

Decision-making Preferences and Levels of Anxiety and Depression in Family Members of Patients Admitted to the ICU

Dinesh Krishnamoorthy¹, Senthilkumar², Ramesh Venkataraman³, Nagarajan Ramakrishnan⁴, Vignesh C⁵

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ABSTRACT

Objectives: We aimed to study decision-making preferences and levels of anxiety and depression in family members of patients admitted to the intensive care unit (ICU).

Materials and methods: This was a prospective observational study done in the mixed medical-surgical ICU. About 127 patients were recruited in first analysis and 100 patients were recruited in second analysis. Decision-making preferences were obtained only during first analysis. Hospital anxiety and depression scale (HADS) scores were calculated during both times. Hospital anxiety and depression scale scores more than or equal to 11 were found to have anxiety and depression. We also aimed to study the association between decision-making preferences and levels of anxiety and depression.

Results: Around 27 relatives did not give consent during second time analysis. About 61% preferred shared decision-making and 27 and 12% preferred active and passive decision-making respectively. About 63% of the relatives had anxiety during first analysis and 54% had anxiety during second analysis. 66.9% had symptoms of depression during first analysis and 62% had depression during second analysis. There was a significant association between decision-making preferences and level of anxiety and depression.

Conclusion: In our study, the majority of the relatives preferred shared decision-making, and the incidence of anxiety and depression seems to be high in the Indian population. A significant association was found between decision-making preferences and level of anxiety and depression, with passive decision-making being associated with a higher risk of anxiety and depression.

Keywords: Anxiety, Decision making, Decision making preferences, Depression, Hospital anxiety and depression scale score.

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HIGHLIGHTS

Family relatives experience anxiety and depression when their loved ones get admitted to the intensive care unit (ICU). Decision-making preferences vary across countries. There is a paucity of data on the incidence of anxiety and depression and decision-making preferences in the Indian population. In this prospective observational study, we aimed to study their anxiety and depression incidence and their decision-making preferences, and as well as the association between decision-preference scales and levels of anxiety and depression.

INTRODUCTION

Admission of loved ones to the ICU and the uncertainties that follow impose a huge emotional burden on the relatives of these patients. Studies exploring anxiety and depression in the past have predominantly evaluated the spouses of the patients admitted to the ICU.¹⁻⁵ While the prevalence of anxiety varies from 35 to 81.4%,⁶⁻⁹ the prevalence of depression was found to be 15-92.4%.^{6,7,9} The main factor associated with anxiety and depression among the spouses was the fear of losing loved ones.¹⁻⁵

Various factors, including patient, family, and ICU-related factors, influence anxiety and depression among family members. Younger age, serious or chronic illnesses, and patient death are the common patient-related factors associated with emotional suffering. Spouses and female family members had a higher risk of anxiety and depression. Educational, sociocultural, and economic

¹⁻⁵Department of Critical Care Medicine, Apollo Hospitals, Chennai, Tamil Nadu, India

Corresponding Author: Dinesh Krishnamoorthy, Department of Critical Care Medicine, Apollo Hospitals, Chennai, Tamil Nadu, India, Phone: +91 9952517417, e-mail: dineshprathick2@gmail.com

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factors can also have an impact on anxiety and depression. Kumar et al. found that the incidence of anxiety and depression was high in the Indian population as compared to the American population.¹⁰⁻¹⁵

Making decisions on behalf of loved ones induces a huge psychological strain on family members, adding to their levels of anxiety.¹⁶ The extent of family member's participation in the decision-making varies among different countries.^{17,18} The studies on the impact of decision-making engagement and levels of anxiety and depression among the family members have demonstrated inconsistent results. While Tidel et al. showed that the written advance directive of the patients' wish reduced the stress among the family members, Azoulay et al. documented a higher incidence of post-traumatic stress disorder among the relatives involved in

decision-making.^{19–21} In contrast, Anderson et al., in their study, showed passive decision-making had a higher incidence of anxiety and depression among family members.^{20,22}

While some data regarding anxiety and depression amongst ICU patients' family members exists across the world, data specific to India is largely lacking. Significant differences in family structure, decision-making preferences and health care delivery exist amongst the Indian population and their effects on family member's anxiety and depression are unknown. Hence, we sought to assess the incidence of anxiety and depression and explore the decision-making preferences amongst the relatives admitted to the ICU. The association between the decision-making model and the incidence of anxiety and depression was analyzed.

MATERIALS AND METHODS

This is a prospective, observational, single-center study done in a multidisciplinary Critical Care unit of a tertiary care referral center (Apollo Main Hospitals, Chennai). The study was done for a period of 1 year starting from Aug 2021 to July 2022. Institutional ethical committee approval was obtained.

METHODOLOGY

The family members of a hundred consecutive patients admitted to the ICU for more than 48 hours in the ICU were contacted. The primary surrogate decision-maker of all patients admitted to the ICU for at least 48 hours was surveyed. Any relative, including parent, spouse, offspring, sibling, or member of the patient's household who is more than 18 years old, was included in this study. Only one family member per family was evaluated. Relatives of patients who died or got discharged from the ICU within 48 hours of admission and relatives who were unable to communicate in English were excluded from the study.

The family members were educated by a research assistant on the study process and written informed consent was obtained. Data including the demographic profile of the family member, including age, gender, educational and marital status, relationship to the patient, and mode of healthcare cost funding (self or insurance), were noted. Patient's data, including age, diagnosis, Acute Physiology and Chronic Health Evaluation IV (APACHE IV) score and source of ICU admission, were also collected.

The presence of anxiety and depression were then evaluated using the hospital anxiety and depression scale (HADS) (Annexure A). Hospital anxiety and depression scale score is a validated tool to assess anxiety and depression, and it comprises 14 questions, 7 for anxiety and 7 for depression, with a maximum score of 3 for each question and a maximum total score of 21 for each.²³ A score of 0–7 was considered normal, 8–10 was borderline, and a score of more than or equal to 11 was considered significant or abnormal (considered to have anxiety or depression) for each section.²³ The control preferences scale (Annexure B), consisting of 5 questions, was then provided to assess the decision-making preference among the relatives of patients admitted to the ICU.²⁴ It categorizes the relative's decision-making preferences into active, passive, and shared, as mentioned in Annexure B.

Hospital anxiety and depression scale score assessments were done twice independently, once on the 3rd day of ICU admission and subsequently on the 10th day or 24 hours before ICU discharge, whichever is earlier. Control preference scale was asked only once on the 3rd day of ICU admission. The research assistant was

Table 1: Patient characteristics

Age (mean/SD)	54.9/18.32
Diagnosis	
Cardio	12 (9.4%)
Respiratory	18 (14.2%)
Neurological	21 (16.5%)
Gastrointestinal	6 (4.7%)
Renal	4 (3.1%)
Sepsis	38 (29.9%)
Trauma	8 (6.3%)
Others	20 (15.7%)
Apache IV score	
Mean/SD	56.91/12.6
Minimum	30
Maximum	85
Source of ICU admission	
Direct	75 (59.1%)
Referred from other hospitals	49 (38.6%)
Ward	3 (2.4%)

available with the family member throughout the completion of the questionnaire for assistance if required.

Statistical Analysis

Sample Size Calculation: As per Anderson et al., the incidence of anxiety was found to be 42% and our study sample was calculated using the formula $n = Z^2pq/d^2$ (n = sample size; Z (standard normal variate) = 1.96; P (prevalence of anxiety) = 43% q (1- p) = 57%; (clinical allowable error) = 10%. The sample size thus calculated was 100.

Data were entered in MS Excel (spreadsheet). Data validation and analysis was done with statistical software SPSS V 25.0. All the continuous variables were assessed for the normality using Shapiro Wilk test and Q-Q plots. The continuous variables meeting the assumptions of normality were expressed as mean \pm standard deviation, and others, expressed as median (interquartile range). All the categorical variables were expressed as either percentages or proportions. Comparison of normally (Gaussian) distributed continuous variables among the categories was done by the "t" test or ANOVAs based on the number of categories present. Comparison of non-normally distributed continuous variables among the categories was done by the Mann-Whitney U test or Kruskal-Wallis H test.

All the categorical comparison was done by Chi-square test or Fisher's exact test based on the number of observations present. The p -values < 0.05 were considered statistically significant. We also did univariate and multivariate analyses to evaluate the factors associated with family member anxiety and depression.

OBSERVATIONS AND RESULTS

A total of 363 family members were screened for eligibility, and 163 patients' relatives met the inclusion criteria. Of the 163 relatives, 36 refused consent, and a total of 127 relatives were included in the study. Among those who consented, 27 relatives refused to participate in the second assessment.

Table 2: Relative's characteristics

Age (mean/SD)	41/10.9
Gender	
Male	70 (55.1%)
Female	57 (44.9%)
Marital status	
Married	115 (90.6%)
Single	12 (9.4%)
Relationship with the patient	
Children	64 (50.4%)
Spouse	39 (30.7%)
Parents	8 (6.3%)
Others	16 (12.6%)
Health care funding	
Self	63 (49.6%)
Insurance	40 (31.5%)
Third-party	5 (3.9%)
Others	19 (14.9%)

Table 3: Comparison of percentage of anxiety score between anxiety levels I and II

Anxiety	First time	Second time	p-value
Normal	18.1%	19.0%	0.302
Borderline	18.9%	27.0%	
Abnormal	63.0%	54.0%	

The baseline characteristics of the patients and their relatives included in the analysis are shown in Tables 1 and 2. The mean age of patients was 54.9 (SD 18.32) and the most common reason for ICU admission was sepsis (29.9%) followed by neurological (16.5%), and respiratory diseases (14.2%). The mean APACHE IV score was 56.9 with a standard deviation of 12.6.

The mean age of the family member in our study was 41 (SD 10.99), with 80% of our study participants aged <50 years. About 55% of the relatives were men and 45% were female, with 90% of them being married. Children of patients comprised 50% of study participants, while 30% were the spouses of the patient.

Symptoms of Anxiety and Depression

A total of 127 patients' relatives participated in the first assessment done on the 3rd day of ICU admission. Second assessment was done only in 100 study participants, since 27 refused consent. Anxiety was noted in 80 (63%) of 127 family members during the first assessment and in 54 out of 100 (54%) during the second assessment. Mean anxiety scores for the relatives who had anxiety were 14.52 (SD 2.12) during the first assessment and 13.77 (SD 2.07) during the second assessment. The anxiety level did not change significantly over the two assessment periods (p-value = 0.30) (Table 3). Depression was seen in 85 of 127 (66.7%) during the first assessment and 62 of the 100 (62%) persons during the second assessment. Mean depression scores for the relatives who had depression were 14.44 (SD 2.24) during the first assessment, and 13.83 (SD 2.13) during the second time. The depression symptoms persisted to be of the same level during both assessments (p = 0.69)

Table 4: Comparison of percentage of depression between depression 1 and depression 2

Depression	First time	Second time	p-value
Normal	12.6%	8.0%	0.687
Borderline	20.5%	30.0%	
Abnormal	66.7%	62.0%	

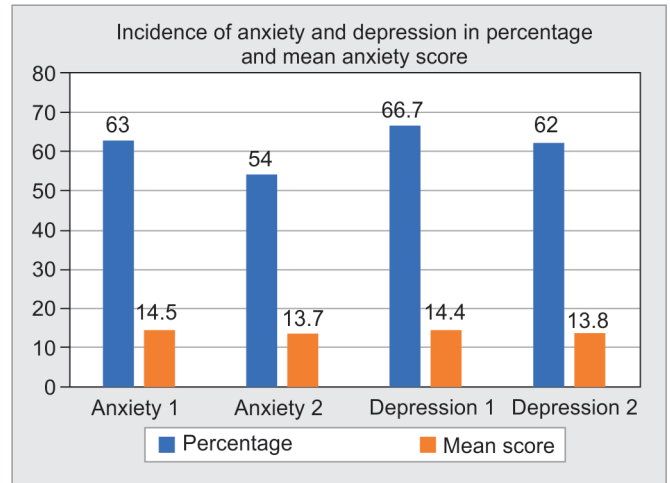


Fig. 1: Incidence of anxiety and depression and mean anxiety and depression scores during both assessments

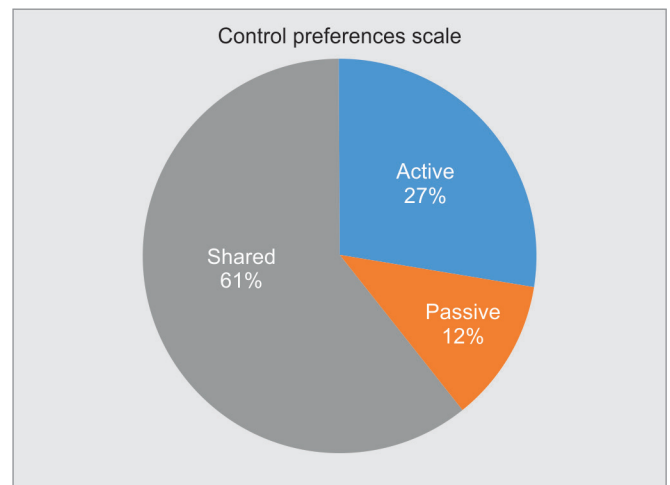


Fig. 2: Decision-making preferences of subjects according to the control preferences scale

(Table 4). The incidence of anxiety and depression and mean anxiety and depression scores during two assessments are shown in Figure 1.

Decision-making Preferences

The most preferred decision-making preference in our study was the shared model (61%) followed by active (27%) and passive (12%) respectively (Fig. 2). The incidence of anxiety among the relatives preferring shared, active, and passive decision-making was 67.5, 45.7, and 80% respectively during the first assessment (Table 5).

Table 5: Control preference scale vs anxiety 1

Decision-making preferences	Normal	Abnormal	Total	p-value
Active	19 (54.3%)	16 (45.7%)	35	0.030
Passive	3 (20%)	12 (80%)	15	
Shared	25 (32.5%)	52 (67.5%)	77	
Total	47 (37%)	80 (67.5%)	127	

Table 6: Anxiety 2 vs control preference scale

Decision-making preferences	Normal	Abnormal	Total	p-value
Active	18 (69.2%)	8 (30.8%)	26	0.011
Passive	3 (23.1%)	10 (76.9%)	13	
Shared	25 (41%)	36 (59%)	61	
Total	46 (46%)	54 (54%)	100	

Table 7: Depression 1 vs control preference scale

Decision-making preferences	Normal	Abnormal	Total	p-value
Active	15 (42.9%)	20 (57.1%)	35	0.124
Passive	2 (13.3%)	13 (86.7%)	15	
Shared	25 (32.5%)	52 (67.5%)	77	
Total	42 (33.1%)	85 (66.9%)	127	

Table 8: Depression 2 vs control preference scale

Decision-making preferences	Normal	Abnormal	Total	p-value
Active	15 (57.7%)	11 (42.3%)	26	0.009
Passive	1 (7.7%)	12 (92.3%)	13	
Shared	22 (36.1%)	39 (63.9%)	61	
Total	38	62	100	

A similar trend was noted during the second assessment with 59, 30.8, and 76.9%, among the shared, active, and passive decision-makers respectively (Table 6). The incidence of depression among the relatives preferring shared, active, and passive decision-making was 67.5, 57.1, and 86.7% respectively during the first assessment (Table 7). A similar trend was noted during the second assessment with 63.9, 42, and 92.3% depression symptoms among shared, active, and passive decision-makers respectively (Table 8). Incidence of anxiety and depression were higher in the passive group during both times of assessment. Incidences of anxiety and depression during both times of assessments among various decision-making preferences are represented in Figure 3.

The factors associated with anxiety and depression among the family members of the patients admitted to the ICU were evaluated with univariate or multivariate analysis as deemed appropriate. Variables included for univariate and multivariate analysis include patient's age, APACHE score, relative's age, gender, relationship to the patient, health care payment model, and control preferences scale. In univariate analysis for anxiety, higher APACHE score (OR 1.04, p-value 0.015), Relative's age more than 40 (OR 1.01, p-value 0.015),

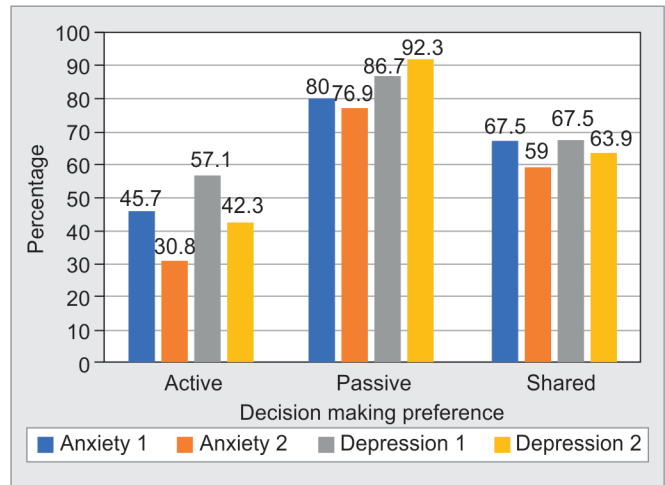


Fig. 3: Incidence of anxiety, and depression among various decision-making preferences

Table 9: Univariate and multivariate model for anxiety

Parameter	Univariate analysis		Multivariate analysis	
	OR (95% CI)	p-value	OR (95% CI)	p-value
Patient age (in years)				
20–40	Ref			
40–60	0.95 (0.36–2.52)	0.923		
>60	0.89 (0.36–2.22)	0.804		
APACHE score	1.04 (1.01–1.07)	0.011	1.05 (1.01–1.08)	0.007
Relative's age				
20–40	Ref	0.015	Ref	0.024
>40	1.01 (0.49–2.09)		2.50 (1.13–5.56)	
Relative's gender				
Male	Ref	0.972		
Female	1.01 (0.49–2.09)			
Relationship of the patient				
Children	Ref			
Spouse	1.17 (0.52–2.64)	0.709		
Parent	5.11 (0.59–43.09)	0.138		
Others	2.19 (0.64–7.53)	0.214		
Mode of payment				
Self	Ref			
Insurance	1.05 (0.47–2.36)	0.898		
Others	2.67 (0.88–8.07)	0.082		
Control preference scale				
Active	Ref		Ref	
Passive	4.75 (1.14–19.84)	0.033	5.98 (1.32–27.04)	0.020
Shared	2.47 (1.09–5.59)	0.030	2.49 (1.03–6.07)	0.044

Bold value is p-value < 0.05 is considered to be statistically significant

Table 10: Univariate analysis for depression

Parameter	Univariate analysis	
	OR (95% CI)	p-value
Patient age (in years)		
20–40	Ref	
40–60	0.67 (0.24–1.88)	0.448
>60	0.61 (0.23–1.61)	0.318
APACHE score	1.04 (1.01–1.07)	0.026
Relative's age		
20–40	Ref	0.234
>40	1.57 (0.75–3.31)	
Relative's gender		
Male	Ref	0.663
Female	0.85 (0.40–1.78)	
Relationship of the patient		
Children	Ref	
Spouse	1.15 (0.50–2.61)	0.748
Parent	4.49 (0.52–38.70)	0.172
Others	4.49 (0.94–21.45)	0.060
Mode of payment		
Self	Ref	
Insurance	0.89 (0.39–2.04)	0.790
Others	2.04 (0.67–6.21)	0.210
Control preference scale		
Active	Ref	
Passive	4.88 (0.95–24.94)	0.057
Shared	1.56 (0.69–3.55)	0.289

Bold value is p -value < 0.05 is considered to be statistically significant

shared decision-making (OR 2.47, p -value 0.030), passive decision-making (OR 4.7, p -value 0.033) were significantly associated with anxiety. In multivariate analysis also, the same factors were associated with anxiety as in univariate analysis (Table 9). In univariate analysis for depression, a higher APACHE score (OR 1.04, p -value 0.026) of the patient was associated with more depression among the relatives. No other factors were significantly associated with depression (Table 10).

DISCUSSION

Our study showed a high incidence of anxiety and depression among the study population. The passive decision-making process and higher APACHE scores of the patients were associated with the highest incidence of anxiety and depression.

Symptoms of Anxiety and Depression

Our study's incidence of anxiety and depression was high, but it is concordant with the findings of a previous study. Kulkarni et al., compared the incidence of anxiety and depression symptoms among family members of patients admitted to Indian and American ICUs.¹⁵ The study showed the prevalence of anxiety and/or depression symptoms was as high as 79% (37/47) among the Indian population as compared to 18% (8/43) among the Americans ($p < 0.0001$; RR = 4.23, 95% CI: 2.23–8.05). The reasons for such

discrepancies in results among the Indian and US populations include the higher literacy rate, fewer out-of-pocket expenses by family, and possibly better communication between healthcare professionals and family in the American ICUs as compared to their Indian counterparts. Visitation policy may differ across Indian and American ICUs and may likely influence the levels of anxiety and depression.^{15,16} Hence, actively identifying the vulnerable population and providing psychological support may reduce levels of anxiety and depression among family members of critically ill patients.

Decision-making Preferences

In our study, 61, 27, and 12% of the family members preferred shared, active and passive decision-making respectively. The findings in our study population are similar to that of Anderson et al.²⁰ To the best of our knowledge, ours is the first study to look into the decision-making preferences among the relatives of the patients admitted to the Indian ICU. Decision-making requires the health care team to offer better communication with clear and consistent information on the patient's condition to the family members and provide assistance and reassurance during the decision-making process. It is also unclear whether the family's decision-making preferences change during the patient's stay in the ICU as it was assessed only once in our study.

Association between Anxiety, Depression, and Decision-making Preferences

The prevalence of anxiety and depression was assessed among various decision-making preferences. The impact of decision-making style on the incidence of anxiety and depression can be difficult to gauge. In our study, families who preferred an active role in the decision-making had the lowest incidence of anxiety and depression, while those who preferred a passive model had the highest incidence of anxiety. Anderson et al., in his study, found a similar trend with the passive decision-making preference frequently associated with anxiety and depression.²⁰ The negative effect of anxiety and depression on the decision-making ability of the family impacts the association of decision-making style and symptoms of anxiety and depression.²⁰ Hence, it is difficult to delineate whether a passive decision-making preference is a cause or effect of anxiety and depression in family members of critically ill patients.

It was also noted that the shared decision-making preference had a higher incidence of anxiety compared to the active decision-making process. This finding is surprising and is discordant to the study results of Azoulay et al., where the incidence of post-traumatic symptoms was significantly higher among the active decision-making family members in French ICUs.²¹ Although active involvement in decision-making process of a loved one can provide a sense of control and participation to the family member, it can simultaneously increase the emotional burden by inducing self-doubt. The net effect on the occurrence of anxiety and depression is unknown. Moreover, the choice of decision-making model can be influenced by the education level of the family member, and the interplay of these two factors on the development of anxiety and depression will be difficult to predict. It is possible that a family member with a high level of education and understanding may have less anxiety and depression in an active decision-making model, while a less educated family member may have high levels of anxiety and depression when an active role is expected of them.

Healthcare professionals should be flexible in their style of decision-making and should be able to adapt to the changing needs of the family members.

The effect of decision-making preference on depression was not consistent in our study. The incidence of depression among various decision-making preferences was not significantly different during the first assessment. However, during the second assessment, passive and shared decision-making preferences had a higher incidence of depression compared to active decision-making processes.

Factors Affecting Anxiety and Depression

Various factors, including the patient's age, APACHE IV score, family member's age, gender, their relationship with the patient, and mode of payment, were studied for their relation with anxiety and depression. While the age of more than 40 of the family members was associated with a higher incidence of anxiety, a higher APACHE IV score of the patient was associated with a higher incidence of anxiety and depression. A similar association of a higher APACHE score with anxiety and depression was noted by Pochard et al.⁷ Being the spouse of the patient, female gender, and lower educational status of the decision-maker were associated with increased risk of anxiety and depression in other studies.¹⁻⁵ In our study, we could not find an association between increased risk of anxiety and depression in spouses and female gender. The possible explanation could be less involvement of spouses (only 30%) in our study.

To the best of our knowledge, our study is the first of its kind done in India to evaluate symptoms of anxiety and depression and the decision-making preferences of family members of patients admitted to the ICU. Our study strengths include an inclusive representative cohort and two measurements across the ICU stay. The study was done using a well-validated scale and measurement objective. The relationship between decision-making preferences and the incidence of anxiety and depression has not been explored in the Indian population. Our study has several limitations. The study was done in a single tertiary care hospital in India with family members who were comfortable communicating in English. Hence, the results cannot be generalized across other ICU settings. Secondly, our numbers are small, precluding us from exploring the incidence and severity of anxiety and depression over time. Decision-making preferences were evaluated only once, and preferences can likely change over time. Even though psychological counseling was offered, the actual counseling sessions and their impact were not followed.

CONCLUSION

The incidence of anxiety and depression among family members of patients admitted to our ICU seems high but comparable to other studies. Shared decision-making was the most common model in our study. Passive decision-making was associated with the highest risk of anxiety and depression. A higher APACHE IV score of the patient was associated with a higher incidence of anxiety and depression among the relatives of the patient.

ORCID

Dinesh Krishnamoorthy <https://orcid.org/0009-0008-4372-6924>

Senthilkumar <https://orcid.org/0000-0001-9117-4003>

Ramesh Venkataraman <https://orcid.org/0000-0003-1949-3979>

Nagarajan Ramakrishnan <https://orcid.org/0000-0001-5208-4013>

Vignesh C <https://orcid.org/0000-0003-2590-1756>

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ANNEXURE A

Control preferences scale

<i>Control preference</i>	<i>Item text</i>	<i>Tick any one</i>
Active	I prefer to make the decisions about which tests or treatments my loved one receives	
	I prefer to make the final decisions about which tests or treatments my loved one receives after seriously considering his/her doctor's opinion	
Shared	I prefer that my loved one's doctor and I share responsibility for deciding which tests or treatments my loved one receives	
	I prefer that my loved one's doctor make the final decision about which tests or treatments my loved one receives after seriously considering my opinion	
Passive	I prefer to leave all decisions about which tests or treatments my loved one receives to his/her doctor	

ANNEXURE B

Hospital anxiety depression scale:

Tick the box beside the reply closest to how you have been feeling in the past week. Don't take too long over your replies: Your immediate is best

D	A		D	A
		<i>I feel tense or wound up</i>		<i>I feel as if I am slowed down</i>
3	Most of the time		3	Nearly all the time
2	A lot of time		2	Very often
1	From time to time, occasionally		1	Sometimes
0	Not at all		0	Not at all
		<i>I still enjoy the things I used to enjoy</i>		<i>I get a sort of frightened feeling like "butterflies" in the stomach</i>
0	Definitely as much		0	Not at all
1	Not quite so much		1	Occasionally
2	Only a little		2	Quite often
3	Hardly at all		3	Very often
		<i>I get a sort of frightened feeling as if something awful is about to happen</i>		<i>I have lost interest in my appearance</i>
3	Very definitely and quite badly		3	Definitely
2	Yes, but not too badly		2	I don't take as much care I should
1	A little, but it doesn't worry me		1	I may not take quite as much care
0	Not at all		0	I take just as much care as ever
		<i>I can laugh and see the funny side of things</i>		<i>I feel restless as I have to be on the move</i>
0	As much as I always could		3	Very much indeed
1	Not quite so much now		2	Quite a lot
2	Definitely not so much now		1	Not very much
3	Not at all		0	Not at all
		<i>Worrying thoughts go through my mind</i>		<i>I look forward with enjoyment to things</i>
3	A great deal of the time		0	As much as I ever did
2	A lot of time		1	Rather less than I used to
1	From time to time, but not too often		2	Definitely less than I used to
0	Only occasionally		3	Hardly at all
		<i>I feel cheerful</i>		<i>I get sudden feelings of panic</i>
3	Not at all		3	Very often indeed
2	Not often		2	Quite often
1	Sometimes		1	Not very often
0	Most of the time		0	Not at all
		<i>I can sit at ease and feel relaxed</i>		<i>I can enjoy a good book or radio or TV program</i>
0	Definitely		0	Often
1	Usually		1	Sometimes
2	Not often		2	Not often
3	Not at all		3	Very seldom

Please check you have answered all the questions

Scoring:

Total score: Depression (D)-Anxiety (A)- 0-7 = Normal 8-10 = borderline abnormal 11-21 = Abnormal