APPROACH TOWARDS CHRONIC ILL PATIENTS – THE FAMILY'S PERSPECTIVE

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ABSTRACT:

Background: *Despite the increasing prevalence of chronic diseases and co-morbidities, the essential attributes of the patient and family approach of care, are still to be defined in terms of disease-specific approaches. Effective improvements in family-based approach will require alternative ways of thinking about chronic care design and practice.*

Objectives: *The study was designed with the objectives of assessing the approach of the family members towards chronic disease persons in their family.*

Methodology: *The study was conducted as a community based cross sectional study during November and December 2013, in a nearby village among the families affected from any of the chronic disease. The study participants were selected randomly from the community and they were interviewed using a preformed pretested questionnaire after getting the informed consent. The questionnaire includes general information about the family and the person affected from the chronic disease, money spent, duration of disease, approach of the family members towards the diseased person. The data were analyzed using EPI-INFO software version 3.5.1.*

Results: *A total of 105 persons were interviewed, among whom 44 (41.9%) were suffered from Diabetes Mellitus, 14 (13.3%) were having Hypertension, tuberculosis 9 (8.6%), Osteoarthritis 8 (7.6%) and the remaining had co-morbid chronic diseases. Among the family members 82 (78.1%) had satisfactory attitude towards the diseased persons. Around 52 (49.5%) ignore the diseased persons for celebrations, 35 (33.3%) ignore them for decision making, 23 (21.9%) gave a separate room and 18 (17.1%) felt that treatment expenditure as waste of money. As far as the knowledge, attitude and practice were concerned, attitude and practice were associated ($p < 0.05$) with lesser age group and nuclear family using chi-square test.*

Conclusion: *Our study had concluded that the overall approach and knowledge, attitude and practice of the family members towards the chronic illness patients in their family was not satisfactory.*

Keywords: *Family practice, chronic illness, economic burden, family approach*

INTRODUCTION

The commission on Chronic Illness in USA has defined "chronic diseases" as comprising all impairments or deviations from normal, which have one or more of the following characteristics like, permanent, leave residual disability, caused by non – reversible pathological alteration and may be expected to require a long period of supervision, observation and care[1]. In short, there is no international definition of what duration should be considered long term, although many consider that chronic conditions are generally those, that have had a duration of at least 3 months[2,3]. Worldwide there were 36 million deaths due to non communicable diseases in 2008 and it is projected that annually it may be 52 million in 2030[4]. Chronic non communicable diseases are assuming increasing importance among the adult population in both developed and developing countries. India is experiencing a rapid transition with a rising burden of Non communicable diseases causing significance morbidity and mortality, both urban and rural population. In low and middle income countries non communicable diseases will be responsible for three to five times as many disability adjusted life years and deaths as compared to other conditions[5]. Owing to rising trend and effects of chronic illnesses, there is a need to study the trend of family members approach towards the patients with chronic illnesses in their family. Very few studies in developing countries like India have been done in this aspect, so this study was designed to explore the attitudes and approaches of the family members towards chronic illness patients.

AIMS AND OBJECTIVES

1. To assess the different types of chronic illnesses among the family members of the study participants
2. To estimate the economic burden faced by the family in caring the chronic illness patients
3. To identify the level of knowledge, attitude and practice of the family members towards chronic patients in their family
4. To analyze the approach of the family members towards the chronic patients in their family

METHODOLOGY

This study was done as a community based cross sectional study in the villages of our field practice area of department of community medicine among the families of chronic disease patients. There are three village panchayat in our field practice area, Kelambakkam, Thaiyur and Pudhuppakam. One of

the village panchayat that is Pudhuppakam was selected randomly by simple random method which has got two small villages namely Pudhuppakam and eshankadu villages with 778 and 260 households and total population was 4538. All the households were visited for a period of 2 months regularly with the help of health inspector and local health volunteer for the study. At the end of the study the investigator surveyed almost all the houses. During the household visits the household in which a chronic illness patients lives was included in the study after getting the informed consent. If any of the houses was locked during the first visit, second and third visits were made within next 15 days. One person from the family or the caretaker of the chronic diseased patient was interviewed using the preformed pre tested questionnaire. The questionnaire included the general socio demographic profile of the family, chronic disease diagnosed, duration of the disease, money spent for treatment, knowledge, attitude and practice of the family members towards the chronic disease, questions on approaches towards the chronic disease patients. Most of the study participants responded to the survey except very few. The data were entered in the MS excel sheet and analysis was done using SPSS software 16 version. Ethical considerations: As far the study design is concerned because of its cross sectional nature and questionnaire based study without any intervention, there are very least ethical issues possible in this study.

RESULTS

A total of 105 study participants were interviewed of which 50 (47.6%) were females and 55 (52.4%) were males. Majority 83 (79) belonged to nuclear family whereas the remaining 22 (21%) were from joint family and 50% of the families income was above INR 10,000 and above. (Table – 1) Around 42% of the study participant's family had a patient with type 2 diabetes, 14 (13.3%) were having hypertension, tuberculosis 9 (8.6%), osteoarthritis 8 (7.6%). The other chronic illnesses were bronchial asthma, coronary artery disease, and hypothyroidism. Approximately 10% of the family had multiple chronic health problems in the same individual, while 20% of the families had patients with disability. The duration of the chronic illness was 1 to 5 years among 70.5% (74), 5 to 10 years among 29 (27.6%) and more than 10 years among 2 (1.9%) of the study participant families. The families spend money for treatment of illnesses up to 500 INR per month among 37%, 500 to 1000 INR among 44% and more than 1000 INR among 19% as expenditure. The study participants of 8.6% felt that treating for chronic illnesses is actually an economic loss for the family. (Table – 2) It is surprising that only 38% of the family members aware about the nature of the chronic illness but satisfactory attitude and practice were shown more than the knowledge aspect towards the chronic illnesses patients in their family.

APPROACH OF THE FAMILY MEMBERS

As far as the approach of the family members was concerned, the approaches like fear 74 (70.5%), angry 46 (43.8%), depression 59 (56.2%), not sharing common properties with the patient 36 (34.3%), ignore the patient during celebrations 52 (49.5%), ignoring for important decisions 35 (33.3%), discriminating by giving a separate room 23 (21.9%), hesitation in introducing them before the guest 20 (19%), feeling uncomfortable because of frequent complaints from the patient 53 (50.5%), forcing the patient to eat food items or unable to prepare special food separately for the chronic patient 57 (54.3%). (Table – 3)The attitudes of the family members towards the expenditure spent for the treatment and management on the chronic patients were very much surprising that they felt like waste of money 17%, unsatisfied 13%, costly 15% and 36% said that it somewhat manageable. (Table – 4) As far as the overall knowledge, attitude and practice were concerned the younger age group and patients in nuclear family were lacking when compared to higher age group and joint families and it was statistically significant. But there was no gender difference in relation to knowledge, attitude and practice in care to chronic patients (Table – 5) and (Table 6) depicts the approach towards the chronic ill patients and various socio demographic variables.

Table 1: General Socio-Demographic Profile of the Study Participants

Variable	Frequency	Percentage
Gender		
Female	50	47.6
Male	55	52.4
Occupation		
Professional	23	22%
Skilled and Unskilled	35	33.3
Unemployed	47	44.7
Type of family		
Joint	22	21
Nuclear	83	79
Family Income per month		
Up to 5,000	18	17.1
5,000 to 10,000	35	33.3
Above 10,000	52	49.6

Table 2: Distribution of Chronic Illnesses and Economic Burden

Disease affected	Number	Percentage
Diabetes mellitus & others (hypertension, asthma, osteoarthritis)	16	15.2%
Diabetes mellitus only	44	41.9%
Hypertension & others (osteoarthritis & asthma)	17	16.3%
Respiratory diseases (tuberculosis & asthma)	14	13.3%
Osteoarthritis & asthma	10	9.5%
Others (CAD, hypothyroidism)	4	3.8%
Disability		
Yes	21	20
No	84	80
Duration		
1 to 5 years	74	70.5
5 to 10 years	29	27.6
More than 10 years	02	1.9
Money spent per month (INR)		
Up to 500	39	37.1
500 to 1,000	46	43.8
More than 1,000	20	19.1
Economic loss		
Yes	9	8.6
No	96	91.4

Table 3: Approach of the Family Members towards Chronic Illness Patients in Their Family

Approach towards the patients	YES	NO
Do you have any fear regarding his/her chronic illness?	74(70.5%)	31(29.5%)
Do you get angry on this patient for his/her small mistakes:	46(43.8%)	59(56.2%)
Is there any depression in your family because of his/her illness	59(56.2%)	46(43.8%)
Do you share common household properties with the patient	69(65.7%)	36(34.3%)
Do you ignore him/her for any celebration because of his/her illness	52(49.5%)	53(50.5%)
Have you lost hope on the patient regarding his/her recovery from that illness	41(39%)	64(61%)
Do you ignore the diseased person for making any important decision in your family	35(33.3%)	70(66.7%)
Did you allot any separate room for him/her in your house, due to the disease	23(21.9%)	82(78.1%)
Do you have any hesitations in introducing him/her to your guest	20(19%)	85(81%)
Do you have any discomfort because of frequent complaints of the patient regarding his/her illness	53(50.5%)	52(49.5%)
Was he forced by your family to eat food items that he/she does not like, because of his/her illness	57(54.3%)	48(45.7%)

Table 4: Attitude of the Family Members towards the Expenditure

What do you think about his/her (Patient's) treatment expenditure?	Frequency	Percentage
Costly	16	15.3%
Manageable	38	36.2%
Waste of money	18	17.1%
No idea	7	6.7%
Satisfied	12	11.4%
unsatisfied	14	13.3%

Table 5: Knowledge, Attitude and Practice versus Socio Demographic Variables

Variables	**Knowledge**			**Attitude**			**Practice**		
	Satis-factory	Unsatis-factory	P value	Satis-factory	Unsatis-factory	P value	Satis-factory	Unsatis-factory	P value
Age group									
20 to 40 years	31	39		62	8		54	16	
41 years and above	9	26	0.088	20	15	0.001	18	17	0.013
Gender									
Female	22	28		39	11		35	15	
male	18	37	0.315	43	12	1.000	37	18	0.835
Type of family									
Joint	5	17		14	8		8	14	
nuclear	35	48	0.138	68	15	0.083	64	19	0.001

Note: Chi-square tests was done.

Table 6: Approach towards Chronic Ill Patients and Socio Demographic Variables

	Age group		**Gender**		**Type of family**	
	20 to 40 years	41 years & above	female	male	Joint	nuclear
Do you have any fear regarding chronic illness?						
Yes	52	22	31	43	17	57
No	18	13	19	12	5	26
Do you get angry on patient for small mistakes?						
Yes	28	18	20	26	11	35
no	42	17	30	29	11	48
Is there any depression in your family because of illness?						
Yes	36	23	26	33	11	48
no	34	12	24	22	11	35
Do you share common household properties with patient?						
Yes	45	24	36	33	11	58
No	25	11	14	22	11	25
Do you ignore him/her for celebration because of illness?						
Yes	35	17	25	27	14	38
No	35	18	25	28	8	45
Have you lost hope regarding recovery from illness?						
Yes	23	18	16	25	13	28
No	47	17	34	30	9	55
Do you ignore the diseased person for making important decision in family?						
Yes	22	13	12	23	8	27
no	48	22	38	32	14	56
Did you allot any separate room in your house due to the disease						
Yes	16	7	11	12	9	14
no	54	28	39	43	13	69
Do you have any hesitations in introducing before guest?						
Yes	15	5	9	11	5	15

no	55	30	41	44	17	68
Do you have any discomfort because of frequent complaints by the diseased person?						
Yes	34	19	18	35	13	40
no	16	16	32	20	9	43
Was he forced to eat food items?						
Yes	39	18	26	31	12	45
no	31	17	24	24	10	38

DISCUSSION

Our study had explored the various aspects and perception of the family members towards the caring of the chronic illness patients in their families. The overall result of the study was not satisfactory, in the sense that the majority of the chronic ill patients were not taken care of properly by the fellow family members. Surprisingly, there was no gender difference found in approach towards the chronic ill patients in this study. There are very much lack of literature on this chronic disease effects on the family members in developing countries. Our country is now bearing the burden of both communicable and non communicable diseases which is pressurizing right from the individual level to the country level. Addressing the chronic management of chronic disease patients in countries like India still we are in rudimentary stage. Many of the developed countries suggested and implemented several measures at the family level to improve the outcomes of chronic disease.

The research studies from developed countries showed clearly that emotional climate of the family directly affects the patient's physiologic systems and many other studies reported that the family hostility and criticism also affects the chronic ill patients. [6,7, 8 and 9] This family hostility almost exists in all the families; even in some of the families the chronic patients were isolated from the complete regular family environment. This was clearly evident in our study. Studies from developed countries suggested that family closeness, problem focused family coping skills, clear family organization and decision making and direct communication among family members regarding the chronic disease serve a protective function against the negative disease management outcomes. [10 – 14] Similarly the following family characteristics that increase the risk of poor disease management outcomes include: intrafamilial hostility, criticism, and blame; psychological impact related to the initial diagnosis and treatment of the disease; extrafamilial stress; lack of an extrafamilial support system. [15 – 18]Although enhancing curative and preventive factors remains an important goal of interventions, the best clinical outcomes appear to be achieved by reducing family risk factors.[19 and 20]The important factors to be focused immediately were creating awareness about the disease to the patient and family members, a comprehensive plan for approach towards the chronic illness patients and reducing the other risk factors in the family like family hostility, criticism and blame which were encountered in our study. Despite the increase in prevalence of chronic conditions and co morbidities, the essential characteristics of the structure and delivery of the care services at the community and family level itself is very much lacking and which should be back bone of the chronic illness management.

CONCLUSIONS

Our study had explored the various perceptions and attitudes of the family members which were not satisfactory towards the caring of chronic illness patients. The approaches can be gradually modified by intensive counseling of the family members and the caregivers of the chronic illness patients.

Strengths of this study: This study had explored various comprehensive aspects of the chronic illness effects on the family members like psychological changes, economic burden, social issues and in addition to that it had also explored and analyzed the knowledge, attitude and practice aspects towards the chronic illness patients by the family members which will pave the way for family based counseling to improve the outcomes of the chronic ill patients.

Limitations: Study design – the study was done as a questionnaire based descriptive cross sectional study which will nullify the effect of follow up and to foresee the outcomes in future.

Acknowledgments: We sincerely thank the College Chairperson Prof Dr. Mala PhD, the Dean Dr. Shantha MD PhD for their immense support in carrying out this research project.

REFERENCES:

1. Commission on Chronic illness (1956) Chronic Illness in the US. Vol 2, Care of the long term patient. Cambridge, Mass, Harvard University Press.
2. WHO (1981). Health for all Sr No.4, p. 80
3. Wilson, R.W. and T.F. Drury (1984) Annual review of public health,5: 83-106 .
4. WHO (2011), Global status report on non – communicable diseases 2010.
5. WHO (2012), World health statistics 2012.

6. JK, Glaser R, Cacioppo JT, et al. Marital conflict in older adults: endocrinological and immunological correlates. Psychosom Med 1997;59:339-49.
7. BN, Cacioppo JT, Kiecolt-Glaser JK. The relationship between social support and psychological processes: a review with emphasis on underlying mechanisms and implications for health. Psychol Bull 1996;119:488-531.
8. R, Carstensen LL, Gottman JM. The influence of age and gender on affect, physiology and their interrelations: a study of long term marriages. J Person SocPsychol 1994;67:56-8.
9. C, Crowley M. The development of emotion regulation: effects on emotional state and expression. In: Blechman E, ed. Emotions and the family: for better or for worse. Hillsdale, NJ: Lawrence Erlbaum Associates; 1990;53-74.
10. L, Nishimoto R, Mediansky L, Mantell J, Hanovitch M. Social relations, social support, and survival among patients with cancer. J Psychosom Res 1992;36:531-41.
11. V, Elad D. The impact of mothers' sense of empowerment on the metabolic control of their children with juvenile diabetes. J PediatrPsychol 1998;23:239-47.
12. K, Rosengren A, Wilhelmsen L. Lack of social support and incidence of coronary heart disease in middle-aged Swedish men. Psychosom Med 1993;55:37-43.
13. N, Hislop GT, Mears B, Kan L. Effects of social relationships on survival for women with breast cancer: a prospective study. SocSci Med 1991;33:177-83.
14. AG, Faust DS, McKee L, Padman R. Outcome of short-term hospitalization for children with severe asthma. J Allergy ClinImmunol 1992;90:66-75.
15. M, Goldberg S. Treatment characteristics of congenital heart disease and behavior problems of patients and healthy siblings. J Pediatr Child Health 1997;33:219-25.
16. A, Stuber M, Barakat L, Meeske K, Guthrie D, Meadows A. Predicting posttraumatic stress symptoms in mothers and fathers of survivors of childhood cancer. J AmerAcad Child Adolesc Psychiatry 1998;37:823-31.
17. PL, Peterson RA, Weihs KL. Dyadic relationship conflict, gender and mortality in urban African American hemodialysis patients. In press.
18. K, Fisher L, Baird MA. Families and the management of chronic disease. Washington, DC: Institute of Medicine, National Academy of Sciences. In press.
19. B, Margolin G. Analysis of the association between marital relationships and health problems: an interactional perspective. Psychol Bull 1992;112:39-63.
20. CK. High blood pressure and marital discord: not being nasty matters more than being nice. Health Psychol 1991;10:155-63.