

IMPACT OF DOWN SYNDROME AMONG FAMILIES WHO HAVE CHILDREN WITH DOWN SYNDROME AND HAVE FOLLOW UP FOR THEIR CHILDREN AT BLACK LION HOSPITAL IN 2019.

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ABSTRACT

Background: Worldwide Down syndrome is a common chromosomal abnormal condition. It is also known as trisomy 21. Children with down syndrome have delay in growth and hypotonic this interfere with feeding, constipation lead to malnutrition, poor motor development, delay cognitive development and mental retardation, congenital heart disease and risk of ear infection. The effect of Down syndrome differs among individual depending on the extent of abnormality and the health care service available even in developed countries despite the extensive knowledge of health conditions in children with Down syndrome, the impact of Down syndrome on families and access to health care for persons with Down syndrome remains understudied. All these will affect family life differently. Therefore exploring the impact of Down syndrome among families who have children with Down syndrome will provide a paramount input for care providers, researcher and policy maker. **Objectives:** To explore the impact of Down syndrome on family among families who have children with Down syndrome and have follow up for their children at black lion hospital 20 in 19. **Methods:** The researcher use phenomenological research design. Data was collected through in depth interview, Focus group discussion and key informant interview. These major categories was aggregate from the raw data collection and then framework analysis and identify themes across all sources of data. **Result:** From the Analysis of the data six major themes were categorized. Non acceptance –Birth of an abnormal child, Lifestyle changes, family relationship, unpredictable future of the child, basic service and Societal and Community acceptance. **Conclusion:** The findings show that birth of a child with Down syndrome produces a lot physical and psychological effect in parents. So parents need adequate support from Government and concerned body in general and also from nurses in particular right from the very birth of a disabled child. Therefore, this study is important for nurses working with families having children with Down syndrome. As nurses are the eye to blind, leg to amputate based on this ,it is their role to realize and aware of the problems faced by the families and should advocate necessary support.

KEYWORDS: Down syndrome, Impact, Parents, Primary Guardian

INTRODUCTION

Background

Down syndrome (DS) is a birth defect with huge medical and social costs, caused by trisomy of whole or part of chromosome 21. It is the most prevalent

genetic disease worldwide and the common genetic cause of intellectual disabilities.^[1, 2]

The historical development of Down syndrome has been remarkable over the years. An earlier description of down syndrome traced back to the first

half of 19th c by Jean Etinne Dominique Esquirol In 1838 and Edouard Sequin in 1844 and 1846. Nonetheless, it was Jhonlondon Down, a British physician who gave a compressive description of Down syndrome in his landmark of presentation titled:” observation on an ethnic classification of IdotsL” in 1866.^[3] DS is a multisystem disorder that affects the individual physically, medically and psychologically.

The physical – head, face and neck – features, Include brachycephaly (disproportionately shorter or small head or skull shape) unusually round face, short neck, low-set, small ears, flat nasal bridge, microgenia (an abnormally small chin), macroglossia (protruding or oversized tongue) due to small oral cavity, small chin, almond shape to the eyes caused by an epicanthic fold of the eyelid and oblique palpebral fissures.^[2]

Other features include shorter limbs, a single transverse palmar crease (a single instead of a double crease across one or both palms), lax ligaments, excessive space between large toe and second toe, dry skin, muscle hypotonia (poor muscle tone) and brachydactyly (shorter fingers and toes). Ocular and visual features of DS include high refractive errors, amblyopia and strabismus, accommodative and vergence anomalies, ptosis, blepharitis, nasolacrimal duct obstruction, nystagmus, keratoconus, speckling of the iris (Brushfield’s spots), cataracts, glaucoma and retinovascular anomalies. DS has considerable health implications and people with DS have an increased risk for certain medical conditions.

The levels of abilities and disabilities vary due to variations in the level of affliction. Some medical conditions are congenital while others are progressive. D S cannot be treated, though many of the associated health conditions are treatable and people with DS now live healthier lives.^[2]

The prevalence of DS in the African populations is not precisely estimated because of inaccuracy of most of the studies concerned with the incidence and prevalence of DS in sub Saharan Africa. This occur due to ignoring the influence of important factors such as socioeconomic, cultural, educational, genetic, racial and environmental character rustics of the different African populations on the prevalence of the condition, thus affecting the reliability of the data.^[1]

There is also higher prevalence (1.88) among the white population compared with the prevalence in black colored (1.54) because the prenatal screened and diagnosis of the condition and the relative distribution of the number of terminal.^[4, 2]

The effect of Down syndrome differs among individual depending on the extent of abnormality, therefore, mental abilities, physical development, personality, capability and talents vary considerably. In this regard the nature of the abnormality and the physical characteristics make the individual with Down syndrome resemble one another rather than their own family member. However, only less than 5% is hereditary.^[3]

Down syndrome has considerable health cost implications, given the individual and socioeconomic consequences. Moreover Down syndrome is found in all races, nationalities, religions or socioeconomic levels. Keeping this in mind; however the life expectancy and quality of life for affected people have increased remarkably due to improved medical care, general awareness, as well as increased social interactions. The estimated life expectancy of person with DS has increase from just 12 years in 1940 to an average of 55-60 years in the present decade, particularly in the developed countries.^[1, 3]

Contrary to the argument given in the preceding paragraph, the reality of down syndrome status in developing countries have been inconsistent due to a number of socioeconomic, low level of technological advancement and above all little or no political commitment of the governments.

Statement of the Problem

As learned from the finding of various researches so far made and available to the academia, down syndrome is the most frequent genetic cause of mental retardation associated with a number of medical problems that may impair growth and development throughout their life.^[3]

Children with Down syndrome are considered as children with special health care needs (CSHCN); CSHCN are defined by the Health Resources and Services Administration (HRSA) as children “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”^[8]

Children with Down syndrome are twice as likely as typical children to have a food/digestive allergy, frequent diarrhea/colitis, 3 or more ear infections, and seizures. Children with Down syndrome have greater than 3-fold higher estimates for nearly all impact on health and need special education use measures compared with age mate children in the general population.^[7]

The co morbidities in children with Down syndrome provide additional challenges with the higher rates of significantly burdensome concurrent health conditions for families. Children with Down syndrome require more care coordination and face serious health care disparities related to their medical complexity, relative lack of health insurance, and decreased likelihood of having a medical home.^[4]

According to the study done in Australia, the family burden with complexity of medical care cost for children with Down syndrome is reflected in higher level associated health care costs compared with typical age mates who are free from DS. The medical care costs for children with Down syndrome and CHD were significantly higher than those for children with Down syndrome without CHD.^[10]

Even in developed countries despite the extensive knowledge of health conditions in children with Down syndrome, the impact of Down syndrome on families and access to health care for persons with Down syndrome remains understudied.^[8]

In connection with it parenting children with Down syndrome has an impact on all aspect of the life of those parents mainly (mothers) in particular and the entire family member at large. In this regard, it has been clearly observed that parent of children with Down syndrome experience a very burdensome responsibilities while carrying their children. Obviously, the economic status and literacy level of parents and the degree of community awareness towards Down syndrome compared with availability of support provided to those parents make a real difference among Ethiopian parents of children with Down syndrome.^[18]

Unlike to the global experience, existence of comprehensive research was not conducted in Ethiopian, and observing the magnitude of the problem itself enhance the need to conduct this research.

Hence, parenting children with Down syndrome has an impact on all aspect life of the parents (mother) in particular and the entire family member at large. Accordingly, to analyze the depth of this problem, one can approach and witness what has been going at Black lion specialized teaching hospital department of pediatric /child health, where parents and their children with Down syndrome are here for medical follow up. Therefore the purpose of this study was conducted to explore multifaceted challenges that encountered by parents who have children with Down

syndrome and follow up at black lion specialized teaching hospital in Addis Ababa in 2019.

Significant of the Study

Information on the special need and care of children with Down syndrome are essential for proper planning and minimizing burden of family care for their children. To the government or concerned body used to facilitate child health intervention programmers.

Accordingly, the following points are considered as the significance of the study:-

- To guide nurses importance of informing the family what is Down syndrome during delivery of children with Down syndrome.
- In assessing the consequence of children with DS on the family life for future intervention.
- To reveal the burden not only on the family but also to the community and initiate prenatal assessment of DS to minimize number of children with Down syndrome.
- Establish rehabilitation center and special education center for the children with Down syndrome to minimize burden on the family.
- To suggest the hospital's and health center obstetric unit to have birth registration of children with Down syndrome.
- To Hospitals pediatric department to have screening mechanism and special registration book for children with Down syndrome and give attention.
- To MOH, and policy makers (for those who are involved) for planning early intervention program of Down syndrome.
- As a base line study on children with Down syndrome.

OBJECTIVES

General objective

To explore the impact of children with Down syndrome on family among families who have children with Down syndrome and have follow up for their children at Black lion specialized teaching hospital in 2019.

Specific objectives

The specific objectives of this study were:-

1. To investigate impact /challenges faced by the family due to having children with Down syndrome at black lion specialized teaching hospital in 2019.
2. To explore e coping strategies by the family at black lion specialized teaching hospital in 2019.
3. To search family need of support for Down syndrome children at black lion specialized teaching hospital in 2019.

RESEARCH METHOD AND MATERIAL

Study area and period

This research was conducted in Addis Ababa city at Black lion specialized teaching hospital where it was considered as the largest medical institution under the governance of the federal ministry of education. Being the largest hospital in Ethiopia, the study area is known in terms of providing comprehensive medical and nursing service for in and out patient department clinics respectively to all citizens that may come from the four corner of the country. It is also a training center for health sciences students in both undergraduate and post graduate programs.

Accordingly, children with Down syndrome are among those who have provided the medical service in the endocrine clinic in pediatric department of black lion specialized teaching hospital. However there no recorded data about the prevalence of Down syndrome even in black lion the hospital host to serve those children with down syndrome once in a week base with minimum of 25 and maximum of 30 children per week. By saying this required data was collected in the month of March and April 2019.

Research Design

A phenomenological study design was performed among parents / primary guardians who have children with Down syndrome and health professionals working with children with Down syndrome.

Population

Source of Population: All parents or guardians whose children are diagnosed with Down syndrome and have medical follow up at black lion specialized hospital to the pediatric endocrine clinic.

Study population: All parents or guardians whose children age is above two years with the diagnosis of Down syndrome and medical follow up for their children at black lion specialized hospital of pediatric endocrine clinic in the months of March to April in 2019.

Sample Population: Rationally selected Parents or guardians who full fill the inclusion criteria and available during data collection time was used as a sample population.

Eligibility criteria

Those parents or guardians who are primary care give Parents or guardian of their Children clinically diagnosis with Down syndrome.

Parents or guardian their Children with Down syndrome and age from 2 years and above. Parents or

guardian their child live together with them not only for bring to medical follow up was eligible.

Sample size determination

Determining about sample size in qualitative study was difficult because it depends on information saturation. Hence, the researcher has 9 in-depth interviews, 2 FGD with parents of children with Down syndrome and 3 Key informant interviews with concerned health professionals working with Down syndrome.

Sampling procedure

Accordingly, Purposive sampling was applied to choose volunteer parent or primary guardian for FGD and in-depth interview. In addition to that key informants from professional who could give firsthand information were included.

Data Collection procedures and tools

Semi-Structured Interviews guide question was used for in depth interview; FGD and key informant interviews were employed.

Informed consent forms was completed by all participants. Throughout the interviews, a probe was used to offer clarification and encourage elaboration form the participant on specific issues or topics that are domains of interest to the researcher. The audio-recorded interviews ranged from 20 to 40 minutes and subsequently, transcribed verbatim to secure accurate participant responses. A typed note was taken throughout the interviews for the purpose of cross validation with the audio recordings and final interview transcripts. Focus group discussion also arranged with a member of six members and trained facilitator was assisted the researcher to lead the discussion. Audio recording provided a more accurate representation of an interview and focus group discussion than any other method and allowed for cross-checking if any notes was missed throughout the interview from the researcher.

Data Analysis

Data analysis for the qualitative interviews and FGD occurred right after the completion of data collection. Prior to data analysis, all electronic transcripts were transcribed verbatim by the researcher. Translation was made for all participants who respond in Amharic language.

The researcher recognized biases and assumptions held by their influence on the emerging theoretical concepts in the data. Accordingly, the researcher followed inductive approach.

The process of data interpretation begin with open coding; all interviews and FGD was first transcribed during the interview, discussion and audio recording, then re-listened to and re-read to identify their intention throughout the data collected. In addition, a journal with notes maintained to track the progress of the study and included memos related to the analysis of the data, including concepts, categories, or possible corroboration that is occurring at specific points in time throughout the data collection.

This was useful in facilitating data analysis and reporting by allowing the researcher to keep track of the interviewees and discussion of the body language and tone of voice when responding to specific questions. Journaling was employed to capture social cues that an audio recording may not be able to pick up.

A triangulation technique was utilized in order to cross verify data sources. To ensure the credibility of the findings, axial coding was used. The observations and any questions that were recorded in memos assisted in developing of an initial coding. Consensus was then achieved on the third version of the coding scheme. These major categories were aggregated from the raw data collection and then content analysis was used to reduce and identify themes across all sources of data. The identified data was categorized to determine relevance and value in describing the impact of children with Down syndrome and associated factor to primary care taker and parents. Interview and FGD discussion transcripts were coded using the domains identified in the interview and discussion guide.

Rigor for qualitative studies

The researchers in this study applied rigor through using appropriate data collection techniques, proper sample size determination. Since the researcher was involved as principal investigator in the data collection and analysis process, she used her expertise and knowledge in analyzing the data for the study. The researcher's hypothesis was tested and the data interpretation was done and disclosed, in order to enhance credibility and validity of the findings of the study results.

Trustworthiness

Credibility: To maintain data credibility the researcher was spend enough time with participants on site and explain the process of data collection to the participants' detail. Provide responses to all questions and concerns of the participants.

Dependability: To ensure dependability the researcher was provide detail description of the process used like the process and reason of selection of participants, process and length of data collection procedure, data analysis and presentation. Audio-recorded interviews, discussion and field notes were kept in safe place.

Conformability: To maintain conformability the researcher was kept field notes, audio-tape record in safe place even after the publication of the research for a period of two years.

Transferability: Was achieved through Conduct in-depth analysis of interview and FGD discussion transcripts, documents and observational notes. The result of this study can be utilized in other areas of Ethiopia.

Triangulate: Different data sources of information by examining evidence from the sources and using it to build a coherent justification for themes. If themes are established based on converging several sources of data or perspectives from participants, then this process can be claimed as adding to the validity of the study.^[10]

Ethical considerations

This thesis was done after the proposal was submitted to AAU College of health science and department of nursing and midwifery then approved by institutional review board officials. Ethical clearance was obtained from AAU, department of nursing and midwifery research committee. Letters of cooperation was written to black lion hospital pediatric endocrine clinic and concerned bodies.

Further permission was obtained from Black Lion Referral Hospital. Participants was aware that participation is completely voluntary and that they may withdraw at any time with no consequences. As well, participants were aware that they may choose not to answer any questions for the interview. During the interview process, the researcher ensured that participants are comfortable with continuing the interview.

Participants were assured study results were not allowing who about of the participants to be identified. With permission, the interview was audio recorded and transcribed. The interview guide was designed beforehand. Interviews were continued until data saturation reached, in which no new information is being provided by participants.

Health professionals were also asked for their consent in written form. Clients were asked for informed

consent after all the necessary information is presented to them for their willingness to participate in the study.

Following these, collecting and obtaining of the data was processed with assigned person. Finally, strict care for the patient's privacy and no personal identification on data collection & was kept confidentially.

Dissemination of the result

Result of the study was submitted and presented to Addis Ababa University, School of Allied Health Sciences, department of Nursing and Midwifery. The study result was also be submitted to black lion specialized teaching hospital and to the Health Bureau. The finding will also be presented in locally or internationally held seminars, workshops, conferences and meetings. For the publication purpose, Presentation on the scientific forum and Publication on the scientific journals will be processed in the future. The output has important contribution for the improvement of the departmental service. There could also presentation of the study to parties interested.

RESULT

Informant's Socio Demographic Distribution

As far as the sex, age, marital status, birth interval, religion, ethnic identity, education and income situations are concerned, the following response was obtained from participants of an in-depth interview. Among the parents who were involved in this interview, seven of them were female: six mother and one Aunt of children with DS, and two of them were male: father of children with DS. All of them were married but one individual divorced very recently due to the misunderstanding of spouse on the future and medical follow up of their daughter for DS. Most of the parents have 2-4 children and one mother from SILTE has seven children.

In terms of religion, seven of them were orthodox Tewahido, two of them were Muslim. With regard to ethnic identity distribution three parents were Oromo, other three were Amhara, one from SILTE, one from GURAGE and the remaining one is not stated his/her identity. The highest Academic status from the nine participants were a nurse from BAHIR DAR and one BA degree accounting from Addis Ababa. Two diplomas and the rest were between only able to read and write to 10th grade completed. In connection with the income they ++were lived below middle level income group.

Theme of Description

The result of findings are summarized and presented in two segments, the first segment structural component show that Major themes and sub themes derived from the analysis is of data. Second explanation and the difference within those theme as experienced by the participants on parenting a child with DS. Each theme of description includes a label and an explanation of the meaning of the commencement related with that segment.^[34]

Colaizzi's data analysis framework was used to analyze the transcripts in this study. Six major themes of description were presented from the analysis. The similarities and variations in families' descriptions are illustrated with excerpts from the transcripts.

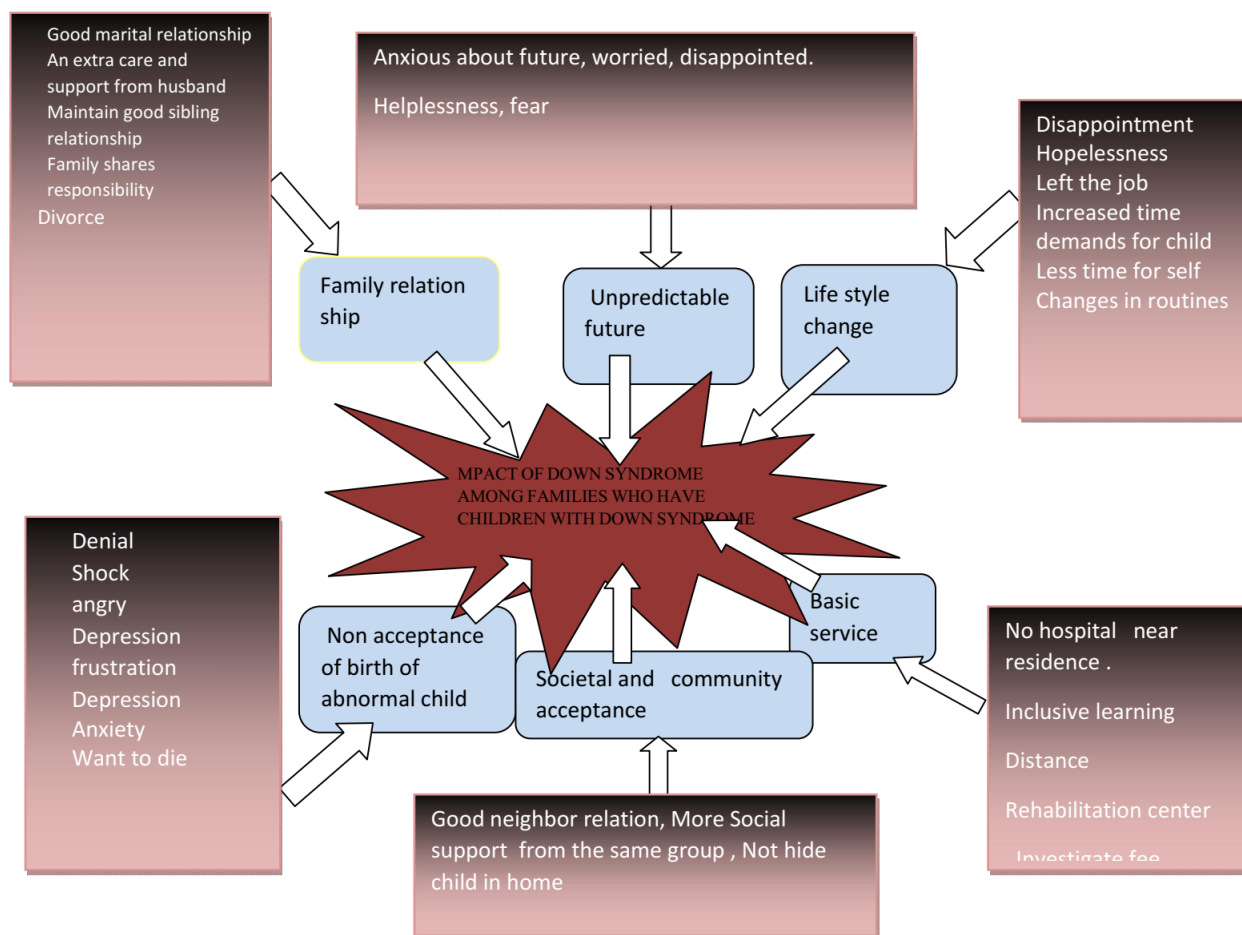


Fig 1 Derived themes and sub themes

The Six Themes Are:

- Theme 1: Non acceptance birth of Down syndrome child
- Theme 2: Family relationships
- Theme 3: unpredictable future
- Theme 4: Societal and community acceptance
- Theme 5 Basic services
- Theme 6: lifestyle change

Theme 1: Non acceptance birth of Down syndrome child

This theme describes the initial impact on the parent due to birth of a child with Down syndrome from 9 participant of in-depth interview 2 group of FGD and 3 participants of Key informant. The circumstances under which this knowledge is received are clearly recalled by some of the parent and primary guardian because this is a significant event that is maintained as a part of the ongoing family narrative. Even though the time and place of informing this bad news was not uniform but they manifest similar feeling.

Majority of the participant initial reaction after informing the child has Down's syndrome is shock and disbelief followed by anger, disappointment, denial and often guilt feeling about this bad news. Because

they possessed little or no knowledge about Down syndrome.

All the participants expressed their feelings of shock and depression at the moment they came to know that their child is having Down syndrome also they were anxious about their child condition.

One mother expressed her doesn't know how to take care of the child:

"I am really shocked"... I am depressed so much. I had no idea what Down syndrome was but the only thing I knew was that it's something that is not normal, but I now feel better when I observe other children here. (FGD G2)

"I fell so offended and angry and even wanted to die, while being informed by the physician. However..., by the advice and hope I was given by the doctor I fell my child will be okay..." (IDI p7)

All the above information shows that family or primary guardian of children with DS has insufficient knowledge regarding the diagnosis of Down syndrome, what are DS and the care of a child with

Down syndrome. Some families or primary guardian had no idea what Down syndrome is and some related the syndrome to hormonal problem. Some families said that they doubted the diagnosis.

“Mother thinks her child problem was goiter. Direct word she said (የ ልጅ ችግር እንቅርት ነው ሌላ የሌለበት ምን)” (FGD G2 P4)

The father said that “when I was informed about the problem: I understand as A hypothyroidism. (አንቅርት ብቻ ነው ያለባት .” (IDI p3)

In addition to this the way in which this bad news informed to parents or primary guardian from health professional side the participant explain in a negative way except professional working in black lion hospital. Because way in which parents are informed about their child's condition often has a profound effect on them.

“ when the professional at Addis Ababa health center inform me about the bad news of my child as simple as he is hope less I felt very bad . As she said this word really touches her mind because they did not explain about the disease condition. (IDI P1).

Even for the nurse participant the impact was significant but different because she was more aware of the condition:

Yes I am a nurse ... the time she was five month old I took her to Bahir Dar hospital the staff did not inform me on time. So I knew something was not right. When I first understand and looked at her I suspect she was with some disability They held back a little bit, because they were not sure how I would react to have a Down syndrome child.... I would say I did not accept her condition but then I still asked myself the question, "Why me, as well?" ... That is the normal question to ask, "Why me?" (IDI P9).

For all participants, an additional concern was how and when to share this knowledge with others. One father participant from Bonga:

I was in shock. I did not know how to react because I never expected him to have this condition; even my wife as well, when hearing the news, she actually broke down. For months, I really did not take it so well.... I was in denial, I was like in total pain and my family as well. (IDI P2).

All participants commented on the personal change over time that had resulted as a consequence of the birth of their child. Because when they come to Black lion hospital for follow up they observe the worst case than their child they become convinced.

Mother participant from Addis Ababa

At first when I here this bad news I choose to die by takingI feel hope less but when I come here I feel disparate with my initial thinking and wrong decision : I have learnt a lot of things through her: When I look at to others now, I say I look at the positive way first because previously when negative things happen usually, I will feel sad but now I look at it from a different angle.... and I start to learn from other. (IDI P4).

The theme illustrates the initial and ongoing effect that the birth of the child with Down syndrome had on the mother and father , as well as the significance impact of the event on other family members and relatives.

Theme 2: Family Relationship

This theme is complex with sub-themes related to the subsystems in family relationships: the marital relationship, sibling relationships and relationships with the extended family. It identifies how the child's condition has affected the closeness and cohesion of the immediate and extended family. It includes individuals' relationships with the Down syndrome child, but also the nature of the relationships between family members that do not include the child but which are affected by the presence of the child. It also reflects the level of acceptance of the child by family members.

Accordingly the result show there was high bonding between family members. Majority parent expressed they are maintaining good relationship with family members. Most mother expressed as husband is most supportive person in caring wife and children with Down syndrome. Father assures this as they take responsibility.

“In my family my husband is supportive. He gives so much care to the child. He always has a loving mind. The younger daughter also help him to compete and to become stronger .and they love each other”. (IDI P1).

Marital relationship: all participants highlighted the importance of support from their partners. Most became less self-centered and focused on her career and how the child had strengthened the relationship with her husband:

We would have been divorced if we didn't get birth to this child it kept as more attached ,I was wrong to decide to leave my husband and home so it have a positive effect I can say ...IDI P4

All parent said that the siblings accepted their child with Down syndrome. Participant expressed especially their elder sibling takes care of their little sister /brother with Down syndrome

"I am really happy because my husband is the most supportive person. Now my child has 2 years and elder sons has 12 and 17 years. So they takes care of their s little sister and they are loving each other" (FGD2 p1)

In contrary participant from DESE town face the reverse family bounding of divorce.

"MY husband was not supporting me and his daughter: Not cooperate to give money even for transport to Addis Ababa for medical checkup of our child .I Always ask money from my brother and sister: no love and peace in our family and we end up divorced ..." IDI P7

Extended family relationships. All participant relates that, grand mother and father, uncle and Aunt are now very supportive, beside care participated for the first diagnosis of Child condition, religious and cultural values played a role.

"My father was very supportive, based on his previous experience and initiates me to gate medical help: Rather not to hide the son in the home..." IDI P5.

Theme 3: Unpredictable future

This them represents how parent /primary guardian perceived their worries in regard to parenting role in relation to their child and the practices in which they engaged to support their child's learning and development. Also parents worry about their child in the near and distant future. Immediate worries were the child's school placement and health status. Looking farther ahead, parents major worries concerned the child's self-caring ability, the ability to make a living and become independent. Most of the participants have worried about whether their child will be able to take care of him or herself in later years.

The entire participant was Worried about the Unpredictable Future of their child. A 51 year old father from Addis Ababa describes his worries like this

" My daughter now is 5 years old she cannot talk and control herself like other kids of her age mate ,me and her mother gets old: unfortunately if I die my wife she do not know how to get medical service even for thyroid problem and fear of future medical follow up after I die..." IDIp3 The other guardian Aunt of one daughter says

"Her parents are farmer who do not care about their daughter. They have never paid a visit. My worries come when I think about her future. I do not know to whom I apply as far as I am concerned about her education concerned. I always pray to lord about her future. (IDI p5) Nurse mother explain her fear like this:

"My daughter now is 4 years old she still cannot stand ,walk and talk : How can I send her to school , I have second daughter of 1 year now in the home I take care for both :her future will be in difficult to....I always got worried : my daughter case was different from other down children." IDI p9.

Theme 4: Societal and Community Acceptance

The fourth theme was societal and community acceptance Most of the participant expressed they got adequate support from society. All parent placed an emphasis on the importance of social support from outside the family and similar victim family of children with disability. The response of most parents indicated that their neighbors, relatives and other members of the society did not attempt to discriminate children with Down syndrome rather than beyond sympathy can be cited as a positive result of this study.

Social support from similar group:

Accordingly I got support from one nongovernmental organization

ZENI YENUS who is the founder of autistic center around KASANCHISI is worth maintaining. She has organized an association with a members of ten women's having children with intellectual disability and Autism spectrum disorder.

I was among the ten mothers she gives us training on intellectual disability and other skill based training. That would reliable us to make our business. She allocated the required budget and helped as to own business.

Above all, the training I got about intellectual disability enhance my awareness and helped me to accept my son's problem. IDIP 1

All participant recognize the help they get from sister in law: to mention one instance:

"My sister in law was very helpful even to support her sister by understanding the situation before my wife ..." IDI p2

The acceptance of neighbor and community towards disable children especially in Addis Ababa good The Aunt of daughter from Addis Ababa

"She had good relation with the kinds of the village and everybody like her. In this regard I have no complained..." IDIp5"

Theme 5: Basic service

This theme deals with the parents basic need to care their children with DS . Primarily health care service, special need rehabilitation center, inclusive education, appropriate timely information and free of laboratory investigation for problem related to being Down. Participant come from region out of Addis Ababa to Black lion hospital for medical follow up face challenges. .The distance affect them economically difficult to come to Addis Ababa every three months in other side lack of family member in the home to take care the rest children.

Mother from Silte express:

“Having a child with Down syndrome is a serious challenge for the family but the problem will be worse for those mothers who have been living in the country side like me. I am expected to bring him for medical follow up every three months but I come every six months because of economical problem and lack of person to take care of other children ” IDIP 6

Regarding to education in Addis Ababa special need school at yekatit 23 but it give service to all disabilities including Autism, So child with DS get confused one mother express :

“My son is 9 years old attending education at yekatit 23 primary school were special need education center to all types of disability including Autism. Nevertheless he doesn't know both Amharic and English alphabets, not able to write, I am not satisfied :the teaching and learning process of the school was not conducive for DS children. After attending to special need education center his mental ability was decreased. She said me and my husband feel disappointed of our economical problem. We wish to have school with Down syndrome along with teacher who had trained how children with such problem in inclusive education program teach.”IDIP1

For children born with Down syndrome it is better to privileged with rehabilitation center and inclusive education was the concern of all participant not only in Addis Ababa but also in other regional state of Ethiopia. But today the participant complain as neglected regarding schooling.. One guardian explain like this:

This daughter was 13 years old, her age mates are known in grade 6 and 7. But she cannot even read and write. Her parents are farmer who do not care about their daughter. They have never paid a visit. My worries come when I think about her tomorrow. All the government school around Ferencai legatsion in Addis Ababa is unwilling accept her. I do not know to whom I apply as far as her education concerned.IDIp5

Most parent and guardian complain when they come to follow up laboratory investigation ordered out of

black lion hospital and too expensive difficult to afford.

To ensure this professional medical doctor working at blak lion hospital say like this:

“Members of a family to children with DS would be victim of psychological, social and economical challenges. The economical challenges are the worst in our case the screening procedure costs parents beyond their capacity.So, I wish if they get the service free of charge”. KI 1

In regard to being informed about their child has Down syndrome most participant complain it was not with appropriate place , condition, manner and time.

Participant one say :

“After three months when my child get sick I took him to health center and inform to me the bad news of my child as simply he is hope less. This word really touches my mind because they were not explaining about the disease condition”IDI 1

Similarly in regard to giving information to the family professionals assure need to work to those professional who has direct and indirect contact to families of children with DS.

One medical doctor work with DS suggest that :

“I believe that either medical doctor or senior and trained nurses should inform about the problem to parents of children having Down syndrome immediately when they know it. And also thinks that midwifery nurses and nurses should have good knowledge about Down syndrome and they must get training how to give consulting parent” KI 2.

Theme 6: Life style change

This them describe how the life of participants were affected after the child's birth, the immediate stressor parents encountered were facing a child who was completely different from their expectations. For those understand the child had Down syndrome and it was not curable. Concerned to the response of the parents who have been involved in an in-depth interview or in the focus group discussion proved that parents or primary guardians of children with down syndrome are not only alienate themselves from social interaction, they are also the subject to give up their job for the sake of parenting these children. All participants experience are changed after the child was diagnosed with Down syndrome. Most of the mothers expressed as they need to spend more time with the child. *As I am nurse by profession and hence supposed to explain the magnitude of the problem. Finally we agreed that I have to give up my job and do our level best for our daughter. One can imagine how*

life would be very challenging: No one will expect rather than a normal baby. Now for every work she wants help from us" I need to spend more time with her ...I left my job after my child birth" (IDIP9)

Father from Bonga describe like this
I had lot of dreams about my child. But all the dreams were hopeless when child was diagnosed with Down syndrome. IDIP2

DISCUSSIONS

Impact of Children with Down syndrome In Relation To Literature

Keeping the research objective of this study in mind the impact of Down syndrome among family of having children with Down syndrome in Ethiopia provide very cumbersome as compared the same case with the experience of parent who have children with down syndrome in north America, western Europe advance country as well as the poor nation of Africa and south Asia.^[15,17,25]

Although the condition is not related to gender, race, nationality or socio economic status. Down syndrome is the most genetic cause of severe learning disabilities in children associated with developmental delays, learning, and difficulties health complication and same physical abnormality.^[16]

All the above information shows that family or primary guardian of children with DS has insufficient knowledge regarding the diagnosis of Down syndrome, what are DS and the care of a child with Down syndrome. Majority of the participant initial reaction after informing the child has Down's syndrome is shock and disbelief followed by anger, disappointment, denial and often guilt feelings.

Similarly study done in Hong Cong and Colombia stated that the birth of a child with Down Syndrome may result in psychological pain for their parents. This psychological impact is responsible for generating confused feelings that may persist throughout life. So Parents need adequate support right from the very birth of a disabled child.^[17,26]

In addition to this the way in which this bad news informed to parents or primary guardian from health professional side the participant explain in a negative way. It indicate health professionals have knowledge deficiency and lack of experience about down syndrome or neglecting human being as respected being .Similar study done in Ecuador, even health communicate the diagnosis of Down syndrome to family rarely in an appropriate manner.^[30] And need to have a number of educational programs developed

to help health care providers feel better prepared to deliver the diagnosis of DS to the family.^[24]

Apart from this similar feature that may happen on children as a genetic disorder, its impact on parent and primary guardians while parenting these children greatly varies depending on the education level ,socio economic status ,political consciousness of the respected government and Technological advancement of countries of the world.^[27]

According to research studies have indicated that parents of children with down syndrome experience a greater level of stress and discomfort than do parents of children without disabilities, psychologically, they have to face the loss of the expected normal child, accept the reality of having a less than perfect child, then need to integrate the child in to the family.^[21,22]

As far as Ethiopian is concerned, down syndrome with included as intellectual disability as one category of persons with disabilities, and they are the least served among them. One simple example for that matter is the nonexistence of independent clinic in the pediatric ward of the black lion referral hospital and nor to find anywhere in Ethiopians referral hospital.

Obviously children with down syndrome having various needs like others children they also have especial needs such as personal, social, physical and especial educational needs more over they have right that other children have and their needs have to be met and their right to be protected.

According to the response from the participant all of participant shoulder the problem of schooling their child with DS. It may be done unknowingly one family send their child to disability school at yekatit 23 only to stay all disability including Autism. Mother complains after school his condition was worsen. Beside to this governmental school are not volunteer to accept those children. The witness for this in depth interviews p1and p7 was evidence. All this shows Ethiopia inclusive education was not practical.

In contrary to this in Ethiopia Article 28 of the CRC affirms the right of the child to education.^[19] According to world education trust for DS and more children with DS have had opportunity to attend mainstream school with their typically developing age mate.^[23]

The entire participant was Worried about the Unpredictable Future of their child. One father describe not only education but also about fear of future medical follow up after his death. Country to the universal human right and other legal presumptions however, the attention and practice of

the Ethiopian government with down syndrome in particular is so weak that parents of the children having down syndrome are being subjected to shoulder the life long process of rearing a child who is different.

Above all, the long term uncertainty the children's viability future health, growth to, and ultimate level of functioning and the families ability to meet the child's need are factors adding stress to parents.

As learned from the response of the parents who have been involved in an in-depth interview or in the focus group discussion proved that parents or primary guardians of children with down syndrome are not only alienate themselves from social interaction, they are also the subject to give up their job for the sake of parenting these children.

All parents of children having Down syndrome are being exposed for additional cost while bringing these children to black lion hospital for medical follow up one can imagine how challenging it could be so long as the Problem is lifelong.

When looking at the geographic distribution of the respondent the problem of parenting children with down syndrome in Ethiopia is nationwide challenge that disrupt the life of the family. Ethiopia is provide a country almost all the required physical and soft infrastructure are neither accessible nor comfortable for parenting children with down syndrome and hence what worries most parent in this regard is how do their children have access to cost free medical follow up near their residence and education to their children.

Witnessing the response of two mothers who bought their child to black lion referral hospital from DESSIE and rural area of SILTE zone showed us that their life is affected badly. In line with it, the reaction of medical doctors who were involved in interview and have been serving at the endocrine clinic of this hospital that their response and view has strong match with the response of parents of children having a down syndrome.

The economic burden also appreciated in the developing and developed country of the world. Study done in Australia families incurred considerable financial cost in rearing children with Down syndrome especially for medical and educational cost.^[28, 32]

As learned from respondent, despite the fact that there is no awareness of society towards children with down syndrome, the response of most parents indicated that their neighbors, relatives and other

members of the society did not attempt to discriminate children with down syndrome rather than beyond sympathy can be cited as a positive result of this study. This was similar to study done in Australia.^[27]

Beside to the above result some of the respondent decides not to expose to the community about their child condition by feeling guilty. And they said we do not know about the feeling of community about children with DS.

Based on the response from participant there was strong bonding between family members. All parent except one mother expressed they are maintaining good relationship with family members. Most of the mothers feel as husband is most supportive person in caring children with Down syndrome.

Based on study done in Filipino and other country reported that siblings were very protective of a child with a developmental delay and would undertake care responsibilities as well as protecting and defending the disabled child. All this have positive impact.^[20,22]

Down syndrome involves a 'change of plans' for families; it does not have to be a negative experience. In fact for many it is a positive, growth producing experience. In contrary participant from DESE town face the reverse family bounding of divorce. As she mention her husband not supporting even for transport to Addis Ababa for medical checkup of their child.

Similarly study done in India mother of DS children suffer to major stress and even to divorce.^[31] Family Support is essential for the mothers of children with disabilities. Coping with the stress, emotions and difficult decisions is often overwhelming and upsetting for families.

Strength and limitation of the study

Strength of the study

Respondent are from different part of country we can generalize the result as a whole Ethiopia.

This study is the first study even in Ethiopia, serve as a wake concerned parties this study helps as base line information for conducting further research in the area.

Limitations of the study

This study represents only family member/or care giver those accompanies children with Down syndrome in the black lion specialized hospital. Hence, family members /caregiver that accompany children with Down syndrome in other hospital are not included.

Knowledge deficit of family due place of visit for those children was at endocrine clinic so family members are not aware of their child problem was Down syndrome, rather thyroid problem Lack related literature in Ethiopia context.

No statically documented evidence of Down syndrome not only in country level but also in Black lion hospital.

CONCLUSION AND RECOMMENDATION

Conclusions

As indicated in the methodology section in order to conduct the thematic analysis on the in depth interview participants to focus group discussion participants and three medical professional key informants providing answer to the question where expressed in the result section.

This section aims to identify major and recurring themes as well as comparing and contrasting response across the participants groups, enabling a wider perspective of the magnitude of the problem and impact on parents while parenting children with Down syndrome in the one hand and the almost no attention of the Ethiopian government towards the problem of Down syndrome.

When focusing on the problem of having children with Down syndrome face most of the respondents in the study indicate that have

- Deliberate denial /non acceptance, in the first place timing and place of informing regarding to this bad news, second thinking about un predictable future of child and third lack of formal support.
- Life style change especially mother not able to participate and even stop office jobs., his lead to Economical burden for rearing and medical fee for children with DS.
- Majority create strong family relationship among family members positive impact. And as remedy Parent have understanding having siblings for child with DS upgrade their development.
- Basic service which determine their future fate and major stress of family members.
- Distance to come to Addis Ababa decrease time of visit and affect family relation in same how. Education level/literacy can affect understanding of parent about DS.
- With the regarded of the attitude of the society towards children with Down syndrome based on the finding of the study it can be concluded that community as a whole have good acceptance.
- Therefore the findings of this study is basically use full for nurses, midwives working with families having children with Down syndrome children need to be aware of the problems faced and should advocate for necessary support. Nurses can play an pivotal role in

helping the parents to deal with the challenges of child with disabilities. They can educate them on many topics ranging from basic and primary care requirements to maintaining the family in making arrangements that will help the child to take care of him or herself. Nurses can support parents' how to develop coping strategies in managing children with disability.

➤ The finding also awake concerned body especially in doing with basic service to those families of children with Down syndrome.

RECOMMENDATIONS

The following recommendations' are forwarded based on the finding of the study:

- Awareness raising activities be cared out to health professional and community.
- Training be provided to nurses and teacher who may have direct contact with parents of children with down syndrome and with the children them self's.
- Parents of children with Down syndrome should be in courage support in many ways.
- Education and other facilities for children with Down syndrome be provided to full fill their need.
- Early diagnosis and early intervention to minimize the number of children with DS.
- Separate developmental clinic for children with DS even at Black lion specialized Hospital.
- Free of medical service to all children with DS.

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