

Original Article

Parents' Perspectives on Family Violence against Children with Autism

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Background: Children are among the most susceptible groups of family violence and this is an important and worrying issue all over the world. Children with disabilities are more vulnerable to family violence. Children with autism are exposed to various types of violence due to their wide range of disabilities, as well as high tensions that are imposed on their families. Family violence against children with autism has not been studied in Iran, therefore, this study was conducted to explain the concept of family violence against children with autism from the perspectives of parents in Iran.

Methods: This is a qualitative research study. Data were gathered using individual and semi-structured interviews. Eighteen parents of autistic children were selected using purposeful sampling. Qualitative content analysis was used to analyze and interpret the data.

Results: Four themes for family violence were defined with 9 sub-categories including physical violence, emotional violence, verbal violence and Sexual violence.

Conclusion: Based on the findings of the present study from the perspective of parents, autistic children need to be cared and educated in a safe environment where they are free from any kind of violence. Their privacy and individual identities are respected, and they are provided with the required treatment and education. These conditions would maintain the dignity of such children and consequently result in appropriate behavioral outcomes. Therefore, it is suggested that a culturally sound, and stable background be provided, which when supported by professional caregivers, will ensure that the rights of autistic children are protected and emphasized.

Keywords: Autism, Children, Family violence, Iran, Parents

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Introduction

Family violence is seen as any physical, sexual or psychological abuse, or the threat of an abuse of that kind, inflicted against an individual by another intimately related to them through marriage or family relations.¹ In all communities, family violence is difficult to investigate as it occurs primarily in the enclosed space of the family environment.² Scientific examinations of family violence started in the United States and have only existed since the 1960s.³ Results from selected Arab countries between 2004 and 2012 showed increase in the presenting rates of family violence.⁴ It is suggested that 29% of children and adolescents in America live in houses where intimate partner violence (IPV) occurs, and an estimated 12% of children (up to age 5 years) have directly experienced physical violence from adults in their home.⁵ The rates of family violence are even higher when IPV is defined more broadly to encompass families experiencing verbal or psychological violence.⁶ According to the Iran's Social

Emergency Department report, 2765 cases of child abuse were reported in 2016 by crisis intervention centers, that 1385 of these were via mobile services, and 1380 by calling 123 (the telephone line for Social Emergency services), and there has also been a high national incidence of child abuse in Fars, Kermanshah, Khorasan and Hamadan provinces.⁷ The types of family violence are physical (intentional use of physical force causing injury, harm, disability, or death), sexual (any sexual act, attempt to perform a sexual act, unwanted sexual words, or advances directed against an individual's sexuality using force), emotional (can humiliate the victim privately or publicly, like name-calling, blaming, managing what the victim can and cannot do, and withholding information from the victim) and verbal violence.^{4,8}

The negative impact of family violence on children is well recognized, however the specific effects of IPV's on children's exposure are not well defined psychopathology. Numerous studies have reported the connections between

IPV exposure and externalizing behavior, traumatic stress, as well as internalizing and social problems among children. Nevertheless, there have been basic variations in the results across different studies considering the types of IPV and also the symptoms associated with IPV.⁹⁻¹² This is perhaps due to the methodological problems. Firstly, there is little agreement among studies on how IPV is defined, that many studies evaluate only physical violence, and others utilize a broader, composite definition encompassing psychological aggression.¹³ suggesting that the effect of other types of violence may be equally important factors to consider.¹⁴⁻¹⁷ While many existing studies have examined the effects of exposure to IPV at school age and adolescence, few studies have evaluated this process at an earlier age. Few studies suggest that pre-school age children are at greater risk of exposure to IPV because of their disproportionate representation in households experiencing physical violence,¹⁸ and they may be equally or more vulnerable to IPV's impact, compared to older children.^{9,11,19} Limited research in this area on younger children is likely due to challenges of distinguishing clinically significant mental health problems from normative types during this developmental period.²⁰ Beside these gaps, little is known about the mechanisms by which exposure to IPV affects young children's development. It is critical to understand and identify young children's exposure-related psychopathology at an early age, before problems become entrenched.²¹

Autism is one of the developmental disorders influencing different aspects of children and their parents' lives. It has been reported that the incidence of autism disorder is between 0.5–1% in each society around the world.²² The prevalence of autism has soared to more than 6%, and this poses challenges for organizations providing healthcare services to children with autism.²³⁻²⁵ Additionally, the characteristic of autism means parents and other family members endure many physical, psychological and social tensions and be burdened with many care responsibilities.^{23,24,26} Hence, it is important to study family violence against these children. Children with any disability, including autism spectrum disorder (ASD), are more than twice as likely to be physically abused as typically developing children. The most common disabilities resulting physical abuse are expressive language disorder and behavioral dysregulation, both are commonly found in children with autism.^{23,27} Based on caregivers report, Mandell et al estimated that 18% of children with autism had been physically abused.²⁷ Reduction of IPV against children with autism is one of the main goals of health systems and society in general. Also explanation and awareness of the factors related to IPV towards children with autism is important for health workers.^{23,24,28} Existing studies on this topic have merely described and examined the stress and adaptive strategies of these parents and little attention has been paid to interpretation and explanations

of the views of parents of children with autism about IPV towards these children.

Violence is a concept related to culture, context, position and individual characteristics. Qualitative studies are based on the social context and culture of each society, therefore these studies can provide an explanation for violence.²⁹ In Iran, the occurrence of violence against children has rarely been investigated due to the sensitivity of the issue in Iranian culture and the unwillingness to intervene in families. In addition, as violence rate against children with disability is high, so conducting a qualitative study to explain the violence against children with autism in Iran is very important. Qualitative methodology is used for this study as it enables examination of different aspects of this issue and provides a better understanding of this phenomenon within a social and cultural context.³⁰

The aim of the study is to explore the concept of family violence against children with autism from the perspective of their parents.

Patients and Methods

In this study, we have sought to explore family violence against children with autism from the perspective of their parents. Therefore, a qualitative methodology was used including a conventional content analysis approach. Content analysis is a systematic and purposeful method for describing and explaining phenomena.³¹

The parents were selected through the purposeful sampling method and were invited to participate in this study. An attempt was made to incorporate diversity within the samples, so that a wide range of parents were considered in terms of age, sex, marital status and their children's diagnosis. The participants were selected from the public centers providing care for autistic children affiliated with the university of medical sciences from November 2016 to July 2017. The inclusion criteria were having the Iranian nationality, having the ability to speak and understand Persian, passing at least 6 months from the definitive diagnosis of autism in their child, willingness to participate in the study, not having acute mental or physical disabilities, and being able to provide rich and sufficient information in the field of study.

Data were gathered using individual interviews. For this purpose, 18 semi-structured in-depth interviews were conducted on 18 parents of autistic children. The interviews were done face-to-face in a private environment with the cooperation and willingness of participants and included a field note recording. The individual interviews initially started with general questions such as "What violence connected with your child, worries you? Can you give an example of family violence?" Then, the next questions were asked based on the answers to these initial questions. There was an attempt to follow the interview process according to the main purpose of the study. Follow-up questions such as "Can you explain more?"

What do you mean?" were also used to increase the clarity of information if it was necessary. The interview duration was 60-90 minutes. These interviews continued until the data was saturated. Saturation occurs when there is no new category and the categories are saturated based on their characteristics and dimensions.³⁰

The data were analyzed using a content analysis method. Initially, each text was reviewed several times allowing immersion in the data, generating insight and creating a sense of the whole of the participants discussion. Then meaningful units were identified based on the purpose and questions of the study. Next, Important topics from the text were extracted in the form of open codes, while taking the explicit and hidden content of meaning units into account. These codes were classified with broader categories based on the differences and similarities and the abstraction process continued until the theme was extracted.³⁰

Lincoln and Guba's evaluative criteria were used to ensure the trustworthiness of the study.³² Allocating sufficient time for data collection, prolonged engagement, maximizing variation in sampling, using member, external and peer checking, negative case analysis and also a team analysis approach were carried out to provide more accuracy.

Results

Eighteen parents of autistic children, including 11 mothers and 7 fathers, participated in this study, with a mean age of 39.27 ± 2.75 years, ranging from 18 to 51 years. The results showed that most of them were female, married with sons and had a high school diploma.

The results of data analysis included 4 themes of emotional or psychological, verbal, sexual and physical violence in 9 sub-categories listed below.

Emotional or Psychological Violence

Regarding to the parents of children with autism, psychological violence is one of the most important forms of violence against these children, leading to the loss of self-confidence in them and reduce their desire to communicate with others. This theme included three categories of isolating autistic children, destruction of the child's self-confidence and neglecting the child's education.

A) Isolating Autistic Children

According to the participants, behaviors such as refusing to communicate, not supporting, communicating with other children without tendency to the autistic children in the game, all make children with autism uncomfortable and involved in their violent behaviors.

B) Destruction of the Child's Self-confidence

Parents participating in the study stated that other people and even family members always criticize these children,

ridicule them, and remind them of their incapacities to learn and take care of themselves.

C) Neglecting the Child's Education

The participants stated that many families do not pay any attention to the educational issues of autistic children and do not pave the ground for their education, going to special schools or even supervise the education of these children, which is the most important type of violence against of these children.

Verbal Violence

Parents who participated in the study said that children with autism need to be safe from any verbal abuse. Verbal violence theme included two categories of verbal harassment and stigma.

A) Verbal Harassment

Verbal harassment is one of the most common forms of ill-treating to these children, usually manifested in behaviors such as shouting loudly, harsh criticism in the presence of others, cursing and malice, lying about the behaviors of these children, attributing inappropriate and inaccurate deeds to these children.

B) Stigma

Parents in the study stated that people attributed offensive labels to these children, including crazy, impulsive, psychotic, retarded and aggressive which makes them distance from others, especially children.

Sexual Violence

Parents stated that one of their concerns regarding autistic children is sexual violence and abuse of these children. According to the parent's perspective, sexual abuse of these children is divided into two categories including touching and looking at the sensitive parts of the child's body and rape.

A) Touching and Looking at the Genitals

The parents of children with autism in the study expressed that forcing the child to be naked, watching, touching or kissing the sexual organs are among obvious cases of sexual violence against these children.

B) Rape

Participants declared that rape is the most terrible and pervasive sexual abuse of autistic children and adolescents, ending more damage to their learning ability and performance.

Physical Violence

Parents stated that the most common violence against these children is physical violence, this theme include two categories of physical neglect and beating.

A) Physical Neglect

Parents participating in this study stated that when parents find that their children are ill with no definite treatment, they sometimes ignore them and do not even pay attention to the basic needs of health, nutrition, sleep and clothing. Parents sometimes leave their children and give them to their grandparents or institutions.

B) Beating

Beating a child following inappropriate behaviors, talking to others about the children and their behaviors and failure to meet the parents' expectations by the child and consequently parental dissatisfaction are the most common forms of violence against the autistic children in many cultures.

Discussion

According to this study, children suffering from autism are subject to physical, emotional, verbal and sexual violence. Some of the violence has been confirmed in other studies as well.^{13,24,33} Nonetheless, none of the other studies have investigated violence against children with autism from their parents' perspectives.

In the present study, the participants stated that physical violence against children with mental and behavioral disabilities is high. Bowen et al. in 2017, also shown that children with mental disabilities are at risk of family violence. In addition, physical violence was the most common form of violence against these children.³⁴ Previous studies have indicated that children with disabilities, including expressive language disabilities, behavioral problems, and/or ASD, are at a higher risk for physical abuse.^{19,35} Studies have also described that children with autism have unusual skin injuries, which when observed in developing children might raise concerns for physical abuse.^{36,37} Slingsby et al in a study on autistic children demonstrated frequent skin injuries in children with significant physical and cognitive disabilities.³⁵

The results of this study confirmed the frequency of physical violence against autistic children. Since physical violence leading to visible marks or injuries, it can be examined and evaluated more easily compared to other types of violence against autistic children. Therefore, many researchers have studied on physical violence against autistic children in other countries. Also, policy makers and managers of health departments in developed countries have taken effective measures in order to reduce physical violence towards disabled children. However, physical violence towards children and specifically disabled children have not been examined enough in Iran, and no governmental organizations support children against physical violence of family members. Apparently, in Iran parents raise their children in any way they like. Sometimes the fundamental human rights and children's rights are respected and sometimes they are not followed,

possibly because there is no support system for children's rights, especially the rights of disabled children in their families. Little information is available regarding physical violence against children in Iran and this point emphasizes the importance of examining and focusing on physical violence against autistic children in Iran.

Another concept of this study was evaluation of emotional violence against children with autism. Although Greene et al revealed that emotional violence has a dramatic effect on children's affections.²¹ The rate of emotional abuse is considered greater than that of physical violence,³⁸ and unfortunately emotional violence has not been properly studied in children with autism.

There have been very few studies completed in order to define and evaluate emotional violence towards children suffering from behavioral and developmental disorders, especially children suffering from autism. The scarcity of such research is perhaps due to the internal and emotional results of this type of violence. However, due to the importance of supporting the autistic children against emotional violence, it is crucial that this concept be examined and evaluated from the perspectives of the caregivers of autistic children, mostly their parents.

Within this study the verbal violence was also confirmed as one of the most common types of violence against these autistic children. Walter et al in their research, emphasized that the verbal abuse as one of the most significant forms of violence against participants.³⁹ Nonetheless, this aspect of violence towards children, especially children with autism, and its impact on the child and the family has not been explained well. On the other hand, violence is a concept related to the culture. In the Iranian culture, having a child with mental or behavioral disorders is considered as a shame or even a disgrace. In addition, many inappropriate or obscene labels are attributed to these families. This stigma afflicts and depresses family members, and it restricts their interactions with others.

Parents who participated in this study expressed that the sexual abuse was among their main concerns. However, given the immense importance of sexual issues in Iranian culture and the tendency to hide it, parents only referred this violence as a concern and did not speak directly about any sexual violence their child experienced.

Many investigations have reported sexual violence against children and specially children with disabilities and revealed that sexual violence affects the onset of puberty, and generates fear and anti-social behaviors.⁴⁰⁻⁴² Monterio et al have shown that sexual violence is one of the most important forms of violence against children from the parents' perspective.³³ In Iranian cultural context, sexual issues are especially important for families and the expectation is that both girls and boys should avoid any sexual contact before marriage. Therefore, any questions regarding sexual interactions are considered as taboo and inappropriate. As a consequence families are likely to try

to avoid confronting any sexual abuse perpetrated on their children, especially as it may be committed by relatives. They also will not allow their children to talk about any such sexual experiences.

Because of these factors it is important that the concept of violence towards autistic children be defined and its different dimensions examined from the parents' perspectives. It helps parents understand and be assured that reporting this type of violence could provide a background for the fulfillment of their children's rights.

All participants in this study were only parents of autistic children who lived in cities and this was a limitation of the present study. Violence is a concept related to the culture and even the difference between attitudes in urban and rural areas can affect the incidence of violence against the child, so violence against the child in rural areas may be different from that in cities, and more studies are needed both quantitatively and qualitatively to explain, identify, and evaluate the factors affecting IPV against children in a variety of environments. Another limitation of this study was the gathering of information using only individual interviews. Utilizing a wider range of information collection methods could lead to a richer outcome. Therefore, it is recommended that further studies on family violence against children with autism be completed using other methods of gathering qualitative data such as observation and focus groups, in addition to individual interviews.

The present study was the first study in Iran to explain and describe the concept of family violence against children with autism. Violence is a concept related to the culture, and it is well documented that children exposed to IPV are at an increased risk for numerous socio-emotional concerns, including internalizing and externalizing problems. However, the mechanisms that create risks are less well understood, especially among autistic children. Recognition and understanding the types of family violence against children with autism is crucial for healthcare workers, including nurses, to reduce the ethical distress on this group of families. Accordingly, the results of this study could pave the ground for further studies regarding IPV in these children and developing specialized tools to measure family violence against these children.

Authors' Contribution

FM, MR, ZM and NZ contributed to the conception, design, data collection, and data interpretation. Then FM, MR and MG wrote and edited the manuscript. All authors read and approved the final manuscript.

Conflict of Interest Disclosures

None of the authors had any personal or financial conflicts of interest.

Ethical Statement

The institutional review board of the medical universities located in the Southeast of Iran provided ethics approval (approval

number: 95-01-08-1168). Also at the beginning of each interview, the researcher introduced herself and explained the aims of this study, and assured that all information would remain confidential, reconfirming that they could withdraw from the study at any time.

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