Royal College of Paediatrics & Child Health

Guidelines on

Perplexing Presentations & Fabricated or Induced Illness

RCPCH's Rationale

This guidance proposes that, in the absence of clear evidence about risk of immediate serious harm to the child's health or life, the early recognition of possible FII … is better termed Perplexing Presentations, requiring an active approach by paediatricians and **an early collaborative approach with children and families**. It is important to recognise any illnesses that may be present, whilst not subjecting children to unnecessary investigations or medical interventions, always bearing in mind the fact that verified illness and fabrication may both be present. The **advice of colleagues is always helpful and tertiary specialist opinion may be very helpful** if these specialists are provided with the holistic picture before assessment.

RCPCH's Aim

The aim of the guidance is to recommend early recognition and intervention in order to explore the possible causes of a perplexing presentation. There is a need to establish whether perplexing presentations are fully explained by a verified condition in the child, or whether there has been some element of exaggeration or fabrication of illness with consequent physical, emotional, social or educational harm to the child.

New definitions

MUS	Medically Unexplained Symptoms
PP	Perplexing Presentations
FII	Fabricated or Induced Illness

Medically Unexplained Symptoms (MUS)

The child’s symptoms, of which the child complains and which are genuinely experienced, are not fully explained by any known pathology but with likely underlying factors in the child (usually of a psychosocial nature), and the parents acknowledge this to be the case. The health professionals and parents work collaboratively to achieve evidence-based therapeutic work in the best interests of the child or young person.

WHY THE TERM MUS WAS DROPPED FROM DSM-5

MUS was dropped from DSM-5 because:

- "… medical diagnosis does not usually define a disorder based simply on the *absence* of something. Instead, disorders are defined according to the presence of certain positive features."
- "the reliability of assessing whether or not there is a medical explanation for somatic symptoms is notoriously poor. … indeed some MUS are not so much "Unexplained" as "Unexamined."
- "just because a disorder is not medically explained does not mean it is a psychiatric disorder"

Perplexing Presentations (PP)

Presence of alerting signs when the actual state of the child's physical/ mental health is not yet clear but there is no perceived risk of immediate serious harm to the child's physical health or life.

Fabricated or Induced Illness (FII)

FII is a clinical situation in which a child is, or is very likely to be, harmed due to parent(s’) behaviour and action, carried out in order to convince doctors that the child’s state of physical and/or mental health or neurodevelopment is impaired (or more impaired than is actually the case). FII results in emotional and physical abuse and neglect including iatrogenic harm.

GUIDANCE IS NOT EVIDENCE -BASED

- No epidemiological evidence – previous research seriously flawed
- No evidence on accuracy & precision of diagnostic tests
- No evidence on how the issues progress
- No evidence on efficacy and safety of therapeutic, rehabilitative, and preventive regimens.

LACK OF AN EVIDENCE BASE

We also considered the limited published evidence on prevalence and management of FII. In the absence of published evidence, we relied on extensive consultation and expert consensus from those with extensive clinical experience of managing these conditions.

ALERTING SIGNS IN THE CHILD

- Reported physical, psychological or behavioural symptoms and signs not observed independently in their reported context
- Unusual results of investigations (eg biochemical findings, unusual infective organisms)
- Inexplicably poor response to prescribed treatment
- Some characteristics of the child's illness may be physiologically impossible eg persistent negative fluid balance, large blood loss without drop in haemoglobin
- Unexplained impairment of child's daily life, including school attendance, aids, social isolation.

ALERTING SIGNS IN THE PARENT

- Parents’ insistence on continued investigations instead of focusing on symptom alleviation when reported symptoms and signs not explained by any known medical condition in the child
- Parents’ insistence on continued investigations instead of focusing on symptom alleviation when results of examination and investigations have already not explained the reported symptoms or signs
- Repeated reporting of new symptoms
- Repeated presentations to and attendance at medical settings including Emergency Departments
- Inappropriately seeking multiple medical opinions
- Providing reports by doctors from abroad which are in conflict with UK medical practice
- Child repeatedly not brought to some appointments, often due to cancellations

ALERTING SIGNS IN THE PARENT

- Not able to accept reassurance or recommended management, and insistence on more, clinically unwarranted, investigations, referrals, continuation of, or new treatments (sometimes based on internet searches)
- Objection to communication between professionals
- Frequent vexatious complaints about professionals
- Not letting the child be seen on their own
- Talking for the child / child repeatedly referring or deferring to the parent
- Repeated or unexplained changes of school (including to home schooling), of GP or of paediatrician / health team
- Factual discrepancies in statements that the parent makes to professionals or others about their child's illness
- Parents pressing for irreversible or drastic treatment options where the clinical need for this is in doubt or based solely on parental reporting.

PROBLEMS WITH THE ALERTING SIGNS

- No evidence base
- Problems with Diagnosis
- Many of the alerting signs will be found where children have undiagnosed illness or unusual presentation
- Lack of gold standard diagnostic test means high likelihood of false positives

SOME IMPROVEMENTS SINCE EARLIER VERSIONS

"Alerting signs by themselves do not amount to fabrication but mandate further investigation to ascertain whether the child has an underlying illness."

"When paediatricians become concerned about a perplexing presentation, an opinion from an experienced colleague needs to be obtained and a tertiary specialist may be necessary. Parents themselves may request another opinion and it is their right to do."

"Alerting signs are not evidence of FII."

"A single alerting sign by itself is unlikely to indicate possible fabrication. Paediatricians must look at the overall picture which includes the number and severity of alerting signs."

WHAT SHOULD THE PAEDIATRICIAN DO

- Collate all current medical/health involvement in the child's investigations and treatment, including from GPs, other Consultants, and private doctors, with a request for clarification of what has been reported and what observed.
- Ascertain who has given reported diagnoses and the basis on which they have been made, whether based on parental reports or on professional observations and investigations.
- Consider whether further definitive investigations or referrals for specialist opinions are warranted or required.

ISSUES WITH RCPCH GUIDANCE

- Chequered history with serious false accusations - Meadows
- Treats a multiple of separate issues as if it is all the same thing
- False positives
- No evidence base
- Concerns about proposed program of treatment

Hopeful Signs

NICE draft guidance on ME challenges RCPCH alerting signs and use of graded exercise

British Association of Social Work producing its own FII guidance

RCPCH's recognition of lack of evidence

Chief Social Workers' recognition of too many children being brought into care and tendency to use child protection approach to disability

Review of children's social care

Increasing recognition of Experts by experience

Media interest

WHAT CAN BE DONE

- Follow example of ME and challenge through NICE
- Try to influence local response – lobby, campaign, co-produce
- Look for opportunities to campaign nationally
- Contact Children's Social Care Review
- Support each other on individual cases
- Identify good solicitors and friendly social workers
- Identify allies
- Support the parent and carer alliance
- Develop advocacy service