AIMS For a better birth...

Post Traumatic Stress Disorder

AIMS Journal 2007, Vol 19, No 1

Jean Robinson asks,`Where do we go from here?

The horror stories still come in from mothers, and I could weep at every one, because almost every case is avoidable.

It is nearly 35 years since I waded through hundreds of letters about induced labour when I was Chair of the Patients Association and realised that what many of the women were describing was like the shell shock I had read about in the histories of the first World War. But those mothers were in limbo: they had a condition which officially did not exist.

We now have a name for it: post partum PTSD, and because it has now been officially named, and described in medical journals, it is more likely to be recognised and understood. But as consumers we have failed to bring about primary prevention, partly because there are multiple causes, which continually change and intertwine as maternity care and its organisation develop.

However one essential factor, common to all mothers' stories, is the problem of staff behaviour and attitudes. Even a home birth can cause PTSD when a midwife is set on giving a hospital birth at home. From 40 years experience AIMS knows how difficult it is for institutions and health care professionals to recognise and admit that staff behaved badly. The defensive culture has changed surprisingly little.

Now consumer groups need to think more strategically.

How consumer protest began

The early 1970s was a time when obstetric enthusiasm for inducing and speeding up labour with an oxytocin drip dominated maternity care. In some hospitals 60% of births were being induced. Before dating scans arrived, expected date of delivery was more likely to be inaccurate, and still isn't 100%. Many of the women had an unripe, tightly closed, cervix (prostaglandins to ripen the cervix were still to come). The effects of the oxytocin dose were unpredictable. Intense, uncontrollably frequent or continuous contractions, pushed against a tight outlet causing levels of pain way beyond those of Nature's devising were common. Epidurals were not yet widely available, and standard pain relieving drugs like pethidine were, and are, known to be inadequate for severe labour pain. I hastily started reading the studies on induction, but the obstetricians - enthusiastic about their `success´ rates - said nothing of the after-effects on the women1.

It was not until much later that the psychiatric journals began describing American veterans of the

Vietnam war. Post traumatic stress disorder was described and given a name, and I realised that it also applied to mothers who had had such birth experiences. It was to be many years before research started looking at PTSD after childbirth - and it was consumers who pushed them, by pressing for researchers to take a broader view of effects of intervention. Beverley Beech and I wrote to the British Journal of Psychiatry over twenty years ago, pleading for doctors to take an interest in the many women who were having nightmares after childbirth[2] but got no response. Did doctors take so long to get around to it because it is uncomfortable for them to admit to damage actually caused by themselves or their colleagues rather than enemy bombs and bullets[3]? Even worse, research might provide evidence which could be used in litigation, if injured mothers decided to sue.

Just as soldiers had PTSD long before the diagnosis existed, I realised from histories and memoirs, women had been traumatised by childbirth long before oxytocin. Why had generations of psychiatrists dealing with all those seriously `depressed´ women not identified or written about a problem we had recognised after listening to, or reading the first dozen or so accounts from the women themselves?

Problems in research

The initial research was done on former military personnel. This was followed by studies of others likely to be exposed to trauma in their jobs, like firefighters and the police. So the foundation literature, and the development of criteria for diagnosis and methods of treatment, were based on a largely male population of a particular kind, and was not particularly suited either to women, or to the context of childbirth. At first it was thought PTSD only happened to people who had been exposed to extraordinary events - but childbirth was not like a train crash, or an explosion. Many women's accounts of their experiences I have read seemed more like the descriptions of rape or torture victims than those military or disaster studies. Soldiers at least expect the enemy to try to kill them; women were faced with harmful care from those they expected to be kind - and while inflicting pain on, or exposing, private parts of their body.

We have seen a couple of postnatal cases where treatment for postnatal PTSD by psychiatrists experienced in treating the military, which included group therapy, was disastrous. I felt strongly that it had to be approached from a different angle.

In her impressive PhD research, Susan Ayers found that women who were profoundly disabled by their condition, nevertheless did not meet all the standard criteria for existing PTSD diagnosis[4].

Unfortunately the useful summary she was finally able to publish in Birth had to omit much of her data[5]. Fortunately more work has now been done on post birth trauma alone, but I feel that not all researchers have understood the complexity of childbirth emotions, and direct accounts from women tell us so much more. In our tiny office at the Patients Association I had been dealing with hundreds of complaints about every kind of medical care, but the childbirth letters stood out. It was their vividness, and the intensity of memories described which made me realise something was happening. It was not just letters from mothers, but those from grandmothers that taught me that memories of childbirth experiences remain for a lifetime - something which research confirmed much later[6].

For the first time I started reading the medical literature, trying to link doctors' findings with what women experienced. I joined AIMS, where Beverley Beech and I worked together, with a huge input from the committee. We are grateful to the many women who gradually were able to share their stories with us, sometimes taking months to do so. We seldom take such detailed histories now, unless the woman wants specific help with a complaint or feels she would like to tell us, because we know what a high price the woman pays in re-living her experience. We consider it unethical because we are not therapists, and we are not usually there to help pick up the pieces. We learn less than we would like nowadays, and get more `bitty´ stories, but it seems the right thing to do.

At first I thought that PTSD was a new problem resulting from intervention and the new obstetrics, with supportive care reducing the risk or the intensity of damage. As time went on, I learned it was more complex than that. AIMS has even seen cases following home birth when women were unsympathetically treated. Postnatal mental illnesses can also include many aspects. Surprisingly often we found that unresolved grief from recent bereavement, or a previous miscarriage may also be part of the picture, and has been missed. Although unnecessary, and unwanted, intervention still appears in more recent stories, shortage of staff and pressures on them have become a more obvious contributing factor nowadays.

It was from women's stories, describing the pattern on the curtains, the scent a midwife was wearing, the expression on a doctor's face, many years after the event, that I realised that when in labour, giving birth, and getting to know and suckle the baby, the woman's hormonal state is designed to make her acutely aware of, and to bond with, the newborn. This hyper-awareness makes her acutely vulnerable to any harmful or malevolent influences around her. Intuition seems to be heightened. Unkindness, brusqueness or cruelty at this time can go so much deeper, do so much more harm, than at other times. Similarly, the right kind of empathy and support can bring long-term benefit, and many women have told us how a good birth has helped to heal previous damage. It seems as if the psychic protective skin of the labouring woman has become paper thin, in order to open her up spiritually, as well as physically, to birth and receive the newborn. Psychologically and spiritually she is ultra-vulnerable, just as the sufferer from immune deficiency is vulnerable to any toxic bug going around.

The literature has not paid nearly enough attention to this point. However, this aspect needs to be studied, and emphasised in training, because it puts greater responsibility on individuals and institutions which provide maternity care. I had already seen many complaints about gynaecology, and women were

sometimes profoundly distressed, and even traumatised. But the birth complaints were something else. It was because I was dealing with 100 complaints a week about every aspect of health care at the Patients Association, that I was able to see this difference.

The same triggers which cause PTSD can also cause psychological birth trauma which does not last long enough to rate the PTSD label (though it can be followed by longer term depression). It is more common, so affects even more women

After I naively began reading medical journals, I soon realised that the direction research takes is not purely `scientific´, but it is influenced by all kinds of political, commercial and cultural forces

Understandably, researchers have looked at which women may be more vulnerable because of preexisting problems - for example those who have already suffered some previous trauma, or have a history of mental illness, and this has become a strong trend in the research. But how much does this knowledge actually help women unless we can afterwards guarantee their care is right? We have known cases where that information actually did harm. Just as surgeons know there is always a possibility that the patient may have previously unknown risk factors, so do midwives. The answer is not - as has been suggested - to quiz all pregnant women about intimate histories they may not want to disclose, which will be forever displayed on their case notes, but to see all women as vulnerable at this time, and to treat them, their babies, and the bond between them, sensitively and respectfully.

After decades of supporting health care complainants I knew how quickly anyone who made a complaint was labelled as hysterical or unbalanced, (nowadays the buzz word is `aggressive´) and how any previous episode of mental illness was used to dismiss the complaint or to ward off potential litigation. The retaliatory `blame the patient´ culture is deeply embedded, and I knew only too well how such information was likely to be used, however pure the intentions of the researcher. Many complaints, of course, don't even get to first base, because they are outside the six months time limit, which is totally inadequate for those with PTSD. The Chief Executive receiving a complaint usually contacts the consultant, so midwives and junior doctors may be unaware of the devastating consequences of care in which they took part, or observed.

But the worst aspect of researchers' concentration on identifying and cherry- picking the `vulnerable´, is that it has drawn attention away from primary prevention. In labour and after birth ALL women are vulnerable - including the middle class, (see Sarah Quipp Stenson, page 14). The actions and attitudes which increase the chances of a woman getting PTSD are crystal clear from an analysis of women's stories. Some are caused by ignorance, some from poor training, some from pressure and overwork, and a few from individuals whose behaviour is described by a number of women over a period of time - health care professionals who are toxic to the psychology of the birthing woman. For example coerced `consent´ is part of many accounts, and there are clearly professionals who do not understand that informed consent cannot exist without informed refusal. Our impression is that women with previous trauma may develop PTSD from what an outsider might consider lesser adverse events, but that no woman - even the strongest - is immune, however stable her previous mental health and background.

There are still gaps in the research. We do not really know about incidence in the UK. Studies of particular centres give a snapshot of one place, at one time.

Projections have been made from local studies, for example, Ayers' study at one London teaching hospital found 2.8% had PTSD at six weeks and 1.5% at 6 months, which if applied nationally, could mean 10,000 chronic cases a year[5]. As yet we do not know how this compares with the incidence at other London teaching hospitals, provincial, smaller hospitals, midwifery units, or home births. Is it higher or lower in Scotland,Wales and Northern Ireland? We should know, because it is a crucial part of measuring quality of care. If, as we suspect, the incidence is lower for comparable low- risk births in midwifery units, this makes them more cost effective.

The incidence, and long and short term effects of post birth emotional trauma which does not last long enough to be labelled PTSD, are woefully under- researched. Yet we know from women how devastating it is to them and their families, and it is more common than PTSD. It is not just the negative - it is the loss of the positive, of what birth should have been, which is deeply mourned, and this can cast a long shadow on the family down the years, just as a good birth can enrich and lift the quality of their life.

Problems with diagnosis

Damage from birth trauma is still under-diagnosed, and we suspect many women nowadays obtain help because they found out what the problem was themselves, or talked to a consumer group. We find they and their families are enormously relieved once they know what is wrong. Husbands and partners are also traumatised by the birth, and we suspect they are even less likely to be identified. Prompt diagnosis is essential, because long standing, chronic PTSD is much more difficult to treat successfully.

We still hear from women who, years after a birth, have `postnatal depression´ and are still on medication. They tell us about their nightmares, flashbacks, and how they cannot go near a hospital or watch a TV medical programme but it is a story their GP has not listened to.*When a woman does not improve, the diagnosis should be re-examined.*

When the Edinburgh Postnatal Depression Scale was introduced, the authors emphasised that a high score did not provide a diagnosis, but showed a need for further investigation However, health visitors and many GPs still assume that a high score means `depression´. Sufferers from PTSD are depressed, but tackling that problem alone does not provide a cure (although it may help with treatment), and as we now know, since health visitors became even more identified with the `health police´ many women lie in their responses[7] - often in fear of referral to social services and losing their children[8].

There are also many women who do not have PTSD, but who have long term depression which elements of a traumatic birth are intensifying and prolonging. They do not recover because this aspect is not acknowledged and dealt with. It has to be remembered that the same treatments, attitudes and behaviours which are causing PTSD are also causing more widespread damage which may be less intense but is harmful, and casts a long shadow.

Problems with treatment

When a woman contacts us with any medical problem and we can suggest an expert source of help near her, we always asked for feedback about her experience. The best source of help in PTSD cases seems to be individual therapists who have experience not merely of trauma, but particularly of childbirth trauma. These are scarce anyway, but even harder to find on the NHS, where all talking therapies are in short supply. The problem is compounded by the fact that Primary Care Trusts are very unwilling to pay for referral outside their own area, even if they have no specialist, but an adjacent area does. In their book any psychologist will do. So even after the woman has persuaded the GP to refer her in the first place, access to optimal, prompt treatment is harder to find for the patient who cannot afford to go private. In view of the seriousness of the condition, and its effects on the family, consumers should be fighting for more specialist care, and the right to referral.

We have also seen cases where semi-trained `counsellors´ and junior therapists way out of their league, have also done harm. We have also had bitter complaints about some general psychiatrists inexperienced in this field. It is now fashionable for GPs to have counsellors attached to the practice, with varying levels of training and supervision, and we have known many cases of mental health problems of all kinds where counsellors and therapists have got out of their depth, uncovered serious problems (including past sexual abuse) and left the patient floundering and worse than before. The same applies to midwives, who have made a disastrous stab at `debriefing´ (I was present at one such session which went badly wrong, and had to stay and help the parents afterwards.) It is, in our view, unethical to refer women with PTSD to those without appropriate experience and qualifications.

The future

We have to think out, and concentrate on a broader strategy for the future. Primary prevention is crucial. We propose the following:

1. Greater emphasis on research and obstetric and midwifery training on the psychological vulnerability of all women around the time of giving birth.
2. Funding of studies of incidence and causes of post birth trauma and PTSD rates in different birth settings and geographical areas. Quality ratings for maternity services to include psychiatric morbidity rates.
3. Investigation of procedures and personnel associated with damage in each case. Support for staff, retraining, suspension or dismissal if necessary - whatever is appropriate.
4. Abolition of the 6 month time limit for complaints; PTSD sufferers often would be incapable of doing so within that time - reading and writing about their experience provokes severe flashbacks.
5. Improve quality of postnatal care in hospital and at home - especially with continuous One Mother, One Midwife care. Restore daily home visits by midwives. This would prevent exacerbation of trauma damage, and also assist early identification of mothers who need help.
6. There should be an enquiry into the availability and effectiveness of treatment, and availability of specialist therapy for post birth trauma, and agreement to fund private or out-ofarea care where necessary. This can be funded by Trusts which caused the damage, who will then have greater incentive to work on prevention. Otherwise women will have a greater incentive to sue in order to cover the costs of private treatment.
7. Confidential Enquiries into Maternal Deaths refer only to postnatal psychosis or depression causing suicide. We think that more detailed enquiries might identify PTSD in some cases; this is known to raise the suicide risk.

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