The Status and Availability of Data on Centenarians:
What Do we Have and What we Would Like to Get?

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Abstract

The growing importance of individuals aged 100 or older for research on aging is undeniable. Since 1998 well over 150 peer reviewed articles have focused specifically on Centenarians; their health, social behavior and longevity. This interest is supported by the concentration of resources for research on this very special population. Since 1990 NIH has funded over 90 new or continuing studies that deal directly with the collection of data and the study of Centenarian populations. This paper adds to our understanding of research on Centenarian populations by linking current research on this topic to the actual data that is used to study this population. More importantly, this paper discusses what data on the study of Centenarians is now available for secondary analysis and what studies will become available in the coming years. By identifying the best data resources available, we will greatly enhance our ability to study this important population.

Introduction

Over the past 5 years well over 150 peer reviewed articles have been published that look specifically at Centenarian, those individuals aged 100 years or older. These articles examine the lives of this special group of aged individuals from a variety of perspectives including health issues such as senescence and longevity and social correlates such as family support and access to infrastructure that enhance quality of life.

The growing interest in this unique population has been driven, at least in part by our recognition of the rapid growth of individuals aged 100 years and older in the United

States and throughout the world. A 1999 report funded by NIA and performed by the U.S. Census Bureau confirms that the number of centenarians in the U.S. is growing rapidly. During the 1990s, the population of centenarians nearly doubled, from about 37,000 counted at the start of the decade, to more than an estimated 70,000 today. Overall there was a 35 percent increase in those aged 100 and older between 1990 and 2000. The Census report suggests that this per-decade doubling trend is expected to continue, with a potential centenarian population of over three quarter of a million individuals by the middle of the next century. Such a dramatic increase in the size of our oldest population has clear implications for our planning in the arenas of health care, family support and social policy.

The growing interest in gerontology for centenarian population has been both encouraged and supported by a concentration of federal and private resources for research on this very special population. Since 1990, for example, NIH has funded over 90 new or continuing studies that deal directly with the collection of data and the study of centenarian populations.   Similarly, private organizations such as ARRP Andrus, Wellcome Trust, and the United Nations as well as foreign governments such as Japan and the European Union have all invested heavily in our understanding of centenarian populations.

This paper adds to our understanding of research on centenarian populations by providing a better understanding of the research data which is available to study these individuals from a demographic perspective, both for the United States and Internationally. By linking current research on this topic to the actual data that is used to study this important population we obtain a more realistic understanding of potential

avenues for new research. This paper discusses what studies have had a major impact on our understanding of the health, social behavior and economic status of centenarians and what data on this population is now available for secondary analysis both in the United States and Internationally. The paper also discusses what studies will potentially become available in the coming years and what barriers exist to the fuller sharing of important datasets related to this population. The paper will discuss emerging issues of confidentiality and respondent protections as well as the particularly troubling challenges seen for future research such as newly instituted HIPPA restrictions on the creation of public use data files for health data on individuals aged 90 years and older.

By identifying and discussion the availability of the best data resources available, we will greatly enhance our ability to study centenarians in a meaningful manner that permits a broad array of researchers to bring their skills to bear on this important population. The research to be presented in this paper represents one aspect of ongoing work being done at the National Archive of Computerized Data on Aging (NACDA) located at the University of Michigan. As the largest existing archive of research data on aging and health, our mission is to identify and acquire seminal studies in aging and to work closely with researchers to formalize protocols that facilitate access to restricted data. This paper represents as valuable contribution to core research issues related to the study of rare populations such as centenarians. The resources emerging from this project will help shape the kinds of research questions that can be posed on this topic in the future and the kind of data resources that will be available to the research community to address these questions.