

Original Article

Caregivers' Perspectives Towards Goals of Care and End of Life Issues in Egyptian Elderly with Dementia Attending Geriatric Hospital

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Abstract

Background: Pre-discussion of goals of care specially at end of life in dementia is not a common practice in Egypt.

Aim: The aim of the current study is to determine caregivers' perspectives towards goals of care and end of life issues in moderate to severe and severe dementia patients.

Methods: A questionnaire was applied on 101 caregivers about perspectives of caregivers of moderate to severe and severe dementia patients toward goals of care and end of life issues.

Results: No one of caregivers had previous training for dementia care or discussed dementia care goals or end of life issues with healthcare providers. Perspectives towards goals of care was 60.4% preferred decreasing patient suffering, 39.6% preferred preserving patient function. No one chose life prolongation as a goal of care. Regarding end of life care, 98% of caregivers accepted mechanical ventilation, 90.1% accepted using pain killers, 74.3% accepted using feeding tube and 97% accepted CPR at late stage. There was significant relation between duration since dementia was diagnosed (>1 year) and choosing nursing home for sleep problems and feeding problems.

Conclusions: Egyptians caregivers' perspectives towards goals of care and end of life issues chose to decrease suffering of patients and improve their quality of life rather than prolonging their life span in late stages of dementia. Educational level and caregivers' relation with the patients didn't influence caregivers' perspectives towards end of life issues yet it slightly affected goals of care.

Keywords: Caregiver; Dementia; End of life, Goals of care, Quality of life

Introduction

Dementia is a worldwide age-related condition that is expected to reach 115 million patients in 2050. [1]

Dementia was found in Egypt with different prevalence range from 2 – 5%. It is common in females in age group 50 to 79 years old. But it increases in males with age more than 80 years old. [2]

Egyptian population above 65 years old are predicted to reach 13.3% by 2050, so, consequences of dementia will also increase.

End of life have different definitions developed over time. [3] Department of Health in United Kingdom defined it as the duration which the person with progressive, advanced, or incurable condition may die within 12 months. [4]

Goals of care of dementia patients are approaches to give care for those patients according to their needs and preferences during end of life by opening communication between patient, family, decision maker and care team. [5]

Many challenges are facing caregivers who provide care for a person with later stages of dementia at home, which may have its impact on their perspectives as lack of enough knowledge regarding dementia progression and how to cope with patients' changes, need for support, parenting the parent and concerns about patient's death and life after it. [6]

Granbo et al. explored some defects related to health care services for dementia patients and found a lack of

knowledge about available services and a gap between health services and patients' needs. [7].

Not all cultures had the ability to talk about end-of-life issues and advanced care planning. Therefore, some caregivers felt regression not to talk about these facilities to help their patients die peacefully. Also, debates between physicians and patients or caregivers about end of life care leads to useless medical measures. [8] It has been reported that many people with dementia were unable to have hospice care, [9] with undertreated pain and avoiding admissions to hospital. [10]

The gap of knowledge arises from the fact that most of the studies concern about cognitive and functional measurements of end of life without concerning about the holistic needs of the patients.

In our culture no enough studies are talking about end of life issues due to little discussion about end of life between health care workers and dementia patients' caregivers. Pre-discussion of goals of care specially at end of life in dementia is not a common practice in Egypt, most of time discussion is done stage by stage. Cultural background surrounding end of life may hinder this discussion. So, the aim of the current study is to determine caregivers' perspectives towards goals of care and end of life issues in moderate to severe and severe dementia patients.

Aim of the work

The aim of this work is to determine caregivers' perspectives towards goals of care and end of life issues in moderate to severe and severe dementia patients.

Subjects and methods

A cross-sectional study was done, involved 101 caregivers of moderate to severe and severe dementia patients according to the global deterioration scale. Participants were interviewed in the geriatric hospital (both outpatient clinics and inpatient department) at Ain Shams university hospitals after taking informed consent from them.

For patients

Comprehensive geriatric assessment was done including age, gender, marital status, educational level, residence, special habits of medical importance and financial support

For caregivers

The data were collected by applying a questionnaire on caregivers including the presence of any burden (psychological, physical and, financial) and the main goal of care whether it was to preserve function, decrease suffering or life prolongation. They were asked also about their preferred place for care if their patients had sleep, behavior, feeding problems or need special care. Regarding end of life issues, they were asked about acceptance using pain control, feeding tube, mechanical ventilation, applying cardiopulmonary resuscitation (CPR) in late stages and were asked if these answers were

patients' preference according to their previous knowledge about him/her or their choices.

Questionnaire

A questionnaire was applied on caregivers about perspectives of caregivers toward goals of care and end of life issues: Jennings et al. performed a study using an interview to explore goals of dementia care from their caregivers' perspectives in all dementia stages. In the light of this interview, caregivers' goals included psychological, physical, medical, social care and presence of support for caregivers and availability of health care services. [11]

According to these goals, our questionnaire was derived to clarify caregivers' perspectives, the needed care and support for patients and caregivers, how caregivers were affected by dementia patients' care; if they suffered any form of burden and what kind of support they needed.

Dassel et al. conducted a study using a survey asking family caregivers regarding their burden during dementia care, if they had physical, psychological or financial burden. They asked about end of life issues, their preference regarding quality of life or life prolongation, using life prolonging measures, controlling the pain and location of care by using Likert scale (strongly agree- strongly disagree). So a section about preference near end of life was added to our questionnaire and a pilot study was done. [12]

Statistical analysis

Data analysis was done by Statistical Package of Social Science program version 23 (IBM Corp., Armonk, NY, USA). Quantitative data were expressed as mean and standard deviation, while qualitative data were expressed as frequency and percentage. Student t-test and One way ANOVA test were used to compare quantitative data while Chi-square test and Fisher Exact were used to compare qualitative data. Probability value (P-value) was considered significant if it is less than 0.01.

Results

The current study is a cross sectional study involved 101 caregivers of moderate to severe and severe dementia patients according to the global deterioration scale. Socio demographic data were obtained from all participants. Their mean age was 46.4 ± 13.76 years, 70.3% of them were females. Sixty two percent got post-secondary education, 81.2% were first degree relatives, 57.4% provide both financial and physical support to the patients and 5.9% had caregiving experience for dementia patients. No one had training for dementia care or discussed dementia care goals or end of life issues with healthcare providers. (Table 1)

Table (1): Socio demographic data of caregivers and burden of caregiving

	Min.	Max.	Mean	SD
Caregiver age	22.00	80.00	46.42	13.76
			N	%
Caregiver gender	Male		30	29.7%
	Female		71	70.3%
Caregiver Education	Illiterate		6	5.9%
	Primary		13	12.9%
	Secondary		19	18.8%
	Post-secondary		63	62.4%
Relation to the patient	First degree		82	81.2%
	Other degree		19	18.8%
	No relation		0	0%
Multiple caregivers for a patient			53	52.5%
Support type offered by caregivers	Physical support		22	21.8%
	Financial support		21	20.8%
	Both		58	57.4%
Previous training			0	0%
Previous care-giving			6	5.9%
Fear of future burden			99	98%
Feeling physical burden			90	89.1%
Feeling psychological burden			90	89.1%
Feeling Financial burden			70	69.3%
Need for support			99	98%
Medical support			81	80.2%
Physical support			60	59.4%
Psychological support			55	54.5%
Financial support			48	47.5%
Social support			9	8.9%
Suitable place of care			44	43.6%

As regards caregivers’ perspectives towards goals of care 60.4% preferred decreasing patient suffering, 39.6% preferred preserving patient function, No one chose life prolongation as a goal of care. Caregivers preferred nursing home placement in the following situations, behavioral problems (65.3%), feeding problems (64.4%), need for special patient care (63.4%) and sleep problems (52.2%), and 98% chose patient’s quality of life rather than life span (Table 2).

Regarding end-of-life care, 98% accepted mechanical ventilation, 90.1% accepted using pain killers, 74.3% accepted using feeding tube and 97% accepted CPR at late stage. All these choices were caregivers’ opinions not patients’ preference (Table 2).

Table (2): Caregivers’ perspectives towards goals of care and end of life issues

		N	%
The main goal of care for dementia patient is	Preserving function	40	39.6%
	Decrease suffering	61	60.4%
	Life prolongation	0	0%
Preferred place for care if behavioral problems are present	Home	35	34.7%
	Nursing home	66	65.3%
Preferred place for care if feeding problems are present	Home	36	35.6%
	Nursing home	65	64.4%
Preferred place for special dementia patient care	Home as possible	37	36.6%
	Specialized Nursing Home	64	63.4%
Preferred place for care if sleep disorders are present	Home	48	47.5%
	Nursing home	53	52.5%
Which is more important for patient?	Life span prolongation	2	2%
	Quality of life	99	98%
	Do you accept using mechanical ventilation?	99	98.0%
End of life issues	Do you accept using pain killer?	91	90.1%
	Do you accept using feeding tube?	75	74.3%
	Do you accept applying CPR at late stage?	98	97.0%

Results showed that the most important significant needed support was well equipped place for care observed among illiterate caregivers (66.7%). The need for psychological support (28.1%) and financial support (21.9%) were prevalent among primary and secondary education population (Table 3).

Table (3): Relation between caregivers’ education and caregivers’ perspectives towards goals of care and end of life issues

		Caregiver’s education						X ²	P value
		Illiterate		Primary/secondary		Post-secondary			
		N	%	N	%	N	%		
The most important needed support	Care specialist	0	0%	6	18.8%	17	27%	28.62	0.02
	Prepared place	4	66.7%	5	15.6%	29	46.0%		
	Financial support	0	0%	7	21.9%	0	0%		
	Medical support	2	33.3%	5	15.6%	12	19.0%		
	Psychological Support	0	0%	9	28.1%	5	7.9%		
Care place if sleep disorders present	Home	2	33.3%	13	40.6%	33	52.4%	1.67	0.23
	Nursing home	4	66.7%	19	59.4%	30	47.6%		
Care place if feeding problems present	Home	2	33.3%	13	40.6%	21	33.3%	0.61	0.63
	Nursing home	4	66.7%	19	59.4%	42	66.7%		
Care place if behavioral problems present	Home	2	33.3%	16	50%	17	27.0%	4.93	0.07
	Nursing home	4	66.7%	16	50%	46	73.0%		
Preferred place for special dementia patient care	Home	2	33.3%	11	34.4%	24	38.1%	0.22	0.70
	Nursing home	4	66.7%	21	65.6%	39	61.9%		
Choosing Life span prolongation or quality of life	Life span	0	0%	0	0%	2	3.2%	1.32	0.53
	Quality of life	6	100%	32	100%	61	96.8%		
Do you accept using mechanical ventilation?	Yes	6	100%	32	100%	61	96.8%	1.32	0.53
Do you accept using pain killer?	Yes	4	66.7%	28	87.5%	59	93.7%	4.55	0.10
Do you accept using feeding tube?	Yes	4	66.7%	25	78.1%	46	73%	0.68	0.83
Do you accept applying CPR at late stages?	Yes	6	100%	32	100%	60	95.2%	1.50	0.37

First degree relative prefer nursing home as a care place for behavioral problems, while other degree relatives prefer home as a care place for sleep disorders, feeding problems and special dementia care, yet the relation between caregivers and patients didn’t significantly affects their choice for end-of-life issues (Table 4).

Table (4): Relation between caregivers’ relation to the patient and caregivers’ perspectives towards goals of care and end of life issues

	Relation with patient				X ²	P value	
	First degree		Other degree				
	N	%	N	%			
Care place if sleep disorders present	Home	31	37.8%	17	89.5%	16.51	0.001
	Nursing home	51	62.2%	2	10.5%		
Care place if feeding problems present	Home	22	26.8%	14	73.7%	14.76	0.001
	Nursing home	60	73.2%	5	26.3%		
Care place if behavioral problems present	Home	21	25.6%	14	73.7%	15.74	0.001
	Nursing home	61	74.4%	5	26.3%		
Preferred place for special patient care	Home	20	24.4%	17	89.5%	28.15	0.001
	Nursing home	62	75.6%	2	10.5%		
Choosing Life span prolongation or quality of life	Life span	2	2.4%	0	0%	0.47	1.00
	Quality of life	80	97.6%	19	100%		
Do you accept using mechanical ventilation?	Yes	80	97.6%	19	100%	0.47	1.00
Do you accept using pain killer?	Yes	76	92.7%	15	78.9%	3.26	0.07
Do you accept using feeding tube?	Yes	58	70.7%	17	89.5%	2.84	0.09
Do you accept applying CPR at late stages?	Yes	79	96.3%	19	100%	0.72	1.00

Finally, results showed that there was significant relation between duration since dementia was diagnosed (more than one year) and choosing nursing home for sleep problems, feeding problems and special patient care but there wasn't significant relation between duration of dementia since diagnosis and caregivers' perspectives towards end-of-life care (Table 5).

Table (5): Relation between duration of diagnosis of dementia and caregivers’ perspectives towards goals of care and end of life issues

		Duration				X ²	P value
		1 year or less		> 1 year			
		N	%	N	%		
The most important support	Care specialist	12	19%	11	28.9%	6.53	0.16
	Prepared place	28	44.4%	10	26.3%		
	Financial support	2	3.2%	5	13.2%		
	Health support	12	19%	7	18.4%		
	Psychological Support	9	14.3%	5	13.2%		
Care place if sleep disorders present	Home	36	57.1%	12	31.6%	6.21	0.01
	Nursing home	27	42.9%	26	68.4%		
Care place if feeding problems present	Home	27	42.9%	9	23.7%	3.80	0.05
	Nursing home	36	57.1%	29	76.3%		
Care place if behavioral problems present	Home	23	36.5%	12	31.6%	0.25	0.61
	Nursing home	40	63.5%	26	68.4%		
Preferred place for special patient care	Home	28	44.4%	9	23.7%	4.40	0.04
	Nursing home	35	55.6%	29	76.3%		
Choosing Life span prolongation or quality of life	Life span	2	3.2%	0	0%	1.23	0.53
	Quality of life	61	96.8%	38	100%		
Do you accept using mechanical ventilation?	Yes	61	96.8%	38	100%	1.23	0.53
	No						
Do you accept using pain killer	Yes	55	87.3%	36	94.7%	1.47	0.23
	No						
Do you accept using feeding tube?	Yes	48	76.2%	27	71.1%	0.33	0.57
	No						
Do you accept applying CPR at late stages?	Yes	60	95.2%	38	100%	1.87	0.29
	No						

Discussion

Alzheimer’s disease facts and figures reported that according to the report of Alzheimer’s, dementia is quickly increasing globally and is expected to be threefold by 2050. [13]

The study showed that 98% of the studied subjects needed support in general (medical, physical, psychological, financial, and social).

This may be due to lack of supportive resources and lack of knowledge about dementia as a disease, its needs and available resources. *Jennings et al.* performed a cross sectional study regarding caregivers’ need in dementia care, only 19% of its caregivers knew how to get community services and find help. [14]

Ninety-eight percent (98%) of our studied subjects was afraid of future burden. *Lindeza et al.* notified that doubt about the future leads to vague situation for the family members and caregiver. [15]

The uncertainty about the future for dementia patients and their caregivers and the lack of training and discussion among our participants (0%) affected caregivers' perspectives for goals of care and end of life issues differently.

This study revealed that more than 50% of caregivers preferred nursing home for care if there are sleep disorders, feeding problems, behavioral problems and if their patients needed special care for dementia. In the same way, *Dassel, et al.* notified that during early stage of the diseases, 54% wanted to receive their care at home but lately 50% wanted to receive the care in residential hospice. [12]

During dementia progression, 98% of the studied population chose quality of life over life prolongation for their patients. In the same way, *Volicer* informed that number of patients with Alzheimer and other dementia increases with prolongation of lifespan. So, quality of life, comfort and dignity are needed in late stages of dementia. [16]

When goals of care near end of life were asked about, 60.4% of caregivers preferred to decrease suffering for their dementia patients, 39.6% chose to preserve patients' function and no one chose patients' life prolongation. In agreement with our results *Volandres et al.* conducted an interview about future medical care in advanced dementia which revealed 64% of participants chose improving comfort, 19% chose limited care and 14% chose prolongation of life. [17].

Regarding end-of-life issues, Although , 99% prefer quality of life over life prolongation; 74.3% of the participants accept tube feeding for their dementia patients, 90.1% accept using pain killers, 98% accept mechanical ventilation and 97% accept CPR. This means that the participants weren't aware of the exact meaning of life prolongation.

These results disagree with *Jennings et al.* who reported that 88% of their participants preferred do not resuscitate (DNR), 48% asked for limited medical interventions, 35% selected comfort-focused care, and 74% preferred no artificial nutrition, including feeding tubes. [18]

We could conclude that our participants' religious and cultural background and the lack of knowledge about the disease nature and its

progression may have its impact on their choices in different sections of the questionnaire. As it was observed that though 99% chose quality of life over life prolongation for their dementia relatives, they still prefer mechanical ventilation (98%) and accept cardiopulmonary resuscitation (97%).

As educational level affects caregivers' knowledge and choices, we studied the effect of caregivers' education on their perspectives towards goals of care and end of life issues it was observed that, 66.7% of illiterate and 46% of post-secondary education caregivers find the presence of well-prepared care place is important. In the same way, *Gaugler et al.* proved that delivery of optimal care, presence of well-trained staff, available health care services, effective care planning, appropriate management of symptoms, and familiar environmental adaptation are important for patients' proper care to decrease the burden on caregivers. [19] Caregivers' education in our study didn't influence caregivers' perspectives towards end-of-life issues including mechanical ventilation, using pain killers, feeding tubes and applying CPR. To our knowledge, we did not find studies relating the educational level of caregivers to their choices regarding end of life issues of dementia patients, but the studies commonly related the

effect of educational programs as an intervention tool on these choices.

The part of further studies can better be transferred to the recommendation section.

As caregivers involved in this study are the most involved in decision making for their relatives and they are usually a family member. We studied the effect of degree of relationship to the patient on care goals and perspectives. Most first-degree relatives chose the nursing home for dealing with behavioral problems. That's agreed with *Kunik et al.* as aggression has been repeatedly experienced in nurse-home placement from patients with Alzheimer and dementia. [20] Daytime and sleep aggression decrease in nursing home residents especially after decrease light and sound environment. [21]

Relatives other than first degree chose home as a caring place for dementia patients who suffer from sleep and feeding problems. *Li et al.* mentioned swallowing difficulty as a physiological challenge which can be solved by proper selection of food textures. [22]

Regarding choices of end-of-life issues, there was no difference between first-degree relatives nor other degree relatives' choices for their patients. Most of them prefer quality of life of the patient over life span. They both accept mechanical ventilation,

using pain killers, feeding tube, and CPR.

The results also revealed that caregivers with more than one-year diagnosis for dementia patients chose the nursing homes as care place for sleep problems, feeding problems and special patient care.

Longer duration of diagnosis and caregiving leads to higher levels of care stress which were noted in cases where people with dementia were placed in nursing homes. [23]

Duration of dementia diagnosis didn't affect caregivers' choices regarding end-of-life issues.

Conclusion

This study is of the earliest to reveal Egyptians caregivers' perspectives towards goals of care and end of life issues in dementia. It revealed that caregivers of moderate to severe and severe dementia patients chose to decrease suffering of patients and improve their quality of life rather than prolonging their life span in late stages of dementia. Educational level and caregivers' relation with the patients didn't influence caregivers' perspectives towards end-of-life issues yet it slightly affected goals of care.

Recommendations

This study highlighted the importance of caregivers' views about end-of-life care of patients with dementia which should be considered during development of individualized care plans among different types of carers. Moreover, future research and clinical care should depend on different domains and measures during definition of end of life in dementia. There is a need for general agreement about definition of end of life in dementia during planning the needs-based approach, practices, policies by the decision makers for allowing convenient care in a timely manner. Awareness campaigns for caregivers regarding disease progression, patients' needs, care needed in late stages, and available community resources are recommended. Training programs for physicians and health care professionals for communicating dementia diagnosis, disease progression, discussing goals of care, end of life issues and decisions should be applied.

Ethics approval and consent to participate.

The study methodology was reviewed and approved by the Research Ethics Committee of the faculty of Medicine, Ain Shams University. Informed

consent was obtained from all participants.

Consent for publication

Not applicable, there no personal data in the manuscript (videos or images)

Availability of data and materials

All supporting data are available in a spreadsheet format and can be provided whenever required.

Competing interests

None declared.

Funding

None

Authors' contributions:

MAA contributed to writing of the manuscript and reviewed the manuscript; NSA contributed to the data collection; SAH contributed to the data analysis; SMM contributed to the study design and reviewed the manuscript; HYK contributed to writing of the manuscript and reviewed the manuscript. All authors approved the final draft of the manuscript.

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