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NHS Inquiries and Investigations; an Exemplar in Peculiarity and Assumption

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Abstract There is little research focussing on how bereaved families experience NHS inquiries and investigations. Despite this gap, there is a consistent assumption that these processes provide families with catharsis. Drawing on my personal experiences of NHS investigations over a five-year period after the death of our son, Connor Sparrowhawk, I suggest the assumption of catharsis is misplaced and works to erase the considerable emotional 'accountability' labour that families undertake during these processes. I further question whether inquiries or investigations are an effective way of holding stakeholders to account. I conclude with two points: first, qualitative research is needed to better understand bereaved family experiences of inquiries and investigations and second, the 'lessons learned' objective underpinning inquiries should be replaced with 'leading to demonstrable change', which is what families typically want. **Keywords**: inquiries, investigations, NHS, bereavement, accountability

THERE IS little research focussing on bereaved families and NHS inquiries and investigations and, as a consequence, we know very little about those families' experiences of these pro- cesses. This is a considerable gap given that inquiries and investigations can continue for extended periods of time, cost substantial amounts of money and may potentially gen- erate further harm and distress for the fami- lies involved. In this paper I explore two of the objectives of inquiries included in Geof- frey Howe's typology: 'providing catharsis or therapeutic exposure' and 'holding people or organisations to account'.[1] I suggest that the presumption of catharsis is misplaced and question whether inquiry or investigation processes are an effective way of holding key stakeholders to account or whether they pro- vide an almost exculpatory opportunity for expressions of regret or apology to be seen as sufficient. I draw on my personal experiences of NHS investigation processes across a five- year period after the preventable death of our eighteen-year-old son, Connor (also known as Laughing Boy or LB), in an NHS hospital in July 2013. Connor had been diagnosed with autism and learning disabilities.

In November 2018, the Health Foundation hosted an event called '50 years of NHS

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inquiries' in London. This was attended by several inquiry leaders from past decades, and other relevant professionals. I was the only family member present. Reference was made across the day to the catharsis NHS inquiries generate for family members. Given the paucity of evidence in this area, it is not clear what the basis is for this presumption by Howe or later commentators. In 2003, Walshe stated 'The inquiry may offer a cathartic release, and an opportunity for rec- onciliation and resolution'.[2] A decade later Black and Mays reflected on the chaotic nat- ure of inquiries in terms of their instigation, process and value, concluding that inquiries are 'public exercises in catharsis, a way of purging public anger whilst also highlighting areas of serious concern and policy failure that need remediation'.[3]

Catharsis is not something I have heard bereaved families describe either experienc- ing or seeking from inquiry or investigation processes. Instead, I have repeatedly in per- son, on social media, at patient safety events, conferences and meetings with public sector bodies such as the NHS and the Care Qual- ity Commission (CQC), listened to bereaved family members state that their aim is quite simply to prevent other families suffering
We the loss that they have experienced. This is
received a copy of Verita 1 in February presented as a pragmatic consideration
2014, seven months after Connor's death. which may be underpinned by strong emo-
During this time there had been repeated tions, but without articulation of the impor-
obstructions by the trust in terms of disclos- tance of experiencing catharsis or therapeutic
ing documents, organising legal representa- exposure. Catharsis is not a term I would
tion for certain bands of staff during use to describe my experiences of the investi-
investigation interviews, and delaying publi- gation processes. I can imagine it may be
cation of the report. I can remember reading generated in a large public inquiry with par-
the report with a sense of horror, distress ticular characteristics. For example, the Hills-
and deep sadness. Unsurprisingly, the borough inquest involved nearly 100 families
reviewers found that Connor's death was with very similar experiences of the catas-

preventable and listed a comprehensive set trophic event at the Sheffield Wednesday
of failings. stadium in 1989, a campaign period lasting
Verita 2 was equally difficult to read, over two decades followed by a two-year
albeit for different reasons. The reviewers inquest which many families attended daily.
identified a range of failings in the takeover The intensity of this process could enable
process of the Oxfordshire provision, but bonds to be formed between family mem-
concluded that these did not contribute to bers and to generate a collective experience
Connor's death. This review was not com- of catharsis at the end of the inquiry. Again,
pleted until October 2015, coinciding with there is no evidence to substantiate this.
Connor's two-week inquest. The inquest My concern is that the assumption that a
involved a jury and eight separate legal cathartic release is a positive (and sought
counsels. After some very challenging ques- after) outcome of an inquiry or investigation
tioning and exchanges, the jury determined may reduce the process to little more than a
that Connor died as an outcome of serious nod to harmed families and the wider pub-
failings by the trust. The Coroner issued a lic, leaving unrealised the effective change
Prevention of Future Deaths report to the trust that is so important to families.

around their epilepsy protocols. The baton was then passed from the police to the

'Catharsis' in practice

Health and Safety Executive (HSE) to further investigate whether the trust should face a Families are not typically familiar with the

criminal prosecution. In March 2018 the trust processes that should take place after the
was charged with the death of Connor and a unexpected death or serious harm of a patient
second patient under health and safety law and will quite likely assume that the NHS
and pleaded guilty at Oxford Crown Court. trust will act appropriately and undertake a
The sentencing remarks by Mr Justice Stuart- full and thorough investigation. There is no
Smith captured the 'time consuming and equivalent of a police liaison officer in the
punishing campaign' we had fought and sta- NHS to guide and support families. In our
ted 'it is clear on the evidence that Dr Ryan experience, which is not unusual, the trust
in particular faced not merely resistance but argued that Connor died of natural causes
entirely unjustified criticism as she pursued and began a process of obstruction and denial
her "Justice for LB" campaign'. The trust that was to last nearly five years.[4] The ease
was fined £2 million, the biggest fine in the with which this was implemented suggests it

history of the NHS. was not an unfamiliar process to them. nor's The death investigatory eventually processes involved around two indepen- Con-

Catharsis

dent investigations by an international
/kəˈhɑːsɪs/ *noun: The process of releasing, and* consultancy called Verita. One focussed on
thereby providing relief from, strong or repressed what happened in the unit at the time of
emotions. Connor's death (Verita 1) and a second,
The experience of gaining accountability wider, investigation focussed on the recent
for Connor's death involved several steps takeover by the NHS trust of the Oxfordshire
across a period of five years, including the provision in which Connor died (Verita 2).
publication of two investigation reports and

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the inquest and criminal prosecution of the trust. There is considerable, emotional labour for families behind each of these steps, which involves, and is exacerbated by, lengthy delays, numerous meetings (often some way from home), reading lengthy and often distressing documents, draft reports and legal submissions, and revisiting har- rowing detail and medical records. The impact of this labour is abstract, and inter- rupts evenings, weekends and even holidays. The weeken after Connor's inquest, I was invited to appear on the BBC Breakfast new programme and the presenters kept hinting at catharsis; 'You must feel pleased, relieved that . . .' I replied, 'I just feel sad'.

Three years later, the comprehensiveness of the judge's sentencin

remarks at the HSE prosecution generated a sense of finality: that justice had finally been served. It was the right outcome. The size of the fine would make it clear to other trusts that they needed to improve the standards of care provided to learning disabled and autistic patients. I felt relief that the trust had been held to account and that an excruciating, exhausting and dis- tressing battle was over. At the same time, Connor was dead and we had learned that the failings that contributed to his death were worse than we initially imagined. The pressures of these processes took their toll emotionally and physically.

There is little doubt that, for the families involved, inquiries and investigations (or non-investigations) can compound and pro- long experiences of grief.[5] There is variability in practice across NHS trusts, with different models of investigation, despite a *Serious Inci- dent Framework* published by NHS Improve- ment.[6] The distress that poorly conducted investigations can cause families was recog- nised in the Parliamentary and Health Ombudsman review into the quality of NHS complaints which involved serious or avoid- able harm.[7] The review concluded that inves- tigation processes were not consistent, reliable or good enough, staff did not feel supported in their investigatory role and there were missed opportunities for learning. A UK study of health professionals' perceptions of the NHS 'Being Open' policy found:

> Even when the best of open disclosure prac- tices are followed, patients and relatives may remain hurt, angry and upset and will not always forgive health care professionals or services. They may continue to pursue fur- ther explanations even after what staff believe were comprehensive enquiries, may be unwilling to accept proffered apologies and may still wish to pursue legal claims against health care providers.[8]

he preventable deaths of patients in mental health and learning dis- at the trust in which Connor died highlighted issues around the of families. The authors raised the fol- lowing questions; 'Are we lies in the right way? How do we know? How can we improve What is best practice for family involvement?'[9] A report published in ighlighted how trusts continue to fail to engage with bereaved se of a lack of train- ing and fear among staff of the potential or them professionally.[10] It seems peculiar that the NHS continues to interactional practices, which should be underpinned by honesty, nd kindness, so consistently poorly.

Walshe earlier linked catharsis with reso- lution and nd it was clear at the Health Foundation event that at least one chair iquiry felt this can happen during the inquiry process as family face to face with staff mem- bers involved in their relatives' care. no research evidence to substantiate this. From my experience, the ome of the investigations into Connor's death was fair and just. The stated that lessons had been learned. Fami- lies who do not get this which there are several high-profile examples, can fight for decades ity. The development of social media platforms has created a space ies to share their accounts of the process publicly, mak- ing clear the l by a lack of comprehensive investigation or an unsatis- factory n investigation. For example, there have been several inquests public domain in the past year, including those of Danny Tozer and y, in which coroners have reached unexpected conclusions, despite

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Having apparently strong evidence that neglect was
reached the end of the investigation involved in the deaths.
journey, we are left unconvinced that what Those advocating catharsis are, I suggest,
happened to Connor will never happen to imposing their view of what they think fami-
another patient. lies *should* feel, or *ought* to feel at the end of
Walshe (in this issue) offers an epistemo- an inquiry or investigation. It is, perhaps,
logical critique of inquiry methods and con- wishful thinking, underpinned by a recogni-
cludes by questioning whether these are tion that preventable harm has occurred. The
effective at addressing the first two objec- assumption, however, creates a neat (and
tives in Howe's typology: 'finding the facts' arguably, appealing) leap from start to finish,
and 'learning from events'. He suggests from death or serious harm to justice and
inquiries may serve other purposes, such as accountability effectively erasing the months
providing opportunities for catharsis or and years of emotional 'accountability' labour
holding stakeholders to account. I have conducted by families at a time when they
argued here that we have no evidence to should be supported in their grief.
support the claim for catharsis or emotional release, and the idea of holding stakeholders

An effective mechanism for accountability?

'to account' is a problematic concept. Saying sorry and, in Connor's case, pleading guilty

Various commentators have highlighted the seemingly *ad hoc* and inconsistent models of NHS inquiries and investigations and ques- tioned how effective they actually are. As mentioned earlier, nearly two decades ago, Walshe made

straightforward recommenda- tions to try to inject rigour and consistency into the inquiry process. These included learning what works best in terms of differ- ent types of inquiries and conducting a com- parative review of different models of inquiry. Walshe also highlighted the absence of any understanding of the experience of inquiries both by families and staff: ‘a quali- tative study of the use of inquiries would draw on the extensive recent and current experience of major inquiries in the NHS . . . and could help to promote a greater dialogue about the future use of inquiries.’[11]

One year on from the HSE prosecution, we have heard anecdotally that there is little real change at the NHS trust involved. The same problems are continuing and, in the wider context of the field of autism and learning disability provision, people are con-

in a criminal prosecution is one thing, but without the actual change that families seek, it is a hollow outcome. Maden argues that it is doubtful that inquiries could ‘satisfy’ bereaved relatives given the enormity of their loss and refers to an annexe in the Jason Mitchell inquiry report in which his family state they are far from satisfied by the report.[12] I have argued here that adding to this loss (rather than easing it in any cathar- tic way) is the emotional accountability labour that families undertake during the inquiry and investigation process.

I would like to conclude with two points. First, it is imperative that the now long-over- due qualitative research is conducted into how bereaved families experience NHS inquiry and investigation processes. We need to better understand both how these pro- cesses are experienced and what families hope to gain from them. Second, the objective of ‘lessons learned’ should be replaced with a new objective: ‘leading to demonstrable change’, in order to provide families with reassurance that changes will be implemented as an outcome of their loved one’s death.

tinuing to lead impoverished lives, with no change in the mortality rates for these patients. The *Prevention of Future Deaths* report generated a response from the trust around ‘lessons learned’ and disappeared into a pool of similar reports from coroners across the country. The various investiga- tions and reviews into Connor’s death have not led to much, if any, discernible change.

Notes

1 G. Howe, ‘The management of public inqui- ries’, *The Political Quarterly*, vol. 70, no. 3, 1999, pp. 294–304. 2 K. Walshe, *Inquiries: Learning from Failure in the NHS?*, London, Nuffield Trust, 2003; https:// www.nuffieldtrust.org.uk/files/2017-01/inquiries-

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