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Multimorbidity patterns in adult day health center clients with dementia: a latent class analysis

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Abstract

Background: Persons living with dementia (PLWD) in adult day centers (ADCs) represent a complex and vulnerable population whose well-being is at risk based on numerous factors. Greater knowledge of the interaction between dementia, chronic conditions, and social determinants of health would enable ADCs to identify and target the use of their resources to better support clients in need of in-depth intervention. The purpose of this paper is to (a) classify PLWD in ADCs according to their level of medical complexity and (b) identify the demographic, functional, and clinical characteristics of those with the highest degree of medical complexity.

Methods: This was a secondary data analysis of 3052 clients with a dementia diagnosis from 53 ADCs across the state of California between 2012 and 2019. The most common diagnosis codes were organized into 28 disease categories to enable a latent class analysis (LCA). Chi-square test, analysis of variance (ANOVA), and Kruskal-Wallis tests were conducted to examine differences among latent classes with respect to clinical and functional characteristics.

Results: An optimal 4-class solution was chosen to reflect chronic conditions among PLWD: high medical complexity, moderate medical complexity, low medical complexity, and no medical complexity. Those in the high medical complexity were taking an average of 12.72 (+/-6.52) medications and attending the ADC an average of 3.98 days (+/-1.31) per week—values that exceeded any other class. They also experienced hospitalizations more than any other group (19.0%) and met requirements for the nursing facility level of care (77.4%). In addition, the group experienced the greatest frequency of bladder (57.5%) and bowel (15.7%) incontinence.

Conclusions: Our results illustrate a high degree of medical complexity among PLWD in ADCs. A majority of PLWD not only have multimorbidity but are socially disadvantaged. Our results demonstrate that a comprehensive multidisciplinary approach that involves community partners such as ADCs is critically needed that addresses functional decline, loneliness, social isolation, and multimorbidity which can negatively impact PLWD.

Keywords: Alzheimer's Disease, Latent Class Analysis, Adult Day Care, Multiple Chronic Conditions

Introduction

Dementia is a chronic and progressive syndrome characterized by cognitive decline that is projected to impair

13.8 million individuals in the United States by the year 2050 [1]. The burden of disease and disability is heightened among persons living with dementia (PLWD) who also experience multimorbidity. Multimorbidity is defined as the coexistence of 2 or more chronic conditions in an individual [2], and it is associated with the need for complex intervention [3]. On average, older

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people have been found to have 4.6 illnesses along with dementia [4].

Research has shown that dementia can complicate other chronic conditions and vice versa. For example, coexisting chronic conditions such as hypertension, diabetes, and coronary heart disease can exacerbate cognitive dysfunction and other symptoms in people with dementia. Conversely, dementia can complicate the care of these illnesses by accelerating functional decline and increasing the potential for adverse complications [5, 6]. Research has affirmed that when multimorbidity intersects with dementia, there is greater incidence of hospitalizations [7] and readmissions [8], emergency department use [9], fragmented care, and reduced quality of life [10]. Effective models of integrated care are urgently needed that help PLWD with multimorbidity preserve function and address unmet needs to reduce costly and traumatic health care utilization.

Adult day centers (ADCs) represent one potentially vital but overlooked platform for chronic disease management and care coordination for PLWD [5]. ADCs are nonresidential community-based facilities that support the health and social needs of adults through health monitoring, socialization, meals, and assistance with activities of daily living (ADLs) [11]. ADCs can follow either a social or health/medical model. Social models place a stronger emphasis on social and recreational activities, whereas health models tend to offer a more sophisticated rehabilitation-oriented program and provide management of current health problems such as dementia [12]. ADCs that follow health models benefit from having interdisciplinary staff (eg, registered nurses, social workers, nursing aides) and deliver culturally and linguistically congruent health and social care to clients [13]. Programs embedded within ADCs that emphasize integrated care, such as the Community Based Health Home (CBHH) model or Programs of All Inclusive Care for the Elderly (PACE) [14], reduce avoidable health care utilization among clients with multimorbidity [11].

Each day in the United States, ADCs provide care to nearly 200,000 PLWD, most of whom suffer from Alzheimer's disease and Alzheimer's disease—related dementias (AD/ADRD) [15]. PLWD in ADCs represent a complex and vulnerable population whose well-being is at risk based on numerous factors. In addition to experiencing a high prevalence of cognitive impairment (upwards of 30% of all clients [16]), ADC clients also face disproportionately high rates of multimorbidity, poverty, disability, limited English proficiency, transportation barriers, and food insecurity [5, 17, 18]. More than 69% of clients suffer from some combination of AD/ADRD, depression, or heart disease, and 30% have a diagnosis of diabetes [16].

Adding to this, nearly 72% of ADC clients live below federal poverty lines, and 58% are racial minorities [15].

Despite the critical implications for disease trajectory, treatments, and caregiving needs, the interrelationships among dementia, concomitant disease, and social determinants of health are not well understood among those who use ADCs [18]. The scarcity of large-scale data on ADC users restricts researchers', policymakers', and caregivers' understanding of ADCs' effectiveness and impact on users' health and functional status [19]. Greater knowledge of the interaction between dementia, chronic conditions, and social determinants of health would enable ADCs to identify and target the use of their resources to better support clients in need of in-depth intervention. However, it is not enough to simply understand the magnitude of individual chronic conditions in PLWD; a more nuanced approach to understanding multimorbidity requires identifying possible combinations of chronic conditions that may interact to affect disease trajectory [20]. Moreover, given the inherent clinical complexity of this population, the interaction between dementia and multimorbidity is likely to be highly variable [13]. Developing an understanding of clusters of co-occurring chronic conditions in the ADC population would allow ADCs to optimize their programming and improve the standard of care for PLWD with multimorbidity. In addition, identifying characteristics of those at the highest risk of adverse health outcomes and directing resources to them can result in reduction of costly and traumatic healthcare utilization in PLWD and yield significant cost savings to healthcare systems. Hence, the purpose of this paper is to (a) classify PLWD in ADCs according to their level of medical complexity using latent class analysis (LCA) and (b) identify the demographic, functional, and clinical characteristics of those with the highest degree of medical complexity.

Methods

Design and data source

The deidentified data for this retrospective analysis of ADC clients with dementia were provided by TurboTAR for the years 2012-2019. TurboTAR is the leading provider of billing and management software to ADCs in the state of California, which is home to 30% of ADCs in the United States [15]. California is one of the few states with regulations that require ADCs to collect and report data on their clients on a serial basis. It is important to note that mandatory data reporting in California ADCs is *only* required for clients whose participation in adult day services is paid for by Medicaid and is not the case for those who pay privately or through other sources. Medicaid is a public health insurance program for people in the United

States with limited incomes (less than 138% of the federal poverty level) [21]. Since Medicaid is the only public payor of adult day services and insures 72% of people in American ADCs [22], the majority of people being cared for in ADCs live below federal poverty levels.

Every 6 months, an eligibility and needs assessment is conducted on Medicaid beneficiaries enrolled in ADCs using the state's Individualized Plan of Care (IPC). The IPC is a 26-page regulatory document that can be completed within TurboTAR, and it contains information on diagnoses, medications, ADLs and instrumental activities of daily living (IADLs) based on assessments by interdisciplinary team members at the ADC [23]. It also captures information on continence, nutrition, living arrangements, health care utilization, clinical risk factors, and social determinants of health. TurboTAR deidentified the data, which were then extracted and securely shared with the principal investigator.

Study population

The study population included individuals aged 50 and over who (a) were clients in California ADCs, between 2012 and 2019, during which the IPC remained unchanged; (b) were Medicaid beneficiaries; (c) had a clinical diagnosis—reflected in ICD-9 or ICD-10 codes—of vascular dementia, Lewy body dementia,

frontotemporal dementia, Alzheimer's disease, or dementia not otherwise specified; and (d) had at least 2 consecutive IPCs completed after enrollment reflecting 12 months of data. Clients in ADCs that did not have data-sharing agreements with TurboTAR were excluded from this analysis. Using these criteria, our sample consisted of 3053 people.

Variables

The study variables are listed in Table 1. We grouped variables as *demographics* (eg, race, primary language, living alone), *clinical information* (eg, number of medications), *functional status* (eg, ADL, medication mismanagement), and *chronic conditions* (eg, gastrointestinal disorders, cardiovascular disease). The 28 chronic condition categories reflect the most common diagnoses—approximately the top 10%—that emerged upon reviewing the dataset.

Statistical analysis

Data were validated and examined for outliers; no major outliers were found. Preliminary descriptive statistics were calculated to examine sample demographics and characteristics. Latent class analysis (LCA) was then used to empirically identify classes of ADC clients with dementia reporting similar patterns of multiple chronic conditions at the time of enrollment. In the LCA, which

Table 1 Study Variables

| Demographics | Clinical Information | Functional Status | Chronic Conditions |
|--|--|--|--|
| AgeGender Minority status Primary Language Race Living Alone | Number of medications daily Planned days at center per week Incontinent of bladder Incontinent of bowel Therapeutic or special diet Difficulty chewing and/or swallowing | Activities of daily living (ADL) Emergency Department (ED) visits baseline Hospitalizations at baseline Meet a nursing facility level of care Use an adaptive device Inappropriate affect/appearance/behavior Poor judgement Medication mismanagement Self-neglect Dementia related behavioral problem Fall risk Isolation Frailty | Hypertension Diabetes Mellitus (DM) with Complication Diabetes Mellitus Without Complication Arthropathies Thyroid Disease Nutritional Deficiencies Cerebrovascular Disease Cardiovascular Disease Cancer Depression Peripheral Vascular Disease Chronic Kidney Disease Chronic Liver Disease Chronic Liver Disease Lipid Disorders Osteoporosis Non-depressive mood Disorder Parkinson's Disease Chronic Obstructive Pulmonary Disease (COPD) Obesity Dorsopathies Chronic Pain Vision Disorders Gastrointestinal Disorders Sastrointestinal Disorders Asthma Neuropathic Pain Disorders Gait Disorders |

is based on structural equation modeling, groups, or classes, are formed by uncovering hidden, or latent, patterns of association between nonordinal observations in a dataset. LCA was the preferred method to assess patterns of multimorbidity in ADC clients because unlike descriptive approaches which would yield counts or frequencies of individual chronic conditions, LCA enables us to establish groupings based on co-occurrence of chronic conditions, and, as a result, identify broad co-morbidity patterns. LCA is a frequently used methodology in analyzing multimorbidity, because it not only enables the identification of clusters of chronic conditions, but also allows examination of differences between clusters in terms socio-demographics, function, and clinical characteristics.

The parameters of the LCA model included the following: (1) the creation of a total count indicator as a simple comorbidity score of all of the co-occurring chronic conditions present to reflect the cumulative exposure to multimorbidity; (2) the probability of each specific chronic condition present within each latent class; (3) the overall proportion of the population in each of the latent classes; and (4) the mean number of comorbid conditions present in each latent class. We fit the LCA model using maximum likelihood in Mplus version 7.31 [24], where the dichotomous chronic condition indicators were modeled with a binomial logit link and the overall count of different comorbid conditions present was modeled with a log Poisson link. The 28 dichotomous indicators of the presence of each chronic condition, as well as an overall count of the number of different chronic conditions, were analyzed using LCA with a varying number of classes, ranging from 1 to 7 [25–28]. We determined the optimal number of classes using the Bayesian information criterion (BIC), Akaike information criterion (AIC), bootstrap likelihood ratio test (BLRT), and the Lo, Mendell, and Rubin Likelihood Ratio Test (LMR-LRT) [29], which balances model fit and parsimony [30, 31] as well as clinical judgment. Once the optimal number of classes was determined, we computed the posterior probability that a certain individual belongs with a certain latent class using Bayes' rule [32]. Labels, reflecting the complexity associated with the average number of chronic conditions individuals in a latent class had, were applied to each group. We also determined that a chronic condition was disproportionately represented within a latent class if its frequency in that class was either 10% above the prevalence within the total sample or double the total prevalence.

Relationship between latent classes and individual characteristics

We then compared the demographic, functional, and clinical variables across classes that emerged within the

LCA, using a chi-square test for categorical predictors and analysis of variance (ANOVA) for continuous predictors. We conducted post hoc multiple comparison tests using a Bonferroni correction, and then we completed Kruskal–Wallis tests in lieu of ANOVA for non-normal distributions of continuous predictors. These analyses were conducted within SPSS (version 25.0).

Ethical considerations

The institutional review board at the principal investigator's (TS) institution classified this deidentified secondary data analysis as nonhuman subjects research.

Results

Sample description

The study sample comprised 3053 ADC clients with a dementia-related diagnosis. The sample was disproportionately female (67.1), with a mean age of 79.57 years (+/-9.44), taking 9.67 medications (+/-6.59), and attending the ADC 3.59 days a week (+/-1.72). Significant data (>30%) were missing for race and English proficiency, which were nonmandatory collection fields. For those who had complete data, 42.2% were non-English speakers, and 32.4% identified as non-White.

Latent class analysis

An optimal 4-class solution was chosen based on comprehensive evaluation of fit indices (BIC, AIC, entropy, LMR-LRT, and the BLRT). Group 1 (n=801; 26.24%) consisted of individuals with an average of 5.67 chronic conditions in addition to their dementia diagnosis. They were deemed as having "high medical complexity." Group 2 (n=1120, 36.69%) had, on average, 3.91 conditions and was labeled "moderate medical complexity." Group 3 (n=802, 26.27%) had, on average, 2.07 chronic conditions and was labeled "low medical complexity." Group 4 (n=330, 10.81%) had none of the 28 chronic conditions and was considered to have "no medical complexity." Tables 2 and Table 3 (at the end before References) present the baseline characteristics of the overall sample and the individuals assigned to the 4 groups.

ADC clients with dementia and high medical complexity Demographic characteristics

The average age of clients with high medical complexity was 79.40~(+/-9.27) years, and 67.9% were female. This was largely consistent with the sample overall. For those who had no missing data on race and language, 49.1% were non-English speakers, higher than any other group, and 31.8% identified as non-White. The proportion of people in the high medical complexity group who lived alone (18.6%) was higher than in any other group.

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Table 2 Percentages and average number of chronic conditions across 4 latent classes

| Chronic Condition | Total Sample (%) | High Medical Complexity (%) | Moderate Medical Complexity (%) | Low Medical Complexity (%) | No Medical Complexity (%) |
|--------------------------------------|------------------|--------------------------------|------------------------------------|-------------------------------|---------------------------------|
| Hypertension | 61.9 | 73.6 # | 84.9 # | 43.4 | 0 |
| DM with Complications | 9.1 | 15.7 | 11.0 | 3.3 | 0 |
| DM without Complications | 22.5 | 24.1 | 35.5 # | 12.3 | 0 |
| Arthropathies | 32.3 | 53.7 # | 35.0 | 19.1 | 0 |
| Thyroid Disease | 11.8 | 18.5 | 13.0 | 7.9 | 0 |
| Nutritional Deficiencies | 6.8 | 12.4 | 6.1 | 4.6 | 0 |
| Cerebrovascular Diseases | 6.8 | 11.6 | 7.3 | 3.9 | 0 |
| Cardiovascular Diseases | 18.7 | 30.6 # | 23.7 | 6.8 | 0 |
| Cancer | 3.6 | 4.9 | 3.8 | 3.5 | 0 |
| Depression | 25.6 | 44.4 # | 23.6 | 18.5 | 0 |
| Peripheral Vascular Disease | 3.1 | 6.4 # | 2.8 | 1.2 | 0 |
| Chronic Kidney Disease | 9.1 | 13.7 | 12.6 | 3.2 | 0 |
| Chronic Liver Disease | 0.9 | 2.0 # | 0.2 | 0.9 | 0 |
| Genitourinary Disease | 11.4 | 22.9 # | 7.2 | 9.4 | 0 |
| Lipid Disorders | 37.4 | 48.2 # | 59.0 # | 12.1 | 0 |
| Osteoporosis | 17.3 | 26.9 | 19.3 | 11.3 | 0 |
| Mood Disorder | 17.3 | 32.9 # | 11.6 | 15.3 | 0 |
| Parkinson's Disease | 2.0 | 3.8 | 0.7 | 2.6 | 0 |
| COPD | 4.4 | 11.3 # | 1.9 | 2.3 | 0 |
| Obesity | 1.7 | 2.4 | 2.6 | 0.3 | 0 |
| Dorsopathies | 7.6 | 17.6 # | 4.7 | 4.1 | 0 |
| Chronic Pain | 1.4 | 3.5 # | 0.5 | 0.8 | 0 |
| Hearing Disorders | 5.0 | 11.6 # | 2.9 | 3.0 | 0 |
| Visual Disorders/Deficits | 5.9 | 12.2 # | 4.6 | 3.2 | 0 |
| Asthma | 4.7 | 9.3 # | 3.9 | 2.7 | 0 |
| Gastrointestinal Disorders | 13.6 | 32.3 # | 8.8 | 5.8 | 0 |
| Neuropathic Pain Disorders | 3.6 | 9.1 # | 2.5 | 0.6 | 0 |
| Gait Disorders | 4.8 | 11.5 # | 1.1 | 4.7 | 0 |
| Average Number of Chronic Conditions | 3.50 | 5.67 | 3.91 | 2.07 | 0 |
| N (%) | 3053 (100.0) | 801 (26.24) | 1120 (36.69) | 802 (26.27) | 330 (10.81) |

Notes: DM Diabetes Mellitus, COPD Chronic Obstructive Pulmonary Disease

Functional characteristics

Relative to all other groups, ADC clients in the high medical complexity group experienced the greatest frequency of (a) difficulty chewing and/or swallowing (8.7%), (b) incontinence of the bladder (57.5%), and (c) incontinence of the bowel (15.7%). They were also the most frequently classified as needing assistance and/or being dependent with ambulation (24.9%), bathing (60.1%), and transferring (30.0%). Notably, the high medical complexity group had the lowest use rate of adaptive devices (3.9%), were more likely to be at risk for falls (74.7%) and experienced the highest degree of social isolation (62.4%). In addition, nearly half (49.2%) of individuals in the high medical complexity group experienced dementia-related

behavioral problems. Notably, those in the low medical complexity group required greater assistance and were dependent with regard to self-feeding, bathing, and toileting compared to all other groups. Nearly half (48.9%) mismanaged their medications, more so than any other group. The low medical complexity group also had a slightly greater proportion group of people with poor judgment (62.8% vs. 60.9%) and inappropriate affect, appearance, or behavior (29.8% vs. 25.3%) compared to the high medical complexity.

Clinical characteristics

ADC clients with dementia who were classified as having high medical complexity were disproportionately

[#] indicated that the prevalence of chronic condition within the class was either 10% above the prevalence within the total sample or double the total prevalence

Table 3 Demographic, clinical, and functional status information across 4 latent classes

| Variables | Total Sample Mean \pm SD or N (%) | High Medical Complexity Mean \pm SD or N (%) | Moderate Medical Complexity Mean \pm SD or N (%) | Low Medical Complexity Mean \pm SD or N (%) | No Medical Complexity Mean ± SD or N (%) |
|--|-------------------------------------|--|--|---|--|
| Demographics | | | | | |
| Age ⁺ | 79.57 ± 9.44 | 79.40 ± 9.27 | 80.14 ± 8.44 | 78.88 ± 10.58 | 79.74 ± 10.02 |
| Gender ⁺ | | | | | |
| Female | 2049 (67.1) | 544 (67.9) | 779 (69.6) | 503 (62.7) | 223 (67.6) |
| Male | 1001 (32.8) | 257 (32.1) | 340 (30.4) | 297 (37.0) | 107 (32.4) |
| Minority status * | | | | | |
| White | 642 (21.0) | 223 (27.8) | 207 (18.5) | 173 (21.6) | 39 (11.8) |
| Minority | 990 (32.4) | 255 (31.8) | 404 (36.1) | 243 (30.3) | 88 (26.7) |
| Primary language * | | | | | |
| English | 602 (19.7) | 154 (19.2) | 179 (16.0) | 205 (25.6) | 64 (19.4) |
| Non-English | 1289 (42.2) | 393 (49.1) | 510 (45.5) | 296 (36.9) | 90 (27.3) |
| Living alone with no family * | 462 (15.2) | 149 (18.6) | 187 (16.7) | 108 (13.5) | 18 (5.7) |
| Clinical information | | | | | |
| Number of medications daily * | 9.67 ± 6.59 | 12.72 ± 6.52 | 9.82 ± 6.49 | 8.07 ± 5.77 | 5.62 ± 5.46 |
| Planned days at center per week * | 3.59 ± 1.72 | 3.98 ± 1.32 | 3.84 ± 1.44 | 3.78 ± 1.58 | 1.31 ± 2.05 |
| Incontinent of bladder * | 1440 (47.2) | 462 (57.7) | 547 (48.8) | 390 (48.6) | 41 (12.4) |
| Incontinent of bowel * | 415 (13.6) | 126 (15.7) | 152 (13.6) | 116 (14.5) | 21 (6.4) |
| Therapeutic or special diet * | 1433 (46.9) | 430 (53.7) | 670 (59.8) | 308 (38.4) | 25 (7.6) |
| Difficulty chewing and/ or swallowing * | 196 (6.4) | 70 (8.7) | 50 (4.5) | 67 (8.4) | 9 (2.7) |
| Functional status | | | | | |
| Any emergency department visits at baseline * | 473 (15.5) | 142 (17.7) | 198 (17.7) | 116 (14.5) | 17 (5.2) |
| Any hospitalizations at baseline | 435 (14.2) | 152 (19.0) | 154 (13.8) | 112 (14.0) | 17 (5.2) |
| Meet nursing facility level of care * | 1834 (60.4) | 620 (77.4) | 637 (56.9) | 499 (62.5) | 78 (24.6) |
| Use an adaptive device * | 261 (8.5) | 31 (3.9) | 102 (9.1) | 102 (12.7) | 26 (7.9) |
| Inappropriate affect/ appearance/behavior * | 743 (24.3) | 203 (25.3) | 262 (23.4) | 239 (29.8) | 39 (11.8) |
| Poor judgement * | 1701 (55.7) | 488 (60.9) | 642 (57.3) | 504 (62.8) | 67 (20.3) |
| Medication misman- agement * | 1231 (40.3) | 392 (48.9) | 463 (41.3) | 338 (42.1) | 38 (11.5) |
| Self-neglect | 933 (30.6) | 260 (32.5) | 343 (30.6) | 294 (36.7) | 36 (10.9) |
| Dementia related behavioral problems * | 1344 (44.0) | 394 (49.2) | 475 (42.4) | 412 (51.4) | 63 (19.1) |
| Fall risk * | 1924 (63.0) | 598 (74.7) | 762 (68.0) | 497 (62.0) | 67 (20.3) |
| Isolation * | 1730 (56.7) | 500 (62.4) | 686 (61.2) | 475 (59.2) | 69 (20.9) |
| Frailty * | 927 (30.4) | 311 (38.8) | 335 (29.9) | 253 (31.5) | 28 (8.5) |
| Activity of daily living Ambulation * | | | | | |
| Independent | 338 (11.1) | 71 (8.9) | 126 (11.3) | 120 (15.0) | 21 (6.4) |
| Needs Supervision | 1514 (49.6) | 449 (56.1) | 607 (54.2) | 408 (50.9) | 50 (15.2) |
| Needs Assistance | 551 (18.0) | 172 (21.5) | 213 (19.0) | 149 (18.6) | 17 (5.2) |
| Dependent | 75 (2.5) | 27 (3.4) | 24 (2.1) | 23 (2.9) | 1 (0.3) |

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Table 3 (continued)

| Variables | Total Sample Mean ± SD or N (%) | High Medical Complexity Mean \pm SD or N (%) | Moderate Medical Complexity Mean \pm SD or N (%) | Low Medical Complexity Mean \pm SD or N (%) | No Medical Complexity Mean ± SD or N (%) |
|-------------------|---------------------------------------|--|--|---|--|
| Bathing * | | | | | |
| Independent | 117 (3.8) | 30 (3.7) | 46 (4.1) | 35 (4.4) | 6 (1.8) |
| Needs Supervision | 705 (23.1) | 206 (25.7) | 286 (25.5) | 192 (23.9) | 21 (6.4) |
| Needs Assistance | 1477 (48.4) | 436 (54.4) | 573 (51.2) | 415 (51.7) | 53 (16.1) |
| Dependent | 168 (5.5) | 46 (5.7) | 59 (5.3) | 53 (6.6) | 10 (3.0) |
| Dressing * | | | | | |
| Independent | 331 (10.8) | 94 (11.7) | 127 (11.3) | 97 (12.1) | 13 (3.9) |
| Needs Supervision | 809 (26.5) | 244 (30.5) | 335 (29.9) | 209 (26.1) | 21 (6.4) |
| Needs Assistance | 1192 (39.0) | 343 (42.8) | 457 (40.8) | 342 (42.6) | 50 (15.2) |
| Dependent | 137 (4.5) | 36 (4.5) | 48 (4.3) | 47 (5.9) | 6 (1.8) |
| Self-feeding * | | | | | |
| Independent | 1304 (42.7) | 387 (48.3) | 531 (47.4) | 350 (43.6) | 36 (10.9) |
| Needs Supervision | 861 (28.2) | 255 (31.8) | 330 (29.5) | 244 (30.4) | 32 (9.7) |
| Needs Assistance | 272 (8.9) | 68 (8.5) | 98 (8.8) | 88 (11.0) | 18 (5.5) |
| Dependent | 33 (1.1) | 8 (1.0) | 7 (0.6) | 15 (1.9) | 3 (0.9) |
| Toileting * | | | | | |
| Independent | 555 (18.2) | 151 (18.9) | 236 (21.1) | 150 (18.7) | 18 (5.5) |
| Needs Supervision | 1119 (36.7) | 337 (42.1) | 457 (40.8) | 295 (36.8) | 30 (9.1) |
| Needs Assistance | 703 (23.0) | 204 (25.5) | 241 (21.5) | 224 (27.9) | 34 (10.3) |
| Dependent | 94 (3.1) | 26 (3.2) | 33 (2.9) | 28 (3.5) | 7 (2.1) |
| Transferring * | | | | | |
| Independent | 462 (15.1) | 98 (12.2) | 173 (15.4) | 163 (20.3) | 28 (8.5) |
| Needs Supervision | 1281 (42.0) | 380 (47.4) | 537 (47.9) | 330 (41.1) | 34 (10.3) |
| Needs Assistance | 686 (22.5) | 224 (28.0) | 244 (21.8) | 190 (23.7) | 28 (8.5) |
| Dependent | 52 (1.7) | 16 (2.0) | 18 (1.6) | 17 (2.1) | 1 (0.3) |

 $Notes: + p < 0.05, *p < 0.001. \ Minority included \ Black, \ Native \ Americans, \ Asians, \ Pacific \ Islander, \ Other \ Race, \ and \ Multiple \ Race; \ and \ there \ are \ 46.5\% \ of \ missing \ data \ on \ minority \ status \ and \ 38.1\% \ of \ missing \ data \ on \ primary \ language \ preference$

impacted by 18 chronic conditions. These conditions, which occurred at least 10% above the total prevalence, are denoted in Table 2 with an asterisk (*). These include hypertension, arthropathies, cardiovascular diseases, depression, peripheral vascular disease, chronic, liver disease, genitourinary disease, lipid disorders, mood disorder, COPD, dorsopathies, chronic pain, hearing disorders, visual disorders/deficits, asthma, gastrointestinal disorders, neuropathic pain disorders, and gait disorders. In the high medical complexity group, individuals were taking 12.72 (+/-6.52) medications and attending the ADC 3.98 days (+/-1.31) per week—values that exceeded any other class. A greater proportion of people with high medical complexity experienced hospitalizations compared to any other group (19.0%). In this group, 77.4% of PLWD met requirements for nursing facility level of care, which is defined by the California Department Aging as requiring the level of intensive care provided by a skilled nursing facility/nursing home.

Discussion

The purpose of this paper was to (a) classify PLWD in ADCs according to their level of medical complexity and (b) identify the demographic, functional, and clinical characteristics of those with the highest degree of medical complexity. Of the 3053 PLWD in our sample, 26.24% were classified as having high medical complexity. Among other conditions, these individuals experienced disproportionately high rates of cardiovascular disease, depression, genitourinary disease, gastrointestinal disorders, and neuropathic pain in addition to cognitive impairment.

The extant literature points to patients with multimorbidity as being high utilizers of health care who are "costly" and "difficult to treat." [33, 34] Care of older adults with multimorbidity who attend ADCs is often complicated by problems with mobility, limited English proficiency, poverty, cognitive impairment, disability and food insecurity [5, 18, 35, 36]. Our data suggest that PLWD in the centers are no exception. In ADCs,

staff are potentially supporting people with multiple chronic conditions who are also cognitively impaired, functionally dependent, impoverished, frequently do not speak English, and experience polypharmacy.

In addition to having multiple chronic conditions that contribute to high medical complexity, in more than 1/4 of our sample, we also saw a high degree of functional dependence, particularly with respect to ambulation, bathing, and transferring. Those with high medical complexity also experienced the greatest frequency of gait, hearing, and visual disorders, and were at risk of falls. Simultaneously, they experienced the lowest rate of use of adaptive devices compared to any other group, suggesting a possible unmet need in this population.

Other factors that heightened the vulnerability of highly medically complex persons with dementia in ADCs are high rates of limited English proficiency (49.2%), their propensity to live alone in spite of having dementia (18.6%), and a high degree of social isolation (62.4%) relative to other groups. Another concerning finding is that, although individuals in this group were taking on average more than 12 medications, nearly half (48.9%) mismanaged their medications. The possible impact of medical complexity and social risk factors on health care utilization among ADC users with dementia is evident in our data. Nearly 1/5 had experienced a hospitalization in the prior 6 months, and approximately 1/3 met requirements for a nursing facility level of care [37].

Proper management of multimorbidity is one of the greatest health-related challenges facing patients, caregivers, health care providers, and payors [31-36], particularly among PLWD. In a survey of clinicians, clinical leaders, and executives at organizations globally that are directly involved in care delivery by the New England Journal of Medicine, 67% reported their organizations do not offer multidisciplinary care, and 62% reported care fragmentation as the biggest barrier to dementia care delivery [38]. There has been much emphasis on coordinating, integrating, and effectively managing the health of individuals with complex health and social needs in order to reduce avoidable health care utilization. The inherent complexity of the ADC population, as evidenced within our data, suggests it is no longer acceptable to continue to have siloed medical systems and community-based support networks. Systematic reviews of the literature call for innovative integrated patient-centered approaches that empower patients and their caregivers in a teambased format [19, 33]. Models such as PACE and CBHH show that these types of programs, which can address both health and social needs, can be effective when headquartered in the ADC.

PACE is a community-based health care program serving people who are over the age of 55 and who require

nursing home—level care but prefer to receive it in their own communities [14]. Services are delivered primarily in an ADC, and they are managed by an interdisciplinary team that includes a geriatric physician as well as nurses, social workers, and therapists. A number of studies provide evidence that PACE is effective in reducing nursing home and hospital utilization and improving health status and quality of life [39, 40].

The CBHH model delivers transitional care support, patient activation, and education to advance health literacy to high-needs individuals in ADCs [5]. These services are provided through the inclusion of a registered nurse navigator (RN-N) within the interdisciplinary team at the ADC [5]. The RN-N deepens understanding of the highest risk individuals' unique challenges and social environments by conducting health and psychosocial assessments, making home visits whenever needed, and facilitating care transitions [5].

One of the greatest barriers to expanding and scaling comprehensive ADC-based programs targeting people with complex needs is reimbursement. Despite facilitating health management and promotion for medically complex PLWD, these centers may not be adequately reimbursed for the services they are providing, which include preventive health services, cognitive and behavioral health services, and nutrition. Medicaid currently reimburses ADCs an average of \$74 per day for this level of care [41, 42]. Many centers have been forced to shut down altogether in the wake of the COVID-19 pandemic [43], potentially leaving a major gap in services for high-needs PLWD. Given that ADCs serve a diverse clientele-58% of whom identify as racial/ethnic minorities—this gap in access to ADCs will likely have a disproportionate effect on communities of color and undermine health equity [16].

In the absence of unlimited funding, information and communication technology represents a scalable and economical approach to integrating ADCs into the care continuum that supports comprehensive coordination of health and social support for PLWD with multimorbidity [44, 45]. Members of the care team (eg, patients, informal caregivers, pharmacists, nurses, social workers) can communicate more seamlessly across settings with the help of shared information systems that leverage technology [46]. Electronic health records, telemonitoring systems, or mobile health applications can support bidirectional information sharing between patients and providers, as well as among individual providers, that lends itself to integrated care for PLWD [45]. However, currently, 92% of ADCs lack the resources to implement interoperable electronic health record systems [15]. Given the ubiquity of tablets and mobile phones, mobile applications that enable secure communication and information exchange

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may be a starting point for improving communication across the community-based care continuum. This would enable ADC staff to advocate on behalf of their clients when they are in other settings.

Our study is not without limitations. First, the sample was limited to adult day health centers. ADCs can follow either a social or health/medical model. The selection of medical model ADCs may have biased our sample toward more frail and complex older adults. Furthermore, our sample was limited to the state of California. Although California is home to 1/3 of adult day programs nationally, and our dataset is one of the largest available on ADC users with dementia, future research should look at trends and variability in ADC users at a national level. Also, our analysis does not include dementia severity assessments which could help explain higher levels of functional dependence in persons with low medical complexity relative to those with high or moderate complexity. In future analyses we plan to examine the interplay between dementia severity and medical complexity. Finally, assessments of participants within the IPC were based on the clinical judgment of social workers and nurses as opposed to validated instruments. This may have led to more inaccuracies or variabilities in assessments than a more standardized approach would have lent itself to.

Conclusion

Health care, including functional and social support for people with multiple health conditions, is not straightforward, and the addition of cognitive impairment adds a further layer of complexity. For future service development to best support the growing number of people with these conditions, the first stage is to describe this population and to understand the interaction between dementia and other common comorbidities. Such an interaction is not simple and is highly variable. Our results should also serve as a signal to primary care providers (PCPs) and health systems about the degree of complexity of clients seen at ADCs. At the very least, if a patient is receiving services at an ADC, this should be a loud signal for their PCP that they need help, are at risk of complications, and are at high risk of nursing home placement. This also means that the patients seen do not just experience multimorbidity but are socially disadvantaged. Our results demonstrate that a comprehensive multidisciplinary approach that involves community partners such as ADCs is critically needed that addresses functional decline, loneliness, social isolation, and multimorbidity which can negatively impact PLWD.

Abbreviations

ADC: Adult Day Care; ADLs: Activities of Daily Living; AIC: Akaike Information Criterion; ANOVA: Analysis of Variance; BIC: Bayesian Information Criterion; BLRT: Bootstrap Likelihood Ratio Test; CBHH: Community Based Health Home; COPD: Chronic Obstructive Pulmonary Disease; COVID: Coronavirus Disease; DM: Diabetes Mellitus; ED: Emergency Department; IPC: Individualized Plan of Care; IADLs: Instrumental Activities of Daily Living; LCA: Latent Class Analysis; LMR-LRT: Lo, Mendell, and Rubin Likelihood Ratio Test; PACE: Programs of All-Inclusive Care for the Elderly; PCP: Primary Care Provider; PLWD: Persons Living with Dementia; RN-N: Registered Nurse Navigator.

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Authors' contributions

TS conceptualized the study and wrote the introduction, background and critically revised the entirety of the manuscript including results and discussion. CP wrote the discussion section. JB and JZ analyzed data and formatted results as well as assisted with critical revisions. GY conceptualized the analysis and wrote the methods. The author(s) read approved the final manuscript.

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Availability of data and materials

The data that support the findings of this study are available from Tina Sadarangani, PhD but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of Tina Sadarangani, PhD.

Declarations

Ethics approval and consent to participate

This research was performed in accordance with all relevant guidelines and regulations within the Declaration of Helsinki. Informed consent and ethical approval were waived by the University Committee on Activities Involving Human Subjects (UCAIHS) at New York University, as this was deemed nonhuman subjects research.

Consent for publication

Not Applicable.

Competing interests

The authors have no competing interests to declare.

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