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Solutions: compassion clinical leadership

The importance of compassion in healthcare has been recognised for over a decade, as have the significant obstacles to its provision. A number of initiatives currently underway, many of which have been started as a response to poor patient experience, are described.



The value of compassion in healthcare has never been so much in the news - with repeated pleas over the last decade for more kindness, compassion and respect for the dignity and privacy.

The Bristol Inquiry report, published in 2000, demanded 'a sense of respect for others' in healthcare - so that patients are 'seen first as people who live complex lives rather than as clinical problems with a collection of symptoms', as 'thinking, feeling, interacting beings'.

The 2008 Darzi's report insisted that 'being treated with compassion, dignity and respect' must be seen as a top priority alongside the need to be cared for in a clean and safe environment. As a surgeon, Lord Darzi said, these factors 'had to be balanced against the success of the treatment patients receive'.

Niall Dickson, former chief executive of the King's Fund has warned repeatedly of a deterioration in compassion in the NHS. He said: 'How we are treated can affect how we recover. For a hospital there is scarcely anything more important than ensuring every patient is treated with kindness and consideration - not as a collection of symptoms, but as an individual with anxieties, feelings and views' (www.hospitalmanagement.net, Jan 2009).

The launch of the Dignity in Care Campaign with 4,500 staff champions to fight for the dignity of older patients was headed by Dignity Ambassador Sir Michael Parkinson. He said: 'My personal experience of treatment for cancer at an NHS hospital in Kettering had led me to believe that dignity and compassion are not a nice-to-have bonus extra. They have got to be hard-wired into the DNA of the NHS.'

Even the Archbishop of Canterbury, Rowan Williams has spoken of the risks of a new 'macho' culture of healthcare in which there is 'no recognition of the professional importance of the personal'. He said: 'Again and again, it seems that the real task for health care in these days is not just to fight the constant battle for proper resourcing, but to hold on to the belief that what needs to be resourced is a system that has to be kept human - that is, a system that puts resources at the service of dignity as an intrinsic and vital aspect of health.'

Yet despite these demands for change, the problem may be getting worse, according to Dr Robin Youngson, a UK trained anaesthetist, now working as a clinical leader in compassion in New Zealand as well as being an advisor to the NHS Confederation. He says:

"The most shocking thing is that these basic failings are the rule rather than the exception. Compassion as a concept is largely missing from health policy. It is an assumed value that has been beaten out of professionals and systems but one that (has had) to be put in the NHS constitution and then upheld as a core value. If we can't provide humane and compassionate care for our patients, we are in trouble. I

don't think there has been a watershed event but things have got accumulatively worse. It is not that doctors and nurses don't care, but aspects of their training, tough professional values and the efficiency-driven institutions they work in limit the possibilities for compassion."

And bowing out of the Dignity in Care network at the end of 2008, Sir Michael Parkinson said:

"I implore Government not to give up on this agenda, not to tick it off as 'job done' – it clearly isn't. There is still a long way to go. There are times when Government needs to stop pandering to the outpourings of the latest focus group and deal with the real issues. My year as Dignity Ambassador has confirmed that ensuring dignity in care is a real issue, one that really matters to people."

As the healthcare academic Valerie Iles, points out in a paper entitled, 'How do good people find themselves offering bad care', the problem does not offer easy solutions.

"Much of the care provided by healthcare staff is not the kind of care any of us wants to receive. And we can assume that the vast majority of the people offering it are good people (people with positive intentions, who behave rationally and are competent at what they do). This lack of ability to offer good care, and of the ability to influence the decisions taken by others that affect the quality of care, is surely a major cause of dissatisfaction among professionals, managers and patients. So it's important to understand how is it that these good people find themselves offering the kind of care they wouldn't want to receive themselves? Indeed the kind of care they don't really want to offer."

Some explanations for this discrepancy are offered by Jocelyn Cornwell, of the King's Fund's Point of Care programme.

"Staff come to work intending to provide the quality of care they would want for themselves and their families but today's hospitals are vast, time is at a premium and in these busy medical factories care of the person can unfortunately get squeezed out." (Jocelyn Cornwell quoted in www.hospitalmanagement.net, Jan 16 2009).

Yet with these issues increasingly confronted, there is now a strong desire to improve the quality of care provided to patients. Here are five ways to ensure that dignity recovers its place as an intrinsic and vital aspect of health.

1. Better leadership

Gill Hicks spent two and a half months in Guy's and St Thomas's Hospital when she lost both her legs in the July 7th London bombings in 2005. This beacon hospital was already running a 'back to the floor' programme to improve dignity in care - and for Gill it bore fruit when she was leaving intensive care to go to a ward and needed a shower.

"The nurse helping me was unable to manoeuvre the shower to do this safely. So instead she jumped into the shower too, fully clothed, to help wash me. The moment was funny but also extremely moving."

Sir Michael Parkinson made the following comment about Gill's experience.

"That story really sticks with me not only because it demonstrates the true meaning of care and compassion but also because I can imagine how, in a less enlightened organisation, that nurse could quite easily have found herself being disciplined for breaching health and safety rules, or desecrating the uniform, or some other such nonsense. It is nice to hear of staff who have the confidence to use their own judgment on how best to meet the needs of their patients, without fear of reprisal."

Dr Robin Youngson, a UK-trained anaesthetist, is now working as a clinical leader in compassion in New Zealand as well as being an advisor the NHS Confederation, believes that leaders at every level create the culture within which compassion can flourish or die.

"The acid test for me is the supervisor's response to witnessing a staff nurse sitting quietly with a patient for ten or 15 minutes, to be present and to listen to concerns. In almost all of the hospitals I have worked in, that behaviour would be reprimanded not rewarded. The reality is that we cannot afford the time NOT to listen."

Indeed, while many staff are motivated by the desire to provide high quality patient care, patients' experience will not be improved 'simply by individual acts and commitment' say Jocelyn Cornwell and Joanna Goodrich, authors of Seeing the Person in the Patient, The Point of Care review paper.

'Recent evidence from organisations that have reputations for providing excellent patient care shows that it means transforming hospital cultures and ordinary working practices ('the way we do it around here'). This is an immense, complex task requiring serious investment at both strategic and operational levels'.

It's difficult to identify the contribution management and senior leaders make to well-run services. But there is no doubt, they say, that:

'According to the Healthcare Commission, the gross failures in service quality that have been subject to investigation (Healthcare Commission 2008a) are invariably associated with senior leaders failing to show interest in the experience of patients and staff and failing to focus systematically on service quality.'

Research (Shaller 2007) into US 'patient-centred' hospitals with a reputation for service excellence shows that these are organisations where 'senior leaders feel directly responsible for the fate of staff and patients', according to Cornwell and Goodrich. These hospitals have seven factors in common:

1. They actively inform themselves about the quality of the service that is on offer, visiting clinical units and wards, talking to staff and patients in lifts and corridors and clinics.
2. They receive training in patient safety and quality improvement and devote time at board and committee meetings to listening to and learning lessons from individual case reviews and groups of patients and families.
3. They develop and resource strategies for improving quality of care and use communication within the organisation to make sure staff understand the strategic goals and their role in achieving them.
4. They invite patients and families to participate in hospital committees and decision-making structures at all levels.
5. They use measures for service quality and have a variety of sources of information about patients' experience including mystery shoppers, patient surveys, open days, focussed discussions with groups and telephone surveys.
6. They provide a supportive work environment for caregivers and pay a great deal of attention to the quality of the physical environment.
7. They are innovative in their use of technology to support patients and families with information.

2. Better teamwork

Compassionate teams don't just happen, says Jocelyn Cornwell of the Kings Fund teams.

"Providing personal care for patients is phenomenally hard work for teams as well as for individuals... The intention to deliver personal care needs to be matched by investment: in practical support for care givers to help them to keep in touch with their own humanity; in training in multidisciplinary team working; and in clinical leadership."

Every detail is shaped by the actions, attitudes and behaviours of individual members of staff, that are in turn shaped by their personal experiences and values (including professional values) and attitudes, and by their colleague. They are also shaped, in ways that are more difficult to discern, by the practices, opportunity and limitations of the organisation in which they work as well as the wider health care system. When that doesn't happen, "everyone dealing with (patients) is left to invent for themselves how to talk and how to behave towards patients and relatives."

Even when doctors have little to offer clinically, the ability of the team to offer kindness, compassion and respect for the patient's dignity are still just as important - as the father of a baby who died on a ventilator aged 12 days old, exemplifies in describing the care his whole family received while in hospital.

"Our baby Dexter was born full-term weighing 8lb 6 oz. He had to be put on a ventilator straight away and was immediately transferred to the neonatal unit. Over the next few days various investigations and tests were done which gave us hope that he could make a full recovery. But then the results of his MRI scan came through; it showed that he was severely brain-damaged due to oxygen starvation. We then made the hardest decision of our lives – to ask the doctors not to resuscitate Dexter if he was unable to breathe on his own."

The staff on the neonatal unit treated Dexter with dignity throughout his short life and also after his life ended. As his parents we were treated with kindness and compassion. No matter how many questions we had, or how many times we asked the same thing, we were given as much time as we wanted with the consultant, paediatricians and nurses. We were always treated with courtesy and respect by everyone on the unit and they did their best to accede to our wishes." (Website on Patient Opinion, extract from Compassion and Caring in Nursing, by Claire Chambers and Elaine Ryder, Radcliffe Publishing 2009).

Dexter's parents left hospital bereaved and highly traumatised by the unexpected death of their new born son. Yet they were 'highly satisfied with the care they received in these dreadful circumstances', explain nursing academics, Claire Chambers and Elaine Ryder. How did that happen?

"The team was probably very experienced in dealing with this sort of traumatic situation and had clarified their own personal beliefs and how this impacted on their professional attitudes and interactions. In addition the care environment was a positive one and there was evidence of clear team working and effective relationships with clarity in relation to the roles they all played. The care environment and person-centred processes encouraged shared decision making and negotiation, based on helping the parents to make sense of what was happening and understanding what was important to them."

In a hospital setting involving different groups of health practitioners, this team-based patient-centred approach doesn't always happen.



This 31-year-old received excellent care from the clinicians closely involved with her caesarean section. But the members of another team - the nurses who provided the aftercare - made it quite clear that she was merely 'one of a throughput of patients'.

"Well, I mean everything was fine during the birth and that and the women down there were, were brilliant, but up, up in the ward, I just... the only way I can describe it - and I can remember saying it to mum and dad - was I felt like a burden on them. And I mean, having a section, I mean, it's major surgery, you're kind of limited, I mean, I was in bed with a catheter and a drip, got new born baby beside me, never held a new born baby in my life, wanting to breastfeed, and I just felt... I felt like I was a burden because I needed people to help me get the baby and I didn't feel like they were very forthcoming in helping. It was like there were no allowances for... you know, it's like, "It's your baby, get on with it". And it doesn't matter that you're hooked onto a drip, catheter, you know, you've had a great big wound in you and you're trying to reach over and... so I did feel really, like... I mean a lot of it could have been made worse... the fact that you've just had a baby and your emotions are all over the place. But I didn't feel like the aftercare was very good at all."

Kieran Sweeney, a GP and Professor of General Practice at Peninsula Medical School, wrote and talked about the care he received during the diagnosis of the terminal cancer that caused his death in December 2009, aged 57. In a video interview, analysing the unsatisfactory nature of some of his care, he looked at the different teams responsible for his care and discussed how successful they were.



"One is for me there is a multi-disciplinary team of cardiologists, oncologists and respiratory guys. They think they work very well and I have absolutely no doubt that they do work well. But that is not team I see. I never see the respiratory guy or the pathology guy and I've only seen the thoracic chap twice. I see the oncologist a lot. So that is a team that works very well but it's not the team that the patient experiences. I visualise a vertical team: the nurses on the ward, the radiographer (lots more) so there is a vertical team who I saw. For example the cancer specialist nurse, the SHO, the anaesthetist, the junior anaesthetist, the nurses on the ward, the radiographers that do my chest X-ray before I left. So there's a vertical team which really starts, really starts with the guy in the car park, who tells you where the ward is, where your bed is and who's going to be dealing with you and so on through these investigations."

This vertical team, most visible to the patient, are least likely to have a detailed understanding of what's wrong with the patient and why he is on hospital. The result can be chronic humiliation - as patients undergoing difficult tests and experiencing profound fears, find themselves - as happened to Dr Sweeney - being treated casually by staff who appear uncaring.

According to Dr Sweeney, the problem is the lack of definition of the healthcare team.



"But because it is so ill defined, people are not sure whether they are in the team or not. Do junior nurses in the team I was on think they were part of the team? Did the radiographers think they were part of my team? I don't think they did but I certainly did because I'm going down to get X rays from them. Scans and stuff. Very much part of the team with whom I interact. But if you asked them, I think they would have said I was just one of a throughput of patients who was coming for important investigations."

And there are other ways in which a team can fail, as Dr Sweeney's experience showed. When his diagnosis of mesothelioma was strongly suspected but not confirmed by histology tests, Dr Sweeney felt let down by the team of specialists whose body language suggested the worst possible news - but who never came out with this bad news to his face.



"I think there may have been something in the fact that being a doctor and being roughly the same age as these guys in my late 50s. Most of the consultants were in their late 50s you know and our kids would be the same age. And this is completely curtains this diagnosis so you could see them thinking God this guys out. And they just weren't...they weren't brave enough. They weren't brave enough to say, this is really bad news for you. And I think the most hurtful interpretation of their actions maybe that they hid behind the science of their biopsy and pathology to avoid confronting the metaphysics of my predicament. I am a man devoid of hope. And I just sense that they hesitated at that point. And my own view is, my own view is, sounds quite hard. I just don't think that's good enough. Medicine is not solely a technical activity and pursuit. Medicine is about understanding and being with people at the edge of the human predicament."

Jocelyn Cornwell says that part of a doctor's job is 'to avoid abandoning patients when they most need human warmth and empathy', teamwork should involve

Here's her five rules to promote compassion in the healthcare team:

1. Promoting a sense of shared work through a commitment to regular planned communication.
2. Acknowledging the possibility of miscommunication, investigating how it occurs, and building the processes to prevent it.
3. Striving to be transparent with one another and allowing members of the team to explore their own questions and vulnerabilities.
4. Inviting members of the team who know something of the personal life of the patient to share what they know in team meetings
5. Reminding team members always to refer to patients by name rather than by diagnosis.

3. Compassion without burnout.

There is a widespread belief that too much empathy and attachment to patients leads to compassion fatigue. Detachment is a necessary defence when witnessing suffering and loss in the course of clinical practice, according to Dr Youngson:

"Research shows that medical students lose the ability to empathise with their patients during clinical training. Instead they identify with the hero model of the medical practitioner, doctors whom they have idealised as healthy and invulnerable." – Dr Youngson.

Here's an example of what it feels like when a heroic oncology specialist is at work with his multi-disciplinary team – through the eyes of a 32-year-old in hospital to have chemotherapy to treat testicular cancer.



"I've found that on the weeks that I was in hospital receiving the chemotherapy the one day a week the oncologist specialist would breeze into the room with his entourage of junior doctors with him, he would stand at the bottom of the bed, er look at your chart, look at the percentage of the different drugs that were being given to you and the chemotherapy treatment. Ask you very quickly how you were feeling, a very quick examination and then he would go out of the room and the door would shut. And you knew because you could hear, hear them speaking outside of the about you. And I almost found myself falling off the hospital bed with a cocked ear to try and hear what they were taking about. It's, that sort of situation is very poor and it shouldn't be happening but it's along the same lines as the old style of doctoring and hopefully at some stage in the future that will change."

Yet research now suggests that the behaviour of this oncologist may be more of a risk for burnout than truly compassionate care.

'Altruistic motives are often what attract people to the caring professions in the first place but these same tendencies can make staff particularly susceptible to burnout when they are not able to follow through their intentions.' (The Point of Care, Firth-Cozens and Cornwell, 2009).

In a 2007 study carried out by Jill Maben, only two of 26 nurses, surveyed at the outset of their careers and again two years later, thought they had managed to put their ideals into practice. The large majority thought they had compromised their ideals in some way –and the result, is often 'high levels of stress, depression and a shutting down of compassion – or 'case-hardening.' (The Point of Care, Cornwell and Firth-Cozens, The Kings Fund).

In a poll of 2000 nurses carried out by the Royal College of Nursing in 2008, eight out of ten nurses said that they had left work distressed because they had been unable to treat patients with the dignity they deserved, with washing and privacy cited as common issues of concern as well as staff shortages, according to a poll. One nurse said: 'Patients seem to be becoming numbers not people. I am having to fight against what the system wants in order to provide dignified care to my patients.'

Yet there are different ways of approaching the problem. Perhaps most important is acknowledgement of the simple rule that while there can be 'a genuine conflict between meeting targets and delivering quality nursing care, compassion isn't an option' - according Chambers and Ryder.

"Caring in nursing is not something we do when we have time. It should be part of what professional nursing care is considered to be. While time, resources and targets are often limiting factors in the care we give, this can sometimes be used as an excuse for inadequate care. We need to accept that time constraints and under-resourcing are often a reality in today's healthcare environment. However, we need to strive to find ways to ensure that compassionate care is built into the time available."

Another approach is the Janki Foundation's Values in Healthcare programme, a training programme aimed at supporting healthcare practitioners to be compassionate to patients by helping them first to be compassionate to themselves.

"The programme addresses a missing link in the education of many healthcare professionals whose training traditionally focuses mainly on acquiring knowledge and learning practical skills, with much less emphasis on interpersonal competence and on looking after ourselves. One of the principles of holism is that we are all connected. It follows that if you are compassionate towards yourself, you will be better able to be compassionate towards your patients. So the spirit of caring must begin by supporting staff, allowing them to work creatively within the framework of best practice and valuing them for their efforts, thus developing a culture of appreciation and humanity." - Stephanie Morrison, Lecturer in the School of Health Sciences at The Robert Gordon University, Aberdeen. Scottish Journal of Healthcare Chaplaincy, Vol 8, No 2, 2005.

The course helps staff to be compassionate without developing compassion fatigue, according to Dr Sarah Egger, chair of the Royal College of Psychiatrists' Spirituality and Psychiatry Special Interest Group and medical advisor to the Janki Foundation's Values in Healthcare Programme. She says:

"Learning to be compassionate without suffering burnout is a skill. Compassion is something that we all innately possess yet we need to practice and refine its use. It is learning to be alongside patients in their suffering by seeing them as souls like ourselves and yet at the same time not to identify personally with all their physical, mental and emotional issues. It is remaining emotionally detached from patients, yet keeping a spiritual, loving connection." Journal of holistic healthcare, Vol 2, Issue 3, August 2005.

4. Can compassion be taught?

Compassion may not be tangible but it can be measured, according to Nursing Times columnist, Mark Radcliffe.

"It is no harder to measure than rain. Is there rain? Stand outside and you'll know. Is there compassion? Be around it and you'll know."

He was commenting on news that nursing students are to be tracked on their ability to show compassion - and how far they possess "personal attributes to do with being kind, compassionate, caring, honest and trustworthy."

Such attributes, however, come from hard experience in the view of many people. That's why, according to Dr Sweeney, older people are often more compassionate.



"I've had outstanding care from the oncologists and oncology nurses. In my experience, the more senior, the older people were, the better the interaction was. The important point - youngsters can qualify as radiologists and physiotherapists at 23, 24, they are young people and they don't have a lot of life experience and I think life experience helps when you are in medicine."

Teaching young people to be compassionate is all about showing by example, he says.



"I've always been worried about young doctors in the first five years of qualification because probably in those first five years, you will see more people die right in front of you than in the next 25 years. I can't remember the last time I saw someone die right in front of me. But you certainly do as a junior doctor. And they are only kids. How do they deal with that stuff? They need to be cared for, they need to be empathetically understood that these are hugely traumatic events to be witness to, and I think that's an important part of medicine that senior doctors need to understand the needs of younger doctors and senior allied healthcare professionals need to understand the stresses on their less experienced and junior colleagues."

And there are other methods of encouraging compassionate care that are now being tried out in the UK.

CARE is a cultural change programme being tested at the Royal Free Hampstead NHS Trust in North London - intended to 'encourage staff to challenge certain behaviours, make staff aware that they were accountable for patients' care, show respect for each other and become experts in escalating concerns when things were not going right'. The aim is to fight compassion fatigue, 'a recognised obstacle across the word, and the price for some of the staff as a result of the organisation's achievements.

Guys and St Thomas's Hospital uses its team of Dignity Champions to further a range of initiatives including: an 'Every patient everyday' programme in which 'every inpatient has a face to face conversation about their care and their needs with the nurse caring for them on a daily basis'. 'Small things matter' focuses on customer care and first impressions - encouraging 'small acts of kindness and compassion to encourage staff to go the extra mile for our patients and their carers to ensure that we meet their needs whenever possible.'

Schwarz Rounds is another initiative currently being tested in the UK under the guidance of the Kings Fund. Every month at the Royal Free, a patient case illustrating an important issue is presented to the staff involved in the care of the patient. The ensuing discussion, facilitated by a trained psychologist, focuses on the feelings staff have when dealing with difficult and stressful events, and enables less experienced staff to see that senior colleagues sometimes struggle with humanitarian issues.

This initiative came into being when Boston lawyer, Kenneth B Schwartz was waiting in a busy waiting room for tests for suspected lung cancer, prior to having exploratory surgery the following day – as Mr Schwartz recalled in an article for The Boston Globe Magazine written in July 1995, shortly before he died.

"The pre-surgery area of the hospital was mobbed, and the nurses seemed harried. Eventually, a nurse who was to conduct a pre-surgical interview called my name. Already apprehensive, I was breathing hard.

The nurse was cool and brusque, as if I were just another faceless patient. But once the interview began, and I told her that I had just learned that I probably had advanced lung cancer, she softened, took my hand, and asked how I was doing. We talked about my 2-year-old son, Ben, and she mentioned that her nephew was named Ben. By the end of our conversation, she was wiping tears from her eyes and saying that while she normally was not on the surgical floor, she would come see me before the surgery. Sure enough, the following day, while I was waiting to be wheeled into surgery, she came by, held my hand, and, with moist eyes, wished me luck."

It was a moment of truth for Kenneth Schwartz.

"This small gesture was powerful; my apprehension gave way to a much-needed moment of calm. Looking back, I realize that in a high-volume setting, the high-pressure atmosphere tends to stifle a caregiver's inherent compassion and humanity. But the briefest pause in the frenetic pace can bring out the best in a caregiver and do much for a terrified patient."

These experiences led the lawyer to establish for The Kenneth B Schwartz Center, a not-for-profit organisation established in Boston, Massachusetts in 1997, dedicated to strengthening the relationship between patients and the people who care for them.

'It recognises the profound importance of the relationship, the 'human connection' between healthcare professionals and patients, with the mission of strengthening that connection'. Jocelyn Cornwell, Nursing Times, Feb 9 2010.

Dr Sweeney believes that Schwarz Rounds could change the culture of healthcare.



"I think at the moment there is no formal mechanism for feeding back on what you might call reflective practice. Feeding back on the day-to-day reflective interactions, junior people in professions allied to medicine as well as junior doctors, junior people have with their patients. But there are people who know how to do this. And there are associations in America which know how to do this. And there is an activity called Schwarz rounds and as I understand them Schwarz rounds are where vertical teams and horizontal teams come together and its open forum and they talk about their feelings they talk about their technical competence, they talk about what's happening to the guy that's on the ward, they talk about operational matters, when's he going home, is his wife OK can he drive what's his job.

But it's a forum where they have a very very wide-ranging discussion. And it legitimizes confidential discussion about one's reflection on one's inadequacies. And I think that's what it boils down to. It's not having feedback saying you interacted terribly with that person, a much better way is to provide a confidential and protected forum where people can say I don't think I did that very well. And people can say, look, we all don't do that very well, I don't. I'm not saying I'm a paragon of virtue here. I get it wrong. Badly wrong with patients too and have done in the past. So it's a requirement for senior and older doctors as well as junior doctors constantly, and I think there is a lovely phrase called respectful uncertainty about one's performance.

It's a lovely phrase that, respectful uncertainty means am I actually doing what I think I'm doing, and to have a confidential forum where people can say, yes you are, or in this case I think it fell short of

your standards which is a confidential and supportive forum I think would be immensely helpful. So coming back to the first point, there are no mechanisms for doing this as I understand in the NHS just now but there are places who do and do it quite skilfully."

5. Seeing the person in the patient.

When the eminent paediatrician, Sir Cyril Chantler retired from Great Ormond Street Hospital in December 2008 after having a new heart valve fitted, he told the BBC that he wished he'd been a patient earlier on in his career.

"I'd have been a much better doctor, during my time as a doctor, if I'd been a patient a bit earlier in my life. You've got to like people to be a nurse or a doctor. Our job is to serve the patient. You shouldn't be there if you don't think the humanity of medicine is as important as the science."

Dr Sweeney found that many of his strong views on the importance of humanity in medicine were confirmed during his interaction with healthcare practitioners at the end of his life. He wrote an article about his experience for the BMJ - and later talked on video about what motivated him to write about his concerns.



"What I was trying to do in publishing the article was say this is what its like to be me in this particular hospital receiving this diagnosis, a kind of cinema verite. In the hope that it would spark off conversations about the nature of the horizontal team versus the vertical team, about who was part of the vertical team, who was responsible to the vertical team, who felt they were inside it or outside it, why did they feel inside it or outside and specifically I wanted to draw attention to the inadvertent way in which insensitive communication can deeply embarrass individuals and convey to those individuals that being a patient is a uniquely uncertain occupation, nobody feels good being a patient. It means you are sick. And in hospital you are quite sick because you have been referred to hospital. So it's a serious business. People feel uncertain; it's not a comfortable place, not like your own home."

Stephen Ramsden, chief executive at Luton and Dunstable Hospital Trust and chair of the Patient Safety First campaign, believes that patients' stories are one of the most powerful instruments for progress.

'One patient's story told in person is worth ten patients' complaints in its impact on the trust board or on clinicians. And if I'm accused of wringing people's heartstrings then I own up to it. I want to make people who work in the NHS feel uncomfortable about not working flat out in this campaign.' Stephen Ramsden quoted in BMJ article on Patient Safety, 6 February 2009.

Many of the 2000 plus patients who have described their experience of being a patient on the website www.healthtalkonline.org are motivated by a desire to bring about changes in the care offered to others. Here are two of them.


First a man with prostate cancer considers the hospital culture that allowed a doctor to shout out personal details about him to a corridor packed with waiting patients.



"Now that was a highly avoidable example. It would have taken literally just seconds longer for me to be taken to a room somewhere or even just behind a curtain somewhere for this information to be imparted to me with a little greater discretion. So I firmly believe that that has nothing to do with resources. It has to do with personal choice, personal practice. It has to do with training. It has to do with culture. Perhaps it has also has to do with managerial performance management practice because these things go on because we work in a system that allows them to go on. If we stopped allowing them to go on then they wouldn't go on. So that, that is one example."

So it's at that kind of level that I think that privacy and dignity are not always well attended to. Although I hasten to add that I did have plenty of exposure to the other end of the spectrum as well. Some really admirable clinicians and wonderful human beings who did a first class job of plying me with information and also attending to my privacy and dignity. They deserve the credit but I'm just making a particular point about what I hope would be the minority of people at the other end of the spectrum. But it's a minority that can make a fundamental difference to the patient's experience of the process of care."

Here, a woman tries to explain how deeply she feels about the need for greater compassion for patients in intensive care.

 *"And if there was anything at all I could do to prevent that feeling of being so, you're completely, you have no control over anything, any of your bodily functions, where you are, what you do, what's said to you. You're so completely out of control. If I could just try and get staff who deal with the patients not to be so desensitised to them, and try and remember that this could be them one day. This could be them. And I am sure that they would have, if it had been someone their age, if it had been one of their colleagues, if it had been a handsome bloke in his thirties or twenties, if it had been a gorgeous girl in her twenties, they would have had a completely different experience to mine."*

A number of influential organisations promoting compassion have been set up by ex-patients. Kissing it Better, a website featuring ideas to promote compassionate care both of whom have also been appointed to the Dignity in Care Stakeholders partnership board at the Department of Health. Here they explain why they took the trouble.

"Things came to a head when Nicola was rushed to hospital with an acute infection and Jill was committed to casualty following a serious fall. Comparing experiences later led them to realise that, although lack of money and poor staffing levels were serious issues, there were also many incidences where tender loving care and simple innovative ideas could have made the world of difference to their recovery. So they decided to do something about it. But it was more difficult than they thought. Scouring the newspapers, it soon became obvious that the press preferred hospital "horror" stories, making it much harder to seek out the countless positive projects that were happening around the country."

"Visiting hospitals across the country, it appeared that a good idea on one ward may not even get passed on to the ward next door, let alone the wider world. And despite award ceremonies at many hospitals which recognised innovative projects, there seemed to be no mechanism which allowed those ideas to become more widely accessible."

Then came the idea to update Florence Nightingale and use the internet to spread ideas. Back in 1860, Florence Nightingale documented her best ideas in her book "Notes on Nursing". Soon, her methods were adopted all over the world. Without antibiotics or any sophisticated machinery, she made the world of difference in the Crimea; her sensible and sensitive ideas reducing the death rate dramatically in a matter of months. She may not have physically "kissed them better" but those soldiers were so grateful, it is said that they "kissed her shadow" as she passed their bed each evening with her famous lamp.

After much discussion and many hours trawling websites around the world, Nicola and Jill decided that a simple easy-to-use website, packed with good ideas from health workers, patients and their carers, and, crucially, backed by media coverage, could make the 'world of difference'.

When Angelica Thierot felt depersonalised by her hospital care, she founded the Planetree Association in 1978 with a vision of a different type of hospital care in which patients become active participants in their own care and well-being. It has now become a non-profit organisation providing education and information and is developing an accreditation system that will assess the degree to which hospitals develop a humanistic approach to healthcare. Here is Angelica's original philosophy updated in 2008.

"The Planetree model of care is a patient-centred, holistic approach to healthcare, promoting mental, emotional, spiritual, social and physical healing. It empowers patients and families through the exchange of information and encourages healing partnerships with caregivers. It seeks to maximise positive healthcare outcomes by integrating optimal medical therapies and incorporating art and nature into the healing environment."

It may seem obvious that it is worthwhile for healthcare practitioners to take notice of patients talking about their experiences of poor healthcare. Yet at a local level, many hospitals will only respond to adverse comments when they arrive in the form of a complaint - as Dr Sweeney discovered when he attempted - and failed - to begin a discussion about his concerns with the healthcare team at his hospital.



"So having got the article drafted I thought it was only right and proper to say to the consultants look this is going to come out in a journal of medical record and the phrase I used in the correspondence was I'm trying to make a point and not a fuss."

"There was no question of making a complaint. Transactionally I was dealt with brilliantly by my local hospital. There was no hesitation about that. It was just the battle of the subsequent unfolding of the story of the narrative of my diagnosis that was deeply disagreeable."

"And trying to separate the fact that I thought they were technically brilliant but relationally I think they could have done better. And the phrase that I used and the phrase that resonated from the correspondence of the article was that they hesitated to be brave. And I received no reply from any of the consultants. Apart from the consultant thoracic surgeon who actually came to my house to discuss the piece and I thought was very open and very understanding of what I was trying to get at. And I think he understood the notion of the horizontal team and the vertical team and he had such little awareness of the activities of the vertical team, in fact he kept on saying I didn't know that happened and I was thinking well he wouldn't because he's in theatre doing surgical things which is what he should be doing. He can't possibly see what the vertical team is doing the rest of the time the patients are in the hospital. But I think what he was beginning to realise was that that is part of care too, so in some ways he was obliged to be part of that vertical team even if he was only peripherally involved in it maybe just being the team leader for example but I don't think he was aware of its existence until I discussed the matter with him."

Was this surgeon able to bring about change? *"I don't know. He seemed very moved by the whole experience, I was very moved by the whole experience. I thought it was a tremendously courageous act for him to come out to my house to discuss the piece. So I don't know if any changes have been made. My experience of dealing with who I deal with in the hospital, radiography mostly and oncology hasn't changed."*

It was a missed opportunity, according to Dr Sweeney - and one that is repeated far too often within the NHS.



"If you are Toyota or Mitsubishi you are dying to have conversations of drivers. They thrive on that. Whereas the NHS is waking it up extremely reluctantly and see it as forbidden territory whereas it is no longer seen as forbidden territory."

6. Going further

When discussing the care provided for Dexter and his family, Chambers and Ryder say that there was something more than good organisation.

"Dexter's parents obviously felt that his care had gone beyond the unremarkable and was more than "good enough" practice. For this to happen, nurses need to sometimes go beyond policies and guidelines and act with humanity to meet an individual's needs, or the needs of their loved ones."

What is involved when the individual practitioner or team 'go beyond policies and guidelines and act with humanity'? Perhaps the first step is to recognise the unique nature of the relationship between practitioner and patient. Here's Dr Sweeney.



"I think that there are a number of interactive bear traps that one can fall into. One of the problems is actually quite a sophisticated problem which is that the health care professional does a job and for many people this job is pretty mundane. They're doing the same kind of thing to the same kind of people pretty well every day. So for them that activity becomes completely routine. And some days rather dull. For the individual it's anything but that. Every individual that comes through a hospital is apprehensive. It's a strange place, you lie in a strange bed, you've strange sheets, you've odd tea in a plastic cup. The whole thing is vibrantly different. So there's this paradox where there's this humdrum conversation or activity that the professional appears to be having, and this unique and rather destabilising experience that the patient feels."

Without this understanding, says Cornwell;

"The professionals can apply their knowledge and expertise; they are efficient and technically competent. But if they ever learnt that, "The treatment of a disease may be entirely impersonal, [while] the care of a patient must be completely personal," they seem to have forgotten. They are unable to make eye contact and they turn a blind eye to patients being stripped of their own clothes, embarrassingly gowned, addressed in derogatory terms and ordered around."

Here's Dr Sweeney again:



"Rediscovering the humanity in a patient I think is a lovely phrase and I think is an infinitely rewarding pursuit for healthcare professionals to pursue. To take an interest in. That's really why I came into medicine. It was to be with people on the edge of the human predicament. But understand them when they were there. And to some extent to let them understand me being with them at that point. At the edge of the human predicament."

Let's not beat about the bush here that's what doctors do. That's our job. And it's a hard old job. And it does require technical competence, but well beyond that the competence of the serious individual and society needs to understand that only serious people can be healthcare professionals because it's a deadly serious job really. And inside that job, if you're able to identify the humanity as well as provide technical competence it's such a win win situation. It's so rewarding for the patient to be treated sensitively and technically competently and for the healthcare professional to feel that they have touched that patient in a way that has technically helped them but also regarded and understood them as an individual."

For the team to 'go beyond' policies and guidelines and act with humanity, it must above all be aware of the importance of privacy, respect and dignity to the patient, as this oncologist explains.

"It is not simply knowledge that we are being asked to bring to the consultation but our experience and humanity. For patients, the realisation of their diagnosis and imminent mortality may undermine their dignity and leave them feeling vulnerable. As healthcare professionals we must shore up their dignity"

and bolster their self-confidence. Thus we might facilitate acceptance of their illness and accompany them on their uncertain journey.” (Dr Elizabeth Toy, BMJ 2009).

* The case studies are taken from www.healthtalkonline.org as well as from other sources. Healthtalkonline.org is an award winning website that allows visitors to share in over 2,000 people’s experience of health and illness. It provides information about conditions, treatment choices and support by allowing visitors to watch or listen to videos of the interviews or read about people’s experiences. The information on Healthtalkonline is based on qualitative research into patient experiences, led by experts at the University of Oxford.

About the author

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