

The Use of Convent Archival Records in Medical Research: The School Sisters of Notre Dame Archives and the Nun Study

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Abstract

The School Sisters of Notre Dame (SSND) archives program is a cooperative system for the arrangement and preservation of the records of the SSND provinces in North America, including records of individual sisters. Archival records include autobiographies, school and college transcripts, employment histories, and family socioeconomic data. The Nun Study, a longitudinal study of Alzheimer's disease and aging in 678 SSND sisters, compares data extracted from these records with data on late-life cognitive and physical function and post-mortem brain neuropathology to explore early life factors that may affect late-life cognitive function and longevity.

Introduction

In 1987, archivist Bruce W. Dearstyne lamented that archivists “have not realized that promoting maximum appropriate use of the holdings should be a centerpiece of the archival mission.”¹ At the time, this was particularly true of religious archives, which had traditionally been used for the study of religious subjects. Since Mennonite archivist David A. Haurly identified seven areas of study other than religious topics for which religious archives might be used—women's history, genealogy, economic and business history, social history, politics, educational methods and curriculum development, and ethnic

¹ Bruce W. Dearstyne, “What Is the Use of Archives? A Challenge for the Profession,” *American Archivist* 50 (Winter 1987): 76–87.

history—the use of religious archives has expanded.² However, there are still new opportunities presenting themselves to conscientious and creative investigators.

Communities of individuals who have experienced similar lifestyles throughout their adult lives are rare, and for this reason religious orders provide a unique opportunity for researchers in the humanities and particularly in the social sciences who need statistical data or data that may easily be converted to a statistical format. Researchers at the Nun Study, a longitudinal study of aging and Alzheimer’s disease in a population of elderly Catholic sisters (nuns), are taking research in religious archives a step further and using the archives of the School Sisters of Notre Dame (SSND) religious congregation for medical research to explore early-life factors that may affect late-life cognitive health and longevity.³

The School Sisters of Notre Dame

The SSNDs were founded in Bavaria in 1833 by Mother Theresa Gerhardinger for the purpose of educating poor girls, based on the belief that women properly educated would reform and transform families and societies. In 1847, Mother Theresa and five other sisters were the first members of the SSND to come to the United States in response to a call to teach German immigrant children. Under the leadership of one of the five sisters, Sister Caroline Friess, by 1879 there were twenty-five hundred SSNDs in the United States. They established a viable parochial school system and staffed orphanages and schools

² David A. Haury, “The Research Potential of Religious Archives: The Mennonite Experience,” *Midwestern Archivist* 11, no. 2 (1986): 135–40. The following year an article by Paul A. Ericksen described specific ways in which the Billy Graham Center processed its collections and encouraged their use by students and scholars studying nonreligious topics. “Letting the World In: Anticipating the Use of Religious Archives for the Study of Nonreligious Subjects,” *Midwestern Archivist* 12, no. 2 (1987): 83–90.

³ Examples of research articles that use statistical data to achieve similar goals to those of the Nun Study are Victoria Mocerri, et al., “Using Census Data and Birth Certificates to Reconstruct the Early-life Socioeconomic Environment and the Relation to the Development of Alzheimer’s Disease,” *Epidemiology* 21 (July 2001): 383–89; and Lawrence J. Whalley and Ian J. Deary, “Longitudinal Cohort Study of Childhood IQ and Survival up to Age 76,” *BMJ* 322 (7 April 2001): 1–5. Mocerri and her associates used census data to determine if there was any risk of Alzheimer’s disease associated with father’s occupation, parental age, household size, number of siblings, or birth order. Whalley and Deary used IQ test results of 2,792 Scottish children born in 1921 and mortality data on the same people gathered from a variety of sources to determine the effect of mental ability on survival. Given legal restrictions on access to school records, it is unlikely that the latter study could have been done in the United States. It should be noted that religious orders have long been the subjects of prospective medical studies in which new data are gathered from religious communities. A large body of literature has been generated by these studies. Of particular note are several studies of diet in monastic communities, including Barbara F. Harland and Michael Peterson, “Nutritional Status of Lacto-ovo Vegetarian Trappist Monks,” *Journal of the American Dietetic Association* 72 (March 1978): 259–64. Currently, the Religious Orders Study at Rush-Presbyterian-St. Luke’s Hospital in Chicago is studying various health factors in members of over forty congregations of both women and men.

for children with special needs, including night schools where girls who worked in factories could receive basic education. Among the institutions founded by the SSND are Mount Mary College in Milwaukee and the College of Notre Dame of Maryland, which was the first Roman Catholic college for women in the United States to grant a baccalaureate degree.

Over the years, the SSNDs established seven motherhouses in the United States: Milwaukee (established 1850); Baltimore (1876); St. Louis (1895); Mankato, Minnesota (1912); Wilton, Connecticut (1957); Dallas, Texas (1961); and Chicago (1965).⁴ Today, the SSNDs are an international congregation of over four thousand members, ministering in more than thirty countries. In the United States, approximately twenty-four hundred sisters minister in thirty-six states and the District of Columbia. The sisters respond to the needs of a global community in a variety of educational ministries, with special focus on women, children, and the poor.⁵

The Nun Study

The Nun Study began when Dr. David Snowdon, a University of Minnesota-based epidemiologist, contacted the SSND's Mankato Province to explore the possibility of recruiting sisters for a longitudinal study of aging. The sisters agreed to participate and a pilot study was initiated in 1986.

The success of the pilot study resulted in the National Institute on Aging's funding of the "SSND Health and Aging Study," now called "The Nun Study," which is based at the Sanders-Brown Center on Aging at the University of Kentucky. Beginning in 1991, participants were recruited from among members of the congregation who were seventy-five years of age and older and who lived in the seven SSND provinces in the United States. Out of 1,031 eligible sisters, 678 agreed to participate, a high participation rate considering that all participants were required to agree to annual assessments of cognitive and physical function and to brain donation at death. The sisters also agreed to allow researchers access to their records that are maintained by the congregation. Two younger members of the congregation were hired and trained to perform assessment tests and the assessments were begun in the fall of 1991.⁶

⁴ Participants in the Nun Study from the Dallas Province all live in a retirement community at a former SSND school in Chatawa, Mississippi.

⁵ For more information on the history and current activities of the School Sisters of Notre Dame, visit their Web site at <http://www.ssnd.org> (accessed 26 February 2004).

⁶ For background information on the Nun Study, see David Snowdon, *Aging with Grace* (New York: Bantam Books, 2001).

In addition to the records of the 678 sisters, the provincial leaders have permitted the Study access to records of sisters who would have been eligible for the Study had they lived long enough or remained in the congregation. Consequently, the Study has at least some information on a total of 3,926 sisters.⁷ The rich data resources available from the archival collections of the SSNDs have allowed the Nun Study to focus on the identification of early-life factors that predict late-life outcomes, particularly cognitive function and longevity. The results have been several important findings.⁸

The SSND Archives

Given the SSND congregation's focus on education and the tendency of the members of the congregation to be well educated, it is not surprising that the SSNDs have a long history of carefully maintaining convent records. While records have been kept since the early days of the congregation, until the early 1980s these documents were arranged and stored according to the policies of each individual province, and no efforts were made to develop a systematic archival program for the entire congregation.

The seeds of the SSND archival program were sown in 1972 when the General Chapter, a representative body that is "the highest legislative authority in the congregation when in session,"⁹ identified as a goal "to provide opportunities for each sister to know and value the heritage of the foundress."¹⁰ By 1974, several provinces had formed small heritage groups and conducted heritage workshops. In 1977, the Interprovincial Spirituality Committee, a body of representatives of each province charged with probing the common elements and diverse expressions of unity among SSNDs, asked provincial leaders to form a special heritage research group.

In 1981, the provincial leaders approved a proposal to

1. Plan for scholarly archives for each province;
2. Make recommendations regarding the storage and retrieval of materials; and
3. Propose guidelines and policies for the collection, management and use of archival materials.

Between 1982 and 1985, the Interprovincial Heritage Research Project laid the foundation for a systematic handling of SSND materials. The stated purpose

⁷ This permission was granted on the condition that the Study would not attempt to contact women who had left the convent or families of sisters who had died.

⁸ Abstracts of published Nun Study findings are available on the Nun Study Web site at www.nunstudy.org.

⁹ *You Are Sent: Constitution of the School Sisters of Notre Dame* (Rome: Generalate, 1970), 121.

¹⁰ *Acts of the Fourteenth General Chapter of the School Sisters of Notre Dame; October 20–November 22, 1972* (Rome: Generalate), 15–17.

of the two-year project was “to locate, identify, preserve, organize, and make accessible for serious study those materials—both historical and current—which are significant in the history of the School Sisters of Notre Dame in North America and in the other cultures where SSNDs of these provinces serve.”¹¹ By November 1983 the congregational newsletter *Soundings* was able to report that the Interprovincial Heritage Research Project was “moving on full-steam ahead. In dusty basements, hot attics, hidden storage cupboards, and rectory vaults, Srs. Barbara Brumleve and Marjorie Myers continue to dig up materials significant to SSND history. . . .” The two sisters spent almost six months traveling to present and former SSND institutions and interviewing over 55 percent of the North American sisters.¹²

In 1986, the convent archivists were organized into the Interprovincial Archivists Group. Each province in the United States and the Canadian Province has an archivist and maintains its own archives. The archivist for the Dallas Province resides in Chatawa, Mississippi, where most records of the Dallas Province are located. Archival materials from interprovincial activities are placed in a special collection in the Milwaukee Province archives. The archivists meet annually at one of the provincial archives. These annual meetings have resulted in the development of an extensive and detailed uniform filing system and indexes of congregational publications.

The main purposes for which the SSND archival program was established were to preserve the culture, history, and heritage of the congregation, provinces, motherhouses, and sites of ministry, and to organize, preserve, and provide access to documents, images, audiovisual materials, and artifacts related to the origins, development, life, and ministry of the congregation, provinces, or individual sisters. The program has increased the archivist’s ability to

- compile lists of current, former, and deceased members;
- compile lists of former and present ministry sites and types of ministry;
- respond to information requests from genealogists;
- respond to requests from former or present places of ministry and dioceses that are preparing anniversary booklets, celebrations, etc.;
- respond to requests from former students for the whereabouts of their teachers; and
- write articles or give presentations on the history and heritage of the congregation, a province or motherhouse, or a local place of ministry.

The program has also facilitated the provision of data to the Nun Study.

¹¹ *Heritage Research of the North American Provinces of the School Sisters of Notre Dame* (St. Louis, Mo.: SSND Heritage Research, n.d.).

¹² Marjorie Myers, “SSND Heritage Research Goes On,” *Soundings*, November 1983, 13.

SSND Documents

The documents maintained on individual sisters vary little from province to province, making the records particularly useful to the Nun Study in reconstructing aspects of the early lives of the sisters.¹³ To facilitate research and to reduce the need for the Study to make frequent demands on the archivists, photocopies of convent documents were made at the outset of the Study and secured in locked files at the University of Kentucky that are accessible only to Nun Study researchers. Because researchers usually extract information on several sisters from a particular document, the records at the university are arranged by document rather than by participant and filed in numerical order using numbers that were assigned to each participant at the beginning of the Study.¹⁴

Confidentiality is critical, both to the SSNDs and to the Study. The *Policy and Procedure Manual of the SSND Interprovincial Archivists Group* designates three classes of records for confidentiality purposes: historical materials published for circulation beyond the congregation, which are open to any user; materials published within the congregation, which are open to the SSND sisters; and all other archival materials, which are subject to restrictions imposed by law, the provincial leadership, the donor, and/or creator of the document(s).¹⁵ For the Nun Study, permission was given to conduct an aggregate statistical study using restricted materials. The names of individuals are not incorporated into Study presentations or publications without the sister's written permission. Consequently, whenever a sister is identified by name in a research article or in the media, either she has granted permission or the name is a pseudonym.¹⁶

As required by federal regulations, the Nun Study obtained informed consent from the participants. The consent form stated: "I understand that researchers will make a copy of my provincial records and medical records to obtain information about my family (such as birthplace, birth date, occupation, and date of death) and about me (such as birth date, birthplace, education, occupation, and health problems)." All files of data extracted from the documents contain only the participant's number and do not contain her name.

¹³ Most of the records on the sisters are contained in individual personnel files in the convent archives, although some are in registers and narrative records of the convent.

¹⁴ For a description of Dr. Snowdon's discovery of the archives, see *Aging with Grace*, 24–25.

¹⁵ *The Policy and Procedure Manual of the SSND Interprovincial Archivists Group* (1997), 33–35.

¹⁶ In one instance, a reporter included the name of a sister in an article about the Study without contacting either the Study or the convent. A sister had died and the reporter thought that he had been able to identify her by comparing information in a research article with published obituaries. Unfortunately for the reporter (and fortunately for the Study and for the sisters), he had identified the wrong sister. This gave the researchers at the Nun Study increased confidence that the system that was set up to maintain confidentiality works well.

Confidentiality extends to the results of the Study. Since there are many possible reasons for the scores that the Study sees on the assessment tests, researchers do not diagnose causes of cognitive impairment in living people. Test results are not shared with the sisters or their superiors. With the participant's permission, however, the Study will share appropriate information with a sister's health care provider. For example, several years ago, while performing a series of physical assessments of the sisters, geriatrician Dr. Christine L. Tully noted that one of the sisters had evidence of having had a minor stroke that had gone undetected. At the sister's request, Dr. Tully shared the information with her physician. The Study will interpret results of brain autopsies for close relatives of participants.

When the Nun Study began, it contracted with the congregation for the services of two sisters—one an archivist with ten years of service in a provincial archives and one a sister with database management skills—because it was felt that data collection could be done more efficiently by people who were familiar with the breadth and character of SSND records. These sisters collected the archival records and entered basic information about the sisters into a database of vital statistics (e.g., date of birth, date of entrance into the convent, province where the sister entered). A separate database describes all fields in the vital statistics database and other databases created by the Nun Study, indicating what specific data appear in a field and from what document or documents the data were extracted.

Archival service provided to the Nun Study has not been limited to the copying of documents when the Study began, but involves a continuing commitment because the Study frequently needs information that may not appear in the documents that were copied. When the Study requests information, archivists who respond submit hours and charges for photocopies, and the congregation is reimbursed from funds that are included in the Nun Study grant. This relieves the archives of any financial burden that might result from having to provide extensive services for purposes that were not anticipated when the archival program was initiated.¹⁷

A survey of the archival literature suggests that the type of contract to support archival services that exists between the SSND and the Nun Study is at least unusual. While most archives charge for photocopies and some charge for staff time, especially for genealogical research, perhaps more archivists should consider asking to be included in grants, especially when studies may generate potentially burdensome requests from researchers from outside the archives' supporting institution.

¹⁷ When the Study was collecting information about high school grades, it was necessary to contact the archivists for information about classes at the schools that the sisters attended. It was also necessary to get information from the sisters themselves. This was done through a research consultant from the convent who serves as the liaison between the sisters and the Study when Nun Study researchers or staff were not present.

Records Storage

Archival documents relating to the 678 participants were initially stored in locked file cabinets in the Nun Study office. Records for other sisters and most medical records were stored offsite at Kentucky Underground Storage, Inc., which provided timely courier service if records in storage were needed by researchers.

In December 2002, the Nun Study moved to new offices with a separate, locked archives room. The room contains compact shelving for storage of documents and audiovisual materials, and it has a separate thermostat for temperature control. As of January 2004, the process of calling records back from storage and arranging them in numbered archival boxes has been completed. A database designed by the Study's computer personnel will enable Nun Study staff to retrieve records by name, number, or type of record. Some records that are unlikely to be used by researchers will remain in off-site storage to leave room in the archives for the addition of records collected when participants die. As of January 2004, there were 150 living participants.

Use of Archival Records by the Nun Study

Several documents have proven to be particularly useful in Nun Study research, while others hold great promise for future mining of data. These include

Autobiographies

Beginning in 1930, sisters were asked to write autobiographies a few weeks before they took their first vows. The autobiographies were to include "place of birth, parentage, interesting and edifying events of one's childhood, schools attended, influences that led to the convent, religious life, and its outstanding events." The autobiographies vary in length and detail, but they are useful for studies involving both the characteristics of the writing and the information contained in the narrative. The autobiographies were written when most of the sisters were in their early twenties. Some sisters later revised their autobiographies or wrote additional autobiographies, which are also available in the convent archives.

Permanent Record

The permanent record form includes basic information on the sister and her family. It includes parents' occupations and the sister's occupation

before entrance into the convent. The form also includes dates and reasons for home visits, which is useful for mortality data on the sisters' parents before 1956.¹⁸

Transcripts of Academic Grades

Convent archives contain transcripts of sisters' coursework and grades. The grades are mainly for high school, college, and university, although there are some transcripts for elementary school, business school, and professional programs such as nursing. Researchers are currently studying whether grades earned in particular high school classes are predictive of late-life cognitive function.

Mission Cards and Mission Records

Mission records (for Baltimore and Milwaukee Provinces only) and mission cards (for all provinces) list the sisters' employment, beginning with their first assignments after entering the convent. These records are useful in distinguishing the teaching sisters from the house sisters, whose responsibilities were primarily domestic duties. Many studies are limited to the teaching sisters because their educational histories and the character of their work are markedly different from the house sisters and because they comprise the vast majority of the sisters. The cards have also been used to distinguish among elementary, high school, and college teachers. The mission records for the Baltimore Province also included information about home visits.

1983 Questionnaire or 1983 Survey

A highly unusual, if not unique, document was produced by the SSNDs in 1983 as part of the Interprovincial Heritage Research Project. Known as "the 1983 questionnaire," the document asked the sisters for specific information about their families and themselves with a view to entering the information into a computer database to save "hours of tedious fact-finding."¹⁹ The information

¹⁸ According to available records, as of 1922, sisters were allowed home visits for the golden wedding anniversaries of their parents, deaths and funerals of both parents, and first mass(es) of priest brother(s). By 1950, American sisters were allowed four home visits. By 1956, this had changed to one home visit of five days every five years, plus one visit for the sickness or death of a parent. In 1967, visits were allowed every five years. The following year, the policy changed to the current policy, which allows sisters to make frequent home visits.

¹⁹ Myers, "Heritage Research Goes On," 13.

requested included the sister's baptismal and religious names;²⁰ date of reception into the Roman Catholic church, if a convert; home parish at entrance; and places and dates of entry into the SSND, first vows, and perpetual vows. The questionnaire also asked for education and work histories.

The 1983 questionnaire is especially valuable for information about the sister's family. The names, religious affiliations, birthplaces, and birth and death dates of parents are included, as well as names of brothers and sisters and whether siblings are living. The sister's place in the birth order of the family is also noted. A section of sociodemographic information includes parents' ethnic backgrounds, first generation of family to be born in the United States, occupation group of head of household, economic class, highest educational attainment of parents, and size of community of origin.

The sisters were also asked to indicate their language proficiency by indicating which languages were their first, second, and other languages. A number of participants were born outside the United States, primarily in Germany. Others were born into communities in the United States where the primary language was other than English, primarily German or Polish. (The SSNDs operated German and Polish language schools to accommodate these communities.) As a consequence of the fact that sisters' primary languages were sometimes other than English, some documents in the archives, such as baptismal certificates and school records, are in other languages. Some studies done by the Nun Study are limited to sisters whose primary language is or was English. Since studies indicate that native and acquired languages activate different parts of the brain, there are also possibilities for exploring differences in life outcomes of native English speakers and those who spent their adult lives using English as a second language. The 1983 questionnaire in particular makes the SSND archives a potentially rich source of data for social science and humanities research. Archivists will accept applications from researchers who want to use archival records.

Death Certificates

The Nun Study collected death certificates from the provinces for all sisters among the 3,926 who had died and for whom the province had such documents. Death certificates on Study participants are collected shortly after death. Until recently, convents provided photocopies of the death certificates, but more

²⁰ Following the Second Vatican Council (1962–1965), which gave religious congregations greater freedom to modify their rules to meet their individual needs, SSND sisters were allowed to return to their baptismal names, if they wished to do so. Frequently, this has resulted in more than one name for particular sisters among their archival records. Both the SSNDs and the Nun Study have databases that show both of a sister's names.

restrictive laws have been passed in some states that now make it necessary for the Study to apply directly to government agencies for some death certificates.²¹ Attempts by the Nun Study to acquire death certificates for sisters who died many years ago have identified three instances in two states in which death certificates for the sisters cannot be located. It cannot be determined whether this is due to the fact that the certificates do not exist or that they are misfiled or contain incorrect data making them impossible to locate. On some death certificates, sisters' names are misspelled and death dates do not correspond to the dates in convent obituaries.

Other research studies have shown that death certificates often have serious limitations as sources of information. Particularly in the case of older people, causes of death are often couched in such general terms that they are useless for research. Particularly problematic are certificates that list "old age," "advanced age," or "natural causes" as either a primary or secondary cause of death.²² The Nun Study makes limited use of death certificates.

Medical Records

The Study has acquired a variety of medical records. A few were created early in the sisters' lives and acquired when the Study began. Some were acquired during a study of mercury dental fillings by Stanley Saxe, D.M.D., of the University of Kentucky.²³ Most of the records are collected postmortem and relate largely to the last years of the sisters' lives. Collection of medical records is challenging because most participants have their own physicians who are not affiliated with the congregation, and many participants die in nursing homes from which it is often difficult to obtain records.

Some provinces maintain voluminous files of medical records covering long periods of the sisters' lives, while others retain very few. The Nun Study offers to store these records and many have been transferred to the University of Kentucky, where they are placed in the Nun Study archives for later use. Records of sisters who died before the Study began are located in off-site storage. Some coding of illnesses and causes of death has been undertaken by the Study. However, the medical records are used primarily to confirm the diagnosis of

²¹ In Wisconsin, death certificates that list the cause of death are now available only to family members. The Nun Study plans to ask the sisters to sign waivers giving the Study permission to obtain their death certificates with the cause of death listed.

²² Ann E. Smith Sehdev and Grover M. Hutchins, "Problems with Proper Completion and Accuracy of the Cause-of-Death Statement," *Archives of Internal Medicine* 161 (22 January 2001): 277-84. Kalman Kafetz, "'Old Age' Should Not Be Acceptable on Death Certificates," *BMJ* 322 (21 April 2001): 993. It should be noted that there were several replies to Dr. Kafetz's letter that contended that "old age" is an appropriate cause of death, at least in rare cases.

²³ Stanley R. Sax, et al., "Dental Amalgam and Cognitive Function in Older Women: Findings from the Nun Study," *Journal of the American Dental Association* 126 (November 1995): 1495-1501.

dementia or to find other causes of cognitive impairment when the pathology of Alzheimer's disease is not present at autopsy.

Variations among the medical records limit their value as data sources. Some files contain detailed medical information that includes results of laboratory or imaging tests. Other files contain primarily nursing notes from long-term care facilities. However, the combining of information from medical records with data collected by the Nun Study may in the future yield important information about the onset and progression of disease in participants. For example, epidemiologist Dr. Suzanne Tyas is considering the possibility of using medical records to examine variations in blood pressure over time in a subset of participants.

Research use of medical records has recently become subject to guidelines issued by the federal government under provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), a law that is designed to protect patient confidentiality. The act includes provisions for the use of some records for research without patient authorization when patient identifiers have been removed. It is expected that the initial experience with HIPAA regulations will result in changes in the next few years, and archivists who have medical records under their control should be alert to these possible changes. Updates can be accessed on the Web at: <http://hhs.gov/ocr/hipaa>. At most institutions, Institutional Review Boards, which are responsible for protecting participants in research projects, oversee compliance with HIPAA regulations. The Nun Study is not greatly affected by HIPAA regulations because the sisters gave written permission for use of their medical records, but the interpretation of these regulations by nursing homes may affect the Study's ability to acquire some records.

Other Documents

Other documents available in convent archives include statements signed by sisters when they made their initial professions and when they took final vows; birth certificates; baptismal certificates; confirmation certificates; convent obituaries; letters written by sisters; literary works written by sisters; and photographs. One file created by the Nun Study contains miscellaneous forms (e.g., naturalization papers) that sisters have completed that were not appropriately placed in other categories. Another file includes tributes given to sisters while they were alive and articles about the sisters that appeared in newspapers or magazines.

Availability of Documents

The number of participants for whom particular records are available is high, contributing to the usefulness of the records for research on the entire population and on large subsets.

Table I Percentages of 678 participants for whom selected records are available

Document	Percentage
Autobiography	98%
Mission record or mission card	96%
Permanent record	99%
High school transcript*	78%
1983 questionnaire	95%

* Many house sisters did not attend high school, and high school records are not available for many foreign-born sisters.

As documents are received, they are labeled with the participant's number. The receipt of the document is recorded in a database and the document is filed in the archives.

Data are extracted from records and entered into database files as needed. Most early-life autobiographies of the 678 participants have been transcribed.

Nun Study Data

While the materials from the SSND archives provide information about early- and mid-life factors that may affect late-life health and longevity, it is necessary to collect new data on living participants so that the Study can explore the aging process and mortality. Late-life data is collected in three data collection programs: annual assessments, neurological examinations, and postmortem neuropathological examination of the brain. All 678 sisters agreed to participate in the annual assessments and brain donation portions of the study; most participants also agreed to undergo neurological examinations, which were added to the Study during the sixth annual assessment period.

Annual Assessments

The annual assessments are performed by two members of the SSND, Sisters Gabriel Mary Spaeth (of the Milwaukee Province) and Mildred Loddeke (of the St. Louis Province), who make an annual circuit, visiting the seven provinces and administering tests of cognitive function and ability to perform activities of daily living.²⁴ The participants are given a battery of cognitive tests, the best known of which is probably the Mini-Mental State Exam, a test of cog-

²⁴ When the Study began, plans called for the hiring of local laypeople to collect data in each province. However, later it was decided that to ensure consistent collection of data it would be best to have the same people conduct the tests at each convent. Members of the SSND were selected because Nun Study personnel stay at the convents when they visit, and it was felt that the sisters would fit more comfortably into the social, cultural, and religious environments of the convents during extended visits.

nitive function.²⁵ They are also asked to perform a series of tasks such as making change and using the telephone.²⁶ The tests are recorded on audiotape and tests on selected participants are recorded on videotape. The results of the tests are recorded in a computer program and on paper. When the assessments are completed at each province, a computer disk containing the test results, the paper records, and the audio and video tapes are sent to the Nun Study offices at the University of Kentucky. The data from the diskette is entered into the master data set, while inventories of the paper, audio, and video records are entered into a database and the records are stored in the Nun Study archives. Some of the tests involve the participant's drawing or writing so retention of the paper records is essential for future verification of test results.

During the third through sixth assessments, the sisters were asked to write autobiographies that contained the same information requested for the autobiographies written at the time they took their first vows. During the same assessments, the sisters were also asked for oral autobiographies, which were recorded on audio or video tape. These autobiographies can be used in the future to test such things as memory and the changing significance of events from childhood to old age. The written autobiographies have been transcribed and are available in computer files as well as in hard copy. Oral autobiographies are transcribed as requested by researchers. The Study is currently seeking funds to convert audio and video records to more durable and convenient formats.

Neurological Examinations

Since January 2000, a team of one registered nurse and two physicians has been conducting neurological examinations of Nun Study participants. The nurse reviews the participant's medical history and does a medication review and a comprehensive neurological examination, the results of which are entered into a computer program. The results of the examinations are then confirmed or modified by the physicians.

Activities of Daily Living in the Last Month of Life

When a participant dies, a caregiver or other person close to the participant, completes a form indicating the participant's ability to remember and her

²⁵ Marshal F. Folstein, Susan E. Folstein, and Paul R. McHugh, "Mini-Mental State. A Practical Method for Grading the Cognitive State of Patients for the Clinician," *Journal of Psychiatric Research* 12 (November 1975): 189-98.

²⁶ For a description of the assessment tests, see, Kathryn P. Riley, et al., "Cognitive Function and Apolipoprotein E in Very Old Adults: Findings from the Nun Study," *Journal of Gerontology: Social Sciences* 55 (March 2000): S69-S75.

ability to perform various common tasks, such as finding her way around familiar places, eating, dressing herself, bathing, using the toilet, and grooming herself, during the last month of life. Special dietary needs and decrements in hearing, vision, and communication are also noted. These forms are stored in the Nun Study archives.

Neuropathological Data

Shortly after death, the participant's brain is removed and shipped to the University of Kentucky where it is examined with magnetic resonance imaging (MRI) and cut for microscopic examination. MRI images and photographs of sections of the cut brain are stored in computer files for use in determining whether the sister met the criteria for dementia and in identifying other pathological conditions. Counts of the plaques and tangles characteristic of Alzheimer's disease are entered into a computer program. Images and results of cognitive tests are used in a consensus conference at which a neuropathologist and a psychologist determine whether or not the participant had Alzheimer's disease. That information and other neuropathological data are entered into a computer program.

Early-Life Factors Affecting Late-Life Cognitive Function and Longevity

Identification of early-life factors that affect late-life cognition and longevity hold the potential to help clinicians to identify people at risk for disease and permit early intervention with one or more of many new preventive measures and treatments that are being developed. The comparison of data extracted from convent records with data collected by the Study has identified several significant early-life factors and suggested other areas for future research.

The Use of Autobiographies

Among the most useful of the documents found in convent archives for research have been the early-life autobiographies. These are being used for studies that examine both the stylistic elements of the writings and the factual content of the narratives.

One of the earliest, and still most striking, findings of the Nun Study resulted from an examination of idea density and grammatical complexity in the handwritten autobiographies of ninety-three participants from the Milwaukee Province. For this study, Dr. Snowdon, along with linguist Susan Kemper and her associates at the University of Kansas, measured the number of ideas per ten



Photographs from the convent archives show reception class from the SSND Mankato Province, 1927 and the survivors of that class sixty years later.

words expressed in the autobiographies (idea density) and the composition of the sentences, ranging from simple one-clause sentences to sentences with multiple forms of embedding and subordination (grammatical complexity). When these characteristics were matched with the results of the cognitive function tests

and neuropathological examinations of the participants' brains, the results indicated that 90 percent of the sisters whose autobiographies exhibited low idea density had developed Alzheimer's disease.²⁷ Grammatical complexity was not a statistically significant predictor of late-life cognitive function.

A growing area of scholarly interest in recent years has been the effect of emotions on the life course. To explore emotion in Nun Study participants, researchers developed a system for counting the presence of positive emotion words in the early-life autobiographies.²⁸ Applying the system to 180 handwritten autobiographies from the Milwaukee and Baltimore Provinces and comparing the results to mortality data, they found a significant relationship between the expression of positive emotions and longevity.²⁹

Example of Participant Writings Coded for Emotional Content

Excerpt from an autobiography written by a sister in 1933:

How {p thankful p} I am that He selected me to be one of a large family for now I realize there is no compensation for those who miss its {p joys p} and {n sorrows n}. It is a big lesson in "give and take" and I am {p glad p} that I have learned at least the rudiments of it.

Excerpt from an autobiography written by the same sister in 1999:

*My family background was a deeply Catholic one, {p loving p} and {p loved p}, {p respected p}, almost {p revered p} father and mother, {p cherished p} siblings—
 ☞ that is certainly a dominant influence.*

* Words enclosed in curly braces and the letter "p" are coded as positive emotion words, while the word enclosed in curly braces and the letter "n" is coded as a negative emotion word.

²⁷ David A. Snowdon, et al., "Linguistic Ability in Early Life and Cognitive Function and Alzheimer's Disease in Late Life: Findings from the Nun Study," *JAMA* 275, no. 7 (February 1996): 528–32. This article includes excerpts from the autobiographies of two participants. Factual data were altered in the excerpts to maintain confidentiality. Low idea density has also been shown to have a negative impact on longevity. D. A. Snowdon, et al., "Linguistic Ability in Early Life and Longevity: Findings from the Nun Study," in *The Paradoxes of Longevity*, ed. J.-M. Robine, et al., (Berlin: Springer-Verlag, 1999), 103–13.

²⁸ Deborah D. Danner, Wallace V. Friesen, and David A. Snowdon, "Written Emotion Expression Code" (unpublished, 2000).

²⁹ Deborah D. Danner, David A. Snowdon, and Wallace V. Friesen. "Positive Emotions in Early Life and Longevity: Findings from the Nun Study," *Journal of Personality and Social Psychology* 80 (May 2001): 804–13.

Memory and the Use of Archival Records

Studies of memory have shown that adults tend to have particularly accurate memories of events that happened during a period known as the “reminiscence bump,” from preadolescence through early adulthood (approximately ages ten to thirty), while they have less accurate recall of the events of early childhood and the more recent past.³⁰ There is also some evidence that people tend to remember events from historically significant periods in communities in which they resided.³¹

In older adults, the ability to remember accurately events from several decades earlier may be affected by cognitive or physical deficits, or simply by a combination of the significance of the event and the interval of time between the event and the attempt to recall it. A recent animal study even suggests that to store new memories, the brain may have to clear away older memories that are no longer significant.³²

Certain types of information tend to be remembered more accurately than others by people of all ages. For example, school grades tend to be remembered with limited accuracy, with a tendency for higher grades to be remembered more accurately than lower grades, while even short-term memory of medical history has been shown to be surprisingly poor.³³

The Nun Study is fortunate to have access to autobiographies produced by sisters who were in their early twenties, which are likely to contain more accurate accounts of events from childhood or adolescence than accounts that are produced from memory from the distance of several decades. The age at which the autobiographies were written may also mitigate the effects of the reminiscence bump, which usually appears between the ages of thirty-five and forty-five, but which has been noted in younger people.³⁴

³⁰ Ashok Jansari and Alan J. Parkin, “Things That Go Bump in Your Life: Explaining the Reminiscence Bump in Autobiographical Memory,” *Psychology and Aging* 11 (March 1996): 85–91.

³¹ Martin A. Conway and Shamsul Haque, “Overshadowing the Reminiscence Bump: Memories of a Struggle for Independence,” *Journal of Adult Development* 6 (January 1999): 35–44.

³² Ruiben Feng and others, “Deficient Neurogenesis in Forebrain-Specific Presenilin-1 Knockout Mice Is Associated with Reduced Clearance of Hippocampal Memory Traces,” *Neuron* 32 (December 2001): 911–26. There is also evidence from neuroimaging studies that autobiographical memories in older adults activate different parts of the hippocampus in the brain than do the same types of memories in younger people. The significance of this with regard to the content of the memories is yet to be determined. Eleanor A. Maguire and Christopher D. Frith, “Aging Affects the Engagement of the Hippocampus during Autobiographical Memory Retrieval,” *Brain* 126 (July 2003): 1511–23.

³³ Harry P. Bahrick, Lynda K. Hall, and Stephanie A. Berger, “Accuracy and Distortion in Memory for High School Grades,” *Psychological Science* 7 (September 1996): 265–71; Gillian Cohen and Rosalind Java, “Memory for Medical History: Accuracy of Recall,” *Applied Cognitive Psychology* 9 (August 1995): 273–88.

³⁴ Jansari and Parkin, “Things That Go Bump in Your Life,” 85–91.

Hierarchy of Documents

For factual data, autobiographies may be useful, but they are rarely the first choice because they tend not to be specific. For example, an autobiography might say, "I attended Rosati-Kain High School for three years," while a transcript of the high school record will indicate exactly which years those were. The Study benefits from the availability of records produced during the process of documenting each sister's career, contemporary with or close to the times of the events that they record. Because elements of data may appear in more than one document, it is often necessary to develop a hierarchy of documents to use to find specific information on each sister. This hierarchy is based on factors such as

- specificity of information;
- number of sisters for whom the document is available;
- point in the sister's life at which the document was produced; and
- source of the document (e.g., the sister or an outside agency).

The document that provides the most accurate information on the greatest number of sisters is the preferred source.

For example, as part of an ongoing research project on the effect of childhood trauma on late-life health and longevity, researcher Lydia Greiner wanted to identify all sisters in a subset of the 678 who had lost a parent before the age of twelve and which parent was lost. To do this, she developed the following hierarchy:

1. **1983 Questionnaire** on which the sister was asked to record her parents' death dates
2. **Autobiography** in which events such as parent death were often, but surprisingly not always, included in the narrative
3. If a parent is listed as next of kin on the **permanent record**, then the parent was known to have been alive after the sister entered the convent. As noted above, this record also sometimes recorded home visits for such events as wedding anniversaries, or the final illness or death of a parent.
4. **Records of siblings.** Several Nun Study participants are siblings of other participants, and records of the siblings may provide information that the participant's own records do not.

When archival resources were exhausted, the Nun Study contracted with the Roman Catholic Archdiocese of Saint Paul and Minneapolis for a further search. The Nun Study provided the names, last known locations, and last known dates alive for parents of remaining participants to a genealogical researcher who is with the Archdiocese. The researcher and his contacts in other jurisdictions were able to locate information on the deaths of the majority of the remaining parents.

Research has suggested that there may be subsets distinguished by birth year or ethnicity for whom outcomes vary. For example, it is possible that nega-

tive life events were more detrimental to the later lives of the very oldest sisters in the Study than they were to sisters who were born later. A historian who is connected with the Study has done some preliminary reviews of the historical literature to try to identify events, such as population migrations and economic depressions, that may have affected the lives of these women.

Photographs

Expanding the Nun Study's research beyond the use of written archival records, Drs. Deborah Danner and Wallace Friesen have used the Facial Action Coding System, developed by Friesen and Dr. Paul Ekman, to measure changes in emotional expression over time, as shown in photographs of Nun Study participants.³⁵ The images used included photographs taken between 1968 and 1978 from convent archives, photographs from pictorial directories, and images from videotaped assessments. The sisters are ideal subjects for this type of study because they do not wear make-up or earrings and because many of the sisters in these photographs are wearing habits thereby reducing the potential confounding effects of distracting elements.

The Future

Encouraged by its principal funding agency, the National Institute on Aging, the Nun Study is committed to sharing its data with researchers outside the Study.³⁶ To this end, the Study has been seeking grant funding for future scanning and digitization projects that, among other things, would make it possible to share data nationally and internationally via the Internet. If successful, this project would have the additional benefit of providing digitized records of SSND archival materials that could be accessed by the convent archivists.

Conclusion

The availability of similar records collected throughout the lives of participants in the Nun Study enhances the Study's ability to reconstruct the early lives

³⁵ Paul Ekman and Wallace V. Friesen, *Facial Action Coding System: A Manual* (Palo Alto, Calif.: Consulting Psychologists Press, 1978).

³⁶ This has already been done to a limited degree, producing three published articles and two that are in press. In addition, Dr. Steven Estus of the University of Kentucky is using Nun Study materials in research that is unrelated to the Nun Study grant, while Dr. Myron Gross, an epidemiologist at the University of Minnesota with a long association with the Nun Study, has a grant from a private foundation to collect additional data on the sisters that will be combined with Nun Study data for a nutrition study.

of participants without reliance on late-life memory of early-life events. In addition, it makes it possible for the study to compare early-life data with similar data collected in late life. In the future, as the necessary funding becomes available, computerization of both convent records and data collected by the Nun Study will allow the Study to make this rich data source available to national and international communities of researchers.

By building a strong cooperative relationship, the archivists of the School Sisters of Notre Dame and the Nun Study have found uses for convent records that were not anticipated when the archives were established. Fortunately, the care and professionalism with which the SSND archives have been developed have allowed for the flexibility necessary to locate and use the records in medical research that will have long-term benefits to both patients and practitioners.