Assisted Living Facility Quality Measures:

An environmental scan

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As a culminating experience of the Master of Nursing program at University of Washington, Tacoma, School of Nursing, fieldwork placement with the Washington State Department of Social and Health Services, Aging and Long Term Support Administration with Candace Goehring MN, Director of Residential Care Services and Cathy McAvoy, ALF Outcome Improvement Program Manager was undertaken. The opportunity learn first-hand policy and program development, legislative and policy support was achieved by participating in the implementation of legislation to design of quality metrics measures for Assisted Living Facilities (HB 2750). This report is provided to summarize an aspect of the activity performed during the field work experience.

Background

The information gathering phase of quality measure development benefits from a using a framework of methodical searching on multiple levels. Quality measures can vary widely as built to serve the goals of across domains of health, facilities and quality of life, to name just a few. To keep focused on the State of Washington's Assisted Living Facility Quality Metrics Workgroup to identify measures meant for use by the public, a targeted environmental scan was designed to cover evidence, measures, and access to reports.

Environmental Scan

An environmental scan consisting of a literature review, quality measure inventory, and a state-by-state internet search. The goal of the scan is to identify evidence supporting the work of the Washington state Department of Aging, Assisted Living Facilities

Literature Review

To discover information that would inform the selection of quality metrics for assisted living facilities, a search of peer-reviewed literature was undertaken. Using the University of

Washington Tacoma Library, the PubMed database was searched using the Medical Subject Headers (MeSH) phrase "Assisted Living Facilities"[Mesh] AND “quality.” Articles were restricted to literature published in the past 5 years and filtered for English language and availability of abstracts. The 104 results were exported to the RefWorks citation management system. Citations underwent a first-level review and articles related specifically to quality of medical care were culled; 56 articles remained.

To support the process of a second-level review, full citations for the final 56 articles were exported from RefWorks into a table (Table 1) with three analysis categories listed. Citations were reviewed and categorized as either related to quality of health, quality of life, or quality of resources. By judgment of the reviewer based on knowledge of the ALF Quality Metrics Workgroup goals, eight articles were selected for standing out as relevant to the discussions of the ALF workgroup. Full text Topics of these articles included resident-focused studies of desired quality conditions, and recommendations for an ideal ALF environment. Full text copies of these articles are included in the appendix:

1. Bennett, C. R., Frankowski, A. C., Rubinstein, R. L., Peeples, A. D., Perez, R., Nemec, M., & Tucker, G. G. (2017) studied Visitors and resident autonomy: Spoken and unspoken rules in assisted living.
2. Han, K., Trinkoff, A. M., Storr, C. L., Lerner, N., & Yang, B. K. (2017). Variation across U.S. assisted living facilities: Admissions, resident care needs, and staffing. Journal of Nursing Scholarship : An Official Publication of Sigma Theta Tau International Honor Society of Nursing, 49(1), 24-32. doi:10.1111/jnu.12262 [doi]
3. Holup, A. A., Dobbs, D., Temple, A., & Hyer, K. (2014). Going digital: Adoption of electronic health records in assisted living facilities.Journal of Applied Gerontology : The

Official Journal of the Southern Gerontological Society, 33(4), 494-504. doi:10.1177/0733464812454009 [doi]

4. Kemp, C. L., Ball, M. M., Morgan, J. C., Doyle, P. J., Burgess, E. O., Dillard, J. A., . . . Perkins, M. M. (2017). Exposing the backstage: Critical reflections on a longitudinal qualitative study of residents' care networks in assisted living. Qualitative Health Research, 27(8), 1190-1202. doi:10.1177/1049732316668817 [doi]
5. Koehn, S. D., Mahmood, A. N., & Stott-Eveneshen, S. (2016) published Quality of life for diverse older adults in assisted living: The centrality of control. *Journal of Gerontological Social Work*
6. Naylor, M. D., Hirschman, K. B., Hanlon, A. L., Abbott, K. M., Bowles, K. H., Foust, J., . . . Zubritsky, C. (2016) reported factors associated with changes in perceived quality of life among elderly recipients of long-term services and supports. *Journal of the American Medical Directors Association*
7. Siegel, C., Hochgatterer, A., & Dorner, T. E. (2014) described contributions of ambient assisted living for health and quality of life in the elderly and care services--a qualitative analysis from the experts' perspective of care service professionals. *BMC Geriatrics*
8. Speller, B., & Stolee, P. (2015) reported Client safety in assisted living: Perspectives from clients, personal support workers and administrative staff in Toronto, Canada. *Health & Social Care in the Community*

Quality Measure Inventory

A scan for existing assisted living facility quality measures was undertaken. The National Quality Forum's (NQF) Quality Positioning System (QPS) was accessed and the search term "Assisted Living Facility" was entered. Of the eight measures produced, four are no longer endorsed by NQF. Of the four endorsed NQF measures related to Assisted Living Facilities, two are related to clinical outcomes of patients who transitioned from assisted living facilities to inpatient care. Two NQF-endorsed measures remain (Figure 1):

1. NQF 3420: CoreQ: AL Resident Satisfaction Measure by American Health Care Association/National Center for Assisted Living. This measure evaluates resident satisfaction through use of the CoreQ: AL Resident Satisfaction Questionnaire.
2. NQF 3422: CoreQ: AL Family Satisfaction Measure by American Health Care Association/National Center for Assisted Living. This measure evaluates family satisfaction through use of the CoreQ: AL Family Satisfaction Questionnaire.

An additional search was performed using the Centers for Medicare and Medicaid Services (CMS) Measures Inventory Tool (CMIT). This database is a collection of all quality and performance measures used for federal payment programs. The initial search returned three measures:

- Percentage of Participants Not in Nursing Homes, designed for use in the Program of All-Inclusive Care for the Elderly (PACE) (Development)
- Discharge to Community-Post Acute Care (PAC) Skilled Nursing Facility Quality, Reporting Program (Required under the IMPACT Act), considered for use in the Skilled Nursing Facility Quality Reporting program
- PointRight Pro Long Stay(TM) Hospitalization Measure, not currently active in any federal payment program

State-by-State Internet Search

A state-by-state internet search was performed to emulate the experience of a prospective ALF resident or family member seeking information about the quality of ALF facilities. Using a standard internet browser, a search was executed using the terms “Assisted Living Facilities” and “quality measures” and “[name of state]”. The searches were performed with “Location Services” turned off to prevent skewing of results by physical location where search was performed. After eliminating any websites marked as paid advertisements, a sample of three sites for each state was documented and reviewed. This assessment demonstrated that quality metric information using this commonly used methodology resulted in limited objective or easy-to-consume information. Currently the top categories of internet sources for ALF quality information available to potential ALF residents via the internet are, in descending order of frequency across multiple states:

- ALF-Lookup
- Consumer Health Ratings – Quality and Cost Guides | Doctor Reviews | Hospitals
- McKnight’s Long Term Care News
- Senior Home Blog
- Blogs produced by elder law attorneys
- State government ALF reports

Of note, the states of Washington and Wisconsin are the only two states whose state-sponsored services appeared first on the search return lists. Also of interest, none of the state websites with current consumer-facing ALF quality measurement programs appeared in the first pages of results using this search engine approach. This may be due to targeted paid promotion of websites by the website domain owners.

As each web site was subjectively viewed, examples of sites considered most usable for their clarity, objectivity, ease of reading and navigation are:

Maryland Health Care Commission

Choose Well in San Diego County

Delaware Long Term Care Guide

Table 3 provides the results of the internet research and includes information for each state.

Discussion

Three levels of environmental scanning were undertaken with the goal to inform the work of the State of Washington Assisted Living Facilities Quality Metrics Workgroup. The literature review revealed over 50 articles related to the topic of quality and Assisted Living Facilities; of these, 8 stood out as especially relevant to the work of the group. While working to identify quality metrics to support resident choice for selection of assisted living facilities, use of peer-reviewed publications can provide the groundwork for measures that matter.

The search of existing quality measures for assisted living facilities revealed a paucity of current measures available for in federal programs. The CoreQ-based measure was developed by the American Health Care Association/National Center for Assisted Living. As the work of the Washington state ALF QM Workgroup evolves, support for development of additional measures is encouraged.

An internet search for public-facing web sites that report ALF quality metrics revealed that little information can be easily-obtained by the public. Once the ALF QM workgroup determines which measures to use, attention to how the information can be promoted on internet browsers should be paid. The best of measures will have limited value if the public has difficulty obtaining access to them.

Conclusion

This environmental scan reported the current state of quality metrics for Assisted Living Facilities. The scan demonstrated that while peer-reviewed literature is available to recommend domains for quality reporting attention, yet limited quality measures have been produced. State and national resources will be necessary to build a library of available ALF quality measures.

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Table 1

REFERENCE	**HEALTH**	**LIFE**	**RESOURCES**
Bekhet, A. K., & Zauszniewski, J. A. (2014). Chronic conditions in elders in assisted living facilities: Associations with daily functioning, self-assessed health, and depressive symptoms. *Archives of Psychiatric Nursing, 28*(6), 399-404. doi:10.1016/j.apnu.2014.08.013 [doi]	**X**		
Bennett, C. R., Frankowski, A. C., Rubinstein, R. L., Peeples, A. D., Perez, R., Nemec, M., & Tucker, G. G. (2017). Visitors and resident autonomy: Spoken and unspoken rules in assisted living. *The Gerontologist, 57*(2), 252-260. doi:10.1093/geront/gnv079 [doi]		**X**	
Carder, P. C. (2017). State regulatory approaches for dementia care in residential care and assisted living. *The Gerontologist, 57*(4), 776-786. doi:10.1093/geront/gnw197 [doi]	**X**		
Carryer, J., Weststrate, J., Yeung, P., Rodgers, V., Towers, A., & Jones, M. (2017). Prevalence of key care indicators of pressure injuries, incontinence, malnutrition, and falls among older adults living in nursing homes in new zealand. *Research in Nursing & Health, 40*(6), 555-563. doi:10.1002/nur.21835 [doi]	**X**		
da Silva Serelli, L., Reis, R. C., Laks, J., de Padua, A. C., Bottino, C. M., & Caramelli, P. (2017). Effects of the staff training for assisted living residences protocol for caregivers of older adults with dementia: A pilot study in the brazilian population. *Geriatrics & Gerontology International, 17*(3), 449-455. doi:10.1111/ggi.12742 [doi]			**X**
Fetherstonhaugh, D., Tarzia, L., Bauer, M., Nay, R., & Beattie, E. (2016). "The red dress or the blue?": How do staff perceive that they support decision making for people with dementia living in residential aged care facilities? *Journal of Applied Gerontology : The Official Journal of the Southern Gerontological Society, 35*(2), 209-226. doi:10.1177/0733464814531089 [doi]			**X**
Galambos, C., Starr, J., Musterman, K., & Rantz, M. (2015). Staff perceptions of social work student contributions to home health care services at an independent living facility. *Home Healthcare Now, 33*(4), 206-214. doi:10.1097/NHH.0000000000000215 [doi]			**X**

Gendron, T. L., Pryor, J. M., & Welleford, E. A. (2017). Lessons learned from a program evaluation of a statewide continuing education program for staff members working in assisted living and adult day care centers in virginia. *Journal of Applied Gerontology : The Official Journal of the Southern Gerontological Society, 36*(5), 610-628. doi:10.1177/0733464816633124 [doi]			**X**
Graybill, E. M., McMeekin, P., & Wildman, J. (2014). Can aging in place be cost effective? A systematic review. *PloS One, 9*(7), e102705. doi:10.1371/journal.pone.0102705 [doi]			**X**
Gudowsky, N., & Sotoudeh, M. (2015). Citizens' visions on active assisted living. *Studies in Health Technology and Informatics, 212*, 43-49.			
Han, K., Trinkoff, A. M., Storr, C. L., Lerner, N., & Yang, B. K. (2017). Variation across U.S. assisted living facilities: Admissions, resident care needs, and staffing. *Journal of Nursing Scholarship : An Official Publication of Sigma Theta Tau International Honor Society of Nursing, 49*(1), 24-32. doi:10.1111/jnu.12262 [doi]			
Harrison, S. L., Bradley, C., Milte, R., Liu, E., Kouladjian O'Donnell, L., Hilmer, S. N., & Crotty, M. (2018). Psychotropic medications in older people in residential care facilities and associations with quality of life: A cross-sectional study. *BMC Geriatrics, 18*(1), 0. doi:10.1186/s12877-018-0752-0 [doi]	**X**		
Hauer, K. (2015). Quality of assistive technologies in the home care for elderly. *Studies in Health Technology and Informatics, 212*, 134-140.	**X**		
Holmes, S. D., Galik, E., & Resnick, B. (2017). Factors that influence physical activity among residents in assisted living. *Journal of Gerontological Social Work, 60*(2), 120-137. doi:10.1080/01634372.2016.1269035 [doi]	**X**		
Holup, A. A., Dobbs, D., Temple, A., & Hyer, K. (2014). Going digital: Adoption of electronic health records in assisted living facilities.*Journal of Applied Gerontology : The Official Journal of the Southern Gerontological Society, 33*(4), 494-504. doi:10.1177/0733464812454009 [doi]			
Hossain, M. A., Alamri, A., Almogren, A. S., Hossain, S. K., & Parra, J. (2014). A framework for a context-aware elderly entertainment support system. *Sensors (Basel, Switzerland), 14*(6), 10538-10561. doi:10.3390/s140610538 [doi]			**X**

Hummer, D. B., Silva, S. G., Yap, T. L., Toles, M., & Anderson, R. A. (2015). Implementation of an exercise program in an assisted living facility. *Journal of Nursing Care Quality, 30*(4), 373-379. doi:10.1097/NCQ.0000000000000125 [doi]	**X**		
Jao, Y. L., Algase, D. L., Specht, J. K., & Williams, K. (2015). The association between characteristics of care environments and apathy in residents with dementia in long-term care facilities. *The Gerontologist, 55 Suppl 1*, 27. doi:10.1093/geront/gnu166 [doi]	**X**		
Jyvakorpi, S. K., Pitkala, K. H., Puranen, T. M., Bjorkman, M. P., Kautiainen, H., Strandberg, T. E., . . . Suominen, M. H. (2016). High proportions of older people with normal nutritional status have poor protein intake and low diet quality. *Archives of Gerontology and Geriatrics, 67*, 40-45. doi:10.1016/j.archger.2016.06.012 [doi]	**X**		
Kaskie, B. P., Nattinger, M., & Potter, A. (2015). Policies to protect persons with dementia in assisted living: Deja vu all over again?*The Gerontologist, 55*(2), 199-209. doi:10.1093/geront/gnu179 [doi]	**X**		
Kemp, C. L., Ball, M. M., Morgan, J. C., Doyle, P. J., Burgess, E. O., Dillard, J. A., . . . Perkins, M. M. (2017). Exposing the backstage: Critical reflections on a longitudinal qualitative study of residents' care networks in assisted living. *Qualitative Health Research, 27*(8), 1190-1202. doi:10.1177/1049732316668817 [doi]			
Kemp, C. L., Ball, M. M., Morgan, J. C., Doyle, P. J., Burgess, E. O., & Perkins, M. M. (2018). Maneuvering together, apart, and at odds: Residents' care convoys in assisted living. *The Journals of Gerontology.Series B, Psychological Sciences and Social Sciences, 73*(4), e23. doi:10.1093/geronb/gbx184 [doi]		**X**	
Koceska, N., Koceski, S., Beomonte Zobel, P., Trajkovik, V., & Garcia, N. (2019). A telemedicine robot system for assisted and independent living. *Sensors (Basel, Switzerland), 19*(4), 10.3390/s19040834. doi:E834 [pii]			**X**
Koehn, S. D., Mahmood, A. N., & Stott-Eveneshen, S. (2016). Quality of life for diverse older adults in assisted living: The centrality of control. *Journal of Gerontological Social Work, 59*(7-8), 512-536. doi:10.1080/01634372.2016.1254699 [doi]		**X**	

Kriegel, J., Reckwitz, L., Auinger, K., Tuttle-Weidinger, L., Schmitt-Ruth, S., & Kranzl-Nagl, R. (2017). New service excellence model for eHealth and AAL solutions - A framework for continuous new service development. *Studies in Health Technology and Informatics, 236*, 275-281.			**X**
Kroemeke, A., & Gruszczynska, E. (2016). Well-being and institutional care in older adults: Cross-sectional and time effects of provided and received support. *PloS One, 11*(8), e0161328. doi:10.1371/journal.pone.0161328 [doi]		**X**	
Laditka, S. B. (2017). "It can't happen soon enough." the role of readiness in residential moves by older parents. *The Gerontologist, 57*(1), 6-11. doi:10.1093/geront/gnw101 [doi]		**X**	
Lauze, M., Martel, D. D., & Aubertin-Leheudre, M. (2017). Feasibility and effects of a physical activity program using gerontechnology in assisted living communities for older adults. *Journal of the American Medical Directors Association, 18*(12), 1069-1075. doi:S1525-8610(17)30373-0 [pii]		**X**	
Matthews, F. E., Bennett, H., Wittenberg, R., Jagger, C., Dening, T., Brayne, C., & Cognitive Function, Ageing Studies (CFAS) collaboration. (2016). Who lives where and does it matter? changes in the health profiles of older people living in long term care and the community over two decades in a high income country. *PloS One, 11*(9), e0161705. doi:10.1371/journal.pone.0161705 [doi]		**X**	
Murphy, K., Liu, W. W., Goltz, D., Fixsen, E., Kirchner, S., Hu, J., & White, H. (2018). Implementation of personalized music listening for assisted living residents with dementia. *Geriatric Nursing (New York, N.Y.), 39*(5), 560-565. doi:S0197-4572(18)30137-X [pii]	**X**		
Nattinger, M. C., & Kaskie, B. (2017). Determinants of the rigor of state protection policies for persons with dementia in assisted living. *Journal of Aging & Social Policy, 29*(2), 123-142. doi:10.1080/08959420.2016.1236324 [doi]	**X**		
Nauha, L., Keranen, N. S., Kangas, M., Jamsa, T., & Reponen, J. (2018). Assistive technologies at home for people with a memory disorder. *Dementia (London, England), 17*(7), 909-923. doi:10.1177/1471301216674816 [doi]			**X**

Navarro, J., Vidana-Vila, E., Alsina-Pages, R. M., & Hervas, M. (2018). Real-time distributed architecture for remote acoustic elderly monitoring in residential-scale ambient assisted living scenarios. *Sensors (Basel, Switzerland), 18*(8), 10.3390/s18082492. doi:E2492 [pii]			**X**
Naylor, M. D., Hirschman, K. B., Hanlon, A. L., Abbott, K. M., Bowles, K. H., Foust, J., . . . Zubritsky, C. (2016). Factors associated with changes in perceived quality of life among elderly recipients of long-term services and supports. *Journal of the American Medical Directors Association, 17*(1), 44-52. doi:10.1016/j.jamda.2015.07.019 [doi]		**X**	
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Rikard, R. V., Berkowsky, R. W., & Cotten, S. R. (2018). Discontinued information and communication technology usage among older adults in continuing care retirement communities in the united states. *Gerontology, 64*(2), 188-200. doi:10.1159/000482017 [doi]		**X**	
Robison, D., McInnis-Perry, G., Weeks, L. E., & Foley, V. (2018). Dignity in older adults with schizophrenia residing in assisted living facilities. *Journal of Psychosocial Nursing and Mental Health Services, 56*(2), 20-28. doi:10.3928/02793695-20170929-01 [doi]	**X**		
Saarela, R. K. T., Muurinen, S., Suominen, M. H., Savikko, N. N., Soini, H., & Pitkala, K. H. (2017). Changes in malnutrition and quality of nutritional care among aged residents in all nursing homes and assisted living facilities in helsinki 2003-2011. *Archives of Gerontology and Geriatrics, 72*, 169-173. doi:S0167-4943(17)30241-8 [pii]	**X**		
Schwartze, J., Prekazi, A., Schrom, H., & Marschollek, M. (2017). Substitution of assisted living services by assistive technology - experts opinions and technical feasibility. *Studies in Health Technology and Informatics, 238*, 116-119.			**X**

Siegel, C., Hochgatterer, A., & Dorner, T. E. (2014). Contributions of ambient assisted living for health and quality of life in the elderly and care services--a qualitative analysis from the experts' perspective of care service professionals. *BMC Geriatrics, 14*, 112. doi:10.1186/1471-2318-14-112 [doi]		**X**	
Siegel, C., Prazak-Aram, B., Kropf, J., Kundi, M., & Dorner, T. (2014). Evaluation of a modular scalable system for silver-ager located in assisted living homes in austria--study protocol of the ModuLAAr ambient assisted living project. *BMC Public Health, 14*, 736. doi:10.1186/1471-2458-14-736 [doi]		**X**	
Simmons, S. F., Coelho, C. S., Sandler, A., Shah, A. S., & Schnelle, J. F. (2018). Managing person-centered dementia care in an assisted living facility: Staffing and time considerations. *The Gerontologist, 58*(4), e259. doi:10.1093/geront/gnx089 [doi]	**X**		
Sloane, P. D., Zimmerman, S., & D'Souza, M. F. (2014). What will long-term care be like in 2040? *North Carolina Medical Journal, 75*(5), 326-330. doi:75505 [pii]			**X**
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Theou, O., Tan, E. C., Bell, J. S., Emery, T., Robson, L., Morley, J. E., . . . Visvanathan, R. (2016). Frailty levels in residential aged care facilities measured using the frailty index and FRAIL-NH scale. *Journal of the American Geriatrics Society, 64*(11), e212. doi:10.1111/jgs.14490 [doi]	**X**		
Thomas, K. S., Dosa, D., Gozalo, P. L., Grabowski, D. C., Nazareno, J., Makineni, R., & Mor, V. (2018). A methodology to identify a cohort of medicare beneficiaries residing in large assisted living facilities using administrative data. *Medical Care, 56*(2), e15. doi:10.1097/MLR.0000000000000659 [doi]			**X**

Tynan, A., Deeth, L., & McKenzie, D. (2018). An integrated oral health program for rural residential aged care facilities: A mixed methods comparative study. *BMC Health Services Research, 18*(1), 5. doi:10.1186/s12913-018-3321-5 [doi]	**X**		
Vandenberg, A. E., Ball, M. M., Kemp, C. L., Doyle, P. J., Fritz, M., Halpin, S., . . . Perkins, M. M. (2018). Contours of "here": Phenomenology of space for assisted living residents approaching end of life. *Journal of Aging Studies, 47*, 72-83. doi:S0890-4065(17)30390-0 [pii]		**X**	
Wijk, H., Corazzini, K., Kjellberg, I. L., Kinnander, A., Alexiou, E., & Swedberg, K. (2018). Person-centered incontinence care in residential care facilities for older adults with cognitive decline: Feasibility and preliminary effects on quality of life and quality of care.*Journal of Gerontological Nursing, 44*(11), 10-19. doi:10.3928/00989134-20181010-04 [doi]	**X**		
Winstead, V., Yost, E. A., Cotten, S. R., Berkowsky, R. W., & Anderson, W. A. (2014). The impact of activity interventions on the well-being of older adults in continuing care communities. *Journal of Applied Gerontology : The Official Journal of the Southern Gerontological Society, 33*(7), 888-911. doi:10.1177/0733464814537701 [doi]		**X**	
Zimmerman, S., Allen, J., Cohen, L. W., Pinkowitz, J., Reed, D., Coffey, W. O., . . . University of North Carolina-Center for Excellence in Assisted Living Collaborative. (2015). A measure of person-centered practices in assisted living: The PC-PAL. *Journal of the American Medical Directors Association, 16*(2), 132-137. doi:10.1016/j.jamda.2014.07.016 [doi]		**X**	
Zimmerman, S., Greene, A., Sloane, P. D., Mitchell, M., Giuliani, C., Nyrop, K., & Walsh, E. (2017). Preventing falls in assisted living: Results of a quality improvement pilot study. *Geriatric Nursing (New York, N.Y.), 38*(3), 185-191. doi:S0197-4572(16)30212-9 [pii]	**X**		

Table 2: Internet Search Results

STATE	WEBSITE(S)
Alabama	https://consumerhealthratings.com/healthcare_category/alabama/ https://www.mcknights.com/news/products/poarch-band-of-creek-indians-opens-assisted-living-facility/ http://alflookup.com/ALABAMA/WILCOX/CAMDENNURSINGFACILITYINC.html
Alaska	http://dhss.alaska.gov/dhcs/pages/cl/all/default.aspx https://www.seniorly.com/assisted-living/alaska http://dhss.alaska.gov/dhcs/Pages/hflc/fac_LTC.aspx https://www.prestigecare.com/blog/news-and-updates/community-and-resources/prestige-care-and-rehabilitation-center-of-anchorage-awarded-for-outstanding-patient-care
Arizona	https://azalfa.org/homepage/guiding-principles/ https://www.azahcccs.gov/Members/ProgramsAndCoveredServices/ https://www.seniorliving.org/arizona/ https://health.usnews.com/best-nursing-homes/area/az/advanced-healthcare-of-mesa-035266
Arkansas	https://aspe.hhs.gov/system/files/pdf/110531/15alcom-AR.pdf https://arhealthcare.com/about-us/assisted-living https://health.usnews.com/best-nursing-homes/area/ar/meadowview-healthcare-and-rehabilitation-045341 https://www.ahcancal.org/ncal/Pages/index.aspx
California	https://consumerhealthratings.com/healthcare_category/state-inspection-reports-and-quality-ratings-long-term-care/ https://www.assistedlivingfacilities.org/resources/choosing-an-assisted-living-facility/making-sense-of-assisted-living-ratings/ https://consumerhealthratings.com/healthcare_category/find-a-nursing-home-assisted-living-facility-geriatric-or-senior-care/ https://choosewellsandiego.org/ https://www.chcf.org/publication/2013-edition-long-term-care-california-ready-tomorrows-seniors/ https://academic.oup.com/gerontologist/article/47/suppl_1/40/614181
Colorado	https://www.assistedseniorliving.net/facilities/colorado/aurora-co/ https://static1.squarespace.com/static/5b3aa3744cde7ae1090463ad/t/5be1d3ea032be41f24c12fb0/1541526508563/LTCCC-Report-on-Assisted-Living.pdf https://theconsumervoice.org/uploads/files/long-term-care-recipient/Residential-Care-and-AL-Compendium07-Report.pdf
Connecticut	https://consumerhealthratings.com/healthcare_category/connecticut/

	https://www.iadvanceseniorcare.com/ https://www.huduser.gov/portal/sites/default/files/pdf/Assuring-Quality-in-Assisted-Living-Guidelines.pdf
Delaware	https://courts.delaware.gov/forms/download.aspx?id=84418 https://www.dhss.delaware.gov/dhss/dsaapd/files/long_term_care_guide.pdf https://consumerhealthratings.com/healthcare_category/delaware/
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Michigan	http://meji.org/topics/long-term-care http://region7aaa.org/assets/Index-of-Fact-Sheets2.pdf

	https://www.jimschuster.com/2019/01/
Minnesota	https://www.ag.state.mn.us/Consumer/Publications/NursingHomesAssistedLiving.asp https://www.lawhelpmn.org/self-help-library/seniors/assisted-living-and-nursing-homes https://consumerhealthratings.com/healthcare_category/minnesota/
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New Hampshire	https://consumerhealthratings.com/healthcare_category/new-hampshire/ https://link.springer.com/article/10.1007/s11149-018-9351-4 https://www.assistedlivingconnections.com/picking-the-right-skilled-nursing-facility/
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	https://ltcombudsman.org/uploads/files/support/nm-2013.pdf https://consumerhealthratings.com/healthcare_category/new-mexico/
New York	https://khn.org/news/assisted-livings-breakneck-growth-leaves-patient-safety-behind/ https://www.nytimes.com/2018/12/13/business/assisted-living-violations-dementia-alzheimers.html https://www.governing.com/gov-institute/voices/col-private-accreditation-oversight-national-standards-assisted-living.html
North Carolina	http://classic.ncmedicaljournal.com/wp-content/uploads/2014/03/NCMJ_75-5.pdf https://mountainx.com/news/navigating-wncs-long-term-care-options/ http://alflookup.com/NORTHCAROLINA/CATAWBA/CONOVERNURSINGANDREHABCTR.html
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Ohio	https://ltc.ohio.gov/NursingHomes.aspx https://www.jstor.org/stable/23273823?seq=1#page_scan_tab_contents http://www.mariettatimes.com/news/2017/05/ratings-reveal-nursing-home-scores/
Oklahoma	https://www.mcknights.com/news/medicaid-payments-tied-to-quality-measures/ https://consumerhealthratings.com/healthcare_category/oklahoma/ http://alflookup.com/OKLAHOMA/KAY/WILLOWHAVEN.html
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Pennsylvania	https://www.mcknights.com/blogs/guest-columns/evaluating-al-versus-personal-care-homes-in-pa/ http://alflookup.com/PENNSYLVANIA/centre/HEARTHSIDEREHABILITATIONANDNURSING.html https://www.seniorliving.org/companies/elmcroft-senior-living/
Rhode Island	https://www.m-n-law.com/rhode-island/personal-injury-attorney/nursing-home-abuse/how-to-choose-a-rhode-island-nursing-home/ https://centershealthcare.com/glossary/

	http://www.seniorhomeblog.com/content/senior-home/assisted-living/forand-manor
South Carolina	https://www.nursinghomelawcenter.org/news/nursing-home-chains/when-it-comes-to-governmental-oversight-assisted-living-residents-are-on-their-own/ https://www.independentmail.com/story/news/local/2017/03/30/question-care-upstate-nursing-homes/99584338/ https://scnursinghomelaw.com/category/ombudsman/
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Texas	https://txhca.org/quality-care https://txhca.org/nhqa http://www.ltco.org/resources1.aspx
Utah	https://www.uthca.org/members/join-as-assisted-living-facility http://slcsuperiorhomecare.com/about-us/ http://alflookup.com/utah/emery/EMERYCOUNTYCARE.html
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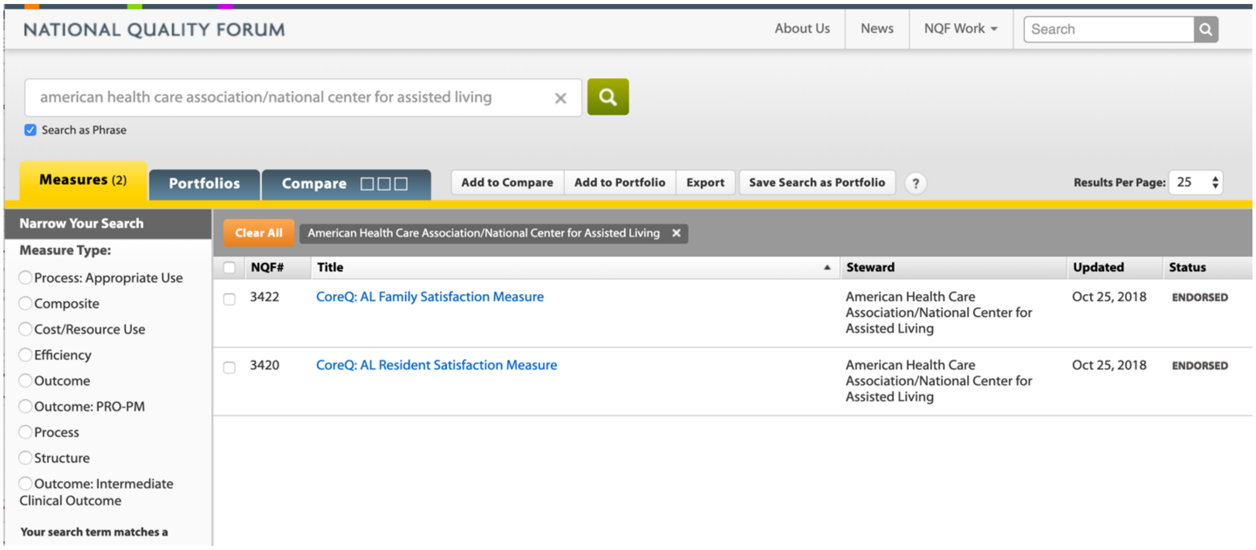
Wyoming	https://health.wyo.gov/aging/hls/educational-training-materials/ https://www.wyoleg.gov/InterimCommittee/2016/10-0825AppendixH.pdf https://www.senioradvice.com/nursing-homes

Figure 1



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Research Article

Visitors and Resident Autonomy: Spoken and Unspoken Rules in Assisted Living

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Abstract

Purpose of the Study: This article explores resident autonomy in assisted living (AL) and the effects that visitors and visiting the AL have on that autonomy. We examine formal and informal policies that govern visiting in AL, stakeholders' views and enforcement of these policies, and the complex arrangements that visiting often entails in everyday life in the setting.
Design and Methods: Data are drawn from a multiyear ethnographic study of autonomy in AL. Research from multiple sites included participant observation, informal and in-depth, open-ended interviews of various stakeholders, and the writing of field notes. Research team biweekly discussions and the Atlas.ti software program facilitated coding and analysis of interview transcripts and fieldnotes.
Results: Our ethnographic data highlight complicated factors related to visitors and visiting in AL. We discuss two important aspects of visiting: (a) formal and informal policies at each setting; and (b) how resident autonomy is expressed or suppressed through rules about visiting in AL.
Implications: Our data underscore the importance of resident autonomy and quality of care in relation to visitors and visiting, especially how this relationship is affected by inconsistent and confusing formal and informal visiting policies in AL.

Keywords: Social networks, Environment or support, Visiting, Formal and informal rules, Residential care

Many older adults in the United States live in long-term care (LTC) settings and the numbers will increase (Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013). While nursing homes (NHs) are among the most widely recognized LTC setting, they house only 2.8% of the over-65 population at any one time (Centers for Medicare & Medicaid Services [CMS], 2013). In response to consumer demand for housing that enhances personal autonomy and dignity, and reflecting public policy to control LTC costs, assisted living (AL) was developed as an alternate residential approach to care for dependent older adults. The needs of dependent older adults range widely. Many needs for activities of daily living (ADLs), such as dressing or toileting, or instrumental activities of daily living (IADLs), such as using a telephone or maintaining personal medications, may be manageable in independent or community residential settings. However, for those individuals who lack a support to continue to age in their own homes, AL was developed as a home-like setting for older adults with acute needs and specifically as a setting that respects resident autonomy. That AL provides a social model of care is an important tenet of AL philosophy. Unlike NHs, which are medical facilities, AL is situated within the larger community and therefore the presence of visitors is, or should be, a normative part of AL life.

This article focuses on two aspects of ALs: resident autonomy and visiting by outsiders. When individuals move into a specialized residential care setting, their social needs are usually addressed in a variety of ways, both internally through programmed activities and externally through visits by family and friends. Both recognition and satisfaction of the social needs of residents are key among the more complex factors of resident autonomy and overall wellbeing.

Based upon our research, this article examines the relationship between resident autonomy in AL and the circumstances of visiting and visitors. We examine formal and informal AL policies on visiting as well as stakeholders'—residents, family members, frontline staff, and administrators—views on these policies as well as the effects of family on social support. Finally, after a background discussion of care issues and a description of our research methodologies, we describe and discuss our findings drawn from data collected at five AL settings over 4 years.

Background

The Growth of AL

There are estimated to be between 36,000 to 68,000 ALs in the United States, serving more than one million residents (Burdick et al., 2005; Eckert, Carder, Morgan, Frankowski, & Roth, 2009; Stefanacci & Podrazik, 2005). While definitions of AL and related forms of residential care may vary by state (Genworth Financial, 2014), there are a number of common features of AL. For example, as many as 90% of AL settings provide assistance with medication management and an additional ADL or IADL (Eckert et al., 2009). AL expanded upon earlier forms of housing into what has been referred to as "high-service, high-privacy" sector (Hawes, Phillips, Rose, Holan, & Sherman, 2003; McCormick & Chulis, 2003). For the purposes of this article, AL will refer to settings that provide room, board, and assistance with ADLs at a non-NH or nonskilled level of care (Gruber-Baldini, Boustani, Sloan, & Zimmerman, 2004; Zimmerman et al., 2005). ALs are usually required by state regulations to coordinate the following services: 24-hr care staff and oversight; provision for help with ADLs and IADLs; health-related services; social services; recreational activities; meals; housekeeping and laundry; and transportation services (Niles-Yokum & Wagner, 2011; Stefanacci & Podrazik, 2005). ALs vary widely in both type and culture. They differ in the extent to which they are willing to admit residents with high care needs, retain residents as their needs change over time, or tolerate degrees of resident autonomy. The services available in ALs may be dependent on philosophy of care, the financial balance-sheet, and on residents' ability to pay (Golant & Salmon, 2004). Further, the availability of services to residents can vary significantly. Some settings have formal arrangements with home health agencies to provide episodic nursing care and assistance with ADLs; some may even encourage residents to leave the AL to attend adult day activity programs in lieu of providing their own (Genworth Financial, 2010). In general, ALs aspire to aid resident autonomy through emphasis on availability of choices and a focus on resident dignity and privacy (Butler, Gomon, & Turner, 2004). Despite the fact that some AL residents may resemble NH residents in acuity, all ALs are *in theory* nonmedical, community-based living arrangements that are not licensed as NHs and therefore do not undergo federal supervision. It is estimated that over 80% of AL residents require assistance with at least one ADL, and over 90% of residents need help with an IADL (Stefanacci & Podrazik, 2005). Understanding life in AL settings, as well as the issues faced by residents and staff members, is complicated as definitions of AL vary from state to state; additionally, AL companies, both non- and for-profit, may use unique designations for levels of care that make generalizations about services and care difficult.

Unfortunately, there has been minimal research on ALs as places of living or as environments analyzed from the residents' points of view. In addition, until recently, there has been almost no research exploring residents' experiences of personal autonomy and the social environment in these settings. This article is a contribution to these topics.

Autonomy

For the research described in this article, autonomy was defined as the ability of the individual to make and carry out decisions about how, with whom, when, and where to spend one's time. The subjective meaning of autonomy for AL residents reflects larger cultural ideas on control and freedom, on personal predilection for self-administration, on a person's assessment of her own state of health and functioning, and, significantly, on opportunities for or limitations to autonomy provided by the AL itself (Ball et al., 2004; Carder, 2002). Autonomy as a *cultural construct* is related most directly to the emphasis on individualism in the United States and its operationalization through control and the making of choices (Eckersley, 2006). The culturally constructed desire to experience autonomy is a deep part of American life and personhood. Americans interpret this cultural goal through a powerful discourse that suggests the preeminent values of control, choice, freedom, and agency, which are tied to the core cultural value of autonomy. Autonomy and agency also relate to issues of power, an important concern in AL (Holstein & Gubrium, 2000). Additionally, part of the discourse of autonomy reflects questions about the social permeability of the AL setting—who can enter and who must stay out—and the degree to which an AL can be freely accessed for social purposes by outsiders such as family and friends of residents (Jackson, Sullivan, & Harnish, 1996).

Maintaining autonomy is also central to quality of life for older adults (Ball et al., 2004; Steverink & Lindenberg, 2006). The presence of functional or cognitive impairments necessitating increasing care does not automatically mean an older adult is willing to forgo autonomy partially or completely, although some may feel more comfortable with proxy control (Morgan & Brazda, 2013). At the same time, however, independent living settings may not provide sufficient support for the increasingly complex needs of older adults (Eckert, Morgan, & Swamy, 2004).

The question of how autonomy is defined, experienced, produced, maintained or thwarted in AL is a critical one. In this regard our research sought to determine the forces that create, insure, or deprive residents of autonomy across several dimensions including visiting. Further, the meaning of autonomy to individuals and how this might be gradually relinquished or significantly claimed are important elements we explored. Specifically, and based on prior work, we also viewed "autonomy" as a practice, reflective of setting factors such as layout, size and profit status as well as variously reflecting individuals' differing experiences and understandings of autonomy. For AL residents, autonomy may be most often expressed by choosing how or where or with whom to spend one's time throughout the day. Personal needs are often fulfilled by interpersonal relationships with others. Within ALs, residents may struggle to remain connected to prior social networks that now are found outside the AL. Friends and peers must physically visit the setting or residents must travel out of the AL for them to feel "fully connected" to outside persons. Research has shown a relationship between social support and decreased levels of depression, increased well-being, and decreased risk of institutionalization for older adults (Steverink & Lindenberg, 2006). Therefore, on-going in-person visits with family and friends are especially critical to the wellbeing and dignity of older adults in AL. Visiting clearly has a role in the provision of social and emotional support to all AL residents regardless of health statuses.

Formal Visiting Policies

Policies such as formal "visiting hours" are common in AL. In many states, visiting rights are outlined under State Health Department statutes. In Maryland, for example, residents have the right to "meet or visit privately with any individual the resident chooses," subject to "reasonable restrictions" (Department of Health & Mental Hygiene [DHMH], 2009). In California, guidelines stipulate that "visits are limited to reasonable hours of the day" (California Advocates for Nursing Home Reform [CANHR], 2013). The vagueness of these guidelines is easily tailored to unique settings, though they do not ultimately provide control by residents over visitor access. Subject to interpretation, staff members in a given AL may enforce guidelines quite variably.

From a policy perspective, erring on the side of caution by limiting outsiders' access can protect ALs from potential liabilities. Safety concerns, in particular, drive many rules about daily life for AL residents, including if, when, and how a guest may visit them. From a policy perspective, one key aspect of visitors is that they are untrained in many activities with which they may wish to help residents. An AL may require a staff member to supervise dining, laundry, showering, or personal care, commonplace activities that can be fraught with potential safety hazards. An untrained visitor helping with dining, for example, may unintentionally facilitate choking, an outcome for which the AL is ultimately accountable. A visitor styling a resident's hair with hot curlers may break in-house rules about appliance use or even start a small fire. Thus, ALs must negotiate risk not only with individual residents but also with each and every guest or visitor. Consequently, ALs may limit or simply reject the involvement of visitors in potentially hazardous daily tasks as the best means of maintaining safety and control. Some ALs may require signed waivers of risk to make ostensibly dangerous behaviors possible for residents. Finally, the safety of visitors themselves is also of concern. Residents may be unpleasant to visitors and staff must then negotiate often complex family dynamics that derive from negative interactions. Ultimately, it may be a safer outcome for residents and their visitors to stay within the AL setting rather than venturing outside for a trip, for example, to go shopping.

Research Design and Methods

This article is based on ethnographic data collected in a multiyear, multisite study of the meaning of resident autonomy in standard ALs and in affiliated dementia care units (DCUs). A key aspect of our research focused on distinctive constructions of autonomy among five AL settings, and these are discussed in this article using pseudonyms.

Research Settings

Our first site, Cedar Grove, is an "affordable" AL licensed for 60 residents in a semirural area. It sits among small homes on a two-lane road one block down from a busy highway. Cedar Grove was chosen for research because of its medium size, geography, socioeconomic status of the residential population, and its for-profit status. There have been a series of owners over time. During our research, a couple bought it as an investment and added a new wing. After sequentially firing two directors and attempting to run the AL themselves, the couple sold the AL to a local for-profit NH chain.

A second site, Walden, is considered a "progressive" AL for its relatively small size and person-centered focus. Walden is located in a suburban area and is composed of two buildings built several years apart, joined by a linking hallway with locked doors at either end. Thoreau House is designed for 16 residents who are described as fairly independent and with minimal medical needs; Emerson House is home to 12 residents with dementia and/or increased care needs. Walden was selected as a research site because of its philosophy, small size, and nonprofit status.

A third site for our research, St. Hildegard, is a religiously-affiliated AL that is joined via a walkway to independent senior apartments and a NH on its campus. Daily Mass is provided for residents. St. Hildegard was chosen as an example of a mid-size AL (60 residents) and for its nonprofit status.

The fourth site discussed in this research is Fairview, a suburban for-profit, chain-owned location that opened in 2010. Fairview offers both a three-story AL of 100 beds and an adjacent skilled nursing and rehabilitation center. Residents of the AL are housed according to acuity level, with the top floor providing the highest level of care.

Lastly, Chestnut Creek, part of a national for-profit chain, opened in 1995. Its two-story building sits on several wooded acres in an affluent suburb. It offers private apartments, companion suites, and shared rooms for 60 in the AL. Many of its residents transition to the DCU on the first floor, which houses 40 residents and includes spacious public areas and a private and secure fenced garden. At the conclusion of our fieldwork, Chestnut Creek's census was struggling due to increased competition in the area from other large, for-profit chains.

Data Collection

Over 4 years, six ethnographers have spent time conducting participant observation and ethnographic interviewing with 68 residents, 65 staff members, 18 administrators, and 47 family members. Field visits occurred at various times of the day and week, including evenings and weekends. Formal ethnographic interviews ranged from 20 to 120 min in length. Interviews were audio-recorded, professionally transcribed and were assigned pseudonyms, yielding numerous documents for analysis. Ethnographic field notes, totaling 370, were made based on participant observation and informal conversations. Consent was gained for all interviews, per approved Institutional Review Board (IRB) protocol (IRBs # Y10AF21138 and Y13AF21058).

Employing qualitative, purposive sampling (Denzin & Lincoln, 2011), we chose to interview: (a) staff across all shifts and job types (administrative, activities, care, dietary, housekeeping, and maintenance); (b) all residents who were cognitively-able to complete an interview, as determined by the ethnographer; and (c) family members who were active participants in the AL. We utilized ethnographic interviewing eliciting informants' initial verbatim statements and responses to initial questions as starting points for additional questions and lines of inquiry, beyond those originally supplied by the interviewer or the interview guide, on critical topics of interest such as autonomy and social relationships. For example, this permitted an exploration of multiple perspectives, experiences, and biographies that were part of the AL setting (Li, 2008). As examples, questions in the open-ended interview guides included: "How do you spend your time here?" "Are you free to pretty much do what you want?" and "Has your idea of independence changed since you moved here?" Multiple terms—freedom, independence, making choices—we used to elicit information about the experience of autonomy in each AL. Interviews with employees focused on their experiences working within AL, in addition to opinions about and observations of the residents in the sites and questions of autonomy. Some individuals or "key informants" were interviewed multiple times to explore selected themes in greater detail and over time (Rubin & Rubin, 2005).

During phases of participant observation, ethnographers separately and together wrote field notes on everyday life in the AL (e.g., on meals; staff; dining; Resident Council meetings; interpersonal interactions among residents, staff, and family members; and various activities such as Bingo, crafts, and holiday parties). Participant observation relied on insights generated by field researchers through repeated observation of residents, family members, and staff members alone or in interaction (Wolcott, 2005). Field notes were made of observations, interactions, insights, and informal interviews with anyone within the AL setting.

Field notes and recorded interviews were transcribed verbatim, checked for accuracy by the ethnographers, and team-coded using inductively derived codes developed by the research team. All field notes and transcripts were entered into Atlas.ti software program to facilitate coding and qualitative analysis (Muhr, 2008). Rotating two-to three-person teams coded each document individually and met to reconcile any differences; this ensured coding integrity and reliability (See Eckert et al., 2009; Morgan et al., 2011, for more detail). Any coding discrepancies that could not be resolved by the coding teams were brought to the larger research team for resolution during biweekly meetings. Once integrity of coding was established, documents were coded individually. Analysis of the data involved running Atlas.ti queries using both code and word searches. For this particular analysis, word searches included "visit," "visitor," "visiting" and "visitation." Word searches for "son/daughter," "significant other," "loved one," "guest," and "in-law" were also conducted. Lastly, we drew from the ethnographers' extensive and detailed field-based knowledge of the five AL settings.

Findings

In our analysis, we identified three key areas that influence outside visitors for residents in these settings. In this section, we will first discuss what we found about visiting (through observations by our ethnographers, and informal and formal interviews) and then relate our findings to issues of resident autonomy. This is followed by a discussion of formal and informal policies on visiting, and finally by a discussion resident autonomy in its relationship to social policies on visiting.

What We Found

Our research led us to conclude that when older adults move into AL, they often newly feel a degree of distance from their previous social circles. For example, at Walden, resident Maureen Durke told us that her friends from the past "have all moved away." Health decline and lack of transportation often inhibit friends from visiting. At all settings, many residents told us that they now have an entirely new circle of persons, and the expectation of AL staff is that new residents will bond with other residents, or, at the very least, spend time with them at meals and other activities. No one ever directly said that this new circle is replacing a resident's old circle, but that appears to be the case; the old circle of significant others, we observed, rarely visits, except for a few close relatives like spouses or children. We also found that both old and new residents of AL often feel uneasy about inviting neighborhood friends and family to visit. We concluded that both diminished social circles due to age and a boundary connected to the institutional quality of the AL setting both acted to diminish outside social connections. We found that, with residence in an AL, visits may now feel contrived both to the resident and the visitor. It was rare to see residents visiting each other's AL rooms; instead, residents congregate in public spaces (e.g., main lobbies, small alcoves, or activities areas).

At Fairview, resident Anna Lux told us how difficult friendships are to maintain, saying, "[There were] people that you could talk with, and we became instant friends – instant friends, but [a friend] got sick here and this is the thing, they pass away, they really do. You get to know them and then the first thing you know, they're gone. They pass away." She also discussed a desire to have a male companion to "sit with and talk with and eat with and just to have somebody that you could just walk with and…pass the time of day and be with. It's just something I would like because in the apartment I had that, I always had that." Lastly, she discussed a male friend who lived nearby in the community, but she hesitated to call him and invite him to visit her in the AL. Most of all she wanted someone "you could maybe shake hands with…or put your arm around them or something like that." While there are no explicit rules at Fairview forbidding an outside visitor, Anna—as is often experienced by AL residents—felt that courting a male friend or visitor would be frowned upon by the staff as well as fellow residents.

We found that residents are often aware that the AL staff or management have the ability (or actively are) observing their visits by outsiders. This "oversight" has two meanings: (a) that staff members and others are observing residents and (b) that it is a possibility that these persons are judging their behavior. Some residents are wary. Given the possibility of such observation by staff members and other residents (real or imagined), residents then may feel uncomfortable inviting a grandchild, for example, to spend the night at the AL or a weekend with them at their new home. Indeed, resident rooms may be too small for guest accommodations and AL settings may be bound by both legal and practical health and safety concerns and so act to discourage or forbid overnight visits, despite the expressed belief that these rooms are a person's home. Visits from a spouse or others who do not reside in the AL may also pose challenges. For example, visiting spouses must not only negotiate transportation, but also entry into the AL setting. Our research found that the AL settings we studied are poorly equipped (i.e., in terms of staff training, policies or protocols), to address sexual needs of residents including conjugal visits (Dobbs et al., 2008; Frankowski & Clark, 2009).

We also found that visiting hours and entry practices varied greatly even among the five settings in which we conducted research. What might be everyday visiting for community-dwelling older adults, such as a friend or relative freely walking into an individual's home for a short social call, can be difficult or even unacceptable in AL settings due to unstated, but enforced, practices concerning the control of boundaries by staff members. Our fieldwork included accessing and analyzing setting websites, handbooks, and move-in materials, among other documentation, for protocols, including visiting hours; we found, unsurprisingly, that a visiting protocol can range from wholly uncomplicated (including little formalized in writing) to the distinctly complex and regimented to an extent that functions to purposefully deter regular and comfortable visits.

Formal and Informal Policies

In general, specific policies on visiting in ALs are often not officially displayed or documented, other than through a general statement about visiting hours, posted or not or part of a "package" of rules given to the resident and family upon arrival. This was the case in the ALs we are discussing here; their written or communicated visiting policies were sometimes obscure. We observed, however, that there are *unspoken rules* about guests and what they are permitted to do, which residents learn by trial and error or through informal word-of-mouth. In these five research settings, such unspoken rules clearly inhibit residents' autonomy and also sometimes curtailed important decision-making in daily life. In some instances, rules about length of visits or staying overnight were unstated. AL staff members may create "informal rules" for particular friends or family, who are disliked by one or more staff members or are viewed as some sort of burden or as an impediment to medical or institutional routine and who are therefore seen by them as "overstaying" their welcome and are unwanted guests in the minds of the staff or management. Some rules can also be quite powerful. For example, in Walden, some family visitors were forbidden entry by the AL as a result of staff members' knowledge of previous family violence or issues related to a previously identified lack of care and concern for the resident. In this case, such ad hoc rules served to protect the resident.

At Walden, formal social policies were also adopted in response to negative individual or troubling family visitors. At St. Hildegard, family members were given the opportunity at intake to provide a list of persons to disallow from visiting. Informational packets at St. Hildegard indicate that "visiting times are flexible" and emphasize that the AL is "the resident's home"; yet the same documents maintain that residents are "subject to reasonable restrictions on visiting hours and places," a term that remains ambiguous and therefore can be interpreted on an individual basis by managers. From 8:00 a.m. to 8:00 p.m., a staff member monitors the main doors at St. Hildegard. "After hours" guests must ring a doorbell in hope that a care staff member will greet them and permit access. For visitors who work full-time or maintain "untraditional" work hours, visiting can therefore become difficult. At the same time, Paula Furst, Executive Director at St. Hildegard, described the expectation of familial involvement, saying, "[T]here's an expectation that [family] will be part of the caregiving, and that part involves them visiting and being in touch… Because until we get to know somebody, you know, we are not their family and that's who they want to see."

During one "new resident meeting" at St. Hildegard, an ethnographer observed a seemingly commonplace discussion of "no access" persons. An adult son, in preparing for his mother's move there, provided a list of names of family members *he* did not want to have access to his mother. No justification or detailed explanation was required or provided in making the list. Nor was there any follow-up to review and approve the list with his mother, a supposedly autonomous resident. It was as if the adult son, not the resident, was the customer. This example in part highlights dynamics within ALs over defining who the real client is. In this case, the son was a private payer for his mother's stay at St. Hildegard and this probably led to his consideration as the most powerful agent. However, there was no information to suggest that his mother was not able to make such choices for herself.

Autonomy Expression or Suppression

Visitors and Visiting

In our research, we saw that there is no standardized method of "informing" a resident of the arrival of a visitor. Even within one site, a visitor may be led directly to a resident's room, asked to wait at the door with a staff member while a resident is told of the visitor's arrival and called to the door, or allowed entrance with unaccompanied "free reign" of the AL. This inconsistency was seen at Cedar Grove, where resident Amelia Larke said, "And you can have visitors anytime really…You have to announce yourself, but there's no problem that way." Another resident at Cedar Grove, Stella Crandall, a resident, noted, "Anybody that wants to come in, they are always welcome."

We also witnessed variation in allowable visiting practices from resident to resident. Some facilities consistently maintained strict, mandatory "sign in/sign out" paperwork, as was the case at St. Hildegard, whereas others kept an informal "in/out" clipboard near a main door that is not enforced or filled out, as was the case at Walden.

At Cedar Grove, we witnessed a variety of family and nonfamily visitors. Nonfamily visitors included social workers, visiting nurses, pastors, club members (e.g., Girl Scouts), community volunteers (Bookmobile), and children and pets of staff members. Indeed, many residents and their families selected Cedar Gove, in part, because of its affordability and close proximity to family and friends. Thus, residents at Cedar Grove received more frequent, albeit short, visits with family members compared to other sites; residents would often leave the AL for short shopping trips, or entertain visitors delivering supplies or special "treats." In this way, many residents at Cedar Grove were kept in an active loop of ongoing family events.

At all of our sites, family visits were often associated only with off-campus medical appointments and many family members did not come at other times. Several family members of Walden residents told us they juggled multiple responsibilities (e.g., sick spouses or children) and consequently visits were short and infrequent. Walden and Cedar Grove were unique in that the staff allowed family members to organize their own in-house activities, such as Bible study.

Residents in the five sites often struggled with maintaining former social networks, but more difficult, we found, was adjusting to the shrinking of their networks as friends moved or passed away. Still other friends may themselves transition into LTC settings, develop transportation difficulties, or move in with family members in distant communities. Similarly, in some sites in which we worked, regulations limited information that AL staff could share with friends. If a resident who has a friendship with another resident moves elsewhere, this information may not be shared, and social contact can end abruptly with no explanation.

Lastly, family members often dominate residents' social circles, and we determined that general AL residents fell into two camps: those with family members that visited regularly, e.g., several times a week; and those whose family members that visited infrequently or sporadically, some only for holidays and special occasions. Johnna Kwiatkowski, an adult granddaughter of a Chestnut Creek DCU resident, discussed her disappointment with her fellow family members following a large family birthday party for her grandmother, Midge, hosted at Chestnut Creek, which included multiple generations of siblings, children, grandchildren, and cousins. Johnna described the majority of guests as "self-absorbed," and "so unaware of [Midge's] needs." She later admitted that the family's disengagement may be related to sadness and anxiety from seeing Midge's deterioration, adding "they were probably so shell-shocked to see [Midge]" and admitting there is a mourning process for family members; the others might have been "trying to just keep it together [for the party]." Johnna's reflection exemplifies a common underlying cause of infrequent visiting by family members; staff echoed this sentiment, noting that families are often in denial about a resident's care needs and that it can be harrowing to watch family visits, particularly as they decrease in frequency the longer a resident lives in AL.

Staff members also raised concern for several married couples at Chestnut Creek in the DCU, saying, "[They are] pretty reclusive within themselves…for the most part, they will stay in their rooms for the majority of the day with their spouse." For other residents, particularly those with dementia, caregivers in particular recognize their central role in the residents' social lives.

Discussion

If resident autonomy is a goal of AL, then it should be expected that residents have some degree of control over a wide variety of life elements, including the presence of visitors. If a programmatic analogy is made between an AL setting and a person's own home, it is right that a person should be able to control who has access to them and who can come into their home. Legally, AL residents are entitled to visiting hours and a degree of control over who has access. However, such autonomous intentions are not even applied in AL. It was clear that the five AL settings that we describe here had no consistent definitions of visitor policies or practices. Control of who was defined and approved as visitors varied by setting and by person with, in at least one case, the approvals being determined by a family member and not the resident herself. Visitors were also "overseen" by staff members and residents were aware of, and uncomfortable with, such surveillance. There were concerns by management about the potential of visitors to do unintentional harm to the resident they visited if they were permitted to help out with daily tasks. Other settings did not trouble themselves much about visitors or the need to control them, and more or less permitted open access. It appears, however, that the mere fact of moving from the general community into an AL often produces changes in the social networks of residents. We found that many of the residents with whom we spoke described a process of separation from most of their friends and some of their family members that accompanied their move into AL. It was not that friends and family became fully detached from AL residents, but rather it was that the AL itself constituted a barrier; there was a disconnect between the institutional world in which residents now lived and the larger world from which they came. If contacts with outsiders continued, they became fewer in that there was now a barrier to negotiate, further complicated when outsiders themselves became frailer or sicker, or even passed away over time.

There is little doubt that the inclusion of visitors is socially and emotionally beneficial to AL residents. Visits from outsiders that are organized by activities staff in ALs are common practice and might include church groups, entertainment, children's visits, and others. However, visits by people who are known personally, as friends, by residents appear to become less common after a move to AL. Commonly, friendship is now sought out among one's peers residing in the AL, although this itself can be problematic, as many coresidents may be cognitively or physically impaired. The observation that close friendships can develop in AL is quite clear from our research and that of others. However, such developing friendships form a type of friendship replacement in which old friends who no longer visit or call are replaced by new friends who live inside the AL. Perkins et al. (2013), in research in ALs in Georgia, found that having a higher proportion of family ties in one's social network was a strong predictor of well-being and that relationships "among coresidents generally were important but not emotionally close" (p. 495). The researchers also found that "having more close ties was associated with lower well-being" (p. 495). The cut-offs, monitoring, and surveillance of visitors, compounded by the fear of AL management of the potential for visitors to unintentionally cause harm to the residents, are not positive contributors to maintaining relationships and clearly impact residents' autonomy and dignity.

Policy Implications

Our data suggest two important conclusions. First, much closer attention needs to be paid to the nature and meaning of visiting in AL. Evidence indicates that residents themselves should have primary input into the forms of their own autonomy if the promise of AL as home is to be met. Visiting must be seen as an expression of resident autonomy and desire, and every opportunity should be given to enhance the quality of this experience. The choice of "acceptable" visitors should not be turned over to adult children or other kin, unless the safety of the resident is at stake and a decision cannot be independently made by the resident herself. In all cases, we believe, the resident's input should be sought. Attention should be also made to optimizing visiting hours for each resident so that all lifestyles can be accommodated and residents' dignity respected. It may be the case that a child or friend cannot visit except at times that are inconvenient for the AL; suitable compromises must be found for such situations to prevent the AL from negatively informing the social environment and quality of life for residents. While the desire of a friend or other visitor to help care for the resident may be problematic in some ways for the AL, again compromise must be sought for in some cases. Individuals may want to continue life-long patterns of interaction that would now be enacted by feeding, setting one's hair, or helping with a shower. It is possible for staff to actually train visitors in these tasks, or for risk agreements to be signed, so that the possibility of problems or liability is minimized, positively shaping the future social environment of AL.

Second, it is clear that ALs should pay much more careful attention to precisely what resident autonomy consists of. Decisions about resident autonomy should be left, as much as is possible, to the residents. Clear ideas of what resident autonomy consists of and what domains of behavior and interaction are to be autonomous should be the object of much more careful thought by staff members, family members and AL management. Sometimes, an inability to promulgate a policy consistently promotes autonomy and other times it may hinder it. Similarly, the effects of "control" and "surveillance" by staff members on individual residents should be thoroughly thought through and evaluated to see if they contribute to a fuller resident autonomy, or not.

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HALTUNGEN
Bildung für meine Kinder (Enkel)
Verkehr
Versorgung mit Politik
GRUNDVERSORGUNG
Eigene Wirtschaft ankurbeln
Leistbares Wohnen/Leben
Leben wird noch teurer
mehr Arbeitsplätze
In Würde altern
soziale Kontakte
GESUNDHEIT
Gesundheit
gesundes Leben
weniger CO2 = bessere Luft
Pension


Soziales Umfeld
Wohnen
Politische Aspekte
Mobilität
Nachhaltigkeit
Lernen & Verantwortung
Pflege & Gesundheit
Finanzielles


SOZIALES
Europa der Menschen (nicht der Märkte)
Regionalität integriert im Europäismus
Länderspezifisches bewahren
Europa-Gefühl
Demokratisierung der EU
mehr Unterstützung für neue Ideen
Familie hält gesund
Aktivität
Inklusion
Bedürfnisse wahrnehmen
UMWELT
INDIVIDUUM
Intakte Umwelt Natur
Eigenverantwortung (Erziehung)
Kultur & Kommunikation


Gesundheit Versorgung Betreuung
Umwelt
Verkehr Mobilität
Öffis
Freizeit
Soz. Miteinander
Auto


technisches
museum wien
joules

Titel der top 10 Visionen

Gemeinsam reifen
Alt lernt von Jung – Jung lernt von Alt
Mehr Investitionen für unsere Gesundheit
Nachhaltiges Leben und Arbeiten
Gelungene Integration
Multilinguales Wien
Mobilität, barrierefreie Bewegung auf allen Ebenen
Gesundheitssystem 2050
Fortschritt durch Rückschritt
Gesellschaft und Einzelne profitieren voneinander

http://leben2050.at/visEinl.php

Beispiel Vision

Mobilität, barrierefreie Bewegung auf allen Ebenen

Die körperliche, geistige und kommunikative Mobilität auf allen Ebenen und allen Generationen

Kurze Beschreibung

- Näheres Wohnumfeld („Grätzel"), das die körperliche, geistige und kommunikative Mobilität fördert:
- Keine Barriere für mobilitätseingeschränkte Personen (Rollstuhl, Rollator, Kinderwagen, ...)
- Soziale Kommunikation (jeweils für Alter, Kultur, Herkunft, generationenübergreifender Dialog)
- Gemeinschaft bilden, = gegenseitige Unterstützung bei Kinderbetreuung, Betreuung bei Krankheit, „Tauschbörse", schwarzes Brett
- Kommunikationszentren=Dorfplatz, Brunnen, öffentlicher Raum ohne Konsumationszwang
- Anbindung an das öffentl. Verkehrsnetz, weniger Individualverkehr
- „Förderband" zur Fortbewegung innerhalb des Wohnumfeldes (z.B. Förderband am Flughafen)

Was ist die Kernbotschaft Ihrer Vision?

Ermöglichung der körperlichen, geistigen und kommunikativen Mobilität durch Schaffung eines weitgehend barrierefreien Wohnbereiches/-umfeldes.

Welche Nutzen und welche Vorteile sind mit Ihrer Vision verbunden?

Förderung von sozialem, generationsübergreifendem Miteinander. Hineinversetzen in die Lebenssituation anderer Menschen (z.B. Dialog im Dunkeln, Rollstuhl für 1 Tag, „GERT", ...).

Nachhaltigkeit durch das Mobilitätskonzept (weniger Individualverkehr) und weniger Energieverbrauch durch kurze Wege, aber auch durch gegenseitige Unterstützung im Leben miteinander.

Was könnten negative Auswirkung dieser Entwicklung sein?

Technik schränkt Mobilität ein, Ziel gerichteter Fortschritt ist im Fokus.

Ghettobildung, falls kein guter Mix im Grätzel zw. Jung und alt, arm und reich erreicht wird.

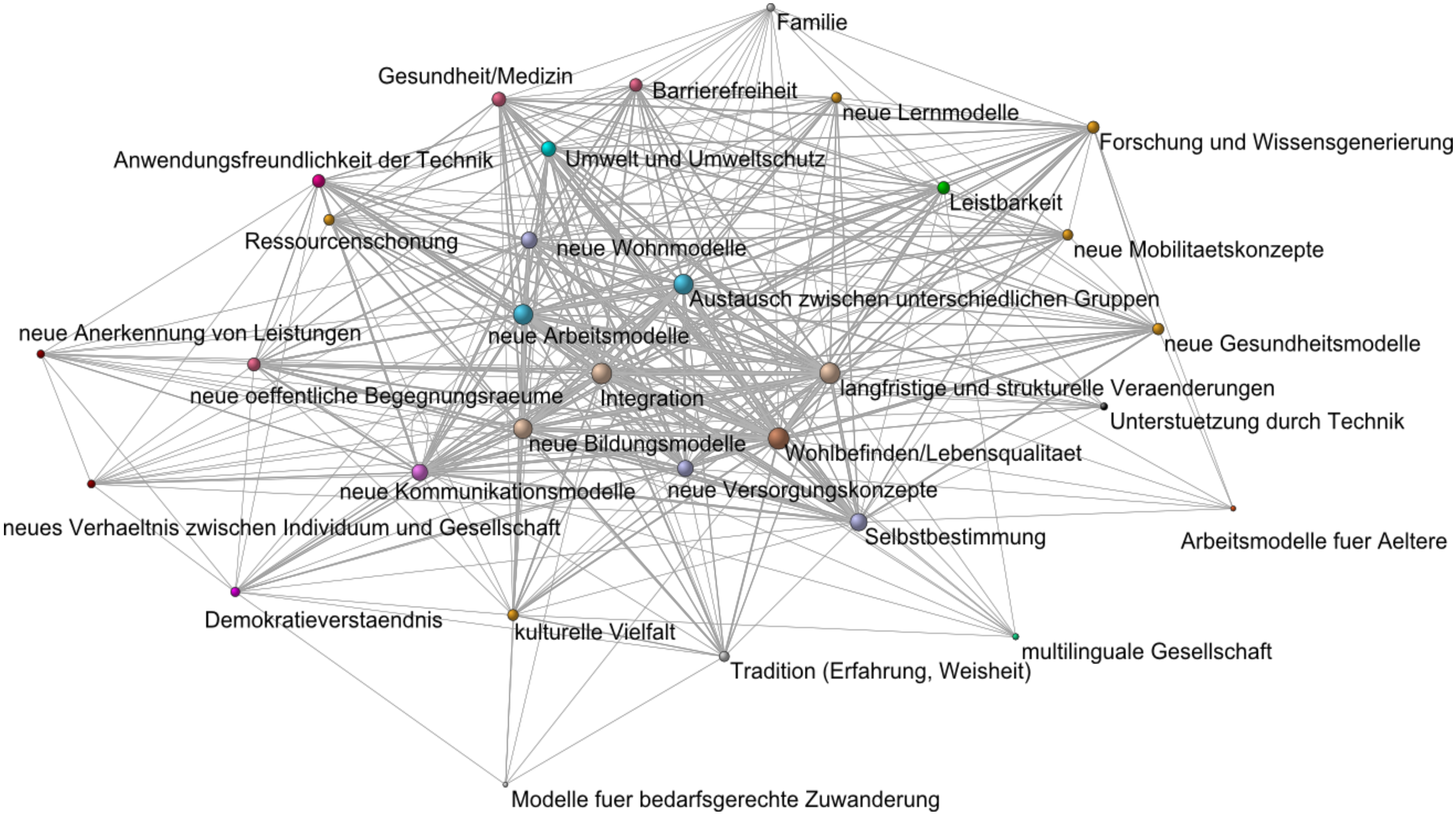
Durch neue Technologie der Kommunikation die persönlichen Kontakte zurückdrängen.

Wer würde unter den negativen Konsequenzen leiden?

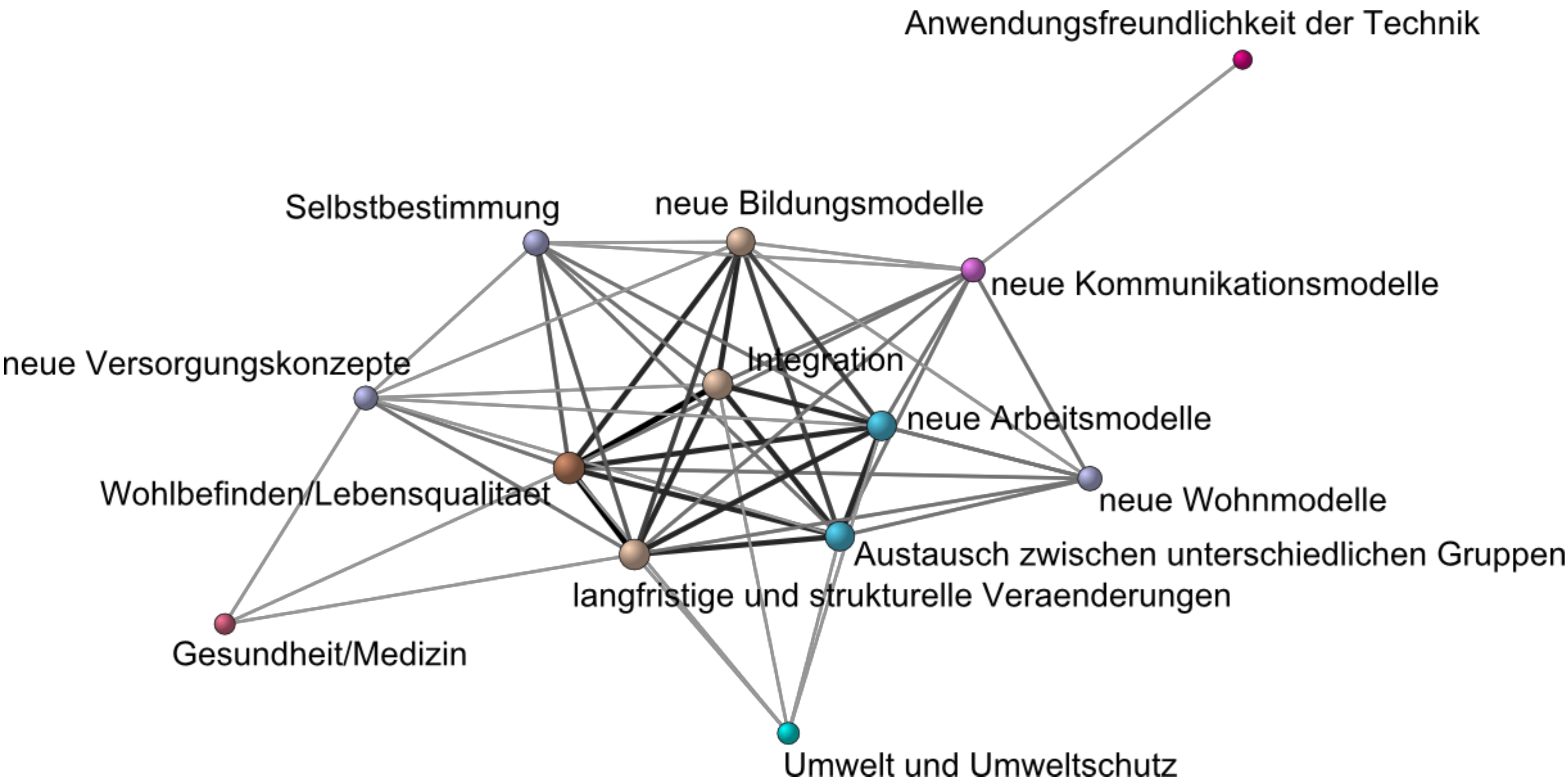
Selbstgewählte Isolation und Anonymität wird erschwert.

Diejenigen Personen, die die neuen Technologien nicht zur Gänze und Zufriedenheit nutzen können und daher ausgeschlossen werden.

Analyse der Visionen I



Analyse der Visionen II



Empfehlungen

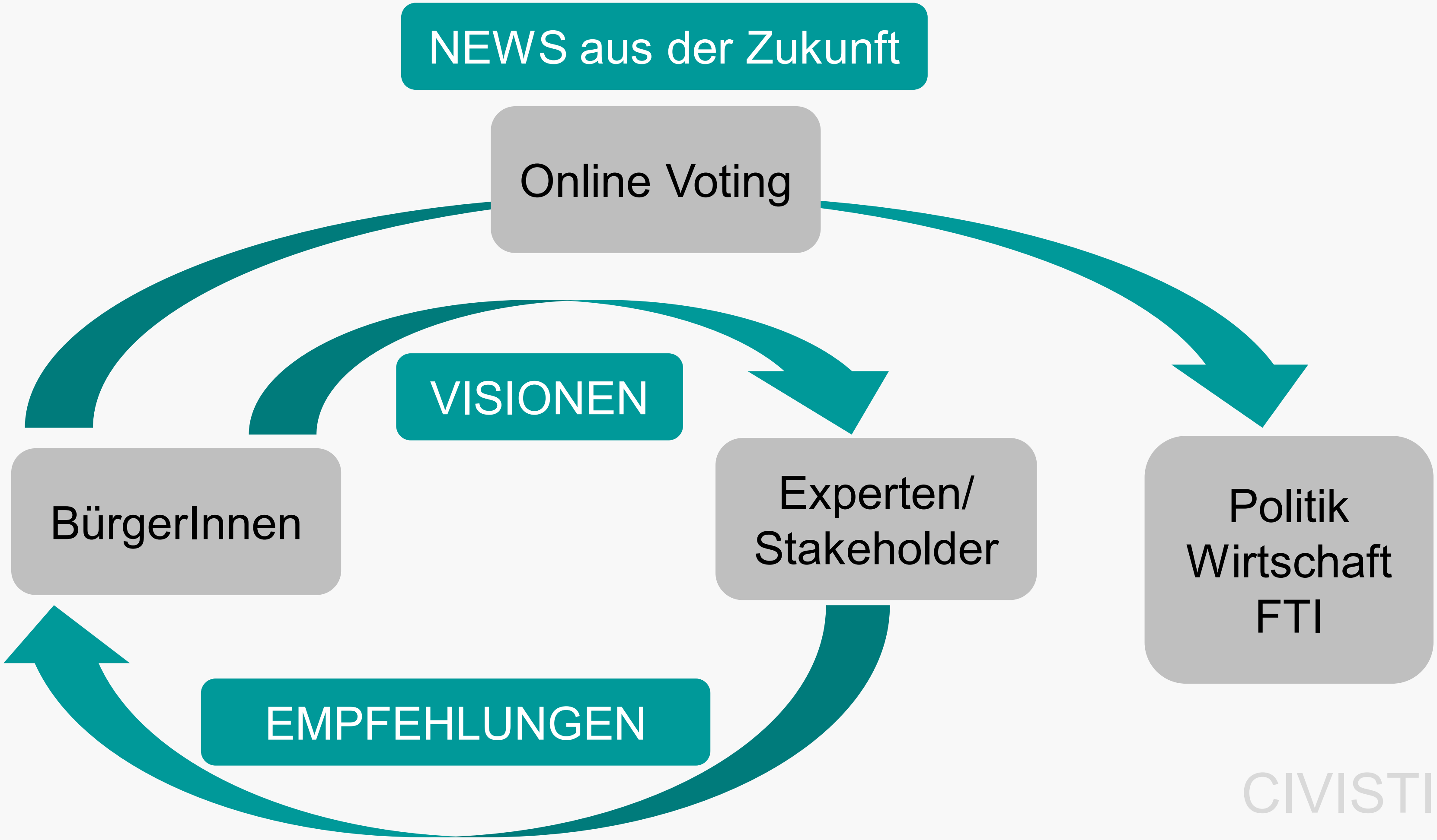
Mehrere Gruppen- und Einzelinterviews

66 kurze Rohempfehlungen

E/S-Workshop:

19 Empfehlungen in 4 Kategorien

- *Öffentliche Begegnungsräume als Plattform der Wissensvermittlung*
- *Neue Wohn- und Transportmodelle in der urbanen Region Wien*
- *Kommunikation, Austausch und Gemeinschaft*
- *Gesundheit und Änderungen in der Gesundheitsversorgung*



NEWS aus der Zukunft

Online Voting

VISIONEN

BürgerInnen

Experten/ Stakeholder

Politik Wirtschaft FTI

EMPFEHLUNGEN

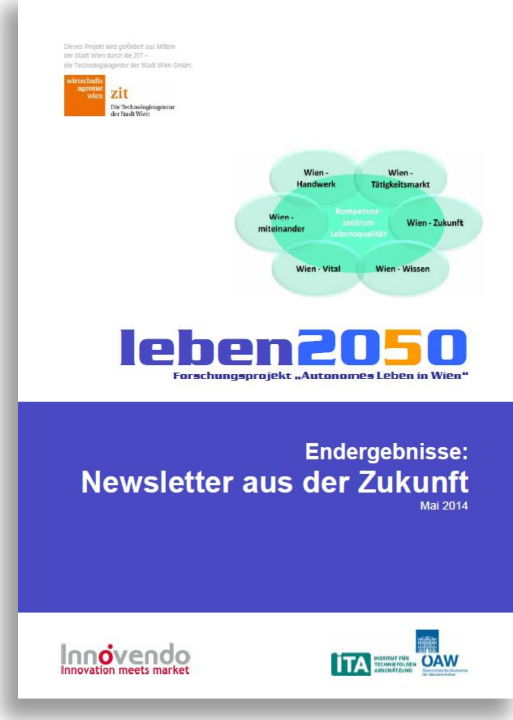
CIVISTI

Newsletter 2050

- **9 Artikel: fiktive Interviews berichten rückblickend aus dem Jahr 2050 wie Ideen umgesetzt wurden.**

- Vom Arbeitsmarkt zum Tätigkeitsmarkt
- Dialog der Generationen schafft Wissen
- Freies Denken, grenzenlose Stadt
- Gemeinsam mehr bewegen
- Zurück in die Zukunft des Handwerks
- Die Stadt der Sprachen neu entdecken
- Inkludiert und integriert: Kooperation auf allen Ebenen
- Einsatz für ein vitales Leben
- Die Zukunft immer im Blick

http://leben2050.at/newslEinl.php



Dieses Projekt wird gefördert aus Mitteln der Stadt Wien durch die ZIT – die Technologieagentur der Stadt Wien GmbH.

leben2050

Forschungsprojekt „Autonomes Leben in Wien“

Endergebnisse:

Newsletter aus der Zukunft

Mai 2014

Mitreden bei Politik und Forschung

Wie wollen wir in Zukunft im Alter leben?
Welche Unterstützung brauchen wir zu Hause?
Wie soll unser Umfeld aussehen?

Newsletter aus der Zukunft

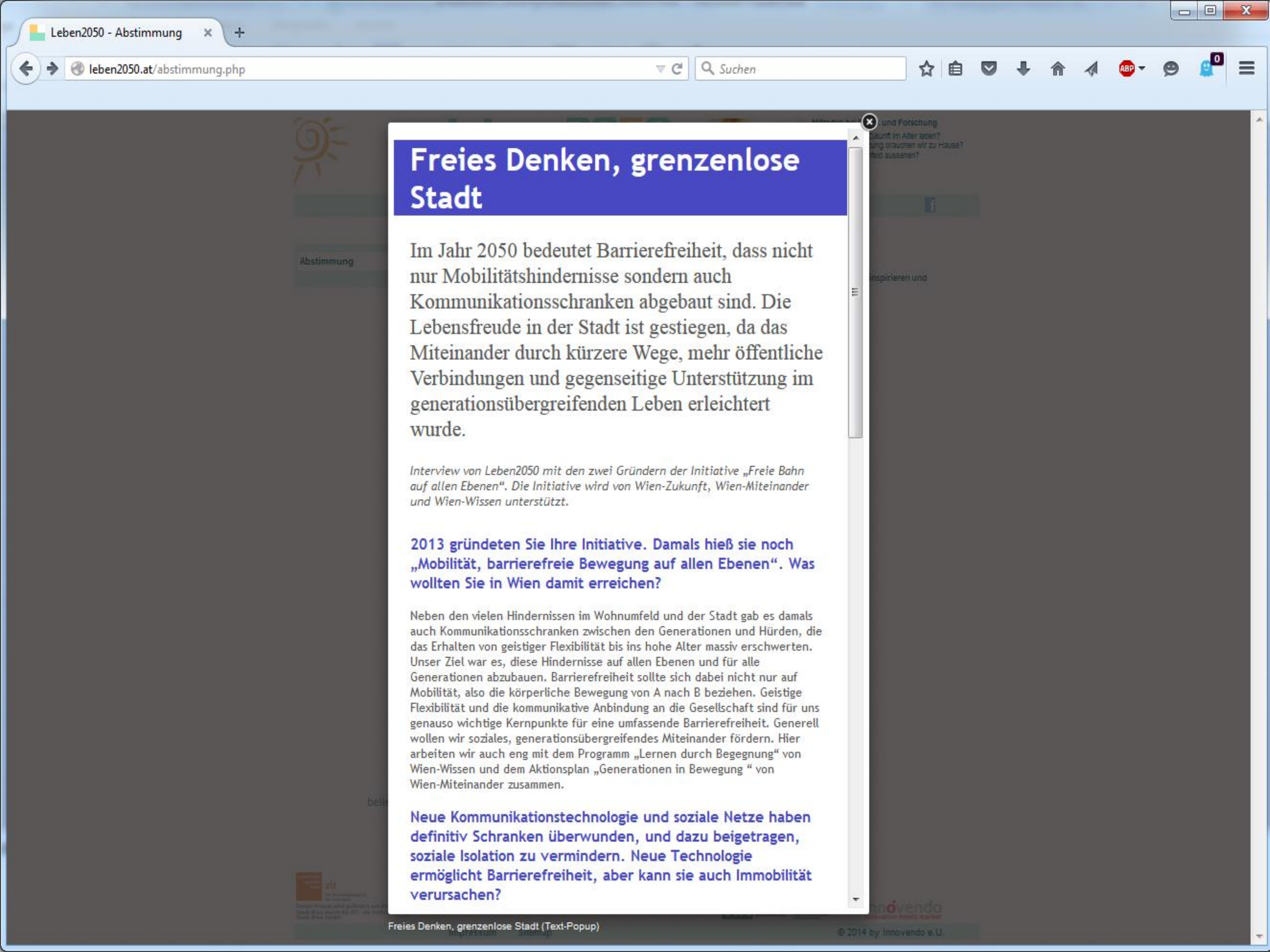
Bei welchen Ideen würden Sie mitmachen? Jede Geschichte beschreibt einen Teil der Zukunft. Lassen Sie sich inspirieren und wählen Sie 1 - 3 Themen, die Sie am liebsten umsetzen möchten.

Beschreibungen zu allen Themen anzeigen ▼	Ihre Wahl
Die Zukunft immer im Blick ▼	☐
Freies Denken, grenzenlose Stadt ▼	☐
Die Stadt der Sprachen neu entdecken ▼	☐
Zurück in die Zukunft des Handwerks ▼	☐
Gemeinsam mehr bewegen ▼	☐
Einsatz für ein vitales Leben ▼	☐
Dialog der Generationen schafft Wissen ▲	☑

Das Programm „Lernen durch Begegnung“ wurde 2020 entwickelt, um den Austausch von Wissen und Erfahrungen zwischen den Generationen zu fördern. In dieser Vision werden stadtweite Begegnungsstätten geschaffen, in denen alle Generationen zusammenkommen. Lernen findet selbstbestimmt statt.

vollständiger Text...

Vom Arbeitsmarkt zum Tätigkeitsmarkt ▼	☐



Freies Denken, grenzenlose Stadt

Im Jahr 2050 bedeutet Barrierefreiheit, dass nicht nur Mobilitätshindernisse sondern auch Kommunikationsschranken abgebaut sind. Die Lebensfreude in der Stadt ist gestiegen, da das Miteinander durch kürzere Wege, mehr öffentliche Verbindungen und gegenseitige Unterstützung im generationsübergreifenden Leben erleichtert wurde.

Interview von Leben2050 mit den zwei Gründern der Initiative „Freie Bahn auf allen Ebenen“. Die Initiative wird von Wien-Zukunft, Wien-Miteinander und Wien-Wissen unterstützt.

2013 gründeten Sie Ihre Initiative. Damals hieß sie noch „Mobilität, barrierefreie Bewegung auf allen Ebenen“. Was wollten Sie in Wien damit erreichen?

Neben den vielen Hindernissen im Wohnumfeld und der Stadt gab es damals auch Kommunikationsschranken zwischen den Generationen und Hürden, die das Erhalten von geistiger Flexibilität bis ins hohe Alter massiv erschwerten. Unser Ziel war es, diese Hindernisse auf allen Ebenen und für alle Generationen abzubauen. Barrierefreiheit sollte sich dabei nicht nur auf Mobilität, also die körperliche Bewegung von A nach B beziehen. Geistige Flexibilität und die kommunikative Anbindung an die Gesellschaft sind für uns genauso wichtige Kernpunkte für eine umfassende Barrierefreiheit. Generell wollen wir soziales, generationsübergreifendes Miteinander fördern. Hier arbeiten wir auch eng mit dem Programm „Lernen durch Begegnung“ von Wien-Wissen und dem Aktionsplan „Generationen in Bewegung “ von Wien-Miteinander zusammen.

Neue Kommunikationstechnologie und soziale Netze haben definitiv Schranken überwunden, und dazu beigetragen, soziale Isolation zu vermindern. Neue Technologie ermöglicht Barrierefreiheit, aber kann sie auch Immobilität verursachen?

Freies Denken, grenzenlose Stadt (Text-Popup)

Mitreden bei Politik und Forschung

Wie wollen wir in Zukunft im Alter leben?
Welche Unterstützung brauchen wir zu Hause?
Wie soll unser Umfeld aussehen?

Newsletter aus der Zukunft

Hier ist die Verteilung der Stimmen aller bisherigen Teilnehmer. Wenn Sie die Maus über die Balkenanzeige halten, sehen Sie die jeweilige absolute Stimmanzahl.

	Beschreibungen zu allen Themen anzeigen ▼	Ihre Wahl	Rang	Gesamtlänge = Rang1	Stimm%
🟩	Gemeinsam mehr bewegen ▼	☐	4		12,5 %
🟪	Inkludiert und integriert ▼	☐	7		8,8 %
🟩	Zurück in die Zukunft des Handwerks ▼	☐	5		10,2 %
🟦	Die Zukunft immer im Blick ▼	☐	8		7,4 %
🟧	Dialog der Generationen schafft Wissen ▼	☐	2		15,5 %
🟥	Vom Arbeitsmarkt zum Tätigkeitsmarkt ▼	☐	1		17,0 %
🟩	Einsatz für ein vitales Leben ▼	☐	3		12,9 %
🟨	Die Stadt der Sprachen neu entdecken ▼	☐	9		6,1 %
🟦	Freies Denken, grenzenlose Stadt ▼	☐	6		9,6 %

Insgesamt gab es bisher **560** Abstimmungen.

Bitte stimmen Sie aus Fairnessgründen nicht öfter als einmal ab!

Newsletter 2050 – Top 3

„Vom Arbeitsmarkt zum Tätigkeitsmarkt

Im Jahr 2050 hat sich der ehemalige Arbeitsmarkt zu einem „Tätigkeitsmarkt" entwickelt. Die finanzielle Grundsicherung ermöglicht allen BürgerInnen eine sinnvolle und sinnstiftende Teilhabe an der Gesellschaft. Auch die Pflege und Betreuung älterer Menschen wurde so aufgewertet und verbessert."

„Dialog der Generationen schafft Wissen

Das Programm „Lernen durch Begegnung", wurde 2020 entwickelt, um den Austausch von Wissen und Erfahrungen zwischen den Generationen zu fördern. In dieser Vision werden stadtweite Begegnungsstätten geschaffen, in denen alle Generationen zusammenkommen. Lernen findet selbstbestimmt statt."

„Einsatz für ein vitales Leben

Einsatz für ein vitales Leben. Vitalität ist die Voraussetzung für ein selbstbestimmtes Leben in allen Lebensabschnitten. Die Stadt und ihre Bewohner setzen mehr Ressourcen wie Zeit, Wissen und Geld gezielt zur Gesundheitsförderung und – vorsorge ein. Vitalität ist dabei mehr als nur Gesundheit und Abwesenheit von Krankheit. Es bleibt viel Raum für soziales Engagement, persönliche Entwicklung, Bildung und Kultur."

Conclusions

- Need: Integration of professional healthcare-services and family support. Integration and training of the family, friends and neighbors in care of older adults is regarded to be very important for a better social inclusion.
- This is against the assumption that voluntary work should reduce the costs of the health system.
- Need: Vitality is essential for citizens and expresses their broader need for better health, while ageing.
- Autonomy is considered to be strongly connected to the education and awareness of individuals
- Need: living in one's familiar surroundings, e.g. own home/ district/ community, if the environment can be *modified according to individual needs without great effort at all times.*
- Overarching importance of social affiliation and social inclusion

Danke für Ihre Aufmerksamkeit!

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JOURNAL OF NURSING SCHOLARSHIP

NEW MODELS OF CARE IN RESIDENTIAL LONG-TERM CARE

Variation Across U.S. Assisted Living Facilities: Admissions, Resident Care Needs, and Staffing

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Key words
Assisted living, personal care aide, residential care needs, staffing, United States

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Abstract

Purpose: Though more people in the United States currently reside in assisted living facilities (ALFs) than nursing homes, little is known about ALF admission policies, resident care needs, and staffing characteristics. We therefore conducted this study using a nationwide sample of ALFs to examine these factors, along with comparison of ALFs by size.

Design: Cross-sectional secondary data analysis using data from the 2010 National Survey of Residential Care Facilities.

Methods: Measures included nine admission policy items, seven items on the proportion of residents with selected conditions or care needs, and six items on staffing characteristics (e.g., access to licensed nurse, aide training). Facilities ($n = 2{,}301$) were divided into three categories by size: small, 4 to 10 beds; medium, 11 to 25 beds; and large, 26 or more beds. Analyses took complex sampling design effects into account to project national U.S. estimates.

Findings: More than half of ALFs admitted residents with considerable healthcare needs and served populations that required nursing care, such as for transfers, medications, and eating or dressing. Staffing was largely composed of patient care aides, and fewer than half of ALFs had licensed care provider (registered nurse, licensed practical nurse) hours. Smaller facilities tended to have more inclusive admission policies and residents with more complex care needs (more mobility, eating and medication assistance required, short-term memory issues, $p < .01$) and less access to licensed nurses than larger ALFs ($p < .01$).

Conclusions: This study suggests ALFs are caring for and admitting residents with considerable care needs, indicating potential overlap with nursing home populations. Despite this finding, ALF regulations lag far behind those in effect for nursing homes. In addition, measurement of care outcomes is critically needed to ensure appropriate ALF care quality.

Clinical Relevance: As more people choose ALFs, outcome measures for ALFs, which are now unavailable, should be developed to allow for oversight and monitoring of care quality.

Journal of Nursing Scholarship, 2017; 49:1, 24–32.

The volume and complexity of care needed for the U.S. elderly population has increased the demand for alternative long-term care residential models (Scan Foundation, 2014). As a result, many people who formerly would have been served by nursing homes now reside in assisted living facilities (ALFs; National Care Planning Council, 2012). Furthermore, ALFs are now the fastest growing sector of the U.S. long-term care market. From 2007 to 2010, the number of ALF beds increased by almost 18%, from 1.05 to 1.2 million beds, while the number of beds in nursing homes decreased slightly during the same time period (Mollica, Houser, & Ujvari, 2012).

ALF growth will likely continue because many prospective residents view ALFs as a more attractive and homelike alternative to nursing homes (Imamoglu, 2007). ALFs are based on a social care model designed to provide supportive housing and meals and some assistance with daily living activities, but were not intended to address serious health needs. Therefore, ALFs are not generally required to have a full complement of nurses, certified nursing assistants, or medical staff.

However, despite the intended purposes of ALFs to provide minimal assistance, the limited data available suggest there are many assisted living residents with considerable healthcare needs (Caffrey et al., 2014; Stearns et al., 2007). A substantial number of assisted living residents have medical and physical conditions, such as multiple chronic diseases, dementia, behavioral impairment, and activities of daily living (ADL) impairment that require regular nursing care (Kane & Mach, 2007; Morgan, Gruber-Baldini, & Magaziner, 2001). Examination of ALF admissions criteria seems warranted, as these criteria could indicate whether ALFs are admitting residents with extensive care needs, or alternatively if residents may be developing these needs after they move in.

Despite considerable care needs reported among ALF populations, there are no federal requirements for staffing of care workers in ALFs, leaving it to states to decide whether and how to regulate and qualify ALF direct care providers. As a result, requirements vary widely (Assisted Living Federation of America, 2013), and most of the care is provided by unlicensed workers, who also may be untrained and unregulated. This can result in a workforce with little understanding of patient care needs, creating possible quality and safety issues. In contrast, nursing homes have federally mandated staffing and training requirements to serve populations with nursing care needs (Social Security, n.d.).

Recognizing this potential gap between ALF staffing and care needs, in 2010 the National Center for Health Statistics (NCHS) surveyed a nationally representative sample of U.S. ALFs as part of their National Survey of Residential Care Facilities (NSRCF; Moss et al., 2011). When NCHS compared ALFs by size (i.e., small [4–10 beds] vs. larger ALFs), they found that small ALFs tended to be private, for-profit facilities, with care mostly reimbursed by Medicaid, while larger ALFs were more likely to be non-profit, chain-affiliated, and supported by private client or family payments (Park-Lee et al., 2011). The proportions of residents with dementia, depression, and needing assistance with activities of daily living were sizable, though smaller ALFs tended to have sicker residents compared to larger ALFs (Caffrey, Harris-Kojetin, Rome, & Sengupta, 2014; Leroi et al., 2007).

Despite the increases in ALF availability and population, little is known about admission characteristics of the facilities, resident care needs, and staffing (Caffrey et al., 2014; Leroi et al., 2007). Therefore, the purpose of this article is to further describe ALF admission policies, resident care needs, and staff characteristics, including care providers and training. We will also include comparisons by ALF size. Study findings will contribute information about the assisted living component of long-term care.

Methods

Design and Data Sources

This is a secondary analysis of findings from a national survey of ALFs. The first survey of its kind, the 2010 NSRCF was designed to describe the nationwide picture of U.S. ALFs, including residents and staff (Moss et al., 2011). To accomplish these goals, the NCHS surveyed directors or administrators of 2,302 ALFs with four or more beds, who completed a computer-assisted personal interview. Our sample includes all sampled ALFs, with data weighted to yield national estimates.

Measures

ALF characteristics. Facility characteristics included ownership (for-profit, not-for-profit), occupancy rate, years of operation (<10 years, ≥10 years), if they were certified or registered to participate in Medicaid (yes, no), availability of skilled nursing services (yes, no), and whether a pharmacist or doctor reviewed medications for appropriateness (yes, no). For the ALF comparison by size, facilities were divided into three categories: small, 4 to 10 beds; medium, 11 to 25 beds; and large, 26 or more beds.

Admission policies. We included all admission policy survey items. These nine items inquired whether an ALF admitted residents with: (a) an inability to leave in an emergency without help; (b) cognitive impairment; (c) behavior problems; (d) skilled nursing requirements on a regular basis; (e) daily monitoring needs (e.g., blood sugar, taking insulin); (f) urinary incontinence; (g) bowel incontinence; (h) a history of drug or alcohol abuse; or (i) a need for two or more staff or a lift to get in or out of bed. Responses included "yes," "no," and "no specific policy." In other words, facilities with no specific policy considered admissions with these conditions as they arose, making a decision whether or not to accept the resident on a case-by-case basis.

Resident characteristics and care needs. The survey assessed seven characteristics or care needs by asking for the proportion of the ALF population served at the facility: (a) age 85 years or older, (b) with short-term memory problems, (c) confinement to bed or chair, (d) require assistance with transfers in or out of bed or chair, (e) eating assistance, (f) assistance with medication self-administration or management or supervision or storage, or (g) bathroom assistance. These seven care needs were selected to reflect the amount and intensity of potential nursing care required (Caffrey et al., 2014; Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013; Morgan et al., 2001; Stearns et al., 2007). For these items, responses were expressed using categories provided by the NCHS in the public use dataset as the proportion of residents with these conditions or needs in the surveyed facility, except for eating assistance, assistance with medication, and bathroom assistance, which were collapsed further due to some small group estimates.

Staffing characteristics included direct care minutes or hours per resident day (PRD) for registered nurses (RNs) and licensed practical nurses (LPNs) and were measured categorically. For RNs and LPNs, categories provided in the public use data were 0, 0.01 to 7.49, and ≥7.5 min PRD, and for patient care aides categories were 0, 0.01 to 0.99, 1 to 1.99, 2 to 2.99, and ≥3 hr PRD. The number of staff on duty and awake on a typical night was categorized as 0 to 1, 2, and 3 or more. Two items described whether ongoing in-service training was provided to aides, and if formal training was required of aides before providing resident care (yes, no).

Data Analysis

Descriptive statistics were used to describe the facility characteristics, admission policies, resident care needs, and staffing among ALFs using proportions for categorical variables, and means and standard deviations for continuous variables. To examine ALF characteristics by facility size, chi-square tests were conducted. SUDAAN was run within the SAS session (SAS-callable SUDAAN version 10.0.1; RIT International, Research Triangle Park, NC, USA) to properly account for the complex sample design features, enabling us to project national (i.e., weighted) estimates.

Results

Most ALFs were for-profit facilities (82%), with about half operating 10 or more years, and half were Medicaid certified or registered. Overall, about 40% of ALFs provided skilled nursing services; this did not differ by facility size. Over two thirds (68%) indicated that they had a pharmacist or doctor review medications for appropriateness. Half (50%) of all ALFs were classified as small (4–10 beds), one third (34.5%) were large (26 or more beds), and the rest (16%) were medium-sized facilities (11–25 beds). As seen in **Table 1**, the proportion of ALFs that were for-profit was highest among small facilities (91.4%), though the for-profit rate was still quite high for larger ALFs (72%–74%, $p < .01$). Significantly more small facilities had been operating for fewer than 10 years (59%) versus only 27% to 34% of medium to large ALFs ($p < .01$). In addition, small ALFs were significantly less likely to have a pharmacist or doctor available to review medications ($p < .01$).

Most ALFs admitted residents with daily monitoring needs (81%) or urinary incontinence (82%; **Table 2**). Over half accepted those needing help to leave in an emergency (56%) or with cognitive impairment (55%), and 45% admitted those with a history of drug or alcohol abuse. Admission policies differed by facility size, with smaller facilities significantly more likely to admit residents with all care needs (e.g., help to exit in emergencies, cognitive impairment or behavior problems, regular skilled nursing care, urinary or bowel incontinence, needing two people or a lift to get in and out of bed; all $p < .01$).

In addition to admission policies, ALF residents showed substantial care needs (e.g., 91% of ALFs reported that 75% or more of their residents required medication assistance). Small facilities had significantly higher proportions of residents with each care need compared to medium and large facilities (**Table 3**). For example, small facilities contained a higher proportion of residents with short-term memory problems, who were confined to a bed or chair, and who needed assistance in transferring in and out of bed or chair, with eating, with medication management or administration, or with using the bathroom ($p < .01$).

Less than half of ALFs had licensed nursing staff direct care hours, though these were not randomly distributed across facilities. In addition, over 60% of ALFs required no formal initial training or less than 75 hr of training for personal care aides prior to caring for assisted living residents, with no differences by facility size. Small facilities

Table 1. Assisted Living Facility Characteristics in the United States, 2010 (unweighted $n = 2{,}302$)

		Facility size				
	Weighted %	4–10 beds *n* (%)	11–25 beds *n* (%)	26+ beds *n* (%)	χ^2	*p*
Total		626 (49.6)	654 (15.9)	1,022 (34.5)		
Ownership						
For-profit	82.4	544 (91.4)	481 (72.4)	751 (74.0)	127.3	<.01
Nonprofit	17.6	82 (8.6)	173 (27.6)	271 (26.0)		
Occupancy rate						
1.0%–65.0%	21.6	117 (20.0)	146 (22.5)	239 (23.3)	177.3	<.01
65.1%–80.0%	25.5	161 (26.2)	124 (19.3)	283 (27.5)		
80.1%–95.0%	27.7	117 (18.5)	253 (38.4)	368 (36.1)		
95.1%–100.0%	25.2	231 (35.3)	131 (19.8)	132 (13.1)		
Years of operation						
<10	43.8	343 (58.6)	219 (34.4)	275 (27.0)	205.3	<.01
≥10	56.1	282 (41.4)	434 (65.6)	747 (73.0)		
Don't know	0.1					
Certified or registered to participate in Medicaid						
Yes	49.7	344 (54.0)	351 (55.0)	426 (41.3)	35.0	<.01
No	50.1	281 (46.0)	301 (45.0)	595 (58.7)		
Don't know	0.2					
Providing skilled nursing service						
Yes	38.8	239 (38.3)	255 (40.8)	398 (38.7)	0.7	.66
No	61.1	386 (61.7)	399 (59.2)	623 (61.3)		
Don't know or no response	0.1					
Having a pharmacist or doctor to review medications for appropriateness						
Yes	67.5	378 (57.8)	457 (70.1)	820 (80.4)	109.9	<.01
No	32.4	247 (42.2)	197 (29.9)	202 (19.6)		
No response	0.1					

were more likely to report no RN or LPN direct care hours (**Table 4**), along with a higher proportion of direct care hours from personal care aides compared to medium and large facilities. Fifty-one percent of small facilities had 3 or more care hours PRD from personal care aides versus only 33% of medium and 9% of large facilities. The proportion of ALFs having three or more staff on night duty was higher in medium and large facilities.

Discussion

We found that resident care needs among all ALFs were substantial, and in some facilities were comparable to some nursing home populations (Kane & Mach, 2007; Zimmerman et al., 2003). However, licensed staffing levels were limited, and many facilities required no training for their direct care workers. Despite these concerns, the number of nursing home beds is declining (Grabowski, Stevenson, & Cornell, 2012; Hawes, Phillips, Rose, Holan, & Sherman, 2003), likely because more clients are choosing ALFs due to their more attractive appearance and homelike atmosphere compared to nursing homes (Imamoglu, 2007). ALFs of all sizes had limited staffing for direct resident care. Even in larger facilities, 80% had fewer than 7.5 min PRD and over 50% had minimal direct LPN staffing. Smaller ALFs had even lower RN and LPN direct care staffing ratios.

Many assisted living residents also suffer from dementia—roughly 81% of residents in small homes and 63% in larger facilities (Leroi et al., 2007). Since dementia is a common condition, such behaviors of dementia may be overtreated with antipsychotics; assisted living residents were found to receive more antidepressant and antipsychotic medications than nursing home residents (Mitty & Flores, 2007). Other studies have found that assisted living resident needs are surprisingly complex, with over 40% of residents needing assistance with three of five activities of daily living (Caffrey et al., 2014) and 86% requiring medication assistance (National Care Planning Council, 2012). In fact, medication assistance is one of the primary reasons given for ALF admission (Mitty & Flores, 2007). Additionally, many assisted living residents are prescribed nine or more medications

Table 2. Admission Policies of Assisted Living Facilities in the United States, 2010 (unweighted $n = 2{,}302$)

		Facility size				
	Weighted %	4–10 beds *n* (%)	11–25 beds *n* (%)	26+ beds *n* (%)	χ^2	*p*
Total		626 (49.6)	654 (15.9)	1,022 (34.5)		
Admit a resident unable to leave in an emergency without help						
Yes	56.3	357 (65.3)	282 (43.7)	505 (49.3)	98.1	<.01
No	29.1	167 (20.3)	279 (42.4)	358 (35.6)		
No specific policy	14.6	101 (14.4)	93 (13.9)	159 (15.1)		
No response	0.1					
Admit a resident with cognitive impairment						
Yes	55.4	380 (66.8)	271 (41.9)	465 (45.3)	140.5	<.01
No	32.5	163 (21.6)	306 (47.2)	423 (41.5)		
No specific policy	12.0	82 (11.5)	77 (10.9)	134 (13.2)		
No response	0.1					
Admit a resident with behavior problems						
Yes	35.9	250 (41.8)	206 (31.7)	301 (29.6)	42.9	<.01
No	48.5	281 (42.4)	365 (56.3)	551 (53.7)		
No specific policy	15.5	94 (15.8)	83 (11.9)	170 (16.7)		
No response	0.1					
Admit a resident needing skilled nursing care on a regular basis						
Yes	20.3	159 (29.8)	103 (15.9)	92 (8.9)	168.3	<.01
No	71.4	402 (59.6)	512 (77.8)	872 (85.6)		
No specific policy	8.2	64 (10.7)	39 (6.3)	58 (5.5)		
No response	0.1					
Admit a resident needing daily monitoring (e.g., blood sugar, taking insulin)						
Yes	81.2	495 (77.5)	542 (82.6)	879 (86.2)	26.0	<.01
No	12.4	88 (15.6)	65 (10.5)	89 (8.8)		
No specific policy	6.3	42 (6.9)	47 (6.9)	54 (5.1)		
No response	0.1					
Admit a resident with urinary incontinence						
Yes	81.5	524 (87.8)	475 (73.1)	779 (76.6)	70.5	<.01
No	10.0	58 (6.9)	114 (17.3)	116 (11.1)		
No specific policy	8.4	32 (5.3)	65 (9.7)	127 (12.3)		
No response	0.1					
Admit a resident with bowel incontinence						
Yes	0.8	455 (78.7)	388 (60.0)	597 (58.9)	109.2	<.01
No	19.5	105 (12.5)	187 (28.5)	261 (25.3)		
No specific policy	11.6	65 (8.7)	78 (11.6)	164 (15.8)		
Refusal or no response	0.1					
Admit a resident with history of drug or alcohol abuse						
Yes	45.4	267 (40.8)	326 (50.6)	511 (49.8)	60.6	<.01
No	25.8	193 (32.8)	144 (21.7)	177 (17.8)		
No specific policy	28.7	165 (26.5)	184 (27.7)	333 (32.4)		
Don’t know or no response	0.1					
Admit a resident needing two people or a Hoyer lift to get in and out of beds						
Yes	32.6	227 (42.7)	151 (24.0)	226 (22.3)	118.4	<.01
No	58.8	344 (47.9)	452 (68.4)	719 (70.2)		
No specific policy	8.5	54 (9.5)	51 (7.5)	77 (7.5)		
No response	0.1					

with additional over-the-counter drugs (Mitty, 2009). For most U.S. states, there are no outcome data for ALFs, and there are no nationwide quality care outcome data available for assisted living. Using data from one state, medication errors were found to be a regular occurrence, as demonstrated by a 61.8% medication-related citation rate (Woods, Guo, Kim, & Phillips, 2010). However, because many unlicensed and untrained staff

Table 3. Residential Care Needs of Assisted Living Facilities in the United States, 2010 (unweighted $n = 2{,}302$)

		Facility size				
	Weighted %	4–10 beds *n* (%)	11–25 beds *n* (%)	26+ beds *n* (%)	χ^2	*p*
Total		626 (49.6)	654 (15.9)	1,022 (34.5)		
Percentage of residents age 85 years and older						
≤25%	33.9	286 (42.6)	247 (36.8)	206 (20.1)	145.5	<.01
26%–74%	42.6	202 (33.0)	245 (38.3)	596 (58.4)		
≥75%	23.5	138 (24.4)	162 (24.9)	220 (21.4)		
Percentage of residents with short-term memory problems or who are disoriented						
<95%	79.4	480 (72.1)	540 (82.7)	913 (89.8)	93.1	<.01
≥95%	20.1	145 (27.9)	112 (17.3)	98 (10.2)		
Don't know or no response	0.5					
Percentage of residents confined to a bed or chair						
≤10%	69.8	376 (54.4)	541 (82.4)	878 (86.4)	279.8	<.01
11%–24%	11.9	100 (16.4)	53 (8.4)	75 (7.2)		
25%–49%	8.7	65 (12.9)	28 (4.4)	49 (4.7)		
50%–74%	4.2	35 (6.8)	17 (2.6)	14 (1.2)		
≥75%	5.3	49 (9.6)	15 (2.2)	5 (0.4)		
Don't know or no response	0.1					
Percentage of residents receiving assistance in transferring in and out of a bed or a chair						
≤10%	40.0	199 (25.4)	379 (56.6)	543 (53.4)	321.9	<.01
11%–24%	16.5	111 (16.0)	74 (11.7)	201 (19.5)		
25%–49%	17.7	113 (20.6)	72 (11.8)	168 (16.4)		
50%–74%	11.3	72 (13.5)	76 (11.7)	80 (7.9)		
≥75%	14.4	130 (24.6)	53 (8.2)	27 (2.8)		
Don't know or no response	0.2					
Percentage of residents receiving assistance in eating						
<75%	85.5	494 (74.9)	602 (91.4)	1,005 (98.2)	216.9	<.01
≥75%	14.4	131 (25.1)	52 (8.6)	17 (1.8)		
No response	0.1					
Percentage of residents receiving medication management/supervising/storing or assistance with self-administration of medications						
<75%	9.0	12 (1.8)	48 (7.6)	209 (20.0)	189.1	<.01
≥75%	90.8	613 (98.2)	606 (92.4)	811 (80.0)		
Don't know or no response	0.2					
Percentage of residents receiving assistance using the bathroom						
≤10%	26.5	173 (20.8)	269 (41.1)	292 (28.2)	377.3	<.01
11%–24%	12.1	43 (6.8)	59 (9.4)	215 (21.1)		
25%–49%	14.1	60 (9.7)	85 (12.8)	215 (21.1)		
50%–74%	14.4	85 (13.3)	80 (12.3)	172 (17.0)		
≥75%	32.7	264 (49.5)	160 (24.4)	124 (12.6)		
Don't know or no response	0.3					

administer medications to assisted living residents, medication management in assisted living has long been a concern (Gruber-Baldini, Boustani, Sloane, & Zimmerman, 2004; Kemp, Luo, & Ball, 2012; Mitty et al., 2010) and needs to be studied further.

We also found that many characteristics varied by facility size. Despite the greater complex care needs of residents in small ALFs, these facilities had a lower presence of licensed nursing staff and less in-service training to personal care aides than mid-sized or larger facilities. Other studies have found that residents in smaller ALFs were more likely to be African American, male, and younger than those in larger facilities (Caffrey et al., 2014; Howard et al., 2002). Because of these differences, disparities in ALF care may exist (Hernandez, 2012). For example, access to larger ALFs may be limited by financial constraints since assisted living is primarily "private pay." Medicaid and Veterans Affairs (VA) payments vary by state, with differences in eligibility and provider participation (Hernandez, 2012).

Finally, as the regulatory situation currently stands, there are no systematic quality data for these facilities, so there is no way to monitor ALF care outcomes. This is of great concern because ALFs are growing in number with

Table 4. Staffing Characteristics of the Assisted Living Facilities in the United States, 2010 (unweighted $n = 2{,}302$)

		Facility size				
	Weighted %	4–10 beds *n* (%)	11–25 beds *n* (%)	26+ beds *n* (%)	χ^2	*p*
Total		626 (49.6)	654 (15.9)	1,022 (34.5)		
RN direct care minutes per resident day						
0	61.3	467 (77.9)	337 (49.9)	428 (42.9)	321.4	<.01
<7.5	20.9	58 (8.0)	160 (25.5)	386 (37.6)		
≥7.5	17.6	101 (14.1)	155 (24.7)	203 (19.5)		
Don't know	0.2					
LPN direct care minutes per resident day						
0	66.5	548 (89.3)	446 (67.6)	338 (33.5)	658.6	<.01
<7.5	10.6	28 (4.2)	47 (7.6)	219 (21.3)		
≥7.5	22.7	50 (6.5)	159 (24.8)	459 (45.2)		
Don't know	0.2					
Personal care aide direct care hours per resident day						
0	5.2	61 (9.2)	21 (3.1)	5 (0.6)	625.8	<.01
<1	16.0	72 (11.5)	89 (13.6)	246 (23.8)		
1–1.999	26.4	73 (11.4)	165 (25.1)	497 (49.0)		
2–2.999	18.5	100 (16.7)	166 (25.1)	182 (18.2)		
≥3	33.6	320 (51.2)	211 (33.2)	83 (8.5)		
Don't know	0.3					
Number of staff on duty and awake at a typical night						
0–1	59.6	541 (86.8)	444 (66.6)	177 (17.5)	1080.9	<.01
2	21.7	72 (11.7)	170 (26.6)	337 (34.0)		
3 or more	18.6	13 (1.6)	39 (6.7)	08 (48.5)		
Don't know	0.0					
Providing ongoing in-service training to personal care aides						
Yes	90.0	517 (82.3)	621 (95.1)	1,011 (98.8)	156.7	<.01
No	3.5	35 (6.3)	8 (1.2)	7 (0.7)		
Having no personal care aides	6.4	73 (11.5)	25 (3.7)	4 (0.4)		
No response	0.1					
Formal training required of personal care aides prior to providing care to residents						
No formal training	3.5	23 (4.2)	32 (4.7)	28 (2.8)	7.5	.29
<75 hr of training	59.5	346 (62.2)	423 (67.3)	647 (64.5)		
75 hr of training	9.7	55 (10.7)	53 (8.4)	113 (11.0)		
>75 hr of training	20.4	127 (22.9)	119 (19.5)	224 (21.7)		
Have no personal care aides	6.4					
Don't know or no response	0.5					

little regulation in many states (Kossover et al., 2014). While a few states have implemented periodic surveys that mirror evaluation outcomes in nursing homes, state-level deficiency databases are not widely available and there are no standardized ALF outcome definitions. Our analyses found that ALFs allow the admission of populations with complex healthcare needs that may be similar to those of the nursing home population. These circumstances highlight the need for research to identify regulatory gaps and suggest evidence-based remedies to address them. Ideally, if appropriate measures were to become available, a large observational study across states could examine effects of regular surveys on resident care quality.

A few limitations of this study merit consideration in interpreting the findings. Data were collected using self-report questionnaires; therefore, there is potential for self-report biases and reporting errors. Analyses were based on secondary data, which does not permit additional data collection beyond the variables already collected. The lack of systematically available outcome data also limits the ability to relate staffing and other characteristics to quality.

Conclusions

In conclusion, this study suggests the need for a policy and regulatory agenda to monitor staffing and care quality in assisted living. The distinctions across ALFs by size also need further scrutiny. Because residential care facilities are gaining an increasing share of long-term care residents in the United States (Kossover et al., 2014), more stringent monitoring and evaluation of ALF staff and outcomes are needed to assess care quality in these settings.

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Clinical Resources

- Assisted Living State Regulations and Licensing: http://www.argentum.org/alfa/State_Regulations_and_Licensing_Informat.asp
- National Center for Assisted Living: http://www.ahcancal.org/
- U.S. National Study of Long-Term Care Providers: http://www.cdc.gov/nchs/nsltcp/index.htm

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Policy Brief # 2 **February 2012**

Going Digital: Adoption of Electronic Health Records in Assisted Living Facilities

BACKGROUND

The 2009 federal Health Information Technology for Economic and Clinical Health (HITECH) Act allocated $27 billion to doctors and hospitals to promote the use of electronic health records (EHR) to improve the quality and safety of health care, eliminate inefficiencies, reduce costs, and encourage greater patient engagement. Although the benefits of EHRs are theoretically promising, adopting meaningful use of this technology has proven difficult. Preliminary 2010 estimates indicate that 44% of U. S. hospitals and 50.7% of outpatient practices reported using EHR systems. Currently, qualified health centers, rural clinics, children's hospitals, and physicians' offices are eligible to receive Medicare and Medicaid incentives payments to adopt EHRs, however, long-term care providers are not eligible for such incentives.

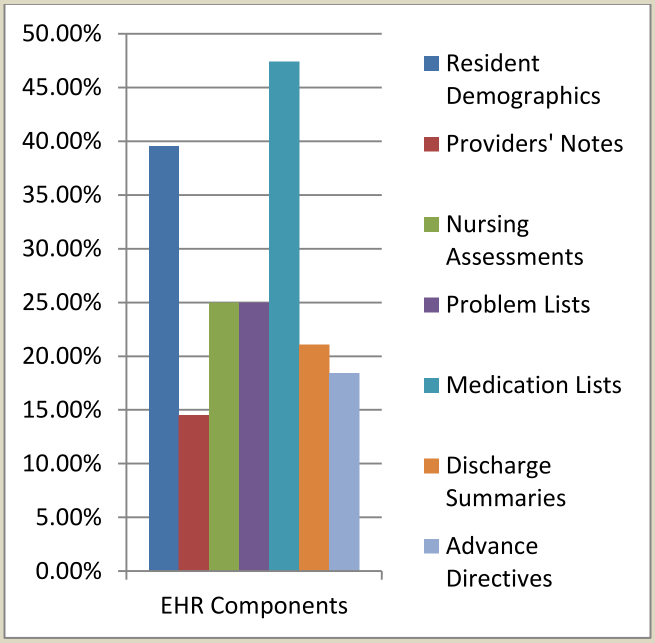
Although ALF residents have been found to not differ from nursing homes residents with respect to depressive symptoms, physical impairments, behavioral problems, and changes in morbidity, ALFs are not a healthcare facility leaving residents vulnerable to a multiple hospitalizations and mismanagement of medications. Consequently, EHR integration into ALFs may improve residents' health outcomes and reduce unnecessary healthcare expenditure.

STUDY METHOD

A sample size of 579 survey participants from the 2768 licensed assisted living facilities and 490 licensed adult family care homes in Florida from 2009 was used based initially on achieving a sample size close to 300 for 80% power for logistic regression analysis for study outcomes. A total of 76 ALFs completed the survey (11.2% response rate). Respondents and non-respondents were similar with respect to facility size, licensure type, and profit status (not reported here). Sample strata only differed between respondents and non-respondents for the low category with fewer small facilities responding to the survey.

A questionnaire was developed to examine the availability of different EHR components in ALFs. The survey also assessed structural characteristics of the facility based on the structure, process, outcome model. Staffing measures included the number of full-time equivalent (FTE) registered nurses (RN), licensed practical nurses (LPN), and personal care aides (PCA). Resident case mix was described by the percentage of females, Caucasians, those with a diagnosis of dementia or Alzheimer's disease, those requiring assistance with 3 or more activities of daily living (ADL), and primary payment source as either Medicaid or private funding. Licensure type and status as a for-profit, publically traded corporation were also examined.

Figure 1: Percentage of AL Communities Using Electronic Health Records



FINDINGS

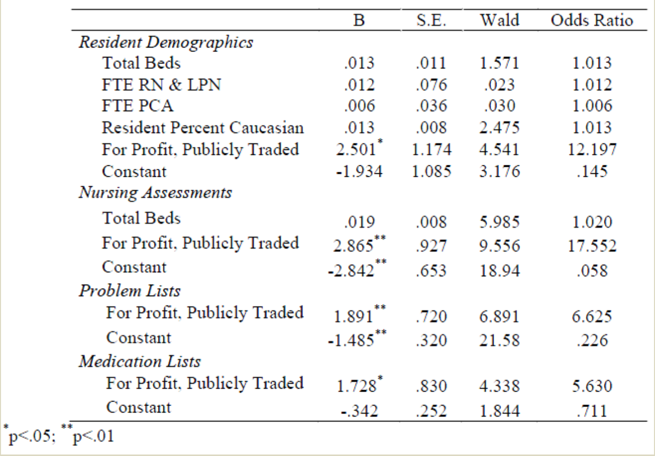
Descriptive statistics were used to examine the frequency of EHR use in AL facilities. To study the relationship between structural characteristics in AL facilities and EHR use bivariate correlations were used. Separate logistic regression models were conducted on EHR outcomes that had significant associations at the bivariate level. Four EHR components (resident demographics, nursing assessments, problem and medication lists) had predictors with significant associations. Predictors that were included in the logistic regression models were facility size, RN and LPN staff, profit status, and specific resident case mix variables including the percent of Caucasian residents.

The findings of this study provide the strongest evidence to date that ALFs are currently utilizing EHRs. Although, considerable variability exists in the proportion of ALFs using EHRs, the technology is most often used to record resident demographics and medication lists. Study findings have indicated that the use of EHR in ALFs is based on organizational characteristics with profit status serving as the strongest predictor of this technology for documenting medication lists, problem lists, nursing assessments, and resident demographics. Although there is no research on this topic for ALFs, the finding that profit status is associated with EHR use for several domains did not follow the direction suggested by existing research in nursing homes. Considering the costly initial investment for establishing and maintaining this technology, for-profit communities may have the financial infrastructure to adopt EHR earlier than other facilities. Additionally, since AL facilities opt to implement specific components with others being used less often, EHR may be implemented in stages with the use of this technology best modeled by a continuum of applicability instead of the current dichotomy.

POLICY IMPLICATIONS

The benefits of EHR use in ALFs may be demonstrated through a reduction in the number of avoidable hospitalizations and medication errors. The presumption is that ALF residents will benefit through widespread implementation of EHR across community and acute care settings by reducing system inefficiencies and costs.

Figure 2: Logistic Regressions Predicting Use of EHR Components



	B	S.E.	Wald	Odds Ratio
Resident Demographics				
Total Beds	.013	.011	1.571	1.013
FTE RN & LPN	.012	.076	.023	1.012
FTE PCA	.006	.036	.030	1.006
Resident Percent Caucasian	.013	.008	2.475	1.013
For Profit, Publicly Traded	2.501*	1.174	4.541	12.197
Constant	-1.934	1.085	3.176	.145
Nursing Assessments				
Total Beds	.019	.008	5.985	1.020
For Profit, Publicly Traded	2.865**	.927	9.556	17.552
Constant	-2.842**	.653	18.94	.058
Problem Lists				
For Profit, Publicly Traded	1.891**	.720	6.891	6.625
Constant	-1.485**	.320	21.58	.226
Medication Lists				
For Profit, Publicly Traded	1.728*	.830	4.338	5.630
Constant	-.342	.252	1.844	.711

$^{*}p<.05$; $^{**}p<.01$

Future studies will have to consider innovative ways to conduct research about smaller, adult family care homes. A key limitation rests in the fact that this study only examined the use of EHRs in ALFs and not the duration of use or the availability of the technology. Future research in this area should explore how barriers to availability and implementation affect the extent to which this technology is used and how it is implemented.

Many policymakers believe that the adoption and subsequent use of EHRs are essential to improving the quality and efficiency of the U.S. healthcare system. Implementing EHR in community care settings including ALFs enables immediate, electronic access to an individual's health record, which can result in more efficient, integrated care across healthcare settings. Further studies that examine the availability and barriers to adopting EHRs across community care settings will be necessary to advise the development of policies and improve the quality of care delivered across the healthcare system.

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Exposing the Backstage: Critical Reflections on a Longitudinal Qualitative Study of Residents' Care Networks in Assisted Living

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Exposing the Backstage: Critical Reflections on a Longitudinal Qualitative Study of Residents' Care Networks in Assisted Living

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Abstract

In this article, we analyze the research experiences associated with a longitudinal qualitative study of residents' care networks in assisted living. Using data from researcher meetings, field notes, and memos, we critically examine our design and decision making and accompanying methodological implications. We focus on one complete wave of data collection involving 28 residents and 114 care network members in four diverse settings followed for 2 years. We identify study features that make our research innovative, but that also represent significant challenges. They include the focus and topic; settings and participants; scope and design complexity; nature, modes, frequency, and duration of data collection; and analytic approach. Each feature has methodological implications, including benefits and challenges pertaining to recruitment, retention, data collection, quality, and management, research team work, researcher roles, ethics, and dissemination. Our analysis demonstrates the value of our approach and of reflecting on and sharing methodological processes for cumulative knowledge building.

Keywords

caregivers / caretaking; families; long-term health care; longitudinal studies; grounded theory; ethnography; southeastern United States

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Supplemental Material

The Table 1 and 2 are available for this article online.

Qualitative research plays an important role in capturing the experiences of giving and receiving care, including the intersection of formal and informal care (e.g., Ward-Griffin & Marshall, 2003). Often by necessity, most qualitative research on care relationships and networks is small-scale, incorporates the perspectives of only one or two stakeholders, or involves a cross-sectional design, limiting explanatory power. Our ongoing grounded theory study of residents' care networks in assisted living, "Convoys of Care: Developing Collaborative Care Partnerships in Assisted Living" involves an innovative complex, large-scale longitudinal research design intended to address these limitations and advance theoretical, empirical, and methodological knowledge.

In this article, we systematically and critically examine our research design and fieldwork experiences and discuss their methodological implications, including lessons learned. Invoking Goffman's (1959, p. 112) dramaturgical metaphor, we expose our study's "backstage" by sharing our methodological journey (i.e., the content and trajectory of our approach and research processes) from beginning to the study's midpoint and completion of the first of two data collection waves. Our focus is on methodological issues. Thus, we present study findings only as they relate to research practices. Discussing methodological issues in depth is not routine scholarly practice, particularly beyond research-team boundaries, but doing so can inform future data collection, facilitate cumulative knowledge building, and lead to scientific advancement.

We begin the examination of our study by contextualizing our research within the broader scientific literature and presenting the key features of our study, including its focus, settings and participants, scope and design, nature and modes of data collection, and analytical approach. Next, we outline the analytical process we used to identify key methodological themes and understand their relationships to key study features. Finally, we examine these relationships, pointing out both the challenges and advantages of each and the lessons we have learned to inform future research, including the second wave of our study.

Research Context

Most frail individuals who receive care, including older adults, are embedded in care networks that involve formal and informal caregivers, require negotiation between parties, and evolve over time in response to multilevel factors and contexts (Gaugler, 2005; Kemp, Ball, & Perkins, 2013). Increasingly, researchers acknowledge the frequent intersections of informal and formal care and the need to understand these linkages (Carpentier & Grenier, 2012), yet existing research does not offer a comprehensive understanding of these networks and how best to study, strengthen, and maintain them. A potentially fruitful research site to examine these linkages is assisted living, a care setting where increasing numbers of older adults with complex care needs reside and where intersections of informal and formal care regularly occur.

Assisted living communities typically offer housing, housekeeping, meals, 24-hour oversight, social activities, and personal care (Carder, O'Keeffe, & O'Keeffe, 2015) and are simultaneously places of residence and sites of work and care. Residents tend to be frail individuals with multiple chronic conditions who require assistance with more than one activity of daily living; almost half have dementia (Caffrey et al., 2012; Sengupta, Harris-Kojetin, & Caffrey, 2015). In the United States, many states prohibit assisted living workers from providing skilled nursing care (Carder et al., 2015), but a growing number of communities have registered nurses and licensed practical nurses on staff (Ball, Perkins, Hollingsworth, & Kemp, 2010; Rome & Harris-Kojetin, 2016). Externally provided care, including the full array of home health and hospice services, increasingly is available (Ball, Kemp, Hollingsworth, & Perkins, 2014; Park-Lee et al., 2011), but most hands-on care is provided by a largely unlicensed frontline workforce with low wages, few benefits, heavy workloads, and high turnover rates (Ball et al., 2010; Dill, Morgan, & Kalleberg, 2012). Informal care from families, friends, and volunteers constitutes another essential dimension of care (Ball et al., 2000; Kemp, 2012) as does resident self-care (Ball et al., 2004, 2005). Thus, in assisted living, residents' care networks typically include multiple care partners, both formal and informal.

Adding to the complexity of assisted living are frequent resident transitions, including transfers to hospitals and other assisted living or rehabilitation facilities (Eckert, Carder, Morgan, Frankowski, & Roth, 2009), dementia care unit moves (Kelsey, Laditka, & Laditka, 2010), death (Ball et al., 2014), and widowhood (Kemp, Ball, & Perkins, 2015). Residents' informal care networks also are dynamic, owing to work, relationship, and other transitions (Ball et al., 2005). Assisted living social and physical environments constantly evolve in response to changes in residents and policies, administration and staff turnover, remodeling, and so forth (Morgan et al., 2014; Perkins, Ball, Whittington, & Hollingsworth, 2012).

Research has not fully addressed the complexity of care arrangements in assisted living or other care settings where formal and informal care intersect, including how and why care varies and is organized within care networks across time. No known in-depth studies, qualitative or otherwise, include all key stakeholders and involve multiple members of an individual's informal care network. Understanding the dynamics and nuances of care processes within and across networks and over time requires research designs that typically are cost and time prohibitive, potentially fraught with methodological challenges, and hence seldom, if ever, fully planned and executed.

Key Study Features

We designed the "Convoys of Care" study to address the aforementioned content and methodological gaps in research. Consequently, certain features make our research innovative and poised to advance knowledge, but also represent formidable challenges. The key study features include the focus; settings and participants, scope and design; nature and modes of data collection; and analytic approach. Identifying and explaining these features helps contextualize our methodological themes.

Research Focus

The study focuses on care networks and is guided by the "Convoy of Care" model (Kemp et al., 2013). The overall goal is to learn how to support informal care and care convoys in assisted living in ways that promote residents' ability to age in place with optimal resident and caregiver quality of life. Derived from our previous grounded theory studies, this care model modifies and expands Kahn and Antonucci's (1980) "Convoy Model of Social Relations" to include formal care providers. Our care model defines care convoys as:

> the evolving community or collection of individuals who may or may not have close personal connections to the recipient or to one another, but who provide care, including help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), socio-emotional care, skilled health care, monitoring, and advocacy (Kemp et al., 2013, p. 18).

Consistent with a grounded theory approach, our model acts as a framework that offers a set of "sensitizing concepts" (Blumer, 1969) that provides "a place to start" or "tentative tools" to guide initial data collection and analysis, and helps position the research within relevant theoretical, social, historical, and interactional contexts (Charmaz, 2006, p. 17).

Settings and Participants

Our study is set in eight diverse assisted living settings purposively selected to maximize variation in size, location, ownership, and resident characteristics and involves data collection in two waves. In this article, we focus on data collection from Wave 1 of the study conducted in four sites between 2013 and 2015. In Wave 1, we recruited 28 focal residents, including 11 with cognitive impairment, as well as 114 convoy members (i.e., assisted living staff, external care workers, and informal caregivers). We purposively selected Wave 1 residents to provide information-rich cases (Patton, 2015) that reflected variation in personal characteristics, functional status, and health conditions typical of assisted living residents nationwide, including some residents with substantial cognitive and physical impairment (see online Table 1). When the study is complete, we anticipate a total sample of 50 focal residents and approximately 225 convoy members. Final numbers may vary based on developing categories and emergent theory. Georgia State University's Institutional Review Board approved the study.

Scope and Design

The convoy model conceptualizes care as a dynamic process involving negotiation among and between multiple care partners over time (Kemp et al., 2013), implying the usefulness of a qualitative approach with an emphasis on understanding meaning, subjective experience, and fluidity of social relations. To understand convoys as they evolved, our study is longitudinal and, insofar as possible, involved all key stakeholders who participated in residents' care, including their informal and assisted living caregivers and external care providers. We included residents frequently excluded from assisted living research, such as low-income, rural, racial and ethnic minority residents, and those without family.

Nature and Modes of Data Collection

We used multiple modes of data collection: (a) formal, semi-structured in-depth interviews; (b) participant observation; (c) informal interviews during observations and via phone, text, and email; and (d) review of residents' facility records and visitor logs. Focal residents' informed consent granted researchers permission to speak with convoy members about their health and care needs and to review facility records. In selecting residents and making initial decisions about their cognitive status, we were guided by assisted living staff, family members, and our own informal assessments— a strategy that has proven successful in our past assisted living research. We used National Institutes of Health (2009) guidelines to assess residents' ability to provide informed consent. We approached potential resident participants, including those with cognitive impairment, and explained the study, including our approach, risks, and benefits. Following Palmer et al. (2005, p. 728), we asked residents with cognitive impairment: (a) "What is the purposed of the study?" (b) "What are the risks?" and (c) "What are the benefits?" For those unable to answer these questions and provide informed consent, we obtained proxy consent from legally authorized representatives and along with established assent procedures (see Black, Rabins, Sugarman, & Karlawish, 2010). Conceptualizing consent an ongoing process, we sought participants' permission to speak with them prior to each interaction throughout the study.

Data Collection Duration and Frequency

We followed convoys prospectively over 2 years, or as long as the resident continued to live in the study home. This time frame reflects the national 22-month median assisted living length of stay (Caffrey et al., 2012) and allows for observation of continuity and change. Our goal was to have weekly contact with all focal residents, usually during facility visits, and twice-monthly contact with at least one informal convoy member. During Wave 1, researchers made a total of 809 field visits with 2,224 hours of observation and conducted 142 in-depth interviews. These activities yielded comprehensive, in-depth qualitative data on 28 convoys and four care communities (see online Table 2). This degree of depth and complexity of data collection necessitated an 18-member research team.

Analytic Approach

Our grounded theory approach involves constant comparison whereby data collection, hypothesis generation, and analysis occur simultaneously (Corbin & Strauss, 2015). Through this process, which is ongoing, we seek to understand and conceptualize care relationships, how they are patterned, and the multilevel factors affecting them. Our analysis involves examining convoys and sites holistically and as cases. Beginning in Wave 1, we developed case profiles for each convoy and setting to facilitate the identification of patterns and allow for comparison (Eisenhardt, 1989; Yin, 2014) within and across convoys and sites. Convoy profiles document properties and activities, changes over time, influential factors, divergent views, and outcomes for convoy members. Facility profiles describe each setting, focusing on key factors, such as size, location, staffing levels, care culture, policies, and practices and their influence on convoys. The creation of diagrams, charts, and memos are part of our analytic procedures. This cross-convoy/cross-setting analysis is enabling us to specify features characteristic of each convoy/setting or convoy/setting type and those that are shared across all 28 convoys and four sites.

Present Analysis

The analytic process for this article centered on methodological matters. In grounded theory, research processes evolve over the course of a study and also are iterative in the sense that researchers may need to "alter procedures to meet the demands of the research situation" (Corbin & Strauss, 2015, p. 13). Reflecting on our research experiences involved analysis of data pertaining to the research process that derived from notes from twice-monthly research-team meetings, field visits, and ongoing analytic memos. Relevant field note data included data coded “research,” which reflected any care interaction or activity participation by a member of the research team, and “operational memos,” which contain methodological issues encountered during the visit. During initial coding of these data, additional categories and subcategories were developed that identified specific study features (e.g., focus, scope, and design) and methodological issues, implications, and outcomes (e.g., recruitment and retention, confidentiality). Next, the relationships between these categories were established, resulting in the development of Figure 1. As Figure 1 illustrates, these features and accompanying areas of methodological influence operate individually and together to shape the research process.

Methodological Issues, Implications, and Outcomes

As shown in Figure 1, our analysis demonstrates that linkages between our key study features have methodological issues, implications, and outcomes related to recruitment and retention, operationalization, the research team, data characteristics, researcher roles and relationships, and confidentiality. Below, we further explore our methodological journey by examining those we identified and pointing out how they relate to features of our study. We discuss advantages and challenges inherent in our study features and our strategies for maximizing and addressing them, respectively. Where appropriate, we offer recommendations and outline changes to Wave 2.

Recruitment and Retention

The research context, focus, scope, duration, and design complexity presented potential challenges to recruiting facilities and individuals willing participate over 2 years. Access to homes was facilitated by our team’s respected reputation and positive connections in the assisted living community and providers’ willingness to showcase their communities. We had pledges of support from administrators of three of the four sites dating back to the proposal-writing phase, 2 years before data collection began. In the interim, our corporately owned home changed ownership and executive directors. Although common in the assisted living corporate world (Khatutsky et al., 2016), the change limited facility assistance with participant recruitment and delayed access to facility records.

The frequency, duration, and sensitive nature of data collection, paired with the tenuous health of the study population, impeded resident recruitment. Ten declined to participate; others were reluctant to talk on the record, were too frail, or believed that participating would be burdensome. One resident agreed and then unexpectedly passed away; chronic pain and frequent hospitalizations prevented formally interviewing another.

Recruitment of different types of convoy members across assisted living settings presented further challenges. Informal caregivers had multiple competing demands, anticipated from existing long-term care research (Kemp, 2008; Morrisey, 2012), and formal caregivers had similarly stressful lives. Our 2-year time frame meant recruitment was ongoing and allowed us to enroll new members as they joined convoys throughout data collection. For example, grandchildren returned from school, out of town family members visited, and health care workers were mobilized. Interviews frequently were scheduled and rescheduled. We were patient, persistent, and adaptive in our research strategies. Conducting phone interviews was a common strategy, particularly for out-of-state caregivers. We also interviewed convoy members in homes, offices, and other locations of their choosing.

Recruitment occasionally was unsuccessful. Consequently, some convoys had more members who participated and richer data than others. Nevertheless, our complex research design and extended time frame, while creating certain challenges, facilitated enrolling initially unavailable individuals and allowed us to access a broader range of stakeholders.

Retention was an ongoing concern, primarily related to resident frailty and caregivers' personal and work life. As anticipated, focal residents experienced frequent transitions, including health crises and decline, often prompting temporary or permanent changes to care and living arrangements, and health improvements, leading to increased self-care and a reduction of convoy member involvement. Capturing how convoys and care processes adapted to such situations were key areas of inquiry in our study and created challenging research issues, while adding to the richness of the data.

Residents had good and bad days; follow-ups depended on availability, ability, and consent/assent on a given day. Persistence and flexibility on the part of researchers were key strategies. Obtaining direct follow-up data proved especially challenging for residents with progressive cognitive decline. Although our consultant with expertise in working with individuals who have cognitive impairment provided upfront training on optimal communication strategies, we sought guidance from him on specific cases throughout data collection. When changes in cognitive function advanced to the point that some residents could no longer provide detailed data (e.g., on health changes), the research team gathered much of these data from convoy members.

During Wave 1, three focal residents died, two were discharged, and two relocated to other communities. Many had temporary care transitions: 20 were hospitalized, 12 multiple times; four went to a rehabilitation facility; 20 received home care services, including skilled nursing, physical, occupational, and speech therapies; and five received hospice care. These transitions impeded follow-up but provided access to external care providers, who joined residents' convoys, usually on a short-term basis. When appropriate, we visited focal residents in hospitals and rehabilitation facilities, observed therapeutic care activities, and attended memorial services, allowing observation of how transitions were negotiated, coordinated, and managed within convoys. We were able to formally interview 21 of these external care workers.

Changes in convoy members' lives affected follow-up data collection and retention. Informal caregivers navigated their own health problems, managed additional care responsibilities, experienced relationship, education, and job changes, went on vacation, and relocated; staff retired, quit, or were terminated. Our extended time frame, though, allowed us to understand the effects of transitions on care and on the structure and function of resident care convoys. At one home, the rapid turnover of multiple long-term staff led to the use of an agency to supply staff as needed, which changed residents' convoy composition and required them to adjust to caregivers unfamiliar with their needs and preferences.

Operationalization

The operationalization of key concepts was shaped in some cases by multiple study features. For example, although "convoy members" are defined in the "convoys of care" model (Kemp et al., 2013), we sometimes grappled with who in fact belonged in a convoy. Initially, we asked focal residents (or proxies) during formal interviews about the makeup of their informal and formal support networks. However, by using multiple sources and modes of data collection to discover the structure and function of convoys and understand their ebb and flow, we learned about convoy members who often are invisible or misunderstood in more static or cross-sectional research. In certain convoys, we identified "shadow" contributors who provided support, but had not been named or acknowledged by the resident. One resident, for example, identified his son and assisted living staff as sources of support, yet about his daughter-in-law said, "I don't depend on her for anything." Over time, we learned that she shopped weekly for his favorite foods, visited regularly, and previously had provided hands-on care, data which confirmed convoy member status.

In other convoys, residents identified caregivers who provided little, if any support as convoy members. We conceptualize these individuals as "honorary" convoy members. They were important to residents and, normatively speaking, might be counted on for support, yet current relationships were estranged or strained and typically incurred emotional or financial costs. Our design allows us to identify, observe, and analyze the full range of relationships and changes over time, as well as to understand residents' support of others. It also allows us to identify and explore emerging concepts such as "shadow" and "honorary" convoy members that will inform theoretical sampling (Corbin & Strauss, 2015) and help advance theoretical and empirical insights.

Research Team

Our scope and design necessitate a large research team composed of smaller teams assigned to each research site. The team included five investigators, one project manager, one research associate, 10 graduate research assistants, and one consultant. Four investigators, all highly seasoned qualitative researchers familiar with assisted living environments, served as team leads. Our age-, gender-, background-, and research experience-diverse team proved beneficial by allowing for triangulation and a range of perspectives and relationships. For instance, less-experienced researchers offered a fresh perspective, and the balance of younger and older researchers provided important generational exchanges. Differences in race and age between researchers and research participants also proved beneficial. For instance, an older African American participant delighted in "teaching" younger White researchers about African American culture. Non-Jewish researchers interviewing Jewish participants had similar experiences.

Investigators were committed to providing graduate students field researcher experience, a high-risk and high-reward endeavor, particularly given the study's duration. During Wave 1, five students left the project; one graduated, and four left unexpectedly for personal reasons, placing extra demand on researchers in the affected homes. Hiring new researchers required time to accommodate Institutional Review Board amendments, training, and integration into the team and setting. In two cases, researchers transitioned between homes to ensure adequate coverage. One student who changed homes felt she did not have the "same rapport" or grasp of residents' "in-depth histories" as she would have by staying in one site. Personnel changes puzzled participants and required explanation. Yet, stable team leadership and a core group of researchers helped preserve consistency and researcher turnover and movement between homes also had positive aspects. New researchers developed "new" relationships, had alternative perspectives, and ultimately have enhanced data quality and, in some cases, facilitated access to participants we previously had difficulty recruiting. While not always possible to predict researcher turnover, we recommend having back up plans in place and if resources allow, a research team that is large and skilled enough to absorb unexpected change.

Data Management, Quality, Depth, and Consistency

The overall scope and design, the duration and breadth of data collection, with a myriad of touch points for focal residents and convoy members across sites, resulted in volumes of data that yielded in-depth information about care relationships, experiences, and processes but also created challenges for data management and information tracking. As Laditka and colleagues (2009) describe, large qualitative projects are time-intensive, demand skillful project management, including the development of clear procedures and protocols, data management tools, and effective communication strategies. Our research team met twice monthly to discuss data collection progress and any problems encountered, including accessing participants, managing relationships, and maintaining adequate coverage. Team members also regularly communicated via phone, email, and text (without participant identifiers), allowing us to quickly address situations in the field. Team leads helped coordinate field visits, interviews, and follow-up communications for each site. The principal investigator, also a team lead, regularly communicated with the other leads and the consultant. The project manager helped to oversee consistency in data collection and management activities across the sites.

During Wave 1, we used multiple data management/analysis programs: (a) SPSS21 to store and manage all participants' demographic information, focal residents' health and functional status, and convoy network properties; (b) Microsoft Access to track resident health and convoy changes, participant contact points, and convoy structure and function over time; and (c) NVivo10 to store, manage, and code qualitative data. Our Access database proved cumbersome and a far more powerful database than our data tracking required. During Wave 2, we replaced this database with a more accessible and streamlined, Microsoft Excel database. This database is populated from the data researchers provide about health and convoy transitions in each focal resident's profile. Researchers are writing focal resident profiles prospectively rather than retrospectively going through the data, a practice which was arduous near the end of Wave 1.

Developing, applying, comparing, and refining a set of "housekeeping" codes (i.e., broad categories of codes organized around our study aims) for our NVivo database took multiple iterations, delaying coding progress. Keeping pace with simultaneously collecting and coding data was challenging. A planned break between waves provided a catch-up opportunity and an opportunity to code Wave 2 data as it is collected.

The study is notable for attempting to obtain a complete picture of residents' convoys. The inclusion of all stakeholders followed over time allows us to advance knowledge by providing a more complete and complex understanding of care networks than previously existed. However, the nature, depth, and volume of data demand rigorous qualitative analysis, which is time- and labor-intensive. It will be challenging to convey the complexity of our findings within the constrained space of the journal article format (see Morse, 2016).

Our approach also presents challenges to getting the story right. As most qualitative researchers do, we acknowledge the fantasy of absolute truth and anticipated inconsistencies in participant accounts (Patton, 2015). Sometimes, focal residents and convoy members provided inconsistent or incomplete accounts either within their individual narratives or as a collective. Some had different interpretation of events over time or relative to others or concealed or omitted details, possibly to protect their own or others' identity or because they perceived the details as unimportant. In a few instances, we noted contradictions between participant accounts and facility records regarding focal residents' health status and clinical diagnoses, particularly surrounding cognitive status (see also Zimmerman, Sloane, & Reed, 2014). One resident, for example, had a diagnosis of dementia, which her daughter felt was inaccurate; researchers observed no evidence of cognitive impairment. This resident had experienced an emotional crisis when her husband died only weeks after they moved to the home, the likely cause of the temporary cognitive loss and the misdiagnosis. Our in-depth and multipronged qualitative approached allowed us to capture and analyze "multiple truths" (see Thomas, 1923) such as these, which are valuable data that must be acknowledged and accounted for analytically to address our study aims and make recommendations to researchers, practitioners and policy makers for developing and supporting collaborative care partnerships.

Studying diverse settings, each with unique culture and organizational structure, also has implications for data quality and consistency. How researchers fit in and were given access within settings differed, which affected the volume and quality of data and demonstrates how facility factors influence the research process. For instance, corporate approval was necessary only at one site. Here, researchers had to coordinate visits with management, and, despite resident consent, administration delayed access to their records until the final months of data collection. Researchers expressed greater difficulty forming relationships with family and staff and described the environment as "very formal" compared with the other sites, where, once permission and informed consent were established, researchers had unrestricted access to the home, residents, and focal resident records and developed a range of relationships, including close connections. Although verbally discussed and worked out in advance, we recommend a formalized document that outlines expectations and timelines for data collection activities, particularly those that are reliant on facility access, such as record review, and is agreed upon by the researchers and facility representatives.

Researcher Roles and Relationships

Building rapport with participants is basic to good qualitative research (Patton, 2015), but alongside the frequency, duration, nature, and focus of our data collection, was a process that rendered the development and management of research-participant relationships a key methodological issue. A related issue pertained to negotiating researcher roles. We had a number of strategies for establishing early on our roles as researchers. All homes posted and circulated flyers with researcher photos and a brief project description. Researchers wore name tags and consistently identified as university researchers. Nonetheless, our roles sometimes were misunderstood; participants assigned us alternate identities. In one setting, for example, researchers frequently were perceived and introduced as volunteers despite ongoing reminders and corrections. Once when a researcher was observing a speech therapy session, the resident referred to researchers as “wonderful volunteers,” even after listening to the researcher describe the project and her role to the therapist. We continue to view such pronouncements as additional opportunities to clarify our roles.

Four researchers had preexisting relationships with care staff and administrators from previous research and aging network connections. Many close researcher–participant relationships were forged. These connections reflect successful rapport- and trust-building and promoted richer data, easier access, and more open communication about significant events, such as focal resident health crises and deaths.

Although unintentional, our presence altered the settings and affected participants’ lives, mostly through relationship-building over time with focal residents and their convoys. Most field researchers became convoy members and sources of support for residents and some family and staff. As documented in assisted living studies of a similar nature (Ball et al., 2005, pp. 13–14), throughout data collection, researchers helped with activities, attended outings, celebrated special events, and provided assistance, such as pushing wheelchairs, helping with technology, retrieving items, moving furniture, and sharing information, books, and photos. Focal residents’ family members routinely thanked us for visiting and spending time with their relative, including a daughter who concluded an email saying, “Thanks again for the friendship you have shown Dad.”

Occasionally, our presence was viewed with ambivalence. A 55-year-old focal resident who resisted developing relationships with the “old people” surrounding him, depended on visits from family and friends for his quality of life and sometimes tried to restrict researcher contact with them, despite incorporating researchers into his own convoy. Obliging him, the researcher interviewed his out-of-town sister by phone after she returned home, rather than during her short visit, and researchers stayed away during a cousin’s twice-monthly visits. Thus, identifying and respecting boundaries became an important requirement of the researcher role and is recommended.

On balance, participants reported positive research experiences. Some found discussions useful, even “cathartic,” including a daughter who ended a follow-up call saying, “Thank-you. I feel like I’ve found a good friend. I always feel better after I talk to you.” The son of a resident with dementia emailed:

> I really appreciate your periodic check-ins. Even with my sisters, aunts, and my wife to talk to, this is a very lonesome experience. It's easy to feel like I'm by myself. I get trapped in my head with my thoughts often enough. It's such a complicated thing to deal with, emotionally speaking.

Participants commonly viewed us as friends, confidantes, and supporters, again leading to a blurring of our researcher roles. Important ethical issues can arise from a participant misunderstanding the researcher role. Throughout the data collection and analysis processes and following Hewitt's (2007) conceptualization of an ethical researcher relationship, we sought to acknowledge our biases, maximized rigor, rapport, and respect for participant autonomy, maintained confidentiality, and avoided exploitation.

Participating in research can be disruptive and upsetting, particularly when it involves sensitive topics (Patton, 2015). Institutional review boards and researchers quite rightly focus on evaluating and minimizing participant risk; our consent form identifies emotional upset as a potential risk. Several Wave 1 participants became emotional during interviews. A highly distressed family member struggling to manage caregiving and other aspects of family life accepted a referral list for possible support. Certain participants perceived us as counselors, "therapists," or care experts. We renegotiated these identities by reinforcing our roles as researchers and by identifying alternative resources. For instance, when a daughter asked a researcher how to manage the holidays without upsetting her mother who had cognitive impairment, the researcher identified resources from the Alzheimer's Association and relayed advice from our team member with expertise in dementia care. It is essential that researchers anticipate and prepare to address such scenarios in a meaningful way.

Qualitative research on sensitive topics can involve emotional labor and vulnerability for researchers (Dickson-Swift, James, Kippen, & Liamputtong, 2008; emerald & Carpenter, 2015), especially when boundaries are blurred between researcher and friend or therapist (Dickson-Swift, James, Kippen, & Liamputtong, 2006). Anticipating this risk, prior to entering the field investigators provided training and prepared researchers, particularly those new to assisted living environments, about what to expect and how to work with frail adults and the range of stakeholders. Expecting participant decline, relocation, and death, we involved a hospice social worker in our training, and, because of a student's emotional distress while visiting a frail focal resident, we identified on-campus counseling resources.

In preparation for exiting the field, we began sharing and discussing researcher emotions in team meetings. The principal investigator also encouraged researchers to reflect on and write about experiences in memos, including documenting emotional responses and reflections on fieldwork and analysis. One researcher noted:

> I felt like everyone I visited except [one] was in poor health and experiencing declining health and spirits. It made me very sad because I've come to know and care about the people that we have been talking to over the last two years.

Researchers also experienced positive, negative, and ambivalent emotions directed at participants, scenarios, and behaviors. As data analysis moves forward, we are keenly aware of the need to examine how researcher biases, including emotional connections between researchers and participants, might enter into our findings. We are using negative case analysis and triangulation of data types, sources, and use of multiple researcher perspectives as strategies to mitigate potential researcher bias.

In hindsight, we could have better equipped researchers to process emotional responses at the outset. Our experience reinforces what others recommend: anticipating, acknowledging, and managing emotional responses in sensitive research (Rager, 2005). Not only, as Gilbert (2001, p. 11) observes, does “awareness and intelligent use of our emotions” benefit “the research process,” but reflexivity is also an effective strategy for emotional processing, promoting self-care, and safeguarding researchers’ emotional well-being (Malacrida, 2007). Fieldwork difficulties of this nature are rarely discussed outside of research teams (Wray, Markovic, & Manderson, 2007), and researcher risk is infrequently or not comprehensively assessed, but should be (Dickson-Swift et al., 2008; emerald & Carpenter, 2015). Debriefing and reflection, accomplished in team meetings, one-on-one discussions, and memoing, became important strategies and are recommended by others (Wray et al., 2007). These techniques sometimes introduced tensions but ultimately strengthened team relationships and cohesion.

Although potentially difficult and as important as the entering process, historically, exiting the field has received infrequent attention (Shaffir, Stebbins, & Turowetz, 1980a). Our close relationships and integration in some sites made leaving somewhat daunting. Concern, though expressed early on, became more intense toward the end. For example, with 4 months of data collection remaining, “Dolly,” a focal resident told a researcher: “Truly one of the best parts of me living here is getting to know y’all.” The researcher reflected, “Dolly’s sentiments were touching and reminded me of how personal this study is and how much we have become involved in their lives … It is going to be difficult to leave.”

We developed group strategies for exiting. For instance, with 6 months remaining in the field, researchers began reminding participants that the end of the study was nearing. Yet, as Shaffir, Stebbins, and Turowetz (1980b, p. 273) note, “the problems, concerns, and ease of field exiting” vary across setting. We thus tailored ways to mark our departure to each site. In three homes, teams worked with staff to develop and host a social event to thank everyone and officially commemorate departure. At the smallest site, a community event seemed inappropriate. Instead, the team lead met with the owners and staff to share preliminary findings, which was disseminated to all participants in a final report. These events and activities advertised our leave-taking and provided a platform to publicly express appreciation and say farewell.

Leaving is shaped by the relationships and identities researchers negotiate in the field (Shaffir et al., 1980b). In our study, to a degree, relationships and identities varied by researcher and participant. Consequently, researchers also negotiated the parameters of leaving the field individually, including whether or not to maintain contact. Those who continue contact are renegotiating their relationships as nonresearchers. In the majority of instances, however, most relationships did not continue. Researchers minimized expectations of continued contact by thanking participants, publicly and privately, verbally and by writing personalized thank-you notes, and by explaining that another study wave involving new settings and participants was on the horizon.

Confidentiality

Our study protocols, procedures, and systems were designed to protect participants' identity and information. Facilities and participants were assigned numeric codes, which appear on paper files stored in locked file cabinets within a locked office within a locked suite. We store electronic data on a secure, remote, password-protected server within a folder accessible only to active team members, a solution which meets requirements for secure storage, including data protected under the Health Insurance Portability and Accountability Act.

Opportunities for confidentiality breeches increase when research involves networks of connected individuals (Damianakis & Woodford, 2012). Our emphasis on gaining knowledge from entire networks across time created numerous scenarios where confidentiality issues arose. In each home, administrators and staff helped us access residents and families and select focal residents and, subsequently, provided access and answered questions about resident records. Most thus knew the identity of focal residents and, by extension, potential convoy member participants. We could not prevent participants from identifying themselves to others as study participants, but researchers protected convoy member participant identity within families and among staff and care workers.

Maintaining confidentiality with multiple informants over time required constant vigilance. Forbat and Henderson's (2003) report being "stuck in the middle" when interviewing caregiver-care recipient spousal dyads. Similarly, participants often asked us who we had spoken to and when, as well as what others said on a given topic. We often were caught in large webs of relationships, including those among residents, family members and friends, volunteers, and multiple care workers. Frequent and prolonged contact and our effort to enroll as many convoy members as possible meant numerous opportunities for confidentiality breeches. One researcher described this challenge:

> On numerous occasions during this visit and in the past, I was asked for information that, if I'd given, would have breached participant confidentiality or violated ethical rules. The executive director asked me what a focal resident told me about her rent increase; one focal resident asked me about another's health condition and her daughter asked me where another focal resident was receiving rehab; and the manager asked me about my "take on" a focal resident's daughter.

Precarious confidentiality situations happened routinely across Wave 1 sites and increased with time. From the participant perspective, asking questions about others was acceptable. Most knew we had information, saw us as accessible and friendly individuals, taking for granted our ability to share. We characterized certain lines of questioning as "ethical landmines," and discussed them regularly as a team. We redefined landmine questions by seeing them as opportunities to remind participants and others in the setting about our researcher roles and expectations of confidentiality. We endorse this as an effective strategy that neither breached confidentiality nor damaged rapport.

The use of in-depth cases at the facility and convoy levels presents further dilemmas. Consistent with our past research (e.g., Ball et al., 2010, 2014; Kemp et al., 2015), we used pseudonyms for participants and facilities. Yet, the difficulty of protecting identity and confidentiality increases when multiple informants are interviewed in a relationship or network (Damianakis & Woodford, 2012). Forbat and Henderson (2003) recommend "a careful and critical fictionalizing of accounts" (p. 1459). Connidis (2007), for instance, changed names and certain facts in her analysis of sibling networks. We currently are considering "the ethics of what to tell" (Ellis, 2007, p. 24), including what details to omit or change about homes, networks, and individuals. As we enter the dissemination phase, our challenge is maintaining confidentiality without compromising explanatory value.

Conclusion

In this article, we have drawn the curtain to reveal our study's "backstage" (Goffman, 1959, p. 112) by discussing our methodological journey, good, bad, and otherwise. To a certain extent, this unconventional behavior is risky; it exposes us to the possibility of criticism and praise. Yet, we believe transparency is essential to cumulative knowledge building and can enhance, advance, and strengthen existing research practices and decision making, including how best to carry out research and minimize participant and researcher risk. We hope by sharing the benefits and challenges from our study's first wave, researchers can learn from our experiences, adapt what works and anticipate and avoid potential pitfalls. We also hope others appreciate the value of our approach and how it expands understanding of care networks beyond existing quantitative or small-scale qualitative studies.

Our experience highlights the dynamism of the research process, particularly when it involves prolonged and in-depth qualitative data collection, and the need for researchers to be aware of and attentive to what transpires as research develops, including contradictions and tensions in the data, ethical considerations, and anticipated and unanticipated researcher intervention in the setting and participants' lives, and the development of project management protocols. As Janesick (1994) notes, "the dance of qualitative research design" is shaped by ongoing unpredictability and decision making in the field; researchers need to continually assess, refine, and adjust to what they learn and encounter (p. 213). Clear and ongoing communication and the development of effective data management tools and systems are vital to accomplishing research goals. We believe that the credibility of qualitative research is predicated on the credibility of the researchers and use of rigorous data collection and analytic strategies, both of which require planning and are labor- and time-intensive.

Our experiences underscore that entering and exiting the field are important dimensions of the research process; both should be treated in a strategic and thoughtful manner (Shaffir et al., 1980a) and where appropriate, involve collaboration among researchers and with participants to develop the most suitable strategies. Relationships are central to all aspects the research process, including recruitment, retention, and data collection. Researcher roles and relationships often become more complex, even blurry, when the research topic is of a personal and sensitive nature, the focus is on entire networks of connected individuals, and when participant-researcher contact is regular, frequent, and prolonged. It is necessary to acknowledge, plan for, and protect participants and researchers alike (Patton, 2015). Along the way, including in the dissemination stage, key decisions must be made about confidentiality, including what can and should be told and in what venue.

Ultimately, our experiences speak to the value of sharing and reflecting on methodological experiences and decision making. Reflecting on the research process is essential as it helps researchers "look to the future through the practice of anticipation" (Hewitt, 2007, p. 1156). Although written decades ago, Snow's (1980) commentary on social research methods still rings true:

> If ethnographers as well as survey researchers and experimentalists would devote more time and energy to providing explicit accounts of their total research experience and the factors that affect it, then perhaps we could begin to round out and demystify our understanding of the entire research process. (p. 119)

Making our methodological backstage public is our contribution to demystifying qualitative research, particularly as it pertains to the study of long-term care, relationships, and care networks in depth and across time. We encourage others to reflect on their methodological experiences and consider reporting aspects that could strengthen others' work and help advance the state of scientific methods and knowledge in health research and beyond.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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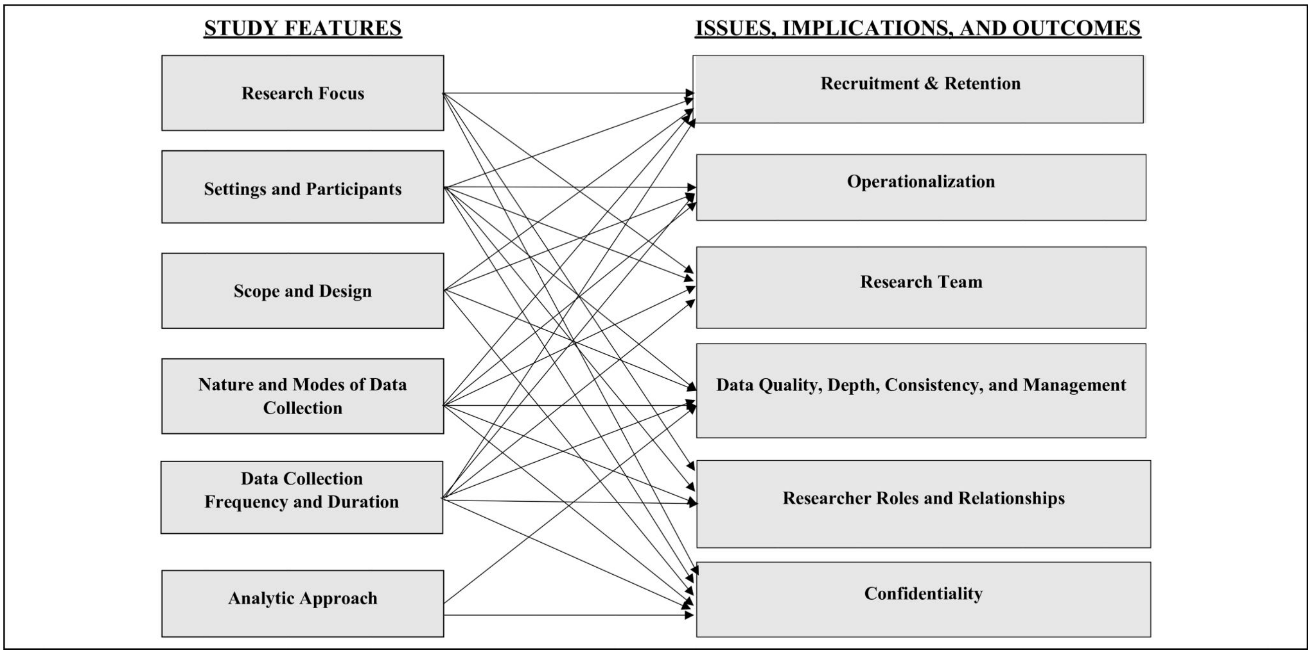

Figure 1.

Study features and methodological issues, implications, and outcomes.

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Quality of Life for Diverse Older Adults in Assisted Living: The Centrality of Control

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Quality of Life for Diverse Older Adults in Assisted Living: The Centrality of Control

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ABSTRACT

This pilot project asked: How do ethnically diverse older adult residents of assisted living (AL) facilities in British Columbia (BC) experience quality of life? And, what role, if any, do organizational and physical environmental features play in influencing how quality of life is experienced? The study was conducted at three AL sites in BC: two ethnoculturally targeted and one nontargeted. Environmental audits at each site captured descriptive data on policies, fees, rules, staffing, meals, and activities, and the built environment of the AL building and neighborhood. Using a framework that understands the quality of life of older adults to be contingent on their capability to pursue 5 conceptual attributes—attachment, role, enjoyment, security, and control—we conducted 3 focus groups with residents (1 per site) and 6 interviews with staff (2 per site). Attributes were linked to the environmental features captured in the audits. All dimensions of the environment, especially organizational, influence tenants' capability to attain the attributes of quality of life, most importantly control. Although many tenants accept the trade-off between increased safety and diminished control that accompanies a move into AL, more could be done to minimize that loss. Social workers can advocate for the necessary multi-sectoral changes.

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Background and rationale

Assisted living (AL) in Canada promises a package of housing, hospitality, and personal-care services for people who do not need 24/7 nursing care, and strives to provide these services in a noninstitutional environment (Canadian Elder Law, 2008; Province of British Columbia, 2007). There is variation across the provinces as to what constitutes AL; on the care continuum, the services that AL facilities offer tend to lie between independent rental housing and licensed skilled nursing facilities. This package is deemed to afford AL tenants[1] improved quality of life (Spencer, 2003), but there are currently no studies to support (or refute) this claim. Nonetheless, the province of British

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Color versions of one or more of the figures in the article can be found online at www.tandfonline.com/WGER.

Columbia (BC) has embraced the model: since the passage of the Community Care and Assisted Living Act (2002), 192 AL facilities (6,684 units) have been registered, of which 66% are publicly subsidized (Office of the AL Registrar, 2010). BC is the only province to register AL facilities (Canadian Elder Law, 2008). Admission criteria for AL facilities in BC specify that

> residents must be able to make the range of decisions necessary to allow them to function safely in the supportive, semi-independent environment of assisted living. For example, tenants must be able to recognize an emergency. (Government of British Columbia, n.d., p. 1)

AL fills the vacuum created when 8–19% of long-term care (LTC) beds were closed (depending on the region of BC) in the preceding years; the bar for placement in the remaining *complex care* beds was set much higher, such that only those either with complex health-care needs or with cognitive impairment would be placed in such facilities (Spencer, 2003). AL facilities were thus touted as the solution to ‘Canada’s long-term care crisis’ (Golant, 2001).

In BC, individuals with anything more than mild cognitive impairment should apply to a LTC facility. This differs from some other provinces in Canada (e.g., Reimer, Slaughter, Donaldson, Currie, & Eliasziw, 2004) and the United States (Golant & Hyde, 2008), where a large proportion of AL tenants are cognitively impaired. Golant (2001, p. 5) further reported that, compared to US facilities, Canadian ALs “have lower staff-resident ratios and are less likely to provide unscheduled personal care assistance or nursing services.” The relevance of the bountiful US research on AL facilities to the BC context is thus limited.

The care crisis is more keenly felt by ethnocultural minority older adults who often resist the move into institutional care, based on cultural mores and the unsuitability of services; many choose instead to remain in their homes with insufficient care (Hikoyeda & Wallace, 2002). Research is, therefore, needed to understand not only how quality of life is experienced cross-culturally in the AL setting, but also to identify which modifiable features of the organizational and physical environments of AL contribute to the quality of life of tenants of different ethnocultural backgrounds. This article reports on a pilot study that compared the quality-of-life of tenants in three AL facilities in BC. Two are targeted at older adults of Chinese and South Asian origins, and the third is nontargeted and hence predominantly Anglophone. Data include qualitative assessments of quality of life by tenants and staff members, as well as objective environmental assessments (Mahmood, Koehn, & Stott, 2013) that can provide a detailed understanding of the features of each AL facility, so as to understand which of these act as determinants of quality of life. This article focuses on the ways in which staff members, such as social workers, nurses, care aides, and recreation coordinators can, optimize the quality of life of diverse AL tenants.

Health and housing needs of ethnocultural minority older adults

The need for culturally responsive care and housing options for ethnocultural minority older adults has been recognized internationally (e.g., Patel, 2003). Research has indicated that ethnocultural minority populations have diverse understandings of concepts such as old age, good health, and autonomy (Chappell, 2005; Koehn, Habib, & Bukhari, 2016; Wray, 2003), and diverse care needs and expectations that are shaped by the intersection of determinants of health (Koehn, 2009; Koehn, Neysmith, Kobayashi, & Khamisa, 2013), as well as unique approaches to the usage of home and community space (Bajekal, Blane, Grewal, Karlsen, & Nazroo, 2004; Dyck & Dossa, 2007; Mahmood, Chaudhury, Sarte, & Yon, 2011). Not surprisingly, an evaluation of four nontargeted LTC facilities in BC, the residents of which included Chinese-origin elders, found that only four of 17 cultural competence criteria were satisfied (Cheng, 2005). Both cultural differences and structural barriers contribute to lower utilization levels of available housing and support services by minority older adults (Koehn, 2009; Teixeira, 2014).

In Metro Vancouver, more than 50% of persons aged 65+ are immigrants, and a third are visible minorities, the majority of whom are of Chinese and South Asian origins (WelcomeBC, 2010). Facilities targeted to these two groups have been successful to varying degrees in overcoming the reluctance of older adults and their families to move into an institutional-care setting (Cheng, 2005; Fung, 2006). Compared to other visible minority groups, Greater Vancouver's longstanding, sizeable, and well established community of Chinese Canadians have more familiarity with and less resistance to institutional care for older adults. A well-organized and volunteer- and resource-rich settlement and immigrant services sector specific to this community has facilitated the development of such institutions (Guo, 2002; Guo & DeVoretz, 2006). Even so, the available AL facilities targeted at Chinese-speakers cannot accommodate all eligible community members in need of their services, and smaller ethnocultural minorities do not have the capacity to build targeted facilities (Koehn, 2009). To date, the limited research available on targeted AL focuses largely on Chinese and Japanese immigrant populations, and there is none on South Asians, one of our selected populations in this study.

Hikoyeda and Wallace (2002) further pointed to some trade-offs that are made by targeted facilities that have implications for quality of life. In their research on LTC facilities for Japanese Americans, they found that, due to their smaller size, facilities targeted at Japanese older adults "were more likely to have few or no meaningful activities beyond the television, contradicting the assumption that they would provide a better quality of life" (Hikoyeda and Wallace, 2002, p. 102). These concerns with resident boredom were attributed to staffing limitations and the cognitive heterogeneity of the resident group. Smaller facilities with fewer resources were also less able to offer the privacy that is deemed to be a prerequisite to autonomy. Hence, although the targeted facilities appealed more to the family members of Japanese residents, the lack of autonomy and boredom experienced by residents in these facilities diminished the quality of life of the residents themselves. Cultural competence may be important to the quality of life of residents in care facilities but, in and of itself, it does not appear to be sufficient.

Accordingly, the question as to how well AL facilities meet the needs of ethnocultural minority older adults cannot be addressed solely in relation to specific ethnocultural groups, for two reasons. First, the majority of ethnocultural minority older adults in BC in need of care are more likely to end up in nontargeted AL facilities, most by necessity and some by choice. It may be impossible to predict the ethnocultural diversity of residents in any given AL home and to tailor programs accordingly, but this does not preclude the importance of understanding how quality of care and quality of life can be sustained for diverse older adults in AL environments (Patel, 2003). Second, as evinced in our own small sample, considerable diversity exists within any given ethnocultural group. Religion, gender, country of origin, migration history, immigrant class, language ability and socio-economic status are among the multiple sources of difference that distinguish people deemed to be of a single ethnic origin from one another. Failure to recognize this diversity can essentialize ethnocultural characteristics and promote stereotypes and racialization (Brotman, 2003; Koehn, 2009).

Quality of life

The exponential growth of literature on quality of life and instruments for its measurement since the 1970s is paralleled by a trend away from expert (often medical) norms to the conceptualization of quality of life as a social construction (Netuveli & Blane, 2008). Thus, although there has been a tendency to use health as a proxy for quality of life (Hunt, 1997), research has also shown that a person's health status is not a reliable predictor of quality of life in isolation; other domains such as social networks, financial security, housing, and social services are also important, as are psychological factors such as attitude and coping strategies (Bryant et al., 2004; Gabriel & Bowling, 2004; Grewal et al., 2006; Higgs, Hyde, Wiggins, & Blane, 2003; Hyde, Wiggins, Higgs, & Blane, 2003; Moons, Budts, & De Geest, 2006). The relationship of aging to quality of life is complex: Negative impacts on quality of life such as declining health, financial constraints in retirement, breakdown of extended families, and isolation due to loss of contemporaries, particularly of a spouse (Netuveli & Blane, 2008), may be offset by religious faith (Ferriss, 2002), positive comparison with contemporaries (Graham

Beaumont & Kenealy, 2004), and adaptation to hardship (Hildon, Montgomery, Blane, Wiggins, & Netuveli, 2010).

A sound measure of quality of life has to be based in theory (Higgs et al., 2003; Moons et al., 2006), but grounded and validated in the realities of research participants (Bowling et al., 2003; Wilhelmson, Andersson, Waern, & Allebeck, 2005). This measure should permit comparisons between groups and must distinguish clearly between determinants (influences on quality of life) and the attributes of quality of life, because the same influences are not experienced in the same way by different people and, therefore, have different effects on the person's quality of life (Higgs et al., 2003; Moons et al., 2006).

Researchers at the UK National Centre for Social Research (NCSR; Bajekal et al., 2004; Grewal et al., 2006; Grewal, Nazroo, Bajekal, Blane, & Lewis, 2004) have developed an approach to understanding quality of life among older adults that meets these criteria and is also grounded in the realities of ethnically diverse older adults. Grewal et al.'s (2006) qualitative research with older adults determined that their quality of life was contingent on their capability to pursue five conceptual attributes of quality of life, which have been adapted from Maslow's well-known hierarchy of needs: attachment, role, enjoyment, security, and control (see Figure 1; Hyde et al., 2003; Wiggins, Higgs, Hyde, & Blane, 2006).

They further draw on Sen's (1993) assertion that quality of life is contingent on an individual's ability to convert goods into *functionings* or capabilities. These capabilities can be promoted or undermined by the sociocultural determinants of health and aging and by the experience of discrimination. An individual's capacity to marshal his or her resources to pursue these attributes is further influenced by factors such as his or her personal characteristics and the social and physical environments in which he or she find himself or herself. Having applied this approach in a qualitative study of 73 community-dwelling, multiethnic older adults, Grewal et al. (2004) found that, although the attributes of quality of life appear to be constant for all older adults, the way in which they are

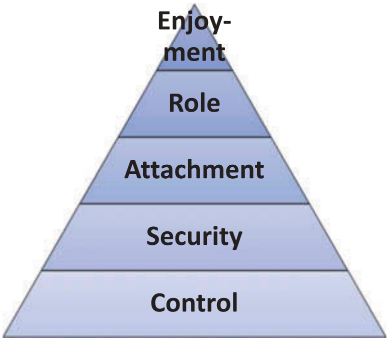

Figure 1. Attributes of quality of life.

achieved differs relative to the person's ethnocultural background, among other factors. Meaningful roles for retirees, for example, can be achieved within the context of the family, religion, or volunteer work. Having a framework that is flexible enough to capture differences across ethnocultural groups, rather than being specifically tailored to one group (be it the Anglo majority or an ethnocultural minority) is important in light of the diversity of tenants served by AL providers and staff.

Quality of life in AL environments

A move to an AL facility brings about significant change in the organizational and built environment of older adults, thus one can argue that this move also affects or changes their capability to pursue the attributes of quality of life. For instance, the support provided in AL facilities reduces the need for tenants to concern themselves with instrumental activities of daily living (IADLs), such as housework, taking medications as prescribed, managing money, and grocery shopping, thus depriving them of some of the roles that they previously occupied (Tompkins, Ihara, Cusick, & Park, 2012; Wolse, 2008). Conversely, the programming of social and recreational based planned activities in AL can offset role deficits and boredom, as well as contribute to the enjoyment of tenants by providing opportunities to engage socially with other tenants and maintain functional and cognitive capacity (Adams, Leibbrandt, & Moon, 2011).

Similarly, the attachments that AL tenants have to others are vital to their quality of life in AL. Perkins, Ball, Whittington, and Hollingsworth (2012, p. 220) found that "most residents [in their synthesis of three qualitative studies of AL residents in the United States] valued family relationships above all others and those with supportive family relationships often were best equipped to cope with the changes of AL life." AL tenants interviewed by Tompkins et al. (2012) were grateful that family members called or stopped by but were also disappointed that they didn't call more often, stay longer, or take them for outings. Family relations were especially scarce for tenants in low-income residences, and staff members often assumed fictive kin relations to replace them (Perkins et al., 2012).

Satisfaction surveys with tenants and their families in US AL facilities point to the importance of the promise of safety (Wylde, 2008). This dimension of quality of life was the third most important contributor to the overall sense of satisfaction for both groups. Yet, according to Spencer (2003), several aspects of safety, such as questions of tenure, hospitality services, and the conduct of staff members (other than allegations of abuse or neglect), sit outside of the narrowly conceived domain of safety for which the BC Ministry of Health and the BC AL registrar are willing to assume responsibility.

Even more contentious is the Eurocentric notion of autonomy. The philosophy of AL promotes tenant choice, privacy and personal decisions, and independence (Government of BC, n.d.; Wolse, 2008), yet the maintenance of a sense of self that underlies autonomy is challenged in both targeted and nontargeted AL facilities for a plethora of reasons (Hikoyeda & Wallace, 2002; Perkins et al., 2012; Tompkins et al., 2012). Some of these relate to factors outside of the direct control of the operators and staff members (e.g., physical and cognitive decline, loss of own home and/or ability to drive or maintain a car, etc.), but others such as tenant profiles, the location of the residence, the availability of material resources and the cultural orientation of the facility are modifiable factors that can promote or hinder autonomy, as perceived by tenants. Our consideration of the five dimensions of quality of life identified by the NCSR researchers in relation to the context of AL residences in BC is thus salient and timely.

Methods

Study sites and interview participants

Our pilot study sought to discover if the attributes of quality of life deemed important to ethnoculturally diverse older adults living in the community in the United Kingdom by Grewal et al. (2004, 2006), were also relevant to diverse Canadian older adults living in AL residences. Specifically, our focus was on understanding if and how environmental features of AL that could be modified by administrators and frontline staff members influenced these attributes. We conducted one focus group of tenants and two one-on-one staff interviews at each of three AL sites in BC, all of which have opened since 2007: Site 1 (50 units) is targeted to South Asians, Site 2 (60 units) is targeted to Chinese, and Site 3 (58 units) caters primarily to a mainstream Anglo-Canadian clientele, although minority language speakers constitute around 15% of its populace.

Languages spoken at each site are detailed in Figure 2. Although only Site 2 provided a breakdown of tenants by gender, we observed a similar distribution at all three sites, with women outnumbering men by approximately three to one.

Each focus group (n = 3) was attended by 8–12 older adults who had lived at least 6 months in their AL residence. Semistructured focus groups were selected as the primary tool for data collection because they are "inexpensive, data rich, flexible, stimulating to the respondents, recall aiding, and cumulative and elaborative, over and above individual responses" (Fontana & Frey, 1994, p. 365). The focus group discussion at Site 1 was facilitated by a graduate student fluent in Punjabi, Hindi, and English, and all three languages were used. The research team was present to field questions. Focus groups at Sites 2 and 3 were facilitated by the lead author. An interpreter provided simultaneous interpretation into Cantonese and then Mandarin at

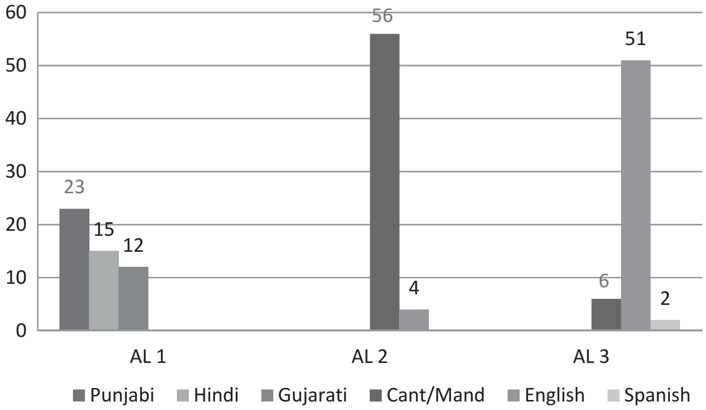

Figure 2. Primary tenant languages by site.

Site 2.[2] No interpretation was provided at Site 3. Individual interviews were better suited to staff schedules, the small numbers of staff people interviewed and honoured the need for some staff member to express views distinct from their peers. Staff interviews (n = 6) were conducted in English with recreation coordinators and care aides who had worked at for at least 6 months at each site. Ethics clearance was obtained from Simon Fraser University before commencing data collection.

Data collection strategy

Each site is distinct in its organizational and physical environmental characteristics, hence we began this mixed-methods study by conducting a series of environmental audits using standardized tools that combine observations and interviews with administrators to elicit a detailed description of each (Mahmood et al., 2011).[3] The organizational environment includes policies, fees, rules, staffing, meals, and activities, and the physical environment refers to both the features and design of the residence and the built environment of the neighbourhood surrounding it. A Behaviour Mapping Tool (Schwarz, Chaudhury, & Tofle, 2004) was also used to document the number and type of people (resident, staff member, visitor) in 4–5 key social spaces (e.g., dining area, lobby, activity room) per site and the type (no/low/high) and frequency of social engagement among them during different times of the day.[4] All of these observations were written up into detailed descriptions of each site.

Following completion of the environmental audits, we put together PowerPoint slide shows specific to each residence in which we described in plain language, and with illustrations, each dimension of the organizational-physical environment examined in our assessments. These were presented at the outset of every focus group or interview. Key characteristics for each feature of the environment were visible on posters throughout the ensuing discussion. Participants were invited to describe their experiences of each feature. This step ensured the trustworthiness[5] of our environmental audits.

The focus group facilitator or interviewer then introduced one quality of life dimension at a time (attachment, role, enjoyment, security, and control). These were displayed on a foam-core arrow in both English and either Punjabi or Chinese. The terms and our descriptions of them used were adapted in consultation with our interpreters for maximum intelligibility to the audience.

Participants considered what features of the organizational and physical environment, if any, influenced each dimension of quality of life. They were also asked if anything else besides the environmental features influenced each of the quality-of-life dimensions and, in conclusion, if all of the things that were important for us to know about their quality of life had been covered in the discussion. The trustworthiness of the associations we reported between the environmental features and attributes of quality of life was ascertained when we returned to each site with a summary of our overall findings. All residents were invited to attend. Participants at these member-checking sessions ranged from 12 to 50 and the ensuing discussions and nodding of heads revealed that our interpretations resonated with most tenants. Tenant council leaders at all sites informed us that our summary would be invaluable to their ongoing conversations about the issues raised.

Coding and analysis

All interviews and focus groups were audio recorded, then simultaneously translated (as necessary) and transcribed. All transcriptions, as well as the environmental audit reports, were coded with the qualitative data management software, NVivo 10®. A coding framework was initially developed to include the features of the environment on the one hand, and of quality-of-life dimensions on the other. Inductive codes were added as coding progressed. The vast majority were subsumed as subcategories of our environment and quality-of-life categories, thus adding depth to each dimension. NVivo allows the coder to apply as many codes to a segment of text (typically a paragraph) as are relevant. Here we report on the intersections between all codes subsumed within these two categories. Using matrix coding queries in NVivo, we were able identify the highest frequencies of overlap between dimensions of the environment and quality of life and to explore the dually coded text accordingly. Exploring intersections of coding rather than independent themes best captures how the tenants choose to relate specific environmental features to attributes of quality of life and reflects what is a dynamic rather than a static or essentialized relationship between the two.

A third major category to emerge from this process was *tenant characteristics*. Nodes within this category captured details of tenants' ethnicity, professions, religious affiliation, and so on. These nodes were insufficiently populated to warrant any substantive conclusions but provide clues as to directions for future research with a larger sample and one-to-one interviews with tenants.

Findings

Given the small sample size and unique nature of these facilities, we have elected not to reveal the site affiliation or sex of either staff or tenant focus groups, to protect their anonymity. We simply distinguish between staff (1, 2, 3 …) or focus groups (FG X/Y/Z) so that the reader can see that the excerpts reflect the perspectives of different individuals or groups.

Counting the appearance of codes in qualitative data should certainly be approached with caution; however matrix queries that reveal the overlap of any code with any other code in the data set can sometimes reveal important relationships, particularly when the frequencies stand out as notably higher than the majority (e.g., in the hundreds, rather than tens of instances). The hierarchy of quality-of-life attributes presented in Figure 1 is supported by these frequencies insofar as the capability of tenants to fulfill these needs is influenced by features of the AL environment and was discussed by them accordingly. It is these notable relationships between determinants and attributes of quality of life that are reported in the following. Those working to improve the quality of life of AL tenants are best served by understanding the dynamic relationship among them, as well as the compromises that may be necessary as efforts to address one need can undermine tenants capabilities to pursue another.

Organizational environment and control

The organizational environment and the quality-of-life dimension of control generated the greatest amount of discussion among our participants and the intersections of these two were most frequent. Organizational environment features include the rules and regulations of an AL, as well as staffing, food preparation, and recreation offerings, and have a considerable impact on tenants' sense of control in both directions. Examples of the ways in which the organizational environment impacts tenants' sense of control were provided by staff and tenants alike.

Staff 1, for instance, dwelt on the difficulties of honoring the tenants' right to live at risk. This could involve behaviors such as smoking, or simply keeping their suites free of clutter to prevent falls, as in this interview excerpt: "It's so hard because there's this edge where we say they're living at risk but we have to let them make decisions about some things, like the stuff in their room as opposed to telling them this is the way to be." Staff 5 provided a similar example that further illustrates the tension between engaging tenants in activities or with other tenants—things that staff members perceive would increase the tenants' quality of life—and respecting the primacy of their right to choose:

> Like anything comes with medications or safety issues then it's us, we would take care but other than that it's up to them, like what they want to do. They want to stay in their room, they want to go out. We try to encourage them as much as we can but again it's up to them. Its flexibility and then it's the independence, we don't want them to feel that everything is we are controlling.

Staff members need to be creative and flexible in their efforts to honor this regulation intended to protect the tenants' right to make decisions concerning their own wellbeing.

Another instrument already in place to this end are the tenant councils. Our initial environmental observations revealed that each site has tenant councils and some have committees as well, as depicted in Table 1.

Some staff members are very positive about the value of the tenant council and committees. For instance, Staff 5 spoke to how less vocal tenants can channel their concerns through their peer representatives on the council to management:

> [The tenants] have a say in everything, what we do here. They can speak for themselves. There are members, so if one of the tenants is not comfortable talking to the staff or the management they can talk to other tenants who are in the committee, … so she can talk on [their] behalf, if the tenant has some issues that need to get looked into.

However some staff members were clearly less comfortable with the role of the tenant councils:

> I find it really difficult because they seem to want to tell us how to run things. I went to one of their first committees and we got off on the wrong foot. I said something they didn't like and that was me toast and so I've never been invited back. (Staff 1)

This hesitation speaks to a lack of willingness to share power on the part of individual staff members, but it can also reflect a stance at the administrative level that is inconsistent with the message that *power is to be shared*

Table 1. Tenant councils and committees.

Site	Number of tenants on council	Meeting frequency	Committees	House meetings (open to all)
AL 1	5	2x/month	(a) food; (b) social	~ every 2nd month
AL 2	8–9	≤ 1x/month	None	~ every 2nd month
AL 3	8–9	≤ 1x/month	(a) food; (b) bed bug	Monthly

communicated by the establishment of tenant councils. Accordingly, some tenants complained that the administrative approach to running the AL was indeed more top-down than they would like: "Staff imposes 'stuff' [rules and regulations] without explaining why, which sometime doesn't feel right, they have to explain it to us what they are doing and why they are doing" (FG Z).

In ALs targeted at their ethnolinguistic group, tenants benefit from being able to speak their own language and eat familiar food. Being able to express oneself in a language in which one is fluent is fundamental, though not always sufficient, to controlling one's environment. Language congruity with staff and tenants and the availability of familiar and appropriate food also contributes to the ability to maintain continuity with the past and social and religious values (MacLean & Bonar, 1983). This control, in turns, adds to their enjoyment: "Tenants enjoy living here because they can speak their own language, enjoy having [ethnospecific] meals and can switch monthly to Western meals if they want to" (FG X).

In the nontargeted AL, Staff 1 observed that tenants who share a particular language "bond together like glue," which s/he attributes to their linguistic affinity; however, there were several tenants from a different language group who did not, which s/he explained as follows: "It's a combination of not having to rely on each other because they can speak the [English] language and personality. They're all so different." Even within ethnolinguistic communities, people are differentiated by multiple markers of identity, lifelong experiences, and personalities that will influence their relations with one another. The advantage in a targeted AL is that the pool of people that tenants can communicate with is larger, thus increasing the chance that they will find other tenants with whom they are compatible.

It is important to realize as well that even within the targeted ALs, tenants are linguistically heterogeneous (see Figure 2), so not all tenants can converse with one another, but they often find ways around it or manage to understand at least some of the other's language, which may be similar. Some tenants interpret for one another across languages from their region of origin as well as English:

> If they talk [to] each other, … they can translate by themselves. You know, you speak [language F] and the other one speak [language E] and one is [language D] but [she] can understand the [language E] so the other lady can translate to the [language F] what she's saying, something like that. (Staff 4)

Targeted ALs certainly do not address all of the factors that may undermine quality of life, but providing ethnolinguistically congruent services, to the extent possible, certainly goes a long way toward addressing the need of tenants to feel a sense of familiarity and to be able to communicate their thoughts and feelings, and it opens the space to creative solutions.

Physical plus organizational environments and control

Tenants' sense of control can be undermined by a combination of environmental features, such as the location of the AL and the organizational response to it. For example, having access to affordable transportation and essential services can also influence feelings of control. When medical services are not on site or within walking distance, and tenants are either not able to get to a transit stop or board the bus without help, they must still rely on family members to take them to medical appointments, as they did when living at home:

> Lots of time, family and friends don't have time for us, to take us to the doctor, and we don't have any transportation. There is HandyDART[6] but it doesn't help in emergency; you have to book HandyDART 7 days [in advance]. It's good otherwise, but transportation is a big, big problem. We don't have any source that if we have any problem, other than ambulance, to go somewhere. We have option of taxi, but that's too expensive. (FG Z)

There was considerable consensus among tenants that the AL should have some form of transportation of its own to meet this need. Without it, many tenants felt stranded and helpless to do anything about it.

Physical environment and security

Many tenants spoke of external physical environmental features, such as the condition of sidewalks and placement of crosswalks that threatened their security, which in turn, influenced their sense of control. If one doesn't feel safe to go out in one's neighbourhood, one can no longer exercise the choice to do so, which diminishes the sense of control.

One of the ALs is close to a church that many of the tenants would like to use, but the grade is relatively steep, and this is exacerbated by uneven pavement on the sidewalks and inappropriate placement of buttons at pedestrian-activated stop lights, such that someone in a walker is at risk of tipping off the sidewalk to reach them: "I think a lot more people might use the church and that if the sidewalks were changed … to lift a walker as well as, you know, the effort to walk over there" (FG Y).

At another site, cars park so close to the crosswalk directly outside the AL that tenants trying to cross to get to the bus-stop cannot be seen by oncoming traffic; several tenants reported close calls (FG X). And at a third site, "There is no crossing [in front of the AL] we have to wait for some decent man to stop so we can cross the street" (FG Z). One of the features on which this site prides itself is the close proximity of ethnospecific shopping venues, but without a safe crosswalk, many of the tenants feel they cannot move quickly enough to dodge the busy traffic to reach them. These examples illustrate the frustration of tenants who would like to get out and use facilities such as the church and shopping facilities to a greater extent but feel thwarted by these physical features in their efforts to do so.

The security/control trade-off

At all sites, safety features that are organizationally mandated, such as emergency alert help buttons (e.g., Lifeline®), having staff available 24/7, rapid responses to emergencies, fire drills, and medication reminders, enhanced the tenants' sense of security and gave their families peace of mind: "I'm quite happy here. … My daughter doesn't need to worry about me because I was living alone by myself and she was very close to me. … Now here, she knows that if something happens, I'm taken care of" (FG Y). As Staff 6 explained, tenants feel safe because staff members enter their suites regularly:

>]hey may be afraid because their cognition is declining so maybe they're feeling—they're forgetting where they are and things like that, so we always reassure them we're always here and that's why, for those people specifically, we do night checks. So we're physically in their suite just checking on them, sometimes they're awake and we're here, you know things like that but I think on the majority, a lot of people feel they're safe because they know us and they know that we're here 24/7.

Yet for many, this type of security measure is an intrusion of privacy, which is illustrative of the (necessary) trade-off that they experience in multiple ways between enhanced security and decreased control. For example, FG X participants told us that medication reminders ensure that tenants take their medications regularly and do not overdose, but they also restrict their movements (and hence control over their time and activities) because they have to be in their rooms at a certain time each day to receive their medications. Similarly, sign in/sign out rules, assigned seating, and set mealtimes are seen to decrease the tenants' control over their daily activities, but they are accepted for the sense of security they also bring, especially to family members who don't have to worry about falls or missed meals. Parallel conversations on this topic occurred at each site and are typified by these comments from tenants (T) in FG X who both accept and resist the safety measures in place:

> **T1**: I feel that the freedom here is less. You can't come and go as you wish. And most of the times, the activities are preplanned and they have an allotted time. Everything is planned well.
>
> **T2**: The staff rotation is around meal times. They start their shift at 7pm so dinner is at 5pm in order for all the tables and dishes to be cleaned before the next shift.
>
> **T3**: I would prefer dinner to be at 5:30 or 6pm. 5pm is too early. But there is nothing we can do about that.
>
> **T4**: Our feelings of being safe come from a "safety bell" that we all have. We're supposed to wear it around our necks, but I believe that no one here today is wearing one. If anything happens, for example, if you fall, then you can press it and the staff will be alerted. But none of us is wearing one [smiling].

Acknowledging the value of the safety bell, which was discussed at length, and simultaneously choosing not to wear it attests to the centrality of control to the tenants' quality of life.

Physical and organizational environments and attachment

Attachment between tenants was positively influenced when spaces were created that served a specific purpose that encouraged interaction. In the observations made for our environmental audits, tenants were seen to socialize most in spaces that they visit for a specific purpose, such as the dining room, the activity room, or the space around the mailboxes. The physical environment within the AL is not easy to change, but the use of available spaces is often under the control of administration or staff members. For example, a staff member mentioned that putting one newspaper in a lounge area encouraged sharing between tenants, which also led to discussions about news items. We also observed that having a whiteboard announcing menus or daily activities, or a photo gallery in the lobby, gave tenants an impetus for discussion.

Unique design features, such as the floor-specific dining areas in one of the ALs, had their pros and cons insofar as promoting attachment was concerned. These smaller dining rooms, each with their own chef and identical to one another, were more homelike in appearance, and had the potential to promote close bonds among tenants, providing they were not too diverse. Focus group participants explained that the second floor had a much more cohesive group of tenants, who spent more time socializing in their dining room:

> We have very different cultures on those three floors. You know, when it comes to the dining room. Like, our floor, I'm on the third floor. Everybody comes early, they rush through eating; they tend not to visit. Coffee time, they don't stay in the [dining room]. They come get their coffee and take it to their rooms. You know they're much less sociable … so some of the people who are social will go down to the second floor now, where they tend to gather in the dining room for the coffee time. (FG Y)

As the focus group participants explained, the tenants of the third floor were simply too different from one another for the environment to have the desired effect, as it did for the more like-minded tenants on the second floor. Staff 1 also observed that the separate dining rooms could be divisive:

> It's lovely having those dining rooms, but it means that it isolates people. So people on the third floor don't meet people on the fourth floor and people on the second floor don't meet people on the third floor and I try to get them coming down to programs and meeting each other, but it does cut them off. It does.

Although thoughtful design is important, staff members are often needed to influence the social interactions within these spaces. For example, they can play an active role in introducing people who share similar backgrounds:

> So we would try to see, like, who speaks what language, so then we will try to say, "Oh, he is from this area or maybe you would prefer" …we would try … [to] introduce them and then we would try to find a place in the dining room where we know that they can get along in that group or they can socialize. (Staff 5)

Similarly, relationships between family members are influenced by a combination of the physical design of the AL and what the regulations allow or how staff members choose to use or limit the available spaces. For example, the tenants in one AL commented that separate dining and cooking areas are needed to allow tenants to host larger family groups:

> I have asked about … being able to cook and have my family in here. At first I was having them upstairs, but it was becoming too much because there's six and my husband and I makes eight, and I was suggested to use this room downstairs: Well, it's not private. You know, you can't really have a family gathering. If the kids want to run around and play and they're making noise, it's going to disturb the office; it's going to disturb everything, so it's not really appropriate. (FG Y)

Tenants in another AL likewise commented that the small size of their suites made it difficult to accommodate overnight stays by family members, but it was their only option, with no guest suite available for their use. In these instances, it is the facility's failure to allocate space to accommodate a tenant need that precludes certain types of interactions with family members, and potentially undermines their quality of life.

In the following example, however, the facility took pains to allocate space, but the staff undermined its intended use. Tenants in one AL complained bitterly that the care staff were reluctant to open a family room for the purpose that it was intended, which had a very detrimental effect on the tenants' maintenance of attachment with their family members who choose to dine with them:

> If there is only one family visiting, the staff doesn't bother opening the family room. They make that one family eat in the dining hall. I really don't like it when they do that. … They split up the family so they can fit or they move the tenants in order to seat the family. (FG X)

Organizational environment and attachment plus role loss

The role loss that can accompany declining health in old age and increasing dependency on busy family members can be offset by the overall support that AL provides. Tenants in FG Z reported feeling a keen sense of role loss when living in their children's homes prior to moving to AL:

> One leaves home when there are problems; like first my wife was sick for 12 years but I was fine, then she passed away and I got surgery and now my arms don't

> work properly. I used to make 100s of dollars at home; I was a tailor. … Here, the staff looks after [me] well.
>
> I used to live with my daughters but I came willingly here. They all used to go to work, no one at the home. … You have to see if you are causing any problems for the kids because I have many diseases and no one to look after me at home. Here it's fine; they look after us.

In the AL, some tenants take on leadership roles in tenant councils and committees, but such roles were limited to a select few with the experience and confidence to assume them. The rules and regulations of the AL, as well as staffing, all influence the roles available to tenants. Only one of the three ALs permitted people who owned pets prior to move-in to bring them with them. This gave a couple of tenants in one AL the opportunity to maintain the responsibilities and enjoyment of dog ownership, but at times, roles such as dog walking proved to be physically challenging.

All of the ALs in our study started up around 2007 and have witnessed the physical decline of many of their original tenants, in tandem with staff cutbacks. This means that staff members are now having to do more with less for this aging and ailing population of AL tenants. Some of these tenants are without family, or feel that that they do not have sufficient contact with them. In such cases, the time that staff members can spend with them to just chat and listen (and fulfill their need for attachment) becomes critical to their mental wellbeing:

> Most of the tenants are single so, you know, sometimes they sit in the room, just the four walls, just thinking too much. So sometimes we have one-to-one visit, the program. It's very good for them and talk to them and they will, I mean they will talk to you about their family, their secret things, so it's I think communication and talking and listening is very important. (Staff 2)
>
> Like most of them they would get depressed and so we just, they want to share something and they just need somebody to listen to [them], I guess. Even though you can't help any, like you can't help much but you just listening to them, they feel happy. (Staff 5)

Yet staff members at all sites reported that they were struggling to complete basic tasks, let alone taking time to just sit with tenants. More able tenants reported that, recognizing this, they have assumed more active roles in helping other tenants (by pushing wheelchairs, for example) and providing more help to staff, by doing more of their own cleaning, for instance. This, in turn, creates a feeling of exercising greater control over one's life, but again, the trade-off is that safety is potentially compromised.

Organizational environment and enjoyment

The organizational environment is also instrumental in promoting enjoyment through the type and delivery of recreation programs offered. Activities that allow tenants to assume different roles and encourage participation seem to maximize enjoyment. As you move up the hierarchy of needs or attributes of quality of life depicted in Figure 1, then, the dimensions that form its base also play a role in influencing higher level dimensions.

Collectively, tenants and staff members across the three sites indicated that the most successful activities are varied (e.g., exercise, news & views, singing, karaoke, bingo, golf, field trips, etc.), well-planned, and clearly communicated. To feel that they are in control, tenants need input on the content and timing of activities. They also need to feel that there is no pressure to participate regularly or be on time. As Staff 2 explained,

> It's retire[ment] already; you don't need to follow the time or you have to hurry, you know, just do the things. Do the stuff. So I just always tell them if you are late [for recreation activities], it's okay, don't worry.

This person-centred approach proved to be very effective, because participation in recreation activities at this site was consistently very high. Conversely, staff members who complained about the tenants' lack of commitment to activities and emphasized the importance of their being on time, also had the greatest difficulty in attracting tenants to activities. Activities that have a positive effect on the roles available to people and their sense of control, thus, promote enjoyment.

Discussion

Overall, then, we found that, consistent with Maslow's hierarchy, on which the NCSR's quality of life model (Grewal et al., 2004) is based, the tenants that we interviewed in all three AL sites—that is, across the different ethnocultural groups—emphasized the importance of having a sense of control over their lives. And this was influenced both positively and negatively by all three types of environmental features, most especially the organizational environment. This is encouraging because it is within the power of policy makers, administrators and frontline staff—care aides, nurses and social workers—to change.

According to the Government of BC (n.d., p.1),

> The philosophy of assisted living is to provide housing with supports that enable tenants to maintain an optimal level of independence. Services are responsive to tenants' preferences, needs and values, and promote maximum dignity, independence and individuality.

Notions of independence and self-determination are, nonetheless, open to the critique that these concepts are ethnocentric and misaligned with the more collectivist or family-centred cultural values more typical of the majority of ethnocultural minority older adults living in Canadian ALs (Perkins et al., 2012). One's own conceptions of a person cannot be treated as unproblematic when approaching cultures distinct from one's own, because "the Western conception of the person as a bounded, unique, more or less integrated motivational and cognitive universe … is a rather peculiar idea within the context of the world's cultures" (Geertz, 1984, p. 126). Even so, people are warned against making too much of the distinction drawn between the *egocentric* 'Western' self—an "inviolate personality free of social role and relationship"—and the *sociocentric* self, attributed to most Eastern cultures, that is said to be characterized by "a tendency not to separate out, or distinguish, the individual from the social context" (Shweder & Bourne, 1984, p.167). Writers such as Gaines (1992) and Rosaldo (1984) argued that this scheme assumes far too great a degree of homogeneity in either sphere, and reflects more "the dichotomies that constitute the modern Western self" (Rosaldo, 1984, p.146).

Perkins et al. (2012, p. 214) have similarly interrogated the notion of "autonomy, with its emphasis on independence, self-determination and independence from interference by others … [that] is fundamental to ethical, social and political discourse in many spheres of western society," including, as we have shown, the rationale behind the creation of AL. Rather than reject autonomy in its totality as irrelevant to the ethnically diverse tenants of the ALs that they have studied, however, these authors distinguish autonomy from independence. Instead, they emphasize "control over one's environment and personal options" and "continuity in one's sense of personal identity over time and decision making consistent with one's long-term values" (Perkins et al., 2012, p. 215). There is space in this conceptualization for the notion of the more sociocentric or relational self, for which control does not necessarily equate to freedom from constraint, and autonomy can also include interdependence, "emerging out of relationships with other individuals, social groups and institutions" (2012, p. 215).

Our application of the NCSR model of quality of life in the AL environment foregrounds the centrality of the notion of control to quality of life for tenants of diverse ethnocultural backgrounds, but is consistent with Grewal et al's (2004) premise that the attributes of quality of life in this model can be realized in diverse ways. Our findings thus provide insight into the mechanisms by which specific environmental characteristics of AL support or oppress the relational autonomy identified as important by Perkins et al. (2012). Linkages made between the different attributes of quality of life reveal that a concern with control of various aspects of one's life are pervasive. They are also strongly linked with evidence of the tenants' efforts to preserve a sense of self, be it an individuated one that prefers solitude and a good book, or the relational self that seeks continuity with strong family values. Although the latter is especially evident in the testimonies of tenants and staff members in the Chinese- and South-Asian-targeted facilities, it is not exclusive to them, nor does it apply to every member of those ALs. Every population is heterogeneous, and it is for this reason that we need to understand quality of life in a way that can be understood cross-culturally, because ethnicity or language is not the only, nor necessarily the most important, identity marker determining how people construct a sense of self and conceptualize the meanings of complex constructs (Koehn et al., 2013).

Conclusions and recommendations

Naturally, our small sample size in this pilot limits our generalization of the findings. Focusing the study on modifiable environmental features also runs the risk of overlooking additional determinants of quality of life, besides the environment, although this was defined broadly and included data not only on physical features, but on organizational and social dimensions. The data thus provide some important clues as to how one might go about (re)designing and/or operating AL residences to maximize quality of life. The strategy of using the detailed descriptions of environmental features proved to be a useful way of grounding the tenants' considerations of their quality of life in relation to their residence in the AL. However, the absence of consideration of the tenants' suites where many of them spent the majority of their time compromised our understanding of the influence of AL living as a whole. This was simply beyond the scope of this pilot and will be included in a follow-up study in which one-on-one interviews with tenants will also allow for greater consideration of the influence of personal characteristics on quality of life.

The fact that the dimensions of quality of life in Grewal's model resonated with the ethnoculturally diverse tenants at all three sites is a positive indication that use of the model can help society to pay attention to concepts that have meaning across cultures, even if these concepts assume different shapes between groups. Importantly, a sense of control was foremost for all groups. Staff people working with older adult populations in AL can support their quality of life by working in multifaceted ways to respect and maintain tenants' sense of control over their lives. This includes, but is not exclusive to the following:

- Make familiar language and food available;
- Educate staff members on the importance of policies and instruments such as the right to live at risk, tenant councils, and person-centred care that puts people before tasks;
- Support tenants to play different roles;
- Provide a variety of recreation options informed by tenants;
- Build listening time into staff activities;
- Create spaces with a purpose to support interaction with other tenants; and

- Optimize tenants' ability to use external facilities, emphasizing sidewalk/crosswalk safety and transportation.

Gerontological social workers are ideally placed to advocate for tenants with administration and care staff. These findings indicate the importance of extending their advocacy to sectors beyond health care, such as governments responsible for services such as transportation, or sidewalk maintenance, all of which impact their sense of control over their lives and hence their quality of life.

Notes

1. The term *tenant* is used here to reflect its common use in BC ALs, in which there is an effort to emphasize the housing over the care dimension of AL. It distinguishes those living in AL from the *residents* of LTC. Accordingly, the term *resident* is reserved for the latter group unless it appears in a quote as such.
2. Loss of fidelity is always a risk when interpreters are used in research. We were therefore extremely careful to select interpreters with whom we have conducted previous research with excellent results. Moreover, in both situations another team member who spoke at least some of the language interpreted was present and provided some degree of assurance that the interpretation was accurate.
3. The tools used to complete the environmental audits were as follows: the Multiphasic Environmental Assessment Procedure (MEAP), specifically the Physical and Environmental Features (PAF) Checklist, the Policy and Program Information Form (POLIF), and the Resident and Staff Information Form (RESIF) (Moos & Lemke, 1996); the Senior Walking Environmental Assessment Tool-Revised (SWEAT-R) (Chaudhury et al., 2011; Michael et al., 2009); the Behaviour Mapping Tool (Schwarz, Chaudhury & Tofle, 2004). Both RESIF and POLIF are completed with input from administrative staff (< 30 min). RESIF provides descriptive data on resident demographics and activities and on staff demographic profiles and job descriptions. POLIF provides information about fee structure, facility policy, capacity, and management strategies. Neither of these interviews were subjected to the qualitative analysis used for the focus groups and staff interviews described in this paper. AM was responsible for overseeing the environmental audits and is leading the generation of a publication on the detailed results of this aspect of the research.)
4. The observations each last for 10 min and are taken every hour for 12 hr (7 a.m. to 7 p.m.), every day for 2 weeks (168 snapshots in each space).
5. Validity, which relies on positivist assumptions that are inconsistent with the critical and constructionist paradigms that inform much qualitative inquiry, including our own, is replaced by the concept of trustworthiness to ensure quality control. Trustworthiness speaks, instead, to the extent to which the researchers' interpretations resonate as true with those who generated the data and/or to whom the findings are likely to be generalized (Rolfe, 2006).
6. HandyDART is "a door-to-door, shared ride service for passengers with physical or cognitive disabilities who are unable to use conventional public transit without assistance" (Translink, 2016, p.1)

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Original Study

Factors Associated With Changes in Perceived Quality of Life Among Elderly Recipients of Long-Term Services and Supports

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Keywords:
Long-term care
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A B S T R A C T

Objectives: Advance knowledge about changes in multiple dimensions of health related quality of life (HRQoL) among older adults receiving long-term services and supports (LTSS) over time and across settings.
Design: A prospective, observational, longitudinal cohort design.
Setting: Nursing homes (NHs), assisted living facilities (ALFs), community.
Participants: A total of 470 older adults who were first-time recipients of LTSS.
Measurement: Single-item quality-of-life measure assessed every 3 months over 2 years. HRQoL domains of emotional status, functional status, and social support were measured using standardized instruments.
Results: Multivariable mixed effects model with time varying covariates revealed that quality-of-life ratings decreased over time ($P < .001$). Quality-of-life ratings were higher among enrollees with fewer depressive symptoms ($P < .001$), higher general physical function ($P < .001$), enhanced emotional well-being ($P < .001$), and greater social support ($P = .004$). Ratings also were higher among those with increased deficits in activities of daily living ($P = .02$). Ratings were highest among enrollees who received LTSS from ALFs, followed by NHs, then home and community-based services (H&CBS), but only findings between ALFs and H&CBS were statistically significant ($P < .001$). Finally, ratings tended to decrease over time among enrollees with greater cognitive impairment and increase over time among enrollees with less cognitive impairment ($P < .001$).
Conclusions: Findings advance knowledge regarding what is arguably the most important outcome of elderly LTSS recipients: quality of life. Understanding associations between multiple HRQoL domains and quality of life over time and directly from LTSS recipients represents a critical step in enhancing care processes and outcomes of this vulnerable population.

In the United States, more than 6 million older adults receive long-term services and supports (LTSS) in their homes, assisted living facilities (ALFs), and nursing homes (NHs)[1]; this number is expected to double by 2030.[2,3] LTSS is defined as assistance and support with basic and instrumental activities of daily living (eg, bathing, dressing, cooking) and can be provided in a variety of settings (eg, home, NHs, ALFs).[4,5] Currently, LTSS are characterized as a rapidly growing, fragmented and costly "system" with substantial and persistent concerns about quality.[6]

Health-related quality of life (HRQoL) has been identified by a committee of the Institute of Medicine[6] and other leading clinical scholars[7–12] as an important outcome for the growing LTSS population. The emphasis on HRQoL is important because the construct underscores this population's perspectives about their well-being, which is affected both

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by changes in their health[12–14] and the quality of the LTSS they receive.[12,13,15,16] HRQoL is now recognized as a complex construct, encompassing multiple domains, including biological and physiological factors, symptom status, physical and cognitive functional status, general health perceptions, emotional status, social support, and overall quality of life.[17]

Although HRQoL is gaining traction as a construct that should supplement or, in some situations, replace traditional measures used to assess LTSS for this population, common methodological issues, the absence of conceptual frameworks and reliance on data from one measure, typically assessed from one LTSS organizational type using a single data collection point or proxies,[18–22] limits its use to advance care processes and outcomes. The few reported longitudinal studies have focused on a single context (eg, NHs) as the unit of analysis,[16,23] focused on a limited set of HRQoL domains[24] or were limited to a specific subgroup, commonly older adults with dementia.[16,25,26]

The paucity of rigorous data on the natural history of changes in multiple domains of HRQoL among elderly LTSS recipients and the possible contributions of diverse LTSS care experiences over time by these same individuals have important implications for current and future LTSS consumers, the LTSS "system" and society. This study was designed to address important gaps in knowledge regarding longitudinal changes in multiple HRQoL dimensions among older adults who receive care from multiple LTSS providers.

The primary aims of this study were to advance knowledge about changes in multiple dimensions of health and quality of life among older adults receiving LTSS over time and across settings (Aim 1); examine relationships between and among HRQoL domains (Aim 2); and explore the influence of selected contextual factors on different trajectories (Aim 3). In this article, associations between changes in key dimensions of health and perceived quality of life (hereafter referred to as "quality of life") of older adults receiving LTSS over a 2-year period (Aim 1) are reported. Among older adults who were new recipients of LTSS at the time of enrollment, the major hypotheses were that (1) overall quality of life would decrease over time and (2) the subgroup of LTSS recipients with higher physical, cognitive, or emotional function and increased social support at baseline would report higher quality of life over time.

Methods

Design

The framework that guided this study, reported in an earlier article,[17] was an adaptation of the Wilson and Cleary HRQoL conceptual model.[11] Briefly, this model describes relationships between and among multiple HRQoL domains, including biological and physiological factors, symptom status, physical functional status, general health perceptions, social support, and overall quality of life.[11] This model was augmented to include additional domains (eg, emotional status, cognitive function, behaviors, and environmental characteristics) identified from a systematic literature review and other quality-of-life conceptual models[27,28] and considered by clinical experts as relevant to elderly recipients of LTSS.[7,9,11,12,29] The adapted model informed study hypotheses and guided study design and methods.

A prospective, observational, cohort design was used to assess changes in each of the aforementioned domains among a sample of older adults who were first-time recipients of LTSS and, at the time of enrollment, receiving services from one of the following common providers: home and community-based services (H&CBS), ALFs, or NHs.

Participating Sites and Sample

A convenience sample of 59 sites derived from 11 LTSS organizations in 3 states on the east coast of the United States (PA, NJ, NY) agreed to participate in this study. Older adults were eligible to participate if they were age 60 years or older, new LTSS recipients (enrolled within 60 days of start of LTSS), able to communicate in English or Spanish, and had a score of 12 or greater on the Mini Mental State Examination (MMSE).[30,31] Older adults were considered ineligible if, at baseline, they had documented severe cognitive impairment (MMSE <12), impaired reality (eg, diagnosis of paranoia), or a terminal prognosis.

Recruitment

Two recruitment approaches were implemented. In 2 states (PA and NJ), a volunteer staff member at each site prescreened older adults and introduced the study to all potentially eligible older adults. This group also received a brochure in English or Spanish that explained the purpose of the study and eligibility criteria. Contact information on those who agreed to be approached was sent by the staff member via secure messaging to the study's project manager. Interested older adults were then visited by a research assistant (RA) who explained the study and obtained assent or consent. In the third state (NY), potentially eligible older adults were identified via an electronic database search and initially contacted by a staff member via phone. After explaining the study, and conducting the Six-Item Screener[32] (SIS) to assess older adults' orientation and recall, eligible participants were scheduled for in-home interviews; the SIS has been validated for telephone use. This procedure was used because, unlike potentially eligible enrollees who are clustered in ALFs or NHs, older adults receiving H&CBS reside in communities spread across a wide geographic area. During subsequent home visits to those who passed the cognitive screen, an RA explained the study and obtained assent or consent.

Human Subjects

The study was approved by the University of Pennsylvania's, the Philadelphia Veterans Medical Center's, and the Visiting Nurse Service of New York's Institutional Review Boards (IRBs). All IRBs approved the use of the MMSE, adjusted for age and education,[30,33] to assess older adults' capacity to provide informed consent. Eligible older adults provided written informed consent using a conservative MMSE cut point of 23 or higher (indicating no cognitive impairment to very mild cognitive impairment). Those whose MMSE scores ranged from 12 to 22 (indicating mild to moderate impairment) provided assent; written informed consent for this latter group was obtained from their legally authorized representatives. The consent form was reviewed in detail and the opportunity to ask questions was provided to all potential enrollees and their legally authorized representatives (if needed). At each follow-up visit, the RA reviewed the purpose of the longitudinal interview study and reiterated the voluntary nature of research, allowing for questions to be asked and seeking continued agreement to be interviewed.

Data

Guided by the adapted Wilson and Cleary HRQoL conceptual framework,[17] a comprehensive assessment tool was developed, refined following pilot testing, and then used to elicit information on all selected HRQoL domains. Data were elicited primarily via in-person interviews with older adults conducted quarterly by bachelor's prepared RAs with specialized preparation in enrollment and data collection processes provided by the study team. Consented older adults received 9 face-to-face interviews at 3-month intervals through 2 years following enrollment. Whenever possible, the same RA conducted these interviews. Among older adults whose negative changes in health status precluded in-person interviews (eg, stroke, decline in cognitive status), selected data about the older adult, specifically performance on basic activities of daily living (BADLs), were obtained via brief interviews conducted with caregivers (eg, nurse assistants, home health aides, family members). Selected health resource use data were abstracted by RAs from enrollees' medical records quarterly. Additionally, quarterly surveys were completed by leaders at participating LTSS site to identify major organizational changes that might influence older adults' health and quality of life. All data are stored on a secure server at the University of Pennsylvania, School of Nursing.

Measures

Individual LTSS recipient characteristics (eg, race, ethnicity, gender, age, education, and marital status) were collected from enrollees at baseline. The primary outcome variable was elicited from all enrollees at baseline and at each follow-up data collection point using the question: "*How would you rate your overall quality of life at the present time?*" Options represented a 5-point Likert scale included the following: poor, fair, good, very good, and excellent.[34–36] Earlier studies have demonstrated that the single item, which asks respondents to rate overall quality of life using a 5-point Likert scale ranging from poor (1) to excellent (5), is a reliable and valid measure of adults' well-being.[34–36]

Several repeated measure predictor variables that align with the HRQoL conceptual framework[17] were gathered at baseline and then quarterly through 2 years using a set of valid and reliable instruments (see Table 1). The instruments selected to assess the primary outcome and each of the aforementioned domains were chosen based on the literature that suggested ample evidence for use with individuals with mild to moderate cognitive impairment (eg, quality-of-life item,[42] Symptom Bother Scale,[43] Geriatric Depression Scale Short Form,[40,44,45] and Medical Outcomes Short Form 12 item [SF-12][46]). The following is a brief description of these measures and the instruments used to generate data on these metrics.

Symptom status was assessed using the Symptom Bother Scale.[37] This instrument measures the presence and severity of 13 physical symptoms typically associated with aging or chronic illness (ie, aching, pain, stiffness, fatigue). Enrollees rated the degree to which they were bothered by each symptom on a 1 to 3 scale, with higher scores indicating more symptomatology. Symptom bother has been positively associated with deficits in activities of daily living and depression, and negatively associated with subjective health, providing support for the validity of the scale.[47,48] Cronbach's alphas were 0.78 to 0.85. A summary score of the total number of bothersome symptoms was generated for modeling.

Functional status

Cognitive function was assessed using the MMSE.[31] This widely used assessment tool measures orientation to time and place, recall ability, short-term memory, and arithmetic ability in elderly patients. This instrument consists of 11 questions, divided into 2 sections. The first section requires verbal responses to questions related to orientation, memory, and attention; the second section requires reading and writing and assesses the individual's ability to name, follow verbal and written commands, write a sentence, and copy a polygon. The MMSE total score ranges from 0 to 30 and reflects the number of correct responses with common cut points for cognitively intact of higher than 23, mildly impaired of 23 to 20, and moderately impaired of 19 to 12. Cutoff scores were adjusted for educational level using the guidelines proposed by Uhlmann and Larson.[49] The MMSE has well-established reliability and validity (test-retest 0.82–0.98; interrater 0.88; internal consistency 0.96) criterion-related validity (confusion) Spearman's rho, 0.76; discriminant validity (depression), $r = 0.38$; concurrent validity (confusion), $r = 0.80$.[50]

Physical function was measured using the Katz BADL[38] tool, which assesses individuals' abilities to perform activities such as bathing, dressing, toileting, transferring, continence, and feeding. Scores range from 0 to 6 with higher scores indicating better function. Interrater reliability of 0.95 and correct classification of 96% of people has been reported using the instrument.[51] Importantly, among cognitively impaired enrollees, caregivers (eg, certified nurse assistant, home health aides, or family caregivers) who assisted this group of older adults with day-to-day activities provided information on BADLs; no other data were elicited from caregivers.

General health perception

The Medical Outcomes Survey Short Form Physical Composite Score (SF-12 PCS) was used to assess enrollees' ratings of their health based on 8 domains: physical functioning, role limitations (physical and emotional), social functioning, pain, mental health, physical health, and vitality.[39,52] SF-12 PCS scores were weighted and summed so that general population scores have a mean of 50 and an SD of 10.[39] Higher SF-12 scores reflect better overall physical health.

Emotional status

Two tools were used to assess emotional status of enrollees: the Geriatric Depression Scale–Short Form (GDS-SF) and the SF-12 Mental

Table 1
Measurement Domains[17] and Data Collection Instruments

Measurement Domains[17]	Data Collection Instruments	Instrument Description
HRQoL		
Quality of life (outcome variable)	Single-item overall quality-of-life rating[34–36]	Five-point Likert scale (1–5) with higher score suggesting higher overall quality of life.
Symptom status	Symptom Bother Scale[37]	13 items summed to create a total number of symptoms.
Functional status	MMSE[31] *Basic Activities of Daily Living (BADL)[38]	MMSE: range 0–30; lower score suggests greater cognitive impairment. BADL: range 0–6; lower score suggests increased functional deficits.
General health perception	Medical Outcomes Survey Short Form (SF-12 v2)[39] - SF-12 PCS	Composite score that ranges from 0–100; higher score suggests better overall physical health perception.
Emotional status	Geriatric Depression Scale - Short Form (GDS-SF)[40] Medical Outcomes Survey Short Form (SF-12 v2)[39] - SF-12 MCS	Range: 0–15; higher score suggests increased depressive symptoms present. Composite score that ranges from 0–100; higher score suggests better overall emotional well-being.
Social support	Medical Outcomes Survey-Social Support Survey (Social Support)[41] - Emotional or informational - Tangible - Affection - Positive social interaction	Five-point Likert scale rating (1–5). Higher subscale score suggests increased feelings of each of these dimensions of social support.
Characteristics		
Individual	Date of birth, gender, marital status, race, education, income	Collected at baseline only.
Environment	Context of LTSS (ie, H&CBS, ALF, or NH)	
Resource use	Total number of hospitalizations and hospice days	

*Asked of formal (eg, certified nurse assistant, home health aides) or informal (eg, family) caregivers for enrollees with MMSE <24.

Composite Score (SF-12 MCS). The GDS-SF[40] was used to assess the presence and severity of depression. This instrument has demonstrated validity and reliability for measuring depression among both institutionalized[53] and older adults with dementia.[44,54] All items answered are in a "yes" or "no" format for ease of comprehension by older adults with cognitive impairment.[40,44,45] The following psychometric indices have been reported: sensitivity, 0.84 to 0.89; specificity, 0.73–0.95; discriminant validity with a clinical diagnosis of depression, 0.84.[40] The SF-12 MCS,[39] similar to the SF-12 PCS, is a weighted summary score of a patient's self-reported overall mental health. Higher scores indicate better overall mental health.

Social support

The Medical Outcomes Survey–Social Support (MOS-SS)[41] was used to assess the availability of 4 types of support: emotional or informational, tangible, affection, and positive social interaction. Each item is rated on a 5-point Likert scale from none of the time to all of the time. Subscales are generated using combinations of items with higher subscale score suggesting increased social support. Internal consistency for the MOS-SS measures are consistently high ($\alpha > 0.90$).[41,55]

In addition to data generated from in-person interviews, selected health resource data were abstracted by RAs from enrollees' medical records. Specifically, the number of hospitalizations between each interview time point (every 3 months through last interview at 24 months) and total days in hospice care were documented.

Analyses

Guided by a comprehensive conceptual model, a single quality-of-life rating elicited from enrolled older adults at all data collection points formed the basis for the use of longitudinal mixed effects modeling to examine the relationship between quality of life and each of the multiple HRQoL domains. Distribution of the quality-of-life measure follows a unimodal symmetric distribution and satisfies the assumptions for mixed-effects modeling. Mixed-effects modeling takes advantage of all available data (up to the point of loss to death or withdrawal) and also can address missing data.[56–58] Because the level of missingness was not excessive due to either death (21%) or withdrawal (7%), and patterns of missingness were not detected, the mixed effects modeling relied on all available data. Sensitivity analyses were conducted that included only those patients remaining alive throughout the study period. Findings remained the same as those observed for the entire sample and, thus, the results of the full dataset are presented here.

Both random slopes and intercepts were modeled to represent the participant level deviation from the average, or fixed-effect, slope over time and intercept, respectively. Restricted maximum likelihood estimation was used, along with a compound symmetry covariance structure. The outcome was analyzed as repeated observations (quarterly assessments over 2 years), with mean-centered baseline outcome scores as a covariate. Potential fixed-effects (eg, age, sex) were identified using simple main effects and 2-way interaction-with-time models on the basis of an inclusion criterion, $P \leq .20$.[59,60] An initial multivariable mixed effects model was constructed using the aforementioned 2-way interaction-with-time covariates, along with the corresponding main effects. Using this full model, interactions were sequentially eliminated on the basis of least significance until only interaction effects demonstrating $P \leq .20$ remained.[59,60] Covariates that were not included in the aforementioned final interaction model but demonstrated $P \leq .20$ in simple main effects models were then added to the final multivariable interaction model and assessed sequentially as described previously. The final multivariable model included covariates and interaction terms demonstrating significance only at the $P \leq .05$ level. Because of confounding between LTSS options (H&CBS, ALF, and NH) and race and ethnicity, neither of these latter variables was included in the multivariable modeling process.

Results

Sample Recruitment and Retention

Between March 2007 and July 2010, 470 older adults, evenly divided among 3 common LTSS provider types (158 in NHs, 156 in ALFs, and 156 in H&CBS), were enrolled. Of 1311 older adults screened, 37% did not meet eligibility criteria, largely due to severe cognitive impairment and/or previous LTSS experience. Of the 831 eligible referrals, 37% refused to participate, primarily reporting lack of interest or time as major reasons for refusals. An additional 6% did not have a legally authorized representative and, thus, could not be enrolled. Five individuals in NY were dropped because the site project coordinator could not confirm the reliability of data entered for these enrollees (see Figure 1). Thus, a total of 470 older adults were enrolled in this study. By the completion of the 2-year follow-up, 21% had died and 7% withdrew. Thus, the sample at the completion of data collection had decreased from 470 to 337. In addition to attrition, a range of issues, including deteriorating health and acute hospitalizations, resulted in missing interviews ranging from 6% to 16% at each of the data collection points throughout the study period. When interviews were not possible, data from chart reviews continued to be collected.

Sample Characteristics at Baseline

A detailed description of the sociodemographic and clinical characteristics of the 470 enrollees at baseline in this study is presented in Table 2. Enrollees were a mean of 81 years of age (range: 60–98); most were women (71%) and widowed (52%). Twenty percent were Hispanic; 16% of interviews were conducted in Spanish. Fifty-one percent were white. Thirty-four percent were African American; 12% reported more than one race. Approximately two-thirds of the sample (64%) completed high school (12 years of education or higher).

Data abstracted from health records revealed that enrollees had a mean of 9 documented chronic health conditions. On average, this sample reported independence in 4 of 6 BADLs; in contrast, 20% reporting being dependent on 4 or more BADLs. Approximately 60% of enrollees were cognitively intact at enrollment (assessed via MMSE). Of the remaining 40%, 24% had MMSE scores suggesting mild cognitive impairment, whereas 16% had scores suggesting moderate cognitive impairment. Forty-three percent scored 5 or more on the Geriatric Depression Scale–Short Form (GDS-SF; range: 0–15) at baseline, which is suggestive of depression and average emotional well-being score was lower than average (SF-12 Mental Composite Score = 37.3), when compared with the norm for this scale (norm = 50; range: 0–100). Eleven percent scored higher than 10 on the GDS-SF, suggesting severe depression.[40] On average, LTSS enrollees reported 6 bothersome physical symptoms, with 34% reporting more than 8 bothersome symptoms.

On average, LTSS enrollees reported lower general physical health (SF-12 Physical Composite Score), when compared with the norm for this scale (norm = 50; range: 0–100). Most enrollees indicated that they had social support (emotional/informational, tangible, affection, and positive social interaction) available most or all of the time. Sixty-three percent of LTSS enrollees rated their quality of life as excellent, very good, or good, whereas 34 percent provided fair or poor ratings; 2% did not provide baseline data on this measure.

Characteristics, including HRQoL Domains, Associated With Single-Item Quality-Of-Life Ratings Over Time

Using separate bivariate mixed effects models, selected HRQoL domains and enrollee characteristics were associated with quality-of-life ratings on the basis of $P \leq .20$. Bivariate mixed effects models of

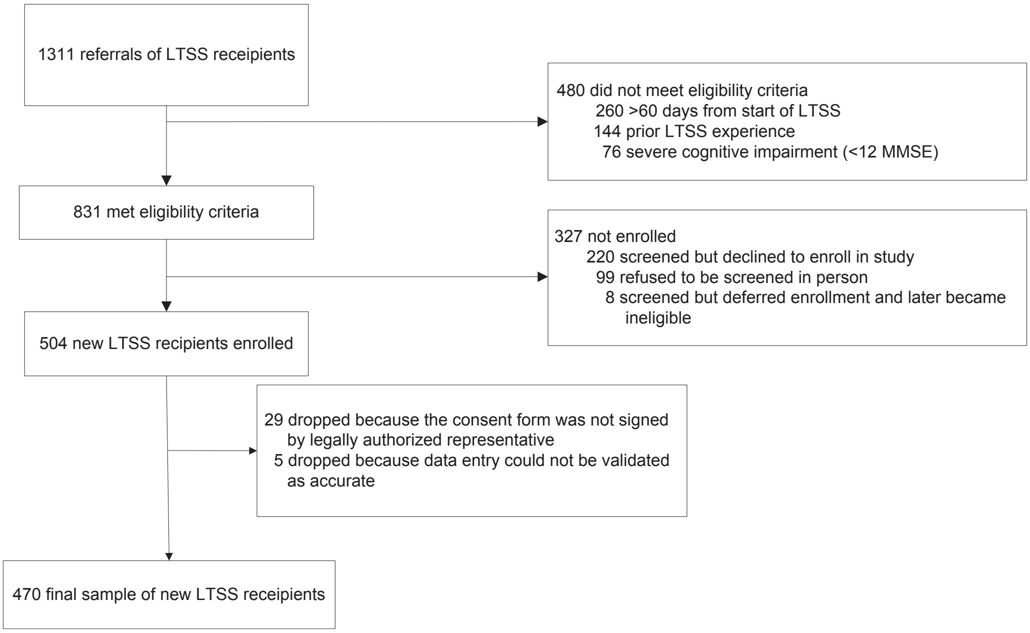

Fig. 1. Number of LTSS recipients who were screened, enrolled, and completed study.

several individual characteristics at baseline (ie, age, education, and mean number of chronic conditions) were associated with quality-of-life ratings (see Table 3). HRQoL domains associated with quality of life included symptom status, functional status (physical and cognitive), perceived general health, emotional status, and social support (all, $P < .001$). Selected health resource use factors (hospitalizations, $P = .06$, and use of hospice services, $P = .12$) were included in the multivariate model building. Additionally, time ($P = .18$) and the interaction of time and cognitive status ($P = .003$) were significantly associated with quality-of-life ratings.

Based on the results of the bivariate analysis, a final multivariable mixed effects model was developed to determine which enrollee characteristics and HRQoL domains were associated with quality of life from the time of enrollment through 2 years. Only variables significant at $P \leq .05$ were kept in the final model. Due to confounding with LTSS options (H&CBS, ALF, or NH), neither race nor ethnicity were included in the final model.

Major Findings

Holding all other variables constant, multiple HRQoL domains were found to be strongly associated with quality of life in this study sample (see Table 4). On average, quality-of-life ratings were higher among those with the following: higher general physical function (SF12-PCS) ($P < .001$) and emotional well-being (SF12-PCS) ($P < .001$) ratings, fewer depressive symptoms (GDS-SF) ($P < .001$), and greater emotional or informational social support ($P = .004$). Notably, average quality-of-life ratings were higher among those with increased deficits in BADLs ($P = .02$).

Quality-of-life ratings were highest among enrollees who at baseline were receiving LTSS from ALFs ($P < .001$), followed by NHs ($P = .12$), when compared to H&CBS (mean scores: 3.4 vs 2.96 vs 2.66, respectively). Overall, major directional changes uncovered using the final multivariable mixed effects model reveal that quality-of-life ratings decreased over time ($P < .001$). Finally, average quality-of-life ratings tended to decrease over time (*interaction term*) among enrollees with greater cognitive impairment (lower MMSE scores), whereas these same scores tended to increase over time among enrollees with less cognitive impairment (higher MMSE scores, $P < .001$).

Discussion

This study offers a unique longitudinal perspective on key dimensions of HRQoL for 470 English- and Spanish-speaking older adults who, at the time of enrollment, were new recipients of LTSS. Over a 2-year period, mean ratings of overall quality of life among this sample declined. The importance of examining changes in this population overall and not just by type of LTSS organization is reinforced by the fact that 13% of the sample transferred from one type of LTSS setting to another during the 24-month follow-up, with the most common transition from ALF or H&CBS to NH, which is consistent with other research findings.[61–64]

Given a common baseline of multiple chronic conditions complicated by a range of physical, emotional, and/or cognitive deficits requiring LTSS and the anticipated progression of these deficits over time, the observed negative directional change in quality of life is not unexpected.[65–67] However, it is important to note that such a trajectory is not necessarily the norm. For example, baseline data for this sample reveal that older adults residing in ALFs had fewer functional deficits at enrollment and, overall, reported a higher quality of life compared with enrollees receiving LTSS from H&CBS or in NHs. One possible explanation is that the LTSS provided to ALF enrollees at critical points earlier in their chronic illness and disability trajectories promoted improvements in key domains, such as physical, emotional, or cognitive function. Alternatively, LTSS interventions may have delayed progression of such deficits. Perhaps the transition to ALFs helped foster social connections and minimized the effects of isolation. The association between enrollees' roles in decision-making regarding LTSS options and quality of life also is important to examine. Further exploration of the influence of these and other factors on the trajectories of changes in HRQoL both overall and among specific subgroups is needed.

In this study, the inclusion of older adults with all but severe levels of cognitive impairment provided a unique opportunity to explore the perspectives of this vulnerable subgroup. Overall, findings reinforce those of other scholars who found increased cognitive deficits have a negative impact on quality of life[15] over time.[25] Findings from other studies revealed that cognitively impaired older adults residing in NHs or ALFs who received care in specific units designed for this

Table 2
Sociodemographic and Clinical Characteristics of Older Adults Receiving Long-Term Services and Supports, n = 470

Variable	n (%) or Mean ± SD (Range)
Characteristics of the individual	
Gender: Female	334 (71.06)
Marital status	
Married	93 (19.78)
Widowed	243 (51.70)
Separated or divorced	82 (17.45)
Single (never married)	51 (10.85)
Unknown/Not reported	1 (0.21)
Race	
White	239 (50.85)
African American	162 (34.47)
More than one race	57 (12.13)
Other (Asian/Native Hawaiian or Pacific Islander/American Indian or Alaskan Native)	9 (1.91)
Not reported	3 (0.64)
Ethnicity, Hispanic	93 (19.79)
Age, y	80.88 ± 8.71 (60–98)
Education, y	11.89 ± 4.42 (0–26)
Missing	1 (0.21)
No. of chronic conditions*	8.63 ± 3.94 (1–27)
0–4	70 (14.89)
5–8	182 (38.72)
>8	218 (46.38)
HRQoL domains	
Symptom status	
No. of symptoms	6.1 ± 3.2 (0–13)
0–3	104 (22.13)
4–8	234 (49.79)
>8	158 (33.62)
Missing	18 (3.83)
Functional status	
Cognitive: MMSE	23.96 ± 4.29 (12–30)
No or little cognitive impairment	278 (59.15)
Mild cognitive impairment	115 (24.47)
Moderate cognitive impairment	73 (15.53)
Missing or unable to complete	4 (0.85)
BADLs	4.3 ± 1.9 (0–6)
No. with no functional deficits	25 (5.32)
No. with 1–3 functional deficits	108 (22.98)
No. with 4 or more functional deficits	92 (19.57)
Missing or unable to complete	17 (3.62)
General health perception	
SF-12 PCS	49.01 ± 10.52 (13.89–76.18)
Missing or unable to complete	17 (3.62)
Emotional status	
Depressive symptoms: GDS-SF	4.55 ± 3.39 (0–15)
0–4 normal	269 (57.23)
5–10 suggestive of mild to moderate depression	173 (36.81)
≥10 suggestive of severe depression	53 (11.28)
Emotional well-being: SF-12 MCS	37.27 ± 10.95 (12.60–61.31)
Missing or unable to complete	17 (3.62)
Medical outcomes survey: social support	
Emotional or informational	2.72 ± 1.02 (0–4)
Tangible	2.97 ± 0.95 (0–4)
Affection	2.79 ± 1.18 (0–4)
Positive social interaction	2.46 ± 1.14 (0–4)
Overall quality of life†	2.97 ± 1.07 (1–5)
Excellent	40 (8.51)
Very good	101 (21.49)
Good	157 (33.40)
Fair	127 (27.02)
Poor	35 (7.45)
Missing	10 (2.13)
Characteristics of the environment	
ALF	156 (33.19)
NH	158 (33.62)
H&CBS	156 (33.19)
Resource use before LTSS	
One or more hospitalizations in past 3 mo	101 (21.49)
Missing or unable to complete	2 (<1.0)

*Number of chronic conditions was limited by the clinical documentation system used by one of the H&CBS. An additional review of records and outreach to primary care physicans was conducted to confirm accuracy of number of chronic conditions (80% response rate). Percent may not add to 100 due to rounding.

†Overall quality of life median = 3.

population or from specially trained staff reported higher ratings of quality of life than the sample in this study.[15,68,69] Once again, most of these studies were cross-sectional and did not include the diverse subgroups represented in this study. Longitudinal changes in quality of life and the relationships to the quality of services provided need further examination. It is important to note that among LTSS enrollees with fewer cognitive deficits, quality of life increased over time. Perhaps this subgroup is better able to adapt to new environments (ALF, NH) or receiving LTSS at home and, thus, their quality of life improves over time. Overall, these findings reinforce the importance of efforts by LTSS providers to promote cognitive health, especially among LTSS recipients with cognitive deficits.

In general, study results have strengthened appreciation of the potential impact of selected HRQoL domains on quality of life. Specifically, findings reinforce the work of other scholars[70–72] relative to the importance of the emotional and social support in relation to quality of life. Increased depressive symptoms appear to have a negative impact on quality of life. Findings also reveal that enhanced emotional or informational social support may be important in promoting an enhanced sense of well-being. Other scholars have reported that the nature of relationships between caregivers and care recipients is likely a significant determinant of quality of life.[73] Knowledge of emotional and social support factors that both enhance and hinder quality of life has care delivery implications for LTSS providers. Efforts to mitigate depressive symptoms, for example, should be accompanied by strategies to promote social networking or informed decision-making to optimize this outcome. Additionally, promoting networking could further increase access to social supports among this population of LTSS recipients.

Study findings raise questions regarding the relationship between LTSS options and quality of life that need further exploration. Although most older adults in the United States may prefer to remain in their homes,[74] increased understanding of the impact of this choice for those coping with deficits that require LTSS is needed. In this study, enrollees receiving H&CBS reported, on average, a significantly lower quality of life than enrollees in ALFs. Overall, the sociodemographic and clinical profile of the H&CBS group is much more similar to those enrolled from NHs than those enrolled from ALFs, suggesting a higher level of physical, cognitive, and emotional deficits at the time this subgroup began to receive LTSS. In addition to the possibility that earlier intervention may play a role, the possibility also exists that the intensity of services available via H&CBS may not be adequate to address this group's complex care needs. There also is growing concern that the decline in social networks is greater among vulnerable older adults served by H&CBS relative to those served in facilities such as ALFs and NHs.

Contrary to the study hypothesis suggested by other scholars,[15,75] quality of life in this sample was higher among those with higher dependency in activities of daily living. This finding may serve as a reminder that older adults have the capacity to adapt to major functional deficits over time, ultimately placing greater emphasis on having a sense of meaning and purpose in life in perceptions of quality of life. Additionally, LTSS may provide greater access to interventions designed to improve or delay progression of deficits. Because BADLs are a common

Table 3
Bivariate Mixed Effects Models Predicting Quality of Life over Time for Older Adults Receiving LTSS

Main Effects for Dependent Variable (Domain)	PE	SE	95% CI	*P*
Characteristics of the Individual				
Gender: female	0.042	0.082	−0.120–0.203	.613
Age, y	0.012	0.004	0.004–0.021	**.004**
Education, y	0.051	0.008	0.036–0.067	**<.001**
No. comorbid conditions	0.017	0.010	−0.002–0.035	**.083**
Symptom status				
No. of symptoms	−0.070	0.007	−0.084 to −0.055	**<.001**
Functional status				
Cognitive: MMSE	0.018	0.005	0.009–0.027	**<.001**
BADLs	0.053	0.011	0.030–0.075	**<.001**
General health perception				
SF-12 PCS	0.023	0.002	0.019–0.027	**<.001**
Emotional Status				
Depressive symptoms: GDS-SF	−0.129	0.006	−0.142 to −0.117	**<.001**
Emotional well-being: SF-12 MCS	0.023	0.002	0.020–0.026	**<.001**
Social support				
Emotional or informational	0.170	0.021	0.128–0.211	**<.001**
Tangible	0.169	0.023	0.123–0.215	**<.001**
Affection	0.128	0.019	0.091–0.165	**<.001**
Positive social interaction	0.149	0.019	0.112–0.186	**<.001**
Characteristics of environment				
ALF	0.641	0.085	0.475–0.808	**<.001**
NH	0.197	0.086	0.029–0.365	**.022**
H&CBS	Reference			
Resource use				
No. of rehospitalizations	−0.057	0.030	−0.116–0.003	**.063**
Not enrolled in hospice	0.271	0.168	−0.081–0.622	**.124**
Time, mo	−0.003	0.002	−0.006–0.001	**.179**
Time interactions with dependent variable (domain)				
Characteristics of the individual				
Time × Gender: Female	−0.001	0.004	−0.010–0.007	.753
Time × Age, y	0.000	0.000	−0.001–0.000	.210
Time × Education, y	0.000	0.000	−0.001–0.001	.497
Time × No. of comorbid conditions	0.000	0.001	−0.001–0.001	.661
Symptom status				
Time × No. of symptoms	0.000	0.001	−0.001–0.001	.770
Functional status				
Time × Cognitive impairment: MMSE	0.001	0.000	0.000–0.002	**.003**
Time × BADLs	0.001	0.001	−0.001–0.003	.328
General health perception				
Time × SF-12 PCS	0.000	0.000	0.000–0.000	.685
Emotional status				
Time × Depressive symptoms: GDS-SF	0.000	0.001	−0.001–0.001	.768
Time × Emotional well-being: SF-12 MCS	0.000	0.000	0.000–0.000	.909
Social support				
Time × Emotional or informational	−0.001	0.002	−0.005–0.003	.570
Time × Tangible	0.001	0.002	−0.004–0.005	.704
Time × Affection	0.002	0.002	−0.002–0.005	.341
Time × Positive social interaction	0.000	0.002	−0.004–0.003	.824
Characteristics of environment				
Time × ALF	0.000	0.004	−0.009–0.008	.934
Time × NH	0.001	0.005	−0.009–0.010	.853
Time × H&CBS	Reference			
Resource use				
Time × No. of rehospitalizations	0.002	0.004	−0.006–0.009	.655
Time × Not enrolled in hospice	0.002	0.024	−0.046–0.049	.951

Note: bold values are statistically significant ($P < .05$).
CI, confidence interval; PE, parameter estimate; Time, 3-month intervals through 24 months.

focus of all LTSS providers, findings also may suggest the value of targeted, evidence-based interventions, designed to promote mobility or enable feeding, bathing, and toileting. Perhaps the combination of focused LTSS interventions and the social contact provided by care team members in their delivery contributed to this unanticipated directional change. These findings require further exploration.

Overall, findings suggest that a complex, interconnected set of factors is associated with quality of life among older adults receiving LTSS. To address the complex needs and goals of this growing group of care recipients, substantive changes in care processes and outcomes may be necessary. The development, endorsement, and use of alternative, evidence-based measures of care quality, such as those suggested by study findings (eg, placing equal attention on care processes that promote health while addressing deficits) and outcomes (eg, considering the interaction of the most relevant domains such as emotional status and quality of life) are needed.[76] Fostering environments where services are guided by the multidimensional nature of factors that influence quality of life are needed.[77] Ultimately, agreement on a new vision that places a premium on the centrality of quality of life as the most relevant construct to guide measurement and improvement of LTSS performance is necessary.

Limitations

Because this study relied on data from a convenience sample of LTSS enrollees from 3 states on the east coast of the United States,

Table 4
Multivariable Mixed Effects Models Predicting Quality of Life Over Time for Older Adults Receiving Long-Term Services and Supports

Variable	PE	SE	95% CI	P
Functional status				
Cognitive −MMSE	0.002	0.007	−0.011–0.015	.771
BADLs	−0.027	0.012	−0.050 to −0.004	.023
General health perception				
SF-12 PCS	0.024	0.002	0.020–0.028	<.001
Emotional status				
Depressive symptoms: GDS-SF	−0.071	0.008	−0.087 to −0.056	<.001
Emotional well-being: SF-12 MCS	0.020	0.002	0.016–0.024	<.001
Social support				
Emotional or informational	0.061	0.021	0.019–0.102	.004
LTSS context				
ALF	0.307	0.067	0.177–0.438	<.001
NH	0.106	0.069	−0.029–0.241	.122
H&CBS	Reference			
Time, 3 mo	−0.038	0.010	−0.058 to −0.017	<.001
Time interaction				
Time × MMSE	0.002	<0.001	0.001–0.002	<.001

CI, confidence interval; PE, parameter estimate; Time, 3-month intervals through 24 months.

findings are not representative of entire population served by LTSS. Additionally, the diversity of enrollees from which the sample was drawn presented multiple methodological challenges. For example, due to confounding, race and ethnicity could not be included in the final model. The vast majority of LTSS recipients who identified themselves as Hispanic were recipients of H&CBS. To address this limitation, a sensitivity analysis of the final model excluding all LTSS recipients that self-identified as Hispanic revealed no changes in directional findings. Findings reported in this article relied on average ratings; subgroup analyses are needed to examine trajectories of changes in HRQoL among diverse subgroups both within and across the LTSS provider options and to explore the individual and environmental factors contributing to these differences. Approximately 15% of the sample was assessed as having cognitive deficits in the moderate range (MMSE = 12–19), which could raise questions about the reliability of their self-reported data including the primary outcome. However, several standardized quality-of-life measures with an item similar to the one used in this study and designed for older adults with dementia have been validated among elders with MMSE scores as low as 10.[27,78] Finally, the study design does not permit the identification of causal linkages.

Conclusion

Despite limitations, findings from this robust set of longitudinal data elicited directly from the voices of a diverse group of older adults advance knowledge regarding what is arguably the most important outcome of elderly LTSS recipients: quality of life. Understanding the associations between multiple HRQoL domains and quality of life over time represents a critical step in the journey to enhance the care processes and outcomes of vulnerable older adults who are served by a range of LTSS providers.

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RESEARCH ARTICLE Open Access

Contributions of ambient assisted living for health and quality of life in the elderly and care services - a qualitative analysis from the experts' perspective of care service professionals

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Abstract

Background: Because of the demographic change in industrial countries new technical solutions for the independent living of elderly will become important in the next years. Ambient Assisted Living seeks to address the upcoming challenges by providing technical aids for elderly and care givers. Therefore it is crucial to understand how those socio-technical solutions can address their needs and quality of life (QOL). The aim of this study was to analyse the main needs of dependent elderly and to investigate how different solutions can contribute to health and quality of life.

Methods: A qualitative study design consisting of interviews with 11 professionals of geriatric care organisations was chosen. The data analysis was done by applying the qualitative content analysis by Philipp Mayring. The analysis was based on the basic principle of the bio-psycho-social model of health

Results: Ambient Assisted Living solutions and assistive technologies can have positive impacts on different dimensions of health and quality of life. The needs and problems of elderly can be addressed by applying appropriate solutions which influence the physical, mental and social dimensions of quality of life. There are also benefits for social care providers, their staff and caring relatives of impaired elderly. Ambient Assisted Living solutions can also be used as a facilitator for operational optimization of care services.

Conclusions: Solutions for telemedicine and telecare which are connected to Ambient Assisted Living solutions will have the biggest positive impact on care giving services. Also simple technical aids can be beneficial for elderly to enhance QOL by enabling autonomy in their familiar surroundings.

Keywords: Ambient assisted living, Quality of life, Independent living, Independent elderly, Assistive technologies

Background

In the following centuries the upcoming demographic change in most of the developed western countries will lead to big social and economic challenges in the daily life and care of elderly people [1]. It will become necessary to develop solutions which facilitate social support for old people, enable workforce availability and make the geriatric care of old people more cost effective for funding the healthcare systems. One of the major challenges in geriatric care is the maintenance of independency and prevention of institutionalization [2]. To address this one approach is to give elderly the possibility to live in the own home as long as possible by applying new technology-based solutions which support a widely self-determined life of aged people. The aim is to combine information and communication technologies and the social environment of elderly to develop new concepts, products and services for their daily life. In Europe such solutions are developed under the term "Ambient Assisted Living (AAL)".

AAL solutions will become economically important for formal as well as other stakeholders involved in care

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[2]. This is because the mostly physically limited elderly people will get new possibilities to organize their life more independently within their familiar surroundings. By giving aged people the chance to live an extensive independent life, the need for care could be reduced.

Currently, a big number of research projects and public financed initiatives (EU-Framework 7 Programme - Projects) started in the last years (e.g. AAL Joint Programme [3], AALIANCE (1 and 2) [4], etc.). These efforts usually focus on usability aspects and the technical feasibility of products.

In most AAL projects it is assumed that the developed technologies and services will improve the quality of life (QOL) and well-being of elderly people. Unfortunately the impact on health and quality of life was documented in only few scientific publications. For example the results of a research project which focussed on the impact on health by adapting of light conditions showed that AATs can have a positive effect on health and quality of life [5]. The concept of QOL represents one of the most important outcome parameters of health promotion interventions, especially in elderly people [6], and is therefore a central point to measure if clinical as well as non-clinical interventions have positive effects on the study population [7,8].

The aim of this study was to explore the influential aspects of AAL solutions on health and QOL of elderly people from the experts' point of view. Their professional role in the field of care giving services gave the chance to take a look behind the marketing aspects of AAL and to investigate how these technologies can contribute to the daily life of aged individuals.

Methods

Design of the study

To gather appropriate information we conducted an explorative qualitative study consisting of problem- focused expert interviews. This method is an established method in qualitative research to collect specialized information and perceptions about specific circumstances from experts. By performing expert interviews, the interviewee doesn't represent the object to be investigated, in fact he or she is the medium which transports and reports the specific knowledge about the topic which is in focus of research [9]. The perceptions of experts can differ from the accessible public information because of the particular role in an organization where the person is faced with situations which are not common for people in general public (for example:. the chief executive officer of a care giving organization can have a broader or deeper understanding of available technical solutions for care than the relatives of dependent elderly). In this study the important advantage of the qualitative approach is to have the chance to gather realistic and experience-based information which can't be easily analysed by numerical or statistical approaches as a part of quantitative research.

Sample

From February to June 2012, 13 experts were contacted via telephone and email to ask for participation in this study. The aim was to conduct interviews with experienced staff of care giving organizations which provide mobile care services. The experts additionally must have existing knowledge about the concept of solutions in the field of Ambient Assisted Living.

The email addresses and phone numbers have been searched on the publicly available websites of the care giving organizations. Out of the 13 contacted institutions 10 declared that they are willing to participate in this study. In one case, two representatives of one social care institution participated in the interview that lead to a total number of 11 interviewees within 10 interviews. The conversation with the interviewees lasted – based on the available time resources – for 22 to 102 minutes. Nine interviews were recorded, and afterwards transcribed almost verbatim according to a set of rules which was developed according to Kuckartz [10]. Only one expert did not want to be recorded during the interview. In this case the answers were documented in an interview-protocol.

The sample of the participants separated in gender, profession and the federal state for which they are responsible for is summarized in Table 1.

Data collection

The problem focused expert interviews were executed in the organizations' offices of the interviewees. The interviews were semi-structured and conducted by CS. In advance of the interviews, an interview-guide

Table 1 Sample of participating experts (N =11)

Gender	
Female	n =6
Male	n =5
Profession	
Chief executive officer of home care institution	n =3
Head of care services (extramural facilities)	n =5
Social care worker	n =2
Head of public relations	n =1
Federal state	
Burgenland (country)	n =1
Lower Austria (country)	n =2
Vienna (city)	n =8

was developed, based on the following main research questions:

- What are the most important needs and challenges for elderly?
- How can assistive technology and Ambient Assisted Living solutions beneficially contribute to the needs and challenges of elderly subjects and care givers?

The used interview-guide also included questions which dealt with the economic impact of AAL solutions. The reported content of these questions did not relate to our research questions and is therefore not part of this publication.

Before conducting the interviews, the objectives of the study were explained to the participants and the informed consent was subscribed by the experts. During the interview-process, the interviewer explained the questions accurately to make sure that the questions were not misunderstood.

Ethics approval

The application for the study was submitted to the ethics committee of the Medical University of Vienna. The application was approved with the vote number 1546/2012.

Data analysis

The expert interviews were carried out between May to August 2012. One Interview was conducted with each expert. The data analysis was performed with structured tables in Microsoft Excel®, based on the approach of the qualitative content analysis of Philipp Mayring [11]. Key findings were identified, paraphrased and generalized by CS. Afterwards the generalized item was reduced to main categories and sub-categories by CS. The inductively developed categories were re-checked to the paraphrased and generalized material to prove consistency and real meaning by CS and TD. The whole analysis was based on the bio-psycho-social model of George L. Engel [12] which provides a more holistic approach of health and disease as it involves factors which influence the physiological, psychological/mental and social health.

In the course of the analysis the aspects of interpretation and the reduced items were continuously developed near to the material and the context of the described answers of the experts. To make sure the topic was sufficiently investigated, the interviewer paid attention on the saturation and comprehensiveness of the study material. After the 8th interview, the saturation of the content was reached.

The cited quotations in this publication were translated from German into English. At this point it is important to notice that the language of the interviewees was coloured by different Austrian dialects and idioms. To keep the real meaning of the reported facts, the dialectic content of the transcribed interviews was only partially translated into English. The quotations were numbered with the coded interview partner and the starting line number of the citation in the transcribed material (e.g. “R3” for “respondent number 3”).

Results

As the first step in our process of analysis we identified the needs and challenges of elderly which were reported from the experts’ perspective (main category “Individual demand”). In the second step we identified the reported basic and advanced technologies and their contributions to organizational aspects for care service provider (main category “Technology for care”). The third main category (“Health and quality of life by AAL”) summarizes the findings of the individual’s benefits of AAL solutions.

Individual demand (C1)

This category defines two sub categories (see Table 2). It describes the most important individual needs and individual problems of elderly with demand for support by care giving organizations or their relatives.

Needs of elderly (C1.1)

In general the experts agree on the point that dependent elderly want to be treated as competent and sovereign individuals, regardless from the disabilities they are suffering from. They have the desire to be supported in a loving way. The individual’s needs are influenced by the personal circumstances of their life and social environment:

> *‘…we do have seniors who put make up on before the nurse comes to visit them. Often this is neglected.’* (R4/123)

> *‘…it sounds like a buzz phrase, but it is not a natural consequence to interact at an eye level with those people – no matter how disoriented they are. It is very important to take them serious and not giving them the feeling of obtrusiveness…’* (R2/101)

The need of continuity, familiarity and respect plays a major role for the dependent persons. If changes in their surrounding are necessary these things always must be done step by step.

Table 2 Categorisation of the results

Main categories	Sub categories
C1: Individual Demand	C1.1: Needs of elderly
	C1.2: Problems of elderly
C2: Technology for Care	C2.1: Basic technologies for care
	C2.2: Advanced technologies for care
C3: Health and quality of life by AAL	

> *'..., I mentioned that familiarity is very important to cope with the daily life...'* (R2/122)

> *'... the biggest possible degree of continuity by considering the individual's needs in the surrounding conditions. This could be banal things, e.g. it is very important for a person to take the shoes off before entering the flat...'* (R8/33)

> *'... my caregiver should come always at the same time, be on time, should be very friendly. (...) That's it. The stability.'* (R9/479)

The elderly do have a strong desire for social interaction, especially with their family members. Also the fulfilments of their wishes is an important need and therefore to be considered by care giving staff and relatives. Two interviewees reported that consuming delicious food plays a major role for aged people because they love to enjoy indulgence as same as young people do. Here, talks about delicious experiences of meals are used as an instrument to create a level of joint interaction and social interactions. In the interviews, it was also reported that the experience of fun in old age is also an important need. But the fulfilment of this very important need is a rare phenomenon.

> *'...The social interaction is an important thing. Gadgets do not fully replace this but they make fun...'* (R7/705)

> *'...Food is the main topic, everything. What is the meal today and what will the meal be tomorrow and what did we have yesterday? For elderly food does play the same role as sex for pubescent...'* (R9/487)

The fulfilment of elderly's′ individual needs like delicious food and the feeling of being secure in the familiar surroundings have positive impacts on QOL.

> *'...the process of having meal as a manner of indulgence. It should have usually play this role for people... food enables social contact, it is living...'* (R9/502)

The experts agree that improving social and personal interaction does influence quality of life and can lead to improved health status by influencing mental health. Furthermore, the communication between relatives and seniors at the one side and between care givers and elderly on the other side does have influence on the well-being of the old person.

> *'...if he goes to a day care centre, the lust for life and emotional appeal. Those minds are in good shape...'* (R7/100)

> *'...we say ... the social contact is the thing that really helps ...'* (R9/169)

> *'...we take care that relatives do visit the residents ... that they communicate. But also when our care staff is visiting the assistive living accommodations they talk to them ...'* (R10/18)

> *'...autonomous and self-determined, but they have the possibility to be a part of our big team ...' (R10/30)*

From the perspective of care staff or care giving relatives, a personal relationship and appropriate personal interaction as well as the possibility to cooperate with the dependent person is highly necessary. The necessity of personal interaction with a familiar assistant is also a main need, especially when the support is on a basic and intimate level of interaction (e.g. feeding, toilet support, personal hygiene).

> *'...as often as possible the same care person. Being on time. Appearance. Reliability. These are the most important aspects...'* (R8/464)

> *'...and the social element he does need. This is the aspect which is claimed by the most of them...'* (R7/722)

> *'..the social dimension is one of the most important ones. In other respect it is "warm, to be full, clean". Some people are embarrassed because of incontinency. They do not want to smell bad; they do not want to lie in a wet bed. Here simply the human being is needed...'* (R7/716)

The QOL can be improved by giving dependent people the possibility to act autonomously within their familiar surroundings. Autonomy can be facilitated and improved by equipping the home with barrier-free gadgets, helping aids and technical gadgets. The main objective is to facilitate the activities of daily living in the elderly (for example: bathing, dressing, etc.).

> *'...most important are low barriers, barrier-free surroundings, I mean in the flat and outside the flat and then the near infrastructure. But it is, this is a key point, the barrier-free, to have different helping aids in the flat which facilitate a lot of things...'* (R6/88)

The need for autonomy could be addressed by (non-technical) services which provide solutions for challenging situations for impaired people. They improve autonomy by giving situational support when it is needed (e.g. cleaning services and other tasks in the household). An expert said that moving to an assisted living facility can lead to improved autonomy, because of the additional services in those homes. Nevertheless, for dependent elderly it is crucial to stay motivated and activated by their care givers to do things on their own and keep them mobile as long as possible.

> *'... it would be easier to open the oven like a wing from the side, like a door of a cupboard, and below of this I can pull out a place of deposit and take the baking tray on it...'* (R6/98)

> *'... imagine the following: ... You have problems with your legs and you have to clean up the flat. How could you do that? Impossible. But you are dissatisfied, because you see that your flat is not administered enough. This means you need someone to do it. ... – this assisting person visits you and does this work with you together...'* (R10/68)

An interview partner said that the autonomy of making decisions about the own body and the home surroundings is a possible aspect, how health and QOL can be improved.

> *'...or it (autonomy) is about the human being who lives here and can decide on his or her own if there is a spot of dirt or not. That is his right to say, "This spot I want to have here. And when I want to have bread crumbs on my table, I want it this way"...'* (R9/310)

Problems of elderly (C1.2)

The most important problems in elderly are physical caused, cognitive limitations, tremor and impairments in mobility. Especially the limitations in mobility lead to declining social interactions and sometimes feeling insecure and imprisoned at the own home. One interview partner stated that losing the mobility means being imprisoned at your own home.

Also mental changes in life of elderly due to dementia are part of the most crucial problems. They lead to disorientation and can have a huge negative impact on the activities of daily living.

> *'...people are often able to walk around at one level of a building but they can't get upstairs more than 3, 4 or 5 stairs and are therefore more or less prisoners in their own flat...'* (R8/57)

> *'...another topic is the tremor ...'* (R8/64)

> *'...under some circumstances also the social surrounding is reduced because of the limitations in mobility , and furthermore the psychological changes which come along with ageing. Also in the direction of being disoriented, dementia diseases which impede activities of daily living...'* (R2/29)

> *'...and for most of the elderly the fear of intrusion of strangers, fear to be alone, fear of isolation...'* (R9/163)

Another identified problem is the thinning of the social environment because of deceased family members and friends. Furthermore, from the expert's view, in today's common perception of society an old person seems not as valuable as a young person. Especially aged people feel this perception which leads to a feeling of not being needed anymore and depressive mood or psychological disorders.

> *'...And then, the social losses, that people often lose their most important persons in this phase of life' (R2/28)*

> *'...because the old person is unpresentable. In Austria, this aspect de facto does not exist (...)' (R8/127)*

> *'...from the perspective of the old people you go to an assisted living home or a nursing home and hand over the individuality at the entry door. That's the way it is, yes...'* (R9/284)

Another domain of problems for elderly was explained by the insufficient financial resources. This is especially a problem for old women and their relatives.

> *'...Furthermore, there are the social problems; most of them do not have a good financial background, the pensions of old women are at the bottom limit ...'* (R2/25)

> *'...I do see it in my own family, we additionally paid, because it was not enough (money)... no problem for paying additional for our mother. They (the government) will not pay additional for it ...'* (R7/876)

The next problem is the transition to the new situation of the need to be cared or supported in any way. For this new unfamiliar situation there are not enough institutions that have the possibility to give appropriate advice to elderly and their relatives.

> *'...there is no good advisory service for old people!... it is all about "how do I motivate people to make use of assistance at home?". They have to go a step forward and allow an unfamiliar person to get into the flat and I have to admit that I am not able to do it anymore. This is the crux of the matters in life...'* (R7/340)

Technology for Care (C2)

In this main category two sub categories were found (see Table 2). It describes the needed basic and advanced technological solutions in geriatric care that could support care giving services and aged people.

Basic technologies for care (C2.1)

The role of simple supportive devices, like nursing beds, can help care staff to activate bed-ridden people. Also physical actions like relocation and mobilisation of clients can be done easier with available assistive aids and technologies like grab handles and patient lifts.

> *'...we have high dropout quotes. If a client is heavy and bedded low, 3 times a day turning him around, changing diaper and mobilizing is not possible. The bed is the next important thing in mobile care...'* (R7/236)

> *'...this is an interesting example...if I can transform a bed into a chair and reversed...'* (R1/77)

> *'... yes, it should simply be barrier-fee. This means beginning with the size of the grab handles, to be able to put a stool under the shower or simply a shower without barrier...'* (R6/138)

One assistive basic technology to facilitate the work of nursing staff is the adaption or adaptability of the sanitary environment. The needed technologies are helping aids in bathrooms that make the care process less stressful for the staff and could decrease the risk of falls, too. Technical solutions for relocation and movement of clients are always useful to prevent the back of the nursing staff of injuries. These kinds of helping aids are very rarely available at the customer's homes. Furthermore, assistive devices that help elderly to stand up and mobilize, are needed.

> *'...electrically adjustable toilets and wash-bowls would influence care positively...'* (R3/48)

> *'...the whole topic "transport, transfer, embedding". This is one thing that is bad for the back of the people, if I can say so...'* (R4/85)

> *'...another thing that would be great, the electrical mobilization aids to stand up...'* (R5/214)

Another technology that could help care givers is a door opening system for flats without an electrical door. This technology is simple and very important because often key-safes are not allowed by property management or not wanted by the clients. Also video systems to open doors remotely would be very useful for clients and care staff.

> *'...The most important thing we would need, and I think the clients too, would be the opening of the doors. It is always a dilemma to get into the flat. If someone is bed ridden... without going to the door, opening the door...'* (R6/110)

> *'...a system... for example a camera in front of the door. So she is able to see who will enter...not the key-safe ... in reality it is not expensive, but it does not exist...'* (R7/535)

One interviewee explained that technical solutions for cleaning up incontinence products could be supportive for care giving staff.

> *'...if I do not need anyone who helps to clean up the incontinency material. If there would be a technology that supports in this action...'* (R1/70)

Advanced technologies for care (C2.2)

General the experts stated that an appropriate way is needed to get informed regarding technical solutions which are already available. Therefore, the experts advised to establish an AAL-platform for information dissemination.

> *'...a platform for AAL-products should be established (the platform for helping aids of the ministry seems to be not suitable for this purpose)...'* (R3/99)

> *'...regardless if there w different providers – but accessible on one platform.'* (R8/431)

In future intelligent assistive technology will be used to foster autonomy of dependent elderly and give relatives the opportunity to have additional spare time in their lives.

> *'...spare time for relatives will be enabled to have the possibility to get out half a day without having fear. There is a huge deficit and here I see the big chances for AAL...'* (R4/42)

An often mentioned area of gadgets needed is the technology with reminder functions. For example medicine dispensers that detect, if a drug had been taken or not would be a valuable assistance. Also devices which have reminder functions for water intake do make additional sense in geriatric care.

> *'...to the automatic medicine box, when taking out the medicine it does not necessarily mean that I took the medicine. Therefore it could also trigger an alarm with the same technology...'* (R1/13)

> *'...a device which stands beside the bed like a little television and shows a glass of water; ... a television...*

> *that says "Mrs. Mayer, please drink a glass of water"…'* (R7/429)

The experts explained that possibilities to interact with the devices more easily are recommended. One approach is the manipulation of the systems via speech recognition. Most experts declared that a remote control via speech recognition is strongly needed to give impaired elderly an appropriate chance of interaction with assistive devices. Because of their declining cognitive abilities, it would be useful to manipulate television, windows, jalousies, lights, and phones via speech control.

> *'…When looking at old people I recognize that there should be much more possibilities of speech recognition. When I become older I will not see the remote control (buttons) as good as now. It would be better if I could give commands to the television…'* (R1/373)

> *'…a phone … that is dialling via voice recognition. None of our clients has such a thing…'* (R7/293)

Experts also described solutions to improve social interaction. One method is the video-communication facilitated by television.

> *'…visual communication is a topic…Two models: a client has the possibility to get in contact with the organization actively via web – regardless if by television or something else. Via camera… Because the client wants to get a brain-training or a nutritional advisory service…'* (R8/257)

The next approach how technology could improve the interaction of care organisations and elderly is to have the possibility to call the service provider on demand. If advice for daily challenges is needed, the qualified staff could give it just in time to the supported person.

> *'…it would be an ideal solution if I could say, "I offer this", as mobile care service provider. The people press a button and we visit them only when they really need us…'* (R5/139)

The experts reported that measuring activity and behaviour via monitoring systems could help the care service provider to optimize its supportive tasks based on the individual's perceptions and habits.

> *'…I could imagine that – before providing care services – to make a technical supported activity check over 3 weeks; what does he or she do on his or her own? What is he or she not able to do? Aiming to provide optimal services to him/her. Because we are supporting in these fields where the human being is not able to act on his or her own anymore…'* (R1/156)

There is also demand for automatic light adaption, which would be useful to prevent falls.

> *'…one topic is light, when getting up at night, there are products of company XY and so on. Guidance systems that recognize activity and turn on the lights…' (R4/95)*

The most important solutions include products which enable monitoring of vital parameters of dependent persons. Here telemedicine and telecare do play a major role for the interaction between care giving institutions, physicians and emergency services. Fall detection systems, location detection and autonomous behaviour recognition solutions with automatic interpretation were mentioned in context with telemedicine solutions. Today, available emergency-call systems can also be coupled with fall detection systems. For disoriented persons systems can be useful that are able to detect their location more easily (stand-alone-locations detectors).

> *'…fall detection systems, these things we do not have at the moment in our organization… This is a very good thing, because it gives the client a feeling of being secure…'* (R7/148)

> *'…fall detection systems are in use in our emergency call devices. With wristbands and neckbands…'* (R10/160*)*

> *'…it would be beneficial, if not only we (the care provider) would get the data. Also the physician should have access…'* (R1/331)

> *'…do you know the emergency call systems? There is a box with a voice speaking out of it. This is a very important contact person for a lot of clients. …they wake up at night and are a little bit of perplex…'* (R7/189)

> *'…a location detection system for disoriented persons who got lost…'* (R2/233)

Emergency-call systems do have a positive influence on caregiving services, because in situations where disoriented persons need support personal contact can be realized.

> *'… and these systems tell us: did he go outside? … The new systems are able to do more, e.g. it could inform: "client leaves the house"…'* (R7/63)

As mentioned it is very important for care services to gather and record vital parameters in the field of telemedicine. AAL could play a supportive and activating role by enabling people to do their daily measurements of e.g. blood pressure on their own. By enabling dependent elderly to do these necessities on their own the resources of care providers can be preserved. Nevertheless this information is not enough for providing professional care services. The data has to be supplemented with additional information about the client's day and the personal situation while doing the measurement, e.g. an exciting talk before measuring blood pressure could increase the values.

> *'...I think telemedicine and telecare will be a topic. For support at home...'* (R1/101)

> *'...the vital parameters. For example blood pressure. This is strongly connected to the agility of the person...'* (R8/86)

> *'...the transmission of vital parameters and other data relevant to medicine or care. ...this would be a benefit, if transmitted, to a call centre...'* (R8/220)

> *'...Every person is able to measure blood pressure on his own. What is relevant for us? For us the following is relevant: Did he measure blood pressure? And additional: What happened? What did he do the whole day? So we are able to draw conclusions. The numbers and values as on its own do not represent anything...'* (R10/108)

Health and quality of life by AAL (C3)

This category summarizes the findings how intelligent assistive technologies, smart homes, and AAL solutions can influence health and QOL of aged people.

Technologies can impact health and quality of life in elderly in various dimensions. When providing technical solutions, it is necessary to focus on and address the individual needs of elderly and also to offer products that provide additional benefits for elderly.

> *'...products... which are adapted to the need of the particular person...'* (R8/287)

> *'...by looking straight forward perhaps intelligent solutions will essentially contribute to quality and well-being and also for preservation of health...'* (R8/506)

The main objective of assistive technologies is to influence QOL of the individual by enabling elderly to live in their familiar surroundings as long as possible.

> *'...the biggest wish of all of them is to stay at home. And the longer I can stay at home by technical aids, the more my quality of life grows and I can stay at home gladly...'* (R1/188)

The experts explained that it is necessary to provide only as much technical and non-technical assistance as necessary because "over-supported" people tend to retreat themselves.

> *'...at the time he gets support, this is our experience – he tends to retreat and does nothing anymore...'* (R1/159)

> *'...it (AAL) would enable them to stay in their familiar surroundings for a long time. If a lot of things are done automatically I am able to stay at home for a longer time. That's it...'* (R7/286)

The QOL and health can be influenced via devices which enable people to improve social contact and interaction. Technologies can have health impact by giving elderly the possibility to participate in societal actions and therefore decrease their loneliness. Another way of improving health and QOL was found in the possibility to communicate in emergency-situations directly with emergency- and care services. The health status can be positively influenced by advices from medical staff or care service providers for after-treatment questions.

> *'...I think that the intelligent devices promote health in a (health) promoting way. Especially by communicating with external contacts...'* (R1/119)

> *'...I think, for me the social inclusion is one key point ... the technology enables me to live the social inclusion in that way that I can be involved more intense, then it operates like in a health promoting way. Here the technology can be supportive...'* (R6/333)

> *'...(communication) with old friends who are, for whatever reason, are not mobile, etc....'* (R8/20)

> *'...we have to recognize AAL as a platform for social contacts. Why it is negative to communicate with the grandchild over a distance of 25.000 kilometres? I see the videoconferences. We don't have to say 'videoconference'; it is a personal call...'* (R10/553)

> *'... It could be hospitals, care service provider, perhaps emergency services, ...' (R8/293)*

Another way of in influencing health and QOL was found in the impact on the physical dimension. Stimulating the activity of elderly people improves the mobility of them. This aspect is important because also depression and sleep disorders can be influenced positively by physical mobilization. Some AAL solutions could be used for physical training and exercises. They could increase, or at least retain, the existing mobility.

> *'...And sophisticated and medical assured with sports science etc., programs for movement- and training in old age...'* (R8/510)

> *'...the systems that are developed will contain the stimulus to get outside. Health, well-being and also less depression, sleep disorders and so on. I think that technology can be supportive...'* (R1/132)

The experts explained that technology based reminders and warning gadgets and functions (for medicine intake, measurement of vital data, food or liquids) are able to improve physical health as well as individual wellbeing. Therefore, the compliance of medicine intake and the feeling of not being thirsty can be influenced. Reminders, warning functions and advisory functions do play an important role in prevention of diseases and other health threatening events.

> *'...but when I do not open it (the medicine dispenser) within the span between 07:00 and 08:00 a voice comes out of the television "I would like you to remind you that you didn't take your medicine"...'* (R8/177)

> *'...the medicine dispenser because does remind you. It supports you with the prescribed medicine. This supports health. Because I keep my abilities at this level. This is why I got my medicine...'* (R7/604)

> *'...measurement of blood glucose. If it is at 300: "hello, something has to be done!" ... Thereby the care staff, the relatives, the medical doctor arranges reactions...'* (R10/497)

> *'...I think of emergency situations. And of course, if I would say I have warning systems like these that tell me: "drink, take the medicine", whatever, I could have an impact (on health)...'* (R9/525)

> *'...and if the milk is not free of lactose: "warning!", and this is the advantage...'* (R10/671)

The elderly's QOL can also be influenced by "technical helping hands" like robots, intelligent adaptable tables or seats which help the dependent person to stand up.

> *'...and the other would be a helping hand. This is the direction of care- and robot systems which are currently under development...'* (R6/62)

> *'...here it is the topic of handling mobility... if the table rolls away ... to have support in that way, however it may be realized...'* (R7/616)

Health and QOL can also be affected by AAL solutions by compensating mental disabilities. Experts mentioned that reminder functions can have positive effects at the self-determination by reducing their daily mental stress of forgetting something important. Here, item-related reminder functions (for example: to find things/ forgetting keys) or space related reminder functions (for example: checklist when leaving flat) were described.

> *'...aids to remember in the household or in the flat. That can take away the stress a little bit: "did I do this and that, did I turn off the stove?" These things that support me by remembering and organizing the daily life...'* (R2/81)

> *'...the key that tells me "take me with you" if I leave the flat. The key wouldn't tell me that, the system does... and applications to stimulate and help me to remember, I mean applications with touch screens for memories, pictures, music...'* (R2/234)

> *'... with RFIDs (computer chips for radio-frequency identification) that help the people to find things they lost or cannot remember the place where they left it...' (R2/245)*

Mental health can also be improved by reducing fear, enhancing the feeling of being secure and thereby improving a more relaxed behaviour. AAL solutions can reduce fear by providing reliable emergency-systems that automatically react in the case of emergency. This is important, because people tend to be less mobile after falls which improves the physical degradation anyway. Another possibility is to enable memory trainings for people with dementia.

> *'...these reminders shall facilitate human beings to be self-determined and active. It is worthless, if a machine takes over all activities...'* (R10/206)

The mental well-being and fear can also be reduced by security-systems (in terms of automatically switching electronic devices) that are convenient for elderly because they don't need to be worried about any switched on devices while being not at home.

> *'...the systems which provide security...'* (R9/35)

> *'...then it would be the security topic, all these things like switching off the stove...'* (R4/62)

> *'...if I forget to switch off the stove. After a defined time it switches off automatically – that's it.'* (R6/184)

> *'...for them the aspects of being secure is not bad. I think, they feel a bit more relaxed and less anxious...'* (R6/342)

> *'...these things help because they take away the anxiety... If I would fall to the ground two times, I am afraid. When I am afraid I will fall again more easily...'* (R7/116)

One expert explained that AAL solutions could increase social and psychological wellbeing by giving elder persons duties and responsibilities.

> *'...If I would have an AAL-system, that tells me "good morning mister XY", and furthermore shows me the activities. And then I measure the blood pressure and it tells me "thank you for your data"... this sounds strange... but sometimes it could be an essential activity. And this could be the task of AAL...'* (R10/520)

Another aspect is that self-confidence can be improved by offering AAL services which can be planned by elderly on their own and therefore make them less independent (e.g. transport services, shopping via television).

> *'...to be valued again. Imagine you do not have a duty. You are sitting around the whole day and looking into the sky. What would happen to your self-esteem? ...'* (R10/531)

The experts explained that applying security solutions can have positive influential aspects to the relative's conscience. Emergency and security solutions are often bought by elderly to calm their relatives.

> *'...yesterday, I saw a movie about residential care. And there is an old woman that says: "my daughter is calmed since I have this emergency wrist band, this is great"...'* (R9/269)

The (partially) manipulation of the home environment could enhance QOL by providing more comfort at home. The elderly's comfort could also be enhanced by giving them the possibility to remote control/trigger (for example: via voice recognition) lights, radiators and windows. Another comfort improving technology is an automatically assistive device which enables impaired people to take a bath independently.

> *'...for me the ecologic components (radiators) of smart homes are more important...'* (R9/254)

> *'...or if I lie in my bed and lower the jalousies without standing up, this is..., let's say, if we are in need of care, and this has a particular benefit...'* (R6/180)

The experts stated that there could be also negative impacts on QOL and health by AAL. For example the electro smog that comes along with technologies could have bad consequences for health.

> *'...in our thoughts, we want less electronic devices where we sleep. And with this (AAL), I will have it exactly there. If the old person lives in one or two rooms, then I will have it (electro smog) there...'* (R9/329)

Monitoring systems could prevent people from living a risky life on their own by being over-supervised by a technical system. This means that the right of living risky and self-determined could be undermined by AAL.

> *'...there is the aspect of controlling someone. And I, as an old person, have the right to live risky. ... the surrounding environment (AAL) limits them (their liberty)...'* (R6/209)

> *'... and I don't want to be put under tutelage by a smart home only because it wants me to drink a litre. Then I simply don't want this. I think I can decide on my own where I want to go...'* (R9/281)

Discussion

This study shows that AAL and assistive technologies can have beneficial impacts in several dimensions of QOL and geriatric care from the expert's perspective. The holistic and multidimensional approach of the bio-psycho-social model of Engel [12] was the most appropriate way to get all results under one conceptual umbrella as it involves the various facets of QOL and health. This is why the results are presented by assigning them to these different dimensions (see Tables 3 and 4).

Previous research showed that physical and mental health problems are relevant risk factors for elderly's autonomy. Thus, it will be a relevant option to apply technologies to address needs in later life [13]. It is necessary to realize that old persons who are dependent have the same basic needs as everyone else (e.g. social interaction, housing, autonomy, control of their lives, etc.) [14].

The most important needs of elderly which were articulated are social interaction, person-centred support, continuity in life, self-determination, having fun and enjoy life. The reported problems are the decline of social involvement, the feeling of being insecure, not being needed anymore, physical, and mental limitations. From care givers' perspective the decline of mobility, sensory abilities, and dementia diseases are the most stressing problems.

Table 3 Impacts of technical solutions to QOL and health of elderly

Technical solution	Impact on QOL and health	Dimension
Automatic switching devices (e.g. stove)	• Feeling secure	Mental
	• Feeling more relaxed	
	• Less anxiousness	
Call-on-demand systems	• Reducing retreatment	Social
emergency call systems	• Calm relatives	Mental
	• Feeling more secure	Mental
	• Directly communication with care giver	Social
	• Direct advisory of medical staff in critical situations	Physical
Fall detectors	• Reaction when threatening event occurs	Physical
Intelligent furniture/ mobilization aids	• Enhanced autonomy	Physical and mental
Medicine dispensers	• Medical compliance	Physical
Memory trainings on AAL-System	• Positive impact an people	Mental
	• With declining mental capacity	
Mobility aids for self-bathing for impaired	• Enhance autonomy	Mental
Planning services (transport, shopping via television)	• Can do it on my own without help	Mental
Reminder and warning functions (medicine intake, vital data, drinks)	• Better medicinal compliance	Physical
	• Compensation of not feeling thirsty	
Reminder functions (medicine, key finders)	• Compensation of mental disabilities	Mental
Remote control of lights, windows, radiators	• Enhance comfort	Physical and mental
Task planning services	• Have duties and responsibilities (self-esteem)	Mental
Training devices/ electronically physical advisor	• Increase or retain mobility (positive impact of activity on sleep disorders)	Physical
	• Positive impact of activity on depressive diseases	Mental
Video communication systems	• Improve social interaction	Social
	• Improve care measures regarding elderly's needs	Physical and mental
AAL-Systems (general)	• Independent living at home	Mental
	• Autonomy	
AAL-Systems (general)	• Being over-supported	Social
AAL-Systems (general)	• Electro smog	Physical and mental
AAL-Systems (general)	• Focusing on individuals needs	Mental

Table 4 Impacts of technical solutions to care givers

Technical Solution	Impact of AAL	Dimension
AAL General	• Have additional spare time for caring relatives	Physical/mental
Aids for mobilization and relocation	• Less burdening for care staff	Physical
Behaviour recognition	• Better focus on needs possible	Organizational
Electrical doors	• Easy access to client	Mental
Emergency call systems	• Reaction if threatening event	Organizational
Fall detection systems	• Reaction if threatening event	Organizational
Location detections	• Finding lost elderly very fast	Organizational
Monitoring systems for analysis of activity and behaviour	• Optimize supportive actions	Organizational
Systems for recording vital data	• Preservation of resources by enabling people	Organizational

AAL solutions can enable elderly people to live a self-determined life if the systems are adjusted to their needs and seek to compensate their problems. Especially for geriatric care services, there are positive influences on the organizational level of measures. Here, the AAL technologies like fall detection, behavioural analysis systems, location detectors, and recording systems for vital data can help to react just in time when assistance or need-focused support is required. Furthermore, the resources of care givers can be preserved by optimizing their care activities based on monitoring systems. For relatives of impaired elderly people, those technologies can provide the possibility to get additional spare time, and therefore have a positive impact on mental health of them. Technical aids for mobilization could make the work of care services less burdening.

For elderly, there are several impacts on a high number of dimensions in QOL and health by applying different systems. The physical domain of health can be influenced with telemedicine and telecare services by providing advisory services for critical situations. Intelligent AAL-devices like medicine dispensers and reminder functions can affect the medicinal compliance and help to compensate mental disabilities of people. Training applications are a good vehicle to enforce elderly subjects to mobilize and train their body on their own.

Mental health can be positively influenced by enhancing autonomy and independent living by giving old people the feeling of being secure. To enable this, there are several solutions like fall detection systems, emergency call systems and automatic switching devices. Autonomy, individual comfort, and security can be impacted by applying mobilization aids like intelligent furniture or remote controlled smart home components like automatic light adaption, window control and heating equipment.

Important elements of AAL solutions are video communication systems, which enable the social inclusion and involvement of elderly people. These systems are especially important, if the dependent person lives in a rural area without frequent visits of relatives, friends or care givers.

In 2002 Van Bronswijk defined different domains of applications where technology can influence QOL [15]. Beneath supportive, preventive and compensative influences that are provided by technologies he reported that technologies for enhancement and satisfaction will become more popular. Our findings confirm this perception in that way that socio-technical, mobility- and comfort-enabling AAL solutions are impacting QOL.

Other available literature of QOL in context of AAL and other technology based support systems focuses on the quantitative evaluation of QOL and health without analysing the modes of how technologies affect these parameters [16-18]. Objective and subjective evaluations provide important information to understand QOL and health outcomes. For dement elderly especially only subjective and user-centred methods, which focus on the individual needs, lead to sufficient information about its impacts [19]. Referring to the investigative questions of this study the lack of existing literature do represent the technology-driven approach of research in the field of AAL where the influences on future users are not taken into account in a sufficient amount until today.

There were some possible negative influences of assistive technologies and AAL found. We identified that there could be a possible threatening because of electro smog in the home of elderly. Another adverse aspect is the potential of getting over-supported by intelligent devices that take over essential tasks in daily life. Due to the aim of AAL to enable a self-determined life of elderly – and therefore enhancing QOL - also ethical considerations have to be undertaken. By applying such systems, e.g. for behaviour monitoring or location detection, there must be a balance between privacy and protection according to their individual needs and abilities [5]. AAL solutions may not be understood as a tool to enhance social inclusion and safety while paying the price of getting overprotected or disciplined by others. This could lead to a lost self-determination via AAL [20].

Strengths and limitations

In our study, experts of care giving organizations in eastern Austria were interviewed. The involved persons are working in different fields of expertise of care service providers. Because of these different professions, the results are balanced concerning the different occupational views of the interviewees. However, the interviewed persons were only from eastern Austria. In some cases this fact could make the findings only conditionally transferable to other regions and cultures. Another limiting issue is that the personal aspects of elderly (needs, problems, health and QOL) were collected only from the caregivers' angle of view. Within this study it was not possible to gather this information from the perspective of aged people but it will be taken into account in further research activities to triangulate the results of this manuscript.

A limitation of this study may be seen in the fact that the interviews and the content analysis were performed by the same person. Strength of the study is the saturation of topics in relation to the sample size which was reached after the 8th interview.

During the interviews the different understanding what AAL does mean and which technologies are subsumed under this term was a problem, This finding proves the fact that there is no national and international consensus on the terminology of these products and solutions [21].

For further understanding of the impact of AAL it will be highly important to organise interviews with aged people regarding their experiences with assistive technologies. Additionally, it is important to do interventional studies in the field of AAL to investigate potential influences, both, positive and negative, of assistive technologies and AAL solutions on health and QOL.

Conclusion

Our findings suggest that there is a wide range of possible impacts of AAL on QOL and health of elderly and care givers. Because of the technology-focused character of research in AAL, there is a lack of resources that describe the interplay of technology and health as well as QOL from a multidimensional angle of view.

This study showed that also indulgence and person centred support do play an important role in the daily life of impaired elderly.

The results show that technology and AAL can have beneficial effects on the perceived needs of old people. The supportive role to compensate or minimize problems of aged people does represent one of the main considerable advantages of AAL.

The application of supportive technologies which enhance the feeling of being secure can lead to valuable contributions to QOL and health. Here, also quite simple technologies like electric door openers were identified.

Telemedicine and telecare technologies as well as smart home technologies seem to have the biggest potential for the future of care giving organisations. These sophisticated solutions can help to optimize their services according to their clients' needs and problems.

Quite in contrast to these complex solutions elderly will prefer simple technologies which are technical aids (for example: grab handles), video communication and emergency call systems. Those systems are not directly connected to the meaning of or even be one part of AAL solutions.

Further research and development of new AAL solutions should focus on the investigation how needs of elderly and care givers can be addressed by these solutions by describing the pathways how AAL can influence health and QOL.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

CS is the main author of this manuscript. CS did the conceptual design of the study with AH. CS carried out the interviews, did the initial content analysis and the first draft of the manuscript. TD and AH participated in the critical review of the manuscript. All authors were involved in drafting and approved the final manuscript.

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