

IN TERMS OF SOME VARIANCES EXAMINATION OF LIFE QUALITIES OF THE FAMILIES THAT HAVE DISABLED CHILDREN

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ABSTRACT

Purpose of this research is to examine the life qualities of the families that have disabled children in terms of gender, number of children, income level variances. There were 322 parents who live in Kayseri province, participated to the processing relational survey model research. Random sample method was used in the research. To the people who participated to the survey, for measuring of personal information-form and life quality the Rolls-Royce Model life quality scale, which was developed by researcher, was used. In the analyzing of datum the t test, F test and Tukey test were used. In the analyzing of the acquired datum it was found that parents' genders created difference, amplitude of children and having low income negatively affects the quality of family.

Key words: disabled children, family/parent, life quality

INTRODUCTION

Child, who the family wait for with a big excitement, when he/she is born with a disability or a serious illness means that the child is going to be in need of a permanent care. Being disabled is a long process that affects both the individual and family spiritual, physical, emotional and socially. Even it is not wished there is a disabled individual live in that family. World Health Organization (WHO) defined the freedom in three types like in the following points and reported that there are differences between them (Çalık, 2004).

Impairment:It is defined as an abnormality or lack in anatomic, physical, psychological structures. This situation is not a kind of illness. It is taken into consideration as organ. It is for example partial talking loss, blindness.

Disability:In result of lack being restricted and/or lack of talent to do an activity or having problems for fulfillment of attitudes that are accepted as normal.

Handicap:It is defined as in a result of disability or lack (changes depend on age, gender and socicultural situation) a person's cannot continue his normal life. In the situation of handicap that person is disadvantageful than other people in terms of his economical and social roles.

Birth of a disabled child's in the family is a situation that affects the family members' life, emotions and attitudes negatively. Also families experience shock, rejecting, excessive sadness, guilty, refusing emotions, they try to adapt themselves to the differences that the child have, searching for solutions to this situation (Akıncı, 1999). During the caring and education of disabled children there are some difficulties families coincide. Rising of economical requirements, not having sufficient information about child's situation, changing roles of family because of disabled child, breaking ups in marriage relations, not participating to the social activities either restricted time or not having much time increase the problems for people in society who live with disabled people and also these people's attitudes towards disabled children's families. (Wallender, Varni, Babani, Dehan, & Banis, 1989; Aydoğan, 1999; Küçükler, 2001; Bilal & Dağ, 2005). Besides the stress that families experience with having a disabled child it is seen that they also experience emotional uneasiness. Resource of tension is created by not having enough information about their disabled children, difficulties that the child cannot tell his situation to the family or other people in society, attitude and health problems that seen in the

disabled individuals, not acquiring enough information about their treatment and educations, efforts for searching for a suitable education institution for their child, being in need of much more time, energy and money (Kavak, 2007).

Existence of a disabled child in the family show that there are important changes created in the structure, processing and roles of family members, it is a stress source that negatively affects the life, emotion and thoughts of family members (Özay, 2004). Tension that occurs in the family leads to distracting situations such as (General being well, social relation and work performace, Insomnina, appetite, sexual function, perception function, medical interaction disorders, physical symptoms and Activities). These distracting situations that the family coincide with may lead to serious damages to the life quality of family members.

Life quality notion had been come up with welfare and happiness word in philosophy scientific area centuries ago (Erdem, 1999). In 1970s-1980s this notion became focus point in the context of medicine science field. After this date life quality notion's importance gradually increased and life quality had started to be examined and researched in an international dimension. And World Health Organization strated determine and define this notion in 1985s (Duran, 2009). Today traditional indicators' (illness, death, expecting life hope) that are used for the measurement of health because of insufficiency in defining the healthiness level of individuals for the issue it is tried to bring clarity with life quality. In another definition life quality is 'individuals own life perceptions in the system of their culture and values system'. Life quality is a notion that beyond the personal health statement, is a wide notion includes personally being well (Eser, Fidaner, Fidaner, Elbi, & Goker, 1999). Life quality cannot only be thought individually, it also come up with encapsulating of family. Family's being pleased from life quality can be defined like this: a) providing of the family's needs, b) indulging of family members for living together, c) Family members' opportunities to do important thing for theirselves (Park, Hoffman, Marquis, Turnbull, Poston, Mannan, & Nelson, 2003).

Parents of a child who was diagnosed with chronichal illness, except for parentage responsibility they they have to burden extra responsibilities and at the same time deal with many problems (Karakavak&Çırak, 2006). Health situation of child also affects the life quality of family meaningfully at a negative or positive level (Gökler, 2008).

In this research whether families', who have disabled child, life qualities change or not depending on demographical features, number of children in the family and family income level was examined. In accordance with this examination answers of the following questions are sought.

1. Is there a meaningful difference between families', who have disabled child, genders and life qualities?
2. Is there a meaningful difference between families', who have disabled child, income level and life quality?
3. Is there a meaningful difference between families', who have disabled child, number of children and life quality?

METHOD

Research's Model

In this research disabled child's effects to families' life qualities were examined. Relational survey model was used in the research. Relational survey models are the survey models that aim to to determine changing together statement and/or degree of two or more than two variances (Karasar, 2007).

Population and Sample

Population of the sample is consisted of families with disabled child from Kayseri. Research's scale was applied to the 322 parents who were determined with randomized sampling method.

Data Collecting Tools

1- Personal Information Form:

The personal information form, which was developed by researcher, was used. Being utilized from family's number of children the classification was done based on family's income levels and minimum wage.

2- Rolls Royce Model Life Quality Scale

Rolls Royce Model was prepared under 8 topics with 49 questions; general being well, physical symptom and activity (symptoms and activity relationship), sleep disorder, appetite statement, sexual function, perception function (perception of ownself and environment), medical interaction (in need of professional help), social relations and work performance. These questions were evaluated by Özyılkan, Firat, Topel, Kars, Baltalı, Tekuzman, Karaağaoğlu, (1995) on 100 people, 7 questions were omitted and internal structure validity was found as $r=0.996$, $p<0.001$. Question paper and scale was filled by researcher through a meeting with each patient. Each meeting lasted approximately 30 minutes. In the evaluation of datum personal characteristics was calculated as independent, and questions in the life quality scale was calculated as dependent variances. For each question on the scale five option was determined, these options were graded 5,4,3,2,1 for positive questions, and for the negative questions they were graded 1,2,3,4,5. According to this ; 1, 4, 5, 7, 9, 10, 11, 16, 20, 22, 24, 27, 29, 35, 40, and

Table 12. Test Results of the Sub Dimensions of Life Quality Scale that If There is a Difference or not Depend on Families' Genders.

* $p<.05$

42 numbered questions were evaluated positive others were evaluated as negative.

Analyzing of Datum

Dimensions	Income Level	N	X	Ss	F	P
General Being Well	0-1300 1301-2500 2500 and over	149 69 104	8,48 19,33 31,81	2,74 6,57 1,21	1269,0 96	,00 0
Physical Symptoms And Activities	0-1300 1301-2500 2500 and over	149 69 104	9,99 22,49 33,29	2,11 5,78 1,88	1627,1 94	,000
Sleep Disorder	0-1300 1301-2500 2500 and over	149 69 104	11,80 9,18 11,46	1,79 2,20 3,76	23,816	,000
Appetite	0-1300 1301-2500 2500 and over	149 69 104	3,99 6,00 8,17	1,13 1,74 ,70	382,68 1	,000
Sexual Function	0-1300 1301-2500 2500 and over	149 69 104	8,23 10,95 17,25	1,14 2,76 1,26	914,12 8	,000
Perception Function	0-1300 1301-2500 2500 and over	149 69 104	10,77 16,11 24,66	1,91 3,89 2,49	852,59 8	,000
Medical Interaction	0-1300 1301-2500 2500 and over	149 69 104	15,72 10,20 6,29	2,19 3,19 1,79	512,80 5	,000
Social Communication and Work Performance	0-1300 1301-2500 2500 and over	149 69 104	10,77 23,52 35,97	2,55 6,26 1,98	1549,1 55	,000

In the evaluation of research datum for the determining of demographical features of families with disabled child the t test, for the determining of if their life quality levels are differed or not depend on family income the F test and for finding out the difference from which group it was derived the Tukey test was used.

Table 13. Test Results of the Sub Dimensions of Life Quality Scale that If There is a Difference or not Depend on Families' Income Levels

*p<.05

FINDINGS

When life quality scale sub dimensions were examined depend on families', who have disabled child, genders: In the sub dimension of general being well; male participants' arithmetical average was (X=20,44), female participants' arithmetical average was found as (X=17,06). Between averages (t= 2,743 p<.05) there was a meaningful difference found. In the

Dimensions	Gender	N	X	Ss	T	P
General well being	Male	122	20,44	10,46	2,743	,006
	Female	200	17,06	10,87		
Physical Symptoms and Activities	Male	122	22,71	9,82	3,332	,001
	Female	200	18,66	11,00		
Sleep disorder	Male	122	10,62	3,35	-2,529	,012
	Female	200	11,44	2,45		
Appetite	Male	122	6,16	2,23	2,535	,012
	Female	200	5,53	2,11		
Sexual Function	Male	122	12,15	4,37	1,382	,16
	Female	200	11,47	4,23		
Perception Function	Male	122	17,28	6,59	1,879	,061
	Female	200	15,86	6,58		
Medical Interaction	Male	122	10,59	4,63	-2,660	,008
	Female	200	12,04	4,79		
Social Communication and Work Performance	Male	122	24,27	11,27	3,229	,001
	Female	200	20,03	11,53		

sub dimension of physical symptoms and activities; male participants' arithmetical average was (X=22,71),

female participants' arithmetical average was found as (X=18,66). Between averages (t= 3,332 p<.05) there was a meaningful difference found. In the sub dimension of sleep disorder; male participants' arithmetical average was (X=10,62), female participants' arithmetical average was found as (X=11,44). Between averages (t= -2,529 p<.05) there was a negative directional meaningfulness found. In the sub dimension of appetite; male participants' arithmetical average was (X=6,16), female participants' arithmetical average was found as (X=5,53). Between averages (t= 2,535 p<.05) there was a meaningful difference found. In the sub dimension of medical interaction; male participants' arithmetical average was (X=10,59), female participants' arithmetical average was found as (X=12,04). Between averages (t= -2,260 p<.05) there was a negative directional meaningfulness found. In the sub dimension of social communication and work performance; male participants' arithmetical average was (X=24,27), female participants' arithmetical average was found as (X=20,03). Between averages (t= 3,229 p<.05) there was a meaningful difference found. In the sub dimension of sexual function; male participants' arithmetical average was (X=12,15), female participants' arithmetical average was found as (X=11,47). Between averages (t= 1,382 p>.05) there was not a meaningful difference found. In the sub dimension of perception function male participants' arithmetical average was (X=17,28),

female participants' arithmetical average was found as ($X=15,86$). Between averages ($t= 1,879$ $p>.05$) there was not a meaningful difference found.

When life quality scale sub dimensions were examined depend on families', who have disabled child, income levels; There were meaningful differences found in the sub dimensions of General Being Well, Physical Symptoms and Activities, Sleep Disorder, Appetite, Sexual Function, Perception Function, Medical Interaction, Social Communication and Work Performance. For the determination of the difference that from which group it was derived according to families' income level the meaningfulness analysis was done. The Tukey Test findings took part in the Table 3 for the determination of the difference that from which group it was derived from according to families' income level.

Table 14. Multiple Comparison Test Results that from which group the difference derived in the life quality scale sub dimensions of the Families' Income Levels

Dimensions	Child Number	N	X	Ss	F	P
General Being Well	1	124	30,73	3,60	1330,53 6	,000
	2	55	16,49	4,50		
	3 and over	143	8,31	3,06		
Physical Symptoms and Activities	1	124	32,17	3,70	1051,55 3	,000
	2	55	19,20	5,29		
	3 and over	143	10,19	3,43		
Sleep Disorder	1	124	11,41	3,43	26,368	,000
	2	55	8,80	2,08		
	3 and over	143	11,79	1,98		
Appetite	1	124	8,04	1,03	419,859	,000
	2	55	5,29	1,34		
	3 and over	143	3,99	1,15		
Sexual Function	1	124	16,58	2,06	715,952	,000
	2	55	9,76	2,08		
	3 and over	143	8,27	1,50		
Perception Function	1	124	23,69	3,39	697,292	,000
	2	55	14,89	2,76		
	3 and over	143	10,66	2,34		
Medical Interaction	1	124	6,56	2,20	453,732	,000
	2	55	11,98	3,17		

	3 and over	143	15,58	2,31		
Social Communication and Work Performance	1	124	34,61	4,43	991,407	,000
	2	55	20,12	5,89		
	3 and over	143	10,97	3,45		

*p<.05

When life quality scale sub dimensions were examined depend on parents', who have disabled child, income levels; It was found that parents whose income level is 0-1300 tl have loss of life quality in the sub dimensions of General being well, physical symptoms and activities, appetite, sexual function, perception function, medical interaction, social communication and work performance when compared to ones with 1301-2500 tl income levels. Yet, in the sub dimension of sleep disorder parents with 0-1300 tl income level and parents with 1301-2500 tl income level; they both have loss of life quality and also there was not a loss of life quality on parents that are with 2501 tl and over income level.

When life quality scale sub dimensions were examined depend on parents', who have disabled child, number of children; There were meaningful differences found in the sub dimensions of General Being Well, Physical Symptoms and Activities, Sleep Disorder, Appetite, Sexual Function, Perception Function, Medical Interaction, Social Communication and Work Performance. For the determination of the difference that from which group it was derived depending on parents' number of children the meaningfulness analysis was done. The Tukey Test findings took part in the Table 5 for the determination of the difference that from which group it was derived depending on parents' number of children.

Table 15. Test Results of the Sub Dimensions of Life Quality Scale that If There is a Difference or not Depend on Families' Number of Children.

Dimensions	(I) Number of Children	(J) Number of Children	Difference Between Averages (I-J)	SH	Sig.
General Being Well	1	2	14,24296*	,57574	,000
		3 and over	22,41919*	,43608	,000
Physical Symptoms and Activities	1	2	12,97742*	,63348	,000
		3 and over	21,98162*	,47982	,000
Sleep Disorder	1	2	2,61129*	,42954	,000
		3 and over	-,37892	,32535	,475
Appetite	1	2	2,74941*	,18570	,000
		3 and over	4,04732*	,14066	,000
Sexual Function	1	2	6,82507*	,29792	,000
		3 and over	8,30899*	,22565	,000
Perception Function	1	2	8,80264*	,46372	,000
		3 and over	13,02921*	,35124	,000
Medical Interaction	1	2	-5,41730*	,39602	,000
		3 and over	-9,02290*	,29996	,000
Social Communication and Work Performance	1	2	14,48563*	,70217	,000
		3 and over	23,63388*	,53184	,000

When life quality scale sub dimensions points were examined depend on parents', who have disabled child, income levels;parents whose income level is 0-1300 tl there were life quality losses found in the sub dimensions of General Being Well, Physical Symptoms and Activities, Appetite, Sexual Function, Perception Function, Medical Interaction, Social Communication and Work Performance when it is compared with parents whose with 1301-2500 tl and 2501 tl and over. Yet, in the sub dimension of sleep disorder parents with 0-1300 tl income level have life quality loss when it is compared with parents whose income level is 1301-2500 tl but there was no life quality loss found when compared with parents whose income level is 2501 tl and over.

DISCUSSION

When findings of the research were examined, it was determined that there is a difference in the life qualities of families with disabled child depend on their genders and females experience much more life quality loss than males.

Contiuing of the health of family, especially providing conservation for children's healt it is suggested that mother's role always stands at forefront. In other words society's ideology and gender roles resign the child and family health to the women. Researches show that when a child is caught to a chronical illness in the situations that is about general family health mothers burden the responsibility (Shore,Austin, Dunn, 2004). In the studies conducted about life quality factors such as gender, being in a bad economical situation affect life quality negatively (Eser,Eser, Özyurt,Fidaner, 2005). Decreasing of the life quality of a member in the family, especially mother's, affects to whole family's life quality. Being examined of the family functions of familes who have disabled child in terms of some variances it is suggested that families with disabled child there was a difference found in variances such as income level, number of children that mother have (Günsel,2010). These findings are in the quality of supporting the result of the research.

When research's findings about income level were dealt, it was seen that families with low income level experience much more life quality loss than families with middle and high income level. Being in need of care leads to physical and spiritual difficulties on the child and it also affects the whole family members both economical and spiritual aspect. There may be serious adaptation problems and mental disorders happen to the family members (Toros, Tot, Düzovalı, 2002). When a child has a chronic illness in the family this changes the physical, emotional an economical balances of the family, inhibits the family to be happy with life and lowers the life quality (Deniz, Dimaç, Arıcak, 2009).These findings are in the quality of supporting the result of the research.

For the determination of the effect of the children and families on the life qualities in the conducted study it was determined that families with low income levels their life qualities are lower (Chia-Ling, 2003). In the conducted study it was determined that while families' number of children increase they have difficulties to carry on the domestic responsibilities and thus they show in family things they show unhealthier functions. In a family when mentally disabled children are much more then mother's responsibilities and roles increased. Families' getting used to live with mentally disabled child, father's not participating the care of child, increase of economical problems, lead to insufficiency of the mothers to complete the needs of family members, mother's exhaustion to show care to all family members same interest and regulating the domestic order in the family. Morover, it can be said that increase of number of the children will increase the fights and jealousy among siblings and at this point mother's burden increases. And this will be a factor that affects the life quality of family (Sarihan, 2007). These findings are in the quality of supporting the result of the research. In the light of the research following suggestions are developed.

1- In the families with disabled children, studies should be increased for the mothers whose life quality is affected so much.

2- From families with disabled child to families with low income level studies should be increased for reaching to external help.

3- From families with disabled child to ones with many children, for the care of them except for disabled child studies, economical and psychological support should be increased.

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