Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

HHS Public Access

Author manuscript

J Am Med Dir Assoc. Author manuscript; available in PMC 2021 February 13.

Published in final edited form as:

J Am Med Dir Assoc. 2021 February ; 22(2): 471–473. doi:10.1016/j.jamda.2020.11.036.

Health Care Needs in Assisted Living: Survey Data May Underestimate Chronic Conditions

Sheryl Zimmerman[1], **Wenhan Guo**[2], **Yunjiao Mao**[2], **Yue Li**[2], **Helena Temkin-Greener**[2]

[1]Cecil G. Sheps Center for Health Services Research and Schools of Social Work and Public Health, University of North Carolina at Chapel Hill, NC, USA

[2]Department of Public Health Sciences, University of Rochester School of Medicine and Dentistry, Rochester, NY, USA

Research using electronic and administrative databases has become increasingly common in post-acute and long-term care – so much so that its use has been conjectured to surpass that based on primary purposive data collection.[1] The benefits of these databases include the large number of observations they contain and the relative ease with which they can be accessed. Data from the National Nursing Home Survey enabled widescale research on nationally representative U.S. samples over more than 30 years,[2] and the availability of the Minimum Data Set (MDS) in 1991[3] expanded nursing home research across the globe; to date, PubMed shows more than 1200 research papers have been published using MDS data. However, while MDS data seem to contain valid indicators of conditions such as nutritional status, incontinence, and many others,[4,5] data accuracy in other areas has been challenged, including related to sleep, medication use, oral hygiene, and payment source.[6,7] Thus, research based on administrative databases must be cautiously interpreted.

This caution is important for assisted living (AL) data as well. National data reporting the status of more than 811,000 older adults residing in 28,900 AL communities across the U.S. [8] have been available since 2010 through the National Survey of Residential Care Facilities, subsequently relaunched as the National Study of Long-Term Care Providers (NSLTCP), and renamed in 2020 the National Post-acute and Long-term Care Study (NPALS).[9] To obtain these data, the AL administrator/executive director completes a self-administered questionnaire, which invites the respondent to consult records and other staff as needed. Questions related to residents (for example, about chronic conditions) are worded “Of the residents currently living in this residential care community, about how many have been diagnosed with each of the following conditions?”[10] These data too must be interpreted cautiously, a case in point being that a variable as key as which residents have dementia differs depending on the items used to derive it.[11] Internal considerations aside, these data are and will remain an important source of information related to AL and the residents who live there.

Address correspondence to: Sheryl Zimmerman, PhD, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, 725 Martin Luther King Jr. Boulevard, Campus Box 7590, Chapel Hill, North Carolina 27599-7590, Sheryl_Zimmerman@unc.edu.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Although AL communities are not required and do not report data on their residents' conditions to any central agency, new analytic methods using zipcodes have enabled the use of Medicare enrollment and claims data to learn about AL residents and their health care.[12,13] This information sheds light on potential discrepancies in information provided by survey versus administrative data. We employed our national directory of AL communities and linked it to the Medicare Enrollment database using 9-digit zipcodes corresponding to the physical AL address. This strategy allowed us to obtained the 2018 Master Beneficiary Summary File (MBSF) for Medicare beneficiaries residing in AL communities.[12] From the MBSF, we identified 455,686 unique Medicare beneficiaries (464,487 resident stays) residing in 28,753 AL communities. We compared these data to data from the 2016 NSLTCP, stratified by size (bed size for the NSLTCP, number of beneficiaries for the MBSF). The table shows that the prevalence of all chronic conditions other than Alzheimer's disease is notably higher in the MBSF data than in the NSLTCP data (e.g., arthritis, 63% vs. 42%). Within the MBSF data, the percent of conditions among residents in communities with 26–50 beneficiaries was not exceeded in any other size stratum; this distribution is not the case in the NSLTCP data, in which the smallest communities evidenced the highest rates of dementia and depression. Although it is not possible to accurately compare health care utilization across the datasets (the NSLTCP measured percent in the last 90 days, whereas the MBSF data reflect use in the last year), the latter indicates 37% of AL residents had an emergency department visit in the last year, and 11% had an an inpatient hospital stay. Thus, not only are their chronic conditions notable, so too are their health care needs.

The data sources necessitate two caveats to these comparisons. The data were collected in different years, but a marked increase in the prevalence of chronic conditions over two years is not likely. In addition, the MBSF data include only Medicare beneficiaries (although virtually all AL residents are Medicare eligible),[14] who may be more likely to receive health care and have chronic conditions than the general AL population. Caveats aside, it is highly likely that chronic conditions of AL residents are underestimated by the NSLTCP and its successor, the NPALS, at least in part because AL staff do not fully know or document residents' medical conditions. Discussions about the need for health care in AL[15,16] must be informed by accurate understanding of the chronic and other health conditions of AL residents.

REFERENCES

1. Sloane PD, Mor V, Preisser JS. Administrative data for research: an increasingly powerful tool, but still with caveats. J Am Med Dir Assoc 2018 2;19(2):97–99. [PubMed: 29413395]
2. Centers for Disease Control and Prevention. National Nursing Home Survey. https://www.cdc.gov/nchs/nnhs/index.htm Accessed on October 20, 2020.
3. Rahman AN, Applebaum RA. The nursing home Minimum Data Set assessment instrument: manifest functions and unintended consequences--past, present, and future. Gerontologist 2009;49(6):727–735. [PubMed: 19531805]
4. Blaum CS, O'Neill EF, Clements KM, et al. Validity of the Minimum Data Set for assessing nutritional status in nursing home residents. Am J Clin Nutr 1997;66(4):787–794. [PubMed: 9322551]
5. Resnick NM, Brandeis GH, Baumann MM, Morris JN. Evaluating a national assessment strategy for urinary incontinence in nursing home residents: reliability of the Minimum Data Set and validity of the Resident Assessment Protocol. Neurourol Urodyn 1996;15(6):583–598. [PubMed: 8916112]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

6. Martin JL, Alessi CA. Limited validity of Minimum Data Set items on sleep and hypnotic use in predicting falls and hip fracture in nursing home residents. J Am Geriatr Soc 2006;54(7):1150–1151. [PubMed: 16866697]
7. Zimmerman S, Austin S, Cohen L, et al. Readily identifiable risk factors of nursing home residents' oral hygiene: dementia, hospice, and length of stay. J Am Geriatr Soc 2017;65(11):2516–2521. [PubMed: 29023625]
8. Harris-Kojetin L, Sengupta M, Lendon JP, et al. Long-term care providers and services users in the United States, 2015–2016. National Center for Health Statistics. Vital Health Stat 3(43). 2019.
9. Centers for Disease Control and Prevention. National Post-acute and Long-term Care Study. https://www.cdc.gov/nchs/npals/about_npals.htm Accessed on October 20, 2020.
10. National Study of Long-Term Care Providers: 2016 Residential Community Questionnaire. https://www.cdc.gov/nchs/data/nsltcp/NSLTCP_RCC_Questionnaire_Version_A.pdf Accessed on November 18, 2020.
11. Zimmerman S, Sloane PD, Reed D. Dementia prevalence and care in assisted living. Health Aff (Millwood) 2014;33(4):658–666. [PubMed: 24711328]
12. Thomas KS, Dosa D, Gozalo PL, et al. A methodology to identify a cohort of Medicare beneficiaries residing in large assisted living facilities using administrative data. Med Care. 2018 2;56(2):e10–e15. doi: 10.1097/MLR.0000000000000659. [PubMed: 27820597]
13. Temkin-Greener H, Guo W, Mao Y, et al. COVID-19 pandemic in assisted living communities: results from seven states. J Am Geriatr Soc. 2020 9 21:10.1111/jgs.16850. doi: 10.1111/jgs.16850 Epub ahead of print.
14. Phillips CD, Holan S, Sherman M, Spector W, Hawes C. Medicare expenditures for residents in assisted living: data from a national study. Health Serv Res 2005;40(2):373–388. [PubMed: 15762897]
15. Katz PR, Kronhaus A, Fuller S. The role of physicians practicing in assisted living: time for change. J Am Med Dir Assoc 2018;19(2):102–103. [PubMed: 29289539]
16. Resnick B, Allen J, McMahon E; American Assisted Living Nurses Association. The role of physicians practicing in assisted living: what changes do we really need? J Am Med Dir Assoc 2018;19(2):104–105. [PubMed: 29413392]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Table.

Percent distribution of assisted living resident characteristics by data source

Resident characteristics	2016 National Study of Long-Term Care Providers				2018 Master Beneficiary Summary File (MBSF)[a]			
	4–25 beds	26–50 beds	> 50 beds	All sizes	4–25 beneficiaries	26–50 beneficiaries	> 50 beneficiaries	All sizes
Female[b]	67	72	71	71	63	67	66	65
Non-Hispanic white[b]	80	88	80	81	80	90	90	86
Age[b]								
< 65	16	7	4	7	12	7	4	8
65–74	13	10	11	11	30	14	12	19
74–85	27	30	31	30	20	25	28	25
≥ 85	44	52	54	52	39	54	55	49
Medicaid recipient[b]	25	18	14	17	23	23	15	19
Medical/health conditions								
Alzheimer's disease/ other dementia[b]	51	44	39	42	38	47	38	39
Arthritis[c]	--	--	--	42	57	67	67	63
Asthma[c]	--	--	--	7	16	18	17	17
Chronic kidney disease[c]	--	--	--	8	40	47	42	42
Chronic obstructive pulmonary disease[c]	--	--	--	14	32	36	32	33
Depression[b]	37	32	29	31	50	57	49	51
Diabetes[b]	19	18	18	18	38	42	37	38
Heart disease[b]	32	35	35	34	35	43	38	38
Hypertension[c]	--	--	--	51	74	83	81	78
Osteoporosis[c]	--	--	--	24	27	35	35	32
Emergency department visit[b,d]	14	14	14	14	37	42	38	37
Overnight hospital stay[b,d]	7	9	9	8	12	13	10	11

--: Not reported

[a] Limiting the smallest category of the MBSF to a minimum of 4 beneficiaries (as opposed to a minimum of 1 beneficiary) resulted in a population of 437,022 unique Medicare beneficiaries (445,194 resident days) residing in 18,784 AL communities.

[b] Source: Caffrey C, Sengupta M. Variation in residential care community resident characteristics, by size of community: United States, 2016. NCHS Data Brief, no 299. Hyattsville, MD: National Center for Health Statistics. 2018.

[c] Source: Harris-Kojetin L, Sengupta M, Lendon JP, Rome V, Valverde R, Caffrey C. Long-term care providers and services users in the United States, 2015–2016. National Center for Health Statistics. Vital Health Stat 3(43). 2019.

[d] In NSLTCP, measured as percent in last 90 days; in MBSF, measured as percent of residents having at least one emergency visit or hospital stay in the calendar year.

Author Manuscript
Author Manuscript
Author Manuscript
Author Manuscript