



Featured Article

Dementia prevalence, care arrangement, and access to care in Lebanon

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Abstract

Introduction: In North Africa and the Middle East, studies about dementia prevalence are scarce. The Arabic-validated 10/66 Dementia Research Group diagnostic assessment was used to assess the prevalence of dementia in Lebanon in a population-based study. The study also examined care arrangement and access to care.

Methods: A random sample of 502 persons older than 65 years and their informant were recruited from Beirut and Mount Lebanon governorates through multistage cluster sampling.

Results: The crude dementia prevalence was 7.4%, and age-standardized dementia prevalence was 9.0%. People with dementia were mainly cared for by relatives at home. Access to formal care was very limited.

Discussion: Dementia prevalence in Lebanon ranks high within the global range of estimates. These first evidence-based data about disease burden and barriers to care serve to raise awareness and call for social and health care reform to tackle the dementia epidemic in Lebanon and in North Africa and the Middle East.

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Keywords:

Dementia; Prevalence; Lebanon; Dementia care

1. Background

In North Africa and the Middle East (EMRO), due to very rapid demographic aging, the estimated number of people with dementia is expected to grow exponentially, two million people in 2015 rising to four million in 2030 and 10 million in 2050 [1], an increase of 329% from 2015 through 2050, the second fastest in the world. Currently,

EMRO is estimated to have the highest age-standardized prevalence globally [1]. Due to lack of studies, these are the best estimates based on consensus judgment of an international panel of experts [2] and studies from Egypt and Turkey [1]. More prevalence studies in the region are needed to assess disease burden, raise awareness, and provide evidence-based data to develop health promotion and disease prevention strategies.

One great challenge has been the lack of well-validated education- and culture-fair screening and diagnostic instrument. Illiteracy among the older generations in EMRO is high. For example, it was estimated in 2009 that about

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50% of people aged 65 years and older in Lebanon were illiterate [3]. Therefore, before this study, we had validated the Arabic versions of the one-stage 10/66 Dementia Research Group (DRG) diagnostic assessment for dementia [4] and two brief screening instruments, the Rowland Universal Dementia Assessment Scale (RUDAS) [5] and the Informant Questionnaire on Cognitive Decline in the Elderly (IQ-CODE) [6]. All three instruments were designed to minimize the effect of education and culture on cognitive assessment and extensively validated across languages and cultures. In the Arabic language, educational, and cultural context, we had demonstrated that the 10/66 DRG diagnostic assessment has excellent psychometric properties to diagnose dementia [7]. Still, it is time-consuming and the subtype classification has not been validated. Alternatively, a two-stage case ascertainment strategy can be used, first with a brief screening instrument to be followed by a comprehensive diagnostic evaluation to diagnose dementia and determine subtypes for those who are screened positive. For this purpose, we had also demonstrated that the Arabic versions of the RUDAS and the IQCODE possess very good discriminatory ability to screen for dementia, and the DemeGraph harnessing the RUDAS and IQCODE has better discriminatory ability than either alone [8–10].

We aimed to conduct a pilot study in two governorates of Lebanon, using the Arabic-validated 10/66 DRG diagnostic assessment for case ascertainment, to field-test this one-stage diagnostic procedure, assess the feasibility of a subsequent nationwide cohort study, generate preliminary data about dementia prevalence, and gather data about care need, care arrangement, and access to care. To have an alternative strategy in case this one-stage diagnostic procedure failed, we also applied the Arabic-validated RUDAS, IQ-CODE, and DemeGraph to the same study population and validated these screening instruments against the 10/66 DRG dementia diagnosis.

2. Methods

2.1. Sample size and sampling frame

The long-term goal was to establish a nationwide community-based cohort of individuals older than 65 years randomly selected from all regions of Lebanon to provide a precise estimate of dementia prevalence and incidence in the country. Based on the estimated prevalence of 5% for EMRO [11] available at the start of the study in 2011, the estimated required sample size was 2500 persons to achieve a maximal error of $\pm 1\%$ with 95% confidence interval and account for 25% nonresponse rate. The targeted number of study participants would be distributed across the 25 districts within the six governorates of Lebanon according to the proportions of people older than 65 years in each district.

Given the aims of this pilot study, we collected data in two governorates: Beirut and Mount Lebanon (Chouf and Aley districts). We computed the sample size for the pilot

study nested within the sample size of the national cohort described previously (2500 persons), with Beirut represented 13.4% of the total sample, Aley 3.2%, and Chouf 4.3%. The targeted sample size for the pilot study was 523 participants, 335 in Beirut, 108 in Chouf, and 80 in Aley (Fig. 1).

A multistage cluster sampling was employed. For Beirut, an existing sampling frame designed for another survey was used in which Beirut governorate was divided into 594 clusters each containing 50 residential buildings with complete detailed household listing of 60 randomly chosen clusters [12]. For this pilot study, seven clusters were randomly selected from the 60 clusters with complete household listing. Within the selected clusters, the trained research workers, who were university graduates, systematically knocked on every door to recruit participants. In Chouf and Aley districts, since there was no existing sampling frame, a number of villages and towns were randomly chosen and weighted according to their respective sizes. The research workers door-knocked the selected households and interviewed any person who was 65 years and older and one informant. The informant was defined as the person who knew best the selected older person. If the selected older person needed care and support, the main caregiver was chosen as the informant. If there was a paid caregiver, the informant was the person who organized and supervised the paid care.

2.2. Instruments

2.2.1. Diagnostic instrument for dementia

2.2.1.1. One-stage 10/66 DRG diagnostic assessment: Both the older person and the informant participated

The Arabic-validated 10/66 DRG diagnostic assessment has demonstrated excellent discriminatory ability to diagnose dementia among older people with low education: 92.0% sensitivity, 95.1% specificity, and 92.9% positive predictive value (PPV) [4,7]. This diagnostic assessment consists of (1) cognitive test battery: the Community Screening Instrument of Dementia (CSI-D) [13] and the Consortium to Establish a Registry of Alzheimer's Disease's animal naming tests and modified 10-world list learning [14]; (2) the Geriatric Mental State, which applies a computerized algorithm to identify organic brain syndrome (dementia), schizophrenia, neurotic and psychotic depression, and anxiety neuroses [15]; (3) physical assessment and brief neurological examination (NEURONEX) [16]; and (4) informant interview on cognitive and functional decline (CSI-D informant interview) [13]. 10/66 DRG dementia diagnosis is defined as scoring above a cutoff point of predicted probability of DSM-IV dementia syndrome from the logistic regression equation using coefficients from the CSI-D, Geriatric Mental State, and modified 10-word list learning of the Consortium to Establish a Registry of Alzheimer's Disease [4]. It takes about one hour to administer.

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