Understanding Dementia through Caregivers' Experiences: Behavioral Challenges and Quality of Life

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INTRODUCTION & AIM

Dementia represents a complex syndrome in which biological, psychological, social, and cultural processes converge. Although its clinical features are well documented, less attention has been given to the lived experiences of patients and caregivers and their role in shaping illness trajectories. This study aimed to investigate risk factors, behavioural manifestations and quality of life in dementia from an anthropological perspective, focusing on the interaction between comorbidity, cognition, lifestyle, cultural beliefs and caregiving contexts.

METHOD

This single-center, observational cross-sectional study involved 73 family caregivers of patients clinically diagnosed with dementia who received care at the Neurology–Psychiatry Department of the C.F.2 Clinical Hospital in Bucharest, Romania, from November 2023 to April 2024. Caregivers completed a newly developed anthropological questionnaire providing socio-demographic, behavioural, lifestyle, and cultural data. Descriptive statistics and exploratory inferential analyses were conducted to assess associations among cognitive performance, comorbidities, lifestyle factors, and socio-cultural variables.

RESULTS & DISCUSSION

People with dementia had a mean age of 79.2 ± 7.5 years (range 66–95) and were predominantly female (71.2%). Multimorbidity was common, averaging 2.22 ± 1.03 chronic conditions, mainly neurological (84.9%) and cardiovascular (68.5%).

Characteristic	Value
Number of patients	73
Age, years (mean ± SD)	79 ± 8
Gender	Female 52 (71.2%) Male 21 (28.8%)
Religion	Christian Orthodox 71 (97.3%) Catholic 1 (1.4%) Other 1 (1.4%)
Residence	Urban 49 (67.1%) Rural 24 (32.9%)
Lives alone	Yes 11 (15.1%) No 62 (84.9%)
Patient education	Secondary 46 (63%) High school 24 (32.9%) Higher education 3 (4.1)
Number of caregivers	73
Caregiver age, years (mean ± SD)	57.12 ± 10.36
Caregiver gender	Female 55 (75.3%) Male 18 (24.7%)
Caregiver education	Secondary 14 (19.2%) High school 32 (43.8%) Higher education 27 (37%)

The mean BMI was 26.1 ± 3.8 kg/m². Cognitive impairment was substantial (MMSE mean 11.47 ± 7), with descriptively lower scores among older individuals and those with lower education or income, although inferential tests were underpowered.

Condition	Value
Neurological diseases	84.9%
Cardiovascular diseases	68.5%
Metabolic diseases	27.4%
Endocrine diseases	15.1%
Digestive diseases	14.1%
Pulmonary diseases	12.5%
Multimorbidity (mean ± SD)	2.22 ± 1.03
Range (min–max)	0.0–6.0
Median [IQR]	2.0 [2.0–3.0]

Domain	Category	Patients (n)	Percentage (%)
Appetite	Reduced / affected	43	58.9
	Normal / no change	28	38.4
	Missing data /unclear	2	2.7
Sleep	Disturbed / reduced	52	71.2
	Normal / no change	19	26.0
	Missing data/unclear	2	2.7

Appetite responses also displayed significant bivariate relationships with sleep disturbance p < 0.01) and with physical activity (p < 0.01).

RESULTS & DISCUSSION

Mealtime behaviors (eating independently, meal regularity, meals/day, skipped meals and reasons) illustrated outlining fragile routines with missed meals due to poor appetite, forgetfulness or distraction.


Eating Habits
- Eats regularly: 71.2%
- Eats alone (independently): 67.1%
- Remembers being hungry: 49.3%
- Remembers being thirsty: 53.4%

Physical Activity Level
- Light (short walks): 45.2%
- Minimal (only in home/yard): 23.3%
- Immobilized / no movement: 11.0%
- Moderate (regular household chores): 5.5%
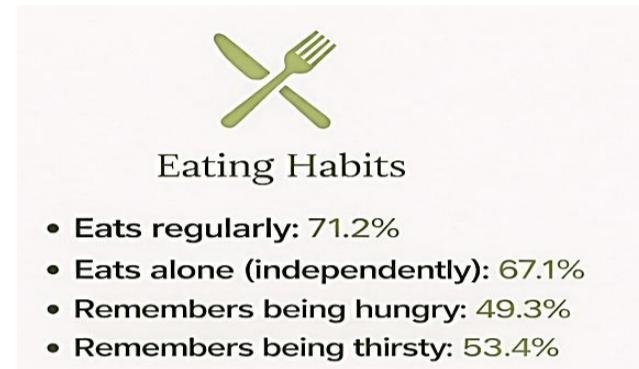
Physical activity was generally low, ranging from minimal in-home movement to homebound or bedbound status; according to caregiver reports, only a small proportion of patients engaged in regular chores or structured exercise. Activity levels showed no meaningful differences across appetite categories, but were significantly related to sleep disturbance (p = 0.01), with lower activity tending to co-occur with poorer sleep patterns.

Food-group consumption (fruits, vegetables, animal-source foods, cereals, milk/dairy) differed by appetite category (Milk/dairy p = 0.023), while the other food groups did not show statistically significant variation across appetite levels. Given the exploratory nature of these analyses and uneven cell distributions, these findings should be interpreted cautiously.

Disclosure of diagnosis occurred in 74% of cases; reactions varied widely, ranging from acceptance to denial, confusion, anxiety and sadness. Family responses likewise reflected a heterogeneous and often ambivalent adjustment process. Cultural beliefs and spirituality played a salient role in shaping explanatory models and coping strategies, with many caregivers attributing importance to religious practices and, to a lesser extent, alternative treatments.
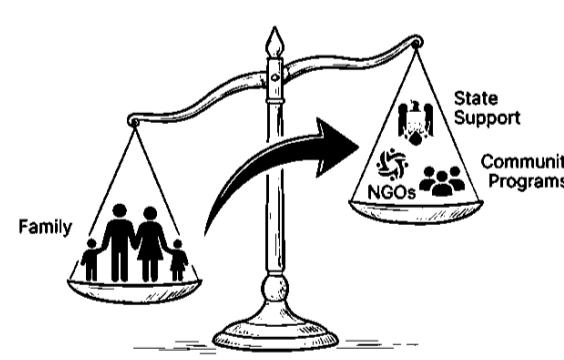
As the social world of people with dementia progressively contracts, care becomes overwhelmingly concentrated within the family network, informal support in order to compensate for the lack of institutional and community assistance.

CONCLUSION

1. The Socio-Demographic Profile Matters

Differences in cognitive status (MMSE score) appeared descriptively along gradients of age and education, suggesting a possible role of cognitive reserve.

2. The Impact of Comorbidities Is Diffuse

Although extremely prevalent, multimorbidity and lifestyle behaviors (smoking, alcohol use) did not differentiate patients according to cognitive severity in this sample.

3. The Behavioral Syndrome Is Central

The constellation of symptoms related to appetite, sleep, and activity represents a defining characteristic of the lived experience, independent of cognitive level.