

# Online Research @ Cardiff

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <http://orca.cf.ac.uk/81815/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Kitzinger, Celia and Kitzinger, Jenny 2014. Grief, anger and despair in relatives of severely brain injured patients: responding without pathologising. *Clinical Rehabilitation* 28 (7) , pp. 627-631. 10.1177/0269215514527844 file

Publishers page: <http://dx.doi.org/10.1177/0269215514527844>  
<<http://dx.doi.org/10.1177/0269215514527844>>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



# Grief, anger and despair in relatives of severely brain injured patients: responding without pathologising

Celia Kitzinger and Jenny Kitzinger

*"I suppose it is tempting, if the only tool you have is a hammer, to treat everything as if it were a nail"<sup>1</sup>*

## Summary

The training and expertise of healthcare professionals in diagnosing and treating pathology can mean that every situation is treated as an instance of illness or abnormality requiring treatment. This medicalised perspective is often evident in clinical approaches to family members of people with prolonged disorders of consciousness. This editorial was stimulated by reviewing an article (final version now published in this issue) concerning the distress of families with severely brain injured relatives,<sup>2</sup> and by reading the larger body of literature to which that article contributes. It was also prompted by the recent publication of national clinical guidelines in the UK about the management of prolonged disorders of consciousness. In this editorial we highlight the depth and range of emotional reactions commonly experienced by families with a severely brain injured relative. We suggest that clinicians should understand such emotions as normal responses to a terrible situation, and consider the ways in which clinical practice can be adapted to avoid contributing to family trauma.

## Introduction

The Royal College of Physicians (RCP) London has recently published guidelines concerning the management of prolonged disorders of consciousness.<sup>3</sup> These guidelines recognize that family members 'often experience very severe distress' (p.2) when a relative is in a prolonged vegetative or minimally conscious state.

There is a considerable body of research to support this observation. Most of this research, however, treats severe distress as evidence of pathology, 'disorder', 'disturbance' or 'maladjustment'. It finds, for example, that up to one-third of the primary caregivers of people with a severe traumatic brain injury have clinically significant symptoms of anxiety and depression<sup>4–8</sup> and that caregivers exhibit high levels of Post Traumatic Stress Disorder (PTSD) and Prolonged Grief Disorder (PGD).<sup>9–10</sup> A recent study of 53 caregivers of patients in vegetative or minimally conscious states found that the majority (45/53= 84.8%) suffered from 'maladjustment'.<sup>11</sup> Researchers regularly suggest that families should be offered counseling to '[support] them in their process of emotional adjustment and in developing the coping skills they need'.<sup>12</sup>

The new RCP guidelines fully acknowledge the distress felt by families of people in prolonged disorders of consciousness but do *not* suggest that these families are exhibiting pathological responses.

One of us (JK) was a member of the working party that drew up the guidelines and they draw extensively on our in-depth narrative interviews with 51 family members (from 30 different families) with a severely brain injured relative in the UK.<sup>13</sup> We draw on those interviews here. (In conformity with ethics guidelines, all research participants completed an informed consent form, and the research received ethics approval from both Cardiff University and University of York Ethics committees.)

### **Distress in family members**

Almost all the family members we interviewed report feeling the kind of prolonged grief, anger and despair described by the psychological literature. For example:

*It would have been a tragedy that Mum had died [...]. But we would have been able to go forward. As it is we're stuck. We're all pressing against this glass wall. [...] This blackness that lives with you and the sort of plunging despair that lives inside you is- I think if she'd died, I don't think that we'd have this. This is the last thing in the world that Mum would ever have wanted for any of us - or for our kids - to be dealing with at all. This is the last thing she would have wanted and I feel so confused and angry.*

The daughter quoted above was unusual among our interviewees in that she (and the whole family) had taken the position that the patient might not have wanted to survive from a very early stage (in intensive care). Her father (the patient's husband) reports saying to the surgeon (who subsequently performed a decompressive craniectomy a couple of days after the accident) 'let her die if you think the prognosis is bad'; another daughter recalls explaining to the surgeon that her mother's strong religious faith coupled with her knowledge of, and views about, brain injury meant that: 'this isn't a complicated or fearful situation. You must let her die if that's a better outcome for her'. Part of the anger and grief felt by members of this family comes from the belief that the patient's continuing existence is a tragedy caused by modern medical science combined with a failure by clinicians to engage with the family's representations of what the patient herself would have wanted.

Most of those we interviewed differed from this family in that they believed that their relative *would* have wanted all available treatments in the immediate aftermath of the precipitating event. They wanted the patient (often characterized as 'a fighter' who would 'defy the odds') to be 'given a chance' to recover to a quality of life that they (the patient) would consider worth living. But few families believed that the patient would want to be maintained indefinitely in a vegetative or minimally conscious state. (Survey research indicates that the majority of health professionals would not themselves want to be kept alive in such states.)<sup>14</sup>

At the point at which we interviewed these families the 'window of opportunity'<sup>15-17</sup> potentially to allow death in the ICU had closed. The only way in which these patients might be allowed to die was by withholding treatment for infections such as pneumonia – decisions which left some interviewees repeatedly witnessing the near-death of their relative, followed by the patient rallying until the next life-threatening incident. The only method *guaranteed* to

allow death – the withdrawal of artificial nutrition and hydration – was an option potentially available to some, but most of our interviewees found ‘barbaric’ and totally unacceptable.<sup>13</sup> They felt that both they and the patient were trapped and helpless in a situation they could never have imagined in advance – and there seemed to them to be no reasonable way forward. Some felt guilty because they had earlier argued with doctors in favour of life-sustaining treatments during critical periods and many were left feeling responsible for decisions to intervene to save the patient’s life – even though, in law (in England and Wales), this was never their decision to make. Family members often felt there was little or nothing they could do now to protect their relative from suffering and/or indignity. Most were also exhausted as they juggled responsibilities to the patient with work commitments and caring for other family members. Those looking after a patient at home reported feeling imprisoned – one spoke of feeling ‘*like a trapped animal*’, another described her (vegetative) daughter as ‘*my jailer*’.

Some interviewees described how they had resisted healthcare professionals who treated their distress as evidence of psychological problems. One described clinicians’ reactions to her concern about her relative’s treatment:

*You know what they did? So that I wasn’t upset, I was offered a cup of tea. “I don’t want fucking tea. I want you to look after John. This isn’t about me. This isn’t about me being neurotic. This is ‘Look after John’”.*

Family members who spoke to us were often angry and unhappy about what they saw as failures in good basic care, lack of continuity of care and limited follow-up and services: ‘*They get you so far and then abandon you*’. They were also distressed at either having been excluded from decision-making (‘*We weren’t told we had any role*’) or at having been inappropriately treated as if the decisions were theirs to make (‘*We shouldn’t have been asked for a decision.... It was almost as if the responsibility was being passed over to us*’).

They had sometimes come to regret that the patient had been kept alive:

*You can bury a son and then move on. You never forget it, but at least he’s at peace. But to actually see him go through what he’s still going through... It’s so cruel and the doctors should have just made it easier for us instead of trying to keep him alive. [...]. They should have just left him and then he would have died of a heart attack [...] and it would have been so much easier in the long run. [...] This is devastating, absolutely devastating.*

### **Responses to distress**

Of course families facing these intolerable situations can find emotional support valuable – especially from someone who has some understanding about severe brain injury (including professional counsel- lers and peer support from other families in similar situations.) Accessing this kind of support should not depend on a diagnosis of mental illness or ‘maladjustment’.

Medicalizing and pathologizing families’ feelings of grief, anger and despair can obscure the social, medical and legal context. It locates the problems inside ‘grieving’ individuals or ‘difficult families’ rather than in the health services or medico-legal system. We suggest that counseling,

while undoubtedly helpful to some relatives on some occasions, is not the only – or necessarily the most appropriate – response to family distress.

Some of the distress experienced by our interviewees could have been avoided if families had been given information and practical support, and regularly updated about the patient's condition. Their situation might have been very different if they had been properly consulted about their loved one's values, wishes and beliefs, and if their role as family members had been made clear – with clinicians owning their own responsibility (in accordance with the law in England and Wales) for best interests decision-making.

The new RCP guidelines for England and Wales recommend that families should be offered information (e.g., about the patient's prognosis, available treatments and management plan) and practical support (e.g., assistance with managing finances and medico-legal issues) (p. 45). They advise that within two weeks of onset of coma the healthcare team should discuss with family and friends the beliefs and values the patient had that would be likely to influence their treatment decisions if they still had capacity. Within four weeks (and at regular intervals thereafter) clinicians should convene a formal best interests meeting, involving family 'as closely as possible in decisions made in the patient's best interests' (p. 45). The guidelines also require clinicians to be clear that (in law) family members are not the decision-makers and to clarify to families that this responsibility rests with the clinical team.

Accurate information about their own role in decision-making (as laid out by statute in the Mental Capacity Act 2005<sup>18</sup>) could have avoided some of our interviewees feeling that expressing their opinion about what the patient would have wanted might have been tantamount to '*delivering a death sentence*' or their feelings now that, having agreed to treatment, they were responsible for condemning their relative to what one interviewee called '*a living death*'. Information about how other families confront the challenges of this situation can also be very valuable (and it is this which lies behinds our current work developing a web resource for families on [healthtalkonline](#)).

Grief, anger and despair are natural human reactions to the severe brain injury of a loved one. It is not helpful to pathologise or medicalise those feelings: they are entirely normal responses, and no guidelines can eradicate them. What adherence to the RCP guidelines (and the law) *could* eradicate is the considerable amount of additional *iatrogenic* distress caused to families by health professionals' failure to follow proper procedures or to act in the best interests of patients. These failures result in families feeling that the original tragedy of the brain injury has been compounded and extended by inappropriate use of medical technologies, combined with poor decision-making and inadequate basic care – and that they are implicated in, and responsible for, at least some of the decisions that resulted in the patients now being maintained in a condition they would never have wanted.

Instead of simply measuring family trauma and recommending counseling, the severe distress of families should also be tackled by addressing the social, medical and legal contexts that generate some of that distress in the first place.

## Acknowledgements

The authors would also like to thank the ESRC for the Knowledge Exchange grant (ES/K00560X/1) which is funding on-going interviews to inform a “healthtalkonline.org” module about the vegetative and minimally conscious state.

## Conflict of interest

The authors (who are sisters) are sisters of a patient who was previously in a prolonged disorder of consciousness. Additionally Jenny Kitzinger is a court appointed welfare deputy for this patient.

## Funding

This editorial is informed by work part-funded by the Wellcome Trust (ref: 097829) through the Centre for Chronic Diseases and Disorders at the University of York.

## References

- 1 Maslow AH. *The psychology of science: A reconnaissance*. New York: Maurice Bassett Publishers, 1966.
- 2 Pasquale M, Estraneo A, De Lucia L, Cardinale V, Loreto V and Trojano L. A study of the psychological distress in family caregivers of patients with prolonged disorders of consciousness during in-hospital rehabilitation. *Clinical Rehabilitation* (in press).
- 3 Royal College of Physicians. *Prolonged disorders of consciousness: national clinical guidelines*. London: RCP, 2013. Available at: [www.rcplondon.ac.uk/resources/prolonged-disorders-consciousness-national-clinical-guidelines](http://www.rcplondon.ac.uk/resources/prolonged-disorders-consciousness-national-clinical-guidelines) (accessed 22 February 2014).
- 4 Kreutzer JS, Gervasio AH and Camplair PS. Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Injury* 1994; 8(3): 211–230.
- 5 Chiambretto P, Rossi Ferrario S and Zotti AM. Patients in a persistent vegetative state: caregiver attitudes and reactions. *Acta Neurol Scand* 2001; 104: 364–368.
- 6 Marsh N, Kersel DA, Havill JH and Sleigh JW. Caregiver burden during the year following severe traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology* 2002; 24: 434–447.
- 7 Schonberger M, Ponsford J, Olver J and Ponsford M. A longitudinal study of family functioning after TBI and relatives' emotional status. *Neuropsychological Rehabilitation* 2010; 20 (6): 813–829.
- 8 Cruzado JA and de la Elvira de la Morena MJ. Coping and distress in caregivers of patients with disorders of consciousness. *Brain Injury* 2013; 27(7-8): 793–798.
- 9 Guarnerio C, Prunas A, Della Fontana I and Chiambretto P. Prevalence and comorbidity of Prolonged Grief Disorder in a sample of caregivers of patients in a vegetative state. *Psychiatric Quarterly* 2012; 83: 65–73.
- 10 Elvira de la Morena MJ and Cruzado JA. Caregivers of patients with disorders of consciousness:

coping and pro- longed grief. *Acta Neurol Scand* 2013; 127: 413–418.

- 11 Cruzado JA and de la Elvira de la Morena MJ. Coping and distress in caregivers of patients with dis- orders of consciousness. *Brain Injury* 2013; 27(7-8): 793–798.
- 12 Schonberger M, Ponsford J, Olver J and Ponsford M. A longitudinal study of family functioning after TBI and relatives' emotional status. *Neuropsychological Rehabilitation* 2010; 20 (6): 813–829.
- 13 Kitzinger C and Kitzinger J. Withdrawing artificial nutri- tion and hydration from minimally conscious and vegeta- tive patients: family perspectives. *Journal of Medical Ethics* Epub ahead of print doi: 10.1136/medethics-2013-101799.
- 14 Demertzi A, Ledoux D, Bruno MA, Vanhauzenhuysse A, Gosseries O, Soddu, et al. Attitudes towards end-of-life issues in disorders of consciousness: a European survey. *J Neurol* 2011; 258:1058–1065.
- 15 Kitzinger J and Kitzinger C. The 'window of opportunity' for death after severe brain injury: family experiences. *Sociology of Health & Illness* 2013; 35(7): 1095–1112.
- 16 Wilkinson D. The window of opportunity for treatment withdrawal. *Archives of Pediatric and Adolescent Medicine* 2011; 165(3): 211–215.
- 17 Wilkinson D and Savulescu J. Knowing when to stop: Futility in the ICU. *Current Opinion in Anesthesiology* 2011; 24:160–165.
- 18 <http://www.legislation.gov.uk/ukpga/2005/9/contents> (accessed 22 February 2014).