



Psychoeducational Program to Reduce Burden and Improve Quality of Life among Caregivers of Children with Intellectual Disability

Faten Mohamed Ahmed Ibrahim^{1,5*}, Fatma Mahmoud Mohamed Elemary^{2,5}, Sahar Elsayed Gaber Behilak^{3,4}, Fathyea Said Sayed Ibrahim¹

¹Department of Psychiatric and Mental Health Nursing, Faculty of Nursing, Benha university, Benha, Egypt

²Department of Psychiatric Mental Health Nursing, Faculty of Nursing, Ain Shams University, Cairo, Egypt

³Department of Nursing, College of Applied Medical Sciences, University of Jeddah, Jeddah, Saudi Arabia

⁴Department of Psychiatric Mental Health Nursing, Faculty of Nursing, Mansoura University, Mansoura, Egypt

⁵Department of Psychiatric Mental Health Nursing, Faculty of Nursing, Jerash University, Jordan.

Abstract

Intellectual disability (ID) is one of the most common developmental disabilities. It can produce psychological, social, and financial distress to parents and/or caregivers. The study aimed to assess the impact of a psycho-educational program on the burden and quality of life of caregivers of children with ID. This study was conducted on 40 caregivers of children with ID. A quasi-experimental design was used, and data collection was completed using three tools; a Structured interview questionnaire; a Burden interviewing questionnaire; and a quality-of-life questionnaire. There was a highly statistically significant improvement in the total mean score of feeling of burden and the total mean score of quality-of-life post-implementation of the program at ($P < 0.001$). The psycho-educational program had a positive impact on the enhancement of burden and quality of life among the caregivers.

Keywords: Psychoeducational Program, Burden, Improve Quality, Caregivers, Intellectual Disability

Full length article *Corresponding Author, e-mail: drfatenwafa2@gmail.com

1. Introduction

Intellectual disability (ID), or mental retardation is a concept that is used to describe low intellectual functioning ($IQ < 70$) related to meta-cognitive skills such as communication, learning, and problem-solving ability, as well as skill deficits related to self-care, and independence [1]. (ID is a very common issue among children, it is estimated about 200-250 million children, or 1-3% of the global population have been affected [2]. However, it is significantly higher in low- and middle-income countries with approximately 16.41 in every 1,000 people (Special Olympics, n.d.). In 2016, it was reported that 52.9 million children under the age of 5 years experienced some type of ID globally, 95% of those from low-income countries [3]. Intellectual disability is a life-long issue with a major impact on the lives of children, their families, and/or caregivers. For this discussion, the term caregiver is used to denote any person who provides day-to-day physical and emotional care to the child, including parents, siblings, or other close and extended family members [4]. Due to the high demands and

complexity of care of an intellectually disabled child, the implications on the physical, emotional, and social aspects of the caregivers and the family members are considerable. It was reported that caring for children with ID is a stressful and challenging experience affecting negatively on several aspects of caregivers' lives, including poor physical and emotional state [5]. Studies that focused on caregivers of children with ID also reported a wide range of emotional and physical effects such as psychological distress, poor parenteral well-being, feeling the burden, low self-efficacy, and health-related quality of life (HRQoL) [6]. An Australian study that focused on studying the relationship between health-related quality of life and financial aspects, reported that caregivers spent an average of 67 hours/week (9.6 hours a day) to care for their disabled child. This puts the family under severe economic, social, and emotional stress. The authors also reported that a higher percentage of caregivers in the study sample experienced different levels of anxiety problems (slight, moderate, severe, or extreme),

depression, pain/discomfort, poor physical health (caused by the physical demand of caring), poorer health-seeking behavior, and risky habits which may impact their employment to earn income [7]. These children along with their caregivers require special support, proper access to health and social services, resources, and education to cope with the care burden and associated psychological distress [8]. The present study will focus on the caregivers of children with ID in Egypt. Based on the World Bank classification, Egypt is classified as a lower-middle-income country. It was reported that the prevalence of ID among children is very high at about 22.4%, or around 1.6 million [9]. Given these statistics, it is important to establish a supportive culturally congruent program to reduce the burden of ID on their families [9]. In Egypt, caregivers of ID children have their unique challenges, they struggle with chronic physical and emotional stressors. This study will be conducted to evaluate the effectiveness of a designed psycho-educational program on the burden and quality of life (QoL) experienced by caregivers of children with ID in Benha City, Qalubia Governorate (which is affiliated with the General Secretariat of Mental Health in Egypt). The findings from this study may empower and educate caregivers to improve their well-being and help them learn the necessary skills to facilitate daily care without feeling the stressful burden [10]. To our knowledge, there are very limited studies related to the impact of psycho-educational programs on the burden and quality of lives of caregivers of children with ID in Egypt, specifically in Benha City. The term “caregiver’s burden” is described as the physical, psychological, emotional, social, and financial problem that is experienced by the family members who take care of an individual with illness or disability” [11]. Although the concept QoL is subjective (people defined it differently based on their perception of quality of life), the World Health Organization’s definition will be used in this study. It is defined as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and about their goals, expectations, standards and concerns” [12]. We hypothesized that the psycho-educational program would have a positive impact on the caregiver’s quality of life and reduce the burden. Psychoeducational programs have been used successfully as interventions to reduce caregivers’ burden and improve quality of life in many studies. For example, it was used for caregivers of patients with cancer, which reported a significant effect on caregivers' burden, QoL, anxiety, and depression [13]; for caregivers of patients with dementia, that resulted in improving caregivers quality of life, reduction of their distress, and helping them to develop problem-solving strategies; and of caregivers burden for mental disorders among Iranian population [14]. The psycho-educational program in the present study is operationally defined as a non-pharmacologic intervention program for the management of psychosocial problems of caregivers. The main objectives of the program were to: educate the caregivers about ID, explore some strategies to adjust to the situation, empower them to develop problem-solving skills, and deal with the demanding needs of their ID children. The program was designed by the researchers based on their expertise and literature reviews. The impact of the program will be measured by the administration of a survey/questionnaire before and after the program

Ibrahim et al., 2024

implementation. Two tools will be used to assess the caregiver’s quality of life (QoL) and caregiver’s burden [15]. Research hypothesis: Psycho-educational programs will have a positive impact on the enhancement of burden and quality of life among caregivers of intellectually disabled children [16]. This study aims to evaluate the impact of a psycho-educational program on the burden and quality of life among caregivers of children with ID.

2. Materials and Methods

This study was conducted on 40 caregivers of children, aged from 3 to 17 years old with clinical criteria of patients diagnosed with ID according to the ICD-10 criteria and (males and females) aged between 18 and 60 years old. This study was done after approval from ethical committee Faculty of Nursing, Benha University, Benha, Egypt. An informed written consent was taken from all patients. Exclusion criteria were caregivers with psychosis, mental retardation, or diagnosed with other mental illnesses, refused to consent, children with ID-associated epilepsy or other significant medical conditions. Research Design: A quasi-experimental design (pre, post-interview questionnaires) was utilized to collect data for the study. The following tools are used for the data collection

2.1. Structured interview questionnaire

Designed by the researchers to collect data related to the sociodemographic characteristics of caregivers such as age, sex, marital status, level of education, occupation, relationship to the child, and kinship between the spouses.

2.2. Burden interviewing questionnaire

Modified version of Zarit Burden Interviewing questionnaire (ZBI) developed by Zarit et al. [17]. This tool was used to measure the extent of a family caregiver’s physical, social, and psychological burden as a result of caring for children with ID. The tool is reliable with a reported Cronbach's alpha at 0.82. It consists of 29 items within three main sections. Physical stress consisted of 4 items, social stress consisted of 10 items and psychological stress consisted of 15 items. Three-point Likert scale of responses for each statement indicated how often the caregiver feels a particular way: never – score (0), sometimes - score (1), and always - score (2). The scale scoring system includes the burden levels at mild, moderate, and severe as the following: (0-19) mild, (<19 >38) moderate, and (38-58) severe.

2.3. Quality of life questionnaires (FACT-BI -Version 4)

Developed by David Cella [18] for caregivers of mentally retarded children. The quality-of-life questionnaire consists of subscales, physical well-being (7 items), social/family well-being (7 items), emotional well-being (6 items), functional well-being (7 items), and additional concerns (12 items). The tool is reliable, Cronbach's alpha was reported at 0.79. Each item is scored on a scale of 0 (not at all) to 4 (very much), with a total score range in physical well-being from 0-28, social/family well-being from 0-28, emotional well-being from 0-24, functional well-being from

0-28, and additional concerns from 0-48. A total score ranging between 0-78 indicates low QOL, 79-116 indicates moderate QOL and 117-156 indicates high QOL. Reliability was applied for testing the internal consistency of the tool, by administration of the same tools to the same subjects under similar conditions on one or more occasions, measured by Cronbach alpha test. For the Zarit Burden interviewing questionnaire, Cronbach's alpha was 0.82, and for quality-of-life Questionnaires, was 0.79. A group of three experts in the psychiatric nursing field tested the content validity of the tools. They checked the relevancy, clarity, comprehensiveness, and applicability of the questions. A pilot study was conducted to assess the clarity and applicability of the study tools as well as the time needed to complete the questionnaires in each tool. It was conducted on 10% of the subjects (about 4 caregivers), who were excluded from the main study sample. Based on the results of the pilot study, there were no modifications required.

2.4. Development of psycho-educational program

The program aimed to minimize the feeling of burden and improve the quality of life among caregivers of children with ID. It included the following eight session titles: Session 1: Acquaintance session & Overview about ID among children. Session 2: Overview of the feeling of burden & quality of life. Session 3: Concept of quality of life, sleep disturbance, nutritional regimen. Applied methods for eating and dressing the child independently. Session 4: Practice steps to help the caregiver manage physical dependency such as toileting. Session 5: Learning how to play with the child and train them to initiate social interaction. Session 6: Relaxation technique. Session 7: Promote self-esteem. Session 8: Developing skills in solving problems and decision-making. Implementation of the Program

2.5. Pre-program interventions

This phase is aimed at meeting the caregivers, collecting the demographic information, assessing their needs, and obtaining pre-program information (baseline information for comparisons). The researchers introduced themselves to the interested caregivers who met the eligibility criteria and explained the study, its purpose and significance, and the confidentiality of the data. They were asked to follow specific Covid-19 precautions such as (wearing facemasks and using alcohol spray) to avoid the transfer of the virus. The researchers interviewed each participant in a quiet, and private room in the hospital at Benha City. During the interview, the caregiver burden and QoL questionnaires were administered by the researchers to obtain pre-program implementation data. The interview lasted between 30-40 minutes from 10 a.m. to 1:00 p.m. for two days/week.

2.6. Program implementation

The 40 caregivers were divided into eight groups; each group was composed of five caregivers. The program consisted of eight sessions, each session was 30-45 minutes long to deliver the theoretical contents (focusing on

Ibrahim et al., 2024

psychosocial education), and 45-60 minutes sessions for training or hands-on skills. These sessions were scheduled to be conducted for two days/week (scheduled on Sundays and Thursdays). The sessions started in October 2021 and went on to the end of March 2022. The researchers implemented the psychosocial educational program, they worked with the eight subgroups for two days/week. Each subgroup was composed of 5 caregivers who received one session/day. All sessions took place in the outpatient clinic for the children's entertainment hall and in the group therapy room. During the session, the researcher used demonstration and modeling (such as watching the video, performing role-playing, initiating social interaction with their children, and practicing relaxation techniques, and coping skills) of the psycho-educational program. After the training, the researcher asked for a re-demonstration of the skills learned by each caregiver to ensure the accuracy of performing the skills. At the end of the training session, verbal gratitude was expressed to all parents and caregivers for participation. They were also encouraged to ask questions and contact researchers if needed. The researchers also provided debriefing and an overview before the new sessions.

2.7. Evaluation Phase

At the end of the program, post-program evaluation was done using the Burden interviewing questionnaire and quality of life Questionnaires. The researchers interviewed the individual caregivers to get their feedback and evaluate the impact of the program on the improvement of burden and quality of life among the participants of ID children.

2.8. Statistical Analysis

Data collected from the pre; post-program was analyzed using the Statistical Package for Social Science (SPSS) version 20. Data analysis was accomplished using numbers, percentage distribution, mean, and standard deviation. A paired t-test was used to compare means within the group, and a t-test was used to compare two independent means. A significant level value was considered at $p\text{-value} \leq 0.05$.

3. Results and discussion

Statistical analysis of 40 participants revealed that (47.5%) of the caregivers were between the age of 31-41 years old, with a mean age of 38.45 ± 8.81 . The majority of participants were females (75.0 %). About 57.5% of them had a kinship with their spouses, and less than two-thirds (62.5%) of them had no history of a mental disorder (Table 1). Regarding educational status, data revealed that more than one-third, or 37.5% had an intermediate education; 25.0% had a university education, while 17.5% could read and write only (Figure 1). As far as the relationship between the participants and their ID children, about 67.5% of the caregivers were the children's mothers; 25.0% were the fathers, and 7.5% were their relatives/caregivers from the first degree (Figure 2). Employment was also assessed, about 52.5% of the participants were employed, and 22.5% worked privately (Figure 3). Data analysis related to pre-, and post-program implementation revealed that there was a highly significant statistical relationship between the mean

scores of the feeling of burden subscales (which includes physical, social, and psychological stress), as well as the total score of the sense of burden among the participants, it decreased from 39.8 ± 5.22 to 29.95 ± 5.38 with a highly statistical significance ($P \leq 0.001$) (Table 2). The feeling of the severity or levels of burden, which was described as mild, moderate, and severe showed an improvement post-implementation of the program. For example, an increased number of participants expressed mild burden from 25% to 52%, and a decrease of moderate feeling of burden from 32.5% to 25%, and a decrease of severe feeling of burden from 42.5% to 22.5% (Figure 4). About the scores related to the quality of life, a comparison between pre- and post-program implementations showed that there was a noticeable improvement in pre; post-program intervention from 38.14 ± 15.30 to 65.08 ± 7.48 with highly statistical significance relationships in the subscale scores and the total quality of life scale post-implementation ($P \leq 0.001$) (Table 3). The program implementation did not only improve the quality-of-life scores but also the levels as well. For example, before the implementation of the program, 12.5% of the study participants described that their quality of life was moderate, however, this number increased to 87.5% post-implementation (Figure 5). Lastly, data analysis showed that there were highly statistically significant negative correlations between quality of life and feeling of burden pre- and post-program ($P < 0.001$) (Table 4). Intellectual disability is a common developmental issue that impacts the physical and intellectual ability of children. Children with ID experience challenges in self-care and are dependent on their caregivers with their demanding needs. Parents or caregivers take more time and effort to meet the necessary daily living needs of their ID child compared to a normal child. They are often stressed out and look for extra help to cope with the challenges they experience [19]. A study by Amulya et al. [20] reported that the mean QOL scores of caretakers of normal children were significantly higher than the mean QOL scores of caretakers of children with developmental disability in all four domains. The present study aimed to evaluate the impact of a psycho-educational program on alleviating the burden and improving the quality of life among caregivers of mentally retarded children. 40 caregivers participated in the study, with a mean age of 38.45 years ($SD \pm 8.81$), and about 47% of them were in the age range between 31-41 years old. This result was consistent with the findings from several research studies, which reported the age of parents and caregivers above thirty [21, 22]. The current study showed that most caregivers of ID children were females. This was expected since in the traditional Arabic culture females are most likely to bear the family responsibility of caring for the children, and males take the role of breadwinners. This result is consistent with other studies such as Fakhary [23], who found that the greatest majority of parents assigned to children were mothers. Data related to the educational levels revealed that the highest percentage of educational level (37.5%) was intermediate school (middle and high school). The result was in agreement with Upendra et al. [24] who found that male and female participants were educated up to secondary education. Based on the statistical analysis, the implementation of the program appeared to be very helpful in improving the feeling of burden and quality of life, which contributed to the reduction of the negative feeling of the

burden. This may reflect the effectiveness of the skill training which made caregivers comfortable in learning specific skills under the guidance and supervision of the researchers (health providers). Data analysis also indicated that there was a highly statistically significant improvement in the mean score of all subscales of the feeling of burden and the total mean score of the post-psycho educational program compared to the pre-intervention program. The training program included learning skills to meet the child's needs, asking questions, expressing their challenges and frustrations, and teaching relaxation strategies that help decrease the stress of the family members. The program also included professional counseling sessions in which participants were introduced to the practice of various stress management strategies (e.g., biofeedback, mindfulness), acceptance, and problem-solving skill strategies. This technique had a positive effect on parents' and caregivers' mental health and psychological well-being. Another benefit of the program was establishing social networks with other caregivers. The impact of the program was reflected by improving the feeling of burden and quality of life scores. Regarding levels of feeling of burden, the current study revealed that the level of burden among participants improved (elevated) post-implementation of the program. These results were consistent with other studies that used psychoeducational interventions [25, 26]. About the QoL, the current study revealed that there was a marked improvement in the mean score of all items related to the studied caregivers' quality of life and the total mean score of the scale post-program than pre-program. The low level of quality-of-life pre-program could be due to high levels of stress, continuous child dependency, lack of social support, lack of knowledge regarding childcare, and exhaustion in the caring role. The significant improvement in the quality of life after the program is a reflection of the positive effectiveness of the content delivered. These results are consistent with other studies that reported statistically significant results across the three domains of quality of life [27]. The program may influence the caregiver's self-acceptance, empower them against feeling insecure, and build their self-esteem and confidence in providing care for their children. It is also worth mentioning that the severity of the children's disability may determine the severity of the burden and quality of life. The result of the current study revealed that there were highly statistically significant negative correlations between the studied caregivers' total quality of life and total sense of burden pre- and post-program ($P < 0.001$). This may be due to the severity of the disability which worsens the caregiver's QOL included in all the four domains. These results were consistent with findings by Arasu, S et al. [28] who found that there is a negative and significant correlation between quality of life and caregivers' burden. It was mentioned that the caregiver's QOL is overall poor, but it was the lowest in the physical domain and higher in the psychological domain. Caregiver burden scores were high and depended on the type of disability. In summary, the results of the current study revealed the importance of adding a psychosocial program for caregivers to the resources available for the children with ID. Such programs should include educational information about intellectual disability, resource availability, and strategies to overcome burnout and stress, social support, and other needs.

Table 1. The socio-demographic characteristics of the participants

Socio-demographic characteristics		(n = 40)
Age (Years)		38.45 ± 8.81
	20 ≤ 30	6 (15%)
	31 ≤ 40	19 (47.5%)
	41 ≤ 50	12 (30%)
	50 +	3 (7.5%)
Sex	Male	10 (25%)
	Female	30 (75%)
Material status	Single	3 (7.5%)
	Married	27 (67.5%)
	Divorced	5 (12.5%)
	Widowed	2 (5%)
	Separated	3 (7.5%)
The kinship between the spouses		23 (57.5%)
History of mental disorder		15 (37.5%)

Data are presented as mean ± SD or number (%).

Table 2. Total mean score of all subscales of feeling of burden among the studied caregivers of mental retardation pre- and post-program

Feeling of burden	Pre-program	Post program	P value
Physical stress	6.4 ± 0.9	3.3 ± 2.35	≤ 0.001**
Social stress	13.29 ± 2.3	6.05 ± 2.54	≤ 0.001**
Psychological stress	20.6 ± 2.31	18.47 ± 4.2	≤ 0.001**

Data are presented as Mean ± SD.

Table 3. Total mean score of all subscales of quality of life among the studied caregivers of mental retardation pre and post-program

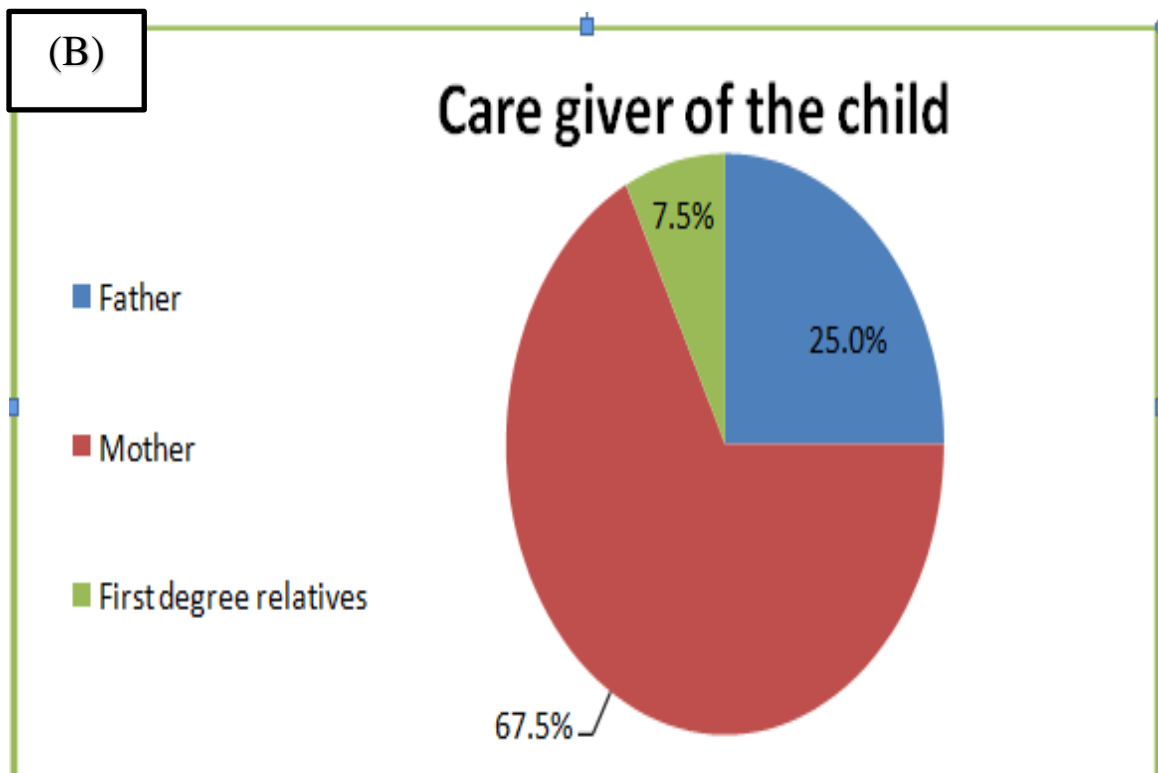
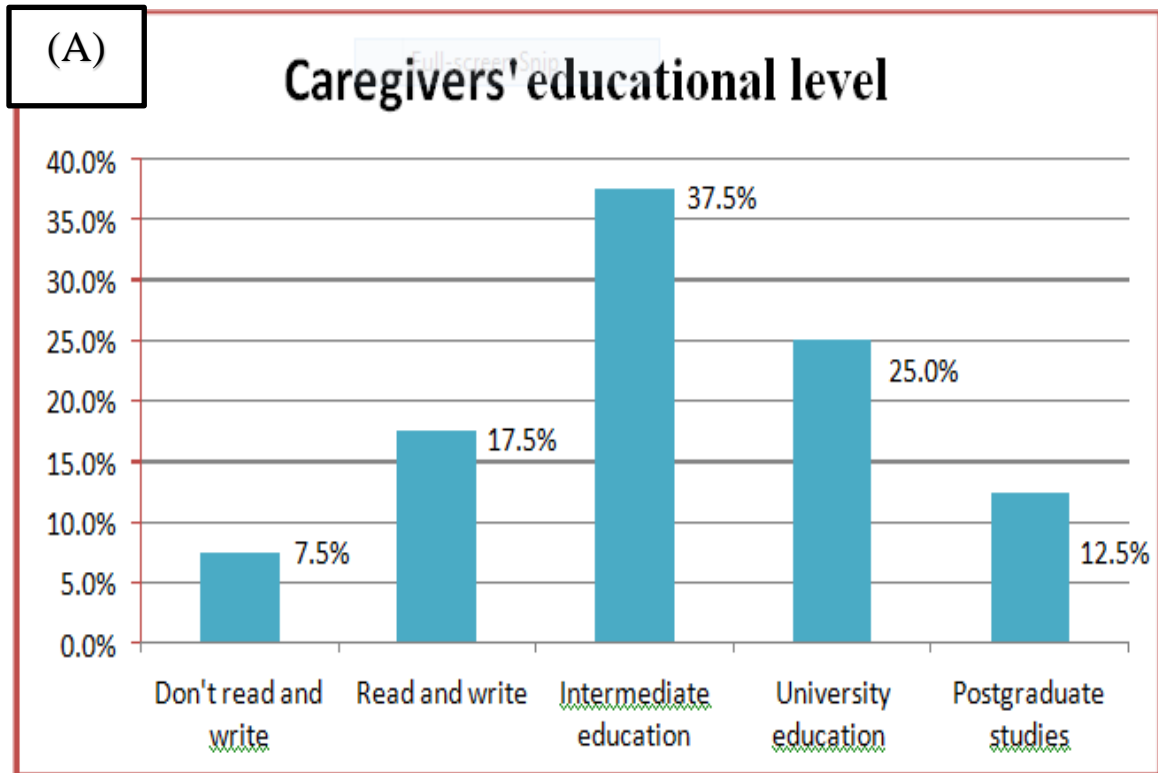
Quality of life subscale	Preprogram	Post-program	T. test	
	Mean ± SD.	Mean ± SD.	X2	P p-value
Physical well-being	19.46 ± 25.54	66.07 ± 11.29	15.93	<0.001**
Social/family well-being	68.39 ± 11.57	77.68 ± 8.81	9.31	<0.001**
Emotional well-being	23.96 ± 31.13	71.04 ± 10.38	10.69	<0.001**
Functional well-being	22.59 ± 24.96	47.77 ± 19.47	10.69	<0.001**
Additional concerns	47.55 ± 5.14	64.27 ± 6.70	12.50	<0.001**
Total Quality of Life levels	38.14 ± 15.30	65.08 ± 7.48	18.26	<0.001**

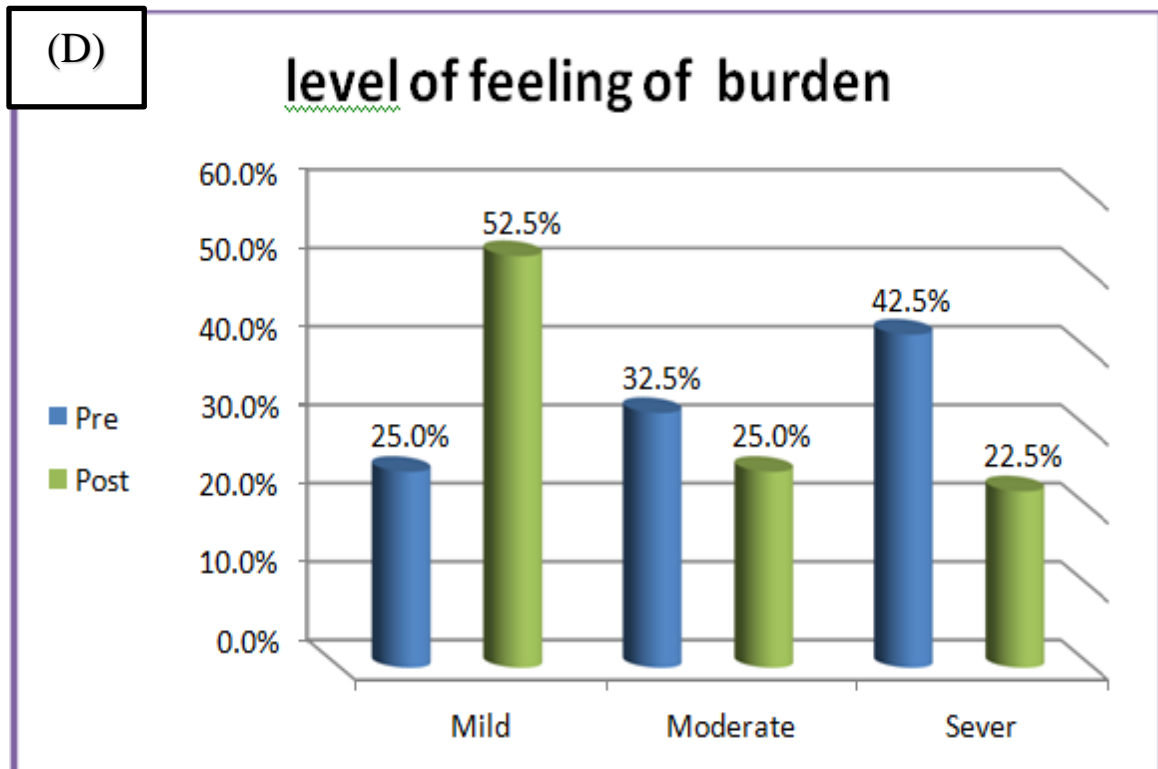
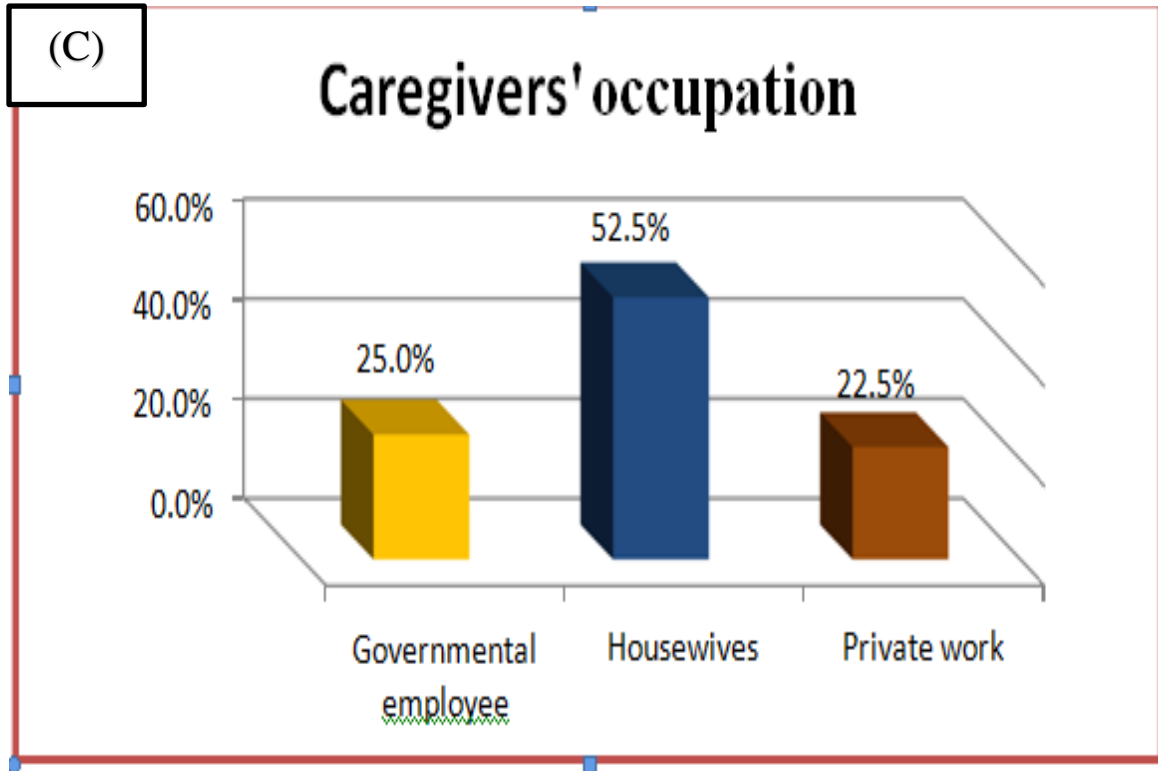
Highly statistically significant at $p < 0.001^{**}$

Table 4. Correlation between the total mean score of perceived quality of life and the total mean score of feeling of burden pre- and post-program

Program	Total quality of life			
	Preprogram		Post-program	
	r	P-value	r	P-value
A total sense of burden	- 0.478	0.001**	-0.699	0.001**

**Correlation is highly significant at the 0.001 level.





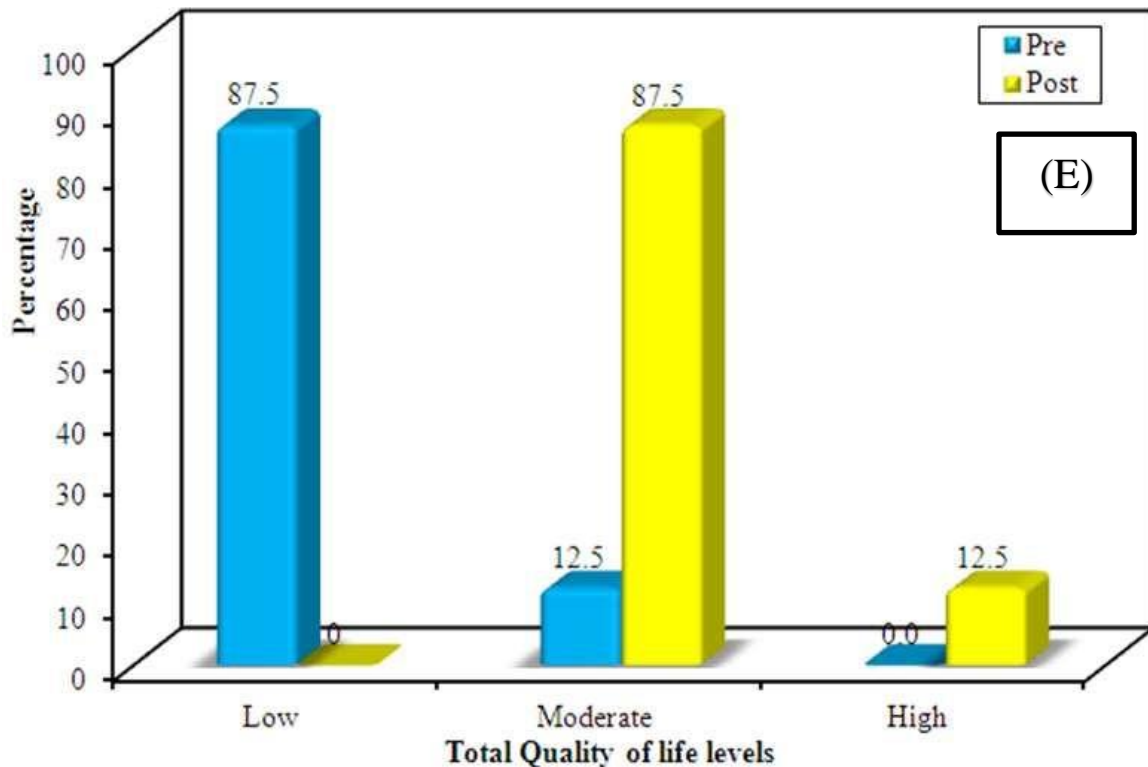


Figure 1. Percentage distribution of the studied caregivers (A) according to their educational level, (B) for the child, (C) according to their occupation, (D) according to the levels of feeling of burden of ID children pre- and post-program and (E) according to the levels of quality of life pre- and post-program

From the policy perspective, there should be considerable flexibility in the employment of caregivers with disabled children, and extended time for a leave of absence if necessary. Our study recommended that psychological counseling should be integrated as a part of routine nursing interventions for caregivers with ID children to enhance their self-efficacy. Raising awareness related to ID children and parenteral education related to early detection, and management of ID children. Further research on a larger number of parents and caregivers about how to cope with their problems effectively.

4. Conclusion

The psycho-educational program had a positive impact on the enhancement of burden and quality of life among the caregivers.

References

- [1] B.K. Gordon, N.J. Bila. (2023). Developing a psychoeducational programme for caregivers of people with intellectual disability. *African Journal of Disability*. 12 1195.
- [2] E. Gonzalez-Fraile, A.I. Dominguez-Panchon, P. Berzosa, A.B. Costas-Gonzalez, I. Garrido-Jimenez, D. Rufino-Ventura, M. Martin-Carrasco. (2019). Efficacy of a psychoeducational intervention in caregivers of people with intellectual disabilities: A randomized controlled trial (EDUCA-IV trial). *Research in Developmental Disabilities*. 94 103458.
- [3] Z. Ghazavi, F. Dehkhoda, M. Yazdani. (2014). The effect of group psycho-educational program on quality of life in families of patients with mood disorders. *Iranian Journal of Nursing and Midwifery Research*. 19 (1) 50-55.
- [4] V. Ramasubramanian, R. Chellamuthu, R. Selvikumari, P.R.S. Pandian, R. Gopi. (2019). Caregiver burden in children with intellectual disability: Does special school education help?. *Industrial Psychiatry Journal*. 28 (2) 176-184.

- [5] G.H. Sulaimani, S. Kamel, G. Alotaibi, N. Telmesani, G. Sulaimani, S. Kamel Jr. (2023). Quality of life among family caregivers of disabled children in Saudi Arabia. *Cureus*. 15 (7).
- [6] C. Xia, M. Sun, X. Li, C. Lu, X. Gao, J. Lu, G. Chen. (2020). Health-related quality of life and related factors among primary caregivers of children with disabilities in Shanghai, China: A cross-sectional study. *International Journal of Environmental Research and Public Health*. 17 (24) 9299.
- [7] S. Farzi, S. Farzi, A. Moladoost, M. Ehsani, M. Shahriari, M. Moieni. (2019). Caring burden and quality of life of family caregivers in patients undergoing hemodialysis: A descriptive-analytic study. *International journal of community based nursing and midwifery*. 7 (2) 88.
- [8] M. Adib-Hajbaghery, B. Ahmadi. (2019). Caregiver burden and its associated factors in caregivers of children and adolescents with chronic conditions. *International journal of community based nursing and midwifery*. 7 (4) 258.
- [9] A.M. Metwally, A. Aboulghate, G.A. Elshaarawy, A.M. Abdallah, E.R. Abdel Raouf, E.M.S. El-Din, A.S. ElRifay. (2023). Prevalence and risk factors of disabilities among Egyptian preschool children: a community-based population study. *BMC psychiatry*. 23 (1) 689.
- [10] H.G. Elnady, L.S. Sherif, R.N. Sabry, D.A. Zeid, H. Atta, A.I. Hassanain, A.A. Gobarah. (2019). Relation of asthma control with quality of life among a sample of Egyptian asthmatic school children. *Open access Macedonian journal of medical sciences*. 7 (17) 2780.
- [11] A. Navidian, F. Kermansaravi, S.N. Rigi. (2012). The effectiveness of a group psycho-educational program on family caregiver burden of patients with mental disorders. *BMC research notes*. 5 1-7.
- [12] R.C. Estoque, T. Togawa, M. Ooba, K. Gomi, S. Nakamura, Y. Hijioka, Y. Kameyama. (2019). A review of quality of life (QOL) assessments and indicators: Towards a "QOL-Climate" assessment framework. *Ambio*. 48 619-638.
- [13] G. Kusi, E.G. Atenafu, A.B. Boamah Mensah, C.T. Lee, A. Viswabandya, M. Puts, S. Mayo. (2023). The effectiveness of psychoeducational interventions on caregiver-oriented outcomes in caregivers of adult cancer patients: A systematic review and meta-analysis. *Psycho-Oncology*. 32 (2) 189-202.
- [14] A. Zarepour, M. Hazrati, A.A. Kadivar. (2020). The Impact of Educational Intervention on the Anxiety of Family Caregivers of the Elderly with Dementia: A Randomized Controlled Trial. *International Journal of Community Based Nursing and Midwifery*. 8 (3) 234.
- [15] S. Sarkhel, O.P. Singh, M. Arora. (2020). Clinical practice guidelines for psychoeducation in psychiatric disorders general principles of psychoeducation. *Indian journal of psychiatry*. 62 (Suppl 2) S319-S323.
- [16] A. Tessier, K. Roger, A. Gregoire, P. Desnavailles, D. Misdrahi. (2023). Family psychoeducation to improve outcome in caregivers and patients with schizophrenia: a randomized clinical trial. *Frontiers in psychiatry*. 14 1171661.
- [17] S.H. Zarit, P.A. Todd, J.M. Zarit. (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study. *The Gerontologist*. 26 (3) 260-266.
- [18] D.F. Cella, D.S. Tulskey, G. Gray, B. Sarafian, E. Linn, A. Bonomi, P. Bonomi. (1993). The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *J Clin Oncol*. 11 (3) 570-579.
- [19] A.L. Pedersen, S. Pettygrove, Z. Lu, J. Andrews, F.J. Meaney, M. Kurzius-Spencer, C. Cunniff. (2017). DSM criteria that best differentiate intellectual disability from autism spectrum disorder. *Child Psychiatry & Human Development*. 48 537-545.
- [20] A. Rao, D. Ramamurthy, U. Kumar. (2021). Quality of life in caregivers of children with developmental delay—A case-control study. *International Journal of Health & Allied Sciences*. 10 (1) 48.
- [21] M.A. El-Bilsha. (2019). Effect of family intervention on family caregivers' burden, depression, anxiety and stress among relatives of depressed patients. *Middle East Journal of Age and Ageing*. 83 (6636) 1-11.
- [22] L.N. Devi, M.K. D'Mello, P.D. Rent. (2019). Stress and burden among parents of students in special schools of Mangaluru: A cross-sectional study. *Muller Journal of Medical Sciences and Research*. 10 (2) 66-72.
- [23] G. Fakhry Elyamany, Z. Fathy El-Sayed, M. Mohamed Hafez. (2019). Parental Patterns of Care for their Children with Mental Disability. *Egyptian Journal of Health Care*. 10 (1) 526-534.
- [24] U. Singh, S. Singh, B. Singh. (2020). Intellectual Disability and its Association with Care Givers Burden at Sasaram. *International Journal of Cognition & Behaviour*. 3 (1) 1-5.
- [25] J.G. Huis in het Veld, R. Verkaik, P. Mistiaen, B. van Meijel, A.L. Francke. (2015). The effectiveness of interventions in supporting self-management of informal caregivers of people with dementia; a systematic meta review. *BMC geriatrics*. 15 1-10.
- [26] A. Yildirim, S. Buzlu, R. Hacıhasanoglu Asilar, T.H. Camcioglu, S. Erdiman, M. Ekinici. (2014). The effect of family-to-family support programs provided for families of schizophrenic patients on information about illness, family burden and self-efficacy. *Turkish journal of psychiatry*. 25 (1) 31-7.
- [27] P. Chippala. (2019). Effect of Caregiver Education on Quality of Life and Burden among Caregivers of Children with Cerebral Palsy: A Quasi Experimental Study. *Indian Journal of Public Health Research & Development*. 10 (8).
- [28] B.K. Gordon, N.J. Bila. (2023). Developing a psychoeducational programme for caregivers of people with intellectual disability. *African Journal of Disability*. 12 1195.