Effect of Educational Intervention on Psychological Well-being and Coping of Mothers Having Children with Down Syndrome

(1) Lecturer at Department of Community Health Nursing, Faculty of Nursing, Port-Said University
(2) Lecturer of Community Health Nursing Department, Faculty of Nursing, Mansoura University, Egypt
(3) Assistant Professor of Psychiatric and Mental Health Nursing Department, Faculty of Nursing Assiut University
(4) Lecturer in Psychiatric Nursing and Mental Health, Faculty of Nursing, South Valley University
(5) Assistant professor of Community Health Nursing, Faculty of Nursing, Mansoura University
(6) Lecturer of Community Health Nursing, Department, Faculty of Nursing, Mansoura University, Egypt

Abstract

**Background:** Mothers of children with Down syndrome (DS) experience stress, they require the use of effective coping strategies help them to cope with this stress to psychological well-being and regulate their emotions. **Aim:** To evaluate the effect of educational intervention on the psychological well-being and coping of mothers having children with Down syndrome. **Subjects and method:** Design: A quasi-experimental research design was used to achieve the aim of this study. Setting: the study was carried out at two special needs schools in Mansoura City (ALtarbih ELfikria). Subjects: A purposive sample of 100 mothers and their children with Down syndrome were selected from the previous setting. **Tools:** Tool (I) structured interviewing questionnaire, which included four parts: Part I: demographic characteristics of mothers, children, history of DS child, and mother’s knowledge regarding DS, Tool (II): Ryff’s Psychological well-being scale (1989), Tool (III): mothers' needs scale, and Tool (IV): mothers' coping scale. **Results:** The study's findings revealed that nearly two-thirds of mothers of children with DS had psychological well-being less than usual pre-educational intervention compared to more than half of mothers of children with DS had psychological well-being better than usual post-educational intervention. There was a highly statistically significant difference between the pre-educational intervention and post-educational intervention regarding mothers' knowledge and practices about Down syndrome. Three-fifths of mothers had negative coping patterns, with more than three-quarters of them never being able to manage their children's disabilities. The most essential needs for mothers were economic needs. **Conclusion:** The educational intervention was effective in improving the psychological well-being and coping of mothers having children with Down syndrome. **Recommendations:** The study suggested organized educational programs are needed to improve mothers' knowledge, psychological well-being, and coping with Down syndrome. **Keywords:** Children with Down syndrome, Coping, Mothers, Psychological well-being.

Introduction:

Down syndrome, the most frequent genetic cause of intellectual disability is usually linked with a distinct phenotype that includes delayed growth, additional health concerns, and difficulties performing daily activities, in addition to intellectual deficits. Caregivers of children with DS may face a variety of problems, including developmental, medical, educational, social, and financial issues (Pisula, 2017).

1 in every 700 newborns born across the world has Down syndrome. It occurs once in every 1000 live births, according to estimates.
Every year, between 3000 and 5000 children are born with Down syndrome. Children with Down syndrome have ongoing intellectual, developmental, and health problems that necessitate medical and rehabilitation treatments, all of which can have a negative influence on families (Gashmard et al., 2020).

Apart from cognitive and social deficits, children with Down syndrome frequently have other comorbid chronic health conditions, such as congenital heart defects, gastrointestinal disease, hypothyroidism, respiratory disorders, ophthalmologic problems, and hearing problems, all of which necessitate extra care and attention and may add to parents' concerns. As a result, on the one hand, these children's families must expend a great deal of energy and patience in dealing with the child's behavioral, emotional, and health issues; on the other hand, these children's families must expend a great deal of energy and patience in dealing with the child's behavioral, emotional (Kazemi & Kheirrollahi, 2016).

Down syndrome can lead to a variety of medical issues, some of which are more significant than others, but the majority of them are treatable. Heart defects, blood issues, hormone disorders, skeletal problems, and immune system problems are among the most serious complications of DS (Ostermaier, 2019).

Mothers of children with Down syndrome confront a variety of obstacles as a result of the need to deal with the illness's social ramifications, such as the risk of stigmatization. They may go through a hard process of relinquishing the fantasy of having a "normal" child and accepting that their child is "different" when they are intra-psychic. Parents sometimes react with a mixture of shock and disbelief, followed by denial, after learning that their newborn infant has a disability (Singh, 2018).

Mothers of children with intellectual and developmental disabilities, such as DS, are experiencing a variety of negative emotions such as stress, anxiety, and depression, as well as increased fear for their own and their children's futures, all of which will have a negative impact on their children's well-being due to their inability to cope with the situation. Despite this, some parents accept reality and strive to live a happy life by honing their coping abilities and boosting their self-esteem (Parameswari & Eljo, 2019).

Mental health and psychosocial wellbeing were defined as an integral part of health by the WHO. It is recognized as a key public health issue for stress-affected populations. Mental health problems may affect the ability of individuals and communities to function, leading to distress, violence, suicidal tendencies, poor physical health, and substance abuse. Improving psychological and mental health and well-being of women is an important public health goal (Moti, 2020).

The sustainable development goals (SDGs) are universal and the need for interdisciplinary and intersectoral solutions to reach the SDGs is highlighted. Specific reference is made to mental health under goal 3. Target 3.4 on premature mortality from non-communicable diseases aims for a reduction by “one third through prevention and treatment and promotion of mental health and wellbeing” (Dybdahl & Lien, 2017).

Women’s mental health is of crucial importance, which is greatly affected by the ways in which they are treated and the status they are given in the society. Community health nursing is a key in improving mental health and well-being of women in communities (Malhotra & Shah, 2015).

Education intervention program is widely accepted for the promotion of mental health. In such programs, mothers receive a comprehensive program within a treatment system with clear and information about effective coping skills. Educational program is a multi-stranded intervention designed to provide mothers with information about DS and concerning social, communication, thinking, and behavioral difficulties of DS children. Mothers can learn skills and strategies in the areas of managing child behavior and communication skills. (Al-Oran et al., 2019).
Significance of the study:

In Egypt, the prevalence of Down syndrome (DS) is rising (Abou-Yossef et al., 2014, Antonarakis, 2017). It is regarded as a major issue for parents, which may result in feelings of guilt and humiliation. Mothers who have a child with DS face unique obstacles in assisting their children with daily living skills, symptom management, and navigating the complex disability service system. Children with DS frequently remain with their carers, resulting in increased caregiving responsibilities, stress, and strain daily.

Negative and positive reactions to raising a child with DS may not fall on the opposite ends of the continuum. Family caregivers of children with disabilities may experience positive psychological changes, and these changes may co-occur with negative symptoms such as distress and depression. Educational intervention programs for mothers of children with DS have become an effective way for promoting successful behavioral strategies to manage child behaviors and to assist mothers to improve child development (Hayat, 2018). To the best authors’ knowledge few studies are conducted on the effect of educational intervention on the psychological well-being and coping of mothers having children with Down syndrome in Egypt.

Aim of the study

To evaluate the effect of educational intervention on psychological well-being and coping of mothers having children with Down syndrome through:

- Assessing mothers' level knowledge about Down syndrome.
- Assessing mothers' coping patterns toward their children with Down syndrome
- Assessing mothers' needs for caring for their children with Down syndrome.
- Designing and implementing educational intervention based on the mothers' and their children's needs.
- Assessing the effect of educational intervention on psychological well-being and coping of mothers having children with Down syndrome.

The specific objectives are to compare the pre and post-intervention knowledge and needs of mothers with DS children as well as their psychological well-being and coping.

Research hypothesis:

Educational intervention will improve knowledge, psychological well-being, and coping of mothers having children with Down syndrome.

Subjects and Method:

Research design:

A quasi-experimental research design was used to achieve the aim of this study.

Setting:

The study was carried out at two special needs schools in Mansoura city (Altarbih ELfikria). These settings were chosen because they are the only special needs schools in the City.

Subjects:

A purposive sample of 100 mothers and their children with Down syndrome (DS) were selected from the previous setting according to the following inclusive criteria:

Inclusion criteria for mothers of children with DS:

1- Mothers who give direct care to the child.
2- Free from any psychiatric illness.
3- Agree to participate in the study

Inclusion criteria for children with DS:

1- A child diagnosed with DS
2- Aged from 6 to 12 years (primary school age)
3- From both sex (boys and girls).
Exclusion criteria for children with DS:

1- Have an impairment that isn't related to Down syndrome.
2- Have a disabled sibling or another family member.

Sample size calculation:

The sample size was calculated based on considering the level of significance of power analysis of 0.95 ($\beta=1-0.95=0.05$) at alpha .05 (one-sided) with a large effect size (0.5) was used as the significance, 0.001 was used as the high significance.

Data collection tools:

Tool (I) structured interviewing questionnaire, was designed by the researcher after reviewing related literature, it was written in a simple Arabic language to suit the participants' categories and included four parts:

Part 1: It included data related to demographic characteristics of mothers such as; age, residence and level of education.

Part 2: It included data related to demographic characteristics of children such as; age, gender, and education.

Part 3: Child history included a child's past health history, child's family history, and current health status of DS child: It was designed to assess the mother's medical history during her pregnancy, child's medical history during his/her birth and after birth and determine if there is consanguinity between the parents and family history of Down syndrome. Also, it included data about complications resulting from Down syndrome and the presence of another chronic disease.

Part 4: Mothers' knowledge regarding Down syndrome: It was modified from (Alhaddad et al., 2017; Jan et al., 2017) and included items related to the meaning of down syndrome, causes, types, signs and symptoms, complications, treatment of down syndrome, and follow-up.

Mother's knowledge scoring system: It consisted of eight questions (ideal score: 8) with correct answers equaling one and incorrect answers equaling zero. The whole knowledge of the mother was divided into two categories: satisfactory knowledge up to 50% and unsatisfactory knowledge below 50%.

Tool (II): Ryff’s Psychological wellbeing scale (1989): It was used to assess the level of psychological well-being among the sample. It consists of 42 items.

Tool (III): Mothers’ needs scale: It was used to measure the mothers' needs for caring of their children with Down syndrome. This tool adapted from (Leyser & Dekel 1991) & (Simeonsson & Bally 1988). It included the following: 1- Cognitive needs, which consists of 10 questions. 2- Economical needs, which includes nine questions. 3- Psychological and social needs which includes 9 questions. 4- Physical needs which consists of four questions.

Scoring system of the mother's needs scale:

I never need it = 1, I need it moderately= 2, and I need it a lot= 3 on the mother's needs scale. Mother's needs scale has a total ideal score of 96. I'll never need it if the score is less than 50%, and I'll need it moderately if the score is between 50% and 75% and equal to or more than 75% was I need it very much.

Tool (IV): Mothers' coping scale: This tool was adapted from (Jalowiec and Power, 1991) & (Yeh 2001) to evaluate the mothers' coping strategies for their DS children. It consisted of 40 statements all on the scale. 1- Physical Coping is an 8-question test. 2- Psychological coping is a seven-question survey. 3- Social coping, which is comprised of seven questions. 4- Emotional coping, which is made up of four questions. 5- Educational coping is a 9-question survey. 6- Religious coping is made up of five questions.
Scoring system:

The total optimal score of the mother's coping scale is 80. A score of less than 60% was a negative coping pattern and equal to or more than 60% was a positive coping pattern.

II. Operational Design:

It included the preparatory phase, content validity, pilot study, and fieldwork.

a) Preparatory phase:

It comprised a review of related material as well as theoretical knowledge of many areas of the study from books, papers, scientific journals, and the internet to gain in-depth knowledge about the subject.

Tool Validity and Reliability:

The content validity of the tools, their clarity, comprehensiveness, appropriateness, and relevance were reviewed by five expert professors; three experts in Community Health Nursing, and two expert physicians from the medical-Psychology department. Modifications were made according to the panel judgment. Content validity index was 97%.

The Reliability of the first tool was assessed through Cronbach’s alpha test α= for a tool I was 0.925, tool II was 0.827, tool III was 0.905 and tool, IV was 0.887 by Cronbach’s alpha.

Pilot study:

The Pilot study was carried out for 10% of the sample (10 mothers of children with Down syndrome) to test the reliability, clarity of questions and applicability of the tools, and the time needed to complete them then the tools were modified according to the findings of the pilot study. Subjects who shared in the pilot study were excluded from the main study sample. The time needed to fill out the tools was about 15 to 20 minutes.

Ethical considerations:

The research approval was obtained from the faculty of nursing at Mansoura University before starting the study. The researchers clarified the aim of the study to mothers with Down syndrome children included in the study to gain their confidence and trust. The researchers assured maintaining anonymity and confidentiality of the subjects' data. Mothers were informed that they are allowed to choose to participate or not in the study and that they have the right to withdraw from the study at any time. They were informed about the confidentiality of data collected and that it will be used for the research purpose only.

Implementation phase:

- The approval to conduct the study was obtained orally after explaining the aim of the study.
- From the beginning of October 2021 to the end of December 2021, data were collected over three months.
- A sample was taken from mothers who attended the previous selected settings between the hours of 9 a.m. and 2 p.m., as well as during the mothers' council's regular meetings.
- The researchers filled up an individual structured interviewing questionnaire sheet for each study participant. It takes between 20 and 30 minutes to fill.
- The researchers interviewed participants, at the beginning they were informed about the aim, nature, and expected outcomes of the study.
- All the data were gathered to evaluate the effect of educational intervention on the psychological well-being and coping of mothers having children with Down syndrome. The tools were used twice, first; pre-educational intervention to assess the mothers' knowledge of psychological well-being and coping of mothers having children with Down syndrome, then, second; repeated after one month during follow-up to evaluate the effect of the educational intervention.
- The educational intervention included simple and clear information about Down syndrome. It also included the preparation of
educational materials such as Photos, videos, and PowerPoint presentations. Arabic brochure was designed by the researchers; including educational intervention regarding Down syndrome was introduced to nurses at the end of the sessions.

- This phase included 8 weeks to implement educational intervention regarding Down syndrome. The subject contents have been sequenced through three theoretical sessions and each session took 40-50 minutes. The total time was about 2 hours for each group; mothers involved in the study were divided into 10 groups. Each group included ten mothers.

**Contents of sessions were carried out as the following:**

**The first session (Theoretical):** At the beginning of this session, the researchers introduced themselves, welcomed the mothers, show gratitude for their sharing in the study, and explained the aim of these educational sessions. The 1st session covered the following items; the meaning of Down syndrome, causes, types, and signs and symptoms.

**Second session (Theoretical):** these sessions covered the items related to complications, treatment of Down syndrome, and follow up

**Third session (Theoretical):**

Started by taking feedback about the previous sessions, these sessions covered the items related to coping strategies, and answering any questions related to Down syndrome, the researcher distributed the post-test, then thanked all the participant's mothers for their sharing in the study.

**The Evaluation phase:**

After one month from implementing the educational intervention regarding Down syndrome, an evaluation of the research sample was done using the same format of tools that were used in the pre-test to evaluate the effect of the educational intervention.

**III. Administrative Design:**

Written consent was obtained from each subject after explaining the aim of the study. To carry out the study, approval was obtained from the Directors of special needs schools (ALtarbih ELfikria) in Mansoura city. A letter was issued to them from the Faculty of Nursing at Mansoura University explaining the aim of the study to obtain permission and cooperation.

**Statistical Design:**

Data were gathered, coded, and entered into a computer. It was analyzed using the statistical package for social science (SPSS) version 20. Data were presented in tables, figures, and diagrams. Count and percentage were used for describing and summarizing the qualitative data. Mean and standard deviation were used for describing quantitative data. The most common and appropriate tests used in SPSS data analysis included Chi-Square for comparing categorical data, t-test for comparing continuous data between two groups, the 0.05 level was used as the cut-off value for statistical significance to assess the significance of the results.

**Results:**

**Table (1):** This shows that the mean mother's age was 34.26±3.54, 68% of mothers were living in a rural area and 34% of them were illiterate.

**Table (2):** Illustrates that 36% of children were between 8 and <10 with the mean of their age was 7.63±3.3, 58.0% of them were boys, and 32% of them were in the first level of education.

**Table (3):** Illustrates that 35% of the studied mothers had previous medical diseases during pregnancy, 58% of the children's had medical history during birth and after birth, 62% of parents had consanguinity between them, and 5% of children had a family history of Down syndrome. Also, 8% of the studied children had complications resulting from Down syndrome.

**Table (4):** Illustrates that there were highly statistically significant differences found between
mothers' knowledge regarding Down syndrome pre and post-educational intervention (P<0.001).

**Figure (1):** Demonstrates that 65% of the studied mothers had unsatisfactory total knowledge regarding Down syndrome pre-educational intervention, which improved post-educational intervention and become 83% had satisfactory knowledge regarding Down syndrome.

**Table (5):** clarifies that one quarter (25.0%) had personal growth, while more than one quarter (26%) had positive relations and purpose in life and less than three-quarters of studied mothers of children with Down syndrome (71%) had no self-acceptance pre-educational intervention. While post-educational intervention (69%) had personal growth, nearly two-thirds (65% and 66%) had positive relations and purpose in life respectively and around three-quarters of studied mothers of children with Down syndrome (72%) had self-acceptance. A highly statistically significant difference was found between the pre-and post-educational intervention.

According to table (6), the study's findings revealed that 66% of the studied mothers of children with DS had psychological well-being less than usual and only (4%) have psychological well-being better than usual pre-educational intervention compared to 59% of mothers of children with DS had psychological well-being better than usual post-educational intervention, with a highly statistically significant difference found between the pre-and post-educational intervention.

**Figure (2):** Showed that 52% of the studied mothers had moderate physical needs, 43% of mothers had very much social and psychological needs, 52% of mothers had moderate economic needs, and 39% of mothers had very much cognitive needs.

**Figure (3):** Showed that 40% of mothers had very much levels of needs, 47% of them had a moderate level of needs, and 13% of them never had needs.

**Figure (4):** Showed that 28% of mothers were always able to cope with their Down syndrome children, 30% of them were sometimes able to cope, and 42% of them were never able to cope.

### Table (1): Distribution of mothers according to their demographic characteristics (N = 100).

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>No</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- &lt;30</td>
<td>37</td>
<td>37.0</td>
</tr>
<tr>
<td>- &gt;30</td>
<td>63</td>
<td>63.0</td>
</tr>
<tr>
<td>Residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Rural</td>
<td>32</td>
<td>32.0</td>
</tr>
<tr>
<td>- Urban</td>
<td>68</td>
<td>68.0</td>
</tr>
<tr>
<td>Level of education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Illiterate</td>
<td>37</td>
<td>37.0</td>
</tr>
<tr>
<td>- Read &amp; write</td>
<td>16</td>
<td>16.0</td>
</tr>
<tr>
<td>- Diploma</td>
<td>34</td>
<td>34.0</td>
</tr>
<tr>
<td>- Bachelor</td>
<td>13</td>
<td>13.0</td>
</tr>
</tbody>
</table>

### Table (2): Distribution of children with Down syndrome according to their demographic characteristics (N = 100).

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>No</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- 6&lt;8</td>
<td>35</td>
<td>35.0</td>
</tr>
<tr>
<td>- 8&lt;10</td>
<td>36</td>
<td>36.0</td>
</tr>
<tr>
<td>- 10&lt;12</td>
<td>29</td>
<td>29.0</td>
</tr>
<tr>
<td>Mean ±SD</td>
<td>7.63±3.3</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Boys</td>
<td>58</td>
<td>58.0</td>
</tr>
<tr>
<td>- Girls</td>
<td>42</td>
<td>42.0</td>
</tr>
<tr>
<td>Level of education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- First</td>
<td>32</td>
<td>32.0</td>
</tr>
<tr>
<td>- Second</td>
<td>26</td>
<td>26.0</td>
</tr>
<tr>
<td>- Third</td>
<td>12</td>
<td>12.0</td>
</tr>
</tbody>
</table>
Table (3): Distribution of children with Down syndrome according to their past health history, family history, and current health status of DS child (N = 100).

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>No</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presence of mother's medical diseases during pregnancy</td>
<td>35</td>
<td>35.0</td>
</tr>
<tr>
<td>Child's medical diseases during birth and after birth</td>
<td>48</td>
<td>48.0</td>
</tr>
<tr>
<td>There is consanguinity between the parents</td>
<td>62</td>
<td>62.0</td>
</tr>
<tr>
<td>Family history of Down syndrome</td>
<td>5</td>
<td>5.0</td>
</tr>
<tr>
<td>Complications resulting from Down syndrome</td>
<td>8</td>
<td>8.0</td>
</tr>
</tbody>
</table>

Table (4) Comparison of mothers' knowledge regarding Down syndrome pre and post-educational intervention (N-100)

<table>
<thead>
<tr>
<th>Knowledge items</th>
<th>Pre-educational intervention</th>
<th>Post-educational intervention</th>
<th>X²</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>%</td>
<td>No</td>
<td>%</td>
</tr>
<tr>
<td>Meaning of down syndrome</td>
<td>38</td>
<td>38.0</td>
<td>92</td>
<td>92.0</td>
</tr>
<tr>
<td>Causes of down syndrome</td>
<td>34</td>
<td>34.0</td>
<td>84</td>
<td>84.0</td>
</tr>
<tr>
<td>Types of down syndrome</td>
<td>26</td>
<td>26.0</td>
<td>86</td>
<td>86.0</td>
</tr>
<tr>
<td>Signs and Symptoms of down syndrome</td>
<td>48</td>
<td>48.0</td>
<td>90</td>
<td>90.0</td>
</tr>
<tr>
<td>Complications of Down syndrome</td>
<td>24</td>
<td>24.0</td>
<td>83</td>
<td>83.0</td>
</tr>
<tr>
<td>Treatment of the down syndrome</td>
<td>46</td>
<td>46.0</td>
<td>88</td>
<td>88.0</td>
</tr>
<tr>
<td>Follow-up</td>
<td>22</td>
<td>22.0</td>
<td>79</td>
<td>79.0</td>
</tr>
</tbody>
</table>

**; Highly significant at p-value < 0.001

Figure (1): Percentage distribution of the studied mothers' total knowledge regarding Down syndrome pre-and post-educational intervention (n-100)
Table (5): Distribution of the studied mothers of children with Down syndrome according to their total psychological well-being pre and post-educational intervention (N = 100).

<table>
<thead>
<tr>
<th>Level of Psychological well-being</th>
<th>Pre-educational intervention</th>
<th>Post-educational intervention</th>
<th>X2</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes %</td>
<td>Sometimes %</td>
<td>No %</td>
<td>Yes %</td>
</tr>
<tr>
<td>Autonomy</td>
<td>23.0</td>
<td>15.0</td>
<td>62</td>
<td>53</td>
</tr>
<tr>
<td>Environmental mastery</td>
<td>30.0</td>
<td>10.0</td>
<td>60</td>
<td>58.0</td>
</tr>
<tr>
<td>Personal growth</td>
<td>24.0</td>
<td>7.0</td>
<td>69</td>
<td>69.0</td>
</tr>
<tr>
<td>Positive relations</td>
<td>26.0</td>
<td>8.0</td>
<td>66</td>
<td>65.0</td>
</tr>
<tr>
<td>Purpose in life</td>
<td>28.0</td>
<td>9.0</td>
<td>63</td>
<td>66.0</td>
</tr>
<tr>
<td>Self-acceptance</td>
<td>22.0</td>
<td>7.0</td>
<td>71</td>
<td>72.0</td>
</tr>
</tbody>
</table>

Table (6): Distribution of the studied mothers of children with Down syndrome according to their level of psychological wellbeing pre and post-educational intervention (N = 100).

<table>
<thead>
<tr>
<th>Level of Psychological wellbeing</th>
<th>Pre-educational intervention</th>
<th>Post-educational intervention</th>
<th>X2</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Less than usual</td>
<td>66</td>
<td>66.0</td>
<td>13</td>
<td>13.0</td>
</tr>
<tr>
<td>Same as usual</td>
<td>30</td>
<td>30.0</td>
<td>28</td>
<td>28.0</td>
</tr>
<tr>
<td>Better than usual</td>
<td>4</td>
<td>4.0</td>
<td>59</td>
<td>59.0</td>
</tr>
</tbody>
</table>

Chi-square **; Highly significant at p-value < 0.001

Figure (2): Percentage distribution of the studied mothers according to their sub-total level of needs (N=100).
Discussion:

The management of children and the psychological well-being for mothers of DS children are both directly impacted by the physical, emotional, economical, and social issues that DS mothers must deal with. When mothers are under stress, they used specific coping mechanisms to control their emotions. This study aimed to evaluate the effect of educational intervention on the psychological well-being and coping of mothers having children with Down syndrome.

The current study results revealed that the mean mother's age was 34.26±3.54, more than two-thirds of mothers were living in a rural area and more than one-third of them were illiterate. From the researchers' point of view, the findings of the current study represent that illiterate mothers were more than one-third of the sample. It may be because more than two-thirds of mothers live in rural areas.

Regarding the children’s demographic characteristics, the current study results revealed that, the mean of children's age with DS was 7.63±3.3. More than one-third of children with DS were between 8 and <10 and more than half of them were male. This result is consistent with that of Corder et al., (2017) who studied a study about "Demographics and co-occurring disorders in a clinic-based cohort with Down Syndrome in the United Arab Emirates," which discovered that DS is more common in boys than in girls.
The findings of the present study highlighted that there were highly statistically significant differences found between mothers' knowledge regarding Down syndrome pre and post-program. From the researchers' point of view, this is reflected in the success of educational intervention implementation and its positive effects. Also, reflects the importance and effectiveness of introducing those guidelines for mothers regarding DS.

The present study results showed that less than two-thirds of mothers had unsatisfactory knowledge regarding Down syndrome pre-educational intervention. This result is in the same line as Alhaddad et al., (2018) who conducted a study in Jeddah to assess knowledge and attitude towards Down syndrome among people and found that two-thirds of mothers had poor knowledge regarding Down syndrome. Similarly, Barnoy et al., (2017) studied in US about "Social Inclusion of Children with Down syndrome: Jewish and Muslim Mothers' Knowledge, Attitudes, Beliefs, and Behavioral Intentions" and found that all mothers stated poor knowledge levels about DS. From the investigator's point of view, it may be due to the low mothers' educational level and lack of media society awareness about Down syndrome.

This finding is similar with a line with that of a study conducted by Shalabi et al., (2020) in their study to assess awareness levels toward Down syndrome in Riyadh, who mentioned that less than one-third of the mothers reported low knowledge about Down syndrome. Also, this result is supported by Barnoy et al., (2017) in their study entitled "Social Inclusion of Children with Down syndrome", and found that the same results.

The present study results showed that the majority of mothers had satisfactory knowledge regarding Down syndrome. From the researchers' point of view, it reflected the positive impact of the educational intervention in improving mothers' knowledge. These confirmed the effective modifications in their knowledge and the success of the main goals of the implementation of the educational intervention.

The current study results represented that post-educational intervention more than two-thirds had personal growth, while nearly two-thirds had positive relations and purpose in life respectively and less than three-quarters of studied mothers of children with Down syndrome had self-acceptance with a highly statistically significant difference found between the pre-and post-educational intervention.

From the researchers' point of view, this reflects the importance and effectiveness of educational intervention implementation that are commonly associated with improving knowledge and a better understanding of the research topic among the studied mothers. It may be an acceptance that pushes mothers to look at the problem from its positive side. This result is in the same line as Parameswari and Eljo, (2019), who conducted "A Study on Psychological Well-Being among the Parents of Children with Intellectual and Developmental Disabilities" and observed that some family caregivers accept reality and live positive lives that help them to improve their coping mechanisms and self-esteem. This gives them the confidence to help their children think about the future and achieve a certain level of child autonomy.

The study findings revealed that more than half of mothers of children with DS had psychological well-being better than usual post-educational intervention, with a highly statistically significant difference found between the pre-and post-educational intervention. From the researchers' point of view, this may be because some family caregivers may still feel stigmatized by the condition of their children, and are not willing to socialize, which may lead to stress and thus affect negatively their psychological wellbeing.

These results are supported by McGuire and Chicoine (2020), who conducted a study on "Life Issues of Adolescents and Adults with Down Syndrome" and explained that such a negative attitude toward socializing may limit crucial opportunities for forming positive relationships with others and may lead to social isolation that leads to decreased psychological
wellbeing. Additionally, the mother's psychological health may be impacted by environmental factors, child factors (such as the child's level of disability, the presence of behavioral issues, and the overall child adjustment), caregiver-related traits (such as coping mechanisms and social support from family and friends), as well as by educational and other demographic factors.

In line with this, Hayat (2015) reported that moms of Down syndrome children experience tension, worry, and a low degree of life satisfaction. They also report having a poor quality of life. Additionally, Parameswari and Eljo (2016) reported that more than half of the family caregivers of children with Down syndrome have a low level of psychological well-being.

Concerning the needs of mothers with DS children, the present study showed that more than half of the studied mothers had moderate physical needs, more than two-fifths of mothers had very much social and psychological needs, more than half of mothers had moderate economic needs, and more than one-third of mothers had very much cognitive need.

From the researchers' point of view, it happens as a result of a general lack of media content teaching the public about disabilities, which fuels unfavorable social attitudes against people with disabilities and their families. This study is matched with Sen & Yurtsever, (2019) in their study about “Difficulties Experienced by Families with Disabled Children”. who reported that most mothers need people in society to understand the disabilities of their children with DS. According to the researcher, this could be linked to mothers' ongoing efforts to help their children adapt to their surroundings, their need for the medical team's practical assistance, and their requirement for patience and empathy to care for the child with DS. Therefore, they viewed the child's impairment as a test from Allah and prayed to Him for assistance so that they could begin providing for the child because religion is widely acknowledged as a major support system for moms in our population when coping with a stressful situation.

This study finding showed that more than one-quarter of mothers were always able to cope with their children, nearly one-third were sometimes able to cope, and more than two-fifths of mothers were never able to cope. This result finding is congruent with Sharma & Gupta, (2017) who conducted a study about "The Everyday Lives and Coping Strategies of Women in Delhi" and reported that more than half of the mothers had a low level of coping strategies, which more than two-fifths of mothers never able to cope. As regard mothers’ economical needs, more than two-thirds of mothers were needed very much to allocate funds to provide additional support services to their children. This study is in the same line as Sen & Yurtsever, (2019) who studied "Difficulties experienced by families with disabled children in Turkey", and reported that mothers needed to allocate funds to provide additional support services to their children was the second economical need for mothers.

Conclusion:

Based on the findings of the current study, aim, and hypotheses, it was concluded that the educational intervention was effective in improving psychological well-being and coping of mothers having children with Down syndrome.

Recommendations:

Based on the findings of the present study, the following recommendations were suggested:

- Organized educational programs are needed to improve mothers' knowledge, psychological well-being, and coping with Down syndrome.
- Repetition of the current study with a larger sample of mothers having children with Down syndrome in different settings is required for generalizing the results.
- Establishing counseling centers for parents of children with DS to help them develop better coping mechanisms
- Financial support for mothers having children with DS to help them cover the financial expenses that are associated with the disability and relieve the financial stress that is negatively affecting mental health

References:


Moti, S. (2020). Role of community-based mental health services, including psychosocial services, in mental health care for conflict-affected forced migrants in low and lower middle-income countries.


