

RESEARCH ARTICLE

The Financial Challenges of Parents of a Child with Autism in Addis Ababa, Ethiopia: A Qualitative Study

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Abstract

Little is known about the financial challenges of autism. This study looks into the financial challenges faced by parents of a child living with autism in Addis Ababa, Ethiopia. Twelve in-depth interviews and four key informant interviews were held with the professionals in Joy and Nehemiah Autism Centers. The participants were selected via the convenience sampling method. The data were transcribed and analyzed through thematic data analysis. All the participants underlined that caring for a child with autism spectrum disorder (ASD) requires extra cost, attention, and effort. Most of the participants complained about the financial burden in relation to the cost of fulfilling the basic needs (high cost of food and clothing), transportation, and medical expenses. The system has to proactively work to address the financial and other concerns of the parents. The service is limited and unsatisfactory compared to the need. On the service provision, the government should try and address the different unmet needs and challenges of these children and their parents by providing proper attention and financial support.

Keywords: Autism; Parents; Financial Challenges

Introduction

Autism is a developmental disorder characterized by difficulties with social interactions, social communications and an unusually restricted range of behaviors and interests (Agyekum, 2018). The economic impact of having a child with the disorder is enormous and families with autistic children often experience a strain on their financial resources (Benson & Karlof, 2009; Linares-Gonzalez, 2006; Rogers, 2008). Glendinning (1986) indicated, Most private health insurance plans do not cover all expenses related to therapy and treatment for children with autism, and the payment for office visits and medications often results in huge financial debt. In addition to therapy and medical expenses, there are added economic burdens such as for accessing specialized educational toys, equipment like weighted blankets and vests, and much more (Cited in Hailemichael, 2014, p. 23).

ASD is known to be a costly disorder (New Zealand Ministries of Health and Education, 2008). Autism can place financial strains on parents in several ways. According to Lavelle et al. (2014), the average annual medical expense for a child diagnosed with autism in 2011 was about \$3,020. This cost was 18% higher than

for a child without a diagnosis of autism. The authors further stated the caregiver of a child with autism may face costly prescriptions, emergency room visits, physician office visits, as well as occupational, speech, and physical therapy.

Costs associated with having a child with autism are not only limited to the cost of interventions. Like other forms of childhood disability, parents of a child with autism often face greater outlays of time and money (Aadil, Unjum, Afifa, & Zahoor, 2014). Participation in an extracurricular activity for children with autism also puts additional costs on the family. Thus, caring for an autistic child requires more expense in the provision of care, special education, day service provisions, and family expenses as compared to a typically developing child. Jarbrink, Fombonne, and Knapp (2003) estimated that the total cost of raising a child with a disability is three times greater than the cost incurred in raising a 'normally' developing child. Similarly, according to Girdler and Brian (2012), the expense for a child with autism is more than triple that of a child without autism. Their results indicated that the financial costs of caring for a child with ASD can be associated with adverse effects in the lives of families of children with ASD (Jarbrink et al., 2003). Unfortunately, only a few studies have directly examined the costs that families of children with ASD must face, but rather implied the costs that families of children with ASD must pay.

Having a child with autism resulted in an average of a 14% loss in total family income. It is often extremely difficult for both parents to continue working full-time, which means a reduction in household income to go along with the increased expenses, thus leaving them with a reduction in financial resources during a time of increased financial need. Since many parents need a full-time job to access health insurance, loss of full-time employment can have a dramatic and negative impact on the family's financial situation (McConachie, Randle, Hammal, & Le Couteur, 2005).

The economic concern of parenting a child with autism is very harsh. The cost of caring for a child with autism in Trinidad throughout their lifetime is estimated to be \$3.2 million compared to an estimated \$1.9 million in caring for a normally developing child (Single Fathers Association of Trinidad and Tobago, 2012). The cost is inclusive of medical fees, therapies, special care education, and child care, which is very demanding. This financial burden can lead to more parental stress and burnout. These expenses are extremely high compared to the general income and cost of living in Trinidad (Single Fathers Association of Trinidad and Tobago, 2012).

Furthermore, in the first attempt to comprehensively survey and document the costs of autism to U.S. society, Michael Ganz, an Assistant Professor of Society, Human Development, and Health at the Harvard School of Public Health, found that the approximate cost of caring for a person with autism over the course of his or her lifetime is \$3.2 million and approximately \$35 billion a year is spent to care for all people with autism over their lifetimes (Ganz, 2006). Ganz (2006) broke down the complete costs of autism into two classifications: direct and indirect costs. There are many areas to consider for both classifications. The direct costs can include medical costs, such as physician and outpatient services, prescribed medications, and behavioral therapies that are estimated to cost on average more than \$29,000 per person in a year. There are also direct non-medical costs, which include special education, special camps, and child care which is estimated to annually cost more than \$38,000 for those individuals considered to have lower levels of disability and more than \$43,000 for those diagnosed with more disabling levels of autism.

There are also many indirect costs associated with autism. Ganz (2006) explains costs associated with the value of lost productivity as a result of a person being diagnosed with autism. Lost productivity is the difference in prospective income between someone with autism and someone without. Indirect costs also encapsulate the value of lost productivity for the parents of a person with autism. These costs can include loss of income due to reduced work hours or not working at all. According to the author, the estimated indirect costs for individuals with autism and their parents can range from \$39,000 to nearly \$130,000 annually. Fletcher, Markoulakis and Bryden (2012) interviewed eight mothers of children with ASD to

analyze the costs and benefits related to all aspects of the participants' lives.

Mothers acknowledged several expenses associated with their day-to-day experiences. For example, they all discussed the changes in their work or financial situations that resulted from raising a child diagnosed with ASD. Common expenses such as treatment costs, special dietary requirements, child care, private lessons, and cleaning/repairing homes were all mentioned as additional financial costs these families had to undergo. In addition, mothers mentioned the lack of funds available for family vacations, household renovations, and/or funds for siblings' future educational pursuits. Jarbrink et al. (2003) explained the added financial strain of caring for children with ASD. Costs associated with out-of-pocket expenses and the inability to use formal and informal services were reported as contributing to the strain experienced by the mothers.

With the estimated cost of caring for a child with autism in the U.S., some of the fathers may not be able to provide specialist care for their child and in some cases, the fathers had to quit their job to be full-time service providers for their children (Fletcher et al., 2012). The absence of outside work and low levels of employment are correlated with greater degrees of psychological distress, higher rates of despair, apprehension, and resentment (Gray, 2006).

Possible indicators of such heightened levels of stress consisted of spending a great amount of time caring for a child with autism, limited adult interaction, and lowered levels of income which are linked to increased economic hardships (Datz, 2008). The stress of time constraints, parental responsibilities, and financial burdens commonly lead to worry about necessary resources and the welfare of the family (Linares-Gonzalez, 2006). Generally, parents are the primary caregivers of a child with autism and often must bear the social challenges (stigma and discrimination), psychological challenges (stress and anxiety), and economic/financial costs associated with the behavior, treatment, and care (WHO, 2003). It appears that the challenges families face in connection with the developmental disabilities of children are more serious and complicated in developing countries like Ethiopia (Amakelew, Daniel, & Fasikawit, 2000). People with special needs in developing countries have encountered many problems as governments of many of those countries have never committed themselves to providing various services for these large groups of citizens (Getnet, 2013).

Method

The current study is done through a qualitative approach to gain insight into the experiences of parents of a child with ASD. A convenience sample of twelve parents and four key informant interviews were conducted. The parents were selected through the teachers and professionals in Joy and Nehemiah Autism Centers. The

collected data through in-depth interviews and key informant interviews were transcribed and analyzed using thematic data analysis.

Results

Financial Challenges of Raising a Child with Autism

Financial challenges are articulated as a constraint in their lives. All the participants agreed that caring for a child with ASD requires extra cost, attention, and effort. Hence, caring for autistic children has its own economic consequence. Financial challenges were commonly mentioned by most of the participants. In their caregiving process, parents incurred different kinds of financial expenses. Some of the participants complained about the financial burden associated with the cost of providing everyday basic needs (such as the high cost of food, clothing, and transportation costs). For instance, Belay and Meseret described the extra expense as:

Caring for the child requires extra expense. You need to provide a balanced diet. Unfortunately, he chooses certain types of food, for example, he likes cooked beef. The cost of buying a slice of meat is very high in which we are unable to afford due to our financial burden. I am also unable to afford the clothes, materials for the child's hygiene, and transportation costs for me and the child (Belay).

Having a child with autism plus the transportation cost for medical treatment or therapies and the increasing cost of food is the main financial burden for our family. ...We are using public transport. But it is not convenient for him, sometimes he cries and his tantrums would come when a lot of people are gathered on public transport. Managing his behavior in this situation is difficult. Let alone using a private taxi, using a minibus taxi is of high cost for me. I think the financial constraint is much stronger even than the emotional or social one for me (Meseret).

Two participants had resigned from their jobs to provide full attention and devote time to care for their child with ASD. Quitting a job has forced them to become a housewife which in turn affected the parents' income in being able to provide better care and treatment for their child. In this regard, Zahara explained:

I did quit my job just to take care of my child. I used to be a cleaner in a private company. I have stopped working and became a housewife believing my child requires more attention and care. Now, we are living by my husband's monthly income. Autism has affected a lot on my employment, income, and work.

Others raised the issues of medical costs and extracurricular services (like speech therapy) the child needed. For example, Ruhama shared:

I have spent all my money on medical services and buying medicines for my child. I am leading my life by petty trade. The money I am making is not sufficient for more than paying for the house rent and our food. If I had money, I would look for better care and treatment for my

child. Now I can't afford it and my only option is praying to God to improve my child's situation.

Two participants identified spending large sums of money on the services and treatment of their children.

Umm, in terms of finance, although we did not have many financial challenges, caring for an autistic child is like an investment venture that requires a huge amount of money. It is not easy; [with long out-breath] we have spent a great amount of money on medical services, medicines, special foods (like imported gluten-free diets), therapies, toys, and school supplies. It makes our finances tight. But still, thanks to God, because we have afforded (Abigail).

According to the key informant from Joy Autism Center, autism adds pressure on parents' expenses and contributes to financial constraints and difficulty:

When poverty is attached to autism, it is really difficult and devastating for the parent. A child with autism requires more time, energy, and money than a typical child. The parent falls into the paradox of making a living to survive and at the same time, they were plagued by providing care and support for their autistic children. Sometimes, the mothers would leave their job and employment and rely on their husband's income to provide better care. ...financially, it would also add pressure by requiring additional expenses for feeding, medication, transport, specialized toys, and services. Fulfilling all these needs, especially for a single and destitute parent, is appalling and overwhelming.

Finally, autism has created a financial challenge and pressure on the participants, meaning, almost all the parents claimed an imbalance between what they are earning and what the child's needs or demand creates stress in their homes and lives. The children require more care, effort, and money to teach them skills at home. Hence, the parents need space, toys, and time. Nonetheless, almost all the parents with financial constraints are not living in their own home and usually rent a small affordable house in a compound where other people live. They are also in need of a space to socialize their children in addition to the financial challenges they are facing.

Discussions

Caregiving for autistic children is expensive for parents. According to Saunders et al. (2015), families of children with ASD had a significant level of financial hardship because of their children's special needs care. Jarbrink et al. (2003) asserted that the financial cost of raising a child with a disability is estimated to be approximately three times greater than the cost incurred in raising a typically developing child. Participants of the current study attributed the financial burdens to clothing, food, medication, additional care, and treatment such as speech, cognitive, social skills therapy, and transportation costs. The parents explained that to keep the personal hygiene of a child with autism, extra clothing and sanitary pads are needed daily. In the provision of a balanced diet, the high

cost of food items is also challenging for the parents. Sharpe and Baker (2007) endorsed that many intervention strategies require long hours of one-to-one interaction with a trained therapist, and the use of costly foods or drug supplements. Parents of a child with autism often face greater outlays of time and money than they would for a typically developing child. However, the finding from the authors did not indicate a specific figure for the cost of intervention strategies and interaction with trained therapists.

According to participants of the current study, children with autism have special needs that require enormous investment. Similar to other children, parents need money to satisfy the needs of their children, including a balanced diet, clothes, and other basic needs. Those with relatively better economic status can at least provide the material needs of the children. However, parents with no sufficient source of income are likely to be challenged to meet their children's needs. For instance, findings from Weiss, Wingsiong, and Lunsky (2013) revealed that parents raising a child face different demands that require adequate income. As parents fail to meet these demands, it can lead to a crisis. A study by Dababnah and Parish (2013) in the West Bank stated that parents raising a child with autism experienced financial hardships to meet their children's needs. Myers, Mackintosh & Goin-Kochel (2009) noted that parents mentioned struggles concerning different expenses while raising their autistic children such as costs for therapies, special schools, and special diets. According to Ganz (2006), the lifetime costs of autism including direct and indirect costs have been estimated at \$1.4 million for someone without an intellectual disability and \$2.3 million for someone with an intellectual disability.

The long-term cost of medical treatment and custodial care is also a challenge for parents (Seltzer, Greenberg, & Krauss, 1995; WHO, 2003). Besides the medical cost and custodial care, costs for livelihood and other basic needs are waiting to be covered by the parents. Furthermore, the impact of autism on parents' labor market participation was noted by Gould (2004) who stated one or both parents often must reduce work hours or step out of the labor market altogether (as cited in Sharpe & Baker, 2007). Financial stresses of parents are also linked to costs of unfunded therapies, unexpected costs, and the necessity of having flexible work schedule/loss of

potential earning (Bevan-Brown, 2004; Hastings & Johnson, 2001; Gupta & Singhal, 2005).

Generally, these financial and caregiving burdens led parents to feel embarrassed about their child's condition. In their responses, participants highlighted the financial burdens associated with raising a child with ASD in Addis Ababa, Ethiopia. This finding is similar to the results of Karst and Van Hecke (2012) that revealed ASD has impacts on parents that included financial burden and poor quality of life; and Lai, Goh, Oei, & Sung (2015) who asserted that individuals with ASD and their parents are facing emotional, social, and financial burdens due to the lack of knowledge about the disorder, and inaccessibility of better supports and services among the public.

Conclusion

It is clear that, the parents faced financial constraints. Autism imposes extra and costly expenses to provide a balanced diet, to cover medical therapies, and to pay for extracurricular activities. The participants agreed that they have incurred extra expenses in an attempt to fulfill their child's needs. Besides the expenses, autism affects parents' income; a few parents were forced to resign from their jobs, or work fewer hours to care for their children. Thus, autism hinders some parents from work and puts a huge financial burden on the parents that in turn make their lives bitter and full of grief.

Implications

The findings of this study also demonstrate that facilities designed to accommodate children with disorders such as autism are not easily accessible to parents. Thus, the government and concerned bodies should try and address the different unmet needs and challenges of these children and their parents by providing appropriate care and financial support.

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