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PRACTICE

When healthcare causes harm

Suzanne experienced a severe and debilitating reaction to a drug given routinely when she was in hospital for treatment. The reaction to this medication included hallucinations and extreme fear and distress. This went unrecognised and Suzanne was sedated in an attempt to manage her distress. However, this only exacerbated her feelings of helplessness and fear. An already difficult situation – a reaction to a routinely administered drug – was made considerably worse by the sedation, which continued over a long period of time, and the experience resulted in a diagnosis of PTSD two years later. Suzanne's life was devastated by fear, hypervigilance, flashbacks and unmanageable, intrusive thoughts. She often felt 'out of it', as if she had lost time, and she described feeling a significant loss of control over her life. She became suspicious of healthcare professionals and was reluctant to access any further treatment, including visiting her GP.

Stories of poor and inadequate care within the healthcare system continually feature in the media headlines. An estimated 500,000 patients are harmed and 3,000 die each year as a direct result of safety failings within the NHS.[1] However this is likely to represent just the tip of a much larger iceberg: not all errors in health settings result from poor care; nor does all harm occur because of unsafe practice or error. It is also rarely acknowledged that non-fatal incidents or even just a difficult interaction with the healthcare system can lead to significant patient harm.

The NHS is expected to monitor adverse incidents but these measures focus specifically on clinical conditions, such as hospital-acquired infections or pressure sores. Other than the well-recognised psychological impact of traumatic birth or intensive care PTSD, the long-term psychological and physical impact of harm goes unacknowledged and is not recorded. The perception from healthcare professionals may be that, if a patient has been discharged from the hospital setting, they are well enough to go home and can have experienced only minimal harm. Hospital staff will be unaware of harm that persists into the medium or long term and, unless a patient has ongoing contact with the healthcare provider or highlights the harm through legal proceedings, formal complaint or other mechanisms, may not even be aware it has occurred or that it has had long-term consequences. It is easy then for the harm to be minimised, not recognised and not acknowledged.

This article is about the psychological effects of the experience of harm in a healthcare setting, whether through intentional abuse, unintentional neglect, misdiagnoses, surgical errors, mismanagement of care or the subsequent failure by healthcare organisations to acknowledge the harm and its resulting long-term damage. It is the subject of my doctoral thesis and much of what is written is based on my personal experience of working with people who have experienced this harm and been damaged by the experience and the way it was handled by the healthcare authorities.

For the purposes of this article, 'harm' is used to describe any physical or psychological injury that has a significant impact on the individual's mental and/or physical health and on their everyday functioning. The psychological injury includes post-traumatic stress disorder (PTSD), as defined in DSM 5,[2] and also more subjective responses that manifest in symptoms of anxiety or depression or in physical symptoms.

Trauma and its aftermath

The impact of a traumatic birth, the psychological aftermath of intensive care and the impact of surviving a serious life-threatening illness, major surgery or physical trauma are all well researched. Much less attention has been given to patients who experience what appears to healthcare professionals to be a non-life threatening event but who go on to develop symptoms of trauma or extreme distress; the possibility of long-term consequences is rarely recognised.[3] Harmful hospital experiences do not always result in a formal diagnosis of PTSD, or even psychological distress. However, for those who do find the experience traumatic, it can change and shape how they view themselves, their future and the world in general, and can result in long-term psychological distress.[4] This, in turn, can impact on their ability to manage daily life, and may lead to a fear of further interaction with the healthcare system.

There is a common misconception that psychological trauma occurs only as a result of a major event – for example, an error or severe neglect. I wonder if this is perhaps in part due to a misunderstanding of the DSM-5 criteria, which seem to suggest that the precipitating event or events must always be life threatening. If you take these criteria at face value, many client experiences of harm in the healthcare setting would not be recognised as traumatic in a clinical sense. However, counsellors of all modalities have described to me encounters with clients who experience traumatic reactions triggered by a range of events, and not just those that are life threatening. Of course the DSM-5 criteria describe a specific 'disorder' and the debate continues around whether a trauma reaction is disordered or a natural reaction to an event or series of traumatic events. According to Elhers and Clarke,[5] it is the client's perception of threat that is important, rather than that of the healthcare professional or other individual making the assessment. As McCaffery has also observed in relation to pain: 'Pain is whatever the experiencing person says it is'.[6] The same could be said of trauma.

The lack of parity of esteem between physical and mental health is particularly pertinent when considering the experiences of those harmed in healthcare. It is so much easier to see, measure and assess physical harm and to directly attribute a consequence, or series of consequences, to that harm.[7] Past and current beliefs, experiences and coping strategies prior to the traumatic situation may all be contributory factors to a client's experience of psychological harm. Elhers and Clarke's[5] cognitive model of PTSD is useful when considering the possible contributing factors, even if the counsellor does not practise CBT. Alongside past experiences, the cognitive processing that occurs during the trauma is seen by Elhers and Clarke as significant. This is particularly important when considering harm in healthcare settings, where cognitive processing might be affected by medication, unfamiliar

surroundings and fear, resulting in a client interpreting a situation as being threatening. The threat might be to physical or psychological integrity, or indeed to both.

Acknowledgement

Many clients will have struggled with their difficult feelings, psychological distress and physical symptoms over many years.[3] The validity of these feelings may never have been acknowledged even by the clients themselves, and may only surface when other issues trigger a crisis, such as a bereavement, a job loss, or a difficult relationship, and bring them to counselling. The impact of harm from healthcare can be one of many losses experienced by clients, and counsellors and therapists may find that a myriad other issues emerge during sessions.

From my own experience with my counselling clients and talking to others who have experienced harm in healthcare, it is clear to me that they have specific needs from the healthcare system. They want an acknowledgement of the harm caused, a meaningful and genuine apology, understanding, and an explanation of what happened. Many individuals want, altruistically, to ensure that what happened to them does not happen to others. Counsellors can offer an opportunity for clients to talk in a non-judgmental space about what happened, where they won't feel pressured to have to evidence their experience, as is likely when talking to the healthcare provider. Counsellors can also provide a much-needed empathic ear and a genuine desire to understand the client's perspective. Those who have had this experience tell me that being understood and heard is crucial for them to be able to explore and address the symptoms, emotions and feelings. Clients have a need to tell their story and for someone to listen, without judgment.

In many cases clients will also be dealing with the long-term effects of the harm when they come to counselling. These may include physical impairments, physical changes, cognitive impairments, loss of abilities, anxiety, distress and depression. Clients may also be dealing with pain, loss, low self-esteem and changes in their financial situation, due to these issues. These effects may require further physical or psychological treatment. But those who are harmed or injured in the healthcare system rarely want further contact with the healthcare system unless there is no alternative. This (understandable) mistrust of the healthcare system is a common feature in clients I have worked with. Clients may present with other issues of loss or bereavement, or may have arrived at such a point of desperation that they feel they have no alternative but to risk coming for counselling. Recognition of their harm is important, as is the acknowledgement of their perspective and unique experience of trauma.[3] for many clients this acknowledgment by someone whom they might view to be a healthcare professional may be highly significant in their moving towards. It is vital that counsellors model the empathic and therapeutic relationship that the client should have experienced in the healthcare setting.

When they enter the healthcare system, clients should at least be able to trust that the professionals within the system have their best interests at heart and that, to the best of anyone's ability, they will be protected from harm. To be harmed by a system that they

believed was there to restore and safeguard their health can be a devastating experience and may lead a person to question other long-held beliefs about the world, as well as their own ability to assess threat and danger. Most counsellors will recognise that trauma reactions are multi-factorial. The traumatic event is experienced from the unique perspective of the individual, who brings all their past understandings, current issues and fears and worries and predications about the future.

The client is likely to bring a complex array of other emotions related to their experience. Guilt is a significant presenting issue. They may feel guilty about being angry with caring professionals; they may feel bad about highlighting the inadequacies of NHS patient care and that they are criticising a much-loved national public institution. Clients may also feel guilty about not speaking up before. Victims of healthcare harm typically berate themselves for being subservient, particularly if they believe that behaviour not to be congruent. They often fail to recognise the pressure on them to take on particular roles, attitudes and values when they enter a healthcare setting. This can be particularly distressing for relatives of those who have been harmed, who feel that they may not have done all that they feel they 'should' to safeguard their loved one.

In my experience feelings of guilt can be particularly problematic when the client who has experienced harm is also a healthcare professional themselves. Feeling betrayed by one's own organisation, whose values and ethos you personally espouse, is both deeply troubling and distressing for healthcare professionals. Having spoken at conferences about the focus of my research work, I am always surprised by how many health professionals approach me and want to talk about their own experience of being harmed, and by how angry and betrayed they feel as a result. Brewin highlights the impact of interpersonal trauma as being significant and this is especially relevant to those harmed in the healthcare setting.[8] People who enter the NHS or access other healthcare providers expect to be kept safe, to be listened to, and to be supported through their patient journey. When they experience the sudden withdrawal of that support following an incident, or it was never there in the first place, they may find themselves questioning their deeply-held, longstanding trust in and beliefs about the healthcare system.

Saying sorry

Healthcare that results in lasting distress or psychological harm is especially difficult to acknowledge for the healthcare system itself.[9] The NHS Litigation Authority guidance on *Saying Sorry*[10] demonstrates something of the attitude in healthcare settings to experiences of harm. The guidance was published to help clinical staff disclose errors to patients. Since November 2015 NHS staff have been subject to a 'Duty of Candour',[11] which requires that certain errors are disclosed, even if harm has not occurred. *Saying Sorry* uses the language of 'suffering', 'distress' and 'upset' to describe the patient experience, but uses the word 'traumatised' only in relation to staff who may have unintentionally harmed patients. While it is important that the traumatic impact on staff is recognised and, indeed, researched, there seems to be a demonstrable lack of parity of recognition in the guidance of the patient's experience. This resonates with Vincent's research,[8] which suggests that patients experience an initial first harm and then a second harm if the experience, trauma and long-term effects are not acknowledged and reparation offered by healthcare professionals.

Nancy Berlinger's[12] work on medical error and ethics considers the kind of apology that patients may receive, if indeed they do receive one. Apologies that are given as part of a formal restitution process, rather than as a genuine expression of sorrow and recognition of harm, are not relational. Formal apologies may be given unwillingly, in the hope that an apology will stave off litigation or will allow the clinician to move on or achieve what Bonhoeffer called 'cheap grace' in the form of forgiveness and the assuaging of guilt. Clients may have complex feelings about the experience of receiving an apology or perhaps they have not accepted it or feel that they should now be able to move on as an apology has been received. Others may not have received one at all. Some clients may have experienced the healthcare system as obstructing their search for answers to what happened to them or others, and the experience of having to fight for information, meaning and justice can exacerbate the trauma.

For many clients a simple acknowledgement or meaningful apology can make a big difference,[11] but in the current litigious climate healthcare providers may be loath to acknowledge damage has occurred, regardless of the statutory Duty of Candour. The Duty of Candour is in its infancy still, and may prove to help restitution. However, concern has recently been expressed that creating a 'safe space' for healthcare professionals to admit their mistakes may allow them also to avoid legal and professional responsibility and accountability[13]. It remains to be seen how the 'safe space' and Duty of Candour will enable improvements in the disclosure of harm in the future.

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