

## Mum's story – refocusing on the human dimension of quality healthcare

**Authors:** Sharon-Ann North<sup>A</sup> and John Walsh<sup>B</sup>

Quality in healthcare comes in many guises; these may be adherence to national best practice guidelines, use of cutting edge technology or the delivery of evidence-based medicine. However, one must not overlook the fundamental human basis of healthcare and always acknowledge that the delivery of a compassionate and caring service, to both patients and their carers, is at the core of delivering a quality service.

The story below is that of my beloved mum, at the end of her life; a life that was filled with kindness and compassion to others. Unfortunately, the care she received in her final days lacked compassion and care; the effect of this lack of empathy for her and my family has left an indelible scar. This article is not meant to be persecutory; however, it is honest and may be uncomfortable to read. Its purpose is to highlight the human face of quality and I share it with you to encourage you to reflect on the impact of delivering high-quality technical care without due consideration of the personal human domain, which is essential in quality improvement (Box 1).

### Mum's story

As I walked through the hospital car park my mind raced, my heart was heavy and I was filled with sadness and anxiety. I felt totally alone and helpless, despite the crowds of people in the hospital. The intensive care unit (ICU) bustled with an array of medical professionals attending to the patients who had tubes and wires connected to a plethora of beeping monitors and ventilators.

In a dream-like state, I edged slowly towards my mum in bed 3 as sheer panic welled up inside me. I felt nauseated and light headed and froze just short of the bed, trying to gather my thoughts and compose myself. I was frantic and distraught, trying to rationalise the enormity of the events that had unfolded since I had received 'that' phone call the day before, informing me that my mum had suffered a life-threatening heart attack.

My younger sister, who had been with mum throughout, was red eyed and swollen faced from crying. She sensed my apprehension and held my hand tight as we both approached the bed. As I gazed upon mum's motionless body, my heart ached at the sight of this beautiful, warm and lively woman now stationary, eye closed and attached to so many tubes and wires.

I felt the warm tears cascade down my cheeks and land on her hand. I held that beautiful hand softly and stroked her forehead and kissed her now wet cheeks. She was unresponsive as I looked hopefully at her soft lined face, seeking any reaction to my presence, words or touch.

This was the beginning of one of the longest, saddest days of my family's life as we kept a vigil throughout her stay in ICU. With a roller coaster of emotions, we shared a mixture of tears and laughter in the family room, as we recounted many a funny story about this formidable and strong lady in bed 3.

As it became clear my mum was not going to make it, the following hours were tense and traumatic for my grieving and heartbroken family. My beautiful mum died peacefully, never waking from her sedated state and never regaining consciousness. She was surrounded by all who loved her dearly. I washed those beautiful cheeks with hot tears and held her close as she had done to me so many times, comforting me in life's sorrow and pain as only a mother can comfort her child.

Although the technical medical care was faultless and the medical staff did all they could to save our mum, the delivery of this care so lacked the compassion and dignity that my mum and all patients deserve. Oblivious to the effect on those around them, suffering the pain of imminent or possible loss, the nursing staff joked and laughed about their lives and gossiped about their colleagues. For us the final straw came when my mum's attending nurse roughly removed her bed socks in a manner that I can only respectfully describe as uncaring and unthinking.

**Written in loving memory of my beautiful mum  
– Mrs Anne Hannon**

In the aftermath of my mum's death I not only had to deal with the intense grief and loss, natural to bereavement, but was also plagued with the memories of the way my mum had been treated in her final hours. I became angry and bitter at the NHS, the doctors and, of course, the attending nurses. Sadly, my mum was not treated with the kindness and compassion that should be afforded to all patients, never mind my beloved mum in her very last hours. Staff were diligent in their attendance to my mum but they lacked kindness, empathy and compassion.

My grief and anger skewed my usually tolerant personality and I wanted the people who had hurt me and my family to be held to accountable for their actions and behaviour. I spoke with the ward sister a few weeks later. She was disappointed that we had suffered as we had done and offered not only advice, counsel and action but, more importantly, a compassionate, considered and empathetic ear.

**Authors:** <sup>A</sup>member of the patient and carer network, Royal College of Physicians, London, UK and serving detective (specialist) office, Leeds, UK; <sup>B</sup>practice manager, York Street Health Practice, Leeds Community Healthcare NHS Trust, Leeds, UK



Fig 1. Anne Hannon, pictured with her daughter Sharon-Ann on her wedding day.

In the weeks and months that followed, I found myself wanting to make a difference to the patient and carer experience that had not been too kind to me and my family. I knew I could not change my own personal circumstances so I decided to invest my energy, purpose and passion into making the journey for others more inclusive, kind and empathetic. In time, I came to see the effect of the pressure on the professionals I had so earlier written off. However, I wanted to highlight to them the insidious effects that potentially manifest with this increased pressure and, through open, honest and kind dialogue, highlight how this pressure can so easily and inadvertently undo all of the technical quality delivered to patients.

I joined the Royal College of Physicians' (RCP) Patient and Carer Network over 18 months ago. I involved myself in their work streams and projects and, in doing so, have channelled the negative energy from my lived experience into a range of works that have greatly benefited from recounting my experience. Recently, I was appointed as a lay member for the second phase of the Future Hospital Programme and am trying to positively add value and experience to the North West Paediatric Allergy Network. My association with the RCP has led me to be an active lay member with the National Confidential Enquiry into Patient Outcome and Death (NCEPOD).

Following my unexpected and initially unwanted life journey, I have met wonderfully passionate people; people who like me have lived health experiences both good and bad. I have been given a voice that my mum sadly was not and, in doing so, have been able to positively, effectively and respectfully influence and add value to many issues from a patient and carer perspective that the medical professionals may have not fully considered, contemplated or implemented.

I hope my involvement, engagement and association continue to honour my mum's memory and leave a legacy of kindness and empathetic care for others. I hope, by sharing the experiences that my mum and her family endured I add value, open hearts and minds, encourage shared decision making and true patient

and carer involvement and engagement. My hope is that this ultimately drives a more holistic and integrated partnership, built on mutual trust and respect, and that delivers quality improvement in the human domain of healthcare delivery.

The story of my mum, my own work and ongoing engagement with the RCP has led me to see the necessity of two inter-related elements of quality improvement. The first is the need for a vision and the second, models of care with the patient and carers, treated as human beings, squarely at the centre of all we do. The vision tells us all – patients, carers and healthcare professionals – what we should aspire to be; it should inspire us to continually improve services, reflect on how we care, and accept and acknowledge that while we will not always succeed, we should be brave in acknowledging our failures and commit to apologising when we fall short and learning from our shortcomings. Healthcare models are descriptions of how this vision can be delivered on the ground.

An example of a model delivering against a vision is York Street Health Practice, part of Leeds Community Healthcare NHS Trust ([www.leedscommunityhealthcare.nhs.uk/our-services-a-z/york-street-health-practice/information-for-professionals](http://www.leedscommunityhealthcare.nhs.uk/our-services-a-z/york-street-health-practice/information-for-professionals)). This practice works with the homeless and those in the asylum system in Leeds. This service works to create safe spaces for some of the most vulnerable people in society. These are marked by respect, listening, empathy and compassion, enabling people to feel included and valued. These spaces are relational spaces. The service seeks to put relationship at the heart of its work.

These relationships are with everyone – patients, staff, carers and families. They are inclusive and value the gifts and insight of all. All can teach and all can learn. In these relational places and value-based experiences, the most important of human needs – hope and meaning – can grow and flourish; without them, we may have clinical or operational skill but miss the deeply human and humane dimension. These models of space and relational vision can offer glimpses of how services can and should be delivered. They offer the real possibility of creating cultures where patients and families feel valued and are heard. These models give structure to how we may move forward to grow quality.

Society and culture are fundamentally about human relationships – about how we interact with others. If we fail to get this right in healthcare, we end up with uncaring services, focused not on people but rather processes and material providing a product. There is a desperate need to create human and humane spaces in and across our healthcare services. This is not a 'nice to have'; it is an essential component and core to your business. It is about how to provide the best and the kindest care for your mum and mine, your child and mine. It makes the difference; kindness and compassion sew the seeds of quality experiences. I believe our services often overlook this. It is needed now and we will depend on it for our future.

To close, I offer you the words of the writer Leo Buscaglia, he sums it up best:

*Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment or the smallest act of caring, all of which have the potential to turn life around.*

My plea to you is that we seek – wherever we are and whoever we are, from cleaner to consultant – to be that conduit for kindness and listening. ■

**Address for correspondence: Ms Sharon Ann North, 19 Angel Row, Rothwell, Leeds LS26 0SG.**

**Email: [sharon-ann.north@westyorkshire.pnn.police.uk](mailto:sharon-ann.north@westyorkshire.pnn.police.uk)**