ARAŞTIRMA / *Research Articles*

Çocuklarında Görülen Kronik Hastalık Tanısıyla Çocuk Servisinde Bulunan Annelerin Yaşam Doyum Alma Durumlarının İncelenmesi

An Examination of Life Satisfaction Situations of the Mothers who is in the Children's Services Because of the Diagnosis of Chronic Illness in Their Children/

Melike YAVAŞ ÇELİK,[1] Yadigar POLAT[2]

ÖZ

Amaç: *Bu çalışmayla kronik hastalıklı çocuğa sahip annelerin yaşam doyumlarının belirlenmesi amaçlanmıştır. Yöntem: kesitsel nitelikte olan bu çalışma soru formu ve yaşam doyum ölçeği kullanılarak yapılmıştır. Verilerin analizinde SPSS programı kullanılmıştır.* ***Bulgular:*** *İlişkili olabileceğini düşündüğümüz annelerin demografik verileri ile yaşam doyum ölçeğinin toplam ortalama puanları karşılaştırıldığında yalnız annelerin medeni durumlarında anlamlılık elde edilmiştir (p<0,05).* ***Sonuç:*** *çalışmamızdaki çocukların kronik hastalık olarak en fazla astım hastalığı ile karşı karşıya olduğu ve yaşam doyumu ölçeğine verilen yanıtlar göz önünde bulundurulduğunda annelerin yaşam doyumlarının düşük olduğu (Tablo 4) ve evli annelerin (16,7) yaşam doyum ölçeği toplam puanlarının evli olmayanlara(18,7) göre daha düşük olduğu belirlenmiştir (p<0,05) (Tablo 3).*

Anahtar Kelimeler: *Kronik hastalıklar, Çocuklar, Yaşam doyumu*

ABSTRACT

Aim: *This study is aimed to determine the life satisfaction of families that have children with chronic ilnesses.* ***Methods:*** *This cross-sectional study was conducted using questionnaire and life satisfaction scale. In the analysis of the data, SPSS program was used. Results: When the total average scores of the life satisfaction scale were compared with the demographic data of the mothers that we thought might be related, only marital status of the mothers was significant(p <0,05)(Table 3).* ***Conclusion:*** *Children in our study are most likely to have asthma as a chronic disease and the life satisfaction of the mothers was low when the responses to the life satisfaction scale were considered (Table 4) and married mothers(16,7)were found to have lower total life satisfaction scores than those who were not married(18,7)(Table 3).*

Keywords: *Chronic diseases, Children, Life satisfaction.*

Introduction

Chronic illnesses are diseases that are not usually cured, permanent, slow-moving, often leave permanent injuries, and have serious effects on the general lifestyle(1,4). Chronic childhood diseases are diverse as orthopedic problems, congenital heart diseases, epilepsy, chronic renal failure, cancers, hemophilia, diabetes, cystic fibrosis, asthma. Family members suffer many losses as the chronic disease enters the family system. In addition to the physical and functional losses experienced by the patient, hopes for the whole family, dreams for the future, definition of roles, identity of the family owned before the disease, loss of freedom due to added responsibilities is experienced. At the same time, having a child with a chronic illness in the family affects the whole family and the cycle of the family. It alters the physical, emotional and economic balances of the family, prevents the family from getting satisfied from life and reduces the quality of life(3,4).

The subjects "happiness of human beings and what conditions provide happiness for people" have been remarkable subjects since ancient times. Recently, happiness of human has been examined in terms of concepts such as psychological well-being, subjective well-being, quality of life, life satisfaction and positive affect (5,6). In Turkey, according to the report of TÜİK (2014); Life Satisfaction Survey, 51.9% of the women identify themselves as happy, 18.5% of these women show their children as the source of happiness and 69.3% of these women show their families as the source of happiness[7]. Life satisfaction represents the cognitive direction of subjective well-being from concep-

1.Arş. Gör. Kilis 7 Aralık Üniversitesi Yusuf Şerefoğlu Sağlık Yüksekokulu *E-posta Adresi: www_com_tr@hotmail.com*
ORCİD ID: 0000-0002-1155-1022
2. Yrd. Doç. Dr. Kilis 7 Aralık Üniversitesi/Sağlık Hizmetleri Meslek Yüksekokulu
ORCİD ID: 0000-0001-5603-2149

Gönderim Tarihi:08.08.2018 - Kabul Tarihi:13.04.2019

ts related to human happiness. Subjective well-being is defined as cognitive and emotional evaluation of a person's life. This assessment includes the emotional response to the events and the cognitive assessment of satisfaction(5,6). According to Diener and Lucas (1999), life satisfaction includes life satisfaction from life, desire to change life, satisfaction from the past, future fulfillment, and the opinions of one's relatives about that person's life. Satisfying areas can be work, family, leisure time, health, money, self, and close surroundings(5,6). Life satisfaction is related to age, sex, working and working conditions, education level, religion, race, income level, marriage and family life, social life, personality traits, biological factors(8).

From the moment a child is born, he/she needs age-specific needs such as love, interest and play in addition to abdominal satiety, cleaning his/her bottom and sleeping[9]. While in developed societies, child care and housekeeping are perceived as the common task of spouses(10), it still dominates the point of view that "the nest is made by a female bird" in Turkey(11). Positive experiences of the individual cause increasig the level of life satisfaction and decrasing the negative experiences(12). However, women are burdened with such heavy burdens that they can not carry home work, as well as children and their needs. To be able to cope with such loads, the woman can become a weary person who does not know where to find her life without sacrificing her special needs by making sacrifices. The lack of social support for a woman and the problem of having a child with a chronic illness, while trying to catch up with housework, can lead to inadequate life and lack of problem-solving skills. It is aimed to determine the life satisfaction of mothers who have chronic ill children by working in this framework.

Materials and Methods

Type of Research

Research is a cross-sectional and descriptive study.

Research Ethics

After obtaining the institutional permission from Kilis State Hospital, necessary permissions were obtained from Gaziantep Clinical Investigation Ethics Committee.

Method of Research:

This cross-sectional study was conducted at Kilis State Hospital between August-December 2016. In the study conducted by the field survey method, the survey technique was used.

The Universe and Sampling of Your Study

Mothers who applied to the hospital created the universe of work. The sample of the study consisted of Turkish citizen mothers who admitted to Kilis State Hospital child service, child policlinic and pediatric emergency services, who met the research criteria (having chronic ill child, volunteering to participate in the study, no hearing problem) and participating in the research between the specified dates.

Collection of Data:

Datas were collected by using a questionnaire on sociodemographic data, 'Life Satisfaction Scale' and interwieving with people face to face.

Data Collection Tools

1. ***Questionnaire on socio-demographic data and child and maternal health:***

The questionnaire prepared by the researcher in the light of literature information; is made up of such questions socio-demographic data; age, gender, marital status, educational status, working status, economic situation.

2.***Life Satisfaction Scale***

The Satisfaction with Life Scale (SWLS) developed by Deiner, Emmons, Larsen and Griffin (1985). Life Satisfaction Scale is a Likert-type self-report scale consisting of 5 items ranging from "not appropriate" (1) to "complete" (7). Diener and colleagues found the reliability of the scale to be Cronbach Alpha = .87 in the original study. They obtained the criterion-dependent validity as .82(5). Adapting to Turkish was done by Köker (1991). The scale consists of five items related to life satisfaction. Each item is answered according to a graded answer system of 7 (1: not suitable - 7: very convenient). The scale, which aims to measure general life satisfaction, is suitable for all ages from adolescents to adults. Translation of scale into Turkish and the validity study with the "superficial validity" technique of the scale was carried out by Köker (1991) (13). Then, Dağlı and

Baysal (2016) conducted validity and reliability as a 5-point likert scale[13]. In our study, we used Likert scale of 5 (1: Absolutely Not Participate - 5: Absolutely Participate). In the study conducted by Yetim (1993), the reliability of the scale was found high (Alpha = .86) and test-retest reliability (.73) was obtained(14,15).

Evaluation of Data

SPSS program was used in the analysis of the data. Frequency analysis was performed at percentages, The Student-T test was used to compare the demographic data of the mothers and the mean of the scales.

Results

Table 1. Distribution of demographic data of the mothers (2016,Kilis State Hospital)

Age of mother	**n**	**%**
Age 15-25	27	25.5
Age 26-35	41	38.7
Age 36-45	30	28.3
Age 46-55	8	7.5
Education level of mother	**n**	**%**
Illiterate	34	32.1
Literate and elementary school	23	21.7
Secondary-high school	41	38.7
College and over	8	7.5
Where do mothers live?	**n**	**%**
Province	61	57.5
District	32	30.2
Village	13	12.3
The working condition of the mother	**n**	**%**
Housewife	88	83
Civil servant	14	13.2
Worker	4	3.8
Number of children of mother	**n**	**%**
1 child	21	19.8
2 children	32	30.2
3 children	23	21.7
4 children and over	30	28.3
Marital status of the mothers	**n**	**%**
Married	99	93.4
Divorced	7	6.6
The family type of mothers	**n**	**%**
Nuclear family	77	27.4
Extended family	29	72.6
Total	106	100

The majority of the mothers are between the ages of 26-35 (38.7%). Education status of mothers was stated respectively that 8.7% of them received secondary-high school education, 32.1% did not receive literacy education, 21.7% said they are literate graduated from primary school, and 7.5% had higher education. The majority (57.5%) of the mothers stated that they are resident in the province center and they are housewives (83%). When we look at the numbers of children, we see that 30.2% have 2 children, 28.3% have 4 children or over. Most of the mothers (93.4%) are married and live in large families (72.6%) (Table 1).

Table 2. Distribution of medical diagnoses of children (2016,Kilis State Hospital)

Children's disease diagnoses	**n**	**%**
Asthma	21	19.8
Heart and vascular diseases	15	14.2
Congenital diseases	13	12.2
Chronic bronchitis	12	11.3
Epilepsy	9	8.5
Chronic renal failure	8	7.5
Thalassemia	7	6.6
Diabetes Type 1	6	5.7
Chronic pneumonia	5	4.7
Hepatitis B	4	3.8
Autism	2	1.9
Other diseases	4	3.8
Total	106	100

When we looked at the medical diagnoses of children, we found that the mostly asthma (29.8%) was observed, and then respectively cardiovascular diseases (14.2%), congenital diseases (12.2%), chronic bronchitis (11.3%), epilepsy (8.5%), chronic renal failure (7.5%), thalassemia (6.6%), diabetes (5.7%), chronic pneumonia (4.7%), hepatitis B (3.8%), autism (1.9%) were observed.

Table 3. Comparison of some of the demographic data of mothers and scale averages (2016,Kilis State Hospital)

The working condition of the mother	**n**	**Average of scale**	**S.D**	**P**
Working	17	15.58	4.30	0.87
Not working	89	17.26	4.27	
Marital status of the mother	**n**	**Average of the scale**	**S.D**	**P**
Married	99	16.87	4.38	**0.07**
Divorced	7	18.7	2.62	
The existence of the social security	**n**	**Average of the scale**	**S.D**	**P**
Available	75	16.92	4.34	0.28
Not available	31	17.19	4.26	
Family type	**n**	**Average of the scale**	**S.D**	**P**
Nuclear family	29	17.93	4.47	0.98
Extended family	77	16.64	4.21	

When the total average scores of the life satisfaction scale were compared with the demographic data of the mothers that we thought she might be related, marital status of the single mothers were significant ($p < 0.05$) (Table 3).

When we look at the answers given by the participants to scale questions about life satisfaction, it is seen that for most of the questions, the most given response is 'undecided', the answer 'strongly agree'that is the positive sign of their satisfaction from life seems to be used very little (Table 4).

Also, the Cronbach's Alpha value of the life satisfaction scale was found to be 0.87. The reliability coefficient of the study by Köker (1991) was found to be .85 (13.Köker 1991). In the study conducted by Yetim (1993), the reliability of the scale was found as 0.86 (14,15)(Yetim 1993;Nergis 2013). It can be said that the reliability level of the scales is higher when the reliability of Cronbach's Alpha approaches to 1.00.

Discussion

Repeated chronic and long-term hospitalizations lead to the emotional, social and economic loss of children and their families. For the family, the sick child brings about dimensions such as child care, limitation of social life and daily activities,

Table 4. Distribution of respondents' responses to the Life Satisfaction Questionnaire (2016,Kilis State Hospital)

	Expressions	**strongly agree**		**agree**		**Undecided**		**Don't agree**		**Stronlgly don't agree**	
		n	**%**	**n**	**%**	**N**	**%**	**n**	**%**	**n**	**%**
1	**My life is close to my ideal from many directions**	1	0.9	2	1.9	65	61.3	28	26.5	10	9.4
2	**My life conditions are perfect**	1	0.9	2	1.9	76	71.7	21	19.8	6	5.7
3	**I am satisfied with my life**	0	0	3	2.9	65	61.3	24	22.6	14	13.2
4	**I've got the important things I want until now**	0	0	4	3.8	72	67.9	23	21.7	7	6.6
5	**If I were to start again, I would not change almost anything**	0	0	6	5.7	76	71.7	17	16	7	6.6

difficulties in family relations and marital relations, economic difficulties and insufficient time for other family members (15). It has been determined that caregivers are compelled in the studies with parents who care for children with chronic illness (16-19).

When we look at the work done with mothers who have child chronically ill, in the study conducted by Durualp and his friends, the quality of life determined according to the views of healthy child-adolescents and their parents was found to be higher than the quality of life determined according to the opinions of the child-adolescents with chronic illness and their parents(23). Çakan and Sezer (2010) found that more than half of the mothers with persistent disease in their children need psychological support (24). In the study by Çoşkun and Akbaş (2009), it was found that there is an inverse relationship between social support level and trait anxiety levels of women who have children with disabilities (21). It was also found that the parents who have disabled people have a lower life satisfaction than the normal parents in the work Akandere and his friends(2009) (22). In all these studies, the child's illness leads to significant changes in the family structure. The parents' lifes before the child's illness change, the child's parents, siblings and their immediate surroundings can be adversely affected by the illness because of the increasing in financial costs, the tension created by the treatment period.

Care is a multidimensional perception in terms of caregivers. Care giving leads to many strengths besides positive features such as sincerity and increase of love, care giving experience, personal development, social support from other individuals, self-esteem and personal satisfaction (1,25). In our study, when we look at the answers given to scale questions about life satisfaction by mothers who have children with chronic illness, it is seen that the most given response is 'undecided', the answer 'strongly agree' that is the positive sign of their satisfaction from life seems to be used very little (Table 4). Since there is no similar study with our study, we can say that the problems experienced in childcare can affect the life satisfaction of mothers negatively.

It has been reported that the incidence of asthma in our country and in the word is increasing and that the highest rates of asthma are seen in children (26). In our study, the proportion of children with asthma was found to be the highest chronic disease with 19.8% (Table 2). At the same time, the rate of cardiovascular disease in our study was 14.2% in the second place. According to TÜİK (2015), in 2015, the death rate of circulatory system diseases was determined as 40%(27). In addition, the proportion of children with congenital anomaly was 12.2% (Table 2). Consanguineous marriage has an important place in the formation of recessive hereditary diseases and congenital defects in society. It also causes serious health problems such as infertility, stillbirth, spontaneous abortions, child deaths, infant deaths, and congenital malformations(28). According to WHO (2013), congenital anomalies account for 23% among the causes of death in children under the age of 5 in our country (29). According to the Demographic and Health Survey (TDHS) 2014 data, the proportion of consanguineous marriages in our country was 21.3% (30). In the study of Sevinc and Yavas Çelik (2016) found that 39% of the women were married to their relatives and 7.9% had unhealthy children in Kilis(31). In the light of this information it is thought that this situation can be caused by the marriage of relatives in this region.

Factors which we think that they can effect the life satisfaction such as working status, marital status, presence of social security, and family type, only married mothers (16.7) were found to have lower total life satisfaction scale scores than those who were not married (18.7) (Table 4). This is thought to be due to the fact that married mothers have to assume the responsibilities of spouses and other children in the family as well as the care of the sick child.

In addition, only 17% of mothers work when we look at the working status of mothers in our work. In the study which is made by İçmeli and his friends, self-esteem points average of working women (75.68 ± 14.35), were found to be statistically significant as compared to the non-working women (68.32 ± 15.68) (32). In another study by Yerlikaya and colleagues (1999), women reported that their performance at work was most affected by fatigue due to the workload at home(33). As can be understood from these studies, it can be said that work is a factor that positively affects the life of the woman, but the workload at home affects the work performance.

As a result; Chronic diseases affect the lifes of both the child and other individuals in the family especially the mothers who take the most care-giving role negatively. Considering the responses to the life satisfaction scale in our study, it is found that mother's life satisfaction was low (Table 3), and married mothers (16.7) were found to have even lower total satisfaction scores than those who were not married (18.7) (Table 4).

Resources

1. Ovayolu N, Ovayolu Ö. Basic Internal Medicine Nursing and Chronic Diseases with Different Dimensions (Chapter: 18 Prevention and Conservation of Chronic Diseases) Nobel Tıp Kitapevi. 2016, Adana. Ss: 590-604.

2. Özdemir U., Taşcı S. Psychosocial Issues and Care in Chronic Diseases. Journal of Erciyes University Faculty of Health Sciences.2013; 1 (1): 57-72.

3. World Health Organization (September 2011), Non-communicable Diseases Country Profiles 2011. Access: 26.08.2012. http://whqlibdoc.who.int/publications/2011/9789241502283_eng.pdf/).

4. World Health Organization (April 2011). Global Status Report on Noncommunicable Diseases 2010, Burden: Mortality, Morbidity and Risk Factors. Access: 26.08.2012, http://www.who.int/nmh/publications/ncd_report2010/en/)

5. Diener, E. ve Lucas, R. E. Subjective well-being: Three decades of progress. Psychological Bulletin, 1999; 125 (2), 276-303.

6. Investigation of Tuzgöl Dost M. University Students' Life Satisfaction According to Some Variables. Pamukkale University Education Faculty Magazine.2007; 2 (22): 132-143

7. TUIK 2014, Life Satisfaction Survey Report.ss: 1-89 file: /// C: /Users/sahide/Downloads/4249809511446806677..pdf ..

8. Yetim U. Life Satisfaction, A study based on the organization of personal projects. Social Indicators Research, 1993, 29: 277-289.

9. Basbakkal Z., Sonmez S., Şen Celasin N., Esenay F. 3-6 Age Group Determination of Behavioral Responses Against Child Admission to Hospital Due to an Acute Disease. International Journal of Human Sciences. 2010; 7 (1): 456-468.

10. Liu M., Anderson SG. Neighborhood effects on working mothers' child care arrangements. Children and Youth Services Review. 2012;34: 740–747.

11. Kakici H., Emeç H., Üçdoğruk Ş. Women's preference for childcare in Turkey. Econometrics and Statistics. 2007; 5: 20-40.

12. Kabasakal Z., Uz Baş A. The problem solving skills as predictors of life satisfaction in teacher candidates. Education and Teaching Research Journal / Journal of Research in Education and Teaching. 2013; 2 (1): 27-35

13. Dağlı A., Adaptation of Baysal N. Life Satisfaction Scale to Turkish and Validity Reliability Study. Electronic Journal of Social Sciences.2016; 15 (59): 1250-1262.

14. Yetim, Ü. (1993). Life satisfaction: A study based on the organization of personal projects. Social Indicators Research, 29, 277-289.

15. Özdemir FK, Şahin ZA, Küçük D. Determination of caring burdens of mothers with cancer. New Medical Journal 2009; 26: 153-158.

16. Stewart MJ, Ritchie JA, McGrath P, Thompson D, Bruce B. Mothers of children with chronic conditions: supportive and stressful ınteractions with partners and professionals regarding caregiving burdens. Canadian J Nurs Res 1994; 26: 61-81. 15.

17. Babaoğlu E, Öz F. The relationship between emotional and social problems of caregivers of terminal cancer patients. Journal of Research and Development in Nursing 2003; 5: 24-33. 16.

18. Ikeda T, Nagai T, Nishimura KK, Mohri I, Taniike M. Sleep problems in pysically disabled children and burden on caregivers. Brain Dev 2012; 34: 223-229.

19. Alahan N., Aylaz R., Yetiş G. Care-giving burden of parents with children with chronic illness. Inonu University Journal of Health Sciences 2015; 4 (2): 1-5.

20. Nergis H. Determination of Difficulties of Parents of Visually Impaired Children and Predictors of Burnout and Life Satisfaction. Liberal arts

21. The Relation Between Continuous Anxiety Levels of Social Support Children and Social Support Perceptions. Ahi Evran University Kırşehir Education Faculty Magazine (KEFAD) .2009; 10 (1): 213-227.

22. Akandere M., Acar M., Baştuğ G. An Analysis of Life Satisfaction and Hopelessness Levels of Mothers and Fathers with Mentally and Physically Handicapped Children. Selçuk University Social Sciences Institute Magazine 2009; 22: 23-

32

23. Durualp E., Kara F., Yilmaz V., Alaybeyoğlu K. Comparison of the quality of life according to the opinions of children with and without chronic illness and the opinions of their parentsAnkara University Medical Faculty Magazine 2010, 63 (2): 55-63.

24. Çakan P., Sezer Ö. An Analysis of Attitudes, Anxiety Levels and Other Variables of Children with Behavioral Disorders. Firat University Journal of Social Sciences Fırat University Journal of Social Science 2010; 20 (2): 161-180.

25. TORNAN EK, Büyükgönenç L. The child with chronic and life-threatening illness. Child Health Basic Nursing Approaches. Göktuğ Publishing Ankara 2012, 185-205.

26. Erboy F., Altınsoy B. Asthma Epidemiology, Incidence Is Increasing Mu? Current Chest Disease Series 2015; 3 (2): 158-163

27. Turkish Statistical Institute, Statistics of Cause of Death, 2014, http://www.tuik.gov.tr/PreHaberBultenleri.do?id=21526 access: 24.01.2017.

28. Sevinç S., Yavas Çelik M. Influence of Relative Marriages on Child Health and Nursing Approach. Health and Society. 2016; 26 (2): 23-28.

29. WHO (2013) Distribution of causes of deaths in children under-5, Http://www.who.int/gho/countries/tur.pdf?ua=1 access: 24.01.2017.

30. The TDNS. Turkey Family Building Survey Findings, Suggestions. 1st Edition, Istanbul: Çizge Tanıtım ve Kirtasiye Ltd. Şti., 2014; 130-140.

31. Sevinç S., Yavas Çelik M. Perceived social competence and child health by consanguineous marriage. Mersin Univ Saglik Bilim Derg 2016; 9 (3): 122-130.

32. The comparison of self esteem of working and non - working women. Haydarpaşa Numune Education and Research Hospital Medical Journal. 2007, 47 (3): 354-359.

33. Yerlikaya N., Yıldırım U., Bumin M.A. Evaluation of problems of working women in terms of time and health. Health and Society. 1999, 9 (3): 27-33.