Chronically Ill Patients' Family Culture Comparative Study

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Abstract: The objective of the present study was to explore the family culture of the chronically ill patients along gender and age. Family Culture is conceptualized along four domains – Transactional, Emotional, System, Growth and Community; which included ten dimensions, namely, Making Significant Decisions, Economic Transactions, Assertiveness, Emotional Atmosphere, Equality, Planning, Family Members' Growth, Coping Strategies, Social Participation and Participation in religious and cultural activities. Chronically ill patient is defined as an individual with physical or psychiatric illness who is unable to perform at least two activities of daily living - eating, toileting, transferring, bathing and dressing; or requires considerable supervision to protect from crisis relating to health and safety. Data were collected on Family Culture Inventory (FCI) with satisfactory reliability and validity, to explore 10 dimensions of family culture. The sample of 106 chronically ill patients (M=55, F=51) with age ranging from 50-95 years (three age groups - 50-59=33, 60-69=33, 70 and above=40) from Pune city, India was included in this study. The families were from middle socio-economic status. The care givers of patients gave written consent, who attempted FCI. Interviews of caregivers having highest and lowest scores on FCI (n=9) were held. The results showed that there was no significant difference in the family culture of chronically ill patients along gender and the three age groups. The interviews threw light on causes of specific family culture.

Keywords: Family Culture, Chronically ill patients

1. Introduction and review

Every family has unique strengths and vulnerabilities. This uniqueness can play a crucial role in a problem situation, like chronic illness of the family members either physical or mental. Many factors that affect the family members are relational process, individual roles and cultural issues which are specific to each family member. The family is neither a pan-human universal nor a stable or essential entity. Families are flexible, fluid and accountable.

Sternberg, et al [12] defined family culture as 'the set of attitudes, values, beliefs and behaviours shared by members of a family, communicated from generation to the next via language or some other means of communication'. It is what the members in a family believe, how they act and interact and the way they live. Specific traits, behavior patterns, attitudes and traditions are passed on through the generations of families. In 2012, the University of Virginia completed a longitudinal study and identified four types of family cultures common in America - Faithful, Engaged Progressive, Detached and American Dreamer. Each type of family culture is almost equally represented by American families from all walks of life, with roughly 20%-25% of families identifying with each type (Meleen) [6].

Chronicle illness exacts a toll on the quality of life of patients and families. The patient's illness symptoms, negative mood and need for emotional support or physical assistance are often taxing to close family members. Family members, in turn, have a strong influence on the patient's psychological adjustment and management of illness, including adherence to a treatment regimen and adoption of other health behaviors that promote functioning and recovery (Martire et al.) [5]. Patients and their relatives are also challenged in their interpersonal relationships, dealing with the stress and the demands caused by the illness.

Arumugam[1] was curious to know the overall approach and knowledge, attitude and practice of the family members towards the chronic illness of the patients in their family. The results showed that they were not satisfactory. Dobrikova[3] showed that there is a negative correlation between emotional instability level and overall quality of life. Significant correlations were found indicating the more the dying patients were satisfied with the social support that they were getting from close people, the higher the life satisfaction he/she indicated. It reveals that there is a need for a complex approach towards seriously ill patients, including social aspects of the patients' life.

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A study by Rodríguez and Gregorio [11] concluded that the length of time a patient spent in the ICU influenced relatives in some clinical variables of personality, family relationships and fear of death. Buchi[2] attempted to identify psychosocial unmet needs of breast cancer patients and relatives. She propounded a higher demand to conduct targeted support to them. The review points out the conspicuous absence of research about patients' family environment or culture.

2. Operational definitions of the key concepts

Chronically ill patient: An individual who is unable to perform at least two activities of daily living, such as eating, toileting, transferring, bathing and dressing, or requires considerable supervision to protect from crisis relating to health and safety for at least 24 hours/ one day due to severe impairment concerning mind. Minimum 3 months of chronicity period (duration) was considered.

The three criteria of labelling chronicle illness were -a. inability to perform at least two activities of daily living out of the five - eating, toileting, transferring, bathing and dressing; b. requires considerable supervision to protect from crisis relating to health or c. requires considerable supervision to protect from crisis relating to safety.

Three levels of chronicity were decided along with how many criteria are present in a patient. Low level, if one criterion is reached; moderate level, if two criteria are reached; and high level, if all the criteria are reached.

Family culture: The 'Family Culture Model(FMC)' in the present study includes four domains and 10 dimensions, which gather information about the significant practices at home revealing specific cultures. It was devised in 2016 [9][10]and revised in 2023 [8]. Here is the figural presentation and description of the four domains with 10 dimensions FMC.

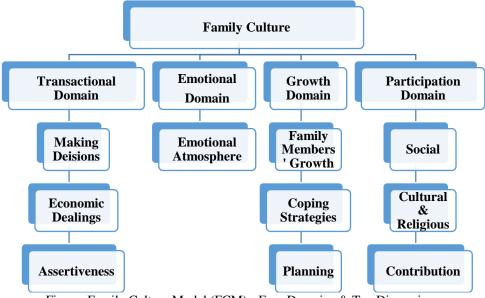


Figure: Family Culture Model (FCM) - Four Domains & Ten Dimensions

Interpersonal Transactions Domain

- 1. Decision Making :Who makes significant family decisions, how, how far in consensus & beneficial to everyone, etc.
- 2. Economic Dealings: Cautiousness, independency, transparency in financial matters; property ownership
- 3. Assertiveness: Family members' respect for oneself as well as for all others
- 4. Emotional EnvironmentDomainUsually dominance of which feelings & emotions

Growth Domain

- 5. Family Members' Growth :Every family member learns something new, advances along own goals
- 6. Coping Strategies: Strategies of facing difficult family situations & problems, effective handling of stress
- 7. Planning: Foreseeing & working about future tasks & responsibilities

Participation in Community Domain

8. Social Participation :Excursions; attending & participating in social events, lectures, seminars, activities; visiting museums, spectacular places; etc.

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9. Cultural&Religious Participation :Appreciating plays, movies, recitals, concerts, etc.; performing religious activities

10. Social ContributionDomain :Engagement in social work, donations, etc.

3. Methodology

3.1 Objective

The objective of this comparative study is to explore Family Culture of Chronically Ill Patients along gender and age.

3.2 Hypotheses

Being an exploratory study, null hypotheses are stated.

Hypothesis One: There will be no significant gender difference in family culture of chronically ill patients.

Hypothesis Two: There will be no significant difference in family culture of chronically ill patients in the three age groups: 50-59, 60-69 and 70 and above.

3.3 Sample

The sample was purposive. In all, 106 chronically ill patients (M=55 or 52%, F=51) with age ranging from 50-95 years [three age groups 50-59 (n=33), 60-69 (n=33), and 70 and above (n=40)]were included in the sample. Table 1 displays age and gender-wise distribution in numbers and percentages of the 106 chronically ill patients. The sample was drawn from hospitals, care giving institutes and support groups. The sample resided in Pune city, Maharashtra, India. The families had middle socio-economic status.Care givers of nine chronically ill patients with extreme performance on Family Culture, were interviewed to probe into the results.

Patients' Age \rightarrow Gender \rightarrow	50-59 Years	60-69 Years	70 & Above Years	Totals
Males	18 (17%)	19 (18%)	18 (17%)	55 (52%)
Females	15 (14%)	14 (13%)	22 (21%)	51 (48%)
Totals	33 (31%)	33 (31%)	40 (38%)	106

Table 1: Age and gender-wise distribution of the chronically ill patients (n=106)

The sample sizes in the cells along gender and age are comparable for analysis along the objectives.

The of chronically ill patient's distribution along other variables was as follows - types of illness (physical 62% or mental38%), levels of chronicity (low 19%, moderate 32% and high 49%), the three durations of chronicity (three months to one year26%, one to three years 32% and more than three years 42%), educational qualifications (illiterate 1%, educated 99%), care giving places (home 15% or day-care/hospital85%), marital status (married 63% or unmarried, widow, other 37%) and family types (joint 42% or nuclear58%) respectively.

Since the chronically ill patients could not and did not directly participate in this study, the sample of the respondents, who were care givers of chronically ill patients, is also stated. There were 33% male and 67% females. The respondents were 36.8% from 50 -59 years age group, 36.8% from 60-69 years age group, and 26.4% above 70 years. Education of the respondents was as: 13.2% up to S. S. C., 9.4% under graduation, 51.9% degree-graduation 17.9% post- degree graduation and 7.5% post- degree graduation and additional education.

3.4 Instruments

The instruments used were - Information of the Project, Informed Consent Form, Personal Data Sheet, Interview Schedule and Family Culture Inventory (FCI)[4].FCI is a self-report inventory developed by JPIP to assess 10 dimensions of 'Family Culture' following standard procedure. The inventory and response sheet are separate. The minimum and maximum possible scores for total FCI are 70 and 280 respectively. The minimum possible score for each dimension of FCI is 7 and maximum possible score is 28.

The test – re-test reliability of FCI was computed with a gap of four to nine weeks for 55 adults and – aspirant administrative officers, school teachers, psychologists and lay persons from Pune city. They were from middle socio-economic status, with age ranging from 25 to 75 years and had varied educational and experience

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backgrounds. The coefficient of correlations for test – re-test reliability of 10 dimensions of FCI ranged from .66 to .80, which are satisfactory. The content validity was established during developing the inventory.

Since this was individual data collection at varied places related to some stressful situation, an 'Examiner Record Sheet' supported FCI, which reported about respondents' general mood, cooperation, time taken, doubts asked, comfort of venue, etc. It helped in judging consistency and soundness of the responses on FCI.

4. Data collection and treatment, and Results

Data were collected on one on one basis by trained psychologists with due confidentiality and assuring comfort of the respondents.

4.1 Chronically Ill Patients' Family Culture: Descriptive Statistics on FCI

It is worth to present and inspect descriptive statistics of FCI for all the 106 chronically ill patients. Table 2 presents means and SDs on the 10 dimensions of Family Culture Inventory (FCI), namely, making significant decisions (MD), economic transactions (ET), assertiveness (AS), emotional (EM), equality (EQ), planning (PL), family members' growth (GR), coping strategies (CP), social participation (SO), participation in participation in religious and cultural activities (RE). Minimum and maximum obtained scoresalso are mentioned.

$\begin{array}{l} \text{Statistics} \rightarrow \\ \text{FCI} \\ \text{Dimensions} \downarrow \end{array}$	Means	SDs	Minimum obtained scores	Maximum obtained scores	
MD	22.08	2.83	13.0	28.0	
ЕТ	22.95	3.19	16.0	28.0	
AS	22.59	3.27	15.0	28.0	
EM	23.13	3.50	14.0	28.0	
EQ	21.92	2.74	14.0	27.0	
PL	23.07	3.81	13.0	28.0	
GR	23.01	2.96	15.0	28.0	
СР	22.63	2.42	15.0	28.0	
SO	21.97	3.88	13.0	28.0	
RE	20.42	4.74	10.0	28.0	

Table 2: Means, SDs, minimum and maximum obtained scores on FCI of chronically ill patients (n=106)

On the 10 dimensions of FCI means range from 20.42 (RE) to 23.13 (EM), SDs from 2.42 (CP) to 3.88 (SO), minimum obtained score 10 (RE) and maximum obtained score 28 on all except EM (27) dimension. The minimum possible score for each dimension of FCI is 7 and maximum possible score is 28. The values suggest that the data is quite homogeneous and negatively skewed lying in the fourth quartile, showing very high family culture along the 10 dimensions of family culture of chronically ill patients.

4.2 Comparison of Family Culture along Chronically Ill Patients' Gender

Table 3 presents the values of chronically ill patients for male (M) and female (F) groups on10 dimensions of FCI and Part II. As shown in the Table 3, the dimension wise values of males and females are presented to see whether there is gender wise significant difference in family culture and care giving family burden of chronically ill patients. All the means lie in the upper quartile, suggesting negative skewness. The SDs indicate homogeneity on FCI for this sample.

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Table 3: Means, SDs, t and P values of on FCIof chronically ill patients along gender (n=106; M=5	5, F=51)
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FCI Total	Gender	Means	SDs	t Values	P Values
\rightarrow Dimensions \downarrow					
MD	Male	22.13	2.84	0.19	0.85
	Female	22.02	2.84	0.17	0.05
ЕТ	Male	23.13	3.01	0.59	0.56
	Female	22.76	3.40	0.37	0.50
AS	Male	22.34	3.15	-0.85	0.40
	Female	22.88	3.42	-0.05	0.40
EM	Male	23.00	3.32	-0.41	0.68
	Female	23.28	3.72	-0.41	0.08
EQ	Male	21.61	2.78	-1.23	0.22
	Female	22.26	2.68	-1.23	0.22
PL	Male	22.98	3.77	-0.24	0.81
	Female	23.16	3.88	-0.24	
GR	Male	23.20	3.02	0.69	0.49
	Female	22.80	2.90	0.09	0.49
СР	Male	22.73	2.19	0.45	0.65
	Female	22.52	2.66	0.45	
SO	Male	22.20	3.76	0.63	0.53
	Female	21.72	4.02	0.03	0.55
RE	Male	20.45	5.18	0.05	0.96
	Female	20.40	4.25	0.05	0.20
	Female	97.92	21.24		

The dimension wise values are: for male group, mean was 22.13, SD was 2.84 on making significant decision dimension and for female group, mean was 22.02, SD was 2.84 and t value was0.19(p<0.85 NS). This result indicates that there was no significant difference between males and females on making decisions in families of chronically ill patients.

On economic transactions, mean was 23.13 and SD was 3.01 for male group and for female group, mean was 22.76, SD was 3.40 and t value was 0.59 (p < 0.56 NS). This result indicates that there is no significant difference between males and females on economic transactions in families of chronically ill patients.

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On assertiveness, mean was 22.34 and SD was 3.15 for male group and for female group, mean was 22.88, SD was 3.32 and t value was-0.85(p < 0.40 NS). This result indicates that there was no significant difference between males and females on assertiveness in families of chronically ill patients.

On emotional dimension of family culture, mean was 23.00 and SD was 3.42 for male group, for female group, mean was 23.28, SD was 3.72 and t value was -0.41(p < 0.68 NS). This result indicates that there was no significant difference between males and females on emotional dimension in families of chronically ill patients.

On equality dimension, mean was 21.61 and SD was 2.78 for male group and for female group, mean was 22.26, SD was 2.68 and t value was - 1.23(p < 0.22 NS). This result indicates that there was no significant difference between males and females on equality dimension in families of chronically ill patients.

On planning dimension, mean was 22.98 and SD was 3.77was for male group and for female group, mean was 23.16, SD was 3.88 and t value was-0.24(p < 0.81 NS). This result indicates that there was no significant difference between males and females on planning dimension in families of chronically ill patients.

On family members' growth dimension, mean was 23.20 and SD was 3.02 for male group and for female group, mean was 22.80, SD was 2.90 and t value was 0.69(p < 0.49 NS). This result indicates that that there was no significant difference between males and females on family members' growth dimension in families of chronically ill patients.

On coping strategies dimension, mean was 22.73 and SD was 3.02 for male group and for female group, mean was 22.80, SD was 2.90 and t value was 0.45(p < 0.65 NS). This result indicates that that there was no significant difference between males and females on coping strategies in families of chronically ill patients.

On social participation dimension, mean was 22.20 and SD was 3.76 for male group and for female group, mean was 21.72, SD was 4.02 and t value was 0.63(p < 0.53 NS). This result indicates that there was no significant difference between males and females on social participation dimension in families of chronically ill patients.

On participation in participation in religious and cultural activities, mean was 20.45 and SD was 5.18 for male group and for female group, mean was 20.40, SD was 4.25 and t value was 0.05(p<0.96 NS). This result indicates that there was no significant difference between males and females on participation in religious and cultural activities in families of chronically ill patients.

As mentioned in Table 4, the results indicate that there was no significant gender difference in any of the 10 dimensions of family culture f chronically ill patients. Thus, hypothesis one is retained.

4.3 Comparison of Family Culture along Chronically III Patients' Age

Table4presents the values of means, SDs and ANOVA of chronically ill patients in three age groups on10 dimensions of FCI. All the means lie in the upper quartile, suggesting negative skewness. The SDs indicate homogeneity of performance on FCI for this sample.

Patients' Age \rightarrow	50 to 60 yrs (n=33)		60 to 70 y	rs(n=33)	70 yrs and above (n=40)		
$\begin{array}{l} \text{Statistics} \rightarrow \\ \text{FCI} \\ \text{Dimensions} \downarrow \end{array}$	Means	SDs	Means	SDs	Means	SDs	P values Between Groups
MD	22.64	2.29	21.36	3.43	22.20	2.62	.18
ЕТ	22.82	2.95	22.52	3.60	23.43	3.03	.46
AS	22.76	2.53	22.42	3.47	22.60	3.70	.92
EM	22.91	2.87	23.33	3.82	23.15	3.77	.89
EQ	22.03	2.98	22.00	2.44	21.75	2.83	.89
PL	22.91	3.08	23.45	4.38	22.88	3.91	.78
GR	23.12	2.38	23.48	2.98	22.53	3.34	.38

Table 4: Means, SDs and P values on FCI of chronically ill patients along age groups (n= 106)

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СР	22.09	2.13	23.09	2.16	22.70	2.78	.24
SO	21.48	3.54	22.27	3.69	22.13	4.33	.68
RE	19.52	4.38	20.97	4.30	20.73	5.35	.41

The dimension wise values for three groups are presented as: on making significant decision dimension, mean was 22.6, SD was 2.29 for 50-59 age group, for 60-69 age group mean was 21.36, SD was 3.43, for 70 and above age group, mean was 22.20, SD was 2.62 and p value was0.18(p<.18 NS). This result indicates that

the three groups were not significantly different on decision making in families of chronically ill patients.
On economic transactions, mean was 22.82, SD was 2.95 for 50-59 age group, for 60-69 age group, mean was 22.52, SD was 3.60 and for 70 and above age group, mean was 23.43, SD was 3.03and p value was.46 (p< .46 NS). This result indicates that the between group differences of the three age groups were not significant on economic transactions in families of chronically ill patients.

On assertiveness, mean was 22.76 and SD was 2.53 for 50-59 age group, for 60-69 age group, mean was 22.42, SD was 3.47, for 70 and above age group mean was 22.60, SD was 3.70 and p value was .92(p < .92 NS). This result indicates that the between group differences of the three age groups were not significant on assertiveness dimension of family culture of chronically ill patients.

On emotional dimension, mean was 22.91 and SD was 2.87 for 50-59 age group. For 60-69 age group, mean was 23.33, SD was 3.82 and for 70 and above age group, mean was 23.15, SD was 3.77 and p value was .89(p < .89 NS). The result indicates that the between group differences of the three age groups were not significant on emotional dimension in families of chronically ill patients.

On equality dimension, mean was 22.03, SD was 2.98 for 50-59 age group. For 60-69 age group, mean was 22.00, SD was 2.44, and for 70 and above age group, mean was 21.75, SD was 2.83 and p value was .89(p < .89 NS). This result indicates that the three groups were not significantly different on equality in families of chronically ill patients.

On family members' growth dimension, mean was 23.12, SD was for 50-59 age group 2.38, for 60-69 age group mean was 23.48, SD was 2.98, for 70 and above age group mean was 22.53, SD was 3.34 and p value was .38(p< .38 NS). This result indicates that the between group differences of the three age groups were not significantly different on family members' growth dimension in families of chronically ill patients.

On coping strategies, mean was 22.09, SD was 2.13 for 50-59 age group, for 60-69 age group mean was 23.09, SD was 2.16, for 70 and above age group mean was 22.70, SD was 2.78 and p value was .24(p<.24NS). This result indicates that the between group differences of the three age groups were not significant on coping strategies dimension in families of chronically ill patients.

On social participation dimension, mean was 21.48, SD was 3.54 for 50-59 age group, for 60-69 age group mean was 22.27, SD was 3.69, for 70 and above age group mean was 22.13, SD was 4.33 and p value was .68(p < .68 NS). The result indicates that the between group differences of the three age groups were not significant on social participation dimension in families of chronically ill patients.

On religious and cultural and cultural activities, mean was 19.52, SD was 4.38 for 50-59 age group, for 60-69 age group mean was 20.97, SD was 4.30, for 70 and above age group mean was 20.73, SD was 5.35 and p value was .41(p < .41 NS). This result indicates that the between group differences of the three age groups were not significant on participation in religious and cultural activities in family culture of chronically ill patients.

As mentioned in Table 5, the results indicate that there was no significant difference in the 10 dimensions of family culture of chronically ill patients in the three age groups: 50-59, 60-69 and 70 and above. Thus, hypothesis two is also retained.

Nine care givers were interviewed on telephone, who scored either very low or very high on FCI. Contents of interviews are interpreted in discussion.

5. Discussion

To include the entire family as a factor in health enlarges the perspective from the traditional concentration on the individual apart from social context.

The distribution of scores on FCIwas negatively skewed in this study. It denotes that the families were high on all the dimensions of family culture of the chronically ill patients. It may be a typical nature of the families in Pune with middle socio-economic status. Family members are burdened economically and emotionally. There is social burden also as due to time pressure, they have to hold social interactions to certain extent and a few may shun the responsibilities of the patients.

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The present study revealed that there were no significant gender and age group differences in the family culture of chronically ill patients. Both the hypotheses in this study are retained. These are ideal results. We expect that equal responsibility should be felt for male and female patients, especially when they are chronically ill. At this point, a need is felt to explore this for other places also. They may be rural residency, other cities and other states in India as well as for other countries. Moos and Moos [7] explored the family culture of adults and children with similar findings for age levels. It focused on the perception of the family members, understand the type of family environment and assessing the family problems.

The type of illness and family culture of chronically ill patients was also studied. It showed that there was no difference in the family culture of chronically ill patients with respect to the type of illness. The reason for this finding can be mentioned that family members are getting aware about the support systems and intervention programs available as per the type of illness and the care taking burden for both the illness types was same.

Another noteworthy finding came up in this study is about the chronically ill patients' family culture with respect to level of chronicity. The level of chronicity showed significant difference on the dimensions of family culture - equality, planning family members' growth, coping strategies, social participation and participation in religious and cultural activities. On other four dimensions a consistent increase in means along higher levels of chronicity is noticed, except for making significant decision dimension. There was a decreasing trend in family culture dimensions as the level of chronicity increased. This could be due to the care giving responsibilities increase and more family members are involved as the level of chronicity increases. Buchi[2] propounded a higher demand to conduct targeted support to the breast cancer patients and relatives.

It was found that duration of illness did not show significant difference in the family culture of chronically ill patients. May be the recovery pace is more important than the duration, which calls for further exploration. Martire et al (2004) found that family members have a strong influence on the patient's psychological adjustment and management of illness, including adherence to a treatment regimen and adoption of other health issues that promote functioning and recovery.

Family culture of chronically patients was compared for their five educational levels. It showed that there was no significant difference in family culture of chronically ill patients along the five educational levels. Irrespective of level of education, the families with chronically ill patients exhibited high family culture. The family culture of chronically ill patients was explored with reference to the two care giving places - Home and Hospital/Day care. The results revealed that there was no significant difference on family culture, except for social participation dimension of chronically ill patients along care giving places. So, by inspecting the two means, we arrive at a conclusion that families participated in social activities more when chronically ill patients were at home as compared to when they were in some other institutions like day-care centres or hospitals. Managing stressors related to time and care giving may be easier at home as compared to at some institution. The comparative results about marital status and about family type of chronically ill patients showed no significant difference on family culture.

Nine care givers were interviewed on telephone, who scored either very low or very high on FCI. The high scorers on FCIhad good communications in the family members; they had practice of making decisions about patients' treatment after discussions; they respected each other. The family members in families shared responsibilities of the patient, had due financial planning and were positive about chronically ill patient's illness. These features were missing in families having low scores on FCI. Management of time and money was a problem for them. Need of interventions for family members of chronically ill patients, is evident through the inspection of the contents of the interviews.

When Ruth Weissberger's, three predominant family patterns, namely Perfect, Chaotic and Overprotective Families, are applied for labelling these results, we may state that the high and low scoring families on FCI and II respectively are 'Perfect' and the low and high scoring families on FCI and II respectively are 'Chaotic' ones. (Source: Research with Patricia Fallow & Maria Root, 120 Linden Oak, Rochester, NY, 14625, 716-385-1950; In Thompson, R. A., 1996). We need to micro-examine the data to label families as 'Overprotective' on these lines.

We can consider findings of this study with sample size as 106 chronically ill patients, who are above 50 years of age, have middle socio-economic status and are from Pune city in relation to same population size having ball-park guess as 1, 00,000. The sample size of this study is 0.1% that of the population. In this light, the obtained results need to check in replicable studies. Similarly, to throw more light on these findings, more studies with varying samples are essential. Implications of this study are interventions to improve Family Culture may be executed based on needs analysis derived from the results. Solutions for problems in caring the patients may be suggested and tried.Medical social workers, psychologists and other support workers will benefit from these findings.

6. Conclusions

- The distribution of chronically ill patients is negatively skewed on FCI measuring family culture showing high level.
- There was no significant gender difference in the 10 dimensions of family culture of chronically ill patients.
- There was no significant difference in 10 dimensions of family culture f chronically ill patients in the three age groups: 50-59, 60-69 and 70 and above.

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Author Profile



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