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Capacity Building in Alzheimer's Disease (AD): Lessons Learned from a Pilot Study in Six Distinct Areas of Lebanon

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Authors' contributions

All authors contributed equally to the study and the preparation of the manuscript. All authors read and approved the final manuscript.

Case Study

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ABSTRACT

Aims: To report the results of a week-long Alzheimer's Disease (AD) pilot training and capacity building program for community caregivers in Lebanon.
Study Design: Using mixed methods instruments, we collected participant demographics, measured participant understanding of baseline issues affecting the local aging population, the role of caregivers, and confidence in community supports. Knowledge gaps and challenges in AD care were identified.
Place and Duration of Study: Six distinct areas of Lebanon including Tripoli, Keserwan/Jbeil, Beirut, Bekaa Valley, Sarafand and Nabatieh, from August 1-6, 2011.
Methodology: Using mixed methods instruments, we measured participant understanding of baseline issues affecting the local aging population, the role of caregivers, and confidence in community supports. We also examined the usefulness of existing AD resources, identified characteristics of these front-line providers, and elicited details about educational and clinical needs in distinct religious and ethnic regions.
Results: Of workshop participants, 94% were women, of whom 36% were 31 to 40 years-of-age. Of the participants, 80% were social workers or nurses, and 65% were government employees. Participant motivation included a desire to mentor others (71%),

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improve communication with elders (69%), and better elderly care (61%). Participants said they learned most age-sensitivity training (74.4%), positive behavioral supports (60%), and strategies for difficult behaviors (55.6%). Incomplete evaluations and workshop fatigue negatively impacted data outcomes.

Conclusion: Cross-cultural understanding of AD training in diverse settings is critical to developing appropriate training programs. Results underscore that community workers, the primary caregivers of AD patients in Lebanon, are sensitized to the disease, and through training, felt empowered to advance elders' quality of care. Study challenges included group heterogeneous backgrounds, unfamiliarity with evaluation methods and the timing of the workshop, the summer heat and time of fasting.

Keywords: Alzheimer's disease; caregiver training; ministry of social affairs; capacity building; Lebanon.

1. INTRODUCTION

There are more than 800 million people in the world over the age of 65 – a number projected to more than double in the next 40 years. Life expectancy at birth has also increased substantially, and is expected to be 83 years of age in developed countries and 74 years of age in developing regions by the year 2050 [1,2]. The rural regions of the developing world house 60% of the world's elderly [1-3], and this number will grow to 80% by 2050 [3]. This becomes an important factor when considering the optimization of services to address the medical and economic challenges of an aging population.

Advances in healthcare have increased the prevalence of age-related diseases, particularly depression and dementia. Alzheimer's disease (AD) is the most common form of dementia. It is a progressive neurodegenerative condition that is characterized by a gradual loss of memory and cognitive functions. There is no cure for AD, and the mainstay of treatment remains psychosocial approaches and lifestyle modifications [4,5]. Today, 5.4 million Americans live with AD with 200,000 under the age of 65 years old. By 2020, 16 million Americans will live with the disease [6]. Worldwide, about 35.6 million people suffer from dementia, this number increasing to 66 million by 2030, knowing that 2/3 of the victims live in low to middle-income countries [7]. Globally, dementia costs 1% of the world's GDP yearly [8,9].

Dementia and elder neuropsychiatric conditions pose new challenges to Lebanon, a developing country in the Middle East with a population of about 4.1 million people, of whom 377,000 are more than 65 years of age [10]. There have been no studies performed assessing the number of elderly people suffering from dementia and AD in community dwelling elders in Lebanon. Some studies have shown that up to 47% of nursing home residents suffer from AD [11]. Other studies have shown that almost 60% of Lebanese nursing home residents suffer from some form of dementia [12]. These issues are increasingly an area of concern as family structures that traditionally assumed caregiver responsibilities for elder populations shift, and the number of elders without such critical support grows. Of the Lebanese elderly, 99% live with family caregivers. Yet with an unemployment rate of 22.1%, many young Lebanese men and women leave the country to make a living [12-18]. This leaves the aging population incredibly vulnerable and without caregivers.

Nursing homes – of which there are 33 in the country – are considered a last resort, and are predominantly for homeless elders. These nursing homes house about 2660 residents-only 1.4% of the elderly population [11]. They follow religious denominations and are scattered in the country according to their religious affiliations. Although most of them try to maintain a good quality of life for the elders, they remain ill-equipped, lack trained staff, financial resources and national recognition to handle the challenges of caring for patients [15,16]. With only few registered geriatricians in the country, non-physicians such as nurses, and social workers coordinate the medical care of many elderly patients. As there is no formal primary care triage or referral system in the Lebanese health care infrastructure, patients and their families tend to seek specialist support rather than go through the primary medicine system [16,18]. There is no insurance plan to cover elder care in Lebanon. Pensions with elderly care plans are available for government employees, but not those in the private sector forcing the majority of Lebanese elders to turn to private insurance for coverage. Only 27% can afford private insurance. Paying for hospitalization or services is often an out-of-pocket expense for most and leads to rapid impoverishment [12,15-18].

There are currently no plans directed at elder care although some limited resources exist. Elders lack social pension and healthcare support [11,12,17]. About 67% of AD patients are women in Lebanon. In addition, women make up 60% of AD caregivers. Women tend to assume the caregiver role because 60% had no family members who would take on the responsibility [11,12,17,19,20]. The burden on these caregivers to keep their patients out of nursing homes is huge, and the health care system in Lebanon is not set up to make this easy. Government plans for developing programs addressing the needs of community dwelling elders and improving healthcare are generally scarce. Despite the (MoSA) best efforts to assess community needs and implement changes, progress has been slowed and even halted by the precarious political climate in the region and the country.

To attend to the limitations and challenges listed above, the National Permanent Committee for Elderly Affairs in Lebanon (PNCE), chaired by the MoSA issued a National Social Development Strategy for the country in 2011, and their implementation plan to target the elderly portfolio. Considering the challenges faced by MoSA in successfully assessing the elderly communities' needs in terms of AD care, this campaign to increase AD awareness and assess the needs of community is the first of its kind. In approaching community workers and training them to recognize AD in community dwelling elders, and getting feedback from them on the needs they identify in the community they serve, the government organization succeeded in gathering valuable data that will inform future programs. Priority efforts included empowering MoSA through funding and organization to manage all NGOs (who provide the majority of services to the elderly), to conduct research on the needs of elderly, to empower communities in caring for their elders, and to promote primary care to ensure preventive medicine and continuity of care [11,21,22].

Our awareness campaign was the fruit of the aforementioned MoSA endeavor, and the authors were involved in the capacity of consultants. By using studied prototypes in public health awareness campaigns to introduce ideas in the publics' collective consciousness and change attitudes, many campaigns have been effective in proactively mobilizing targeted members of the community to initiate change [23-25].

We looked to capitalize on the strength of the community in caring for the elderly as family members and community members care for 99% of the elderly in Lebanon. In learning to identify illnesses of the elderly, assess their severity, and see them often, the community can act as a primary care intermediary for the elderly, and enhance their quality of life. The

campaign was the first of its kind in Lebanon, as we were not aware of any previous program promoting AD capacity building.

In collaboration with MoSA and Alzheimer's Association Lebanon (AAL), investigators organized a workshop that complimented an AD awareness campaign. With workshops spanning 6 key hubs in the country, investigators objectives included advancing community staff and caregiver knowledge of AD and related elder issues (such as depression), and to empower participants as first response professionals to refer elders for further evaluation and care if/when necessary. The workshops included training in evidence-based best practices for community AD care, elderly health and wellbeing (including definition, presentation, and management options for dementia), and behavioral, psychiatric, and neurological strategies for effective management of AD. In addition, the program had secondary objectives of providing the MoSA Community Development Centers with AD education materials, identifying the needs of the AD community through working directly with the community caregivers attending the workshops, understanding the needs of the caregiver population/issues affecting elders in Lebanon, and using these newly identified needs to inform development of future workshops and programs that would address the particular needs of the community.

2. METHODOLOGY

This capacity building program with a convenient-sample of trainees was conducted in August 2011 in Lebanon, a country located on the Mediterranean in the Middle East. Investigators used a workshop format to administer half-day-long training from 9am-2pm in community-based settings in six distinct areas of the country: Tripoli, Beirut, Bekaa, Mount Lebanon (Chouf), Mount Lebanon (Keserwan/Jbeil), and Nabatieh. MoSA selected these sites to encourage a balanced participation of religious and ethnic communities, and to attract a wider number of participants. The program's trainers were three Lebanese women of diverse backgrounds. They included a Lebanese-born neuro-psychiatrist and psychiatry resident who both practice and live in the United States and who are both fluent in Arabic and English, and the President of AD Lebanon, a focused Non-Governmental Organization dealing with AD.

The program was conducted in Arabic with trainers presenting to participants, and time allotted for trainee interaction and discussion. In line with the program objectives – to increase knowledge and improve confidence in disease management – the presentations focused on the following areas: issues affecting aging populations globally and specifically in Lebanon, psychiatric manifestations of AD and behavioral management techniques, and neurological manifestations and etiology of AD. Investigators also provided case-directed training on the administration of the Mini Mental Status Examination and the Geriatric Depression Scale. All presentations were tailored to a Lebanese audience with careful consideration of the country's social, political and economic contexts. The training workshop and its accompanying evaluation were approved by the Lebanon MoSA and the Partners Human Research Committee. All participants gave written, informed consent.

2.1 Participant Selection

Workshop participants were recruited by MoSA via word-of-mouth and advertisements posted in community centers that invited trainees to learn more about AD and disease management. Persons who were interested in aging related issues, were registered to a

local community center, and had at minimum a bachelor's degree were eligible to participate in the training program. MoSA pre-registered trainees and assigned them to a workshop date based on their location, and provided introductory reading material in advance. Government affiliated staff who completed the program received reimbursement for lunch and transportation. Caregivers who were not government-affiliated staff could attend the training but did not receive transport or lunch compensation.

2.1.1 Evaluation instrument

Trainees evaluated the program at the end of each workshop day using an instrument with quantitative and qualitative Arabic questions translated from English by the bilingual investigators. Questions were developed based on the investigators' expertise in this areas, a review of similar training programs in other countries, aging-related concerns in the Middle East, and gaps in the current literature.

The evaluation instrument included demographic inquiries (gender, age, occupation, region of affiliation, employment affiliation) and questions that assessed importance of the AD resources and information outlets, and participant motivation and interest of the training. Trainees were asked to rank quantitative evaluation questions on a five-point likert-scale (1=least important to 5=most important). Likert scale questions included the following: "What sources of continuing training and education do you currently use?" (Each of the following was ranked from least important to most important: in-house training; professional journals; internet; books; training though church-Mosque; training provided by State; no formal training; learned by practical experience). Another example question included "The program met its goal and helped with?" (Each of the following was ranked from least important to most important: (job development, knowledge of dementia in elderly, aging sensitivity training, positive behavioral support, dealing with difficult behavior).

Additionally, trainees were asked to rate the program and its objectives on a 5-point likert scale (1=terrible to 5=excellent). Questions included: "Your understanding of the differences between normal aging and dementia;" "Your ability to differentiate cognitive and personality changes in normal again compared to AD"; "Your understanding of at least five approaches to helping Alzheimer's patients cope with the disease's impact on their lives and that of their caretakers"; and "Your ability to identify and share resources available in your community and in Lebanon to improve quality of life and care of AD patients."

The final section of the program evaluation included qualitative open-ended questions that sought to elicit information about areas of improvement for future training, community training needs, and general feedback. Questions aimed to gather participant feedback about the workshop they had just completed. These open-ended questions included: "Has this course changed your perspective on AD? If yes, how? If no, why not?"; "Did this training change the way you approach AD patients and their families?" "Which projects do you feel would benefit your community the most in the near future"; and "Please list areas you feel we can improve on this training". Please see appendix for the complete evaluation scale.

2.1.1.1 Data analysis

All quantitative data analysis was conducted using SPSS 17.0. Descriptive statistics including frequencies/percents and means/standard deviations were computed for all study variables. The two lead investigators, both fluent in Arabic and English, translated the qualitative data from Arabic to English. The translation was done by each clinician separately

and then compared. All discrepancies were discussed and revised based on consensus. Four coders elicited all the qualitative open-ended questions. The research staff members initially developed the code-book. The four coders used the same analysis process for all the surveys. First, the content of participant's responses was group thematically, thematic groupings were then labeled, and these group labels were used to generate broad themes. These broad, overarching themes were divided into sub-themes. Responses were tallied to determine the number that represented each theme and subtheme. The four coders discussed and agreed upon the initial draft of the codebook. The text of the initial five surveys were re-coded to reflect the agreed upon codebook. The authors independently coded all the subsequent surveys and then met to discuss. A consensus of the coding of the surveys and the revision of the codebook had to be reached before proceeding. This process was conducted to ensure inter-coder reliability. Additionally, all previous surveys were re-coded to reflect any changes that were made to the codebook.

3. RESULTS AND DISCUSSION

3.1 Qualitative and Quantitative Results

Workshop participants included male and female social workers, nurses, midwives, and staff members of MoSA, community care givers, and others. Of the participants, 94% were women, of whom 36% were 31 to 40 years-of-age. Of the participants, 80% were social workers or nurses, and 65% were government employees. Please see Table 1 for the demographic characteristics of the trainees by study site.

In terms of the continuing training and education that trainees were currently using at the time of the workshop, the majority of them cite the following as the most important: practical experience (51.3%), the internet (50%), and the training provided by the MoSA (46.5%). These represent the trainees' main source of encouragement and education, as well as their source of training. However, of the trainees, 60.5% cited that the church/Mosque was the least important in terms of continuing training and education.

Participant motivation to participate in training included a desire to mentor others (71%), improve communication with elders (69%), and better elderly care (61%) (Table 2). The majority of respondents (80%) rated monetary benefit (e.g. a bonus) and professional gains as unimportant. The driving force for participants in coming for training was collaboration. Please see Table 2 delineating participants' motivation for training. They aimed to benefit from the collaboration between the MoSA and AAL to gain much needed education on AD, its manifestations, its comorbidities, the application of tools such as the MMSE and the GDS in practice to help AD patients in the community (Table 2). Additionally, they collaborated with one another, meeting other community workers struggling with the same challenges they were in working with AD patients, and feeling that they have a government organization such as MoSA to turn to for support and resources. In rating the understanding of the elderly and contributing to the community highly, the participants were asking for help and guidance from the MoSA in this endeavor. Almost 90% of participants rated the program as excellent on its ability to improve their understanding of the difference between normal aging and dementia. About 70% of the respondents said they wanted to take what they learned from the training back to community. The majority of respondents felt that the program increased their knowledge of dementia in the elderly (74.4%) and provided ageing sensitivity training (70.5%) but did not provide job development (41%).

Table 1. Demographic characteristics of the study sample

	Overall sample (n=146)	TRIPOLI (n=24)	BYBLOS (n=17)	BEIRUT (n=30)	BEKAA (n=30)	SARAFAND (n=17)	NABATIEH (n=27)
Age N (%)							
20-30	24 (16.6)	3 (12.5)	4 (23.5)	3 (10.0)	9 (30.0)	3 (17.6)	2 (7.4)
31-40	52 (35.9)	11 (45.8)	2 (11.8)	11 (36.7)	9 (30.0)	9 (52.9)	10 (37.0)
41-50	45 (31.0)	5 (20.8)	7 (41.2)	9 (30.0)	8 (26.7)	5 (29.4)	11 (40.7)
More than 50	24 (16.6)	5 (20.8)	4 (23.5)	7 (23.3)	4 (13.3)	0 (0)	4 (14.8)
Gender N (%)							
Male	8 (5.5)	3 (12.0)	1 (5.9)	0 (0)	2 (6.7)	1 (5.9)	1 (3.6)
Female	138 (94.5)	21 (84.0)	16 (94.1)	30 (100)	28 (93.3)	16 (94.1)	27 (96.4)
Occupation N (%							
Nurse	62 (42.2)	10 (41.7)	5 (29.4)	13 (41.9)	11 (36.7)	11 (64.7)	12 (42.9)
Social Worker	55 (37.4)	8 (33.3)	8 (47.1)	16 (51.6)	10 (33.3)	3 (17.6)	10 (35.7)
Teacher	7 (4.8)	0 (0)	0 (0)	0 (0)	4 (13.3)	2 (11.8)	1 (3.6)
Caregiver	5 (3.4)	1 (4.2)	3 (17.6)	1 (3.2)	0 (0)	0 (0)	0 (0)
Psychologist	2 (1.4)	1 (4.2)	0 (0)	0 (0)	0 (0)	0 (0)	1 (3.6)
Other	16 (10.9)	4 (16.7)	1 (5.9)	1 (3.2)	5 (16.7)	1 (5.9)	4 (14.3)
Employment Affiliation N (%)							
State Agency	65 (64.4)	5 (33.3)	5 (62.5)	15 (83.3)	12 (46.2)	9 (69.2)	19 (90.5)
Community Based Program	6 (5.9)	2 (13.3)	0 (0)	0 (0)	4 (15.4)	0 (0)	0 (0)
Non-Governmental Organization	14 (13.9)	2 (13.3)	2 (25.0)	1 (5.6)	5 (19.2)	3 (23.1)	1 (4.8)
Other	16 (15.8)	6 (40.0)	1 (12.5)	2 (11.1)	5 (19.2)	1 (7.7)	1 (4.8)

Table 2. Program evaluation quantitative question: "the organizational education training will help you?"

The organizational education training will help you: N (%)	Most important (5)	Important (4)	Neutral (3)	Slightly important (2)	Least important (1)
Leadership Job	10(21.3)	9(19.1)	6(12.8)	9(19.1)	13(27.7)
Build Team	12(21.4)	16(28.6)	15(26.8)	6(10.7)	7(12.5)
Mentor Others	27(40.3)	21(31.3)	5(7.5)	11(16.4)	3(4.5)
Adapt to Change	11(18)	14(23)	25(41)	8(13.1)	3(4.9)
Gain More Money	5(11.9)	4(9.5)	2(4.8)	7(16.7)	24(57.1)

When asked qualitatively how the course changed the trainees' perspectives on AD, trainees identified increased knowledge such as general, behavioral, scientific and treatment knowledge. Several quotes illustrate this increase of knowledge such as:

"I know the hard truth about the disease and how to deal with it'
"We were ignorant about this topic. So the workshop was a success"
"Yes, it introduced the notion of how important this topic is, how to treat the patient with the disease and deal with it"
"This training changed the way I view the disease. It gave me more knowledge and added depth to how I have to deal with patients"

Additionally trainees cited the personal impact the training had on them such as it changed their view of AD. One trainee stated:

"It changed my whole view on understanding the disease and how to deal with patients"

Trainees also reported several ways that the training changed the way they approached AD patients and their families. Trainees reported increased knowledge but also an increased understanding when dealing with the family of an AD patient. They cited how the training taught them the importance of providing more family care.

***"**Yes, I am now more affectionate towards the caregiver in the family"*
"It taught me to have patience for the patients and their family members"

Additionally, trainees referenced the increased understanding of dealing with patients and providing more patient care.

"Yes, now that I understand better the disease, I am accepting patients with this disease and learning how to care for them and give them better QOL"

The majority of trainees felt that awareness trainings would greatly benefit their community. Trainees reported the following:

"Awareness training to deal with all aspect of geriatric diseases"
"More frequent meetings and continuous education seminars about this topic"
"We need sustainable training throughout the year"
"More of the same. Keep it coming this good"
"More awareness training to better ourselves in the care of patients"

Participants felt there was a significant increase in their understanding of the treatment of AD, the psychiatric and behavioral manifestations of the illness. Participants gained an appreciation of the personality changes that accompany AD and that agitation and fearful reactions can be controlled with behavioral interventions rather than medications.

"Now I understand that if an elder with AD is agitated it is not on purpose. His brain cannot let him do things right"
"Patient is sick. This is not about being stubborn or rude"

Many participants were surprised to learn that simple changes in the environment of patients can improve their behavior, and give them a sense of familiarity and safety, making patients' behavior more predictable.

"Now I know if my aunt (she is sick with AD) is agitated I can show her love and hug her or sing with her to contain the behavior and she will feel better"

Respondents across all sites were asked how this training changed their perspective and their approach with AD patients and their families. Overwhelmingly across the sites, respondents cited an increase in their knowledge about the topic including general, scientific and treatment knowledge, that it changed their personal views about AD, and it trained them on interacting with the patients and their families with an increase understanding, and the importance of providing more family care.

Respondents had two major suggestions on improving the training which included more practical applications of the training material and a better training site location. This was consistent throughout all the different sites.

Many participants wanted guidance on how to disseminate concepts most effectively, as well as MoSA guidance on resources and continued training. Although some participants wanted more information on treatment and prevention of AD, many asked for resources to train the community on working with the elderly with AD. They also asked for future seminars on AD, comprehensive training on geriatric care, in depth training on psychiatric issues in the elderly, as well as strategies to guide them in collaborating with others on improving public knowledge on AD.

Participants were interested in following the results of the program evaluation, and thought it was important that investigators return in a year to evaluate what changes they were able to implement. They suggested that we visit nursing homes and community centers, we do a quantitative analysis of the training, and we evaluate both the public and private sectors for changes in elderly care, as well as follow up with elders and their caretakers to ask about changes. There was a marked sense of community and an interest in making changes that was noted in participants.

In addressing the question "Which projects do you feel would benefit your community in the future?" the participants at most sites said that community awareness training, offering continuous training programs and health care/day care centers for the elderly would most benefit the community.

Table 3 illustrates the key qualitative open-ended results.

3.1.1 Conclusion and Limitations

Capacity building programs for elder caregivers are critical for healthcare development and population wellbeing, particularly in low and middle-income countries where there is less access to state-of-the-art, culturally adapted information and where the elder population is predominantly cared for in home settings. Day-long training programs for local providers that involve teamwork and collaboration between government and community stakeholders can successfully empower trainees to further their knowledge, inform priority areas of need, provide important opportunities to galvanize a workforce, and reveal critical information about the caregiver population for a disease that is not well studied and minimally supported in such contexts. It is important for participants to learn and digest information on how to deal with a geriatric population, including difficult cases of agitation, severe cognitive changes and emotional distress. It is equally important to build positive behavioral supports around family members and caregivers and encourage meaningful networking.

Table 3. Program Evaluation Open-Ended Question: "How did this training course change your perspective and the way you approach AD patients and their families?

	TRIPOLI (n=24)	BYBLOS (n=17)	BEIRUT (n=30)	BEKAA (n=30)	SARAFAND (n=17)	NABATIEH (n=27)
THEMES	**Subthemes**	**Subthemes**	**Subthemes**	**Subthemes**	**Subthemes**	**Subthemes**
Increased Knowledge	General Knowledge Behavioral Knowledge Scientific Knowledge Treatment Knowledge	General Knowledge Behavioral Knowledge	General Knowledge Behavioral Knowledge	General Knowledge Behavioral Knowledge Scientific Knowledge	General Knowledge Behavioral Knowledge	General Knowledge Behavioral Knowledge
Personal Impact	Changed View			Changed View Family Member has disease	Changed View	Changed View
Family Interactions	Increased Understanding Providing More Family Care		Increased Understanding Providing More Family Care Teaching Families	Increased Understanding Providing More Family Care Teaching Families	Increased Understanding Providing More Family Care Teaching Families	Providing More Family Care Teaching Families
Patient Interactions	Increased Understanding Providing More Patient Care	Increased Understanding Providing More Patient Care	Providing More Patient Care	Increased Understanding Providing More Patient Care	Increased Understanding Providing More Patient Care	Increased Understanding Providing More Patient Care

In our case, the training program helped increase knowledge of dementia in the elderly as well as provided general awareness of aging sensitivity. The trainees were receptive to advancing their skills and knowledge – reflected in their high rating of the program's effectiveness, and their strong desire for additional sessions. It is important to stress that participants did not report being motivated to participate in the training by financial gain or professional promotion. Most reported that they were driven by the desire to help others, and because they sought collaborative opportunities to more effectively work with the elderly in the community.

In addition, the training program highlighted the importance of offering compassion to the Lebanese elders and their families. Participants gained an understanding of the behavioral changes associated with normal aging and dementia, and as a result, increased empathy for the challenges they face. Learning how to educate families was recognized as an important aspect of improving community tolerance of AD patients. Empowerment of the participants with knowledge of the illness and with an understanding of caregiver burnout was apparent.

The program also showed how a short-course training program help stimulate stakeholder interest in a disease outside of the popular health discourse. As a result of the workshop, MoSA and AAL – two of the most active organizations working in AD in Lebanon – developed wider partnerships and extended collaborative work throughout all of Lebanon over many months after this first workshop was initiated. They also engaged further with other providers including geriatric academic faculty, geriatric program directors, nationally renowned geriatricians, psychologists and social workers to push the campaign forward. Undoubtedly, engaging this workforce outside of the framework of the program helped incite change and stimulate interaction with a wider health community.

One of most surprising findings was that the participants unequivocally validated the leadership role of MoSA and the Lebanese State in their training on elder care. They identified MoSA as their go-to sector for continued education, training resources and needs – more so than the Internet, publications or NGOs. This finding was quite unexpected in a country such as Lebanon where the private sector primes any governmental effort and where individual endeavors abound. Government participation was an important part of legitimizing the program, and also empowering the government to be a key workforce leader in this area.

Moreover the capacity building program helped strengthen caregivers' social and professional networks, and united providers often working in isolation. It underscored how training programs are an important mechanism to support and engage community health workers, and provide them opportunities to interact, share experiences, identify common goals, and mobilize to drive forward key areas of need. The majority of the participants thought of ways to network and build teams to give back to the community. Many (>70%) stated they wanted to expand the knowledge circle through mentorship with a focus on implementing changes within one's own area of jurisdiction and power. The authors believe that this ripple effect could spread in the community to increase the understanding of Lebanese elders, the importance of rapidly working to address their needs and be sensitized to their issues. The authors believe that the ripple effect could be used by the community in Lebanon in combating the stigma faced by AD patients.

The literature on stigma and attitudes towards AD patients is scant (particularly in Lebanon), though some studies have reported that it is similar to rates of patients with schizophrenia. Studies have shown that the severity of the disease was predictive of greater discrimination

against those suffering from it, but that familiarity with it was associated with decreased discrimination [26]. Studies of Arabic speakers in Australia found that shame and stigma hindered use of services due to the strong cultural prohibitions on exposing personal or family matters to outsiders. This may be particularly true in a country such as Lebanon and non-western societies, where people find psychiatric and neurological interventions stigmatizing to families.

Finally, the program evaluation revealed key areas for the future. Using the suggestions and data collected from participants, the authors suggest that follow up workshops aim to address the needs of community at large. Future training is needed, not only to improve practical skills of caregivers, but also to address the specific needs of different populations within Lebanon.

Lebanese caregivers, policy makers, and AD patients need to be aware of unfamiliar challenges that lie ahead. As community awareness of AD grows, issues such as testamentary capacity and guardianship will come to light. In Lebanese populations with little experience with forensic psychiatry and legal implications of aging, implementing resources to address potential concerns should be considered.

There were a number of limitations to the implementation and evaluation of this AD capacity building program in Lebanon. The sample of participants was a convenient sample, in that the participants were themselves interested, engaged with the MOSA, and were motivated to come for training. The sample of participants were also not randomized to condition so therefore we did not have a control group. Second, many trainees returned partially completed or incomplete evaluations. This may suggest that the Lebanese civil society and its representative community may be resistant to testing or are not prepared for such forms of evaluation and monitoring. It may also be the result of timing and format. The investigators developed the surveys in English, and issues with translation and formatting of the Arabic instruments likely contributed to participant confusion. We surmise the questions may have been unclear and too long. Investigators did not explain carefully how to complete the survey and participants may have been unfamiliar with the format of the questions that ranged from Likert-scale ratings, true/false and open-ended sections. As many of the presentations ran long and given participant fatigue, the authors focused on material review, and less on detailed instruction of the evaluation.

We have also to take into account that the workshop took place during the hot summer month of August, and during a religious fast. These factors likely contributed to participant fatigue as trainees could not eat or drink, and some workshops were held in locations without air-conditioning. This was a major drawback in accurately analyzing the assessment tools. One session was also administered on Friday, a day when some participants had prayer obligations, and thus many of the participants left early without completing training or the evaluation survey. Careful review of the holiday calendar is an absolute necessity in future programs.

The neuro-psychiatrist and the psychiatry resident that translated the questionnaires are fluent in both Arabic and English. Nevertheless, the authors did not translate the questionnaires using back translation combined with monolingual or bilingual tests.

In this study, women outnumber their male counterparts. Although this finding mirrors the gender bias in care giving role in Lebanon, we may have missed to capture the impression and impact it would have had if men were more evenly represented in the sample.

4. CONCLUSION

This workshop was the first AD capacity building program in Lebanon. It catalyzed increased interest by the Lebanese government in this area, reflected most by continued funding for training sessions and workshop presentations led by MoSA. As a result of the community needs identified in this workshop, MoSA received positive feedback in the form of enthusiasm and funding for an enlarged initiative involving improving comprehensive geriatric care in Lebanon. Currently, MoSA is heading a year round geriatric workshop to train community workers in recognizing and managing geriatric illnesses in community dwelling elders. The authors have been invited to return in a consulting capacity, and contribute to the content of these workshops. There is no doubt that the demand in this area by community caregivers is huge despite that the program remains limited by the lack of data on this incredibly vulnerable population and increasingly important disease, as well as the general capacity of the health system to meet the needed demand. Studies are critically needed on the stigma surrounding ageism, and family stigma faced by the caregivers of AD patients[26]. Additional research into the role of the elders in the community, the prevalence of AD in the country, services and system hurdles in the delivery of care to Lebanese elders and in-depth geriatric care.

The hope is that the research coupled with the national enthusiasm will lead to continuous additional resources and support by the Lebanese government in aging-related population programs and care. Indeed, empowering MoSA as a leader in this area in partnership with the Lebanese civil society and NGO (AAL) will allow workshops similar to this one to take place. There are individuals and organizations with exemplary visions for the future of healthcare in Lebanon, the direction of any endeavor in Lebanon is colored by the geopolitical situation in the region. Although politics tend to limit any social growth in the country, there is always a way to attempt to learn from the community and improve the quality of life of its members. The broader potential benefits of programs such as the one described in this manuscript include assisting individuals, organizations and public ministries in managing, developing and utilizing local resources at their disposal to solve their problems, and move the national healthcare agenda in the right direction for the country.

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CONSENT

All authors declare that written informed consent was obtained from all study participants for publication of the results of the study.

ETHICAL APPROVAL

All authors hereby declare that all experiments have been examined and approved by the appropriate ethics committee at Partners Human Research Committee and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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APPENDIX 1

PARTICIPANT PROGRAM EVALUATION

Program Title: Capacity Building AD Program 2011

Date Seminar Completed _____

Gender

Male
Female

Age

20-30
31-40
41-50
>50

Occupation

Teacher
Social Worker
Nurse
Physician
Therapist
Psychologist
Caregiver
Other- Please specify

Region of Affiliation

North Lebanon-Tripoli Center
Bekaa- Horsh Al Omara Center
Nabatieh- Nabatieh Center
South Lebanon-Sarafand
Mount Lebanon- Byblos
Beirut-Shouf-Badaro Center

Employment Affiliation

State Agency
Community-Based Program
NGO
Other –Please specify

Please rank the following using a scale from 1 (least important) to 5 (most important)

What sources of continuing training and education do you currently use?

In house training	1	2	3	4	5
Professional Journals	1	2	3	4	5
Internet	1	2	3	4	5
Books	1	2	3	4	5
Training through church-Mosque	1	2	3	4	5
Training provided by State	1	2	3	4	5
No formal training-Learn by practical experience	1	2	3	4	5

You need training to:

Improve care	1	2	3	4	5
Improve communication with elderly	1	2	3	4	5
Problem-solving	1	2	3	4	5
Collaboration	1	2	3	4	5
Help others	1	2	3	4	5
Volunteer in my community	1	2	3	4	5
Someone in my family has AD	1	2	3	4	5

The Organizational Education Training will help you

Get a leadership job in your community	1	2	3	4	5
Build Team	1	2	3	4	5
Mentor others	1	2	3	4	5
Adapt to change	1	2	3	4	5
Gain more money	1	2	3	4	5

This program met its goal and helped with

Job development	1	2	3	4	5
Knowledge of dementia in elderly	1	2	3	4	5
Aging Ethics	1	2	3	4	5
Aging sensitivity training	1	2	3	4	5
Positive Behavioral Support	1	2	3	4	5
Dealing with difficult behavior	1	2	3	4	5

What influenced your coming to Training:

Travel distance to center	1	2	3	4	5
Convenient time	1	2	3	4	5
Monetary support	1	2	3	4	5
Agency/State Encouragement	1	2	3	4	5
Interested in Topic	1	2	3	4	5
Training Notification-Speaker	1	2	3	4	5

Learning objectives of training seminar:

- Define normal aging and dementia

- Understand cognitive and personality changes that occur in normal aging vs. those in Alzheimer's disease.
- List five approaches that can be used to help those with Alzheimer's and their families understand and cope with the manifestations of AD and its impact on daily life.
- Identify the resources available to AD patients, their families/caretakers, and their physicians to improve care and quality of life for AD patients in the Lebanese community.
- Identify the resources available in your community and what you can offer patients with dementia and their families.
- Learn to administer Arabic- adapted version of MMSE and GDS to patients in office/center visits.
- Learn to quantify results (severity of progression) over time.

Scale: 5=Excellent, comprehensive and thorough. My understanding is complete.
4=Good, meets high standards, would recommend program to others.
3=Satisfactory, acceptable results but not outstanding.
2=Poor, the program has at least one serious deficiency. Left feeling confused.
1=Terrible, would not recommend this program.

Using the above scale, please rate the program and its objectives listed below (circle one):

Your understanding of the differences between normal aging and dementia
1 2 3 4 5

Your ability to differentiate cognitive and personality changes in normal aging compared to AD.
1 2 3 4 5

Your understanding of at least five approaches to helping Alzheimer's patients cope with the disease's impact on their lives and
that of their caretakers.
1 2 3 4 5

Your ability identify and share resources available in your community and in Lebanon to improve quality of life and care of AD
patients
1 2 3 4 5

Your comfort in administering the Arabic adapted versions of MMSE and GDS to your patients during office visits
1 2 3 4 5

Your comfort and ability to assess the severity of progression of AD over time in your clients/patients
1 2 3 4 5

The impact the course will have on your future practice/care for people with dementia
1 2 3 4 5

The usefulness of the MMSE and GDS in working with clients.

1 2 3 4 5

____ Overall rating

Has this course changed your perspective on AD?
If yes, how? If no, why not?

Did this training change the way you approach AD patients and their families from now on?
If yes, how? If no, why not?

What topics did you feel this training did not address adequately?
1)
2)
3)

What are the topics you would like addressed in the future?
1)
2)
3)

Which projects do you feel would benefit your community the most in the near future?
1)
2)
In which way we should evaluate changes in the care you provide if we were to come back in a year?
1)
2)
3)
Please tell us what you believe to be the most important training needs in your region for community AD awareness:
Please list a few of the best trainings you have received and why you benefited from them.
Please list areas you feel we can improve on this training in:
Do you think these training sessions should be given regularly? If yes how often?
Other comments, ideas, or suggestions appreciated:

Thank you for your time.

Peer-review history:
The peer review history for this paper can be accessed here:
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