the voice of NHS leadership

THE NHS CONFEDERATION

Futures debate

MAY 2008 PAPER 2

Compassion in healthcare

The missing dimension of healthcare reform?

Key points

- Care, compassion and some aspects of basic care delivery appear under strain in health systems around the world.
- Is compassionate care fundamentally at odds with modern healthcare?
- Individuals, including clinicians, can feel powerless to raise concerns.
- Aligning policy, leadership and practice can make real, practical differences to the way in which patients are cared for.
- Putting compassion and care back into healthcare requires action at system level; by organisational leaders; and by individuals.

Both here and around the world, there is a concern that, despite the increasing scope and sophistication of healthcare, the huge resources devoted to it and the focus on improvement, it is still failing at a fundamental level. Caring and compassion, the basics of care delivery, and the human aspects that define it seem to be under strain.

Robin Youngson is a UK-trained anaesthetist and clinical leader working in New Zealand who has reflected deeply on these issues. Below, he gives his personal view on the need for more attention to be given to the central role of compassion in healthcare.

Chloe's story: a defining moment

In any campaign to change a system there comes a defining moment when personal commitment becomes absolute: choice is removed. That moment came to me on witnessing the plight of my 18-year-old daughter Chloe, tied to a hospital bed in traction for a broken neck. Flat on her back, her head was completely immobilised so that she could see only the ceiling. She was unable to see people who came into her room, she couldn't see out of the window, she couldn't see a television or read a book. To sensory deprivation was added starvation. There was no system to ensure that my daughter would receive adequate food – a critical component of her healing and recovery. Although she had the use of her limbs, she was unable to feed or toilet herself. For a day or two this might be a tolerable state of affairs; her sentence was three months.

In the beginning, we imagined that this neglect was a simple oversight

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The debates will feed into the NHS Confederation's annual conference and exhibition, Delivering the future today, in Manchester from 18 to 20 June.

in a busy public hospital with the usual chronic shortage of staff. However, annoyance turned to disbelief and anger when it became apparent that the hospital system was incapable of responding to these simple human needs.

There was no system to respond to the disability needs of hospital inpatients, nor was it anyone's job to ensure that patients received good nutrition on a daily basis on a busy acute ward. The potential clinical consequences of these failures were severe depression, malnutrition, delayed healing and the requirement for prolonged rehabilitation. I had worked in this hospital as a senior clinician and manager and I had extensive networks of influence. But no amount of pleading, persuasion or anger would overcome the fact that there was a systemic failure or that the culture of the hospital was allowing it to happen.

Loved one in pain

"I doubt there is a more distressing experience for a health professional than seeing a loved one in excruciating pain within a system with the resources to treat that pain rapidly, but where no-one is willing to take responsibility for the necessary steps. I watched Chloe lie for four hours in nine out of ten pain [on the pain measurement scale] as I called every professional I could think of to respond to the situation. The drug required was visible to me through the glass window of the locked medication store."

"In every workshop I have ever run, the participants tell me that my daughter's experience is typical of what they see every day. In nearly 25 years of practice I have yet to find a hospital that responds compassionately to the basic human needs of its patients."

In the event, Chloe walked unaided out of the hospital seven days after being released from her bonds. That she did so was a testament to the support of family and friends. I designed and built all of her disability and communication aids. My wife, Meredith, attended the hospital every one of the 100 days that Chloe was in hospital and ensured that she had tasty and nutritious food. We spent more than NZ$1,000 on hospital car parking. The impact on the whole family was profound. We felt deeply fearful for the patients whose families did not have the privilege or resources to provide this kind of support.

In general, the standard of clinical care was excellent and we are deeply grateful that our daughter was able to heal from her injuries with the dedicated care of many professionals. However, the neglect she experienced of her basic human needs can only be described as callous.

I wish Chloe's experience was an isolated case, but it is not. Ever since I began at medical school in 1980 I have been profoundly concerned about the experience of patients within the system. I have campaigned for patient-centred care, I teach communication skills to health professionals, I run workshops on humanity and compassion and I provide support for our vulnerable junior staff. In every workshop I have ever run, the participants tell me that my daughter's experience is typical of what they see every day. In nearly 25 years of practice I have yet to find a hospital that responds compassionately to the basic human needs of its patients.

I define compassion as "the humane quality of understanding suffering in others and wanting to do something about it".

How could so many health professionals witness so much suffering and yet fail to respond? The problem seems to exist at two levels. In the experience of Chloe, most of the failings were not the fault of individuals but were the consequences of gaps in the system – human needs that were simply not catered for. But there is also the failure of individual practitioners to respond with simple measures to relieve distress, even when all the necessary resources are present. One of the commonest causes of complaints by patients in emergency departments is the lack of pain relief while waiting many hours for assessment and treatment. This failure is universal; it is the rule rather than the exception.

Has the healthcare system become less compassionate?

I do not think we have the data to answer that question, but I have observed changes in the hospital system that have profound

consequences for the experience of patients and their families.

Some things have improved to lessen suffering. In general, the standard of post-operative analgesia has improved beyond recognition. The introduction of acute pain teams in the 1990s replaced the hideously inadequate four-hourly intra-muscular injections of morphine with sophisticated techniques such as patient-controlled analgesia and epidural infusions. The widespread availability of such proven techniques makes the failure to apply them ever less defendable.

The organisation and context of nursing and medical care in hospital has changed profoundly during my career. When I was a house surgeon, the average length of stay of patients was eight to nine days. Now it is three and a half. Where previously we had the luxury of waiting three or four days for trust to build and for the patient to open up about deeper concerns, now we need exceptional communication and relationship skills to get to the heart of the matter in hours.

The times have changed, but skill development has not. As a resident doctor, I worked inhuman hours, but I was the one and only doctor responsible for the coordination of care of all the patients on a ward. I knew my patients well, sometimes intimately, and I had a profound sense of personal responsibility. In recent times, the reduction of junior doctors' hours has resulted in shift work and extreme fragmentation of care. The opportunity to build a trusting relationship with patients and the sense of personal responsibility has been lost.

"Healthcare professionals who previously enjoyed high status and unquestioning authority now feel beleaguered and threatened. It's hard to feel compassionate if you think that your patients are enemies who are just looking for the opportunity to complain or to sue."

In that same period of time, in New Zealand and other developed countries, nursing training has moved out of the hospitals and into the universities. I wonder how much the roles of caring, comfort and compassion have been replaced with a critical focus on pathways, tasks and documentation. In my country, ever-increasing demand on acute care systems and staff shortages have led to work environments in emergency departments and wards that resemble battlefields more than healing sanctuaries. In the meantime, as nursing practice extends farther into the previous domains of medical practice, there is increasing tension between evidence-based nursing care with its scientific research agenda, and broader policy directions for nursing with a holistic concern for the whole patient.

Societal expectations have changed, too. Almost every industry except healthcare provides exceptional levels of personal service. My bank provides a 'personal relationship manager' who knows me by name and who has the authority and resources to solve problems on my behalf. I can get a bank loan the same day and I receive a text message to confirm that the funds are available. In contrast, the lack of personal service and the highly visible reminders of unreliability in healthcare lead to ever-growing criticism. Healthcare professionals who previously enjoyed high status and unquestioning authority now feel beleaguered and threatened. It's hard to feel compassionate if you think that your patients are enemies who are just looking for the opportunity to complain or to sue.

A prescription for compassion?

Far from feeling helpless about the situation, I have left behind my fear and destructive beliefs after a long personal journey. Now I am delighted to report that my own personal practice of medicine has never been more joyful, satisfying

Action plan

- Declare 'compassion' as a core value.
- Reward rather than punish compassionate caring.
- Hone communication and relationship skills.
- Provide space for staff to discuss difficult issues.
- Challenge models of professionalism.
- Hard-wire new behaviours.
- Declare compassion as a management and leadership competence.
- Engage health consumers in the change.

and fearless than it is today. I have no 'difficult' patients, nor do I experience what I perceive to be unreasonable demands. I try to bring open-hearted compassion to my patients and I am able to witness suffering and loss in a way that brings deep meaning rather than personal trauma. Along that journey I have hopefully helped others strengthen their humanity and compassion and have begun to see how that might be woven into the fabric of a whole organisation.

In New Zealand, we have founded a national Centre for Compassion in Healthcare as a charitable trust. These are the things we think may help strengthen the heart of healthcare.

Declare 'compassion' as a core value

I believe the first step is to declare compassionate caring as a core value of our healthcare services.

Compassion is an assumed value but it is scarcely mentioned in any of the documents about healthcare strategies or aspirations. When I searched the websites of all the quality-improvement organisations, I was unable to find the word 'compassion' at all. In New Zealand, the word 'compassion' is not mentioned in the national healthcare strategy, it is not a dimension of healthcare quality and it is not mentioned in the NZ Code of Health and Disability Services Consumers' Rights. After my daughter's experience, I vowed to begin a campaign to amend the Code of Rights and to add, "The right to be treated with compassion".

I think that the overwhelming majority of health professionals are motivated by a desire to serve. I am unconvinced of the arguments about 'Generation Y' and greater self-centredness. When I have deep conversations with health professionals of any generation the response is always the same – a passion to do the best for their patients and to relieve suffering. Organisational support for this core value deepens the commitment of health professionals.

> "There is compelling research to show that empathic concern and investing time up front to check a patient's needs increases efficiency, safety and patient satisfaction. An hourly round of patients by nurses dramatically reduces the use of call buttons, freeing up nursing time."

Reward rather than punish compassionate caring

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. There is compelling research from the Studer Group to show that empathic concern and investing time up front to check a patient's needs increases efficiency, safety and patient satisfaction. An hourly round of patients by nurses dramatically reduces the use of call buttons, freeing up nursing time. Patient satisfaction improved 8.9 points on a 100-point scale and patient falls reduced by 60 per cent.

To the daily reinforcement of good, compassionate practice should be added the celebration of star performers. A simple thank-you card from the general manager to a staff member acknowledging the positive impact on patient care of an act of listening or kindness has an enormous impact on morale.

Hone communication and relationship skills

In today's pressured healthcare environment, we cannot afford to wait days to learn what our patients really need. I have learned that it is possible to build trust in minutes and to get to the heart of concerns in the course of one visit. For most of my career I did not have those skills and I was completely unconscious of the way I used power to control the agenda of a patient consultation. Empathy is as much a skill as an inborn character trait.

Although most health professionals have very good communication skills, further training can make a measurable difference, including a reduction in the risk of being sued. The Medical Insurance Groups of Australia (MIGA) offer a 10 per cent discount on medical indemnity fees for doctors who complete a programme in communication skills and risk management.

Given the evidence of the relationship between communication skills and patient satisfaction and

outcomes, a case might be made for mandatory annual training of all staff. Communication skills should be regularly measured by the use of patient satisfaction surveys. Individual performance can be ranked on a percentile basis against national data sets for well-validated survey instruments.

Create a safe space for deep conversations in the workplace

The deep meaning and purpose of our work is not a safe conversation to have in the workplace. For several years I have been meeting with two medical colleagues over a shared concern for the health and well-being of doctors. One day our conversation deepened and we began to talk about the spiritual nature of the work we do. In over 50 years of hospital practice (between us), that was the first time we had ever used the 's' word in front of another doctor.

Talking about personal vulnerability is another conversation that is 'off limits'. I can recall only a handful of occasions in my whole career when a fellow health practitioner has spoken openly about personal fears or feelings of professional inadequacy.

We cannot expect health professionals to bring compassionate caring to their patients without some personal healing, and the first place to start is with open conversation on these difficult issues.

In the United States, the Kenneth B. Schwartz Center sponsors compassion rounds in 139 hospitals. The Schwartz Center Rounds are multidisciplinary forums in which care-givers discuss difficult emotional and social issues that arise in caring for patients. Over 27,000 clinicians across the US participate in these interactive discussions and share their experiences, thoughts and feelings on different topics. These kinds of conversations need to be sponsored in every hospital.

"There is also a widespread belief that too much empathy and attachment to patients would lead to compassion fatigue and that clinical detachment is a necessary defence when witnessing so much suffering and loss in the course of clinical practice."

Challenge models of professionalism

The Western model of medical professionalism rests on foundations of a bio-medical approach, rational detachment and objectivity. There is also a widespread belief that too much empathy and attachment to patients would lead to compassion fatigue and that clinical detachment is a necessary defence when witnessing so much suffering and loss in the course of clinical practice.

Research shows that medical students lose the ability to empathise with their patients during clinical training and instead identify with the hero model of the medical practitioner. Professor Johanna Shapiro, author of *Walking a mile in their patients' shoes*, says they are "drawn to doctors whom they have idealised as healthy, invulnerable, authoritative, skilled and effective individuals who possess powerful and still somewhat mysterious knowledge and skills".

We have much to learn from other cultures. Contrary to prevailing Western beliefs, the experience of all who empathise deeply with their patients and bring open-hearted compassion to their work is that they increase their store of love. Empathy, compassion and loving kindness have a biological basis. The daily practice of compassion may immunise the practitioner from negative emotions and diminish the risk of burnout.

There is a world of difference between open-hearted compassion with non-attachment and the Western model of clinical detachment, which leaves patients feeling so abandoned.

In *Walking a mile*, Professor Shapiro writes a comprehensive review of the psychological and emotional responses to the traumas of clinical training and practice and shows how a more humanistic approach can strengthen empathy and the capacity for compassionate caring. It should be compulsory reading for every professional body reviewing models of professionalism and codes of practice.

Hard-wire new behaviours into the organisation

It is often easier to change people's behaviours first and allow the experience to shift beliefs. Those who practice empathic communication with their patients are instantly rewarded by the changed quality of relationship with their patients.

The Studer Group is leading change of this type in many US hospitals through a didactic programme of practices that 'hardwire' some key behaviour into the fabric of daily practice. Hourly 'rounds' by nurses in which they proactively recognise patient needs and demonstrate empathic concern were mentioned earlier. The precise form of words used is important.

Careful scripting teaches staff to use 'key words at key times' such as concluding with, "Is there anything else I can do for you at this moment? I have the time".

Define compassion as a management and leadership competence

Healthcare organisations are a mirror. The experience of people and their families seeking care is a reflection of how the organisation treats its own employees. The leaders of the very best healthcare organisations provide role models for the values and principles underlying people-centred care: they are deeply respectful, humane and compassionate towards their employees, they celebrate diversity, they act fearlessly against bullying, abuse or discrimination, they listen deeply, they role model openness and integrity, and they are not afraid to say sorry.

But what is the experience of the most vulnerable young healthcare professionals starting out? Bullying and abuse are widespread. When our new graduates feel truly safe and supported in the workplace, and have great role models, they will have an opportunity to develop as humane and compassionate practitioners.

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Compassionate leaders create compassionate organisations.

Engage health consumers in the change

There is no greater moral authority than a patient or family member who with dignity speaks of grievous loss and who challenges health leaders to prevent such catastrophe from happening again.

Health practitioners have an odd capacity to dissociate their own less-than-ideal experience of healthcare from their thinking about their own practice. The most powerful way to open hearts is to put a patient in the room to speak about their experience of the behaviour of health practitioners, the devastating impact of cold detachment, and the deep gratitude for compassionate caring.

Speaking out

It is not always easy for patients and carers to speak out.

"In trying to get the right care for Chloe I felt completely impotent in a hospital in which I had been a senior leader. I escalated the pleas and requests and demands for help until eventually I was taken aside by the duty manager. We had to be extremely circumspect within a system on whose goodwill we depended for the survival of our daughter."

Final word

I will finish as I began, with the story of my daughter Chloe. I am still completely undone by the memory of one act of kindness on the first day of our shared trauma.

Chloe made many trips within the hospital on the first day: from the resus room to the CT scanner; back to the trauma unit; off to the MRI scanner; transfer to the operating theatre; back to the intensive care unit. As parents, we followed our daughter in these journeys and witnessed the loving care of a transit nurse. He came wonderfully prepared and was enormously thoughtful about Chloe's potential needs, with a whole kit of drugs, including a generous supply of analgesia.

At the junction between two hospital buildings, there is a join in the floor. Mindful of Chloe's broken neck, this wonderful nurse stopped the trolley and carefully lifted each wheel over the join in the floor to prevent any painful jolting of her injuries. To bewildered and frightened parents he was a trusted guide in a foreign land. He did not give us directions but took us by the hand to the places we needed to find. As the months went by, we met this nurse from time to time. He would mysteriously appear on the ward at a time when Chloe was most distressed and offer wise counsel and loving concern.

Few hospital patients ever remember what was said to them, or what was done, but the emotional experience is lived for a lifetime.

Our questions

The NHS Confederation believes Robin's powerful case for change and call for action has a strong resonance for the NHS, particularly in the light of the results of the recent staff survey which showed that only 46 per cent of staff thought that patient care was their organisation's top priority. The patient survey and research by the Picker Institute, *Which?*, Age Concern and others highlight many of the same issues. Do all of the causes he identifies apply in the NHS: are there additional issues that he has not mentioned?

Does the leaching of compassion from the system that Robin describes explain other failures of basic care such as poor cleanliness, problems with nutrition, lack of respect for privacy and other criticisms of the NHS and other healthcare systems?

"Are staff too ready to blame the system or others rather than take action themselves? If they want to make a change for the better do they know how, do they have the time and do their managers and the organisation support them when they do?"

Robin places a strong emphasis on personal responsibility for compassion being taken by all staff – a theme echoed in Royal College of Nursing (RCN) chief executive Peter Carter's recent address to the RCN conference. Are staff too ready to blame the system or others rather than take action themselves? If they want to make a change for the better do they know how, do they have the time and do their managers and the organisation support them when they do? Do they understand the organisation or have the improvement skills to make a difference?

Compassion, safety and quality all seem to be part of a growing movement that requires a focus on the basics: measurement systems, new skills, time to change, curiosity and the willingness to admit personal and organisational weaknesses. This is a major cultural, clinical, management and leadership challenge. Is the NHS ready for this?

How much do some of the current changes facilitate or threaten compassionate care? Does the education and training strategy that we have pay enough attention to these issues? Does the European working-time directive, an all graduate nursing profession and other changes undermine the development of a more caring and compassionate service?

If we tried to follow Robin's action plan, how would we know that we were succeeding? The traditional approach of metrics and targets hardly seems to fit this agenda, but measurement will be needed and it will need to be designed in ways that ensure that measuring does not destroy the very thing we are trying to nurture.

Robin does not mention the current favourite policy instruments of incentives, penalties, contracts and regulation. Instead he argues for something much more emotionally engaging and personal that speaks to the basic values of staff and professionals. His argument suggests that technocratic solutions of this sort not only have limits but may fundamentally miss the point. It might be that the exclusive pursuit of incentives and the avoidance of penalties might detract from what is truly important: nurturing a "humane quality of understanding suffering in others and [the desire] to do something about it".

Resources

Studer Group. Call light study. www.studergroup.com/dotCMS/knowledgeAssetDetail?inode=262036

Youngson R. The organisational domain of patient centred care. www.wpro.who.int/sites/pci/publications.htm

Dignity and the essence of medicine. bmj.bmjjournals.com/cgi/content/full/335/7612/184

World Health Organisation. Patients for patient safety. www.who.int/patientsafety/patients_for_patient/en

Essence of care. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005475

Picker Institute. www.pickereurope.org

Join the debate

- Has the healthcare system become less compassionate and less focused on getting the basics of care right?
- How can we help both organisations and individuals admit when there are weaknesses and help them take appropriate action?
- Are staff too ready to blame the system or others rather than take action themselves?
- Would Robin Youngson's prescription for compassion work in the NHS? And if we tried to follow his action plan, how would we know we were succeeding?
- Does the pursuit of incentives and avoiding penalties detract from focusing on compassionate care?

Have your say now in our forum at **www.debatepapers.org.uk**

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The content of this briefing does not represent the views of the NHS Confederation. The NHS Confederation is grateful to Robin Youngson, consultant anaesthetist, Waitakere Hospital, Auckland, New Zealand, and co-founder of a national Centre for Compassion in Healthcare in New Zealand for contributing his ideas.

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