Cultivating compassionate care: why does it matter and what can we do to promote it?

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> 'You can't look at compassion in healthcare without looking at compassion in society.' *John Carnochan*

Perhaps a good sign for an event designed to trigger debate is when, prior to it beginning, you need to change the title. 'How compassionate is our NHS?' Or the reformed title, 'How compassionate is our health and social care?' was jointly organised by Royal College of Physicians of Edinburgh, the University of Edinburgh's Global Compassion Initiative and the Scottish Public Services Ombudsman's Office. Based on a fictional patient's tale, Mary, an elderly lady, falls at home and is admitted to hospital. The tale follows Mary's journey though initial consultations and ward moves towards discharge. It is added to by a fictional complaint, not dissimilar to those that occur in real life, from Mary's daughter regarding aspects of her care. The day itself allowed the audience, comprising people ranging from patients, nurses, managers, senior and junior doctors (in hospital and general practice), psychologists, social care and third sector representatives, in addition to representatives of the funding and organising bodies themselves, to discuss and comment on the case. It also invited perspectives from invited speakers from health, social care, academia and humanities to discuss compassion in our care systems.

In shaping the event in this way, we hoped to gather a variety of differing perspectives on what compassion actually means in practice in healthcare in Scotland, and what actions are required to effect change in the contemporary NHS to enhance and develop compassion. The short talks were followed by group discussions within the audience. These generated questions that were fed back and discussed by a panel. A set of actions were subsequently generated to take forward suggestions from the day. Through this event summary we hope to demonstrate and build on the integral ideas from the speakers and audience to show not only why compassionate care is essential, but how we can overcome the challenges and barriers to provide compassionate care.

Setting the scene – an introduction to compassion

Professor Derek Bell reminded us of William Osler's words: 'The good physician treats the disease; the great physician treats the patient who has the disease', and suggested that compassionate care, while not a new topic, is arguably now more important than ever. Professor Bell asked 'how can we use technology as a neighbour to compassionate healthcare?' Introducing the University of Edinburgh's interest in compassionate care, Professor Liz Grant, Assistant Principal, Global Health, explained that compassion is extremely important not just in medicine and healthcare, but in business studies, law and in the design, development and use of informatics and robotic systems. She asked us to imagine 'what would it be like if all our students could move forward with not only a great degree, but an awareness of what makes us care for ourselves and others and with a sense of what truly matters in the world'. Professor John Gillies, Co-director of the Compassion initiative, summarised some definitions of compassion. Compassion is more than an emotion; it is a felt and enacted response to suffering, according to the organisational psychologists Worline and Dutton. In analysing compassion, Worline and Dutton describe it in four stages: the recognition of pain; the ability to understand it and then empathise with it and finally the act of actually doing something about it.[1] Gilbert suggests the actions to address or relieve suffering through compassion suggest that compassionate practices can lead to better performance, increased customer satisfaction and better productivity.[2]

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Mary's Story

'Mary's story' was created by Professor Andrew Elder and Dr Dorothy Armstrong. They based it on a composite of the many patient stories they encountered over time in clinical practice as well as components of stories from various complaints in the Ombudsman's Office.

Mary is 85 years old, and living on her own at home where she was becoming increasingly isolated and housebound. After a fall she was admitted to hospital for assessment, treatment and rehabilitation. The tale follows the story of Mary telling and re-telling her story to different healthcare professionals during admission; of her losing her hearing aids, being the subject and the object of clinical and social care discussions, including important but distressing discussions on resuscitation, and her inpatient experiences of being boarded to different wards away from a clinical team she has grown to know while waiting for home services to be set up. The story of Mary and her family highlighted a significant personal upheaval, angst and distress, as they were left not only feeling the personal difficulties of being unwell but struggling to understand how the system was trying to help them.

In concluding the story Professor Elder poignantly reminded the audience that the story while familiar was also not complete – as every day within the NHS patients experience goodness and caring from compassionate staff as evidenced by the boards of 'thank you' cards. The NHS of everyday is characterised by simple acts of compassion, consideration and care.

Perspectives

Prior to opening up discussion for everyone in the room, a panel of professionals from different specialisms gave their perspectives. Dr Cliona McGovern, a lecturer in Forensic & Legal Medicine at University College Dublin, began by explaining that the striking aspect of the tale for her was the need to feel compassion for everyone in the patient's tale. Not just Mary but her family and all the staff involved need, and deserve, to be treated compassionately. She noted that despite suffering with reduced mobility for nine months, to the point that Mary became housebound, it took a fall for anyone to consider that she might require assessment and support. Quickly the consequences of the fall, which was initially a minor event, snowballed out of control, with Mary initially losing confidence, and then progressing to a loss of privacy and dignity.

Dr McGovern focused on the description of the early attempt to discuss resuscitation decisions with Mary by medical staff. She questioned whether this was the right time to initiate such a complex conversation. Such a conversation needs breathing space and time yet in Mary's case it took place just at the time when she had been moved to another ward and unfortunately in the move found that both her hearing aids had been misplaced.

Dr McGovern explored the unintentional insensitivity of staff conversations. As Mary began to recover from her fall she was made to feel that she was of less importance than others with comments such as 'the bed is needed for someone more unwell than you'. Nurses who routinely apologised to Mary that they couldn't make the 'system' work, had the effect of making Mary feel that she was an inconvenience to them – a 'bed blocker'. Respecting Mary's autonomy did not appear foremost during her time in hospital. However looking at the other ethical principles when you also consider the principle of justice, including the allocation of scarce resources, it becomes more complex. The option, not taken, of keeping Mary at home as long as possible would have retained her privacy, dignity and family connections.

Dr McGovern asked: 'How do we maintain dignity by keeping patients in their own environment with technology when we have such scarce resources?'

Mr John Carnochan, a retired Chief superintendent and previous licensed hostage negotiator, focused on the compassion in the story, which he felt was seen in human connections through little actions such as offering a cup of tea and the provision of a notepad to aid communication. But he noted these little compassionate acts did not seem central to the process. 'Is compassion in healthcare different to compassion outwith healthcare, he wondered?' We assume that because we employ humans, they will bring human skills including compassion to the job as well as clinical skills. 'I'd like to live in a country where we don't have to medicalise and institutionalise compassion. We need to speak some uncomfortable truths. Not every nurse or doctor is a saint'.

In raising this challenging thought that some staff may not be able to be readily compassionate, Mr Carnochan suggested that technical skills and humanitarian skills should be *equally* valued. Supporting staff to recognise that sometimes 'this is not the right thing to do', is as important as taking action. He emphasised that compassion needs to be about a connection between one human and another. Why don't we recruit for compassion and humour, and then assess for technical skills?

There is a danger to 'operationalising' compassion which Mr Carnochan focused on. His message became keep it simple, it's about humans, and it's not about time and money; what it is we want to do; how we are going to do it and WHY are we doing it? Compassion in healthcare is not something saintly and unique; it is the same as compassion in society.

Professor John Swinton, Professor in Practical Theology and Pastoral Care, School of Divinity, Religious Studies and Philosophy, University of Aberdeen, spoke of how Mary's story was deeply spiritual and deeply personal. Mary was faced with major existential questions:

- Who am I?
- Where do I come from?
- Where am I going?

- Why?
- What is my identity?

She was seen by others as 'geriatric' but she didn't relate to this. The story highlighted that there can be a tension between quality of care and quality of life, and what matters is thinking how the two come together.

Professor Swinton felt the compassionate moments of interaction in Mary's story seemed to stand separate from the mainstream system, which was driven by its own protocols. Mary saw many professionals with clinical skills. What consideration was given to how disorientating that cacophony of voices could be for her? Was her angst and anxiety recognised? Having a multitude of professionals meant that Mary could not form a *relationship* with any. In particular he addressed the comment 'this happens a lot', expressed by staff when Mary reports that her hearing aids are missing. This was a highly significant event for Mary and it was dismissed as a problem of lost property. Nobody identified the nature of the suffering that resulted from this loss. It was disabling and disempowering. She was isolated, afraid, anxious and unable to communicate.

Professor Swinton spoke of how compassion has to be practised in the whole community and wondered if the spirit and culture of the NHS was compassionate. He raised searching questions of the service – are members formed and trained in a way that works against compassion (implicitly or explicitly)? Does the spirit and ethos of the organisation mirror compassion or work against it? If the community navigates against compassion, how hard it is to act compassionately. He ended with:

> 'Don't let the awareness of limitations in the system limit our compassion'

Mr Mark Miller, currently undertaking a PhD in philosophy of cognitive and neuroscience at the University of Edinburgh, began his reflections on Mary's story by quoting Amber Carpenter's definition of suffering in relationship to control:

- Increased control => Reduced suffering
- Reduced control => Increased suffering[3]

Discussing the predictive processing theory, Mr Miller explained how compassion and empowerment are linked.[4] He explained that the majority of what the brain does is trying to reduce discrepancies between what we expect the world and life to be and what it actually is. We either change our expectations to fit what is going on or change the world to meet our expectations. In order to provide compassionate care we have to bridge the difference between expectation and reality.

Mary was experiencing physical pain from her injured hip, but he argued perhaps what Mary was more acutely tuned to was the suffering she was feeling because her expectations were so very different from what she was experiencing. She was unable to maintain her privacy, unable to keep information from her daughter when she wanted to and unable to move because of her hip pain. The way she expected her life to be was frustrated by the way things happened to her. There was a constant mismatch.

How do we reduce these mismatches? Mr Miller explained that the predictive brain reduces error in one of two ways: i) through actions to change what is going on around us, and ii) by inciting neuroplasticity so that the model comes closer to the reality of life.

Using Buddhist philosophy, he described how wisdom allows individuals to realise that reality cannot always be changed to meet expectations. Indeed the greatest demonstration of this is in death. We will all die and everyone we love will die. The reality of the fabric of society, therefore, is that suffering is 'how it is'. There is a need for acceptance that we can never reduce suffering completely; therefore it is important to educate ourselves and each other about 'how it is'.

Mr Miller ended by reminding us of the real problem of compassion burnout: 'If you go into a relationship in healthcare thinking that you will reduce all that suffering, then you will never meet that expectation.' So, we need to weave into our conversations that suffering is part of our existence. This allows us the space to accept and understand the suffering. He ended with the serenity prayer:

> 'Grant me the serenity to accept the things I cannot change, courage to change the things I can and wisdom to know the difference'

Panel discussion

The panel shared the importance of being able to see one another – patients, managers, clinicians – as humans. Being able to make connections may be more important than driving compassion inappropriately in the system that we work in. Courageous leadership is the cornerstone of developing an insightful, responsive compassionate NHS. Technology should be an enabler of human, relational, compassionate healthcare, rather than being seen as the main driver. Patients need to have more influence within the system; this will help to avoid over-medicalisation and restore a focus on the goals of the patient.

After the panel members shared their reflections, the audience had an opportunity to raise a series of questions and respond collectively. The following questions were asked:

Q1. What are the dangers of compassion as a 'have' to do rather than a 'should'?

Training, role modelling and education can engender behaviours which show compassion. However, this can be edged out by excessive expectations, time pressures, inappropriate targets and poor or bullying organisational culture in both health and social care.

If professionals consistently show a lack of compassion, this should be picked up by colleagues as well as by appraisal and regulation, and addressed. 'Be compassionate' cannot be part of a job description but can be part of organisational culture. Some specialities in medicine are more technically based, e.g. surgery, and some more relationship based, e.g. general practice. However, the consensus was that compassion was necessary for all disciplines to behave professionally.

Q2. Can we have a compassionate connected patient journey within the entire health and care system?

This may depend on having a better understanding of what 'health' is, and bridging the gap better between the means tested social care system and the NHS, which is free at the point of care. People have to be allowed more say in determining what they want from the system and helped to achieve that, rather than what the system drives them towards. This depends on seeing not just the illness but the whole patient.

Q3. How do we promote compassionate leaders and avoid compassion being eroded in clinical professionals?

The decline in the status of ward sister/charge nurse was felt to be detrimental to sensible decisions being taken quickly, e.g. to address the reheating of food and loss of hearing aids in Mary's story. Career structures may in fact have the perverse effect of removing such people into managerial, advanced nurse practitioner roles or often clinical directors and educators in the context of medical professionals. The 'heavy lifting' in the hospital is left to relatively junior people whom may not feel confident in exploring different methods to problem solve or able to take on the 'risk' of reheating food for example. Shift patterns for nurses and junior doctors also adversely affect continuity and building relationships with patients.

This could be redressed by more attention to continuity, and more emphasis in pay and career structures which value direct patient care. More generally, to have compassionate leaders we need to pay attention to organisational culture and what enables and detracts from a compassionate culture. They must be supported by colleagues who are able to give immediate feedback staff in clinical settings to acknowledge what they are doing well in order for them to learn.

Q4. What can you do to support your workers to be courageous?

The thread that ran through responses to this question was the need to place importance on developing and maintaining relationships with all staff so they feel able to respond honestly and courageously when things go wrong. This includes being honest about what we as professionals can and cannot do because of resource and workforce constraints in the NHS and social care. Not everything can be easily 'fixed' or 'sorted'. Empowering and trusting staff, giving them an awareness that you will support them and will 'have their back' when things are difficult is very important.

Q5. How do we retain the central value of relational care while retaining high quality bio-technical care?

We are living in a period of extraordinary technical change, the speed and pace of which accelerates constantly. This event was felt to be part of redressing the balance by talking positively about the need for compassion. Training is vital for professionals to retain a focus on the relational. Most medical specialities have good educational practices in this area and all medical students are taught and assessed on their ability to try and understand and address patient concerns and expectations. However, we need to improve the NHS environment to support the workforce to better deliver good relational care. It is possible to demonstrate the wish to give compassionate care in a brief examination but being able to do so in reality is different.

The point was made that twice as many people sleep in nursing and residential homes in Scotland every night than in hospital beds. The patients there are frail, have multi-morbidities and need technical and relational care. The suggestion was made that they offer opportunities for both education and research.[5] The NHS has much to learn from social care and vice versa.

Q6. How do we compassionately discuss Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) in a language that patients and their relatives can understand?

No one on the panel or the audience was happy with a system that subjects many elderly people to distressing discussions during dying. The system, which drives medical professionals to discuss resuscitation early into an admission, was seen as being driven by a process that had lost sight of human outcomes. The low success rate of CPR is poorly understood by the public and DNACPR is wrongly confused with euthanasia.

An audience member suggested that many elderly patients are scared of being subjected to resuscitation. The current goal to reduce the number of arrest calls alongside the admirable, though challenging, goal that all decisions are made with patient knowledge, means these discussions are often had by professionals that have only just met the patient.

Such conversations should ideally be with a trusted clinician with enough time. It was suggested that these should happen in the community rather than in hospital and that technology supports the timely ability for clinicians in hospitals to access the outcome of these decisions. We need to encourage both patients and clinicians to be more courageous and have open and honest conversations. Society needs to adjust to the reality that everyone is ageing and that we will all die. A DNACPR form does not preclude a patient from any form of treatment except for CPR in the case of an arrest. We have a duty to ensure this is understood.

Q7. How can we recognise and replicate staff members' actions that create a human connection with patients and identify what is important to them?

We need to focus on compassionate encounters rather than compassionate care; *Realising Realistic Medicine*, the

Scottish Chief Medical Officer's report,[6] recognises health is in communities where people live and work. We should not be doing things to people but with people. No encounter with a patient should be a passive encounter. We need to empower patients to discuss healthcare and manage, as far as possible, their own health care. We need to bring innovation into the system to do things differently and change the locus of control.

If we want better relational outcomes, we need to change what we measure. The quantitative work of Stewart Mercer shows that only empathic consultations lead to more empowered patients.[7] We need to teach staff to listen and understand as well as perform technical information gathering. It is not the diabetic patient but the patient who suffers with diabetes.

Q8. Does compassionate care take more time?

There was agreement that it may take more time in the short term but save time in the longer term. The example of advanced incurable cancer was given. The quickest thing is to request another scan and 'reassess' while talking through results and discussing where things are takes initially take more time and mental energy. However, through 'continuing treatment' in ordering another scan, a patient could easily be misled about their prognosis. Taking the time to discuss options straight away is the correct compassionate response and in the longer run it will be less wasteful and save time.

Q9. How can we encourage compassion in our communities to support older people like Mary?

This provoked a variety of innovative ideas and included:

- A national care service – which could include six months of voluntary community service with older people for some school leavers
- Those involved in healthcare spending time with funeral directors and florists and observe their skills in dealing with grieving people
- Community group sessions such as leg clubs – where leg ulcers are reviewed and dressed and patients then lunch together; mental health conversations in pubs and community nurses supporting those discharged from hospital
- An example from the prison service was to encourage simple dialogue between people. Through initiating basic morning greetings between staff and prisoners, i.e. saying 'good morning', there was a reduction in prison violence. Simple things make a difference

Closing the session

Professor Bell suggested that we need to work with head, heart and hands and use discernment and wisdom to improve encounters. Remember that most people in health and social care are doing a remarkable job under difficult circumstances. The UK spends 2% less of its GDP on health than most other northern European countries so we should not forget the resource context. Staying compassionate under difficult circumstances is to be rewarded. We need to address the fear of over regulation, complaints and litigation. A focus on compassion may allow us to be more innovative and kindle new ideas. Moving forward, we need to support staff and carers as well as patients. We need to get actions out of today as well as a report. Compassion should be stamped through the system like rock.

Moving forward and promoting compassion

Compassion is vital in providing the best healthcare. There are many ways we can all support 'the system' and those that work within it to be compassionate. Following the event, the organisers defined five simple principles through which we will try to demonstrate how we can promote compassion care.

1. Prime responsibility as a healthcare professional is duty of compassionate care to the patient, families, colleagues and self

Worldwide healthcare is designed predominately to treat illness, while the majority of care is given by relatives, particularly at the younger and older stages of life. While the expectation in the UK is that all care within hospitals will be delivered by employed hospital staff this is not the case in many low and middle-income countries. In such contexts relatives are often the major carers of patients on wards, washing hospital bed sheets and preparing meals. Kangaroo mother care, or skin to skin care, was actually documented in Bogota and was brought about by the lack of incubators.[8]

Recently there has been a push from the Scottish Government to encourage open visiting. Through their 'Open all Hours' scheme, ward 10 at Monklands Hospital, NHS Lanarkshire, improved their communication, reduced complaints and pressure ulcers. *Mylittleone* is an example of the use of technology to live-stream images and videos between neonatal units and families, which has been shown to help with early bonding and emotional wellbeing.[9]

2. Explore your patient's concerns and goals

For anyone who has been to medical school in the last decade, it has been made explicitly clear that if you do not seek to understand and address a patient's concerns you will not pass your clinical exams, nor will you pass your postgraduate exams. What about real medicine though, does it make a difference and can we do it? As described by Mr Miller, helping to match patient expectations and reality will reduce suffering, thereby giving more compassionate care. National schemes in Scotland such as 'What Matters to you' and Realistic Medicine call for a wider discussion with patients, encouraging patients to input their ideas into consultations and giving medical professionals the encouragement to tailor treatments where possible.[10,11] Don Berwick, Institute for Healthcare Improvement (IHI), calls for this as a part of Era 3 medicine. Era 3 medicine builds on the premise that so far there have been two eras of medicine, with era 1 giving medical professionals the authority to judge the quality of its own work, and era 2 focusing on accountability, scrutiny, measurement, incentives, and markets. Berwick calls on era 3 to be the 'moral era' where an appropriate balance is

struck between promoting professionalism and professional regulation alongside appropriate checks and balances with a reduction on the monetary values of treatments. Importantly he asks era 3 medicine to 'Hear the voices of people served' and asks us to move on from 'What's the matter with you' to 'What matters to you'.[12]

3. Think positively – is this possible?

There is no escaping the reports and concerns about doctor and nursing burnout at present. In their paper assessing the scale of workplace burnout, Hultell and Gustavsson describe it as 'a crisis in one's relationship with work, not necessarily as a crisis in one's relationship with people at work', which consists of three dimensions: 'Emotional exhaustion, depersonalization and reduced personal accomplishment'.[13] In order to try and promote a positive workplace experience the IHI, through the paper *Joy at Work*, suggests we need to 'remove barriers that rob the worker of their pride of workmanship'.[14] Studies looking at workplace engagement found that the statements such as 'I've got a worthwhile job that makes a difference to patients' and 'I am able to improve the way we work in my team' significantly correlated to levels of patient satisfaction with the care they received.[15] Thinking positively and trying to meet our patients' goals in order to gain our own sense of satisfaction is essential not just to our patients but for the sustainability of our workforce.

4. How can I make today better?

The 2008 Darzi review, *High Quality Care For All*, stated a clinician's first and primary duty was delivering high quality care based on patients' individual needs and in order to achieve this there was a need to utilise professional judgement, creativity and innovation.[16] Throughout this event it was noted that compassion was often delivered through small acts: the cup of tea, the provision of a notepad when hearing aids are lost. Hospitals that are shown to be promoting a higher level of compassion than others are found to run initiatives such as compassion training courses. These hospitals in turn see lower rates of rehospitalisation, better health outcomes, and fewer costly procedures among a host of benefits to staff.[17] Setting out with an aim to provide above average care everyday will raise standards not only through individual care but through inspiring others.

5. Find the courage to support and encourage other colleagues to do this

Many of those attending described how they feel they were practising medicine in a 'litigious' era and felt unable to work outside the norm for fear of the regulator. They feel compelled to investigate and 'treat', even if perhaps it would not be their personal choice. There needs to be a shift in the way professionals feel they are 'judged' by the system. Addressing over-investigating is a key component of Realistic Medicine. Catherine Calderwood, Chief Medical Officer Scotland, explains that a significant proportion of medical staff will recommend treatments to patients that they would not undertake themselves.[10] She calls for us all to ensure that we move to practice 'Realistic Medicine' – defining 'realistic' as having or showing a sensible and practical idea of what can be achieved or expected and representing things in a way that is accurate and true to life.[6]

More local schemes to improve staff support include hospitals introducing things such as yoga, mindfulness and Schwartz rounds. Bringing the multidisciplinary team together, the aim of Schwartz rounds is to have a space to discuss specific patient care. Analysis of Schwartz rounds by Maben et al., while acknowledging challenges, found outcomes included increased empathy, compassion, peer support, reflection, work engagement and communication with patients.[18]

Discussing why she become involved in the analysis of compassion, Jane Dutton reports that it was her experience of a compassionate workplace that demonstrated the difference it made not only to her own healing during a traumatic experience but also the ability to perform her job and improved her loyalty and attachment to her workplace.[1]

Conclusion

Compassion, like everything, will be valued variably between people and the impact it has on them; however, what we hope we have demonstrated is that we *must* provide compassionate care. The human touch, the ability to see the patient, the translation of knowledge into sense despite often working in a context of distress, pain, etc. and the ability to give care and build trusting relationships is what separates physical doctors from robots, protocols and 'standard operating procedures'. The ability to be compassionate and provide relief to those in distress is what provides doctors with the sense of worth that is integral to their practice and essential in the provision of care and in reducing burnout.

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