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ORIGINAL ARTICLE

Public Knowledge of, Perceptions About and Attitudes Towards Dementia: A Cross-Sectional Survey Among Lebanese Primary Health Care Attenders

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Abstract

Dementia is a leading cause of dependency and disability among older adults. Minimal knowledge, poor attitudes and negative perceptions are barriers of dementia early screening, diagnosis and treatment. This is the first study that assesses knowledge, attitudes and perceptions of dementia among a Middle Eastern population. Two hundred and fifty-four Lebanese adults not having dementia attending primary healthcare centers in the capital of Lebanon were interviewed using an Arabic version of the 2010 Northern Ireland Life and Times survey. The highest proportion of the participants (61%) had low knowledge score. Low knowledge was associated with older age and lower education. The majority had a negative perception towards people living with dementia and these perceptions were significantly different by gender, education and exposure. Participants perceived people with dementia as helpless and dependent. Public interventions should address stigma and increase knowledge while understanding the socio-cultural beliefs associated with dementia. The study calls for policy developments and conducting a qualitative study.

Keywords Dementia · Knowledge and attitudes study · Lebanon

Introduction

With the demographic transition affecting both developing and developed countries, the number of older people is expected to increase by 56%, 138%, 185% and 239% in high, upper and middle, lower middle and low-income countries respectively between 2015 and 2050 (Prince et al. 2015). This rise is associated with an increase in chronic diseases including dementia. The prevalence of dementia is estimated to reach globally 74.7 million by 2030, and 131.5 million by the year 2050, 58% of whom resides in middle and low-income countries (Prince et al. 2015). Those numbers put a high toll on the public health system globally. In Lebanon, the prevalence of dementia among nursing homes' residents was 60% in 2007 (Chahine et al. 2007) and 7.4% among community older people residing in two governorates in Lebanon (Phung et al. 2017).

Negative attitudes towards people living with dementia stimulate many emotional reactions such as fear and anger among others that ultimately contribute to stigma (Ludecke et al. 2016). Negative attitudes towards Alzheimer's disease, the most common type of dementia, are also reported and are significantly associated with a higher caregiver's burden (Gove et al. 2016). Dementia is perceived as stigma by patients with dementia, older people, caregivers, general practitioners, healthcare professionals and the public (Gove et al. 2016). Poor attitudes, minimal knowledge and stigma are barriers to early screening, diagnosis and treatment of dementia (Arai et al. 2008; Cohen et al. 2009; Gove et al. 2016; Ludecke et al. 2016; Seo et al. 2015). Hence, enhancing knowledge towards dementia will reduce the physical

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and psychological burdens on caregivers, families and others, and help them better cope with dementia-related behaviors (Ludecke et al. 2016).

In the Arab countries, clinical and population-based studies exploring dementia are rare. There is no systematic investigation to assess people's attitudes towards and knowledge of dementia. Karam and Itani (2013) reported a delay in seeking care among older adults with dementia which is mainly due to confusion between symptoms of dementia and ageing as well as lack of knowledge about the availability of specialist services. With an expected increase in the percentage and number of older people, projected to reach 10.2% by the year 2025 in Lebanon (Naja 2012), there will be a dramatic increase in dementia patients. Therefore, there is a need to address the issue among the general public and investigate the level of knowledge, attitudes and common perceptions about dementia as a step towards improving the quality of life of people with dementia and their caregivers within the Lebanese context.

To our knowledge, this study is the first to assess the level of knowledge about dementia, as well as attitudes and perceptions towards it among an Arab Middle Eastern population.

Methods and Subjects

Study Design and Subjects

A cross-sectional study was conducted in three conveniently selected primary healthcare centers (PHC) in Beirut, the capital city of Lebanon. These PHCs cater for middle and low-income people and provide a wide range of services, including preventive, curative and social services. Inclusion criteria included all Lebanese PHC attendees, aged 18 and above and not having dementia. If the attendees were 65 and above and appeared to have cognitive problems, a Decision-Making Capacity (DMC) test was conducted to make sure that they were competent to answer the questionnaire. After securing approval of the PHC directors, trained research assistants approached the attendees to complete a face-to-face interview. Consecutive patients attending the PHC who fulfilled inclusion criteria were selected at different times of the day and different weekdays. Out of 284 approached, 254 adult PHC attendees consented to participate in the study.

The study was approved by the institutional review board (IRB) at the American university of Beirut.

Questionnaire

A structured questionnaire consisting of an Arabic translated version of the 2010 Northern Ireland Life and Times Survey (NILT)_ Dementia module (Dowds et al. 2010) and a section inquiring about of basic sociodemographic information was administered. The translated version was examined for appropriateness of language and context. For instance, the Arabic translation of dementia is stigmatizing and belittling, hence, we wrote "التراجع الادراكي المعروف شعبيا بالخرف" (cognitive decline known as dementia) followed by "dementia" throughout the questionnaire to secure the understanding of the term. The survey consisted of three main sections addressing (1) knowledge, (2) attitudes and (3) perceptions of dementia.

Knowledge

Knowledge section was composed of seven true/false/do not know questions regarding the disease. Respondents who answered at least four questions correctly were classified as having "low level of knowledge", five as "medium" and six to seven as "high" knowledge (Dowds et al. 2010). The knowledge section also included two yes/no questions about the participants' awareness of healthcare organizations and healthcare professionals who provide medical care or other services to people with dementia. Participants were also asked if they knew anyone with dementia and their relationship with this person.

Attitudes

Nine statements related to stigmatizing people with dementia were used to evaluate participant's attitudes toward people with dementia. Answers were analyzed on a scale of 1 (strongly disagree) to 5 (strongly agree).

Perceptions of People with Dementia

Perception section was composed of two parts. The first part consisted of thirteen yes/no/do not know questions on perceived characteristics of individuals who have been living with dementia for a long time. The characteristics were being kind, gentle, happy, funny, lost, pathetic, unpredictable, trapped, frightened, confused, angry, sad and dangerous. The second part consisted of four questions that inquired about the capacity of people, newly diagnosed with dementia or have been living with dementia for a long time, to live independently. Answers were analyzed on a scale of 1 (strongly disagree) to 5 (strongly agree).

Analysis

Frequency distributions of all variables were conducted for descriptive purposes. Knowledge level and perceptions were stratified by gender, education and previous exposure to a person with dementia. Furthermore, bivariate and multivariate ordinal logistic regressions were conducted to assess the factors affecting knowledge level of dementia. P-values ≤ 0.05 were considered statistically significant. All analyses were performed using STATA software version 11.1 for Windows.

Results

The highest proportion of sampled participants was females (73%), aged between 25 and 44 years old (40%), ever married (74%), employed (58%) and did not reach university (67%) (Table 1). Half of the respondents personally knew someone who had dementia with about a quarter having a family member with dementia (Table 2).

Table 1 Demographic characteristics of 254 PHC attendees in the capital of Lebanon

Variables	N (%)
Age (mean ± SD)	40.93 (14.36)
18–24	45 (18)
25–44	102 (40)
45–64	92 (36)
64+	15 (6)
Gender	
Female	186 (73)
Male	68 (27)
Marital status	
Ever married	189 (74)
Never married	65 (26)
Educational level	
Below intermediate	53 (21)
Intermediate/secondary/technical	116 (46)
University	85 (33)
Previous exposure to a person with dementia	
Exposed	126 (49)
Not exposed	128 (51)
Work status	
Workers	146 (58)
Non-workers	108 (43)

Knowledge

Most of the participants knew that dementia is a brain disease (83%), not curable (70%) and is less likely to affect people who exercise and eat healthy (71%) (Table 2). Around 57% of them knew about the availability of a treatment for dementia. Less than half (46%) knew that dementia is not a normal process of aging. Only one-fifth of the participants knew that Alzheimer's disease is not another term of dementia.

The highest proportion of participants (61%) had a low knowledge score, 27% medium and 12% high (Table 3). Participants aged 45 to 64 had a significantly higher proportion of low knowledge (70% compared to 53% in the youngest age group). Having low education level was also significantly associated with low knowledge. Gender and previous exposure to a person with dementia were not significantly associated with knowledge level. At the multivariate level, previous exposure and educational level remained significantly associated with knowledge level.

Only one in five attendees (19%) knew about Lebanese healthcare organizations that take care of persons with dementia. The two most commonly cited types of care providers were geriatricians (59%) and family members (51%).

Perceptions

Participants perceived persons with dementia mostly as lost (91%), pathetic (85%), unpredictable (81%) and trapped (78%) (Table 4). Less than half perceived them as being funny and happy. Participants significantly differed in their perceptions according to gender, education and previous exposure to a person with dementia. For instance, while a higher proportion of females significantly perceived a person with dementia as being unpredictable and trapped, a higher proportion of males significantly considered them as funny. A higher proportion of low educated participants

Table 2 Percentage distribution of participants' knowledge on dementia

Statements	Correct answers	% of correct answers
Dementia is a disease of the brain	True	83
People who eat healthily and exercise are less likely to get dementia	True	71
Dementia can be cured	False	70
There are many different kinds of dementia	True	66
There are drug treatments that help with dementia	True	57
Dementia is part of the normal process of ageing	False	46
Dementia is another term for Alzheimer's disease	False	20

Table 3 Bivariate and multivariate analyses of knowledge level by socio-demographics

Variables	Knowledge level			Bivariate	Multivariate
	Low N = 155 n (%)	Medium N = 68 n (%)	High N = 31 n (%)	P-value	P-value
Age					
18–24 (reference)	24 (53)	13 (29)	8 (18)	–	–
25–44	58 (57)	32 (31)	12 (12)	0.54	0.40
45–64	64 (70)	19 (20)	9 (10)	0.05*	0.06
64+	9 (60)	4 (27)	2 (13)	0.62	0.90
Gender					
Male (reference)	42 (62)	22 (32)	4 (6)	–	–
Female	113 (61)	46 (25)	27 (14)	0.11	0.16
Educational level					
Below intermediate (reference)	39 (74)	8 (15)	6 (11)	–	–
Intermediate, secondary, technical	72 (62)	37 (32)	7 (6)	0.40	0.47
University	44 (52)	23 (27)	18 (21)	0.00*	0.04*
Previous exposure to a person with dementia					
Not exposed (reference)	82 (64)	37 (29)	9 (7)	–	–
Exposed	73 (58)	31 (25)	22 (17)	0.08	0.22

*Indicates statistical significance at a P-value ≤ 0.05

Table 4 Percentage distribution of participants who reported yes on the perceived characteristics of individuals with dementia by selected socio demographic variables

Characteristics	Total (%)	Gender			Educational level				Previous exposure to a person with dementia		
		Female	Male		Below intermediate	Intermediate/secondary/technical	University		Not exposed	Exposed	P-value
		(%)	(%)	P-value	(%)	(%)	(%)	P-value	(%)	(%)	
Lost	91	92	90	0.58	92	93	88	0.46	91	92	0.82
Pathetic	85	87	82	0.40	87	88	81	0.39	87	84	0.60
Unpredictable	81	85	71	0.00*	75	83	82	0.50	81	81	1.00
Trapped	78	82	68	0.01*	72	83	76	0.24	81	75	0.29
Kind	75	76	72	0.54	83	75	69	0.20	67	73	0.27
Gentle	70	70	72	0.74	79	70	66	0.24	74	75	0.89
Frightened	61	62	58	0.66	64	64	55	0.41	73	49	0.00*
Confused	58	56	62	0.45	55	64	52	0.20	60	56	0.53
Angry	57	58	53	0.47	60	60	49	0.25	59	54	0.45
Sad	55	56	53	0.67	62	57	48	0.24	62	48	0.04*
Dangerous	50	52	43	0.18	66	49	40	0.01*	53	46	0.26
Fun	47	42	59	0.02*	55	50	38	0.10	45	49	0.53
Happy	32	29	40	0.11	47	29	26	0.02*	27	37	0.08

*Indicates statistical significance at a P-value ≤ 0.05

perceived them as being happy and dangerous, whereas, a higher proportion of non-exposed people perceived them as frightened and sad.

Close to 80% agreed that people with dementia should have an electronic device to locate them, and very few reported that those newly diagnosed or have lived a long time with dementia should continue to live independently and manage their own medication (Table 5).

Attitudes

When the participants were asked about their attitudes, there was a high agreement that persons with dementia are helpless, dependent and deprived of their rights (Table 6). The majority considered them unable to make their own decisions and therefore other people should take over. Moreover, there was a paternalistic attitude towards them whereby an overwhelming proportion of participants (85%) considered that these people are like children. Nevertheless, 75% of the participants were in favor of persons living with dementia being involved in community activities.

When the participants were asked about their attitudes towards a person living with dementia, the majority (more than 80%) agreed on the following statements: "there comes a time when all you do for a person with dementia is to keep them clean, healthy and safe"; "there are other people who take over making decisions for people with dementia far too much"; and "people who have just been diagnosed with dementia are unable to make decisions about their own care". Moreover, participants agreed that people with dementia are like children, need similar care and are not treated as human beings anymore after being diagnosed with dementia. In addition, there is somehow high agreement (60% and above) that persons with dementia should be involved in community activities, and that it is better for them and their families if they are cared for in a nursing home or residential unit. Whereas, around half of the respondents disagreed that there is no point of talking to a person with dementia since they will not be able to understand (58%), and that life is not worth living for people with a really bad dementia (48%) (Table 4).

Discussion

The overall knowledge on dementia was low and this finding was consistent with previous studies (Arai et al. 2008; McManus and Devine 2011; Nielsen and Waldemar 2016; Seo et al. 2015; Tan et al. 2012). Examining specific knowledge items, our sample knew better than other population samples (Dowds et al. 2010) that dementia is a brain and a non-curable disease. Unlike the population in the UK (58%) (McManus and Devine 2011) and similar to the Irish population (36%) (Dowds et al. 2010), very few were able to recognize the difference between Alzheimer's disease and dementia. Public awareness campaigns should highlight that

Table 5 Percentage of the participants who agreed on selected perception statements regarding the perceived capacity for independent living for someone who is newly diagnosed or who had been diagnosed for a long time with dementia

Perceived capacity for independent living	Someone newly diagnosed with dementia (%)	Someone who had been diagnosed with dementia for a long time (%)
Continue to live alone	9	2
Continue to manage their own medication	15	8
Continue to drive	6	1
Have an electronic device fitted so they can be located if they wander	77	79

Table 6 Percentage distribution of the participants' attitudes towards people with dementia

Statements	Agree N (%)	Neither agree nor disagree N (%)	Disagree N (%)
There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe	231 (91)	5 (2)	18 (7)
Other people take over making decisions for people with dementia far too much	215 (85)	21 (8)	18 (7)
People with dementia are like children and need cared for as you would a child	215 (85)	20 (8)	19 (7)
As soon as someone is diagnosed with dementia they are not treated like a thinking human being any more	214 (84)	16 (6)	24 (10)
People who have just been diagnosed with dementia are unable to make decisions about their own care	212 (83)	19 (8)	23 (9)
People with dementia should be involved in activities in the community	191 (75)	22 (9)	41 (16)
There is little or no benefit to be gained from telling someone they have dementia	183 (72)	23 (9)	48 (19)
It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home	153 (60)	31 (12)	70 (28)
For people with really bad dementia I don't think life is worth living	101 (40)	32 (12)	121 (48)
There is no point in trying to talk to people with dementia as they won't be able to understand	85 (33)	22 (9)	147 (58)

"while Alzheimer's disease is a dementia, not all dementias are Alzheimer's disease".

There was a considerable variability in the distinction between dementia and normal ageing depending on the culture being surveyed (Dowds et al. 2010; Li et al. 2011; McManus and Devine 2011; Sahin et al. 2006; Tan et al. 2012; Woo 2013). Our findings showed that Lebanese adults were able to acknowledge that dementia is not part of normal ageing at similar rates as the populations surveyed in Singapore (Tan et al. 2012), Shanghai (Li et al. 2011) and Turkish and Pakistani immigrants in Copenhagen (Nielsen and Waldemar 2016). The rates were lower when compared to the Northern Irish (Dowds et al. 2010) but higher compared to Chinese (Woo 2013) and Turkish populations (Sahin et al. 2006). The reason behind having a relatively high percentage perceiving dementia as an age-related normal process might be due to Lebanese people's knowledge and experiences that dementia is frequent among the older population similarly to Turks' experiences, which is a cultural bias (Sahin et al. 2006). Therefore, if we increase the knowledge of dementia among the Lebanese community, where they could really understand and know that dementia is not part of ageing, the community could provide the proper support to people with dementia and their family members in order to keep them independent and involved rather than isolate them from the society (McCullough and Devine 2015). The negative relationship between knowledge level and age was similar when compared to the Korean (Seo et al. 2015) and Shanghai studies (Li et al. 2011) and not in line when compared to the Turkish study (Sahin et al. 2006). This could be explained by the fact that higher proportion of older people (45–64 years) have a low level of education and therefore they are less likely to be exposed to information about dementia at school, written media or other sources. Results showed no gender differences with respect to knowledge about dementia. Although women in our culture are the main caregivers of older adults at home (Hussein and Ismail 2017) similarly to the women's role in Turkey (Sahin et al. 2006), and specifically with regards to elderly with dementia, this does not make them more aware of the disease than men. However, this was not the case in Turkey where women were more aware of dementia and its symptoms although they were less educated than men (Sahin et al. 2006). In addition, being in contact with someone who has dementia had no effect on the public perception. This implies that the Lebanese culture plays a more important role than knowledge about the disease. Moreover, a large majority had no idea about healthcare organizations that cater for the needs of people living with dementia. Not surprisingly, few mentioned geriatricians as a source of care, who appeared to be only few, in Lebanon, when data was collected.

Overall, Lebanese attitudes and perceptions towards dementia were mainly negative. These findings were consistent with previous published reports (Cohen et al. 2009; Dowds et al. 2010; Ludecke et al. 2016; McManus and Devine 2011; Seo et al. 2015). For instance, perceiving persons with dementia as helpless and dependent was somehow similar to findings in Ireland and UK where paternalistic attitudes are dominant (Dowds et al. 2010; McManus and Devine 2011). The fact that the Lebanese population perceives people with dementia in this manner might be due to lack of awareness of dementia etiology and basic facts. Moreover, education influenced the Lebanese perceptions, but not the Turkish ones and gender influenced both the Lebanese and Turkish attitudes (Sahin et al. 2006).

There was a consensus that care is a necessity for people living with dementia and institutionalization is an option. These findings are in line with the high rates of agreement that people with dementia, whether newly diagnosed or had been diagnosed for a long time, are not capable to live independently. A reasonable proportion viewed the life of a person with dementia as not worth-living and agreed that there is no point of telling them they have the disease because they will not understand. These findings were inconsistent with the results of the studies in Northern Ireland and UK which were more humanitarian in terms of communication (Dowds et al. 2010; McManus and Devine 2011). Therefore, the rights of people with dementia are breached in our society, thus, public campaigns are needed to address and highlight them.

The use of Arabic translated version of the 2010 Northern Ireland Life and Times Survey was a main limitation. This tool had not been validated among Arab speaking communities; hence, some concepts related to attitudes that are culturally specific might have been missed. Because of accessibility, adults were chosen from PHCs and therefore did not represent all adults living in Beirut but they represented the middle to low socioeconomic status persons who are seeking healthcare services. Their attitudes and knowledge might be different from the general population. We expected that they would be more exposed and more knowledgeable, but they were not.

As a conclusion, this is the first study in Lebanon that assessed the knowledge level, attitudes and common perceptions of dementia. Stigma, poor attitudes and knowledge are the main barriers to receiving adequate patient care. More qualitative studies are needed to understand the socio-cultural factors shaping attitudes and perceptions as an important step towards adapting public interventions with an aim to decrease the burden caused by dementia and guide future practices and policy development. Culturally sensitive interventions should address stigma, increase knowledge of dementia and change attitudes towards persons with dementia. One such intervention could be public awareness campaigns that communicate basic facts of dementia etiology, type of health services that deal with the disease and older people's rights. Such an intervention could improve detection of the illness at its earliest stages, revert negative attitudes, reduce stigma, and encourage a more supportive environment (Karam and Itani 2013). Finally, policy makers should invest in these plans of action and translate them into an effective national health program to improve the health outcomes of people with dementia and alleviate the financial burden on individuals, families and society.

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