The Need for a New Approach to the Identification of Fabricated and Induced Illness

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Summary

There has been an increase in the number of parents investigated for 'Fabricated or Induced Illness' - a rare condition where a parent makes up symptoms or causes physical harm to a child. The purpose of these investigations is to find cases where harm is being done to a child through physical abuse, or by parents 'making up' issues because of a need for attention from the medical profession.

Recently, the concept has been widened beyond the original formulation to consider a parent (almost always a mother) who is thought to be causing harm by, for example, insisting on further assessments (potentially traumatic for a child) or being excessively protective, or unnecessarily keeping a child away from school. In addition, children with 'perplexing presentations', where there is no clear medical explanation for symptoms seen, may be considered in need of action as it could potentially be an early stage of FII on the part of the parent.

Professionals are expected to look out for 'warning signs' that someone may be making up or exaggerating problems and report it as a safeguarding issue. Investigations by the medical profession and/or social services are conducted. The majority do not result in a conviction.

There is some evidence to suggest that the use of warning signs as an approach is inappropriate as it creates a significant proportion of false-positives. This is exacerbated by the fact that there are groups of people whose actions, for a variety of reasons, might naturally fall into the description of the warning signs.

Unfortunately, the process of going through an investigation can also cause significant harm to the child. The RCPCH and NICE both acknowledge that the use of warning signs is not yet tested by research.

We are calling upon the RCPCH to:

- look again at their use of terminology and definitions in this area,
- develop the evidence to check for unintended consequences of the current guidance (RCPCH, 2009) and consider the value of moving away from the risk-based approach,
- withhold publication of updated guidance while reviewing the evidence-base, and
- work with other professional groups, such as the British Association of Social Workers (BASW), to update training to reduce the overall harm to children and young people.

Introduction

For some years in the UK we have been hearing about an increase in the numbers of families investigated for 'Fabricated or Induced Illness' – a rare condition where a parent makes up symptoms or causes physical harm to a child.

It used to be the case that accused parents (usually mothers), or 'perpetrators' would be identified as having a motive for doing this – such as having the aim of getting additional attention from medical services.

These days, even if your intentions are good, you can still be accused of FII if you are considered to have exaggerated a child's difficulties e.g. as an 'over-anxious' parent. The reason for concern is that the child could suffer harm: trauma from repeated unnecessary assessments, from being over-protected or missing out on education through being kept off school.

An investigation seeks to determine the truth, but especially in the wider definition this may hinge upon the opinion of medical professionals. As a safeguarding issue and criminal offence, this can result in the child (or children) being taken into care.

There are many more investigations than identified cases of FII. This is problematic given that there is evidence that the investigations themselves can cause significant harm to children and families.

Diagnosis and terminology

Fabricated or Induced Illness (FII) and Perplexing Presentations (PP) are terms used by the Royal College of Paediatrics and Child Health rather than clinical diagnoses. FII is generally considered broader than Munchausen Syndrome by Proxy (MSbP) or the current diagnostic label, Factitious Disorder Imposed on Another (DSM-5) and does not require the intention to deceive.

'Perplexing Presentations' is a new term described in a recent paper by Glaser and Davis as '*where a child is reported to have symptoms or disabilities that impact significantly on their everyday functioning and yet thorough medical evaluation has not revealed an adequate and realistic medical explanation*' (Glaser & Davis, 2019). They suggest that PP may progress to FII, and that early intervention '*may reduce the potential for iatrogenic harm….and may reduce the need for safeguarding interventions'*.

They describe 'alerting signs', while recognising '*While the alerting signs have been widely disseminated, they have not been tested prospectively for specificity and sensitivity'* and in reference to the proposed management of PP and FII state '*the extent to which this can prevent harm to children, or progression to more damaging FII, remains untested systematically*'.

The expectation for medical practice and guidance is that it should be evidence-based, so the lack of evidence in this case is concerning.

Problems of the current approach

Whilst there is of course a need to identify children who are being harmed, the practice of casting a wide net in order to capture every true case unfortunately brings with it a high potential for false positives.

This risk-based approach to identification and early intervention in FII / MSbP leads to a very high proportion of individuals being suspected and investigated but where there is no fabrication or inducement of illness involved. Evidence suggests that cases of FII are rare, yet the alerting signs are quite general and more easily applied to some groups, leading to discrimination and systemic failures. In false positive cases, the process of investigation and the after-effects are very likely to cause harm to children, so it appears that a greater level of harm is being caused by the current process than is being minimised through the correct identification of cases.

Consideration of FII causes harm to parents and children in the immediate and long-term:

- Parent is disbelieved and child doesn't receive need much-needed support
- Conditions remain 'perplexing' with further assessments denied and no final resolution or understanding
- Parents are stigmatised and disbelieved by services in the long term, even if exonerated (investigations remain on record)
- Family stress, already very high because of need for answers and services, becomes trauma as parent is blamed and investigated. This can increase actual and apparent family dysfunction, further leading to risk of children being taken into care
- Incorrectly taking children away from their parent, even in the short term, is exceptionally traumatising for them.

Importance of motive

The original diagnosis of Munchausen's Syndrome by Proxy relies on the parent being motivated to fabricate or induce illness and aware of the consequences. The broadening of the terminology means that motive is no longer relevant, and so well-meaning but over-anxious parents can be included if it is felt that their actions are causing harm to a child. This blurring of the boundaries means there is much greater reliance on 'professional opinion' in determining whether the effect of a parent's seeking of answers or nurturing in a particular fashion, is harmful to the child or not.

In describing 'causes', the NHS highlight that a high proportion of mothers accused of FII are diagnosed with a borderline personality disorder. However, in recent years, new understanding has led to a proportion of women first thought to have the personality disorder being re-diagnosed (when services are available) as autistic.

Alternative explanations

Those with possible neurodevelopmental conditions such as Austism Spectrum Disorder (ASD) or those with multi-systemic conditions such as hypermobility syndrome or Ehlers Danlos Syndrome (in either the parent or child) are more likely to be considered as candidates for investigation because the nature of these conditions triggers the 'alerting' or 'warning signs' as described on the NHS website (last updated in October 2019).

There is no suggestion that caution should be applied in determining whether FII is a possibility when such conditions are present. In practice, even having an existing diagnosis does not protect against an accusation of FII. Despite disproportionately being investigated, there is no evidence of direct connections between these conditions and the likelihood of abuse.

The NHS suggest it is sufficient to look for '1 or more' signs. The signs don't directly relate to the description of 'types of abuse in FII', and NICE state that research is needed to determine whether they are 'valid to discriminate FII from other explanations'. They fail to acknowledge that our understanding of autistic mothers and children (for example) would lead to the prediction of some of these signs (also see Gullon-Scott and Bass, 2018):

Warning sign	**Alternative explanation**
The only person claiming to notice symptoms is the parent or carer	**Children can behave very differently in different settings - 'masking' and the impact of internalising / externalising behaviours are now well understood.**
The affected child has an inexplicably poor response to medicine or other treatment	**There are limited 'treatments' available for some conditions – e.g. hypermobility syndrome and some, such as the PDA profile of ASD, can only be supported well when fully understood.**
If 1 particular health problem is resolved, the parent or carer may then begin reporting a new set of symptoms	**This is not abnormal parenting. The anxious or concerned parent is highly likely to want to check out any behaviours or symptoms of concern. A number of conditions result in a changing pattern of symptoms over time.**
The child's alleged symptoms do not seem plausible – for example, a child who has supposedly lost a lot of blood but does not become unwell	**This assumes the symptoms and their cause have been correctly identified**
The parent or carer has a history of frequently changing GPs or visiting different hospitals for treatment, particularly if their views about the child's treatment are challenged by medical staff	**An autistic parent would be expected to have the potential for intense focus, black and white responses, and a drive to find answers. No parent is happy with being disbelieved, and the greater the concern, the more likely you are to look for answers elsewhere.**
The child's daily activities are being limited far beyond what you would usually expect as a	**This assumes the 'certain condition' has been correctly identified.**

result of having a certain condition – for example, they never go to school or have to wear leg braces even though they can walk properly	
The parent or carer has good medical knowledge or a medical background	**Any parent with a chronically sick child or a child with unexplained difficulties may develop a good medical knowledge. An autistic parent would be expected to have the potential for developing a detailed knowledge, with the potential for intense focus and need for facts / concrete information.**
The parent or carer does not seem too worried about the child's health, despite being very attentive	**An autistic parent may come across somewhat differently to a neurotypical parent, but difference shouldn't imply deficit.**
The parent or carer develops close and friendly relationships with healthcare staff, but may become abusive or argumentative if their own views about what's wrong with the child are challenged	**An autistic parent may come across somewhat differently to a neurotypical parent, but difference shouldn't imply deficit. A parent who has developed a personal level of expertise is likely to challenge when disbelieved.**
1 parent (commonly the father) has little or no involvement in the care of the child	**Single mothers are more likely to be investigated because they don't have a partner to corroborate.**
The parent or carer encourages medical staff to perform often painful tests and procedures on the child (tests that most parents would only agree to if they were persuaded that it was absolutely necessary)	

These 'warning signs' don't tie in well with the specific 'types of abuse in FII' described by the NHS (2109) who state that "previous case reports of FII have uncovered evidence of:

- parents or carers lying about their child's symptoms
- parents or carers deliberately contaminating or manipulating clinical tests to fake evidence of illness – for example, by adding blood or glucose to urine samples, placing their blood on

the child's clothing to suggest unusual bleeding, or heating thermometers to suggest the presence of a fever

- poisoning their child with unsuitable and non-prescribed medicine
- infecting their child's wounds or injecting the child with dirt or poo
- inducing unconsciousness by suffocating their child
- not treating or mistreating genuine conditions so they get worse
- withholding food, resulting in the child failing to develop physically and mentally at the expected rate"

NICE reports a child will be taken into care in almost all cases of physical harm and around half of cases where the mother is only fabricating, not inducing, the illness of the child.

Process of investigation

There is no formal process defined, and therefore there is variation in practice according to circumstances and locality. Experience shows that:

- Accusation of FII is a safeguarding issue and therefore, commonly, social services are alerted, sometimes without a suitable involvement of the medical profession.
- Paediatricians, psychologists and psychiatrists vary in their mind-set and level of expertise which can have a significant influence on outcome.
- Those with perplexing presentations are more likely to have complex difficulties that have not yet been understood than FII, yet once doubt is cast on the parent's believability, it can become impossible to access support and further advice.
- Crucially, a parent is unable to defend themselves effectively as asking for further medical opinions or showing a good knowledge of medical matters is seen as an indication of guilt.
- In court proceedings, the prosecution's assertion that doctors can't provide a sufficient explanation for behaviours is (but should not necessarily be) seen as evidence that the accused is behaving untruthfully.
- Expert witnesses – clinicians – have themselves been targeted and undermined in court for giving an unpalatable (but plausible) clinical explanations.

To summarise

The current and proposed 'Perplexing Presentations and FII Guidance' from RCPCH is likely to be having significant unintended consequences through miscarriages of justice and harm being caused to the disproportionately large number of families investigated.

The lack of evidence for the use of warning signs to trigger investigations, which may have other explanations, is acknowledged.

There is no consensus on question of the need for motive. The widening to include those who want the best for their children and whose actions are being judged by others as inappropriate, is a highly significant step.

Identification of the root causes of complex and perplexing presentations relies on significant expertise, not always available, and sometimes is not possible with our current state of knowledge. The implications of parental autism are not recognised as a source of misunderstanding and the innate difficulty of diagnosis in multi-systemic conditions which cross over medical specialties are not acknowledged with no safeguards in place to prevent potential miscarriages of justice.

Solutions

Professionals suggest that there should be consideration of a move back to the position of assessing for diagnosable conditions in the parent such as the current DSM-5 Factitious Disorder Imposed on Another. Consideration of FII should be on the basis of specific concerns around physical harm and not only issues such as the regularity of accessing services or a failure to attend school; a review of the relevance of intent is needed.

The approach of using warning signs to trigger an investigation could be changed, instead these signs could trigger a determined effort to understand underlying causes and provision of appropriate support to the family in a co-operative and blame-free manner. Where neuro-developmental conditions are a factor, effort should be made to avoid stigmatisation, and to recognise that a level of expertise is required to support and unpick difficulties.

The process may include support to reduce maternal anxiety, to understand her point of view and to explore new ways of meeting a child's needs; putting the child at the centre but using an alternative, open mind-set.

The guidance suggests that an investigation into FII involves the responsible Paediatrician doing a chronology. Such an investigation could be done as part of a positive attempt to understand the family's difficulties, indeed a chronology should be part of any good diagnostic assessment. If conducted with the mind-set of 'the explanation is <u>unlikely</u> to be FII' the family are likely to be benefited rather than harmed.

A common cause of repeat visits and complaints is the major systemic problems of assessment and diagnosis in this country. As such it can be the professions themselves which create the conditions for the suspicion of FII. Increasing use of integrated pathways, improved pre-registration training, and better development of and availability of specialists will help.

In addition, in the world we live in now, the likelihood of a parent being highly educated on their child's condition should be welcomed and worked with, and not seen as a problem, even when their conclusions are incorrect.

We are calling on the RCPCH to work with professionals across the sector to look at the existing evidence and work on developing an improved evidence-base.

More specifically, to:

- look again at their use of terminology and definitions in this area,
- develop the evidence to check for unintended consequences of the current guidance (RCPCH, 2009) and consider the value of moving away from the risk-based approach,

- withhold publication of updated guidance while reviewing the evidence-base, and
- work with other professional groups, such as the British Association of Social Workers (BASW), to update training to reduce the overall harm to children and young people.

Glaser, D. & Davis, P. (2019) Forty years of fabricated or induced illness (FII): where next for paediatricians? Paper 2: Management of perplexing presentations including FII. *Archives of Disease in Childhood*, 104, 7-11.

Gullon-Scott, F.J. & Bass, C. (2018) Munchausen by Proxy: Under-recognition of autism in women investigated for fabricated or induced illness. *Good Autism Practice*, 19 (2), 6-11.

NHS guidance (updated Oct, 2019)

NICE Child maltreatment: when to suspect maltreatment in under 18s Clinical Guideline CG89 Last updated October 2017

RCPCH (2009) Fabricated or Induced Illness by Carers – A Practical Guide for Paediatricians

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