



KNOWLEDGE , ATTITUDE AND PERCEPTION REGARDING PALLIATIVE CARE AMONG FAMILIES OF STROKE PATIENTS: A CENTER BASED SURVEY IN RIYADH CITY OF SAUDI ARABIA

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ABSTRACT

Background: Palliative care service is a comprehensive and specialized service which can help in improving the quality of life among the sufferers. It is required of disease for treatment of physical, psychological and spiritual symptoms experienced by the patient. Stroke with its different types is considered an important target for palliative care given the natural history of some strokes leading to morbidities and mortalities. According to one estimate, 56.8 million people need palliative care service every year. Unfortunately, only about 14% currently receive it. Institutional and community barriers to initiate palliative care among stroke patients have been discussed in few studies. Stroke guidelines have addressed the palliative care as a growing need to face the demands. However, a major gap continues to influence the effective implementation of the service in stroke population. In order to understand the challenging factors in designing a stroke palliative pathway in our region the present study was conducted to assess the knowledge, attitude and perception of families members whose relatives suffered stroke and needed palliative care service. **Materials And Methods:** It was a cross-sectional survey conducted at King Fahad Medical city (KFMC) in Riyadh, Kingdom of Saudi Arabia. Included patients were admitted to the comprehensive stroke program between January 2018 to March 2022. The study included subjects with high modified Rankin scale (5 and 6) including patient died during admission. A predesigned and pre tested questionnaire was distributed via Google form. The questionnaire test their knowledge regarding the palliative care and their attitude and perception towards the palliative care service that could have been offered. Data were entered and analyzed by using SPSS Version 20. Data were calculated with respective 95 % Confidence Interval and presented as mean. A P value of < 0.05 was considered as statistically significant. **Result:** A total of 124 family members participated in this survey. Most of the participants (55.6%) did not hear about palliative care. Majority of the participants (73.4%) responded that they were never offered by any of the hospital staffs for palliative care service for their patients. More than (61.3%) had poor knowledge about palliative care. Those with higher education, married, caregiver related to medical field were having significantly higher knowledge of palliative care. Participants in the study emphasized the need for palliative care to be reframed and better explained by health care professionals.

KEYWORDS

Stroke, Palliative care, knowledge, perception

INTRODUCTION:

Palliative care service is a specialized medical care delivered by a range of professional and each profession has equally important role. Palliative care involves physicians, nursing, support workers, paramedics, pharmacists, physiotherapist, and volunteers with the support of patients and their families^[5].

Such service should be part of stroke care program since that stroke considered as the second leading cause of death and the third leading cause of disability in the world. The incidence of stroke in Saudi Arabia is 43.8 per 100,000, Stroke incidence and standardized death rates are falling but population growth and ageing are likely to increase the burden of stroke.^[1] Saudi Arabia is a rapidly developing country that evolved drastically in the last two decades. Major lifestyle and environmental factors have changed and increased the risk and incidence of stroke. The increased burden of stroke has created a need for suitable palliative care which can help in improving the quality of life among the sufferer.^[2] The success of any palliative care service depends on the shared decision making after integration with the best available evidence and patients' values and preferences about quality of life after stroke.

The other angel of palliative care service, it looks after caregivers and families of patients since they face variety of physical, financial and psychological challenges. Hence, efficient palliative care program should provide comprehensive assessment to all necessary aspects of patient's life as well as their families.^[4] According to one estimate 56.8 million people are in need of palliative care service every year.

Unfortunately only about 14% of the people who need palliative care currently receive it. This suggests that tremendous efforts are required to address the barriers, find solutions and reduce the gap to implementation.

However, barriers to palliative care have been noted by various researches which include misconception about palliative care and inadequate palliative care education. The study suggests that early delivery of palliative care service reduces unnecessary hospital admission and the use of health services which directly influence the health cost. According to one study the average willingness to accept palliative care was 65.02 points in a visual analogue scale of 0-100 points. Higher education of the family, higher perceived pressure and family with access to medical insurance providing higher re imbursement were more willing to accept the palliative care service.^[6] In a study utilization of the palliative care service is adversely affected by the lack of knowledge among the general population.^[5]

In order to understand the challenging factors in designing a stroke palliative pathway in our region, the present study was conducted to assess the knowledge, attitude and perception of families members whose relatives suffered stroke and needed palliative care service.

MATERIALS AND METHODS:

It was a cross-sectional survey conducted at King Fahad Medical city Riyadh, Saudi Arabia of patients admitted to the comprehensive stroke program between January 2018 to March 2022. We identified subjects with high modified Rankin scale (5 and 6) including patient died inside

King Fahad Medical City and those transferred to another institutes. All the involved family members whose relatives were admitted in the stroke program during the study periods were the study population. The epi info software (Version 6) was used to calculate the sample size .For sample calculation it was assumed that only 10% to 15% The calculated sample size was 217 family members based on 95% confidence level .A convenience sampling method was used to collect the study sample. A predesigned, pre tested questionnaires were distributed via Google form. The questionnaires consisted of three sections. Section 1 consisted of demographic characteristics of the participants (Age, educational qualification, marital status, place of residence, Degree of caregiver kinship, type of caregiver job, their awareness regarding palliative care etc). The section 2 consisted of questions about the knowledge of Palliative care service (palliative care service definition, purpose and Meaning of DNR). The section 3 focused on the attitude and perceptions on the palliative care service (such as acceptance and refusal of palliative care service , causes of acceptance and refusal etc. There were 4 questions to test the knowledge of the participants about the palliative care service and the answers of which were in close ended form. There were 6 questions to assess the perception of the participants towards the palliative care. The data were entered and analyzed by using SPSS Version 20. Frequency distribution of basic information, knowledge, perception and attitude was constructed and expressed as numbers and percentages. BI-variate analysis was conducted by using a Chi-squared test to examine the association between variables and to assess the relationship between basic information and knowledge and perception scores. Data were calculated with respective 95 % Confidence Interval and presented as means. A P value of < 0.05 was considered as statistically significant a correct answer was awarded with 1 score while an incorrect with zero score. In the knowledge sections score ranged from 0 to 4, By using the mean as a cutoff point, the level of knowledge was measured. The participants were classified as having poor knowledge and good knowledge on the score range of 0 to 4 points. A good knowledge score range was above the mean cut off point while the poor knowledge was below the mean cutoff point. Similarly the participants were classified as either having a poor perception and attitude or positive attitude and good perception. The score ranged of 0 to 56 points. A positive attitude and good perception was above the mean score while below the mean score was considered as having negative attitude and poor perception. A prior permission from the local ethical research committee was taken before the start of the study.

RESULTS:

Socio-Demographic Characteristics Of The Participants.

A total of 124 family members participated in this survey making the response rate of 57%. The mean age of the participants was 44 years $\pm$ 9.13 years (Range 23-65 years). As far as the educational qualification of the participant is concerned 34.7% of them hold a bachelor degree followed by those (33.1%) had postgraduate certificate, secondary school educated (18.5%) and primary school educated (18.5%). Only 7.8% of the participants were uneducated. The majority of the participants (65.3%) were married while 25.6% were unmarried and 8.1% divorced. Almost sixty seven percent (66.9%) of the participants belonged to rural area while the rest were from urban area. More than three fourth of the participants (76.6%) were first degree caregiver kinship while 19.4% were second degree and only 4% were third degree. The majority of the caregivers belonged to non medical service (73.4%) while 26.6% were from medical service. The majority of the participants (55.6%) did not hear about palliative care. More than twenty five percent (25.8%) of the participants heard the information about palliative care from families receiving palliative care treatment from different disease. While 11.3% of them heard about the palliative care from the physicians and only 7.3% through the media. Majority of the participants (73.4%) responded that they were never offered by any of the hospital staffs for palliative care service for their patients. After offering the palliative care service by the hospital 18.5% of the participants did not accept while only 8.9% of them accepted. Majority of the participants (72.6%) answered that the service has not been offered to them. The details of the demographic characteristics of the participants and their basic association with palliative care service is shown in table 1.

Table 1: Showing Demographic Characteristics And Their Basic Association With Palliative Care Service

Variables	No.	Percentage
Age:		
44 years $\pm$ 9.13 years (Range 23-65 years)		

Location		
Urban	83	66.9
Rural	41	33.1
Educational Qualification		
Uneducated	9	7.3
Primary educated	8	6.5
Secondary Educated	23	18.5
Graduate	43	34.7
Post graduate	41	33.1
Marital status		
Unmarried	33	26.6
Married	81	65.3
Divorced	10	8.1
Degree of caregiver kinship		
First degree	95	76.6
Second Degree	24	19.4
Third degree	5	4.0
Type of caregiver		
Medical service	33	26.6
Non medical service	91	73.4
Have you heard about the palliative care service		
Yes	55	44.4
No	69	55.6
If yes then		
What was the source of information (N=55)		
Family	18	32.74
Friends	14	25.45
Social media	9	16.36
Physicians	14	25.45
Did anyone of hospital staff offer you palliative care service		
Yes		
No		
Did you ever accept the palliative care service		
Yes	33	26.6
No	91	73.4

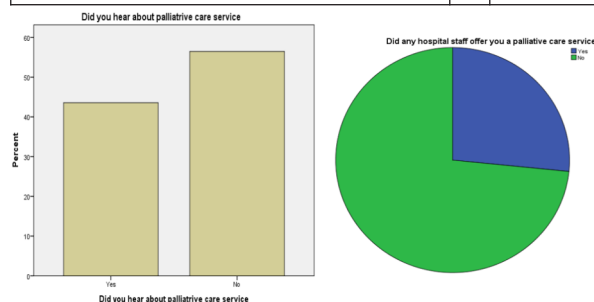


Figure 1: showing the response on the awareness question Figure 2: Showing the response on offer of service

Responses On The Knowledge Questionnaires On Palliative Care Service:

On the statement that palliative care service covers the psycho social symptom of the patient, 18.5% of the participants agreed with this while 17.7% of them did not agree and 63.7% stated that they did not know about it. Majority of the participants (58.9%) did not know that palliative care service is aimed to improve the quality of life of the patients while 25.0% of them agreed with this statement and 16.1% disagreed. Almost fifty-nine percent (58.9%) of the participants agreed with the statement that palliative care service offer a support to the patients and their family while 22.6% of the participants did not agree with this statement and 18.5% of them did not know about it. Majority of the participants (67.7%) did not know the meaning of DNR. The details of the response on the knowledge question on palliative care service are shown in table 2.

Table 2: Showing The Details Of The Responses On The Knowledge Questionnaires On Palliative Care Service

Knowledge Questionnaires	No.	percentage
Palliative care service cover the psychosocial symptom of the patient		
Yes	23	18.5
No	22	17.7
I don't know	79	63.7

Palliative care service is to aim to improve the quality of life of the patient		
Yes	31	25.0
No	20	16.1
I don't know	73	58.9
Palliative care service offer support to the patients and his family member		
Yes	73	58.9
No	28	22.6
I don't know	23	18.5
Do you understand the meaning of DNR (Do not resuscitate)		
Yes	40	32.3
No	84	67.7

Responses On The Perception Questionnaires Towards Palliative Care Service:

Majority of the participants (67.7%) answered that the palliative care service was not offered to them when asked about acceptance or refusal of services. While only 17.7% responded by refuse comparison to 14.5% of responder accepted the palliative care service. Almost seventeen percent (16.93%) of the participants stated that they regretted refusing palliative care for their relative once offered by the hospital. However 69.35% of the participants replied that they were not offered any palliative care service and 13.71% did not regret refusing palliative care service. Out of 22 participants who refused to accept the palliative care service, 40.90 % of them cited the religious, cultural and emotional (guilty) as the main causes of the refusal. However 13.63% of the participants cited other reasons of refusal. The expectation of the participants on the service of palliative care provided by the hospital was measured on the scale of 1-10. The vast majority of the participants (91.8%) perceived it on the scale between 6-10. Majority of the participants (79.0%) would accept the service if Palliative care service were offered to them in future, while others would reject or stay undecided. On the likelihood of recommendation to their friends and relatives for palliative care service the response of 98% of the participants was on the scale 6-10. The responders were affirmative on choosing the palliative care service even with lack of supporting service such as (Long Term Facility and Home Health care). The details on the response of the knowledge questionnaires is shown in table 3.

Table 3: Showing Details On The Response Of The Knowledge Questionnaires

Perception questionnaires	No.	Percentage
Did you ever refuse palliative care service offered to your relative		
Yes	22	17.7
No	18	14.5
The service was not offered	84	67.7
Did you ever regret refusing palliative care service		
Yes	22	16.94
No	16	13.71
The service was not offered	86	69.35
What does make you to refuse the palliative care service(N=22)		
Religious reason	9	40.9
Guilt feeling	4	18.2
Customs and tradition	6	27.3
Others	3	13.6
On scale 1-10 how well have we met your expectation regarding palliative care service		
Scale 1-5	10	8.2
Scale 6-10	114	91.8
If the service is offered to you now , will you accept the service		
Yes	98	79.0
No	16	12.9
I don't know	10	8.1
On a scale of 1 to 10 how likely are you to recommend palliative care service to your friends and family		
Scale 1-5	14	11.3
Scale 6-10	110	88.7

Would you like to choose palliative care service if there is no support offered by the country (e.g No LTC facility and No home care service)		
Yes	87	70.2
No	37	29.8

Knowledge Score On Palliative Care Service:

The mean knowledge score of the participants was $1.62 \pm$ Std. Dev. 1.08. (Range 1-4) More than sixty one percent of the participants (61.3%) had poor knowledge about the palliative care. The details of the knowledge status of the participants regarding the palliative care is shown in table 4.

Table 4 . Showing The Details Of The Knowledge Status Of The Participants Regarding The Palliative Care.

Knowledge score	No.	Percentage
Mean knowledge score: 1.62 Std. Dev. 1.08 (Range 1-5)		
Good knowledge	48	38.7
Poor Knowledge	76	61.3

The Perception Score Of The Participants On Palliative Care Service:

The mean perception score of the participants was $3.37 \pm$ Std. Dev. 1.01. Majority of the participants (66.9%) had positive perception towards palliative care. The details of the perception status of the participants towards palliative care service are shown in table 5.

Table 5: Showing The Details Of The Perception Status Of The Participants Towards Palliative Care Service

Perception score	No.	Percentage
Mean perception score: 3.37 $\pm$ Std. Dev. 1. (range 1-5)		
Good perception	83	66.9
Poor perception	41	33.1

Association Of Knowledge Regarding Palliative Care Service And The Socio Demographic Characteristics

The urban participants had better knowledge than those of rural participants but it was not statistically significant (40.96% vs. 34.14%, $P=0.076$). As educational level increased the level of knowledge about the palliative care also increased significantly. The good knowledge about the palliative care was highest among the post graduate as compared to Others. The good knowledge about palliative care was significantly more among higher among married participants compared to those who were unmarried and divorced (49.0% vs. 33.33% vs. 30%, $P=0.045$). The good knowledge about palliative care was also significantly higher among the third degree caregiver than those of first degree and second degree (60.0% vs. 47.34% vs. 29.1%, $P=0.032$). The caregiver related to medical field had better knowledge about palliative care service than those who belonged to non medical branches (57.57% vs. 29.69%, $P=0.009$). Those participants who had heard about the palliative care had better knowledge than those who did not hear, however it was not significant (44.44% vs. 34.28%, $P=0.270$). The details of the association of the knowledge score about the palliative care service and the socio demographic characteristics are shown in table 6.

Table 6: Showing The Details Of The Association Of The Knowledge Score About The Palliative Care Service And The Socio Demographic Characteristics

Variables	Good knowledge No.(%)	Poor knowledge No. (%)	P value
Location			0.076
Urban	34(40.96)	49(59.04)	
Rural	14(34.14)	27(65.86)	
Educational Qualification			0.013
Uneducated	2(22.23)	7(77.77)	
Primary educated	2(25.0)	6(75.0)	
Secondary Educated	8(34.79)	15(65.21)	
Graduate	15(34.89)	28(65.11)	
Post graduate	17(41.47)	24(58.53)	
Marital status			0.032
Unmarried	11(33.33)	22(66.67)	
Married	41(49.30)	40(50.70)	
Divorced	3(30.0)	7(70.0)	

Degree of caregiver kinship			0.032
First degree	45(47.34)	50(52.66)	
Second Degree	7(29.10)	17(70.90)	
Third degree	3(60.0)	2(40.0)	
Type of caregiver			0.009
Medical Background	19957.57)	14(42.43)	
Non-Medical Background	29(29.89)	62(70.11)	
Have you heard about the palliative care service			0.272
Yes	24(44.44)	30(55.56)	
No	24(34.28)	46(65.72)	

Association Of Perception Status With The Socio Demographic Characteristics Of The Participants:

The participants from the urban area had significantly higher good perception towards the palliative care service than those living in rural area (80.72% vs. 39.02%, $P=0.000$). Similarly as the educational increased the good perception towards palliative care service also increased significantly. It was highest among the post graduate as compared to others. Good perception regarding the palliative care was significantly higher among married as compared to those who were unmarried or divorced (70.37% vs. 69.609% vs. 30%, $P=0.035$). Good perception regarding the palliative care service was significantly more among the first degree caregiver kinship than those of third degree and second degree caregiver kinship (82.10% vs. 40.0% vs. 12.5%, $P=0.000$). The good perception about the palliative care service was almost similar regardless of the medical background. Those participants who had previously heard about the palliative care service had better perception about the palliative care than those who did not hear about it (77.77% vs. 56.57%, $P=0.019$). The details of the association of perception status with the socio demographic characteristics of the participants is shown in table 7.

Table 7: Showing The Details Of The Association Of Perception Status With The Socio Demographic Characteristics Of The Participants

Variables	Good perception No.(%)	Poor perception No. (%)	P value
Location			0.000
Urban	67(80.72)	16(19.28)	
Rural	16(39.02)	25(60.98)	
Educational Qualification			0.002
Uneducated	2(22.22)	7(77.78)	
Primary educated	2(25.0)	6(75.0)	
Secondary Educated	15(65.21)	8(34.79)	
Graduate	33(76.74)	10(21.26)	
Post graduate	32(78.04)	9(21.96)	
Marital status			0.035
Unmarried	23(69.69)	10(30.31)	
Married	57(70.67)	24(29.33)	
Divorced	3(30.0)	7(70.0)	
Degree of caregiver kinship			0.000
First degree	78(82.10)	17(17.9)	
Second Degree	3(12.5)	21(87.5)	
Third degree	2(40.0)	3(60.0)	
Type of caregiver			0.566
Medical service	22(66.66)	11(33.34)	
Non medical service	61(67.03)	30(32.97)	
Have you heard about the palliative care service			0.019
Yes	42(77.77)	12(22.23)	
No	41(58.57)	29(41.43)	

DISCUSSION:

The present study was done to assess the knowledge, attitude and perception regarding palliative care service of the caregivers (family members). The palliative care service is important because it not only gives the patients an option for pain and symptoms management but also a higher quality of life while still pursuing curative measures. The present study has shown that majority of the family members had poor knowledge about the palliative care. A similar Pakistani study has also reported a lower understanding about the palliative care among the caregivers. Only 45% of the respondents had good knowledge about the palliative care.^[7] Majority of the participants (69%) did not hear about the palliative care service. An Ireland study has also reported that only 20% of the participants had previously heard about the palliative care^[8] and had an accurate understanding of the term. However one

Lebanese study has reported a low level of awareness regarding the palliative care among the family members where only 17% of them had heard about the palliative care service.^[9] One Canadian study has also shown that 45% of its participants had high perceived knowledge, of whom 46% had high knowledge regarding palliative care.^[10] However, an Ethiopian study has shown a high level of knowledge about the palliative care service among its 62.8% of the participant.^[11] One Chinese study has also reported the similar result where 81% of the participants never heard about the palliative care service and only 5% of them had somewhat or totally understanding of palliative care.^[12] Stroke outcome can be quite variable, ranging from minor deficits to serious or life-threatening. This generates a pressure on stroke chain of care and adds complexity on the process of decision making in terms of appropriate goals after stroke. Palliative care comes to play in optimizing the needs of stroke care when it comes to end-of-life discussion. Palliative care would offer patients and their families the opportunity to have a better quality of life through a family-patient centered practice.

However, integrating both services together is not away from limitations and challenges that interfere with optimal delivery of palliative care among stroke patients. Our study explored additional and unique elements that have implications on implementation of palliative care for stroke patients in KSA population. There are gaps related to patients and families but interestingly the medical system is still not fully prepared as well to engage families to palliative care. An example in our study we observed that families have low level of knowledge about palliative service but at the same time such care was not introduced to them by the treating teams. This probably suggests a hesitancy from physicians to open the discussion given lack of systematized approach or pathway of care, although most interviewed families expressed positive feeling about the palliative care. This observation supports the necessity of increasing palliative care education and awareness of both the stroke teams and communities as part of the pathway.

Moreover, our study showed different factors that might affect implementation on several levels of stroke system. Such factors could be relevant to patients' condition, caregivers, cultural fears and religious beliefs. In our study, up to 80% might consider cultures, guilty feeling and religious boundaries as potential obstacles for accepting palliative care. Hence, presence of a spiritual therapist as part of the palliative team would be an important element. We always consider that the cost of care or the financial aids could influence families' decisions. However, the majority of families interestingly did not consider the governmental supports as important as we thought in the signing for palliative care.

Several studies demonstrated high chance of positive attitude toward palliative care but with variable level of knowledge, ranging between 20-70% among studies participant. This might suggest difference in study methodology and the presence of different factors playing in the decision process of palliative care. In a systematic review, cultural, social, attitudes, and organizational barriers are felt to be major causes for refusal of palliative care service provided by the hospital.^[14] As seen in a Lebanese study, we found that most commonly reported reason for non-acceptance of the palliative care service by the participating families was religious followed by customs, tradition and feeling of guilt. Although this could reflect resistance of families, in fact positive attitude was demonstrated on other studies in up to 90% after families being educated and familiarized with goals of the services and how such care would minimize the overwhelming emotional and physical pressure. (reference). Hence, There is a need for strategic programs to target families and teach communities about the benefits of palliative care service which certainly would influence the perception toward palliative system of care, as we observed in our study.

Palliative care is a complimentary service in the stroke network. There is supporting evidence of including palliative care as standard care. Stroke guidelines addressed the necessity of palliative care and importance of overcoming the barriers in a multidisciplinary approach. The identified challenges or limitations in our study are comparable to other places outside the kingdom and we share the urge to improve the quality of stroke patients. We still lack a comprehensive view of all domains in palliative care offered to stroke patients and how this would influence the financial cost on the health system. Based on this study, building nationwide strategic plans and criteria is necessary as initial step to establish a stroke palliative program.

CONCLUSION:

Our study is leading the call for transformation in the Stroke Palliative Care. This work widely discussed several relevant factors influencing palliative care implementation and integration to stroke care within the kingdom of Saudi Arabia. There is a need of formulation and implementation of public teaching program to teach them about the benefits of palliative care service. The study provides an insight about this ongoing issue among stroke community. Building the infrastructure of Stroke Palliative Care within our country is not impossible and it certainly removes a tremendous pressure on families and health organizations. Further studies about cost effectiveness of stroke palliative care would also explore the financial influence and help in driving the local authorities to support such program at national level.

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