

Leveraging the Health and Retirement Study To Advance Palliative Care Research

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Abstract

Background: The critical need to expand and develop the palliative care evidence base was recently highlighted by the *Journal of Palliative Medicine's* series of articles describing the Research Priorities in Geriatric Palliative Care. The Health and Retirement Study (HRS) is uniquely positioned to address many priority areas of palliative care research. This nationally representative, ongoing, longitudinal study collects detailed survey data every 2 years, including demographics, health and functional characteristics, information on family and caregivers, and personal finances, and also conducts a proxy interview after each subject's death. The HRS can also be linked with Medicare claims data and many other data sources, e.g., U.S. Census, *Dartmouth Atlas of Health Care*.

Setting: While the HRS offers innumerable research opportunities, these data are complex and limitations do exist. Therefore, we assembled an interdisciplinary group of investigators using the HRS for palliative care research to identify the key palliative care research gaps that may be amenable to study within the HRS and the strengths and weaknesses of the HRS for each of these topic areas.

Conclusion: In this article we present the work of this group as a potential roadmap for investigators contemplating the use of HRS data for palliative care research.

Introduction

THE FIELD OF PALLIATIVE CARE is growing rapidly in the United States. Advances in public health have extended our life span. New medical technologies often slow progression of disease and sustain life through circumstances that were previously unimaginable. Along with these benefits, our society is facing new challenges: tremendous unmet care needs for both patients with serious illness and their families, as well as unsustainable growth in health care costs. These challenges have created unprecedented demand for palliative care services, with the goal of increasing the value of health care (i.e., maximizing quality while reducing costs). Meeting these challenges will require substantial expansion of the palliative care evidence base. Research is needed to support clinical services by expanding our knowledge of the epidemiology of serious illness and its impact on patients and

families and to develop and refine health care service models by understanding the factors influencing treatment decisions and the impact of those decisions on patients, families, and caregivers.

The Health and Retirement Study (HRS) is uniquely positioned to address many priority areas of palliative care research.¹ Funded by the National Institute on Aging and collecting data since 1992, HRS is an ongoing longitudinal study designed to be representative of the U.S. population over 50 years of age. The spouses or partners of potential subjects are also recruited to the study, regardless of age. HRS conducts biennial waves of core interviews with approximately 20,000 participants and, within 2 years of a participant's death, conducts a postdeath interview (i.e., an "exit" interview) with a knowledgeable proxy, usually a surviving spouse or family member. Together, the core and postdeath interviews include detailed survey data including

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demographics, health and functional characteristics, information on family and caregivers, and personal finances. The longitudinal design also frequently captures the onset and trajectory of serious illness. The HRS can be linked with Medicare claims data and many other data sources, e.g., U.S. Census, *Dartmouth Atlas of Health Care*. The Medicare linkage, in particular, provides an exceptional opportunity to pursue policy-relevant research questions that are central to the expansion and improvement of palliative care in the United States.

The *Journal of Palliative Medicine* recently published a series of articles outlining the top research priorities in geriatric palliative care.² The HRS offers extraordinary opportunities for addressing many of these pressing and challenging research questions. However, the data are complex and understanding what high quality research can be conducted within this dataset requires substantial knowledge of the HRS. Therefore, with the support of the National Palliative Care Research Center (NPCRC) and the National Institute on Aging (NIA), we assembled an interdisciplinary group of investigators using the HRS for palliative care research to identify the key palliative care research gaps that may be amenable to study within the HRS and the strengths and weaknesses of the HRS for each of these topic areas. In this article we present the work of this group as a potential roadmap for investigators contemplating the use of HRS data for palliative care research.

Identifying and Describing the Population that may Benefit from Palliative Care

“Palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.”³ Clinical palliative care programs are rapidly expanding, with most large hospitals now offering palliative care services.⁴ Yet no unifying definition of the target population for palliative care services exists; an important gap in palliative care research. Many clinical programs and research studies focus on particular diagnoses of serious illness (e.g., cancer); others consider clinical or psychosocial needs (e.g., uncontrolled pain); and some, particularly those focused on policy, highlight those most ill and complex patients who disproportionately account for the majority of health care spending. The HRS, given the breadth of demographic, clinical, and social characteristics measured, offers a platform for identifying and comprehensively describing the seriously ill population that may benefit from palliative care services. It also offers the opportunity to assess the impact of varying definitions of serious illness on patient quality of life and health care outcomes.

In addition, current evidence reveals an even wider range of factors that may influence, or are associated with, the medical treatments provided to patients with serious illness.^{5,6} These factors include the patient and family’s demographic, psychosocial, cultural, medical and functional characteristics, but also individual provider factors, regional patterns of care, local supply of and access to specific medical resources, structure of reimbursement models, and the incentives influencing provision of specific treatments. This evidence suggests that consideration of all relevant factors

simultaneously is necessary when considering the care patterns, treatment decisions, and outcomes for patients with serious illness. Very few studies to date have included this full range of factors. Specifically, many studies are based upon administrative and claims data, yet these data offer no psychosocial, socioeconomic, cultural, or functional measures. The HRS provides a much greater breadth of available measures, which when linked with Medicare claims data, offers a particularly rich dataset for this area of inquiry (Table 1). The limitations of HRS data, however, are that the biennial data collection intervals are often too infrequent to capture the onset of serious illness and the evolution of many factors (symptoms, function, preferences) over the course of illness.

Dementia and Cognitive Impairment

The prevalence of dementia is rising with the aging of the U.S. population and is currently a leading cause of death and health care expenditures.^{7,8} The past two decades have witnessed a boom in dementia research with significant advancements in evidence-based assessments and treatments. Priority areas for advanced dementia research currently include health services and outcomes research, as well as health policy evaluations, aiming to improve the care experience and quality of life of persons with advanced dementia and that of their families.⁷ The HRS may offer a unique laboratory for some of these studies. Beginning in 2001, the HRS was funded by the NIA to conduct a supplemental study: Aging, Demographics, and Memory Study (ADAMS). ADAMS aimed to obtain gold standard diagnoses using a

TABLE 1. DOMAINS THAT MAY DEFINE A POPULATION WITH SERIOUS ILLNESS POPULATION, INFLUENCE TREATMENT, AND SERVE AS KEY PALLIATIVE CARE OUTCOMES

<i>Domain</i>	<i>HRS measures available^a</i>	<i>Linkable data sources</i>
Demographics	Excellent	
Psychosocial factors	Good	
Socioeconomic factors	Excellent	
Religion/culture	Good	
Functional status	Good	
Cognitive measures	Excellent	
Health conditions	Good	CMS and VHA datasets ^b
Health care utilization	Fair	CMS and VHA datasets
Symptoms	Fair	
Care preferences/goals	Fair	
Caregiver factors	Good	
Regional factors		<i>Dartmouth Atlas</i> , US Census, others
Provider factors		CMS and VHA datasets

^aThe authors have provided a subjective assessment of the measures available in the HRS for each domain.

^bThe Centers for Medicare and Medicaid (CMS) and the Veterans Health Administration (VHA) offer a range of linkable datasets. HRS, Health and Retirement Study.

detailed in-home clinical evaluation and population estimates of dementia, cognitive impairment, and normal cognition.⁹ Initial ADAMS evaluations were completed from 2001–2005 and targeted follow-up continued through 2010. In addition to cognitive and neuropsychiatric batteries, the ADAMS study collected biological data, caregiver data, and engaged an expert panel to complete consensus diagnoses. HRS investigators have developed methods, based upon the ADAMS data, to impute dementia and cognitive impairment diagnoses to all HRS respondents.^{8,10–13} Investigators can therefore select an HRS subgroup based upon cognitive characteristics or consider dementia and cognitive impairment as a covariate or predictor of interest in the study analysis.

Caregivers and Caregiving

While many caregivers care for patient with life-threatening illnesses, the caregiving literature rarely focuses on the needs and outcomes of family caregivers during palliative or end-of-life phases.¹⁴ The HRS may provide unique advantages for research into the role of family caregiving in palliative care. In the biennial core interview of HRS, caregiving is determined via the subject's report of care received. The care recipient (or proxy respondent if the subject is not able to complete the interview independently) reports whether they needed help with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) in the last month, who provides it and how often help is provided (days per month, hours per day). Type of caregiving is determined based on who provides the help: formal, i.e., from a paid nonrelative or from someone affiliated with an organization; informal, i.e., from a relative (paid or not) or unpaid nonrelative with no organizational affiliation.¹⁵ While measures of caregiving can be defined in various ways using the HRS data, the level of care has most often been determined based on number of hours of care provided weekly (in some cases dichotomized into high and low levels of care using a median cut-point of 14 hours per week).¹⁶ Additionally, during the exit interview, the next-of-kin reports whether anyone assisted with individual ADLs and IADLs in the last 3 months, how long help was needed, who helped most, and the frequency of help provided. Data on multiple helpers at the end of life are also captured, although descriptive information is limited for non-spouse caregivers. The HRS also captures detailed information on coresidents at all waves of follow-up. For example, subjects are asked if a son, daughter, or other family member has moved in since the last interview.

The longitudinal nature of the HRS allows researchers to examine changes in caregiving status and the caregiver network over 2-year intervals and as illnesses progresses. While the HRS study does not include an independent interview of all caregivers and their outcomes, spouses of all participants are recruited for enrollment in the HRS sample by design. As such, the HRS provides a unique opportunity to follow patient–spousal dyads throughout the course of illness.^{17,18} Spousal caregivers (and spouses in general) can be followed before and after the care-recipient's illness, and even following the care-recipient's death. This provides the opportunity to explore how caregivers impact end-of-life treatment decisions and communication with providers as well as offer insights on spousal bereavement and caregiving outcomes. The HRS currently does not collect outcomes for other

caregivers besides spouses or examine the extent of care provided by caregivers beyond ADLs and IADLs (e.g., complex medical/nursing tasks and pain and symptom management). An additional shortcoming of the HRS for caregiving research in the realm of palliative care is the very limited information collected about the care preferences of patients and families throughout the course of illness and the lack of a standardized instrument to measure caregiver burden and stress.

Palliative Care in Nursing Homes and Long-Term Care

An overall agenda for palliative care research in the nursing home setting has been reviewed elsewhere.¹⁹ In consideration of pursuing these investigations within the HRS, two issues are of particular note relative to the observational design of the HRS. First, the last decade has seen tremendous growth in hospice enrollment among nursing home residents, leading some to call for reduced payments to hospice for these patients.²⁰ The HRS and linked Medicare data could potentially be used to examine the additional value of hospice services for long-stay nursing home residents. Second, the patient and payer profile of the nursing home population has shifted over time, with fewer long-stay residents, primarily paid for by Medicaid, and more postacute care patients, paid for by the Medicare Skilled Nursing Facility (SNF) benefit.²¹ Patients with serious illness are often discharged from the hospital to the SNF, but we know little about quality of life for these patients.

The HRS has two main strengths when used for palliative care nursing home research. Because the HRS tracks subjects through death, including after death interviews with next-of-kin, the HRS can be used to describe subjects who die in nursing homes and the nature of the care they received prior to death. For example, Kelly et al.²² used the HRS to describe the length of stay of HRS subjects who died in the nursing home, finding that the median of 5 months was far less than the mean of 14 months. There is a need, however, to create and test the use of the HRS measures for examining quality of care for nursing home residents with serious illness. Second, the HRS is a good vehicle for studying transitions in care. The HRS enrolls community dwelling subjects and follows them as they move into and out of nursing home settings. Furthermore, by linking to Medicare, the HRS can be used to examine hospital and hospice use by nursing home residents, and use of the SNF benefit by community-dwelling elders. Aragon et al.,²³ for example, used the HRS combined with Medicare claims to find that 30% of older adults used the SNF benefit in the last 6 months of life, and 9% died while in SNF.

Investigators must recognize the limitations of using the HRS for nursing home research. Unlike community-dwelling older adults, subjects who enter nursing homes are given a zero subject survey weight.²⁴ The current recommendation from the HRS investigator team is to use the last non-zero weight in settings where survey weights are needed²⁴; more accurate weights are forthcoming in future waves of HRS data collection. Second, other alternative datasets, such as the Minimum Dataset (MDS), that track nursing home residents contain quarterly assessments, more frequent than the biennial surveys conducted by HRS. In the future, HRS will include linkages with the MDS, in addition to the current

HRS-Medicare linkage. This will create a powerful method of tracking a number of measures critical to palliative care, including pain, advance care planning, and burdensome transitions in care.

Advance Care Planning and Preferences for Care

In the setting of serious illness, treatment decisions should be guided by patient-centered goals and values. Advance care planning and discussions to elicit preferences for care have been promoted as a means to better align medical treatments with patients’ personal goals. Ongoing investigation is needed in areas of communication training for providers and interventions to elicit patient preferences and healthcare systems design to record preferences and reconcile care plans and quality metrics with these stated goals.²⁵

While many of these research questions cannot be addressed within HRS, the HRS has been successfully used to examine prevalence of advance directives and advance care planning activities, as well as to describe the preferences of older adults and the outcomes of end-of-life decision-making.^{26–28} HRS does not collect this information prospectively, however, and relies on proxy reports of these data after the subject has died. These postdeath interviews with proxies occur, on average, 12 months (and up to 24 months) after the subject’s death, thus raising concerns about the accuracy of the information provided. Future research in this area could be strengthened by supplementing the biennial interview with survey items regarding: (1) the timing, place, and content of advance care planning conversations; (2) goals for care and preferences around surrogate decision makers, and (3) preferred means for discussing, documenting and disseminating their wishes. Currently such additions are not planned given the biennial interview’s time and length constraints.

Symptoms (Pain and Nonpain)

The current evidence regarding symptom burden, symptom management, and related outcomes in older adults is insufficient. Available studies are generally limited to a specific population or treatment setting, such as a cohort of patients receiving a particular chemotherapy regimen. Conducting symptom-focused research among older adults with serious illness and multimorbidity is a top priority.²⁹

HRS investigators have gathered data regarding symptoms since 1992 and these data have been used to describe the symptom burden of community dwelling older adults and examine the clinical and socioeconomic factors predictive of their symptomatology.^{30–36} Pain and depression have been examined the most extensively. HRS asks subjects directly about pain, shortness of breath and depressive symptoms in the core interview, but asks about other symptoms to the proxy (namely, confusion, dyspnea, anorexia, edema, dizziness, headaches, cough, and insomnia) only after the subject’s death. Many symptoms commonly experienced by elderly adults are not assessed by HRS, e.g., stiffness, constipation, and joint pain. Furthermore, there are a number of limitations relating to how HRS assesses symptoms. Symptoms are not assessed using well-validated measures, raising concerns about the reliability of the data and limiting one’s ability to compare data to other studies. The clinical characteristics or etiology of the subject’s symptoms are also not

identified, making it difficult to know the clinical relevance of findings stemming from these data. Most symptoms, other than pain, are assessed in only one dimension (either frequency or severity), further limiting the ability to understand the clinical relevance of findings. Last, HRS typically asks subjects and proxies to rate symptoms over a 12-month interval, raising questions regarding symptom acuity and recall bias.

Psychosocial Factors

Psychosocial factors, such as religion and spirituality, social relationships and support, life experiences, and others, are critical to understanding the experience of persons with serious illness. These factors influence quality of life, treatment decisions, and clinical, as well as other, outcomes. However, evidence regarding best methods for assessment and potential interventions is limited.

The HRS Psychosocial Supplement, also known as the “Leave Behind Questionnaire” (LBQ) or the “Lifestyle Questionnaire,” can be a powerful tool for geriatric and palliative care researchers. The LBQ is a supplemental hardcopy survey left behind in the homes of core HRS participants who complete face-to-face interviews. It presents respondents with a battery of items to capture information about social, psychological, spiritual and historical/contextual dimensions. Measures include perceptions of social support, quality of relationships, religiosity/spirituality, psychosocial well-being, perceived discrimination, work-related beliefs, and personality traits, among others. Although these variables are known to be key outcomes and covariates in geriatric and palliative care research, to date the HRS LBQ measures have been used infrequently in this field of research.

Users of the LBQ should be aware that its administration differs substantially from the approach used for core survey waves, which has implications for the design, analysis and interpretation of future studies. As Table 2 illustrates, beginning in 2006 the LBQ was given to 50% of the core HRS sample (those households randomly selected to receive enhanced face-to-face interviews; Sample A). The LBQ was subsequently given to the remaining half of HRS participants (Sample B) in 2008. Due to the rotating administration of the LBQ, longitudinal data are only available for each half of the sample in 4-year increments, rather than in 2-year intervals. Although response rates for the LBQ have been generally

TABLE 2. TIMELINE FOR HRS PSYCHOSOCIAL SUPPLEMENT DATA COLLECTION AND RESPONSE RATES

	PLANNED						
	2004	2006	2008	2010	2012	2014	2016
Sample	Pilot	A	B	A	B	A	B
Response Rate	68%	74%	71%	N/A	N/A	-	-

A = 50% of the core HRS sample receiving in-person interviews; B = the remaining 50% of the sample. In 2004 measures for the Psychosocial Supplement were piloted with a random subsample of 4000 HRS participants. Reported response rates account for compound non-response from both the HRS core wave and the psychosocial supplement.

HRS, Health and Retirement Study.

high (approximately 90% across available waves), non-response error is higher than that of the core survey because some HRS participants did not return the supplemental questionnaire. Survey weights, however, are included in the cross-tracker file so users can adjust for the compound error.

Because LBQ items are subjective in nature, it would be inappropriate to use proxy-report for such information. Thus, data are unavailable for institutionalized participants or those who died prior to survey administration. In this regard, concerns about loss to follow up may limit generalizability to individuals nearing the end of life. Furthermore, due to a few minor changes in items/wording, there are notable variable inconsistencies between LBQ waves. Researchers who are interested in conducting longitudinal analyses using psychosocial variables should consult the variable concordance (<http://hrsonline.isr.umich.edu/concord>) before performing any cross-wave analyses.

Available and Future Data Linkages

In addition to the rich, primary data collected by the HRS investigative team, several complementary datasets are available for current linkages. These include Social Security earnings and benefits, Medicare records, National Death Index, and Veterans Affairs records. Note that restrictions apply to which additional datasets can be linked together simultaneously. Employers' data from pension plans and the Census Business Register are also available. In the future, HRS plans to offer linkages to additional files from the Centers for Medicare and Medicaid (CMS), including the Medicaid Analytic eXtract file (previously called the State Medicaid Research Files), the Minimum Data Set (MDS), and the Home Health Outcome and Assessment Information Set (OASIS) (used by Medicare-certified skilled home health agencies). The timeline for release of these data linkages are not yet available.

Finally, regional variation in diagnostic and treatment patterns is an active area of research, both within the field of palliative care and beyond.^{37,38} In order to study or adjust for regional characteristics or practice variations, investigators using HRS may consider linkages to other data sources via subjects' geographic information. For example, past studies have linked to the US Census, Dartmouth Atlas of Health Care, American Hospital Association, Centers for Disease Control, RAND Center for Population Health and Health Disparities and others.^{27,39-43}

Conclusion

The field of geriatric palliative care is rapidly growing and clinical and policy changes are in many cases outpacing the evidence base. Recognizing this critical gap, the NIA and NPCRC have collaborated to identify the top priorities for research in the field. Both funding bodies have also released requests for applications that target these high priority areas. As described above, the HRS offers a wealth of secondary data well suited for the pursuit of some of these key topics. However, due to the key limitations of the HRS described, investigators must exercise informed caution in their analyses and interpretation of their results. In sum, through thoughtful and rigorously designed studies, the HRS can serve as a valuable tool to rapidly advance the evidence base for geriatric palliative care and thereby meet the needs of a growing population of older adults with serious illness.

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