Misdiagnosis of Child Abuse Related to Delay in Diagnosing a Paediatric Brain Tumour©

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Abstract: Conflicting opinion regarding the relative weight that should be allocated to the investigation of organic causes of child illness, compared to the pursuit of suspicions of child abuse, has generated considerable public debate. The discourse of Munchausen Syndrome by Proxy/Fabricated and Induced Illness is at the centre of contention. In particular, concern has arisen that children's medical needs are being neglected when their conditions are misdiagnosed as child abuse.

This paper documents a case study in which the use of Child Protection procedures was linked to the belief that the child's illness had "no organic cause." The case study is contextualised in a review of literature relevant to the diagnostic process.

The deployment of the Child Protection perspective resulted in significant delay in the diagnosis of the child's brain tumour. The child was ultimately found to be suffering from an optic chasm mass lesion involving the hypothalamus and the medial temporal regions, resulting in Diencephalic Syndrome. The evidence in this case is that erring on the side of suspecting Munchausen Syndrome by Proxy/Fabricated and Induced Illness, was not "erring on the side of the child."

Several lessons need to be learned from the case. The importance of ensuring that the Child Protection perspective does not displace adequate assessment of alternative explanations for the child's condition is emphasised, as is the need for good communication in medical relationships. Strategies involving empathy, mediation, negotiation and conflict resolution may provide a more appropriate and therapeutic alternative to the use of Child Protection procedures in cases where the diagnosis is contentious. The need to re-write relevant policy, protocols and guidance is imperative.

Keywords: delayed diagnosis, miscarriages of justice, intracranial neoplasm, medical error, human rights, service user perspectives

Background

Diagnosis of child abuse in the medical context has been highly contested for some time (Hayward-Brown, 2003, 2004; Hayward-Brown et al. 2004). In the specific case presented here, the misdiagnosis of child abuse involving the discourse of Munchausen Syndrome by Proxy/ Fabricated and Induced Illness [MSbP/FII] displaced the medical knowledge necessary to assist a child.

The Child Protection discourse of MSbP/FII that permeated the exposit case was launched in an article in The Lancet by the controversial paediatrician, Roy Meadow. Meadow (1977) presented two case studies alleging that parents had fabricated and induced their children's illness. Since then, the definitions of MSbP/FII have varied considerably across the literature and amongst differing professional groups. Broadly put, the discourse of MSbP/FII is constituted by allegations of child abuse centred around claims that parents and carers, usually Mothers, are harming children by causing them to suffer a fictional or induced illness (Wrennall, 2007:961). Proponents of the discourse argue that MSbP/FII is common, extremely dangerous and frequently fatal (Meadow, 1977; Davis et al. 1998).

The discourse has been implicated in some of the major murder trials involving women and in numerous cases in the Children and Family Courts in English speaking countries around the world (Wrennall, 2007). Subsequent critique of Meadow's evidence as an expert witness (Royal Statistical Society, 2001; Nobles and Schiff, 2005; Streater, 2006: 7–11; Watkins, 2000) and the role of the discourse in false allegations, Miscarriages of Justice and hostile adoptions, is now well known (Wrennall, 2007; Raitt and Zeedyk, 2004).

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MSbP/FII discourse has been critiqued on several grounds. Morley (1995) and Baldwin (1996) issued warnings about the non-specific diagnostic criteria in MSbP/FII discourse. Baldwin (1996) warned about the contradictory diagnostic criteria, essentially setting up what have come to be regarded as "ducking stool" criteria (Wrennall et al. 2003; Wrennall, 2007). Mart (1999) warned that MSbP/FII is highly prone to misdiagnosis, on statistical grounds. He has also criticized the confusion between continuous variables and discrete variables within the MSbP/FII discourse (Mart, 2002).

Bergeron (1996) has criticized MSbP from a feminist perspective, Wrennall (2005) highlighted the role of the discourse in disempowering service-users. Alison and Roberts (2000) have confronted the use of the diagnosis on philosophical grounds. In the context of a significant case study, Baldwin (2005) has analysed the techniques of power that are deployed in MSbP/FII narratives. Hayward-Brown (2003) has assembled evidence suggesting that the misdiagnosis of MSbP/FII is highly likely in a context of failure in medical relationships. Pankratz (2006: 90–95) reports that multiple problems with the diagnosis continue unabated.

Alertness in regard to possible child abuse in the medical setting is entirely appropriate. Increasingly though, there is an awareness that Child Protection procedures and specifically, the discourse of MSbP/FII, are open to inappropriate use. This awareness has stimulated major government reviews in the UK (Goldsmith, 2004a, 2004b, 2007). Numerous critics have alleged that MSbP/FII discourse has been deployed for ulterior motives and camouflages agendas that are hostile to the best interests of children (outlined in Wrennall, 2007). D'Cruz (2004: 102) argues that "the dominant medico-scientific paradigm underpinning contemporary policy and practice is criticized because claims of objectivity associated with it mask profound political and discursive practices, outcomes and consequences."

In the context of the critiques of Child Protection, outlined by Parton (1991); Parton et al. (1997) and Thorpe (1994); D'Cruz (2004) presented two case studies, demonstrating how medical, social and legal constructions in Child Protection marginalized other valid knowledge claims, with profound implications for children. Baldwin's case study (2005) demonstrates the strategies and tactics used to disenfranchise competing knowledge claims, as does a case study presented by Urek (2005). The exposit case study presented here, follows this tradition and moves the argument forward by providing strong evidence of the harm to a child that can result when Child Protection discourse displaces other valid knowledge claims. The misdiagnosis in this case was contested by service user advocacy at the time and was at odds with a vast corpus of existing medical knowledge. The relevant planks in that corpus are cited in this paper.

Introduction

The paper presents a case study on misdiagnosis and delayed diagnosis, contextualised in a review of relevant literature on the assessment of Failure to Thrive in relation to Intracranial Neoplasms and Diencephalic Syndrome. The diagnosis of Failure to Thrive is typically linked to the suspicion of child abuse and neglect (Block et al. 2005). In the exposit case, a child's long term Failure to Thrive was interpreted in the context of MSbP/FII discourse and was consequently misdiagnosed as having "no organic cause".

The Child Protection perspective displaced the medical knowledge that was necessary to assist the child. Appropriate testing was not initiated in a timely manner and hence the accurate diagnosis of an optic chasm mass lesion involving the hypothalamus and the medial temporal regions, resulting in Diencephalic Syndrome, was delayed.

Diencephalic Syndrome was first identified by Russell (1951). It is conceptualized by Fleischman et al. (2005: 742) as a "rare but potentially lethal cause of failure to thrive in infants and young children." Clinical characteristics include "severe emaciation, normal linear growth, and normal or precocious intellectual development in association with central nervous system tumors" (Fleischman et al. 2005: 742).

The two main types of error evident in the case, delay in diagnosis and failure to employ indicated tests are among some of the most common types of medical error noted by Leape, Lawthers, Brennan, et al. (1993: 144–149) and included in the Institute of Medicine's Report on Medical Error, famously titled *To Err is Human*.

Rationale

This case is being presented for the purposes of education and training and the relevance of the

experience to debate on Child Protection policy and practice. The importance of publication is in drawing out the contested approaches and suggesting alternative more constructive responses to these sensitive issues. Although there has been extensive work published on Child Protection disasters involving a failure to protect children from abuse, there has been far less work on examining the harm resulting from unnecessary Child Protection interventions. Yet there is no reason to assume that false allegations and miscarriages of justice in Child Protection are less numerous or less serious than cases of failure to protect.

Specifically, there are five main reasons for reviewing this case. First, the case provides practical evidence of the harm to a child, caused by a false allegation of child abuse. Second, the need for adequate medical assessment to precede an allegation of child abuse is emphasized. Third, the warnings about the need to include Diencephalic Syndrome in the differential diagnosis for failure to thrive need to be communicated more fully. (Ertem et al. 2000; Fleischman, 2000).

Fourth, evidence is presented, of a case in which service user advocacy was more accurately centred on the best interests of the child than was the perspective from within the Child Protection discourse. This is of considerable interest in the current climate in which service user perspectives are valorised. (Secretary of State for Health 2004).

Fifth, more enlightened approaches are necessary to resolve the current impasse regarding the crisis of credibility surrounding the discourse of MSbP/FII, (Hayward-Brown, 2003) and to more generally resolve the crisis in Child Protection (Parton, 2006). Many disputes that unfold through the use of the Child Protection procedures could be more effectively handled clinically. (Pankratz, 2006). Mediation, communication, negotiation and conflict resolution provide appropriate and therapeutic alternatives to the use of MSbP/FII discourse in certain medical settings.

Over-reliance on n = 1 case studies should be counseled against. However, an appropriate consideration of individual case studies can be instructive within the larger picture of policy and practice considerations. Given the importance of this case to current debate about policy and practice in Child Protection, a detailed discussion of the aspects of the case is imperative.

Methods

This paper presents a case study[1] analysed in the context of an extensive review of literature on the appropriate assessment of Failure to Thrive in relation to Intracranial Neoplasms and Diencephalic Syndrome.

Research methods included interviews with the child and her parents and observations of the family *in situ*. Written documents prepared by the parents, minutes of the Child Protection meetings and all the available medical records were subjected to textual analysis. Interviews with peer analysts and numerous literature searches on differing key words were also undertaken. Subject validation of the manuscript by Melissa's parents was achieved throughout the process.

Significant representative medical professionals involved in the case declined to be interviewed even though the parents had agreed to waive their rights to confidentiality, sufficient to allow interviews to occur. These opportunities to be interviewed were declined, presumably for the usual legal reasons. However, the parents' account was confirmed by the documents.

Chronology of the Case

Low and declining weight problems stimulated a diagnosis of Failure to Thrive in a young female child, whom we shall call Melissa. Symptoms begin to be presented to medical and Home Visiting staff from age four months, but the accurate diagnosis of an optic chasm mass lesion involving the hypothalamus and the medial temporal regions, resulting in Diencephalic Syndrome is not obtained until the child is aged fourteen months. Briefly outlined, the case history is this.

Melissa [dob 24.1.2000] is referred to a Community Paediatrician by her Primary Care Physician on 6.9.2000 for Failure to Thrive. Weight is being monitored by the Primary Care practice and it is continuing to decline. She is not feeding well and is regurgitating her food. It is reported that Mum and Dad are feeding Melissa appropriately and are "very competent parents."

On 26.9.2000 the Community Paediatrician reports to the Primary Care Physician that she has concerns about Melissa's "poor growth and her current discomfort and very poor appetite."

[1]The child's name has been changed for anonymity. No other details have been altered.

Melissa's "birth weight was 6 lb 4 oz and she remained on the 25th percentile until the age of three months. She slipped to the 9th percentile between 5 and 6 months but since then has plateaued and more recently actually lost weight." She "vomits small amounts occasionally but this does not seem to be a major problem." The Community Paediatrician also points out that Melissa "has become less settled and having previously slept through the night has been waking crying with pain during the night." Bloods were taken "for a number of investigations including antiendomesial antibodies to exclude Coliacs disease and to check liver and kidney function as well as a full blood count and iron levels." Urine microscopy was reported to be normal "again" and the family were asked to collect stool sample to test for "ova, cysts and parasites and reducing substances."

The Community Paediatrician's letter dated 15.10.2000 to the Primary Care Physician reports that Melissa "appears to become uncomfortable whenever eating" and is "waking during the night apparently in pain." Her thinness and wasting is contrasted to her alertness. The Community Paediatrician makes a referral to Paediatric Gastroenterology specialists who institute several attempts to modify Melissa's diet, including naso-gastric feeding and in-patient treatment.

In November, the parents express their concerns over the paucity of diagnostic investigations, the lack of an effective diagnosis and the inadequate effects of treatment. On 28.11.2000 a Specialist Registrar in Community Paediatrics reports to the Primary Care Physician that Melissa's mother is concerned that there is still no diagnosis despite the hospital referral. The next day, Specialist Registrar notes report the father expressing a concern that Melissa may have bowel cancer. The Mother is criticized over her lack of confidence in naso-gastric feeding as the solution to Melissa's problem. The notes also report Melissa's mother saying that she will not be happy until she has a second opinion from another Paediatrician in another hospital. Gastro Round notes on 1.12.2000 express concern about interaction with the family. On 11.12.00 medical notes document a meeting to address the parents' "list of problems and grievances".

In early December, the suspicion of child abuse held by medical and nursing staff hardens into a more formal recourse to Child Protection procedures. Detailed procedures are set down for communications with the family and among the professionals. A date is set for a "multidisciplinary meeting" on 11.12.2000. As the month progresses, Melissa's medical condition goes into further decline. December ends with a Doctor's Urgent Care report being drawn up in respect of Melissa's "malnutrition" and "chest infection".

A planning meeting among the medical personnel and a Paediatrician from the hospital Child Protection Unit takes place 22.2.01. Case notes report that there is "Unanimous agreement that the only acceptable course is for hospital admission." There will be liaison with Social Services "as necessary." Twelve professionals are reported to have attended. [The Senior Consultant Paediatrican from the Child Protection Unit is subsequently arraigned before the General Medical Council's Professional Conduct Committee regarding numerous false allegations of child abuse, unrelated to the exposit case.]

On 27.2.01 Melissa's nystagmus is reported to have been observed by the Home Visitor from the Primary Care Practice and on 1.3.01 mention of the nystagmus is made in case notes. A referral is made to a Paediatric Neurologist. Despite the documentation of the nystagmus, Melissa is to be admitted to hospital under the supervision of the Senior Consultant Paediatrician from the Child Protection Unit. Before the Paediatric Neurologist has assessed the child, a Child Protection Strategy meeting is held on 2.3.2001 between the medical staff and the Social Services Department from the Local Authority. The minutes of the strategy meeting note that "a medical perspective regarding [Melissa's] needs has been thoroughly investigated by paediatrician and consultants." It is reported that "All medics concerned are of the opinion that there is no organic cause for [Melissa's] faltering weight." At this meeting it is decided that a Care Order would be sought from the Family Court in respect of Melissa.

Later in the day, a clinical assessment by the Paediatric Neurologist confirmed by MRI scan establishes that Melissa is suffering from an optic chasm mass lesion involving the hypothalamus and the medial temporal regions, resulting in Diencephalic Syndrome. Consequently, legal proceedings against the family are withdrawn.

The Paediatric Oncologist reports that the MRI scan revealed a presumed hypothalamic glioma which was then stereotactically biopsied showing a pilocytic astrocytoma. "There was one mitosis

in the field and one Rosenthalor fibre among the tumour cells and no evidence of necrosis." Melissa subsequently "underwent a years worth of chemotherapy on Vincristine and carboplatin." "However in October 2002 there was a progression of the tumour and we elected to treat her with radiotherapy that commenced in January 2003." During the radiotherapy a cyst developed that had to be drained. An MRI scan showed a post-radiation "reduction in the size of her recurrent tumour which was in the region of 30%–40%."

Sadly, a scan in February 2005 shows an increase in the size of the tumour. Melissa underwent surgery in April 2005. A left frontal craniotomy with a midline approach was performed, but "the tumour was unfortunately indistinguishable from the optic nerve." Although some tumour was removed, Melissa "subsequently has lost useful vision in her right eye (post surgery)." Useful vision in left eye has been retained with "decreased visual acuity." She is being referred for further investigation in the United States.

Some nine months elapsed between symptom onset and eventual accurate diagnosis. When the symptomatology of the case is assessed against the available knowledge, the delay is found to have been avoidable.

Discussion

I will address the significant questions, issues and evidence relating to the case, in the context of the relevant research.

The Frequency of Neoplasms in Babies and Children

One of the most important issues arising from the case, is the relative emphasis that should be placed on suspecting organic disease, as compared to suspecting child abuse. At the centre of this issue, is a question about the attention that ought properly be paid to the risk of diseases perceived as rare. The frequency and outcome of Neoplasm in children are therefore significant factors to be weighed in the balance. Young et al. (2000: 2144) point out that: "Although cancer has an annual incidence of only about 150 new cases per 1 million U.S. children, it is the second leading cause of childhood deaths." In the U.K. Stiller et al. (2004: 13) report that cancer accounts for "around 20 per cent of all deaths among children aged 1 to 14 years."

"It is a fact that in the United States and in most economically advantaged countries of the world, cancer kills more children over the age of six months than does any other disease" (Beyer, 1990: 2). "Cancer accounts for more deaths than any other disease and is the second most prominent cause of death among children and young people aged 1–14" (Parker et al. 1997: 20).

Cancer is, as Beyer (1990: 2) reports, "the number one disease killer in children from late infancy through early adulthood." It is "the leading medical cause of death in both males and females from age 1 to 34." (Beyer, 1990: 2). Drawing on the work of Parker et al. (1997: 20) and Young et al. (2000: 2144), Parisi et al. (1999: 283–297) reiterate this finding. "With the exception of accidents, childhood cancer is the most common cause of death in persons under 15 years of age (excluding the neonatal period) in the United States." Parisi et al. (1999: 283–297).

Given this level of frequency and the seriousness of outcome risk, it is prudent to consider cancer in the differential diagnosis of otherwise unexplained illness in children, particularly where symptoms are congruent with a diagnosis of cancer. There was a high degree of congruence between symptoms and the eventual, albeit delayed diagnosis in the exposit case.

The Frequency of CNS Cancers

CNS cancers "are the second most frequent malignancy in childhood and the most common of the solid tumours" (Gurney, Smith and Bunin, 1999: 51). "Astrocytomas account for 49.6% and 52.25 of CNS malignancies in children and young people under the ages of 15 and 20, respectively" (Gurney, Smith and Bunin, 1999: 53). "The average annual incidence of CNS cancers" varies only slightly by age from infancy to age seven and is higher in young males and among white children (Gurney, Smith and Bunin, 1999: 51–55).

Kumar, Jones and Tekkok (1990: 327) report that "The incidence of intracranial tumour was 1 in 25,000 live births, and 85% of the tumours were malignant." Visudhiphan, Chiemchanya and Dheandhanoo (1989: 72) found that brain tumors were the second most common neoplasm of childhood. Intracranial Neoplasm may be present in neonates and may form pre-birth. (Takaku, Kodama, Ohara, Hori, 1978: 365) reported "5 cases of brain tumor in newborn babies under 2 months."

The rate of CNS cancer has been increasing over the last two decades (Gurney, Smith and Bunin, 1999: 55). CNS cancers do not share the favourable prognosis of most other pediatric cancers and the overall survival rate, excluding astrocytomas "is probably less than 60%" (Gurney, Smith and Bunin, 1999: 55). "Leukemias and brain cancer accounted for 57% of cancer deaths in US children" (Ries, 1999: 166).

The Importance of Early Diagnosis of Paedeatric Neoplasm

The literature substantiating the importance of early diagnosis in this field, is extensive. In their review, Young, Toretsky, Campbell and Eskenazi (2000: 2144) argue that: "Early detection and prompt therapy have the potential to reduce mortality." In advice that was written to prevent the type of medical misadventure that occurred in Melissa's case, Ertel (1980: 306) warns that

"since tumor-free survival so heavily depends upon an early diagnosis, a high index of suspicion must be maintained for commonplace nonspecific symptomatology. The primary physician must pursue critical aspects of the medical history at the first suggestion of an atypical course."

Similarly, Starling and Shepherd (1977: 144) counsel that cancer in children,

"is often more insidious than in adults and may well mimic many other diseases, developmental processes, or childhood psychological problems. The knowledge that cancer kills more children than any other disease and the awareness of the presenting symptoms and signs may well save a child's life. Early detection with prompt, aggressive therapy is of paramount importance in achieving cures in childhood cancer."

The rationale supporting early diagnosis contains numerous factors. Early diagnosis "is absolutely necessary for surgical treatment," according to Takaku et al. (1978: 365). Tubiana and Koscielny (1999: 295) emphasise that the "main advantage of early diagnosis of cancer is the reduction of tumor size at initial treatment and thereby an increase in the proportion of patients without distant dissemination". They established that the relationships between early diagnosis and "tumor size, histologic grade, and lymph node involvement on the probability of distant spread" were highly significant. Their model demonstrated how early diagnosis could be successful in avoiding histologic progression.

For Martinez Ibanez et al. (1992: 42) early diagnosis and effective management of the side effects of chemotherapy "are key factors in the better prognosis and increased life expectancy" of children treated for neoplasm during the first year of life. "Early detection may improve patient outcome because late diagnosis of a brain tumor may affect brain tumor resectability, neoplasm stage, and risk of cerebral herniation" according to Medina, Kuntz and Pomeroy (2001: 255). "Early detection of these tumors can reduce overall morbidity and improve the patient's chances of returning to a normal lifestyle" (Mason et al. 1996: 108).

Relationship factors are also important. "Children with cancer and their families benefit from early referral and a close working relationship between the oncology team and the primary care physician. In addition to providing or arranging psychosocial support, the primary care physician can assist in numerous aspects of care." (Young, Toretsky, Campbell and Eskenazi, 2000: 2144) These factors are further elaborated by Ertel (1980: 306), "the primary clinician should maintain close contact with the patient not only to provide medical and psychological support, but also to monitor the clinical response or side effects of therapeutic agents and to serve as the patient advocate at times of great personal and family need."

There is extensive evidence that the benefits of early diagnoses are numerous. Conversely, for children whose diagnoses are delayed, the risks are therefore considerable.

How Easy is It to Diagnose Intracranial Neoplasm?

As adjuncts to clinical assessment, MRI and CT scans are the most powerful, though not infallible, tools for diagnosing the most common forms of cancer in children. Considerable debate exists over the relative merits of each and the point at which radiological referral should occur. Citing Dunnick and Connan (1994: 527–529) and McClennan (1994: 29:S46–S50), Medina et al. (2001: 256) point out that "CT traditionally has been the imaging study of choice because of its availability and lower cost per case. However, CT has disadvantages, including posterior fossa beam

hardening artifacts and potential iodinated contrast reaction."

On the other hand, they cite evidence from Bell (1996: 10–25) and an American College of Physicians Revised Statement regarding Magnetic Resonance Imaging of the brain and spine (1994: 872–875) to establish that "MRI with its high soft-tissue characterization, multiplanar capability, and lack of ionizing radiation has emerged as the technically optimal imaging modality. However, its added cost and time, higher sedation rate, and limited availability has hampered its universal use as the first imaging modality." Medina et al. (2001: 256).

Nevertheless, it can be argued that the difficulties associated with radiographic diagnoses arising from sedation, are not substantive. On the contrary, they relate to the absence of appropriate protocols, rather than to intrinsic pharmacological factors. Beebe (2000: 205–210) established that when the University of Minnesota protocol was used for Magnetic Resonance Imaging of children, that safety and accuracy were achieved over a three year period. They report that "91.8% (525/572), of the MRIs were successfully completed in 445 patients" and "There were no deaths or unexpected admissions as a result of the sedation program."

It is most noteworthy in Melissa's case that the Paediatric Neurologist was able to make a correct diagnosis on clinical examination, that was later verified by MRI scan. This demonstrates the importance of referral to the correct specialism. A referral was made to a Speech Therapist, with very little justification, whilst a specialist Neurological referral was significantly delayed.

In What Circumstances Should Testing for Intracranial Neoplasm be Undertaken?

There is a general consensus in the literature that Neurological assessment should precede Radiological testing. There is less clarity regarding the factors that justify specialist Paediatric Neurological assessment. There is also considerable difficulty in assessing children who are neither ambulatory or vocal.

Lewis et al. (2002: 490) identify the main variables "that predicted the presence of a space-occupying lesion." These "included 1) headache of less than 1-month duration; 2) absence of family history of migraine; 3) abnormal neurologic findings on examination; 4) gait abnormalities; and 5) occurrence of seizures."

Young and Salcman (1987: 149) report that "Early general signs, such as headache, seizures and psychologic changes, are followed by specific localizing signs that can be elicited by meticulous neurologic examination. A computed tomographic scan should be obtained long before signs of increased intracranial pressure appear."

Young et al. (2000: 2144) argue that "Diagnostic imaging of the brain is recommended if headaches are awakening a child from sleep, are associated with neurologic signs (including seizures) or occur with vomiting in the absence of a family history of migraine."

The general position taken in Barnes' Editorial (2002: 67), is that, "the key to properly "triaging" these children, whether at initial presentation or on follow up, is a thorough medical history and physical examination, including a detailed neurologic assessment."

Barnes (2002: 67) also points out that headache is "a common and nonspecific symptom in childhood and adolescence," "that when isolated is diagnostically "low yield" for significant pathology. However, the significant pathology that may be associated with headache is "high-risk" when one considers the catastrophic outcome from a delayed diagnosis, particularly for children with space-occupying intracranial lesions (SOL)."

In their Cost-Effectiveness Analysis of Diagnostic Strategies for assessing children with headache suspected of having a brain tumor, Medina et al. (2001: 255–263) argue that radiological scans should be undertaken for those children assessed as high risk due to an abnormal neurological examination. Nowhere in their report is it indicated whether they recommend that the neurological examination be undertaken by a Paediatric Neurologist or by a Primary Care physician. They do not assess the relative risks of aneasthesia/sedation following different protocols. Nor do they take account of the data on incidental findings.

Incidental findings have now been found to be significant in apparently healthy subjects, not merely those referred for other suspected illness (Kim et al. 2002: 1674). In a retrospective review "of 225 conventional brain MR imaging studies obtained during structural and functional brain imaging research in a cohort of neurologically healthy children (l00 boys [44%] and 125 girls [56%]) ranging in age from younger than 1 month

to 18 years… Incidental abnormalities were detected in 47 subjects (21%)" (Kim et al. 2002: 1674) Of these, "17 (36%) required routine clinical referral; a single lesion (2%) required urgent referral." (Kim et al. 2002: 1674).

Incidental findings have been found to be so significant that the entire issue of the American Journal of Neuroradiology in which Kim et al.'s, 2002 article was published, was devoted to the topic. The extent of indicative findings provides evidence to support erring on the side of specialist referral and testing in cases of unexplained illness.

Pain in the region of the head, vomiting, loss of appetite and hyperactivity despite serious weight loss were among Melissa's symptoms that were congruent with brain tumour. Correct diagnosis would have been made more difficult by her inability to communicate verbally and by her non-ambulatory status. However, these factors are reasons for allocating greater care in assessing whether organic disease is present. They do not justify a pre-emptory resort to Child Protection concerns. Since early diagnosis in this area can be made with relative ease and modest expense, appropriate testing is clearly more favourable than the risk of misdiagnosis or delayed diagnosis.

Time Lapse Between Symptom Onset and Diagnosis

The warning by Salander et al. (1999: 143) is apt: "The time between experiencing symptoms and treatment in cancer diseases is a time of insecurity and despair. Brain tumour disease is a severe disease with dramatic manifestations and it is important that this time be kept as short as possible."

Several studies have measured the lag between symptom onset and diagnosis. Flores et al. (1986: 684) found that "patients with brain tumors had a significant delay from symptom onset to diagnosis." Nevertheless "38% of primary brain tumors were diagnosed within the first month after the onset of symptoms." Visudhiphan et al.'s (1989: 102) Thai study, found that: "The duration of illness before admission ranged from a few days to 4 years, with over 70 per cent within 3 months."

Pollock, Krischer, and Vietti (1991: 725) measured "Lag time (the interval between symptom onset and diagnosis)" "for 2665 children with lymphoma or a solid tumor who participated in Pediatric Oncology Group therapeutic protocols from 1982 until 1988." They estimated that "Median lag time ranged from 21 days for neuroblastoma to 72 days for Ewing sarcoma."

Gatta et al.'s EuroCare study (2003: v119) concluded that: "The Nordic countries represent a survival gold standard to which other countries can aspire. Since most childhood cancers respond well to treatment, survival differences are attributable to differences in access (including referral and timely diagnosis) and use of modern treatments; however, the obstacles to access and application of standard treatments probably vary markedly with country."

Reasons for Delay in Diagnosis

The most significant findings in Pollock, Krischer, and Vietti's (1991: 725) analysis of the factors implicated in diagnostic lag were that "Type of tumor and age were strongly associated with lag time. Within diagnostic groups, age, gender, and race failed to explain more than 16% of the variance in lag time, suggesting that other factors may play more prominent roles."

Ertem et al. (2000: 453–7) contest that "The diagnosis of an intracranial mass is usually delayed, because more common causes of wasting are investigated at first." Not considering brain tumour early in the diagnostic process can result in delayed diagnosis (Young Poussaint et al. 1997: 1503). "Salander et al. (1999: 143) reported that "'physician's inflexibility' and 'physician's personal values' were identified as obstacles on the pathway to appropriate medical care."

In the exposit case, the mindset produced by MSbP/FII discourse, displaced appropriate and necessary medical investigations that could have produced a timely and correct diagnosis.

Relationship Between Failure to Thrive (FTT) and Diencephalic Syndrome (DS)

Diencephalic Syndrome (DS) is one of the most serious causes of Failure to Thrive (FTT). "The most common feature of DS is severe FTT, which is reported in all patients." Ertem et al. (2000: 453–7). In "infants with unexplained failure to thrive, the diagnosis of diencephalic syndrome should be considered. (Young Poussaint et al. 1997: 1504) Ertem et al. were concerned that Diencephalic Syndrome had "received little mention in pediatric gastroenterology literature" and was often overlooked. Their report (Ertem et al. 2000: 453–7) was "intended to alert the pediatric

gastroenterologist who might have first contact with these children who have profound weight loss." They emphasise the following:

"Diencephalic syndrome may easily be overlooked in the differential diagnosis of FTT during the first few years of life. Widespread use of computed tomography and MRI has made the diagnosis more easily and quickly obtained. Such radiologic investigations should be included in the work-up of an emaciated child when the reason for the nutritional state is not clear.' Ertem et al. (2000: 453–7).

Summation

Matching of Melissa's symptoms with the indicators of intracranial tumour indicates a high degree of congruence. With appropriate assessment and testing, the medical misadventure occurring in this case was avoidable. The conclusion that there was "no organic cause" for Melissa's condition, which girded the Child Protection perspective, was made prior to the appropriate tests having been undertaken and was therefore pre-emptive.

The case presents evidence of delayed diagnosis in an area where early diagnosis is particularly important. The Child Protection approach to the case is implicated in the delay in securing an accurate diagnosis of the child's condition. Neoplasm in babies and children is not so rare that it should be excluded from the differential diagnoses in cases where 'failure to thrive' is evident. Young, Toretsky, Campbell and Eskenazi (2000: 2144) advise that "Primary care physicians should be alert for possible presenting signs and symptoms of childhood malignancy."

The documents demonstrate the presence of two narratives, the parents' and the professionals'. Very little disagreement between the professionals is in evidence up to the point where the services of a Paediatric Neurologist were secured, some nine months after the original symptoms appeared and long after the Child Protection view had become entrenched. The parents' desire for oncological testing was appropriate to Melissa's real needs but it was misconstrued through the judgmental narrative of professionals on the case.

Appropriate parental behaviour was easily able to be interpreted as falling within the MSbP/FII profile, for example, requesting tests which medical personnel felt were unnecessary, requesting a second opinion, anxiety over the treatment being enforced by the medical personnel, non-cooperation with treatment that they believe is ineffective and counterproductive. This shows the danger of overly judgemental, imprecise discourse.

No counseling or pychosocial support was offered to the family during what was clearly a profoundly difficult time. The parents felt that their child was dying of cancer and appropriate diagnostic tests were not being undertaken. No empathy for their plight is apparent in the documents and despite criticism of their parenting skills, no guidance on parent child interaction appears to have been offered. Despite the clearly deteriorating relationship between hospital staff and the parents, no mediation services were sought.

Even when Melissa's nystagmus had been noted by the gastroenterologists, the child protection strategy continued unabated. A Paediatrician from the Child Protection Unit, who has subsequently been found by the General Medical Council to have been responsible for numerous false allegations of child abuse, was placed in charge of the child's hospital admission. Fortunately, referral to the Paediatric Neurologist was also made at this time and this latter referral resulted in an accurate, though tragic, diagnosis.

According to documentation, twelve professionals attended the planning meeting and seven attended the Child Protection Inter-agency strategy meeting. Yet not one, appears to have placed on the record, a concern that the parents' views ought to be given serious consideration. Even though Melissa's nystagmus was mentioned during the strategy meeting, referred to as "shaking in the eyes," it did not deflect the assurance that Melissa's condition had "no organic cause." This phenomena may be referred to as a manifestation of what Janis and Mann (1977) termed "Groupthink" resulting in "risky shift" thinking. The role of power in the production of diagnostic 'truth' is evident. Baldwin (2006) has also noted the role of "risky shift thinking" in the case of another Child Protection misadventure.

If this type of misadventure is to be prevented, change is needed. The case study supports arguments for working in partnership. Concordance, rather than authoritarian practice, would have been more closely centred in the child's best interests. Indeed, current European legal precedents, re-enforce the need for working in partnership with parents (for example, Venema v The Netherlands and TP and KM v The United Kingdom.)

The exposit case demonstrates how a child may be endangered when Child Protection discourse is substituted for appropriate investigation of possible organic causes of her condition. So serious was Melissa's malnutrition that she was on the verge of multiple organ failure when the intervention of a Paediatric Neurologist was sought. An accurate diagnosis of the tumour pressing on her optic nerve was thereupon obtained.

The full organic, social and psychological implications for the child require long term assessment. As a consequence of the delayed diagnosis, significant pain relief and surgical, chemotherapeutic and radiological treatment were delayed. This demonstrates an unacceptably high degree of serious risk and harm to the child. Erring on the side of suspecting MSbP/FII was not erring on the side of the child.

Conclusion

The discourse of MSbP/FII has been linked to medical, forensic and legal misadventure. In the exposit case, the misdiagnosis of child abuse, delayed accurate medical diagnosis and caused serious harm to a child. It is imperative that suspicion of child abuse does not displace appropriate medical investigations.

Learning Points

- The differential diagnosis should afford due diligence to the consideration of the views of service users and their advocates.
- From the outset, the differential diagnosis should allow for relevant rare medical conditions of a serious nature.
- Claims of "no organic cause" for illness are vulnerable to refutation and should be avoided.
- The threshold for referral to relevant medical specialists should be lowered, especially where pediatric neoplasm is, or should be, included in the differential diagnosis.
- Consultants should make Primary Care Physicians aware of the limits to their knowledge and suggest referrals to other specialisms where appropriate.
- A risk analysis should properly weigh the costs of undertaking tests requested by service users against the risk of delayed diagnosis.
- Erring on the side of diagnosing child abuse, may not "err on the side of the child." Judgmental narratives can have an adverse impact on accurate diagnostic practice.
- The potential for "Groupthink" to produce "risky shift" judgment in the context of Child Protection multidisciplinary teams, needs to be considered.
- Strategies involving empathy, communication, mediation, negotiation and conflict resolution should be trialed, in cases where suspicions of child abuse have arisen,
- Policy, protocols and guidance relating to Munchausen Syndrome by Proxy/Fabricated and Induced Illness must be re-written to better protect the interests of health and social care service users.

Further Research

Strategies involving empathy, communication, negotiation and conflict resolution should be trialed, in cases where there is no unequivocal evidence of abuse. There may also be a case for researching the deployment of these strategies in cases where abuse is evident.

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