ORIGINAL ARTICLE

OLDER ADULTS WITH COGNITIVE IMPAIRMENT LIVING IN MALAYSIAN NURSING HOMES – HAVE WE MET THEIR NEEDS?

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Abstract

Objective: Transition of people with cognitive impairment to nursing home is often an option when their disease progresses and their needs become too complex. The aim of this study was to identify the needs of people with cognitive impairment living in nursing homes and factors associated with higher level of needs. Methods: A cross sectional survey involving 110 respondents with cognitive impairment aged ≥60 was carried out. Respondents were assessed using the Short Mini Mental State Examination (SMMSE), Camberwell Assessment of Needs for Elderly (CANE), Barthel Index (BI), Friendship Scale (FS), and Geriatric Depression Scale (GDS). Results: Respondents with cognitive impairment had a mean of 2.81 (SD=3.72) for unmet needs and 11.95 (SD=3.14) for the met needs, with higher mean suggesting a better outcome measure. The most frequent unmet needs were intimate relationships (66.40%), company (40.00%), and daytime activity (34.50%). Unmet needs were significantly associated with depression, social isolation, and cognitive impairment. Conclusion: Most of the needs of people with cognitive impairment in nursing homes were fulfilled, except in social area. Therefore, attention should be given in improving the care system, which emphasizes collaboration between people with cognitive impairment, family members, community, and government in helping to reduce the risk of loneliness in those with cognitive impairment. ASEAN Journal of Psychiatry, Vol. 16 (1): January – June 2014: XX XX.

Keywords: Care, Cognitive Impairment, Malaysian Nursing Home, Needs Assessment, Older Adult

Introduction

Malaysia, like any other country in the world, is facing an increased number of people reaching old-age. Given a population growth rate of 1.5% per annum in 2012, which is three folds higher compared to Thailand (0.5% per annum) [1], it is predicted that Malaysia will experience the full impact of an ageing population in 2035 [2]. As such, it was expected that the prevalence of people with cognitive impairment and the number of dependent older adults will be increasing as well. According to the survey, the prevalence

of Alzheimer's Disease (the most common type of dementia) in Malaysia approximately 50,000 people [3] with a total dependency ratio of the elderly expected to increase from 12.1% (2010) to 16.5% (2020) [4]. Thus, leading to increased responsibilities, including forcing family members into the stressful roles of providing care for ailing family members [5, 6]. This escalating care demands will eventually prompt the caregivers to place their relatives in institutional care [7, 8].

In Malaysia, there are thirteen nursing homes provided by the Ministry of Women, Family and Community Development of Malaysia (i.e. the Social Welfare Department) to accommodate older adults especially those without the next of kin [9]. These nursing homes were built based on a mixture of a home-like environment and hospital model. It is a secured facility and fully funded by the government. Services offered in these facilities medical include treatment. counseling. rehabilitation, physiotherapy services. financial assistance, prayer facilities, and recreation services to ensure well-being and quality of life (QoL) [10].

However, these nursing homes have not specifically been designed to provide care for people with complex needs such as those with cognitive impairment. Therefore, it remains unclear to whether those living in the institutions have their needs met. Compared to those who live in the community, studies have shown that people with cognitive impairment who live in institutions reported to have more complex and unmet needs, such as inadequate daytime activities, psychological distress, mobility, and incontinence[11-13]. Factors such as complexity of behaviour, inadequate communication, having limited income, delays follow-up for diagnostic tests and treatments, and medication errors are among the reasons for their needs being overlooked [14-16]. These unmet needs can cause misunderstandings, frustration, neglect or abuse of the older person and consequently lead to poor quality of life and increased mental health problems.

Alarmed by potential consequences of these unmet needs, this study aimed to examine self-reported needs of people with cognitive impairment who were living in government institutional care. The findings will provide evidence-based information, which may assist policy makers (government) in decisions concerning management for people with cognitive impairment in the institutions and providing a better life for those suffering cognitive impairment.

Methods

Participants

This was a cross sectional study involving people with cognitive impairment residing in government nursing homes. Of the nine government nursing homes in West Malaysia, four were selected based on geographical factors and accessibility. The four nursing homes who agreed to participate in this study were Rumah Sri Kenangan Seremban, Rumah Sri Kenangan Melaka, Rumah Sri Kenangan Ulu Kinta, and Rumah Sri Kenangan Kelantan.

All residents aged 60 years old and above were invited to participate in the study. The selection of cases in this study was made based on the information documented in the residents' medical records. However, not all participants' medical records provided the diagnosis for cognitive impairment. This was probably due to the fact that cognitive impairment is normally underdiagnosed and undertreated, particularly for those in the nursing homes. In the cases where a specific diagnosis was not recorded in the medical records (in 33.6% participants), cognitive impairment was defined following the Short Mini Mental State Examination (SMMSE) score performed by the researcher. A cut-off 10 point out of 12 points was used as an inclusion criterion [17] and those who scored 11 and above were excluded from the study. This cut-off was selected since a score of 10 or lower corresponds with the likely presence of cognitive impairment [17]. Those who were unable to communicate in or understand Malay or English were excluded. For this process, only one researcher was involved in assessing and interviewing the participants.

Procedure

The managers of the nursing homes provided the researcher a list of residents which contain residents' information such as personal details (e.g.: name, age, identification number, address, contact number), diagnosis, and dormitory number. Potential participants (age between 60 years old and above) were identified following the sequence from the list until the requisite sample size was reached.

Potential participants were then introduced by the allied health staff to the researcher and they were directly invited for their participation in the study. The nature and purpose of the study were explained to the participants before getting their verbal consent.

Following verbal consent, participants were invited to a meeting room and provided with a consent form and participant information sheet (PICF). Relatives and medical doctors were not involved in this process as is commonly the case in Malaysia for research occurring in nursing homes. Participants were excluded if the clinical impression showed that they were not competent for this study i.e. unable to follow the consenting process or it was evident that they could not understand verbal language to a degree where they understood the nature of this research study.

Consenting participants were then assessed the Short Mini Mental using Examination (SMMSE). Responses from the SMMSE were scored at that particular time. Only participants with a SMMSE score of less than 11 [17] were included and proceeded with the interview. The interview covered a set of the questionnaires consisting sociodemographic information, the Geriatric Depression Scale [18] to assess depression, the Camberwell Assessment of Need for Elderly (CANE) to assess needs [19], the Friendship Scale (FS) to assess isolation/connectedness [20], and the Barthel Index (BI) to assess activities of daily living (ADLs) [21].

Questionnaires were translated into Malay using forward and backwards translation with reconciliation by the Malaysian National Institution for Translation. It took an average of 30 minutes to conduct each interview. Participants were offered a break during the procedure.

Measures

Demographic data: age, gender, ethnicity, education attained, marital status, length of stay in nursing home, number of children, relationship satisfaction with children, financial situation. In addition, six questions were asked regarding health condition,

medication, and length of suffering from cognitive impairment.

Assessment of Cognitive Severity: The Short Mini Mental State Examination (SMMSE) [17] is a brief cognitive screening tool derived from the original Mental State Examination [22]. It consists of 12 items namely, year, month, date, day, country, postal code, spell backwards, recall, repeat sentence, three stage command, write a sentence, and copy design. Each of these items was scored binomially which gave a total score of 12. Giving a sensitivity of 98% and specificity of 91%, a cut off score of 10 was used to differentiate those with cognitive impairment [17]. Classification of cognitive impairment was defined based on the SMMSE score as; 1) mild to moderate cognitive impairment (a score between 5 to10) and 2) moderate to severe cognitive impairment (a score between 0 to 4).

Assessment of Needs: Camberwell Assessment of Need for the Elderly (CANE) is a comprehensive yet easy tool which assesses the needs of older people with mental health problems [19]. It was derived from the earlier Camberwell Assessment of Need (CAN) designed for mental health patients [23, page 83]. The CANE is a structured interview that assesses met and unmet care needs and care use in 24 areas (social, medical, and psychological needs, and needs regarding the living environment) [24]. Participants are asked about any difficulties or problems with performing activities in each of the areas. Needs are rated as 0 = no need (no problem), 1 = met need, 2 = unmet need or 9 = unknown. Needs are met when a difficulty in a particular area is being provided for, in such a way that the person no longer feels its negative impact on his or her overall QoL. Unmet needs are experienced when a person is not supported for a problem that occurs in a particular area, or receives insufficient or inadequate support [23, page 86]. Total scores for met needs and unmet needs are calculated separately by counting the number of 1s (met needs) and 2s (unmet needs) in all the 24 items. These two scores can be added to derive total score for overall needs.

Assessment of Depression: The Geriatric Depression Scale (GDS) [25] is a self-rated

scale developed to screen depression in elderly population [26]. The original version of GDS consists of 30 items (GDS-30), while a short version of the GDS contains 15 items (GDS-15). These items seek information representing lowered affect, decreased activity levels, irritability, withdrawal, distressing thoughts, and negative judgments about the past, present and future [25]. It is presented in a yes/no response format with one point assigned to each answer. Items were summed and higher scores indicate higher depression level. In Malaysian population, validation study done by Teh & Hasanah [27] revealed good psychometric purposes with Cronbach's alpha coefficient of 0.84 and test-retest reliability of

Assessment of social isolation/connectedness: The Friendship Scale (FS) [20] is an instrument which assesses aspects of both perceived social isolation and loneliness. It consists of 6 items with three of the items covering the feelings of loneliness and the other three items probing the importance of contacts. actual social Responses categorized into 5 levels of perceived social isolation (Almost always/Most of time/About half the time/Occasionally/Not at all). A total score is derived from the summation of item responses (items 1, 3 and 6 are reversed prior to scoring). A score of '0' indicates complete social isolation and a score of '24' indicates high social connectedness [20].

Assessment of Activity of Daily Living: The Barthel Index (BI)[21] consists of 10 items; feeding, moving from wheelchair to bed and return, getting on and off toilet, bathing self, walking on level surface, ascending and descending stairs, dressing, and controlling bowels and bladder [21]. Each item is scored on a 3-point scale, with 0 = totally dependent. 1 = some help needed and 2 = totallyindependent [28]. Items are weighted and summed to give a score range from 0 to 100, with higher scores indicating total independence[29].

Ethical consideration

Ethical approval was sought and granted from the Human Research Ethics Committee of The University of Melbourne, Victoria, Australia, the Malaysia Research Ethics Committee, and the National Institute of Health, Malaysia.

Statistical methods

Data were analyzed using the Statistical Package for the Social Sciences Version 16[30]. Descriptive statistics and categorical variables are presented as counts, proportions or percentages. Categorical data was analyzed using $\chi 2$ (Chi-square); where distributional assumptions were violated, the Fisher Exact test was used. Analysis of variance (ANOVA) was used to examine differences between groups and a multiple linear regression analysis was conducted to determine the predictors of unmet needs.

Results

Demographic

A total of 149 older adults aged between 60 to 89 years old from 4 nursing homes were approached. In all, 129 gave their verbal consent but only 127 were screened for evidence of cognitive impairment. The remaining 2 were not screened due to the presence of psychotic symptoms and being bed ridden. Of 127, 110 met the inclusion criteria for the study and completed the questionnaires. Following the recommendation for calculating response rate by Lynn and colleagues, the response rate for the study was 74% [31]. There was no significant difference between consenting and non-consenting participants with regards to gender and age.

The mean age for study participants was 71.6 years (SD=7.8). Seventy six of the participants (69.1%) were Malays and 64 were single/separated (58.2%). Participants who were widowed were significantly older in age (mean=74.4, SD=7.7) compared to those who were partnered (mean=66.6, SD=7.4) or single (mean=70.4, SD=7.4) (ANOVA, F (2,110) =5.2, p<0.01). Seventy four (67.3%) of participants had formal education with 56.4% having at least a primary school education. Participants with a formal education were significantly younger with a mean of 69.8 years (SD=6.9) (primary school), and a mean of 69 years (SD=8.7) (secondary school) compared to those who received informal education (mean=75.5 years, SD=7.7) (F

(2,110) = 7.6, p<0.01). The majority (89.1%) of participants reported to have below average income. The average length of stay in the nursing homes was 56.5 months(SD=54.8). On a self-rated health condition question, 48

(47.5%) of participants reported feeling unhealthy, and they were significantly older in age (F (1,110) = 6.7, p=0.01) compared to those who reported feeling healthy.

Table 1. Demographics data of people with cognitive impairment in nursing homes

Variables		N (%)
		(if not otherwise specified)
Age	Mean (SD*)	71.6 (7.8)
Gender	Male	55 (50)
	Female	55 (50)
Ethnicity	Malay	76 (69.1)
	Chinese	15 (13.6)
	Indian	19 (17.)
Education	Non-formal	36 (32.7)
	Primary school	62 (56.4)
	Higher	12 (10.9)
Marital status	Single/separated	64 (58.2)
	Partnered	7 (6.4)
	Widowed	39 (35.5)
Family support	No partner/child	62 (56.4)
	Either partner or child	48 (43.6)
Relationship	Satisfied	4 (8.7)
Satisfaction (dichotomized)	Dissatisfied	42 (91.3)
Financial status	Average	12 (10.9)
	Below average	98 (89.1)
Months of stay in nursing	Mean (SD)	56.5 (54.8)
home		
Health condition	Not healthy	48 (47.5)
	Healthy	62 (52.5)

*SD = Stamndard deviation

Health functions and other measures

The median for functional measure (as assessed by Barthel Index) for the study sample was 80 (IQR 25-100), reflecting moderate dependency. About 15% of people with cognitive impairment in this study were independent and more than half of the patients (53.6%) were moderately dependent. The median score for depression as assessed by the GDS was 14 (IQR=2-15), which represents

major depression. The majority (85.5%) of people with cognitive impairment in this study suffered from major depression with only 4.5% not depressed. As for cognitive impairment, the mean score on the SMMSE was 5.1 (SD=2.4), indicating mild to moderate cognitive impairment. Social isolation/connectedness was measured using the Friendship Scale. A mean score of 8.5 (SD=3.4) indicated that people with cognitive impairment in this study were very isolated.

Table 2. Health function and other measures of people with cognitive impairment in nursing homes

Variables		N (%)
		(if not otherwise specified)
BI*	Median (IQR##)	80 (25-100)
Physical function category	Independent	16 (14.5)
	Slightly dependent	12 (10.9)
	Moderate dependent	59 (53.6)
	Severely dependent	23 (20.9)
GDS**	Median (IQR)	14 (2-15)
Depression category	Major depression	94 (85.5)
	Mild depression	11 (10)
	Non-case	5 (4.5)
SMMSE***	Mean (SD [#])	5.11 (2.4)
Cognitive impairment	Moderate to severe	48 (43.6)
category	cognitive impairment	
	Mild to moderate cognitive	62 (56.4)
	impairment	
FS^	Mean (SD [#])	8.47 (3.4)
Social isolation category	Very isolated	89 (80.9)
	Isolated	16 (14.5)
	Some	5 (4.5)
	isolation/connectedness	
CANE^^	Mean (SD [#])	14.75 (3.7)
Needs category	Met needs (Mean, SD [#])	11.95 (3.1)
	Unmet needs (Mean, SD [#])	2.81 (3.7)

*BI = Barthel Index, **GDS = Geriatric Depression Scale, ***SMMSE = Short Mini Mental State Examination, ^FS = Friendship Scale, ^^CANE = Camberwell Assessment of Needs for Elderly

Assessment of Needs

The mean total number of needs for nursing home group was 14.8 (SD=3.7), with 11.9 (SD=3.1) being met needs and 2.8 (SD=2.0) being unmet (Table 2). Table 3 gave a proportion of met and unmet needs as reported by the study participants. In total, participants in this study sample had 1618 needs. Of these, 1311 (81%) were met and 307 (19%) were

unmet. The most frequent met needs were accommodation (109, 99.1%), looking after home (108, 98.2%), food (106, 96.4%), and money (97, 88.2%). The most frequent unmet needs for people with cognitive impairment in nursing homes were intimate relationships (73, 66.4%), company (44, 40%), daytime activity (38, 34.5%), and caring for another (35, 31.8%).

^{*}SD = standard deviation, ***IQR = inter-quartile range

Table 3. Frequency (%) of met and unmet needs of people with cognitive impairment in nursing homes

	Nursing home (N=110)			
Variables	No need N (%)	Met needs N (%)	Unmet needs N (%)	
Accommodation	1 (0.9)	109 (99.1)	0 (0)	
Looking after home	1 (0.9)	108 (98.2)	0 (0)	
Food	3 (2.7)	106 (96.4)	1 (0.9)	
Self-care	36 (32.7)	74 (67.3)	0 (0)	
Caring for another	30 (27.3)	45 (40.9)	35 (31.8)	
Daytime activity	18 (16.4)	54 (49.1)	38 (34.5)	
Memory	14 (12.7)	73 (66.4)	23 (20.9)	
Eyesight/hearing	27 (24.5)	70 (63.6)	13 (11.8)	
Mobility	50 (45.5)	59 (53.6)	1 (0.9)	
Continence	71 (64.5)	38 (34.5)	1 (0.9)	
Physical health	38 (34.5)	70 (63.6)	2 (1.8)	
Drugs	22 (20)	66 (60)	22 (20)	
Psychotic symptoms	103 (93.6)	7 (6.4)	0 (0)	
Psychological distress	42 (38.2)	51 (46.4)	17 (15.5)	
Information	78 (70.9)	28 (25.5)	4 (3.6)	
Deliberate self-harm	2 (1.8)	0 (0)	0 (0)	
Inadvertent self-harm	1 (0.9)	0 (0)	0 (0)	
Abuse/neglect	41 (37.3)	54 (49.1)	15 (13.6)	
Behavior	74 (67.3)	33 (30)	3 (2.7)	
Alcohol	108 (98.2)	2 (1.8)	0 (0)	
Company	8 (7.3)	58 (52.70)	44 (40)	
Intimate relationships	5 (4.5)	32 (29.1)	73 (66.4)	
Money	4 (3.6)	97 (88.2)	9 (8.2)	
Benefits	26 (23.6)	77 (70)	7 (6.4)	

Table 4. Multiple linear regressions predicting unmet needs in people with cognitive impairment

Predictors	В	SE^	Beta	95% CI [#]	\mathbb{R}^2
Social isolation	203	.060	335**	323083	
Cognitive severity	205	.100	244*	403007	
Physical function	007	.012	060	031018	
Depression	040	.086	058	210130	
(Constant)	6.60	1.929			0.45

Notes: *p≤0.05; **p≤0.01

^SE = Standard error $^{\#}CI =$

Key predictors of unmet needs

People with cognitive impairment who had depression, had significantly more unmet needs compared to those without depression, F (2,107) = 5.4, p=0.01. Participants with moderate to severe cognitive impairment had more unmet needs when compared to those with mild to moderate cognitive impairment, F (1, 108) = 7.5, p=0.01 and those who were very socially isolated had more unmet needs compared to those with some

isolation/connectedness, F (2,107) = 10.3, p<0.01. No significant differences were found between physical function and unmet needs in people with cognitive impairment.

A multiple linear regression analysis was conducted to determine the predictors of unmet needs. Total unmet need was used as the dependent variable, while the SMMSE, BI, FS and GDS were the multiple independent variables. These variables explained 45% of the variance, F (4,105)=6.8, p<0.01 with social

isolation as the strongest predictor of unmet needs among people with cognitive impairment (Beta=-0.3, p<0.01). Unmet needs was also significantly predicted by the SMMSE score (Beta= -0.2, p=0.04).No

Discussion

This study was undertaken to gain knowledge about people with cognitive impairment in Malaysian nursing homes, particularly with regards to their QoL and needs. In this study, older adults with cognitive impairment living in the institutions had majority of their needs being met, particularly in the area of medical, psychological, and environmental.

The most frequent unmet needs reported by the people with cognitive impairment in this study were social needs (i.e.: intimate relationships, company, caring for another), sensory or physical disability (i.e.: daytime activity, eyesight/hearing, mobility) and environmental needs (including food, medication used, information, abuse/neglect and money). These findings were similar to those reported by two other studies among dementia patients in residential care [11, 13].

The mean of unmet needs among dementia patients in this current study (mean=2.81) was lower compared to the mean of unmet needs reported by these studies (mean=4.4 and mean=4.8). This may be due to the differences in type of living arrangement, physical functions and mental health status of the participants between the studies. Indeed, participants in this current study were younger, physically more independent, and had better cognitive functions compared to other studies [11, 13, 32]. Another possible reason could be cultural factors: maybe in some western societies there are greater personal expectations (i.e. expressed as greater unmet needs) as compared to Malaysia, where there be more acceptance of existing may conditions.

Various factors such as living situation, financial status, and relationship satisfaction with children, age, QoL, depression, cognitive impairment, and social isolation/connectedness have been identified as factors associated with unmet needs in people with cognitive impairment. Having

significant association was observed between physical function and depression with unmet needs.

limited income could also restrict their choices of choosing a better or quality nursing home facility; a choice which may be directly related to having most of their needs fulfilled or unfulfilled [14].

Based on bivariate analyses, unmet needs in this study were associated with depression, severe cognitive impairment, and social isolation, which agrees with the findings by others [11, 33]. Naturally, people who are depressed, cognitively impaired, and lonely were more reserved and have difficulty communicating their needs to others. As reported by other studies, depression is a predictor for unmet needs among dementia patients in residential care [11, 33]. However, it is also important to note that both depression and physical function are not predictors for unmet needs among people with cognitive impairment in this study, which may suggest that the unmet needs expressed by people with cognitive impairment were not accounted by their emotional or physical states.

There are several limitations to this study which must be acknowledged. The study was carried out in a naturalistic setting and the findings are subject to the associated limitations. This study was cross-sectional in nature and the results point to relations between variables but cannot imply causation. Though this is the first study of identifying needs of dementia patients in Malaysia, the findings of this study are likely not able to be generalized to the dementia patients in Malaysia as the sample was not a nationally representative sample.

In conclusion, the findings indicated that older adults with mild dementia living in nursing homes had most of their needs fulfilled, except for certain areas such as intimate relationships, company, daytime activity, memory, and caring for another. Indeed, social isolation has been reported to be the strongest predictor for unmet needs in this population. Therefore, it is highly recommended that the care system to be built based on the concept of aging in the community, emphasize collaboration between

people with cognitive impairment, family members, community, and government. Various activities and services such as health care, medical services, and social activities (e.g. family day, school visits, events invitation) could be offered and integrated in the care system. Thus, older adults could benefit from the interaction with others, the exchange of ideas, and the discussion of problems, enhancing social interaction and sense of belonging. This could potentially help to reduce the risk of loneliness.

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