



Quality of life in mothers of children with cerebral palsy

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ABSTRACT

Cerebral palsy is the mental disorder that affects movement and body position due to brain damage happened before the baby was born, at birth or as a baby. It is considered as a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to nonprogressive disturbance that occurred in the developing fetal or infant brain. Cerebral palsy is the most common of all childhood disabilities affecting most of the population. The prevalence rate is estimated as 2.5 per 1000 but may vary from 1 to 6 per 1000.

Objective of the study: To evaluate the quality of life of caregivers (mothers) of children with cerebral palsy.

Material and Method: A Descriptive Cross sectional study design was used to evaluate the quality of life of caregivers or mothers of children with cerebral palsy among 100 caregivers from ACELP. Only female caregivers were included in this study. A non-probability convenient sampling was used. Data was obtained by using SF36.

Results: The overall response rate was 100%. Most of the caregivers show mild to moderate level of mental illness regarding their social, physical, emotional domain. Most of the caregivers were disturbed socially around 56%, physical functioning limitation 45%, physical health disturbance 41%, fatigue 55.6% etc.

Conclusion: The study concluded that most of the caregivers have mild to moderate level of disturbance in all domains of life. Physical health was not satisfactory among caregivers and mothers of those children which have the problem of cerebral palsy.

INTRODUCTION

1.

CEREBRAL PALSY

Definition: The actual meaning of CP (cerebral palsy) is "Paralysis of brain". CP is defined as "an abnormal movement of muscles and body posture caused by brain injury that happens prior to delivery/during birth or after birth. It is the collection of long term disablement that affects the gross and fine motor activities of children along with the postural abnormalities which also hinders the way of living of these children. It is also contemplated as non-degenerative disablement that happens during the early phases of growth cycle. "The motor disorder of cerebral palsy is frequently accompanied by disturbances of sensory response, observation, cognition, communication and behavior, seizure and secondary MSK problems. (1)

2.

TYPES OF CP (CEREBRAL PALSY)

There are three basic types of cerebral palsy.

2.1 Spastic

In this type of CP child has muscle tightness or muscle stress that causes parts of the body to be rigid. Movements of the body are sluggish and discomfited. In most of cases the position of the head triggers unusual positions of the upper and lower limbs and body posture. The rigidity increases when the child is disturb or agitated or when the body is in definite positions. The pattern of rigidity varies significantly from child to child. It can be further divided into diplegic, hemiplegic or quadriplegic. (1)

2.2 Uncontrolled Movements or 'Athetoid'

These are considered as lazy, quick and jerky movements involving the whole body of the child. There is no known cause of abnormal movement patterns of all limbs and trunk. The quickest and the abrupt movements of whole body increases while child attempts to walk or do any sort of physical exertion. Abnormal synergic pattern rapidly comes and goes while performing any movement and motor activity. Due to the abnormal firing of nerve conduction, there is loss of coordination and balance so child attempts to fall again and again. When talk about the intellectual level of such children, there is no disturbance of intellectual level of children with disability. They have good communication skills while interacting with society. (2)

2.3 Ataxic Gait

Due to lack of coordination and poor body control, they acquire abnormal gait pattern that is called as "Ataxic gait" and also they are not able to perform normal activities of daily living properly. Difficulties occurs to achieve different milestones. The abnormal coordination persists throughout the whole life and child does not attempt to adopt sitting and standing balances. (2)

3. PREVALENCE OF CEREBRAL PALSY

CP has various sort of prevalence among the children of Pakistan. It is prevalent among the young age of children. 1% to 5% birth from 1000 is thought to be a disable child with cerebral palsy. The mean occurrence is only 3% per thousands of children.(3)

4. QUALITY OF LIFE

It is defined as the generalized state of mind and body's good health (4). A child with physical or mental disablement, has poor impression on the society and also directly on their siblings and family members. A care taker whether he or she is a family member or non-family member has poor impact of that disabled child on their level and standard of life. Cerebral palsy is the combination of various defects in the body which provide hindrance in gross motor functions. The overall societal involvement of a disabled child remains closed for overall life span. All the domains of a mother disturb badly which involve the psychological and psycho-social health. The interaction of caregivers with society also gets disturbed. The financial issue grown up more and more as the time passes. The overall summation involves the disruption of overall status of life of mother (5)

Children having such disability are thought to be handled with difficulty. They put an impact on the overall status of life style. Reduction in the health of a mother occurs both mentally as well as physically. Most of the problems which are often seen in the caregivers of disabled children are: poor psychological health, deteriorate physical health and lack of sleep. Handling a child with CP is a hectic activity and it puts an overall impression on the health of a person. The big and the major impact which affects the life of a caregiver is the detachment from social circle. Most of the parents lost their job or leave their job due to the disabled children at their home. So collectively we can say that such individuals have poor social standard. (6)

The constant progress in the child's wellbeing and growth is according by confusion, culpability and disgrace, which lowers the QOL of parents. Practicing rigorous anxiety frequently leads to feeling of defenselessness and abandon, and as a result it may leads to the feeling of parental ineptitude. Exhaustion and

frequent isolation lower confrontation to strain and bother the normal parameter
of emotions. (7)

5. DATA COLLECTION TOOL

A short form SF-36 is used for the data collection. It is commonly used to assess the related quality of life and can be used to show differentiation between subjects and other contant diseases with different severity levels of the same condition. This Short Form 36 was originated from the General Health Survey of the Medical Outcomes Study by Stewart and colleagues (1988). This form consists of 8 subscales. That includes:

1. Limitation of physical activity resulting from health problems;
2. Limitation of social activity caused by physical or emotional problems;
3. Physical health problems limiting usual activities.
4. Physical discomfort
5. Psycho-social wellness.
6. Laziness or less interest in work.
8. Generalized Healthy ideas. (8)

6. RELATED RISK FACTORS

There are number of relative risk factors that induce the cause of cerebral palsy which can be prenatal or postnatal. CP is the combination of various defects including motor, sensory, behavioral, cognitive etc. It doesn't promote or get severe day by day because it is persistent disorder not degenerative. The major symptom which is usually prominent is the seizure disorder. Most of the children with cerebral palsy have history or complaints of seizures. It is estimated that most of the population have prevalence of cerebral palsy by the ratio of 3 out

of 1000 births. Pakistan is also full of having number of cases in the hospitals and rehabilitation centers. A study was conducted on the prevalence of CP child so it was estimated that out of 100%, 75% babies were diagnosed with CP. Most of the children were at drastic state with having abnormal tone, poor postural pattern, development of synergies and poor motor control. Various risks factors are associated with having cerebral palsy like; the premature delivery, poor dietary patterns during pregnancy, infection to mother, alcohol, multiple pregnancies at a time and also the genetic factor. The CP is categorized as; spastic with abnormal synergic patterns and tones. Spastic CP is further sub- divided into different sub-classes like; monoplegic, diplegic, paraplegic, hemiplegic and tetraplegic. Flaccid CP is further categorized as ataxic and athetoid with abnormal and un-usual movements of the whole body. (9)

7. SYMPTOMS OF CP

CP is considered as the motor activities limitation that affects almost all the active participation of a child toward his or her role play in self maintenance. The abrupt causes of cerebral palsy involve the prenatal and post natal stage of early life. It's not a progressive disorder it's just called the early or childhood stroke. The life expectancy of such individuals leads up to the adulthood. A study on the prevalence of child or individual with cerebral palsy were estimated in United states as four lakh which is growing more and more as the time passing. Most of the individuals and children with cerebral palsy lead to the permanent cut off of their role in their society so most of the medical or rehabilitative therapies are given at their homes. Most of the medical studies have been reported most of the pain in individuals with cerebral palsy. The painful condition varies only from sub-acute to chronic condition. Among all other anomalies in individuals with

cerebral palsy, fatigue or generalized reduction in the endurance is also a major course of issue. Generalized fatigue leads to the chronic painful situation of the body, reduction in the motor activities, and reduction in the overall status and standard of life with poor quality regarding their psycho-motor and psycho-social involvement. The major symptoms in the individuals with cerebral palsy are also the generalized weakness. Muscular weakness leads that individual toward the poor coordination and action of motor activities, such weakness is caused due to many reasons including, abnormal connection between central and peripheral nervous system, tightness of overall musculature of the individuals, incensement in the abnormal muscles firing and normal tone. As the motor activities of reduced then generalized body weakness causes in an abnormal pattern. As the physical activities reduction happens in the special children, there is the origin of respiratory complications. Most of the children die due to their respiratory complications. SOB is preliminary symptom of respiratory complication. All the pulmonary complications cause the disruption in the normal sleeping patterns leading to the generalized weak body and early stamina reduction. Such abnormal symptoms are caused due to their wheel chair roundedness. Postural deformities also persist in the children including the lateral deviation of spine in C or S shape. Along with the all symptoms, the ophthalmologist also receives many CP children which have the visual difficulties or disabilities involving nystagmus, atrophy of the optic nerves, inflammation of retina of eyes, cataracts or bipolar visual problem. Cognitive issues also pay their contribution to the overall pathological condition of the body. Cognition and the learning disabilities also a major issue in children with CP. There are many less evidences which support the cognitive and learning disabilities among the children with CP. Most of the studies which have been done in the past on the CP children did not work

completely on the psychological and psycho-social impairment of children with CP, despite that most the studies focuses on the symptoms and physical disabilities of special children. Symptomatic studies are mostly done which includes the variation of different symptoms as the time passes. All the symptoms including musculo-skeletal, cardiopulmonary, ophthalmological and ocular, genito-urinary etc, badly affect the life of a child having the cerebral palsy. (10)

CHAPTER-II LITERATURE REVIEW

A study was done to assess the status of lifestyles of family member who have CP children and to assess the effect of behavior problems on their life by Romeo DM (2010). It showed the poorer QOL scores of their parents. (12)

A study was done in 2013 by Barasan A, to review the status and standard of life and lifestyle barriers of caregivers of CP children concluded that the quality of life of most of the caregivers was affected.

Deprived psychological status, and increased burden than the parents of healthy children. (13)

Another study was done by Dehghan L in 2016, to assess the status of parents who have children with CP showed that the mothers of children with CP suffers from poor physical and mental health. (14)

A study has been done in 2004 by Eker L, to evaluate the standard and barriers of life of parents having CP child compared with parents of children with other health problems concluded that the quality of life of mothers having CP child is quite different in comparison with parents having child with other health problems. (15)

Another study was done to assess the QoL and mental health in mothers of CP children in 2005 by Ones K, showed that QoL in mothers of CP child is poorer than that of mothers having healthy child. (16)

A study was done in 2013 by Yilmaz H, to evaluate lifestyle barriers and problems in caregivers and parents having children with cerebral palsy. Most of

the caregivers and parents have poor status of life. They mostly have anxiety and mental distress which is the prevalent and most dominant feature in their life. (17)

A study was carried out in 2013 by Noemi Guillamon, to evaluate the QoL and psychological status of parents and caregivers of CP children. It showed that QoL and psychological status are highly affected in mothers of CP children. (18)

Another study was done to assess the general health of parents of CP children in 2004 by Brehaut JC. It showed that care giving can directly or indirectly affect the health of caregivers. (19)

Another study has been done to assess the mental health and lifestyle of parents of CP children in 2012 by Marcia A Z, indicated that caregivers have severe anxiety and hopelessness. They also have poor quality of life and their social life is limited. (20)

A study was carried out in 2010 by Davis E, to evaluate the QOL of parents of children with CP. This study indicated that having a child with CP can adversely affect the parent's life. (21)

A study was carried out to evaluate the strain experienced by the parents of CP children in 2015 by Dambi JM, that showed that the burden on caregivers has increased and most of the parents have poor life. (22)

A study has been carried out to assess the standard of life of Caregivers of CP children in 2011 by Deepthi K. It showed that the Caregivers of CP children have lower HRQoL and altered mental health when compared to those children with minor health problems. (23)

A study has been carried out in 2015 by Dambi JM, to assess the psychological status and QoL of caregivers of persons with disabilities, that indicated that psychological status and the QoL can be affected in caregivers of persons with disabilities. (24)

Another study was done in 2011 by Okurowska ZB, to evaluate QoL of parents having CP children. The result indicated that quality of life was poor in parents of children with cerebral palsy as compared to the parents having healthy children. (25)

A study was carried out to evaluate the health status and lifestyle of parents of children with cerebral palsy by Parvinder Riana in 2005 which concluded that the mental and general health of caregivers was highly affected by children health. (26)

Another study was carried out to assess the general well being of mothers of CP children by Samira borzoi in 2014. This research found that the lifestyle and the health of caregivers of CP children was highly influenced by the health of their children. (27)

Similar study has been done to evaluate lifestyle of mothers of CP children by Cezanne Oliveira in 2010 that found that lifestyle and social well being of mothers of CP children was highly affected. (28)

Another study was carried out to assess quality of life of caregivers of children with cerebral palsy (CP) by Elena M. Marrón, Diego R, Mercè B., Rubén N., Noemí Guillamón in 2012. It showed that the health of caregivers of CP child was highly affected. (29)

Another study was done to assess health and lifestyle of mothers of children and adolescents with health problems by Eliza C. Leila R., Mirian S. in 2010, which indicated that the life and the social well being of the mothers and caregivers was highly affected. (30)

A study was done to assess the lifestyle of mothers of a Child with Cerebral Palsy by Modesta P, Noemi G, Elena M, Diego R, Merce B in 2013, which showed that child's altered level of self-efficacy and social support are the factors that are consistently related with anxiety and depression in parents with CP child. (31)

A study was carried out to evaluate the QoL in mothers of children with down syndrome by Saied A., Firoozeh S. and other associates in 2016 which showed that there were certain factors that significantly affect the life of mothers. (32)

Another study was done to assess the lifestyle of mothers of children with cerebral palsy and their age matched controls in 2014 by BOA Adegoke, O O Adenuga, O A Olaleye and others. This study showed that life of parents of a child with CP directly affect the QoL and health of the mothers. (33)

A study was carried out to assess the QoL of parents of CP patients and their caregivers in 2014-2015 by Fadwa M, S Mohammed, Saud M Ail which indicated that many feasible changes can be adopted to improve the QoL of CP patient and their caregivers. (34)

A study was done to observe the depression and QoL in mothers of CP child by Dr Shradda Divan, Dr Hetal Chovatiya, Dr Jasmine Divan in 2011 that

showed that 70% of mothers of children with CP were suffering from mild to moderate level of depression and their QoL was affected.(35)

A study was done to evaluate the QoL of Iranian mothers of CP child compared with mothers of healthy child in 2015 by Zarah Ahmadizadeh, Mehdi Rassafiani, Majid Mir Mohammad Khani. It showed that QoL of mothers with CP child is adversely affected.(36)

Similar study was done in 2015 by R.Sridhar,Dr D Nirmala to assess QoL among the caregivers of CP children and it was found that parenting a child with CP needs an ocean of patience , talent, courage and energy.(36)

Another study was carried out to assess the QoL of caregivers of CP children in Ireland by byrne MB, Hurley DA, Dayl L, Cunningham CG in 2010.That study showed that the QoL of caregivers of CP child is remarkably lower.(37)

A study was carried out to assess the mental health of mothers of CP children and other related factors in turkey by Dellialioglu S, Kaya K, Ozel S, Gorgulu G in 2009, that indicated that the level of depression in caregivers of CP children is higher than that of healthy children.(38)

A study was done to explore the level of fatigue in parents of children with cerebral palsy, and to determine its association with depression and quality of life (QoL) in 2016 by Garip Y, Ozel S, Tunser OB, kilinc G, Seckin F, Arazsil T.It was found that the fatigue levels of mothers with CP children are higher than those with the healthy children and association with the depression and deterioration in QoL in terms of physical, social and emotional functioning. (39)

1. OBJECTIVES OF THE STUDY

To assess the quality of life of mothers having child with Cerebral Palsy.

2. RATIONALE OF THE STUDY

There is a considerable lack of research on the QoL of mothers having CPchild. To improve the quality of life of mothers in all aspects, concerned authorities have to work on the child physical commitment and on the entire family's lifestyle especially the mother, because she is the one who is mostly involved in caring of child.

3. SIGNIFICANCE OF THE STUDY

This study provides us a profound knowledge about the problems of the mothers of CP child and how the disease affects the families. More advanced programs and good quality care must be delivered to caregivers. With these interventions and knowledge of all aspects of these mothers' lives, health care professionals can act not only on the child's lifestyle, but also on the whole family routine, especially on the mother's life, who is most involved person in this process.

CHAPTER III MATERIALS AND METHOD

1. STUDY DESIGN

It was a cross-sectional study.

2. SETTING

Data was collected from Institute of Child Development, Association of children with emotional and learning problem (ACELP)

3. DURATION OF STUDY

6 months after the approval of synopsis

4. SAMPLE SIZE

100

5. SAMPLING TECHNIQUE

Non-probability convenient sampling

6. SAMPLE SELECTION

6.1 Inclusion Criteria

- Diagnosed and registered cases of CP in ACELP.
- Children affected with CP (congenital and acquired cases).
- Mother of CP child living in extended and nucleated system.
- CP Children between 3-15 years.

6.2 Exclusion Criteria

- Mothers not willing to participate.
- Children other than Cerebral Palsy
- Children less than 3 years and more than 15 years of age
- Participants who were not able to comprehend to complete the Questionnaire.

7. DATA COLLECTION TOOL

A short form SF-36 was used for the data collection. This Short Form 36 was originated from the General Health Survey of the Medical Outcomes Study by Stewart and colleagues (1988). This form consists of 8 subscales. That includes:

1. Limitation of physical activity resulting from health problems;
2. Limitation of social activity caused by physical or emotional problems;
3. Physical health problems limiting usual activities.
4. Physical discomfort
5. Psycho-social wellness.
6. Laziness or less interest in work.
8. Generalized Healthy ideas. (8)

8. DATA COLLECTION PROCEDURE

The data was collected from Institute of Child Development, Association for Children with Emotional and Learning Problem by conducting face to face interviews of mothers who fulfilled the inclusion criteria and questionnaires were filled.

9. DATA ANALYSIS PROCEDURE

Data was analyzed by using Statistical Package for Social Sciences (SPSS) version 20. Descriptive statistics; frequency and percentage, mean and standard, deviation was used.

10. BUDGET

10000 Rs.

11. ETHICAL CONSIDERATION

- Participants were informed about the research before filling the questionnaire.
- Permission was taken from all participants regarding usage of data for research and publication purpose.
- All the personal information of the participants was kept confidential.

CHAPTER IV RESULTS

A total of 100 participants were included in this study in which all were females. The age of participants was not mentioned but after data collection the candidates were ranging from 18 to 67 years old. 19 % females were ranging from 18 to 27 years old, 52 % females were 28 to 37 years old, 24 % females were 38 to 47 years old, 3% females were 48 to 57 years old and only 1% females were ranging from 58 to 67 years old.

Now move toward the physical functioning of the mothers. 25% females were Assumed that their physical functioning was limited a lot most of the times, 57% Of the mothers described that they have limited physical functioning but not fully, And 15% of the female were not having any functional limitation at all due to their Special children.

When data was collected on the basis of limitation due to physical health in physical activities. 41% women have no complaint regarding their limitation due to physical activity and health, 52 % women or mothers were having the limitation but very less limitations in physical activity due to health, 53% of mothers were have moderate limitation of physical activities due to health and 54% women have difficulty in performing tasks and functions due to health.

Such mothers greatly affected by emotional stress. So the findings regarding emotional problem includes here were: 65 % mothers were greatly affected due to emotional stress so that they decrease the time of work, 47% of others were moderately affected while 45% of mothers were have limitations in working due to emotional problems.

When asked about fatigue or energy level of mothers the answers were as: 32% mothers said that they feel full of pep some of the time, 10% said all of the time while only 2% said that they feel pep none of the time. 24% mothers said that they feel a lot of energy a good bit of time, 21% said most of the time 16% said a little bit of time and only 4% said that they doesn't feel energetic at all. 28% mothers said that they worn out a little bit of time, 5 % said all of the time and 11 % said that they don't get worn out at all. 29% mothers said that they feel tired some of the time, 8% said most of the time, 6% said all of the time and 11% said none of the time.

When mothers were asked about emotional well being they answered accordingly: only 26% mothers answered that they were a nervous person for a good bit of time and 10% said that they don't get nervous at all. 28% mothers think that some of the time they feel so down that nothing could cheer them up on the other hand 25 % females said that they felt calm and peace some of the time and 14% said that they don't feel calm and peace at any time. 26% mothers said that they have been a happy person a good bit of time while 10% said that have not been a happy person at all.

When mothers were asked about their social life 48% mothers answered that due to their physical and emotional problems their social functioning was slightly affected. 32% said moderately affected, 4% said severely affected and only 1% said that it was very severely affected and 13% mothers said that there was no impact of physical and emotional problems on their social functioning.

In this section 28% mothers said that their social activities like visiting friends or relatives were affected most of the time, 20% said some of the time, 17% said a little bit of time, 16% said all of the time while 17% said that it was not affected at all.

When asked about pain during past 4 weeks 34% mothers answered that they had mild pain, 24% reported moderate pain, 21% reported very mild pain, 10% reported severe pain, only 3% reported very severe pain while 8% mothers reported no pain.

Regarding pain interference with normal work 37% mothers reported that pain interfere with normal work moderately, 26% said it affected little bit, 18% said quite a bit, 7% said it affected extremely, while 11% said it didn't interfere.

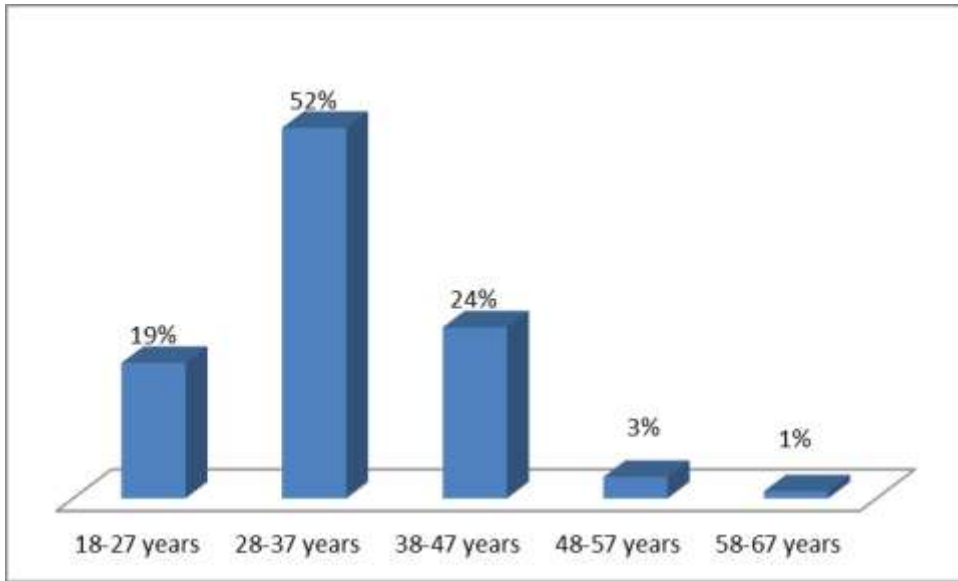
Asking about their general health (A) 46% mothers thought that they had good health, 18% said very good health, 15% said fair, 8 % said that they had excellent health, while only 5% thought that they had poor health.

When asking about general health (B) 38% mothers said that it is mostly true that their health is excellent, 39% mothers said that they expect their health to get worse, 40% mothers said that they know that they are as healthy as anybody while 25% mothers said that it is mostly true that it seems to get sick little easier than other people.

According to mean of subscales physical functioning was 45.75, role limitations due to physical health was 41.25, role limitations due to emotional problems was 44.33, energy/fatigue was 55.65, emotional well being was 54.16, social functioning was 56.37, pain was 55.15, general health 52.1.

Table IV-1: Age of Mothers

	Age of mothers	Freq	%
1	18-27 years	19	19
2	28-37 years	52	52
3	38-47 years	24	24
4	48-57 years	3	3
5	58-67 years	1	1



Graph IV-1: Age of Mothers

Table IV-2: Physical Functioning

	Physical functioning	Yes, limited a lot		Yes, limited a little		No, not limited at all	
		Freq	%	Freq	%	Freq	%
1	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	25	25	57	57	15	15
2	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	23	23	59	59	16	16
3	Lifting or carrying groceries	31	31	45	45	21	21
4	Climbing several flights of stairs	34	34	45	45	20	20
5	Climbing one flight of stairs	8	8	52	52	39	39
6	Bending, kneeling, or stooping	26	26	57	57	16	16
7	Walking more than a mile	30	30	50	50	18	18
8	Walking several blocks	38	38	42	42	18	18
9	Walking one block	27	27	48	48	23	23
10	Bathing or dressing yourself	11	11	53	53	25	25

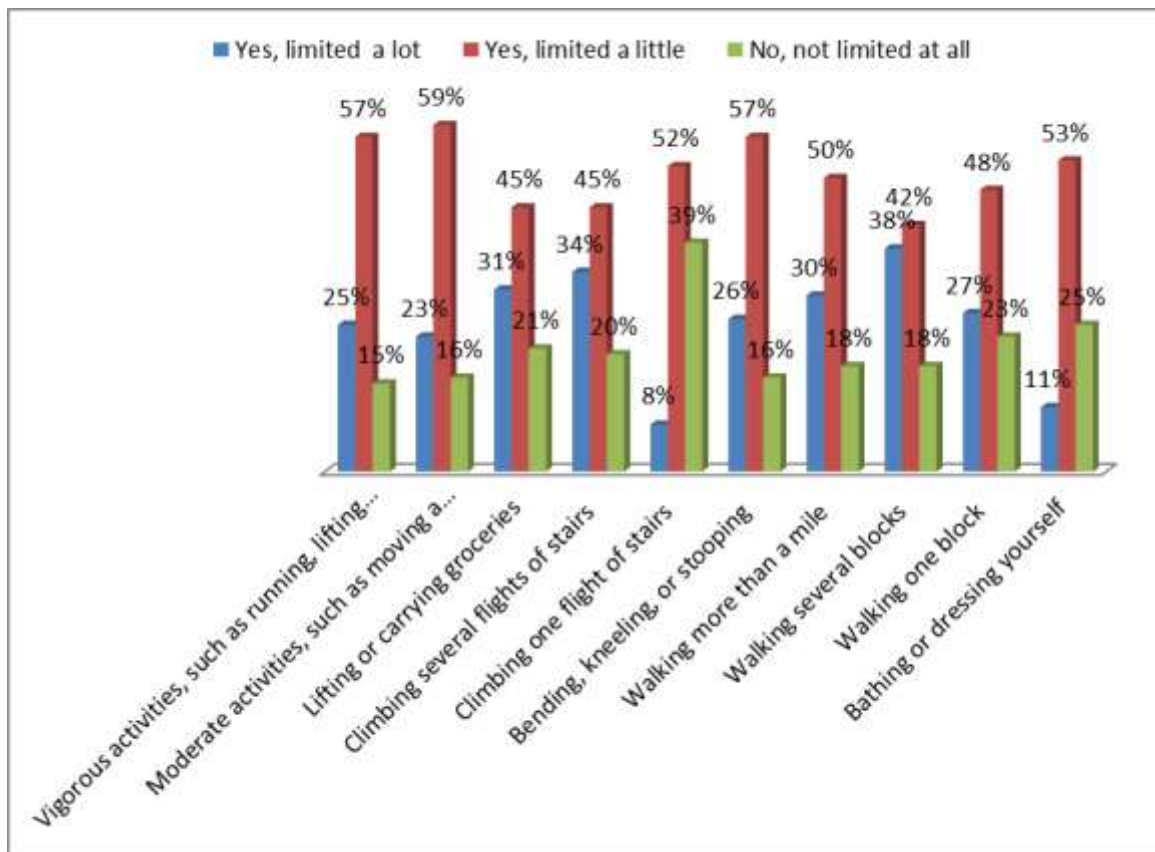


Table IV-2: Physical Functioning

Table IV-3: Role of limitation due to Physical health

S.no	Role limitations due to physical health	Yes		No	
		Freq	%	Freq	%
1	Cut down the amount of time you spent on work or other activities	56	56	41	41
2	Accomplished less than you would like	52	52	45	45
3	Were limited in the kind of work or other activities	53	53	43	43
4	Had difficulty performing the work or other activities (for example, it took extra effort)	54	54	40	40

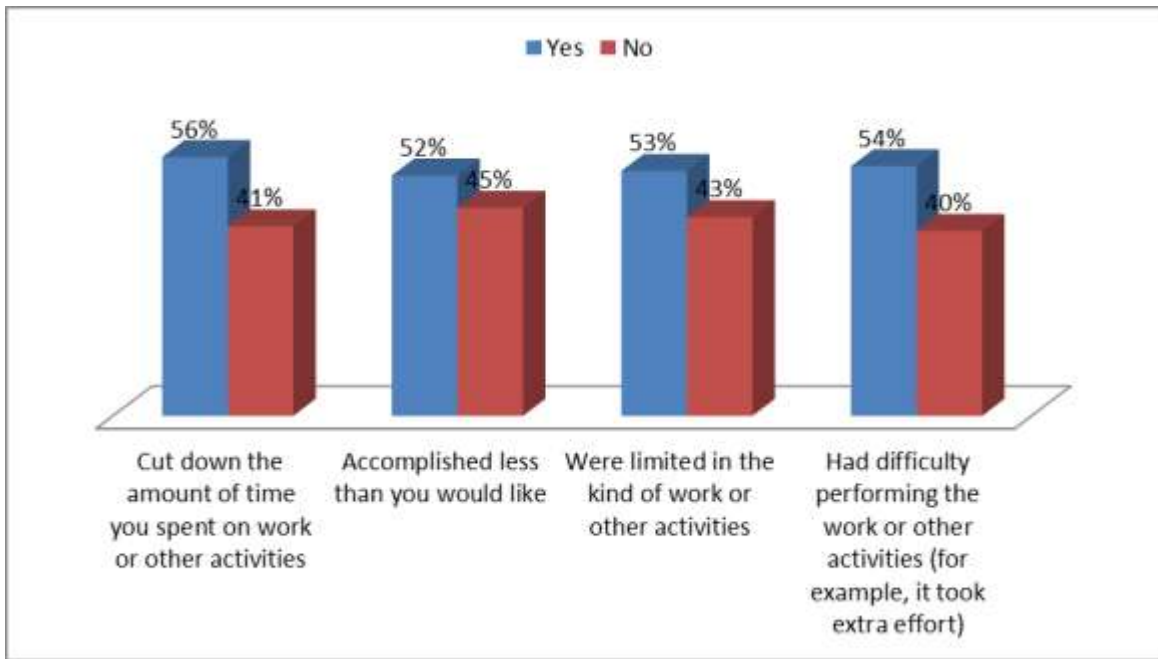


Table IV-3: Role of limitation due to Physical health

Table V-4: Role limitation due to emotional problems

S.no	Role limitation due to emotional problems	Yes		No	
		Freq	%	Freq	%
1	Cut down the amount of time you spent on work or other activities	65	65	31	31
2	Accomplished less than you would like	47	47	47	47
3	Didn't do work or other activities as carefully as usual	45	45	55	55

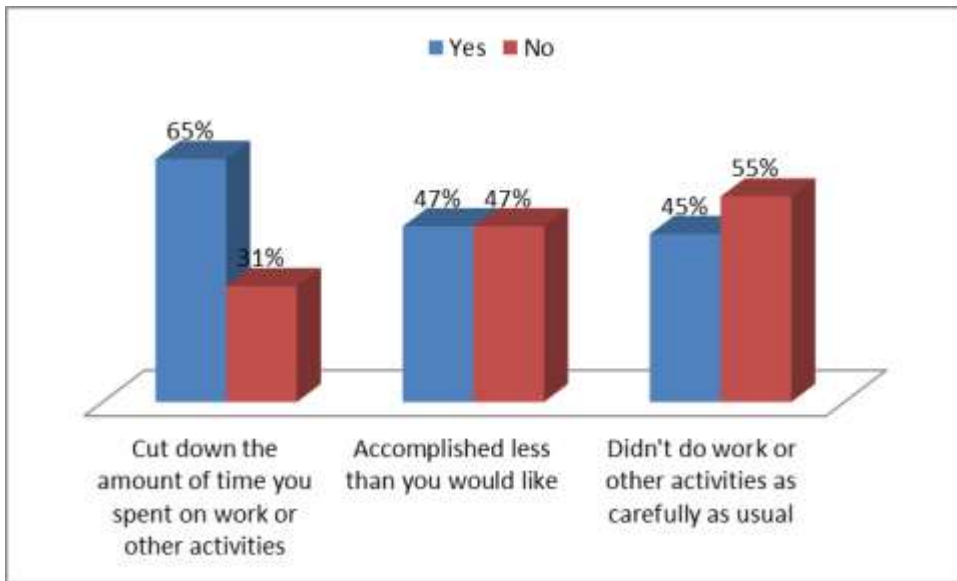


Table V-4: Role limitation due to emotional problems

Table IV-5: Energy/fatigue

S. no	Energy/fatigue	All of the time		Most of the time		A good bit of the time		Some of the time		A little bit of the time		None of the time	
		Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
1	Did you feel full of pep?	10	10	27	27	16	16	32	32	11	11	2	2
2	Did you have a lot of energy?	14	14	21	21	24	24	19	19	16	16	4	4
3	Did you feel worn out?	5	5	10	10	16	16	25	25	28	28	11	11
4	Did you feel tired?	6	6	8	8	23	23	29	29	18	18	11	11

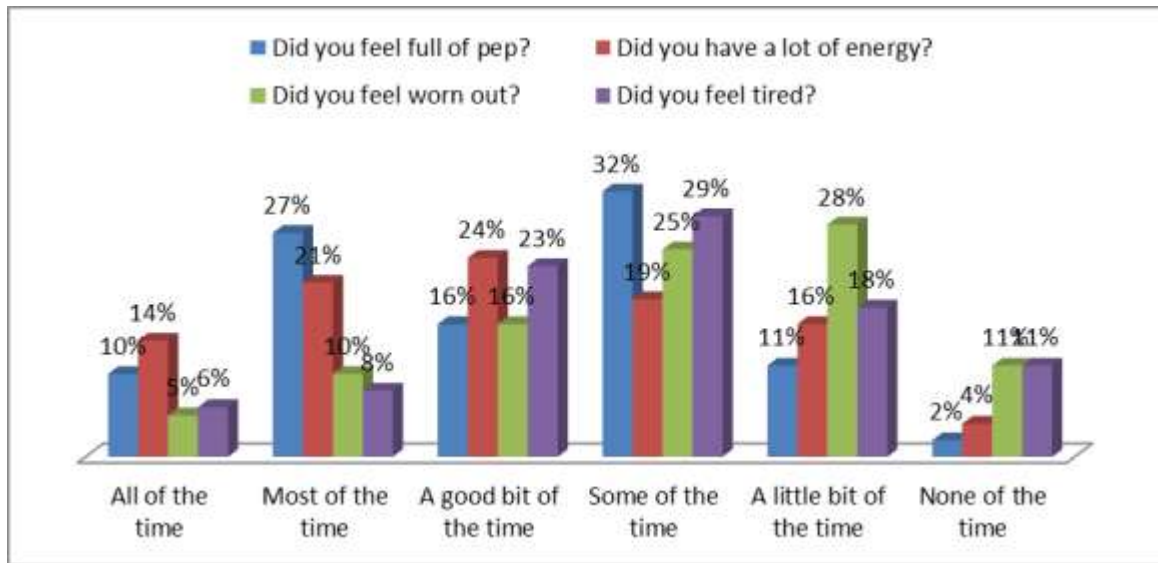


Table IV-5: Energy/fatigue

Table IV-6: Emotional well-being

S. no	Emotional well-being	All of the time		Most of the time		A good bit of the time		Some of the time		A little bit of the time		None of the time	
		Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
1	Have you been a very nervous person?	3	3	12	12	11	11	28	28	25	25	19	19
2	Have you felt so down in the dumps that nothing could cheer you up?	3	3	21	21	12	12	28	28	24	24	9	9
3	Have you felt calm and peaceful?	7	7	14	14	24	24	25	25	14	14	14	14
4	Have you felt downhearted and blue?	4	4	6	6	17	17	21	21	29	29	18	18
5	Have you been a happy person?	9	9	14	14	26	26	20	20	16	16	10	10

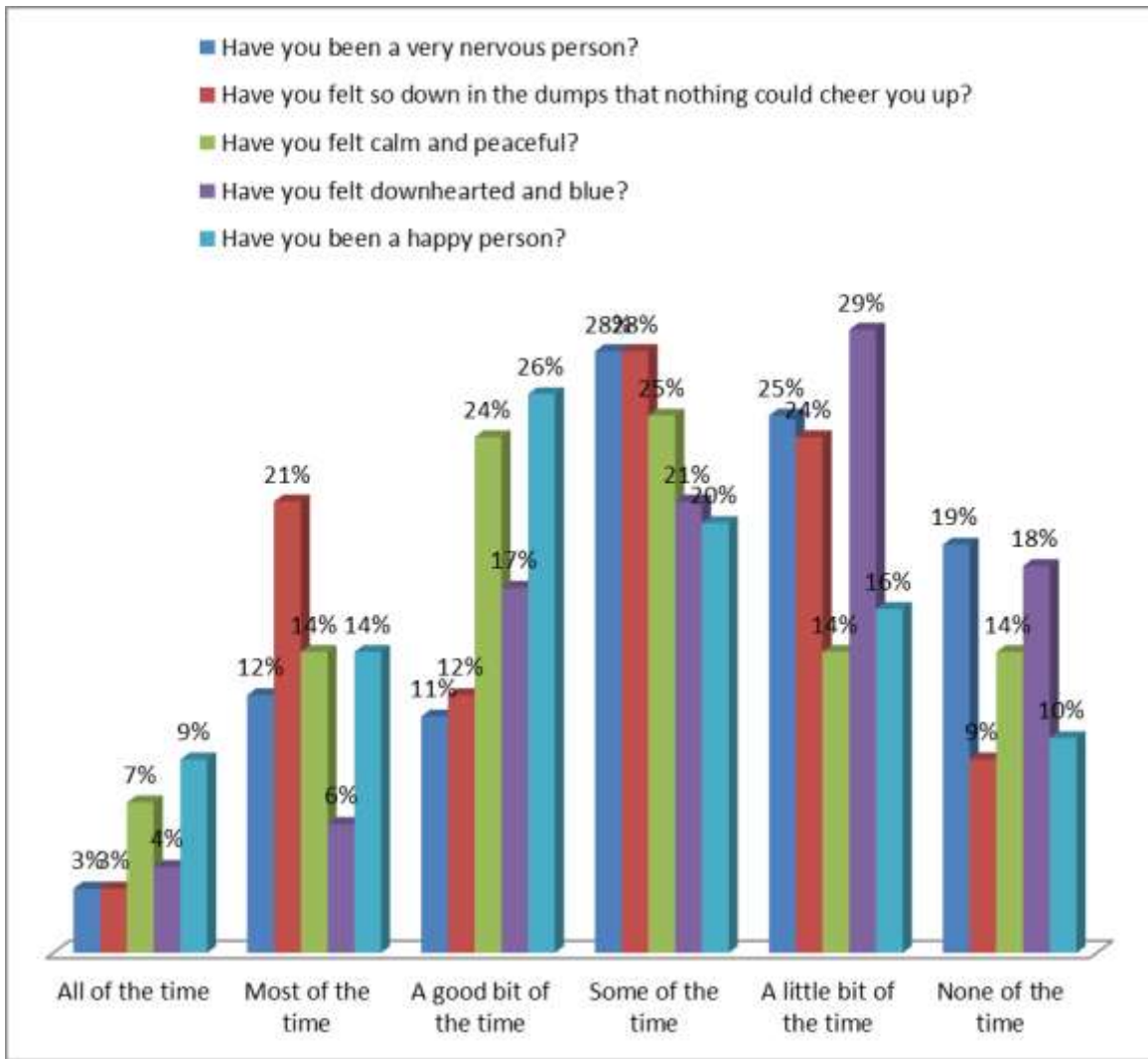


Table IV-6: Emotional well-being

Table IV-7: Social functioning (A)

S. no	Social functioning(A)	Not at all		Slightly		Moderately		Severe		Very severe	
		Fre q	%	Fre q	%	Fre q	%	Fre q	%	Fre q	%
1	During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal socialactivities with family, friends, neighbors, or groups?	13	13	48	48	32	32	4	4	1	1

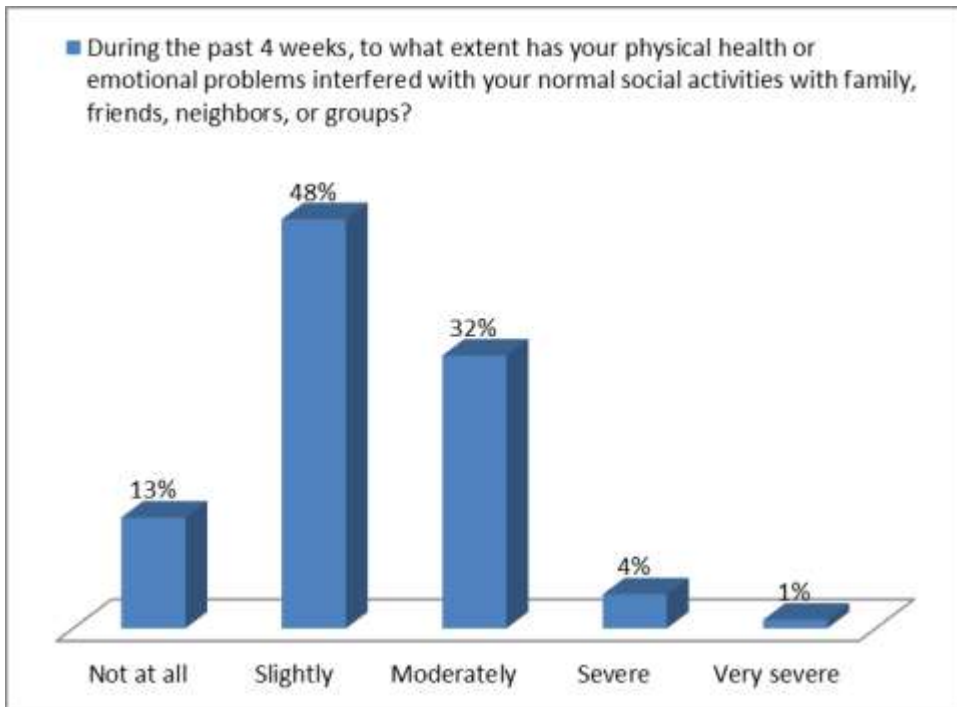


Table IV-7: Social functioning (A)

Table IV-8: Social functioning (B)

	Social functioning(B)	All of the time		Most of the time		Some of the time		A little bit of the time		None of the time	
		Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
2.	During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?	16	16	28	28	20	20	17	17	17	17

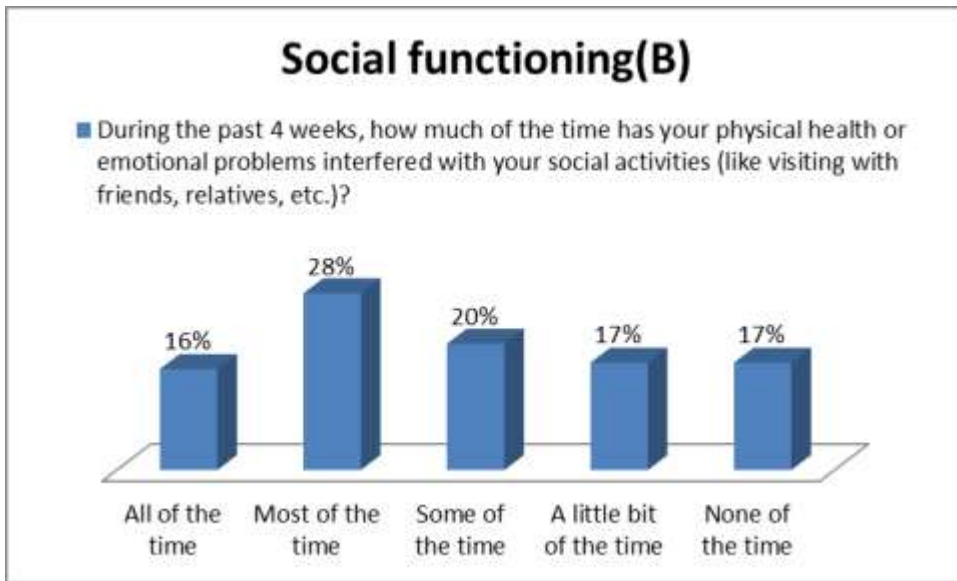


Table V-8: Social functioning (B)

Table IV-9: Pain (A)

S. no	Pain (A)	None		Very mild		Mild		Moderately		Severe		Very severe	
		Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
1	How much bodily pain have you had during the past 4 weeks?	8	8	21	21	34	34	24	24	10	10	2	2

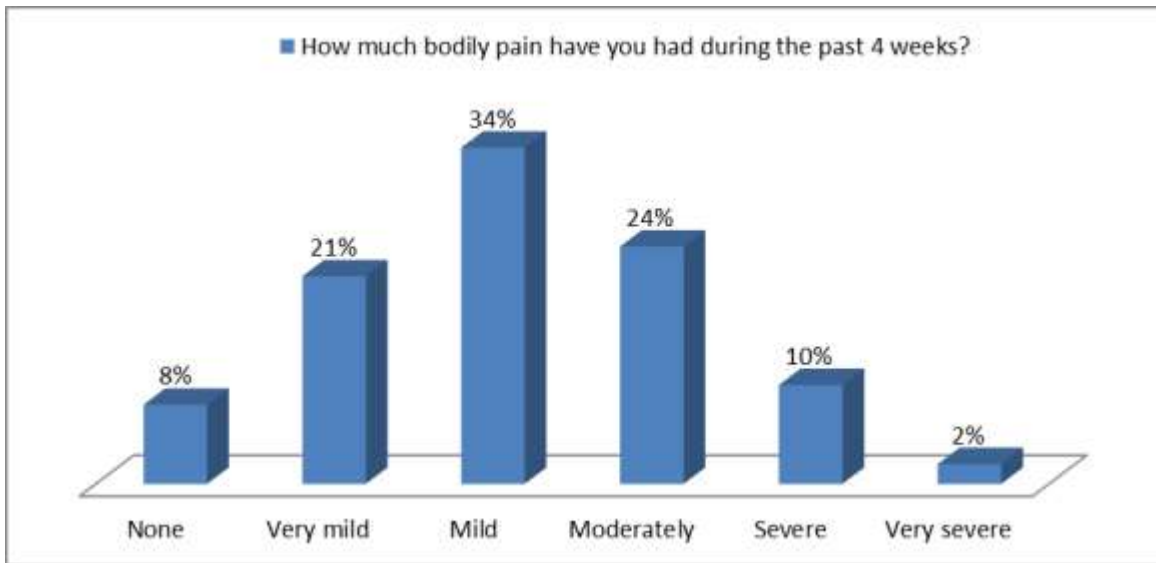


Table IV-9: Pain (A)

Table IV-10: Pain (B)

2	Pain (B)	Not at all		A little bit		Moderately		Quite abit		Extremely	
		Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
	During the past 4 weeks , how muchdid pain interfere with your normal work	11	11	26	26	37	37	18	18	7	7

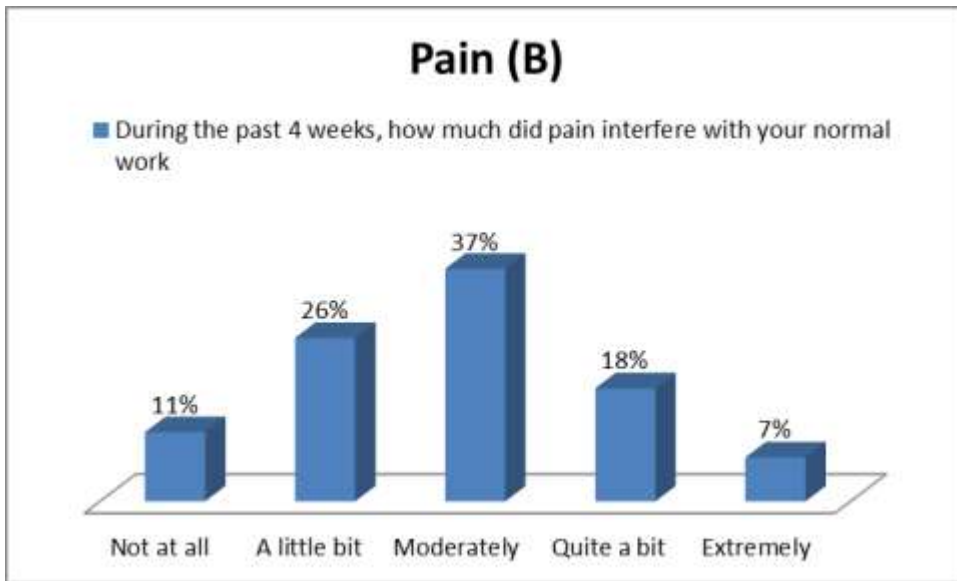


Table IV-10: Pain (B)

Table IV-11: General Health (A)

	General health(A)	Excellent		Very good		Good		Fair		Poor	
		Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
1	In general, would you say your health is	8	8	18	18	46	46	15	15	5	5

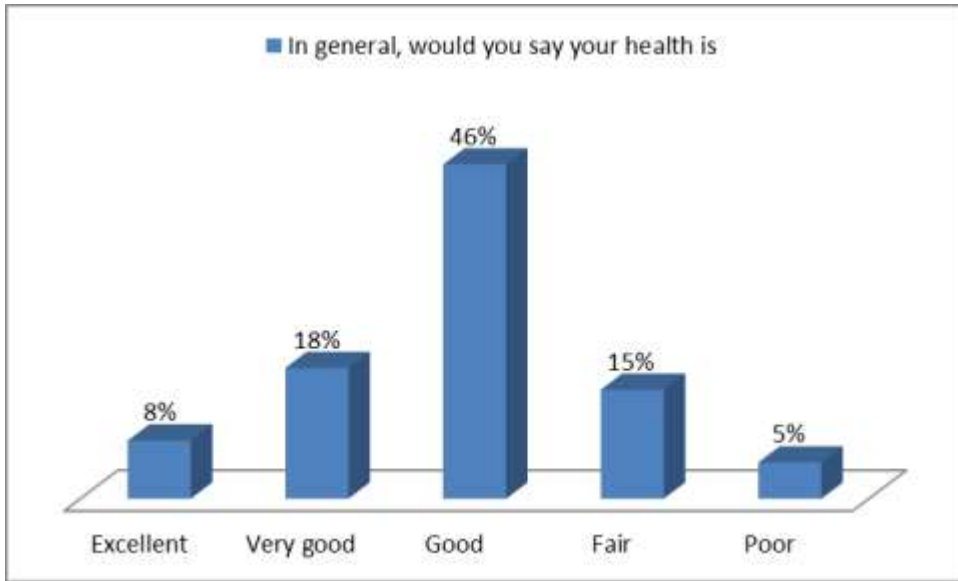


Table IV-11: General Health (A)

Table IV-12: General Health (B)

	General health(B)	Definitely true		Mostly true		Don't know		Mostly false		Definitely false	
		Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
2	I seem to get sick a little easier than other people	5	5	25	25	38	38	19	19	12	12
3	I am as healthy as anybody I know	15	15	40	40	32	32	8	8	4	4
4	I expect my health to get worse	12	12	34	34	39	39	6	6	8	8
5	My health is excellent	10	10	38	38	31	31	13	13	7	7

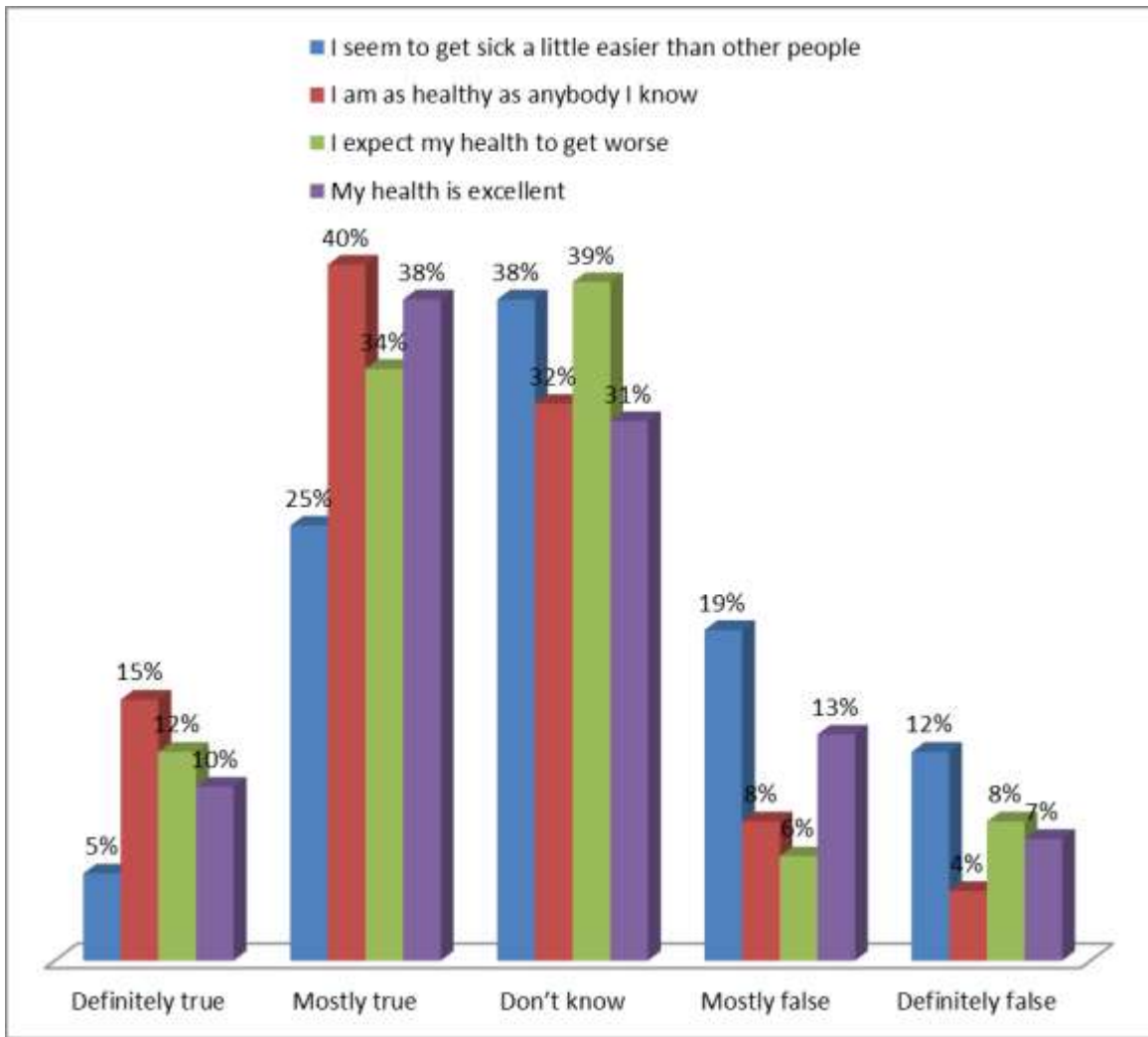


Table IV-12: General Health (B)

Table IV-13: Means score

	Mean of subscale of SF 36	Mean	Standard deviation
1	Physical functioning	45.7500	22.60078
2.	Role limitations due to physical health	41.2500	33.78015
3.	Role limitations due to emotional problems	44.3333	36.71561
4.	Energy/ fatigue	55.6500	18.11377
5.	Emotional well-being	54.1600	19.35877
6.	Social functioning	56.3750	21.50398
7.	Pain	55.1500	22.72980
8.	General health	52.1000	15.42627

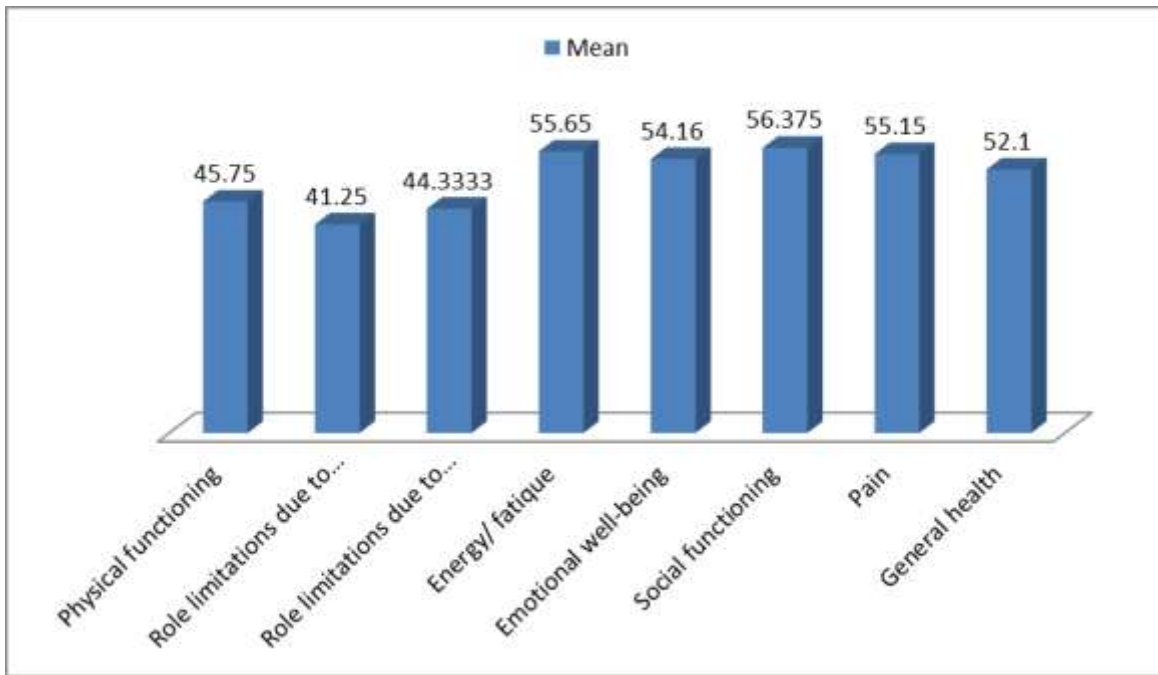


Table IV-13: Means score

CHAPTER V DISCUSSION

A study was done in 2013 by Barasan A, to review the status and standard of life and lifestyle barriers of caregivers of CP children concluded that the quality of life of most of the caregivers was affected.

Deprived psychological status, and increased burden than the parents of healthy children.(13)

A study was done in 2013 by Yilmaz H, to evaluate lifestyle barriers and problems in caregivers and parents having children with cerebral palsy. Most of the caregivers and parents have poor status of life. They mostly have anxiety and mental distress which is the prevalent and most dominant feature in their life. (17)

There are several factors that influence the quality of life and general health of mothers of CP children. The result of our study also showed that the mother of CP children had poor quality of life and high level of stress than overall population and the level of depression is high may be due to chronic illness or long course of the disease.

Another study has been done to assess the mental health and lifestyle of parents of CP children in 2012 by Marcia A Z, indicated that have poor quality of life and their social life is limited.(20)

Our study concluded that 28% mothers reported that social activities gets affected most of the time due to the poor physical and emotional health that they have. This may be due to the fact that our society has a conservative thinking towards having a child with special needs, they don't consider a child with his/her special needs and bring their parents towards social isolation by the negative impacts.

A study was done to observe the depression and QoL in mothers of CP child by Dr Shradda Divan, Dr Hetal Chovatiya, Dr Jasmine Divan in 2011 that showed that 70% of mothers of children with CP suffering from mild to moderate level of depression and have affected QoL.(35)

Our study also concluded that 65% of mothers were greatly affected due to emotional stress and they decrease the time of their work.

The psychological and physical health of mothers were strongly influenced by child behavior and care giving needs. In fact the child behavior problems are the single most important child characteristic that predict mother's psychological health. It is not fully understood why some mothers cope well and other do not. Several studies showed that the behavior problems were adversely affect the mental and general health of mothers of CP children.

The majority of mothers in our study showed physical strain and pain or discomfort due to needs for assistance such as lifting and carrying children.

CHAPTER VI CONCLUSION

The results of my study concluded that mothers of children with CP had poor QoL along with the mental and social problems. Majority of the mothers in our study sample suffered from pain, discomfort, anxiety and depression as well as this also has impact on their normal working patterns.

CHAPTER VII RECOMMENDATION

It is recommended that most of mothers should have proper counseling regarding their child's disability. They should be taught by their health care providers and also by Physical Therapists for the actual cause and management of disability. Mothers should be counsel on regular basis for maintaining and managing stress and health. It is important to provide the mothers with continual support through interventions which may help to improve QoL and assist mothers to improve their lifestyle

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