

The Crisis in Caring: An Evidence-Based Response

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# The Crisis in Caring: An Evidence-Based Response

Fergus O'Ferrall

'First do no harm' - Dr Thomas Inman (1820-1876).

Aneurin Bevan, seeking to establish the National Health Service 'on a new path entirely' – medical care for all free at the point of use – told the House of Commons on 9 February 1948, that 'we ought to take pride in the fact that, despite our financial and economic anxieties, we are still able to do the most civilised thing in the world - put the welfare of the sick in front of every other consideration'. There is mounting evidence that health systems are failing to do this and a crisis concerning the quality of care has emerged in recent decades. Ann Marie Hourihane's articles documenting examples of very poor care have unleashed a new round in the long-running public debate concerning the quality of care in Irish hospitals. The inquest into the death of Savita Halappanavar disclosed serious failures in clinical care in her case.

In Britain, too, there is growing evidence and public alarm about the quality of care in the NHS. The Francis Report into the Mid-Staffordshire Trust, published in February 2013, sought to explain why hundreds of patients died needlessly at the Trust Hospital between 2005 and 2009; other Trust Hospitals are also under investigation.<sup>3</sup> There have been recurring and well-documented examples of very poor care well *before* the 2008 recession. In the light of Bevan's observation, we need to focus on the much deeper causes of the malaise than the current recession if we are to address why we have a crisis in caring.

Healthcare is an activity deeply embedded in institutions and in our social practices. What ingredients are essential to foster caring within institutions, such as hospitals? What are the wider social values and practices conducive to ensuring that caring for the sick and vulnerable takes precedence in the provision of healthcare? Since the 1980s, values in healthcare have become embedded in what may be described as 'managerialism', which seeks to manage health systems along business or

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corporate lines from a central point of control. This approach is associated with the selfish values of neo-liberalism which have predominated in Irish society. As Fr Gerry O'Hanlon SJ put it as far back as 1993, 'individualism is the rampant habit of our heart'.<sup>4</sup>

# Lessons from Mid-Staffordshire

The recent Francis Report showed that the NHS culture, focused on doing the system's business and not that of the patients, was responsible for the appalling failure to care in Mid-Staffordshire.<sup>5</sup> This was a 'target culture', akin almost to a managerial cult, inspired by a managerial ideology. Poor standards of patient care were tolerated because of 'an institutional culture' where, for example, nurses felt penalised for taking time with patients. Francis identifies a need for a 'cultural care barometer' to measure the internal health of relationships between front-line nursing and hospital management. It identifies a critical issue concerning how non-executive Board members are to learn about or monitor the quality of care in the hospitals they govern.

The damning assessment of Martin Yeates, chief executive of Mid Staffs during the crisis is one we might well recognise in the Irish health service: 'He was much better at giving an appearance of intent to address issues raised with him than he was at ensuring that the appropriate action was actually taken. In short he was that most dangerous of leaders; one who was persuasive but ineffective'. Regarding the key need for public and patient involvement in healthcare, it is important to note that it was a voluntary group called 'Cure the NHS', founded by Julie Bailey, which campaigned to highlight a disastrous situation which might otherwise have continued and been ignored.

Dr Chris Turner told the inquiry that, when he started work at Stafford A&E in 2007, the place was 'an absolute disaster', so bad that no one could remember what good care looked like. The overworked staff were threatened with losing their jobs if they did not get patients through the department within the four-hour target. When John Moore-Robinson was admitted after a cycling accident, he was swiftly diagnosed with bruised ribs and sent away with some painkillers. He died a few hours later from a ruptured spleen, which doctors could have spotted if they had given the 20-year old the tests he needed.

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The Francis Inquiry prompts many key questions. Why does a hospital stop being sensitive to patients' needs and their distress? What about the consultants doing their ward rounds every day? Did none of them hear the cries and smell the smells? What about the hospital's Director of Nursing? If the buck does not stop with her or him, who does it stop with? A recent UK survey found that one in four medical personnel would not send their own relatives to the hospital where they work because the care is so poor.

The Department of Health in London produced Patients First and Foremost: The Initial Government Response to the Report of The Mid Staffordshire NHS Foundation Public Inquiry in March 2013. This proposes a number of actions, including the appointment of a new Chief Inspector of Hospitals and a review, led by Professor Don Berwick, 'to ensure a robust safety culture and a zero tolerance of avoidable harm is embedded in the DNA of the NHS'. While full of the usual laudable – and sometimes sadly amusing, rhetoric about patient care (thus, the Department of Health 'will need to reconnect with the patients it serves'), the document responds with largely 'top down' solutions. Apparently, every civil servant in the department over the next four years 'will have sustained and meaningful experience of the front-line with Senior Civil Service and Ministers leading the way'. There is some comfort in the recognition that 'blind adherence to targets or finance must never again be allowed to come before the quality of care'.

# Could we have a Mid-Staffordshire here?

In recent decades there has been a litany of high profile cases of patients failed and harmed in Irish healthcare: Baby Bronagh Livingstone; Roisin Ruddle; Frances Sheridan; Patrick J. Walsh; the Harding Clark Inquiry into peripartum hysterectomy at Our Lady of Lourdes Hospital, Drogheda in 2006; the cancer reports and inquiries into failures such as those relating to Rebecca O'Malley and the late Susie Long; those harmed by blood transfusion; and others. We ought to have paid far more attention to the Ombudsman Emily O'Reilly's investigations into episodes of poor care in our health service. As far back as 2006, she was saying that our 'care culture needs to change', Undignified deaths, a failure by medical professionals to engage with patient complaints, and poor record keeping were then some of the recurring themes she reported. At that time, she published her detailed Statement of Good Practice for the Public Health Service in Dealing With Patients.

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As a result of a number of these high-profile cases, a Commission on Patient Safety and Quality Assurance, chaired by Dr. Deirdre Madden, was appointed. Its report, *Building a Culture of Patient Safety*, appeared in 2008. In addition, the Health Information and Quality Authority (HIQA) was established in 2007. Despite all the recommendations of the various reports and inquiries and the efforts of the HIQA, it appears from recent debate that the 'culture of patient safety' is as elusive as ever. In June 2012 HIQA published *National Standards for Safer Better Care*. It is unclear whether statements of the obvious (e.g., 'Your healthcare professional decides your healthcare needs in partnership with you') make any practical difference. The Savita case springs instantly to mind. The same reservation applies to the HSE *National Healthcare Charter* published in 2012.

The recession may have further impoverished an already worryingly poor quality of care. The HSE Service Plan for 2013 states that the total reduction to HSE budgets since 2008 is €3.3bn. – a 22% decrease. Staff levels have reduced by over 11,268 whole-time employees since the peak of 2007. Given the record of known adverse events and poor care *before* the recession, when expenditure was rising, the current situation in terms of both access and quality must be a matter of very serious concern. Questions about this haunt many across the services who are seeking to provide for patients: do we have more failures to communicate with patients, more unsafe practices, more errors in diagnosis and treatment and more non-compliance with espoused standards than is realised or we are prepared to admit? We may yet have our own Mid Staffordshire, if we do not rapidly learn its lessons.

One reason why we really cannot answer the questions, and have to rely on anecdotal but real experiences of patients willing to go public, is that the recommendations of *Building a Culture of Patient Safety* have not been implemented. A key part of that report was about building a *partnership* between patients, carers and service-users in healthcare governance and delivery, but the 25 key recommendations concerning this have been mostly ignored. *The National Strategy for Service User Involvement in the Irish Health Service 2008-2013*, as implemented by the HSE, has not amounted to a cultural shift of power towards patients and the public in respect of policy development, service delivery and evaluation. There is, as yet, no 'robust and validated patient and public involvement', which the report

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recommended 'should be a requirement for all healthcare oversight, scrutiny, quality control and other accountability mechanisms'.

A key feature of Ann Marie Hourihane's account of the Irish health care system is how powerless relatives feel, despite their responsibility for the patient. Information is inadequate as staff 'routinely withhold information from patients', while consultants are not available to relatives as required. Dr Hilary Dunne, chief executive of the Irish Society for Quality and Safety in Healthcare (whose funding has just been withdrawn by HSE) states that Hourihane 'has captured the reality of many patients receiving health services in Ireland', based on surveys undertaken by ISQSH. Hourihane herself observes that 'there is an anger and a resentment in the health service —across all interest groups—that is palpable.....All groups within the health service seem isolated, furious and fractured from one another—let alone the patients'. There appears to be a great gulf between the official version of our health service and the experienced reality.

# The key ingredients of a caring culture

Effective hospital board governance, based on appropriate values, is a vital ingredient in seeking to ensure a caring culture. A major public debate is needed on how the new hospital groups will be governed in the light of the report presented to the Minister for Health by Professor John R. Higgins. Will there be adequate public and patient representatives on the new Independent Hospital Trusts Boards and will the contribution of spirituality to high quality care be recognised at all levels within each hospital group? Appropriate board governance is, however, only one of the necessary core elements. If priority and resources are to be provided, we must reconsider our fundamental values and concepts concerning social solidarity, the dignity of human life, spirituality, religious faith, and the vocation of the caring professions.

The debate about our wider societal values, led by President Michael D. Higgins, is very germane to the core elements necessary to restore care as the central value in healthcare and to ensure that caring is sustained as the *sine qua non* of a high quality, high performing health system. Jean Monnet is understood to have remarked that 'people only change when they are faced with necessity, and only recognise necessity when a crisis is upon them'. We certainly have the crisis. We are challenged, in the midst of recession, to sustain a caring high quality system: to meet both the crisis and

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the challenge successfully will require us to understand and practise social solidarity. That is where Christian social teaching has a major contribution to make to the restoration of high quality caring.

#### The Christian contribution

It is important to reflect on where individuals and societies of diverse culture and religion obtain their values about the human person, about social relationships, about what quality of care we owe each other. In the Irish context, it is in the Christian heritage that we must, in large part, seek the wellsprings of our attitudes and behaviours in these matters.

From the Christian perspective, we are all brothers and sisters in Christ; we owe each other solidarity; as a population, we share the risks and burdens of health and, collectively, we commit to carry the financial, social and emotional costs in order to care for each as we would wish to be cared for ourselves. We face 'sinful social structures' when we face structural barriers to the practice of love and care for each human being, especially when they are sick and most vulnerable. Christian social teaching has influenced the European secular approach of building their health systems around the concept of social solidarity. This is now the Irish government's officially declared policy in reforming our health system towards universal healthcare. However, given the deep-seated embrace of managerialism, the question is: will there be room in our health service for those religious and voluntary organisations which witness to values of compassion and caring and who provide convincing evidence of quality of care in what they do? There is a grave danger of a total erosion of the very sources of values that are essential in building a culture of holistic personal care.

As Fr O'Hanlon observed, in a remarkable presentation to staff, healing is a 'service of love'. He reminds of us of the need for 'institutional grace'-our hospitals need to be in accord with this ideal of compassionate care for each patient mind, body and spirit: '... work as love, healing work as the service of love, has an indispensable institutional as well as "front-line", more interpersonal, focus. And that, to a considerable extent, is your focus. Not that what you do is not also inter-personal and does not require personal virtues and integrity, but your particular skills are also in service of the institution, to enable it to function in accord with the values you espouse. This too is a work of grace, is absolutely crucial; it too, despite appearances, is holy ground'. <sup>10</sup>

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The HSE has published an important, if neglected, research report, A Question of Faith – The Relevance of Faith and Spirituality in Health Care (2011). The context of this well-researched report, focused on a hospice and a general hospital in County Donegal, is that the 'relevance and role of spirituality, religion, and culture in health care has gained prominence over the last number of years. Today, spiritual and faith/religious care is recognised as an integral component of holistic patient care. Indeed, there is a growing body of evidence emerging that is demonstrating the positive role faith/spirituality can have on health outcomes'. It is evident that, where spiritual care is diminished, holistic, high quality patient care is put at risk. If all staff (not just chaplains) do not have a primary responsibility for spiritual care of each patient, the needs of patients for the highest quality of care may not be met.

Therefore, if we are serious about ensuring that caring remains paramount, we have to develop in all professional staff the attitudes, knowledge, skills and competences necessary for high quality, holistic care, which makes the patient the priority. Here we need to look at our model of chaplaincy. As A Question of Faith points out, healthcare chaplaincy is 'still principally framed within the Roman Catholic Church tradition and there are no common standards of healthcare across the main Christians churches in Ireland'. The perceived scope of chaplaincy is narrow and sacramental. We need a concept of chaplaincy which deconstructs the prevailing medical model of care and sees the spiritual care of all – religious and non-religious – to be an essential and holistic dimension of healthcare for which the whole health service is responsible and accountable. A Question of Faith makes a number of important recommendations about developing a 'spiritual care strategy', which would set out a vision and core values, and include all care settings. We need a bolder vision for pastoral care in healthcare.

Such a strategy will require focus on staff education and development. This would involve re-imagining 'caring' as an enormously and fulfilling vocation. Doctors, nurses and other healthcare staff need to be comfortable with their own spiritual self-understanding and self-care. Dr Therese Meehan of the School of Nursing and Midwifery and Health Systems, University College, Dublin, has contributed seminal work on 'the careful nursing philosophy' and the professional nursing practice model that flows from it as well as the way spirituality is interwoven with nursing and health. <sup>11</sup>

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# Caring for the carers

A new report entitled Through the Eyes of the Workforce Creating Joy, Meaning, and Safer Health Care <sup>12</sup> spells out how the healthcare workplace prevents staff in the USA providing the quality of care they would wish: '..many health care workers suffer harm - emotional and physical - in the course of providing care. Many are subjected to being bullied, harassed, demeaned, ignored, and in the most extreme cases, physically assaulted. They are also physically injured by working in conditions of known and preventable environmental risk. In addition, production and cost pressures have reduced complex, intimate, care-giving relationships into a series of demanding tasks performed under severe time-constraints. Under these conditions, it is difficult for care-givers to find purpose and joy in their work, or to meet the challenge of making health care safe for patients they serve'.

The report recommends a range of strategies to ensure healthcare workplaces develop and embody shared core values of mutual respect and civility, transparency and truth-telling; safety for all workers and patients; and alignment from the boardroom through to the front-line of caring. What is most valuable is the report's explicit recognition of 'meaning' and 'joy' as critical for staff. Meaning is the 'sense or importance of an action', and joy is 'the emotion of pleasure, feeling of success, and satisfaction as a result of meaningful action': 'Without joy and meaning, the workforce cannot perform to its potential. Joy and meaning are generative and allow the best to be contributed by each individual, and the teams they comprise, to the work of safe health care every day'.

If we expect nurses, doctors and other staff to care excellently for each patient, we need to care excellently for them. The report enquires: 'Can each person in the work-force answer yes to these three questions each day? 1. Am I treated with dignity and respect by everyone? 2. Do I have what I need so I can make a contribution that gives meaning to my life? 3. Am I recognised and thanked for what I do?'

Creating 'the culture' of patient care at the highest levels will require a new mindset in the direction of our health system, counter to the prevailing 'command and control' corporate culture imported into healthcare. It is apparent that failed approaches to corporate governance in business have been well-nigh disastrous for caring in health services. *Through the Eyes of the Workforce* states that 'Workplace preconditions of respect and safety, in which the well-being of every person is a priority, create the conditions for

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the workforce to habitually pursue excellence. Meaningfully engaged members of the workforce deliver more effective and safer care, are more satisfied, are less likely to experience burnout, and are less likely to leave the organisation or the profession. They are more likely to go beyond the call of duty, consistently exhibit citizenship behaviours, and be patient-centred, leading to greater patient satisfaction'.

# Conclusion: what if...? 13

A number of key messages are needed to restore and sustain the highest quality of patient care and safety and, at least, 'do no harm'. Sadly, many patients now fear they may be harmed when they enter a hospital.

- 1. We need a new focus on using the needs and expectations of patients and their families to guide the delivery of high-quality care. We need a mindset shift from management target-setting by a bureaucracy, which has power but no direct responsibility for front-line caring, to a system of hospital governance which incorporates patient experience and which acknowledges that patients' expertise about themselves, their health and the care they receive are essential to care improvement efforts.
- 2. Patient information needs to be consistently gathered, analysed and synthesised and then, most importantly, utilised in care provision. <sup>14</sup> Long-term transformational change can only be achieved by giving patients real power, using their wisdom and experience to help design care processes and systems that are truly patient-focused.
- 3. To shape care improvement using patient experience, hospitals must have a culture and leadership that explicitly values including patients in all decision-making. Hospitals need what may be called a 'quality improvement infrastructure' to gather, analyse and systematically respond to the feedback that patients offer. This involves a major culture change it is more than having any specific measurement methods it depends on achieving a culture of trust, reporting, transparency and discipline. We must move *from* what has been described as a 'sick system syndrome', a hierarchical set-up deficient in mutual respect, teamwork, and transparency, where blame is a mainstay solution and mechanisms for ensuring accountability are weak and ambiguous and so many work in 'silos', *to* a new patient-centred culture,

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which is open, transparent, supportive and committed to learning; where doctors, nurses and all health workers treat each other with respect; where the patient's interest is always paramount; where patients and their families are fully engaged in their care: 'We envision a culture centred on teamwork, grounded in mission and purpose, in which organisational managers and boards hold themselves accountable for safety and learning to improve. In a learning organisation, every voice is heard and every worker is empowered to prevent system breakdowns and correct them when they occur. The culture we envision aspires to, strives for, and achieves unprecedented levels of safety, effectiveness, and satisfaction in healthcare'. <sup>15</sup>

How do we get there? The Lucian Leape Institute, established to provide strategic guidance for achieving safe patient care, has identified five major transforming concepts:

- Transparency must be a practised value in everything we do
- Care must be delivered by multidisciplinary teams working in integrated care platforms
- · Patients must become full partners in all aspects of healthcare
- Healthcare workers need to find joy and meaning in their work
- Medical education must be redesigned to prepare doctors to function in this new environment.

These messages are very challenging; we have to confront the fact that the transformation of healthcare from a public service to a business model in the last quarter of the 20<sup>th</sup> century reduced complex, highly intimate care processes to transactional 'industrial production schemata', divorcing work from meaning and diminishing the intangible but crucial aspects of care of each person. *Healthcare policy-makers and leaders have a choice:* they can view hospitals as industrial models and focus on restructuring, production and regulation, *or* they can view them as being composed of people with the values, skills and energy to perform meaningful care and focus on the shared vision and values that provide meaning and joy in caring.

There is a major need to articulate afresh the place of spirituality and religious faith in both the delivery of the highest quality of care to each person and in the governance and delivery of healthcare services. Professional competence is, of course, a primary, fundamental requirement, but it is not of itself sufficient. We are dealing with human beings and care of human beings always needs *something* 

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*more* than technically proper care - they need the practice of love from dedicated carers.

In the Irish context we draw to a very large extent from Christian sources for this 'something more'. Pope Emeritus Benedict put it very well in his encyclical, *Deus Caritas Est*: 'Those who practise charity in the Church's name will never seek to impose the Church's faith on others. They realise that a pure and generous love is the best witness to the God in whom we believe and by whom we are driven to love. A Christian knows when it is time to speak of God and when it is better to say nothing and to let love alone speak. He knows that God is love (cf.1 John 4:8) and that God's presence is felt at the very time when the only thing we do is love'. 16

A wise and prudent government will ensure that the wellsprings of the practice of love in healthcare are drawn upon and facilitated in making such a fundamental contribution to the common good.

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#### Notes

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- Gerry O'Hanlon SJ, 'The Christian Vision of Solidarity: Pie in the Sky or Our Daily Bread?', *Studies*, Winter 1993, vol.82, n.328, p.428.
- See Independent Inquiry into Care Provided by Mid Staffordshire NHS Foundation Trust January 2005-March 2009. Chaired by Robert Francis, QC., 2 volumes (London: Stationery Office, 2013).
- <sup>6</sup> 'Care Culture Needs to Change', *The Irish Times*, 9 May 2006.

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- <sup>8</sup> The Irish Times, 29 April 2013.
- See Professor John R. Higgins, The Establishment of Hospital Groups as a Transition to Independent Hospital Trusts: A Report to the Minister for Health, Dr. James Reilly TD (Department of Health, 2013).
- Gerry O'Hanlon SJ, 'Mission Statement of the Mater Hospital and the Reality on the Ground' presentation to Mater Hospital staff members, 17 January 2013 (available from the Jesuit Centre for Faith and Justice).
- Therese C. Meehan, 'The Careful Nursing philosophy and professional practice model', *Journal of Clinical Nursing*, Vol. 21, 2012, pp.2905-2916. See her 'Spirituality and spiritual care from a Careful Nursing perspective', *Journal of Nursing Management*, Vol. 20, 2012, pp.990-1001
- Lucian Leape Institute at the National Patient Safety Foundation, Boston, 2013.
- See the briefing by Carol Fancott, 'What if: Patients' Experiences Guided Quality Improvement and Organisational Change?, on the Canadian Foundation for Healthcare Improvement website www.cfhi-fcass.ca. The question is now being asked in many countries. See also L. Leape, et. al., 'Transforming Healthcare: A Safety Imperative', Quality & Safety in Healthcare, Vol. 18, 2009, pp.424-428.
- In this regard see the valuable Understanding What Matters A Guide to Using Patient Feedback to transform services (Department of Health, London, 2009).
- <sup>15</sup> L. Leape et. al., op.cit., p.425.
- Benedict XVI Deus Caritas Est (God Is Love) (Dublin: Veritas, 2006), 31c, p.48.