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Understanding and responding to severe and enduring patient distress in the healthcare setting.

### *Aims and Intended learning outcomes*

The aim of this article is to help nurses understand and consider the implications of caring for individuals that have experienced severe and enduring distress as a result of interaction with healthcare services.

After reading this article and completing the timeout activities you will be able to:

1. Define severe and enduring distress experienced as a result of the healthcare setting.
2. Understand the importance of recognising that severe and enduring distress happens.
3. Consider your own reaction and feelings toward those that have experienced severe and enduring distress within the healthcare setting and how your feelings and reactions might help or hinder the therapeutic relationship
4. Reflect on the support that you can give to those who have experienced severe and enduring distress as a result of their interactions with the healthcare setting.

### *Introduction*

With a review of UK nurse education following the Shape of Caring Review (2015), this article emphasises the need for nurses to be able to respond to a broad array of presenting issues in their patients, specifically awareness of mental health issues regardless of the nurse's field of practice. The focus of this article will be on severe and enduring distress experienced by patients as a result of interaction with the healthcare system. This may not just be in the form of unintentional neglect, misdiagnoses, surgical errors and mismanagement of care but also severe and enduring distress that occurs merely by the interaction between patient and the healthcare system itself. Severe and enduring distress is any distress that occurs as a result of interactions within the healthcare setting, with systems, organisations or healthcare professionals.

Timeout 1 - Read the following case study about Sally. Reflect and note down your initial feelings about this case.

Sally, a young 29 year-old woman describes to her counsellor an experience that she had in a busy hospital ward. She was admitted for investigations into chronic diarrhoea during a particularly unpleasant bout. She found it very difficult to get to the toilet in time and was anxious that she be near the toilet. She was placed in a four-bedded bay near the toilet. She reported feeling tired and faint and so was asked by the nurse, Karen, to ring her bell to alert her that she needed assistance to the toilet. Sally was reassured that she would be helped to the toilet.

During a busy afternoon when visitors were present in the ward Sally rang her bell needing to visit the toilet urgently. No one responded, she rang again. Needing to go urgently Sally got out of bed and began to walk very quickly to the toilet. Half-way there, in the middle of the ward she had what she described as a 'terrible accident'. This incident was very public and it was clear to everyone what had happened.

On discharge from hospital Sally began to experience extreme anxiety and panic attacks reporting that she was often hyper vigilant, constantly looking for the nearest toilet assessing

whether she could 'make it in time'. She experienced anxiety about her looks, her smell and about interacting with others in social situations. This was beginning to impact upon her social life and her family life, especially her ability to take her son to the park where there was a lack of toilet facilities.

What were your initial reactions to Sally's incident. If you had been a member of staff on the ward you probably would have felt great empathy for her situation and could identify with how she was feeling. However, would you have considered the wider impact of this incident for Sally and how it might contribute to her feelings of anxiety outside the practice setting after her discharge from hospital?

Harm happens in healthcare systems. The World Health Organisation (WHO 2015) estimates that complications after surgery occur in up to 25% of patients and that in industrialised countries, nearly half of all in-patient adverse events are related to surgical care. At least half of these cases leading to harm are preventable. Even in the most carefully managed environment mistakes are made. In the UK the rhetoric around cultures of care and patient safety changed with the realisation that abuse, negligence and errors happen more regularly than is desirable and a greater emphasis on compassion and patient safety has come from a recognition of past mistakes and the desire and drive of healthcare professionals to improve care as well as the increasing fear of litigation (Illingworth 2014). In the UK, it has been suggested that approximately one in ten patients experience harm when they are in hospital (Campbell 2014) and a report prepared for the UK Department of Health in October 2014 by Frontier Economics estimated that a total of 755,000 preventable adverse events across the National Health Service occurred each year (Frontier Economics 2014).

With the roll out of the duty of candour, there is an increased awareness of the role of honesty in the relationship between patients and healthcare professionals (Care Quality Commission 2014). The fact that avoidable deaths occur as a result of the poor quality of care has been a recent feature of investigative reports such as the recent Kirkup Report (2015) however, the recognition that non-fatal incidents or even merely interaction with the healthcare system itself might lead to significant and long-term distress is hardly every acknowledged, other than in specific settings or situations.

In nursing settings, the recognition of the impact of traumatic births is well researched as is the psychological impact of treatment in ITU resulting in Post-Traumatic Stress Disorder (PTSD) or serious psychological long term implications (Oldea et al 2006, Ratzner et al 2014). Work has also been undertaken on the psychological impact on patients of a range of acute medical conditions commonly found in hospital such as myocardial infarction (MI) as well as the long-term impact of acute psychotic symptoms and major physical trauma (Hunter et al 2015). Bienvenu and Neufeld (2011) acknowledged that PTSD was common among survivors of critical illness with some illnesses, such as MI, linking more directly to the development of PTSD. This has contributed to a better understanding of the prevalence and development of PTSD in some limited settings. However, patients who experience what appears to healthcare professionals as non-life threatening events may still go on to develop severe and enduring distress resulting in symptoms that might include hyper-vigilance, flashbacks, vivid and distressing dreams, acute fear or anxiety and feelings of re-experiencing the event (Vincent and Coulter 2002). Vincent and Coulter acknowledge that even routine events may produce what they describe as 'post traumatic

symptoms' (p 78). It is this group of patients that rarely have their difficult experiences acknowledged or the long term consequences recognised.

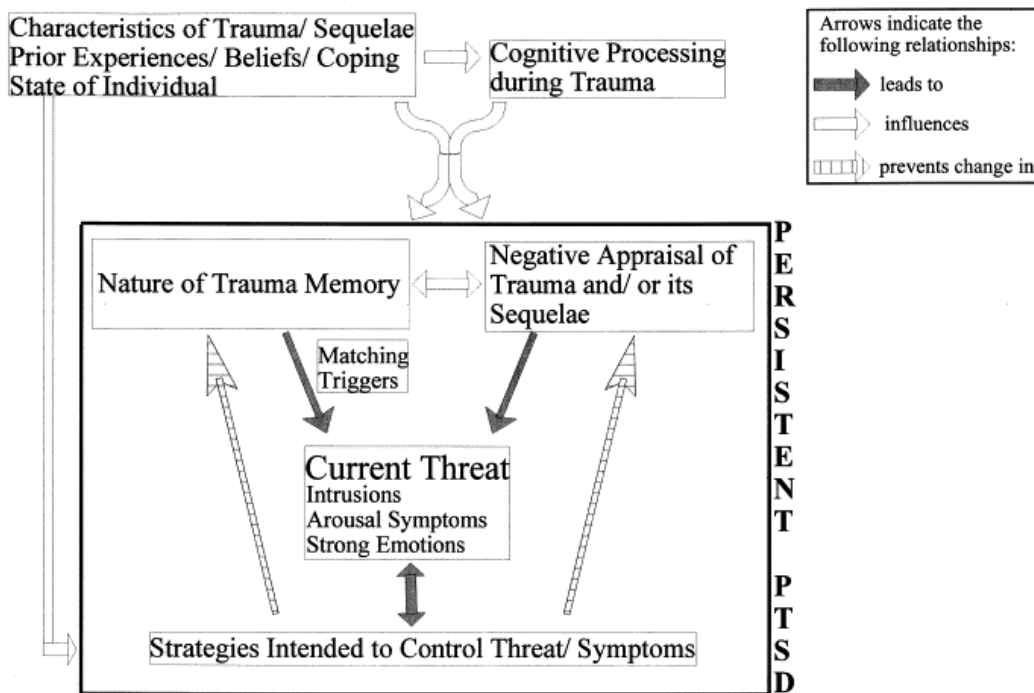
Distressing and frightening hospital experiences may not result in a formal diagnosis of PTSD, but for those who develop serious symptoms of extreme distress that continue after a patient goes home it is an experience that changes and shapes the way in which an individual view themselves, their future or the world resulting in long term psychological distress (Berlinger, 2005). This impacts on patients' ability to manage daily life and a fear of the future (Beck 1979), and may cause anxiety around the possibility of further interaction with the healthcare system.

Levenson (2007) acknowledged that a hospital experience that was perceived as threatening physical or psychological safety could precipitate incidences of psychological distress. However, this distress can often go unacknowledged or be minimised by healthcare staff following formal apologies or compensation offers giving the perception that the matter has been addressed (Ocloo 2010). Patients frequently hear that 'lessons have been learnt' following serious incidents but rarely see the long term benefits of those lessons in the embedding of learning or the reshaping of services to allow acknowledgement of the severe distress caused (Ocloo 2010). The idea that patients experience significant and long term distress, not only caused by illness, but by the manner that care is delivered or managed is an uncomfortable one. This discomfort extends not only to patients themselves but also to healthcare staff whose focus it is to care and minimise harm. Patients coming into the healthcare setting generally feel that the setting itself provokes anxiety due to concern about their health, unfamiliarity with the systems and processes, feelings of helplessness and uncertainty about what the outcome of their visit may be (Brewin 2003). The current trend in media reporting that rightly highlights failings does little to instil confidence in the healthcare systems and might be said to contribute significantly to fears and anxiety about the quality of care provided despite the fact that many patients have at least reasonable care. Patients in an unfamiliar environment, already anxious, will seek reassurance and cues to confirm that the health care team can be trusted with their care (Mollon 2014). Conversely, patients will notice when uncaring or thoughtless actions occur as well as when significant mistakes are made. The information that patients use to build up the picture of the healthcare teams competence or trustworthiness is from their own experience, and may not necessarily accurately reflect the perspective of the professionals. One model of psychological distress - Elhers and Clarkes' (2000) model of PTSD, notes factors that go towards the perception of a threatening and distressing situation. While this model is based on the medical model of trauma that results in PTSD, it is a useful one in helping nurses to understand the component parts of distress that may result in difficult and long lasting symptoms. It is important to recognise that the concept of trauma is, in itself a contentious one. Professor Gordon Turnbull (2011) whose work has contributed significantly in this field, in his discussion of the medical model of trauma recognises that there is a specific disorder that is PTSD and associated symptoms described in DSM5 (APA 2014). He argues that the event that triggers this reaction is secondary to the reaction itself and that the event becomes traumatic only due to the meaning placed upon it by the individual. Therefore, there is more to trauma, he argues than just PTSD. The Elhers and Clark model (2000) specifically emphasises a number of key features that might be useful in helping nurses understand the experience of those who have experienced extreme distress.

- First, the perception of the patient in the interpretation of the event, categorised as the 'negative appraisal of trauma and its sequelae'. The model looks at what factors contribute to the belief that a threat is present (current threat) and the resulting behaviour which manifest as symptoms utilised by the patient to control the overwhelming threat.
- The initial contribution of the patient's beliefs, past experiences and coping strategies prior to the distressing situation are also an important aspect of the model.
- Alongside past experiences, the cognitive processing that occurs during the event is seen by as a factor. This is particularly important when considering those in the healthcare setting where cognitive processing might be affected by medications, unfamiliar surroundings and fear that may result in an interpretation of the situation as being threatening.
- Elhers and Clarke do not suggest that this model only applies to life threatening issues but, more importantly for nurses and healthcare professionals, emphasise the interpretation of the individual that there is a threat to either the external person or the internal integrity of that individual. The interpretation, categorised as a negative appraisal, therefore might manifest as a global generalised belief that the world is a more dangerous place (external threat) or as a belief that the patient does not have the ability to cope (internal threat).

The nature of the memory along with corresponding triggers might be better understood by considering an example. A patient whose traumatic experience included constant vomiting in an in-patient setting talks to her psychological therapist about vomiting and feeling nauseous, panicked and distressed when out shopping for curtain material for her new house. She is able to recognise that her trigger was a particular pattern on the material that was similar to that on the curtains within the hospital setting. Having seen the pattern in the shop, she re-experienced her original traumatic experience with one of the main physical symptoms, the nausea. While in this example the patient can recognise her trigger, this is not universal in those with this experience. Often the therapist has to work carefully to deconstruct the nature of the memory to enable a thorough understanding of the trigger. It is not uncommon to experience a particular smell that brings back a very vivid memory, perhaps forgotten and allows the individual to experience past thoughts and emotions as if they were back in that moment (Rothschild 2000). You may have had this experience yourself.

Elhers and Clarke (2000)



Time out activity 2.

Identify an incident when you had a difficult experience that resulted in you feeling anxious (Do choose something that was not recent or too difficult or painful to reflect on). Reflect on the experience you had, the way it made you feel about yourself, your perception of safety or your relationship with others who may not have behaved as you had hoped in the situation.

You may have experienced a difficult event yourself such as a road traffic incident or an incident that made you feel unsafe. Did this incident impacted on your feelings of safety for some time or not at all. We are all different and what makes us feel safe is very personal. Feelings of safety can often be related to safe places or people. Hospitals and other healthcare settings are unfamiliar places filled with professionals that patients generally don't know well, if at all.

Timeout activity 3.

Consider the nurse is the case study about Sally. What impact might the incident have on the relationship between Sally and her nurse Karen? What might have been the impact on Karen's feelings about her practice? Make a note of your thoughts to come back to later.

The characteristics of a very distressing experience itself, previous life experience and the current psychological and physical state of the individual as well as the cognitive processes during the trauma, all contribute to setting the scene for the possible development of a long-term stress reaction. For example, a patient who has never had a serious or life threatening

illness, has never been in hospital, is extremely unwell, feels vulnerable, in pain, frightened and sedated (impairing the cognitive processes that help process memories), is likely to appraise the situation negatively if they perceive that the healthcare team are not behaving in the way that gives the patient confidence and makes them feel safe. Additionally, if the patient believes that the resulting consequences (sequelae) of what has happened to them are negative and/or long-term, this in itself may be a distressing and catastrophic event for that individual. Once the current threat is acknowledged as a threat to physical or psychological wellbeing patients may feel panic, extreme fear, intrusive thoughts, arousal symptoms and strong emotions (Vincent 2010). The feeling of being in a threatening situation brings about the normal reaction of developing strategies to enhance safety and repel threats, which may not necessarily manifest until some time after the initial activating event (Thwaites and Freeston 2005). This may result in patients avoiding places, people or cues that remind them of the original trigger event. A normal reaction to a situation of threat is the flight, fight or freeze reaction, but this may not be evident in a healthcare setting where behavioural norms around what a patient 'should' and 'should not' do are very strong and are often reinforced by everyone in the setting (Brewin 2003).

Extreme distress may occur as a result of:

- surgical error
- medical/drug error
- misdiagnosis
- lack of empathy conveyed to patient during a particularly painful, difficult or worrying procedure even if it is a minor procedure in the eyes of the healthcare team.
- neglect of important patient needs
- deficits in the quality of care
- delay in dealing with need for analgesic medication, important procedures or fundamental care
- lack of dignity, privacy and agency from the patient's perspective

(Mollon 2014).

Sally's experience in the healthcare setting is not an unusual one and it is easy to see how this experience might distress Sally and shape her future thinking in situations where she is exposed to feeling of insecurity, for example where there may not be easily accessible toilet facilities.

Alongside a lack of recognition that the healthcare system can itself harm and cause extreme and lasting distress goes an understandable reluctance to talk about this. The literature around extreme distress within healthcare that does not include ITU or traumatic birth episodes is therefore sparse in the UK and Europe. However, mental health settings in the USA and Australia have made significant strides in recognising that harm that can be caused purely by interaction with the system and are currently moving toward trauma informed care (Bremness and Polzin 2014, Watson et al 2014). Randall and Haskell (2013) define becoming trauma informed as:

*'..becoming more astutely aware of the ways in which people who are traumatized have their life trajectories shaped by the experience and its effects, and developing policies and practices which reflect this understanding'* (pp. 501).

Trauma is, in this case not defined as merely PTSD but experiences that cause distressing and long term impacts upon mental health and wellbeing. Trauma informed care has yet to happen

widely within general healthcare in the UK and Europe, but it seems as though this might be a timely and appropriate discussion. Trauma informed care comes from the premise of not asking patients what it is that is wrong with them, but asking what has happened to them. This emphasis on injury and not illness fits well with the ethos of care when an individual has been injured by the healthcare system.

In order to change what happens when people experience extreme and enduring distress in a healthcare setting there needs to be a greater understanding and acknowledgement by healthcare staff of the contributing factors to the experience. However, progress towards change is hampered by the fact that no major study has as yet researched the long-term impact of this kind of distress. The study of stress and stress reactions has been important in moving forward treatments for those experiencing a stress reaction generally (NICE 2014). Studies show that trauma caused by the actions or omissions of people rather than, for example natural disasters, has the potential to cause significantly greater harm psychologically and that Interpersonal factors seems to compound the distress (Brewin 2003). This is particularly significant in incidents experienced in the healthcare setting, as patients generally enter the system with an expectation of care, even if the system is acknowledged as not being perfect (Berlinger 2005). Brewin's work considers the fact that not all those who experience a distressing event go on to develop an extreme reaction but that a range of factors including previous life experience, attachment style, personal beliefs about oneself and others, all impact on whether a long-term stress reaction occurs (Brewin 2009).

The work of Vincent on patient safety emphasises that unsafe acts happen all the time but that many are picked up sufficiently early to allow outcomes not be damaging (Vincent 2010). It seems then that a 'perfect storm' of a vulnerable individual, in terms of the factors mentioned by Brewin, and an adverse event or series of events connect to make a specific set of circumstances that may bring about a distressing and extreme reaction. The work of Wu (2000) and Scott et al (2009) on the 'second victims' of errors in healthcare also considers the impact of an error on the healthcare professional. Wu and Scott's work, and that of others in their field examines the emotional reaction of the professional to making errors in practice. It is acknowledged that healthcare workers can also develop a reaction similar to that of the patient. This recognition in the USA has brought about advanced second victim programmes for healthcare professionals alongside trauma informed care programmes for patients (Krzan et al. 2015). It is interesting that the current NHS Litigation Authority Leaflet 'Saying Sorry' reminds staff of the 'suffering and distress' that these incidents can cause to patients, yet refers to the fact that staff will have been 'traumatised' by their involvement (NHS Litigation Authority 2016). This marked difference in recognition of experience is notable.

It is significant to note two things in the body of research work already undertaken. First, it is noticeable that in reports of the management or aftermath of errors it is the description of what occurred in factual terms that is the focus of the research work. Human emotion and feelings are rarely seen as significant when the primary focus is in finding ways of managing harm. Secondly, there is no recognition of what helps the situation for patients and therefore what might protect them from developing a distressing and extreme reaction in the future. The work of Vincent (2010) acknowledges the need for candour that since 2014 is now firmly in place following the Mid Staffordshire Review (2013). While simply being honest, open and transparent with patients is a major step forward, an acknowledgement of the barriers that make this difficult when experiencing a distressing patient event is also a key aspect of the patient-professional relationship. One of the significant factors in enabling those who have experienced extreme distress to have access to appropriate initial and long-term support (Andrews et al 2003).



However, Robinaugh et al (2011) established through their work that the support would need to be positive in relation to allowing the individual to reframe and to reappraise the distressing experience rather than just a traditional debriefing. This fits well with the current Cognitive Behavioural Therapy (CBT) practice in terms of cognitive restructuring, exposure therapy and Eye Movement Desensitisation and Reprocessing (EMDR) as recommended by National Institute for Health and Care Excellence (NICE). While extreme distress may occur in the normal everyday business of the healthcare environment it is perceived as being more common as a reaction to a particular incident. What then can a nurse do in relation to supporting and potentially preventing a stress reaction to a significant event?

First, nurses need to develop an understanding of the possible emotional trajectory followed by patients and by professionals that is involved in any incident. A possible trajectory of emotions for both first (patient) and second (staff) victims is offered for discussion and has been developed through informal work with patients and an appraisal of the relevant literature on second victims.

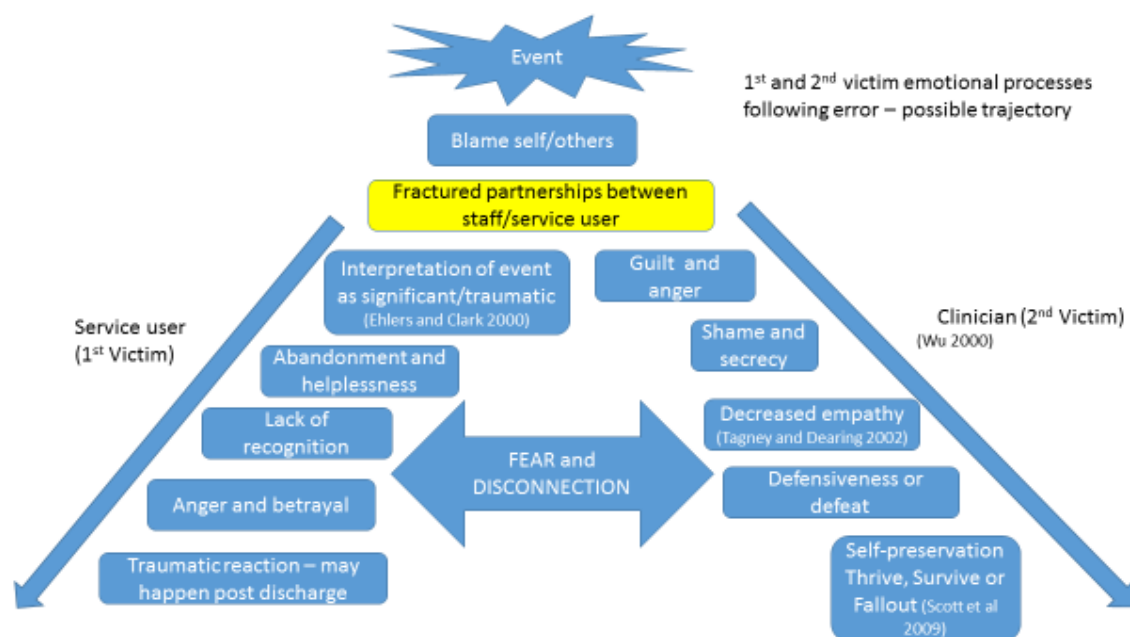


Fig 1.

This trajectory requires further work including a pilot project to ensure a robust evaluation and reworking but a key feature in patient reports is the fracturing of the patient/clinician relationships at an early stage following the incident. This feature has also been identified by Vincent (2001) as being a ‘second trauma’ to those involved and cuts across the need for support that distresses patients need to aid recovery. Systems and processes are set up to avoid errors and ensure that they are anomalies or ‘never events’, yet they still happen (Jones et al 2012). Expectations of both patients and professionals are shattered and the patient–nurse relationship breaks down. This can be compounded by a lack of honesty and an unwillingness to admit mistakes which may lead to the professional avoiding engagement with the patient. At that point the mutual respect and support that each has for the other may be replaced for the patient by a distrust of the professional and a reappraisal of what has occurred as being harmful and threatening. The clinical setting feels like a dangerous place. The trajectory of emotions felt by healthcare professionals has been researched by Wu (2000), Scott et al (2009) and Jones et al (2012) with the acknowledged impact of these emotions upon the professional being considerable. Disappointment in performance, shame, guilt and fear are key emotions for

professional following a difficult patient event. Shame researchers Tagney and Dearing (2002) found a clear link between the emotions of guilt, shame, and anger with a decrease in the ability to be empathic which clearly has implications for the continued care of traumatised patients. Davidoff (2012) in his discussion of the relationship between shame and perfectionism notes that healthcare professionals are self-selected for perfectionism when entering the profession – they want to be good at what they do. What matters then, is the response in the professional to these feelings that ensures that difficult feelings do not distance them from the patient at a time when the relationship is crucial. Maintaining the relationship gives the professional a significant opportunity to allow for further planning, support and care that may help to minimise, validate and acknowledge the trauma felt by the patient. Repairing of the relationship can only take place whilst dialogue continues and this requires healthcare professionals who are aware of their emotions, who understands the trajectory of emotions when things go wrong and are astute enough to be able to respond to the emotional distress of their patients appropriately.

Timeout activity 4.

Considering Sally's experience in the healthcare setting, how might you, as a nurse talk to Sally about what happened to her. Consider what Sally might need to make her feel safe again and how you might manage Sally's care if she was readmitted into hospital at a later date. You may also need to consider your own reactions to Sally and how you might manage those. Sally actually reported that she blamed herself for what happened; not getting out of bed quickly enough, relying on the nurses when she knew they were busy and berating herself for her seeming to have a lack of control.

Compare Sally's feelings and your list of thoughts and feelings with those in the Fig 1. What are the similarities and differences? Is there anything there that surprises you?

Nurses are generally highly competent and confident in their practice but given the challenging nature of practice settings, nurse education both pre and post registration must also respond in recognising that extreme distress can occur and be caused by the healthcare setting. Education has a role in raising awareness of the nature of extreme distress, helping understand responses as well as the fostering the ability in the nurse to respond appropriately to the difficult circumstances and feelings around a significant event (as defined by the patient). Nurses require a greater awareness of their own difficult feelings, including feelings of inadequacy, failure and shame in a profession that fears vulnerability and inadequacy and sometimes maintains 'professionalism' as a barrier. Qualified nurses and nurse educators are well placed to make explicit the importance of maintaining a strong therapeutic relationship after significant events even when feelings of vulnerability, shame and distress run counter intuitively in the professional. Ensuring healthcare professionals are aware of their own usual cognitive processes, systems of support, strengths and weaknesses as well as their professional responsibilities is an initial step forward in providing nurses that can support and respond to patients should adverse events occur.

Timeout activity 5.

Identify support systems for Sally and for Karen at the point of the incident. What could Karen have done to help Sally with the aftermath of the incident and what help could Karen have accessed for herself.

Think about what support mechanisms are available in your practice setting as well as what you would like to be available.

## Conclusion

The case study of Sally and her nurse Karen demonstrates the nature of severe and enduring distress and the ease with which individuals can be psychologically harmed within the healthcare setting. Ineffective health care is just one factor of a number of factors resulting in difficult and damaging patient and staff experiences, but ineffective healthcare that results in psychological and lasting distress or psychological harm is rarely discussed or acknowledged. This article highlights the need for healthcare professionals to understand the nature of severe distress and the need to recognise and acknowledge when a patient has experienced this even when the healthcare professional may not recognise that the situation was in itself life-threatening or distressing. Recognition and acknowledgement are important steps in recovery and resolution of harm and distress, but are only first steps. Nurses will be called upon to manage those who have previously experienced extreme distress in the healthcare setting when a patient accesses services again. This article and the associated activities serve to raise awareness and begin conversations in healthcare settings that will help staff to move towards being more trauma informed.

Timeout activity 7. Write a short piece considering the following questions.  
Why is awareness of the impact and recognition of severe and enduring distress important in my practice.

Look back at the article to prompt you with this if you need to.

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