

Original Article

Factors Affecting Health Related Quality of Life and Depression Levels of Mothers in Families Having Children with Chronic Disabilities

İE ŞİMŞEK, TT ŞİMŞEK, S EREL, S ATASAVUN UYSAL

Abstract

Purpose: This study aimed to investigate the contributing factors to health related quality of life (HRQoL) and depression levels of mothers in families having children with chronic disabilities. **Methods:** The study was designed as a cross-sectional survey including 580 families recruited from 45 cities across Turkey. HRQoL, depression levels and impact of chronic disabilities of a child on the mothers were gathered by using Nottingham Health Profile, Beck Depression Inventory and Impact on Family Scale (IPFAM), respectively. Other data were acquired using a face-to-face interview method. **Findings:** Regression analysis showed that the time spent for daily caring activities, disruption of social relations and coping subscale-scores of IPFAM were significant contributors to poor HRQoL and higher depression levels ($p<0.05$). **Conclusion:** The results suggest that providing a release time from daily caring tasks, increasing level of social interaction and provision of sustained assistance to help to develop coping strategies, would likely increase HRQoL and decrease level of depression of the mothers.

Key words

Children with chronic disabilities; Health related quality of life; Impact on family; Quality of life

Introduction

The concept, advocated by World Health Organization under the framework of International Classification of

Functioning, Disability and Health indicates an important relationship between the health of children with chronic disabilities and the health of caregiver(s).¹ Current body of evidence suggests that parenting children with chronic disabilities has consequences on the health of parents/caregivers and as a result on family functioning.²

The impact of children with chronic disabilities on family functioning may be defined as the varying implications of care that are propagated over the family members throughout the life of children with disabilities.³ These implications are further described as effectively coping with cultural, environmental, psychosocial, and socioeconomic stresses throughout the family life cycle, which are underestimated over the years due to the complexities of care. The focus usually resides on the primary disabling condition of the child; hence, even the closest environmental factors such as family are often underestimated and even neglected. However, as Reichman et al⁴ stated, care giving process for children with chronic disabilities is completely different from raising a healthy child, which presents unique challenges for all members of the family, especially the parents.⁵

Dokuz Eylül University, School of Physical Therapy and Rehabilitation, İzmir, Turkey

İE ŞİMŞEK PT, PhD
TT ŞİMŞEK PT, PhD

Pamukkale University, School of Physical Therapy and Rehabilitation, Denizli, Turkey

S EREL PT, PhD

Hacettepe University, Faculty of Physical Therapy and Rehabilitation, Ankara, Turkey

S ATASAVUN UYSAL PT, PhD

Correspondence to: Dr TT ŞİMŞEK
Email: tulay_tarsuslu@yahoo.com

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Some of the many challenges for families raising children with chronic disabilities may include economical, physical, psychological and social issues that may contribute to health related quality of life (HRQoL) which is "an all-inclusive concept incorporating all factors that impact upon an individual's life".⁶ After the birth of a child with chronic disabilities, financial restraints may alter the occupational course of the family. Several financial needs may give rise to unexpected crisis. Besides, integrating into the community life with a new and different daily routine causes an extra social pressure on the family. Eventually, economical and physical burden, combined with psychological distress and a set of negative emotions may develop detrimental effects on the HRQoL of parents/caregivers.^{7,8} These negative emotions include anxiety, depression, and worrisome thoughts.² In addition, low levels of energy, physical activity and impaired social relationships are common findings in families having children with chronic disabilities.⁷

Parents/caregivers of children with chronic disabilities also experience higher rates of depression compared to parents of children without disabilities. This rate increases proportionally with the impact exposed on the family/caregiver(s).² The process of adaptation to daily stressing conditions and changes in community and family life seems to trigger a negative mood over the family, which concludes with varying levels of depression.

These major differences, differentiating a normal family life from the altered functioning of families having children with chronic disabilities, also necessitate measuring the burden on the families and its relation to the parents'/caregivers' HRQoL. In a recent Canadian survey by Brehaut et al, it is concluded that the number of studies on the issue with large sample groups is limited.¹ Thus, the aim of the current study was to project the status of HRQoL and the level of depression of mothers having children with chronic disabilities and quantify the contributing factors. It was hypothesized that as the impact of children with chronic disabilities on the mothers increases, the level of depression would increase and the HRQoL would decrease.

Methods

Participants

The study was designed as a cross-sectional survey study. The participating mothers were recruited from 45 cities in Turkey, representing all seven regions of the country. The participants were recruited from special

education and rehabilitation centres and physiotherapy and rehabilitation departments of the universities located in Turkey. A total of 580 families were included in the study between May 2008-March 2012. The data related to informative socio-demographic characteristics were gathered in a face-to-face interview session by the primary physiotherapist from only the mothers who lived in the same household with the child and spent most of her time for the provision of caregiving activities to the child with chronic disability. The self-report instruments were completed only by the mothers. The families of the children with non-progressive chronic disorders were also included in the study. Mothers with insufficient Turkish language and those who declined to participate in the study were excluded (a total of 10 caregivers). Informed consent was obtained for all subjects and ethical approval was obtained from the university's ethics board and commissions (non-interventional clinical research ethics board) (FON07/17).

Instruments

Socio-demographic data of the children and mothers were collected via a structured form including presence of mental retardation, presence of medical insurance, duration of the disorder, duration of daily care-time and total income. The impact of children with chronic disabilities on their families, HRQoL, and depression levels were evaluated using Impact on Family Scale (IPFAM), Nottingham Health Profile (NHP) and Beck Depression Inventory (BDI), respectively.

IPFAM, is a 33 item inventory that takes approximately 10-15 minutes to complete and can be used either as a questionnaire, when reading levels are adequate, or an interviewer-administered form. It measures a parent's perception of the effects of the child's ongoing health condition on family life. The instructions on the instrument asks parents to rate each item on a scale from 4 (strongly agree) to 1 (strongly disagree). The first 27 items are reflective of impact on the family in general, while in the last six items of the scale, the respondent is asked to rate the impact of the child with disability on his/her siblings. The subscales of IPFAM are: total score, general impact, disruption of social relations, coping and financial impact. Lower scores indicates lower impact. Internal consistency (Cronbach's Alpha) for the total impact ranges from 0.83 to 0.89 according to important normative samples.⁹ For the Turkish version test-retest reliability (ICC) was found to range between 0.787 and 0.953 and the internal consistency (Cronbach's Alpha) was reported to be 0.902

for total impact. Construct validity was tested against WeeFIM (Functional Independence Measure for Children) and physiotherapists' evaluation of disability using visual analogue scale (VAS). Inter-correlations among IPFAM items and the benchmark criterion were $r=-0.532$ ($p<0.001$) for WeeFIM and $r=-0.519$ ($p<0.001$) for VAS. In this study, the Turkish version of IPFAM was used.^{10,11}

In order to evaluate the HRQoL the Turkish version of NHP was used. All subjects completed NHP once. The NHP is a self-administered questionnaire composed of two sections containing 45 items. The first section contains 38 items assessing physical mobility (8 items), pain (8 items), sleep (5 items) emotional reactions (9 items), social isolation (5 items) and energy level (3 items). All items have a yes/no answer format. Scores for each section can range from 0 (no problems) to 100 (all problems listed are present).¹² Reported test-retest reliability and internal consistency of the English version range between 0.77-0.85 and 0.61-0.88, respectively.^{13,14} The analysis for the Turkish version indicated that internal consistency (Cronbach's Alpha) ranges between 0.56-0.83 and test-retest reliability between 0.70-0.92. Construct validity of the Turkish version was assessed using correlations between the sections of NHP and Health Assessment Questionnaire ($r=0.15-0.73$).¹⁵

BDI was used to evaluate the symptoms of depression of the mothers. BDI is a 21-item scale that gathers information on different symptoms of depression. Summary scores quantify depression as follows: minimal depression (0-13), mild depression (14-19), moderate depression (20-28), and severe depression (29-63). Convergent validity of the English version ranges from 0.58 to 0.79.¹⁶ Internal consistency for the English version is 0.81 for non-psychiatric subjects.¹⁷ The Turkish version of BDI was used in the present study.¹⁸ The validation of BDI was studied against Minnesota Multiphasic Personality Inventory-Depression scale and the correlation was found to be $r=0.63$ ($p<0.001$).¹⁹ The internal consistency (Cronbach's Alpha) was reported to be 0.89.

Statistical Analysis

For statistical analyses statistical Package for Social Sciences™ (SPSS) 20.0 program was used. Means and standard deviations ($X\pm SD$) were calculated and percentages were provided for all variables. The variables were investigated using visual (histograms, probability plots) and analytical methods (Kolmogorov-Smirnov/Shapiro-Wilks's test) to determine whether or not they are normally distributed. If the data were normally distributed

Pearson correlation analysis (and if not spearman correlation analysis) was used to analyse the effects of socio-demographic characteristics, the duration of the disorders and the duration of care time on families. A multi-linear regression model was used to identify independent predictors of NHP and BDI. The model fit was assessed using appropriate residual and goodness-of-fit statistics. The correlation coefficient was accepted as 0.05.

Results

All data were normally distributed. The socio-demographic data related to the children and their families are presented in Table 1.

The correlation indicated that the total impact was negatively correlated with the educational level of the mothers and the presence of medical insurance ($p<0.05$). The same relation was also detected between the level of depression and the level of education of the mothers, the level of income, presence of medical insurance. The duration of daily care time was the only exception that showed a positive correlation with depression levels ($p<0.05$). Meanwhile, HRQoL was negatively correlated with the level of education of the mothers, the level of income and presence of medical insurance ($p<0.05$) (Table 2). HRQoL, total impact and the level of depression were not related to the age of the mothers and the duration of the disorder ($p>0.05$). The duration of care was also not correlated to total impact and HRQoL ($p>0.05$) (Table 2). Total impact and all subscales of IPFAM were correlated to NHP and BDI ($p<0.05$) (Table 3).

The regression analysis indicated that the daily care time spent for the child, coping and disruption of social relations subscale scores were significant contributing factors to HRQoL in families having children with chronic disabilities ($p<0.05$). Marital status, diagnosis, mothers' age, level of education, the duration of the disorder, total income and the remaining subscales of IPFAM (financial support and general impact) were not found to be significant contributors for HRQoL ($p>0.05$) (Table 4).

The time spent for daily care activities, disruption of social relations and coping subscales of IPFAM all contributed to depression level ($p<0.05$). Marital status, diagnosis, mothers' age, level of education, the duration of the disorder, total income, financial support and general impact subscale scores were not found to be significant contributors to the depression levels ($p>0.05$) (Table 4).

Discussion

This study showed that in mothers having children with chronic disabilities the main contributors to depression levels and HRQoL were the daily care time spent for the child, disrupted social relations and the coping ability.

In families having children with chronic disabilities, stress may not always be the result of the ongoing disability, but also of multi-factorial reasons (i.e.

environmental factors). This had most assuredly been stated in Folkman and Lazarus's study that defined stress as a resultant of the interaction of an individual (or family) with the environment.²⁰ Stress levels directly increase as the family cannot cope with problematic situations. In other words, parents are usually stressed when a stressor is introduced through daily life and the general family coping strategies fail, resulting in depression, fatigue and restlessness.²⁰⁻²³ Thus, it is not surprising that in this study one of the main contributors to depression level is found to be the coping ability along with disrupted social interactions, which are both routine stressors throughout the daily life of a family (especially the mothers) having a child with chronic disability. Whiteneck et al also indicated that the factors encompassing a child's (with chronic disabilities) social, physical and political environment may hamper inclusion in leisure activities initiated by the parents/caregivers.²³ This may affect familial sense of fit to their environment as termed by Park et al, which may also be considered as among the parameters of family quality of life.²⁴ One of the most important factors related to the environment is the access to health care services as advocated by several researchers that may change quality of life outcomes.^{25,26} Furthermore, simple access seems to be not necessarily enough, also meeting the families' needs by the disability related services that may have a great influence on familial quality of life as Jones et al reported.²⁷ In parallel with these notions, we have found that presence of medical insurance is negatively correlated to depression levels.

In some studies, comparing families having children with various chronic disability conditions (down syndrome, cerebral palsy, autistic spectrum disorders, fragile X syndrome, cystic fibrosis) and families having children with typical normal development, it has been suggested that in those families having children with chronic disabilities stress factors were higher than the latter.^{21,28-31} In parallel, it is also known that in those families, depression levels were higher and well-being was negatively affected. Another study indicated that in fathers having children with chronic disabilities life satisfaction was lower and that they needed support for developing coping strategies with stress.³²⁻³⁴

In the present study, it was shown that the impact was, in part, related to educational status and the presence of medical insurance. Also the increased impact level was related to decreased levels of HRQoL and higher depression levels. The family income was positively related to HRQoL and negatively with depression levels.

Table 1 Demographic data related to families and children

N=580	X±SD	
Age (years)	6.74±3.71	
Duration of the disorder (months)	67.80±37.68	
Daily care time spent (hours)	9.77±4.89	
Presence of mental retardation	n	%
Yes	369	63.6
No	211	36.4
Diagnosis	n	%
Cerebral palsy	312	53.8
Muscle disease	159	27.4
Meningitis	6	1
Mental motor retardation	74	12.8
Hydrocephalus	5	0.9
Myelomeningocele	17	2.9
Obstetric brachial plexus palsy	2	0.3
Down syndrome	1	0.2
Rare disorders	2	0.3
Neuropathy	1	0.3
Amputation	1	0.2
Educational level (mothers)	n	%
None	23	4
Primary school	317	54.7
Secondary school	67	11.6
High school	127	21.9
University	44	7.6
Postgraduate	2	0.4
Presence of medical insurance	n	%
Yes	28	4.8
No	552	95.2
Marital status	n	%
Married	559	96.4
Divorced	17	2.9
Living separately	4	0.7
Total income	n	%
Very low	108	18.6
Moderate	275	47.4
Moderate-high	197	34

Meanwhile, the daily time spent for caring activities, disrupted social relations and decreased coping abilities detected by IPFAM seem to enhance depression. Caring demands of children with chronic disabilities that increase day by day and various unpredicted or obscure needs (education of the child, additional and regular health problems, variability in medical services, financial issues) may hamper coping strategies with the ongoing disability. All of these reasons may eventually cause increased stress levels and result in depression and/or anxiety problems.

The impaired psychological status (depression) may lead to decreased HRQoL. Likewise, in this study it was shown that increased time consumption for daily care giving activities, increased total impact and disruptions in social relations all negatively affect the HRQoL of the mothers

having children with chronic disabilities. Although there was a relation between mothers' educational level, total income and HRQoL, HRQoL was not affected by the duration of the disability, mothers' age, educational status and family income according to the regression analysis. Besides, the general impact (burden) is affected by several other factors in those families. The severity of these influences may change when in combination. Socio-demographic factors and economic status are among the indicators of HRQoL, however, when considered with the diagnosis, mental status and severity of the disability, their resultant effect may be lesser than predicted.

In the literature, it is indicated that the families are affected by the duration of the disability.³⁵⁻³⁸ In our report, the average duration of the disability was approximately

Table 2 The relation between NHP, BDI, IPFAM (total impact) and socio-demographic data

N=580	Total impact		BDI		NHP	
	r	p	r	p	r	p
Age (mother)	-0.016	0.708	-0.027	0.527	-0.028	0.496
Educational level (mother)	-0.092	0.028*	-0.160	0.000**	-0.154	0.000**
Duration of the disorder	0.029	0.481	0.072	0.091	-0.017	0.683
Total income	-0.050	0.231	-0.142	0.001**	-0.079	0.049*
Presence of medical insurance	-0.103	0.014*	-0.148	0.000**	-0.097	0.020*
Daily care time spent for the child	0.057	0.175	0.129	0.002**	-0.014	0.728

*Correlation is significant at the 0.05 level (2-tailed), **Correlation is significant at the 0.01 level (2-tailed). Pearson correlation coefficient.

NHP: Nottingham Health Profile; IPFAM: Impact on Family Scale; BDI: Beck Depression Inventory

Table 3 The relations between the subscales of IPFAM, total impact and NHP and BDI

	BDI		NHP	
	r	p	r	p
Financial support	0.299	0.000*	0.413	0.000*
General impact	0.231	0.000*	0.278	0.000*
Disruption of social relations	0.301	0.000*	0.423	0.000*
Coping	0.294	0.000*	0.405	0.000*
Total impact	0.151	0.000*	0.120	0.004*
BDI	–	–	0.126	0.003*

*Correlation is significant at the 0.01 level (2-tailed).

NHP: Nottingham Health Profile; IPFAM: Impact on Family Scale; BDI: Beck Depression Inventory

5.6 years. Thus HRQoL and the impact may differently be affected as the years go by due to the stress influence of a child with chronic disability on the mothers and indirectly on the family which increase as the child grows older.^{39,40} It has been previously reported that the families with older children with disabilities feel more isolated with increased demands for services compared to when their children were younger.⁴¹ It is obvious that the aging child with increased caring demands will result in increased time consumption for the primary caregiver (usually the mother). This may cause social isolation for the mothers with no spare time left for social and personal self-caring activities. In this respect, there are insufficient number of studies in the literature that have long follow-up durations. Observing the ever changing economic, social and personal

necessities of these families in the long term may help to acquire important data to fully understand the ongoing situation which require further studies on the topic.

In studies related to the impact of children with chronic disabilities on their families, it has been suggested that these families need a different kind of medical service and social support. One of the policies that has been widely advocated and implied is providing financial support, which at least is hoped to alleviate the economic burden. Another one is preventing social isolation by supporting the establishment of associations and leagues to provide a basic structure for families to integrate into community life. Also specialised psychologists may provide family rehabilitation in order to decrease depression related reduction in HRQoL. Still, in practice it is not recognised

well enough that the overall burden of families having children with chronic disabilities is multi-dimensional; demanding professionals like rehabilitation nurses and physical therapists who may offer some practical information as well as helping families to achieve their social or economic rights.⁴²

Limitations of the Study

This study was designed to present an overall perspective related to the impact of children with chronic disabilities on their mothers. Keeping this mind, the readers should note that although there are referrals to "family", these are indirect conclusions and presented just to provide some insight. In addition, due to heterogeneity of the disabilities included in the study, one should carefully make

Table 4 Regression analysis related to HRQoL (NHP) and Depression Level (BDI)

	Unstandardised coefficients		Standardised coefficients		P
	B	Standard Error	Beta	t	
Dependent variable: NHP, R²: 0.211					
Diagnosis	0.246	0.789	0.012	0.312	0.755
Marital status	-6.248	6.368	-0.037	-0.981	0.327
Age (mother)	-0.071	0.216	-0.012	-0.329	0.742
Education level (mother)	-2.959	1.25	-0.103	-0.952	0.342
Daily care time spent for the child	-0.238	0.25	-0.037	-2.368	0.018
Total income	1.079	1.912	0.025	0.564	0.573
Duration of the disorder	-0.031	0.032	-0.038	-0.974	0.330
Financial support	-0.771	0.552	-0.262	-1.396	0.163
General impact	-0.134	0.878	-0.009	-0.153	0.879
Disruption of social relations	2.331	0.642	0.422	3.631	0.000
Coping	1.811	0.577	0.304	3.141	0.002
Dependent variable: BDI, R²: 0.128					
Diagnosis	-0.34	0.723	-0.019	-0.471	0.638
Marital status	3.22	5.585	0.023	0.576	0.565
Age (mother)	-0.096	0.196	-0.02	-0.492	0.623
Education level (mother)	-1.801	1.135	-0.075	-1.586	0.113
Daily care time spent for the child	0.646	0.234	0.115	2.765	0.006
Total income	-1.778	1.712	-0.049	-1.039	0.299
Duration of the disorder	0.042	0.029	0.061	1.454	0.147
Financial support	-0.811	0.504	-0.333	-1.61	0.108
General impact	0.339	0.804	0.028	0.422	0.673
Disruption of social relations	1.664	0.577	0.365	2.885	0.004
Coping	1.261	0.521	0.255	2.420	0.016

NHP: Nottingham Health Profile; BDI: Beck Depression Inventory

assumptions related to a single chronic disorder as the construct behind different disabilities may well change.

Furthermore, our convenience sample of participants does not cover mothers having typically developing children. It is recommended that, in future studies, a group of mothers having typically developing children as a control group would also be included in order to present data from a comparative perspective. In addition, all the contributing factors and correlations presented may also work the other way around (for example caregiver burden may cause depression and meanwhile depression may cause an extra burden).

Another limitation is the allocation of participants from various regions of the country with different access to health care services, leisure and other activity participation opportunities. This point should be addressed in future studies as advocated in other studies.

Conclusion

In conclusion, in mothers having children with chronic disabilities, depression and HRQoL seem to be correlated to several parameters like level of education, financial status, presence of medical insurance, and daily care time spent for the child. In addition, multivariate regression analyses indicated that the main contributors to depression levels and HRQoL were daily care time spent for the child, level of coping and disrupted social relations. Still, one should note that among the variables investigated in this study, the above mentioned factors explained relatively a small percent of the multi-factorial nature of these two constructs. Thus, it is obvious that more research is needed to determine the most significant factors so that they could be handled properly. In addition, in order to allocate resources and/or make policies, more focused research is needed for specific types of disabilities.

This study was designed to generally describe the influence of having a child with chronic disability and its relation to HRQoL and depression levels in mothers. We believe the results of this study present a perspective of the mothers having children with chronic disabilities.

Conflict of Interest

The authors reported no conflict of interest.

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