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INITIAL REACTIONS OF PARENTS AT THE TIME OF RECEIVING THE DIAGNOSIS OF DOWN SYNDROME: A QUALITATIVE STUDY

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ABSTRACT

Background

Parenting the children with Down syndrome is considered to be a life changing experience for parents and requires them to analyze their personal belief systems. Often when parents are unable to accept the diagnosis of Down syndrome of their child, they react to this disability with anger and fear.

Purpose

The purpose of this study was to explore initial reactions of parents receiving their child's diagnosis of Down syndrome.

Methods

A qualitative study was conducted in the pediatric outpatient units of a private hospital in Karachi, Pakistan. In total, 89 children with DS were identified and telephone numbers of the parents of these children were collected from the medical record office from January 2013-December 2014. Forty parents were contacted by telephonic calls for the first time on different days. Of the 40 parents, 15 parents refused to participate, one couple was not available, two telephone calls were left unattended, and two parents left the city and moved to another place.

Finally, 15 parents agreed to participate in the study therefore written informed consents were obtained and appointments were scheduled for face to face in-depth interviews.

Findings

It was found that the news concerning Down syndrome was often shared with the father alone of the children. Nearly all fathers found the news a shock .

The common initial reactions were : lack of acceptance of the diagnosis and denial (to the extent that even a few mothers of children aged 5 years with Down syndrome still had hope that one day their child would be free from this disability); delay in seeking assistance pertaining to the diagnosis of DS and visiting different doctors to deal with the common problems from which DS children suffer, e.g. nose blockage, sneezing, not eating properly, slow growth, etc.

Conclusion

The results indicate that improving communication with the parents, listening to their concerns, and facilitating active participation in treatment should all be central to the care that is provided at the time of diagnosis. The vast majority of the parents were not satisfied with the amount of information and support that been provided to them, and they perceived it as too negative.

Keywords: Down syndrome; children with disability; parent reactions

INTRODUCTION

Down syndrome (DS), originally known as Mongolian idiocy, is the most common genetic syndrome. The disorder was not known until 1886 when the English doctor John Langdon Down published a description of the condition, which subsequently took his name. A group of 20 twenty of the world's leading geneticists suggest that the disorder should be known from now and onward as "Langdon Down anomaly, Down's syndrome (DS), or anomaly or congenital, Acromicria and the designation was confirmed by the World Health Organization in 1965.DS is diagnosed in one per 650-1000 live births, with an estimated that 5500 infants born annually in the United States (Bittles, Bower, Hussain, & Glasson, 2007).It is difficult to find out the specific statistical data on incidence of DS because many pregnancies may not complete until full term and spontaneous miscarriages takes place in some cases. A study was done in London and Wales and it was estimated that 43% of pregnancies ended in a miscarriage or still birth, and 12% of births were stillborn or resulted in neonatal deaths (Morris, Wald, & Watt, 1999).Down syndrome generally gets marked under other ailments, most commonly it is wrongly interpreted with cardiac anomaly or respiratory disorders and which further delays the defects. The situation becomes worse where the majority of the births takes place at home where proper newborn assessment does not exist. If it exists, it is mostly minimal and substandard.

Down syndrome diagnosis disclosure is difficult for the doctors and health care professionals because of the uncertain reaction of Pakistani parents. Parenthood is a tough job whether they are Pakistani or not, and having a child with disabilities is difficult for the mothers,as they have to spend more time at home with the child. King et al., (2006), through a qualitative study 15 parents of children with DS, found out that parents consider caring for child with DS a life changing experience which requires them to analyze their personal belief systems. Parents gain a sense of satisfaction and control of their parenting roles by using different ways to care for their child. Also, the parents were optimistic, hopeful, and looked for the future possibilities in the child's life. Van Riper, Ryff, and Pridham (1992) studied the well-being of families of children with Down syndrome and found that many parents responded with adaptive functioning to the challenges associated with parenting their child. Studies have not explicitly examined changes in the belief systems of families of children with these conditions. Another study by Hedov, Annerén, and Wikblad (2002) assessed the experiences of parents and results showed that, out of 165 parents, half of the parents were not satisfied with the late timing of the information, and 70 % parents considered that information given was not sufficient. Poor communication and lack of openness are the major causes of a parent's traumatic reaction towards the disability of their child with DS. Health providers need a greater depth of understanding and empathy for reactions and experiences of parents with DS than they have at present. Beyond studies of parents' experiences with the initial diagnostic process (Howlin& Moore 1997; Mansell & Morris, 2004), we are not aware of studies addressing how families of children with autism or Down syndrome have navigated subsequent transition points and life experiences.

According to the March of Dimes, Global report on birth defects, 2006 shows that every year an estimated 7.9 million children, 6 percent of total births worldwide are born with a serious birth defect of genetic or partially genetic origin. Birth defects are global problems, but their impact is particularly severe in middle and low income countries where more than 94% of the births with serious birth defects and 95 % of deaths occur in children. The report highlights the five common serious birth defects of genetic or partially genetic origin, and Down syndrome is the fourth most serious genetic defects worldwide. Children with DS have different special needs and primarily the parents play an important role in providing care to them. When parents are informed that their newborn has DS, they initially deny in accepting the diagnosis and express anger and fear in reaction to coming to know about the disability. This indicates a need to study the reactions of parents with children with DS. This need is consistent with the findings of an integrative literature review that highlighted the need of study in different cultural settings using qualitative methods (Cuskelly, Hauser-Cram, & Van Riper, 2008).

STUDY RATIONALE

Down syndrome is one of the commonest chromosomal, genetic syndromes. Because of a combination of the physical and mental problems associated with this condition, children have frequent illnesses and require special and constant attention. Providing care is a natural part of being parents of a young child, but this role becomes much more demanding when a child experiences functional limitations and possible long-term dependence. Consequently, whenever parents are informed they react negatively towards this disability. Parents are primarily informed about the disability by the general physician, and formal counseling related to the genetic deformity is very limited. Moreover minimal attention is usually paid to the reactions of parents with DS. In addition it was also observed that many parents were not aware of the diagnosis of

DS, and they were informed very late. Moreover, very few parents were informed about the disability by their primary physician and parents refused counseling,denying the truth of the diagnosis. Those parents who react negatively towards the disability of their child have difficulty in taking care of the child in the future also.

The aim of this study was to build an in-depth knowledge and insight about the reaction of parents whose newborn was diagnosed with Down syndrome, so that the health care providers would be able to improve communication and promote openness between the parents and health care team. Moreover the study will assist me to take parents' views and wishes into account. In addition I hope to produce an information booklet on Down syndrome, so parents can refer to the written material time to time. Because health providers may not explain everything about the disability in the first meeting, the written information could be referred to as the needs of learning arise by the parents.

PURPOSE

The purpose of this study was to explore the initial reactions of parents receiving their child's diagnosis of Down syndrome.

METHODS

A qualitative approach was used and the study was conducted in the pediatric outpatient units of a private hospital in Karachi, Pakistan. The study participants comprised parents of children with DS aged 0-3 years.In order to recruit the participants, the head of Pediatrics department was contacted and permission was sought to get phone numbers from the medical record. Additionally, permission was sought from the three primary physicians caring and treating the children. In total, 89 children with DS were identified and telephone numbers of the parents of these children were collected from the medical record office from January 2013-December 2014. Forty parents were contacted by telephone calls for the first time on different days. Of the 40 parents, 15 parents refused to participate, one couple was not available, two telephone calls were left unattended, and two parents left the city and moved to another place. Finally, fifteen parents agreed to participate in the study, therefore written informed consents were obtained and appointments were scheduled for face to face in-depth interviews. The mother and father were interviewed individually on the same day. Of the 15 parents, 3 parents could come for interview together while ten mothers came without their husbands and were accompanied with their children or a relative. Each interview lasted for 40-45 minutes and was tape recorded to clearly document the information about the reactions and feelings that the parents had experienced.

DATA COLLECTION

In order to ensure the rigor of this study the interviews were audio-taped. Before each interview written informed consent was obtained from the participants. The informed consent included information about the researchers, study purpose, time required for interview, possible risks and benefits, and the intended use of data. During interviews the interviewers used bracketing and intuiting. Bracketing is a procedure that entails purposely putting aside one's own belief about the phenomenon under investigation throughout the phenomenological investigation and intuiting refers to focusing on the actual lived experiences of respondents during data collection. These techniques ensure the validity of data collection (Streubert & Carpenter, 2011). The researcher used communication skills such as reflection, nodding, questioning, clarification, and maintaining eye contact, to facilitate and encourage participants to talk. The interviews were conducted by one researcher. The interviewer summarized the data immediately and sought validation of the interview findings at the end of each interview in the presence of the patient. Prior to interview, the researcher noted personal thoughts and experiences which are common in parents having a child with DS, to avoid any bias of the interview findings.

DATA ANALYSIS

Lindseth and Norberg (2004) method of data analysis was used for analysis. This method comprised of three steps: (i)*naïve reading*, in which the researchers read the interviews several times to familiarize themselves with the text and reach an initial understanding. During reading all the emerging ideas were written down on paper. Each interview transcript was analyzed twice and validated with the audio recordings in order to seek the core sense of data, (ii) in *structural analysis*, the initial understanding was tested separately by each researcher. In this phase meaning units were identified and grouped into themes and subthemes and, (iii) in *comprehensive understanding* the text was read again and the researchers reflected on the extracted themes.

ETHICAL CONSIDERATIONS

The ethical approval for the study was obtained from the Institutional Review Board of the Hospital where the study was conducted. Written informed consent was obtained from the study participants. They were informed of their rights to withdraw from the study at any time. They were continuously reminded and informed of their right to review the consent and strict protocols were set to maintain their confidentiality. Data access was only granted to researchers after the completion of study. Data was kept locked in a safe place and the tapes were destroyed at the end of the study. Revealing materials, such as names of participants, were withdrawn during data collection. The researcher upheld privacy in all personal matters such as feelings, beliefs or attitudes, and opinions arising from information coming from the participants.

STUDY RIGOR

The criteria for assessing validity and reliability of quantitative studies are not suitable in qualitative studies. Streubert and Carpenter (2011) stated that qualitative studies are considered trustworthy when the actual experience of participants is described. Therefore, the experiences of the participants were explored and transcribed explicitly. Credibility is demonstrated when participants recognize the reported research findings as their own experiences (Streubert & Carpenter, 2011).Shenton (2004) suggested various strategies to ensure credibility of qualitative research. The researcher will take the following measures: i) adoption of well adapted research methods such as data collection and data analysis. The data collection and data analysis methods for this study are adopted fromLindseth and Norberg (2004), ii) each participant was given open choice to refuse or accept the participation in the study so as to ensure the inclusion of only those participants who are genuinely willing to take part, and iii) the interviews were tape-recorded and transcriptions were made for each interview.The researchers followed up the participants and validated the interview findings to determine whether the transcribed data represents their experiences.Confirmability refers to the researchers' equivalent concern for objectivity and it encompasses the extent to which the researchers' admits their own predispositions (Shenton, 2004). Therefore, the researchers analyzed the data, accounted for any biases, and were open about them, and used the appropriate qualitative methodological practices to respond to any emerging biases.Transferability refers to the probability that the study findings have meaning for others in similar situations (Streubert & Carpenter, 2011). Since the findings of a qualitative study are generalizable to specific population, it was impossible to establish their applicability to other situations. However, the researchers provided a thorough description of the research methodology, the participants' background, and the research context to enable future researchers interested in making a transfer.

RESULTS

The following were the common themes that were found repeatedly in interview. The news was often broken with the father alone of a child with DS. Nearly all fathers found the news a shock .The common initial reaction was lack of acceptance, denial to the extent that even a few mothers of children with DS aged 5 still had hope that one day their child would be free of this disease. Another evident reaction was delay in seeking assistance pertaining to diagnosis of DS, and visits to different doctors to deal with the common problems such as those related to nose blockage, sneezing, not eating properly and slow growth. Mothers still felt upset because the child will be dependent on other siblings. They also had feelings of hopelessness because of the things that the child cannot do and often felt like crying. It was observed that many mothers were unable to talk about the disability of their children and became upset during the interview, and stopped talking for a while to absorb their sadness related to the disability of their child.

It was reported that none of parents were aware, before the birth, about Down syndrome (DS), except one mother. In addition parents did not recognize their babies different from their other children at the time of birth. All of them were not told by their primary physician about DS.

Each parent has unique experiences to share, but on the other hand all of them had gone through the similar kind of feelings towards the disability of their child. The initial reaction among all parents was denial and refusal to accept that their child has some kind of weakness and delay in brain development. The common statement that was used by the physician to explain DS was “dhamagh ki kamzori---- Brain weakness”. In all interviewers only the fathers were informed first by the Pediatrician as it was a suspected case of child with Down syndrome.

Mothers were informed about the mental disability of their children by their husband and few of them still took a long time to accept the diagnosis of DS. In addition mothers never visited again the same physician who had initial suspiciousness about DS. All mothers had different periods of adjustment; it took them from 11 months to 2 years to become adjusted to the various challenges related to the disabilities of their child. All mothers found their husbands to be supportive and encouraging to manage the child with this disability. Parents shared different experiences of the first time disclosure of diagnose with DS. A common statement was that they were given information about DS as a medical terminology and it was very late and many of them did not understand what it meant.

Few parents still had criticism about the attitude of their physician, and found them very unsupportive at the time of diagnosis. DS is the disorder most commonly associated with mental retardation and it was feared by most of the parents, because parents thought that they received insufficient information about DS as much medical jargon was used to explain the condition. In addition parents felt that they were not counseled sufficiently on such matters, and were informed as if it was a usual infection that the child had.

The results showed that educated parents were more content and supportive of the care of their children as compared to the less educated parents. They contacted different people for guidance and were aware about the need of vocational training for their child and showed concern about the future life in terms of education and social life. However many parents accepted that they would not be able to obtain education in the normal school system. Very few parents were aware about the availability of the vocational training. Those parents who were registered with different rehabilitation centers expressed positive views, as compared to the parents who were managing their children at home.

Parents shared about their attitude as having to be extra caring, and were always concerned about the well-being of their child. This is something unique in nature, and a few parents thought of this child as a token of blessing to their family and found significant financial and economical improvements after the birth of their child with DS.

A few mothers still have hope for the normality of their child, and pray fervently, and find it hard to accept any disability or limitation in their child, saying that, “hamara bacha ziada beemaar nehi hai” (that their child is not sick and does not look sick from any aspect, except being a little slow in performing different activities). In addition all parents said that this disability is all because of Allah’s wish and we cannot fight with God; however we will do our best to look after our children for their whole life. One parent even said that “I have written down my wish that after my death my child with DS should inherit half the portion of my property. I have made legal provision in favor of my son with DS, so that his siblings will look after him and he will be financially secure for the rest of his life”

DISCUSSION AND CONCLUSION

The results concerning the reaction of parents with DS shows improving communication with parents, listening to their concerns, and facilitating active participation should be central to care being provided around the time of diagnosis. The majority of the parents in the present study were first informed about their child's condition between 3hrs -7 months of age. The vast majority of the parents were not satisfied with the amount of information and support that had been provided to them and they perceived this as too negative. It is clear from this study that more training of physicians in communication skills and in the provision of information and support to parents of children with lifelong disabilities, such as DS is required to increase the parental satisfaction. Special attention should be paid to counseling the parents around the time of sharing the diagnosis, and there must be a team involved in managing each case.

This study did not focus on the standard timings of disclosure of the diagnosis; however there is often a huge time gap, as found in the present data, of time for giving the initial diagnosis, but delays in this have adverse effects on the overall growth and development of the child with DS **.** It is now well known that early identification and proper interventions, such as speech and physical therapy and other vocational therapies, as well as home teaching for the child and family, will promote the well-being of children with DS.This must be clearly understood by the parents and other care workers, that these therapies can have a lifelong impact on children with DS, and parental teaching must be supplemented with some written materials for future reference. In the first few years, children learn more and at a faster pace than at any other time in life, but children with DS and their parents must be involved as partners for taking care of the child at least for the initial five years of age. At less than five years of age a child with DS is particularly vulnerable and shows significant delay in growth and development. Early detection of DS can help prevent some of these problems.

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