

Self-Care Education Effect on Patient Quality of Life with Phenyl Ketone Urea in Medical Center in Tehran, Iran

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Abstract. Chronic diseases are common health problems around the world. Although health behavior habits are affected by the incidence and severity of them. Phenyl ketone urea disease is an autosomal recessive disorder with enzymatic deficiency that causes these patients to be at risk by developing mental disorders. This study attempts to investigate the effect of self-care education on the quality of life of phenyl ketone urea in Tehran Children Medical Center in order to improve the quality of life in the country. This study is cross-sectional and interventional, in which patients between 7 to 35 years old were 99. Data collection tool was a standard questionnaire of quality of life with 36 questions including 9 quality of life components. For data analysis, T-Test and linear regression were used. In the control group, the mean change in quality of life and the study group were 37.99 ± 13.21 and 55.64 ± 5.57 respectively ($p < 0.001$), and the results showed a significant correlation between self-care education and quality of life. According to the heritability of the Phenyl Ketone Urea disease as well as lack of control of physical and mental health disorders that cause illness, continuing education programs could lead to a dramatic reduction in behavioral disorders. Self-care education can be designed to comply with the patient which plays an important role in improving the quality of life and level of public health of society.

Keywords: Self-Care, Quality of Life, Phenyl Ketone Urea, Education.

INTRODUCTION

Chronic diseases are common health problems around the world that creates health behavior habits affected by the incidence and severity of them (Newby, 1996). Recently human thoughts have changed about health and diseases, and this change is as a result of people's perception of the modification of lifestyle, and chronic disease prevention are remarkably effective or to be controlled (Karen, 1997). Diseases can cause changes in

quality of life (Lawrence *et al.*, 1998). Phenyl ketone urea disease is an autosomal recessive disorder. Phenylalanine hydroxylase enzyme that is essential for the metabolism of phenylalanine in the blood, if decreases in the liver, leads to increasing phenylalanine in the blood and finally leads to brain damage (Banta-Wright, 2015).

The disease, without treatment, leads to severe mental

retardation, seizures, behavioral problems and delay in the development of language. Children who are treated early have average intelligence, however they differ in cognitive performance relative to peers growing. Academic and cognitive performance in children with phenyl ketone urea are significantly less than healthy peers (Soleymani, 2015). It has been reported then there are mental disorders such as low self-esteem, less motivation, loss of independence and reduced social competence in the early treatment of children. However, youth and adults may be at risk for depression, anxiety and social isolation (Phenylketonuria - Quality of life questionnaires). Untreated disease leads to severe mental retardation. By early diagnosis with treatment of appropriate regimen, one can take advantage of normal Intelligent Quotient in life. So in this class of diseases, screening is very valuable (Eijgelshoven, 2013). Self-care education as an independent factor can reduce the risk of complications from lack of care. Non-communicable disease control policy managers have plans for health improvement action in order to control the diseases and health development. According to the preferences in Ministry of Health and policy development programs in the control and priority prevention to treatment, this study determined the role of education in controlling and improving the health of people. In the past, studies were conducted on other diseases that are effective in patients, so this study was conducted in order to improve the conditions of phenyl ketone urea patients in Iran. Phenylalanine is an essential amino acid for the body that a complete removal of it can cause undesirable changes in the bone tissue, stop in development, loss of appetite, fever and fatigue. Though it is impossible to remove completely. Therefore, in terms of tolerance, the amount of phenylalanine intake should be limited that the amount of blood remains in the permissible level. People with this disease cannot freely choose their favorite foods. The use of foods containing high amounts of phenylalanine, causing severe limitations of other foods and then lack of energy and nutrients is required. Phenyl ketone urea may impose the patients and society on economic burden. These costs includes direct costs of the disease related to the use of resources to manage their condition, such as low-protein foods, supplements, medications, laboratory monitoring and health visiting. In addition, indirect costs related to loss of efficacy (Bosch *et al.*, 2015). Training regimen is the only way to control this disease. Early diagnosis, development and maintenance in diet and self-care education throughout the life is very effective for that patient to be healthy. Informing the patient through self-care education will help to promote self-management, reduction of pain and prevent other injuries. The patient with enough knowledge and skills can make decisions to solve their related problems. Education is a low-cost way to reduce pain and drug and its benefits also remains for years.

Most studies in this area suggest that the patients with better care, had significant pain relief and have been able

to cope and adapt to their problems. Therefore, the objective of this study is to determine the effect of self-care education on quality of life for phenyl ketone urea patients at Children's Medical Center in Tehran.

METHODS

A randomized clinical trial were conducted for the phenyl ketone urea patients admitted to the clinic in Children's Medical Center, Tehran. Participants in the study were divided randomly into two groups. Block randomization is done by the software Stata version 14. Lists groups to intervene in this process with the coordinator remain reserved. The person in charge of the evaluation process did not know about the criteria for entry, exit and registered people.

The sample size according to previous studies was considered with 0.05 Cronbach's alpha .Considering the standard deviation of 9.2 and 20.86 to improve quality of life, at least 10 increase points are expected. The formula for calculating the sample size of 84 patients in each group item was formulated, and placed 42 people in each group assuming 15% loss during the study, and 48 patients in each group were required. In this study, the sample size that was used to measure quality of life was questionnaire SF36. A questionnaire composed of 36 questions, including questions related to physical health, mental health, social relationships and environmental health which varies were prepared based on the Likert scale. In the questionnaire, the score for the positive changes was 5 and for the negative points 1 was considered. Statistical analysis on quality of life was compared before and after intervention by using the paired T-Test mean scores. For the variables of age, sex and quality of life, multiple linear regression model was considered for each dimension with Cronbach's alpha 0.05. All of the analysis were performed by using SPSS version 22. Afkhami and Mazloomi (2002) have translated and validated the questionnaires used in this research.

RESULTS AND DISCUSSION

Results showed that between girls and boys in the intervention group referred to the clinic of Children's Hospital Medical Center of Tehran by assumption of homogeneity of variance with age 7 to 35 years old, and there is a significant increase of 5-10% in physical performance and other variables in the study. The results of test research hypotheses based on the variables show respectively according to the values obtained from tests performed between self-care education with elements of physical performance, Physical limitations, pain management, emotional problems, vitality and control fatigue, emotional health, social functioning, general health and quality of life. There is a meaningful relationship.

Table 1- T-Test results

Variable	Paired Samples Correlations				
	Control	Before Intervention	Control	After Intervention	P-Value
		Mean±SD		Mean±SD	
	group 0	Group 1	group 0	Group 1	
Physical Function	10.49±61	29.18 .28±76.22	48.100±29.4	91.33±10.59	
Physical limitation	36.30±38.12	37.65±38.40	80.35±09	9.64±19.00.38	.000
Emotional problem	71.32±85.08	31 .37±85.35	04.31±85	7.46.35±57.11	.000
Vitality .control exhaustion	10.52±30.10	93.51±49.11	20.52±67.10.30	63±59.6	.000
Emotional Health	36.08±9.64	39.67±12.29	39.08±6.64	62.69±9.10	.000
Social Function	31.75±19.59	36.73±24.79	32.75±20.80	83.41±14.25	.000
Pain management	56.15±21.38	61.10±21.03	57.05±22.26	87.19±14.30	.000
General Health	15.50±6.26	16.83±9.77	15.45±6.15	39.74±7.09	.000
Quality of Life	38.71±12.83	37.99±13.21	38.60±12.59	55.64±5.57	.000

Table 1. T-Test results showed that physical function from baseline increases from 39.24 to 69.49 after the Program.

Table 1. T-Test results showed that emotional health from baseline increases from 37.85 to 49.25 after the Program.

Table 1. T-Test results showed that social function from baseline increases from 34.21 to 58.72 after the Program.

Table 1. T-Test results showed that quality of life from baseline increases from 38.35 to 47.03 after the

Program. In the control group, the mean change in quality of life was 37.99±13.21 and in the intervention group, the mean change in quality of life was 55.64 ± 5.57, (P<0.001). Hence, there is a significant correlation between self-care education and quality of life.

The results showed that self-care indicates the person's ability to separate from each other's intellectual and emotional processes. In other words, there is a degree of emotional independence that a person can be in the autonomous and rational decision without drowning in the emotional atmosphere or situations.

Thus, according to the results of this research, it can be said that in this regard the control group have less ability than intervention group. This result was consistent with the study of Schneider *et al.*, (1985), as they stated that self-care is dependent on several factors such as quality of life.

Statistical analysis showed that with 95% confidence the hypothesis is confirmed, so that self-care variables in the control group less than intervention group referred to clinic Children's Medical Center of Tehran. In general, numerous studies have shown that many health problems and mental disorders have emotional and psychosocial roots. Research in phenyl ketone urea disease has shown that three major factors are associated with the disease such as poor mental health, disabilities in community health and lack of communication skills (Mac Donald *et al.*, 1991). Thus, according to the scientific evidence and the results of this research in order to prevent social damage, it is necessary to increase the issue of mental health because of its importance (Moradi, 1389: 33).

Quality of life is an ability and creativity to influence in different environments and situations of life and somehow show life satisfaction. Quality of life represents a kind of life satisfaction, which can be seen by looking at the values of each person in his life and his interactions (Ryan 2001).

Ilen and Morof (1998) also found that changes in social functioning domains motivate adaptive behavior, social support and self-worth.

The results of this study in the areas of public mental status and role limitations shows that there was significant difference in the two groups due to the psychological situation. It is for this reason that they can learn more about the disease and realize that self-care are important points, and patients under study with greater knowledge about controlling disease and self-care have more autonomy and self-esteem in terms of mental status in better conditions, and their ability and strength have increased.

In this regard, Molassiotis (1997) stated that positive attitude towards the disease, having the confidence and effective internal health control has importance over the quality of life.

CONCLUSION

According to the scientific evidence and the results of this research in order to prevent social damage, it is necessary and important to give more attention to mental health topics. Meanwhile, the self-care program is one of the most headlines targets for senior managers. Therefore, self-care education programs that promote health and quality of life of a community is recommended.

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