The neglect of older people in NHS hospitals - a view from within

This article was written before the publication in February 2013 of the Report of the Public Inquiry chaired by Robert Francis QC into the Mid Staffordshire Foundation Hospital Trust.

Every time the neglect of older people in NHS hospitals hits the news I feel collective shame for this failure in our duty of care. Every time I hear the responses of the great and the good of the NHS I am left uninspired: determination to improve, stricter standards to be published, extra training to be given, insistence that neglect will not be tolerated in NHS hospitals. The most recent damning report was published by the Parliamentary and Health Service Ombudsman in February 2011(1). Before that was the Patients Association (PA) report in December 2010(2) and others in 2010 and 2009 including the report into the high death rates at the Mid Staffordshire Foundation Hospital Trust (3,4). NHS spokespersons remind us that the vast majority of older patients are well cared for in NHS hospitals. This is true, and there are very many unsung examples of dedication and commitment to the highest standards of care and compassion throughout the NHS. However, it is not hard to find stories like the ones in these reports. Having spent 30 years as a GP, 15 years of which I also worked in our local community hospital looking after older people, I can vouch for both the excellence and the neglect.

This essay offers a fresh view of the problem. I have chosen to use examples from the most recent PA report(2). The body of the report consists of 17 stories, all but one told by a grieving close relative. The hospitals concerned are both small and large, teaching and not teaching, and scattered over England and Wales. Some are Foundation Trusts, most are not. The events recounted have recurring themes of the neglect of basic human needs such as hygiene, food and dignity, and of undertakings not fulfilled, phone calls not returned, complaints not taken seriously; of poor nursing technique, lack of communication, equipment not working, arrangements not made, appointments not kept, and most of all, of worried and incredulous families faced with the callous indifference of staff.

Many plausible explanations have been offered: political interference, staff shortage, unmanageable bureaucratic systems, perverse incentives from targets, poor performance information, poor buildings, lack of skills at various levels and frequent reorganizations. Whilst all of these are variously implicated, I want to focus on a more illusive underlying problem which is given too little attention.

"On both the wards she was on I was struck by the lack of compassion and care in the nursing. This was not just the occasional nurse, in fact the odd caring nurse proved to be the exception." (story 3)

Being uncaring and lacking a humane response has become like the wallpaper in parts of the NHS. It easily goes unnoticed by staff. Yet, I contend that all those involved will have, as individuals, humanity to offer. The problem is surely with the culture of the institutions – a culture of callousness.

I noticed the call bell had been taken away, put where he couldn't use it. (story 16)

Why is this so? To be callous is to be defended against personal hurt. For me, the stories depict a workforce that has learned to avoid engagement with the patients and relatives at an emotional level. Nurses have eyes for the medicine chart, doctors for the electrocardiogram, managers for the budget: all esoteric and inanimate symbols of hospital life that manage to fill the working day. These objects, being empty of human meaning in themselves, are easily disconnected from the suffering person whose name is on them. The tasks become a matter of ward routine that provides little emotional reward and, perhaps as a consequence, are often done badly.

I think the general attitude of the Doctors, nurses and carers on ward 33 was incredibly unprofessional in their care, hygiene practices, basic nursing skills, communication skills and most painful of all, their inability in simply offering human kindness to another human being who was very poorly. (story 17)

Why do the staff avoid emotional contact? I suggest that this is not because they are bad people, but rather good people in a bad situation. Modern healthcare is overwhelmingly mechanistic and often conceived as a battle against ageing and disease, the ravages of time and nature. This has been the case in medicine for fifty years but whilst nurses at one time held the baton for winning hearts and minds, nurse education now mirrors the focus on technology. Here the patient is represented by test results and diagnoses, and their cure is enshrined in a protocol. This is a form of industrialization which works tolerably well where the problems are essentially mechanical in nature and amenable to technique, such as cataract surgery. But it applies much less to people with 'complex' life problems not reducible to a single disordered mechanism: the machine metaphor works poorly here and must be replaced by something quite different(5). Without that different way of seeing the young nurse or doctor can feel at a loss when their technical skills and knowledge lets them down. Then patients and relatives so easily seem to be the cause of their problems. Perhaps the staff are seeing their own impotence reflected in the frail being of the patient. So is set up a vicious cycle of demoralization and of shrinking away from the suffering person until they become almost invisible.

I got the impression that because they couldn't look after patients in the way they wanted to, they had learnt to switch off. (story 7)

It is as if the professional carers have exhausted their capacity to care and they linger in a place that feels safe, apart from the tragedy of human suffering surrounding them.

The nurse did not return and I went to find her. I found her chatting to other nurses at the nurses station/ward reception. I say chatting as the nurses/staff were not discussing patients or hospital procedures etc, they were laughing and joking. I explained to the nurse who had placed mother on the bedpan that my mother had finished but she did not end her private conversation/chat. (story 13)

Young recruits to nursing and medicine may start with the intention of providing the highest standard of care through their largely technical education. But when the technology fails many will not have had role models for stable, loving and compassionate relationships to fall back on. Even those with the capacity for a warm response will know (whatever they are told in their training) that nurturing and caring have low status and value in our 21st century society. Sadly, this is exactly mirrored within many NHS hospitals so that, far from being a haven from the hard world, they are a microcosm of it.

There is another strand of meaning emerging from the stories. This is about the individuality of each patient. Within the world of social welfare provision importance is attached to treating everyone the same. This is reinforced in healthcare by the contemporary emphasis on research evidence, most of which relies on statistical methods to generalise from the experience of the few to the experience of the many. This methodology, embedded in the laws of natural science and mathematics, sets out to find sameness, not difference. Yet what patients and relatives see and feel is difference.

> Every year in the summer we would end up somewhere on holiday, in a caravan by a sea…It was on one of these holidays in Felixstowe that dad took me to see my first wrestling match; dad loved his wrestling… He used to get so excited, jumping up and down and grabbing the air, you would think he was in the ring with them….[Now] I see my father pleading for help and painkillers which I could get from the chemist quicker than my father got them…. To see someone who has done so much for you in so much need without being able to help is heartbreaking. (story 16)

There are many accounts like this. The writers were perhaps given a brief to include personal details but this does not diminish their significance. In his book, *The Needs of Strangers*, Michael Ignatieff draws out some of the dilemmas at the heart of welfare provision.

> Giving the aged poor their pension and providing them with medical care may be a necessary condition for their self-respect and dignity, but it is not a sufficient condition….[just as important is] whether the ambulance man takes care not to jostle them when they are taken down the steep stairs of their apartment building, whether a nurse sits with them in the hospital when they are frightened and alone. Respect and dignity are conferred by gestures such as these. They are gestures too much a matter of human art to be made a consistent matter of administrative routine. (6)

What lies behind this 'human art' that cannot be prescribed in a manual or protocol? Ignatieff distinguishes care given as either a matter of right, a matter of deserving, or a matter of charity(6). In the light of current commercial trends he could have added 'as a consumer'. All of these are potentially problematic. Though the nurse did not bring the analgesics she might have said that her patients do have a right to expect pain relief (more about this paradox below) – rather than deserving it (which requires prior knowledge and implies that some will not deserve it) or making it a charitable act (which people often find demeaning). Ignatieff writes on the next page:

> The most common criticism of modern welfare is precisely that in treating everyone the same

it ends up treating everyone as a thing. (6)

Of course, rights are expected to apply equally to everyone, but if the patient has become a 'thing' there is somehow less urgency. To counter this, we may be told that nurses and doctors should try to treat each patient as if they were their own close relative. But the filial feelings expressed in the 16 stories told by close relatives are based on shared lives and shared heritage which cannot be conjured from nowhere. The difficulty is compounded by the professional's duty to weigh up the needs of each patient against another, the individual against the common good (or what it is reasonable to expect under the circumstances). This extends beyond the hospital confines – space must be made for those needing admission tomorrow and the next day. There is an irreconcilable paradox here: between treating everyone the same so they become things, or treating them as unique individuals and therefore differently and unequally. Yet we are told in the stories that some nurses and doctors manage to contain this tension. Perhaps this is the human art: listening well, working creatively with ambiguity and uncertainty, being open-hearted, having enough kindness to take the risk of giving some to the stranger. Sometimes it will be returned with interest, sometimes it won't. A small gesture is often enough.

The staff nurse kindly came to see me before she went off shift, to say that I would probably be transferred to another ward, so I probably would not see her again. A very nice and important touch. (story 4)

The analysis offered above amounts to a series of five barriers to compassion: staff (especially new staff) ill-prepared for emotional engagement, the temptation to hide behind technology and protocols, the fragmentation of our individualistic society with its frequent family breakdown, the hegemony of generalized scientific evidence and the emphasis on sameness rather than difference. It is perhaps surprising that some exceptional individuals manage to cling onto their humanity sometimes at great personal cost. Indeed some wards, even whole hospitals, succeed in creating a truly healing ethos. How is this possible? Do these units happen to be full of exceptional people?

They had the same shortage of staff, but there was never anybody congregating around desks, they were always trying to help, always made sure you had your call bell. I cannot tell you how different it was. (story 7)

Complexity science tells us that the culture of an organization is dynamic and co-created by the innumerable interactions between all the people who constitute the hospital – patients, staff and visitors(7) including the non-verbal gestures described by Ignatieff(6). Together with some aspects of the building, these *are* the culture of the institution. They both portray and constantly re-create the culture. If our conversations and gestures are mostly about science or money or hedonism, so will be the culture. If our conversations are informed by an empathic concern for one another and our world, so that none of us becomes a 'thing', then the culture that emerges will be one of kindness, compassion and trust.

So how can the hospitals described in the 17 stories change their culture? The

Patients Association suggests the introduction of 'patient safeguarding champions'(2). These would be independent clinicians focusing 'on the essential standards of nursing care that every patient should expect..' and would monitor compliance with these basic standards. I believe this approach may help some hospitals to achieve a minimum level but it is unlikely to address the underlying problems I have outlined. If kindness and compassion are the essential missing ingredients no amount of monitoring or cajoling or target-setting will bring them out. In fact, the opposite might occur. It is Ignatieff's 'human art' that we need, and this cannot be made 'a matter of administrative routine'.

There is a lesson here from Shakespeare's *King Lear*. At the start of the play, the protagonist sits at the head of his kingdoms, surrounded by his retinue of servants. He can command any material comfort, but like all of us, is looking for something deeper. Kingship is lonely. Shakespeare shows that we can command the satisfaction of some human needs but not others. Lear learns at terrible cost that the first of these is love. His attempts to buy love lead him to part with all of his kingdoms, his wealth and his status. By the middle of Act 3 Lear is stripped of his fine clothes and even of his senses; he is homeless on a heath, sheltering from a storm in a hovel and surrounded by just a few true friends. So recently a monarch, Lear, even in his confusion, recognizes himself in a fellow vagrant.

> Is man no more than this? … thou art the thing itself; unaccommodated man is no more but such a poor bare, forked animal as thou art. (8)

This is a turning point in the play: Lear is touched with compassion for the poor wretch sharing the hovel. This is not because his fellow vagrant has rights, nor that he deserves better, nor that he is a suitable object of charity. The king's compassion is finally drawn out by realizing that he too is a 'poor bare, forked animal'. He too is human.

I contend that it is this deep recognition of shared humanity that is missing in too many NHS hospitals. As already suggested, this is partly because it is also missing in large sectors of our society. This gives the NHS an opportunity to become a haven from the hard world, to set an example to our wider society, to be a leader in health rather than a repository of suffering – patients and staff alike. Shared humanity entails recognition of the needs of all those involved. It is not a coincidence that a higher than average proportion of NHS staff suffer from stress-related illness(9). King Lear provides another lesson here:

> *King Lear* is also a play about blindness, in particular our blindness to our own needs. What we need, Lear discovers, we can barely admit; we learn what we need by suffering. We learn how much is enough by learning what it is like to have less than enough. Our education in need is a tragic passage from blindness to sight. (10)

How can we apply these lessons about human need to the contemporary NHS hospital without following Lear to his abject misery in a hovel? I suggest that we need *empathy*, literally translated as 'in-feeling'. This is probably what Ignatieff called 'a matter of human art'. It is experienced by the person with whom we are relating as

compassion, literally translated as ‘suffer with’. The capacity for empathy is achieved through a journey of self-discovery. It was empathy that Lear finally felt for his fellow vagrant in the hovel. Here is another example:

A medical student told of how he and a group of residents were laughing and joking through “work-rounds” one morning; they expressed amused resentment toward their next patient, a comatose old man awaiting his PEG (11) ticket to a “nursing warehouse”. After the ritual chest examination and a few shouts in his ear, they turned to go, when their attention was caught by a new card on the wall, colored by a child’s hand. “Get well soon, Grandpa,” it read. The troupe fell silent as they left the room, and for a moment the joking ceased. That was empathy, with the child if not with the old man. (12)

If you had feelings welling up when you read the above extract, this was empathy. You were feeling “I am you” or perhaps “I might be you”. To feel it you must have already experienced something like the story yourself so through your imagination you become part of the story. It is a recognition of shared humanity and its power lies in being experiential. To use this imaginative projection in the service of professional caring it needs to be combined with curiosity, not so much about the disease a person might have but about the person who might have the disease(13). You need a specific interest in the *person* who is suffering, and in the nature of their suffering, which is often much more complex than it first appears, possibly having little to do with the disease or even with pain(14). You also need to cultivate your imagination and a sensitivity to subtle verbal and non-verbal cues. All of this sets you onto a virtuous cycle of self-discovery and the ability to give out compassion to others.

The capacity for empathy is present in all of us. It can be finely tuned but also wither through disuse. Sadly, medical and even nursing training may fail to nourish it perhaps because, being part of a process of self-discovery, it will expose vulnerability. We have to be able to tolerate being vulnerable and this requires emotional support and recognition that vulnerability is part of our power to heal. If the university who is training us or the hospital in which we work does not explicitly affirm this, our capacity for empathy will wither on the vine. Unless we are one of the exceptional people with a deeply embedded empathic nature (usually from childhood) we will avoid emotional engagement and the sad cycle of patient neglect and personal stress will grind relentlessly onward whilst clever minds gather in back rooms hopelessly trying to impose order on the muddle of life.

So what do we do in practical terms to cultivate empathy in our NHS hospitals? My own experience suggests that senior medical and nursing staff and senior managers have a crucial role in setting the culture that determines the ethos of care. Though they may not realize it, they are the scriptwriters and directors of the tragedies described in the 17 stories. The nurses, junior doctors and other staff act out the parts they are given. Over the past 10-15 years the proportion of non-contact time with patients for senior staff has greatly increased. Their world is now often about such relatively abstract activities as interpreting ambiguous scans, weighing one therapy against another, setting strategy and objectives, bed turnover, length of stay, trolley waits, outcome measures, marketing and developing the service, meetings, more meetings. Whilst the reduction in patient contact can be a strategy to avoid burnout, it allows the “empathy muscle” to waste away and sets a poor example to

those who are daily and intimately engaged with patients.

Senior staff may have more life experience but be less good at empathy than some exceptional junior staff (King Lear again). This will require humility: a willingness to appear clumsy in front of others and to learn from those who are natural empathisers – including perhaps a healthcare assistant. For empathy transcends hierarchies and is independent of knowledge. This is part of the self-discovery which empathy requires. These senior staff members (clinical and managerial) could be called 'champions' because they are championing the cause of compassion and not because they are champion empathic performers. Note that this is quite different from the Patients Association suggestion for 'patient safeguarding champions' who appear to be independent scrutineers. This is also different from academic approaches(15,16) and from calls for respecting dignity(17). A patient's dignity (or lack of) is experienced by the patient whereas empathy is experienced by the nurse or doctor. Experiential learning can eventually penetrate even a calloused outer shell, as Shakespeare so vividly shows.

It should be clear by now that it is vital that all staff are supported to risk showing their feelings. This may not be easy, especially for busy senior staff who may be reluctant to prioritize an activity likely to expose their own vulnerability. Poetry, stories, the visual arts and dramatic productions can be used to explore empathy and self-discovery in a relatively unthreatening way(18).

One word to describe all of this is *spirituality*, a word that has barely any currency in modern healthcare but is crucially relevant to these problems. Our secular English language has difficulty articulating this. Spirituality is often equated with religion, but religious ritual and belief is only one of many approaches to spirituality. This essay has explored using the cultivation of empathy through emotional support and involvement of senior staff, perhaps using creative arts, to achieve a stronger sense of connectedness and deeper respect for ourselves, for others and for our world – a deeper spirituality.

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