

Down Syndrome Families' Views On Different Perspectives

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KEYWORDS Behavior. Counseling. Healthy. Late Onset. Psychosocial. Sibling

ABSTRACT Saudi Arabia has a high prevalence of Down Syndrome (DS) cases. Down Syndrome has different age-related clinical problems. Early childhood problems in DS children are mainly related to congenital malformations. But late onset problems are psychosocial, behavioral, obesity, allergic problems, arthritis, malignancy, premature aging and Alzheimer disease and these problems are not related to congenital malformations. The aim of this study was an evaluation of the families' views regarding these complications. Preformed question form were given to families of Down syndrome cases referred to the department of Medical Genetic, KAU, Jeddah, and KSA, which had questions and four options related to different complications of Down syndrome especially psychosocial and behavior status. Thirty-eight Saudi families were interviewed. Affected individuals' ages ranged from 1 to 30 years and forty-seven percent were females. The most common concern for the parents was behavioral problems in 68.4 percent (26/38). In most of these parents (32%), a depression episode occurred at the initial time of diagnosis and was temporary. The most commonly identified cause of depression was insecurity about long-term future care of their offspring. Eighty percent (30 out of 38) of them were proud of their affected children. Down syndrome's families need proper psychological counseling and training for management of these different problems.

INTRODUCTION

Down Syndrome (DS) and its related health problems are a major health concern in Saudi Arabia as the incidence is high and the prevalence of cases has been on the rise due to more and more cases surviving into adulthood (Niazi et al. 1995).

Additionally, Down Syndrome without life incompatible malformations is ethically unacceptable to terminate in Saudi Arabia (Al-Matary and Ali 2014). Early childhood problems are related mainly to the congenital malformations associated with DS. On the other hand, late onset problems occur due to obesity, malignancy, premature aging, arthritis, and psychosocial, behavioral, and memory problems (Head et al. 2012).

Having a child with DS may have various influences on parent and siblings. However, there

is no lack of adjustment between healthy sibling and DS in early ages (Cuskelly and Gunn 2006; Naerland et al. 2017). But adjustment between healthy sibling and DS with advanced ages or after parent death will be continuing same or modified deficit in literature. Understanding the adaptation for parenting of a DS is useful for supporting the family and counseling (Hsiao and Van Riper 2011). Failure to consider families' perspectives has led to a relatively poor understanding of the psychosocial impact of the syndrome. There is a lack of knowledge regarding family views about the complications associated with DS, and how different is an individual affected with DS in comparison to a healthy sibling in the eyes of the parents. There is still room for significant improvement in detection and management of the psychopathological aspects specific to DS. Early identification and proper management of these problems prevent or alter the course of the disease and save time and money for the family and society (van Gameren-Oosterom et al. 2013).

Aims of the Study

Although DS is one of the most common genetic disorders, with a prevalence of 7.28 out of 1000 in the United States (Presson et al. 2013),

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there is still a gap in research pertaining to the behavioral and psychosocial burden of the syndrome and its effect on families. The aim of this study was to evaluate parental views on different perspectives including the psychosocial and behavioral aspects of individuals with DS in comparison to their healthy siblings.

METHODOLOGY

Participants

It was aimed at parents of individuals affected with DS who had been referred to the Genetic Medicine clinic at King Abdulaziz University Hospital, Jeddah, Saudi Arabia. This cross-sectional study was conducted during the time period from June 2015 to December of 2015.

Instrumentation

Sampling was done by a non-stratified random method. Data was collected by means of a self-administered and enveloped anonymous questionnaires randomly distributed to parents of individuals with DS. A verbal consent was obtained from all participants.

Procedures

The questionnaire comprised fifteen multiple-choice questions with four options related to different complications of DS focusing on the psychosocial and behavioral status. Parents were asked to compare these complications with the healthy siblings. These questions included items enquiring about the parental level of knowledge, their thoughts and feelings about being a parent of someone affected with DS and how that might affect their lives and relationships, and their concerns regarding the future of their affected children.

RESULTS

In this study, out of 45 families, only 38 families were interviewed due to the absence of a healthy sibling in the remaining seven families. Affected individuals in the families ranged from 1 to 30 years of age with median age 9 years, and forty-seven percent were females. Most of the responders were both parents.

As demonstrated in Table 1, around forty-seven percent of the participants believed that their knowledge about DS was very good, and an additional forty percent believed they had good knowledge.

Table 1: Parental self-assessment regarding of their own knowledge about DS

<i>Variable</i>	<i>Percent</i>
Very good knowledge	47
Good knowledge	39
Little knowledge	11
No knowledge	3

Table 2 shows parental views on the differences between a parent of a DS affected individual in terms of the the life schedule (left), the hospital visits (middle) and the comfort and care needed (right) in comparison to healthy siblings. There was no disturbance in the life schedule of 84.2 percent (32 out of 38) families of individuals with DS as shown in Table 2 while 36 of the 38 families felt that they practice little to moderate difference in caring for them in comparison to healthy siblings. Feeding difficulties were reported by twenty-four percent. Seventy-nine percent of families reported differences in the number of hospital visits seen with DS children in comparison to their healthy siblings.

Table 2: Effect of DS on family dynamics

<i>Dynamics</i>	<i>Life schedule (%)</i>	<i>Hospital visit and care (%)</i>	<i>Comfort (%)</i>
No difference	84.2	21	5.3
Little difference	2.6	47.4	50
Moderate difference	13.2	23.7	44.7
Major difference	0	7.9	0

Only 2.6 percent (1 out of 38) of families experienced severe depression (Table 3) while 31.6 percent (12 out of 38) reported depression occurred only at diagnosis. Among parents, thirty-seven percent felt slightly more insecure about

Table 3: Depression reported among parents caring for individuals with DS

<i>Variable</i>	<i>Percent</i>
Severe depression	2.6
Occasional depression	31.6
Mild depression	21.1
None depression	44.7

the child's future as compared to healthy siblings, while sixty-three percent felt the insecurity was equal to that of the sibling's. Also, 42.1 percent of parents believed that an individual affected with DS could actually lead an independent life (Table 4). The majority (93%) reported being proud of their DS child and felt privileged to bring up such an individual.

Table 4: Parental view of the DS individual leading an independent life

<i>Variable</i>	<i>Percent</i>
Yes, he can live independently	42.1
No, he cannot live independently	28.9
I do not know about it	21.1
Impossible to live independently	7.9

Although in comparison to healthy siblings it was reported to only be mild to moderate difference, behavior was the most troublesome for 68.4 percent of parents (Table 5), topping both heart and intellectual problems. The feeding difficulty was reported by thirty-two percent of the parents, and expectedly, higher education of an individual affected with DS was not of equal ease as the healthy sibling (84% of replies).

Table 5: The most troublesome complication to a parent of a DS affected individual

<i>Variable</i>	<i>Percent</i>
Cardiac problems	5.3
Behavioral problems	68.4
Intellectual disability	5.3
None	13.1
All	7.9

According to the parents, fifty-eight percent (22 out of 38) of DS cases were better at making new friends (Table 6) and eighty-seven percent (33 of 38) of DS cases were better at maintaining social relationships in comparison

Table 6: The reported comparison of ability to make new friends between an individual affected with DS and healthy siblings

<i>Variable</i>	<i>Percent</i>
Much better than healthy siblings	13
Better than healthy siblings	45
Equal to other siblings	32
Worse than healthy siblings	5
Did not answered this question	5

to other healthy siblings. While one parent reported the poor relationship between an individual with DS and his sibling, all others had good relationships with them.

DISCUSSION

The majority of parents believed they had good knowledge and a positive attitude related to Down syndrome. None of the parents thought the burden of caring for an affected child was too much to handle and the majority felt proud to have a down syndrome child (Skotko et al. 2016). Most of the parents followed the Islamic religion and culture, which may also influence their views positively towards Down syndrome cases (Ahmed et al. 2013). DS families were financially supported by the Saudi Government for proper management of DS cases. Over half of the parents reported that there was a little difference in the number of hospital visits between healthy siblings and children with the syndrome while a quarter actually reported no difference. These findings imply a good attitude and devotion from the parents and that the physical abnormalities are not as important as the behavioral problems associated with Down syndrome, especially since nearly half of parents perceived behavioral issues as more troublesome to them than the medical problems. It is known that late neurobehavioral disorders have a major influence on family dynamics, more so than structural complications do (Head et al. 2012). Neurobehavioral and psychiatric disorders are estimated to occur in approximately eighteen to thirty-eight percent in people with DS (Naerland et al. 2017). These problems may be due to the insecurity of life in adults with DS, different solemn life issues, like marriage, responsible duties or jobs. Their predisposition to such disorders is, however, manageable (Capone et al. 2006). Early identification and understanding of these neurobehavioral problems by physicians and families lead to better management with more a productive life (Bourke et al. 2008).

Genetic counseling is an important factor that drives families towards better understanding and optimistic views of DS (Kallen et al. 1996). According to most parents, their children who have DS were better socializers than their other healthy children and were better at maintaining relationships. There was no inconvenience or disturbance due to DS according to nearly eighty-

four percent of the respondents. However, over half of the parents occasionally have felt down and depressed in attribution to having a child with DS in their family, mainly attributed to the initial shock at diagnosis, where five percent actually classified themselves as very depressed (Sloper et al. 1991).

Although research has shown an inverse relationship between age and IQ in DS (Nicham et al. 2003), most parents in this study thought their affected children could lead a normal independent life in the future while only a minority (8%) thought it was impossible for them to do so.

CONCLUSION

Less is known about the psychosocial aspects of Down syndrome as most previous studies focused on the medical issues associated with it. The researchers believe that these issues do not have to affect the individuals or their families negatively. Proper counseling and training of families about the expected behavioral aspects of individuals with DS is necessary for optimal outcomes. These families' psychosocial status needs to be noticed for early optimum management and enhance the life quality of affected individuals and their families.

Practice Implications

Newly diagnosed cases may be helped by connecting different families together and the establishment of support groups. This may aid in coping with the initial shock of the diagnosis.

These studies will help both health professionals and the families of recently diagnosed individuals to understand the needs regarding DS especially on the following points:

- ♦ What parents think about differences between DS and normal siblings.
- ♦ What genetic counselors should know about parent views for sibling and DS.
- ♦ That it is not the physician but the family who will decide the difference between a healthy sibling and one with the syndrome.
- ♦ Psychosocial status of family needs to be noticed for early optimum management.

RECOMMENDATIONS

Further research on the late psychological issues is needed for guidance into effective pre-

vention and management. Health care experts ought to enhance their insight about these families' views for DS when contrasted with healthy siblings. It will enhance the life standard of DS's and their families.

LIMITATIONS

Besides the test size as a one of the limitations, the authors did not order families on the premise of financial status. Authors also did not classified families on the basis of DS patients' sex, age and associated major structural malformations. However, this constraint was partially adjusted because of authors discussed just an intra-familial comparison between DS and healthy siblings. Authors did not discuss in detail for cause and severity of depression because there are various causations for depression and it was beyond the study plan.

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Paper received for publication on August 2016
Paper accepted for publication on May 2018

APPENDIX

Questionnaires Performa for Family

Down Syndrome -DS

1. Knowledge about the Down syndrome
 - a. Not known b. little known c. known well d. known very well
2. Being a DS parent what you think as a social status
 - a. Not think much b. it does not affect c. think d. think much
3. Mental difference between DS and other healthy siblings
 - a. No difference b. little difference c. much difference d. very much difference
4. The difficulty for caring for a DS in comparing to healthy siblings
 - a. No difficulty b. little difficulty c. much difficulty d. very much difficulty
5. Difference in hospital visits between DS and healthy siblings
 - a. No difference b. little difference c. much difference d. very much difference
6. Feeling of depression due to DS
 - a. Very much, b. Little c. No difference d. occasionally
7. Relationship of DS with another sibling
 - a. Very friendly b. Friendly c. Not difference d. Not having good relationship
8. Feeling proud of being a parent of a DS as compared to other sibling/ children
 - a. No feeling b. Slight feeling c. feeling proud d. feeling very proud
9. The level of higher education of a DS as compares to other sibling/ children
 - a. Never be equal b. Maybe equal c. Not sure d. Slight lesser
10. Insecurity regarding the future of a DS as compares to other sibling/ children
 - a. Very much b. Slight c. Equal d. None
11. The most important problem in his/her DS case
 - a. Heart b. Behavioral c. Mental retardation d. All e. None
12. The behavior of a DS in comparison to healthy siblings/ children
 - a. Much better b. Better c. Equal d. worse
13. Social relationship of a DS in comparison to healthy siblings/ children
 - a. Much better b. Better c. Equal d. worse
14. Disturbance of life schedule due to a DS case in comparison healthy siblings
 - a. No disturbance b. Disturbance c. Marked disturbance d. Initial period not now
15. Feeding difficulties in a DS in comparison to healthy siblings/ children
 - a. No difficulties b. Difficulties c. Equal d. Better