



Myths and Misconceptions about Cerebral Palsy: Testimonies of a Coptic Priest from Eritrea

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Abstract

Cerebral palsy (CP) is the most common motor disability worldwide with an incidence of 1.6/1,000 Live Birth (LB) for high income and 3.0033/1000 Live Births (LB) for low and middle income countries(4). Over the past 10 years, there has been rising trends in the number of children with cerebral palsy (CP) in Eritrea; the reasons of which are not clear to date. With the Eritrean family system being restrictive, derogatory and stigmatizing, experiences of guilt and shame from having a child with cerebral palsy is unlikely to be shared. Families therefore, singlehandedly and covertly bear the pains of trauma and ridicules emanating from within and outside of the domestic sphere. Of note, the fear of having another child with similar problem may lead couples to separation, divorce or abstinence from further sexual contact. From the vantage point, the case report discussed hereunder presents experiences of a Coptic family from Eritrea who had a first born child with spastic cerebral palsy of quadriplegic type - Stage 4. The relevance of this case report lies in the absence of experience sharing within the cultural milieu of Coptic Tigrinya ethnics of Eritrea and the lack of therapeutic centers in the nascent nation to helping children with CP and their families to have restored hope and meaningful lives within the mainstream society.

Keywords: Cerebral Palsy; Coptic Tigrinya; Eritrea; Therapeutic Centers

Abbreviations

CP: Cerebral Palsy; LB: Live Births

Introduction

Eritrea being a nascent and war-torn nation, lacks well-developed health infrastructure and trained health personnel [1]. The number of children born with cerebral palsy of varying degrees and intensities have been on the rise, especially over the past 10 years (Eritrea). Cerebral palsy: the focus of this case report like other intellectual disabilities is usually misconceived among the vast majority of Eritrean families. In lieu of medical intervention therefore, various types of traditional healing sources are sought under the pretext that recovery would become a reality someday [2]. It is a widely held view that many people in Eritrea associate CP with intergenerational curse, past sinful acts, divine retribution

and evil spirit possession with similar narratives being the reality elsewhere [3,4]. Ipso facto, concoctions, fumigation with tree barks, animal waste and donkey's heel, water sprinkling, magical spells, blood bathing and related rituals are among the preferred healing sources. In light of the paucity of relevant studies in the area and the presence of wide-ranging misconceptions among families of children with CP and the broader social milieu, this case report is of tremendous significance and a milestone for further studies.

Case Report

Rev. Erimias and Rahel are Coptic couples who married on the 14th of September 2014 and had their first son, named Mishael on June 20, 2015, the birth of the Mishael was of immense delight to the family. But, as the birth of Mishael was on June 20 - Eritrea's Martyrs Day, there were no enough midwives to help Rahel and

other women in the maternity ward. Being her first experience, the event was traumatic to my wife Rahel, and she had no whatsoever clue what to do in that critical moment. Contrary to the expectation of every family member, her delivery was prolonged, painful and strenuous accompanied by intermittent bleeding. For reasons that are not clear to the pediatricians, the baby was asphyxiated and soon encountered permanent brain damage. Pediatricians at Orrotta National Referral and Medical Surgical Hospital therefore, recommended a 10 days' hospitalization and intensive care at the neonatal care which indeed brought promising improvement in the health condition of Mishael.

After discharge from the hospital, Rahel and Rev. Erimias had never been at ease even for a single day in the sense that Mishael's cranial size was small, cone shaped and overlapped, especially on both sides of his temporal lobes. Unlike any normal neonate, his cranium was not delicate, rather hard and stiffened. Three months after his delivery, he began to experience difficulty of breathing and mild spasticity. Having worked as a Project Coordinator for the National Association of Intellectual and Developmental Disability of Eritrea and as a Psychiatric Social Worker at the country's only Neuropsychiatric National Referral Hospital, I had the chance to observe children with various types of disabilities and talk to their families in several occasions. With that foreknowledge therefore, my tension and emotional disturbance was escalating day in and day out. In the aftermath, Mishael was kept under close follow up and overprotection – subjecting both parents to emotional vulnerability. Those days were painful and unbearable as indicated by Rahel's post-partum depression. Soon after, Quarrels, nagging, and exchange of hateful and denigrating words, especially from my side became a daily habit. There were occasions where I used to blame Rahel as if she was the only person responsible for the disability of Mishael.

Although Mishael was in fairly good health condition during the first three months, later on, he began to experience spastic movement accompanied by poor (head control, eye contact, attention and concentration), loud cry, jerky movement on the lower extremities and the head, loss of weight and appetite. Quite often, he used to make a U-shaped turn and had been tossing to and from sides of the bed, mainly because of incessant spasticity, which later became generalized. Overall, his physical and developmental milestone was below expectation.

With a foreknowledge of childhood disability, Rahel took Mishael to a pediatrician and came to know that he was suffering from spastic cerebral palsy of quadriplegic type. Upon return from the hospital, she shared sad news with me and we were literally destroyed and desperate.

In response to the sad moment, both of us wailed for days and associated the disability of our son with bad intents of preternatural forces and wicked human intentions. Presuming that recovery would become a reality one day, we looked for all sorts of healing sources and no stone was left unturned. In nutshell, we used to keep him lie down on the ground and put over him a sand filled sack of about 10 kilograms, anointed him with olive oil so as to keep his muscles relaxed, took him to different holy water sites and bathed him for several weeks. In one holy water site, we were told to leave him unattended for two days as there is a profound belief among the community that God gives a reply whether to heal or kill the patient. Alas! Nothing worked out and we felt that as if everything we did was nihilistic and fruitless.

On the medical side, he was seen by physiotherapists, pediatricians and German Psychiatrists. But none of them were able to make a difference in the life our lovely son. The only thing we were told to do was to perform basic caring practices. Despite all the relentless efforts, the spastic movement and pricking pain showed no signs of abating, rather worsened day in and day out. In the 6th year, Mishael began to suffer from muscle stiffness, clenching teeth, and incessant spasticity. Further, he had significant weight and appetite loss, loss of sleep, pricking pain, crossed legs, and fastened fingers. In the very last of his earthly life, there were occasions where he used to spend sleepless night, mainly because of gross physical pain as indicated by groaning and moaning. Worst of all, food and liquid intake dropped to almost degree-zero level; making him to lose his stamina and vigor, especially a week before his final departure from this earthly planet. As he became emaciated, he passed away on June 28, 2021. A painful and obliterating sorrow on us, but an eternal farewell and relief for Mishael in light of the arduous and merciless pain he suffered from for more than six years.

Discussion and Conclusion

Having grown up among traditionally bound communities and as a Coptic priest, raising a child with cerebral palsy was unbearable and intolerable in whatsoever way. In view of that, I tried to

recall and reckon all sorts of bad deeds I have committed in my past life and associated the incident with divine retribution and/or wicked human intentions. Thus, in fear of having another child with similar disability, I did not dare to engage in further sexual relationship with my wife.

That stated, what I want to bring into the fore here is that there are times where many families receive miraculous healing. After all, there is no doubt that religion has many secrets that science hasn't discovered yet. It is crystal clear that faith and miraculous healing are the quintessence of the vast majority of Coptic Tigrinya of Eritrea. Of note, in a society where people are devout religious practitioners, but with fifty-fifty faith in the worth and efficacy of the current medical system, it is not uncommon to see people going for alternative healing sources in the treatment of developmental delays and motor disabilities. Whatsoever the angle might be, preternatural healing sources and mainstream communities of Coptic Tigrinya ethnics are inseparable parts of a coin. From the vantage point, although at the highest level of secular knowledge and in an age of information technology where present-day society is driven and governed by science and scientific innovation, as a Coptic priest and being grown up in a traditionally bound society, I still hold an unshakable belief in the worth and efficacy of religio-cultural healing sources even for disabilities with known medical causes. Parallel to that, it is worth mentioning that there are plenty of detrimental cultural practices that annihilate the life and life chance of millions of children on the planet. As such, I dare to say that I am still at a cross-road with the ambition to have a share and benefit from both healing sources. Often times, biomedicine and religion are syncretized to form a blended whole treatment strategy among Coptic Tigrinya of Eritrea even this post-modern era.

To make a long story short, as part and parcel of a religio-culturally bound community, what we tried to apply on our son was not something that originated from nowhere, rather deeply enshrined within the broader socio-cultural and religious milieu of the community I grew up; making myths, misconceptions and realities to prevail together to this day in the war-shattered East African state.

Conflict of Interest

The author declares that there is no conflict of interest concerning the publication of this case report.

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