Challenges Facing Mothers of Mentally Disabled Child: A Qualitative Study of the Mothers' Experiences

Hanan Hosni El Sherbini[(1)], **Abeer AbdElrazik Ahmed** [(2)], **NeamaYousef Mohammed**[(3)]
[(1)]Lecturer, Community Health Nursing, Faculty of Nursing, Alexandria University
[(2)]Lecturer,Pediatric Nursing, Faculty of Nursing, Alexandria University
[(3)]Lecturer, Community Health Nursing, Faculty of Nursing, Alexandria University

Abstract:

Background: The childhood period can be a challenging time for all parents; however, parents of children with disabilities may experience specific sources of burden. Consequently, they have been viewed as being at risk for a variety of family life problems and challenges. **Aim of the study**: Identify the challenges facing mothers of mentally disabled child. **Subjects& Methods: Research design:** A descriptive Phenomenological study design (multi-method component triangulated design) . **Setting:** The study was carried out in 5 nongovernmental organizations providing health care and rehabilitative services for mentally disabled children in Alexandria. **Subjects:** 60 mothers having mentally disabled children were included in the study. **Tools of data collection:** Two tools were used for data collection. The first tool was personal and socio-demographic structured interview questionnaire for the mothers of mentally disabled child to assess personal and socio-demographic data about the participants and their children . The second tool was focus group discussions guide for the mothers of mentally disabled child that used to identify challenges experienced by the mothers. **Results:** Findings of the present study revealed that 23.3% of the mothers have more than one mentally disabled child. 60% of them were unable to pay for health services. The emerged raw qualitative data were clustered intothree categorical schemes: **Firstly**, challenges facing mothers of mentally disabled children whether child related, family related or community related challenges. **Secondly**, the adaptation of the mothers' with these challenges and **Thirdly,** Maternal Feelings Regarding the Future. **Conclusion:** The study concluded that mothers of mentally disabled children experience various psychological and emotional, social, economic and physical challenges. **Recommendations:** Establishing a special unit for mentally disabled children within the family health centers and pediatric hospitals.Use mobile equipped units to provide appropriate free health care services for disabled children in remote areas provided by highly qualified team.

Keywords: Disability, Mental health, Mental disabilities, Challenges,adaptation

INTRODUCTION

Children with mental disabilities are one of the most marginalized and excluded groups of children, experiencing widespread violations of their rights[(1)]. Despite the obligation in the Convention on the Rights of Persons with Disabilities are provided with equal access to and quality of health care, their access to health services is often limited, leading to health inequalities unconnected to their disabilities[(2)].

Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations[(3)].

According to the World Health Organization intellectual or mental disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development [(4)]. mental retardation refers to a condition which is marked by subnormal intellectual functioning and adjustment difficulties which occur before a person is eighteen years of age[(5)].

According to the estimates based on the World Health Organization (WHO) Global Burden of Disease study,15.3% of the world population had moderate or severe disability. While 93 million (5.1%) of children aged 0–14 years has moderate or severe disability. Additionally, in high income countries 2.8 % of people aged 0–14 years have moderate or severe disability, while in Eastern Mediterranean region they constitute 5.2% of those at age 0-14 years [(6)].

In 2005 the United Nations Children's Fund (UNICEF) estimated the number of children with disabilities under age 18 at 150 million worldwide[7]. In Egypt, there is a limited statistical data about disability. According to Egypt population census of 2006, the population with disabilities is representing 0.7% of the total Egyptian population. While, in Alexandria governorate they represent 0.5% of Alexandria population[8].

The childhood period can be a challenging time for all parents; however, parents of children with disabilities may experience specific sources of burden[9].The presence of a mentally challenged child in the family has far reaching implication for the family as a whole. The impact of the disability and problem associated with it is not restricted to the child but extended far beyond the child and affects all family members[10]. Consequently, parents of mentally disabled child have been viewed as being at risk for a variety of family life problems and challenges[11].

Mothers as a main family caregiver play a vital role in caring for mentally disabled individuals including children and adolescents[12]. Mental disability of the child causes a great amount of challenges to the mother. Presence of behavior problems in mentally disabled children is a serious concern for the mothers. It produces variant forms of challenges among them including; social, emotional, economic, and physical challenges. Some mothers shamed to participate in social functions with their mentally disabled child. Even though, some mothers cope well and get adjusted to their situation, but some cannot cope better[13].

It is important for any child to be healthy and free from any disabilities. Many children may face life with physical or mental disabilities that deprive them a normal childhood [5]. Disabled are particularly vulnerable to health problems and experience difficulties in meeting their healthcare needs [14].

Mental disability in a family is perceived in different ways and creates uncertainty for parents, family members and the community at large. It is important that health care providers have an in-depth understanding of the experiences encountered by these families[15]. Learning the challenges they face in caring for children is the first step in identifying ways to improve support for such caregivers [12]. The mothers, who benefited from a social support network, have more positive reactions to emotional and physical challenges [16].

Nursing as a family-oriented profession involves supporting mothers of children with disabilities to gain an awareness of their role and to cope appropriately with the challenges facing them[17,18].

Significance of the study

Parents of mentally challenged children commonly experience a gamut of emotions over the years. They often struggle with guilt. One or both parents may feel as though they somehow caused the child to be disabled, whether from genetics, alcohol use, stress, or other logical or illogical reasons. This guilt can harm the parent's emotional health if it is not dealt with. Raising a child who is mentally challenged requires emotional strength and flexibility, adequate support can be provided by nursing team who will minimize such challenges facing these parents.

AIM OF THE STUDY:

The aim of the study was to:

Identify the challenges facing mothers of mentall disabled child.

Research questions:

What are the challenges facing mothers of mentally disabled child?

Subjects and Methods:

Research design:

A descriptive Phenomenological study design (multi-method component triangulated design) was adopted to carry out this study.

Study Setting:

The study was conducted in 5 randomly selected Non-Governmental Organization (NGOs) providing health care and rehabilitative services for mentally disabled

children in Alexandria. These organizationswere Dar Al-shahied Mohamed Mahmoud El Saied (Ali ibn Abi Talib Association), Al Wafaa Association for Mentally Handicapped, Caritas Association - Egypt, Nour El Tawheed Center**,** and Agial Center.

Study Subjects:

The target populations for this research were the mothers of mentally disabled children who were selected randomly from the previously mentioned settings. In-depth interview and Five Focus Group Discussions (FGDs) were conducted in the NGOs having the largest number of mother's attendance. Each focus group was composed of 10-12 mothers. The total number of mothers included in this study was 60 mothers.

Tools of data collection:

Two tools were used to collect the necessary data:

Tool I: Personal and Socio-demographic Structured Interview Schedual for the Mothers of Mentally Disabled Child:

It was developed by the researchers after a thorough reviewing of related literature to identify personal and socio-demographic data about the participants and their children; it included the following: the mothers'age, marital status, level of education, occupation, abilityto pay for health services, and weather they have more than one mentally disabled child or not. Data about the mentally disabled child include, age, sex, birth order, and the type of child's disability.

Tool II: Focus Group Discussions Guide for the Mothers of Mentally disabled child:

It was developed by the researchers to collect the qualitative data from the mothers of the mentally disabled child, to identify challenges experienced by them when caring for their children and what they do to address or deal with these challenges. It consisted of the following parts: **Part I: Introduction**; in this part the researchers introduce themselves (name, occupation), and explain the study purposes and confirming the confidentiality of data.**Part II: Engagement questions (ice breaking questions)** these questions were used to help participants ease into the discussion and being free to express their opinions, these questions such as what is their opinion regarding children, the care provided for them and the difference in providing care for normal child and mentally disabled one.**Part III: Exploration questions(Key questions)** which addressed the key issues the researchers wanted to cover in FGDs session, these included; the challenges facing the mothers, and mothers' adaptation with these challenges and mothers' feelings about the future.Finally, **Part IV: Exit question (closing question)** such as: is there anything else they would like to say?

Content validity & reliabilty:

Tool (I) and (II) were developed by the researchers and validated by juries of five experts in the field of community health nursing and pediatric nursing. Their suggestions and recommendations were taken into consideration.

Field work:

Data were collected by the researchers over a period of three months from March to May 2015.

Pilot study (Mock):

Focus group study pilot(**Mock**) was done by the researchers on 6 mothers in order to ascertain the relevance, clarity and applicability of the tools, test wording of the questions and estimate the time required for the focus group discussion. Based on the obtained results, the necessary modifications were done.

Administrative & Ethical considerations:

An official letter from the Faculty of Nursing was directed to the NGOs in Alexandria that provide health care and rehabilitative services for mentally disabled children in order to obtain their approval to carry out the study in the above mentioned selected settings.

Meetings were held with the directors of the selected settings to clarify the purpose of the study and to gain their cooperation and support during data collection. Informed consent was obtained from all mothers after providing an appropriate explanation about the purpose of the study and nature of the

research. Their permission was obtained before using tape for data recording.

The confidentiality and anonymity of individual responses, volunteer participation and right to refuse participating in the study were emphasized to the women

Statistical analysis:

The collected quantitative data were coded and analyzed using PC with the Statistical Package for Social Sciences (SPSS version 16) and tabulated frequency and percentages were calculated.Whereas, the collected qualitative data were transcribed verbatim (word for word) in order to capture the exact words, phrases voiced by the participants. Proofread (read through for errors) in order to check the accuracy of all transcripts against the audiotape were done.Sensitive information as the accidental use of an individual's name during the discussions was replaced by appropriate participant ID. Findings together with pertinent quotations were then organized according to the discussed topics. After that, the main categories covering the objective behind the research were formulated and clustered into themes. These themes provided the major heading for the results. Finally, trustworthiness and quality of the qualitative data were ensured by adopting triangulation, member checking, peer debriefing, inquiry audit and thick description strategies.

RESULTS

In this study the results were divided into two main parts. Part I: quantitative results and part II: qualitative results.

Part (I) Quantitative results: Table (1): illustrates the personal and socio-demographic data of the studied mothers and their children. It was found that slightly more than two thirds (66.7%) of the studied mothers were aged 40 to less than 50 years old, with a mean age of 45.76 ± 6.58 years. 60% of the mothers were either illiterate or can just read and write. More than three quarters of them were married. The majority of the mothers (80%) were housewives. Slightly less than quarter (23.3%)ofthem have more than one mentally disabled child. In addition, 60% of them were unable to pay for health services for their children. Regarding the socio-demographic data of the mentally disabled child, it is clear from the table that more than half (53.3%) of the children were aged 12-15 years old, with a mean age of 10.70 ± 5.01 years.More than half (56.7%) of the children were female and a similar percentage of them hadDown's syndrome as their type of disability. The second birth order or more constitutes three fifths (60%) of the mentally disabled children.

Part (2): Qualitative Results: The emerged raw qualitative data in the current study can be clustered under the following categorical schemes: **Firstly**, the challenges facing mothers of mentally disabled children either child related, family related or community related. **Secondly**, the adaptation of the mothers' regarding these challenges.**Thirdly,**Mothers' feeling about the future.

Firstly: Challenges Facing mothers of mentally disabled children:

There are three major themes emerged from the study that explains the mothers' challenges in the everyday life of caring for the mentally disabled child. These were **child related challenges**, **family related challenges** and**community related challenges**.

I) Child related challenges:

The major themes emerged from the study that explain the child related challenges includes:Extraordinary care and additional responsibilities to meet the physical needs of the mentally disabled children, communication problems and behavioral and emotional problems.

1. Extraordinary care and additional responsibilities to meet the physical needs of the mentally disabled children:

Extraordinary care and additional responsibilities can take a physical toll on mothers leading to exhaustion. Most of mothers in the present study stressed that raising mentally challenged child is so exhaustive and difficult compared with typical children.

"تربية الأطفال مش سهلة وبالذات لو كان الطفل معاق"

"في فرق كبير فى العناية بالطفل المعاق عن العناية بالطفل الطبيعى،التعامل مع المعاق اصعب بكتير من التعامل مع السليم"

Additionally, mentally disabled ones require extraordinary comprehensive care including aspects regardingfeeding, bathing, movingand clothing. Some participant pointed out that that the mentally **disabled girl needs** more care, especially when they reach **puberty** and have **menarche**. Also boys need especial care that cannot be fulfilled by mothers alone, such as hair cutting.

"أنا كأم المسئولة عن كل حاجة لابنى المعاق لأنه مش بيعرف يعمل حاجة خالص أنا اللى بأكله وأشربه وأحميه"

"ده انا بعمله كل حاجة من اكل وشرب وحمي وتلبيس وتقليع"

"البنتممكن تحتاج عناية اكتر بالذات لما تبلغ وتجيلها الدورة الشهرية"

"كمان فى بعض المواقف برده الولد بيكون محتاج عناية مش بتقدر عليها الأم زى مثلاً لما شعره يطول ويحتاج يروح للحلاق"

"انا بنزيل و بطلع شايلة ابنى اربع تدوار "

Some mothers added that children also require more physician and other health-care appointments and may need close medical monitoring.

"ده غير متابعة الدكتور والعلاج الطبيعي"

"جلسات التخاطب كمان بتبقي مرتين في الاسبوع ولازم مقطعش"

children may also need to be monitored to avoid inadvertent self-harm such as falling down stairs or walking into the street.

"لازم يبقي تحت عيني طول اليوم لو واربت يفتح الباب وينزل"

" عنده ١٤ سنة وممكن يؤذي نفسه ده لسة معور نفسة بالسكينة"

" احنا ركبنا ترباس علي الباب بعيد عن ايده"

Moreover, some mothers pointed out that their mentally disabled children require extra attention and protection from being **physically andsexually abused**.

" الكلام ده واقع فى حياتنا احنا بنشوف المصايب كتير حوالينا من كل ناحيه"

"بصراحه كده اذا كان السليم او الطبيعى بيتأذى وبتغرر بيه او بيغتصب فما بالك انت بالمعاق!!!"

The majority of the mothers believes that they must **act as a protector** of their child; also some of them **wish to live more** than their children, in order to provide **lifelong protection** for them.

"أنا بأشوف نفسى الحماية الوحيدة لإبنى ، علشان كده نفسى عمرى يكون اطول منه بس علشان احميه، طول ما أنا موجوده هحميه انشاء الله" ، "فعلاً انا نفسى اعيش اكتر منها علشان احميها"

Sometimes the mothers become **overwhelmed by caring**which leads to negative physical effects on the mother's body. They may have a lot of physical problems due to **extra effort**. **Musculoskeletal disorders** were the main complains of the mothers. Others added that they have **chronic diseases** that result from over stress. **Backache**, **strain**, **fatigue**, **knee pain**, **muscle aches**, **joint stiffness** and **spinal disc herniation** were the major physical challenges facing the participants in this study. Also, **hypertension** and **Diabetes** were prevalent among those mothers.

"طبعاً كلنا عارفين الخدمة دي كلها بتيجي على صحتنا كتير واكترنا فعلاً بيعانى من مشاكل كتيره خالص،

"الواحد بيتعب قوى وبيتهد حيله من الشيل والحط فى العيل وكمان طلوع السلالم واحنا شايلين العيل ده بيهدنا وبيوجع" ضهرنا وركبنا و وعضلاتنا وكمان بيضغط على فقرات الضهر وبيجيب الغضروف" ، " انا كمان جالى السكر والضغط من كتر حرق الدم اللى بشوفه".

2. Communication problems:

The majority of mothers stated that they have **communication problems** with the child, as they sometimes **cannot express their feelings** properly, they cannot state exactly what they need.

"احيانا ابنى بيقعد يعمل حاجات مش مفهومه ومش بيعرف يعبر هو عايز ايه"

"مش بيعرف يعبر عن اللى جواه وممكن يقعد يقول "مام مام" مع انى بكون لسه مأكلاه ومش بفهم هو عايز ايه"

"بيبقي عيان ومش عارف يعبر ولا يقول فيه ايه"

3. Behavioral and emotional problems:

Many parents find it difficult to handle behavior problems like screaming, crying, inability to concentrate, aggressiveness, etc that a child with mental retardation might have.Some of the mothers suffer from **unexpected behavior** from their children, as they sometimes become **angry**, **crying**, **nervous** without apparent cause.

"كتير منهم بتلاقيه عصبى مره واحده من غير سبب وكمان ممكن يضرب اللى قدامه"،

"احيانا كمان ممكن يؤذى اخته لو طال شعرها ممكن يقطعه ويكسر اى لعبة قدامه ويقطع اى ورق"

"بيبقوا جامدين ده الاسبوع اللي فات هاجم عليا انا وابوه واحنا صحتنا في النازل مبقناش نقدر نصد"

A number of respondents revealed having **disturbing thoughts** about living with a mentally disabled child. They expressed being **stressed** by the explicit behavior of the child that caused problems not only for the parent but also to people nearby such as neighbors. Behaviors of the children that were of particular concern to mothers were being **aggressive**, **destructive**, **restless** or **hyperactive**, **making noise**, and **lack of proper eating skills**.

"بصراحه احيان كتير بأكون مش عارفه اتصرف ازاى لما بتكون البنت عدوانيه وبالذات لو عندى حد من الجيران وكمان لما تقعد

تكسر وتخبط ، احيانا كمان البنت بتخاف وتتفزع وتتصرف تصرفات غريبه حتى لو سمعت بس صوت جرس الباب او التليفون"، "لما بيجى عندنا حد من الجيران مش بعرف اتصرف ازاى لما تقعد تتكلم وتتحرك حركات غريبه ملهاش معنى"، "احيانا والله البنت بتعضنى او تضربنى جامد قوى بس بأستحمل هعمل ايه، والكسوف بقى لما تضرب حد غريب فى البيت"،"بقي جامد محش بيقدر عليه ده لسة زاقق ابوه موقعه"

II) :Family related challenges:

***The major themes emerged from the study that explain the family related challenges includes:*Helpless and lack of interfamilial support, lack of child acceptance, familial social isolation, family distruction and break down and Familial economic challenges**

1. Helplessness and lack of interfamilial support:

Sometimes, mothers devoted heroic efforts to help his/hermentally challenged child while the other parent may opt to take the opposite approach.mothers might feel they are not getting enough support from their husband in taking care of the child.The majority of mothers in the current study reported that they felt **helpless**; they provide all care without support from others. Additionally, some mothers expressed that their partners were only supportingthe children financially.

"مفيش حد بيساعدنى خالص فى رعاية ابنى"

" كل دور الأب هو الفلوس وكل حاجه بتقوم بيها الأم لوحدها"

Only few mothers stated that like **husband and daughter supports** them in providing care.

"لأ بصراحه جوزى لما بيكون موجود بيساعدنى فى رعاية ابنى"

"بنتى الكبيرة ساعات بتساعدنى"

2. Lack of Child Acceptance

The majorityy of mothers complaining from the lack of the childrens' acceptance **by their brethren (Sisters and brothers)** and other family members like mothers in law, aunts and uncles.

"احياناً اخته بتكون زهقانه منه لأنها مش عارف تذاكر ولا تركز بسبب تصرفات اخوها"

القرايب بيشوفوا ان المعاق ده وصمة عار وبيستعروا منه ومش بيحبوا حد يعرف انه قريبهم"

" الأصعب بقى ان القريب اكتر من الغريب وبالذات الحما والعم والعمه اكتر حد بيبقى مش قابل الطفل ده"

" دول بيطلبوا منى اربطه واحبسه لو ضيف جاى علشان محدش يشوفه"

On the otherhand, soms mothers stressed that their children aer well accepted among their families and pointed out that family members share him/her their activities like playing.

"اخواتها بيحبوها وبيلعبوا معاها"

"حماتي بتحبه وبتقول عليه بركة"

3. Familial social isolation:

The social life of the family was found to be disrupted by the presence of mentally disabled child. Sometimes parents avoide going with the child to any **social gatherings** such as parties because of the child's **disturbing behavior**.

" احيان كتيره مش بنعرف نشارك فى واجب اجتماعى زى اننا نروح فرح مثلاً او عزومه لأننا بنخاف الولد يعمل مشكله فى المكان"

"بطلنا نروح لحد لانه بيضايق اللى احنا رايحين عنده"

" اغلبنا مش بيروح عند حد ومعزول عن الناس علشان ميشوفش فى عنيهم نظرة الشفقه"

" اخته بتكون منطويه لأنها مش لأقيه حد تلعب معاه او تكلمه، لأننا كمان مش بنخرج"

4. Family distruction& break down

Some respondents pointed out thst disability may lead to **family distruction**and some mothers were **divorced** as a result of having a mentally disabled child. Some respondents added that mothers in law in some cases ask her sons to **re-marry** to have a healthy child.

" بصراحه احيان كتيره بيتخرب البيت وبيحصل طلاق لأن الأم جابت طفل معاق"

" احيانا بتكون الحما هى السبب فى خراب البيت لأنها بتطلب من ابنها يتجوز تانى مخصوص علشان يجب عيل طبيعى"

Also some mothers agreed that **morals and ethics** play an important role in accepting the mentally disabled person.

" بصراحة الأخلاق والتربية ليها دور فى التعامل مع اى بنى ادم سواء كان معاق او لأ"

5. Familial economic challenges:

Poverty was revealed by mothers as being responsible for their inability to meet certain important needs of the mentally disabled child. Some mothers were house wives who did not have any **means of earning** income and depended solely on their husband; those who did not have husbands expected to get help from other people, especially relatives. This was a problem if they could not get help they needed. They could not manage **buying drugs** for their children and physiotherapy when they did not receive them at the hospital. They also could not afford bus fare to attend the clinic with their children on the day of their appointment.

Overcrowded **transportations** put extra burden on the familial income as a private transportation is needed to reach to the clinics in order to receive the needed care.

" الفقر والظروف المادية هى اكبر الصعوبات اللى بتقابلنا بصراحه ، وده لأن احنا اصلاً داخلنا يدوب على القد"

" تكلفة الجلسه فى العلاج الطبيعى والعمليات اللى بتتعمل للعيل من دول وكمان ناهيك عن الكلام عن اجرة التاكسى اللى هروح بيه الدار او المكان اللى بأعمل فيه الجلسه"

"الجلسه الواحده بتتكلف ١٥ جنيه للجلسه نفسها غير ٣٠ جنيه للتاكسى رايح جاى، وده والعيل بيحتاج ٣ او ٤ جلسات فى الأسبوع طاب ازاى!!!!"

Some respondents added that financial burden of the physiotherapy may lead to **non compliance** of care; that may affects **negatively on the progress of the child's condition**.

" طبعاً لأن مفيش دخل للأسرة غير مرتب الزوج ده بيخلينا منكملش الجلسات المطلوبه فى الأسبوع يعنى بنمشى على سطر ونسيب سطر وده بيخللى الحاله ماتتحسنش"

Activity of daily living of the mothers were affected by the presence of a mentally disabled child. Much time was spent in providing care for the disabled child which hinder other important activities such as working. Income generation in the family was affected and this further escalated family poverty.

" وطبعاً لأن ابنى محتاجنى باستمرار علشان ارعاه وأأكله وأشربه وأعمله كل حاجه ده بيخلينى مستحيل اعرف اشتغل وأساعد فى دخل البيت، وده برده هيخلى المشكله تكبر... طب نعمل ايه؟"

III) Community related challenges:

The major themes emerged from the study that explain thecommunity related challenges that mothers experiencein the everyday life of caring for the mentally disabled child includes: **Lack and poor quality of governmental health services and Community related social challenges**

1. ***Lack and poor quality of governmental health services.***

Inadequate and poor quality health care and rehabilitative services for mentally disabled children were the most challenging issue reported by the majority of mothers. Most of them spent a lot of time looking for hospitals and rehabilitative centers that could accommodate the child **physiotherapy** needs.

"الخدمه فى المستشفيات الحكومى وحشه قوى"،"مفيش رعايه ولا اهتمام للسليم فمابالك بالمعاق"، " المراكز والأماكن يعنى اللى فيها علاج طبيعى اغلبها بعيده ومفيهاش خدمة كويسه وأحيانا نروح ونتعب ومانلاقيش الخدمة اللى احنا عايزينها" " جلسات العلاج الطبيعى مكلفه وياريتنا بنقدر نلاقيها"، كمان احنا نفسنا نلاقى اماكن تخدم ولادنا وتوفر لهم التأهيل اللازم".

Mothers mistrust governmental services: The majority of mothers in this study believes that the government didn't help them; they also believe that the government did not punish the persons who are responsible about the occurrence of disability among poorer. All of them agreed that there are **lack of accountability** in the governmental hospitals which cause a lot of suffering for the poor families.

" السبب الرئيسى فى الإعاقات اللى حصلت لولادنا هو نقص الأكسجين وده حصل لأن العناية فى المستشفى مش سليمه وبالذات فى المستشفى الحكومى اللى مش بيروحها غير الفقراء اللى ملهومش تمن عند الحكومة"، " لو كان فى محاسبه او مسائلة للدكاترة اللللى بيغلطوا فى شغلهم مكانش ده حصل لولادنا"، " بالرغم من اننا مقتنعين ان كل شئ بأمر الله لكن برده كل شئ وليه سبب والدكاتره اللى مدخلوش العيل العنايه او معرفش يشفطله كويس وقت الولاده هو السبب"

Mothers mistrust health care providers: The majority of mothers in this study believe that the junior physicians in the general hospitals had **no skills in diagnosis and management**; especially for mentally disabled. Also they added that **improper diagnosisdelay the care** which leads to subsequent complications for their children.

"تأخير الولاده هو اللى عمل نقص اكسجين وده لأن الدكاترة مكانتش بتعمل اللى عليها ، اصلهم دكاتره صغيرين يعنى تحت التمرين ولسه بيتعلموا فى عيالنا ، اكتر الدكاتره فى الحكومى بتدرب" ، "كمان الدكاتره مش بيشخصوا الحاله صح، انا ابنى روحت بيه للدكتوره وعمره ٣ شهور وهو عنده كهربه زايده فى المخ وبيتشنج وقالوا قد يكون سخونيه او قد يكون برد او قد يكون او قد يكون وخلاص معرفوش حالته الا بعد سنه من عمره"، " انا اللى عرف يشخص ابنى دكتور كبير لما حط ايده على دماغه ولقى نافوخه جامد عرف انه قفل قبل معاده وعلشان كده جاله ضمور"

2. Community related social challenges:

Caring for a child with mental disabilities was found to be associated with many social challenges. **Stigmatization**,**lack of public awareness**, **social support**, and **marginalization**, in addition to lack of familial support.**Rejection for disabled** child also considered as the most distressing factor that leads to a negative effect on the mothers' abilities to accommodate with these disabilities. Sometimes relatives considered as the weapon that hit the mothers, especially "mothers in law, aunts, and uncles".

"على فكره نظرة المجتمع للطفل المعاق سلبيه جداً"

" مفيش تقبل ولا حنيه ابداً على البنى ادم منهم"،

"اشي يقول عليه بالله واشي يقول عبيط ببقي بتقطع"

Also some of the mothers raise an important issue that reflects poor community awareness about the mental disabilities, as they considers all mental disabilities categorized as **a hereditary disease**.

" ناس كتير لما بتعرف ان فى العيله حد معاق على طول بترفض الجواز من العيله دى وبتعتبر ان اى اعاقه ممكن تتنقل عن طريق الوراثه"

Secondly: Adaptation of the mothers' with these challenges.

Mothers expressed various ways they used in order to address the challenges they were facing by living with a mentally disabled child. A variety of coping mechanisms and adaptation were employed in different situations depending on what seemed to be helpful to the mothers. All mothers agreed that, they support each others (**social support group**), they believe that the person who have the same problem like you, able to advice and helps you. They also believe that, the real family is there in the center.

"احنا الحمد لله اتأقلمنا دلوقت عن الأول بكتير وبقينا نعرف نواجه الصعوبات اللى بتقابلنا بطرق كتيره، زى مثلاً اننا نروح للدكتور المتخصص علشان ينصحنا ويعالج ابننا"،

" وكمان احياناً بنرقى العيل او بنشوف الوصفات اللى ممكن نعرفها من بعض احنا كأمهات ونعملها"

" بصراحه ما بيحسش بالنار الا اللى كابشها (ماسكها) علشان كده ضرورى نعرف ان محدش هيساعدك ويصبرك غير اللى زيك"

" الأسرة الحقيقية هنا فى السنتر او الدار دى ، والله الواحد مش بيضحك غير هنا".

Thirdly: Maternal Feelings Regarding the Future

One of the main concerns of mothers of mentally retarded children is about how their children will be taken care of when they die. Most of the respondents were **anxious** and **worry** and have **fear from the future**. Varying degrees of emotional distress were experienced by mothers as feelings of **sadness** and **inner pain or bitterness**, feel **unhappy**, **guilty** and have **hopelessness**.

" انا بصراحه خايفة وقلقانه قوى من بكره ومش عارفه ازاى ومين هيرعاه" ، " القلق ده بيخلينى فعلاً احس بالذنب انى اتجوزت وخلفت وهسيب الطفل المعاق ده من غير اى حاجه يتسند عليها وتحميه من اللى جاى بكره، وبصراحه معنديش امل خلاص انه يتحسن انا بقاللى سنين بعالج فيه وعملت اكتر من ستة عمليات ومفيش فايدة" ،" حيعمل ايه من بعدي خايفة يتمرمط"،

" انا بصراحه بشوف نفسى انى السبب فى اللى حصل لإبنى لأنى وانا حامل اتعرضت لضغط نفسى جامد بالذات بعد وفاة جوزى، وده هو اللى خلا ابنى كده"

DISCUSSION

Mental retardation is a condition of arrested or incomplete development of the mind characterized by impairment of skills and overall intelligence in areas such as cognition, language, motor and social abilities W H O [19]. For that reason, providing care for mentally disabled child poses a lot of challenges for the caregivers especially mothers. The findings of the current study revealed various psychological, social, physical and economic challenges that mothers experienced in providing care fortheir mentally disabled child. The mothers emphasizing on the great differencein providing care for normal child and mentally disabled one. Also, parents of children diagnosed with autism, cerebral palsy, down syndrome, fetal alcohol spectrum disorders, and other types of disabilities pose different and increased challenges compared with raising children without a disability.These findings agreed with Nurullah's findings [20] who found that parents of children with developmental disabilities can experience negative feelings as stress, burden, sorrow, and physical exhaustion .

Moreover, the mothers in the current study pointed out that, generally there are no differences between the care provided to mentally disabled boy than girl. But some of them stated that the mentally disabled girl needs more protection and attention, and sometimes they need more care especially when they reach puberty and have menarche. Additionally, few mothers added that, eithergirlsor boys were at risk of being physically andsexually abused such as being burned or raped. These findings confirmed by a study conducted in Australia by Ann Davis[21]. whoreported that individuals with developmental disabilities which include people with mental retardation, autism, cerebral palsy, epilepsy and learning disabilities were sexually assaulted ten times higher than the rate for non-disabled individuals

Mental retardation places a severe burden on the individual and the family this involves assistance in carrying out activities of daily living and self-care, all evidence points towards a substantial burden caused by this condition. In most cases, this burden continues throughout life W H O [22].This was agreed by the mothers in the current study as

most of them stated that, they sometimes become overwhelmed by caring, for every member within the family, which leads to negative physical effects on the mother's body. They may have a lot of physical problems due to extra effort. These physical challenges can be decreased by proper support from others in caring. The presence of a mentally retarded child in the family becomes a source of stress so that, support from other family members helps in reducing this stress. Grandparental support is an important factor in reducing stress Havalappanavar[23].

The current study found that, sometimes relativesespecially mothers in law, aunts, and uncles.areconsidered as the weapon that hit the mothers. Respondents pointed out thatsome mothers were divorced as a result of having a mentally disabled child. The mothers in law sometime ask her son to re-marry to have a healthy child.In contrast Upadhyayaand Havalappanavar [23], revealed that none of the parents were having any problems with their grandparents and they were satisfied with their support.

The findings of the current study also shed the light on an important aspect of social challenges facing mothers asstigmatization,social isolation, lack of public awareness, social support, and marginalization. In addition, lack of familial support and rejection for disabled child were reported by the mothers in the current study. These findings werein line with Bauman [24] who reported that, parents of mental disabled children face a multitude of challenges. The first challenge faced by these parents is social isolation. Friends and family members may not understand the special needs of a mentally retarded children. The second challenge frequently is that parents of children with mental retardation are subject to stigma.

Additionally, the majority of mothers in the current study stated that they have communication problems with their children, as they sometimes cannot express their feelings properly, they cannot state exactly what they need. These findings were supported by Pisula et al [25].study WHO found social communication and language deficits in first-degree relatives of individuals with Autism spectrum disorders (ASD). Both receptive and expressive language is affected

The world health report 2001 found that mental health was neglected for far too long period and must be universally regarded in a new light W H O [19]. This statement was congruent with the current study findings as the majority of mothers in this study believe that the government didn't help them; they also believe that the government did not punish the persons who are responsible about the occurrence of disability among poorer. All of them agreed that there is a lack of accountability in the governmental hospitalswhich cause a lot of suffering for the poor families. The most distressing aspect was inability of the child to acquire enough care due to an inadequate number of centers and hospitals. Mothers spent a lot of time looking for hospitals that could accommodate the child physiotherapy needs. So that, more focus on mental retardation care is needed, in order to decrease the psychological and emotional challenges facing mothers.The management and treatment of mental disorders in primary level of care are a fundamental step which enables the largest number of people to get easier and faster access to services.

Generally, inservice training for health care personnel regarding the essential needs and problems of the children with special needs is mandatory. Such training will ensurethe best use of available knowledge of the largest number of people and makes possible the immediate application of interventions. Additionally, Mental health issues should be included in training curricula, with refreshing courses to improve the effectiveness of the management of mental disorders in general health services U.S[26]. This will in return decrease mothers mistrust for medical care that was reported by the mothers in the current study, where the majority of mothers believes that the junior physician in general hospital had no skills in diagnosis and management; especially for mentally disabled. Also, they added that improper diagnosisdelay the care which leads to subsequent complications for their children.

Another type of challenges facing mothers in the current study wasthe economic challenges, there are two major themes

emerged in the current study that explained how living with a mentally disabled child interfered with the economic activities of the families, these wereexisting poverty that interfere with various income generating activities and extra expenditure due to the presence of disability. Furthermore, the mothers added that, overcrowded transportations put extra burden on the familial income as a private transportation is needed to reach to the clinics in order to receiving the needed care for the child. This findings confirmed by U.S [26] report which documented that transportation plays a critical role in providing access to employment, health care, education, and other community services. The transportation problem and such as scarcity and overcrowding affects the accessibility of services especially among handicapped

Finally, this study sheds the light on many forms of challenges facing the mothers of mentally disabled child. So the mother support is considered to be the first responsibility of the medical team,especially nurses as they can help these mothers to deal with all forms of challenges.Public education and awareness campaigns on mental health and needs of mentally disabled should be launched in all primary health care settings and pediatric hospitals. The human rights of people with mental disability must be highlighted. Community health nurse and pediatric nurse together must be defended to protect the disabled child and provide adequate support for their mothers to have control over all types of challenges facing them.

CONCLUSION:

The findings of the present study revealed that, mothers of mentally disabled children experience various psychological and emotional, social, economic and physical challenges. Professional assistance, public awareness of mental disability in children, social support from the government, private sector, and non-governmental organizations are important for addressing these challenges

RECOMMENDATIONS:

Based on the results of the present study,the following recommendations are suggested:

1- Establishing a special unit for mentally disabled child checkups and health counseling about mental health within the family health centers and pediatric hospitals.
2- Use mobile equipped units to provide appropriate health care services for disabled children in remote areas, which to be provided free of charge, and services must be provided by highly qualified team.
3- Developing comprehensive coordination and cooperation protocol among Alexandria Health Directorate, Alexandria University, NGOs, and other different sectors of the community to raise community awareness about mental health and care for disabled children.
4- Health care providers need to play a more visible role in continuously assessing mental disabled needs as well as to implement appropriate health education program to raise community awareness and to improve their knowledge, attitude, and practices toward mental health care.
5- More government-owned schools are needed, including schools providing special education for children with mental disability. These schools should be well equipped with resources (both human and materials), and should provide education free of charge or at reduced fees.
6- Encouraging the mass media to highlight disabled child's health needs and coping measures of this critical condition. Families should be made aware of existing facilities and be encouraged to use them. Media should advocate on human rights, empowerment and development of policies governing mentally disabled.
7- Further researches on child's disability with more emphasis on misconception and myths regarding mentally disabled care, which might hinder utilization of community health services.

Table (1): Personal and Socio-demographic Data of the Studied Mothers and their Children

Characteristic:	No	%
Mother's age (years)	n=60	
< 40	4	6.6
40-	40	66.7
50- 60	16	26.7
Min-Max	35 – 60	
Mean ± SD	45.76 ± 6.584	
Level of education		
Illiterate/read and write	36	60.0
Primary education	0	0.0
Secondary education	12	20.0
University education	12	20.0
Marital Status		
Married	46	76.7
Divorced	4	6.6
Widow	10	16.7
Occupation		
Worker	12	20.0
Nonworking	48	80.0
Ability to pay for health services		
Able	24	40.0
Unable	36	60.0
Types of child's disability		
Down syndrome	34	56.7
Cerebral palsy	26	43.3
Sex of mentally disabled child		
Male	26	43.3
Female	34	56.7
Have more than one mentally disabled child		
Yes	14	23.3
No	46	76.7
Birth order of mentally disabled child		
First	24	40.0
Second and more	36	60.0
Age of the mentally disabled child (years)		
< 6	12	20.0
6< 12	16	26.7
>12	32	53.3
Min-Max	4 – 18	
Mean ± SD	10.70 ± 5.011	

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