

Examination of Affiliate Stigma, Hopelessness and Life Satisfaction in Parents of Children with Intellectual Disability

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Abstract

Introduction. While expecting a healthy child, having a child with a disability can be quite traumatic for all family members, especially parents.

The objective of the research was to evaluate affiliate stigma, hopelessness, and life satisfaction in parents of children with intellectual disability.

Materials and Methods. The descriptive research included 203 parents of children with intellectual disabilities, who met the research inclusion criteria and agreed to participate in the study. The data were collected using the Personal Information Form, the Affiliate Stigma Scale, the Beck Hopelessness Scale, and the Satisfaction with Life Scale.

Results. The mean age of parents included in the study was 40.74 ± 7.22 years, with 67.5% of caregiving mothers. The levels of affiliate stigma and hopelessness among parents were low, and they were satisfied with their lives. In case of increasing parental affiliate stigma, their hopelessness was found to increase, while life satisfaction was found to decrease.

Conclusions. In order to increase public acceptance of people with disabilities by society, it is recommended to provide trainings and raise awareness against individuals with disabilities and their families.

Keywords

Affiliate Stigma; Child; Hopelessness; Intellectual Disability; Life Satisfaction; Nurse

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Problem statement and analysis of the latest research

Each couple wants to experience the family phenomenon, strengthen marriage and family ties, ensure the continuity of their generations, and have children in order to secure their future [1]. The fact that parents with normal development and expectation of a healthy baby learn that the development of their children to be born is abnormal, creates a very traumatic effect on parents, regardless of the degree of disability [2].

Intellectual disability refers to a particular state of functionality that begins before the age of 18 and is characterized by significant limitations in both conceptual, social, and practical adaptability skills, and intellectual and adaptive behavior [3].

The birth of a baby brings innovations, changes and dif-

ficulties in family routines and relationships. The birth of a child with any disabilities may cause parents to face some difficulties in maintaining their daily lives and adapting to social life [4].

Studies conducted with parents of children with intellectual disabilities indicated that families do not receive social acceptance and support by society, disability is seen as a contagious disease by society, and they have difficulties in caring for their children due to negative perceptions of their children such as stigma [5, 6]. As the treatment and rehabilitation of their children requires more manpower, cost and time than in case of caring for a healthy child, it has been observed that the physical, emotional, economic, social burden and time requirement of such families increased [7, 8]. Compared to parents of normally developing children, parents of children with intellectual disabilities have been determined to have

higher levels of depression, anxiety, and stress, and lower capacity to accept and cope with distress [2].

Since the behaviors of children with intellectual disabilities are considered inappropriate and dangerous by society, both children and their families may be subjected to negative attitudes and discrimination by other individuals in society [9].

Stigmatization can be defined as attributing features that damage people's reputation in society due to their characteristics placing them in a low position. Affiliate stigma is defined as the perception of public stigmatizing views that create an acceptance in the individual's inner world affecting the dimension of emotions, thoughts, beliefs and fears [10].

Hopelessness is a state of emotion characterized by the absence, or inadequacy of hope and is a concept that defines that the individual usually has a pessimistic expectation or has no expectations for the future. Despair can negatively affect a person's ability to perceive themselves, their environment and other people around them, often causing a low mood [11].

Life satisfaction reflects an individual's overall feeling about their life and is considered a measure of emotional happiness. Life satisfaction, often defined as happiness, is one of the most important factors affecting people's mental health and social relationships [12].

Disabled individuals and their relatives exposed to stigmatization may experience varying levels of emotional injury, hopelessness, decreased self-esteem and life satisfaction, as well as cognitive, affective, and behavioral problems that negatively impact quality of life [13, 14].

Nurses should protect individuals exposed to stigma through training to reveal their beliefs and attitudes, provide information to eliminate a lack of knowledge to prevent stigma, and change the false beliefs and information in this regard.

The objective of the research was to evaluate affiliate stigma, hopelessness, and life satisfaction in parents of children with intellectual disability.

The research sought to answer the following question:

- What is the mean score for internalized stigma, life satisfaction and hopelessness in parents who have a child with intellectual disabilities?
- Is there a relationship between the levels of internalized stigma, life satisfaction and hopelessness in parents having children with intellectual disabilities?

Materials and Methods

This descriptive study was conducted in rehabilitation and special education centers in the principal city of a province located in eastern Turkey. The sample group consisted of 203 parents who were admitted to special education and rehabilitation centers to receive training and were selected through random sampling as they met the research inclusion criteria. The adequacy of the sample size was determined by the post hoc power analysis. According to the results of this analysis, the significance level was 0.05, and the confidence interval was 95%. The effect size of the study was 0.1163, and the power was 0.97, indicating a sufficient sample size [15].

Research inclusion criteria: parents' children should

- have been in rehabilitation for at least 6 months;
- be 18 years of age or younger and have an intellectual disability;
- not have a very severe orthopedic disability;
- be registered in a rehabilitation center;
- live with their family.

Data Collection

The research was conducted between April 2016 and May 2017. The data were collected using the Personal Information Form, the Affiliate Stigma Scale (ASS), the Beck Hopelessness Scale (BHS), and the Satisfaction with Life Scale (SWLS).

Personal Information Form

The "Personal Information Form" was developed by the researcher in accordance with the literature and consisted of 11 items about the socio-demographic characteristics of children with disabilities and their families [13, 16, 17].

Affiliate Stigma Scale

The Turkish study of the validity and reliability of the scale developed by Mak and Cheung (2008) was carried out by Kasimoğlu and Arıkan (2020). It is a 4-point Likert-type scale consisting of 22 items (scored from 1 - "strongly agree" to 4 - "strongly disagree"). The scale items measure the cognitive, emotional, and behavioral components of affiliate stigma. The scale scores range from 22 to 88, and the increasing scale scores indicate increased affiliated stigma [9, 18]. In this study, the total Cronbach's alpha value of ASS was found to be 0.973.

Beck Hopelessness Scale

The Turkish study of the validity and reliability of the BHS which was developed by Beck *et al.* (1974) in the UK was carried out by Durak (1994) [19, 20]. The scale is a personality test consisting of 20 items aimed at measuring individuals' expectations for the future. The scale scores range from 0 to 20, and the increasing BHS total score indicates the increased levels of hopelessness. The scale consists of "Feelings About the Future", "Loss of Motivation", and "Hope" sub-scales [20]. In this study, the total Cronbach's alpha value of the BHS was 0.823, and Cronbach's alpha values of its sub-scales were as follows: 0.671 for Feelings About the Future sub-scale (FFS), 0.682 for Loss of Motivation sub-scale (LMS), and 0.691 for Hope sub-scale (HS).

Satisfaction with Life Scale

The SWLS was developed by Diener *et al.* [21]. The Turkish study of the validity and reliability of the SWLS was carried out by Köker [22]. The SWLS is a 5-point Likert-type scale consisting of 5 items. The total score determines the level of satisfaction with life. The total scores are classified as follows: 30-35 = "extremely satisfied", 25-29 = "very satisfied",

20-24 = "satisfied", 15-19 = "less satisfied", 10-14 = "dissatisfied", 5-9 = "extremely dissatisfied" [22]. In this study, the total Cronbach's alpha value of the SWLS was 0.856.

Data Analysis

The data were evaluated with SPSS 17 and Lisrel 8.80 package programs. In data evaluation, the percentage, the mean score, the minimum and maximum values, the Cronbach's coefficient were used, as well as the Shapiro Wilk test was applied for normal distribution of the data and the Spearman correlation analysis was used for correlational inferences [23, 24].

Results

The mean age of parents included in the study was 40.74 ± 7.22 years, with 67.5% of caregiving mothers. Among them, 92.1% were married; 44.8% were primary school graduates; 59.1% lived in the city center; 74.9% had balanced income; 68% were unemployed; 77.3% had social security; 64.5% had male children with intellectual disabilities; 44.8% of the children had mild intellectual disabilities, and the average age of children was 11.40 ± 4.62 years.

The mean score of parents was 36.21 ± 15.11 in the ASS, 20.69 ± 7.33 in the SWLS, 5.13 ± 5.02 in the BHS, 0.99 ± 1.29 in the FFS, 2.47 ± 1.98 in the LMS, and 1.68 ± 1.70 in the HS (Table 1).

Table 1. Parents' ASS, SWLS, BHS and sub-scale mean score.

Scales	n	Min-Max	X \pm SD
ASS	203	22-85	36.21 \pm 15.11
SWLS	203	5-35	20.69 \pm 7.33
BHS and sub-scales			
BHS	203	0-18	5.13 \pm 5.02
FFS	203	0-5	0.99 \pm 1.29
LMS	203	0-8	2.47 \pm 1.98
HS	203	0-7	1.68 \pm 1.70

According to Table 2, there was a statistically significant positive correlation between the ASS and the FFS, the LMS, the HS and the BHS ($p < 0.05$). As the ASS score increased, the FFS, the LMS, the HS and the BHS scores also increased. In addition, there was a statistically significant negative correlation between the ASS and the SWLS scores ($p < 0.05$). The SWLS score decreased as the ASS score increased (Table 2).

There was a statistically significant negative correlation between the SWLS and the FFS, the LMS and the HS scores. The SWLS score decreased as the FFS, the LMS and the HS scores increased (Table 2). According to Table 2, there was a statistically significant negative correlation between the BHS total score and the SWLS score. The SWLS score decreased as the BHS total score increased.

Discussion

In the study, conducted to investigate affiliate stigma, hopelessness, and life satisfaction among parents of children with intellectual disabilities, parents were found to score 22 to 85 points on the ASS, and the total mean score was 36.21 ± 15.11 . As the total ASS score ranges between 22 and 88, parents were found to have low levels of affiliated stigma. In the literature, there are very few studies investigating the level of affiliate stigma in parents of children with intellectual disabilities. According to Werner & Shulman's study, the level of internalized stigma among parents with disabled children was low [25]. The low level of affiliate stigma is believed to be related to the spirituality of society and may be due to their beliefs that their disabled children are a God-given trust.

Parents were found to receive the mean score of 20.69 ± 7.33 on the SWLS, indicating that they were satisfied with their lives. In a study conducted by Kaçan Softa *et al.*, parents of children with intellectual disabilities were found to be very satisfied with their lives [26]. In other studies, contrary to our findings, parents were found to be less satisfied with their lives [27, 30].

According to our study, parents scored 0 to 18 points on the BHS, and their mean total score was found to be 5.13 ± 5.02 . As the total BHS score ranges between 0 and 20, parents were found to have low levels of hopelessness. There have been studies in which the hopelessness level in parents of children with intellectual disabilities was high [31] and moderate [32]. In some studies, similar to our findings, the hopelessness level of parents with children with mental disabilities was observed to be low [33, 34]. The low level of hopelessness may be due to parental spirituality along with the increased legal rights the state provides for individuals with disabilities and their families, and the institutions and organizations that provide services in this regard.

In our study, parents were found to score 0-5 points on the FFS of the BHS, with the total mean score of 0.99 ± 1.29 . As the minimum and maximum scores are 0 and 5, respectively, parents were found to receive a low score on the FFS, meaning that their expectations for the future were high.

Parents were found to score 0-8 points on the LMS of the BHS, with the total mean score of 2.47 ± 1.98 . As the sub-scale scores range from 0 to 8, the loss of motivation levels among parents were found to be low.

According to our study, parents were found to score 0-7 points on the HS of the BHS, with the total mean score of 1.68 ± 1.70 . The study with parents having children with intellectual disabilities conducted by Eş revealed that the levels of the FFS, which is one of the hopelessness sub-scale, were high and the levels of the LMS and the HS were low [35]. Contrary to our findings, the study carried out by Cabar revealed high levels of the FFS, the LMS and the HS [32].

The levels of affiliate stigma in parents increased, the levels of life satisfaction decreased, and the levels of hopelessness increased. The presence of a child with a disability causes many difficulties and drastic changes in the family [13, 36, 39].

Table 2. Relationship between parents' ASS, SWLS, BHS and sub-scales (n=203).

Scales		BHS and Sub-Scales				SWLS
		FFS	LMS	HS	BHS	
ASS	r	0.390**	0.182**	0.297**	0.321**	-0.306**
	p	0.000	0.009	0.000	0.000	0.000
SWLS	r	-0.349**	-0.311**	-0.396**	-0.434**	-
	p	0.000	0.000	0.000	0.000	-

Contrary to these findings, Beighton & Wills found that having a child with a disability brings about many positive changes. Parents expressed that having a child with a disability empowered them, increased their self-confidence, gave more meaning in their lives, increased their spirituality, and that they had positive experiences as a result of the disability of their child and these attitudes led to a change in negative thoughts in society [40]. Parents also stated that they have successfully adapted to the stress of raising children, in line with all these experiences. In the study conducted by Akçamak, mothers expressed that being a mother of children with intellectual disabilities is not only difficult, but also a happy feeling [41]. These positive feelings and spirituality of parents of children with disabilities are believed to be able to decrease hopelessness and increase life satisfaction, to decrease discriminatory attitudes and behaviors of the society. In line with these results, life satisfaction of parents is believed to lead to a reduction in their future anxiety and a more hopeful view of life.

Hope is one of the most important factors affecting life satisfaction positively [42, 43]. In this study, there was a weak negative correlation between the BHS total score and the SWLS score. Life satisfaction refers to a person's overall positive evaluation of their life and satisfaction with their whole life. In the literature, positive emotions have been reported to increase life satisfaction [12]. Parental lack of expectations from life due to their children's disability is thought to cause them to not enjoy their lives, and consequently their life satisfaction may decrease.

The FFS, LMS, and HS scores increased as the ASS score increased as well. Exposure to negative community attitudes may lead to an increase in better life expectations in the future, loss of motivation due to the influence of negative judgments, and an increase in the parents' hope for a better life for their child with a disability and themselves.

The SWLS score was found to decrease as the FFS score increased. Having exaggerated and unrealistic expectations, instead of embracing the current situation and opportunities, especially about their children and their future, is believed to decrease parental life satisfaction.

Motivation is defined as the activation of the inner state that causes individuals to behave in a certain direction, pushes them to act in order to realize the behavior and induces individuals to do something [44]. In our study, the SWLS score decreased as the LMS score increased. The increased loss of motivation in parents is believed to make it difficult for

parents to act against the negative impact of having a child with a disability and cope with stress, negatively affecting their efforts to find solutions to problems, and increased stress may decrease parental life satisfaction.

Hope can be defined as the desire for something to happen [45]. In our study, the SWLS score was found to decrease as the HS score increased. Several studies revealed that hope increased life satisfaction [42, 43]. Parental increasing unrealistic expectations for their children with intellectual disabilities and realizing the fact that these expectations cannot be met by their children may lead to a decrease in their life satisfaction.

Conclusions

In case of increasing parental affiliate stigma, their hopelessness increased, and life satisfaction decreased. In line with these results, it may be suggested to plan awareness training and repeat these trainings at regular intervals to increase social acceptance and attitudes towards people with disabilities, as well as hope and life satisfaction of parents having children with intellectual disabilities.

Prospects of Further Researches

There are very few studies on the levels of affiliate stigma in parents having children with intellectual disabilities, and this paper is one of the first studies in this area in our country. This study emphasized that parents of children with intellectual disabilities are exposed to negative attitudes by society that negatively affect parental life satisfaction and hope. Therefore, it drew attention to the necessity of psychological support for nurses, considering the family in a holistic way. It can theoretically contribute to understanding the difficulties experienced by parents having children with intellectual disabilities, addressing and solving the problems of these parents.

Ethical Statement

Before starting the research, the approval of the Ethics Committee and the written permission of the Provincial Directorate of National Education were obtained for the studied rehabilitation centers. The parents, who met the research inclusion criteria and agreed to participate in the research, were informed about the research in accordance with the "Principle of Informed Consent" and told that they were free to participate in the study according to the "Principle of Respect

for Autonomy”, and they were ensured that their information would be kept confidential in accordance with the “Privacy and Confidentiality Protection” policy. Written consent was obtained before participating in the study.

Informed Consent

Informed consent was obtained from all the parents before the study.

Conflict of Interest

The authors stated no conflict of interest.

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