Guidelines For The Management Of Children In Relation To Fabricated Or Induced Illness

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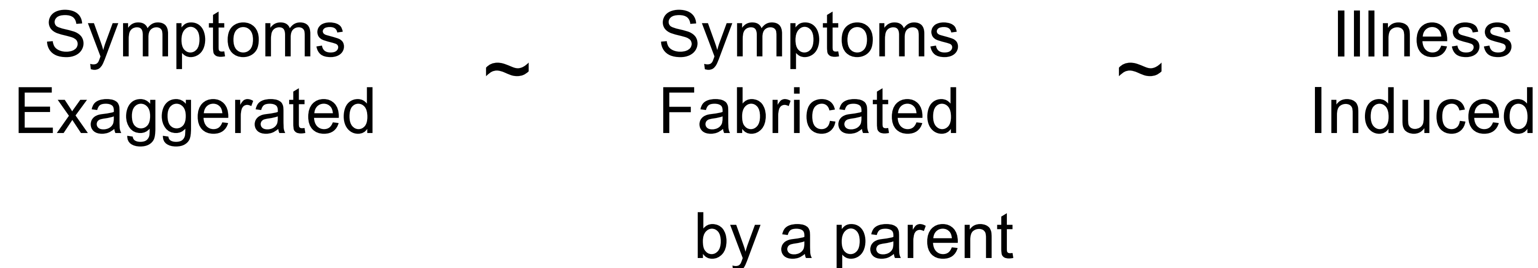
The presentation overview

Guidelines address the management of children in whom there is a concern that:-



Based on guidelines from Sydney Children's Hospital & Women's & Children's Hospital, Adelaide.

Reference to:-

RCPCH – Fabricated or Induced Illness by Carers (2002, 2003)

UK DoH - Safeguarding Children in Whom Illness is Fabricated or Induced (review of 2002 guidance within NHS)

Terminology

Munchausen Syndrome by Proxy

Meadow, 1977

Fabricated or induced Illness (FII)

RCPCH, 2002

Position Paper: Definitional Issues in Munchausen by Proxy (Pediatric Condition Falsification [PCF])

APSAC Taskforce on Munchausen by Proxy, Definitions Working Group, 2002

Fabricated or Induced Illness

The manifestation of parental behaviour (namely the reporting of symptoms that don't exist or the induction of symptoms which suggest that a disease exists – known or unknown) that has harmed or has the potential to harm a child.

Categories of Fabricated or Induced Illness:-

- Fabrication

  Symptom exaggeration, symptom pre-occupation

- Induction

  Active production of symptoms (eg haematuria) or disease (eg septicaemia)

Fabricated or Induced Illness

- FII can cause harm in a number of ways:

  Direct harm through symptom induction

  Unnecessary and sometimes dangerous medical investigations or treatments

  Removal from school and other developmentally enhancing activities due to ‘illness’

  Psychological effects on the child of being regarded as sick
- Not a diagnosis – no-one ‘has the disease’:

  The term diagnosis should be restricted to a specific condition. The ‘condition’ may or may not be a disease. Eg haematuria caused by the addition of blood to a urine specimen is a condition, haematuria, rather than a disease. A disease can also be induced; for example septicaemia induced by the injection of faecal material is a disease.

Fabricated or Induced Illness

- Best not referred to as a syndrome.

  The term syndrome describes a concurrence of several Symptoms (signs) which are manifestations of a particular condition.

  In FII the term syndrome is not applicable in relation to;

  - *the presentation (of induced or fabricated symptoms [signs])*

    There is no consistent cluster of symptoms (signs) which reliably indicate that illness induction or symptom fabrication has occurred.

Fabricated or Induced Illness

- *the behaviours of the suspected perpetrator.*

  There is no reliable cluster of behaviours uniquely associated with fabricated or induced illness. Using the term syndrome to describe the behaviour of illness induction or symptom falsification implies that the suspected perpetrator has a disease (an implied psychiatric diagnosis). No such 'disease' exists.

- *the psychological characteristics of the perpetrators.*

  Attempts to create a 'profile' of psychological characteristics of perpetrators have been unsuccessful.

Fabricated or Induced Illness

- There is no clear answer as to whether or not fabrication ever proceeds to induction.
- Verbal fabrications may occur over many years and not progress to illness induction attempts.
- Fabrication is present in most cases of induced illness.
- Induction produces direct and often serious physical harm (apart from the secondary harm of medical investigations)
- Fabrication or induced illness can co-exist with an underlying medical condition in the child.
- Cases of induction are more directly physically dangerous, cases of fabrication can be more difficult to assess (eg induced hypoglycaemia compared with multiple reported seizures).

Fabricated or Induced Illness - Symptom Exaggeration

Symptom Exaggeration refers to the embellishment of true symptoms (which in reality do indicate the presence of a disease, for example asthma, epilepsy).

Symptom exaggeration is considered to be more common and on average, more benign than symptom fabrication (which refers to the false reporting of symptoms which, in fact, do not exist).

However whenever symptom exaggeration occurs it needs to be assessed in relation to whether it's directly harming the child and for its potential to harm the child.

Fabricated or Induced Illness - Symptom Pre-occupation

Symptom pre-occupation - a situation where a parent insists that a real symptom is more important or dangerous than it is medically considered to be.

- It is not clear whether symptom preoccupation might be a precursor to induction of more serious symptoms to support the parent's preoccupation (eg stopping anticonvulsant medication $\therefore$ increasing seizures to support the assertion of severe epilepsy refractory to treatment).

- Symptom pre-occupation damaging in its own right by leading to dangerous interventions and/or restrictions of the child's lifestyle ('allergic to the world').

Fabricated or Induced Illness

Symptomatology

Fabrication or illness induction can simulate almost any disorder.

Symptomatology has been identified in each of the major body systems. No system is ‘most represented’.

Fabricated or Induced Illness

Epidemiology

BPSU study

0.4 per 100,000 children <16yrs per year

2.8 per 100,000 children in first year life

One UK health district 65,000 children <16yrs over 2 yrs

(excessive seeking of healthcare, abnormal illness behaiviour caused concern of harm to the child)

45 per 100,000

NZ study

2.0 per 100,000 children <16 yrs per year

The Basis for Concern – Could this be FII?

General Comments

- Potential for misrepresentation by a parent in any presentation of a child for medical attention.

- The task of identifying injury suspected of having been inflicted is relatively straightforward, most often based on the lack of an adequate explanation.
- The complexity and range of medical presentations precludes the straightforward development of a suspicion of FII.

The Basis for Concern – Could this be FII?

Guidance to the development of concern

- Clinical progress of the ‘condition’ doesn’t make sense
- Clinician uncomfortable with the clinical situation
  - the manner of the presentation
  - ‘apparent’ diagnosis (eg symptoms of epilepsy, no fits)
  - child’s clinical course
  - Parent response to process of investigation and medical decision making
- Treatment ‘failure’ that is not plausible
- Intrusive investigations or treatments very readily accepted by parent; parent suggests others with enthusiasm
- Parent becomes actively involved with the ‘treatment team’

The Basis for Concern – Could this be FII?

Situations where particular care is needed in assessment

It may not be appropriate to sustain a suspicion of FII when

- Parent has impaired cognitive ability, particularly when this predisposes to hostile interactions with clinicians
- Issues such as compensation claims, parental incompetence ('covering up' behaviour), using 'illness' to gain access to services (eg housing)
- High levels of overt parent anxiety
- Parent hostility towards the health system
- Initial medical response overzealous because of diagnostic uncertainty (in paediatric practice generally, in 9% of inpatients and 24% of outpatients no confirmed diagnosis is able to be made)

Process for Assessing Concerns of FII
The Development of a Suspicion

Preliminary issues

- The clarification and establishing of a suspicion of FII is protracted & difficult

- The primary focus must constantly consider the child’s welfare (health and development) as well as safety.

Process for Assessing Concerns of FII
The Development of a Suspicion

Preliminary issues (contd)

At any stage in the assessment there may be:

- A need to protect the child (including urgent action). This requires the active involvement of the State statutory agency (hence the importance of a timely notification)

- A realisation that the symptoms have not been fabricated or induced. It is inevitable that some children will be rightly investigated over concerns about FII but are found to have organic disease.

Process for Assessing Concerns of FII
The Development of a Suspicion

Preliminary issues (contd)

Because symptoms are sometimes considered not to have been fabricated or induced:-

- The assessment process must incorporate mechanisms to minimise stress for the child, carers & professionals involved.
- The child will need appropriate treatment with support to the family and continuing medical review (in consultation with family and child).
- The ongoing needs of the family must be assessed and services provided.
- Those who first became concerned should be supported, their initial views respected and not criticised.

The Initial Concerns - 1

Concerns rather than Suspicions

(this distinction is necessary because of mandatory reporting requirements)

- Concerned non-paediatrician health professionals refer the child to a paediatrician (who will address the concern & resolve it or sustain the suspicion).
- Concerned paediatricians refer to a tertiary paediatric facility - to an appropriate generalist or sub-specialist.
- Tertiary facility paediatricians consult with a child protection paediatrician (before notification).
- The child protection paediatrician oversees the assessment without having initial direct contact with the child or the parent.

The Initial Concerns - 2

Occur in a nurse, GP, general or sub-specialist paediatrician, less often in a non-health professional (teachers or police).

The individual with the initial concern will need to decide whether a child protection notification should be made, in the first instance;

- Non-health professionals with **suspicion** of FII should notify (because they are outside the health system & have limited access to specialist advice). Consultation regarding concerns may help clarify the situation but notification of the concern

- Health professionals who are **suspicious** that FII is present should notify (mandatory reporting requires this).

The Initial Concerns - 3

Child protection paediatricians should support the <u>suspicion</u> of others and therefore endorse their notification.

Subsequently the child should be referred by the statutory agency to a child protection paediatrician for a comprehensive investigation, supported by the agency

The Initial Concerns - 4

Concerns rather than Suspicions

It may be necessary to make an urgent notification before the suspicion has been consolidated because of the possibility of the child being exposed to an unacceptable level of danger, eg

- situations of possible illness induction
- threats being made to remove the child to another hospital or to the care of another doctor in another location.

In such situations the subsequent, necessary assessment becomes very difficult but transfer of the child to the care of another paediatrician should be avoided.

When transfer is insisted upon by the parents then the statutory agency should be asked to intervene.

Assessing the Concerns

This process is used when:

- There has been a referral to a child protection paediatrician by the statutory agency because of a notified concern or suspicion – the parent will know of the notification.

- A concern has arisen in relation to a child under the care of a paediatrician (usually in a tertiary institution) – generally the parent will not be aware of the concern until it becomes a suspicion and a notification is made.

Primary aim of the process is to
EITHER
resolve the concern
OR
consolidate the concern into a suspicion,
which then leads to a notification

Issues of Documentation in Hospital records 1

1. Objectivity in the hospital file
   - Avoid labels such as MBPS or factitious illness. Describe what is seen, eg unobserved but reported seizure

   - Provide detailed accounts of observations, especially when what is reported is at odds with what has been observed

   - Document who was present during any episode, and the source of all data

Issues of Documentation in Hospital records

2. All documentation of any confidential information that is not relevant to day to day management of child should be placed in the **child protection file** eg, records of case discussions, information about carers

3. All discussions must be documented in the **child protection file**

As with all information in health records, parents have the potential to access the file

When a notification is made, the notifier's right to confidentiality must be respected.

The Assessment Process 1

Under the guidance of the child protection paediatrician

1. Discussion of concerns with referring professional/statutory agency worker
   - the basis for concern
   - the other professionals currently/previously involved
2. Initial confidential case conference with professionals currently/previously involved
   - Inform all participants of the concerns & ascertain their considered opinions
   - Engage previously involved clinicians who may not have considered FII; they may be embarrassed & hostile to the assessment
3. Case record review
4. Subsequent Case Conference

The Assessment Process – 1. Referral Details

The information that should be exchanged at referral from the primary paediatrician to the tertiary centre:-

- The reason for referral to the primary paediatrician
- The findings in assessing & investigating the child
- What led to considering the possibility of FII?
- Evidence that the parent pushed for non-indicated interventions?
- The views of other previously involved health professionals in relation to the possibility of FII, and the level of consensus/disagreement.
- Whether or not the concerns of FII have been mentioned to the parent; and the parent's response.

The Assessment Process – 2. The initial Case Conference

A. Called jointly by the tertiary paediatrician and the child protection paediatrician

B. The attendees, purpose, content & resolutions of the meeting recorded in the **child protection file**

C. Carefully consider what should be included in the **child's hospital case notes** eg;
   - concern/suspicion of FII should not be recorded
   - the symptoms reported by the parent & the lack of or extent of supporting observations made by ward staff is appropriate to record
   - not usually appropriate to record the holding of a case conference

The Assessment Process – 3. The Record Review i

The **Record Review** analyses information obtained with the consent of the parent. All recorded information is potentially relevant to the presenting problem.

For the Record Review it is not prudent to seek permission from the parent for their & other family member's records.

The extent & source(s) of the recorded material to be reviewed is derived from:-

- the case conference
- the primary paediatrician's comprehensive history of the child's symptoms obtained from the parent
- previous recorded material contained within the tertiary institution's records

The Assessment Process – 3. The Record Review ii

The aims of the **Record Review** are to have:-

- Established the means by which the child entered the health system
- An accurate chronology of the child's contact with the health system
- A comprehensive list of all of the health professionals involved with the child
- A complete set of information obtained from involved health professionals (including letters, reports and sometimes written notes).
- The complete range of diagnostic considerations and opinions, from those health professionals involved, emphasising those that they have provided to the parent (and the relevant documentation).

The Assessment Process – 4. The Subsequent Case Conference i

The **Subsequent Case Conference** brings together the synthesis of information from the **Initial Case Conference** & the **Record Review**

At the completion of the **Record Review** the goal is to have:-

1. Identified & reviewed any additional points in the chronology where FII has been a concern
2. EITHER consolidated any FII concerns into a suspicion OR resolved the concern
   – If a suspicion is established then a notification must be made (if this is anticipated prior to the case conference then the statutory agency is invited)
   – If the concern is resolved then a plan for ongoing medical and psychological care must be formulated

The Assessment Process – 4. The Subsequent Case Conference ii

- Established suspicion is notified (if anticipated prior to the case conference then the statutory agency is invited). The content & means of delivery of the notification must be formulated.
- Plan how and who to approach parent (generally the responsibility of the child protection paediatrician), what to say and when (parent informed **after** the notification and the management plan has been formulated).
- The degree of seriousness of maltreatment must be considered. In severe cases of symptom induction, the statutory authorities should be responsible for approaching the parent as the safety of the child at this time is paramount.

The Assessment Process – 4. The Subsequent Case Conference iii

- When it is concluded that FII is present, but no harm has been done to the child, the consultant paediatrician should speak to the carers.

- Once child safe then a comprehensive assessment of the child must occur – from physical and psychological perspective. This advice must be given to the statutory agency.

- Older children should be interviewed by child mental health expert in relation to the FII behaviours.
- Advice should be given regarding suspected perpetrator assessment.

- Notification of appropriate executives, health authority, risk management, particularly if the parent’s response is hostile.

The Assessment Process – 4. The Subsequent Case Conference iv

If the concern is resolved then a plan for ongoing medical and psychological care must be formulated:-

Will the previous concern be discussed with the parent?

Which paediatrician will be most appropriate and accepted by the child and family?

How will the final opinion be promulgated to previously involved health professionals?

Concerns

Paediatric consultation

Resolved

Concern

Suspicion → Notify

± Stat interventn.

Tertiary centre
Gen. paediatrician
Sub-specialist

Child protection paediatrician

Assessment process

1st Case Conf

Record review

2nd Case Conf

Concerns resolved → Family support

Notificatn if suspicion

Stat. Agency Actn