ORIGINAL ARTICLES

Follow up of victims of fabricated illness (Munchausen syndrome by proxy)

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Abstract

Fifty four children were studied 1-14 (mean 5.6) years after fabrications of illness had been identified. Thirty of the 54 children were living in families with their biological mothers and 24 were with other family members or in substitute families. Further fabrications were identified for 10 children who had been living with their mothers and there were 'other concerns' for a further eight children.

Thirteen children residing with mother and 14 not residing with mother at follow up had a range of disorders including conduct and emotional disorders, and problems related to school, including difficulties in attention and concentration and non-attendance. Overall, 20 children (49% of those successfully followed up) had outcomes that were considered to be unacceptable.

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The dangers of fabricated illness (Munchausen syndrome by proxy) to the child victims has been documented in many reports.¹ Physical danger is immediate with smothering,² usually presented as apnoeic episodes or fits, and with poisoning,^{3,4} often presented as drowsiness or fits. The usual perpetrator of fabrications is the child's mother. For some children, whether or not the mother actively produces 'symptoms', iatrogenic problems may be inflicted on the child as a result of investigations, medication, or surgery.⁵ In addition, although less immediately evident, there is a risk of impaired psychosocial development (psychological morbidity) as a consequence of repeated fabrications of illness and other unusual aspects of the mother's behaviour.⁶ There have been no reports of systematic investigations concerning the longer term outlook for these children.

We carried out a systematic study of 56 families in which the mothers had fabricated illness in at least one child. The nature of the fabrications and the 'co-morbidity' for 56 index children and their 103 siblings has been reported previously.⁷ This paper reports the follow up of the index children from these families.

Subjects and methods

Initially 62 families were selected from about 100 families in which a child had suffered from the effects of a fabricated illness. They were selected on the basis of their recent address being known and availability for the study (including the fact that we believed we had, or could obtain, comprehensive medical records relating to the index child and siblings). During the course of the investigation it became apparent that we had insufficient information on six families and, as a result of the original fabrications, two children had died so this part of the study was limited to 54 families.

The examples of fabricated illness met the following four criteria, modified from Rosenberg and Meadow^{1,5}: (1) Illness in a child is fabricated by a parent, or someone who is in *loco parentis*. (2) The child is presented for medical assessment and care, usually persistently, often resulting in multiple medical procedures. (3) The perpetrator denies the aetiology of the child's illness. (4) Acute symptoms and signs of illness cease when the child is separated from the perpetrator.

After reviewing medical notes of the index child, and sometimes the siblings, the last professional known to have been involved with each family was contacted. The professionals were mainly paediatricians, social workers, psychiatrists and general practitioners, some of whom were still in regular contact with the families, while others had ceased to be involved. In order to proceed it was sometimes necessary to contact several professionals. A small number of families who had moved were traced using family practitioner committee registers. In specific cases permission was sought from the relevant court to obtain information about a child. Our aim was to assess if there had been further fabrications, or if there were other concerns in the follow up period and to gather as much information as possible about the current states of the children.

In order to assess each child it had to be decided whether to use only indirect information from the medical notes and accounts from professionals, or whether parents and substitute parents were to be interviewed. After discussion with the involved professional, direct contact with the family was made only if it was considered that there would be no adverse effect.

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The interviews with parents and substitute parents (conducted by CNB and BAN) took the form of a suitably adapted clinical interview, of the sort usually carried out in child psychiatry practice, to enable an assessment to be made of the child's developmental, educational, and psychosocial state. The assessment was assisted by the use of questionnaires in an attempt to standardise information. The Rutter 'A' scale⁸ for children aged over 5 and the behavioural screening questionnaire for preschool children⁹ were used. The former was completed by parents and the latter by the interviewer. In order to assist in the assessment of functioning at school, and after permission from the legally responsible adult, schools were contacted and teachers asked to complete the Rutter 'B' questionnaire.¹⁰ When the children had been fostered or adopted descriptions of the children's behaviour were obtained when they were first placed with the family and how this had changed.

The findings are reported in three parts, firstly the fabrications and 'other concerns', secondly psychosocial, educational and developmental problems, and thirdly the children are divided into two groups – with outcomes judged to be either 'unacceptable' or 'acceptable'. While bearing in mind the miscellaneous nature of the index fabrications and the complexity of surrounding events it was hoped that, by comparing the children with acceptable outcomes and those with unacceptable outcomes using selected features, some indicators of a better prognosis might be revealed.

Results

There were 26 boys and 28 girls. At the time of follow up there were 13 preschool children (below 5 years), 34 of school age (5–16), and seven over age 16. The interval from the index fabrication to the time of follow up, for the children for whom adequate data was obtained at follow up, ranged from 1–14 years with a mean of 5.6 years. At the time of the study 30 children lived with both parents, or their mother alone. The other 24 children were living with either father alone, foster parents, or had been adopted.

The 54 children were grouped according to the most serious variety of fabrication that had occurred. The resulting four groups were: smothering, poisoning, seizures, and miscellaneous; these groups contained 15, 13, 14, and 12 children, respectively. More information about the fabrications is given in an earlier paper.⁷

FABRICATIONS AND OTHER CONCERNS IN THE FOLLOW UP INTERVAL

The finding of further fabrications and other concerns about the care of the 30 children residing with their mothers at follow up are summarised in table 1. Examples of the further fabrications included bleeding ears, epilepsy, glycosuria, 'brain damage' (causing 'hyperactivity'), and coeliac disease. Two of the children were presented as having 'physical disabilities' and suffered restricted lifestyles. One was the continuation of a chronic fabrication of a mobility problem with insistence on the use of a wheelchair, and the other was an extreme exaggeration of the chest condition resulting from genuine, mild, congenital heart disease.

The management of the 10 children with subsequent fabrications had included court orders in four cases, child protection case conferences only in two cases (that is not going to court proceedings), medical management only in two cases, voluntary social work help in one case, and no intervention in one case.

There were a variety of 'other concerns' for eight of the children. Two children had attended specialist paediatric clinics and no physical cause had been found for the symptoms presented (by the mothers). One could only speculate if these presentations had been fabrications and for this reason are not included above. One mother continued to lie extensively (including during the research interview) and had a recent conviction for fraud. We considered that this behaviour was having an adverse effect on her child. There were concerns about the quality of relationship between three mothers and their children. The seventh mother had continued to be grossly over involved with her child. The eighth mother required extensive social work input to learn about and cope with the basic care of her child – the intervention was proving effective and mother had a positive relationship with the child – the concern was the level of dependence on professionals and when it would be possible to reduce their input. For the eight children with these other concerns there had been court orders in six cases and medical management alone for the remaining two cases. There had been no fabrications of illness by foster or adoptive parents.

STATE OF THE CHILDREN

It proved possible to obtain adequate data to report on the current state of 38 of the 54 children (tables 2 and 3). Twenty seven

Table 1 Further fabrications and other concerns: 30 children residing with mother

Fabrications and concerns	No of children*	Main abuse				Mean age at follow up (years)	Follow up interval (years)
		Smothering	Poisoning	Seizures	Miscellaneous		
Adequate data	23 (11)	3	4	10	6	11.0	6.3
Fabrications	10 (5)	1	1	5	3	12.7	7.3
Other concerns	8 (2)	1	3	2	2	10.5	5.4
No concerns	5 (4)	1	0	3	1	8.2	5.2
Incomplete data	7 (4)	3	2	1	1	7.0	–
Total	30 (15)	6	6	11	7	10.0	–

*Numbers in parentheses refer to boys.

Table 2 Disorders at follow up: 30 index children residing with mother

Disorder	No of children*	Main abuse				Mean age at follow up (years)	Follow up interval (years)
		Smothering	Poisoning	Seizures	Miscellaneous		
Adequate data	18 (9)	2	4	8	4	11.4	6.2
Disorder	13 (6)	1	3	6	3	12.7	6.6
Not improving	9 (4)	0	2	5	2	15.1	7.9
Improving	4 (2)	1	1	1	1	7.3	3.8
No disorder	5 (3)	1	1	2	1	8.0	5.0
Incomplete data	9 (5)	1	2	3	3	9.4	6.6
No data	3 (1)	3	0	0	0	3.7	—
Total	30 (15)	6	6	11	7	10.0	—

*Numbers in parentheses refer to boys.

children were judged to have significant disorders and these were divided into 17 children whose difficulties were not improving and 10 children whose difficulties, although still present, were showing signs of gradual improvement. The interviews and casenote data were complemented by the parent rating scales for 25 children and teacher rating scales for 15 children. Only three children were rated above the recommended cut off points on the respective rating scales and these were judged to have disorders that were not improving. In addition five children not achieving scores above the respective cut off points plus nine other children for whom no rating scale data was obtained were judged to have disorders that were not improving.

CHILDREN RESIDING WITH MOTHER

The 30 children remaining with mother were the most difficult to study in detail, especially in the families who had not had statutory intervention. There was, however, direct information from the family regarding 11 of the 18 children with adequate data. For all 18 children hospital notes were available and for 15 also the general practitioner notes. Social services files were available for nine children. There were nine completed rating scales from parent or substitute parents and six completed teacher rating scales. Table 2 gives a summary of the findings.

There was evidence of a disorder for seven of the 10 children who had experienced further fabrications, with incomplete data for three. For six children school non-attendance was a serious difficulty: for two children (one boy and one girl) associated with apparent physical disability as described earlier, for one girl associated with an emotional disorder and complaints of somatic symptoms, and for one boy with a mixed emotional and conduct disorder together with concentration problems. There were no apparent associated problems

with the school non-attendance for the other two children. A seventh subject, now an adult, had continued to complain of headaches and fits that his mother had previously presented and had not been able to work as a result.

There was evidence of a disorder for five of the eight children for whom there were other concerns, with no disorder identified for one child and incomplete data for two children. One boy had an emotional disorder together with concentration difficulties and poor progress in school, and a girl a mixed emotional and conduct disorder, with secondary nocturnal enuresis. A teenage girl had recently suffered emotional upset as the result of her mother's behaviour and a teenage boy had a marked conduct disorder, had been expelled from school, and has started offending. A preschool girl had developmental delay, behavioural problems, and was socially inhibited. Three of these children plus another child (for whom no fabrications or other concerns had been identified) who had difficulties in school were judged to have disorders that were improving.

CHILDREN NOT RESIDING WITH MOTHER

There was direct information from the carers of 19 children together with 16 completed parent rating scales or questionnaires and nine school questionnaires for the 20 children with adequate data. Table 3 gives a summary of the findings.

There were eight children with disorders that were continuing at a similar level. Five of these children (three boys) of school age had concentration difficulties in school with under achievement and behavioural difficulties at school and at home. One of these boys had reached the age of 17 and continued to steal and tell lies. One girl, who had suffered irreversible brain damage as a result of repeated smothering, had quadriplegia and severe learning difficulties. One 4 year old girl had serious

Table 3 Disorders at follow up: 24 children placed away from mother

Disorder	No of children*	Main abuse				Mean age at follow up (years)	Follow up interval (years)
		Smothering	Poisoning	Seizures	Miscellaneous		
Adequate data	20 (9)	7	6	2	5	7.1	4.8
Disorder	14 (8)	4	5	2	3	6.9	4.9
Not improving	8 (5)	3	4	0	1	8.1	5.4
Improving	6 (3)	1	1	2	2	5.2	4.2
No disorder	6 (1)	3	1	0	2	7.7	4.5
No data	4 (2)	2	1	1	0	9.8	—
Total	24 (11)	9	7	3	5	7.6	—

*Numbers in parentheses refer to boys.

Table 4 Features of 41 children placed with mother, or not with mother, at follow up; history of abuse in index child and siblings, and aspects of management

Residence at follow up and outcome for index child	No of children	Index child					Siblings		Management		
		History of co-morbidity									
		Failure to thrive	Non-accidental injury	Neglect	Multiple fabrications	Mean age at discovery (months)	Known deaths	Affected by abuse or neglect	Sibling(s) removed from mother	Court order made	Short term fostering of index
With mother											
Unacceptable	12	2	0	1	7	104	2	8	1	6	2
Acceptable	9	2	1	1	6	44	2	3	1	8	9
Not with mother											
Unacceptable	8	4	3	2	8	39	2	7	6	8	7
Acceptable	12	6	4	3	9	30	1	3	2	12	12

emotional and conduct problems and an adoptive placement had broken down. A 4 year old had developmental delay believed to have been contributed to by the lack of stimulation when residing with the mother, the child also continued to soil.

Six children had disorders that had shown signs of gradual improvement. A 9 year old girl was described by her long term foster parents as displaying hypochondriacal behaviour, complaining of physical symptoms each day. In addition the girl was telling lies and having substantial difficulties relating to her peer group. A 3 year old boy continued to have regular nightmares. A 6 year old boy had concentration difficulties, speech difficulties, delay in social development, and was enuretic at night. A 7 year old boy had concentration difficulties in school combined with coordination problems, being generally fearful, restless, and telling lies. Two younger children had displayed marked social disinhibition which improved in both cases in the new placements, one with a grandmother and the other with foster parents.

In addition to the difficulties present at the time of the study, a number of the children who had been smothered had displayed emotions and behaviour in the first months after placement with foster/adopting families that seemed directly related to their experience. Three children had been frightened of bathrooms, one to the extent that it took the caregivers a year to encourage the child to use the bathroom, and another had to be accompanied to the bathroom by the father for many months. The third child was also fearful of cushions and pillows. A fourth child, while playing with other children, had been observed to cover their faces with his hands (presumably as had been done to him) and a fifth had played at choking a toy while in the bath. Two children had suffered from severe nightmares and one of them had been found cowed underneath his bed on a number of occasions in a frightened state.

OVERVIEW OF FINDINGS

There was no excess of boys or girls in those with disorders at follow up (tables 2 and 3). There were differences in the types of disorders encountered: more boys were reported to have disturbance of conduct and concentration difficulties than girls. There was a trend for the children with improving disorders, both those

living with their mothers and those away from mothers, to be younger than the children whose disorders were not improving (tables 2 and 3).

Finally, a global rating was made depending on whether, in our opinion, the state of the child and/or the child care situation was acceptable or unacceptable. The rating of unacceptable was made for all children with disorders that were not improving plus three children placed with the mother for whom there were concerns in the follow up period, although with incomplete data on the present state of the child.

Twenty index children had outcomes that were rated as unacceptable at the time of the study. These 20 children were then compared with the 21 with acceptable outcomes; each group was separated into those placed with, or not with, the mother and were compared for a number of features relating to the history of the index child, siblings, and aspects of management (table 4). Index children with unacceptable outcomes had been older at the time of discovery of the fabrication, and more often had siblings who had been affected by abuse or neglect. Children placed with the mother at follow up and who had an acceptable outcome were more likely to have been temporarily fostered.

FEATURES OF BETTER OUTCOMES

When the histories of the children with better outcomes were looked at the following features were felt to be relevant: (1) Continuous positive input from the father for three children (and additionally the paternal grandparents for two of these children). (2) Successful short term fostering before return to mother for five children. (3) A long term therapeutic relationship with a social worker for three mothers. (4) Successful remarriage for two mothers. (5) Early adoption for three children. (6) Long term placement with the same foster parents for one child.

Discussion

The nature of this study presented substantial methodological difficulties. Firstly, our criteria for Munchausen syndrome by proxy allowed the inclusion of a variety of fabrications with a wide range of both severity and duration of physical and/or emotional abuse of the child. Secondly, the collection of reliable data was a

concern given the nature of the problem under investigation, in particular the objectivity of the mothers' perceptions of their children. This problem was avoided for most children by using multiple sources of information including mothers and fathers, grandparents, foster and adoptive parents, child care professionals, school teachers, doctors, medical and social work notes.

It is worrying that a substantial number of children continued to be subjects of their mothers' fabrications, in some cases for a number of years after the initial discovery of the index fabrications and after interventions by professionals. For another group of the children there were a variety of other concerns, either in the relationship between the mothers and their children or because of other aspects of the mothers' behaviours. In all about three quarters of the children remaining with their mothers, for whom there was adequate data, either suffered further fabrications or were subject to other concerns. The infrequent use of court procedures for the children suggests that the management strategies used were not as strongly interventionist as may have been required. It is important to note, however, that the decisions taken concerning management were taken some time ago, more than 10 years in some cases, and that at the time little was known about the nature of Munchausen syndrome by proxy or the best management strategies.

Many of the children who had remained with their mothers and had been exposed to further fabrications or the other problems displayed various disorders; these were mainly emotional and conduct disorders, and school difficulties, including non-attendance. There may be an implication here for future research into the classification of school non-attendance,¹¹ in that the possibility of fabrication of illness, past or present, may be occasionally relevant in a small minority of cases. The finding of two children with imposed physical disability and an associated problem or school non-attendance is notable.

Many children placed with new families also suffered from psychological disorders, in many cases a continuation of an earlier disorder, perhaps, combined with a reaction to the change of environment. The difficulties experienced by five children who had been smothered were very clearly related to their experiences, with fears and avoidance of specific places or situations and sleep disturbance including nightmares, well recognised features of post-traumatic stress disorders. The finding of a girl presenting with hypochondriacal behaviour was of particular interest. It seemed likely that the behaviour had been learnt during the time spent with the natural mother.

The presence of such extreme psychological disturbance in so many of the children several years after the abuse is of great concern. This finding is in agreement with earlier reports of Munchausen syndrome by proxy, including those that have indicated the difficulties in treating the mothers who fabricate illnesses in their children.^{6 12 13} In a similar manner to that

reported by McGuire and Feldman,⁶ we found that children displayed disturbances that were (in)appropriate to their developmental stage including difficulties in psychosocial development, and in older children conduct problems and school non-attendance. The quantity and quality of problems were broadly similar to those reported in a follow up study of children who had been physically abused.¹⁴ The excess of boys with conduct disorders is interesting; other workers have reported that abused and neglected boys (not suffering fabricated illness) had more diagnoses of conduct disorders than boys who had not been abused.¹⁵

Factors that may have led to less reliable, and possibly over optimistic, findings include the difficulties of identifying a number of problems: the symptoms of emotional disorders (which are known to be more prevalent when children themselves are interviewed than when their parents are interviewed,^{16 17} subtle cognitive deficits in children who had previously suffered from physical abuse (especially smothering), and emotional abuse and its consequences.¹⁸ In addition, it was generally too early to look at specific difficulties with child care when the subjects become parents themselves. There were 16 children for whom detailed information concerning their state was not available. Therefore, for all of the above considerations, as in the previous report concerning co-morbidity,⁷ it would be wise to regard the levels of morbidity reported here as a minimum.

It is not possible to summarise which group of children (grouped by variety of fabrication) had the most favourable outcomes because within each group there was a range of severity of fabrications, not all children were followed up, and different proportions were followed up in each of the four groups. It is also not possible to comment overall on whether better outcomes were obtained when children remained with their mother, or were separated, as many factors had influenced the legal decision to separate a child from his mother. The children who had remained with their mothers on the whole had been judged to have been less severely abused and it had been predicted that remaining with, or returning to, mother would be favourable for a variety of reasons.

This report has not focused upon which factors in the original family environment were most relevant in influencing the development of emotional and behavioural problems in the children. We consider it likely, however, that the over closeness directed by the mother and, perhaps combined with, the lack of normal encouragement to follow social rules (including attending school and respecting authority outside the family) may be important elements. The findings certainly support the finding of other workers that the cessation of fabricated illness does not, in itself, indicate that the child will thrive.^{6 19}

It was notable that there were no deaths of children during the follow up period, especially when bearing in mind the number of unexplained deaths of children (11) in these

families, before the identification of index fabrications.⁷ Not all families had been followed up in detail; however, children in the families considered to be at higher risk for physical abuse had usually been placed away from their families or had been followed up with their families of origin and were known to be alive. The absence of fatality may be the result of a number of possible reasons: a change in behaviour of the mothers, the increasing resilience of older children to physical abuse, and also successful management strategies employed by child protection agencies. In the UK the organisation and procedures of social services may be more coherent across the country than in the USA, where Waller reported the death of a child whose family moved to a new state.¹² The child had initially been reported by Kurlandsky *et al.*²⁰ Additionally Waller noted that five of 20 children reported in the literature had subsequently died.¹² Our experience was that some of these families did move more often than one might expect, necessitating close liaison between social service departments when children were either subject to court orders or registered as 'at risk'.

Because it had been decided not to subject children to individual examination, it was not possible to say if the boys who had restlessness and concentration difficulties affecting their school performance had suffered cognitive impairment as a result of anoxia at the time of smothering, or whether these symptoms were, at least in part, psychologically determined. The hyperkinetic syndrome has been reported to result from the disruption of early attachments, including emotional and physical deprivation, without biological risk factors being present.²¹

The small numbers of children preclude meaningful statistical analysis of the factors that might have affected the outcome of children in the study. Nevertheless, our findings indicate that for those 21 children who were with their mothers at the time of the study and for whom an outcome rating had been made, a greater proportion of those with an acceptable outcome had received short term fostering before returning to mother (9/9) than had remained continuously with mother (2/12). Although other factors will have been relevant, this finding suggests that active management that includes a therapeutic programme is usually the best approach. In addition, the finding that children living with the mother with better outcomes were younger at the time of discovery of the fabrications suggests that early intervention is of benefit.

This study indicates that the longer term psychological morbidity of victims of fabricated illness can be substantial. It also suggests that active intervention does reduce the risk of long term difficulties for the children. Intervention requires detailed assessment and tailored management strategies with child protection agencies working closely together with paediatric and mental health services.²²

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