Commentaire/Commentary

'Invalidé' or 'Invalid'?
Critical Reflections on Health, Self, & Identity

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> Only through the experience of trial and suffering can the soul be strengthened, vision cleared, ambition inspired, and success achieved. The world is full of suffering; it is also full of overcoming it.[1 p205]

Introduction

For all of my professional life, vision has been a central, yet largely unacknowledged, part of the work that I do. As a mental health nurse I have been practitioner, educator, and researcher. In each role, 'sight' represented a critical component of 'insight'; whether that be engaging with clients/patients, students, or study participants. Observation, and interrogation of ideas, is essential to the way we help to enable and empower individuals, or explore our own understandings of the world around us. It is a social world mediated and constructed by seeing, talking and sense-making, but each of these can be too easily taken for granted. The following narrative is a reminder of human fragility in the context of healthcare needs that extend beyond the 'blind' rhetoric of health policy. It is the personal account of a 'wounded story teller',[2,3] where loss precipitated a new way of 'seeing' familiar environments. Illness is often spoken about in episodic terms and, if mapped as a journey, charted by the discourse of those in control.[4] Sickness connotes lack of control, adoption of a 'sick role',[5] and surrender to the knowledge(s) of a body of experts. Illness is never planned, seldom predicted, often disguised, and easily denied by delusions of invulnerability.

A short time ago I was working away from home on a research project that involved qualitative observation and interpretation; watching, note-taking and, later, re-telling everyday events within appropriate theoretical frameworks. Sitting alone in a hotel room, with a flickering but silent

television for company, evenings were spent re-working hastily scribbled observations while they remained fresh in mind. It was a commonplace activity, defined by confidence and personal satisfaction. Like all original inquiry the accompanying sensation of uncertainty was balanced by an informed sense of self-identity as 'social researcher'; in short, I felt in charge of the situation.

This intellectual labour, like any creative and meaningful work, constructed and embodied what Marx characterised as 'species being',[6] in part approximating to Maslow's[7] ideal of 'actualisation'. The latter has sadly been abased, and abused, by several generations of 'nurse tutors' whose focus on a 'hierarchy of needs' is usually removed from concerns about relations between the individual 'self' and the state. Within the constraints of historical and material social relations, it is suggested humanity can reclaim and re-shape lives in opposition to an overpowering sense of 'alienation'. These ideas, though, are more than philosophical abstractions. They are central to understanding what is, increasingly, spoken about as 'the core business of healthcare'; neo-liberal language that commodifies compassion, and reduces caring to a profit-driven and target-directed enterprise, where market forces represent the basis of political liberty.[8-10]

I spent a considerable part of my academic career in healthcare as a researcher and writer, where journal publications need to be submitted in accordance with a universal and formulaic set of rules, and an account of 'research design' is pivotal; a failure to include this section inevitably results in rejection of the manuscript. In contrast, this article derives from personal experience expressed as an illness narrative (e.g. Roberts[11], Richman[12]).

The discussion that follows is an attempt to breathe new life into old theoretical perspectives in the context of a life-changing experience of serious illness – recounted by an 'insider' who became an 'outsider'. To describe it as reflective narrative rather than a scholarly paper is only partly accurate, capturing a dissonance between the two worlds of 'patient' and 'provider', and prompting the question of what we really mean by an 'evidence-base for practice'? Informed by the work of critical thinkers, and writers, such as Szasz[13-15], Goffman[16,17], Foucault[18,19], and Kafka[20] it is, at heart, a few pages from the diary of a 'man' who felt himself transformed into a 'disattended social object'.

A brief note on 'method'

What follows is a 'story' but, arguably, 'all research can be considered a form of story-telling',[21 p151] and this recognition is particularly important in the domain of health inquiry. It is acknowledged that narrative is one way of making sense, or meaning of life, and has evolved as a vital branch of interpretive approaches to exploring the social world: 'Critical exploration of both the content and structure of stories is therefore vital to qualitative health research'.[22 p1648] For critical discourse analytic work, in its many guises, language and text are central to, not only data collection and analysis, an epistemological critique of dominant knowledge(s) and techniques of knowledge production.[23,24] Giving expression to those groups marginalised, and oppressed, by social structures and systems, offers a space for 'resistance' to powerful institutions and ideologies; research with potential to empower and emancipate.[25,26]

More specifically, the 'illness-narrative' plays an important role in the way that individuals make sense of ill health and manage, rather than cope, with their experiences. Moving emphasis from the modernist appropriation of the corporeal being, in medical technology and treatment, Frank's[1] 'wounded story teller' lives in a 'remission society'. Rather than Parsons[5] 'patient' who was expected to comply with medical language and power, the postmodern narrator shares her/his story/suffering as a way of staying well and helping others.[21] In this way, it is suggested that from autobiographical forms of self study '...a radically different understanding of the nature of research and subject/object relations has emerged'.[27]

Retinal and social detachment: 'Falling to pieces'

In clinical terms, retinal detachment describes the moving away of the retina from the main wall of the eye, the light sensitive membrane which receives images and transmits them to the brain, causing loss of vision where separation occurs. It constitutes a medical emergency, and without immediate treatment the entire retina may detach leading to vision loss and blindness. This, though, says nothing about how it feels. Diagnosis of the 'condition' came some days after 'symptoms' first appeared – incremental visual disturbances in the sight of the right eye, flashing lights and shadowy shapes that drifted across a screen of vivid colours. It was not, initially, a permanent loss of vision. When the eye was rested, or held stationary, things could look much as they always had, and it was easy to attribute the strange experiences as a product of strain or tiredness. Indeed, in the triage of the Ophthalmic Accident and Emergency Department, the first contact with healthcare services, an attending nurse remarked that my eyesight was 'fine'. Of course, during the eye test I was passively standing, looking at

a Snellen chart in one fixed direction. This was not reassuring and, despite supportive words from my partner, Ashay, three anxious hours were spent waiting to see a physician.

The first intervention was an attempt to reattach the damaged retina using a laser, an uncomfortable procedure undertaken in a small, hot, and airless room. Sitting upright, with sweating hands clenching the grips of a device designed to keep my head static, an intense beam of light was fired into the eye. Punctuated by sharp sounds, that resembled the firing of an air rifle, was a painful burning sensation at the back of my eye. I cannot estimate how long this took, but imagine it seemed greater than was actually the case. I was left feeling nauseous and faint as the doctor walked from the room, muttering only that I should arrange a follow-up appointment at the Out-Patient Clinic. There was no member of staff present and, again, it was Ashay who ventured into the laser-suite to help me collect myself. Two weeks later I was informed the laser work had not been effective, the damage was worse, and the remaining option was a vitrectomy under general anaesthetic. This is an invasive surgical procedure commonly used to fix a retinal detachment, where vitrious gel which pulls on the retina is removed from the eye and replaced with a bubble of liquid gas.

At this point I was reminded that in the 'old days', 'removal of the eye' would have been necessary to reduce longer-term pain; a somewhat perverse interpretation of 'breaking bad news'. My only response was to ask, with a degree of timidity: 'That option's not still on the table is it?' When, during the process of recovery, the retina in my left eye also detached the attending consultant declared that 'the chances of it happening at the same time are about the same odds as winning the national lottery'. I easily grasped the statistical rarity, but found the comparison more than a little unsettling. During all of this, little was explained, and the chance to talk was minimal. The nicest and most sensitive person, I recall, was a consultant anaesthetist immediately prior to the operation. This was not reflected in what ensued.

Care and compassion: 'A numbers game'

Wandering from one hospital department to another for a series of tests and examinations in the 'production-line' of treatment it was hard not to notice, for me at least, the '6C' stickers on the floor coverings; permutations of six factors identified by the Chief Nursing Officer for England (CNO) at the NHS Commissioning Board, and the Director of Nursing at the Department of Health, to sustain high-quality services;[28] care, compassion, competence, communication, courage, and commitment. I was hunched

over, feeling down, and looking down. Unconcerned, others walked over them, contributing to eventual erosion; a metaphoric display of missed messages that has dogged the history, and present, of how care and compassion are conveyed to embryonic practitioners, and maintained in qualified staff. These six constructs, none of which are divisible, represent the latest 'mystery' in a healthcare creed that genuflects before dual deities of policy directive and pseudo-science. It can be argued that for too long nurse educators, managers, and policy makers have been playing a 'numbers game'; an obsessive belief that the most important aspects of empathic, enabling, approaches can be numerically indexed and quantified. Positing another 'C' for inclusion on the list, how about picking between context or collectivism?

I spent only a couple of days on the 'recovery' ward, which was large and mostly filled with empty beds for those in transit. Waking up from nineteen hours without food, and no meal available, the offer of tea, with toast and biscuits was incredibly appealing. Asking for both, I was harshly rebuked by a female Health Care Assistant (HCA) and informed that it was a choice between either one or the other. This reaction was explained by an embarrassed student nurse, who had been similarly chastised, as something that paralleled the 'less eligibility' policy introduced in the Poor Law Amendment Act to deter people claiming 'poor relief' by making conditions inside Victorian workhouses worse than those outside.[29] My experience brought a novel twist to the ideology of a 'deserving' and 'undeserving patient'. It was commonly accepted that some individuals would lie to gain extra portions and, to deal with this, everyone was assumed to be dishonest. The young student remarked that 'To me, putting the patient at the centre of care is what nursing's all about, that's what I've been taught, but this is what happens'; a lamentable episode that underpins the whole problem.

With mediated stories of declining standards of care in the NHS, a body of international literature attests to the negative impact of a 'hidden curriculum' in healthcare training across professional disciplines.[30] Quantitative studies, typically using some form of validated empathy rating scale, have recorded incrementally reduced scores throughout the duration of professional education programmes,[31] but explanations of this finding are best served by inquiry which situates its rationale and design in clinical culture and the ethnography of the ward.[32,33] Medical students, for example spoke about oppressive, discriminatory and prejudicial attitudes which were expressed as a process of 'learning through humiliation'.[34] Nurse respondents in

research studies can clearly articulate the constituents of respectful and dignified care, but struggle to deliver this within organisational systems and cultures. Jakobsen and Sorlie[35] theorise this in the context of contemporary society, where healthcare represents one sub-system of a market-driven, global, economy in which workers have a 'colonised status'. A short time spent as a patient in a large, inner city, teaching hospital made these critical commentaries more understandable, if not acceptable.

Nurse education: 'A house of mirrors'

In contemporary nursing curricula, the concept and practice of 'reflection' has assumed pivotal prominence as a way of engaging learners with the emotional labour of caring. Typically, it contributes to a portfolio of skills that approximate to a set of nationally agreed, or imposed, domains that represent eligibility to register with the professional body, the Nursing and Midwifery Council. Mapped against the learning outcomes of a three-year undergraduate programme, the emphasis is on acquisition and ongoing development of clinical competencies marked by degrees of progressive sophistication. Having previously expressed reservations about the value of reflection, I contend that promoting a 'looking glass world'[36] can potentially invert understanding unless it is anchored in a more robust theoretical critique of healthcare cultures; something entirely different from a criticism of individuals.[4]

Reflective practice in nursing and healthcare education is typically formulaic, based upon uncritical acceptance and implementation of specific 'models' (e.g. Gibbs[37]), much like attempts in the 1980s to systematically plan care, or develop a theoretical basis for caring. Emphasising cyclical stages, disconnected from bigger socio-political debate, reflection is reduced to an individual, and at best interpersonal, exercise. Ng and colleagues (2015) make this same point in relation to medical education, identifying two relevant theoretical orientations of reflection; respectively, 'epistemology of practice' and 'reflection as critical social inquiry'. They note: 'These directions offer medical education research broad and deep potential in theories of reflection, particularly in relation to knowledge creation within uncertain and complex situations, and challenging of dominant discourses and structures".[38 p469, emphasis added]

Previous ministerial calls for nurse education to 'return to the bedside'[39] have re-emerged in recent proposals to introduce an 'apprenticeship' in caring[40] where 'student nurses will be asked to do up to a year of practical training

in basic care before they turn to the textbooks' as part of recruitment and admission to healthcare courses. This represents a damaging rhetoric that de-politicises health education at a time when it has never been more needed. A 'sociological imagination'[41], critical social policy, and an 'archaeology' of nursing knowledge/science[42,43] have been relegated to the fringes of curriculum content. Educational programmes, like modularised jigsaws, often allow 'pieces of the picture' to go missing.

Moving pre-registration nurse education into the higher education sector could be, controversially, interpreted as squandering great potential advances for the profession, and sacrificing what was most valuable in the old hospital-based 'schools of nursing'. An ethos of corporatism now characterises both healthcare and university systems.[44,45] Though student nurse tuition fees are still funded through the NHS, via Clinical Commissioning Groups (CCGs), the educational culture is undoubtedly compromised by neo-imperialist international expansion of the 'global campus'; investment of foreign capital and ever expanding IT strategies of 'on-line' provision, with profit as the driving force. Multiple intakes per year of student nurses, with large cohort numbers is, arguably, not the best approach to teaching and learning in a vocation where inter-personal relations are central to communicating the core values of caring practice.

A production-line of care: 'Belief and betrayal'

Overall, this experience was a painful one. Not physical pain, which was well controlled, but the hurt of betrayal and loss. For over three decades I have proudly worked in, and steadfastly supported, the NHS as an institution founded on ideals of welfare and justice.[46] Working in the broad field of mental health, and specific domain of high-security forensic services, the struggle for advocacy, service-user involvement, and social inclusion has a respected pedigree. [47-49] Likewise, an increasingly vocal and influential contemporary cadre of 'experts by experience' where narrative, understanding, and bearing witness to illness are part of 'the resources through which patients make sense of their condition, and thus reflect upon and evaluate the very notion of a desirable outcome'.[50 p165] Offender-patients, for many people, are not a popular client group – spoiled identities and master-statuses constructed from a dual stigma of 'criminality' and 'madness',[16-19] forged in the powerful institutional discourses of law and psychiatry. With colleagues in the UK, and internationally, I supported professional (practice) and intellectual (praxis) avenues to offer 'voice' to service-users and staff in marginalised

peripheries of service provision (e.g. Holmes et al.[51,52]). At the time of my illness, I was jointly working on a project to evaluate the introduction of recovery-based care in maximum security settings.[47]

The ideals of working in collaboration and partnership are now accepted as foundational in any caring relationship across the spectrum of caring services. In contrast, as 'patient', rather than 'person' it felt very different. The standards of caring varied widely between genuine attempts at 'being human(e)' to an almost callous disregard, which meant that the overall experience could only be rated in negative terms; of anticipating the worst, and being pleasantly surprised by small acts of kindness. I felt old, alone, and unheard in an organisation where previously, in 'another life', I had been respected and valued. I experienced familiar territory as the 'product' of a monolithic machine, of being 'passed around', interspersed by interminable waiting, while being told next to nothing. Nursing care, generally, was ritualised; temporality measured by the unchanging rhythm of medicine rounds, routine observations, and mealtimes – all done, or dispensed, without 'talk'.

Postural positioning meant that time in hospital was spent lying down on my left side for fifty minute periods broken up by ten minutes of respite. Apart from visiting times, interaction was minimal; this regime continued for two weeks following discharge. Usual pastimes, like reading, were impossible and enforced idleness provided ample opportunity to think and to reflect. I began trying to make sense of things by 'writing inside my head'; memorising chunks of 'text', and eventually putting them to paper in a childish scrawl, it marked the beginning of 'recovery'. Acknowledging that surgical skill and medical technology had, likely, salvaged some degree of

sight, something was very wrong. It resided in a total failure to recognise, let alone implement, the central message of healthcare educators – the intrinsic, unconditional, worth of those seeking help in time of need. Given colossal investment in support for student nurses undergoing clinical practice (academic tutors, placement co-ordinators, link tutors, practice education facilitators, mentors, and sign-off mentors) invites the question: 'How could this be so'?

Recent healthcare scandals, and high-profile inquiry reports[53,54], have posed similar questions. In the spirit of Wright Mills[41], there are no simplistic ways of translating 'private troubles' into 'public issues', but the culture of caring in relation to health education is in need of critical attention and interrogation. Some ideas about how we might begin working towards this are expressed [see text box 1] as observations and opportunities:

Conclusion

Shortly before the events outlined in this paper took place, myself and a colleague were commissioned by NHS North West to undertake an evidence review into 'NHS values and behaviours'[55] precipitated by reported 'failings' in UK health and social care services (e.g. CQC[56]). National and international evidence, in relation to the core values of caring, was appraised and presented as a narrative review. Discussion about care and compassion, and conjecture about how best to embed these within healthcare cultures, was told from the perspective of 'objective outsiders'. In contrast, it was a sudden experience of ill health which precipitated an illness narrative that centred on the same sort of issues, where the evidence was experiential, but the story-teller remained an 'outsider'; this time in terms of dignity,

Text Box 1
-Re-politicise health and healthcare curricula, where nurse educators work collectively with trade union members, community activists, and social movements to defend the principle of socialised welfare. -Conceptualise nursing as a political force in the larger struggle for human rights and social justice. Support critical nursing research that locates practice in the context of social structures such as sexuality, gender, ethnicity, and disability that promote division and discrimination. -Avoid isolating nursing, as a professional group, from academic related disciplines within the university system. Good 'health science' requires strong links with departments like clinical psychology, sociology, critical criminology, and anthropology. Recognition that 'clinical skills' are essential to competently practice as a nurse, but 'critical skills' are what shape the way that job is actually undertaken. -In the UK there is a statutory requirement (NMC) that to hold a teaching post in a nursing department the member of staff has to be a registered nurse and that registration has to be 'live'. This precludes the employment of individuals who may possess a wealth of skills in the biological, behavioural, or social sciences.

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respect, and the process of care as 'subjectively' constructed.

The quote from Helen Keller that introduced this account was cited in a journal publication titled 'Finding Meaning in Suffering' that describes the contribution of patients, as 'wounded story tellers', to the art and practice of nursing: 'The process of caring for a suffering person is painful for the nurse and requires exceptional effort on the nurse's part, but the very act that drains the nurse can also create the fuel for compassionate care'.[1 p205] This sentiment expresses perfectly the message that I have tried to convey. I cannot claim that the illness experience was 'transcendental', but it was certainly 'transformative'; a story remembered in the dark, and written as the light began to filter through.

As a final word, and note of levity, I recall many years ago a nurse tutor bitterly complaining to me that his students knew more about 'Foucault on the eye, than the physiology of the eye'. There is much to be learned from the wisdom and curiosity of the young, where our role as health educators is to enable rather than to prescribe.

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