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CASE REPORT OPEN ACCESS

Reducing the isolation: A malaysian family in need

Fairuz Nazri Abd Rahman,Wan Salwina Wan Ismail, Nik Ruzyanei Nik Jaafar, Loh Sit Fong, Shalisah Sharip, Marhani Midin

ABSTRACT

Introduction: Many challenges are faced in the optimum management of a family caring for children with developmental disorders (FCCDD). Case Report: This case report highlights an isolated Malaysian family as victims of discrimination against special children, illustrates the factors and challenges that are associated with it. We report our experience, as part of a multiprofessional team in managing an isolated FCCDD. Our role of service providers, became that of the sole lifeline the family depended upon. We helped the family return from the brink of death; they helped us understand that no family should be an island and every family has a right to optimum care. Conclusion: Isolation that occurs in FCCDD is real and can be influenced by multiple factors such as low education and income. To help an FCCDD is to help Malaysian society overcome its prejudices. Getting FCCDD to participate in decisions regarding treatment and in other bio-psycho-social needs is crucial in helping them prepare for the trials and tribulations of life. Strong awareness must be present in all Malaysian service providers to prevent neglect and mistreatment in this population as well as to effect early and appropriate intervention.

Keywords: Children, Developmental disorder, Family, Multiprofessional, Service provider

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INTRODUCTION

Stress levels of families caring for children with developmental disorders (FCCDD) are high, more so for autism compared to other developmental problems or special health care needs [1]. The same goes for parental depression scores [2]. Discrimination against FCCDD is a grave problem in almost every society, to the extent that some may be driven to suicide. Suicide pacts are rare, only one occurring in four hundred completed suicides, mostly developed out of the dynamics of the relationship between husbands and wives [3]. In spite of the grave consequences, the scenario of such families at risk in Malaysia has not been well studied. In such a country steeped in multiple traditions and cultures, such issues have not been discussed openly, as it customarily also imbues disgrace and dishonor to both the special children and their families. The family suicide pacts highlighted in the media [4] have served as an impetus for psychiatric services to look out

specifically for families with risk factors for such acts and reach out to them actively.

The objectives of this case report are to highlight an isolated Malaysian family as victims of discrimination against special children, illustrate the factors that are associated with it, and outline the challenges faced in the management of a family caring for children with developmental disorders (FCCDD). We present here a case of a family with such risk factors and the measures taken so far in engaging with them and improving their psychosocial support.

CASE REPORT

C, a 36-year-old Chinese housewife with previous history of overdose presented with 6-month history of major depression, mainly stemming from becoming housebound with the care of her special children and her worries regarding husband. She could not get help from her own family because of their own on-going problems. She was treated with fluvoxamine 200 mg ON. The clinician's main concern was patient's suicidal ideation.

Her 7-year-old daughter, G, diagnosed with autism, had defaulted the hospital's occupational therapy and speech therapy, as well as a non-governmental organization (NGO)'s early intervention program. She had marked behavior problems in terms of being clingy, self-injurious behavior and hyperactivity. She was treated with methylphenidate (SR) 20 mg OM and risperidone 5 drops BD, while planned for behavior therapy and re-engagement with special education. C's 9-year-old son, J, diagnosed with pervasive developmental disorder not otherwise specified and attention deficit hyperactive disorder (ADHD), was also treated with methylphenidate while missing government special education because his father was too tired to send him. J had become disturbed and angry by family members' behavior towards each other. C's husband, L, a 39-year-old Chinese snooker centre night supervisor was the sole breadwinner as well as the main transport provider for the family. He was a known case of depression who had been self-medicating himself with alcohol. For the past decade he had been rejected by his own family, believing his past wrongdoing had led to him being cursed with autistic children. Asian society often assumes the misdeeds of the parents brought the misfortune upon their children. L also feared C would one day leave him for another man.

Foreseeing a gloomy future for them and being of absent religious conviction, he contemplated a family suicide pact. They lived in a high-rise condominium.

The family was extremely isolated, with no contact with neighbors nor extended family, language barrier to engagement with Malay-speaking services providers and previous bitter experience with religious groups and NGOs. The family slept during daytime while stayed up at night as they depended on the father for permission and transport for outings. They shied away from the public because of shame regarding daughter's disruptive behavior. So much so they kept to themselves during Chinese New Year while others celebrated with family and friends.

The main focus of management was positive engagement with the family as a whole unit. While each family member was assigned to individual therapy, a family meeting was carried out with a multiprofessional team, including adult and child psychiatrists, psychologist, social worker and community psychiatrist. It became apparent that parent education and training were required to control the children's disruptive behavior and dispel L's myths. Both parents had not completed secondary education. Home visits were planned in light of their suicidal ideation, however only one could be carried out as the family proved to be difficult to contact.

Five years on, many interventions have been attempted. Their suicidal ideation subsided as they became engaged with psychiatric services. However, the therapeutic relationship was challenging in that they mainly came for medication, and outside appointment hours. This behavior and father's false convictions made engagement with other services such as social welfare, education, parent groups, religious groups and NGOs impossible. Eventually both children stopped schooling and L moved the whole family to Borneo due to work commitments. They continue to come every few months for their prescriptions. However, L's mistrust of the outside world continues to limit the development of the other family members. C has learnt to compensate for this by reading self-help books.

DISCUSSION

Features of suicide pacts include social isolation, dependence on one another, unemployment, serious physical illness and being under threat of separation [3]. The family had several of these features, thus in absence of a fully supportive family-centred service network, it was thought unwise to separate the family members by admitting any one of them to hospital. Besides this extreme outcome, adverse outcomes of being children to mentally ill patients are well-established [5, 6]. Such children are at risk of developing psychiatric disorders, poor physical health, abuse and neglect.

Having psychiatric disabilities and co-morbidities such as autism, mental retardation and ADHD places them at higher risk for abuse [7]. This could be due to multiple reasons, such as inability to differentiate between normal behaviour and abusive behaviour, difficulties in reporting due to lack of communication skills, difficulty in being educated regarding issues due to their learning disability and impaired judgement in differentiating 'safe' and 'unsafe' environments and persons. Family factors such as level of income and education contribute to the increased risk of abuse and neglect.

There were barriers to services in terms of provider and patient issues. Provider issues include encounters

with staff and ability/flexibility to accommodate patients' diverse needs. Patient issues include fulfilling basic needs first, cultural and language differences, as well as ability to come, in terms of time, transport and finances. The family's problems in themselves were not impossible to solve. For example, G's challenging behavior could be treated with targeted behavioral interventions and specific medications [8]. The real challenge came in widening social support for the family which traditionally would have included extended family members and neighbors. A way of reducing stigma is via public campaign. One example is 'Changing Minds' by the British Royal College of Psychiatrists [9].

The increased stress experienced by patients and need for support for families require family-centered and culturally-sensitive services [10], especially in Malaysia. Here, there is a clear need for a patient-focused multidisciplinary team delivering a family-centered service [11]. Principles embodied in family-centered services include respect for all families, recognition of each family's strengths, unbiased information-sharing, collaborating with families and empowering them, continuity of care, provision of a family-friendly environment and ability to care for other family members besides the patient [12].

Integrated services between adult and child mental health services are also essential. They need to be responsive depending on the urgency of the situation, all staff trained to support and protect patients and their families. They need to be able to work together in meetings and visits, engage patients and manage crises as well as community interventions [13].

CONCLUSION

In conclusion, the isolated must be given serious attention. Children with special needs can be very challenging for parents and treatment providers alike. We should continuously look for psychiatric problems in patient's family and manage them accordingly. Many barriers stop patients from receiving help and family-centered, integrated services are required.

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Author Contributions

Fairuz Nazri Abd Rahman – Conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Critical revision of the article, Final approval of the version to be published
Wan Salwina Wan Ismail – Acquisition of data, Analysis and interpretation of data, Critical revision of the article, Final approval of the version to be published
Nik Ruzyanei Nik Jaafar – Acquisition of data, Analysis and interpretation of data, Critical revision of the article, Final approval of the version to be published
Loh Sit Fong – Acquisition of data, Critical revision of the article, Final approval of the version to be published
Shalisah Sharip – Acquisition of data, Critical revision of the article, Final approval of the version to be published
Marhani Midin – Acquisition of data, Analysis and interpretation of data, Critical revision of the article, Final approval of the version to be published

Guarantor

The corresponding author is the guarantor of submission.

Conflict of Interest

Authors declare no conflict of interest.

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