Original Article

Quality of Life and the Associated Psychological Factors in Caregivers of Children with PKU

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Objectives: The main objective of this study was to investigate the association of psychological factors and life stressors with quality of life in caregivers of children with PKU.
Methods: Participants were caregivers of children with PKU who were referred to a child and adolescent consultation-liaison psychiatry clinic for a clinical follow up. Their demographic characteristics were recorded at first. WHOQOL-BREF and Depression-Anxiety-Stress Scale (DASS) were used to assess quality of life, depression, anxiety and stress in participants. Data analysis was performed using SPSS-11.5 statistical software.
Results: A total number of 49 caregivers were enrolled for the study. The mean age of participants and their children were 35.63±8.82, and 9.84±6.62 respectively. Of the participants, 59.2% were mothers and 40.8% were fathers. Of the children, 51% were girls and 49% were boys. According to the results, 57.1, 50.1 and 57.1 percent of the participants had mild to severe levels of depression, anxiety and stress scores respectively. The most associated factors with quality of life were as follows: caregivers' occupation; anxiety; and depression mean scores .
Conclusion: Results of the current study showed that caregivers of children with PKU have lower levels of quality of life in comparison with the general population; and the most correlated factors with quality of life were the caregivers' occupation (especially unemployment) , and high levels of depression and anxiety.

Keywords: *Caregivers, Phenylketonurias, Psychological factors, Quality of life*

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A chronic illness in children is a source of stress which affects parents' psychological wellbeing and ability to deal with negative events (1). Families of children with chronic illnesses should cope with various stressors and demands (2). Coping is a longtime process which may occur during the life course (3). Several researches have investigated the family coping capabilities and the role of risk factors and protective factors in the family of children with chronic medical or psychological illnesses. These researches have shown the importance of different factors such as socioeconomic status, demographic characteristics, family belief system, spiritual beliefs and parental self efficacy in dealing with stressors (3).

PKU disease is a chronic disorder which needs parents' daily effort to deal with the child's disabilities and to maintain a special rehabilitation and diet program; and coping with such demands and stressors may be difficult (4). Maintaining longtime nutrition regimens and applying complementary diets are the main therapeutic tasks in treating children with PKU which require perfect collaboration of the parents, and could be an important source of stress for them (4).

Once a child is born with the PKU disease, the parents are encountered with the fact that they have a child with special needs and may think that they are responsible for the child's disability because of their deficient genes (5). Feeling guilty and blaming themselves for transferring the PKU gene to their children (which is common in all of the parents of children with PKU) besides dealing with the other stressors and needs, may challenge parents' self efficacy and affect their quality of life (6).

Quality of life is a multi-aspect concept which shows performance and emotional wellbeing of a person. Different variables such as cultural, family and personal demographic factors, life stressors, psychological or medical illnesses may affect quality of life. Up to now, no study has investigated quality of life and the associated factors in parents of children with PKU. In this study, we investigated the quality of life and the role of demographic characteristics, and psychiatric conditions in a group of caregivers of children with PKU.

Materials and Method

Participants were caregivers of children with PKU who were referred to the child and adolescent consultation liaison psychiatry clinic of children medical center in Tehran for a routine clinical follow up. Participants were selected based on convenient sampling method.

Procedure

The current study was cross sectional. After describing the objectives of the study to the parents, the consent form was obtained; and the caregivers were asked to complete the demographic characteristic questionnaire. Depression-Anxiety-Stress Scale (DASS) and WHOQOL-BREF were also completed by the parents under the supervision of a trained clinical psychologist. If a caregiver was unable to complete the questionnaire by him/her self, the clinical psychologist asked the questions orally and completed the questionnaires.

Instruments

Demographic questionnaire was a self made questionnaire which consisted of questions about age, gender, marital status, economic status, educational level, occupation, and history of medical, psychiatric and substance use disorders.

Quality of life was assessed using the Farsi version of WHOQOL-BREF. The WHOQOL-BREF is a 26 item questionnaire consisting of four sub domains including: physiological, psychological, social relationship and environmental health and also two overall QOL and general health items. Its psychometric properties were evaluated for the Iranian population. According to the results of this evaluation, the Farsi version of WHOQOL-BREF had acceptable validity and reliability in Iranian population (7).

3. Depression, Anxiety and Stress Scale (DASS) was used to evaluate the severity of depression, anxiety and stress symptoms in participants. DASS is a 42 item self-report measure. This measure is used to evaluate the negative emotional states of depression, anxiety and stress; and its psychometric properties were evaluated and had satisfactory validity and reliability (8-10). The Farsi version of DASS was used for Iranian studies.

Data analysis

Descriptive characteristics and the severity of WHOQOL-BREF sub scales and DASS are reported by statistics including frequency, percentage, mean and standard deviation. Pearson and Spearman correlation and stepwise linear regression statistical analysis were used to detect the association between different variables. Data analysis was performed using SPSS-11.5 statistical software.

Results

The participants were 49 caregivers of children with PKU. The mean age of care givers and their children were 35.63±8.82 and 9.84±6.62. Of the participants, 59.2% were mothers and 40.8% were fathers; and of children, 51% were girls and 49% were boys. All the participants were married. The mean age of PKU diagnosis and the mean age for prescription of special diet were 4.72±3.75 and 5.87±5.41 respectively. Of the participants, 16.3% and 6.1% have reported another chronic illness and sever psychiatric disorder in their first degree family members. History of current substance use disorder was found in 22.4% of the participants' family members. The mean scores of depression, anxiety and stress levels in participants were 15.81±11.79, 12.10±11.19 and 18.73±11.23 respectively. Table 1 demonstrates the distribution of participants in mild to severe levels of depression, anxiety and stress. The mean scores of quality of life subscales and total score in participants are reported in Table2.

Correlations

According to the results, among demographic characteristics, the most correlated factor with quality of life was caregivers' occupation; and among life stressors, the most correlated factor was history of substance use (see Table 3). These results also showed that depression, anxiety and stress were associated with quality of life in participants (see Table 4).

To detect the most predictor factors for quality of life subscales, stepwise linear regression model of analysis was used. Accordingly, the most correlated factors with the physiological subscale were caregivers occupation (Beta:-.482 & CI:-5.169 to -1.805), and anxiety (Beta:-.335 & CI:-.551 to -.099). For the psychological subscale, depression (Beta:-.437 & CI:-.865 to -.214); and for the social subscale caregivers' occupation (Beta:-.362 & CI:-8.898 to -1.398), and depression (Beta: -.294 & CI:-1.010 to -.055) showed the most correlation. The most correlated factors for the environment subscale were caregivers' occupation (Beta:-.342 & CI:-5.898 to -.768) and anxiety (Beta: -.297 & CI:-.732 to -.044). Between different occupations, the employed participants had the highest scores of quality of life subscales, and unemployed participants had the lowest, and those with other jobs were in the middle range.

Discussion

The birth of a child with PKU is a great psychological stressor for parents who are faced with this fact that they ought to care for a child with special needs and diet. The objectives of the current study were to investigate demographic factors and the means of depression, anxiety and stress scores in caregivers of children with PKU. The next objective was to investigate the association of demographic characteristics, life stressors frequencies and depression, anxiety and stress mean scores with quality

Table 1. The distribution of participants in different levels of depression, anxiety and stress

	normal	mild	moderate	sever	Very sever
	N (%)	N (%)	N (%)	N (%)	N (%)
Depression	21 (42.9)	4 (8.2)	10 (20.4)	5 (10.2)	9 (18.4)
Anxiety	23 (49.9)	6 (12.2)	4 (8.2)	4 (8.2)	12 (24.5)
Stress	21 (42.9)	7 (14.3)	9 (18.4)	5 (10.2)	7 (14.3)

Table 2. The WHOQOL-BREF subscales mean scores in the parents

WHOQOL-BREF subscales	Raw scores Mean (SD)	Transformed scores: (0-100) Mean (SD)
Physiological	13.36±2.83	49.97±10.85
Psychological	11.28±2.90	50.22±14.55
Social	12.54±3.42	53.40±21.37
Environmental	10.42±2.34	40.14±14.62

Table3: Correlation between demographic characteristics and life stressors with quality of life sub scales

	Physiological		Psychological		Social		Environmental		Total	
	r	p	r	p	r	p	r	p	r	p
Caregivers' gender	-.109	.461	-.233	.111	-.385	.007	-.446	.001	.056	.704
Caregivers age	-.099	.492	-.007	.961	-.286	.046	-.044	.763	.218	.132
Caregivers education	.132	.365	.103	.479	.065	.657	.281	.050	-.204	.160
Caregivers job	.382	.007	.137	.349	.330	.021	.284	.048	.152	.296
Gender of children	.048	.743	-.230	.112	-.221	.127	-.030	.836	-.102	.485
Children age	-.092	.529	.080	.583	-.051	.729	.123	.400	.285	.048
Children education	.044	.766	.095	.514	.120	.412	-.065	.655	.208	.152
Age at diagnosis	.097	.509	.074	.613	-.016	.914	.001	.996	.006	.966
Age at special diet prescription	.043	.768	.060	.683	.087	.553	.261	.070	.155	.287
History of chronic medical illness	-.012	.936	.112	.443	.154	.292	.259	.073	-.128	.382
Family history of substance use disorder	.305	.033	.110	.452	.303	.034	.175	.228	-.305	.033
History of psychiatric disorder in the family	.073	.619	.182	.210	.112	.442	.015	.918	-.145	.321

Table4: The correlation between quality of life subscales and depression, anxiety and stress mean scores

	Physiological		Psychological		Social		Environmental	
	r	p	r	p	r	p	r	p
Depression	-.432	.002	-.437	.002	-.385	.007	-.379	.007
Anxiety	-.441	.002	-.351	.031	-.280	.054	-.369	.009
Stress	-.415	.003	-.411	.003	-.228	.119	-.363	.010

of life in the parents of children with PKU. Such a study has not been conducted in Iran up to now, and the results of this study can demonstrate the necessity of attending to psychological aspects of having a child with PKU or other chronic diseases.

The results of the current study showed that depression, anxiety and the stress level of these parents are higher than the parents with healthy children.

This study also showed that occupation, depression and anxiety are the most important factors that may affect the quality of life of these parents.

Dealing with the PKU demands is an important concern that therapists and professionals have focused on for many years. A study conducted in Iran revealed that the rate of PKU in the Iranian population is predicted to be one in 3672 (11).

Some studies have shown that those parents, who have started their children's treatment earlier, experienced fewer difficulties. In addition, these studies have shown that nutrition regimen is one of the most important stressor factors affecting parents. They ought to keep their child's diet without being inflexible or restrictive; this can be a main source of stress for parents of children with PKU (12). This kind of stress affects marital relationships and child's dietary control as well. However, it should be considered that If PKU is diagnosed early and the appropriate diet is kept, parents could be more confident and less concern about their children's treatment outcomes (13).

In a study, Nedjat et al have investigated the quality of life in Tehran capital city community population. According to their results the mean scores of WHOQOL-BREF subscales were 14.3 (SD=2.6) for physical health, 13.4 ±2.6 for psychological health, 13.9±2.6 for social relationships, and 12.3±2.4 for environment (14). The comparison of our findings with these results shows lower levels of quality of life in caregivers of children with PKU than the general population. The results of our study also showed that depression, anxiety and stress levels of these parents are higher than the general population; and our results is congruent with that of Read and et al (5) study in which they showed parents of children with PKU have difficulty accepting the disease; and awareness of their children's illness could be a great stressor for them; and therefore, they show more frequent depression and anxiety symptoms.

Conclusion

Results of the current study demonstrates that caregivers of children with PKU have lower levels of quality of life in comparison with the community population; and the most correlated factors with quality of life in them are caregivers' occupation (specially unemployment), and high levels of depression and anxiety.

Limitations

This study has been conducted in the children medical center in Tehran as a cross sectional design. The sample size was small and participants were the parents of children with PKU. Conducting a study with a larger sample of both caregivers and patients is recommended; and it is also recommended that such a study be conducted in other provinces of the country.

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References

1. Bromley J, Hare DJ, Davison K, Emerson E. Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. Autism 2004; 8: 409-423.
2. Summers JA, Behr SK, Turnbull AP. Positive adaptation and coping strengths of families who have children with disabilities. In: Singer GHS, Irvin LK, eds. Support for caregiving families: Enabling positive adaptation to disability. Baltimore: Paul H. Brookes Publishing; 1989.
3. Levinson DJ. A conception of adult development. Am Psychol 1986; 41: 3-13.
4. Coyne JC, Racioppo MW. Never the Twain shall meet? Closing the gap between coping research and clinical intervention research. Am Psychol 2000; 55: 655-664.
5. Read CY. Using the impact of event scale to evaluate psychological response to being a phenylketonuria gene carrier. J Genet Couns 2004; 13: 207-219.
6. Weil J. Psychosocial genetic counseling. New York: Oxford University Press; 2000.
7. Nedjat S, Montazeri A, Holakouie K, Mohammad K, Majdzadeh R. Psychometric properties of the Iranian interview-administered version of the World Health Organization's Quality of Life Questionnaire (WHOQOL-BREF): a population-based study. BMC Health Serv Res 2008; 8: 61.
8. Lovibond PF, Lovibond SH. The structure of negative emotional states: comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. Behav Res Ther 1995; 33: 335-343.
9. Brown TA, Chorpita BF, Korotitsch W, Barlow DH. Psychometric properties of the Depression Anxiety Stress Scales (DASS) in clinical samples. Behav Res Ther 1997; 35: 79-89.
10. Antony MM, Bieling PJ, Cox BJ, Enns MW, Swinson RP. Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. Psychological Assessment 1998; 10: 176-181.
11. Azadi B, Seddigh A, Tehrani-Doost M, Alaghband-Rad J, Ashrafi MR. Executive dysfunction in treated phenylketonuric patients. Eur Child Adolesc Psychiatry 2009; 18: 360-368.
12. Bilginsoy C, Waitzman N, Leonard CO, Ernst SL. Living with phenylketonuria: perspectives of patients and their families. J Inherit Metab Dis 2005; 28: 639-649.
13. Simon E, Schwarz M, Roos J, Dragano N, Geraedts M, Siegrist J, et al. Evaluation of quality of life and description of the sociodemographic state in adolescent and young adult patients with phenylketonuria (PKU). Health Qual Life Outcomes 2008; 6: 25.
14. Nedjat S, Montazeri A, Holakouie K, Mohammad K, Majdzadeh R. Quality of Life of Tehran's Population by WHOQOL-BREF questionnaire in 2005. Hakim Research Journal 2007; 10: 1- 8.