

Reflections on delirium – A patient's perspective

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Abstract

Delirium, and its importance, is briefly discussed to contextualise the intricate story of one patient's experience of the condition. This recounting of the main episodes of delirium shows how its nature and severity changed with time and location, from ICU to the surgical ward. Reflection on these experiences provides insights and conclusions for consideration by the medical profession. Discussion of the nature of delirium, and the sort of interventions that helped, or might be provided, for recovery from, or reduction of, the condition are considered. Thought is given to what might be done to aid recovery and reduce severity. Some suggestions are made as to what education might be provided and the research required to better detect the condition and understand its nature and prevention.

Keywords

Delirium, critical illness, intensive care

I don't know where I am or where I have been, but I am suddenly awake and terrified! I am being held down by shadowy people who have a knife down my throat. They are demanding a ransom from my family who are far far away. All I can do is fight; fight for my life; keep on fighting with all my strength. It is kill or be killed!

Introduction

Delirium, as a condition, its identification and amelioration; its emotional and physical impact on the patient and relatives; and its effect, both clinical and financial, on the National Health Service (NHS), is rarely high on any list of priorities of healthcare professionals. It is frequently found only when an ex-patient is, subsequently, able and prepared to talk about their experiences that the full force and importance of the condition is brought home to nurses, medics and others.

This is surprising, since it is estimated that between 16 and 80% of hospitalised patients are affected,¹ with those in the ICU at the highest risk, and that the cost to the health system can run into many thousands of pounds per patient.² In addition, longer term outcomes are also severely compromised, both for future mental health and mortality rates, with a significant increase in the latter being recorded for patients who have experienced delirium.³

On the other hand, this apparent lack of awareness of the condition is probably not so surprising. Much of what is going on inside the patient's head is frequently not overtly manifested in observable behaviours, the so-called hyper state, and when it is, may be of perceived minor importance in the face of other, more immediate and manifestly life-threatening, infections or trauma. In the list of treatable or preventable conditions, it does not rank very highly.

As one of those patients who has gone through several weeks of delirium of various types and levels of severity, I have, on several occasions, spoken to a large number of health professional groups. In so doing, I have been surprised by how relatively unaware they have been of the condition and its impact on the sufferer. Typically, only when encountering the disorder in the ICU has its significance been recognised, and then more usually by the nursing and auxiliary staff. It is also noticeable that, for whatever reason, non-ICU staff and medics have been poorly represented at most conferences and seminars I have attended where delirium has been discussed.

As a consequence of my experiences, and incidentally as part of my self-devised rehabilitation, it has

A Previous Intensive Care Unit Patient

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become my mission to get delirium a higher profile. Amid all the demands placed upon emergency and ICU staff and beyond, I accept this is difficult and a lot to expect. It is, however, in my opinion, as important as pain and its relief and the recently highlighted condition of sepsis – both of which are closely associated with, and affect the onset and severity of, delirium.

With the new emphasis being afforded to mental health in the recently announced 10-year plan for the NHS in the UK, now is perhaps an opportune moment to get delirium firmly on the agenda. For it to be given a wider profile beyond the ICU and, perhaps, eventually to make its way onto the medical and other health workers, initial and in-service training curricula.

To highlight the importance of the condition, it can be useful to see it through the eyes of a sufferer. As I have already noted, I went through a prolonged period of distress, during the best part of a week in the ICU and for further weeks on the surgical ward. Since then, I have had time to reflect upon my experiences and draw out some conclusions from the general mist and entanglement of delirium.

What did I experience?

As my condition progressed, and I moved to different bed spaces within the ICU and finally onto the surgical ward, so my experiences changed and developed. The episodes of delirium I experienced ranged from absolute terror and fear; through anger, the unnerving and bizarre; to paranoia, the annoying, interesting and, with hindsight, the vaguely funny.

The opening paragraph to this paper is but a feeble attempt to put into words the enormity of the absolute terror of being suddenly catapulted from some eternal blackness into the hands of terrorists who were going to kill me. Totally on my own with nobody to help, it was the most traumatic episode of my life. It has left a deep emotional scar that still hurts years later.

I was frightened on several nights by the appearance of eerie children at the foot of my bed. With long black wavy hair flowing down their backs they never turned to face me but moved very slightly almost turning towards me. They were very sad as they had been exiled and would never return home. Made of chocolate, they were part of an exhibition to illustrate a Cretan myth that two, self-congratulatory consultants had arranged. Despite shouting at them, they never acknowledged my anger at their irresponsibility.

A nurse, who had recently been in India, came on a number of occasions to sit beside my bed where he practiced what he had learned from his guru. He could produce a low hum while still carrying out a conversation. More spectacular and bizarre however, was his new found ability to take his food. He would place columnar biscuits, about 5 cm tall, on the table

and, with a quick downward thrust of his head, ingest them through his nose!

Other upsetting and annoying scenes also played out during my time on the ICU but on moving out to the surgical ward I became paranoid. Convinced that I was in a small, poorly funded cottage hospital, I was certain that the staff resented having me there, as I was a serious drain on their resources. They were constantly trying to get me removed and annoyed with me and the demands my condition was making on them. This cottage hospital scenario developed into a complex, soap opera of events that included the continued plotting against me and the repeated demands every morning at the back door (despite the ward being eight stories up.) by the local homeless for food, with the threat of violence if not forthcoming. The constant barking of a huge blue dog that lived in the corrugated iron-roofed sluice in the backyard and the torment of not being able to join in the breakfasts and late night tea parties (I was nil by mouth for over three weeks) were some of the other episodes I experienced.

I was fascinated at the sight of a new patient being brought into ICU whose bed was surrounded by banks of plastic lemonade bottles with yellow drinking straws in them. I was both intrigued, and at the same time rather put out that I was not having this same up-to-the-minute advanced treatment that he was getting. I was also fascinated that I was being fed only sardines. The pump connected to the feeding tube was obviously a sardine tin; I could clearly see the sardines when it was opened!

On being taken into a lift, it became a stifling hot red room with black spiders and flies everywhere, crawling among marching purple trees that looked as if they had been taken from a Matisse collage.

These, and many other episodes, filled my days and, more importantly, my nights. They kept me awake, on edge, and on the brink of despair. Their intensity did not diminish, only their frequency eventually.

I have provided here what I hope is a flavour of what one patient's suffering of delirium is like. I have not mentioned all the different episodes or the details within them; that I have written elsewhere as part of my coming to terms with my experiences.

It is also important to note that even after leaving hospital there has been a recurrence of incidents. For some time, there was a wariness of crowds and not wanting meet anybody outside the immediate family. Many months after my discharge from hospital, I was 'visited' by the same people who had threatened to come into the hospital if not fed. They stood for some time at my bedroom door. When feverish during a bout of urinary infection, I was concerned that the chocolate children knew where I was and asked my wife to make sure they were kept away. I am told that I have had disturbing dreams, causing me to shout and thrash out, although I do not

recall them. I have also awakened to a rotting corpse beside me in the bed. Momentary flashes of fear and anxiety, but enduringly disturbing.

What have I learned?

I have reflected on my experience and come to some conclusions that might be useful when considering the condition.

The most important of these, and one that I emphasise regularly when given the chance to talk to the medical profession, is that delirium is real for the patient. This cannot be stressed enough. Delirium is a true, actual and powerful experience and to say it is merely imagined, or that the patient is confused, is to severely diminish the significance of the condition. I was sometimes perplexed, but I 'knew' things were actually happening. I was not confused. I was actively caught up in the situation surrounding me and clearly understood what I was doing and why. What long-term memories I have of a month in hospital are dominated by the periods of delirium. Only the more dramatic, or out of the ordinary experiences, such as visiting the CT scanner or having a third chest drain inserted by the radiographer, are equally memorable.

Delirium can take on a life of its own and become a long-lasting, soap opera-type experience: the same situation being revisited time after time over a period of days. Characters develop and new ones enter the scene and the story the patient is living through becomes more and more complex. Details emerge filling in the narrative and making it more convincing. I remember, for example, the colour, smell and texture of the biscuits the nurse was ingesting through his nose and the fact that the table he was sitting by was a small card table and covered in white heat rings left by hot coffee cups.

I found that my delirium tended to be either 'set', or actually happened, at night. Consequently, a fear of the night and being left alone became all consuming. This fear can be compounded when the patient is moved from ICU, where there is constant attention and company, to the main ward where, understandably, there is much less personal attention. This feeling of isolation is possibly worse when the patient is in a single room. While the privacy and use of an ensuite bathroom is normally to be welcomed, if the patient is lonely and fearful, then a means of countering it needs to be sought.

While not associated with a delirious episode, this situation of being alone also contributed to another incident that had a profound emotional and psychological impact. The first sight I had of myself in the mirror, as a wasted, emaciated old man, occurred when I was alone. To see my father, hours before his death, staring back at me was very hard to take and left me profoundly depressed and with suicidal thoughts for some time.

During an occurrence of delirium, everyday items and language can be interpreted to 'fit' the episode. While fighting terrorists, I clearly recall them saying 'Put him down' which was presumably nursing staff, suggesting that I should have further sedation. For me, this meant something much more sinister. Equally, soap and paper towel dispensers, wash basins and taps and clocks all took on menacing significance once the lights had been dimmed for night. Similarly, the barking of the blue dog was almost certainly the sound of the vacuum tube system that took the blood samples up to the laboratory every morning.

Since leaving hospital and having read around the topic, it occurs to me that the hypo/hyper classification might need to be rethought. In particular, the hypo state that describes the withdrawn passive patient. I think there might have been times when, although possibly presenting as being in an unresponsive state, I was in fact scared, angry and highly verbal, but without any outward indications as to what was going on in my head. It is at this point that I come perhaps to the nub of the issue. Detecting delirium is difficult. Even I, as a reflecting ex-patient, am not sure I can describe with any real accuracy what I went through. The incidents I have described may only be part of my experience, and there may have been times when other events were neither visibly or audibly evident to nursing staff, nor even remembered by me. How is delirium detected when it is not overtly observable?

The current CAM-ICU instrument leaves a lot to be desired. When administered (at least when I remember it being administered), I simply found it to be annoying and pointless, and certainly it was not detecting any delirium. If, on the other hand, it is administered only when nurses have the time, particularly on the busy non-ICU ward, then episodes may well be missed. Equally, since many episodes occur at night, and with a regime that tries to encourage normal circadian rhythms, administration at night might be seen as intrusive and counterproductive with a consequent under detection of the condition.

Finally, it is interesting to note that, on the final discharge report sent to my GP, no mention was made of the fact that I had suffered from delirium. Was this because it was not thought to be useful information for my GP, or had it not even been reported in my medical notes?

What has helped?

Since returning home, I have tried to come to terms with my experiences. Obviously getting into as normal a rhythm of life as soon as possible is important. However, I personally felt I had to openly confront what I went through. At first, this was simply to talk to family and friends about the experiences and, in so doing, release the emotional pressures. By sharing the

terrors and fears and easing tensions through tears and embraces, a slow coming to terms is being achieved. With an academic background to fall back on, some more intellectual engagement with the condition also played an important part in my personal journey, hence the participation in conferences, the writing down of details and the present article.

Another important aid was the patient diary that had been written for me by nurses and family. Reading it at a time of my own choosing, it filled in important gaps in the amnesia of the first week of illness and located some of the traumatic episodes I had experienced to a place and time.

While these are things that have helped me, I know that other ex-patients benefit from such things as painting and drawing, music, movement and pet therapies. A common, and hugely important, aspect of recovery would seem to be the sharing of experiences with other sufferers, since they are the only ones who can truly empathise.

What might be done?

After thinking about these issues, it is possible to come up with some suggestions as to what might be done to help alleviate and improve the situation surrounding delirium. This can be thought of in terms of recovery, reduction, education and prevention.

Recovery

Once out of hospital, there is very often a need for continuing and sometimes, long-term support for both patients and relatives/carers. While this can be usefully provided in follow-up clinics, these can be rather short and medically orientated. Emotional support is much more subtle and difficult to provide. Professional psychological help is provided for those who are suffering from post-traumatic stress disorder (PTSD). However, some patients may not wish to acknowledge that they have a mental health condition and shy away from this 'professionalised' approach. Furthermore, until someone has actually experienced delirium, it is difficult for an outsider to fully appreciate and empathise with the suffering. It is here that the ex-patient support group can play a hugely important role. Supported by professionals, these more informal meetings can be an extremely useful and, incidentally, cost-effective, means of providing empathetic support for both ex-patients and carers. While a few of these groups have been set up around the country, there does not seem to be any general network. The ICU-Steps programme provides a comprehensive set of guidelines,⁴ and it is to be hoped that more of these groups would be actively encouraged if a critical mass of appropriate ex-patients can be identified to help take them forward.

In conjunction with such initiatives, some thought needs to be given as to how such support could be

provided for those patients who do not have easy access to urban meeting places, through innovative use of the internet perhaps.

Reduction

Given the lack of time available, particularly on the main wards, there would seem to be scope for volunteer support for overworked professionals. It is possible to conceive of some ex-patients being trained to offer a 'listening' service, whereby they can provide bedside empathy and perhaps help a sufferer to become more grounded in objective reality. Similarly, they might also be trained to administer some of the more simple diagnostic tools, or at least flag up to nursing staff the need for further investigation if delirium is suspected.

One simple way a volunteer force could be used would be to help orientate patients in their surroundings by taking them on a tour of the ward. My belief that I was in a small cottage hospital might have been quickly removed had someone had the time to wheel me out of my room onto the ward; show me where I was and generally introduced me to my new environment.

This volunteer force may be on hand all the time. Relatives are usually the truly trusted faces at the bedside and if they were allowed to stay for longer periods, particularly at night, the security their presence provides might well result in a reduction of fears and terrifying experiences and better sleep.

Assistance with mobility is another area where volunteer help might be used and which has been shown to be of great value in reducing delirium.⁵ Incidentally, a redesign of drip stands would help immensely in this aspect. Again, from my personal experience, it was impossible for me, with three chest drains, two drips, catheter, feeding line and oxygen supply, to get around without considerable and lengthy help. Had all the accoutrements surrounding me been on a well-designed, easy to handle, stand I could have been virtually independent after a few days. Instead, I was dependent on busy staff finding time to secure everything onto a precarious base before I could move from my bed.

Education

There is, I feel, a need for improved education to be provided at two levels. At one level, patients and relatives probably require better preparation. While this cannot be done for emergency admissions, it may be possible for those who undertake elective procedures, in areas where delirium is known to be a high risk. By providing more information, both patients and carers might be better equipped to cope.

Equally important, I believe there is a need for more information to be provided for professionals in the field. Awareness of the condition could be

usefully engaged with and providing nurses and medics with coping techniques. From discussions I have had, it would seem that the topic of delirium is given scant, if any, attention in either initial or in-service training and I would make a plea for it to be afforded greater importance during medical school and nursing degrees.

Prevention

The prevention of delirium, I would suggest, needs further research. The whole condition requires a better understanding. Far be it for me to propose what might be done, but I can make some suggestions.

A more robust tool for the identification of delirium is one clear candidate for further work. Not only is the current instrument rather poor, it is also reliant on it being administered at appropriate times – particularly at night, but other considerations for patient wellbeing at that time, plus availability of overworked staff make that difficult. If some physiological/chemical marker could be identified and monitored regularly, then the prevalence and severity of the condition might be more readily recorded.

There may be a case for trying to identify more precisely both the type of illness/trauma that is associated with delirium and also the various factors, or markers both physical and psychological, that might make a particular patient more susceptible.

A reconsideration of pain relief regimes might be usefully investigated. Reduction in pain relief drugs may reduce or alleviate the condition and some low-level pain being tolerated might in fact help to 'ground' the patient in objective reality. Self-administration of pain relief has been shown, I believe, to lead to a reduction in the quantity of drug use.

Finally, it is interesting to note that NICE find delirium to be 'a massively neglected condition relative to its frequency and serious consequences' and to be

- Hugely under recognised and under diagnosed in the NHS

- Approximately one-third of all episodes could be prevented
- Prevention would be a hugely cost-effective strategy for the NHS.⁶

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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