ORIGINAL RESEARCH PAPER
Volume - 13 | Issue - 08 | August - 2024 | PRINT ISSN No. 2277 - 8179 | DOI : 10.36106/ijsr
INTERNATIONAL JOURNAL OF SCIENTIFIC RESEARCH

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

Emergency Medicine

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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 sufferer. The success of the palliative care service depends on the shared decision making. The palliative care service not only improves the quality of life of the patient and that of the caregivers but also provide confidence among their families who are facing the challenges. It is the comprehensive assessment and treatment of physical, psychological and spiritual symptoms experienced by the patient. 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. Barriers to palliative care have been noted by various researches which include misconception about palliative care, inadequate palliative care education. The present study was conducted to assess the knowledge, attitude and perception of those 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 hospital between January 2018 to March 2022. All the family members whose relatives were admitted with stroke during the study periods were the study population. The epi info software(Version 6) was used to calculate the sample size .which was calculated to be 217 families . A pre designed, pre tested questionnaires were distributed via Google form. The questionnaires consisted demographic characteristics of the families , their knowledge regarding the palliative care and their attitude and perception towards the palliative care service. The data were entered and analyzed by using SPSS Version 20.Frequency distribution of basic information and knowledge and 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 was 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 .The mean age of the participants was 44 years ±9.13 years .Almost thirty five percent of the participants were graduate followed by those (33.1%) who were postgraduate, secondary school educated (18.5%) and primary school educated (18.5%). The majority of the participants (65.3%) were married Almost sixty seven percent (66.9%) of the participants belonged to rural 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 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 sixty one percent of the participants (61.3%) had poor knowledge. Majority of the participants (66.9%) had positive perception towards palliative care. The urban participants (P=0.076), those with higher education(P=0.013),married (0.045),third degree caregiver (0.032) , caregiver related to medical field (P=0.009) were having significantly higher knowledge of palliative care. Similarly The participants from the urban area(0.00) ,higher educational qualification((0.002) ,married (0.035) ,first degree care giver (P=0.000) and those who heard about the palliative care service (P=0.019) were having positive attitude and better perception towards palliative care.

KEYWORDS

Stroke , Palliative care ., knowledge, perception

INTRODUCTION:

Stroke is 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 changed and increased the risk and incidence of stroke. Increased cases of stroke have created a need for suitable palliative care which can help in improving the quality of life among the sufferer.[2] The success of the palliative care service depends on the shared decision making. Shared decision making (SDM) is an integral aspect of palliative care. SDM involves combining the best available evidence and patients' values and preferences into decisions about care, including decisions about interventions that improve survival but with severe disability, and about transitions between care settings.[3]

The palliative care service not only improves the quality of life of the patient and that of the caregivers but also provide confidence among their families who are facing the challenges. It then is the comprehensive assessment and treatment of physical, psychological and spiritual symptoms experienced by the patient.[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. 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].

However barriers to palliative care have been noted by various researches which include misconception about palliative care, inadequate palliative care education. The study suggests that early delivery of palliative care service reduces unnecessary hospital admission and the use of health services. 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]

Inspire of the supporting evidence of the inclusion of palliative care as standard care, studies suggest a widening gap between those who benefit from palliative care service and those who receive it. Utilization of the palliative care service is adversely affected by the lack of knowledge among the general population.[5] To achieve the best utilization of the palliative care service the knowledge and perception of the family members must be positive. The present study was conducted to assess the knowledge, attitude and perception of the family members of the local population towards the palliative care service.

MATERIALS AND METHODS:

It was a cross sectional survey conducted at King Fahad Medical city hospital between January 2018 to March 2022. All the family members whose relatives were admitted with stroke 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 pre designed, 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 on the knowledge of Palliative care service (palliative care service definition, purpose and Meaning of DNR) .The section 3 consisted of the questionnaires 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 on the palliative care service the answers of which was 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 and knowledge and 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 was presented as mean . A P value of < 0.05 was considered as statistically significant Correct answer was awarded with 1 score while 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 having poor perception and attitude and positive attitude and good perception. The score ranged of 0 to 56points. A positive attitude and good perception was above the mean score while below the mean score were considered as having negative attitude and poor perception. A prior permission from the local 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 ±9.13 years (Range 23-65 years). As far as the educational qualification of the participant is concerned 34.7% of them were graduate followed by those (33.1%) who were postgraduate, 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 caregiver 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 on palliative care by their friends and family while 11.3% of them heard about the palliative care from the physicians while only 7.3% of them heard from 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. On 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 ±9.13 years (Range 23-65 years)		
Location Urban Rural	 83 41	 66.9 33.1
Educational Qualification Uneducated Primary educated Secondary Educated Graduate Post graduate	 9 8 23 43 41	 7.3 6.5 18.5 34.7 33.1
Marital status Unmarried Married Divorced	 33 81 10	 26.6 65.3 8.1
Degree of caregiver kinship First degree Second Degree Third degree	 95 24 5	 76.6 19.4 4.0
Type of caregiver Medical service Non medical service	 33 91	 26.6 73.4
Have you heard about the palliative care service Yes No If yes then What was the source of information (N=55) Family Friends Social media Physicians	 55 69 18 14 9 14	 44.4 55.6 32.74 25.45 16.36 25.45
Did anyone of hospital staff offer you palliative care service Yes No		
Did you ever accept the palliative care service Yes No	 33 91	 26.6 73.4

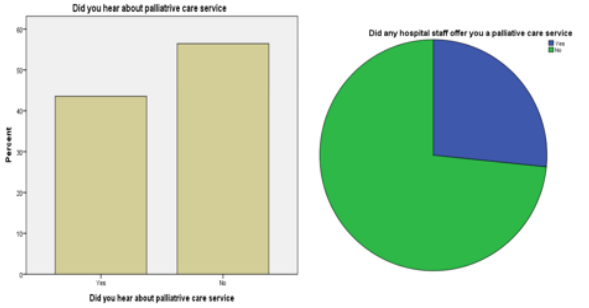

Figure 1: showing the response on the awareness question Figure 2: Showing the response on offer of service

Responses on the Knowledge questionnaires on Palliate 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 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 whether they ever refused palliative care service offered by the hospital while only 17.7% replied that they refused it and 14.5% answered that they did not refuse 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 region followed by those who mentioned customs and tradition (27.27%) and those who narrated guilt feeling (18.18%) as the main causes of the refusal. However 13.63% of the participants cited other reason 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%) were of the opinion that if Palliative care service is offered to them in future, they will accept it while 12.9% of them opined that they will reject and 8.1% did not know what to do. 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. On the likelihood of choosing the palliative care service if there is no support offered by the country (e.g No LTC facility and No home care service),the answers of seventy percent of the families was in affirmative. 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 ± Std. Dev. 1.08. (Range 1-4) More than sixty one percent of the participants (61.3%) had poor knowledge about the palliative care while the rest 38.7% of the participants had good 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 ± 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 ±Std. Dev. 1.(range1-5)		
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 graduate , secondary educated ,primary educated and the uneducated participants (41.47% vs.34.89% vs.34.79%vs.25.0% vs.22.23$, P=0.013). The good knowledge about palliative care was significantly more among the married than 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 kinship than those of first degree and 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 branch (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			
Urban	34(40.96)	49(59.04)	0.076
Rural	14(34.14)	27(65.86)	
Educational Qualification			
Uneducated	2(22.23)	7(77.77)	0.013
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			
Unmarried	11(33.33)	22(66.67)	0.032
Married	41(49.30)	40(50.70)	
Divorced	3(30.0)	7(70.0)	
Degree of caregiver kinship			
First degree	45(47.34)	50(52.66)	0.032
Second Degree	7(29.10)	17(70.90)	
Third degree	3(60.0)	2(40.0)	
Type of caregiver			
Medical service	19957.57)	14(42.43)	0.009
Non medical service	29(29.89)	62(70.11)	
Have you heard about the palliative care service			
Yes	24(44.44)	30(55.56)	0.272
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 graduate. Secondary educated, primary educated and uneducated participants (78.04% vs.76.74% vs. 65.21% vs..25% vs.22.22%. P= o.002). Good perception regarding the palliative care was significantly higher percentage of participsants who were married as compared to those who were unmarried and 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 of 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 a bit higher among the caregiver from non medical service back ground than those coming from medical background but it was not statistically significant (67.03 vs.66.63% ,P= 0.566). 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			
Urban	67(80.72)	16(19.28)	0.000
Rural	16(39.02)	25(60.98)	
Educational Qualification			
Uneducated	2(22.22)	7(77.78)	0.002
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			
Unmarried	23(69.69)	10(30.31)	0.035
Married	57(70.67)	24(29.33)	
Divorced	3(30.0)	7970.0)	
Degree of caregiver kinship			
First degree	78(82.10)	17(17.9)	0.000
Second Degree	3(12.5)	21(87.5)	
Third degree	2(40.0)	3(60.0)	
Type of caregiver			
Medical service	22(66.66)	11(33.34)	0.566
Non medical service	61(67.03)	30(32.97)	
Have you heard about the palliative care service			
Yes	42977.77)	12(22.23)	0.019
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 palliative4 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] The present study has shown that majority of the participants had positive attitude and perception towards palliative care service. A favorable attitude towards palliative care service has also been reported in the Ethiopian study [11] where 56.3% of the participants had a favorable attitude towards Palliative care. High percentage of the (90%) had shown their positive attitude towards palliative care service. In the Chinese study [12] also most participants (75.3%) had supportive attitudes towards palliative care. One Iranian study has showed the caregivers had moderate level of knowledge and attitude towards palliative care.[13] Almost ninety percent of the patients and their caregivers had positive attitude towards palliative care service in one Korean study.[13] The most cited reason for non acceptance of the palliative care service by the participant families was religious followed by customs and tradition and feeling of guilt. Religious and spiritual engagement and overwhelming negative emotions were most cited barriers to palliative care for the families in the Lebanese study also. One systematic review has also identified, Cultural, social and organizational barriers, attitudes and cultures, barriers related to the patient's family to be the main causes for refusal to accept the palliative care service provided by the hospital.[14] The good knowledge about the palliative care service was significantly higher among the family living in urban area, higher educational qualification, married, those who were third degree caregiver, and those who belonged to medical field. However in the Korean study [13], the researchers have found that opposition to palliative care was significantly associated with not thinking death should be feared, not thinking people should be remembered, and lower educational level. Financial burden as a reason was more evident in caregivers (23%) than in patients (17%) in a Chinese study.[16] The present study has also shown that the perception of the participants families changed to positivity if there is no support offered by the country (e.g No LTC facility and No home care service).

CONCLUSION:

The present study has found poor knowledge among the families of stroke patients towards palliative care which might be the reason of less utilization of this service .However majority of the participants complained that the palliative care service was not offered to them. However the perception and attitude towards the palliative care was in positive direction. There is a need of formulation and implementation of public teaching programme to teach them about the benefits of palliative care service.

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 remove 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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