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Knowledge, Attitudes and Beliefs of Caretakers of Children with Down Syndrome

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Abstract

Background: Down syndrome is the commonest cause of intellectual impairment but many of the parents and caretakers are not fully aware of the strengths and challenges involved in bringing up a child with this condition. Misconceptions about their ability to live in an inclusive society is very high and hence this study was conducted to have an insight about their knowledge attitude and beliefs.

Aim: To study the personal and social impact in the families of persons with Down syndrome.

Method: A questionnaire with 28 questions was given to parents/caretakers who attended a meeting for parents of persons with Down syndrome and their reponses were analyzed.

Results: The group had a fairly good knowledge of the condition when compared to others as seen from some similar studies. But late counseling and lack of awareness of the various therapies resulted in delayed start of early interventional programmes. The majority still preferred to send their child to a special school but a large number opted for education in a normal school. The society was over sympathetic and over inquisitive and some were harsh to the mothers. The mothers usually responded patiently to the questions by others but made them cry at times. The fact that they can be trained is well understood but there were only few who were actually working. The other aspects are detailed in the discussion.

Conclusions: Most families adjusted well to a child with Down syndrome and received good support from spouses and siblings. But improving early diagnosis, counseling and initiating therapies have to be strengthened. The need to help them to get a good vocational training and thereafter a suitable job can go a long way in helping them lead as normal a life as possible.

Keywords: Down syndrome, attitudes and beliefs, education, vocation, response of society

Introduction

Down syndrome (Trisomy 21) is the most common genetic etiology of mild to moderate intellectual disability. The incidence of Down syndrome in live birth is approximately one in 733 [1]. Understanding the individual development strengths and challenges is necessary to maximize the educational process. Persons with Down syndrome often benefit from programs aimed at cognitive training, stimulation, development and education [1].

Majority of the parents are unaware of the condition and do not possess any knowledge about the possible etiological factors [2]. Perception of the disease and the public attitude towards people with Down syndrome are very important in the inclusion of these people in the family and community, and early intervention can improve their quality of life [3]. Persisting misconceptions and stereotypes about Down syndrome can lead to unnecessarily low demands and low expectations for persons with Down syndrome, which can impede their development and social integration. Educational materials designed to address and correct misconceptions about Down syndrome would benefit the families who have a child with Down syndrome [4].

The current study was done to assess and analyze the impact of this condition in persons with Down syndrome and their families, so that they can be used to develop/improve the attitude in bringing up the child.

Materials and methods

The study was done at the department of Paediatrics, Baby Memorial Hospital, Calicut, to know the knowledge, attitudes and beliefs of caretakers of persons with Down syndrome and thereby analyze the personal and social impact of this condition in persons with Down syndrome and their families.

A total of 63 families who attended a meeting for persons with Down syndrome were included in the study. Printed proforma was used for evaluation. The questionnaire included 28 questions related to medical knowledge, attitude towards people with Down syndrome, educational, job related and social problems faced by people with Down syndrome.

Results

The answers to the 28 questions were analyzed and some of them are presented in this paper. Of the 63 participants who were given the questionnaire, 68.25% were females and 31.75% were males, and the majority (35%) of them belonged to the age group 31to 40 years. Only 23.8% of the participants were graduates and above. Majority of the respondents were Muslims (52.5%), followed by Hindus (38%), and Christians (9.5%).

In 30% of cases the maternal age at birth of the child was 26-30 years, with only 19% in the age group 36-40 yrs. 14% were in the age group 21-25 years, 12% in 31-35 year group, and 9% each in the age group less than 20 years and also more than 40 years (**Figure 1**). Child with Down syndrome was born as the first-born child in 39% of families.

Discussion

Analysis of the questionnaire regarding the attitude of having a child with Down syndrome showed that majority (71%) were happy/proud of having such a child. 3% did not answer the question and the others were sorry/dejected (**Figure 2**). 96% felt their spouses were helpful and supportive.

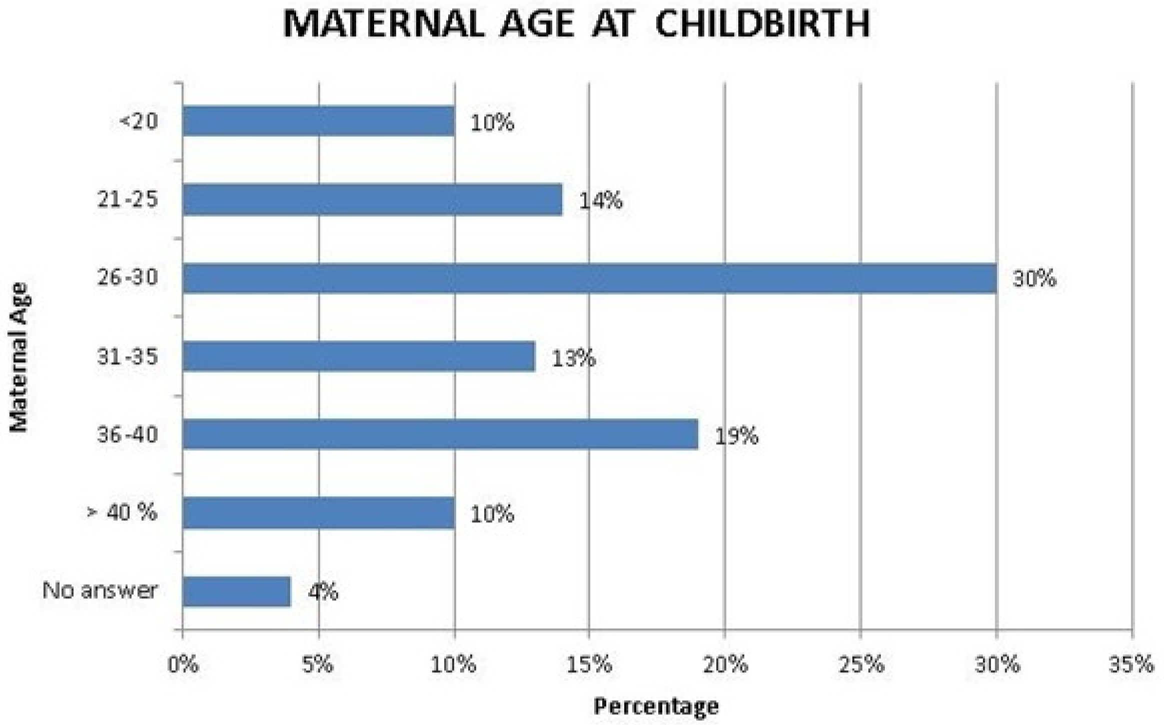

Figure 1

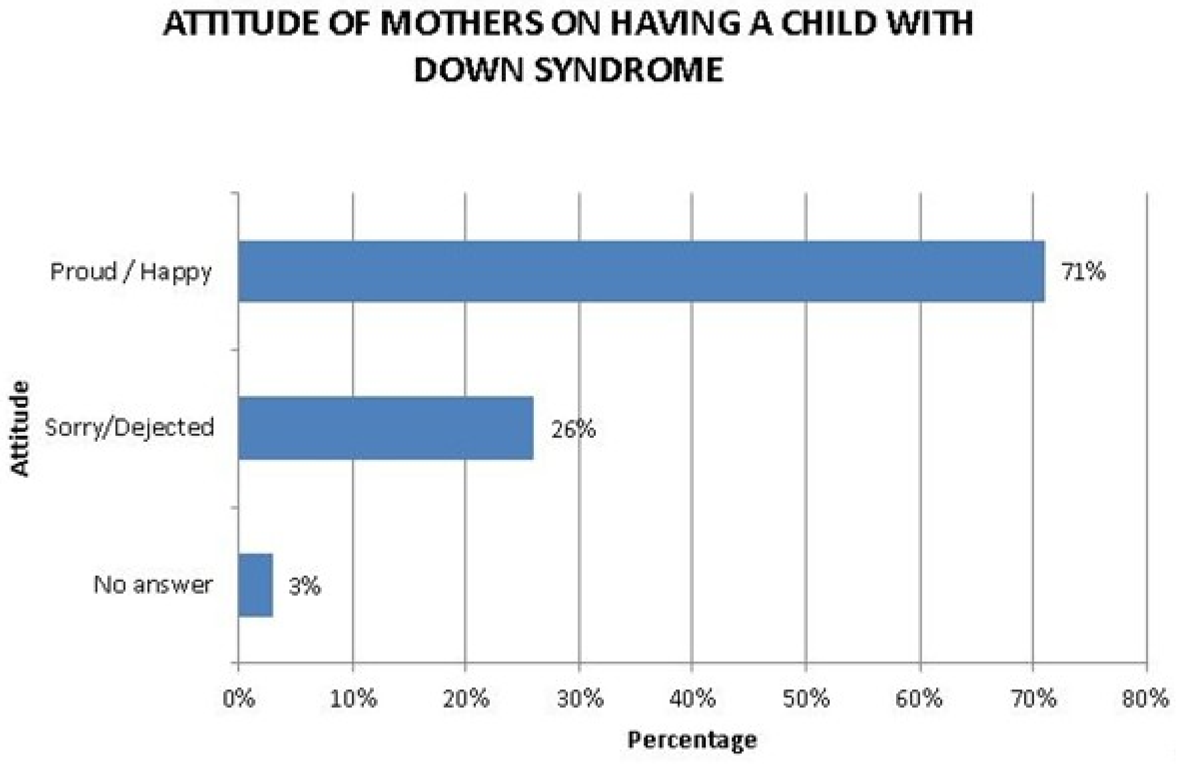

Figure 2

In a study conducted by Korenromp et al at Netherlands, half of the women cited concerns over their relationship with their spouse after having a child with Down syndrome [5]. Whereas Urbando, Hodapp et al noticed that divorce rates were lower among parents who have children with Down syndrome than among parents who have children without disabilities or other birth defects [6]. In another study conducted by Lakshminarayana et al in 1989 at Institute of Child Health and Hospital for children, Madras, on being informed that their child was having Down syndrome 52% were depressed [2]. But Sue Buckley from UK noticed that all families loved and valued their child with Down syndrome as the years went by [7].

More than 68% of those who responded to our survey indicated that the siblings were loving and helpful. About 5% were indifferent and detached but the rest were supportive (**Figure 3**). In a study conducted by Brian et al in USA, more than 96% had affection towards their sibling with Down syndrome and 94% of elder siblings expressed feeling of pride. Less than 10% felt embarrassed and less than 5% expressed a desire to trade their sibling for another brother or sister without Down syndrome [8].

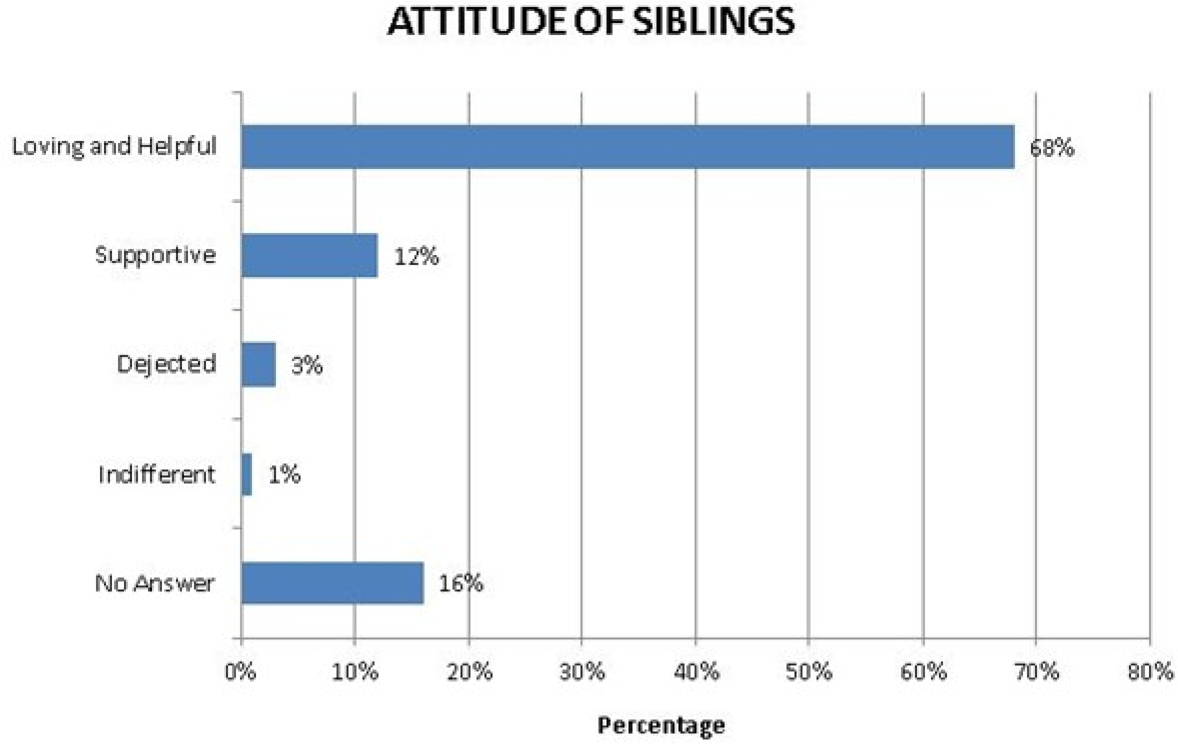

Figure 3

The medical knowledge of the family regarding the condition was assessed. Most (85%) of the people were aware that the condition is a chromosomal problem; and 77% knew that it was due to a problem in cell division. 82% were aware that the condition is not reversible. 7.9% believed it occurred due to various perinatal events, and a small proportion of people (4.7%) did not know what caused Down syndrome.

Lakshminarayana et al in his study in 1989 found out that 64% of mothers did not possess any knowledge about the possible etiological factor, whereas 36% attributed it to some form of antenatal event [2]. Whereas Glimore et al found that majority of teachers and community members surveyed in Australia knew that Down syndrome is a chromosomal disorder [9].

In our study 46% of the mothers were aware that their child had Down syndrome at birth, and the physicians had counseled them; while 46% did not know this and came to know only later on, even as late as one and half years, when they approached their physicians with various other problems. Hence their early interventional therapies were delayed.

The common ailments among children with Down syndrome were recurrent cough and cold (54%), followed by recurrent fever (22%), recurrent vomiting (6%) and recurrent diarrhea (2%). Other ailments constituted 16% (**Figure 4**). General awareness about thyroid disease was poor, but some of them were aware that thyroid hormone level had to be monitored regularly. Majority (92%) knew about immunization and 90% of them were fully immunized. As far as the life expectancy of their children were concerned, the families were mostly unsure.

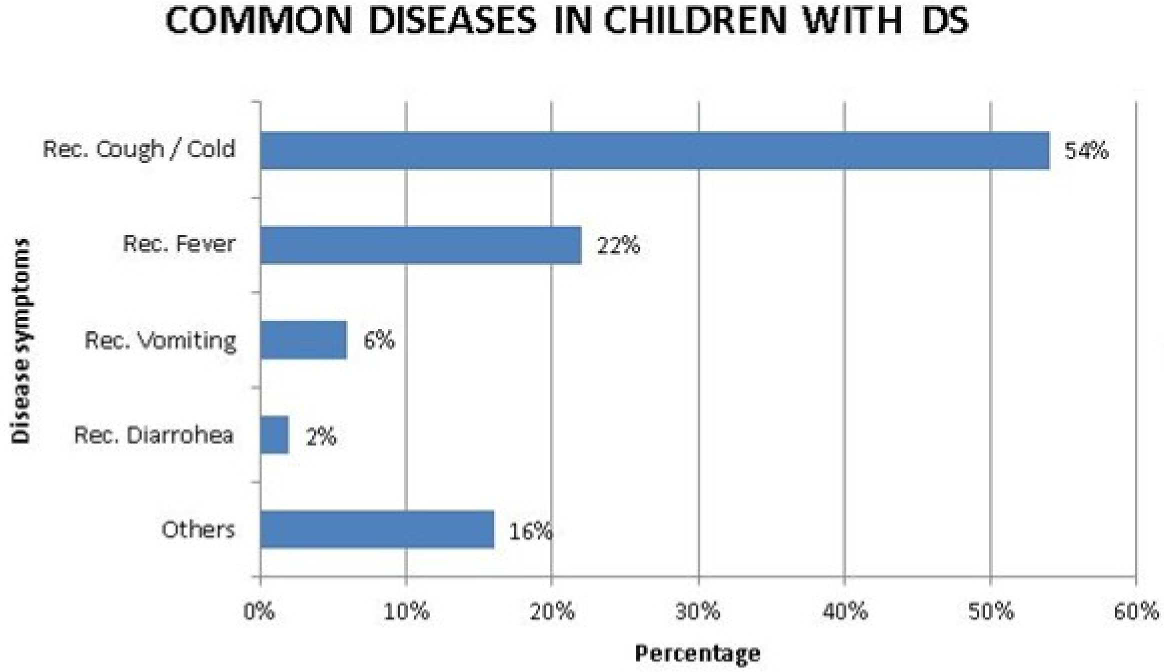

Figure 4

Many (55%) of them had knowledge of the various rehabilitation therapies available. But among those who did not, a large number of them believed that only speech therapy is required (23.8%). Some knew only about Physical therapy and Occupational therapy (6.4% each) (**Figure 5**).

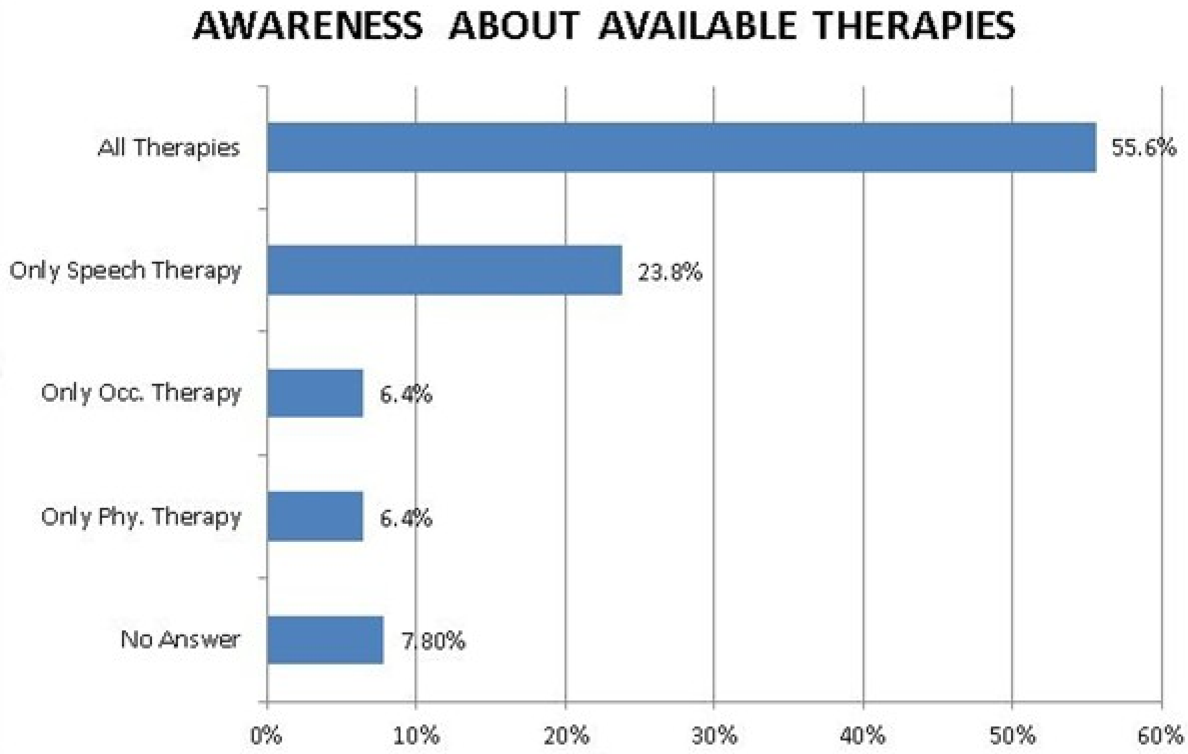

Figure 5

Integrating children with Down syndrome in mainstream school is a very important aspect as it helps to improve their communication and cognitive skills, gets them involved in regular activity and enhances their socialization process [4]. In our study majority of the participants were aware that their children could learn (90%) and they could be trained (98%). Most of them (95%) felt that a child with Down syndrome should be sent to school whereas only less than 1% were of the opinion they should not be; some were not sure about it. 55% of the respondents preferred special school, 35% normal school, 5% integrated school and 2% play school (**Figure 6**).

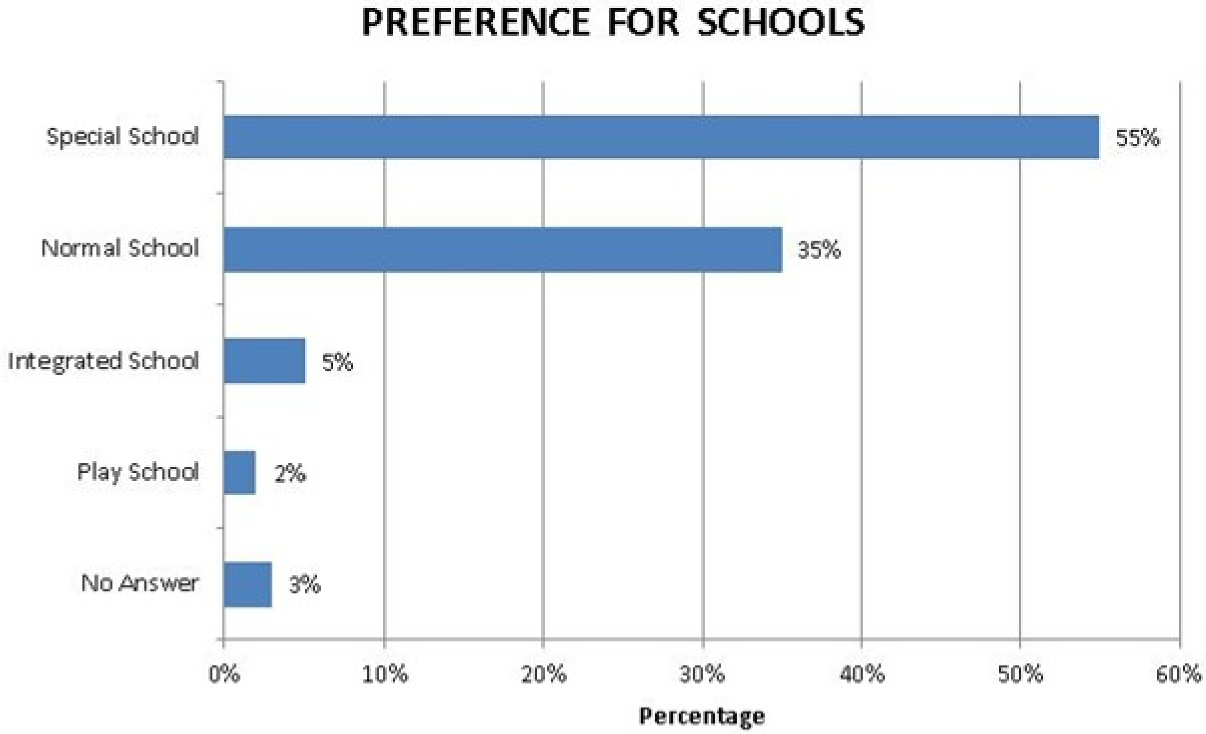

Figure 6

In the study conducted by Alhaddad et al in Jeddah, 89% believed that the children with Down syndrome could attend main stream school [10]. In another study conducted by Denis et al regarding children with Down syndrome in schools, the opinions varied. Some believed that all children could benefit from interactions with a diverse group of children and that the presence of children with Down syndrome in main stream classrooms would teach other children empathy. Others felt that, including children with Down syndrome in mainstream class rooms would distract typically developing children. Some others were of the opinion that mainstream classrooms hinder children with Down syndrome because they would not receive specialized attention [4].

In our study though 96% of respondents believed that their child could be trained for a job, only 77% of the families believed that their child could do an independent job. But only 11% of the families had a child with Down syndrome who was working. Whereas Allhadda et al observed in his study that majority of the participants thought that persons with Down syndrome cannot get employment [10]. Studies also suggest that a small but significant proportion of people with Down syndrome could be employed with a regular contact, while the employment rate seems to depend on the age category and academic achievement [4].

Inclusive education, health care and inclusiveness in the society were the primary problems faced by the children with Down syndrome in our study. They had to bear with over sympathy (52%), over inquisitiveness (29%) and staring looks from the public (16%) (**Figure 7**). Most of the families handled the questions put forth by the society by patiently answering them (76%), 14% used to ignore them, and 14% also felt like crying when they were asked about their child (**Figure 8**) Most of them were generally unsure of the possibility of children having an independent life (61%) and the possibility of a marital life (53%) though 23 % believed that they can have a married life.

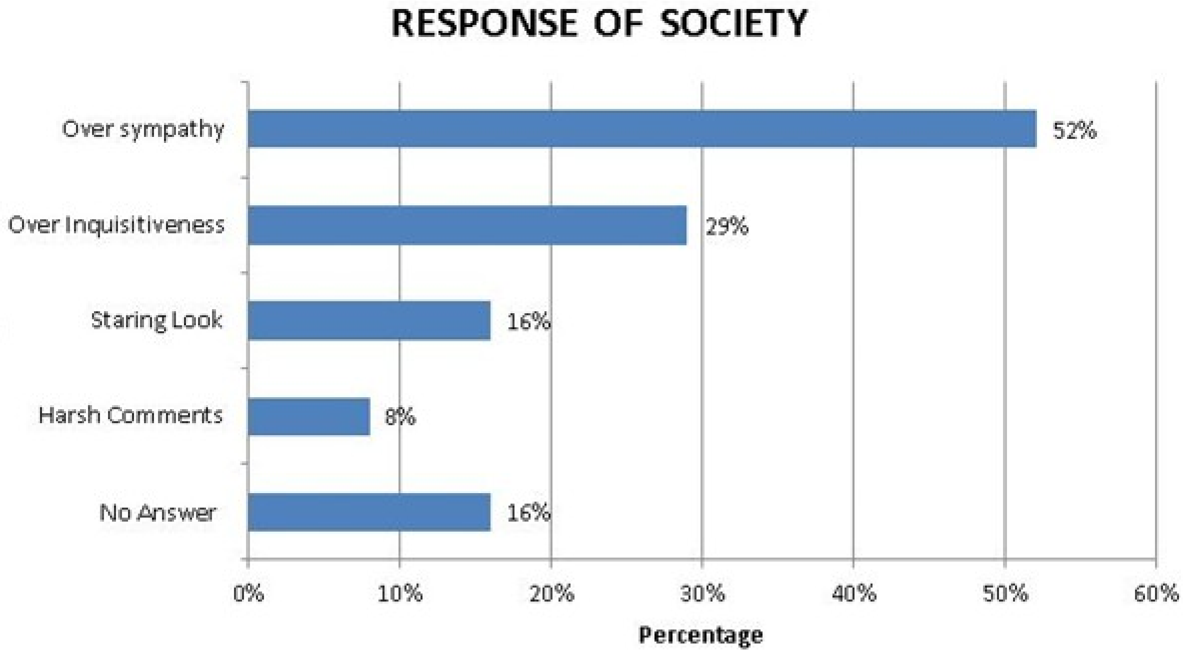

Figure 7

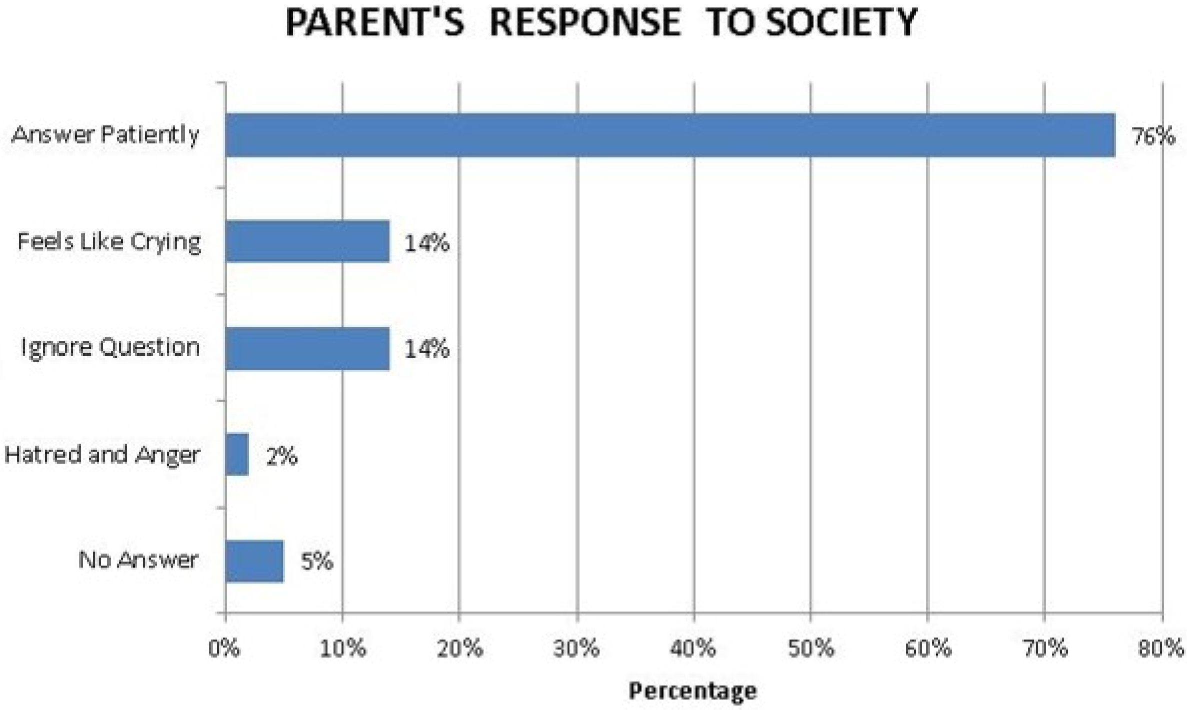

Figure 8

Conclusions

This study found that most families were happy after having a child with Down syndrome and the spouses and siblings were supportive towards the child. They had, in general, good knowledge about the condition and the necessary supportive measures needed for the betterment of their children, when compared with studies from other parts of the world. But improving early diagnosis, counseling and initiating therapies have to be strengthened. The need for an inclusive education, inclusive health and inclusiveness in society needs to be highlighted. Parents should be encouraged to train their child for a suitable vocation and help them to stand on their own feet as the majority rightly believed that they are trainable.

Recommendations

1. Medical personnel should be encouraged to find sufficient time to counsel the parents at birth itself, so that early interventions are not delayed.
2. Parents should be educated about the need to put children with Down syndrome in normal schools so that they are better equipped in life.
3. The society should be made aware of the various positive aspects of the condition, so that these children are accepted and embarrassing question to the parents are avoided.
4. Persons with Down syndrome should be imparted vocational training at the appropriate time so that they can pursue a meaningful job.

Limitations

The sample size is very small therefore a study with a larger group would only reflect the true status. Many of the parents who participated in the study were from the urban area and had attended awareness classes earlier; hence it need not represent the actual status of the society especially in the rural areas.

Acknowledgements

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