

Draft Comparative Effectiveness Review

Number XX

Long-Term Care for Older Adults: A Review of Home and Community Based Services versus Institutional Care

Prepared for:

Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
540 Gaither Road
Rockville, MD 20850
<http://www.ahrq.gov>

Contract No.

Prepared by:

Investigators:

AHRQ Publication No. xx-EHCxxx

Date

Statement of Funding and Purpose

This report is based on research conducted by an Evidence-based Practice Center (EPC) under contract to the Agency for Healthcare Research and Quality (AHRQ), Rockville, MD (Contract No. xxx-xxxx-xxxxx). The findings and conclusions in this document are those of the author(s), who are responsible for its content, and do not necessarily represent the views of AHRQ. Therefore, no statement in this report should be construed as an official position of AHRQ or of the U.S. Department of Health and Human Services.

The information in this report is intended to help health care decisionmakers—patients and clinicians, health system leaders and policymakers, among others—make well-informed decisions and thereby improve the quality of health care services. This report is not intended to be a substitute for the application of clinical judgment. Anyone who makes decisions concerning the provision of clinical care should consider this report in the same way as any medical reference and in conjunction with all other pertinent information, i.e., in the context of available resources and circumstances presented by individual patients.

This report may be used, in whole or in part, as the basis for the development of clinical practice guidelines and other quality enhancement tools, or as a basis for reimbursement and coverage policies. AHRQ or U.S. Department of Health and Human Services endorsement of such derivative products or actions may not be stated or implied.

Public Domain Notice

This document is in the public domain and may be used and reprinted without special permission. Citation of the source is appreciated.

Disclaimer Regarding 508-Compliance

Persons using assistive technology may not be able to fully access information in this report. For assistance contact info@ahrq.gov.

Financial Disclosure Statement

None of the investigators has any affiliations or financial involvement that conflicts with the material presented in this report.

Preface

The Agency for Healthcare Research and Quality (AHRQ) conducts the Effective Health Care Program as part of its mission to organize knowledge and make it available to inform decisions about health care. As part of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, Congress directed AHRQ to conduct and support research on the comparative outcomes, clinical effectiveness, and appropriateness of pharmaceuticals, devices, and health care services to meet the needs of Medicare, Medicaid, and the Children's Health Insurance Program (CHIP).

AHRQ has an established network of Evidence-based Practice Centers (EPCs) that produce Evidence Reports/Technology Assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care. The EPCs now lend their expertise to the Effective Health Care Program by conducting comparative effectiveness reviews (CERs) of medications, devices, and other relevant interventions, including strategies for how these items and services can best be organized, managed, and delivered.

Systematic reviews are the building blocks underlying evidence-based practice; they focus attention on the strength and limits of evidence from research studies about the effectiveness and safety of a clinical intervention. In the context of developing recommendations for practice, systematic reviews are useful because they define the strengths and limits of the evidence, clarifying whether assertions about the value of the intervention are based on strong evidence from clinical studies. For more information about systematic reviews, see <http://www.effectivehealthcare.ahrq.gov/reference/purpose.cfm>

AHRQ expects that CERs will be helpful to health plans, providers, purchasers, government programs, and the health care system as a whole. In addition, AHRQ is committed to presenting information in different formats so that consumers who make decisions about their own and their family's health can benefit from the evidence.

Transparency and stakeholder input from are essential to the Effective Health Care Program. Please visit the Web site (<http://www.effectivehealthcare.ahrq.gov>) to see draft research questions and reports or to join an e-mail list to learn about new program products and opportunities for input. Comparative Effectiveness Reviews will be updated regularly.

We welcome comments on this CER. They may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by e-mail to epc@ahrq.hhs.gov.

Carolyn M. Clancy, M.D.
Director
Agency for Healthcare Research and Quality

Jean Slutsky, P.A., M.S.P.H.
Director, Center for Outcomes and Evidence
Agency for Healthcare Research and Quality

Stephanie Chang, M.D., M.P.H.
Director
Evidence-based Practice Program
Center for Outcomes and Evidence
Agency for Healthcare Research and Quality

Suchitra Iyer, Ph.D.
Task Order Officer
Center for Outcomes and Evidence
Agency for Healthcare Research and Quality

Acknowledgments

Key Informants

Technical Expert Panel

Long-Term Care for Older Adults: A Review of Home and Community-based Services Versus Institutional Care

Structured Abstract

Objectives. To compare long-term care (LTC) for older adults delivered through home and community-based services (HCBS) with care provided in institutional settings such as nursing homes (NHs) by evaluating (1) characteristics of older adults served in HCBS and NHs, (2) the impact of HCBS or NH care on outcome trajectories of older adults, and (3) costs of HCBS and NH care per person and in the aggregate, as well as indirect costs such as resource utilization, family burden, and overall social costs.

Data Sources. Bibliographic databases MEDLINE[®] and AGELINE[®]; grey literature in the form of program evaluation reports and reports and analyses from Web sites of relevant state and federal agencies and research organizations; citation searches of articles; and hand searches.

Review Methods. Randomized controlled trials (RCTs) and observational studies that directly compare LTC for older adults (age ≥ 60) served in HCBS and NHs were included. Studies were limited by date (1995-August 2011), language (English), and geographical location (United States and countries with comparable health systems). We treated assisted living (AL) as a separate category because it contains elements of both NH and HCBS. We compared the characteristics of LTC recipients and the impact of setting on outcome trajectories for physical function, cognition, mental health/affect, use of acute care services, costs, and harms. We quantitatively synthesized results. We assessed the risk of bias and applicability of individual studies, and graded the overall strength of evidence for each examined outcome domain.

Results. We identified 46 studies (38 peer reviewed, eight grey literature). No RCTs were identified. Of the 38 peer-reviewed articles, 22 evaluated recipient characteristics at a specific time point; and 16 analyzed outcome trajectories over time. Populations in NHs were consistently more impaired than those in AL or using HCBS. When data on both HCBS and AL facilities were available in the same study, HCBS clients were more impaired. A limited set of studies (with a high risk of bias) that compared trajectories of HCBS recipients and NH residents showed no differences in the rate of decline in physical or cognitive function or mental health outcomes. LTC costs measured as Medicaid expenditures were lower for HCBS, whereas medical care costs were higher. Strength of evidence for the outcomes examined was low.

Conclusions. Despite issues around comparable measures, studies reviewed showed that the NH population is more impaired than the HCBS population. Medicaid costs were higher for NH than for HCBS. More and better research is needed to draw firm conclusions on the influence of NH or HCBS settings in moderating the rate of decline of older adults with functional limitations. Cost comparisons should examine costs from a broad societal perspective and should include costs borne by families and by other public programs such as Medicare.

Contents

Executive Summary	ES-1
Introduction.....	1
Definition	1
Background	2
Comparing HNs and HCBS	3
Reason for the Review	3
Scope and Key Key Questions.....	4
Scope of the Review	4
Key Questions	5
Methods.....	7
Topic Refinement and Review Protocol.....	7
Literature Search Strategy.....	7
Inclusion and Exclusion Criteria.....	8
Study Selection	8
Data Extraction	9
Risk of Bias of Individual Studies	9
Data Synthesis.....	9
Strength of the Body of Evidence	10
Applicability.....	10
Results.....	11
Introduction.....	11
Results of Literature Searches.....	11
Description of Included Studies	13
Key Question 1. Benefits and Harms of HCBS Compared to NHs for Older Adults Needing LTC.....	13
Key Question 2. Costs of HCBS and NH	15
Discussion	47
Research Gaps.....	49
References	55
Abbreviations	59

Tables

Table 1. Perspectives and Organizations Represented by Key Informants	7
Table 2. Inclusion Criteria	8
Table 3. Criteria for Assessing Applicability	10
Table 4. Description of Participant Characteristics—Physical Function (Cross-sectional and Longitudinal Studies) – Domestic	16
Table 5. Description of Participant Characteristics—Physical Function (Cross-sectional and Longitudinal Studies) – International.....	18
Table 6. Description of Participant Characteristics—Physical Function (Grey Literature Studies) – Domestic.....	19
Table 7. Description of Participant Characteristics—Cognitive Function (Cross-sectional and Longitudinal Studies) – Domestic	20

Table 8. Description of Participant Characteristics—Cognitive Function (Cross-sectional and Longitudinal Studies – International	22
Table 9. Description of Participant Characteristics—Cognitive Function (Grey Literature Studies) – Domestic.....	23
Table 10. Description of Participant Characteristics—Mental Health/Affect (Cross-sectional and Longitudinal Studies) – Domestic	24
Table 11. Description of Participant Characteristics—Mental Health/Affect (Cross-sectional and Longitudinal Studies) – International.....	25
Table 12. Description of Participant Characteristics—Mental Health/Affect (Grey Literature Studies – Domestic	26
Table 13. Description of Participant Characteristics—Conditions/Comorbidities (Cross-sectional and Longitudinal Studies – Domestic	27
Table 14. Description of Participant Characteristics—Conditions/Comorbidities (Cross-sectional and Longitudinal Studies) – International.....	29
Table 15. Description of Participant Characteristics—Conditions/Comorbidities (Grey Literature Studies) – Domestic	30
Table 16. Analysis and Outcome Domains (Longitudinal Studies) – Domestic	31
Table 17. Analysis and Outcome Domains (Longitudinal Studies) – International.....	34
Table 18. Analysis and Outcome Domains (Grey Literature Studies) – Domestic	35
Table 19. Outcome—Physical Function (Longitudinal Studies) – Domestic	36
Table 20. Outcome—Cognitive Function (Longitudinal Studies) – Domestic	37
Table 21. Outcome—Mental Health/Affect (Longitudinal Studies) – Domestic.....	38
Table 22. Outcome—Mortality (Longitudinal Studies) – Domestic	39
Table 23. Outcome—Mortality (Longitudinal Studies) – International.....	40
Table 24. Outcome—Mortality (Grey Literature Studies) – Domestic	41
Table 25. Outcome—Harms (Longitudinal Studies) – Domestic	42
Table 26. Outcome—Utilization (Longitudinal Studies) – Domestic	43
Table 27. Outcome—Utilization (Grey Literature Studies) – Domestic	44
Table 28. Outcome—Costs (Longitudinal Studies) – Domestic	45
Table 29. Outcome—Costs (Grey Literature Studies) – Domestic	46
Table 30. Summary of conclusions and strength of evidence for outcome domains	47
Table 31. Summary of Research Gaps to Address	50

Figures

Figure 1. Analytical Framework	6
Figure 2. Literature Flow Diagram for Long-term Care for Older Adults	12

Appendixes

Appendix A: Search Strategy
Appendix B: Sources of Grey Literature
Appendix C: Excluded Studies
Appendix D: Evidence Tables
Appendix E: Risk of Bias for Individual Studies
Appendix E: Overall Strength of Evidence Assessment
Appendix F: Outcome – Other (Longitudinal Studies)

Executive Summary

Introduction

Long-term care (LTC) represents the intersection of two distinct realms: (1) assistance with essential, routine tasks of life such as eating, bathing, dressing, and tasks required to maintain independence, such as preparing meals, managing medications, shopping for groceries, and using transportation; and (2) housing and medical care. Although LTC is typically associated with institutional settings such as nursing homes (NHs), much of LTC is provided in the community in a variety of settings collectively referred to as home and community-based services (HCBS).

LTC compensates for loss of function as a result of chronic illness or physical or mental disability, and it includes both hands-on, direct care and general supervisory assistance. LTC is distinct from acute or episodic medical interventions because care must be integrated into an individual's daily life over an extended time period.¹ The type, frequency, and intensity of services vary considerably; some people need assistance for a few hours each week, whereas others need full-time support.

More than 10 million Americans need LTC. Of those, only about 55 percent are age 65 or older.² In order to accommodate programs like PACE (Program of All-Inclusive Care for the Elderly), this report addresses LTC issues for those 60 and older. Among older adults, the risk for needing LTC increases sharply with age.² The need for LTC is often accompanied by other health care requirements, such as treatments for multiple chronic conditions. Currently, these care needs are addressed through a fragmented and uncoordinated financing and service delivery system: acute care is largely the responsibility of Medicare and the federal government, and LTC is dominated by Medicaid and state governments.²

LTC needs are met through a combination of paid assistance and unpaid services provided by family members. More than three-quarters of community-dwelling adults rely exclusively on unpaid assistance from family members.^{2, 3} Paid services are provided through a combination of private and public financing. Medicaid, the public program jointly funded by federal and state governments and administered by the states, is the largest source of public funding, accounting for 44 percent of national LTC spending.^{2, 4}

NH care is an entitlement for all Medicaid beneficiaries who qualify for such care based on disability and income requirements. To qualify for Medicaid-funded services, individuals generally must have monthly incomes equal to or below the eligibility level for the Supplemental Security Income program. Individuals with incomes above this threshold may have to spend down their personal resources to meet income-based requirements.

States have various options for financing HCBS. The Section 1915(c) Medicaid waiver program is most common. Waivers basically allow states to provide services not typically covered under a Medicaid state plan and to offer these services to subsets of Medicaid beneficiaries rather than as a universal benefit. Thus, states are able to provide a broad range of HCBS services under Medicaid to a specific, limited population of eligible individuals. Waiver programs are subject to cost-effectiveness requirements; they should be budget neutral. Unlike NH costs, waiver programs do not cover housing costs.

The majority of Medicaid LTC spending supports institutional care. However, the proportion spent on noninstitutional care has been growing steadily. This trend is driven by consumer preference for community-based LTC and by the Supreme Court *Olmstead* decision stating that LTC services should be provided in the most integrated (least restrictive) setting appropriate to the individual's needs. Because HCBS typically costs less per recipient than NH care, it has been

viewed as a way to restrain LTC costs. The primary argument in support of home care's cost-saving potential is that average per person Medicaid expenditures are significantly lower for HCBS than for NH care; however, whether aggregate costs (i.e., total costs from multiplying the number recipients by the cost per recipient) are lower is not clear.⁵

Though equivalent services may be offered in either setting, the philosophy and emphasis of care differs between NH and HCBS. Each setting may have nuanced strengths and weaknesses that require attention for any overall comparison to be meaningful. Outcomes in LTC are a result of a complex interplay among the characteristics of older adults, the environment, and the actual services delivered.

A successful care modality meets the need for assistance, moderates the rate of decline in function, and improves quality of life. For older adults who need LTC, the choice of one form of care over the other requires a careful evaluation of tradeoffs between competing priorities—for example, between safety and independence. Multiple factors such as access, affordability, availability of informal support, and individual preferences and values play a role in choosing a mode of care. In addition, regulatory framework and reimbursement policies in individual states have a profound impact on the type of services offered and their availability across settings.

Thinking has shifted regarding the role of HCBS. Initially, HCBS was considered an alternative to NH care. Early demonstration projects (from the mid 1970s through the late 1980s) on the effectiveness and costs of expanding LTC to include HCBS generated a large empirical literature as well as literature reviews.⁵ By the mid 1990s, newer models of organizing, financing, and delivering care were implemented. These advances have not been adequately synthesized in the literature.⁵ A synthesis of the latest evidence and an assessment of the state of the literature may help inform the policy debate as well as highlight areas for future research.

Scope and Key Questions

This comparative effectiveness review targets direct comparisons of LTC provided to older adults through HCBS and NHs. There is some concern that case mixes differ too greatly between the modalities to allow for indirect comparisons. We examined studies with both cross-sectional and longitudinal designs. Cross-sectional studies compared outcomes across settings at a specific time point, whereas longitudinal studies compared change in outcomes over a defined time period ranging from 6 months to 5 years. We examined published and grey literature from the United States and countries with comparable health systems.

The definitions of population, intervention, comparator, outcomes, setting, and timing are as follows:

Population

The target population for this review was older adults (age ≥ 60) receiving LTC in NHs or through HCBS. Older adults who need LTC are a heterogeneous group with varying degrees of physical and mental disability and/or chronic illness. They require different levels of assistance with tasks of daily living. Moreover, LTC recipients include those who acquire a disability as a concomitant of aging as well as those with long-standing disability who are now aging within the LTC system. We excluded short-stay NH residents and those receiving exclusively Medicare home-health services.

Intervention

HCBS refers to services provided in an array of noninstitutional settings. These include recipients' homes; community group living arrangements such as congregate housing, adult foster care, residential care facilities (RCFs), and assisted living (AL) facilities (the last two terms may be used interchangeably); and community settings such as adult day care and adult day health. HCBS includes care coordination or case management, personal care assistant service, personal attendant service, homemaker agency and personal care agency services, home hospice, home delivered meals, home reconfiguration or renovation, medication management, skilled nursing, escort service, telephone reassurance service, emergency help lines, equipment rental and exchange, and transportation. HCBS also include educational and supportive group services for consumers or their families, and some aspects of HCBS are construed as respite care meant to bring relief to family caregivers.

Comparator

NH settings are state-licensed institutional facilities offering 24-hour room and board, supervision, and nursing care. The package of NH services may include personal care, support for activities of daily living (ADL), medical management, nursing management, medication management, restorative nursing, palliative care, physical rehabilitation (either as a short-term service associated with post-acute care or as maintenance rehabilitation), social activities, and transportation.

For this review, we examine AL separately, because in many ways, it represents aspects of both institutional and community-based care.

Outcomes

Our key outcomes of interest included resident outcomes and LTC costs, and other costs. We used data from cross-sectional studies to compare resident outcomes across NH and HCBS settings. We used longitudinal data to assess change in outcomes over time across settings. Outcomes across settings involved multiple domains, such as physical function, cognition, social function, pain, mental health outcomes (e.g., depression and anxiety), quality of life, outcomes related to family caregivers, death, place of death, frequency of use of acute care services (e.g., hospitals, emergency departments), and satisfaction.

Setting

This review includes studies from the United States and international studies from countries with comparable health systems: Canada, Australia, Britain, Norway, Sweden, and other European countries.

Timing

The outcomes were assessed at 6 months to many years.

Key Questions

Key Question 1

What are the benefits and harms of long-term care (LTC) provided through Home and Community-based Services (HCBS) compared with institutions such as nursing homes (NHs) for adults age 60 and older who need LTC?

- a. To what extent do HCBS and NHs serve similar populations?
- b. How do the outcomes of the services differ when tested on similar populations?
- c. What are the harms to older adults as a result of HCBS and NHs?

Key Question 2

What are the costs (at the societal and personal levels) of HCBS and NHs (per recipient and in the aggregate) for adults age 60 and older? Costs may include direct costs of care as well as resource utilization and family burden.

The analytical framework (available in the full report) reflects the fact that LTC for older adults provided through HCBS and NHs results in specific outcomes across a range of domains, such as physical function, social function, cognition, pain, death, place of death, mental health outcomes, satisfaction, quality of life, outcomes related to family caregivers, and cost outcomes (including utilization of acute care services). Reported harms include safety, inadequate preventive care, unnecessary hospitalizations, and concerns about abuse or neglect. We anticipated that the outcomes could be moderated by residents' sociodemographic characteristics (age, sex, race), health status (functional, clinical status, morbidities, mental illness, disability), and cognition, as well as by rural/urban location, payer status, and prior service use.

Methods

Topic Refinement and Review Protocol

The topic for this comparative effectiveness review was nominated by a public process available through the Effective Health Care Web site. Investigators developed preliminary key questions with input from stakeholders representing policy, consumer, and research perspectives. The key questions were posted on AHRQ's Web site for public comment for 4 weeks. Public comments and input from the Technical Expert Panel (TEP), convened to provide methodological and content expertise, were used to develop the final key questions and protocol. The methods and analyses were determined *a priori*.

We developed the key questions after a topic refinement process that included a preliminary review of the literature and consultation with a key informant panel of LTC experts and stakeholders. The draft key questions were posted for public comment on the AHRQ Effective Health Care Program Web site from October 10, 2011, to November 3, 2011. Public comments did not result in changes to the key questions. We also received input from the TEP members, who deemed the key questions to be appropriate, and recommended lowering the age limit for inclusion from 65 to 60 years. We revised the age limit and added specific sub-questions (1a and 1b) to address the issue of differences in case mix across settings. The final key questions are below.

Literature Search Strategy

We used several strategies to identify potential relevant studies from the published literature and grey literature sources. We searched the bibliographic databases MEDLINE (via OVID) and AGELINE for randomized controlled trials (RCTs) and observational studies of LTC published from 1995 to August 16, 2011. We supplemented bibliographic database searches with backward and forward citation searches of relevant articles and by hand searching. To assure completeness of the review and in order to identify missing publications, we compiled a list of prominent authors in the field and searched specifically for their work. Finally, we requested that the TEP members review the included set and provide missing literature (if any) from their personal files. We searched grey literature sources including Web sites of relevant federal and state agencies (such as the Centers for Medicare and Medicaid Services and Administration on Aging), research organizations (such as the Lewin Group, Abt Associates, and Mathematica Policy Research), foundations (such as the Robert Wood Johnson Foundation), and advocacy groups for relevant reports.

Eligibility Criteria

The target population was older adults (age ≥ 60) needing LTC. RCTs and quasi-experimental observational study designs were eligible for inclusion. Studies needed to include some comparison of HCBS and NHs. Studies could compare the populations across HCBS and NHs at a particular time point (cross-sectional design) or evaluate changes in outcomes over time (longitudinal design). To capture studies most relevant to the current landscape of LTC in the United States, we limited studies by date (1995-August 16 2011), language (English), and geographical location (United States and countries with comparable health systems (Canada, Australia, Britain, Norway, Sweden, and other European countries)).

Study Selection

Bibliographic database search results were downloaded to an Endnote reference management system. Eligible studies were identified in two stages. In the first stage, two investigators independently reviewed titles and abstracts of all references; studies deemed eligible for inclusion by either investigator were further evaluated. In the second stage, two investigators independently reviewed full text to determine whether studies met inclusion criteria. Differences in full-text screening decisions were resolved by discussion or, when necessary, by consultation with a third investigator. We documented eligibility status and at least one exclusion reason for all studies evaluated at the full-text screening stage. Reasons for exclusion were coded as: non-English language study, pre-1995 study, participants under age 60, not a geographical setting of interest, postacute care population, not a relevant comparison, no relevant settings or sample, and no relevant characteristics or outcomes.

Data Extraction

We abstracted data from included studies directly into evidence tables by one reviewer/investigator and validated by a second reviewer/investigator. Disagreements were resolved by consensus or, when needed, by consultation with a third reviewer. We abstracted data on study design, location (U.S. or International), eligibility criteria, characteristics of study participants, descriptors to assess details of the intervention (setting, services provided), outcomes reported, and length of followup. We abstracted data on characteristics of populations

served from cross-sectional studies and studies that reported case mix. Data elements included descriptors to assess methodological quality and study applicability.

Risk of Bias Assessment of Individual Studies

Methodological risk of bias of longitudinal studies was assessed using criteria specific to study design according to current AHRQ guidance.⁶ Risk of bias of each study was assessed independently by two reviewers and validated by the full team of investigators.

Evaluation of selection bias was a key component of the risk of bias assessment; studies that accounted for differences in case mix across settings using techniques such as multivariate analysis, propensity score matching, or instrumental variables were given a higher rating. In addition to selection bias, we evaluated completeness of intervention specification, use of equivalent outcome measures across experimental and control groups, and attrition as a result of death or transfer to other settings.

Study risk of bias was assessed independently by two reviewers and validated by the full team of investigators. Summary risk of bias was assessed as high, moderate, low, or unclear based on individual components assessed.

Data Synthesis

Heterogeneity in populations, interventions, and settings across studies precluded quantitative synthesis of results. Instead, we analyzed results qualitatively to arrive at conclusions regarding the extent to which HCBS and NHs serve similar populations and to assess the differences in outcomes of the services when tested on similar populations. Throughout the analysis, we considered AL as a separate category within HCBS because it combines elements of institutional and community care. We separately analyzed international studies in order to account for differences in context. Results from grey literature were analyzed separately.

We compared characteristics of populations served by HCBS versus NH settings using data from cross-sectional studies and studies that reported case mix. HCBS/AL and NH populations were compared across the domains of physical function, cognition, mental health/affect, and comorbidities. We used data from longitudinal studies to compare changes in outcome trajectories over time across HCBS and NHs for a range of outcome domains such as physical function, cognitive function, mental health/affect, utilization of acute care services, costs, and harms.

Strength of the Body of Evidence

We evaluated the overall strength of evidence using methods developed by the AHRQ Evidence-based Practice Center Program⁷ for the following outcomes: physical function, cognitive function, mental health/affect, mortality, costs, utilization, and harms. We evaluated strength of the evidence on four required domains:

1. Risk of bias (do the studies for a given outcome or comparison have good internal validity). The risk of bias, based on study design and conduct, is rated low, medium, or high.
2. Consistency (the degree of similarity in the effect sizes and same direction of effect of the included studies). Consistency is rated consistent, inconsistent, or unknown/not applicable (e.g., a single study was evaluated).
3. Directness (reflecting a single, direct link between the intervention of interest and the outcome). Directness can either be direct or indirect.

4. Precision (degree of certainty surrounding an effect estimate of a given outcome). Precision is either precise or imprecise. A precise estimate is one that would yield a clinically meaningful conclusion.

We rated the individual domains qualitatively and assigned an overall strength of evidence summary rating of high, moderate, or low strength of evidence for domains in KQ 1. We graded an outcome as insufficient when evidence was either unavailable or did not permit a conclusion. Given the absence of RCTs, we graded no outcome as having high strength of evidence.

Applicability

We assessed applicability separately from strength of evidence⁶ based on the following criteria: eligibility requirements for enrollment; case mix; type, frequency, and intensity of services delivered; outcomes measured; and setting (country/geographical region; rural/urban).

Results

Results are presented by key question. Detailed evidence tables are available in the full report.

Results of Literature Searches

Our search of bibliographic databases yielded 2,043 unique references. Review of titles/abstracts of these references identified 73 articles as potentially relevant to the comparisons. Full-text screening resulted in a final list of 37 eligible articles. Hand searching produced an additional nine articles, eight of which were grey literature reports, resulting in a final tally of 46 articles addressing 36 unique studies.

Our list of eligible articles included no RCTs. Of the 46 observational studies identified, 38 were peer-reviewed journal articles, and eight were from grey literature reports. The peer-reviewed journal articles included 22 cross-sectional studies and 16 longitudinal studies. Eight international studies were included in the review.

Key Question 1: Benefits and Harms of HCBS Compared to NHs for Older Adults Needing LTC

Key Question 1a: Characteristics of Populations in HCBS and NH

NH populations were consistently more impaired than their counterparts in AL or HCBS when compared on a range of measures including physical function, cognition, depression, clinical status, and number of comorbidities. Parallel data from grey literature studies reflected the same pattern. When data on HCBS and AL were available in the same study, HCBS populations were more impaired.

Key Question 1b: Change in Outcome Trajectories Over Time for HCBS and NH Residents

The small set of studies comparing the trajectories of HCBS recipients and NH residents over time generally had high risk of bias. They showed that setting has a limited influence in slowing the rate of decline for the outcome domains examined. Sparse literature and design problems

(selection bias and attrition due to death) resulted in low strength of evidence for all outcomes measured.

Key Question 1c: Harms in HCBS and NHs

The strength of evidence from two studies was low that the overall rate of harms, inappropriate medication use, and pain and shortness of breath were higher for HCBS clients than for NH residents.

Key Question 2: Costs of HCBS and NH

HCBS tended to be less expensive than NH care; medical care costs were higher, but LTC costs were lower. In most cases, the total costs (typically expressed as total Medicaid expenditures) were higher for NH than for either HCBS or AL.

Few studies looked at combined Medicare and Medicaid costs. A single study that analyzed Medicare payments found that HCBS clients had higher total Medicare payments per member per month than NH residents. When these payments were broken down into components, HCBS clients had higher Medicare hospital, home health, hospice, and physician payments per member per month; NH residents had higher skilled nursing facility and outpatient payments per member per month.

No studies examined the costs related to family burden.

Key Findings and Strength of Evidence

The literature base for head-to-head comparisons between HCBS and NHs is limited. A considerable body of literature separately addresses HCBS and NH populations, but few studies directly compare the two. Based on our review of this literature, we find that:

- Despite some issues regarding comparable measures, those served in NHs are more impaired (including physical and cognitive function, mental health, and clinical conditions) than those served by HCBS, but the distributions overlap.
- The very small set of studies of generally high risk of bias that compare the trajectories of HCBS recipients and NH residents found no differences in the rate of decline for the outcomes examined.
- Total costs expressed in terms of Medicaid expenditures were higher for NH than for HCBS recipients, but medical care costs were higher for HCBS.

Sparse literature and design problems resulted in a low or insufficient strength of evidence for the outcomes examined. We found very few studies from which to draw conclusions for any given outcome of interest. Most studies did not provide detailed descriptions of settings and services received. Studies often failed to specify the type, frequency, and intensity of services. Additionally, most studies did not report whether participants received any informal care, how this may have affected the type, frequency, or intensity of formal care services, or how it may have interacted with other care provided.

Discussion

Several factors must be considered in interpreting this body of evidence. RCTs are difficult to apply in this context, thus the studies reviewed were quasi-experiments. Most studies did not adequately address the problems of selection bias or attrition. Settings where individuals are located may be largely a function of payment systems and policy environments, and not necessarily indicative of individual choice or fit.

Issues of selection and case mix complicated attempts to make indirect comparisons of the effects on trajectories. Often, followup times were short for tracing these clinical trajectories. Few studies used an admission cohort, which made it difficult to distinguish between long-standing and new users of LTC.

Outcomes may differ between clients who are new to the LTC system and those who have lived with limitations or received services for a long time, but few studies distinguish between the two. The variation in outcome measures and data collection methods across studies also made it difficult to compare results. Outcomes may be sensitive to the measurement used. Assessments of NH residents tend to rely on a standardized approach to data collection called the Minimum Data Set, which is used in all Medicare and Medicaid-certified nursing homes. The NH Minimum Data Set has been replicated in a home care version, but other measures of presumably similar domains are also used; this difference presents a particular problem for measuring cognition. In most instances, different people collected the data in each setting. Much of the data were collected by individuals working in each location.

Although policy debates about the relative merits of HCBS and NHs have typically assumed that these are consistent entities serving homogeneous populations, the underlying empirical evidence requires more detailed examination. Specifically, comparisons between these modes of care are complicated by the fact that HCBS clients and services can vary widely, and complete descriptions of either are rarely presented in the analyses. AL likewise varies widely in terms of its clientele and its services. Any analysis of the effectiveness of these modalities needs to describe both the clientele and the services in enough detail to provide the necessary context and to make it possible to judge applicability.

Given the variation in clientele and the low likelihood of random assignment to HCBS versus NH, selection bias will continue to be a major concern, as with the studies reviewed here. Typical efforts to adjust for this bias, such as propensity scores, may be impeded by the large degree of heterogeneity, which makes predictive equations less accurate. Multivariate analyses will encounter similar problems. Strong candidates for instrumental variables will be hard to identify. One possible alternative may be to use “ideal types” as subgroups. This approach identifies groups who have characteristics that lead to better outcomes. It has been used in addressing diabetes care and could be applied here.⁸

Given the weak literature assessing the relative effectiveness of HCBS and NHs, policy decisions will likely continue to be made on the basis of individuals’ and policymakers’ preferences and beliefs. The paradigm for comparing HCBS and NHs has shifted over time. Whereas HCBS was earlier seen as a potentially less expensive alternative to NHs, it is now increasingly viewed as a preferable care modality that enhances clients’ quality of life. NH environments and living settings are frequently very restrictive, and few would now be surprised that quality of life was higher for those in HCBS.

Table A provides a summary of the conclusions and strength of evidence for the key questions addressed in this review.

Table A. Summary of conclusions and strength of evidence for outcome domains

Domain/outcome	Conclusions/strength of evidence
Key Question 1b	
Changes in physical function	The rate of change in physical function did not differ between HCBS and NH recipients over time. Low strength of evidence due to small number of studies and high risk of bias.
Changes in cognitive function	The rate of change in cognitive function did not differ between HCBS and NH recipients over time. Low strength of evidence due to small number of studies and high risk of bias.
Changes in mental health/affect	The rate of change in mental health/affect did not differ between HCBS and NH recipients over time. Low strength of evidence due to small number of studies and high risk of bias.
Mortality	Mixed evidence on mortality between HCBS and NH users, with studies finding no significant differences between HCBS and NH and higher mortality among NH. Low strength of evidence due to small number of studies and high risk of bias.
Utilization	Mixed evidence on utilization of acute care. HCBS users had higher hospital care use compared to NH in some studies but no significant difference in others. Low strength of evidence due to small number of studies and high risk of bias.
Key Question 1c	
Harms	Harms were higher among HCBS users than among NH residents. Low strength of evidence due to small number of studies and high risk of bias.
Key Question 2	
Costs	NH residents had higher LTC costs. HCBS users had higher medical care costs. Total costs (measured as total Medicaid costs) were higher for NH residents. No studies addressed costs related to family burden. Low strength of evidence due to small number of studies and high risk of bias.

Applicability

Applicability is limited; many of the samples are not generalizable (often small, limited by geography, or specific programs that do not apply to populations outside the study). Most of the studies were conducted on samples of Medicaid patients.

Research Gaps

The weakness of the literature stands in sharp contrast to the importance of the topic. Many stakeholders desperately want to know about the relative effectiveness of alternative modes of LTC. As budgets tighten, and as demographically driven demand increases, states and other entities are seeking more efficient ways to deliver LTC.

Better research is needed to address the questions related to the changes in outcome trajectories over time, harms, and costs for LTC delivered through HCBS versus NH. Many of the studies we reviewed relied on administrative data sets, sometimes linked to Minimum Data Set data provided by caregivers. Designs for future research should use prospective cohort studies. Care should also be taken to use independent data collectors (not part of the service provision) and identical psychometrically sound instruments.

Randomization to HCBS or NH can ensure that NH and HCBS populations are comparable on measured as well as unmeasured factors. However, practical and ethical issues make the use of randomized designs highly unlikely. In the absence of RCTs, well-designed prospective studies with careful attention to selection bias could yield useful information.

Future research needs are extensive, and they reflect both methodological issues as well as more fundamental questions such as the tradeoffs residents face in choosing one setting over

another. Table B summarizes the research gaps. Addressing these questions will enable better analyses and help consumers and policymakers make informed, evidence-based choices. Areas of future research, organized by key question, are provided in the main body of the report.

Table B. Summary of research gaps to address

Methodological Issue	Findings	Research Needs
Composition of persons served	NH residents were generally more disabled than HCBS clients Measures were not always comparable Method of ascertainment varies	More systematic data collection using standardized measures
Outcomes measures	Outcome measures were not always similar across settings and weighted heavily to MDS measures	Use standardized measures. Choose those most capable of showing meaningful change and measure at appropriate intervals.
Declines in function and cognition	Similar rates of decline for HCBS/AL recipients and NH residents Possible ceiling and/or floor effects	Better analyses to examine floor and ceiling effects Better adjustment for case mix differences
Selection bias	Efforts to account for case mix differences were often weak	More/better efforts to adjust for selection bias Propensity scores Instrumental variables Ideal types ⁸ Multivariate analysis Include social support and attitudes
Attrition bias	Attrition bias was often ignored	Methods to deal with attrition, especially death Use death as worst functional case Use two stage models
Utilization of acute care	NH residents generally had lower utilization of hospital care	More efforts to adjust for selection bias Better adjustment for case mix
Quality of life		Use standardized measures of QOL and social functioning applicable to both settings
Costs	Costs per person are generally lower for HCBS but results on aggregate Medicaid spending are inconclusive Medicare costs generally overlooked No consideration of family burden	Cost comparisons should account for all relevant costs on either side of the HCBS/ NH ledger. i.e., cost of room and board, costs of public subsidies (rent, transportation and food stamps), costs of informal care provided by family members and impact on other public programs such as Medicare.
Define interventions	Descriptions of interventions were vague	Need to carefully describe the nature and extent of the intervention
Dealing with change in status		How do you account for persons moving from one type of care to another?
Topical Issues	Findings	Research Needs
Longitudinal studies	The numbers of longitudinal studies were limited	More studies that trace change in status over time
Applicability/Generalizable populations	Samples were often drawn from unique settings	More generalizable samples
Differences within subgroups		More attention to samples that capture various subgroups by major problem (e.g., diagnosis, functional level) or SES Dementia maybe a special problem
Defining and weighting outcomes	Most studies looked at discrete outcomes	Determining what kind of care is best requires weighting the multiple possible outcomes. Outcomes are multidimensional. Some form of utility weighting exercise with relevant respondents is needed
Private market	Most studies focused on Medicaid	Need studies on private pay clients

Conclusions

Despite issues regarding comparable measures, studies reviewed show that the NH population is more impaired than the HCBS population. LTC costs expressed in Medicaid expenditures are lower for HCBS, but medical care costs are higher. The question of how LTC delivered in NHs or through HCBS affects outcome trajectories of older adults is difficult to resolve based on limited evidence and the methodological limitations of studies reviewed. More and better research is needed to draw firm conclusions about how setting influences the rate of decline of older adults with functional limitations.

References

1. Kane RA, Kane RL, Ladd RC. *The Heart of Long-Term Care*. London: Oxford University Press; 1998.
2. Kaye HS, Harrington C, LaPlante MP. Long-term care: who gets it, who provides it, who pays, and how much? *Health Affairs*. 2010;29(1):11-21.
3. Feinberg L, Reinhard S, Houser A. *Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving*. Washington, DC: Institute APP; 2011.
4. Kaiser Commission on Medicaid and the Uninsured. *Medicaid Home and Community-Based Service Programs: Data Update*. 2009. http://www.kff.org/medicaid/upload/2186_06.pdf.
5. Grabowski DC. The cost-effectiveness of noninstitutional long-term care services: review and synthesis of the most recent evidence. *Med Care Res Rev*. 2006;63(1):3-28.
6. Agency for Healthcare Research and Quality. *Assessing the Quality and Applicability of Included Studies*. In: Agency for Healthcare Research and Quality, ed *Methods Reference Guide for Effectiveness and Comparative Effectiveness Reviews*. Rockville, MD: Agency for Healthcare Research and Quality; 2007.
7. Owens DK, Lohr KN, Atkins D, et al. AHRQ series paper 5: grading the strength of a body of evidence when comparing medical interventions - agency for healthcare research and quality and the effective health-care program. *Journal of Clinical Epidemiology*. 2010 May;63(5):513-23. PMID 19595577.
8. Johnson PE, Veazie PJ, Kochevar L, et al. Understanding variation in chronic disease outcomes. *Health Care Manag Sci*. 2002 Aug;5(3):175-89. PMID 12363045.

Introduction

Definition

Long-term care (LTC) refers to a broad range of services designed to provide assistance over prolonged periods to compensate for loss of function due to chronic illness or physical or mental disability.¹ LTC represents the intersection of personal services, housing, and medical care (especially chronic disease management). LTC varies in frequency and intensity according to the needs of the recipients, and it includes both hands-on, direct care as well as general supervisory assistance. LTC includes support for activities of daily living (ADLs), instrumental activities of daily living (IADLs), and routine nursing services such as administration of medications.² LTC may affect older people's quality of life. Its impact also extends to family members, who are often the primary source of support for older adults with functional limitations.²

For this report, we compare LTC for older adults delivered through home and community-based services to care delivered in nursing homes.

Home and community-based services (HCBS) refers to services provided in an array of noninstitutional settings. Settings include recipients' homes; community group living arrangements such as congregate housing, adult foster care, residential care facilities (RCFs), and assisted living (AL) facilities (the last two terms may be used interchangeably); and community settings such as adult day care and adult day health.

Nursing home (NH) settings are state-licensed institutional facilities offering 24-hour room and board, supervision, and nursing care. The package of NH services may include personal care, ADL support, medical management, nursing management, medication management, restorative nursing, palliative care, physical rehabilitation (either as a short-term service associated with post-acute care or as maintenance rehabilitation), social activities, and transportation.

AL—which appeared as a care modality in the 1980s and is now offered and licensed under a variety of names—presents a taxonomic problem. AL varies in the degree of privacy and space of living arrangements offered and in the extent and range of services provided; the variation stems both from state licensure policies that either require or prohibit specified services or living characteristics and from the business models of the providers.³ For this review, we categorized care provided in AL facilities as a subset of HCBS; however, we also examined AL separately, because in many ways, it represents a midway position between NH care and care in a recipient's own home.⁴

The services provided through HCBS resemble those provided in NHs, but they may need to be pieced together from multiple agencies and independent providers, with or without overall coordination or management. HCBS includes care coordination or case management, personal care assistant service, personal attendant service, homemaker agency and personal care agency services, home hospice, home-delivered meals, home reconfiguration or renovation, medication management, skilled nursing, escort service, telephone reassurance service, emergency help lines, equipment rental and exchange, and transportation. HCBS also includes educational and supportive group services for consumers or their families, and some services provided through HCBS are construed as respite care meant to bring relief to family caregivers. Formal rehabilitation may also be provided at home, usually as a short-term postacute service associated with Medicare.

Background

Currently, more than 10 million community residents and 1.8 million nursing home residents rely on LTC to assist them with life's daily activities.⁵ The majority of these individuals (55 percent) are more than 65 years of age.⁵ About two-thirds of Americans age 65 and older will eventually need some type of LTC, for an average of 2 years.^{6, 7}

Approximately 5 percent of older adults live in nursing homes,⁸ accounting for 1.5 million residents served by 16,000 U.S. nursing homes as of 2009.⁹ Because Medicaid pays over 40 percent of LTC costs, and because per-individual costs for HCBS are generally lower than for NH care, emphasis on HCBS has grown. In 2006, about 2.9 million individuals received HCBS through Medicaid; 54 percent were over age 65.¹⁰

Notably, HCBS Medicaid dollars for all forms of community residential care are for the service component only, not for room and board costs, which consumers are expected to cover through their own income. NH care also requires most of the income of residents who are financed all or in part by Medicaid, but the NH payment includes room and board, leaving the resident with only the state-permitted small personal needs allowance.

About 43 percent of Medicaid LTC dollars are dedicated to HCBS programs. Medicaid spending is rising faster for HCBS than for NH. Specifically, the national percentage of Medicaid spending on HCBS more than doubled from 1995 to 2007, from 19 percent to 41 percent.¹⁰ The use and economic consequences of LTC services are expected to increase in the next few decades as the population ages.

Of the various options that states have for delivering HCBS, the Section 1915(c) Medicaid waiver program is most common. Waivers basically allow states to provide services not typically covered under a Medicaid state plan and to offer these services to subsets of Medicaid beneficiaries rather than as a universal benefit. Thus, individuals who meet certain eligibility criteria (e.g., disability and income requirements) are able to receive HCBS under Medicaid in lieu of NH services. Subject to cost-effectiveness requirements, waivers are approved for 3 years, with potential for renewal every 3 or 5 years.¹¹ With states as the major decisionmakers for LTC policies and care, HCBS has been increasingly prioritized to restrain LTC costs. Other reasons for increased focus on HCBS include consumer preferences for more LTC in the community, and the Supreme Court Olmstead decision stating that LTC services should be provided in the most integrated setting appropriate to the needs of qualified individuals with disabilities.

Thinking has shifted regarding the role of HCBS. Initially, HCBS was considered an alternative to NH care. Early demonstration projects (from the mid-1970s through late 1980s) on the effectiveness and costs of expanding LTC to include HCBS generated some empirical literature as well as literature reviews. By the mid 1990s, newer models of organizing, financing, and delivering care were implemented. Medicaid-funded HCBS expanded substantially through waivers that allowed states to implement such care on a limited basis with funds that would have traditionally gone to NH care. Many studies, including the National Long-Term Care Channeling Demonstration, found that HCBS did not reduce overall LTC spending.^{12, 13} Some studies found that HCBS actually increased expenditures.¹⁴ Other studies found that states with well-established noninstitutional programs experienced a decrease in spending compared with states with minimal noninstitutional services, after the initial increase required to start a new HCBS program.¹⁵ Assessing the cost and effectiveness of HCBS has been difficult, because findings across states have been inconsistent.¹¹ Also, many studies have compared dissimilar populations, or failed to use a control group.¹¹ A synthesis of the latest evidence and an assessment of the state of the literature may help inform the policy debate as well as highlight areas for future research.

Some programs loom in the background of this analysis. PACE (Program for All-Inclusive Care of the Elderly) is a program designed to use capitated payment to better integrate services for older persons who are eligible for both Medicare and Medicaid and for NH care. It attempts, whenever possible, to substitute HCBS for NH care. Various types of residential housing for older people have begun to offer ascending levels of support in order to allow residents to remain in these housing settings as their care needs increase.

Comparing NHs and HCBS

Apples-to-apples comparisons and meaningful evaluations of outcomes between HCBS and NHs are challenging. Heterogeneity is significant among LTC recipients, both within and across settings. The type, frequency, and intensity of services delivered also vary. Any comparisons of NH care and HCBS will require an understanding of the actual comparisons that investigators made—i.e., the characteristics of those served, the service mix, and the methods used to assess NH and HCBS populations.

A key measure of LTC effectiveness is the extent to which NHs and HCBS moderate the rate of functional decline or other well-being measures. Multiple measures across a range of domains (physical function, cognition, mental health/affect, and quality of life) are used to assess outcome trajectories of NH and HCBS residents over time.

Assessments of NHs residents tend to rely on a standardized approach to data collection called the Minimum Data Set (MDS). Since 1999, the MDS has been in use in all Medicare- and Medicaid-certified nursing homes see <https://www.cms.gov/site-search/search-results.html?q=minimum%20data%20set>). The MDS relies exclusively on data derived from staff observations and interpretations of behavior over a period of time. As a tool designed to assess function in an institutional setting, the MDS emphasizes elements and domains relevant to the institutional experience. Full re-assessments are performed annually; specific parameters are re-assessed quarterly or if significant change has occurred.

The MDS plays a crucial role for Medicare and Medicaid reimbursement. The NH MDS has been replicated in a home care version (interRAI HC or MDS-HC), but it relies on a different set of observers, namely those providing home care, and the items are not completely consistent with items from the NH MDS (see <http://www.interrai.org/section/view/?fnode=15>).¹⁶ Unlike the MDS, which is widely used in NHs, the home version of this tool has not been widely adopted for individuals receiving HCBS.

Moreover, the majority of assessment protocols used to define eligibility and establish plans for LTC services delivered through Medicaid and Medicaid waivers are based on direct assessments of clientele by case managers; they are not aligned with the MDS. To effectively compare and interpret outcome trajectories of NH and HCBS residents over time, careful attention must be given to the domains addressed by each tool, the measures of disability they use, their methods of ascertainment, and the appropriateness of their followup periods.

Comparisons of costs between the two settings must account for both individual and aggregate costs. From a societal perspective, costs include those borne by individuals and their families as well as by Medicaid and other public programs. People receiving HCBS continue to be eligible for a variety of transfer programs not available to NH residents, including food stamps and housing subsidies. Also, from a societal perspective, relevant costs in addition to direct costs of LTC include those for acute care services such as physician care and hospital care under Medicaid, and medications; therefore, it may be appropriate to look at total Medicaid costs. Moreover, for older people, most acute care costs are borne under the Medicare program,

although for those financially eligible, Medicaid pays premiums, deductibles, and co-pays. Finally, the out-of-pocket and opportunity costs to families providing LTC assistance are relevant. Family care occurs for both NH and HCBS clientele; in both cases, the time commitment is challenging to measure and itemize, because of the difficulty of discerning the burden of additional care from ordinary family activity.

Reason for the Review

This review is timely, as policymakers try to determine the effectiveness and costs associated with different types of LTC. Current financial retrenchment and budgetary pressures intensify the need to identify effective means of delivering LTC services while minimizing costs. For the growing number of older adults who need LTC, identifying the setting or program that comports with their preferences while best serving their needs is a critical priority. This work complements an ongoing review on outcomes for cognitively impaired AL residents, conducted by the RTI-UNC Evidence-based Practice Center.

Scope and Key Questions

Scope of the Review

This comparative effectiveness review targets direct comparisons of LTC provided through HCBS and in NHs. Case mixes between the two modalities differ too greatly to allow for indirect comparisons. The population for this study included older adults (age ≥ 60) receiving LTC either through HCBS or in NHs, with adjustment for the age ceiling for the Program of All-Inclusive Care for the Elderly (PACE), where eligibility begins at 55. Patient characteristics that may modify outcomes include age, race, sex, functional status, clinical status, cognition, rural/urban, morbidities, mental illness, payer, prior service use, and disability history. Excluded services were Medicare home health services.

Our key outcomes of interest included differences in LTC costs, and consumer outcomes between HCBS and NHs. For the outcome of LTC costs, we included costs related to housing, services provided, health care utilization (including acute care services such as emergency rooms and hospitals), and expenses borne by individuals and their families. We examined costs separately from effectiveness; we did not evaluate cost effectiveness. For resident outcomes, we used measures of function, including both ADLs and IADLs. ADLs include eating, bathing, dressing, getting into and out of bed or a chair, and using the toilet. IADLs are additional tasks necessary to maintain independence, such as preparing meals, laundry, housekeeping, managing medication, grocery shopping, and using transportation. We also examined additional resident outcomes such as cognition, social function, pain, mental health outcomes (e.g., depression and anxiety), quality of life, outcomes related to family caregivers, death, place of death, frequency of utilization of acute care services (e.g., hospitals, emergency departments), and satisfaction. We examined studies with both cross-sectional and longitudinal designs. Cross-sectional studies compare outcomes across settings at a specific point in time; whereas longitudinal studies compare change in outcomes over a defined time period from 6 months to 5 years.

To make meaningful comparisons between HCBS and NHs requires acknowledging that the outcomes for different types of LTC are complicated by a number of factors, including underlying functional status, social support, ability to pay, preferences, and knowledge about options. Accounting for this heterogeneity is essential.

Key Questions

We developed the key questions after a topic refinement process that included a preliminary review of the literature and consultation with a key informant panel of LTC experts and stakeholders. Key informants affirmed the importance of the issue of differences in case mix across settings in evaluating studies on LTC. Discussions with key informants also helped us define the settings and services covered under HCBS. Based on key informant input, we (1) identified HCBS settings to include recipient's own home, group living arrangements such as room and board, adult foster care and assisted living, and nonresidential settings such as adult day care, and (2) excluded short-stay NH residents and those receiving Medicare home health services.

The draft key questions were posted for public comment on the Agency for Healthcare Research and Quality (AHRQ) Effective Health Care Program Web site from October 10, 2011, to November 3, 2011. The comments addressed three general topics: (1) whether individuals with specific diagnoses fare better in HCBS versus NHs, (2) the impact of caregivers and caregiver-related outcomes across settings, and (3) the availability of HCBS and its effect on use of NHs. Public comments did not result in changes to the key questions.

We also received input from the technical panel of experts who deemed the key questions to be appropriate, and recommended lowering the age limit for inclusion from 65 to 60 years. We revised the age limit, and added specific sub-questions (1.a and 1.b) to address the issue of differences in case mix across settings. The final key questions are below.

Key Question 1. What are the benefits and harms of LTC provided through HCBS compared to institutions such as NH for older adults, aged 60 and older, who need LTC?

- a. To what extent do HCBS and NHs serve similar populations?
- b. How do the outcomes of the services differ when tested on similar populations?
- c. What are the harms to older adults as a result of HCBS and NHs?

Reported harms include safety, inadequate preventive care, unnecessary hospitalizations, and concerns about abuse or neglect.

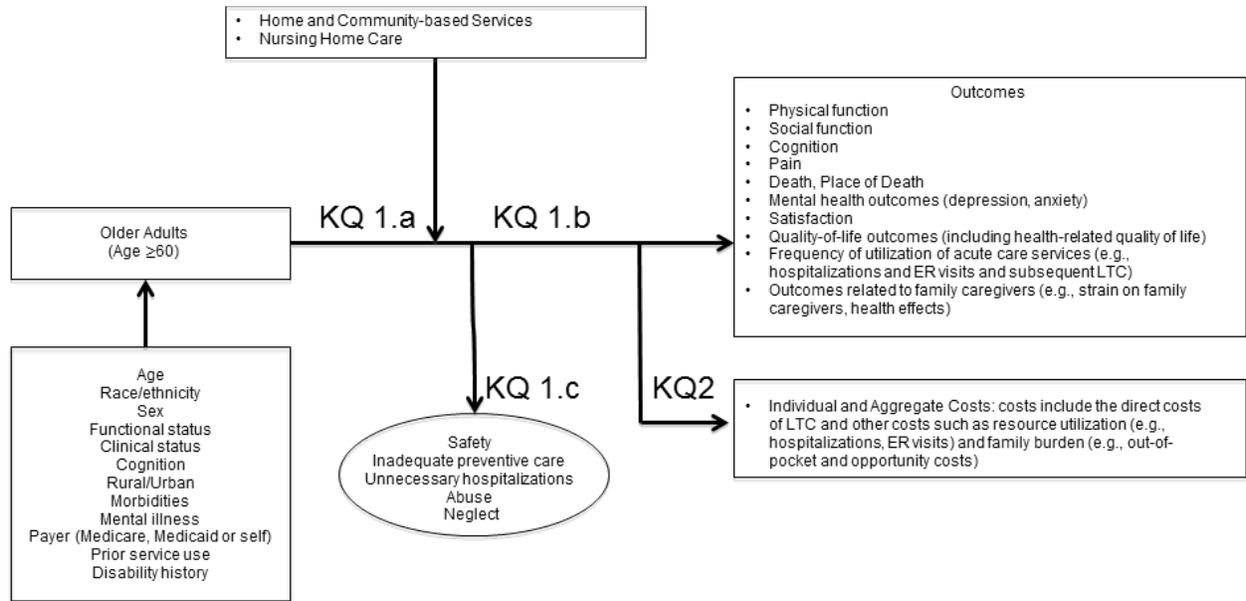
Key Question 2. What are the costs (at the societal and personal levels) of HCBS and NHs (per recipient and in the aggregate) for adults age 60 and older? Costs may include direct costs of care as well as resource utilization and family burden.

Direct costs of care refer to the LTC costs of HCBS recipients and NH residents. Resource use includes the costs of acute care services such as physician and hospital care as well as the costs of other subsidies or transfer programs. Family burden includes both the out-of-pocket and opportunity costs of care.

We anticipated that the relationships reflected in both questions could be moderated by residents' socio-demographic characteristics (age, sex, race); health status (functional, clinical status, morbidities, mental illness, disability); and cognition, as well as by rural/urban location, payer status, and prior service use.

Figure 1 shows the analytical framework for our key questions.

Figure 1. Analytical framework



Methods

We conducted the comparative effectiveness review of LTC for older adults following the methods suggested in the AHRQ Methods Guide for Effectiveness and Comparative Effectiveness Reviews (available at <http://www.effectivehealthcare.ahrq.gov/methodsguide.cfm>). The main sections in this chapter reflect the elements of the protocol publicly posted on the AHRQ Effective Health Care program Web site, and they correspond to the PRISMA checklist.¹⁷ The methods and analyses were determined *a priori*.

Topic Refinement and Review Protocol

The topic for this comparative effectiveness review was nominated by a public process available through the Effective Health Care Web site. Investigators developed preliminary key questions with input from various stakeholder groups (Table 1). The key questions were posted on AHRQ's Web site for public comment for 4 weeks. Public comments and input from the Technical Expert Panel (TEP), convened to provide methodological and content expertise, were used to develop the final key questions and protocol.

Table 1. Perspectives and organizations represented by key informants

Perspective	Organization
Policy	<ul style="list-style-type: none">Centers from Medicare and Medicaid ServicesOffice of Disability, Aging and Long-term Care Policy, Assistant Secretary for Planning and Evaluation, Department of Health and Human Services
Provider	<ul style="list-style-type: none">American Health Care AssociationLeading Age
Consumer	<ul style="list-style-type: none">National Center for Assisted LivingAARP
Research	<ul style="list-style-type: none">Scripps Gerontology Center, Ohio

Literature Search Strategy

An exploratory search indicated that relevant literature would be scarce and difficult to locate. Therefore, we used several strategies to identify potential relevant studies. We searched the bibliographic databases MEDLINE (via OVID) and AGELINE for randomized controlled trials (RCTs) and observational studies of LTC published from 1995 to August 16, 2011. The search algorithm, developed with input from content experts and a biomedical librarian and independently reviewed by another librarian, consisted of a combination of text words and subject index terms in the following categories: intervention (long-term care); services (NH and various types of HCBS); and study design (RCTs and observational studies). We collected search terms related to NHs and HCBS, and combined them using the Boolean AND operator to retrieve articles that compare NHs and HCBS. Relevant RCTs and observational trials were retrieved using search filters specific to study design. The search algorithm with the specific strings and index terms is listed in Appendix A. We used an equivalent search strategy for AGELINE database by adapting the search terms to meet database specific syntax requirements.

Bibliographic database searches were supplemented with backward and forward citation search of relevant articles and by hand searching. We compiled a list of prominent authors in the field and searched specifically for their work to identify missing publications. Finally, we asked the TEP to review the included set and provide missing literature (if any) from their personal

files. We searched the grey literature in the form of program evaluation reports, reports to government, and analyses from research organizations and foundations. We developed a comprehensive list of grey literature sources with input from the TEP. Grey literature sources (Appendix B) included Web sites of relevant federal and state agencies (such as the Centers for Medicare and Medicaid Services and Administration on Aging), research organizations (such as the Lewin Group, Abt Associates, and Mathematica Policy Research), foundations (such as the Robert Wood Johnson Foundation), and advocacy groups.

Inclusion and Exclusion Criteria

The target population was older adults (age ≥ 60) needing LTC. RCTs and quasi-experimental observational study designs were eligible for inclusion. Studies needed to include some comparison of HCBS and NHs. Studies could compare the populations across HCBS and NHs at a particular time point (cross-sectional design) or evaluate changes in outcomes over time (longitudinal design). To capture studies most relevant to the current landscape of LTC in the United States, we limited studies by date (1995 to August 16, 2011), language (English), and geographical location (United States and countries with comparable health systems: Canada, Australia, New Zealand, Britain, Norway, Sweden, and other European countries). Specific eligibility criteria organized by PICOTS framework are listed in Table 2. Grey literature studies that satisfied the above criteria were also eligible for inclusion.

Table 2. Inclusion criteria

Domain	Criteria for Inclusion
Population	<ul style="list-style-type: none"> Older adults (age ≥ 60) needing LTC (including recipients of PACE (Program of All-Inclusive Care for Elderly where eligibility begins at 55))
Intervention	<ul style="list-style-type: none"> Long-term care through HCBS
Comparison	<ul style="list-style-type: none"> Long-term care in NH
Outcomes	<ul style="list-style-type: none"> Physical function, social function, cognition, pain, death, place of death, mental health outcomes, satisfaction, quality of life outcomes, frequency of utilization of acute care services, outcomes related to family caregivers Individual and aggregate costs including direct costs of care and costs such as resource utilization and burden on families Harms: safety, inadequate preventive care, unnecessary hospitalizations, abuse, or neglect
Timing	<ul style="list-style-type: none"> Longitudinal studies: varying periods ranging from 6 months to many years
Setting	<ul style="list-style-type: none"> USA; countries with comparable health systems (Canada, Australia, Britain, Norway, Sweden, and other European countries)
Study Design	<ul style="list-style-type: none"> Cross-sectional studies and longitudinal studies that directly compare populations and outcomes of care between NH and HCBS
Publication dates	<ul style="list-style-type: none"> 1995 to August 16, 2011
Language	<ul style="list-style-type: none"> English

HCBS=Home and Community-based Services; NH=Nursing Home

Study Selection

Bibliographic database search results were downloaded to an Endnote™ reference management system. Eligible studies were identified in two stages. In the first stage, two investigators independently reviewed titles and abstracts of all references; studies deemed eligible for inclusion by either investigator were further evaluated. In the second stage, two investigators independently reviewed full text to determine if studies met inclusion criteria. Differences in full-text screening decisions were resolved by discussion or, when necessary, by consultation with a third investigator. Eligibility status and at least one exclusion reason were

documented for all studies evaluated at the full-text screening stage. Reasons for exclusion were coded as: non-English language study; pre-1995 study; participants under age 60; not a geographical setting of interest; postacute care population; not a relevant comparison; no relevant settings or sample; no relevant characteristics or outcomes. The excluded articles and the reason for exclusion are listed in Appendix C.

Data Extraction

Data from included studies were abstracted directly into evidence tables by one reviewer/investigator and validated by a second reviewer/investigator. Disagreements were resolved by consensus or, when needed, by consultation with a third reviewer. We abstracted data on study design; location (U.S. or international); eligibility criteria; characteristics of study participants; descriptors to assess details of the intervention (setting, services provided); outcomes reported; and length of followup. We abstracted data on characteristics of populations served from cross-sectional studies and studies that reported case mix. Data elements included descriptors to assess methodological quality and study applicability. Appendix D is an evidence table, organized alphabetically by author name.

Risk of Bias of Individual Studies

Methodological risk of bias of longitudinal studies was assessed using criteria specific to study design according to current AHRQ guidance.¹⁸ The risk of bias of each study was assessed independently by two reviewers and validated by the full team of investigators.

We found no RCTs that met inclusion criteria. We assessed risk of bias of longitudinal studies using questions adapted from the RTI item bank for risk of bias.¹⁹ Evaluation of selection bias was a key component of risk of bias assessment; studies that accounted for differences in case mix across setting using techniques such as multivariate analysis, propensity score matching, or instrumental variables were given a higher rating. In addition to selection bias, we evaluated completeness of intervention specification, use of equivalent outcome measures across experimental and control groups, and differential loss to followup. Summary risk of bias was assessed as high, moderate, low, or unclear based on the overall risk of bias created by the individual components assessed.

Data Synthesis

Heterogeneity in populations and interventions/settings across studies precluded quantitative synthesis of results. Instead, we analyzed results qualitatively to arrive at conclusions regarding the extent to which HCBS and NHs serve similar populations and the differences in outcomes of the services when tested on similar populations. We separately analyzed the results from the grey literature.

We compared characteristics of populations served by HCBS versus NH using data from cross-sectional studies and studies that reported case mix. We evaluated differences in populations across settings in the domains of physical function, cognition, mental health/affect, and comorbidities. Results from individual studies were qualitatively synthesized to evaluate the extent to which HCBS and NHs serve similar populations.

To compare outcomes of care for HCBS versus NHs, we first categorized longitudinal studies by the outcome domain investigated. We compared results across settings for specific outcome domains such as physical function, cognitive function, mental health/affect, utilization

of acute care services, costs, and harms. Results were synthesized qualitatively to evaluate the differences in trajectories of older adults as a result of care provided through HCBS or NHs. Throughout the analysis, we considered AL a separate category within HCBS, because it combines elements of institutional and community care. International studies were analyzed separately to account for differences in context.

Strength of the Body of Evidence

We evaluated the overall strength of evidence using methods developed by the AHRQ Evidence-based Practice Center Program²⁰ for the following outcomes: physical function, cognitive function, mental health/affect, mortality, costs, utilization, and harms. We evaluated strength of the evidence on four required domains:

1. Risk of bias (do the studies for a given outcome or comparison have good internal validity). The risk of bias, based on study design and conduct, is rated low, medium, or high.
2. Consistency (the degree of similarity in the effect sizes and same direction of effect of the included studies). Consistency is rated consistent, inconsistent, or unknown/not applicable (e.g., a single study was evaluated).
3. Directness (reflecting a single, direct link between the intervention of interest and the outcome). Directness can either be direct or indirect.
4. Precision (degree of certainty surrounding an effect estimate of a given outcome). Precision is either precise or imprecise. A precise estimate is one that would yield a clinically meaningful conclusion.

We rated the individual domains qualitatively and assigned an overall strength of evidence summary rating of high, moderate, or low strength of evidence for domains in KQ1. Given the absence of RCTs, we graded no outcome as having high strength of evidence. We graded an outcome as insufficient when evidence was either unavailable or did not permit a conclusion.

Applicability

According to AHRQ guidance,²¹ we assessed applicability, defined as the extent to which effects observed in published studies are likely to reflect the expected results when the specific intervention is applied to the population of interest in “real world” contexts. We assessed applicability separately from strength of evidence based on the following criteria: eligibility requirements for enrollment; case mix; type, frequency, and intensity of services delivered; outcomes measured and the timing of measurement; and sources of financing (Table 3).

Table 3. Criteria for assessing applicability

Domain	Criterion Used to Assess Applicability
Population	<ul style="list-style-type: none"> • Criteria for enrollment into the program • Characteristics of population enrolled: demographics; clinical status; functional status; morbidities; cognition; mental illness; and source of finance (Medicaid or self)
Intervention	<ul style="list-style-type: none"> • Long-term care through HCBS <ul style="list-style-type: none"> ○ Type, frequency, and intensity of services ○ Availability and access to programs
Comparison	<ul style="list-style-type: none"> • Long-term care in NHs
Outcomes	<ul style="list-style-type: none"> • Outcomes assessed (or not assessed) and the time period over which they were assessed.
Setting	<ul style="list-style-type: none"> • Country/geographical region; rural/urban

Results

Introduction

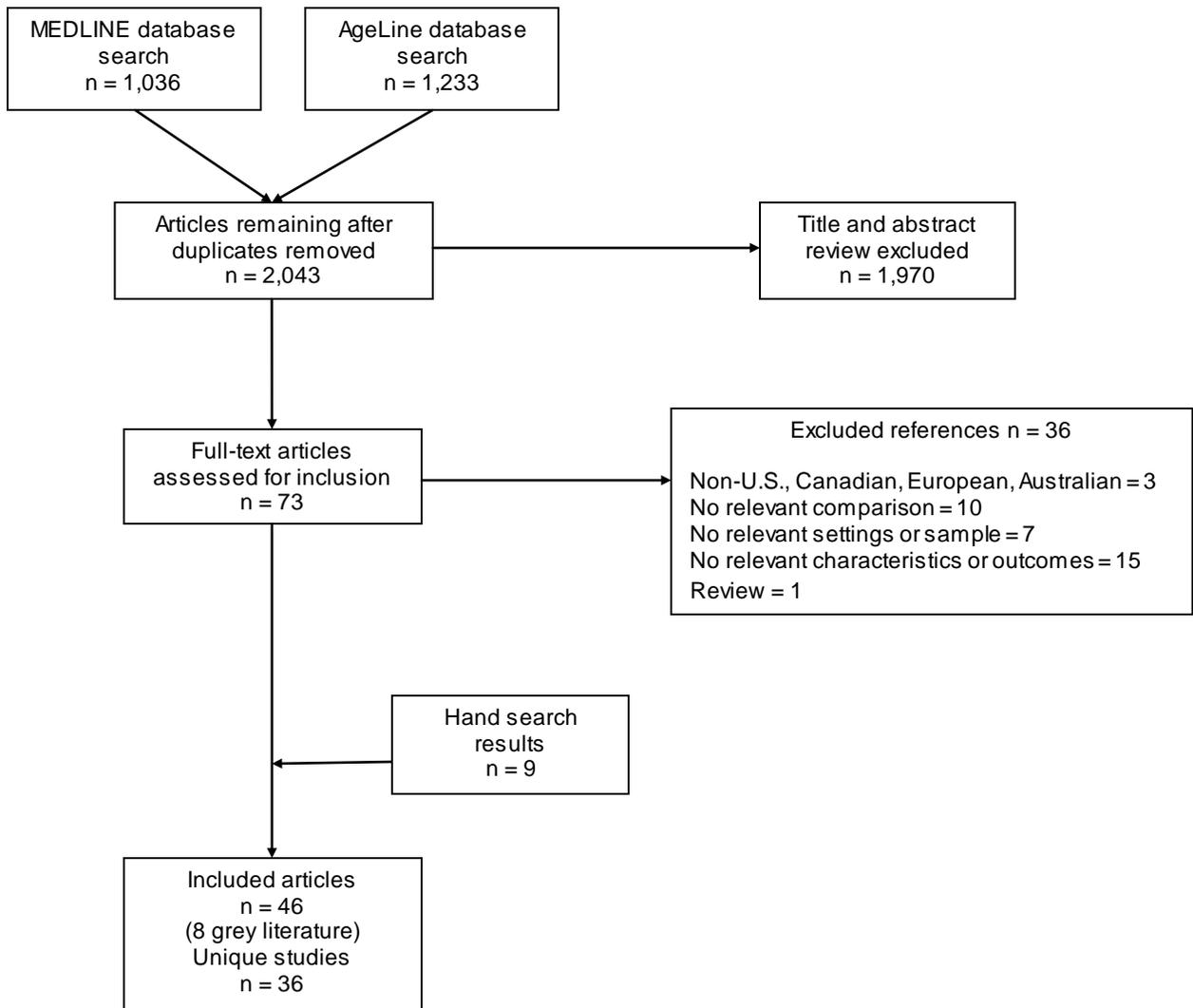
Our findings are organized according to each key question, following an overview of the literature search results and a description of the included studies. The section ends with tables with characteristics and outcomes for each key question. Articles that used the same population sample are grouped together within these tables. Only outcomes that were assessed for strength of evidence are reported in the evidence table in Appendix D.

Because of the heterogeneity of studies across populations, settings, and measurement of outcomes, we could not synthesize results quantitatively. Therefore, all conclusions are based on qualitative analysis. Cross-sectional studies were used only to examine case-mix. We assessed risk of bias only for the longitudinal peer-reviewed studies for key questions 1b, 1c, and 2. The risk of bias assessments and overall strength of evidence ratings appear in Appendix E and F. We did not exclude any studies from analysis based on risk of bias.

Results of Literature Searches

Our search yielded 2,043 unique references. Figure 2 describes the results of the literature search and screening process. A total of 73 full-text articles were screened for final inclusion. Of the 36 excluded articles at the full-text screening stage, three were non-U.S. (Canadian, European, Australian), 10 had no relevant comparison, seven had no relevant settings or sample, 15 had no relevant characteristics or outcomes, and one was a review. Excluded references and reasons for exclusion are listed in Appendix C. This step in database searching produced a total of 37 articles for final inclusion. Hand searching produced an additional nine articles, eight of which were grey literature reports, for a total of 46 articles that addressed 36 unique studies.

Figure 2. Literature flow diagram for long-term care for older adults



Description of Included Studies

No RCTs were identified. Of the 46 observational studies included in the review, 38 are peer-reviewed journal articles,²²⁻⁵⁹ and eight are grey literature reports.⁶⁰⁻⁶⁷ The peer-reviewed journal articles include 22 cross-sectional studies^{24-28, 30, 31, 33, 35-37, 39, 43, 45, 47, 50, 52, 54, 56-58, 61} and 16 longitudinal studies.^{22, 29, 32, 34, 38, 40-42, 44, 46, 48, 49, 51, 53, 55, 59} Of the set of 16 peer-reviewed longitudinal studies, 15 were used as the analytic set for outcomes for key questions 1b, 1c, and 2.^{22, 29, 32, 34, 38, 40, 42, 44, 46, 48, 49, 51, 53, 55, 59} Five grey literature reports that provided longitudinal data are also included as part of the analytic set for outcomes for key questions 1b, 1c, and 2, but we did not assess risk of bias for these reports. Eight studies included in the review are international.^{22, 25, 27, 28, 39, 47, 48, 57} Twelve studies focused on populations with dementia.^{24, 25, 30, 35, 37, 39, 42, 43, 49, 53, 56, 59}

Key Question 1: Benefits and Harms of HCBS Compared to NHs for Older Adults Needing LTC

Key Question 1a: Similarity of Populations in HCBS and NHs

Key Points

- The NH samples were consistently more impaired than HCBS samples in terms of both physical function and cognition.
- The picture with depression and clinical status is more mixed.

Detailed Synthesis

Tables 4-15 present cross-sectional data that compare samples of individuals receiving care in NHs, through HCBS, and/or in AL settings at baseline. Tables 4 and 5 contrast the physical function (measured in various ways) for those in NHs with those in HCBS and/or AL settings. In all cases, NH residents were more disabled than their counterparts. When data on both HCBS and AL were available in the same study, HCBS clients were more impaired.

Tables 7 and 8 contrast levels of cognitive functioning. Once again, the NH samples were consistently more impaired. However, the contrast between HCBS and AL was mixed. AL residents had more cognitive impairment in one study²⁹ and less in two.^{26, 33}

The picture with depression is more mixed. As shown in Tables 10 and 11, two studies^{38, 46} but not a third⁵⁵ found more depression in NH residents than in those receiving HCBS. Compared to AL, more NH residents were depressed in two studies^{35, 44} and fewer in two.^{30, 53}

Tables 13 and 14 summarize a mixed set of information on clinical status. In one study,⁴⁹ NH residents had more chronic conditions than those in HCBS, but in another,²⁶ the number of conditions was lower for NH than HCBS. One study⁴² found that NH residents had more of three specific conditions than did HCBS recipients, but the differences were not significant. The comparison is likewise mixed with AL. The rate of conditions among NH residents was higher in two studies,^{26, 53} but lower in a third.³⁰

Parallel information from the grey literature reflects a similar pattern. As shown in Table 6, physical function was more impaired in NH residents than in HCBS or AL recipients. The relative levels in AL and HCBS present a mixed picture. Likewise, cognitive function was more impaired in NH residents than in persons in HCBS or AL (Table 9), although one study showed a similar rate of cognitive impairment between AL and NH.⁶⁰ The prevalence of depression was

similar between NH and transitional care facilities (a NH variant), but both were higher than for HCBS.⁶⁴ Rates of mental disorders (Table 12) were similar for those receiving care in NHs and HCBS settings.⁶⁵ As shown in Table 15, the rates of comorbidities were similar across HCBS and NHs, but higher for transitional care.⁶⁴ NH residents generally had more comorbidities than those in AL.⁶⁵

Key Question 1b: Differences in Outcomes in HCBS and NHs

Key Points

- The impact on rate of change in physical function, cognition, and/or mental health/affect did not differ significantly between HCBS and nursing home recipients.
- Studies assessing physical function found AL residents to be more functional at baseline; however, there were no significant differences in rate of change in physical function between AL and NH residents.
- AL and NH residents had no significant differences in changes in cognition over time. AL and NH residents did not differ significantly in changes in mental health/affect domains over time.
- Results regarding differences in mortality are mixed. Some studies found no difference in mortality between AL and NH residents, and others suggested higher mortality risk for NH residents.
- Results regarding use of hospital care found either no significant difference between HCBS/AL recipients and NH residents or higher use among HCBS/AL recipients than among NH residents.
- The overall strength of evidence for the outcomes examined was low.

Detailed Synthesis

Tables 16-18 summarize the outcome domains addressed in the modest collection of longitudinal studies. Most outcomes were measured in terms of functional change (physical and/or cognitive) or utilization of acute care services.

Table 19 summarizes the outcomes expressed in various ways for functional decline. Frytak et al. 2001³² showed that AL residents were more functional at the outset of the study, but the rate of decline was equivalent to that of NH residents. In the study by Pruchno and Rose 2000,⁴⁴ AL residents maintained better function throughout, but rate of change in functional ability did not differ for AL and NH residents over time. Sloane et al. 2005⁵³ found no significant differences in the change in function between AL and NH residents. Marek et al. 2005³⁸ found that NH residents remained more disabled than HCBS clients over 24 months, but they did not evaluate rate of change in function across settings.

Table 20 summarizes the longitudinal studies that examined changes in cognitive function. Two studies^{44, 53} showed no significant differences in trends in cognition between AL and NH residents. Marek et al. 2005³⁸ showed that NH residents remained more impaired than HCBS clients, but they did not evaluate rate of change in cognition.

Table 21 summarizes the outcomes in terms of depression and other mental health problems. Two studies^{44, 53} found no significant differences in changes in depression scores between AL and NH residents. Frytak et al. 2001³² found no difference in psychological well-being scores from the SF-36 between AL and NH residents. Marek et al. 2005³⁸ found that depression was

higher for NH residents than for HCBS clients at 6 and 12 months, but not at baseline, suggesting an increase in NH rates. However, the difference disappeared by 18 months.

Two studies compared mortality in AL versus NH (Tables 22 and 23),^{44, 53} and both found no differences. A study from the grey literature (Table 24) showed the highest odds of mortality for NH residents, followed by those in HCBS and AL, compared with individuals not yet receiving LTC.⁶³ A similar pattern was seen in two international studies; individuals in nursing homes had a higher risk of mortality.^{40, 48} Another study found that median survival was lowest for NH residents and highest for PACE enrollees, with HCBS clients falling between the two.⁵⁵

As shown in Table 26, several studies examined the use of medical services. Mitchell et al. found no significant difference in the use of hospitals by HCBS clients compared with NH residents,⁴² but the latter were less likely to use hospice services. In contrast, Sands et al. found higher hospital use among HCBS clients than among NH residents.⁴⁹ Sloane et al. found that among persons with mild dementia, those in AL used hospitals more than those in NHs,⁵³ but they found no difference for those with moderate or severe dementia. Table 27 presents utilization of services from one grey literature study.⁶⁶ HCBS clients had higher hospital use, whereas NH residents had higher skilled nursing facility and outpatient service use.

The strength of evidence across all outcome domains was low.

Other outcomes are presented in Appendix G, Tables G1 and G2.

Key Question 1c: Harms in HCBS and NHs

Harms were measured in two studies (Table 25). Rigler et al. examined inappropriate medication use;⁴⁶ the overall rate was higher for HCBS clients than for NH residents. Mitchell et al. compared end-of-life care of older individuals with advanced dementia;⁴² compared with HCBS recipients, NH residents had less pain and shortness of breath. The overall strength of evidence was low.

Key Question 2: Costs of HCBS and NH

Key Points

- Compared with NH residents, HCBS recipients' LTC costs were lower.
- Compared with NH residents, HCBS recipients' health care costs were higher.
- No studies addressed costs related to family burden.

Detailed Synthesis

Table 28 compares data on expenditures from two studies.^{49, 51} HCBS tended to be less expensive. However, health care costs were higher, whereas LTC costs were lower. Table 29 presents cost data from grey literature studies. In most cases, the total costs (typically expressed as total Medicaid expenditures) were higher for NH compared to either HCBS or AL.⁶⁰⁻⁶³ One study⁶⁶ that analyzed Medicare payments found that HCBS clients had higher total Medicare payments per member per month. When these payments were broken down into components, HCBS clients had higher Medicare hospital, home health, hospice, and physician payments per member per month, while NH residents had higher skilled nursing facility and outpatient payments per member per month. No studies addressed the costs related to family burden. The overall strength of evidence for costs was low.

Table 4. Description of participant characteristics – physical function (cross-sectional and longitudinal studies) - domestic

Study	Measure of Physical Function	HCBS	NH	Significance
Ohio HCBS Waiver Applebaum et al., 2004 ²³	Mean number ADL impairments; range 0-6	HCBS: 3.0	3.9	NR
Borrayo et al., 2002 ²⁶	Mean number ADL impairments; range 0-5	HCBS: 2.24 (SD 1.81) AL: 2.21 (SD 1.82)	3.98 (SD 1.32)	NR
^a Dementia Care Project Port et al., 2005 ⁴³	Mean number of ADLs in which resident was independent; range 0-7	AL: 3.4 (SD 2.4)	2.4 (SD 1.8)	p = 0.001
^a Edelman et al., 2005 ³⁰	Mean number of ADL dependencies; range 0-6	AL: 2.5 (SD 2.0)	3.8 (SD 2.2)	p < 0.01
Gaugler 2006 ³³	Mean number ADL dependencies; range not specified	HCBS: 2.04 (SD 3.01) AL: 1.75 (SD 1.86)	5.59 (SD 3.57)	p < 0.05 for NH vs. HCBS and for NH vs. AL
Lee et al., 2001 ³⁶	Mean ADL dependency; range 0-14 with higher scores indicating more dependency	HCBS: 5.07 (SD 2.13)	7.67 (SD 3.72)	p < 0.001
Mehdizadeh 2002 ⁴¹	Mean number ADL impairments; range 0-6	HCBS: 2.6	3.2	p ≤ 0.05
Oregon Assisted Living Frytak et al., 2001 ³²	Mean ADL score; range 0-100 with higher scores indicating more dependence	AL: 16.88	57.09	NR
Collaborative Studies of Long-Term Care sub-sample ^Sloane et al., 2005 ⁵³	Mean ADL impairment score from MDS ADL; range 0-28 with higher scores indicating more impairment	AL: 7.6 (SD 7.9)	11.9 (SD 8.2)	p = 0.001
Wieland et al., 2010 ³⁵	Mean number of ADL dependencies; range 0-6	HCBS: 0.45 PACE: 1.05	2.25	NR
Shugarman et al., 1999 ³²	Mean ADL Index score; range 4-18 with higher scores indicating more dependence	HCBS: 6.99	9.74	p < 0.001
ASPE private LTC insurance cohort Doty et al., 2010 ²⁹	ADL impairments (percentage)	HCBS: 18% with <2, 52% with 2-4, 30% with 5+ AL: 36% with <2, 44% with 2-4, 20% with 5+	12% with <2, 31% with 2-4, 57% with 5+	NR
^a Mitchell et al., 2004 ⁴²	MDS ADL score with higher scores indicating more dependence (percentage)	HCBS: 70.2% score 0-20, 23.1% score 21-27, 6.7% score 28	24.3% score 0-20, 36.2% score 21-27, 39.3% score 28	p < 0.001, p < 0.001, p < 0.001
Reinardy & Kane 1999 ⁴⁵	Number of ADLs requiring some help (percentage)	HCBS: 85% with 0-1, 9% with 2-3, 6% with 4+	54% with 0-1, 14% with 2-3, 32% with 4+	NR
Collaborative Studies of Long-Term Care sub-sample Zimmerman et al., 2003 ⁵⁸	Impairment in at least one of six ADLs (percentage)	AL(a): 37% AL(b): 25% AL(c): 15%	83%	NR
^a Beattie et al., 2005 ²⁴	Mean motor ability item average; range 0-4 for six items, with higher scores indicating poorer motor ability	AL: 0.35 (SD 0.48)	0.76 (SD 0.71)	p < 0.01
Franks 2004 ³¹	Mean SIP-NH score; higher scores indicate more disability	AL: 22.8	41.7	NR

Table 4. Description of participant characteristics – physical function (cross-sectional and longitudinal studies) – domestic (continued)

Study	Measure of Physical Function	HCBS	NH	Significance
^a Leon & Moyer 1999 ³⁷	Mean SF-36 Physical Functioning Subscale score; range 0-100, with higher values indicating higher functioning	AL: 46.7 (SD 32.04)	20.15 (SD 23.30)	p < 0.001
Pruchno and Rose 2000 ⁴⁴	Mean MAI functional ability; range 15-45, with higher scores indicating better function	AL: 40.03	34.89	p < 0.001
Schroeder et al., 1998 ⁵⁰	Mean Physical Activity Questionnaire for the Elderly score; higher score indicates greater physical activity levels	AL: 6.8 (SD 1.4)	1.2 (SD 0.3)	p ≤ 0.05
Collaborative Studies of Long-Term Care sub-sample Sloane et al., 2003 ³⁴	Required partial or complete assistance with locomotion at study enrollment (percentage)	AL: 20.0%	38.1%	p = 0.021

Table rows ordered by similar measures of physical function

^aStudy focused on participants with dementia.

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; PACE = Program of All-Inclusive Care; RH = Residential Home; ADL = Activities of Daily Living; SIP-NH = Sickness Impact Profile for Nursing Homes; SF-36 = Short-Form Health Survey; MAI = Multilevel Assessment Instrument; NR = Not reported Do your footnotes in alphabetical order.

Table 5. Description of participant characteristics – physical function (cross-sectional and longitudinal studies) - international

Study	Measure of Physical Function	HCBS	NH	Significance
^a Boersma et al., 1997 ²⁵	Mean ADL score; range 0-10	HCBS: 4.2 RH: 4.9	8.4	NR
Challis et al., 2000 ²⁷	Median Barthel score; range 0-20 with lower scores indicating more dependency	RH: 14.3	8.7	p < 0.001
^a Margallo-Lana et al., 2001 ³⁹	Mean Barthel score; range 0-20 with lower scores indicating more dependency	HCBS: 14.8	11.0	NR
Nottingham Studies Rothera et al., 2003 ⁴⁷	Median Barthel score; range 0-20 with lower scores indicating more dependency	RH: 13	7	p < 0.001
Chappell et al., 2004 ²⁸	Functional Autonomy Measurement System score			Scores were not significantly different for HCBS and NH participants
Wodchis et al., 2003 ⁵⁷	Total dependence in mobility (percentage)	HCBS: 2% Supportive housing: 0%	28%	NR

Table rows ordered by similar measures of physical function

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home; RH = Residential Home; ADL = Activities of Daily Living; NR=Not Reported

Table 6. Description of participant characteristics – physical function (grey literature studies) - domestic

Study	Measure of Physical Function	HCBS	NH	Significance
ASPE private LTC insurance cohort Miller et al., 2008 ⁶³	Mean number of ADL limitations; range 0-6 with higher scores indicating more dependence	HCBS: 3.4 AL: 2.9	4.5	NR
Department of Elder Affairs, State of Florida 2009-2010 ⁶⁰	Mean number of ADLs requiring assistance; range 0-8	HCBS: 3.54 Managed care HCBS: 5.06 AL: 4.35	5.15	NR
Applebaum et al., 2009 ⁶¹	Mean number of ADL impairments; range 0-6	HCBS: 2.9 AL: 2.6	4.5	NR
Ohio HCBS Waiver Mehdizadeh 2007 ⁶²	Mean number of ADL impairments; range 0-6	HCBS: 3.0	4.4	NR
Spillman et al., 2002 ⁶⁵	ADL or IADL impairments (percentage)	AL: 3.8% with no ADL/IADL, 32.5% with 1-2 ADL, 52.1% with 3 or more ADL, 11.1% with IADL only	2.2% with no ADL/IADL, 19.9% with 1-2 ADL, 74.4% with 3 or more ADL, 2.9% with IADL only	NR
Youngs et al., 2005 ⁶⁷	ADL hierarchies (percentage)	Transition: 1% independent, 13% supervision, 33% limited, 27% extensive 1, 14% extensive 2, 8% dependent, 4% total dependence	7% independent, 8% supervision, 16% limited, 26% extensive 1, 12% extensive 2, 18% dependent, 14% total dependence	NR

Table rows ordered by similar measures of physical function

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; ADL = Activity of Daily Living; IADL = Instrumental Activity of Daily Living; NR=Not Reported

Table 7. Description of participant characteristics – cognitive function (cross-sectional and longitudinal studies) – domestic

Study	Measure of Cognitive Function	HCBS	NH	Significance
^a Beattie et al., 2005 ²⁴	Mean MMSE score; range 0-24 with lower scores indicating more impairment	AL: 8.40 (SD 7.06)	7.56 (SD 7.10)	Not significant
^a Edelman et al., 2005 ³⁰	(All participants had MMSE score of 10 or higher) Mean MMSE score; range 0-30 with lower scores indicating more impairment	AL: 11.1 (SD 6.8)	7.9 (SD 6.8)	p < 0.01
Pruchno and Rose 2000 ⁴⁴	Mean MMSE score; range 0-30 with lower score indicating more impairment	AL: 23.57 (SD 4.25)	23.09 (SD 4.06)	Not significant
Lee et al., 2001 ³⁶	MDS-COGS; range 0-9 with higher scores indicating more impairment			Mean score of HCBS participants was significantly lower than NH participants (p<0.05)
Collaborative Studies of Long-Term Care sub-sample [^] Sloane et al., 2005 ⁵³	(All participants had diagnosis of dementia) Mean MDS-COGS score; range 0-10 with higher scores indicating more impairment	AL: 5.3 (SD 2.4)	5.7 (SD 2.3)	p = 0.005
Borrayo et al., 2002 ²⁶	Mean cognitive impairment; range 0-3 with higher scores indicating more severe impairment	HCBS: 1.72 (SD 1.23), 18% AL: 1.60 (SD 1.12), 42%	1.42 (SD 1.05), 56%	NR
	Alzheimer's disease or other dementia (percentage)			
Gaugler 2006 ³³	Mean SPMSQ score; range 0-10 with higher scores indicating more impairment	HCBS: 3.02 (SD 2.67) AL: 2.30 (SD 2.20)	3.20 (SD 2.46)	Not significant
^a Leon and Moyer 1999 ³⁷	(All participants met criteria for probable Alzheimer's disease) Mean CDRS score; range 0.5-6 with higher scores indicating more severe dementia	AL: 2.16 (SD 0.97)	2.72 (SD 0.97)	p < 0.001
Oregon Assisted Living Gaugler and Kane 2005 ³⁴	Mean MSQ score; range 0-10 with lower scores indicating more impairment	AL: 7.07 (SD 2.30)	6.46 (SD 2.18)	p < 0.001
^a Dementia Care Project Port et al., 2005 ⁴³	(All participants had diagnosis of dementia) Classified with mild, moderate, severe or very severe dementia based on MMSE or MDS-COGS (percentage)	AL: 13.3% mild, 28.8% moderate, 23.8% severe, 29.2% very severe	8.0% mild, 13.3% moderate, 22.1% severe, 56.6% very severe	p = 0.003
Kansas Medicaid Studies Shireman and Rigler 2004 ⁵¹	Diagnosis of Alzheimer's disease or dementia (percentage)	HCBS: 6.1%	34.6%	p < 0.01
Reinardy and Kane 1999 ⁴⁵	Dementia diagnosis (percentage)	HCBS: 15%	20%	Not significant
Collaborative Studies of Long-Term Care sub-sample Sloane et al., 2003 ⁵⁴	Moderate or advanced dementia at study enrollment (percentage)	AL: 38.6%	67.2%	p = 0.001
Wieland et al., 2010 ⁵⁵	Diagnosis of dementia (percentage)	HCBS: 18.0% PACE: 80.9%	50.2%	p < 0.001

Table 7. Description of participant characteristics – cognitive function (cross-sectional and longitudinal studies) – domestic (continued)

Study	Measure of Cognitive Function	HCBS	NH	Significance
^a Mitchell et al., 2004 ⁴²	(All persons in sample had diagnosis of dementia and Cognitive Performance Score of 5 or 6 at admission) CPS score of 6 versus 5 (percentage)	HCBS: 34.6%	57.1%	p < 0.001
ASPE private LTC insurance cohort Doty et al., 2010 ²⁹	Cognitive impairment (percentage)	HCBS: 28% AL: 63%	64%	NR
Mehdizadeh 2002 ⁴¹	Cognitively impaired (percentage)	HCBS: 16%	49%	NR
Collaborative Studies of Long-Term Care sub-sample Zimmerman et al., 2003 ⁵⁸	Cognitive impairment indicated by diagnosis of dementia, MMSE score, or information on MDS (percentage)	AL(a): 42% AL(b): 35% AL(c): 23%	51%	NR

Table rows ordered by similar measures of cognitive function

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; PACE = Program of All-Inclusive Care; RH = Residential Home; MMSE = Mini-mental State Exam; NS = Not significant; SPMSQ = Short Portable Mental Status Questionnaire; MDS-COGS = Minimum Data Set Cognition Scale; CDRS = Clinical Dementia Rating Score; CPS = Cognitive Performance Score; MSQ = Mental Status Questionnaire; AGE-CAT = Automated Geriatric Examination Computer Assisted Taxonomy; NR=Not Reported

Table 8. Description of participant characteristics – cognitive function (cross-sectional and longitudinal studies) – international

Study	Measure of Cognitive Function	HCBS	NH	Significance
^a Boersma et al., 1997 ²⁵	Mean MMSE score; range 0-28 with lower scores indicating more impairment	HCBS: 14.8 RH: 13.6	5.5	NR
Challis et al., 2000 ²⁷	Median MMSE score; lower scores indicate more impairment	RH: 16	12	p < 0.001
^a Margallo-Lana et al., 2001 ³⁹	Mean MMSE score; lower scores indicate more impairment	HCBS: 15.3	7.0	NR
Nottingham Studies Rothera et al., 2003 ⁴⁷	Median MMSE score; range 0-30 with lower scores indicating more impairment	RH: 17	14	NR
Resource Implications Study Group 2000 ²²	Mean AGE CAT score; higher scores indicate more impairment	HCBS: 0.9	2.2	NR
Wodchis et al., 2003 ⁵⁷	Severe cognitive impairment (percentage)	HCBS: 4% Supportive housing: 0%	34%	NR

Table rows order by similar measures of cognitive function

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home; RH = Residential Home; MMSE = Mini-mental State Exam; AGE CAT = Automated Geriatric Examination Computer Assisted Taxonomy; NR=Not Reported

Table 9. Description of participant characteristics – cognitive function (grey literature studies) – domestic

Study	Measure of Cognitive Function	HCBS	NH	Significance
<i>Domestic</i>				
Department of Elder Affairs, State of Florida 2009-2010 ⁶⁰	Dementia (percentage)	HCBS: 32% Managed care HCBS: 63% AL: 62%	60%	NR
Ohio HCBS Waiver Mehdizadeh 2007 ⁶²	Cognitively impaired (percentage)	HCBS: 13.5%	70.7%	NR
Ormond et al., 2006 ⁶⁴	Diagnosis of dementia (percentage)	HCBS: 12.9% Transition: 20.3%	31.9%	NR
Spillman et al., 2002 ⁶⁵	Alzheimer's disease and other dementia (percentage)	AL: 35.3%	46.1%	NR
Youngs et al., 2005 ⁶⁷	CPS scores (percentage)	Transition: 38% intact, 24% borderline intact, 17% mild impairment, 13% moderate impairment, 5% moderately severe impairment, 2% severe impairment, 1% very severe impairment	11% intact, 9% borderline intact, 14% mild impairment, 33% moderate impairment, 12% moderately severe impairment, 10% severe impairment, 11% very severe impairment	NR

Table rows ordered by similar measures of cognitive function

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; CPS = Cognitive Performance Score; NR=Not Reported

Table 10. Description of participant characteristics – mental health/affect (cross-sectional and longitudinal studies) – domestic

Study	Measure of Mental Health/Affect	HCBS	NH	Significance
Marek et al., 2005 ³⁸	Mean score on MDS-based depression rating scale; range 0-21 with lower scores indicating less depressive symptoms	HCBS: 0.7 (SD 1.1)	1.1 (SD 1.9)	NS
Pruchno and Rose 2000 ⁴⁴	Mean CES-D score; higher scores indicate more depressive symptoms	AL: 13.92 (SD 10.85)	17.98 (SD 11.10)	p < 0.05
Collaborative Studies of Long-Term Care sub-sample ^a Sloane et al., 2005 ⁵³	Mean CSDD score; higher scores indicate greater depression	AL: 4.5 (SD 4.8)	3.6 (SD 4.6)	p = 0.001
^a Dementia Care Project Gruber-Baldini et al., 2005 ³⁵	CSDD score of 7 or greater indicating clinically significant depression (percentage)	AL: 23.9%	26.6%	NS
^a Edelman et al., 2005 ³⁰	CSDD score of 7 or greater indicating depression (percentage)	AL: 36.4%	21.4%	NR
Kansas Medicaid Studies Shireman and Rigler 2004 ⁵¹	Diagnosis of depression, any psychosis (percentage)	HCBS: 6.9%, 10.4%	9.8%, 24.6%	p < 0.01, p < 0.01
Wieland et al., 2010 ⁵⁵	Diagnosis of anxiety/depression (percentage)	HCBS: 26.6% PACE: 26.2%	22.6%	
Gaugler 2006 ³³	Mean positive affect subscale score from the Dementia Quality of Life scale; higher scores indicate better psychosocial status	HCBS: 3.65 (SD 0.79) AL: 3.73 (SD 0.71)	3.83 (SD 0.71)	NS
Oregon Assisted Living Frytak et al., 2001 ³²	Mean psychological well-being score from SF-36 mental health subscale; range 0-100 with higher scores indicating better psychological well-being	AL: 76.04	71.35	NR
Schroeder et al., 1998 ⁵⁰	Mean SWLS score; range 0-35 with higher score indicating higher life satisfaction	AL: 28.2 (SD 1.3)	29.5 (SD 1.0)	NS

Table rows order by similar measures of mental health/affect

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; PACE = Program of All-Inclusive Care; RH = Residential Home; MDS = Minimum Data Set; NS = Not significant; CSDD = Cornell Scale for Depression in Dementia; SF-36 = Short-Form Health Survey; SWLS = Satisfaction with Life Scale; CES-D = Center for Epidemiological Studies Depression Scale; CAMDEX = Cambridge Examination for Mental Disorders of the Elderly; NR=Not Reported

Table 11. Description of participant characteristics – mental health/affect (cross-sectional and longitudinal studies) – international

Study	Measure of Mental Health/Affect	HCBS	NH	Significance
<i>Domestic</i>				
Nottingham Studies Rothera et al., 2003 ⁴⁷	Median Geriatric Depression Scale score; lower scores indicate less depression	RH: 5	7	Categorical depression not significantly different between types of care
^a Boersma et al., 1997 ²⁵	CAMDEX indicator for depression (percentage)	HCBS: 14.3% RH: 10.5%	16.2%	NR
Chappell et al., 2004 ²⁸	Terrible Delightful Scale and life satisfaction question			Scores were not significantly different for HCBS and NH participants, indicating they were comparable in terms of life satisfaction
Wodchis et al., 2003 ³⁷	Generally happy/free from worry (percentage)	HCBS: 53% Supportive housing: 84%	29%	NR

Table rows order by similar measures of mental health/affect

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home; RH = Residential Home; MDS = Minimum Data Set; CAMDEX = Cambridge Examination for Mental Disorders of the Elderly; NR=Not Reported

Table 12. Description of participant characteristics – mental health/affect (grey literature studies) –domestic

Study	Measure of Mental Health/Affect	HCBS	NH	Significance
<i>Domestic</i>				
Ormond et al., 2006 ⁶⁴	Diagnosis of depression (percentage)	HCBS: 8.9% Transition: 19.2%	20.4%	NR
Spillman et al., 2002 ⁶⁵	Mental disorder (percentage)	AL: 25.2%	28.9%	NR

Table rows ordered by similar measures of mental health/affect

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; NR=Not Reported

Table 13. Description of participant characteristics – conditions/comorbidities (cross-sectional and longitudinal studies) – domestic

Study	Measure of Conditions/Comorbidities	HCBS	NH	Significance
Borrayo et al., 2002 ²⁶	Mean number of chronic diseases; range 0-16	HCBS: 3.34 (SD 1.80) AL: 2.01 (SD 1.25)	2.55 (SD 1.56)	NR
^a Dementia Care Project Port et al., 2005 ⁴³ , Williams et al., 2005 ⁵⁶	Mean number of 11 comorbidities Score of 2 or more on PGC-PIS indicating pain (percentage)	AL: 2.0 (SD 1.5, range 0-7), 38.9% with pain	2.4 (SD 1.6, range 0-7), 25.0% with pain	NS; NS
^a Edelman et al., 2005 ³⁰	Mean number of mild to severe comorbid conditions (out of 11 conditions) from the CIRS-g	AL: 3.6 (SD 2.0)	2.8 (SD 1.5)	p < 0.05
^a Leon and Moyer 1999 ³⁷	Mean CIRS-g Severity Index score excluding psychiatric illness; higher scores indicate more severity Has possible terminal conditions (percentage)	AL: 2.06 (SD 0.53), 34% (s.e. 0.04)	2.11 (SD 0.36), 54% (s.e. 0.04)	p < 0.001 for terminal conditions
Collaborative Studies of Long-Term Care sub-sample ^a Sloane et al., 2005 ⁵³	Mean number of comorbid conditions	AL: 3.6 (SD 2.3)	4.4 (SD 2.2)	p = 0.001
Kansas Medicaid Studies Rigler et al., 2004 ⁴⁶	CIRS-g summed disease burden score indicating disease categories but not severity (percentage)	HCBS: 27.4% score 0 or 1, 21.0% score 2 or 3, 21.0% score 4 or 5, 30.8% score ≥6	19.3% score 0 or 1, 39.7% score 2 or 3, 19.4% score 4 or 5, 21.6% score ≥6	
^a Sands et al., 2008 ⁴⁹	Charleson comorbidity score with higher scores indicating greater number and severity of comorbid conditions (percentage)	HCBS: 36% score 0, 19% score 1, 45% score 2+	24% score 0, 25% score 1, 51% score 2+	p < 0.01
Shugarman et al., 1999 ⁵²	Mean Case-Mix Index score; higher scores indicate more resource intensive	HCBS: 0.84	1.03	p < 0.001
Lee et al., 2001 ³⁶	Top 3 primary diagnoses for residents in each setting (percentage)	HCBS: 47.8% disease of circulatory system, 19.4% endocrine disorder, 10.4% disease of musculoskeletal system	29.9% disease of circulatory system, 28.4% disease of nervous system, 16.4% fracture	p < 0.001
Mehdizadeh 2002 ⁴¹	Number of diseases diagnosed including cancer, diabetes and/or other gland diseases, circulatory diseases, musculoskeletal diseases, and respiratory diseases (percentage)	HCBS: 36% with 0, 34% with 1, 22% with 2, 8% with 3, 0% with 4	31% with 0, 36% with 1, 25% with 2, 8% with 3, 0% with 4	NR
^a Mitchell et al., 2004 ⁴²	Diagnoses of cancer, congestive heart failure, and chronic obstructive pulmonary disease (percentage)	HCBS: 13.7%, 11.6%, 29.6%	11.4%, 15.6%, 29.6%	NS, NS, NS

Table 13. Description of participant characteristics – conditions/comorbidities (cross-sectional and longitudinal studies) – domestic (continued)

Study	Measure of Conditions/Comorbidities	HCBS	NH	Significance
Reinardy and Kane 1999 ⁴⁵	Diagnoses of heart condition, stroke, skeletal-muscular (percentage)	HCBS: 21%, 19%, 16%	30%, 19%, 25%	p < 0.05 for heart condition and skeletal-muscular
Wieland et al., 2010 ⁵⁵	Top 3 diseases/conditions for residents in each setting (percentage)	HCBS: 39.2% with diabetes, 27.1% with congestive heart failure, 26.6% with anxiety/depression PACE: 80.9% with dementia, 40.6% with stroke, 35.7% with diabetes	50.2% with dementia, 29.5% with diabetes, 23.5% with stroke	NR
Collaborative Studies of Long-Term Care sub-sample Zimmerman et al., 2003 ⁵⁸	Diagnosis of heart condition (percentage)	AL(a): 38% AL(b): 49% AL(c): 48%	48%	NR
Oregon Assisted Living Frytak et al., 2001 ³² ; Gaugler and Kane 2005 ³⁴	Mean pain and discomfort score from scale developed at RAND; higher scores indicate more pain and discomfort Mean subjective health impairment; range 0-4 with lower scores indicating better health	AL: 12.62, 2.53 (SD 0.87)	12.97, 2.73 (SD 0.92)	p < 0.001 for subjective health
Pruchno and Rose 2000 ⁴⁴	Mean subjective health from 4-item scale from the MAI; higher scores indicate better health	AL: 8.86	8.07	p < 0.05

Table rows ordered by similar measures of conditions/comorbidities

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; PACE = Program of All-Inclusive Care; RH = Residential Home; NS = Not significant; NR=Not Reported; PGC-PIS = Philadelphia Geriatric Center-Pain Intensity Scale; CIRS-g = Cumulative Illness Rating Scale-for Geriatrics; MAI = Multilevel Assessment Instrument

Table 14. Description of participant characteristics – conditions/comorbidities (cross-sectional and longitudinal studies) – international

Study	Measure of Conditions/Comorbidities	HCBS	NH	Significance
<i>Domestic</i>				
McCann et al., 2009 ⁴⁰	Limiting long-term illness (percentage)	RH: 89%, 31%	99%, 64%	NR
	General health poor (percentage)			
Wodchis et al., 2003 ³⁷	Severe pain (percentage)	HCBS: 6% Supportive housing: 4%	30%	NR

Table rows ordered by similar measures of conditions/comorbidities HCBS = Home and Community-based Services; NH = Nursing Home; RH = Residential Home; NR=Not Reported

Table 15. Description of participant characteristics – conditions/comorbidities (grey literature studies) – domestic

Study	Measure of Conditions/Comorbidities	HCBS	NH	Significance
Ormond et al., 2006 ⁶⁴	Diagnosis of stroke; other cardiovascular; endocrine, nutritional and metabolic diseases and immune disorders; diseases of the nervous system and sense organs; respiratory system diseases (percentage)	HCBS: 11.3%, 70.7%, 41.0%, 22.4%, 14.3% Transition: 16.6%, 79.1%, 41.1%, 19.8%, 17.3%	11.7%, 68.2%, 30.8%, 24.2%, 11.6%	NR
Spillman et al., 2002 ⁶⁵	Has diabetes; hip fracture; emphysema/asthma/COPD; stroke (percentage)	AL: 14.9%, 6.8%, 8.5%, 14.9%	19.7%, 5.4%, 9.6%, 21.5%	NR

Table rows ordered by similar measures of conditions/comorbidities

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; COPD = Chronic obstructive pulmonary disease; NR=Not Reported

Table 16. Analysis and outcome domains (longitudinal studies) – domestic

Study	Sample/Services	Analysis	Outcome Domains
Doty et al., 2010 ²⁹ ASPE private LTC insurance cohort	Private LTC insurance policyholders using HCBS, AL, or NH; longitudinal panel starting at initiation of services and followed for 28 months	Descriptive statistics; logistic regression was used to predict transitions	Satisfaction
Frytak et al., 2001 ³² (Oregon Assisted Living study)	AL and NH residents in Oregon followed for 1 year	Hierarchical linear models were used to examine how setting (AL or NH) affected growth trajectories for each outcome (ability to perform activities of daily living, psychological well-being, and pain and discomfort) studied; models adjusted for resident characteristics including health status variables, demographic variables, and social measures	Physical function, mental health/affect, pain and discomfort
Gaugler and Kane 2005 ³⁴ (Oregon Assisted Living study)	AL and NH residents in Oregon followed for 1 year	Used the Heckman two-stage approach to model the decision to move into an AL or NH setting and then used the information about the likelihood of choosing an AL or NH (Mills ratio) to correct for selection bias in the subsequent models; ANCOVA models were used, including the Mills ratio, to determine if resident activity varied among AL and NH respondents at baseline, 6 months, 1 year, for the change from baseline to 6 months and baseline to 1 year	Activity
Marek et al., 2005 ³⁸	Medicaid HCBS Aging in Place program participants and NH residents in Missouri followed for 30 months	Individually matched NH residents were compared to HCBS participants with matching based on Medicaid eligible, ADLs (within 2 points), cognitive performance (within 1 point), age (within 4 years), and admission date (within 90 days); rank-based nonparametric methods were used for testing differences in outcomes; the baseline value of each outcome was used as the stratifying variable to further adjust for individual differences in initial status	Physical function, cognitive function, mental health/affect
^a Mitchell et al., 2004 ⁴²	A retrospective cohort of HCBS and NH users in Michigan with dementia; all persons in sample died within 1 year of admission to either HCBS or NH	Bivariate analyses were used to compare end-of-life outcomes; logistic regression for end-of-life outcomes that differed significantly ($p < 0.05$) between settings in the bivariate analyses with age, race, sex, functional status, ethnicity, cognitive status	Utilization, advance care planning, nonpalliative treatments, symptoms, other treatments

Table 16. Analysis and outcome domains (longitudinal studies) – domestic (continued)

Study	Sample/Services	Analysis	Outcome Domains
Pruchno and Rose 2000 ⁴⁴	All participants lived on a single LTC campus in Cleveland, Ohio; residents lived in AL or NH with follow-up for 15 months	(Cognitive Performance Score of 6 versus 5), and days between admission and death included as covariates in all multivariate models, with other potential confounders includes as covariates in individual models depending on the outcome being examined Logistic regression was used to estimate effects of facility on mortality; repeated ANOVA was used for cognitive status, functional ability, and depression to estimate time, facility, and time by facility interaction effects	Physical function, cognitive function, mental health/affect, mortality
Rigler et al., 2004 ⁴⁶ (Kansas Medicaid study)	Kansas Medicaid ambulatory cohort (community-dwelling older adults not receiving any HCBS or NH care during study year), HCBS cohort, and NH cohorts with follow-up for 1 year	Logistic regression was used to examine associations between level of disease burden and inappropriate medication use for each cohort separately without adjustment and with adjustment for sex, age, race, and mean total number of prescriptions per month	Harms
^a Sands et al., 2008 ⁴⁹	Medicaid recipients in Indiana with dementia who lived in the community 6 months before receiving HCBS or NH care with follow-up for 1 year	Longitudinal logistic regression was used to assess temporal trends in utilization between recipients in different settings, with probabilities adjusted for time, type of LTC, time by LTC interaction, utilization in the 6 months prior to LTC use and baseline and time-varying covariates that reached a significance level of 0.05 or less; longitudinal generalized linear models were used to assess temporal trends in expenditures including the same covariates and the expenditures in the 6 months before beginning LTC	Utilization, Costs
Shireman and Rigler 2004 ⁵¹ (Kansas Medicaid study)	Kansas Medicaid HCBS and NH cohorts with follow-up for 10-12 months	Multiple linear regression was used to test for differences in costs between the settings; all demographic and major chronic condition variables were included in the models	Costs
^a Sloane et al., 2005 ⁵³ (Collaborative Studies of Long-Term Care sub-sample)	Residential care/assisted living facility (AL) residents stratified by (a) facilities with < 16 beds; (b) facilities with ≥ 16 beds of the “new-model” type that provide nursing care and cater to an impaired population; and (c)	Modeled functional change using generalized estimating equations; modeled rates of mortality, hospitalization, and incidence of new or worsening morbidity using generalized estimating equations;	Physical function, cognitive function, mental health/affect, mortality, utilization, behavior, social function, social withdrawal, morbidity

Table 16. Analysis and outcome domains (longitudinal studies) – domestic (continued)

Study	Sample/Services	Analysis	Outcome Domains
	“traditional” facilities with ≥ 16 beds not meeting the “new-model” criteria and NH residents with dementia in four states with follow-up for 1 year	adjusted for baseline age, gender, race, education, marital status, length of stay, cognitive status, and number of comorbid conditions; to adjust for differential selection probabilities among the settings, they incorporated sampling weights into all outcome analyses	
Wieland et al., 2010 ⁵⁵	Entrants into HCBS, PACE, and NH in two counties in South Carolina with follow-up for 5 years	Kaplan-Meier curves tested with log-rank statistics for cohort survival comparisons (overall and stratified by mortality risk)	Mortality
^a Zimmerman et al., 2005 ³⁹ (Dementia Care Project study)	Residential care/assisted living facility (AL) residents stratified by (a) facilities with < 16 beds; (b) facilities with ≥ 16 beds of the “new-model” type that provide nursing care and cater to an impaired population; and (c) “traditional” facilities with ≥ 16 beds not meeting the “new-model” criteria and NH residents with dementia in four states with follow-up for 6 months	Linear mixed regression models with random effects were used to adjust the standard errors of the quality of life measures for clustering; estimated adjusted change in quality of life outcomes as the residual from regression of raw change on the baseline value	Quality-of-life

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; PACE = Program of All-Inclusive Care; ADL = Activity of Daily Living

Table 17. Analysis and outcome domains (longitudinal studies) – international

Study	Sample/Services	Analysis	Outcome Domains
Resource Implications Study Group 2000 ²²	Care-recipients receiving HCBS or NH care in the United Kingdom with follow-up for 2 years	Tested significance of changes over time in General Health Questionnaire (GHQ) score of caregivers using <i>t</i> test for paired samples	Family caregivers' psychological morbidity
McCann et al., 2009 ⁴⁰	Residents in residential homes (RH), nursing homes (NH), and dually registered residential and nursing homes (Dual) in Northern Ireland with follow-up for 5 years	Cox proportional hazards models were used to examine the relationship between resident and setting characteristics and risk of death during the 5 year follow-up adjusted for age, sex, general health, and marital status	Mortality
Rothera et al., 2002 ⁴⁵ (Nottingham study)	Residents in residential homes (RH), nursing homes (NH), and dually registered residential and nursing homes (Dual) in the United Kingdom with follow-up for 20 months	Survival function was calculated for the number of days survived within the 20 month period; univariate and multivariate Cox analyses controlling for age, gender, and prior placement were performed	Mortality

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; PACE = Program of All-Inclusive Care; ADL = Activity of Daily Living

Table 18. Analysis and outcome domains (grey literature studies) – domestic

Study	Sample/Services	Analysis	Outcome Domains
Miller et al., 2008 ⁶³ (ASPE private LTC insurance cohort)	Private LTC insurance policyholders using HCBS, AL, or NH; longitudinal panel starting at initiation of services and followed for 28 months	Multivariate logistic regression predicting mortality controlling for disability, medical conditions, and demographic characteristics at baseline; multivariate fixed effects model predicting expenditures on LTC controlling for disability, demographic characteristics, and utilization	Mortality, costs
Department of Elder Affairs, State of Florida 2009-2010 ⁶⁰	Medicaid LTC users in Florida in HCBS waiver, managed care HCBS program, AL, and NH for fiscal year 2009-10	Reports annual cost per client	Costs
Applebaum et al., 2009 ⁶¹	Medicaid LTC users in Ohio in AL waiver and NH	Reports annual Medicaid expenditures for AL and NH residents	Costs
Mehdizadeh 2007 ⁶² (Ohio HCBS Waiver)	Medicaid LTC users in Ohio in HCBS waiver and NH	Reports annual Medicaid and other public expenditures for both settings	Costs
Tucker et al., 2010 ⁶⁶	Dual eligible Medicare and Medicaid recipients in Maryland in 2006 in HCBS waiver and long-term nursing facility care	Used propensity score matching to create comparable HCBS and NH groups; reports total and component Medicare resource use and costs	Utilization, Costs

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living

Table 19. Outcome – physical function (longitudinal studies) – domestic

Study	Measure	Result	Risk of Bias Rating
Frytak et al., 2001 ³² (Oregon Assisted Living study)	Functional ability, measured as need for assistance in ADLs, over 1 year	<i>Intercept coefficient:</i> -29.863, p = 0.000 <i>Slope coefficient:</i> 0.656, p = 0.465 The type of setting (AL or NH) was strongly related to functional ability at the start of the study, but it was not significantly related to individual growth rates. Conclusions: Residents in AL and NH experienced change in physical functioning over the study period, but the change was not related to the type of setting they lived in, so there were no differences in the trajectory of physical functioning for residents in AL and NH.	High
Pruchno and Rose 2000 ⁴⁴	Mean MAI functional ability over 1 year; higher score indicates better function	There was a significant main effect for facility (AL versus NH) in the repeated ANOVA analysis, indicating that AL residents had higher mean functional scores across time compared to NH residents. The interaction term for time versus facility was not significant, indicating that there were not different trends over time in functional ability for residents in AL versus NH. Conclusions: Functional ability for residents in AL and NH did not change at different rates.	High
^a Sloane et al, 2005 ⁵³ (Collaborative Studies of Long-Term Care sub-sample)	Mean increase in ADL dependency per 12 months; measure based on MDS ADL items	Residents with mild dementia: AL 4.29, NH 5.80, p = 0.059 Residents with moderate or severe dementia: AL 0.87, NH 1.13, p = 0.807 Conclusions: Mean rates of decline in ADL dependency did not differ between residents in AL and NH for the cohort with mild dementia or for the cohort with moderate or severe dementia.	High
Marek et al., 2005 ³⁸	Mean impairment in ADLs; measured from MDS ADL items, with a range of 0-20 where higher scores indicate greater impairment	6 months: HCBS mean 1.3, NH mean 3.2, p = 0.02 12 months: HCBS mean 1.7, NH mean 3.5, p = 0.04 18 months: HCBS mean 1.4, NH mean 3.8, p = 0.08 24 months: HCBS mean 0.8, NH mean 3.2, p = 0.00 Conclusions: ADL functioning was significantly better in the HCBS group compared to the NH group at all time periods except the 18-month time period.	High

Table 16 reports analysis performed in each study

Table rows ordered by analyses of AL versus NH then by analyses of HCBS versus NH

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; ADL = Activity of Daily Living; MDS = Minimum Data Set; MAI = Multilevel Assessment Instrument

Table 20. Outcome – cognitive function (longitudinal studies) – domestic

Study	Measure	Result	Risk of Bias Rating
Pruchno and Rose 2000 ⁴⁴	Mean MMSE score over 1 year; range 0-30 with lower score indicating more impairment	There was no significant time, time by facility, or facility effects (for AL versus NH) in the repeated ANOVA analysis, indicating that residents in AL and NH had similar trends in cognitive ability over time. Conclusions: Trends in cognitive ability for AL and NH residents were similar.	High
^a Sloane et al., 2005 ⁵³ (Collaborative Studies of Long-Term Care sub-sample)	Mean increase in cognitive impairment per 12 months; measure based on MDS-COGS	Residents with mild dementia: AL 0.41, NH 0.71, p = 0.181 Residents with moderate or severe dementia: AL -0.13, NH 0.45, p = 0.093 Conclusions: Mean rates of decline in cognitive function did not differ between residents in AL and NH for the cohort with mild dementia or for the cohort with moderate or severe dementia.	High
Marek et al., 2005 ³⁸	Mean cognitive impairment; measured from MDS Cognitive Performance Scale, with a range of 0-6 where higher scores indicate greater impairment	6 months: HCBS mean 0.8, NH mean 1.4, p = 0.00 12 months: HCBS mean 0.7, NH mean 1.8, p = 0.00 18 months: HCBS mean 0.6, NH mean 1.8, p = 0.00 24 months: HCBS mean 0.8, NH mean 2.1, p = 0.38 Conclusions: Cognition was significantly better in the HCBS group compared to the NH group at the 6, 12, and 18 month time periods, but not at the 24 month time period.	High

Table 16 reports analysis performed in each study
Table rows ordered by analyses of AL versus NH then by analyses of HCBS versus NH

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; MDS = Minimum Data Set; MMSE = Mini-Mental State Examination; MDS-COGS = Minimum Data Set Cognition Scale

Table 21. Outcome – mental health/affect (longitudinal studies) – domestic

Study	Measure	Result	Risk of Bias Rating
Frytak et al., 2001 ³² (Oregon Assisted Living study)	Psychological well-being, measured by SF-36 mental health subscale, over 1 year	<i>Intercept coefficient:</i> 2.197, $p = 0.361$ <i>Slope coefficient:</i> 1.575, $p = 0.235$ Average baseline levels of psychological well-being were similar across both settings (AL and NH), and individual growth rates were insignificant. Conclusions: Residents in AL and NH experienced no change in psychological well-being on average.	High
Pruchno and Rose 2000 ⁴⁴	Mean CES-D score; higher scores indicate more depressive symptoms	There was no significant time, time by facility, or facility effects (for AL versus NH) in the repeated ANOVA analysis, indicating that residents in AL and NH had similar trends for depression over time. Conclusions: Trends in depression for AL and NH residents were similar.	High
^a Sloane et al., 2005 ⁵³ (Collaborative Studies of Long-Term Care sub-sample)	Mean increase in depressive symptoms per 12 months; measure based on CSDD	Residents with mild dementia: AL 1.33, NH 1.53, $p = 0.753$ Residents with moderate or severe dementia: AL 1.52, NH 0.85, $p = 0.409$ Conclusions: Mean rates of change in depressive symptoms did not differ between residents in AL and NH for the cohort with mild dementia or for the cohort with moderate or severe dementia.	High
Marek et al., 2005 ³⁸	Mean score on MDS-based depression rating scale; range 0-21 with lower scores indicating less depressive symptoms	Baseline: HCBS mean 0.7, NH mean 1.1, $p = 0.76$ 6 months: HCBS mean 0.5, NH mean 1.4, $p = 0.00$ 12 months: HCBS mean 0.3, NH mean 1.5, $p = 0.00$ 18 months: HCBS mean 0.5, NH mean 1.4, $p = 0.14$ 24 months: HCBS mean 0.4, NH mean 1.3, $p = 0.39$ Conclusions: Depression was significantly better in the HCBS group compared to the NH group at the 6 and 12 month time periods, but not at baseline, 18, or 24 month time periods.	High

Table 16 reports analysis performed in each study

Table rows ordered by analyses of AL versus NH then by analyses of HCBS versus NH

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; MDS = Minimum Data Set; SF-36 = Short-Form Health Survey; CES-D = Center for Epidemiological Studies Depression Scale; CSDD = Cornell Scale for Depression in Dementia

Table 22. Outcome – mortality (longitudinal studies) – domestic

Study	Measure	Result	Risk of Bias Rating
Pruchno and Rose 2000 ⁴⁴	Mortality	Facility coefficient (NH versus AL): -1.50, s.e. 0.88 The type of facility (NH versus AL) had no effect on mortality after controlling for other demographic characteristics. Conclusions: Patterns of mortality were not significantly different for residents in AL and NH.	High
^a Sloane et al., 2005 ⁵³ (Collaborative Studies of Long-Term Care sub-sample)	Mortality incidence rate per 100 participants per quarter	Residents with mild dementia: AL 3.2, NH 4.2, p = 0.409 Residents with moderate or severe dementia: AL 3.7, NH 4.2, p = 0.683 Conclusions: There were no significant differences in mortality between residents in AL and NH for the cohort with mild dementia or for the cohort with moderate or severe dementia.	High
Wieland et al., 2010 ⁵⁵	Median survival	Median survival (unstratified): HCBS 3.5 years, PACE 4.2 years, NH 2.3 years	High

Table 16 reports analysis performed in each study

Table rows ordered by analyses of AL versus NH then by analyses of HCBS versus NH

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living

Table 23. Outcome – mortality (longitudinal studies) – international

Study	Measure	Result	Risk of Bias Rating
McCann et al., 2009 ⁴⁰	Median survival; mortality risk	<p>Median survival: RH 4.51 years (3.92, 4.92), NH 2.33 years (2.25, 2.59), Dually registered homes 2.75 years (2.42, 3.17)</p> <p>Mortality risk hazard ratios: Not in care home: reference RH: 1.63 (1.44, 1.85) NH: 2.17 (1.96, 2.41) Dually registered homes: 2.09 (1.96, 2.41)</p> <p>Conclusions: Residents in nursing care homes had the highest mortality risk compared to those not in care homes.</p>	High
Rothera et al., 2002 ⁴⁸ (Nottingham study)	Mortality	<p>Mortality over 20 month period: RH 23.3%, NH 39.1%, Dually registered homes 38.4%, p<0.001</p> <p>Mortality (multivariate Cox): RH: reference NH: 1.85 (1.50, 2.23) Dually registered homes: 1.80 (1.46, 2.21)</p> <p>Conclusions: Residents in nursing and dually registered homes had higher odds of mortality than residents in residential homes.</p>	High

Table 17 reports analysis performed in each study

NH = Nursing Home; RH = Residential home; Dual = Dual registered residential and nursing home

Table 24. Outcome – mortality (grey literature studies) – domestic

Study	Measure	Result
Miller et al., 2008 ⁶³ (ASPE private LTC insurance cohort)	Mortality over 28 month study period; examined characteristics at baseline (including service setting) that predict mortality	Mortality odds ratio: Not yet receiving LTC: reference HCBS: 1.497, p = 0.039 AL: 1.329, p = 0.147 NH: 1.822, p = 0.013 The odds of mortality are highest for those receiving NH services at baseline.

Table 18 reports analysis performed in each study
AL = Assisted Living; NH = Nursing home

Table 25. Outcome – harms (longitudinal studies) – domestic

Study	Measure	Result	Risk of Bias Rating
Rigler et al., 2004 ⁴⁶ (Kansas Medicaid study)	Inappropriate medication use defined as any paid claim for an unconditionally inappropriate medication during the study year based on Beers criteria	Overall rates of any inappropriate medication use: HCBS 48%, NH 38% Conclusions: The rate of any inappropriate medication use (unadjusted) was higher in the HCBS cohort compared to the NH cohort.	High
^a Mitchell et al., 2004 ⁴²	Whether or not subjects had an advance directive; perceived life expectancy <6 months; use of feeding tube; pneumonia; daily or almost daily pain; shortness of breath; pressure ulcers; oxygen therapy in the 14 days prior to last assessment; in-dwelling bladder catheters; antianxiety agents in the 7 days prior to last assessment	Adjusted odds ratio advance directive: HCBS reference, NH 1.48 (1.11, 1.96) Adjusted odds ratio perceived life expectancy <6 months: HCBS reference, NH 0.31 (0.20, 0.48) Adjusted odds ratio feeding tube: HCBS reference, NH 1.70 (1.01, 2.84) Adjusted odds ratio pneumonia: HCBS reference, NH 2.86 (1.62, 5.04) Adjusted odds ratio daily or almost daily pain: HCBS reference, NH 0.38 (0.29, 0.50) Adjusted odds ratio shortness of breath: HCBS reference, NH 0.20 (0.13, 0.28) Adjusted odds ratio pressure ulcers: HCBS reference, NH 1.46 (1.04, 2.03) Adjusted odds ratio oxygen therapy: HCBS reference, NH 2.47 (1.51, 4.05) Adjusted odds ratio foley catheter: HCBS reference, NH 1.06 (0.73, 1.53) Adjusted odds ratio antianxiety medications: HCBS reference, NH 0.63 (0.44, 0.89)	High

Table 16 reports analysis performed in each study

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home

Table 26. Outcome – utilization (longitudinal studies) – domestic

Study	Measure	Result	Risk of Bias Rating
^a Sands et al., 2008 ⁴⁹	Monthly rate of inpatient services Monthly rate of emergency department services	The adjusted probabilities of inpatient admission were significantly higher for HCBS subjects beginning at month 5; by month 12, the adjusted probability of an inpatient admission was 0.12 for HCBS subjects compared with 0.06 for NH subjects (p<0.001); the time by type of LTC care interaction (estimate = 0.06, p = 0.05) indicates that the rate of inpatient admissions increased significantly more for HCBS subjects than for NH subjects over the 12 months. HCBS subjects were significantly more likely to use emergency department services, but HCBS and NH subjects were similar in their time trends over the 12 months; by month 12, the emergency department admission adjusted probability was 0.23 for HCBS subjects and 0.12 for NH subjects (p<0.001). Conclusions: Adjusted rates of inpatient use significantly increased for HCBS recipients with dementia over 12 months. HCBS recipients with dementia had significantly higher adjusted rates of emergency department services over 12 months.	Moderate
^a Sloane et al., 2005 ⁵³ (Collaborative Studies of Long-Term Care sub-sample)	Hospitalization reported as incidence rate per 100 participants per quarter	Residents with mild dementia: AL 14.2, NH 8.4, p = 0.009 Residents with moderate or severe dementia: AL 14.2, NH 10.0, p = 0.115 Conclusions: Hospitalization rates were significantly higher among AL residents with mild dementia than among NH residents with mild dementia, but hospitalization rates were not significantly different between AL and NH residents with moderate or severe dementia.	High
^a Mitchell et al., 2004 ⁴²	Hospitalization in 90 days prior to last MDS assessment	Adjusted odds ratio hospitalization HCBS: reference NH : 1.30 (0.98, 1.74) Conclusions: The odds of hospitalization did not differ between individuals in HCBS or in NH in the adjusted model.	High
^a Mitchell et al., 2004 ⁴²	Hospice referral any time prior to death	Adjusted odds ratio hospice referral HCBS: reference NH: 0.26 (0.16, 0.43) Conclusions: The odds of hospice referral were significantly lower among NH residents compared to HCBS clients in the adjusted model.	High

Table 16 reports analysis performed in each study

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; MDS = Minimum Data Set

Table 27. Outcome – utilization (grey literature studies) – domestic

Study	Measure	Result
Tucker et al., 2010 ⁶⁶	Medicare hospital stays; Medicare skilled nursing facility stays; Medicare physician use; Medicare outpatient use	The HCBS group had a statistically higher probability of having any hospital stay or day and more stays or days given any stay/day. The NH group had greater probability of having a skilled nursing facility stay but there was no statistically significant difference in the number of skilled nursing facility stays or days given any stay/day. The HCBS and NH group were not statistically significantly different in physician use. The NH group had statistically significantly greater outpatient use.

Table 18 reports analysis performed in each study
HCBS = Home and Community-based Services; NH = Nursing Home

Table 28. Outcome – costs (longitudinal studies) – domestic

Study	Measure	Result	Risk of Bias Rating
^a Sands et al., 2008 ⁴⁹	Monthly total Medicaid expenditure including inpatient, outpatient, pharmacy, LTC, and other expenditure	In month 1, adjusted total expenditures were \$1,419 for HCBS subjects and \$3,412 for NH subjects (p<0.001) and in month 12, adjusted total expenditures were \$2,002 for HCBS subjects and \$3,336 for NH subjects. Adjusted total expenditures significantly increased over the 12 months for the HCBS group, but remained stable for the NH group over time. Differences in total expenditures primarily can be attributed to LTC expenditures which averaged \$1,688 per month higher for NH subjects.	Moderate
Shireman and Rigler 2004 ⁵¹ (Kansas Medicaid study)	Mean monthly total Medicaid expenditures (inpatient, outpatient, prescription, and LTC)	Adjusted mean monthly expenditures for HCBS enrollees were \$1,281 (p < 0.001) lower per month than mean monthly expenditures for NH residents.	High

Table 16 reports analysis performed in each study

^aStudy focused on participants with dementia

HCBS = Home and Community-based Services; NH = Nursing Home

Table 29. Outcome – costs (grey literature studies) – domestic

Study	Measure	Result
Miller et al., 2008 ⁶³ (ASPE private LTC insurance cohort)	Monthly costs of care	Fixed-effect model coefficient results No paid LTC at baseline: reference HCBS: 0.557, p = 0.000 AL: 0.618, p = 0.000 NH: 1.133, p = 0.000 HCBS users had 56%, AL residents had 62%, and NH residents had 113% higher monthly expenditures compared to individuals who were not receiving paid care at baseline.
Department of Elder Affairs, State of Florida 2009-2010 ⁶⁰	Annual Medicaid cost per client, FY 2009-10	HCBS: \$9,026 Managed care HCBS: \$18,504 AL: \$9,902 NH payments only: \$58,055
Applebaum et al., 2009 ⁶¹	Medicaid expenditures per person, per year July 2006-March 2008	AL: \$28,678 NH: \$57,920
Mehdizadeh 2007 ⁶² (Ohio HCBS Waiver)	Medicaid expenditures per person, per year, October 2004-September 2005	HCBS: \$23,702 NH: \$55,571
Tucker et al., 2010 ⁶⁶	Total Medicare payments per member, per month in 2006; Total Medicare hospital payments per member, per month in 2006; Total Medicare skilled nursing facility payments per member per month in 2006; Total Medicare home health payments per member per month in 2006; Total Medicare hospice payment per member per month in 2006; Total Medicare physician payments per member per month in 2006; Total Medicare outpatient payments per member per month in 2006	<i>Total Medicare payments:</i> HCBS: \$1,227; NH: \$786 <i>Total hospital payments:</i> HCBS: \$545; NH: \$312 <i>Total skilled nursing facility payments:</i> HCBS: \$68; NH: \$76 <i>Total home health payments:</i> HCBS: \$89; NH: \$0 <i>Total hospice payments:</i> HCBS: \$44; NH: \$2 <i>Total physician payments:</i> HCBS: \$254; NH: \$191 <i>Total outpatient payments:</i> HCBS: \$149; NH: \$163

Table 18 reports analysis performed in each study

HCBS = Home and Community-based Services; AL = Assisted living; NH = Nursing Home

Discussion

The literature base is limited for head-to-head comparisons between HCBS (including AL) recipients and NH residents. Although a considerable body of literature in the LTC field separately addresses NH and HCBS populations, few studies directly compare the two.

Some literature examines the relative effectiveness of various programs aimed at reducing admittance to NHs, thus assuming NH admission to be a negative outcome. Yet, in reality, HCBS may not result in benefits that exceed those from care in NHs for all people, and care through HCBS may not justify increased private and public costs. (This is especially true if the individuals are unaware of their environments.) Moreover, NHs theoretically could have some benefits in quality of care domains that affect outcomes.

Several studies show that—despite some issues regarding comparable measures—the case mix is more impaired for NH residents than for HCBS recipients, but the distributions overlap. The general results for AL fall between those of NH and HCBS, but with great variation, reflecting the substantial diversity in AL. This suggests that many people could be cared for by either approach. However, the difference in care location (HCBS versus NH, or AL versus NH, or HCBS versus AL) likely reflects other concerns, especially the availability of informal support for HCBS recipients, availability of housing (including residential homes), and state and provider policies that render HCBS flexible and affordable.

Table 30 provides a summary of the conclusions and strength of evidence for the outcome domains addressed in the review. The small set of studies of generally high risk of bias that compare the trajectories of outcomes experienced by HCBS recipients and NH residents suggests that the rate of change in outcomes over time was similar for both groups.

Any comparison of outcome trajectories must take into account the differences in care environments. NH policies and environments restrict residents’ activities. For example, few, if any, NH residents are allowed to bathe by themselves, leading to measures of activities of daily living (ADLs) that reflect less ability for self-care. Additional concerns about ceiling or floor effects in these measures arise from the differences in case mix and, hence, in the starting points of any trajectory plot. Given their greater level of disability at the outset, NH residents may have less opportunity to get worse. To this consideration must be added the potential for right censoring, whereby the higher mortality rate in NHs may remove the most disabled residents. Few studies adjusted for this potential effect.

Table 30. Summary of conclusions and strength of evidence for outcome domains

Domain/outcome	Conclusions/strength of evidence
<i>Key Question 1b</i>	
Changes in physical function	The rate of change in physical function did not differ between HCBS and NH recipients over time. Low strength of evidence due to small number of studies and high risk of bias.
Changes in cognitive function	The rate of change in cognitive function did not differ between HCBS and NH recipients over time. Low strength of evidence due to small number of studies and high risk of bias.
Changes in mental health/affect	The rate of change in mental health/affect did not differ between HCBS and NH recipients over time. Low strength of evidence due to small number of studies and high risk of bias.
Mortality	Mixed evidence on mortality between HCBS and NH users, with studies finding no significant differences between HCBS and NH and higher mortality among NH. Low strength of evidence due to small number of studies and high risk of bias.
Utilization	Mixed evidence on utilization of acute care. HCBS users had higher hospital care use compared to NH in some studies but no significant difference in

Domain/outcome	Conclusions/strength of evidence
	others. Low strength of evidence due to small number of studies and high risk of bias.
Key Question 1c	
Harms	Harms were higher among HCBS users than among NH residents. Low strength of evidence due to small number of studies and high risk of bias.
Key Question 2	
Costs	NH residents had higher LTC costs. HCBS users had higher medical care costs. Total costs (measured as total Medicaid costs) were higher for NH residents. No studies addressed costs related to family burden. Low strength of evidence due to small number of studies and high risk of bias.

Studies rarely describe actual components of service in any setting. For NHs and ALs, particular settings studied will circumscribe the services potentially available, but much individual variation in care plan remains possible (if not likely). In HCBS, the service variation is potentially even greater.

Sparse literature and design problems result in a low strength of evidence for the seven outcomes we examined in detail. We found very few studies from which to draw conclusions for any given outcome of interest. Most studies did not provide detailed descriptions of settings and services received; the type, frequency, and intensity of services were often unspecified. Additionally, most studies did not report whether participants received any informal care, or how this may have affected the type, frequency, or intensity of formal care services, or how informal services may have interacted with outcomes.

Applicability is limited. Many of the samples are not generalizable because they are often small or limited by geography, or because they are drawn from specific programs that do not apply to populations outside the study.

Several factors must be considered in interpreting this body of evidence. Most studies do not adequately address the problems of selection bias or attrition. Settings where individuals are located may be largely a function of payment systems and policy environments, and they are not necessarily indicative of choice or fit. Issues of selection and case-mix complicate attempts to make indirect comparisons of the effects on trajectories. The followup times for tracing these clinical trajectories are often short.

Distinguishing long-standing from new LTC users is difficult. Few studies used an admission cohort. Outcomes may differ for those who are new to the LTC system compared with those who have lived with limitations or received services for a long period of time, but studies infrequently distinguished between the two.

The variation in outcome measures and data collection used across studies made it difficult to compare results. Outcomes may be sensitive to the measurement used. A home care version of the NH MDS is available for some programs, but the measures of presumably similar domains are not identical, especially with regard to cognition. In most instances, different people collected the data in each setting. Much of the data were collected by caregivers or other individuals working in each location.

Although policy debates about the relative merits of HCBS and NH have typically been presented as if NH and HCBS were simple, consistent concepts, and the populations served were homogeneous, the underlying empirical evidence requires more detailed examination. Specifically, comparisons between these modes of care are made more complicated by the considerable diversity in HCBS. The nature of HCBS clients and services can vary widely and complete descriptions of either are rarely presented in the analyses. AL likewise varies widely in clientele and services. Any analysis of the effectiveness of these modalities needs to describe

both the clientele and the services in enough detail to provide the necessary context and to allow for judging applicability.

Given the variation in clientele and the low likelihood of random assignment to HCBS versus NH, selection bias will continue to be a major concern, as it was with the studies reviewed here. Typical efforts to adjust for this bias, such as propensity scores, may be impeded by the large degree of heterogeneity, which would make predictive equations less accurate. Likewise, multivariate analyses would encounter similar problems. Strong candidates for instrumental variables will be hard to identify. Variation in supply is a candidate instrumental variable, but only in large-scale studies with multiple counties or areas. One promising alternative may be to use “ideal types” as subgroups. This approach identifies groups with characteristics that lead to better outcomes. It has been used in addressing diabetes care and could be applied here.⁶⁸

Given the generally weak literature to assess the relative effectiveness of HCBS and NHs, policy decisions will likely continue to be made on the basis of preferences and beliefs, largely at the policy level and perhaps at the consumer level. The paradigm for comparing HCBS and NHs has shifted over time. Whereas HCBS was earlier seen as a potentially less expensive alternative to NHs, it is now increasingly viewed as a preferable care modality that enhances clients’ quality of life. NH environments and living settings are frequently very restrictive, and few would now be surprised that quality of life was higher for those in HCBS.

HCBS and even NH services are in rapid transition, although competing trends may simply result in a continuation of the variability we have noted. One trend in HCBS is toward more flexible “consumer directed” services provided by self-employed “independent” providers. These developments may allow HCBS to offer more care and at more flexible times. A slow but growing trend in NH services is toward either smaller settings in households within a NH or small self-contained houses licensed as NHs. Privately occupied rooms are becoming more available as well. If these trends continue, we can hypothesize better quality of life outcomes for NHs than we would presently expect. The ever-shifting patterns of LTC settings make the careful measurement of the interventions even more important.

Research Gaps

The weakness of the literature stands in sharp contrast to the importance of the topic. Many stakeholders want to know about the relative effectiveness of alternative modes of LTC. As budgets tighten and as demographically driven demand increases, states and other entities are seeking more efficient ways to deliver LTC. Better research is needed.

Table 31 summarizes several issues for future research. Many of the studies we reviewed relied on administrative data sets, sometimes linked to MDS data that caregivers (facility staff) document. Designs for future research should be prospective cohort studies, preferably with direct and comparable measurement and assessment in both sectors.

Table 31. Summary of research gaps to address

Methodological Issue	Findings	Research Needs
Composition of persons served	<ul style="list-style-type: none"> NH residents were generally more disabled than HCBS clients Measures were not always comparable Method of ascertainment varies 	<ul style="list-style-type: none"> More systematic data collection using standardized measures
Outcomes measures	<ul style="list-style-type: none"> Outcome measures were not always similar across settings and weighted heavily to MDS measures 	<ul style="list-style-type: none"> Use standardized measures. Choose those most capable of showing meaningful change and measure at appropriate intervals.
Declines in function and cognition	<ul style="list-style-type: none"> Similar rates of decline for HCBS/AL recipients and NH residents Possible ceiling and/or floor effects 	<ul style="list-style-type: none"> Better analyses to examine floor and ceiling effects Better adjustment for case mix differences
Selection bias	<ul style="list-style-type: none"> Efforts to account for case mix differences were often weak 	<ul style="list-style-type: none"> More/better efforts to adjust for selection bias Propensity scores Instrumental variables Ideal types⁶⁸ Multivariate analysis Include social support and attitudes
Attrition bias	<ul style="list-style-type: none"> Attrition bias was often ignored 	<ul style="list-style-type: none"> Methods to deal with attrition, especially death Use death as worst functional case Use two stage models
Utilization of acute care	<ul style="list-style-type: none"> NH residents generally had lower utilization of hospital care 	<ul style="list-style-type: none"> More efforts to adjust for selection bias Better adjustment for case mix
Quality of life		<ul style="list-style-type: none"> Use standardized measures of QOL and social functioning applicable to both settings
Costs	<ul style="list-style-type: none"> Costs per person are generally lower for HCBS but results on aggregate Medicaid spending are inconclusive Medicare costs generally overlooked No consideration of family burden 	<ul style="list-style-type: none"> Cost comparisons should account for all relevant costs on either side of the HCBS/ NH ledger. i.e., cost of room and board, costs of public subsidies (rent, transportation and food stamps), costs of informal care provided by family members and impact on other public programs such as Medicare.
Define interventions	<ul style="list-style-type: none"> Descriptions of interventions were vague 	<ul style="list-style-type: none"> Need to carefully describe the nature and extent of the intervention
Dealing with change in status		<ul style="list-style-type: none"> How do you account for persons moving from one type of care to another?
Topical Issues	Findings	Research Needs
Longitudinal studies	<ul style="list-style-type: none"> The numbers of longitudinal studies were limited 	<ul style="list-style-type: none"> More studies that trace change in status over time
Applicability/Generalizable populations	<ul style="list-style-type: none"> Samples were often drawn from unique settings 	<ul style="list-style-type: none"> More generalizable samples
Differences within subgroups		<ul style="list-style-type: none"> More attention to samples that capture various subgroups by major problem (e.g., diagnosis, functional level) or SES Dementia may be a special problem
Defining and weighting outcomes	<ul style="list-style-type: none"> Most studies looked at discrete outcomes 	<ul style="list-style-type: none"> Determining what kind of care is best requires weighting the multiple possible outcomes. Outcomes are multidimensional. Some form of utility weighting exercise with relevant respondents is needed
Private market	<ul style="list-style-type: none"> Most studies focused on Medicaid 	<ul style="list-style-type: none"> Need studies on private pay clients

When outcomes include affective well-being, social well-being, pain, and satisfaction, among others, resident self-report is needed. Arguably, we may need more sensitive measures of outcomes. Attention needs to be given to particular problems, including accurate measurement of outcomes for persons with dementia who cannot self-report, choice of a reasonable proxy, and measures of the quality of dying and quality of life immediately before death. Care should be taken to use independent data collectors and identical instruments.

Future research needs are extensive. They reflect both methodological issues and substantive clinical and policy questions, such as the tradeoffs residents face in choosing one setting over the other. Addressing these questions will enable better analyses and will help consumers and policymakers make informed, evidence-based choices. We highlight important areas of future research, organized by key question, and provide specific recommendations for each.

Key Question 1a. To what extent do HCBS and NHs serve similar populations?

NH residents are generally more disabled than HCBS clients. However, the measures used to characterize NH and HCBS populations are not always comparable and the method of ascertainment varies. Measures of disability in NH and HCBS environments should be similar; measures should not be keyed to the supposed limitations of functioning in the nursing home in a misguided effort to provide “a level playing field.” For example, NH residents may have a lower level of disability on the bathing item because of availability of bathing equipment or help with bathing, and the solution may be to avoid that comparison. Similarly, IADLs are typically omitted in head-to-head comparisons of NH and HCBS because investigators apparently assume that NH residents will have no opportunity to prepare food, spend money, take medications, and the like. Leaving out an ADL such as bathing and most IADLs forces the comparable measures to conform to the low expectations about nursing homes, thereby suppressing the potential benefits of HCBS. Studies of benefits tend not to examine constructs of increasing policy significance such as community integration (meaning integration with a wider community than one’s own home, AL, or NH). Yet community integration is an important policy goal under the Olmstead decision, which mandated access to community care whenever feasible. Measures of social support and family functioning are also weak, in part because of the tendency to use a single family member as the informant.

Studies also need to tease out differences in the intervention. Using terms such as NH care, HCBS, and AL is insufficient; studies must carefully describe the actual interventions. Because of the considerable within-setting variation (in all settings, but especially in HCBS), the descriptors of type, frequency, and intensity of service will vary with individual client characteristics. In turn, this means that larger sample sizes will be needed to be able to allow for subgroup and interaction analyses.

Given the current attention to how some RCF or AL services are institutional in nature, further segmentation is likely to occur. As a result, not all AL now counted as HCBS will be so counted in the future. For both AL/RCF and NH, being able to discern the detailed nature of the setting in terms of privacy, autonomy, and independence-enhancing amenities will be desirable. Using general characteristics of the setting is insufficient, because some residents in both NH and AL/RCF have no access to the features that render the setting less institutional. Cutler et al. developed a method of assessing the environment as it is actually experienced by each resident in a NH.⁶⁹ Such methods would be superior to global ratings of a NH environment or even a NH unit, but they are expensive to implement.

Recommendations

- Studies that use comparable measures to characterize NH and HCBS populations. Differences in disability in NH and HCBS environments should be measured in a way that allows for examining a full range of ADL and IADL outcomes in both NHs and HCBS rather than suppressing outcomes to match the assumed limitations in a NH. The measures should allow for meaningful comparisons. For example, IADLs are typically not assessed in NHs and hence comparisons with HCBS are not possible, although they would likely show benefits from HCBS.
- The timing of measurement—the point in LTC trajectory at which the populations are compared across settings—is as important as the type of measure used.
- Benefits and harms need to be measured fully, including psychological and social benefits and harms.
- HCBS and NH service packages need careful description.

Key Question 1b. How do the service outcomes differ for similar populations?

Given the differences in case mix, comparing outcome trajectories of older adults across NHs and HCBS presents numerous analytical challenges. Randomization can increase the likelihood that NH and HCBS populations are comparable on measured as well as unmeasured factors. However, randomization to NH versus HCBS or even to NH versus AL is precluded for practical and ethical reasons.

Therefore, studies need to adjust for selection bias using statistical techniques such as multivariate analysis, propensity scores, or instrumental variables. Factors considered for adjustment should go beyond demographics, physical status, and cognitive status to include LTC attitudes of both clinicians and consumers and availability of informal support. (Frontier analysis that defines archetypes may also be used to identify specific subtypes.) In addition to adjusting for case mix, studies must account for changes in the composition of NH and HCBS populations that result from deaths or transfers to different settings. In some cases, HCBS residents may transfer to NHs. The impact of such transfers should be analyzed and interpreted.

Outcome measures should define and measure resident experiences in NHs and HCBS across multiple domains, including quality of life and social functioning.

Ultimately, the choice between NH and HCBS involves competing goals and necessary tradeoffs (for example, independence and safety). Comparing NHs and HCBS along multiple domains will provide LTC users with information that helps them to better evaluate NH or HCBS settings based on their needs, preferences, and values.

Key Question 1c. What are the harms to older adults as a result of HCBS and NHs?

Studies of comparative harms must take into account psychological and social harms as well as physical and functional harms. Hypothetically, loss of identity, helplessness, and depression are risks of NH care (and perhaps some AL environments as well). These outcomes are rarely looked at as harms, and indeed, sometimes investigators use depressive affect to risk-adjust away the impact of negative self-report when in fact the setting may cause the depressed affect. A distinction must be made between endogenous and situational depression.

Also, studies will need to tease out harms attributable to treatment, such as overmedication, undermedication, or inappropriate medication. For example, cognitive function becomes a

reasonable outcome to examine if one considers the possibility that treatments and environments increase confusion.

KQ1 Summary of Research Gaps

- Longitudinal studies should adjust for selection bias using statistical techniques such as multivariate analysis, propensity score methods, or instrumental variables. Studies should adjust for attrition as a result of deaths or transfers of residents to other settings.
- Studies should follow admission cohorts through various stages of LTC service use and evaluate transfers between settings.
- Subgroup analyses should capture major groups defined by diagnosis, functional capacity, socio-economic indicators, and access to care.
- Studies of comparative harms must take into account psychological and social harms as well as physical and functional harms

Key Question 2. Comparative costs of NH and HCBS per person and in the aggregate from an individual and societal perspective

Costs of LTC are typically measured in terms of Medicaid expenditures. However, these expenditures represent only a portion of the total costs, in two ways. First, LTC outlays can be seen in both Medicare and private insurance (e.g., MediGap). Second, payment by public and private programs ignores several other sources of direct or indirect spending.

Thus, from a societal perspective, costs of LTC should include costs borne by other public programs such as Medicare and the costs borne by individuals and their families. This will enable policymakers to have a true cost comparison and will perhaps help them avoid shifting costs from one program to another, between state and federal funds, and from formal to informal care. True cost comparisons between HCBS and NH should account for all relevant costs on both sides of the HCBS/NH ledger including:

- Cost of room and board (included in NH but not usually in HCBS costs).
- Cost of public subsidies such as Title XX, housing subsidies, aging services through Older Americans Act or Title XX, (available to HCBS consumers but not to NH residents).
- Costs of informal care (financed by family members or provided as in-kind services) may often be substantial and are worth consideration, especially if family contributions and care have negative effects on the care-providing family member. Family contributions occur in both HCBS and NHs, although they are likely greater in HCBS. Measuring and monetizing these contributions are both very difficult analytic steps, however. In addition, investigators may overestimate costs of family care if they rely on accounts of what family members do, because much of what they do in both HCBS and NHs falls in the realm of family relationships rather than care per se (e.g., visiting relatives, going on outings with them, and supplying food). In addition, some of what family or informal caregivers do is discretionary (e.g., doing laundry for a NH resident in the family home to improve quality of laundry). Estimating the cost of family care in HCBS is a very difficult conceptual problem for live-in relatives.
- Utilization of hospital and emergency care and primary medical care is covered by Medicare for elderly or dually eligible beneficiaries.
- Private pay clients should be further studied. Most of our information comparing NHs and HCBS comes from the Medicaid population.

KQ 2 Future Research Needs Summary

- Studies should compare NH and HCBS costs, accounting for individual as well as total costs. Costs should be viewed from a societal perspective and should include impact on public programs such as Medicare.
- Studies of costs for non-Medicaid LTC users are needed.

Current or Ongoing Studies

A study by a University of Pennsylvania team, headed by Mary Naylor, is just completing its analysis phase. The final sample (468 English- and Spanish-speaking older adults who had recently begun to receive LTC) has been recruited (156 from nursing homes, 156 from assisted living facilities; 156 from their homes). Quarterly interviews with these older adults designed to elicit data regarding changes in multiple dimensions of health and quality of life will continue for 2 years; these data will be supplemented by medical record data (e.g., use of health resources) and survey data (e.g., major organizational changes). Data collection on the last few participants enrolled in the study will be completed in early summer of 2012. In addition to a number of presentations, a paper on the conceptual model used to guide this effort is under review.

References

1. Feder J, Komisar H.L., M. N. Long-term care in the United States: an overview. *Health Affairs*. 2000;19(3):40-56.
2. Feinberg L, Reinhard S, Houser A. Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving. Washington, DC: Institute APP; 2011.
3. Stone RI, Reinhard SC. Place of assisted living in long-term care and related service systems. *Gerontologist*. 2007;47(Special Issue 3):23-32.
4. Kane RA, Cutler LJ. Promoting Homelike Characteristics and Eliminating Institutional Characteristics in Community-Based Residential Care Settings: Insights from an 8-State Study. *Seniors Housing and Care Journal*. 2009;17(1):15-37.
5. Kaye HS, Harrington C, LaPlante MP. Long-term care: who gets it, who provides it, who pays, and how much? *Health Affairs*. 2010;29(1):11-21.
6. National Council on Disability. The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities. 2005.
7. U.S. Dept. of Health and Human Services. Who Needs Long-Term Care? National Clearing House for Long-Term Care Information. 2008. http://www.longtermcare.gov/LTC/Main_Site/Understanding_Long_Term_Care/Basics/Basics.aspx
8. AARP Public Policy Institute. Fact Sheet: Nursing Homes. 2007. <http://www.aarp.org/research/ppi/>.
9. Centers for Disease Control and Prevention (CDC). Nursing Home Care report. 2009.
10. Kaiser Commission on Medicaid and the Uninsured. Medicaid Home and Community-Based Service Programs: Data Update. 2009. http://www.kff.org/medicaid/upload/2186_06.pdf.
11. American Health Care Association. Medicaid-Financed Home and Community-Based Services Research/A Synthesis. 2007.
12. Kemper P. The Evaluation of the National Long-Term Care Demonstration. *Health Services Research*. 1988;23(1):161-73.
13. Weiner J. State Cost Containment Initiatives for Long-Term Care Services for Older People Congressional Research Service. 2000.
14. Levine SA, Boal J., et al. Home Care. *JAMA*. 2003;290:1203-7.
15. Kaye HS, LaPlante MP, Harrington C. Do noninstitutional long-term care services reduce Medicaid spending? *Health Aff (Millwood)*. 2009 Jan-Feb;28(1):262-72. PMID 19124878.
16. Morris JN, Fries BE, Steel K, et al. Comprehensive clinical assessment in community setting: applicability of the MDS-HC. *J Am Geriatr Soc*. 1997 Aug;45(8):1017-24. PMID 9256857.
17. Liberati A, Altman DG, Tetzlaff J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *J Clin Epidemiol*. 2009 Oct;62(10):e1-34. PMID 19631507.
18. Agency for Healthcare Research and Quality. Assessing the Quality and Applicability of Included Studies. In: Agency for Healthcare Research and Quality, ed *Methods Reference Guide for Effectiveness and Comparative Effectiveness Reviews*. Rockville, MD: Agency for Healthcare Research and Quality,; 2007.
19. Viswanathan M, Berkman ND. Development of an Item Bank on Risk of Bias and Precision of Observational Studies. *Journal of Clinical Epidemiology*. 2011;Forthcoming.
20. Owens DK, Lohr KN, Atkins D, et al. AHRQ series paper 5: grading the strength of a body of evidence when comparing medical interventions--agency for healthcare research and quality and the effective health-care program. *Journal of Clinical Epidemiology*. 2010 May;63(5):513-23. PMID 19595577.
21. Atkins D, Chang SM, Gartlehner G, et al. Assessing applicability when comparing medical interventions: AHRQ and the Effective Health Care Program. *J Clin Epidemiol*. 2011 Nov;64(11):1198-207. PMID 21463926.
22. Psychological morbidity among informal caregivers of older people: a 2-year follow-up study. The Resource Implications Study Group of the MRC study of cognitive function and ageing (RIS MRC CFAAS). *Psychological Medicine*. 2000;30(4):943-55. PMID 11037102.
23. Applebaum RA, Mehdizadeh SA, Straker JK. The changing world of long-term care: a state perspective. *Journal of Aging & Social Policy*. 2004;16(1):1-19. PMID 15040704.
24. Beattie ERA, Song J, LaGore S. A comparison of wandering behavior in nursing homes and assisted living facilities. *Research & Theory for Nursing Practice*. 2005;19(2):181-96. PMID 16025697.

25. Boersma F, Eefsting JA, van den Brink W, et al. Care services for dementia patients: predictors for service utilization. *International Journal of Geriatric Psychiatry*. 1997;12(11):1119-26. PMID 9427096.
26. Borrayo EA, Salmon JR, Polivka L, et al. Utilization across the continuum of long-term care services. *Gerontologist*. 2002;42(5):603-12. PMID 12351795.
27. Challis D, Mozley CG, Sutcliffe C, et al. Dependency in older people recently admitted to care homes. *Age & Ageing*. 2000;29(3):255-60. PMID 10855909.
28. Chappell NL, Dlott BH, Hollander MJ, et al. Comparative costs of home care and residential care. *Gerontologist*. 2004;44(3):389-400. PMID 15197293.
29. Doty P, Cohen MA, Miller J, et al. Private long-term care insurance: value to claimants and implications for long-term care financing. *Gerontologist*. 2010;50(5):613-22. PMID 20299425.
30. Edelman P, Fulton BR, Kuhn D, et al. A comparison of three methods of measuring dementia-specific quality of life: perspectives of residents, staff, and observers. *Gerontologist*. 2005 Oct;45 Spec No 1(1):27-36. PMID 16230747.
31. Franks JS. Comparing Perceived Quality of Life in Nursing Homes and Assisted Living Facilities. *Journal of Gerontological Social Work*. 2004;43(1):119-30. PMID 14590069.
32. Frytak JR, Kane RA, Finch MD, et al. Outcome trajectories for assisted living and nursing facility residents in Oregon. *Health Services Research*. 2001;36(1 Pt 1):91-111. PMID 11324746.
33. Gaugler JE. Family Involvement and Resident Psychosocial Status in Long-Term Care. *Clinical Gerontologist*. 2006;29(4):79-98. PMID 22624576.
34. Gaugler JE, Kane RA. Activity Outcomes for Assisted Living Residents Compared to Nursing Home Residents: Findings from a Longitudinal Study. *Activities, Adaptation & Aging*. 2005;29(3):33-58. PMID 18418292.
35. Gruber-Baldini AL, Zimmerman S, Boustani M, et al. Characteristics associated with depression in long-term care residents with dementia. *Gerontologist*. 2005;45(Special Issue 1):50-5.
36. Lee T, Kovner CT, Mezey MD, et al. Factors influencing long-term home care utilization by the older population: implications for targeting. *Public Health Nursing*. 2001;18(6):443-9. PMID 11737813.
37. Leon J, Moyer D. Potential cost savings in residential care for Alzheimer's disease patients. *Gerontologist*. 1999;39(4):440-9. PMID 10495582.
38. Marek KD, Popejoy L, Petroski G, et al. Clinical outcomes of aging in place. *Nurs Res*. 2005 May-Jun;54(3):202-11. PMID 15897796.
39. Margallo-Lana M, Swann A, O'Brien J, et al. Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments. *International Journal of Geriatric Psychiatry*. 2001;16(1):39-44. PMID 11180484.
40. McCann M, O'Reilly D, Cardwell C. A Census-based longitudinal study of variations in survival amongst residents of nursing and residential homes in Northern Ireland. *Age & Ageing*. 2009;38(6):711-7. PMID 19752201.
41. Mehdizadeh SA. Health and Long-Term Care Use Trajectories of Older Disabled Women. *Gerontologist*. 2002;42(3):304-13. PMID 6815490.
42. Mitchell SL, Morris JN, Park PS, et al. Terminal care for persons with advanced dementia in the nursing home and home care settings. *Journal of Palliative Medicine*. 2004;7(6):808-16. PMID 15684848.
43. Port CL, Zimmerman S, Williams CS, et al. Families filling the gap: comparing family involvement for assisted living and nursing home residents. *Gerontologist*. 2005;45(Special Issue 1):87-95.
44. Pruchno RA, Rose MS. Effect of long-term care environments on health outcomes. *Gerontologist*. 2000;40(4):422-8.
45. Reinardy J, Kane RA. Choosing an adult foster home or a nursing home: residents' perceptions about decision making and control. *Soc Work*. 1999 Nov;44(6):571-85. PMID 10568028.
46. Rigler SK, Perera S, Jachna C, et al. Comparison of the association between disease burden and inappropriate medication use across three cohorts of older adults. *American Journal of Geriatric Pharmacotherapy*. 2004;2(4):239-47. PMID 15903282.
47. Rothera I, Jones R, Harwood R, et al. Health status and assessed need for a cohort of older people admitted to nursing and residential homes. *Age & Ageing*. 2003;32(3):303-9. PMID 12720617.
48. Rothera IC, Jones R, Harwood R, et al. Survival in a cohort of social services placements in nursing and residential homes: factors associated with life expectancy and mortality. *Public Health*. 2002;116(3):160-5. PMID 12082598.

49. Sands LP, Xu H, Weiner M, et al. Comparison of resource utilization for Medicaid dementia patients using nursing homes versus home and community based waivers for long-term care. *Medical Care*. 2008;46(4):449-53. PMID 18362827.
50. Schroeder JM, Nau KL, Osness WH, et al. A comparison of life satisfaction, functional ability, physical characteristics, and activity level among older adults in various living settings. *Journal of Aging & Physical Activity*. 1998;6(4):340-9. PMID SPHS-18451.
51. Shireman TI, Rigler SK. Penny wise, pound wise: a comparison of Medicaid expenditures for home and community-based services versus nursing facility care for older adults. *Home Health Care Services Quarterly*. 2004;23(4):15-28. PMID 15778150.
52. Shugarman LR, Fries BE, James M. A comparison of home care clients and nursing home residents: can community based care keep the elderly and disabled at home? *Home Health Care Serv Q*. 1999;18(1):25-45. PMID 10947561.
53. Sloane PD, Zimmerman S, Gruber-Baldini AL, et al. Health and functional outcomes and health care utilization of persons with dementia in residential care and assisted living facilities: comparison with nursing homes. *Gerontologist*. 2005;45 Spec No 1(1):124-32. PMID 16230759.
54. Sloane PD, Zimmerman S, Hanson L, et al. End-of-life care in assisted living and related residential care settings: comparison with nursing homes. *Journal of the American Geriatrics Society*. 2003;51(11):1587-94. PMID 14687388.
55. Wieland D, Boland R, Baskins J, et al. Five-Year Survival in a Program of All-Inclusive Care For Elderly Compared With Alternative Institutional and Home- and Community-Based Care. *Journals of Gerontology: Series A: Biological Sciences and Medical Sciences*. 2010;65A(7):721-6.
56. Williams CS, Zimmerman S, Sloane PD, et al. Characteristics associated with pain in long-term care residents with dementia. *Gerontologist*. 2005;45(Special Issue 1):68-73.
57. Wodchis WP, Hirdes JP, Feeny DH. Health-related quality of life measure based on the minimum data set. *International Journal of Technology Assessment in Health Care*. 2003;19(3):490-506. PMID 12962335.
58. Zimmerman S, Gruber-Baldini AL, Sloane PD, et al. Assisted living and nursing homes: apples and oranges? *Gerontologist*. 2003;43(Special Issue 2):107-17. PMID 95573. Note: Included in special issue "Challenges in Nursing Home Care," with guest editors Jill Quadagno, Sidney Stahl, and Laurence G. Branch.
59. Zimmerman S, Sloane PD, Williams CS, et al. Dementia care and quality of life in assisted living and nursing homes. *Gerontologist*. 2005;45(Special Issue 1):133-46.
60. Long-Term Care Community Diversion Pilot Project 2009-2010 Legislative Report Prepared by Department of Elder Affairs State of Florida. 2011. <http://elderaffairs.state.fl.us/english/legis/2009%20Long-Term%20Care%20Community%20Diversion%20Pilot%20Project%20Annual%20Report.pdf>.
61. Applebaum R, Wellin V, Mehdizadeh S, et al. An Evaluation of the Assisted Living Medicaid Waiver Program Prepared by the Scripps Gerontology Center, Benjamin Rose Institute, and Jesse Richardson Foundation. Oxford, OH: March 2009. <http://www.scripps.muohio.edu/sites/scripps.muohio.edu/files/AssistedLivingMedicaidWaiverProgramfinal.pdf>.
62. Mehdizadeh S. PASSPORT Cost Neutrality: How Do the Total Medicaid and Other Public Costs of Maintaining a PASSPORT Consumer in the Community Compare to That of a Nursing Facility Resident? Scripps Gerontology Center Miami University. Oxford, OH: May 2007.
63. Miller JS, Shi X, Cohen MA. Private Long-Term Care Insurance: Following an Admission Cohort over 28 Months to Track Claim Experience, Service Use and Transitions Prepared by LifePlans, Inc. for the Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services under Contract #HHS-100-02-0014. Washington, D.C.: April 2008. <http://aspe.hhs.gov/daltcp/reports/2008/coht28mo.pdf>.
64. Ormond BA, Sommers AS, Black KJ. Examination of Texas Rider 37: A Medicaid "Money Follows the Person" Long-Term Care Initiative Prepared by The Urban Institute for the Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services under Contract #HHS-100-03-0011. Washington, D.C.: May 2006. <http://aspe.hhs.gov/daltcp/reports/2006/TXltc.pdf>.

65. Spillman BC, Liu K, McGuilliard C. Trends in Residential Long-Term Care: Use of Nursing Homes and Assisted Living and Characteristics of Facilities and Residents Prepared by The Urban Institute for the Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services under Contract #HHS-100-97-0010. Washington, D.C.: November 2002. <http://aspe.hhs.gov/daltcp/reports/2002/rltct.pdf>.
66. Tucker A, Johnson K, Huang Y, et al. Examining the Medicare Resource Use of Dually Eligible Medicaid Recipients The Hilltop Institute, UMBC. Baltimore, MD: January 2010.
67. Youngs D, Clifford C, Perry S. Michigan Nursing Facility Transition Initiative: Project Evaluation Report Transition Component Prepared by DYNs Services, Inc. & Center for Information Management, Inc. for the Michigan Department of Community Health, Mental Health and Substance Abuse Administration, Division of Community Living from the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services under Grant Number P-91667/5. 2005. http://www.dynsinc.com/Documents/NFTI%20Evaluation%20Transition%20Final%20Report_1.pdf.
68. Johnson PE, Veazie PJ, Kochevar L, et al. Understanding variation in chronic disease outcomes. Health Care Manag Sci. 2002 Aug;5(3):175-89. PMID 12363045.
69. Cutler LJ, Kane RA, Degenholtz HB, et al. Assessing and comparing physical environments for nursing home residents: Using new tools for greater specificity. The Gerontologist. 2006;45(1):42-51.

Abbreviations

ADL	Activities of daily living
AGECAT	Automated Geriatric Examination Computer Assisted Taxonomy
AHRQ	Agency for Healthcare Research and Quality
AL	Assisted living
CAMDEX	Cambridge Examination for Mental disorders of the Elderly
CDRS	Clinical Dementia Rating Score
CES-D	Center for Epidemiological Studies Depression Scale
CHIP	Children's Health Insurance Program
CIRS-g	Cumulative Illness Rating Scale for Geriatrics
COPD	Chronic obstructive pulmonary disease
CPS	Cognitive Performance Score
CSDD	Cornell Scale for Depression in Dementia
EPC	Evidence-based Practice Center
HCBS	Home and community-based services
IADL	Instrumental activities of daily living
LTC	Long-term care
MAI	Multilevel Assessment Instrument
MDS	Minimum Data Set
MDS-COGS	Minimum Data Set Cognition Scale
MDS-HC	Minimum Data Set – Home Care version
MMSE	Mini-Mental State Exam
MSQ	Mental Status Questionnaire
NH	Nursing home
NR	Not reported
NS	Not significant
PACE	Program of All-Inclusive Care for the Elderly
PGC-PIS	Philadelphia Geriatric Center-Pain Intensity Scale
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCF	Residential care facilities
RCTs	Randomized controlled trials
RH	Residential Home
RTI-UNC	RTI International-University of North Carolina
SF-36	Short-form Health Survey (Medical Outcomes Study Short-form 36)
SPMSQ	Short Portable Mental Status Questionnaire
SWLS	Satisfaction with Life Scale
TEP	Technical Expert Panel