



## ARTICLE

Jarrold Irwin

Eastern Michigan  
University

To cite this article:  
Irwin, Jarrod. 2024.  
“You Have to Do This  
When You’re Healthy’:  
An Introduction to  
Library Involvement in  
Programming on End-  
of-Life Issues,” *Journal  
of Library Outreach and  
Engagement* 4, 82-.

DOI: 10.21900.j.jloe.  
v4..1495

# “You Have to Do This When You’re Healthy’: An Introduction to Library Involvement in Programming on End-of- Life Issues

## ABSTRACT

While the library literature shows that librarians work to address information needs about end-of-life issues, no systematic research on library involvement in programming about these issues yet exists. The author conducted a preliminary study of library staff whose libraries had been involved in end-of-life programming or had considered but decided not to offer this programming between 2018 and 2023. The study consisted of an online survey, followed by an interview with respondents whose libraries had been involved in this programming. The study sample (N=13) included public and academic libraries around the United States in rural, suburban, and urban settings. Reported activities included speaker series, Death Cafes, instruction on obituary writing, support for palliative and pastoral care groups by gathering information resources into an online guide, and a virtual training for public library staff about meeting patrons’ needs for end-of-life health information. Topics covered medical, financial, legal, emotional, and spiritual matters related to death and dying. Respondents described a variety of partners as valuable contributors to programs’ success. Some respondents actively attempted to manage program participants’ anxieties about the subject matter. Respondents reported positive experiences with these programs and positive feedback from participants, but possible effects of volunteer bias and the small sample size prevent conclusions about how typical this is. More research is necessary to understand patterns among these programs, ways to protect the emotional well-being of those involved, and strategies to tailor programs to best meet library patrons’ needs for information on end-of-life issues.

## KEYWORDS

library programming, end-of-life issues, death, grieving, partnerships

**L**ibraries have opportunities to perform valuable work on information needs around end-of-life issues, including through programming. While discussing death can be uncomfortable, planning for it can offer important benefits to the dying and people close to them. In hospital settings, patients who engage in facilitated advance care planning may have lower

health care expenses for end-of-life treatments (Klingler, in der Schmitten, and Marckmann 2016, 431). Advance care planning can also improve doctor-patient communication and patients' feelings of internal conflict about their care decisions (Malhotra, Shafiq, and Batcagan-Abueg 2022, 4). Furthermore, making plans for the end of one's life simplifies issues of inheritance and estate management, which may become a source of tension among a person's loved ones if clear instructions are not in place beforehand (Felton 2022, 24).

I became interested in library programs about these issues while creating and teaching a professional-development course about end-of-life health topics for the Network of the National Library of Medicine (NNLM), an organization that trains librarians and others in providing health information. NNLM had never offered formal instruction on this topic, even though people nearing death often face difficult medical decisions where quality health information may be useful. During the course, several participants reported that their libraries were already doing work about this topic or wanted to start. Despite this, I found very little in the library literature about these programs. Publications describe individual programs about end-of-life issues, but there is currently no systematic research about them.

While I now work at a public university that primarily teaches undergraduates, my desire to help other librarians serve patrons' needs for end-of-life information persists. Supported by a research stipend from my current institution, I conducted a preliminary study about how US libraries have approached programming on end-of-life topics, including the program models used, the topics covered, methods for handling sensitive issues, partners who played a role, and the feelings of library staff members and program participants afterward. The study's goals were to describe examples of these programs for library staff who are interested in providing information on these topics and to identify specific questions that further research might address.

## Literature Review

There is scant literature about library involvement in programming on end-of-life issues, and the little I found focuses on individual programs and program models. However, useful insights also come from publications that recommend books or other resources to meet information needs about end-of-life issues. This literature suggests that patrons come to libraries seeking information about these topics. Therefore, research on libraries' role in programming on end-of-life issues may benefit libraries and the people they serve.

While it is easy to think of end-of-life information needs in terms of medical issues or estate planning, the literature on library work around end-of-life issues reflects a broader view of the topic. Bensing (1996, 43) observes that the range of useful resources on end-of-life issues represents "almost every subject category in library classification schemes." One important theme in resource lists on this topic is the emotional well-being of the dying and their loved ones. Materials on this topic appear in the resource lists developed by Zarzycki (2023), Rosenbloom (2020), Broadway (2008), Brady (2001), Reid and Van Hemert (2000), and Bensing (1996). The value of these materials extends beyond public libraries. Byars (2012, 17) describes a medical library serving a hospice, where the collection covers both clinical matters and "the psychosocial and spiritual aspects of chronic, serious illness, grief and bereavement." Pitsillides et al. (2023, 394) also favor a broad understanding of resources that aid reflection on one's life and its end, suggesting that "wider literatures such as genre fiction or contemporary novels can be useful." The literature reflects the need to view end-of-life information expansively, encompassing practical matters, emotional well-being, and the task of meaning-making in the wake of loss.

The literature about libraries and end-of-life issues also acknowledges children's experiences of grief and bereavement. Rosenbloom (2020, para. 6), Brady (2001, 44), and Reid and Van Hemert (2000, 42) include literature focused on children in their resource lists. Broadway (2008, 45-46) offers a focused list of these materials and criteria for evaluating them. Dreffin (1998, 47) describes a school that created a "grief library" for use by both classrooms and parents. These publications suggest that librarians are aware that children sometimes suffer loss and need information resources focused on their experiences of grief.

Some authors suggest that patrons seek library programming and resources about death or grieving in response to tragedies. One sobering example is Reid and Van Hemert (2000), public librarians who worked a quarter mile from Columbine High School at the time of the 1999 massacre there. They report that, afterward, patrons' interests shifted away from fiction depicting violence and toward nonfiction about its causes and prevention. They also note that participation in their summer reading program spiked, which they attribute to community members' greater desire for positive children's activities (40). Given the United States' continuing struggle to address mass violence in schools, Reid and Van Hemert's insights into how major tragedies may affect library use remain depressingly relevant.

More recently, Rosenbloom (2020, para. 1) cites the COVID-19 pandemic to explain the importance of materials on end-of-life issues. Pitsillides et al. (2023, 394) argue that COVID-19 raises the question of how libraries can aid reflection on end-of-life issues, while conceding that the pandemic complicated program planning. Sánchez-Carretero et al. (2011, 5) describe librarian involvement in the "Archive of Mourning," a project documenting the public memorials and mourning that followed the 2004 train bombings in Madrid, Spain. However, smaller-scale tragedies may also prompt responses from libraries. Seymour (2016) describes a makerspace that a high school library established after the sudden death of a recent graduate. The makerspace allowed students to make objects like memorial buttons with the graduate's photo (29).

The literature specific to programming reflects a similar range of topics and concerns. One program model of note is the Death Cafe<sup>1</sup>, an informal small-group discussion focused on sharing questions, fears, and hopes related to death and dying, without a specific agenda or intended conclusions to reach (Death Cafe, n.d.). Inklebarger (2015, 21) notes that as of his writing, libraries in the United States had hosted more than one hundred Death Cafe events. Although the present study focuses on libraries in the United States, notable programming has also happened in England. In 2018, a library in Ilford organized Death Cafes, an event for Día de los Muertos<sup>2</sup>, and events with funeral professionals and scholars (Pitsillides et al. 2023, 389). Other libraries in England expanded on this idea, resulting in the Death Positive Library initiative. During the COVID-19 pandemic, this project included many online events, such as book discussions with authors, showings and discussions of movies, and an interactive installation called Tickets for the Afterlife (398).

## **Methodology**

This study consisted of a survey followed by interviews with selected survey respondents. Eligible respondents were library staff at libraries that have been involved in this programming in the United States between 2018 and 2023, or at libraries where staff have considered these programs but not implemented them

---

1 The official website for Death Cafe events spells the name without an accent over the letter E in "Cafe," as in the common British word for inexpensive eateries.

2 Día de los Muertos, or Day of the Dead, is a holiday celebrated primarily in Mexico when people honor the memories of loved ones who have died.

during the same period. The study excluded respondents from libraries that had decided to implement these activities but had not yet done so. Because one goal of the study was to document examples of these programs with information about lessons learned and patrons' reactions, it was helpful to focus on libraries that had completed programming. Respondents from libraries that considered but made the decision not to implement programs on end-of-life issues were included because they can shed light on barriers to implementing these programs. The literature notes potential barriers like concerns about patron disapproval of the subject matter; a public library director interviewed by Inklebarger (2015, 21) reports that some patrons complained when her library organized a Death Cafe. The present study attempted to confirm whether these potential barriers dissuaded any libraries from implementing programs. By understanding the barriers to programming on end-of-life issues, library staff may be better prepared to overcome them.

Survey questions asked about respondents' libraries, the types of programs implemented or discussed, programming topics, the libraries' priorities for outreach to specific groups of patrons, partners who played a role in programming, feedback from program participants, and respondents' feelings about their experiences. Some of the questions on the survey differed based on whether the respondent's library had been involved in programming. For respondents who indicated that programming did not occur, the survey asked about the topics and program types considered and reasons given at the time for not pursuing the programs. All questions from the survey appear in Appendix 1. Respondents whose libraries were involved in programming could also give consent to receive an invitation to a follow-up interview. I distributed the survey via the national email lists PUBLIB and MEDLIB-L and on three online discussion boards hosted by the Association of College & Research Libraries, each targeting libraries at a different type of institution: community and junior colleges, four-year colleges, and universities. The survey was open from May 1 to June 30, 2023. After collecting the survey data, I used Google Sheets to analyze it.

I extended interview invitations to respondents whose libraries had been involved in programming and who consented to be contacted about an interview. Interviews occurred on Zoom between May and July 2023, lasting from approximately thirty to sixty minutes. The interview addressed the origins of the programming idea, the initial reactions to the idea from coworkers and supervisors, promotional strategies, respondents' feelings about programming on end-of-life issues before and after the programming occurred, and feelings about potential future programs. All questions from the interview script appear in Appendix 2. Zoom recorded the interviews, and the software's automatic transcription tool produced a draft of interview transcripts. I anonymized these transcripts and corrected them by comparing them to the recordings. I then used the transcripts to review interview respondents' input.

The study design, survey, interview script, informed consent document, and communications with potential respondents received IRB approval in February 2023.

## Results

In total, fourteen respondents completed the survey. Data from one respondent were excluded because, while programs on this topic were under active development at this respondent's library, none had occurred yet. Ten respondents were at institutions that had been involved in these programs, and three were at institutions that had discussed but decided not to implement them. Respondents included staff from public libraries and college or university

libraries. Of the ten respondents whose libraries had been involved with programming on end-of-life issues, eight reported being involved in either spearheading, planning, or working on them, while two said that they were not involved in the programs at their institutions. Six respondents whose libraries had been involved with programming participated in an interview. This set of respondents cannot give a nationally representative look at this programming, but their insights remain useful for library staff and researchers interested in it.

Type of library	Frequency among all respondents	Frequency among interview respondents
Public library	9	4
College or university library	4	2

Table 1. Q4. Type of library respondents work at. Note: Asked of all respondents; N=13.

**Program Models and Approaches.** Guest speakers or speaker series were the most popular program model reported. The second most popular answer was partnerships with other organizations, a category that can itself include a variety of activities. Although respondents did not report resource fairs among the programming that their libraries had been involved with, one respondent reported discussion about a resource fair that did not lead to the event happening, and one interview respondent mentioned working on an end-of-life resource fair scheduled for later in the year.

Of the three respondents from academic libraries, only one reported a program model in which library patrons interacted directly with the respondent’s library; this programming included guest-speaker and discussion events about end-of-life issues. Two other respondents from academic libraries answered “Other type(s) of programming” and described a program model not listed in Table 2. One worked on a recorded video to train staff in public libraries on providing end-of-life health information to their patrons.

Program models	Public library respondents	Academic library respondents	Total
Guest speaker or speaker series	4	1	5
Partnership with other organization(s)	3	1	4
Death Cafe	3	0	3
Book club	1	0	1
Resource fair	0	0	0
Other small-group discussion	0	0	0
Other type(s) of programming	0	2	2

Table 2. Q10. Types of programs about end-of-life issues that respondents’ libraries have been involved with in the last five years. Note: Asked of respondents whose libraries were involved in programming; N=10.

The third respondent from an academic library developed information resources to support the activities of pastoral and palliative care groups at the hospital connected with the university, without directly participating in those activities. In contrast, all activities reported by respondents in public libraries were patron-facing.

The survey question about groups that have been the focus on engagement or outreach activities was not specific to libraries' end-of-life programming; instead, it reflects which groups among their patrons are priorities for dedicated outreach efforts. The most common response was older adults. Only one respondent indicated that religious minority groups had been a focus of outreach and engagement, even though religious and philosophical aspects of death were a popular topic among respondents whose libraries had been involved in such programming. One respondent from a public library selected "Other groups" and named teenagers and immigrants as two focuses for library outreach.

Participant focus of libraries	Public library respondents	Academic library respondents	Total
Older adults	7	2	9
Racial minorities	5	3	8
LGBTQIA+ communities	4	2	6
Women	4	2	6
Disabled people	4	1	5
Religious minorities (including non-religious people)	1	0	1
None selected	1	0	1
Other group(s)	1	0	1

Table 3. Q7. Groups that have been the focus of engagement or outreach activities at respondents; N=13.

**Topics Covered.** Respondents whose libraries had been involved in programming on end-of-life issues reported programming about spiritual, religious, and philosophical dimensions of death; estate planning; health needs; and open-ended discussion with nearly equal frequency. However, notable differences appeared between public and academic libraries. Each respondent from an academic library reported covering end-of-life health needs, but the only other topics any of them reported were emotional or social support for people who have lost loved ones and open-ended discussions, reported by one respondent each. Respondents from public libraries reported a broader range of topics. Two respondents from public libraries reported topics not listed on the survey. One of these respondents reported bedside comfort as a topic, referring to a performance at the library by a chapter of the Threshold Choir, an organization that sends singing ensembles to perform music for terminally ill people. The same respondent also reported the grieving process as an additional topic. A second respondent mentioned a program about how to write an obituary.

Additionally, a suburban public librarian in the southern US who was not able to offer the program described a topic that no other respondent reported: what to do with loved ones' social media accounts after they have died. This

respondent described it as “a confusing topic on digital literacy” that library patrons had expressed curiosity about.

Topics of programming	Public library respondents	Academic library respondents	Total
Estate planning (including wills or trusts)	6	0	6
End-of-life health needs (information, options, or planning)	3	3	6
Spiritual, religious, or philosophical discussions of death or dying (including interfaith events)	5	0	5
Open-ended discussion about death, dying, or end-of-life issues	4	1	5
Body disposition or funerals/memorials (information, options, or planning)	4	0	4
Legal arrangements (including guardianship, power of attorney or similar arrangements)	3	0	3
Emotional or social support for people who have lost loved ones	2	1	3
Emotional or social support for terminally ill people	1	0	1
Other end-of-life topic(s)	2	0	2

Table 4. Q9. End-of-life topics that respondents’ libraries have been involved in programming about. Note: Asked of respondents whose libraries were involved in programming; N=10.

**Partnerships.** Of the ten respondents whose libraries had been involved in programming about end-of-life issues, eight indicated that outside partners also participated. The most common type of organizational partner was hospices or home hospice organizations, reported by four respondents. A variety of organizational partners worked with public libraries. The two respondents at public libraries who organized speaker series reported the most types of organizational partners, each selecting five categories. One of these respondents specified that a senior center helped with overall planning for the series, while other partners participated in individual events.

Five respondents selected “Other organization(s)” and supplied one or more types of organizational partners that were not on the survey. Two respondents at public libraries named organizations that serve seniors. A different respondent from a public library described partnering with a nonprofit organization. Among academic librarians, the librarian who supported the activities of hospice and palliative care groups with information resources indicated hospital pastoral care groups as an additional type of partner, along with hospitals or medical clinics and hospices or home hospice organizations. The librarian who had worked on a train-the-trainer program for public librarians identified public libraries as partners.

The other respondent from an academic library also reported the involvement of an organizational partner. This respondent selected schools, colleges, or universities as a type of partner in the guest-speaker and discussion events that the respondent helped to plan and facilitate.

Organizational partners	Public library respondents	Academic library respondents	Total
Hospices or home hospice organizations	3	1	4
Law offices	2	0	2
Funeral parlors	2	0	2
Religious congregations	2	0	2
Hospitals or medical clinics	0	1	1
Cemeteries, crematoria, or other body disposition services	1	0	1
Schools, colleges, or universities	0	1	1
Nursing homes or other long-term care facilities	0	0	0
Other organization(s)	3	2	5

Table 5. Q16. Types of organizational partners that respondents’ libraries worked with on programming about end-of-life issues. Note: Asked of respondents whose libraries worked with outside partners on programming that was implemented; N=8.

No type of individual partner was much more common than any other. Three public librarians reported partnering with death doulas, professionals who work with people who are seriously ill to provide “emotional, spiritual, and practical care” (International End-of-Life Doula Association, n.d.). One respondent from a public library, who had organized a speaker series, selected “Other individual(s)” and described three types of partners not listed on the survey: representatives from the Society for the Prevention of Cruelty to Animals, who participated in a presentation that discussed pet death; authors; and hospice workers. All respondents at academic libraries worked with individual partners, but these partners were exclusively either health care professionals or clergy.



Individual partners	Public library respondents	Academic library respondents	Total
Clergy	2	1	3
Death doulas	3	0	3
Other health care professionals	1	2	3
Counselors or psychotherapists	2	0	2
Attorneys	2	0	2
Morticians or funeral directors	2	0	2
Social workers	1	0	1
Teachers (at any level)	1	0	1
None selected	1	0	1
Other individual(s)	1	0	1

Table 6. Q17. Types of individual partners that respondents’ libraries worked with on programming about end-of-life issues. Note: Asked of respondents whose libraries worked with outside partners on programming that was implemented; N=8.

**Program Participants’ Response and Respondents’ Feelings.** Respondents at public libraries were more likely to describe program participants’ response as very positive, while two of the three respondents at academic libraries described participants’ response as somewhat positive. One respondent who was not involved in the library’s programming did not answer.

Participants’ response	Public library respondents	Academic library respondents	Total
Very positive	4	1	5
Somewhat positive	2	2	4
Neutral or mixed	0	0	0
Somewhat negative	0	0	0
Very negative	0	0	0
No answer	1	0	1

Table 7. Q19. Respondents’ descriptions of program participants’ response to end-of-life programs. Note: Asked of respondents whose libraries were involved in programming; N=10.

Among respondents who were involved to any extent in their institutions’ program, seven respondents out of eight described their experiences as very positive, with no significant difference for respondents from public libraries compared to those from academic libraries.

**Barriers That Prevented Programming.** Three survey respondents’ libraries discussed but decided not to implement a program related to end-of-life issues. The survey asked them, “What reasons, if any, were discussed as to why this program might not be a good idea?” Two reported that concerns about the subject matter were a reason the programming did not go forward.

Respondents' feelings	Public library respondents	Academic library respondents	Total
Very positive	4	3	7
Somewhat positive	1	0	1
Neutral or mixed	0	0	0
Somewhat negative	0	0	0
Very negative	0	0	0
No answer	0	0	0

Table 8. Q20. Library staff's feelings about their experiences with end-of-life programs.  
Note: Asked of respondents who were involved with their libraries' programming; N=8.

One of these respondents, an academic librarian who wanted to organize Death Cafes with nursing students, reported that there were also concerns about offending library patrons and about the library staff's expertise on the topic. The third of these respondents reported that the COVID-19 pandemic prevented a guest-speaker event from occurring.

## Interviews

Six respondents participated in interviews to provide further insights into the programming their libraries were involved with.

**Topics Pursued by Public Librarians.** Four interview respondents were public librarians. One respondent in a small city in the western US organized a book club about end-of-life issues as a complement to programs at a local hospice. Every three months, the club met to discuss a book for one hour and receive the next book for discussion. The respondent said their institution is hesitant to add book clubs because of the cost of providing copies of each book to participants. Quarterly meetings helped to keep logistical aspects of the book club manageable.

A suburban public library in the southern US offered a one-time instructional presentation about obituary writing. While this program was similar in format to other educational programs that many libraries offer, this respondent said that the topic is important and underrecognized; people rarely think about how to write an obituary until they need to do so, and they might not know where to seek help with it. The respondent reported strong attendance and positive feedback from program participants, who believed that this instruction would make a difficult task easier.

Two interview respondents organized speaker series covering a variety of topics, with much overlap between them. One of these was a series of eight events, one each month, taking place at a public library in a large city in the western US. The other speaker series was a weekly program of six events, most of which took place during Older Americans Month in May. This series occurred at a public library that serves a rural community in the South with a large proportion of older library patrons. Topics in one or both series included various religious perspectives on death and dying, estate planning, legal considerations, the grieving process, body disposition, the death of pets, and a conversational activity using GoWish, a deck of cards used to help people discuss their hopes about their end-of-life processes. Both respondents highlighted their respective interfaith events as receiving especially positive feedback.

**Topics Pursued by Academic Librarians.** Two academic librarians were interviewed. One, who works in a rural setting in the Midwest, worked on a train-the-trainer series for public librarians about providing health information to their patrons, which included a module about end-of-life health issues. The creators of the program originally intended it to be an in-person group training, but COVID-19 necessitated a change of formats. The training took the form of a video presentation that participants viewed on their own.

Another interview respondent, who works at a university library in a mid-sized city in the southern US, developed an online collection of information resources to support the activities of existing palliative and pastoral care groups at the hospital connected with their university. These groups shared these resources with their members. The guide focused on topics related to end-of-life health needs and emotional support.

**Challenges Reported by Public Librarians.** Because the library literature about end-of-life issues describes anxieties that people might have about these topics, interview respondents were asked about any messaging used to address this challenge: "When promoting this programming, how was it framed or presented? Or to put it another way, what kind of messaging did the library use to raise awareness about it?" This question's purpose was to learn about strategies that respondents used to ease potential concerns among patrons. While some discussed promotional messaging as an important part of this, others discussed how the program models they chose can accommodate patrons who may have anxieties around certain topics. The interview also contained a more general question related to challenges posed by these programs: "How was the process of planning, hosting, or facilitating this programming different compared to other library programming that you have been involved with?"

The respondent whose library organized a workshop on obituary writing focused on the sensitivity of the topic as a challenge, discussing how the library crafted messaging to alleviate these concerns for this workshop as well as for future events that the library is planning. Strategies employed in this messaging included acknowledging discomfort that may arise from conversations about death, emphasizing that people can prepare for death in ways that make the experience less difficult for their loved ones, and using the word "conversation," which may help these topics sound less threatening. As a separate challenge, this respondent said that the COVID-19 pandemic forced the library to delay implementing many planned programs.

The organizer of the monthly speaker series framed the events as an opportunity for education and preparation for common end-of-life challenges. Messaging like this suggests that there is something participants can do about an issue that might otherwise be scary or intimidating. This respondent also described the wide range of topics covered in the series and the fact that, at the end of each event, the library announced the topic of the next event, making it easy for participants to select which topics they wished to engage with. The respondent also noted the credibility that comes from this library's history of successful programs related to health. If patrons already view the library as a source of quality programming about health topics, they might be more willing to engage with end-of-life programming from the library too. Finally, this librarian described the library setting itself as something that can help defuse anxieties around discussions of death, noting that compared with settings like hospitals or hospices, libraries are "not quite as in-your-face in that scary kind of way." The series concluded before the COVID-19 pandemic started, so unlike other interview respondents, this respondent did not discuss the pandemic as a challenge. The biggest challenges, instead, involved the logistical demands of holding multiple events and recruiting presenters for each.

The organizer of the weekly speaker series described promotional messaging that highlighted the range of different topics, similar to the messaging for the other speaker series. The press release for the series also mentioned death as something that is inevitable and common to all people. This respondent described challenges related to COVID-19, especially technological issues with hybrid programming. Virtual participants could hear the library's doors opening and closing throughout the programs, which was a source of negative feedback for otherwise well-received events. This respondent also said that the amount of work involved with offering six programs over six weeks was challenging, especially given the library's relatively small staff.

The respondent who organized a book club discussed a few factors that helped reduce possible anxieties about discussing death. First, participants understood that they could withdraw from the club temporarily if they believed the subject matter of a certain book would be too troubling for them, then return for the next book. This respondent mentioned a book about the death of a child as an example of an especially sensitive title; the library deliberately avoided scheduling that book for the club's first year. Second, this librarian described the importance of carefully choosing the first book to set the right tone for the group. This book club started with the memoir *When Breath Becomes Air* by Paul Kalanithi. The book's brevity, along with its inclusion of other aspects of the author's life besides his terminal illness, made it a good choice. Third, this respondent noted that in a book club, the facilitator can help maintain participants' emotional comfort by steering the topic of conversation. If certain topics seem too personal or sensitive in the moment, the discussion could switch to general impressions of the book or the quality of the writing. Finally, the setting of the library provides a "familiar neutral zone" where patrons can feel safe while broaching difficult topics.

Participants' anxieties were not the only challenge the book club grappled with. The librarian who organized it said that COVID-19 forced the club to go on hiatus for several months, as the participants preferred to wait until in-person meetings could resume instead of meeting online. This librarian also commented on emotional challenges connected with planning and leading discussions about books that deal with death and dying: "You're having to process your own emotions as you're going through it."

**Challenges Reported by Academic Librarians.** For the academic librarian who worked on a train-the-trainer program for public librarians, precise messaging and managing anxieties around the topic were not concerns. The program's intended audience knew that library patrons ask about these topics, so it would help them serve their patrons' needs. This respondent also observed that the program on end-of-life health issues was treated as one health topic among many. It was one of several trainings on senior health, which were themselves part of a larger project about health literacy, so it was not the subject of dedicated messaging or promotion on its own. This respondent also said that COVID-19 was a major challenge, forcing the program to switch from in-person instruction to a video format. Although the video training has continued to show signs of use, this respondent was disappointed by the low initial uptake: "I don't think watching these things alone is what people wanted. I think they wanted that face-to-face communication."

The other academic librarian interviewed, who supported the activities of hospice and palliative care groups by creating information resources, did not face direct logistical challenges because the librarian's role was more indirect in this case. The online resources the respondent created were shared through the palliative and pastoral care groups by word of mouth, without specific thought to messaging on the librarian's part. However, this respondent reported

that existing online information about end-of-life health issues proved more challenging to locate and validate than anticipated.

**Thoughts About Further Programming.** Interview respondents were asked, "If your library were to offer further programming about end-of-life issues, what do you think would be done differently?" Three respondents from public libraries replied with ideas about additional end-of-life programming. The public librarian whose library had offered instruction on obituary writing discussed working on a resource fair scheduled for later in the year, saying that the library plans to seek patrons' input on this future programming, while continuing to build relationships with partners that they worked with during their previous activities. Both respondents who organized speaker series had additional ideas for topics to cover. The organizer of the monthly series at an urban library in the western US wanted to examine grieving and funeral customs of specific ethnic groups that are part of the local community. This respondent also mentioned end-of-life options, such as medical aid in dying, while acknowledging that the topic would be controversial. The organizer of the weekly series at a rural library in the South expressed interest in more detailed programming about different kinds of grief, even those that involve losses other than death, and further programming about different faiths' beliefs about death and dying. The interfaith program in this series focused primarily on funerary practices rather than beliefs. The same respondent also stressed that the library would test the streaming technology before any future hybrid programs.

The academic librarians interviewed focused on establishing new partnerships when discussing how future programs might differ from their previous work. Both mentioned the value of potential partnerships with public libraries. The respondent who worked on the train-the-trainer program also discussed programming tailored to LGBTQIA+ audiences, referring to unique legal issues that may be relevant to end-of-life planning for these groups.

**Other Observations.** Three of the six interview respondents said that their interest in programming on end-of-life topics arose partly because of a difficult experience with losing a loved one or a serious health concern of their own. The frequency of personal connections to the subject matter is striking because the interviewer did not ask about personal experiences with illness or loss. Respondents who volunteered this information typically did so when asked, "What were your feelings about this programming when the idea(s) for it first came up?"

Interview respondents from both academic and public libraries spoke highly of partners they worked with. The two who organized speaker series both mentioned specific individuals who had many helpful contacts and were essential for finding presenters. Both said this partner made planning the series much easier. The academic librarian who worked on the train-the-trainer program noted that one partner helped establish end-of-life issues as a priority within the larger project: "Our public health professor just kept saying over and over again, you have to do this when you're healthy." Although student workers within respondents' libraries are not outside partners, both academic librarians noted valuable contributions by students who worked with them on their projects.

Three interview respondents mentioned benefiting from a work culture where library staff had autonomy in selecting projects or new programming ideas. For the librarian who developed resources to support a hospital's palliative and pastoral care groups, working at an academic library provided the freedom to focus on "individual research agendas" while still supporting colleagues. The organizer of the weekly speaker series noted that the library had made a priority of expanding programming for adults, so the leadership

actively sought new ideas. For the librarian whose institution offered instruction on writing obituaries, the work culture encouraged experimentation with low-cost programming: “We just try things, especially if it’s free.”

## Limitations

The biggest limitation of this study is the small number of respondents. This makes it impossible to reach broad conclusions about how these programs might vary across geographic regions, library types, or community sizes. It also prevents strong conclusions about which factors contribute to the success of these programs. As a result, this study only describes examples of library involvement in programming about end-of-life issues through the impressions of the library staff.

In addition, the self-selected respondents in this study may lead to a volunteer bias that makes their responses atypical of library staff who have sought to work on this programming. For example, respondents overwhelmingly reported positive experiences and positive feedback from program participants, but it is not clear how common this experience is. Someone who worked on a successful and popular program about end-of-life issues may be more willing to discuss it with a researcher than someone who had a less positive experience. The respondents whose libraries had discussed but not implemented programming represent one type of negative experience, but only three respondents fit this description.

Finally, this study does not consider programming that library patrons initiate or direct because it specifically recruited library staff. Additional patron-led programs might use library space or other resources. These could include support groups for survivors of loss, Death Cafes, meetings of religious or spiritual groups, and programs in response to local tragedies. Libraries are not merely their staffs, and it is important to understand the contributions that patrons make to libraries’ activities around end-of-life issues.

## Discussion

The program models and topics reported by respondents include those found in the existing literature, but they also suggest a wider array of options for libraries that are exploring programming on this topic. The diversity of programs offered reflects the importance of this information to library patrons. It also indicates the flexibility of this topic for developing programs. It might seem intimidating to introduce a program about an end-of-life topic, but libraries have implemented many approaches that have worked in different settings. A variety of partnerships are possible, providing opportunities to determine a feasible role for the library. It is not even necessary for librarians to spearhead these programs; they may be able to find roles supporting existing programs or activities with information resources.

Although only one respondent mentioned this topic, the issue of handling a deceased loved one’s social media accounts may represent an emerging need that librarians are well-positioned to address. Scholars of social media and other technologies have paid attention to this and related matters in recent years. Kasket (2020, 245) argues that people should have a plan for the management of the digital data they leave behind, whether they use social media or not, and communicate about this with those who have an interest in that data. Sisto (2020, 13-14) believes that there is an emerging need for a profession that provides guidance on decision-making about these matters. However, librarians may be able to help address the needs that Sisto identifies. Librarians could bring professional expertise on the storage, organization, and retrieval of

information to conversations with people preparing for their deaths, along with practical knowledge about the technologies involved.

Specific end-of-life topics may be more sensitive than others, requiring different treatment in library programming. Child death emerged as an example: the organizer of the book club discussed in this study avoided scheduling a book on this topic during the club's first year. Nonetheless, librarians have recognized the information needs of families who have experienced the loss of a child. Bensing (1996, 45)'s resource recommendations cover child death and pregnancy loss. Broadway (2008, 47-48) even discusses a couple books suitable for elementary and middle school readers who have lost a sibling. Another potentially sensitive topic is medical aid in dying, due to political and religious controversy about it. Library programs about this or other end-of-life options should carefully follow health librarianship's rule to offer information without giving advice. In general, when considering programs on difficult topics, libraries may benefit from offering programming on less sensitive end-of-life issues first. If a library has established itself as a trusted resource for information about these issues generally, community members may be more willing to engage with sensitive topics. For long-running programs like a book club, it may help to wait until the regular participants have developed mutual trust before introducing more challenging subject matter.

In contrast to the literature that discusses life-and-death crises as key occasions for libraries to serve end-of-life information needs, no respondent named the COVID-19 pandemic as the cause of personal interest in end-of-life programming, even though it occurred during the period covered by this study. Respondents mentioned COVID-19 as an impediment to program planning, not as something that highlighted the need for information about end-of-life issues. The reasons for this difference between the literature and this study's respondents are unclear. It may result from the self-selected sample: perhaps library staff who volunteer for a study about end-of-life programs are more likely to have an interest in these issues that predates the pandemic. The difference might also relate to COVID-19's months-long disruption of both workplace operations and public events in general; the duration of these challenges distinguishes COVID-19 from other emergencies considered in the library literature.

The respondents did not include any K-12 school libraries or hospital libraries, two categories that appeared as options for respondents to describe the library they work at. This absence is noteworthy, but the small sample size of this study makes it impossible to draw conclusions about how involved these libraries are with programming on end-of-life issues. These programs may be less common in K-12 school libraries because of these libraries' younger patron populations and primary mission of supporting their schools' curricula. Hospital libraries might be less likely to work on programming on these matters if other groups in their hospitals already do so. In addition, they may struggle to support new projects of any kind due to financial and logistical pressures that have led many hospital libraries to face closure or consolidation. In the years leading up to the period considered in this study, the number of hospital libraries in the United States shrank considerably (Harrow et al. 2019, 129). Understanding the role that K-12 school libraries and hospital libraries play in programming about end-of-life issues would require further research, using recruitment and sampling strategies tailored to these institutions.

### **Avenues for Further Research**

A key step in understanding these programs would be research involving a large sample of libraries. A more comprehensive picture of this type of

programming, including the full spectrum of library types, promotional strategies, and any local or regional variations, will benefit library staff who are interested in this work. This research could shed more light on how common these programs are, what topics might be underdiscussed in the programming that has occurred so far, and whether interest in these programs increases in moments of crisis. It would also help develop a fuller catalog of program models and topics for staff at libraries to consider.

Further research on the discussion and handling of sensitive topics in these programs would also be valuable. This study suggests that library staff involved with these programs think about ways to alleviate possible discomfort with the subject matter. Along these lines, research could consider what types of messaging are likely to be effective at reassuring different audiences of library patrons. Furthermore, because beliefs and practices around death and mourning often relate to people's cultural, racial, and religious identities, research and reflection on how to discuss these topics with different audiences can support libraries' commitments to equity, diversity, and inclusion. Libraries must handle programming and its promotional messaging in ways that welcome everyone.

Finally, because library staff may attribute their interest in these programs to personal experiences with loss or serious illness, research should examine how staff can practice self-care while working on programs that relate to sources of personal trauma. As valuable as programming on end-of-life issues can be, library staff who work on these programs must do so in a healthy and sustainable way. By understanding how library staff care for their own emotions, the library profession can improve strategies for protecting the well-being of staff involved in these programs. This would be an important consideration if library work on end-of-life issues is to become more prevalent. These insights may also assist libraries in offering programming on other sensitive matters.

## Conclusion

Library staff already perform valuable work around important issues related to death, dying, and grief. For readers who are exploring this programming for their own institutions, this study may suggest existing work to emulate. Perhaps it hints at unexplored ideas, visible in the negative space of what is missing from the discussion above. However, it is also clear that much remains unknown about these programs and the impact that they have. It will be useful to learn more about how they serve the practical, emotional, and spiritual needs of participants, and how they educate people on the full range of issues within this broad subject. Therefore, my dual hope is that further research about these programs will occur, and that libraries will continue experimenting with them despite unresolved questions, being brave enough to try new things and sometimes fail. Information and conversations about the end of life are important enough to warrant these attempts, even when clear answers remain scarce.

## References

- Bensing, Karen McNally. 1996. "Words of Comfort: Resources for the Living and Dying." *Library Journal* 121 (13): 43-44. ProQuest One Literature.
- Brady, Denise. 2001. "Building up a Bereavement Library." *Bereavement Care* 20 (3): 43-45. <https://doi.org/10.1080/02682620108657530>.
- Broadway, Marsha D. 2008. "Dealing with Death: Books to Help Young People Cope with Grief." *Teacher Librarian* 35 (5): 44-48. Education Database.
- Byars, Susan. 2012. "The Hospice Library." *Kentucky Libraries* 76 (4): 16-17. Library & Information Science Source.



- Death Cafe. (n.d.). "What is Death Cafe?" Accessed March 13, 2024. <https://deathcafe.com/what/>.
- Dreffin, Kate Roden. 1998. "Teaching Grief Work as an Aid to Life." *Montessori Life* 10 (Winter): 47-48. Education Source.
- Felton, Jarrett. 2022. "Estate Planning: Why Wait? Do It Now." *Rochester Business Journal* 38, no. 14 (September 2): 24. ProQuest One Business.
- Harrow, Andrea, Lisa A. Marks, Debra Schneider, Alexander Lyubchansky, Ellen Aaronson, Lynn Kysh, and Molly Harrington. 2019. "Hospital Library Closures and Consolidations: A Case Series." *Journal of the Medical Library Association* 107 (2): 129-136. <https://dx.doi.org/10.5195/jmla.2019.520>.
- Inklebarger, Timothy. 2015. "When the Subject Is Death." *American Libraries* 46, no. 11/12 (November/December): 21-22. <https://www.jstor.org/stable/24604291>.
- International End-of-Life Doula Association. n.d. "What Is an End-of-Life Doula?" Accessed April 7, 2024. <https://inelda.org/about-doulas/what-is-a-doula/>.
- Kasket, Elaine. 2020. *All the Ghosts in the Machine: The Digital Afterlife of Your Personal Data*. London: Robinson.
- Klingler, Corinna, Jürgen in der Schmitt, and Georg Marckmann. 2016. "Does Facilitated Advance Care Planning Reduce the Costs of Care Near the End of Life? Systematic Review and Ethical Considerations." *Palliative Medicine* 30 (5): 423-433. <https://doi.org/10.1177/0269216315601346>.
- Malhotra, Chetna, Maham Shafiq, and Ada Portia Macarubbo Batcagan-Abueg. 2022. "What Is the Evidence for Efficacy of Advance Care Planning in Improving Patient Outcomes? A Systematic Review of Randomised Controlled Trials." *BMJ Open* 12 (7): e060201. <https://doi.org/10.1136/bmjopen-2021-060201>.
- Pitsillides, Stacey, Claire Nally, Anita Luby, Rhonda Brooks, Fiona Hill, Joanne Ghee, Katherine Ingham, and Judith Robinson. 2023. "The Death Positive Library." In *The Routledge Handbook of Museums, Heritage, and Death*, edited by Trish Biers and Katie Stringer Clary, 389-401. Abingdon: Routledge. <https://doi.org/10.4324/9781003195870-33>.
- Reid, Martha, and Shannon Van Hemert. 2000. "Shelter from the Storm." *School Library Journal* 46 (1): 40-45. Education Database.
- Rosenbloom, Megan. 2020. "Resources for Those Facing Grief and Mortality." *Library Journal*, April 22, 2020. <https://www.libraryjournal.com/story/resources-for-those-whove-lost-loved-ones-grief-loss-self-help>.
- Sánchez-Carretero, Cristina, Antonio Cea, Paloma Díaz-Mas, Pilar Martínez, and Carmen Ortiz. 2011. "On Blurred Borders and Interdisciplinary Research Teams: The Case of the 'Archive of Mourning.'" *Forum: Qualitative Social Research* 12 (3): art. 12. <https://doi.org/10.17169/fqs-12.3.1737>.
- Seymour, Gina. 2016. "The Compassionate Makerspace: Grief and Healing in a High School Library Makerspace." *Teacher Librarian* 43 (5): 28-31. Education Database.
- Sisto, Davide. 2020. *Online Afterlives: Immortality, Memory, and Grief in Digital Culture*. Translated by Bonnie McClellan-Broussard. Cambridge: MIT Press. <https://doi.org/10.7551/mitpress/12553.001.0001>.
- Zarzycki, Jenna. 2023. "May You Find Some Comfort Here." *Alki: The Washington Library Association Journal* 39, no. 3 (December 27). <https://alki.pubpub.org/pub/gt3b6g53/>.

## Appendix 1: Survey Questions

To proceed with the rest of the survey, respondents must answer Yes to question 1 and Yes to either question 2 or question 3.

1. Are you a librarian or other library staff member at a library in the United States of America? [Yes/No]

2. Within the last five years, has your library facilitated or hosted any programming about end-of-life issues? [Yes/No]
3. Within the last five years, has your library internally discussed facilitating or hosting programming on end-of-life issues? [Yes/No]
4. What type of library do you work at?
  - Public library
  - K-12 school library
  - College or university library
  - Hospital library
  - Other type of library: [Free text]
5. Which of the following best describes the community where your library is located?
  - Rural
  - Suburban
  - Small city
  - Mid-sized city
  - Large city
  - Other: [Free text]
6. Which U.S. state or territory is your library located in? [Drop-down menu selection]
7. At your library, which of the following groups have been the focus of engagement or outreach activities in the last five years? Select all that apply.
  - Racial minorities
  - Religious minorities (including non-religious people)
  - LGBTQIA+ communities
  - Women
  - Disabled people
  - Older adults
  - Other groups: [Free text]
8. Please list the specific communities within the categories above, if any, who have been the focus of outreach or engagement activities at your library. [Free text]

Questions 9 through 19 appear only if the answer to question 2 is Yes.

9. What specific end-of-life topics has your library facilitated or hosted programming about? Select all that apply.
  - Estate planning (including wills or trusts)
  - Body disposition or funerals/memorials (information, options, or planning)
  - End-of-life health needs (information, options, or planning)
  - Legal arrangements (including guardianship, power of attorney or similar arrangements)
  - Spiritual, religious, or philosophical discussions of death or dying (including interfaith events)
  - Emotional or social support for terminally ill people
  - Emotional or social support for people who have lost loved ones
  - Open-ended discussion about death, dying, or end-of-life issues
  - Other end-of-life topic(s): [Free text]
10. What types of programs has your library offered related to end-of-life issues in the last five years? Select all that apply.
  - Guest speaker or speaker series
  - Book club

**“You Have to Do This When You’re Healthy”: An Introduction to Library Involvement in Programming on End-of-Life Issues**  
*continued*

- Partnership with other organization(s)
  - Resource fair
  - Death Cafe
  - Other small-group discussion
  - Other type(s) of programming: [Free text]
11. Were there specific audiences or groups within your library’s community that this programming was intended to reach or engage? [Yes/No/Unsure]

Questions 12-13 appear only if the answer to question 11 is Yes.

12. Please briefly describe the specific audiences or groups of community members that the library attempted to reach or engage with this programming. [Free text]
13. Please briefly describe any specific ways in which this programming was designed or promoted to engage the intended audience(s) described above. [Free text].
14. Which of the following best describes your involvement with your library’s recent programming on end-of-life issues?
- I was not involved.
  - I was involved in discussions about them, but not planning or implementing them.
  - I was involved in planning them but did not facilitate them.
  - I helped facilitate them but did not plan them.
  - I was involved in planning and facilitating them.
  - I took the lead on planning and facilitating them.
15. Were any partners from outside the library (whether individuals, organizations or other entities) involved in planning or facilitating any of your library’s recent programming on end-of-life issues? [Yes/No]

Questions 16-18 appear only if the answer to question 15 is Yes.

16. Please indicate what types of organizations, if any, your library worked with in planning and facilitating any end-of-life programming. Select all that apply.
- We did not work with organizational partners.
  - Hospitals or medical clinics
  - Nursing homes or other long-term care facilities
  - Hospices or home hospice organizations
  - Law offices
  - Funeral parlors
  - Cemeteries, crematoria, or other body disposition services
  - Schools, colleges, or universities
  - Religious congregations
  - Other organization(s): [Free text]
17. Please indicate what types of individuals outside the library, if any, your library worked with in planning and facilitating any end-of-life programming. Select all that apply.
- We did not work with individual partners.
  - Counselors or psychotherapists
  - Other health care professionals
  - Social workers
  - Teachers (at any level)
  - Attorneys
  - Morticians or funeral directors

- Death doulas
- Clergy
- Other individual(s): [Free text]

18. Please briefly describe the role(s) that any partners had in your library's programming about end-of-life issues. [Free text]

19. Overall, how would you describe the response of library patrons who participated in your library's programming on end-of-life issues?

- Very positive
- Somewhat positive
- Neutral or mixed
- Somewhat negative
- Very negative

Question 20 does not appear if the answer to question 14 is "I was not involved."

20. Overall, how would you describe your own experiences discussing, planning, and/or facilitating this programming at your library?

- Very positive
- Somewhat positive
- Neutral or mixed
- Somewhat negative
- Very negative

21. Please provide any other details that you believe are important for understanding the programming your library has offered about end-of-life issues. [Free text]

Questions 22-29 appear only if the answer to question 2 is No and the answer to question 3 is Yes.

22. What specific end-of-life topics, if any, were being discussed within your library as topics for possible programming? Select all that apply.

- No specific topics were discussed.
- Estate planning (including wills or trusts)
- Body disposition or funerals/memorials (information, options, or planning)
- End-of-life health needs (information, options, or planning)
- Legal arrangements (including guardianship, power of attorney or similar arrangements)
- Spiritual, religious, or philosophical discussions of death or dying (including interfaith events)
- Emotional or social support for terminally ill people
- Emotional or social support for people who have lost loved ones
- Open-ended discussion about death, dying, or end-of-life issues
- Other end-of-life topic(s): [Free text]

23. What types of programs, if any, has your library discussed within the last five years for programming on end-of-life issues? Select all that apply.

- No specific types of programming were discussed.
- Guest speaker or speaker series
- Book club
- Partnership with other organization(s)
- Resource fair
- Death Cafe
- Other small-group discussion

- Other type(s) of programming: [Free text]
24. What reasons, if any, were expressed about why programming about end-of-life issues was worth considering? Select all that apply.
    - No specific reasons were discussed.
    - Expressed interest by library users
    - Desire to help people have difficult conversations
    - Universality of the topic
    - Belief that information and planning are helpful with these issues
    - Aftermath of a tragedy
    - Other reason(s): [Free text]
  25. What reasons, if any, were discussed as to why this program might not be a good idea? Select all that apply.
    - No specific reason; it just never happened.
    - No evidence of interest from library users
    - Uncomfortable subject matter
    - Concerns about offending library users
    - Concerns that library staff don’t have the needed knowledge or expertise
    - External pressure not to go forward with the programming
    - Logistical constraints: not enough staff, time, money, or space
    - Other reason(s): [Free text]
  26. Which of the following best matches your overall sense of how librarians and other staff felt about the programming being discussed?
    - Very supportive
    - Somewhat supportive
    - Neutral or mixed
    - Somewhat opposed
    - Very opposed
  27. Which of the following best matches your overall sense of how leadership at your library felt about the programming being discussed?
    - Very supportive
    - Somewhat supportive
    - Neutral or mixed
    - Somewhat opposed
    - Very opposed
  28. Which of the following best matches your own feelings, at the time, about the programming being discussed?
    - Very supportive
    - Somewhat supportive
    - Neutral or mixed
    - Somewhat opposed
    - Very opposed
  29. Please provide any other details that you believe are important for understanding the discussion that took place within your library about programming on end-of-life issues. [Free text]

## **Appendix 2: Interview Questions**

1. How did the idea(s) for this programming first come to staff or leadership in the library?
2. What were your feelings about this programming when the idea(s) for it first came up?
3. What did your coworkers say about this programming when it was being discussed?

4. What led the leadership at your library to believe that your patrons would be interested in this programming?
5. What methods were used to promote this programming to your library's patrons?
6. When promoting this programming, how was it framed or presented? Or to put it another way, what kind of messaging did the library use to raise awareness about it?
7. How was the process of planning, hosting, or facilitating this programming different compared to other library programming that you have been involved with?
8. What goals did the library hope to accomplish with this programming?
9. How successful was the library at achieving these goals, and how did you know?
10. What feedback has the library received from library patrons who participated in this programming?
11. If your library were to offer further programming about end-of-life issues, what do you think would be done differently?
12. How have your feelings about library programming on end-of-life issues changed over the course of being involved with this programming, if they have?
13. We are at the end of the interview, but before we wrap up, is there anything else you'd like me to know about your experiences, or your library's experiences, with this programming?