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Caregiving And Coping Challenges of Mothers with Autistic Spectrum Disorder (ASD) Child

Johnson

Abstract

Families who have children with ASD face many caregiving and coping challenges, as the disorder is associated with disruptive antisocial behaviour. Purposive sampling was used in this qualitative research, where two schools that specifically cater to children with autism were selected. Data were collected using the Coping Health Inventory for Parents (CHIP) to measure the extent to which mothers aware of several coping strategies with the autistic child(ren). The scale comprised 45 items with 3 subscales. The findings highlight the major challenges and difficulties faced by mothers of children with Autism Spectrum Disorders (ASD). The outcomes of the research can help social workers and other practitioners to develop a deeper understanding of the experiences and challenges facing mothers of autistic children.

Introduction

Families who have children with ASD face many caregiving and coping challenges, as the disorder is associated with disruptive antisocial behaviour. Purposive sampling was used in this qualitative research, where two schools that specifically cater to children with autism were selected. Data were collected using the Coping Health Inventory for Parents (CHIP) to measure the extent to which mothers aware of several coping strategies with the autistic child(ren). The scale comprised 45 items with 3 subscales. The findings highlight the major challenges and difficulties faced by mothers of children with Autism Spectrum Disorders (ASD). The outcomes of the research can help social workers and other practitioners to develop a deeper understanding of the experiences and challenges facing mothers of autistic children.

Autism spectrum disorder (ASD) is a neurological and developmental disorder that begins early in childhood and lasts throughout a

person's life. It affects how a person acts and interacts with others, communicates, and learns. It includes what used to be known as Asperger syndrome and pervasive developmental disorders. It is called a "spectrum" disorder because people with ASD can have a range of symptoms. People with ASD might have problems talking with you, or they might not look you in the eye when you talk to them. They may also have restricted interests and repetitive behaviours. They may spend a lot of time putting things in order, or they may say the same sentence again and again. They may often seem to be in their "own world."

Definition

Autism spectrum disorder (ASD) is the name for a group of developmental disorders. ASD includes a wide range, "a spectrum," of symptoms, skills, and levels of disability. People with ASD often have characteristics such as ongoing social problems that include difficulty communicating and interacting with others, repetitive behaviours, and limited interests or activities. These symptoms typically are recognized in the first two years of life, and may hurt the individual's ability to function socially, at school, at work, or in other areas of life. Some people are mildly impaired by their symptoms, while others are severely disabled. Treatments and services can improve a person's symptoms and ability to function. Families with concerns should talk to their paediatrician about what they've observed and the possibility of ASD screening. According to the Centre for Disease Control and Prevention (CDC), around 1 in 68 children have been identified with some form of ASD (NIMH, 2015).

Literature Review

Types of Stress Experienced by Caregiving Mothers

Cousino and Hazen (2013) conducted a

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systematic review of approximately one hundred studies on caregivers' stress from the United States, Europe, and Asia. The authors found that, on average, parents caring for a chronically ill child reported significantly higher levels of general parenting stress than parents caring for healthy children. From the meta-analysis, the effect size for this result was medium, having a Cohen's d of .40. The researchers also reported that stress levels differed by the type of the child's illness; for example, parents caring for children with diabetes or asthma had higher stress levels than those parents caring for children with cancer or cystic fibrosis. However, the research showed that, regardless of the type of chronic illness experienced by a child, the parents of chronically ill children were negatively affected to a greater extent by their caregiving tasks than parents of healthy children. Dabrowska and Pisula (2010) conducted research in Poland and also found differences in stress levels between parents caring for chronically ill versus healthy children. The researchers compared 51 parents whose child had autism, 54 parents whose child had Down syndrome, and 57 parents with healthy children. As predicted, those parents whose child had autism or Down syndrome reported significantly higher levels of stress than parents with healthy children. Further, parents with autistic children reported the highest stress levels in most questionnaire categories. Interestingly, among parents with autistic children, mothers scored higher in stress level than fathers, but no gender difference in stress was found among parents of children with Down Syndrome. Parental stress was also positively predicted by a higher number of children in the family, lower parental education level, and using emotion-focused coping strategies.

Additionally, in Sweden, Lindstrom, Aman, and Norberg (2009) compared the levels of burnout in parents of children with Type 1 Diabetes and Inflammatory Bowel Disease (IBD) against parents of healthy children. Burnout, defined as psychological and physical reactions to long-term strain, was assessed in several categories including emotional exhaustion, physical fatigue, and cognitive difficulties. The

parents of children with chronic disease scored significantly higher in burnout than parents in the control group. Specifically, mothers of the children with Type 1 diabetes or IBD scored higher in most of the eight subscales of the burnout measure than mothers with healthy children. Thus, the research showed that mothers experienced negative long-term physical and psychological effects of caring for their chronically ill children. Further, Compas et al. (2015) surveyed over 400 parents in the midwestern and southern United States to examine their responses to stressors related to caregiving for children with cancer. The researchers found that in response to caregiving stressors, mothers scored higher than fathers on the Beck Depression Inventory II, with 29% of mothers reporting moderate to severe depressive symptoms compared to only 13% of fathers. These findings were significant as they illustrated that mothers caring for chronically ill children appeared to be at risk for developing clinical depressive symptoms.

In Malaysia, however, Saadah, Hajar, and Islam (2014) conducted qualitative research using case studies of five caregiving mothers. From the in-depth interviews, the researchers identified four main types of stress reported by the mothers: financial, emotional, environmental, and health stress. All five mothers experienced financial difficulties, as the demands of caregiving prevented them from maintaining full-time employment. Increasing medical expenses for the children's illness was also a concern. Regarding emotional stress, relationships with spouses and other family members deteriorated due to the significant proportion of time the mothers spent with the ill child. One mother reported that her spousal relationship worsened to the point of physical abuse from, and marital infidelity by, her husband. Environmental stress was also experienced by one mother, who reported receiving no care and support from community members, who instead shunned her, spread rumours about her, and isolated their own children from the mother's family. Additionally, one mother experienced worsened physical health as her own pre-existing illness was compounded

by the physical tasks required to care for her child. Unlike the previously discussed studies, Saadah, Hajar, and Islam (2014) provided a useful qualitative analysis that allowed the mothers themselves to explain, in-depth, the unique stresses they each experienced in caring for their ill children.

Coping Strategies used by Caregiving Mothers

Dabrowska and Pisula (2010) measured the extent to which parents used task-oriented, emotion-oriented, and avoidance-oriented coping styles in response to their caregiving stress. Using regression analyses, the researchers found that for parents of children with autism or Down syndrome, using an emotion-oriented coping style significantly predicted a higher total level of parental stress. Conversely, scoring higher on the task-oriented coping measure predicted a lower level of parental stress. Interestingly, no significant relationship was found between using an avoidance-oriented coping style and parental stress. While Cousino and Hazen (2013) also reported that emotion-focused coping was linked to higher parenting stress, using problem-focused coping was found to be unrelated to stress in the study they reviewed. Saadah, Hajar, and Islam (2014) found that all five women in their sample used an emotion-focused coping style to counteract their caregiving stress. Further, all mothers emphasized the importance of receiving social and emotional support, especially from family members, over the other coping strategies. Receiving assistance with caregiving duties, expressing an understanding attitude, and receiving a listening ear from relatives were highly valued. Other coping strategies reported were self-control and positive reappraisal. One mother exerted self-control by suppressing negative feelings about her situation and using prayer and faith to encourage herself. However, another mother focused on the positive aspects of her caregiving duties, and so became more confident in her abilities to care for her child. Although the mothers reported using emotion-focused coping strategies to alleviate their emotional stress, the nature of the research

study did not allow the researchers to statistically analyse whether the reported coping mechanisms did indeed have a significant positive or negative influence on mothers' caregiving stress.

Compas et al. (2015) surveyed 317 mothers in the United States to examine the relation between depressive symptoms and three types of coping mechanisms. Primary control coping was defined as attempts to change the nature of the stressful situation or one's emotional reaction to it. Secondary control coping included ways of adapting to the stressor, such as cognitive reappraisal and distraction. Disengagement coping referred to attempts to avoid the stressor or to avoid one's emotional reaction to it. While primary and secondary control coping were related to lower levels of depressive symptoms among mothers, disengagement coping was linked to higher levels of depressive symptoms. Han, Cho, Kim, and Kim (2009) surveyed 200 mothers of children with cancer in South Korea. The researchers found that two major patterns of coping strategies were correlated to less psychological distress and less impairment in family and social relationships. These were: the use of family integration, cooperation, and having an optimistic outlook of the situation (coping pattern one); and maintaining social support, self-esteem, and psychological stability (coping pattern two). However, using coping pattern three (receiving information about the child's illness and consulting with other parents and health professionals) was linked to higher levels of maternal stress and dysfunction in family and social relationships. Taanila, (2002) noted that among eight pairs of parents interviewed, the most frequently reported coping strategies were information and acceptance, good family cooperation, and seeking social support. The first strategy involved seeking out information about the child's illness and holding a realistic, accepting attitude towards the situation. Strengthening the togetherness and participation of all family members in caregiving tasks and housework was also noted to help parents cope with stress. Also, parents stated that receiving help from friends, family, and social support services was essential in the coping process.

While both high-coping and low-coping families reported these strategies, the former group appeared to use the strategies to a greater extent. Conversely, almost none of the parents in the low-coping families had strong support networks with family and friends, and household tasks were often unequally managed by the mothers only.

Methodology

Purposive sampling was used in this qualitative research. Mothers who were known to the researcher, as well as two schools that specifically cater to children with autism, were approached to participate in the study. Twenty questionnaires were handed out, of which five were returned. To fit the criteria for participating in this study, the mother must be the primary caregiver and living with the autistic child. Mothers who participated in this study ranged in ages between 29-66 and provided care for at least one other child in addition to the child living with autism. These mothers also ranged across race (Caucasian, Afro, Indo, and Mixed Trinidadians), educational attainment (tertiary, primary, and secondary level education), and income brackets (between \$60 000-120,000 per annum). Their coping and caregiving challenges are reflected in analysis of the CHIP scale used to collect data, in which mothers indicated coping levels to be across the scale; there was no dominant coping level.

The Use of Scale (CHIP)

The Coping Health Inventory for Parents (CHIP) is a 45 item, -3 sub-scale instrument developed by McCubbin et al. (1983) that is divided into: Coping Pattern 1: Family Integration, Cooperation, & Optimistic Definition of the Situation; Coping Pattern 2: Maintaining Social Support, Self-Esteem, and Psychological Stability; and Coping Pattern 3: Understanding the Healthcare Situation through Communication with other Parents and Consultation with the Healthcare Team. Coping behaviours were understood to be extremely helpful, minimally helpful, moderately helpful, or not helpful.

Analysis

Findings reveal that two mothers who found the scale to be minimally helpful scored low in scale two (Maintaining Social Support, Self-Esteem, and Psychological Stability), where they indicated believing things will always work out is not helpful and believing in God is extremely helpful. One mother indicated that having her child seen at the hospital was not possible, while another found this to be moderately helpful. On the question of getting away by oneself, one mother indicated that was not possible, while the other found it was minimally helpful. Both mothers found that engaging in relationships and friendships which help them feel important and appreciated was moderately and minimally helpful, respectively.

On scale three (Understanding the Healthcare Situation through Communication with other Parents and Consultation with the Healthcare Team), low scores were attributed to one of the participants indicating involvement in social activities with friends is not helpful, while the other chose not to do it. Going out with spouses or partners on a regular basis was found to be minimally helpful, and one participant chose not to do it, others deemed reading about how others in their situation handle things was moderately helpful.

Average scores on scale one (Family Integration, Cooperation, & Optimistic Definition of the Situation) were indicated by notions that it was impossible and minimally helpful to believe things will get better and doing things with children was experienced as minimally and moderately helpful. Talking with other parents in the same type of situation and learning about their experiences, as well as reading about the medical problem of concern, were found to be moderately helpful.

The mother whose scores showed the scale was moderately helpful had very low indicators on scale 3 (Understanding the Healthcare Situation through Communication with other Parents and Consultation with the Healthcare Team). She indicated that she found telling herself she had lots to be thankful for and reading

about how others in the same situation handle things was extremely helpful. She chose not to go out with her spouse/partner regularly, engage in social activities, keep herself in shape and well-groomed, or allow herself to get angry. On scales one and two this mother scored average, indicating on scale one that she chose not to do activities to include all family members nor purchase gifts. Doing things with her children and believing the child will get the best medical care possible were classified as moderately helpful. The indicators of extremely helpful for this parent were believing her child will get better, building a closer relationship with her spouse, talking with other parents in the same situation, and sharing her concerns with the doctor, as well as making sure prescribed treatments are carried out at home. Talking to other parents in the same situation, reading more about the problem, and explaining to those around her were also found to be extremely helpful.

The scale was found to be extremely helpful to two participants by above average scores on all three levels of coping patterns. Some indicators were moderately helpful. On scale one, these indicators included believing the child will get better; on scale two, they included getting away by herself, concentrating on hobbies, and talking with medical staff and nurses upon visits at the medical centre. On scale three, going out with her spouse and allowing herself to get angry were moderately helpful.

The scale was found not helpful in some cases and supported by a majority of below average scores in each category of coping patterns. On scale one, one participant indicated two items were extremely useful (believing things will get better and doing things with children); on scales two and three, the participant found that believing things will always work out, telling herself she had many things to be thankful for, and showing her strength were moderately helpful, respectively. All other indicators among the scales were not helpful, not possible, or the participant chose not to use them. (see Table 1-Demographic Representation)

Discussion

It can be agreed that caring for a child with Autism is a challenging job for mothers, especially those who are aging (50 and above), single, separated or divorced, and have other children to simultaneously attend. The pressure and stress seem insurmountable, as apart from their personal challenges, mothers are expected to attend to the many needs of their child with autism. A child with autism according to the literature may exhibit delayed language development, impairment in their ability to relate to others, and restricted patterns of behaviour. These can take the form of self-injurious behaviour, aggression, and tantrums (McCracken et al., 2002). Literature shows that parents of children with autism experience challenges in all areas: stigma, lack of appropriate treatment, financial and caring burdens (Gona et al., 2016), dealing with challenging behaviour, dealing with judgements from others, lack of support, impact upon the family, and coping and the importance of appropriate support (Ludlow, Skelly & Rohleder, 2011), among others.

Mothers' Challenge with Autistic Children

Mothers in this study appeared to face challenges on each item of the scale represented, which showed them referring to coping strategies as helpful, moderately helpful, not helpful, or extremely helpful. While maintaining social support, psychological stability, and self-esteem may appeal to human aspirations, some mothers in this study found it to be of minimal help on their journey. Relationships with friends that reinforce importance and worth in a person were found to be not helpful, which suggests that self-esteem of mothers as well as their social support may be negatively affected and low. Their psychological ability can also be affected when their children cannot access needed care at hospitals, since sometimes the issues are behavioural and there is no immediate treatment at the emergency room for this. Some psychological impacts may also include marital discord, higher risks of depression, and social

isolation (Bashir, Bashir, Lone, & Zahoor, 2014). Mothers indicated their choice not to go out with friends or spouse, purchase gifts for themselves, or plan family activities. Kheir (2012, p 296) posits that “autism imposes burdens on families and forces family members to modify their daily lives to suit their different reality when their child is diagnosed with autism.” This modification can lead to breakdowns in family interaction and relationships if not managed well. Part of the burden can also be encountered due to society’s stigma attached to the disorder caused by societal misconceptions and myths. Sometimes families are judged based on the behavior of their autistic child or sibling, causing shame and hesitancy for integration or seeking out public services that may be useful (Bashir et al., 2014).

Financial challenges can also be experienced among mothers in this study, as most of them indicated their educational level to be at secondary level and earnings at least (\$5000tttd) per month. This may pose strain for mothers who are trying to work in sync with health care providers to ensure their child’s health, since it consist of activities such as maintaining visits to clinics; purchasing special equipment, books, medication for the child(ren); paying for therapy that is not offered within government institutions; fees for special school care and carers at home, etc. In Trinidad there is the Autistic Society, which is a non-governmental organization that seeks to provide support for parents whose children are living with autism. Parents can also apply for disability assistance from the government based social welfare department; however, the allowances when compared to needs of the child seem not to be enough on a monthly basis for a family that earns average wages.

Spirituality (belief in God) was found to be extremely helpful, while labelling all other forms listed on the scale minimal or moderately helpful and can also be seen as a form of resilience among mothers. Given their vulnerability to stress, literature recommends social support (Bashir et al., 2014) for families/mothers with autistic children. The type of social support was not listed, nor was it named by mothers in the study; however, it is noted that social support for

each family may be different based on their circumstances.

Regardless of social class, talking more about the problem to others in the same situation, reading and gathering more information, as well as sharing it, helps. This was found to be a coping theme in a study by Wei and Oei (2014). They also highlighted studies by Susan et.al (2011) based on the chip scale that showed families benefitted from mutual support in stressful times. Mutual aid is the hallmark of social work; with groups where people with similar experiences provide help and support for each other, it is very therapeutic.

It should be considered that the scale used may not comprise items that formed the daily experiences of mothers in its entirety, thereby limiting their options in some answers. It should also be noted that literature used was not derived from a Caribbean nor Trinidadian perspective but reflected wide experiences of autism coping and challenges. This paves the way for more work to be done seeking detailed accounts that will fill the gaps that are now exposed via use of the CHIP scale in the interim.

Conclusion

The study clearly highlights that having a child with Autism Spectrum Disorders (ASD) in a family can result in extreme challenges in dealing with the behavioural problems associated with the disorder. Mothers with an autistic disorder child may experience rejection, hatred, deep sadness, depression, self-blame, helplessness, feelings of inadequacy, anger, shock, and guilt. Family life may be vastly altered if the primary wage earner is unable to work because of taking care of the child or if treatment of the child requires long-term changes in the family routine and activities. Learning how to follow medical instructions, managing medication, working out financial challenges, and adapting to limitations and changes created by the illness all require learning new skills and ways of coping. Those who cope successfully usually have a supportive network of people who help them to maintain a sense of dignity and self-worth.

Procedures

Compliance with Ethical Standards

All participants of this study were asked to sign a consent form of which they were given a copy. Ethical approval was obtained from the Campus Ethics Committee. Ethical protocol was strictly observed by the authors. The researcher kept in mind the sensitive nature of research. Therefore, Biestek's (1961) principles of confidentiality, acceptance, non-judgmental attitude, and client's right to self-determine provided the impetus to facilitate the research process. Emotional issues that came up and had to be addressed urgently were dealt with by utilizing Social Work skills.

Ethical Approval

All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Conflict of Interest

The authors have no conflict of interest in this research.

Table 1– Demographic Representation

Age of Parent	Marital Status	Race	Religion	Education	Annual Income \$	Other Children	Coping Level (CHIP)	Age of Child
66	Married	Caucasian	Christian	Tertiary	60,000-120,000	1	Minimal	36
59	Common law	Afro Trini-dadian	Christian	Primary	NR	1	Moderate	16
54	Divorcee	Mixed Descent	Christian	Secondary	60,000	1	Extremely Helpful	23
38	Divorcee	Afro Trini-dadian	Christian	Secondary	62,000	3	Not helpful	08
29	Separated	East Indian Trini-dadian	Hindu	Secondary	60,000	1	Minimal	10

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