

Munchausen by proxy: under-recognition of autism in women investigated for fabricated or induced illness

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Editorial comment

In this brief paper, the authors provide case study evidence to advise caution when making the diagnosis of Fabricated or Induced Illness (FII), formerly known as Munchausen's by Proxy. Professionals often meet parents who have felt blamed or criticised by people working in education, social care and health. These criticisms may relate to how they interact with their child or the way in which they respond to the diagnosis or to the approaches or provision offered. This can occur before and after a diagnosis has been made and in some instances, the parents might be seen as the creators of the child's problems. The authors of this paper argue that mothers with diagnosed or undiagnosed autism might frequently express serious concerns about their child's health and wellbeing. They may also discount and argue against the evidence from assessments and investigations. However, the reasons underlying their behaviour are likely to be different and anxiety-driven and their views may be hard to shift due to the rigidity found in autism. What they lack, and why caution is needed in making the diagnosis of FII, is the intention to deceive or to exacerbate their child's symptoms to gain attention.

The authors argue that great care must be taken by professionals in making the diagnosis of FII and that autism should be borne in mind as a possible explanation for some of the behaviours seen. There are other implications beyond FII, for the ways in which the behaviour of autistic mothers might be misinterpreted or misconstrued. Professionals in services who have little experience of autism can easily draw faulty conclusions from the behaviours seen in parents. The Editor would welcome papers on how services can be enabled to better ascertain and understand parents' perspectives.

Introduction

In a recent presentation by Pohl et al (2016) at the International Meeting for Autism Research (IMFAR) of a study of 325 mothers with autism and a further 91 mothers of children with autism, it was reported that

one in five mothers of an autistic child reported being assessed by social services. They were 100 times more likely to be investigated for Fabricated Induced Illness (FII), previously known as Munchausen-by-Proxy (Department of Health, 2002) than those in the

general population. Furthermore, anecdotal evidence from families of children with autism reports that social care and education may refuse to accept their child's diagnosis and instead investigate parents for fabricating or exaggerating their child's symptoms (eg McNeil, 2014). These figures are significant, and indicate that mothers with autism, and mothers of children with autism, may face stigmatisation and potential discrimination.

Fabricated Induced Illness (FII)

FII is defined as a disorder in which a person is identified as fabricating or inducing illness symptoms in the child, often leading to the child being given potentially harmful medical investigations and treatments. It is considered a form of 'Medical Child Abuse' (MCA). In DSM-5 (APA, 2013), it is termed 'Factitious disorder imposed on another' and consists of falsification of physiological or psychological symptoms in another, or induction of injury or disease in another, and is associated with deception. The individual presents the 'victim' as ill, impaired or injured, and the deceptive behaviour is evident in the absence of obvious external rewards. The behaviour must not be better explained by another mental disorder, or another psychotic disorder. The behaviour is believed to be related to a desire to gain sympathy or attention from others. Epidemiology of FII is unknown, with estimates ranging from 0.5 cases per 100,000 (McClure et al, 1996) through 89 per 100,000 with broader criteria (Denny et al, 2001). In a recent, small-scale study, Ferrara et al (2013) identified as many as 0.5 cases per 100.

Fabricated Induced Illness (FII) and autism

There is little literature on the presentation of FII associated with autism, and where research can be found, it focuses on autism in the child (McNicholas et al, 2000; Blakemore-Brown, 2001). Recently, however, there has been increasing interest in mothers who may themselves have autistic features (the broader phenotype) or have undiagnosed autism. This needs to be taken into account before assumptions are made about the motivation behind a parent's claims about her child. It is widely accepted that there is a strong genetic component in autism (eg Gerdts et al, 2013),

and that awareness and identification in females is limited. Women are often missed or misdiagnosed with other psychiatric disorders (Gould and Ashton-Smith, 2011). Added to this, understanding of FII is varied and limited (Bass and Glaser, 2014), with little information on its psychological or physiological underpinnings, or on the interaction between the person concerned and professionals in services.

Issues in differential diagnosis of FII

There are significant diagnostic dilemmas when a diagnosis such as FII relies on evidence that the fabrication is intentionally deceptive or manipulative, and/or cannot be better explained by another mental health condition. In these circumstances, it then becomes a case of 'if we can't find a reason, then the assumption is that it must therefore be FII' (see eg Day and Mosely, 2010). This immediately presents difficulties if those carrying out the investigation are not aware of, or skilled in identifying, alternative explanations for the presenting behaviours. Furthermore, there is evidence that the majority of cases of FII relate to erroneous reporting of symptoms, and not to illness induction, and erroneous reporting may not necessarily entail active deception (Bass and Glaser, 2014). It may be, for example, anxiety-driven 'Hypochondria by Proxy' where the caregiver uses frequent medical appointments to seek reassurance that their child is healthy (eg Moreira and Moreira, 1998; Lockhart, 2016), or may be due to obsessive compulsive disorder, extreme help-seeking behaviours, or overly-anxious parenting (Schreier, 2004). Comorbid anxiety and associated mental health presentations are common in adults with autism (Mazzone et al, 2012; Bejerot et al, 2014), so the risk for diagnostic overlap is significant.

Potential for the misinterpretation of behaviours observed in autistic mothers

In the case of autism, the risk that a mother who has social communication difficulties and a tendency for rigid thinking styles, potentially coupled with clinical levels of anxiety, may have her behaviours and intentions misinterpreted by professionals unfamiliar with the autistic presentation in adults and particularly in females, is arguably very high.

Three case examples

Details are given here of three women referred for assessment with a putative diagnosis of FII, who were subsequently identified as women with undiagnosed autism. The similarities between the cases, and the differences from 'typical' presentations of FII should help practitioners to explore the possibilities of alternative explanations for abnormal health beliefs reported by caregivers, before jumping to the conclusion that the caregiver has FII. Details are anonymised to protect the identities of the women concerned.

Each of the women had children diagnosed with autism. In addition, each woman shared the following similarities:

- High levels of anxiety and illness worries relating to their children, and to themselves.
- Frequent consultations with both primary and secondary care services.
- Fixed and unshakeable beliefs that symptoms and behaviours seen in their children must have identifiable causes that must be treated to effect 'cure'.
- A tendency towards medicalisation of 'normal' symptoms.
- Maintaining their belief that the child was ill despite evidence from professionals to the contrary. Failure to be reassured by appropriate medical investigations.
- Rigid and fixated thought processes, and often intense or obsessive investigating of symptoms on the Internet.
- Seeking out alternative explanations (and practitioners) for cures, treatment, or continued tests to exclude all illness possibilities.
- Beliefs that vitamin/mineral/hormone or other physiological deficiencies or allergies were responsible for their (or their child's) diverse and non-specific symptoms.
- Significant interpersonal difficulties with medical practitioners and other professionals (eg education professionals, social care, etc). Reference to the mothers as 'rude' 'confrontational' or 'challenging'.

- Negative experiences with and mistrust of professionals such that they present with persecutory style thought processes.

Impact of the mother's behaviour on the child(ren)

An amalgam example of cases is presented to maintain anonymity. At the time of interview, the mother documented a list of problems she had diagnosed in her child, which she presented to her primary care doctor. These included a confirmed diagnosis of autism. Other problems reported were hypermobility, multiple vitamin deficiencies, calcium deficiency, epileptic seizures, multiple allergies and ME (myalgic encephalomyelitis). None of these latter disorders had been confirmed. The mother sought medical help both privately and abroad in order to confirm her beliefs that her child was seriously ill. In order to reduce her anxiety the mother was administering special 'detox diets' to 'cleanse (her child's) insides' and was consulting numerous doctors online to procure specific remedies for her child, none of which were indicated and many of which had serious adverse health risks. In short, she was subjecting her child to unnecessary tests and investigations, as well as bogus treatments, which led the child to adopt an invalid role and avoid school. When the child did attend school, her mother insisted on accompanying her to ensure that she was 'not exposed to unpleasant toxins.' She also demanded that the child took antispasmodics for asthma, which was not medically confirmed.

In all three women a diagnosis of FII was considered by social care professionals as a putative diagnosis and children were either being considered for removal from the family, or had already been placed under a care order. Clinical assessments of the mothers by professionals specialising in autism, using standardised screening and diagnostic tools (ie the Autism Diagnostic Observation Schedule, ADOS, Lord et al, 2000; the Autism Diagnostic Interview-Revised, ADI-R. Rutter et al, 2003; the Autism Spectrum Quotient, AQ, Baron-Cohen et al, 2001, Woodbury-Smith et al, 2005; and the Empathy Quotient, EQ, Baron-Cohen and Wheelwright, 2004) established a diagnosis of Asperger syndrome (AS) in all three women. (Note:

under the latest DSM 5 – there is no longer a separate diagnosis of Asperger syndrome, and it now sits under the diagnostic label Autism Spectrum Disorder).

Similar patterns of behaviour have been noted in a previous case series published over 30 years ago, before autism was widely known (see Warner and Hathaway, 1984). In this study of mothers preoccupied with food allergy and intolerance in their children, the following characteristics were noted in the mothers, which bear some resemblance to the cases outlined above:

- Mothers obsessed with a diagnosis of food allergy in their child.
- Mothers refusal to accept medical advice and opinion.
- Vehement disagreements with consultants.
- Mothers maintained diets for their child against professional advice.
- Potentially adverse effects on the child's life (eg removal from school, submission to dietary restrictions, frequent changes of house).
- Mothers were devoted parents and had not fabricated symptoms in their children.

The key differences between the cases outlined, and those of 'typical' FII, include the lack of evidence of intentional deception or of fabrication/exaggeration of the symptoms. Furthermore, there was no evidence of illness induction, and no desire to gain sympathy or attention from others. The mothers here were concerned only to protect and support their children.

Discussion

The psychopathology of women who involve their children in abnormal illness behaviour is complex, and to date there is sparse data on this topic (Bass and Jones, 2011; Yates and Bass, 2017). In the cases reported here, the preoccupation with physical illness in the mothers (which involved the children) could be conceptualised as a restrictive, circumscribed and repetitive pattern of behaviour that proved difficult for them to change, coupled with a genuine desire to do the best for their

children. None of these women fabricated symptoms in their children, but were rigidly fixated in their beliefs that the children had multiple underlying physical illnesses, and consequently they had been erroneously accused of exaggerating the symptoms due to professionals failing to find any underlying physiological illness. Baron-Cohen (2003) notes that in Asperger syndrome, individuals

“hold their views very strongly and often exhibit black and white thinking....They do not understand one's beliefs can be a matter of objectivity or just one point of view. Rather, they believe that their own beliefs are a true reflection of the world and, as such, that they are correct” (page 147).

All three women presented with high levels of anxiety, particularly relating to concerns for their children, as well as high levels of suspicion towards professionals.

Direct observations by the authors suggest that a diagnosis of Asperger syndrome or autism should be considered in parents referred for assessment when a diagnosis of FII is considered, particularly when the following features are present:

- The child presents with difficulties consistent with autism, or has a diagnosis of autism
- The parent presents with high levels of illness worry/anxiety.
- The parent presents as rigid in their beliefs, and may present as challenging or confrontational with professionals.
- The parent is engaged in obsessive or intense trawling through the Internet for information around the believed ailments in the child.

There are simple screening tools available that can quickly establish the possibility of autism in a parent (eg Baron-Cohen et al, 2001) and these could be easily employed to indicate whether this was indeed a presentation warranting further exploration. The clinical and social implications of failing to identify autism in

the parent in such cases are significant, both in terms of strategies for therapeutic support for the parent and family, and in terms of the risk for the potentially inappropriate removal of the child (eg Pohl et al, 2016). Therapeutic approaches with autistic adults can be successful, but only when used with an understanding of autism (eg Conner and White, 2018; Langdon et al, 2013; 2014).

Concluding comments

The circumstances and events of the cases presented here point to the wider need to educate health, care and education professionals to consider the possibility of autism in parents where there are expressed concerns about the excessive 'medicalisation' of their children. Professionals need to be vigilant and consider all possible explanations for parents' behaviours before moving to suggest FII, in particular when their children have a diagnosis of autism.

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