
which the university secures and backs up. She also has a backup copy in cloud
storage that she regularly backs up.

DOCUMENT AND DESCRIBE

The student does not have a formal protocol for metadata, but she has created
“guide” files (with file names leading with 0s so they are at the top of the direc-
tory). They have some documentation and description of the files in each of her
folders. Unfortunately, she has not made a guide file for all her files and folders,
and she does not always keep them up to date.
SHARE

The student is benefitting from the availability of public data, which she is repurposing for her own research. She would also like to share her data. After she finishes her project, the student intends to enter some of her relevant field data into ebird.org, an online archive of ornithological sightings maintained by Cornell University.

GUIDING QUESTIONS FOR IN-CLASS DISCUSSION

1. What is this research project about? What are some of the goals/expected outcomes?
2. If you were assisting with a literature review for this project, what areas of research would you explore? Can you think of keywords? Where would you look?
3. What kinds of data are being collected?
4. How is the data in this project organized, described, stored/backuped, and shared?
5. What would someone need to know if they planned to replicate this study in another field location?
6. Does anything surprise you about this case study? Are there details that you wouldn’t have expected/thought of? What questions do you still have about the study?
APPENDIX 1.2

Improving End-of-Life Care for African Americans*

An MD applied for grant funding to study physician communication with African Americans and their relatives when their patients were receiving end-of-life care. After conducting an extensive literature review and discovering gaps in the research literature, the MD decided to conduct a qualitative study to expand knowledge about African Americans’ experiences and opinions about end-of-life care. Following a review by a Community Advisory Board (CAB), protocols were approved by the University’s Institutional Review Board.

Convenience sampling by staff and CAB members was used to recruit participants, and flyers were distributed at neighborhood activities. Multiple-meeting focus groups were held to build trust and allow time for full participation. Participants were assigned to one of two focus groups: Focus group 1, which met for four sessions and was comprised of African Americans with family members who had died at home, and Focus group 2, which met for three sessions and included African Americans with family members who had died in the hospital. An average of five individuals attended each session. Three participants worked in healthcare, and their observations reflected experiences with a dying family member as well as experiences with caring for terminally ill African American patients.


Included with permission from Lamar Soutter Library, University of Massachusetts Medical School, Worcester, MA, Improving End-of-Life Care for African Americans (Case Study), New England Collaborative Data Management Curriculum (NECDMC). (This project was funded by the National Library of Medicine under a contract (HHS-N-276-2011-00010-C) with the University of Massachusetts Medical School in Worcester.)

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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 healthcare providers, (3) communication issues, and (4) end-of-life decision-making pertaining to living wills and advance directives. An African American member of the project staff moderated the focus groups.

Each session was recorded. Unlabeled audio files were shared with a transcriptionist via cloud file sharing. During the uploading process, the files were renamed, and metadata was overwritten. The data, however, were not corrupted. The transcriptionist transcribed the files, and the transcripts were emailed 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. The analysis was systematic. 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. 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

Analysis of the transcripts revealed five major theme groupings:

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 African Americans 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 African Americans 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 audio files were eventually deleted. 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 reused as examples for a qualitative analysis class taught by the analyst; however, for the reuse, all participant IDs were changed to P1, P2, etc.
GUIDING QUESTIONS FOR IN-CLASS DISCUSSION

1. What are your initial thoughts about this case study? Do you see any major red flags?
2. If you were going to replicate this study, what might you need to consider/reconsider?
3. How have the researchers addressed any ethical or privacy issues?
4. This case features collaborative research. What issues does the case raise about collaborating with others?
5. What data management issues does this case raise?
6. What questions do you still have about the study?