

The Experiences of Parenting Children with Autism Spectrum Disorder (ASD) in Bhutan

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ABSTRACT

The World Health Organization (2001) acknowledges that when a person in a family has a disability, the family members also experience the disability due to close contact with the disability, terming it as “third-party disability.” Parents in general, are the primary caregivers to children with disabilities and are bound to face challenges as a result of the disabilities. This study explores the lived experiences of parents of children with Autism Spectrum Disorder (ASD) in Bhutan; the challenges they face, and the coping strategies they adopt in parenting a child with ASD. Semi-structured interviews were conducted with 15 participants who were parents of a child with ASD. Three stages that exhibit the experiences of the parents were discovered, namely crisis event, stressors, and coping and adaptation, using the double ABC-X model. The findings of the study can provide insights into the lives of Bhutanese parents of children with ASD, and deliver information on how it impacts the parents. This will create awareness and understanding about ASD and how it affects not just the child with disabilities but also the caregivers. It will also help parents, especially new parents to children with ASD, on how to tackle the stressors they are likely to face and how to adapt to raising a child with ASD through the experiences of the other parents. In addition,

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the study provides recommendations on how government and society can help better the lives of children with ASD and their families.

Keywords: Adaptation; Autism spectrum disorder; Caregivers; Coping; Crisis event; Stressors; Third-party disability

INTRODUCTION

Individuals with Autism Spectrum Disorder (ASD) encompass abnormal communication, repetitive and constricting behaviour, and impaired social functioning (American Psychiatric Association, 2013). Findings report that “ASD affects 1 in every 110 children with a growth rate of 10% to 17% per year” (Meadan, Halle and Ebata, 2010).

Given the environment of this condition, parents face diverse challenges as caregivers. Children with ASD are less able to express their needs creating communication issues between the parent and the child (Peppé et al., 2007), and parents of children with ASD experience higher stress levels than parents of children without ASD (Sivberg, 2002).

Understanding their lived experiences is vital as getting an insight into the daily family lives, and the ways that ASD influences parents’ personal and social dynamics, will help create awareness and understanding of ASD and its impacts not just on the child, but on the parents as well.

Problem Statement

According to the 2017 Population and Housing Census of Bhutan, 2.1 per cent of the population (15,567 persons) have a disability (National Statistics Bureau, 2018). However, there are no data that shows how many of these people make a living and/or if they have to depend entirely on their family for survival, and how caregiving for Persons with Disabilities (PWDs) affects the caregivers.

A study on the impact of experiencing disability through association, especially by the parents as the prime caregivers, is important. This will help Bhutanese society understand the challenges parents as caregivers face, how they cope with it, and how it can be addressed. Of the many disabilities diagnosed, ASD is an intellectual disability that has no cure and would affect both the child and the caregivers for life.

Hence, this paper examines the impacts of autism on the parents of a child with ASD and shows how they negotiate the experience of disability in their daily lives in Bhutan.

Objectives

The objectives of the study are:

- To examine the impacts of autism on the Bhutanese parents of a child with ASD.
- To find out how they negotiate the experience of disability in their daily lives.

LITERATURE REVIEW

Understanding ASD

ASD is a pervasive neurodevelopmental disorder characterized by difficulties in social communication and limited, repetitive patterns of behaviour, and activities (American Psychiatric Association, 2013). In 1943, Leo Kanner recognized ASD as a clinical disorder. Before the recognition, children were categorized as “emotionally disturbed or mentally retarded” (MacFarlane and Kanaya, 2009).

The spectrum of autism ranges from low to high with some symptoms being more extreme than others. ASD is usually detected in children by the age of three, where complications are recognized in the area(s) of “social interaction, language for communication, and/or restricted, repetitive, and stereotyped patterns of behaviour” (MacFarlane and Kanaya, 2009).

Challenges caregivers face

When a person is diagnosed with a disability such as ASD, the family members also experience the disability due to the close contact with the person with a disability and their symptoms, termed by the World Health Organization as “third-party disability” (World Health Organization, 2001).

Disability within the family can have a vivid impact on family interactions and functioning across the course of the family life cycle (DeMarle and LeRoux, 2001). Learning that one’s child is autistic can result in a mix of emotions for the parents. A study to see the initial reactions of the parents upon knowing about their child’s diagnosis found that 52% felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame (Banach et al., 2010).

Parents often experience stressful situations when they know about their child’s diagnosis. Stressors from an ASD diagnosis can affect a parent’s marital relationship, increase financial burden and result in parents’ social isolation. Findings show that mothers experience more stress than fathers as they are usually the primary caregivers and are more involved in the child’s daily activities (Dabrowska and Pisula, 2010).

A primary stressor for a parent is their child’s failure to express their basic needs. The parent faces difficulty in understanding the needs of the child, while the child experiences difficulty in expressing their own needs. This results in showcasing aggressive behaviours by the child. Extreme worry may also be present in parents as they fear their child will be abused and harmed due to their vulnerability, and will not be able to report it (Knox, 2000). Feelings of grief can be stressful for the parents as having a child with a disability is compared to that of a “grieving process when a child dies” (DeMarle and LeRoux, 2001). When the ‘typical’ child that the parents expect is no longer a reality, parents are confronted with lifestyle changes and variations in their family dynamics. Hence, parents grieve

the loss of the child they anticipated for themselves and their family.

Stigma is abstracted as a “set of prejudicial attitudes, stereotypes, discriminatory behaviours and biased social structures endorsed by a sizable group about a discredited subgroup” (Corrigan, 2006). However, stigma disturbs not only the targeted individuals, but the people associated with the targeted individuals (e.g., family members, caregivers, and friends). As a result, the associates are likely to develop “affiliate stigma” making them feel “unhappy and helpless” about their affiliation with the stigmatized person (Mak and Cheung, 2008).

Caregiving for children with disabilities is influenced by parents’ willingness and their aptitude to “adapt themselves to ‘informal caregiving careers’, roles that typically span over a child’s life” (Raina et al., 2004). As informal caregivers, parents deliver long-term supervision that demands extensive physical, emotional, social and financial resources. Besides, “they must coordinate their child’s several medical, educational and developmental interventions while corresponding competing family needs” (Silver, Westbrook and Stein, 1998). Studies show that lifelong caregiving for a child with disabilities is linked with poor emotional and physical health in caregivers (Murphy et al., 2007). Caregivers who are impacted the most are those who devote the most hours in caregiving tasks and care for children who are older and/or of high severity in the spectrum (Leonard, Johnson and Brust, 1993).

Adaptation

Despite the challenges parents are facing, they make “necessary adjustment to living with disability” (Stalker and Connors, 2004). Studies find that parents accept the disability as a part of their normality, and living with disability grafts an “understanding of disability as an everyday experience” (Stalker and Connors, 2004). A family’s ability to adjust to its environment is influenced by several factors that include “the

family's resources, interactional patterns, functioning, and transitions through the family life cycle" (DeMarle and LeRoux, 2001). Their early tumult changes to love and acceptance as they get to know the child. The resources to help parents and families with such issues are: identifying strengths in their child, so they see the improvement in their child, instead of the disability, and creating an acceptance to the disability.

A study to check the resilience in the families of children with disabilities showed evidence of family resiliency such as "family connectedness and closeness, positive meaning-making of the disability, and spiritual and personal growth" making the family "stronger as a result of disability in the family" (Bayat, 2007). Specific resilience processes, such as making positive meaning of disability, mobilization of resources, and becoming united and closer as a family, finding greater appreciation of life, and achieving spiritual strength were some of the findings.

Positive Impacts

While most research findings showed a negative impact of being associated with a child with intellectual disability, a study found nine core themes, which include "source of joy and happiness; increased sense of purpose and priorities; expanded personal and social networks and community involvement; increased spirituality; source of family unity and closeness; increased tolerance and understanding; personal growth and strength; and positive impacts on others/community" as positive impacts of having a child with disabilities (Stainton and Besser, 1998). However, "chronic sorrow" was seen as an inevitable result of having a child with an intellectual disability in a study conducted by Olshansky in 1962.

Therefore, a wide range of research to know the impact of disability on family members of a person with an intellectual disability, such as autism, resulted in finding both positive and negative impacts of experiencing disability by association.

THEORETICAL FRAMEWORK

The Double ABC-X model of stress and coping adapted from

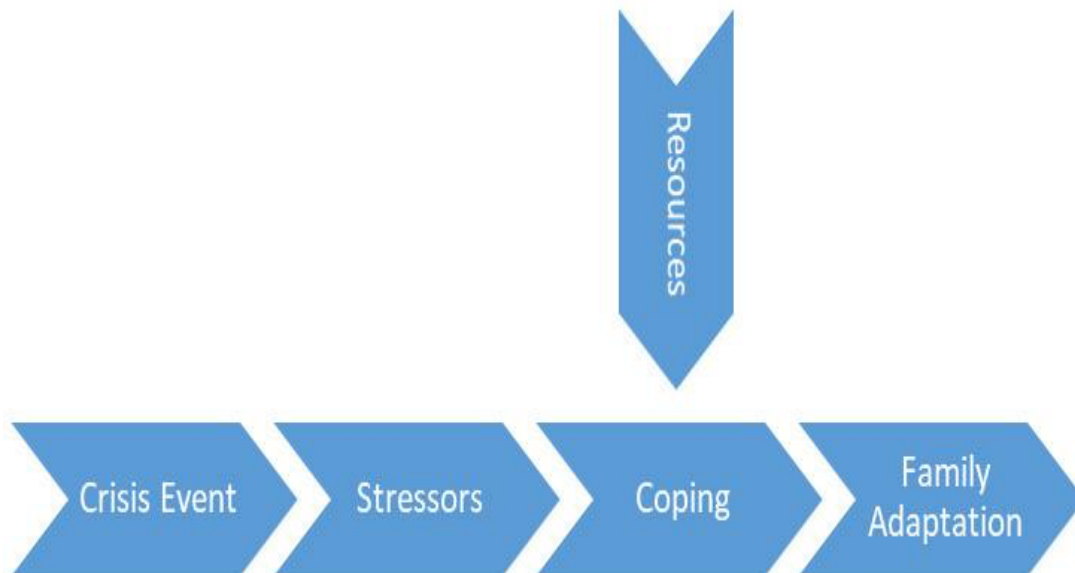


Figure 1: Variables adopted from the model for the study

McCubbin and Patterson (1983) was used for the study. In this model, a parent's ability to cope with a stressful condition is determined by the interaction of the stressor event and subsequent life stressors, family resources, parental perceptions and coping strategies. The outcome of this interaction is the level of family adaptation ranging from severe stress to successful adaptation. Using the Double ABC-X model as a theoretical framework for the study, helped identify the stressors caused by autism for the parents. When the stressors were known, coping strategies used by the family members through the help of available resources were identified and revealed how they adapted to the stressors as the outcome.

The variables used in the study, adopted from the model are Crisis Event (diagnosis of ASD), Stressors (challenges faced by the parents after the crisis event), Resources (support available for the parents), Coping (strategies used to deal with the

stressors) and Family Adaptation (adjusting to living with a child with ASD).

METHODS

Research Method

The study followed a qualitative research method as getting in-depth knowledge about the experiences of the parents in parenting a child with ASD could be best achieved through personal interviews. The Double ABC-X model was used.

Sampling

Convenience Sampling was used to select the 15 participants for the study as it allowed choosing participants based on their availability and willingness to take part in the study.

Participants

From the records of the school administration in Changangkha Middle Secondary School and Draktsho Vocational Training Institute, there were a total of 10 and 20 students with ASD respectively, of which 15 parents who spent most of their time with the child were selected for the study. The participants consisted of 7 fathers, 7 mothers and 1 step-mother of children ranging from 8-26 years old.

Data Collection Instrument

Interviews were conducted using 10 semi-structured questions. The questions were developed based on the objectives of the study, categorized into the five stages drawn from the theoretical framework. However, further questions like “how?” and “why?” were probed as and when necessary to get more details, always taking into consideration the willingness of the parents. Using semi-structured questions allowed the participants to delve into their experiences of parenting a child with ASD without the researcher limiting their expressions.

The questionnaire was pilot-tested through a face-to-face interview with a mother of a child with ASD.

Data Analysis

Content analysis was used to analyze the data as a detailed and systematic examination and interpretation of the data was required. The collected data (narratives) were transcribed and encoded into the different themes and categories that were predetermined using the framework.

ANALYSIS OF DATA AND FINDINGS

Analysis

From the data analysis, three prominent themes representing the stages parents of children with ASD go through were identified as: (a) crisis event, (b) stressor, and (c) coping and family adaptation.

Crisis Event

In this stage, parents discovered at various points in their child's development that something was wrong and began their quest for answers from the health and religious sections. Parents reported mixed emotional reactions when confronted with their child's diagnosis for the first time, which is discussed in the following four sub-themes.

The Quest for Answers

Parents reported that their search for answers began after noticing inconsistent normal developmental milestones in their child such as lack of communication and walking.

My daughter at the age of 2 did not speak a single word and was not able to walk when other children of her age started speaking and walking – Parent I.

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Their journey started with taking the child to the hospital and making visits to monasteries. For some parents, the search for answers was quick, but for most parents, the search for answers took longer.

I took my son to the hospital and the doctor said they think my son has deafness and cannot make an exact diagnosis – Parent A.

Their search for answers led them to take their child to monasteries and lamas.

I took my son to a Lama and he said my son will take longer than other kids to speak. I thought my son would speak eventually but he didn't. Not knowing what was wrong with him made me feel frustrated and helpless – Parent O.

According to Parent C,

the doctor did not tell me my son had autism. I saw 'autism' written in the prescription and had to find out about it myself.

Guilt and Helplessness

Parents felt confused over what ASD meant when first knowing about their child's diagnosis. The concept of autism was new to them. They wondered what they could do as parents to help their child, where they should take him/her and from where to seek help.

I didn't know anything about autism. I didn't know where to take him for treatment...I felt helpless. – Parent A.

After the diagnosis, most parents reported feeling guilty for their child's disability. They blamed themselves for their child's condition and felt devastated.

I felt, guilty. I felt because of the sins I committed in my past life. I'm being punished with a son who has autism" – Parent M.

"I felt sorry for my son. I would see my son and feel devastated for having to pay for my sins and felt guilty for not being able to help and understand him. – Parent C.

Stressors

Parenting a child with autism came with various challenges for parents; it impacted their daily lives, their interaction with society, created difficulty in managing resources and put them under a lot of stressful situations.

Pattern of Life

Parents reported spending all their time on their child's caregiving which left them little or no time for themselves and their family.

All my time is spent looking after my son. I have to be with him all the time...I don't have the time to do anything else. – Parent C.

Communicating with their child was a major issue for the parents making them angry, sad and helpless.

Since he has no language, he gets frustrated when we can't understand what he is trying to say...he gets angry and aggressive. I feel helpless and end up crying. – Parent G.

Parents also reported suffering from health problems like high blood pressure and being beaten by the child.

I have to take medicine for my hypertension because of my son ... I'm tense all the time. – Parent C. "We need to be very alert as his mood changes unexpectedly and hits us when he gets angry" – Parent E.

I even broke my leg because of him (son). It is time for my review but I haven't had the time as when I'm in the hospital, there won't be anyone taking care of him. – Parent C.

Finances and Career

Parents reported changes in their financial situation following the diagnosis of their child. There were increased financial expenses initially as parents tried different ways to treat their child like medical treatments and rituals. Gradually, with not much improvements and limited facilities, they reported stopping with treatments and rituals which decreased the financial burden. However, some parents had to resign from

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their jobs to take care of their child, making the burden of providing for the family solely on one spouse.

I resigned from my job 2 years ago so I can look after him full time. – Parent F.

Initially, there were more expenses as we took her on treatment...now we know there is no cure, so we stopped taking her for treatment. Now, we spend less on her compared to our elder daughters as she does not make many demands like her siblings. – Parent H

Family Relationships

Parents reported that parenting a child with ASD had both positive and negative impacts on their spousal relationship. Some parents reported growth in their relationship while some reported having fights with their spouse.

My husband used to go out all the time not spending time with the family...after my son was diagnosed, he spends time with the family and is more concerned. – Parent A.

On the other hand, Parent K reported, “my wife left me and my daughter after her diagnosis.

Parents reported having a negative influence on their relationship with their other children.

My daughter always complains that we are taking my son’s side when they fight. We have to explain that her brother is not like her and needs more care, but she does not understand and gets angry. – Parent F.

Interactions with Society

Parents reported receiving criticism when going out in public. Strangers believed their child should be disciplined.

People stare at us because of his behaviour...he doesn’t sit still and they tell me I should discipline my son. – Parent L.

While some parents ignored what other people said, some parents confronted them and got into fights.

When people criticize my son, I feel hurt and get angry, and fight back...I had to go to jail one time. – Parent C.

Parents also reported cutting down their social interactions.

When we take him out to a new environment, we feel ashamed as people find him different so we stopped going out in public. – Parent E.

Discrimination and stigmatization did not just come from strangers, but also relatives and teachers.

Even in school, teachers don't treat my son the same as the rest of the children ... and some of my relatives gossip about us. If the teachers and relatives are not inclusive, how can we expect other people to be understanding of our situation? – Parent A.

Future Caregiving

The worry of future caregivers when parents are no longer there for the child was found to be the most stressful for parents.

Our main worry is about his future caregiving. We do not know whether his sister will be able to take care of him...I cannot sleep at night thinking about it” – Parent F. “It is very stressful for us thinking about his future. After we are not there, who will look after him? We have to make him independent anyhow and that is our main goal in life” – Parent G.

Coping and Adaptation

Under this theme, parents reported making use of the available resources to educate themselves about ASD and their child. Implementing diverse strategies helped them cope up with the challenges they face and accept their child as they are, helping them move forward with their lives. However, parents also thought of the future and wondered about the long-term outcome for their child and hoped for changes that would help their child.

Resources

By navigating through the available resources, parents found the school and social support groups helpful. Parents mentioned

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about their child's improvement after being admitted to the school. It helped in developing routines and social interaction of their child. Parent H reported,

I'm very proud that my daughter goes to school like any other child...attending school is improving her social interaction."

Schooling helped him improve, but the improvement is slow and needs constant reinforcement. – Parent K.

However, parents expressed worries about the continuity in their education. Parent H said,

My daughter is about to complete her schooling...I don't know what should be my next step. Other kids go to college after school but there is nothing for my daughter.

Parents reported benefiting from social support groups. In Thimphu, parents reportedly mentioned a social service group called Phensem Group.

Phensem Group gives us ideas through meetings to help and include our children in the society but such activities are not conducted often. – Parent N.

Support from the health sector was not as vivid as autism had no cure.

I used to take my son for treatment but there wasn't any improvement. Since then, I've focused on taking my son to social gatherings organized by Ability Bhutan Society and Phensem Group...it helps in his social interaction...helps me learn about his disability. – Parent F.

Parental Empowerment

Parents reported having scarce information about ASD from the health workers. They mentioned knowing more about ASD from the teachers and school.

Whatever the teachers teach him in school, I reinforce it at home...repetition helps him learn and remember. – Parent C.

However, parents reported they did not limit their learning just from the teachers. They went out joining support groups and learned about ASD by reading articles and watching YouTube videos.

Sometimes what the teacher suggests doesn't work. I then search online to learn the different ways to help my son. – Parent A.

Some parents created their own strategies to cope with caregiving. Parents mentioned maintaining a routine for their child made their lives easier as it helped the child relieve stress by making sense of his/her surroundings. Parents also reported advocating on ASD and volunteering for organizations to help other children with ASD.

I tried a sensory massage technique called the Qigong Sensory Treatment (QST) on my son which I learned from YouTube...it made him calm and establish a routine. Now I'm volunteering for ABS to use QST on other children. – Parent G.

I always try to find out different ways to make him learn, such as promising to give something he likes after he completes a certain task. This forces him to do things and learn. – Parent C.

Acceptance

Parents mentioned the acceptance of their child with the disability is the first step in moving forward. As they accepted their child along with the disability, they started feeling the normalcy in their family lives.

We have to own the fact that this is my child and accept her as she is...I have a responsibility to take care of her and not be bothered by what other people say. – Parent O.

We have accepted that he is going to be like this...be positive and help him for as long as we are there. – Parent F.

It was difficult to accept and move on but we had to as parents. We have accepted that this is what normal is for our family now. – Parent L.

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Positive Impact

Though raising a child with ASD came with many negative impacts, parents also mentioned having positive impacts. Parents reported feeling more united as a family, being more humane and understanding of other people and their situations, and that their child is the source of joy in the family.

Because of my son, I have become a positive and an understanding person...not everyone has the chance of raising a child with ASD...I feel privileged to be raising my son. – Parent D.

To take care of my son, I need support from other people so that way we try to get along with other people making us more involved and helpful members of the community. – Parent F.

My son is the source of joy in the family...a small improvement in him makes us very happy. When my son first said 'baba' (father), it was the happiest time in my life and we kept on trying harder. – Parent G.

Changes

Despite the acceptance of a child with ASD and the positive impacts they have, parents felt the need for the government and people to do more for persons with disabilities. The parents hoped for specialized teachers to teach their child, and training to be made available not just for the teacher and children, but also for the parents to learn how to deal with an autistic child.

Parents also mentioned the need for more awareness in society and orienting people on autism.

Parents need to be trained and taught how to deal with an autistic child. – Parent M.

There should not be a differentiation between children with and without special educational needs...people should be made aware of autism. – Parent B.

DISCUSSION

When first knowing about the diagnosis of ASD in their child, parents have mixed reactions (Banach et al., 2010). Similarly, this study found that parents experienced guilt, devastation, self-blame, confusion, and helplessness initially. However, these feelings changed to love, appreciation, and care for the child over the years. Though changes in feelings were reported, major stressors were experienced while parenting a child with ASD.

The study is answered by identifying the stressors or challenges Bhutanese parents face while parenting a child with ASD. The child's future caregiving worries were identified as the chief stressor for parents as they worried about their child not being taken care of after their death. This shows that Bhutan lacks the educational facility to give children with ASD skills-based teaching. Since the child does not have and/or learn any skills through which she/he can make a living, parents worry about how their child will survive on their own when the parents are no more there to care for them.

Communication issues with the child and the fear of the child not being able to report abuse and harm were also found as shown by studies reporting communication gap being a major challenge for the parents (Knox, 2000). Parents feared their child will be at a higher risk of being a victim of abuse when they are not around.

Family functioning is impacted as a result of ASD in the family, impacting marital relationship and parent-child dynamics (DeMarle and LeRoux, 2001). Similarly, this study found that some parents saw growth and improvement in their marital relationship while some parent's relationship deteriorated after their child's diagnosis. The parent-child dynamics worsened as the siblings felt neglected by the parents as a result of more time spent on the child with ASD. This study also found parents to be socially isolated and had limited social interactions as a result of

'affiliate stigma', as reported in the study by Mak and Cheung (2008). Though the child was stigmatized, the child's inability to process the situation meant that it did not affect the child much. However, the parents were affected as people stared and criticized their child, revealing that parents suffer from affiliate stigma.

Parents assuming the career of informal caregivers leading to poor emotional and physical health was found in this study. Caregivers who are impacted the most are those who devote the most hours in caregiving tasks and care for children who are of high severity in the spectrum (Leonard, Johnson and Brust, 1993). Parents whose children had severe ASD had to resign from their jobs to devote full time to caregiving. Moreover, parents reported suffering from hypertension as a result of putting up with their aggressive behaviours.

The second aspect of the study involved identifying the coping strategies parents use to adapt to living with a child with ASD. Despite the challenges, parents were found to make use of resources such as school and social support groups, and varied coping strategies to adapt to living with a disability such as being positive, establishing a routine, and empowering themselves by learning about it. Parents reported improvement in their child with speech and communication after being admitted to a school. Moreover, parents were found to be searching for answers on their own through the internet as the only resource person for them is the teachers, who are given limited training and at times do not know how to deal with the child. This finding shows that despite the teachers being the immediate resource persons for the parents, they still lack expertise. Therefore, imparting teachers with professional training on not just educating the child, but also on how to help the parents and families, would be much more helpful for the parents. Such an intervention could help the parents reinforce what is taught to the children in school.

Parents reported difficulties in obtaining a diagnosis and accessing information about their child's disability from doctors. The health sector is one of the first places parents visited when they felt something was wrong with their child. However, the failure to give a correct diagnosis and information about ASD to the parents added to the stressors of the parents. The healthcare professionals reportedly only gave a letter that suggests the child's admission to a Special Educational Needs (SEN) School. This shows the health sector's shortfall in orienting the parents about ASD, and the need to diversify the expertise of the health workers through further studies and training. Such measures could prevent the parent's initial stages of feeling confused and helpless besides avoiding the wastage of time in trying to understand what was wrong with their child. Moreover, early interventions from both the health and education sectors would prove to be helpful for both the parent and the child.

Parents also reported that though social support groups helped broaden their understanding of ASD, events are seldom organized indicating the lack of interest and awareness by the community members. It can be concluded that though parents tried to cope using the systems provided by the government and Civil Society Organizations, the services are limited. Parents usually have to empower themselves by learning on their own despite their educational backgrounds. Educated parents reported learning about ASD through articles and videos online, and the uneducated through experience and asking other parents of children with ASD on what strategies worked for their child. However, situations would likely be improved after the implementation of the National Disability Policy on 3rd December 2019 which empowers and provides for persons with disabilities and their caregivers.

Parents also make "necessary adjustment to living with disability" (Stalker and Connors, 2004) to adapt themselves with the disability. The study found that parents accept ASD as a normal part of their lives and make a new meaning of 'normal' in

their lives to adapt to living with the disability. This helped in improving their family functioning, ease their experience of parenting and adapt to living after their child's diagnosis.

Contrary to some of the findings in the literature review, some results of this study were unique to the Bhutanese society. Studies in other parts of the world found that raising a child with ASD resulted in additional financial burden, but this study found otherwise. Parents reported that since there is no cure for ASD, medical expenses were almost nil and, comparatively, they had to spend less on the child with ASD than on their children without ASD. This was found as a result of having limited access to medical facilities in Bhutan, and the child with ASD making lesser demands compared to their siblings without an intellectual disability.

Parents experiencing 'guilt' after the diagnosis of their child as a result of blaming themselves for the sins committed in their past life was unique to the Bhutanese context. While parents blamed themselves and experienced guilt as a result of their carelessness in childcare as found in studies conducted in other countries, Bhutanese parents of children with ASD experienced guilt and self-blame as a result of their sins and did not second guess their caregiving shortfalls. Moreover, parents accepting their child's disability as a normal part of their lives also resulted from their belief of not being able to escape from the sins committed in the past life and accepting one's fate as a way of making amends for their sins.

Generally, Buddhism looks at sufferings including disability from the 'karmic effect' which is the 'law of cause and effect'. Thus, the parents believe that one has to bear the consequences of one's previous deeds. An advantage of such belief is that those with disability are given more care and their welfare is looked after to accumulate good deeds. However, care and help often come as a form of sympathy - feeling sorry for the condition of the person with a disability as a result of his/her karmic deed.

Such perception by the community members can deepen the family's sorrow and add to the 'affiliate stigma' they face.

CONCLUSION AND RECOMMENDATIONS

Conclusion

The study highlights the lived experience of parenting a child with ASD by identifying the events/stages from the diagnosis of ASD to family adaptation. Each theme represents how each stage influences family adaptation as the outcome. Challenges/stressors parents face, the resources they use and the coping strategies they adopt for family adaptation are identified in the study. Future caregiving worries, the experience of affiliate stigma, social isolation, deteriorated marital and parent-children dynamics and time management are some major stressors.

However, the parents cope as they navigate through the available resources like schools and joining support groups. As they accept ASD as a normal part of their lives, parents make a positive meaning of ASD, and implement varied strategies such as establishing a routine to help adapt to the crisis event. Moreover, with not much support from the health and social groups, parents try to advocate for ASD and help other children with ASD through the new strategies they learn on their own.

RECOMMENDATIONS

To better the lives of the parents and families of children with autism and other intellectual disabilities, the following are some of the recommendations:

Diagnosis and Information from the Health Sector

The health sector was one of the first places parents visited to find out what was wrong with their child. However, most children were diagnosed with deafness and in some cases, "Autism" was written on the prescription with the healthcare

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professionals giving no information about the disability to the parents. Therefore, more doctors could be trained for the future so that they could diagnose such cases on time and provide early intervention. Similarly, counsellors could be trained to help both parents and family so that they can overcome their initial stages of grief.

Provide skills-based education

As most parents are worried about the future of their child as a result of not possessing any skills and no scope for further education, it is recommended that students are taught the right skills to earn a living, take care of themselves and continue their education. This would alleviate the worries of parents and family about their child's future and their caregiving.

Provide trained and specialized teachers to teach children with ASD

The government should provide trained and specialized teachers to teach students with ASD, focused on skills-based teaching. This could help children earn a living in the future as it was found that parents worry that their child will have nothing to do and remain idle after the completion of their schooling. Government and Civil Society Organizations could support in this area towards building expertise of teachers for the children with ASD.

Training, counselling and orientation for parents and caregivers

Apart from the training of teachers and educating children, parents and caregivers of children with ASD should also be oriented about ASD so that they know how to deal with ASD and look after their child. The study found that parents spent the initial years feeling helpless and confused due to the lack of awareness and understanding of ASD. Hence, parenting approaches and coping strategies need to be recommended and taught to parents.

Platform to gather and share the experiences of the caregivers

The study found that social support groups benefited the parents as they shared their experiences of raising a child with ASD, but such gatherings were limited. More platforms and timely gatherings should be created so that they can learn from each other and create awareness as caregivers are the best resource persons in dealing with ASD.

Creation of awareness and advocacy:

The community members should be oriented and made aware of ASD to eradicate stigma. The study found that more than the child, the caregivers/parents are victims of stigma and experience affiliate stigma. Hence, awareness programmes should be initiated to create more understanding in society and lessen the stigma. Media including Bhutan Broadcasting Service, Civil Society Organizations and other social support groups could extend their support on creating awareness in the society.

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