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

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 longitudinal 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.

Instrumnts
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).

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...
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 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. 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 child's dietary control as well.

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.

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 the families of children with PKU than the general population. Such a comparison can demonstrate the necessity of attending to psychological aspects of having a child with PKU or other chronic diseases.

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

|                      | normal (%) | mild (%) | moderate (%) | sever (%) | Very sever (%) |
|----------------------|------------|----------|--------------|-----------|----------------|
| 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         | 11.26±2.90           | 50.22±14.55                            |
| Social                | 12.54±3.42           | 53.40±21.37                            |
| Environmental         | 10.42±2.34           | 40.14±14.62                            |

Table 3: 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  | 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     | .007 | .509 | .074 | .613 | -.016 | .914 | .001 | .996 | .006 | .966 |
| Age at special diet prescription | .043 | .768 | .060 | .683 | .087 | .555 | .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 |

Table 4: 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  | r  | p  |
| Depression           | -.432 | .002 | -.437 | .002 | -.385 | .007 | -.379 | .007 | -.441 | .002 | -.351 | .031 | -.280 | .054 | -.369 | .009 |
| Anxiety              | -.441 | .002 | -.351 | .031 | -.280 | .054 | -.369 | .009 | -.415 | .003 | -.411 | .003 | -.228 | .119 | -.363 | .010 |
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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