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PERSPECTIVES OF IRANIAN MOTHERS WITH CEREBRAL PALSY CHILD ABOUT FAMILY COPING

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ABSTRACT

Introduction: The child with cerebral palsy is a serious challenge to families. It is essential to determine coping style adopted by these families.
Purpose: The aim of this study was to assess family coping and its dimension in Iranian mothers with cerebral palsy children and the relationship between demographic characteristic and family coping.
Materials and method: This was a descriptive study on 208 mothers with cerebral palsy children who referred to seven rehabilitation centers in Kermanshah, Iran. The subjects were selected through convenience sampling. The instruments were the demographic characteristics and family crisis Oriented Personal Evaluation Scales. The data was analyzed in SPSS (v16).
Results: The mean age of mothers was 32±6.4 years and mean age of children was 59±3.75 months. The mean family coping score was 97±16.80. Reframing and passive appraisal were the most and least common strategies used in the families from the mothers' viewpoint. Age, job, education, type of cerebral palsy had no significant correlation with family coping.
Conclusion: Assessment of family coping is important and useful for the development of nursing intervention aimed at facilitating family adaption in families with a child with cerebral palsy.

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Introduction

Parenting is a stressful job not to mention intensity of the stresses of having a child with a disability [1]. A child with disability is a serious crisis in the family [2]. Cerebral palsy is the third prevalent developmental disability and the top prevalent progressive motor disability that causes variety of motor-sensory problems, mental damages, developmental disorders, and functional limitations [3, 4]. Different countries publish inconsistent statistics as to prevalence of the problem; still, global prevalence of the problem is 2-2.5 per 1000 live births [5]. The statistics in this regard in Iran are not reliable [6].

Cerebral palsy is a complicated condition that creates different challenges for the child and family so that these families have to handle special stresses and needs [7]. Evidences hint that parents of these children experience stress level higher than those

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with normal children [8]. Brehaut et al. (2004) found that psychological distress and physical and emotional problems of care givers to cerebral palsy children (mothers in 95% of cases) were significantly higher than those of other care givers [9].

Functional limitations caused by cerebral palsy influences self-care capability of the child so that they need more attention. In many cases, these children live with the family and mothers are the main care givers [3, 10, 11]. Therefore, not only it affects the life of the child [12], the disabilities consume main portion of the energy of the family and mother in particular [13]. In general, the special needs of a cerebral palsy child cause general changes in the function of the family so that it leads to disassociation among family members in absence of a proper coping strategy [14]. Researchers in coping field believe that the way people approach stresses may increase or decrease the negative effects of life events and situations [15].

The main trend of papers about families with a disable child or children with chronic diseases once was to emphasize on the negative outcomes for the family; however, recently the coping style and adaptation to the hard situation have been accentuated [7]. Improvement of coping skills of the parents of children with chronic condition is effective on attenuation of anxiety and depression [16] (Churchill, et al., 2010), adaptability of the parents and better performance of children [17], and quality of life of the children [18].

Different families have their own unique and different coping strategy and system. Professionals need to know what is the exact coping strategies used in a family and what approaches are most helpful for a family [1].

As providers of an efficient support services, nurses need to have insight into the family coping strategies with disable children [19]. They can help the mothers to have better comprehension about their disabilities and strengths, spot the problems, develop solutions, and learn about new coping strategies [1]. Mothers' responses to the pressures caused by having a disable children ranges from a variety of psychological distresses to a successful adaptation [4]. The extent of successful adaptation depends on using internal and external coping strategies. The internal family coping strategies are rooted in the family and passive appraisal and reframing are among them(20); while the external family coping strategies are rooted in external sources. Families may also rely on the society and social support [21]. Seeking support spiritual and acquiring social supports are of the external coping strategies [20]. The families that use the both internal and external supports tend to be more efficient in adapting to stressful situations [21].

Family coping strategies in families with cerebral palsy children have not been thoroughly examined [14]. As recommended by the literature review, coping strategies and attitudes are functions of different factors such as social, cultural, economic, and political backgrounds [22]. Cultural beliefs about disabilities are key factors in family's perceptions of children's disability. Positive perceptions, on the other hand, have the key role in coping so that they may lead to better coping with stressful events [23]. Determining how the parents use coping strategies to manage problems [22] and knowing the differences are of clinical value for the professional practitioner [24]. When the health providers learn that a family is dealing with adaptation problems, they can adopt most efficient intervention depending on the situation [25]. The best way that health providers may ensure about efficiency of their services is to evaluate family's coping strategy as a whole [26]. The present study is an attempt to determine coping style of family and its aspects from point of view of Iranian mothers with cerebral palsy children. Moreover, the relationship between family coping and some of demographics of the mothers was examined.

Methodology

A descriptive cross-sectional study was carried out as a part of a PhD dissertation on nursing in Shahid Beheshti University of Medical Sciences. Data gathering was done in a seven-month period from March 2015 to September 2015. Participants were 208 mothers with cerebral palsy child at the age range 1-12 years who referred to seven rehabilitation centers in Kermanshah city. Inclusion criteria were definite diagnosis of cerebral palsy by a pediatrician, the problem be diagnosed for more than one year, only one children with cerebral palsy or any other disability in the family, the both parents live with the child, ability to speak Farsi, no mental disease in the mother.

The participants were selected through convenient sampling and the participants were briefed about the purpose and process of the study before signing an informed letter of consent.

Data gathering tool included a demographics questionnaire (age, gender, type of cerebral palsy, duration of the disease, gross motor function level, mother's age/occupation/education, and number of children) and family crises oriented personal evaluation scales (F-COPES) to determine family coping strategy and its aspects. F-copes was designed by Olson, Larsen and McCubbin in 1981 including 30 statements designed based on Likert's five-point scale (1= completely agree,…, 5= completely disagree) with five subscales of passive appraisal, family mobilization to acquire and accept help, seeking spiritual support, acquiring social support, and reframing. Maximum and minimum scores are 150 and 30 respectively and the higher the score the better the coping behavior with stressful situation.

Internal consistency of F-COPES ($\alpha = 0.86$) is supported and α-value of the subscales ranges from 0.63 to 0.83. Retest consistency coefficient with four weeks internal is 0.81, which is acceptable. Subscales consistency coefficient was between 0.61 and 0.95 (20, 27).

The collected data was analyzed in SPSS (v.16) and the results were represented using descriptive and analytical statistics such as mean, standard deviation (SD), frequency, percentage, quantitative variables, and tables. To examine relationship between the variables, t-test, ANOVA, and post-hoc tests were used. Level of significant was ($p<0.05$).

Results

The demographical findings are listed in [Table 1]; 88.5% of the mothers were 20-40 years old, 11.5% were older than 40 years, 90.9% were housewives, and 83.6% had one or two children.

Table 1: Demographic characteristics of mothers of children with cerebral palsy, Kermanshah, Iran (2015)

Variable	Cluster	N	%
Mothers' age (year)	20-30	93	44.7
	31-40	91	43.8
	41>	24	11.5
Mothers' education	Illiterate	5	2.4
	Elementary	47	22.6
	Junior high school	55	26.5
	High school	77	37
	Higher education	24	11.5
Occupation	Housewife	189	90.9
	Office employee	16	7.7
	Others	3	1.4
Number of children	1	102	49
	2	72	34.6
	3	23	11.1
	4≥	11	5.3
Child's age (months)	12-36	79	38
	37-83	77	37
	84-144	52	25
Gender of the child	Girl	99	47.6
	Boy	109	52.4
Type of cerebral palsy	Quadriplegia	34	16.3
	Diplegia	70	33.7
	Hemiplegia	69	33.2
	Athetoid	9	4.3
	Hypotonus	18	8.7
	Ataxic	8	3.8
GMFCS	Level 1	41	19.7
	Level 2	30	14.4
	Level 3	52	25
	Level 4	53	25.5
	Level 5	32	15.4
Duration of disease (month)	12-24	47	22.6
	25-36	48	23
	37-48	22	10.6
	49-60	28	13.5
	61>	63	30.3

Normal distribution for all the variables was tested and supported by Kolmogrov Smirnov (KS) (p>0.05). **(Table 2)** lists mean score of family coping and the subscales; as listed, all the subscales were used in the families. Reframing and passive appraisal were the most and least common strategies used in the families from the mothers' viewpoint. **(Table 2)**

Table 2: The scores of F-COPES and its dimensions in mothers of children with cerebral palsy, Kermanshah, Iran (2015)

Element	**Minimum obtained score**	**Maximum obtained score**	**Mean**	**SD**	**Mean item score**
Acquiring social support	9	45	24	9.6	2.66
Seeking spiritual support	6	20	14.5	3.6	3.63
Passive appraisal	4	20	9.9	4.9	2.49
Reframing	9	40	30.8	8.1	3.85
Mobilizing family to acquire and accept help	4	20	15	4.5	3.75
Total score of family coping	49	136	97.3	16.8	3.25

In terms of the items of F-copes, the item No. 30 (I have absolute trust in God) and the item No. 29 (I inform my neighbors about my problems) obtained the highest (4.72) and lowest (2.03) mean scores respectively.

Results of t-test showed that mean score of family coping of the mothers was not significantly different in terms of gender of the children with cerebral palsy (p=0.289, f=0.332). ANOVA showed that there was no significant difference in mean score of family coping in terms of the child's age, the mother's education, number of children, type of cerebral palsy, gross motor function level, and duration of the disease (p>0.05; **Table 3**). The only significant difference in coping performance was in terms of mother's age (p<0.05). Moreover, there was a significant difference in passive appraisal coping strategy in terms of mother's age and occupation, and gross motor function level **(Table 3)**. Post-hoc comparison showed that the mothers who worked in an office, older mothers, and those with children with gross motor function level of 4 and 5 had more tendency to passive appraisal. As to spiritual support and mobilizing family to seek social acceptance and support, Tukey test showed that mean score of spiritual support strategy was higher in the mothers with high school diploma than those with elementary education. Moreover, mean score of family mobilizing to seek support was higher in the mothers whose child's problem duration was more than five years comparing with those whose child's problem duration was less than three years.

Table 3: Relationships between scores on the F-COPES and demographic characteristics of mothers of children with cerebral palsy, Kermanshah, Iran (2015)

Demographic characteristics	**Acquiring social support**	**Seeking spiritual support**	**Passive appraisal**	**Reframing**	**Mobilizing family**	**F-COPES**
Mothers' education **F** **Sig**	1.50 0.203	2.44 0.048*	1.59 0.178	0.419 0.795	0.725 0.576	0.098 0.983
Job of mother **F** **Sig**	2.343 0.099	0.126 0.881	3.053 0.049*	1.693 0.187	0.878 0.467	0.961 0.384
Type of cerebral palsy **F** **Sig**	0.231 0.949	1.224 0.299	0.972 0.436	1.378 0.234	0.833 0.527	0.523 0.759
GMFCS **F** **Sig**	1.361 0.249	0.351 0.843	3.764 0.006*	1.470 0.123	0.826 0.511	1.178 0.322
Mothers' age **F** **(year)** **Sig**	2.148 0.119	0.201 0.818	4.129 0.017*	1.206 0.301	0.879 0.480	3.416 0.035*
Duration of disease **F** **(month)** **Sig**	0.422 0.792	0.070 0.991	0.993 0.412	1.275 0.281	3.199 0.014*	1.193 0.315
Child's age **F** **(month)** **Sig**	0.769 0.465	0.800 0.451	0.142 0.868	0.306 0.737	0.886 0.413	1.323 0.269
Number of children **F** **Sig**	1.039 0.376	0.809 0.490	1.822 0.144	1.783 0.152	0.347 0.792	2.182 0.091

Discussion

Adaptation is not possible in the families with a cerebral palsy child without an efficient coping strategy. Since mothers are the main care givers in Iranian families(28), their point view was assessed in the present study.

The results indicated that mean score of family coping was 97.3, which is close to the score obtained for the mothers of autism children (95.5) [21]. Since the family coping score is comprised of five subscales and the three subscales of reframing, seeking spiritual support, and mobilizing family to acquire support and acceptance were measured by the present study and Twoy et al.'s study, the results of these two studies are comparable.

Additionally, the results indicated that reframing was the most commonly used strategy in families with cerebral palsy child; this result in consistent with Twoy et al. (2007), Kristic and Oros (2012), and Churchill et al., (2010)(14, 16, 21).

Lin (2000) showed that successful adaptation was significantly related to using reframing in the mothers of cerebral palsy child at school age [7]. Reframing helps the mothers in cognitive reformation of problems in painful and unpleasant situations so that such situations become more acceptable(14). Apparently, the families had come to an understanding that the stressors were indispensable part of life and reframing enabled them to redefine the themes in a positive manner. Through this, they can find a solution to deal with the problems.

The study showed that the subscale social support was less frequently used by the families; so that the item No. 29 (I inform my neighbors about my problem; score = 2.02) and the item No. 8 (I accept my neighbors' gifts and supports; score = 2.20) obtained the lowest scores. Ayrault (2001) showed that some their participants tended to keep their distance from their friends, neighbors, and relatives as the mothers were afraid that they might not understand specific needs of their children [29]. Twoy (2007) reported that the neighbors' score was low and 68% of the participants tended to share their problems with their friends [21]. Lin (2000) reported that the item No.29 (mean score=3.29) and the item No. 8 (mean score = 3.33) obtained the highest scores [7]. In addition, Pritzlaff (2001) showed that gaining social support was a frequently used approach by the mothers [30]. Moawad (2012) maintained that following reframing and seeking social support was the mostly used approaches by the families from the mothers' point of view. Given that seeking social support is defined in F-COPES with the elements friends, neighbors, and relatives' support, the inconsistent findings by different studies can be explained by families' different attitudes and cultural differences about disabilities. At any rate, there is a need for further studies on families' attitudes and cultural differences as to disabilities and seeking social support.

Given the necessity of gaining social support, it seems that preventive plans need to be implemented for the families with cerebral palsy children and it is imperative to design interventions to support seeking social support in these families.

The results also showed that there was no significant relationship between family coping score based on demographical specifications except for mothers' age. The results were consistent with the studies that showed there was no significant relationship between coping and education level(1, 21). However, Kumar (2008) showed that the mothers with higher education level tended to have higher coping score [31].

Passive appraisal score of the mothers of children with gross motor function level of 4 and 5 was higher than that of the rest of participants. Since the higher motor problems mean that the child would have more problems, parents of such children tend to adopt passive appraisal approach as a passive approach.

Post hoc test (Tukey) showed that the mothers older than 40 years had more tendency to use passive appraisal; so that other aspect of life of these mother may change along with aging and lead to more tendency to passive appraisal. There is a need for further studies in this field.

As to higher mean score of family mobilization to seek support and acceptance, increase of duration of disease increases the necessity of seeking medical advices and to cover this need, families tend to consult with other families in similar situation, social institutes, and physicians. Twoy et al. (2007) showed that 93% of the participants sought information from other families in similar condition [21]. It is notable that the score of the item No.4 ("asking for information from families in similar situation) was 4.10.

In terms of limitations of the present study, small study group and the fact that participants were selected only among the mothers who had referred to rehabilitation centers are notable. Therefore, the results cannot be generalized to other mothers with cerebral palsy children. Similar studies can be done on other family members such as siblings. Comparative studies on mother and fathers at different stage of development of the child with cerebral palsy is also recommended. A quantitative study may examined the different aspects of the phenomenon.

Conclusion

From mother's perspective, different coping strategies are adopted to face the problems. Reframing was the most common strategy used by families. The results can be used by healthcare givers for implementing better support programs and improving coping skills of the parents and families. Without the support provided by healthcare givers, families might be led toward using improper coping method, which is not constructive for long/short-term adaptation to the disease of children. Moreover, psychological stresses of the caregivers of cerebral palsy children decrease the chance of finding a proper coping strategy.

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